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WHY LACKING MORALITY MEANS LACKING
TOTALITY IN THE MENTAL CAPACITY ACT
2005*

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**LESSONS FROM ODYSSEUS AND BEYOND: WHY LACKING MORALITY MEANS LACKING
TOTALITY IN THE MENTAL CAPACITY ACT 2005**

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2014



For the people who told me to always follow my dreams, to my parents, Sharon and Paul Robinson, and for my Grandfather and life mentor, Bob Hopper.

TABLE OF CONTENTS

ABSTRACT	i
TABLE OF LEGISLATION	ii
TABLE OF CASES.....	iii
STATEMENT OF COPYRIGHT	v
ACKNOWLEDGEMENTS	vi
CHAPTER ONE: ETHICS, ODYSSEUS AND THE MENTAL CAPACITY ACT 2005	1
1.1 Introduction.....	1
1.2 The Relevance of Odysseus.....	3
1.3 Objectives	4
1.4 Chapter Outline.....	6
1.5 Moral Basis	10
1.5.1 Dialectically Necessary	11
1.5.2 Dialectically Contingent Argument to the PGC.....	13
1.6 The Relevance of Agency, Autonomy and the PGC.....	15
CHAPTER TWO: A BACKGROUND AND GENERAL ANALYSIS OF THE EFFICACY OF THE MCA 2005'S MAIN PROVISIONS	16
2.1 Finding the Value in Advance Refusals.....	16
2.2 The Law on Advance Refusals: From <i>Re T</i> to the MCA 2005: A U- Turn?	19
2.3 The MCA 2005	21
2.4 Best Interests Test?.....	25
2.5 In Reality	27
2.5.1 Integration.....	28
2.5.2 Clarity.....	29
2.5.3 'Morally Unsound'	30
2.5.4 Other Issues.....	34

2.6 Summary.....	36
CHAPTER THREE: PERSONHOOD, AUTONOMY AND LIFE	39
3.1 Why Who We Are Matters	39
3.2 Life As We Know it	40
3.3 Who Are We to Judge?.....	41
CHAPTER FOUR: BETWEEN AUTONOMY v THE RIGHT TO LIFE: LESSONS FROM <i>THE X PRIMARY CARE TRUST V XB</i>	45
4.1 Competence, Autonomy and Agency	45
4.1.1 The Relevance of Gewirth’s Agent Autonomy.....	46
4.2 Autonomy v Life: Ameliorating the Grand Illusion	48
4.2.1 The Choice of Death	54
4.3 The Goodness of an Act: Why Agents can Choose How They Live, and Die.....	57
4.4 Restoring Balance.....	60
CHAPTER FIVE: CAN IGNORING THE PERSONAL IDENTITY PROBLEM BE JUSTIFIED?	61
5.1 Personal Identity and Dementia	61
5.2 A Legislative Obligation to Consider the Personal Identity Problem?.....	62
5.3 Reason in ‘Precautionary Reasoning’	65
5.3.1 The Precautionary Reasoning Argument	65
5.3.2 Why Relevant Behavioural Display Should Also be Included in Legislation	67
5.4 Filling Lacunae with Precaution	68
5.4.1 Dworkin’s Margo: Questioning the Notion of Experiential Interests	72
5.4.2 So Who is Margo and Does She (and her Advance Refusal) Matter?	74
5.4.3 Advance Directives for Dementia Patients: Why the Dutch System is Too Ambitious.....	75
5.5 Problem-proofing Legislation.....	77
CHAPTER SIX: PAVING A NEW WAY FORWARD.....	81
6.1 Whose Best Interests?	81
6.1.1 Changes to Be Made to the Current Test.....	81
6.2 Using the Substituted Judgment Standard With Caution: <i>Strunk v Strunk</i>	86

6.3 The Overall Interests Test.....	89
6.4 Updating the MCA 2005: A New Model of Deciding What is Best.....	91
CHAPTER 7: CONCLUSIONS.....	93
BIBLIOGRAPHY	99

ABSTRACT

The law of England and Wales provides that an adult with capacity has the right to refuse medical treatment both contemporaneously and in an advance refusal. Legislation separates general advance refusals of treatment from advance refusals of life-sustaining treatment. The law, outlined in ss.24 to 26 of the Mental Capacity Act 2005, is stricter for creation of the latter. These sections brought with them a new age of interests by purporting to elevate individual autonomy as the primary concern. Beginning with the classical tale of Odysseus and a general discussion of the value to be found in a law seeking to preserve individual autonomy, this thesis seeks to act as a critique of the current enactment in practice.

The provisions are already under-used and under-applied; without change, they may never reach the stage where they are ethically and practically viable. It is argued that the advance refusals provisions are not taking full effect due to a combination of lacking moral grounding and general dismissal of key ethical dilemmas at the forefront of application. Building on this, the moral basis for this thesis is found in Alan Gewirth's Principle of Generic Consistency (PGC) which links directly with the general application of human rights. The PGC becomes a compass for determining how best to treat persons when addressing the three most prominent challenges faced by the Act which are: the debate between the conferred right of autonomy versus the right to life; the issue of personhood; and, the personal identity problem. Ultimately, unless framework provisions are strengthened, and the MCA 2005 is rethought in light of prominent ethical, legal and social considerations, the constraints of the Act on paper will continue to suppress the important underlying values promulgating individual autonomy.

TABLE OF LEGISLATION

Primary

Human Rights Act 1998

Mental Capacity Act 2005

Mental Health Act 1983

Mental Health Act 2007

Suicide Act 1961

Bills

Assisted Dying Bill 2013-14

The Assisted Decision-making (Capacity) Bill 2013

International Instruments

European Convention on Human Rights and Fundamental Freedoms (ECHR) 1957

Universal Declaration of Human Rights (UDHR) 1948

UNESCO's Universal Declaration on the Human Genome and Human Rights 1997

TABLE OF CASES

- A (Mental Patient: Sterilisation), Re [2000] F.L.R. 549; [2000] 1 F.C.R. 193 CA (Civ Div).
- A (Children) (Conjoined Twins: Surgical Separation), Re [2001] Fam 147.
- A Local Authority v E; [2012] EWHC 1639 (COP).
- A Local Authority v K (by the Official Solicitor) Mrs K and Mr K A NHS Trust [2013] EWHC 242 ;(COP) 2013 WL 552275.
- Aintree University Hospitals NHS Foundation Trust v James on appeal from: [2013] EWCA Civ 65SC; [2013] UKSC 67; 2013 WL 5730338.
- Airedale NHS Trust v Bland [1993] A.C. 789.
- AK (Adult Patient) (Medical Treatment: Consent), Re [2001] 1 F.L.R. 129.
- B (Wardship: Medical Treatment), Re [1990] 3 All E.R. 927.
- B (Adult: Refusal of Medical treatment), Re [2002] EWHC 429.
- HE v Hospital NHS Trust [2003] EWHC 1017 (Fam).
- Jerry Strunk v Ava Strunk, Committee for Jerry Strunk, Incompetent et al, appellees, sub.nom Strunk v Strunk (1969)Court of Appeals Kentucky.
- M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment), Re [2011] EWHC 1197 (Fam); 1 W.L.R. 287 (2011).
- MB (Caesarean section), Re [1997]; sub nom. MB (Medical Treatment), Re [1997] 2 FLR 426; [1997]2 F.C.R. 541 CA (Civ Div).
- Nicklinson v Ministry of Justice [2012] EWHC 304 (QB); [2012] H.R.L.R. 16.
- NHS Trust v L; EWHC 2741 (COP) (2012).
- Pretty v UK (No. 2346/02) (2002) 35 E.H.R.R. 1.

R (on the application of Pretty) v DPP [2001] UKHL 61.

R. (on the application of Purdy) v DPP [2008] EWHC 2565; [2009] EWCA Civ 92; [2009] UKHL.

R. (N and Another) [2009] HRLR 31.

R. (on the application of Nicklinson) v Ministry of Justice [2013] EWCA Civ 466 (Civ Div).

R. (on the application of Jane Nicklinson) and Lamb v Ministry of Justice; R (on the application of AM) v Director of Public Prosecutions [2013] EWCA Civ 961.

R. (on the application of Tony Nicklinson) v Ministry of Justice [2012] EWHC 2381 (Admin), 2012 WL 3491755.

T (Adult: refusal of medical treatment), Re [1993], Fam. 95.

The X Primary Care Trust v XB, (By the Official Solicitor as Litigation Friend) [2012] EWHC 1390 (Fam); (2012) 127 B.M.L.R. 122; [2012] W.T.L.R. 1621.

Whitbread Ex parte in the Matter of Hinde, a Lunatic (1816) 2 Meriv 99; 35 E.R. 878.

Y (Mental Patient: Bone Marrow Donation), Re [1997] Fam. 110; [1997] 2 W.L.R. 556.

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CHAPTER ONE: ETHICS, ODYSSEUS AND THE MENTAL CAPACITY ACT 2005

1.1 Introduction

The law of England and Wales¹ provides that a competent adult with capacity has the right to refuse medical treatment both contemporaneously² and in an advance refusal.³ General advance refusals regarding treatment (herein general advance refusals) are separated from advance refusals of life-sustaining treatment (herein advance refusals). Governed by ss.24 to 26 of the Mental Capacity Act 2005 (herein 'MCA 2005' or 'the 2005 Act'), the law is stricter for creation of the latter. These sections brought with them a new age of interests by purporting to elevate individual autonomy as the primary concern.

It is important here to draw the seminal distinction between competence and legally recognised capacity. For the purposes of definition, an adult⁴ is found to be 'competent' when their cognitive abilities are at a level where they can make a voluntary decision in a certain situation – on the contrary, they are deemed 'incompetent' where they cannot make such decisions. Building on this, Shaun Pattinson's 'task-specific' competence⁵ is the main definition of competence used in this piece. Defining competence in this way helps build on the notion of autonomy especially when looking at the decision-making abilities of those with dementia because of the 'sliding scale' of ability experienced. It makes sense to assess competence subjectively, by reference to an individual's ability to perform or partake in certain activities

¹ In both Scotland and Northern Ireland, the situation regarding advance refusals is regulated by common law only. In Scotland, there is no law defining a document or registering body for advance decisions of any form. For further information on the proposed system in Ireland please see The Assisted Decision-making (Capacity) Bill 2013 and for discussion over provisional implementation see Morrissey 2013, 69.

² The principle that contemporaneous treatment may be refused by an adult with capacity is dealt with only at common law see for e.g. *Re T* [1993] Fam. 95.

³ MCA 2005 s.1 to 4 and ss.24 to 26.

⁴ MCA 2005 s.24 (1) an 'adult' is defined as over 18 for advance refusals but an 'adult' is also classed as those over 16 (s.2 (5)(b)) generally for application of the other principles in the Act.

⁵ See Pattinson 2002a, 78 and Pattinson 2011, 148 and 150.

because the distinction between having competence to read a book and having competence to make future decisions about healthcare treatment are very different. It is disturbing that there are currently no specific provisions within the 2005 Act to this effect.⁶

Capacity and competence are two separate states – a person may be deemed competent at one level, but this may not lead to a legally recognisable level of competence entailing legal capacity. Michael Gunn summarises this point:

“Capacity/incapacity are not concepts with clear a priori boundaries... The challenge is to choose the right level to set as the gateway to decision-making and respect for persons and autonomy”.⁷

Thus the gateway to decision-making is set as follows: a legally recognised level of decision-making capacity is achieved when a person satisfies the two stage test laid down ss.2 to 3 of the MCA 2005. The opposite applies where a person does not have capacity. For the first part of the test, capacity is presumed; a patient will only lack capacity if they are unable to make decisions for themselves ‘because of an impairment of, or a disturbance in the functioning of, the mind or brain’ and includes temporary damage to cognitive abilities (s.2(2)). The second part per s.3(1) of the MCA 2005 declares that a patient will be classed as unable to make a decision, if they are unable to:

- i) Understand information relevant to the decision;
- ii) Retain that information;
- iii) Use or weigh that information as part of the process of making the decision ; or
- iv) Communicate the decision by any means.

⁶ Whilst it is understood that even in periods of lucidity in capacity, a person cannot necessarily be viewed as not having capacity, there is no exception for dementia patients where competence may still be established, but legally recognised capacity is not. Dementia is described as being ‘a disturbance in the functioning of the mind or the brain’, see further Disability Law Service (2009) guidance on Mental Capacity, http://www.dls.org.uk/advice/factsheet/community_care/mental_capacity/Mental_Capacity.pdf <accessed 20/12/13>. 3.

⁷ Gunn 1994, 8.

1.2 The Relevance of Odysseus

The MCA 2005 purports to champion the autonomous decision of a once capacitated person over their future incapacitated person – this principle applies only to refusals of healthcare, not requests.⁸ Where a person makes a contemporaneous refusal of medical treatment, the assertion of legal capacity is more easily provable than its advance counterpart.

The title to this thesis relates to the first ever documentation of an advance refusal presented in a fictional account through the character of Odysseus in Homer's⁹ 'The Odyssey'.¹⁰ Odysseus is warned by Circe that during his travels, his return journey will involve an encounter with the 'Sirens', ethereal singing entities which lure men to their deaths. With this knowledge, Odysseus plugs his men's ears with beeswax and has them bind him to the mast of the ship. He issues an advance directive that they are not, in any event, to untie him as he will beg of them. Instead, he urges them to pull the bindings tighter – so he can still witness the Sirens and hear their song, but at the same time, avoid their mortiferous effect. Because of the knowledge he gained from Circe, Odysseus anticipated two things as a consequence of his meeting with the deadly enticers:

- 1) That the situation he engineered would entail him begging to be released by his shipmen which would result in his own death; and
- 2) That he would return to his usual level of consciousness afterwards.

These anticipations became true. This type of advance refusal in itself is presented as being straightforward – both at the time of making the advance refusal and afterwards, Odysseus remained competent. From this, on an ethical level, there could be no case for deviation from his wishes. In reality, the situation is far more complex. Comparatively, Odysseus' desire was to prolong his life by not being lured by the Sirens, yet the MCA 2005 only allows for the rejection

⁸ At this juncture it is of note that this thesis focuses only on rights in relation to advance refusals, not advance requests. As stated, this is also the position at law.

⁹ The Greeks believed the story was created by Homer; in modern day, he is always mentioned as the author but this can never be proven.

¹⁰ See Homer BCE, as translated in Rieu and Rieu 2003, 158-159 and 161-162 and Pattinson 2011, 531-532.

of treatment which can shorten life. Far from the situation of Odysseus, conceptually advance refusals at law in the modern day present as being both ethically and legislatively problematic. Odysseus' account relates directly with the central purpose of this thesis: to investigate whether or not the current law of advance refusals adequately addresses preservation of the wishes, values, views and beliefs of persons through the main provisions. Building upon Homer's account of an advance refusal, three inter-connected central areas of concern are explored within this thesis; the ongoing debate at law between autonomy and the preservation of life, and the problems faced specifically by the MCA 2005 regarding the ethical issues around personhood and personal identity.

1.3 Objectives

The general approach of this piece is that the spirit of the law around advance refusals, respecting the autonomy of the individual, is propitious, but that further developments both in the legislation on paper, and within the law in practice, must be made to adequately fill lacunae which still exist. The recurrent fundamental theme throughout this piece is that without attempting to fill such lacunae, the 2005 Act is precluded from preserving the wishes, values, views and beliefs of persons (which was a theme at least to an extent, intended by the Act).

Applying the main provisions in real terms has caused a significant departure of the law from reality. As a result, high levels of confusion are bred, affecting those making advance refusals,¹¹ through to the decision makers in the Court of Protection.¹² Henry Small recently emphasised the importance of clarity in this area:

“Nowhere is the requirement for legal certainty more important than where personal autonomy and human dignity are concerned”.¹³

¹¹ To see the extent of difficulty encountered for creators of advance refusals see for e.g. Craigie 2013, 4-19.

¹² *A Local Authority v E*; [2012] EWHC 1639 (COP) at 129 ; here, Jackson J. described reaching a decision as being 'intuitive' as opposed to 'mechanistic' in granting an anorexic palliative care as opposed to rehabilitative, lifesaving treatment.

¹³ Small, H. 2014.

Existing problems need to be rectified by way of unity between the spirit of the 2005 Act and the advance refusal provisions. Examples causing this current 'non-unity' include:

1) The historical dominance of the Article 2 (European Convention on Human Rights ; herein 'ECHR') 'right to life' over the right to autonomy (loosely defined as an individual's free ability to make decisions for the purposes they choose; this right is codified in art.8 right to respect for private and family life). Where the 2005 Act purports to grant advance decisions to those who fulfil the strict criteria laid down , it must also consider widening its ambit so as not to exclude the permissibility of such advance refusals based upon small issues.¹⁴ Classically, the right to life has always 'trumped' any other right when such cases have been heard in court – if the 2005 Act is really going to do what it set out to do, such long-standing commitment to this right must be weighed more evenly against its counterpart right to autonomy.

2) The lack of guidance for the treatment of those who suffer from dementia and advance refusals. If a person is no longer exhibiting the same behaviours and there is a question around their identity, as seen with those suffering late stage dementia, there must be a degree of consensus for understanding how best to treat such persons with severe personality changes. A person can have dementia, but can still be classed as 'the same person'. There must be some further guidance in this matter other than the General Medical Council's (herein 'GMC') requirement that such persons require 'extra support'¹⁵ during the decision-making process. Where the MCA 2005 treats all persons as if they do not have capacity if there is a question as to their personal identity (early-mid stage dementia) it is here contended that where such individuals have a level of task-specific competence this should be used as the starting point, not the legal test for capacity which is set at an unreachably high level. If relevant competence is established, and until the personal identity problem is proven to be a problem, an advance refusal should not be automatically excluded from applying today.

¹⁴ This was the case in *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam); this point is fully explored at 4.2.1 and 4.3.

¹⁵ GMC 2008, para 67.

3) The current standards used for judging what is in the 'best interests' of persons when there has been no advance refusal created, or where that advance refusal is 'ambiguous' is not consistent with the moral basis for this thesis. It is urged that new systems of deeming what is best should be made after consideration of all of the above issues. The current 'catch-all' test does not in fact produce the best results as each patient is a person, and each person is different.

It is argued that these various issues present themselves as significant flaws which should have been digested in the under-belly of the MCA during the draft stages of the 2005 Act; as problems prevail, legislative overhaul is needed. Such legislative harmony could be achieved through a codified injection of moral grounding.

1.4 Chapter Outline

The last part of this introductory chapter is a brief overview of the moral basis for this thesis which is the suggested model to be used in improving efficacy of the main provisions. This introduction aims to set the scene for chapter two's promulgation of the message that advance refusals have an important role to play in protecting autonomy despite appreciation that their effect is often denied in practice.

Later in the second chapter, I argue that the 2005 Act's codification of the right to refuse life-sustaining treatment in particular has not produced the desired effect. This, it is argued, is due to flaws in implementation. This conclusion is reached by exploring the notion that the MCA 2005 has exacerbated many of the problems which were, and still remain, unresolved at common law.

In keeping with the moral basis for this thesis (the Principle of Generic Consistency (herein 'PGC') outlined at 1.5), I explain why there should be some consideration of a person's 'moral status' as part of any system for advance refusals. Accordingly, the third chapter begins with an outline of the concept of personhood as foundation for discussion of the ongoing debate between life and autonomy (i.e. the general aim adopted by the State to preserve life

where possible versus one's personal right to express the moral self in the form of an advance refusal). Personhood is a relevant topic as the defining components of persons allow us to realise moral status, in law, philosophy, and our everyday lives in general. It is in this chapter that the philosophical framework of the PGC begins linking with real life in this thesis. This chapter aims to highlight the perils of the MCA 2005's lack of regard for the issues of personhood and of the moral status of persons. Of course defining 'personhood' is a task beyond this thesis, but this chapter aims to give a firm grounding for an argument to strengthen the MCA 2005 so that the question of 'to what extent does this person matter?' can be answered in each particular case. Without answering this question, it is argued that a person's wishes, values, views and beliefs can never be fully addressed. So, it is presented that if we can consider what makes us people per se, that is, the attributes and features forming a person, and their unique moral status, we can understand further the importance of understanding philosophical concepts of agency. This will be in-keeping with the foundational principle that a law concerning only those who 'matter' must get those who matter *right*.

I then outline the main reasons for the primacy of the right to autonomy in chapter four, as supported by the ethical theory of Gewirth. I discuss the fundamentally anomalous results produced by the debate between life and autonomy which are incompatible with the powerful undercurrents of autonomy in the main provisions of the MCA 2005. The concluding remarks in this chapter focus mainly on analysis of the varied concoction of judgments in the recent cases of *NHS Trust v L*¹⁶, *A Local Authority v E*¹⁷, *The X Primary Care Trust v XB*¹⁸ and *Re M*.¹⁹ It is argued that the inconsistent results produced in judgment from these cases must be stabilised to preserve autonomy where possible. This becomes problematic, however, when the usual features of personal identity become blurred which is an issue addressed in the next chapter.

¹⁶ *NHS Trust v L* [2012] EWHC 2741 (COP).

¹⁷ *A Local Authority v E*; [2012] EWHC 1639 (COP).

¹⁸ *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam).

¹⁹ *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287.

The fifth chapter builds on ideas in chapters three and four, to the effect that that the primacy of the right to autonomy ought to be stabilised in reality; this perspective is grounded in the ideal of making the MCA 2005's visions more realistic. The main issue to be addressed in this chapter is the MCA 2005's disregard of the challenges provoked by the personal identity problem which should not be, as it is argued, unjustifiably ignored. The personal identity problem itself is a problem that considers the relationship between a person and their identity, adducing the relevance of the way that we address the continuity of person. The problem builds on the notion of personhood. In this thesis, where the question around personhood and moral status is:

“To what extent does this person matter?”;

When a person undergoes a severe change in their personality, this question evolves to become;

“To what extent does this person's identity matter?”

Both questions are yet to be fully explored as there is no separate consideration for those who suffer from dementia in the MCA 2005. Actually, current legislation does not give clear guidance regarding how best to treat those persons who have undergone severe changes in personality and what a severe change of personality may constitute. Varying degrees of dementia, for example, may mean that at one moment an advance refusal is valid, and the next it is not – there are not even loose guidelines for the point at which a person with dementia changes so significantly that an advance refusal no longer applies. I highlight that whilst the personal identity problem is not considered as part of the MCA 2005's main provisions, in truth, judges and medical practitioners must recognise this problem, and such recognition needs regulation. From this perspective, the MCA 2005 in practice is also analysed – as the medical profession is reluctant to apply advance refusals to dementia patients in England and Wales and beyond.²⁰ This reluctance equates to recognition of the problem indirectly. It is important to outline that the personal identity problem is not always problematic but it is in situations where it is arguable that a person's identity has changed and the person no longer has capacity, it is.

²⁰ Sheldon 2013.

The difficulty arises when a person becomes incompetent. In these circumstances, there are three positions that may be taken in relation to a person (herein 'P'):

- 1) As soon as P becomes incompetent, he becomes someone else;
- 2) When incompetent, P is always the same person;
- 3) When P becomes incompetent, he could be the same person, or he could be a different person.

In this thesis, the view taken is based upon the last as I apply precaution where possible.

The penultimate chapter forms an enquiry as to the integrity of the 'best interests test' – the current welfare test used to judge what is thought to be in a patient's best interests considering all the circumstances, applying, among other occasions, where no valid advance refusal has been made. There are issues with the application of this test which jeopardise the preservation of a patient's former wishes, values, views and beliefs. For example, this test neither considers what the patient would have wanted if he could have made the decision for himself now, nor does it honour consideration of the conflicting rights of others.²¹ This broad criticism of the test is explored further and, as an alternative, I explore the use of a system of order for use of tests which combines the 'best interests test', the 'substituted judgment standard', (a standard which attempts to establish with as much accuracy as possible what decision the patient would have made if that patient were competent to do so) and the 'overall interests test' (a concept created by Shaun Pattinson considering the rights of all parties involved where rights conflict²²).

Chapter seven concludes the thesis by summarising disparities between the intentions of the MCA 2005 and the application of the main provisions in reality. This concluding chapter explores the notion that without attending to such difficult ethical and social problems in implementation, the MCA 2005 fails to do what it set out to do.

²¹ I return to this point about conflicting rights at 6.2 & 6.3.

²² Pattinson 2011, 166.

1.5 Moral Basis

“Persons guide their lives in many different ways. Among the various goals, rules, habits, ideals, institutions that figure more or less explicitly in such guidance, morality has a unique status”.²³

The subject of this thesis is ethically controversial. I therefore need a criterion of morality. The ethical approach taken in this thesis is based on a model of morality devised by Alan Gewirth in the PGC.²⁴ I offer two reasons as to why I use this:

1) The theory seeks to use logic as grounds for morality. The first part of the argument seeks to show that an agent denies they are an agent if they do not accept the PGC. This element of the argument is termed ‘dialectically necessary’; it is ‘dialectical’ as it relates to agency and it is deemed ‘necessary’ as all steps are necessary leading to it. For Kant, Gewirth and Beyleveld, in (respectively) the Categorical Imperative (Kant)²⁵ and the PGC (Gewirth²⁶ and Beyleveld²⁷), the dialectical necessity element of each argument is central.

2) The second (and most relevant) reason (developed by Beyleveld²⁸) is that the argument is also ‘dialectically contingent’, again the ‘dialectical’ element relates to agency, and this presentation of the argument is ‘contingent’ as it contingently relies on the existence of human rights in practice.

Building on this, a brief description of the relevance of my use of the PGC is outlined succinctly here:

²³ Gewirth 1978, 1.

²⁴ See Gewirth, 1978.

²⁵ Kant, 1785, as translated in Paton 1948.

²⁶ See Gewirth 1978.

²⁷ See Beyleveld 1991.

²⁸ Beyleveld 2012.

“Like Kant’s argument for ‘the moral law’, this (PGC) aims to demonstrate that the idea of morality, viewed as a categorically binding set of norms requiring all agents to be treated with equal concern and respect, is not a delusion. Kant cogently maintains that if morality is characterised as categorically binding such a demonstration must establish that the moral law is connected (completely a priori) with the concept of the will of a rational being as such”.²⁹

The purpose of this thesis is only to use the PGC as the basis for moral discussion, not to defend it.

1.5.1 Dialectically Necessary

Per Deryck Beyleveld, the three main stages of the dialectically necessary argument to the PGC are as follows:³⁰

(I) “I am an agent” so “I accept that I ought to pursue the Generic Conditions of Agency (herein ‘GCA’- those conditions conducive to agency)”. The GCA are divided into three hierarchical levels of ‘needs’, beginning with those classed as ‘basic’:

- 1) ‘Basic needs’ (needed to be able to act at all).
- 2) ‘Non-subtractive needs’ (needed to maintain an agent’s ability to act), - those actions an agent pursues to maintain the current level.
- 3) ‘Additive needs’ (needed in order to be able to improve an agent’s ability to act); additional action(s) pursued to the end of further fulfilment.

Therefore, in relation to the fact that “I am an agent, I have some purposes that I must accept”, it follows that “I ought to defend my possession of the GCA”.

(II) It then follows analytically from “I ought to defend my possession of the GCA” that “I have the Generic Rights (herein ‘GR’; those rights enabling action)”. Where the criterion is that I categorically instrumentally ought to defend my having the GCA, it is dialectically necessary for

²⁹ Beyleveld 2012, 3.

³⁰ The basis for the format of argument is derived from lectures delivered by Deryck Beyleveld in 2008/2009 (as part of the Law and Medicine module of the Law (LLB) course at Durham University).

me to prescriptively accept this criterion, which means that I must prescriptively accept that others categorically ought not to interfere with my having the GCA (i.e. categorically ought not to interfere with my having the GCA against my will) etc. Hence I must accept that I have the GR. Some allege that it is not intelligible to prescribe that others not interfere with my having the GCA in this context. This is where the PGC is met with criticism, as is the next stage of the PGC.

(III) It must follow purely logically from $\{I \text{ am an agent} \rightarrow I \text{ have the GR}\}_1$ that $\{X \text{ is an agent} \rightarrow X \text{ has the GR}\}_1^{31}$. This aspect of the dialectically necessary argument relies on two reasons for acceptance; a categorical prudential reason (i.e. denial of stage 2) and to the avoidance of contradicting that I am an agent (stage 1).

Stages II) and III) of the PGC have not been met without criticism, indeed Brown remarked that such criticism was 'widespread'³² but that the argument was fundamentally misunderstood, which was also a view taken by Gewirth³³. Such criticism has stemmed most significantly from Marcus Singer,³⁴ Bernard Williams³⁵ and Christine Korsgaard.³⁶ Singer's criticism was responded to in full by Beyleveld,³⁷ a modern day Gewirthian. The criticism itself mainly focused on definition and interpretation of and wording used in what Beyleveld labelled the argument for 'sufficiency of agency' as central to an aspect of dialectically necessity criterion for agency.³⁸ Particular doubt has been expressed over stage 3 of the argument and the internal viewpoint of the agent, i.e. 'why I ought I to defend the rights of others and respect these in the same manner as respecting and upholding my own'?³⁹

Since an argumentative chain is only as strong as its weakest link, and because proving the dialectically necessary argument for the PGC is a matter to be dealt with in and of itself, I

³¹ *Ibid.*

³² Brown 2004, 93.

³³ Gewirth 1978.

³⁴ Singer, M. 1985, 297-301.

³⁵ Williams 1985, see particularly chapter 4.

³⁶ Korsgaard 1996, 93-96.

³⁷ Beyleveld 2002.

³⁸ *Ibid.*

³⁹ See Williams 1985, chapter 4 for further. See also Korsgaard 1996, 93.

will be referring only to the first stage of Gewirth's dialectically necessary argument in this thesis. I contend that this stage is sound and building on this, the argument that I use is a dialectically contingent argument to the PGC.

1.5.2 Dialectically Contingent Argument to the PGC

Again taken from an argument formulated by Deryck Beyleveld,⁴⁰ if we add stage 1 of the dialectically necessary argument and combine it with the existence of human rights legislation, we have a dialectically contingent argument which is undeniable on pain of contradiction. From the Human Rights Act 1998 (herein 'HRA') to the fundamental principles of the all-governing Universal Declaration of Human Rights (herein 'UDHR') we find that rights are conferred on all individuals in equal measure from birth. As an example, adding stage one of the PGC i.e. 'I am an agent- I have the Generic Rights' to the following excerpt (from the UDHR), equates to the first stage of the PGC in action:

"All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood".⁴¹

The same applies to part of the foundation for Articles 1 and 2 of UNESCO's Universal Declaration on the Human Genome and Human Rights 1997:⁴²

Article 1

"The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity";

Article 2

⁴⁰ Please see Beyleveld 2012 for further expansion of this point.

⁴¹ UDHR Preamble (art.1).

⁴² The principle works also with Article 2 of the UDHR.

“(a) Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics”; and

“(b) That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity”.⁴³

The first stage of the PGC is also embedded⁴⁴ in the ECHR.

The nature and principle of these rights revolve around equality, in this way, forming a network of rights based upon a dialectically contingent⁴⁵ argument implying a distinct commitment to universalisability of rights. This dialectically contingent argument means that anyone who accepts human rights must accept stage 1 of the PGC and all of the elements in stage 1. This is clearly reflected in the law as shown in sections from human rights legislation above so this thesis follows the premise laid out by Beyleveld:

“It follows, on pain of denying that all human beings are equal in dignity and inalienable rights, that it is dialectically necessary for those who accept and implement the UDHR to consider that all permissible action must be consistent with the requirements of the PGC. It follows that all agents (including judges and legislators) purporting to interpret the instruments of the international legal system of human rights must likewise do so in accordance with the PGC. In this sense, the validity of stage one of the dialectically necessary argument entails that the PGC is the supreme principle of human rights”.⁴⁶

As described, the PGC has two justificatory strategies. The first is the three stage dialectically necessary argument; the second is a combination of stage one of that argument added to the existence of human rights, thus giving us a dialectically contingent argument. Where the law is morally controversial, I will address matters using the dialectically contingent argument to the PGC.

⁴³ Universal Declaration on the Human Genome and Human Rights November 11th 1997.

⁴⁴ To an extent; the Article 12 (ECHR) right to marry is not universalisable, for example, as ages of consent vary.

⁴⁵ See Beyleveld 1997 for further.

⁴⁶ Beyleveld 2012, 8.

1.6 The Relevance of Agency, Autonomy and the PGC

A fundamental principle employed in Gewirth's theory is the freedom of action of agents. The success of autonomous action has been dual categorised; 'agent autonomy' per Alan Gewirth and Deryck Beyleveld, and, building on this, 'task-specific' competence, per Shaun Pattinson.⁴⁷

Gewirth's PGC, supports the notion of autonomy (whilst not absolutely). This is presented by the presupposition that agents ought to pursue their purposes freely and voluntarily regardless of what these may be. Autonomy is at the heart of the PGC. This is demonstrated as Gewirth defines action as holding two broad features – voluntariness (or freedom) and purposiveness (or intentionality) and these two requirements for action relate directly to the definition of competence. Also, as a generic condition of agency, one of the 'basic freedoms' granted to agents includes the freedom to act according to one's chosen purposes and freedom of thought.⁴⁸ Under the PGC, contemporaneous decisions would be treated with the same respect as advance decisions (both general advance refusals and advance refusals of life-sustaining treatment) remembering that the PGC also allows people to be released from all duties (i.e. the duty to sustain life per the Hippocratic Oath). From this, if I can make a decision now to refuse treatment, this can also apply to a later date, where I can no longer make or communicate it.

⁴⁷ Pattinson 2011, 148 and 150.

⁴⁸ Gewirth 1978, 52-53.

CHAPTER TWO: A BACKGROUND AND GENERAL ANALYSIS OF THE EFFICACY OF THE MCA 2005'S MAIN PROVISIONS

2.1 Finding the Value in Advance Refusals

An advance refusal is a decision made by a person addressing a later inability to make decisions on treatment. Such decisions can demand or refuse the kinds of treatment specified by their maker. From classical folklore⁴⁹ through to statutorily regulated modern day application, the implications of advance refusals, valid or not, have induced widespread legal and ethical debate.

Advance refusals may be made by the person themselves or/and through the appointment of another person, a 'Lasting Power of Attorney'.⁵⁰ An advance refusal must exist, be valid,⁵¹ and applicable.⁵² To satisfy these requirements, it must be shown that the creator (here 'C'):

- 1) Had capacity at the time of creating the advance refusal;
- 2) Specified the particular treatment in question;
- 3) Has not done anything else clearly inconsistent with the advance refusal. And specifically with advance refusals of life-sustaining treatment;
- 4) Made the advance refusal in writing, authenticated by two signatures, one from C (or on behalf of C), and one from a witness; and finally,
- 5) Expressly states that it is to apply even if life is at risk.

⁴⁹ This point refers particularly to the tale of Odysseus discussed at 1.2.

⁵⁰ Per ss.9 to 11 of the MCA 2005.

⁵¹ A valid advance refusal must be made according to criterion outlined in ss.24 to 26 MCA 2005.

⁵² Yet even this is rebuttable as in *R. (N and Another)*[2009] HRLR 31 and where it is 'necessary in a democratic society' the right will be overridden via art. 8(2) ECHR.

There is without doubt some degree of value in the use of advance refusals. They protect the autonomous interests of their creator, and in turn, they also preserve the creator's values and desires; amounting to a snap-shot of the creator's mindful intentions and an embodiment of their own choice and direction. Respect and dignity are two key components in any law pledging to uphold advance refusals.

The importance of advance refusals is also highlighted when considering the danger of others assigning the wrong values and attitudes to a person. It is undeniably difficult, outside of the realms of first-person autonomy, to vicariously prescribe a person's wishes, values, views and beliefs in every circumstance. This is illustrated in the contrasting accounts of life ambitions and directions of Ruth Sienkiewicz-Mercer and Tony Nicklinson. Both parties were severely disabled with degenerative conditions which would eventually lead to death. Both parties placed differing significance on their lives.

For Nicklinson, a right-to-die activist, who suffered a devastating brain-stem stroke resulting in locked-in syndrome (where a person has a level of consciousness but cannot move (with the exception usually, of the eyelids) or communicate verbally), death was something actively welcomed:

"My life can be summed up as dull, miserable, demeaning, undignified and intolerable. ...it is misery created by the accumulation of lots of things which are minor in themselves but, taken together, ruin what's left of my life. Things like...constant dribbling; having to be hoisted everywhere; loss of independence...particularly toileting and washing, in fact all bodily functions (by far the hardest thing to get used to); having to forgo favourite foods; ... having to wait until 10.30 to go to the toilet...in extreme circumstances I have gone in the chair, and have sat there until the carers arrived at the normal time".⁵³

⁵³ *R. (on the application of Nicklinson) v Ministry of Justice* [2012] EWHC 2381 at 13.

Yet Sienkiewicz-Mercer, a lifetime quadriplegic and victim of cerebral palsy, who was 'confined to a wheelchair or bed for every waking hour of her life' with a 'functionally useless' body,⁵⁴ considered her life worth living. Thus, although life was similarly reminiscent of an everyday struggle, hers became dedicated to her 'triumphant'⁵⁵ career as an American disability rights activist, living by the mantra, 'I could overcome my physical limitations by hard work and education'.⁵⁶

Advance refusals also serve as shields, protecting the bodily integrity of their creators, especially pragmatic where medical intervention becomes an endurance in itself which is less welcome than death.

There are, of course limits as to the efficacy of advance refusals which any law providing for them must attend to. Alan Buchanan describes the main issues as the 'three asymmetries':⁵⁷

1) Even where an advance refusal was issued and the individual was well-informed about the options available, both therapeutic options and prognosis may change;

2) It is always, in any case, questionable that a competent person is the best judge of her own interests under conditions in which those interests have changed in 'radical and unforeseen ways',⁵⁸ and in any case

3) 'Important informal safeguards' should be in place to restrain important decisions or bad choices are not likely to be present, or effective, in the case of an advance refusal.

Whilst the issues highlighted by Buchanan's model are partially accounted for in the 2005 Act,⁵⁹ there are many more issues to be ironed out within our own framework for advance refusals.

⁵⁴ Sienkiewicz-Mercer and Kaplan 1989, 1.

⁵⁵ The Washington Post commented (on Ruth's biography); 'what Sienkiewicz-Mercer has made of her life is nothing short of a triumph'. See front cover, Sienkiewicz-Mercer and Kaplan 1989.

⁵⁶ Sienkiewicz-Mercer and Kaplan 1989, 157.

⁵⁷ Buchanan 1988, 278-281.

⁵⁸ Buchanan 1988, 279.

⁵⁹ *Ibid* s.4 (b) and c)) where an advance decision is not applicable to the treatment in question if—
(b) any circumstances specified...are absent, or

Thus, whilst there is value to be found in advance refusals as a concept, their implementation in practice can either be a means of respecting individual autonomy, or of providing a false sense of the same. When this occurs, the 'right' conferred (in this case, the right to present and future preservation of autonomy) is too difficult to invoke in practice due to complexities. At the very heart of this is the fact that no 'universal moral approach' is entrenched in the MCA 2005, so the application of advance refusals is curtailed by the issues faced in everyday life application including the conflicting rights of others, the right to autonomy, issues around personal identity and so on. If a clear-cut moral code was seen to be embedded in the 2005 Act, this would allow for full effect to be given to the value to be found in advance refusals.

2.2 The Law on Advance Refusals: From *Re T*⁶⁰ to the MCA 2005: A U- Turn?

Preceding the enactment of the MCA 2005, confusion surrounding validity, applicability, extent and the role of first-person capacity arose from the myriad of judicial dicta in this area. Individual autonomy over future decisions was either restricted or valorised, but often for the wrong reasons.⁶¹

*Re T*⁶² is a prime example of a case detailing lack of consideration of the decision-making capacity of persons (the same case set out the first guidelines specifically relating to advance refusals by incapacitated adults). The case concerned a pregnant Jehovah's Witness who, following a car crash, had refused to consent to a blood transfusion. This refusal was in writing, and was a direct result of a conversation with her mother, also a staunch Jehovah's Witness. Due to an emergency caesarean section, where Ms T needed a blood transfusion, the applicability of this advance refusal came under scrutiny. As she was unconscious at this time,

(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.

⁶⁰ *Ibid* [1993] Fam.95.

⁶¹ See for example *Re T* [1993] Fam. 95 even though an advance refusal was made, the court declared a presumption in favour of life and enforced the blood transfusion despite the fact that Lord Donaldson himself declared that an advance refusal was as valid as a contemporaneous refusal if it was 'clearly established and applicable in the circumstances'.

⁶² *Re T* [1993] Fam.95.

her brother and boyfriend sought a declaration from the court to the effect that, despite the advance refusal made by Ms T, the transfusion would not be unlawful. The Court of Appeal authorised the treatment. Ms T's rights to bodily integrity and personal autonomy were overridden by the sanctity of life presumption;⁶³ it was held that this would be the case where doubt existed and an advance refusal could not be deemed as 'clearly established and applicable in the circumstances'.⁶⁴ In *Re T*, the court also addressed the matter of undue influence — where a patient's decision is influenced in way meaning that they are pressurised by another — and it was decided that where this could be established, a patient could not be seen to have made an advance refusal.⁶⁵ The problem was that personal autonomy had not been exercised as undue influence had occurred. The outlook that the sanctity of life presumption would be invoked where doubt exists over an advance refusal was also reaffirmed in the later case of *Airedale NHS Trust v Bland*.⁶⁶ It was also held in *Re T*⁶⁷ that where an advance refusal was ambiguous, this was a matter to be presented at court. This is a principle which remains in operation today.

In *Re AK*,⁶⁸ the NHS trust responsible for the treatment of a 19 year old patient with motor neurone disease (herein 'MND'), sought a declaration that it would be lawful to comply with his advance refusal. Particularly, AK had communicated, through the use of his eyelid, his wishes that the artificial nutrition, hydration (herein 'ANH') and ventilation he relied on, be removed, which was to occur two weeks from the date at which point he completely lost the ability to communicate. The advance refusal was declared valid by Hughes, J. on the basis that AK had full capacity and was able to refuse in advance. At the time of judgment, the HRA 1998 was in the process of giving full effect to the ECHR which Hughes, J. also declared as being consistent with his view.

⁶³ *Ibid*, Lord Donaldson at 103. And affirmed in the latter cases of *Airedale NHS Trust v Bland*. [1993] A.C. 789 and *Re MB (Medical Treatment)* [1997] 2 FLR 426.

⁶⁴ *Ibid* at 103 to 104.

⁶⁵ *Re T* [1993] Fam.95.

⁶⁶ *Airedale NHS Trust v Bland* [1993] A.C. 789.

⁶⁷ *Ibid* [1993] Fam.95.

⁶⁸ *Re AK* [2001] 1 F.L.R. 129.

The last significant judgment concerning the validity of an advance refusal prior to the MCA 2005 is to be found in *HE v Hospital NHS Trust*.⁶⁹ HE, the father of the 24 year old patient D, applied for a declaration that a blood transfusion could be administered to his daughter as a means of life-sustaining treatment. D had signed an 'advance medical directive' four years earlier rejecting a blood transfusion on the basis of her faith, as at this time she was a practising Jehovah's Witness. D also stated that the directive could only be revoked in writing. HE's declaration was granted on two grounds. The first of these was that D's beliefs and values were not reflected in the advance refusal; as D ceased to worship as a Jehovah's Witness for some months before her illness, and was currently engaged to a Muslim man and in the process of committing to his faith. The second was that an advance refusal can be revoked in any way— orally, by conduct, or by other means (i.e. not restricted to written revocation).

From these three cases, any doubt concerning the validity of an advance refusal before the MCA 2005 took effect meant that decisions over the treatment of patients were to be made in favour of preservation of life. Many of the decisions at common law restricted the use of advance refusals. Indeed pre-MCA 2005, advance refusals were not treated uniformly due to a lack of boundaries indicating the need for delineated threshold criteria. Hence, after much call for statutory reform regarding the treatment of adults lacking capacity,⁷⁰ the MCA 2005 was enacted.⁷¹

2.3 The MCA 2005

The main purpose of the MCA 2005 was to unite the notion of patient autonomy, both future and present, with the best interests principle. The default presupposition of individual autonomy can be overridden where a lack of capacity is ascertained. In this instance, the best interests test is triggered. The MCA 2005's Code of Practice (herein 'MCA CoP') outlines the

⁶⁹ *HE v Hospital NHS Trust* [2003] EWHC 1017 (Fam).

⁷⁰ Michalowski 2005, 960.

⁷¹ The need for statutory provision concerning the creation of advance directives was highlighted in the Law Commissions Report no.231 'Mental Incapacity' 1995. Created ten years later, the MCA 2005 provides such statutory regulation in ss.24 to 26.

process of capacity and decision-making per the Act, supporting the Act's s.1 provisions. Here, family and other carers must assume that a person has the capacity to make decisions, unless it can be established that they do not. The MCA CoP encourages that help is offered to patients so that they can make their own decisions. The MCA CoP affirms the MCA 2005 in that unwise decisions are still valid decisions if the maker has capacity⁷² and urges that, in the absence of any advance refusal, a person's 'best interests', and 'basic rights and freedoms', are the sole and prime considerations to be made.⁷³

In addition to codifying common law principles, the MCA 2005 provides many new optional formalities. These include advance refusals of life-sustaining treatment, provision for any Lasting Power of Attorney (herein 'LPA') which enables a person to choose others to act on their behalf when mental capacity is lost (in the case of health and welfare LPAs),⁷⁴ appointment of deputies, and creation of the Court of Protection. The Act gives effect to an advance refusal that is both 'valid' and 'applicable to the treatment in question' if it was made by an adult with capacity to make it at the time.

In terms of 'validity' per s. 25(2), an advance refusal need not be created or evidenced in writing unless it regards the rejection of life-sustaining treatment in which case it must be signed by both the author and a witness and in writing.⁷⁵ There are no formal requirements for revocation of either. An advance refusal is not valid if a person has:

- "1) Withdrawn the decision at a time when he had capacity to do so;
- 2) Conferred authority on the donee/s (LPA) to give or refuse consent to the treatment to which the advance refusal relates; or

⁷² *Ibid* s.2(3).

⁷³ See the Code of Practice: DoCA 2007, 20.

⁷⁴ MCA 2005 s.25(2)(b)and(7).

⁷⁵ S.25(5)and(6) MCA 2005.

3) Done anything else clearly inconsistent with the advance refusal (remaining his fixed decision)".⁷⁶

The new Court of Protection is afforded statutory power⁷⁷ to decide the validity and applicability of an advance refusal where they seem ambiguous. The ruling given by Theis, J. in *The X Primary Care Trust v XB*⁷⁸ has been the latest notable decision in the Court of Protection regarding the validity of an advance refusal of life-sustaining treatment. Here, a very pragmatic overall approach was taken to what could have otherwise been a lexical minefield. In this case, the issue was the accidental inclusion of an 'end-date' in the advance refusal due to the template being obtained from an internet website – as a bi-product of the degenerative nature of the patient's illness, there was, in reality, no 'end-date' where the refusal would expire logically. There are, of course, numerous issues thrown up by the term 'validity' – these refer to the timeframe of the refusal, any ostensible change in thought or behaviour patterns of the creator and other generic changes in circumstances.

Under the MCA 2005, an advance refusal is not applicable to the treatment in question if a person has not defined such treatment unequivocally. To be 'applicable' the treatment refused must:⁷⁹

- "a) Be specified;
- b) Include all circumstances present; and
- c) Refer to circumstances presently existing which the maker did not anticipate at the time of making the advance decision which would have affected his decision, had he anticipated these present circumstances".

As discussed in the introduction to this piece, the bar is set higher for the process of creating applicable advance refusals of life-sustaining treatment. These must be signed, witnessed and in writing, but their revocation may be oral. In addition, to establish whether an advance refusal

⁷⁶ *Ibid* s.25(2)(a) to (c)

⁷⁷ S.26(4).

⁷⁸ *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam).

⁷⁹ MCA 2005 s.25(4)(a) to (c).

is valid and applicable (even where it appears to be so based upon all other criteria), medical professionals must attempt to find out if the person:

“Has done anything that clearly goes against their advance refusal, has withdrawn their decision (and/or), has subsequently conferred the power to make that decision on an attorney, or would have changed their decision if they had known more about the current circumstances”.⁸⁰

The position of those in the medical profession is also provided for; under s.26 (1) of the MCA 2005, a person does not incur liability for carrying out or continuing treatment unless, at the time, he is satisfied that an advance refusal exists which is valid and applicable to the treatment. Also, per s.26 (2), any medical professional who reasonably believes that an advance refusal is valid and applicable to the treatment concerned will avoid liability. If the healthcare professional in question is unsure as to the effect or validity of an advance refusal, they may refer this to the Court of Protection. In actuality, per s.26 MCA 2005, a healthcare professional is presented with four outcomes if the patient has made an advance refusal:

- 1) If the doctor ignores a valid advance refusal, he is guilty of committing the tort of battery, and the crime of assault;
- 2) If the doctor ignores an advance refusal that cannot be deemed valid and applicable for the purposes of the act, he is not guilty of anything;
- 3) If he follows an advance refusal which is either valid or invalid, this is likely to result in the death of his patient; and
- 4) If he follows an advance refusal which is not valid (and he does not reasonably believe it is valid s.26(2)), he is guilty of murder.

In practice, where an advance refusal has been made and is slightly ambiguous, doctors who are afraid of committing murder would rather commit a potential tort or battery, and courts

⁸⁰See the Code of Practice: DoCA 2007, 159.

adopt a presumption in favour of life.⁸¹ This adds to what has been described as ‘dangerous’; the problem of ‘paternalism’ in the medical practice.⁸² By the same token, where there is an existing and lawful advance refusal, if this is ignored doctors face criminal and civil action and being struck-off by the GMC. This new-age of not endlessly attempting to save the lives of patients has even been reported as inconsistent with the Hippocratic Oath – a newspaper commented on the then Lord Chancellor’s heavy-handed ‘draconian’ approach towards ‘enforcing living wills’:

“Lord Falconer's message to the medical profession told doctors and nurses that new laws will require them to end lives rather than save them... Those who decline to do so will face jail or, alternatively, big compensation claims in the courts”.⁸³

2.4 Best Interests Test?

In the absence of a valid and applicable advance refusal, and where a patient is unable to give consent, his treatment is viewed in line with what is in his best interests. *Re F*⁸⁴ saw the revitalisation of the ‘best interests test’ (i.e. an assessment of what is best for that incapacitated patient all circumstances considered) and the welfare principle long preceding it. The position at common law is now the position in the MCA 2005. From *Re F*⁸⁵, the medical profession were asked to holistically consider the patient’s needs, weighing these against action in the face of refusal of treatment and to consider their capacity to make such decisions. The outcome of the same case provided that lawfully, healthcare professionals were able to operate on those adults unable to consent to or to refuse treatment by way of ‘emergency’ or

⁸¹ See *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287 for example where Mrs. M after 8 years of receiving ANH was deemed able to appreciate her surroundings enough in a state of MCS to remain in this state despite regular communication to her family throughout her life detailing that she would not want to be kept alive in such circumstances.

⁸² Buchanan 1988, 279. As explicated by Buchanan, the ‘well documented persistence of unjustified paternalistic behaviour by physicians indicates that this is a significant danger’.

⁸³ See <http://www.dailymail.co.uk/news/article-417093/Doctors-face-prison-denying-right-die.html> <accessed 14/11/13>

⁸⁴ *Re F* [1990] 2 A.C. 1.

⁸⁵ *Re F* [1990] 2 A.C. 1.

'mental disability' if the treatment could be shown as being in the patient's 'best interests'. Here, sterilisation was held to be in the patient's best interests, attracting great criticism over replication of the Nazi attitude towards de-sexualisation of the mentally disabled.⁸⁶ Although more regulated, this approach is still taken now.⁸⁷ The law of England and Wales offers no system by which the expressed opposition of a mentally handicapped person to an operation is considered fully where it is judged by others as being in their best interests. With regard to the matter of conflicting rights of others, the PGC, and specifically, the three levels of generic rights outlined at 1.5.1 earlier, would provide guidance.

Due to the extent of argument, there is a whole chapter⁸⁸ dedicated to discussion of the efficacy of this test. As a brief outline, in the absence of capacity, Lord Goff's objective best interests test as established in *Re F*⁸⁹ is now partly codified in the 2005 Act.⁹⁰ The test allows for judgment of what is best for an incapacitated patient 'all things considered'. Yet, in line with Mary Donnelly's assessment the test is ambiguous and 'what exactly is meant by patient's best interests is neither self-evident nor all together clear'.⁹¹

The standard for judging best interests is in fact applied subjectively. Most recently, in the cases of *A Local Authority v E*⁹² and *Re M*⁹³ the patient's best interests were decided on the basis of the value of their lives, despite the fact that the patients themselves were both in the

⁸⁶ Shaw 1990, 93.

⁸⁷ It may be said as an aside that any non-therapeutic sterilisation of a mentally handicapped persons is always to be regulated and assessed by the courts by way of Practice Direction 9E to the Court of Protection Rules 2007, and Para.6.18 and Paras.8.18-8.29 of the Code of Practice: DoCA 2007. This position was most recently affirmed in *A Local Authority v K* (by the Official Solicitor) [2013].

⁸⁸ See chapter six.

⁸⁹ *ibid* [1990] 2 A.C. 1.

⁹⁰ S.4 of the MCA2005 outlines the test as follows s.4(1); that the decision must not be made in light of i.e. person's age or appearance, s.4(2)-(3); considerations to be made by those 'making the determination', s.4(4)-(11) the specifics, and for this piece most importantly for this thesis; s.4 (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.

⁹¹ Donnelly 2011.

⁹² *A Local Authority v E*(2012) EWHC 1639 (COP); 2 F.C.R. 523

⁹³ *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287.

latter stages of palliative care. There is a compelling argument that the best interests test is flawed. Such argument seems to be categorised into three main areas: lack of consideration of first-person autonomy; the patronising, paternalistic use of Article 2 ECHR (the right to life); and the lack of consideration of the conflicting, overall rights of others. Too regularly, the competing interests of first-person autonomy and the right to life clash – this is discussed more comprehensively in the next chapter.

Undoubtedly, the best interests test throws up issues around whether or not a person's past wishes, values, views and beliefs are being preserved. Questions left unanswered in many cases revolve around the required level of evidence needed to show what the patient wanted. Other issues are centred around the motives or capabilities of those communicating the incapacitated person's 'past wishes and feelings'. As well as this, the overarching worry in general is the verity of those who are not appointed as legal guardians as having an influence on the fate of someone connected to them. Additionally, even those who are appointed may be unsuitable decision-makers. In the latter parts of this thesis, this aspect becomes the foundation for an argument that the test should be changed and re-formulated, and a hierarchy of tests are outlined to allow for negation of problems caused under the current system.

2.5 In Reality

The main provisions of the MCA 2005 allow for the autonomous decisions of a person concerning their medical treatment where proved valid and applicable. Yet, there are a number of practical problems to consider with implementation.

When relating these elements to the advance refusal provisions in the MCA 2005, there are three major design flaws (among others), which amount to problems with 1) integration, 2) clarity; and, 3) morality. These will be addressed in turn.

2.5.1 Integration

The danger of a law which is not properly integrated into society is that the law itself becomes defunct. A good example of this is found in the (very short) Female Genital Mutilation Act 2003 (herein 'FGMA 2003') which, through lack of promulgation and integration into society, has fallen on deaf ears. The spirit of the act was to make any degree of non-medicinal genital mutilation on women and girls, completely illegal (ss.1 to 2 FGMA 2003). Additionally, the Act's ascribed maximum penalty for perpetrators of the crime is imprisonment for up to 14 years (s.5 (a)). Despite promises, and recent hopes of the Crown Prosecution Service (herein 'CPS') that arrests will be made imminently,⁹⁴ there have been absolutely no prosecutions what-so-ever⁹⁵ of those committing this crime which reportedly affects around 3000 women and girls in the UK each year.⁹⁶

There are many failings of the FGMA 2003 that the MCA 2005 can learn from. One shared issue between the two pieces of legislation is that access to the provisions has been stunted. The FGMA 2003 must blame associated reporting measures for victims, lacking deterrence and other procedural defects as impairing implementation per se.⁹⁷

The difficulty of creating an advance refusal is preventing osmosis of the provisions. This does not seem to be ameliorated by healthcare professionals. As stated in the Mental Health Foundation's literature review of the MCA 2005 'the creation of advance directives was facilitated through early introduction by practitioners and continuous discussion between practitioners and service users'.⁹⁸ Unfortunately, it is without doubt that the healthcare profession is overlooking the importance of advance refusals today – this has especially been proven in the treatment of those who already have pre-existing cognitive impairments who are found to be prejudged as being incompetent. The decisions made by such persons are being

⁹⁴ See Gerry 2012.

⁹⁵ However, this may change for the better See Torjesen 2013.

⁹⁶ See Chalabi 2013.

⁹⁷ See Gerry 2012.

⁹⁸ Mental Health Foundation 2012, para 8.3 at p. 56.

questioned as healthcare professionals are deeming them 'unwise'.⁹⁹ These are two direct violations of principles 1 and 3 of the Code of Practice and of s.1(4) and s.1(2) MCA 2005.¹⁰⁰ In addition, from a transparency perspective, there are no recordings of the amount of advance refusals in existence, granted, or ignored, and with this, no archiving or registration system. Keeping records and copies stored centrally does occur in relation to LPA documents which are safely stored with the Office of the Public Guardian. Invariably, a paper trail is especially helpful when documents are lost or where it is uncertain as to whether a document exists.

2.5.2 Clarity

The advance refusals provisions within the MCA 2005 are largely unheard of. If they are known, they are thought of as being too difficult to use. This view is supported by a recent poll showing that only 8% of the population had already created a living will with over 50% pledging that they would, if it was 'easier'.¹⁰¹

There are number of pro forma advance refusals available on various sites across the internet with Mind, Age UK, Compassion in Dying, Alzheimer's Society and Help the Hospices being just a few providers. Despite the attempts of such charities, where online templates are readily available,¹⁰² the layperson is still having difficulties in giving effect to their autonomous wishes. One of the difficulties in using these pro formas is that they can be discombobulating for the potential advance refusal creator. In the recent case of *The X Primary Care Trust v XB*,¹⁰³ inclusion in the pro forma of a 'valid until' date led to a degree of scrutiny from the Court of Protection. There is an argument that those organizations that have such terms in their pro formas may want to look again at the necessity of such terms. It is clearly in the interests of the person who has made the advance refusal, their family, and those who have responsibility for providing or withholding treatment that there is clarity in relation to what the terms of the

⁹⁹ Mental Health Foundation 2010.

¹⁰⁰ See the Code of Practice: DoCA 2007, 20 and 24.

¹⁰¹ Alderson, 2010.

¹⁰² For more information please see the extensive websites of Mind available at <http://www.mind.org.uk/> and Alzheimers Society at <http://www.alzheimers.org.uk/> respectively <accessed 03/05/2013>

¹⁰³ *Ibid* [2012] EWHC 1390 (Fam).

advance refusal are. It has been suggested that this may be addressed through a new registration system, amongst other things, but this remains to be seen. The difficulties around the creation of both general advance refusals and advance refusals of life-sustaining treatment have also been notably recognised in the Mental Health Foundation's literature review of the MCA 2005:

“Advance directives were often limited and views were divided about how specific and detailed they should be. Advance directives that were too specific became difficult to adhere to. If they included a broad range of specific preferences, it may reduce the number of best interests refusals and dilemmas for practitioners”.¹⁰⁴

The caveats laid down in ss.24 to 26 of the MCA 2005 are essential. However, to a layperson, the formalities of execution render the process complicated. Another issue, uncovered of late in *The X Primary Care Trust v XB*¹⁰⁵ and *Re M*,¹⁰⁶ is that where the modern day allows for a person's thoughts, wishes and feelings to be shared through a vast array of means of communication, many do not understand or appreciate the formalities of the MCA 2005. In *Re M* specifically, there was no 'valid and applicable' advance refusal held to exist, although M had, throughout her life, made a series of advance refusals orally with several members of her family as witnesses.¹⁰⁷ Three of the main issues rendering the main provisions inaccessible are the rigidity of the guidelines for creation, lack of support and guidance from healthcare professionals and the general attitude of persons that such a process is 'morbid'.¹⁰⁸

2.5.3 'Morally Unsound'

Naturally there are complex moral implications of the advance refusals (and other) provisions within the MCA 2005. One moral problem is that due to the level of capacity required by the Act, many with pre-existing cognitive defects are unable to 'make the grade'. Mackenzie and

¹⁰⁴ Mental Health Foundation 2012, 56.

¹⁰⁵ *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam).

¹⁰⁶ *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287.

¹⁰⁷ *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287, 41 to 46.

¹⁰⁸ Dear 2008.

Rogers attribute this not to the standard set by the MCA 2005, but by the higher standards presented in the guidelines in the Code of Practice (see 1.4):

“In order to effectively implement its governing principles and promote the autonomy of persons whose capacities are impaired, health and social welfare professionals must go beyond a primarily cognitive approach to capacity assessment and refer to a range of more demanding autonomy conditions relating to authenticity, diachronic coherence and consistency, accountability to others, and affective attitudes towards oneself”.¹⁰⁹

Another major criticism of the MCA 2005 is the lack of consideration for the view that the s.24 to 26 provisions should only relate to those who will later experience natural, terminal situations. This would exclude those who attempt suicide and make an advance refusal not to be ‘saved’ when attempting suicide. This issue was presented in the 2007 case of Kerrie Wooltorton, which saw the MCA 2005 being used as a sword, and the subject of a call for ‘new boundaries’.¹¹⁰ Wooltorton, a suicide victim with a borderline personality disorder, executed a living will preventing medical intervention after poisoning herself. When she presented herself at the hospital requesting palliative care with the advance refusal she had drafted in possession, she was found to have capacity to refuse life-sustaining treatment. This was determined by the consultant renal physician who felt intervention may have led to ‘assault’ and ‘being sued’, leaving medics unable to save her life.¹¹¹

The Mental Health Act 1983¹¹² (herein ‘MHA 1983’) enables the treatment, admittance and detention (in hospital) of people with ‘mental disorders’¹¹³ without consent where necessary for the health or safety of the patient, or for the protection of others. Under the

¹⁰⁹ Rogers 2013.

¹¹⁰ Richardson 2013.

¹¹¹ Comments given by treating consultant Alexander Heaton, see BBC News (2009) ‘Doctors ‘forced’ to allow suicide’ available at <http://news.bbc.co.uk/1/hi/england/norfolk/8284728.stm> <accessed 14/03/2013>.

¹¹² Applicable in England and Wales only, and substantially amended in 2007 under the new Mental Health Act.

¹¹³ See s.3(2)(a) 1983 Act and 1(2)) 2007 Act for further.

1983 Act this principle only applies where a person *should* receive such treatment (and it cannot be provided unless they are detained). This can include treatment for ‘symptoms or manifestations’ of a disorder, which based on presumption, may include suicidal acts. It has been reported that medical professionals found that Woollorton’s situation rendered her ineligible for such compulsory treatment under the MHA 1983, but psychiatrists have questioned this determination. Thus, the floodgates remain ajar due to lack of cohesion between the two acts when considering those with borderline personality disorders (which, for the purpose of assessing capacity, are not automatically excluded s.2(1) MCA 2005).

Woollorton’s parents unsuccessfully attempted to sue the Norfolk and Norwich University Hospitals Trust on the basis that their daughter was not mentally competent at the time of creating the advance refusal at a solicitor’s office as:

“The coroner reached a clear verdict which established that Kerrie was mentally competent, had refused treatment in the full knowledge of the consequences, and died as a result... any attempt to treat Kerrie without her consent would have been unlawful”.¹¹⁴

In addition, a recent Parliamentary Postnote made comment about the cases’ re-ignition of concern over the ‘Euthanasia by Omission’ worries eminent during the birth of the MCA 2005’s advance refusal provisions:

“Although she (Woollorton) was, at the time of admission, thought to be capable of refusing,¹¹⁵ uncertainty has persisted about such refusals where anticipatory decision-making is involved. The Department of Health viewed the MHA as a possible resolution to such legal and clinical difficulties. Under it, anticipatory decision-making does not have legal force and adults with the capacity to decide mental health treatment can be treated compulsorily”.¹¹⁶

¹¹⁴ The Christian Institute 2009.

¹¹⁵ This confusion could be quelled if her multiple personality disorder was defined per s.1(2) MHA 2007 where ‘mental disorder’ means any disorder or disability of the mind.

¹¹⁶Parliamentary Office of Science and Technology 2011, 3.

This message seems eclectic. By the NHS Trust, we are told that Woollorton had the requisite levels of capacity to make a decision about her treatment, yet, by the DoH we are guided towards Part IV of the MHA on treating people without consent, which only applies to treatment for mental disorder (and this does not apply when treating physical disorders unless the physical disorder is reasonably linked as a symptom/ underlying cause of a mental disorder). If Woollorton's personality disorder had been defined as a mental disorder, there would have been no question at all under the MCA 2005 – she would have lacked capacity. Because of avoidance of issues, the implications for allowing what seems like incidental assisted suicide for the able-bodied but mentally unsound (if not incompetent) are worrying. The inevitable difficulties of allowing such wide interpretation of this aspect of the Act do not marry in with the constrictive current law on assisted suicide, leading one academic, rightly, to pose the question:

“When, if ever, does someone with a mental disorder have an equal right to end her life to that enjoyed by someone with a physical disorder?”¹¹⁷

Rebecca Smith suggested, following this case, that ss.24 to 26 were used simply for those dying of an illness or disease, as to exclude opening up the floodgates to arguments of assisted suicide.¹¹⁸ This makes sense when we view the situation from the perspective of the parents of Woollorton:

“Try this: just for a moment, imagine that the police visit your home to tell you that your child has committed suicide. Now imagine that they tell you that the ambulance and hospital staff could and would have saved her life, but she handed them a letter asking them not to”.¹¹⁹

Another pertinent dilemma here is the contrast with the obstinate assisted suicide rules which, due to public support, may soon be relaxed; the passage of such movement is in its early stages

¹¹⁷ Richardson 2013.

¹¹⁸ Smith 2009.

¹¹⁹ Pitcher 2009.

of development at the time of writing.¹²⁰ Despite promises of change by the then Health Secretary, Andy Burnham, to restrict the advance refusal provisions to declining and ultimately terminal illness,¹²¹ the advance refusal provisions are still arguably not accommodating the correct audience. In addition, although not a personality disorder per se, the MCA 2005 does not cover the question of how to treat persons who have made an advance refusal with dementia. Plainly, these persons may be the same person, or another person according to the stage which their condition reaches. For the purpose of the 2005 Act, if an advance refusal is deemed as existing, valid and applicable, we must then delineate whether or not it is relevant that a person remains the same throughout their life. The argument for the importance of considering the personal identity problem is discussed more substantively in chapter five but it is worth mentioning here as this too is a substantial contributor to the questionable ethics of the main provisions.

2.5.4 Other Issues

There are also other issues, there is a major problem around alleged practical incompatibility with the United Nations Convention on the Rights of Persons with Disabilities 2006. The General Assembly Resolution 61/106, Article 12(3) requires that States must:

“Take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacities”

It has been reported in general that the MCA 2005’s s.1 2)-4) requirements of presumption of capacity, provision of information and respect, particularly for the mentally disabled, are being bypassed by many healthcare professionals. Indeed, one study by the Mental Health Foundation exposed that 52% of health and social care professionals assumed that mentally and physically disabled service users did not have capacity *before* conducting health assessments.¹²² This amounts to what Toby Williamson, Head of Development and Later Life at Mental Health Foundation, has coined a ‘high and worrying level of misunderstanding’ amongst

¹²⁰ Assisted Dying Bill [HL] 2013-2014.

¹²¹ Bingham 2009.

¹²² Pitt 2010.

such professionals.¹²³ There are other design flaws in the Act per se which have attracted negative attention such as the pre-existing 'Bournewood Gap'¹²⁴ relating to deprivation of liberty safeguards arguably bridged by the Mental Health Act 2007 and other inconsistencies with the MHA 1983 (even following the 2007 Act's input), highlighted in, for example, a 2011 Parliamentary Postnote:

"The introduction of the MCA 2005 does seem to have made it clearer that a tension exists between two legal traditions for substitute decision-making in health: one that is based explicitly on the principle of capacity and personal autonomy (now the MCA 2005) and one that is not (the MHA). The MCA 2005 and the MHA now exist side by side and both can apply to the same person. When these two structures meet – in anticipatory decision-making, in deprivation of liberty and in community treatment orders – there is evidence of complexity and confusion. Case law is evolving in these areas but it is unlikely to provide an easy legal fix".¹²⁵

Finally, the burden of proof is on those seeking to establish an advance directive as being binding and effective. Thinking about the complexities of a terminal illness when you are in the early stages of it is not easy. But thinking of these situations when you are not unwell is more difficult unless you are attempting to commit suicide and wish to evade all medical intervention (such as in the Wooltorton case). From this, many, from groups such as the Christian Medical Fellowship,¹²⁶ through to journalists and academics such as Pitcher,¹²⁷ have called for reform for the ss.24 to 26 provisions to apply only to those who are terminally ill or dying naturally anyway.

¹²³ Quoted in Pitt 2010.

¹²⁴ See further Allen, N 2010.

¹²⁵ Parliamentary Office of Science and Technology 2011, 4.

¹²⁶ Groom 2010.

¹²⁷ Pitcher 2009.

2.6 Summary

There are issues highlighted in this chapter that need to be resolved. The common law preceding the MCA 2005 contained many anomalies which still resound today. The existing problems with the legislation itself have formed what Polly Botsford aptly terms a 'few cracks'.¹²⁸

The problems still faced by the MCA 2005 are:

- 1) A lack of integration due to lack of advertising and education about the provisions;
- 2) A lack of clarity which stems from this lack of information – a problem due to the wording and formalities used within the 2005 Act. On top of the formalities of signatures and witnesses for advance refusals, there is also a demand for intuitive forethought. The patient must specify the treatment rejected and all circumstances in the advance refusal (this is not always possible considering the ever-evolving advances in healthcare treatment), and must not do anything inconsistent with their advance refusal. In any case, the transparency of application is not recorded as advance refusals are not centrally documented;
- 3) Morally unsound aspects of the MCA 2005 where issues such as assisted suicide are not considered, along with other issues which are later addressed, such as the decision-making capabilities of persons with dementia, and consideration of the personal identity problem (at chapter five specifically).

There are fundamental flaws in the MCA 2005's main provisions – these issues need to be cleaned up before they can be fully implemented. When this is the case, the solutions I would propose for the widespread implementation would be:

- 1) The answer to integration of the MCA 2005 may be better 'advertising' of the provisions which could spur on wide-spread understanding and advertisement. This would need to come by way of a system for educating people about their rights

¹²⁸ Botsford 2007.

under the main provisions of the MCA 2005, as well as a system of registration and information aided by medical professionals. As inspiration, there are 19 million people on the organ donors register at this moment¹²⁹ and 4% of the population on the blood donors register. For both campaigns you can click 'like' on Facebook, comment on Twitter, etc. Despite the fact that both sorts of donation are in parts, morbid, they are successful. There have already been talks of an 'advance refusal' card which received widespread comment.¹³⁰

- 2) Today, persons express themselves orally, through videography, online and through other social media means; there are issues around the strict guidelines for composing an advance refusal. A suggestion for greater clarity of the formalities guiding the creation of advance refusals would be to riddance the internet pro formas that have been seen to cause havoc.¹³¹ Instead, advance refusals should be made after consultation with healthcare professionals, that way, many of the formalities, particularly the question of what treatment may be available, will be addressed. This process would allow for greater peace of mind of the advance decision-maker, as well as the healthcare professional. In addition, the format of the advance refusal should be less rigid, and possibly combined with its more widely-used counterpart, the LPA.¹³² The LPA for health and welfare mentioned at 2.3 provides guidance for what appointed attorneys can, and cannot make decisions on (such as refusal of life-sustaining treatment without prior consent of the creator of the LPA (also known as the 'donor')). The donor, or creator of the LPA can only specify more particular requirements through wishes in the document which are not enforceable. If the LPA for health and welfare was used more proficiently, it could provide an answer to the problems faced by using varied internet pro formas.¹³³

¹²⁹ McGuinness 2013.

¹³⁰ Bingham 2012.

¹³¹ Seen most recently in the case of *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam).

¹³² This approach is taken in California, and succeeds in being widely used; I return to this point in chapter 7.

¹³³ For the official template used for an LPA of health and welfare please see the Office of the Public Guardian website. The document is accessible here;

- 3) I would suggest that the main provisions are tempered to separately address the issues of persons suffering from severe personality disorders, and that these persons are treated as incapacitated during periods of personality 'switch' – in the same manner that we treat persons between periods of lucidity in capacity per s.2(2) of the 2005 Act. This would invoke fully the protection mechanisms under the MHA 1983. The treatment of persons with dementia is an issue which merits separate discussion because of the sliding scale of personality disorder that can occur (further discussed in chapter five). Those with dementia also need to be considered separately under the MCA 2005.

In sum, legislative change is necessary. Unsurprisingly, one national newspaper recently revealed the effect of the rigidity of the provisions in their strap line; 'Half the population would make a 'living will' if it was easy'.¹³⁴ The message is already underlying that there are matters which need to be addressed in the main provisions of the MCA 2005 before they can fully take effect. Turning to the next three chapters in this thesis, I now consider the wider ethical implications for the advance refusals provisions in the 2005 Act concerning personhood, autonomy, the sanctity of life, and personal identity.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/245571/LPA114_Health_welfare_LPA.pdf <accessed 22/12/2013>

¹³⁴ Alderson 2010.

CHAPTER THREE: PERSONHOOD, AUTONOMY AND LIFE

3.1 Why Who We Are Matters

The definition of 'who we are' holds great significance in the discussion over advance refusals at any time, and especially during the transitional period where the factors once defining 'me' or 'you' change. This is largely due to the pre-supposed relationship that we have with the 'self' and the resulting right to autonomy.

As set out in the introduction to this thesis, the notion of personhood provides a firm grounding for understanding the importance of ascertaining (in as far as possible) the moral status of a person. Presently, the advance refusal provisions within the MCA 2005 do not offer guidance on understanding the importance of establishing this. To treat patients in line with the PGC, firstly an assessment must be made as to their 'moral status' hence the exploration of personhood in this chapter. Taking this catch-all approach means that incorrect decisions are being made about how best to treat people. It is urged that answering the question of 'who we are' can lead to us addressing questions such as 'to what extent does this person matter?' Where the law says we all do, the PGC would contend that this could only stretch as far as to include agents (ourselves) and ostensible agents (those beings outside ourselves who act like agents and must be treated as so; discussed further at 4.3 and 4.4). It follows that without attempting to address the issue of 'does this person matter' (which is currently the approach of the MCA 2005), advance refusals become virtually meaningless, or at least precarious.

3.2 Life As We Know it

“To live is the rarest thing in the world. Most people exist, that is all”.
— Oscar Wilde

Life as we know it is generally protected by what we have known as the ‘sanctity’ or ‘inviolability’ of life approach which originates in religion and ethics. The principle revolves around the implicit protection of life which is depicted as being sanctified or holy and as holding great value. The concept has been entrenched in the ECHR’s universal Article 2(1) ‘Right to life’. It was also recognised in the works of Kant:

”To preserve one’s life is a duty, and besides everyone has an immediate inclination to do so... The often anxious care that most people take of it still has no inner worth and their maxim has no moral content... They look after their lives in conformity with duty but not from duty... On the other hand, if adversity and hopeless grief have quite taken away the taste for life; if an unfortunate man... more indignant about his fate than despondent or dejected, wishes for death, and yet preserves his life without loving it, not from inclination or fear but from duty, then his maxim has moral content”.¹³⁵

Because the matter of ‘life’ per Article 2 is invoked concerning the treatment of persons where an advance refusal is ambiguous, or non-existent, the question of what it is to be ‘living’ is important for us to consider so that the preservation of life’s true extent can be reasoned. From this, some degree of thought regarding the relationship between ourselves and others becomes necessary. This may lead to postulation of the possibility of one existence within ourselves, or, in varying forms, multiple existences in multiple locations, or of a single, ulterior existence such as that shown in movies akin to ‘The Matrix’¹³⁶ or ‘Source Code’.¹³⁷ Thinking in this way allows for some degree of assessment of the relationship between a person’s choices and rights, and

¹³⁵ Kant, 1785, as translated in Paton, 11.

¹³⁶ ‘The Matrix’ 1999 (movie; dir., Andy Wachowski).

¹³⁷ ‘Source Code’ 2011 (movie; dir., Duncan Jones).

further, the extent that these are interrelated with the choices and rights of others, and the treatment of these by the community as a whole.

3.3 Who Are We to Judge?

For animals, bacteria, plants, and other life forms, the act of 'life' also involves all of the simple but key components; movement, respiration, sensitivity, growth, reproduction, excretion and nutrition (the 'MRS GREN' style acronym taught in schools). There are a number of ways to define life, this can be achieved biologically, or this can be defined as capable of exercising some preferences or values. The important factor here is that we are not talking about 'life', we are talking about a *meaningful* life. From this, the way in which we define 'life' has extremely important implications for the way we are to be treated. Under the PGC, it is not 'life' that matters, but agency; this holds important consequences for the status of persons because the rights of agents differ greatly to the rights of non-agents.¹³⁸

Conceptually, life is something which humans experience. Yet, theoretically, the act of 'being alive' carries with it a more succinct meaning and in turn, varying degrees of respect. For a human, being alive is having the ability to pursue purposes, to retain memories, to feel emotions, to act autonomously, cognitively, consciously,¹³⁹ and with meaning – it is much, much more than just the 'MRS GREN' style acronym. The value of life for both the person living it, and for those looking on, is subjective.

We may look to our philosophical predecessors to find inspiration about what it is to be living if 'life' is not obvious. These accounts are varied. Plato's metaphysical account of the person revolved around the 'Form' or shadow being beyond ourselves in a dualist existence

¹³⁸ See 4.1.1 and 5.3.1-5.3.2 for further discussion of this point.

¹³⁹ Lord Goff comments on the subject of consciousness (as integral to life) in *Airedale NHS Trust v Bland*. [1993] A.C. 789 at 868-9 ; '[F]or my part I cannot see that medical treatment is appropriate or requisite simply to prolong a patient's life, when such treatment has no therapeutic purpose of any kind, as where it is futile because the patient is unconscious'.

with the mind being entrapped in the body.¹⁴⁰ Aristotle proposed that the ultimate ‘good’ for humans, and the ultimate ‘aim’ of life, would be the maximum realization of the function that was unique to humans, with human virtuousness being buried deep in our souls.¹⁴¹

For some the so-called ‘artificial life’, a simulated version of life created through non-natural means usually aided by technology, is argued to be changing the face of the definition of ‘life’ as we know it. From this view, the certain attributes and functions which were formerly thought to be sole defining features of living things can be now be copied which may lead to such robots being considered as ethically on a par with their human counterparts. This view becomes even more unconventional when we consider that humans may install a number of pre-programmed ethical decisions into robots. This would enable the robots to choose their own actions, and ‘life’- path, exhibiting a degree of consciousness, which may not be ruled out.

Thus, for the present purposes, and due to absent technological advances, such ‘robots’ can be deemed as non-living. But the area of the life versus ‘non-life’ distinction is a fundamental one with very practical consequences. Looking to future possible advances, these consequences are amplified when considering the treatment of a human who looks like other adult humans, but who breathes through an electrically powered respirator, and eats through a force feeding tube, and who has no thought at all whatsoever. The question arising from this has been considered at law as well as theoretically; do we class such an entity as a human? The view taken by the PGC (where it could be established that a person was not an ostensible agent) would be that keeping a person alive by way of artificial means without any hope of regaining consciousness is inhumane but that provision of ANH and ventilation to an extent could not be automatically ruled out. This outlook was given recognition in the well-known case of Tony Bland¹⁴² but such an approach is only just and fair where a ‘PVS’ is confirmed which entails:

¹⁴⁰ See Plato (BCE) as translated in Lee and Lee 2007. See in particular Books III and V for further discussion.

¹⁴¹ Aristotle (BCE) *Nicomachean Ethics* translated by Roger Crisp (Cambridge , Cambridge University Press, 2000).

¹⁴² *Airedale NHS Trust v Bland* [1993] A.C. 789 at 819 (per Butler-Sloss L.J.).

“an absence of awareness of one's self and one's environment, a sleep/wake cycle, no demonstration of purposeful movement, no experience of suffering and no evidence of comprehension. Behaviours are limited to reflexive activities indicating no cortical involvement”.¹⁴³

In line with this thinking, Constable formulated the view that ‘patients in PVS should have life-sustaining care withdrawn when their wishes are unknown’, with the exception of; 1) The ‘families or other surrogates of the patient should be given the last word’; and 2) ‘a reasonable effort should be made to know whether the patient has expressed a preference either way’.¹⁴⁴ Constable goes on to say that:

“where there is no advance directive, the family should instead be encouraged to consider whatever factors that they deem useful, whether it be the patient's expected preferences, the family's own views about his best interests, or any other guiding principle”.¹⁴⁵

Ultimately she decides ‘In the case of PVS, when in doubt as to a patient's wishes, it is better to discontinue life-sustaining treatment’.¹⁴⁶

Craigie postulates that it is usually considered that decisions around treatment ought to be respected because of what she terms their ‘assumed connection to the self’.¹⁴⁷ However, there are circumstances where selfhood, that is the status of a person, means that such a hard and fast rule is not appropriate, particularly when we are addressing the problems faced by those with dementia because the connection with the self is difficult to define. There are other problems with defining the ‘self’ and understanding the moral status of a person. To illustrate, problems have been known to arise when patients have been treated as being in a PVS, but were locked-in. This is now less known considering advancements in a variety of brain-scanning

¹⁴³ *The NHS Trust v AW* (by her litigation friend, the Official Solicitor) [2013] EWHC 78 (COP), at 16 (per Jackson, J.).

¹⁴⁴ Constable 2012, 163.

¹⁴⁵ *Ibid.*

¹⁴⁶ *Ibid* 163 to 164 for this conclusion.

¹⁴⁷ Craigie 2013,16.

mechanisms designed to detect neural activity so defining the brain-states of persons. It is difficult to imagine the frustration of such patients who have been, and remain, undiagnosed or misdiagnosed such as Canadian Scott Routley who, until last year, was believed to have been in a PVS for 12 years following a car crash. He was actually locked-in. This point becomes more poignant considering that Scott's family maintain that he could communicate with them using his eyelids and his thumb, for all that time but the treating healthcare professionals dismissed this.¹⁴⁸

When applying the main provisions of the MCA 2005, the PGC requires, at the outset, an assessment as to a person's 'moral status'. It is hoped that this chapter has given grounding to show that for the MCA 2005 to give effect to any kind of advance refusal, it must first distinguish between different levels of moral status practically, and where practicable. Where an advance refusal has been made this should be preserved where possible, and at least considered, even where formalities fall short. The MCA 2005 does not allow for this. The principle's most recent criticisable application has forced 'life' on two women who arguably did not want it; one was in a minimally conscious state¹⁴⁹ (herein 'MCS'; a state of consciousness just above that of PVS), and the other was receiving end stage palliative care for anorexia nervosa.¹⁵⁰ This leads us into an argument which favours first-person autonomy where legally recognisable capacity is present *and/or* as it is argued in this thesis (where appropriate) task-specific competence is demonstrated.

¹⁴⁸ See Walsh, 2012.

¹⁴⁹ *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287.

¹⁵⁰ *A Local Authority v E* (2012) EWHC 1639 (COP).

CHAPTER FOUR: BETWEEN AUTONOMY v THE RIGHT TO LIFE: LESSONS FROM *THE X PRIMARY CARE TRUST V XB*¹⁵¹

4.1 Competence, Autonomy and Agency

As early as 1914 Justice Cardozo viewed the primacy of autonomy as the right of 'every human being of adult years and sound mind ... to determine what shall be done with his own body'.¹⁵² The word autonomous is taken from the Greek word 'autonomos'. From this definition, to be autonomous is literally to live under one's own laws. This is a freedom codified in Article 8 ECHR.

As opined by Samanta and Samanta, autonomy is 'the bedrock of medical law'.¹⁵³ The importance of autonomy resounds in the philosophy of Gewirth where morality itself rests on the notion of freedom of action, with which freewill and autonomy are the basis of all action. The GR all have waivable benefits as others owe duties, but these duties can be released through autonomous decisions. The alternative is that a person's autonomous actions and thoughts are guided (in various ways) by pre-determinism. This is the view that our actions are heavily influenced due to cultural, social, geographical, and other reasons; an approach championed by soft-determinists such as John Locke.¹⁵⁴ More radically, hard determinists claim that no action or thought is autonomous. Resulting from this view, morality is not even applied subjectively, even the concept of morality becomes elusive. This is because a person's actions, for better or worse, may not carry any level of accountability.

The danger of buying into a 'predetermined' ethical construct is well illustrated in the defence prepared by the famous US attorney Clarence Darrow in the 1924 murder case of *The*

¹⁵¹ *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam).

¹⁵² *Schloendorff v Society of New York Hospital* (1914) 211 NY 125 at 129.

¹⁵³ Samanta and Samanta 2013, 690.

¹⁵⁴ John Locke quoted in E. J. Lowe 1986, 149.

State of Illinois v. Leopold & Loeb.¹⁵⁵ The defendant murder suspects were two educated young adults, described as ‘rich and blood-thirsty’, and the victim, 14 year old Bobby Franks. In a reportedly 12 hour long statement, the basis of Darrow's plight was founded on his strong belief that the biological and sociological influences the young men had undergone caused the crime, and not the suspects themselves. The argument rested on the notion that the young men's immoral choice, and action, was out of their hands:

“If there is a responsibility anywhere, it is back of him; somewhere in the infinite number of his ancestors, or in his surroundings, or in both. And I submit, Your Honour, that under every principle of conscience, or right, and of law, he should not be made responsible for the acts of someone else”.¹⁵⁶

Indeed, if the actions of human beings were completely predetermined, in line with Darrow's thinking, one main contention would be that human life, and the sociological systems we have in place as we know them, would be replaced with lawlessness, rebellion and anarchy. The other side of the coin outlines that we have complete ‘freewill’ and free thought and choice to create our own destiny autonomously, with complete self-actualization as the ultimate goal in the same manner outlined by Maslow.¹⁵⁷

4.1.1 The Relevance of Gewirth's Agent Autonomy

The problem of determinism is addressed in the PGC through the concept of agency. Agents are autonomous, and pursue their own purposes freely. Indeed, without autonomy, agency is not

¹⁵⁵ *The State of Illinois v. Leopold & Loeb* 1924 (USA) See further; Newman, Stephen A. 2000. "Leopold and Loeb." 223 *New York Law Journal* (February 16), 2.

¹⁵⁶ *Darrow, L and L* (1924) at line 2030. The defendant's pending death sentence was quashed and replaced with 99 years behind bars. After assessment of the case transcript, it would appear that whilst the defence presented by Darrow secured mitigating results, this was not because of the conviction of argument, but because his philosophical views at the time were considered to render him a member of the educational elite; this, informally speaking, led to his running rings around the prosecution and judiciary who were sitting. Please see case transcript (particularly for quote at p.55) through this link; http://darrow.law.umn.edu/documents/Leopold_Loeb_Darrow_Crowe_arguments.pdf at as published by Wilson Publishing Co. (undated) (Chicago:USA) <accessed 09/12/2013>

¹⁵⁷ Maslow, A. H. 1943, 382.

possible. Gewirth's theory does not allow for any doubt about where actions come from; they come from agents, and each agent is responsible for pursuing their own goals and values.

Importantly, agency under the PGC has many advantages. The PGC allows for contemporaneous *decisions* as well as *refusals*. In the same manner that contemporaneous decisions are allowed, future, advance decisions are also considered appropriate. From this, if I can refuse treatment *now*, I can refuse treatment *later*. More importantly, I can refuse now to refuse to be treated later:

- a) I am an agent, I have decision-making abilities and I am autonomous;
- b) I can make decisions here and now (contemporaneous);
- c) I can also make decisions about my future in the event that I later do not have decision-making capacity;
- d) Moreover, agents may choose to release others from all of their duties to them, encouraging positive intervention where accepted by the rights-subject.¹⁵⁸ This notion shares values akin to what Samanta and Samanta term 'holistic determination for oneself'¹⁵⁹ and includes the right to heteronomy, autonomy and any other considerations as part of the advance decision-making process. Referring back to Beyleveld,¹⁶⁰ it would not be inconsistent with the PGC for the notion of autonomy to be extended to include other considerations where rights conflict. The only problem with this in practice, and left unexplored by Samanta and Samanta, is that such decisions, unless properly executed, may amount to being written off due to undue influence. This is especially the case remembering that, *prima facie*, medical professionals determine outcomes where advance decisions are ambiguous and most of these professionals want to maintain their livelihood,¹⁶¹ also ;
- e) Because defining agency is not always clear-cut, especially in cases of those with dementia, the PGC points towards a view that the validity of advance refusals would rely

¹⁵⁸ Beyleveld 2012, 14.

¹⁵⁹ See Samanta and Samanta 2013, 719.

¹⁶⁰ Beyleveld 2012.

¹⁶¹ I explore the notion of balancing competing interests of others in the penultimate chapter.

upon whether there were issues around personal identity. Pattinson's task-specific competence model becomes relevant here.¹⁶² The model is task-specific as the difference between being able to read a book differs greatly from being able to refuse a life-saving blood transfusion. This 'building block' approach becomes particularly helpful when exploring further the main issues at the heart of any confusion over autonomy in advance refusals which are;

- 1) How sure can we be that it was this person's decision?
- 2) Is it the same person making the decision?

The MCA either ignores the personal identity problem or assumes it is valid. However, it does, to an extent, address question 1 through urging evidence-gathering of written statements detailing what the person would have wanted (MCA 2005 s.4(6)(a) to (c)). Yet no attempt has been made to set out guidelines relating to question 2 and such issues stemming from dementia have never been dealt with at court. The problems presented as a result are elucidated further in chapter five.

4.2 Autonomy v Life: Ameliorating the Grand Illusion

In 2005, Sabine Michalowski forewarned that the MCA 2005 could emulate the common law trend of bias towards the sanctity of life.¹⁶³ Despite codification that advance refusals are to be treated with as much respect as contemporaneous refusals, this presentiment has since been authenticated.

In *Re M*,¹⁶⁴ the mother of a 52 year old woman sought authorization for the withdrawal of ANH and ventilation from her daughter in a MCS. MCS was here described by Baker, J. as:

"involving significant (sic) limitations on consciousness with a quality of life that many would find impossible to accept were they able to consistently express themselves with full competence".¹⁶⁵

¹⁶² See Pattinson 2002a, 78 and Pattinson 2011, 148 and 150.

¹⁶³ See Michalowski 2005, 958- 959.

¹⁶⁴ *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287.

The application was made on this 'low quality of life' basis. In addition, there was evidence to suggest M's former wishes and feelings indicated that she would want this. Considered per the court's obligation (s.4 MCA 2005), three separate witnesses described M's advance wishes as a fiercely independent woman. All witnesses recounted her fervent desire to have her life ended if she became dependent like Tony Bland in the media, and similar to her late father and grandmother who had also ended up in a PVS. Despite recognition that M's life consisted of pain and suffering which would not be ameliorated until death, Baker, J. dismissed any statements made by M as informal¹⁶⁶ and refused to sanction the withdrawal of ANH. After adopting the same 'balance sheet approach' that Thorpe, LJ. did in *Re A (Mental Patient: Sterilisation)*,¹⁶⁷ weighing up the positive aspects of withdrawal versus continuing ANH, Baker, J. held that M:

"will be kept alive for ten years. The preservation of life is a fundamental principle... She will continue to experience life as a sensate being with a degree of awareness of herself and her environment".¹⁶⁸

The lack of recognition of M's past wishes and feelings, coupled with the overbearing application in favour of life where life is almost non-existent, leads down a dark, draconian path. If the law is taken at face value, it is inhumane and undignified. As opined by Alexandra Mullock:

"where there is good reason to doubt that a person has a reasonable quality of life, together with clear evidence that the person would not choose life if they were able to communicate, sanctity of life concerns should not overshadow the other factors".¹⁶⁹

M did not create a valid and applicable advance refusal. As such, ignoring her previous wishes and feelings (the only link to the generic rights she exercised as an ostensible agent concerning

¹⁶⁵ *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287 at 34.

¹⁶⁶ *Re M*; EWHC 1197 (Fam); 1 W.L.R. 287, at 6, 83-85 and 250.

¹⁶⁷ *Ibid.* [2000] F.L.R. 549; [2000] 1 F.C.R. 193 CA (Civ Div).

¹⁶⁸ *Re M* [2011]; EWHC 1197 (Fam); 1 W.L.R. 287, at 248.

¹⁶⁹ Mullock 2012 at 470.

this matter), although inexcusable, was not unjustified. *A Local Authority v E*¹⁷⁰ concerned E, a 32 year old woman, who, after a lifetime of struggling with anorexia nervosa to the point of attracting palliative care, created an advance refusal. For the purposes of the MCA 2005, this advance refusal was ‘valid and applicable’ – complete with two signatures, a witness signature, and a verification of her legal capacity at the time (as conceded by a mental health advocate). Indeed E was so desperate to ensure compliance with her advance refusal, she followed the required steps meticulously.¹⁷¹

Before she had written this advance refusal, she was, at several points during the two year period previously, viewed as having the legal and mental capacity to make one to this effect. But, on the same day that the advance refusal was eventually created, E was detained under s.3 of the MHA 1983 and the day after that she was admitted to an eating disorder unit.

On the issue of capacity Jackson, J. found, beyond doubt, that E’s anorexia itself rendered her incapacitated¹⁷² and amounted to ‘an impairment of, or a disturbance in the functioning of, the mind or brain’ per s. 2(1) MCA 2005. There were two reasons given as to why E lacked the capacity for this advance refusal to be deemed valid:

- 1) E’s fear of weight gain rendered her incapable of ‘weighing the advantages and disadvantages of eating in any meaningful way’. The meagre example used to illustrate this lack of judgment was when E cried in August 2011, when the question of weight gain and the achievement of a Body Mass Index of 16 was mentioned to her by her clinician;¹⁷³ and,
- 2) E, being prescribed sedative medication was considered as being in a ‘severely weakened condition...’a drug haze’.¹⁷⁴

¹⁷⁰ *Ibid* EWHC 1639 (COP); 2 F.C.R. 523, 2012.

¹⁷¹ E even went to the length of including the provision (evading the quagmire of s.25) that; ‘*If I exhibit behaviour seemingly contrary to this advanced directive this should not be viewed as a change of decision.*’ This clause, pursuant to s.25 of the 2005 Act, was rejected.

¹⁷² [2012] EWHC 1639 (COP) at 48.

¹⁷³ [2012] EWHC 1639 (COP) at 49.

¹⁷⁴ [2012] EWHC 1639 (COP) at 50.

Contrastingly, it was accepted that E could understand and retain the information relevant to the treatment decision and, communicate her decision (demonstrative of partially satisfying the definition of capacity and of having task-specific competence). The decision of Jackson, J. recognised that E’s family, many of her former clinicians, and E herself, agreed with E following a palliative care plan. Despite this, due to the misplaced use of intuition,¹⁷⁵ the balancing exercise was tipped in favour of life:

“Against them, I place E’s life in the other scale. We only live once – we are born once and we die once – and the difference between life and death is the biggest difference we know. E is a special person, whose life is of value. She does not see it that way now, but she may in future”.¹⁷⁶

In this case, no issues of personal identity arose. Combining the general rules of the PGC with task-specific competence, the elements of irrationality shown in emotion over weight gain must be assessed as against E’s weighing and understanding the consequences of rejection of treatment. Application of the PGC would not advocate such a sanctimonious ascription of ‘value’ on E’s life outside of E’s own assessment, avoiding the ‘slippery slope’ of subjective judgments arising from the few advance refusal cases which are reported each year.

Despite the trend discussed, there has been some deviation from the approach in favour of Article 2 in the cases of *The X Primary Care Trust v XB*¹⁷⁷ and *NHS Trust Authority v L*,¹⁷⁸ which show promise. *The X Primary Care Trust v XB*¹⁷⁹ concerned an application made to the court as to the validity of an advance refusal. XB, a 66 year old, had suffered from MND for over a decade, eight years of which he spent breathing using a ventilation device attached to his windpipe and gaining sustenance through ANH. Through communicating with his eyes, with his wife as witness and using an internet pro forma template, he created an advance refusal. XB knew about the pathway of regression his illness would entail, so the life-prolonging treatment

¹⁷⁵ *Ibid* [2012] EWHC 1639 (COP) at 129. Jackson, J. ‘The balancing exercise is not mechanistic but intuitive and there are weighty factors on each side of the scales’.

¹⁷⁶ *Ibid* [2012] EWHC 1639 (COP) at 137.

¹⁷⁷ *Ibid* [2012] EWHC 1390 (Fam).

¹⁷⁸ *Ibid* [2012] EWHC 2741 (COP).

¹⁷⁹ *Ibid* [2012] EWHC 1390 (Fam).

was specified, and the advance refusal was to apply at the point where he lost the ability to communicate. The issue to be resolved with the advance refusal was whether or not the included 'date of review' and 'valid until' date (ending the day following the hearing), could amount to dissolution of the refusal.¹⁸⁰ Relying on witnesses to the case, Theis, J. approached this in a practical way with a declaration that the advance refusal was not 'time-limited' and gave direction for future cases that 'there is no set form for advance refusals' referring to the Mental Capacity Code of Practice as mere guidance for what should be included.¹⁸¹ An opposing outcome would have ensued if the MCA 2005 main provisions were applied literally: the included 'end-date' may have been treated as rendering the advance refusal non-existent or non-valid in line with (s.26(4)(a)/(b)) and, witness accounts, although considered as part of XB's wishes and feelings, could have been replaced with the conferred 'best interests' test i.e. what the sitting judge deems fit at that time. In fact, MCA 2005's main provisions were not elided; and the judgment itself became an obstacle course which included the hurdles, but was not defeated by them.

The outcome of *The X Primary Care Trust v XB*¹⁸² demonstrates that judicial discretion can accommodate and respect both the main provisions and the spirit of the MCA 2005 in juxtaposition. This application of the law in XB would be consistent with rights conferred under the PGC – such preservation of autonomy in this case amounts to a welcome decision, as summarised by Foster:

“The care with which the court examined the validity and applicability of the advance refusal should give some comfort to those who worry that advance refusals will be waved blithely and followed with slavish and deadly literalism”.¹⁸³

The more recent outcome of *NHS Trust v L*¹⁸⁴ builds on the approach taken in *The X Primary Care Trust v XB*¹⁸⁵ and serves as direct contrast to the ruling in the case of E. L, also a critically ill

¹⁸⁰ *Ibid* at 26.

¹⁸¹ *Ibid* at 34.

¹⁸² *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam).

¹⁸³ Foster, 2012.

¹⁸⁴ [2012] EWHC 2741 (COP).

adult sufferer of anorexia nervosa, did not create an advance refusal. The NHS trust caring for L sought a declaration that it was not in L's best interests to be forcibly fed, or given any other such medical treatment, even where it would result in her death. L accepted sustenance through a naso-gastric tube, but only at a rate that would not allow her to gain any weight. Whilst she did not want to die, she would not intake the extra calories needed to survive, resulting in end stage organ damage.

The court heard compelling medical evidence that if L was to be forcibly fed, she would have to be sedated which due to her fragile state, would undoubtedly result in her death. Having determined that L did not have the requisite capacity to make decisions about her treatment for the same reasons laid down in the above case of E, the court applied the best interests test laid down in s.4 MCA 2005. Pursuant to this, L's best interests were assessed by reference to all the circumstances, including that she would not regain capacity in the future due to the nature of her anorexia s.4(2) and (3). Other requirements of the test are to encourage L to participate as fully as possible in the decision, and to consider the past wishes, values, views and beliefs of both L and those of her family (s.4(4) and (6)). The application of the test in this case resulted in King, J. carrying out the balancing exercise between life and autonomy, adopting the same approach as Lord Goff in *Bland*, which explicated that whilst the preservation of life is a primary aim, it is not absolute.¹⁸⁶ There was no consideration as to whether or not L's desire to live could amount to a viable 'advance request' even if it could be established that she had capacity. The interesting matter was that at that same time at which L communicated her hopes of survival, she was competent enough to understand the consequences of her actions. Therefore it follows that when L rejected the higher caloric intake, and this was honoured, it was considered she did have capacity to make her own decisions, and she chose to reject life. This path was reconstructed for her as such a route would have been painful, degrading and inhumane in line with the judgment in *A Local Authority v E*¹⁸⁷ and positively, the decision was made according to E's wishes by way of her continued conduct

¹⁸⁵ *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam).

¹⁸⁶ A point also reiterated in the Code of Practice: DoCA 2007, 79.

¹⁸⁷ *A Local Authority v E* [2012] EWHC 1639 (COP) at 129.

which, consumed by illness, did not reflect the will to live a long, healthy life. Again, this would be a welcome decision under the PGC's guidelines.

4.2.1 The Choice of Death

As a closely related and highly current topic, it is worth mentioning that the amount of autonomy allowed in death is minimal. The act of withholding life-prolonging or life-sustaining treatment is not itself classed as illegal in England and Wales.¹⁸⁸ The act of aiding someone to administer life curtailing or terminating treatment is.¹⁸⁹ This equation is puzzling because the end aim is the same yet the modality taken to get there is very different – one may be long and drawn out, the other may be dignified, quick and humanitarian. Whilst this thesis does not concentrate on the area of 'assisted dying' or euthanasia per se, some degree of exploration of this topic is necessary; if the MCA 2005's promulgation of first-person autonomy as the primary right were truly justified, this would govern the application of the right to life, carrying with it the right to choose one's purposes freely, including the right to die. Under the current law of England and Wales assisting a person to die is not lawful, by anyone.

In 2012, locked-in syndrome sufferers Tony Nicklinson and an anonymous man named 'Martin' sought to alter the unkindness of the law through vividly outlining their own circumstances.¹⁹⁰ Martin wished to die by assisted suicide, by visiting Dignitas in Switzerland. The main declaration sought by Martin was to the effect that the Director of Public Prosecutions (herein 'DPP') needed to clarify his published policy¹⁹¹ so that the healthcare profession and others, willing to assist Martin in his desire to commit suicide, would know more clearly their position and whether or not they could be prosecuted. The latest decision in this case (Court of Appeal) was successful but has since been appealed by the DPP to the Supreme

¹⁸⁸ See for e.g. judgment in *Airedale NHS Trust v Bland* [1993] A.C. 789. particularly at paras.822- 835.

¹⁸⁹ Codified in s.2(1)The Suicide Act 1961.

¹⁹⁰ *R. (on the application of Jane Nicklinson) and Lamb v Ministry of Justice; R (on the application of AM) v Director of Public Prosecutions* [2013] EWCA Civ 961.

¹⁹¹ Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide Director of Public Prosecutions Feb 2010, CPS available at http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html <accessed 08/12/2013>

Court. If Martin succeeds in his claim against the DPP, he also seeks declarations that there will be no risk of prosecution or disciplinary proceedings in relation to all solicitors (i.e. through the Solicitors Regulation Authority) and doctors (through the General Medical Council) who aid in making the journey to Dignitas possible. This matter is ongoing in the Supreme Court¹⁹² at the time of writing.

In the 2012 case, Tony Nicklinson set forth his and absolute desire to emancipate himself from a life he did not wish to live through seeking three declarations, namely:

“i) A declaration that it would not be unlawful, on the grounds of necessity, for Mr Nicklinson's GP, or another doctor, to terminate or assist the termination of Mr Nicklinson's life;

ii) further or alternatively, a declaration that the current law of murder and/or of assisted suicide is incompatible with Mr Nicklinson's right to respect for private life under Article 8 , contrary to ss.1 and 6 Human Rights Act 1998 , in so far as it criminalises voluntary active euthanasia and/or assisted suicide; and,

iii) further or alternatively, a declaration that existing domestic law and practice fail adequately to regulate the practice of active euthanasia (both voluntary and involuntary), in breach of Article 2”.¹⁹³

Nicklinson’s desired declarations echoed those also sought (unsuccessfully) by Deborah Purdy¹⁹⁴ three years earlier regarding the matter that the law relating to assisted suicide/ murder was incompatible with his right to respect for private life under the art.8 ECHR. It was held that the legal prohibition on providing assistance to those wishing to die was not a disproportionate interference with art.8 after some consideration of pertinent cases preceding

¹⁹² In this case has shown agreement that the DPP guidelines and the factors to be considered when deciding whether to prosecute such cases are insufficiently clear in relation to healthcare professionals which does fall foul of meeting the art.8 requirements *R. (on the application of Tony Nicklinson) v Ministry of Justice* [2013] EWCA Civ 961.

¹⁹³ *Tony Nicklinson v Ministry of Justice* [2012] EWHC 304 (QB); Para 5.

¹⁹⁴ *R. (on the application of Purdy) v DPP* [2009] UKHL 45; [2010] 1 A.C. 345; [2009] 3 W.L.R. 403; [2009] 4 All E.R. 1147.

this one.¹⁹⁵ His case was guided towards scrutiny under legislative review, and was rejected by the sitting judges.¹⁹⁶ Additionally, the court refused to create a defence of necessity to a charge of murder or assisting suicide. Tony Nicklinson died just six days after this judgment was handed down.

Following his death, Tony's case has since been carried on by his wife, Jane, and two other appellants, Martin and Mr Lamb¹⁹⁷ who were most recently heard together at the Supreme Court in the latter part of 2013. Jane Nicklinson and Paul Lamb have sought (jointly) a declaration that the prohibition on assisted suicide per the Suicide Act 1961 is not consistent with the right to respect for private and family life under art.8 ECHR. Mr Lamb, 58, is paralysed from the neck down following a car accident over two decades ago. He has sought the same declaration as Tony Nicklinson, that, under certain conditions, necessity should be a defence to the criminal charge of euthanasia and assisted suicide.

Separately, Martin, in addition to his desire for clarification on the DPP's policy on the process of prosecution for those committing the offences of euthanasia and assisted suicide, has also argued that existing domestic law and practice has failed to regulate the practice of euthanasia in general. He submits that this amounts to a breach of art.2 ECHR and also that the legal prohibition of assisted suicide overall constitutes a disproportionate interference with art.8 ECHR.

The Supreme Court will deliver a ruling in 2014 on the above two cases (to be heard together). We must wait with baited breath for what will hopefully be a landmark decision in this area. In addition, a Bill concerning similar issues is currently being considered by Parliament entitled 'The Assisted Dying Bill'.¹⁹⁸

¹⁹⁵ *R (Purdy) v DPP* [2009] UKHL 45, [2010] 1 AC 345 para 101-115 and *Pretty v United Kingdom* (2002) 35 EHRR 1 considered at para 96-100.

¹⁹⁶ *R. (on the Application of Tony Nicklinson) v Ministry of Justice* [2012] EWHC 2381 (Admin), 2012 WL 3491755 para 150.

¹⁹⁷ In *Nicklinson V Ministry of Justice* [2013] EWCA Civ 961; [2013] H.R.L.R. 36; (2013) 16 C.C.L. Rep. 413; (2013) 133 B.M.L.R. 46; and also in and also in *R (on the application of Jane Nicklinson) and Lamb v Ministry of Justice; R (on the application of AM) v Director of Public Prosecutions* [2013] EWCA Civ 961.

¹⁹⁸ Assisted Dying Bill [HL] 2013.

The future may bring hope for those fighting for the right to autonomy in life, as well as in death. Speculatively this also leads to the question as to whether or not there could be a place in future for the provision of an assisted dying wish per an advance refusal. For all who believe in an overarching supreme principle of morality it must be difficult to understand the reasoning behind the judicial decision to keep Nicklinson alive via means of ANH and ventilation which seemed to revolve around any decision in court being a matter for Parliament. Some would consider this evasion of the issues. As such, there is urgent call for clarification, and change, in the law regarding assisted suicide.¹⁹⁹

4.3 The Goodness of an Act: Why Agents can Choose How They Live, and Die

For those who are locked-in agents, competency is presumed when expressing voluntariness of freedom of action in alternative ways such as blinking and using computerised aids as it would be presumed in any 'fully functioning' agent. This is not a problem. There are, however, possible problems of implementing an advance refusal where the creator is still able to exhibit the GR, but is not able to fulfil these alone due to physical impairments. To answer this problem, in addition to the requirement of considering other-regarding agents as being positive rights-interveners where invited, the 'goodness' of an action may also be called into question:

“first, he should regard as good those aspects of his wellbeing that are proximate necessary preconditions of his performance of any and all of his decisions. Second, he regards it as good that his level of purpose fulfilment not be lowered by his losing something that seems to him to be good. Third, he regards it as good that his level of purpose fulfilment be raised by his gaining of something that seems to be good, namely the goal or objective for which he acts”.²⁰⁰

¹⁹⁹ For more information on the progress of this Bill please see <http://www.appg-endoflifechoice.org.uk/pdf/appg-safeguarding-choice.pdf> <accessed 11/11/2013>

²⁰⁰ Gewirth, 1978 233-234.

The degree of 'goodness' of an action is instrumental; by this, the GR would be viewed not as ends in themselves, but as means to pursuing and defending the means to one's desired end. In this sense, there is no assumption that agents 'ought' to value': If an agent chooses a purpose, they must take necessary steps contingent with this purpose, and they need to have/ do certain things to achieve this. There could be no onerous requirement on the forfeiting of one agent's GR as against another, unless this produced the positive, desired effect. So to kill, or want to kill, oneself is not inconsistent with the GCA when we talk about goodness. However the actual act of choosing to pursue a cause, and to attach a value, renders this attachable value simply a subsisting value, not an instrumental value. So, it is viewed that Gewirthian agents may pursue any objective whatsoever within their remit of agency, even if this becomes the rejection of life completely. These purposes are particular to such an agent and are what they do when exercising their GR. One's total autonomy rests with the being which was at one point autonomous. In this sense, the generic rights can be termed 'waivable' benefits. Of course asking another agent to interfere positively may be done, but any other agent may reject such a positive interference with another's rights as being a negative right of their own.²⁰¹ Agents (in this example an agent '(Y)') may decide through their generic freedom of action which route is best to take for example:

"my killing x is good for x. This is because carrying out an act leading to the inevitable death of x (such as withdrawing AHN) is the purpose which x wishes to pursue as an agent; or,

"my not killing x is not an act which I will pursue as it is my generic right to pursue only those acts concurrent with my rights of agency, and the purposes I wish to pursue, and this act is not something I wish to pursue therefore carrying it out cannot be expected of me"²⁰²

²⁰¹ Deryck Beyleveld developed this concept and discusses this in more detail in Human Rights article see Beyleveld 2012.

²⁰² The idea for this concept came from the lectures delivered by Deryck Beyleveld in 2008/2009 (as part of the Law and Medicine module of the Law (LLB) course at Durham University).

From this, we cannot 'force' or require anything of Y excepting that Y does not interfere negatively with x's rights. In this sense, the execution of a person's advance directive or in assisted dying, the same principles would apply when looking at the role of a clinician and their patient. In a similar vein to the current law concerning abortion, doctors would be able to choose this path at will.

The s.24 (MCA 2005) provisions state that any refusal may not be motivated by the desire to bring about death, quoted by Mrs. Justice Eleanor King in *NHS Trust Authority v L*²⁰³:

"In carrying out the balancing exercise I bear in mind that our law contains a strong presumption that all steps will be taken to preserve life save in exceptional circumstances, this is reflected in Article 2 EHCR".²⁰⁴

This led to opinion that:

"there comes a point in the treatment of any patient where, regardless of the diagnosis, the slavish pursuit of life at any cost becomes unconscionable. I believe, sadly, that this point has been reached in Ms L's treatment".²⁰⁵

The same view has been amplified in the MCA 2005 Code of Practice (para.5.31):

"All reasonable steps which are in a person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery".²⁰⁶

In this case, the court approved a declaration that it was not in the best interests of a person suffering from the latter stages of anorexia nervosa, where her body was shutting down after a 16 year battle, to be the subject of forcible feeding or medical treatment notwithstanding that in the absence of such nutrition and treatment she would inevitably die. As seen in this brief

²⁰³ *NHS Trust v L*; EWHC 2741 (COP) (2012).

²⁰⁴ *Ibid* at 66.

²⁰⁵ *Ibid* at 67.

²⁰⁶ See the Code of Practice: DoCA 2007, 79.

overview regarding the law's stance on assisted dying, the rights we are granted in life do not entirely extend to the way in which we die but this is very much a work in progress.²⁰⁷

4.4 Restoring Balance

In terms of the right to life, this does not yet stretch to the right to death, but there is hope that the right to autonomy will prevail and that art.2 will be balanced by a similar provision for those wishing to end their lives in certain circumstances with assistance.

The divergence between the cases of L and of E²⁰⁸ above is startling. Both L and E were in the palliative care aftermath of long term anorexia and treated as incompetent, yet L wished to live but it was decided that she would not be the subject of all possible life-sustaining treatments, and E was to be the subject of such life-sustaining treatment, despite vehemently rejecting this by way of an arguably valid advance refusal. The notion of first-person autonomy is integral to what constitutes us as conscious, self-driven, decision-making beings; these are also key attributes of Gewirthian agents. Without the right to autonomy, we would have little or no individual identity. So it is paramount that first-person autonomy is accorded respect.

Decisions at common law both preceding and following the creation of the MCA 2005 have amounted to an array of mixed messages. Thus, the grand illusion of the 'autonomy as king' premise emanating from ss.24 to 26 MCA 2005 forms no compelling magic trick. The main provisions of the 2005 Act attribute the utmost importance to autonomy, yet in reality, it is well documented that this right is still a relative featherweight as against its brawny competitor which seeks always to preserve life. Despite some positive advances, especially in the case of *The X Primary Care Trust v XB*,²⁰⁹ there is little or no consistency in application of the main provisions supported by contrasting the cases of *A Local Authority v E*²¹⁰ and *NHS Trust v L*.²¹¹

²⁰⁷ Assisted Dying Bill [HL] 2013.

²⁰⁸ *A Local Authority v E*; EWHC 1639 (COP); 2 F.C.R. 523, 2012.

²⁰⁹ *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam).

²¹⁰ *A Local Authority v E* [2012] EWHC 1639 (COP) at 129.

²¹¹ *NHS Trust v L* [2012] EWHC 2741 (COP).

The question then follows, why are the provisions producing such a concoction of results? Among other reasons, the provisions are not strong enough because they do not consider deeper issues, let alone address these.

CHAPTER FIVE: CAN IGNORING THE PERSONAL IDENTITY PROBLEM BE JUSTIFIED?

5.1 Personal Identity and Dementia

It is well documented²¹² that the nature and importance of personal identity is subject to a wide scope of debate and is an unavoidable area of consideration for policy on advance refusals of any kind. Disappointingly, under the MCA 2005, there is no separate regulation for patients who suffer from dementia, indeed those suffering from dementia are viewed in exactly the same way as all other patients who lack capacity. Again, Pattinson's task-specific competence is relevant. Whilst a person who suffers from dementia may not have capacity to refuse ANH, they may have a level of competence, allowing them to make certain decisions about their lives. When such decisions coincide with former wishes, values, views and beliefs exhibited by a person, this builds up a strong picture of what they may desire now in respect of the more complex decisions they are unable to make. In the absence of such consideration, the MCA 2005 prescribes that if the patient had the requisite capacity, and the other criteria are satisfied, an advance refusal remains in existence and is valid. Yet, there are in fact two diametrically opposed alternative routes. The first; the dementia patient is now a separate person from the original creator of the advance refusal, rendering it invalid and inapplicable. The second; the advance refusal remains applicable because at the time of creating it, the patient had the requisite levels of (legally recognised) capacity and that the wishes they created when they were able to do so take precedence over any new decisions made without capacity. The MCA 2005 does not consider the 'sliding scale' of dementia and the effect that such a condition has on personal identity – this chapter seeks to prove that such consideration can no

²¹² See for e.g. Buchanan 1988, 279-281 and Parfit 1984, 282- 302.

longer be avoided. In setting aside discussion of differing thought camps around freewill and determinism in the last, this chapter focuses more on the issue of personal identity per se as the foundation for autonomy, and autonomy is a prerequisite of agency. Beauchamp summarises this approach:

“if discussions of freedom could be grounded in a clearer view of the nature of persons rather than in abstractions like ‘freewill’ and ‘determinism’, they might avoid some of the fruitless controversies and ideological distortions that have plagued them in the past”.²¹³

5.2 A Legislative Obligation to Consider the Personal Identity Problem?

The main provisions in ss.24 to 26 of the MCA 2005 explicitly apply to ‘P’ as the person making an advance refusal. But how do we know that P is still P when an act or event renders P, in any degree, physically or psychologically ‘different’?

The ‘personal identity problem’ is an exploration of the issue of providing conclusive criteria for evidence of the continued existence of a human being. The debate shows that defining ‘who I am’ in relation to my past, future and present self, is not easily answerable. For some, attributes such as physicality²¹⁴ and personality define us. For others, the ongoing person is defined in the ability to; recall memories, make autonomous decisions, forge and maintain relationships with others, have personal preferences, values, beliefs and habits. These attributes can define us as being a person; but the personal identity problem relates to whether or not a person can be either the same or, a continuously different person. To demonstrate the difficulties presented in this problem, imagine an experiment in which the memories, values, habits and beliefs of two separate people are swapped as in the classic film ‘Freaky Friday’²¹⁵ where a mother and daughter traded bodies. In this scenario, the two people exchange all physical attributes, except their psychological self remains. Any close relationships in this

²¹³ Beauchamp 1999, 281.

²¹⁴ Buchanan 1988, 279.

²¹⁵ ‘Freaky Friday’ 1976 (movie; dir., Gary Nelson).

scenario would realise that the obtuse, rapid changes within such a person could render them 'different'. But when would these to people cease, if at all, being their former selves?

Historically, the debate has been vigorously divided as between those who argue that personal identity is established by physical continuity and those who opt instead for psychological continuity.

One line of thinking which details reasoning as to why personal identity is not, as he describes, 'of importance', is Derek Parfit.²¹⁶ His line of thought follows a 'no-self' concept of the individual. For Parfit, identity involves 'Relation R' — a type of psychological continuity—where a person is an endless continuum of psychological experiences or events. From this, on his account, because of the constant changes in a person rendering them an evolutionary process of change, advance refusals could not hold any force. At the very least, a person is not the same person they were due to loss of capacity/ autonomy, and in the extremities, a person is not the same person they were due to constancy in time and space.²¹⁷

Alan Buchanan's argument sets out a view, with the basis of consciousness as the linking matter, that there are certain characteristics which lead to questioning a person's identity. From this perspective, where there is no degree of psychological continuity whatsoever in a person (i.e. in a person with acute dementia), there is an argument that an advance refusal could not stand due to a 'switch' in person. Comparably, Derek Parfit's version of this argument is more extreme; in his estimation, a person is not the same person they once were due to continuation in time and space.²¹⁸ Parfit's model is incompatible with the PGC: to say that we never change would be more absurd than saying that we change rapidly in every second that we live and breathe. However, and pursuant to the PGC, to say that personal identity changes is a thoroughly bold statement. If this were true, we would never know who we were, and there could be no accountability for, or purpose in, our actions, with the exception of change itself for the sake of changing. As we know, the heart of agency is autonomy, and the application of autonomy is seen in the notion that purposes are pursued for whatever reasons an agent

²¹⁶ Parfit 1984, 282- 302.

²¹⁷ Parfit 1984, 282- 302.

²¹⁸ Parfit 1984, 282- 302.

ascribes. If we do say that personal identity changes, this means that any previously expressed wishes and feelings would have to be ignored. This approach is only legitimate if there are very strong reasons to believe this; in turn, a person's identity could be said to have changed. If an agent's whole ethos, thought process, memories and everything else making them a particular agent changes, we can no longer treat them as the same agent. Such an occurrence is rare, and would apply predominantly to those suffering from the more severe stages of dementia.

So whilst it is agreed that you can lose personal identity in a number of ways, it cannot be agreed per Gewirth that personal identity changes rapidly and regularly as in the above 'space and time' instrument. However, the PGC would support the view held by Buchanan that the necessary criterion for personal continuity requires some degree of psychological continuity.²¹⁹

For the purposes of this chapter, and because the theory fits with Gewirth's PGC, I will be using a model loosely based on the 'psychological continuity' model outlined by Buchanan above. In defining 'personal identity' as a referendum for continuity of the person, I look to using the patient's having consciousness as the *de minimis* basis of psychological continuity, a slight variation on the model presented by Buchanan.

Currently, as outlined in the first chapter of this thesis, where an adult in law executes a valid and applicable advance refusal, he may refuse any treatment indefinitely. Yet, the physical and psychological development of a person through time, particularly where severe neurological change occurs, causes that person to change. Without addressing the matters presented by the personal identity problem, the MCA 2005 is evading consideration of those key ethical implications for patient care and will in turn continue to produce a mixed-bag of results. Such consideration should be an obligation as the absence of guidance often leads to misguidance.

²¹⁹ Buchanan 1988, 279.

5.3 Reason in 'Precautionary Reasoning'

The practical difficulties presented in the personal identity problem in respect of dementia patients relate to delineating where a person loses their autonomy and many of the characteristics once determining them 'unique'. The two issues here to be addressed are i) whether the person is an ostensible agent and ii) whether that ostensible agent (if yes) is the same agent as before. These levels of 'attachment' of being with the dementia patient's former self will indicate (in the relevant stages of dementia), where/ if A person ends and B person begins. The approach can never be broad-brushed and ought to be based upon the medical presentation and psychological and physical continuity of the dementia patient. We look to precautionary reasoning now to address these issues.

The precautionary reasoning argument developed by Beyleveld and Pattinson attempts to fortify the PGC in its pragmatic approach to showing where agency does and does not exist:

"Quite simply, this argument establishes that any agent must treat other (epistemically) possible agents who are able to behave as though they are agents (viz., ostensible agents) as agents whether or not they (unknowably for the agent) actually are agents, which means that they must be granted the generic rights by all agents. Furthermore, it entails that those behavioural capacities and associated physical/biological structures that provide evidence for ostensible agency must be taken morally (for precautionary reasons) as evidence (but not necessarily complete evidence) of agency in other beings by agents. The precautionary argument that we apply to apparent non-agents is developed from this basic precautionary argument and must be understood as such".²²⁰

5.3.1 The Precautionary Reasoning Argument

The argument is as follows:

We are asked to consider three beings:

- i) oneself (A) (the only being we can be certain is an agent);

²²⁰ Beyleveld and Pattinson 2010, 260-261.

- ii) an 'ostensible agent' (B) (another being who behaves as if it is an agent and is therefore ostensibly an agent); and
- iii) a non-ostensible agent (C) (another being who does not display the abilities of an agent and hence is not an ostensible agent).

The inter-relationship of agent-statuses as between the parties A, B and C, is a seminal consideration when applying the PGC in practice. We are told that, as A cannot know B is not an agent without making ill-founded metaphysical assumptions, A must suppose B to be an agent, B is an ostensible agent so we must, and can, treat B as an agent. This is because acting on this presumption does not violate the PGC if B is not in fact an agent, but treating B as a non-agent if B is in fact an agent would violate the PGC, and it is possible to treat B as an agent.

Beyleveld and Pattinson configure that the argument of precaution imposes duties on A in relation to C. These duties amount to moral duties, but not rights. In this way, C could be viewed as what they term 'an object of a degree of moral concern' from the perspective of A in 'proportion to (variously) the probability that C might be an agent under precaution'. This element of the argument relies on how easy it is to imagine that C is an agent; or how close C's observable characteristics, which are displayed, are similar to that of an ostensible agent. This aspect really revolves around a balancing act as against the competing attributes of agency.

Because the precautionary reasoning argument requires only those possible agents who are categorised ostensible agents to be actually treated as agents the demarcation of agency and agent rights is concise. This distinction is drawn because 'to treat a being as an agent is to grant it the generic rights and to impose the correlative generic duties on it'.²²¹ This view is logical – we cannot grant rights to those things which we cannot class as agents because this would be impracticable and irrational.

Patients are always a B or a C. Those in category B would include patients with dementia as well as any other human beings, aside from ourselves, who pursue purposes voluntarily. Those who are in a PVS would be classed as being in category C.

²²¹ Pattinson 2010, 261.

While it is accepted this approach does not ‘answer’ the personal identity problem, at least this approach does provide an answer to the important question; ‘does this person matter?’ And when you look at the world around, you can only be sure about yourself as voluntarily choosing purposes, therefore classing another being as an ostensible agent is the highest classification grantable.

5.3.2 Why Relevant Behavioural Display Should Also be Included in Legislation

Precautionary reasoning per Beyleveld and Pattinson proliferates to provide further categorization, distinguishing between at least four qualitatively different levels of ‘relevant behavioural display’ (herein ‘RBD’). As I have distinguished between the levels of ‘beings’; I will only set out the four levels of RBD categorised L1-L4 which are relevant to this thesis (although there are more):²²²

- 1) L1 includes those who clearly behave like agents and are ostensible agents, i.e. human beings and hypothetical non-human animals or plants which behave as agents (category B).
- 2) L2 entails beings that we are uncertain behave like agents (such as human children at early stages of communicative competence; dolphins; whales; non-human primates; some birds) (category B).
- 3) L3 beings are those who do not quite behave like agents but have some of the behavioural capacities that apparent agents display i.e. that have the necessary but not sufficient characteristics to be classified as ostensible agents (which, arguably, includes, whether adult or not, dogs, cats, pigs, horses, cattle, sheep, earthworms, plants, bacteria; computers with some self-regulating functions). At least some display of evidence of consciousness is needed at this level and the two levels above (category C).
- 4) L4 includes beings that do not behave like agents and exhibit no behavioural capacities of ostensible agents²²³ (e.g., rocks) (category C).

²²² Please see Beyleveld and Pattinson (full article) 2010 for expansion of this point.

²²³ Beyleveld and Pattinson 2000 Beyleveld and Brownsword 2001, esp. 124, and Pattinson 2002, esp. 73).

5.4 Filling Lacunae with Precaution

If we imagine the below four different categories of persons, the problem of not addressing the identity of persons with a moral-compass becomes apparent. Relating back to the issues thrown up by the personal identity problem, and to the answer of the question ‘does this person matter?’ discussed under the chapter three, the law says that we all matter. The difficulty in answering this question so succinctly occurs where there is a significant personality change. Using the PGC and precautionary reasoning argument due to the logical reasoning I earlier presented, I will now explore this point.

Imagine four different people. Person A finds themselves in a state of PVS person B in a MCS, person C is ‘locked-in’ and the next (person D), has dementia. The ostensible difference here in each case is that each person’s connection with their former selves, due to varying levels or at least displays of consciousness (and therefore psychological continuity), varies greatly. In the event that each has made a valid and applicable advance refusal in line with the MCA 2005, the PGC is a good place to start as a referral point.

Person A: Outlined by William James,²²⁴ the stream of consciousness itself is founded in a person’s ability to experience environment, existence, thought and sensations as an ongoing process in tune with their inner voice, creating episodic memories. Consciousness is the grounding for ostensible agency. The controversial Peter Singer put forward that:

“the most significant ethically relevant characteristic of human beings whose brains have ceased to function is not that they are members of our species, but that they have no prospect of regaining consciousness. Without consciousness, continued life cannot benefit them”.²²⁵

Whilst there have been a multitude of cases of misdiagnosis of patients in a PVS,²²⁶ there has never been any recovery from this state where it is proven. It is therefore widely accepted that,

²²⁴ James, 1890.

²²⁵ Singer, P. 1995, 207.

²²⁶ One such case saw a 12 year-old boy’s parents being forced into signing organ donation agreements in the same minute that EEG scans picked up signs of brain activity see further Bohannon 2012.

if there are no positive aspects of keeping a person alive, and where attempting to do so is inhumane unnecessary and futile (where no degree of consciousness may be established), there should be no obligation to do so or to attempt to do so. As discussed at 3.2 this was the outcome in *Bland*,²²⁷ which would also be supported by Gewirthian theory as patients proven to be in a PVS are non-ostensible agents (see further 4.1.1 & 5.3.1-5.3.2).

In one article, Catherine Constable suggests that the current medical presumption favouring provision of ANH to PVS patients is a 'violation of autonomy'. Constable objects to such interference on the grounds that it 'goes against the best interests of the patient' in scenarios when there are either doubts about a patient's wishes or where such wishes are unknown.²²⁸ Actually, for the purpose of the PGC, person A is classed as belonging to L4 so if an advance refusal did not exist, the PGC would not rule out this approach. It is accepted under the PGC that because agents would have a correlative moral obligation towards such beings to primarily preserve their wishes, values, views and beliefs, if previous wishes had been expressed (even if these were not in the format the MCA 2005 requires) the substituted judgment approach would be more appropriate as the default position. This would be the case unless the personal identity problem applied (I return to this notion at 6.2).

In the case of Person B there are widespread issues of misdiagnosis of those in MCS where 'locked-in' syndrome has been undetected (although this is now rare with the introduction of very specific testing for electro-neural activity). This was one of the issues brought to light in the case of *Re M* discussed in the previous chapter.²²⁹ Criteria for diagnosis as to the level of brain activity has been created – indeed the most recent revelation has been made by Professor Adrian Owen leading research at the Brain and Mind Institute of Western Ontario.²³⁰ Owen's pioneering method of communication with his most recent patients (in a PVS) used the technique of encouraging a level of physical reaction through the pretence of playing tennis or walking around their own homes. From this, answers 'yes' and 'no' were

²²⁷ *Airedale NHS Trust v Bland*. [1993] A.C. 789.

²²⁸ Constable 2012,163.

²²⁹ *Re M* [2011].

²³⁰ Smith, 2012.

obtained from one patient to ascertain whether or not they were in a state of pain, whether they knew who they were, and so on. Such communicative strategies are absolutely seminal to understanding the link between a person's former and current self. The operation of these strategies means that families 'fighting' for the right of their loved ones to be kept alive artificially in line with pre-existing staunch religious beliefs or advance refusals²³¹ can be done morally.²³² Yet this approach sparks the worry that the thought of playing tennis or walking around one's home are gravely different to expounding one's wishes and feelings about more pivotal questions such as whether or not a formerly executed advance refusal to remove ANH and ventilation ought to be enforced. Relating more generally to MCS, in one article, a doctor was reported as saying 'it is difficult to tell whether she is oblivious or struggling to respond'.²³³ Despite difficulty in being certain, those in a MCS would be classed as ostensible agents under precautionary reasoning, as we could not rule out the existence of consciousness in their neural-activity; they would be classed under L3 above.

Person C: When considering the treatment of person C, prima facie this is straight forward – if a person is able to communicate a contemporaneous decision made by them, and can adequately weigh, believe and understand the information and decision they make, in line with s.3 MCA 2005 then this remains their final decision. Prior to losing all ability to communicate and with the help of advances in aiding-equipment, many who suffer from the most common cause of locked-in syndrome express themselves with the use of blinking letters

²³¹ Marsden, 2012.

²³² The Vatican's Congregation for the Doctrine of the Faith (CDF) stated in 2007 the withdrawal of artificial nutrition and hydration from PVS patients is immoral; 'The administration of food and water even by artificial means is, in principle, an ordinary and proportionate means of preserving life. It is therefore obligatory to the extent to which, and for as long as, it is shown to accomplish its proper finality, which is the hydration and nourishment of the patient. In this way suffering and death by starvation and dehydration are prevented.' Their statements were approved by Pope Benedict XVI (Levada, 2007) available at http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20070801_ris_poste-usa_en.html <accessed 14/10/2012>

²³³ McGowan, 2011.

to loved ones or by using Eye-gaze Response Interface Computer Aid (ERICA).²³⁴ ERICA enables user to write emails and letters using the computer – this software can also produce a computerised voice, allowing the patient to ‘talk’ to others (this is the same system used daily by Stephen Hawking). Locked-in syndrome occurs where a person has a level of consciousness without the ability to move or communicate verbally due to complete paralysis of nearly all voluntary muscles in the body except for the eyes. Total locked-in syndrome occurs where the eyes are also paralyzed.²³⁵ Person C, in being-locked in (thus a locked-in ostensible agent), would amount to an L1 being. When those who are locked-in lose the ability to communicate, then their final word remains the last expressed and there can be no reason to doubt that they are the same person as before. But there are ensuing issues as person C may experience severe difficulty with communicating their wishes, values, views and beliefs.

Finally, in person D — deep set dementia such as the latter stages Alzheimer’s may change the person’s identity significantly. Those suffering from dementia would also be classed as L1 ostensible agents if they still retained their ability to communicate and had based competence; where task based competence and the ability to communicate are both lost, such a person would be classed as belonging to L2 or even L3 So it is apparent that dementia sufferers could either come under category B or C. Categorisation is key and understanding that the personal identity problem is a problem for many dementia sufferers, namely those whose personalities have changed significantly, is the first step towards offering such persons better treatment in line with the MCA’s main provisions. And until the personal identity problem does become an issue (i.e. for some persons in early-stage dementia), advance refusals should not be automatically ruled out as not being binding which is the current stance. Defining when the personal identity problem becomes a problem is a matter for the medical profession to consider; in the case of those with deep set dementia for example, applying the pre-dementia patient’s wishes would be exactly the same as considering one person’s rights over the next. In

²³⁴ This, for example, uses a camera and infrared light to detect the position of a person's gaze on a computer screen. In this way, a person can essentially type with his or her eyes, performing computer tasks normally.

²³⁵ Locked-in syndrome is also known as cerebromedullospinal disconnection de-efferented state, pseudocoma ventral pontine syndrome.

this way, any application of rights considering the ‘former’ person would be inconsistent with the PGC where such a drastic change in personality renders this the case. Conversely, in the early stages of dementia, where it could reasonably be believed that an advance refusal would still apply, it should. In both of the afore mentioned cases, a person’s former wishes, values, views and beliefs must be considered, and the careful balancing act between granting autonomy where possible, as well as considering the implications of the personal identity problem – this would need to be done on a case-by-case basis and would always need to be addressed by the medical professionals dealing with the patient, and by the Court of Protection. This leads us into Dworkin’s argument which is more complicated to dissect.

5.4.1 Dworkin’s Margo: Questioning the Notion of Experiential Interests

Dworkin presents an interesting argument concerning the matter of personhood and builds on the personal identity problem. In *Life’s Dominion*²³⁶ Dworkin targets the applicability of advance refusals in relation to those suffering from dementia. His theory is based on the integrity view; which does not assume that people have consistent values or make consistent choices during life. He opposes the evidentiary view of autonomy which outlines the absolute respect of a decision made by a competent adult – the same view reflected in the MCA 2005. Dworkin’s reasoning behind such rejection springs from the patient’s precedent autonomy, this being that:

“a competent person’s right to autonomy requires that his past decisions about how he is to be treated if he becomes demented be respected even if they contradict the desires that he has at that later point”.²³⁷

From this, we are presented with Margo, a resident patient suffering from Alzheimer’s who enjoys her life perfectly according to a medical student regularly attending to her and taking reports – she attends art classes, greets people generically, etc. The student assesses Margo as being ‘one of the happiest people’ he has ever known. However, prior to becoming ill with the

²³⁶ Dworkin 1993, 222-237.

²³⁷ Dworkin 1993, 228.

disease, Dworkin asks us to consider that Margo made a very clear advance refusal that, in the case of Alzheimer's:

“she should not receive treatment for any other serious, life-threatening disease she might contract, or even in that event, she should be killed as soon and as painlessly as possible”.²³⁸

At this juncture, we are asked to weigh up her interests in a subjective manner. Following on from any precedent autonomy she has exerted by way of her advance refusal, we must consider Margo's interests in her current environment and in her present state today. This must then be weighed against her former interests exhibited through a completely express, clear statement of wishes made autonomously. These are separated; 'experiential' and 'critical' interests respectively. Those interests categorised as 'experiential' concern the ability to value the things one experiences, such as eating a favourite food, listening to certain pieces of music. Those termed 'critical' interests preside over these, and concern more than that which we experience, these concern our core values. For Dworkin, Margo's critical interests which were considered when she was able to form an advance refusal, override her experiential interests. In this case, an advance refusal made by a person pre- dementia, could and would still apply to their later selves, arguably different persons. Dworkin treats the advance refusal as binding due to its nature, and due to the severity of consideration of the subject given when the competent patient made a decision. To disregard such critical interests and to view Margo in her current, 'happy' state would, in Dworkin's view, disrespect the wishes of that once competent patient. It must be noted here that Dworkin's Margo is seen as being the same person at all times despite the fact that the core aspects of her being have, on the whole, changed adversely, as will be argued in line with the PGC.

From this, the matter really does not concern critical or experiential issues as we see them presented by Dworkin. This is because dementia renders Margo an L1 being — i.e. those who clearly behave like ostensible agents, but the issue at hand is that she may not be the same person who made the advance refusal. If it is seen that she is now a derivation of her

²³⁸ Dworkin 1993, 226.

former self, then she is a being who must be assessed in its own right and on the basis of what is best for her now. If a patient is the same patient they were when making an advance refusal, i.e. they share some degree of psychological continuity with their former selves in the absence of being able to communicate or act otherwise, then an advance refusal still stands. If, however, they are a different patient, then the advance refusal does not hold effect and instead, some form of addressing the patient's best interests must be employed. Dworkin hints that an essential ingredient of personhood is a competent adult's right to autonomy; this is true also for ostensible agents. Margo is only autonomous now in that she can decide in that moment some simple matters. Intriguingly, Margo is presented as two different people – Margo the competent decision maker – and Margo the dementia patient. Yet, Dworkin treats them as one, not taking into account Margo I's wishes and instead replacing these with the 'experiential' interests of her later counterpart Margo II; yet his whole argument is enshrouded in avoidance of the question, are these same people? If the answer is yes, as the argument seems to suggest at first blush, then it follows that Margo I's original advance refusal be followed as her last wishes expressed when she had capacity to do so are her wishes *in toto*. If the answer is no, this is because the loss of autonomy that Margo II's condition entails has rendered her at the very least a radically changed ostensible agent, to be assessed in its own right.

5.4.2 So Who is Margo and Does She (and her Advance Refusal) Matter?

For a Gewirthian, it follows that when dealing with Margo in the present day, she would be classed as an ostensible agent, a B) and a L1. This is supported by the duties-based approach outlined by Beyleveld and Pattinson.²³⁹ Margo 'matters'.

However, the personal identity problem is next to be considered. With Alzheimer's , because of the 'change' or 'break' in continuity of the person due to loss of memory, preferences, and the ability to recognise those once loved, there will be circumstances where neither an advance refusal of treatment (where there is one), nor the best interests test (where there is not) would apply; a point which I return to later. In this situation, a form of assessment

²³⁹ Beyleveld and Pattinson 2010.

would need to be made as to the probability that the former advance refusal could still apply. The PGC would first want to consider, where practicable, what they would have wanted if they could have communicated it at that time. Such assessment would not need to be made, for example, in early-stage dementia, where it could be proven by medical professionals that Margo was still Margo, for the purpose of the personal identity problem. Any assessment would also need to take into consideration whether or not she had task-specific competence to understand more how best to treat her – enjoying art classes is different to being able to make decisions concerning health, life and death.

Dworkin's presentation of Margo overlooks the critical need for understanding of the implications of the personal identity problem when dealing with dementia. It is imperative to consider the elements which make us the person that we are particularly, as opposed to another person. In addition, the scale of 'needs' is not fixed as per the two segregated categories of interests Dworkin believes them to be.

It is imperative that personal identity is considered in relation to those suffering from dementia, as this allows for use of the most appropriate 'test' if no advance refusal has been made. Similarly, if an advance refusal has been created, this would allow for proper consideration of its effectiveness. Autonomy could not always preside where psychological continuity is deficient.

5.4.3 Advance Directives for Dementia Patients: Why the Dutch System is Too Ambitious

Where Dworkin argues that the critical interests of persons prevail, the law, and the PGC, would deem this as a harsh approach. This is because when the personal identity problem is invoked, an advance refusal could not automatically apply. Murdering the now happy Margo to satisfy the wants of her former self would be inconsistent with agency. To merge Dworkinian terms with Gewirthian theory, Margo II's critical and experiential interests may have changed, but they exist now, as they are, in the midst of dementia. They must be treated now.

In the case of 'happy' dementia patients who once made an advance refusal, the treatment of the patient as 'new' may not be difficult. A 'live' system taking the opposite view,

is found in the Netherlands. Where it is assessed that where the dementia patient, is experiencing ‘unbearable suffering’, an ‘Advance Directive for Euthanasia’ (herein ‘ADE(s)’) may be upheld. This approach affords utmost autonomy over any future derivation of self, as supported by the following statement from a GP cited by Dutch newspaper De Volkskrant:

“In respecting his or her will, we pay homage to a patient who was once alive, and not to a human being who no longer knows if he or she exists”.²⁴⁰

Dutch euthanasia directives are legally available for all persons with a legally recognised level of capacity from as young as 12 with parental consent, and over 18 without, and may expressly apply where dementia occurs. Article 2.2 in The Dutch Euthanasia Legislation (WTL) dictates the law in this area. In terms of applicability, these directives must be directive made out to this effect in writing²⁴¹ and if the doctor is satisfied that the patient is experiencing ‘unbearable suffering with no prospect of improvement’, they can administer the treatment to end that person’s life.

In a 2010 study on the operation of Dutch ADEs, 434 elderly care physicians (herein ‘ECP’s’ – the sector dealing with 92% of all dementia patients) were asked to consider whether the legality of ADEs led to more euthanasia.²⁴² In response to the statement; ‘it is impossible to determine at what moment an Advance Directive for Euthanasia of persons with dementia is to be carried out’, 76.2% of all physicians in the state asked at least agreed more than they disagreed with this statement (with the majority fully agreeing).²⁴³ The same survey found that the law around ADEs was ‘morally problematic’ for these main reasons:

“Determining the (unbearableness of) suffering of the patient and planning the moment of executing the ADE becomes very difficult, making it virtually impossible for (physicians) to perform euthanasia...ADEs may fulfil a complimentary role, in the sense

²⁴⁰ De Volkskrant, See <http://www.presseurop.eu/en/content/news-brief/3779801-doctors-euthanasia-dementia-patients-should-be-restricted> <accessed 28/05/2013>

²⁴¹ It is even currently being debated whether this particular kind of euthanasia directive may also be made orally by the euthanasia committee in the Netherlands, calling for a widening of the applicability of euthanasia advance directives for patient with dementia.

²⁴² de Boer et al 2010.

²⁴³ de Boer et al 2010.

of initiating or supporting discussions between the patient, physician, family and other health care professionals, in the early stages of dementia, but where the possibility for communication and joint decision-making is lost, they offer no viable approach towards a good death".²⁴⁴

Resulting newspaper headlines such as 'Dutch Docs Pushed to Euthanise More Patients with Dementia'²⁴⁵ are cause for concern. The area of euthanasia directives on the whole has been summarised as a 'grey area' as reported by Sheldon.²⁴⁶

Although ambitious to preserve patient autonomy, unfortunately the Dutch system is riddled with inadequacies from an ethical viewpoint as the personal identity problem is not fully considered. The Dutch approach highlights the danger of legislation leaving behind the professionals who use it, such 'grey areas' seen in the law in the Netherlands are also seen, to a different degree, in England and Wales.

5.5 Problem-proofing Legislation

In addition to what he termed the 'three general asymmetries'²⁴⁷ which translates as the main challenges to the value to be found in advance refusals per se, Alan Buchanan also provided a succinct account as to why personal identity could prove to be the most prolific objection to the argument outlining the value to be found in advance refusals:

"this is the objection that the very process that renders the individual competent and brings the advance directive into play can – and indeed often does – destroy the conditions necessary for her personal identity and thereby undercut entirely the moral authority of the directive".²⁴⁸

²⁴⁴ de Boer et al 2010.

²⁴⁵ Smith, W.J. 2013.

²⁴⁶ Sheldon 2013.

²⁴⁷ Buchanan 1988, 279.

²⁴⁸ Buchanan 1988, 280.

Because there is, ostensibly, no recognition of the problem of personal identity in the MCA 2005, this is problematic in itself. Whilst it is maintained under the PGC, that is difficult to lose personal identity, it is still possible for this to happen. If, in the extremity we claim akin to the theory of Parfit²⁴⁹ that personal identity changes with ‘time and space’, this means that any previously expressed wishes and feelings would have to be ignored. For a Gewirthian a loss of personal identity would rely upon strong evidence of a complete change of personality – in real terms this would apply mainly those with severe cases of dementia. I once again return to the premise that just because capacity cannot be established with some persons suffering from with dementia, this does not mean that task-specific competence is not present.

As legislation is not tackling the problem of personal identity, Penney Lewis offers up two exclusions as to be inserted into s.26 of the 2005 Act:

- 1) a dementia-only exclusion: ‘P is not suffering from dementia’;
- 2) a personal identity exclusion ‘P’s personal identity has not been seriously compromised by P’s impairing condition’.²⁵⁰

Recognised by Lewis,²⁵¹ both of these provisions may be subject to difficulty in implementation. The dementia-only exclusion would be very ethically problematic in application as in the early-onset of dementia, advance refusals may still be applicable. Moreover, the latter of the two proposed additions would be almost impossible to uphold, but at least this provides a starting point for consideration of the problem.

Any legislative change would need to revolve around the two main issues to always be reasoned which I reiterate are:

- 1) Whether or not the person ‘matters’; and whether ostensible agency can be established (following consideration of personhood); and,
- 2) How proximate the personal identity of the now person is to their former selves.

This is a very subjective test. As will be discussed in the following chapter, the

²⁴⁹Parfit 1984, 282- 302.

²⁵⁰ Lewis 2006, 232-233.

²⁵¹ *Ibid*, 230.

welfare and treatment of those who exhibit dramatically separate behaviours, values and characteristics from their former selves are currently judged on the best interests test. This test may not always be considered accurate. This is due to contention around what action can be viewed as being truly in their best interests as opposed to what the person applying the test believes is in another person's best interests. If this person does matter and if their personal identity is a problem, what would they want now, if they could choose for themselves?

Lewis insists that consideration of the personal identity problem, that is excluding advance refusals as not applying for those who have suffered severe personality changes, in and of itself can lead to violation of Article 8 ECHR. Following this assertion, it is viewed that in the case of those with dementia, 'translating this in to the legal arena is likely to be extremely difficult, if not impossible'.²⁵² It is here contended that lack of consideration of the problem in practice is actually doing this. Indeed, the redundancy of advance decisions where extreme personality changes have occurred, and in particular for those with end stage dementia, it would rarely be prudent to apply an advance refusal. Why? Because the personal identity problem is invoked. Facing the problem would actually, against Lewis' view, be in line with the PGC, and would enable persons with dementia to have their wishes, values, views and beliefs assessed as part of a framework. Such a framework is imperative as, currently, no stabilisers exist to ensure careful consideration. On the whole, it is more consistent with Article 8 that a person with dementia is viewed from the above perspective and in terms of personhood, personal identity and finally, preserving their autonomous wishes where possible.

In the MCA 2005's main provisions for advance refusals, the importance of self-ascribed value and autonomy is central. Because self-awareness and consciousness are central to determining moral status, without this, dementia patients cannot be treated as being the person they were pre-dementia. Currently, dementia patients are always viewed as a derivation of their former selves in an unregulated manner, which I have coined a 'new' self. This 'new self', much like Dworkin's Margo will have new interests, and a new personal identity for the

²⁵² Lewis 2006, 234.

purpose of the argument. As it is difficult to lose identity under the PGC, declaring a person a 'new self' would require a great degree of evidence.

It is hoped that this chapter has highlighted the importance of the issues of personal identity and personhood and the lacunae existing within the MCA 2005 which do not address these matters fully. If we do not legislatively address the issue of personal identity, and we leave it up to medical practitioners and judges alone, this could be fateful. Codification is needed so the provisions purporting to elevate self-determination are only accessible by those to whom they will still apply. This will not be an easy process remembering, as adduced by Alan Fox, that:

“a person should be understood as an active process, not a thing – not even a thing that undergoes change and self-replacement during its lifetime”.²⁵³

At the forefront, the personal identity problem affects patient care, the role of the medical profession, scientific research, public policy and life and death. Not considering the problem is a breach of the obligations of the 2005 Act and a direct infringement of the UDHR requirement of treating all beings as equal in dignity and respect.

²⁵³ Fox 2007.

CHAPTER SIX: PAVING A NEW WAY FORWARD

6.1 Whose Best Interests?

The best interests test is very difficult to apply in circumstances where an advance refusal is either not enforceable or where one has not been made. Pattinson warns of the caveats when using such a test:

“If application of the best interests test does not operate according to the explicit criteria specifying what are relevant ‘goods’ or ‘interests’ (or at least how they are to be determined) and specifying the approach that is to be taken to weighing those goods where they point in different directions, the best interests tests will operate as little more than a cloak for the application of the decision makers’ contingent values... there is an unavoidable element of ethical evaluation inherent in the attempt to determine what is ‘best’ for the patient under the guise of the best interests test”.²⁵⁴

In relation to advance directives made by dementia patients it is arguably more difficult to know how best to preserve a person’s wishes, values, views and beliefs. This is especially true without the direction of clear guidelines to navigate the personal identity problem.

6.1.1 Changes to Be Made to the Current Test

Currently, in the absence of a valid and applicable advance refusal, and in the absence of capacity, a patient’s welfare is judged in line with the best interests test found in s.4 of the MCA 2005. Per s.4(6) of the MCA 2005, when judging what is in a patient’s best interests as far as ‘reasonably ascertainable’, consideration must be given to:

- (a) the person's past and present wishes and feelings;

²⁵⁴ Pattinson 2011, 166.

(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.

When assessing what is best, the person making the determination must not do so 'merely on the basis' of the 'person's age or appearance', 'or a condition or an aspect of behaviour'... 'which may lead to assumptions about what might be in his best interests.'²⁵⁵ The MCA 2005 does allow for the external consultation of the patient's close contacts to gain knowledge as background i.e. those named by the patient (e.g. LPAs), anyone engaged in caring for or interested in the patient's welfare, and any deputy.²⁵⁶ It is noteworthy that, when making a Lasting Power of Attorney for health and welfare, if a person does not tick the relevant box, even appointed attorneys cannot make decisions about life-sustaining treatment.²⁵⁷

This test does not sit well with the bold intentions of respecting autonomy – a theme resounding through the MCA 2005. The truth is that advance refusals are too readily ignored or overridden.²⁵⁸ Most people in England and Wales do not make an advance refusal; the notion of what is in the patient's best interests is therefore paramount. It is here submitted that what Fox and McHale term the 'vague rhetoric of best interests'²⁵⁹ is in need of a serious revamp; the test is only rarely relevant today as it largely serves as a repressor of autonomy and a vehicle for those applying it to make whichever decision they deem fit. The case of *Re Y*²⁶⁰ illustrates the difficulties encountered when applying the best interests test. The case was brought about by P, the sister of Y, a woman who was incapacitated physically and mentally from birth. P sought a declaration that the removal and transplantation of Y's compatible bone marrow to keep P alive was lawful. Without such a transplant, P would have no reasonable prospect of

²⁵⁵ s.4(1)(a)and(b) MCA 2005.

²⁵⁶ s4(6)(7)(a) to (d) MCA 2005.

²⁵⁷ This features on p.6 of the document. For the official template used for an LPA of health and welfare please see the Office of the Public Guardian website. The document is accessible here; https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/245571/LPA114_Health_welfare_LPA.pdf <accessed 22/12/2013>

²⁵⁸ Such as in the case of *A Local Authority v E* (2012) EWHC 1639 (COP); 2 F.C.R. 523. See 4.2 for further discussion of this case.

²⁵⁹ McHale, 1997.

²⁶⁰ *Re Y* [1997] Fam. 110.

survival. Connell, J. held, granting the declarations, that the operations and transplant were in Y's best interests as this would provide emotional, physical and social benefit to Y with 'minimal detriment'.²⁶¹ Another 'benefit' to Y was that the transplant would sustain familial ties between Y and her visiting mother and sister. Pattinson summarises this blatant misapplication of the best interests test:

"a cynic might be tempted by the view that *Re Y* did not strictly adhere to the patient's best interests at all, especially since she did not appreciate that the lady who visited her was her mother".²⁶²

There are three main issues which remain unresolved in the use of the best interests test as it is. First of all, the definition of 'best interests' has never been laid down specifically. This is inadequately justified 'because so many different types of decisions and actions are covered by the Act, and so many different people and circumstances are affected by it'.²⁶³ The MCA 2005 is expected to go further than simply admitting to this; 'because every case ...is different, the law can't set out all the factors that will need to be taken into account in working out someone's best interests'.²⁶⁴ Recently, an application was made to the Supreme Court for an order that life-sustaining treatment be withheld in the best interests of a mentally incapacitated patient. The three five sitting justices in the case ruled that the focus had to be on whether or not it would be in the patient's best interests to administer the treatment, rather than to withhold it. This is one example of how the best interests test is moulded for use in practice.²⁶⁵

The second issue, and discussed by Tomossy and Weisstub,²⁶⁶ is that the test does not lay down any real objectives.²⁶⁷ Their argument sets out that the standards of 'best interests' generally 'fail to distinguish between what they aim to do and how their aims might be

²⁶¹ *Re Y*, 1997.

²⁶² Pattinson 2011, 165.

²⁶³ as confirmed at 5.5. in the MCA CoP.

²⁶⁴ MCA CoP Para. 5. 13.

²⁶⁵ See *Aintree University Hospitals NHS Foundation Trust v James* on appeal from: [2013] EWCA Civ 65SC; [2013] UKSC 67; 2013 WL 5730338 (per Lady Hale) esp. at 45.

²⁶⁶ Tomossy and Weisstub 1997,10-13.

²⁶⁷ *Ibid*, 10-13.

operationalised'.²⁶⁸ This 'unregulated' approach is a danger in itself as interpretation of 'best interests' depends on the decision-making judge (or medical professional) in question. Lacking any main objective, the test becomes moulded to the ways and wants of those applying it which was seen in the cases of *A Local Authority v E*²⁶⁹ and *Re M*²⁷⁰ above. It is from this view that Hope et al urge that the MCA CoP should contain deeper objectives for determination of what a person's best interests comprise.²⁷¹ Although somewhat of a protagonist of the best interests test, Mary Donnelly highlighted that an objective test which in reality contains subjective elements involves a lack of precision in practice.²⁷²

Owing to the benefit to be found in clarity, it is suggested here that the MCA 2005 would benefit from the introduction and concentration of one key objective when it comes to the best interests test (or any of the other, suggested applicable tests):

"To preserve the person's wishes, values, views and beliefs in as much as possible as they would be now could he/she communicate them, and if he/she had capacity to do so as supported by evidence".

This key objective is seen to work immediately when applied to the currently confusing demands of s.4(6) MCA 2005.²⁷³ This proposed underlying objective is more in line with the spirit of the MCA 2005, and where no advance refusal is in place, such an attitude would not allow for such misdirection of what is best for a person as if those applying the test had free rein (as they do currently) to decide what is best for a person. Hope et al²⁷⁴ detail this approach as being 'what advance decision the person might have made' when he had capacity, which is really a semi-version of the substituted judgment test (for substituted judgment, the standard

²⁶⁸ Tomossy and Weisstub,1997,12.

²⁶⁹ *A Local Authority v E* (2012); EWHC 1639 (COP); 2 F.C.R. 523 2012.

²⁷⁰ *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287.

²⁷¹ Hope et al 2009, 735.

²⁷² Donnelly 2011, 313.

²⁷³ Where there are currently three key factors set out in s.4(6)(a) to (c) of, only subsection (a) (consideration of the person's past and present wishes and feelings) provides the foundation for ascertaining the best interests of a person who lacks capacity. The others will then follow from this

²⁷⁴ *Ibid.*

would be what he would have decided if he could). Again this approach could be workable with evidence to prove it.

The third issue revolves around a major flaw which arises in 5.38 in the MCA's CoP which is that the best interests test, despite consideration of past wishes and feelings, also acts as authority to override these:

“In setting out the requirements for working out a person's ‘best interests’... Any such assessment must consider past and current wishes and feelings, beliefs and values alongside all other factors, but the final decision must be based entirely on what is in the person's best interests”.

This presentation of three main problems is not exhaustive, yet it shows that the best interests test needs some direction – as it stands currently the test is allowing others to make decisions for persons without any real attempt²⁷⁵ to preserve what they would have wanted. The subjectiveness of the test is not the problem, the lack of overarching objectives and guidance that goes with this, are. In any case, the best interests test will not always be the most appropriate mechanism for judging how best to consider the treatment of persons where an advance refusal cannot be applicable. There are times when the substituted judgment standard is appropriate for the basis of determining what is best for patients. In actual fact, the substituted judgment test is already being applied under the guise of the best interests test. This was most recently confirmed in October 2013 in the Supreme Court ruling in *Aintree University hospitals NHS Foundation Trust v James and Others* by Lady Hale:

“Insofar as Sir Alan Ward and Arden, LJ. were suggesting that the test of the patient's wishes and feelings was an objective one, what the reasonable patient would think,

²⁷⁵ It is acknowledged, as above, that the family and friends of patients who are the subject of the tests are consulted in an attempt to gain insight into what they would have wanted and this is echoed in s4(6)(a) to (c). More guidance needs to be given around the objectives of the best interests test, and how to achieve these.

again I respectfully disagree. The purpose of the best interests test is to consider matters from the patient's point of view.”²⁷⁶

In this chapter, it is argued that a new system is to be applied for gauging what is best for adults who lack capacity in healthcare decisions. It is sought that an effective standard must be defined which principally preserves the individual incapacitated person’s values, wishes, views and beliefs.

6.2 Using the Substituted Judgment Standard With Caution: *Strunk v Strunk*²⁷⁷

The substituted judgment standard relies on the assessment, made by an external decision maker, as to what decision an incompetent patient would make if they were competent at that time (and based upon past displays of competence). If the patient has never been competent as in the case of *Re Y*,²⁷⁸ then this approach may not be taken. This test is to be carried out with as much accuracy as possible in determining what a person would decide for themselves, if they could. The test is complex and amounts to a resurrection of the person’s wishes and beliefs at the last documented point and to the application of this in the here and now. As first articulated almost 200 years ago in the case of *Re Hinde; Ex parte Whitbread*.²⁷⁹

“the court will act with reference to the lunatic, and for his benefit, as it is probable that the lunatic himself would have acted had he been of sound mind”.²⁸⁰

This section therefore is dedicated to showing that the efficiency of using substituted judgment has attracted a wide spectrum of opinion. Dubbed a ‘legal fiction’ by Caroline Somers,²⁸¹ if used incorrectly, the test can produce unwilling results as attaining a level of substituted judgment relies on gathering information about a person from various sources. In the event of lacking

²⁷⁶See *Aintree University Hospitals NHS Foundation Trust v James* on appeal from: [2013] EWCA Civ 655; [2013] UKSC 67; 2013 WL 5730338 (per Lady Hale) esp. at 45.

²⁷⁷ *Strunk v Strunk* (1969)

²⁷⁸ *Re Y*, 1997.

²⁷⁹ *Re Hinde; Ex parte Whitbread* (1816) 2 Meriv 99; 35 ER 878

²⁸⁰ *Ibid.*

²⁸¹ Quoted in Donnelly 2011, 313.

associated persons, the evidence pointing towards a person's values, views and beliefs, as they would be now, is difficult to understand. Whilst a Gewirthian would advocate using the substituted judgment standard where possible, caution should always be taken and evidence should always be gathered to attempt achievement of what the person would have wanted now if he had capacity to communicate this. Such evidence could include material (not exhaustively) from any form of diarised thoughts even those found online i.e. from video blogs, Facebook and Twitter accounts, and the like. Widening the sources of evidence allowed could facilitate further exploration of religious, spiritual or other values and beliefs, views on politics, the World, life, death and all other matters in between. Even still, using such sources may be impugnable as updates can be conceived as being a social bravado, and may not be relied on as such. Hope, Slowther and Eccles expand upon this point; their scepticism of the efficacy of the substituted judgment standard due to wishes, values, views and beliefs being 'fatally underspecified'.²⁸² One of their contentions is that in a Margo-type scenario, applying the substituted judgment standard would be impossible. To illustrate this point, they speak of former vegetarians who, as a result of having Alzheimer's, become carnivorous. They ask whether or not those caring for them should prevent this. Such a question is very simply answered by referring to said patient after going *back* to the original assessment to be made about personhood and personal identity. If the new carnivore is an ostensible agent, and the personal identity problem arises, then the substituted judgment standard cannot be applied, so the best interests test would apply (and vice versa).

In the UK, the substituted judgment standard is not used and was most recently rejected in the case of *Bland*.²⁸³ In *Strunk v Strunk*,²⁸⁴ Judge Osborne opened proceedings as follows:

"The specific question involved upon this appeal is: Does a court of equity have the power to permit a kidney to be removed from an incompetent ward of the state upon petition of his committee, who is also his mother, for the purpose of being transplanted

²⁸² Hope and Slowther 2009.

²⁸³ *Airedale NHS Trust v Bland*. [1993] A.C. 789.

²⁸⁴ *Strunk v Strunk* (1969).

into the body of his brother, who is dying of a fatal kidney disease? We are of the opinion it does".²⁸⁵

The case concerned an obscure application of the test and involved two brothers – Tommy, 28 and Jerry, 27. Due to contraction of a fatal kidney disease, Tommy required a transplant. His younger brother Jerry deemed ‘incompetent’, and ‘handicapped’, was not considered to have the legal capacity to consent to being the donor for his brother’s transplant, but he was assessed as being a suitable match for this. In using the substituted judgment standard, the case was put forward on Appeal that Jerry’s welfare revolved around the existence of his brother (a reminder of judgment in the later case of *Re Y*²⁸⁶) and that his love and dependence as such meant that he would have consented to the removal of his own kidney to this end, if he could have. This was weighed against the dissenting judges of the case. Steinfeld, J. dissenting, likened the process (of removal with substituted consent) on these grounds as being on the same debauched level as genocide and experimentation:

“My sympathies and emotions are torn between a compassion to aid an ailing young man and a duty to fully protect unfortunate members of society ... I am unwilling to hold that the gates should be open to permit the removal of an organ from an incompetent for transplant, at least until such time as it is conclusively demonstrated that it will be of significant benefit to the incompetent”.²⁸⁷

The ‘benefit’ to Jerry is very difficult to reconcile. The use of the substituted judgment test in *Strunk*²⁸⁸ was in fact a misapplication of the overall interests test. This is based on the simple premise; how can it be deduced that a person would think and feel something now if he has

²⁸⁵ *Strunk v Strunk* (1969) at para 1.

²⁸⁶ *Re Y*, 1997.

²⁸⁷ *Ibid* per Judge Steinfeld.

²⁸⁸ *Strunk v Strunk* (1969).

neither thought nor felt it previously? The standard of substituted judgment has been further extended since *Strunk* to include parental substituted judgment where the patient is a minor.²⁸⁹

As argued by Berghmans,²⁹⁰ the substituted judgment standard could never be applied to those with severe dementia due to the problem of conflicting interests between the person who was, and is now. Whilst this may be true in the later stages of dementia (i.e. L3-L4), until the personal identity problem applies, this would be a view inconsistent with the PGC as autonomy, and the purposes we pursue as ostensible agents, ought to be at the forefront of any proxy decision-making, and the best way to do this (where possible and where there is evidence) is through imagining what this person would have wanted now if they could make that decision. This should always be the case until the personal identity problem becomes a problem. Also guided by the PGC, there are other considerations to be made where competing interests overlap between persons which I will now discuss as an option where this is the (usually rare) case.

6.3 The Overall Interests Test²⁹¹

Developed by Shaun Pattinson,²⁹² the overall interests test requires a direct assessment of what is best for all of the main involved parties considering the interests of others. As set out by Pattinson, the overall interests test involves three main ways that one person's interests may be overridden by another's, (as warned by Pattinson, this test is not a Utilitarian model).²⁹³ First, the interests in question could be less worthy of protection, second, the participant could be worthy of lower protection and thirdly, the aggregated interests of others could outweigh the interests of the person in question. This test is a helpful aid when the conflicting rights of ostensible agents are to be accounted for, which is limited to applying only in certain

²⁸⁹ See *Stump v. Sparkman*, (1978) (435 U.S. 349) Which saw a petition to sterilise an incompetent fifteen year old deemed 'retarded' which was approved without notice, without a formal judicial hearing, and without a guardian ad litem, using solely her mother's substituted judgment.

²⁹⁰ Berghmans, 1993.

²⁹¹ Invented by Pattinson 2011, 399.

²⁹² *Ibid.*

²⁹³ *Ibid.*

circumstances. Such circumstances would be assessed on their own merit and an assessment would need to be made based upon the interference of rights relying on the 'needs' set out at 1.5.1 i.e. the 'additive', 'non-subtractive' and 'basic' needs of persons. Putting this into practice if we imagined a millionaire (without an appointed LPA) who is in a PVS where no prior wishes had been expressed and no advance refusal pertaining to this situation. The same millionaire has made out a will leaving his whole estate to his four motherless children: the children are left penniless during this time, leading to misery, starvation, illness and homelessness. The millionaire can never recover from his current state. From the PGC's perspective, and applying the overall interests test, a careful balancing act must be executed where the rights of parties conflict. Here, the balancing is tipped in favour of preservation of the children's rights and needs as the 'personhood' factor is not present for those in a PVS. However this is only accepted remembering that those in a PVS under the PGC need to be given ANH, but that such positive interference with the GR need not continue indefinitely (where inhumane or futile). This thought would be weighed to an extent against the needs of his family. Where the same category of 'needs' and correlating rights conflict an assessment would need to be made based upon the situation itself.

Practically, the overall interests test is based upon what course of action is deemed to be in a person's interests 'all circumstances (including acting in the best interests of others) involved'. A vital reference to the overall interests test is made out in the MCA CoP where a decision made in best interests 'might include the effect of the decision on other people, obligations to dependants or the duties of a responsible citizen' (at 5.47). The MCA CoP also allows for actions which benefit other people, as an example, allowing for extension of the best interests test to enforce the giving of blood samples from an incapacitated person, to test for genetic links to cancer in a family (to benefit another family member, at 5.48). It is yet to be seen how far this principle would stretch. So where the MCA CoP stresses here that 'best interests goes beyond the person's medical interests', again, guidance must be given as to the limit and extent of this ad hoc licence to use what is tantamount to Pattinson's overall interests test. The test in and of itself is in keeping with the PGC's requirement that all agents (pursuant

to the UDHR) are to be treated with equal dignity and rights, as where rights conflict, this must be accounted for – but leaving this open could lead to Utilitarian abuse ringing true of the outcome in *Re Y*.²⁹⁴

6.4 Updating the MCA 2005: A New Model of Deciding What is Best

It is hoped that this chapter has demonstrated the benefits of a new model, based upon the PGC as an ethical foundation, for judging what is best for persons who cannot decide, or have not decided, this for themselves. The best interests test alone is not always adequate in achieving this. My suggestions for a new model for assessing what is best will now be laid down. I have also provided for how best to treat advance refusals when ambiguity is involved about their validity and applicability in what I call the ‘First Assessment’ which I start with as a reference point:

- 1) The First Assessment: this stage includes an assessment firstly of the moral status of a person (personhood). When person is classed as an ostensible agent, but cannot be viewed as having legal capacity, the second assessment applies;
- 2) The Second Assessment: does the person have task-specific competence? If they do, this must be taken into consideration to ensure the right to autonomy is elevated;
- 3) The Third Assessment: this is an assessment to always be carried out unless the first assessment proves that the subject is not an ostensible agent. This stage requires viewing whether or not the personal identity problem is a problem. If it is not a problem, any former wishes, values, views and beliefs of the former person should be applied, and the substituted judgment test should be the default position. The type of situation where this is appropriate would be in the circumstances outlined in *Re M*²⁹⁵ above at 4.2. If the personal identity problem is a problem;
- 4) The Fourth Assessment applies if it is beyond all reasonable doubt that a person is no longer the same person, with radically different characteristics and a severe

²⁹⁴ *Re Y*, 1997.

²⁹⁵ *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287.

personality change. Under these conditions, the best interests test would apply. The caveat always with employing the best interests test is that we could not know what a person's memories were, thus we could never be certain of the radical change assumed (hence the use of 'beyond all reasonable doubt' as certainty is impossible); and,

- 5) The Fifth Assessment: a consideration of the rights of others by way of the 'overall interests test' is always to be considered when rights of persons (in the same 'needs' categories) conflict, remembering the universalisability stage in the PGC.

CHAPTER 7: CONCLUSIONS

The application of the main provisions of the MCA 2005 should reflect the spirit of the advance refusals sections and the best interests test. These provisions without doubt were nobly created at a time when they were needed, to enable the regulation of respect for an incapacitated person's general wishes, values, views and beliefs. Unfortunately, lacking objectives and theoretical applicability have rendered the conferred rights virtually unused and unusable.

Whilst this thesis has argued for change, it is accepted that most people do not make an advance refusal of any kind, let alone advance refusals of life-sustaining treatment. Various reasons are given for this; the most compelling is probably that people do not want to think about the worst, the inevitable, death.²⁹⁶

However, many people do have strong feelings about what they want to happen to them when they can no longer decide for themselves. As a trainee solicitor, I have noticed that the demand for the creation of LPAs for health and welfare is often driven by the donor's (creator's) desire to include their feelings about how events will play out regarding their end of life care. Most people describe conferring power on others regarding life-sustaining treatment as being much more satisfying than making a refusal themselves. This is generally felt on the basis that the attorney will be in a position to know more about modern medicine, treatment, and about what may be best, when the donor is unable to know these things. Such power is conferred to attorneys by way of the 'tick the box' exercise offered in this type of LPA²⁹⁷ which allows or disallows appointed attorneys to either make decisions about life-sustaining

²⁹⁶ BBC, available at <http://www.bbc.co.uk/ethics/euthanasia/overview/livingwills.shtml> <accessed 11/11/2013>

²⁹⁷ There is also another kind of LPA, for financial matters.

treatment or not. The LPA also allows for the donor to create 'wishes' regarding various issues (these wishes are not formally enforceable). These wishes could include donation of the body to science, through to who is allowed to be present at the donor's hospital bed. There are disadvantages of an LPA of this kind, mostly due to the non-enforceability of wishes included, and also because any advance decision made by the donor (on the same subject) can be overruled by the appointed attorneys through the LPA. This can be problematic if the attorney's decision greatly conflicts with a person's identity and former wishes, values, views and beliefs.²⁹⁸ The alternative of course is making an advance refusal in line with the MCA 2005; such a decision could prove more capable of ensuring the autonomous decisions of a person who once had capacity (after it is lost). Use of the LPA for health and welfare indicates that people are willing to think about the unthinkable, and to exercise autonomy in the face of its loss. Yet, the process for creating advance refusals can be onerous, confusing, and, after enduring and meeting all legislative requirements, they can be ignored or overridden all too easily. Building on this, even with legislative change, the main provisions for creation of advance refusals have a long way to go before they reach widespread implementation, if ever. Ways to address this deficit may be found in an online registration, general advertising, advice lines, GP driven schemes, registration cards and so on. The approach in California is highly accessible and user-friendly. The Californian Advance Health Care Directive (herein 'CAHCD') is a clear-cut, easy-to-use, easy-to-execute document that enables a person to make an array of decisions about current and future treatment including organ donation, consent to autopsy, and refusal of life-sustaining treatment. The CAHCD combines what we know to be an LPA of health and welfare with an advance refusal of any kind. An amalgamated document of this type would further empower donors, adding substance to the LPA we already have in England and Wales.

To date, thankfully, there has been little opportunity for the MCA 2005 to encounter many of the difficulties discussed in this thesis. Nevertheless, it is only a matter of time before lacking substance in the legislation results in yet more issues. Stark reminders of problems

²⁹⁸ Sulmasy, D, et al 1998, 621-629.

already encountered were shown in the haunting tales of patients alike M²⁹⁹ and E³⁰⁰ who were wrongfully treated in line with conferred ‘best interests’, and not forgetting *The X Primary Care Trust v XB*³⁰¹ case where a man’s family had to fight for the preservation of his wishes due to a small error in the way an advance refusal was executed.³⁰² The current state of the law on advance refusal needs to undergo change to evolve with the times. The main issues revolve around the lack of cohesion between the aims of the MCA 2005 which claim to offer extensive autonomy to persons beyond the here and now, and the actuality of the provisions which are curbed by the application of Article 2’s right to life. As discussed, there are a multitude of other problems with definition, interpretation and implementation – generally speaking many of the issues presented at common law preceding the act still exist today.

This thesis has sought to draw attention to the fact that there are elements of the MCA 2005 that do not address the distinct ethical challenges presented. Once these practical, social and ethical issues are addressed, the 2005 Act, if modified, could present itself as being an opportunity for people to reserve autonomy, to reserve the wishes, values, views and beliefs of persons as was first hoped by its introduction.

An Act granting rights must also grant access to them, otherwise such rights are inadmissible. Any right conferred under any piece of legislation in England and Wales must be compliant with human rights and with the UDHR. Such access, therefore, must also coincide with the PGC due to synonymy (the dialectically contingent argument at 1.5.2). At the core of the PGC therein lies agency, and agency’s core is autonomy. Ignoring the notion of personhood is leading to inefficiency of the MCA 2005 as without addressing this key matter, the main provisions in relation to advance refusals, can never be meaningful. The danger of this has been shown in practice as even with the introduction of the Act and the concomitant Court of Protection, legislative regulation is still translated in a minefield of jumbled judicial decision.³⁰³

²⁹⁹ *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287.

³⁰⁰ *A Local Authority v E*; EWHC 1639 (COP); 2 F.C.R. 523, 2012.

³⁰¹ *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam).

³⁰² *The X Primary Care Trust v XB* [2012] EWHC 1390 (Fam).

³⁰³ Most recently (and notably) shown in cases such as *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287.

Using the PGC would have a bearing on the consistency of how the MCA is applied in practice. It is hoped that this thesis has demonstrated the benefits of employing a succinct mechanism for determining the moral status of a being. Without determining the moral status of a person, one cannot determine how best to attribute rights; the rights grantable to a person in a PVS differ greatly to the rights grantable to those who have full capacity and consciousness.

Once moral status is determined, the problem of personal identity (where it is a problem) must be addressed. Using Pattinson's model for task-specific competence means that autonomy is preserved in as far as possible, which the legal test for capacity does not allow for. Autonomy cannot be respected if it is not applicable – dementia, in many forms, invokes the personal identity problem. Whilst the PGC would not agree with the presupposition that persons change with every moment per Parfit, it is accepting that people can, and do, change. Regardless of the contributors, if a person's personality severely changes, the PGC would not encourage that they are treated as the same person, this would apply with or without an advance refusal. Whilst Dworkin advocated that any decision be made after consideration of the subject's 'critical' and 'experiential' interests, as argued, these interests are somewhat irrelevant and leave the floodgates ajar for decision-making as any assessment would need to be made on the basis of the needs hierarchy outlined in the PGC. The personal identity problem needs to be accounted for in the MCA 2005, if it is not, the act will have a reverse effect to that which was hoped and anticipated.

As I have argued in chapter five, the current 'catch-all' best interests test is unworthy of acclamation in the modern day, and has passed its sell-by date. In a modern age, people are demanding more respect for what they want, regardless of what judges, medical professionals, friends and other close links want them to want as shown in discussion of outcomes in the cases of *A Local Authority v E*³⁰⁴ and *Re M*.³⁰⁵ This thesis maintains that the starting point in assessing whether or not an advance decision applies (differing from validity and applicability) should be 'does this person matter?'. This is for the reasons set out in chapter three, and is to be the building block for thought on whether or not an advance decision can apply. To ensure

³⁰⁴ *A Local Authority v E*; EWHC 1639 (COP); 2 F.C.R. 523, 2012.

³⁰⁵ *Re M* [2011] EWHC 1197 (Fam); 1 W.L.R. 287.

compliance with the PGC, and with human rights in general, such as upholding the rights to dignity, equality and autonomy, a new attitude must be taken towards advance decision-making. With a more general application of the framework set out at 5.5, the suggested process for determining whether an advance refusal does or does not apply is as follows:

- 1) 'does this person matter?';
- 2) if the answer is 'no' then the person is not considered an ostensible agent under the PGC. If it is yes, we look to the next question;
- 3) 'is the personal identity problem present?' If the answer is no and the person does not have legal capacity but has a level of task-specific competence to that effect, an advance refusal should still be applicable based upon substituted judgment; but
- 4) if the answer to 3) is yes, then the best interests test is applicable (based upon his former wishes, values, views and beliefs);
- 5) The overall interests test would always apply, if rights were conflicting.

Ultimately, this thesis has tried to show that the advance refusals provisions, and the best interests test, amount colloquially, to being the 2005 Act's Achilles' heel. Critics' concerns regarding the enactment as simply embedding the mistakes of common law have undeniably materialised.³⁰⁶ It is not news that legislative change is needed, indeed many more concerns have since arisen over the past eight years.³⁰⁷ Whilst the spirit of the Act may be supported in a new and updated version of the MCA CoP, this is not binding on those making decisions, be it in court or in hospitals. Because supporting provisions are not strong enough to knit the Act together, a new Mental Capacity Act is needed. The improved Act could do everything the MCA 2005 set out to do, but in a more realistic fashion. A PGC-friendly version of the 2005 Act, that is inclusive of key ethical considerations of personhood, personal identity issues, preserving autonomy in real terms, and preserving the wishes, values, views and beliefs of persons, could stand a fighting chance of achieving what it sets out to do.

³⁰⁶ See Michalowski 2005, 958- 959.

³⁰⁷ At the time of writing; royal assent occurred 7 April 2005.

Without some degree of change in legislation and judicial decision it is argued that the main provisions for advance refusals may not gain the momentum needed to make a difference in practice, and advance refusals may become redundant. Generally speaking, the law in this area here in England and Wales is still producing volatile and unpredictable results.³⁰⁸

The question then follows, why do we have the provisions at all if we cannot inject the requisite considerations into legislation to make them ethically and practically viable? Unless the MCA 2005 is rethought in light of prominent ethical, legal and social considerations, the constraints on paper will continue to suppress the important underlying values promulgating individual autonomy. In 2004, Americans Fagerlin and Schneider gave up hope, declaring the failure of the living will and the exposition 'It is time to say, 'enough''.³⁰⁹ Whilst it is time to say 'enough' to the inertia which stultifies any improvement; for those of us wishing to avoid the Sirens, this is an area of law which we cannot disregard.

³⁰⁸ *Ibid* ; [2012] EWHC 1639 (COP) at 129

³⁰⁹ Fagerlin & Schneider 2004.

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