End of Life Issues

Edited by Justin Healey

ISSUES IN SOCIETY
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THE SPINNEY PRESS
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End of Life Issues is Volume 414 in the ‘Issues in Society’ series of educational resource books. The aim of this series is to offer current, diverse information about important issues in our world, from an Australian perspective.

**KEY ISSUES IN THIS TOPIC**

Death eventually comes to claim us all, yet most people live in denial of it until they are confronted with their own mortality. In order to ultimately have a ‘good death’ – such as dying comfortably at home, supported by family and friends and effective services – discussion, decisions and planning are required to put things into place, knowing your family is acting according to your wishes.

Planning for the end of one’s life may entail making an advance care plan; funeral and estate planning; palliative care; understanding the legal status and complexities of voluntary euthanasia; and being prepared for what to expect during a loved one’s final hours, including ensuing feelings of bereavement and loss.

This book explores a range of issues for us all to anticipate and evaluate at some stage: end of life attitudes and decisions; end of life care; and coping with death and grief. What are your wishes and rights (and those of your loved ones) when it comes to the personal and practical considerations we have to deal with at the end of life?

**SOURCES OF INFORMATION**

Titles in the ‘Issues in Society’ series are individual resource books which provide an overview on a specific subject comprised of facts and opinions.

The information in this resource book is not from any single author, publication or organisation. The unique value of the ‘Issues in Society’ series lies in its diversity of content and perspectives.

The *content comes from a wide variety of sources and includes*:  
- Newspaper reports and opinion pieces  
- Website fact sheets  
- Magazine and journal articles  
- Statistics and surveys  
- Government reports  
- Literature from special interest groups

**CRITICAL EVALUATION**

As the information reproduced in this book is from a number of different sources, readers should always be aware of the origin of the text and whether or not the source is likely to be expressing a particular bias or agenda.

It is hoped that, as you read about the many aspects of the issues explored in this book, you will critically evaluate the information presented. In some cases, it is important that you decide whether you are being presented with facts or opinions. Does the writer give a biased or an unbiased report? If an opinion is being expressed, do you agree with the writer?

**EXPLORING ISSUES**

The ‘Exploring issues’ section at the back of this book features a range of ready-to-use worksheets relating to the articles and issues raised in this book. The activities and exercises in these worksheets are suitable for use by students at middle secondary school level and beyond.

**FURTHER RESEARCH**

This title offers a useful starting point for those who need convenient access to information about the issues involved. However, it is only a starting point. The ‘Web links’ section at the back of this book contains a list of useful websites which you can access for more reading on the topic.
Chapter 1 End of life attitudes and decisions

CREATING CHOICE IN END OF LIFE CARE

This report summary from the Australian Centre for Health Research recommends transforming end of life care by creating choice through conversations.

WHAT IS THE CHALLENGE?

The way people are cared for when they are dying is important. End of Life Care impacts everyone, at every age – the living, the dying and the bereaved. It is not a response to a particular illness or condition. It is not limited to a particular group or section of the community.

When it comes to death the statistics are clear. We will all die.

We assume that we will always have control of our care decisions. However, many people nearing the end of life are not physically or cognitively able to make their own care decisions, and their choices and wishes remain unknown. This means too many people are dying in a way they wouldn’t choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain.

The care most Australians receive at the end of life often does not reflect their values, goals, or informed choices. The majority of Australians say they would prefer to die at home, however most will die in a care institution, such as a hospital intensive care unit. Dying has become institutionalised, and evidence shows there is a significant mismatch between what people most often say they want (supportive services) and the services they actually get (acute care). Acute health systems are focused on providing treatment and cure – increasing survival and reducing mortality. For patients who are at the end of life, this can result in the delivery of care that is inappropriate, inadequate or futile. People frequently endure unwanted aggressive, costly treatments and suffer from insufficient management of symptoms such as pain and shortness of breath.

Reports and investigations too frequently identify poor End of Life Care. Access to care is largely determined by age, diagnosis and geography rather than individual need. It is often characterised by fragmented care systems; poor communication among doctors, patients, and families; and enormous strains on family caregiver and support systems. It can create significant moral distress for health professionals working in these systems, especially for those who recognise that the care they provide in some cases is not what they would want for themselves or for their families.

There is, however, a simple yet significant way to improve this care. The road map to reform starts with a conversation.

Too many people are dying in a way they wouldn’t choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain.

End of Life conversations improve End of Life Care, patient and family satisfaction and reduce stress, anxiety and depression in surviving relatives. These conversations offer people the opportunity to define their values, goals, and informed choices for the care they want and don’t want for themselves and their loved ones.

KEY MESSAGES

What:
It’s time to transform our culture so we shift from not talking about dying to talking about it. It’s time to share the way we want to live at the end of our lives. And it’s time to communicate about the kind of care we want and don’t want for ourselves and our loved ones.

Why:
1. Currently, too many Australians experience pain and suffering in the final months and days of their lives, and die in a way they would not choose. These outcomes ripple out beyond the dying person to their families, loved ones, caregivers, and communities.
2. As a nation we are paying a high price for care we don’t want, in a place we don’t want it.
3. Caring for the dying is a fundamental responsibility of all societies and good stewardship of national resources requires an evidence-based approach to meet the ever-increasing and insupportable demands on hospital facilities, health professionals and ineffective resource utilisation.

How:
The pathway to reform starts with one simple step – conversation.
Conversations increase public awareness that End of Life Care can be guided in ways that responded to parents’ choice. When it comes to End of Life Care, one conversation can make all the difference.
A roadmap for action
End of life care is everyone’s responsibility

1. **People** to talk about their wishes for End of Life Care with family and loved ones at the kitchen table – not in the intensive care unit when it’s too late. Encourage people to document their choices of care and initiate a conversation with their health professional.

2. **Communities** to build capacity to become compassionate and support people to live well and die well in partnership with health professionals through a health promoting approach to End of Life Care.

3. **Health providers** to initiate honest, timely and culturally-sensitive conversations with patients so they are a routine part of health care delivery. Establish a dedicated Medicare reimbursement system to facilitate End of Life Care conversations and planning.

4. **Universities, colleges and training organisations** to help health professionals, across all chronic care and complex care specialities, have difficult conversations and improve end of life communication with patients, families, and colleagues.

5. **Policy makers** to acknowledge End of Life Care as a national health priority, promote public awareness programs and fund End of Life Care conversations with dedicated Medicare item numbers.

6. **Employers** to better support staff who are living with an advanced illness, carer responsibilities or grief, and help them have conversations about their options and choices.

7. **Media** to demystify dying and help normalise the experience for the general public. Greater public discussions about the limits of health care as end of life approaches informs the public about their options and helps them translate these into personal choices.

8. **Researchers** to conduct randomised trials examining new approaches and models for enhancing conversations. These trials would include measures of the frequency and quality of end of life discussions, perceived control, quality of life, and pain/symptom management. Combined with a cost-benefit analysis, provide the data needed for a reimbursable End of Life Care management strategy.

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their goals and expectations for the personal, medical, emotional and spiritual care they want to receive at the end of their life. Conversations emphasising patient choice, including treatment preferences, are a powerful determinant of care. Patients are more likely to receive care that is consistent with their choices when they have had the opportunity to discuss their choices for End of Life Care with their loved ones as well as a health professional. Patient conversations with health professionals are a better predictor of patients’ End of Life Care outcomes than the place they are being treated.

Not everyone will want to talk about the end of their life, but the ‘right conversations, with the right people, at the right time’ can enable a patient and their loved ones to make the best use of the time that is left and prepare for what lies ahead.

Overwhelmingly, there is recognition that open conversations about death, dying and bereavement play a fundamental role in the:

- Changing of attitudes towards death and dying
- Successful planning and delivery of person-centred choice in End of Life Care
- Quality of End of Life Care
- Availability of support for the bereaved, and the
- Long-term health and wellbeing of individuals and communities.

Public awareness, engagement and community development work on dying, death, and End of Life Care are increasingly identified as priorities in government health strategies and policies worldwide. Policymakers, health systems and palliative care services are seeing conversations as important areas of action to improve end of life experiences. Countries such as England, Scotland, Ireland, Canada and the US are implementing public awareness campaigns to promote End of Life Care conversations so that people are aware of ways to better live with death, dying and bereavement.

End of Life Care has a low profile in Australia. It is not recognised as a public health concern, and we lack the national awareness and engagement programs evident in other countries. Our impressive global record of health promotion and public education is not being matched in the process of dying, death or bereavement.

Unless we take personal, professional, and political action, we will not be able to afford to die with dignity in the future. For multiple reasons that include an ageing population, escalating health care spending, and an approach to End of Life Care that often does not conform to the wishes of patients, we cannot delay action.

The Australian Centre for Health Research (ACHR) seeks to transform End of Life Care through a conventional research and practice development program, as well as innovative community awareness initiatives that help people have conversations about their end of life choices.

We present eight simple, cost effective recommendations to transform End of Life Care in Australia by creating choice through conversations (see above).
For most of us, death conjures up strong feelings. We project all kinds of fears onto it. We worry about it, dismiss it, laugh it off, push it aside or don’t think about it at all. Until we have to. Of course, death – our own, a friend’s, a family member’s – will arrive sooner or later, and when it does, we are forced to confront it, whether we like it or not ...

Despite all progress in ‘normalising’ death and dying from a medical perspective, making it something that patients and families can talk about together, they all too often remain taboo – no-go areas shunned as legitimate topics in polite circles. Western societies continue to have a strained relationship with the concepts – and realities – of death and dying.

I’m involved in a three-year study in Queensland of doctors’, nurses’, patients’ and families’ experiences of managing and recognising medical futility as well as facilitating the transition to end-of-life care. We’ve already found that doctors, patients and families often work together to resist futility. They don’t want to tell families to give up hope. This reluctance to look death in the face can delay a shift toward more appropriate life-improving care at the end of life.

So why is it so difficult for us to talk about death? One argument put forward over the last few decades is that dying is increasingly alarming in modern societies given the lack of rituals surrounding it. With ever fewer people holding religious beliefs, so the argument goes, there is crisis of meaning around death and dying.

In contemporary Australian life, on present trends, ‘no religion’ will be the most popular response to questions about religion in the 2016 census. In increasingly secular societies, cultural taboos form a protective layer against the dreaded inevitability of death.

Others insist that such arguments are simplistic and don’t take into account widespread variation in beliefs about death and dying. Certainly, in Australia indigenous beliefs around death and dying remain organised and meaningful.

New forms of spirituality have also taken hold in many western contexts around death and dying. For example, the 1993 Tibetan Book of Living and Dying by Sogyal Rinpoche introduced new understandings of consciousness after death, gaining widespread popularity as an alternative to other dominant religious frameworks.

Yet, in health care we continue to see ‘death denial’ in action, along with its serious consequences.

In a 2008 study of chronic heart failure people were shown to overestimate their life expectancy by a full three years. This kind of optimism was also shown in a 2011 study of lung cancer patients who were deemed to have inaccurate perceptions of the purpose of their treatment (i.e. cure versus palliation) and their chances of mid to long-term survival.

Is this about faith in medicine? Or do doctors and patients collude in unwarranted hopefulness? Or perhaps it is a cultural denial of death? Our research would suggest it is probably all of the above.

Despite establishing futility and the actual referral for end-of-life care being the doctor’s decisions, we’ve discovered that Australian nurses often have to informally intervene to ensure patients get the timely end-of-life care they need. A polite tap on the doctors’ shoulder to let them know the patient has in fact had enough and can’t take our tendency to think we will ‘beat the odds’ is risky – and may mean that we are not being properly prepared for death.
any further medical attempts at life-prolongation.

Our tendency to think we will ‘beat the odds’ is risky – and may mean that we are not being properly prepared for death.

These days, palliative care doctors and nurses can make a significant difference to our quality of life and death, with a 2010 study showing that if doctors refer patients earlier, acknowledging the point of futility, it can actually extend life rather than representing a ‘loss of hope’ or process of ‘giving up’.

But the shift to palliative care relies on a preparedness on the part of doctors, patients and families to accept that the dying process has begun.

Acknowledgement of dying also relates to the level of influence we are able to have over the circumstances of our deaths, and this includes place of death. Fewer than 20% of Australians actually die at home – earlier discussions of futility and dying enhance our capacity to express our preferences, including for place of death.

There are other layers of complexity to consider. Assisted dying is unlikely to be formally supported in a hospital, hospice or aged-care facility in Australia, regardless of personal preference. And early recognition of dying by patients and families will allow more time for financial matters to be sorted, not to mention allowing more time for the person involved and their loved ones to come to terms with the reality of death.

It’s often the economically less well off who suffer disproportionately in the dying process. Despite Mark Twain’s famous suggestion that death is “the great leveller”, it’s not.

How and where you die – home, hospice or hospital – is heavily dependent on your wealth, geographical location and whether you have private health insurance.

These days, private cover extends to specialised palliative care services, providing a level and quality of care not always available in the public sector. Death denial will thus adversely impact on the most vulnerable in Australian society.

Taboo or not, death and dying are part of a conversation we all need to have. If nothing else, doing so will ensure our choices are respected at the end of life, the best death possible for each of us is within reach, and the vulnerable do not suffer.

Denial has its advantages – protecting us from things we are not ready to face. But it’s now the major barrier to ensuring that a life otherwise well-lived ends with a good enough death.

Alex Broom is Associate Professor of Sociology and Australian Research Council Future Fellow, The University of Queensland.

What you should know before you go

- Make a plan. Fewer than 5 per cent of people have an end of life plan.
- Write a will. Only 55 per cent of people who die have a will.
- Tell someone what you want. Of those who know they are dying, only 25 per cent will have spoken to their families about their wishes.
- Only 30 per cent of deaths are unexpected. Make a decision about how you want to die while you have time.
- Doctors don’t die like the rest of us. They are more likely to die at home with less invasive intervention at the end of their lives.
- Earlier referral to palliative care means living longer with better quality of life.
- You don’t need a funeral director. DIY funerals are becoming more popular.
- The majority of Australians choose cremation but there are alternatives including natural burial, burial at sea or donating your body for research.
- We don’t grieve in stages. Only 10 per cent of us need professional support after a death.
- 60 per cent of people think we need to spend more time talking about death.

Browne, R, ‘Everything you ever wanted to know about death but were too afraid to ask’, The Sydney Morning Herald. Source: The Groundswell Project.

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YOUR RIGHT TO PLAN YOUR WILL AND OTHER END OF LIFE DECISIONS

This chapter from a retirement rights guide published by the Australian Human Rights Commission explains how you can plan ahead to ensure your choices are respected as you get older. It explains how to choose someone to make financial decisions on your behalf if you can’t make them yourself; how to record your preferences for medical treatment; and how to make a will.

You have the right to make your own decisions as long as you have the capacity to do so. Having ‘capacity’ when making a decision means that you have the ability to:
- Understand the facts and main choices involved
- Weigh up the consequences of the choices, and
- Communicate your decision.

Capacity can be lost through sickness or because of an accident. If you lose the ability to make decisions, someone else will have to make them for you.

Appointing a person to make your financial decisions

At some point as you age, you may decide that it is in your best interests to appoint someone to make decisions on your behalf. This is generally known as appointing a ‘power of attorney’ and people do this when they have a health condition that affects decision making or they think they may lose the capacity to make decisions in future.

In most cases people give power of attorney to one or more trusted family members, to a lawyer of their choosing, to a government public trustee, or to a combination of these.

It is important to take steps to appoint a power of attorney well before you lose your ability to make decisions independently. If you do lose the ability to make decisions before you have appointed a power of attorney, the government will appoint someone to make decisions for you.

To appoint a financial decision maker you will need to complete a legal form called a ‘power of attorney’.

The person who you appoint to be your ‘attorney’ will be able to make legal and financial decisions as if they were in your shoes. They will be able to do things like pay bills, sell your property and receive money on your behalf.

A ‘general power of attorney’ is the document used to give another person the power to make financial decisions temporarily. For example, if you go on holiday overseas, you may require someone to make decisions in your absence.

An ‘enduring power of attorney’ is the document used to give another person the power to make decisions for you when you no longer have capacity. For example, if you have an illness that prevents you from making decisions, or lose cognitive ability.

The process of making a power of attorney is different across the states and territories of Australia. In some states and territories creating a power of attorney allows another person to make decisions on your behalf across a range of matters in addition to financial matters. They may be able to make decisions about your health care and where you live for example. In these circumstances, you can limit the powers to the particular areas that suit your individual needs.

Choose someone who you trust, who is available to help when needed and is capable of making good decisions. You are also able to choose more than one person. You may decide to choose a family member and your lawyer for example. If you do not know anyone suitable, the Public Trustee or Advocate in your state or territory can be appointed as your decision maker. This is an independent and impartial body established by the government with responsibility for substitute decision making.

Once you have appointed a power of attorney, they have a responsibility to act in your best interests. They cannot use your money to benefit themselves unless you say so. If you notice this happening, seek legal advice immediately.

You can revoke a power of attorney as long as you have capacity to do so. A court or relevant tribunal can also review the actions of the attorney and suspend or revoke their powers.

Where to go for help

Contact the Public Trustee or Advocate in your state or territory for general information or to begin the process.

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<td>ACT</td>
<td>Office of the Public Advocate 02 6207 0707</td>
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<td>NSW</td>
<td>NSW Trustee and Guardian 1300 364 103</td>
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<td>NT</td>
<td>Office of the Public Trustee 08 8999 7271</td>
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<tr>
<td>QLD</td>
<td>The Public Trustee 1300 651 591</td>
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<td>SA</td>
<td>Office of the Public Advocate 1800 066 969 or 08 8342 8200</td>
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<td>Tas</td>
<td>Public Trustee 1800 068 784</td>
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<td>Vic</td>
<td>Office of the Public Advocate 1300 309 337</td>
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<tr>
<td>WA</td>
<td>Office of the Public Advocate 1300 858 455</td>
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Seek legal advice before you create a power of attorney. If you have concerns about your attorney you may ask a third party to review the appointment. Contact the Public Trustee or Advocate in your state or territory.

You can also contact legal aid in your state or territory for legal information, referrals, and in some cases advice.
Advance care planning: expressing your wishes about medical treatment

You have a right to make your own decisions about your health care and medical treatment as you age, but you will need to plan ahead. If you become sick or develop a form of dementia, you may lose the ability to make future health decisions.

Therefore, it is a good idea to plan your medical treatment in advance and record the health and medical treatment that you want in future. This process is called ‘advance care planning’. With advance care planning, doctors, family and friends will know what treatment you would and wouldn’t want, even if you can’t communicate your wishes. You may also use the ‘advance care planning’ document to indicate who you would like to make decisions about your health care and medical treatment if you are unable to do so.

You can record your wishes using a document commonly known as an advance care directive. The name given to this document and the procedures you must follow differ in each state and territory.

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<td>03 6234 4133</td>
<td>03 9607 9550</td>
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A directive can be legally binding. This depends on how it was made, how current it is and what it contains.

Where to go for help

Visit the Respecting Patient Choices website at www.respectingpatientchoices.org.au to access information and to find the forms that are relevant to your state or territory.

Contact your local authority for more information and forms.

Making a will

Making a will is essential if you want to have a say over who will get a share of your money and property when you die. If you die without a will your assets will be divided among relatives according to a pre-determined formula contained in the law. If you don't have close relatives according to the law, your estate will go to the government.

Making a will is simple and need not be expensive. A solicitor, Public Trustee, or Public Advocate can help you write or update your will. Some Public Trustees or Public Advocates will not charge you to prepare or update your will. However, fees may be payable in the future when your estate is administered.

There are will kits available to assist you to make your will. You need to ensure that your will shows your intentions clearly and meets the formal requirements to be valid. It is safer to have a professional make your will to ensure it is done properly.

Plan ahead because you must make a will while you still have capacity.

Update your will regularly, especially if you marry or divorce; have children or grandchildren; if your spouse or beneficiaries die; or if your financial circumstances change.

If you feel you are being pressured when making or changing your will, read Chapter 5.1 of Your Rights at Retirement on financial abuse for information about how you can avoid family pressures.

Where to go for help

To get started on making a will, contact a solicitor. The
Law Society in your state or territory can help you find a private solicitor. If you can’t afford a private solicitor, speak to the law society about community legal centres in your local area.

The Public Trustee in your state or territory can prepare your will directly or act as an executor. Fees usually apply.

Nominating a person to receive your superannuation death benefits

When a person dies, the balance of their superannuation fund will be distributed to a single or multiple beneficiaries.

People often think that they can use their will alone to nominate the person to whom they wish to leave their superannuation after their death.

In fact, superannuation is not considered to be an ‘estate’ asset and therefore it is not automatically distributed as part of your will.

The trustee of your superannuation fund decides the distribution of your superannuation ‘death benefits’. The benefits can be paid to your legal representative (the executor of your estate) or to your dependants.

A dependant includes:

- A spouse (it does not matter if the spouse is not financially dependent on you)
- A child of the member (it does not matter if the child is not financially dependent on you, and
- A person in an interdependency relationship with you at the time of your death (this is defined in the superannuation law, but generally ‘interdependency’ means people who have been living together and providing support to each other).

If you want to nominate the person or people who will receive your superannuation death benefits, then you must make a death benefit nomination. There are two types of nomination – binding and non-binding death benefit nominations.

Your superannuation fund may allow you to make a binding death benefit nomination. If the nomination is valid under the law, the superannuation benefits must be paid in accordance with the nomination. Binding death benefit nominations must be confirmed every three years otherwise they lapse.

Your superannuation fund may allow you to make a non-binding death benefit nomination. Non-binding nominations allow you to inform your superannuation fund trustee of your wishes, although the trustee is not bound to follow the nomination.

Not all superannuation funds accept binding or non-binding death benefit nominations. Each fund’s governing rules are different and may impose other restrictions on the trustee’s discretionary power to pay superannuation ‘death benefits’. You need to check with your superannuation fund to find out the rules that apply to death benefits.

In deciding how to distribute a death benefit, the trustee of a superannuation fund must act fairly and reasonably. While the trustee’s discretion is not overridden by a will, if a trustee does make a distribution to your legal representative, the benefits will be distributed in accordance with your will.

Where to go for more information

Contact your superannuation fund to find out whether the rules of the fund allow binding death benefit nominations and/or non-binding death benefit nominations. Your superannuation fund will be able to help you through the process of making a nomination.

Financial planners and advisers can give you more information and advice about superannuation ‘death benefit’ distributions.

For help finding a financial planner you can contact:

- The Financial Planning Association on 1300 626 393
- The Association of Financial Advisers on 02 9267 4003, or
- CPA Australia on 1300 73 73 73.

PLANNING FOR END OF LIFE

For someone nearing the end of their life, aged care services may be able to provide additional help and support. This may be through therapies or other services to provide physical, emotional, cultural and spiritual support to the person and those around them. This advice is courtesy of the Department of Social Services website, myagedcare

Help staying at home
Many people feel more comfortable spending their last days at home. General care services are available to assist with care at home.

Help in aged care homes
Aged care homes will help people who are nearing the end of their life feel as comfortable and supported as possible.

Support for families and carers
If you're the carer of someone nearing the end of their life, there is emotional support, counselling or help caring for the person available to you. If you would like more information or suggestions from other carers, you can read more about caring for someone at end of life at myagedcare.gov.au

Palliative care
The aim of palliative care is to improve the quality of life for a person with a life-limiting illness and their families.
Some of the common illnesses of people requiring palliative care include: cancer, HIV/AIDS, motor neurone disease, muscular dystrophy, multiple sclerosis and end-stage dementia.
Doctors, aged care providers and community nurses can help access palliative care if required.

Care plans
It’s a good idea to have a care plan. The people who provide aged care may be able to help develop a care plan to best support your care needs.
A good care plan may:
• Show how pain and other symptoms might be managed.
• Show how cultural, emotional and spiritual support can be provided.
• Help family members make decisions about care options.
• Help those involved know what to expect.
• Show how support to families and carers through the bereavement process could be provided.

Advance care planning
Advance care planning lets everyone involved in the care process know the wishes of the person approaching the end of their life in regards to their health and medical care. It can make sure that the person’s wishes about future care are taken into consideration. It can also help with difficult last-minute decisions about treatment when a person may no longer be able to have their say.
A person nearing the end of their life may also choose to give someone they trust an enduring power of attorney or enduring guardianship (the requirements for these vary from state to state) to make medical treatment and other decisions if they are no longer able to do so. However, they must make an enduring power of attorney or enduring guardianship while they are still fully able to understand the action they are taking.

Medicines used in end of life care
Affordable access to medicines is an important part of end of life care. Doctors, aged care or palliative care providers will ensure the appropriate medicines are prescribed. Many medicines used in end of life care are available under the Pharmaceutical Benefits Scheme (PBS).
NPS MedicineWise also provides information about the use of medicines. Alternatively, the NPS Medicines Line (on 1300 633 424) is available to give specific information about medicines, doses, interactions and side effects.

What costs are involved?
Depending on the circumstances, costs involved with end of life care could include:
• Medicines – may be available through the Pharmaceutical Benefits Scheme (PBS).
• Fees for private hospital patients – usually covered by private health insurance if you have insurance. Ask your health insurance fund.
• Equipment to use at home – you may have to pay to use equipment such as hospital beds, wheelchairs or commodes at home.
• Medical supplies – you may be required to pay for these.
• Palliative care services – most are free through Medicare. You can check with Palliative Care Australia’s National Palliative Care Service Directory to find a palliative care service in your local area.
• Costs for aged care services provided in your home or an aged care home.

Carers may be able to get some medicines or supplies through their hospital, but this will vary between each state and territory.

Need financial advice?
The Department of Human Services can help with...
USEFUL RESOURCES

Many organisations and programs around Australia provide support for people who are in their final stages of life—whether as a patient, a carer, a family member or a friend. A few of these organisations are listed below.

<table>
<thead>
<tr>
<th>ORGANISATION OR RESOURCE</th>
<th>WHAT THEY DO</th>
<th>CONTACT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance Care Planning Australia (Respecting Patient Choices)</td>
<td>This website provides information on advance care directives. It also helps individuals choose their end of life care and to inform their families, carers and health professionals of the choices that they have made.</td>
<td>03 9496 5660</td>
</tr>
<tr>
<td>Start2talk (Alzheimer’s Australia)</td>
<td>This website will help you to plan ahead for your future. Planning ahead is thinking about if you have a sudden accident, become very ill or develop a condition such as dementia that affects your memory and your planning ability.</td>
<td>1800 100 500</td>
</tr>
<tr>
<td>Carers Australia</td>
<td>The peak national body representing Australia’s carers. They provide information, support, education, training and counselling.</td>
<td>1800 242 636</td>
</tr>
<tr>
<td>Commonwealth Respite and Carelink Centres</td>
<td>These centres, located across Australia, provide a link to a wide range of community, aged care and support services that are available locally and nationally.</td>
<td>1800 052 222</td>
</tr>
<tr>
<td>Volunteers Australia</td>
<td>Volunteers Australia may be able to connect you with local volunteers who can help and provide friendly support.</td>
<td></td>
</tr>
<tr>
<td>Department of Human Services</td>
<td>Provides financial information that can advise on wills, enduring powers of attorney, funeral plans, bonds and how to administer a deceased estate. Payments may also be available when caring for someone who has a life-limiting illness, including Carer Payment, Carer Allowance and a Bereavement Payment.</td>
<td>13 23 00 13 27 17</td>
</tr>
<tr>
<td>Department of Veterans’ Affairs</td>
<td>Veterans may be able to receive support services particularly targeted to their end of life needs through various Department programs.</td>
<td>13 32 54</td>
</tr>
</tbody>
</table>

Financial information or payments for carers through the following services:

- Social workers can help you during difficult times by providing confidential counselling, support and information.
- The Financial Information Service is a free, confidential service. It helps people make informed decisions about investment and financial issues for their current and future needs.
- Authorising a person or organisation to be your nominee or make Department of Human Services payments and service enquiries on your behalf.
- Payments to assist when caring for someone who has a life-limiting illness, including Carer Payment, Carer Allowance and a Bereavement Payment.
- Financial support following the death of a partner such as the Bereavement Allowance, Bereavement Payment.

Who else may be able to help?

There are a number of people who may support someone approaching the end of their life and help them to feel as comfortable as possible.

Such people might include:

- Doctors, including general practitioners, palliative care specialists and other specialist physicians.
- Nurses, including general and specialised nurses in the community, hospitals, palliative care units and aged care homes.
- Allied health professionals, including social workers, physiotherapists, occupational therapists, psychologists, pharmacists, dietitians and speech pathologists.
- Support workers, such as assistants in nursing, personal care attendants and diversional therapists.
- Therapists skilled in music, massage, aromatherapy or colour.
- Bereavement counsellors.
- Spiritual advisers from different pastoral, spiritual and cultural backgrounds.
- Workers who have language skills and knowledge of various cultures.
- Aboriginal or Torres Strait Islander health workers.
- Volunteers.

Family members are also an important part of the support team, particularly if a person has chosen to receive end of life care in their own home.

Many people find that administrators or business managers can also provide essential support to the end of life care team. Experts in financial planning and legal issues can also provide support.

Extra assistance

Extra assistance is available if you are hearing and speech impaired, or where translating services are required.


MAKING PLANS AND DECISIONS FOR THE END OF YOUR LIFE
FACT SHEET ADVICE FROM BETTER HEALTH CHANNEL

**Summary**
- Planning ahead will make it easier for your family to put things into place and know they are acting according to your wishes.
- Making an advance care plan means your care and treatment preferences will be known to your loved ones in the event that you cannot make these decisions yourself.
- Appointing someone as an ‘enduring power of attorney’ means they can make decisions for you if you are unable to.
- Consider getting professional financial advice so you and your family know how you can get access to superannuation and insurance.

Planning ahead will enable you and your family to take advantage of the many different services that exist to help you prepare for the end of your life. This planning will make it easier for your family to put things into place knowing they are acting according to your wishes.

**End-of-life planning**
Planning and making decisions about the end of your life can be a positive experience. It is a good opportunity to reflect on the things that are important to you, and to make arrangements that suit you.

**Learn more about your condition**
To put good plans in place, you will need to learn more about your condition and understand what you are facing. Your doctor will work with you to help you understand how your condition will progress. Don’t be afraid to ask questions – it’s important to learn as much as you can.

Some of the types of questions that you might ask your doctor include:
- If I am thinking about being cared for at home, what medications or treatment and equipment will be available to me?
- How will this medication and treatment be administered?
- What would this mean for my carer? Knowing what you and your carers should expect will help you to plan for your situation.

**Make an advance care plan**
Advance care planning is the process of making your care and medical treatment preferences known to your loved ones in the event that you cannot make these decisions yourself.

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By putting a plan together, your family will know in advance about the level of health care and quality of life you would want if, because of your illness or medical condition, you are unable to participate in the discussions and make the decision for yourself.

You can talk with those close to you, your family, your doctor and treating team to make sure they are aware of what is important to you.

Although these plans should be respected by your family and medical team, they can be overridden by an enduring power of attorney (medical treatment).

In some instances, you may want to complete a ‘refusal of treatment certificate’ if you wish to refuse a treatment related to a specific illness you may have. Your doctor needs to assist you to complete this form. More information is available from the Office of the Public Advocate (in Victoria only).

**Enduring power of attorney**

Another option you have is to appoint another person to make decisions for you. This is done using a legal document called an ‘enduring power of attorney’, which means a person can make decisions when you are unable to participate in the decision making.

There are different kinds of enduring powers of attorney:

- **Enduring power of attorney (medical)**
  - can manage your medical needs
- **Enduring power of attorney (financial)**
  - can manage your finances
- **Enduring power of guardianship**
  - can make personal and lifestyle decisions such as accommodation and health care decisions and whether to consent to medical treatment.

Once appointed, each of these people can make decisions on your behalf. The Office of the Public Advocate outlines the roles of each of the powers of attorney and provides support for them in their role.

Think about who you want to take on these responsibilities and then approach them to have the conversation. You will be trusting this person with your life and finances, so they should be someone you know very well and who you can speak to about sensitive issues. They should understand what is important to you, and be able to act on your wishes – even when faced with opposition from doctors or other family members.

After you have made your decision, there are necessary legal steps you will have to follow to appoint your power of attorney.

Find out more by downloading information sheets and the legal forms from START2TALK, [http://start2talk.org.au](http://start2talk.org.au)

**Financial planning**

When you’re coming to the end of your life, it’s a good idea to put your finances in order.

If you have appointed an enduring power of attorney (financial), you can work with them to ensure that your wishes are known and documented.

Making sure that your will is up-to-date and understanding what will happen to your financial accounts will make it easier for those managing your estate after your death. You may want to consider seeking professional financial advice to ensure that you and your family know how to access your superannuation and insurance.

**Planning personal matters**

There may be other personal matters you would like to put into place. You might like to visit a special place with friends, have particular requests for your funeral or organise other personal matters.

Regardless of your wishes, you may want to talk about these things with your family and friends. Together, you will be able to make them happen.

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Advance care planning is a process to help you plan your medical care in advance. It is important because some time in the future you may become too unwell to make decisions for yourself.

If you have no problems communicating and can make your own health decisions, your advance care plan will not need to be used. Your doctors will talk to you about your health care choices.

Doctors will refer to your advance care plan if you can no longer communicate or make decisions. For example, this might happen if you have a stroke or serious accident, or become unconscious, or if you develop dementia. In some cases illnesses, such as cancer, may mean the medication you take or the pain you have may make you unable to communicate.

Benefits of advance care planning

If you were very sick, it may fall to your family or close friends to make decisions about your health care. That can be a very stressful time where family members or loved ones may not agree with approaches to your care.

You never know when you might be in an accident, or face a serious health condition. It is never too early to plan ahead.

If they have a document where you talk about the type of care that you would want, this can help them make decisions on your behalf.

It can help you too. For example if you were very sick, you might know that you don’t want to be kept on life support if you were not likely to recover. You might know that you want all available treatment, even if that treatment might have side-effects that make you very sick. Writing down what is, and is not, okay for you can help doctors consider your wishes and individual preferences when planning your care.

When should I do it?

You never know when you might be in an accident, or face a serious health condition. It is never too early to plan ahead. This can be as simple as talking to your family and close friends about your health care wishes. Some people see the completion of an advance care plan being just like filling in a Will. In fact, many people complete both documents at the same time.

If you have a chronic disease, if you are elderly or if your health seems to be getting worse, it is even more important to have a plan in place. Talk to your family about your health care wishes and document your advance care plan.
ADVANCE CARE PLANNING
IN 3 EASY STEPS

1. Talk to your family, trusted friends and carers about what you want, and don’t want, when it comes to your future medical treatment and care

Take some time to reflect about the care that you would want. Don’t just think about whether you want to be resuscitated if your heart stopped or you stopped breathing. Also think about what outcomes would not be acceptable to you.

Tell your family who you have nominated for doctors to contact if someone needs to make medical decisions for you.

2. Write down your wishes in an advance care planning document

Advance care planning can be an informal process, where you write down your wishes on any form or paper. It can also be more formal, including having documents that are legally recognised.

An advance care plan usually has the following parts:

- A list of the names and contact details of who can speak on your behalf with your doctors, if you are unable to. This person is sometimes called your ‘substitute decision maker’
- A description of the care outcomes that would, and would not be acceptable to you
- A description of any treatments or services that you do or do not want
- Other wishes, such as wanting to die at home or in a hospital, having your family with you or having your pet with you
- Your signature, a witness signature and the date.

It is OK to upload an advance care plan that you have written. It may not be legally binding in every state and territory, but should be respected by people making health care decisions for you.

To formalise your advance care plan, and to appoint a legally recognised substitute decision maker, the process is a bit different in each state and territory.

The legal document about your health care wishes is called an advance care directive (or other similar term depending on where you live). An advance care directive is often restricted to what treatments you do and not want, such as restarting your heart if it stops. Even if you have an advance care directive, your advance care plan may have more information about your goals of care. It will help your family and doctors to understand your values and may help in a broader range of situations.

The legal document about who you want to make health care decisions for you is called an enduring power of attorney (or other similar term depending on where you live). If you want to make sure that doctors listen to the decisions of this person, it is very important to have this document. It is particularly important if the person you want making decisions for you is not your next of kin.

3. Share your advance care planning documents

You should share your advance care planning documents with the people who can be contacted should the need arise.

There is now a space for you to save your documents online. Your My Health Record (https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/content/acp) is a great place for this.

This will help make your treating doctors, hospitals and other health care providers aware that you have specific wishes about your future medical treatments or care given to you. Of course, you can also share your documents with your GP, aged care facility and other health care providers who are involved in your care.

Remember to review your plan regularly, and update whenever your wishes change. You can change it at any time.

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PCA provides these links for information purpose only. It is not responsible for the content of these websites. If you notice any of the links are broken, or would like to suggest additional information resources to be added, please contact Palliative Care Australia.

ADVANCE CARE PLANNING: FREQUENTLY ASKED QUESTIONS

ADVANCE CARE PLANNING AUSTRALIA ANSWERS SOME OF THE MOST COMMON QUESTIONS REGARDING HOW TO PLAN FOR FUTURE MEDICAL TREATMENT OPTIONS

What is advance care planning?
Advance care planning provides an opportunity for people to think, discuss and plan for the medical treatment they would prefer if they became too ill in the future to express their wishes.

Do I have the right to refuse medical treatment?
Yes, you can legally refuse treatment or ask for some types of treatment to be withdrawn. In some jurisdictions, nominated substitute decision makers can also refuse treatment on your behalf if they know or believe that to be your wish.

What is an advance care directive?
An advance care directive is a written record of a person’s preferences for future care, which is recognised by common law or specific legislation. It is completed and signed by a competent adult. In a separate document, a substitute decision maker may be appointed to make decisions about health care and personal life management if you were no longer able to do this for yourself.

When is an advance care directive used?
Advance care directives only become effective if a person is unable to make or communicate their own decisions concerning their medical care. The directive would guide the decision making of medical staff, substitute decision maker (if appointed) and family.

Who can make an advance care directive?
Any person over 18 years of age can make an advance care directive, unless they are already unable to make their own decisions about medical treatment due to a disability, illness or injury.

Advance care directives are particularly relevant to people who:
• Have multiple or complex medical problems
• Are elderly or frail
• Are approaching end of life

• Are isolated or vulnerable
• Have cognitive impairment
• Are relatively healthy but keen to plan for future health care.

Do I need a lawyer to complete an advance care directive?
No, a lawyer is not required to complete an advance care directive. Your doctor or someone experienced in advance care planning can help you to complete this document.

Do I need a doctor to complete an advance care directive?
Ideally you should discuss your advance care directive with your doctor and those responsible for your care. This means that any decisions you make will be made on current, accurate and objective information.

To whom do I speak with about this?
• Those close to you in knowledge, care and affection.
This may include biological family, family of acquisition (by marriage or contract) and family and friends of choice. Loved ones don’t necessarily know or understand your preferred wishes in relation to future medical care.
• Those involved in the current care of your health.
This may include your general practitioner, specialist, practice or community nurse, social worker etc. Talking to those involved in your health care can help you to understand your current health and what you may need in the future. They can also provide information about the potential outcomes of medical treatment.
• You may also wish to speak to your religious, spiritual or cultural advisor, if applicable.

Who should I choose to be my substitute decision maker?
Anyone who:
• Is eighteen years of age or over
• Knows you well
• You trust to act in your best interests and to make decisions you would have made for yourself
• Will be able to make decisions under potentially difficult situations
• Is willing to take on this role
• Is not your paid carer.

Some jurisdictions allow for more than one substitute decision maker to be appointed.
What happens if I don’t appoint a substitute decision maker?
If you are unable to make or communicate decisions about your own health care then a hierarchy of appropriate people including spouse/partner, carer or nearest relative is employed.

The first person in the order of the list who is available, willing and able to make medical decisions on behalf of the person is considered the ‘person responsible’ and can provide consent.

What if I become ill or are injured while away from home?
If you have discussed your wishes with your substitute decision maker and family, they will be able to pass on this information to medical staff as they will be the ones contacted to discuss your condition.

They will also be able to provide your advance care directive to whoever is responsible for your care. While the legislation varies from different jurisdictions if an advance care directive exists then this is likely to be taken into consideration when medical decision making is involved.

What happens in an emergency?
When there is an emergency and your advance care directive is available, medical decisions will be made by reviewing your wishes and discussing your situation with your substitute decision maker and family.

If your directive is not immediately available, life-prolonging measures may be started until medical staff can contact your family. If it is clear after discussions with your substitute decision maker and family that you would not want life prolonging treatments or the likely outcomes associated with these then treatments would be stopped, however ongoing care would still continue.

What happens if I don’t have an advance care plan?
If you become unwell and cannot communicate for yourself, doctors will make medically related decisions based on your best interests. This could include treatments that you might not want or outcomes that are not acceptable to you.

Your family may find it extremely distressing trying to make decisions ‘in your best interests’ without being informed of your wishes. If you feel strongly about certain types of treatments that you would not want to receive, then an advance care directive is a good way to communicate those wishes.

Is there a national registry for advance care directives?
No, currently there is no nationally registry for advance care directives. However you can share this information in your My Health Record which is a secure online summary of your health information where you control what goes into it and who is allowed to access it.
CHAPTER 2
End of life care

CHANGING PATTERNS OF MORTALITY REFLECT AGEING POPULATION

Heart disease, dementia, stroke, lung cancer and chronic lower respiratory diseases remain the top 5 leading causes of death in Australia, accounting for more than one third of all deaths, according to the latest figures from the Australian Bureau of Statistics.

BS Director of the Health and Vital Statistics Section James Eynstone-Hinkins said the ABS Causes of Death report focuses on the underlying and associated causes of the 153,580 deaths reported in 2014.

“Changes in the leading causes of death over time provide an insight into the effects of population ageing, increased life expectancy, lifestyle factors and advancements in medical treatments,” said Mr Eynstone-Hinkins.

Life expectancy continues to increase in Australia, reaching 80.3 years of age for males and 84.4 years of age for females. As the population has aged, diseases such as dementia (including Alzheimer’s disease) have increased.

“There were close to 12,000 deaths from dementia in 2014, compared with 8,200 deaths in 2009. Dementia became Australia’s second leading cause of death in 2013, surpassing strokes,” said Mr Eynstone-Hinkins.

Heart disease remains the leading cause for both males and females. Deaths from heart disease have decreased over the past 20 years, but still accounted for one in seven male deaths and one in eight female deaths in 2014.

“Changes in the leading causes of death over time provide an insight into the effects of population ageing, increased life expectancy, lifestyle factors and advancements in medical treatments.”

There are seven types of cancers included in the top 20 leading causes of death, comprising lung, blood, colon, prostate, breast, pancreatic and skin cancers. Over the past 10 years, all forms of cancer combined have consistently accounted for close to 30 per cent of all deaths.

Leading causes of death naturally reflect causes most common among the elderly. Patterns of mortality among younger people are quite different. Among people 15-44 years of age, the leading cause of death is suicide, followed by accidental poisonings and land transport accidents.

Suicide is the leading cause of premature mortality in Australia, occurring at a rate of 12.0 deaths per 100,000 people in 2014. This is the highest rate of suicide deaths recorded in the past 10 years, with previous rates ranging from 10.2 to 11.2 deaths per 100,000 people.

“We understand that factors contributing to suicide and many other causes of death are complex, and we are actively working to expand the range of information to assist research in these areas,” said Mr Eynstone-Hinkins.

Comprehensive data and analysis can be found in Causes of Death, Australia (cat. no. 3303.0), available for free download from the ABS website, www.abs.gov.au

**LEADING CAUSES AS A PROPORTION OF ALL MALE AND FEMALE DEATHS, 2014**

<table>
<thead>
<tr>
<th>Lead Cause</th>
<th>Male Proportion</th>
<th>Female Proportion</th>
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</thead>
<tbody>
<tr>
<td>1. Ischaemic heart diseases</td>
<td>1 in 7 deaths</td>
<td>1 in 8 deaths</td>
</tr>
<tr>
<td>2. Dementia, including Alzheimer’s disease</td>
<td>1 in 19</td>
<td>1 in 10</td>
</tr>
<tr>
<td>3. Cerebrovascular diseases</td>
<td>1 in 18</td>
<td>1 in 12</td>
</tr>
<tr>
<td>4. Cancer of the trachea, bronchus and lung</td>
<td>1 in 16</td>
<td>1 in 23</td>
</tr>
<tr>
<td>5. Chronic lower respiratory diseases</td>
<td>1 in 19</td>
<td>1 in 21</td>
</tr>
</tbody>
</table>

A GOOD DEATH: AUSTRALIANS NEED SUPPORT TO DIE AT HOME

Most Australians want to die at home but just 14% are able to do so, write Hal Swerissen and Stephen Duckett, authors of a report aimed at improving how we die

The baby boomers are growing old and in the next 25 years the number of Australians who die each year will double. People want to die comfortably at home, supported by family and friends and effective services.

But more than half of Australians die in hospital and about a third die in residential care. Sometimes they have impersonal, lingering and lonely deaths; many feel disempowered.

Grattan Institute’s new report, Dying Well, released today, sets out how we can improve the quality of dying in Australia. With an investment of A$237 million, we can double the number of people who are supported to die at home – and the same amount could be released from institutional care spending to pay for it.

Institutionalised death

Over the past 100 years, home deaths have declined and hospital and residential care deaths have increased. Even over the past decade, the hospitalisation rate for those aged over 85 increased by 35% for women and 48% for men. Hospitals and residential care – nursing homes – are the least preferred places to die.

More than half of Australians die in hospital and about a third die in residential care. Sometimes they have impersonal, lingering and lonely deaths; many feel disempowered.

### FEW AUSTRALIANS DIE AT HOME

<table>
<thead>
<tr>
<th>Country</th>
<th>Home</th>
<th>Hospital</th>
<th>Residential aged care</th>
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<tbody>
<tr>
<td>Cyprus</td>
<td>5%</td>
<td>55%</td>
<td>40%</td>
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<td>Croatia</td>
<td>5%</td>
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<td>Singapore</td>
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<td>Australia</td>
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<tr>
<td>Iceland</td>
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<td>40%</td>
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Around 70% of Australians want to die at home, yet only 14% do so. People die at home at twice this rate in New Zealand, the United States, Ireland and France, partly because of the differences in support systems.

Deaths for younger people are now rare; about two-thirds of Australians die between the ages of 75 and 95. These days older people are more likely to know when they are going to die in the relatively near future. But we are not taking the opportunity to help people plan to die well.

When asked, most people have clear preferences for the care they want at the end of their life. But rarely do we have open, systematic conversations that lead to effective end-of-life care plans. Most people do not discuss the support they would like as they die.
Dying at home puts pressure on families and informal care, and this pressure is exacerbated in the absence of good support systems. With social change and increased population ageing, the carer ratio—the number of people who need a carer to the number of people who have one—is falling. Already, a significant proportion of dying people do not have a carer.

The result of these problems is that many experience a disconnected, confusing and distressing array of services, interventions and relationships with health professionals. They also end up dying in the very places they expressed a preference not to.

Towards better deaths

A good death gives people dignity, choice and support to address their physical, personal, psychological, social and spiritual needs. As we outline in Dying Well, this would happen more often with three reforms.

First, we need more public discussions about the limits of health care as death approaches, and what we want for end-of-life care. Public education campaigns are a well-established way of promoting change. A national public education campaign would focus on encouraging people to discuss their preferences and choices for end-of-life care with health professionals, including GPs.

Second, individuals need to plan better to ensure that our desires for the end of life are met. Too often we have not appointed someone we trust to make health care decisions when we are unable to, nor set out our wishes for treatment when there is little chance of recovery.

We need trigger points as we get older to remind us to have a conversation about what we want in terms of end-of-life care. Potential trigger points are:

- Over-75 health assessments
- Entry to a residential aged care facility
- Hospital in-patients assessments that conclude the person is likely to die in the next 12 months.

Third, services for those dying of chronic illness, such as cancer or heart disease need to shift their focus from institutional care and often unrealistic attempts at cures to supporting people’s preference to die at home and in home-like settings, in less pain.

The burden on carers can be reduced by providing more coordinated home care services for dying people including access to personal care and practical support, and symptom management for pain and nausea. Such services will become increasingly important as the number of informal carers declines as a result of more women working and smaller family size, among other changes.

Greater investment

If more people are to die at home, investment in community-based support is needed. Doubling the number of people who are supported to die at home will cost A$237 million a year. However, about the same amount could be released from institutional care spending to pay for it.

Contrary to widespread assumptions about the cost of end-of-life care, only about A$5bn a year—about 5% of the health budget—is spent on the last year of life. Admittedly this spending is only for about 1% of the population who die each year, so the cost per person is high. But less than A$100 million is spent on helping people to die at home. A change in focus will be cost neutral, and help more people to die well.

When death comes for each of us, we want to die comfortably, in surroundings we choose. We need the courage to promote mature discussions about a topic we may dislike but cannot avoid if we are to have better deaths in Australia.

Hal Swerissen is Fellow, Health Program, Grattan Institute.
Stephen Duckett is Director, Health Program, Grattan Institute.

THE CONVERSATION

To die at home or in hospital? Aussies want one but we fund the other

Most Australians would rather die at home than in a hospital ward, so why aren’t we enabling this? Nikki McCaffrey investigates

Where do you want to die? Provided symptoms can be controlled, most people at the end of life prefer to die at home. However, just over half of Australians who died in 2011-12 died in hospital.

In the same year, about A$2.4 billion was spent on hospital care for people aged 65 or older in their last year of life. But only a small fraction of that amount is spent supporting people to die at home.

Public money is being wasted on ineffective and inefficient treatments and health services which do not meet patients’ and families’ needs and wishes at the end of life.

This money would be better spent on palliative care services. Among other benefits, these more than double the chance of dying at home through the provision of home-based support services such as nursing.

Health funds spent on treatments and health services of negligible and questionable value, such as chemotherapy at the end of life, should be reallocated to palliative care services. This would improve our chances of dying well and in accordance with our wishes.

Palliative care is care provided to people living with a terminal illness where a cure is no longer possible. The aim of palliative care is to achieve the best quality of life possible for patients and their families during the illness and after death by relieving symptoms, addressing emotional, social and spiritual needs and reducing suffering.

This type of care is provided by teams of assorted professionals such as chaplains, doctors, nurses, pharmacists, physiotherapists and social workers. It is provided across all types of settings, including hospitals, hospices, residential care facilities and at home.

Public money is being wasted on ineffective and inefficient treatments and health services which do not meet patients’ and families’ needs and wishes at the end of life. This money would be better spent on palliative care services. Among other benefits, these more than double the chance of dying at home through the provision of home-based support services such as nursing.

A recent report suggested investing A$237 million in providing palliative care services at home rather than in hospital wouldn’t raise the total health care spend but would increase the proportion of Australians dying at home from 14% to 30%.

High-quality palliative care is person-centred and

TREND IN HOSPITALISATIONS FOR PALLIATION IN AUSTRALIA 2002-3 TO 2011-12

Source: Australian Institute of Health and Welfare.
We are all going to die, but how will we die? Investing in palliative care services will improve our chances of dying well and in accordance with our wishes.

Compassionate. Emerging evidence suggests this type of care could even lower health costs, mainly by reducing hospitalisations at the end of life.

PALLIATIVE CARE IN HOSPITAL
Inevitably, and appropriately, some people will need or desire hospital care at the end of life. The Australian Institute of Health and Welfare's recent update on palliative care services in Australia showed that over the past ten years there has been a 52% increase in hospitalisations for which the main purpose of care is palliation.

This trend will continue rising due to our increasing, ageing population and earlier warning of death.

In 2012-13, 42% of people who died in hospital were receiving palliative care. Providing specialised palliative care in hospitals, particularly early on, can reduce hospitalisation costs by shortening the hospital stay and reducing intensive care and laboratory costs, as well as improving quality of life.

WHAT ABOUT INFORMAL CARE?
In 2011-12, Australia spent A$140.2 billion on health. Roughly a third of total health costs is associated with people in the last year of life.

But this estimate does not include costs to the individual or their family. Recent research suggests as much as a third of total spending on caring for people at the end of life falls on family and friends.

Without the support of informal carers, home-based care at the end of life would often be unachievable. Smaller, more geographically spread out families, higher divorce rates and changing communities mean these support networks are likely to shrink at a time when the need for them is growing.

When planning health care services in this setting, it is essential we also think about informal care costs. We need to make sure we avoid over-burdening families who are a vital part of end-of-life care.

ACHIEVING A BETTER DEATH
Without adequate palliative and end-of-life care, people will continue to be cared for and to die in hospitals despite most Australians wishing otherwise. Patients will have a poorer quality of life at the end of life. Families will suffer unnecessarily. Care will not be provided efficiently.

We are all going to die, but how will we die? Investing in palliative care services will improve our chances of dying well and in accordance with our wishes.

Nikki McCaffrey is Health Economist with the Palliative Care Clinical Studies Collaborative (PaCCSC), Department of Palliative and Supportive Services, and Flinders Health Economics Group (FHEG), Flinders University.

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HOW SHOULD CARE BE DELIVERED AT THE END OF LIFE?

Information for patients and their families and carers, from the Australian Commission on Safety and Quality in Health Care

INTRODUCTION

The way that we look after people who are dying is important. Good care at the end of life can help to reduce distress and grief for the person who is dying and for their family, friends and carers.

Doctors, nurses and others working in hospitals do what they can to make sure that people get the best possible care at the end of life. But sometimes the care that is provided is not as good as it could be. Many family members, carers and clinicians have had experience of this.

If you are a patient, family member, carer, consumer or consumer advocate, this information sheet will give you useful information about how care should be provided to people at the end of life in hospitals.

This information sheet supports the National Consensus Statement: essential elements for safe and high-quality end-of-life. The Consensus Statement is the result of work by the Australian Commission on Safety and Quality in Health Care to reach agreement about the way care should be provided at the end of a person’s life. The Consensus Statement actions are based on evidence, expert knowledge, and the experiences of patients, families and carers.

When this information sheet talks about clinicians, it means trained health professionals such as doctors, nurses, occupational therapists and social workers.

HOW CARE SHOULD BE DELIVERED AT THE END OF LIFE

Ten elements are required for safe and high-quality end-of-life care. Following is a summary of what each element means for you as a patient, and for families, carers and consumers.

1. Patient-centred communication and shared decision making

You are supported to make decisions about your care to the extent that you want to.

When clinicians communicate with you, they try to understand your wishes and preferences about your care at the end of life.

Clinicians talk to you openly, honestly and in a way that you can understand about your medical situation and care.

You have the opportunity to have multiple conversations with clinicians about your care at the end of life.

2. Teamwork and coordination of care

Your clinicians work together as a team so that you get the best possible care.

You, and your family, carers and substitute decision maker are part of the team for your care.

You are told about who is responsible for leading and coordinating your care, and the roles and responsibilities of other team members.

The clinicians in hospital work with the people who look after you in the community, such as your GP.

3. Components of care

You are always treated with dignity, respect and compassion.

Clinicians ask you, and your family and carers about what is important in your life and your wishes for your future care.

As much as possible, these wishes are taken into account when care is provided.

You have the right to refuse medical treatments.

Clinicians avoid providing treatments that will not help.

You continue to receive care
that keeps you comfortable and fits with your wishes, even after other treatment stops.

4. Use of triggers to help recognise patients approaching the end of life

Clinicians look at your situation and condition. Based on this, they may talk to you about end-of-life care.

Having early and repeated conversations about end-of-life care is useful; it does not necessarily mean that you will die soon.

You can start to talk to your family and carers about your wishes for your end of life before you are in hospital.

5. Response to concerns

You can raise concerns about your care at the end of life and have these concerns addressed.

If you are distressed in any way, you receive rapid assistance from clinicians who can reduce your suffering.

If you, or your family or carers disagree with clinicians about your care, there is a process to manage this, including getting a second opinion.

If disagreements about your end-of-life care are complicated, it may be necessary to ask an independent person for help.

6. Leadership and governance

Health services have processes in place to make sure that care for people at the end of life is always safe and of high quality.

There are people throughout the health service who are responsible for end-of-life care.

Health services make sure that their processes for providing end-of-life care work and are available for all patients.

7. Education and training

Clinicians and others know how to provide the best possible care to people at the end of life.

8. Supervision and support for interdisciplinary team members

Dealing with death and dying can be difficult. Health services ensure that there are processes for clinicians and others to be supervised and supported to prevent burnout and chronic stress.

9. Evaluation, audit and feedback

Health services look at the way they provide end-of-life care to see whether this care is safe and of high quality.

Feedback from families and carers is part of this process.

10. Systems to support high-quality care

Health services ensure that there are processes in place so that people at the end of life always get safe and high-quality care.

Health services aim to improve end-of-life care, where possible.

Processes for end-of-life care align with best practice and nationally agreed standards.

HOW YOU CAN BE INVOLVED

It is important that you are involved in making choices about your care at the end of life.

This means working with clinicians to understand your situation, thinking about who you would like to be involved in making decisions about your care, and nominating someone to speak for you if you are no longer able to communicate for yourself.

Decision making about care at the end of life

You, and your family and carers can participate in discussions and decision making with your clinicians about what happens at the end of your life. Alternatively, you might prefer to leave decision making to your clinicians.

Either way, you might want to think about appointing a substitute decision maker (often a trusted family member or friend) who can act for you if there is a time when you are no longer able to speak for yourself.

Depending on where you live, a substitute decision maker may also be called an enduring guardian or enduring power of attorney.

Advance care planning

The clinicians looking after you may ask if you would like to make an advance care plan. An advance care plan sets out your wishes for care if you are no longer able to speak for yourself. You can prepare an advance care plan before you enter hospital. Talking to your family or your GP is a good way to start this process.

If you have not already done so, you may wish to talk to your family about your wishes about organ and tissue donation.

Making decisions if I can’t speak for myself

If you have an advance care plan, this will help to guide the decisions of the clinicians who are providing your care. You can also appoint a substitute decision maker to speak for you.

If you do not have an advance care plan or a substitute decision maker, there is legislation in the state or territory where you live that will determine who can speak for you.

If you are no longer able to make your own decisions, your substitute decision maker, family and carers will work with the clinicians looking after you to make decisions about your care.

WHERE YOU CAN GET MORE INFORMATION

National Consensus Statement: essential elements for safe and high-quality end-of-life care

The Consensus Statement and this guide are available from the Australian Commission on Safety and Quality in Health Care. www.safetyandquality.gov.au/endoflifecare

Advance care planning

Many websites have information about advance care planning. States and territories have different legislation and ways of dealing with advance care plans.

A good place to start is the Advance Care Planning Australia website, which has links to information that is...
relevant for each state and territory. www.advancecareplanning.org.au

Alzheimer’s Australia has developed a website about planning ahead so that your choices will be known if you are not able to express these choices later in life. www.start2talk.org.au

MyValues is a website that guides you through a series of statements to help you identify, consider and communicate your wishes about the medical treatment you would want in the later stages of life. It generates a report based on your responses, which you can share with others about your wishes and values. The website was developed by Barwon Health, funded by the Victorian Department of Health. www.myvalues.org.au

Carers
Carers Australia is the national body representing carers. The website includes links to the carers association in your state or territory, which will have links to local services and supports. www.carersaustralia.com.au

Palliative care
Palliative Care Australia is the national body that supports and promotes quality care at the end of life for everybody. The website includes resources for consumers, patients, family members and carers. Palliative Care Australia has also developed the National Palliative Care Service Directory to help members of the community and clinicians to access information about palliative care services, primary care services that provide care at the end of life, and a range of other services that provide support to people with life-limiting illness. www.palliativecare.org.au

Organ and tissue donation
In Australia, many organisations are involved in improving organ and tissue donation, and the process for donation is coordinated at a national level. The DonateLife website contains information for people in the community, including fact sheets about having conversations about organ and tissue donation. www.donatelife.gov.au

ACKNOWLEDGEMENTS
This information sheet was developed by the Australian Commission on Safety and Quality in Health Care. The Commission would like to thank the individuals who reviewed an earlier draft of the information sheet and provided feedback on it.

DISCLAIMER
The National Consensus Statement: essential elements for safe and high-quality end-of-life care describes suggested practice for the provision of end-of-life care in settings where acute care is provided. It is a guiding document designed to inform clinicians and others of recommended practice. The Consensus Statement is not a legal document, and clinicians must continue to be aware of, and abide by, the laws of the jurisdiction in which they practise. Any inconsistency between the Consensus Statement and a law of a state, a territory or the Commonwealth will be resolved in favour of the relevant law.

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**What is palliative care?**

Palliative Care Australia explains the role that palliation plays in end-of-life care

Palliative care is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness.

Palliative care identifies and treats symptoms which may be physical, emotional, spiritual or social. Because palliative care is based on individual needs, the services offered will differ but may include:

- Relief of pain and other symptoms e.g. vomiting, shortness of breath
- Resources such as equipment needed to aid care at home
- Assistance for families to come together to talk about sensitive issues
- Links to other services such as home help and financial support
- Support for people to meet cultural obligations
- Counselling and grief support
- Referrals to respite care services.

Palliative care is a family-centred model of care, meaning that family and carers can receive practical and emotional support.

**Who is palliative care for?**

Palliative care is for everyone of any age who has been told that they have a serious illness that cannot be cured. Palliative care assists people with illnesses such as cancer, motor neurone disease and end-stage kidney or lung disease to manage symptoms and improve quality of life.

For some people, palliative care may be beneficial from the time of diagnosis with a serious life-limiting illness. Palliative care can be given alongside treatments given by other doctors.

**Who is in the palliative care team?**

Your GP, aged care worker and any other health care provider plays an important role in providing palliative care, as do family carers. They are supported by specialist palliative care services if symptoms become difficult to manage.

**Where is palliative care provided?**

Palliative care is provided where the person and their family wants, where possible.

- This may include:
  - At home
  - In hospital
  - In a hospice
  - In a residential aged care facility.

Many people indicate a preference to die at home and making this possible often depends on several factors, including:

- The nature of the illness and amount of care the person needs
- How much support is available from the person’s family and community
- Whether the person has someone at home who can provide physical care and support for them.

**How do I get palliative care?**

For help and information ask your:

- Doctor
- Aboriginal Health Worker
- Hospital Liaison Officer
- HACC Worker
- Nurse.

**Where can I find more information?**

For more information visit [www.palliativecare.org.au](http://palliativecare.org.au) or contact the palliative care peak body in your state [www.palliativecare.org.au/members](http://www.palliativecare.org.au/members)

Palliative Care Australia is funded by the Australian Government.

The goal of palliative care is to improve the quality of life of patients with an active, progressive disease that has little or no prospect of a cure. With the growth and ageing of Australia’s population, and an increase of chronic and generally incurable illnesses, the types of patient groups requiring palliative care has widened.

62,200 hospitalisations were palliative care-related in 2013-14, an 11% increase from 2009-10.

44% of patients who died as an admitted patient received palliative care.

5% of residential aged care residents were assessed as requiring palliative care.

1 in 1,000 GP encounters were palliative care-related (BEACH data).

1 in 6 public acute hospitals had a hospice care unit.

79% increase in Medicare benefits paid on palliative medicine specialist services from 2010-11 to 2014-15.

51,200 prescriptions that were palliative care-related were provided to almost 25,900 patients.

7 in every 1,000 employed medical specialists are specialist palliative medicine physicians and 1 in every 90 employed nurses are palliative care nurses.

90% of new patients commenced palliative care within a day of being ready for care (Palliative Care Outcomes).

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OVERVIEW OF PALLIATIVE CARE

COURTESY OF THE AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE

The World Health Organization (WHO) describes palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:
- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (WHO 2015).

In January 2014, the WHO and the Worldwide Palliative Care Alliance released the Global Atlas of Palliative Care at the End of Life – a tool to advocate for including palliative care in the global, regional and national health agendas (WHO 2014). This tool supports countries to develop palliative care policies and services that integrate palliative care into their health systems. The WHO regard palliative care as a human right in high demand, with an estimated 20 million people needing end-of-life care each year. In May 2014, the World Health Assembly unanimously passed a resolution to strengthen palliative care as a component of comprehensive care throughout the life course.

PALLIATIVE CARE IN AUSTRALIA

In Australia and many other parts of the world, the demand for palliative care services is increasing due to the ageing of the population and the increases in the prevalence of cancer and other chronic diseases that accompany ageing (WHO 2014).

Palliative care is provided in almost all settings where health care is provided, including neonatal units, paediatric services, general practices, acute hospitals, residential and community aged care services, and generalist community services. Specialist palliative care services operate from a variety of settings, including specialist inpatient consulting services, specialist inpatient settings, hospices and community-based specialist services (DoHA 2010).

The exact model of care provision differs across Australia. Each state and territory has specified an approach to palliative care in its jurisdiction (Senate Community Affairs References Committee 2012). The states and territories have different approaches to planning and delivering publicly funded services, different local service delivery practices and differently structured health care systems. They also have varying demographics and remoteness profiles, and varying demands for particular types of services. In recent years, there has been a focus on expanding the practice of specialist palliative care teams to support primary palliative care providers, often through consultative or consortium arrangements (AIHW 2010).

While palliative care can be provided to patients in a variety of settings, a distinction is commonly made between care provided in hospitals (includes hospices or dedicated palliative care wards) and care provided in the community (such as in the patient’s home or in residential aged care facilities).

NATIONAL POLICIES FOR PALLIATIVE CARE

State and territory governments and the Australian Government have committed to addressing the palliative care needs of Australians through the National Palliative Care Strategy 2010: supporting Australians to live well at the end of life (the Strategy) (DoHA 2010).

The Strategy was endorsed by Australian health ministers in 2010 to promote a coordinated and consistent approach to the delivery of high-quality palliative care across Australia. The Strategy outlines a number of priority ‘goal areas’ and ‘measures of success’ which aim to meet the identified demand for high-quality palliative care services across Australia. These ‘goal areas’ encompass building and enhancing the capacity of all relevant sectors to provide quality, appropriate and effective palliative care to all Australians who need it.

In addition to the Strategy, each state and territory has a range of initiatives in place to improve the delivery of palliative care services. For example, a 2015 Victorian government consultation ‘Greater say for Victorians: Improving end-of-life care’ generated a diverse range
of views and demonstrates the importance given to ensuring that palliative care services reflect and meet the community’s needs.

The National Palliative Care Strategy acknowledges that responsibility for providing palliative care services ultimately rests with the states and territories, and that each state and territory has specified an approach to palliative care in its jurisdiction (DoHA 2010). The Strategy aims to enhance and build on the work occurring within jurisdictions.

In October 2012, the Senate Community Affairs References Committee released its report into palliative care in Australia (Senate Community Affairs References Committee 2012). The Committee made 38 recommendations about palliative care, including the need for improved access to information on services. Noting the lack of comprehensive palliative care data, the Committee highlighted in its report the need for consistent data collection practices to become fixed in the clinical environment and for systems to be set up to enable palliative care data to be accurately measured. The collection, analysis and reporting of palliative care data will assist policy makers, palliative care providers, researchers and the general public to better understand the amount and nature of palliative care activity in the Australian health care sector.

Reliable, accurate and comprehensive data about health care services can improve the quality of care and lead to better health outcomes through:

- Highlighting areas in need of more or different types of services
- Highlighting inequalities and inequities in access to and outcomes of care
- Helping to assess the uptake of guidelines and evidence-based practices and to evaluate the effects these practices have on patient outcomes, as well as other consequences
- Helping to detect barriers to and facilitators of the uptake of best-practice patterns of care
- Helping to recognise changes in practice and consequent changes in outcomes
- Informing evidence-based policy and strategy decisions
- Providing practitioners with information and the ability to make appropriate decisions and to provide high-quality care (AIHW 2008).

REFERENCES

Euthanasia: let’s clarify what the law is before we debate changing it

Euthanasia proponents often express incredulity that in a supposedly humane society, the ‘right to die with dignity’ remains unsupported by law. Paul Komesaroff explains his concerns in this article from The Conversation

The subject of tonight’s ABC Australian Story is 70-year-old Bernard Erica. He has terminal cancer and was promised the strong sedative Nembutal to end his life by prominent euthanasia advocate Rodney Syme, according to the ABC. For this, Dr Syme claims he may lose his medical licence and could even face criminal charges.

Pressure to legalise euthanasia, or assisted dying, has become a somewhat fashionable, progressive cause in Australia today. In increasingly urgent statements, many proponents express incredulity that, in a supposedly humane society, the “right to die with dignity” remains unsupported by law.

Advocate and broadcaster Andrew Denton has written of how “hard to believe” it is that “a competent adult who is dying, and who begs for help to die quickly, [is] told they have to die slowly ...”.

Statements like this – and equally polemical responses from opponents of euthanasia – create the false impression that the subject of euthanasia is simple. In fact, it is extremely complex. What is more, the debate has been stuck for decades in polarised and simplistic proclamations and slogans. If we are ever to make progress we have to change this.

The first step towards achieving such change is to clarify where the law actually stands with regard to euthanasia.

A range of issues

The euthanasia debate encompasses a range of difficult issues. There is the question of how, in a pluralist and multicultural society, we can ensure respect for diverse ethical viewpoints and prevent noisy interest groups from using their media power to overwhelm opponents.

There is also the question of the proper role of the law in deciding ethical disputes in civil society. Traditionally, the job of legislation was not to enforce one particular ethical viewpoint over others but to provide a safe framework within which all of them could flourish.

There are concerns about the extent to which we can have confidence that the limits and safeguards necessary for a system of assisted dying will remain secure forever.

Certainly, the ease with which accepted rights have recently been disregarded under the guise of fighting terrorism, or restricting the movements of refugees – in Australia and other countries – doesn’t provide much comfort.

Many doctors have expressed concern that legalising assisted killing would undermine the core values of medicine. Shifting the focus from relieving suffering to terminating life might sound like a small step to some, but in reality it represents a reversal of very fundamental precepts.

In medicine, life has never been the disease and death has never been the cure. Rather, the commitment has always been to care for living persons, even in the darkest and most hopeless of circumstances.

In medicine, life has never been the disease and death has never been the cure. Rather, the commitment has always been to care for living persons, even in the darkest and most hopeless of circumstances.

Clarifying the law

Above all, the settings in which euthanasia could be invoked vary widely.

In medicine, life has never been the disease and death has never been the cure. Rather, the commitment has always been to care for living persons, even in the darkest and most hopeless of circumstances.
There are, for instance, the cases of terminal illness accompanied by intractable pain. Then there are cases of chronic, but not terminal illness, where a person seeks death over living with the disease. And there are the cases where a person in apparent distress is unable to express an opinion for reasons of cognitive or psychological incapacity.

The appropriate responses to all these situations are likely to be quite different.

The first case is the one that tends to dominate public debate and the response to it seems obvious. It is claimed the law condemns dying patients to continued suffering and therefore needs to be changed.

In fact, this is the one setting where change in the law isn’t needed. In English and Australian law, it has long been recognised that there is no limit to the medical treatments that can be given to alleviate suffering – even if the only way to achieve this involves the death of the patient.

This principle is crucial for medicine, because it means the toolbox to respond to suffering is never empty. A doctor acting humanely and within the bounds of normal professional practice to relieve suffering that incidentally hastens death has never been subject to criminal prosecution in Australia.

Rodney Syme, for instance, has reportedly helped over 100 people end their life. Although he has been interviewed several times by police, he has never been charged, presumably because it has been recognised that in each case he has acted in accordance with this principle.

There is confusion around a lack of certainty in the common law, which tells us that some reform is indeed necessary, both to restate current values and to reassure doctors and the broad community.

This would be easy to achieve and would carry the dual benefits of allaying understandable fears and allowing the debate about assisted dying to move on to address the more difficult, complex issues outlined above.

There are big issues at stake. Let’s find a way to debate them in a mature, careful, respectful, carefully nuanced and evidence-based way.

Paul Komesaroff is Professor of Medicine, Monash University.

**The CONVERSATION**


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### The legal framework that operates at the end of life in Australia needs to be reformed

The summary from an *Australia21* report by Bob Douglas, Lindy Willmott and Ben White following a roundtable discussing, “How should Australia regulate voluntary euthanasia and assisted suicide?”

- Voluntary euthanasia and assisted suicide are currently unlawful.
- Both activities nevertheless occur not infrequently in Australia, in part because palliative care cannot relieve physical and psychological pain and suffering in all cases.
- In this respect, the law is deficient. The law is also unfair because it doesn’t treat people equally. Some people can be helped to die on their own terms as a result of their knowledge and/or connections while some are able to hasten their death by the refusal of life-sustaining treatment. But others do not have access to the means for their life to end.
- A very substantial majority of Australians have repeatedly expressed in public opinion polls their desire for law reform on these matters. Many are concerned at what they see is happening to their loved ones as they reach the end of their lives, and want the confidence that when their time comes they will be able to exercise choice in relation to assisted dying.
- The most consistent reason advanced not to change the law is the need to protect the vulnerable. There is a concern that if the law allows voluntary euthanasia and assisted suicide for some people, it will be expanded and abused, including pressures being placed on highly dependent people and those with disabilities to agree to euthanasia.
- But there is now a large body of experience in a number of international jurisdictions following the legalisation of voluntary euthanasia and/or assisted suicide. This shows that appropriate safeguards can be implemented to protect vulnerable people and prevent the abuse that opponents of assisted dying have feared. It reveals that assisted dying meets a real need among a small minority of people at the end of their lives. It also provides reassurance to people with terminal and incurable disease that they will not be left to suffer the indignities and discomfort of a nasty death.
- Australia is an increasingly secular society. Strong opposition to assisted death by religious groups that is based on their belief in divine sanctity of all human life is not a justification for denying choice for those who do not share that belief.
- It is now time for Australian legislators to respond to this concern and this experience by legislating to enhance the quality of death for those Australians who seek assisted dying.

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Issues in Society | Volume 414

End of Life Issues
From ‘right to die’ to ‘right to choose the way you die’ – the shifting euthanasia debate

Peter Saul explains the changing nature of the euthanasia debate

ABC’s Q&A program took on euthanasia last night, and in the process reinforced its reputation as the leading television forum for political and social debate.

Former broadcaster and television producer Andrew Denton led with a strongly held and persuasively (if at times abrasively) argued position in favour of assisted dying. He moved the issue’s debate platform from the ‘right to die’ to the ‘right to choose the way you die’. This subtly but importantly changed the nature of the debate.

A telling exchange also took place between palliative care specialist Dr Ralph McConaghy and prominent euthanasia advocate Dr Rodney Syme. It emerged that both were prepared to use Nembutal, a sedative that can cause death by suppressing breathing.

The difference was that the former’s intention would be to relieve suffering only, while the latter was fully aware that death was the means by which this suffering would cease.

While many could argue that a ‘good death’ is an oxymoron, there is some consensus that good pain relief, choice about where death happens and having time to say goodbye all matter.

The separation between these two views seemed paper thin, and the Twitterverse lit up to highlight this. To an agnostic observer, it seemed entirely possible that the difference between Australia and the Netherlands (where euthanasia and assisted suicide are legal) lies more in the way we think about what we are doing than what actually happens.

Letting Die

Research into how patients are treated at the end of their life found that more than a third of Australian surgeons reported giving drugs at doses higher than necessary to relieve suffering for terminal patients, with the ambiguous intention of hastening death. But within this passive form of euthanasia, most doctors were uncomfortable to engineer a death in too speedy a fashion.

Described by critics as “slow euthanasia”, terminal sedation is where patients with symptoms unresponsive to all other treatments are rendered unconscious. Commonly used drugs include propofol, an intravenous anaesthetic, or barbiturates such as Nembutal. Generally, the patient would live for days rather than the few minutes that a large single dose would allow.

While I am not a palliative care specialist, I regularly manage dying patients in the intensive care unit (ICU), where removing life support is commonly accompanied by sedation and opiates. This process happens in ICU’s around Australia 40,000 times a year (or once every 15 minutes).

There is a somewhat fine distinction here as well, between letting die, and actively ending a person’s life. Perhaps the Australian public is not aware of how actively we already intervene to reduce suffering at the end of life.

Or maybe Australians are, and this apparent convergence between the practice of terminal sedation and speeding up of dying lobbied for by euthanasia advocates explains a puzzling finding. That is the rarity of direct requests doctors receive for euthanasia.

Not in High Demand

On Q&A, Dr McConaghy said that among the 5,000 dying people he had cared for, only one had explicitly requested euthanasia. In my own practice of 40 years and 4,000 deaths, I also have only been directly asked once. It was by an elderly lady with a broken hip who wanted to be put under for the operation and not woken up again, thinking that I could euthanise her under the cover of an anaesthetic.

Recently, oncologist Ranjana Srivastava wrote that she too had only ever been approached once in the 15
years of practising medicine with a similar request.

It seems then, that although the demand for legalising euthanasia is high in the general population, the demand for the practice in real life in Australia may be very low.

So why do we care so much? Although the Q&A audience was as generally divided as the panel, a clear uniting thread was the agreement that people who are suffering deserve a choice about how their suffering is managed.

Although we may weary of talk of ‘patient autonomy’, it clearly drives passion for change in the way we treat the elderly, the suffering and the dying. People want choice – indeed choice and control feature in half of the twelve components of a ‘good death’.

**A GOOD DEATH**

While many could argue that a ‘good death’ is an oxymoron, there is some consensus that good pain relief, choice about where death happens and having time to say goodbye all matter. Sadly, many deaths in acute care don’t tick any of these boxes.

Ralph McConaghy described the status quo as patients being treated like “cardboard boxes on a conveyor belt”, and this may well represent popular perception. So the real work, the real debate, becomes how to actively provide choices for elderly, chronically ill and dying patients.

Evidence exists to show the medical system is not only uninterested in the choices and preferences of its customers, but may downright disregard or even misrepresent them.

How do we manage the necessary conversations, and how do systems of care have to change in order to become responsive?

Advocates would do well to get behind promoting a ‘right to choose’, with a corollary of an obligation on doctors to communicate; rather than a ‘right to die’, with its unfortunate corollary of an obligation to kill.

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Predicting how long a patient will survive is critically important for them and their families to guide future planning, yet notoriously difficult for doctors to predict accurately. While many patients request this information, others do not wish to know, or are incapable of knowing due to disease progression.

Fuelling this complexity are families who prefer the patient not to be told for fear of torpedoing hope and reducing the quality of time remaining. Conversely, patients may want to know themselves, but do not want to distress their loved ones with this knowledge.

Providing a meaningful survival time to patients is often genuinely challenging for doctors. Accuracy declines further the longer the patient is expected to live.

Central to these scenarios is whether accurate prognostication at end of life is actually possible. Providing a meaningful survival time to patients is often genuinely challenging for doctors. Accuracy declines further the longer the patient is expected to live.

A number of studies indicate clinicians tend to be over-optimistic in predicting survival times. Research from 2011 indicated surgeons’ prognosis for survival time for patients with abdominal malignancies was accurate in 27% of cases, too optimistic in 42% and too pessimistic in 31% of cases.

This is one of the reasons some doctors are reluctant to attempt to predict survival time at end of life. This has traditionally been seen as part of the doctor’s special domain of knowledge to be communicated at the doctor’s discretion (if and when it is the right time to tell the patient, so it is not going to cause harm).

This archaic and paternalistic view melds conveniently with popular positive thinking, replete with militaristic vocabulary such as “fighting to the end”, which some doctors share.

This mindset views meaningful discussions of prognosis as harmful, as it may cause the patient to lose hope and give up the fight. It underpins those not uncommon cases when a family requests the clinician not to disclose a prognosis or a diagnosis to their dying relative. Unfortunately, it may also shut down meaningful end-of-life discussion and planning and result in harm, including to the grieving who remain.

When patients do not want to know their prognosis, this should be respected. For others who ask and the outlook is poor, a relationship built on trust is important.

Author Bill, an emergency and palliative care physician, is asked to give a prognosis every day. A discussion about prognosis includes...
the caveat that the accuracy the patient usually seeks is elusive, if not impossible to nail down.

Much can be said, however, including an explanation of why there is no firm prognosis. If it is possible to estimate survival time (derived from a mixture of medical details about the clinical history, prior response to treatment, imaging results, pathology results, functional status of the patient and experience), this is best communicated in terms of a short number of months, (long months is very difficult), long weeks or short weeks, a week or a few days or a few hours.

The accuracy of survival time can become more obvious as time progresses, just as the doctor-patient relationship develops, enabling more explicit discussions about survival time. In emergency medicine, when there is no time for these relationships to develop and time is short, patients frequently seek honesty and are extremely good at telling if the doctor is hiding something. This may then lead to them imagining something worse than the reality.

If the doctor does get the prognosis wrong, there is surprisingly little Australian authority as to whether a doctor will be liable.

Considering the general principles of medical negligence is useful here. It suggests that if a doctor provides a prognosis that is widely accepted as competent professional practice, shared by other respected clinical peers, then that prognosis is not negligent.

Even if the doctor provided a prognosis that was not widely accepted as competent professional practice, provided the incorrect prognosis did not cause additional damage to the patient, then no liability will follow.

**How long have I got, doc?**

Most of us are going to have to ask this one day – presuming we have not confronted it personally or through close relationships already. Despite the understandable imperative for those who want to know, the answer is rarely as crisp or accurate as the original diagnosis.

Breaking bad news to a patient is much more a process than an event, unfolding as symptoms develop and viable treatments recede. Best medical practice aims consistently for open, honest communication that is delivered sensitively.

Most doctors try to provide accurate information if able, despite clinical uncertainty. The aim is to maximise the good and minimise harm. When a prognosis appears wildly inaccurate, is not supported by a group of peer doctors and causes significant harm, Australians may be able to pursue the matter through legal action.

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A number of studies indicate clinicians tend to be over-optimistic in predicting survival times.
Unfortunately for every ‘good’ death, there are many which are drawn out and traumatic, write Charles Corke and Peter Martin

It’s hard to predict events in the final days and hours of a person’s life. Some deaths are wonderful – a gentle decline preceding a gracious demise. Certainly these are the sorts of deaths we see in films or on television, where the dying patient bids farewell to gathered family and friends before softly closing his eyes.

These gentle departures happen in real life too – many people simply die in their sleep, and many families and friends share the privilege of witnessing the calm and serene departure of a loved one. Of course, grief follows, but those left behind are able to take solace in the knowledge and memory of a peaceful passing.

Unfortunately for every ‘good’ death, there are many which are much more stormy and drawn out. These deaths can leave families traumatised for many years or simply make the grief that much harder.

Out of sight

Most people in western societies die in hospital or in institutional care. Keeping death out of sight and out of mind in this way means that most people have little real experience of death and dying.

The dying process is unpredictable. While dying may occur quickly and unexpectedly, it can take many, many hours or even days.

Some families interpret a long process as a reflection of the strength of their dying relative, and see this time positively, often as an opportunity for reflection.

But many struggle to find any positive meaning in a prolonged, confronting bedside vigil, observing and awaiting an inevitable outcome. For frail elderly family members this can be especially stressful, with other family members worrying about the impact, physical and emotional, on them.

This is particularly the case when the changes accompanying the process are not as gentle and predictable as we would like. The bodily reactions that accompany dying can be quite florid. The majority of patients become unsettled as they approach death.

Bodily reactions

As the end nears, it’s not uncommon for the breathing pattern to change, involving repeated cycles of breathing stopping (for what seems like ages) only to start up again. This restarted breathing is often quite rapid and deep. It then slows and stops again, and this cycle repeats over and over. (This sort of breathing is called Cheyne-Stokes respiration, named after Dr John Cheyne and Dr William Stokes who described it in the 19th century).

For family this can be difficult for each time the breathing stops it seems death has finally come, but no. Death seems to toy with them.

On top of this, breathing often becomes noisy. This is the so-called ‘death rattle’. During dying, swallowing
becomes impaired and secretions, which would normally be swallowed or would provoke a brisk cough, sit at the back of the throat. With each breath, air bubbles through this fluid, and the resulting guttural noise often causes concern and distress to onlookers.

Medications to dry the secretions may help, and positioning the patient differently may also assist, but rarely do they stop the noise completely.

Warning families of these common changes that they may witness may help prepare them for the time ahead, but some are still disturbed.

Waiting game
For some people – both patients and their families – dying is difficult. Irish author Sheridan le Fanu (1814-1873) commented, “Old persons are sometimes as unwilling to die as tired-out children are to say good night and go to bed.” And it can seem this way to exhausted and emotional relatives.

Frequently family members ask if anything can be done to speed up the process – the patient is unconscious anyway, and the outcome will be the same. Others worry that symptom-relieving medication may hasten death.

A recent letter I received from a grief-stricken lady who sat with her husband for many hours through a long and difficult death, reported how he coughed, choked and wheezed, breathed erratically and gasped sporadically. He kept appearing to have died, only to start breathing again. This poor woman was completely traumatised, sitting through a night and day with her much-loved husband.

“It was a complete nightmare, like something out of a horror movie,” she wrote “... I just wanted it to end, but it went on interminably. I will never forget it and I so wish it could have been made more dignified.”

Unfortunately for every ‘good’ death, there are many which are much more stormy and drawn out. These deaths can leave families traumatised for many years or simply make the grief that much harder.

The death of a loved one is sad and challenging enough without having to cope with extra trauma that results from a difficult end.

Minimising distress
When illness or age present an inescapable conclusion to life, then it is the doctor’s dilemma to ensure a good death. However, the challenge is that this good death must occur within the constraint that medication must not be given to accelerate death, nor to relieve symptoms that are distressing to the family (as treatment is only permitted for the direct benefit of the patient).

Maybe it is time to question the belief that it is wrong to treat a dying patient in order to minimise the distress that their dying may cause their closest relatives. After all, few of us would desire our own deaths to be viewed as “something from a horror movie” and would support actions that might help our family at this difficult time.

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The Conversation
WHAT TO DO FOLLOWING A DEATH
A PRACTICAL FINANCIAL GUIDE FROM THE DEPARTMENT OF HUMAN SERVICES

We provide payments, counselling and financial services to help people adjust to life after someone close to them has died.

What happens first
When someone dies, a doctor must sign a certificate that confirms the death. Funeral arrangements cannot be completed until the doctor has signed and issued this certificate. It is generally called a Doctor’s Certificate of Cause of Death. The funeral company can then take the deceased into their care.

The funeral director in charge of the funeral arrangements will collect all the information needed for registering the death and send it to the relevant state or territory government office. The funeral director may also help with things such as newspaper notices, flowers and religious services.

Read more about who to contact on the Australian Funeral Directors Association website.

If a funeral director is not involved with the funeral arrangements, the person who manages the final arrangements for the deceased is responsible for registering the death.

Insurance policies, funeral plans and wills
Sometimes private health, sickness, accident or life insurance policies may help to pay funeral and other expenses. If you find that the person who died had insurance, call the company and ask if assistance is available.

Some people pay for their funerals in advance. Funeral plans involve paying in advance for an agreed funeral service. Funeral bonds represent money the person has put aside to cover their funeral costs.

If you think there may be a prepaid funeral or a funeral bond but cannot find the paperwork, it may have been left with someone such as a solicitor or the Executor of the Will.

A Will is a legal document that states how the deceased person’s belongings are to be distributed after their death. The Executor of the Will is responsible for distributing the person’s assets to the people named in the Will. This happens after any debts are paid.

If the person has not left a Will, the estate is shared under a formula set by law. If there are no close relatives there is a chance the estate could be paid to a state or territory government.

Who to notify
When someone dies, a number of people and organisations need to be told. It is important that we are informed when someone has died. Call us on 132 300, visit us, or complete the advice of death form (SA116A) and fax 1300 786 102 or post to:
Centrelink
Reply Paid 7800
Canberra BC ACT 2610

After locating personal records and documents, you can use the following checklist for people and organisations you may also need to contact, www.humanservices.gov.au/sites/default/files/documents/who-to-notify-checklist.pdf

Removing someone’s name from mailing lists
Register the details on the Association for data-driven marketing and advertising website or write to them at:
ADMA
GPO Box 3895
Sydney NSW 2001

Social media accounts
Social media networks usually have procedures in place to deal with the accounts of deceased members. As these procedures can differ between networks the best thing to do is to search the ‘help’ section of the network in question if you wish to close an account.

Assistance from us
Read about eligibility and how to start the claiming process for the following payments and services:
- Bereavement Allowance – a short term income support payment for recently widowed people to help them adjust after the death of their partner
- Bereavement Payment – helps ease your adjustment to changed financial circumstances after the death of your partner, child or person you were caring for
- Double Orphan Pension – provides help with the costs of caring for children who are orphans or who are unable to be cared for by their parents in certain
circumstances – there is no income or assets test required

- Pension Bonus Bereavement Payment – a payment to the surviving partner of a deceased member of the Pension Bonus Scheme, who did not make a successful claim for the bonus before their death

- Widow Allowance – ensures women have an adequate income if they have become widowed, divorced or separated later in life, were born on or before 1 July 1955 and have no recent workforce experience

- Social work services – our social workers can help you during difficult times by providing counselling, support, and information

- Financial Information Service – a free, confidential service available to all Australians to help you make informed decisions about investment and financial issues for your current and future needs

- Someone else to deal with us on your behalf – if you would prefer to have someone else deal with us on your behalf about our payments and services, you can authorise a person or organisation to be your nominee or make enquiries only.

You may also be eligible for Parental Leave Pay, Stillborn Baby Payment or Dad and Partner Pay in the case of a stillbirth or infant death. Read more about Bereavement Payment at www.humanservices.gov.au/customer/services/centrelink/bereavement-payment or call 136 150.

Financial matters

After the death of a loved one, you may need to understand more about the investments you own. When a member of a couple dies, the survivor usually inherits assets previously held in joint names. You should advise us of any changes to your income and assets as they may impact any payment you receive or become eligible for.

If your partner had superannuation you may also be entitled to a superannuation payment. You need to contact the relevant superannuation organisation and find out if you could be eligible for any payments.

You should also carefully consider the implications of passing on assets to children or other family members and friends and bypassing yourself, as this can affect your asset position and may result in changed payment rates.

Relatives and friends do not have to pay the debts of the person who has died unless the debts are in joint names. Debts can be paid from the estate.

Financial assistance

If you would like assistance to work out a budget, manage your financial affairs or help if you are in financial trouble, you can speak to a financial counsellor by contacting any of the following:

- Your local Community Information and Referral Service
- A Welfare Rights Centre
- Rural Financial Counselling services
- Financial Counselling Australia
- Financial Information Service.

Early superannuation release

Superannuation cannot generally be accessed before you reach your preservation age. However, in some specific circumstances, the law does allow you to access your superannuation early. These limited circumstances include specified compassionate grounds and severe financial hardship.

Read more about the early release of superannuation on compassionate grounds at www.humanservices.gov.au/customer/services/centrelink/early-release-superannuation, call 1300 131 060, or contact your superannuation fund.

For more information about early release of
superannuation for severe financial hardship, contact your superannuation fund.

**Support for you after someone has died**

**Grieving**

Grieving is a natural part of losing someone close to you, so adjusting to your new circumstances may take time. Counsellors can often assist people who are grieving. Our social workers can refer you to grief counselling. Counsellors can also be contacted through organisations such as community health centres, the National Association for Loss and Grief or Lifeline.

**Loneliness**

It may seem difficult at first to take part in social groups and activities. You may or may not want people around you. With time, the company of others may help you develop new interests. Your local council, community health centre or our social workers can put you in touch with organisations such as Rotary or Apex that would value your assistance as a volunteer. You can also join in their activities and outings.

**Health**

Taking care of your diet and regular exercise can assist you to re-establish a routine. We can arrange for visits by a community nurse if necessary. Community groups or local councils may arrange services to help care for your house or garden. Some of these services are free and some may be provided only after your needs have been assessed.

**Housing**

You may want to stay in your family home. However, if this is difficult, think about all the options carefully before you decide on a change. Moving too quickly may not be the best solution.

You can talk to a Financial Information Services officer who can give you information about how any decisions you make could affect the payment you receive from us.

**Other government and community support services**

There are a range of other organisations that provide support services and useful information you may find helpful. You can use Service Finder to locate assistance in your local area, [www.humanservices.gov.au/customer/service-finder](http://www.humanservices.gov.au/customer/service-finder)

ASIC’s MoneySmart website has information to help you make the most of your money. Read the Losing your partner section of the website at: [www.moneysmart.gov.au/life-events-and-you/life-events/losing-your-partner](http://www.moneysmart.gov.au/life-events-and-you/life-events/losing-your-partner)

Financial Counselling Australia is the peak body for financial counsellors in Australia and provides information about how financial counsellors can support and advocate for people experiencing financial difficulty, [www.financialcounsellingaustralia.org.au/Corporate/Financial-Counselling](http://www.financialcounsellingaustralia.org.au/Corporate/Financial-Counselling)

Headspace is the national youth mental health foundation and can help young people who are going through a tough time, [https://headspace.org.au](https://headspace.org.au)

If you are experiencing depression, anxiety or stress, you may find it helpful to talk to somebody about your mental health. (see link for Service Finder)

Lifeline is a national charity providing all Australians experiencing a personal crisis with access to 24-hour crisis support and suicide prevention services, [www.lifeline.org.au](http://www.lifeline.org.au)

Solace Australia provides support for people who have lost their partner, [www.solace.org.au](http://www.solace.org.au)

**Related services**

- Bereavement Allowance
- Bereavement Payment
- Dad and Partner Pay
- Double Orphan Pension
- Early release of superannuation
- Family Tax Benefit
- Financial Information Service
- Parental Leave Pay
- Pension Bonus Bereavement Payment
- Social work services
- Stillborn Baby Payment
- Widow Allowance

**Related subjects**

- Concession and health care cards
- Crisis and special help

**PAYING FOR YOUR FUNERAL**

Options on how to make it easier for others, from ASIC’s MoneySmart website

**MAKING IT EASIER FOR OTHERS**

Funerals in Australia can cost anywhere from $4,000 to $15,000 depending on whether they are simple or elaborate.

If you want to make things easier for your family by paying in advance for your funeral here are some options to consider:

- How much does a funeral cost?
- Super and other ways to pay for funerals
- Pre-paid funerals
- Funeral bonds
- Funeral insurance.

**How much does a funeral cost?**

Most of us only find out about funeral costs when we need to arrange the funeral of a family member or friend.

Funerals can cost from $4,000 for a basic cremation to around $14,000 for a more elaborate casket, burial and flowers.

Here are the typical items you need to pay for when arranging a funeral:

- Funeral director fees
- Transport
- Coffin
- Death certificate
- Permits
- Burial/cremation
- Cemetery plot
- Other expenses, such as a celebrant or clergy, flowers, newspaper notices and the wake.


**Super and other ways to pay for funerals**

If you have super, when you die your super fund will pay out your super balance and any life insurance to your dependents or your estate. This money can be used to pay for a funeral but it can take some time for it to be paid out. Your family may need to pay for your funeral and then be reimbursed once probate is granted. Talk to your super fund to see what approach it takes. See Super death benefits for more details. [www.moneysmart.gov.au/superannuation-and-retirement/how-super-works/insurance-through-super/super-death-benefits](http://www.moneysmart.gov.au/superannuation-and-retirement/how-super-works/insurance-through-super/super-death-benefits)

**Save for your funeral**

You can save for your funeral by setting up a term deposit or online Savings account and saving until you reach an amount that will cover the type of funeral you want. This could be all you need to do. You may find that you can save enough money to pay for your funeral this way. [www.moneysmart.gov.au/managing-your-money/banking/savings-accounts](http://www.moneysmart.gov.au/managing-your-money/banking/savings-accounts)


Keep these savings separate from your everyday accounts. This account will form part of your estate when you die, so make sure you tell your beneficiaries about the account so they can access it to pay for your funeral when it is needed.

**Pre-paid funerals**

Pre-paid funeral plans allow you to choose and pay in advance for your funeral. This is important if you have strong cultural reasons for wanting a certain type of funeral or certain features. If you want to pay for the funeral up front but don’t want to be faced with all the details yet, you can pay for the funeral and leave the details for your relatives to decide later.
You should ask for a full description of the costs to see exactly what you are paying for. Funeral service operators who don’t reveal the costs of a funeral are in breach of the Competition and Consumer Act 2010.

You can either pay for the funeral in full or pay it off in regular instalments over a period of time. A deposit is usually required but you can negotiate the amount you pay up front.

It’s important to shop around when you are looking for a pre-paid funeral as different funeral directors offer different packages.

**Pros**

- Costs are fixed in today’s dollars even if your funeral is not for many years
- You can control funeral arrangements if you want to (such as casket, flowers etc)
- You can pay in instalments over time
- Can be a lot cheaper than a funeral bond or funeral insurance if you live for another 5-10 years.

**Cons**

- Can be inflexible if you move interstate to live with family. Some pre-paid plans are transferrable to different providers
- If you change your mind about a pre-paid funeral you may not be able to get your money back. Check the terms and conditions.

**Check for registration**

Some states require prepaid funerals to be registered. The following state fair trading offices can help you with more information about prepaid funerals.

- **NSW** – Fair Trading: Contributory and pre-paid funerals
  www.fairtrading.nsw.gov.au/Consumers/Buying_services/ Funerals/Contributory_and_pre_paid_funerals.html
- **Queensland** – Fair Trading: Funerals
- **South Australia** – South Australian Government: Planning ahead for a funeral

It’s important to shop around when you are looking for a pre-paid funeral as different funeral directors offer different packages.

**CASE STUDY: ALAN GETS A FUNERAL BOND**

When he decided to retire at 65, Alan wanted to get his finances sorted. Apart from sorting out his will and other paperwork, he wanted to make arrangements to pay for his funeral.

Alan didn’t want to think about the details of the funeral itself so he decided to purchase a funeral bond with some of his retirement savings. He knew the investment would grow over time and if he lived another 15 years the bond would cover all his funeral costs. He was happy for his family to assign the bond to a funeral director of their choice at the time of his death. He felt satisfied that he had sorted out his funeral costs and his family would not have to worry about them.
Funeral bonds

Funeral bonds are an investment product that can help you save for funeral expenses. Funds can only be withdrawn after your death to pay for your funeral.

Money invested in burial plots, pre-paid funeral plans or funeral bonds (up to the Funeral Bond Allowable Limit) is not subject to the asset or income test for the Age Pension. See the Centrelink’s page on Funeral bonds and prepaid funerals for more detail on how Centrelink treats these assets.


You can invest in a bond either directly through an investment company, such as a friendly society or life insurance company, or directly from a funeral director.

Many funeral bonds can be assigned to a funeral director of your choice.

You can pay for the funeral bond in instalments but make sure you understand all the costs before you sign up. You should read the bond’s prospectus to find out the details.

**Pros**

- Exempt from the asset and income test (the test used to assess eligibility for the Age Pension)
- Keeps funeral money separate from other accounts and investments
- Good for people who want to pay in advance but may not want to think about all the details
- As an investment, your savings will generally grow over time – check out investment returns and information about fees in the product disclosure statement (PDS)
- You are not locked in to using a specific funeral director
- You can buy your bond upfront or you can pay in regular monthly payments until you reach the chosen value of your bond. For example, for a $6,000 bond, you may need to pay a deposit of around $500 followed by monthly instalments of around $40 to $50 per month.

**Cons**

- If you pay in instalments and die before the bond is fully paid for, you will only receive what you have paid into the bond and any money earned on the investment
- Investment returns on your bond may not keep up with inflation. (For example, if you invest in a $6,000 bond and die in 10 years and your funeral is $8,000, your family or estate may need to top up your bond to meet your funeral costs if the returns

**CASE STUDY: ALICE GETS FUNERAL INSURANCE**

Alice was 58 and still working when she took out funeral insurance costing $20 per fortnight. She wanted funeral cover so her family did not have to worry about paying for her funeral.

By the time Alice was 71, her premium had doubled and cost her more than $40 per fortnight. It had gone up every year as she aged and to cover inflation. She struggled to pay the higher premium on her much lower, post-retirement income. She also knew it would continue to go up each year.

Alice added up all the premiums she had paid over the last 13 years and worked out that they had cost her more than $10,000.

Alice had a tough decision to make. If she stopped paying the premium she would lose all the money she had already paid and if she died her funeral would not be covered.

If she continued to pay her premium her funeral would be covered but she would not be able to afford the things she needed.

Alice realised that she wouldn’t be in this situation if she had put the money into a savings account rather than towards funeral insurance. If she had saved the money she would now have enough to pay for her funeral and her fortnightly payments would have been available for her to cover her everyday expenses.
Your own funeral can be hard to think about, but if you want to sort it out in advance, make sure you check out your options to get the best value for your money.

are not enough to meet the total cost)
- Will not lock in the funeral costs in today’s dollars
- You may not be able to get your money back if you decide to discontinue the bond. Check the PDS.

**Funeral insurance**

Like other types of insurance, you pay monthly or fortnightly premiums (ongoing payments) for a fixed amount of cover. Usually you can choose between $5,000 to $15,000 cover which will be paid to your beneficiary when you die.

With funeral insurance, you are not saving for funeral costs but buying insurance to meet those costs at some future date.

Unlike taking out insurance for a car accident which is an unknown event, we all know that we will die sometime. Because you don’t know when you are going to die, you need to think about whether you can afford funeral insurance over the next 10, 20 or more years.

**Increasing premiums**

Not only will you need to keep making payments over the years, but premiums are usually ‘stepped’ which means they increase with age and grow over time.

Funeral insurance premiums tend to rise steeply for people over 50 and this can cause people to cancel their policy in the first few years, losing the benefit of premiums already paid.

If the premium payments become unaffordable for you and you stop paying them, your policy is likely to be cancelled. You will not get back the money that you have paid towards your policy. Different insurers have different rules, so read the PDS carefully before you sign up.

Read ASIC’s media release on their 2015 funeral insurance report that shows how sharply premiums rise for people over 50 and outlines the types of funeral policies that have high cancellation rates.


**Things to consider**

Before you buy funeral insurance, check whether it is worth the money.

Will you be paying more for the insurance than the funeral will actually cost? Have you considered other options you might have for paying for a funeral?

Will your premiums increase and will you be able to keep paying them? Think long term and remember if you can’t keep up the payments you are likely to lose all the money you have paid towards the insurance.

Your insurance premiums will go up over time. The PDS will tell you if your cover will also increase by the Consumer Price Index (CPI) or by a predetermined
amount – which will result in your premium rising to cover the larger amount of cover. If you don’t want your cover to increase you can usually opt out of this, but you must contact your funeral insurance provider. Check the PDS.

**Pros**
- You can get cover from day one but most policies only cover accidental death in the first year or two
- Insurance may seem familiar and affordable when you take it out and may suit you if you aren’t sure if you can save for funeral costs.

**Cons**
- Premiums generally go up over time. This means what started out as a cheap way to pay funeral costs can become very expensive, especially if you are living on a fixed income
- If you can’t afford to keep up the premiums or want to cancel your policy you are not likely to get back the premiums that you have paid
- If you live another 5 to 10 years you may end up paying more in premiums that the cost of the funeral. Visit the My Longevity website to work out your life expectancy at www.mylongevity.com.au/index.aspx
- As most insurers only cover accidental death in the first 2 years, if you die from a terminal illness in this time you may not be covered. Check the policy’s terms and conditions.
- Sometimes it can take a while for your family to receive the insurance payout to cover funeral costs.

Your own funeral can be hard to think about, but if you want to sort it out in advance, make sure you check out your options to get the best value for your money.

ABOUT GRIEF

Australian Centre for Grief and Bereavement explains common responses to grief

“I’d never had a serious loss before and I thought grief was basically lots of crying which peaked at the funeral and then you ‘got over it’ and ‘moved on.’ I wasn’t prepared for the utter emotional, physical, and mental chaos that it was. I wasn’t prepared for all the other emotions that came with it – the guilt, the anger, the fear.” (Annie)

Grief is our response to loss. It is the normal, natural and inevitable response to loss, and it can affect every part of our life, including our thoughts, behaviours, beliefs, feelings, physical health and our relationships with others.

With the support of family and friends, many people adapt to loss well and may not experience intense and persistent feelings; however, for some, the experience of grief can be overwhelming and further support may be helpful.

Common grief responses
After a death, we may experience a range of intense feelings, such as sadness, anger, anxiety, disbelief, panic, relief, irritability or numbness. Grief can also affect our thinking. We may think we will never get over this, or that we are going crazy.

Sometimes grief can also cause difficulty in sleeping and physical symptoms such as headaches, nausea, aches and pains. If physical symptoms persist, check with your GP to exclude other causes.

Grief is an individual experience
Everyone grieves in their own way. Your grief is unique to you, and as long as you are not causing harm to yourself or those around you, there are no ‘right’ or ‘wrong’ ways to grieve.

We do not always know how people are grieving simply by what we see. Some people are open and expressive with their grief, crying, and wanting to talk, whilst others are more private, may be reluctant to talk and prefer to keep busy. Other factors, such as culture, gender and belief systems can also influence the ways that people grieve.

Grief is individual and personal, and it’s important to respect each other’s way of grieving, even if we don’t necessarily understand it.
Life grows around grief
It is a common myth that people ‘get over’ grief. The reality is, a part of us will always grieve the loss of our loved one. With time, the pain will lessen, but the sorrow we feel will always be a part of us. When people grieve they are coming to terms with what has changed in their lives. There is no ‘return to normal’; rather, we have to learn to live around a new kind of normal – re-learning the world and re-learning ourselves within it.

Grief doesn’t have a timeline
Grief can be triggered at any time, and it’s not unusual for grief to be felt over an extended period of time. It’s okay to admit you are struggling with your grief, whether it be weeks, months, years or even decades after the death.

Looking after yourself
When grieving, or supporting someone who is grieving, it can be all too easy to neglect our own needs. Taking the time to look after yourself, however, can make a big difference in your ability to function on a day-to-day basis, especially in the longer term. Below are some suggestions about how to get through some of the difficult times.

Privately and personally
• Try to delay major decisions that cannot be reversed for 6-12 months, e.g. disposing of belongings
• Keep a diary or journal
• Create a memorial – do or make something to honour your loved one
• Develop your own rituals, e.g. light a candle, listen to special music, make a special place to think
• Allow yourself to express your thoughts and feelings privately. Write a letter or a poem, draw, collect photos, cry, etc
• Exercise – do something to use pent-up energy, e.g. walking, swimming, cycling, gardening
• Draw on your religious or spiritual beliefs and practices
• Explore other people’s experiences through books, movies, articles, etc
• Do things that are relaxing and soothing
• Some holistic or self-care ideas that may assist include meditation, distractions, relaxation and massage
• To help with sleeplessness: exercise, limit alcohol and caffeine and try to maintain a routine, especially around bedtime.

With other people
• Sharing with other people can reduce the sense of isolation and loneliness that comes with grief
• Allow people to help you; don’t be embarrassed to accept their help. You will be able to help someone else at another time. It is your turn now
• Talk to family and friends; sharing memories and stories, thoughts and feelings can be comforting and strengthen your connection with your loved one

Grief can be triggered at any time, and it’s not unusual for grief to be felt over an extended period of time. It’s okay to admit you are struggling with your grief, whether it be weeks, months, years or even decades after the death.

• Consider joining a support group to share with others who have had similar experiences
• Take opportunities to join in public ceremonies where you can be private, yet part of a larger group
• Use rituals and customs that are meaningful to you
• Talk with a counsellor to focus on your unique situation, to find support and comfort, and to find other ways to manage, especially when your life or your grief seems to be complicated and particularly difficult.

When to seek further help
Although grief can be very painful, most people (85-90%) find that with the support of their family and friends and their own resources, they gradually find ways to learn to live with their loss and do not need to seek professional help.

Sometimes however, the circumstances of the death may have been particularly distressing, such as a traumatic or sudden death, or there may be circumstances in your life which make your grief particularly acute or complicated. If you are finding it difficult to manage on a day-to-day basis, it may be helpful to see a counsellor or other health professional. It’s okay to admit you are struggling with your grief. No one will think any less of you if you ask for help along the way.

Grief is the feelings we have after a loss. We may feel overwhelmed with emotions like pain, anger and sadness. Sometimes you can even feel numb.

There is very good information about loss and grief on these two Youth Mental Health websites:

Youthbeyondblue
www.youthbeyondblue.com

Headspace
www.headspace.org.au

Loss can come into our lives in lots of ways, and it affects each of us differently. One of the biggest and most difficult losses is the death of someone really important to you.

There are many types of loss where you might feel sadness, confusion and anger:
• The death of a pet
• Your parents or other important people splitting up or getting divorced
• Separation from a parent, both parents, your family
• Separation from friends or your community
• Moving away from home or leaving your country
• Splitting up with your partner
• Being forced to give up something you want to keep (like your job, your child, or your home)
• Losing your job
• Leaving school or university
• Losing the ability to do some things through disability
• Becoming really sick or seeing someone else become really sick.

Even when something happens that appears positive, such as leaving school and starting work, we can experience some feelings of grief for what we’ve left behind.

When we have a loss in our life, we go through reactions of grief. These reactions and feelings are different for everyone. You always feel loss in your own unique way.

WHAT IS GRIEF?
When you grieve you might notice some of these feelings. You might not feel all of them, and you might not feel them in the same order.

• Denial, shock or disbelief – “It hasn’t really happened”, “This isn’t real”, “I must be dreaming”, “She is just fooling around”, “He will be back”. This is like a temporary relief and helps you to avoid getting completely taken over by grief.
• Questions, questions, questions – You try to make sense of the loss. These might be related to feelings of guilt – “Why didn’t I?”, “If only I had ...”, “I should have ...”, or confusion – “What is going on?”, “I don’t understand”, “What happened?”.
• Anxiety – Loss can be scary. You might think about your future – “What will I do?”, “How will I cope?” – or have a fear of losing control – “I’m going to lose it ...”, “I can’t stop it ...”, “What else might I lose without me being able to stop it?”
• Anger – Anger comes from other feelings, like feeling
abandoned, hurt or scared. You might express anger in lots of ways. You might direct your anger at people you think caused the loss. “Why did you...?” “You always...” “You never cared” – or feel helplessness – “I couldn’t stop it”, “I can’t change anything”, “I can’t cope”.

• Crying, sobbing, depression. Sadness might feel like a black cloud over your whole world. You might long for what you have lost. You might lose interest in life – you don’t want to go out, or see or do things you usually do. You might feel loneliness, or feel you have no one to turn to.

• Reality and acceptance and adjusting to new life patterns – You realise what has happened and the pain does not hurt so much. Everything is different but the struggle is not so huge. Life goes on with the memories and experience of knowing what you once had. You start looking toward the future.

• Grief can cause physical symptoms like headaches, feeling sick in the stomach, aching muscles, feeling run down, trouble sleeping, feeling tired, having no energy. You might find you get sick more easily.

These feelings can happen at any time and for any length of time. You might have more than one at once. You might feel really good one day and awful the next. Special times like Christmas, birthdays or anniversaries can be difficult. You may return to a feeling and go through it again. Sometimes it can feel worse in the morning, or as you are about to go to sleep. Sometimes you might wonder if you will ever feel ‘normal’ again.

You will – gradually the pain is with you less often and life finds a new sense of meaning.

If you find you are stuck in one of these feelings and not gradually moving on over time, it would be a good idea to talk to a counsellor about it.

DEALING WITH LOSS IN HARMFUL WAYS
Grief affects you in lots of ways. Not only do you have a rush of emotions that can be hard to cope with, but you might also do things that can be harmful!

• You might use drugs and alcohol to try and cover up the pain or make it go away. Many people think using drugs or alcohol is the only way, or a good way to deal with the pain. But this method may just ‘put off’ or prolong the natural process of grief, as well as doing you harm.

• You might hurt other people. It’s natural to feel angry when you grieve. Anger is sometimes the emotion you show when there are a whole heap of other emotions happening underneath. If you think you’ve no safe place to express yourself or don’t understand what’s going on, you might turn anger on other people. Anger is a natural emotion; violence is a chosen behaviour. Anger can be expressed in a safe way without hurting others.

• You might hurt yourself. Choosing to hurt yourself is only one choice to express the pain that is happening for you.

There are lots of other ways you can choose to express yourself.

If you have chosen any of these things, it can be useful to talk to someone you trust or find other ways to express yourself. Some people express themselves through art or music, others like to write down what they are feeling. This can also be a stepping stone to explaining how you feel to other people.

TIPS TO HELP
• Accept your own feelings – understand that what you are feeling is natural. Let yourself cry, talk about the loss, or have a laugh. Check out the stages of grief. Let yourself feel what you are feeling. The feeling will pass.

• Express your feelings – talk to someone you trust. Write a letter, poetry or a journal. Paint, draw or sing. Express what you are feeling – your fear, your hurt and your loss. Talk about what you have gained by knowing the person or having the experience you have had. Talk about the good and not so good times.

• Ceremonies – funerals, ceremonies or memorials can be important. They are opportunities to share your grief with other people, or help accept the end of a part of
your life. This is an ending of one phase in your life and the beginning of a new one. Maybe you could do something special with friends and family, like have a remembrance meal.

A young woman who had a lot of loss in her life said to me:

“My grandma taught me something I will never forget – that there are no endings in life, only new beginnings.”

She said this had helped her cope with loss and to move on in her life.

Community Health Worker

- Take each step at a time – live each day as it comes. Understand and accept disruption in your life. Take control of things you can. Understand there are things you have little or no control over. Give yourself permission to grieve.

- Move forward – what have you learnt from that person, place or experience? What memories do you have? How have they become part of your life? How might you carry these on? How might you share them with children or others? What place might these skills, attributes, stories or knowledge hold in your future?

- Support – support is essential. Talk to a friend, family or someone you trust. Sometimes it might feel people ‘don’t understand’ or ‘get sick of your grieving’. It can be useful to check out a counsellor or have a network of supports in your life.

- Have a laugh – your sense of humour can be a great tool at any hard time. It is OK to laugh at things you would usually laugh at. Advantages of laughter are that they give you just a little break from the pain and release healthy, healing chemicals into your body.

- Celebrate your memory – plant something as a living memorial. Carry or wear something that reminds you of the person who died or the thing you have lost. Create a memory book or journal with photo’s, stories, pictures or poems. Put up a photo or something else that reminds you of that person. Spend time at a place or doing things that you used to do.

- Explore your spirituality – pray, meditate or spend some time with nature. Use your own personal spirituality to explore what death or loss means to you and your spiritual self.

- Change – be open to new ways of doing things. When it feels right, start something new. Don’t feel guilty about this, it is part of healing and you will never lose what your relationship with the person you have lost has given you.

- Be aware – it is natural to become more dependent on others immediately after a loss. It is not useful to keep this going for a long time. Keep an eye out for signs that indicate that you are not gradually feeling better. Give yourself a pat on the back when you do things for yourself.

- Reward yourself – be kind to yourself. Do things you like doing. Treat yourself to things that make you happy. When you feel ready, do something to help someone else. Soak up the enjoyment as much as you can!

- Write down the things you have learnt – what have you noticed about yourself in this time? What have you found hardest? How did you overcome the hard things? What did you find easiest? What does this tell you about yourself? What have you learnt about your life? What beliefs have you gained, let go of or are new to you? How might you use this knowledge in your future? If you write it down, you will see how you are gradually feeling better.

Note: It is not usually a good idea to make major life changing decisions in the first few months after the loss. It is often better to wait until your life is back in balance again.

Remember that others around you may be feeling grief too. You may be able to help them.

DOES GRIEF AFFECT PEOPLE DIFFERENTLY?

Sure does! Some people don’t like to make a fuss; others let everyone know how they are feeling. Men and women are treated differently in our society. This can mean they may express their grief differently. Different cultures and religions see death, loss and grief in different ways. How you express your grief and the meaning you give to loss will be in your own way, based on your own beliefs and view of the world.

I had never felt such grief and pain as when my little baby Stevie died. I was scared that I was going insane because I felt like dying. I was too afraid to tell anyone. Then I met a woman whose son had also died. She told me there was many a time she felt like dying but always found reasons to stay alive. Relief flooded through me. I wasn’t insane after all. Other people felt this way too. This was a natural feeling to the situation I was in.

– Tracy, 23 years

When you are grieving for someone or something you have lost, it is natural to feel that you are alone in this. Everyone in the world has to deal with loss. Know that you are not alone, and reach out to others. Some may not be good at supporting you, but all will understand what you are going through.

Resources

- Kids Help Line
  1800 55 1800
  www.kidshelp.com.au

- Youthbeyondblue
  www.youthbeyondblue.com

- Headspace
  www.headspace.org.au

Many people feel such intense emotional pain following a death that they wonder if they can survive. It may be hard to believe in the early days, but the pain does ease and thoughts about the person who has died become more comfortable and the happy memories are treasured.

Bereaved people may wonder how to get through their grief. The grief process is like a journey running from the starting point of bereavement to a new life. Progress is made through grief as the feelings are worked through. Freud called this grief work.

SOME STRATEGIES FOR DEALING WITH GRIEF

Grief time
Some people find it helpful to spend fifteen to twenty minutes alone every day. They put on the answering machine so they won't be disturbed. This time acts as a safety valve. In it they deal with any emotions they have stored up during the day.

There are different ways of grieving at these times: thinking, crying, praying, meditating, writing or drawing, talking to the dog!

Some people like to keep a diary. They write down their feelings and the memories of the loved one. They can then see how their grief changes over a period of weeks and months. This is proof of progress. If the diary is kept in a safe place the written memories become precious in the future. Alternatively some people feel more comfortable with pictures or diagrams.

Many people feel less alone by also grieving with other family members, including the children.

Tears
Many people find crying a relief. Rather than being an indication of weakness, tears are often a sign of strength and show that the bereaved person is prepared to work through their grief. Some people find it difficult to cry, and yearn for tears to release their grief.

Enlisting help
The process can seem long and lonely, so many people find someone whom they can confide in, for example, a relative or friend. Doctors or the local community health centre may be able to help in this way, or refer bereaved people to a specialist grief counsellor.

Some people find the experience of another person who has been through a similar situation invaluable, and so contact a support group.

Some other useful strategies
• Live a day at a time
• Do something special for yourself every day
• Do not make any major decisions, such as selling the house, in the first year if possible.

Some other strategies
• Talk to a caring friend, pastor or counsellor
• Join a bereavement support group

COPING WITH GRIEF

GRIEFLINK OFFERS SOME USEFUL STRATEGIES TO COPE WITH BEREAVEMENT
• Read books on grief
• Write letters to the person you have lost to express your feelings or as a way of saying goodbye. You can then keep these in a safe place, or bury them under a bush you plant in their memory, or scatter the pieces in a significant place
• Keep a journal as a record of your own journey of grief
• Create a memorial for the person who died: plant a tree, create a memory book or photo album. Children often like to collect items for a memento box
• Commemorate the person you lost on special days, such as birthdays, Christmas, Father's Day. Light a candle, drink their favourite bottle of wine, talk about them. Then go and do something special for yourselves – you deserve it! Plan these activities with the rest of the family.

Self care
Self care is important to prevent further stress to the body.

The following have been found to be helpful in coping with grief:
• A regular daily routine. Have set times for getting up, meals and going to bed.
• A balanced diet. Include: breads and cereals; meat, fish and dairy products; fruit and vegetables.
• Avoid too much coffee and tea to help you sleep at night.
• Outdoor activities, such as going for a walk or gardening take you away from the stress, and refresh you mentally.
• Exercise, such as swimming, walking and team games, will produce chemicals called endorphins in the body which help to counteract depression and make you feel good. The exercise does not need to be strenuous. If you have doubts about your fitness consult your doctor.
• Relaxation: meditation, massage, music.
• A relaxing pre-sleep routine: winding down before bed and not watching television.
• Avoiding seeking relief through alcohol, smoking, medication and other drugs.
• Consulting the doctor about physical symptoms, for a blood pressure check, for practical help, for medical certificates, and for help with the grief.

Be patient, tolerant and gentle with yourself as you grieve. It is important to seek professional help when you feel overwhelmed by your grief or memories. No one has to bear it all alone. There is help available.

HOW TO HELP SOMEONE WHO IS GRIEVING

AUSTRALIAN CENTRE FOR GRIEF AND BEREAVEMENT OFFERS ADVICE TO THOSE HELPING OTHERS WITH THEIR GRIEF

“When no one else could even meet my eyes one friend said, ‘I was so sorry to hear about Matthew.’ It meant so much to me then. And now over 30 years on, her courage and kindness still bring me comfort.” (Wendy)

There is no doubt that having the love and support of family and friends is one of the most important ways that grieving people manage personal crises and tragedies. There are many ways you can be supportive and helpful to people you know who are grieving. Your care and support is very important, probably more important than you realise. No one can take away the pain and sadness, but knowing that people care is comforting and healing.

SOME THINGS TO KNOW ABOUT GRIEVING PEOPLE

Grief is a personal experience; however, we can provide significant support and comfort to people during this time. Everyone grieves in their own way, and so long as there is no risk or harm to them or anyone else, there is no ‘right’ or ‘wrong’ way to grieve. It is important to remember that grief is a process, not an event. Profound grief is not something that we just ‘get over’, but rather is something that we gradually learn to live around as we continue to lead our lives.

Grief can make people very sensitive and they may react or respond in unexpected ways. Grief can be likened to having an open wound, and it can be easy for others to inadvertently ‘touch a nerve’ or say or do the wrong thing. There is no formula for what is right or wrong. What one person finds helpful, another person may not.

The most important thing is to make sure your friend or relative knows that you care. Find a way to show them this, perhaps by visiting, calling or texting them, giving food, bringing flowers, or sending cards and letters.

Death can be a difficult subject and it can be hard to know what to do or say to someone who is grieving, but don’t allow this to keep you away, as silence and distance can be very hurtful. If you feel you have made a mistake and perhaps said the wrong thing, it is never too late to say you are sorry. Don’t allow your relationship with your grieving friend or relative to be damaged.

Be patient

People who are grieving will not necessarily know themselves what will be the most helpful. This may be a new experience for them too. Try to offer support in different ways and at different times. If you are unsure, ask. For example you could ask: “Would you like me to do some shopping for you?” or “Would you like me to go to the cemetery with you?” Grief doesn’t have a timeline, so keep in mind that it may take some time, even years, for them to adjust to life without their loved one.

Keep in touch

Make sure your friend or relative knows you have not
Death can be a difficult subject and it can be hard to know what to do or say to someone who is grieving, but don’t allow this to keep you away, as silence and distance can be very hurtful.

forgotten about the person they have lost, or about them. Be prepared to reach out to them and be supportive on an ongoing basis. Even something as simple as a “how are you” text message can make a difference.

Be prepared to spend time listening
One of the greatest gifts you can give someone who is grieving is time and the ability to listen. Be prepared to listen if the person who is grieving wants to talk – even over and over about the same things.

Share memories and stories
Most people are glad to hear of ways that their loved one was remembered and valued by other people, and to have the opportunity to talk about them.

Don’t be afraid to use the name of the person who has died
As time goes on, the bereaved person will probably be glad to know that their loved one is still remembered and to have the opportunity to hear and say their name.

Encourage them to accept help and support
Encourage the person who is grieving to seek help from other sources too. Support groups, the internet, books, brochures, counselling or other professional help may be useful for them. Other comforting things might include distractions, meditation, relaxation and massage.

Take care of yourself
Listening and sharing someone else’s pain can be personally demanding and exhausting. Make sure you have good supports yourself and that you are not inhibiting your own capacity to grieve, whether it be for the person who has died, or for your own experiences of loss that may come back to the surface. You need to be fair to yourself, as well as the person who needs support, so be careful not to overcommit yourself.

HOW YOU CAN HELP SOMEONE WHO IS GRIEVING
You cannot ‘fix’ things for them, but there are a range of ways you can help, including:

- Offering to come over and just be there for them
- Listening and accepting strong emotions
- Showing that you care; a hug might be helpful, but check it out with them first
- Offering practical support, e.g. cooking, mowing the lawn, taking the kids to school
- Using their loved one’s name
- Sharing your memories and stories of their loved one with them
- Acknowledging birthdays, anniversaries, milestones and other significant occasions
- Asking how they are, both initially and on an ongoing basis
- Not saying “I know” or “I understand” unless you really do
- Avoiding platitudes – “It’s God’s will”, “They had a good innings”, etc.
- Not taking their responses personally – grief is an emotional rollercoaster and the reactions of the bereaved are not a personal attack on you
- Not avoiding them – while there are no words that can heal their pain, the absence of family and friends can make the pain much worse
- Encouraging them to make their own decisions
- Helping them find information and further help if needed.

WHEN TO SEEK FURTHER HELP
Although grief can be very painful, most people (85-90%) find that with the support of their family and friends and their own resources, they gradually find ways to learn to live with their loss, and do not need to seek professional help.

However, sometimes the circumstances of the death may have been particularly distressing, such as a traumatic or sudden death, or there may be circumstances which make the grief particularly acute or complicated. You could consider suggesting that your friend or relative seeks professional help if, over time, they seem to be finding it difficult to manage their day-to-day life.

WORKSHEETS AND ACTIVITIES
The Exploring Issues section comprises a range of ready-to-use worksheets featuring activities which relate to facts and views raised in this book.

The exercises presented in these worksheets are suitable for use by students at middle secondary school level and beyond. Some of the activities may be explored either individually or as a group.

As the information in this book is compiled from a number of different sources, readers are prompted to consider the origin of the text and to critically evaluate the questions presented.

Is the information cited from a primary or secondary source? Are you being presented with facts or opinions?

Is there any evidence of a particular bias or agenda? What are your own views after having explored the issues?

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MULTIPLE CHOICE 56
Brainstorm, individually or as a group, to find out what you know about end of life issues.

1. What is ‘palliative care’, and who is it provided to?

2. What is the difference between a ‘life-limiting’ illness and a ‘terminal’ illness?

3. What is advance care planning, and why is it important?

4. What is the difference between a ‘general’ power of attorney and an ‘enduring’ power of attorney?
Complete the following activity on a separate sheet of paper if more space is required.

Planning and making decisions about the end of your life can be a positive experience. It is a good opportunity to reflect on the things that are important to you, and to make arrangements that suit you.

Consider the above statement. Form into groups of two or more people and identify at least five things that you think would need to be considered when planning and making decisions about the end of your life. Using the space provided below list the things you have identified and explain how you would go about ensuring these things are considered. Discuss your ideas with other groups in the class.
Complete the following multiple choice questionnaire by circling or matching your preferred responses. The answers are at the end of this page.

1. Respond to the following statements by circling either ‘True’ or ‘False’:
   a. Fewer than 5% of people have an end of life plan. True False
   b. Heart disease, dementia, stroke, lung cancer and respiratory diseases are the leading causes of death in Australia. True False
   c. More than half of Australians die at home. True False
   d. Assisted dying is legal in Australia. True False
   e. Palliative care is care specifically for old people. True False
   f. If you don’t have an advance care plan doctors will make decisions based on what they believe to be in your best interests, which could include treatments you do not want. True False

2. Match the following terms to their correct definition:
   a. Funeral insurance
   b. Superannuation fund
   c. General power of attorney
   d. Will
   e. Substitute decision maker
   f. Advance care directive
   g. Enduring power of attorney
   h. Pre-paid funeral
   i. Funeral bond

   1. An investment product that can help you save for funeral expenses. Funds can only be withdrawn after your death to pay for your funeral.
   2. A document used to give another person the power to make decisions when you no longer have the capacity.
   3. A legal document outlining who you would like to make decisions about your health care and medical treatment.
   4. A person who can speak on your behalf with your doctors if you are unable to.
   5. A document used to temporarily give another person the power to make financial decisions on your behalf.
   6. A legal document that states how your assets will be distributed when you die.
   7. You pay monthly or fortnightly for a fixed amount of cover. Usually you can choose the amount of your cover which will be paid to your beneficiary when you die.
   8. You pay for your funeral and leave the details for your relatives to decide how the money is spent.

   MULTIPLE CHOICE ANSWERS
   a. True
   b. True
   c. False
   d. True
   e. True
   f. True
   g. True
   h. True
   i. True

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There are 7 types of cancers included in the top 20 leading causes of death, comprising lung, blood, colon, prostate, breast, pancreatic and skin cancers. Over the past 10 years, all forms of cancer combined have consistently accounted for close to 30% of all deaths (ABS, Changing patterns of mortality reflect ageing population). (p.16)

Suicide is the leading cause of premature mortality in Australia, occurring at a rate of 12.0 deaths per 100,000 people in 2014. This is the highest rate of suicide deaths recorded in the past 10 years, with previous rates ranging from 10.2 to 11.2 deaths per 100,000 people (ibid). (p.16)

The baby boomers are growing old and in the next 25 years the number of Australians who die each year will double (Swerissen, H and Duckett, S, A good death: Australians need support to die at home). (p.17)

More than half of Australians die in hospital and about a third die in residential care (ibid). (p.17)

Over the past 100 years, home deaths have declined and hospital and residential care deaths have increased. Even over the past decade, the hospitalisation rate for those aged over 85 increased by 35% for women and 48% for men (ibid). (p.17)

The AIHW’s recent update on palliative care services in Australia showed that over the past 10 years there has been a 52% increase in hospitalisations for which the main purpose of care is palliation (McCaffrey, N, To die at home or in hospital? Aussies want one but we fund the other). (p.20)

Voluntary euthanasia and assisted suicide are currently unlawful in Australia (Douglas, B, Willmott, L and White, B, The right to choose an assisted death: Time for legislation?). (p.29)

Research into how patients are treated at the end of their life found that more than a third of Australian surgeons reported giving drugs at doses higher than necessary to relieve suffering for terminal patients, with the ambiguous intention of hastening death (Saul, P, From ‘right to die’ to ‘right to choose the way you die’ – the shifting euthanasia debate). (p.30)

A number of studies indicate clinicians tend to be over-optimistic in predicting survival times. Research from 2011 indicated surgeons’ prognosis for survival time for patients with abdominal malignancies was accurate in 27% of cases, too optimistic in 42% and too pessimistic in 31% of cases (Winch, S, Lukin, B and Devereux, J, How much time have I got, doc? The problems with predicting survival at end of life). (p.33)

When someone dies, a doctor must sign a certificate that confirms the death. Funeral arrangements cannot be completed until the doctor has signed and issued this certificate. It is generally called a Doctor’s Certificate of Death. The funeral company can then take the deceased into their care (Department of Human Services, What to do following a death) (p.36)

Paying for your funeral can cost from $4,000 for a basic cremation to around $14,000 for a more elaborate casket, burial and flowers (ASIC’s MoneySmart, Paying for your funeral). (p.39)
Advance care directives
Documents containing instructions that consent to, or refuse, specified medical treatments and that articulate care and lifestyle preferences in anticipating future events or scenarios. They become effective in situations where the person is no longer able to make decisions. The documentation differs across Australian states and territories.

Advance care planning
The process of preparing for likely scenarios near the end of life that usually includes assessment of, and discussion about, a person’s understanding of their medical condition and prognosis, values, preferences and personal and family resources. Advance care planning supports patients in communicating their wishes about their end of life.

Bereavement
Bereavement is defined as a desolation through loss, especially when death is involved. It also pertains to being deprived of hope, joy etc. Bereavement is reserved specifically for the response to the death of a significant person in your life, whereas grief can be the result of incidents of loss not involving death such as the loss of job, loss of a limb, or the loss of status.

Caregiver
The primary person in charge of care of a patient, usually a family member or a designated health care professional. A person who provides care to those who need supervision or assistance in illness or disability. They may provide the care in the home, in a hospital, or in an institution. Although caregivers include trained medical, nursing, and other health personnel, the concept also refers to parents, spouses, or other family members, friends, members of the clergy, teachers, social workers, fellow patients, etc.

Cremation
Reducing a corpse to ashes by fire.

Depression
Depression is a common condition that has many forms. It may vary from a mild, long-standing sadness to a deep despair making it difficult to function from day to day. Depression affects how a person feels, thinks and behaves and it tends to impact on physical health. Often people feel empty, worthless, apathetic and irritable and they have a loss of pleasure in daily activities. People who are depressed often find basic activities such as sleeping, eating and thinking very difficult.

Enduring power of attorney
A legal document appointing another person to make decisions for you when you are no longer able to participate in the decision making.

Euthanasia
The deliberate action or inaction with the intent of ending a person’s life.

Funeral
The ceremony which is connected with the disposition of the body of a dead person.

Grief
A deep mental suffering or distress arising from affliction or loss and can also be in the form of a sharp sorrow or painful regret. It is often associated with bereavement and the death of someone close. Generally grieving is associated with death and dying, however, in recent years the association of grief is being recognised beyond simply death and dying. Grief can happen with any loss, being the deprivation of a meaningful relationship. Grief can be the response to death or loss regardless of intensity, for example in the case of the death of a relative, friend or pet, or even marriage, job, health, loss of a significant possession, lifestyle, role and identity.

Life-limiting illness
Used to describe illnesses where it is expected that death will be a direct consequence of a specified illness, but is not restricted to the terminal stage when death is imminent.

Loss
The state of losing or having lost; the privation, defect, misfortune, harm, etc, which ensues from losing. Loss can come into our lives in lots of ways and affect each of us differently. One of the biggest and most difficult losses is the death of someone important to you.

Mourning
Bereavement and mourning are sometimes used interchangeably when in fact a distinct difference exists between these two terms. Bereavement identifies the specific reactions experienced following the death of a significant other, whereas mourning refers to the way an individual displays his or her grief, and is the act of expressing grief, lamentation or sorrow over the loss of a loved one.

Palliative care
Care provided to people living with a life-limiting or terminal illness. The aim of palliative care is to achieve the best quality of life possible for patients and their families during the illness and after death by relieving symptoms, addressing emotional, social and spiritual needs and reducing suffering.

Power of attorney
When you appoint someone to make decisions on your behalf. This is generally done when people have a health condition that affects decision making or they think they may lose the capacity to make decisions in future.

Quality of life
Term used to describe a person’s perception of their position in life within the culture and value system he or she lives in and in relation to his or her goals, expectations, standards and concerns.

Terminal illness
An illness or condition that is likely to result in a death.

Will
Legal document which sets out how a person wants their belongings to be distributed after their death. The Executor of the Will is responsible for distributing the person’s assets to the people named in the Will. This happens after any debts are paid.
Websites with further information on the topic

Advance Care Planning Australia  http://advancecareplanning.org.au
Australian Centre for Grief and Bereavement  www.grief.org.au
Australian Centre for Health Research  www.achr.org.au
Australian Institute of Health and Welfare  www.aihw.gov.au
Bereavement Care Centre  www.bereavementcare.com.au
Better Health Channel  www.betterhealth.vic.gov.au
Beyondblue  www.beyondblue.org.au
GriefLink  www.grieflink.asn.au
Lifeline  www.lifeline.org.au
My Aged Care  www.myagedcare.gov.au
National Association for Loss and Grief  www.nalag.org.au
Palliative Care Australia  http://palliativecare.org.au

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