

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 24 "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.

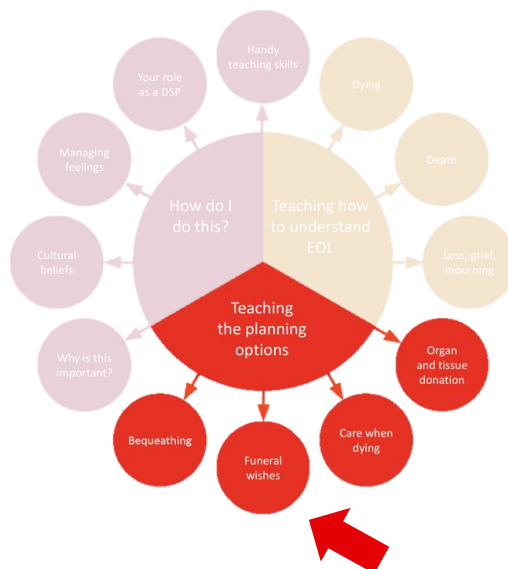
Important information for participants

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: Funeral wishes

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



Suggested duration:



30-35 minutes

This guide includes:



Main ideas





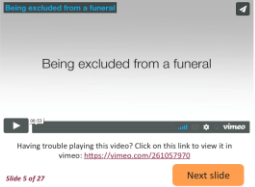

Links with other modules











Points to highlight from video










<p>Talking End of Life ...with people with intellectual disability</p> <p>Teaching the planning options: Funeral wishes</p> <p><small>UNIVERSITY OF SYDNEY WESTERN SYDNEY UNIVERSITY HammondCare UNISON Flinders University</small></p> <p><small>This TEL project is supported by funding from the Australian Government Department of Health under the Public Health and Chronic Disease Fund</small></p> <p>Start</p>	
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<p>Welcome to the module about: Funeral wishes</p> <p>Many people have ideas about what they would like to happen at their funeral.</p> <p>After completing this module you can support a person with intellectual disability to understand:</p> <p><i>"I can choose what happens at my funeral if I want to."</i></p> <p>Go back Slide 2 of 27 Next slide</p>	
<p>Learning about funerals</p> <p>A lot of people learn what a funeral is by going to funerals for family members or friends. They may also ask questions or see funerals on TV shows or movies.</p> <p>In this video, Sally describes what she learned about funerals after going to her friend's funeral.</p> <p>What happens at a funeral?</p> <p>Go back Slide 3 of 27 Next slide</p>	 <p>The key point for discussion from this video clip is listed below:</p> <p>Sally shows us that people with intellectual disability can understand what happens at a funeral.</p>
<p>Saying goodbye at funerals</p> <p>Funerals are an important opportunity to say goodbye to the person who has died. It is also a chance to grieve with other people.</p> <p>In this video, Richard describes what he felt when he went to his mother's funeral.</p> <p>Being included in events related to dying and death</p> <p>Go back Slide 4 of 27 Next slide</p>	 <p>The key point for discussion from this video clip is listed below:</p> <p>Although Richard said going to the funeral was "upsetting", he also said it "was good". These are common responses. People with intellectual disability should be able to go to funerals, say goodbye, and feel proud that they attended, just as Richard did.</p>





<p>Some people are not invited to funerals</p> <p>Unfortunately, not everybody gets the same opportunity to say goodbye that Richard had.</p> <p>Often people with intellectual disability are not invited to funerals^[1] because their loved ones are trying to protect them from sadness or believe they can't cope or understand.^[2]</p> <p>In this video, Kathie describes what it felt like when she was not able to go to her own mother's funeral.</p> <p>1. Forrester Jones (2013) 2. Wiese et al. (2015)</p> <p>Go back Next slide</p> <p>Slide 5 of 27</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>Kathie's experience was different to Richard's shown in Slide 4. Kathie felt "sad" and "bad" because she wasn't invited to her mother's funeral.</p> <p>What feelings might Kathie be left with compared to Richard?</p>
<p>Think about...</p> <p>If Kathie was your client, what would you do to help her say goodbye to her mother, even though she was not able to go to her mother's funeral? Type your answer in the box below.</p> <p>Go back Next slide</p> <p>Slide 6 of 27</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>If Kathie was your client, what would you do to help her say goodbye to her mother, even though she was not able to go to her mother's funeral?</p> <p>Go back Next slide</p> <p>Slide 7 of 27</p>	

<p>Was your answer like this?</p> <p>In this video, Kathie describes being able to visit her mother's grave to say goodbye. She put flowers on the grave and talked to her mother.</p> <p>Some other ways Kathie could have said goodbye to her mother include:</p> <ul style="list-style-type: none"> • Holding a memorial • Writing a goodbye letter • Having a special ceremony on her mother's birthday <p>Go back Next slide</p> <p>Slide 8 of 27</p>	 <p>Key points for discussion from this video clip are listed below:</p> <p>Saying goodbye really helps, even if it's a long time after the loved one died.</p> <p>It's never too late to help a person with intellectual disability say goodbye to a loved one.</p>
<p>People with intellectual disability should be able to go to funerals</p> <p>Just like anybody else, the best way for people with intellectual disability to understand what happens at a funeral is to go to one.[1]</p> <p>People with intellectual disability can and should be able to go to funerals if they want to.</p>  <p>Go back Next slide</p> <p>Slide 9 of 27</p>	
<p>Preparing for a funeral</p> <p>If there are concerns that a person with intellectual disability will not cope or understand what is happening in a funeral, it may be useful to prepare.</p> <p>This animation shows the basics of what happens at a funeral and could be a starting point for more conversation.</p>  <p>Go back Next slide</p> <p>Slide 10 of 27</p>	 <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>
<p>From understanding to planning</p> <p>When a person with intellectual disability understands what a funeral is, they may start thinking about what they would like at their own funeral.</p> <p>In this video, Caroline goes to her mother's funeral and starts thinking about what she wants at her own funeral.</p>  <p>Go back Next slide</p> <p>Slide 11 of 27</p>	 <p>The key point for discussion from this video clip is listed below:</p> <p>The conversation about what Carolyn might like at her funeral comes up naturally. Anna uses this opportunity to help Carolyn plan for her own funeral.</p>  <p>Anna uses a lot of good teaching skills and you can find these in the <i>Handy teaching skills</i> module.</p>  <p>The animations shown in this video are also available in the <i>Videos</i> tab</p>

<div data-bbox="199 212 279 280"></div> <h2>Think about...</h2> <p>In the video, Caroline talks about the music she would like at her funeral. What are some other choices that people might have about what happens at their funeral? Type your answer in the box below.</p> <div data-bbox="199 291 657 436"></div> <div data-bbox="199 436 657 459"> Go back Slide 12 of 27 Next slide </div>	
<h2>Your answers to the 'Think about...' question</h2> <p>In the video, Caroline talks about the music she would like at her funeral. What are some other choices that people might have about what happens at their funeral?</p> <div data-bbox="199 571 657 694"></div> <div data-bbox="199 694 657 716"> Go back Slide 13 of 27 Next slide </div>	
<h2>Did you get...?</h2> <ul style="list-style-type: none"> Where the funeral ceremony is held Location of grave or ashes Music Flowers and other decorations Readings, such as a favourite poem or story A photo to be included on the funeral handout or placed on the coffin Whether the person would like to be buried or cremated Whether people that go to the funeral should wear dark or colourful clothes <div data-bbox="462 806 638 929"></div> <div data-bbox="199 963 657 985"> Go back Slide 14 of 27 Next slide </div>	
<h2>'My end of life choices' book</h2> <p>'My end of life choices' book includes lots of choices about what happens at a funeral, including:</p> <ul style="list-style-type: none"> The location The music Whether the person would like to be buried or cremated. <p>You can print a copy of 'My end of life choices' book by clicking on this link: https://www.carsearch.com.au/death-planning/prepare/21/Complete-Modules/Documents/My-End-of-Life-Book-Template.docx (117kb.pdf)</p> <div data-bbox="446 1075 654 1187"></div> <div data-bbox="199 1232 657 1254"> Go back Slide 15 of 27 Next slide </div>	

<p>'My end of life choices' book</p> <p>In this video, Anna supports Caroline to use the 'My end of life choices' book as part of person-centred planning for a funeral.</p>  <p>Having trouble playing this video? Click on this link to view it in Vimeo: https://vimeo.com/259072783</p> <p>Go back Slide 16 of 27 Next slide</p>	 <p>Key points for discussion from this video clip are listed below:</p> <p>(00:17-00:25) Have one place where everything can be written down so the person's wishes don't get lost.</p> <p>(00:40-00:44) People can change their minds about their funeral wishes if they want to.</p> <p>(00:44-00:50) Anna encourages Carolyn to talk to her family about her funeral wishes.</p> <p>Does your organisation have a way that it could safely record a person's wishes about their funeral?</p>  <p>There is more information about making end-of-life decisions in the <i>Your role as a DSP</i> module.</p>
<p>Do things to encourage understanding</p> <p>You may have noticed that Anna didn't just start by giving Caroline a 'My end of life choices' book. She took the time to explain the choice between burial and cremation by visiting a grave and a crematorium with Caroline.</p> <p>Anna also used animations, like the one on this slide. The animation about cremation is on the next slide.</p>  <p>Having trouble playing this video? Click on this link to view it in Vimeo: https://vimeo.com/239578902</p> <p>Go back Slide 17 of 27 Next slide</p>	 <p>The animation is also available in the Videos tab. You could show this video to a person with intellectual disability to help them understand burial.</p>
<p>Cremation animation</p> <p>You may consider using these animations when explaining burial and cremation to a person with intellectual disability.</p> <p>If you want to use these videos in the future, you can also find them on the Videos tab of this website.</p>  <p>Having trouble playing this video? Click on this link to view it in Vimeo: https://vimeo.com/239578906</p> <p>Go back Slide 18 of 27 Next slide</p>	 <p>The animation is also available in the Videos tab. You could show this video to a person with intellectual disability to help them understand cremation</p>
<p>Different cultures have different ceremonies</p> <p>Different cultures have different ceremonies to mark important parts of life. This includes funerals.</p> <p>On the next slides, you will see videos that are included in the Cultural beliefs module.</p> <p>If you want more information about being respectful of other people's beliefs, please complete the Cultural beliefs module.</p>  <p>Go back Slide 19 of 27 Next slide</p>	 <p>For more information about how cultural beliefs influence dying and death you can go to the <i>Cultural beliefs</i> module</p>

<p>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>  <p>Having trouble playing this video? Click on this link to view it in Vimeo: https://vimeo.com/260003289</p> <p>Slide 20 of 27</p> <p>Go back Next slide</p>	 <p>Key points for discussion from this video clip are listed below:</p> <p>Eutropia, John, Paddy and Damien each talk about their funeral experiences depending on their different cultures. Discuss with participants their own experiences about how culture influences funerals.</p> <p>Just like everyone else, people with intellectual disability are from different cultures. We need to understand this when helping them understand funerals, as well as what wishes they may have.</p>
<p>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.</p> <p>In this video, a manager reflects on the steps her organisation took to respect the wishes of an Aboriginal client.</p>  <p>Having trouble playing this video? Click on this link to view it in Vimeo: https://vimeo.com/260009282</p> <p>Slide 21 of 27</p> <p>Go back Next slide</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 funeral wishes of the dying person.</p>
<p>Seek help if you are unsure</p>  <p>If you are unsure what your role is when talking about funeral wishes with a client, please talk about it with someone you trust.</p> <p>Slide 22 of 27</p> <p>Go back Next slide</p>	 <p>Someone you trust could be your supervisor, a colleague, a friend or family member.</p>

<p>Key concepts</p> <p>The best way for people with intellectual disability to understand what happens at a funeral is to go to funerals.</p> <p>When a person with intellectual disability understands what a funeral is, they may start thinking about what they would like at their own funeral.</p> <p>There are lots of choices involved in planning a funeral.</p> <p>It is your role to support a person with intellectual disability to understand that they can make and record choices, if they wish.</p>  <p>Go back Slide 23 of 27 Next slide</p>									
<p>For more information</p> <table border="1"> <thead> <tr> <th>Resource</th><th>About</th></tr> </thead> <tbody> <tr> <td>My funeral wishes: Get peace of mind by planning ahead</td><td>Information about the kinds of wishes that some people make for their funeral</td></tr> <tr> <td>When I die</td><td>An example of a completed plan, including a section on funeral wishes</td></tr> <tr> <td>Celebration of life checklist</td><td>An easy read checklist to help people plan their funeral wishes</td></tr> </tbody> </table> <p>Go back Slide 24 of 27 Next slide</p>	Resource	About	My funeral wishes: Get peace of mind by planning ahead	Information about the kinds of wishes that some people make for their funeral	When I die	An example of a completed plan, including a section on funeral wishes	Celebration of life checklist	An easy read checklist to help people plan their funeral wishes	<p>Click on the links on this page to show participants what these resources look like.</p>
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<p>Research supporting this module</p> <table border="1"> <thead> <tr> <th>Reference</th><th>About</th></tr> </thead> <tbody> <tr> <td>1. Forrester-Jones, R. (2013). The road barely taken: Funerals, and people with intellectual disabilities. <i>Journal of Applied Research in Intellectual Disabilities</i>, 26, 243–256. doi:10.1111/jar.12022 https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12022</td><td>This study sought participants' views and experiences about funerals. People with intellectual disability talked about not being invited to a funeral. Many felt that they should go to show respect to the dead person. They discussed how death-related rituals can provide comfort and social support. Some reported aspects of the funeral they were uncomfortable with (e.g., cremation). The study also showed that adults with intellectual disability were very willing to talk about funerals.</td></tr> <tr> <td>2. Wiese, M., Stanciffla, R. J., Read, S., Jethes, G. & Clayton, J. (2015). Learning about dying, death and end-of-life planning: Current issues informing future actions. <i>Journal of Intellectual & Developmental Disability</i>, 40(2), 230–235. doi:10.3109/13668250.2014.998183 https://doi.org/10.3109/13668250.2014.998183</td><td>This article discusses the importance of talking to people with intellectual disability about end of life, including their right to know about death.</td></tr> </tbody> </table> <p>Go back Slide 25 of 27 Next slide</p>	Reference	About	1. Forrester-Jones, R. (2013). The road barely taken: Funerals, and people with intellectual disabilities. <i>Journal of Applied Research in Intellectual Disabilities</i> , 26, 243–256. doi:10.1111/jar.12022 https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12022	This study sought participants' views and experiences about funerals. People with intellectual disability talked about not being invited to a funeral. Many felt that they should go to show respect to the dead person. They discussed how death-related rituals can provide comfort and social support. Some reported aspects of the funeral they were uncomfortable with (e.g., cremation). The study also showed that adults with intellectual disability were very willing to talk about funerals.	2. Wiese, M., Stanciffla, R. J., Read, S., Jethes, G. & Clayton, J. (2015). Learning about dying, death and end-of-life planning: Current issues informing future actions. <i>Journal of Intellectual & Developmental Disability</i> , 40(2), 230–235. doi:10.3109/13668250.2014.998183 https://doi.org/10.3109/13668250.2014.998183	This article discusses the importance of talking to people with intellectual disability about end of life, including their right to know about death.	<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>  <p>Print your answers to the Think About questions</p> </div> <div>  <p>Email your answers to yourself</p> </div> <p>Go back Slide 26 of 27 Next slide</p>									
 <p>Congratulations!</p> <p>You have completed the module</p> <p>You can now print a certificate</p> <p>Go back Slide 27 of 27 Go to home page</p>									