

What is a good death? (transcript)

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The Ethics of Life and Death

Are you scared to die? I'm not, but I am scared of how I'm going to die. There are certain ways I'd prefer not to. But it is certain that we are all going to die so its of interest to us all to think about what constitutes a good death.

Slide 2 Introduction.

There has been very little research done on what patients themselves would consider a good death. It's mainly professionals, doctors, nurses and the hospice sector who have put their opinions forward.

So I'm going to look first at hospices, and their view of a good death. I'm going to give a brief look at end of life planning and also the concept of dignity, which is often mentioned around end of life care. I shall point out that death in poorer countries of the world is very different from death in affluent countries. And finally, a look at the way socially privileged groups have dominated the field of study.

Slide 3 Hospices

The majority of us die in hospital, or at home. One in 3 of us don't have access to adequate palliative care at the end of our lives. You are less likely to have palliative care available if you are an older person, if you are from a minority community, from socio-economically deprived area, or if you don't have cancer.

We think of hospices as places where people go to die, but they provide many more services than that. Hospices provide day centres, home care, respite care, (so family carers can take a break) bereavement support and complementary therapies.

A Panorama programme which was broadcast in mid-March this year, and which addressed the subject of assisted dying, visited Dorothy House, a hospice near Bath. It cost 19 million pounds a year to run. Only 20% of their costs comes from the government, leaving 80% to be raised from charitable funding.

Not everyone who wants hospice care will get it. Although the hospice movement has been influential in suggesting what makes a good death, the reality is that very few people get the services they want and need.

Slide 4

Next I'm going to consider some of the ideas that people have suggested as proving a good death. To retain control of what happens. Actually, I don't think you are in control of the process of dying, but it helps to know something about what is likely to happen, to be reassured about pain relief etc. and to make any choices that are open to you.

Everyone wants to be treated as an individual, and very few have access to hospice care. Most people would prefer to die at home, surrounded by loved ones, and to choose which loved ones to share the end of their lives with.

I come from a generation where not everyone wanted to know they were dying. My parents' generation thought it was kinder not to discuss it. And children were never included in discussions about death. I have seen conflicts resolved when someone knows they will die soon. Dying well being a gift to those left behind? I find that very interesting. Perhaps because it provides a certain peace of mind and acceptance, and reassurance that there was no unnecessary suffering leading to a sense of closure.

Slide 5

Everyone would like to have care which is compassionate and personalised, but that is often difficult to provide in, say, a busy NHS ward. Access to doctors and information can also be limited. Some people ask for spiritual or psychological support, and that may not always be available when asked for. Advanced care planning I will deal with later. The person dying may be very concerned about the wellbeing of the soon-to-be bereaved. And of course, a good death should be free from pain or panic.

Slide 6

Is it good to be mentally aware? Some people would prefer to die in the middle of the night of a massive heart attack so they are not aware of what is happening. This may be a good death for the deceased, but not for those left behind. The same could be said for death not being sudden or unexpected. If it is expected, there is a chance to prepare, put one's affairs in order, and to say goodbye to loved ones. But if the dying person lingers too long, then it becomes psychologically painful for everyone.

To feel that your life was meaningful, for me, at least, presupposes that during one's lifetime you have the opportunity, mental ability and mental space to reflect on one's life. Not everyone has that. Being near death is not suddenly going to bring meaning into your life.

Everyone wants to be treated with dignity and respect. And that is what ought to happen. But these concepts mean different things to different people. Familiar surroundings and familiar people is what most people would want. And to understand what can be expected, but of course things can go differently, and the unexpected does happen. **What one wants in a good death is going to be different for everyone.**

Slide 7

The word 'dignity' is often used in the context of a good death. It is about how humans **ought** to be treated and is viewed as due to everyone equally, and is inherent, not merit-based.

We can recognise the absence of dignity, as in embarrassment, humiliation, rape, slavery, torture, genocide. But in itself is an ambiguous term, because it has too many **meanings**, and means something different to those who use the term. It is probably better to define more closely what is meant in each particular usage.

Slide 8

End of life planning ensures that the dying person's wishes are respected, and eases the burden on relatives and friends. A life book keeps all information in one place and enables your loved one(s) to sort something out when they need to.

Financial details such as will, power of attorney, insurance policies, credit and store cards

etc.

Documents such as passport, birth certificate, deeds to property etc.

Possessions such as property, vehicles, watches, books, jewellery etc.

Final wishes – funeral wishes, leaving a message.

Slide 9

The majority of people dying in the world do not have the choices of people in the rich global North. We tend to think the principles of a good death as held in the global North as the gold standard, and to think that the global south should adopt those standards.

The idea of personal autonomy as the right of individuals to make their own choices about how they should die is deeply rooted in individualistic societies. But in Bangladesh, a good death is defined by the presence of loved ones. In an Indian context, secrecy about a terminal illness is a strategy of endurance and love.

How death is experienced is determined by socio-political factors, culture and personal and family issues. Death and dying are social issues and we are trying to solve them medically. We need to talk about death openly, what we want for ourselves and what we want as a society.

Slide 10

Socially privileged groups have an excess of credibility. That is, they are treated as an authority for other peoples' experiences. Members of marginalised groups experience a credibility deficit. This leads to various forms of injustice.

We have to focus on what is actually going on, rather than on what we think they might be.

Slide 11. Conclusion

This presentation has taken us through rich countries beliefs as to what constitutes a good death, seen through the eyes of the hospice movement, and best palliative care. But most people are not going to get those sort of choices, since resources are limited, and expensive, are often not known about, and only certain sorts of people will have access to them.

People's opinions about a good death vary, in any case. Perhaps we should think about 'good enough dying?' Or should we dispense altogether with the concept of a good death? Or try and use it in the most open, flexible and inclusive way?

Given that we shy away from discussing death altogether, perhaps we can start by having the conversations with our loved ones, and discussing what death means to our society as a whole, and to our relationships with countries who deal with death in a very different way.