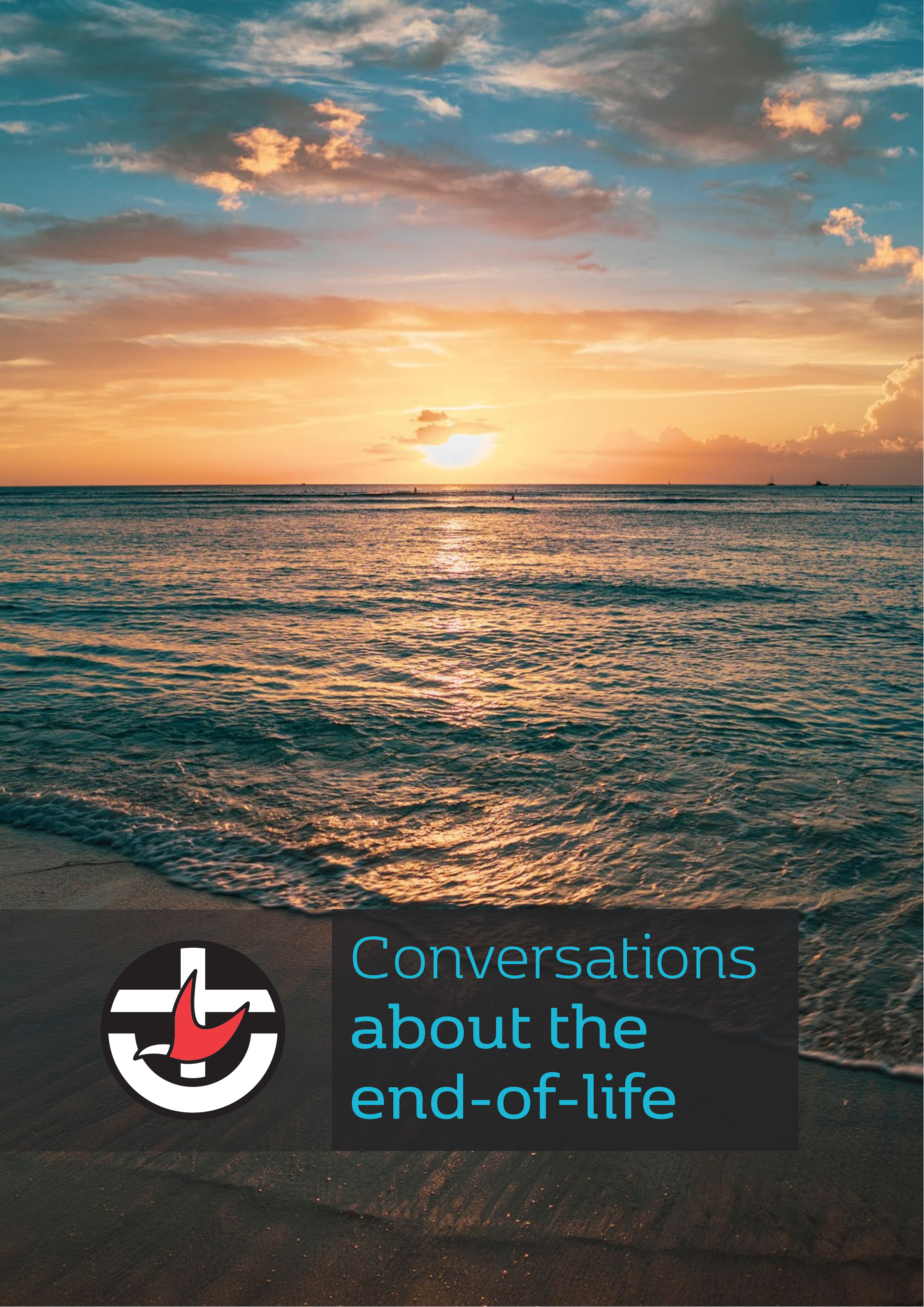

Conversations about the end-of-life

A project of the

Uniting Church in Australia
Synod of Western Australia
End-of-Life Care Task Group

GPO Box M952 PERTH WA 6843

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Conversations about the end-of-life

A resource produced by the
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Australia, for community
discussion seminars

2021

Initial thoughts, feelings, questions

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Prologue

After receiving the doctor’s message, Greg drove to the hospital, dreading what he would find. Although he visited his elderly mother regularly, he had a feeling that this time it would be different.

At 82, his mother’s mind was still sharp, but for years she had been battling with a nerve disease that had paralysed her throat and was now making it hard to either talk or eat. The doctor had just been talking to her about inserting a tube into her stomach for feeding. She knew that while this would enable her to live longer, she would slowly become more paralysed until she died. She had asked for Greg to be called in.

He suspected that she would want to talk about her death. Greg had never seen anyone dying, and he always changed the subject if death was ever mentioned. Sure enough, she wanted to tell him that she had decided to discontinue all food and drink and wished to leave the hospital. There was no talking her out of it.

With grief in his heart, Greg arranged for his mother to be transferred to a hospice. At her request, he brought the family together for a birthday party, which was surprisingly joyous. And a roster was set up to ensure there was always a family member with her – until, 17 days later, after having lapsed into unconsciousness, she died peacefully.

Have you ever been in this situation, regarding a dying relative or friend? It is good to talk about this before it happens. Then we will be able to comfort and be comforted when it happens. Ten other scenarios follow as well. Use them as talking points with family and friends.

Moderator’s Introduction

In times past, death was a very visible part of life, often linked with extended community rituals to honour the dead person and comfort family and friends. But in mainstream Australian culture today, death is much less visible. When portrayed in film and television, it is often in ways that sensationalise or trivialise it.

Many people have never actually seen a dead body or sat with a dying person. Rather than engaging in a conversation about the challenge to live and die well, people often change the subject by saying, “Don’t be morbid” or “Let us leave that topic for further down the track”. We feel such avoidance is not healthy, either emotionally or spiritually. It does not help a family cope if one of them is suddenly and unexpectedly at the point of death.

This booklet is an initiative of the Uniting Church Western Australia to help people have healthy conversations with family, friends and perhaps with their doctor, about their preferences regarding death and dying. It also seeks to develop an informed awareness of the recent legislation in WA to allow “Voluntary Assisted Dying” (VAD). Conscious of the diversity of opinion regarding this legislation, the series does not attempt to prescribe, but to clarify, and encourage open dialogue about dying well.

It has been prepared to resource people who would value help in processing end-of-life issues, whether concerning themselves or others they are caring for. There are ten case studies. They can be used individually or as topics for day seminars where two to three case studies are discussed on any one day. All stories are from real life, though names have been changed to protect privacy.

A companion booklet, *Resources for End-of-Life Care* will also become available discussing related medical, legal, ethical and faith issues in a little more detail. For churches interested in conducting a series of local conversations on the topic of dying, and preparation for the last stage of life, this booklet would be an essential resource for the leaders of such conversations.

The Uniting Church in Australia is committed, particularly through its churches and caring agencies, to offering pastoral care and counselling to individuals and families that reflect Christian values. This includes the worth of every individual in God's eyes, their entitlement to effective palliative care when the dying process is gradual, and opportunities for honest grieving and open celebration of the years lived.

This booklet was commissioned by the Uniting Church Western Australia, to assist churches to sponsor open conversations and explorations on these matters in their local communities.

We are grateful to the members of the task group who brought this booklet into being out of their diverse experience and points of view. We hope that many will derive insight, comfort, and courage from the conversations it seeks to stimulate. Talk with God about it in prayer too!

For their work in preparing this booklet, our thanks go to Dr Douglas Bridge, Dr Arthur Criddle, Dr Rachel Currie, Rev Ken Devereux, Rev Steve Francis and Professor Brian Hill.

Susy Thomas
Moderator
Uniting Church WA

Rev Ken Devereux
Convener
End-of-Life Care Task Group

Session 1: “You’re just prolonging a living death!”

Forty-six-year-old Sally had been battling with Motor Neurone Disease[1] for several years and knew that she was not likely to live much longer. The muscles which enabled her to breathe were becoming so weak that her life depended on the ventilator mask that was strapped to her face. But her mind was clear, and she felt she had achieved all her goals in life.

All patients have the legal right to refuse treatment. During yet another hospital admission to treat a chest infection, Sally decided that the ventilator was “prolonging death” rather than “prolonging life.” She wanted the mask to be removed, allowing a swift death, preceded by heavy sedation to prevent the respiratory distress which she experienced every time her mask was briefly removed. Her medical staff prescribed increasing sedation over 18 hours before removing her mask.

She died peacefully two hours later surrounded by her family, who were aware of her choices, and accepting of them. Death does not always come as quickly as in Sally’s

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[1] Nerve cells (neurones) control the muscles that enable us to move, speak, breathe, and swallow. Motor Neurone Disease (MND) is the name given to a group of diseases in which these neurones fail to work normally. As they degenerate, the muscles gradually weaken and waste, ultimately causing death.

case. Some of the nursing staff perceived the administration of the high doses of sedation as a form of suicide.

> Before discussing Sally’s story, re-read for comparison the story of Greg’s elderly mother, described in the Prologue at the beginning of this booklet.

Discussion Questions

1. Imagine that Sally was a good friend of yours. How would you have felt about her decision to remove the mask to allow death?
2. What ethical issues does the story of Sally’s end-of-life care raise for you?
3. Does the age difference between Sally (46) and Greg’s mother (87) make any difference to how you perceive their choices regarding the end of their lives?

Notes:

Session 2: “She’s refused to eat or drink!”

Margaret, aged 82, was diagnosed with a form of Motor Neurone Disease known as Bulbar Palsy. She was still able to walk and use her hands, but her throat was paralysed, and she was unable to talk. She communicated by writing. When she swallowed food, some trickled into her trachea, causing fits of coughing and the risk of pneumonia.

Her doctors explained that they could provide good nutrition by inserting a tube into her stomach. She reflected on this option for several days. She understood that artificial feeding could prolong her life, but would not stop the progression of the disease. She knew she would slowly become more paralysed until she died.

Instead, she made a clear and unhurried decision to discontinue all food and drink. She was transferred to a beautiful hospice environment which she thoroughly enjoyed.

One day, surrounded by her extended family, she celebrated her 83rd birthday, complete with a huge birthday cake, which she was unable to eat. For two weeks her family surrounded her, taking turns to ensure she was never alone.

Margaret drifted into unconsciousness in her final days and died peacefully after 17 days in the hospice.

Discussion Questions

1. Margaret, like Sally, had a terminal illness. In her place, would your choices have been the same?
2. Some patients refuse both food and water. Is there a difference between starving to death and fasting till death?[2]
3. What counsel would you give to a family concerned about a relative's decision to fast?

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[2] A starving person is hungry, but has no food. A fasting person has food, but chooses not to eat. Dying patients do not usually feel hungry, and a dry mouth can be alleviated by sips of water. Death while fasting usually comes peacefully within two weeks.

Session 3: Where do you want to die?

Excerpts adapted from a conversation Perth Palliative Care Specialist, Dr Doug Bridge had with an Indigenous patient.[3]

Doug: Hello ‘Yarran’. Thanks for agreeing to talk to me today. Because you are from the bush, I am sure you have a lot of things you could teach us. I want to ask you first of all: tell me what is really going on inside your belly, what the doctors have told you.

Yarran: I’ve got stomach cancer, and it’s spreading. They tried to cut it out, but it’s too late. They couldn’t do it. The doctor who was supposed to cut it out sewed me back up and gave me another chance to see my family and have a bit longer life. I thank him very much for that.

Doug: You want to get out of this hospital soon. Where do you want to go?

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[3] Condensed from: Doug Bridge, *Conversations with people facing death*, Royal Perth Hospital: Dept of Health, Western Australia, 2012, pp. 5-8. Used with permission from Dr Bridge. Video resource and scripts including this, and other people’s conversations may be available for loan from the End-of-Life Care Task Group or accessed at the State Library WA.

Yarran: Back to [country]. Most of my family will come from the bush to support me and comfort me.

Doug: Who will be living in the house?

Yarran: Me and my partner and the three girls.

Doug: Good.

Yarran: I really miss the bush, but I just have to go to the White-fellas to learn. I’ve still got my culture, but I have to learn that Whitefellas’ culture too: to speak English, and paperwork. Without the doctors I would not have found out that I have cancer.

Doug: So, you use Whitefella medicine and bush medicine, both of them?

Yarran: Yes, both medicines. Whitefellas’ medicine – the painkillers, it helps a lot.

Doug: I want to ask you another question. You don’t have to answer this one. But I just wonder if you could tell me how you feel about the possibility that you could die, and what that means for you? Is that too private?

Yarran: No. It’s too late for me to be sorry now, you know. I feel hurt and sad about dying, but I’ve got no choice.

Doug: And do you have a feeling about after you die, what happens to your spirit, or your person?

Yarran: No, I just leave it up to [sacred Creator being] who for us is the Lord. He is the Judge for everyone, you know.

Doug: So, there will be a new life for you? Is that your understanding, or you don’t know?

Yarran: Um, I don’t know. When you rest in peace, it’s up to Him up here. (Points upwards) So I just hope my spirit goes back to that country where I belong.

Doug: I am told that it is important for Aboriginal people to die “in country”, in their own country. Is that true?

Yarran: Yes. So, they don’t have to wander around.

Doug: To find the place?

Yarran: So, they are already back home.

Doug: Do you have to die in the same house you were born? Or the same town, or the same district?

Yarran: For most, yes, but for some, they die in another town, and then they go back to their country to get buried. But I want to go back to the country while I’m still around. And then get buried there, you know.

Doug: I want to ask you a sensitive question. I have been told that when an Aboriginal person dies, you must not talk about them, say their name, or show their picture. Is that what you feel?

Yarran: Yes. You are not allowed to mention their name. Their name must rest in peace. If you keep saying the name, we are disturbing them from peace, trying to bring them back up again. The name has to rest in peace.

Doug: Some people have told me that if I talk to an Aboriginal patient, I should not look at them. I should not look into their eyes. Is that true?

Yarran: For most of them, yes. Some you can look in and for some you can't. Most Aboriginals feel the same about looking into other people's eyes, you know. You can just have a quick look at them, and then look away.

Doug: Sometimes they don't talk to me very much. But you seem very confident and happy to talk.

Yarran: When I get the feeling that someone is the right person that I can talk to. He is going to help others, so it is best to talk to them. That's the way to be, you know? You get to communicate and get to know each other. You can tell my story to other people to help them understand, even after I die.

Discussion Questions

1. Cultures differ in how they approach the death of their members. Does mainstream Australian culture, in general, have a healthy attitude towards care for the dying?
2. Regarding care for the dying, how do traditional practices among Australia's Indigenous people contrast with Western culture?
3. What can people in Western culture learn from how Indigenous traditions handle issues of death and dying?

Notes:

Session 4: “How do non-Western migrant cultures approach dying and death?”

[This is a big question. As an example, we asked Hana, a Samoan Australian, to tell us how her birth culture handles these issues. Here is a precis of her reply. Our thanks to Hana].

A typical Samoan family embraces an extended family which can consist of as many as 100 persons, from great-grandparents to distant cousins, often living together on family land in the village. Lines of authority define roles and responsibilities, and members share resources.

When someone dies, the Chief of the family convenes a meeting to arrange the funeral. Some family members may have to travel long distances to participate. All are sensitive to the wishes of the immediate family, e.g. as to whether the deceased member will be buried at the family home, or in the extended family’s cemetery.

The whole extended family contributes gifts of money, cultural wealth, food and help, but members who are unable to give generously are just as welcome. It also elects as spokesperson someone known to the family who has skills of oratory.

The general Samoan attitude towards VAD[4] would be that to the extent that it sanctions the deliberate shortening of someone's life, that would be sinful. However, after watching her father live till 90, but in sustained pain for the last few years, Hana admits that the move to make VAD legal is causing her to give more careful consideration to the question of what constitutes morally acceptable end-of-life care.

Discussion Questions

1. Have you ever experienced how friends with a cultural tradition different from yours handled the dying of a family member? How did it make you feel?
2. How would you want to be treated or cared for if you were disabled and rendered comatose by a stroke or some other catastrophic injury?
3. Do you see any need to revisit your viewpoint regarding the place that conversation and education about death should have in family life?

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[4] *Voluntary Assisted Dying* (VAD) refers to a provision in recent legislation in some states, including WA, which under certain circumstances permits medical personnel to provide a dying person with lethal medication if the patient requests it. A fuller description of provisions in the WA Act may be found in Appendix 4. Neither a patient nor a health worker may be pressured to engage in this procedure. There is much disagreement in the wider community about whether it is an ethical thing to do.

Notes:

Session 5: “Resuscitation? We are family! Don’t we have any say?”

At 89, Victor, despite occasional falls and one recent interval in hospital with pneumonia, was still mobile and feeding himself. One night he was well enough to attend a grandchild’s birthday party, after which his son and daughter-in-law helped him to their car to take him home.

Victor suddenly became distressed and vomited in the car. They took him straight to the nearest hospital emergency department. The son was required to wait in another room while the daughter-in-law went in with him.

As she sat with him waiting for attention, she asked “Are you feeling any pain?”. “No”, he calmly replied, and at that moment his heart stopped, and he collapsed.

Despite the couple’s protests, given that in previous months they had discussed with Victor how he would want to be treated in such a situation, the staff then unsuccessfully applied CPR and other procedures for a very lengthy time to resuscitate Victor.

This reflected deeply ingrained anxiety in medical ranks that patients must be first resuscitated and then the situation assessed. Not to have done so might have exposed them to legal action. However, the *Four principles of medical* *ethics*[5] would suggest more gentle and consultative handling of this situation.

Discussion Questions

1. This incident occurred several years ago in a private hospital. Have you had any similar experiences?
2. Victor's family had no paperwork on hand to support their claim that Victor would not have wanted resuscitation to be attempted. An *Advance Health Directive (AHD)*[6] would have helped. Do you know what that is?
3. Do you need to prepare an AHD for yourself? Or for an elderly relative? In the case study above, how would it have helped to have on hand a completed AHD signed by the dying person?

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[5] A standard often quoted with reference to medical ethics. Briefly, the four *prima facie* moral principles are autonomy of the patient, non-maleficence (do no harm), beneficence (the aim is healing), and justice.

[6] Go to website healthywa.wa.gov.au then search '**Advance Health Directives**' for information about this valuable tool that can inform your family and medical personnel of your wishes in the event you cannot speak for yourself. The form is being revised but was last available on the above website under 'Making an Advance Health Directive' > 'Preparing an Advance Health Directive' [See also WA Cancer & Palliative Care Network]

Notes:

Session 6: Dealing with the death of a young person

Jules was a young tradesman who left home early one morning for work. As he rounded a hill on a country road, the driver of a car coming from the opposite direction was blinded by the rising sun and crossed the double lines at the crest of the hill. The vehicles crashed head-on.

In the days that followed, Jules was cared for in the Intensive Care Unit of a hospital. When the family gathered around the bedside, doctors explained that because of a traumatic brain injury he was in a coma, and had other critical injuries as well. The outlook was uncertain, but they were doing all they could to care for him in the hope of the best possible recovery.

Tests over several weeks showed that there was minimal brain activity. The family was asked whether Jules had ever expressed a view about how he would like to be treated in the event of a catastrophic injury or medical event. The thought had never occurred to any of them.

Discussion Questions

1. Has a young person close to your family ever been in a comatose state and close to death? How did you cope?
2. How would you want to be treated if you were disabled by a stroke or some other catastrophic injury? Would

you want to have CPR[7] to revive you? How would you feel about being placed on a ventilator long-term to keep you breathing?

3. At what time of life should we prepare an *Enduring Power of Guardianship*[8] identifying someone else as having authority to make decisions on our behalf if we became disabled or unable to speak for ourselves?

Notes:

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[7] “Cardiac Pulmonary Resuscitation” is a first aid technique which can be used when a person is not breathing properly, or their heart has stopped. It involves chest compressions and mouth-to-mouth breaths which help to keep blood circulating to vital organs.

[8] “An Enduring Power of Guardianship is a legal document which enables you (the appointor) to appoint a person of your choice to make **personal, lifestyle** and **treatment decisions** on your behalf if you lose the ability to make these decisions for yourself because of an illness or injury. This person (the appointee) becomes your enduring guardian.” See: https://www.publicadvocate.wa.gov.au/_files/epg_kit.pdf

Session 7: “Is it time to bring in the family?”

Raymond had lived an active life working until the age of 83 in the business he had established 40 years earlier. Now, at 87, he was experiencing the stiffening of the heart muscle and lymphoma.

His health deteriorated to the point where he required hospital care and lost 30kg in a short time. He had trouble performing any self-care tasks because of severe breathlessness due to end-stage heart failure.

He was resigned to his imminent death and half-seriously asked his geriatrician if she could leave a shotgun with him. Ultimately, Raymond elected to stop all medications, while continuing to receive palliative care for his symptoms. Gradually he lapsed into unconsciousness and died peacefully surrounded by his family.

A family member looking back on the experience said, “We all knew he was in charge and making decisions for himself. Would he have asked about VAD if it had been a legal option at the time? Probably he would have. Would he have accessed VAD rather than accept palliative pain relief until death occurred naturally? Probably not, but he would have wanted some reassurance that he would not linger on in extreme pain.”

Discussion Questions

1. When should dying people talk to their family about death and clarify their wishes concerning their dying?
2. What do you know about "Palliative Care"? How does it differ from general hospital treatment?[9]
3. How can an *Enduring Power of Guardianship* (see footnote[8] in the previous session) reduce tension at the time of dying?

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[9] **Palliative care** is a relatively recent adaptation of medical care for patients who are perceived to have a life-limiting illness. A multidisciplinary team is convened to relieve suffering and maintain as comfortable and supportive an environment as possible as the patient approaches their death. Palliative Care affirms life and regards dying as a normal process, trying neither to hasten or postpone the death itself. Liaison with family and friends as well as recognition of the spiritual dimension are also important elements in maintaining 'quality of life'. See also: https://palliativecarewa.asn.au/

Session 8: “When is the pain too much?”

Lorrie had metastatic cancer[10]. She was a thoughtful person who from the start followed closely the progress of her illness and ongoing diagnoses. She agreed to take part in medical trials and underwent radiation, CT scans, and blood transfusions as advised by her medical team. At times she had unusually painful biopsies in the hope of getting on top of the condition.

In time, cancer moved into her bone marrow. The medical people said that no further treatment could be offered.

Lorrie was still mentally alert and knew that she was getting close to death. She said she wanted to say her goodbyes, and she decided to refuse any further treatment.

She was on powerful doses of painkillers, but even though she was unresponsive, there were signs that she could still feel pain. On momentary lucid occasions, she could talk to family members and knew that she was being given “painkillers.” She asked for “the biggest dose they could give.” On the third morning, she begged the nurse: “Please tell me this is going to kill me.” The distress of those last few agonising days before her death was not only experienced

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[10] “Metastatic” implies that a cancer originating in one part of the body has spread to other parts of the body, and/or has reached a stage where it cannot be cured.

by Lorrie. It rippled out to her loved ones and to the medical team who were caring for her.

Discussion Questions

1. Have you ever personally known a dying person in Lorrie's situation? Describe the stages in their dying process and who was with them?
2. If you had been able to counsel Lorrie about her approaching death, knowing her wish for medication that would probably be lethal, how would you have handled it?
3. If a patient has a disease, illness or medical condition that is advanced and likely to cause death within six months, and is causing suffering that cannot be adequately relieved, the person can now legally request Voluntary Assisted Dying (VAD). If they meet various requirements, they can then ask for and be given a known lethal substance that will promptly and peacefully bring their life to a close. What do you think of this provision?

Notes:

Session 9: “Let’s not talk about dying yet.”

Maria was 55 years old. She lived with her elderly parents and her sister, although she was often admitted to hospital for several weeks at a time to sort out her symptoms of bleeding, pain, or breathlessness. She had severe kidney disease and acute leukaemia requiring that she be on a dialysis machine three times a week and given daily transfusions of blood to stop her from feeling breathless and tired.

About five years earlier, she had been given a prognosis of a few years to live, but she outlived that prognosis by several years. Many times, she discussed end-of-life care with her doctors and the Palliative Care Team. But she did not want to talk about anything to do with death, the dying process or possible relocation to a hospice.

Equally, she did not want to talk to her parents about her dying, knowing that they had experienced the death of another daughter when she was only 18-years-old. Maria feared that to do so would bring up bad memories from many years ago.

A few weeks into her admission, Maria took a turn for the worse. She became confused, drowsy and was unable to communicate. Her family were advised that she was dying.

There was insufficient time to organise her transfer to a hospice. Instead, she was moved to a bigger room and her large extended family visited her before she died, though Maria was too drowsy to talk to them.

Discussion Questions

1. How does the fact that one day you will die affect you? Why don't many people want to talk about it? How would you like it to happen? Would Maria's refusal to talk about death have helped or hindered her family in their efforts to come to terms with her dying?
2. Have you encountered people who were disturbed by someone's difficult death to such an extent that it hindered their capacity to deal with their dying?
3. Can you suggest some ways of drawing family members into discussing "end-of-life" issues frankly and calmly?
4. At what age or period of life should we encourage people to talk about the dying process?

Notes:

Session 10: Strong mind, strong faith.

Daphne was 91, weak, and had been in hospital for weeks. She was immobile, the ulcer on her leg would not heal, and she had had two recent strokes.

She had been receiving conscientious palliative care at the hands of very competent and caring staff. Though still very aware of her situation, she reached the point of not being able to talk. She knew she would eventually die, but how much longer?

Daphne decided she would reject all offers of food and drink. Her gestures were unmistakable. The staff honoured her clear wish and simply tried to minimise pain and keep her comfortable.

A member of Daphne's family was a hospital chaplain and was present when Daphne was dying. She also knew that people in a comatose state can often still hear and understand things said to them. Knowing that Daphne was a firm Christian, she read aloud a few reassuring Bible verses about life after death. Her death followed soon after.

Discussion Questions

1. Have you ever been present at the actual moment of a person's death? Would you prefer to be there, or not?
2. Was Daphne's decision to decline food consistent with the Christian ethic?

3. Such a decision is often made by patients who have lost their desire for food and fluid anyway. But what if that desire does not go away easily?
4. Was the chaplain’s reading of Bible verses appropriate in the circumstances?

Notes:

Appendices

Appendix 1: The usual pattern of dying

It can be quite difficult to tell when someone is near to death, even for doctors. It is impossible to predict exactly when someone will die.

Some of the first signs that someone is in the final days or weeks of life include: reduced appetite, reduced thirst, spending more time in bed, becoming restless or confused, and being quite sleepy or tired.

These symptoms tend to increase over time. Sometimes people experience all of these symptoms, and sometimes they experience fewer of them. At the end of their lives, patients who choose to fast do not feel hungry, and thirst is not a significant problem. They have a dry mouth which is readily relieved by sips of water.

After a time, the person usually, but not always, becomes unconscious. They may require additional help to keep them comfortable, such as having pain relief given through a small needle under the skin, regular repositioning to help prevent bedsores, and mouth and eye care.

When a person is unconscious, they are also unable to cough. This means that secretions can pool at the back of the throat and cause rattling or gurgling noises. This rarely distresses the person; however, they can be given medications to reduce the production of secretions if it is distressing for their relatives and friends.

While a person is unconscious, they may still be able to hear what is going on around them, and so their relatives may be encouraged to talk to, or play music for, the person who is dying.

At this time, it is very common for a person's heart rate and breathing to change. The heart may beat slower or more irregularly, and the breathing may go through periods of being rapid and then pausing for a short time (known as Cheyne Stokes respirations). Their skin may change colour and become waxy, and they may become cooler.

When someone dies, they will stop responding to their surroundings. Their heart will stop beating, and they will stop breathing. Their eyes will fix in one place with the pupils slightly dilated, and their mouth may rest open a little.

At this point, death can be certified by a medical professional.

Further Reading:

Bridge, Doug, *Conversations with people facing death* (Royal Perth Hospital, Dept of Health, Western Australia, 2012) [Video + Scripts]

Mannix, Kathryn, *With the end in mind: How to live and die well* (London: William Collins, 2017), pp. 11-25.

Kübler-Ross, Elisabeth, On death and dying: What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families (London: Routledge, 1969).

Palliative Care Australia, *The Dying Process* (Aust. Govt. Dept of Health). See: https://palliativecare.org.au/wp-content/uploads/2019/04/PCA_The-Dying-Process.pdf

Cullicutt, Joanna; Moore, Lucy; Payne, M; Slater V. *Seriously Messy: Making Space for families to talk together about death and life* (Bible Reading Fellowship, Oxford 2019)

Zimmerman, Dennis L. Healing Death: Finding wholeness when a cure is no longer possible. The Pilgrim Press, Cleveland 2007

Appendix 2: The ethics of assisting a dying person.

Some contributors' viewpoints:

A major reason why many people argue for the right of individuals to end their own lives when the inevitable is getting close is that medical advances like antibiotics have enabled us to live longer than our forebears, but often at the cost of becoming more vulnerable to diseases and weaknesses. This might include a prolonged and painful dying process.

This booklet is sponsored by the Uniting Church WA. We would therefore be expected to have a view on the ethics of ending one's own life. It has been a long-held view in Christian circles that suicide is self-murder, and murder is wrong.

The question is not directly addressed in the Bible, though several examples of people committing suicide are mentioned, simply as historical fact. The question can be asked, how much were these people prepared to trust that God had a purpose for their lives? Given that it is for God, not us, to decide when our spiritual apprenticeship in this life was over.

The general issue can be highlighted by contrasting two scenarios. In the first, an elderly person in pain is offered palliative care, which combines loving attention to her needs with sedatives to dull the pain. It becomes clear that her condition is not going to improve. She is irreversibly on the path to dying.

She is given progressively more painkiller drugs, but still the pain persists. She indicates, as is her legal right, that she does not wish to be given any more food or drink. The doctor just seeks to make her more comfortable by increasing the sedative dose. She eventually dies, whether from starvation or overdose is not clear.

In the second case, an elderly man is in pain and often lapses into unconsciousness, until eventually, he is clearly in a deep coma, though still obviously experiencing some pain. The medical decision is to steadily increase the dosage, knowing that the point could be reached where the strength of the dose could be enough to cause death.

Was the first case suicide? Was the second, assisted suicide? Neither of these cases is generally regarded as self-murder in the first case, or murder-of-another in the second. It could be argued that in both cases the body was allowed to die when it had had enough of treatments that were generally good in themselves.

A third case is where a patient with a terminal and painful condition is conscious enough to ask for assisted suicide, by being given a known lethal poison. This is the ‘Voluntary

Assisted Dying' (VAD) scenario. It grants authority to a consenting medical professional to supply a known lethal substance.

Potentially it could lead to people not at death's door committing suicide for other reasons, and to health workers playing God and deciding to terminate, for the wrong reasons, even quite young people. Aside from extreme pain, people often have other reasons for wanting to leave this life.

The use of drugs known to be quickly lethal is in a different category from drugs used for pain control. The VAD law does its best to provide protection and safeguards. This debate will continue in our community. The Uniting Church is aware of differences of opinion in its ranks on this question.

What we **are** agreed on, however, is the value of human life, however, disabled it may have become. We affirm that death is a part of this life and that it can and ought to be a time of loving care and affirmation of the dying person. And while not everyone agrees on the meaning of life beyond physical death, this conviction prompts us to honour those who minister to the terminally ill with love and patience.

Appendix 3: Some foundational Christian values

(a) Life is a gift of God, and all human life, regardless of circumstance, is precious to and has dignity before God.

(b) ‘Neither death nor life, neither suffering nor anything else in all creation will be able to separate us from the love of God in Christ Jesus our Lord’ (see Romans 8:38-39).

(c) As followers of Christ and through God’s accompanying grace, gifts of fresh wisdom, peace, courage, and compassion can be birthed amid suffering, which is a deep and abiding mystery.

(d) ‘While death is the end of mortal life it marks a new beginning in our relationship with God’ (see Uniting in Worship 2; Funeral Liturgy; John 14:1-7; 1 Corinthians 15:12-26, 50-57).

(e) As followers of Christ, we are called to spiritual discernment and responsibility as we journey through life and death; (Matthew 22:23-33).

(f) As ‘the body of Christ’ we are called to be a loving and supportive community around people in need of care as they or their loved ones move closer to the end of mortal life.

(g) As citizens in a pluralistic culture, we also seek to care for and respect our neighbours who may not hold to our faith in God yet may experience fear, uncertainty, pain, grief or sometimes, extreme, and extended suffering, as they prepare for their own death or that of their loved ones.

(h) Multi-disciplinary palliative care is a vital service that can optimise the quality of life for someone who has an active, progressive, advanced disease, with little or no prospect of cure even as they move closer to their death. This can open a window on the emotional and spiritual dimensions of life at a time when aspects such as work, finance, or travel have shrunk in significance.

(Drawing on Affirmations in Clause 1 of *Uniting Church WA Synod Resolution 26/2020* re Voluntary Assisted Dying.

The Synod acknowledged that within the Church there is a diversity of faithful Christian understandings and responses to dying and to ‘voluntary assisted dying’, and that we seek to live respectfully together in that tension.

There is a wealth of other resources exploring the meaning of death and compassionate care in the Bible and in the Christian tradition).

Appendix 4: A summary of the main provisions in WA's *Voluntary Assisted Dying Act 2019*[11]

Numbers inserted in the summary below indicate sections [s] in the *Voluntary Assisted Dying Act 2019.*

The West Australian *Voluntary Assisted Dying Act (VAD) of 2019* insists that the rights of a person who is clearly approaching the end of their life must be respected, especially regarding their right to be given clear medical advice about their condition [4] and their right to decide (if they are over 18 [16] and still have decision-making capacity) how they want to be treated.[4,16]

If a patient requests VAD, numerous legal and other arrangements must be addressed. The patient has the right to continue to receive high-quality palliative care during this time.[4]

All persons involved in the care of a dying person, including health care workers, have the right to expect that their own beliefs and values will be respected, including the right to not participate in providing a lethal substance to the patient.[9,10,20]

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[11] The Act may be viewed in full at: https://www.legislation.wa.gov.au/. Search for Acts Passed 2019 VAD.

Patients nearing the end of life are encouraged to openly discuss death and the dying process.[4] Health care workers must not suggest VAD to them, but if the patient asks about VAD, then it may be discussed. Authorised registered health practitioners and nurse practitioners may raise the topic if appropriate with open disclosure about other treatment options and palliative care.[10]

The person seeking assistance to die must be in an advanced medical condition that is causing intolerable suffering and is medically predicted to cause death within 6-12 months [16]. Mental illness does not make a person eligible for VAD, but neither does it necessarily exclude them if other criteria apply[16].

The patient may, at any point in the process of preparing for VAD, decide not to go through with it [57]. On the other hand, if both patient and authorised medical practitioner mutually consent to the patient receiving VAD, from a legal point of view this is not considered suicide [12].

If an eligible patient asks for VAD and it is medically approved, the CEO of the Department of Health must approve the lethal substance that is to be administered to them [7].

The patient is authorised to self-administer the lethal substance [58]. If this is not possible, an approved and consenting health worker may administer it, subject to it having been clearly established that the patient was voluntarily asking for this to be done. An independent witness must be present [59,62].

Detailed conditions have been laid down for the obtaining, storing, and disposing of the prescribed lethal substance [69-79]. A registered health worker who is a member of the patient’s family, or who knows they are likely to benefit financially from the patient’s death, may not administer the lethal substance [17,26,37,54].

Care must be taken to ensure that the patient has been fully briefed on their diagnosis, prognosis, treatment options and how they would be assisted to die. Even at this stage, they should be informed what palliative care options are still open to them [27].

Relevant paperwork, including signatures of both the patient and the health workers involved, must be completed before the step is taken [29,42]. If it is necessary to bring in an interpreter to help the patient fully understand the process, and communicate their wishes, the interpreter’s details must be recorded also [40,51,60]. All documentation must be kept confidential and lodged with the VAD Board. The patient may share their decision as they wish.

When a death certificate is supplied for a person who has been authorised and assisted to die, no reference may be made on the certificate to VAD as the cause of that death [82].

From 1 July 2021, Western Australians will have access to Voluntary Assisted Dying and the State-wide VAD Care Navigator Service. Further information is available from the Department of Health website: https://ww2.health.wa.gov.au/, search for ‘VAD Implementation’.

Further concerns and questions?

It is hoped that this booklet will be explored in a supportive pastoral context where a minister or leader will be available to offer emotional and pastoral support. General Practitioners (GPs) can be approached for medical advice or support. Other community support agencies include:

- **Lifeline:** Phone 13 11 14 for telephone support and counselling 24/7
- **Australian Centre for Grief and Bereavement:** Phone 1800 642 066 (free call, Australia-wide) for bereavement services and support
- **Palliative Care WA:** Phone 1800 573 299 (free call, WA) 9am to 5pm, any day for support on advance care planning, palliative care, and grief and loss

Feedback about this resource may be sent to:

Convener
End-of-Life Care Task Group
Uniting Church Synod of Western Australia
GPO Box M952
PERTH WA 6843

Email: eol.care@wa.uca.org.au

My concluding questions, thoughts, intentions

End-of-Life Care Task Group

Uniting Church Western Australia

85-89 Edward Street, Perth

GPO Box M952, Perth 6843

Phone: (08) 9260 9800

Email: eol.care@wa.uca.org.au

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Western Australia