

MY DEATH, MY DECISION?

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In her early 90's my mother suffered from the early stages of dementia, and several other problems which gave her severe pain which could not be adequately treated. On several occasions, she asked me to help her to die. I sympathised with her condition. It seemed a rational request – she had lived a good life, her condition was incurable and her quality of life was increasingly unbearable. If I were in her position, I know I wouldn't want to continue living. After careful consideration, I refused her request, explaining how it was against the law. She asked if doctors could help her. I carefully explained how they too were unable to help in the way she wished. "Make them see sense" was her response, "make them see sense".

I believe I made the right decision. I am not a health care professional. I was emotionally involved. I had no idea how to help my mother end her life – it could have gone horribly wrong if I tried. There could be no witnesses that I was carrying out my mother's own wishes.

We are living longer. Traditional killers such as heart disease and some cancers are increasingly curable. This is wonderful when it leads to extra years with an acceptable quality of life. But eventually we all die. An increasing number of people are dying from degenerative diseases. In November 2016, the Office of National Statistics reported that dementia is now the leading **cause** of death in England and Wales – and that excludes those who die **with** dementia but not **of** it.

Despite excellent care, my mother had a "bad death". But what is a "good death" and how can we ensure more of us have one? Being free from physical pain is a minimum. Dying in a place of our choosing, often at home rather than a hospital or nursing home, with close relatives or friends present, is important for many. Dignity is often mentioned – being able to manage our basic personal care; retaining our mental faculties so that we keep some control of our lives; retaining the ability to hold a conversation and recognise those close to us. My mother just wanted to go to sleep and not wake up – over two years before she eventually did. For people like her a "good death" requires medical assistance to die at a time they feel is right for them.

The campaign group My Death, My Decision believe that medical assistance to die should be an option for adults who are suffering from incurable health problems which permanently reduce their quality of life below the level they can accept. To be eligible such a person would need to be mentally competent to make the decision, and it must be their own persistent choice. People who make this choice are typically elderly, believing that their life is complete.

Why hasn't the law changed to allow this? In September 2015, the House of Commons debated a Private Members Bill proposed by Rob Marris. It would apply to mentally competent adults who were terminally ill (expected to die within 6 months), and who had a voluntary, clear, settled and informed wish to end their life. The Bill was based on a law which has been working successfully in Oregon since 1997. It was defeated, 118 votes for, 330 against.

The defeat does not mean the issue will go away. It won't. An increasing number of people are witnessing "bad deaths", and are deciding "not for me". Instead they are contemplating one way trips to Switzerland; starving themselves to death; or unassisted suicide. None of these alternatives are satisfactory. How do we find an acceptable, better solution?

An important place to start is to look at the things that unite people on both sides of the debate. We all feel that end-of-life care can, and should, be significantly improved. We share a concern that

people should not be pressurised into requesting an assisted death if it is not what they themselves want.

Many MPs spoke in favour of better care for the elderly, especially palliative care. The disagreements here concern the extent to which the best possible care can make life bearable. Physical pain can usually (but not always) be treated successfully. Other forms of suffering, and feelings of loss of dignity, can be harder to resolve. The last two years of my mother's life became a living nightmare for her, despite excellent specialised dementia care. The UK is recognised as having some of the best palliative care in the world. But for some people, with some conditions, even this is inadequate. It is sometimes kinder and more compassionate to allow an assisted death, if that is the person's wish.

MPs made many strong speeches supporting the Bill, but it is important to consider carefully the opposing arguments, if we are to find a way forward.

We can divide the concerns into two groups. First there are objections which, on principle, oppose any movement towards allowing people to have a say in the timing and manner of their own death. Second, there are issues concerning how the Bill would work in practice. Underlying the reasons, MPs are no doubt cautious of supporting such an emotive and controversial issue, while the BMA, palliative care groups, and many leading religious figures remain opposed.

A fundamental concern in the first group relates to the value of life itself. People on all sides value life which is of high quality – or has the potential to recover a quality which is acceptable to the patient. The difference comes when we consider people who have a quality of life which is permanently below the level they can tolerate. Is it acceptable to insist that such people continue living against their will? Or is it more compassionate to accept the situation realistically, easing the person's suffering with a medically assisted death, if that is their wish? MDMD, along with around 80% of the country, think the latter. We respect those who have different views, often based on religious beliefs. However, in a multi-cultural society, with people of many faiths, and increasingly none, we need to be respectful of different views. One group should not prevent others from having the "good death" they seek, when that means an assisted death. Instead we should respect the wishes of the person whose life and suffering is concerned.

Another fundamental objection to change is the view that the current law is adequate. Guidelines from the director of public prosecutions clarify that it is "not in the public interest" to prosecute in cases of assisted suicide done for compassionate reasons. As suicide is not a crime, people can kill themselves if they want to.

But where is the compassion? People who are desperately ill are generally not able to end their own lives unassisted. Instead, some people are choosing to end their lives too soon, while they still can. This is a tragedy. Ironically, when people know that medically assisted suicide is available they sometimes find they can carry on for longer. The security of knowing that they have an option to end their life, if it becomes totally unbearable, can raise the quality of their final stage of life – sometimes allowing a natural death.

How exactly do those resisting a change of law expect chronically ill, desperate people to end their lives unaided? The drugs which can do this painlessly and efficiently are, rightly, carefully controlled. People who try to end their lives themselves are left with horrible alternatives, which can fail disastrously.

The DPP guidelines acknowledge that in some circumstances assisting suicide is acceptable. But, unless you go to Switzerland, there are no safeguards, no checks, no professional counselling and help. Any investigation that occurs is after the death, too late to prevent foul play. The potential for ill-advised, botched suicides, possibly coerced, or worse - not even requested at all, is very real.

However, it is not easy to decide what an acceptable law should be. A major criticism of the Marris Bill was the restriction to only helping people with a life expectancy of 6 months or less. Doctors oppose this as they are often not able to give an accurate prognosis. Others oppose the criterion as it excludes people with long term intolerable conditions, including dementia.

Recognising this, some MP's felt that the proposals could be the start of a "slippery slope" towards a situation where it was too easy for people to end their lives. There needs to be extreme care in how assisted dying is introduced. It may be that a cautious, step-by-step approach would be prudent, each step being carefully considered, debated in parliament, and evaluated in practice, before progressing to the next. An example of how this approach has worked in the past is the extension of the right to vote. In the early 19th century less than 3% could vote. This increased, in a series of hard won steps, to now include everyone over 18. Was that a "slippery slope"? No, it was cautious gradual change to reflect a changing, better educated society.

MDMD believe that the six-month criterion causes more problems than it solves. We advocate its replacement with a clause limiting assistance to die to those suffering from incurable medical conditions resulting in intolerably low quality of life. It is interesting that in Canada, where an assisted dying law was introduced in 2016, a fixed life-expectancy time limit was rejected in favour of the more flexible "reasonably foreseeable death".

Perhaps the most important issue MP's raised was how people would be protected from coercion. In the Bill two doctors must certify that the person had mental capacity and had not been coerced. In addition, the High Court must give consent. The Bill did not give detailed guidance in how the process would work. This caused concern. There are many professionals in healthcare and social services who are experienced in interviewing elderly patients to elicit their own views. It should perhaps be made clearer how this expertise can best be brought to bear – especially if there is any suspicion of coercion. A video of a professional interview with the person asking for assistance to die could be required as evidence for example. The interviewer could probe the background to the decision, with the requestor, for others to see.

A new safeguard, being suggested by MDMD, is for people to make an advance statement of their wish for the **option** of a medically assisted death at some point in the future. The proposed new statement would need to be made well in advance of vulnerability. Should a person, at a later stage, decide that they have reached the point of wanting assistance to die, their advance statement would provide strong evidence that the decision had been reached after serious consideration over a long period, without coercion. If the statement was a requirement for vulnerable people, those without it would enjoy the same legal protection as today, while those with it could safely be permitted the assisted death they crave.

In conclusion, MDMD believe that to move forward we need to constructively address valid concerns. Our suggestions of avoiding the six-month criterion; and adding a strong safeguard requiring a formal statement of wish for the future option of assisted dying, are two contributions we hope will prove useful.

As a compassionate society, we must do more to help avoid suffering at the end of life. Yes, we need to ensure the best palliative care options for all, but when someone's idea of a good death cannot be met by palliative care, but instead requires a medically assisted death, we should respect their wishes. MDMD are doing what we can to work through the many difficult issues to identify a safe, acceptable solution - to help "them" – the politicians, the doctors, the religious leaders – "see sense", as my mother put it.