

Facilitator's guide

The combination of this facilitator's guide and the module is designed so you can offer training to a group of people with minimal preparation. We assume that you have facilitation skills, so this guide is not a script. Instead, it provides some notes and hints that may help guide group discussion.

Materials and additional information

The following materials and information may help you prepare for a facilitated TEL session:

- Your organisation's policies and procedures relating to the topic covered
- Real-life examples from your organisation that relate to the topic
- The listed resources given on slide 29 "For more information" of this module, as these may be particularly useful for your staff (also found in the Resources tab)
- Printer access, as answers typed throughout the modules can be printed at the end and certificates can also be printed for staff in attendance
- A projector and speakers to play videos, especially in a large group.

Encourage self-care

At commencement of this session, it is important to remind staff that talking about the end of life may not be easy, and that staff should take care of themselves and each other. Think in advance about what you could do if one of the participants becomes very upset.

Consider confidentiality

Be aware that that it is very common for people to share personal experiences when discussing end of life (both their experience with people with intellectual disability, and personal/family experiences).

Think about the degree of confidentiality that is appropriate for the group you are facilitating, and whether any ground rules are needed about:

- Discussing clients' end of life experiences
- Talking about one's personal dealings with dying and death.

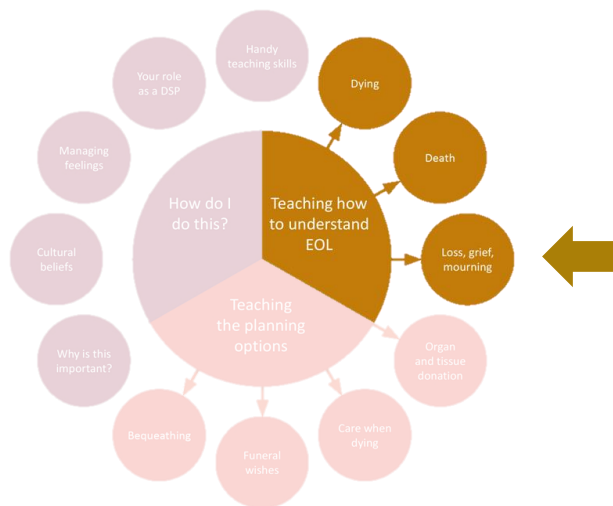
Important information for participants

We recommend that you explain to participants in the group that:

- The videos show real disability staff and people with intellectual disability (not actors) talking about real experiences
- The stories are almost all based on real events (with names and identifying details changed)

Module: Loss, Grief and Mourning

Consider showing participants where this module fits in with the other 11 TEL modules.



Suggested duration:



35-40 minutes

This guide includes:



Main ideas












Links with other modules









Points to highlight from video




<p>Talking End of Life ...with people with intellectual disability</p> <p>Teaching how to understand end of life Loss, grief and mourning</p> <p> </p> <p>The TEL program is supported by funding from the Australian Government Department of Health and the Public Health and Clinical Research Council of Australia.</p> <p>Start</p>	
---	--

<p>Welcome to the module: Loss, grief and mourning</p> <p>People with intellectual disability grieve, just like everyone else.</p> <p>This module introduces how to recognise signs of loss and grief and support a person with intellectual disability to mourn.^[1]</p>  <p>1. Dodd et al. (2005)</p> <p>Go back Slide 2 of 33 Next slide</p>	<p>Clicking on the link [1] opens a new window showing published research that supports the information in the slide. The footnote lists the first author and date of this publication.</p> <p> Can you think of a person with intellectual disability you know who experienced grief? What happened?</p>
<p>Let's get started</p> <p>There are lots of words to describe feelings and behaviours to do with end of life.</p> <p>The most common words are:</p> <ul style="list-style-type: none"> • Loss • Grief • Mourning <p>While these words are all used a lot, they do not mean the same thing.</p>  <p>Go back Slide 3 of 33 Next slide</p>	
<p>What is loss?</p> <p>Loss is the sense of being without.</p> <p>It is a feeling that often happens when someone or something that is really important to you is gone.</p>  <p>Go back Slide 4 of 33 Next slide</p>	
<p> Think about...</p> <p>List at least 3 examples of loss.</p> <p>Type your answer in the box below.</p> <div style="border: 1px solid #ccc; height: 100px; width: 100%;"></div> <p>Go back Slide 5 of 33 Next slide</p>	<p>This is the first example of a text box in this module. You may choose to use this box to type in key points raised during discussion. Answers to this and any future reflection questions can be printed or emailed at the end of the module.</p>
<p>Your answers to the 'Think about...' question</p> <p>List at least 3 examples of loss:</p> <div style="border: 1px solid #ccc; height: 100px; width: 100%;"></div> <p>Go back Slide 6 of 33 Next slide</p>	







<p>Did you get...?</p> <ul style="list-style-type: none"> Someone dying Losing a job Losing a precious object Losing your hair following cancer treatment Losing your home A relationship ending  <p>Go back Slide 7 of 33 Next slide</p>	
<p>What is grief?</p> <p>Grief is the response to loss. Grief includes feelings, how our body feels, thoughts and how we behave.</p>  <p>Go back Slide 8 of 33 Next slide</p>	
<p>Think about...</p> <p>What are some ways a person experiences grief?</p> <p>Type your answer in the box below.</p> <div style="border: 1px solid #ccc; height: 100px; width: 100%;"></div> <p>Go back Slide 9 of 33 Next slide</p>	
<p>Your answers to the 'Think about...' question</p> <p><i>What are some ways a person experiences grief:</i></p> <div style="border: 1px solid #ccc; height: 100px; width: 100%;"></div> <p>Go back Slide 10 of 33 Next slide</p>	
<p>Did you get...?</p> <ul style="list-style-type: none"> Feelings such as sadness, loneliness, numbness, anxiety and guilt Physical reactions such as a tight throat, tight chest and lack of energy Thoughts such as confusion and disbelief Changes in behaviour such as poor sleep, low appetite and crying  <p>Go back Slide 11 of 33 Next slide</p>	 <p>Take note of these experiences of grief and watch out for some of them in the videos later in the module.</p>

<p>People grieve in different ways</p> <p>Sometimes people with intellectual disability may show changes in behaviour such as:</p> <ul style="list-style-type: none"> • Shouting • Arguing • Isolating oneself • Refusing to do things • Self-injury. <p>As can be seen in the video, these changes could be responses to grief. [1]</p> <p>1. Dodd et al. (2005)</p> <p>Go back</p> <p>Next slide</p> <p>Slide 12 of 33</p>	<p></p> <p>Key points for discussion from this video clip are listed below:</p> <p>What changes in Sam's behaviour may show that he is grieving?</p> <p>(00:58) The disability support professional (DSP) knocks but respects Sam's privacy. Sam is withdrawn and has no energy.</p> <p>(01:13) The DSP talks to his supervisor to try to figure out why Sam is acting the way he is.</p> <p>(02:17) The DSP encourages Sam to <i>do something</i> - gardening - as a way of honouring his dead friend Lewis.</p> <p>(02:22) The DSP helps Sam name and understand his feelings – sadness, grief.</p> <p>In the later part of the video, Sam and the DSP openly talk about the dead person Lewis. Does this help Sam?</p>
<p>Norman</p> <p>In the video we just saw, Sam's behaviour changed in response to the death of his friend Lewis. However, grieving doesn't always happen after someone dies.</p> <p>For example, Norman's wife of 14 years is dying and has been in and out of hospital during the last year.</p> <p>Norman's disability support professional (DSP), Terry, has recently noticed that Norman makes sure his cat follows him before he leaves any room and that he often holds his hand to his throat when sitting.</p> <p>Go back</p> <p>Next slide</p> <p>Slide 13 of 33</p>	

<p>Terry talked to Norman</p> <p>Terry sat down with Norman and asked him why he gets the cat to follow him everywhere. Norman responded "Don't know, just do".</p> <p>Terry also asked Norman if he feels like his throat feels tight. Norman confirms that it does. Terry explains that these feelings and behaviours might be part of a thing called 'grief'.</p>  <p>Go back Slide 14 of 33 Next slide</p>	 <p>Norman is unable to explain why he behaving in this way. What does this suggest about his understanding of grief?</p> <p>Go back to the list on slide 11 and remind participants that "tight throat" was listed as a physical response to grief.</p>
<p>What did Terry do?</p> <p>Terry explained what grief is, and some of the other symptoms. He asked Norman to repeat the word and asked questions to check his understanding.</p> <p>Terry also helped Norman to arrange a visit to his GP to make sure the throat tightness wasn't caused by a physical illness.</p> <p>Terry printed off an easy English document called <i>Grief and Loss</i> and brought it with him on his next visit. With this document, Terry checked Norman's understanding about grief again.</p>  <p>Go back Slide 15 of 33 Next slide</p>	 <p>Terry did 2 important things:</p> <ol style="list-style-type: none"> 1. Checked for health problems (throat) 2. Helped Norman to name and understand grief.
<p>Think about...</p> <p>If you were Norman's DSP, what else could you do to support Norman?</p> <p>Please type your answer in the box below.</p>  <p>Go back Slide 16 of 33 Next slide</p>	
<p>Your answers to the 'Think about...' question</p> <p>If you were Norman's DSP, what else could you do to support Norman?</p> <p>Go back Slide 17 of 33 Next slide</p>	
<p>Did you get...?</p> <ul style="list-style-type: none"> • Support Norman to do special things for his wife, such as cooking a meal or doing an activity that she loves • Ask Norman whether he has talked to his wife about any end of life wishes she may have – such as what she wants at her funeral • Offer Norman emotional support, such as saying "It sounds like it's really hard seeing her so sick"  <p>Go back Slide 18 of 33 Next slide</p>	

<p>What is mourning?</p> <p>Mourning is the process of handling a loss.</p> <p>In the past, it was commonly believed that mourning has an end point. For example, you may have heard about the 'stages of grief' or the word 'closure'.</p> <p>In reality, everybody mourns differently. For some people it may never end. For others, it may end when they can think about the dead person without pain, or with less pain.</p>  <p>Go back Slide 19 of 33 Next slide</p>	 <p>The module <i>Managing feelings</i> also contains information about what to do if a person with intellectual disability becomes very upset when dealing with dying or death.</p>
<p>Loss, grief and mourning</p> <p>It's important to remember that loss, grief and mourning don't just happen after death. They can happen during the dying process too.</p> <p>In the story we just saw, Norman was experiencing grief while his wife was dying.</p> <p>The person who is dying may also have these experiences.</p>  <p>Go back Slide 20 of 33 Next slide</p>	

<div data-bbox="199 224 699 470"> <h3>Rob</h3> <p>In the video, Rob's housemate Jim dies.</p> <p>Disability support professional (DSP) Miranda helps Rob mourn through supporting Rob to:</p> <ul style="list-style-type: none"> • Speak at Jim's funeral [2] • Put up Jim's photo <p>By supporting Rob to do these sorts of activities, Miranda helps Rob to mourn. [3, 4]</p> <p>2. Forrester-Jones (2013) 3. Read (2008) 4. Read & Bowler (2007)</p> <p>Go back</p> <p>Slide 21 of 33</p> <p>Next slide</p> </div>	<div data-bbox="746 241 831 315"> </div> <p>Key points for discussion from this video clip are listed below:</p> <p>(01:03) Miranda asks Rob “Would you like to go to the funeral?”. She offers to support him to go.</p> <p>(01:08) Miranda uses animation to explain what happens at a funeral.</p> <p>(01:31) Miranda asks Rob if he wants to <i>do</i> something at Jim’s funeral.</p> <p>(01:54) Do you think Miranda helped Rob think about what to say? Did she help him practise how to say it?</p> <p>(02:29) Rob puts up his dead friend Jim’s photo at home. Is this a good idea?</p> <div data-bbox="751 1227 820 1301"> </div> <p>The animation is also available in the Videos tab. You could show this video to a person with intellectual disability to help them prepare for a funeral.</p>
<div data-bbox="199 1523 699 1776"> <h3>Think about...</h3> <p>What else could Miranda do to help Rob mourn?</p> <p>Type your answer in the box below.</p> <div data-bbox="199 1608 699 1753"></div> <p>Go back</p> <p>Slide 22 of 33</p> <p>Next slide</p> </div>	

<p>Did you get...?</p> <ul style="list-style-type: none"> Remember anniversaries of Jim's death Tell stories about Jim Talk about Jim fondly when the topic arises Celebrate Jim's birthday  <p>Go back Slide 23 of 33 Next slide</p>	
<p>Think about...</p> <p>What should Miranda do if she is feeling upset about Jim's death?</p> <p>Type your answer in the box below.</p> <div style="border: 1px solid #ccc; height: 100px; width: 100%;"></div> <p>Go back Slide 24 of 33 Next slide</p>	
<p>Your answers to the 'Think about...' question</p> <p><i>What else could Miranda do to help Rob mourn?</i></p> <p><i>What should Miranda do if she is feeling upset about Jim's death?</i></p> <p>Go back Slide 25 of 33 Next slide</p>	
<p>Did you get...?</p> <p>It is not unusual for a DSP to grieve when a client dies. A lot of the strategies are the same as how Miranda could help Rob mourn, such as:</p> <ul style="list-style-type: none"> Remember anniversaries of Jim's death Tell stories about Jim Talk about Jim fondly when the topic arises Celebrate Jim's birthday <p>However, Miranda could also speak to her supervisor if struggling with Jim's death.</p>  <p>Go back Slide 26 of 33 Next slide</p>	 <p>Many DSPs grieve when a client dies. This is a normal response to the loss.</p>
<p>Seek help if you are unsure</p>  <p>If you are worried about grief (either someone else's or your own), please talk about it with someone you trust. You might also think about whether professional help is necessary. Involving a professional should not be the first step you take to help someone with grief. Rather, it is a step that should be taken if someone needs more or different emotional support to everyday reassurance and comfort.</p> <p>Go back Slide 27 of 33 Next slide</p>	 <p>Someone you trust could be your supervisor, a colleague, friend or family member.</p>
<p>Key concepts</p> <p>People with intellectual disability experience loss, grief and mourning, just like everyone else:</p> <ul style="list-style-type: none"> Loss is the sense of being without Grief is the response to loss. It includes feelings, physical reactions, thoughts and behaviours Mourning is the process of handling a loss <p>Changes in behaviour such as shouting, arguing, isolating oneself, refusing to do things and self-injury may be signs of grief. You can support clients to understand what grief is and do things to remember the person who has died.</p>  <p>Go back Slide 28 of 33 Next slide</p>	

You can now [print a certificate](#)