

ADVANCE DECISIONS TO REFUSE TREATMENT: AUTONOMY AND GOVERNMENTALITY AT THE END OF LIFE

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SUMMARY

Advance decisions to refuse medical treatment (“ADRTs”) have been recognised in English law through a series of cases which arose at the end of the Twentieth Century and subsequently by the Mental Capacity Act 2005. ADRTs allow adults, with the requisite mental capacity, to refuse forms of medical treatment that they anticipate being provided with at a time when they have lost mental capacity in respect of the anticipated treatment. The most frequently advanced argument for the recognition of these instruments is to respect and extend personal autonomy and/or self-determination. However, this thesis treats that particular normative ground as but one among a number of factors which have been crucial to the emergence of ADRTs. It is argued that the advancement in medical capabilities for prolonging life in its final stages is a *sine qua non* of ADRTs in practical terms. The demographic and financial pressures in which end-of-life care is provided add impetus to the argument for the recognition of ADRTs. However, it is suggested that the political environment in which ADRTs have emerged has also been of fundamental significance to their recognition in law. Using Michel Foucault’s theory of governmentality it will be shown ADRTs have been developed within advanced liberal programmes of government, in response to the inability of the traditional approaches of those forms of government to govern individuals who lack capacity at the end of life. The employment of this theory provides a novel perspective on the debates which have raged in this area of law and bioethics, allowing for a focus on the population, as well as the individual, and a focus on practices rather than on the outcomes.

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INTRODUCTION

Healthcare law and bioethics are frequent sites of debate over various dilemmas encountered in medical practice and contain many areas of fierce contestation (e.g. stem cell research, organ donation, abortion, euthanasia). One matter which is now relatively free from such dispute is that of contemporary refusal of medical treatment. Few would suggest today that an adult with mental capacity should have treatment given to him or her against his or her will.¹ It is widely recognised that medical treatment given to such persons must be provided on the basis of informed consent² and the most frequently relied upon reason for this requirement is that it protects personal autonomy.³ However, the putative consensus on quickly disintegrates when considering refusals of treatment in different circumstances. This is particularly true when a person for whom treatment is clinically indicated lacks the mental capacity to make a treatment decision. In such circumstances, he or she is deemed to lack the ability to make an autonomous decision and therefore additional factors and principles take on a much heightened relevance in determining whether treatment should be provided. While there is broad agreement over the kinds of factors and principles which are relevant in the determination of such decisions, the question of how much weight to give the various factors (especially personal autonomy and beneficence) is eminently debateable. The outcomes of such debates take on added significance where the treatment decision under consideration pertains to life-sustaining treatment.

Advance Decisions to Refuse Treatment (“ADRTs”) purport to provide a means by which we can avoid straying into this problematic zone of contested decision-making involving the weighing of an assortment of values and interests. In particular, these purport to base the recognition of such decisions on the pre-existing autonomy of the decision maker. ADRTs take effect for those who, while now lacking capacity, had once prudently considered the possibility of requiring the kind of treatment now indicated before he or she lost mental capacity in respect of that decision. Described in this way, on the basis of a simple extrapolation of the individual right to personal autonomy, we could readily

¹ But NB J Herring, ‘Where Are the Carers in Healthcare Law and Ethics?’ (2007) 27 *Legal Studies* 51

² *Chester v Afshar* [2004] UKHL 41 (HL)

³ *ibid*

anticipate that ADRTs would be welcomed by healthcare lawyers and bioethicists alike. However, it will be argued in this thesis that that account alone provides an inadequate basis for the understanding of the development and operation of ADRTs. Rather, it will be suggested instead that ADRTs have arisen as the result of a congress of multiple factors, political, economic, personal, interpersonal and populational. Taken together, these factors, which have resulted a crisis in end-of-life government to which ADRTs are the response. Consequently the emergence of ADRTs is a matter of greater complexity than that which the more doctrinal accounts may suggest.

One of the most obvious areas of complexity lies in the definitional uncertainty which surrounds ADRTs. They have previously been known by other names in England and Wales, such as “living wills” and may be known by slightly different terms in other jurisdictions.⁴ Any analysis that fails to clearly identify the specific jurisdictions to which it pertains carries a real danger of muddling various concerns together or of misattributing matters which may be of concern in other jurisdictions to that of England and Wales. That is why the first part of this thesis is devoted to elucidating the legal definition of ADRTs in England and Wales as the jurisdiction to which the discussion here primarily applies. Many aspects of the discussion may be of interest to those concerned with the law in other jurisdictions, but there is much variation in the manner in which ADRTs are recognised and therefore it should not be assumed that all aspects of the discussion will be applicable across the board.

This part will further provide occasion to specify the particular kinds of ADRTs with which this thesis is concerned. Although ADRTs can be created in respect of any kind of ‘treatment’, the focus in this thesis will be on those ADRTs which purport to refuse life-sustaining treatment, which are the variety of ADRTs that carry the highest stakes. Getting it wrong in respect of such ADRTs means that either the patient will lose his or her life, through withholding treatment in circumstances in which he or she would have wanted treatment, or the patient will be kept alive through medical treatment in circumstances in which she or he would have wanted to have been left to die. ADRTs for the refusal of treatments which pertain to mental disorders will be beyond the purview of this work, so too will similar instruments such as Lasting Powers of Attorney (“LPAs”) and Advance Care Plans (“ACPs”).

⁴ see A Simon, ‘Historical Review of Advance Directives’ in Peter Lack, Nikola Biller-Andorno and Susanne Brauer (eds), *Advance Directives* (Springer Science & Business Media 2013)

The discussion in the first part also provides an introduction to some of the legal antecedents to the modern law on ADRTs. This will involve a detailed discussion of the law on mental capacity and the law on the contemporary refusal of treatment. Some critical observations shall be made at this point concerning the relationship between the general principle that adults with capacity have the right to refuse medical treatment for any reason, and a more detailed appreciation of the law, which can be realised through an examination of the important cases, principles and formalities. Notwithstanding the bombast and gusto with which the right to refuse treatment is often asserted, taking a more in-depth appreciation of the law reveals a much more nuanced and fragile right. This fragility colours the claim made by the courts in being guided to protect the right to self-determination or patient autonomy.

A greater focus on the normative underpinnings of ADRTs will be examined in the second part of this thesis. Given the extent to which it is relied upon in justifying the law on ADRTs, the value of autonomy will be examined in particular detail. Again, at this juncture it will be seen that there is a great potential for confusion, as the term autonomy is capable of bearing a number of different meanings. The thesis as a whole draws on a wide range of scholarship which highlights distinctive understandings of the concept of autonomy, but the work of Kant and Mill will be focussed upon to illustrate the breadth of understandings of this concept. The reason for considering the work of these authors specifically is that their work is often drawn upon in philosophical literature as providing the foundation for our contemporary respect for autonomy. However, these philosophers had radically different conceptions of autonomy. Moreover, in legal discourse, the term autonomy has been frequently confused with that of 'self-determination' and this has resulted in a dearth of conceptual clarity. As a result, on a set of identical facts, the case can be made for both providing treatment and for not providing treatment based on autonomy. Ultimately, therefore, the claim that ADRTs act as an extension of autonomy is an untestable assertion in the absence of a clear and accepted definition. From this mere possibility, it is understandable that some have suggested that moral concepts have been deployed as much for their rhetorical value as for the ability to derive concrete rules from their conceptual depth.⁵

In spite of the absence of a clear and universally accepted definition of autonomy, many have suggested that there is a general tendency for autonomy to be defined in highly

⁵ See e.g. J Harrington, 'Law's Faith in Medicine' (2008) 9 *Medical Law International* 357; J Harrington, 'Of Paradox and Plausibility: The Dynamic of Change in Medical Law' (2014) 22(3) *Medical Law Review* 305

individualistic terms in English law. Some of those making such claims suggest that the law, grounded in this form of autonomy, fails to adequately reflect the way that people make decisions. In turn, this also leads some to claim that the law perpetuates a kind of undesirable individualist tendency in modern society. In addition to these generalist critiques of one of the foundations of the chief normative underpinning of the law on ADRTs, some have criticised the extrapolation of the concept of autonomy in the recognition of ADRTs. The law does offer certain safeguards which address some of these concerns (such as allowing revocation of ADRTs without formality and offering healthcare professionals a generous interpretative discretion). However, these critiques serve to highlight the plurality of meaning and expectation accorded to the concept of personal autonomy. The law, in its alleged incorporation of law an individualistic form of autonomy, can be criticised for different reasons and with different concerns in mind. Supposing that one of these lines of critique were accepted, there is every chance that it would not be accepted, by advocates of different lines of critique. On this basis, it seems unlikely that a version of autonomy will be arrived at that can successfully evade criticism of this kind.

Unlike the majority of critiques of the interpretation of autonomy in law, what will be termed here ‘the personhood critique’, does not suggest there is anything problematic with relying on the principle of personal autonomy as currently recognised in law to justify recognition of ADRTs. Instead, this line of critique casts doubt on the possibility of individuals maintaining a morally significant continuity between the point in time at which the ADRT was created and the future point at which it comes to be relied upon. This is a powerful line of critique, because it accepts the basic normative premises of ADRTs, but its weakness is that its acceptance as a principle in this area would put it out of kilter with other important areas of law, such as criminal law and contract law.

The personhood critique is revisited in the third part of this thesis, in chapter six, where Foucault’s theory of governmentality is presented for the purposes of offering a novel analytical basis for the evaluation of the development and operation of the law on ADRTs. Significantly however, it should be noted from the outset, that as this theory is a non-normative, this thesis does not provide any particular practical solution to the questions surrounding the manner in which ADRTs should be recognised in law, or to the kinds of principles which should underpin their operation. Rather it problematises the supposed normative bases for the recognition of ADRTs and for the expectations which surround the way in which they operate. Debates on these matters will continue to rage precisely because there is no agreement on the proper basis for ADRTs other than at the general level of autonomy, but without an agreed definition of that concept it provides little assistance for

those wishing to draft legislation. This dearth of consensus, highlighted in Part II, is easily attributable to the pluralistic society in which these conceptual battles are joined. However, of itself, this conclusion leaves open the question as to why the existence of value pluralism should prevent the imposition of a supposedly superior conceptualisation of autonomy. An explanation for this state of affairs can be provided through the theory of governmentality and in particular the development of modern modes of government with a commitment to liberalism. This commitment to liberalism has arisen in consequence of a series of ‘crises of government’. This process was set out in chapter five, in which a detailed discussion of what Foucault describes as the “governmentalization of the state” is provided.⁶

This discussion focuses attention on the formations of modes and practices of government which have arisen through problematisations and resistances that emerged at various points in history. This account pertains to developments in Western Europe and consequently a further geographical caveat must be conceded, but the employment of this theory in respect of the law of England and Wales is apt in that these areas lie within the region Foucault discusses in respect of governmentality. Through the consideration of the various problematisations and adjustments in modes of government, we can glean an explanation as to why we have arrived at a form of liberalism in which a kind of value pluralism is inevitable. It is not suggested that value pluralism is necessarily to be considered preferable to a more limited or homogenous approach towards the recognition of values in society, but merely explains why this state of affairs has arisen as a product of a certain orientation of government.

Significantly, Foucault’s understanding of the term government is not restricted to ideas of state government, but includes all practices involving the “conduct of conducts”.⁷ This discussion enables us to return to the idea of autonomy, but does so with an emphasis on autonomy’s role in government. It is this way of conceiving of autonomy as a practice, which is potentially the most challenging to orthodox Healthcare law and Bioethics, where the movements to recognise autonomy are viewed as having a different purpose (i.e. the protection of Human Rights⁸ or the empowerment of patients *vis-à-vis* the medical

⁶ M Foucault, *Security, Territory, Population: Lectures at the Collège de France* (Palgrave Macmillan 2009) 109

⁷ See M Foucault, ‘The Subject and Power’ in James D Faubion (ed), *Power*, vol 3 (Penguin Books 2002) 341

⁸ See K Veitch, *The Jurisdiction of Medical Law* (Ashgate 2007) 20-25

profession⁹) is in positing the idea of autonomy not simply as a means of empowering patients against the paternalist drive of medicine, but as part of the ‘practices of government’. This idea will be fully elaborated upon in chapters six and seven.

The final two chapters of Part III are concerned with examining the operational aspects of governmentality *vis-à-vis* ADRTs. At this stage Foucault’s description of modern practices of government operating through the interplay of the technologies of the self and the technologies of government will take prominence. Pursuant to that characterisation, the operation of ADRTs within each of these technological groupings will be considered in the final two chapters of Part III.

An examination of ADRTs as part of the technologies of the self will be conducted in chapter six through a re-consideration of two prominent cases on ADRTs, *Re E*¹⁰ and *W v M*.¹¹ in which the purported ADRTs were not recognised by the courts. To some this may indicate that the autonomy of the people in those cases was not respected and adds weight to the argument that ADRTs fail to extend autonomy in practice. However, in this thesis, these cases will be drawn upon to anchor the examination of the processes involved in the creation of ADRTs. Focussing on the practice demanded and fostered by ADRTs could lead to a different conclusion, given that the process of creating an ADRT requires an individual to subjectivise themselves as a responsible citizen with an interest not only in his or her future healthcare, but also in his or her existential disposition. The manner in which this can be achieved will be discussed.

In addition to highlighting the role ADRTs play in facilitating the government of the self, a further role is played by the establishment of a framework on ADRTs in governing others. Three varieties of other, whose futures are shaped through the practices government¹² of ADRTs, can be identified as the population, the ‘future-self’ and the interpersonal other. Since the middle of the Eighteenth century the population became the most important object of government and therefore it is important to consider the effect that ADRTs have on the population. At this time Foucault identified biopower as a new form of power that was not only capable of interacting both with individuals in society, but also with the population. One aspect of the operation of biopower is the securitisation of the population against

⁹ See e.g. D Wilson, *The Making of British Bioethics* (Manchester University Press 2014) 107-115; J Harrington, ‘Privileging the Medical Norm: Liberalism, Self-Determination and Refusal of Treatment’ (1996) 16 *Legal Studies* 348

¹⁰ *Re E (Medical treatment: Anorexia) (Rev 1)* [2012] EWHC 1639 (COP)

¹¹ *W v M* [2011] EWHC 2443 (Fam)

¹² See T Lemke, *Foucault, Governmentality, and Critique* (Paradigm Publishers 2011) 17

threats. The existence of individuals whose lives can only be sustained through medical intervention, but who cannot make a decision for themselves about whether that treatment should be continued represents a kind of threat to modern governmental reason because it demands that a decision be made on behalf of another, rather than allowing the individual to determine their own interests. ADRTs facilitate the possibility of avoiding this dilemma through obtaining the treatment choices of individuals prior to their loss of capacity.

The need for ADRTs is heightened by the current surroundings of the population, in which there are multiple pressures resulting from increased life expectancy, rising rates of mortality, a lack of funding for healthcare in the wake of the financial crisis of 2008. In these circumstances, where citizens can make provision for the end of life through ADRTs, which have the potential to avoid delay and excessive treatment (defined in the individual's own terms) the population as a whole could benefit through greater efficiency in the health service. However, in order to create a noticeable effect in the population requires interpersonal acts of government, where a citizen can be assisted in the formation of an ADRT. Although there are routes through which this can be achieved, they have seemingly proven ineffectual, in that they have not produced a great uptake in ADRTs. For those that do learn of their rights to create an ADRT and engage in the practice of the formation of an ADRT, they must engage in a process of governing their 'future self'. Here we can return to an idea proposed in chapter four on the 'future-self' taking on a distinct form of personhood from the present self.

The discussion at this juncture will differ from the earlier discussion in that it shall not focus on the moral case for allowing the 'present-self' to make legally binding decisions for his or her future incarnation. Rather, the focus is on the operation encouraged by the legal framework, to think about the future-self who has lost capacity as a kind of other. This objectification of the 'future-self' is what legitimises decisions being made on their behalf and further legitimises the very notion that it is legitimate to make decisions on behalf of a person who lacks mental capacity and that such a person lacks the right to refuse treatment for themselves. In this way the manner of autonomy's recognition in law may be conceptually inconsistent, but it takes shape through the problematisations of government and is both constitutive and supportive of modern modes of government.

CHAPTER ONE

THE LEGAL FRAMEWORK

INTRODUCTION

This thesis examines the development and operation of the law on advance decisions to refuse treatment (“ADRTs”) in England and Wales. The primary role of the first substantive chapter is to define the key legal terminology that will be employed throughout the remainder of this work as well as the legal environment in which the law on ADRTs operates. In providing a definitional foundation for the remainder of the thesis, this chapter will serve an important role in anchoring the theoretical discussion which will be developed in the second and third parts of this thesis. As such, the task to be engaged with here is largely doctrinal, but some elements of doctrinal orthodoxy will be problematised as part of the process of setting out the law (especially the law on capacity and its implications for the right to refuse treatment).

The first part of this chapter will distinguish ADRTs from other similar instruments and ADRTs in other jurisdictions. Following this, the legal environment of ADRTs will be set out. This will involve a discussion of the law on the refusal of treatment and the law on mental capacity. As will be discussed, mental capacity is one of the most important requisites of the right to refuse treatment. Its importance for ADRTs is compounded by the fact that ADRTs require determinations of capacity at two points in time. Where mental capacity is found lacking treatment can be provided in the best interests of the patient and the law on the determination of best interests will be discussed. Following this, some of the cases that recognised ADRTs prior to the enactment of the Mental Capacity Act 2005 (“MCA”) will be discussed, before an analysis of the law on ADRTs as enacted in the MCA.¹³

¹³ Various parts of this chapter have been published in T Hayes, ‘A (Social) Room with a View (to the Future): Advance Decisions and the Problem of Personhood’ in Richard Huxtable and Ruud ter Meulen (eds), *The Voices and Rooms of European Bioethics* (Routledge 2015); T Hayes, ‘Informed Choice over Informed Consent: Cracking the Old Chestnut’ in Anthony Wrigley and Nicky Priaux (eds), *Ethics, Law and Society* (Vol V, Ashgate Publishing 2013); T Hayes, ‘Balancing Principles, Forcing Food: Self-Determination and Best Interests’ (2012) 9 *Journal of Bioethical Inquiry* 387; T Hayes, ‘Donation and Devolution: The Human Transplantation (Wales) Act 2013’ in Ralf J Jox, Galia Assadi and Georg Marckmann (eds), *Organ Transplantation in Times of Donor Shortage*, vol 59 (Springer International Publishing 2016)

ADVANCE DECISIONS TO REFUSE TREATMENT

This thesis takes the advance decision to refuse medical treatment (“ADRT”) as its focus. It is therefore imperative to define this term clearly at the outset. In offering as clear and as precise a definition of ADRTs as possible, I will examine how ADRTs are framed in law through a detailed examination of both the case law and statutory provisions of the MCA. By way of disambiguation, I will also seek to distinguish ADRTs from their analogues.

To begin with, the general definition of ADRTs is provided by s 24(1) MCA. It states:

24 Advance decisions to refuse treatment: general

(1) “Advance decision” means a decision made by a person (“P”), after he has reached 18 and when he has capacity to do so, that if—

(a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and

(b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.

This is the current definition of the ADRT in English law. It is this definition that shall be relied upon in this thesis when referring to either ADRTs, or simply “advance decisions”. Later in this chapter this basic definition will be elaborated upon in detail with reference to the rest of section 24 and sections 25-26 MCA. These sections describe the conditions under which ADRTs are recognised as valid and applicable and the interpretative rules for ADRTs, among other matters.

From the outset it should be noted that ADRTs have also been known by other terms such as ‘advance directives’ and ‘living wills’ in the past in English law and are known by different terms where they are recognised outside England and Wales.¹⁴ However, as this thesis is based primarily on the law of England and Wales the term ‘advance decision’ in this thesis both for the avoidance of ambiguity and as it is the phrase now used in the MCA.¹⁵

¹⁴ see P Lewis, ‘Medical Treatment of Dementia Patient at the End of Life: Can the Law Accommodate the Personal Identity and Welfare Problems’ (2006) 13 *European Journal of Health Law* 219

¹⁵ Royal College of Physicians *Advance Care Planning* (Concise Guidance to Good Practice Series, No 12, 2009) 2

Thus, in the absence of a clear definition, there is the potential for great confusion. This potential is heightened by the employment of multiple terms to express the same, or similar, ideas of a person being able to make decisions about medical treatment that may become clinically indicated for them in future. Such confusion is especially problematic in that some expressions of wishes regarding future treatment may be recognised as binding decisions and others may be seen only as of a persuasive, rather than a binding, nature. The distinction is that, in the latter case, healthcare professionals should have regard to the wishes that the patient has expressed, but if they act at variance to those wishes there will be no penalty, whereas, if the decision is binding, failure to respect that decision will result in the same legal sanctions which apply to failures to respect contemporaneous medical decisions.¹⁶ This is why clarity here is of great practical importance.

Another source of confusion undoubtedly arises from the fact that outside of the jurisdiction of England and Wales¹⁷ (the jurisdiction upon which this thesis focuses), it is not universally possible to express wishes as to the refusal of treatment that are binding in law.¹⁸ Notably, this is the case in France in relation to “*directives anticipées*”¹⁹ and also in Scotland where the Mental Health Care and Treatment (Scotland) Act²⁰ provides for the creation of “advance statements”²¹ to which medics “shall have regard”²², but which are not binding.²³

However, England and Wales is not the only European jurisdiction in which advance decisions are binding. In Germany, for instance, “*Patientenverfügungen*” (‘living wills’) are legally binding.²⁴ This means that care must be taken when discussing the way in which ADRTs operate in different jurisdictions in general terms.

Problematically, some authors rely on the term “advance directives” to cover a broad range of instruments, such as “written statements about a person’s preferences regarding

¹⁶ MCA, s 26 (1)

¹⁷ Unless otherwise indicated, where the term “English law” is used, it is to reference to the law of England and Wales

¹⁸ see Lewis (n 14) 225-227

¹⁹ Article L1111-11 Code de la Santé Publique; and see R Horn, “‘I don’t need my patients’ opinion to withdraw treatment’: patient preferences at the end-of-life and physician attitudes towards advance directives in England and France” (2014) 17 *Medicine, Health Care and Philosophy*, 425

²⁰ Mental Health (Care and Treatment) (Scotland) Act 2003 (asp 13)

²¹ *ibid*, s 275

²² *ibid*, s 276(3)

²³ In relation to advance statements relating to psychiatric treatment in Scotland, see J Reilly, and JM Atkinson, ‘The Content of Mental Health Advance Directives: Advance Statements in Scotland’ (2010) 33 *International Journal of Law and Psychiatry*, 116

²⁴ § 1901a *Bürgerliches Gesetzbuch* (Germany)

possible future medical decisions”.²⁵ Weller goes further, employing the phrase “mental health advance directives” as a term designed to house a number of different instruments such as ADRTs, advance statements and Ulysses contracts.²⁶ While these terms might have some value for grouping similar kinds of instrument together, the employment of such generalised categories limits the potential for more precise analysis.

Even where a relatively narrowly-defined term such as ADRT is used (to refer to legally binding refusals of treatment designed to take effect following the loss of capacity), there may still be variations in definition across different jurisdictions. This is especially likely in respect of the formalities that must be observed and any temporal limitations placed on the effectiveness of ADRTs. Consequently, there is an ongoing danger that some definitional rigour and precision may be lost in translation (both between languages and in translating the idea of the ADRT into legislation).

The phrase ‘advance directive’ may additionally face the semantic objection that the legal instrument found in the MCA does not entitle the author to ‘direct’ their medical care following the loss of capacity. In England and Wales, all that can be done with binding force is to refuse treatment²⁷ and therefore the suggestion that future treatment can be ‘directed’ is rather disingenuous. In this sense, what the phrase Advance Decision to Refuse Medical Treatment (ADRT) lacks in elegance (and succinctness) it certainly makes up for in precision. This provides another reason to prefer the more cumbersome phrase ‘ADRT’ in this thesis.

Sadly it is not only the inherent pitfalls of translation, which lie across linguistic divides, problematic in the quest for accuracy. Professional cultures sometimes develop and employ their own terminology such as the Advance Care Plan (“ACP”)²⁸ and Values History (“VH”)²⁹. These are documents which are designed to record the treatment wishes of

²⁵ MP Van Wijmen and others, ‘Advance Directives in the Netherlands: An Empirical Contribution to the Exploration of a Cross-Cultural Perspective on Advance Directives’ (2010) 24 *Bioethics* 118, 118

²⁶ P Weller, *New Law and Ethics in Mental Health Advance Directives: The Convention on the Rights of Persons with Disabilities and the Right to Choose* (Routledge 2012) 2; see T van Willigenburg and PJJ Delaere, ‘Protecting Autonomy as Authenticity Using Ulysses Contracts’ (2005) 30 *Journal of Medicine and Philosophy* 395; C Andreou, ‘Making a Clean Break: Addiction and Ulysses Contracts’ (2008) 22 *Bioethics* 25; I Gremmen and others, ‘Ulysses Arrangements in Psychiatry: A Matter of Good Care?’ (2008) 34 *Journal of Medical Ethics* 77

²⁷ *R (Burke) v The GMC* [2004] EWHC 1879 (Admin)

²⁸ see e.g. Royal College of Physicians *Advance Care Planning* (n 15); S Conroy and others, ‘Advance Care Planning: Concise Evidence-Based Guidelines’ (2009) 9 *Clinical Medicine* 76; Department of Health, *Advance Care Planning: A Guide for Health and Social Care Staff* (The NHS End of Life Care Programme, 2007)

²⁹ see DJ Doukas and LB McCullough, ‘The Values History: The Evaluation of the Patient’s Values and Advance Directives’ (1991) 32 *Journal of Family Practice* 145

patients about their future medical treatment. Such documents may contain ADRTs, but there is no requirement for them to do so.³⁰ In addition to stating any forms of treatment that the patient would wish to refuse, ACPs may also contain details of how the patient would like to be treated in a positive sense i.e. ways in which they would like their medical practitioners to treat them and the kinds of medications that they would like to be prescribed. Such requests are not binding.³¹ Moreover, providing treatment that is not considered clinically indicated would likely be a breach of the clinical duty of care.

ADRTs can therefore be housed under the taxonomic umbrella of Advance Care Planning. To this extent, they are indeed similar to what might be termed as advance statements or advance directives, but the crucial distinguishing feature and *sine qua non* of ADRTs is that they are legally binding. In contradistinction, other forms of advance statements do not have binding force except in so far as they adhere to the relevant provisions of the MCA. This distinction has important consequences when there is a conflict between a proposed course of treatment and the anticipatory instrument and an ADRT with legally binding force ought to offer greater theoretical protection to the will of the patient than a non-binding instrument.

Anyone seeking greater definitional clarity from the leading medical law textbooks is likely to be disappointed, as among them there is little consensus as to which phraseology should be adopted. For example, Jackson states that “Sections 24 and 25 of the MCA deal with advance directives, which are referred to as Advance Decisions (ADs) and defined in section 24”;³² Fennell adopts the terminology of the MCA in his textbook on *Mental Health: Law and Practice*;³³ Brazier and Cave³⁴ draw a distinction between advance decisions and advance directives,³⁵ but do so under the in-text heading “Advance Directives” which is to be found in the index of their book under the heading “Advance Decisions” (in which there is no reference to “Advance Directives”).³⁶ By contrast, Herring³⁷ refers to “Advance Decisions” in main text³⁸ but, rather confusingly, this passage is indexed under the heading “advance directives”.³⁹ In another of Herring’s books on medical law⁴⁰ (“Medical Law”

³⁰ S Conroy and others, ‘Advance Care Planning: Concise Evidence-Based Guidelines’ (n 28)

³¹ *R (Burke)* (n 27)

³² E Jackson, *Medical Law: Text, Cases and Materials* (3rd ed, Oxford University Press 2013) 243

³³ P Fennell, *Mental Health: Law and Practice* (2nd ed, Jordans 2011) paras 6.55-6.56

³⁴ M Brazier and E Cave, *Medicine, Patients and the Law* (5th ed, Penguin Books 2011)

³⁵ *ibid* para 6.14

³⁶ *ibid* 589

³⁷ J Herring, *Medical Law and Ethics* (5th ed, Oxford University Press 2014)

³⁸ e.g. *ibid* 175-178

³⁹ *ibid* 641

⁴⁰ J Herring, *Medical Law* (Oxford University Press 2011)

2011) he uses the term “advance decision” in text and employs a compromise chimera phrase “advance decisions/directives” in the index.⁴¹ Jean McHale et al refer to “Advance Directives” in their 2007 textbook in both the index⁴² and the main text⁴³ where they state that advance directives are “also known as living wills”.⁴⁴ Some confusion on the part of students, practitioners and the public is therefore forgivable, but by no means commendable, and is certainly to be avoided if possible. That is why the term used in this thesis will be the mature and precise term for a refusal of consent to medical treatment, which is accepted in English law from the Mental Capacity Act 2005 *viz* “advance decision” or ADRT.

Compounding the potential confusion that may arise through inconsistent use of conceptual labels and through the close proximity of certain concepts to one another, common understanding of ADRTs may be harmed by false information. On this point, it is alarming that mistruths about ADRTs have found their way into academic journals. In the *British Journal of Social Work* (a peer reviewed academic journal) Stein and Fineberg claim that:

“The Advance Decisions to Refuse Treatment (ADRT) process and documentation also require formal legal involvement and registration in order to be binding (Holman and Hockley, 2010).”⁴⁵

This claim, made under the heading “Advance Care Planning in the UK” is totally false. In England and Wales, the validity of ADRTs is not contingent on any “formal legal involvement” (in fact section 24(2) states that ADRTs can be written in layman’s terms with no lesser binding effect) or registration and there is no formal mechanism for their registration. Informing others of an ADRT may of course be *advisable*, as might the taking of legal advice, but failing to do either of these things will not diminish the legal force of the decision at all. In addition, treating the UK as having a uniform position in respect of ADRTs is erroneous: the MCA only operates in England and Wales.⁴⁶

That such an erroneous claim could be published in an academic journal does not bode well for any expectation that healthcare professionals, social workers or indeed the general public, may have a clear and accurate understanding of the law. It raises the worrying possibility that healthcare professionals who encounter statements that purport to be ADRTs

⁴¹ *ibid* 283-284

⁴² McHale J and others, *Health Care Law: Text and Materials* (2nd edn, Sweet & Maxwell 2006) 1182

⁴³ *ibid* 1078

⁴⁴ *ibid* 1078

⁴⁵ GL Stein, and IC Fineberg, ‘Advance Care Planning in the USA and UK: A Comparative Analysis of Policy, Implementation and the Social Work Role’ (2013) 43 *British Journal of Social Work* 233, 239

⁴⁶ MCA, s 68(4)

and who may need to assess the purported ADRT's validity and applicability will be misled or confused through having read misinformation and might therefore provide unlawful treatment to patients.

Academics and healthcare professionals are not the only groups who have been inconsistent in the conceptual labels applied to ADRTs. It is apparent that the law courts too are guilty of some muddlement of the concept. It is understandable that some of the important cases on ADRTs did not employ the terminology that would later be used in the MCA. In *HE v A Hospital NHS Trust*,⁴⁷ for instance, reference was made to 'advance directives' rather than ADRTs.⁴⁸ Harder to forgive are those judgments delivered after MCA had come into force, but which fail to adopt the terminology of the current law. For example, in *Re E*⁴⁹ the patient's ADRT was referred to by her solicitors as a "living will" and this terminology was unfortunately adopted by Senior Judge Lush.⁵⁰ Although in the case reference was made to the terminology of the MCA, it is difficult to understand why it was felt necessary to employ a different label at a later stage in the judgment. Greater consistency in the use of conceptual labels would be welcome.

Having gone to some effort to illustrate the variation in terminology that is used in this area and having suggested why the practice of employing varied terminology is problematic, it is apposite to turn to consider some of the law that underpins the law on ADRTs. The meaning and significance of mental capacity will be explored as part of this exercise at a later point in this chapter, as will the concept of 'best interests' which is significant because *in lieu* of an advance decision, treatment can be provided in accordance what is deemed to be in accordance with a patient's best interests. In addition to the discussion of these important legal concepts, the details surrounding the recognition of advance decisions, which is contained in the remainder of section 24 MCA and in sections 25-26 MCA, will also be discussed later in this chapter. This will involve looking at when the law says that advance decisions can be recognised as being valid and applicable to medical treatment. However, before any of this, the law on consent to medical treatment must be discussed, because it provides the legal basis for advance decisions. This will be discussed in the next section.

⁴⁷ [2003] EWHC 1017 (Fam)

⁴⁸ [37] (Munby J)

⁴⁹ [2014] EWCOP 27

⁵⁰ [2014] EWCOP 27 [43] (Lush J)

LEGAL BACKGROUND TO THE ENGLISH LAW ON ADVANCE DECISIONS

CONSENT TO MEDICAL TREATMENT

The law of consent to medical treatment forms the bedrock of ADRTs, as the rights accorded to a patient through ADRTs are based on the patient right to refuse treatment contemporaneously.⁵¹ It is therefore appropriate to set out how the law currently addresses the question of consent to medical treatment in some detail. Greater discussion on the development of the law on consent to treatment will be provided in the next chapter, together with a discussion of the ethical underpinnings of the law in the respect for personal autonomy.

Currently the law demands that any kind of touching involved in a medical procedure process must be approved in advance of its application.⁵² The most important way that the kind of touching that is incidental to medical treatment can be authorised is through consent. In acknowledging this point we are confronted with another conceptual uncertainty, as there is no explicit statutory definition of consent in this area of law. Consent has been defined in other areas of law, for example section 74 of the Sexual Offences Act 2003 states:

“For the purposes of this Part, a person consents if he agrees by choice, and has the freedom and capacity to make that choice.”

However, the precise meaning of consent varies across different areas of law and there have been calls for a greater level of consistency.⁵³ Nonetheless, the common idea in the understanding of consent is that there is agreement and authorisation for a specified act to proceed, in circumstances where the party whose consent is sought is free to make a choice as to whether to consent or not and has the mental capacity necessary to make that decision.⁵⁴

In simple terms, adults who have mental capacity, in respect of a specific treatment-decision, are entitled to refuse that treatment, with full legal force, for any reason or indeed for no reason at all.⁵⁵ This holds true even if the refusal of treatment is likely to lead to the

⁵¹ MCA, s 26(1)

⁵² *Collins v Wilcock* [1984] 3 All ER 374 at 378 (Robert Goff LJ)

⁵³ C Elliott and C De Than, ‘The Case for a Rational Reconstruction of Consent in Criminal Law’ (2007) 70 *The Modern Law Review* 225

⁵⁴ *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 (CA)

⁵⁵ *ibid* 113 (Donaldson of Lynton MR)

death of the patient or a viable foetus (a state of affairs not “axiomatic”⁵⁶ but arising by virtue of legal recognition).⁵⁷ Arguments in favour of so-called ‘normative consent’ (which says that where a person has a moral duty to consent, any refusal they make is potentially void)⁵⁸ hold no weight in English law. Moreover, the patient is under no obligation to justify their decision to refuse treatment to any other person.⁵⁹

Consent is recognised as ambulatory in law.⁶⁰ This construction is consistent with the underlying principle that the law aims to protect in upholding the right of each individual to determine what can be done to her by way of medical intervention. This means that a person who withdraws their consent mid-way through a procedure ought to be able to expect that the procedure should be stopped within a reasonable time, because their withdrawal of consent during the procedure ought to have the same force as the refusal prior to the procedure.⁶¹ Any refusal of treatment is of course only binding in as far as the patient does not change their mind in the intervening period.⁶²

The ordinary requirement that medical procedures must be conducted on the basis of informed patient consent is protected through law in two ways. One aspect of legal protection arises through battery which is both a criminal offence in English law as well as a civil wrong.⁶³ The courts have been reticent to treat medical cases where there has been a lack of consent under the heading of battery. In most cases, the deficiency in the consent procedure will not be so fundamental as to invoke a claim in battery.⁶⁴

By far the most important legal mechanism for protecting the consent process is negligence. Conceptually, this is unsatisfactory, as the wrong that eventuates through failing to ensure adequate consent before providing medical treatment is surely ought to be considered as a wrong not because the medical practitioner has failed to adhere to the

⁵⁶ *Contra* J Samanta and A Samanta, *Medical Law* (2nd edn, Palgrave Macmillan 2015) 428⁵⁷ *St George’s NHS Trust v S* [1999] Fam 26; *Re MB* (1997) 38 BMLR 175

⁵⁷ *St George’s NHS Trust v S* [1999] Fam 26; *Re MB* (1997) 38 BMLR 175

⁵⁸ see B Saunders, ‘Normative Consent and Opt-Out Organ Donation’ (2009) 36 *Journal of Medical Ethics* 84, 85-86

⁵⁹ *Wye Valley NHS Trust v B (Rev 1)* [2015] EWCOP 60, [5] (Peter Jackson J)

⁶⁰ See *Cooper and Schaub* [1994] Crim LR 531; Sexual Offences Act 2003 s 79(2) c.42; *R v Ashlee* 2006 CarswellAlta 1076 [25]

⁶¹ *Ciarlariello v Schacter* [1993] 2 SCR 119, 135

⁶² MCA, s 24(3)

⁶³ *Airedale NHS Trust v Bland* [1993] AC 789 (HL) 882 (Browne-Wilkinson LJ)

⁶⁴ *Chatterton v Gerson* [1981] 1 All ER 257; *Hills v Potter* [1984] 1 WLR 641

standards of their profession (as is the basis of the claim in the tort of negligence) but rather that they have failed to respect the autonomy and physical integrity of the patient.⁶⁵

The development of this area of law and the values it protects will receive further discussion in Chapter Two. For current purposes it can be observed that the logic of consent, embraced by English law, prioritises the lattermost decision in time and fully accepts the right to revoke the decision while capacity is retained.⁶⁶ The problem arises when we accept the idea that not all people are recognised as being autonomous and that people who are autonomous may lose their autonomy, through their loss of their capacity. There is no guarantee that those who have capacity in relation to a specific decision at one time will necessarily continue to have capacity in future, when they may wish to change their minds. And when we consider the refusal of future treatment, it has long been recognised that it is possible to refuse treatment prospectively as well as contemporaneously.⁶⁷ ADRTs therefore provide a means of “[c]utting across the dichotomy between the competent and incompetent”⁶⁸ through “a logical and appropriate continuation of respect for a patient’s individual autonomy in matters of medical treatment”⁶⁹ and present themselves as a possible solution for those who fear being provided with treatment that they do not want after they have lost capacity. This is the strongest legal reason for accepting the right to refuse medical treatment.⁷⁰

The recognition of ADRTs might not only be seen as a logical extension of a legal principle and normative argument, but also as concession to pragmatism. It is not at all uncommon for people to make decisions which are intended to take future effect, or apply to future conditions. Indeed, most decisions about healthcare are actually anticipatory decisions as there will usually be some temporal interlude between the communication of the

⁶⁵ T K Feng, ‘Failure of Medical Advice: Trespass Or Negligence’ (1987) 7 *Legal Studies* 149

⁶⁶ *HE v Hospital NHS Trust* [2003] EWHC 1017 (Fam) [38] (Munby J)

⁶⁷ *ibid*; *Bland* (n 63) (CA) 816-817 (Butler-Sloss LJ)

⁶⁸ *R (Burke)* (n 27) [43] (Munby J)

⁶⁹ Joint Committee on the Draft Mental Incapacity Bill, ‘Draft Mental Incapacity Bill: Volume 1’, HL (2002-2003) 189-I, HC (2002-2003) 1083-I para 199; see also *Re AK (Medical Treatment: Consent)* [2001] 1 FLR 129 (Fam) 41; *HE v Hospital NHS Trust* (n 66) [37] (Munby J); *W v M* (n 11) [226] (Baker J)

⁷⁰ see AR Maclean, ‘Advance Directives, Future Selves and Decision-Making’ (2006) 14 *Medical Law Review* 291, 291-295; *HE v Hospital NHS Trust* (n 66) [37] (Munby J); *W Healthcare NHS Trust v KH* [2004] EWCA Civ 1324 [15] (Brooke LJ); R Andorno, N Biller-Andorno and S Brauer, ‘Advance Health Care Directives: Towards a Coordinated European Policy?’ (2009) 16 *European Journal of Health Law* 207, 208; P Lack, N Biller-Andorno and S Brauer (eds), *Advance Directives* (Springer Science & Business Media 2013) vi; C Johnston, ‘Advance Decision Making – Rhetoric or Reality?’ (2014) 34 *Legal Studies* 497, 497-499; Department of Health (n 28) 10; see also R Huxtable, *Law, Ethics and Compromise at the Limits of Life: To Treat or Not to Treat?* (Routledge 2013) 65

decision and the administration of the proposed activity, be that treatment or examination, and the action to which the consent relates should occur at some point in the future. However, the kind of ADRT under discussion here are those which only take effect upon the loss of mental capacity, because such ADRTs necessarily cannot be revoked past the moment from which they take binding effect (again, unless capacity is regained).⁷¹ In this sense, they represent decisions which might warrant more serious thought on the part of the decision-maker/patient than contemporaneous treatment decisions. This would seem particularly appropriate, as unlike other forms of future medical decision, these ADRTs are applicable in circumstances in which the creator is not able to change her decision with legal effect during the treatment process itself (unless capacity is regained).

One of the most prominent and limiting features of the law on consent to treatment in English law is that the right to refuse treatment is recognised in negative terms; patients have no right to demand treatment.⁷² This point is well illustrated by the case of *R (Burke) v General Medical Council*.⁷³ The case arose from a challenge that was made to the classification of artificial nutrition and hydration as a form of medical treatment it was said that where doctor is asked provide treatment that is “not clinically indicated he is not required (i.e. he is under no legal obligation) to provide it”.⁷⁴ A similar point was also made in *Re J (A Minor) (Child in Care: Medical Treatment)*⁷⁵ where there was a question as to whether the court’s inherent jurisdiction could be used to override the “bona fide clinical judgment of the practitioner concerned”⁷⁶ regarding whether to continue life-saving or life supporting treatment for a seriously ill infant with multiple morbidities. Moreover, the provision of treatment that is not in a patient’s best interests would be unlawful.⁷⁷

This explains why the law can protect ADRTs, but cannot treat advance requests for treatment as binding. If these requests for treatment were binding it would create a disparity between the law on anticipated treatment and the on current treatment, without justification.

In addition to confining the law of consent to treatment to the negative right to refuse rather than to demand treatment, Grubb has also suggested that patient’s “probably” cannot

⁷¹ *HE v Hospital NHS Trust* (n 66) (Fam) [38] (Munby J)

⁷² *Re T* (n 54) 112 (Donaldson MR); *Bland* (n 63) (HL) 864 (Goff LJ); *AC v Berkshire West Primary Care Trust* [2010] EWHC 1162; *R (Burke)* (n 27); see also D Wendler, 'Are physicians obligated always to act in the patient's best interests?' (2010) 36 *Journal of Medical Ethics* 66

⁷³ [2005] EWCA Civ 1003

⁷⁴ *ibid* [50] (Lord Phillips MR)

⁷⁵ [1993] Fam 15

⁷⁶ *ibid* 26-27 (Donaldson of Lynton MR)

⁷⁷ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 [19] (Hale LJ)

refuse “what is often termed as ‘nursing care’”.⁷⁸ It would be unlikely that someone would wish to refuse this kind of palliative care in any case, but if this Grubb is correct, then logically, it would not be possible to refuse this kind of care through an ADRT either. This conclusion is also supported by the MCA code (to which anyone providing treatment to an incapacitated adult must ‘have regard’)⁷⁹ which indicates that an ADRT cannot be used to refuse “basic or essential care”.⁸⁰

Perhaps the next most significant restrictions on the availability of ADRTs are that they cannot be created by children or by those who lack mental capacity to make the relevant decision.⁸¹ This reflects the rule that children generally lack the right to refuse treatment that is in their best interests⁸² and similarly, adults who lack mental capacity to make the specific decision in question can be provided with treatment in their best interests.⁸³ However, there is no provision to allow *Gillick*-competent⁸⁴ children to create an ADRT and it is not impossible to envisage circumstances in which a child may wish to create an ADRT (e.g. following the diagnosis of a terminal illness) and on this point English law stands in contrast to Belgian law under which it is not only possible for children to make ADRTs, but also to make advance requests for euthanasia.⁸⁵

This position is consistent with the rights that children enjoy in relation to consent to contemporaneous treatment. In such cases, children can consent to treatment if they can demonstrate that they have capacity,⁸⁶ but they do not have the same rights as adults to refuse consent treatment. Lord Hoffmann remarked in *Bland*, “English law is, as one would expect, paternalist towards minors. But it upholds the autonomy of adults”.⁸⁷ The court retains the power to override a refusal of treatment from a minor in his or her best interests where that refusal of treatment would be likely to result in serious injury or death.⁸⁸

In respect of adults, the qualification on the right to refuse treatment that has the greatest potential effect is that the right can only be enjoyed by those who have mental capacity.

⁷⁸ A Grubb ‘United Kingdom: Treatment Without Consent: Adult: Re T (Adult: Refusal of Treatment)’ (1993) 1 Medical Law Review 83, 85

⁷⁹ MCA, s 42(4)

⁸⁰ Department for Constitutional Affairs, *Mental Capacity Act 2005: Code of Practice* (The Stationary Office, 2007) para 9.28

⁸¹ MCA, s 24(1)

⁸² *Re W (A Minor Medical Treatment: Court's Jurisdiction)* [1992] 4 All ER 627

⁸³ MCA, s 24(1); *Re E* (n 10)

⁸⁴ *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112

⁸⁵ The Belgian Act on Euthanasia Chapter III, s 4, §1

⁸⁶ *Gillick v West Norfolk and Wisbech AHA* [1986] 1 AC 112; *R (on the application of Axon) v Secretary of State for Health* [2006] EWHC 37 (Admin)

⁸⁷ *Bland* (n 63) (CA) 827 (Hoffmann LJ)

⁸⁸ *Re KW and H (Minors) (Medical Treatment)* [1993] 1 FLR 854

Restricting the right to refuse treatment to those with capacity is a significant deviation from the trajectory of the political project aimed at granting individuals greater control and responsibility over their lives through choice,⁸⁹ while restricting patriarchal control. Central among the reasons for granting the right to create ADRTs is to provide a means for resting back control over medical treatment during a period of incapacity.

In the foregoing discussion I have sought to explain why the concept of mental capacity holds a central place in the law on consent to treatment and *a fortiori* to the law on ADRTs. In the next section, I will turn to explain how the law defines mental capacity and the tests the law institutes for its assessment.

CAPACITY

One of the most important principles of the MCA is that everyone is presumed to have mental capacity unless they are found to lack capacity.⁹⁰ A finding that a person lacks capacity can only be made upon assessment and in relation to a specific decision.⁹¹ As discussed above, a finding that an individual lacks capacity is the primary way in which any person can lose the right to refuse treatment (this right might also be lost in the event that the person is being detained under the Mental Health Act 1983 (“MHA”) for the assessment or treatment of a mental disorder). As such, the construction of capacity and the rules governing its assessment are of great legal and practical significance.

If a patient is found to lack capacity in respect of a specific treatment decision, she can be given treatment that is in her best interests notwithstanding her refusal of treatment. This possibility marks a radical departure from the legal rights enjoyed by adults with capacity and given that capacity is a quality that is dependent on a ‘functional test’ (which will be discussed later in this section) rather than a particular status, it is possible that any individual may lack capacity at a future point in time. Adult persons who satisfy the test of capacity are accorded the full support of the law in denying any medical intervention to which they do not consent.⁹² Patients need give no reason for any refusal of treatment and if they do give a

⁸⁹ K Veitch, ‘The Government of Health Care and the Politics of Patient Empowerment: New Labour and the NHS Reform Agenda in England’ (2010) 32(3) *Law & Policy* 313; K Veitch, *The Jurisdiction of Medical Law* (n 8) 42-47

⁹⁰ MCA, s 1(2)

⁹¹ MCA s 1(2); see J Coggon, ‘Alcohol Dependence And Anorexia Nervosa: Individual Autonomy And The Jurisdiction Of The Court Of Protection: *An NHS Foundation Trust v Ms X* [2014] EWCOP 35; (2014) 140 BMLR 41” (2015) 23(4) *Medical Law Review* 659; T Hayes, ‘Balancing Principles, Forcing Food: Self-Determination and Best Interests’ (n 13)

⁹² *St George’s NHS Trust* (n 57)

reason, there is no requirement that it be rational, or moral.⁹³ The possibility that capacity might be lost in future and might be averse to receiving treatment that might otherwise be provided in his or her best interests is the sole *raison d'être* of the ADRT.

The current law that governs mental capacity in England and Wales is found in the MCA. One of the central objectives of the MCA was to draw together the common law on capacity into one statute.⁹⁴ The pursuit of that objective has meant that the MCA addresses matters beyond the provision of medical treatment, but those matters will be the focus of the discussion here. To begin with, section 1 lists some general principles that apply.

1 The principles

- (1) The following principles apply for the purposes of this Act.
- (2) A person must be assumed to have capacity unless it is established that he lacks capacity.
- (3) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
- (4) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- (5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
- (6) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Perhaps the most important of these principles is that no one can be deemed as lacking in capacity unless this is proven in relation to a specific decision.⁹⁵ This is a principle that reflects the pre-existing common law position.⁹⁶ Its effect is that the evidential burden of establishing incapacity falls on the party who contests the capacity of the patient. Section 1(3) imposes an obligation to assist a person in arriving at a decision before concluding that they lack capacity to decide. Section 1(4) rearticulates the common law position from *Re T* that the perceived wisdom of a decision is not to be considered as a factor in the assessment of capacity.⁹⁷ A post-MCA example of the application in this section can be seen in *Heart of England v JB* in which it was said that the “isolated instances of eccentric reasoning” were

⁹³ *Re T* (n 54); *Wye Valley NHS Trust v B* (n 59)

⁹⁴ The Law Commission *Mental Incapacity* (LC231, 1995); Explanatory Notes to the Mental Capacity Act 2005, paras 3-5

⁹⁵ J Coggon, ‘Alcohol Dependence And Anorexia Nervosa’ (n 91) 666–667

⁹⁶ *Re MB* (n 57)

⁹⁷ *Re T* (n 54)

not sufficient evidence from which incapacity could be deduced.⁹⁸ Section 1(5) demands that decisions are made in the best interests of those who lack capacity. It has been suggested that that section 1(5) impliedly precludes the possibility of relying on ADRTs that are not in accordance with the best interests where a person has changed so much since creating the ADRT that they might be considered to be a different person.⁹⁹ However, such a reading of the law would render the provisions of sections 24-26 MCA redundant and is at odds with the way the law has subsequently been interpreted.¹⁰⁰ On the basis that Parliament would not have gone to the trouble of debating and enacting redundant legislative provisions, section 1(5) cannot be read in such a way as to require the terms of ADRTs to conform with the best interests test (from section 4 MCA).

Section 1(6) sets out a principle of minimum intervention in seeking to achieve a person's best interests in order to maximise the "rights and freedom of action" of the person being treated. The application of this principle can be seen clearly in applications for sterilisation which have been dismissed by the courts such as *A Local Authority v K*¹⁰¹ and *Re A (Medical Treatment: Male Sterilisation)*¹⁰² where the courts decided that there were other, less invasive, ways that could be employed to avoid conception.

One principle not directly stated but which can be identified from the totality of the provisions in section 1, and in the MCA more generally, is that of functionalism. The functionalist doctrine prescribes a test for capacity based on the ability of the assessed person to function and can be contrasted with the status-based approach, which is grounded in the contention that capacity can be discerned from a person's status (particularly in relation to any mental health diagnoses).¹⁰³ The 'status approach' can be considered problematic because evidence of a mental disorder does not necessarily, and of itself, render a person incapable of making decisions. Under the auspices of the functionalism, whether the patient has a mental disorder is considered irrelevant (although they must be suffering an "impairment of, or a disturbance in the functioning of, the mind or brain"¹⁰⁴), as is all the patient history irrelevant. The main concern is whether the patient can satisfy prescribed tests which are used to identify competence to make the particular decision being faced. This

⁹⁸ *Heart of England NHS Foundation Trust v JB* [2014] EWCOP 342, [40] (Peter Jackson J)

⁹⁹ See C Foster, 'Advance Directives and Personality-Changing Illness' (2010) 19 *British Journal of Nursing*, 986; see also Chapter Five

¹⁰⁰ See e.g. *W v M* (n 11) [6] (Baker J)

¹⁰¹ [2013] EWHC 242

¹⁰² [2000] 1 FLR 549

¹⁰³ J Jackson, 'Determining Incompetence: Problems With the Function Test' in A Grubb (ed) *Decision-Making Problems of Incompetence* (John Wiley & Sons 1994) 56

¹⁰⁴ MCA, s 2(1)

is related to the principle that no one is to be treated as being unable to make a decision merely on the basis that the decision they wish to make may be considered unwise.¹⁰⁵ The functionalist credentials of the MCA are made plain in section 2 which describes when a person lacks capacity:

2 People who lack capacity

(1) For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.

The MCA code of practice lists dementia, learning difficulties and the “symptoms of alcohol or drug use” among other things as factors which may lead to the relevant kind of “impairment of, or a disturbance in the functioning, of the mind or brain”.¹⁰⁶ Section 2(2) makes clear that the relevant kind of impairment or disturbance can be of a transient nature or of a longer lasting nature. The relevant kind of impairment or disturbance must be established as part of the assessment of capacity prior to considering the next question, which is whether the disturbance or impairment has caused the person to be unable to make a decision.

The current test for determining whether a person is unable to make a decision is found in section 3 MCA and owes much to the three stage test propounded by Thorpe J in *Re C*¹⁰⁷ viz 1) whether the patient can comprehend and retain the relevant information, 2) whether the patient believes the information being given to them and 3) whether the patient can weigh and balance the information they have received in order to arrive at a decision. Section 3 of the MCA states:

3 Inability to make decisions

(1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable—

(a) to understand the information relevant to the decision,

(b) to retain that information,

(c) to use or weigh that information as part of the process of making the decision, or

¹⁰⁵ MCA, s 1(4)

¹⁰⁶ Department for Constitutional Affairs (n 80) para 4.12

¹⁰⁷ *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 All ER 819 (Fam)

(d) to communicate his decision (whether by talking, using sign language or any other means).

The first requirement of the test is that the person being assessed must be able to “understand the information relevant to the decision”.¹⁰⁸ This is aimed at ensuring that those making decisions are able to do so on an informed basis. The MCA makes clear that this is not a requirement to be able to retain the information permanently. Section 3(3) MCA states that no one is to be treated as being unable to make a decision where they only retain the relevant information for a “short period”, indeed the information need only be retained for as long as is necessary to make the decision.¹⁰⁹ The prominent place of these informational tests reflects the great weight bestowed upon the communication of information as part of the consent process. The next requirement is that the person must retain that information.

Section 3(4) provides an indication of the kind of information that is material to the capacity assessment. It states that the relevant information includes “information about the reasonably foreseeable consequences of – a) deciding one way or another b) failing to make a decision”. In the case of *A Local Authority v A*¹¹⁰ Bodey J opined that “wider social consequences”¹¹¹ should not be included in the purview of the information required to make the decision and that where a decision can be construed as a medical decision, it is the “proximate medical issues”¹¹² which comprises the relevant information.

The requirement for the information to be ‘believed’ that was espoused in *Re C* has not been replicated in s.3 of the MCA. However, it has been argued that a person who does not believe in the information that is presented to them would still fail the test of capacity under the new law on either section 3(1)(a) or section 3(1)(c).¹¹³ The belief criterion found in the pre-MCA version of the test for capacity was also alluded to in the 2014 case *A NHS Foundation Trust v Ms X (By Her Litigation Friend, the Official Solicitor)*¹¹⁴ as part of a capacity assessment made by Dr A (a consultant psychiatrist who was held out as being experienced in making such assessments).¹¹⁵ This insistence on the belief criterion was erroneous, but of no material consequence in that case.

¹⁰⁸ s 3(1)(a)

¹⁰⁹ See Explanatory Notes to the Mental Capacity Act, para 26; see also Department for Constitutional Affairs (n 80) para 4.20

¹¹⁰ [2010] EWHC 1549 (Fam)

¹¹¹ *ibid*[60] (Body J)

¹¹² *ibid* [64] (Body J)

¹¹³ N Hoppe and J Miola, *Medical Law and Medical Ethics* (Cambridge University Press 2014) 92, FN57

¹¹⁴ [2014] EWCOP 35 [27]

¹¹⁵ see J Coggon, ‘Alcohol Dependence And Anorexia Nervosa’ (n 91) 666-667

One important objection to the reliance on these tests for capacity is that whether the patient can satisfy the tests may be heavily influenced by the adequacy of the communication and presentation of that information by the healthcare professional (“HCP”).¹¹⁶ Chapter Three of the MCA Code of Practice sets out how people should be helped to make decisions. It explains how information can be presented to make it easier for patients to understand and how people should be given time and support to make their decisions. The aspiration is very noble, but it is by no means certain that this advice is adopted in practice and unless a case is brought to the attention of a court or an ethics committee, it is unlikely that a capacity assessment will be scrutinised. Consequently there is a considerable component of what is being tested here which is not entirely attributable to the patient. In this respect, these first two criteria could also serve as a test for the competence of the HCPs communication; however the substantive consequence of failing the test is only directly felt by the patient, and not the HCP.

The third requirement in the assessment criteria is that the patient must be able to weigh and balance the information given to them. This criterion is said to require “emotional competence”¹¹⁷ on the part of the patient. However, the patient’s ability to demonstrate this will be looked at from the perspective of, in the first instance, the assessor, and ultimately, the court and these perspectives are value-laden prisms.¹¹⁸ It may be difficult for the assessor to detach themselves from their own opinion on what weight should be given to the relevant factors (particularly as the assessor is likely to be the HCP who has proposed the particular treatment).¹¹⁹ This may be a particular risk where the outcome of the decision may risk the life of the patient.¹²⁰ This is perhaps the most controversial element of the test for capacity, because it intrudes so far into the patient’s judgement process and gives the appearance of prescribing certain decision-making criteria of the kind that cannot be required of those with mental capacity.¹²¹ Herein lies the paradox: one who has capacity is free to make an unbalanced judgement, but where capacity is under examination, evidence that the material decision is unbalanced is evidence, in part, that capacity is lacking.

In a more fundamental sense, we might ask why a person should be required to weigh and balance information before making a decision. What is wrong with making snap

¹¹⁶ E Jackson, *Medical Law: Text, Cases and Materials* (n 32) 198

¹¹⁷ P Fennell, 'Mental Capacity' in L Gostin et al (eds), *Principles of Mental Health Law and Policy* (Oxford University Press Oxford 2010) para 4.69

¹¹⁸ see T Grisso and PS Appelbaum, 'Values and Limits of the MacArthur Treatment Competence Study' (1996) 2 *Psychology, Public Policy, and Law* 167, 169

¹¹⁹ see *A NHS Trust v Dr A* [2013] EWHC 2442 (COP) [34] (Baker J);

¹²⁰ P Fennell, *Mental Health: Law and Practice* (n 33) para 2.69

¹²¹ *Re T* (n 54)

decisions? What is wrong with making decisions on the basis of intuition without comparing alternative possibilities? Indeed, society promotes some decisions to be made under conditions which are known to militate against rationality. For example, it is commonly thought that people get married because they have fallen in love, but (even accepting the empirical veracity of this) we know that love can become delusional¹²² and yet “we allow people to consent to marriage who are ‘madly’ in love”.¹²³ Arguably, the bias in favour of the decisions involving weight and balance promotes a certain kind of decision-making and excludes the making of ‘irrational’ decisions. This is to be contrasted with the way in which the principle of individual autonomy is construed in law as allowing a person to make a decision for any reason, even ones which are irrational, or no reason at all.¹²⁴ Coupled with this, the foundation of the MCA (which has codified the old law¹²⁵ and many of the principles already to be found in the common law¹²⁶) is the doctrine of functionalism.¹²⁷ The functionalist aspirations of the MCA can be seen in the provisions that ensure that people should not be treated as though they lack capacity based on assumptions relating to their behaviour.¹²⁸ Instead the focus is on the ability to process information (s.3) and this focus prevents untested behavioural assumptions being used to deny a person’s capacity.

Although the functionalist approach can be implied in the written law, this is no guarantee that functionalism will be realised in practice. Where the reasons underlying a decision are deemed to be absurd or irrational, there would seem to be a greater likelihood that capacity will be scrutinised more closely. And given that those who will be placing it under scrutiny (at least in the first instance) by those who have some cause to doubt capacity, it would seem that there would be a greater likelihood that capacity would be found lacking. Because whatever picture of disinterested functionalism is painted, assessing capacity is ultimately a normative endeavour¹²⁹ and by denying capacity under certain conditions, but not others, a view is declared regarding which kind of decisions are good, as well as which kind of conditions are necessary for good decision-making.

¹²² Z Lothane, 'Omnipotence, or the Delusional Aspect of Ideology, in Relation to Love, Power, and Group Dynamics' (1997) 57 *The American Journal of Psychoanalysis* 25, 30-31

¹²³ J Jackson, 'Determining Incompetence: Problems With the Function Test' (n 103) 55

¹²⁴ *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC 871 (HL) 904-905 (Templeman LJ)

¹²⁵ M Brazier and Cave E (n 34) 125

¹²⁶ P Fennell, 'Mental Capacity' (n 117) para 4.14

¹²⁷ M Brazier and Cave E (n 34) 126

¹²⁸ MCA, s 2(3)(b). But, compare this with the broadening of the definition of mental disorder under the Mental Health Act 2007 c.12

¹²⁹ ER Saks and DV Jeste, 'Capacity to Consent to or Refuse Treatment and/or Research: Theoretical Considerations' (2006) 24 *Behavioural Sciences and the Law* 411, 413

Suspensions over the true commitment to a functionalist standpoint may be fuelled by part of the recommendations of Joint Parliamentary Committee's report on the Mental Incapacity Bill¹³⁰, which stated:

We recognise that advance decisions which they may not otherwise wish to make may be made by those suffering from depression, stress or other conditions that would affect their judgment... We therefore recommend that the Codes of Practice should require doctors to satisfy themselves that any advance refusal of treatment is valid and applicable.¹³¹

The implied message is that people who are suffering from depression or even mere stress are not competent to make valid advance directives and that HCPs can rely on evidence of such a state of mind at the material time in order to avoid being bound by any such decision. Plainly this message is at odds with the functionalist approach and the spirit of the provisions of section 4 of the MCA. It might also be questioned whether a true functionalism is really possible in practice.

Moreover, special concerns have been raised over the assessment of capacity of psychiatric patients¹³² and Haywood has also argued that in practice it may be difficult to dissociate the existence of a mental disorder from the assessment of capacity because "there is a view among judges that the very nature of the underlying mental illness from which a patient is suffering makes it impossible to meet the functional requirement of using and weighing the relevant information to make a decision".¹³³ This lends to the suspicion that test for capacity is not merely a scientific test of cognitive functionality, but a "moral" test.¹³⁴

Concerns over the strict adherence to functionalist pretensions aside, the MCA also adds a new stage to the old common law test from *Re C*: the requirement that the patient must be able to communicate their decision. The MCA explanatory notes also suggest that section 3(1)(d) is a "residual category" and that it will "only affect a small number of persons".¹³⁵ At face value this provision seems sensible, but in practice, the ability to communicate a decision may be affected by factors which are beyond the control of the patient. In order to attempt to counteract the possibility that a person could be unfairly denied her or his

¹³⁰ As it then was

¹³¹ Joint Committee on the Draft Mental Incapacity Bill (n 69) para 206

¹³² J Vollmann, 'Advance Directives in Psychiatry' in Peter Lack, Nikola Biller-Andorno and Susanne Brauer (eds), *Advance Directives* (Springer Science & Business Media, 2013) 42-45

¹³³ R Heywood, 'Revisiting Advance Decision Making Under the Mental Capacity Act 2005: A Tale of Mixed Messages' (2015) 23 *Medical Law Review* 81, 91

¹³⁴ T Grisso and PS Appelbaum (n 118) 169

¹³⁵ Explanatory notes to the Mental Capacity Act, para 27

opportunity to make a choice, the MCA imposes an obligation to take “all practicable steps” have been taken to help the person to make the decision. It is slightly unclear as to what all practical steps may mean in day-to-day reality with all the time pressures of modern medical practice. If a very restrictive view is taken as to what constitutes “all practicable steps” a person with a stammer, for example, may be rendered incompetent by an impatient or unsympathetic HCP. This requirement also could deny the legal rights of some patients, such as those in a persistent vegetative state, who might be able to communicate, where they can be provided with the technological means to do so.¹³⁶

Theoretically these problems are set to arise frequently as capacity should be established prior to each occasion on which consent is sought and as has already been discussed, any patient wishing to create an ADRT must have capacity and it must be shown that they have lost capacity before the ADRT will come into actual effect. However, the Code of Practice¹³⁷ states that a full assessment should only be made where capacity is in doubt.¹³⁸ Again though, it seems implicit that the party casting doubt will be an HCP and the discretion that this affords them surely beholds a significant retention of systemic paternalism. So it can be seen that the repeated invocation of the tests for incapacity could be used instrumentally, in order to create self-doubt in the mind of the patient and pressurise them to comply. For if an HCP decides to test the patient’s capacity following their refusal to undergo a specific form of treatment, even if the patient is found to have capacity, an air of suspicion will have been raised over his or her mental capacity. This suspicion may be implied in the written records that the doctor makes and may be transmitted to other healthcare professionals, which may, in turn, influence their perception of the patient.¹³⁹ The influence of this suspicion is heightened by the fact that it is made by a well-respected class of person (a doctor or HCP) and is made during the course of a professional activity which considered of great social utility: the practice of medicine. The ultimate consequence may be that the patient will be found to lack capacity and those who test for capacity may find the result they sought.

The courts have noted that there is a danger that those who perform capacity assessments may have a bias towards protecting the patient, because that is one of the central

¹³⁶ Recent research indicates that this is something that could be relevant for patients in persistent vegetative states: <http://www.telegraph.co.uk/science/7159464/Do-we-want-brain-scanners-to-read-our-minds.html> (accessed 5/2/2010)

¹³⁷ Department for Constitutional Affairs (n 80)

¹³⁸ *ibid* para 4.34

¹³⁹ See MK Temerlin, 'Suggestion Effects in Psychiatric Diagnosis' in TJ Scheff (ed) *Labelling madness* (Prentice-Hall 1975)

functions of their job.¹⁴⁰ Moreover, it should be remembered that the assessment of capacity is something that happens routinely without going to court¹⁴¹ and many assessments of capacity are unlikely to receive legal scrutiny. Problems such as these pre-existed the MCA framework, particularly in relation to decisions where life-saving treatment was being refused, people were found to lack in capacity e.g. *Re E*.¹⁴² This brought into plain view the tension between the law's commitment to autonomy and its commitment to the sanctity of life.¹⁴³ However, it has also been suggested that in other cases, such as *Re C*, the courts have not found capacity lacking where the patient has refused life-saving treatment, because the life of that particular patient is implicitly not considered to be of sufficiently great value.¹⁴⁴ The possibility that there could be some truth in such a suggestion demands that we give greater thought to the level of discretion available to HCPs and the courts in determining capacity.

This is not to suggest any malevolent attitude on the part of the HCP, but when HCPs carry out capacity assessments, they will be doing so in a particular environment, with a particular professional identity and may thus embody certain values, which, in turn, may have some effect on their assessment.¹⁴⁵ This is not the fault of HCPs it is merely to be expected. But we must therefore be alive to the fact that the decision to declare another person incapable of making a specific decision may be motivated by personal opinion regarding what is best for that person. If it is known that a certain kind of treatment is commonly indicated as being within a person's best interests in a given situation as is facing the patient under assessment, which the assessor also considers best for the patient, there may be some motivation to find the patient lacking in capacity, because then the best interests treatment could be provided (even if it went against the will of the patient). Indeed, in relation to mental disorders, it has been found that where treatment is refused, capacity is found to be lacking on more than 90% of instances.¹⁴⁶ At first sight, ADRTs might be thought of as a way to nullify such a problem, for if the HCP (assessor) does consider there to be a lack of capacity in relation to a specific decision, then the ADRT, in so far as it speaks to the circumstances of the decision, should take effect. However, if the patient does

¹⁴⁰ *A NHS Trust v Dr A* (n 119) [34] (Baker J)

¹⁴¹ *A Local Authority v A* [2010] EWHC 1549 (Fam) [60] (Bodey J)

¹⁴² *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386

¹⁴³ S Michalowski, 'Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right' (2005) 68 *The Modern Law Review* 958; AR Maclean, 'Advance Directives and the Rocky Waters of Anticipatory Decision-Making' (2008) 16(1) *Medical Law Review* 1, 3-7

¹⁴⁴ *ibid* 5

¹⁴⁵ M Donnelly, 'Capacity assessment under the Mental Capacity Act 2005: Delivering on the functional approach?' (2009) 29 *Legal Studies* 464, 474-477

¹⁴⁶ *ibid* 477 citing Appelbaum, 1994

have such an ADRT, there may be a motivation, in addition to finding the patient incapable of making the relevant decision, to find fault with the ADRT. One way to do this would be for the HCP to cast doubt on the capacity of the same person both at the time that they present themselves, but also at the time that they created the ADRT itself. A successful argument in relation to both of these factors would result in the ability to provide treatment to the patient in accordance with her best interests.

Added to the concerns that HCPs may be motivated to find capacity lacking, there remains the considerable concern that those assessing capacity may not know how to assess it correctly.¹⁴⁷ For instance, in *NHS Trust v T (Adult Patient: Refusal of Treatment)*¹⁴⁸ the consultant psychiatrist who interviewed the patient who had signed an ADRT said: “I say she does not have the capacity because she is affected by [borderline] personality disorder”.¹⁴⁹ A person is not to be deemed to lack capacity merely on the strength of a diagnosed mental disorder. However, similar objections might be raised against Wall P’s judgment in *DH NHS Foundation Trust v PS*¹⁵⁰ where he concluded from a psychiatrist’s report that PS did not have mental capacity “to make decisions concerning her future medical treatment”.¹⁵¹ The MCA is concerned with capacity at the point of making a specific decision¹⁵², not future decisions in general.

MENTAL CAPACITY ASSESSMENT AND ADRTS

Various problems with these criteria, which cannot be explored in detail here¹⁵³, but given that the test for capacity is of such importance for the validity of ADRTs something must be said. This is because assessment of capacity is relevant on at least two separate occasions for ADRTs: at the moment of their creation¹⁵⁴ and at the moment of their application.¹⁵⁵ This double relevance of assessment compounds problems associated with each separate aspect of the test. But there is an additional difficulty here, because at least one assessment of capacity is likely to be retrospective (unless the patient had their ADRT witnessed by an HCP or had other evidence that they had capacity at the material time) this means that the assessment must be made based on current information about a previous state

¹⁴⁷ See *ibid* 471-474, 480

¹⁴⁸ [2004] EWHC 1279 (Fam)

¹⁴⁹ *NHS Trust v T (Adult Patient: Refusal of Treatment)* [2004] EWHC 1279 (Fam) [16] (Charles J)

¹⁵⁰ *DH NHS Foundation Trust v PS* [2010] EWHC 1217 (Fam)

¹⁵¹ *ibid* [4] (Wall P)

¹⁵² Department for Constitutional Affairs (n 80) para 4.3

¹⁵³ But see M Donnelly, 'Capacity assessment under the Mental Capacity Act 2005: Delivering on the functional approach?' (n 145)

¹⁵⁴ s 24(1), MCA

¹⁵⁵ s 25(3), MCA

of mind, which may often be sparse and incomplete. This requires assessors to make important judgments with limited evidence.¹⁵⁶

This places anyone wishing to create an ADRT in an invidious position, because they must express their decision in a clear and precise way if it is to be recognised as valid¹⁵⁷ and naturally the author may wish to offer the reasons for their decision to demonstrate that they comprehend the kind of medical treatment which they are minded to decline. However, in doing so, it would be legitimate to have concern that the reasons given might not be considered sound or rational by others. Indeed, anyone making an ADRT will necessarily reason differently from what they anticipate others would consider to be in their best interests. In turn, it is possible that such people may be discouraged from making an ADRT, if they consider that their decision, or the reasons for it, may cast doubt on their mental constitution.

At the beginning of this section, it was emphasised that the concept of capacity and the rules surrounding its assessment are of great importance for the law on ADRTs, because mental capacity is a fundamental condition on the creation of ADRTs. Its importance is so great in this area, because a person must have capacity to create an ADRT¹⁵⁸ in the first place and must lack mental capacity before the ADRT can take binding effect as a refusal of treatment.¹⁵⁹ It is for this reason that it has been vital to look at some of the defects in the law on capacity and its assessment. The commonality of the concerns that have been identified and discussed thus far is their paternalism. Providing greater power and discretion to HCPs in the assessment of capacity and of the validity of ADRTs increases the fragility of the patient's right to autonomy in practice insofar as ADRTs are designed to increase patient autonomy (or self-determination, or choice, or empowerment etc). These themes will be considered further in the second part of this thesis.

However, any fears of patient's the will being substituted with that of the HCP can be somewhat allayed, because where capacity is lacking, treatment can only be given if it is in accordance with the best interests of the patient.¹⁶⁰ The modern conceptualisation of best interests is designed at creating a significant protective boundary from the decision-making of the HCP. Furthermore, as shall be seen in the next section, the patient's own views have

¹⁵⁶ See R Heywood, 'Revisiting Advance Decision Making Under the Mental Capacity Act 2005: A Tale of Mixed Messages' (n 133) 91

¹⁵⁷ MCA, s 25(4)

¹⁵⁸ MCA, s 24(1)

¹⁵⁹ MCA, s 25(3)

¹⁶⁰ MCA, s 1(5)

taken on an even more prominent role since the enactment of the MCA. This change is well aligned with the more general move towards increased patient rights and patient choice.¹⁶¹ Given this, it becomes crucial to explore further the meaning of the legal conceptualisation of best interests.

BEST INTERESTS

In stark contrast to the legal position that governs mentally competent adults, persons who lack capacity can be given treatment if that treatment is shown to be in their ‘best interests’.¹⁶² Indeed, HCPs are under a duty to provide patients with treatment that is clinically indicated and in best interests of the patient.¹⁶³ Therefore, it is important to have some appreciation of how best interests are determined.

Best interests treatments were once determined in accordance with the *Bolam* test.¹⁶⁴ This test required a doctor to be able to prove that, under the same circumstances, “a responsible body of medical men”¹⁶⁵ would have thought the same treatment to be proper, for the court to recognise that they had acted in accordance with their duty of care. As such, it was very difficult for the claimant to prove that any treatment given was not in his or her best interests. This gave doctors near total control in deciding what treatment to administer where capacity was lacking.¹⁶⁶

It has been argued that *Bolam* could have been interpreted imposing a normative standard on the medical profession (i.e. setting a standard to which practitioners should adhere), but it was instead interpreted as merely placing an onus on medical practitioners to prove that their actions were in accordance the standard of care that was observably normal in practice.¹⁶⁷ Such an interpretation would have enabled the courts to intervene more readily to regulate medical standards through the imposition of external norms. However, subsequent legal developments, particularly the case of *Bolitho*, have largely achieved that goal and have reined-in the power of medics in the determination of best interests by

¹⁶¹ see *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 [75] (Kerr and Reid LLJ); see K Veitch, ‘The Government of Health Care and the Politics of Patient Empowerment: New Labour and the NHS Reform Agenda in England’ (n 89)

¹⁶² MCA, s 5

¹⁶³ *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1 (HL) 17-19 (Donaldson MR)

¹⁶⁴ *F v West Berkshire Health Authority* [1989] 2 All ER 545 (HL)

¹⁶⁵ *Bolam v Friern Hospital Management Committee* [1957] 2 All ER 118 (QBD) 122

¹⁶⁶ M Brazier and Cave E (n 34) para 6.6

¹⁶⁷ J Miola, *Medical Ethics and Medical Law: A Symbiotic Relationship* (Hart 2007) 11-12

introducing the onto the *Bolam* test the rider that demands that the standards of medical practice must withstand logical scrutiny.¹⁶⁸

Section 4 of the MCA now stipulates a number of factors that must be taken into account in the assessment of best interests. Notably, it has made extra-clinical matters relevant such as the emotional and social impact of the treatment to consider in the determination of best interests.¹⁶⁹ Significantly, HCPs are now under a duty to consider the preferences of the individual and to take reasonable steps to establish what those preferences would have been where that person cannot express them for themselves.¹⁷⁰

These various factors are to be assessed in relation to the ‘balance sheet’ approach advocated in *Re A (Male Sterilisation)*¹⁷¹, which involves consideration of the *pros* and *cons* of each particular possible treatment, which fall within the range of treatments available under a *Bolam* assessment¹⁷², on a balance sheet before deciding on whether the treatment should be provided.¹⁷³

This appears to be an even-handed and sensible way of finding out what is in a person’s best interests. However, the decision as to what weight to give these preferences is ultimately one for the courts to make. Mr Justice Munby made clear in *ITW v Z* that the weight that would be given to patient preferences would vary from case to case.¹⁷⁴ He also suggested that the weight that should be attached to the patient’s own views could vary with the degree of their incapacity and an assessment as to whether the views are sensible.¹⁷⁵ Such a position can be read in contrast to the fierce defences of the right to refuse treatment espoused some cases on consent to treatment.

The question of how much weight to accord to the patient’s own wishes becomes particularly acute when there is a conflict between the wishes of the patient and medical opinion. Clearly, for all its simplistic appeal, the ‘balance sheet’ approach still requires the taking of normative decisions and therefore reasons which may be very important to some people may be accorded ‘no weight’ on the normative outlook of HCPs or the courts. This is

¹⁶⁸ *Bolitho v City and Hackney HA* [1998] AC 232, 243 (Browne-Wilkinson LJ); see also M Brazier and J Miola, ‘Bye-Bye *Bolam*: A Medical Litigation Revolution?’ (2000) 8 *Medical Law Review* 85

¹⁶⁹ MCA, ss 4(1)-(7); Department for Constitutional Affairs (n 80) paras 5.13-5.15

¹⁷⁰ MCA, s 4(6)

¹⁷¹ [2000] 1 FLR 549 (CA)

¹⁷² P Fennell, *Mental Health: Law and Practice* (n 33) para 6.50

¹⁷³ *Re A (Male Sterilisation)* [2000] 1 FLR 549 (CA) 560 (Thorpe J); *NHS Trust v T* (n 149)

¹⁷⁴ [2009] EWHC 2525 (Fam) [32] (Munby J)

¹⁷⁵ *ibid* [35] (Munby J)

illustrated in the case of *NHS Trust v T (Adult Patient: Refusal of Treatment)*.¹⁷⁶ The court was asked to grant an interim declaration against the patient's purported ADRT and to permit her carers to administer treatment. The declaration was granted because, after balancing a number of factors, the scales tipped in favour of providing treatment (which was considered life-saving). In his judgment, Judge Charles gave "no weight" and no "great weight" respectively for the two reasons that she provided in refusing treatment (she thought that her blood was evil and she thought that the patient was in a vicious cycle of circumstance which she felt she could not endure) in the assessment of her best interests.¹⁷⁷ This notwithstanding the fact that factors which relate to the patient's views and beliefs are required to be taken into account (according to the MCA code of practice¹⁷⁸) in the assessment of best interests. In this case, it appeared that this requirement did not present any kind of obstacle to the overriding of her wishes. If such factors can be quite so easily dismissed, it must be questioned exactly how much of a safeguard this new requirement is.

Examples such as these show a certain reluctance to retreat too far from traditional paternalistic reasoning. Jackson highlights the central tension surrounding the competing tests for capacity as being the desire to retain individual control and autonomy over decision-making and the desire to protect the vulnerable from harm.¹⁷⁹ However, if we accept the premise that mental capacity should determine the legal right to refuse treatment¹⁸⁰ then the erroneous acceptance of consent of someone who in fact lacks capacity could be as harmful as wrongfully finding someone lacking in capacity and providing them with treatment which they do not want. Though this may not be recognised by the legal system as tort lawyers would immediately demand to know what harm has been done in the former situation, because if the patient was not capable of consenting, then the same treatment could have been provided in their best interests in any case, and the HCP has a duty to provide treatment which is clinically accepted. Therefore there is likely to be little difference between any treatment provided and any treatment that would have been provided following a 'best interests' assessment. The suspicion therefore remains that as long as the patient agrees with medical opinion, their mental capacity is unlikely to be contested in court.

¹⁷⁶ [2004] EWHC 1279 (Fam)

¹⁷⁷ *NHS Trust v T* (n 149) [66] (Charles J)

¹⁷⁸ Department for Constitutional Affairs (n 80) paras 5.37-5.48

¹⁷⁹ J Jackson, 'Determining Incompetence: Problems With the Function Test' (n 103) 57

¹⁸⁰ see *contra* Art 12 CRPD

The same paternalistic rationale which underlies the rhetoric of protecting the vulnerable, which Jackson discusses,¹⁸¹ is similar to that which is used to justify the provision of treatment without consent in emergency situations.¹⁸²

Where, for example, a surgeon performs an operation without his consent on a patient temporarily rendered unconscious in an accident, he should do no more than is reasonably required, in the best interests of the patient, before he recovers consciousness. I can see no practical difficulty arising from this requirement, which derives from the fact that the patient is expected before long to regain consciousness and can then be consulted about longer term measures.¹⁸³

Though this statement of law pre-dates the MCA, the same immunity still presumably subsists for HCPs under the doctrine of necessity.¹⁸⁴ This situation could be greatly complicated if it were unclear as to whether the injury was, in fact, accidental in nature. Would the same reasoning hold in a situation where it was clear that the injured party had attempted suicide? In such a situation, the will of the injured party was to die and thus a deliberate decision to intervene and attempt to prevent their death is surely a violation of their autonomous wishes. However, the MCA Code states that “if the person is clearly suicidal, this may raise questions about their capacity to make an advance decision”¹⁸⁵, which suggests that an attempted suicide is commonly a decision taken without capacity. The same may be true for emergency surgery to repair a partially severed limb, where the patient had tried to remove the limb themselves pursuant to their apotemnophilia.¹⁸⁶

However, the very idea that we (or the courts), as an extraneous entity, can arrive at a determination that person’s best interests is internally contradicted in medical law.¹⁸⁷ As a proposition, it plainly relies on an objective yardstick in its suggestion that those other than the patient themselves can define ‘best interests’ for the patient. This idea sits uneasily with the way in which the law on the refusal of treatment has developed to protect self-determination¹⁸⁸ and informed consent.¹⁸⁹ These developments are normatively subjectivist: the patient themselves should be able to refuse treatment they believe is not in their best

¹⁸¹ J Jackson, 'Determining Incompetence: Problems With the Function Test' (n 103) 57

¹⁸² See *F v West Berkshire Health Authority* [1989] 2 All ER 545, 566 (Goff of Chieveley LJ)

¹⁸³ *ibid*

¹⁸⁴ see *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1

¹⁸⁵ Department for Constitutional Affairs (n 80) para 9.9

¹⁸⁶ see A Bridy, 'Confounding Extremities: Surgery at the Medico-ethical Limits of Self-Modification' (2004) 32 *The Journal of Law, Medicine and Ethics* 148

¹⁸⁷ See K Veitch, *The Jurisdiction of Medical Law* (n 8) 84-92

¹⁸⁸ *Re T* (n 54) 112 (Donaldson MR); *HE v Hospital NHS Trust* (n 66) (Fam) [37] (Munby LJ)

¹⁸⁹ *Chester* (n 2)

interests rather than a medical professional. The development of ADRTs is an acknowledgement that individuals may well not agree with the objective determination of what is best for them.¹⁹⁰ The increasing importance of the consideration of the individual preferences and wishes in the determination of best interests can be seen as a further indication of the problematic nature of an objective standard of best interests and this theme will be taken up in the second and third parts of this thesis. Consequently, as will be discussed, the modern manifestation of best interests as a legal standard demonstrates a much greater sensitivity to those subjective interests than ever before.

Some of the most difficult cases in which the court must make a decision on behalf of a person who lacks capacity arise from applications for the sterilisation of the patient. *A Local Authority v K* was one such case.¹⁹¹ K was a 21 year old woman with Down's syndrome and learning difficulties. Her parents were concerned that, as she became sexually active, there was a risk that she may become pregnant and would be unable to cope with motherhood. At first, hormone-based contraceptives were trialled, but these produced behavioural difficulties in K. In consequence, her parents wanted thought that it would be best for K to be sterilised. However, the Court of Protection found that this would not be in K's best interests, because it was a more invasive and a more permanent step than was required to achieve the goal of preventing her pregnancy. This provides an illustration of the kinds of concerns that the courts must balance.

Similar difficult decisions had also been discussed in earlier cases, such as *Re A (Medical Treatment: Male Sterilisation)*.¹⁹² At the time of the judgment A was a 28 year old man who had Down's syndrome and an intellectual impairment that bordered on severe. He was being cared for by his mother who was 63, but there was a concern that if she became incapable of caring for him (her own health was deteriorating) and he were then moved into a residential care facility, that he might fraternise with other people and might become sexually active.

One of the interesting aspects of this case, in terms of the procedure that was adopted in determining best interests, was Lord Thorpe's use of a 'balance sheet' approach. This involved the listing of all of the benefits of the operation, set against a list of all of the disbenefits of the operation, before judging as to whether the benefits outweighed the disbenefits. As this was a pre-MCA case, Lord Thorpe was not bound to consider all of the

¹⁹⁰ C Johnston (n 70) 513

¹⁹¹ [2013] EWHC 242 (COP)

¹⁹² [2000] 1 FLR 549

factors listed in section 4 and as a consequence of this did not consider the past or present views of the patient.¹⁹³

Difficulties can also arise in demonstrating that a particular procedure is in the best interests of the patient themselves where the primary beneficiary of the procedure may appear to be another person. One pre-MCA example of this is *Re Y (Mental Patient: Bone Marrow Donation)*.¹⁹⁴ It was held to be in the best interests of a patient who lacked capacity to donate bone marrow to her sister, who was suffering from a form of leukaemia. The rationale was that if Y's sister were to die, it would be very harmful for Y's mother with the result that she may not be able to maintain contact with Y. If all this were to come to pass, it would have been socially and psychologically detrimental to Y's health.

In *Re S and Another (Protected Persons)*¹⁹⁵ Judge Hazel Marshall QC opined that the MCA has effected "a whole sea change in the attitude of the law to persons whose mental capacity is impaired".¹⁹⁶ Following the MCA entering into force, determining what form of treatment may be provided patient's best interests is a judgment to be made in accordance with the process that is set out by section 4 MCA, which states the following:

4 Best interests

(1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of—

(a) the person's age or appearance, or

(b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.

(2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.

(3) He must consider—

(a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and

(b) if it appears likely that he will, when that is likely to be.

¹⁹³ Donnelly M, 'Determining Best Interests Under the Mental Capacity Act 2005' (2011) 19 Medical Law Review 304, 306

¹⁹⁴ [1996] FLR 787

¹⁹⁵ [2010] 1 WLR 1082

¹⁹⁶ *ibid* [51] (Hazel Marshall QC)

(4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.

(5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.

(6) He must consider, so far as is reasonably ascertainable—

(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.

(7) He must take into account, if it is practicable and appropriate to consult them, the views of—

(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,

(b) anyone engaged in caring for the person or interested in his welfare,

(c) any donee of a lasting power of attorney granted by the person, and

(d) any deputy appointed for the person by the court, as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

(8) The duties imposed by subsections (1) to (7) also apply in relation to the exercise of any powers which—

(a) are exercisable under a lasting power of attorney, or

(b) are exercisable by a person under this Act where he reasonably believes that another person lacks capacity.

(9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.

(10) "Life-sustaining treatment" means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.

(11) "Relevant circumstances" are those—

(a) of which the person making the determination is aware, and

(b) which it would be reasonable to regard as relevant.

Section 4(1) reflects the MCA's commitment to the 'functional approach' to capacity in that it prohibits decisions from being taken on the basis of a person's age, appearance or their behaviour. This means that assessments should be conducted through the examination of particular observations (which section 4(2) demands the assessor to have in contemplation) and conclusions should not be drawn on the mere basis of generalised, prejudicial, assumptions about certain people or groups (although it is questionable whether this is possible in practice)¹⁹⁷. Section 4 also serves as a reminder that once capacity is lost, it is not necessarily lost forever. Thus, section 4(3) emphasises the need for those making decisions on best interests to consider whether the person will regain capacity and when they are likely to do so.

Even though the corollary of the loss of capacity is the loss of the right to make a legally binding refusal of treatment, the MCA makes it clear that the person to whom the treatment decision will apply should be involved in the decision-making process as far as possible even if she or he is not permitted to determine the outcome of the decision.¹⁹⁸ A related requirement which keeps the best interests assessment focussed on the patient is to be found in the requirement to consider the patient's past and present wishes.¹⁹⁹ A good example of the approach of the courts can be seen in the case of *A local Authority v JH*.²⁰⁰ In that case there was a question as to whether it was in the best interests of an elderly woman to remain at home with her husband or to be taken into a care home. It was suggested that the care home could have provided better medical and nursing care, but JH wanted to remain at home with her husband of thirty years and the judgment was swayed by JH's strong desire to remain at home. More recently, in *Re N* the strong indication that N would not have wished to have been kept alive in an MCS led to the determination that treatment should be withdrawn.²⁰¹ These cases illustrate how patient preferences can sometimes be the deciding factor, even when they run counter to the medical conception of what would be best.

In *Re S and Another (Protected Persons)*²⁰² Judge Hazel Marshall QC suggested that the way the MCA is structured indicates that "the views and wishes of P in regard to decisions

¹⁹⁷ R Heywood, 'Revisiting Advance Decision Making Under the Mental Capacity Act 2005: A Tale of Mixed Messages' (n 133) 91

¹⁹⁸ MCA, s 4(4)

¹⁹⁹ MCA, s 4(6); see also M Donnelly, 'Best Interests, Patient Participation and the Mental Capacity Act 2005' (2009) 17 Medical Law Review 1

²⁰⁰ [2011] EWHC 2420 (COP)

²⁰¹ [2015] EWCOP 76

²⁰² [2010] 1 WLR 1082

made on his behalf are to carry great weight”.²⁰³ In *R (Burke) v General Medical Council*²⁰⁴ it was said that the MCA emphasises the need to “see the patient as an individual”.²⁰⁵

Mr Justice Munby gave further detail as to the weight to the patient’s wishes in *Re M (Statutory Will)*²⁰⁶ remarking that the patient’s wishes may carry “preponderant” weight.²⁰⁷ Despite this rhetorical support, other cases have given less prominence to the views of the patient.²⁰⁸ In *Sheffield Teaching Hospitals NHS Foundation Trust v TH*²⁰⁹ the patient, TH, was described as someone who had a general dislike of authority and as a “non-tactile person”.²¹⁰ TH was a drummer, but became unable to continue playing after developing Ataxia. It was reported that he “hated the fact that he had to rely on people”²¹¹ and that he wanted to leave hospital and go home to die.²¹² Despite these strong feelings TH had not made an ADRT,²¹³ thus these feelings could only comprise one component of the assessment of best interests that must be put into the matrix of best interests.²¹⁴

This requirement to consider the patient’s views and interests was absent from old common law approach to the assessment of best interests.²¹⁵ Its inclusion within the MCA has been welcomed by Donnelly, but she also sounded a warning about the evidential difficulties that may arise in ascertaining past (and perhaps present) wishes.²¹⁶ Cases such as *A Primary Care Trust v P* illustrate the potential for family members to influence the construction of the patient’s preferences.²¹⁷

The problem of the influence of those close to the patient may be compounded by the requirement of section 4(7), which stipulates that the views of certain other people must be sought as part of the process of determining best interests. The categories persons whose views must be considered are listed in section 4(7). The list includes anyone nominated by the person (in respect of whom the decision is being made) with an interest in that person’s

²⁰³ *ibid* [55] (Judge Hazel Marshall QC)

²⁰⁴ [2005] EWCA Civ 1003

²⁰⁵ *ibid* [26] (Hale LJ)

²⁰⁶ [2009] EWHC 2525 (Fam)

²⁰⁷ *ibid* [35] (Munby J)

²⁰⁸ See H Biggs, “‘Taking Account of the Views of the Patient’, but Only if the Clinician (and the Court) Agrees!’ (2007) 19 Child and Family Law Quarterly 225

²⁰⁹ [2014] EWCOP 4 (COP)

²¹⁰ [2014] EWCOP 4 (COP) [45] (Hayden J)

²¹¹ *ibid* [49] (Hayden J)

²¹² *ibid* [53] (Hayden J)

²¹³ *ibid* [38] (Hayden J)

²¹⁴ *ibid* [54] (Hayden J)

²¹⁵ see *Re A (Medical Treatment: Male Sterilisation)* [2000] 1 FLR 549

²¹⁶ M Donnelly, ‘Best Interests, Patient Participation and the Mental Capacity Act 2005’ (2009) 17 Medical Law Review 1, 26-27

²¹⁷ [2012] EWHC 2922 (COP)

welfare and any donee of a lasting power of attorney (“LPA”) or any court appointed deputy.

LASTING POWERS OF ATTORNEY

The confines of space preclude a detailed discussion of LPAs, and indeed, because their existence has a different ethical and political basis to that of ADRTs, they are not of direct relevance to this thesis. However, as instruments which may be created alongside ADRTs, a brief discussion of LPAs is certainly warranted at this juncture.

LPAs are instruments which give authority to a nominated person (or persons), i.e. the donee or donees of an LPA, to make decisions on behalf of a person should they lack capacity in future (or, more precisely, if they should be reasonably thought to lack capacity).²¹⁸ They can be created by adults with capacity.²¹⁹ However, decisions made under an LPA must be made in accordance with the best interests of the patient²²⁰ and therefore the power conferred under an LPA is lesser than the power that a patient has to decide on their own medical treatment contemporaneously or anticipatorily. This requirement is consistent with section 1(6) MCA which states the principle that all decisions made on the basis of the MCA must be made in accordance with the best interests of the person to whom the decision applies. Thus, although there are similarities between LPAs and ADRTs, they present their own particular set of challenges.

Sometimes the court may appoint a deputy to make decisions on behalf of someone who lacks capacity.²²¹ The powers that the deputy has are similar to those that can be possessed by the donee of an LPA, but can be defined by the court in a specific case. The main difference is that the donee of an LPA is nominated by the person to whom it may apply, whereas the deputy is appointed by the court.²²²

In practice, those who are concerned with their end of life care may wish to make an LPA as well as an ADRT. However, great care must be taken when creating both kinds of instrument. This is because section 25(2)(b) states that an ADRT will not be valid if powers are subsequently conferred on the donee of an LPA in respect of the same areas of medical treatment as those covered by the ADRT. Furthermore while the creation of both LPAs and

²¹⁸ Explanatory Notes to the Mental Capacity Act 2005, para 34

²¹⁹ MCA, s 9; LPAs are the developed successor to Enduring Powers of Attorney which could be created under the Enduring Powers of Attorney Act 1985 (which was repealed by section 66(1)(b) MCA)

²²⁰ MCA s 9(4)(a)

²²¹ MCA, s 16

²²² MCA ss 9 and 16(2)(b)

ADRTs (concerning the refusal of life-sustaining treatment) require written documentation, LPAs require registration before they are deemed to have been created under section 9(2)(b) of the MCA. In *Re E*²²³ the documentation was completed on the same day, but the LPA was registered subsequently and consequently invalidated the ADRT. The court remedied the problem in this case by re-validating the ADRT through a court order (using section 24(4) MCA). But, this was only possible as the matter came before the court prior to the need for the ADRT to be relied upon. If the patient had already lost capacity and the specified treatment had become indicated, the LPA would have taken precedence over the ADRT.

Section 4(5) reiterates one of the central principles of the MCA: that a decision made under the MCA cannot be motivated by a desire to hasten death. This section is clearly designed with the right to life Art 2 ECHR in mind and to support the ethical principle which asserts that life has a special value.²²⁴ It does not mean, however, that doctors are obliged to continue treatment at all costs.²²⁵

Section 4(9) states that where the matter is not brought before a court, it will be sufficient for a person providing treatment to demonstrate that they have arrived at the decision as to the kind of treatment that should be given, having complied with sections 4(1)-(7), where the provider of treatment reasonably believes that the treatment is in the best interests of the patient. This means that the treatment provider will be judged by an objective standard. By contrast, life sustaining treatment is defined subjectively in accordance with what the person providing treatment considered as necessary to sustain the patient's life.²²⁶ A discussion of section 4(10) is absent from the explanatory notes, but the lack of any objective gloss is notable and provides medical practitioners with a wide discretion.

For all of the specific requirements of section 4 MCA, there remains, in the determination of what is in a person's best interests, considerable scope for variations in approach, depending on the values that are given priority. This is because even after all of the matters in section 4(1)-(7) have been contemplated, there is no guidance as to what weight to give each of the factors that must be considered. As lady Hale remarked in *Aintree NHS Hospital v James*²²⁷ “[b]eyond this emphasis on the need to see the patient as an

²²³ [2014] EWCOP 27

²²⁴ J Keown, *Euthanasia, Ethics and Public Policy: An Argument against Legalisation* (Cambridge University Press 2002) 39-51

²²⁵ Explanatory Notes to the Mental Capacity Act, para 31

²²⁶ MCA, s 4(10)

²²⁷ [2013] UKSC 67

individual, with his own values, likes and dislikes, and to consider his best interests in a holistic way, the Act [the MCA] gives no further guidance [on determining best interests].”²²⁸

The aim of this section was to set out the law on the assessment of best interests under the MCA and to indicate some of the important tensions and difficulties that will be encountered when making a determination of best interests in individual. One of the most notable features of the new law on best interests contained in the MCA is that it requires due consideration to be given to the patient’s preferences.²²⁹ However, as the discussion in this section indicates, the extent to which a patient’s preferences will outweigh other considerations is unclear. Having earlier framed ADRTs as mechanisms for avoiding the application of treatment in accordance with the best interests standard, it should be pointed out that ADRTs can play an important role in the determination of best interests where they have failed.

BEST INTERESTS AND ADRTs

The only reason for creating and ADRT is in the anticipation that a form of treatment may be provided in future in accordance with a best interests assessment that the patient would not wish to receive. ADRTs allow this kind of treatment to be refused in a way that will become legally binding in the event that capacity is lost and the treatment contemplated becomes both clinically indicated and in the best interests of the patient. Where the ADRT is effective there is no cause to attempt a determination of best interests.²³⁰ If the ADRT is defective in a material way, or if it indicates circumstances that have not arisen in the way that is specified, it will not be binding. However, a conclusion that the ADRT is not binding is not to conclude that it is entirely irrelevant, because its provisions can helpfully assist in the determination of best interests.²³¹

Examples of this are provided by *Westminster City Council v Manuela Sykes (By her RPR and Litigation friend RS)*²³² and in *An NHS Trust v D*²³³ where the ADRT had not been correctly witnessed (a requirement under section 25(6) MCA that will be spelled out in greater detail below). The latter case concerned an application by the hospital trust that it would be lawful to withdraw medical treatment from D who was in a vegetative state with

²²⁸ [2013] UKSC 67 [26] (Hale LJ)

²²⁹ MCA, s 4(7)

²³⁰ see Department for Constitutional Affairs (n 80) para 9.36

²³¹ See eg *Sheffield Teaching Hospitals NHS Foundation Trust v TH* [2014] EWCOP 4

²³² [2014] EWHC B9 (COP)

²³³ [2012] EWHC 885 (COP); *Re D* [2012] EWCOP 885

“no prospect of recovery”.²³⁴ The declaration was granted on the grounds that he was in a PVS and to continue treatment would be “futile”²³⁵, it was also likely that D would not have wished to have been kept alive in the circumstances in which he found himself.

As discussed above, in determining what course of treatment is consistent with a patient’s best interests the court retains significant discretion. Despite the heralding of a more patient-focussed best interests test through the MCA, the extent to which patient preferences are truly accounted for is uncertain. Part of the theoretical attraction of ADRTs is that they provide a greater level of certainty for patients with strong preferences to avoid being provided with certain forms of treatment. Thus, and having discussed the law concerning consent to treatment, capacity and best interests, as part of the background to the law on ADRTs, the task in the remainder of this chapter is to set out the provisions that specifically define ADRTs.

THE COMMON LAW ON ADVANCE DECISIONS PRIOR TO THE MCA

The law on contemporaneous refusals of treatment was discussed earlier in this chapter and it was suggested that this area of law forms the foundation of the law of ADRTs. The modern law on ADRTs is widely considered to have been heavily influenced by a paper written by the US lawyer Luis Kutner.²³⁶ In his 1969 paper, he argued that patients ought to have the right to refuse treatment anticipatorily in the same way, and with the same legal force as they may refuse treatment contemporaneously (as discussed above). This reasoning was subsequently recognised by Mr Justice Munby in *HE v Hospital NHS Trust*,²³⁷ where he stated that:

“An advance directive is after all nothing more or less than embodiment of the patient’s autonomy and right to self-determination...”²³⁸

This statement was not the first time ADRTs were recognised in English law. Indeed the right to create an ADRT was recognised *obiter* in one of the most important cases in English medical law *Airedale NHS Trust v Bland*.²³⁹ The case arose after a patient who had been injured in the Hillsborough disaster entered into a Vegetative State (“VS”). In the circumstances, the question arose as to whether the patient, Anthony Bland, should be kept

²³⁴ [2012] EWHC 885 (COP) [5] (the Judge)

²³⁵ *ibid* [18] (the Judge)

²³⁶ L Kutner, ‘Due Process of Euthanasia: The Living Will, A Proposal’ (1969) 44(4) *Indiana Law Journal* 539; and see R Huxtable, *Law, Ethics and Compromise at the Limits of Life: To Treat or Not to Treat?* (n 70) 65

²³⁷ *HE v Hospital NHS Trust* (n 66)

²³⁸ *ibid* [37] (Munby J)

²³⁹ [1993] AC 789

alive (and indeed whether the cessation of the medical treatment that was supporting his life would give rise to any liability). The medical practitioners treating Anthony would not face prosecution for withdrawing the treatment which was sustaining his life as there was no duty on medical practitioners to continue treatment that was not in a patient's best interests.²⁴⁰ In Anthony's case, the withdrawal of artificial nutrition and hydration ("ANH") could be characterised as an omission to provide treatment rather than a positive act of killing.²⁴¹ But the courts laid claim to a continuing role for themselves in this area as overseers through the suggestion this case should not be seen as a general precedent applicable to all PVS patients, but that all cases in which there is a question about the possible withdrawal of ANH from PVS patients should be adjudicated by the court.²⁴²

Lady Butler-Sloss went further and (in a line of argument that will be considered in much greater detail in the next chapter) asserted that this right of "self-determination" entailed a right to make anticipatory legally binding refusals of treatment.²⁴³

Further notable confirmation of the possibility of creating ADRTs at common law was given in the 2001 case of *AK*.²⁴⁴ The patient in that case had Motor Neurone Disease ("MND"), a progressive and degenerative neurological condition, which can result in the loss of movement. He created an advance statement to refuse treatment through the only means of communication he had left: blinking. The decision that was created in this way was clear and was upheld. This result was achieved in similar circumstances under the MCA in *X v XB*.²⁴⁵

The case of *Re T*²⁴⁶ gave further discussion of the parameters of the law on ADRTs. Miss T was injured in a road traffic accident. She was pregnant at the time of the accident and her child was subsequently delivered stillborn by caesarean section and because of this Miss T required a blood transfusion. However, Miss T was a Jehovah's Witness (although there was a dispute as to her degree of commitment to the tenets of that faith) and blood transfusions are strictly prohibited for adherents of that faith.

²⁴⁰ *Bland* (n 63) (HL) 858-859 (Keith of Kinkel LJ) and 877 (Lowry LJ)

²⁴¹ *ibid* (HL) 866 (Goff of Chieveley LJ)

²⁴² K Veitch, *The Jurisdiction of Medical Law* (n 8) 38-41

²⁴³ [1993] AC 789, *Bland* (n 63) (CA) 816 (Butler-Sloss LJ); see C Kitzinger and J Kitzinger, 'Court Applications for Withdrawal of Artificial Nutrition and Hydration from Patients in a Permanent Vegetative State: Family Experiences' (2016) 42 *Journal of Medical Ethics* 11

²⁴⁴ *Re AK (Medical Treatment: Consent)* (n 69)

²⁴⁵ [2012] EWHC 1390 (Fam)

²⁴⁶ [1993] FLR 95

Lord Donaldson MR restated the principle that all patients have a “right to self-determination” but noted that this right can come into conflict with the societal interest in the preservation of life.²⁴⁷ However, he opined, in respect of individuals who retain capacity, that such conflicts must be resolved in favour of the rights of the individual.²⁴⁸ Further, Lord Donaldson implied that refusals of treatment can take future effect and can survive the loss of capacity. If the patient had made an anticipatory refusal of treatment the medical team must ask whether the scope of the refusal of treatment includes the circumstances that are presented.²⁴⁹ If this is the case and if the anticipatory choice is “clearly established” then it “would bind the practitioner”.²⁵⁰

However, ADRTs arguably bring with them additional concerns beyond those which are at issue in ordinary refusal of treatment cases. One such concern is that ADRTs could be expressed in vague terms, which would then create problems as to whether any circumstances that later arise are within the parameters of those specified by the author. It would then be unclear whether the author would have wanted to refuse treatment in the obtaining circumstances and this would create a dilemma for medical practitioners and the courts in a pressured situation.

Consequent on such concerns, the pre-MCA case law emphasised the qualities of clarity and specificity as requisites of the recognition of ADRTs. The case of *W v KH*²⁵¹ illustrates this point. The patient, KH, had Multiple Sclerosis, required constant care and had been reliant on a percutaneous gastrostomy tube before it became detached. KH’s family argued that KH had suggested that she did not “want to be kept alive by machines”²⁵² and were unanimous that she would not wish to be kept alive in these circumstances.²⁵³ However, this was deemed to be insufficiently clear to form the basis of a binding ADRT.

In particular, it was suggested that the wishes that she had expressed did not cover the range of circumstances in which she was found.²⁵⁴ This meant that the wishes that she had expressed were not legally binding on the medical team and KH could be given treatment that was in her best interests, which the court at first instance determined meant that the reinstatement of the feeding tube.

²⁴⁷ *Re T* [1993] FLR 95, 112 (Donaldson MR)

²⁴⁸ *ibid*

²⁴⁹ *ibid* 114 (Donaldson MR)

²⁵⁰ *ibid* 103 (Donaldson MR)

²⁵¹ [2004] EWCA Civ 1324 CA

²⁵² *ibid* [6] (Brooke LJ)

²⁵³ *ibid* [11] (Brooke LJ)

²⁵⁴ *ibid* [21] (Brooke LJ)

W v KH therefore cautions would-be advance decision makers of the importance of carefully considering the precise kinds of circumstances in which they intend their advance decision to take effect. A similar problem was cited by the Scottish Action on Dementia Society's evidence to Select Committee on Medical ethics in the US case of *Evans v Bellevue Hospital* (unreported) in which the court had suggested that the terms 'no reasonable prospect of recovery' and 'meaningful quality of life' were too vague.²⁵⁵

This principle was taken to an even greater extent in *W v M* in which the patient's wishes were not recognised as an ADRT because, in part, she had not specified that her refusal should operate in the event of being diagnosed as being in a minimally conscious state (MCS), as she was, as well as a vegetative state (VS).²⁵⁶ Her purported ADRT therefore lacked specificity, in spite of the fact that her condition was almost unknown to medical science at the time she expressed her wishes.

These cases point to an inherent difficulty involved in advance decision-making that was previously highlighted by Montgomery: the author of the ADRT must make sure to have defined his or her wishes in sufficiently specific terms in order for a court to respect them, but, if the author couches his or her refusal in overly specific terms, then they run the risk that the circumstances that later obtain will be deemed distinguishable from those specified.²⁵⁷ It seems that this is a difficulty inherent in interpretation and perhaps the most that can be done is to mitigate the problem through a specification of details and circumstances in which the ADRT is to apply and when it is not to apply, as well as a statement of general values and aspirations which could be used to assist with the interpretation of the ADRT.

Another concern with which the common law grappled was the possibility that a person could create an ADRT and then subsequently change their mind without clearly expressing revoking or altering his or her decision and would then be bound by a decision not reflected by her or his will.²⁵⁸ The danger would be that the person may then be bound by the ADRT against the final disposition of his or her will. It was for this reason that Munby J suggested that ADRTs that had been created a long time ago, or where there had been any suspicion that the author may have changed their mind, "may require especially close, rigorous and

²⁵⁵ Select Committee on Medical Ethics, *Report of the Select Committee on Medical Ethics* (HL 1993-94, 21-II) 228

²⁵⁶ *W v M* (n 11) (Fam)

²⁵⁷ J Montgomery, 'Power Over Death: The Final Sting' in RG Lee and D Morgan (eds), *Death rites: law and ethics at the end of life* (Routledge 1996) 37-53

²⁵⁸ see RJ Jox, 'Revocation of Advance Directives' in Peter Lack, Nikola Biller-Andorno and Susanne Brauer (eds), *Advance Directives* (Springer Science & Business Media 2013)

anxious scrutiny”.²⁵⁹ The case of *HE v Hospital NHS Trust*²⁶⁰ provides some instruction as to the approach to be taken when a patient has an ADRT, but that since having made the ADRT and having lost capacity has undergone some significant change, or life event, that might cast doubt on their continued acceptance of the terms of their ADRT.

The case concerned a patient, Ms AE, who had a congenital coronary defect. It was anticipated that her condition would give rise to the need for surgery in future. AE was raised in the Islamic faith, but following the separation of her parents she became a Jehovah’s Witness. Pursuant to her religious beliefs, AE therefore made an advance statement in which she sought to refuse medical treatment involving blood transfusions under any circumstances (it is not clear what would have happened if the terms of the ADRT corresponded so closely with the tenets of the religion that AE was later to renounce). However, once AE had lost capacity and an application was made to court regarding her Mr Justice Munby said that once the issue of validity of an advance decision had been raised, there was an evidential burden on those seeking to uphold the ADRT to prove that it was of continuing validity.²⁶¹ In the case of AE, this burden of proof had not been discharged and the ADRT was therefore not upheld.

Although some ADRTs may specify certain circumstances in which treatment is refused and other circumstances in which treatment is not refused. It has been suggested that it is possible to refuse treatment in *all* circumstances. Mr Justice Thorpe acknowledged in *Re C*²⁶² that it was possible to make “a declaration of intention never to consent in future or never to consent in some future circumstances”²⁶³ and held that the court could use its inherent jurisdiction to determine the validity and applicability of advance directives.²⁶⁴ However, in practice making an ADRT in such terms may leave it open to challenge on the grounds that the author may not have intended it to apply in the particular circumstances which later obtain, because they had not been contemplated. This happened in the case of *HE*, with a purported ADRT which sought to refuse treatment in any circumstances, but was not recognised as having continuing applicability following the author’s change of faith.²⁶⁵

It is also to be noted that the common law has always recognised capacity as being a prerequisite to the power to create an ADRT. The case of *The NHS Trust v Ms T*

²⁵⁹ [2003] EWHC 1017 (Fam) [25] (Munby J)

²⁶⁰ [2003] EWHC 1017 (Fam)

²⁶¹ *ibid* (Fam) [23] (Munby J)

²⁶² *Re C* [1994] 1 WLR 290

²⁶³ *ibid* 294 (Thorpe J)

²⁶⁴ *ibid*, 295-296 (Thorpe J)

²⁶⁵ *HE v Hospital NHS Trust* (n 66)

demonstrates the importance of capacity at the moment of the creation of an ADRT.²⁶⁶ The patient, T, suffered from Borderline Personality Disorder (“BPD”) and had a history of self-injuring through cutting herself. She occasionally required blood transfusions following blood-letting, but in January 2004 she created an ADRT refusing blood transfusions. One of the reasons that she gave for creating the ADRT was that she believed her blood to be evil. This reasoning was considered to be result of a mental disorder and was taken as further evidence that she was unable to ‘weigh information’ to make a decision and therefore lacked capacity at the time she created the ADRT.²⁶⁷ This meant that the ADRT was void *ab initio* and she could be treated in accordance with her best interests which included providing blood transfusions.

The case law in this area (on consent to treatment, capacity and best interests) has played a major role in informing the codified version of the law that was enacted in the MCA. Thus, and having discussed this case law, as part of the background to the law on ADRTs, the task in the remainder of this chapter is to set out the provisions that specifically define ADRTs in the MCA.

ADRTS AND THE MENTAL CAPACITY ACT 2005

The Bill that began life as the Mental Incapacity Bill was eventually enacted as the Mental Capacity Act in 2005. The Act came into force in 2007. As mentioned above, the MCA is a wide-ranging piece of legislation which covers many aspects of decision-making. However, the focus here will of course be on the parts of the MCA that cover advance decision-making.

Given the central place advance decisions in this thesis, the full text sections 24-26 MCA is reproduced in this section of the thesis for definitional clarity. Section 24 provides the basic definition of advance decisions, which is qualified and explained by sections 25 and 26. Section 24 states the following:

24 Advance decisions to refuse treatment: general

(1) “Advance decision” means a decision made by a person (“P”), after he has reached 18 and when he has capacity to do so, that if—

(a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and

²⁶⁶ *NHS Trust v T* (n 149)

²⁶⁷ *ibid* (Fam) [63] (Charles J)

(b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.

(2) For the purposes of subsection (1)(a), a decision may be regarded as specifying a treatment or circumstances even though expressed in layman's terms.

(3) P may withdraw or alter an advance decision at any time when he has capacity to do so.

(4) A withdrawal (including a partial withdrawal) need not be in writing.

(5) An alteration of an advance decision need not be in writing (unless section 25(5) applies in relation to the decision resulting from the alteration).

The case of *Re E* provides a good illustration of the how the courts approach section 24(1) and, specifically, the requirement that the person making the ADRT must have capacity to refuse the treatment specified.²⁶⁸ E was 32 years of age and suffered from an eating disorder originating from her desire to control her eating at the age of 11 following a period of "serious sexual abuse"²⁶⁹ to which she was subject since the age of four. She then developed eating control patterns between the ages of 12 and 13 and concurrently began drinking alcohol, which was later to form a dependency. Following a gap year, she was admitted to hospital (at the age of 26) for treatment of her eating disorder and in the following period up until the age of 30 she had been to "four eating disorder units and one alcohol treatment unit"; during this period "E spent more than half of her time in one or other of these placements".²⁷⁰ She was then treated in the community due to a lack of funding for the provision of any other treatment, but this "led to a 'revolving door' series of emergency admissions for medical and psychiatric care".²⁷¹

It was since the period of her care in the community began that she became interested in making an ADRT to ensure that she would not be fed against her will, if she was later deemed to have lost capacity. This culminated in her signing a document in July 2011 expressing her wish not to be resuscitated or to be given any form of medical treatment and another advance decision document (using a standard form) in October 2011 with the assistance of "her mother and mental capacity advocate".²⁷² During this period of care in the community E's body mass index (BMI) fluctuated between 11 and 12 (where it was said that

²⁶⁸ *Re E* (n 10); Much of the discussion which appears here on this case has now been published: see T Hayes, 'A (Social) Room with a View (to the Future): Advance Decisions and the Problem of Personhood' (n 13)

²⁶⁹ *Re E* (n 10) [16] (Peter Jackson)

²⁷⁰ *ibid* [17] (Peter Jackson)

²⁷¹ *ibid* [17] (Peter Jackson)

²⁷² *ibid* [20] (Peter Jackson)

a “figure of less than 17.5 is in the anorexic range”²⁷³), and at the time of the proceedings her BMI was 11.3, a level that put her at risk of “sudden cardiac death”.²⁷⁴ Dr Glover (a consultant psychiatrist specializing in eating disorders) diagnosed her as having severe anorexia nervosa, unstable personality disorder (borderline subtype), a dependency on both alcohol and opiates, and the attendant physical effects of her behavioural patterns.²⁷⁵ All things considered, hers was an “extraordinarily complex” case.²⁷⁶

E had made obvious attempts to ensure that her ADRTs were created in accordance with the legal requirements such that they could take legal effect. She even took the precaution of having her second ADRT witnessed by a mental health professional²⁷⁷ and had been created following advice from an Independent Mental Capacity Advocate (IMCA) and a solicitor.²⁷⁸ At this time the general view was that she had capacity, but no formal capacity assessment was undertaken at the time in relation to the ADRT specifically.²⁷⁹ Despite this, Judge Peter Jackson ruled that E did not have the capacity to make either ADRT at the material times.²⁸⁰ In consequence, neither of E’s purported ADRTs was considered valid.

The verdict in this case has serious implications for patients wishing to create ADRTs, as it seems that no assurance can be given that their ADRT will be invulnerable to challenge through a retrospective analysis of capacity, even if a mental health worker acts as witness. Mr Justice Peter Jackson had referred to E’s background as being ‘alerting’ suggesting that the question of capacity should receive additional scrutiny, but as Johnson suggests, this rationale for categorising E in this way cannot be solely due to her mental health problems.²⁸¹ Although as a matter of practicality it might be advisable for those with mental health problems to ensure that their ADRTs are witnessed by a mental health professional or to ensure that their capacity is assessed by a mental health professional at the same time as the ADRT is created, this may incur extra costs. Moreover, as this case demonstrates, there is no guarantee such a precaution would be effective.

²⁷³ *ibid* [25] (Peter Jackson)

²⁷⁴ *ibid* [25] (Peter Jackson)

²⁷⁵ *ibid* [23] (Peter Jackson)

²⁷⁶ *ibid* [24] (Peter Jackson)

²⁷⁷ *ibid* [61] (Peter Jackson)

²⁷⁸ *ibid* [64] (Peter Jackson)

²⁷⁹ *ibid* [64] (Peter Jackson)

²⁸⁰ *ibid* [59] and [65] (Peter Jackson)

²⁸¹ C Johnston (n 70) 502-503

However, a different result was reached in a case with very similar facts, *A NHS Trust v Ms X*.²⁸² Both cases involve anorexic patients who had long histories of substance misuse and who both strongly opposed being provided with medical treatment. Both E and Ms X had made ADRTs, but in the case of Ms X, her ADRT was said to have been made with capacity and was therefore valid. The difficulty was that at the time of the trial Ms X retained capacity in respect of her consumption of alcohol, but not in respect of her decision to eat more generally. Moreover there was a great difficulty in determining whether the cause of her disorder was her alcoholism or her eating disorder and so it was suggested that the terms of her ADRT should take effect. The judgment of Mr Justice Cobb however, proceeds to discuss the best interests of the patient in respect of her eating disorder, acknowledging that Ms X retained capacity to decide whether to drink²⁸³ and decided that it would not be in Ms X's best interests to be force fed. One of the important factors in distinguishing the case of Ms X from E was that Ms X merely had a 5% chance of recovery, whereas E's chances of recovery were estimated at 20%.²⁸⁴ Additionally in E's case there were unexplored forms of treatment, but this was not the case with Ms X.

Another important provision in section 24 relates to the kind of language required in drafting an ADRT. Section 24(2) MCA makes it possible to create ADRTs without taking professional advice, because although there is a requirement that any ADRT should specify the relevant medical decision/decisions²⁸⁵ to which it is intended to apply, this can be done in "layman's terms" with no lesser legal effect.²⁸⁶ Care must be taken, however, to ensure that whatever terminology is used, that the language of the ADRT is sufficiently clear, otherwise there may be uncertainty as to whether the decision was intended to apply to the relevant circumstances. This is what happened in *W v KH*²⁸⁷ under the common law and as a consequence the ADRT was not treated as binding. The same outcome would now be realised by virtue of section 25(4) MCA.

The case of *W v M*²⁸⁸ provides another example of the level of precision that the courts may expect from the terms of an ADRT. In this case M had expressed the view, on more than one occasion, that she would not wish to be kept alive by artificial means if she were in a Persistent Vegetative State (PVS). However, M ultimately found herself not in a PVS, but

²⁸² *A NHS Foundation Trust v Ms X (By Her Litigation Friend, the Official Solicitor)* [2014] EWCOP 35 (COP)

²⁸³ *ibid* [42] (Cobb J)

²⁸⁴ *ibid* [56i] (Cobb J)

²⁸⁵ MCA, s 24(1)(a)

²⁸⁶ MCA, s 24(2)

²⁸⁷ *W v KH* [2004] EWCA Civ 1324 (CA)

²⁸⁸ *W v M* (n 11)

in a Minimally Conscious State (“MCS”) after contracting viral encephalitis and thus it was said that M’s earlier decision could not be taken to apply to her the circumstances in which she later found herself. The difficulty with this analysis is that at the time when M expressed her wishes the condition known as MCS was scarcely known to medical science.²⁸⁹ On this basis it sets a very, arguably an unfairly, high bar for the degree of specificity needed in an ADRT.

Furthermore, M could not have known of the legal requirement for her ADRT to be made in writing for it to be considered binding, as even though the Transitional Order states that ADRTs made prior to October 2007 not comply with the provisions of the MCA in order to attain binding effect, there was no pre-existing common law requirement for ADRTs to be made in writing.²⁹⁰ Thus the Transitional Order imposes a retrospective requirement on the recognition of ADRTs made before the MCA entered into force, which arguably does not accord with the rule of law and the principle of legality.²⁹¹

The formalities for creating an ADRT will be considered in the next section in the discussion of section 25 MCA. However, at this stage it should be noted that in spite of the formality requirements stated in section 25 MCA, any advance decision can be withdrawn at any time *without* formality.²⁹² As a consequence it is easier for those who change their minds to give effect to their change of mind, which goes some way to addressing the ethical concerns regarding the binding of the ‘future self’,²⁹³ but the effect may well also be that it creates added uncertainty for the practitioners treating the patient.

It also means that the formalities required in respect of decisions relating to life-sustaining treatment²⁹⁴ do not offer the same degree of certainty as, say, those stipulated by the Wills Act 1837. Usually a will cannot be retracted or varied without formality (in the case of the creation of a new will or codicil or some written instruction adhering to the formalities in section 9 Wills Act 1837)²⁹⁵, or a specified formal event (such as a marriage or a civil partnership). However, a will or codicil can also be revoked by the destruction of the document by the testator or his agent with the intention of it being revoked thereby.²⁹⁶ Thus

²⁸⁹ R Huxtable, ‘Treating the Minimally Conscious Patient: Life Before Choice?’ (2012) 9 *Journal of Bioethical Inquiry* 9, 11-12

²⁹⁰ *HE v A Hospital NHS Trust* [2003] EWHC 1017 [33], [41] (Munby J)

²⁹¹ see European Convention on Human Rights, Art 7

²⁹² MCA, s 25(2)(a)

²⁹³ An area of concern which will be discussed in Chapter Five

²⁹⁴ see MCA, ss 25(5)-(6) below

²⁹⁵ See R Kerridge, *Parry & Kerridge, The Law of Succession* (12th edn, Sweet & Maxwell 2009) paras 7-32

²⁹⁶ Wills Act 1837, s 20

even if there is evidence that the deceased had changed his or her mind and did not wish to make the same dispositions as his or her will indicated, the will that accords with the relevant formalities must be executed notwithstanding other evidence suggesting the will did not accord with the testator/testatrix's later desires. Section 24(4) of the MCA makes matters more complicated in relation to ADRTs, because revocation (or 'withdrawal' as it is termed in the MCA) can occur by parole.²⁹⁷ However, the formalities of section 26 must be complied with if the author of the ADRT wishes to vary (rather than entirely withdraw) her or his ADRT.²⁹⁸ The practitioner could therefore face a difficult judgment in deciding whether any alleged withdrawal was actually in evidence or not, or whether there had only been a variation in the ADRT which would require (and therefore whether there is still a valid ADRT). As we shall see from section 26 MCA, where there is doubt, there is a structural bias to decide that there is no ADRT and to provide treatment (at least prior to seeking a declaration from the court under section 26(4) MCA).

Another notable factor in the MCA is the absence of a statutory time limit on ADRTs (this is something that has been introduced in other jurisdictions e.g. Austria)²⁹⁹. However, some prefabricated forms designed to assist people in making an ADRT contain an option for the author to specify a date after which the decision lapses.³⁰⁰ The MCA code also encourages people to renew their ADRTs regularly and particularly following a change in circumstances.³⁰¹ The MCA code also warns healthcare professionals to "take special care if the [ADRT] does not seem to have been renewed or updated for some time".³⁰²

However, it is clear from the case of *The X Primary Care Trust v XB*³⁰³ that if a renewal period is specified in the ADRT and a renewal has not been completed at the date at which the ADRT is called upon, the failure to renew *per se* will not invalidate the ADRT. In *X v XB*, XB suffered from Amyotrophic Lateral Sclerosis: ALS (MND), which was diagnosed in 2001.³⁰⁴ His condition impaired his physical movement and the ventilation device that he required to keep him alive prevented him from speech, with the result that XB had to communicate through moving his eyes. This was the mode of communication through which XB was able to draft an ADRT. However, the ADRT that he drafted specified renewal dates

²⁹⁷ See also Department for Constitutional Affairs (n 80) para 9.31

²⁹⁸ MCA, s 24(5)

²⁹⁹ See 55. § 7. Bundesgesetz über Patientenverfügungen (Patientenverfügungs-Gesetz - PatVG) BGBl I NR 55/2006 (Austria)

³⁰⁰ See *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam)

³⁰¹ Department for Constitutional Affairs (n 80) paras 9.29-9.30

³⁰² *ibid* para 9.51

³⁰³ *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam) (Theis J)

³⁰⁴ *ibid* [8] (Theis J)

and an expiry date,³⁰⁵ which had all passed by the time that XB lost capacity. Even though the MCA makes no requirement of attaching any kind of time limit to an ADRT, the fact that such a time limit had voluntarily been included gave rise to a question as to whether the ADRT should be relied upon as a binding instrument. Ultimately it was decided that the ADRT was binding, because there was evidence from those who assisted in the drafting of the ADRT that no renewal or expiry dates had been agreed upon and hence it was said that XB had not intended the ADRT to be bound by the purported temporal limitations.³⁰⁶

Though not explicitly cited in the judgment, there is a clear parallel to be drawn between XB's case and Bristow J's dictum in *Chatterton v Gerson* in which it was said that mere evidence of a signed consent form does not constitute definitive evidence of consent.³⁰⁷ The same point was confirmed in *Taylor v Shropshire Health Authority*.³⁰⁸ Another interesting aspect of the case was that before XB had written the ADRT, he had asked for the machine providing him with ventilation to be removed, but "it was explained to him that that could not be done".³⁰⁹ It is unclear why this wish was not respected contemporaneously, especially as Johnston points out that his capacity to make an ADRT was never called into question.³¹⁰

The temporal gap between the creation of the ADRT and the time at which it is called upon may have a further powerful indirect relevance in that a greater the length of time between these two points, the more closely the likely scrutiny will be of the terms of the ADRT. This is illustrated by Mr Justice Munby's *dictum* in the pre-MCA case of *HE*, in which he stated:

"In my judgment no less rigorous an evidential approach is required where the inquiry is not as to the initial validity of an advance directive but (as here) the continuing validity and applicability of an advance directive given in what may be the more or less remote past. Indeed, depending upon the time that has elapsed, and any known changes in the patient's circumstances during that time, the question of whether an advance directive admittedly made at some time in the past is still valid and applicable may require especially close, rigorous and anxious scrutiny."³¹¹

³⁰⁵ *ibid* [26] (Theis J)

³⁰⁶ *ibid* [29] (Theis J)

³⁰⁷ *Chatterton v Gerson* (n 64) 443 (Bristow J)

³⁰⁸ *Taylor v Shropshire Health Authority* [1998] Lloyd's Rep Med 395

³⁰⁹ *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam) [13] (Theis J)

³¹⁰ C Johnston (n 70) 505

³¹¹ *HE v A Hospital NHS Trust* [2003] EWHC 1017 (Fam) [25] (Munby J)

Thus, although renewal may not be a strict requirement for the preservation of validity and applicability of ADRTs, periodic renewal is a prudent practice as failure to renew will invite closer scrutiny.³¹²

Aside from the point made in *X v XB* on the effect of express temporal limitations, this case also demonstrates that rectification of ADRTs may be possible in some cases. XB's ADRT specified "non-invasive ventilation" when he was actually receiving "invasive ventilation",³¹³ but the evidence was accepted from a GP who helped in the process of drafting the ADRT and who claimed that he had discussed the removal of a device from XB that provided invasive ventilation. This oral evidence was thus permitted to contradict the over the written instrument in order to get to arrive at the result that XB had intended. This case provides further illustration of courts' willingness to use discretion and flexibility in the adjudication of ADRTs.

Having considered the general requirements of the creation of ADRTs laid down by section 24 MCA, the specific matters relating to 'validity' and 'applicability' must now be discussed. Section 25 of the MCA sets out the conditions under which advance decisions will take binding force. Particularly it looks at when ADRTs will not be considered valid and when they will not be considered applicable to the treatment that is proposed. In addition, it introduces special formalities on the creation of advance decisions which pertain to the refusal of "life-sustaining treatment". These matters are set out in section 25 MCA which states:

25 Validity and applicability of advance decisions

(1) An advance decision does not affect the liability which a person may incur for carrying out or continuing a treatment in relation to P unless the decision is at the material time—

(a) valid, and

(b) applicable to the treatment.

(2) An advance decision is not valid if P—

(a) has withdrawn the decision at a time when he had capacity to do so,

(b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or

³¹² Department for Constitutional Affairs (n 80) para 9.29

³¹³ *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam) [20] (Theis J)

(c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision.

(3) An advance decision is not applicable to the treatment in question if at the material time P has capacity to give or refuse consent to it.

(4) An advance decision is not applicable to the treatment in question if—

(a) that treatment is not the treatment specified in the advance decision,

(b) any circumstances specified in the advance decision are absent, or

(c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

(5) An advance decision is not applicable to life-sustaining treatment unless—

(a) the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and

(b) the decision and statement comply with subsection (6).

(6) A decision or statement complies with this subsection only if—

(a) it is in writing,

(b) it is signed by P or by another person in P's presence and by P's direction,

(c) the signature is made or acknowledged by P in the presence of a witness, and

(d) the witness signs it, or acknowledges his signature, in P's presence.

(7) The existence of any lasting power of attorney other than one of a description mentioned in subsection (2)(b) does not prevent the advance decision from being regarded as valid and applicable.

This section establishes two broad paths to failure for ADRTs in addition to those implied by section 24. Section 25 requires ADRTs to be valid and to be applicable to the particular treatment under consideration. Validity is defined in negative terms in section s 25(2).

There are three ways in which an ADRT can fail through invalidity under section 25(2). The first is where the ADRT has been revoked. This revocation must happen while the person who created the ADRT retains capacity, but requires no formality.³¹⁴ The second way

³¹⁴ see above; MCA, s 25(2)(a)

the ADRT can be invalidated is through the creation of an LPA³¹⁵ which gives decision-making power over the area to which the ADRT purported to apply. The creator of an ADRT can also invalidate their ADRT through any conduct which is deemed to be inconsistent with the provisions of the ADRT. This provision gives effect to the ruling in *HE*.

Applicability is defined in negative terms throughout sections 25(3)-(6). Section 25(3) states that an ADRT will not be applicable to treatment if it was made without capacity. The presence of capacity is one of the fundamental conditions for the creation of an ADRT as it is for the refusal of treatment. The requirement of capacity was discussed in relation to section 24 above and, in particular, in relation to *re E*.³¹⁶

Section 25(4) lists three ways in which an ADRT may fail due to a lack of applicability based on the content of the ADRT. The ADRT will not be held to be applicable if it does not specify the treatment to be refused. An example of this from the pre-MCA common law can be found in *W v KH*³¹⁷ in which the reports about what the patient would have wanted to happen in the condition in which the patient found herself were *inter alia* insufficiently precise to form an ADRT. In particular there was no evidence that the patient, KH, had directed her mind to the question of the withdrawal of the Percutaneous Endoscopic Gastrostomy (“PEG”) feeding tube.

ADRTs will also lack applicability unless the specified circumstances obtain when treatment becomes clinically indicated.³¹⁸ This is a point well illustrated by the case of *W v M* (discussed above).³¹⁹ This case suggests that, patients must demonstrate that they have considered the circumstances in which he or she might lose capacity in order to maximise the possibility that his or her ADRT will take effect at the relevant time. Alternatively, the author of the ADRT may wish to specify circumstances under which they would not wish to refuse treatment i.e. circumstances in which they would wish to receive treatment. For example, a person could conceivably wish to refuse any life sustaining treatment only in the event that when such treatment was indicated, their spouse was still alive (perhaps in order that they could become a posthumous organ donor for his or her spouse). Demonstrating sufficient balance of specificity and generality will be an ongoing challenge for authors of ADRTs.

³¹⁵ see above section LASTING POWERS OF ATTORNEY p 40

³¹⁶ *Re E* (n 10)

³¹⁷ *W v KH* [2004] EWCA Civ 1324 (CA)

³¹⁸ MCA, s 24(4)(b) and see Department for Constitutional Affairs (n 80) para 9.16

³¹⁹ *W v M* (n 11)

As a further safeguard, there is a third way in which an ADRT can fail on applicability grounds. Specifically, if the circumstances in which capacity is lost are different from those which the author anticipated and, on a reasonable assessment, this variation in circumstances would have led the author to making a different decision, then the decision will not be applicable to the treatment.³²⁰

From the preceding discussion, the conclusion of Brazier and Cave that “the task of making a fire-proof advance decision [is] nigh on impossible” is quite understandable.³²¹ They illustrate their claim with the example of someone who makes an ADRT following treatment they have received for a brain tumour that aims to refuse resuscitation and antibiotics if the cancer recurred and caused her medical situation to deteriorate.³²² However, if the immediate need for treatment did not arise from the cancer but stemmed instead from a stroke or from a head injury the ADRT may not apply. This point has also been acknowledged by the Royal College of Physicians in respect of non-legally binding Advance Care Plans (“ACPs”).³²³ They query whether it would be better to be less specific about the circumstances in the ADRT, but then point out that this may lead to a lack of compliance with section 25(3) MCA.³²⁴

FAILURE OF FORMALITY

Another requirement to be satisfied by certain ADRTs is that they must comply with certain formalities. Sections 25(5) and (6) pertain to the special formalities applicable to ADRTs required for the refusal of “life-sustaining treatment” e.g. refusing “artificial nutrition and hydration”³²⁵. These formalities are aimed at two main, sensible, functions: the drawing of attention to the mind of the author that an important decision is being made and the function of using the formalities to provide evidence of the decision and that it represents the creator’s true wishes.³²⁶

Under the MCA framework, it is possible for people to refuse treatment which would only be clinically indicated under, such as certain circumstances in the event of entering a prolonged comatose state. In contrast to the pre-MCA common law position,³²⁷ such a

³²⁰ MCA, s 24(4)(c)

³²¹ M Brazier and Cave E (n 34) para 6.14

³²² See also S Michalowski (n 143) 966-969

³²³ Royal College of Physicians *Advance Care Planning* (n 15) 12, 4

³²⁴ C Johnston (n 70) 506-508

³²⁵ Institute of Medical Ethics (1991) cited in *Bland* (n 63) (CA) 812. Hereafter “ANH”

³²⁶ See JH Lanbein, 'Substantial Compliance With The Wills Act' (1975) 88 *Harvard Law Review* 489, 492-498

³²⁷ *HE v A Hospital NHS Trust* [2003] EWHC 1017 [33] (Mr Justice Munby)

decision would now have to be made in writing for it to be valid.³²⁸ Though this formality is only made necessary in relation to life-saving or life-sustaining treatment, it would appear sensible for patients to follow the same procedures for most major treatment decisions to obtain the same advantages.

Any promotion of such a course of action would not be without its problems however, as the requirement of disclosing future treatment decisions to others, would open those to attempts to persuade the maker of the future decision to change their mind (i.e. to accept the treatment) and would act as an impediment to autonomous decision-making. The same argument could be levelled at the formality requirements for creating an ADRT to refuse treatment for life-saving or life-sustaining treatment, because true respect for individual autonomy ought not to be dependent on the willingness of others to act as witnesses.³²⁹ Though on balance, this incursion on the principle of self-determination is relatively slight and it does provide practical advantages over the old common law position.³³⁰

If the author of an ADRT fails to comply with the formalities requirements, the failed ADRT will not bind those seeking to provide treatment in the patient's best interests. However, the provisions of the ADRT will be used in the assessment of best interests section 4(7) MCA. This is what happened in *NHS Trust v D*³³¹ where there was a failure to comply with section 25(5)-(6). D's purported ADRT was a letter which he had signed that indicated that he refused any treatment to be given merely for the purposes of extending life, but did not make it explicitly clear that he wanted to refuse treatment even if doing so would shorten his life, nor did he comply with section 25(6)(c) in that D's signature was not made in the presence of a witness. Thus D failed to comply with the formalities and the purported ADRT was not upheld as binding.³³² Nonetheless, the wishes D expressed in the letter carried great weight in the assessment of best interests, upon which point it was concluded that it was not in D's best interests to continue to receive medical treatment being, as he was, in a VS.³³³

Similarly, in *A NHS Trust v Dr A*³³⁴ the patient, Dr A was a 55 year old Iranian GP with a history of depression who had come to the UK for a language course before making an application for asylum. However, his application was unsuccessful and Dr A's passport was confiscated and he was held under section 136 of the mental health act 1983. After being

³²⁸ MCA, ss 25 (5)-(6)

³²⁹ MCA, ss 24-26

³³⁰ See S Michalowski (n 143)

³³¹ *An NHS Trust v D* [2012] EWHC 885 (COP)

³³² *ibid* [16] (Peter Jackson J)

³³³ *ibid* [17] (Peter Jackson J)

³³⁴ *A NHS Trust v Dr A* (n 119)

released, A went on hunger strike in protest at the rejection of his asylum claim. In a letter to his psychiatrist he wrote, “please don’t try to save me and I decided (sic) to refuse any treatment and receiving fluid (sic) or food”, but at around the same it was said that his wish to die was not consistently held and that he had actually thanked his doctor for saving him.³³⁵ Importantly, although the letter was in writing, it was not witnessed and therefore was not in compliance with the formalities of the sections 25(5) and (6).³³⁶ As Dr A’s condition deteriorated, an interim declaration was granted which ruled that Dr A lacked both the capacity to litigate and the capacity to refuse nutrition and hydration. A full hearing was held subsequently and there it was again decided that Dr A did lack capacity to refuse treatment and that force feeding would be in his best interests.³³⁷

However, the stringency with which the rules on formalities are enforced has been far from consistent. The case of *Newcastle Upon Tyne Hospital Trust v LM*³³⁸ was far more relaxed in its interpretation of the formalities requirements in section 25-26 MCA.³³⁹ Most surprisingly, the advance decision was upheld notwithstanding its formal deficiencies. Mr Justice Peter Jackson made clear that the decision was not based on best interests. The decision to prevent the blood transfusion was not a conclusion reached on the basis of best interests, because Judge Peter Jackson stated:

*"In the alternative, if LM had not made a valid, applicable decision, I would have granted the declaration sought on the basis that to order a transfusion would not have been in her best interests."*³⁴⁰

This suggests that the primary reason for the refusal of the blood transfusion was the ADRT and the opinion proffered that the blood transfusion would not be in LM’s best interests was expressed *obiter* and as an alternative. Thus the formality requirements of s 25(5)-(6) appear to have been ignored.

A less radical example of judicial generosity in the interpretation of these formalities can be found in *Nottinghamshire Healthcare NHS Trust v RC*.³⁴¹ In this case, the ADRT made by RC did not explicitly state that the author’s signature had been made in the presence of a witness as is required by section 25(6)(c) MCA. However, despite the lack of written

³³⁵ *ibid* [18] (Baker J)

³³⁶ *ibid* [33] (Baker J)

³³⁷ *ibid* [53] (Baker J)

³³⁸ *Newcastle Upon Tyne Hospital Trust v LM* [2014] EWHC 454 (COP)

³³⁹ *ibid* [12] (Peter Jackson J)

³⁴⁰ *ibid* [12] (Peter Jackson J) (my emphasis)

³⁴¹ *Nottinghamshire Healthcare NHS Trust v RC* [2014] EWHC 1136 (COP)

evidence on this point, it was found that on the balance of probabilities the signature had been witnessed and there was compliance with the relevant formalities.

MENTAL CAPACITY AND MENTAL DISORDER

An added complication can occur where the person who lacks mental capacity also has a mental disorder. More specifically there is a potential difficulty with the traditional legal right to refuse treatment and the powers available under the Mental Health Acts for the compulsory detention for the purposes of the treatment or assessment of a mental disorder. Section 63 of the Mental Health Act 1983 (as amended) states:

The consent of a patient shall not be required for any medical treatment given to him for the mental disorder from which he is suffering, not being a form of treatment to which [section 57](#), [58](#) or [58A](#) above applies, if the treatment is given by or under the direction of the approved clinician in charge of the treatment.

Effectively therefore, it allows treatment to be provided to treat a mental disorder, or its symptoms, even where consent for the treatment is refused. The exercise of the power to provide treatment without consent under this section is conditional on the treatment being in the best interests of the patient, being a proportionate interference with the patients human rights (especially their right to self-determination under Art 8 ECHR) and being pursued in promoting the health of the patient: *R (B) v Ashworth Hospital Authority*.³⁴² Section 63 allows for treatment to be provided even if the patient has mental capacity to make a decision about the specific treatment option themselves while that person is detained under the MHA: *R (on the application of PS) v (1) Dr G and (2) Dr W*³⁴³ (a case on section 58, but the same principles are thought to apply to section 63)). On this basis, it is unremarkable that section 63 can be used to provide treatment in contravention of a *prima facie* valid and applicable ADRT even where it goes against a valid ADRT.

An interesting question arose in the case of *Nottinghamshire Healthcare NHS Trust v RC* as to whether the power available under section 63 is obligatory or permissive.³⁴⁴ It was held that the power is permissive and that there is no obligation on the medical professionals providing treatment to use the power to override the ADRT. This decision might be cited as a further example of the increasing importance of the will of the individual patient as opposed to medical power.

³⁴² *R (B) v Ashworth Hospital Authority* [2005] UKHL 20 (HL)

³⁴³ *R (on the application of PS) v (1) Dr G and (2) Dr W* [2003] EWHC 2335

³⁴⁴ *RC* (n 341)

EFFECT OF VALID ADRTS

In addition to the substantive points to consider when asking whether an ADRT is valid and applicable, there is also the question of when ADRTs should be recognised and when they do meet the requirements in sections 24-25 what effect they should have. These questions are addressed by section 26, which states:

26 Effect of advance decisions

(1) If P has made an advance decision which is—

(a) valid, and

(b) applicable to a treatment,

the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.

(2) A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment.

(3) A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment.

(4) The court may make a declaration as to whether an advance decision—

(a) exists;

(b) is valid;

(c) is applicable to a treatment.

(5) Nothing in an apparent advance decision stops a person—

(a) providing life-sustaining treatment, or

(b) doing any act he reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court.

An ADRT which is formulated in accordance with the requirements in the MCA will have the same force and effect as a refusal of treatment that is made by a competent adult.³⁴⁵ The law relating to contemporaneous refusals of treatment was discussed above. In summary, it will be recalled that mentally competent adults can refuse treatment for any

³⁴⁵ MCA, s 26(1)

reason of for no reason at all³⁴⁶ and their refusals are legally binding. Thus, providing treatment which has been refused through a valid and applicable ADRT is a *prima facie* battery a breach of duty for the purposes of the tort of negligence.³⁴⁷ Therefore treating someone in contravention of a binding ADRT will give rise to the same legal consequences. For would-be treatment providers, such as medical professionals therefore, there is great importance in being able to identify when an ADRT takes effect with legal force.

Some concessions have been made to treatment providers in section 26(2)-(3) recognition of the fact that serious consequences may arise from delaying the provision of treatment and that treatment providers may therefore have to make assessments as to the legal standing of particular ADRTs in highly pressured circumstances. This part of the MCA sets out when a person will not incur liability based on his or her assessment as to the validity of an ADRT. Here there is an interesting difference when it comes to two possible kinds of mistake that could be made in the assessment of the validity of an ADRT. Section 26(2) states that a person will not incur liability for providing treatment if they believed that the ADRT was not legally binding. Whereas if the treatment provider omits to provide treatment in reliance on an ADRT that he or she believes to be valid, the treatment provider will only have a defence if she or he *reasonably* believed that the ADRT was invalid. These evidentiary tests therefore institute a structural bias in favour of the continuation or commencement of treatment³⁴⁸ and it has been argued that this provision protects “clinical discretion” at the expense of patient autonomy.³⁴⁹

CONCLUSION

The primary purpose of this chapter is to provide a detailed overview of the legal landscape pertaining to ADRTs, as the area of law examined in this thesis. The definition of ADRTs is crucial to the ongoing analysis, which is why much effort was spent in attempting to distinguish ADRTs from other similar instruments which will not be discussed here. In addition, it was made clear that the kinds of ADRTs under discussion in this thesis are those which purport to refuse life-sustaining treatment under the law of England and Wales.

In order to define this area of law clearly, it has been necessary to set out the law on contemporaneous refusals of treatment, as this law upon which ADRTs are founded. From this examination it could be seen that certain patients have a very strong, but also very

³⁴⁶ *Re MB* (n 57) 186 (Butler-Sloss LJ); *Re T* (n 54) 113 (Donaldson of Lymington MR)

³⁴⁷ *Chatterton v Gerson* (n 64)

³⁴⁸ S Michalowski (n 143) 960; AR Maclean, 'Advance Directives and the Rocky Waters of Anticipatory Decision-Making' (n 143) 21

³⁴⁹ E Jackson, *Medical Law: Text, Cases and Materials* (n 32) 252

limited, right to refuse treatment. One of the most significant limitations on the right to refuse treatment is that it can only be exercised by those with mental capacity. Where mental capacity is lacking, medical practitioners are permitted to provide clinically indicated treatment in accordance with the best interests of the patient. Since the enactment of the MCA, the concept of best interests has been reoriented to require the consideration of a number of a number of factors including the patient's own wishes and feelings, but these wishes and feelings will not be determinative of the outcome and will rather be one factor among many.

The doctrinal function of ADRTs is to provide patients the opportunity to make legally binding decisions, prior to the loss of mental capacity, which will become binding should mental capacity be lost. They offer nothing to in legal terms above to rights to refuse treatment contemporaneously. The only change is that this power is projected into the future and can apply to circumstances that have not yet arisen and indeed may never arise.

As mental capacity is one of the most important factors in determining the basis on which treatment can be provided (i.e. whether it is to be provided on the basis of patient consent or whether it can be provided on the basis of a best interests assessment) it was imperative to provide a detailed discussion of the definition of mental capacity in English law and the rules which govern its assessment. Several contentious aspects of mental capacity assessment were highlighted at this juncture, including the possibility for the normative commitments of the assessor to enter into capacity assessments, the difficulty of differentiating mental disorders from matters affecting mental capacity and the manner in which capacity has been recognised by the court. Such difficulties place a notable qualification on the rhetorical bombast with which the right to refuse treatment has been portrayed and they take a special salience in respect of ADRTs which are dependent on the assessment of capacity at two points in time.

The examination of the terms on which ADRTs are recognised in the MCA reveals further hurdles for those who wish to assert a right to refuse treatment in future. In particular the requirement to specify the circumstances in which the ADRT should apply is always open to interpretation and the manner in which some purported ADRTs have been interpreted highlights the considerable uncertainty associated with predicting whether an ADRT will provide the outcome sought by its creator.

Thus, from a purely practical perspective, the degree of additional control offered by ADRTs is greatly dependent on a number of factors including the approach taken towards mental capacity and the interpretation of the terms of the ADRT. However, in order to

understand why the law operates as it does requires an appreciation of the arguments for recognising ADRTs in the first place. Although the incorporation of ADRTs into the legal order did not require a change to the fundamental legal principles in this area, their recognition was contentious from other normative perspectives. When justifying the legal position in respect of consent to treatment, leading commentators and members of the judiciary often invoke notions of autonomy and self-determination. As ADRTs are seen as a mere extension on the contemporaneous rights of individuals the same moral justifications underpin ADRTs. In terms of understanding the rationale for the law on ADRTs it is therefore imperative to examine the meaning of these concepts of self-determination and autonomy. This task will be undertaken in the next chapter.

PART II

THE NORMATIVE UNDERPINNINGS OF ADRTS

Having set out the law on ADRTs in the first part of this thesis, the task of the second part is to examine the normative underpinnings of the law and some of the ways in which those underpinnings have been contested.

There are a number of reasons why it might be said to be important to recognise ADRTs, but, as will be discussed in this part of the thesis, special emphasis has been placed on respect for autonomy and self-determination as grounds for the development of the law. ADRTs perform a temporal extension of the idea that everyone should be able to determine what should be done with their own body, to enable people to make decision about what should happen to their bodies following a future loss of capacity. That being the case, a considerable part of the discussion will be comprised of a discussion of the meaning and development of the concepts of autonomy and self-determination.

Given the extent of the reliance placed on personal autonomy, it might be thought that the law would have developed a clear idea of the meaning of that term. However, the concept of autonomy itself remains heavily disputed. A significant line of critique has been generated around the claim that autonomy has been conceptualised in an overly individualistic manner and this critical analysis would apply *a fortiori* to ADRTs to the extent that they are justified by an extended version of autonomy. Another important claim is made by those who accept the individualistic nature of autonomy, but who claim that it cannot form the normative basis for ADRTs, because the individual to whom an ADRT may apply will not necessarily be the same as (or sufficiently similar to) the individual that created the ADRT in the first place. This forms a powerful ‘personhood argument’ which is discussed in Chapter Five.

Behind this discussion is the position advocated here, which is that the normative concepts of autonomy and self-determination have clearly been important for the development of the law, but that there are other important factors which have been instrumental in the development of the law too: the advances in medical technology enabling life to be sustained in circumstances of low function; the political organisation of society in accordance with an advanced liberal rationality; the aging population; the financial crisis and scarcity of resources available for healthcare. These are themes which will be more fully in Part III. This part of the thesis provides a challenge to the orthodox overemphasis of the importance of autonomy for the development of the law on ADRTs.

CHAPTER TWO

THE NORMATIVE BASES FOR ADRTS

INTRODUCTION

The previous chapter set out the law on advance decisions to refuse treatment (“ADRTs”) in England and Wales. There it was explained that the law on ADRTs is parasitic on the law that regulates consent to treatment, because, in legal terms, ADRTs do no more than temporally extend the right of patients to refuse treatment contemporaneously into the future. Specifically, ADRTs extend this right beyond a time at which there is a loss of mental capacity. That being the case, it was necessary to explain English law’s definition and approach towards the concept of ‘mental capacity’. Pursuant to this explanation, the substantive law from the MCA and the common law was set out. Some critical discussion was offered on the possibility of realising the truly functionalist approach towards capacity, to which the law aspires, within the legal framework of the MCA and in relation to other difficulties associated with the way in which capacity can be assessed under the MCA.

The concept of ‘best interests’ was also discussed in order to illustrate the determination of the kinds of treatment that can be provided to a person who lacks capacity without consent. This discussion further highlighted the changes wrought by the MCA. Of particular significance has been the fact that it introduced an explicit requirement to incorporate patient wishes as part of the determination of best interests. It was suggested that the elevation of the importance of patient wishes is indicative of a move towards greater patient choice and control in the ‘medical encounter’,³⁵⁰ which is often referred to as ‘patient empowerment’³⁵¹ (a theme that will further be discussed in the third part of this thesis).

Still, the very possibility of treatment being provided to a patient against his or her will, even in the name of his or her ‘best interests’, is anathema to the post-war political project of protecting the rights of patients and of patient empowerment.³⁵² As a result, ADRTs serve as remedial instruments, which purport to allow patients to assert control over the kind of medical treatment that they may receive following a loss of mental capacity. For those who

³⁵⁰ J Bensing, and P Verhaak, ‘Communication in medical encounters’ in A Kaptein and J Weinman (eds) *Health Psychology* (Blackwell 2004) 266

³⁵¹ K Veitch, ‘The Government of Health Care and the Politics of Patient Empowerment: New Labour and the NHS Reform Agenda in England’ (n 89)

³⁵² *ibid*

have strong preferences relating to their future treatment, ADRTs therefore may offer a degree of reassurance against the possibility of being given unwanted treatment.³⁵³ Theoretically, the level of control that ADRTs offer is significant, in that individuals are free to refuse any form of treatment through an ADRT that could be refused contemporaneously and in addition, a refusal of treatment through an ADRT offers the same level of protection as a contemporaneous refusal of treatment. Moreover, individuals have the right to make this kind of refusal pre-emptively, meaning that they do not need to wait for the medical circumstances warranting treatment to occur combined with an invitation from a medical practitioner to make a decision about the treatment for that condition. This possibility may be considered empowering of itself.

However, it was suggested that the way the law is framed and the experience of those who have created ADRTs illustrates that the guarantee offered by ADRTs is fragile in a number of important respects.³⁵⁴ ADRTs are heavily contingent on the assessment of capacity, because their operation requires mental capacity to be tested at two points in time (at the point of authorship and at a future time when there are doubts about the patient's capacity to decide) and these capacity tests may be conducted by any person involved in the treatment or care of the patient. Those who perform those tests may have an imperfect understanding of the law³⁵⁵ and whatever steps may be taken to ensure adequate legal knowledge, their judgment may be swayed by their own interests.³⁵⁶ There are also a number of formality requirements (outlined in Chapter One), which, if not adhered to, may cause the ADRT to fail. Similarly an ADRT will not take effect unless the specified treatment becomes clinically indicated in the specified circumstances and the question of whether this has happened is a crucial question of interpretation.³⁵⁷ Additionally, as discussed in Chapter One, there is a structural bias in the drafting of the MCA to promote the provision of life saving treatment over applying the ADRT.³⁵⁸

In this chapter, the underlying normative bases for the recognition of ADRTs will be explored in more detail. A number of possible bases for recognising ADRTs will be suggested in the first section. However, the argument most frequently relied upon in law and

³⁵³ M Brazier, 'Do No Harm - Do Patients Have Responsibilities Too?' (2006) 65(2) *The Cambridge Law Journal* 397, 418

³⁵⁴ AR Maclean, 'Advance Directives and the Rocky Waters of Anticipatory Decision-Making' (n 143) 21-22; S Michalowski (n 143)

³⁵⁵ see M Donnelly, 'Capacity assessment under the Mental Capacity Act 2005: Delivering on the functional approach?' (n 145) 472-473

³⁵⁶ *ibid* 489-490; see also *A NHS Trust v Dr A* (n 119) [34] (Baker J)

³⁵⁷ *W v M* (n 11)

³⁵⁸ see S Michalowski (n 143) 960

bioethics centres on the alleged tendency of ADRTs to increase or ‘extend’ the right to personal autonomy or self-determination.³⁵⁹ Thus, the predominant focus will be on the examination of this claim. Part of this examination will involve considering how autonomy is protected in relation to consent to treatment, as the legal foundation of ADRTs. Here it will be argued that the legal understanding of autonomy varies and is not precisely defined in accordance with philosophical ideas.

NORMATIVE BASES FOR ADRTS

“Counsel all agree that the right to reject treatment extends to deciding not to accept treatment in the future by way of advance directive or “living will.”³⁶⁰

“The basis for the moral (and legal) validity of advance directives is the patient’s right to autonomy, also known as the right to self-determination.”³⁶¹

A number of reasons have been suggested as to why individuals ought to be entitled to the right to refuse treatment pre-emptively through ADRTs. In the previous chapter it was suggested the right to refuse treatment and the very existence of ADRTs in law indicates that an objective determination of treatment through the best interests test is actually not what the law considers best for the patient, rather it is only ‘best’ in the absence of an ADRT. On this reading of the law, there is a tacit acceptance of the argument that the (proto-)patient³⁶² is a better person to decide what kind of treatment they should receive than the medical practitioner. ADRTs therefore establish a lawful basis to support this normative commitment.

It has also been argued that present welfare can be increased through the creation of an ADRT, because the author will thereby be able to assure themselves that her life will not be prolonged in circumstances in which she would not have wished to have been kept alive.³⁶³

³⁵⁹ *HE v Hospital NHS Trust* (n 66) (Fam) [37] (Munby J); *W Healthcare NHS Trust v KH* (n 70) [15] (Brooke LJ); R Andorno, N Biller-Andorno and S Brauer, ‘Advance Health Care Directives: Towards a Coordinated European Policy?’ (n 70) 208; P Lack, N Biller-Andorno and S Brauer (eds), *Advance Directives* (n 70) vi; C Johnston (n 70) 497-499; Department of Health (n 28) 10; Foster C, *Choosing Life, Choosing Death* (1 edition, Hart Publishing 2009) 152; Joint Committee on the Draft Mental Incapacity Bill (n 69) para 199

³⁶⁰ *Bland* (n 63) (CA) 816 (Butler-Sloss LJ)

³⁶¹ T Goffin, ‘Advance Directives as an Instrument in an Ageing Europe’ (2012) 19 *European Journal of Health Law* 121

³⁶² NS Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (Princeton University Press 2007) 85

³⁶³ M Brazier, ‘Do No Harm - Do Patients Have Responsibilities Too?’ (n 353) 418; Select Committee on Medical Ethics, *Report of the Select Committee on Medical Ethics* (HL 1993-94, 21-I) [187]

The degree to which this holds true is likely to vary between individuals and may depend on the intimacy of the author's familiarity with the law on ADRTs and precariousness of the guarantee offered by an ADRT (see previous Chapter).

Similarly, it has been suggested that establishing the right to create ADRTs provides an opportunity for dialogue between medical professionals and patients.³⁶⁴ Although, of course, it should be remembered the validity of ADRTs is not contingent upon prior medical advice. As such, this reason appears rather as a possible side benefit, rather than a core argument.

A seldom articulated reason for people to make ADRTs, which will be further discussed in Chapter Seven, is in order to alleviate 'burdens' at the end of life. This may refer to the ethical difficulty of arriving at an ethically sound treatment decision on behalf of another person who is at the end of life. However, the idea of burden may also refer to the brutal economics of the situation in which there is a choice between the continuation or the cessation of treatment and care of a person with a terminal condition. In this sense, and particularly within a collectively funded healthcare system, the creation of an ADRT may be considered laudable as an act of solidarity. Such arguments are rarely aired in such terms to avoid the risk of being interpreted as suggesting that those who require care, support and possibly expensive forms of treatment are a burden on society (especially as a similar argument was used by the Nazis). In addition, there is no evidence that ADRTs do reduce healthcare expenditure (although most research in this area focuses on ACPs rather than ADRTs and some countries do employ provisions which prevent financial incentives being given to those that create ADRTs e.g. Germany).

Other reasons for recognising ADRTs might be considered close cousins of those deployed in support of the recognition of autonomy. Some may argue that ADRTs should be recognised as part of a broader programme of patient empowerment, which has as its goal the redistribution of decision-making authority from doctor to patient and the limitation of medical power.³⁶⁵ They may be considered good in order to provide individuals with the opportunity to consider their own preferences and to take greater responsibility for their own health.

It has been argued that Human Rights law is essential to the development of medical law as a discipline³⁶⁶ and the normative power of Human Rights law has been relied upon in aid

³⁶⁴ *ibid* Select Committee on Medical Ethics [188]

³⁶⁵ see D Wilson, *The Making of British Bioethics* (n 9) 121

³⁶⁶ see I Kennedy, *Treat Me Right: Essays in Medical Law and Ethics* (New edition, Clarendon Press 1991) 385-413

of the recognition of ADRTs.³⁶⁷ This is tied to the individual right to determine what should happen to their body in accordance with the right of self-determination, protected by Art 8 ECHR. However, the degree of overlap between this goal of protecting Human Rights and the goal of respecting autonomy is dependent on how autonomy is defined. This point will be discussed further in the next section.

All of the legal developments promoting patient's legal rights to refuse treatment have been accompanied and to some extent supported by a growing recognition in the value of the concept autonomy in bioethics.³⁶⁸ In order to better understand the legal development of autonomy it is important to consider how the value has been developed as a moral principle in the disciplines allied to bioethics.

THE DEVELOPMENT OF THE PRINCIPLES OF AUTONOMY AND SELF-DETERMINATION

The purpose of this section is to provide some explanation of the key terms 'autonomy' and 'self-determination'. Providing a comprehensive account of the historical transformations in defining these terms would require far greater space than is available here, but it is hoped that by focussing on the thought of two of the most influential authors philosophers on this subject, Immanuel Kant and John Stuart Mill, an insight may be gleaned into the difficulties associated with defining these concepts. One of the aims is to highlight the contested nature of these concepts that have been relied upon so heavily in law and also to dispel any suggestion that the development of these concepts can be viewed as the product of a neat process of logical rationalisation or indeed that we have arrived at a position in which there is any agreement on the meaning of these concepts. Further discussion of some of the political problems with the individualistic form of autonomy which is alleged to have prevailed in law and bioethics will be provided in the next chapter.

To begin, it is trite to observe that, in its core sense, autonomy concerns the government of the self. The word autonomy is derived from the Greek *auto* meaning 'self' and *nomos* meaning 'government'.³⁶⁹ At this linguistic level of analysis, *autonomy* can be contrasted

³⁶⁷ Council of Europe, Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo, 4.IV.1997)

³⁶⁸ Chester (n 2); R Huxtable, *Euthanasia, Ethics and the Law: From Conflict to Compromise?* (Routledge-Cavendish, 2007) 13

³⁶⁹ G Dworkin, *The Theory and Practice of Autonomy* (Cambridge Studies in Philosophy, Cambridge University Press 1988) 108; see also J Feinberg, *The Moral Limits of the Criminal Law: Harm to Self* (Vol 3, Oxford University Press 1986) 27-28

with *heteronomy* which describes government exercised by others.³⁷⁰ The term ‘autonomy’ was first used in relation to city states,³⁷¹ was later used by Kant in relation to decisions³⁷² and others argue that it is a quality that persons can possess.³⁷³ The literal meaning therefore suggests that the individual is in control of the decisions that they make rather than any third party. On this simple understanding then, respecting autonomy entails respecting the decision of the decision-maker without making decisions on the other person’s behalf. In respect of medical treatment, this principle would therefore suggest that medical treatment should only be given with the continuing agreement of the patient. Respect for autonomy would equally demand that a decision to refuse treatment should be a matter for the individual. Protecting autonomy in law may therefore guard against the possibility of doctors conducting experiments on patients without consent.

Many have argued that the concept of autonomy is more complex and nuanced than this³⁷⁴ and that the simple right of individual choice, as regards matters which primarily affect them, is better described as a right of “self-determination”.³⁷⁵ In straightforward terms, ‘self-determination’ describes the right of an individual to determine what is done to them. In context of medical law, it was defined by Lord Scarman as “the right of a patient to determine for himself whether he will or will not accept the doctor’s advice” and indeed any particular form of treatment.³⁷⁶ Self-determination is, therefore, a close cousin of autonomy, but the two concepts are distinguishable (depending on which conception of autonomy – of which there are many³⁷⁷ – is used as a comparator).

Perhaps the most widely-known and cited conceptualisations of autonomy in medico-legal and bioethical literature are those of Immanuel Kant³⁷⁸ and John Stuart Mill. However, though they may have shared a research interest, these two philosophers arrived at very different conceptions of autonomy. Despite this, the distinctions between their positions have not always been clearly acknowledged by commentators who draw upon this work.

³⁷⁰ Z Bauman, *Freedom* (Concepts in the Social Sciences, Open University Press 1988) 10-11; see also I Berlin, ‘Two Concepts of Liberty’ in Henry Hardy (ed), *Liberty* (Oxford University Press 2002) 21; see also A Reath, *Agency and Autonomy in Kant’s Moral Theory: Selected Essays* (Clarendon Press 2006) 128-129

³⁷¹ G Dworkin, *The Theory and Practice of Autonomy* (Cambridge Studies in Philosophy, Cambridge University Press 1988) 12

³⁷² O’Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002) 83

³⁷³ G Dworkin (n 371) 12

³⁷⁴ see generally JB Schneewind, *The Invention of Autonomy: A History of Modern Moral Philosophy* (Cambridge University Press 1998)

³⁷⁵ e.g. O’Neill (n 372)

³⁷⁶ Sidaway (n 124) 882

³⁷⁷ J Gray, *Two Faces of Liberalism* (The New Press 2002) 99

³⁷⁸ J Feinberg (n 369) 94

Part of the blame for the confusion may well lie at the door of the authors of one of the seminal bioethical texts of the Twentieth Century, “*Principles of Biomedical Ethics*”, because arguably Beauchamp and Childress’ discussion of autonomy “fused the Kantian concept of respect for persons with John Stuart Mill’s quite different notion of liberty ... Folding together the distinct views of Kant and Mill blurred the edges of both the Kantian and the Millian notions”.³⁷⁹ Highlighting some of the differences between certain approaches to autonomy³⁸⁰ will help to explain why the term use of the term ‘autonomy’ without further specification can elicit such confusion.

KANTIAN AUTONOMY

Kant clearly viewed the rational will as the foundation of moral action.³⁸¹ He argued that “[o]nly a rational being has the power to act *in accordance with the representation* of laws, that is, in accordance with principles, or has a will [*wille*]”.³⁸² Simultaneously, Kant posited categorical imperative (“CI”) *a priori* as a norm and argued that rational agency depended upon an adherence to this norm.³⁸³ Kant expressed the CI in several different ways in an attempt to better explicate its meaning.

The first expression of the CI was that all moral decisions must be capable of general application, such they are capable of being applied as a law.³⁸⁴ Consequently suicide is impermissible in Kant’s moral framework,³⁸⁵ because if suicide were to be universalised as law, human existence would cease.³⁸⁶ Secondly, the CI suggests that a person cannot use themselves, as a moral agent, as a means to an end: “Act so that you treat humanity whether in your own person or in that or in that of any other, always as an end and never as a means only”.³⁸⁷ Thus, a person cannot sell themselves into slavery. Kant further asserts that all rational agents are ends in themselves and should never be treated as mere means to other ends. The third expression of the CI is “all maxims that proceed from our own making of

³⁷⁹ Jonsen AR, *The Birth of Bioethics* (Oxford University Press 1998) 335

³⁸⁰ The term autonomy has been widely studied and debated throughout the ages. For an excellent overview of the development of the concept see JB Schneewind (n 374)

³⁸¹ J Feinberg (n 369)35

³⁸² Cited in A Reath (n 370) 76

³⁸³ R Johnson, ‘Kant’s Moral Philosophy’ in *The Stanford Encyclopedia of Philosophy* Edward N. Zalta (ed) (<http://plato.stanford.edu/archives/sum2014/entries/kant-moral/>. [Accessed 22nd June 2015], 2014)

³⁸⁴ Kant, 1949, 64 cited in K Veitch, *The Jurisdiction of Medical Law* (n 8) 58

³⁸⁵ I Kant, ‘Foundations of the Metaphysics of Morals’ cited in RJ Sullivan, *An Introduction to Kant’s Ethics* (Cambridge University Press 1994) 56; J Feinberg (n 369) 94-97

³⁸⁶ Although is some dispute about whether Kant’s theory may permit and indeed require suicide in certain circumstances see DR Cooley, ‘A Kantian Moral Duty for the Soon-to-Be Demented to Commit Suicide’ (2007) 7(6) *American Journal of Bioethics* 37; See also J Feinberg (n 369) 95-96

³⁸⁷ I Kant, ‘Foundations of the Metaphysics of Morals’ cited in RJ Sullivan, *An Introduction to Kant’s Ethics* (Cambridge University Press 1994) 56; J Feinberg (n 369) 29

law ought to harmonize with a possible kingdom of ends as a kingdom of nature”.³⁸⁸ This places greater emphasis on the collective good of protecting the conditions in which autonomy can be exercised and aspiring towards a society in which individuals can act autonomously.³⁸⁹

Kant was deliberate in his usage of the term ‘autonomy’ and was careful to define it as part of the CI. He said

“[t]he principle of autonomy is therefore: choose only in such a way that the maxims of your choice are also included as universal law in the same volition. (g 4: 440; ii, ¶ 80)”.³⁹⁰

This definition pertained to the individualised character of autonomy, but Kant was also concerned with the operation of autonomy in society, where he acknowledged that “[a]utonomy is meaningfully exercised among other autonomous agents, whose rational capacities serve as a constraint on, and confirmation of, its exercise.”³⁹¹ Thus, in spite of charges of individualism levelled at Kant, he acknowledged that the meaningful exercise of autonomy requires sensitivity to the fact that moral action occurs in communities of other agents whose capacity for rational action should not be impinged upon.

Having outlined Kant’s conceptualisation of autonomy, a similar outline can be provided in respect of Mill’s work in the next section. This will provide an opportunity to contrast the approaches of the two philosophers and the definitions of autonomy that they provide.

MILLIAN AUTONOMY

Mill was one of the chief proponents of liberal thought in the Nineteenth Century. However, his approach to the question of autonomy differed quite significantly from Kant’s. Indeed, most notably, he rarely employed the term autonomy,³⁹² but in spite of this, his work has been routinely drawn upon by commentators for the purposes of defining and conceptualising autonomy.³⁹³ The reliance on Mill’s ideas in the definition of autonomy indicates the importance of liberal thought to the definition of autonomy and this is a theme

³⁸⁸ *ibid* I Kant, ‘Foundations of the Metaphysics of Morals’ 56; J Feinberg (n 369) 29, see further 84-93

³⁸⁹ Sullivan RJ, *An Introduction to Kant’s Ethics* (Cambridge University Press 1994) 84-93

³⁹⁰ A Reath (n 370) 125 and see *ibid* 125-131

³⁹¹ *ibid* 192

³⁹² O’Neill (n 372) 30

³⁹³ e.g. C Foster, ‘Autonomy in the Medico-Legal Courtroom: A Principle Fit for Purpose?’ (2014) 22 *Medical Law Review* 48; AE Fuchs, ‘Autonomy, Slavery, and Mill’s Critique of Paternalism’ (2001) 4(3) *Ethical Theory and Moral Practice* 231

that will be taken up in the third part of this thesis with the examination of Foucault's work on governmentality.

One of Mill's most important contributions to political philosophy was his establishment of the Harm Principle. Through this principle Mill set out the limits of legitimate state interference in the actions of its citizens in the following way:

“That the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others”.³⁹⁴

Thus, Mill argued that the decisions of each adult person should be respected on the basis that no other entity, including the state, has the right to interfere in the lives of an individual, unless that individual causes harm to others. From this, Mill drew the conclusion that “[o]ver himself, over his own body and mind, the individual is sovereign”.³⁹⁵

It is therefore clear that the individual occupies a central role in Mill's theory.³⁹⁶ It would be mistaken, however, to characterise Mill's argument as based on unbridled individual self-determination. Mill did believe that there should be some restriction on individual action. For instance, he considered that it would be legitimate to interfere with the actions of certain persons, such as children³⁹⁷ and suggested that people could be compelled to do certain acts.³⁹⁸

Further, we can observe that Mill's theory was not solely directed at the vindication of individual rights. Mill also highlighted the instrumental value of autonomy in suggesting its importance in the promotion of human development. For Mill, the normative force of the harm principle does not simply rely on the wrongness of interference with the body or in the affairs of an individual, but it also suggests that the lack of interference gives the individual space to develop their own ideas and preferences and to thereby become a better person. He claimed that this was character building and that without the formation of character people would be nothing more than machines:³⁹⁹

³⁹⁴ JS Mill, *On Liberty* (Project Gutenberg 2011) 17

³⁹⁵ *ibid* 18

³⁹⁶ *ibid* 124

³⁹⁷ *ibid* 18

³⁹⁸ *ibid* 20

³⁹⁹ *ibid* 112

“He who lets the world, or his own portion of it, choose his plan of life for him, has no need of any other faculty than the ape-like one of imitation. He who chooses his plan for himself, employs all his faculties.”⁴⁰⁰

Similarly, Feinberg criticises Kant’s insistence on a rational mode of decision making⁴⁰¹ as a requisite of autonomous decisions and instead promotes a “personal sovereignty”⁴⁰² (or “self-sovereignty”⁴⁰³) model of autonomy, which conforms closely with the rhetorical use of the term autonomy found in many cases on consent to treatment (considered in the next section). The core idea is that sovereign individuals have dominion over themselves and therefore cannot be forced to take action, or have action forced upon them by any external party. Feinberg would admit there ought to be certain limits on individual action, which are particularly evident through his distinction between ‘self-regarding’ and ‘other-regarding’ actions.⁴⁰⁴ This adds some nuance to Mill’s Harm Principle, by considering situations such as the garrison society in which there may be a clearer case for imposing restrictions on actions such as recreational drug taking as although they might be primarily directed towards the individual, may have significant consequences for the rest of society.⁴⁰⁵

Personal sovereignty has much in common with Berlin’s idea of negative liberty, which describes an area of liberty carved out by the limitations on the power of others: negative liberty may exist in the spaces not subject to the control of others.⁴⁰⁶ An example of autonomy as negative liberty might be seen in Law Commission’s understanding of autonomy in terms of the absence of ‘intervention’ in its report on Mental Incapacity⁴⁰⁷ that preceded the Mental Incapacity Bill.⁴⁰⁸ Berlin contrasted this with an idea of positive liberty, which describes the actual ability to pursue and obtain certain goals or being enabled to do the same.⁴⁰⁹

Plainly then, there are significant differences between Mill’s liberal position (with its similarities to Feinberg’s notion of ‘personal sovereignty’ and Berlin’s idea of negative liberty⁴¹⁰), based on defining the legitimate scope individual action through a principle

⁴⁰⁰ *ibid* 109-110

⁴⁰¹ J Feinberg (n 369) 43-45, 35-36

⁴⁰² *ibid* 48

⁴⁰³ N Naffine, ‘Who Are Law’s Persons? From Cheshire Cats to Responsible Subjects’ (2003) 66 *The Modern Law Review* 346, 194

⁴⁰⁴ see J Feinberg (n 369) 22-23

⁴⁰⁵ *ibid*

⁴⁰⁶ see I Berlin, ‘Two Concepts of Liberty’ (n 370) 169-178

⁴⁰⁷ The Law Commission *Mental Incapacity* (LC231, 1995)

⁴⁰⁸ *ibid* para 8.4

⁴⁰⁹ See further T Takala, ‘Concepts of “person” and “liberty,” and Their Implications to Our Fading Notions of Autonomy’ (2007) 33 *Journal of Medical Ethics* 225

⁴¹⁰ see J Feinberg (n 369) 52-97; I Berlin, ‘Two Concepts of Liberty’ (n 370) 169-178

limiting state action and Kant's deontological position based on the CI as an *a priori* principle facilitating rational decision-making. Kant conceived of autonomy in terms of a *duty* (*Verpflichtung*) to make decisions consistent with the CI, whereas Mill imposed minimal obligations on the individual in terms of the kinds of decisions that they could make (the primary one being that third parties would have an interest in the decision where it is one that may cause harm to others). Further, and in more general terms, the political focus of Mill's approach can be contrasted with the more abstract, moral, approach of Kant. These important distinctions, among others, suggest that positions of the two philosophers should not be quickly conflated.

Given their influence in bioethics and law, having an appreciation of the difference in approach of these philosophers and the difference in definition that results is therefore crucial. Having identified some of these differences, we can now consider how these philosophical theories of autonomy map onto the legal recognition of autonomy, particularly in respect of medical law.

AUTONOMY, SELF DETERMINATION AND THE CONTEMPORANEOUS REFUSAL OF MEDICAL TREATMENT

Having outlined the concepts of autonomy and self-determination in the previous section, we must now consider how those terms have been understood and drawn upon in medical law. In particular, the discussion will focus on the implicit and explicit use of the concepts of autonomy and self-determination in relation to cases on the refusal of treatment and on advance decisions to refuse medical treatment. The reason for this focus is because, as discussed above, the law on ADRTs is contingent on the law on contemporary refusals of treatment. The case law on contemporary refusals of treatment also offers an important insight into the normative basis for the development of the law in this area. Of particular note is that respect for personal autonomy has not always been the primary ground for requiring consent to be obtained for treatment.

“It is now well recognised that the interest which the law of negligence protects is a person's interest in their own physical and psychiatric integrity, an important feature of which is their *autonomy, their freedom to decide what shall and shall not be done with their body...*”⁴¹¹

The relationship between the greater prominence of recognition given to autonomy and the strengthening of the rights to refuse treatment is complex. We can observe that lawyers, and particularly academic lawyers, who position themselves within the medical law or

⁴¹¹ *Montgomery v Lanarkshire Health* (n 161) [108] (Kerr and Reed LLJ) (my emphasis)

healthcare law traditions, commonly take their understanding of the concept of autonomy from bioethics,⁴¹² which might be considered the applied field of moral philosophy. Testament to the significance of this relationship, many of the leading textbooks on medical law contain reference to ‘ethics’ or ‘bioethics’ in their very titles (although arguably these terms are under theorised in the medical law literature)⁴¹³.

Even those textbooks that do not contain a reference to ‘ethics’ in their titles inevitably make reference to ethical principles in the body of the work, because these ethical principles are intimately bound up with the legal principles they seek to describe.⁴¹⁴ Miola characterises this relationship between medical law and medical ethics as ‘symbiotic’.⁴¹⁵ The two (sub-) disciplines mutually rely upon, reinforce, and perhaps, reproduce each other. The law is able to draw upon the philosophical gravitas of ethical argumentation in establishing legal principles governing the roles of doctors and patients. While medical ethics can draw upon a ready source of ethical dilemmas arising from case law and can then respond to legal developments and requirements which shape roles and expectations. In part, this is due to the complex interplay between medical law and medical ethics.⁴¹⁶

However, although autonomy may have come to be the most frequently cited and dominant principle in bioethics,⁴¹⁷ it is a term which has rarely received express recognition, much less express discussion, in case law. Hoppe and Miola note that two of the most important cases on the law of informed consent (and medical negligence) *Blyth v Bloomsbury HA* and *Sidaway* are “autonomy-free zones”.⁴¹⁸ Neither case employs the term autonomy, but despite this, such cases are taken, to be part of the case law that expands patients’ rights to respect for their autonomy.

Where ideas of autonomy and self-determination are directly relied upon by the courts they are seldom clearly defined, nor consistently applied.⁴¹⁹ In *Ms B v An NHS Hospital Trust* a number of exceptions from precedent case law are provided under the heading “The principle of

⁴¹² See K Veitch, ‘Medical Law and the Power of Life and Death’ (2006) 2(2) *International Journal of Law in Context* 137, 138

⁴¹³ K Veitch, *The Jurisdiction of Medical Law* (n 8) 55

⁴¹⁴ but see *RC* (n 341) [15] (Holman J)

⁴¹⁵ J Miola, *Medical Ethics and Medical Law: A Symbiotic Relationship* (n 167)

⁴¹⁶ See e.g. *ibid*; E Jackson, ‘The Relationship between Medical Law and Good Medical Ethics’ 41(1) *Journal of Medical Ethics* 95

⁴¹⁷ D Callahan, ‘Principlism and Communitarianism’ (2003) 29 *Journal of Medical Ethics*, 287, 288 and see C Foster, ‘Autonomy in the Medico-Legal Courtroom: A Principle Fit for Purpose?’ (n 393) 51-53

⁴¹⁸ N Hoppe and J Miola, *Medical Law and Medical Ethics* (n 113) 81

⁴¹⁹ J Coggon, ‘Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?’ (2007) 15(3) *Health Care Analysis* 235

autonomy”, disappointingly only one of the excerpts actually employs the term “autonomy” (from *Re T*) and it provides no definition, but merely an association of the term with others such as bodily integrity, self-determination and choice.⁴²⁰ The case of *A Local Authority v JH*⁴²¹ gives a cogent illustration on the point. There it was suggested that “[the patient] is still able to appreciate and express the value of being at liberty and being allowed autonomy”⁴²² but footnote at this point states that this meant “[a]utonomy in the practical, everyday sense, rather than a strict legal or philosophical sense (i.e., autonomy vs heteronomy of the will)”.⁴²³

A much more convincing engagement with the concept of autonomy can be found in *Chester*,⁴²⁴ where the term autonomy was explicitly employed⁴²⁵ and a passage from Ronald Dworkin’s *Life’s Dominion* was quoted.⁴²⁶ In this passage Dworkin suggests that autonomy has value because it protects the individual capacity to define her own character.⁴²⁷ However, this should not immediately be taken as an endorsement of Dworkin’s conception of autonomy throughout this body of case law. It is plain that Dworkin’s account of autonomy would introduce certain conditions on the recognition of a particular action as being autonomous which the law may not accept (e.g. there is no requirement when refusing treatment requiring that refusals accord with the individual’s deeply held values etc).

In particular, Dworkin argues that a decision is only to be respected as autonomous if it reflects the critical interests of the individual.⁴²⁸ By contrast the law would, in theory, be bound to respect the decision of individuals who made a decision which did not conform to their deeply held values or which was even made for no reason at all.⁴²⁹

Indeed, when considering the law on the refusal of treatment, much of the focus of the case law has not on the patient at all, but on the actions of the doctor. The case of *Slater v Baker and Stapleton*⁴³⁰ is one of the earliest cases in English law to recognise consent as a requisite of lawful medical treatment. The case involved a patient who had a cast removed from his leg in the absence of his clear consent, causing him pain. His claim against the

⁴²⁰ [2002] EWHC 429 (Fam) [16]-[21] (Butler-Sloss P)

⁴²¹ [2011] EWHC 2420 (COP)

⁴²² *ibid* 42 (Eldergill J)

⁴²³ *ibid* 42 FN 39

⁴²⁴ *Chester* (n 2)

⁴²⁵ *ibid* [18] (Steyn LJ)

⁴²⁶ R Dworkin, *Life’s Dominion: An Argument about Abortion and Euthanasia* (HarperCollins 1993)

⁴²⁷ *ibid* 224

⁴²⁸ *ibid* 201–202

⁴²⁹ *Re T* (n 54)

⁴³⁰ (1767) 95 ER 860, see MK Mayberry and J Mayberry *Consent in Clinical Practice* (Radcliffe Medical 2003) 33-34

surgeon upheld in court and he was awarded damages. However, the rationale given for requiring patient consent was somewhat different to that which might be proffered today (along the lines of a violation of the patient's right to determine what should be done with his body). It was said that "...it is reasonable that a patient should be told what is about to be done to him [sic]".⁴³¹ This portrays the failing more as one of etiquette than of the violation of the physical integrity of the patient, a failure to respect his autonomy, or an interference with his right to self-determination.⁴³²

Even as late at the Nineteenth Century, the seeking consent was viewed as a practice designed more to improve therapeutic outcomes than protect any supposed patient rights.⁴³³ Taking this view would suggest that there is no necessary link between institution of a body of laws which safeguard the right to refuse treatment and autonomy in the sense of patient empowerment.

The themes of autonomy and self-determination came to greater prominence in this area in the Twentieth Century. One of the most important drivers for this change of focus was the Second World War and the atrocities uncovered following its conclusion. Although it has been reported that informed consent requirements were in existence in Germany at the beginning of the Twentieth Century,⁴³⁴ the orthodox medical law narrative holds out the discovery of Nazi atrocities during WWII as a watershed moment for the development of informed consent and patient rights more generally, following which there was recognition that patients required greater protection from the medical profession and medical researchers to safeguard them from abuse.⁴³⁵ This resolve that the atrocities perpetrated by Nazi doctors should never be repeated was manifested in the Nuremberg Code in 1947, which made the voluntary (i.e. uncoerced) consent of human subjects the *sine qua non* of participation in medical research for adults with capacity.⁴³⁶

⁴³¹ (1767) 95 ER 860, 862

⁴³² see also J Miola, *Medical Ethics and Medical Law: A Symbiotic Relationship* (Hart 2007) 28-30

⁴³³ Beauchamp TL and JF Childress, *Principles of Biomedical Ethics* (6th ed, Oxford University Press 2009) 56

⁴³⁴ J Vollmann and R Winau, 'Informed Consent in Human Experimentation before the Nuremberg Code.' (1996) 313 *British Medical Journal* 1445

⁴³⁵ J Miola, *Medical Ethics and Medical Law: A Symbiotic Relationship* (Hart 2007) 33; J Miola, 'Making Decisions About Decision-Making: Conscience, Regulation, and the Law' (2015) 23 *Medical Law Review* 263, 267

⁴³⁶ 'The Nuremberg Code', 1947. <http://ohsr.od.nih.gov/guidelines/nuremberg.html>. [accessed 25/03/2012]

The revelations at Nuremberg did great damage to the trust to which medical practitioners were formerly accustomed⁴³⁷ and which is now widely recognised as being so important in medical practice.⁴³⁸ Committing to new ethical standards of consent to medical treatment and experimentation was therefore vital for the future of medical practice and the restoration of trust. Thus, the development of a body of law on consent was also important for the protection of the medical profession as well as for patients.

Although the increased recognition in patient autonomy and self-determination should not be construed as being linear and continuous following Nuremberg, as medical doctors retained significant control and long afterwards,⁴³⁹ it has been suggested that modern “consent-centric” ethical standards have been developed as “a direct consequence of the Nazi atrocities”.⁴⁴⁰ Beauchamp and Childress also point to this episode in history as the basis for a much greater level of attention being paid to consent to treatment.⁴⁴¹

The victims of the Nazis were denied their humanity and were treated instrumentally, they were experimented upon against their will without any and were thus denied respect for their rights to refuse treatment and this was seen as the core of the violation that they suffered. The principle of autonomy provided an important philosophical basis for the condemnation of atrocities perpetrated during WWII, but so too did the more general idea of Human Rights and it was the idea of human rights that provided the practical means for offering protection through the development of Human Rights Laws.

The Universal Declaration of Human Rights (UDHR) and the European Convention on Human Rights (ECHR) can be seen as attempts to define the minimum acceptable standards for the treatment of human beings in law. The rights surrounding medical treatment which were developed following Nuremberg were accompanied by, and largely incorporated within, a new codified recognition of Human Rights particularly in the ECHR and in the UNHR. The rights set out in these Convention documents define certain rights which are enforceable against the state. For example, article 2 protects the right to life⁴⁴²; article 3 Charter of Fundamental Rights of the European Union⁴⁴³ prohibits torture, defined as

⁴³⁷ J Miola, *Medical Ethics and Medical Law: A Symbiotic Relationship* (Hart 2007) 43

⁴³⁸ GMC, *Good Medical Practice* (GMC, 1995) [12]

⁴³⁹ J Miola, ‘Making Decisions About Decision-Making’ (n 435) 267

⁴⁴⁰ N Hoppe and J Miola, *Medical Law and Medical Ethics* (n 113) 101

⁴⁴¹ TL Beauchamp and JF Childress (n 433) 117

⁴⁴² e.g. Centre for Legal Resources on behalf of Valentin Câmpeanu v. Romania [GC], no. 47848/08, ECHR 2014

⁴⁴³ UN Economic and Social Council *General Comment* 14 (discussing article 12 of the International Covenant on Economic, Social and Cultural Rights, 2000)

“inhuman and degrading treatment”⁴⁴⁴. Article 8 guarantees the right to a private and family life through the recognition of “personal autonomy and self-determination”.⁴⁴⁵ This right provides similar protection to patients as that which is provided under the common law, because it is engaged “even minor interference with the physical integrity of an individual”.⁴⁴⁶ However, this article of the Convention is subject to qualification on various grounds including ‘the protection of health’ and ‘public safety’.⁴⁴⁷ This allows for medical treatment to be provided in the absence of consent in certain circumstances.

While philosophical theories were important in providing a robust and precise basis for understanding why the violations that occurred during the war were so heinous, and offered a platform for theorising the kinds of rights that ought to be recognised to prevent any repetition, it is also important to note the human rights recognised by the ECHR are rights held by individuals by virtue of their very human existence. This can be contrasted with those theories of autonomy that only recognise certain *decisions* (rather than *persons*) as being autonomous if they conform to certain criteria. The only criterion for enjoying human rights is being human.

THE POST-WAR RECOGNITION OF AUTONOMY AND SELF-DETERMINATION IN LAW

One of the most widely cited expositions of the modern rationale for the consent process is to be found in *Schloendorff v Society of New York Hospital*⁴⁴⁸ where it was said that:

“Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages.”

This was followed by the expression of similar sentiment in English law cases such as *Airedale NHS Trust v. Bland*:⁴⁴⁹

“...the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give

⁴⁴⁴ e.g. *Budanov v Russia* (Application no. 66583/11) ECHR 2014

⁴⁴⁵ *R (on the application of Purdy) v Director of Public Prosecutions* [2009] UKHL 45 (HL) [82] (Brown LJ); see also *NHS Trust A v M* [2001] Fam 348, 361 (Butler-Sloss P)

⁴⁴⁶ *Storck v Germany* (2005) 43 EHRR 96 [143]

⁴⁴⁷ Art 8(2) ECHR and see M Brazier and Cave E (n 34) para 2.10

⁴⁴⁸ [1914] 211 NY 125, 126 (Cardozo J)

⁴⁴⁹ [1993] AC 789

effect to his wishes, even though they do not consider it to be in his best interests to do so"⁴⁵⁰

The employment of this kind of language illustrates a shift in attention towards the patient and away from the conduct of the healthcare professional. It represents a shift towards patients' rights and away from the professional standards to which the medical practitioner should adhere.

However, although a change of language in that direction is plainly observable, the means by which the law has protected the rights of patients has been through the tort of negligence, whose conceptual concern lies with the failure of the medical practitioner, rather than the interference with the rights of the patient.⁴⁵¹ Despite the conceptual strain necessary to protect patient rights through the tort of negligence, the English courts made clear that actions against medical practitioners in battery would only be entertained in very limited circumstances.⁴⁵² This provides further indication that many of the cases concerned with the development of the law on the refusal of treatment has not been solely motivated by a concern to further the cause of patient autonomy, but has in addition been designed to protect patients.

One of the chief ways in which the law has sought to protect patients against the abuses of medical power has been by entitling them to information relevant to their treatment.⁴⁵³ Imposing a duty on medical professionals to provide more information to patients is also seen as a method for reducing the "power imbalance" between doctor and patient.⁴⁵⁴ Moreover, meaningful decisions about treatment can only be made when they are accompanied by certain pieces of information.

The informational rights of patients have been greatly extended in the post war period through the development of the common law: the right to have questions answered truthfully,⁴⁵⁵ the right to be told of the material risks⁴⁵⁶ involved (not just in the proposed

⁴⁵⁰ At 864 (Goff of Chieveley LJ)

⁴⁵¹ See TK Feng, 'Failure of Medical Advice: Trespass Or Negligence' (n 65); see also Crisp R, 'Medical Negligence, Assault, Informed Consent, and Autonomy' (1990) 17 *Journal of Law and Society* 77; see also J Miola, 'On the Materiality of Risk: Paper Tigers and Panaceas' (2009) 17 *Medical Law Review* 76, 78–80

⁴⁵² *Chatterton v Gerson* (n 64); *Hills v Potter* (n 64)

⁴⁵³ Jones MA, 'Informed Consent and Other Fairy Tales' (1999) 7(2) *Medical Law Review* 103

⁴⁵⁴ *ibid* 129

⁴⁵⁵ *Pearce v United Bristol Healthcare Trust* [1998] EWCA Civ 865

⁴⁵⁶ see J Miola, 'On the Materiality of Risk: Paper Tigers and Panaceas' (2009) 17 *Medical Law Review* 76

treatment, but also in alternative procedures⁴⁵⁷ and moving away from the *Bolam v Friern Hospital Management Committee*⁴⁵⁸ test of information disclosure (i.e. disclosing only that which a reasonable body of medical men would disclose) towards a standard based on what the patient wants to know⁴⁵⁹ represents a significant stride forward for the patient's ability to control their what kind of medical treatment they receive.

The courts demonstrated their commitment to upholding the decisions of individuals even where the implications of so-doing risked significant harm for the patient or others. Particularly fraught decisions were made in favour of the patient even in cases where pregnant women risked the loss of their pregnancy.⁴⁶⁰ One important case in the formation of the modern right to refuse treatment was that of *Re MB*.⁴⁶¹ Here it was said that if a pregnant woman is competent, she can refuse treatment for any or no reason and can do so even if her decision endangers the health of the foetus. Lady Butler-Sloss made the point forcefully:

“A competent woman, who has the capacity to decide, may, for religious reasons, other reasons, for rational or irrational reasons or for no reason at all, choose not to have medical intervention, even though the consequence may be the death or serious handicap of the child she bears, or her own death.”⁴⁶²

The legal consequences of the failure to respect a refusal of treatment made by a competent adult are primarily based around the idea of trespass to the person and medical negligence. Although battery may be the best theoretical fit with the modern ideas of self-determination, the courts have made it clear that they consider the appropriate legal ground for the protection to be medical negligence in the majority of cases.

“...failure to go into risks and implications is negligence not trespass.”⁴⁶³

Hence although vociferous judicial backing has been given in support of the right to refuse treatment,⁴⁶⁴ it is only where the nature and purpose of the procedure has not been explained that the courts will consider actions in battery.⁴⁶⁵ Consequently, by far the greatest amount of legal activity has been in respect of the development of the relevant principles of negligence.

⁴⁵⁷ *Birch v University College London Hospital NHS Foundation Trust* [2008] EWHC 2237 (QB)

⁴⁵⁸ [1957] 1 WLR 582

⁴⁵⁹ see e.g. *Rogers v Whitaker* [1992] HCA 58; *Chester* (n 2)

⁴⁶⁰ *St George's NHS Trust* (n 57)

⁴⁶¹ (1997) 38 BMLR 175

⁴⁶² *ibid* 186 (Butler-Sloss LJ)

⁴⁶³ *Chatterton v Gerson* (n 64) 443 (Bristow J)

⁴⁶⁴ *Re T* (n 54)

⁴⁶⁵ *Chatterton v Gerson* (n 64)

The establishment of a duty of care between the healthcare professional and the patient is straightforward, but the determination of the precise standard of care to be expected is less clear. One of the most important cases to establish a test, which turned out to be one which was very long-enduring was *Bolam*. This case established that medical practitioners must provide the same standard of care as would be provided by a ‘responsible body of medical men’ and thus gave medical practitioners a significant hand in the definition of the standards by which they would be judged.

However, this test was subsequently circumscribed by the decision in *Bolitho*⁴⁶⁶ in which the court put a gloss on the *Bolam* method for defining the standard of care by expressing a willingness to subject the putative consensus of a reasonable group of medical practitioners to scrutiny. If the court did not consider that the standard of care being operated by the medical collective was not sufficiently high in some respect, the court would not be bound to accept it as the standard of care expected of the reasonable doctor. This principle of judicial supervision of medical opinion has also been applied with respect to applications to determine the lawfulness of a particular treatment in future in the case of *Re T* where the court preferred the parents’ opinion, that a liver transplant was not in the best interests of their child to the opinion of doctors that the transplant should go ahead.⁴⁶⁷

A long line of cases have thus come to define the kind and quality of information that patients could expect from their medical practitioners. One of the most important recent developments on this point came through the decision in *Montgomery v Lanarkshire Health Board*.⁴⁶⁸ Here the supreme court departed from the majority in *Sidaway*, in respect of their view that the test for the disclosure of information to the patient should be based on what the reasonable doctor would disclose, adopting instead a test based on the information that a reasonable patient would want to receive, while remaining responsive to the informational needs of the specific patient whose treatment is under discussion.⁴⁶⁹

Aside from the battle for information, patients faced a further hurdle in trying to recover damages in negligence actions through the requirement to prove causation. Particularly, the medical team might have failed to disclose the right information or explain a procedure to the same standard as a reasonable doctor, but nonetheless, if the patient could not establish that they would have refused the treatment following a proper explanation and disclosure of information, they could not recover damages. However, in the case of *Chester* even though

⁴⁶⁶ *Bolitho* (n 168); see M Brazier, and J Miola (n 168)

⁴⁶⁷ *Re T (A Minor) (Wardship: Medical Treatment)* [1996] 35 BMLR 63 (CA)

⁴⁶⁸ [2015] UKSC 11

⁴⁶⁹ [2015] UKSC 11 [46]

the claimant could not establish that she would have refused the treatment, had she been given the correct information, the view was taken that in order to give effect to Ms Chester's right to self-determination, she would have to be allowed to recover damages.⁴⁷⁰ Through this strained interpretation of causation, the explicit reference to autonomy⁴⁷¹ and the explicit endorsement of the right to informed consent,⁴⁷² this case demonstrates a notable shift in judicial attitude in favour of patients.

These developments in medical negligence have had the effect of requiring greater levels of information disclosure to patients and can be seen as an ostensible attempt to protect patients from the potential abuses of medical power, by making patients party to information relevant to their treatment.⁴⁷³ However, the greater extent of these requirements of disclosure also puts a greater demand on patients to process this kind of information for themselves, which places a commensurately greater degree of responsibility on the patient.

This case can be seen in the context of political programmes aimed at the empowerment of citizens and patients. The state has created requirements and frameworks for the greater disclosure of information and the facilitation of decision-making, which open up a greater degree of choice and normalise the disclosure of information and of choosing (e.g. star ratings from the care quality commission)⁴⁷⁴. Interaction with this kind of information demands individuals with different abilities and different dispositions. In addition to laws protecting patient choice, programmes have been designed to encourage patients to be active partners in decision-making particularly in medicine. Outside of medicine, consumerism has become one of the dominant modes of interaction between individuals and authority. These are themes which will be taken up and discussed further in the third part of this thesis. For present purposes, it will suffice to say that the development of the rights protecting autonomy have themselves been shaped by broader political objectives and by the demands of advanced liberal rationalities of government.

⁴⁷⁰ *Chester* (n 2) [57] (Hope of Craighead LJ)

⁴⁷¹ *Chester* (n 2) [18] (Steyn LJ)

⁴⁷² *Chester* (n 2) [14] (Steyn LJ)

⁴⁷³ see *R (on the application of Tracey) v Cambridge University Hospitals NHS Foundation Trust* [2014] EWCA Civ 33

⁴⁷⁴ <http://www.cqc.org.uk/> [accessed 17/08/2015]

MAKING SENSE OF THE RELATIONSHIP BETWEEN MEDICAL LAW AND THE CONCEPT(S) OF AUTONOMY

“Whatever else people think about individual or personal autonomy, they do not equate it with mere choice”⁴⁷⁵

Given the foregoing discussion in this chapter, the assertion that there is one unitary and universally accepted version of autonomy is immediately contentious and the suggestion that there might be “practical, every day sense” of autonomy, while intriguing, remains a bare assertion without supporting evidence of its existence, let alone any explanation as to how it might be distinguished from other notions of autonomy.⁴⁷⁶

Such inconsistency may well suggest that the concept of autonomy is being invoked for its conceptual cache and rhetorical value⁴⁷⁷ as much as for a belief in its worth among other normative considerations. The appearance of inconsistency is perhaps an inevitable consequence of the attempt to simultaneously satisfy the objectives of patient empowerment and conceptual fidelity. The variation seen within the common law when approaching matters of autonomy demonstrates limits of purely philosophical or bioethical analysis in respect of the law.⁴⁷⁸ However, considerable criticism has been levelled at the dominant form of autonomy that has been developed within bioethics and law and some of these criticisms must be highlighted.

A product of the imprecise and rhetorical usage of the concept of autonomy is the apparent willingness to treat it as being interchangeable with the concept of self-determination.⁴⁷⁹ Conceptual conflation of this kind suggests the adoption of a ‘thin’ approach to the construction of autonomy.⁴⁸⁰ From this, it is reasonably clear is that the law does not strictly adhere to Kant’s concept of autonomy. It is common in bioethics and law (should autonomy be explicitly referred to at all) to speak in terms of respecting a person’s autonomy.⁴⁸¹ However, for Kant it is *decisions* that may possess the quality of being autonomous, not individuals.⁴⁸²

⁴⁷⁵ O’Neill (n 372) 28

⁴⁷⁶ see A Reath (n 370) 128-129

⁴⁷⁷ K Veitch, *The Jurisdiction of Medical Law* (n 8) 55

⁴⁷⁸ *ibid* 56

⁴⁷⁹ *ibid* 78

⁴⁸⁰ O’Neill (n 372) 37, 47-48; M Holstein, JA Parks and MH Waymack, *Ethics, Aging, and Society: The Critical Turn* (Springer 2011) 21

⁴⁸¹ O’Neill (n 372) 29; A Reath (n 370) 127-131

⁴⁸² O’Neill (n 372) 83

By contrast, in English law, it is more common to speak of autonomy as a quality that is in the gift of those who of adult years who retain capacity to decide (see e.g. *HE*). Moreover, not all decisions will adhere to Kant's requirements for autonomous decision-making, because for a decision to be truly autonomous it must be one which does not offend the Categorical Imperative. Adhering to this requirement means the decision must be universalisable (i.e. it must be one which would be just in all circumstances) and that it must be one which respects the status of human beings as ends in themselves (and never merely as *means to ends*). These requirements place a significant qualification on the legitimate scope of individual choice.

The Categorical Imperative precludes acceptance of the idea of self-ownership⁴⁸³ as well as intentional self-harm (one could not will self-harm as a universal law). Other related theories of autonomy would also preclude such action on different grounds. English law is somewhat incompatible with this suggestion too. It is certainly not the case that English law fully recognises individual self-ownership (one cannot, for instance, sell one's own organs).⁴⁸⁴ However, the extent to which English law would impose a duty on individuals to act in their own interests is limited, because patients are entirely within their rights to refuse treatment which will inevitably lead to their death.⁴⁸⁵ Indeed since the Suicide Act 1961 English law allows people to commit suicide and this decriminalisation of suicide has been held out as an example of the triumph of self-determination over the sanctity of life.⁴⁸⁶ More recently it has been suggested that such a choice can be made autonomously.⁴⁸⁷ This is a position that, as mentioned above, Kant's theory of autonomy would not admit.⁴⁸⁸

In further contradistinction to the Kantian position, under English law individuals are entirely free to make decisions which are inconsistent with their past decisions and to make decisions which they would not wish to hold out as universalised principles (i.e. to be applied in all like cases). A person may refuse treatment arbitrarily⁴⁸⁹ and then later accept the same treatment presented to them at his or her discretion.

⁴⁸³ GA Cohen, *Self-Ownership, Freedom, and Equality* (Cambridge University Press 1995) 211

⁴⁸⁴ Human Tissue Act 2004, s 32; Directive 2010/45/EU Of The European Parliament And Of The Council of 7 July 2010 on standards of quality and safety of human organs intended for transplantation

⁴⁸⁵ *Re T* (n 54)

⁴⁸⁶ *Bland* (n 63) (CA) 827 (Hoffmann LJ)

⁴⁸⁷ See *Commissioners of Police for the Metropolis v Reeves* [2000] AC 360, 394

⁴⁸⁸ I Kant, 'Foundations of the Metaphysics of Morals' cited in RJ Sullivan, *An Introduction to Kant's Ethics* (Cambridge University Press 1994) 56

⁴⁸⁹ *Re T* (n 54)

Mill's position appears more compatible with English law, because, as discussed, it centres not from the question of what kind of decisions are the right decisions to make *per se*, but rather by questioning the legitimacy of interference with individual choice and action. It thereby foregrounds the role of the individual in a similar way to general post-war approach of the courts in medical cases.⁴⁹⁰

However, a closer examination of certain cases suggests that we cannot simply declare English Law as being aligned with an idea of Millian autonomy or indeed an idea of self-determination. Certainly cases like *Re T*, *Re B* and *Re C* can be held out as examples of cases in which the patients have defied powerful orthodox medical wisdom in taking decisions, in spite of grave consequences, with the backing of the courts, but different cases can just as easily be found in which the courts have denied patients' wishes.⁴⁹¹

The absence of an agreed definition of autonomy means the suggestion that Parliament and the courts have not correctly, or fully, produced laws which guarantee respect for autonomy an easy, but ultimately inconsequential, argument to make. Quite apart from the lack of a clear philosophical pedigree in the definition of autonomy, however, those seeking to criticise the law might also point to internal inconsistencies in relation to the law's working definition(s) of autonomy.

Some have attempted to rationalise the differences in the approaches taken in different cases through recourse to new sub-typologies of autonomy.⁴⁹² Such analysis usefully highlights variation in the approach of the courts, but this empirical approach has its limitations in that it attempts a categorisation of observed and interpreted body of law, while already being well disposed to the idea of autonomy. Although it is not disputed that autonomy is an important value, there are competing values (e.g. self, determination, liberty, bodily integrity and choice)⁴⁹³ and practical concerns which impinge upon the court's judgment (indeed it has been suggested that the concepts of autonomy and liberty are often conflated).⁴⁹⁴

The court does not begin with the objective of protecting autonomy, or respecting other ethical concepts for that matter, but rather with the commitment to upholding the written

⁴⁹⁰ C Foster, 'Autonomy in the Medico-Legal Courtroom: A Principle Fit for Purpose?' (n 393) 49-50

⁴⁹¹ e.g. *Re E* (n 10); AR Maclean, 'Advance Directives and the Rocky Waters of Anticipatory Decision-Making' (n 143) 3-8

⁴⁹² e.g. see J Coggon, 'Varied and Principled Understandings of Autonomy in English Law' (n 419)

⁴⁹³ see *W v M* (n 11) [226] (Baker J)

⁴⁹⁴ J Coggon and J Miola, 'Autonomy, Liberty, And Medical Decision-Making' (2011) 70 *The Cambridge Law Journal* 523

law.⁴⁹⁵ In addition, this kind of analysis, on its own, leaves open the *normative* question of which form of recognition of autonomy is to be preferred and the basis for any such preference (and whether these conceptions of autonomy are to be read in a way that is peculiar to the law itself)⁴⁹⁶. Thus, while there is clearly a relationship between the law in this area and (certain conceptions of) autonomy, attempting to distil a more precise conclusion about the nature of this relationship is a much more complex task and it may, ultimately, be one which is unlikely to bear fruit.

Having this brief overview of the complexity and contentiousness of the definition of autonomy, it is now important to consider how this imperfect understanding feeds into English law's understanding of ADRTs. The relationship between autonomy and ADRTs will be explored further in the following section.

ADRTS AUTONOMY AND SELF DETERMINATION

Having considered the relationship between the law on consent to medical treatment and the ideas of autonomy and self-determination, we can now turn to consider the way in which the idea of autonomy has been employed as a justificatory platform for the recognition of the right to create ADRTs. It has been assumed that the oft-conflated concepts of autonomy and self-determination form the basis for legitimising ADRTs, as Mr Justice Munby suggests:

“An advance directive is, after all, nothing more or less than the embodiment of the patient's autonomy and right of self-determination.”⁴⁹⁷

However, when considering ADRTs in English law, we must remember the significance of the legal limitations, which mean that ADRTs only take effect once their author has lost capacity to make the material decision (i.e. the specific decision about treatment which is being posed). This is important, because as was discussed in the first chapter, English law does not recognise as binding the contemporaneous decisions of those who lack mental capacity.⁴⁹⁸ Such persons can be provided with whatever treatment is deemed in her or his best interests without the need to seek consent.⁴⁹⁹ This is the sense in which it might be said

⁴⁹⁵ See K Veitch, *The Jurisdiction of Medical Law* (n 8) 56

⁴⁹⁶ *A London Local Authority v JH* [2011] EWHC 2420 (COP) 42 FN 39

⁴⁹⁷ *HE v Hospital NHS Trust* (n 66) (Fam) [37] (Munby J)

⁴⁹⁸ *Re C* (n 107); MCA, s 5

⁴⁹⁹ MCA, s 5

that the right to create ADRTs enables this right to refuse that treatment in advance and it is in that way that it might be considered to *extend* this right of autonomy:⁵⁰⁰

“The patient has a measure of autonomy in choosing between available alternatives. Advance decisions are a means by which such *autonomy can be extended* to a situation when the patient has become incompetent, by stating in advance the types of treatment which the patient would or would not find acceptable in certain circumstances.”⁵⁰¹

Though elegant in its simplicity, this seemingly common-sense explanation demands some further discussion. It cannot refer to an extension of the willingness to respect patient choice in those situations where mental capacity is considered lacking. The legal recognition of ADRTs has done nothing to alter the test for capacity. Rather it surely describes the willingness to respect the decisions made by the author of the ADRT in respect of what we might, as a mere “*façon de parler*”⁵⁰² term his or her ‘future self’ (i.e. the person she or he will become in future) where that future self is one that has lost mental capacity. As such, the ‘extension of autonomy’ could more precisely be said to be a temporal extension of the autonomy of the ‘present self’. Through the creation of an ADRT the present self not only has legitimacy in contemporary decision-making, but who is also accorded decision-making authority over his or her (possible) future self.

AUTHENTICITY

Ronald Dworkin, whose conception of autonomy was cited with approval in *Chester*,⁵⁰³ has suggested that this ‘extension of autonomy’ is aimed at respecting “precedent autonomy”; that is respecting the decision of the last instantiation of the self, capable of exercising autonomy.⁵⁰⁴ He argues that respect for precedent autonomy is preferable to alternative ways of making treatment decisions in situations where the patient lacks the mental capacity to express a decision contemporaneously:

“If I decide, when I am competent, that it would be better for me not to remain alive in a seriously and permanently demented state, then a fiduciary could contradict me only by exercising an unacceptable form of moral paternalism”.⁵⁰⁵

⁵⁰⁰ eg *HE v Hospital NHS Trust* (n 66) (Fam) [37] (Munby J); Select Committee on Medical Ethics, *Report of the Select Committee on Medical Ethics* (HL 1993-94, 21-I) para 181

⁵⁰¹ *ibid* Select Committee on Medical Ethics para 181 (my emphasis)

⁵⁰² J Feinberg (n 369) 83

⁵⁰³ *Chester* (n 2) [12] (Steyn LJ)

⁵⁰⁴ R Dworkin (n 426) 227

⁵⁰⁵ *ibid* 231

Dworkin argues that this would be the case even where the incapacitated person may appear relatively contented. In order to advance this argument, he relies on a case study based on a patient called Margot:⁵⁰⁶ a person who had earlier expressed a wish not to be given life-sustaining drugs should she ever suffer from dementia, but who she appeared relatively happy when she did later develop dementia. The question therefore arose as to what should happen in the event that she should require antibiotics to treat an infection. In order to answer this question, Dworkin separates out what he sees as her ‘critical’ and ‘experiential’ interests.⁵⁰⁷ He suggests that her experiential interests (her state of contentedness) must yield to her critical interests (her deeply held values). Thus the ADRT should take effect.

The reason for preferring critical interests over experiential interests is said to be aimed at the protection of the ‘authentic self’.⁵⁰⁸ Clearly the idea of the protection of the authentic self is a different goal from the simple protection of individual choice. It is equally plain that idea that a decision would have to pass a hurdle of authenticity before being upheld would not meet with the concerns of libertarians who believe in unimpeded free choice for the individual. Such a requirement would also implicitly rely upon of an external person with the authority to determine the question of authenticity. Such an objective would be incompatible with the aims of those who seek to draw on autonomy as a means of patient empowerment. However, including a requirement of authenticity in the criteria for autonomous decision-making may better attend to the concerns over refusing treatment to those who appear to undergo significant personal change in the period intervening the formation of the ADRT and the point at which it is relied upon.⁵⁰⁹

This argument has been taken up by the creators of so-called ‘Ulysses contracts’ in the United States. These are similar to ADRTs, in that they concern decisions made in advance of the question of treatment arising, but crucially these decisions may take effect while the patient retains capacity. As they are often drafted in relation to addiction services, a common trigger is the relapse into addictive behaviour, but the precise trigger can be chosen by the creator of the decision. Such arrangements are similar to the way that ADRTs might be recognised if England and Wales were to become compliant with the UN convention on the rights of persons with disabilities (“CRPD”), because in such as case ADRTs could not be triggered by the loss of mental capacity (because mental capacity cannot be used as a means

⁵⁰⁶ AD Firlik, ‘Margo’s Logo’ (1991) 265 *Journal of the American Medical Association* 201

⁵⁰⁷ R Dworkin (n 426) 201-208

⁵⁰⁸ see also R Dworkin (n 426) 32-39

⁵⁰⁹ see Chapter Four

of determining a person's legal rights or 'legal capacity' article 12) and therefore the trigger for the ADRT would have to be specified by the creator of the instrument.

Ulysses contracts would therefore not respect autonomy in the broad manner recognised by English law; rather the proponents of such agreements they say they respect a form of autonomy grounded in "authenticity".⁵¹⁰ They construct a notion of the authentic self whose views should be prioritised over the present-self, or any other kind of self. This means that the power to legislate is not presumed to reside in the voice of the individual, but in some notion of her or his authentic essence.

This position surely begs the questions: how is authentic self is to be determined and who can legitimately make such a determination. To be of any differential consequence, the authentic self must be determined by some form of other (if it could be determined by the patient themselves in their current state, they would naturally claim that their current self was their authentic self, in order that their current wishes be accorded legal force!) And, as there is no truly objective way in which authenticity can be determined whichever person is granted the power to make the determination is invited to make a choice about what qualities of the patient and their decisions are deserving of respect. Thus, the person who determines authenticity will introduce their own values, or those of the group to which they contemporaneously identify, into the decision-making process and simultaneously relegate the importance of the patient's values. Any such move is therefore to be considered regressive.

⁵¹⁰ T van Willigenburg and PJJ Delaere, 'Protecting Autonomy as Authenticity Using Ulysses Contracts' (n 26) 396–397

CONCLUSION

The purpose of this chapter was to highlight the importance of certain factors to the emergence of ADRTs. It was suggested that one of the only reasons ADRTs have arisen was because of the advancements in medical science which have enabled life to be sustained in conditions of low mental and bodily functionality without an envisioned prospect of recovery. These advances have been coupled with a shift in the nature of the relationship between patient doctor, and expert authority more generally. Resultantly there is no obvious source of direction for the decisions about when life support should cease. This vacuum of direction can be filled by ADRTs wherein the patient provides their own decision in respect of their own treatment.

The most heavily relied upon normative argument for the recognition of ADRTs in the courts and the legislative process is the characterisation of ADRTs as a mere extension of the legal right to refuse treatment.⁵¹¹ This is a right whose modern interpretation rests on the ideas of self-determination and autonomy. Hence it is argued that ADRTs extend of autonomy.

The main part of this chapter was taken up with a discussion of the meaning of autonomy. Philosophers have differing definitions of autonomy and that the law has not selected any of the various definitions on offer, but has adopted a rather looser understanding of the term which has fluctuated over time and between cases. This means that the suggestion that ADRTs are based on an extension of autonomy offers a weakly-specified normative basis for their definition in law.

In order to better appreciate the values that the law is trying to protect therefore we must give thought to the question of why the value of autonomy has risen to such prominence in Western society. Doing so will enable us to consider the purposes for which autonomy is put to work and this will enable a better understanding of the aim of the invocation of autonomy.

However, as we have also seen, the law does tacitly accept a form of personhood that provides the opportunity to produce binding ADRTs and this may demonstrate a preference for patient choice over a fidelity to a philosophically coherent

⁵¹¹ *HE v Hospital NHS Trust* (n 66) (Fam) [37] (Munby J)

understanding of personhood. These critiques based around personhood offer some of the most compelling arguments against the recognition of binding ADRTs, but acceptance of them would entail far-reaching and fundamental changes to the other areas of law. It is unclear whether the proponents of these arguments in respect of ADRTs would wish to see them accepted beyond the realm of ADRTs in a logical manner. If not then the deployment of the personhood argument might be seen as a sophisticated way of stymying the law on ADRTs rather than promoting a genuine concern for a philosophically rigorous conceptualisation of personhood in law.

In the next part of this thesis it will be suggested that a different basis for the critique of ADRTs might be found in Foucault's work on governmentality. It will be argued that Foucault's work will allow a richer understanding of both the development and operation of ADRTs than can be attained through an analysis based on more abstract philosophical approaches. It will demand a focus on the historical conditions which have made the acceptance of ADRTs possible, particularly surrounding the use of autonomy as an organising principle in society, and this will provide a stronger basis for understanding the seemingly inconsistent way in which ADRTs are recognised in practice. Furthermore this analysis will allow us to step back from an analysis of ADRTs based on their benefits for individuals and consider what benefits society might derive from a system of ADRTs.

CHAPTER THREE

CRITIQUES OF MODERN CONCEPTUALISATIONS OF AUTONOMY

INTRODUCTION

In Chapter Two it was suggested that in spite of the frequency with which autonomy is drawn upon in support of the law on the refusal of treatment and ADRTs, it remains a concept unfurnished with a clear and settled meaning in law, or indeed in philosophy. This has meant that appeals to autonomy might be made for developing the law in different directions and that the concept of autonomy can only claim partial responsibility for the current shape of the law.

Regardless, it seems, the law has implicitly and explicitly placed reliance upon the concepts of autonomy and self-determination (seldom, if ever, making a clear distinction between them)⁵¹² in developing the law on the right to refuse medical treatment. Autonomy (and self-determination) is used as the primary explanatory concept for narrating the development of the law.⁵¹³ Consequently, one of the most well-worn tropes of healthcare law is to question whether the law provides adequate protection for patient autonomy.

Yet, given the uncertainty over the meaning of autonomy,⁵¹⁴ and the purposes for which it is put to work (e.g. the protection of human rights, or the empowerment of citizens) evaluating the extent to which the law protects autonomy is far from straightforward. Indeed without agreeing on a definition it is impossible to do so precisely. For instance, for some, autonomy may be increased by increasing the levels of information available for individuals, while for others the acceptance of mere choice without reflection cannot be described as increasing autonomy.⁵¹⁵

The discussion in this chapter will explore some of the reasons why the development of laws based around autonomy has not been universally welcomed. A selection of critical perspectives on the development of autonomy will be considered by way of illustration.

⁵¹² e.g. *Re AK (Medical Treatment: Consent)* (n 69) (Fam) 41 (Hughes J)

⁵¹³ *Montgomery v Lanarkshire Health* (n 161) [68] (Kerr and Reed LLJ); *Birch* (n 457) [72] (Cranston J)

⁵¹⁴ G Dworkin (n 371) 6

⁵¹⁵ O O'Neill (n 372) 37, 47-48

These critiques can be juxtaposed with the critique that will be developed in the next part of this thesis, based upon Foucault's work on governmentality.

The present chapter (and the one that follows) will afford the opportunity to situate the governmentality perspective in relation to a body of critical literature. The critical literature discussed in this chapter will relate to modern conceptualisations of autonomy in a general way, which may apply to all forms of consent to treatment but one which might also apply to ADRTs. Chapter Five will relate to critical perspectives on ADRTs specifically. It will be argued that governmentality offers a distinctive way to understand the development and operation of the law on ADRTs. Unlike the critiques presented here, the critique grounded in governmentality does not rest upon the adoption of any particular substantive normative commitment (e.g. to Human Rights, to community or individualism). Rather it suggests that the law has evolved in order to address crises of government and the ADRT has been developed in order to address a crisis in the government at the end of life.

AUTONOMY IN LAW MEDICAL LAW

In spite of the fact that no precise definition of autonomy has been ventured explicitly by parliament or the courts, many commentators have suggested that the way in which autonomy is commonly invoked in modern times does point towards a range of definition which has been adopted for practical purposes. Many commentators have been critical of both the assumed meaning of this value and its pre-eminence among other values and considerations.⁵¹⁶ This chapter will offer a discussion of these critical perspectives on modern conceptualisations of autonomy as the basis for the right to refuse treatment and the right to create ADRTs.

Critics have suggested that a 'thin', individualistic version of autonomy has been promoted in law and more generally in society. In contrast to some philosophical conceptualisations of autonomy (discussed in the second chapter) which put certain constraints on the exercise of autonomy, many commentators have suggested that there is a tendency to adopt an understanding of autonomy that is merely synonymous with individual choice:⁵¹⁷ e.g. "autonomy – freedom of choice as an end in itself".⁵¹⁸

⁵¹⁶ eg M Brazier, 'Do No Harm - Do Patients Have Responsibilities Too?' (n 353) 398-401

⁵¹⁷ O'Neill (n 372) 47

⁵¹⁸ GR Sullivan, 'Liberalism and the Constraining of Choice: The Cases of Death and Serious Bodily Harm' in Stephen W Smith and Ronan Deazley (eds), *The legal, medical and cultural regulation of the body: transformation and transgression* (Ashgate 2009) 217

This kind of understanding of autonomy complements ideas of negative liberty⁵¹⁹ and empowerment,⁵²⁰ but arguably it is not consistent with criteria of universalisation, personal development and authenticity (see previous chapter). This is because patients might make impulsive decisions which are out of keeping with an observable pattern of their decision-making and if choice alone is sufficient for autonomy, the decision must be respected.

The move towards recognising greater patient rights can be viewed, in general terms, as one from paternalism to individualism, from medical control to patient choice.⁵²¹ Positive though that may sound, it is a trajectory that has not passed without criticism. It has already been noted that autonomy is a broad term, with a number of divergent and in some cases contradictory definitions posited from various quarters, but uniting the goals of recognising autonomy and empowering patients through choice has led to the adoption of a ‘thin’ version of autonomy, which is unedifying for some.

For instance, Onora O’Neill has argued that the legal recognition of autonomy has become synonymous with ‘self-determination’, because the mere choice of an individual has become more than simply a necessary condition of ethical action and has moved to become “sufficient” for the purposes of respecting the decision.⁵²² This is a common line of critique against a ‘thin’ version of autonomy, which suggests that “personal autonomy is more than uncoerced choice”.⁵²³ That is to say that the mere fact that a choice has been made by an individual is taken as being sufficient ethical justification for the decision in and of itself.⁵²⁴ It has therefore been alleged that autonomy is invoked merely as “a right to what ‘I want’”⁵²⁵ however unreflectively or inconsiderately that decision is arrived at.

A related source of criticism has been the alleged one-sided nature of autonomy’s development. It is often noted that patients have accrued many rights during the post war period, but have inherited few duties in return (although this was the goal of the project of patient empowerment⁵²⁶). Maclean has advocated greater obligations for patients.⁵²⁷

⁵¹⁹ I Berlin, ‘Two Concepts of Liberty’ (n 370) 169-178

⁵²⁰ See LP Fumagalli and others, ‘Patient Empowerment and Its Neighbours: Clarifying the Boundaries and Their Mutual Relationships’ (2015) 119 Health Policy 384

⁵²¹ M Brazier, ‘Do No Harm - Do Patients Have Responsibilities Too?’ (2006) 65 The Cambridge Law Journal 397; J Herring, ‘Where Are the Carers in Healthcare Law and Ethics?’ (n 1) 66

⁵²² O O’Neill (n 372) 47

⁵²³ M Holstein, JA Parks and MH Waymack (n 480) 21

⁵²⁴ O O’Neill (n 372) 47-48

⁵²⁵ M Brazier and Cave E (n 34) para 3.7

⁵²⁶ K Veitch, *The Jurisdiction of Medical Law* (n 8) 62

⁵²⁷ A Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 250

These misgivings might also be levelled at ADRTs. In theory there is no questioning of the reasoning behind the patient's ADRT as long as it is in compliance with the formalities laid down by the MCA, although Maclean has suggested that, in practice, the reasoning used in an ADRT might be used by an assessor in determining whether the ADRT was made with capacity.⁵²⁸ Moreover there appears to be no obligation on patients to make particular kinds of decision, or to consult any third party about their decision (e.g. a medical practitioner or a family member).

However, those who advocate an idea of autonomy that is empowering of patients have sought to criticise the implementation of laws designed to protect autonomy on the grounds that they do not function as they should in offering individuals enough freedom and choice.

FUNCTIONALIST CRITIQUE

The efficacy of the law has been challenged by 'functionalist' critiques, which have highlighted the gap between the promise of the law and what its capacity to deliver practical change. Underpinning the functionalist critique of individualistic version of autonomy is the contention that the law fails to offer a sufficient level of *genuine* choice to patients making medical decisions. The blame for this state of affairs might be channelled in different directions.

One reason might be the under-provision of information to patients. Certain studies have suggested that patients would like to be provided with more information in certain circumstances.⁵²⁹ Along these lines, battles have been fought to increase the *quantum* of information that must be provided and professional codes have been developed that require that information is provided in such a way that it can be understood easily by the recipient.⁵³⁰ Such moves have been reinforced by legal developments such as *Sidaway*,⁵³¹ *Pearce*⁵³² and *Montgomery v Lanarkshire*⁵³³ in which patient rights to information were protected and extended.

⁵²⁸ AR Maclean, 'Advance Directives and the Rocky Waters of Anticipatory Decision-Making' (n 143) 13-14; see also M Donnelly, 'Capacity assessment under the Mental Capacity Act 2005: Delivering on the functional approach?' (n 145) 474-477; *A NHS Trust v Dr A* (n 119) [34] (Baker J)

⁵²⁹ A Maclean, 'Giving the Reasonable Patient a Voice: Information Disclosure and the Relevance of Empirical Evidence' (2005) 7 *Medical Law International* 1, 15

⁵³⁰ see GMC, *Good Medical Practice* (GMC, 1995) 4; General Medical Council (GMC), *Consent: Patients and Doctors Making Decisions Together* (GMC 2008) 9-12; Department for Constitutional Affairs (n 80) 22-24; see also Chapter Two

⁵³¹ *Sidaway* (n 124)

⁵³² *Pearce* (n 455)

⁵³³ *Montgomery v Lanarkshire Health* (n 161)

However, concerns have been raised that simply increasing the quantum of informational disclosure, could ultimately be counterproductive in removing the limiting the opportunities for medics to employ their conscience in decision-making⁵³⁴ and from the patient's perspective because as it can hinder understanding and complicate decision-making. Schwartz⁵³⁵ claims that the proliferation of choice in many areas has gone past the point at which it is of benefit to us and that, far from empowering people, the level of choice in modern life now constitutes a burden for many.⁵³⁶ Along similar lines it has been argued that the range of choice in informed consent situations should be limited.⁵³⁷

Criticism has not only been made of the law for failing to require the disclosure of a sufficient quantum of information, but also for requiring an inadequate *quality* of information in the consent process has also been criticised. Especially following *Sidaway*,⁵³⁸ it has been suggested that the law privileges information on risk over other kinds of information that patients may also be important for some patients.⁵³⁹ Taking the view that risk is central to the decision-making process also tacitly endorses a rationalist model of decision-making behaviour,⁵⁴⁰ which may not accord with the way that some people wish to make decisions.

In terms of ADRTs, the fact authors are not obliged to seek medical or legal advice before making an ADRT has been a source of criticism for some.⁵⁴¹ However, implementing such a requirement would have the potential to impede the independence the decision-making of the authors of ADRTs and would lengthen the process of creating an ADRT which in turn disincentivise the creation of ADRTs.

FEMINIST CRITIQUES AND RELATIONAL AUTONOMY

Some feminists have argued that the modern form of autonomy is entirely geared towards a male way of thinking and does not take account of the practical and socially

⁵³⁴ J Miola, 'Making Decisions About Decision-Making' (n 435) 267

⁵³⁵ B Schwartz, *The Paradox of Choice: Why More Is Less* (ECCO 2004)

⁵³⁶ B Schwartz, 'The Tyranny of Choice' [2004] *Scientific American* 71

⁵³⁷ N Levy, 'Forced to Be Free? Increasing Patient Autonomy by Constraining It' (2014) 40 *Journal of Medical Ethics* 293

⁵³⁸ *Sidaway* (n 124)

⁵³⁹ See R Heywood, 'Excessive Risk Disclosure: The Effects of the Law on Medical Practice' (2005) 7 *Medical Law International* 93; see generally AR Petersen and D Lupton, *The New Public Health: Health and Self in the Age of Risk* (Sage 1996)

⁵⁴⁰ For discussion see HJ Einhorn and RM Hogarth, 'Behavioral Decision Theory: Processes of Judgment and Choice' (1981) 19 *Journal of Accounting Research* 1

⁵⁴¹ For discussion see C Johnston (n 70) 510-511

situated way in which women reason and make decisions.⁵⁴² Thus, the idea of a person weighing medical decisions with cold rationality, in the way that some modern conceptions of autonomy may demand, has been portrayed as an androcentric caricature,⁵⁴³ objectionable on functionalist grounds (because it might not be possible to make medical decisions in that way in reality), but which may also contribute to the subjugation of women in a more general sense.

Feminist bioethics has been built up from the views that the field of bioethics is inherently gendered, privileging a male perspective and subjugating a female perspective.⁵⁴⁴ It has been suggested that Kantian autonomy structured around a quintessential "young, white, bourgeois male who stands before endless possibilities"⁵⁴⁵ and ideas of autonomy ought to conform to the "actual experiences and capacities" of those who are asked to make decisions.⁵⁴⁶ Along these lines, Fineman argues that people are not truly autonomous, in the sense of being independent, because they always rely on the support of others to make decisions and that rather than being given more space in which to make their own decisions, they should therefore be provided with greater rights to care and support in order for them to make decisions.⁵⁴⁷ Gilbar suggests that this does not happen sufficiently in English law, claiming that patients' families tend to be treated with suspicion and hostility and that the involvement of the family should be embraced as part of the consent process.⁵⁴⁸ Veatch goes further in suggesting that the idea of informed consent should be abandoned and replaced with a desire to arrive at 'deep values' together through a pairing of doctor and patient.⁵⁴⁹

The feminist scholarship in this area has been constructed in part through the experiences of women. It has been observed that women are "disproportionally represented among patients" "are more likely to be employed in health services as *carers*".⁵⁵⁰ Women are overrepresented as applicants in cases involving decisions to withdraw treatment at the

⁵⁴² K McGuinness, 'Gene Sharp's Theory of Power: A Feminist Critique of Consent' (1993) 30 *Journal of Peace Research* 101; H Biggs, 'A Pretty Fine Line: Life, Death, Autonomy and Letting It B' (2003) 11 *Feminist Legal Studies* 291, 298

⁵⁴³ E Jackson, 'Catharine MacKinnon and Feminist Jurisprudence: A Critical Appraisal' (1992) 19 *Journal of Law and Society* 195

⁵⁴⁴ Scully JL and Fitzpatrick P, 'Introduction to Feminist Bioethics' in Jackie Leach Scully, Laurel Baldwin-Ragaven and Petya Fitzpatrick (eds), *Feminist Bioethics: At the Center, on the Margins* (Johns Hopkins University Press 2010) 3

⁵⁴⁵ M Holstein, JA Parks and MH Waymack (n 480) 22

⁵⁴⁶ *ibid* 23

⁵⁴⁷ MA Fineman, *The Autonomy Myth: A Theory of Dependency* (The New Press 2004)

⁵⁴⁸ R Gilbar, 'Family Involvement, Independence, and Patient Autonomy in Practice' (2011) 19 *Medical Law Review* 192; see also M Holstein, JA Parks and MH Waymack (n 480) 234

⁵⁴⁹ RM Veatch, 'Abandoning Informed Consent' (1995) 25 *The Hastings Center Report* 5

⁵⁵⁰ E Jackson, *Medical Law: Text, Cases and Materials* (n 32) 22

end of life.⁵⁵¹ Furthermore, many of the important pre-MCA cases in which the person seeking recognition for an ADRT was female resulted in the ADRT not being upheld.⁵⁵² However, by contrast, cases involving male patients tended to result in the ADRT being successfully upheld.⁵⁵³ Of course, the number of reported decisions is relatively small, too small to make a claim to representativeness, and the broader reality may well have been different. However, early indications in the post-MCA case law have not shown a continuation in this trend.⁵⁵⁴

CULTURAL CRITIQUES

One suggested remedy to the complaint that the current prevailing definitions and practices of autonomy are too individualistic in character has been advanced by the advocates of ‘relational autonomy’.⁵⁵⁵ Drawing inspiration from certain branches of feminist critique, (in particular, the work of Carol Gilligan)⁵⁵⁶ relational autonomy promotes the *empirical* claim that people tend to make decisions collectively rather than as atomised individuals and the *normative* claim that more communal or collective models of decision-making should be supported and promoted. This is not only said to be true for patients, but also for doctors and medical teams, who are encouraged to work in a collaborative way.⁵⁵⁷ This form of autonomy is a close cousin of the ‘ethic of care’⁵⁵⁸ and some commentators are proponents of both relational autonomy and of the ethic of care.⁵⁵⁹

While relational conceptualisations of autonomy suggests that more attention should be paid to the collective nature of decision-making, the ethic of care invites the paying of greater attention to the role and function of the carer. Its advocates argue that the carer is often forgotten in bioethical discourse that is overly focussed on narrow decision-making

⁵⁵¹ H Biggs, ‘A Pretty Fine Line: Life, Death, Autonomy and Letting It B’ (n 542)

⁵⁵² This point arose during a discussion with Richard Huxtable in 2013 e.g. *W v KH* [2004] EWCA Civ 1324 CA; *The NHS Trust v Ms T* [2004] EWHC 1279 (Fam); *HE* [2003]; *Re MB* (n 57); *Re T* [1993] FLR 95

⁵⁵³ e.g. *Re AK (Medical Treatment: Consent)* (n 69)

⁵⁵⁴ e.g. *LM* (n 338); *A NHS Foundation Trust v Ms X (By Her Litigation Friend, the Official Solicitor)* [2014] EWCOP 35

⁵⁵⁵ See eg A Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (n 527); R Russell and JG Tokatlian, ‘From Antagonistic Autonomy to Relational Autonomy: A Theoretical Reflection from the Southern Cone’ (2003) 45 *Latin American Politics and Society* 1, 13-14; R Gilbar, ‘Communicating Genetic Information in the Family: The Familial Relationship as the Forgotten Factor’ (2007) 33 *Journal of Medical Ethics* 390, 390

⁵⁵⁶ J Herring, ‘Where Are the Carers in Healthcare Law and Ethics?’ (n 1) 69

⁵⁵⁷ GMC, *Treatment and Care Towards the End of Life: Good Practice in Decision Making* (GMC, 2010) para 47

⁵⁵⁸ See Robinson in C Koggel and J Orme, ‘Care Ethics: New Theories and Applications’ (2010) 4 *Ethics and Social Welfare* 109

⁵⁵⁹ eg J Herring, *Caring and the Law* (Hart Publishing 2013)

scenarios which invite abstract thinking rather than an appreciation of the realities of living with illness and of caring for patients.⁵⁶⁰ It has been argued that such a conceptualisation of autonomy is simply too far removed from the realities of the experience of being a patient to be meaningful.⁵⁶¹ Therefore it is said that patients want and need care as much as the bare right to choose between alternative forms of treatment.⁵⁶²

One of the great difficulties for the proponents of anything other than a liberal system of consent to treatment occurs where the will of the patient is at variance to the will of the family or society etc. Herring even suggests, on an ethic of care approach, that such is the importance of community in decision-making, people who want to refuse treatment could be given treatment against their will, if their refusal would cause significant hardship or burden to their carers.⁵⁶³ Such an outcome would be radically different under the current law and it will be argued in Part III of this thesis that the concept of autonomy, in the imprecise terms in which it has been developed in the law, is broadly reflective and supportive the advanced liberal system of government in which it operates. A push to recognise forms of autonomy that are not obviously compatible with that rationality of government will be unlikely to be adopted.

Adopting Herring's position in respect of ADRTs, could mean subjecting all decisions to an additional test of whether they would cause an unacceptable level of burden to others. Such a test would not only have to be satisfied at the moment of the creation of the ADRT, but also at its point of application. As a result it would be impossible know in advance whether an ADRT would be binding in future, because the future circumstances of the author's dependents could not be known in advance. ADRTs would therefore be no better than ACPs.

LACK OF CHOICE

To the contrary, however, some have criticised the development of autonomy in law for failing to offer enough choice to the individual. One of the chief grounds for this criticism is that patients have no right to compel treatment to be given to them, but can merely refuse treatment they do not wish to receive.⁵⁶⁴ Therefore the law establishing the right to refuse treatment can claim a very limited role in the empowerment of the individual and the

⁵⁶⁰ J Herring, 'Where Are the Carers in Healthcare Law and Ethics?' (n 1)

⁵⁶¹ A Mol, *The Logic of Care: Health and the Problem of Patient Choice* (Routledge 2008)

⁵⁶² e.g. *ibid*

⁵⁶³ J Herring, 'Where Are the Carers in Healthcare Law and Ethics?' (n 1)

⁵⁶⁴ *R (Burke)* (n 27); but see *St George's Healthcare NHS Trust v P and Q* [2015] EWCOP 42

promotion of choice.⁵⁶⁵ Those elect to have surgery or procedures (e.g. cosmetic surgery or fertility treatment) remain at the mercy of medical opinion and the law as regards whether the particular treatment is appropriate for them to receive.⁵⁶⁶ Such medical decisions about whether to provide treatment will be guided by codes of ethics,⁵⁶⁷ but these ethical codes may still afford considerable discretion to the medical practitioners who have responsibility for their interpretation in the first instance. This problem is most starkly illustrated by cases such as *Pretty*⁵⁶⁸ and *Nicklinson*⁵⁶⁹ in which patients who may have wished to end their own lives but who lacked the physical capacity to do so were denied their request for assistance or any assurance that any person who were to assist in accelerating their death might be prosecuted as a result.

Furthermore, as the right to refuse treatment is couched exclusively in negative terms, it will often entail negative health consequences for the patient where it is exercised. Thus, even where the right can be exercised, patients may be reluctant to use it for fear of damaging their own health. Limitations of this variety, which pertain to the conditions in which choices are made and the power relations with which they are permeated,⁵⁷⁰ are masked by the law's recognition of and reliance upon the idea of autonomy.⁵⁷¹

There is an odd parallel with between this line of critique that patients are insufficiently empowered to make healthcare decisions and the Marxian critique that the choices offered within liberal systems of government are often illusory, because liberal systems fail to guarantee the conditions in which choices can be freely made.⁵⁷² As Marxists view liberalism as an ideological form of governance designed to maintain a system of capital which exists for furtherance of the interests of the ruling class and the oppression and

⁵⁶⁵ see further J Harrington, 'Privileging the Medical Norm: Liberalism, Self-Determination and Refusal of Treatment' (n 9)

⁵⁶⁶ The law may limit what constitutes 'proper medical treatment' *R v Brown* [1993] 2 All ER 75

⁵⁶⁷ General Medical Council (GMC), *Consent: Patients and Doctors Making Decisions Together* (GMC 2008)

⁵⁶⁸ *R (Pretty) v Director of Public Prosecutions* [2002] 1 AC 800

⁵⁶⁹ *R (on the application of Nicklinson) v Ministry of Justice* [2014] UKSC 38

⁵⁷⁰ S Dodds, 'Choice and Control in Feminist Bioethics' in Catriona Mackenzie and Natalie Stoljar (eds), *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (Oxford University Press 2000) 216; J Harrington, 'Privileging the Medical Norm: Liberalism, Self-Determination and Refusal of Treatment' (n 9)

⁵⁷¹ O Corrigan, 'Empty Ethics: The Problem with Informed Consent' (2003) 25 *Sociology of Health & Illness* 768, 789

⁵⁷² see T O'Shea, 'Critics of Autonomy' (Essex Autonomy Project, 2012) 11-13

subjugation of the working class,⁵⁷³ the increase in informational rights that has been described above would do little to quell this concern.

Further to this critique, Marx drew a distinction between ‘formal freedom’ and ‘real freedom’.⁵⁷⁴ The right to refuse medical treatment could be used as an example. This right is often proclaimed with hyperbole but when we examine more closely the circumstances in which it can be exercised as well as the kind of person who may be empowered to use this right, it may appear less egalitarian its practical effects. Those with greater access to information and who are better educated will be in a better position to resist the medical authority through which the treatment is offered. They will likely have a better awareness of the legal right of refusal and they might be more inclined to enter into a dialogue with the medical team about which kind of treatment they should be given. Those from disadvantaged backgrounds who may be less likely to be aware of their rights, or of the possibility of receiving alternative forms of treatment, would be less likely to actually exercise their rights as they would be impeded by their structurally determined ignorance. In that sense, the legal right, which, on the face of it, applies equally to all adult citizens can only be exercised by a certain section of society a few in an empowered way. It is thus, according to the Marxist argument, a right which is illusory for a great number of people.⁵⁷⁵

Even if rights to information are seen as being inherently valuable, they are rights which may be more readily utilised by certain people than by others. The passing of decision making responsibility on to those who lack the ability to make a good decision for themselves can make the process of consent seem daunting and bamboozling at the best of times,⁵⁷⁶ but for those with a limited capacity for comprehending such information it could be even more problematic. For those who lack some capacity or who are in a somewhat vulnerable position, the rights that have been accrued through cases such as *Pearce*⁵⁷⁷ (which demands truthful information to be given in response to patients questions) are of very limited utility. In order to take full advantage of the protection the law offers, patients must actively become proficient at using risk-based information in order to make decisions. Additionally, they must learn to ask questions in order to get the kind of information that is important to them. Faden Beauchamp and King suggest that

⁵⁷³ K Marx, *The Communist Manifesto: Prefaces by Marx and Engels, Annotated Text, Sources and Backgrounds, the Communist Manifesto in the History of Marxism, Interpretation FL Bender (ed)* (Norton 1988)

⁵⁷⁴ T O’Shea (n 572) 11

⁵⁷⁵ See also JP Bishop, *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying* (University of Notre Dame Press 2011) 216

⁵⁷⁶ B Schwartz, ‘The Tyranny of Choice’ (n 535)

⁵⁷⁷ *Pearce* (n 455)

“Professionals [should]... establish a climate that encourages the patient or subject [sic] to ask questions.”⁵⁷⁸

Admittedly, there is an obligation to make an effort to present information in terms that the patient can understand and to as part of the consent process under the MCA and the MCA Code of Practice, and practitioners must have regard to this code.⁵⁷⁹ Of course the law does make some provision for those whose vulnerability manifests itself as a lack of capacity. This is also underpinned by the decision in *Montgomery v Lanarkshire* which suggests a shift in the legal approach towards information disclosure as the court made clear that the consent process (and the process of information disclosure) should operate as a “dialogue” which has patient understanding as its aim.⁵⁸⁰

Those who do lack capacity receive additional support and are not expected to make decisions for themselves (although they are expected to be included in the decision-making process), but even here some claim that the ‘best interests’ standard contained in the MCA causes medical practitioners to focus too heavily on what the patients desires in that situation without regard to what is wanted by the family.⁵⁸¹ In addition, there may be people who satisfy the test for capacity by a small margin, or those who for some other reason we may consider vulnerable who might pass through the protective framework of the MCA.

However, even for those without cognitive impairments, it might be said that most people might struggle to interrogate the treatment information when they are in ill health and need of treatment. Decisions to consent to medical treatment might be taken while under the influence of drugs, or following the receipt of a life changing diagnosis. Such factors may, of course vitiate capacity⁵⁸², but often this will not be the case (especially given that there is a presumption of capacity under the MCA).

As this brief overview of critical perspectives illustrates, the conceptualisation of autonomy as a basis for the law and its development is a matter of frequent contention. It is therefore unsurprising then that the implementation of laws based on such a contentious concept has been the subject of much critical attention. Many of these critical perspectives suggest that some individualistic interpretations of autonomy, which some suggest have

⁵⁷⁸ “A History and Theory of Informed Consent” cited in E Jackson, *Medical Law: Text, Cases and Materials* (n 32) 187

⁵⁷⁹ MCA, s 44

⁵⁸⁰ *Montgomery v Lanarkshire Health* (n 161) [90] (Kerr and Reed LLJ)

⁵⁸¹ W Martin and others, ‘An Unblinkered View of Best Interests’ (2012) 345 *BMJ* e8007

⁵⁸² *Re T* (n 54) 113 (Donaldson of Lynton MR)

prevailed in general terms,⁵⁸³ fail in practice. Patients may feel overwhelmed and unable to take in, remember and process the risk based information they are given. At a more fundamental level, some argue that individualistic models of autonomy fail to take adequate account of the social conditions in which autonomy is practiced. For example, they fail to take account of the oppression that is generated from the ruling classes, or the patriarchy, or the simple fact that people tend to make their decisions within social networks rather than entirely alone. This tends to normalise and reproduce problematic social relations in this field.

What can be taken from each of these perspectives collectively is that abstract notions of autonomy, devoid sensitivity for the social context in which they are designed to operate, are problematic. Such accounts may fail to adequately appertain to the reality of every-day decision-making and may therefore be descriptively deficient. But in addition, although the normative claims of abstract philosophical reasoning which supports autonomy demonstrably lacks persuasive force for many commentators. For these reasons, appeals for laws to be brought into line with particular versions of totalising philosophical concepts ought to be treated with caution.

In addition, the suggestion that the particular way in which the concept of autonomy has been developed philosophical development of autonomy can explain the emergence of ADRTs cannot be considered more than a partial success at best. With due acknowledgment to the importance of the philosophical analysis of autonomy, it is argued here that the law on ADRTs has not been developed in a vacuum as the result of a process of metaphysical argumentation, but rather through a complex interplay of values and objectives, together with social and technological conditions. In order to attain a fuller understanding of the law on ADRTs we therefore need to look beyond the traditional confines of analytic moral philosophy and bioethics. This is a task that will be undertaken in the second part of this thesis using Foucault's theory of governmentality.

Part of the argument will be to retract from abstract normative pronouncements about the kind of system that best protects values and rights which are held out as being important. Rather the concern is more pragmatic: medical technology has advanced to the point that it can routinely sustain life at very low levels of functionality for prolonged periods and there is a lack of clear authority for determining when treatment should be withdrawn in such situations in the context of an advanced liberal society. It is argued here that ADRTs have

⁵⁸³ O'Neill (n 372) 47

emerged more as a response to a crisis of government than as a product of the elaboration of a normative position.

CONCLUSION

This chapter has provided a discussion of some of the most prominent criticisms of modern recognitions of autonomy, which are taken underpin the recognition of the right to refuse treatment and ADRTs. The critical perspectives discussed in this chapter illustrate that in so far as it is true that the law has developed along the lines of a particular conception of autonomy, it has not been universally greeted as a positive development. To the contrary, many have found the organisation of the law around this conception of autonomy to be problematic.

With so many criticisms of the kind of autonomy which has allegedly been relied upon, the question arises as to why such a version of autonomy has been adopted at all in law. Some feminist and Marxist scholars suggest that it is part of a wider societal project of female subjugation and/or class oppression. These perspectives are valuable in highlighting the potential for ideas such as autonomy to structure social relations. In this thesis it will be suggested that the development of ADRTs is indeed part of a broader project, but rather than one of domination, it is a project aimed at the government of society. Moreover, the structural considerations merely make up a part of the story, because ADRTs have important implications for the way in which people relate to and govern themselves (a point which will be considered in detail in Chapter Six).

A common source of criticism is the individualistic spin put on the concept of autonomy, resulting in what some describe as being a ‘thin’ version of autonomy,⁵⁸⁴ lacking in moral depth. The individualised conception of autonomy has also been the subject of criticism from feminists and cultural theorists who dispute the descriptive and normative validity of a system that suggests people make decisions as individuals and that they *should* make decisions as individuals rather than in their family. Relational autonomy has been advanced by some as a more acceptable alternative to individualistic conceptions of autonomy. However, acceptance of such a form of autonomy would entail significant change in the law on the refusal of treatment, allowing refusals of treatment to be overridden where they would cause a significant burden to others. Adopting this model of autonomy in medical law would render all refusals of treatment subject to a ‘burdensomeness test’ and ADRTs no better than ACPs. It would not be impossible for the law to embrace relational

⁵⁸⁴ O'Neill (n 372) 28-48

autonomy in this way, but to do so may not accord with the broader objectives and purposes for which autonomy is put to work that were discussed in the previous chapter. Particularly, placing an additional criterion to be met before a decision will be respected would conflict with the goals of empowerment and the protection of patient choice, which have come to prominence in recent times. Thus the greatest problem for those advocating alternative versions of autonomy on which to base the law is that those they are not aligned with the prevailing model of decision-making upon which advanced liberalism depends. This is the most important reason why these kinds of criticism have not translated into a radically different legal approach.

Criticisms of the individualistic conceptualisation of autonomy and its legal implementation notwithstanding, autonomy has been relied upon as the fundamental ethical principle justifying the development of the law on ADRTs. Thus the orthodox understanding of ADRTs as instruments which merely ‘extend autonomy’ appears to rest on a broad-based, perhaps rhetorical, version of autonomy. The simplicity of this orthodox narrative can be contrasted with the many challenges and objections made to the legal recognition of ADRTs in the MCA, described as the most contentious part of the bill,⁵⁸⁵ as the law went through parliament. Some of these are set out in the next chapter.

⁵⁸⁵ Joint Committee on the Draft Mental Incapacity Bill (n 69) 6

CHAPTER FOUR

SPECIFIC CRITIQUES OF MODERN CONCEPTUALISATIONS OF AUTONOMY IN RELATION TO ADRTS

INTRODUCTION

A number of critiques of modern conceptions of autonomy and their incorporation into healthcare law were set out in the previous chapter. These arguments clearly speak to ADRTs, as the notion of autonomy forms the principle normative basis for their recognition,⁵⁸⁶ but these arguments were not specifically directed towards ADRTs *per se*. The purpose of this chapter will be to consider how concerns surrounding the construction of the principle of autonomy have been specifically raised against the kind of autonomy that underpins the recognition of ADRTs.

These concerns, many of which were aired in the pre-Legislative Scrutiny Committee on the Mental Incapacity Bill,⁵⁸⁷ will be set out and considered in this chapter. Attention will first turn to these concerns and then attention will turn to a different line of critique based on the idea of personhood. The latter is one of the most interesting and important challenges to the operation of ADRTs, because it does not ostensibly take issue with the current interpretations of autonomy, but rather with the question of whether autonomy can operate as the moral foundation of ADRTs if the creator of the ADRT is deemed to be a different agent from the one to whom the ADRT later purports to apply. This is significant because it was claimed in the previous chapter that the critiques which cut across some of the fundamental assumptions of the broader political rationality in which the law operates would struggle to gain traction and effect change. The personhood critique cuts into the very foundations of the legal framework on ADRTs and does so ‘along the grain’ i.e. accepting the assumptions of the advanced liberal rationality in which the law operates.

However, before turning to the critiques grounded in ideas of personhood, some of the objections raised to the enactment provisions that make ADRTs possible will be discussed. A number of these were considered in the Pre-Legislative Scrutiny

⁵⁸⁶ T Goffin (n 361)121

⁵⁸⁷ Joint Committee on the Draft Mental Incapacity Bill (n 69)

Committee for the legislation that was eventually enacted as the MCA and these will be considered in the next section.

THE MCA PRE-LEGISLATIVE SCRUTINY COMMITTEE

The 1995 Law Commission Report, “Mental Incapacity” made a series of recommendations that paved the way for the Mental Incapacity Bill (my emphasis), which was later to be enacted as the Mental Capacity Act 2005. The Law Commission’s central aim was “that [the] new legislation should provide a unified and comprehensive scheme within which people can make decisions on behalf of, and in the best interests of, people who lack capacity to make decisions for themselves”.⁵⁸⁸

Many of the principles that were ultimately written into the MCA were principles that had already received recognition in the common law. Perhaps the most important among these was the principle that everyone has capacity, unless the contrary is proven.⁵⁸⁹ This principle is reflected in the functional approach to mental capacity, which the Law Commission favoured⁵⁹⁰ and which, as they noted, was already being used in many areas of law at the time.⁵⁹¹ A similar principle has long been recognised in the criminal law in relation to the so-called *M’Naghten* rules,⁵⁹² which governs the defence of insanity: everyone is presumed sane (and therefore capable of having criminal responsibility) unless the contrary is proven.⁵⁹³ Similarly, the principle that a person must not be treated as lacking in capacity merely on the grounds that they have made an “unwise decision” was enshrined in section 1(4), but was already clearly established in cases such as *Re T*.⁵⁹⁴

The theme of a continuity, or extension, of existing legal principles is one of the most prominent in the reasoning which has led to the recognition of ADRTs.⁵⁹⁵ As the right to make anticipatory refusals of treatment had already received recognition at common law, as an extension of an existing and well-established right,⁵⁹⁶ prior to the enactment of the MCA, it was not seen as a legal development that required novel justificatory argumentation.

⁵⁸⁸ The Law Commission *Mental Incapacity* (LC231, 1995) para 3.1

⁵⁸⁹ *ibid* para 3.2

⁵⁹⁰ *ibid* paras 3.5-3.6

⁵⁹¹ *ibid* 3.5

⁵⁹² *M’Naghten* [1843] UKHL J16

⁵⁹³ *ibid* 210 (Tindal LCJ)

⁵⁹⁴ *Re T* (n 54)

⁵⁹⁵ Joint Committee on the Draft Mental Incapacity Bill (n 69) para 199

⁵⁹⁶ *HE v Hospital NHS Trust* (n 66) (Fam) [37] (Munby J); *W v M* (n 11) [226] (Baker J)

During the legislative process, however, it was argued that the law should not permit ADRTs that “effectively shorten life”.⁵⁹⁷ This line of argument contests the idea that respect for autonomy entails respecting all decisions of the patient. Further to this, Age Concern argued that “the concept of advance directives is morally wrong because in no circumstances has any person the right to refuse measures which will prolong life”.⁵⁹⁸ This claim was put in stronger rhetorical terms by those who claimed that the provisions on ADRTs would lead to “euthanasia by the backdoor”.⁵⁹⁹

There was also concern that failure to provide Clinician Assisted Nutrition and Hydration (“CANH”) may cause suffering and a loss of dignity at the end of life.⁶⁰⁰ However, the idea of limiting the individual power to refuse treatment based on a conception of dignity demands a robust definition of dignity and a serious commitment to the protection of dignity through the limitation of choice would have to apply to choices beyond those made at the end of life. Moreover justifying such limits on choice would be challenging in advanced liberal democracy, which relies on individuals who can exercise free choice.⁶⁰¹

These objections appear difficult to sustain in light of the fact that no more can be achieved through an advance decision than can be achieved through contemporaneous refusals of treatment.⁶⁰² Logically, if there were an objection to people making anticipatory decisions which would abbreviate the lifespan of their author (should they ever be relied upon) the same objection should apply to contemporaneous refusals of treatment which abbreviate lifespan. Of course, some would argue that the special value of life means that it should never be intentionally shortened by act or the omission of ‘ordinary’ or ‘proportionate’ treatment (i.e. that which is not considered ‘futile’ or burdensome)⁶⁰³ but this argument is not one that is accepted in English law, where sanctity of life concerns yield to those of self-determination.⁶⁰⁴ As there was no argument to change the existing law on this point, it appears that the principle pleaded in support of this argument (i.e. that there should be no hastening of death by withdrawing

⁵⁹⁷ Joint Committee on the Draft Mental Incapacity Bill (n 69) para 195

⁵⁹⁸ Age Concern Institute of Gerontology, Centre of Medical Law and Ethics, *The Living Will, Consent to Treatment at the End of Life* (Edward Arnold, 1988) 2

⁵⁹⁹ Joint Committee on the Draft Mental Incapacity Bill (n 69) para 196; see e.g. *ibid* Ev 292 MIB 20, Ev 307 MIB 403

⁶⁰⁰ *ibid* para 197

⁶⁰¹ see Part III

⁶⁰² What might be problematic is the point at which advance decisions come into effect i.e. following the loss of capacity, as setting up a framework in which people can refuse medical treatment at this point may offer the impression that it is thought that people ought to refuse treatment if they lack capacity.

⁶⁰³ J Keown (n 224) 40-43

⁶⁰⁴ *Re T* [1993] FLR 95, 112 (Donaldson MR)

life-saving or life sustaining treatment) is not one that has been advanced consistently. However, this line of argument is to be commended for its bold honesty in that it makes no secret of its aspiration to limit the level of choice that individuals may exercise over their medical treatment.

A slightly different concern was raised by some medical groups, who argued against the right to be allowed to make ADRTs, because they claimed that people cannot foresee what their treatment preferences might be following the loss of capacity.⁶⁰⁵ This problem is peculiar to ADRTs, because in cases of contemporaneous refusals of treatment, knowledge of the circumstances of the decision can readily be imputed to the decision-maker. However, with anticipatory decisions there is a possibility that new forms of treatment could emerge in the time intervening the making of the decision and the time when the decision is called upon. These considerations were certainly important, but further to the recommendations of the Scrutiny Committee⁶⁰⁶ safeguards were written in to the MCA designed to allay some fears of this kind: ADRTs will not be applicable where there has been a change in the circumstances of the patient⁶⁰⁷ and this provision cannot be avoided even where the author of the ADRT expressly states that they do not wish to be bound by its terms.⁶⁰⁸ The requirement to specify the circumstances in which the ADRT will apply has also led to the avoidance of a *prima facie* ADRT in *W v M*⁶⁰⁹ on the grounds that the patient had specified what should happen if she were to receive a particular diagnosis (*viz* a Vegetative State (“VS”)) but in the event, she was diagnosed with a condition of a similar kind that was almost unknown to medical science at the time she expressed her wishes).⁶¹⁰ Cases such as these illustrate the considerable level of discretion that is available to the healthcare professionals and the courts when adjudicating the applicability of ADRTs.⁶¹¹ The existence of this discretion, which has been retained in the MCA, weakens the argument that ADRTs are too rigid and lock their authors in to decisions regardless of changes in future circumstances.

Similarly, some opined that it would be improper for a person to make a decision about the refusal of treatment in the absence of professional advice.⁶¹² Imposing such a

⁶⁰⁵ Joint Committee on the Draft Mental Incapacity Bill (n 69) para 198; see also Select Committee on Medical Ethics, *Report of the Select Committee on Medical Ethics* (HL 1993-94, 21-I) para 194

⁶⁰⁶ Joint Committee on the Draft Mental Incapacity Bill (n 69) para 209

⁶⁰⁷ See MCA, ss 25(4)(a)-(b)

⁶⁰⁸ *Re E* (n 10) [63] (Peter Jackson J)

⁶⁰⁹ *W v M* (n 11)

⁶¹⁰ R Huxtable, ‘Treating the Minimally Conscious Patient: Life Before Choice?’ (n 289) 12

⁶¹¹ AR Maclean, ‘Advance Directives and the Rocky Waters of Anticipatory Decision-Making’ (n 143)

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⁶¹² Joint Committee on the Draft Mental Incapacity Bill (n 69) para 200

requirement would demand an additional service from healthcare professionals and would place additional costs on the health service. Great controversy followed the decision in the United States to use state funding (through Medicare) to pay for professionals discuss advance care planning with individuals.⁶¹³ Moreover, a requirement to consult a medical professional would extinguish one of the only genuine claims that ADRTs can make to empowerment of patients. By affording medical professionals the possibility of persuading the other party (the ‘proto-patient’) to making certain decisions (although Maclean believes that medical professionals should be under a duty to persuade their patients)⁶¹⁴, citizens would lose the power of pre-emption.

A further concern was that some may be placed under undue influence to create an ADRT.⁶¹⁵ This kind of concern is partially addressed by the inclusion of formality requirements, which require ADRTs which purport to refuse life sustaining treatment to be witnessed.⁶¹⁶ If the witness suspected that the person was being forced to make the ADRT, they could refuse to sign the document. Requiring creators of ADRTs to consult with medical practitioners would not eliminate this kind of concern, because medical professionals could equally apply persuasive pressure on people making important decisions,⁶¹⁷ indeed some think that they should be under an obligation to do so.⁶¹⁸

These concerns and objections are worthy of serious consideration, but as discussed, many of them represent objections not only to an extension of the law into ADRTs, but also to the very foundation of ADRTs in the ‘individualistic’ conception of personal autonomy, which allows individuals to refuse any treatment that they do not wish to receive. Moreover, by the time that Parliament was legislating for the MCA it was already apparent that ADRTs had received legal recognition through the common law⁶¹⁹ and, in consequence, the MCA did nothing radical in providing for the creation of ADRTs. It was also apparent that the courts had considered some of the potential problems associated with the recognition of anticipatory decision-making of this kind and had considered the imposition of certain safeguards to guard against abuse. However, one line of criticism that was not considered by the courts in the pre-MCA

⁶¹³ Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (The National Academies Press 2015) ix

⁶¹⁴ A Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (n 529) 250

⁶¹⁵ Select Committee on Medical Ethics, *Report of the Select Committee on Medical Ethics* (HL 1993-94, 21-I) para 199

⁶¹⁶ MCA, s 25(5)-(6)

⁶¹⁷ *U v Centre for Reproductive Medicine* [2002] EWCA Civ 565

⁶¹⁸ A Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (n 527) 125

⁶¹⁹ Joint Committee on the Draft Mental Incapacity Bill (n 69) para 198

case law, at least directly, but which has subsequently come to prominence is the personhood argument. This will be considered in the next section.

*THE PERSONHOOD CRITIQUE*⁶²⁰

Many criticisms of autonomy considered thus far might apply equally to contemporary refusals of treatment as they apply to ADRTs. However, what I will refer to as “the personhood argument” that will be discussed in this section is one that applies to ADRTs specifically. Mclean has neatly summarised the major premise of what I will refer to as the personhood problem in the following way:

“If advance directives are predicated on the basis of personal autonomy then... their authority only applies to an individual if he or she is the same moral entity that created the directive.”⁶²¹

A significant problem would thus occur were the author of the ADRT to be treated as a different ‘moral entity’ if his or her ADRT were to be relied upon. A problem of this order goes directly to the moral legitimacy of the ADRT,⁶²² because if the author has become a different moral entity, she or he would lack the moral legitimacy to bind her or his future self.⁶²³ On that basis, the present self would purport to bind a different person.

As the personhood argument is one that goes to the moral core of advance decision making, it demands serious attention. However, even if it is accepted that this kind of change is possible, the moral legitimacy ADRTs is only threatened if such a change has actually occurred (i.e. whether the author has actually become a different moral entity). Therefore the ability to identify when such a change might happen is crucial for the strength of this critique.

Different approaches have been suggested for the identification of change in ‘moral entities’ and many of these theories revolve around the concept of personhood. Legal personhood can be taken to mean the recognition of a person before the law.⁶²⁴ Other aspects of personhood may include moral personhood and it is this aspect of personhood, which refers to the moral status of a person. Fluctuations in moral personhood may not automatically affect legal personhood, but it could be argued that

⁶²⁰ Much of the discussion in this section has been published as T Hayes, ‘A (Social) Room with a View (to the Future): Advance Decisions and the Problem of Personhood’ (n 13)

⁶²¹ AR Maclean, ‘Advance Directives, Future Selves and Decision-Making’ (n 70) 298

⁶²² R Dresser, ‘Dworkin on Dementia: Elegant Theory, Questionable Policy’ in Helga Kuhse and Peter Singer (eds), *Bioethics: An Anthology* (2nd ed, Blackwell, 2006) 369

⁶²³ PR Sailors, ‘Autonomy, Benevolence, and Alzheimer’s Disease’ (2001) 10 *Cambridge Quarterly of Healthcare Ethics* 184, 192-193

⁶²⁴ See N Naffine, ‘Who Are Law’s Persons? From Cheshire Cats to Responsible Subjects’ (n 403)

there should be a moral basis for the law's recognition of personhood and any fluctuations thereto.

Invoking the concept of personhood makes it possible to divide aspects of existence between the biological and the political, what the ancient Greeks termed *bios* and a *zoē* respectively.⁶²⁵ Since then, various theories of personhood have emerged in moral philosophy,⁶²⁶ which suggest different criteria for the recognition of personhood and for identifying material changes in personhood. These theories can be divided between the *animalist*, and the *psychological*.

Animalist theories of personhood refer heavily to the biological makeup of the person. On this view, if a person remains biologically the same, then they should be recognised as the same moral entity.⁶²⁷ An immediate difficulty arises from the idea of an entity remaining the same and how much change might be admissible before the organism might be considered to have changed.⁶²⁸ If a broad view of biological makeup is taken (i.e. if we do attach moral significance to changes at the cellular level, or even to larger scale changes such as organ transplantation or limb amputation) then such theories may suggest a high degree of continuity of personhood especially in relation to adults who may create ADRTs. Animalistic theories could found a basis for challenging the arbitrary restriction on the ability to create an ADRT at the age of 18 and why legal personhood might be affected by a loss of mental capacity.

Accepting such an animalist theory as a universal principle of law would have far-reaching consequences. For instance, the recently deceased might have biological or genetic identity with the person they were when they were alive. The law would not recognise this: one cannot murder a corpse in the same way that one can murder a living human person.⁶²⁹

Locke argued against animalist conceptions of personhood by drawing attention to the absurdity of treating someone as a new person if his or her hand were to be cut off.⁶³⁰ He developed a theory of personhood grounded in psychological persistence.⁶³¹ He argued that “whatever has the consciousness of the present and past actions, is the same person to whom they both belong”.⁶³² On this basis the continuation of personhood

⁶²⁵ G Agamben, *Homo Sacer: Sovereign Power and Bare Life* (Stanford University Press 1998) 9

⁶²⁶ see MF Goodman, *What Is a Person?* (Springer Science & Business Media 1988)

⁶²⁷ A Wrigley, ‘Personal Identity, Autonomy and Advance Statements’ (2007) 24 *Journal of Applied Philosophy* 381, 386-387

⁶²⁸ D Parfit, *Reasons and Persons* (Clarendon Press 1987) 234-236

⁶²⁹ *R v Malcherek and Steel* [1981] 2 All ER 422

⁶³⁰ J Locke, ‘An Essay Concerning Human Understanding’ in John Perry (ed), *Personal Identity* (University of California Press 2008) para 13

⁶³¹ *ibid* para 9

⁶³² *ibid* para 16

requires that one must be able to remember one's previous states of consciousness. Therefore, according to Locke, if a person has memory problems, perhaps owing to a condition such as dementia, and cannot remember an earlier state of mind, they must be treated as a distinct moral entity from that forgotten person.⁶³³

There are obvious objections to Locke's theory of the continuity of personhood. For instance, the defendant who committed *prima facie* offences whilst intoxicated, but who later became sober and could not remember her actions would be able to argue that they should not be held liable for her intoxicated actions. Taking a broader appreciation of the arguments which cast doubt on the right of the present self to make decisions for the future self (where the future self lacks capacity), we might ask why such arguments cannot apply equally to other areas of the law? The pragmatic answer is that acceptance of such an argument would have radical implications for the entire legal system.

Accepting these arguments would potentially allow the debtor to claim no longer to be the same person as she who incurred the debt and on that basis ought no longer to have a duty to account for that debt; the convicted criminal might argue that they are not the same person as the one who was convicted and therefore they ought not to suffer the penalties of the conviction; and the husband might argue that he is not the same person as he was at the time of his marriage and that consequently he ought not to be bound by his marital vows. According to Locke, all that such people would have to demonstrate (or prevent the other side from demonstrating, depending on the burden of proof) in order to achieve this would be to say that they could not remember their state of consciousness at the time of making the agreement or committing the crime.⁶³⁴ This would have radical implications for the entire legal system and it is unclear that such changes would be compatible with the prevailing advanced liberal mode of government, which relies on individual choice, the persistence of legal relations and of individual responsibility.

A more sustained and nuanced theory of personhood was devised by Parfit. He grounded his argument for the superiority of psychological criteria for identifying personhood in a series of thought experiments involving cerebral transplantation and

⁶³³ e.g. see AD Firlik (n 506)

⁶³⁴ D Shoemaker, 'Personal Identity and Ethics' in Edward N Zalta (ed), *The Stanford Encyclopedia of Philosophy* (online <<http://plato.stanford.edu/archives/spr2012/entries/identity-ethics/>> [accessed 18 September 2012], 'Historical Highlights of the Relation', 2012) §.1; Much of this discussion on personhood has been published as T Hayes, 'A (Social) Room with a View (to the Future): Advance Decisions and the Problem of Personhood' (n 13)

cloning.⁶³⁵ The conclusion of these experiments was that the changes in the bodily make-up of a person would not be sufficient per se to give rise to a change in personhood.

Furthermore, he argued that the most important factor, in terms of decision-making legitimacy, is not whether the person remains identical to the former self, because all people are subject to continual experiences which may adjust their psychological make-up in small ways, but rather whether a sufficient psychological connection between the two selves (or the self at both point in time) remains.⁶³⁶ On this basis, he suggested that although people may undergo change over time, the present-self has a legitimate claim in making decisions for the future-self, where a psychological link with the future-self is retained.⁶³⁷ Parfit claims that a persistent psychological connection between the present and the future self is “*as good as personal identity*”.⁶³⁸ It is this psychological connectedness⁶³⁹ that forms the basis for legitimate self-regarding decision-making.⁶⁴⁰

The idea of a sufficient degree of connectedness invites the question as to what that might mean in more precise terms. Parfit uses the character “R” to represent a sufficient degree of connectedness.⁶⁴¹ This degree of connectedness can be measured by counting the ‘quasi-memories’⁶⁴² shared between the two incarnations of the self (i.e. the past and the present self). This criterion places a great deal of weight on task of interpreting these quasi-memories and according weight to them. This would render R highly debatable in respect of any past and present self pairing. For the purposes of creating ADRTs, this would add a great deal of complexity to the question of whether the ADRT should be applied or not. In order to use Parfit’s theory for this purpose we would require “far richer data than we ordinarily have or could acquire, even with great cost and effort”⁶⁴³ before deciding whether an ADRT was created by a sufficiently connected former self as to bind the present self. Specifically, making an assessment as to whether we can identify R would require the gathering of data at two points in time: the point at which the ADRT is written and the point at which the treatment it specifies becomes indicated, the circumstances it details obtain and the person lacks the capacity to make a contemporaneous decision. The complexity and indeterminate nature of such a criterion

⁶³⁵ e.g D Parfit, *Reasons and Persons* (n 628) 267-270; 253-266

⁶³⁶ *ibid* 245-280

⁶³⁷ D Parfit, 'Personal Identity' (1971) 80 *The Philosophical Review* 3, 21

⁶³⁸ D Parfit, *Reasons and Persons* (n 628) 209 (emphasis in original)

⁶³⁹ *ibid* 245-280

⁶⁴⁰ D Parfit, 'Personal Identity' (1971) 80 *The Philosophical Review* 3, 21; Much of this discussion on personhood has been published as T Hayes, ‘A (Social) Room with a View (to the Future): Advance Decisions and the Problem of Personhood’ (n 13)

⁶⁴¹ see M Belzer, ‘Notes on Relation R’ (1996) 56 *Analysis* 56

⁶⁴² D Parfit, *Reasons and Persons* (n 628) 220

⁶⁴³ A Buchanan, ‘Advance Directives and the Personal Identity Problem’ (1988) 17 *Philosophy & Public Affairs* 277, 296

would render it extremely difficult to reconcile with the legal goal of a clear demarcation between those ADRTs which are binding and those which are not.

As discussed, the way in which personhood is recognised in law has serious implications for the operation of ADRTs. As a consequence, a number of authors have considered the implications of this personhood critique specifically for advance care planning and advance decision making.⁶⁴⁴ Maclean is one author who has considered how these arguments may affect English law and the MCA specifically. In so doing, he has lent his support to Parfit's theory of personhood.⁶⁴⁵ On this basis, he suggests that there will be many occasions the author of an ADRT will lack a sufficiently strong psychological connection with the person to whom the ADRT may apply (i.e. the person who lacks capacity when the specified treatment is indicated and the specified circumstances obtain). As a result, Maclean argues that it would be inappropriate accord the ADRT full binding force against the future self.

In such circumstances in which there is a low degree of a psychological connectedness, Maclean analogises the relationship between the author of the ADRT and future self as on a par with that of a parent and child.⁶⁴⁶ As discussed in Chapter One, the law allows parents to make medical decisions on behalf of their children, but those decisions will only be binding on the parent in so far as they are within the best interests of the child.⁶⁴⁷ Consequently, Maclean argues that where there is an insufficient psychological connection between the author and the person to whom the ADRT purports to apply, then the decision contained in the ADRT will only be valid in as far as it accords with the best interests of the patient at the time.

Such a position would clearly be at odds with the current ethos of respect for autonomy as patient choice and its corollary that an unwise or irrational decision is not destructive of its validity.⁶⁴⁸ It would also mean that there would be little difference in outcome between those who had made an ADRT and those who had not (and instead

⁶⁴⁴ See eg MJ Newton, 'Precedent Autonomy: Life-Sustaining Intervention and the Demented Patient' (1999) 8 Cambridge Quarterly of Healthcare Ethics 189; A Wrigley (n 627); D DeGrazia, 'Advance Directives, Dementia, and "the Someone Else Problem"' (1999) 13 Bioethics 373; S Holm, 'Autonomy, Authenticity, or Best Interest: Everyday Decision-Making and Persons with Dementia' (2001) 4 Medicine, Health Care and Philosophy 153; C Lemmens, 'End-of-Life Decisions and Demented Patients. What to Do If the Patient's Current and Past Wishes Are in Conflict with Each Other?' (2012) 19 European Journal of Health Law 177; MG Kuczewski, 'Commentary: Narrative Views of Personal Identity and Substituted Judgment in Surrogate Decision Making' (1999) 27 Journal of Law, Medicine & Ethics 32

⁶⁴⁵ AR Maclean, 'Advance Directives, Future Selves and Decision-Making' (n 70)

⁶⁴⁶ *ibid* 315-320

⁶⁴⁷ *ibid* 304 and 315

⁶⁴⁸ *Bland* (n 63), *Re T* (n 54)

relied on the doctrine of best interests under the MCA) as both decisions would have to be made in accordance with the best interests doctrine.⁶⁴⁹

However, if Maclean's position were to be accepted and implemented into law here it would render ADRTs near-redundant. As has been explained in the first chapter, ADRTs are concerned exclusively with the refusal of treatment projected into the future and that in the absence of an ADRT a person can be provided with medical treatment in accordance with her best interests. In legal terms, the only reason for which a person should make an ADRT, therefore, is if they anticipate that they might be provided with treatment in their best interests that they would not wish to receive. If they are happy with the treatment that they may be given in their best interests, they have no reason to create an ADRT. If the operation of ADRTs were restrained on the grounds of personhood, in the way that Maclean advocates, ADRTs would hold no advantage over simple statement of wishes to be taken into account as part of the best interests assessment (see Chapter One).

However, even if we accept the premise that the ADRT is made by someone of different personhood (S_1 – the current-self) to the person to whom it applies (S_2 – the future-self), the person who has developed into S_2 has always had the opportunity in the intervening period to revoke or otherwise alter their ADRT. Implicitly this indicates that there is a strong psychological connection, and little difference between S_2 and $S_{2-\delta}$.⁶⁵⁰ Ethically therefore, there is a strong case that her or his decision contained in the ADRT is the decision that they want to be made at S_2 .

Dworkin's position on this point is similar, but does not rely on an acceptance of the argument of substantive metaphysical change; his position is that the decision at S_1 should be accepted because it is the last autonomous decision made by *that* agent.⁶⁵¹ On either approach there is no genuine difficulty with accepting the decision of S_1 as being straightforwardly applicable to S_2 .⁶⁵²

In addition, we might analogise the ADRT with testamentary devices in order to show that there is no barrier in general terms to according legal force the wishes of the present-self over the future-self. Maclean claims that such an analogy fails as it would amount to “commodify[ing] the present-self”⁶⁵³ and goes on to allude to examples in bioethics where other forms of commodification are deemed to be unacceptable.

⁶⁴⁹ Much of this discussion on personhood has been published as T Hayes, ‘A (Social) Room with a View (to the Future): Advance Decisions and the Problem of Personhood’ (n 13)

⁶⁵⁰ Where ‘ δ ’ represents ‘a very small change’

⁶⁵¹ R Dworkin (n 425) 227

⁶⁵² R Huxtable, ‘Advance Decisions: Worth the Paper They Are (Not) Written On?’ (2015) 5 *End of Life Journal* 1, 5

⁶⁵³ AR Maclean, ‘Advance Directives, Future Selves and Decision-Making’ (n 70) 318

However, his argument is undermined by the fact that the purpose of a testamentary device is not limited to the disposal of property: provisions can also be made for the guardianship of the testator/testatrix's children for instance.⁶⁵⁴ The analogy does not rest on the subject matter of the testamentary disposition, so much as its ability to give legal force to the wishes of a person who is no longer able to express those wishes autonomously for themselves. As such it holds true.⁶⁵⁵

In highlighting these objections to Maclean's argument it is not to suggest that the law cannot admit the possibility that individuals change their minds over the course of time. It is important to acknowledge the safeguards that already subsist in the MCA. One of the most important is that ADRTs can be revoked without formality.⁶⁵⁶ If the author changes their mind, perhaps because they consider themselves to have undergone a significant personal change, they can revoke or modify their ADRT through words alone (although it would certainly be prudent to do so in writing). Reliance on the author of the ADRT to revoke the ADRT in these circumstances avoids the difficulty of a third party having to determine when an individual has undergone sufficient personal change to warrant ignoring their ADRT.

Of course this argument may be subject to the objection that it is based on the fiction that anyone that creates an ADRT has a permanent awareness of her decision and keeps that decision under constant review. Such an expectation is patently unrealistic, but it might be retorted that even if the creator of the ADRT does not keep her decision at the front of her mind, they do have the opportunity to reconsider their decision and while they retain capacity. Moreover, there is an argument that anyone who elects to make an ADRT must take with it the responsibility for reviewing and amending that decision in future should they no longer wish that decision to apply. The law even offers additional protection for those who fail to revoke or modify their decisions as perhaps they should and these provisions may address some of the personhood concerns.

For instance, ADRTs will not be applicable where the author of the ADRT has done anything that is deemed inconsistent with his or her decision.⁶⁵⁷ Behaviour that is inconsistent with the decision may be indicative of a change in personhood and even if the creator of the ADRT does not take action to revoke or amend his or her decision, it may not be upheld on these grounds.

⁶⁵⁴ Wills Act 1837, s.1

⁶⁵⁵ Much of this discussion on personhood has been published as T Hayes, 'A (Social) Room with a View (to the Future): Advance Decisions and the Problem of Personhood' (n 13)

⁶⁵⁶ MCA, s 24(4)

⁶⁵⁷ MCA, s 25(2)(c)

Additionally, the provisions relating to the interpretation of an ADRT could be used to avoid applying the terms of the decision in circumstances where it is thought that there has been a significant change in personhood. As Michalowski and Maclean point out,⁶⁵⁸ those who are faced with the interpretation of ADRTs need only an honest belief that an ADRT lacks applicability or validity⁶⁵⁹ to avoid being bound by its terms, whereas if they wish to rely on the terms of the ADRT they must have a reasonable belief in the applicability and validity of ADRT.⁶⁶⁰ Thus, if a healthcare practitioner believed that there had been a significant change in personhood which cast doubt on the applicability or validity of the decision⁶⁶¹ they would have to satisfy a lower burden of proof, should they decide to provide treatment against the terms of the ADRT than if they were to accept its validity and applicability.

Although it may be argued that the manner of autonomy that has received recognition in law has been overly individualistic in general terms and that such a conceptualisation may be damaging to certain groups.⁶⁶² In view of these provisions in the MCA and in view of the way the ADRTs have been interpreted in the case law,⁶⁶³ it would seem that the argument that the individual has received too much power to bind his or her future self through ADRTs is greatly weakened.

CONCLUSION

The purpose of this chapter was to offer a critical discussion on the relationship between the principal normative concept relied upon in the recognition of ADRTs and the legal recognition of ADRTs. It was argued that, at least rhetorically, autonomy plays a central justificatory role for ADRTs (as it now does for contemporaneous refusals of treatment that were considered in the previous chapter). However, the ill-defined and contentious nature of autonomy in law means that appeals to autonomy cannot be precisely mapped on to a legal framework, and even were they to do so, that framework would be unlikely to receive universal support. Indeed, on a given set of facts it is possible to envisage autonomy being pleaded in aid for those advocating the withdrawal of treatment (e.g. on a strict individualist reading of autonomy for instance) as well as

⁶⁵⁸ S Michalowski (n 143) 960; AR Maclean, 'Advance Directives and the Rocky Waters of Anticipatory Decision-Making' (n 143) 21

⁶⁵⁹ see Chapter One

⁶⁶⁰ see *ibid*

⁶⁶¹ see *ibid*

⁶⁶² see Chapter Three

⁶⁶³ see Chapter One

those advocating the continuation of treatment (e.g. on the basis that the person who made the refusal was inadequately informed of the consequences of his or her refusal).

This contentiousness is visible in the objections raised to the development of the law on ADRTs in the Pre-Legislative Scrutiny Committee⁶⁶⁴ prior to the enactment of the MCA. Prominent among these objections was the fear that the development of the law was really a furtive first step towards the legalisation of euthanasia. The strength of such claims appears greatly limited by the fact that the MCA did not provide any new rights for patients, but rather made possible the extension of existing rights into the future. The concern that people should not be entitled to make binding ADRTs on the basis that they could not know the future state of medical science at the time of creating an ADRT must be read in the light of the provisions of the MCA itself.

The law does not simply respect a purported patient choice in the form of an ADRT without further question and it never has done so.⁶⁶⁵ We have seen that ADRTs must be expressed in clear terms, must apply to the treatment which becomes clinically indicated and in the circumstances envisioned by the author, before they will be treated as binding.⁶⁶⁶ If there is a suggestion that the decision has not adhered to the formalities of the MCA,⁶⁶⁷ or if the author has done anything inconsistent with the decision in the ADRT,⁶⁶⁸ the decision can be avoided. In this respect, the charge that the law has moved too far in the direction of accepting a thinly veiled version of self-determination through its recognition of ADRTs appears weak.

However, one very important line of criticism was not explicitly highlighted in the Pre-Legislative Scrutiny Committee. This was the ‘personhood argument’ that was discussed in the second part of this chapter. It is powerful and novel line of critique, because it does not contest the extant conceptualisation of personal autonomy on which ADRTs have been developed, as most other critiques do in some way, but rather contests the notion that there is moral continuity between the individual who makes an ADRT and the person to whom it may eventually apply. On that basis, autonomy would not provide an adequate justification for the recognition of ADRTs.

A line of critique that addresses ADRTs on their own terms is deserving of serious attention. However, its success as a line of critique may be limited for two important reasons. Firstly, the MCA does tacitly accept, and attempts to offer safeguards against

⁶⁶⁴ Joint Committee on the Draft Mental Incapacity Bill (n 69)

⁶⁶⁵ see *HE v Hospital NHS Trust* (n 66)

⁶⁶⁶ MCA, s 25(4); *W v KH* [2004] EWCA Civ 1324 (CA); J Montgomery, ‘Power Over Death: The Final Sting’ (n 257)

⁶⁶⁷ MCA, ss 25(5)-(6)

⁶⁶⁸ MCA, s 25(4)(c)

the kinds of concerns raised by the personhood argument. ADRTs are revocable without formality, will lack applicability if there is a material change in circumstances and are subject to an interpretative bias which makes it less onerous to avoid an ADRT than to apply it. Secondly, if the personhood argument were accepted here then it ought to be accepted *mutadis mutandis* to other areas of law and to do so would render many areas of law, such as criminal law and contract law, unrecognisable. These are areas of law which are essential to the functioning of advanced liberal programmes of government which rest on the ability of individuals to take choices and take responsibility for those choices.

These critiques based around personhood offer some of the most compelling arguments against the recognition of ADRTs, but acceptance of them would entail far-reaching and fundamental changes to the other areas of law. It is unclear whether the proponents of these arguments in respect of ADRTs would wish to see them accepted beyond the realm of ADRTs in a logical manner. If not then the deployment of the personhood argument might be seen as a sophisticated way of stymying the law on ADRTs rather than promoting a genuine concern for a more philosophically rigorous conceptualisation of personhood in law.

Through the analysis and discussion in the first part of this thesis it has been argued that the assertion that ADRTs have been developed pursuant to an extension of autonomy belies a number of contentious and complex factors. The question of whether to continue medical treatment at the end of life has only arisen since there has been the possibility of significantly prolonging life. Moreover, the kind of autonomy being developed has arguably been invoked as a strategy for empowering patients and disempowering doctors in the context of a pluralistic world advanced liberal society in which the authority of the expert must itself become subject to market forces.⁶⁶⁹ Advanced liberal democracy demands, and depends upon, the existence of individuals who can make decisions for themselves and who can take responsibility for their own futures and ADRTs are one way of fostering this kind of attitude. Individual choice has become an organising principle in advanced liberal western society and having a situation in which individuals decisions about the end of life must be made on behalf of others is highly problematic a system of government organised along these lines.

It is argued here that some of these complexities can be best brought out through their consideration in relation to Michel Foucault's work on governmentality. This theory will be set out in the next chapter and will be related back to ADRTs in the two

⁶⁶⁹ NS Rose, 'Government, Authority and Expertise in Advanced Liberalism' (1993) 22 *Economy and Society* 283, 295-296

chapters that follow. This theoretical perspective will allow for a richer understanding of both the development and the operation of ADRTs than one which could be attained through an analysis based on abstract philosophy alone. In a similar way to some of the Marxist and feminist critiques of autonomy that were outlined in the previous chapter, governmentality demands an appreciation of the broad social changes and forces which have helped to shape the context in which ADRTs have emerged. Concurrently, however, it demands attention on the microplays of power and particularly on the way in which the individual becomes a subject attuned to the exercise of power over themselves. This is a theme that will be taken up in Chapter Seven. The way in which the law has developed and the fact that ADRTs are recognised by the law will neither be proclaimed as a victory or a defeat, but rather as an instantiation of a modern mode of government.

Moreover, governmentality can speak to some of the concerns raised in respect of the development of forms of autonomy that support the right to refuse treatment and ADRTs, which have been explored in both this and the previous chapter. However, unlike some of the critical positions considered in this part of the thesis it will also allow for an appreciation of the productive aspects of the development of the law.

Viewing ADRTs as part of the technologies of government and the technologies of the self suggests that ADRTs should bear certain properties in order that citizens can be subjectivised as active, responsible, healthcare consumers who bear responsibility for their future treatment. ADRTs have arisen in the context of the possibility of prolonging life through modern medical apparatus and the lack of a clear source of authority for determining when that extension of life should cease.

The employment of governmentality in the next part of this thesis will demand a focus on the historical conditions which have made the acceptance of ADRTs possible, particularly surrounding the use of autonomy as an organising principle in society, and this will provide a stronger basis for understanding the seemingly inconsistent way in which ADRTs are recognised in practice. Furthermore this analysis will allow us to step back from an analysis of ADRTs based on their benefits for individuals and consider what benefits society might derive from a system of ADRTs.

INTRODUCTION TO PART III

The previous part of this thesis provided a detailed discussion of the normative arguments relied upon for the justification and critique of ADRTs commonly invoked in bioethical and healthcare law analyses. It was suggested that the principle justification drawn upon in recognition of ADRTs is based on the supposed role of ADRTs in extending personal autonomy. However, doubt was cast upon the extent to which the extension of autonomy argument holds true and the extent to which it is a useful claim to make.

This part of the thesis will offer a novel basis for the critique of the law on ADRTs using Foucault's theory of governmentality. The theory of governmentality will be set out in Chapter Five and its application in respect of ADRTs will be considered in Chapters Six and Seven, where the operation of ADRTs as part of the technologies of the self and the technologies of government will be discussed respectively. Autonomy remains a central theme in this part of the work, but by using governmentality as a theoretical platform a different conceptual and operative understanding can be obtained. Here the focus shall be on the practices which autonomy elicits and its role in government. This approach makes possible the consideration of the practices which are bound up with the production and the operation of ADRTs in respect of the individual (as is the traditional point of focus) and in respect of the seldom considered aspect of ADRTs in the population.

CHAPTER FIVE

THE THEORY OF GOVERNMENTALITY

INTRODUCTION

The second part of this thesis examined some of the most important precursors to the recognition of ADRTs. Although there are a number of possible contributory factors, it was suggested that the factor given most theoretical attention for the development of ADRTs lies in the idea of autonomy. Much simplified, those advocating the recognition of ADRTs suggested that they are nothing more than extensions of the right of patients to refuse medical treatment, a well-established (if under theorised)⁶⁷⁰ principle in both bioethics and law, into the future. It was suggested that the ideas of autonomy and, perhaps to a lesser extent, self-determination, which provide the normative grounding for this legal development are capable of bearing a number of different meanings, not all of which would accord with the legal framework of the MCA (e.g. requiring that decisions must be considered in keeping with a person's authentic self before they can be considered autonomous). Notwithstanding degree to which the definitions of these keystone concepts are unclear and have been contested, many consider that an individualistic variant of autonomy has won out over all others.⁶⁷¹ This individualised nature of the concept of autonomy has attracted criticism for Marxists and some feminists alike. In respect of ADRTs, some argued that ceding this level of choice to the individual leaves open the undesirable possibility that people will make ADRTs when ill-informed of the kinds of treatment they are refusing and may leave them open to coercion. It was also suggested that this kind of advanced refusal of treatment might be considered tantamount to a request for euthanasia. These points were discussed in the previous chapter.

Another important line of critique that was considered in the previous chapter did not challenge the way in which the concept of autonomy has been construed and constructed, but rather suggests that even on its own terms, autonomy cannot provide for a simply right to make decisions about possible future events, because it should not be presumed that the person who makes the decision would share a relationship of sufficient moral proximity with the person to whom the decision may eventually apply.

⁶⁷⁰ K Veitch, *The Jurisdiction of Medical Law* (n 8) 55

⁶⁷¹ But NB J Coggon, 'Varied and Principled Understandings of Autonomy in English Law' (n 419)

Many accounts of the development of the idea of personal autonomy and the right to refuse medical treatment in bioethics and law posit the Nuremburg trials as a fundamental turning point.⁶⁷² As such, there is a degree of recognition of the historical contingency of the development of the constitutive values of medical law. However, as important as the Nuremburg trials undoubtedly were in the development of the values relied on today in the recognition of the right to refuse treatment, the idea that there is a simple and direct relationship between these trials and the way the law is recognised today is highly contestable. As exemplified by cases like *Bolam*, the law continued to provide medics with a great deal of deference and cover long after the Nuremburg trials and by the same token gave a far more limited recognition to the idea of patient autonomy than that which pertains today. In addition to the graduated change that has taken place following Nuremburg, important developments also took place in the centuries prior. These developments may not appear to be immediately important to the concerns of bioethics, but in terms of the development of the idea of individual autonomy on which ADRTs rest, they are of critical importance. Part III of this thesis builds on the position that it is important to interpret key concepts in light of the historical conditions of their emergence using Foucault's theory of governmentality, which adopts a genealogical method concerned with writing a history of the present.⁶⁷³

This chapter will provide a detailed exposition of Foucault's theory of governmentality. Foucault develops this theory with respect to changes in the practices of government which took place prior to Nuremburg, primarily between the Sixteenth and Twentieth centuries (although, Foucault does admit that he "skips two centuries" i.e. he jumps from the Eighteenth to the Twentieth).⁶⁷⁴ The idea of governmentality is developed with reference to various moments throughout govern this period at which the prevailing circumstances gave rise to questions over how to because old systems of government broke down, or were unable to cope with the new conditions which faced them.⁶⁷⁵ These moments led to innovation in the practices of government, as government itself developed into an art.⁶⁷⁶

Perhaps the most important moment in this development of the practices of government came in the Eighteenth Century, when size and complexity of society led to the population

⁶⁷² J Miola, *Medical Ethics and Medical Law: A Symbiotic Relationship* (Hart 2007) 34-37

⁶⁷³ M Foucault, *Discipline and Punish: The Birth of the Prison* (Penguin Books 1991) 31; NS Rose, *Governing the Soul: The Shaping of the Private Self* (2nd edn, Free Association Books 1999) xi

⁶⁷⁴ M Foucault, *The Birth of Biopolitics: Lectures at the Collège de France, 1978-79* (Palgrave Macmillan 2008) 78

⁶⁷⁵ see N Rose and P Miller, 'Political Power Beyond the State: Problematics of Government' (1992) 43 *The British Journal of Sociology* 173, 181-183

⁶⁷⁶ See M Foucault, *The Birth of Biopolitics* (n 674) 27-29

being considered to have taken on its own ontological status rather than being merely considered the collective term for a multitude of bodies. This change prompted a new mode of government that was reflective of, and orientated towards, the body of the population. It was also at this time that the rationality of liberalism was developed in response to the totalising rationality of the police state.

This development of the liberal practices of government, which has since further transformed into advanced liberalism, has played a crucial role in the development of autonomy. Indeed autonomy and liberalism can be viewed as mutually constitutive,⁶⁷⁷ which provides some indication as to why these terms are so often conflated in law.⁶⁷⁸ As such, it is argued here that ethical and political developments should not be held separate⁶⁷⁹ and that a great deal can be learned about autonomy, as a moral principle, from examining the development of political rationalities, which took place during a quiet period for bioethics.⁶⁸⁰ Many forms critique grounded in particular branches of ethics and metaphysics tend to neglect an important factor in the political significance of the development of a form of consent which prioritises individual choice and consequently responsabilises the individual (which takes place in conjunction with their individualisation)⁶⁸¹ for the purposes of governmental expediency.⁶⁸² It is argued here that this kind of responsabilisation has developed over time and as a strategy of government in that the apportionment of responsibility has varied over time, but at the current point in history more and more responsibility is being shifted onto individuals.⁶⁸³ Thus, the central objective of this chapter is to explain some of the ‘problematics of government’⁶⁸⁴ that have led to the conclusion that ‘individual autonomy’, broadly conceived, is a necessary component of modern forms of

⁶⁷⁷ B Hindess, ‘Liberalism, Socialism and Democracy: Variations on a Governmental Theme’ (1993) 22 *Economy and Society* 300, 301

⁶⁷⁸ See J Coggon and J Miola, ‘Autonomy, Liberty and Medical Decision-Making’ (2011) 70 *The Cambridge Law Journal* 523, 539

⁶⁷⁹ M Dean, ‘Governing the Unemployed Self in an Active Society’ (1995) 24 *Economy and Society* 559, 562

⁶⁸⁰ J Miola, *Medical Ethics and Medical Law: A Symbiotic Relationship* (Hart 2007) 30

⁶⁸¹ J Vollmann, ‘Advance Directives in Psychiatry’ (n 132) 39

⁶⁸² M Foucault, *Security, Territory, Population* (n 6) 353; M Foucault, *The Government of Self and Others: Lectures at the Collège de France, 1982-1983* (Palgrave Macmillan 2010) 23; and see G Burchell, ‘Liberal Government and Techniques of the Self’ in A Barry, T Osborne and N S Rose (eds), *Foucault and Political Reason: Liberalism, Neo-Liberalism, and Rationalities of Government* (University of Chicago Press 1996) 29; M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 193; U Bröckling, S Krasmann and T Lemke, *Governmentality: Current Issues and Future Challenges* (Taylor & Francis 2010) 5

⁶⁸³ T Lemke, ‘“The Birth of Bio-Politics”: Michel Foucault’s Lecture at the Collège de France on Neo-Liberal Governmentality’ (2001) 30 *Economy and Society* 190, 201

⁶⁸⁴ N Rose and P Miller, ‘Political Power Beyond the State: Problematics of Government’ (n 675)

government and that the individualistic form of autonomy that is espoused by the courts owes much to the prevailing, advanced liberal, historical context of our times.

Chapters Six and Seven take the idea of the operation of governmentality through the technologies of the self and the technologies of government and apply those approaches to government to the operation of ADRTs. In this way it will be seen that we can view ADRT can be viewed through the kinds of practices they elicit and require in respect of the government of the self and the government of others.

*THE GOVERNMENTALISATION OF THE STATE*⁶⁸⁵

In order to have a sound appreciation of the prevailing rationalities of government, which approximate to forms of liberalism and neoliberalism (or ‘advanced liberalism’)⁶⁸⁶ in Western society, we must look at how these rationalities of government came to prevail (for they, as other political rationalities are historically situated). Through tracing the developments of rationalities of government in this way we can better understand the kinds of problems that the contemporary forms of government in the West have been created to work around. The central argument of this thesis is that the development of ADRTs can be viewed as a response to a problem of government at the end of life. This area has become problematic as the result of the combination of a number of factors: the medical technology that now enables life to be sustained in circumstances of low functionality (e.g. Persistent Vegetative States (“PVS”s) and Minimally Conscious States (“MCS”s)); the aging population; the financial crisis and the pressure it has placed on the provision of healthcare; *and* the development of an idea of autonomy that serves advanced liberal rationalities of government.

By adopting this focus it is hoped that it will be possible to avoid getting bogged down in debates concerning the ‘true’ meaning of autonomy⁶⁸⁷ and instead gain an understanding of the role that individual autonomy plays within the legal system and society. The concern is with how the idea of personal autonomy and by extension, the idea of ADRTs, has been used as part of the practices of government.

⁶⁸⁵ M Foucault, *Security, Territory, Population* (n 6) 109

⁶⁸⁶ see NS Rose, ‘Governing “Advanced” Liberal Democracies’ in A Barry, T Osborne and NS Rose (eds), *Foucault and political reason: liberalism, neo-liberalism, and rationalities of government* (University of Chicago Press 1996) 40-41; see P Miller and NS Rose, *Governing the Present: Administering Economic, Social and Personal Life* (Polity Press 2008) 18

⁶⁸⁷ see Part II

From this it will be seen that, far from regarding the establishment of ADRTs as a victory for the advocates of individual autonomy arising from a stronger ethical argument, we can see the triumph of individual autonomy as a result of its necessity to advanced liberal society.⁶⁸⁸ Moreover, it will be argued that this kind of bioethical rationality is itself bound up with the practices of the liberal state in supporting and reproducing liberal modes of government, defined as ‘conducting the conduct’ of the self and of others.⁶⁸⁹ As will be discussed, this liberal strategy of government implies the calculated direction of free subjects, capable of some resistance,⁶⁹⁰ rather than their domination. It is hoped that this critical methodology will offer an improved way of understanding the current state of the law.

The first part of this chapter will therefore examine at the development of early forms of government and some of the reasons for the development of a liberal art of government. This transition has been made possible by the rise of a new form of power in governmental practices themselves, which came to stand alongside, if not ahead of, sovereign power in import. The discussion will then move to focus on liberalism and neo-liberalism (or advanced liberalism as it is termed by Rose)⁶⁹¹ and the various techniques and technologies which have grown up around it, with a particular focus on the technologies that promote and aim to secure autonomy. This discussion should not be seen as a way of merely categorising different historical epochs together with their historical practices. The idea is rather that through looking at practices of government and their development, we can make visible some of the complex factors that combined to make an imperative of change: the ‘problematics of government’.⁶⁹² It will be argued that it is through considering these problematics and technologies of government within the (neo)liberal political rationalities that we can explain the progression in medical law from paternalism to the individualism⁶⁹³ that dominates modern medico-legal discourse and expresses itself most clearly in the legal

⁶⁸⁸ see T Lemke, “‘The Birth of Bio-Politics’” (n 683) 191

⁶⁸⁹ M Foucault, ‘The Subject and Power’ (n 7) 341; M Foucault, *Security, Territory, Population* (n 6) 193; C Gordon, ‘Governmental Rationality: An Introduction’ in Graham Burchell et al (eds), *The Foucault effect: studies in governmentality: with two lectures by and an interview with Michel Foucault* (University of Chicago Press 1991) 2

⁶⁹⁰ see M Foucault, ‘The Subject and Power’ (n 7) 341

⁶⁹¹ NS Rose, ‘Governing “Advanced” Liberal Democracies’ (n 686) 40-41

⁶⁹² N Rose and P Miller, ‘Political Power Beyond the State: Problematics of Government’ (n 675); NS Rose, ‘Government, Authority and Expertise in Advanced Liberalism’ (n 669) 285

⁶⁹³ C Foster and J Miola, ‘Who’s in Charge? The Relationship Between Medical Law, Medical Ethics, and Medical Morality?’ (2015) 23 *Medical Law Review* 505, 508 citing Lord Woolf: H Woolf ‘Are the Courts Excessively Deferential to the Medical Profession?’ (2001) 9 *Medical Law Review* 1; D Wilson, *The Making of British Bioethics* (n 9) 107-115

construction of the consent process and even more strongly when it comes to advance decision making.

EARLY FORMS OF GOVERNMENT

SOVEREIGNTY

Throughout the Middle Ages sovereignty could be understood as a form of transcendent and absolute power within the bounds of a territory.⁶⁹⁴ Sovereign power was of a deductive nature whose power was chiefly exercised through their commands assured by their ability to effect death as a penalty for disobedience:⁶⁹⁵ the power “to kill and let live”.⁶⁹⁶ This power was personally embodied by, and resided in, the autocratic figure of the sovereign.⁶⁹⁷ It was for the sovereign alone to decide on the exercise of the power of exile or death. However, this power was intimately linked to, and limited by, the extent of the sovereign territory as the sovereign could only exercise power within their realm. Hence great stock was placed on the expansion and securing of the realm as a means of increasing and consolidating power. As such sovereign, or ‘juridicial’, power⁶⁹⁸ operated through a direct relationship between the sovereign and their subject.⁶⁹⁹ As a form of power, it was a potent and direct means of giving effect to the sovereign will, by controlling individuals and maintaining a necessary link of authority between sovereign and subject. The will of the subject would always be bounded and shaped by the will of the sovereign and there would be little guarantee of how the sovereign might use their power. Similarly therefore, there would be little guarantee of the occasions on which the sovereign might override the subject’s own autonomy.

This, together with the appearance of a concentration of power such as this in one person as absolute sovereign, became problematic in the Sixteenth Century when questions of legitimacy began to arise⁷⁰⁰ together with many normative questions, such as: how to govern oneself, how to be governed and how to govern others.⁷⁰¹ There is an “immense, as well as monotonous literature”⁷⁰² on this subject through which Foucault offers a selective overview passing from the Machiavellian rationalities of government as a set of tactics for

⁶⁹⁴ M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 124

⁶⁹⁵ P Rabinow and N Rose, ‘Biopower Today’ (2006) 1 *BioSocieties* 195, 196

⁶⁹⁶ M Foucault, *Society Must be Defended* (Picador 2003) 241

⁶⁹⁷ *ibid* 34, 26

⁶⁹⁸ see *ibid* 34, 25; M Foucault ‘Governmentality’ in Graham Burchell, Colin Gordon, and Peter Miller (eds), *The Foucault Effect: Studies in Governmentality: With Two Lectures by and an Interview with Michel Foucault* (University of Chicago Press 1991) 95

⁶⁹⁹ M Foucault, *Security, Territory, Population* (n 6) 70

⁷⁰⁰ M Foucault, *Society Must be Defended* (n 696) 34, 26

⁷⁰¹ M Foucault, *Security, Territory, Population* (n 6) 89; M Foucault, ‘Governmentality’ (n 698) 126

⁷⁰² M Foucault, *Security, Territory, Population* (n 6) 89

enabling the prince to retain control of their kingdom, through to the anti-Machiavellian literature, which sought to distinguish government from being a mere tactics of self-preservation and towards an art.⁷⁰³

The immediate solution for keeping hold of such a potent power was to develop a way of legitimising sovereign power and domination⁷⁰⁴ through what Foucault terms the “theory of right”.⁷⁰⁵ This involved the establishment of certain limitations on the occasions upon which sovereign prerogatives could be properly exercised, such that they could not be seen as arbitrary deployments of force. For example, one of the most potent sovereign powers, the right to kill, could only be legitimately called upon in response to a direct threat to the sovereign themselves⁷⁰⁶ which ensured its object was therefore solely self-preservational.⁷⁰⁷ this remained true in later centuries even though there was a creeping of additional requisites and restrictions placed on the use of sovereign sanctions, particularly in that they should only be used to preserve the common good⁷⁰⁸, but in actual fact, this may have amounted to little more than an tautologous imperative to be obedient to the sovereign law.⁷⁰⁹

RAISON D’ÉTAT

A similar imperative towards self-preservation can be found in the abiding feature of Machiavelli’s advice to the prince: how to retain his hold on power. Machiavelli’s work was subject to a great deal of attention around the time of its publication and during a revival of it in the Nineteenth Century.⁷¹⁰ In response to Machiavelli’s treatise, thinkers began to explore what should be compromised in the art of government.⁷¹¹ François de la Mothe le Vayer was one such thinker who drew distinction between three layers of government that of the self (morality), the family (economy) and the state (politics).⁷¹² He asserted the existence of “an upward continuity”⁷¹³ of government, such that in order to be able to govern a family one first had to be able to govern oneself and before governing a state, a family and by implication oneself;⁷¹⁴ an idea later adopted and continued by Rousseau and Quesnay.⁷¹⁵

⁷⁰³ M Foucault, *Security, Territory, Population* (n 6) 92. However, NB some aspects of Foucault’s account of this historical development has been criticised see P-E Korvela, ‘Sources of Governmentality Two Notes on Foucault’s Lecture’ (2012) 25(4) *History of the Human Sciences* 73

⁷⁰⁴ M Foucault, *Society Must be Defended* (n 696) 26-27

⁷⁰⁵ *ibid* 26

⁷⁰⁶ M Foucault, *The History of Sexuality: The Will to Knowledge* (vol 1, Penguin Books 1998) 135

⁷⁰⁷ M Foucault, ‘Governmentality’ (n 698) 95

⁷⁰⁸ *ibid* 94

⁷⁰⁹ M Foucault, *Security, Territory, Population* (n 6) 98

⁷¹⁰ M Foucault, *Security, Territory, Population* (n 6) 90

⁷¹¹ *ibid* 92

⁷¹² *ibid* 93-94

⁷¹³ *ibid* 94

⁷¹⁴ *ibid* 94

This brought the question of government away from the individualised focus of Machiavelli's treatise and put conditions and measures on government outside of mere continuation.

However, one of the immediate developments of the government away from the focus on an autocratic prince as the leader of the state was in the re-focussing of attention on the state itself.⁷¹⁶ Self-preservationism at the level of state was the core part of *raison d'état* the doctrine by which the state sought to maximise itself through its own rationality.⁷¹⁷ This rationality of *raison d'état* gave rise to a need on the part of the state for knowledge about its own strength in the form of a "political arithmetic"⁷¹⁸ and it also meant the worth of individual citizens consisted only in their capacity to assist the state in consolidating or increasing its power.⁷¹⁹

POPULATION

One of the major indicators of the strength of the state was to be found in the health of its population. Prior to the Eighteenth Century, Foucault claims that this concern was essentially couched in negative terms and arose particularly at times of epidemics such as the plague in the Fourteenth and Fifteenth Centuries).⁷²⁰ However, Foucault describes the recording of birth and mortality in England from around the sixteenth century onwards as an early indication state concern with the population.⁷²¹ This concern with the population continued into later centuries when ensuring that the population was healthy (particularly with respect to members of the armed forces)⁷²² became aligned with the objective of strengthening the state.

As a result, the population became a problematic of government: something to which the state government needed to turn its attention if it was to secure state prosperity along the lines of *raison d'état*. The political rationality of the mercantilists was to maximise the population in order to maximise economic output⁷²³ and consequently new ways were

⁷¹⁵ *ibid* 95

⁷¹⁶ *ibid* 240

⁷¹⁷ M Foucault, 'The Political Technology of Individuals' in James D. Faubion (ed), *Power* (vol. 3 (Penguin Books 2002) 403, 405-410

⁷¹⁸ *ibid* 408

⁷¹⁹ *ibid* 409

⁷²⁰ D Lupton, *The Imperative of Health: Public Health and the Regulated Body* (Sage 1995) 20

⁷²¹ M Foucault, *Security, Territory, Population* (n 6) 67

⁷²² see T Osborne, 'Security and Vitality: Drains Liberalism and Power in the Nineteenth Century' in Andrew Barry, Thomas Osborne, and Nikolas S. Rose (eds) *Foucault and Political Reason: Liberalism, Neo-Liberalism, and Rationalities of Government* (University of Chicago Press 1996) 109

⁷²³ M Foucault, *Security, Territory, Population* (n 6) 337

sought to the increase of the population and the safeguard its wellbeing. During the Seventeenth and Eighteenth Centuries, this task fell to the “great technological assemblage” of the police.⁷²⁴ This ‘assemblage’ was developed in Germany following the treaty of Westphalia in which a disparate group of smaller states were united into a federation, with a new federal administration.⁷²⁵ This new administration developed a new disciplinary science, *Polizeiwissenschaft* (which was fostered by university system).⁷²⁶ At this time, the meaning of the word ‘police’ took on a meaning close to the English word, ‘policy’⁷²⁷ which entailed the establishment of techniques and agents of the state with an interest in “increasing the state’s forces... while preserving the state in good order”.⁷²⁸ It also entailed a duty on the part of patients to look after their own health.⁷²⁹

The remit of the police traversed the entirety of the functions of government, but was particularly influential in education and the generation of hierarchies and professions.⁷³⁰ Their generalized function was ensuring that the activity of individuals was aligned with the goal of increasing the state’s forces⁷³¹ and according to their theoretical outlook, the state would be strongest when it had the largest possible population which can be supported by the means that are necessary to support them in good health who can work efficiently, travel freely and trade effectively.⁷³² Thus, it was for the police to intervene to ensure each of these objectives; to ensure, what might be more broadly termed ‘wellbeing’ (and everything which gives rise to that state of being)⁷³³, and thereby could increase the state’s forces by having a healthy and contented populous. This at once linked “the state’s strength and individual felicity” which makes “men’s [sic] happiness the very strength of the state”.⁷³⁴

Healthcare provision was no longer an activity aimed primarily at individuals, because when the focus of government turned towards the population, the health of the body of the population came to be just as important.⁷³⁵ Moreover, the concern with the health of the population was not only to be considered in negative terms in the sense of reacting to

⁷²⁴ *ibid* 312

⁷²⁵ *ibid* 317-318

⁷²⁶ *ibid* 318

⁷²⁷ T Osborne, ‘Of Health and Statecraft’ in Robin Bunton and Alan Petersen (eds), *Foucault, Health and Medicine* (Routledge 1997)

⁷²⁸ M Foucault, *Security, Territory, Population* (n 6) 313

⁷²⁹ T Osborne T, ‘Of Health and Statecraft’ (n 727) 177

⁷³⁰ M Foucault, *Security, Territory, Population* (n 6) 321

⁷³¹ *ibid* 323

⁷³² *ibid* 323-326

⁷³³ *ibid* 328

⁷³⁴ *ibid* 327

⁷³⁵ M Foucault, ‘The Politics of Health in the Eighteenth Century’ in James D. Faubion (ed), *Power* (vol. 3, Penguin Books 2002) 94

outbreaks of ill health and at times of epidemic,⁷³⁶ but rather it was to become positive such that the concern was “how to raise the level of health of the social body as a whole”⁷³⁷ in order to improve productivity and utility in a broader sense. It was therefore not a solely reactive and restorative pursuit, but it was to incorporate strategies of prevention and surveillance. In an attempt to achieve this, special attention was paid to the family and the cultivation of obligations for them as in respect of the rearing of children in order to ensure the reliable resupply of the workforce with healthy, educated and self-disciplined individuals.⁷³⁸ Within the field of medicine, hygienists took on the role of disseminating public health messages and collecting populational medical data as a form of social control.⁷³⁹ Their work was particularly important in the new urban environments being created through the increasing population and changes in the modes of production.⁷⁴⁰ The surveillance of society, and the information derived from it, allowed for detailed categorisations to be made of the ill and those otherwise unfit to work.⁷⁴¹ The family also played a significant role in acting as a conduit between the public and individual health concerns,⁷⁴² as it could operate with a far more consistent presence than the clinic could.⁷⁴³

Importantly, the objective of the police in improving the conditions and wellbeing of the population was not motivated out of benevolence for the population, or to increase the personal power of the sovereign, but rather out of concern for the state itself. However, this objective shifted again in the Eighteenth Century, when a rapid expansion in the population gave rise to new problematics of government. At this time the physiocrats and economists began to view the population less as a ‘multiplicity’⁷⁴⁴ of individuals and more as a kind of natural phenomenon, incapable of direct control through sovereign orders or regulations,⁷⁴⁵ which constituted a body in itself. Rather, a series of techniques were developed to shape the conditions under which the population exists.⁷⁴⁶

Foucault accords great significance the recognition of the population at this point in Eighteenth Century, because its recognition prompted a change in the art of government

⁷³⁶ see also M Foucault, *Security, Territory, Population* (n 6) 67

⁷³⁷ M Foucault, ‘The Politics of Health in the Eighteenth Century’ (n 735) 94

⁷³⁸ *ibid* 96 see also M Foucault, *Discipline and punish* (n 673) 159-162

⁷³⁹ M Foucault, ‘The Politics of Health in the Eighteenth Century’ (n 735) 98-100

⁷⁴⁰ *ibid* 99

⁷⁴¹ *ibid* 94; see also D Lupton, *The Imperative of Health* (n 720) 26 - 30

⁷⁴² M Foucault, ‘The Politics of Health in the Eighteenth Century’ (n 735) 98

⁷⁴³ *ibid* 101-102

⁷⁴⁴ M Foucault, *Security, Territory, Population* (n 6) 129

⁷⁴⁵ *ibid* 69-71

⁷⁴⁶ *ibid* 72

based on outdated models of sovereignty and the family.⁷⁴⁷ Sovereignty alone was simply too inefficient a means of governing a political body undergoing “a demographic explosion and industrialization”⁷⁴⁸ and it was also too blunt and unwieldy to micromanage “the fine grain of individual behaviours”⁷⁴⁹ this could be achieved through using other forms of power and different technologies of government. Therefore in response, new and more expedient ways of governing and propagating power were sought.

The population took on a separate existence from its constituent “man-as-body” subjects, to become collectively embodied as “man-as-species”.⁷⁵⁰ This recognition co-emerged, in the latter part of the Eighteenth Century, with a form of power that Foucault termed biopolitics: “the science and technologies pertaining to the management of the population”.⁷⁵¹ In this new world, it became clear that “government is basically much more than sovereignty... [it is] absolutely linked to the population”⁷⁵² and to an extent the role of individual subordinated and instrumental towards the needs of the state in securitising the population.⁷⁵³

Thus the modern practices of governmental power which focus on the population, can be contrasted with the mode of governing exercised through the power of sovereignty alone.⁷⁵⁴ As discussed, sovereignty can be thought of as a deductive form of power⁷⁵⁵ which has its mode of operation in taking.⁷⁵⁶ By contrast, the new governmental rationalities have as their goal the fostering of the society that they govern, through *inter alia* increasing wealth, health and welfare.⁷⁵⁷ This governmentality aimed to promote a greater level of production and to “increase the happiness and prosperity of all [of society’s] inhabitants and to multiply their numbers”.⁷⁵⁸ Therefore these new governmental rationalities have a productive disposition⁷⁵⁹ and are concerned not so much with the extent of the sovereign territory and the expansion of the realm as with those that inhabited it.⁷⁶⁰ This move is explained by Foucault with the

⁷⁴⁷ *ibid* 103-108

⁷⁴⁸ M Foucault, *Society Must be Defended* (n 696) 249

⁷⁴⁹ M Foucault, *Security, Territory, Population* (n 6) 66

⁷⁵⁰ M Foucault, *Society Must be Defended* (n 696) 242

⁷⁵¹ Nadesan MH, *Governmentality, Biopower, and Everyday Life* (Routledge 2011) 21

⁷⁵² M Foucault, *Security, Territory, Population* (n 6) 8th Feb 1978, 106

⁷⁵³ *ibid* 42

⁷⁵⁴ A d Boever, "Agamben and Marx: Sovereignty, Governmentality, Economy." (2009) 20 *Law and Critique* 259, 260; see also M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 105, 123-126

⁷⁵⁵ M Foucault, *The History of Sexuality: The Will to Knowledge* (n 706) 136

⁷⁵⁶ M Foucault, *Society Must be Defended* (n 696) ch 2, 32-39

⁷⁵⁷ M Foucault, 'Governmentality' (n 698) 100

⁷⁵⁸ M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 125

⁷⁵⁹ *ibid* 254

⁷⁶⁰ M Foucault, *Society Must be Defended* (n 696) 36

assistance of the Christian shepherd metaphor, in which it is the security of the flock which is to be held above all else by the authority of the sovereign who pays attention to the flock as a whole as well as to each individual.⁷⁶¹ Adopting a simultaneous concern for the individual and the collective concern marks another point of distinction between sovereignty and the new rationalities of government. In addition, these different approaches to government have different claims to legitimacy. While sovereignty drew its authority from the assertion of a transcendent right to rule, often pronounced in western monarchies as a right bestowed on them by god,⁷⁶² the new rationalities of government are immanent to their objects.⁷⁶³ That is to say that the new rationalities of government are dependent upon their relationship to the population.

Pastoral power is similar to the power exercised through sovereignty in that ought to be put to use for the good of the society as a whole,⁷⁶⁴ but it differs from sovereignty because it is not bounded by territory, but rather the ‘multiplicity’⁷⁶⁵ and “[i]t is therefore a power with a purpose for those on whom it is exercised, and not a purpose for some kind of superior unit like... [a] sovereign”.⁷⁶⁶ The purpose of these forms of government therefore is of the protection of the population that it governs. It is important to note, however, that although new forms of governmentality became necessary in order to govern the population, these new practices of government did not expunge the old power of sovereignty as an active form of power.⁷⁶⁷ Rather it sovereignty was translocated it into a triangular array with discipline (which took on a new importance when it came to managing the population)⁷⁶⁸ and “governmental management”.⁷⁶⁹ Governmentality can thus be understood as the result of this need for change prompted by the recognition of the population as a body *per se* and the acknowledgement that the power of sovereignty alone was insufficient to guide and manage this complex body.

⁷⁶¹ S Prozorov, ‘The Unrequited Love of Power: Biopolitical Investment and the Refusal of Care’ [2007] Foucault Studies 53, 54

⁷⁶² see King James I, *Basilikon Doron or His Majesties Instrvctions To His Dearest Sonne, Henry the Prince* (Reprinted from the Edition of 1616, Harvard University Press 1918)

⁷⁶³ M Foucault, *Security, Territory, Population* (n 6) 125; M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 254

⁷⁶⁴ M Foucault, *Security, Territory, Population* (n 6) 128

⁷⁶⁵ *ibid* 129

⁷⁶⁶ *ibid* 129; but see Prozorov S, ‘The Unrequited Love of Power: Biopolitical Investment and the Refusal of Care’ [2007] Foucault Studies 53, 54

⁷⁶⁷ M Foucault, ‘Governmentality’ (n 698) 101-102; see J Přibáň, ‘Multiple Sovereignty: On Europe’s Self-Constitutionalization and Legal Self-Reference’ (2010) 23 Ratio Juris 41

⁷⁶⁸ M Foucault, *Security, Territory, Population* (n 6) 107

⁷⁶⁹ *ibid* 107

The recognition of the population led to the development of a whole host of techniques and processes designed for interaction with it. From the Sixteenth Century, statistics had gained increasing importance in managing the population.⁷⁷⁰ But one of the most ingenious diversifications of governmental practice that emerged at around this time was the ability to govern *through* autonomy.⁷⁷¹ This idea, which will be further discussed below, marks one of the central pillars of this new ‘liberal’ art of government.

LIBERAL FORMS OF GOVERNMENT

Colbert (a finance minister): “What can I do for you?”

Le Gendre (a merchant): “What can you do for us? Leave us alone (*Laissez-nous faire*)”⁷⁷²

THE CRITIQUE OF STATE INTERVENTIONISM

As discussed in the previous section, the move towards a liberal political rationality came about through the recognition of the population as a body in itself, the central object and as being immanent to the new governmental rationality.⁷⁷³ Some put this mode of government in direct opposition to the *Polizeistaat* that has just been considered,⁷⁷⁴ but perhaps the better view is to see it as part of a continuum particularly with respect to some of the disciplinary practices that were used Europe throughout many centuries.⁷⁷⁵ Through the challenges posed by the expanding population, there eventually came a recognition that the state and its reliance on sovereign power or totalising police power was inept to “undertake the infinite task of superintending the totality of the economic processes”⁷⁷⁶ taking place within its territory. Since the role of government is to maximise the population, this could only be achieved if government conducted itself in an efficient way. This theme of efficiency was taken up by the *économistes* who launched a strong criticism of the regulatory *Polizeistaat* model which had taken hold in a number of European countries in the Seventeenth and Eighteenth centuries.

The *économistes* claimed that the police disposition towards creating an abundance of cheap food so that workers could survive on low wages ignored the concerns of the

⁷⁷⁰ *ibid* 100-101

⁷⁷¹ N Rose and P Miller, ‘Political Power Beyond the State: Problematics of Government’ (n 675) 174

⁷⁷² cited in M Foucault, *The Birth of Biopolitics* (n 674) 20

⁷⁷³ See M Foucault, ‘Governmentality’ (n 698) 100

⁷⁷⁴ see NS Rose, ‘Government, Authority and Expertise in Advanced Liberalism’ (n 669) 289

⁷⁷⁵ A Hunt, ‘Governing the City: Liberalism and Early Modern Modes of Governance’ in Andrew Barry, Thomas Osborne and Nikolas S Rose (eds), *Foucault and political reason: liberalism, neo-liberalism, and rationalities of government* (University of Chicago Press 1996) 184

⁷⁷⁶ M Foucault, *The Birth of Biopolitics* (n 674) 281

agricultural producers who needed the possibility of making a profit so that they could reinvest in their land.⁷⁷⁷ The removal of police price controls on grain was also contended to impede the market from arriving at “just price”.⁷⁷⁸ Their concern was that it manipulated the market based price discovery mechanism. Placing arbitrary and extraneous regulation on the market was unnecessary, because the market would arrive at this price on its own. Moreover, forcing producers to sell produce, for which there was a low supply and high demand, at a lower price would encourage hoarding and ultimately would militate against the goal sought.⁷⁷⁹

The *économistes* further extended the principle of the market onto the population, in opposition to the thesis espoused by the police mentality, such that did not hold the maximization in the numbers of the population to be a good in itself, but rather that the material conditions necessary to sustain a population would generate a populous of optimum size.⁷⁸⁰ They further asserted that it should be for the market to determine trade with foreign markets in opposition to the mercantilist policy of trying to sell as much as possible abroad, in order to accumulate the maximum gold at home.⁷⁸¹

However, it was not only argued that the interventionist state was ineffectual in a pragmatic sense; strong normative arguments were also made to the effect that it was not right for the state to intervene in the affairs of private citizens.⁷⁸² These arguments can be traced back to the liberal turn during the Eighteenth Century, when increased pressure was put onto the state to withdraw from overseeing and providing of health services directly to allow different social organisations and charities to perform these functions.⁷⁸³

POLITICAL ECONOMY AND RAISON D'ÉTAT

The liberal rationality which sprang forth as a response to the problematisation of interventionism and comprehensive regulation sought the reduction in the influence of the state and the minimization of state intervention.⁷⁸⁴ Its chief point of emphasis is on the ‘natural processes’ in society, which are to be given the privileged status as being beyond the proper remit of government intervention. It maintains the *économistes*’ prohibition on the

⁷⁷⁷ M Foucault, *Security, Territory, Population* (n 6) 342-343

⁷⁷⁸ *ibid* 343

⁷⁷⁹ *ibid* 344

⁷⁸⁰ *ibid* 344-345

⁷⁸¹ *ibid* 344-346

⁷⁸² D Lupton, *The Imperative of Health* (n 720) 2

⁷⁸³ M Foucault, ‘The Politics of Health in the Eighteenth Century’ (n 735) 90, 92

⁷⁸⁴ See P Miller and NS Rose, *Governing the Present* (n 686) 77-82

interference with natural processes, relating to the population⁷⁸⁵ and it also disqualifies *raison d'état*, in the sense “in which a sovereign exercised his totalising will across a national space”,⁷⁸⁶ however their reasoning did admit a kind of *raison d'état* in which the goal was to increase the forces of the state.⁷⁸⁷ In a subtle but important departure from the reasoning of the mercantilists (who sought to maximise the population), the concern of the new liberal forms of government moved towards the maintenance and management of civil society, to promote scientific knowledge, administer a population of interests and to frame natural processes through securitisation and the injunction against transgressing onto the space of individual freedom⁷⁸⁸ all of which may run counter to the to the ability of the state to grow unrelentingly.⁷⁸⁹

NATURAL PROCESSES

One of the central justifications for limiting the power of government was in order to protect the so-called “natural processes”.⁷⁹⁰ These are processes, such as the birth rate, which cannot be controlled by sovereign command alone.⁷⁹¹ Foremost among these was the economy, as a natural process that is intimately bound up with liberal thought. The idea of economy has more than one sense. In a literal, sense, it describes the operation of productive, consumptive and trading activities in the market, but there is also a sense of the word, which is broadly analogous to ‘efficiency’ and it is this sense of the word which is active in the phrase “political economy”.⁷⁹² This idea described the liberal imperative for “cheap government”⁷⁹³ involving the “self-limitation of governmental reason”⁷⁹⁴ which acts as an internal limitation on the practices of government.⁷⁹⁵ Consequently the limitation on action is not based on economic science as an external factor, which dictates governmental intervention; rather economic science is a mere supplement to governmental reason.⁷⁹⁶

⁷⁸⁵ T Osborne T, ‘Of Health and Statecraft’ (n 727) 183

⁷⁸⁶ N Rose and P Miller, ‘Political Power Beyond the State: Problematics of Government’ (n 675) 179 crediting Graham Burchell

⁷⁸⁷ *ibid* 348

⁷⁸⁸ *ibid* 348-353

⁷⁸⁹ *ibid* 355

⁷⁹⁰ see *ibid* 45, 65-66, 352-353, 5th April lecture

⁷⁹¹ *ibid* 65

⁷⁹² see M Foucault, *The Birth of Biopolitics* (n 674) 13-20; M Foucault, *Security, Territory, Population* (n 6) 95

⁷⁹³ G Burchell, ‘Liberal Government and Techniques of the Self’ (n 682) 26

⁷⁹⁴ M Foucault, *The Birth of Biopolitics* (n 674) 13

⁷⁹⁵ *ibid* 14

⁷⁹⁶ *ibid* 286

The crucial facet of the “modern governmental reason”⁷⁹⁷ lies in a continual state of self-questioning and self-limitation.⁷⁹⁸ This norm of self-monitoring becomes just as important for the individual in liberal society as well as for political governments in a way reminiscent of de la Mothe le Vayer’s idea of ‘upward continuity’ and the need for one that holds themselves out as being a governor of others to first be able to govern themselves.⁷⁹⁹ One of the most important applications of self-monitoring for the purposes of this thesis is the self-monitoring of one’s own health (which will be explored in greater detail at a later point in the thesis).

In terms of the ‘market sense’ of the economy, there were competing views on how the sovereign could observe its processes: Quesnay and the physiocrats⁸⁰⁰ thought that the sovereign could divide up different economic processes into a table over which the sovereign could have knowledge and retain control, but Foucault read Adam Smith’s theory as a critique of this position suggesting that “the sovereign is, can, and must be ignorant”⁸⁰¹ such that the totality of economic processes are not capable of being known by the sovereign⁸⁰² or indeed by any individual within the market.⁸⁰³ Government, therefore, must address a “realm of processes” that it cannot govern through sovereignty alone, because the sovereign “lacks the requisite knowledge and capacities” to do so.⁸⁰⁴ This realisation heralded the end of the dream of the sovereign totalisation of *raison d’état* and *Polizei*. However, the possibility that more attention could be paid to the interests of subjects and that in turn, those interests could be governed in certain ways, meant that the reach of government could extend out even further than it could within the *Polizeistaats* of Seventeenth and Eighteenth Century Europe.

This powerful liberal idea of the futility of the quest for total knowledge about a population might also be seen as the first sign of the retreat of the totalising authority of moral authorities. If the interests of individuals within the population are, to an extent, unknowable, then perhaps so too are the moral principles on which they are to operate. This

⁷⁹⁷ *ibid* 10

⁷⁹⁸ NS Rose, ‘Government, Authority and Expertise in Advanced Liberalism’ (n 669) 292

⁷⁹⁹ see M Foucault, *Security, Territory, Population* (n 6) 94

⁸⁰⁰ M Foucault, *The Birth of Biopolitics* (n 674) 284

⁸⁰¹ *ibid* 281

⁸⁰² *ibid* 292

⁸⁰³ *ibid* 279

⁸⁰⁴ N Rose and P Miller, ‘Political Power Beyond the State: Problematics of Government’ (n 675) 179-180

moment might be seen as the origins of liberal secularism and the ‘value pluralism’⁸⁰⁵ which has it made possible.

Adding to this injunction against excessive state intervention, arising for the desire for an efficient market based system of governance and a normative disposition towards a small state that has been under consideration here, Rose identifies three further features inherent in liberal government: the use of knowledge as a form of authority, the fostering and instrumentalisation of expertise, and the cooption of individuals as agents directed towards their own government.⁸⁰⁶ These will be explored in turn beginning with the governmental imperative to know.

EPISTEMOLOGICAL AUTHORITY

From the previous discussion it can be understood that the place of an all-powerful sovereign stood in opposition to the liberal ideology of the *économistes* and their problematisation of the economy that was emerging around the middle of the Eighteenth Century.⁸⁰⁷ Foucault articulates their conclusion in an uncharacteristically pithy form, “[t]here is no sovereign in economics”.⁸⁰⁸ The *économistes* argued for a *laissez-faire* approach towards governance and economic regulation, which was thought to increase the overall wealth of the state through increasing economic prosperity.⁸⁰⁹ They saw government’s role as being in the fostering of a civil society and in order to do this effectively,⁸¹⁰ it was necessary to foster technologies that allowed the state to acquire knowledge about the processes that affected the population because “[t]he finitude of the state’s power to act is an immediate consequence of the limitation of its power to know”⁸¹¹ even though it was acknowledged that the state could not have a comprehensive knowledge in this regard. Hence a determined effort was made towards the gathering, collating and processing of information relevant to the population.

Much of this was achieved through the development of scientific practice, which became imperative for the sovereign and for the functions of good government and political rationalisation⁸¹² through the enlightenment. One particularly notable example of this is the

⁸⁰⁵ see J Coggon and J Miola, ‘Autonomy, Liberty and Medical Decision-Making’ (n 678)

⁸⁰⁶ NS Rose, ‘Government, Authority and Expertise in Advanced Liberalism’ (n 669) 290-292

⁸⁰⁷ M Foucault, *Security, Territory, Population* (n 6) 341-347

⁸⁰⁸ M Foucault, *The Birth of Biopolitics* (n 674) 283

⁸⁰⁹ G Burchell, ‘Liberal Government and Techniques of the Self’ (n 682) 19, 22

⁸¹⁰ see M Foucault, *Security, Territory, Population* (n 6) 356

⁸¹¹ C Gordon, ‘Governmental Rationality: An Introduction’ (n 689) 16

⁸¹² M Foucault, *Security, Territory, Population* (n 6) 315

science of statistics⁸¹³ whose importance had been recognised for centuries, but in which even greater governmental stock was placed from the beginning of the Seventeenth century.

However, on its own, this information (including statistical information) was mere data. It was only once the information had been analysed and interpreted that it could be put to use. Those who could develop and harness this kind of information in this way became experts; symbiotic coemergents of fields of knowledge; who could assist with the use of their knowledge for the effective securitisation of the population. Their accrued knowledge-power⁸¹⁴ and epistemic authority could in turn be drawn upon for the purposes of government.⁸¹⁵ Thus this expertise could be used to the benefit of government programmes by encouraging experts to develop their knowledge to address aspects of life that have been problematised by government (particularly those problems which related to the processes of the population). Disciplinary power became more important as a means of governing individuals as the population grew larger⁸¹⁶ and gave rise to techniques, technologies and experts who could help to govern the population through generating discourse and knowledge particularly in quantifiable terms.⁸¹⁷ Public health experts of various kinds were used to “make subjects more governable”.⁸¹⁸ Some of these techniques (particularly those pertaining to health and autonomy) will be discussed in the next chapter.

EXPERTISE

Expertise also played a vital role in the new governmental strategy of ‘governing at distance’,⁸¹⁹ which was a strategy strongly endorsed by Adam Smith’s metaphor of the invisible hand.⁸²⁰ This feature of liberal forms of government can again be contrasted with the very direct way in which the sovereign would exercise their power *vis-à-vis* their subjects. Distancing the site of the propagation of government power from its site of application was achieved because the ‘regimes of truth’⁸²¹ developed and communicated by these experts, (which, in turn, begat social norms) were not the direct product of the state.⁸²²

⁸¹³ *ibid* 274, 104; and see B Sokhi-Bulley, ‘Governing (Through) Rights: Statistics as Technologies of Governmentality’ (2011) 20 *Social & Legal Studies* 139

⁸¹⁴ M Foucault, *Discipline and punish* (n 673) 27

⁸¹⁵ NS Rose, ‘Governing “Advanced” Liberal Democracies’ (n 686) 45

⁸¹⁶ M Foucault, *Society Must be Defended* (n 696) 35-38

⁸¹⁷ NS Rose, ‘Governing “Advanced” Liberal Democracies’ (n 686) 44-45

⁸¹⁸ AR Petersen and D Lupton, *The New Public Health* (n 539) 15

⁸¹⁹ see P Miller and NS Rose, *Governing the Present* (n 686) 18; NS Rose, *Powers of Freedom: Reframing Political Thought* (Cambridge University Press 1999) 49 fn 78 for the etymology.

⁸²⁰ C Gordon, ‘Governmental Rationality: An Introduction’ (n 689) 15

⁸²¹ see M Foucault, ‘Truth and Power’ in Paul Rabinow (ed), *Power*, vol 3 (Penguin Books 2002) 131-133

⁸²² NS Rose, *Powers of Freedom* (n 819) 285

For example, in the Nineteenth Century expertise was used in the shaping of the family and through the incorporation of expert advice into the family itself the composition and behaviour of members of the family could be modified at a stage removed from the state itself.⁸²³ Therefore the link between experts and government was at least more opaque than the relationship between the state and those agents who served it directly (in the manner of the police). Adherence to a norm would not therefore be seen as an act of loyalty towards a sovereign, so much as an act of fidelity to society.

In terms of the consent process and medical decision-making, the doctor (and their public health counterpart, the hygienist) played important roles as experts who could forge a link between observable trends in the human body and extrapolate that knowledge in order to achieve a stronger understanding of the population in general. One side effect of this was that doctors became much better aware of how diseases were spread⁸²⁴ and the acknowledged cost of widespread disease and epidemic to society and to the economy. Large scale outbreaks of disease and epidemics, and the threat of them, made those with this kind of expertise very important.⁸²⁵

INDIVIDUAL LIBERTY AND AUTONOMY

“Power is exercised only over free subjects, and only insofar as they are
“free”.”⁸²⁶

Liberalism and its propensity to ‘govern at a distance’ further entailed a strong recognition of individual rights and freedoms. This protection of rights and the movement away from the centralised, totalising, power of the sovereign is routinely lauded as a move away from domination and towards freedom, but we should not automatically see this as the case,⁸²⁷ as it is entirely possible for forms of domination and ‘illiberality’ to continue in liberal forms of government.⁸²⁸ Equally it would be simplistic, even meaningless, to attempt to analyse the relative freedoms of those who lived under a sovereign in the Sixteenth or Seventeenth Centuries and those who lived under the liberal regimes of the late Eighteenth

⁸²³ NS Rose, *Governing the Soul* (n 673) 131

⁸²⁴ see D Lupton, *The Imperative of Health* (n 720) 21-24

⁸²⁵ NS Rose, *Governing the Soul* (n 673) 125

⁸²⁶ M Foucault, ‘The Subject and Power’ (n 7) 342

⁸²⁷ M Foucault, *Society Must be Defended* (n 696) 27

⁸²⁸ M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 156-163

and Nineteenth Centuries⁸²⁹ because freedom, for Foucault, is not an ahistorical constant concept, but rather one which is historically conditioned.⁸³⁰

A strong sense of the historically particular kind of freedom that emerged and was promoted during the period of classical liberalism can be obtained from the writings of John Stewart Mill, and in particular his exegesis of the harm principle (for which he is best known) from his canonical and influential work, ‘*On Liberty*’.⁸³¹ This work (which was referred to in Chapter Two) provides an explanation which is perfectly in keeping with this liberal rationality for the way that these natural rights were framed. The individual was to be accorded rights and liberties, the corollaries of which were state duties and injunctions from interference in so far as their acts or omissions did not cause harm to others. Importantly, Mill’s thesis is not contingent on a transcendental notion of values, but is deeply rooted in liberal pragmatism and a concern for the effects of actions rather than their inherent morality.

This sentiment is echoed by Adam Smith who advocated the recognition of individual rights through reference to the economic markets: “[e]very man, as long as he does not violate the laws of justice, must be able to pursue his interest and bring his capital where he pleases”.⁸³² The principle underlying the work of both Locke and Smith in this respect is that the state ought to limit the scope of its own legislative intervention in the lives of its citizens in a manner paradigmatic of liberal government. In so doing, the continued struggle with the question of the legitimacy of intervention must be weighed against encroachment on individual autonomy and other natural processes.⁸³³

The novelty in Smith’s reasoning came with its tacit recognition of *homo œconomicus* (the ‘subject of interest’) was that the sovereign had to refrain from interfering, not because there was a law prohibiting their interference, but because the sovereign was necessarily ignorant of the full extent of individual interests.⁸³⁴ In addition, these rights and liberties formed out of the injunctions on state intervention, were instrumental to the formation of a civil society, a key reference point of liberal government,⁸³⁵ and it is where civil society was brought together with the imperative for economic maximisation embodied in *homo*

⁸²⁹ M Foucault, *The Birth of Biopolitics* (n 674) 62

⁸³⁰ *ibid* 63; see also M Dean, ‘Governing the Unemployed Self in an Active Society’ (n 679) 562

⁸³¹ JS Mill, *On Liberty* (Project Gutenberg, 2011)

⁸³² *Wealth of Nations* cited in M Foucault, *The Birth of Biopolitics* (n 674) 281

⁸³³ NS Rose, ‘Governing “Advanced” Liberal Democracies’ (n 686) 47

⁸³⁴ M Foucault, *The Birth of Biopolitics* (n 674) 282-283

⁸³⁵ *ibid* 295

œconomicus that allows for a form of liberal government which sovereignty alone could not achieve.⁸³⁶

An important challenge for liberal government, however, was in how to direct the free choosing, autonomous subject behave in a manner that was in alignment with the overall objectives of particular government programmes.⁸³⁷ One way of achieving this was through the codes of civility that were developed by civil society, which helped to keep order at both a private and a public level.⁸³⁸ As rose claims, the practice of carving out freedom from the state “...goes hand in hand with the emergence of a range of novel practices which seek to shape and regulate individuality in particular ways”.⁸³⁹ some of these processes will be looked at in greater detail in chapter seven, however by way of example, hospitals, schools and prisons all set about ways to encourage the formation of the free individual who did not require the direct oversight of the state, but who could be relied upon to have such concern for their own state of being that they would actively seek their own betterment and maximisation.⁸⁴⁰

However, this classical liberal approach also came up against problems as a result of its stand-offish approach to regulation and business practice. It gave scant incentive for employers to offer their employees anything in the way of benefits, protection or other social assistance. Insofar as this led to social problems, which affected contentment and productivity and harmed the population in other ways, remedial strategies were sought. And the response to this problematic of ill health and joblessness was a greater level of state intervention in the form of welfarism.

WELFARISM

“The people of England appeared for the first time to acquire a sense of sight and smell and realise that they were living on a dungheap”⁸⁴¹

The perceived deficiencies of *laissez-faire* capitalism were problematised and led, in some places, to a new era of Welfarism.⁸⁴² The failure was diagnosed through the appearance of social problems that arose at the time which included crime, ill health and

⁸³⁶ M Foucault, *The Birth of Biopolitics* (n 674) 295-296. The work on the formation and administration of the subject of interest will be revisited in greater detail in the next chapter

⁸³⁷ NS Rose, *Powers of Freedom* (n 819) 50

⁸³⁸ *ibid* 69

⁸³⁹ NS Rose, ‘Governing “Advanced” Liberal Democracies’ (n 686) 45

⁸⁴⁰ *ibid*

⁸⁴¹ SE Finer “The Life and Times of Sir Edwin Chadwick” pp 211-212 quoted in M Bruce, *The Coming of the Welfare State* (4th edn, Batsford 1968) 63

⁸⁴² NS Rose, ‘Government, Authority and Expertise in Advanced Liberalism’ (n 669) 293

unemployment. These phenomena were all perceived as threats to the security of the population and society. In response, it was argued that the state should step in by finding new ways to bring collections of liberal individuals together and to endear a sense of collectivity between them to secure the population. And it was this process of the state (or at least the collective, or the social) stepping in, taking a greater level of responsibility for various aspects of social life including employment, health, housing etc and additionally administering social benefits that characterises Welfarism⁸⁴³ in very broad terms.

Orthodox wisdom suggests that the dawn of this rationality, in the UK at least, was announced by William Beveridge's 1942 report identified five great evils of society: squalor, ignorance, want, idleness and disease, which government should be disposed to guard against.⁸⁴⁴ In order to address these problems there were drives to improve housing conditions, to guarantee every citizen a basic level of education and right to healthcare services through the establishment of the NHS. However, it should be borne in mind that this welfarist approach was not a binary dialectical response to *laissez-faire* capitalism (Beveridge himself was of "liberal origins")⁸⁴⁵ but it was rather a limited form of intervention designed to help those most in need.⁸⁴⁶

Many of these technical projects of intervention may be thought of as constituent aspects of what is commonly called the "welfare state"; a phrase which Briggs claimed was coined in the UK in 1945.⁸⁴⁷ However, both the timing and location of its inception are much disputed.⁸⁴⁸ What might be said however, is that there was no single moment of collective demand for an end to the *laissez-faire* capitalism, which flourished under liberal government, and a new era of welfarism, but rather a gradual change punctuated with a series of problematisations centred on the population. Indeed, one of the strongest critics of this project, Hayek, saw the welfare state a threat to liberty that was more difficult to counter than it was the arguments of socialism, precisely because welfarism lacked a strong definition.⁸⁴⁹

⁸⁴³ P Miller and NS Rose, *Governing the Present* (n 686) 71-72

⁸⁴⁴ W Beveridge, *Social Insurance and Allied Services* (CMND 6404, 1942)

⁸⁴⁵ M Bruce, *The Coming of the Welfare State* (n 841) 307

⁸⁴⁶ *ibid* 307

⁸⁴⁷ D Wincott, 'Images of Welfare in Law and Society: The British Welfare State in Comparative Perspective' (2011) 38 *Journal of Law and Society* 343, 343

⁸⁴⁸ *ibid* 343-349 and see Veit-Wilson J, 'States of Welfare: A Conceptual Challenge' (2000) 34 *Social Policy & Administration* 1

⁸⁴⁹ *ibid* D Wincott, 'Images of Welfare in Law and Society' 366-367; *ibid* Veit-Wilson J, 'States of Welfare: A Conceptual Challenge'

Some view the roots of this idea of the welfare state in the interwar period around the time of the Wall Street Crash and the resulting Great Depression⁸⁵⁰ which prompted the establishment of regulatory mechanisms and bodies such as the Securities and Exchange Commission (SEC).⁸⁵¹ It also led to nations being forced into co-operation and to experiment with the adoption of Keynesian policies internationally in an attempt to revive the economy.⁸⁵² However, it has been argued that increased government spending is not the sole indicator of whether a nation is truly a 'welfare state'. According to Esping-Anderson this can be better measured by taking account of the extent to which "social rights" were increased labour power was "decommodified" and attempted to quantify this.⁸⁵³

In any case, one of the social rights most pertinent to this thesis which underwent a significant development at this time was the 'right to healthcare'.⁸⁵⁴ The goal of improving the health of the population was to be assured not with a return to a *medischinische Polizei*, but through collective insurance schemes, which meant that the risks associated with ill health could be spread across the population rather than being born by the individual and the family.⁸⁵⁵ Such schemes operated by encouraging or requiring payment into a collective scheme which would pay out according to the needs of any of its members. Insurance of this kind had a rectificatory effect on the risks and hardships of life which created the conditions for social problems.

However, these insurance schemes also prompted a greater need for knowledge and information concerning relationships and processes that one may have been considered private, such as eating habits or family relationships. This kind of information was needed so that the insurer could calculate the likelihood that workers would fall ill (or outside of the medical sphere that harvests would fail or workers would be laid off). Once those calculations are made, it is possible to work out the annualised cost of guarding against such events on a per member basis. Where the insurance scheme is run by the state of insurance in which the state itself adopts the role of insurer, it becomes directly in the government interest to reduce these risks.

This gave rise to a proliferation in state agencies whose aim it was to eliminate or at least mitigate the risks inherent in everyday life at this time was testament to the state's

⁸⁵⁰ M Bruce, *The Coming of the Welfare State* (n 841) ch 6

⁸⁵¹ MH Nadesan (n 751) 69-70

⁸⁵² *ibid* 69-72

⁸⁵³ D Wincott (n 847) 351

⁸⁵⁴ See T Osborne T, 'Of Health and Statecraft' (n 727) 179

⁸⁵⁵ NS Rose, 'Government, Authority and Expertise in Advanced Liberalism' (n 669) 293

adoption of responsibility for these risks and its putative interest in their reduction. Legislation from the Nineteenth Century had already introduced environmental and public health regulations which sought to protect the health of the population and its productive capacities.⁸⁵⁶ This was further extended during the Twentieth Century most notably with legislation in the UK to guarantee the provision of healthcare to all of its citizens regardless of their ability to pay through the establishment of the National Health Service (“NHS”). Environmental legislation also became more stringent with the accession of the UK to the European Union (“EU”) in 1975.

However, the point of the UK’s accession to membership of the EU coincided with the beginning of a broader decline in welfare state provisions and by the time Margaret Thatcher became Prime Minister, the so-called ‘Golden Age’ of the welfare state was at an end.⁸⁵⁷ The political rhetoric of the time asserted that the state had become too large, and that its citizens had become too dependent.⁸⁵⁸ Thatcher and her US counterpart Ronald Regan were the paragons of the next political rationality that came to dominate US and UK politics in response to a populous perceived as being too comfortable, neoliberalism. This thinking was influential in the development of the individual autonomy.⁸⁵⁹ The next section will provide a discussion on the meaning of neoliberalism and its significance in the development of our current conceptions of individual autonomy.

NEOLIBERALISM

“Government can give people the information, legislate and regulate to encourage sustainable living, help business to function in a more environmentally responsible way: work with other nations to develop the right international framework. But it can't 'do it' by itself. 'Doing it' will depend on the decisions and choices of millions of individuals and companies. Our task is to empower them to make the right ones.”⁸⁶⁰

Neoliberalism as a term is still all too frequently used to describe a particular kind of political rationality, but it should be remembered, particularly when we are using the term in the context of Foucault’s lectures on governmentality, that neoliberalism is not a

⁸⁵⁶ T Osborne, ‘Security and Vitality: Drains Liberalism and Power in the Nineteenth Century’ (n 722) 99

⁸⁵⁷ but c.f. D Wincott (n 847) 356

⁸⁵⁸ see G Burchell, ‘Liberal Government and Techniques of the Self’ (1993) 22 *Economy and Society* 267, 274

⁸⁵⁹ See D Wilson, *The Making of British Bioethics* (n 9) 120-129

⁸⁶⁰ ‘Tony Blair’s speech on healthy living’, July 26, 2006. Available at <http://www.guardian.co.uk/society/2006/jul/26/health.politics> [accessed 11/4/2012]

homogenous, ahistorical rationality, but rather that it can exist in different forms.⁸⁶¹ In general terms however, there was a resurgence in the ideas of classical liberalism from the 1970s onwards.⁸⁶²

Foucault identified this reemergence of liberalism in a new form following periods of increased state intervention in economic processes at different places and times (namely Freiburg following the demise of the Weimar republic and, in one instance, and the USA in the 1960s in the other), which were considered to have failed. Both kinds of intervention were born of a concern that this kind of government interference would lead to a growth in an expensive and rigid new state bureaucracy which would harm productivity and create ‘distortions’ which would necessitate yet more government involvement to rectify.⁸⁶³ However, differences emerged in respect of the correct response to these failures.

The German Ordoliberals considered that state intervention was warranted to the extent of fostering competitive mechanisms⁸⁶⁴ especially as regards facilitating the German “individual social security” in designed to encourage the individual to take more responsibility for themselves by making sure that they had made sufficient contributions to ensure that they would be insured against life’s dangers.⁸⁶⁵ Whereas the American brand of neoliberalism sought to attain the same goals through extending market principles beyond the areas in which it traditionally operated, with more limited state intervention, to generate competition in the same way.⁸⁶⁶ While these neoliberal movements did retain the core concerns of classical liberalism in maintaining the importance of the economy, both in terms of the capital market and in terms of limiting government activity.

Though there are clearly distinctions between the German approach, the US approach, the French approach (and perhaps between the British approach too) towards what might be broadly classed as neoliberalism,⁸⁶⁷ the reason they can all be considered as forms of neoliberalism is precisely because they share certain common features. Harvey describes the common ground as being centred on the idea that “human well-being can be best advanced by liberating individual entrepreneurial freedoms”,⁸⁶⁸ which compliments Foucault’s analysis. Governments employing a neoliberal strategy would seek to nurture the population

⁸⁶¹ M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 69

⁸⁶² P Miller and NS Rose, *Governing the Present* (n 686) 18

⁸⁶³ M Foucault, *The Birth of Biopolitics* (n 674) 323

⁸⁶⁴ *ibid* 145

⁸⁶⁵ *ibid* 144

⁸⁶⁶ *ibid* 323

⁸⁶⁷ See *ibid* 75-265

⁸⁶⁸ D Harvey, *A Brief History of Neoliberalism* (Oxford University Press 2005) 2

through the expansion of the role of markets. Where markets already exist, the government is forbidden from interfering with them (as was the case in classical liberalism) but where markets do not exist, they are to be created by the state.

As discussed, the liberal rationality of government which construed the market as a quasi-sacred natural occurrence can be contrasted with that of the pre-war German *Ordo-Liberalism* and the Chicago school who did not see the free market economy as a kind of natural phenomenon which the state should refrain from interfering with, but rather something which could only arise if the right conditions for its emergence were set.⁸⁶⁹ Under these rationalities the responsibility for setting the conditions of the market fell to government. One of the most significant requirements of a free market along with goods and means of exchange, is individuals who are free to go to the market and to interact with it. Thus, it became imperative for government to accord certain rights to individuals (the right to own property and the right to their own physical integrity) to subjectivise them as part of their creation of a functioning free market.

An example of the extension of market principles in healthcare can be seen in the creation of “star ratings”⁸⁷⁰ in hospitals in the England stands out as a cogent example of the expansion of market principles into areas that were traditionally not in operation. The problem which gave rise to this star ratings initiative was the variation in performance in hospitals as well as the need, along economic lines, to secure better value for the public money spent in hospitals. Previous governments had imposed targets upon the NHS in order that they should meet certain expectations (eg in respect of waiting times) however the current initiative based on star ratings⁸⁷¹ ensures that it is not the state that acts as the enforcer of standards, but rather the individual ‘health consumer’⁸⁷² (formerly known as the patient) acting in accordance with market principles.

This also means that the state shirks from providing substantive definitions of the good, in that it is for the patient to choose their own course of action and this leads to the prospect of the development of the good itself within the regulated freedom of the market. The absence of clear direction in respect of medical choices arguably creates a vacuum of ‘under-

⁸⁶⁹ G Burchell, ‘Liberal Government and Techniques of the Self’ (n 682) 22-24

⁸⁷⁰ see S Boyle, *Health Systems in Transition: UK (England) Health System Review* (European Observatory on Health Systems and Policies 2011) 364

⁸⁷¹ see *ibid* 37-38

⁸⁷² A Petersen, “Governmentality, Critical Scholarship, and the Medical Humanities” (2003) 24(3) *Journal of Medical Humanities* 187, 193; I Greener, ‘Towards a History of Choice in UK Health Policy’ (2009) 31 *Sociology of Health & Illness* 309, 320-322

determination' from which individual freedom is generated⁸⁷³ and enables a plurality of values to be drawn upon in society. Under advanced liberal regimes of government there is no single source of moral authority, but rather a constellation of expertise available to guide the consumer.

EXPERTISE UNDER NEO-LIBERALISM

The advanced liberal conception of expertise differs slightly from its liberal forebear, in that expert knowledge was not allowed to exist free from contestation. Rather expertise was to be subject to market forces, such that the regimes of truth⁸⁷⁴ developed and presided over by experts could be challenged if consumers did not buy in to their discourse, thus opening up a market in expertise itself. Techniques such as auditing aided this scrutiny of expertise.⁸⁷⁵

This marketisation was further prosecuted through subjecting experts to financial scrutiny through the 'grey sciences' of accounting practices, audits and enumeration.⁸⁷⁶ Thus, with the use of those techniques, expertise could become measurable in order that consumers could make choices about the worth of the knowledge derived from that expertise. These steps are imperative for the establishment of functioning markets in expertise and in healthcare that ensure patients can seek out the best doctors and the best healthcare facilities.⁸⁷⁷

Pressure could also be brought to bear upon expertise from capital interests in the form of lobby groups that suppress or aim to discredit information derived from scientific discourse, thus opening a market in expertise. However, political forces could also use expertise and scientific knowledge to their own ends, particularly in supporting government strategies. In this sense knowledge and expert authority entered the market and became commodified.

Expertise in respect of healthcare no longer resides with the doctor, nor even within a broader range of medical opinion. Techniques such as audit were developed and other methods accountability were produced which limit the control of the medical profession and increase patient choice.⁸⁷⁸ A whole range of specialists, coaches and gurus have emerged to

⁸⁷³ NS Rose, *Powers of Freedom* (n 819) 66 citing Zygmunt Bauman

⁸⁷⁴ M Foucault, 'Truth and Power' (n 821) 131-133; see also N Rose, *Inventing Our Selves: Psychology, Power, and Personhood* (Cambridge University Press 1998) 55-57

⁸⁷⁵ NS Rose, 'Government, Authority and Expertise in Advanced Liberalism' (n 669) 295-296

⁸⁷⁶ P Miller and NS Rose, *Governing the Present* (n 686) 212

⁸⁷⁷ see Chapter Six

⁸⁷⁸ D Wilson, *The Making of British Bioethics* (n 9) 121

produce different kinds of knowledge aimed to assist consumers in making choices. This kind of freedom of choice could be seen as empowering, but it can also create situations of unresolvable uncertainty. In particular, the problem of when to switch off the life support machine is a question that cannot be determined solely with reference to expert medical opinion.

INDIVIDUAL FREEDOM AND NEOLIBERAL ENTREPRENEURIALISM

The rights conferred on individuals included the promotion of individual freedom and simultaneously encouraged the exercise of that freedom in a particular way that is deemed responsible.⁸⁷⁹ This was in contrast to the welfarist government programmes in which it was the state that assumed responsibility for aspects of individual lives such as healthcare and social security. The public health movement began to change at around the same time as advanced liberalism began to take hold in the UK to focus on the effect of lifestyle choices on public health.⁸⁸⁰ This brought the seemingly mundane choices under the expert gaze and further offloaded the responsibility for wellbeing onto individuals and further introduced the concept of risk into lifestyle choices. The neoliberal calculation being that “choice-makers can be assumed to make rational decisions that accord with the aims of government, providing they are given ‘accurate’ information and the skills required to make choices... the role of government is to provide access to the necessary skills and information”⁸⁸¹ and therefore that people should be given the (qualified) freedom to enter the market and to actively pursue their own interests.

Before the individual enters the marketplaces established through government, they are to be actively subjectivised or ‘made up’, in Hacking’s terms, in order to be prudent, responsible and active in their own lives.⁸⁸² This involves a process of discipline and responsabilisation of the individual so that they adhere to the norms promoted in society.⁸⁸³

Health is one norm that has been promoted consistently for millennia, but in a neoliberal framework the individual must become a consumer of health. Citizens in neoliberal regimes of government are to take an active role in self-monitoring and the monitoring of possible

⁸⁷⁹ G Burchell, ‘Liberal Government and Techniques of the Self’ (n 682) 26

⁸⁸⁰ AR Petersen and D Lupton, *The New Public Health* (n 539) 15

⁸⁸¹ P O’Malley, ‘Consuming Risks: Harm Minimization and the Government of “Drug Users”’ in Russell Charles Smandych (ed), *Governable Places: Readings on Governmentality and Crime Control* (Ashgate 1999) 202

⁸⁸² I Hacking, ‘Making up People’ in Thomas C Heller (ed), *Reconstructing Individualism: Autonomy, Individuality, and the Self in Western Thought* (Stanford University Press 1986); T Lemke, “‘The Birth of Bio-Politics’” (n 683) 201

⁸⁸³ See NS Rose, *Powers of Freedom* (n 819) 76

treatments.⁸⁸⁴ In some cases this may go as far as to view their own bodies as commodities (e.g. Organ sales (although this is prohibited by law),⁸⁸⁵ sale of ova (which remains illegal in the UK subject to the possibility of reimbursement for expenses, but in it is legal some states in the USA),⁸⁸⁶ the employment of surrogate mothers). This represents a distinct change in expectation which calls for closer examination in the next chapter.

As well as the ways in which individuals *per se* were made up, there were also techniques for making up collective groups of individuals. Social enterprises were decentralized or destatised at this time (particularly in the UK through ‘quangoisation’)⁸⁸⁷ where certain groups and communities were given responsibility for themselves, but were also governed and brought into alignment with the political programmes through techniques such as targets and performance indicators etc.⁸⁸⁸ The state could dictate the objects of measurement and incentivise the expert actors to work towards certain objectives aligned with the objectives of government in its fostering of the population.

CONCLUSION

Although Foucault’s development of the theory of governmentality in his lecture series ‘*Security, Territory Population*’ centres on the way in which the government of the state changed and became more de-centralised and complex as a result of various factors, the most important theme underlying this discussion of that theory in this chapter has been the development of autonomy.

This part of the thesis presents the theory of governmentality as a critical approach that differs significantly from those approaches explored in the second part of this thesis. Governmentality, as we have seen, concerns the changes in the practices of government that took place over the centuries in response to various challenges and variations in material conditions, whereas moral philosophy is concerned with the elaboration and refinement of moral principles using philosophical argumentation. The theory of governmentality suggests that the development of autonomy cannot be explained as the result of the simple refinement and elaboration of posited moral principles. Rather personal autonomy emerges both as a *product* and as a necessary *component* of modern practices of government. Thus, the kind of autonomy that has come to be recognised in law and society is an eminently functional form

⁸⁸⁴ T Lemke, “‘The Birth of Bio-Politics’” (n 683)

⁸⁸⁵ Human Tissue Act ss 32, 41

⁸⁸⁶ Human Tissue Act s 32(7); see also DB Resnik, ‘Regulating the Market for Human Eggs’ (2001) 15 *Bioethics* 1, 2

⁸⁸⁷ P Miller and NS Rose, *Governing the Present* (n 686) 213

⁸⁸⁸ *ibid*

of autonomy that can be seen as the product of the limitations that state government has come to impose upon itself in recognition of its inevitable ignorance of the interests of individuals, but it can also be seen as a phenomenon that has aided the development of certain forms of government. The market can only function with the existence of active consumers, capable of assessing their own interests, following advice that best accords with those interests and taking responsibility for their own decisions.

The functional dependence on the kind of individual with these kinds of capacities means that those individuals who are incapable of making choices (paradigmatically through a lack of mental capacity) present a challenge to modern modes of government. This challenge is compounded by the emergence of medical technology that enables life to be sustained for long periods at the end of life and the lack of a clear and legitimate authority who can direct the continuation or the cessation of treatment in the absence of an autonomous decision from the individual receiving treatment. These challenges are made more pressing in the context of an aging population and a recent economic crisis that has resulted in pressure being put on the provision of healthcare services.

The central argument made in this work is that it is the combination of all these factors has resulted in a crisis of government, the response to which has been the institution of ADRTs. A case might be made for ADRTs being the logical extension of an underlying philosophical principle of autonomy, but this factor alone cannot explain the development of ADRTs in their current form. It is the crisis in government as a result of a number of factors that has led to the need to recognise ADRTs.

In the remainder of this part of the thesis some of the technologies and techniques that government can use in the pursuit of its objectives will be considered. The next chapter will consider the operation of ADRTs as part of the technologies of the self. In broad terms, this will involve an exploration of the way that ADRTs can be put to use for the generation of the kind of prudent, responsible and autonomous individuals that advanced liberal society requires in order to function.

CHAPTER SIX

ADRTS AS A TECHNOLOGY OF THE SELF

INTRODUCTION

The second part of this thesis was devoted to a discussion of the normative precursors of ADRTs. There it was suggested that the primary normative basis for extending the law to enable individuals to do this was to protect the right to personal autonomy. However, autonomy is a term capable of bearing a multitude of meanings and the law has not consistently favoured any particular definition. Consequently, the law may frequently face the charge of lacking sufficient adherence to the principle of autonomy, but the strength of this argument entirely depends upon the definition of autonomy used as a referent.

It is in this respect that we confront something of an evaluative bind; there is no 'true' notion of autonomy. Its interpretation within law and indeed by members of the bioethical and medico-legal community is read through and interpreted by reference to different ideological commitments, aspirations and contexts which shape its meaning and indeed, its critical reception. When translated as part of a project of the self, which I suggest has been a dominant approach in bioethical-legal thinking, the concept of autonomy as it arises within statute and in judgment invites a very particular critique. Although a specific definition of autonomy may not have been clearly articulated in law, many have suggested that the law has tended to respect a constellation of individualistic, narrow or 'thin' versions of autonomy. This tendency has been the source of much criticism. Some concern was expressed that with such an interpretation of autonomy individuals would too easily be able to make decisions by which they would be bound in future and that the law would not take into account changes in the personhood of the author of the ADRT over time. In the previous chapter it was argued that the particular conceptual direction that autonomy has taken must be viewed in the context of developments in governmental rationalities. The advanced liberalism which has emerged has meant that, aside from the establishment of markets, government has limited its interventions and the individual citizen has been charged with a

more active, consumerist role.⁸⁸⁹ In order to encourage individuals to adopt such a role, various programmes of government have sought to ‘empower’ individuals.⁸⁹⁰ ADRTs might be considered within such a project in that they purport to allow individuals to control their future treatment following a loss of capacity. However, while ADRTs do have the potential to offer an extension of autonomy in the ‘thin’ sense of empowerment in offering the right to make *pre-emptive* choices about future healthcare choice to patients, it is arguable that ADRTs fail to reliably facilitate the ultimate recognition of these choices in practice.

Significantly, this failure puts into question the true extent to which the putative liberal form of autonomy has empowered patients in practice.⁸⁹¹ In the first part of this chapter, then, critical consideration will be given to the extent to which ADRTs can truly provide people with a greater degree of control over their medical treatment at the end of their lives. The limitations of ADRTs will be highlighted through the examination of two prominent cases. No claim is made that these cases are representative of the law in this area, but these cases do helpfully illustrate some of the operational challenges of the creation and recognition of ADRTs. These cases concern individuals who express wishes to refuse treatment in the event of losing capacity, but in both the court failed to recognise a valid ADRT. On an orthodox bioethical analysis might conclude that the failure to recognise these wishes as ADRTs is demonstrative of a failure to accord sufficient respect to patient autonomy.⁸⁹² It might even be argued that the extent to which ADRTs permit individuals to exercise practical control over their end of life treatment, in a meaningful way, is greatly limited (which is not a novel position)⁸⁹³ and therefore that ADRTs are legal instruments without purpose, hollow, or perhaps ideological, instruments of advanced liberalism. That will not be the conclusion of this chapter. Rather, these cases will be drawn upon to exemplify how the law on ADRTs relies upon and facilitates certain practices of the self, which can be considered as part of the ‘technologies of the self’, which makes possible the formation of ‘ethical subjects’.⁸⁹⁴

⁸⁸⁹ See D Wilson, *The Making of British Bioethics* (n 9) 122; A Cronin, ‘Consumerism and “Compulsory Individuality”: Women, Will and Potential’ in Sara Ahmed (ed), *Transformations: thinking through feminism* (Routledge 2000) 279

⁸⁹⁰ K Veitch, ‘The Government of Health Care and the Politics of Patient Empowerment: New Labour and the NHS Reform Agenda in England’ (n 89)

⁸⁹¹ J Harrington, ‘Privileging the Medical Norm: Liberalism, Self-Determination and Refusal of Treatment’ (n 9) 358

⁸⁹² see eg A Mullock, ‘Best Interests and the Sanctity of Life after *W v M*’ (2013) 39 *Journal of Medical Ethics* 553

⁸⁹³ A Fagerlin and CE Schneider, ‘Enough. The Failure of the Living Will’ (2004) 34 *The Hastings Center Report* 30

⁸⁹⁴ M Foucault, *The History of Sexuality: The Use of Pleasure* (vol 2, Penguin Books 1998) 26-27

This mode of analysis shifts the focus away from the kinds of *results* that ADRTs are able to produce (i.e. whether or not they are respected by medical professionals and prevent treatment from being provided)⁸⁹⁵ and instead homes in on the *practices* that are instituted, required and fostered by ADRTs. Regardless of whether an ADRT is to succeed or not (in the sense of the outcome according with the stated wishes), the very creation of an ADRT demands certain practices on the part of the individual acting on themselves. Establishing a legal framework that provides for the possibility of creating ADRTs constitutes a strategy for governing others and represents an attempt to address what has been characterised in this thesis as a ‘crisis of government’⁸⁹⁶ at the end of life. In this sense ADRTs are not without purpose, however infrequently they may be upheld. Indeed, and to the contrary, the operation of ADRTs appears well aligned with the (advanced) liberal imperatives of active decision-making⁸⁹⁷ and self-authorship.⁸⁹⁸

TWO RECENT CASES ON ADVANCE DECISIONS

The cases of *W v M*⁸⁹⁹ and *Re E (Medical treatment: Anorexia) (Rev 1)*⁹⁰⁰ highlight some of the difficulties to be faced when creating an ADRT, which are resultantly recognised as legally binding refusals of treatment upon the loss of mental capacity. In both cases, the women who had expressed their wishes not to receive treatment in the future found that the courts were not prepared to accord their decisions binding force and instead permitted their medical teams to provide treatment deemed to be in their respective best interests.

These cases illustrate some deficiencies with the arguments that ADRTs are empowering and the more general claim that the idea of individual autonomy has become overly individualised. One of the first problems to be encountered by would-be advance decision makers is the problem of specificity. This is a problem that was introduced in Chapter One, but the case of *W v M* offers one of its starkest illustrations.

M, fell into a coma after a sudden and unexpected illness. She was later diagnosed as suffering from a disorder of consciousness known as a Vegetative State (“VS”).⁹⁰¹ However,

⁸⁹⁵ See eg A Fagerlin and CE Schneider (n 893); Foster C, *Choosing Life, Choosing Death* (1 edition, Hart Publishing 2009) 152-161

⁸⁹⁶ M Foucault, *The Birth of Biopolitics* (n 674)

⁸⁹⁷ See NS Rose, *The Politics of Life Itself* (n 362) 63; P Miller and NS Rose, *Governing the Present* (n 686) 49

⁸⁹⁸ A Cronin, ‘Consumerism and “Compulsory Individuality”: Women, Will and Potential’ (n 889) 276-279

⁸⁹⁹ [2011] EWHC 2443 (Fam)

⁹⁰⁰ [2012] EWHC 1639 (COP)

⁹⁰¹ See Parliamentary Office of Science and Technology, *Vegetative and Minimally Conscious States* (PN 489, 2015) 2

when later reassessed by a different consultant neurologist, she was given a new diagnosis of being in a Minimally Conscious State (“MCS”). The diagnosis of VS can only be made after six months and a diagnosis of MCS requires 3-5 years.⁹⁰² MCS was a newly defined neurological condition (only recognised by specialists in 2002)⁹⁰³, which describes those whose brain activity reaches slightly greater level than that which is attained by PVS patients. Crucially, patients who are diagnosed as being in a MCS are able to respond to stimuli on some occasions, as was M.

Nonetheless M’s family applied for a court order for the cessation of life support, grounded in the belief that M would not have wished to have been kept alive in such a state. This belief was supported by the fact that in 2003 M had stated that she would not wish to be kept alive with clinically-assisted artificial nutrition and hydration (“CANH”) if she ever found herself in a state of existence analogous with that Anthony Bland or persistent vegetative state (“PVS”) or a state similar to that in which some of her family members had found themselves.⁹⁰⁴

It will be remembered from Chapter One that ADRTs must be composed in such a way as to specify the kind of treatment to be refused and the kind of circumstances in which that treatment is to be refused.⁹⁰⁵ In order to meet this requirement it might be thought that the author ought to provide a high degree of specification in order that there could be no doubt over when treatment should not be provided following the loss of capacity. Perversely however, drafting ADRTs with a high degree of specificity risks reducing the kind of treatment to which the ADRT may apply, because if a very detailed specification of treatment or circumstances has been provided a person interpreting the ADRT might take this to mean that the author of the ADRT would not have wanted it to apply in similar, but not identical, circumstances to those that obtain. This could result in the provision of treatment of a similar kind or in a similar set of circumstances to those in which the author wished to refuse. Much therefore rests upon the way ADRTs are interpreted in practice.

However, in M’s case, the application for the cessation of treatment was refused on the grounds that firstly there was no “formal” advance decision to refuse treatment (the meaning of which is unclear), which was applicable to her state of health at the date of the hearing. M had failed to specify that her refusal of treatment should apply in the event that she should

⁹⁰² Royal College of Physicians *Advance Care Planning* (n 15) 22-23

⁹⁰³ Royal College of Physicians, *Prolonged Disorders of Consciousness: National Clinical Guidelines (RCP 2015)* 6

⁹⁰⁴ *W v M* (n 11)

⁹⁰⁵ *ibid*

fall into an MCS. However, in order to have done this, M would have required ‘almost clairvoyant’⁹⁰⁶ powers, because the MCS diagnosis was not widely known or employed at the time she made her wishes known about her future care. The denial of M’s purported ADRT meant that the medical team were entitled to provide treatment in M’s best interests. It was further held in court that continued CANH was in M’s best interests as M continued to experience some positive experiences. And although her prior-stated wishes were taken into account as part of the ‘balance sheet’ approach to the assessment of her best interests under s.4 MCA, as she had not anticipated falling in to an MCS specifically, the scales tipped in favour of continuing with life support and CANH.

A complicating factor in M’s case was that although her case was reported in 2011, she had made the relevant statements about her future treatment wishes prior to the publication of the MCA 2005 and its coming into force in 2007 and had suffered the disorder of consciousness (PVS/MCS) which caused the loss of her mental capacity before this date too. Parliament had made provision for such an eventuality through a Transitional Order which made clear that those who had expressed their wishes to refuse future treatment prior to 1st October 2007 and who had lost capacity prior to that date would not be bound by the formality requirements of the MCA.⁹⁰⁷ Thus, in these circumstances any claim as to the existence of an advance decision should be judged in accordance with the common law as it stood prior to the MCA.⁹⁰⁸ However, the Transitional Order also stipulates that in such circumstances purported ADRTs must be made in writing.⁹⁰⁹ And although the *pre*-MCA common law did set out some principles for the recognition of advance decisions to refuse treatment, there was never a requirement that the decision should be made in writing. On this basis it appears that the Transitional Order demands adherence to formalities imposed in retrospect. If so, it is arguable that this requirement is incompatible with Art 7 ECHR which prohibits retroactive legislation.

Today, anyone who wishes to create an ADRT must comply with the formalities of sections 24-26 MCA. As discussed in chapter one, these stipulate that advance decisions to refuse life-saving treatment must be made in writing, as well as being signed and witnessed. The MCA further requires that the provisions must be applicable to the circumstances that emerge before they can have binding force (a fact well illustrated by *W v M*).⁹¹⁰ Another

⁹⁰⁶ R Huxtable, ‘Treating the Minimally Conscious Patient: Life Before Choice?’ (n 289)

⁹⁰⁷ The Mental Capacity Act 2005 (Transitional and Consequential Provisions) Order 2007, s5(2)

⁹⁰⁸ *ibid* s5

⁹⁰⁹ *ibid* s 5(3)

⁹¹⁰ See also *W Healthcare NHS Trust v KH* (n 70)

requisite is that anyone who wishes to create an ADRT must be over 18 years of age and must have the capacity to make the decision.⁹¹¹

A further potential pitfall for would-be creators of ADRTs can be found in the requirements on capacity and its assessment in the MCA and the way in which these requirements have been interpreted. The MCA enshrines a number of principles relating to mental capacity and its assessment. The most pertinent of these principles for would-be creators of advance decisions are the legal principle that everyone is presumed to have capacity unless the contrary is proven⁹¹²; that capacity is to be assessed in accordance with particular decisions being taken at the particular time it is being taken⁹¹³ (and should not be assumed to be lacking without assessment⁹¹⁴); and that a person with capacity should be free to withdraw their consent at any point in future while they retain capacity. The latter point is implied by section 25(3), which states that an advance decision only takes effect where the person in question lacks capacity to make the decision and by section 24(3) which states that the advance decision can be varied or withdrawn until the point at which capacity is lost.

The operation of capacity as a requisite for the creation of advance decisions is well illustrated in the case of *Re E (Medical treatment: Anorexia) (Rev 1)*.⁹¹⁵ The central question to arise was whether the advance decisions that E had made to refuse medical treatment (especially being given artificial nutrition) were valid. At the date of the application it was agreed that E lacked capacity to refuse nutrition and therefore E could be treated in accordance with her best interests in spite of her protests unless she had a valid advance decision refusing any such treatment. Ultimately both of E's purported ADRTs were found to lack validity for want of capacity at the time of their creation.

As discussed in Chapter One, the MCA test for mental capacity asks whether the assessed person has “an impairment or disturbance in the functioning of the mind or brain”⁹¹⁶ and if so, whether that person is able to understand, retain, and ‘weigh information in the balance’ to make a decision, as well as whether they can communicate their decision.⁹¹⁷ If a person cannot pass one of these tests, then they lack capacity for the decision. Thus the test does not depend on evidence of a mental disorder, nor can such

⁹¹¹ MCA, s 24(1)

⁹¹² MCA, s 1(2)

⁹¹³ MCA, s 2(1) This provision does not fall under the heading of “The Principles” in the Act, but it is a principle nonetheless. The same applies to the provision *infra*.

⁹¹⁴ MCA, s 2(3)

⁹¹⁵ [2012] EWHC 1639 (COP)

⁹¹⁶ MCA, s 2

⁹¹⁷ MCA s 1

evidence *per se* found a conclusion that capacity is lacking.⁹¹⁸ That being said, it is entirely possible that mental disorders may produce effects which preclude decision-making capacity and to that extent the background is of some relevance.

E was 32 by the time of the local authority's emergency application to court and had been suffering from eating disorders for around 20 years. There was a strong suggestion that this problem had been triggered by a number of years of sexual abuse as a child which also led to alcoholism and as a result of being entered onto a palliative care pathway in hospital she had become dependent on diamorphine too.⁹¹⁹ E had been admitted to hospital on numerous occasions because of her eating disorders, but owing to the financial pressures on the hospital trust there was no long term place for E in hospital or in residential accommodation. This meant that the care she received between 2010 and 2012 was primarily in her own flat and its insufficiency was marked by the "revolving door" series of emergency admissions for medical and psychiatric care⁹²⁰ she experienced during this time.

E made two attempts at creating advance decisions to refuse resuscitation and artificial feeding. One in July 2011 and the other in October 2011. E had been assessed as having capacity in a general sense the day prior to writing the July decision by a doctor, but no formal assessment had been completed.⁹²¹ The latter of these was made "using a standard form" with the help of "her mother and mental capacity advocate"⁹²² as well as E's solicitor and was witnessed by a mental health professional. In October the "general medical view" was that E had capacity, but yet again, there had been no formal capacity assessment. The lack of formal capacity assessments, coupled with E's ongoing medical and mental health problems gave Mr Justice Peter Jackson enough cause to doubt that on either occasion, E had sufficient capacity to make that decision.

There are, of course, many critical observations that could be made about the assessment of mental capacity in English law⁹²³ (at both theoretical and practical levels), but when thinking about advance decisions it is notable that we are doubly reliant on the test for capacity, because it is the sole means of determining the moment at which an advance decision becomes binding and, as E's case illustrates, it is determinative of whether an advance decision is valid at its very inception. E went to great lengths to make her

⁹¹⁸ *Heart of England NHS Foundation Trust v JB* [2014] EWHC 342 (COP)

⁹¹⁹ *Re E* (n 10) [91] (Peter Jackson J)

⁹²⁰ *Re E* (n 10) [17] (Peter Jackson J)

⁹²¹ *ibid* [56] (Peter Jackson J)

⁹²² *ibid* [20] (Peter Jackson J)

⁹²³ see e.g. M Donnelly, 'Capacity assessment under the Mental Capacity Act 2005: Delivering on the functional approach?' (n 145)

opposition CANH clear and seemed to take all reasonable steps in attempting to conform to the legal requirements of the MCA. In spite of both this, and the fact that E had not failed a contemporary assessment of capacity, her purported ADRTs were not recognised as such. Moreover, it was decided that CANH coupled with a complete care programme was in her best interests on balance even considering her consistent and strong opposition to it.

If it is possible to take the kinds of steps that E took and still end up with an ineffectual ADRT, it must be asked whether ADRTs really do fulfil their apparent promise of empowerment and extending autonomy. This concern is highly pertinent to the discussion in the second part of this thesis, given that the inclusion of provisions on ADRTs in the MCA were made on the understanding that they would extend individual self-determination and autonomy.⁹²⁴

However, such an analysis leads us back to the problematic nature of the definitions of autonomy and self-determination. The second part of this thesis provided evidence of a great deal of disagreement over the definition of these concepts in philosophical and bioethical circles, as well as a considerable level of ambiguity over the definitions of autonomy and self-determination that are relied upon in this area of law. Therefore, an analysis that suggests that ADRTs provide inadequate recognition of personal autonomy is eminently contestable on fundamental, definitional grounds. And while it may be useful to highlight inconsistencies in the approach of the law,⁹²⁵ with this approach the normative question remains as to which conception of autonomy should be selected.

This part of the thesis adopts a different kind of analysis based on a conception of ADRTs as a governmental response to a crisis in end of life treatment. This analytical strategy is based on Foucault's work on governmentality as detailed in the previous chapter and particularly an assessment of whether ADRTs can be seen as a kind of technology of the self.

The previous chapter explained how advanced liberal rationalities of government have been shaped by historical factors, but in the next section a brief overview will be provided of the operational aspects of modern governmentality. Particular focus will be given to the idea of the practices of government operating through the technologies of government and the technologies of the self. As the focus of this chapter is on how ADRTs operate as part of the technologies of the self and given the importance of the idea of autonomy to ADRTs, the

⁹²⁴ *W v M* (n 11) [226] (Baker J)

⁹²⁵ see e.g. J Coggon, 'Varied and Principled Understandings of Autonomy in English Law' (n 419)

goal will be to explain how a liberal version of autonomy expects and facilitates certain practices of the self.

GOVERNMENTALITY

As discussed in the previous chapter, Foucault's lectures in the *Collège de France* developed an idea that he defined with the 'ugly word', 'governmentality'.⁹²⁶ Unfortunately Foucault did not bestow this term with a consistent meaning.⁹²⁷ But we can take an understanding of modern forms of governmentality as the product of various problematisations of government which arose at various points in history. These problematisations ultimately led to the emergence of a liberal art of government during the Eighteenth Century, which was characterised by a commitment to self-limitation through the idea of 'political economy'. This advent of liberal governmentality arrived at time when the population was in the process of rapid expansion and came to be recognised as a body in itself, rather simply a multiplicity of individuals. The importance of the population was such that it became the primary referent of government, or as it is sometimes put, a body that was 'immanent to government'.⁹²⁸

During this time, the practices of government were transformed. The traditional conception of an activity predominated by the sovereign will, backed up by the right to "kill and let live",⁹²⁹ inherent to the transcendent sovereign right to office, and morphed into an art with diverse and decentralised sites of propagation. This art of government operated through practices of normation and normalisation⁹³⁰ rather than commanded imperatives⁹³¹ and was geared towards the securitisation of the population as a new and discrete body immanent to government.⁹³² As such, the modern powers of government which emerged from the process of governmentality remained purposeful,⁹³³ but their purpose resided not in the preservation of the leader (as with Machiavellianism)⁹³⁴ or the state (as with *raison d'état*)⁹³⁵ but rather with the population. This change, described as 'the governmentalisation

⁹²⁶ M Foucault, *Security, Territory, Population* (n 6) 115

⁹²⁷ T Lemke, *Foucault, Governmentality, and Critique* (n 12) 88

⁹²⁸ M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 254

⁹²⁹ M Foucault, *Society Must be Defended* (n 696) 241; see also M Foucault, *The History of Sexuality: The Will to Knowledge* (n 706) 138

⁹³⁰ M Foucault, *Security, Territory, Population* (n 6) 55-63

⁹³¹ *ibid* 25th January 1978, 107

⁹³² M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 254

⁹³³ NS Rose, *Powers of Freedom* (n 819) 20; 52; M Dean, 'Powers of Life and Death Beyond Governmentality' (2002) 6 *Cultural Values* 119, 58

⁹³⁴ M Foucault, *Security, Territory, Population* (n 6) 65

⁹³⁵ *ibid* 237-248

of the state⁹³⁶ resulted in sovereignty becoming merely one form of power among others, incident to the processes of government.⁹³⁷

Thus, government is not to be equated with the idea of *state government*, but is a far broader phenomenon pertaining simply to the “conduct of conducts”.⁹³⁸ Foucault employs the word government in a sense which is not restricted to decisions made by officials or other arms of the state,⁹³⁹ but instead is concerned with the processes by which conduct is conducted⁹⁴⁰ or ways to ‘structure possible fields of action’.⁹⁴¹ It is also certainly not to be construed as an act of domination, oppression or as ‘antithetical’ to freedom⁹⁴² a fact which should be apparent from Foucault’s particular way of conceiving of power.⁹⁴³ Indeed, Foucault sees the practices of good government as being contingent upon a certain kind of freedom.⁹⁴⁴ This means that government is something that can emanate from others directing individual conduct, but it can also involve the individual governing themselves.⁹⁴⁵ This is the process by which individuals constitute themselves as ethical subjects.⁹⁴⁶ The development of responsible individuals with the powers of self-scrutiny and self-government acquired through the technologies of the self are essential to the functioning of liberal government.⁹⁴⁷

Foucault described modern forms of governmentality as operating at the intersection of the ‘technologies of the self’ and the ‘technologies of government’.⁹⁴⁸ This conceptualisation of governmentality can be applied to the law on ADRTs in order to demonstrate how ADRTs accord with, and support, modern practices of government. To this end the next part of this chapter will provide an explanation of the meaning of the term technology in this context and will then proceed to focus on the technologies of government and how ADRTs facilitate and require certain practices of the self.

⁹³⁶ *ibid* 108-109

⁹³⁷ M Foucault, ‘Truth and Power’ (n 821) 122

⁹³⁸ M Foucault, ‘The Subject and Power’ (n 7) 341

⁹³⁹ N Rose and P Miller, ‘Political Power Beyond the State: Problematics of Government’ (n 675)

⁹⁴⁰ C Gordon, ‘Governmental Rationality: An Introduction’ (n 689) 2

⁹⁴¹ M Foucault, ‘The Subject and Power’ (n 7) 341

⁹⁴² NS Rose, *Governing the Soul* (n 673) 69

⁹⁴³ see eg M Foucault, ‘The Ethics of Concern for the Self as a Practice of Freedom’ in Paul Rabinow (ed), *Ethics: subjectivity and truth* (Penguin Books 2000)

⁹⁴⁴ M Foucault, *Security, Territory, Population* (n 6) 353; M Foucault, ‘The Subject and Power’ (n 7) 342

⁹⁴⁵ See M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 19-21

⁹⁴⁶ M Foucault, *The History of Sexuality: The Use of Pleasure* (n 894) 26-27

⁹⁴⁷ NS Rose, *Powers of Freedom* (n 819) 68

⁹⁴⁸ M Foucault and M Blasius, ‘About the Beginning of the Hermeneutics of the Self: Two Lectures at Dartmouth’ (1993) 21 *Political Theory* 198, 203

TECHNOLOGIES

Modern governmentality can be said to operate through the interplay between the technologies of the self and the technologies of government⁹⁴⁹ (also referred to as the ‘technologies domination’). Technologies, in this sense of the word, are “for the shaping of conduct in the hope of producing certain desired effects and averting certain undesired events”⁹⁵⁰ through the “regular application of... knowledge... to the pragmatic problems of the exercise of authority”.⁹⁵¹ Consequently, technologies can become part of the *technēs* (i.e. practical knowledge, or ‘practical reason’⁹⁵²) of government when they involve using “systematized knowledge” to address the “pragmatic problems of the exercise of authority”.⁹⁵³

As such technologies have an instrumental value in the practical assistance they are able to render government for the advancement of governmental programmes. That is not to say that technologies are to be viewed solely as instrumental devices; they are also “assemblage[s] of different techniques of government, technical objects, actors, financial and other resources and ‘sociotechnical’ forces”.⁹⁵⁴ Thus, technologies help forge new and productive relationships between all of those components and actors which therefore result in much more than the attainment of a specified goal.

The conceptualisation of technologies as networks draws on the work of Bruno Latour who studied the effects of power as resulting from the interaction between different actors⁹⁵⁵ and the role of technical objects, “inscription devices” and “forms of architecture” in regulating conduct.⁹⁵⁶ The particular importance of the concept of a network is that it can demonstrate how non-human technical objects can modify human behaviour and thus can rebuff the “neo-Kantian” “ontological separation”⁹⁵⁷ between the human and the technological. In other words, the technological domain becomes visible as a result of the interplays and reflexive modulations between technical means and human interactions (both personal and interpersonal), which has the ultimate result of affecting conduct (e.g. the

⁹⁴⁹ *ibid* 203

⁹⁵⁰ NS Rose, *Powers of Freedom* (n 819) 52

⁹⁵¹ M Dean, ‘Putting the Technological into Government’ (1996) 9 *History of the Human Sciences* 47, 59

⁹⁵² see M Foucault, ‘Technologies of the Self’ in Paul Rabinow (ed) *Ethics: subjectivity and truth* (Penguin Books 2000) 225

⁹⁵³ M Dean ‘Putting the Technological into Government’ (n 951) 59

⁹⁵⁴ *ibid*

⁹⁵⁵ *ibid*

⁹⁵⁶ *ibid*

⁹⁵⁷ *ibid*

mechanical and organisational processes which *inter alia* combined to make Taylorism possible).⁹⁵⁸

Technologies thus pertain to complex interactions between programmes, persons and machinery and are not to be simply construed as direct mappings of commands and programmes of government onto reality.⁹⁵⁹ Instead, they seek to “structure the field of possible actions”⁹⁶⁰ and thereby exert control, but not direct determination, through delimitation. The technologies of government comprise of the practical techniques through which government is mapped onto and shapes the real⁹⁶¹ together with the assemblages of connections of agencies and persons that make this possible. Taking the technologies of government as an example, it is plain that they do not offer governing powers perfect, or precise, control in attaining their objectives within the practices and conduct of those they govern; their operation and effect is far messier, “more Heath Robinson than Audi”⁹⁶² with multiple sites of propagation and relational influence. Hence technologies really can make no bolder causative claim than to affect the mere tendency to influence decision making and conduct.⁹⁶³ This is particularly true of the technologies used in modern, liberal, styles of government and their affinity for self-limitation⁹⁶⁴ through ‘political economy’⁹⁶⁵ and ‘action at a distance’⁹⁶⁶ rather than direct and overt intervention.

These ideas can be readily related to the law on ADRTs. It will be remembered from the previous chapter that it was argued that the emergence of ADRTs can be considered a product of an emerging ‘crisis of government’⁹⁶⁷ as much as a rationalisation of autonomy as their supposed underlying norm. As such, introducing a framework for the creation of ADRTs appears as a *technical* attempt to address the crisis i.e. an intervention aimed at producing a certain practical outcome. This is because ADRTs promise to provide a practical means of addressing the problem of individuals who are at end of life and lack the mental capacity to decide whether to continue treatment. They operate on the basis of voluntary consent and there is no direct requirement for citizens to create ADRTs at all. Thus the aspiration of ADRTs is accords closely to the precepts and injunctions of

⁹⁵⁸ see NS Rose, *Powers of Freedom* (n 819) 52-53

⁹⁵⁹ M Dean ‘Putting the Technological into Government’ (n 951)

⁹⁶⁰ *ibid* 61

⁹⁶¹ M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 42

⁹⁶² NS Rose, ‘Government, Authority and Expertise in Advanced Liberalism’ (n 669) 287

⁹⁶³ N Rose and P Miller, ‘Political Power Beyond the State: Problematics of Government’ (n 675) 183

⁹⁶⁴ NS Rose, ‘Governing “Advanced” Liberal Democracies’ (n 686) 47

⁹⁶⁵ M Foucault, *The Birth of Biopolitics* (n 674) 13-20

⁹⁶⁶ Bruno Latour cited in P Miller and N Rose, ‘Governing Economic Life’ (1990) 19 *Economy and Society* 1, 2

⁹⁶⁷ M Foucault, *The Birth of Biopolitics* (n 674) 68-69

liberalism. They provide the medical team with the requisite cover of legitimisation that they require. Moreover, as ADRTs are accessible to those the strategy of governing through ADRTs can be seen as part of a (neo)liberal⁹⁶⁸ approach towards government in instituting certain conditions under which it is possible for the responsible, entrepreneurial citizen⁹⁶⁹ to make provision for themselves, to develop and take care of their own preferences.

This can be seen in the way that it has created a framework within which ADRTs can be made, specifying when such decisions take effect (i.e. only following the loss of mental capacity in respect of the specific decision) and what such decisions may consist in (i.e. only the refusal of treatment), but importantly making this a mere possibility rather than a requirement for citizens. Simultaneously ADRTs establish the conditions that actualise health concerns in the minds of citizens in such a way that they are more likely to understand that they have a responsibility for both their current and future health.⁹⁷⁰

Furthermore, the assemblage-like nature of ADRTs can be appreciated through considering the interaction of people and institutions who may become involved in the formation of the ADRT. The nature of these assemblages will vary, but it is likely that the author of the ADRT would first need to be informed of their legal right to make an advance decision. The most likely source of this information would be a member of the medical profession that the person might come into contact with such as their general practitioner (“GP”). Naturally there will be some discretion and variation regarding when, how and indeed whether patients are informed of this right by their GPs, but the policy for GPs to make this information available (primarily to certain patient groups) is formulated the medical regulatory bodies which derive their authority from the state. In addition, the kinds of published guidance on the formation of a legally binding ADRT and template forms (inscription devices)⁹⁷¹ might be considered technical means for the completion of ADRTs. It is possible to view all of these elements as part of an assemblage of ADRTs.

In the case of *Re E*, the idea of creating an ADRT was said to have been the product of E’s own research, but her research was prompted by her regular contact with psychiatric services and the attendant threat of compulsory treatment and force-feeding. In addition, E had a medical background and sought assistance in an attempt to make her wishes take a legally binding form in an ADRT. Contact with IMCAs, or legal representatives, is another possible route to the creation of ADRTs. aside from situations such as e’s, the consultation

⁹⁶⁸ or “advanced liberal”

⁹⁶⁹ M Foucault, *The Birth of Biopolitics* (n 674) 226

⁹⁷⁰ see AR Petersen and D Lupton, *The New Public Health* (n 539) 51

⁹⁷¹ M Dean ‘Putting the Technological into Government’ (n 951) 56

with solicitors in contemplation of making a will might be a more common opportunity to be told of the right to make an ADRT. As part of the will drafting service, attention may be drawn to the possibility of creating an ADRT (perhaps in addition to giving advice on creating lasting powers of attorney).⁹⁷²

The third most likely way in which a person might be informed of their right to make such a decision is indirectly, through media articles or through friends or family who may have had learned of this right. social networks are also likely to be important for the creators of ADRTs who may wish to discuss the creation of the decision (and the reasoning behind it), perhaps for reassurance, advice, or simply to inform another person of the decision so that they might be able to draw the medical team's attention to the existence of an ADRT in the right circumstances. This is similar to what happened in *W v M* where M's mind was directed to the question of her future treatment upon learning of the plight of Anthony Bland.

CONTRASTING TECHNOLOGIES

The technological assemblages discussed thus far have been based on the formation of groups that are external to the individual themselves and, in terms of an analysis grounded in governmentality, are concerned with the ways in which they come to shape the conduct of individuals. Foucault makes the distinction between these kinds of technologies and those which are employed by the self to be exercised upon the self, namely the 'technologies of the self'. This thesis argues that the operation of the law on ADRTs involves both practices of self-government and practices of the government of others. In this chapter the focus is on the government of the self and in the following chapter greater attention will be given as to how ADRTs can function in relation to the government of others.

Although both the technologies of the self and the technologies of government are both aimed at the regulation and direction of conduct, they can be distinguished by the fact that the practices of government involve the way in which government attempts to regulate the body of the population, whereas the 'practices of the self' concern the ways in which people

⁹⁷² See <http://www.lawsociety.org.uk/advice/practice-notes/lasting-powers-attorney/#lpa123> [section 12] [accessed 16/8/2013]

are enjoined to regulate their own bodies and conduct⁹⁷³ and to speak ‘the truth’ about themselves.⁹⁷⁴

The techniques (*technēs*), or practices, used in these self-oriented technologies of the self can be put to work to by “individuals in order to determine their identity, maintain it, or transform it in terms of a certain number of ends”.⁹⁷⁵ In that respect, the kinds of practices which are fostered by ADRTs *qua* technologies of the self can also be channelled towards certain ends, such as self-responsibilisation especially concerning healthcare.

THE TECHNOLOGIES OF THE SELF

In simple terms, the technologies of the self are groupings of techniques, which can be used by the individual to “affect their body, thoughts and behaviors (sic)”.⁹⁷⁶ Dean uses the term ‘self-directed’ technologies and ‘other regarding’ technologies to emphasise the fact that these are techniques which are applied by the self and to the self.⁹⁷⁷ Thus, an analysis of the operation of ADRTs, as part of the technologies of the self, demands an examination of those techniques that the individual practices upon themselves which are elicited through the creation of ADRTs. In other words, ‘how to ADRTs facilitate self-directed techniques’?

For analytical purposes, aspects of the technologies of the self can be broken down into four fundamental facets, which Dean rearticulates as: “the governed ethical substance”, the “governing or ethical work”, the “governable subject” and the “telos of governmental or ethical practices”.⁹⁷⁸ Examining these components in further detail in respect ADRTs will aid the illustration of the distinction between the practices of the self and the practices of government. The aim is to explain how this particular kind of advance decision-making can be regarded as a technology of the self.⁹⁷⁹

⁹⁷³ M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 20

⁹⁷⁴ M Foucault, ‘Technologies of the Self’ (n 952); N Rose, *Inventing Our Selves* (n 874) 29; M Foucault, *The Courage of Truth: (The Government of Self and Others II), Lectures at the Collège de France 1983–1984* (Palgrave Macmillan 2011) 2-3

⁹⁷⁵ M Foucault, ‘Subjectivity and Truth’ in Paul Rabinow (ed) *Ethics: subjectivity and truth* (Penguin Books 2000) 87

⁹⁷⁶ A Macmillan, ‘Michel Foucault’s Techniques of the Self and the Christian Politics of Obedience’ (2011) 28 *Theory, Culture & Society* 3, 7

⁹⁷⁷ M Dean, ‘Governing the Unemployed Self in an Active Society’ (n 679) 563

⁹⁷⁸ M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 26-27; see M Foucault, *The History of Sexuality: The Use of Pleasure* (n 894) 32

⁹⁷⁹ Along the same lines as M Dean, ‘Governing the Unemployed Self in an Active Society’ (n 679)

WHAT IS TO BE GOVERNED?

The first characteristic of the technologies of the self is that they must specify the aspect of the self which is to be governed (e.g. the soul, or the flesh).⁹⁸⁰ For example, in his work on the *History of Sexuality*, Foucault argues that Christianity aimed to govern the flesh through an examination of the development of ethical practices around the ‘pleasures of the flesh’.⁹⁸¹ In respect of his work on prisons, the subject of government was the very soul of the prisoner who was to be governed.⁹⁸²

At first sight, ADRTs appear to straightforwardly pertain to the existence of the ‘future self’ (the way in which the body of the future self is to be treated and indeed the conditions under which its existence may be ended). Therefore it might be concluded that the ‘future self’ is the substance which is to be affected, or acted upon, by the (present) self.⁹⁸³ However, further consideration of what is entailed by the formation of ADRTs through the present-day individual making decisions on behalf of their future-self, the ethical substance being governed might be better regarded as the ‘existential disposition’ of the individual (not simply the future state of existence itself). The creation of an ADRT is to indicate the value its creator places on certain states of existence.

Both E and M had clearly contemplated the possibility of entering into a state of existence that they would have found unacceptable and on that basis made statements about their continued existence in those states. Both E and M specified states of existence under which they would wish to refuse life-saving or life-sustaining treatment. Arriving at a decision to refuse medical treatment in future will necessarily involve some engagement with profound philosophical questions concerning the value of existence in conceivable circumstances. Such exercises pertain to the question of how the existential disposition is to be governed.

HOW SHOULD THE OBJECT OF GOVERNMENT BE GOVERNED?

Having identified the ethical substance to be governed as the *existential disposition* of the subject, the question then arises as to *how* this is to be governed. This question invites consideration of the technical means through which the individual can govern their existential disposition.

⁹⁸⁰ M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 26

⁹⁸¹ M Foucault, *The History of Sexuality: The Use of Pleasure* (n 894) 14-93

⁹⁸² M Dean, ‘Governing the Unemployed Self in an Active Society’ (n 679) 565

⁹⁸³ See Chapter Four

The good functioning of modern day health promotion rests on individuals playing an active role in their own treatment.⁹⁸⁴ In order to garner the cooperation of people to “invite or incite [people] to recognise their moral obligations”,⁹⁸⁵ policy makers have made efforts to encourage individuals to make choices which align with their values and goals. Consequently, those who do not take good care of themselves and who fail to exercise their responsibility in accordance with the advice of experts may be subject to social stigmatisation,⁹⁸⁶ in some cases, failure to take responsibility for one’s health can even result in the denial of healthcare services.⁹⁸⁷ Hence, individuals find themselves under a duty to safeguard their own health and, given the way that health is defined as an optimal state, to be health-aware and to take active steps in educating and informing themselves about their own medico-existential condition.⁹⁸⁸

A long-running and potent method of inciting individuals to acknowledge and regulate their own behaviour was the inculcation of moral principles into everyday life through religious discourse. Foucault argues that the central moral imperative of Ancient Greece “take care of yourself” (“*epimeleislhai sautou*”)⁹⁸⁹ had been forgotten (or at least underplayed) in the Twentieth Century, whereas the other related maxim of the Delphics, “know yourself” (“*gnōthi seauton*”⁹⁹⁰) has been held in constant high regard since the enlightenment. This is due, in part, to the influence of Christian moral values and their persisting echoes in the contemporary world. In particular, the need to renounce oneself in order to achieve salvation appeared to preclude ‘taking care of oneself’.⁹⁹¹ In the ancient world the ‘care of the self’ was acknowledged as having an instrumental value in being not merely a self-directed practice, as it emanated from the will to govern others, because in

⁹⁸⁴ R Bunton, ‘Popular Health and Advanced Liberalism’ in Robin Bunton and Alan Petersen (eds), *Foucault, Health and Medicine* (Routledge 1997) 228-229; AR Petersen and D Lupton, *The New Public Health* (n 539) 48

⁹⁸⁵ M Foucault, ‘On the Genealogy of Ethics’ in Paul Rabinow (ed), *Ethics: subjectivity and truth* (Penguin Books 2000) 264

⁹⁸⁶ see D Lupton, *The Imperative of Health* (n 720) 10-11

⁹⁸⁷ NS Rose, ‘Genomic Susceptibility as an Emergent Form of Life? Genetic Testing, Identity and the Remit of Medicine’ in Regula Valérie Burri and Joseph Dumit (eds), *Biomedicine as culture: instrumental practices, technoscientific knowledge, and new modes of life* (Routledge 2007) 148

⁹⁸⁸ see P Rabinow and N Rose, ‘Biopower Today’ (n 695) 197

⁹⁸⁹ See also M Foucault, *The History of Sexuality: The Care of the Self* (vol 3, Penguin Books 1990) 45-50

⁹⁹⁰ M Foucault, ‘Technologies of the Self’ (n 952) 226

⁹⁹¹ *ibid* 211

order to be able to govern others effectively one first had to become aware of how to govern oneself.⁹⁹²

The Christian influence on the practices of the self was linked to the goal of self-knowledge and involved self-renunciation, which was considered a necessary means towards the salvation of the soul.⁹⁹³ However, the changes that took place in the Eighteenth Century brought with them a move away from these Christian techniques, which concerned renunciation of the self and towards techniques that focused on *cultivation*. This ‘cultivation of the self’ was achieved through the technologies of the self and, in particular, the ways that people are enjoined to form themselves through self-writing and verbalisation.⁹⁹⁴

“By the Hellenistic age, though, writing prevailed, and real dialectic passed to correspondence. Taking care of oneself became linked to constant writing activity.”⁹⁹⁵

“One of the tasks that defines the care of the self is that of taking-notes on oneself to be reread, writing treatises and letters to friends to help them, and keeping notebooks in order to reactivate for oneself the truths one needed.”⁹⁹⁶

The practice of writing for oneself, whether in correspondence, or in notes which are not shared with others has a long history.⁹⁹⁷ The modern ways in which people can engage in self-writing and self-narrative discourse are manifold. This can be seen as a response to the “crisis of subjectivation” where the need to find a way to allow the subject to submit to themselves so that they can follow rules which would give their lives meaning.⁹⁹⁸ Foucault examined the patterns of self-writing that took place in ancient Greece and Rome, which included writing about oneself in correspondences with others. Letter writing of this kind may have subsided, but the spirit of the activity has shown a great resurgence with those who use social media. For example, the once burgeoning, now positively ballooning popularity Facebook (which had “21 million users” in 2008⁹⁹⁹ and “an audience of over 606

⁹⁹² M Foucault, *The Hermeneutics of the Subject: Lectures at the College de France 1981-1982* (Picador USA, 2005) 36-39, 51-52; M Foucault, *The History of Sexuality: The Care of the Self* (vol 3, Penguin Books 1990) 344

⁹⁹³ M Foucault, ‘Technologies of the Self’ (n 952) 242-245

⁹⁹⁴ *ibid* 249

⁹⁹⁵ *ibid* 232

⁹⁹⁶ *ibid*

⁹⁹⁷ M Foucault, ‘On the Genealogy of Ethics’ (n 985) 277

⁹⁹⁸ M Foucault, *The History of Sexuality: The Care of the Self* (vol 3, Penguin Books 1990) 95

⁹⁹⁹ Buffardi LE and Campbell WK, ‘Narcissism and Social Networking Web Sites’ (2008) 34 *Personality and Social Psychology Bulletin* 1303, 1303

million” in 2011¹⁰⁰⁰ and in October 2012 the number of users reached one billion¹⁰⁰¹), affords its users the ability to create their own interactive timeline and to share with ‘friends’. Through all these seemingly trivial acts of self-expression it is possible to build up a persona and to thereby engage in a process of continual entrepreneurial self-renewal.

ADRTs can be seen as a more formal and solemn opportunity for individuals to self-author in such a way as to constitute themselves as subjects. Any person who specifies the circumstances under which they would not wish to continue living necessarily makes a profound statement about the value they ascribe to their own existence. As the formation of an ADRT is a voluntary undertaking it will involve its creator engaging in various thought processes. They must contemplate different possible future states of existence and must evaluate those against their own individual system of values. This was evident in both E and M’s cases where both had considered the possibility of a certain state of existence and had rejected it. Following this, they must commit their decision to writing because, as discussed in chapter one, any person who wishes to make a decision to refuse life-saving treatment must acknowledge this in writing.¹⁰⁰²

This demand for written documentation acts as an imperative towards both an inscription and transcription, or subjectivation, of the self. It enjoins individuals to adopt an entrepreneurial approach towards their own healthcare and to consider confronting ‘ethical’ questions in practical, medico-legal terms, through the objectification of the future self as an external entity to be governed.¹⁰⁰³ This is a practice the E engaged in, but M did not (although it is questionable whether the law required writing at the time M expressed her wishes).

The act of writing an ADRT, in addition to being an exercise of self-elected self-expression, involves entering into a medico-legal discourse and consequently submitting its limits and structure. The expression must meet certain criteria and must acknowledge the risk of death. As the purpose of an ADRT is to refuse treatment and therefore the author must envision the circumstances under which they would wish for that to happen (and must educate themselves as to when the law says their decision can take effect). They must also confront their own mortality in this exercise and in this respect a parallel might be drawn

¹⁰⁰⁰ Ryan T and Xenos S, ‘Who Uses Facebook? An Investigation into the Relationship between the Big Five, Shyness, Narcissism, Loneliness, and Facebook Usage’ (2011) 27 *Computers in Human Behavior* 1658, 1658

¹⁰⁰¹ <http://www.guardian.co.uk/business/feedarticle/10468914> [accessed 16/10/2012]

¹⁰⁰² MCA, ss 25(5)-(6)

¹⁰⁰³ M Foucault, *Discipline and punish* (n 673) 170

with the practice of *praemeditatio futurum malorum*,¹⁰⁰⁴ in which an individual engages in a meditative thought exercise concerning their own future misfortunes in order that they might to prepare themselves for the worst to happen.

This kind of contemplation ‘seals off’ future possibilities and fixes on one kind of eventuality, which in the case of ADRTs is that capacity will be lost and in circumstances where the medical team may wish to continue treatment.¹⁰⁰⁵ Related to this is the *meletē thanatou*¹⁰⁰⁶ as it requires the author to ‘actualise’ their death and to think closely about when they would want to be allowed to die.¹⁰⁰⁷ ADRTs can only be created following an engagement with these processes and through such engagement; a more responsabilised subject can be formed. The contemplation of one’s own mortality and making decisions about what kind of treatment one would wish to receive at the end of life indicates not just a concern for the so-called ‘future self’, but a concern for the present self.

CREATING GOVERNABLE SUBJECTS “MODE D’ASSUJETTISSEMENT”¹⁰⁰⁸

“To live as an autonomous individual is to have learned these knowledgeable techniques for understanding and practising upon yourself. Hence the norm of autonomy produces an intense and continuous self-scrutiny, self-dissatisfaction and self evaluation in terms of the vocabularies and explanations of expertise.”¹⁰⁰⁹

The third element of the technologies of the self is that they must specify the kind of governable subjects that are to be produced by the practices of the self. A functioning and relevant system of ADRTs requires people who are concerned for their own health to have an appreciation of the risks to their future health, especially the potential infirmities they will encounter in old age, and people who can have a sense of what kind of circumstances of life they would be prepared to tolerate (i.e. people with a considered ‘existential disposition’). Health is paradigmatic as one such normative end which is strongly linked to the practices of the self and is increasingly defined, as well as promoted, by experts.¹⁰¹⁰ The World Health Organisation allows this concept of health to bear a very broad contemporary definition as: “a state of complete physical, mental and social well-being and *not merely the absence of*

¹⁰⁰⁴ M Foucault, *The Hermeneutics of the Subject* (n 992) 468-473

¹⁰⁰⁵ *ibid* 470-471

¹⁰⁰⁶ *ibid* 477-480

¹⁰⁰⁷ *ibid* 479

¹⁰⁰⁸ see M Foucault, ‘On the Genealogy of Ethics’ (n 985) 266

¹⁰⁰⁹ NS Rose, *Powers of Freedom* (n 819) 93

¹⁰¹⁰ D Lupton, *The Imperative of Health* (n 720) 77

disease or infirmity”.¹⁰¹¹ This definition highlights the nature of health as an *optimal* state, which therefore gives weight to the notion that health is to be thought of as a continual project of surveillance, precaution and work, rather than as a static outcome.¹⁰¹²

This definition also entails a responsibility to be vigilant and guard against what Rose calls ‘protodiseases’¹⁰¹³ i.e. those lifestyle factors and choices inimical to the optimisation of health. Health-messages are frequently propagated by a wide range of medical and non-medical institutions, and experts who promote “the primacy of health”.¹⁰¹⁴ Often these messages come in the form of a highlighting of the risk of future ill health, which increases the purview of medicine from the actual to the potential.¹⁰¹⁵ ADRTs are plainly concerned with bringing forward concern for future health (and indeed future states of existence) to the present.

Individual autonomy plays a critical role in the establishment of responsibility of this kind. As a value that has come to constitute a fundamental pillar of modern modes of government, it has been explicitly, albeit imprecisely, incorporated, protected and defended in law as a right for patients.¹⁰¹⁶ At the same time, it has become a value which patients are functionally *expected* to embrace.¹⁰¹⁷ The corollary of this valorisation of ‘choice-making autonomy’ is that the onus of decision-making responsibility is transferred from the state and the clinical team onto the individual.¹⁰¹⁸ Thus, the pursuit of good health has become normalised as an individual responsibility¹⁰¹⁹ and has been increasingly recognised as such.¹⁰²⁰

Individuals must understand that they can take *active* control of their future through the creation of an ADRT and do not need to adopt a passive-responsive stance towards their

¹⁰¹¹ Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948. Available at <http://www.who.int/about/definition/en/print.html> [accessed 22/08/2012] (my emphasis)

¹⁰¹² see MH Nadesan (n 751) 158

¹²⁹ NS Rose, *The Politics of Life Itself* (n 362) 85

¹⁰¹⁴ D Lupton, *The Imperative of Health* (n 720) 11

¹⁰¹⁵ Lupton D, ‘Foucault and the Medicalisation Critique’ in R Bunton and A Petersen (eds), *Foucault, Health and Medicine* (Routledge 1997) 101

¹⁰¹⁶ see Chapter two

¹⁰¹⁷ NS Rose, *Governing the Soul* (n 673) 231

¹⁰¹⁸ K Veitch, *The Jurisdiction of Medical Law* (n 8) 42-47; AR Petersen and D Lupton, *The New Public Health* (n 539) 175

¹⁰¹⁹ AR Petersen and D Lupton, *The New Public Health* (n 539) 51; M Foucault, ‘The Politics of Health in the Eighteenth Century’ (n 735) 94

¹⁰²⁰ AR Petersen and D Lupton, *The New Public Health* (n 539); M Foucault, ‘The Politics of Health in the Eighteenth Century’ (n 735) 94

medical care. As discussed, the creation of an ADRT calls for a level of responsabilised, self-directed thought, which can be developed through self-reflection, narrative, prediction and analogy to the circumstances of others.

Causing people to actively consider the creation of their own ADRT can be achieved through a number of techniques to enhance and facilitate a perceived sense of individual responsibility and choice making obligations. These reflexive thought processes are likely to heighten the sense of individual mortality and generalised health-awareness.

TELOS OF GOVERNMENT

“[T]here is no power that is exercised without a series of aims or objectives”¹⁰²¹

“[A] sick man lives more carelessly when he is under medical observation than when he attends to his own health.”¹⁰²²

Finally, there must be a *telos* of governance (a point which the technologies of the self shares with the technologies of government).¹⁰²³ This idea of the ultimate purpose of this mode of self-government raises the question of the kind of society and the kind of subjectivities that these practices of the self attempt to lead us towards or the kind of world these practices seek to produce.¹⁰²⁴

One aspect of this *telos* might be seen in the resurgence of the care of the self. This has not taken the form of a revalorisation of the pleasures of the self *per se*, but in making self-care a priority for all. But, rather than merely promoting the practices of self-control (or *enkrateia*) that allows one to avoid becoming a slave to one’s own desires and urges in order to become a ‘wise moderate’ instead (*sōphrosynē*),¹⁰²⁵ the modern imperative to care for the self is directed towards self-optimisation.¹⁰²⁶ As discussed, under advanced liberal modes of government, one is to make a continual project of oneself: analysing, testing and comparing oneself to certain norms.¹⁰²⁷ Thus, modern practices of the self are also to be distinguished from the practices of the self which were induced by Christian discourse in two important respects. Firstly because it does not require the destruction of the self, prior to the attainment of a new subjectivity (as Christian discourse does), but rather seeks to shape subjectivity in a

¹⁰²¹ M Foucault, *The History of Sexuality: The Use of Pleasure* (n 894) 94-95

¹⁰²² Nietzsche FW, *The Dawn of Day* (Project Gutenberg 2012) 322

¹⁰²³ M Foucault and M Blasius (n 948) 203

¹⁰²⁴ M Dean, ‘Governing the Unemployed Self in an Active Society’ (n 679) 577

¹⁰²⁵ M Foucault, *The History of Sexuality: The Use of Pleasure* (n 894) 62-64

¹⁰²⁶ MH Nadesan (n 751) 158

¹⁰²⁷ See A Cronin, ‘Consumerism and “Compulsory Individuality”’: Women, Will and Potential’ (n 889) 276

positive way, based on a “permanent anthropologism of Western thought”.¹⁰²⁸ Secondly, modern practices of the self are such that it is now no longer sufficient to be without sin (as was the promise of leading a good life according to Christian mores), we must all aspire towards ‘sainthood’ i.e. the optimal. This is not something that Christian discourse would expect for all. Indeed, in this respect, an analogy with the ethical codes of ancient Greece and particularly the “*mode d’assujettissement*”¹⁰²⁹ is perhaps therefore stronger than the Christian analogy to the modern practices of the self. This entails that the self must labour under continual self-reflection in order to work on and improve itself in pursuance of the elusive (and unreachable) optimum.

The *telos* of this process would most obviously be to ensure that individuals make medical decisions about their own lives, ultimately about when they find it acceptable to end their own lives by the refusal of life-sustaining or prolonging medical treatment. This result would lead to the great advantage of reducing the incidence of the governmental crisis of individuals whose lives can technically be sustained, but who cannot make a decision for themselves as to whether to refuse such treatment. Even where the decision of the individual is not ultimately accepted in practice, as was the case in *W v M* and *Re E*, the encouragement of individuals to undertake the kinds of processes which prepare them for these kinds of possibilities at the end of life is ultimately beneficial to state government, because it provides a more legitimate basis on which end-of-life decisions can be made.

However, it has been argued here that the purpose is broader than this. As the level of control ceded to individuals by ADRTs is of a precarious and contingent nature, they can be viewed as having a broader purpose in fostering a general acceptance that individuals have an obligation to safeguard their own health and healthcare preferences, not only in the present but also in respect of future contingencies,¹⁰³⁰ through the practices of ‘autonomous’ decision-making and accepts that the right to self-determination should be lost in the absence of capacity. This promotion of individual autonomy and choice, which underpins ADRTs, allows the state to extricate itself from making moral decisions on controversial subjects in which the state lacks the necessary knowledge and authority.

As discussed earlier, the neoliberal turn has engendered a marketisation of knowledge and expertise itself. As such, there is no inherent authority in expert knowledge without consumer validation and similarly there is no inherent authority in the sovereign without

¹⁰²⁸ M Foucault and M Blasius (n 948) 222

¹⁰²⁹ see M Foucault, ‘On the Genealogy of Ethics’ (n 985)

¹⁰³⁰ See NS Rose, ‘Genomic Susceptibility as an Emergent Form of Life? Genetic Testing, Identity and the Remit of Medicine’ (n 987) 147-148

democratic backing. In this sense, ADRTs must have individual choice at their core in order to remain in line with advanced liberal programmes of government, but also to offer support to those programmes of government. Thus medical experts can be drawn upon to explain the potential consequences of reading the end of life without an ADRT and those with an expert understanding of ADRTs can provide technical advice as to how to create an ADRT that will be clinically effective. The use of expertise in this way is paradigmatic of modern governmentality's proclivity for 'governing at a distance'¹⁰³¹ and facilitates alignment of individual choices with programmes of government at a broader level.¹⁰³² In this way, expert advice can be used to promote the kinds of individual choice and active consumerism on which advanced liberalism depends.

CONCLUSION

This chapter sought to explain how ADRTs function within modern governmentalities. This discussion built on the work of the previous chapter on the development of modern governmentalities, and liberal governmentalities in particular. It was explained that modern liberal and advanced liberal governmentalities can be understood as operating through the technologies of the self (i.e. conducting the conduct of the self) and the technologies of government (i.e. conducting the conduct of others). The effects of ADRTs can be examined in these terms too, with this chapter focussing on ADRTs role within the technologies of the self.

The cases of *W v M* and *Re E* were discussed in detail in order to illustrate how ADRTs both foster and require self-directed practices of government. It was not suggested that these cases are representative of the case law on ADRTs, but rather they were drawn upon to demonstrate the distinction an analysis grounded in governmentality and one grounded in traditional bioethics.

From an orthodox bioethical standpoint it might be asked whether the autonomy of M and E had been given adequate respect in these cases. The failure of the ADRTs in both cases might suggest a negative answer. However, a governmental analysis is aimed at consideration not only of the effect of ADRTs, but also the kinds of practices that they institute. Thus, in terms of self-directed practices, both M and E expressed wishes that addressed their existential dispositions as they decided that they would rather forego medical treatment in certain circumstances rather than receive the treatment. Both purported ADRTs

¹⁰³¹ NS Rose, 'Governing "Advanced" Liberal Democracies' (n 686) 46

¹⁰³² P Miller and NS Rose, *Governing the Present* (n 686) 50

were created as the product of certain reflective processes undertaken with an awareness of the possibility of being treated in a manner that neither would desire, should that treatment to become clinically indicated when mental capacity was lacking. In expressing their wishes in this manner, both M and E constituted themselves as responsible, ethical subjects, with an interest in their own state of health and of existence. The ultimate purpose of this form of self-government was to provide a clearer, more legitimate, basis for end of life decisions and to reduce ethical dilemmas and problematics of government at the end of life.

CHAPTER SEVEN

ADRTS AS TECHNOLOGIES OF GOVERNMENT

INTRODUCTION

The current chapter builds upon the analysis of the theoretical precepts of governmentality, set out in Chapter Five in examining the role played by ADRTs in the government of others as part of the technologies of government and the securitisation of the population. The idea that governmentality can operate through interplay between the technologies of the self and the technologies of government was discussed in chapter six.¹⁰³³ These two technological groupings operate together in an overlapping manner,¹⁰³⁴ and to that extent, many practices relating to ADRTs will comprise techniques which might fit under both technological banners. However, in this final chapter the focus will be on the development and operation of ADRTs as part of the technologies of government and of security. The goal of this analytic approach is to situate ADRTs within a broader advanced liberal political project of government. As such, it can be distinguished from more conventional analyses of ADRTs within the fields of law and bioethics, discussed earlier in this thesis, which tend to emphasise the project of ethical rationalisation and development of a legal framework on ADRTs as part of the vindication of individual rights. As a critical rejoinder to the view that ADRTs constitute legal instruments designed to enhance individual rights and advance the cause of the individual, it is argued in this chapter that ADRTs play a role among the practices aimed at shaping the conduct others as part of the technologies of government.¹⁰³⁵

Far from suggesting that individuals are *required* to create ADRTs, what is argued here is that the establishment of the possibility for individuals to take binding decisions over their future medical treatment, individual behaviour can be augmented and channelled. Moreover, it is suggested that the establishment of a framework to permit the creation of ADRTs is not merely aimed at individuals, but is also directed towards the population as whole.

¹⁰³³ M Foucault, 'Technologies of the Self' (n 952) 225; G Burchell, 'Liberal Government and Techniques of the Self' (n 682) 20

¹⁰³⁴ M Dean, 'Governing the Unemployed Self in an Active Society' (n 679) 563

¹⁰³⁵ M Foucault, 'The Subject and Power' (n 7) 341

The focus on the population is faithful to a critique couched in governmental terms, because as will be recalled from Chapter Four, following the ‘governmentalisation of the state’,¹⁰³⁶ the population became the chief referent of government and its defining object.¹⁰³⁷ Such a perspective will also provide an opportunity to analyse the operation of ADRTs at a public health level.

In considering ADRTs’ effects on the population, discussion will be given to the securitising role played by ADRTs. Security techniques, in this sense, are aimed at achieving a kind of homeostatic order¹⁰³⁸ in respect of the vital processes of the population.¹⁰³⁹ This part of the chapter will emphasise the emergence of ADRTs in an advanced liberal political rationality, which relies upon individuals who are subjectivised in a certain manner such that they are attuned to govern their own interests. Those who lack mental capacity at the end of life and whose lives could be sustained through the intervention of advanced medical technology are, by definition, incapable of the kind of self-government upon which advanced liberalism depends and therefore, at one level, the existence of such persons in such situations represents a ‘threat’ to the prevailing rationality of government. Foucault discussed the emergence of such ‘threats’ to the population in terms of racism¹⁰⁴⁰ and thus the possibility that ADRTs effect a kind of racism will be discussed.

In addition to the role that ADRTs can play in the government of population, it will be suggested that ADRTs can also be employed in the government of two additional categories of ‘other’. Firstly, it will be suggested that ADRTs can play a role in the government of the ‘future self’, who was discussed in the fourth chapter, if this person can be considered as an entity which is separate from the present self in a sense. This discussion will offer a novel perspective on the problem of the ‘future self’ through an engagement with Foucault’s idea of the formation of subjectivities through objectification.¹⁰⁴¹ However, in order for any person to come to think about the future self as a kind of separate entity will often require a kind of intermediate governmental action at the interpersonal level. This is where experts can be drawn on to inform individuals and assist them in creating their own ADRTs with legal effect.

¹⁰³⁶ Discussed in detail in Chapter Six

¹⁰³⁷ M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 254; and see Chapter Five

¹⁰³⁸ see M Foucault, *Society Must be Defended* (n 696) 249

¹⁰³⁹ See M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 29

¹⁰⁴⁰ See M Foucault, *Abnormal: Lectures at the Collège de France 1974-1975* (Verso 2003) 316-317

¹⁰⁴¹ M Foucault, ‘The Subject and Power’ (n 7) 326

Before examining the role of ADRTs in the government of these various varieties of government, it is opportune to reconsider the emergence of ADRTs in light of the preceding discussion of governmentality. This will allow the emergence of ADRTs to be presented to be understood as a result of the co-emergence of a number of factors which have resulted in combination to a crisis of government. It will be argued that the traditional accounts, couched in bioethical terms, fail to take adequate account of the governmental aspects of ADRTs, which become visible when thinking about ADRTs in terms of their role in the government of others and in addressing the ‘crisis of government’,¹⁰⁴² which arose as the product of multiple factors. The object of this discussion will be to emphasise the congress of factors which have combined to make ADRTs possible and to distinguish the analysis presented here from analyses which suggest that ADRTs are to be understood as the product of a bioethical rationalisation and extension of the concept of autonomy.¹⁰⁴³ Viewed as a crisis of government, it can be argued that one of the most significant drivers for developing a legal framework for ADRTs is the need to address this crisis.

CONDITIONS OF EMERGENCE OF ADRTS

In the second part of this thesis it was suggested that the orthodox account of the development of ADRTs posits that the right to create ADRTs was primarily developed as a relatively straightforward extension of the individual right to personal autonomy and self-determination (those concepts being used interchangeably in medico-legal discourse).¹⁰⁴⁴ Although it is not disputed that the conceptual development and extension of autonomy has been important for the development of ADRTs, it should also be remembered that the manner of the autonomy’s conceptual development in English law has been highly contested and somewhat inconsistent.¹⁰⁴⁵

Many consider that the idea of autonomy has been interpreted in a ‘thin’ way, i.e. as being used synonymously with mere choice (as it is frequently presumed to be) in medical law, and thus, in a sense closely linked to ideas of ‘self-determination’, ‘empowerment’ and ‘liberty’.¹⁰⁴⁶ Assessing the recognition of ADRTs against this benchmark would suggest that they are a rather limited and unreliable means of ‘extending autonomy’, in this sense. There are a number of cases in which purported ADRTs not been upheld (because of the way they

¹⁰⁴² M Foucault, *The Birth of Biopolitics* (n 674) 68-69

¹⁰⁴³ *W v M* (n 11) [226] (Baker J); *HE v Hospital NHS Trust* (n 66) (Fam) [37] (Munby J)

¹⁰⁴⁴ see Chapter Four

¹⁰⁴⁵ see Chapter Three

¹⁰⁴⁶ J Coggon and J Miola, ‘Autonomy, Liberty and Medical Decision-Making’ (n 678); and see O’Neill (n 372) 37, 47-48; M Holstein, JA Parks and MH Waymack, (n 480) 21

have been interpreted with respect of the formalities of the MCA).¹⁰⁴⁷ In addition to the uncertainty surrounding the court's willingness to recognise ADRTs, there are important structural limitations¹⁰⁴⁸ which bear upon the capacity of ADRTs to extend choice and empower their creators. One reason for this is that the operation of ADRTs is restricted to the *refusal* of treatment; autonomous choices requesting medical treatment are not legally binding *per se*¹⁰⁴⁹ and it is unlawful to provide active euthanasia in England and Wales.¹⁰⁵⁰

It is, however, easier to identify a theoretical extension of autonomy, if a 'thinner' definition is relied upon. In terms of patient empowerment, ADRTs clearly do allow individuals to make pre-emptive decisions without the need to be prompted to make a decision by another and, in some cases, they can prevent the administration of unwanted treatment. Thus, the realm of individual choice is increased by ADRTs, but it is the extent to which ADRTs successfully force the practical adherence to individual choices which is limited.¹⁰⁵¹ This is why it is far easier still to identify an extension of autonomy, if autonomy is understood as a practice of government, than as a matter of *empowerment*. On such an understanding, ADRTs have opened up a realm of choice and concomitant individual responsibility through the practices of autonomy.¹⁰⁵² Regardless of whether those choices are ultimately respected, ADRTs have expanded the potential areas in which an individual may exercise choice and therefore the areas for which the individual may be considered responsible.¹⁰⁵³ Although freedom is a *sine qua non* of advanced liberal modes of government, the individuals within such programmes of government do not have an unrestricted power to *exercise* their freedom. Their freedom is to be considered a product of proper cultivation of the self through subjectification and must be exercised responsibly.¹⁰⁵⁴ Negative consequences for the individual may flow from such a categorisation, but the existence of those who cannot function in accordance with the expectations of an advanced liberal system of government puts a strain on the systems of government and necessitates agencies to take decisions on behalf of individuals considered within the proper realm of

¹⁰⁴⁷ e.g. *Re E* [2014] EWCOP 27 and *W v M* (n 11)

¹⁰⁴⁸ See Chapter One

¹⁰⁴⁹ *R (Burke)* (n 27)

¹⁰⁵⁰ *R v Malcherek and Steel* [1981] 2 All ER 422; *R v Adams* [1957] Crim LR 365

¹⁰⁵¹ C Kitzinger, 'Advance Decisions Do They Work?' (2014) 4 Journal of Elder Law 198

¹⁰⁵² See P Miller and N Rose, 'Governing Economic Life' (n 966) 23–27

¹⁰⁵³ NS Rose, *The Politics of Life Itself* (n 362) 63

¹⁰⁵⁴ See M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 193; K Veitch, *The Jurisdiction of Medical Law* (n 8) 46

individual decision-making.¹⁰⁵⁵ This strain might be experienced by other people through, for example the idea of the ‘burden of care’.¹⁰⁵⁶

This aspect of ADRTs may therefore play a role in the subjectivisation of individuals as choosing agents, enjoined to make choices and to accept responsibility for themselves.¹⁰⁵⁷ This is why, although it may seem counterintuitive (given that the word autonomy is suggestive of the government of the self)¹⁰⁵⁸, the chief mode in which ADRTs facilitate the government of others is *through* autonomy.

In addition to these conceptual disputes about the proper meaning of autonomy, it has been argued here that other factors have been equally significant in the development of ADRTs. The admixture of these multiple factors has resulted in a ‘crisis of governance’¹⁰⁵⁹ signified by the inadequacy of the pre-existing modes of government and the consequent need to find new strategies of government. Former approaches to the administration of treatment did not lend themselves well to the new circumstances in which people began to find themselves at the end of life. Consequently, in the absence of ADRTs, there was no clear way in which to govern the end of life that was truly faithful to the tenets of advanced liberalism and their inclusion of individual choice. In this section some of the significant factors that have driven the development of ADRTs will be discussed. In particular, it is suggested that the advances in the technical medical ability to sustain life, combined with an aging population, a financial crisis (with its implications for the funding of healthcare services) and the pre-eminence of the advanced liberal rationality of government have all been as important to the development of ADRTs as the claim that they have been developed pursuant to a bioethical principle. ADRTs represent a response to this crisis of government that is most faithful to advanced liberal programmes of government.

"[W]e have become so good at keeping people alive that we've succeeded in keeping them alive when, in biological terms, they should have been dead long ago."¹⁰⁶⁰

ADRTs have only entered into thought because of the advent of the technical ability to maintain life at low levels of functionality for extended periods using life-support

¹⁰⁵⁵ See MH Nadesan (n 751) 212-213

¹⁰⁵⁶ See e.g. As Kraus, ‘The Burden of Care for Families of Elderly Persons with Dementia’ (1984) 3 Canadian Journal on Aging 45; see also AR Maclean, ‘Advance Directives and the Rocky Waters of Anticipatory Decision-Making’ (n 143) 5

¹⁰⁵⁷ NS Rose, *Governing the Soul* (n 673) 231

¹⁰⁵⁸ G Dworkin, (n 371) 108

¹⁰⁵⁹ M Foucault, *The Birth of Biopolitics* (n 674) 68-69

¹⁰⁶⁰ M Foucault, *Society Must be Defended* (n 696) 248

machines.¹⁰⁶¹ This technical capacities for sustaining life has advanced to the point that it is relatively common, albeit resource intensive.¹⁰⁶² Currently there are up to 16,000 people in vegetative states in the UK and up to three times as many in minimally conscious states.¹⁰⁶³ However, while the technical capacity to sustain life has dramatically advanced, our ethical capacity to answer the question of whether, and the extent to which, such technical measures *should* be deployed has lagged woefully behind.¹⁰⁶⁴ This disjuncture between the technical capacity to sustain life and means of legitimate decision making regarding the ongoing sustaining treatment has been a major factor that has influenced the development of ADRTs. Without such technical advances, the questions surrounding ADRTs would be redundant.

Coupled with this increase in the technical capacities for sustaining life, it is significant that this enhanced ability to save and maintain life has arisen against a background of advanced liberalism.¹⁰⁶⁵ These capacities have not arisen in an idealised space abstracted from all social and material contingencies. That is why it has been argued throughout this thesis that an understanding of the development and operation of ADRTs cannot be adequately formed in the absence of an appreciation of their historical context.¹⁰⁶⁶

A fuller discussion of the significance of the development of advanced liberalism for the practices of was provided in Chapter Five with reference to what Foucault termed the ‘governmentalisation of the state’,¹⁰⁶⁷ but at this stage, when focussing on the operation of ADRTs, it is useful to focus the analysis on the move from liberalism to advanced liberalism to examine how this governmental shift is reflected in the emergence of ADRTs. It will be recalled that liberalism is concerned with an economy of government, which demands the avoidance of excessive state intervention.¹⁰⁶⁸ In order to achieve this, programmes of government must be kept under constant scrutiny through a process of problematisation.¹⁰⁶⁹ If state intervention in a particular area is deemed unnecessary, the state could withdraw and

¹⁰⁶¹ K Veitch, *The Jurisdiction of Medical Law* (n 8) 34-39; Institute of Medicine (n 613) xii; S Halliday, A Formby and R Cookson, ‘An Assessment of the Court’s Role in the Withdrawal of Clinically Assisted Nutrition and Hydration from Patients in the Permanent Vegetative State’ (2015) 23 *Medical Law Review* 556, 557

¹⁰⁶² see *ibid* S Halliday, A Formby, and R Cookson, 580; Institute of Medicine (n 613) 267-307

¹⁰⁶³ Parliamentary Office of Science and Technology (n 901) 1

¹⁰⁶⁴ see K Veitch, ‘Medical Law and the Power of Life and Death’ (n 412) 140

¹⁰⁶⁵ see Chapter Five

¹⁰⁶⁶ See M Foucault, *Discipline and punish* (n 673) 31

¹⁰⁶⁷ M Foucault, *Security, Territory, Population* (n 6) 118

¹⁰⁶⁸ M Foucault, *The Birth of Biopolitics* (n 674) 13-20; M Foucault, *Security, Territory, Population* (n 6) 95

¹⁰⁶⁹ N Rose and P Miller, ‘Political Power Beyond the State: Problematics of Government’ (n 675) 181

leave the matter to other agencies or to the individual. Reducing state intervention over individuals provides the opportunity for greater levels of individual choice and therefore, if autonomy is taken to be a near-synonym of liberty (which it sometimes is),¹⁰⁷⁰ greater individual autonomy too.

By contrast, advanced liberal programmes of government are characterised by a greater proclivity for intervention of a certain kind. The beatified idea of ‘the natural’ gives way to the extolment of the market and, on this basis, legitimate interventions can be made to establish markets where none exists.¹⁰⁷¹ A further hallmark of the practices of advanced liberalism can be seen in their attempt to govern others through the employment of multiple agencies and techniques working together and often ‘at a distance’.¹⁰⁷² Achieving this ideal of ‘government at a distance’, advanced liberalism places a heavy reliance on (a certain kind of) personal autonomy and the extension of choice.¹⁰⁷³

A considerable discussion of the development of the concept of autonomy was provided in the second part of this thesis. From this it will be recalled that there has been much criticism of the shift towards a more individualised, ‘thin’ and choice-based conception of autonomy of the variety that many suggest has come to represent the predominant conception of personal autonomy in medical law.¹⁰⁷⁴ There are various reasons why construing autonomy in such a way might be considered problematic in philosophical and bioethical terms (e.g. choice might be considered necessary but not sufficient justification)¹⁰⁷⁵ and various reasons, underpinned by bioethical rationalities, might be found for suggesting that citizens ought not to have access to unrestricted choice over their own healthcare. Some of these reasons were highlighted in chapter three, but the acceptance of any alternative conception of autonomy, of the broad variety which is putatively recognised and which facilitates the operation of ADRTs, would place restrictions on the right of individuals to choose between alternatives.¹⁰⁷⁶ Bioethicists might advance arguments which suggest that personal autonomy ought to be considered but one among a number of important ethical principles¹⁰⁷⁷ which ought to influence decision-making. Such arguments have merit in bioethical circles, but viewed from the perspective of advanced liberal government, the difficulty with placing such restrictions on the individual ability to choose

¹⁰⁷⁰ J Coggon and J Miola, ‘Autonomy, Liberty and Medical Decision-Making’ (n 678)

¹⁰⁷¹ M Foucault, *The Birth of Biopolitics* (n 674) 145

¹⁰⁷² NS Rose, ‘Governing “Advanced” Liberal Democracies’ (n 686) 43

¹⁰⁷³ see P Miller and N Rose, ‘Governing Economic Life’ (n 966) 23-27

¹⁰⁷⁴ O O’Neill (n 372) 37, 47-48; M Holstein, JA Parks and MH Waymack, (n 480) 21

¹⁰⁷⁵ See O O’Neill (n 372) 47-48

¹⁰⁷⁶ See eg J Herring, ‘Where Are the Carers in Healthcare Law and Ethics?’ (n 1)

¹⁰⁷⁷ See TL Beauchamp and JF Childress (n 433)

lies in justifying the basis of the restriction. Such restrictions must not only be justified with respect to bioethical principles, but also with reference to the tenets of the political rationalities which prevail in the government of society.

As mentioned, one of the senses in which it has been argued that the concept of autonomy is (mis)used is where it is equated with liberty¹⁰⁷⁸ in the sense of conflating a greater level of autonomy with a greater freedom from the intervention of government. However, this is certainly not the kind of autonomy that Rose and others associate with advanced liberalism. Indeed “[p]ersonal autonomy is not the antithesis of political power, but a key term in its exercise.”¹⁰⁷⁹ More autonomy does not mean less government, rather it means government of a different kind. Autonomy here is a call to become an active citizen and far from freeing the individual from government it operates as one of the most important means by which people are governed in advanced liberal programmes of government. The challenge lies in seeking to align the conduct of autonomous individuals towards a particular strategic end.¹⁰⁸⁰ From this perspective, according subjects a kind of decision-making capacity and responsibility is well-aligned with the objective of ‘governing at a distance’¹⁰⁸¹ and through the practices of autonomy.¹⁰⁸²

Thus, under advanced liberal programmes of government, individual citizens are not merely to be understood as passive agents, awaiting direction; nor are they to be considered to possess an inherent, natural, kind of autonomy as assumed in classical liberalism.¹⁰⁸³ Instead individuals are to be made into (or subjectivised as)¹⁰⁸⁴ *active* nodes of government, who are both subject to, and complicit in, the practices of government pertaining to themselves and others.¹⁰⁸⁵ Within advanced liberal rationalities of government, therefore, the idea of autonomy does not simply entail the right to make decisions on questions posed by others. It additionally *demand*s individuals taking an active approach in the management of their interests, by making decisions for themselves, supported by experts whose role

¹⁰⁷⁸ J Coggon and J Miola, ‘Autonomy, Liberty and Medical Decision-Making’ (n 678)

¹⁰⁷⁹ N Rose and P Miller, ‘Political Power Beyond the State: Problematics of Government’ (n 675) 174

¹⁰⁸⁰ NS Rose, ‘Governing “Advanced” Liberal Democracies’ (n 686) 45

¹⁰⁸¹ see *ibid* 43

¹⁰⁸² see NS Rose, *Governing the Soul* (n 673) 231

¹⁰⁸³ see B Hindess, ‘Liberalism, Socialism and Democracy: Variations on a Governmental Theme’ (n 677)

¹⁰⁸⁴ see M Foucault, ‘Two Lectures’ in *Power/knowledge: Selected Interviews and Other Writings, 1972-1977* Colin Gordon (ed) (Vintage, 1980), 97, 78–108; I Hacking, ‘Making up People’ (n 882); NS Rose, ‘Government, Authority and Expertise in Advanced Liberalism’ (n 669) 288; J Read, ‘A Genealogy of Homo-Economicus: Neoliberalism and the Production of Subjectivity’ (2009) 6 Foucault Studies 25

¹⁰⁸⁵ NS Rose, *Powers of Freedom* (n 819) 46

becomes more advisory than directive. Citizens are formed into agents¹⁰⁸⁶ who are not only capable of choice but who are *expected* to make choices for themselves¹⁰⁸⁷ in the furtherance of their own interests, because they are deemed to be in the best position to assess their own interests. They are to become, as Foucault suggested *homines oeconomici*:¹⁰⁸⁸ i.e. individuals concerned with maximising their own interests through their own choices, expected to act as “entrepreneurs of themselves”.¹⁰⁸⁹

However, mental incapacity exposes an important limitation on the extent to which individual choice can be relied upon, because individuals who lack mental capacity are incapable of self-government (in respect of specific areas of decision-making) and therefore cannot adhere to the standards of *homo economicus* and the demands of advanced liberalism. The MCA does provide a safeguard in such situations for individuals who are unable to govern themselves in the form of best interests treatment interventions, but such interventions are problematic because of the imperative of modern governmentality that the state is only permitted to intervene to ensure individuals can pursue their own interests, rather than defining those interests.¹⁰⁹⁰ Although the best interests test allows for different interests to be considered, there can be no guidance on the relative weightings to be given to those competing interests.

The alternative to making end-of-life decisions based on ADRTs is for decisions to be made on behalf of individuals. While this is possible, and in some sense inevitable (particularly in respect of children), it is generally considered as something to be avoided from the perspective of advanced liberal government. Famously, Adam Smith noted that the restrictions on the activity of the state were not simply the result of State ignorance,¹⁰⁹¹ but its lack of capacity to know.¹⁰⁹² Expertise cannot be relied on as a source of authority because expertise itself is open to question and thus the idea of the individual being the best judge of their own interests and *homines oeconomici*,¹⁰⁹³ is closely associated with advanced liberal government.¹⁰⁹⁴ The development of this rationality of government has led to the

¹⁰⁸⁶ see I Hacking, ‘Making up People’ (n 882)

¹⁰⁸⁷ NS Rose, *Governing the Soul* (n 673) 231; K Veitch, *The Jurisdiction of Medical Law* (n 8) 42

¹⁰⁸⁸ M Foucault, *The Birth of Biopolitics* (n 674) 225-226; TH Hamann, ‘Neoliberalism, Governmentality, and Ethics’ (2009) *Foucault Studies* 37

¹⁰⁸⁹ M Foucault, *The Birth of Biopolitics* (n 674) 226; J Read (n 1084); NS Rose, *Governing the Soul* (n 673) 230; C Gordon, ‘Governmental Rationality: An Introduction’ (n 689) 41

¹⁰⁹⁰ M Foucault, *The Birth of Biopolitics* (n 674) 271–286

¹⁰⁹¹ See also Hayek, 1988, 77 cited in MH Nadesan (n 751) 30

¹⁰⁹² M Foucault, *The Birth of Biopolitics* (n 674) 280-284

¹⁰⁹³ *ibid* 225-226

¹⁰⁹⁴ TH Hamann, ‘Neoliberalism, Governmentality, and Ethics’ (n 1088)

commodification of expertise and the presentation of new challenges to expert authority.¹⁰⁹⁵ Such challenges are especially noticeable in respect of medical practice, where, despite an ongoing deferential disposition towards medical practitioners,¹⁰⁹⁶ the authority of practitioners, is confronted by the practices of empowered, health consumers,¹⁰⁹⁷ even ‘expert patients’,¹⁰⁹⁸ and the courts have shown a greater willingness to draw sharper boundaries around the areas in which medical expertise holds sway.¹⁰⁹⁹

The facilitation of ADRTs offers the solution to this dilemma which is most faithful to the precepts of advanced liberalism in that it affords individuals the opportunity to make future decisions for themselves in an absence of any other clear and legitimate source authority regarding the profoundly difficult question¹¹⁰⁰ of precisely when life-sustaining measures should cease or be withdrawn. In the age of empowered patients, such a question cannot be reduced to a technical matter to be left to the medical profession.¹¹⁰¹

The challenges presented by the technical capacities and political environment as described, have been heightened by demographic changes¹¹⁰² being experienced in the United Kingdom (and other countries such as the United States),¹¹⁰³ often referred to as the aging population, which mean that a large proportion of the population is approaching the end of life.¹¹⁰⁴ Impetus is thus added to the need for a satisfactory resolution to this crisis of government. To put this in more specific terms, there has been a considerable increase in the number of citizens of pensionable age relative to those of working-age in the population. This change may be to a large extent attributable to the surge in the birth rate during the post-war ‘baby boom’ years, combined with a trend, in subsequent years towards lower fertility rates.¹¹⁰⁵ The overall effect is that there is high frequency of people within the baby boomer generation relative to other generations and as the baby boomers become eligible for

¹⁰⁹⁵ NS Rose, ‘Government, Authority and Expertise in Advanced Liberalism’ (n 669) 295-296; see also D Wilson, *The Making of British Bioethics* (n 9) 121

¹⁰⁹⁶ See H Woolf (n 693)

¹⁰⁹⁷ P Miller and NS Rose, *Governing the Present* (n 686) 76; I Kennedy, ‘Patients Are Experts in Their Own Field’ (2003) 326 *BMJ* (Clinical Research Ed.) 1276; D Wilson, *The Making of British Bioethics* (n 9) 122, 221, 235

¹⁰⁹⁸ See SM Glasgow, ‘The Politics of Self-Craft’ (2012) 2 *Sage Open* 1; *ibid* I Kennedy; also c.f. D Lupton, *Medicine as Culture: Illness, Disease and the Body* (3rd ed, Sage 2012) 126

¹⁰⁹⁹ *Montgomery v Lanarkshire Health* (n 161) [46] (Kerr and Reid LLJ)

¹¹⁰⁰ see NS Rose, *The Politics of Life Itself* (n 362) 40

¹¹⁰¹ *Montgomery v Lanarkshire Health* (n 161) [46] (Kerr and Reid LLJ)

¹¹⁰² BJ Winick, ‘Foreword: Planning for the Future Through Advance Directive Instruments’ (1998) 4 *Psychology, Public Policy, & Law* 579, 580

¹¹⁰³ Institute of Medicine (n 613) 268

¹¹⁰⁴ Select Committee on Public Service and Demographic Change, *Ready for Ageing?* (2012-13 HL140) paras 1-7

¹¹⁰⁵ European Commission, *The Demographic Future of Europe - From Challenge to Opportunity*, (Directorate-General for Employment, Social Affairs and Equal Opportunities, 2006) 5

retirement the ‘dependency ratio’ (i.e. *simpliciter* the number of working adults divided by the number of non-working persons)¹¹⁰⁶ is forecast to increase over the coming decades.

This demographic change is important for a number of reasons germane to the development of the law on ADRTs. One is that the elderly demographic puts specific demands on the health service, particularly in respect of the increased costs associated with caring for people with age-related health conditions, such as dementia. The cost of providing care for dementia patients in England alone is set to increase from £15Bn in 2007 to a conservative estimate of £26Bn by 2026¹¹⁰⁷ the cost including “real pay and price effect” could be £34.79Bn and that estimate rests on the assumption that among this population of dementia sufferers, that will increase from 580,000 to 940,000 there will be no loss in rates of employment.¹¹⁰⁸ Although it is much harder to accurately quantify the increase in health and social care costs than the increase in pension costs¹¹⁰⁹ (discussed below) concerns have been raised that the likely increases in health and social care costs will create a “substantial economic”¹¹¹⁰ burden on the UK.

In addition, those who fall within the elderly demographic are likely to approach the end of their lives and will require end-of-life medical treatment in the medium term. It has been suggested that “...a significant proportion of healthcare expenditure on an individual is concentrated at the end of life”,¹¹¹¹ which has been estimated to amount to around 25% of total health costs.¹¹¹² This spending is not directly related to people living longer, but the fact that more people are living for longer means that there are many people who are approaching the end of their lives and thus mortality rates are predicted to increase sharply in the coming years.¹¹¹³ The significance of these increased costs must be read together with the fourth condition that has prompted the emergence of ADRTs: the financial crisis.

¹¹⁰⁶ See further J Falkingham, ‘Dependency and Ageing in Britain: A Re-Examination of the Evidence’ (1989) 18 *Journal of Social Policy* 211, 218

¹¹⁰⁷ P McCrone and others, *Paying the Price: The Cost of Mental Healthcare in England to 2026* (The King's Fund, 2008) xv

¹¹⁰⁸ *ibid* xviii table 1

¹¹⁰⁹ A Gray, ‘Population Ageing and Healthcare Expenditure’ (2005) 2005 *Ageing Horizons* 15

¹¹¹⁰ M MacDonald and others, ‘Distal and Proximal Resource Influences on Economic Dependency among the Oldest Old’ (2010) 56 *Gerontology* 100, 100

¹¹¹¹ K Syrett, *Law Legitimacy and the Rationing of Health Care: A Contextual and Comparative Perspective* (Cambridge University Press 2007) 35

¹¹¹² GF Riley and JD Lubitz, ‘Long-Term Trends in Medicare Payments in The Last Year of Life’ (2010) 45 *Health Service Research* 565

¹¹¹³ N Calazani, IJ Higginson and B Gomes, *Current and Future Needs for Hospice Care: An Evidence Based Report* (Help the Hospices, 2013)

Fourthly, the collapse of Lehman Bros in 2008¹¹¹⁴ saw the beginning of one of the greatest crises of capitalism since the Wall Street Crash of 1929. The fallout from this event has caused great and enduring economic pressure globally. Notwithstanding the magnitude of this shock to the economic system, the logic of capitalist realism¹¹¹⁵ has remained apparently unassailable. In that spirit the response of the UK government was to attempt to reassure the financial markets of its creditworthiness by reducing its rate of borrowing by cutting public spending as part of a ‘deficit reduction programme’.¹¹¹⁶ This has meant that all government departments have been under pressure to significantly reduce their expenditure. This imperative towards ‘austerity’ measures has coincided with the emergence of additional costs posed by the ‘aging population’ i.e. the increasing numbers of people in the eldest portion of the demographic relative to the rest. One of the most important cost pressures arising from an aging population is the increase in pension costs from the increased number of people who become eligible for state pension benefits.¹¹¹⁷ Consequently, even to maintain present levels of pension-age-related benefits will require additional public spending.¹¹¹⁸

A considerable portion of overall social security spending in the UK currently goes on the payment of pensions and other benefits to the retired population (e.g. the ‘winter fuel payment’).¹¹¹⁹ For the financial year 2011/2012 pensions accounted for the single greatest part of government expenditure at £129Bn, above even the healthcare (at £124Bn) part of which will also be consumed by the retired population.¹¹²⁰ The Institute for Fiscal Studies (“IFS”) have acknowledged that the aging population will put a strain on the money available for other departments.¹¹²¹

These suggested changes funding changes for social care will not, however, address the significant systemic problem of having a healthcare system oriented towards the provision of acute care rather than long-term social care that enables people to live independently for longer.¹¹²² Such a large scale reconfiguration of an organisation the size of the NHS is likely to be a very costly exercise. As a result of all of these financial headwinds, there is more pressure than ever to rationalise the provision of healthcare in order to ensure the best value

¹¹¹⁴ D Harvey, *The Enigma of Capital: And the Crises of Capitalism* (Profile 2010)

¹¹¹⁵ see MR Fisher, *Capitalist Realism: Is There No Alternative?* (Zero Books 2009) 16-17

¹¹¹⁶ http://www.hm-treasury.gov.uk/pfg_deficit_reduction.htm accessed 11/09/2011

¹¹¹⁷ <http://www.statistics.gov.uk/cci/nugget.asp?id=949> [accessed 6/7/2011]; D Demery, and NW Duck, ‘Demographic Change and the UK Savings Rate’ (2006) 38(2) *Applied Economics* 119, 119

¹¹¹⁸ M Mrsnik, DT Beers and I Morozov, *Global Aging 2010: An Irreversible Trend* (Standard & Poor’s Global Credit Portal RatingsDirect, 2010)

¹¹¹⁹ <https://www.gov.uk/winter-fuel-payment/overview> [accessed 17/01/2014]

¹¹²⁰ <http://www.ukpublicspending.co.uk/breakdown> [accessed 11/09/2011]

¹¹²¹ Institute for Fiscal Studies *A Survey of Public Spending in the UK* (Briefing Note, 2009) 44

¹¹²² R Humphries, *Paying for Social Care: Beyond Dilnot* (King’s Fund, 2013) 3

for money. As a consequence, unnecessarily elongated hospital stays and unnecessary medical treatment (and even perhaps unnecessary legal processes concerning the provision of treatment treatment)¹¹²³ are all to be avoided in the name of efficiency and cost savings. It reportedly costs around £122K to provide treatment and care for a PVS patient.¹¹²⁴ For patients in vegetative states and minimally conscious states, there is a requirement under a Practice Direction¹¹²⁵ to seek declaratory relief from the Court prior to the withdrawal of treatment. This process is said to cost £122K per patient based on a nine months of medical treatment and legal expenses.

The pressures of an aging population, at a time of fiscal austerity combined with the technical capacity to sustain life at low levels of functionality, at the level of “anatomy in motion”,¹¹²⁶ for ever longer periods without an obvious sense of when such treatment should cease¹¹²⁷ and the demands of an advanced liberal rationality of government provide scope for arguing that we ought to be wary of placing too much reliance on the traditional rationale presented for the introduction of ADRTs: i.e. that they have been introduced pursuant to a process of ethical rationalisation in extending the well-recognised right of personal autonomy into the future. Instead, it is argued that the establishment of the legal framework for creating ADRTs is better viewed as part of a governmental strategy aimed at addressing the crisis of government arising through the convergence of multiple factors.

None of this, however, is to deny the importance of ethical argumentation in the development of the legal framework on ADRTs, or to suggest that ADRTs cannot extend autonomy (although, as discussed, the answer to this very much depends on way this term is defined). Certainly there have been cases in which individuals have expressed wishes not to be provided with treatment and ultimately have been provided with treatment.¹¹²⁸ Such cases demonstrate that ADRTs do not guarantee that express wishes will be honoured or acted upon in future. However, there have also been cases in which the courts have been more willing to recognise prior wishes as ADRTs even where it appears that the wishes have not been expressed in full compliance with the formality requirements.¹¹²⁹ Indeed, as was argued

¹¹²³ see S Halliday, A Formby, and R Cookson, ‘An Assessment of the Court’s Role in the Withdrawal of Clinically Assisted Nutrition and Hydration from Patients in the Permanent Vegetative State’ (n 1061)

¹¹²⁴ see *ibid* 580

¹¹²⁵ PD 9E (Court of Protection)

¹¹²⁶ G Agamben (n 625) 104

¹¹²⁷ see also J Miola, *Medical Ethics and Medical Law: A Symbiotic Relationship* (Hart 2007) 36-37

¹¹²⁸ e.g. *Re E* (n 10)

¹¹²⁹ e.g. *Re E* [2014] EWCOP 27; *LM* (n 338)

in the previous chapter, ADRTs can be viewed enjoining individuals to undertake certain practices on themselves by way of self-government and in this sense do extend autonomy.

Moreover, affording individuals the possibility to create ADRTs makes visible the end of life, through the provision of the opportunity to exercise immediate choice to safeguard against future eventualities. However, the kind of end of life decisions which can be made through ADRTs are heavily constrained in a manner designed to resolve otherwise difficult decisions about the continuation of end-of-life care by the MCA. As such, at the level of the population, ADRTs tend towards rendering the end of life more predictable and the decisions taken at the end of life more legitimate.

Having drawn together the most prominent factors that have led to the establishment of ADRTs, we can better understand the emergence of ADRTs as a response to a crisis of government (i.e. an emergent state of affairs with which the pre-existing mechanisms of government failed to address) rather than merely as the logical extension of a pre-existing right. As was discussed in the previous chapter, part of the exploration of the involvement of ADRTs in the practices of government demands consideration of their operation as *technologies of the self*, but another part of this exploration must include a consideration of their role within the *technologies of government*. This will be the work of the following section in exploring the concept of the technologies of government.

THE TECHNOLOGIES OF GOVERNMENT

The concept of a ‘technology’ was described in the previous chapter *vis-à-vis* the *technologies of the self*. As part of this discussion it should be remembered that the term ‘technology’ is to be understood as a term of art in governmental analyses. Foucault spoke of four ‘main technologies’, which he held to be as technologies of ‘production’, ‘sign systems’, ‘power’ and technologies ‘of the self’.¹¹³⁰ However, this list may not have been intended to be exhaustive and it has been argued that there are many technologies that can be identified, which, of itself, presents challenges for the concept of a technology.¹¹³¹ It is therefore a term which may be accorded a relatively broad meaning in relating to matters such as “the technical assembly of a means of judgement... the techniques of reformation and cure... the apparatus within which an intervention is to take place”.¹¹³² On this

¹¹³⁰ Discussed in the previous chapter; M Foucault, ‘Technologies of the Self’ (n 952) 225

¹¹³¹ M Dean ‘Putting the Technological into Government’ (n 951)

¹¹³² NS Rose, *Governing the Soul* (n 673) xi; see also NS Rose, *The Politics of Life Itself* (n 362) 16-18

understanding, the concept of a technology houses techniques, *technēs*,¹¹³³ apparatus and groupings, which can be put to use for the purposes of government. They “form a crucial nexus between the study of forms of knowledge and the ‘regimes of practices’”.¹¹³⁴ Construed in this way, they are the inverse of the political rationalities, which aim to translate realities into thought.¹¹³⁵

Technologies of government should not, however, be considered merely as instrumental means employed by government aimed at achieving a particular result.¹¹³⁶ They also have a role in establishing and shaping the various normative positions including “who we are or what we would like to become”,¹¹³⁷ which are to be operationalised. In this way they might not only be thought of in terms of directly causing intended outcomes, but also as establishing the spaces in which more generalised aims can take shape. This might include the establishment of multiple bodies and technical operations which are brought together in common cause. In relation to accountancy, for example, Miller describes the creation of ‘calculable spaces’, which make “visible the hierarchical arrangement of persons and things.”¹¹³⁸

The argument in this chapter is that the recognition of ADRTs both relies upon and gives rise to, techniques which fall within the broad category of the ‘technologies of government’. This is to say that ADRTs comprise and require techniques which seek to shape behaviour, thought and decisions i.e. techniques which govern (i.e. ‘conduct the conduct of’)¹¹³⁹ others. These techniques and practices rely on a loose alignment of multiple bodies and agencies as an assemblage of power.¹¹⁴⁰ The law must be disseminated to individuals who might wish to create an ADRT, which can be achieved through arms of the state government (e.g. the Department of Health), organisations such as health authorities, medical practitioners, carers, lawyers, media organisations and charities with an interest in matters at the end of life (following training from their respective professional bodies).¹¹⁴¹ In order to create an ADRT, individuals may require the support of advocates, such as

¹¹³³ M Dean ‘Putting the Technological into Government’ (n 951) 61

¹¹³⁴ *ibid* 52

¹¹³⁵ P Miller and N Rose, ‘Governing Economic Life’ (n 966) 8

¹¹³⁶ M Dean, ‘Governing the Unemployed Self in an Active Society’ (n 679) 581

¹¹³⁷ *ibid*

¹¹³⁸ P Miller ‘Accounting and Objectivity: The Invention of Calculating Selves and Calculable Spaces’ (1992) 9(2) *Annals of Scholarship* 61, 75 cited in M Dean ‘Putting the Technological into Government’ (n 951) 51-52

¹¹³⁹ C Gordon, ‘Governmental Rationality: An Introduction’ (n 689) 188

¹¹⁴⁰ N Rose and P Miller, ‘Political Power Beyond the State: Problematics of Government’ (n 675) 201; see also M Foucault, *Security, Territory, Population* (n 6) 312

¹¹⁴¹ See T Osborne, ‘On Liberalism, Neo-Liberalism and the “Liberal Profession” of Medicine’ (1993) 22 *Economy and Society* 345, 350-355

IMCAs,¹¹⁴² or interpreters. ADRTs may then have to be interpreted and assessed by carers, medical practitioners and ultimately by the courts. All of these bodies, and many more besides, must operate together in order to offer the mere possibility of individuals being able to make legally binding decisions about their future healthcare.

Thinking about ADRTs in this way invites us to consider how they may be employed, not only for the individual to govern their own future, but how others might be governed though facilitating this possibility of creating self-directed legislation. Having provided a definition of the technologies of government and suggested why ADRTs might have a role within this category of government, the next task is to define the target of ADRTs *qua* practices of government i.e. the question of the identity of the other who is to be governed through ADRTs. It is to this task that we now turn.

THREE OTHERS OF GOVERNED BY ADRTS

Making the case for recognising the operation of ADRTs as part of the technologies of government requires a definition of the objects to be governed. Mirroring the broad distinction between the technologies of the self and the technologies of government, ‘the other’ might be crudely defined as any entity apart from the self. However, at first blush, it might be thought a strain to interpret ADRTs as having a role in the government of others when they appear to be eminently self-oriented instruments: as set out in the first chapter ADRTs are created by the self, for the self, in a self-elected manner and without prompting or direction from the medical profession or any third party. Appearances aside, it is argued here that ADRTs do play a role in contemporary society in the *government of others* and they might be regarded as governing three categories of other: the population, the ‘future self’, and the interpersonal other. These different categories of other will be considered in turn.

THE POPULATION

“...[M]edicine is a social practice, and only one of its aspects is individualistic and valorizes the relations between the doctor and the patient”¹¹⁴³

As discussed earlier in this thesis, the orthodox view of the development of ADRTs in law and bioethics centres on the individual, a person who’s right to personal autonomy ought

¹¹⁴² *Re E* (n 10)

¹¹⁴³ M Foucault, ‘The Birth of Social Medicine’ in *Essential works of Foucault, 1954-1984: vol 3 Power*, James D Faubion (ed), (Penguin Books 2002) 136

logically to extend to decisions about her future healthcare.¹¹⁴⁴ Some have suggested that the development of autonomy which underpins ADRTs, is based on a political project that sought to empower patients and problematised the extent of medical control patients and sought to limit medical power and the legitimisation of legal regulation of the area.¹¹⁴⁵ Here, however, a more complex narrative is provided in asserting that ADRTs have an additional role *vis-à-vis* in respect of the population (*man-as-species*).¹¹⁴⁶ This involves paying attention to the general tendencies of the law on ADRTs in society, rather than to the effect it has in individual cases. Rather than simply seeking to establish the legitimate bounds of individual decision making in respect of future healthcare and how to construct a legal framework to best protect their wishes, an additional can be identified in respect of what the effects the system of ADRTs might have at the level of the population. Such a consideration is crucially important in the context of a governmental analysis, because Foucault made repeated reference to the fact that the population became the “end and instrument of”¹¹⁴⁷ government during the Eighteenth Century, such that all governmental interventions must be refer to the population in some way.¹¹⁴⁸ And although we have moved beyond the pitting of populations against one another for the purposes of expanding the interests of the state, there is still an interest creating the conditions under which the population can flourish. In order to better appreciate how ADRTs might be concerned with the government of the population, it is useful to consider the idea of ‘biopower’.¹¹⁴⁹

BIOPOLITICS AND BIOPOWER

“What can the end of government be? Certainly not just to govern, but to improve the condition of the population, to increase its wealth, its longevity, and its health.”¹¹⁵⁰

Foucault’s work on governmentality and the governmentalisation of the state was set out in detail earlier in this thesis.¹¹⁵¹ This discussion charted the shifts in power relations and strategies of government that occurred in western society, driven by the various crises of government that periodically emerged. Foucault devoted considerable attention to the changes of this kind that took place in the Eighteenth Century with the advent of modernity and the industrial revolution. As a result of these changes, the state became acephalous and

¹¹⁴⁴ See Chapters One and Two

¹¹⁴⁵ J Herring, ‘Where Are the Carers in Healthcare Law and Ethics?’ (n 1) 65-66; see K Veitch, *The Jurisdiction of Medical Law* (n 8) 18-25

¹¹⁴⁶ M Foucault, *Society Must be Defended* (n 696) 242

¹¹⁴⁷ M Foucault, *Security, Territory, Population* (n 6) 105

¹¹⁴⁸ *ibid* 78-79; 350

¹¹⁴⁹ M Foucault, *Society Must be Defended* (n 696) 243

¹¹⁵⁰ M Foucault, *Security, Territory, Population* (n 6) 105

¹¹⁵¹ Chapter Six

the role of sovereignty was changed,¹¹⁵² and was offset by the new practices of government and security that emerged.¹¹⁵³ The most important impetus behind these changes in power relations was the recognition of the population as a collective body, *man-as-species*.¹¹⁵⁴ Following this recognition, it was the population, rather than the state, which came to represent the central object of government. The need to govern this new body brought with it a need to develop knowledges for the monitoring and protection of the population.

Historically, this need was addressed in different ways. Prussia pioneered *Staatsswissenschaft*¹¹⁵⁵ and enforceable public health measures through the *Medizinischepolizei*¹¹⁵⁶ that could be activated in order to intervene in the population with the goal of protecting and improving health. The ultimate goal of this police action aimed at the improvement of health was to strengthen the state powers as part of the *raison d'état*.¹¹⁵⁷ A more liberal approach was developed in England, which did not seek to secure these policies through a police model, but rather operated through, techniques such as the recording of the rates of births and deaths.¹¹⁵⁸ This approach was directed towards fostering the population, for the sake of the population (rather than to strengthen the state).¹¹⁵⁹ Since then, numerous public health programmes have been developed incorporating different strategies and focussing on different aspects of health (e.g. restrictions on the availability of tobacco and alcohol, encouragement to lead active lifestyles and eat a certain quantity of fruit and vegetables), but all of which are aimed at the maintenance and production of a healthy population.

The development of these practices of government was identified by Foucault as a new form of power called biopower, “a continuous, scientific power to make live”,¹¹⁶⁰ which could be exercised both on and through bodies, both individual and collective.¹¹⁶¹ Unfortunately the term biopower was used almost interchangeably with the ‘biopolitics’ in

¹¹⁵² M Foucault, *Society Must be Defended* (n 696) 241

¹¹⁵³ M Foucault, *Security, Territory, Population* (n 6) 104-108

¹¹⁵⁴ M Foucault, *Society Must be Defended* (n 696) 242

¹¹⁵⁵ M Foucault, ‘The Birth of Social Medicine’ (n 1143) 137

¹¹⁵⁶ Which might be roughly translated as ‘medical police’, but with the understanding that the term ‘police’ bore a meaning that went beyond prevention and extended to positive promotional activities.

¹¹⁵⁷ M Foucault, *Security, Territory, Population* (n 6) 237; M Foucault, *The Birth of Biopolitics* (n 674) 1-21

¹¹⁵⁸ M Foucault, *The Birth of Biopolitics* (n 674) 31

¹¹⁵⁹ See M Foucault, *Security, Territory, Population* (n 6) 348

¹¹⁶⁰ M Foucault, *Society Must be Defended* (n 696) 247

¹¹⁶¹ see M Foucault, *The History of Sexuality: The Will to Knowledge* (n 706) 139; T Lemke, *Foucault, Governmentality, and Critique* (n 12) ch 3

Foucault's work, which has produced some ambiguity of meaning.¹¹⁶² Some have developed particular readings of biopower based on an idea of the domination and oppression of certain groups among the population (e.g. Agamben, Hardt and Negri),¹¹⁶³ but others tend to view this form of power as a productive force, entailing "modes of subjection", "strategies for intervention" and "truth discourses about the 'vital' character of living human beings".¹¹⁶⁴

On this understanding, biopower can be juxtaposed with the idea of sovereignty. Sovereign power has always been concerned with the end of life (and particularly ending life),¹¹⁶⁵ and was always exercised at the discretion of the sovereign.¹¹⁶⁶ Biopower, by contrast, is not merely concerned with the end of life, but brings all of the processes of life, from its inception to conclusion, within its purview.¹¹⁶⁷ It operates in the opposite direction to sovereign power in 'making live' rather than killing, but does not exclude the existence of sovereign power, which still underlies the productive forces of biopower.¹¹⁶⁸

It is significant that biopower co-emerged with the political rationality of liberalism.¹¹⁶⁹ Liberalism, as an art of government,¹¹⁷⁰ drew much from the discourse of political economy,¹¹⁷¹ which centres on a continual questioning of the actions of government in order that they may be minimised and confined to their most expedient. Biopower applies this logic to biological processes in what might be considered as a kind of economic government of life.

The liberal rationality of government sought, above all, to protect 'the natural', as its "permanent correlate".¹¹⁷² So much so, that the safeguarding of 'natural processes'¹¹⁷³ (e.g. births, deaths, the economy)¹¹⁷⁴ became a governmental priority through practices of security, wherein the corpus of society was to be safeguarded threats both internal and external.¹¹⁷⁵ This proscription of state intervention in natural processes emerged alongside a

¹¹⁶² M Foucault, *Society Must be Defended* (n 696) 243; see also T Lemke, *Foucault, Governmentality, and Critique* (n 12) 34; see also P Rabinow and N Rose, 'Biopower Today' (n 695)

¹¹⁶³ see P Rabinow and N Rose, 'Biopower Today' (n 695)

¹¹⁶⁴ *ibid* 197

¹¹⁶⁵ M Foucault, *The History of Sexuality: The Will to Knowledge* (n 706) 135-145

¹¹⁶⁶ see M Foucault, 'Technologies of the Self' (n 952) 46

¹¹⁶⁷ see M Foucault, *Society Must be Defended* (n 696) 243-248

¹¹⁶⁸ MH Nadesan (n 751) 35

¹¹⁶⁹ M Foucault, *The Birth of Biopolitics* (n 674) 22; T Lemke, *Biopolitics: An Advanced Introduction* (NYU Press 2011); and see Chapter five

¹¹⁷⁰ see M Foucault, *The Birth of Biopolitics* (n 674) 318

¹¹⁷¹ M Foucault, *Security, Territory, Population* (n 6) 106-110

¹¹⁷² T Lemke, *Biopolitics: An Advanced Introduction* (NYU Press 2011) 43

¹¹⁷³ see M Foucault, *Security, Territory, Population* (n 6) 45, 65-66, 352-353

¹¹⁷⁴ M Foucault, *The Birth of Biopolitics* (n 674) 31

¹¹⁷⁵ see below

greater recognition for individual autonomy, as a requisite of liberalism and the need for the means to create individuals that do not need to be governed by others, but who "will govern themselves, master themselves, care for themselves"¹¹⁷⁶ through their own freedom.¹¹⁷⁷

Two of the fundamental constitutive components of the practices of biopower are discipline and security.¹¹⁷⁸ Discipline is of a venerable ancestry and was used to mould individual bodies long before the processes of governmentalisation of the state took shape in earnest during the Eighteenth Century.¹¹⁷⁹ Discipline is a kind of power that operates centripetally, with a tendency to break down, focus on smaller and smaller zones, whether spatial (e.g. within the barracks, or the school) or temporal (e.g. the precise time for morning prayers in the monastery), of normalised action.¹¹⁸⁰ The exercise of discipline was visible in the actions of state institutions,¹¹⁸¹ who performed disciplinary techniques as part of an 'anatomy-politics'¹¹⁸² on individual bodies in order to make them docile and useful.¹¹⁸³ The importance of these kinds of disciplinary practices increased through their symbiotic relationship with the 'governmental forces', which were established following the displacement of sovereignty (as discussed above).¹¹⁸⁴

In contrast to a deductive *modus operandi* that was characteristic of the exercise of sovereignty,¹¹⁸⁵ techniques of *security* involved the construction of "regulatory controls"¹¹⁸⁶ to guard the populational 'milieu'¹¹⁸⁷ against perceived 'internal threats'.¹¹⁸⁸ This is achieved through the "gentle shaping of reality" rather than the establishment of prohibitions.¹¹⁸⁹ These regulatory techniques may also be contrasted with the operation of disciplinary power being *centrifugal*,¹¹⁹⁰ spreading out to reach the entire population and rather than being concerned with the analytical minutiae, focussing on generalities and equilibrium (or

¹¹⁷⁶ NS Rose, 'Governing "Advanced" Liberal Democracies' (n 686) 45

¹¹⁷⁷ See also G Burchell, 'Peculiar Interests: Civil Society and Governing "the System of Natural Liberty"' in Graham Burchell, C Gordon and P Miller (eds), *The Foucault effect: studies in governmentality: with two lectures by and an interview with Michel Foucault* (University of Chicago Press 1991) 119; T Lemke, *Foucault, Governmentality, and Critique* (n 12) 22

¹¹⁷⁸ M Foucault, *The History of Sexuality: The Will to Knowledge* (n 706) 139; M Foucault, *Society Must be Defended* (n 696) 249

¹¹⁷⁹ M Foucault, *Discipline and punish* (n 673) 146

¹¹⁸⁰ M Foucault, *Security, Territory, Population* (n 6) 44

¹¹⁸¹ see further M Foucault, *Society Must be Defended* (n 696) 250

¹¹⁸² M Foucault, *The History of Sexuality: The Will to Knowledge* (n 706) 139

¹¹⁸³ *ibid* 139-141

¹¹⁸⁴ M Foucault, *Security, Territory, Population* (n 6) 107

¹¹⁸⁵ M Foucault, *Society Must be Defended* (n 696) 241

¹¹⁸⁶ M Foucault, *The History of Sexuality: The Will to Knowledge* (n 706) 139 emphasis removed

¹¹⁸⁷ see M Foucault, *Security, Territory, Population* (n 6) 20-24

¹¹⁸⁸ M Foucault, *Abnormal* (n 1040) 317; M Foucault, *Society Must be Defended* (n 696) 216

¹¹⁸⁹ M Foucault, *Security, Territory, Population* (n 6) 47

¹¹⁹⁰ *ibid* 44

homeostasis).¹¹⁹¹ The ‘biopower’ that emerged, pertains to a form of power inherently bound up with the vital processes of bodies both individual and collective. This kind of operation of the government of others through the practices of biopower allows the reach of government to be extended into far more intimate aspects of life than was previously possible under disciplinary regimes.¹¹⁹² The expansive reach of biopower can be seen in the establishment of a legal framework on ADRTs.

Thus far, the development of ADRTs has been characterised as the legal manifestation of a process of normative rationalisation of the individual right to refuse treatment, grounded in ideas of autonomy and self-determination. By contrast, construing ADRTs as a form of biopolitical intervention encourages attention to be paid to the shift in the operation of sovereign power which occurred as part of the “governmentalisation of the state”¹¹⁹³ and the shift in the manner of interaction between ADRTs and the population.

As discussed in previous chapters, the considerable obstacles to drafting an ADRT that will ultimately be viewed as being both valid and applicable, highlighted in previous chapters, limit the capacity of ADRTs to deliver predictable outcomes at the end of life at the level of the individual.¹¹⁹⁴ However, taking a more generalised view at the level of the population, may allow for a more “gentle shaping”¹¹⁹⁵ of end-of-life processes. This could help to increase the predictability of decisions at the end of life. As ‘inscription devices’,¹¹⁹⁶ they draw out information about the individual’s end of life decisions through impelling their creators to state the state the kind of decisions they would like to take in circumstances that they specify. This kind of knowledge facilitates the practices of government at the end-of-life. As a consequence, ADRTs may strengthen the population and the possibility of governing through advanced liberal practices, through relieving some of the difficulties associated with making end-of-life decisions on behalf of others.

One of the ways that ADRTs facilitate the government of the population is through their tendency towards the legitimisation and regularisation of medical intervention at the end of life. In facilitating refusals of treatment medical treatment at the end of life, ADRTs offer one possibility for resolving dilemma of when to cease the provision of medical treatment at the end of life and consequently provide one way of regulating the extent of life-saving and

¹¹⁹¹ M Foucault, *Society Must be Defended* (n 696) 249

¹¹⁹² See P Rabinow and N Rose, ‘Biopower Today’ (n 695) 196-197

¹¹⁹³ M Foucault, *Security, Territory, Population* (n 6) 109

¹¹⁹⁴ See M Brazier and Cave E (n 34) 162; A Fagerlin and CE Schneider (n 893); C Kitzinger (n 1051); see Chapters One and Six

¹¹⁹⁵ M Foucault, *Security, Territory, Population* (n 6) 47

¹¹⁹⁶ See M Dean ‘Putting the Technological into Government’ (n 951) 56

life-sustaining medical intervention at the end of life. The strategies of subjectivity which valorise *homo oeconomicus* invite prudent and responsible individuals¹¹⁹⁷ to predict and make provision for their end-of-life interests. The simple provision of a framework for creating such decisions marks out end-of-life decision-making as an appropriate zone of individual decision making, and consequently, a zone of individual responsibility. The legal framework for ADRTs will tend towards an increasing visibility and intelligibility of possible medical interventions at the end of life for the population. Consequently, the tendency of the framework on ADRTs, together with other strategies of government (e.g. Quality adjusted life years (“QUALYs”)¹¹⁹⁸, increasing rights over where a person will die) should tend towards an increase in the predictability of end of life care in a homeostatic manner¹¹⁹⁹ characteristic of the practices of security.

It is opportune to reemphasise the function of ADRTs in that they are simply devices for refusing treatment. The possibility of refusing treatment in advance through ADRTs extends the range of people who may consider end of life treatment beyond those who are immediately confronted by such decisions. As ADRTs can be formed by any member of the adult population, because all individuals in society are susceptible¹²⁰⁰ to losing mental capacity in circumstances in which their lives could be extended through medical intervention.

Granting individuals the right to make ADRTs might be seen as ceding a degree of sovereign power in that the individual becomes the master of her own date of expiry.¹²⁰¹ However, a closer examination of the restrictions in the framing of the law¹²⁰² some of the more contentious decisions that have been reported on ADRTs from the court of protection¹²⁰³ suggest that the true amount of control that has been ceded is far from complete.¹²⁰⁴ A level of residual sovereignty becomes visible at the point of interpretation of an ADRT. Although the creator of an ADRT has total discretion in stating the kinds of medical treatment they can refuse and the circumstances under which that refusal is to take effect. The refusal to uphold a purported ADRT aimed at refusing life sustaining treatment on the grounds that it is not applicable or is lacking in validity could be seen as an act of sovereignty, because the consequences of such an interpretation would be to make the author

¹¹⁹⁷ See T Lemke, “The Birth of Bio-Politics” (n 683) 201

¹¹⁹⁸ S Barrie, ‘QALYs, Euthanasia and the Puzzle of Death’ (2015) 41 *Journal of Medical Ethics* 635

¹¹⁹⁹ M Foucault, *Society Must be Defended* (n 696) 246

¹²⁰⁰ NS Rose, *The Politics of Life Itself* (n 362) 84-95

¹²⁰¹ See Memmi cited in T Lemke, *Biopolitics: An Advanced Introduction* (NYU Press 2011) 91-92

¹²⁰² See Chapter One

¹²⁰³ see Chapter Six

¹²⁰⁴ see e.g. *Re E* (n 10) and *W v M* (n 11)

of the ADRT live (if accompanied by a best interests assessment), while the recognition of a valid and applicable ADRT is tantamount to letting the individual die.¹²⁰⁵ This expression of sovereignty is masked by the ADRT and the idea that it offers a degree of legitimation for the decisions taken.

As highlighted earlier in this chapter, the general tendency for individuals to live longer lives is a well-documented phenomenon in England and Wales (and in the West more generally). Historically, one of the objectives of government was to simply increase lifespan in the population,¹²⁰⁶ and, in terms of that objective, the increased life-expectancy now enjoyed by so many is an achievement to celebrate. However, in more recent times, the effectiveness of the strategies for increasing lifespan have coincided with the demographic swell created by the large-scale repopulation which occurred following the Second World War as the elderly population has grown. Some fear that this has created an imbalance in society, with a greater 'dependency ratio' between those who are capable of gainful employment and those who are not. In this sense, the increasing success of medical intervention at the end of life is at once "a cause for celebration"¹²⁰⁷ and a cause for concern as the ethical guidance on the deployment of these life-sustaining treatments has lagged behind the scientific achievements, which have made it possible to extend ever further.

The strategy of facilitating ADRTs does not ostensibly compel any individual or part of the demographic to refuse treatment or to make an ADRT, but enabling that option will naturally tend towards more refusals of treatment being made at the level of the population. Moreover, unlike Ulysses contracts,¹²⁰⁸ ADRTs in English law are specific in respect of the event that will trigger their application and in respect of the group of persons to whom they apply *viz* those who have lost mental capacity for particular decisions. It so happens that those who lack capacity at the end of life are precisely the group that is unable to be governed in accordance with the advanced liberal orthodoxy of governing through autonomy.¹²⁰⁹

As discussed above, the realisation that those who lack capacity at the end of life present such a difficulty to a system of government based on advanced liberalism and that ADRTs are targeted to take effect against this group is suggestive of a certain rational alignment of government through ADRTs. However, the legislative identification of a group of society

¹²⁰⁵ see M Foucault, *Society Must be Defended* (n 696) 241

¹²⁰⁶ M Foucault, *Security, Territory, Population* (n 6) 105

¹²⁰⁷ A Dillnot, *A Fairer Care Funding* (The Commission on Funding of Care and Support, 2011) 2

¹²⁰⁸ see Chapter One

¹²⁰⁹ see MH Nadesan (n 751) 181; and see NS Rose, *Powers of Freedom* (n 819) 50, 68

who may wish to consider the possibility of refusing life sustaining treatment accords with Foucault's counterintuitive conceptualisation of racism as an aspect of government that emerged with the biopower.

Foucault discussed racism during his lectures at the Collège de France, but particularly in *Abnormal*¹²¹⁰ and in *Society Must be Defended*.¹²¹¹ In this discussion he departed from more conventional understandings of racism based on race and ethnicity,¹²¹² as he did not define race in biological or ethnographical terms. Consequently, his interest in racism centred not on the attitudes and activities that accompanied a period of European colonial expansion, (indeed this was an aspect of racism that he neglected),¹²¹³ but rather as arising from the recognition of the population and the need for government to orient itself towards the protection of the population through the identification of persons and groups which threaten its flourishing. It was the need to protect the population which made possible the categorisation of groups of people being categorised as 'threats' to the whole population.¹²¹⁴

Racist rationalities go further than merely establishing and identifying different categories of people. It further suggests that those who can be categorised as threats are to be 'killed' for the protection or the betterment of the population as a whole further to the ends of government.¹²¹⁵ However, particular care must be taken at this juncture to appreciate that, in Foucault's usage of the term, 'killing' does not necessarily mean killing in a literal sense. In addition to the actual ending of life it also includes the exposure of a person to the mere *risk of death*.

In *Society Must be Defended* Foucault drew a link between racism, which relies on this kind of killing, and biopower.¹²¹⁶ An analytical distinction is made between the operation of biopower, wherein the governor aims to foster the health and wellbeing of the populational stock¹²¹⁷ and 'internal racism', which seeks to draw distinction between the worthy from the unworthy lives.¹²¹⁸ That is, the ability to "introduce a break in the domain of life that is

¹²¹⁰ M Foucault, *Abnormal* (n 1040)

¹²¹¹ M Foucault, *Society Must be Defended* (n 696)

¹²¹² C Taylor, 'Race and Racism in Foucault's Collège de France Lectures' (2011) 6 *Philosophy Compass* 746, 749

¹²¹³ KS Rasmussen, 'Foucault's Genealogy of Racism' (2011) 28 *Theory, Culture & Society* 34, 35

¹²¹⁴ M Foucault, *Society Must be Defended* (n 696) 258

¹²¹⁵ M Foucault, *Security, Territory, Population* (n 6) 353

¹²¹⁶ T Lemke, *Biopolitics: An Advanced Introduction* (NYU Press 2011) 40-50

¹²¹⁷ M Foucault, *Society Must be Defended* (n 696) 105

¹²¹⁸ See KS Rasmussen (n 1213) 35-44; 44; see also U Bröckling, 'Human Economy, Human Capital: A Critique of Biopolitical Economy' in Ulrich Bröckling, Susanne Krasmann and Thomas Lemke (eds), *Governmentality current issues and future challenges* (Routledge 2011)

under power's control"¹²¹⁹ between those whose lives should be supported and those who should be 'let to die'. Thus, the idea of 'killing' certain sections of the population is not only to be identified in the starkest events of mass slaughter, such as the Holocaust, but is also to be found in the outwardly innocuous public health decisions which allow some sections of society to be exposed to a greater risk of death (e.g. through environmental hazards or crime) or through the control of reproduction (e.g. through sterilisation and abortion services).¹²²⁰

Another way to approach the identification of 'internal threats', would be to give further thought to the functional foundations of advanced liberal programmes of government and, in particular, their reliance on individuals acting 'autonomously', or in a way that is self-directed, self-determined and responsible.¹²²¹ However, there are sections of the population that cannot fulfil these responsibilities. They then present difficulties to the functioning of this entire rationality of government. This state of affairs means that decisions which ought to be made by the individual (in accordance with the advanced liberal rationality) must be made by another party. However, making decisions on behalf of those who cannot make decisions for themselves raises a tension within the advanced liberal rationality of government, which eschews the dictating of values, other than the obligation to choose.

Crucially, both ADRTs, and the MCA more generally, are aimed precisely this 'ungovernable' group. Those who can no longer participate as agents within a liberal system of government, which depends, as it does, upon individuals making independent, self-determined decisions. Their inability to make choices stymies the operation of this kind of government because those who cannot be taught to govern themselves through their own free will fall outside the type of population that can be governed. Moreover, while death may not be the optimal result for such individuals, it could still be viewed as being consistent with the traditional bio-political goal of maximising wellbeing at the populational level,¹²²² if that were to mean more resources freed up to support those who remain economically active, or for the provision of other healthcare resources. By way of example, a recent piece of research has analysed the cost of the process of seeking court approval for the withdrawal of medical treatment from PVS patients, not simply in terms of the sterling quantum, but also

¹²¹⁹ M Foucault, *Society Must be Defended* (n 696) 254

¹²²⁰ NS Rose, *The Politics of Life Itself* (n 362) 61

¹²²¹ See e.g. B Hindess, 'Liberalism, Socialism and Democracy: Variations on a Governmental Theme' (n 677) 301; K Veitch, *The Jurisdiction of Medical Law* (n 8) 42

¹²²² M Foucault, *Society Must be Defended* (n 696) 242

in terms of the number of quality adjusted life years (“QUALYs”) the process would cost.¹²²³

The incidence of people to falling into this category (i.e. being at the end life and lacking mental capacity) is set to increase as a result of the UK’s demographic changes noted above and this arguably represents not merely a growing mass of individual dilemmas regarding end of life treatment, but also a threat to the management of the population, arising from within, at the end of life. An appreciation of ADRTs in terms of their alleviation of decision making and governmental dilemmas at the end of life presents them as devices which are not merely directed to address individual dilemmas, but also the kinds of dilemma posed for society more generally. In bioethical parlance, we might say that this perspective emphasises the operation of ADRTs as public health interventions.

This analysis of ADRTs, as practices of government directed towards the population, can be contrasted with the more traditional analyses of ADRTs as medico-legal interventions aimed at the protection and vindication of individual rights at an individual level. That is, where individuals carefully consider their own circumstances and values, and decide whether they would wish to be kept alive in those circumstances. This analysis does not deny the association of ADRTs with individuals making decisions in accordance with their own preferences, but rather it is to suggest that the framework which enables the creation of ADRTs has also been shaped in such a way as to enable the government of the population as a form of ‘other’.

ADRTS AND BIOWEAPON – RETURN OF THE KING?

At this juncture, an apparent contradiction must be confronted. Biopower, by nature, is a productive force. By contrast, the racism described in the previous section, is paradigmatically deductive in that it is enforced through killing. How, therefore, does the ethos of biopolitics sit with the deductive operation of racism?

Having considered Foucault’s discussion on racism, a view can be taken that the biopolitical objective of fostering the population need not entail the preservation of each of the lives of its constituents. Indeed, there are some lives which, according to Foucault, come to be characterised as ‘threats’ to the rest of society through neoracist discourse, in that they harm the general prosperity of society.¹²²⁴ Far from fostering these lives, the ‘proper

¹²²³ S Halliday, A Formby, and R Cookson, ‘An Assessment of the Court’s Role in the Withdrawal of Clinically Assisted Nutrition and Hydration from Patients in the Permanent Vegetative State’ (n 1061)
¹²²⁴ See M Foucault, *Abnormal* (n 1040) 316-318

management' of the population requires that these lives are brought to an end, or simply not supported and exposed to a greater risk of death. Such action could be taken in the name of reducing the purported harm caused by the 'threat', but it can also be taken in order to foster a sense of core identity among the population which is to be fostered.¹²²⁵

This mode of thought was writ large in Nazi ideology. The idea that the German *Volk* was a superior to all other races and peoples was manufactured by the and, at the same time; those who were not deemed to belong to *Volk* were portrayed as threat to the prosperity of the nation.¹²²⁶ Propaganda purported to show the cost of educating 'normal' children and children with disabilities to suggest that there was an increased financial cost associated with bringing up children with disabilities which would be borne by the German state. Such logic could have been taken directly from Rudolf Goldscheid, who drew analogy between the safeguarding of the population, in this way, and the rearing of farmyard animals, wherein the whole farm suffers from animals that are sick and non-productive.¹²²⁷

This taking of life is traditionally associated with the exercise of sovereign power. As discussed above, this is a form of power that Foucault describes as having been displaced between the Sixteenth and Eighteenth centuries as part of the so-called 'governmentalisation of the state'.¹²²⁸ In speaking of the displacement of sovereign power, Foucault maintained the view that the King's head has not been entirely severed and thereby hinted at a continuing role for sovereignty in modern society.¹²²⁹ Having suggested a role for sovereignty persisted in the modern era, Foucault, nevertheless, left the precise nature of its role tantalisingly undefined. Many commentators have since sought to theorise the role of sovereignty (and the law with which it is bound)¹²³⁰ in contemporary society.

One of the best known, and most provocative, accounts of the function of sovereignty in modern society is offered by Giorgio Agamben. Among others, his thesis draws on the work of Karl Schmitt, who suggested that the sovereign can be identified as the person who can suspend the ordinary operation of law and define 'states of exception' (*Ausnahmezustände*).¹²³¹ Individuals within these states of exception lose the rights afforded to ordinary citizens and come to be recognised as mere biological entities. Agamben invokes

¹²²⁵ see KS Rasmussen (n 1213)

¹²²⁶ *ibid* 42-46

¹²²⁷ see U Bröckling, 'Human Economy, Human Capital' (n 1218) 254-255

¹²²⁸ see Chapter Five

¹²²⁹ M Foucault, 'Truth and Power' (n 821)

¹²³⁰ See e.g. B Golder and P Fitzpatrick, *Foucault's Law* (Routledge-Cavendish 2009) and A Hunt, and G Wickham, *Foucault and Law: Towards a Sociology of Law as Governance* (Pluto Press 1994)

¹²³¹ see G Agamben (n 625) 19

the ancient roman character, Homo Sacer, as an example of a person who could be stripped of their political rights as a citizen by the sovereign and reduced to the animal status of a 'bare life' that could be killed but not sacrificed.¹²³² A more recent example, upon which Agamben draws heavily, is that of the concentration camp. Those tortured and murdered in such camps were stripped of their humanity. The atrocities carried out within the camps, as part of the Holocaust, were facilitated by the designation of spaces in which the normal order and ordinary rights could be suspended for particular groups.¹²³³

Importantly, those examples are not merely to be viewed as egregious historical phenomena; rather they are presented to advance an argument about the general nature and function of sovereignty. Consequently, the idea of the creation of 'states of exception' is a practice that Agamben views as taking place within modern forms of liberal government as well as within murderous totalitarian regimes. Moreover, Agamben claims that there has been a pervasive reliance on the technique of generating exceptions and that this practice has developed to the extent that states of exception have been blended into the normal order:

“instead the decisive fact is that, together with the process by which the exception everywhere becomes the rule, the realm of bare life – which is originally situated at the margins of the political order – gradually begins to coincide with the political realm, and exclusion and inclusion, outside and inside, *bios* and *zoē*, right and fact, enter into a zone of irreducible indistinction.”¹²³⁴

However, not all commentators are prepared to acknowledge such a role for sovereignty. Rabinow and Rose argue that although thanatopolitics of this kind may occur within totalitarian regimes, modern biopolitics is more closely associated with the function of sovereignty that Foucault articulated in *The History of Sexuality* viz the power to make live and to let die.¹²³⁵ They claim that theorists such as Agamben, Hart and Negri have overemphasised the role of sovereignty's killing function within biopower and have neglected attention on its productive effects. Rose doubts the historical continuity inherent in Agamben's argument¹²³⁶ and further raises a strong objection that not all biopolitical interventions are made at the direction of the sovereign.¹²³⁷

Another invocation of sovereignty (briefly considered in Chapter Two), pertinent to this area of study can be found in relation to the individual right to refuse treatment. Joel

¹²³² *ibid* 53

¹²³³ see *ibid* 90-101

¹²³⁴ *ibid* 12

¹²³⁵ P Rabinow and N Rose, 'Biopower Today' (n 695)

¹²³⁶ NS Rose, *The Politics of Life Itself* (n 362) 59

¹²³⁷ *ibid* 58, 63

Feinberg advocates a libertarian account of personal autonomy that he terms “personal sovereignty”.¹²³⁸ This likening of the individual to a state sovereign is productive in that it allows the individual to be thought of as having a right of death over herself. If this right is exercisable by the individual over themselves pursuant to a sovereign right, its exercise would not be subject to some of the more exacting requirements imposed by some of the ‘thicker’ conceptions of autonomous decision making considered in chapter three.

This idea of individual sovereignty can readily extend to ADRTs as legal instruments purporting to allow individuals to take these kinds of sovereign decisions over life. In turn, the idea of extending individual sovereignty through ADRTs can be read with the arguments of those, such as Memmi, who claim that there has been a broader devolution or democratisation of sovereignty in modernity.¹²³⁹ According to this claim, the concentration of sovereignty in a single head of state has been distributed out and ordinary citizens now enjoy some sovereignty over themselves. Such arguments have a strong *prima facie* association with those deployed in support of ADRTs in terms of self-determination.¹²⁴⁰ The idea of self-determination being enshrined in law and extended through ADRTs can be portrayed as the culmination of a process of wresting part of the ancient right of death from the sovereign. Nevertheless, we must also remember the further difficulties with accepting the simple proposition that a right to self-determination is extended. In particular, it must be remembered so much of the potential of ADRTs is dependent not merely upon the will of their creators, but also upon the spirit in which they are interpreted by others. Further, it will be recalled from Chapter One that the way the law on ADRTs is framed, supports considerable discretion to those charged with the interpretation of ADRTs.

The ideas of personal sovereignty and self-determination appear therefore to readily complement each other as they apply to ADRTs, but the invocation of the idea of personal sovereignty quickly invites a reconsideration of the critiques discussed in Chapter Three. There the premises of modern individualist forms of autonomy were highlighted and questioned. The critical accounts considered in chapter three argued that the kinds of assumption made by advocates of individualistic conceptions of personal autonomy are problematic in their tendency to overlook the social factors that may inconveniently colour decisions about medical treatment, failing to account for the imbalances of knowledge and the multitude of motivations which may lie behind decisions, in assuming that everyone is free to make a decision and that such decisions are made in idealised spaces that are free

¹²³⁸ 48 and see ch 19

¹²³⁹ See T Lemke, *Biopolitics: An Advanced Introduction* (NYU Press 2011) 91-92

¹²⁴⁰ See Chapter Two

from such pressures and imbalances. The reality for many is likely to be a far cry from this idealised expectation and thus the appositeness of an individualised conception of autonomy as a practical basis for the law on consent and on ADRTs appears questionable.

In the light of these critiques, though likening individuals to sovereigns is a neat analogy, it is also one which fails to fully account for, and perhaps masks, the multitude of external pressures and particularly that those who are sovereign over those individual sovereigns. On this basis, the utility of the idea that the individual can be treated as sovereign over the territory of their body seems questionable. For even accepting that the individual can be considered sovereign in a sense, we must surely recognise that their bodily territory is landlocked and subsumed within that of the state sovereign, whose territory authority is in turn tempered by her membership of international treaties and organisations. Sovereignty must be understood in context.

Thus, even if individual has been ceded the right to end his or her own life, that legal right is subject to the adherence to certain formalities and to the interpretation of others. Consequently, if we are to regard the individual's right to create ADRTs as indicative of individual sovereignty, that understanding must be understood alongside an understanding of the extent to which the effect and practical utility of ADRTs is shaped by others. The individual can make a decision that purports to be sovereign over their existence, but it is not they who will ultimately decide whether they are to be 'let die' through the upholding of their ADRT or made to live through the rejection of their ADRT.

It is in the realisation of the contingent nature of the right of decision-making of the individual, particularly in respect of end-of-life decisions, that it is possible to see the connection with Foucault's argument about the modern operation of sovereignty: 'making live and letting die'.¹²⁴¹ The individual plainly does not have a right framed in such terms. Individuals cannot make themselves live. This is true both in a practical sense and in the legal sense, explored in Chapter One, in which it was stated that there is no right compel the provision of treatment. Nor can they command the administration of substances to accelerate their own death by another.

Moreover, the limited right that individuals do have to refuse treatment, and thereby control the point of their demise, is subject to the interpretation of others before its practical effect can be known. Chapter One drew attention to the fact that a higher evidential burden falls on those purporting to treat an ADRT as binding (and thus withhold or withdraw

¹²⁴¹ see M Foucault, *The History of Sexuality: The Will to Knowledge* (n 706) 139

treatment) than falls on those purporting to treat the ADRT as non-binding (and thus provide or continue treatment). In difficult cases such as *W v M* and *Re E* (considered in detail in Chapter Six) the court-sanctioned interpretation of the purported ADRTs as being inapplicable led to the continuation of treatment and the prolongation of life. Viewed in this way, this act of interpretation appears very much like the exercise of the right to make live, the operation of sovereignty. Equally, cases in which ADRTs are upheld, treatment is withheld or withdrawn, and death results are capable of being considered decisions to ‘let die’ made by those who might have interpreted the ADRT differently. In this sense, ADRTs can be thought of as exemplifying the operation of a sovereignty held not so much by the individual, newly empowered to assert their rights against the world, but rather by the state as a limiting factor on this individual power.

Consequently, sovereignty and the right of death can certainly be seen as having a role within modern biopolitics and the manner in which that role is played out in the context of ADRTs. However, given the preceding discussion, it would be too simplistic to conclude that the role is simply about giving individuals the right of death over themselves. The right that individuals have won is contingent.

BIOPOLITICS, SOVEREIGNTY AND ADRTS

In Chapter Six it was argued that the formation of an ADRT necessitates the engagement with processes of self-government. ADRTs cannot be created without the contemplation of a future state in which capacity is lacking, medical treatment is clinically indicated and a certain form of treatment, of a variety that the creator of the ADRT would wish to refuse (in all cases, or in whatever further circumstances they may specify), is envisioned. Making a decision of this nature, in the knowledge that if the decision should take effect it will determine the lifespan of its creator, demands more than trivial thought.

Given that the creator of an ADRT must engage with his or her possible future medical treatment in this prudent and proactive way, the process of creating an ADRT may lead that person to engage with other long term questions regarding their lives and their future health. In this sense, ADRTs might be seen as part of a constellation of long-term planning instruments, such as life insurance, insurance against funeral costs and testamentary dispositions. It would be unsurprising if the engagement with such forward-planning acts of self-care may also lead to engagement with further practices of self-care pertaining to the life and health of the creator.

Taken together, these kinds of instruments and practices of self-care are likely to have a cumulative effect across the population in ameliorating some of the difficulties associated

with the dying process. Improving the efficiency of decision making across the population has obvious advantages in enabling resources to be freed up to be expended on other aspects of life.

One sense in which ADRTs foster the life of the population is through the valorisation of a kind of health-based prudentialism: a disposition towards active responsibility for future states of health. Encouraging individual constituents of the population to consider their future health and can be beneficial to the population as an organism. If the constituents of the population become attuned to managing their own responsibilities through creating ADRTs, it will lead to a greater engagement with useful forms of behaviour. ADRTs necessarily entail an engagement with, and concern for, one's own health. More than this, they entail a concern for *future* states of health. In consequence, ADRTs demand a kind of concern that is not reactionary but proactive. It is not a case of analysing the current state of health and contemplating how that state might be improved. Rather it is concerned with how one might react to a future state of health. This kind of practice is therefore somewhat distinct from a reaction to a state present state of health that one wishes to improve, but rather to an anticipated state of health that one would not wish to endure. This proactive disposition may make salient the kinds of health choices which could impinge on the future state of health. Concern is not restricted to the present state of health and the problems which may attend the individual in their current state, but also includes the future state of health of their creator

The discussion of individual sovereignty thus far has centred on a critique of the extent to which the individual right to make an ADRT is analogous with the rights of state sovereigns. However, an additional line of critique can be pursued in respect the idea of individuality. This critique can be produced through a return to the idea of the 'future self', explored in the Fourth Chapter, in order to analyse the so-called 'future self' and the challenge it poses to a coherent sense of individuality. In developing this critique, we can also begin to view the 'future self' as an additional category of other that can be rendered governable through ADRTs.

THE 'FUTURE SELF'

“The subject is either divided inside himself or divided from others. This process objectivizes him. Examples are the mad and the sane, the sick and the healthy, the criminals and the ‘good boys’.”¹²⁴²

A specific and powerful objection to ADRTs, based on the idea of personhood, was explored in Chapter Four. The intricacies of the argument in that chapter need not be retold here, but the idea of a ‘future self’ will be drawn upon in this section in order to illustrate an alternative way of conceiving of the government of others: namely, the construction of the future self as ‘other’.

Much simplified, this personhood critique was premised on the acceptance of the idea that the moral authority of ADRTs resided in the proximity of creator of the ADRT to that person’s ‘future self’, but suggested that the inevitable personal changes that all individuals experience throughout their lifetimes are such that ADRTs should not be capable of binding the future self. The argument goes that so much personal change is likely to occur in the period between the creation of the ADRT and its application that the ADRT cannot legitimately bind the future self.

The encouragement to construe the ‘future self’ as a kind of other is deeply ingrained within the structure of the legal framework on ADRTs. This process of division and ‘othering’ is arguably a tendency of advanced liberal society and to emphasise its divisive nature Deleuze coined the term “dividuals”.¹²⁴³ Envisioning a ‘future self’, who lacks mental capacity for certain medical decisions entails envisioning a person who thereby loses part of her or his political rights (*bios*)¹²⁴⁴ to make decisions. As such, the ‘future self’ is held out by the law as an entity lacking in full agency and becomes instead someone on whose behalf decisions must be made.

ADRTs bring this legal distinction sharply into focus, by enabling individuals with capacity to make decisions on behalf of a future incarnation of their own self who lacks mental capacity to make particular decisions. The law invites the possibility for an individual to take decisions on behalf of this imagined ‘future self’ and therefore of governing that self by restricting the kinds of medical treatment that they may be provided with in future. By opening up the possibility of refusing treatment anticipatorily at the end of life (and once mental capacity for the decision is lost), individuals are encouraged to

¹²⁴² M Foucault, ‘The Subject and Power’ (n 7) 326

¹²⁴³ G Deleuze, ‘Postscript on the Societies of Control’ (1992) 59 October 3, 5

¹²⁴⁴ see G Agamben (n 625) 9-10

conceive of their future self as an alien entity, for whom they, as a competent ancestor-to-be of that ‘future self’, are made responsible.

Thinking about the ‘future self’ in this way entails a number of self-directed practices. These were explored in the previous chapter, where the function of ADRTs *vis-à-vis* the technologies of the self was discussed. However, these technologies of the self are facilitated by and interact with the technologies of government, which enable such thought processes to take place in a practical sense. The legal framing of these kinds of decisions is one way in which individuals can be governed across the jurisdiction. In respect of ADRTs, we can see the interrelation between the practices that individuals are expected to apply to themselves and the practices which apply to them in that citizens require a certain level of information knowledge and support in order to conduct these practices to themselves. In order for individuals to become aware of their end-of-life treatment possibilities and the possibility of creating an ADRT, may require interpersonal governmental techniques.

THE INTERPERSONAL OTHER

In order for the individual to become cognisant of their future self, the travails of their existence and the possibility of making decisions which may save that future person from suffering, they must be informed of these possibilities. Cognisance of these one or more of these matters may arise spontaneously, but awareness of the combination of these possibilities is only likely to arise through interaction with another agent or institution with the requisite kinds of knowledge. However, the MCA fails to identify a relevant body or agency with responsibility for informing citizens of their rights.

In adherence to the rationalities of advanced liberalism, jurisdictions such as England and Wales cannot overtly *require* individuals to make anticipatory decisions about their end-of-life treatment. Rather they have established a framework, such as that which is brought into being by the MCA, in which advance decision making is made possible. However, in the United States a statutory duty requires medical facilities to inform patients of their right to create an ADRT on admission to a medical facility.¹²⁴⁵ There is no equivalent provision in England and Wales and this may provide one explanation as to why the uptake of ADRTs has been so low. This low uptake was lamented by the House of Lords Select Committee which called for urgent action to improve uptake, but which provided no detail on how this

¹²⁴⁵ Patient Self-Determination Act 1991 §127.652 of the Omnibus Reconciliation Act of 1990, Pub L No. 101-508 (November 5, 1990)

should be achieved. A rapid increase in uptake would appear unlikely in the absence of a resolution of this difficulty.

Various possible interventions could be made, which may improve uptake, ranging from information campaigns at one end to mandated decisions at the other extreme. However, promotion of ADRTs is a sensitive matter and the attitude of this Post-Legislative Scrutiny Committee differs markedly from some of the evidence provided to the Joint Committee on Medical Ethics prior to the enactment of the MCA,¹²⁴⁶ in which fears were expressed over the probity of allowing individuals to make these kinds of decisions and whether these decisions were in fact a way of introducing a law on euthanasia. Targeting certain groups, such as the elderly or those with certain medical conditions runs the risk of suggesting that persons in with such conditions *ought* to make an ADRT and this would destroy the voluntaristic foundation of the ADRT. These fears appear to have been rapidly eroded or displaced by an international policy drive to encourage the enactment of legislation, such as the MCA, which makes provision for individuals to make decisions about their possible future healthcare.

The establishment of such frameworks is internationally mandated through various conventions, including the Oviedo Convention,¹²⁴⁷ which suggest that individuals should be given at least the opportunity to make provision for their end of life care in advance. This suggests that advance care planning and advance decision making is not a phenomenon peculiar to England and Wales, or even to common law jurisdictions. Indeed most developed nations have now introduced legislation to establish the possibility of making advance care plans or ADRTs.

In Europe the promotion of advance decision making powers is actively encouraged by the major European institutions, such as the Council of Europe (“CoE”), the Committee of Ministers and the Parliamentary Assembly of the Council of Ministers.¹²⁴⁸ The 1997 “Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and

¹²⁴⁶ See Chapter Four

¹²⁴⁷ “Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine” (Oviedo, 4.IV.1997)

¹²⁴⁸ See also R Andorno, N Biller-Andorno and S Brauer, ‘Advance Health Care Directives: Towards a Coordinated European Policy?’ (n 70)

Biomedicine” (Oviedo, 4.IV.1997)¹²⁴⁹ (the “Oviedo Convention”) emphasises the requirement that medical intervention is to be based on informed consent¹²⁵⁰ and states that where individuals cannot provide express consent for treatment “previously expressed wishes... shall be taken into account” (Art. 9). Shortly afterwards the Parliamentary Assembly of the CoE issued Recommendation 1418 (1999) “Protection of the Human Rights and Dignity of the Terminally Ill and the Dying”, which *inter alia* drew attention to the fact that it is increasingly possible to prolong the final stages of life and urged member states to guard against this¹²⁵¹ and to ensure that advance directives are “observed”.¹²⁵² Recommendation CM/Rec(2009)11 of the “Committee of Ministers to Member States on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity” made further recommendations to promote the creation of ADRTs.

These Conventions are of interest in that they suggest that the concerns regarding end of life treatment are not confined to the jurisdiction of England and Wales, but are rather of general human concern. It is perhaps unsurprising therefore that where a rationale for strengthening end of life decision making is explicitly stated, it is often linked to the advancement of Human Rights. Indeed, Resolution 1859 of the Council of Ministers suggests that the failure to create a legislative framework to enable advance decision making means that Human Rights cannot be respected.¹²⁵³ This suggests that the framework for advance decision making represents an essential component in the respect of Human Rights at the end of life. In this sense, the Human Rights basis for the recognition of ADRTs is folded into the argument for the recognition of ADRTs based on empowerment.

However, although legal frameworks are promoted, there is a failure to specify any set of individuals or groups with responsibility for advising individuals or assisting them in the preparation of an ADRT. Medical practitioners might be an obvious candidate, but to provide satisfactory advice they would require legal training particularly to enable them to distinguish ADRTs from other provisions which might appear in an ACP advanced care plan

¹²⁴⁹ <http://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164> The UK is not a currently signatory to this convention, although most other EU member states are. See <http://conventions.coe.int/Treaty/Commun/ChercheSig.asp?NT=164&CM=8&DF=21/08/2014&CL=ENG>

¹²⁵⁰ Art 5

¹²⁵¹ Recommendation 8.ii

¹²⁵² Recommendation 8.b.iv

¹²⁵³ 2012, Resolution 1859 of the Parliamentary Assembly of the Council of Ministers on “Protecting human rights and dignity by taking into account previously expressed wishes of patients” “only a tiny minority of the Council of Europe’s 800 million citizens actually have advance directives, living wills and/or continuing powers of attorney – making it difficult, if not impossible, to take their previously expressed wishes into account, and thus effectively protect their human rights and dignity” (Art 4)

(although arguably this kind of training should be provided in any case).¹²⁵⁴ Equally important is the question of funding for providing this advice,¹²⁵⁵ which is a particularly thorny issue in the context of the competing pressure to reduce costs following the financial crash of 2008. Discussing the possibility of creating an ADRT may require a lengthy conversation and the MCA suggests that such decisions should be kept under review. The provision of such a service within the NHS would involve the commitment of significant resource (although it may ultimately save resources in the avoidance of the provision of unnecessary treatment).

Another candidate would be solicitors or other professionals specialising in the preparation of wills. However, such persons may require some medical training regarding the likely causes of incapacity at the end of life to be able to provide good advice. In addition, legal fees may prohibit some from accessing this kind of advice through a solicitor. The next most likely institutional source of guidance would be a specialist charity, such as Compassion in Dying, who provide information leaflets and skeleton forms for creating ADRTs¹²⁵⁶ or Advance Decision Assistance.¹²⁵⁷ However, people are possibly less likely to come in to contact with charitable organisations such as these without specific cause to do so (e.g. a terminal diagnosis). More prosaically, people may have important discussions about their end of life preferences with their loved ones. However, in the absence of the awareness of the possibility of creating an ADRT there is little prospect of such discussions being converted into the formation of ADRTs.

Thus, it is likely that the formation of ADRTs may involve contact with a combination of actors in these spheres, as part of an ‘assemblage of advanced decision-making’. However, if the success or otherwise of these assemblages is to be measured by the uptake of ADRTs, it would seem that the lack of coordination across the various limbs of the assemblage is responsible for the low uptake at present.

Having considered three potential objects of government in the population, the future-self and the interpersonal-self, we can now consider in more detail the way in which these objects of government can be governed. As discussed throughout this chapter, ADRTs are frequently pitched as instruments aimed at the empowerment of individuals and the diminishment of medical control at the end of life. However, in as much as they are successful in meeting such aspirations, and are successful in opening up a new domain of

¹²⁵⁴ See Chapter One

¹²⁵⁵ Institute of Medicine (n 613) 181, 184-185

¹²⁵⁶ See <http://compassionindying.org.uk/library/advance-decision-pack/> [accessed 17th August 2015]

¹²⁵⁷ See <http://adassistance.org.uk/about-us/> [accessed 17th August 2015]

individual decision-making, they also invite and expect individuals to exercise self-control. The decision to create an ADRT entails the acceptance of certain propositions which tends to aid the legitimacy of the law.

For instance, one must first accept one's own mortality, the possibility of losing capacity, and a system of laws that denies those who lack capacity with the right to make binding refusals of treatment. The creation of an ADRT further necessitates the engagement with certain thought processes (e.g. reflection, prediction, comparison etc) which pertain to the medico-existential conditions of their authors.¹²⁵⁸ These kinds of thought processes, the weighing of different options and the formation of values, are operations that individuals undertake on themselves, and as such can be seen, in Foucault's terms, as 'technologies of the self'.¹²⁵⁹ The manner in which individuals do this in a practical sense can be categorised as part of the technologies of the self, but the facilitation of this mode of self-government in general terms across the population can be viewed as part of the technologies of government.

However, the cognisant failure to create an ADRT (i.e. being aware of the possibility of creating an ADRT and intentionally not doing so) could also be regarded as entailing the tacit acceptance of certain systemic propositions. There are various reasons why a person who is aware of the possibility of creating an ADRT may not wish to do so, but ultimately the failure to do so in these circumstances indicates, at least minimally, a preference for being treated in accordance with the best interests test¹²⁶⁰ over a self-authored ADRT. In this sense, the choice presented by ADRTs cannot be avoided simply through the failure to create an ADRT. Having created the framework in which such choices can be made a decision not to create an ADRT might also be considered to be a choice.

Such a conclusion has important consequences for the analysis of the effectiveness of ADRTs as a strategy of government. It means that the success of ADRTs cannot be measured simply by the frequency of their uptake i.e. by the number of people who have actually created ADRTs. In this sense, part of the governmental ends of ADRTs can be achieved by merely informing eligible members of the public of their right to create an ADRT.

The 'decision' not to make an ADRT may be made cognisantly (i.e. in awareness of the possibility of creating an ADRT at all) or not. The former case is effectively a choice to be treated in accordance with the best interests test contained in s.4 MCA following the loss of

¹²⁵⁸ See Chapter Six

¹²⁵⁹ *ibid* and see M Foucault, 'Technologies of the Self' (n 952)

¹²⁶⁰ s 4, MCA

capacity. Admittedly, it is certainly more of a conceptual strain to categorise the non-cognisant, or ignorant, failure to create an ADRT as a choice. However, the decision to categorise this omission as a choice should be read together with the general obligation on individuals to take responsibility for maximising their own state of health¹²⁶¹ and to act as ‘active health consumers’.¹²⁶² Those individuals who fail to at least consider the creation of an ADRT might be considered to have failed in their obligation to protect their own future health interests and arguably in their obligations of citizenship.¹²⁶³ Seen in this way, ignorance is also a choice.

On such a view, where even the failure to create an ADRT might be seen as a choice, ADRTs represent an unavoidable choice that is thrust upon all adult citizens with capacity to make any kind of ADRT. From this perspective, the legal framework for ADRTs at once empowers and, by the same token, *responsibilises* citizens. Such an analysis accords with Bauman’s view that the degree of choice which opens up through the removal of sources of authority ultimately amounts to a “privatization of blame”.¹²⁶⁴ The possibility of creating an ADRT does not preclude anyone from placing faith in the best interests test to provide them with the kind of treatment that they would want at the end of life, but it suggests that doing so is itself a kind of choice.

This reliance on the individual capacity to choose has never been greater in medical law. In the first Chapter it was argued that one of the most important legal developments, made under the auspices of improving personal autonomy, was to require more information to be disclosed about the risks of treatments as part of the consent process. This strategy places a responsibility of greater disclosure of information on the medical profession, but it also subtly places a responsibility on patients to learn how to cope with and process the information with which they are provided. Programmes of empowerment aimed at increasing standards of healthcare explicitly borrow from market principles in offering choices between hospitals and providing people with complex care needs with personal care budgets.¹²⁶⁵ These developments can be regarded as moves towards the empowerment of patients or the better recognition of autonomy. However, it is argued here that they can also

¹²⁶¹ see A Petersen (n 872) 193-194

¹²⁶² see e.g. *ibid*; NS Rose, *Governing the Soul* (n 673) 231; NS Rose, *The Politics of Life Itself* (n 362) 63

¹²⁶³ S Sevenhuijsen, *Citizenship and the Ethics of Care: Feminist Considerations on Justice, Morality and Politics* (Routledge 1998) 130

¹²⁶⁴ K Veitch, *The Jurisdiction of Medical Law* (n 8) 42

¹²⁶⁵ see e.g. M Kremer, ‘Consumers in Charge of Care: The Dutch Personal Budget and Its Impact on the Market, Professionals and the Family’ (2006) 8 *European Societies* 385

be viewed as part of a liberal proclivity to exercise “wise restraint”¹²⁶⁶ and avoid ‘governing too much’.¹²⁶⁷ From this perspective, those patients who are unable to deal with the increased informational demands are problematic. In this sense, the provision of healthcare information can be empowering for some, but can equally be considered burdensome for others.¹²⁶⁸ At the same time, the advanced liberal challenge to the authority of experts, through the subjection of their knowledge and authority to market forces,¹²⁶⁹ means that those who wish to receive assistance in making choices cannot receive the kind of clear direction that they once could. Expert advice itself has become a commodified subject of choice within advanced liberal constructs¹²⁷⁰ and is subject to technologies of performance, calculation and audit, in lieu of trust.¹²⁷¹ This plainly has advantages for the individual who is capable of engaging with such decisions, as they are no longer required to fall into line behind expert instruction, but can instead follow their own direction in a way that they choose and instead seek out advice which accords with their own outlook on life.

This model also heavily relies on individuals who can operate as *active* decision-makers.¹²⁷² Advanced liberalism requires individuals who are capable of acting in their own interests, as consumers.¹²⁷³ To operate as an informed and active decision-maker requires certain capacities, particularly the ability to absorb information and make decisions between competing options.¹²⁷⁴ Those who cannot engage with the market in this way, therefore pose a fundamental problem to the functioning of advanced liberal government. ADRTs offer a mechanism through which those who would otherwise be immune to government can be brought the purview of advanced liberal government.

CONCLUSION

This chapter has revisited ADRTs conditions of emergence in light of the theory of governmentality set out in the previous two chapters. It has been argued that the development of medical capacities to sustain life in circumstances of low functionality has arisen in the absence of clear, universalisable, and because authoritative direction on moral questions at the end of life. This kind of direction is absent in advanced liberalism precisely

¹²⁶⁶ C Gordon, ‘Governmental Rationality: An Introduction’ (n 689) 15

¹²⁶⁷ M Foucault, *The Birth of Biopolitics* (n 674) 319; M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 64, 144

¹²⁶⁸ see Chapter Three

¹²⁶⁹ See NS Rose, ‘Government, Authority and Expertise in Advanced Liberalism’ (n 669) 290-292

¹²⁷⁰ *ibid* 295-296

¹²⁷¹ M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 197-198

¹²⁷² see A Petersen (n 872) 193; NS Rose, *The Politics of Life Itself* (n 362) 63

¹²⁷³ P Miller and NS Rose, *Governing the Present* (n 686) 49

¹²⁷⁴ NS Rose, *Governing the Soul* (n 673) 231

because individuals are expected to govern their own interests and outside forces are not expected to make these decisions on behalf of others. This situation has emerged at a time of increasing rates of mortality due to the aging population and significant financial pressure on the provision of healthcare following the great financial crash of 2008. These factors have combined to form a *crisis of government* under advanced liberal regimes of government.

A governmental analysis of this kind of crisis seeks not only to discover the most efficient solution to the problem, but also one which the most legitimate¹²⁷⁵ and the continual questioning of legitimacy of governmental practices epitomises liberal government.¹²⁷⁶ There is no obvious answer the question of whether, and to what extent, life should be prolonged in highly fragile and dependent states (e.g. PVS and MCS) in the absence of an indication from the person to whom the decision will apply. It has been argued that a law on ADRTs has been developed and the objections considered in the second part of this thesis have been unable to prevail.

Moreover, it has been argued in this chapter that ADRTs should not only be regarded as self-directed means of individual empowerment, but also as part of the technologies of government directed at ‘others’. Indeed, there may be said to be three levels of the government of others through ADRTs, namely the government of population, of interpersonal other and of the future self.

The facilitation of advance decision making enables the transfer responsibility for end of life decisions increasingly onto the individuals. This transfer of responsibility is entirely consistent with the tenets of advanced liberalism, which foreground the role of the individual and individual choice.¹²⁷⁷ However, this can also be seen as a biopolitical intervention aimed at securing the population through protecting the exercise of ‘responsible freedom’¹²⁷⁸ protecting the population from the ‘threat’ of acquiring a large number of individuals whose lives can be sustained and prolonged, but only at great expense and who are unable to make medical decisions for themselves. This threat to the prevailing mode of governmentality is heightened in the context of limited resources available for healthcare, which has been amplified by the financial crisis of 2008; there is an increasing pressure to provide value for money in healthcare spending.

¹²⁷⁵ M Foucault, *The Birth of Biopolitics* (n 674) 319

¹²⁷⁶ NS Rose, *Powers of Freedom* (n 819) 27; NS Rose, ‘Governing “Advanced” Liberal Democracies’ (n 686) 47

¹²⁷⁷ P Miller and N Rose, ‘Governing Economic Life’ (n 966) 24

¹²⁷⁸ See M Dean, *Governmentality: Power and Rule in Modern Society* (Sage 2010) 139

In addition to this focus on the population, it has been argued that taking a different perspective on the problem of the ‘future-self’, which was first considered in Chapter Four, can allow us to view our future selves as an object of government as far as ADRTs are concerned. The re-evaluation of these personhood arguments involves returning to advanced liberalism as a rationality of government. As discussed, advanced liberalism places such stock in the autonomous and entrepreneurial individual as an active node of government. Therefore the possibility that the individual might one day lose the ability to make their own decisions represents a serious problem for advanced liberal programmes of government. This possibility not only means that incapacitated individuals will no longer be able to govern themselves through their choices, but also that they will not be *governable* through their lost capacity to choose. In this sense, the incapacitated ‘future-self’ becomes a threat to the project of the advanced liberal mode of governance at the end of life.

However, for citizens to begin to think about their ‘future self’ in this way requires an intermediate, interpersonal process of government, in which one person can advise the other as to possibility of losing capacity at the end of life and the right to refuse treatment in anticipation of such circumstances. The MCA does not prescribe any one person or body to do this and professional guidance for medical practitioners suggests that discussions on such topics should not be instigated by the professional. The lack of individuals or agents tasked with having such conversations is perhaps one explanation as to the low uptake of ADRTs notwithstanding the aspirations of state government.

CONCLUSION TO THE THESIS

Orthodox accounts in bioethics and healthcare law tend to assume that the primary rationale for the recognition of ADRTs is the extension of the right to autonomy (or self-determination). This work has problematised that assumption in arguing that the development and operation of ADRTs can only be adequately understood through an appreciation of the congress of a number of factors of which the extension of autonomy is but one.

A strong moral case can be made for ADRTs using the orthodox doctrinal presumption of the extension of autonomy. However, having considered the legal framework surrounding ADRTs in detail as well as some of the power interactions and economic considerations which attend the operation of ADRTs, the strength of the orthodox claim is far more limited. The examination of the legal framework for ADRTs in Chapter One highlighted the narrowness of the range of decisions which ADRTs facilitate. Chapter One further emphasised the multiple legal routes to the failure of ADRTs in individual cases. Thus, a closer and more dispassionate appreciation of the law, beyond the extension of autonomy headline, shows ADRTs to be quite precarious instruments, subject in large part to the spirit in which they are interpreted by the healthcare professionals and the courts. This rather sober conclusion is some way off the expectations that might be derived from some of the glowing rhetoric associated with the protection of the right to refuse treatment contemporaneously and through ADRTs by extension.

That said, ideas of autonomy have clearly played an important role in the development of the legal framework on ADRTs. However, notwithstanding autonomy's conceptual centrality it has never been furnished with a clear and settled definition in law. Its treatment as a well-worn, widely accepted concept in this area belies significant theoretical disagreements in the philosophical literature. Given the nature of these disagreements, the court might be forgiven for its hesitancy in making proclamations on ethical principles, but in the absence of a clearer definition, the suggestion that the law on ADRTs is based an extension of autonomy is ultimately an unfalsifiable assertion. At the same time, it is an assertion which has a ring of credibility in broad terms, because individuals who have strong views about the refusal of treatment at the end of life can at least increase their chances of their views honoured and at the least, their voices heard in the discussions about treatment. ADRTs might also be seen as empowering in the sense that individuals can become the instigators of treatment decisions, rather than having to wait for treatment decisions to be presented to them. Nonetheless, given the lack of concrete conceptual content accorded to

the term autonomy by those who employ it, the true extent of this empowerment, grounded in autonomy, is questionable..

This lack of clear definition makes terms like autonomy malleable to the needs governmental programmes (e.g. the law on ADRTs can be contrasted with the approach taken in respect of organ transplantation)¹²⁷⁹. One of the most important factors considered in this thesis and unexplored in other literature in this area, is the emergence of ADRTs against a backdrop of advanced liberalism. A greater understanding of the development of advanced liberalism in England and Wales, which can be readily gleaned through the theory of governmentality, allows for the development of a richer understanding of the operation of ADRTs. This mode of government requires individuals who are capable of making choices about their own healthcare. Those who cannot make healthcare decisions present a considerable problem to the continuation of government along the lines of advanced liberalism.

Foucault described the operation of programmes of government in terms of an interaction between the technologies of the self and the technologies of government. These ideas were embraced in the final two substantive chapters. The idea of autonomy lends itself well to an analysis based on an idea of self-government. In Chapter Six this idea of self-government was explored using Foucault's understanding of the term government, based on the 'conduct of conducts'. An analysis of the interaction that a person must have in order to shape their own conduct, specifically in relation to ADRTs, using two prominent cases as a concrete basis for analysis. Here it was suggested that individuals wishing to create ADRTs must perform several mental processes in respect of their existential disposition, and in so doing, subjectivise themselves as responsible, active citizens through their choice and through narrating their own values. The *telos* of this process of self-government is to ensure that individuals take active steps to contemplate and express choices about their possible end of life treatment. In consequence, they alleviate a potential crisis of government at the end of life in which a choice about the continuation of treatment must be made in the absence of a clear indication of choice from the individual.

The practices inherent in advance decision making processes place certain demands on their creators. They must firstly recognise themselves as mortal beings, who may, one day, find themselves transformed into a state of dependence on medical support for their lives to be sustained and, additionally, may lose the ability to make decisions about their treatment.

¹²⁷⁹ See T Hayes, 'Donation and Devolution: The Human Transplantation (Wales) Act 2013' (n 13)

They must consider what kind of treatment they would want (or more specifically, what kind of treatment they would not want) and then commit their decision to a text to be read by another person in future. Such a manner of thinking necessitates a reflection on personal values in order to make such a decision in an imagined scenario. Engaging with advance decision-making and performing these exercises reinforces an active consumerist self-image. This kind of subjectivisation fits precisely with the kind of subject that advanced liberalism requires in order to function. Gone are the days of medical practitioners making all treatment decisions, today the patient is enjoined to participate in such decisions and even to do so in advance of the presentation of the decision.

In the final substantive chapter, the rather counterintuitive idea that the concept of autonomy can be used for the government of others, through priming individuals to actively look after their own interests as *homines economici*, was explored in detail. The idea of fostering an ability to interact with markets actively through choice enables the formation of assemblages of government which foster and cater to the needs of individuals with such capacities. These kinds of assemblage are depended upon by modern regimes of government which cannot intervene in the markets that they help to establish.

Establishing a legal framework for the creation of ADRTs is akin to the establishment of a consumption-based market in end of life preferences, because individuals are free to choose how to direct their future treatment within the confines of the law. This is potentially empowering for those individuals who can actively engage with such choices and who are inclined to do so. However, it underlines a more troubling aspect of advanced liberalism; for those adults who find themselves at the end of life, but whose lives could be sustained through medical technology (a further material factor in emergence of ADRTs) present a tremendous dilemma for advanced liberal governments which abhor intervention in the field of individual interests.¹²⁸⁰ This dilemma is heightened in circumstances of greater numbers of people coming to the end of life and the financial pressures that this brings while still in the long shadow of the Financial Crisis of 2008. In this sense, the solution that ADRTs present might be seen as a structural reinforcement of a very negative attitude towards the disabled, one which sees fit to facilitate the ending of the lives of such people. Indeed, returning to the idea of the ‘future self’, which was discussed in relation to the personhood critique that was explored in Chapter Four, the idea that the law in the way it is structured, invites citizens who wish to avail themselves of it, to objectify their future self and view that self as a kind of threat. Thus, although the idea of the personhood critique may struggle to

¹²⁸⁰ M Foucault, *The Birth of Biopolitics* (n 674) 280-283

find purchase against in seeking to limit the expansion of market logics, it finds some utility when it is conjugated with the theory of governmentality.

More than this, the challenge laid down by this thesis is to critically reflect on the principles and values propounded within bioethics and healthcare law in terms of their historical establishment and operation. A failure to heed this call will risk excessive faith being continually placed in concepts, such as autonomy, which have become deeply ingrained within the orthodoxy of the disciplines. By contrast, it is hoped that through embracing the broader view of the development and operation of important normative values, as suggested in this thesis, a richer understanding of these values in their social context will be attained.

BIBLIOGRAPHY

ABBREVIATIONS

ACP	Advance Care Plan
ADRT	Advance Decision to Refuse Medical Treatment
CI	Categorical Imperative
CRPD	Convention on the Rights of Persons with Disabilities
ECHR	European Convention on Human Rights
GMC	General Medical Council
LPA	Lasting Power of Attorney
MCA	Mental Capacity Act 2005
MCS	Minimally Conscious State
PVS	Persistent Vegetative State

BOOKS AND JOURNAL ARTICLES

- Agamben G, *Homo Sacer: Sovereign Power and Bare Life* (Stanford University Press 1998)
- Andorno R, N Biller-Andorno, and S Brauer ‘Advance Health Care Directives: Towards a Coordinated European Policy?’ (2009) 16(3) *European Journal of Health Law* 207
- Andreou C, ‘Making a Clean Break: Addiction and Ulysses Contracts’ (2008) 22 *Bioethics* 25
- Barrie S, ‘QALYs, Euthanasia and the Puzzle of Death’ (2015) 41 *Journal of Medical Ethics* 635
- Bauman Z, *Freedom* (Concepts in the Social Sciences, Open University Press 1988)
- Beauchamp TL and JF Childress, *Principles of Biomedical Ethics* (6th edn, Oxford University Press 2009)
- Belzer M, ‘Notes on Relation R’ (1996) 56 *Analysis* 56
- Bensing J and P Verhaak, ‘Communication in medical encounters’ in A Kaptein and J Weinman (eds) *Health Psychology* (Blackwell 2004)
- Berlin I, ‘Two Concepts of Liberty’ in Henry Hardy (ed), *Liberty* (Oxford University Press 2002)
- Biggs H, ‘A Pretty Fine Line: Life, Death, Autonomy and Letting It B’ (2003) 11 *Feminist Legal Studies* 291
- Bishop JP, *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying* (University of Notre Dame Press 2011)

- Boever A d, 'Agamben and Marx: Sovereignty, Governmentality, Economy' 20 *Law and Critique* 259-270
- Brazier M and E Cave, *Medicine, Patients and the Law* (5th ed, Penguin Books 2011)
- Brazier M, 'Do No Harm - Do Patients Have Responsibilities Too?' (2006) 65 *The Cambridge Law Journal* 397
- Brazier M, and J Miola, 'Bye-Bye Bolam: A Medical Litigation Revolution?' (2000) 8(1) *Medical Law Review* 85
- Bridy A, 'Confounding Extremities: Surgery at the Medico-ethical Limits of Self-Modification' (2004) 32 *The Journal of Law, Medicine and Ethics* 148
- Bröckling U, S Krasmann and T Lemke, *Governmentality: Current Issues and Future Challenges* (Taylor & Francis 2010)
- Bröckling U, 'Human Economy, Human Capital: A Critique of Biopolitical Economy' in U Bröckling, S Krasmann and T Lemke (eds), *Governmentality current issues and future challenges* (Routledge 2011)
- Bruce M, *The Coming of the Welfare State* (4th edn, Batsford 1968)
- Buchanan A, 'Advance Directives and the Personal Identity Problem' (1988) 17 *Philosophy & Public Affairs* 277
- Buffardi LE and WK Campbell, 'Narcissism and Social Networking Web Sites' (2008) 34 *Personality and Social Psychology Bulletin* 1303
- Bunton R, 'Popular Health and Advanced Liberalism' in Robin Bunton and Alan Petersen (eds), *Foucault, Health and Medicine* (Routledge 1997)
- Burchell G, 'Peculiar Interests: Civil Society and Governing "the System of Natural Liberty"' in Graham Burchell, C Gordon and P Miller (eds), *The Foucault effect: studies in governmentality: with two lectures by and an interview with Michel Foucault* (University of Chicago Press 1991)
- Burchell G, 'Liberal Government and Techniques of the Self' (1993) 22 *Economy and Society* 267
- Burchell G, 'Liberal Government and Techniques of the Self' in Andrew Barry, Thomas Osborne and Nikolas S Rose (eds), *Foucault and political reason: liberalism, neo-liberalism, and rationalities of government* (University of Chicago Press 1996)
- Callahan D, 'Principlism and Communitarianism' (2003) 29 *Journal of Medical Ethics*, 287
- Coggon J 'Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' (2007) 15(3) *Health Care Analysis* 235
- Coggon J and J Miola, 'Autonomy, Liberty, and Medical Decision-Making' (2011) 70 *The Cambridge Law Journal* 523

- Coggon J, 'Alcohol Dependence And Anorexia Nervosa: Individual Autonomy And The Jurisdiction Of The Court Of Protection: *An NHS Foundation Trust v Ms X* [2014] EWCOP 35; (2014) 140 BMLR 41.'" (2015) 23(4) Medical Law Review 659
- Cohen GA, *Self-Ownership, Freedom, and Equality* (Cambridge University Press 1995)
- Conroy S et al, 'Advance Care Planning: Concise Evidence-Based Guidelines' (2009) 9 Clinical Medicine 76
- Cooley DR, 'A Kantian Moral Duty for the Soon-to-Be Demented to Commit Suicide' (2007) 7(6) American Journal of Bioethics 37
- Corrigan O, 'Empty Ethics: The Problem with Informed Consent' (2003) 25 Sociology of Health & Illness 768
- Cronin A, 'Consumerism and "Compulsory Individuality": Women, Will and Potential' in Sara Ahmed (ed), *Transformations: thinking through feminism* (Routledge 2000)
- D Parfit, 'Personal Identity' (1971) 80 The Philosophical Review 3
- Dean M, 'Governing the Unemployed Self in an Active Society' (1995) 24 Economy and Society 559
- Dean M, 'Powers of Life and Death Beyond Governmentality' (2002) 6 Cultural Values 119
- Dean M, 'Putting the Technological into Government' (1996) 9 History of the Human Sciences 47
- Dean M, *Governmentality: Power and Rule in Modern Society* (Sage 2010)
- DeGrazia D, 'Advance Directives, Dementia, and "the Someone Else Problem"' (1999) 13 Bioethics 373
- Deleuze G, 'Postscript on the Societies of Control' (1992) 59 October 3
- Demery D, and NW Duck, 'Demographic Change and the UK Savings Rate' (2006) 38(2) *Applied Economics* 119
- Dillnot A, *A Fairer Care Funding* (The Commission on Funding of Care and Support 2011)
- Dodds S, 'Choice and Control in Feminist Bioethics' in Catriona Mackenzie and Natalie Stoljar (eds), *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (Oxford University Press 2000)
- Donnelly M, 'Best Interests, Patient Participation and the Mental Capacity Act 2005' (2009) 17 Medical Law Review 1
- Donnelly M, 'Determining Best Interests Under the Mental Capacity Act 2005' (2011) 19 Medical Law Review 304
- Donnelly M, 'Capacity assessment under the Mental Capacity Act 2005: Delivering on the functional approach?' (2009) 29 Legal Studies 464
- Doukas DJ and LB McCullough, 'The Values History: The Evaluation of the Patient's Values and Advance Directives' (1991) 32 Journal of Family Practice 145

- Dresser R, 'Dworkin on Dementia: Elegant Theory, Questionable Policy' in Helga Kuhse and Peter Singer (eds), *Bioethics: an anthology* (2nd edn, Blackwell 2006)
- Dworkin G, *The Theory and Practice of Autonomy* (Cambridge University Press 1988)
- Dworkin R, *Life's Dominion: An Argument about Abortion and Euthanasia* (HarperCollins 1993)
- Einhorn HJ and RM Hogarth, 'Behavioral Decision Theory: Processes of Judgment and Choice' (1981) 19 *Journal of Accounting Research* 1
- Elliott C and C De Than, 'The Case for a Rational Reconstruction of Consent in Criminal Law' (2007) 70 *The Modern Law Review* 225
- Fagerlin A and CE Schneider, 'Enough. The Failure of the Living Will' (2004) 34 *The Hastings Center Report* 30
- Falkingham J, 'Dependency and Ageing in Britain: A Re-Examination of the Evidence' (1989) 18 *Journal of Social Policy* 211
- Feinberg J, *The Moral Limits of the Criminal Law: Harm to Self* (Vol 3, Oxford University Press 1986)
- Feng TK, 'Failure of Medical Advice: Trespass Or Negligence' (1987) 7 *Legal Studies* 149
- Fennell P, 'Mental Capacity' in L Gostin et al (eds), *Principles of Mental Health Law and Policy* (Oxford University Press 2010)
- Fennell P, *Mental Health: Law and Practice* (2nd ed, Jordans 2011)
- Fineman MA, *The Autonomy Myth: A Theory of Dependency* (The New Press 2004)
- Firlik AD, 'Margo's Logo' (1991) 265(2) *Journal of the American Medical Association* 201
- Fisher MR, *Capitalist Realism: Is There No Alternative?* (Zero Books 2009)
- Foster C and J Miola, 'Who's in Charge? The Relationship Between Medical Law, Medical Ethics, and Medical Morality?' (2015) 23 *Medical Law Review* 505
- Foster C, 'Advance directives and personality-changing illness' (2010) 19 *British Journal of Nursing*, 986
- Foster C, 'Autonomy in the Medico-Legal Courtroom: A Principle Fit for Purpose?' (2014) 22 (1) *Medical Law Review* 48
- Foucault M and M Blasius, 'About the Beginning of the Hermeneutics of the Self: Two Lectures at Dartmouth' (1993) 21 *Political Theory* 198
- Foucault M, 'Governmentality' in Graham Burchell, Colin Gordon and Peter Miller (eds), *The Foucault effect: studies in governmentality: with two lectures by and an interview with Michel Foucault* (University of Chicago Press 1991)
- Foucault M, 'On the Genealogy of Ethics' in Paul Rabinow (ed), *Ethics: subjectivity and truth* (Penguin Books 2000)
- Foucault M, 'Subjectivity and Truth' in Paul Rabinow (ed) *Ethics: subjectivity and truth* (Penguin Books 2000)

- Foucault M, 'Technologies of the Self' in Paul Rabinow (ed), *Ethics: subjectivity and truth* (Penguin Books 2000)
- Foucault M, 'The Ethics of Concern for the Self as a Practice of Freedom' in Paul Rabinow (ed), *Ethics: subjectivity and truth* (Penguin Books 2000)
- Foucault M, *The Courage of Truth: (The Government of Self and Others II), Lectures at the Collège de France 1983–1984* (Palgrave Macmillan 2011)
- Foucault M, 'The Political Technology of Individuals' in James D. Faubion (ed), *Power* (vol. 3, Penguin Books 2002)
- Foucault M, 'The Politics of Health in the Eighteenth Century' in James D Faubion (ed), *Power* (vol 3, Penguin Books 2002)
- Foucault M, 'The Birth of Social Medicine' in James D. Faubion (ed) *Power* (vol 3, Penguin Books 2002)
- Foucault M, 'The Subject and Power' in James D Faubion (ed), *Power* (vol 3, Penguin Books 2002)
- Foucault M, 'Truth and Power' in Paul Rabinow (ed), *Power* (vol 3, Penguin Books 2002)
- Foucault M, *Discipline and Punish: The Birth of the Prison* (Penguin Books 1991)
- Foucault M, *Security, Territory, Population: Lectures at the Collège de France* (Palgrave Macmillan 2009)
- Foucault M, *Society Must be Defended* (Picador 2003)
- Foucault M, *The Government of Self and Others: Lectures at the College de France, 1982-1983* (Palgrave Macmillan 2010)
- Foucault M, *The Hermeneutics of the Subject: Lectures at the Collège de France 1981-1982* (Picador USA, 2005)
- Foucault M, *The History of Sexuality: The Will to Knowledge* (vol 1, Penguin Books 1998)
- Foucault M, *The History of Sexuality: The Use of Pleasure* (vol 2, Penguin Books 1998)
- Foucault M, *The History of Sexuality: The Care of the Self* (vol 3, Penguin Books 1990)
- Foucault M, 'Two Lectures' in Colin Gordon (ed), *Power/knowledge: Selected Interviews and Other Writings, 1972-1977* (Vintage, 1980)
- Foucault M, *Abnormal: Lectures at the Collège de France 1974-1975* (Verso 2003)
- Foucault M, *The Birth of Biopolitics: Lectures at the Collège de France, 1978-79* (Palgrave Macmillan 2008)
- Fuchs AE, 'Autonomy, Slavery, and Mill's Critique of Paternalism' (2001) 4(3) *Ethical Theory and Moral Practice* 231
- Fumagalli LP and others, 'Patient Empowerment and Its Neighbours: Clarifying the Boundaries and Their Mutual Relationships' (2015) 119 *Health Policy* 384
- Gilbar R, 'Communicating Genetic Information in the Family: The Familial Relationship as the Forgotten Factor' (2007) 33 *Journal of Medical Ethics* 390

- Gilbar R, 'Family Involvement, Independence, and Patient Autonomy in Practice' (2011) 19 *Medical Law Review* 192
- Glasgow SM, 'The Politics of Self-Craft' (2012) 2 *Sage Open* 1
- Goffin T, 'Advance Directives as an Instrument in an Ageing Europe' (2012) 19 *European Journal of Health Law* 121
- Goodman MF, *What Is a Person?* (Springer Science & Business Media 1988)
- Golder B and P Fitzpatrick, *Foucault's Law* (Routledge-Cavendish 2009)
- Gordon C, 'Governmental Rationality: An Introduction' in Graham Burchell et al (eds), *The Foucault effect: studies in governmentality: with two lectures by and an interview with Michel Foucault* (University of Chicago Press 1991)
- Gray A, 'Population Ageing and Healthcare Expenditure' (2005) *Ageing Horizons* 15
- Gray J, *Two Faces of Liberalism* (The New Press 2002)
- Greener I, 'Towards a History of Choice in UK Health Policy' (2009) 31 *Sociology of Health & Illness* 309
- Gremmen I, G Widdershoven, A Beekman, R Zuijderhoudt, and S Sevenhuijsen, 'Ulysses Arrangements in Psychiatry: A Matter of Good Care?' (2008) 34(2) *Journal of Medical Ethics* 77
- Grisso T and PS Appelbaum, 'Values and Limits of the MacArthur Treatment Competence Study' (1996) 2 *Psychology, Public Policy, and Law* 167
- Grubb A 'United Kingdom: Treatment Without Consent: Adult: Re T (Adult: Refusal of Treatment)' (1993) 1 *Medical Law Review* 83
- Hacking I, 'Making up People' in Thomas C Heller (ed), *Reconstructing Individualism: Autonomy, Individuality, and the Self in Western Thought* (Stanford University Press 1986)
- Halliday S, A Formby, and R Cookson, 'An Assessment of the Court's Role in the Withdrawal of Clinically Assisted Nutrition and Hydration from Patients in the Permanent Vegetative State' (2015) 23(4) *Medical Law Review* 556
- Hamann TH, 'Neoliberalism, Governmentality, and Ethics' [2009] *Foucault Studies* 37
- Harrington JA, 'Privileging the Medical Norm: Liberalism, Self-Determination and Refusal of Treatment' (1996) 16 *Legal Studies* 348
- Harvey D, *A Brief History of Neoliberalism* (Oxford University Press 2005)
- Harvey D, *The Enigma of Capital: And the Crises of Capitalism* (Profile 2010)
- Hayes T, 'Donation and Devolution: The Human Transplantation (Wales) Act 2013' in Ralf J Jox, Galia Assadi and Georg Marckmann (eds), *Organ Transplantation in Times of Donor Shortage* (vol 59, Springer International Publishing, 2016)

- Hayes T, 'A (Social) Room with a View (to the Future): Advance Decisions and the Problem of Personhood' in Richard Huxtable and Ruud ter Meulen (eds), *The Voices and Rooms of European Bioethics* (Routledge 2015)
- Hayes T, 'Balancing Principles, Forcing Food: Self-Determination and Best Interests' (2012) 9 *Journal of Bioethical Inquiry* 387
- Hayes T, 'Informed Choice over Informed Consent: Cracking the Old Chestnut' in Anthony Wrigley and Nicky Priaux (eds), *Ethics, Law and Society* (Vol V, Ashgate Publishing, 2013)
- Herring J, *Caring and the Law* (Hart Publishing 2013)
- Herring J, *Medical Law* (Oxford University Press 2011)
- Herring J, *Medical law and ethics* (5th ed, Oxford University Press 2014)
- Heywood R, 'Excessive Risk Disclosure: The Effects of the Law on Medical Practice' (2005) 7 *Medical Law International* 93
- Heywood R, 'Revisiting Advance Decision Making Under the Mental Capacity Act 2005: A Tale of Mixed Messages' (2015) 23 *Medical Law Review* 81
- Hindess B, 'Liberalism, Socialism and Democracy: Variations on a Governmental Theme' (1993) 22 *Economy and Society* 300
- Holm S, 'Autonomy, Authenticity, or Best Interest: Everyday Decision-Making and Persons with Dementia' (2001) 4 *Medicine, Health Care and Philosophy* 153
- Holstein M, Parks JA and Waymack MH, *Ethics, Aging, and Society: The Critical Turn* (Springer 2011)
- Hoppe N and Miola J, *Medical Law and Medical Ethics* (Cambridge University Press 2014)
- Horn R, "'I Don't Need My Patients' Opinion to Withdraw Treatment": Patient Preferences at the End-of-Life and Physician Attitudes towards Advance Directives in England and France' (2014) 17 *Medicine, Health Care and Philosophy* 425
- Hunt A, and G Wickham, *Foucault and Law: Towards a Sociology of Law as Governance* (Pluto Press 1994)
- Hunt A, 'Governing the City: Liberalism and Early Modern Modes of Governance' in Andrew Barry, Thomas Osborne and Nikolas S Rose (eds), *Foucault and political reason: liberalism, neo-liberalism, and rationalities of government* (University of Chicago Press 1996)
- Huxtable R, 'Advance Decisions: Worth the Paper They Are (Not) Written On?' (2015) 5 *End of Life Journal* 1
- Huxtable R, *Euthanasia, Ethics and the Law: From Conflict to Compromise?* (Routledge-Cavendish, 2007)
- Huxtable R, *Law, Ethics and Compromise at the Limits of Life: To Treat Or Not to Treat?* (Routledge 2013)

- Huxtable, R, 'Treating the Minimally Conscious Patient: Life Before Choice?' (2012) 9
Journal of Bioethical Inquiry 9
- Jackson E, 'Catharine MacKinnon and Feminist Jurisprudence: A Critical Appraisal' (1992)
19 Journal of Law and Society 195
- Jackson E, 'The Relationship between Medical Law and Good Medical Ethics' 41(1) Journal
of Medical Ethics 95
- Jackson E, *Medical Law: Text, Cases and Materials* (3rd ed, Oxford University Press 2013)
- Jackson E, *Medical Law: Text, Cases and Materials* (Oxford University Press 2006)
- Jackson J, 'Determining Incompetence: Problems With the Function Test' in A Grubb (ed)
Decision-Making Problems of Incompetence (John Wiley & Sons, 1994)
- James I, *Basilikon Doron or His Majesties Instrvctions To His Dearest Sonne, Henry the
Prince* (Reprinted from the Edition of 1616, Harvard University Press 1918)
available at
[http://www.perseus.tufts.edu/hopper/text?doc=Perseus%3Atext%3A1999.03.0071%
3Asection%3D3%3Asubsection%3D1%3Asubsubsection%3D1](http://www.perseus.tufts.edu/hopper/text?doc=Perseus%3Atext%3A1999.03.0071%3Asection%3D3%3Asubsection%3D1%3Asubsubsection%3D1) [accessed
23/07/2012]
- Johnson R, 'Kant's Moral Philosophy' In *The Stanford Encyclopedia of Philosophy* Edward
N. Zalta (ed) (<http://plato.stanford.edu/archives/sum2014/entries/kant-moral/>.
[Accessed 22nd June 2015], 2014)
- Johnston C, 'Advance Decision Making - Rhetoric or Reality?' (2014) 34 Legal Studies 497
- Jones MA, 'Informed Consent and Other Fairy Tales' (1999) 7(2) Medical Law Review 103
- Jonsen AR, *The Birth of Bioethics* (Oxford University Press 1998)
- Jox RJ, 'Revocation of Advance Directives' in Peter Lack, Nikola Biller-Andorno and
Susanne Brauer (eds), *Advance Directives* (Springer Science & Business Media,
2013)
- Kennedy I, *Treat Me Right: Essays in Medical Law and Ethics* (New edition, Clarendon
Press 1991)
- Kennedy I, 'Patients Are Experts in Their Own Field' (2003) 326 BMJ (Clinical Research
Edition) 1276
- Keown J, *Euthanasia, Ethics and Public Policy: An Argument against Legalisation*
(Cambridge University Press 2002)
- Kerridge R, Parry & Kerridge, *The Law of Succession* (12th edn, Sweet & Maxwell 2009)
- Kitzinger C and J Kitzinger, 'Court Applications for Withdrawal of Artificial Nutrition and
Hydration from Patients in a Permanent Vegetative State: Family Experiences'
(2016) 42 Journal of Medical Ethics 11
- Kitzinger C, 'Advance Decisions Do They Work?' (2014) 4 Journal of Elder Law 198

- Korvela P-E, 'Sources of Governmentality Two Notes on Foucault's Lecture' (2012) 25(4) *History of the Human Sciences* 73
- Kraus AS, 'The Burden of Care for Families of Elderly Persons with Dementia' (1984) 3 *Canadian Journal on Aging* 45
- Kremer M, 'Consumers in Charge of Care: The Dutch Personal Budget and Its Impact on the Market, Professionals and the Family' (2006) 8 *European Societies* 385
- Kuczewski MG, 'Commentary: Narrative Views of Personal Identity and Substituted Judgment in Surrogate Decision Making' (1999) 27 *Journal of Law, Medicine & Ethics* 32
- Kutner L, 'Due Process of Euthanasia: The Living Will, A Proposal' (1969) 44(4) *Indiana Law Journal* 539
- Lack P, Biller-Andorno N and Brauer S (eds), *Advance Directives* (Springer Science & Business Media 2013)
- Lanbein JH, 'Substantial Compliance With The Wills Act' (1975) 88 *Harvard Law Review* 489
- Lemke T, *Biopolitics: An Advanced Introduction* (NYU Press 2011)
- Lemke T, "'The Birth of Bio-Politics": Michel Foucault's Lecture at the Collège de France on Neo-Liberal Governmentality' (2001) 30 *Economy and Society* 190
- Lemke T, *Foucault, Governmentality, and Critique* (Paradigm Publishers 2011)
- Lemmens C, 'End-of-Life Decisions and Demented Patients. What to Do If the Patient's Current and Past Wishes Are in Conflict with Each Other?' (2012) 19 *European Journal of Health Law* 177
- Levy N, 'Forced to Be Free? Increasing Patient Autonomy by Constraining It' (2014) 40 *Journal of Medical Ethics* 293
- Lewis P, 'Medical Treatment of Dementia Patient at the End of Life: Can the Law Accommodate the Personal Identity and Welfare Problems' (2006) 13 *European Journal of Health Law* 219
- Locke J, 'An Essay Concerning Human Understanding' in John Perry (ed), *Personal Identity* (University of California Press 2008)
- Lothane Z, 'Omnipotence, or the Delusional Aspect of Ideology, in Relation to Love, Power, and Group Dynamics' (1997) 57 *The American Journal of Psychoanalysis* 25
- Lupton D, 'Foucault and the Medicalisation Critique' in R Bunton and A Petersen (eds), *Foucault, Health and Medicine* (Routledge 1997)
- Lupton D, *The Imperative of Health: Public Health and the Regulated Body* (Sage 1995)
- Lupton D, *Medicine as Culture: Illness, Disease and the Body* (3rd ed, Sage 2012)
- Maclean A, 'Giving the Reasonable Patient a Voice: Information Disclosure and the Relevance of Empirical Evidence' (2005) 7 *Medical Law International* 1

- Maclean A, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009)
- Maclean AR, 'Advance Directives, Future Selves and Decision-Making' (2006) 14 *Medical Law Review* 291
- Maclean AR, 'Advance Directives and the Rocky Waters of Anticipatory Decision-Making' (2008) 16(1) *Medical Law Review* 1
- MacDonald M and others, 'Distal and Proximal Resource Influences on Economic Dependency among the Oldest Old' (2010) 56 *Gerontology* 100
- Macmillan A, 'Michel Foucault's Techniques of the Self and the Christian Politics of Obedience' (2011) 28 *Theory, Culture & Society* 3
- Martin W and others, 'An Unblinkered View of Best Interests' (2012) 345 *BMJ* e8007
- Marx K, *The Communist Manifesto: Prefaces by Marx and Engels, Annotated Text, Sources and Backgrounds, the Communist Manifesto in the History of Marxism, Interpretation* FL Bender (ed) (Norton 1988)
- Mayberry MK and J Mayberry *Consent in Clinical Practice* (Radcliffe Medical 2003)
- McGuinness K, 'Gene Sharp's Theory of Power: A Feminist Critique of Consent' (1993) 30 *Journal of Peace Research* 101
- McHale J et al, *Health Care Law: Text and Materials* (2nd edn, Sweet & Maxwell 2006)
- Michalowski S, 'Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right' (2005) 68 *The Modern Law Review* 958
- Mill JS, *On Liberty* (Project Gutenberg, 2011) (available at <http://www.gutenberg.org/files/34901/34901-h/34901-h.htm>)
- Miller P and Rose N, 'Governing Economic Life' (1990) 19 *Economy and Society* 1
- Miller P and Rose NS, *Governing the Present: Administering Economic, Social and Personal Life* (Polity Press 2008)
- Miola J, 'Making Decisions About Decision-Making: Conscience, Regulation, and the Law' (2015) 23 *Medical Law Review* 263
- Miola J, 'On the Materiality of Risk: Paper Tigers and Panaceas' (2009) 17 *Medical Law Review* 76
- Miola J, *Medical Ethics and Medical Law: A Symbiotic Relationship* (Hart 2007)
- Mol A, *The Logic of Care: Health and the Problem of Patient Choice* (Routledge 2008)
- Montgomery J, 'Power Over Death: The Final Sting' in RG Lee and D Morgan (eds), *Death Rites: Law and Ethics at The End of Life* (Routledge 1996)
- Mullock A, 'Best Interests and the Sanctity of Life after W v M' (2013) 39 *Journal of Medical Ethics* 553
- Nadesan MH, *Governmentality, Biopower, and Everyday Life* (Routledge 2011)

- Naffine N, 'Who Are Law's Persons? From Cheshire Cats to Responsible Subjects' (2003) 66 *The Modern Law Review* 346
- Newton MJ, 'Precedent Autonomy: Life-Sustaining Intervention and the Demented Patient' (1999) 8 *Cambridge Quarterly of Healthcare Ethics* 189
- Nietzsche FW, *The Dawn of Day* (Project Gutenberg, 2012) available at <<http://www.gutenberg.org/ebooks/39955>> accessed 8 August 2015
- O'Malley P, 'Consuming Risks: Harm Minimization and the Government of "Drug Users"' in Russell Charles Smandych (ed), *Governable Places: Readings on Governmentality and Crime Control* (Ashgate 1999)
- O'Shea T, 'Critics of Autonomy' (Essex Autonomy Project, 2012) available at: <http://autonomy.essex.ac.uk/critics-of-autonomy> accessed 12/07/2013
- O'Neill O, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002)
- Osborne T, 'On Liberalism, Neo-Liberalism and the "Liberal Profession" of Medicine' (1993) 22 *Economy and Society* 345
- Osborne T, 'Security and Vitality: Drains Liberalism and Power in the Nineteenth Century' in A Barry, T Osborne, and NS Rose (eds) *Foucault and Political Reason: Liberalism, Neo-Liberalism, and Rationalities of Government* (University of Chicago Press 1996)
- Osborne T, 'Of Health and Statecraft' in Robin Bunton and Alan Petersen (eds), *Foucault, Health and Medicine* (Routledge 1997)
- Parfit D, 'Personal Identity' (1971) 80 *The Philosophical Review* 3
- Parfit D, *Reasons and Persons* (Clarendon Press 1987)
- Petersen AR and D Lupton, *The New Public Health: Health and Self in the Age of Risk* (Sage 1996)
- Petersen, A "Governmentality, Critical Scholarship, and the Medical Humanities" (2003) 24(3) *Journal of Medical Humanities* 187
- Přibáň J, 'Multiple Sovereignty: On Europe's Self-Constitutionalization and Legal Self-Reference' (2010) 23 *Ratio Juris* 41
- Prozorov S, 'The Unrequited Love of Power: Biopolitical Investment and the Refusal of Care' [2007] *Foucault Studies* 53
- Rabinow P and Rose N, 'Biopower Today' (2006) 1 *BioSocieties* 195
- Rasmussen KS, 'Foucault's Genealogy of Racism' (2011) 28 *Theory, Culture & Society* 34
- Read J, 'A Genealogy of Homo-Economicus: Neoliberalism and the Production of Subjectivity' (2009) 6 *Foucault Studies* 25
- Reath A, *Agency and Autonomy in Kant's Moral Theory: Selected Essays* (Clarendon Press 2006)

- Resnik DB, 'Regulating the Market for Human Eggs' (2001) 15 *Bioethics* 1
- Riley GF and Lubitz JD, '*Long-Term Trends in Medicare Payments in The Last Year of Life*' (2010) 45 *Health Service Research* 565
- Robinson in C Koggel and J Orme, 'Care Ethics: New Theories and Applications' (2010) 4 *Ethics and Social Welfare* 109
- Rose N and P Miller, 'Political Power Beyond the State: Problematics of Government' (1992) 43 *The British Journal of Sociology* 173
- Rose N, 'Government, Authority and Expertise in Advanced Liberalism' (1993) 22(3) *Economy and Society* 283
- Rose N, *Inventing Our Selves: Psychology, Power, and Personhood* (Cambridge University Press 1998)
- Rose NS, 'Genomic Susceptibility as an Emergent Form of Life? Genetic Testing, Identity and the Remit of Medicine' in Regula Valérie Burri and Joseph Dumit (eds), *Biomedicine as culture: instrumental practices, technoscientific knowledge, and new modes of life* (Routledge 2007)
- Rose NS, 'Governing "Advanced" Liberal Democracies' in A Barry, T Osborne and NS Rose (eds), *Foucault and political reason: liberalism, neo-liberalism, and rationalities of government* (University of Chicago Press 1996)
- Rose NS, *Governing the Soul: The Shaping of the Private Self* (2nd edn, Free Association Books 1999)
- Rose NS, *Powers of Freedom: Reframing Political Thought* (Cambridge University Press 1999)
- Rose NS, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (Princeton University Press 2007)
- Russell R and Tokatlian JG, 'From Antagonistic Autonomy to Relational Autonomy: A Theoretical Reflection from the Southern Cone' (2003) 45 *Latin American Politics and Society* 1, 13-14
- Ryan T and S Xenos, 'Who Uses Facebook? An Investigation into the Relationship between the Big Five, Shyness, Narcissism, Loneliness, and Facebook Usage' (2011) 27 *Computers in Human Behavior* 1658
- Sailors PR, 'Autonomy, Benevolence, and Alzheimer's Disease' (2001) 10 *Cambridge Quarterly of Healthcare Ethics* 184
- Saks ER and DV Jeste, 'Capacity to Consent to or Refuse Treatment and/or Research: Theoretical Considerations' (2006) 24 *Behavioural Sciences and the Law* 411
- Samanta J and A Samanta, *Medical Law* (2nd edn, Palgrave Macmillan 2015)
- Saunders B, 'Normative consent and opt-out organ donation' (2009) 36 *Journal of Medical Ethics* 84

- Schneewind JB, *The Invention of Autonomy: A History of Modern Moral Philosophy* (Cambridge University Press 1998)
- Schwartz B, 'The Tyranny of Choice' [2004] *Scientific American* 71
- Schwartz B, *The Paradox of Choice: Why More Is Less* (ECCO 2004)
- Scully JL and Fitzpatrick P, 'Introduction to Feminist Bioethics' in Jackie Leach Scully, Laurel Baldwin-Ragaven and Petya Fitzpatrick (eds), *Feminist Bioethics: At the Center, on the Margins* (Johns Hopkins University Press 2010)
- Sevenhuijsen S, *Citizenship and the Ethics of Care: Feminist Considerations on Justice, Morality and Politics* (Routledge 1998)
- Shoemaker D, 'Personal Identity and Ethics' in Edward N Zalta (ed), *The Stanford Encyclopedia of Philosophy* (online <<http://plato.stanford.edu/archives/spr2012/entries/identity-ethics/>> [accessed 18 September 2012], 'Historical Highlights of the Relation', 2012)
- Sokhi-Bulley B, 'Governing (Through) Rights: Statistics as Technologies of Governmentality' (2011) 20 *Social & Legal Studies* 139
- Stein GL, and IC Fineberg, 'Advance Care Planning in the USA and UK: A Comparative Analysis of Policy, Implementation and the Social Work Role' (2013) 43 *British Journal of Social Work* 233
- Sullivan GR, 'Liberalism and the Constraining of Choice: The Cases of Death and Serious Bodily Harm' in Stephen W Smith and Ronan Deazley (eds), *The Legal, Medical and Cultural Regulation of The Body: Transformation and Transgression* (Ashgate 2009)
- Sullivan RJ, *An Introduction to Kant's Ethics* (Cambridge University Press 1994)
- Syrett K, *Law Legitimacy and the Rationing of Health Care: A Contextual and Comparative Perspective* (Cambridge University Press 2007)
- Takala T, 'Concepts of "person" and "liberty," and Their Implications to Our Fading Notions of Autonomy' (2007) 33 *Journal of Medical Ethics* 225
- Taylor C, 'Race and Racism in Foucault's Collège de France Lectures' (2011) 6 *Philosophy Compass* 746
- Temerlin MK, 'Suggestion Effects in Psychiatric Diagnosis' in TJ Scheff (ed) *Labelling Madness* (Prentice-Hall, 1975)
- Van Wijmen MP s. and others, 'Advance Directives in the Netherlands: An Empirical Contribution to the Exploration of a Cross-Cultural Perspective on Advance Directives' (2010) 24 *Bioethics* 118
- Veatch RM, 'Abandoning Informed Consent' (1995) 25 *The Hastings Center Report* 5

- Veitch K 'The Government of Health Care and the Politics of Patient Empowerment: New Labour and the NHS Reform Agenda in England' (2010) 32(3) *Law & Policy* 313
- Veitch K, 'Medical Law and the Power of Life and Death' (2006) 2(2) *International Journal of Law in Context* 137
- Veitch K, *The Jurisdiction of Medical Law* (Ashgate 2007)
- Veit-Wilson J, 'States of Welfare: A Conceptual Challenge' (2000) 34 *Social Policy & Administration* 1
- Vollmann J and R Winau, 'Informed Consent in Human Experimentation before the Nuremberg Code.' (1996) 313 *British Medical Journal* 1445
- Vollmann J, 'Advance Directives in Psychiatry' in Peter Lack, Nikola Biller-Andorno and Susanne Brauer (eds), *Advance Directives* (Springer Science & Business Media, 2013)
- Weller P, *New Law and Ethics in Mental Health Advance Directives: The Convention on the Rights of Persons with Disabilities and the Right to Choose* (Routledge 2012)
- Wendler D, 'Are physicians obligated always to act in the patient's best interests?' (2010) 36 *Journal of Medical Ethics* 66
- Willigenburg, TV and PJJ Delaere, 'Protecting Autonomy as Authenticity Using Ulysses Contracts' (2005) 30 *Journal of Medicine and Philosophy* 395
- Wilson D, *The Making of British Bioethics* (Manchester University Press 2014)
- Wincott D, 'Images of Welfare in Law and Society: The British Welfare State in Comparative Perspective' (2011) 38 *Journal of Law and Society* 343
- Winick BJ, 'Foreword: Planning for the Future Through Advance Directive Instruments' (1998) 4 *Psychology, Public Policy, & Law* 579, 580
- Woolf H, 'Are the Courts Excessively Deferential to the Medical Profession?' (2001) 9(1) *Medical Law Review* 1
- Wrigley A, 'Personal Identity, Autonomy and Advance Statements' (2007) 24 *Journal of Applied Philosophy* 381

REPORTS

- Age Concern Institute of Gerontology, Centre of Medical Law and Ethics, *The Living Will, Consent to Treatment at the End of Life* (Edward Arnold 1988)
- Beveridge W, *Social Insurance and Allied Services* (CMND 6404, 1942)
- Boyle S, 'Health Systems in Transition: UK (England) Health System Review' (European Observatory on Health Systems and Policies 2011) 1
<<http://www.euro.who.int/en/who-we-are/partners/observatory/health-systems-in-transition-hit-series/countries/united-kingdom-of-great-britain-and-northern-ireland-hit-england-2011>>
- Calazani N, Higginson IJ and Gomes B, *Current and Future Needs for Hospice Care: An Evidence Based Report* (Help the Hospices 2013)
- Department for Constitutional Affairs, *Mental Capacity Act 2005: Code of Practice* (The Stationary Office 2007)
- Department of Health, *Advance Care Planning: A Guide for Health and Social Care Staff* (The NHS End of Life Care Programme 2007)
- European Commission, *The Demographic Future of Europe - From Challenge to Opportunity*, 2006: 5 (Directorate-General for Employment, Social Affairs and Equal Opportunities)
- Explanatory Notes to the Mental Capacity Act 2005
- General Medical Council (GMC), *Consent: Patients and Doctors Making Decisions Together* (GMC 2008)
- General Medical Council (GMC), *Treatment and Care Towards the End of Life: Good Practice in Decision Making* (GMC 2010)
- General Medical Council (GMC), *Good Medical Practice* (GMC 2013)
- Humphries R, *Paying for Social Care: Beyond Dilnot* (King's Fund 2013)
- Institute for Fiscal Studies *A Survey of Public Spending in the UK* (Briefing Note 2009)
- Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (The National Academies Press 2015)
<<http://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near>> [accessed 17 August 2015]
- Joint Committee on the Draft Mental Incapacity Bill, *Draft Mental Incapacity Bill: Volume 1* (2002-03 HL 189-I, HC 1083-I)
- McCrone P et al *Paying the Price: The Cost of Mental Healthcare in England to 2026* (The King's Fund 2008)

Mrsnik M, DT Beers and I Morozov, *Global Aging 2010: An Irreversible Trend* (Standard & Poor's Global Credit Portal RatingsDirect, 2010)

Parliamentary Office of Science and Technology, *Vegetative and Minimally Conscious States* (PN 489, 2015)

Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948. Available at <http://www.who.int/about/definition/en/print.html> [accessed 22/08/2012] (my emphasis)

Royal College of Physicians *Advance care planning* (Concise Guidance to Good Practice Series, No 12, 2009)

Royal College of Physicians, *Prolonged Disorders of Consciousness: National Clinical Guidelines* (RCP 2015)

Select Committee on Medical Ethics, *Report of the Select Committee on Medical Ethics* (HL 1993-94, 21-I)

Select Committee on Medical Ethics, *Report of the Select Committee on Medical Ethics* (HL 1993-94, 21-II)

Select Committee on Public Service and Demographic Change, *Ready for Ageing?* (HL 2012-13 140-I)

The Law Commission *Mental Incapacity* (LC231, 1995)

CASE LAW

AC v Berkshire West Primary Care Trust [2010] EWHC 1162
A Local Authority v A [2010] EWHC 1549 (Fam)
A Local Authority v K [2013] EWHC 242 (COP)
A London Local Authority v JH [2011] EWCOP 2420 (COP)
A NHS Foundation Trust v Ms X (By Her Litigation Friend, the Official Solicitor) [2014] EWCOP 35 (COP)
A NHS Trust v Dr A [2013] EWHC 2442 (COP)
A Primary Care Trust v P [2012] EWHC 2922 (COP)
Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67
Airedale NHS Trust v Bland [1993] AC 789 (CA)
An NHS Trust v D [2012] EWHC 885 (COP)
Birch v University College London Hospital NHS Foundation Trust [2008] EWHC 2237 (QB)
Bolam v Friern Hospital Management Committee [1957] 1 WLR 582
Bolitho v City and Hackney Health Authority [1998] AC 232
Chatterton v Gerson [1981] 1 All ER 257, [1981] QB 432
Collins v Wilcock [1984] 3 All ER 374
Commissioners of Police for the Metropolis v Reeves [2000] AC 360
Cooper and Schaub [1994] Crim LR 531
F v West Berkshire Health Authority [1989] 2 All ER 545
Gillick v West Norfolk and Wisbech AHA [1986] AC 112
HE v Hospital NHS Trust [2003] EWHC 1017 (Fam)
Heart of England NHS Foundation Trust v JB [2014] EWCOP 342
Hills v Potter [1984] 1 WLR 641
ITW v Z [2009] EWHC 2525 (Fam)
M’Naghten [1843] UKHL J16
Montgomery v Lanarkshire Health Board [2015] UKSC 11
Ms B v An NHS Hospital Trust [2002] EWHC 429 (Fam)
Newcastle Upon Tyne Hospital Trust v LM [2014] EWHC 454 (COP)
NHS Trust A v M [2001] Fam 348
NHS Trust v T (Adult Patient: Refusal of Treatment) [2004] EWHC 1279 (Fam)
Nottinghamshire Healthcare NHS Trust v RC [2014] EWHC 1136 (COP)
Pearce v United Bristol Healthcare Trust [1998] EWCA Civ 865
R (B) v Ashworth Hospital Authority [2005] UKHL 20 (HL)
R (on the application of PS) v (1) Dr G and (2) Dr W [2003] EWHC 2335

R (on the application of Purdy) v Director of Public Prosecutions [2009] UKHL 45 (HL)

R (on the application of Tracey) v Cambridge University Hospitals NHS Foundation [2014] EWCA Civ 33

R (Pretty) v Director of Public Prosecutions [2002] 1 AC 800

R (Burke) v The General Medical Council [2004] EWHC 1879 (Admin)

R v Malcherek [1981] 2 All ER 422

Re A (Conjoined Twins: Medical Treatment) [2001] 1 FLR 1

Re A (Medical Treatment: Male Sterilisation) [2000] 1 FLR 549

Re AK (Medical Treatment: Consent) [2001] 1 FLR 129

Re C (Adult: Refusal of Medical Treatment) [1994] 1 All ER 819

Re D [2012] EWCOP 885

Re E (A Minor) (Wardship: Medical Treatment) [1993] 1 FLR 386

Re E (Medical treatment: Anorexia) (Rev 1) [2012] EWHC 1639

Re E [2014] EWCOP 27

Re F (Mental Patient: Sterilisation) [1990] 2 AC 1 (HL)

Re KW and H (Minors) (Medical Treatment) [1993] 1 FLR 854

Re M (Statutory Will) [2009] EWHC 2525 (Fam)

Re MB (Medical Treatment) (1997) 38 BMLR 175

Re N [2015] EWCOP 76

R (on the application of Nicklinson) v Ministry of Justice [2014] UKSC 38

Re S and Another (Protected Persons) [2010] 1 WLR 1082

Re T (A Minor) (Wardship: Medical Treatment) [1996] 35 BMLR 63 (CA)

Re T (Adult: Refusal of Treatment) [1993] Fam 95, [1993] FLR 95 (CA)

Re W (A Minor Medical Treatment: Court's Jurisdiction) [1992] 4 All ER 627

Re Y (Mental Patient: Bone Marrow Donation) [1996] FLR 787

Sheffield Teaching Hospitals NHS Foundation Trust v TH [2014] EWCOP 4 (COP)

Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital [1985] AC 871

St George's NHS Trust v S [1999] Fam 26

St George's Healthcare NHS Trust v P and Q [2015] EWCOP 42

Taylor v Shropshire Health Authority [1998] Lloyd's Rep Med 395

The X Primary Care Trust v XB [2012] EWHC 1390 (Fam)

U v Centre for Reproductive Medicine [2002] EWCA Civ 565

W Healthcare NHS Trust v KH [2004] EWCA Civ 1324

W v KH [2004] EWCA Civ 1324 (CA)

W v M [2011] EWHC 2443 (Fam)

Westminster City Council v Manuela Sykes (By her RPR and Litigation friend RS)

[2014] EWHC B9 (COP)

Wye Valley NHS Trust v B (Rev 1) [2015] EWCOP 60

X v XB [2012] EWHC 1390 (Fam)

FOREIGN CASE LAW

Budanov v Russia (Application no. 66583/11) ECHR 2014

Centre for Legal Resources on behalf of Valentin Câmpeanu v. Romania [GC], no. 47848/08, ECHR 2014

Ciarlariello v Schacter [1993] 2 SCR 119

R v Ashlee 2006 CarswellAlta 1076

Rogers v Whitaker [1992] HCA 58

Schloendorff v Society of New York Hospital [1914] 211 NY 125

Storck v Germany (2005) 43 EHRR 96 [143]

LEGISLATION

Enduring Powers of Attorney Act 1985 c.29

Human Tissue Act 2004 c 30

Mental Capacity Act 2005 (Transitional and Consequential Provisions) Order 2007

Mental Capacity Act 2005 c 9

PD 9E (Court of Protection)

Sexual Offences Act 2003 c.42

Wills Act 1837 1 Vict. c. 26

OTHER LEGISLATION

§ 1901a Bürgerliches Gesetzbuch (Germany)

55. § 7. Bundesgesetz über Patientenverfügungen (Patientenverfügungs-Gesetz - PatVG)

BGBI I NR 55/2006 (Austria)

Article L1111-11 Code de la Santé Publique (France)

Directive 2010/45/EU Of The European Parliament And Of The Council of 7 July 2010 on standards of quality and safety of human organs intended for transplantation

Mental Health (Care and Treatment) (Scotland) Act 2003 (asp 13)

Patient Self-Determination Act 1991 §127.652 of the Omnibus Reconciliation Act of 1990, Pub L No. 101-508 (November 5, 1990)

CONVENTIONS

‘The Nuremberg Code’, 1947. <http://ohsr.od.nih.gov/guidelines/nuremberg.html>.
[accessed 25/03/2012]

Council of Europe, *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine* (Oviedo, 4.IV.1997)

CRPD Convention on the Rights of Persons with Disabilities 2007

ECHR European Convention on Human Rights 1950

European Directive (2010/45/EU) DIRECTIVE 2010/45/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL

Parliamentary Assembly of the Council of Europe, *Protection of the Human Rights and Dignity of the Terminally Ill and the Dying* Recommendation 1418 (1999)

Parliamentary Assembly of the Council of Ministers, *Protecting Human Rights and Dignity by Taking into Account Previously Expressed Wishes of Patients* (Resolution 1859, 2012)

UN Economic and Social Council *General Comment 14* (Discussing Article 12 of the International Covenant on Economic, Social and Cultural Rights, 2000)

WEBSITES

<http://www.lawsociety.org.uk/advice/practice-notes/lasting-powers-attorney/#lpa123>

[section 12] [accessed 16/8/2013]

<http://www.guardian.co.uk/business/feedarticle/10468914> [accessed 16/10/2012]

<http://www.telegraph.co.uk/science/7159464/Do-we-want-brain-scanners-to-read-our-minds.html> [accessed 5/2/2010]

<http://www.cqc.org.uk/>

<http://compassionindying.org.uk/library/advance-decision-pack/> [accessed 17/8/ 2015]

http://www.hm-treasury.gov.uk/pfg_deficit_reduction.htm accessed 11/09/2011

<http://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164>

<http://conventions.coe.int/Treaty/Commun/ChercheSig.asp?NT=164&CM=8&DF=21/08/2014&CL=ENG>

http://www.hm-treasury.gov.uk/pfg_deficit_reduction.htm [accessed 11/09/2011]

<http://www.statistics.gov.uk/cci/nugget.asp?id=949> [accessed 6/7/2011]

<https://www.gov.uk/winter-fuel-payment/overview> [accessed 17/01/2014]

‘Tony Blair’s speech on healthy living’, July 26, 2006. Available at <http://www.guardian.co.uk/society/2006/jul/26/health.politics> [accessed 11th April 2012]

<http://www.ukpublicspending.co.uk/breakdown> [accessed 11/09/2011]

<http://adassistance.org.uk/about-us/> [accessed 17/11/2015]

<http://www.statistics.gov.uk/cci/nugget.asp?id=949> [accessed 6/7/2011]