

Death & Dying



Making sense of the end of life



I'm 72, but like the vast majority of us, I've done nothing to prepare for my demise. So why is it we don't make plans? Are we scared because we don't know enough about what happens when we die? ... Making this programme, I've thought about death more than I ever have in my life - and it's changed the way I approach it. Making a journey like this makes you appreciate life so much - one should live for the day and enjoy it.

Richard Wilson

Introduction

The title of this booklet suggests that it might be possible to make sense of death and dying, and provide some ‘answers’. But is this possible?

While death is universal, attitudes to death and dying can vary enormously both between individuals and within different groups in society.

The BBC One programme which this booklet accompanies saw Richard Wilson challenging the processes, traditions, taboos and myths that surround death in this country. He questioned the way death is often sanitised and shut away from everyday life, and met people who shared a different and resoundingly positive approach to the end of life. In the associated programme for BBC Four, Dan Cruickshank faced the inevitability of death, seeking – and testing – the solace to be found in faith, philosophy and ultimately in art.

Dan points out that,

When it comes to the mystery of death there are no experts. Ever advancing scientific developments mean that much of what was mysterious about the natural world only a hundred years ago has now been explained. But not death – it remains the great abiding mystery about which we know no more now than did the priests of Egypt 3,500 years ago.

In the face of this enigma, Dan asks, “What can help us prepare for the unpalatable, the unavoidable, the unimaginable – our own absence from all of this?” While observing that “as death is a lonely and solitary business, so is the search for its meaning”, he also concludes that the process of searching for meaning is in itself an act of life: “it affirms life in the face of death.”



Death and the search for meaning

Our own death is indeed quite unimaginable, and whenever we make the attempt to imagine it we can perceive that we really survive as spectators. ... [A]t bottom nobody believes in his own death ... in the unconscious every one of us is convinced of his own immortality.

Sigmund Freud

Thinking about death often raises larger questions which resonate with questions about the meaning of life. This quest divides those who consider that fate is in the hands of a superior being and is predetermined from those who believe that fate is of people's own making.

Within Islam, death in its most fundamental sense is a passage to accountability before Allah, and yet it is also a tearing away from loved ones in this life. There is that moment of grief and shock, but Islam, like Judaism and Christianity, asserts that ultimately the person is not dead, there has been no death; rather, there has been a passage.



In the absence of religious faith, the idea of an afterlife cannot provide a basis for finding meaning. The existentialist Jean-Paul Sartre (1905–1980) argued that there is no predetermined meaning to human existence, only that which people define for themselves. From this line of reasoning, it follows that, if life has no meaning, existence is arbitrary.

The founder of the psychodynamic school of ideas Sigmund Freud (1856–1939), quoted above, claimed that people are concerned with two competing impulses: the first for survival and the second towards death. He believed that the conflict that results from managing these competing drives results in high levels of anxiety.

In contrast to this explanation, German philosopher Arthur Schopenhauer (1788–1860) painted life as a continuous alternation between pain and boredom:

The striving after existence is what occupies all living things, and keeps them in motion. When existence is assured to them, they do not know what to do with it. Therefore the second thing that sets them in motion is the effort to get rid of the burden of existence, to make it no longer felt, 'to kill time', in other words, to escape from boredom.



Questions about the meaning of death can be directly relevant to the day-to-day experiences of people's lives. For example, Viktor Frankl (1905–1997) was a psychiatrist who spent years in Nazi death camps. He wrote about the quest for meaning when there appears to be no reason to continue to live. Frankl concluded:

- ✦ Life has meaning under all circumstances, even the most miserable ones.

- ✦ People's main motivation for living is their will to find meaning in life.
- ✦ People have the freedom to find meaning in what they do, and what they experience, or at least in the stand they take when faced with a situation of unchangeable suffering.

Challenging the meaning of life is the truest expression of the state of being human.

Viktor Frankl

You can take as a starting point that death is not separate from society, but rather something that is part of life and shaped by society. This booklet offers an introduction to three dimensions of death and dying.

- ✦ How do people prepare for death and is it possible to have a 'good death'?
- ✦ How does UK society care for dying people?
- ✦ What rituals take place after death and how are people remembered?



Meg died at 52, but she told me that she was not afraid to die and that she was weary of her illness and her body that had let her down. She knew she would live on in her children and that was the most important thing to her.

Meg's sister

Preparing for death

The extent to which people prepare for death and the ways in which death is handled have changed over time but are there any lasting beliefs that do not change?

The idea of continuity can be important to people in preparing for death. Some religions offer a set of beliefs about an afterlife, in which there is a form of social and moral order, which believers hold as their personal truth. Continuity through genetic or biological inheritance, as the quote from Meg's sister shows, can also be called a form of immortality: people's children might offer meaning to their life. People who have no religious faith and do not believe in any form of continuity might be more likely to contemplate the notion of a useful life. Concern for society through such things as the campaign to 'save the planet' with its underlying theme of continuity and immortality, could be seen as a shared concern for continuity.



Is a good death possible?

A 'good death' is a term that is commonly used to capture the ideals of death. Age, timeliness, the needs of the dying person, their readiness for death, the place of

death and the degree of suffering are all important factors in determining how the quality of death is perceived. A good death not only means different things to different people, it can be a source of conflict when dying people and their carers do not agree about best interests and what is practically possible. This potential for conflict can be the source of much family distress, and people involved in end-of-life care work hard to ensure that the needs of the dying person are paramount. Regardless of how difficult it might be to achieve a good death, much depends on knowing that one is dying.



The sociologist Allan Kellehear wrote in 2007 that, historically, being ready for death had many advantages and that the need to anticipate death remains a constant thread:

Stone Age peoples probably desired to anticipate their own dying by acting beforehand – by preparing and planning for death. In other words, we may expect that a

desire to ‘die’ before the ‘real’ biological dying may have been born in the Stone Age because it is here, at the dawn of our history, that the advantages of such preparation were first recognised.

If one could have a ‘dying’ in this world – even for a small period – that time could be used to gain some knowledge to help one in the otherworld journey. One could

solicit counsel, prayers, even equipment for the journey. Think of it. One might actually have time to ask for a certain weapon, food or rites to be performed.

Here is a quote from a woman who decided to prepare for death in an emphatically personal way:

When I was finally given the news that I had been dreading, I felt a combination of shock and relief. I planned the last few months very carefully – I sold my house and then spent the money on a very expensive red sports car, visiting Rome, my brother in America and showing off my new slim figure in fabulous clothes at my last birthday party.

Sociologist David Clark and colleagues have provided insight into key components of a ‘good’ death. Their research in 1999 showed the importance of a choice about where people die, and who is with them at the time of death. Physical and emotional comfort and dignity were also important. The degree to which people exercise these choices can be restricted by wider features such as poverty, ethnicity and social marginalisation, leading Clark to refer to people facing these obstacles as ‘the disadvantaged dying.’

In 2005 a UK report by the charity Help The Aged found that some 3 per cent of deaths in England and Wales were attributed to 'old age'. Help The Aged has suggested that such a categorisation reveals "how we tend to assume that these deaths are 'timely' or 'natural' and therefore less worthy of our time and concern". Such attitudes towards older people's deaths can have an impact on older people's experience of dying and their access to care.



The population profile and the increasing numbers of people who will die in older age with complex conditions, many of whom are in care homes, is likely to make even higher demands on end-of-life care provision. A study published by Age Concern in 1999 reported older people's views about what makes a 'good death', which can be viewed as ideal principles:

- ✦ knowing when death is coming and what can be expected
- ✦ retaining control of what happens
- ✦ dying with dignity and privacy
- ✦ having pain relief and other symptom control
- ✦ choosing and controlling where death occurs
- ✦ having access to information and expertise of whatever kind is necessary
- ✦ having access to any spiritual or emotional support required
- ✦ having access to hospice care in any location
- ✦ controlling who is present and who shares the end
- ✦ issuing advance directives to ensure that wishes are respected
- ✦ having time to say goodbye, and control over other aspects of timing
- ✦ dying when ready, and not having life prolonged pointlessly.



How people die remains in the memory of those who live on.

Dame Cicely Saunders (1918–2005)

Making sense of dying

End-of-life care in the UK and the western world has been greatly influenced by the modern hospice movement with Dame Cicely Saunders considered as the founder.

The approach provided an alternative to seeing death as failure. Much more than this, it was also a campaign to ensure that people should not die in pain and distress – but in a pain-free and dignified way. Cicely Saunders created a model of ‘total pain’ which can be described as encompassing physical, social, psychological and spiritual areas. This is a holistic approach, which places the dying person at the centre of all treatment decisions. The modern hospice movement has evolved over time into a resource that is highly specialised and limited (in terms of its reach), but also highly valued.

Today, hospice care is usually referred to as specialist palliative care, and it continues to develop and expand throughout the world. While using the principles of

hospice care, it typically focuses on people who have moderate to complex needs and who require expert help from professionals trained in palliative care (NICE, 2004). Terminal care is the care of people who are in the final stages of their illness, where the time remaining is seen in days rather than weeks or months.

Sociologist David Clark estimated in 2007 that there are 56 million deaths in total each year throughout the world, of which 60 per cent could benefit from some form of palliative care. In the UK, the care of people who are dying is central to health policy. Sadly, the rhetoric about how people should be cared for when they are dying is not always matched by the reality. One of the difficulties in providing palliative care to all dying people in need

and requiring multiprofessional teams is that the possible combinations of care are seemingly endless.





Access to end-of-life care is unequal and sometimes far from adequate. In a 2004 publication, NICE indicated that good multiprofessional palliative care is patchy and bereavement support is poor across the UK. It seems that the inequalities that exist in life are also present in dying and

death, as illustrated by this quote from a prison doctor:

So you have somebody who dies away from their family, as often as not away from their friends, away from the society in which they grew up, in a room which is clearly a prison cell and attended by people who, while

doing their best for that prisoner are there to protect the security of the establishment, and clinicians who work within a confined and custodial setting. As hard as one tries to make the room in which the patient is going to die as comfortable as possible, it will stay a prison cell and there is no getting round that.

There might be an assumption that people are cared for in hospices or by palliative home care teams, but most deaths in the UK take place in hospital. This raises the question of the extent to which death has become entirely medicalised, at the expense of meeting the social, emotional, spiritual and cultural needs, for which Saunders fought so hard. Some deaths inevitably take a toll on health-care professionals, as this Accident and Emergency sister relates:

It is very hard when there is a child death in the department because you can feel just sadness in the department when you come on. I remember a recent death where the paediatric nurses who were dealing with the death were very upset and visibly crying.

Death on a paediatric neurology ward

We started to spend hours with Ollie's mum, sitting in the room with both of them, talking about his life and listening to her thoughts and fears ... we would also discuss what would be likely to happen when Ollie died – the physical aspects of his death, and what she wanted to happen after this time ...

One morning it happened by chance that three of the nurses from our team were on the

shift together. ... Without warning, I knew that my colleague (and best friend) needed me, in Ollie's room, a corridor away. When I entered the darkened room it was clear that Ollie was close to death. ... His mum was sat holding his hands, head bowed over him; talking gently to him, telling him that she loved him and that she would be okay. My colleague was sitting with her, holding her. I reached out and laid my hand on my colleague's shoulder to let her know that I was there with her as he died ... [R]ather than just saying we would be there for each other –

we were there for each other – in touch with each other.

Later on that day, we washed and dressed Ollie in his favourite football kit – another of his requests – and the rest of his family came to say goodbye.

A ward sister quoted in *Making Sense of Death, Dying and Bereavement*, Sarah Earle et al. (2009)





Sorrow makes us all children again.

Ralph Waldo Emerson (1803–1882)

Making sense of what happens after death: *funerals*

Following death, how are people's wishes carried out?

This question is faced by those who are close to the 1600 people on average who die every day in the UK. Funerals require the organisation of families, friends, work colleagues, funeral directors, cemetery and crematorium staff, and features like flower arrangements and catering.

Victorian tradition still informs our image of the UK funeral: people wear black, sombre behaviour is expected, respectful solemnity predominates. However, as society becomes more diverse, so too do funerals. Britain is becoming increasingly multicultural and secular; there is no longer one dominant religious frame to guide what happens after death. One growing trend is that services are presented as a celebration of someone's life.

The BBC 1 programme *Richard Wilson: Two Feet in the Grave* featured a celebratory event held in memory of a woman whose last request was that her ashes should be dispersed in a firework display. Her daughter explains:



She was a very sort of quirky woman, ... She believed that the world was created with a bang, therefore she wanted to go out with a bang.

Despite this diversity, there are some legal requirements in the UK that everyone must undertake. All deaths must be formally registered using a death certificate, usually within five days.

If the person did not die from natural causes or had not recently seen a doctor, the death must be reported to the coroner, who has legal responsibility to establish why someone died. The coroner might request a post mortem if there are any uncertainties about the cause of death.



I've been to some funerals and when I see sometimes it's just the hearse, one car, maybe ten people – I'm thinking "did this person not know anyone?" and then when people see West Indian funerals, they're like it's a road stopper, everyone comes out of the shops and ... it's so nice to see.

Mourner at a funeral featured in the BBC 1 programme *Richard Wilson: Two Feet in the Grave*

Once the death has been registered, further forms need to be signed by the next of kin or executor and medical personnel. These forms allow the body to be cremated or buried. Local authorities, funeral directors, or cemetery and crematorium staff can advise.

While these formalities take place the body is usually kept in a mortuary; sometimes contained in a funeral director's premises. The body might go to a private residence, although this is now rare.

Some people choose to prepare the body themselves before burial or cremation, often guided by religious beliefs. For example, according to Islamic funeral rites, the close family wash and tend to the body of the deceased person. This can also be the case for Hindu, Sikh and Jewish families. While washing the body is a tradition for some, it can also be a simple act of caring for someone who has died, as described here by a ward sister:

After he had died his parents came and wanted to cuddle him. We had to tell them that he would feel different. They held him for a long time. Then we washed and dressed him and they watched us do so.

The demand for ever more varied practices has led to the expansion of services supplied by funeral directors. Many now provide a washroom enabling the family to cleanse and tend to the body of the deceased person. Some crematoria have also changed, for example by incorporating viewing platforms so that at traditional Hindu funerals mourners may witness the coffin enter the cremator.

A funeral can be understood as ‘a ritualized event that allows bereaved individuals to celebrate the life of a loved one, mourn his or her death, and receive the support of others’ according to Bert Hayslip Jr. and colleagues (2007). Sociologists, psychologists and anthropologists widely agree that people benefit from a ceremony or ritual after someone has died. It can

help them to recognise that the deceased person is no longer alive, share their sense of loss with others, and begin to address the hole that the deceased person has left in their social networks.

A popular trend now is for funerals to be uniquely personalised for the deceased person, acting as what Tony

Walter, writing in 1990, called their ‘final statement’. This reflects a broader social shift in the power of consumer choice. What has grown from this is a funeral industry where ‘the public are simultaneously bereaved relatives and consumers, and ... the funeral industry is both a service industry and a vocation’ according to Peter Jupp in 2004.

This has contributed to a move towards a professionalised funeral and death care industry, seen in codes such as the Charter for the Bereaved (ICCM, 1996). This creates a sense that there is ‘expertise’ in knowing how to deal with both deceased and bereaved people. On the other hand, a natural death movement and advocacy of do-it-yourself funerals has grown out of an argument that death and bereavement should not be the preserve of professionals, and should be dealt with firsthand.





There's a clump of people all around the school gates. What are they looking at? There by the road, right where Vicky lay, is a bunch of red roses. It's as if any spilt blood has been magically morphed into sweet-smelling flowers.

I stand still, swaying, staring at the bouquet. Someone has written a message: FOR VICKY. I WILL ALWAYS REMEMBER YOU. Vicky's only been dead an hour and yet she's already a memory.

Jaqueline Wilson, from *Vicky Angel*

Making sense of what happens after death: *memorialisation*

For some people, the funeral is the end of the public mourning process and they choose not to do anything else.

For other people, it is important to visit the location of the deceased person's remains, or to do something meaningful with their ashes. Often, these activities result in memorialisation, which refers to the objects, events, words and practices used to remember someone, something or some time. As Michael Parker Pearson pointed out in 2003 from an archaeological perspective, memorialisation after death has been in existence as long as human beings have had a conscious awareness of their own mortality, but the way in which it takes place now is hugely varied and can be very controversial. It is not uncommon for

there to be disagreements in cemeteries about memorialisation when people's expectations about what is an appropriate and respectful way to remember someone differ. Roadside memorials are becoming an increasingly common sight, but they have not been universally welcomed.

Mass death

It is especially challenging to find a way to commemorate an event that results in the death of many people at once. These are often referred to as 'mass deaths' and can be the result of accidents, war, natural disasters, suicides or murders. They are often also referred to as 'traumatic'. One

of the most difficult features of mass death is deciding how to mark the event and commemorate the people who died. Should a memorial to those who died be a communal and collective effort, or should individuals commemorate the deceased individuals separately? To what extent should other people (that is, those not directly affected) be involved?

Sociologist Anne Eyre has written extensively on the experience and management of mass death situations. She argues that 'searching' is a common theme following a mass death situation, be that literal searching for survivors, or for causes of the event, or trying to find

reasons to make sense of it. From talking to people who have experienced a mass death situation, such as emergency service personnel, she observed in 2009 that although

Much of the disaster mental health focuses disproportionately on extreme negative reactions following such direct experiences... (the accounts I have heard) highlighted for me how resilient people can be in the face of collective death and dying.

It is common practice after a mass death to create some kind of public memorial to mark the event and provide a shared place for people to visit. For example, the Memorial Garden at Aberfan and the plaque to commemorate the Hillsborough Disaster at Liverpool Football Club's home, Anfield Football Stadium, or the plaque in Portsmouth to commemorate soldiers who died in war, such as Dan Cruickshank's grandfather:

My grandfather died in September 1918. His small ship was torpedoed off the coast of Devon, within sight of home, within sight of the end of a terrible war. His body was



never found. This was a bad death, for both the dead and the living, and a bad death reverberates through time – becomes almost unbearably sad. I visited the monument that bears his name in Portsmouth. Is it a work of art that offers insights that heal wounds? Does it make sense of death? Well, at the very least it is a memorial. It helps keep his memory alive. It commemorates, and that, by tradition, has always been one of the key roles of death art.

Sometimes, memorials can be very political, not only in that there is disagreement over what they should be, but also in the way that they provide a public landmark to remind those who are still alive that something significant happened that led to the deaths of many people and efforts should be made to avoid it happening again. You may well be aware of some kind of public memorial that serves this purpose in your local area.

Increasingly, these types of public memorials are complemented by activity on the internet, with many sites now providing online memorials and campaign groups. Sometimes these online memorials turn into ways of communicating with the deceased person, or offer a day-to-day diary of someone's experience of grief. Many of these are publicly accessible to anyone in front of a computer, and are therefore changing the way in which we memorialise and remember deceased

people. Changing technology has led to growing possibilities for watching the recording of a funeral and memorialising deceased people on line. These developments are something to watch for the future.

Death and dying are subjects that have a long association with the Open University through its research and teaching. Over 13,000 students have studied the course about death and dying since it was first presented in 1992. The course team have also worked on several research projects investigating the needs of dying and bereaved people.



Parents planted coconut saplings in memory of each of their lost children and this memorial will stand as a living reminder of the loss the village suffered as well as a tribute to the compassion of an administration that used a novel method to share in the grief of a traumatised people.

Prathap Tharyan,
writing about the Asian Tsunami
in *Making Sense of Death, Dying and
Bereavement*, Sarah Earle et al. (2009)

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Published in 2009 by The Open University, Walton Hall, Milton Keynes, MK7 6AA, to accompany *Richard Wilson: Two Feet in the Grave* and *The Art of Dying*, first broadcast on BBC1 and BBC4 respectively in 2009.

Richard Wilson: Two Feet in the Grave

BBC Executive Producer: Dinah Lord

BBC Programme Producer: Daniel Child

The Art of Dying

BBC Executive Producer: Basil Comely

BBC Programme Producer: Matt Hill

Open University Academic Consultants:
Dr Carol Komaromy and Dr Kate Woodthorpe

OU Broadcast and Learning Executive:
Kirsten Dwight

OU Broadcast Project Manager: Sally Ashwell

OU Designer: Glen Darby

OU Editor: Jenny Barden

BBC Multiplatform Commissioning
Executive: Emma De'Ath

Acknowledgements:

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Edited, designed and typeset by The Open University.

Printed in the United Kingdom by Streamline Press Ltd.

Where to turn

If you are experiencing bereavement and loss, there are several organisations you can turn to for guidance and help

www.helptheaged.org.uk

Help the Aged's website provides advice on preparing for the death of someone close, and on bereavement.

www.childbereavement.org.uk

Provides specialised support to all those affected when a child dies, or is bereaved.

www.childhoodbereavementnetwork.org.uk

Works with service providers to improve bereavement support for children.

www.crusebereavementcare.org.uk

Provides free support, information and advice to bereaved people.

www.disasteraction.org.uk

Offers support and information for the bereaved and survivors of major disasters.

www.roadpeace.org

Road Peace supports victims of road crashes and campaigns for road safety.

www.mariecurie.org.uk

Marie Curie Cancer Care provides free nursing care to people with terminal illnesses in their own homes. The website includes helpful information on bereavement.

www.uk-sands.org

The Still Birth and Neonatal Death Society can offer you support if your baby dies during pregnancy or after birth.

www.winstonswish.org.uk

The leading childhood bereavement charity providing services to bereaved children and their families.

Representative organisations for UK cemeteries, crematoria and funeral directors

www.iccm-uk.com

Institute of Cemetery & Crematorium Management

www.fbca.org.uk

Federation of Burial and Cremation Authorities

www.nafd.org.uk

National Association of Funeral Directors

www.saif.org.uk

The National Society of Allied & Independent Funeral Directors

www.naturaldeath.org.uk

The Natural Death Centre advises on environmentally friendly funerals and natural burial grounds.