

Dementia, Death and Advanced Directives

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People generally express the view that they do not want life-extending treatment if they become ill while severely demented. The Dutch minister of health, some years ago stated that in case she became demented, she would not want to be kept alive if she would be unable to recognize her family and friends (Widdershoven 2001a: 179).

Those sympathetic to the view of the Dutch minister of health may argue that if they became severely demented or mentally incapacitated in other respects, they would not wish to have life-extending treatment, and to 'die with dignity'. One possible way of facilitating this would be to allow 'living wills' or 'advance directives', whereby individuals, while still mentally competent, set out their instructions for treatment if they were to suffer dementia or similar incapacity (Hope, 1992, Brock 1993). On the face of it, advance directives are to be welcomed. They appear to respect the autonomy and dignity of the patient, and release the patient's family from agonising decisions when the patient is no longer in a position to exercise his or her own judgement.

One moral philosopher who argued forcefully to be permitted to set out an advance directive is Soran Reader. Soran had just been diagnosed with a brain tumour and was advised to have a biopsy. However given the location of the tumour the biopsy alone would have been a highly dangerous procedure and could have killed her or left her severely brain damaged. As it happened the biopsy did not take place and a

different course of action was followed. But at the time she thought she was due for the operation she wrote a passionate article in the *Times Higher Education Supplement* arguing for the right to make a living will:

I believe with Hannah Arendt that our first duty is to think. To face this surgery, I have to think the real but unbelievable possibility that when I come round, I may be unable to think, remember or speak.

In all that mind-blowing horror, though, the possibility that really threatens to break me is that I may be unable to remember my children. I have already had a glimpse of life without those memories. During recent seizures, I lost my memories of when my daughters were born. The loss of mere dates may seem trivial, but the abyss it has opened to thought is terrifying, a glimpse of my life without my connections and my history.

I am certain that I do not want to live on if that happens. I am terrified by the spectre of loss of self. But I am out of my mind with anger that my own country does not allow me to protect myself and my family from this horror safely. I am anguished at the thought that my children, on top of their grief at the loss of their mother, may have to cope with me as someone else, someone lost in the world or in a vegetative state (Reader, 2009).

One can, I believe, have a great deal of sympathy for Soran Reader's position. Yet she would be the first to emphasise that there are many different possible cases to consider – a range of different possible futures – and morally it is quite likely that they are not all on a par.

The most straightforward case to think about is that in which the future person has no conscious mental life. This is what Soran Reader refers to as a 'vegetative state'. Yet

she also contemplates a second possibility, that she survives as 'someone lost in the world'. This, itself, could be interpreted in a variety of ways. Although Soran Reader is considering other possibilities, the different possible ways of being 'lost in the world' can be illustrated by considering people with moderate to severe Alzheimer's disease and other forms of dementia. In the worst cases life is experienced primarily in highly negative terms. In such a state people are often confused, frustrated, anxious, and distressed at being unable to recognise people around them or their surroundings. They are unable to gain much, if any, pleasure from activity. At the other end of the scale are people like 'Margo', introduced into the literature by Andrew Firlik (1991) and discussed by Dworkin (1993) and Dresser (1995). Margo seems contented and reports enjoying reading mystery stories, and art classes, yet when reading appears to jump from page to page at random, and always paints the same picture time after time.

Now it may be that Margo also has moments of torment, and it may also be that the majority of Alzheimer's patients resemble both extremes: they have good days and bad days. However for the purposes of this paper I shall primarily discuss the extreme cases, as my purpose is not to give a definitive guide to the permissibility of advanced directives, but rather to consider the circumstances under which they may be particularly morally troubling.

There are also other situations where living wills or advance directives are also relevant, such as those of temporary psychosis, especially in cases of bipolar disorder or schizophrenia, where one may wish to bind doctors to override treatment preferences expressed during a psychotic episode. These have been called 'Ulysses contracts' (Widdershoven, 2001b). However in order to keep the current discussion within bounds I will leave such cases aside. But I do need to introduce one further situation: where a person emerges from a procedure, such as a brain operation, and to all appearances is capable of autonomous thought and action, but has lost connection with the earlier self through changed values and/or lost memories.

Not only do the circumstances of the future person vary, so too does the scope of, possible advance directives. They can contain instructions to cover a range of situations. So, for example, they could cover issues that are often, if not always, ethically relatively uncontroversial, but personally vital, such as whether one wishes to be cared for at home or move to institutional care. But they can also cover ethically more difficult questions about whether one should receive life-extending treatment. This, naturally, shades into a third area, of passive euthanasia, where life-preserving measures are withdrawn. And finally, there could be directives to carry out physician assisted suicide (active euthanasia) in certain circumstances.¹

Although there are very many other possibilities, we have simplified to a point where we have four states of a human being and four types of treatment options, which therefore generates sixteen focal types of cases that advanced directives could cover, as set out in the grid below:

	Particular Care Options	Do not pursue life saving interventions	Remove life-preserving equipment	Actively bring about death
Persistent Vegetative State				
Conscious				

¹ In reality, of course, Alzheimer’s patients often have a co-morbidity, such as cancer, and sometimes their death is hastened by the use of high doses of pain killers in a highly ambiguous fashion, where the exact purpose of the high dose is not brought to the surface. However it is very hard to see how such treatment could explicitly be allowed for by means of an advanced directive, where, given the nature of the document, the terms must be set out very clearly.

awareness, no autonomous capacity, life a torment				
Conscious awareness, no autonomous capacity, life contented				
Autonomous capacity but no memories and/or changed values				

Roughly, as we travel from top left to bottom right of this grid, matters become more troubling. No objections can be made, surely, to advance directives about care if one were to fall into persistent vegetative state (unless the obligations on others were especially onerous). Yet the bottom right hand cell is the demand for active intervention to end the life of an autonomous person, even against their will. In other circumstances this would be considered simple murder.

On the face of it, though, Soran Reader is arguing for the opportunity to make advance directives in the bottom right hand area of the grid. She maintains that does not want her life to continue if she emerges from the procedure 'lost in the world' unable to recognise her children. She is a step beyond – possibly two steps beyond – the Dutch minister who only asked to be spared life-extending treatment. Now it may be that Soran Reader was supposing future situations in which either she had

no future experience or that her future situation was one of overwhelming misery. But consider another case in which someone were to emerge from the procedure 'lost in the world' but able to take pleasure in food and listening to music, analogous to the situation of Margo. Could it possibly be right that anyone should be bound by an advance directive to administer to her a lethal injection? Physician assisted suicide is clearly the most ethically difficult issue. It is currently not legal in the UK even for those who retain full autonomy, and so providing such a possibility as part of an advance directive would be a huge step.

Generally, in dementia cases there are special reasons for concern. As many authors have noted, there is a question about the degree to which personal identity is preserved through the changes in mental state that can characterise dementia (e.g. Hope, 1992), raising the question of whether an advance directive is in effect one person's decision about another person's continued existence. There is also a general question about the autonomy with which advance directives are formulated. Presumably there are cases where setting out an advance directive is a result of implicit family or social pressure, rather than a real expression of values (Gastmans and de Lepeleire 2010, p. 83). I will leave both these considerations to one side here, however, as I want to pursue a different issue, about prediction and adaptation. I will introduce this by means of the now well-known disability paradox, which highlights the point that those who have not experienced a condition may well provide a valuation of it that is at odds with the valuation of those who do, and there is, therefore, a question of which valuation to use (Wolff et al 2011).

Consider first a study undertaken in the early 1980s when the Department of Transport asked Michael Jones-Lee and associates to consider the question of how the negative cost of motor accident injuries should be valued. The Department operated with a distinction between death, serious injury and injury, and wanted to put a relative financial valuation on the different categories, for the purpose of safety cost-benefit analysis. Early on it was discovered that the department had no

definition of the distinction between serious and non-serious injury, and so the first stage of the study was to ask the public whether they regarded certain consequences of accidents as serious or non-serious.

Around 1100 people were surveyed and were asked how they regarded various conditions. They were asked whether they regarded them as:

- i) Not Serious
- ii) Serious but death worse
- iii) As bad as death
- iv) Slightly worse than death
- v) Much worse than death
- vi) Very much worse than death

One might feel that there is a somewhat morbid emphasis on the degrees in which something can be worse than death in this schema, but in any case the results are interesting. The most minor condition was 'Cut and bruised but can leave hospital with a couple of days and recover fully within a month.' 81% said not serious, and the remaining 19% judged it serious, but not as bad as death.

At the other end of the scale were the conditions 'Confined to a wheelchair for the rest of your life' and 'Permanently bed-ridden'. Of these roughly half, and two-thirds, respectively, rated them as bad or worse than death. That is to say, only half the people surveyed thought it better to be confined to a wheelchair for life than dead, and only a third thought this of being permanently bed-ridden. (Jones-Lee, 1985, p. 54).

Yet, as is now well known, when we switch perspectives and ask people with serious disabling conditions about the quality of their life, we receive unexpected, quite different, answers. In a famous study Albrecht reported that more than 50% of people with serious disabilities report an excellent or good quality of life. This he terms the 'disability paradox'. He reports that within his sample that the main cause

of poor quality of life is episodes of intense pain, and great fatigue, and, to some extent, lack of physical or mental control.

The moral of this comparison is to make explicit a point that has been noted in the literature about advance directives in dementia care: can the earlier self really think itself into the position of the later self? (Hope, 1992). Like the Dutch minister of health, many of us dread the onset of dementia, just as we would dread becoming permanently confined to a wheelchair. But in the latter cases the evidence is that many people adapt very successfully to those conditions. May that not also often be the case with dementia? Dementia is very often hugely demanding on carers. Is it also (always) so demanding on the person with dementia?

Consider again the physical disability case. It may be that one of the people who in the Jones-Lee study rated being confined to a wheelchair as 'very much worse than death' might have written an advance directive asking for active euthanasia if this became their fate. Imagine now, by tragic coincidence, it does, and they are paralysed, believing it to be temporary. After a year in a wheelchair it becomes clear that the paralysis is permanent. The advance directive now applies. However, suppose that in that year the individual has achieved sufficient adaptation as to now report a good quality of life and no wish to die. Nevertheless, the doctor points to the advance directive and suggests that everyone is morally and legally bound to follow it, and active euthanasia is required. This would be the most horrifying form of 'Ulysses contract' where an earlier declaration of values and preferences is taken to override a later set. I take it that it is not controversial that the correct solution here is for the advance directive simply to be ignored, and explained away as an example of the difficulty of predicting how anyone will respond to future situations.

Now the dementia case is not the same as this, as the person suffering from severe dementia will have lost the ability to make autonomous choices. They may, of

course, be able to express their values in other ways (Jaworska, 1999) but even if that is not so, they may be able to derive various forms of pleasure and enjoyment from life, as noted earlier. If that is so – and for as long as their life is not a torment to them – then to follow any advance directive that leads to an earlier death than might otherwise have been achieved, defers to earlier autonomous choice rather than current well-being. Can this be justified?

In fact, we are very used to situations in which early choice overrides later well-being. Many contractual situations take this form, where my previous agreement to do something takes precedence over my current desires. However these are situations where, typically, someone else is relying on my performance, and there are a variety of good reasons to hold people to commitments they have made to others. An advance directive, however, does not involve third parties in the same way, and if it is to be enforced in circumstances where the person has a fair quality of life then special reasons need to be given.

On one view, if the person suffering from dementia is able to sustain a fair quality of life, this should override any advance directive that would bring about an earlier death than would otherwise be possible (while sustaining a decent quality of life). How could this be denied? Well, Jaworska has noted (without endorsing the reasoning) that in some cases, 'The author of the advance directive would be dismayed to learn that in her demented state, a dreaded state of alienation from many things she now holds dear, she would have the power to overrule the well-considered wishes she has conveyed in her directive' (Jaworska, 1992, p. 137). Those pursuing this line give absolute priority to earlier, competent, self, over the later self, suffering from dementia.

This position can receive some support by considering the question of whether one can be harmed after one's death (ignoring any questions about the possibility of an after-life). A scientist with a highly successful career could presumably be harmed by the later revelation that all of his or her famous research findings were in some way defective. The person could also be harmed if such a thing was widely believed to be the case, even if it wasn't true. Therefore one can suffer serious reputational

damage by things that happen after one's death, and in at least one sense harm has been suffered. Therefore it is easy to see how the later self, suffering from dementia, can harm the earlier self, and thereby the life of the person as a whole, by acting in ways that bring ridicule or humiliation. Indeed dramatic depictions of the later self on film – think of the films *Iris*, based on Iris Murdoch, and *The Iron Lady*, based on Margaret Thatcher – have been accused of diminishing the life of the person, replacing it with a distorting picture.

The earlier self may strongly wish not to be remembered in the form the later self will become, even if the later self generally has a contented life. On this view the reason for advance directives to bring about early death has nothing to do with the valuation of the quality of life of a person suffering from dementia, or the failure to project oneself into a future state. It may be fully realized that many people with dementia appear to be content. Rather, for some people, it is about protecting the integrity of a life, and not wishing to become something very different. Soran Reader's reasons also included something else: the protection of her daughters from having to cope with someone in the world who is not recognisably their mother, but nevertheless their emotional, and perhaps financial, responsibility. Yet even this is highly troubling. How would her daughters feel if they knew that their biological, if not psychological, mother's life had been brought to an end in order to spare them emotional distress?

Advance directives to end one's future life, even if it is of reasonably quality, are, I think, understandable, and not necessarily based on a false assessment of the quality of that life, as there are other weighty reasons to write such directives. And yet it seems to me very hard to justify giving priority to the earlier life, or to the well-being of surviving relatives, however insistent and determined people are when they set out their advance directive. After all, even though quality of life factors may not have been paramount when the advance directive was composed, it is arguable that quality of life factors, for the person suffering from dementia, should be paramount in deciding whether or not to carry out the directive. This seems especially so in end-of-life decisions, but may also be so even for decisions about care, although here

issues could be more finely balanced.

In conclusion, some advance directives, such as over whether one's life should end at home or in a hospice, seem very enlightened and helpful. Others, such as those to end the life of an autonomous subject, against their will, have no moral appeal and would rightly be ignored. As we have seen, however, there is a wide range of intermediate cases, where matters are less clear cut. I have argued, however, that given our typical lack of insight into how changes in our health condition will affect us in other ways, we should be very cautious indeed in promoting the use of advance directives in end of life decisions, at least where a reasonable quality of life remains. There may be some reasons for giving priority to the earlier autonomous self over a later, contented but non-autonomous self, but these reasons seem far from compelling.²

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