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Jonathan Herring

## **LOSING IT? LOSING WHAT?** **THE LAW AND DEMENTIA \***

### **INTRODUCTION**

'The fear of dementia is stronger than the fear of death itself.'<sup>1</sup>

This perception may explain the relative paucity of writing from lawyers on dementia. It does not justify it. This article will argue that the legal principles governing those suffering dementia and others losing capacity are crude and unsophisticated. It will attempt to reveal the inadequacies of the current law and indicate ways in which the law should develop.

Dementia has been defined as follows:

'Dementia is the clinical syndrome of mental life characterized by substantial global decline in cognitive function that is not attributable to alteration in consciousness.'<sup>2</sup>

Clearly this definition requires substantial unpacking and that is not possible here.<sup>3</sup> The focus of this article will be on those suffering dementia who are of borderline mental capacity.<sup>4</sup> It would, of course, be quite wrong to suggest that a diagnosis of dementia means that a patient automatically lacks capacity.<sup>5</sup> It is perfectly possible, for example, to suffer from Alzheimer's Disease and yet retain full capacity. However, the loss of cognitive faculties, difficulties with memory, communication problems and depression associated with Alzheimer's and other forms of dementia can all contribute to a gradual loss of capacity.<sup>6</sup>

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\* *Exeter College, Oxford University. An early version of this paper was presented as the Smith Lecture at Indiana University on 12 September 2007 while I was the George P. Smith II Distinguished Visiting Professor-Chair. A later version was given at King's College London as one of their Lent Lectures. I am grateful to participants at both of these events for their comments. I have also benefited from the comments of Penney Lewis and José Miola.*

<sup>1</sup> M. Williams, as quoted in K. Greider and J. Neimark, 'Making Our Minds Last a Lifetime' (1996) *Psychology Today* November 43, at 43.

<sup>2</sup> J. Breitner, 'Dementia—Epidemiological Considerations, Nomenclature, and a Tacit Consensus Definition' (2006) 19 *Journal of Gerontology, Psychiatry and Neurology* 129, at 130, referring to P. McHugh and M. Folstein, 'Dementia Syndrome in Depression', in R. Katzman, R. Terry and K. Bick (eds.) *Aging* (Raven Press, 1977), at 94 -96.

<sup>3</sup> See J.C. Hughes, S.J. Louw and S.R. Sabat, *Dementia: Mind, Meaning and the Person* (Oxford University Press, 2005). For a non-technical discussion of the impact of this condition see John Bayley, *Elegy for Iris* (St. Martin's Press, 1999).

<sup>4</sup> In this article the terms competence and capacity will be used interchangeably.

<sup>5</sup> E.g. L. Pickering Francis, 'Decision-making at the End of Life: Patients with Alzheimer's or Other Dementias' (2001) 35 *Georgia Law Review* 539.

<sup>6</sup> Although, for a discussion of attempts to maximise capacity among those with dementia see S. Slaughter and J. Banks, 'The Functional Transitions Model: Maximizing Ability in the Context of Progressive Disability Associated with Alzheimer's Disease' (2007) 26 *Canadian Journal on Aging* 39.

For many sufferers there will be a period of time during which their degree of competence is unknown. 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.'<sup>7</sup>

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.<sup>8</sup> The article will, therefore, discuss two categories of individuals: those who are assessed as still having capacity, but only just.<sup>9</sup> And those who are assessed as lacking capacity, but only just.

### ***Basic legal principles***

Medical law tends to draw a sharp divide between those who have capacity and those who do not. Indeed textbooks on medical law often have separate chapters on each.<sup>10</sup>

For the competent the key principle is the right of self-determination or autonomy.<sup>11</sup> Subject to the requirements of criminal and civil law, people are free to choose how they wish to live their lives. Adults cannot be controlled by others, however much it might be thought they are wasting their time or engaging in immoral activities. It is not for the state or anyone else to tell us we would be far better off not reading academic journals and instead going jogging or reading poetry, however true that might be. Allied to this is the right to bodily integrity: the right not to be touched or have our bodies interfered without our consent.<sup>12</sup> Indeed the judiciary have told us that competent people are entitled to refuse to consent to treatment whether their are 'rational, irrational, unknown or even non-existent'.<sup>13</sup>

For those who lack capacity the guiding principles are very different. Their consent is not required before medical treatment is given to them. Instead others make decisions on their behalf based on what is in their best interests.<sup>14</sup> This involves a consideration of all the relevant issues to determine what will best promote their welfare. The Mental Capacity Act 2005's Code of Practice states:

'When working out what is in the best interests of the person who lacks capacity to make a decision or act for themselves, decision-makers must take into account all relevant factors that it would be reasonable to

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<sup>7</sup> M. Gunn, 'The Meaning of Incapacity' (1994) 2 *Medical Law Review* 8, at 9.

<sup>8</sup> R. Jones and T. Holden, 'A Guide to Assessing Decision-making Capacity' (2004) 12 *Cleveland Clinical Journal of Medicine* 971.

<sup>9</sup> The term 'mild cognitive impairment' is sometimes used, although its use is controversial: J. Hughes, 'The Heat of Mild Cognitive Impairment' (2006) 13 *Philosophy, Psychiatry, & Psychology* 1.

<sup>10</sup> See e.g. A. Grubb (ed) *Principles of Medical Law* (OUP, 2004) where chapter 3 concerns the competent patient and chapter 4, the incompetent patient.

<sup>11</sup> D. Beyleveld and R. Brownsword, *Consent in the Law* (Hart, Oxford, 2007), ch 1.

<sup>12</sup> *S v St George's NHS Trust* [1998] 2 FLR 228.

<sup>13</sup> *Re T (Refusal of Treatment)* [1993] Fam 95.

<sup>14</sup> Although quite what best interests mean in this context is hotly debated.

consider, not just those that they think are important. They must not act or make a decision based on what they would want to do if they were the person who lacked capacity.’<sup>15</sup>

The meaning of best interests will be considered further later.

### ***The test for capacity***

The definition of mental capacity is found in section 2(1) of the 2005 Mental Capacity Act:

‘a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.’

Section 3(1) explains that

‘for the purposes of section 2, a person is unable to make a decision for himself if he is unable –

- (a) to understand the information relevant to the decision,
- (b) to retain that information,
- (c) to use or weigh that information as part of the process of making the decision, or
- (d) to communicate his decision (whether by talking, using sign language or any other means.’

It is not possible here to go into a detailed analysis of this definition. It is fairly self-explanatory.<sup>16</sup> But, it is necessary to emphasise three points. First, there is a presumption in favour of a person having capacity.<sup>17</sup> Second, a person can be found to have capacity to make some decisions, but not others.<sup>18</sup> They might, for example, have capacity to decide they prefer strawberry ice cream to chocolate, but lack the capacity to make a will. Third, the wisdom of the decision should not affect the issue of competence.<sup>19</sup> Apparently even competent people make foolish decisions. The Mental Capacity Act 2005 makes this explicit: ‘A person is not to be treated as unable to make a decision merely because he makes an unwise decision’.<sup>20</sup> 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 before that conclusion can be reached.

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<sup>15</sup> Department of Constitutional Affairs, *Mental Capacity Act 2005: Code of Practice* (TSO, 2007), para 5.7

<sup>16</sup> See e.g. J. Herring, *Medical Law and Ethics* (2nd ed) (OUP, 2008), ch. 4.

<sup>17</sup> Mental Capacity Act 2005, s. 1(2).

<sup>18</sup> *Re MM (An Adult)* [2007] EWHC 2003 (Fam), para [64].

<sup>19</sup> Mental Capacity Act 2005, s. 1(3).

<sup>20</sup> Mental Capacity Act 2005, s. 1(3).

It should be added that the definition of incapacity and its use is not uncontroversial. Women and ethnic minorities are particularly vulnerable to assessment of lacking capacity.<sup>21</sup> It has been argued that while notions of competence purport to be neutral they in fact reflect majority interests and values.<sup>22</sup> Assessments of capacity can hide the values and subjective values of physicians, especially where an emotive end of life issue is involved.<sup>23</sup>

### ***Practical point***

The usefulness of these legal principles for those dealing with demented people is limited. No doubt carers, both professional and unpaid, are constantly having to balance protecting the welfare of the individual and respect for their wishes. It is doubtful that the legal principles are always followed to the letter. Carers and staff do restrict the freedoms of those who are just competent in order to protect them from serious harm. No carer could take every decision for a person who had lost capacity based solely on what is in that person's best interests. Certainly, to require the staff at a care home to do so for every resident would simply be impossible. For an informal carer life would be utterly unbearable if they were not permitted to take account of their own interests at least now and then.

Further, those making 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.<sup>24</sup> Empirical evidence indicates that medical professionals regularly rely on the consent of non-competent people.<sup>25</sup> As long as the patient is being compliant there is no need for those caring for her to question her competence. In truth those caring for the demented generally 'bumble through',<sup>26</sup> with the legal principles appearing to be of limited practical relevance. One of the aims of this article will be to set legal standards which provide more realistic, and therefore effective, guidance for practitioners and care-givers.

### ***On the edges of the two categories***

There is, then, a sharp line drawn by the law between those who are competent and those who are not. Fall on the side of competence and your right to autonomy requires your decisions be respected. Fall on the side of incapacity

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<sup>21</sup> P. Foster, 'Informed Consent in Practice', in S. Sheldon and M. Thomson *Feminist Perspectives on Health Care Law* (Cavendish, London, 1998).

<sup>22</sup> N. Knauer, 'Defining Capacity: Balancing the Competing Interests of Autonomy and Need' (2003) 12 *Temple Political & Civil Rights Law Review* 321.

<sup>23</sup> S. Martyn and H. Bourguignon, 'Physicians' Decisions about Patient Capacity' (2000) 6 *Psychology Public Policy and Law* 388.

<sup>24</sup> R. Jones, 'Ethical and Legal Issues in the Care of People with Dementia' (2001) 11 *Reviews in Clinical Gerontology* 245.

<sup>25</sup> V. Raymont, W. Bingley, A. Cuchanan A. David, P. Hayward, S. Wessley and M. Hotopf, 'Prevalence of mental incapacity in medical inpatients and associated risk factors: Cross sectional study' (2004) 364 *The Lancet* 1421.

<sup>26</sup> M. Kapp, 'Decisional Capacity in Theory and Practice: Legal Process versus 'Bumbling Through'' (2002) 6 *Aging & Mental Health* 413.

and the decision is made on your behalf. This sharp distinction can produce difficulties for those on the borderline.

Take two hypothetical cases. Andrew has early stages of Alzheimer's. At nighttimes he has taken to wandering off in the local woods for hours at a time, often without sufficient clothing to keep him warm. Further, it has been discovered that he has been spending substantial sums of money viewing internet pornography. This despite the fact that previously he had been a devout religious man of conservative moral views, who has been carefully saving money for his care in old age. His wife and other relatives are concerned for his well-being. This is not, they think, how he would have wished to live his life. It is accepted by Andrew's doctors that the case is not a straight-forward one, but they are persuaded, just, that he has had capacity to make decisions about his lifestyle. The law is clear he has capacity and so he is free to choose how to live. No one has the right to restrict his expenditure nor his movements.

Now consider a different kind of case. Bertha has more developed dementia. She now lives in a home. She has taken to visiting the services at a mosque which is just across the road from the home. It is not clear how much she understands of what is going on, but they seem to give her great pleasure. Her family are shocked given that Bertha was a vehement atheist during her life and are concerned that the journeys across the road could be dangerous. When she is stopped from going to the mosque she is distressed and agitated. This time the law states that the decision is taken based on her best interests, taking into account the values she held, while she was being competent and her present wishes. Doing so could mean that the decision is taken that going to the services is contrary to her best interests and she should be stopped from attending.<sup>27</sup>

Views on what should be done in these cases may differ, but it is argued that the focus on a simplistic understanding of autonomy or best interests, fails to capture the range and complexities of the issues raised. These will be considered next.

## **THOSE DEEMED JUST COMPETENT**

There are two main kinds of cases where families and professionals may raise concerns about the behaviour of a person found just competent. Both are highlighted by the hypothetical case of Andrew mentioned earlier. The first are those where a person wishes to embark on a course of action which creates a risk of significant harm. Second, are cases where a person seeks to engage in behaviour which is uncharacteristic and would be contrary to the values upon which their previous life was built.

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<sup>27</sup> Of course it may well be that the best interest test would not reach that conclusion and decide that it would promote her welfare if she were to attend the services.

The standard legal approach is that once a person is assessed as having capacity their decisions are entitled to respect.<sup>28</sup> The fact their decision risks causing them harm is no basis for intervention. Indeed nearly everyone chooses to engage in activities which are harmful. We all have our vices! Similarly, the fact their lifestyles reflect different values from those they espoused in the past is no legal ground for preventing them acting. We are all relieved we are not stuck with the views and interests of our late teens. Yet it will be argued that this standard approach is insufficiently subtle to deal with the issues at stake.

It is generally agreed that where a person wants to make a decision which appears bizarre, this provides reasons for re-examining the original assessment of capacity. What is controversial, is what will be argued next, which is that even if the reassessment concludes that the individual is indeed competent, the law should, in some cases, allow intervention to prevent the individual.

### **(i) The importance of autonomy**

To start we need to consider why it is that the law generally respects people's rights to autonomy. We treasure people's autonomy and the power it gives to shape their lives according to their own values. It is seen as a fundamental aspect of our humanity that we should be free to fashion our lives and live out our version of the 'good life'.<sup>29</sup> Ronald Dworkin explains:

'autonomy 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 be allowed its own distinctive integrity.'<sup>30</sup>

Does this mean that we must respect autonomous decisions, however bizarre and however harmful? It is suggested not.

### **(ii) Autonomy and harmful decisions**

Some commentators have developed the notion of 'risk-relative capacity'. Although it will be argued this is not a completely convincing concept, discussion of it is productive. The 'risk-relative capacity' approach requires a higher standard of competency where an act poses a serious risk of great harm than is

<sup>28</sup> See the discussion in J. Herring, *Medical Law and Ethics* (2nd ed) (OUP, 2008), ch. 4.

<sup>29</sup> J. Raz, *The Morality of Freedom* (Clarendon Press, Oxford, 1986), ch 1.

<sup>30</sup> R. Dworkin, 'Autonomy and the Demented Self' (1986) 64 *The Milbank Quarterly* 4, at 5.

required where the decision risks less harm.<sup>31</sup> In other words there is a sliding scale for capacity, depending on the risk of harm the decision carries.<sup>32</sup> The higher the risk of harm, the higher the bar of competence is set.<sup>33</sup> Note that the claim is not that riskier decisions involve more complex issues and therefore require a greater level of capacity, but rather that even if two decisions are equally complex, if one involves a higher degree of risk than the other, a greater degree of competence is required.

There are several difficulties with 'risk-relative capacity'.<sup>34</sup> First, it can mean that whether a patient is deemed competent to make a particular decision may depend upon the decision they reach.<sup>35</sup> Imagine a case where a patient is offered a life-saving treatment. If they refuse, this is a decision which will cause them a serious harm and therefore a high level test for capacity is used. If, however, they are to consent to the treatment then there is less risk of harm 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. The objection to this is that it is illogical to say that a person has capacity to make a decision if they say 'yes'; but not if they say 'no'.<sup>36</sup> They either have the capacity to make the decision or they do not.

A second concern with the risk relative capacity approach is that it involves a conflation of two issues: whether a person has capacity to make a decision; and whether or not a person's decision can be overruled on paternalistic grounds.<sup>37</sup> 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. As Nancy Knauer has argued, risk relative capacity 'has the potential to become the ultimate self-fulfilling doctrine: those who exercise approved choices have capacity, whereas those who exercise socially undesirable choices lack capacity.'<sup>38</sup>

These objections to risk-relative capacity are compelling, however a consideration of them does indicate a more persuasive approach. The argument in favour of risk relative capacity is that in deciding whether to comply with a person's decision we need to weigh up the importance of respecting autonomy and the value of preventing harm to others.<sup>39</sup> Normally when these two values

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<sup>31</sup> J.F. Drane, 'The Many Faces of Competency' (1985) 15 *Hastings Center Report* 17. For some judicial support see *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 at 113.

<sup>32</sup> M. Tunzi, 'Can the Patient Decide? Evaluating Patient Capacity in Practice' (2001) 64 *American Family Physician* 299.

<sup>33</sup> T. Buller, 'Competence and Risk-relativity' (2001) 15 *Bioethics* 93; M. Wicclair, 'The Continuing Debate over Risk-related Standards of Competence' (1999) 13 *Bioethics* 199.

<sup>34</sup> J. DeMarco, 'Competence and Paternalism' (2002) 16 *Bioethics* 231; G. Cale, 'Continuing the Debate over Risk-related Standards of Competence' (1999) 13 *Bioethics* 131.

<sup>35</sup> I. Wilks, 'The Debate over Risk-related Standards of Competence' (1997) 11 *Bioethics* 416.

<sup>36</sup> One response to this may be to say that if a potential answer to the question involves a high degree of harm then a high level of capacity is required to answer the question. This sidesteps the symmetry problem because the test for capacity does not depend on the answer given. However, it means a wide range of questions would have the heightened degree of capacity. Even 'what would like for breakfast?', has some possibly dangerous answers!

<sup>37</sup> C. Culver and B. Gert, 'The Inadequacy of Incompetence' (1990) 68 *The Milbank Quarterly* 619.

<sup>38</sup> N. Knauer 'Defining Capacity: Balancing the Competing Interests of Autonomy and Need' (2003) 12 *Temple Political and Civil Rights Law Review* 321, at 344.

<sup>39</sup> I. Wilks, 'The Debate over Risk-related Standards of Competence' (1997) 11 *Bioethics* 416.

are put in the scales autonomy will win out. However, when very serious harm is done then the scales become more evenly balanced.<sup>40</sup> The argument, then, is that while a decision made by a fully autonomous person will always weigh heavily, the decision of a barely competent person is lighter and can be outweighed by a serious harm. Where, therefore, a serious harm is caused, we need to ensure that the decision is fully autonomous if it is to win out the balancing exercise.<sup>41</sup> This is not as radical an approach as might at first appear. The law often puts in place procedural barriers where a person is about to make a decisions with important consequences (e.g. marriage; the purchase of land), in part, to ensure that the decision is fully autonomous one. Notably supporters of a change in the law so as to permit euthanasia, nearly always insist that the person requesting euthanasia must have had a period of lengthy deliberation and discussed the issue with a medical professional before their wishes are complied with.

The difficulty with using this argument in favour of risk-relative capacity is the way it is presented. To say the level of capacity that is expected changes with the degree of risk is misleading. It is not the level of capacity that changes, but rather the weight that is attached to the autonomous decision. Quite simply, not all autonomous decisions carry the same weight.

When a person is going to make a decision which severely restricts their options as to how they wish to live their life in the future, supporters of autonomy are rightly concerned. Doing so involves an exercise of autonomy *now* which will limit their autonomy *later in life*. It may be that where we are convinced that the decision is a genuine part of their life vision with a full understanding of the consequences we can justify respecting the decision. Where, however, we are uncertain whether the decision has been fully thought through with a full understanding of the consequences less weight attaching to the decision. This should not necessarily be seen as disrespecting their autonomy, but rather preserving it for future use. A key issue then, where a person is wishing to engage in a act which will cause them harm is to consider whether the act is a full exercise of autonomy. That is whether it reflects beliefs that are central to him- or herself and are an expression of identity. Where they are, they deserve respect; where they are not then they count for less.

When, therefore, we have a case, like Andrew, where a person is on the borderline of incapacity, but who wishes to engage in behavior which 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 that he is risking with its consequent impact on autonomy later is such that autonomy requires the decision not to be respected.

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<sup>40</sup> Indeed for most commentators there becomes a point at which your autonomy may not be respected. If you wish to remove all your limbs to make a political protest the law in many jurisdictions will prevent you. For further discussion on this see J. Herring, *Medical Law and Ethics* (2<sup>nd</sup> ed) (OUP, 2008), at 171-2.

<sup>41</sup> S. Kadish, 'Letting Patients Die: Legal and Moral Reflections' (1992) 80 *California Law Review* 857.

## (ii) 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.<sup>42</sup> 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 his 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.'<sup>43</sup>

Indeed if a person could 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 which only allowed you 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.<sup>44</sup> As Jonathan Glover explains:

'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 secondhand 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.'<sup>45</sup>

This is persuasive, but this explanation does not require us to follow the views of the courts and decide that a decision is worthy of respect even if the reasons for it are 'irrational, unknown or even non-existent'.<sup>46</sup>

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<sup>42</sup> M. Parker, 'Competence by Consequence: Ambiguity and Incoherence in the Law' (2006) 25 *Medicine and Law* 1.

<sup>43</sup> I. Kennedy, *Treat Me Right* (Clarendon, 1992), at 56.

<sup>44</sup> J. Eekelaar, 'The Emergence of Children's Rights' (1986) 6 *Oxford Journal of Legal Studies* 172, at 182 writes of 'that most dangerous but most precious of rights: the right to make their own mistakes'.

<sup>45</sup> J. Glover, *Causing Death and Saving Lives* (Penguin, 1990), 80-1.

<sup>46</sup> *Re T (Refusal of Treatment)* [1992] 4 All ER 649 at 653,

Philosophers debate the extent to which in order to be autonomous a person must be able to reflect on their desires and preferences; be capable of changing their desires in response to 'higher-order values'; or be free from irrational, neurotic or futile desires.<sup>47</sup> Few take the view that all decisions of those 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 requires the decision to be 'self-reflective.'<sup>48</sup> This contains 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 behaving in a way that reflects her wants and values as she would reflect on an reaffirm them under noninterfering conditions.'<sup>49</sup>

Second she argues that

'[Autonomous choices and behaviour] 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.'<sup>50</sup>

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 justify many of her more specific choices.'<sup>51</sup> A rich requirement of autonomy would find sudden desires of a person losing capacity, which contradict values they have held dear during their life, not to be protected by the right of autonomy.<sup>52</sup> Where the decision is impulsive or irrational in the light of their long term goals, it ceases to deserve the same respect as those motivated by the values that underpin their 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 which are fully reasoned and are based on deep held values of the individual are entitled to the most respect, but those which are, for example, based on fleeting desires; or impulses are entitled to less. So applying such principles to Andrew 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 which are

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<sup>47</sup> J. Savulescu and R.W. Momeyer, 'Should informed consent be based on rational beliefs?' (2000) 23 *Journal of Medical Ethics* 282.

<sup>48</sup> I. Hyun, 'Authentic Values and Individual Autonomy' (2001) 35 *Journal of Value Inquiry* 195 argues that to be autonomous a person's decisions need to be based on authentic values, which can be regarded as appropriately called the person's own.

<sup>49</sup> M. Friedman, *Autonomy, Gender, Politics* (Oxford University Press, Oxford, 2003), at 5-6.

<sup>50</sup> *Ibid*, 6.

<sup>51</sup> *Ibid*, 6.

<sup>52</sup> B. Rössler 'Problems with Autonomy' (2002) 17 *Hypatia* 143.

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 carers are entitled to take some steps to prevent him acting in the way he is.<sup>53</sup>

***(iv) 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 which will cause them serious harm or which 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.

**INCOMPETENT DECISIONS: DO THEY DESERVE ANY RESPECT?**

As already mentioned once a person is found to be incompetent, then under the Mental Capacity Act 2005, decisions can be made on their behalf based on what is in their best interests. A patient's current wishes and feelings can be taken into account, but only in so far as they might reveal what is in their best interests.<sup>54</sup> As the Code of Practice on the Mental Capacity Act puts it:

Even if the person lacks capacity to make the decision, they may have views on matters affecting the decision, and on what outcome would be preferred. Their involvement can help work out what would be in their best interests.<sup>55</sup>

And

People who cannot express their current wishes and feelings in words may express themselves through their behaviour. Expressions of pleasure or distress and emotional responses will also be relevant in working out what is in their best interests.<sup>56</sup>

So the current views and feelings of individual are relevant in ascertaining their present emotional and physical status.<sup>57</sup> There is the very practical point that giving treatment to a patient which they oppose may well not be clinically

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<sup>53</sup> Precisely what the limits would be on this are outside the scope of this article.

<sup>54</sup> MCA 2004, s. 4(6). Although see A. Boyle 'The Law and Incapacity Determinations' (2008) 71 M.L.R. 433 who regards the Mental Capacity Act 2005 as legislation which maximises autonomy.

<sup>55</sup> Department of Constitutional Affairs, *Mental Capacity Act 2005: Code of Practice* (TSO, 2007), para 5.22.

<sup>56</sup> Para 5.40.

<sup>57</sup> N. Cantor, *Making Medical Decisions for the Profoundly Mentally Disabled* (MIT Press, 2005), at 204.

effective. Many treatments require the co-operation of the patient, if they are to be effective.<sup>58</sup> In cases of forced treatment, the physical and emotional harm to the patient and those administering the treatment may outweigh its benefits.

However, the views of the individual do not appear to carry any weight in and of themselves. They are relevant only in so far as they can tell us something about their best interests. The reason for this is that their decisions are not protected by the principle of autonomy. Their decisions cannot be assumed to be an assessment of what they want for their lives, because they lack the ability to make any assessment of that kind. Dementia, in particular, it has been said can cause a loss of memory; an instability in desires; and an absence of connection between desires and personality which render the decision not worthy of respect.<sup>59</sup> It is that which I will now challenge and argue that the views of incompetent people in themselves should have value.

### ***Giving weight to the view of the incompetent person***

Although the principle of autonomy is the primary reason for respecting a competent patient's decision over medical treatment, it is not the only one. Even though a loss of capacity may mean the autonomy principle is no longer applicable, that does not mean that the others are not. So what are the other reasons for valuing a person's views and feelings?

#### *(i) Right to dignity*

Much academic attention has been paid to the notion of dignity.<sup>60</sup> There is no getting away from the fact that the concept is unclear and that it means a variety of things to different people.<sup>61</sup> To some dignity and autonomy are intertwined. Respecting a person's dignity means simply respecting their competent decisions.<sup>62</sup> Others, however, see dignity having a broader meaning than simply respecting autonomy.<sup>63</sup> It is not possible to resolve that disagreement here, but it is asserted that dignity involves more than respecting autonomy.

Norman Cantor has argued 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'.<sup>64</sup>

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<sup>58</sup> E.g. *Re JT* [1998] 1 FLR 48.

<sup>59</sup> See S. Holm, 'Autonomy, authenticity, or best interest' (2001) 4 *Medicine, Health Care and Philosophy* 153, at 154-5.

<sup>60</sup> E.g. D. Beylveland and R. Brownsword, *Human Dignity in Bioethics and Biolaw* (OUP, 2001).

<sup>61</sup> R. Brownsword, 'Human Rights – What Hope? Human Dignity – What Scope?', in J. Gunning and S. Holm (eds) *Ethics Law and Society* (Ashgate, 2005).

<sup>62</sup> E.g. I. Randers and A-C Mattinasson, 'Autonomy and Integrity: Upholding Older Adult Patients' Dignity' (2003) 45 *Journal of Advanced Nursing* 63.

<sup>63</sup> See the discussions in J Miola, 'The Need for Informed Consent: Lessons from the Ancient Greeks' (2006) 15 *Cambridge Quarterly of Healthcare Ethics* 152; L. Nordenfelt, 'The varieties of dignity' (2004) 12 *Health Care Analysis* 69.

<sup>64</sup> N. Cantor, *Making Medical Decisions for the Profoundly Mentally Disabled* (2005, MIT Press) at 206.

To count the wishes and desires of an incompetent person as no more than the grunts of an animal, is to show a lack of respect.<sup>65</sup> To force treatment on an objecting person (even if they lack capacity) contravenes their dignity.<sup>66</sup> It 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.<sup>67</sup> 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.<sup>68</sup> This represents an acknowledgement that the individual, whatever their mental capabilities, deserved to be treated as a fellow human being.<sup>69</sup>

### *(ii) 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 or 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.<sup>70</sup>

The freedom of bodily integrity and movement should be protected even if the individual's capacity to understand this is restricted.<sup>71</sup> Where, therefore, the person is unwilling to undergo the treatment or conduct their view is protected by their rights of bodily integrity and freedom of movement.<sup>72</sup>

### *(iii) Patient-doctor relationships*

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<sup>65</sup> L. Nordenfelt, 'Dignity of the Elderly' (2003) 6 *Medicine, Health Care and Philosophy* 99.

<sup>66</sup> S. Pleschberge, 'Dignity and the Challenge of Dying in Nursing Homes: The Residents' View' (2007) 36 *Age and Ageing* 197.

<sup>67</sup> See the discussion in L. Örulv and N. Nikku, 'Dignity Work in Dementia Care: Sketching a Microethical Analysis' (2007) 6 *Dementia* 507.

<sup>68</sup> V. Molinaril et al 'Principles and practice of geriatric assent' (2006) 10 *Ageing & Mental Health* 48. Such an approach also improves compliance and co-operation.

<sup>69</sup> For a discussion of how this might be put into practice see Department of Health, *Dignity in Care* (DoH, 2007).

<sup>70</sup> I. Berlin, 'Two Concepts of Liberty', in I. Berlin, *Four Essays on Liberty* (Oxford University Press, 1969), at 131.

<sup>71</sup> It is protected, for example, under article 5 and 8 of the European Convention on Human Rights.

<sup>72</sup> See further Mental Capacity Act 2005, s. 1(6) which requires the decision-maker to consider whether to minimise restrictions of peoples rights and freedoms of action in so far as is consistent with their best interests.

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 they are incompetent. Further, it will challenge the infantilising attitudes that are often presented when dealing with demented people. 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 patient being forced to receive treatment against their will is likely to be traumatic for staff and patients.

#### (iv) *Pluralism*

It can be tempting to assume that 'best interests' or beneficence is a straightforward issue. Of course, it is not. There are many medical scenarios in which a reasonable case can be given for alternatives. More significantly, 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 not be) 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 that professionals and courts are not drawn into making controversial decisions that may lead them to losing the respect of sections of the public. There is, therefore, a good case for respecting the decision of the incompetent person especially where no serious harm will be caused and the issue is one of moral controversy.

### **Conclusion**

As these points demonstrate even though a person is judged to be lacking capacity and their views are thus no longer protected by the right of autonomy, their preferences do still count for something. 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'.<sup>73</sup> Its key 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. These things are, of course, easier to state than to put into practice. Valuing a person requires an acknowledgement that they are still sentient and a person worthy of respect and being listened to.<sup>74</sup>

The argument made here is only the modest one that the views and feelings of the incompetent person should carry some weight. The argument is not that an incompetent patient's wishes should be followed regardless of the

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<sup>73</sup> D. Brooker, 'What is Person-centred Care in Dementia?' (2004) 13 *Reviews in Clinical Gerontology* 215.

<sup>74</sup> E. Koppelman, 'Dementia and dignity: Towards a new method of surrogate decision making' (2002) 27 *Journal of Medicine and Philosophy* 65.

consequences. Rather, the wishes of the incompetent person should be followed unless there is a good reason for not doing so.<sup>75</sup>

## **ADVANCE DIRECTIVES**

### *Introduction*

If it is accepted that some weight should be attached to the wishes and feelings of incompetent people it is still necessary to consider how these should be taken into account in a case where there is an advance directive. There has been much dispute between those who emphasise the importance of 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.'<sup>76</sup>

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.<sup>77</sup>

### *Dworkin's approach*

To advocates of advance directives, it is the fear of losing control which is at the heart of the issue. Few of us like being told what to do or have decisions made on our behalf without our consent. Advance directives offer the possibility of being able to make decisions about how we will be treated, when we are not able to make decisions for ourselves. They enable us to make arrangements for the final chapter of our lives, if we are not able to write it

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<sup>75</sup> E. Miller 'Listening to the Disabled: End-of-life Medical Decision Making and the Never Competent' (2006) 74 *Fordham Law Review* 2889, at 2920.

<sup>76</sup> R. Dworkin 'Autonomy and the Demented Self' (1986) 64 *The Milbank Quarterly* 4.

<sup>77</sup> M. Newton, 'Precedent Autonomy: Life-Sustaining Intervention and the Demented Patient' (1999) 8 *Cambridge Quarterly of Healthcare Ethics* 189.

ourselves.<sup>78</sup> 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.'<sup>79</sup>

Ronald Dworkin has written one of the persuasive cases in favour of placing weight on advance directives.<sup>80</sup> 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.'<sup>81</sup> At the heart of his thinking about advance directives is the distinction between critical and experiential interests.<sup>82</sup> 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.

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.'<sup>83</sup> Jeff McMahan even suggests that the competent person is retrospectively harmed if

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<sup>78</sup> L. Francis, 'Decision-making at the End of Life: Patients with Alzheimer's or Other Dementias' (2001) 35 *Georgia Law Review* 539.

<sup>79</sup> I. de Beaufort, 'The View from Before' (2007) 7 *American Journal of Bioethics* 57.

<sup>80</sup> See also M. Quant, 'Precedent Autonomy and Personal Identity' (1999) 9 *Kennedy Institute of Ethics Journal* 365.

<sup>81</sup> R. Dworkin, *Life's Dominion* (Harper Collins, 1993), at 224.

<sup>82</sup> For a critical look at Dworkin's writings on this area see, J. Finnis, 'Euthanasia, Morality, and Law' (1998) 31 *Loyola of Los Angeles Law Review* 1123.

<sup>83</sup> R. Dworkin, *Life's Dominion* (Harper Collins, London, 1993), at 224.

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'<sup>84</sup>

Dworkin does not shy away from the implications of his approach. He refers to the much discussed case of Margo.<sup>85</sup> 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.

### 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.<sup>86</sup> As is well known Derek Parfit, building on the work of John Locke,<sup>87</sup> has argued that central to personhood is consciousness and psychological awareness. Where a person loses capacity this can cause a break in 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.<sup>88</sup>

This response to Dworkin, unsurprisingly, has, in turn, its critics.<sup>89</sup> It appears to place a lot of weight on a Cartesian dualist split between the mind

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<sup>84</sup> J. McMahan, *The Ethics of Killing* (Oxford University Press, 2002), at 502-503.

<sup>85</sup> A. Firlik, 'Margo's Logo' (1991) 9 *Journal of the American Medical Association* 201.

<sup>86</sup> J. Hughes, 'Views of the Person with Dementia' (2001) 27 *Journal of Medical Ethics* 86; D. Degrazia, 'Advance Directives, Dementia and 'the Someone Else Problem'' (1999) 13 *Bioethics* 373.

<sup>87</sup> J. Locke, *An Essay Concerning Human Understanding* (1690; A. Wozzley (ed.); William Collins/Fount, 1964); D. Parfit, *Reasons and Persons* (Oxford University Press, Oxford, 1984), at 205-7.

<sup>88</sup> An extreme view is that a person with severe dementia ceases to be a person at all. See the discussion in A. Buchanan, 'Advance Directives and the Personal Identity Problem' (1988) 17 *Philosophy and Public Affairs* 277.

<sup>89</sup> E. Olsen, *The Human Animal* (OUP, 1997), chapter 1.

and the body. It does not recognise the part bodies play in identity.<sup>90</sup> 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.<sup>91</sup> Even more significantly these critics of Dworkin overlook the fact 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 they somehow cease 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.<sup>92</sup> 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.<sup>93</sup> We hardly treat a change in personality as a death of a legal identity.<sup>94</sup> For example, 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, 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.<sup>95</sup> Rebecca Dresser suggests:

'many people take life one day at a time. The goal of establishing a coherent narrative may be a less common life theme than the simple effort to accept and adjust to the changing natural and social circumstances that characterize a person's life.'<sup>96</sup>

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.<sup>97</sup> Further, 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.<sup>98</sup> At most these arguments seem to suggest

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<sup>90</sup> A. Maclean, 'Advance Directives, Future Selves and Decision-making' (2006) 14 *Medical Law Review* 291.

<sup>91</sup> C. Taylor, *Sources of the Self: the Making of the Modern Identity* (Cambridge: Cambridge University Press, 1989), ch. 1.

<sup>92</sup> See the discussions in B.A. Rich, 'Prospective Autonomy and Critical Interests: A Narrative Defense of the Moral Authority of Advance Directives' (1997) 6 *Cambridge Quarterly of Healthcare Ethics* 138; J.C. Hughes, 'Views of the Person with Dementia' (2001) 27 *Journal of Medical Ethics* 86; T. Kitwood, 'The Experience of Dementia' (1997) 3 *Aging & Mental Health* 179.

<sup>93</sup> N.K. Rhoden, 'The Limits of Legal Objectivity' (1990) 68 *North Carolina Law Review* 845, at 852.

<sup>94</sup> B.A. Rich, 'Prospective Autonomy and Critical Interests: a Narrative Defense of the Moral Authority of Advance Directives' (1997) 6 *Cambridge Quarterly of Healthcare Ethics* 138, at 146.

<sup>95</sup> M. Friedman, *Autonomy Gender Politics* (2006 Oxford University Press), at 39.

<sup>96</sup> R. Dresser, 'Dworkin on Dementia: Elegant Theory, Questionable Policy' in H. Kuhse and P. Singer (eds.), *Bioethics: An Anthology* (Blackwell Publishers Ltd. 1999), at 316.

<sup>97</sup> A Maclean 'Advance directives and the rocky waters of anticipatory decision-making' [2008] *Medical Law Review* 1.

<sup>98</sup> D. Gilbert, *Stumbling on Happiness* (Vintage, New York, 2005), 1-15.

that there may be circumstances in which an advance directive is flawed by a lack of knowledge of some subsequent unforeseen development. They do not argue against their use in a situation where a fully informed decision is made about a particular condition which then materialises in exactly the circumstances foreseen by the person while they 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.'<sup>99</sup> 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. Take, for example, a patient of devout religious belief who 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 incompetent person displays great anguish 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, but here the succor from knowing we are reaching for a higher goal and this may make the suffering more bearable. But for the incompetent there is no compensation in relation to the crucial interests for the pain.

### Dresser's approach

To some commentators the basic duty that is owed to those who have lost capacity is that we should protect them and promote their best interests.<sup>100</sup> Rebecca Dresser has been most prominent in promoting this approach.<sup>101</sup> She rejects an argument that the views of the competent person as expressed in an advance directive should dominate the decision as to how they should be treated, because she sees the demented person as vastly altered from the previous person:<sup>102</sup>

'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

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<sup>99</sup> M. Moody-Adams, 'On the old saw that character is destiny' in O. Flanagan and A.O. Rorty (eds.), *Identity, Character, and Morality: Essays in Moral Psychology* (MIT Press, 1990), at 124.

<sup>100</sup> R. Dresser, 'Schiavo's Legacy: The Need for an Objective Standard' (2005) 35 *Hastings Center Report* 20.

<sup>101</sup> R. Dresser, 'Missing Persons: Legal Perceptions of Incompetent Patients' (1994) 46 *Rutgers Law Review* 609.

<sup>102</sup> *Ibid*, at 611.

them.’<sup>103</sup>

Instead of focusing on what they would have wanted when competent she proposes promotion of their best interests. 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.’<sup>104</sup>

Dresser points out that 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 and views. In other words although the person may once have had certain critical interests when they wrote the advance directive, there is no reason to assume the current person still has them.<sup>105</sup> It is therefore inappropriate to attach weight to the views of the person before they were in an incapacitated state. Professor Jaworska<sup>106</sup> puts the point this way:

the 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.’<sup>107</sup>

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<sup>103</sup> On the difficulties of imagining what it would be like to be different see, e.g. D. C. Dennett, *Consciousness Explained* (Little, Brown & Co., 1991), at 441-42.

<sup>104</sup> J. Robertson, ‘Second Thoughts on Living Wills’ (1991) 21 *Hastings Center Report* 7.

<sup>105</sup> S. Holm, ‘Autonomy, Authenticity, or Best Interest: Everyday Decision-making and Persons with Dementia’ (2001) 4 *Medicine, Health Care & Philosophy* 153.

<sup>106</sup> A. Jaworska, ‘Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value’ (1998) 28 *Philosophy and Public Affairs* 105.

<sup>107</sup> R. Dresser, ‘Dworkin on Dementia: Elegant Theory, Questionable Policy’ (1995) 22 *Hastings Center Report* 32, at 36.

### 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 disagreements over the '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.<sup>108</sup>

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'.<sup>109</sup> 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 her approach could lead some people to adopt 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 carers do instinctively try to treat the incompetent person in line with the values they lived their life by. In a recent English decision<sup>110</sup> 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 special treatment. The judge thought it was beyond doubt that she should be treated in accordance with her religion. This seems entirely correct.

### 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.<sup>111</sup> In relation to the 'one person or two' debate, the best answer appears to be that there are senses in which the person is the same as the person they were. This is so in a bodily sense, but also in the context of their relationships with others. However, there is another sense where the psychological break is such that 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.

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<sup>108</sup> A. Buchanan, 'Advance Directives and the Personal Identity Problem' (1988) 17 *Philosophy & Public Affairs* 277.

<sup>109</sup> D Davis, 'Help! My Body is being Invaded by an Alien' (2007) 7 *American Journal of Bioethics* 60.

<sup>110</sup> *Ahsan v University Hospitals Leicester NHS Trust* [2006] EWHC 2624 (QB).

<sup>111</sup> E. Boetzkes Gedge, 'Collective Moral Imagination: Making Decisions for Persons with Dementia' (2004) 29 *Journal of Medicine and Philosophy* 435.

On the central policy to adopt it seems that both camps are too extreme. Dresser's refusal to place any regard to advance directives or the views of the competent person appears too strong. The case of the Muslim woman mentioned earlier is compelling. As Hegarty J said in that case:

'I do not think for one moment that a reasonable member of the public would consider that the religious beliefs of an individual and her family should simply be disregarded in deciding how she should be cared for in the unhappy even of supervening mental capacity. On the contrary, I would have thought that most reasonable people would expect, in the event of some catastrophe of that kind, that they would be cared for, as far as practicable, in such a way as to ensure that they were treated with due regard for their person dignity and with proper respect for their religious beliefs.'<sup>112</sup>

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. Indeed Penney Lewis suggests that a failure to allow a person to exercise some control over what happens to them when they lose capacity could infringe their human rights.<sup>113</sup> The desire people have to exercise control over what happens to them when they are no longer able to control their destiny appears to be a strong one, as is demonstrated by the use of wills. Why should it be that if a patient has requested in an advance directive that they be fed vegetarian food if they lose capacity that this wish should not be respected. Allowing some enforcement of advance directives will provide comfort to people when facing the prospect of incapacity.

On the other hand I am not convinced by Dworkin's view that we should comply with an advance directive in relation to an critical interest, regardless of the pain it will cause the individual. Consider the example that I considered above of the person asking for a religious service to be performed regularly in their presence but which is 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 that promoted by Dworkin and that by Dresser. One solution has been proposed by Alasdair Maclean.<sup>114</sup> He recommends following a clear advance directive unless the result would be 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. He accepts that such guidelines will lead to debates over when the harm will be sufficient to mean that the directive will not be followed,

'[b]ut they seem to capture what is morally important about precedent autonomy-guidance for how one's life winds down; as well as what is

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<sup>112</sup> *Ashan v Universities Hospitals Leicester* [2006] EWHC 2624 (QB).

<sup>113</sup> P. Lewis, 'Medical Treatment of Dementia Patients at the End of Life: Can the Law Accommodate the Personal Identity and Welfare Problems?' (2006) 13 *European Journal of Health Law* 219.

<sup>114</sup> A. Maclean, 'Advance directives, future selves and decision-making' (2006) 14 *Medical Law Review* 291.

morally important about experiential interests: avoiding pain and continuing experiences of relative quality to the extent that clear prior autonomy is not compromised.’<sup>115</sup>

My view would be similar to that but with greater respect for following the views and feelings of the incompetent person. Maclean, in common with so many others writing in this area, has 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.

### **The law on advance directives**

Could this proposed approach to advance directives be adopted under the law? The Mental Capacity Act 2005 gives statutory force to ‘advance decisions to refuse treatment’.<sup>116</sup> Under section 26 (1)

‘If P has made an advance decision which is –

(a) valid, and

(b) applicable to treatment,

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

It should be emphasised that although an effective decision can be used to forbid the giving of certain treatment, it cannot be used to require treatment. In other words a patient cannot issue an effective advance decision that he or she be given a certain form of treatment.<sup>117</sup> Second the definition of an advance decision in section 24 relates to treatment ‘proposed to be carried out or continued by a person providing health care for him’.<sup>118</sup> That indicates that it is not possible to make an advance directive that will be effective under the Act to deal with non-medical issues. For example, it would not be possible to issue a directive that you not be fed meat.<sup>119</sup> Other carers will need to act in the best interests of a patient, and in considering their best interests they must also consider any past or present wishes.<sup>120</sup> That, however, is much weaker than the provisions dealing with health care issues.

The key question for this article is how a case should be dealt with where the current wishes of the incapacitated patient are in conflict with an applicable advance decision. For example, an incompetent patient is requesting treatment, even though there is in force an advance decision refusing consent. At first sight it might be thought that the Act requires health care providers to comply

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<sup>115</sup> *Ibid*, at 310.

<sup>116</sup> These are defined in section 24, Mental Capacity Act 2005

<sup>117</sup> *R (Burke) v GMC* [2005] EWCA Civ 1003, paras [1-2].

<sup>118</sup> Mental Capacity Act 2005, s. 24(1).

<sup>119</sup> Although it may be arguable that feeding is a form of treatment, if it is necessary to keep a person alive.

<sup>120</sup> Mental Capacity Act 2005, section 4(6).

with the advance decision. Section 24 explains that the refusals become effective when the patient loses capacity. A person can revoke an advance decision,<sup>121</sup> but needs to have capacity to do that. However, as Peter Bartlett points out, in fact the answer to our scenario is 'not obvious'.<sup>122</sup> He refers to section 25(2)(c), which states that an advance decision will be invalid if the individual 'has done anything...clearly inconsistent with the advance decision remaining his fixed decision.'<sup>123</sup> He argues that as the provision is not expressly limited to acts while the person has capacity, then acts during incapacity could be taken to be inconsistent with the directive and hence render it invalid. Another sub-section that could be used to bolster such an argument is section 25(4)(c) which states that the advance decision will not apply if '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.' I suggest that when making an advance decision few people will have in mind the situation that even though they have lost capacity they are desperately keen to be given the treatment. Of course, some will.

In the context of non-medical treatment section 4 specifically provides that when determining the best interests of the individual their past and present wishes can be taken into account. I have argued that unless doing so will cause serious harm the person's past or present views should be followed. However, where the two clash their current views and feelings should be followed.

## **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.

In UK 683,597 people suffer Dementia and this is predicted to rise to 1 million in next decade or two and to 1.7 million by 2050.<sup>124</sup> One in 88 people in the UK lives with dementia and over half of those living in care homes do.<sup>125</sup> It has been estimated that nearly 50% of people over the age of 85 will develop the condition.<sup>126</sup> This means that the 'them' and 'us' image that can pervade the discussion of dementia is unconvincing. Alzheimer's Disease and other forms of dementia are becoming the norm for ageing, rather than a disease affecting the few.

Indeed, even the description of dementia as a disease is open to question. In Japan, for example, there is a widespread cultural belief that Alzheimer's disease is no more than the normal process of ageing.<sup>127</sup> If an older person manifests publicly signs of dementia this is seen as indicating a failure in the

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<sup>121</sup> Mental Capacity Act 2005, section 25(2).

<sup>122</sup> P Bartlett, *Blackstone's Guide to The Mental Capacity Act 2005*, para 2.115.

<sup>123</sup> *Ibid.*

<sup>124</sup> Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry, *Dementia UK* (2007), at 2

<sup>125</sup> *Ibid.*

<sup>126</sup> American Alzheimer's Association, *Basics of Alzheimer's Disease* (American Alzheimer's Association), at 7.

<sup>127</sup> P. Whitehouse, 'The End of Alzheimer Disease' (2001) 15 *Alzheimer Disease & Associated Disorders* 59.

care of the family, rather than an illness. I do not doubt that there are scientifically observable characteristics of dementia, but there are valid points to be made by those who are more cynical about it.<sup>128</sup> 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 the low level of care demented patients often receive.<sup>129</sup> 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 an 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.<sup>130</sup> 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 the brain 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.<sup>131</sup> Just because a person lacks capacity and is unable to make decisions does not mean that they lack rights or interests. Even if the views 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, that does not mean they have lost the ability to feel, care or value. The emphasis on rational thought is reflected in the way that assessments of capacity are made. These tend to be cognitivistic and rationalistic.<sup>132</sup> Matters such as emotion, personal identity and narrative are not included as ways decisions can be reached.<sup>133</sup> The fact that a finding of incompetence leads us to attach no weight to the views of the incompetent in themselves shows that we have elevated reasoning over other ways of interpreting and responding to the world.<sup>134</sup> 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 to pay much more attention to the lived experiences of those with dementia and finding ways of appreciating and respecting their views, emotions and humanity.<sup>135</sup>

A third point that emerges from the discussion is the individualistic nature of the legal approach. Incompetent people assessed and treated in isolation,

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<sup>128</sup> J. Bond, 'The Medicalization of Dementia' (1992) 6 *Journal of Aging Studies* 397; D. Davis 'Dementia: Sociological and Philosophical Constructions' (2004) 58 *Social Science and Medicine* 369.

<sup>129</sup> See the research summarised in Kings Fund, *Older People and Mental Health* (King's Fund, 2008).

<sup>130</sup> P. Whitehouse, 'The Next 100 years of Alzheimer's – Learning to Care, not Cure' (2007) 6 *Dementia* 459.

<sup>131</sup> C. Sargent and C. Smith-Morris, 'Questioning our Principles: Anthropological Contributions to Ethical Dilemmas in Clinical Practice' (2006) 15 *Cambridge Quarterly of Healthcare Ethics* 123.

<sup>132</sup> R. Berhmans, D. Dickenson and R. Ter Meulenl, 'Mental capacity: in search of alternative perspectives' (2004) 12 *Health Care Analysis* 251.

<sup>133</sup> *Ibid.*, at 258.

<sup>134</sup> *Ibid.*

<sup>135</sup> S. Post, 'Comments on Research in the Social Sciences Pertaining to Alzheimer's Disease: a More Humble Approach.' (2001) 5 *Ageing and Mental Health* 17.

and 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.<sup>136</sup> 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.<sup>137</sup>

Further, assessment of best interests tends to view patients in isolation. Whether 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.<sup>138</sup> 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.<sup>139</sup>

A final point is to emphasise our vulnerabilities. Quite rightly there is much emphasis on the vulnerability and dependence of the demented. 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.<sup>140</sup> Taubner has pointed out that

'Frightened and in psychological, if not also physical distress, the patient is fundamentally diseased. 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'<sup>141</sup>

Although those comments are made in the context of life and death decisions they are true about many important decisions we take. 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'

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<sup>136</sup> H. Mun Chan, 'Sharing Death and Dying. Advance Directives Autonomy and the Family' (2004) 18 *Bioethics* 87.

<sup>137</sup> S. Horton-Deutsch, P. Twigg and R. Evans, 'Health Care Decision-making of Persons with Dementia' (2007) 6 *Dementia* 105.

<sup>138</sup> See further J. Herring 'Where are the Carers in Healthcare Law and Ethics?' (2007) 27 *Legal Studies* 51.

<sup>139</sup> I have expanded and justified this approach in J. Herring, 'The Place of Carers' in M. Freeman (ed) *Law and Bioethics* (OUP, 2008).

<sup>140</sup> S. Adler Channick, 'The Myth of Autonomy at the End-of-life: Questioning the Paradigm of Rights' (1999) 44 *Villanova Law Review* 577.

<sup>141</sup> A. Tauber, *Patient Autonomy and the Ethics of Responsibility* (MIT Press, 2005), at 143.

is reported as the main goal of their lives by patients living in nursing homes.<sup>142</sup> 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 of our lives. Sometimes receiving, sometimes giving, care; 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 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 developing dementia who are on the borderline of incapacity. This is a borderline of huge legal significance with quite 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 lives then those decisions should not be regarded as necessarily protected by the principle of autonomy. I have also argued that the views and feelings 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 focussing on best interests and the right of autonomy.

I have also argued that the discussion reveals some broader points about the law's approach to those lacking incapacity. 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.

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<sup>142</sup> S. Pleschberge, 'Dignity and the Challenge of Dying in Nursing Homes: the Residents' View' (2007) 36 *Age and Ageing* 197.

**Research, including talking to those suffering dementia shows that what was most important to them was that they were regarded as of value and of use. They 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 others.<sup>143</sup> 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:

'[A]lthough 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.'<sup>144</sup>

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.<sup>145</sup> The law must find ways of interacting with those who have lost competence.<sup>146</sup> We can start by valuing the non-rational and listening to the demented. Listening hard.

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<sup>143</sup> E. Steeman et al, 'Living with Dementia from the Perspective of Older People: Is it a Positive Story?' (2007) 11 *Aging and Mental Health* 119.

<sup>144</sup> D. H. Smith, 'Seeing and Knowing Dementia' in R. Binstock and S. Post (eds), *Dementia and Aging: Ethics, Values, and Policy Choices* (Baltimore, John Hopkins University Press, 1992), at p. 51

<sup>145</sup> Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First* (Open University Press, 1997); A. Jaworska, 'Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value' (1998) 28 *Philosophy and Public Affairs* 105.

<sup>146</sup> There are signs that this is beginning to happen: Government project to produce the first ever national dementia strategy: work programme doh 2008