



Dying to Talk Together

Activity Booklet



PalliativeCare
AUSTRALIA

A *Dying to Talk* initiative
Palliative Care Australia is funded by the Australian Government

“

We cannot control
the wind, but we
can direct the sail.

– Unknown



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What is Dying to Talk Together?

Every person will at some time plan ahead for something, be it a holiday or a significant life event such as a wedding or the birth of a child.

People understand the value of being prepared and how it can relieve pressure and stress when these events occur. Despite knowing how planning can help, most people are not comfortable discussing and planning for an event that will affect everyone: death.

It is never too early to start a discussion about what is important to you at the end of life. Talking now can help your family and friends in the future. It can help to make sure **you** receive the type of care that **you** want. These discussions do not just have to be about your medical care. They can also help you reflect on your values, the kind of environment you would want to surround yourself in, and how decisions would be made about your care.

It's not easy to talk about death and sometimes it's hard to know where to start, but in the trusted company of close friends, family and/or community, these conversations can be a little easier. 'Dying to Talk Together' has been created to support people to come together and have these important discussions.

This booklet contains some activities to support group of friends, family, associates, club members, or teammates, to talk about what's important at the end of life. It will cover the importance of planning, explore the role of the 'Dying to Talk' resources and support people to think about how they might start a conversation with someone they love.

The activities in this booklet have been designed for you to use as you choose. They are *suggestions only* and can be altered depending on what you think will work best for you and your group.

Note



This booklet contains activities only, for more information about Dying to Talk Together, and how to prepare for a session please review the Session Guide available at www.dyingtotalk.org.au.

If you have any questions about these activities or would like any further information, please call Palliative Care Australia on 02 6232 0700.

Part 1

Reflection

This section will help you introduce the discussion and highlight the importance of planning for the end of life. It contains activities to support your group to reflect on things that might be important in their lives, or their priorities if they were to become very ill.

Preparation notes



- All participants will need a notepad and pen, tablet, or mobile device to allow them to write down thoughts as they arise. Writing things down can be helpful both for the present conversation, and for later conversations with loved ones.
- The initial part of each activity is completed individually. However, if your group feels comfortable sharing their answers, you can expand to group conversations or split into smaller groups of 2-3.
- If you have not already completed the activities before the session, you can complete each activity at the same time as the group during the session.

Activity 1.1 Introduction

5 MINUTES



To get your group warmed up, you may choose to begin your session with a general open discussion. When you are ready to begin the activities, you can start off with some basic introductions and why you thought it was important to bring the group together to talk about the end of life.

You should explain that the process has been designed to be non-confronting and is intended to get people thinking and talking about the things that are important to them both in life, and in death.

Option 1: Personal examples

Highlight to your group some of the reasons why it can be beneficial to plan for the end of life. The Session Guide will help you provide some examples.

Key points may include:

- You never know what the future holds.
- Planning can allow you to have control over decisions about your care, even if you are unable to communicate.
- Planning can help reduce stress and support your loved ones to make decisions.

You might also like to provide some of your own personal examples. For example, why you felt it was important to talk about the end of life, and what prompted you to bring the group together.

Option 2: Jean Kittson video – “Why should I talk?”

If you have a computer or tablet available, you can play the video “Why should I talk?” available on **YouTube**. To find the video go to www.youtube.com and search for “Dying to Talk: Why should I talk?”.

This video explores Jean Kittson’s thoughts on the importance of talking about the end of life and the value of the Dying to Talk Discussion Starter.

When you are ready, hand out the *Dying to Talk* Discussion Starter booklets to your group. Explain that the Discussion Starter has been designed to support people to work out what is most important to them, and to think about how they might like to be cared for at the end of life. The reflections and discussions contained in the Discussion Starter are personal and are for sharing with loved ones.

Tip



Let your group know they can work through the Discussion Starter at home, when they are ready, but that today they will be doing some of the activities to begin thinking about their own priorities.

Activity 1.2 Identity and values

5-10 MINUTES



Many people spend a lot of time thinking about the wants and needs of others, but do not spend much time thinking about their own wants, needs and values. Helping your group to think about what is important to them may help prepare them for using the Discussion Starter and for talking to their loved ones.

Reflection activity



Ask the group: "What makes you who you are?"

Ask your group to think about the things that most shape their identity, or that define who they are as a person. This could relate to their occupation, role in their family, values or beliefs, hobbies, hometown, or their cultural or religious background.

The answers to this question will likely form the core aspects that will shape the care they would like to receive, and the environment they want to be in at the end of life.

If your group needs some extra prompting or ideas, a fictional example has been included below:

- My family means everything to me. I've been married to Michael for 25 years.
- I was born in Griffith, NSW, and have lived here ever since.
- I'm very proud of my Italian heritage and enjoy cooking from my own grandmother's recipe book.
- I am a nurse by trade, helping people gives me a sense of purpose.
- I love to read and try to read a book every few weeks. I think it keeps me sharp.
- I go to the local church every Sunday; my faith gives me strength to get through hard times.
- I love animals, and my two dogs are part of my family.
- Classical music always helps me relax and enjoy life.
- I love tennis. I still play most weekends for some exercise and a bit of fun.

Tip



Allow a few minutes for people to think about their answers, then open up for conversation. If no one speaks after a few moments, volunteer some of your own answers, and talk about why these things are important to you. Reassure your group they don't need to share publicly if they are not comfortable to do so.

Activity 1.3 Key priorities

10-15 MINUTES



Many people will have several key things they worry about as they get older, or if they become sick. Usually these relate to maintaining aspects of their life that make them most happy or avoiding those things which could bring themselves or their family pain.

It is important to take time to acknowledge these key priorities; to explore them while we are healthy; and to develop plans - so that when the time comes, we can put our plans into action.

Reflection activity



Ask the group: *"What would be your main priorities if you were suddenly to become very ill?"*

If your group needs some extra prompting or ideas, some fictional examples have been included:



Allow a few minutes for people to think about their answers, then open up for conversation. If no one speaks after a few moments, volunteer some of your own answers, and talk about why these things are important to you. Reassure your group they don't need to share publicly if they are not comfortable to do so.

Tip



Don't force anyone to share their concerns. It is ok to just start thinking about these things. Sometimes just knowing someone else is concerned about the same or similar things may encourage people to speak more openly with a loved one or a friend.

Activity 1.4 Self reflection – Option 1

10-15 MINUTES



This activity will introduce your group to some of the content within the Discussion Starter and will ask them to begin reflecting on various aspects of their life, in preparation for a conversation with their loved ones.

You'll need to ensure each member has a copy of the Discussion Starter before you begin the activity. An editable PDF of the Discussion Starter can be downloaded from dyingtotalk.org.au for anyone working from a laptop or smart device.

Reflection activity

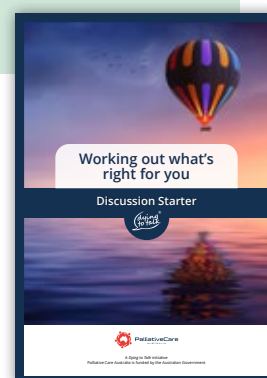


Ask the group: To consider the questions on page 7–8 of the Discussion Starter.

This activity will help your group to consider:

- What things are important to them
- What makes them happy
- What brings them strength
- What brings meaning to their life or gives them purpose
- Any cultural, religious or family traditions that are important.

Allow a few minutes for people to think about their answers, then open up for conversation. If no one speaks after a few moments, volunteer some of your own answers. Reassure your group they don't need to share publicly if they are not comfortable to do so.



This activity can be found on page 7–8 of the Discussion Starter.

Tip



Even if people are not ready to have a conversation with loved ones, this activity is a great prompt for working out what is important and what they might talk about when they are ready.

Activity 1.4 Self reflection – Option 2

10-15 MINUTES



This activity will introduce your group to the Discussion Cards. These cards have been designed as a non-confronting introduction to end of life discussions. They aim to remove some of the guesswork by providing some helpful prompts about things which might be important to people at the end of life.

You'll need to ensure each member has a set of the *Dying to Talk* Discussion Cards before you begin the activity. A digital version of the card activity is also available online via www.dyingtotalk.org.au/card-game, for anyone working from a laptop or smart device.

Reflection activity



Ask the group: To review each of the discussion cards.

Encourage the group to take a few moments to think about each card. When they have reviewed the whole set, have them go back through and put aside 5 cards which they feel are very important to them.

Ask the group to focus on the cards they have selected and consider **why** they might be important to them. What does each look like in practice?

Allow a few minutes for people to think about their answers, then open up for conversation. If no one speaks after a few moments, volunteer some of your own answers. Reassure your group they don't need to share publicly if they are not comfortable to do so.



Tip



If anything is not listed on the cards, there are blank cards in the set for people to write their own responses.

Check-in

To avoid overwhelming your group, now is a good chance to stop, check-in, and take a break.

You and your group have already made great progress, so congratulate them for their contributions so far.

Check-in with your group to see how they are feeling. Encourage them to take some time to chat amongst themselves, have a drink, or to go to the bathroom. This will help your group to refresh and recharge before the next activities.

Tip



Sometimes reflecting on healthcare can trigger an emotional response that requires support. If you or anyone in your group are feeling overwhelmed or depressed, or need support services, there are support services available:

Beyond Blue Support Service – phone 1300 224 636 (24 hours/7 days) provides free, immediate, short-term counselling, advice and referral to anyone in Australia via telephone, webchat or email 24/7.

Lifeline Crisis Support – phone 13 11 14 (24 hours/7 days) or chat to a crisis supporter online (7pm – midnight/7 nights). This is a confidential service providing support to anyone in Australia who is feeling overwhelmed, having difficulty coping, or thinking about suicide. This service also provides advice to anyone caring for that person.

GriefLine Community and Family Service – (phone 1300 845 745) listens, cares and supports people experiencing loss and grief, at any stage in life.

Talking about what you want in advance can help you and your loved ones make decisions when it matters most.

Part 2

The conversation

This section will help your group to begin thinking about having a conversation about their end of life preferences. Activities will encourage your group to consider who they might want to talk with and what they might like to share.

Preparation notes



- Encourage your group to write down their thoughts, especially as these activities are about preparing to have a conversation. Taking a few notes now will help them when it comes to having the conversation later.
- If your group includes family members or close friends, it's quite possible the people they want to have a discussion with are already in the room together. It's important to recognise this and allow open discussion when it occurs. However, the aim of these activities is to get people to begin *thinking* about the conversation. Group members do not need to discuss in detail during the session if they are not comfortable or would prefer to wait to have a private conversation.
- As in Part 1, the initial component of each activity is completed individually. However, if your group feels comfortable in sharing their answers, you can open it up for group conversation, or split into smaller groups of 2-3.
- If you have not already completed the activities before the session, you can complete each activity at the same time as the group.

Activity 2.1 Starting the conversation

20-30 MINUTES



Death can seem a taboo subject. As a result, most people do not want to talk about it. Even though these discussions might be hard, it doesn't mean we should avoid them. They can actually be very therapeutic, helping both you and your loved ones to better-understand your wishes, and reducing the stress which often comes with making decisions at the end of life.

This activity will support your group to think about who they might like to have this conversation with and how they might approach the discussion.

Option 1: Jean Kittson Video 2 – ‘Starting the Conversation’

If you have a computer or tablet available, you can play the video “Starting the Conversation” available on **YouTube**. To find the video go to www.youtube.com and search for “Dying to Talk: Starting the conversation with Jean Kittson”.

This video looks at Jean Kittson’s advice on how to start an awkward conversation and the importance of talking about end-of-life wishes.

Option 2: Personal examples

Discuss your own experience of having this discussion and how it helped you and your family.

Some key points from Jean Kittson’s video you might like to discuss with your group are:

Tip



Scheduling regular conversations can be useful to reflect on whether your priorities have changed, and enable you to adjust your plans for the future.

- There is no need to be afraid of the conversation. You may feel sad but that is normal.
- Having a conversation now can help reduce fear and stress for you and your family in the future.
- Many people assume their family already knows what their wishes are, without actually having the conversation with them.
- Planning what you might say before the conversation can be helpful. The Discussion Starter is a helpful tool supporting people to think about what is important both in life, and in death.
- You don't need to jump straight into confronting topics. Instead ease into the conversation by talking about things such as the music you like, the places you want to spend time, or the people and things you want with you).

Activity 2.2 Who, how and what?

20-30 MINUTES



Who you are speaking with can have a big influence on both how you approach the discussion and what you discuss. It can be helpful to think about the people in your life who you feel are most-likely to be in a position to support you at the end of your life, and put together a plan to have a conversation with them.

Reflection activity

Part A



Ask the group: To consider the questions on page 17 and 18 of the Discussion Starter

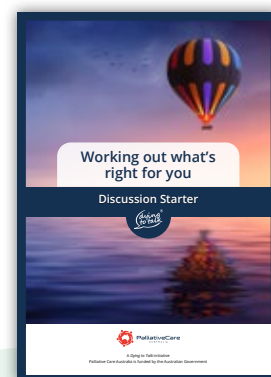
These questions will help the group think about who they would like to speak to, what they could talk about, and how they would you approach the discussion. The activities completed so far should help people answer these questions.

Explain that it does not need to be a formal conversation, nor does it have to be with their partner or a family member. It just needs to be a trusted person (or people) with whom they would like to share their preferences for the end of life.

Each person is unique, so each conversation will be different. Some examples of topics that people may want to discuss are:

- How decisions would be made
- Where they want to live or be cared for
- Medical care and treatment options
- Potential impact on their family and/or loved ones.

Once your group has had time to answer the above questions, open up the floor for conversation. Encourage your group to share and discuss their responses but reassure them they do not have to share publicly if they are not comfortable to do so.



This activity can be found on page 17-18 of the Discussion Starter.

Tip



If someone in your group doesn't have anyone who they feel comfortable with, suggest they book a long appointment to talk about it with their General Practitioner.

Part B



Ask the group: *“Why is it important for you to have this conversation?”*

As with any difficult conversation, people are likely to want to understand why there is a need to have the conversation in the first place.

Before initiating the conversation, it can be useful to think through some of the reasons you want to talk, so you can draw upon these reasons during the discussion.

Remember there are no right or wrong reasons for wanting to have this discussion. Each person’s reasons are likely to be unique to their own situation and circumstances.

Once your group has had time to answer the question, open up the floor for conversation. Encourage your group to share and discuss their responses but reassure them they do not have to share publicly if they are not comfortable to do so.

Tip



Talking about your wishes for the end of life does not mean the other person needs to talk about theirs. Even if the other person is not comfortable discussing their own wishes, it can still be a valuable experience for both parties involved. It may help strengthen a friendship or relationship; reduce their anxiety about making the right decisions for you; and it may prompt them to think about what is important to them.

Home activity

Encourage your group to complete Part 2 of their Discussion Starter at home and have a discussion with their chosen person/people.

Tip



- Setting a date and time is helpful. When would it be best to have this conversation? It is best to find a quiet space, where you are not likely to be interrupted.
- Having the conversation may reveal that you and your loved ones disagree. That’s normal. It’s important to be aware of this and to continue talking about it now—not during a medical crisis.
- You don’t need to cover everything in a single conversation. When you are comfortable, you can have a more detailed conversation, or several short conversations if that is easier.
- Keep your completed Discussion Starter with you so you can refer to it throughout your conversations if you need to.

Part 3

At Home

This section provides a brief overview of some of the next steps and activities people may like to consider following a Dying to Talk Together session. It also provides some final comments to help you bring your session to a close.

Preparation notes



- These additional planning activities will be unique to each individual so participants should only explore those things that are relevant to their own circumstances.
- The session has already covered some significant ground. If it seems like your group has reached its limits, it's OK to finish up your session here, and encourage your group to review some of the resources on the PCA website in their own time.
- Whether you continue with the discussion now or not, group members may still find it helpful to make some notes about additional things they want to explore before they leave. Jotting some thoughts down while the discussion is fresh will help when they come back to it at a later date.
- If you do decide to continue with the discussion, allow some time for people to consider the different topics individually, and then if your group feels comfortable open it up for group conversation, or split into groups of 2-3.

Activity 3.1 Other planning activities

5-10 MINUTES



You've already come so far and taken some big steps towards starting a really important discussion. The activities you've completed have hopefully got you thinking and given you some ideas about what is important and what you may want for your own end of life. But this is just the beginning, and there are other things you might like to consider before you have that next conversation.

These might include:



Palliative Care Australia has a number of resources containing helpful information about these and other topics, which may help you build a more complete picture of your end of life care. Encourage your group to review these resources and go through the additional planning activities in their own time.

All Dying To Talk Together resources are available to download and print from the Dying to Talk Together webpage at www.dyingtotalk.org.au.

Tip



If you have some extra time in your session, feel free to talk about the importance of these activities and why they should be considered. If your group has any questions you can direct them to Palliative Care Australia for more information.

Closing comments

5-10 MINUTES



You've reached the end of your Dying to Talk Together discussion; an important and challenging step which has likely got your group thinking about things they had never previously considered. Take some time to acknowledge this and congratulate your group for their contributions.



Ask the group: *How they felt with the day's discussion, and what were their key takeaways?*

If you are comfortable to do so, you can facilitate any questions your group might have. You may like to refer to the FAQs available in the Session Guide to help you to answer these questions, or you can direct them to Palliative Care Australia for more information.

Encourage your group to go back through the Discussion Starter and Card Activity in their own time and to have a conversation with someone about their end of life wishes. Remind your group that the more information they share with their loved ones, the better equipped they will be to make decisions on their behalf.

Jane Kittson Video: "Three Things"

If you have a computer or tablet available, you can play the video "Three Things" available on **YouTube**. To find the video go to www.youtube.com and search for "Dying to Talk: Three things that are important to Jean Kittson".

In this video, Jean Kittson outlines some of the things that are most important to her at the end of her life. She provides several great examples which may inspire your group to consider aspects of their own end of life they may not have thought of.

The video is a nice way to wrap-up your discussion and demonstrates the kind of outcome the Discussion Starter aims to support people to achieve.

Tip



Even if you're not quite ready to have a conversation with someone else, you can still start to think about these topics. Take some time to go through your Discussion Starter. When you are finished store it away somewhere safe, and tell someone where it is. This way, if you were no longer able to communicate, there would be a record of things that are most important to you. However, remember that this document is not considered to be an Advance Care Plan, and therefore is not legally binding.

Notes

Help



For more information about Dying to Talk Together:

- Visit www.dyingtotalk.org.au
- Contact Palliative Care Australia P: 02 6232 0700
E: pca@palliativecare.org.au with **Subject: DTTT**



PalliativeCare
AUSTRALIA

Palliative Care Australia (PCA) is the national peak body for palliative care. PCA represents all those who work towards high quality palliative care for all Australians.

Working closely with consumers, our Member Organisations and the palliative care and broader health, aged care and disability care workforce, we aim to improve access to, and promote the need for palliative care. More information is available at palliativecare.org.au



palliativecare.org.au

Palliative Care Australia is funded by the Australian Government