



Shaw, D. *A direct advance on advance directives*. *Bioethics* . ISSN 0269-9702

<http://eprints.gla.ac.uk/56935/>

Deposited on: 26 October 2011

# A Direct Advance on Advance Directives

## Introduction

Advance directives (ADs), which are also sometimes referred to as “living wills”, are statements made by a person that indicate what treatment she should not be given in the event that she is not competent to consent or refuse at the future moment in question. As such, ADs provide a way for patients to make decisions in advance about what treatments they do not want to receive, without doctors having to find proxy decisions makers or having recourse to the doctrine of necessity.<sup>1</sup> While patients can request particular treatments in an AD, only refusals are binding.<sup>2</sup> This paper will examine whether ADs safeguard the autonomy and best interests of the incompetent patient, and whether legislating for the use of ADs is justified, using the specific context of the legal situation in the United Kingdom to illustrate the debate. The issue of whether the law should permit ADs is itself dependent on the issue of whether ADs are ethically justified; thus we must answer a normative question in order to answer the legislative one. It emerges that ADs suffer from two major problems; one related to autonomy and one to consent. First, ADs’ emphasis on precedent autonomy effectively sentences some people who want to live to death. Second, many ADs might not meet the standard criteria for informed refusal of treatment, because they fail on the crucial criterion of sufficient information. Ultimately, it transpires that ADs are typically only appropriate for patients who temporarily lose physical or mental capacity.

## Important cases

There have been relatively few legal cases involving ADs in Britain, but many of the important issues involved in advance refusals of treatment were resolved in the UK legal cases of *Re T*, *Bland* and *Re C*. There is not room here for a detailed consideration of these cases, but a summary of the main points follows. *Re T* set precedents in the aspects of informed consent and voluntariness, but the key judgement for our purposes was that “An adult patient who, like Miss T., suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered.”<sup>3</sup> T’s advance refusal of a blood transfusion was ruled invalid due to insufficient information and her mother’s coercive influence, but it was made clear that the law permits such advance decisions, provided they meet the three key criteria for medical decision making: sufficient information, competence and voluntariness. Furthermore, Lord Donaldson stated that “consultation with the next of kin may reveal that the patient has made an anticipatory choice whether to accept or refuse specific treatment, eg a blood transfusion, which if clearly established and applicable in the circumstances – two major “ifs” - will bind the medical practitioner.”<sup>4</sup> In *Bland* it was stated that “if, presciently, Mr Bland had given instructions that he should not be artificially fed or treated with antibiotics if he should become a PVS patient, his doctors would not act unlawfully in complying with those instructions but would act unlawfully if they did not comply.”<sup>5</sup> *Re C* was important because it

---

<sup>1</sup> A Maclean. Advance directives and the rocky waters of anticipatory decision-making. *Medical Law Review* 2008; 16: 1-22, p.1.

<sup>2</sup> Ibid.

<sup>3</sup> *Re T*. [1992] 3 W.L.R. 782, p.121.

<sup>4</sup> *Re T*. [1992] WLR 787.

<sup>5</sup> *Airedale NHS Trust v Bland* 12 BMLR 64 (HL), at p80 [[1993] 1 All ER 821

confirmed the judgement in *Re T* that adults have a right to refuse medical treatment even if it results in their death; also, C's decision was binding even if he should become incompetent in future.<sup>6</sup>

Another relevant case was that of AK, a young man who suffered from motor neurone disease and as a consequence was "locked in" to his body, with no ability to communicate. He had previously been able to use his toe to operate a computer, and then to indicate "yes" or "no" by moving his eyelid, but even these minimal methods of communicating were no longer available to him. Two weeks after he had lost all ability to communicate, the hospital sought permission to remove life support as he had requested in advance of losing his physical capacity. The judge in this case stated simply that:

Motor neurone disease does not affect intellectual capacity. AK can hear, see, think and understand. He is no sense impaired in his brain or in his rational processes. It follows that he has, in addition to his terrible physical disability, the quite appalling burden of fully understanding it. It also follows that he is capable of forming his own wishes about matters including about his future. He has, I am satisfied, done so and with what some may think is no little courage.<sup>7</sup>

AK's wish was granted and he was allowed to die. (Of course, the danger of ADs in such circumstances is that there is no way of knowing whether the patient has changed her mind, but there is a similar concern in dementia cases, as we shall see).

One very recent case is also worth mentioning briefly here. Kerrie Woollorton was allowed to die after ingesting antifreeze because she refused treatment on arrival at casualty. The case made the headlines, however, because Woollorton also had an AD that stated she wanted to die and refused all treatment. Other relevant aspects to the case were that she had dialled the ambulance herself and had drunk antifreeze on nine previous occasions but had accepted treatment, and that she also suffered from a personality disorder. Woollorton had stated that she had called the ambulance on this last occasion because she didn't want to die alone and in pain. Predictably, many stories appeared in the media suggesting that this was a travesty and that she should have been saved, and that living wills shouldn't apply in such cases. Sheila Maclean has correctly stated that the AD element of this case was a red herring, as Woollorton was deemed competent to refuse treatment before losing consciousness. However, she goes on to state:

had Ms Woollorton arrived at hospital in an unconscious state and with no advance directive, the chances are that doctors would have done everything in their power to save her, and this would have been justified by the legal doctrine of necessity. Had she arrived unconscious but with an applicable advance directive, equally no attempt at treatment would have been lawful.<sup>8</sup>

The first part of this is correct, but if she had arrived unconscious it seems quite likely that the previous nine attempts would cast sufficient doubt on the applicability of the directive; as Justice Munby stated in the case of *HE v A Hospital NHS Trust*, "if there is doubt that doubt falls to be resolved in favour of the preservation of life."<sup>9</sup> Assuming that the doctors knew that she had changed her mind nine times before, how could they know that the AD was valid? Indeed, how could Woollorton know that she wouldn't change her mind again? These are counterfactual considerations, but

---

<sup>6</sup> JK Mason and GK Laurie. *Law and Medical Ethics*. P. 375

<sup>7</sup> *Re Ak*. [2000] 58 BMLR 151 at 154

<sup>8</sup> S Mclean. *BMJ* 2009;339:b4112

<sup>9</sup> *HE v A Hospital NHS Trust* [2003] EWHC 1017, para 23

they do raise some doubts about the chances of an AD being respected in an emergency situation.

## Legislation

In England and Wales, the aforementioned cases were to some extent superseded by the Mental Capacity Act (2005), which enshrines ADs in law. It states that

“Advance decision” means a decision made by a person (“P”), after he has reached 18 and when he has capacity to do so, that if— (a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and (b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.<sup>10</sup>

The MCA also allows for verbal ADs, and insists on written and witnessed ADs only in the case of refusal of life-sustaining treatment. This all seems straightforward enough, and it is also made clear that no-one will be liable for continuing to provide treatment while a court examines the issue of whether an AD exists, is valid, or is applicable to a treatment.<sup>11</sup> However, the MCA adds several caveats, notably that an advance decision is not valid if the patient “has done anything else clearly inconsistent with the advance decision remaining his fixed decision”<sup>12</sup> or 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”.<sup>13</sup> These are also big “ifs”, and we shall return to them during the theoretical analysis of ADs later in this paper.

## ADs in Different Situations

Before proceeding to a theoretical analysis of ADs, it is worth pointing out that there are several different situations in which an AD could be brought to bear. First, a patient might have drafted an AD for situations where she has temporarily lost consciousness but wishes to refuse certain treatments; an example would be a properly produced and witnessed AD refusing blood products for a Jehovah’s Witness, in a similar manner to the rejected directive in *Re T*<sup>14</sup>. (Of course, if the directive is followed in a case where transfusions are essential, the loss of consciousness is very likely to be permanent. Another problem with ADs is that the verbal variety lends itself to distorted representations by family members: in *Re T*, if T’s mother been consulted she would probably have said T refused blood and T would have died.) Second, a patient might be suffering from a degenerative physical illness that will ultimately render them into a situation like that of *AK*<sup>15</sup>, and want treatment to be withdrawn in such a situation. Third, a patient might have a more

---

<sup>10</sup> Mental Capacity Act (2005). Section 24(1)  
[http://www.opsi.gov.uk/acts/acts2005/ukpga\\_20050009\\_en\\_3#pt1-pb6](http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_3#pt1-pb6)

<sup>11</sup> Mental Capacity Act (2005). Section 26(4)

<sup>12</sup> Mental Capacity Act (2005). Section 24(2)(c)

<sup>13</sup> Mental Capacity Act (2005). Section 25(4)(c)

<sup>14</sup> *Re T*. [1992] 3 W.L.R. 782

<sup>15</sup> *Re AK*. [2000] 58 BMLR 151

general directive stating that, should they enter a permanent vegetative state like Tony Bland<sup>16</sup>, they would want all treatment (and nourishment) to stop. And finally, a patient might fear the permanent irreversible loss of competence brought about by dementia, like Margo in Ronald Dworkin's famous case<sup>17</sup>. We shall see that some of these categories are a lot more practically, legally and ethically problematic than others.

## Autonomy and Best Interests

The purported purpose of ADs is to allow the incapacitated patient to maintain control over what happens to her by allowing her to refuse certain treatments in advance. ADs thus allow patients to exercise their autonomy without anyone having to try to second-guess what is in their best interests. Unfortunately, there are a number of problems with this high-minded concept. In cases where an AD is valid, situations involving temporary loss of consciousness and permanent loss of physical capacity might seem straightforward, but we have already seen the problems that arose in *Re T*, and it is possible (though unlikely) that AK might have changed his mind once he became fully "locked-in", but was unable to express this change of heart. Nonetheless, if we remove the complicating factors of *Re T* and accept that AK was perfectly able to anticipate what it would be like to be entirely locked in (we will return to the issue of foresight later), we can see that ADs might be very useful to patients in such cases, and would indeed enhance their autonomy by allowing them to express and protect their best interests. But what about cases like those of Bland and Margo?

There is not space here for any in-depth consideration of the Bland case. He was a patient in a permanent vegetative state, and the debate centred on how to justify legally what was clearly in his best interests: allowing him to die. Had Bland signed a valid and applicable AD, things would have been a lot simpler, as the courts would not have had to come up with such tortuous excuses for legitimising his death. However, it could equally be argued that "the law is an ass" in this particular regard<sup>18</sup>, and all patients in PVS should be allowed to die, whether they have an AD or not. If we accept that miracles are unlikely, it is entirely futile to keep such a patient alive. As Derek Morgan states, "Tony Bland's doctors wanted to discontinue the treatment that *they* had concluded was futile."<sup>19</sup> The issue of withdrawing support from PVS patients is outwith the scope of this paper, but it seems plausible that a case could be made that futility should be the deciding factor in such cases and ADs are not really necessary.

In his famous example of a dementia patient, Dworkin describes Margo as a 54-year-old woman who suffers from dementia but is very happy. She has contracted a chest infection and will die without antibiotics; normally, such a person would be given the treatment and probably survive, but the complicating factor in Margo's case is that she has signed an advance directive refusing any life-saving treatment in the event that she is demented.<sup>20</sup> Should the directive be binding, and must her doctors allow Margo to die? If ADs really do respect the patient's autonomy, why should we overrule them?

---

<sup>16</sup> *Airedale NHS Trust v Bland* [1993] 12 BMLR 64

<sup>17</sup> R Dworkin, *Life's Dominion*. Harper Collins 1993.

<sup>18</sup> C Dickens.. *Oliver Twist*

<sup>19</sup> D Morgan. *Odysseus and the binding directive: only a cautionary tale?* *Legal Studies* 1994: 411-442, p. 418.

<sup>20</sup> R Dworkin, *Life's Dominion*. Harper Collins 1993, p.226.

Perhaps the most obvious answer is that respecting the AD would not be in demented Margo's best interests: she has a life worth living, even if competent Margo would not have wished it for herself. The question is no longer what is in Margo's best interest, but which Margo's best interests we should be protecting; if we hold to the morally persuasive but legally difficult 'different persons' theory put forward by Derek Parfit, the two Margos are in effect different people because there is no psychological continuity between them.<sup>21</sup> It could well be argued that respecting Margo's AD involves disrespecting the autonomy of the demented person in favour of that of her earlier competent self. Let's call this the different person argument. (Another problem is that, when she wrote the AD, Margo was engaging in an attempt at self-determination, but the problem is that her future self was not yet determined, so she could not know whether she would be happy demented - see the next section for more on this point.)

In an acknowledgment of the different person argument, Dworkin describes the problem in terms of there being two types of autonomy at play here: as Alasdair Maclean puts it, "Focusing on prospective autonomy makes the competent person the morally relevant subject, while the backward-looking 'precedent' autonomy recognises the incompetent person as the subject."<sup>22</sup> Dworkin also makes the further distinction between critical interests, which only competent people have, and purely experiential interests, which are the only interests that demented Margo has. Because critical interests are more important, Dworkin argues, the AD should remain valid and Margo allowed to die, because her interests are more morally relevant; thus prospective autonomy is paramount: this is his *critical interests* argument. But it should be borne in mind that the directive only comes into force once Margo becomes demented, and in a very real sense becomes a different person. This would tend to suggest that the focus should now shift to the person who is currently in existence.

Dworkin makes the two perspectives of precedent and prospective autonomy sound equally valid. But when we remember that ADs only affect the future 'different person', a massive asymmetry emerges: precedent autonomy actually disrespects the principle by having someone who is unaffected by an illness dictate what will happen to another person (or at least her later self), thus completely negating that future person's (or self's) autonomy. Decisions affecting persons should be made by those who will be affected: in the normal run of medicine, this statement is obvious as to hardly need mentioning. Incompetent patients do sometimes need to have others make the decisions for them because they can't do it themselves. But there are many people who are much better placed to decide what is better for a demented person than his or her earlier self, not least because they are actually there at the same time as the demented person, unlike the previously competent patient. If we accept that demented patients are really different people, it is hard to see why their earlier selves should have a veto over their continuing life; as Maclean says, "Kuhse still needs to explain why the competent Margo, rather than someone else, should be allowed the authority to terminate the life of the demented Margo."<sup>23</sup> Demented patients might not be able to articulate that they want to keep living, but if they seem to want to, why should this 'decision' not be respected?

---

<sup>21</sup> D Parfit. *Reasons and Persons*.

<sup>22</sup> A Maclean. *Advance Directives, Future Selves and Decision-Making*. *Medical Law Review* 24, 2006: 291-320, p. 295.

<sup>23</sup> *Ibid.* p.306.

There is also a more fundamental self-contradiction at play here: the reason that autonomy has assumed paramount importance in biomedical ethics is that patients know their own interests better than their doctors (who may know medically what's best); autonomy is valued largely because respecting it leads to the best results for the patient via letting him decide what is best for her.<sup>24</sup> But enforcing ADs on now-demented patients entirely misses this point: if the patient is happy and has a life worth living, it should be obvious that what they want is to carry on doing so, even if they are not competent enough to express this wish. It does not serve autonomous interests in any way to honour the wishes of their previously competent selves. As Erwin Bernat puts it, "if...the life of the incompetent patient at  $t_2$  is free of pain and seems to be happy, the proposition that it is in the best interest of the patient at  $t_2$  to let him die is not free of inconsistencies."<sup>25</sup> Dworkin's argument seems to overlook the possibility that demented patients can be happy without having any critical interests; they nonetheless have an interest in being demented rather than being dead. We can call this the demented interests argument.

Dworkin defends his critical interests argument against the attack of the different person argument by claiming that we allow parents to make decisions for their children, and they are obviously not the same person. He concludes that psychological continuity is therefore not necessary in order to make binding decisions. But this overlooks two points: first, parents exist contemporaneously with their own children, and can change their decisions if they don't seem to be working out; the same is not true of people and their future demented selves. Second, parents are not allowed to choose to let happy but mentally disabled children die, which is what competent earlier selves do to the different person that they will become with ADs.

If we were to approach a person considering drafting a directive similar to Margo's, we could ask them why they would want to die if demented. He or she might well answer because they wouldn't be the same person any more, and this indicates the fundamental absurdity of ADs for demented patients: they only become applicable when the competent person has disappeared, but once this has occurred they lose any moral authority they had. This point can be used to draw a distinction between dementia ADs and the three other types described above: in all the other cases, the AD applies when there is no longer a patient present from whom we can establish their best interests. In cases of irreversible but not total loss of mental function such as dementia, while the patient is not competent to refuse or consent to treatment, we can nonetheless observe them and say whether her life is worth living; in other words, whether she has demented interests. Just as ADs should not be necessary for cases like that of Tony Bland because futility should be the decisive factor, so they are not necessary (or valid) in cases where continued care is clearly not futile due to the patient's happy if demented life. As the patient advocacy group CARE put it in evidence to a House of Lords select committee: "it would be bizarre in the extreme to require a skilled, professional doctor to adhere to the stipulations of a living will which did not accord with his/her expert opinion of what would be in the best interests of the patient's health."<sup>26</sup> (Of course, if an AD is regarded as invalid, consent to Margo's antibiotics treatment will have to come from somewhere – depending on the jurisdiction this could come from a welfare attorney or her main clinician. It should also be remembered that in some cases mildly demented patients

---

<sup>24</sup> T Beauchamp and J Childress. *Principles of Biomedical Ethics* (Sixth edition).

<sup>25</sup> E Bernat. The living will: does an advance refusal of treatment made with capacity always survive any supervening incapacity? *Medical Law International*, 1999, 4: 1-21.

<sup>26</sup> House of Lords Select Committee on Medical Ethics, at 196. In D Morgan. *Odysseus and the binding directive: only a cautionary tale?* *Legal Studies* 1994: 411-442, p. 424 (ref 80)

can make competent decisions, but for the purposes of this paper we are focussing on the seriously demented who cannot.)

Dworkin's response to the demented interests argument would be that the person either has critical interests, in which case an AD would not be valid, or they don't, in which case the AD must be enforced. But as already stated, it is not clear why it should be, if the person is demented but happy. It can also be argued that Dworkin's argument is discriminatory: if someone were born disabled and incapable of critical interests, but still happy, we would still treat them if they became incompetent, and there would be an outcry if a doctor withheld treatment because he were only capable of experiential interests. Why should it matter that someone *once* had critical interests? Dworkin basically seems to be arguing that the lives of those who were once not disabled are worth less than those who were always disabled. A similar concern arises with regard to euthanasia: people who sign ADs refusing life-sustaining treatment are effectively consenting to their euthanasia (by withholding of that treatment) some time (perhaps years) in the future. This seems logical given that patients enjoy the contemporaneous right to refuse treatment. But one of the principal reasons given for denying people's requests for active euthanasia is that this put the vulnerable at risk. Is the same not true of competent people sanctioning years in advance the euthanasia of their future selves?

In further defence of his belief that prospective autonomy is more important, Dworkin also argues that life is a narrative unity, so the focus should be on the "overall shape of the kind of life he wants to have led". It is true that, from the perspective of the Greek concept of *eudaimonia*<sup>27</sup> (flourishing across one's whole life, and also the way one is viewed after death), it would be better to respect ADs, as people's memories of a person would be coloured by seeing their dementia. However, it is only from other people's perspectives that a demented person's life maintains a narrative unity, so it is difficult to see the relevance of this or *eudaimonia* from the demented person's perspective. A similar approach might be to argue that we should respect AD out of respect for a patient's integrity, but the different person argument raises serious doubts about this very issue; if the person has changed so fundamentally, what does it really mean to speak of their integrity?<sup>28</sup>

In a similar vein, Michael Quante has argued that the persistence of the human organism is sufficient grounds for holding that there is continuity between the non-demented and later demented selves.<sup>29</sup> There is not room to explore this view here, but it does not seem plausible. Quante argues that "we do not have to distinguish clearly between our being human beings and our being persons", but why should an organism who doesn't want to die be allowed to because an earlier version of the same organism thought it would probably want to? Quante's approach changes the terms of the debate about dementia and directives without really advancing it.

Perhaps the most obvious and least practical solution to the problem of ADs for demented patients would be to put the different persons theory into action, and acknowledge that the person who was Margo actually died when she became demented. Theoretically, many people believe this anyway, and giving the status legal force might make things a lot easier, as Maclean has suggested.<sup>30</sup> There could be no question of demented Margo being bound by a dead person's AD, and there

---

<sup>27</sup> D Shaw. Euthanasia and Eudaimonia. *Journal of Medical Ethics* 2009;35:530-533.

<sup>28</sup> Thanks to an anonymous reviewer for this point.

<sup>29</sup> M Quante. Personal identity between survival and integrity. *Poiesis & Praxis* 2005: 145-161.

<sup>30</sup> Maclean, 2006, op cit., 299.



would possibly be less distress for her family at seeing her in a demented state – which itself might have been one of the reasons she wrote an AD in the first place.

## Consent

Some commentators seem to think that the Margo problem is the key dilemma for advance directives; John Davis states that “if advance directives lack moral authority, there is no reason to work on solving the practical problems”<sup>31</sup>. But this overlooks the earlier point that there are many situations where ADs could be applicable and valid, and dementia is only one of them. Even if the aforementioned problems with ADs for demented patients did not exist, there are a number of issues centered on whether patients are properly able to refuse treatment so far in advance, some of which also concern patients like AK (but not patients like Bland and T).

The MCA Code of Practice reiterates that ADs must meet the three criteria of existence, validity and applicability.<sup>32</sup> Each of these has its own potential problems. Issues concerning the existence of ADs are most relevant in emergency situations, where it might not be clear whether a directive exists at all. The Code makes it clear that doctors only face prosecution if they treat someone in the knowledge that an AD exists and is valid and applicable, and that they should “not delay emergency treatment to look for an advance decision if there is no clear indication that one exists”. Even if a patient were to gasp that they had an AD before lapsing into unconsciousness, doctors would be unlikely to delay resuscitation (for example) while trying to establish whether the directive prohibited that particular intervention.

Applicability is more complicated, largely because of the difficulty of drafting ADs in such a way that they will accurately represent a patient’s wishes. If Alex signs an AD refusing all blood products because he is a Jehovah’s Witness, and is then critically injured in an accident, one would normally expect doctors to honour his refusal. But what if, in the intervening years, the Watchtower Organisation has rescinded its ban on blood products, and Alex was either not aware of this or had not bothered to withdraw or clarify his directive? It could well be argued he would not refuse blood if he were conscious and knew this, so the AD is not applicable in these circumstances. Of course, if the original directive had stated specifically that he did not want to receive any treatments specifically forbidden by his religion, the AD would still be applicable and he could be given blood without disregarding it. In other words, if people are clear about the reasons behind their advance decisions, questions regarding applicability will be much easier to resolve.

The thorniest of the three criteria, however, is validity. As the Code states, “it is important to be able to establish that the person making the advance decision was 18 or over when they made their decision, and that they had the capacity to make that decision when they made it”,<sup>33</sup> in line with the test laid out elsewhere in the Code. However, it is actually Chapter 3 of the Code that raises most issues regarding ADs. (Interestingly, the Code discusses the issue of the capacity of the person who made the advance decision under the “existence” heading rather than “validity”.<sup>34</sup> This seems inappropriate, as an AD can exist whether or not the person who it concerns

---

<sup>31</sup> JK Davis. Precedent Autonomy, Advance Directives, and End-of-Life Care. In B. Steinbock (ed.). *The Oxford Handbook of Bioethics*. Oxford University Press, 2007, 349-374.

<sup>32</sup> MCA Code of Practice, section 9.38, p.169.

<sup>33</sup> MCA Code of Practice, section 9.39, p.169. [www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf](http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf)

<sup>34</sup> MCA Code of Practice, section 9.39, p.169.

was competent at the time; one would think that this would actually call validity into question.)

The very first question that is asked in the chapter on helping people make decisions in the MCA Code of Practice is: “Does the person have all the relevant information they need to make a particular decision?”<sup>35</sup> In the case of ADs, the answer to this question is very possibly “no”. We have already mentioned the possibility that a demented patient might not be able to accurately predict whether they would be happy once demented. In the previous section, this formed part of my argument that existing ADs should not be enforced in cases where demented patients have lives worth living. But it is quite possible that such directives were not even technically valid in the first place, for the simple reason that the competent person had insufficient information about their future condition – and this criticism is not limited only to cases involving dementia. (Although in this latter case the criticism is strongest: how could someone know how a different person would feel about being demented?)

Although a patient may have capacity and be uncoerced, her refusal must also be informed. On a basic level, then, ADs face the problem of technical ignorance: a person might misunderstand their prognosis. While most patients are able to decide on the options available to them *now*, it would take a great deal of explanation and time to explain and get the patient’s opinion about different potential scenarios that may come to affect them in the future. In this sense, the information criterion for valid refusal might not be met, precisely because it is an *advance* directive. Maclean states that “there is no formal requirement that the author of an advance directive be sufficiently well informed to make a reasonable decision”,<sup>36</sup> but the MCA Code states that sufficient information is necessary (although it does not mention reasonableness). Normally reasonableness is not a requirement for an autonomous decision, but it could be argued that decisions that will affect a person’s future demented self should be held to at least a low standard of reasonableness, given that he or she is a different person to some extent (unfortunately there is not room here to explore this notion).

When we think again of Margo, this seems like an absurd situation: in order to refuse treatment, a patient must have sufficient information in order for that refusal to be valid. Why should a future self be bound by a decision made by a younger self who did not have enough information (even if it were possible to obtain it)? In this sense, the standard for refusal is set lower for ADs than for normal refusals. Maclean is quite right when he states that “the impossibility of predicting exactly what the future would be like means that any advance decision must be one made in ignorance and so, while it may be self-determining, it is not autonomous.”<sup>37</sup> Thus the paucity of information about their future states may render some patients’ ADs invalid. Meeting the standards of the MCA is a legal requirement, but there are obviously ethical reasons to respect the requirement of sufficient information; the reason that we seek informed consent is so that a patient knows what they are agreeing to, which is of even more importance when it comes to the issue of ADs. Information is essential to respecting a patient’s autonomy.

Some have speculated that “we might wonder whether courts will require a higher standard of competence from making an advance directive than from a patient refusing treatment while competent” (with regard to [2005] 1 W.L.R. 834) but this is

---

<sup>35</sup> MCA Code of Practice, section 3, p.29.

<sup>36</sup> Maclean, 2008, op cit., p.14.

<sup>37</sup> A Maclean. 2006, op cit., p. 292.

not quite right: although a high standard of competence may be necessary, the point is that the advance director must meet the *same* standard of information and understanding as is normal – but this standard indeed requires *more* information at the time of writing the directive because the patient is required to consider many different scenarios rather than her immediate one, which is normally all that is necessary when refusing or consenting to treatment. Even if we don't accept the different persons theory, it could well be argued that no-one could ever give valid consent to an AD refusing treatment after the onset of dementia because no-one can know (a) what it's like to be demented, and (b) whether their demented self would be happy demented. If Margo is demented and dying and needs antibiotics and wants them, we would give them to her. While such patients might not have any higher-order autonomous critical interests, the closest we can get to respecting their autonomy is to do what they (seem to) want.

It might be objected that my argument rests on too strong an information requirement for refusal. But the MCA Code states that “healthcare officials must try to find out if the person would have changed their decision if they had known more about the current circumstances.”<sup>38</sup> This is perhaps unfortunate phrasing, as almost anyone who signs or verbally expresses an AD will know less than they would know at the time the AD may come into effect: nevertheless, it seems clear that, in some cases at least, people would very probably change their decision if they knew more, for the simple reason that they didn't know enough when they signed the AD.<sup>39</sup> Furthermore, as stated earlier, the MCA itself states that ADs may not be valid 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”<sup>40</sup>. In the case of dementia, a person could simply not have enough information to anticipate whether she would be happy in such a state – even if she is certain that she would hate to see herself in such a state. In non-dementia cases, it is also possible that patients simply would or could not have enough information for any AD to be valid.

Another potential objection is that we frequently make decisions without knowing in advance how we will feel in the future. For example, having a child might seem like a great idea now, but I might regret it in future and there won't be anything I can do about it then.<sup>41</sup> But it seems reasonable to argue in response that dementia is qualitatively different from having a child or getting married; it changes the person that you are more fundamentally than other life events. In a sense, it is precisely because dementia is a mental disability that reduces capacity that we cannot predict what we'll feel like when we have it. If I have a child I will still be the same person when that happens, and will still be capable of autonomous decision-making.

A more reasonable objection is that being happily demented is simply one other possibility that people who are drafting ADs need to be made aware of; if they want their AD to be inapplicable if their future self appears to be happy, they can include that as one of its conditions.<sup>42</sup> This is a sensible suggestion for people who have not yet drafted a directive, but it seems likely that many currently competent people would rather die than be demented, regardless of how happy they might be in their diminished mental state, which returns us to the problem of enslavement of future

---

<sup>38</sup> Moodle.

<sup>39</sup> MCA Code of Practice, section 9, p.159.

<sup>40</sup> Mental Capacity Act (2005). Section 25(4)(c)

<sup>41</sup> Thanks to an anonymous reviewer for this point.

<sup>42</sup> Thanks to an anonymous reviewer for this point.

selves. And again, some people might simply not believe that they could ever be demented and happy, which returns us to the problem of insufficient information.

Any statute concerning ADs would have to forbid under-specificity such as “don’t want to become senile”; definitions must be provided to support such statements. But over-specificity requires foreknowledge that simply does not exist, and might well encounter the problem of technical ignorance mentioned above. If ADs are to be any use at all, a balance must be struck: reasons must be given for directions, and the directions must be neither too general nor too specific. As already mentioned, it would help if people drafting ADs were very clear about their reasons. There is also the issue of ignorance of future value changes: a person may completely change their mind, making their AD invalid. But again, this could be addressed by updating the directive accordingly.

## Conclusion

Overall, the problems raised in this paper suggest that legislating for the use of ADs in all circumstances is unwise at best and could lead us towards the nightmare world envisaged by Bob Dylan in ‘Desolation Row’:

Now his nurse, some local loser; she’s in charge of the cyanide hole  
And she also keeps the cards that read “Have Mercy On His Soul”.

Many people would be better off without such a card dictating when they will be allowed to die, even if cyanide is not involved. We have seen that ADs only facilitate autonomy and best interests in certain circumstances. This table indicates the possible problems with ADs in different situations.

	Temporary loss of capacity (cases like T)	Permanent total loss of physical capacity (AK)	Permanent total loss of consciousness (Bland)	Permanent total loss of capacity (Margo)
Existence	√	√	√	√
Validity	√	√	√	X
Applicability	√	√	X (no more than futility)	X

In cases like that of T, assuming the particular problems of that case were removed, ADs can play an important role. They can also be useful in cases like that of AK, although cases of patients with “locked-in” syndrome present the particular problem of not being able to tell whether they have changed their minds about wanting treatment to cease. In cases like that of Tony Bland, ADs could make things easier, but would be unnecessary if futility were used as the criterion for withdrawing treatment. And in dementia cases, for the numerous reasons outlined above, they do not respect autonomy and should be avoided.

Another problem, as we saw in the previous section, is that there is a risk in all situations that patients don’t have enough information about what they’re refusing in advance, thus invalidating their ADs. The MCA and its accompanying code, if taken at their word, would invalidate many ADs, so it should be made clear to people considering drafting one the limitations of the current system. Advance directives have good intentions, but all too often the consequences that follow from honouring them are not what was foreseen.