

Can we
talk about
the future?

Sure, just
don't mention
the asteroid



Discussion Starter

WORKING OUT WHAT'S RIGHT FOR YOU

dyingtotalk.org.au

dying to talk

Disclaimer

Palliative Care Australia (PCA) thanks The Conversation Project and the Institute for Healthcare Improvement in Boston, MA, USA. Their Conversation Starter Kit is in many ways the inspiration for this resource.

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Why talk?

Every day you make decisions.
Some are easy.

When do I need to get up?

What do I want to eat?

Who shall I call next?

Some are more difficult.

Will we have children?

When should I retire?

*How do I want to spend
my last days?*



So what if you unexpectedly became very sick? It might be hard for you to think about what treatment or care you may want. You might even be so sick that you cannot communicate. If that happens, your doctors and family may need to make decisions for you.

Planning ahead can be helpful and it is easier to do this planning when you are well. Talking about the type of health care you might prefer will help others to understand your wishes and help them to make decisions for you if they ever need to. Even though you might find this discussion a bit hard now, it will make their decisions less stressful later.

This guide will help you with that discussion. It will help you prepare, so that you know what you want to say and it will provide you with tips about how to start talking.

Talking about dying might be hard, but it won't kill you. You might even find that your family is *dying to talk*.

How to use this guide

The guide is broken down into small activities.

Activity 1: Reflecting

Activity 1 is all about reflecting on what is important to you. It allows you to think and prepare what you want to say.

You might find some of the questions too hard, or they might upset you. You don't need to answer every question and you don't need to write your answers down if you don't want to. This guide will help you think about what is important to you so that you can then tell those around you what you would like your future health care to be like.

Take your time. After you have completed Activity 1 you can decide when you feel ready to talk.

Activity 2: Talking

Activity 2 prepares you for talking with your family members. When we say family, we mean anyone close to you that you see as your family or close friend. This can be a difficult topic to start, so this activity will give you some tips on how you might want to introduce the topic.

Activity 3: Reviewing

Activity 3 will help you reflect after your discussion. It might have been easy, with you getting across everything you wanted to say. On the other hand, it might have been more difficult. You might decide to have many smaller conversations, rather than trying to get through it all at once. Just do what feels right to you.

Activity 4: Follow up activities

Activity 4 takes you through some activities that might support you in your planning. This includes writing down your wishes for end-of-life care. It also covers topics like organ donation and planning for what you want done with your social media accounts. Any early planning you do will make that difficult time easier for your family.

Appendix: Extra reflection prompts

At the end, there are some extra questions. If you aren't ready to talk at the end of Activity 1, take a look here. You might find these questions help you prepare what you want to say.

Activity 1: Reflecting

Give yourself some time to think about what is important to you and what you value in life. Remember, this is a personal reflection. You do not need to share these responses with anyone else unless you want to.

- 1) If you were very sick, how much information would you want to know about your illness? Information might include why you are sick, the treatment options available and the risks and benefits of different treatment options. Put a mark on the line to show your preference.

Only basic information about my condition and treatment
 All the details about my condition and treatment

- 2) How much information would you want your family to know about your illness?

Only basic information about my condition and treatment
 All the details about my condition and treatment

- 3) If you were very sick, would you like the doctors to provide you with (tick which one most applies to you):

- A best case picture of the likely outcome and chance of survival
 A worst case picture of the likely outcome and chance of survival
 A detailed explanation about likelihood of the best and worst cases and the most likely case
 Very little information about the likely outcome and chance of survival

- 4) How involved would you want to be in decisions about your care if you were to become unwell? Put a mark on the line to show your preference.

Doctors to decide about my care
 To be very involved in deciding on my care

Activity 1

- 5) Have you heard of a 'bucket list'? It is a list of things that you would like to do or achieve before you die. If other people understand what is important to you, it might help them make decisions for you if you were too sick to do that yourself.

What is on your 'bucket list'? An example might be a holiday, seeing your grandchild born, seeing your child graduate or getting married. Write them down here.

- 6) Sometimes treatment options can have very severe side effects. Think about whether you would want to have your life extended for a short time, even if this meant you might be sicker during that time. Mark on this scale which one is the most important to you.

Quality of life Length of life

- 7) If you were diagnosed with a condition that you could not recover from, would you prefer your care to be at (tick one):

- A hospital
- A hospice
- An aged care facility
- At my home or the home of a family member

- 8) How important is this preference to you?

Not very important Very important

- 9) If you were diagnosed with a condition that you could not recover from, are there other things apart from the location of care that may be important to you? For example, think about the following questions and write any notes that might help you talk to someone about your wishes.

Are there any pets that you would like to see or be with you, if this is possible?

Would you prefer a quiet environment or do you prefer activity and chatter around you?

Would you like music to be playing and if so, what style or what music?

If possible would it be important to you to have time outside?

Would you prefer to be surrounded by lots of family and friends, or would you prefer one or two closest people to be with you?

Are there any cultural or religious practices you would like to observe?

Is there anyone particular you would like to see or talk to?

Is there anything else you can think of that you would like?

- 10) When you die, do you want to donate your organs?
Write your answer and the reason for your answer below.

- 11) Thinking back on your responses above, what are the most important things about the kind of care you would want to receive? Some examples might include having time to say goodbye to my family, being at home, not being a burden on my family or not having treatment that might leave me unable to eat or walk. Make some notes here.

Not quite ready to talk?

If you aren't quite ready to talk and want to reflect on your values and how these might influence the care you want, check out the Appendix at the back of this workbook.

Activity 2: Talking

Now that you have reflected on what matters to you most, you need to decide who to talk to. You can tell them as much or as little as you like. Remember that knowing this information will help them if they ever need to make decisions for you about your health care.

Prepare by thinking about who you want to have this conversation with. Is it your spouse or partner, your child, your sibling, your doctor, a good friend or neighbour?

I want to talk to (write as many people as you like):

The three most important things that I want to share during this discussion are (tip: look at your answer to Question 11 from Activity 1 for some guidance):

1.

2.

3.

Before you start, think about when it would be best to have this conversation. It is best to find a quiet space, where you are not likely to be interrupted.

If you set yourself a target day, it may encourage you to jump in and start the discussion. Write down when and where you will talk below:

Activity 2

Here are some suggestions for getting the discussion started.

- 🗨️ “I have just filled out a questionnaire that I found online. It made me think about the things most important to me and how I would like to be treated if I got sick or was dying. Maybe you could do it too and we could compare answers”.
- 🗨️ “I really hope that [insert person] received the care they wanted to when they were dying. I’ve been thinking about the kind of care I would want.”
- 🗨️ “Now that you (or I) have been diagnosed with [insert condition], I want to make sure that we know each other’s wishes for care. Can we talk about this?”

Another way to broach the discussion is to link it with your Will or Enduring Power of Attorney.

- 🗨️ “I have just updated my Will. They asked me to think about who should make decisions about my care if I weren’t able to do so. I wanted to ask if you would do that? Maybe we should talk about how I would like to be cared for so that it would be easier for you to make those decisions.”

If it is going to be very difficult, you don’t need to cover everything in a single conversation. Maybe just start by talking about a story about healthcare or someone who has died that has been in the media. You could relate this to yourself.

- 🗨️ “I just read an article about [e.g., David Bowie] dying. It said he had his family with him when he died. When I die I hope that ...”

You could leave it there and then do this again once or twice more. When you are more comfortable, you could have a more detailed conversation.

Remember ...

Talking about dying won’t kill you. You might even find that your family is *dying to talk*.



Activity 3: Reviewing

Now that you have talked, how do you think it went?

- Did you feel like you were able to share your wishes?
- Are there other topics that you might need to cover in a future conversation?
- Are there other people you should also have this discussion with?

Make some notes below.

As with any difficult discussion, it is hard to communicate everything in one sitting. You have finished the hard part of raising the subject. If you can, talk regularly about values and how these relate to decisions about your health care. Remember, you can change your mind at any time. If you do, you should let your family know.

If you have no success in talking to your chosen person after a few attempts, you might need to talk to someone else. If they really can't talk to you, how can you be sure they will be able to make health care decisions for you?

Activity 3

Activity 4

Activity 4: Follow up activities

Talking to your family about your health care is very important. There are also some other activities you can do to plan for the end of your life. Planning can reduce the stress for your family at that difficult time.

1. Document your wishes

You might be sure that the person closest to you knows what you would want should they ever need to make decisions about health care for you. Having your wishes written down can help them and your doctor make sure your care aligns with your wishes.

An advance care plan is a document outlining your end-of-life health care goals and wishes. The Australian Government has developed a My Health Record, which is a place to electronically store important health information about you. You can upload your advance care plan to your My Health Record. This will ensure it is available when it is needed. You can attach this document or you can attach a legally recognised plan. To find out more talk to your doctor or go to palliativecare.org.au/advance-care-planning.

2. Identifying your decision maker

You may have spoken to someone about the kind of care you want at the end of

your life. You might have told them you want them to make decisions about your care if you can't do it. It is good to document this.

The person I would like to be making decisions for me if I am unable to do so is...

The reason for this choice is...

How will your doctors and family know who you have chosen to make those decisions? An Enduring Power of Attorney can legally identify a person as your chosen decision maker if you were no longer able to make decisions. This is particularly important where that person is not your legally recognised next of kin. You can find more information at palliativecare.org.au/advance-care-planning or talk with a solicitor, lawyer or financial planner.

3. Reviewing your Will

Do you have a Will?
Many Australians don't.

A Will is a legal document that communicates what you would like to have happen to your assets if you die. Not having a Will can create additional stress for your family. If you don't have a Will, or you haven't reviewed it recently, think about whether you should do that now.

If you can tell your family what you want, it might reduce arguments and stress at a time that will already be difficult for them.

If you are planning on taking out insurance, it pays to look carefully. Other options might include pre-paying for your funeral or having a savings account set aside to cover the costs of your funeral.

4. Organ and tissue donation

People who need an organ or tissue transplant are usually very sick or dying because an organ is failing. If you want to donate your organs when you die, you should register your decision. You should also make sure that your family know about your decision and about why it is important to you.

7. Letting a trusted person know where they can find things

If you have documents like an Advance Care Plan, a Will or life insurance policies, it is important your family can find them if you were not around. This may be a physical location or it may be on a computer.

Think about whether you want to tell someone where to find your documents and how they can access them.

5. Social media planning

Have you ever thought about what happens to your social media accounts when you die? Each social media platform (for example Facebook, Twitter, Instagram or Google) has its own rules about what to do with your account when you die. Palliative Care Australia has developed a guide to help you with this.

For more information visit
dyingtotalk.org.au

6. Funeral and burial planning

You might think that preparing for your own funeral is a bit morbid. While it might be hard for you, it will be harder for your family when you die.

Appendix 1

Appendix 1: Extra reflection prompts

One of the things I value most in life is...

Thinking back on my life, something that brought me great joy was...

One of the most difficult times of my life was...

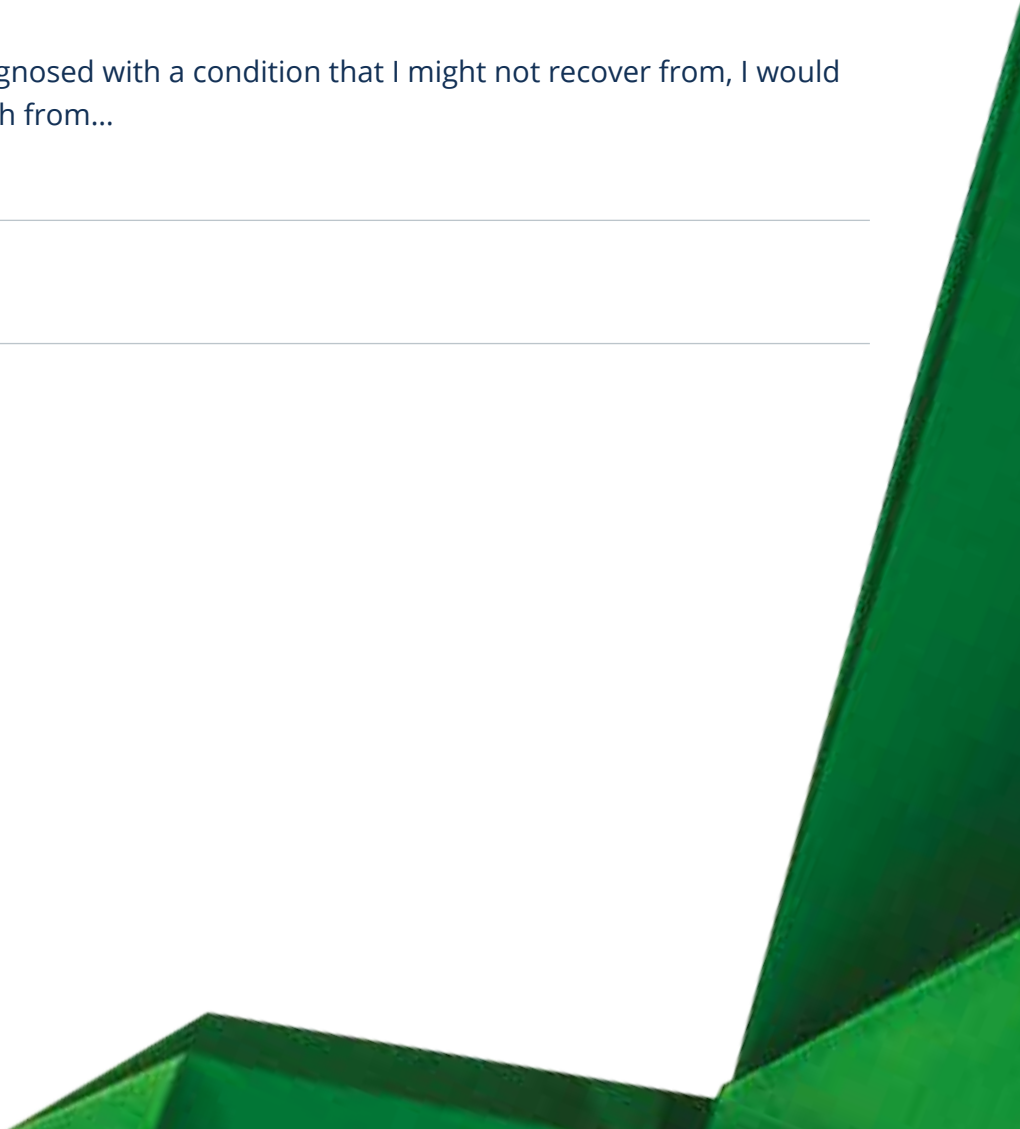
From the difficult times in my life, I have learnt...

I would like to be remembered for...

My greatest fear if I were very sick and may not recover would be...

I think my family and friends would react to me being very sick by...

If I was diagnosed with a condition that I might not recover from, I would get strength from...





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