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Entering the Fog: On the Borderlines of Mental Capacity

JONATHAN HERRING*

INTRODUCTION

Professor George P. Smith II, in whose name this lecture is held, has a world-wide reputation as a scholar of medical law and ethics. His work manages, unusually, to combine the qualities of being vast in quantity and rich in quality. His abilities as a scholar are fortunately matched by his compassion as a person. One area of his work that is of particular interest to me relates to the law and older people. He brings a keen mind, a sensitivity to the issues raised, and an outrage at mistreatment of older people that combine to produce a powerful contribution to the literature on elder law. His writings on the issues of older people and autonomy especially drew me to the topic of this lecture.

This article considers issues of legal competency raised by individuals who possess borderline mental capacity. This involves thinking about two categories of individuals: (1) those assessed as possessing capacity, but only just; and (2) those assessed as lacking capacity, but only just. Finding a patient of uncertain competence is common. Practitioners report that even the most seasoned experts in the field can struggle to determine a person’s decision-making ability. As Professor Gunn has pointed out, capacity and incapacity are not “concepts with clear a priori boundaries. They appear on a continuum . . . . There are, therefore, degrees of capacity.”

These issues are particularly significant for patients suffering from Alzheimer’s Disease or other forms of dementia. It would, of course, be quite wrong to suggest tat

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3. Especially Smith, Ethics supra note 1.

4. In this article, the terms “competence” and “capacity” are used interchangeably. Some lawyers suggest that the two terms have different meanings in that competence/incompetence is a legal standard, while capacity/incapacity refer to facts about a patient’s abilities, although there is no consistency in this usage. See Philip Bielby, The Conflation of Competence and Capacity in English Medical Law: A Philosophical Critique, 8 MED., HEALTHCARE & PHIL. 357 (2005).

5. The term “mild cognitive impairment” is sometimes used to describe those who possess borderline mental capacity, although its use is controversial. Jullian C. Hughes, The Heat of Mild Cognitive Impairment 13 PHIL., PSYCHIATRY, & PSYCHOL. 1 (2006).


8. For a non-technical discussion of the impact of Alzheimer’s Disease, see John Bayley,
a diagnosis of dementia means that a patient automatically lacks capacity.\(^9\) It is perfectly possible, for example, to suffer from Alzheimer’s Disease and yet retain full capacity.\(^10\) However, the loss of cognitive faculties, difficulties with memory, communication problems and depression associated with Alzheimer’s may contribute to a gradual loss of capacity.\(^11\) For many Alzheimer’s sufferers, there will be a period of time when their degree of competence is unknown.

**Basic Legal Principles**

The central legal issues in this area are similar in both American and English law. Both legal traditions draw a clear and strong line is drawn between the law governing those who have capacity and those who do not. Indeed, textbooks on medical law often contain separate chapters on each.\(^12\)

For those who possess legal capacity, the cardinal principle is the right of self-determination or autonomy.\(^13\) Subject to the constraints of the law, people remain generally free to live their lives as they wish. The government may not prevent us from acting as we choose nor compel us to act against our will. It is not for the state to tell us we would be better off reading poetry or train timetables instead of law reports. This view sounds in the right to bodily integrity—the right for our bodies not to be touched or interfered with without our consent.\(^14\) Unfortunately, the English judiciary does not quote its American counterpart with appropriate frequency. However, Judge Cardozo’s famous quotation about bodily integrity has entered the U.K. legal canon\(^15\):

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Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent, commits an assault... 16

English judges have emphasized that the right not to be treated against your will may be exercised even if the reasons for the decision are "rational, irrational, unknown or even non-existent." 17 The right exists even if the decision will lead to death. 18

For those who lack mental capacity, the guiding principles are very different. Their consent is not required before medical treatment is administered. Instead others make decisions on behalf of persons who lack mental capacity based on what is perceived to be in their best interests. 19 The parens patriae jurisdiction in Anglo-American jurisprudence protects those who lack mental capacity from harming themselves. 20

The question whether a person possesses mental capacity is therefore "critical." 21 Consider the English decision In re C (Adult: Refusal of Treatment), 22 C was a patient at a secure hospital. Doctors diagnosed C with paranoid schizophrenia and found he had a number of delusional beliefs, including a belief that he was a great doctor who had a 100 percent record of restoring injured limbs. Ironically, C suffered an injury to his foot that developed gangrene. His doctors informed him there was an eighty-five percent chance he would die if the foot were not amputated. C disagreed; believing that God would heal him of any medical problems. The court found C to be competent and to possess mental capacity. The court reasoned that C understood the doctors' prognosis, but that he disagreed with them. His disagreement did not render him incompetent. C was able to comprehend and retain the information that his doctors told him, and to reach a decision based on that information. The fact that many would find his decision bizarre or irrational does not mean that he should have been judged incompetent. As an adult possessing mental capacity, C had the right to refuse treatment and the doctors were therefore forbidden by the court from amputating his gangrenous foot. Had C been deemed incompetent, no doubt the court would have judged the amputation operation to be in C's best interest. 23

This case had a happy ending. Predictably, perhaps, C's foot made a surprising recovery. Whether this was due to C's great medical skill or divine intervention we may never know!

19. Although quite what "best interests" mean in this context is hotly debated.
22. [1994] 1 W.L.R. 290 (Fam.) (Eng.).
23. In re W (Adult: Refusal of Medical Treatment), [2000] EWHC 901(Fam.) (Eng.), a prisoner was found to have capacity to refuse treatment even though he was convinced there was a conspiracy against him.
On the Edges of the Two Categories

The law draws a sharp line between those who are competent and those who are not. Fall on the side of competence and your right to autonomy requires that your decisions be respected. Fall on the side of incapacity and the decision is made on your behalf by others. This creates difficulties for those on the borderline of mental competence. Imagine a person in the early stages of dementia. Let’s call him Albert. Albert’s character has already started to change. Prior to the onset of his condition he opposed the drinking of alcohol with vehemence and promoted and practiced a most conservative sexual ethic. With the onset of his illness, however, he has suddenly taken to getting drunk and visiting prostitutes. Both of these activities are expensive; before the onset of his condition he was most prudent in his expenses. His wife and other relatives are concerned for his well-being. Albert’s doctors accept that his case is not a straightforward one, but they are persuaded that he just about had capacity to make decisions about his lifestyle.

The legal principles that apply to Albert are those that apply to anyone who has mental capacity. Albert may freely engage in activities of his choice, however harmful these activities may be, and however irrational his decisions may seem in light of the way he lived his life prior to the onset of dementia. Many find such a case troubling. Should Albert be left alone while he loses capacity and engages in activities that may cause himself and his family serious harm and that appear to go against the values he held dear? Does Albert’s right to autonomy mean that there should be no legal means to prevent him acting in this way?

Imagine a different kind of case. Martha suffers from a more developed dementia than Albert. She retains no memory of her life, and cannot recall her family, although they visit her regularly. Martha’s doctors assess her generally to lack capacity, although it is a close call. Throughout her life Martha was a vehement atheist, but recently she makes her way to the chapel at the retirement home where she lives and attends Mass. It is unclear how much Martha understands about what is going on at the chapel, but she seems to receive pleasure by going there. Her shocked relatives have asked the staff to ensure that Martha is prevented from going to chapel. They are sure she would never have wanted to be involved in religious activity. When the staff stop Martha from going to the chapel, she becomes distressed and agitated. Since Martha’s doctors judged her to lack capacity, the law states that the decision whether to allow her to attend Mass is made based on what is in Martha’s best interest, taking into account the values she held prior to the onset of dementia. This could mean that Martha would be prevented from attending Mass. Is this a correct approach or should Martha’s current views, however incompetent, be taken into account?

Before addressing such questions in more detail, the following section makes a few points about how cases like Albert’s and Martha’s are handled in “real life.”

24. Of course, the best interest test may not reach this conclusion but instead decide that it would promote her welfare to attend the services.
Although the issues raised by the cases examined above are of great practical importance, they rarely enter the courts. Finding the exact balance between respecting autonomy and protecting the best interests of those of doubtful capacity presents a daily problem for practitioners and caretakers. However, they generally "bumble through." Unsurprisingly, relying on lawyers for solutions is not regarded as being particularly helpful. In part, this may be because the relevant legal principles do not seem appropriate for the day-to-day issues that arise.

In the real world, despite the legal niceties, caretakers who make decisions on behalf of people lacking capacity often do allow them to do what they want to do, even if that may not be in their best interests. For a caretaker to constantly protect an incompetent person from harming themselves would be an intolerable burden, impractical, and humiliating for the patient. To force caretakers to constantly promote the best interests of each patient in every decision may be an unrealistic standard for the law to set. Further, even if a person is assessed as just having capacity, caretakers and professionals do intervene to prevent them from committing acts that would cause them serious harm. Empirical evidence indicates that medical professionals regularly rely on the consent of non-competent people.

As long as the patient is compliant there is no need for caretakers to question the patient's competence. As one leading medical law textbook states, "typically, competence is questioned only when a patient refuses to consent to a recommended treatment or chooses a course different from the one the doctor finds most reasonable." In Lane v. Candura, a woman required treatment for gangrene in her leg. Initially, she consented to treatment and preparations were made for the surgery. She then changed her mind and refused to consent. Only then were concerns about her capacity raised and legal intervention sought. As this case shows, if the patient appears to be compliant issues of competency may be overlooked.

31. One explanation for the use of a higher test in practice is that where the decision appears bizarre it is more likely the decision will be challenged in court and therefore the medical practitioner will want to do be doubly sure that the finding of capacity is beyond question. See Alec Buchanan, Mental Capacity, Legal Competence and Consent to Treatment, 97 J. ROYAL SOC'Y OF MED. 415 (2004).
This article aims to set legal standards that better reflect what actually happens in practice, and provide more realistic, and therefore effective, guidance for practitioners and caretakers.

The Test for Capacity

The search for a single test for legal competency has been said to be like the search for the Holy Grail. In the United States, the assessment of legal competency is seen as largely one for physicians, rather than lawyers. In England, the assessment is seen as a matter of law, although judges normally rely heavily upon the evidence of experts. Nevertheless common principles emerge among the definitions of competence:

1. A presumption exists in favor of a person having capacity.

2. Competence means one possesses an ability to understand one's current medical condition, the possible treatments, the risks associated with those treatments, and their consequences.

3. One must possess the ability to use relevant information in a rational way to reach a decision.

4. One must be able to communicate one's decision.


36. For the U.K. law, see Mental Capacity Act 2005, c. 9, s. 1(2). For the U.S. law, see Winick, supra note 17, at 21–27.

37. N.H. REV. STAT. ANN. §§ 137-J:2 (V) (2005) (“Capacity to make health care decisions means the ability to understand and appreciate generally the nature and consequences of a health care, including the significant benefits and harms of and reasonable alternatives to any proposed health care.”).

38. S.C. CODE ANN. §§ 44-66-20(6) (2005) (“‘Unable to consent’ means unable to appreciate the nature and implications of the patient’s condition and proposed health care, to make a reasoned decision concerning the proposed health care, or to communicate that decision in an unambiguous manner.”).

39. Mental Capacity Act 2005, c. 9, s. 3(1) (Eng.); see also MO. REV. STAT. § 404.805.1(2)
As these principles indicate, a person may be found to possess mental capacity to make some decisions, but not others. A person may, for example, have the requisite mental capacity to decide to prefer strawberry ice cream to chocolate ice cream, but lack the requisite capacity to execute a will.

Both legal systems emphasize that the determination of legal competence should not rest on the wisdom of the person's decision. Even sane people make foolish decisions. The English Mental Capacity Act of 2005 makes this explicit: "A person is not to be treated as unable to make a decision merely because he makes an unwise decision". Of course, as the word "merely" in the statute indicates, the fact that a decision is widely regarded as bizarre may indicate that a patient is incompetent, but further evidence is required. Despite the court's insistence that it does not do this, academics on both sides of the Atlantic have accused their respective judiciaries of finding a patient incompetent simply because the judges disagreed with the decision that the patient had made.

It should be emphasized that the definition of incapacity and its use is not uncontroversial. Women and ethnic minorities remain particularly vulnerable to assessments that they lack mental capacity. It has been argued that while notions of competence purport to be neutral, these notions in fact reflect majority interests and values. Assessments of capacity may hide the subjective values of physicians, especially when an emotional end-of-life issue is involved.

**Outlining the Approach of This Article**

Having set the scene and covered some introductory material, I will now outline this article. First, in section one of this article, I will consider people deemed just competent. I will make a strong case for not following the wishes of those who are just competent, where what they want to do will cause them serious harm or go against values they have held dear during their life. In section two, I will discuss how the law should treat the opinions of those who are found to lack capacity. I will argue that the best interests test fails to place adequate weight on their views. In section three, I will discuss advance directives and their role in dealings with the incompetent. In section four, I will make some points in the broader context of the legal treatment of those suffering from dementia.

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41. Mental Capacity Act 2005, s. 1(3) (England).


I. THOSE DeEMED JUST COMPETENT

There are two main kinds of cases in which families and professionals may raise concerns about the behaviour of a person found just competent. The hypothetical case of Albert, discussed previously, highlights both of these cases. The first kind of case involves a person that wishes to embark on a course of action which will cause the person significant harm. The second kind of situation involves a person who seeks to engage in uncharacteristic behaviour that would be contrary to the values upon which the person’s former life was built.

As discussed previously, the standard legal approach provides that once a person is judged to possess the requisite mental capacity, that person must be treated with as much respect as any competent person and, therefore, that person’s decisions must be respected. A competent person is free to engage in harmful activities if he or she wishes. Indeed, nearly everyone chooses to engage in activities which are harmful. We all have our vices! Furthermore, competent adults are free to change their minds about issues and take up new hobbies and interests, even if previously they would not have espoused them. I am sure we are all relieved we are not stuck with the views and interests of our late teens. However, I will argue that the standard legal approach to determining mental capacity is insufficiently subtle to effectively deal with these issues.

When a person chooses to engage in an activity that carries a significant risk of harm, or when a person repudiates a long-held belief, that person’s original assessment of competence should be re-examined. This is not a controversial position. I argue, however, that even if the reassessment leads to a conclusion of competency, the person’s views should not necessarily be followed because of the principle of autonomy.

A. Autonomy and Harmful Decisions

First, I consider cases where the just competent person wants to make a decision that is going to cause that person serious harm. Must the decision be respected once it is determined that they are indeed competent? Some commentators argue that it should not be respected, relying on the notion of “risk-relative capacity”. I will discuss this notion, although I will suggest it is not a completely convincing approach.

The “risk-relative capacity” approach requires a higher standard of competency where an act poses a serious risk of great harm than is the required where the decision involves less harm. Professors Strang, Molloy, and Harrison suggest that when considering harm in this context, practitioners may take into account “the degree of risk to the person, the risks to others, and the indirect consequences to society.” They


argue that a sliding scale of capacity exists that depends on the risk of harm associated with a decision. The higher the risk of harm, the higher the bar of competence is set.

Before examining this argument, a point of clarification should be made. As mentioned at the start of this article, a person may be found to be competent for some purposes but not for others. For example, a person of limited capacity may be able to make simple decisions, but not difficult ones. Of course, many decisions that could cause serious harm involve consideration of difficult issues. It is uncontroversial to claim that a person of restricted capacity may not have capacity to make a decision because it is complex. Supporters of risk-relative capacity argue that if two decisions are equally complex but one involves a highly risky activity and the other does not, a different level of competency should be set for each decision.

There are several difficulties associated with "risk-relative capacity". First, whether a patient is deemed competent to make a particular decision may depend upon the decision they reach. Imagine that a patient is offered a life-saving treatment. If the refusal to consent may cause the patient serious harm, the risk-relative capacity approach requires a stringent test for capacity. If however, the patient consents to the treatment, then the risk of harm is significantly reduced and, therefore, the test for capacity is easier to satisfy. A person of borderline capacity may, therefore, have the capacity to consent to a particular treatment, but not to refuse it. Objectors counter that it is illogical to find that a person has capacity to make a decision if they say "yes"; but not if they say "no."

Second, the risk relative capacity approach involves a conflation of two issues: (1) whether a person has capacity to make a decision, and (2) whether or not a person's decision may ever be overruled on paternalistic grounds. Varying the test for capacity because we do not like (or might not like) the answer given by the patient disguises the real issue, some argue. If the real reason why we wish not to respect a person's decision is that we do not agree with it, then we should be open about doing this. Describing the issue as one concerning capacity, is misleading. Further, this position sits unhappily with the view that a person's decision is worthy of respect even if it is considered unwise by others. As Nancy Knauer has argued, "risk-relative capacity has the potential to become the ultimate self-fulfilling doctrine: those who

52. Wilks, supra note 51. Contra Cale, supra note 50.
exercise approved choices have capacity, whereas those who exercise socially undesirable choices lack capacity.  

Though the objections to the risk-relative capacity approach are compelling, they should not lead to a rejection of the concept out of hand. When considering how to respond to a case where a person wishes to do something that will cause harm, it is important to balance the values of preventing harm and respecting autonomy. When these are two values are weighed, normally, autonomy will win out. However, when the risk of very serious harm is present, then the scales become more evenly balanced. So, a decision made by a fully autonomous person will always weigh heavily, but the decision of a barely competent person is lighter. Therefore, only a fully autonomous decision wins the balancing exercise against the risk of serious harm. This is not as radical as it might at first appear. The law often erects procedural barriers around important decisions (for example, marriage; the purchase of land), in part, to ensure that the decision is not a flippant one.

The difficulty with the above stated argument in favor of the risk-relative capacity approach is the way it is presented. To say the level of capacity changes with the degree of risk is misleading. The weight attached to a decision under the principle of autonomy does not depend alone on whether or not the individual satisfies the competence test. Not all autonomous decisions carry the same weight. To understand this point, it is important to consider what it is about the nature of autonomy causes us to attach such weight to an autonomous decision.

We treasure autonomy and the power it gives us to shape our lives according to our own values. That we should be free to fashion our lives and live out our version of the "good life" is seen as a fundamental aspect of humanity. Autonomy enables us to develop and express our characters and beliefs. Ronald Dworkin explains:

[A]utonomy makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction, and interest. It allows us to lead our own lives rather than being led along them, so that each of us can be, to the extent a scheme of rights can make this possible, what he has made himself. This view of autonomy focuses not on individual decisions one by one, but the place of each decision in a more general program or picture of life the agent is creating and constructing, a conception of character and achievement that must bellowed its own distinctive integrity.

I discuss autonomy later in this article, but for now, an important point to appreciate is that where a person is going to make a decision that severely restricts his or her

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55. Id. at 343.
56. Wilks, supra note 51.
57 Indeed, for most commentators there becomes a point when autonomy may not be respected. If you wish to remove all your limbs in political protest, the law in many jurisdictions will prevent you from doing so. See Jonathan Herring, Medical Law and Ethics 123 (2006).
60. Kadish, supra note 58.
options as to how to live life, supporters of autonomy are properly concerned because doing so involves an exercise of autonomy now which will limit their autonomy later in life. We may be convinced that the decision is a genuine part of the person’s life vision and, made with a full understanding of the consequences. Then we can justify respecting the person’s decision to take the risk. Where, however, we are uncertain whether the decision has been fully thought through with a full understanding of the consequences, we may decide to attach less weight to the decision. This should not necessarily been seen as disrespecting autonomy, but rather preserving it for future use. A key issue then, where a person wishes to engage in an act that will cause them harm, is whether the act is a full exercise of autonomy. That is, whether the decision reflects beliefs that are central to the person and are an expression of identity. Where they are, they deserve respect; where they are not, then they count for less and it may be that the argument for restricting autonomy now in order to maximize autonomy later is overwhelming.

Therefore, in a case like Albert’s, where a person lies on the borderline of incapacity, but wishes to engage in behavior that may be harmful to himself, it may properly be said that although competent, his decision does not reflect a decision based on a higher-order preference. The harm risked, with its consequent impact on autonomy later, is such that autonomy requires the decision not to be respected.

B. Autonomy and Decisions Contrary to the Individual’s Previous Values

Can the fact that a decision appears bizarre, given the individual’s values and ideals up until that point in life, itself be evidence of incapacity? The orthodox view on this is clear—it cannot. The assessment of incapacity should be independent of any assessment of whether a patient is making a wise or sensible decision. Professor Ian Kennedy argues

If the beliefs and values of the patient, though incomprehensible to others, are of long standing and have formed the basis for all the patient’s decisions about is life, there is a strong argument to suggest that the doctor should respect and give effect to a patient’s decision based on them . . . . To argue otherwise would effectively be to rob the patient of his right to his own personality which may be far more serious and destructive than anything that could follow from the patient’s decision as regards a particular proposed treatment.

Indeed, if a person would be assessed as incompetent because she wished to make a bizarre or even mistaken decision then autonomy would be robbed of much of its value. A right of self-determination that only allowed one to make well-reasoned, careful decisions would be of limited value. Indeed, the right to be able to make mistakes is an essential part of autonomy. As Jonathan Glover explains:

64. John Eekelaar, The Emergence of Children’s Rights, 6 OXFORD J. LEGAL STUD. 161, 182 (1986) ("[T]hat most dangerous but most precious of rights: the right to make their own mistakes.").
For many of us would not be prepared to surrender our autonomy with respect to the major decisions of our life, even if by doing so our other satisfactions were greatly increased. There are some aspects of life where a person may be delighted to hand over decisions to someone else more likely to bring about the best results. When buying a second-hand car, I would happily delegate the decision to someone more knowledgeable. But there are many other decisions which people would be reluctant to delegate even if there were the same prospect of greater long-term satisfaction. Some of these decisions are relatively minor but concern ways of expressing individuality . . . . Even in small things, people can mind more about expressing themselves than about the standard of the result. And, in the main decisions of life, this is even more so.65

This is persuasive, but this explanation does not require us to follow the views of the English courts and some academics that a decision is worthy of respect even if the reasons for the decision are “irrational, unknown or even non-existent.”66

Philosophers debate whether to which in order to be autonomous, a person must be able to reflect on his or her desires and preferences, be capable of changing these desires in response to “higher-order values,” or be free from irrational, neurotic or futile desires.67 Few take the view that all decisions of persons with capacity are to be respected by the principle of autonomy. Marilyn Friedman has argued that to be a decision that requires respect under the principle of autonomy, the decision must be “self-reflective.” This includes two requirements. First, she explains that:

what autonomy requires . . . is the absence of effective coercion, deception, manipulation, or anything else that interferes significantly with someone’s behavior in a way that reflects her wants and values as she would reflect on an reaffirm them under noninterfering conditions.68

Second, she argues that:

[Autonomous choices and behavior] must reflect, or mirror the wants, desires, cares concerns values, and commitments that someone reaffirms when attending to them. To mirror someone’s concerns is to accord with them and, especially, to promote them. Choices and actions mirror wants and values by, for example, aiming at the attainment of what is wanted or valued, promoting its well-being, or protecting it from harm.69

She explains further that to be autonomous, actions and choices they must stem from what an agent cares deeply about. Such deep wants and desires need to be “abiding” and “constitute the overarching rationales that an agent regards as justifying many of her more specific choices.”70 This rich conception of autonomy would not protect the sudden desires of a person losing capacity, which contradict the values the

66. In re T (Refusal of Treatment), [1993] Fam. 95 (Eng.); see also Winick, supra note 17.
68. MARILYN FRIEDMAN, AUTONOMY, GENDER, POLITICS 5–6 (2003).
69. Id. at 6.
70. Id.
person held dear during his or her life.\textsuperscript{71} Where the decision is impulsive or irrational in light of a person’s long term goals, the decision ceases to deserve the same respect as those motivated by the values that underpin the person’s life. This view takes the approach that not all decisions made by a competent individual are entitled to equal respect under the principle of autonomy. Those decisions that are fully-reasoned and based on the individual’s deeply held values are entitled to the most respect, whereas those that are, for example, based on fleeting desires or impulses are entitled to less. So, applying these principles to Albert, we must ask whether his recent sexual escapades are in fact the result of a reasoned decision to reject his previous value system, or whether they are fleeting, ill-considered decisions that are entitled to only limited respect under the principle of autonomy. If they are the latter, then there is a case for saying that his family or caretakers are entitled to take some steps to prevent that behavior.\textsuperscript{72}

\textit{C. Conclusion on the Just Competent}

It has been argued that respect for autonomy does not automatically require us to allow people who are just competent to act in a way that will cause them serious harm, or that contradicts values they held dear during their life. First, it has been argued that where a decision will cause the individual serious harm, this will itself interfere with their ability to subsequently exercise autonomy, and so, unless we are sure that the decision is a richly autonomous one, it need not be respected. Second, where the decision is one that contradicts values that underlie the individual’s life, it may also be regarded as not autonomous, or only weakly protected under the principle of autonomy, unless it can be shown that the individual has made a conscious decision to depart from the values that previously underpinned their life.

\textit{II. INCOMPETENT DECISIONS: DO THEY DESERVE ANY RESPECT?}

As discussed previously, once a person is found incompetent, then decisions may be made on that person’s behalf based on what is in his or her best interests. A patient’s current views can be taken into account, but only insofar as they might reveal what is in the patient’s best interests. The current views do not appear to carry any weight in and of themselves. This is because these decisions are not protected by the principle of autonomy. Current decisions cannot be assumed to be an assessment of what patients want for their lives, because they lack the ability to make assessments of that kind. In particular, dementia may cause loss of memory, instability of desires, and an absence of connection between desires and personality that render decisions not worthy of respect under the principle of autonomy.\textsuperscript{73} It is this view that I wish to challenge. But first, I will explain more about how the law, under the standard approaches, takes account of the wishes of an incompetent person.

\textsuperscript{71} Beate Rössler, \textit{Problems with Autonomy}, 17 HYPATIA 143 (2002).
\textsuperscript{72} Precisely what the limits would be lie outside the scope of this article.
Anglo-American lawyers are familiar with the dispute between those who support a best interests test and those who support a substituted judgment test. Under the "best interests" approach, the decision-maker decides what is in the best interests of the person lacking capacity. Under the substituted judgment approach, decisions are made based on an assessment of what the person would have decided if they had had capacity. These two approaches are commonly presented as competing approaches and fierce debate has surrounded which is preferable, especially in the context of end of life decision-making.

In fact, the two approaches are more similar than might at first appear. In the Mental Capacity Act of 2005, English law firmly nailed its colours to the "best interest" mast. However, the Act explains that in determining a person’s best interests consideration should be taken of “the person’s past and present wishes and feelings” and “the beliefs and values that would be likely to influence his decision if he had capacity”. So, the decision that the person would have taken can carry some weight in determining what is in his or her interests. Of course, under the substituted judgment approach, best interests may play an important role. Decision-making should require some convincing that a person, if competent, would choose to do something that would harm them. As this shows the differences between a best interests and substituted judgment approach are less than may initially be supposed. Indeed, quite a number of commentators have recommended a mid-way position between the two approaches.

The purpose of this article is not to consider whether or not the best interests approach is preferable to the substituted judgment approach. The question I want to
focus on is, under either of these approaches, what weight is to be attached to the
current wishes of the patient.

A. Substituted Judgment and the Wishes of the Incompetent Person

As already explained, in a substituted judgment the decision maker is attempting to
make the decision which the incompetent person would have made had they not lost
capacity. Clearly the views and opinion of the person while competent are an essential
element of making any substituted judgment. Less obvious is whether their current
incompetent views are relevant.

It appears that there have been some cases where the court, using the substituted
judgment doctrine, has focused on the subjective wishes of the incompetent person. In In re Hier,\(^5\) Mary Hier, aged 92, suffered a mental illness. She had an obstructed
esophagus and a surgically implanted abdominal feeding tube. She repeatedly pulled
out the feeding tube. The court said that the substitute judgment doctrine “focuses
attention on, and requires giving weight to, the subjective wishes of the incompetent
patient.”\(^6\) In In re Guardianship of Ingram,\(^7\) the Washington Supreme Court said that
the wishes of an incompetent person should be given weight as “a strong indicator of
what treatment she would choose if competent to do so.” With respect, the strength of
that claim may depend on the cause and impact of the mental impairment. If the
person’s personality has changed beyond recognition or where their wishes are the
result of delusion it seems hard to accept that their current views indicate what a
person would have chosen if competent. What may be said is that unless there is
evidence to suggest otherwise an incompetent person’s current views can be taken to
represent what the person would have decided if competent.

B. Best Interests and Incompetent People’s Views

“Best interests” are often characterized as the objective assessment of the patient’s
welfare. Therefore, the current wishes of the incompetent individual carry no weight.
However, they can be relevant as evidence. They are useful in ascertaining the present
emotional and physical status of the patient.\(^8\) There is the very practical point that
giving a patient treatment that he or she opposes may well not be clinically effective.
Many treatments require the co-operation of the patient, if they are to be effective.\(^9\)
There may be difficulties in administering treatment which the person is opposing. The
physical and emotional harm to the patient and those administering the treatment may
counterbalance its benefits.

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\(^5\) Constructive Preference Standard for Dying, Previously Competent Patients Without Advance
\(^7\) Id., at 965. But see George J. Annas, Law and the Life of Sciences: The Case of Mary
Hier: When Substituted Judgment Becomes Sleight of Hand 14 HASTINGS CENTRE REP 23
\(^8\) 689 P.2d 1363, 1370 (Wash. 1984).
\(^9\) CANTOR, supra note 20, at 204.
\(^E.g.,\) Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 432
evidence of incapacity).
C. Giving Weight to the View of the Incompetent Person

I have argued that under either a substituted judgment approach or a best interest approach, the current views of the patient will count for little apart from as evidence of what the patient is feeling or whether the patient is likely to co-operate in treatment. I now want to argue that there are good reasons for respecting the decisions of a person lacking capacity in their own right. Their value lies not just in providing us with information upon which an assessment of best interests can be made.

The most common reason given for respecting a competent patient’s decision over medical treatment is the right of autonomy. As I have pointed out, when a person loses capacity the right of autonomy no longer applies. However, I will argue now that autonomy is not the only reason why a patient’s views deserve respect. While the autonomy arguments may no longer apply when capacity is lost, the other reasons remain. Reasons to respect patient decisions regardless of capacity include: the right to dignity; the right to liberty; the patient-doctor relationship; and the idea of pluralism.

1. Right to Dignity

Much academic attention has been paid to the notion of dignity. There is no getting away from the fact that the concept is unclear and that it means a variety of things to different people. To some, dignity and autonomy are intertwined. Respecting a person’s dignity means respecting their competent decisions. Not respecting a person’s choices means showing disrespect to their dignity. Others, however, see dignity having a broader meaning than simply respecting autonomy. Indeed the United Nations Universal Declaration of Human Rights in its first article opens with the statement: “All human beings are born free, equal in dignity and human rights.”

Forcing treatment on an objecting person (even if they lack capacity) contravenes their dignity. Norman Cantor has argued however, that “It would be dehumanizing to ignore the will and feelings of a profoundly disabled person and to simply impose a surrogate’s will. This would treat the prospective patient as if he or she were an inanimate object.”

95. Cantor, supra note 20, at 206; see also Elysa R. Koppelman, Dementia and Dignity: Towards a New Method of Surrogate Decision Making, 27 J. MED. & PHIL. 65 (2002).
To count the wishes and desires of an incompetent person as no more than the grunts of an animal, is show a lack of respect. This viewpoint fails to show appropriate reverence of the person. However confused and muddled and misled, the individual’s views are those of a person and dignity requires that they be respected as such. This is reflected in the common practice among health care professionals of obtaining the assent of a person to treatment, even if they clearly lack capacity to make a decision. This represents an acknowledgement that the individual, whatever their mental capabilities, deserved to be treated as a fellow human being.

2. Right to Liberty

It is argued that liberty is a basic good. Isaiah Berlin captured this in a famous passage:

I wish my life and decisions to depend on myself, not on external forces of whatever kind. I wish to be the instrument of my own, not of other men’s, acts of will. I wish to be a subject, not an object; to be moved by reasons, by conscious purposes, which are my own, not by causes which affect me, as it were, from outside. I wish to be . . . a doer—deciding, not being decided for, self-directed and not acted upon by external nature or by other men as if I were a thing, or an animal, or a slave incapable of playing a human role, that is, of conceiving goals and policies of my own and realising them. . . . I wish, above all, to be conscious of myself as a thinking, willing, active being, bearing responsibility for my choices and able to explain them by reference to my own ideas and purposes.

The freedom of bodily integrity and movement should be protected even if the individual’s capacity to understand this is restricted. Where, therefore, the person is unwilling to undergo the treatment the person’s rights of bodily integrity and freedom of movement deserve protection.

3. Patient-doctor relationships

Requiring medical professionals to respect the wishes of an incompetent person will promote good patient-doctor relationships. It will encourage truth telling, openness, and trust which are more likely to be fostered by listening to and attaching weight to the wishes of a patient, even where the patient is incompetent. Linked to this argument is the fact that a hospital is meant to be a place of cure and recovery. The sight or
sound of a patients being forced to receive treatment against their will is likely to be traumatic for staff and patients.

4. Pluralism

Medical lawyers can be tempted to assume that “best interests” or beneficence is a straight-forward issue—of course it is not. There are many medical scenarios in which a reasonable case can be given for alternatives. Many day-to-day issues involving the care of the demented are not medical and can involve religious, social, and cultural issues. While we may be (or may be not) confident that a doctor or other medical professional can assess what is medically in a patient’s best interests, we may not want them deciding social and religious issues. Deferring to the patient avoids this, to the relief of many medical professionals, no doubt. Indeed one of the benefits of autonomy is that it means professionals and courts are not drawn into making controversial decisions about which they may feel uncomfortable and where they might lose the public’s respect. There is, therefore, a good case for respecting the decision of the incompetent person especially where there no serious harm will result and the issue is one of moral controversy.

D. Conclusion

As these points demonstrate, even though a person is judged to lack capacity and the right of autonomy no longer protects the person’s views, this does not mean the views count for nothing. There are several other legal principles and values which can be used to give weight to their views. These principles, set out above, are reflected in the practice of “person-centred care.” Its keys principles are valuing people with dementia and those who care for them; treating people as individuals; looking at the world from the perspective of the person with dementia and creating a positive social environment. Theses things are, of course, easier to say than to put into practice. Valuing someone as a person requires an acknowledgement that the person still is a sentient person and a person worthy of respect and being listened to.

The argument made is only a modest one that the views of the incompetent person do carry some weight on their own. The argument is not that incompetent patient’s wishes should be followed regardless of the consequences. Rather the wishes of the incompetent person should be followed unless there is a good reason for not doing so.

102. Koppelman, supra note 95, at 65.
III. ADVANCE DIRECTIVES

A. Introduction

If it is accepted that some weight should be attached to the wishes of incompetent people then this leaves the issue of how these are to be taken account of in a case where there is an advance directive. There has been much dispute between those who emphasise the importance the interests of the demented person as they are now and those who seek to elevate the importance of the views of the person they once were. Ronald Dworkin sets out the two views:

We may think of that person, as the putative holder of rights, in two different ways: as a demented person, in which case we emphasize his present situation and capacities, or as a person who has become demented, in which case we emphasize that his dementia has occurred in the course of a larger life whose whole length must be considered in any decision about what rights he has.104

Of course in many cases there is no difficulty. The proposed treatment or course of action is in the best interests of the patient, they appear content with it, and there is nothing in an advance directive or from their earlier life which would suggest any other course of action. But it is where there is a clash between a patient’s current wishes or current best interests and their views expressed in an effective advance directive that the problems arise.105 Before entering that debate something needs to be said about the use of advance directives in practice.

B. Practical points on advance directives

Most people do not execute advance directives.106 Even though patients are generally positive about them in theory, they appear reluctant to actually use them in practice.107 There may be many reasons for this. The most prominent, no doubt, is inertia. But research has also indicated a range of other reasons. One noticeable one is a concern that medical professionals will “misuse” directives. In particular that they will be interpreted widely to justify withdrawing or withholding treatment when the patient might have wanted the treatment to continue.108 Another issue was the difficulty people had in deciding how they would want to be treated in the event of a serious medical illness.109 Even where an advance directive is written, one study found

104. Dworkin, supra note 61, at 4.
that only thirty-nine percent of the sample wanted their advance directives to be interpreted “strictly.” A striking forty-two percent wanted physicians to have a lot or complete leeway to depart from the directive if they felt it was inappropriate.110

C. Dworkin’s approach

To many people, keeping control of their lives is extremely important. Few of us like to be told what to do. The fear of losing control and having others take decisions for us is nightmarish. Hence the attraction of advance directives. They will appeal particularly to those who are concerned that surrogate decision-makers will fail to safeguard the values they hold dear.111 Advance directives enable us to make plans for the future and make arrangements about how we will be remembered and live out the end of our lives.112 One academic has reproduced her own advance directive, which reveals the concerns of many people. It reads:

When I suffer from Alzheimer’s disease and I do not recognize my children anymore, and I have to reside in a nursing home permanently, I refuse lifesaving or prolonging treatment. I would hope for euthanasia. I realize there may be a time that I myself am past caring and not unhappy. But I do not want my children to witness and to suffer from my steady decline into nothingness. I see no point at all in continuing my life when I have lost the dignity, the purposes and the emotional commitments that I consider essential to the story of my life and my person.113

Ronald Dworkin has written one of the persuasive cases in favour of placing weight on advance directives.114 Only a brief outline of his views can be presented here. To him the right of autonomy is central to our humanity. It “encourages and protects people’s general capacity to lead their lives out of a distinctive sense of their own character, a sense of what is important to and for them.”115 At the heart of his thinking about advance directives is the distinction between critical and experiential interests.116 He sees experiential interests as concerning the quality of enjoyment or pleasure. They might include pursuing activities such as watching television or drinking tea. Critical interests are all about doing or having in our lives the things that we consider good or valuable. Often critical interests are pursued despite the fact they do not provide enjoyment or pleasure. Sacrifices are made for family; projects are pursued even when they have lost some of the “first love.” Critical interests will involve matters which go to the core of the person such as religious beliefs and important life projects.

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110. Leslie P. Francis, supra note 9, at 572 (2001)
112. Francis, supra note 9, at 572.
113. Inez de Beaufort, The View from Before, 7 AMER. J. BIOETHICs 57 (2007).
114. See also Michael Quant, Precedent Autonomy and Personal Identity, 9 KENNEDY INST. ETHICS J. 365 (1999).
Dworkin argues that it is our critical interests that are most important to our autonomy. These are the things that are at the heart of our plans for our lives. For Dworkin, a person's critical beliefs survive incapacity. A person having lost capacity should be treated in a way which would be consistent with their critical interests, or at least not inconsistent with them. Dworkin can accept that some people without capacity may have experiential interests. They may be able to experience pleasure in certain activities, but respect for these experiential interests should never be at the expense of the patient's critical interests articulated during their competent life. The incompetent person's current wishes should be ignored "because he lacks the necessary capacity for a fresh exercise of autonomy. His former decision remains in force because no new decision by a person capable of autonomy has annulled it."\(^{117}\) Jeff McMahan even suggests that the competent person is retrospectively harmed if an advance directive is not followed. He argues that the competent part of a person's life should be seen as dominant over the demented part which should be "sacrificed for the greater good of her earlier self."\(^{118}\)

Dworkin does not shy away from the implications of his approach. He refers to the much discussed case of Margo.\(^{119}\) Much discussed not because her scenario is unusual, but because it is so typical. She is described as a 54-year-old-woman, suffering from dementia, but extraordinarily happy. Each day is the same. She rereads pages of a book she never finishes, eats the same food (peanut butter and jelly), and paints the same picture. Dworkin argues she has experiential interests: she is able to gain great pleasure from her activities. But no critical interests (in respect of her current state). She has lost the ability to develop the life goals central to one's critical interests. Dworkin asks us to imagine that when previously competent she had written an advance directive refusing life saving treatment, if she were ever to suffer dementia. She now has a chest infection and needs antibiotic treatment to cure her. Should it be provided? The scenario is well chosen because of course she is happy in her current state. Dworkin argues that her critical interests as expressed in her advance directive should trump any experiential interests. In short, she should be allowed to die.

**D. Criticisms of Dworkin**

Critics of Dworkin have attacked his argument from a number of perspectives. First, and perhaps most prominently, has been the argument that he assumes that the competent person has the right to speak for and about the incompetent person. The objection to this centres on the nature of personhood.\(^{120}\) As is well known, Derek Parfit, building on the work of John Locke,\(^{121}\) has argued that central to personhood is consciousness and psychological awareness. Where a person loses capacity this can

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cause a loss of psychological continuity. Where the person has no recollection of who they were and loses connections with the values which governed their life then they have, in effect, become a different person. The psychological continuity of the previous person has ceased and a new person(s) has been created. Therefore, when making decisions about the person who has lost capacity the views of the person with capacity are not the same person’s views. They are no more relevant than the views of any other person.\(^\text{122}\)

This response to Dworkin, unsurprisingly, has, in turn, its critics.\(^\text{123}\) It appears to place a lot of weight on a Cartesian dualist split between the mind and the body. It does not recognise the part bodies play in identity.\(^\text{124}\) Even if there is a psychological discontinuity, there is a physical continuity. The current person is still part of the narrative of the life of the earlier person.\(^\text{125}\) Even more significantly, these critics of Dworkin overlook the fact that to those who know them, the incompetent person is connected to and represents the competent person. No one, for example, believes that if their parent develops dementia the person somehow ceases to be their mother or father. When the individual is seen within a relational context they are to their family and community the same person they have always been.\(^\text{126}\) There is an additional difficulty for lawyers in accepting Parfit’s arguments in this context. That is that it does not fit with all kinds of legal doctrines.\(^\text{127}\) We hardly treat a change in personality as a death of a legal identity.\(^\text{128}\) A person facing a criminal charge has no defence based on the fact that the person who committed the crime is psychologically disconnected from them.

A second set of criticisms of Dworkin’s views question the weight he places on experiential interests. It may be questioned whether it is possible to divide up a person’s interests into critical and experiential ones. At what point does a person’s enjoyment of a hobby become a critical interest? Further, it may be claimed that it presents an idealized view of how people, in fact, live out their lives. Do people really sit down and plan a great vision for their lives ruled by higher order preferences or do they live each day as it comes or at least a life marked by contradiction and chaos, rather than a grand plan?\(^\text{129}\) Rebecca Dresser suggests: “[M]any people take life one day at a time. The goal of establishing a coherent narrative may be a less common life

\(^{122}\) An extreme view is that a person with severe dementia ceases to be a person at all. See the discussion in Allen Buchanan, *Advance Directives and the Personal Identity Problem*, 17 PHIL. & PUB. AFF. 277, 280 (1988).


\(^{124}\) Maclean, *supra* note 111, at 291.


\(^{129}\) Friedman, *supra* note 68, at 39.
theme than the simple effort to accept and adjust to the changing natural and social circumstances that characterize a person's life."\textsuperscript{130}

These criticisms of Dworkin's approach carry some weight. However, the difficulty in applying the distinction he seeks to draw does not necessarily mean it is of no use. Many of the fundamental distinctions drawn by lawyers are difficult in application, but that does not mean they are not good ones to make.

A third set of criticisms highlights the difficulties in determining whether when the person made the advance directive they had sufficient information to make an informed decision about how they should be treated if they were to lose capacity. For example, they will not know what medical treatment may be available in the future for conditions they fear or even know precisely what it is like to suffer the condition they fear.\textsuperscript{131} There is much evidence that although people are terrified of certain conditions, when in fact they suffer them they are far happier than they thought they would be.\textsuperscript{132}

At most, these arguments seem to suggest that there may be circumstances in which an advance directive is flawed by a lack of knowledge some subsequent unforeseen development. Hence, some critics do not argue against the use of advance directives where a fully informed decision is made about a particular condition which then materialises in exactly the circumstances the person expected when he or she had capacity.

There is, it is argued, a more powerful objection to Dworkin's approach and that is the lack of weight attached to the views and welfare of the current incapacitated person. Placing all the weight on critical interests means that in the words of one learned commentator the current individual is a person "to treat, control, restrain, or perhaps simply tolerate.... To take this sort of attitude towards someone is to see him as no longer fully human."\textsuperscript{133} It is suggested that Dworkin's views have gained much support because they have been used in the context of life or death issues. But outside that arena, the problems are immediately apparent. If a patient of devout religious belief is concerned that if they lose capacity they will no longer continue their religious devotions and therefore create an advance directive that religious services are performed in their presence weekly. Such a directive may indeed reflect a critical interest, but should it be followed even if the great anguish the incompetent person is feeling when the services take place? Should strict dietary requests expressed in an advance directive be followed if it is causing the individual serious pain? It is hard to justify the pain to the current person caused in the name of values to the previous person of which they have no recollection. While competent we are willing to accept suffering in the name of pursuing our critical interests and the succor from knowing we are reaching for a higher goal may make those suffering more bearable. But for the incompetent there is no compensation in relation to the crucial interests for the pain.

\textsuperscript{130} Ronald Dresser, \textit{Dworkin on Dementia: Elegant Theory, Questionable Policy, in Bioethics: An Anthology} 312, 316–17 (Helga Kuhse & Peter Singer eds., 1999).

\textsuperscript{131} Callahan, \textit{supra} note 58, at 26.

\textsuperscript{132} DANIEL GILBERT, \textit{STUMBLING ON HAPPINESS} (2005). I am grateful to Dean Lauren Robel for introducing me to this book.

E. Dresser’s approach

To some commentators, the guiding principle for all those who have lost capacity is that that we should promote their best interests. This should be done even if it means going against any advance directive. Our basic duty is to protect those who have lost capacity.134 Rebecca Dresser has been most prominent in promoting this approach.135 She rejects an argument that the views of the competent person as expressed in an advance directive should dominate because she sees the demented person is so vastly altered from the previous person.136 “Courts have a hard time understanding the subjectivity of the incompetent patient. They sometimes speak as if a patient were still the competent person she once was; they sometimes construct a mythical, generalized competent person to inhabit the body that lies before them.”

Instead of focusing on what they would have wanted when competent she proposes a different approach:

We should seek a more reciprocal relationship with these patients. Rather than making them the mirror of our own fears about debilitation and the end of life, we should attempt to ascertain their point of view, their perspective, on what is to be decided. If they have none, if their consciousness of self and others is lost, then we can safely resolve the cases on other grounds. If they do have a perspective, a set of interests, then this should be the focus of treatment decision-making.138

John Robertson takes a similar line arguing:

The values and interests of the competent person no longer are relevant to someone who has lost the rational structure on which those values and interests rested. Unless we are to view competently held values and interests as extending even into situations in which, because of incompetency, they can no longer have meaning, it matters not that as a competent person the individual would not wish to be maintained in a debilitated or disabled state. If the person is no longer competent enough to appreciate the degree of divergence from her previous activity that produced the choice against treatment, the prior directive does not represent her current interests merely because a competent directive was issued.139

Dresser points out throughout our life we change our views and perspectives on the world. Things we dread turn out to be surprisingly enjoyable; people we thought we would not like become friends. Fortunately we are not tied to our initial experiences

136. Id. at 611.
137. On the difficulties of imagining what it would be like to be different see Daniel C. Dennett, Consciousness Explained 441–42 (1991); Thomas Nagel, The View From Nowhere 13–27 (1986).
and views. In other words, although the person may once have had certain critical interests when he or she wrote the advance directive, there is no reason to assume the current person still has them. It is, therefore, inappropriate to attach weight to the views of the person before they were in an incapacitated state. Professor Jaworska puts the point this way:

[T]he moral pull of Dresser’s position is undeniable: the caregiver . . . is faced with a person—or if not a fully constituted person, at least a conscious being capable of pleasure and pain—who, here and now, makes a claim on the caregiver to fulfil her needs and desires; why ignore these needs and desires in the name of values that are now extinct?

Considering the case of Margo, Dresser argues that following Dworkin’s approach and letting her die from an infection will mean that: “Happy and contented Margo will experience clear harm from the decision that purports to advance the critical interests she no longer cares about.”

F. Problems with the Dresser approach

Critics of Dresser’s position often criticise her argument that the two people are no longer the same. We have already discussed the arguments over “two person” argument. There is, in fact, no need to adopt that theory to support Dresser’s approach. One could readily accept that the two people are indeed the same, but argue that the claims of the now incompetent person to have their welfare promoted trump the views of the competent person expressed in the advance directive.

A second problem posed by Dresser’s argument is exemplified by Dena Davis’s article which accepts Dresser’s argument. She entitles her article “Help! My Body is being invaded by an alien.” She expresses concern that if she develops Alzheimer’s a new form of person will take over her body. To avoid this suicide when the first stages of Alzheimer’s appear is discussed as a sensible option. This is hardly the kind of thinking Dresser would advocate, but it lends itself to it. Dresser’s approach offers no hope to those who are terrified of what will happen to them if they lose capacity and want to exercise some control over it. Nor does it readily explain why in fact most caregivers do instinctively try and treat the incompetent person in line with the values by which they lived their life. In a recent English decision, a dispute arose over treatment of a Muslim woman who had lost capacity. It concerned whether or not she should receive care in line with Muslim tradition, or whether, as was argued on the other side, as she did not know what was happening to her she should not receive

140. Holm, supra note 73, at 156–58.
142. Dresser, supra note 130, at 36.
143. Buchanan, supra note 122, at 280–83.
144. Dena Davis, Help! My Body is Being Invaded by an Alien!, 7 AMER. J. BIOETHICS 60 (2007).
special treatment. The judge thought it was beyond doubt that she should be treated in accordance with her religion.

G. Compromise views

The debate between these two views has raged for some time and no consensus has emerged. Several commentators have sought to develop compromise views, and this seems the sensible way ahead. On the “one person or two” debate the correct answer seems to be that there are senses in which the person is the same as the one they were—both in a bodily sense but also within the context of their relationships with others. There is another sense where there has been such a psychological break and such a difference in what is important about a person has been lost and it makes sense to talk of being only the most tenuous link between the past and present person. So the solution there appears to lie in an acceptance of the view that the incompetent person is in some sense the same person as the competent person and in others a different person.

On the central policy to adopt, it seems that both camps are too extreme. Dresser’s refusal to pay any weight on advance directive appears too strong. Where the advance directive applies in relation to an issue which will not seriously harm the patient, it seems a good argument can be made for respecting it. The desire people have to exercise control over what happens to them when they are not longer able to control their destiny appears to be a strong one, as the use of wills demonstrates. I can see no reason why if a patient has requested in an advance directive that they be fed vegetarian food if they lose capacity that this should not be respected unless there are strong countervailing reasons. Allowing this will provide comfort to people when facing the prospect of incapacity. Indeed, Penney Lewis suggests a failure to allow people to exercise some control over what happens to them when they lose capacity could infringe their human rights. On the other hand, I see no reason for following Dworkin’s view and attaching all weight to an advance directive, regardless of the pain it will cause the individual. I refer back to my example of the person asking for a religious service to be preformed regularly in their presence but which are now causing them anguish. While some weight can be placed on the directive, this should not be at the expense of harm to the current individual.

The correct approach it is suggested is somewhere in between Dworkin and Dresser. One suggestion comes from Alasdair Maclean. Maclean recommends following a clear advance directives unless the result would cause significant harm, pain, or terror to the patient. In the case of less clear directives, a balancing exercise would be required between the views expressed in the directive and the experiential interests of the person lacking capacity. Leslie Francis taking a similar approach accepts that such guidelines will lead to debates over when the harm will be sufficient to mean that the directive will not followed, but they seem to capture what is morally

148. Maclean, supra note 111, at 291.
important about precedent autonomy-guidance for how one’s life winds down; as well as what is morally important about experiential interests: avoiding pain and continuing experiences of relative quality to the extent that clear prior autonomy is not compromised.  

My view would be similar to that but with greater respect for following the views of the incompetent person. Maclean, as so many others writing in this area, have focused on autonomy to the exclusion of dignity and liberty. I would follow the current wishes of the individual unless those would cause the patient serious harm. Where the current individual does not have strong views, then an advance directive can be used to determine how the patient is treated.

IV. SOME BROADER OBSERVATIONS

In the light of the discussion above, I now want to take a broader look at the issues surrounding dementia and loss of capacity.

According to the American Alzheimer’s Association there are 4.5 million American suffering from Alzheimer’s disease: nearly 50% of people over the age of 85 will develop the condition. This means that the “them” and “us” image that can pervade the discussion of dementia is unconvincing. Alzheimer’s is becoming the norm for ageing, rather than a disease affecting the few. Indeed, even the notion of Alzheimer’s as a disease is open to question. In Japan, for example, there is a widespread cultural belief that Alzheimer’s is no more than the normal process of ageing. Where the symptoms are publicly manifest that indicates a lack of adequate care by the family, rather than an illness of the individual. I would certainly not go so far as to deny the existence of the medical condition, but those who are more cynical about it have valid points.

First, there is an issue over the extent to which manifestations of the dementia are a result of the disease and to what extent they are a response to the social situation sufferers find themselves in, especially given low level of care demented patients often receive. Second, there is no getting away from the fact that prior to the discovery of Alzheimer’s Disease there was no separation between those with Alzheimer’s and others ageing in a “normal” way. There is a case for acknowledging that with old age comes brain ageing which affects us all in different ways. The social narrative of Alzheimer’s as a horrific terrifying disease, which is widely feared, has meant that the truth, that brain deterioration is extremely common in old age and is a natural part of ageing, has been lost. We need to find a way of valuing and treasuring the natural progression of old age, just as we value the earliest stages of life. The ageing of brain

149. Francis, supra note 9, at 592.
151. Id.
153. JOANNE LYNN, SICK TO DEATH AND NOT GOING TO TAKE IT ANYMORE!: REFORMING HEALTH CARE FOR THE LAST YEARS OF LIFE (2004).
will affect nearly all of us and needs to be regarded as part of being human, rather than a humiliating disease.

Another point that emerges from the discussion in this article is that lawyers so easily over-emphasise the importance of autonomy. Just because a person lacks capacity and is unable to make decisions does not mean that they lack rights or interests. Even if the view and desires of the incapacitated person are not the result of a rational decision, respect due to them as people requires us to give them weight. While rational decisions are worthy of legal respect and attention so too should be our values, feelings, emotions, and the other aspects of our humanity. The demented may have lost the full power of rational thought, but that does not mean they have the ability to feel, care, or value. The emphasis on rational thought is reflected on the way assessments of capacity are made. These tend to be cognitivist and rationalistic. Matters such as emotion, personal identity, narrative are not included as ways decisions can be reached. The fact a finding of incompetence leads us to attach no weight to the views of the incompetent in themselves show that we have elevated reasoning over other ways of interpreting and responding to the world. It is only a failure to value our non-rational humanity that can lead to an assumption that the incompetent person has "nothing to tell us." We need much more attention to be given to the lived experiences of those with dementia and finding ways of appreciating and respecting their views, emotions, and humanity.

A third point that emerges from the discussion is the individualistic nature of the legal approach. Incompetent people are assessed and treated in isolation and are not seen as relational people, in mutually inter-dependant relationships. An assessment of capacity should be of an individual located within their network of family, friends, and care-givers. Instead, the assessment is made of the individual sitting alone in a doctor’s office. Few of us, in fact, make important decisions on our own and without consultation and discussion with those around us. At least part of the assessment of capacity should be the extent to which the person within their support group of family and/or friends is able to make choices. Further, when decisions need to be made for a person of doubtful capacity, decisions should be made within the person’s relational context. George P. Smith II has argued in this context for “negotiated consent” rather than informed consent. He explains:

156. Berghmans et al., supra note 33, at 252.
157. Id., at 258.
158. Id.
Under the negotiated consent standard, many legitimate views must be considered involving the patient, family, and institution. The results are shared or dispersed authority for decision-making in which no single party has the exclusive power of decision and a nonalgorithmic process whereby negotiation is not governed by strict deductive rules.163

Further, assessment of best interests tends to view patients in isolation. Where a person lacking capacity is being cared for informally by family and friends or in an institutional setting, it is simply impossible to make every decision based on what will promote the best interests of the incapacitated person. In caring relationships, it becomes impossible to separate out the interests of the carer and the cared for. Indeed, it is sometimes difficult to determine who is the carer and who is the person being cared for.164 That would put an intolerable burden on those caring for them. Inevitably within a caring relationship there is give and take. Some decisions will benefit one party more than the other, but other decisions will make up for that. This is how it is in real life in a well-working caring relationship and this is how it should be.165

A final point is to emphasise our vulnerabilities. Quite rightly there is much emphasis on the vulnerability and dependence of those lacking capacity. There are concerns that they may be taken advantage of by others or be unable to care for themselves. But it is easy to overlook the vulnerability and the dependency of the competent too. Very few patients consenting to medical treatment or people making financial decisions are in fact fully informed or acting on the basis of a rational decision. We often delegate such decisions to others.166 Taubner has pointed out:"Frightened and in psychological, if not also physical distress, the patient is fundamentally dis-eased. To think rationally and dispassionately about life-and-death choices is all too often beyond normal human ability. Indeed, fear about sickness or death is the appropriate response when we ourselves are the subject of calamity."167

Although those comments are made in the context of life and death decisions, they are true about many important decisions we make. Similarly, dependency should not be something to be afraid of or ashamed of. Something has gone very wrong with our care of vulnerable older people when “not being a burden” is reported as the main goal of their lives by patients living in nursing homes.168 Dependency on others is an aspect of our humanity. From our earliest beginnings, we are in relationships of dependency and we are for much if not all in of our lives—sometimes receiving, sometimes giving, and often doing both. We may look to puff our selves up on our independence and boast of the rational powers we use to exercise our autonomy. The truth is a little less grand. Many decisions we take are based on little evidence and made based on irrational fears and emotions. Relationships of dependency are central to our lives. We

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163. Id. at 122.
165. I have expanded and justified this approach in Jonathan Herring, The Place of Carers, in LAW AND BIOETHICS (Michael Freeman ed., 2008).
168. Pleschberge, supra note 94 at 197.
may point to rationality and independence as marking the line between competence and incompetence, but, in fact, they demonstrate how blurry that line is.

CONCLUSION

This article has considered the position of those on the borderline of incapacity. This is a borderline of huge legal significance with different legal regimes governing those on one side of the line and those on the other. I have sought to blur that line. It has been suggested that where those who are assessed as just competent make decisions to engage in behaviour which causes them significant harm or is contrary to values they have followed during their life then those decisions should not be regarded as necessarily protected by the principle of autonomy. I have also argued that the views of incompetent people should be given far more respect under the law. Principles of dignity and liberty require us to let incompetent people decide how they wish to live unless doing so will cause them significant harm. Following the approach set out in this article is more likely to accord with what actually happens in the care of incompetent people than in the orthodox legal principles focusing on best interests and the right of autonomy.

We have elevated autonomy to such a status that the other ways of relating to the world outside the rational have been ignored by the law. We are not respecting the humanity of incompetent people by attaching no legal weight to their feelings and wishes, beyond what they may reveal about a person’s best interests.

Researchers that have talked to those suffering dementia have reported that what was most important to those persons was that they were regarded as of value and of use. Sufferers reported their major concern being not so much a loss of cognition or identity, but the loss of value and the loss of relationships with other. Our legal system, with its emphasis on rationality and individuality, reinforces these concerns rather than seeks to address them. Rational decisions are not the only forms of human interaction that deserve protection and respect.

Professor D.H. Smith writes of dementia:

[Although cancer kills you, . . . it doesn’t remove your very humanity. . . . It doesn’t turn you into a vegetable. . . . All diseases are depersonalizing to some extent. But you’re still human. . . . But a person with a serious dementia is no longer human. He’s a vegetable. That’s devastating. Fearsome. Terrifying, to anyone who’s ever seen it—the thought that it could happen to you.]

Such a view that a person with serious dementia is just a vegetable is repugnant. The lives with those with dementia are richer than is commonly supposed by those looking at the outside. The law must find ways of interacting with those who have

171. Jaworska, supra note 141, at 130.
lost competence. We can start by valuing the non-rational and listening to the demented. Listening hard.