
Editorial

Advance directives

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The principle of respect for patient autonomy has been the key used to unlock many a puzzle in medical ethics. Until recently it had one major limitation: it was irrelevant for incompetent patients. Then along came advance directives. If all people could be persuaded to say, whilst fully competent, what health care they would want to have in all possible futures, were they to become incompetent, then autonomy could still be respected. There would no longer be a need for doctors to make judgments about their patients' best interests.

The legal status of advance directives, however, remains problematic. The Law Commission has recently recommended that the British Parliament should consider passing legislation. Such legislation would aim to clarify the circumstances under which health professionals would be obliged to carry out the instructions given in an advance directive. The Lord Chancellor's office has indicated that it will not, at the moment, implement these recommendations. Wider public debate is required. In this issue of the journal, Ryan¹ argues that certain types of advance directive should be abolished. Luttrell and Sommerville² respond to Ryan's proposal. These articles are a timely contribution to the debate over the strengths and limitations of advance directives.

Ryan examines specifically "advance directives made by essentially healthy individuals who opt for withdrawal of active care in a situation where their inability to consent is potentially reversible". He argues that advance directives, in these circumstances, should be abolished. His argument centres on the claim that "people are likely grossly to underestimate their desire to have medical intervention should they become ill". Most doctors, I imagine, have experience which supports Ryan's claim. For example, one patient, who suffered a stroke, had previously made an advance directive (Malcolm Benson, personal communication). This directive was to the effect that were she to suffer a stroke she would not want any treatment that might prolong her life. Following the stroke, she was not initially able to communicate her wishes although she was fully conscious. Fortunately, she made a good recovery and was able later to talk about her experiences. She told her physician that she had

been terrified that she would not be given active treatment because of her advance directive. Although, following the stroke, she had been in the condition that she had earlier imagined, and although she had stated that she would not want life-saving treatment, she nevertheless experienced, after the stroke, a strong desire to live. This example is by no means unique.³ Such examples need to be taken seriously in the debate over the extent and limits of the usefulness of advance directives. Luttrell and Sommerville provide carefully reasoned arguments against Ryan's thesis.

Ryan limits his arguments to the situation where the inability of patients to consent to treatment is potentially reversible. I would like to consider the situation where the ability to consent is not reversible. Dementia provides a common example. Many people consider the possibility of dementia with horror. Were they to become demented they would wish to have no life-prolonging treatment at all, and indeed may wish for any opportunity to be taken which would hasten comfortable death.

Two views about advance directives can be contrasted by considering a fictional case, that of Mr W H. Mr W H values intellectual pursuits. He writes a directive to the effect that if he were to suffer from Alzheimer's disease he should not receive active treatment for pneumonia. He would prefer death to continuing dementia. Suppose that Mr W H develops Alzheimer's disease but appears to live a happy life, enjoying simple things such as walking round the garden looking at the flowers and drinking tea. He no longer cares, as far as can be judged, about the intellectual pursuits which formerly had been so important to him. The question is whether his previously held intellectual values, and his earlier wish not to have any life-saving treatment, should hold, even though he now appears to be enjoying life.

Those who argue that the advance directive should be followed, do so on the grounds that the person, because incompetent, cannot be said to have changed his mind or values: it is, rather, that he is no longer competent to express, or even to form, such views and values. Dworkin⁴ further argues that we have "critical interests" which are the hopes and

aims which lend genuine meaning and coherence to our lives. Supposing Mr W H says, before the onset of the dementia, that it is important to him to be remembered as someone with an intellect. He does not want to be remembered, or indeed seen, as someone able to enjoy only flowers and tea. According to Dworkin the fact that, when demented, he is quite happy, should not overrule his previous competent desire for life not to be prolonged. A person's life, on this view, is more than the sum of the moments of which it is made. There is a sense in which it is a whole. The fact that Mr W H is content when severely demented is not enough. His ending, as a severely demented person, does damage his life as a whole.

Those who argue that Mr W H's advance directive should not be followed do so on a number of grounds.⁵ I will focus on two. First, he may have made his advance directive on the basis of inadequate information. This is a similar argument to that proposed, in this issue of the journal, by Ryan. Mr W H may have presumed, when he made his advance directive, that the experience of dementia would be neutral at best and probably unpleasant. He may have failed to understand or imagine a situation like that which subsequently occurred.

Second, the situation with dementia is very different from that of coma. A person with dementia still has experiences which give pleasure or pain. Furthermore, a person's values are expressed not only in what the person can articulate but also in his or her behaviour. If Mr W H with dementia behaves in a way which shows that he enjoys certain pursuits (the flowers and the tea) and has no interest in other pursuits (intellectual) then this is evidence that he has changed his values. How we treat Mr W H, on this view, should not be determined by his former wishes, based on different values which are no longer of relevance to him.

This case of the "happily demented person" tends to divide people into those who would wish to respect the previous wishes, and those who would wish to pursue the best "experiential" interests of the person in front of them.

Let me consider another, somewhat unrealistic, example – but one which tests Dworkin's position. Suppose that Mr W H, instead of valuing intellectual pursuits, valued a kind of hardy machismo. He prided himself on never having a local anaesthetic when visiting the dentist. In his advance directive he states that he should be given no medication at all and in particular no pain-killers or sedatives. Should

we follow this directive when the demented Mr W H is suffering the pain of toothache? At this stage he is incompetent intellectually to balance the interest in treating his current pain against his "critical interest" in preserving his macho values. Here, at least, it seems clear that we should not allow Mr W H, when demented, to suffer even though his advance directive had stated, quite clearly, that he should suffer.

One way in which advance directives are conceptualised is that they are essentially no different from any other consent procedure. Thus, if we allow the fully competent person to refuse *any* current treatment, we should allow the fully competent person to refuse *any* future treatment, as long as the future circumstances have been precisely considered and imagined, and as long as there is no subsequent *competent* change in the directive. After all, if a Jehovah's Witness categorically refuses a blood transfusion, we do not normally argue that once he is under the anaesthetic he is incompetent and therefore that we should apply a best interests standard. The case of the "macho Mr W H" and his toothache provides a counter-example to this claim. What is interesting about dementia, from the philosophical point of view, is that unlike when under a general anaesthetic, or in a persistent vegetative state, a person can be both incompetent and therefore incapable of giving or withholding consent, and yet able to have desires and experiences.

The limits of advance directives need to be clarified. The debate, in this issue, between Ryan on the one hand, and Luttrell and Sommerville on the other, is an important contribution to such clarification. Perhaps the Lord Chancellor's office is right: further debate is required before the legal status of advance directives is considered by Parliament.

References

- 1 Ryan CJ. Betting your life: an argument against certain advance directives. *Journal of Medical Ethics* 1996; **22**: 95–9.
- 2 Luttrell S, Sommerville A. Limiting risks by curtailing rights: a response to Dr Ryan. *Journal of Medical Ethics* 1996; **22**: 100–4.
- 3 Hope T. Advance directives about medical treatment. *British Medical Journal* 1992; **304**: 398.
- 4 Dworkin R. *Life's dominion: an argument about abortion, euthanasia and individual freedom*. New York: Alfred A Knopf, 1993.
- 5 Dresser RS. Dworkin on dementia: elegant theory, questionable policy. *Hastings Center Report* 1995; **25**: 32–8.