What is it?

Euthanasia is the act of intentionally killing a person, painlessly, when this may be construed as beneficial (for example, to relieve suffering) to the person who dies.

There are different types of euthanasia:

Voluntary euthanasia is at the request of a fully competent person who wishes to die.

Non-Voluntary euthanasia takes place when a person is unable to consent due to age, physical and/or mental incapacity. An example of this would be the decision to stop artificial feeding and hydration for someone in a Persistent Vegetative State.

Involuntary euthanasia occurs when a dying person could have been but was not asked for their consent, or when a request for continued treatment is refused. Attaching DNR notices to the medical notes of elderly or disabled patients without their knowledge can be considered a form of involuntary euthanasia.

Assisted suicide, which is often considered a form of euthanasia, happens when a person is given the means or the information to kill themselves. A third party is involved but may or may not be present during the act. When a doctor is implicated this is known as ‘physician assisted suicide.’ In the US this is most notoriously associated with Dr. Jack Kevorkian.
Euthanasia can be active or passive,

- **Active euthanasia** describes cases where an action is performed with the intention of causing death. An example of this would be giving a lethal injection. This is currently illegal in the U.K.

- **Passive euthanasia** describes cases where death is intentionally caused by inaction. An example of this would be withdrawing or withholding artificial nutrition or hydration or the use of a ventilator.

There are also times where increasing pain relief such as morphine may shorten a person’s life but this is not the intention so is seen as morally different.

The latter case is an example of the doctrine of double effect. This principle, developed from Catholic moral theology, maintains that an effect that would be morally unacceptable if it came about intentionally would be acceptable if unintended, even if it could have been predicted.
Guidance Notes for Trainers

This issue touches on:

- Human rights
- How disabled peoples’ lives are viewed
- Quality of life issues
- How disability is defined
- Eugenics

Remember that disabled people hold a variety of views on euthanasia.

- Some disabled people see allowing voluntary euthanasia as increasing personal choice.
- Others think it may lead to coercion.

This is a hugely emotive subject and support must be given to allow participants the space they need.
What are the arguments?

In favour

Pro-euthanasia groups, which include some disabled people, concentrate on voluntary euthanasia and assisted suicide, deeming it a matter of respect for personal autonomy. If someone has an incurable disease or is in great pain they should be afforded the dignity of choosing the manner and time of their death and be assisted if necessary. Furthermore they claim that medical improvements will mean an increasing number of terminally ill people will be kept alive, some against their wishes.

Those who advocate non-voluntary euthanasia, such as Peter Singer, contend that we are in a period when the traditional ideas about the sanctity of life are being overturned by new medical practices which can keep people alive artificially. He argues that in cases such as irreversible brain injury there is a loss of those attributes which make someone a person, such as consciousness, communication, ability to enjoy life and so on. Because of this there is little point in maintaining, and every argument for ending, what can be regarded as a life without quality or moral status.

Utilitarians maintain there is no moral difference between killing and allowing to die. If the consequence is death, it does not matter if it is achieved by an act or omission, and it is preferable therefore that the death is brief and painless.

Arguments

Legal euthanasia is right.

It would give people choice about how and when to die.

- It's my decision
- I choose when and how
- I can go with dignity
- I won't be kept alive in a horrible state

I see suicide as a 'reasonable way out' but I have no physical strength.

- It's my decision
- I choose when and how
- I can go with dignity
- I won't be kept alive in a horrible state

Utilitarians maintain there is no moral difference between killing and allowing to die. If the consequence is death, it does not matter if it is achieved by an act or omission, and it is preferable therefore that the death is brief and painless.
Arguments

Legal euthanasia is wrong.

Disabled people would be put at risk

- I’m such a burden.
- I’ll have no-one to look after me when I get home.
- I can’t afford to pay someone.
- No-one cares, why should I?
- I’m not worth saving.

Opposed

Many arguments against euthanasia start from the proposition, either religious or secular, that all human life has intrinsic value and therefore to take a life in the ordinary course of events is wrong.

Disability rights advocates maintain that if euthanasia or physician assisted suicide was legalised this would put pressure on some disabled people to use them because of a lack of social support, poverty, inadequate health care, social exclusion and internalised oppression. Disabled people are also often more vulnerable than most to undue persuasion and that informed consent would be an illusion. Furthermore, some people who feel they are a ‘burden’ would be faced with the ‘obvious’ solution. Overall, the argument is that you should support people to live, not create structures which encourage them to want to die.

People need support to live, not systems that lead them to want to die.
Real cases to discuss

Miss B. was disabled and wanted life support turned off.

Tony Bland was in a coma and others decided to turn off life support.

Sample Exercise

You can give one, some, or all of these cases to tease out the issues. Alternatively, you may prefer to use the more detailed case studies given below as a basis for discussion.

1. Miss B

Miss B was a fully competent patient who no longer wished to live after becoming quadriplegic following a haemorrhage in her upper spinal cord. She had been a senior social worker and had led an active life. Now, connected to a ventilator and unable to move any part of her body below the head, she felt that life was not worth living. She was resident in hospital and wanted her life support to be switched off. She petitioned the courts for this to happen and her wish was granted.

Her death can be seen as passive euthanasia as she was allowed to die as a result of the withdrawal of breathing assistance.

Q. What are the implications for disabled people?

Q. What are the moral differences, if any, between active and passive euthanasia?

2. Tony Bland

Tony Bland was an incompetent patient. Following the Hillsborough disaster, he suffered such severe brain injuries that his cerebral cortex was irreparably damaged. Consequently, he was in a persistent vegetative state (PVS). His parents and the medical personnel at Airedale Hospital were in agreement that he should no longer be kept...
Dianne Pretty wanted to be helped by her husband to die.

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alive. The only way for him to die was for his artificial hydration and nutrition to be stopped. This was granted by the House of Lords.

This was classified as passive euthanasia as it was stated that he died from his disease. But, he may have lived for many years if his hydration and nutrition had not been removed.

Q. What are the implications for disabled people?

Q. What are the differences, if any, between active and passive euthanasia?

3. Dianne Pretty

Diane Pretty was a competent, terminally ill patient. She petitioned the courts in England and finally the European Court of Human Rights for the right to die.

Dianne was unable to take her own life because she was paralysed from the neck down due to motor neurone disease. She was tube fed but did not wish to die by starvation i.e., by removal of the tube. Rather, she wanted to die by active means, assisted by her husband. Her case failed, in England because active euthanasia is not allowed, and in Europe because it was not felt that her human rights were being violated.

Soon after her last petition failed she died naturally, in the care of a hospice.

Q. What are the implications for disabled people?

Q. What are the moral differences, if any, between active and passive euthanasia?
4. The Disability Rights Commission has written that on balance, it is against the legalisation of euthanasia, including assisted suicide.

- Do you agree with this view?
- If so, why have you reached this decision?
- If you think that voluntary euthanasia should be legalised, under what circumstances should it be allowed?

**Case Studies**

We are including a number of case studies in this section which trainers may want to use as the basis for exercises or discussion.

**Example 1 - Mercy Killing**

A recent example is the story of Carol Carr, 63, who was charged with two counts of murder last month for shooting to death her two sons, Andy Byron Scott, 41, and Michael Randy Scott, 42. Both men had Huntington’s disease and were living in an Atlanta-area nursing home.

The Chicago Tribune published a commentary in defense of Carr’s alleged actions. Lewis Whittington wrote of the ‘nightmarish’ existence of living with a ‘degenerative’ disease. And what a parallel living hell it is, he said, to have to be the one who lives with them, who has to bathe them and move their limbs and dispose of their bodily waste.

“When he talks about people with degenerative diseases, he’s talking about me. I have muscular dystrophy. I need someone every day to
Killing a non-disabled person intentionally is always murder. Killing a disabled person intentionally can be “mercy killing.”

help me bathe and move my limbs and dispose of my bodily waste. And when he talks about family members who can’t give them the help they need, he’s talking about me too. My mother loves me dearly as I love her. She would do anything for me. But she’s in her seventies and she just can’t do everything I need.

So do I deserve a bullet in the brain?

The hell Whittington described is a hell of our own creation. I live in my own condo and a state program pays for people to assist me at home under my direction. My situation is light years away from hopeless. Hope comes in many forms. For me it comes in the form of those who come assist me. Everyone deserves these options that bring hope, whether it’s pain management or technology that facilitates communication or whatever.

But it makes me wonder how we ever reached the level of enlightenment necessary to create such programs when we are still capable of treating people like the Scott brothers with such profound contempt. When they need help, we shrug and say it’s a family responsibility. When it’s too much for the family, we offer no alternatives but surrender to a nursing home or death. No wonder they perceive themselves as hopeless.

And then we mock their memories by dismissing their deaths with the disdainful oxy-moron of mercy killing. We say killing a human being is murder but killing them is something less.

How demoralizing it is to be reminded just how unwelcome people with disabilities still are in our culture. We should use the death of the
Scott brothers to dedicate ourselves to creating the kind of supportive society where no one is ever made to feel like a burden.”

For full article see Mike Ervin, *There’s No Such Thing as a Mercy Killing*, *Chicago Sun Times*, July 21, 2002.
http://www.euthanasia.com/notmercy.html

**Example 2 - Why not help people to live?**

“I was born with spinal muscular atrophy, a so-called ‘terminal’ condition. I cannot lift my head from the pillow unaided and I need a ventilator to help me breathe at night. I use a powered wheelchair and have a computer on which I type with one finger. I have a high-powered and fulfilling job as the head of a major national organisation. More importantly, I am fortunate to live in a borough that provides exemplary social care: a 24-hour personal assistant enables me to have an independent life, to be a wife to my husband and a person to my family and friends.

I know that if this care were to end tomorrow my life would be intolerable and I would consider suicide. Without my care package I would have to give up my job and rely on my husband to care for me. Epithets such as ‘tragic’, ‘burdensome’ and even ‘desperate’ are frequently used to describe disabled people’s lives, and unless you are extraordinarily strong it’s all too easy for disabled people to succumb to this negativity.

Every day in Britain a disabled person is made fully aware that his or her life is contingent, reliant on the goodwill of others; that it is a life placing untold strain and pressure on somebody who was once their
Many people say they have chosen euthanasia because they “don’t want to be a burden”

husband, daughter or parent but whose character has been eclipsed by their role as a full-time carer; that rather than a fulfilled life, theirs is a life that has become a burden to others.

Such feelings are well-chronicled in research into why people choose to die. Studies in Oregon and Holland, where euthanasia is legal, revealed that a substantial number of people seeking assisted suicide gave ‘not wanting to be a burden’ as the principal reason for seeking death.

In January I was hospitalised with severe pneumonia in both lungs. On two separate occasions, doctors told me they assumed that if I fell unconscious I wouldn’t want to be given life-saving treatment. I was so frightened of what might happen to me that I kept myself awake for 48 hours. My husband brought in a photo of me in my graduation gown and stuck it on the bed-head to remind the hospital staff that there was more to me than the shrivelled form they saw lying in front of them. I was lucky: although I could barely breathe, I had an assertive husband insisting to the authorities that I had everything to live for. Imagine what it would be like if you were too weak to communicate. Or your relatives less positive about the quality of your life.

Our underfunded and discretionary systems of health and social care, coupled with rampant discrimination, are having fatal consequences for disabled people. But, rather than tackle these issues head on - to choose life, in Irvine Welsh’s now famous phrase - the warping effects of our discourse on disability seem to have made death the only humane option.

Local authorities are having to limit the cost of care packages - often to the lower cost of living in residential care. There are wide discrepancies in provision for disabled people with similar needs;
Disabled people must be supported to live in the community.

where you live and when you joined the queue are the determining factors for the type and quality of support you receive.

Disabled people are living in institutional care against their will - disability charity John Grooms, for example, has reported that 8,000 young adults are living in care homes designed primarily for elderly people - and otherwise have their independence threatened by lack of support on their own terms. Research by the disability rights commission identified a long list of barriers to independent living, including inadequate support to continue or take up employment, that are constantly being thrown up by social service departments.

A report by the Joseph Rowntree Foundation concluded that the government’s economic and social policy initiatives treated the families of disabled children as ‘peripheral or invisible’. Tackling inequality in this field, it said, will require ‘resources which policy initiatives to date have not allowed for’.

In the 21st century, it is still seen as acceptable for disabled people to be living in institutions against their wishes, to be denied access to basic support to enable them to enjoy a family or social life, and to be guaranteed no more than the bare minimum of services necessary for day-to-day survival.

The arguments for a right to independent living are complex but vital. What level of independence are we trying to achieve, how integrated should it be with other services such as transport and leisure, who should be entitled to it and who should meet the costs? These are questions that society has a moral priority to answer before we take the path of legislating for assisted death.
Disabled people are still fighting for full participation and inclusion in life. We are decades away from a society embracing the quality of our lives as equal to those of non-disabled people. Only when, or if, this is enshrined in law and reflected in every aspect of our lives should we ever begin to consider legislation that assists people to end their lives.

Without our lives being seen as having equal value, any attempt legally to sanction hastening our death will exacerbate a culture that fears incapacity so much that it wants to extinguish it.”

http://www.guardian.co.uk/comment/story/0,3604,1029148,00.html

Quotes

“While the terror of state-sponsored euthanasia may never grip America as it once did Germany, it is possible that the terror of the euthanasia ethic - tolerated by medicine and an indifferent public and practiced by a few physicians - may grip many invisible and vulnerable Americans. Over fifty years ago, German doctors and courts collaborated to identify millions of people who were labeled ‘devoid of value’. Some Americans are labeled the same today: members of a racial or ethnic ‘underclass’, a sidewalk screamer ... an illegal alien ... a nursing home resident with Alzheimer’s disease ... an abandoned migrant worker ... or anyone too old or weak or poor to help himself or herself. For two millennia the Hippocratic tradition has stood for the ‘sanctity’ of human life. We can alleviate the unbearable in life better than ever before. We can do that

Statements to discuss

“Medicine cannot be both our healer and our killer.”
and not eliminate life itself. As I have said many times, medicine cannot be both our healer and our killer.”

C. Everett Koop, M.D. former US Surgeon General
http://www.euthanasia.com/koop.html

“The energetic commitment of the disabled-rights community, more than any other single factor, has thwarted the assisted-suicide movement. Because disability-rights activists are generally politically liberal, distinctly secular in outlook, and often supportive of abortion rights, the media can no longer caricature assisted-suicide opponents as religious busybodies. Moreover, people who would jump head first off a skyscraper if pro-lifers told them not to will listen to the opinions of disability-rights activists with open minds. As a result, some polls now show a sharp drop in the support for legalizing assisted suicide.”

Wesley J. Smith Disabling Assisted Suicide, Why a deadly movement hasn’t been contagious, National Review Online, Jan. 19, 2004.
http://www.nationalreview.com/comment/smith200401190806.asp

“Within the scope of the law, decisions about the end of life should rest in the individual’s hands. We believe that no government entity should insist on a particular course of death, and that depriving individuals of either choice or dignity in this process is wrong. In addition, our principles maintain that no physician should be culpable for allowing a terminally ill adult to achieve a peaceful, dignified death according to the patient’s own informed and stated wishes.”

End of Life Choices http://www.endoflifechoices.org/learn/index.jsp
Points to discuss

Euthanasia – whose human rights?

Discussion Points

• If a competent adult wishes to die, why should we stop them?
• If it is OK to allow someone to die, is it OK to kill them?
• If the consequence is death, it does not matter if it is achieved by an act (active euthanasia) or an omission (passive euthanasia?)
• If you legalise active euthanasia this will increase pressure on disabled people not ‘to be a burden’.
• How and when to end one’s life is a fundamental human right.
• Legal euthanasia threatens the human rights of disabled people.

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International Task Force on Euthanasia and Assisted Suicide, Website http://www.internationaltaskforce.org/
And more!

Not Dead Yet, the resistance, Website http://www.notdeadyet.org/


