

Facing death in Villa Dementia

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On the 17th of December 2015 minister Schippers (Ministerie van Volksgezondheid, Welzijn en Sport) published a long-expected instruction for the use of written advance directives (living wills, euthanasia passports). There is a section on euthanasia and dementia in it. This is what dutch physicians literally can read in the manual:

Patiënten met gevorderde dementie wekken soms de indruk niet ondraaglijk te lijden aan de dementie. Wel kan het duidelijk zijn dat een patiënt met vergevorderde dementie ondraaglijk lijdt aan bijkomende aandoeningen, zoals ernstige benauwdheid of pijn, maar ook angst, agressie of onrust kunnen bijdragen aan ondraaglijk lijden. In die gevallen mag een arts gehoor geven aan het euthanasieverzoek, ook als een patiënt dit niet meer duidelijk kan maken in woorden of gebaar. Het is dan wel noodzakelijk dat er een eerder door de patiënt zelf opgesteld schriftelijk euthanasieverzoek is.

So the message is: physicians are allowed to kill patients being in a state of advanced dementia who do not unbearably suffer from dementia but who are unbearably suffering from additional complaints such as severe tightness of the chest or pain, but also fear, aggression or agitation. Euthanasia is allowed even if the patient is no longer capable to express his wish to die in word and gesture. There is one necessary condition, though: a living will written by the patient himself must be available.

There is a lot to say about this ministerial advice. I will concentrate on the moral status of the crucial document: the advance directive. I think that the moral weight of advance directives in the face of Alzheimer's disease is overestimated.

1. Dworkin's shaky argument for precedent autonomy

Advance directives in the face of Alzheimer's disease are usually justified in the manner of Ronald Dworkin's proposal: by relying on the principle that prescribes 'respect for autonomy'. To be autonomous is to act within a framework of rules that one poses to oneself, and a kind of authority held over oneself, as well as the ability to act on that authority. Setting a will autonomously presupposes the authority and the ability to take care of personal matters within a structure of values and interests of one's own choice. At the same time, we know that

this capacity for self-determination is greatly diminished if the person finds himself in a state of severe dementia. According to Ronald Dworkin, the author of the advance directive holds moral authority over the future demented patient, because autonomy is centrally important to personhood. The autonomously chosen values and interests of the author are said to trump the non-autonomously chosen interests and values of the severely demented. Allow me to elaborate this a bit more.

In an impressive chapter in *Life's Dominion* on dementia, which has dominated the moral discussion on the subject for decades, Dworkin distinguishes between experiential interests and critical interests. People perform many actions because they value the experience of performing them: cycling, cooking or listening to the *St Matthew Passion* for the fourteenth time. The importance of these activities lies in the quality of the experience, from moment to moment. By contrast, critical interests are based on a value judgment about life as a whole, for instance the interest people have in living a dignified existence.¹ An advance directive, Dworkin writes, should be regarded as an authoritative rendering of someone's critical interests. The autonomously chosen 'critical interests' of the author of an advance directive trump the less weighty 'experiential interests' of the demented. Hence the moral authority of an advance directive. According to Dworkin, a critical interest can also be meaningfully represented when it has not been ratified in a long time. An advance directive is warranted to continue to represent the critical interests of a formerly autonomous person, including his interest in avoiding the degrading nature of dementia, even if said person has lost his capacity for making autonomous choices and is no longer able to understand said critical interests. Unfortunately, Dworkin does not supply any argument in support of his claim that critical interests survive the interest-holder. Defenders of a Dworkinian approach claim that the values deposited by the demented patient at some earlier point have never been revoked and "have only disappeared beyond the horizon". That is why they are still relevant to evaluating what his life means for him, even if he is now unable to do the evaluating. His categorical, critical interests are still in full force during the final phase of dementia, in the same way as before.

¹ It is possible to call this value 'integrity', as Dworkin does. Or the wish to lead one's life as a coherent whole; in this context, D. Brudney speaks of the value 'authenticity'.

2. Some doubts

I am not so sure of that. I have some doubts. For one thing, human values and interests are usually values and interests ‘for the time being’. Even if they concern life as a whole. Values and interests are less stable aggregates than Dworkin suggests; over the course of a lifetime they are regularly reconsidered. Even people with an advance directive, determined not to end in disgrace, sometimes ‘sit through’ the stage of the disease they had wished to be helped at. They wish to carry on living and do not flinch even when they suffer visibly and, in the eyes of those near to them, have nothing more to live for. Often, people are poor predictors of their future well-being.² Putting the limits on human fidelity to values and interests to one side for the moment, I don’t see why autonomously chosen critical interests should continue to hold when the person has deceased or is severely demented. Dworkin’s framework assumes that this is the case, but does not provide convincing reasons.²

Another complication is that Alzheimer’s patients do not know from their own experience what it is like to suffer from severe dementia. Dementia is an extremely variable and unpredictable process and most of the time – say the experts – without unbearable suffering in its final phase. So what exactly is the composer of an advance directive anticipating? Note that in the ministerial advice there is no link left between intolerable suffering and dementia. Different other types of suffering are put in the place of suffering from dementia! I think that what the author of an advance directive facing Alzheimer’s disease wants to avoid is: the destruction of the person. But why has the person one once was to be respected at the expense of the unknown human being one will be? On what moral grounds? Does a human being totally coincide with what he thinks to be as a person? Or is a human being after being booked out as a person still a sensitive human being, that has to be respected, to be taken seriously, with whom one can have a meeting, who has preferences, and who has to be treated with kindness and compassion?

² Two questions that underly the assumption have to be answered: what, exactly, is the ontological status of critical interests? And what is the temporal reach of autonomously chosen interests and values?

³ We should distinguish between negative and positive advance directives. Negative advance directives (foregoing treatment) are often respected in nursing homes. Positive advance directives (killing) are typically not enforced.

3. The limited scope of the argument

Here is my deepest worry. The moral debate on advance directives in the face of Alzheimer's disease has a limited scope. It mainly focuses on the individual patient. This approach underdescribes what is morally at stake. After all, others are to enforce the advance directive by administering euthanatica to the patient.³ Citing precedent autonomy, the patient asks that potential survivors end his life. But should he saddle others with the request to permanently remove him from the realm of the living while he is (in all probability) not suffering from dementia, for the sake of his present evaluation of his future condition? And when exactly is he to be removed? Dementia is a highly heterogeneous, complex, impenetrable, fickle process with ups-and-downs. How should the patient's wishlist be interpreted? Does it enter into effect, for instance, when the patient ceases to recognize his loved ones? When he definitively ceases to recognize them? Even if he is content, smiles, strolls, hums, and is responsive to affection? And who is to take the final decision? The moral cost incurred as a result of killing a fellow human being who is reasonably comfortable, is not suffering and can easily be kept alive, is high. To many, it will not offset the moral cost incurred as a result of lost personal autonomy.

I think this last problem tips the balance and places the matter that has to be solved by the advance directive far beyond our reach. One who has been diagnosed with Alzheimer's disease, then, would be unwise to organise his death by means of an advance directive. Advance directives can only play a modest and supportive role.

4. Two alternatives

Happily, other options are available. Alzheimer's patients confronted with a catalogue of horrors can employ two strategies without resorting to advance directives. One possibility for those unwilling to descend into dementia is to insist on their autonomy by taking their own lives betimes after they have been diagnosed with the disease. This does not imply that death is preferable to dementia. But to some people autonomy, being the master of one's own life with the inclusion of future care, is a cherished value that should not be surrendered and is more valuable than life itself. No price is too high to secure control over their lives and prevent a confused and lost state of existence. For such patients *Romana mors*, dying on one's own terms in the face of Alzheimer's disease, is a morally justifiable deed of autonomy, a

final attempt to keep life in one's own hands even in the act of losing it. There are methods of humane suicide ('self-euthanasia') available. By committing suicide one retains control of one's own life, without asking others to perform euthanasia. There is also a price to be paid: time has to be forfeited. Life is ended while it remains at one's disposal. A tragic and painful choice. But, in my view, the ultimate consequence of the cherished value of always being in charge.

A second alternative is open to advance directives in the face of Alzheimer's disease. Persons may also accept that autonomy will no longer be an 'issue' in their future, incompetent state of dementia and that they will depend on the help of others if hurt and injury are to be prevented. Once the phase of severe dementia dawns, others decide, either in the spirit of the advance directive or not so. Of course it is still possible for persons to write an advance directive. Perhaps the advance directive can provide a measure of comfort and peace of mind in the face of Alzheimer's disease, to the patient as well as to his 'survivors' who may act in the spirit of said advance directive. But comfort and peace of mind need not depend on an advance directive. It is also possible to fully trust one's loved ones and to leave them free to decide on one's unknown fate. Does this second option place an excessive moral burden on the shoulders of friends and family? Not so, in my opinion. Someone who suffers from severe dementia may have clocked out as a person - let's call him a post-person -, but is still a human being. 'One of us', someone with whom we share a common humanity, someone who wants to live and should be able to count on our respect for his particular, vulnerable and irreplaceable human life.