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An introduction to death, dying and grief

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An introduction to death, dying and grief

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Contents

Introduction 4
Learning Outcomes 5
1 Understanding death 6
1.1 Talking about death 7
2 Exploring Western ideas about ‘a good death’ 11
2.1 Preparing for death 15
3 Assisted dying 18
3.1 Assisted dying legislation and policy 22
4 Considering ethics in death and dying 24
5 Exploring grief 27

Introduction

Welcome to this free course, *An introduction to death, dying and grief*. It is comprised of five sections that will take about 7 hours to complete in total. In Section 1, you will be introduced to different ways in which death is understood, by looking at language around death and how language conveys how people make sense of death. In Section 2, you will examine the meaning of a 'good death' and how this principally applies in the West. In Section 3, you will learn about assisted dying and will consider the different sides of the assisted dying debate. In Section 4, you will briefly be introduced to ethics and ethical dilemmas in practice. In the final section, you will explore grief and the expression of grief in private and in public.

This OpenLearn course is an adapted extract from the Open University course K220 *Death, dying and bereavement*.

Please note that this course includes video about people talking personally about their experiences in relation to death and dying.

If you have been affected by the issues in these videos, you can call Macmillan Cancer Support free of charge on 0808 808 00 00. You can also call Samaritans free from any phone on 116 123 (it will not appear on your phone bill), email jo@samaritans.org, or visit www.samaritans.org to find details of your nearest branch. The Motor Neurone Disease Association also provides support to people affected by motor neurone disease in England, Wales and NI - 03457 626262 or visit The Motor Neurone Disease Association

Learning Outcomes

After studying this course you should be able to:

- understand that individuals and societies make sense of death in different ways
- understand that there is diversity in our beliefs about death and dying
- understand some key ethical dilemmas in dying and assisted dying decisions
- understand some of the diverse expressions of grief.

1 Understanding death

Death is a central aspect of the human condition. At some point in time, human beings developed an awareness that life was finite, and from that moment on, people have tried to 'make sense' of death. Yet the way in which death is understood and represented, and the extent to which it is a taboo topic (which refers to how comfortable people feel talking about it), varies hugely depending on place, historical period and culture.

This has led to questions like:

- Why do we die?
- What happens after we die?
- How can we prolong life?
- How can we experience a 'good' death?

Over the course of human history, people including philosophers, theologians and artists have attempted to address these questions. More recently, scientists and medics have had a significant impact upon how people (particularly in the West) understand death, dying and grief. Our understandings of death have also been influenced by the work of social scientists and 'thanatologists' (people who specialise in the academic study of death and dying).

However, what is so fascinating about this topic – once you start to dig a little deeper – is that there continues to be so much variation in how death is understood by different people and different cultures.

Figure 1 The Tana Torajen community believes that relationships with the deceased continue after their biological death.

1.1 Talking about death

The meanings people ascribe to death (i.e. what is important to people, or what matters to them) are not static. They change over time, within and between cultures. In the west, death is sometimes considered a taboo topic and we use careful or sensitive language when talking about death. In Activity 1, you will explore different perspectives on talking about death.

Figure 2 How we are introduced to the topic of death as children or young people can shape our attitudes later in life.

Activity 1 Talking about death

Allow approximately 1 hour.

Part A

Think about the terms to describe death that you have used or heard. What do you think might be the purpose of these terms, and do you consider them to be helpful?

When have you heard these terms used, or when might you use them? Enter the terms against the following categories in the table below (there is no right or wrong answer here). Two examples have been added to the first box, to help get you started.

Table 1 Talking about death in different contexts

Context	Language or words used to talk about death
Talking to family/friends about the death of a loved one	'Passed away' 'died peacefully'
Expressions in popular culture (TV, film, music, books)	*Provide your answer...*
Language used in funeral services	*Provide your answer...*
Talking about death with colleagues	*Provide your answer...*

Talking about someone you don't know personally (for example, a famous person)	*Provide your answer...*
Talking to someone who is ill, or vulnerable	*Provide your answer...*

Discussion

You may have noticed that the language you use or hear in association with death and dying varies depending on the context. Perhaps there are some terms that you would use with colleagues but not with vulnerable people. Perhaps you adjust the language you use depending on the belief system of the person who you are talking with; maybe your own belief system means that the terms you use are consistent. You may have found yourself using humour to talk about death as a coping mechanism, or have been aware of others doing this. Many people adapt the way they talk about death depending on the context they find themselves in.

An Open University academic wrote: ‘After my mum died, I struggled for a long time to find the words to talk about what had happened. I fluctuated between expressions such as ‘she passed away’ and ‘I lost my mum’ (to which a close friend replied, jokingly – ‘how careless of you!’), until eventually I found the confidence to say that ‘she died’ (which somehow felt more final to me). But when talking to others about the death of their loved ones, people often feel the need to ‘say the right thing’. This can be very hard to do, and may explain why many bereaved people feel that others avoid them, for fear of getting it wrong.

Part B

Now watch this short clip in which Open University lecturer Dr Erica Borgstrom describes why language matters when we talk about end-of-life care or death and dying. As you watch the clip, note down some of the key points made by Dr Borgstrom that really made you think.

Video content is not available in this format.

Provide your answer...

Discussion

Here are some key points that were identified by an OU academic:

- phrases are code which can help control the flow of information
- code language can make things unclear for some people to understand or follow
- euphemisms in death and dying might be perceived as being an easier way to talk about a difficult subject matter
- the use of code gives some indication of how taboo the subject is, or whether it's a more open culture around death
- language conveys our values about life and death.

This first activity shows that there is a lot of variation in our language and the words that we use to describe death and dying. It is important to remember that our language can convey our values and may reflect culture and wider society. Words do not necessarily directly reflect what is thought to be reality, but language can provide some clues about the openness, or otherwise, of society to the idea of death. The use of language is just one aspect of how death is expressed and understood, but language is something that is shared between groups in society and can provide a wider perspective than the individual expression of what death means to that person. Exploring how language connected with death and dying is used provides a brief glimpse of its power and its role in the social fabric of people's lives.

2 Exploring Western ideas about ‘a good death’

What is a good death? If you were tasked with improving the experiences of dying or bereaved people, what would you aspire towards? This question may leave you wondering what makes one dying experience ‘good’, and another ‘bad’. You may speculate on what has shaped your own personal views concerning a ‘good death’ and how your perspective on a good death might differ from family and friends, or people in different communities or countries. And you may wonder whether any death can be inherently ‘good’.

The concept of the ‘good death’ has been central to the development of the modern hospice movement. It presents a view of death that is peaceful, gentle, and anticipated, free of unnecessary medical intervention. In many ways it connects with the natural birth movement. But the notion of a good death is one that needs to be explored in its social, historical and cultural context.

Figure 3 In this painting (‘The Triumph of Death’) by an anonymous painter from Sicily around 1445, Death is depicted as a skeleton on a skeletal horse who is picking off victims, which indicates ideas about the role of fate or luck in death and dying at this time.

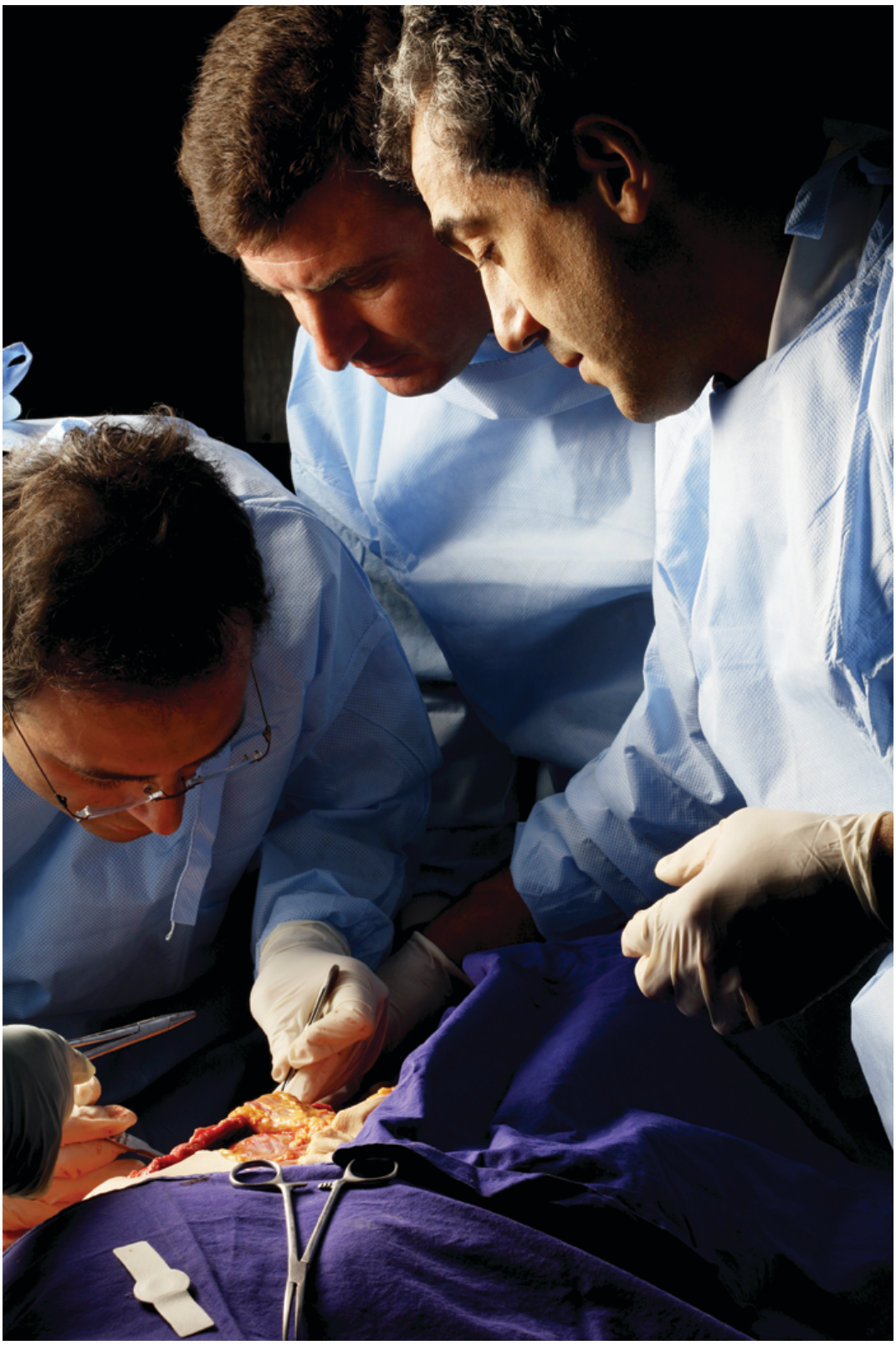

Figure 4 Demonstrating how death is managed medically in the modern age, this image shows how the body is subject to scientific examination as part of an autopsy to understand cause of death.

The backlash to what has been described as the ‘medicalisation of death’ has been the modern hospice movement. Emerging from that movement was a new articulation of a good death. In their extensive reviews of the academic literature, Erica Borgstrom (2014)

and Cottrell and Duggleby (2016) have suggested there are a number of key features that have become synonymous with ideas about a ‘good death’ in contemporary Western societies. These include:

- awareness and acceptance of dying (viewed as a positive)
- preparedness (getting one’s affairs in order)
- comfort (minimisation of pain)
- closure (addressing and resolving difficult issues)
- peacefulness and dignity
- presence of family and being in familiar home (or ‘home-like’) surroundings
- personhood (a sense that an individual’s wishes and preferences have been accounted for)
- timeliness (dying at an older age; and a dying process that is predictable, with an identifiable start and end point).

Central to all of these components is **control** – control over dying activities (like preparing for death); control over the time and place of death; and control of unpleasant symptoms.

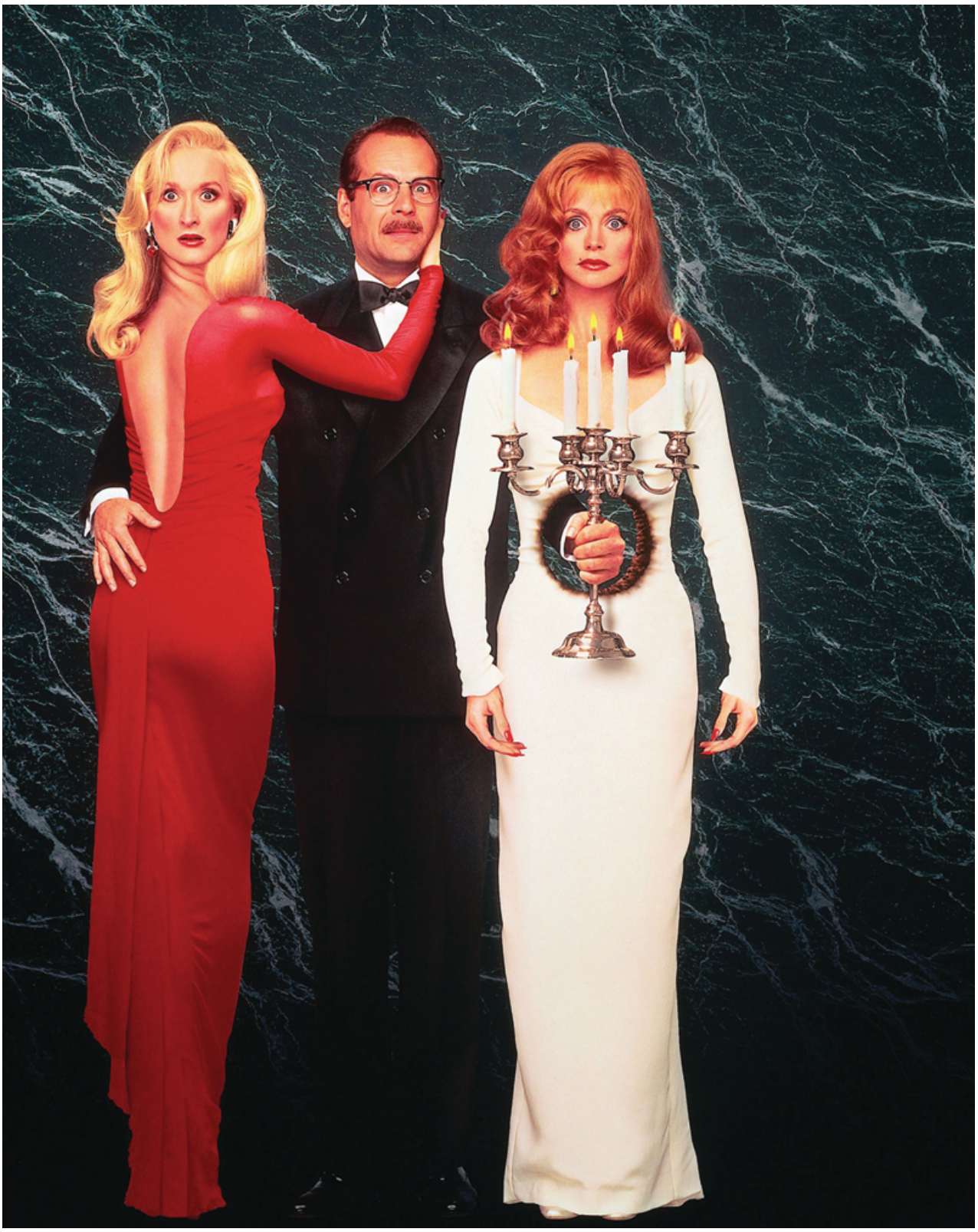

Figure 5 Lack of control over their bodies forms the basis for the dark humour, focused on death, in the black comedy film Death Becomes Her in which Meryl Streep and Goldie Hawn play characters who take a magic potion that promises eternal youth but suffer unpleasant effects which they cannot control when their bodies physically die.

2.1 Preparing for death

In the next activity, you will explore personal perspectives on the end-of-life and preparing for death and the extent to which they draw on these contemporary components of a good death.

Activity 2 Preparing for death

Allow about 1 hour

Part A

Watch these three extracts from a BBC documentary *A Time to Live*, which explored the perspectives of people who had received a terminal prognosis. Although the interviewees were not specifically asked about their views on a good death, their interviews nonetheless reveal some interesting perspectives on the issue. For this activity, you will watch excerpts from three people: Kevin, Anita and Jolene.

As you watch the films, click the drop-down tabs to indicate if you have heard examples from the interviews that map onto the components of a good death outlined by Borgstrom (2014) and Cottrell and Duggleby (2016). You have the option of ‘no’ and ‘not sure’ as well.

Video content is not available in this format.
Video 1 A Time to Live: Kevin

Interactive content is not available in this format.

Video content is not available in this format.
Video 2 A Time to Live: Anita

Interactive content is not available in this format.

Video content is not available in this format.
Video 3 A Time to Live: Jolene

Interactive content is not available in this format.

Discussion

The answers are collated here for comparison purposes:

Table 2 Example answers

Contemporary Western features of a good death	Kevin	Anita	Jolene
awareness of dying (viewed as a positive)	yes	yes	no
preparedness (getting one’s affairs in order)	yes	yes	not sure
comfort	not sure	not sure	not sure
closure	yes	yes	not sure

peacefulness and dignity	not sure	yes	not sure
presence of family and being in familiar surroundings	not sure	no	yes
personhood (a sense that an individual’s wishes and preferences have been accounted for)	not sure	yes	yes
timeliness – death at the ‘right’ time? A dying period that is predictable?	yes	not sure	no
control	yes	yes	no

Part B

Now draft some writing about the films you have just watched. Answer the three questions below. Write one paragraph of about 100 words for each question.

1. What similarities did you identify between the three films?

Provide your answer...

2. What differences did you notice?

Provide your answer...

3. Did anything surprise you about these films?

Provide your answer...

Discussion

A student wrote the following answers:

1 I noticed that both Kevin and Anita valued that their diagnosis had given them time to get their affairs in order, and make preparations for their death. They both suggested that receiving a terminal diagnosis had enabled them to make the most of the life they have left. So the awareness of forthcoming death seemed to be a positive – perhaps even something quite transformational. Control over one’s destiny in the final stages of life seemed to be very important to all three people; they all seemed independent and headstrong, wanting to make decisions for themselves.

2 Jolene’s interview was very different in tone to Kevin and Anita. Awareness of her forthcoming death did not seem to be a positive for Jolene, and she had no interest in getting her affairs in order. This seemed to be a waste of precious life for Jolene. She also expressed anger, sadness and frustration that the end of her life was near, and that she had been ‘robbed’ of more time. I think age played a big part in how people responded to news of their terminal prognosis. How can a good death apply to someone so young?

3 I found Anita and Kevin’s interviews unexpectedly uplifting; I did not anticipate that before I watched them. I was perhaps a little surprised that the people on the film did not speak more about their forthcoming death, and how they envisaged this happening. Maybe people don’t want to talk about this when they know it’s

coming? Perhaps it's just too painful? I was also struck by the strong emotions in Jolene's interview. How does that relate to ideas about a 'good death'? It seemed that Jolene couldn't see anything 'good' about her diagnosis, and I wondered what support there was for someone in her situation.

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3 Assisted dying

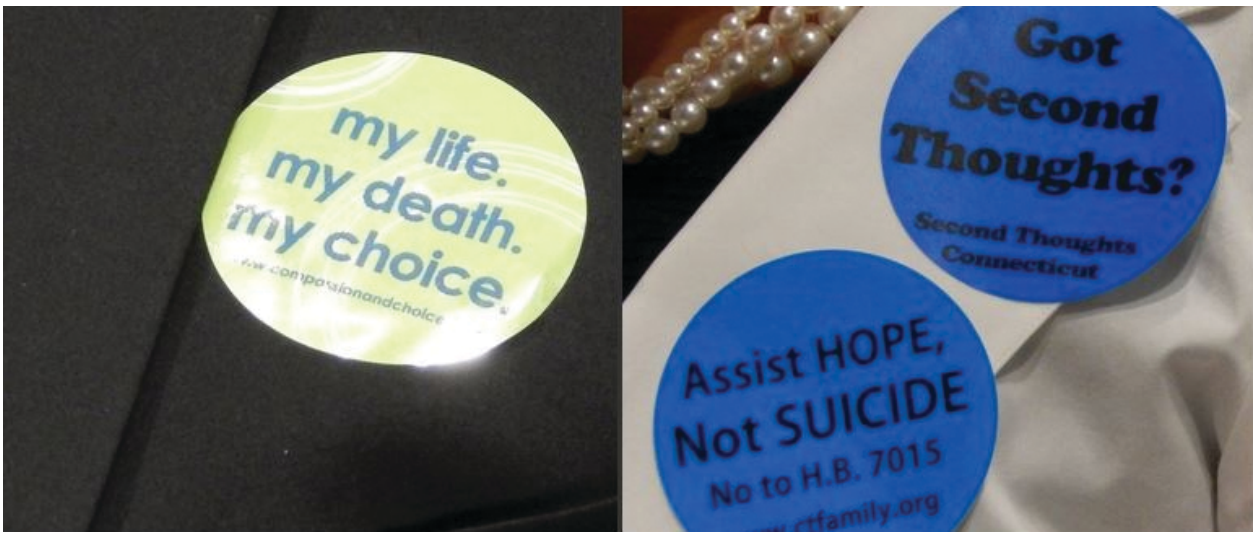

Figure 6 The debate on assisted dying is polarised and often features in the news media.

Assisted dying is currently not a feature of end-of-life care policy in the UK. The assisted dying debate is one that continues to divide opinions and is now regularly debated within the courts and parliaments. In countries that do allow it, it is offered alongside palliative and end-of-life care (e.g. the Netherlands).

Figure 7 In 2002, Terminally ill Diane Pretty (here with her husband Brian) lost her petition for her right to die. She took this to the European Court of Human Rights but the petition was denied.

Some people argue that if end-of-life care was better, people would then not want assisted dying because their pain and other symptoms, including psychological and social, would be managed. Others argue that even with such holistic care, some individuals may wish to choose when and how they die. However, research suggests that requests for assisted dying or euthanasia actually increase among people receiving hospice (i.e. end-of-life) care (Chapple et al., 2006; Lawton, 2000; Seale and Addington-Hall, 1995). A number of reasons for this have been suggested, including the greater openness of expression encouraged in hospices, the distress of witnessing other people's deaths and wanting to avoid a similar experience, and the wish to remain physically independent and 'in control' (Chapple et al., 2006). In countries where assisted dying is legal, there is some evidence to suggest that not everyone who requests assisted dying follows through with the act (Warnes, 2014).

Before you look into the reasons for and against assisted dying in more detail, it is useful to understand the range of terminology that is used within this topic. As with end-of-life care, there are several terms used to describe a range of subtle differences. This is explained in Figure 8.

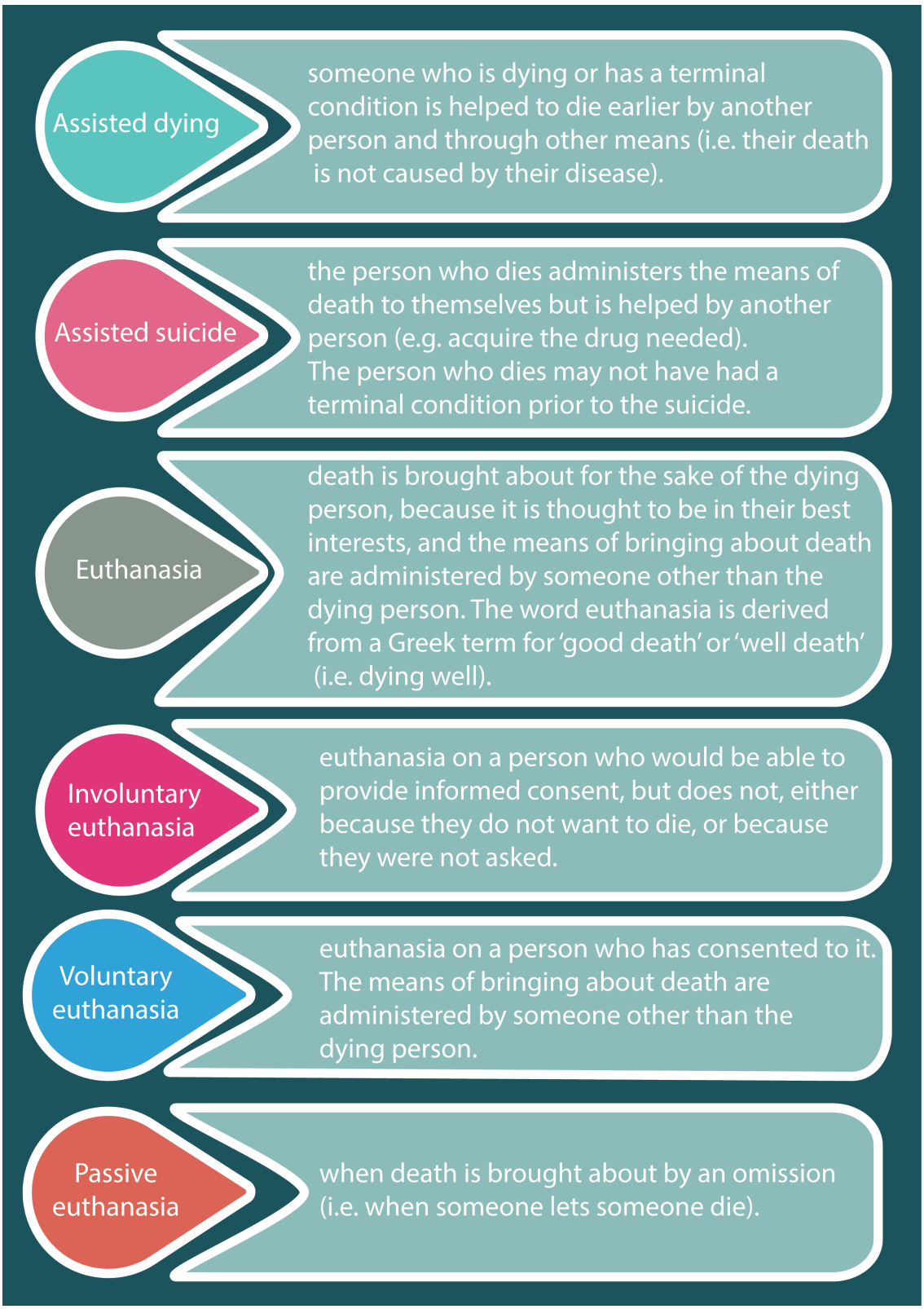

Figure 8 Different terminology relating to dying and end-of-life care.

Note how there are differences in these terms about who does the action, the intention of the action, and if the person who dies had a choice about the matter. In the media, there are often debates around legalising assisted dying. For example, assisted dying may be seen to some as more ethically defensible than prolonging a slow or painful death. Also some believe that it is an individual's right to choose their death (personal autonomy) and

achieve the death that they want at a time that they want which might allow them to have a dignified death (Rodgers, Booth, Norman, & Sowden, 2016). The debate about the right to die is often covered in the news media, such as when Paul Lamb (who was a paralysed former builder) and Jane Nicklinson (a widow of a man who had locked-in syndrome) lost their legal fight to allow disabled people the right to die. This issue was covered and reported in the news (ITV News. *Hope remains despite Supreme Court rejection of right to die campaign*, 2014). In the entertainment media, the UK TV drama Coronation Street has also included a storyline in which a long-standing character, Hayley Cropper, die in an assisted suicide (ITV News, *Coronation Street shows controversial right to die scene*, 2014).

In the next activity, you will be asked to watch a video featuring Actress and Activist Liz Carr who is speaking against legalising assisted dying.

Activity 3 A case against legalising assisted dying

Allow approximately 30 minutes.

Watch this video featuring British actress Liz Carr describe why she opposes legalising assisted dying:

Video content is not available in this format.
Video 4

Make a few notes about what problems or issues Liz Carr thinks that legalising assisted dying might raise.

Provide your answer...

Discussion

Liz Carr argues that there is often a fine line between what people consider terminal illness and disability and that legalising forms of assisted dying may mean that people who are disabled may inadvertently be subject to subtle or direct coercion. Liz raises many points, including how there is no evidence to assure vulnerable people (older and disabled people) that their voices will be heard if assisted dying was legal. There is little or no evidence about how this is done successfully in places which have already

legalised some forms of assisted dying. Liz highlights that assisted dying offers benefit for the few but is a risk to many (vulnerable) people. Liz also explains that in the cases of physician-assisted deaths, it is often the same doctors who assess the patient, who will carry out and evaluate whether the death was a good death – which doesn't allow for much oversight. You may have written down other points.

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3.1 Assisted dying legislation and policy

Should individuals have the right to an assisted death? This question is central to debates about voluntary euthanasia and assisted suicide (both of which are forms of assisted dying). There are some situations where a dying person might conclude that theirs is a life 'worth not living'. Arguably, only the person who is living that life can decide on its value to them, but they might not be able to end their life without assistance from someone else or they might be afraid of surviving the suicide attempt and end up worse off. On some occasions, the help of a relative or friend might be sought, while, on others, help might be requested from doctors involved in caring for the dying person.

At the time of writing (2018), health professionals, relatives and other people who help a dying person to end their own life in the UK run a serious risk of being prosecuted, but it is up to the discretion of the courts when the case is judged. Under the UK's Suicide Act 1961, anyone who 'aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide' commits an offence and may be sentenced to up to 14 years in prison. People assisting in suicide can also be charged with attempted murder under certain circumstances (Fox, McHale & Murphy, 1997). When assisted suicide is alleged, the evidence that is available about the beliefs and intentions of the alleged 'assistant' is crucially important and is often what determines the outcome.

The case of Eleanor Samra

To understand the implications of this, here is a fictitious example.

Eleanor Samra lives with her daughter, Judith. Eleanor is virtually bedridden because of leg injuries sustained during recent falls. She also has bowel cancer which, her doctors say, will cause her to die quite soon. Although well cared for, she is understandably very unhappy and has, on several occasions, said to Judith (and to her other carers) that she doesn't see any point in carrying on living, that she 'feels like a burden' and wishes that they'd 'end it for her'. One evening, Eleanor asks Judith to get a box for her from the back of the wardrobe. While getting it out, Judith drops the box. The lid falls off, revealing several bottles of pills. On closer inspection, these turn out to be sleeping pills, which Eleanor – it seems – has been hoarding for some considerable

time. Judith's initial response is to throw the pills away. But after a lengthy and painful discussion with her mother, she is persuaded to leave the box on the bedside table, so that Eleanor can reach the pills easily and take them whenever she feels ready. Later that evening Eleanor takes a large overdose of the pills and dies in her sleep. In theory, Judith has probably broken the law, because she knew that her mother was contemplating suicide, knew that the pills would help her to kill herself, and intended the pills to help her mother's suicide attempt. Successfully prosecuting Judith, however, might prove difficult in practice because of a lack of evidence. When similar cases have been brought to court, they have not necessarily attracted long sentences and have challenged the definition of 'mercy killing'.

Carers and family members can come under very intense emotional pressure as a result of the distress and physical pain that they witness. The legislation acts as a means of protection for carers of dying people and also protects dying people from involuntary euthanasia. Moreover, legislation acts to protect people who may not be able to protect themselves. John Keown notes that, internationally, the main obstacle to legalising assisted dying, even if considered morally acceptable in some cases, is that it may be difficult to control (Keown, 2002). This is sometimes called the **slippery slope** argument, suggesting that once a practice is started for some people, it may begin to be used for other people who it was originally not intended for. This is of particular concern where consent (e.g. involuntary euthanasia) is not required or where there is the risk that someone may be pressured into opting for assisted dying. In the next activity, you will consider the slippery slope argument and your perspective on assisted dying.

Activity 4 The slippery slope

Allow approximately 30 minutes

Part A

Look at Figure 9 below representing the slippery slope argument. Using the slider button, choose a location on that slope that you think is appropriate for policy to take. For example, you may believe assisted dying should not be allowed at all (far left) or that it should be allowed for someone who is disabled.

Interactive content is not available in this format.

Figure 9 The slippery slope argument

After you have made your selection, note down why you have placed your marker on that position of the slope. To aid your reflection, consider the following questions:

1 What did you consider in making your decision?

2 Do you think you may ever change your mind? Why or why not?

3 What implications do you think your position has for how you view end-of-life care?

1.
2.
3.

Discussion

Someone who previously completed this task marked that they would allow assisted dying for terminally ill people, but no one else. Here is a section of their reflections:

> I think if a person is dying anyway, like within the next year, they should have a say about how much suffering they endure before death. Even with good end-of-life care, people may not wish to have pain (either physical or emotional) and their life is limited anyway. I realise this decision impacts others (like their family) and is not one to be taken lightly. I previously believed no one should have the ability to end their life when they wanted to, but having spoken to people who want to be able to die earlier and why they feel this way, I can sympathise with this. However, I think there needs to be very clear and strict safeguards in place, which I realise can be difficult to do legally, to protect others from being 'forced to die'. We all value life differently but I don't think others should be able to end someone's life without their permission.
>
> I think my position makes me realise that even if end-of-life care is really good, it still might not be enough for some people. One solution does not fit all. But this doesn't mean that people who want assisted dying should not have access to good end-of-life care. I am not sure if I think assisted dying should formally be part of end-of-life care or something that is alongside of it.

The response above is just an example of one perspective on assisted dying. People will have different opinions about what policy should be about assisted dying. This will be influenced by their own beliefs about life and death, about the ethics and values that they believe in, and their own personal experiences.

While people will have differing viewpoints, the role of policy is to find a position that can be applied for the whole population. The current stance about assisted dying policy in the UK is one that promotes the ethical principle of 'do no harm' over personal autonomy.

4 Considering ethics in death and dying

In the previous sections of this OpenLearn course, you have considered whether it is wrong or right to let someone die, and evaluated your own personal opinion about assisted dying. These are ethical questions because they evaluate to what extent an action, event, or opinion is appropriate, right, or good in a particular context. The issues of a 'good death' and assisted dying have ethical dimensions in that they are commenting on the appropriateness of a situation or event. Ethical issues around death and dying are often talked about in terms of decision-making and actions. In this section, you will be given an introduction in how to recognise and discuss ethical issues.

It is important to realise that ethics is not the same as the law or professional codes (i.e. ethical standards professionals are expected to work within), although 'doing the right thing' or 'doing good' is a common feature of all of these. Ethics is specifically about the moral reasoning applied to a situation. A useful way to begin to recognise ethical issues, is to look at examples where questions are raised about what should happen. One of the first steps in studying ethics is to understand your own ethical perspective, which this next activity enables you to do.

Figure 10 A word cloud with words often associated with ethics and morals.

Activity 5 Considering ethical viewpoints

Allow approximately 30 minutes.

Part A

Consider the following statements in Table 3. State whether you agree or disagree and then write in the table why you chose this answer. If you are undecided, why are you undecided?

Table 3 Viewpoints

Statement	Agree or disagree, and why?
Dying people should **always** be told the truth.	*Provide your answer...*
End-of-life care is a human right.	*Provide your answer...*
Health care professionals should determine when a person has died.	*Provide your answer...*
Everything possible should be done to keep people alive.	*Provide your answer...*

People who are bereaved should talk about their emotions.	*Provide your answer...*

Part B

Choose two of the statements above. Write one argument supporting each statement and one argument disagreeing with each statement.

Provide your answer...

Discussion

Here's an example of what some students have written in response to their selection about the statement that end-of-life care is a human right:

One student who agreed wrote 'Everyone has the right to care throughout their life, including at the end-of-life.'

Another student, who chose disagree wrote 'end-of-life care focuses on particular cultural understandings of what health, death, and care are, which are not necessarily universally agreed upon by all people. Saying it should be a right privileges certain ways of dying over others, and this may not be appropriate for an individual or the society in which they live in.'

Another responder found it they often wrote 'it depends' but then struggled to say exactly what would make it clearer for them to answer. For example, they were not sure under what circumstances they thought a dying person should not be told the truth, but nevertheless did not agree with the statement that they should always be told. This shows us that there is more to ethical decision making than just saying 'it depends on the situation' – there are principles and frameworks people use to guide their decisions.

It is important to remember that ethics is inherently a 'grey area' – there is always an element of debate on what is right.

Peter Singer has written extensively about end-of-life ethics. He argues that ethics requires people to move beyond being self-interested and engage with a level of objectively, for example by using agreed ethical principles (Singer, 2011). In other words, he believes that ethical principles provide standards that guide actions that should be applicable to all similar situations. Whatever your perspective, you need to be able to justify your position by providing a logical, coherent, and consistent account.

In some ways, ethical decision-making in the context of death and dying is different from choices in other areas of health and social care, not least because time is limited. However, the context of ethical decision-making at the end-of-life has much in common with other care situations. For example, the question about whether someone should be told all information about their health condition is not only an issue that comes up at the end-of-life. Uncertainty is often a feature of health and social care situations, and it might not be clear why something has occurred or how long it will last. Not knowing what might happen in the near future can make decision difficult. Health and social care professionals are also obliged to follow their own professional ethical codes of conduct, and these might conflict with their personal views or the views of others. Furthermore, individuals and their family members might not agree about what constitutes the best course of action in a given circumstance. People may also change their minds as events unfold. It is not

uncommon for families and professionals to disagree, for example, about how much a dying person should be told about their condition and likely remaining lifespan. These complications, which include competing ethical perspectives, uncertainty, and disagreement about the value of information or action, as well as the emotional pain that is often associated with death and dying, all complicate the task of making ethical decisions in this context. Consequently, what is considered 'right' can vary depending on the situation and is often debatable.

If this introduction to ethical decision making has sparked your interest, you may be interested in learning more through a video drama and accompanying quiz on the challenges of making ethical decisions on behalf of others. You will have the opportunity to watch a series of events unfold and be intermittently asked what decisions you would make in each situation. So what would you do? Access this interesting interactive quiz activity here.

In this brief introduction to ethics, you should now be able to identify and recognise what constitutes an ethical dilemma in death and dying and how there might be different perspectives on what is right and wrong. In the next and final section, we will move on how people demonstrate grief both privately and publicly.

5 Exploring grief

This final section is focused grief and bereavement – particularly the social context of bereavement and grieving behaviour (social norms). In this section, you will explore the public dimensions of grief (such as by examining the deaths of celebrities) and the way in which grief is portrayed in popular culture (such as in film and music).