Conversations that Count
Helping communities think and talk about death and dying
Toolkit for volunteer communicators
Thank you to all the people involved in the development of this toolkit including:

- All the participants who came to the co-design workshops and shared their experiences and ideas.
- Our volunteer Communicators who willingly participated in the pilot training and went out into the community.
- Members of the Conversations that Count Project Group for their ongoing support and advice.
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Suggested citation:
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What’s it all about?

Traditionally, in New Zealand, many families are reluctant to think and talk about death and dying and the type of treatment and care they may want at the end of their lives. Some people do not think or talk about these at all, many do not do so until they are very sick. This can leave their families and healthcare providers making decisions about their care and treatment without knowing what the person would have wanted.

Conversations that Count is a pilot programme which aims to encourage conversations in communities about the treatment and care at the end of life. It does this by training volunteers, known as ‘communicators’, to get community groups talking about planning for death and dying in a positive and productive way.

The communicator’s purpose is to help community groups hold their own discussions about planning for death and dying in a positive and productive way.

How did it come about?

The idea came from a series of workshops run by Auckland District Health Board (ADHB) in 2011 with consumers who had either experienced the death of a loved one or were facing death themselves. These consumers wanted to promote thinking and talking about death and dying in their communities but needed training and resources before they could do this.

Along with support from the community, ADHB successfully received funding from the Health Quality and Safety Commission (HQSC) to run a pilot project to develop resources and training, and recruit volunteers to facilitate community sessions. This toolkit is for people who train as volunteer communicators.

“We want to encourage families and communities to think and talk about the treatment and care they want at the end of their lives.”

Community Involvement

This toolkit was developed with the community and took a lot of hard work and goodwill on their part. Four co-design workshops were held which tackled issues such as the words used for death and dying, scenarios and role-plays for working with communities and how to train volunteers.

The modules in this toolkit are what workshop participants have suggested would work well in their communities.
Part I

Talking about death and dying

This gives you some introductory information about:

- **Advance care planning** - a way of helping people think about, talk about and share their thoughts and wishes about their future health care.

- **Advance care plans** – a way of helping people write down their wishes, preferences, values and goals about current and future health care.

New Zealand resources

Part II

Preparing for a session

Once you have been to the training the next step is to run a session with a group from within your own community. Here, you can learn about the key steps for how you go about setting up a session.

The steps are:

1. Understand the programme
2. Be clear about your roles and responsibilities
3. Contact the community group
4. Decide whether to agree to a community session
5. Make the arrangements

Part III

The session modules

These are the modules for you to use when you work with a community group. You are able to pick and mix from the modules to suit the needs of the group you are holding a session with, your own personal style and time constraints. Apart from the opening and closing modules (these are the compulsory ones), the modules are grouped into three categories:

- **Thinking and talking about death** - These are the easier, less challenging modules which encourage communities to get started. They normally take between 20 and 40 minutes to complete.

- **Preparing for death and life afterwards** - These modules are more challenging and consequently are longer with most modules estimated to take between 30 and 60 minutes depending on the size of the group.

- **Preparing for the death of someone you know** - These modules are the most challenging (both for the you and the community group) as they encourage participants to delve deeper in their thinking. These modules may take 60 minutes or longer.
Part I

Talking about death and dying
Advance care planning

Many people don’t like to think and talk about death and dying. For some communities talking about death is taboo. Often discussions do not happen in families until someone is very unwell and may be in hospital. When people get sick, families and healthcare providers are often left to make difficult decisions without knowing what the person wants. Advance care planning can help with this.

The official definition

“Advance care planning is a process of discussion and shared planning for future health care. It involves patient, whanau and health care professionals. Advance care planning gives patients the opportunity to develop and express their preferences for end of life care based on:

• Their personal views and values
• A better understanding of their current and likely future health
• The treatment and care options available.”

(National Advance Care Planning Cooperative)

Planning gives people the chance to develop and express their preferences for care informed not only by their personal views and values but also by an understanding of their current and anticipated future health status and the treatment and care options available.

Advance care planning can be many things, such as:

• Having a conversation about illness, prognosis and treatment
• Having a discussion about death and dying
• Talking about treatment preferences, now and in the future
• Writing down values and beliefs to inform treatment decisions now, or for a time when a person is no longer capable.

Benefits of planning

“It encourages conversations about what is important for a person, providing them with the opportunity to discuss their hopes and expectations, as well as their fears and anxieties about their future health and about death and dying.”

“It helps a person achieve a sense of control as their illness progresses and death approaches.”

“It engages others, including family/whanau and caregivers, in the advance care planning process to help them understand the person’s wishes and to support them through the process.”

“It reassures the person that discussions and plans can change over time and in particular if circumstances change.”

(New Zealand Ministry of Health & Hospice New Zealand, 2011, p7)
Advance care plans

An advance care plan is an oral or written instruction (written is preferred) which articulates a person’s wishes, preferences, values and goals about current and future health care. The plan will only be used to direct future medical treatments and procedures when the person loses capacity to make their own decisions.

(New Zealand Ministry of Health & Hospice New Zealand, 2011).

Steps to making an advance care plan

“Think about what values and beliefs around end-of-life issues are important to you. What makes life meaningful to you and what situations might make it seem pointless?

“Talk to health professionals to learn about medical treatments for the very ill or injured. Ask about the benefits and risks of these treatments.

“Decide at what point you would want your future healthcare to focus on comfort care rather than life-saving measures which may be uncomfortable or unpleasant.

“Choose what medical care you do or don’t want, to honour your values, beliefs and faith.

“Discuss your choices and wishes with those closest to you, so they know what you would want if the worst should happen.

“Choose who would you want to speak for you if you could no longer make your own medical decisions, and sign over ‘enduring power of attorney’ to them.

“Put your advance care plan in writing and keep a copy in your medical record. It will not be used while you are capable of making your own decisions and speaking for yourself.”

(Advance Care Planning Cooperative, 2011, p.7.)

Can I change my advance care plan once I’ve written it?

Sure. You can change your advance care plan whenever and as often as you wish, as long as you are competent.

Yeah. It’s important to review your plan if things have changed for you.
Advance care planning

Resource list

Advance care planning. Preparing for the end of life. 2011
A 2-page leaflet which explains advance care planning.
Available from: Advance Care Planning Cooperative.
www.advancecareplanning.org.nz

Making the most of your final years. Practical and spiritual things to think about and plan for end of life. 2011
A 2-page leaflet which details practical and spiritual things to think about and plan for the end of life
Available from: Advance Care Planning Cooperative.
www.advancecareplanning.org.nz

My advance care plan
A 4-page form that people can use to record and let others know the care they want towards the end of their lives. Available from: Advance Care Planning Cooperative.
www.advancecareplanning.org.nz

Planning your future and the role of enduring powers of attorney. November 2008 (2nd edition)
A booklet which explains how people can arrange to have their affairs managed if they lose mental capacity, either through accident or illness. Available from: Community Law
www.communitylaw.org.nz

Keeping you protected – enduring power of attorney
A suite of resources about enduring powers of attorney including information, worksheets and forms. Available from: Office for Senior Citizens
www.osc.govt.nz/enduring-powers-of-attorney
Part II

Preparing for a Session

Understand the programme
Be clear about your roles and responsibilities
Contact the community group
Decide whether to agree to a community session
Make the arrangements
Step one: Understand the programme

Conversations that Count is a pilot programme which aims to encourage conversations in communities about the treatment and care at the end of life. It does this by training volunteers, known as ‘communicators’, to get community groups talking about planning for death and dying.

As a communicator, your purpose is to help community groups hold their own discussions about planning for death and dying in a positive and productive way. You can do this by running sessions with interested community groups.

Programme Elements

Commitment
- An organisation such as a district health board or disability organisation agrees to be a host for the programme.
- At the time of writing this toolkit, Auckland District Health Board is the only host organisation as this is a pilot project.

Expertise
- The host organisation appoints a trainer who is familiar with the Conversations that Count Programme or has had specific training.
- The trainer has access to a companion document which outlines the training schedule.

Volunteers
- Volunteers are recruited from the local community.

Training
- Volunteers have two days of intensive training on the material in the toolkit and the skills they will need in the role. These people are known as communicators.

Community
- Communicators run sessions with groups in their local community.

Evaluation
- Communicators meet as a group with the trainer after they have completed at least one session to evaluate how the sessions have gone and receive follow-up assistance.
Step two:

Be clear about your roles and responsibilities

Before having contact with a community group you need to be clear about your roles and responsibilities and be able to explain these to other people.

What does a communicator do?

Your purpose is to help community groups hold their own discussions about planning for death and dying in a positive and productive way. You are there to provide inspiration and help communities apply what they have learnt to their own situation.

You do this by:
1. Sharing information and facilitating discussions that encourage and enable communities to talk about:
   - Death and dying
   - Preparing for death
   - The treatments and care people may want at the end of their lives
2. Facilitating discussions that help communities work through issues and decisions for themselves.
   - You are not there to:
     - Give formal advice or guidance or help a community to resolve specific issues
     - Help a community grieve a recent death (see note at bottom of page for exception).

The communicator’s responsibilities

Your primary responsibility is to the community you are supporting.

You can do this by:
- Presenting information that helps communities talk about and manage the decisions for themselves
- Helping the community group keep safe
- Remembering that you are not responsible for helping community groups deal with issues, make specific decisions or prepare for specific situation (see note at bottom of page for exception).

Your secondary responsibility is to yourself and your colleagues.

You can do this by:
- Helping communities that match your background and skills (or those of you and your colleagues in combination), or
- Referring a community group to someone whose background and experience better matches the group’s needs.

Note: In some instances if the community has participated in the programme previously, you may decide to support a group to prepare for a specific person’s death (as in Module 16, Honouring the Legacy and Module 17, The Celebration).
Step three:
**Contact the community group**

Once you understand the programme and are clear about your roles and responsibilities, you are ready to approach a group in your community to see if they are interested in a session.

**Start by working out which groups to approach:**
You can begin this by brainstorming all the different groups you have a relationship with. It is important to think laterally here: it may be a formal community group such as a sports or church group or it may be a less formal group such as a social group at work or a coffee club.
You need to be aware that some communities may prefer to have communicators that are independent of the community, while others may want a partnership.

**Next get in touch with the group and arrange a meeting with the community group leader or representative.**
At the meeting you should explain the Conversations that Count Programme, your roles and responsibilities and the type of session that could be offered.
At the meeting find out the level of interest from the community group and any needs they may have.

The following questions may help you:
- Who specifically is the session for?
- What are the community members like?
- How many people are likely to attend a session?
- What is the background or context that has led to them wanting a session?
- What results and outcomes do they want from the session?

See [Your First Meeting with a Community template](page 13)

**TIPS**
- Go to your first meeting well prepared. Have some ideas about which modules may suit the group.
- Be confident. Be able to articulate:
  - Why the topic is important
  - What your role is
  - How you can help
- "To overcome your fear the 'why' has to be big enough."
### Your First Meeting with a Community template

<table>
<thead>
<tr>
<th>Who specifically is the session for?</th>
<th>What is the background or context that has led to them wanting the session?</th>
<th>What results and outcomes do they want from the session?</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are these people like?</td>
<td>LIST THE DETAILS OF THE CONTEXT.</td>
<td>LIST THEIR DESIRED RESULTS AND OUTCOMES.</td>
</tr>
<tr>
<td>How many people are there?</td>
<td></td>
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<tr>
<td>LIST THE DETAILS OF THE AUDIENCE.</td>
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What is the make-up of the community – what kinds of people, cultures, values, languages etc.
Are they a community you can relate to personally?
Can they easily recognise and respect your identity and role?

What is the background or context that has led to them wanting the session?
LIST THE DETAILS OF THE CONTEXT.

Are they being proactive?
Are they a community that has not recently experienced a death (or is not expecting one soon) or that does not need help grieving.

Are they forward-looking and wanting better ways to talk, prepare and plan?
Are they a community that does not want to grieve a specific death (in the recent past or immediate future)?

Overall, does your decision best address the needs of the community?
Are you ensuring they receive support they most need at this time (either way)?

Given this information, should you:
- [ ] Go ahead on your own
- [ ] Go ahead, with other volunteers helping you
- [ ] Say "no" with integrity and refer the community to others.
Step four:
Decide whether to agree to a community session (or not)

Decision time!

Before agreeing to hold a community session it is important for you to assess:

- Whether the content of the session will be appropriate for the community, and
- Whether you are the best person to provide assistance to the community group

Some communities may approach you with simple or complex needs, and further, they may not appreciate how complex their needs are. Signs of potential complexity might be a recent or an impending death in the community, or concerns over topics such as euthanasia, abortion and other controversies.

Some communities may prefer to have a communicator that speaks as a person independent of the community, while others may want a partnership so that members within the community might take a lead in future conversations.

You can use the questions below to assess how simple or complex the community's needs are and whether the preferred role is independent or partnering.

How to decide

To assess the community's needs
There are three initial questions that you can ask a community group to help assess their needs.
1. Who specifically are they? For example, how many people are in the group?
2. What has led them to ask for (or show an interest in having) a session?
3. What results and outcomes do they want?

To assess your involvement
Answer the questions below.

- Is it a community group that you can relate to personally? Can the group easily relate to you?
- Is the community group being proactive? Are they a group that has not recently experienced a death (or is not expecting one soon) and that does not need help grieving?
- Is the community group forward-looking and wanting better ways to talk, prepare and plan? Is this a group that does not want to grieve a specific death (in the recent past or immediate future)?
- Overall does your decision best address the needs of the community? Are you ensuring they receive the best support they most need at this time?

✓ If you answered ‘yes’ to all the questions and you can work with the group safely, then you may support the group.

✗ If you answered ‘no’ to one or more of the questions or cannot work safely, then you need to work with colleagues or refer the community group to specialists.
1. Once you and the community group have made the decision to have a session, it is important to formalise the arrangements so both parties have an understanding of the aims, roles and limits of the communicator and the session. In most cases this would involve you discussing and signing a community session agreement or something similar.

See Community Session Agreement (page 16) for an example

2. The next step is to go through some of the details, such as:
   • Who needs to be on the team for setting up the session?
   • Who needs to be on the team running the session?
   • What jobs need to be done before the session?
   • When and where the session will be held?
   • What resources will you need?

Planning a Session template (page 17) can help you with this.

NOTE If you need resources such as paper & pens, copies of evaluation forms and so on, ask the community group if they can provide them.
Community Session Agreement
(Optional)

Communicator Aims
1. We aim to present information that helps your community group to work independently on the issues that arise and any decisions that have to be made.
2. We aim to do this in ways that are safe and useful for your community group, and safe and responsible for us.

Communicator Role
We aim to share information and facilitate discussions that encourages and enables your community group to talk about:
• Death and dying
• Preparing for death
• The treatments and care people may want at the end of their lives

Communicator Limits
Please note, we are unable to:
1. Give advice or guidance, help your community group resolve specific issues or make decisions related to death and dying
2. Help your community group grieve a recent death or prepare for the death of a specific member in the near future (unless you have participated in the programme previously and it is appropriate for us to do this)
3. Discuss euthanasia and any other practices which are illegal or controversial
While we might want to help, we are neither trained nor tasked to provide more specialised support. If needed we will help you contact specialists who can support your community appropriately.

We agree to work under the conditions outlined above.

Communicator: __________________________________________________________

Community group representative: __________________________________________
Planning a Session template

Who needs to be on the team setting up the session?

Who needs to be on the team running the session?

What jobs need to be done before the session?
   Who will do them?
   By when?

Where and when will the session be held?
   What is the deadline for setting everything up?
   How will the room be set up?
   What modules will you do?

Go through the specific arrangements:
   Where is the venue?
   Will you have refreshments?
   How will the room be set up?
   What do you need to bring?
Part III
Session modules
Starting a Session

01 Session Opening: Prepare a group for the session ahead

Thinking and talking about death

These are the easier, less challenging modules which encourage communities to get started. They take between 20 and 40 minutes to complete.

02 Finding the Words: Identify the words people use to talk about death and dying
03 Four by Four: Identify all the positive things death can mean for people
04 Things to Know: Think about the basic arrangements needed to be made to prepare for death and dying
05 Fears and Hopes: Identify fears and hopes about preparing for death and dying
06 Facing Death: Identify the amazing things people can say and do when faced by their own death
07 Death of a Pet: Reflect on how the death of a pet can help people manage the death of a person they know
08 Expert Interviews: Talk confidently with others about preparing for death and dying

Preparing for death and life afterwards

These modules are more challenging and consequently will take longer. Most modules are likely to take between 30 and 60 minutes depending on the size of the group.

09 The Wall: Identify the things that prevent people preparing for death and dying
10 The Gate: Manage the things that prevent people preparing for death and dying
11 Information Bank: Understand the range of issues death poses
12 Make Friends with Death: Become comfortable with death
13 Conversation Cards: Talk about the issues and situations that arise when someone is preparing for death

Preparing for the death of someone you know

These modules are the most challenging (for you and the community group) as they encourage participants to delve deeper in their thinking. These modules may take 60 minutes or longer.

14 Sharing your Wishes: Plan for the death of someone you know
15 The Boat: Look to life beyond death without someone you know
16 Honouring the Legacy: Explore deeper meanings in the life of the person who is dying
17 The Celebration: Celebrate the life of someone you know

Ending a session

18 Session Closing: Summarise and reflect on the session
**Session Opening**

*Duration: approximately 15 minutes.*

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**What?**

This introductory module ensures that the community group is prepared for the session ahead.

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**Why?**

If the community group is well prepared for the session then things are likely to go more smoothly.

*This is a compulsory module.*

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**Steps**

Prior to the session starting, complete the Planning a Session template *(page 17)*

- Participate in the welcome (or powhiri) by the community group, observing any specific group protocols.
- Participate in any formal opening of the session, observing any specific group protocols.
- Once you have been introduced, thank and acknowledge the community group.
- Explain the purpose of the session and its benefits.
- Summarise your own experiences.
- Give an outline of the session including approximate times and when there will be breaks.
- Check for questions and address before moving on.
- Finish and move on to the next module.

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**Materials**

- Whiteboard
- Whiteboard markers

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**TIPS**

Focus on a positive, clear and confident start. Address any difficulties immediately.

Acknowledge that during the modules participants may feel distressed or have a range of emotions. Let them know that it's okay to feel this way. After all, discussing death and dying is a difficult topic.
Finding the Words
talking about death

Duration: approximately 20-30 minutes.

Steps

- Introduce the module.
- Ask people to brainstorm and write down all the words they can think of to describe death and dying. People can do this individually, in breakout groups or in one large group.
- Explain that there are no right or wrong answers, all words and phrases are acceptable.
- Once this is completed, ask people to call out the phrases and words used and write them on the whiteboard.
- Ask people: “What does the range of words suggest to you?”
- Ask people to summarise what they have learnt. “So, what we are learning is...?”
- Acknowledge how well people have done. “You’ve done really well. It’s amazing how many different ways you have for talking about death and dying.”
- Finish and move on to the next module.

Materials

- Whiteboard
- Whiteboard markers
- Pens and paper

What?
This is a fun, light-hearted, exploratory module to identify the words people use to talk about death and dying.

Why?
People use different words to describe death and dying and it’s important to be aware of and able to use the range of words. This introductory module generates discussion and raises participants’ awareness of different approaches to talking about death and dying.

How?
Brainstorm all the words participants can think of to describe death. This can be done individually, in breakout groups or in one large group.

TIPS

Ask people who’s got the longest list and give a “round of applause”.

Get people to read out the lists.
Four by Four ways people think and talk about death

Duration: approximately 20-40 minutes.

Steps

- Introduce the module.
- Ask participants to break into groups and sit in circles.
- Make sure each group has the handout: Four by Four template, pens, post-it notes and a large sheet of paper. Ask each group to copy the Four by Four template onto the large sheet of paper.
- Ask groups to brainstorm and write down on post-it notes all the positive things experiences of death can mean for people. Allow 10-15 minutes for people to do this.
- Ask groups to place the post-it notes onto their large sheet.
- When this is done, ask people to reflect back on what they have learnt.
- Summarise what they learnt (in their words).
- Finish and move on to the next module.

Materials

- Large sheet of paper and pens for each group
- Module 03 handout: Four by Four template (page 24)

TIPS

Remain positive, open minded and upbeat and encourage others to do the same.
<table>
<thead>
<tr>
<th>Physical</th>
<th>Emotional</th>
<th>Social</th>
<th>Spiritual</th>
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**Four by Four template**

- **LIFE AFTERWARDS**
- **DEATH**
- **DYING**
- **PREPARING**
What?
This exploratory module helps people think about the basic arrangements they need to make to prepare for death and dying.

Why?
Death and dying can seem difficult to deal with but there are a lot of services and people who are ready to help.
By thinking about and planning for the basic arrangements people can make things much easier and much less stressful to deal with.

How?
In groups, participants discuss the information and resources about preparing for death and dying.

Steps
- Introduce the module.
- With the whole group, brainstorm all the things participants want to learn about preparing for death and dying. Write these on the whiteboard.
- In breakout groups, give each group several copies of the handouts. Ask participants to:
  1. Read the information looking for answers to their questions,
  2. Discuss what they have found within their groups, and
  3. Make a plan for finding out information that is missing.
- Ask each breakout group to present their understanding of the information back to the whole group using their own words.
- Lead an interactive discussion about the information asking each group to reflect back on what they have learnt.
- Summarise what they learnt (in their words).
- Finish and move on to the next module.

Materials
- Whiteboard and whiteboard markers
- Advance care planning resource list (page 8)
- Module 04 handout: FAQs about Death and Dying (page 26)
- Advance Care Planning leaflet
- Making the most of your final years leaflet
- My Advance Care Planning guide

Things to Know
Talking about preparing

Duration: approximately 20-40 minutes.
FAQs about Death and Dying

Q: How do I deal with grieving, anger and other feelings?
A: Grieving and expressing feelings is important and healthy. The Grief Centre [www.griefcentre.org.nz](http://www.griefcentre.org.nz) and Skylight [www.skylight.org.nz](http://www.skylight.org.nz) both offer support, advice and counselling to people affected by grief and loss.

Q: What are the options for treatment and care?
A: Options depend on the person who is unwell and can vary a lot. Medical professionals who know the person can give the best information.

Q: What about suicide?
A: Suicide is more common among older people but a disproportionate number of young people choose suicide. For further information and resources on suicide prevention go to Suicide Prevention Information New Zealand [www.spinz.org.nz](http://www.spinz.org.nz) or the Office for Senior Citizens [www.osc.govt.nz/enduring-powers-of-attorney](http://www.osc.govt.nz/enduring-powers-of-attorney).

Q: What is an advance directive?
A: “Advance directive” means a written or oral directive (a) By which a consumer makes a choice about a possible future health care procedure; and (b) That is intended to be effective only when he or she is not competent. “(Health and Disability Commissioner, 2004)

Q: Can someone change his or her advance care plan?
A: People can change their advance care plan whenever and as often as they wish, as long as they are competent. Reviewing a plan is especially important if any aspect of a person’s life or health status has changed.
Fears and Hopes in a Bowl

talking about feelings

Duration: approximately 20-40 minutes.

Steps

• Introduce the module.
• Ask each group to sit in a circle.
• Give each group a bowl and ask them to place it in the centre.
• Ask participants to write down their fears about preparing for death and dying – one ‘fear’ per sheet of paper – and place these in the bowl. After shuffling the pieces of paper, each person draws one out and talks about the fear and how they might explain it to someone else.
• When everyone has had a chance to talk repeat the same process but this time get people to write down their ‘hopes’ about death and dying.
• Ask the whole group: “What are we learning? What difference does this make for us?”
• Summarise what they learnt (in their words).
• Acknowledge how well people have done: “You’ve done very well to express your fears and hopes. Expressing both gives you ways to think about and prepare for a death with greater dignity. Congratulations.”
• Finish and move on to the next module.

Materials

✦ Sheets of paper or post-it notes & pens
✦ A large bowl (or similar object) for each group

What?
This open-minded and exploratory module helps people identify and discuss their fears and hopes about preparing for death and dying.

Why?
Many things can make people anxious and afraid or hopeful and optimistic. Talking about these feelings helps people learn how to manage them. For example, fears that can stop people sleeping at night may seem silly during the day. Talking fears through can make all the difference.

How?
In groups, write down the fears and hopes about preparing for death and talk about how to express these to others.

TIPS

Encourage people to talk, share and stay focused on the positive.

If a participant has trouble talking, ask others to gently encourage them and support them. If a person does not want to talk, ask someone else to talk on his or her behalf.
Facing Death

talking about death and dying

Duration: approximately 20-30 minutes.

Steps

- Introduce the module.
- In breakout groups, get participants to recall and share stories about the ways people they know have faced up to and prepared for death. Ask people to keep stories focused on the positive and how people deal with preparations successfully.
- Get the whole group to discuss: “What are the ways people deal with death? What does this suggest for us?”
- Summarise what they learnt (in their words).
- Acknowledge how well people have done: “You’ve done very well to share your stories and express your feelings. Congratulations.”
- Finish and move on to the next module.

What?
This creative module helps people identify the amazing things they can say and do when faced by their own death.

Why?
Death and dying can bring out the best in people. Recognising this can help people see the whole picture, not just the bad stuff.

How?
In groups, participants share stories about the ways people they know faced up to and prepared for their own death.

TIPS

Not everyone in the group needs to share a story. If stories are limited ask people to focus on and amplify even the smallest examples of what worked well.
Death of a Pet

talking about death and dying

Duration: approximately 20-30 minutes.

Steps

- Introduce the module.
- Individually or in breakout groups, ask participants to imagine that a pet they love has died naturally. Then ask participants to describe what their experiences might be during and after the death of their pet using words, images and anything else they want.
- Get the whole group to discuss: “What are we learning about dealing with death? What differences does this make for us?”
- Acknowledge how well people have done: “You’ve done very well to share your stories and express your feelings. Congratulations.”
- Finish and move on to the next module.

Materials

✏ Paper and pens

What?

This creative module helps people indentify things they can say about their own experiences of someone else’s death and dying.

Why?

Talking about death and dying of pets can help people learn how to manage a death when it’s someone they know.

How?

- Individually or in breakout groups, participants imagine a pet they love has died naturally and then describe their likely experiences.
- This module works best with creative and open-minded groups.

TIPS

For those working in groups:
if a participant has trouble talking, ask others to gently encourage them and support them to talk.
Encourage participants to share and explore ideas.
Note: for many people the death of pet and its impact goes unacknowledged by other people.
Expert Interviews

talking about preparing for death and dying

Duration: approximately 20-30 minutes.

Steps

- Introduce the module.
- In groups of 3 or 4, ask people to role-play a TV chat show. Ask participants to take the parts of the interviewer, the expert and the audience.
- The interviewer asks the expert questions about preparing for death and dying.
- People in the audience can also ask questions.
- Afterwards, get the whole group to discuss what they have learnt.
- Summarise what the group has learnt (using their words).
- Finish and move on to the next module.

Materials

✎ Paper and pens

What?
This interactive module helps people talk confidently with others about preparing for death and dying.

Why?
It is important to have a knowledgeable, confident approach when talking with other people about death and dying.

How?
In small groups of 3 or 4, role-play a TV interview with participants playing the part of interviewer, expert and audience. This module works best with confident groups.

TIPS

Encourage confident, positive and genuine interactions. Encourage groups to manage any difficulties themselves.
The Wall

barriers to preparing for death and dying

Duration: approximately 30-60 minutes.

Steps

• Introduce the module.
• Decide whether you are going to do this module individually or in groups.
• Ask each participant or group to work through The Wall template. Start with the left hand side: “What prevents you from preparing for death and dying?” Then move to the right hand side: “What would death and dying be like if you talked and prepared better?”
• After the template has been completed get the whole group to discuss what they are learning about their lost opportunities.
• Acknowledge how well people have done: “It’s great that we can now see both sides of preparing – the barriers and the things we gain. An important next step is to look at how we can manage these.”
• Finish and move on to the next module. Module 10, The Gate is recommended.

Materials

✦ Whiteboard and markers
✦ Paper and pens
✦ Module 09 handout, The Wall template (page 32).

What?
This exploratory module helps people identify the things that prevent them from preparing for death and dying.

Why?
Many things can prevent people preparing for death and dying including beliefs, feelings and practicalities. Identifying these can make preparation easier and beneficial for everyone.

How?
• Individually or in groups of any size, work through The Wall template.
• This module works well if it is followed by Module 10, The Gate.

TIPS

Keep the focus open-minded and exploratory and remind participants to focus on preparing for death. Time management is important. So, make sure enough time is given for participants to complete the right hand side of the template.
The Wall template

What prevents you from preparing for death and dying?

What would death and dying be like if you talked and prepared better?
What?
This exploratory module helps people manage the things that have prevented them from preparing for death and dying.

Why?
Many things can prevent people preparing for death and dying including beliefs, feelings and practicalities. Managing these can make preparation easier and beneficial for everyone.

How?
• Individually or in groups of any size, work through The Gate template.
• This module works well if it is completed after Module 09, The Wall.

The Gate
ways to help prepare for death and dying

Duration: approximately 30-60 minutes.

Steps
• Introduce the module.
• Decide whether you are going to do this module individually or in groups.
• Ask each participant or group to work through The Gate template. Start with the left hand side: “What could you do to make preparing for death and dying easier?” Then move to the right hand side: “List up to three things that would make the most difference for you right now.”
• After the template has been completed get the whole group to discuss what they are learning about their lost opportunities.
• Acknowledge how well people have done: “It’s great that we can now identify ways of managing preparing for death and dying.”
• Finish and move on to the next module.

Materials
☞ Whiteboard and markers
☞ Paper and pens
☞ Module 10 handout, The Gate template (page 34).

TIPS
Keep the focus open-minded and exploratory and remind participants to focus on preparing for death.
Time management is important. So, make sure enough time is given for participants to complete the right hand side of the template.
What could you do to make preparing for death and dying easier for you now?

What 1 - 3 things would make the most difference for you now?
What? This exploratory module helps people become aware of and understand the range of issues death poses.

Why? Death poses a range of issues. When people know who can help with these they can avoid experiencing some of the stress and difficulties. This is similar to Module 04: Things to Know but is designed for working with a community that needs practical solutions to specific information needs.

How? In breakout groups, brainstorm the issues about preparing for death and who might be able to help with these. Make a plan to find out any additional information needed.

Steps
- Introduce the module.
- Ask participants to brainstorm all the issues related to preparing for death that they can think of. This includes financial, legal, practical, emotional and social issues. Write the issues on the Information Bank templates.
- Then review any information they have and fill in the contact details for as many sources as they can.
- Identify any gaps in the handouts and suggest other sources of information.
- Get the whole group to discuss what they have learnt.
- Finish and move on to the next module.

Materials
- Pieces of paper or post-it notes and pens
- Module 11 handouts: Information Bank templates 1 and 2 (pages 36 & 37)
- Resource List (page 8) and FAQs about Death and Dying (page 26)
- Insert 01: Advance care planning
- Insert 02: Making the most of your final years
- Insert 03: Advance care planning guide

TIPS
During the brainstorm encourage participants to freely share information. Be positive and supportive. Answer any questions participants may have and ask others to help a person with any difficulties.
### Information Bank template 1

<table>
<thead>
<tr>
<th>What are the financial, legal and practical issues?</th>
<th>Who might be able to help you with these issues?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Contact details</td>
</tr>
</tbody>
</table>
## Information Bank template 2

<table>
<thead>
<tr>
<th>What are the emotional and social issues?</th>
<th>Who might be able to help you with these issues?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Name</td>
</tr>
<tr>
<td></td>
<td>Contact details</td>
</tr>
</tbody>
</table>
TIPS

Encourage people to stay in role. If they have difficulty, ask others to support them.

What?
This module helps people become comfortable dealing with death.

Why?
Sometimes people avoid thinking and talking about death. By acknowledging and addressing this they can learn to be more practical and useful when dealing with death and its effects on other people.

How?
In groups of 3 or 4, role-play ‘Death’ as if he or she was an ordinary tradesperson working in the neighbourhood. Get one person in each group to play the part of ‘Death’ and ask the others to befriend Death.

Steps
• Introduce the module.
• In groups of 3 or 4, ask people to role-play ‘Death’ as if he or she was an ordinary tradesperson working in the neighbourhood. Get one person in each group to play the part of ‘Death’ and ask the others to befriend Death.
• Ask the others to learn about Death’s ambitions, fears, values, skills and behaviours. Then ask them to learn how Death wants people to prepare to make Death’s work easier.
• At the end of the role-play ask the whole group to reflect on what they learnt.
• Summarise what they learnt (in their words).
• Finish and move on to the next module.

Materials

Paper and pens

Make Friends with Death

talking about preparing

Duration: approximately 30-60 minutes.
What?
This module helps people explore ways of talking about the different issues and situations that arise when someone is preparing for death.

Why?
Exploring the topics and practicing conversations can help people prepare for death and dying.

How?
In breakout groups, use the Conversation Cards to prompt discussions about death and dying.

Steps
- Introduce the module.
- Give each group a random conversation card (or get them to pick one themselves at random).
- Ask groups to look at the picture on the card and select a topic related to death and dying that the picture could represent. For example, Conversation 2 could represent a list of things to do to prepare for death or a list of people a dying person may need to talk to.
- Once the group has agreed on what topic the picture represents to them, get them to discuss the topic. The discussion may involve one person asking questions of another so they can practice talking, or participants testing their own knowledge of the topic.
- At the end of the discussion, ask the whole group: “How did you find talking about the range of issues and situations that can arise?”
- Summarise what they learnt (in their words).
- Acknowledge how well people have done: “It’s amazing how many different ways you have of talking about death and dying.”
- Finish and move on to the next module.

Materials
- Post-it notes and pens
- Module 13 handouts, Conversation Cards 1-12 (pages 40 - 42)
Sharing your Wishes
preparing for a death

Duration: approximately 60+ minutes.

Steps

- Introduce the module.
- Ask the whole group to brainstorm the issues associated with planning for the person’s death. Write each idea on a post-it note and stick it on the wall.
- When the group has finished brainstorming ask them to arrange the post-it notes by themes or person responsible.
- Ask the group to write a plan on the large sheet of paper. You will need to facilitate this. During this process ask people to respect and support each other, sharing the load generously.
- Participants can then copy their roles and tasks onto A4 sheets.
- Ask the group to reflect on the process and what they learnt about talking and working together.
- Summarise what they have learnt (in their words).
- Finish and move on to the next module.

Materials

🔹 A4 paper, large sheet of paper, post-it notes and pens

What?
This module helps people plan for the death of someone they know.

Why?
People can try too hard to care for their loved one and this can cause disagreements and stress. When carers share their wishes in relation to a death in a positive way it can bring families/friends together, help spread the burden and support each other as well as the dying person.

How?
As a group, brainstorm the issues associated with preparing for a person’s death and then develop a plan. This module is designed for confident communities who are preparing for an individual’s death and, if appropriate, the dying person may participate. This module suits community groups that have already participated in the programme previously and have completed a number of modules with the communicator.

TIPS
This is a difficult module and participants may get upset and experience conflicts. You will need to be positive and support the group’s desire to be practical and plan, in spite of upsets.
What? This module helps people build a way of dealing with death and looking to life beyond it without someone they know.

Why? Sometimes people can feel very alone when someone they love is dying. By preparing for death and the future people can learn to see death in the context of life.

How? In breakout groups, participants use the metaphor of ‘a boat’, i.e., going on a journey, to explore the challenges people face ahead and the ways that they can deal with these.

Steps
- Introduce the module.
- Using the **The Boat template**, ask groups to discuss the challenges they face and how they would address them from the time of a person’s funeral.
- Write each idea on a post-it note and stick it on the wall.
- When the groups have finished brainstorming ask them to arrange the post-it notes by themes.
- Ask the whole group to reflect on the process and what they learnt about talking and working together.
- Summarise what they have learnt (in their words).
- Finish and move on to Module 18, **Session Closing**.

Materials
- **Post-it notes and pens**
- **Module 15 handout, The Boat template (page 45)**.

**TIPS**
During the brainstorm encourage participants to focus on the future and stay positive. Ask participants to support those needing help.
The Boat template

What are the challenges of moving ahead?

What can keep us safe and strong during this time?

Who is in the boat and sharing this with us?

What can the future hold for us as a result of this?
Honouring the Legacy
preparing for life after a loved one’s death

Duration: approximately 60+ minutes.

Steps

- Introduce the module.
- Using the Honouring the Legacy template, ask groups to discuss the history and experiences of the person who is dying, how the person dealt with these experiences, the strengths and opportunities they are giving people and what the future may hold as a result.
- Ask the groups to start the discussion as far back in history as they can.
- Write each response or thought on a post-it note and stick it on the wall.
- When the groups have finished the discussion ask them to arrange the post-it notes by themes.
- Ask the whole group to reflect on the process and what they learnt.
- Summarise what they learnt (in their words).
- Finish and move on to Module 18, Session Closing.

Materials

- Post-it notes and pens
- Module 16 handout, Honouring the Legacy template (page 47).

What?
This module will help people build a way of dealing with death by exploring deeper meanings in the life of the person who is dying.

Why?
Sometimes people can feel that death is the end or that something is taken away from them forever. But it is also a time when people can recognise the strengths and values that have been passed on to other generations. This can be a very spiritual time.

How?
In groups (or in one large group), participants discuss the history and experiences of the person who is dying and the legacy they are leaving.

Only do this module if the community group has participated in the programme previously and you are confident in your abilities to manage the complex emotions which may arise for people.

TIPS

During the brainstorm encourage participants to focus on the future and stay positive. Ask participants to support those needing help.
<table>
<thead>
<tr>
<th>Question</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>What can the future hold for us as a result of this?</td>
<td></td>
</tr>
<tr>
<td>What strengths and opportunities are they giving us?</td>
<td></td>
</tr>
<tr>
<td>How did the person deal with these and succeed?</td>
<td></td>
</tr>
<tr>
<td>What histories and experiences shaped the person’s life?</td>
<td></td>
</tr>
</tbody>
</table>
The Celebration

Celebrating a life

Duration: approximately 60+ minutes.

What?
This module helps people share ideas for celebrating a life before the person dies.

Why?
Sometimes people don’t reflect on someone’s life until at the person’s funeral or tangi. Celebrating a life while the person is alive can be very moving and a wonderful way of expressing love and respect.

How?
As a group, participants discuss ideas for how to celebrate somebody’s life and agree on ideas so that planning can start.

This module is being done before the life ends so if appropriate the dying person can be included.

Only do this module if the community group has participated in the programme previously and you are confident in your abilities to manage the complex emotions which may arise for people.

Steps

- Introduce the module.
- Get the group to sit in a circle and ask them to brainstorm: “How we can best celebrate this life?”
- Write the ideas on a whiteboard or large sheet of paper.
- After the brainstorm is competed, try and decide on 1-3 key ways of celebrating so that the planning can start.
- Ask participants to reflect on the experience of working together on a celebration.
- Summarise what they have experienced and congratulate them.
- Finish and move on to Module 18, Session Closing.

Materials

- Paper and pens

TIPS

During the brainstorm encourage participants to think laterally, share stories and explore alternatives.
18

Session Closing

Duration: approximately 15 minutes.

What?
This final module provides the opportunity for the community group to summarise and reflect on the session.

Why?
It is important that the community group is able to reflect on what may have been a difficult session for them and to have the opportunity to consider any future steps they may want to take.
This is a compulsory module.

How?
Follow the steps below.

Steps
• Review the information on the whiteboard and sheets and summarise.
• Discuss with the community group what the next steps are and their commitment to future use of the information.
• Check that the community group is ready to finish then ask for any closing comments.
• Ask participants to fill in the feedback form: “As this is a new project I am going to hand out an evaluation form for you to complete. If you know of another group who would like a session, please write it on the form.”
• Focus on a positive, clear and confident end.
• Thank and acknowledge the community group for working on this together.

Materials
(WIN) Whiteboard and whiteboard markers
(WIN) Module 18 handout: Your Feedback on the Session (page 50).

TIPS
Once you have completed your session it is important that you take the opportunity to reflect on how the session went and what could be done differently. This is often best done a few days after the session when you have had the opportunity to recover from the stress and busyness of the day and have gained the perspective that time gives, but while things are still fresh enough for you to remember things accurately.
Your Feedback on the Session

Please give us your feedback on the community session by ticking the box which represents your feelings at each stage.

Arriving at the session

At the start of the session

During the session

At the end of the session

What can we do better?
References


Inserts

Inserted into this toolkit are some New Zealand resources which may help. These are:

1. Advance care planning: Preparing for end of life.
2. Making the most of your final years: Practical and spiritual things to think about and plan for end of life.
3. Advance care planning guide: Planning for the medical treatment and care you want in the future.

Extra copies of these resources can be downloaded from www.advancecareplanning.org.nz