

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.

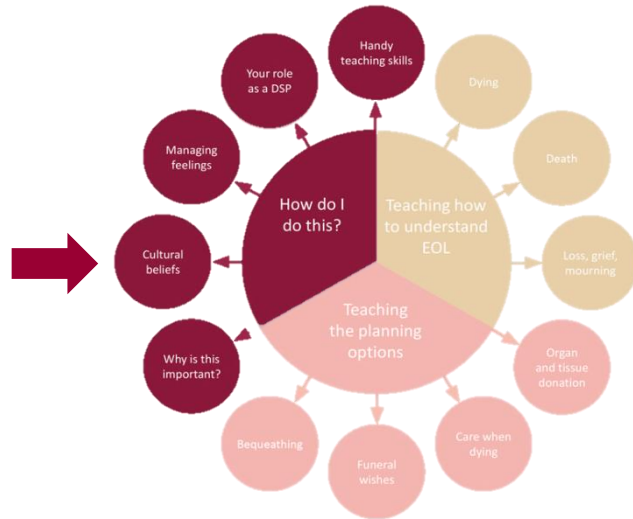
Important information for participants

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: Cultural beliefs

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

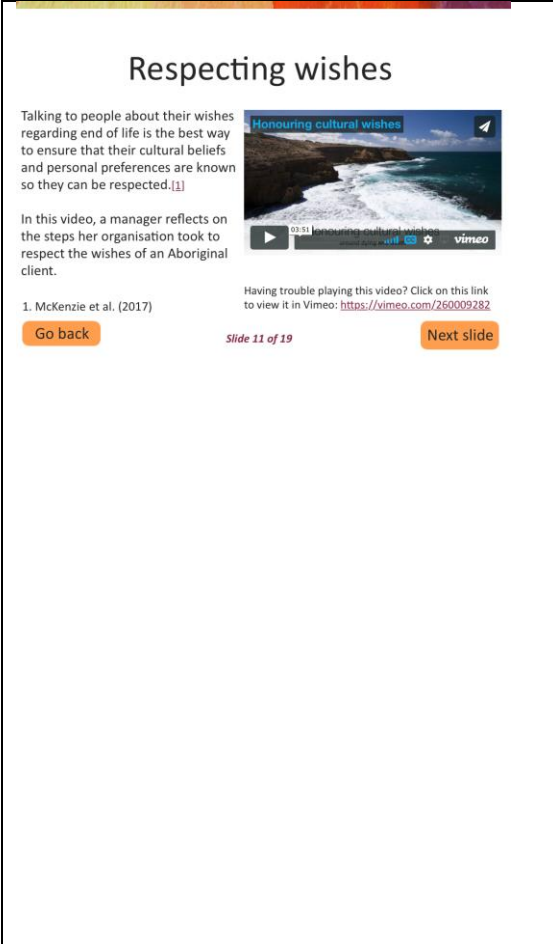


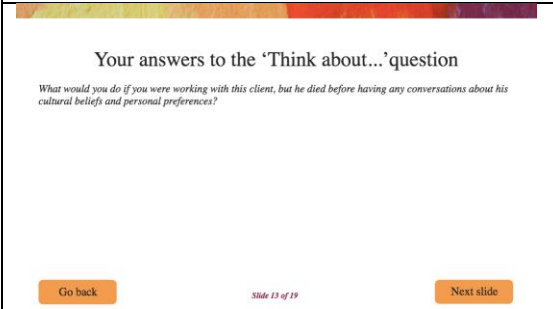









Points to highlight from video

<p style="text-align: center;">Talking End of Life ...with people with intellectual disability</p> <p style="text-align: center; font-size: 1.2em;">How do I do this?</p> <p style="text-align: center; font-size: 1.5em;">Cultural beliefs</p> <div style="display: flex; justify-content: space-between; align-items: center; margin-top: 10px;"> <div style="font-size: 0.8em;"> </div> <div style="font-size: 0.7em; text-align: center;"> <p>The TEL project is supported by funding from the Australian Government, Department of Health under the Public Health and Chronic Disease</p> </div> <div style="background-color: #f4a460; color: white; padding: 2px 10px; border-radius: 5px;">Start</div> </div>	
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<p style="text-align: center;">Welcome to the module: Cultural beliefs</p> <p>Cultural beliefs can affect both you and your client when talking about end of life.</p> <p>This module will provide an opportunity to reflect on how culture can play a part in understanding and planning for end of life.</p> <p>This reflection will help you when supporting a client who may be from a different cultural background to you.</p>  <p style="text-align: center;">Go back Slide 2 of 19 Next slide</p>	<p style="text-align: center;"></p> <p>Culture is about the customs or social behaviours of a people or society.</p> <p>Everyone has different ways (customs) that influence how they understand end of life, plan for it, and how they conduct rituals when people die.</p>
<p style="text-align: center;">Think about...</p> <p style="text-align: center;">What are some examples of cultural beliefs about end of life? Type your answer in the box below.</p> <div style="border: 1px solid #ccc; height: 100px; width: 100%;"></div> <p style="text-align: center;">Go back Slide 3 of 19 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 style="text-align: center;">Your answers to the ‘Think about...’ question</p> <p style="text-align: center;"><i>What are some examples of cultural beliefs about end of life?</i></p> <div style="border: 1px solid #ccc; height: 100px; width: 100%;"></div> <p style="text-align: center;">Go back Slide 4 of 19 Next slide</p>	
<p style="text-align: center;">Funeral practices</p> <p>People have lots of different beliefs about death, which often affect the rituals that happen after somebody dies.</p> <p>In the following video, disability support professionals (DSPs) reflect on different funeral practices.</p> <div style="border: 1px solid #ccc; padding: 5px;"> <p style="font-size: small;">Cultural beliefs (staff)</p> <p style="text-align: center;">Cultural beliefs about dying and death</p> <p style="font-size: x-small;">03:38</p> <p style="font-size: x-small;">Having trouble playing this video? Click on this link to view it in Vimeo: https://vimeo.com/260001269</p> </div> <p style="text-align: center;">Go back Slide 5 of 19 Next slide</p>	<p style="text-align: center;"></p> <p>Key points for discussion from this video clip are listed below:</p> <p>Eutropia, John, Paddy and Damien each speak differently about their funeral experiences. Discuss with participants their own experiences of funeral practices.</p> <p>(02:38-03:36) Damien described how his family’s cultural funeral ritual helped him to process his father’s death.</p>

<p style="text-align: center;">More than just funerals</p> <p>The most obvious way that cultural beliefs relate to end of life is through different funeral practices.</p> <p>In the video you just watched you heard about how funerals held in India, Ireland and the Philippines can be different from funerals in Australia.</p> <p>However, cultural beliefs can also affect other parts of end of life, including decisions about care when dying.</p> <p>This can be seen in the scenario on the next page...</p> <div style="display: flex; justify-content: space-between; align-items: center;"> <div style="border: 1px solid orange; padding: 2px 5px;">Go back</div> <div style="text-align: center; font-size: 0.8em;">Slide 6 of 19</div> <div style="border: 1px solid orange; padding: 2px 5px;">Next slide</div> </div> 	<div style="display: flex; align-items: center;">  <p>See the <i>Dying</i> module about how people with intellectual disability can understand when someone they care about is dying, and how they could become involved in their care.</p> </div>
<p style="text-align: center;">Noya</p> <p>Noya lives in supported accommodation and is supported by Belinda, among other support workers.</p> <p>Noya's family are Arabic and practising Muslims. Noya visits her family often.</p> <p>Noya's oldest brother is dying. Noya's family have explained to Belinda the Muslim custom about modesty and that Noya's brother and the rest of the family are trying to ensure that only men care for him. Belinda knows that Noya really wants to help look after her brother.</p> <div style="display: flex; justify-content: space-between; align-items: center;"> <div style="border: 1px solid orange; padding: 2px 5px;">Go back</div> <div style="text-align: center; font-size: 0.8em;">Slide 7 of 19</div> <div style="border: 1px solid orange; padding: 2px 5px;">Next slide</div> </div> 	
<p style="text-align: center;">Think about...</p> <p>How could Belinda help Noya to have a caring role that is in keeping with the family's cultural beliefs?</p> <p>Type your answer in the box below.</p> <div style="border: 1px solid gray; height: 100px; width: 100%;"></div> <div style="display: flex; justify-content: space-between; align-items: center;"> <div style="border: 1px solid orange; padding: 2px 5px;">Go back</div> <div style="text-align: center; font-size: 0.8em;">Slide 8 of 19</div> <div style="border: 1px solid orange; padding: 2px 5px;">Next slide</div> </div> 	
<p style="text-align: center;">Your answers to the 'Think about...' question</p> <p><i>How could Belinda help Noya to have a caring role that is in keeping with the family's cultural beliefs?</i></p> <div style="display: flex; justify-content: space-between; align-items: center;"> <div style="border: 1px solid orange; padding: 2px 5px;">Go back</div> <div style="text-align: center; font-size: 0.8em;">Slide 9 of 19</div> <div style="border: 1px solid orange; padding: 2px 5px;">Next slide</div> </div>	
<p style="text-align: center;">Did you get...?</p> <ul style="list-style-type: none"> • Cook for him • Visit him • Speak to him on the phone • Play music with him • Look through a family photo album together <div style="display: flex; justify-content: space-between; align-items: center;"> <div style="border: 1px solid orange; padding: 2px 5px;">Go back</div> <div style="text-align: center; font-size: 0.8em;">Slide 10 of 19</div> <div style="border: 1px solid orange; padding: 2px 5px;">Next slide</div> </div> 	<div style="display: flex; align-items: center;">  <p>There are a lot of different ways to care, while still respecting cultural traditions. Sometimes we just need to get a bit creative.</p> </div>

<p style="text-align: center;">Respecting wishes</p> <p>Talking to people about their wishes regarding end of life is the best way to ensure that their cultural beliefs and personal preferences are known so they can be respected.^[1]</p> <p>In this video, a manager reflects on the steps her organisation took to respect the wishes of an Aboriginal client.</p> <p>1. McKenzie et al. (2017)</p> <p>Having trouble playing this video? Click on this link to view it in Vimeo: https://vimeo.com/260009282</p> <p style="text-align: center;"> Go back <i>Slide 11 of 19</i> 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> Key points for discussion from this video clip are listed below:</p> <p>(00:40-01:31) Karen describes how they took advantage of all the available resources to ensure the dying client’s wishes were known about, and honoured (e.g., indigenous staff person, and the use of a formal service to help find family members).</p> <p>(03:25-03:42) Karen describes how good it felt to honour the cultural wishes of the dying person.</p>
<p style="text-align: center;">Think about...</p> <p>What would you do if you were working with this client, but he died before having any conversations about his cultural beliefs and personal preferences? Type your answer in the box below.</p> <p style="text-align: center;"> Go back <i>Slide 12 of 19</i> Next slide </p> 	
<p style="text-align: center;">Your answers to the ‘Think about...’question</p> <p>What would you do if you were working with this client, but he died before having any conversations about his cultural beliefs and personal preferences?</p> <p style="text-align: center;"> Go back <i>Slide 13 of 19</i> Next slide </p> 	

<p style="text-align: center;">Did you get...?</p> <ul style="list-style-type: none"> • Talk to family or friends who knew the client well • Do things that match what the client wanted, such as returning to country. • Consult with Aboriginal elders from the client's place of birth to see what cultural considerations may be appropriate • Talk to your supervisor about the need to discuss funeral wishes before a client dies so that doesn't happen again  <p style="text-align: center;"> Go back Slide 14 of 19 Next slide </p>					
<p style="text-align: center;">Seek help if you are unsure</p>  <p>If you are unsure what your role is when talking about end of life with a client, please talk about it with someone you trust.</p> <p style="text-align: center;"> Go back Slide 18 of 23 Next slide </p>	 <p>Someone you trust could be your supervisor, a colleague, a friend or family member.</p>				
<p style="text-align: center;">Key concepts</p> <p>You should provide your client with information that will help them make informed decisions about end of life.</p> <p>You should not make decisions about end of life for your client.</p> <p>If your client wants to make a decision about end of life, your role may be to support them to participate in person-centred planning.</p>  <p style="text-align: center;"> Go back Slide 19 of 23 Next slide </p>					
<p style="text-align: center;">Research supporting this module</p> <table border="1" data-bbox="204 1189 651 1279"> <thead> <tr> <th>Reference</th> <th>About</th> </tr> </thead> <tbody> <tr> <td>1. McKenzie, N., Mirfin-Neitch, B., Conder, J., & Brandford, 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), 1089–1098. doi: 10.1111/jar.12335 https://www.ncbi.nlm.nih.gov/pubmed/28378405</td> <td>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> </tbody> </table> <p style="text-align: center;"> Go back Slide 17 of 19 Next slide </p>	Reference	About	1. McKenzie, N., Mirfin-Neitch, B., Conder, J., & Brandford, 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), 1089–1098. doi: 10.1111/jar.12335 https://www.ncbi.nlm.nih.gov/pubmed/28378405	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.	<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>
Reference	About				
1. McKenzie, N., Mirfin-Neitch, B., Conder, J., & Brandford, 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), 1089–1098. doi: 10.1111/jar.12335 https://www.ncbi.nlm.nih.gov/pubmed/28378405	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.				
<p style="text-align: center;">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 style="display: flex; justify-content: space-around;"> <div data-bbox="284 1541 395 1621">  <p>Print your answers to the Think About questions</p> </div> <div data-bbox="475 1541 619 1621">  <p>Email your answers to yourself</p> </div> </div> <p style="text-align: center;"> Go back Slide 27 of 28 Next slide </p>					
 <p style="text-align: center;">Congratulations!</p> <p style="text-align: center;">You have completed the module</p> <p style="text-align: center;">You can now print a certificate</p> <p style="text-align: center;"> Go back Slide 28 of 28 Go to home page </p>					