

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.

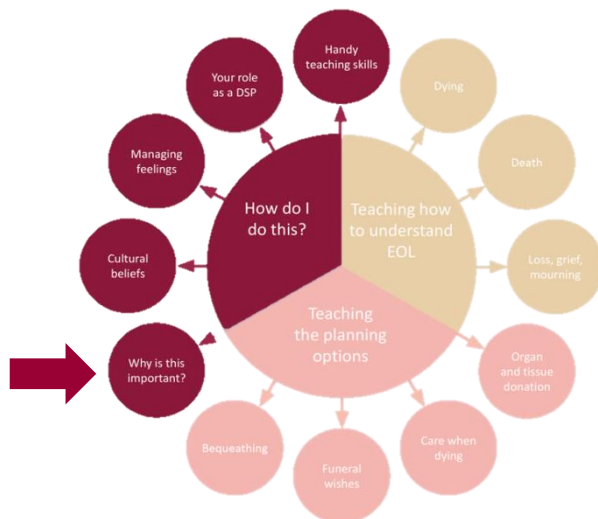
Important information for participants

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: *Why is this important?*

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



Suggested duration:



20-30 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>How do I do this? Why is this important?</p> <p><small>SYDNEY WESTERN SYDNEY HARRIMOND GATE UNISON Hinders</small></p> <p><small>The TEL project is supported by funding from the Australian Government and the NSW Government under the DPEP (Disability Prevention and Early Intervention) program.</small></p> <p>Start</p>	
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<p>Welcome to the module: Why is this important?</p> <p>For many people, talking about end of life is hard. It can seem even harder when talking to a client with intellectual disability.^[1,2]</p> <p>However, death is part of life and ignoring it won't make it go away. In fact, ignoring death can make things worse.</p> <p>1. Todd (2013) 2. Wiese et al. (2013)</p> <p>Go back Slide 2 of 27 Next slide</p> 	 <p><i>“ignoring death can make things worse”</i></p> <p>Discuss problems that can arise for people with intellectual disability if you don't help them to understand dying and death by talking about these issues.</p> <p>Think about examples of problems caused by lack of planning (e.g., an impersonal or unsuitable funeral).</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>Think about...</p> <p>As a Disability Support Professional (DSP), why is it hard to talk to a client about end of life?</p> <p>Type your answer in the box below.</p> <p>Go back Slide 3 of 27 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>As a Disability Support Professional (DSP), why is it hard to talk to a client about end of life?</p> <p>Go back Slide 4 of 27 Next slide</p>	
<p>Did you get...?</p> <ul style="list-style-type: none"> • Feeling unsure whether the client knows what death is • Worrying that the client will become upset • Thinking that it is not your role as a DSP to explain what dying and death are to a client • Feeling uncomfortable talking about death in general • Not knowing what to say <p>Go back Slide 5 of 27 Next slide</p> 	 <p>Understanding death is dealt with in the module <i>Death</i>.</p> <p>Becoming upset and feeling uncomfortable are covered in the module <i>Managing Feelings</i>.</p> <p>A DSP's role is addressed in the module <i>Your Role as a DSP</i>.</p>

<p>Some thoughts from disability support professionals</p>  <p>Having trouble playing this video? Click on this link to view it in Vimeo: https://vimeo.com/238698490</p> <p>Go back Slide 6 of 27 Next slide</p>	 <p>Key points for discussion from this video clip are listed below:</p> <p>(00:32) “if people can talk about it it’s not going to be such a taboo subject”.</p> <p>(01:16) “you only get one chance of providing that [end of life care]”.</p> <p>(01:33) “It’s just an everyday conversation that [we have] continually”.</p> <p>(02:10) “by not having those conversations we’re disadvantaging people”.</p>
<p>Why do we need to talk about it now?</p> <p>Research shows that people with intellectual disability:</p> <ul style="list-style-type: none"> • Are not always told if they are dying.[1,3] • Are not always told if a family member, partner or friend is dying.[4] • If told about their own or someone else’s dying, it might be the first time the topic has ever come up.  <p>1. Todd (2013) 3. Kirkenrath et al. (2017) 4. Todd (2004)</p> <p>Go back Slide 7 of 27 Next slide</p>	 <p>What problems can arise if people are not told about a person dying?</p>
<p>Part of everyday life</p> <p>Talking about dying and death is not going to make it happen faster.</p> <p>Rather, it can help a person with intellectual disability understand, cope and plan.</p> <p>It is important to teach people about dying and death as part of everyday life while people are well, anywhere and at any time.</p>  <p>Go back Slide 8 of 27 Next slide</p>	
<p>The benefits</p> <p>A person with intellectual disability has the right to know about death, just like everyone else. With this right, a person will:</p> <ol style="list-style-type: none"> 1. Better understand what is happening when someone they know dies 2. Plan for and make decisions about their own end of life, if they choose to [5]  <p>5. McKenzie et al. (2017)</p> <p>Go back Slide 9 of 27 Next slide</p>	

<p>Some thoughts from people with intellectual disability</p>  <p>Having trouble playing this video? Click on this link to view it in Vimeo: https://vimeo.com/259797538</p> <p>Go back Slide 19 of 27 Next slide</p>	 <p>Key points for discussion from this video clip are listed below:</p> <p>How comfortable do these people seem about discussing dying and death?</p> <p>How do you think your clients would answer the same questions?</p> <p>(00:54) “I’d like to die at home”.</p> <p>(01:13) “I think it’s good to talk about it more”.</p> <p>(01:54) “You don’t have to keep it to yourself”.</p>
<p>What can happen</p> <p>Through two case studies, you will see what can happen when a person with intellectual disability is not supported to understand end of life.</p> <p>In the first case study, Genevieve is not supported to understand what is happening when her grandmother dies....</p>  <p>Go back Slide 11 of 27 Next slide</p>	
<p>Genevieve</p> <p>Genevieve has intellectual disability. She hasn’t seen her sick grandmother for many weeks, and then her grandmother dies.</p> <p>Genevieve isn’t invited to the funeral. Everyone just keeps saying “Grandma’s now upstairs”.</p>  <p>Go back Slide 12 of 27 Next slide</p>	 <p>“Grandma’s now upstairs” Is this “softer” way of saying that grandma is dead helpful or confusing?</p>  <p>Look at the module <i>Handy teaching skills</i>, especially the section on “clear and direct language”.</p>
<p>Think about...</p> <p>What could happen next?</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 13 of 27 Next slide</p>	

<p>Your answers to the 'Think about...' question</p> <p><i>What could happen next?</i></p> <p>Go back Slide 14 of 27 Next slide</p>	
<p>Genevieve</p> <p>Genevieve worries that she has done something wrong and that's why she wasn't allowed to see her grandmother when she was ill, or go to the funeral. (6)</p> <p>Genevieve becomes scared of going upstairs in her family home. She also begins refusing to do things that she formerly did with her grandmother, such as going to the library.</p> <p>6. Forrester-Jones (2013)</p> <p>Go back Slide 15 of 27 Next slide</p> 	
<p>Trying to protect a person from death can make things worse</p> <p>Genevieve's family were trying to protect her from her grandmother's death, but things ended up worse than if Genevieve had been supported to understand what was happening.</p> <p>People with intellectual disability can and should be included. The best way to do this is to start talking about death well before a loved one dies.</p> <p>Go back Slide 16 of 27 Next slide</p> 	
<p>Planning for your own death</p> <p>You will now look at the case of a DSP, Mary, and think about what can happen if someone isn't given the choice to plan for their own death.</p> <p>Go back Slide 17 of 27 Next slide</p> 	
<p>Mary</p> <p>Mary has provided drop-in support to Neil in his home for 7 years. Neil, who is 65, dies suddenly and unexpectedly. At his funeral the flowers are pink, the music is bland and afterwards everyone gathers at a nearby hall for coffee and cake.</p> <p>Go back Slide 18 of 27 Next slide</p> 	
<p>Mary</p> <p>Mary feels sad because she knows that Neil did not like pink flowers, loved rock music, and that he would have liked everyone to enjoy a beer at the much-loved local rugby club that he and Mary went to each week. Mary feels like it could have been anyone's funeral, and that it did not reflect who Neil was.</p> <p>Go back Slide 19 of 27 Next slide</p> 	

<h2>How could have things been different?</h2> <p>In the <i>Funeral Wishes</i> module you will learn how to support a client to write down choices in a 'My end of life choices' book (117kb Word doc).</p> <p>If Mary had been confident that Neil knew about death, she could have supported Neil to record his funeral wishes, just like any other person-centred plan.</p>  <p>Go back Slide 20 of 27 Next slide</p>							
<h2>Gaining confidence with experience</h2> <p>It is understandable that Mary had not done a person-centred plan with Neil about his funeral wishes.</p> <p>A lot of people don't feel confident talking about dying and death, especially with a person with intellectual disability.</p> <p>If you practise having these conversations, you will feel more confident over time.</p>  <p>Go back Slide 21 of 27 Next slide</p>	 <p>Gaining confidence in talking about dying and death is covered in the module <i>Managing Feelings</i>.</p>						
<h2>Seek help if you are unsure</h2>  <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>Go back Slide 23 of 28 Next slide</p>	 <p>Someone you trust could be your supervisor, a colleague, a friend or family member.</p>						
<h2>Key concepts</h2> <p>Death is a part of life and ignoring it isn't going to make it go away. In fact, ignoring death can make things worse.</p> <p>People with intellectual disability are not always told if they are dying or about the death of a loved one, but they have the right to know about death, just like everyone else.</p> <p>Knowing about death means a client will better understand what is happening when someone they know dies. As well, they can plan for and make decisions about their own end of life, if they choose.</p>  <p>Go back Slide 25 of 27 Next slide</p>							
<h2>Research supporting this module</h2> <table border="1"> <thead> <tr> <th>Reference</th> <th>About</th> </tr> </thead> <tbody> <tr> <td>1. Todd, S. (2013). 'Being there': The experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities. <i>Journal of Applied Research in Intellectual Disabilities</i>, 26, 215-230. doi:10.1111/jar.12024 https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12024</td> <td>Disability staff who had experienced a resident death were interviewed. Themes included: 'being there' to support the dying person; having the opportunity to die at home with familiar people; the person often not being told that they were dying, sometimes because staff were unable to find a way to tell them. Staff involvement included dying, death and remembrance. There were some tensions between the roles of staff and family.</td> </tr> <tr> <td>2. Wiles, M., Dew, A., Standiford, R. J., Howarth, G., & Balandin, S. (2019). '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/jir.12593 https://onlinelibrary.wiley.com/doi/abs/10.1111/jir.12593</td> <td>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>Go back Slide 24 of 28 Next slide</p>	Reference	About	1. Todd, S. (2013). 'Being there': The experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities. <i>Journal of Applied Research in Intellectual Disabilities</i> , 26, 215-230. doi:10.1111/jar.12024 https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12024	Disability staff who had experienced a resident death were interviewed. Themes included: 'being there' to support the dying person; having the opportunity to die at home with familiar people; the person often not being told that they were dying, sometimes because staff were unable to find a way to tell them. Staff involvement included dying, death and remembrance. There were some tensions between the roles of staff and family.	2. Wiles, M., Dew, A., Standiford, R. J., Howarth, G., & Balandin, S. (2019). '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/jir.12593 https://onlinelibrary.wiley.com/doi/abs/10.1111/jir.12593	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>Your answers for this module</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>   </div> <div> <p><u>Print your answers to the Think About questions</u></p> <p><u>Email your answers to yourself</u></p> </div> <div> <p>Go back</p> <p>Slide 27 of 28</p> <p>Next slide</p> </div>	
<div>  </div> <p>Congratulations!</p> <p>You have completed the module</p> <p>You can now <u>print a certificate</u></p> <div> <p>Go back</p> <p>Slide 28 of 28</p> <p>Go to home page</p> </div>	