



Do those afflicted with dementia have a moral duty to die? A response to Baroness Warnock

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Abstract

In October 2008 Baroness Warnock, medical ethicist and veteran British governmental advisor, claimed that an individual afflicted with dementia may have a moral duty to die when their continued living “wastes” the lives of others and the resources of the National Health Service. Her comments were widely publicised and largely condemned by those who responded.

In this paper I consider the comments made by Baroness Warnock. She claims that some individuals and groups within society may have a moral duty to die when their lives become burdensome either to themselves or to others. I conclude that no-one has a moral duty to die, but especially not those who are afflicted with dementia.

Our population is rapidly aging and more people now die of serious chronic diseases instead of acute illnesses. Health care resources are under increasing pressure. In New Zealand, people over the age of 65 currently make up around 12% of the population but they use 37% of total public health expenditure.¹ In 2008 nearly 41,000 people had dementia; by 2050 it is predicted that over 44,000 new cases of dementia will occur each year.²

We need to address how we will care for those who are near the ends of their lives; especially as that care will increasingly require more human and health care resources.

In October 2008 Baroness Warnock, medical ethicist and veteran British governmental advisor, claimed that individuals afflicted with dementia may have a moral duty to die when their continued living “wastes” the lives of others and the resources of the National Health Service.³ Her comments were widely publicised and largely condemned by those who responded.⁴

Warnock stated the following in the interview she gave to the Church of Scotland’s Life and Work magazine:

If you’re demented, you’re wasting people’s lives—your family’s lives—and you’re wasting the resources of the National Health Service. I’m absolutely, fully in agreement with the argument that if pain is insufferable, then someone should be given help to die, but I feel there’s a wider argument that if somebody absolutely, desperately wants to die because they’re a burden to their family, or the state, then I think they too should be allowed to die.

Actually I’ve just written an article called “A duty to die?” for a Norwegian periodical. I wrote it really suggesting that there’s nothing wrong with feeling you ought to do so for the sake of others as well as yourself. If you’ve an advanced directive, appointing someone else to act on your behalf, if you become incapacitated, then I think there is a hope that your advocate may say that you would not wish to live in this condition so please try to help her die. I think that’s the way the future will go, putting it rather brutally, you’d be licensing people to put others down. Actually I think why not, because the real person has gone already and all that’s left is just the body of the person, and nobody wants to be remembered in this condition

Warnock's comments are not made in isolation. Over the past two decades many commentators have both supported and criticised the claim that some members of society may have a moral duty to die,^{5,6} and not just those who are afflicted with dementia.⁷ Indeed John Hardwig claimed there "*can be a duty to die even when one would prefer to live*".⁸

Should we pay any attention to the claims that some individuals or groups may have a duty to die, or should we dismiss such claims as the misguided comments of individuals out of touch with society and reality?

Although it is easy to reject the comments made by Warnock and others as offensive it is important to look at what they say because their comments may have practical and conceptual implications for those near the end of life. For instance: in policy decision making, or in (not so) subtle societal pressuring of those near the end of life to 'hurry up and die'.

This issue is far from theoretical. If we accept the claim that individuals do have a duty to die we may shift the burden of proof to now requiring those same individuals justify their continued existence.⁹ Making explicit what was said and responding to it critically and deliberatively advances informed debate.

What exactly is Warnock stating in her interview? She makes a number of different claims:

- Those who are afflicted with dementia are wasting the lives of their families and so may have a duty to die
- Those who are afflicted with dementia are wasting precious health care resources and so may have a duty to die
- Assisting another individual to die is morally appropriate if that person is suffering unbearably and wants help to die
- If someone feels they are a burden on their loved ones, they should be allowed to die. Warnock is not clear whether this means they should be actively assisted to die (euthanasia), or whether their decision to voluntarily stop eating and drinking, to have medical treatment withdrawn, or to invoke a DNR order (letting die), should be respected
- If a person has an advance directive stating they do not wish to continue living if they were to become incapacitated by dementia, their advocate should be authorised to request assistance for the person to die (it is not clear whether this implies that a health professional should hasten their death)
- If personhood (the "*real person*") is lost we are justified in putting those persons who are incapacitated "*down*"

Warnock raises an important point about the ethical permissibility of assisting competent individuals who are suffering unbearably to die. She quite clearly advocates euthanasia or physician-assisted suicide for those persons who make an explicit request for death.

The focus of this paper however is not on the ethical (im)permissibility of euthanasia or physician-assisted suicide, but rather on critically discussing two claims she makes:

first; that individuals afflicted with dementia have a duty to die because they are a burden on their families, and second; that because individuals with dementia are not persons but merely bodies, we (who exactly?) are morally justified in ending their lives.

Before discussing her two claims, it is important to be clear exactly what is meant by the terms, 'duty' and 'moral duty' for these are crucial to the claims she makes and the conclusions she reaches.

Duties

Philosopher Joel Feinberg states that "*a duty, whatever else it be, is something required of one*".¹⁰ In other words if we have a duty, we are required to do or to refrain from doing something.

A duty may be imposed by law such as one's duty to pay taxes and debts, or as in New Zealand, to register on the electoral roll in order to vote. Similarly I have professional duties that obligate me to perform certain tasks—turning up prepared to lectures and marking student's assignments on time. These duties issue from the legally binding contract I have with my employer to carry out certain professional requirements.

A duty may also be required by morality. Thus I have duties that compel me to follow or refrain from certain actions that are derived from moral rules.¹¹ For instance, I have moral duties to tell the truth, to refrain from harming innocent others, to keep my promises, and respect the property of others. Some of these are also legal duties.

It has been argued I also have moral duties to give to the poor,¹² or to participate in biomedical research.¹³ Essentially if I have a moral duty I am required by moral reason to act or refrain from acting in certain ways. I owe something important to others. If I do not fulfil the demands of my moral duties I act immorally and can be judged morally blameworthy.

Central to having and therefore fulfilling my duties to others is my capacity to understand what is required of me. If I do not have the capacity to reason and reflect on what it means to have duties to others; to understand how my actions impinge on those around me; and the ability to communicate with others, I do not and cannot have duties to others. This is because I am not responsible for my actions (or indeed my omissions).

What this means is that some individuals and groups in society have no duties (either moral or legal) to others. These are the most vulnerable members of our community. I will comment on this further where I discuss the issue of personhood.

Individuals with dementia have a duty to die because they are a burden on their families

When Warnock claims that individuals with dementia have a moral duty to die, what specifically is she saying? *Prima facie*, it would appear that if someone had a duty to die it meant morality required that their lives ought to end (presumably sooner rather than later). They are obliged to die. In fact if the individual did not fulfil their duty to die they would be morally blameworthy.

Is it possible morality might demand such a duty of us? Warnock's claim would seem to issue from two positions: first that we have important filial duties that emerge from the special ties we have with our families, and second that we have a duty not to become a burden on the health care system (I will not address this latter duty).

What kind of duties do we have to members of our family? At the heart of the family are the relationships we have with others—to our siblings, our parents, and extended family members, and them to us. Generally these relationships are defined by love and nurturance, respect, reciprocity, and seeking the good of the other.¹⁴

It has been suggested that grown children have special duties to their parents for several reasons: as parents do so much for their children, children owe their parents in return. Parents do good things for their children, therefore children have a debt of gratitude, and the relationship between children and their parents is one of friendship—*“the duties between grown children and their parents are the duties of friends”*.¹⁵

Very little however, has been written on the duties elderly parents may have to their grown children, especially in relation to a putative duty to die. This area requires more critical thought and discussion.

Warnock claims that elderly individuals afflicted by dementia may have a duty to their families to die when they become a burden on them (financially and emotionally). However, we are not required by the dictates of morality to sacrifice so much for others that our lives become impoverished.

In other words, our duties to others are not so demanding that we must give to the point of exhaustion so that our lives and goals are adversely affected. Of course there is a valid question here about how much we ought to give, and obviously some families and individuals are in a position to give far more than others.

But even if we have reached the point where we cannot give any more to our family—either financially or emotionally—it does not follow that another must now make plans to end their life because duty demands it.

I noted earlier that what is central to most families are the special ties of love, nurturance, respect and reciprocity that bind us together. It is therefore rather surprising to claim that these same ties also demand that when the going gets tough, those who are a burden should get going (and die).

Warnock comments, *“if you're demented, you're wasting people's lives—your family's lives—and you're wasting the resources of the National Health Service”*. The word ‘wasting’ is surely instructive here.

Warnock suggests that the fact I am afflicted with dementia implies my family's lives will be ruined, leading to her assertion that it would be better for them if I was dead. And there is evidence that for some families, the financial and emotional costs of caring for those relatives with dementia is burdensome and onerous.^{16,17}

But dementia is not a ‘one size fits all’ condition. An individual's progression of dementia can pass through a number of different stages from very mild cognitive decline, where an individual can live reasonably independently with some assistance, to very severe cognitive decline where verbal abilities are lost, the individual requires

assistance with every facet of care and they lose basic psychomotor skills such as walking, sitting, and head control.²

Although there is considerable overlap between the various stages of dementia it is surely mistaken to categorize all those afflicted with dementia as wasting the lives of their families, or placing unreasonable sacrifices on them, requiring at the end of the day, a duty to die.

Many individuals will remain involved and interested in their families and will continue to contribute as loving and productive members. Others will require assistance that will be gladly and unselfishly given by their families.

Individuals afflicted with dementia are not persons but merely bodies

Warnock states:

I'm absolutely, fully in agreement with the argument that if pain is insufferable, then someone should be given help to die, but I feel there's a wider argument that if somebody absolutely, desperately wants to die because they're a burden to their family, or the state, then I think they too should be allowed to die

Receiving assistance to die because suffering is unbearable, and being allowed to die (*how* exactly is one *allowed* to die?) because one believes one is a burden are two very different claims. I may believe I am a burden to my family because I require considerable care but that does not entail a duty to die.

Warnock continues:

If you've an advanced directive, appointing someone else to act on your behalf, if you become incapacitated, then I think there is a hope that your advocate may say that you would not wish to live in this condition so please try to help her die. I think that's the way the future will go, putting it rather brutally, you'd be licensing people to put others down. Actually I think why not, because the real person has gone already and all that's left is just the body of the person, and nobody wants to be remembered in this condition

It is what she claims at the end of this passage that is illuminating and disturbing. What Warnock actually seems to be suggesting is that being a person is what really matters in the context of those elderly afflicted with dementia. It is not that I have a duty to die because I have dementia and am a burden on others; rather, it is because I am no longer a person. I am just a body. It is important therefore to consider what it means to be a person.

What does it mean to be a person, and if you are not a person, what might follow? Philosophically speaking, the issue of personhood is a complex and contentious one. Generally speaking, persons are those entities who have the capacity to reason and reflect, to have preferences, to be able to communicate with others, to interact socially with others, to have feelings, to experience pleasure and pain, to be conscious (the ability to consider oneself as oneself), and self-aware (awareness of oneself existing over time).¹⁸

These are the capacities that contribute to making human life valuable. They accord us respect, protection, concern and understanding. To be a person then is to matter morally; and to have rights against, and duties to others. Non-persons do not and can not have duties or responsibilities to others.

*“To identify individuals as persons is to bring them into the same moral category as ourselves and to judge someone to be a pre-person or a non-person is to distance them in some sense from ourselves”.*¹⁹

As noted earlier, how we understand the importance and relevance of these capacities is challenging. What if I have feelings and experience pleasure and pain yet I am not self aware? Am I still a person? If the capacity to reason and reflect is all that is required to be respected as a person, then many individuals will never become persons and many will lose their personhood status at some point in their lives.

There is a further point to be made about whether individuals could be more or less of a person depending on their capacities: is there some kind of hierarchy of capacities – do some confer greater importance than others? In other words, could some persons be considered more or less important than others simply on the basis of the capacities they possess?

Harris¹⁹ argues that if what we are really asking is what kinds of lives are ultimately valuable, we will answer that it is the lives of those who can value his or her own existence. We are still left though with the important question of how we understand those lives when the individual cannot value his or her own existence.

What are we to make of the individual afflicted with dementia who cannot reason or reflect, has no capacity to consider oneself over time anymore, and who does not value his or her own existence? What indeed! According to Warnock such a person is just a body, a shell, of little concern or consequence. Coupled with the fact that such a person wastes precious resources (both human and health care), and is a burden on their family is enough to justify Warnock’s charge that individuals with dementia should be assisted to die.

But this has nothing at all to do with any moral requirement to die. It would appear to have far more to do with attempting to justify ending the lives of individuals whom society views as worthless, burdensome, and of little value.

Warnock claims that it would be morally permissible to end someone’s life because they are no longer a person. She steps beyond respecting a competent, autonomous individuals advance directive not to endure living a certain way (which many individuals have some sympathy for), to claiming that dementia negates personhood and that alone is sufficient reason to justify ‘assisting’ them to die.

Warnock is not clear how we assist such individuals to die. Do we fail to provide nutrition and hydration; do we withdraw or withhold medical treatment so that death will be hastened; or do we introduce a lethal threat such as a fatal bolus? What if there is no medical treatment to withhold or withdraw?

Warnock surely steps on dangerous ground for there are many others who also stand perilously close to those who are afflicted with dementia in terms of lacking personhood. If those with dementia are non-persons—bodies—who waste precious, scarce resources then what of those who also take up valuable resources who are also not persons?

For instance, those in persistent vegetative states, those in a coma, the very young and the severely cognitively disabled? Perhaps they too have a duty to die. But this cannot

be the case for as Warnock has suggested those with dementia are not persons. If they are not persons—merely bodies—they cannot have a moral duty to die.

It would seem then that what Warnock is really suggesting is that certain individuals ought to die, not because they have any moral duty, but rather because they are burdensome as they waste valuable human and health care resources. And allegedly because they are merely bodies with little or no value to the rest of us, their death is preferred to their living. Coming to such a conclusion is abhorrent for it attempts to justify terminating the lives of the most vulnerable and powerless under the guise of moral duty.

I argue it is not morally appropriate to place so much importance on the concept of personhood in the context of thinking about the moral status of those elderly afflicted with dementia. The more important moral duty here is the duty of care to those who are vulnerable and near the end of their lives.

In responding to Hardwig's claim that "*we fear death too much*", Hentoff pithily states, "*my sense is we do not fear bioethicists enough*".²⁰ Those with dementia have no moral duty to die; but perhaps they have much to fear from certain others.

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