

# Dying to Talk Together

## Session Guide



**PalliativeCare**  
AUSTRALIA

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

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# What is Dying to Talk Together?

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Every person will at some time plan 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 with, 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 Session Guide has been developed to help you to bring together a group of friends, family, associates, club members, or teammates, to talk about what is important to them at the end of life. It covers the importance of planning; exploring the role of the *Dying to Talk* resources; and helps support your group to think about who they might like to talk with about this subject matter and how they might start the conversation.

The Session Guide has been designed for flexible use to meet the needs of different groups. It steps you through some key points to think about before bringing your group together and provides you with tips and information to support you and your group throughout the conversation.

## Help



If you have any questions about this Session Guide or would like any further information, please contact **Palliative Care Australia** or engage with the palliative care organisation in your state.

For information about the palliative care organisation in your state go to [www.palliativecare.org.au/members](http://www.palliativecare.org.au/members)



# What Australians think about preparing for the end of their lives

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Palliative Care Australia (PCA) commissioned a national survey for National Palliative Care Week 2020, which indicated that Australians are not preparing for the end of their lives while they have the opportunity to.

The survey of 1,003 Australians, conducted by Pure Profile, found that over eight in ten Australians think it's important to talk about their end-of-life care wishes, but only one in two have done anything to share these wishes.

The results of the survey highlighted a disconnect between what people think and what people do. 84% of people agree they should plan for their end-of-life care, with key benefits of planning being identified as:

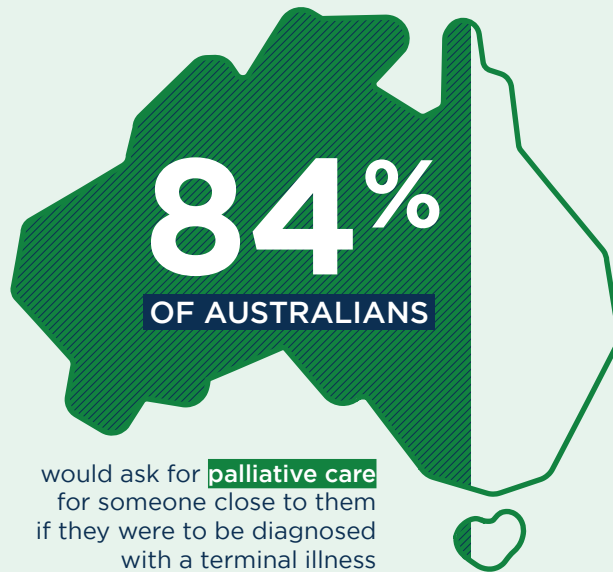
- Control over their care
- Having a say in where they spend their final days
- Reducing the stress on loved ones.

Some Australians have a documented plan in place. Of those who have documentation in place:

- 45% have a will
- 21% have a power of attorney
- 19% have a nominated person to make health care decision
- 9% have an Advance Care Directive and 6% have an Advance Care Plan.

These results are consistent with previous surveys conducted by PCA and support the need for resources that assist people to start conversations about the end of life.





84%

of people consider it is  
important to start thinking  
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YET

54% of people **have not done anything**  
to share these wishes



45%

have a  
**will**



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have a  
**power of attorney**



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decision



9%

have a  
**Advance Care Directive**

# The Dying to Talk Initiative

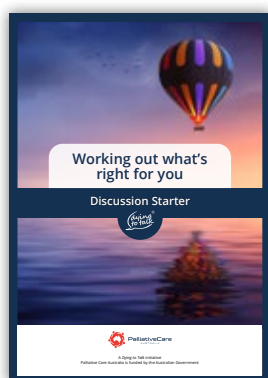
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The *Dying to Talk* Initiative, launched by PCA in 2015, encourages Australians of all ages and health statuses to talk about their preferences at the end of life, for quality of life until death.

The initiative aims to normalise conversations about death and dying, helping Australians to work out what's right for them at the end of their lives. With more clarity, conversations can lead to better support for people nearing the end of their life, and assists in reducing stress for loved ones.

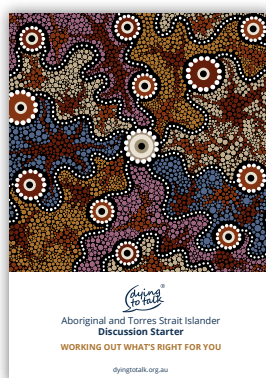
The *Dying to Talk* resources include a Discussion Starter booklet, a Discussion Cards pack, and a Facilitator Guide for relevant health or care professionals. Currently (2020) there are three versions of these resources, with each having been co-designed to support discussions with a specific audience.

The *Dying to Talk* resources available include:



## Working out what's right for you

For general and rural populations



## Aboriginal and Torres Strait Islander

Supporting Indigenous Australians to plan for the end of life



## What Matters Most

Supporting older people to work out what's right for them

'Dying to Talk Together' is the next expansion of the initiative. It aims to support groups to come together within their own communities, to have conversations about what is important to each person at the end of life. This work has been developed from a pilot originally rolled-out in collaboration with the Country Women's Association of Australia in 2017.

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Talking about dying might be hard, but it won't kill you. You might even find your loved ones are dying to talk.

## Reasons you should begin planning now

1

### **You never know what the future holds**

Whether you are thinking about travel, retirement, or your health, it is never too early to make plans

If you were to unexpectedly become very sick, do you know what might be most important to you? Is fresh air important? What about seeing your animals? Or sharing meals with your family?

It might seem hard to think about the end of life but making plans can be much easier when you are healthy and will support you and your family to make important decisions when the time comes.

It can be difficult to know what type of care you might want, or even what options there are. Planning also gives you the freedom to explore the many ways palliative care can support your quality of life, throughout illness and at the end of life. It might be a little difficult for you to think about these things now, but during a time of crisis it can be even more challenging.

2

### **Talking now means you can have input into decisions about your care, even if, in the future, you became so sick that you could not communicate for yourself.**

End of life planning can be a therapeutic and empowering experience because it allows you to have control over your health and wellbeing, even if you become unable to communicate.

Planning for the end of life allows you to choose:

- The type of treatment or care that you want, and where or when you want it
- Where you would like to spend your final days and who you would like to be with you
- If you would like your children and/or pets to be involved in your care
- If you would like to become an organ or tissue donor
- The type of funeral or burial you would like
- Who you would like to leave your estate and/or specific belongings to.

3

### **Putting a plan in place can support your loved ones to make decisions**

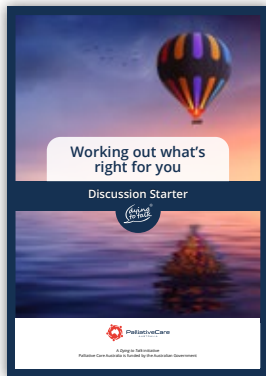
Talking now with your loved ones about your values, wishes and preferences for the end of life, can ensure that they are able to make informed decisions for you that reflect your wishes.

Family members often say it is hard to make decisions for their loved ones if they didn't receive enough (or any) information from them at a time when they were able to clearly communicate. On the other hand, 99% of Australians who had to make healthcare decisions on behalf of a terminally ill loved one found that knowing their end-of-life wishes was important. Talking with your loved ones can make a very stressful time just a little easier. The more information you provide, the more confident they will be to make decisions for you.

# Using The Dying to Talk Resources

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The Dying to Talk resources aim to support people to think and talk about the end of life. The activities are intended as an introduction to the discussion, encouraging people to consider what is most important to them, and then to begin planning.



## Discussion Starter Booklet

The Discussion Starter is an important tool to help people begin to document their wishes and plan for the end of life. It contains a range of activities that will guide you through:

- Reflecting on the things that are important to you and what your care might look like
- Having a conversation with a loved one about your wishes
- Planning other important decisions and activities



## Discussion Cards

The Discussion Cards are a good introductory tool to help people start thinking about what might be important to them.

Starting a conversation or even thinking about the end of life can be difficult, and sometimes it can be hard to even know where to start. The Discussion Cards provide some helpful prompts about topics which might be important to a person at the end of life. A person can go through the deck of cards alone or with a family member or close friend to identify those things which are most important to them.

### When using the Discussion Starter and Discussion Cards it is important to remember:

- There are no right or wrong answers
- You don't need to answer all questions, only the ones you are comfortable to answer
- You can skip and return to questions once you have had time to consider
- You can go through the questions in any order
- It is OK to change your mind
- It is OK to feel sad, uncertain, or any other emotion
- You can stop at any time.





### *Tip for those running sessions*



Take some time to go through the Discussion Starter and Discussion Card Activity for yourself before you bring your group together. If you are comfortable to do so, you might find that sharing your own responses could be a good icebreaker, and a great way to encourage your group to share their own.

# Key pointers for running a Dying to Talk Together session

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It is important to be well prepared before you bring your group together for a Dying to Talk Together discussion. Below are some points to consider before the session:



## Prepare yourself

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- Familiarise yourself with the Discussion Starter and Discussion Card Activity and review the supplementary Session Guide available at [dyingtotalk.org.au](http://dyingtotalk.org.au)
- It can be helpful to consider how you might respond to different activities so you can provide examples to get the conversation started.
- Take note of your own feelings, emotions and assumptions so you can help guide your group through these activities.
- Practice verbalising your responses to increase your familiarity and comfort level in using terms like 'dying', 'death' and 'end of life'. You can still be sensitive and compassionate while being direct.



## Setting the scene

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- Participation in a Dying to Talk Together session is voluntary. **People should never feel pressured** to participate.
- When scheduling the meeting, you should **clarify its purpose** and confirm each person is aware that you plan to talk about subjects related to the end of life. These kinds of conversations can be confronting for some people so it's important they are able to make an informed decision about their participation.
- Ensure your group knows the purpose of the session is only to begin exploring what is important to them, and what their care might look like at the end of life. They **don't need to have all the answers** already.
- You **don't need to be elderly or nearing the end of life** to participate. Discussions about end of life wishes don't need to be in response to a crisis. Putting a plan in place early will not make it happen quicker, but it will allow you to be prepared if something unexpected were to happen.



## Time and place

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- **Arrange a quiet location** or somewhere you can minimise disruptions. Depending on the characteristics of your group, this can be a helpful step to create a safe environment where people are open to share their thoughts. Of course, if your group is comfortable, you can always hold a session at your local bar or café, but it is best to check this with your group beforehand.
- To allow enough time to cover all the activities, we suggest you **set aside about 90 minutes** for the discussion. You might like to block-out extra time in case the session runs longer (e.g. if you spark productive discussions, or if someone becomes distressed and you need to provide support).



## During the session

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- Remember there are **no right or wrong answers**.
- Some people feel more comfortable using euphemisms such as 'passing away', but it is okay to use the words 'die', 'died', 'death' and 'dead'. Use whatever you think is most appropriate for your group.
- **Provide your own examples** to help get the conversations started.
- **Scheduling breaks** between activities can be a great chance for your group to unwind, chat amongst themselves, or go to the bathroom, allowing participants to be refreshed and ready for the next activity.
- **Allow time for questions** and open discussion throughout the session and also at the end of the session.



## Handling emotion and tough conversations

- Remind your group they do not need to participate in every activity. It is ok to remove themselves from a conversation at any time.
- It is normal for people to feel emotional during the discussion. **Allow time for pauses and acknowledge emotions** that are expressed during discussions.
- Don't feel like you need to take on a counsellor role yourself. Sometimes you just need to allow a person some space or **make yourself available to listen**. When in doubt, you can refer a person to a telephone support service such as 'Lifeline' via their 24-hour support line on 13 11 14.
- **Take time for yourself** throughout the session (or as needed). These can be challenging discussions and it's important to take care of your own wellbeing as well as that of your group. Have a cup of tea or take a moment away from your group to help reset and prepare for the next part of the session.

### Help

For more information about Dying to Talk Together:

- Visit [www.dyingtotalk.org.au](http://www.dyingtotalk.org.au)
- Contact Palliative Care Australia  
P: 02 6232 0700  
E: [pca@palliativecare.org.au](mailto:pca@palliativecare.org.au)  
with **Subject: DTTT**



## Everyone is different

- Not everyone will be comfortable with the discussion. It's important that you **allow each person to progress at a pace they are comfortable with**.
- Some people may choose to bring a support person with them, someone they trust and can confide in. This may be helpful for them both during the session, but also when they return home where the conversation may continue.
- There may be many reasons why people may be hesitant to think or talk about death. These could include:
  - Cultural or religious traditions
  - Fear of dying
  - Belief that they are too young
  - Belief that they are too healthy
  - Reliance on others to raise the conversation
  - History of trauma and/or abuse
  - Not wanting to upset others
  - Not having anyone to talk with.
- You don't need to know specific details about every person's background before the meeting, but just remember **everyone's experience will be unique to them**, and each is equally important to acknowledge.
- Each person will differ in the level of information they share but it should be acknowledged that this conversation is an important milestone. **Each person needs to be treated with respect** regardless of what or how much they share.



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

– Unknown



# Frequently Asked Questions

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The following section provides you with some tips to help you run your Dying to Talk Together session.

It includes answers to Frequently Asked Questions about Dying to Talk Together, and covers a range of topics relating to why you should run a session, how to bring your group together, where to run your session, how to handle difficult conversations, and numerous other helpful topics.

## Questions about why run/participate in a session



### ***I'm young and healthy, why should I talk about death now?***

Imagine if you were to unexpectedly become seriously ill or injured. During this stressful time, it might be hard for you to think clearly about what you want. You might even become so unwell that you are unable to communicate. If this happens, your doctors and family may need to make decisions for you. Planning can be helpful for both you and your loved ones, but it is much easier to do this planning when you are well. Talking about your preferences and the type of health care you want will help others understand your wishes and help them to make decisions for you if they need to.

### ***How could a Dying to Talk Together session help me and my loved ones?***

Talking about death and dying can be difficult, and sometimes it's hard to know where to start, but in the trusted company of close friends and family these conversations can be a little easier. Dying to Talk Together aims to eliminate some of the guess work, supporting people to come together and guiding them through how to have these important discussions. You might find this discussion to be challenging, but it can make future decisions much less stressful for you and your loved ones.

### ***Why should my community organisation get involved?***

We recognise the powerful connections and relationships that are developed through the many wonderful community organisations in Australia. Community organisations and associations, such as the Country Women's Association of Australia, Rotary Clubs, Lions Clubs, sporting clubs, etc. are the fabric of strong and resilient communities. These groups are often like extended families and therefore can be the perfect environment for discussing tough topics such as the end of life.



## Questions about what is involved in a session



### ***What is involved in a session?***

A Dying to Talk Together session helps to guide participants through a series of activities exploring:

- The importance of talking about dying, planning, and the role of the Discussion Starter resources.
- Things that are important, both now and at the end of life.
- What end of life care might look like, who might be involved, how decisions are made, and the care setting in which it takes place.
- Tips for starting the conversation, and considerations about what to say to loved ones or health professionals.

### ***How long is a session?***

To allow enough time to cover all topics we encourage you to set aside about ninety minutes. Time will vary depending on the group size and the depth of discussion. Ultimately, take as much time as you need.

### ***How much does it cost to run a session?***

Running a Dying to Talk Together session is completely free. PCA will provide you with all the resources you will need, and the session can be held anywhere your group will be comfortable having the discussion.



## Questions about who can be involved



### ***How many people can be involved in a session?***

The Dying to Talk Together sessions can be as small or large as you like. You can hold one with a group of friends, at your next family gathering, or at the next meeting for your community organisation. It is often wise to have just enough participants that the person/people running the session can check in with each participant across the session.

### ***Is the session appropriate for people who have already been diagnosed with a life-limiting condition?***

It's never too late to have a conversation about your end of life care. Many people do not have a plan in place and are not aware of the services and care that is available through palliative care services, or at the end of life. Participating in an activity like this can be helpful to get them thinking about their preferences, and a good step towards accessing care that reflects their wishes. If they are unable to attend themselves, a family member or close friend could participate instead and pass on resources and ideas.

### ***Is there an age limit for participants in my session?***

There is no age limit to participate in a Dying to Talk Together session. People of all ages die and it's important for everyone to plan. However, these resources have not been designed for use by children, or those under 18 years, and given this, the subject matter may be distressing for this group. If you plan to include members under the age of 18 in your session, you should seek parental/guardian permission. Parents who would like to explore these concepts with their children are encouraged to participate in a session themselves and take home resources to discuss as appropriate within their home environment.



## Questions about how to run a session



### ***What will I need to run a session?***

Everything you need to run a session is available at [dyingtotalk.org.au](http://dyingtotalk.org.au). This includes digital copies of this Guide, the Dying to Talk Together Activity Booklet, Discussion Starter Booklets, Discussion Cards and more.

### ***Can I deviate from the activities to run a more informal discussion?***

Your session does not need to run in a structured manner. The activities provided are only a suggested starting point. Follow the journey that feels natural with your group and refer to the resources when you need more guidance. Just starting a conversation and beginning to think about what might be most important at the end of life is a success!

### ***Who can lead a session?***

The Session Guide and Activity Booklet have been put together in a way so that anyone can lead the discussion. You can do it on your own, with a friend, or your whole group can take turns to lead different activities. Follow a structure that suits the needs of your group, and your own comfort levels.

### ***Where should I hold my session?***

You might find some of the topics of conversations are quite personal, so a private space is ideal to foster an open and productive discussion. Many towns will have a library or community centre where you can book a room; you could hold a session outdoors at your local park; or you might find someone in your group who is willing to host a group at their home. Alternatively, if you and your group are comfortable to do so, you could find a space at a local café, or pub, and hold your session over a meal.

### ***What should people do after a session?***

The Dying to Talk Together session is just the starting point. Participants are encouraged to take resources home to complete in their own time. They may also wish to start a conversation with their family or GP to update them on their decisions. Completed Discussion Starter Booklets should be stored somewhere they can easily be located if needed. Remember, what is important to people can change over time. So perhaps every couple of years, or if life circumstances change, people should go back and review their answers and make sure they still reflect their wishes.

## Questions about resources



### ***Can I order printed resources?***

You can order up to 20 printed copies of the Discussion Starter Booklets and Discussion Card Sets at [dyingtotalk.org.au](http://dyingtotalk.org.au). If you would like printed copies of the Session Guide and Activity Booklet you can also include these when you place your order.

### ***Does the Discussion Starter Booklet serve as an Advance Care Plan?***

No. None of the 'Dying to Talk' resources or forms provided by Palliative Care Australia should be considered as a substitute for the prescribed or recommended 'Advance Care Plan' forms of each state or territory.

All resources provided by Palliative Care Australia are for the purposes of providing information in relation to advance care planning and palliative care. All information provided is general in nature and people should consult their health professionals for advice about their specific circumstances, including the legislative requirements of advance care planning in their state or territory.

For additional information relating to advance care planning, please speak to your health professional, visit the Advance Care Planning Australia website [www.advancetocareplanning.org.au](http://www.advancetocareplanning.org.au) or call the Advance Care Planning Advisory Service on 1300 208 582, 9am – 5pm (AEST) Monday to Friday.

### ***Are there any resources about what palliative care is?***

There is lots of information about palliative care on the PCA website. Check out the "What is palliative care" page at [palliativecare.org.au/what-is-palliative-care](http://palliativecare.org.au/what-is-palliative-care), which includes a range of multilingual brochures. You can also go through some the Frequently Asked Questions about palliative care at [palliativecare.org.au/frequently-asked-questions](http://palliativecare.org.au/frequently-asked-questions).

### ***Does the resource cover religious or cultural beliefs?***

There are many religious and cultural beliefs and practices that are associated with death and the dying process. While the resources are intentionally general in nature, and applicable to the Australian population irrespective of cultural or religious beliefs, there are some questions and activities which will provide participants an opportunity to consider and discuss their own individual beliefs.

### ***Are the dying to talk resources available in any other languages?***

The Discussion Started Booklet most commonly used in Dying to Talk Together sessions is the 'Working out what's right for you' resource, developed for the general and rural populations. This resource is currently only available in English. However, there are other versions of the Discussion Starter booklet and Cards available. Specifically, the 'What Matters Most' resource, which has been designed for older populations and people living with dementia, has been translated into ten different languages and would act as a substitute resource. Translated resources are not available in hard copy, however they are available for download via [www.dyingtotalk.org.au](http://www.dyingtotalk.org.au). There is also an Aboriginal and Torres Strait Islander version developed in collaboration with the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM).

## **Questions about handling difficult situations**



### ***How can I encourage people to get involved?***

Bringing a group of people together to exclusively talk about death might seem like a challenge, but it doesn't need to be as daunting as it can seem. Holding your session in conjunction with another activity, such as a dinner party, high tea, or over a few beers, can be a good way to break the ice and help people to feel comfortable and lower any anxiety.

Similarly, don't feel like you need to jump straight into the discussion. It's also ok to wait until your group is warmed-up a little before you begin. You might also find some people are uncomfortable with the use of language like death or dying; instead you could let your group know it's an opportunity to explore what would be most important to them if they became really unwell or injured, especially at the end of life.

### ***What if we get off track? Does the whole session need to be about death and dying?***

This is as much about a quality life as it is about a quality death, so don't feel that the focus needs to be on the death aspect throughout the entire session. The most productive 'breakthroughs' will often come during conversations about other completely unrelated subjects, when people are feeling most comfortable talking. Follow where the groups conversations take you, but every now and then bring focus back to the original question or activity.

### ***What should I do if people aren't participating in the session?***

Not everybody needs to contribute to every question or activity, and sometimes just listening to others talk will be enough to get them thinking about their own values and wishes. Talking about death and dying can be difficult for many people. While we do encourage people to explore subjects they might not have previously thought about, it's also important not to push people beyond their limits on any given day.

### ***What should I do if someone begins to dominate the discussion?***

There may be situations where one individual begins to take-over the discussion. While it is important that you allow this person the opportunity to share, it is equally important to ensure everyone in your group has the same opportunity. If you feel other members of your group are not able contribute (and they would like to) you can politely interrupt during natural breaks in the conversation, and direct follow-up questions to different people in the group. You may find that using a statement or idea from the individual who was speaking, and directing it to the group for comment, can be a good way to transition the conversation more smoothly. Remember some people may not want to contribute yet may still benefit from just listening to the other members of the group.

### ***What should I do if members of my group become distressed by the conversation?***

Discussions about the end of life are likely to bring up a range of different emotions for people. It's important to allow room for the expression and acknowledgement of these emotions during your discussions. Some people may need to leave the room to take a few moments for themselves. You do not need to take on a counselling role yourself. Sometimes it's enough to let them know you are available to listen if you are comfortable to do so.

Alternatively, where appropriate, you could also refer them to a support service. For example **Lifeline** (13 11 14), and **Beyond Blue Support Service** (1300 224 636), both provide free, counselling, advice and referral to anyone in Australia via telephone, webchat or email 24/7.

### ***What if our conversations stir-up emotions of grief due to the past death of a loved one?***

These kinds of discussions often lead people to think about their own past experiences with friends and family who have died. This can be distressing for some people especially if their past experiences were not positive. If members of your group do become distressed whilst discussing the loss of a loved one, you could refer them to Grief Line on 1300 845 745 (6am-2am 7 days/week) or online counselling at [www.griefline.org.au](http://www.griefline.org.au). The Australian Centre for Grief and Bereavement is also available on 1800 642 066 or via [www.grief.org.au](http://www.grief.org.au)





## Questions about the role of Palliative Care Australia (PCA)



### ***Will you send someone to run a session?***

Palliative Care Australia (PCA) has developed this Dying to Talk Together Session Guide and the Activity Booklet to empower individuals to be champions in their own communities by leading their own discussions.

While PCA does not deliver 'Dying to Talk' sessions directly, you're never in it alone. You can always contact PCA for support as you prepare for your Dying to Talk Together session, or to follow up on any outcomes.

Additionally, many of the state and territory based palliative care peak organisations do support or deliver sessions directly. You can contact your local organisation to seek advice for engaging with your specific community, or to discuss their services. The details of the palliative care peak organisation in your state or territory is available at [www.palliativecare.org.au/members](http://www.palliativecare.org.au/members).

### ***Do I need to inform Palliative Care Australia before I hold a session?***

The Dying to Talk Together resources have been developed with funding from the Australian Government, so for our reporting purposes, we do ask that you register your session via by emailing us at [pca@palliativecare.org.au](mailto:pca@palliativecare.org.au).

We would also love to hear about the wonderful work you are doing in your community, and share your experiences if appropriate. Tell us about what you have planned, or if you have already held a session, let us know how it went! Please use #dyingtotalktogether and #palliativecare on any social media you post.

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## Help



For more information about Dying to Talk Together:

- Visit [www.dyingtotalk.org.au](http://www.dyingtotalk.org.au)
- Contact Palliative Care Australia P: 02 6232 0700  
E: [pca@palliativecare.org.au](mailto:pca@palliativecare.org.au) with **Subject: DTTT**



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](http://palliativecare.org.au)



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*Palliative Care Australia is funded by the Australian Government*