



Euthanasia Discussion Kit

Discussion Part Three: Case Studies

NSW.ACT

Introduction

People often talk about euthanasia in broad general terms, without considering specific circumstances. People often make assumptions about what can or cannot be done, or about what they will or will not want in particular circumstances.

There are several points we need to remember when considering the question of euthanasia:

Often people's needs can be met through various forms of treatment or through exercising rights they already have to refuse treatment, even in cases where people think they want euthanasia to be an option. We should not assume that euthanasia is the only possible solution. Often patients will find their need met through either active treatment or palliative care.

Different people respond to treatment in different ways. While palliative care works for most patients, it does not adequately relieve the suffering of a small number of patients. Within this small group, a small number would like euthanasia. Many others choose to live with the pain until the disease runs its course. We should not assume that people can, or should, respond to such situations in a particular way.

Situations can look different to the observer than to the patient. When we look at someone's suffering, or their situation of dementia or disability, we are likely to either overestimate or underestimate the suffering, depending on our own experiences, values, and pain threshold. Sometimes it is harder to cope with the suffering of other people than with our own. On the other hand, some people seem to have no idea of how unbearable the suffering can be. We should not assume that people should all be able to cope with their situation of suffering, but we also should not assume that when people suffer they would prefer death.

The case studies are intended to help the reader understand the options already available to people, and the particular situations where voluntary euthanasia is being proposed by some people as an option. The circumstances where non-voluntary euthanasia might be suggested, such as permanent vegetative state, are not included here, since they raise somewhat different issues.

As you read each case:

Readers may like to think about their initial reactions as they read each case. What is your initial reaction to the situation? What is your reaction to the choice the patient, their doctor or family makes? What questions do you have at the end of the case? Does it help clarify your thinking?

Some people argue that people should recognise that health services are expensive, and argue that people have no right to expect support services, palliative care, dementia care and so on. Given these case studies, what is your reaction to that proposal - should people choose to die instead of choosing care? What health care policies should the church be advocating for people who are elderly, are elderly with dementia, have a disability, or are terminally ill? What changes in the Medicare levy would you be prepared to pay to ensure adequate care was available to all these groups on the basis of need?

These stories do not mention whether any of the people were Christian or not, but Christians find themselves in each of these situations. For each case, you might consider what aspect of Christian faith might lead the person to the particular decision they made? Are there things you believe that might suggest a different decision?

The questions at the end of each case suggest some of the issues raised in that case. There are also some questions at the end, to help bring together some of the issues raised by comparing the cases.

Case Study 1. Palliative care and refusal of treatment

Amanda had Cystic Fibrosis. She was 16 years of age, and was in and out of hospital for most of her life. In the last couple of years the treatment had less and less effect.

In her final stay in hospital, despite extensive physiotherapy and constant medication, she grew weaker and was a constant discomfort and pain.

Amanda asked the doctors questions about her illness, and she knew that even with treatment she would die within the year. She had been on the waiting list for a heart/lung transplant, but her condition was now too weak and frail to be able to withstand such an operation.

Without the treatment, death would come more quickly.

When the treatment itself, with its wires, tubes and machines and uncomfortable hospitalisation became more of a burden than an illness, she requested that treatment be stopped and that she be allowed to go home to die in the company of her family.

She knew that the end would come, but also knew that the morphine injections would keep her as comfortable as possible and she would not have to fight any longer.

Amanda was at home for twelve days before she died. Her large close family stayed day and night. The community nurse visited twice a day. Amanda received oxygen to help her breathe.

The grieving and bonding of those last twelve days is one of the blessings of a "good death". It was an honour to be part of those twelve days.

One of the first things that Amanda did when she got home was to write once again to the Federal Minister for Health, imploring her to make available on the prescription list new medication at a cost that all her friends with cystic fibrosis could afford.

During Amanda's final days she spent time with others organising and arranging her funeral service. She had never been baptised and asked could she be baptised.

Placed inside her coffin at her funeral were many souvenirs, drawings and letters. One was the first ticket to be printed for her Year 12 Formal Dance. Amanda could not use her ticket. I suspect her dancing in heaven will be with much more ease and energy now that she is fully healed.

*Amanda chose to **refuse treatment**. She did not need any changes in the law to do this. It is the right of every patient to decide whether or not they want the treatment the doctor offers.*

Amanda also received palliative care - medical treatment to make her last days more comfortable.

What is your reaction to this story? What issues does it raise for you?

Amanda had a disability that imposed unbearable suffering, but that also required ongoing treatment. What about situations where people find their disability unbearable, although it does not require ongoing treatment to keep them alive?

Case study 2 Alzheimer sufferer - appropriate dementia care

Mavis is a woman 84 years of age, a widow with one son, currently residing in a unit for the Confused and Disturbed Elderly (CADE).

Mavis grew up in the country, her father was an opal miner. She had six siblings, and enjoyed horse riding and dancing.

She worked as a maid and governess, and later married and had one son.

Until recently Mavis lived in Broken Hill. Her personal care was poor, including nutrition. Her physical and mental health deteriorated. She became aggressive and sometimes violent, also paranoid, not trusting friends or relatives.

A woman working for a charitable organisation gained her trust and access to her bank account. She embezzled money from her account, depleting Mavis' finances.

Her son tried to manage Mavis' care from Sydney as she refused to leave Broken Hill, but eventually had to bring her to Sydney.

Mavis took every opportunity to abscond from their home. Family members slept on the floor to block exits.

The family realised their need for respite and are fortunate to have in their area a CADE unit.

Mavis was treated for her physical condition and after a brief period her mood settled and she now enjoys a relaxed life style. Her dementia has increased, with memory loss and greater confusion. However, she is rarely without a smile, is the life of the music therapy group, loves to dance and attempts all activities, enjoying the giving and receiving of love.

Her son and daughter-in-law are delighted with her life style, having first felt much guilt about placing her in the unit. Her son continues to be amazed at his mother's enjoyment of life and often comments that he didn't think he would ever be in the position of seeing his mother "flirting".

Mavis has responded to specialised care for the disturbed elderly, including pastoral ministry, in a caring and homely environment. She is a valued resident in the unit, adding to the quality of life for other residents.

The quality of life of Alzheimer's sufferers is often questioned.

Neurologist Oliver Sacks challenges us not to define others' worth primarily by their ability to communicate with us, and cautions against underestimating any ill person's struggle to maintain personal identity even with dementia and delusional behaviours. Alzheimer's victims, for example, enjoy human companionship, giving and receiving love, long after they have lost the ability to talk clearly or to care for themselves. The ability to feel and respond to feelings remains...God does not forget us even though our memories fail. (Fredrica Harris Thompsell *Courageous Incarnation - in intimacy, work, childhood and aging* Cowely Publications 1993)

Mavis needed specialist care, in an appropriate setting.

Some people fear dementia as they grow older, and want euthanasia to be something they can organise ahead of time in case they develop dementia (they want to leave instructions with their doctor or family).

The Uniting Church in Australia is actively involved in lobbying government for better dementia care services. Uniting Ministry with the Aging has some dementia care units.

Is this an adequate response to the issue of dementia? Is it realistic to expect all stories of dementia patients to be like this? What are some of the other experiences people might have?

Do you think all needs of dementia patients can be met through adequate provision of care, or should people be able to say while they are still healthy: if I develop dementia, I want euthanasia? Why would people want this option?

Case Study 3 Community and Palliative Care

Carole is 55 years old, divorced and lives alone in a unit in a high rise Department of Housing Building. She has severe financial difficulties.

She has one child, a daughter aged 32 who is mildly developmentally disabled, with whom she has little contact. A severely physically disabled son died shortly after birth.

Carole is estranged from her only sibling and her elderly mother has dementia.

She effectively has no friends; one couple visit her on occasions when they are in Sydney.

Her neighbours are from non-English speaking backgrounds and contact is minimal.

Carole was sexually abused as a child and later sexually and physically abused by her husband. After one episode of abuse she attempted suicide and was admitted for a brief period into a large psychiatric institution.

Carole is physically and emotionally isolated.

She has diabetes and multiple sclerosis (MS). She has had her bladder removed, and as a result has regular severe kidney infections which are damaging her kidneys, to the point where she will die from renal failure. There is no option for further surgery.

Her pain is managed with narcotic analgesics on advice from a pain clinic.

Intervention from a social worker and a chaplain has resulted in Carole receiving Home Care services, community nursing, meals on wheels, financial advice and emotional and spiritual support.

18 months ago a psychologist from the MS Society contacted a mental health chaplain to help Carole "live until she dies".

The intervals between periods in hospital have decreased as infections become more difficult to control and pain levels increase.

Carole has the courage to suffer, but the times when life seems unbearable and she feels she cannot go on are becoming more frequent.

The emotional and spiritual support Carole receives from the chaplain through regular visits and telephone calls coupled with community and palliative care enable her to journey through the valley of the shadow of death, in her words "to live one day at a time".

*Even though I walk through the valley of the shadow of death
I fear no evil;
Your rod and your staff they comfort me.
(Psalm 23:4)*

Carole relies on **community support, palliative care, and chaplaincy** to enable her to cope with her suffering.

What is your response to this story?

Do you think that everyone in Carole's situation receives this level of help? How can we ensure that such help is available to everyone who needs it?

Carole has the courage, with the help that she receives, to go on living. We can admire her courage, but can we expect everyone to cope with such situations?

If Carole decides one day she has had enough, what options are available to her at present? Do people in Carole's situation need the option of euthanasia to be available so that when necessary they can say "I've had enough", and receive help in dying?

Case study 4 Palliative Care

Jim had prostate cancer, which had spread to the bone and was incurable. The doctors told him that he would live for several years. His first thought was fear and a desire to avoid any pain. He thought of the pain an uncle had experienced twenty years before, with a similar illness. His uncle's agony was vivid in his mind, and he was sure that he did not want to go through that experience. If that was the way life would be, he would be better off dead. He asked his doctor about euthanasia.

The doctor explained that they could provide radiotherapy to limit the growth of the cancer, and medication to control the bone pain. He assured him that most patients find that such treatment provides good pain control and leaves them relatively free of symptoms. Only a small minority of patients, he explained, find that pain cannot be effectively controlled and that their lives are unbearable.

Jim agreed to these treatments and found that he was able to lead a constructive life. If the doctors had agreed to his initial request for euthanasia, he would have been deprived of several years of "normal" life.

*Jim found that **appropriate treatment and pain palliation** satisfied his needs.*

What might have happened if euthanasia had been readily available?

What about if the treatment had not adequately relieved his symptoms?

Case study 5 Withdrawal of futile or overly burdensome treatment

Alan was eighty two, in a nursing home for elderly people with dementia. Each day was a separate experience, with no memory of yesterday and no thought of tomorrow. He no longer knew his family when they visited him. He seemed to have little interest even in what went on around him.

Alan developed pneumonia. His doctor suggested to the family that it would be best not to treat him with antibiotics, but rather to let nature take its course. The family agreed. They had loved Alan, but there seemed to be so little left of the Alan whom they had known that it seemed presumptuous to intervene to keep him alive. Treatment, it seemed to them, would be futile, imposing life as a burden rather than a gift.

*Alan was no longer able to make a decision for himself. His doctor and family decided that this was a case of **withdrawal of futile treatment**.*

Why would this be considered to be withdrawal of futile treatment?

What is your response to this story?

What would you have decided if he had been your father, husband, or brother?

If you become like Alan one day, what do you want your family to decide for you?

Case Study 6 Withdrawal of futile treatment

June was sixty eight. She had discovered a month ago that she had cancer. Not one of those cancers that is caught early and can be easily treated, but a cancer which had already spread throughout her body, causing it to break down. Now she had renal failure as well. The doctor was about to ring the hospital to arrange for renal dialysis. She told him "No. Before you do that, there are some things I want to know. This is my decision, not yours."

The doctor explained that renal dialysis would prolong her life. It would involve being connected to a machine several times a week, for several hours at a time.

"I know that", she said, "but is it what I want? I know what it does, but what will it feel like? How long will it keep me alive? What part of me will stop functioning next?"

The doctor admitted that it would only extend her life by six weeks at the most, and that something else could go wrong tomorrow. The treatment would be inconvenient, uncomfortable, and possibly painful.

"This is not what I want", she said. "Look, when you told me I had cancer, I went home and talked about it. My husband and children and I have talked about this. We all know my death is soon. I wanted time to sort out the row my son and I had six months ago. I didn't want to die before I did that. Now it's sorted. We're talking to one another again. My time has come. You're offering me more discomfort, more pain, more trips to a hospital to sit in some sterile little room clinging on to life as if death was something to be scared about. I can't take any more of hospitals. I've had a good life, and now my time has come. You can't make me better, so let's get on with it. What do we have to do so I die without pain in my own home with my family?"

"But what about your family", asked the doctor. "I'm sure they would want you to live as long as possible".

"My family objected when I first told them I would refuse further treatment, but now they accept it. Death is part of life. Let's not turn it into a failure of medical technology. I'm going home to my family, to die in peace. Give me something to control the pain, and let me get out of here. It's my right, and my choice".

To which the doctor could only agree. The NSW Department of Health Dying with dignity guidelines indicate that no treatment in this case was good medical practice. His role was no longer active treatment, but only pain control so that those last hours would be peaceful.

*June chose **refusal of burdensome/futile treatment, plus good palliative care.***

Did you respond to this story in the same way as to the story of Amanda (Case 1)? In what ways are the stories similar, and in what ways different? How does this affect the issues they raise?

In what circumstances do you think you would refuse treatment?

Some people argue for euthanasia on the grounds that when people are aged or close to death, they should not "waste" society's resources on medical treatment. We only have so much money for the health budget. We have to have priorities. They don't go quite as far as proposing compulsory euthanasia, but the argument tends in that direction.

Do you think it would have been appropriate for June to choose the dialysis treatment?

What are we entitled to expect from the health care system, and when should we not expect treatment?

Case study 7 Euthanasia - legal assisted suicide

Arnold is a man in his fifties who has stomach cancer. It is incurable and is causing him prolonged suffering (severe pain and discomfort). He no longer wants to go through this. He has no family, and lives in a rural town which has trouble getting doctors. This means that the possibilities of palliative care are limited. He does not want to move from the town to somewhere else just for the sake of palliative care. He would rather use the Northern Territory legislation to die, now.

There is a Northern Territory doctor willing to organise euthanasia at his request. This doctor has set up a computer based system at the hospital, to administer the lethal injection at the patient's request. Arnold would first make a request to the doctor, and then be examined by several other doctors to ensure the diagnosis was correct, that he was not depressed, and

that he understood what palliative care was available. The doctor would check out a number of matters with Arnold, in accordance with the legislation. Seven days after his original request, the computer would be brought to his bedside in hospital. He would have to answer several questions on the computer. When it comes to the end of the questions, the computer will ask the patient if he want to be injected with a substance that will kill them, and if he answers "yes", will ask him to confirm this answer. It will then cause Arnold to be injected with a lethal dose of a drug.

However, when Arnold goes to Darwin, he find that legal action has resulted in other doctors refusing to participate in euthanasia. The legislation requires more than one doctor. Since no one will cooperate with Arnold and the first doctor, he cannot proceed with euthanasia. He is angry about this, and appears on TV condemning the people who have taken the legal action which is preventing him from dying.

*This is a case where the person seeks **euthanasia in which the patient takes the initiative**. It is suicide in that the patient takes the action which kills them. It is euthanasia because it is doctor-assisted suicide - the doctor sets up the computer and links it to the drug injection.*

What is your reaction to this story? How do you think that you would feel if you were Arnold, at each stage of this story?

What do you think about using a computer based system in this way?

Do you think it is a good way of ensuring the patient makes their own decision and dies only as a result of their own decision? Why?

Do you think it would be easy or difficult for someone else to make the decision for the patient, using this system? Why?

Is it fair and reasonable that people have intervened to stop the legislation being used?

Society has stopped Arnold choosing euthanasia. What responsibility does society have to meet his needs in some other way, and how can this be done?

Case study 8 Euthanasia - assisted suicide.

(This is an actual case, abbreviated from HIV/AIDS Legal Link, Vol 7, No 1, March 1996. Used at suggestion and with permission of the AIDS Council of NSW. The article was written by David Buchanan)

A man who helped his lover with HIV to die has been acquitted of manslaughter. He received a good behaviour bond for aiding and abetting an attempted suicide.

Leslie Hoddy, 30, was charged with manslaughter, and aiding and abetting suicide, after he contacted police and told them he had helped his lover to suicide using prescription medications.

The body of Ricky Brooks was found in a Sydney hotel room on 7 October 1994. Subsequently Mr Hoddy told police that he and Mr Brooks had been hospitalised with HIV related conditions a number of times and had previously attempted suicide. Mr Brooks' doctor told the court which sentenced Mr Hoddy that Ricky Brooks had been quite unwell, and that the combination of his illnesses, disabilities and his medications would have left him very unhappy. Mr Brooks had been diagnosed HIV positive in the early 1980s.

Tablets to help lover die

Mr Hoddy said his lover had telephoned him saying he had messed up his attempt to kill himself. He asked his boyfriend to help him "do it properly". Mr Hoddy, an enrolled nurse, went to the hotel room where he and Mr Brooks talked about their lives and hugged and cried together before Mr Hoddy crushed 15 codeine phosphate tablets for Ricky to take with juice. When Mr Hoddy left, his lover was still alive although slurring his speech and slumped on the bed. Police later found two suicide notes in the room, one of them to Mr Hoddy.

A magistrate discharged Mr Hoddy on the charge of manslaughter on the basis of the toxicology evidence and Mr Brooks' medical history. The later showed Mr Brooks was habituated to morphine derivatives and thus the level of codeine phosphate found on post-mortem would not in Mr Brooks' case have necessarily been fatal. The drugs found on post-mortem included lethal levels of at least one other drug, plus a number of other drugs. Further, based on Mr Hoddy's statement to police, Mr Brooks had already consumed codeine phosphate before Mr Hoddy arrived.

Accordingly, the magistrate found that it was not possible to say that the drug administered by Mr Hoddy had caused Mr Brooks' death. For this reason, the prosecution then changed the second charge to one of aiding and abetting attempted suicide. To this charge, Mr Hoddy pleaded guilty and he was committed for sentence.

Sentence

At Sydney District Court on 28 November 1995, Judge Solomon heard testimony by Mr Brooks' and Mr Hoddy's doctors. Mr Hoddy is a "long term survivor" of HIV. As well as psychiatric and psychological evidence as to the effects of the case on Mr Hoddy, the judge received evidence from the Director of the AIDS Council of NSW, and Ankali, an HIV/AIDS support group, about the increased hardship suffered by people with HIV if they are imprisoned.

Mr Hoddy's barrister told the court that HIV related suicides were not uncommon and that a heavy sentence would not deter AIDS suicides, rather it would only affect the reporting of suicides to police.

Judge Solomon imposed a three year good behaviour bond on Mr Hoddy. He took into account the "tragic circumstances" of the case and the ill health of Mr Hoddy. The judge said that Mr Hoddy was not motivated by anything but his affection for Mr Brooks, who had terminal AIDS and "was in great physical and psychological distress".

*The court accepted that Ricky Brooks **chose to end his life, by suicide, and then by assisted suicide.** Assisted suicide is illegal, and one reason for euthanasia legislation is to make assisted suicide in such cases legal, so people like Leslie Hoddy do not have to go to court for helping someone die at their own request.*

What do you think you would have done if you had been in Leslie Hoddy's place? What do you think you would have wanted Mr Hoddy to do if you had been Ricky Brooks?

Suicide is not illegal. What do you think are the reasons the law makes it illegal to assist someone to suicide?

The court accepted that this was a case of assisted suicide. AIDS sufferers say that many of them will continue to choose to die by suicide, rather than wait for AIDS to run its full course. On the other hand many AIDS sufferers do not suicide, and wait for the disease, or some complication, to end their lives.

How should society deal with such situations?

Euthanasia legislation would provide a process for requesting help with dying, so that there were at least some safeguards for all involved. What would be the advantages and disadvantages of such legislation (if carefully formulated with adequate accountability mechanisms - Discussion Paper 2) compared to the present situation?

Comparing cases: there is a time to live, and a time to die, but how do we know the time?

Some people who are against euthanasia seem to assume that at the present time, "nature" takes its course and the time of death is not affected by human decision. These cases make it clear that human decision is already involved in many deaths.

- **The cases of Amanda, Carole, Jim and Arnold have some similarities.** All had the potential to live some time longer. Amanda chose to let her life end sooner but euthanasia was not involved. Carole and Jim have chosen to extend their life through treatment. Arnold chose to die but was not allowed to do so.
 - What do we learn from the stories about their reasons for their different choices? Is the length of time that we live the most important thing about life? When is it appropriate to live a shorter rather than a longer time?
 - While Jim seems to be relatively symptom free, Carole experiences great suffering. Do either or both need the option of euthanasia to be available?
 - Do you see any substantial difference between the decisions made by Amanda, and June , on one hand, and Ricky Brooks and Arnold on the other? In what ways is voluntary euthanasia similar to and different from refusing medical treatment? Should we continue to differentiate between them in law?
 - What are some of the problems in keeping the law as it is, and some of the problems if we change the law to allow voluntary euthanasia?
 - If Mavis develops pneumonia, what decision do you think her family should make? What would be the reasons for making the same decision for Mavis as Alan's family made? What would be the reasons for making a different decision for Mavis than for Alan?
 - What are the implications of these case studies for government policy on health and community services? What are the implications for the church, especially for chaplaincy services?
 - Are there any other comments you want to make about what you have discovered as you discussed these case studies?
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The case studies are based on material provided by Dr Graeme Morgan, Margaret Brookfield, Rev Irene Smith, and the AIDS Council of NSW. The paper was edited and discussion questions supplied by Rev Ann Wansbrough.

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