

## 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
- 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.

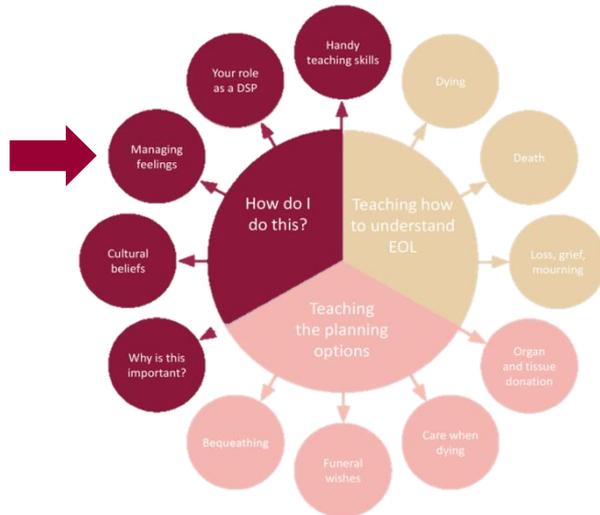
### Important information for participants

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: **Managing Feelings**

This module is mainly intended for disability support professionals (DSPs). Consider showing participants where this module fits in with the other 11 TEL modules.



**Suggested duration:**



30-40 minutes

**This guide includes:**



Main ideas



Links with other modules



Points to highlight from video

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<p style="text-align: center;"><b>Welcome to the module: Managing feelings</b></p> <p>Talking about death may bring up uncomfortable feelings for both disability support professionals (DSPs) and clients.[1] After completing this module, you will feel ready to respond to these feelings and start talking about death with clients.</p>  <p>1. McKenzie et al. 2017</p> <p style="text-align: center;">Slide 2 of 28</p> <p style="text-align: center;">Go back      Next slide</p>	<p style="text-align: center;"></p> <p>Feelings are important, but this module is about trying not to let them stop people talking about end of life.</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 style="text-align: center;"><b>Managing your own feelings</b></p> <p>As a DSP, there are lots of feelings that may come up when talking about death with a client. You may feel:</p> <ul style="list-style-type: none"> <li>• Upset</li> <li>• Uncomfortable</li> <li>• Confident</li> <li>• Anxious</li> </ul>  <p style="text-align: center;">Slide 3 of 28</p> <p style="text-align: center;">Go back      Next slide</p>	<p style="text-align: center;"></p> <p>This part of the module is about disability staff members' feelings.</p>
<p style="text-align: center;"><b>John, Janice, Amir and Angela</b></p> <p>To show some ways that DSPs may manage their own feelings, we are going to look at an imaginary scenario. In this scenario, John, Janice, Amir and Angela are DSPs. All four of them complete training about how to talk to their clients about death, but each person reacts differently....</p>  <p style="text-align: center;">Slide 4 of 28</p> <p style="text-align: center;">Go back      Next slide</p>	
<p style="text-align: center;"><b>Different support worker reactions</b></p> <div style="display: flex; justify-content: space-around;"> <div style="text-align: center;">  John feels upset         </div> <div style="text-align: center;">  Janice feels uncomfortable         </div> </div> <div style="display: flex; justify-content: space-around; margin-top: 10px;"> <div style="text-align: center;">  Amir feels confident         </div> <div style="text-align: center;">  Angela feels anxious         </div> </div> <p style="text-align: center;">Slide 5 of 28</p> <p style="text-align: center;">Go back      Next slide</p>	<p style="text-align: center;"></p> <p>Individuals will have different feelings.</p>
<p style="text-align: center;"><b>John feels upset</b></p> <p>John feels upset. His father died six months earlier and talking about death brings back a lot of pain and sadness. A few weeks after the training, one of John's clients, Brian, asks what happens if someone dies in hospital. John explains that he feels too upset to talk about that topic because his father died recently. John doesn't want Brian's question to be ignored. So he suggests that Brian think of someone else he could talk to. Brian says he will ask another support worker, Hannah.</p>  <p style="text-align: center;">Slide 6 of 28</p> <p style="text-align: center;">Go back      Next slide</p>	

<p><b>When it is not a good time to talk</b></p> <p>There are times when your own feelings make it hard to talk about death with clients.</p> <p>John was not ready to have these conversations himself because of his father's death.[2]</p> <p>However, he did not stop these conversations from happening. With his help, the client Brian spoke to DSP Hannah instead.</p> <p>Later, John checked in with Hannah to see how the conversation went.</p> <p>2. Wiese et al. (2013)</p> <p><a href="#">Go back</a> <span style="margin-left: 100px;">Slide 7 of 28</span> <a href="#">Next slide</a></p> 	 <p>John didn't feel comfortable to have conversations about end of life, but did not ignore his responsibility to his client.</p>
<p><b>Janice feels uncomfortable</b></p> <p>Janice feels uncomfortable. When Janice was growing up, no-one in her family talked openly about death. When her grandmother died Janice's mother always said that she had 'gone up there'.</p> <p>Janice doesn't think she's the right person to explain death to her clients. She does not know what to say because she never talked about it in her own family. [2]</p> <p>2. Wiese et al. (2013)</p> <p><a href="#">Go back</a> <span style="margin-left: 100px;">Slide 8 of 28</span> <a href="#">Next slide</a></p> 	 <p>Research shows that many disability staff feel that they “don't know what to say”. You could discuss ways of starting to talk about dying and death. Other modules have helpful examples such as:</p> <ul style="list-style-type: none"> <li>• Using everyday situations to start a conversation of activity, found in the <i>Handy teaching skills</i> module</li> <li>• Using something on TV to start a conversation, like Rezgar does in the <i>Organ and tissue donation</i> module</li> <li>• Using a sick plant or old pet to start a conversation, like Georgia does in the <i>Dying</i> module</li> </ul>
<p><b>Gaining confidence with experience</b></p> <p>Janice talks to her supervisor about her concerns. They discuss the importance of every DSP being honest and open with clients.</p> <p>After finishing the training and talking to her supervisor, Janice starts having conversations with clients about dying and death, a little bit at the beginning and then expanding the conversations each time.</p> <p>A few months later, she feels a lot more confident talking about the topic and even started talking to her parents about their own funeral wishes.</p> <p><a href="#">Go back</a> <span style="margin-left: 100px;">Slide 9 of 28</span> <a href="#">Next slide</a></p> 	
<p><b>Amir feels confident</b></p> <p>Amir feels confident. He already has a lot of experience talking to clients about dying and death. However, Amir has always waited for the client to start the conversation.</p> <p>After the training, Amir feels inspired to look for opportunities to start even more conversations and to use clear, direct language when explaining death to his clients.</p> <p>He also starts talking about these conversations in team meetings. He wants to encourage his colleagues to support each other in discussing end of life issues.</p> <p><a href="#">Go back</a> <span style="margin-left: 100px;">Slide 10 of 28</span> <a href="#">Next slide</a></p> 	

<p style="text-align: center;"><b>Angela feels anxious</b></p> <p>Angela feels anxious. She is worried that talking about death will make her clients very upset and she will not know what to do.</p> <p>After the training, Angela still avoids talking to her clients about death. When her clients bring up the subject, Angela still feels anxious every time and changes the topic.</p>  <p style="text-align: center;"> <span>Go back</span>      Slide 11 of 28      <span>Next slide</span> </p>	
<p style="text-align: center;"><b>Angela's plan</b></p> <p>Angela talks to Amir about her anxiety. They come up with a plan.</p> <p>Amir talks about death with a client while Angela is on shift. Angela listens in on the conversation and sees that the client does not become upset.[3]</p> <p>A week later, Amir is talking to a client about funerals. Angela joins in the conversation. After Amir leaves, Angela continues the conversation.</p>  <p style="text-align: center;"> <span>Go back</span>      Slide 12 of 28      <span>Next slide</span> </p>	 <p>Staff can get support and advice from colleagues, not just supervisors.</p>
<p style="text-align: center;"><b>Think about...</b></p> <p>What are some other strategies that may help Angela manage her anxiety when talking about death with her clients? Type your answer in the box below.</p> <div style="border: 1px solid #ccc; height: 100px; width: 100%;"></div> <p style="text-align: center;"> <span>Go back</span>      Slide 13 of 28      <span>Next slide</span> </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 style="text-align: center;"><b>Your answers to the 'Think about...' question</b></p> <p><i>What are some other strategies that may help Angela manage her anxiety when talking about death with her clients?</i></p> <p style="text-align: center;"> <span>Go back</span>      Slide 14 of 28      <span>Next slide</span> </p>	
<p style="text-align: center;"><b>Did you get...?</b></p> <ul style="list-style-type: none"> <li>• Practising talking about death with a close friend</li> <li>• Starting small – for example, answering direct questions from clients about end of life</li> <li>• Talking to her supervisor about what strategies to use if a client becomes upset</li> <li>• Refreshing her training on discussing end of life with clients</li> <li>• Talking to someone she trusts about her anxiety</li> </ul>  <p style="text-align: center;"> <span>Go back</span>      Slide 15 of 28      <span>Next slide</span> </p>	
<p style="text-align: center;"><b>Clients' feelings</b></p> <p>In the previous scenario, Angela felt anxious about how her clients would react to talking about death.</p> <p>Becoming emotional or teary is normal, especially if someone close to you has died. It's the same for people with intellectual disability.</p> <p>Like Angela, having an idea of what you will do if a client becomes upset may help reduce your anxiety.[1]</p>  <p style="text-align: center;"> <span>Go back</span>      Slide 16 of 28      <span>Next slide</span> </p>	 <p>This part of the module is about clients' feelings.</p>

<p><b>If the client becomes upset</b></p> <p>If a client becomes upset while talking about dying and death you should provide the usual comfort and support.</p> <p>You can also ask if the person wants to stop talking about it, respect that decision, and just try another time. Remember it's just a natural everyday life-long approach. Don't rush it.</p> <p>If the client is upset about the death of a particular person, you may want to use some of the strategies suggested in the <i>Loss, grief and mourning</i> module, such as doing something special to remember that person.</p>  <p>Go back <span style="margin-left: 100px;">Slide 17 of 28</span> <span style="float: right;">Next slide</span></p>	 <p>See slides 20 and 24 of the <i>Loss, grief and mourning</i> module for ideas about doing something to remember a person who has died.</p>
<p><b>Some thoughts from DSPs</b></p>  <p>Having trouble playing this video? Click on this link to view it in Vimeo: <a href="https://vimeo.com/260093950">https://vimeo.com/260093950</a></p> <p>Go back <span style="margin-left: 100px;">Slide 18 of 28</span> <span style="float: right;">Next slide</span></p>	 <p>Key points for discussion from this video clip are listed below:</p> <p>(01:53-02:01) Eutropia says that with repeated conversations her clients became far more willing to talk about dying, after initial reluctance.</p> <p>(02:43-03:16) Eutropia talks about a client who was dying and receiving palliative care. By visiting the dying person often, other clients were helped to understand and be prepared emotionally.</p> <p>(04:54-04:58) Karen makes the important point “Just because we are talking about it doesn’t make it happen any sooner”.</p>
<p><b>Think about...</b></p>  <p>What would you do if a client started crying when you were talking to them about end of life? Type your answer in the box below.</p> <div style="border: 1px solid black; height: 100px; width: 100%;"></div> <p>Go back <span style="margin-left: 100px;">Slide 19 of 28</span> <span style="float: right;">Next slide</span></p>	
<p><b>Your answers to the ‘Think about...’ question</b></p> <p><i>What would you do if a client started crying when you were talking to them about end of life?</i></p> <p>Go back <span style="margin-left: 100px;">Slide 20 of 28</span> <span style="float: right;">Next slide</span></p>	

<p style="text-align: center;"><b>Did you get...?</b></p> <ul style="list-style-type: none"> <li>• Ask if they would like a tissue or a cup of tea</li> <li>• Provide emotional support - for example, saying "Sometimes it's sad to think about the people we love dying, isn't it?"</li> <li>• Ask if there's anything you can do to help</li> <li>• Ask if they would like to stop talking about the topic, but sometime later see how they are doing</li> <li>• Offer to help the client do something, such as sending a card</li> </ul>  <p style="text-align: center;"> <span>Go back</span>      <i>Slide 21 of 28</i>      <span>Next slide</span> </p>							
<p style="text-align: center;"><b>When more support is needed</b></p> <p>Very rarely, the person may be inconsolable, distressed, depressed or anxious for a long time (days or weeks). If so, it is important to have a planned procedure.</p> <p>You could seek the advice of someone you trust on what to do, or refer the client to a grief counsellor or psychologist with experience working with people with intellectual disability.</p> <p>Such a referral 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 what you can provide.</p>  <p style="text-align: center;"> <span>Go back</span>      <i>Slide 22 of 28</i>      <span>Next slide</span> </p>	 <p>Discuss the steps that disability support professionals (DSPs) in your organisation should take in this situation.</p>						
<p style="text-align: center;"><b>Seek help if you are unsure</b></p>  <p>If talking about death and dying is distressing for you, or you are unsure what to do, please talk about it with someone you trust.</p> <p style="text-align: center;"> <span>Go back</span>      <i>Slide 23 of 28</i>      <span>Next slide</span> </p>	 <p>Someone you trust could be your supervisor, a colleague, a friend or family member.</p>						
<p style="text-align: center;"><b>Key concepts</b></p> <p>Talking about death may bring up uncomfortable feelings for both DSPs and clients.</p> <p>DSPs are responsible for making sure clients can talk about it if they want to.</p> <p>If you are feeling upset, uncomfortable or anxious when talking to clients about end of life issues, seek support.</p> <p>If a client gets upset when talking about end of life, that's usually normal. Referral to professional support should not be the first step.</p> <p>If a client is inconsolable for a long time, talk with your supervisor about whether further steps should be taken.</p>  <p style="text-align: center;"> <span>Go back</span>      <i>Slide 24 of 28</i>      <span>Next slide</span> </p>							
<p style="text-align: center;"><b>Research supporting this module</b></p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="background-color: #e6f2ff;">Reference</th> <th style="background-color: #e6f2ff;">About</th> </tr> </thead> <tbody> <tr> <td style="font-size: 0.8em;">1. McKenna, M., Merfin-Velich, B., Conder, J., &amp; Bradford, S. (2017). "I'm still here": Exploring what matters to people with intellectual disability during advance care planning. <i>Journal of Applied Research in Intellectual Disabilities</i>, 30(6), 1069-1098. doi: 10.1111/jar.12355 <a href="https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12355">https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12355</a></td> <td style="font-size: 0.8em;">This study reports on Advance Care Planning by 4 adults with intellectual disability. All knew of their life limiting (terminal) condition. The article provides practical information on when to start, openness, supporting emotional wellbeing, skilled facilitation, ongoing conversations at the person's pace, clear information, the person making their own decisions, planning for life (not just death), and having a planning template.</td> </tr> <tr> <td style="font-size: 0.8em;">2. Wiese, M., Dew, A., Standcliffe, R. J., Howarth, G., &amp; Balardin, S. (2013). "If and when?": The beliefs and experiences of community living staff in supporting older people with intellectual disability to know about dying. <i>Journal of Intellectual Disability Research</i>, 57, 980-992. doi:10.1111/j.1365-2788.2012.01593.x <a href="https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2788.2012.01593.x">https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2788.2012.01593.x</a></td> <td style="font-size: 0.8em;">In theory, community living staff supported the right of a person with intellectual disability to know about dying and death. In practice, staff supported some opportunities to know, such as when a family member died, but avoided or protected the person from others. Staff felt daunted by talking to a dying person about their terminal condition. They saw clients' capacity to understand as a barrier.</td> </tr> </tbody> </table> <p style="text-align: center;"> <span>Go back</span>      <i>Slide 25 of 28</i>      <span>Next slide</span> </p>	Reference	About	1. McKenna, M., Merfin-Velich, B., Conder, J., & Bradford, S. (2017). "I'm still here": Exploring what matters to people with intellectual disability during advance care planning. <i>Journal of Applied Research in Intellectual Disabilities</i> , 30(6), 1069-1098. doi: 10.1111/jar.12355 <a href="https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12355">https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12355</a>	This study reports on Advance Care Planning by 4 adults with intellectual disability. All knew of their life limiting (terminal) condition. The article provides practical information on when to start, openness, supporting emotional wellbeing, skilled facilitation, ongoing conversations at the person's pace, clear information, the person making their own decisions, planning for life (not just death), and having a planning template.	2. Wiese, M., Dew, A., Standcliffe, R. J., Howarth, G., & Balardin, S. (2013). "If and when?": The beliefs and experiences of community living staff in supporting older people with intellectual disability to know about dying. <i>Journal of Intellectual Disability Research</i> , 57, 980-992. doi:10.1111/j.1365-2788.2012.01593.x <a href="https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2788.2012.01593.x">https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2788.2012.01593.x</a>	In theory, community living staff supported the right of a person with intellectual disability to know about dying and death. In practice, staff supported some opportunities to know, such as when a family member died, but avoided or protected the person from others. Staff felt daunted by talking to a dying person about their terminal condition. They saw clients' capacity to understand as a barrier.	<p>This slide lists in full all the research mentioned in this module. The <i>About</i> column gives a brief summary of the relevant information from each research publication.</p>
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<p><b>Your answers for this module</b></p> <p>If you would like to keep a copy of your answers for this module, you can print them out or email them to yourself.</p> <div data-bbox="284 327 392 416"></div> <p><b>Print your answers to the Think About questions</b></p> <div data-bbox="469 327 609 416"></div> <p><b>Email your answers to yourself</b></p> <p><a href="#">Go back</a>      <small>Slide 27 of 28</small>      <a href="#">Next slide</a></p>	
<div data-bbox="209 555 331 696"></div> <p><b>Congratulations!</b></p> <p>You have completed the module</p> <p>You can now <a href="#">print a certificate</a></p> <p><a href="#">Go back</a>      <small>Slide 28 of 28</small>      <a href="#">Go to home page</a></p>	