

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 28 "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.

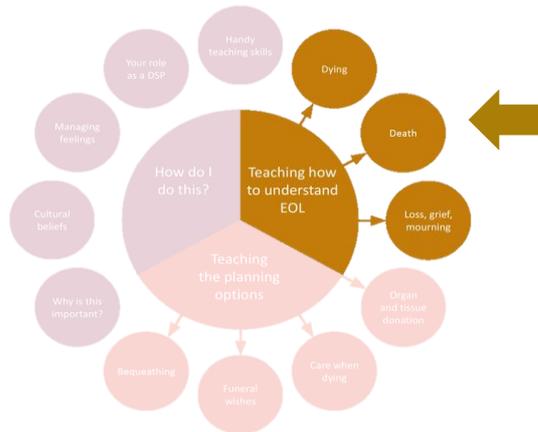
Important information for participants

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: **Death**

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>Welcome to the module about: Death</p> <p>A person with intellectual disability has the right to know about death, just like everyone else.^[1]</p> <p>This module introduces some key ideas to think about when talking about death with a person with intellectual disability.</p>  <p>1. Wiene et al. (2015)</p> <p>Go back Slide 2 of 11 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>How did you learn about death?</p> <p>Many people learn about death:</p> <ul style="list-style-type: none"> • From a young age • Gradually coming to know more as they get older • Through the death of pets or grandparents • Going to funerals • Through TV shows or movies <p>A lot of people learn about death through asking questions.</p> <p>Many people with intellectual disability have not had similar learning opportunities.</p>  <p>Go back Next slide</p> <p style="text-align: center;"><small>Slide 3 of 31</small></p>	 <p>We learn about death with a lot of different experiences throughout life. Participants could discuss how they each learned about death.</p>
<p>Gaining confidence with experience</p> <p>A lot of people don't feel confident talking about dying and death, especially with a person with intellectual disability. This does not mean they'll 'stuff it up'.</p> <p>In fact, feeling anxious shows that they are taking it seriously and really thinking about their actions.</p> <p>The best way to overcome uncomfortable feelings is to start practising.</p>  <p>Go back Next slide</p> <p style="text-align: center;"><small>Slide 4 of 31</small></p>	 <p>See slides 3 to 15 in the <i>Managing feelings</i> module for more information about staff feelings when talking about end of life with people with intellectual disability.</p>
<p>We want you to get talking!</p> <p>By the end of this module, we hope you will feel more confident having conversations about death.</p> <p>Through these conversations you can support a person with intellectual disability to understand:</p> <p><i>"Death is when the body stops working. It is permanent and the person will never come back. It happens to every living thing. That includes me."</i></p>  <p>Go back Next slide</p> <p style="text-align: center;"><small>Slide 5 of 31</small></p>	
<p>What death is</p> <p>There are three important ideas that a person with intellectual disability needs to understand about death.^[2]</p> <p>These are that:</p> <ul style="list-style-type: none"> • When a person dies the body stops working • The dead person will never come back • Death happens to every living thing. That includes me  <p>2. McEvoy et al. (2012)</p> <p>Go back Next slide</p> <p style="text-align: center;"><small>Slide 6 of 31</small></p>	 <p>Research shows that people with intellectual disability often don't fully understand what death is.</p> <p>It's important that the person understands all three things that define death.</p>
<p>The body stops working</p>  <p>When you are teaching a person with intellectual disability about death, it is important to be very clear.</p> <p>A way to be clear is to say something like:</p> <p><i>"When someone dies their body stops working. The heart stops beating, breathing stops, and the brain stops working. The person cannot see, cannot hear and cannot feel pain."</i></p> <p>Go back Next slide</p> <p style="text-align: center;"><small>Slide 7 of 31</small></p>	

<p style="text-align: center;">Holly</p> <p>You can use the death of people or pets as a way to start a conversation about how the body stops working.</p> <p>In the video, Eric sees that Holly's budgie has died. He uses this to teach Holly about death.</p> <p>Having trouble playing this video? Click on this link to view it in Vimeo: https://vimeo.com/228702246</p> <div style="text-align: center;">  <p><small>This video is from the <i>Living to Talk</i> research project, funded by the Australian Research Council and funded (via Unisoc Disability). See Videos on the home page for more information.</small></p> </div> <p style="text-align: center;">Slide 8 of 31</p> <p style="text-align: center;"> Go back Next slide </p>	<p> Key points for discussion from this video clip are listed below:</p> <p>(00:45-00:48) Eric uses clear and direct language, for example, he says “dead”.</p> <p>The budgie was not real. It was a statue.</p> <p> Eric’s use of clear and direct language is similar to David’s use in slide 5 of the <i>Handy teaching skills</i> module.</p>
<p style="text-align: center;">Think about...</p> <p> How could you check that Holly understood what death means? What questions could you ask? Type your answer in the box below.</p> <div style="border: 1px solid gray; height: 100px; width: 100%;"></div> <p><small>3. Finlay & Lyons (2001)</small></p> <p style="text-align: center;">Slide 9 of 31</p> <p style="text-align: center;"> Go back 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><small>How could you check that Holly understood what death means? What questions could you ask?</small></p> <p style="text-align: center;">Slide 10 of 31</p> <p style="text-align: center;"> Go back Next slide </p>	

<p>Did your answers sound like this?</p>  <p>Having trouble playing this video? Click on this link to view it in Vimeo: https://vimeo.com/238700184</p> <p><small>This video is from the <i>Dying to Fall</i> research project, funded by the Australian Research Council and Sunshine (now Unisson Disability). See Videos on the home page for more information</small></p> <p>Slide 11 of 31</p> <p>Go back Next slide</p>	<p> The key point of discussion from this video clip is:</p> <p>In the video Eric asks questions to check whether Holly understands death.</p> <p> This is an example of the “Ask questions to check for understanding” teaching skill on slide 7 of the <i>Handy teaching skills</i> module.</p>
<p>Death can have many different causes</p> <p>When a person with intellectual disability learns about death, they may not understand that death can have many different causes.</p> <p>It is important to talk about death in a variety of ways, and make it clear that whether death happens suddenly or after a long time the final result is the same - the person is dead.</p>  <p>Slide 12 of 31</p> <p>Go back Next slide</p>	
<p>Think about...</p> <p>What are five ways you could start a conversation about death? <small>Hint: Think about all the things that die, all the causes of death (e.g., accident, war, murder, illness), and when these things come up naturally in conversation. Type your answer in the box below.</small></p> <div style="border: 1px solid #ccc; height: 100px; width: 100%;"></div> <p>Slide 13 of 31</p> <p>Go back Next slide</p>	
<p>Your answers to the ‘Think about...’ question</p> <p>What are five ways you could start a conversation about death?</p> <p>0</p> <p>Slide 14 of 31</p> <p>Go back Next slide</p>	

<p style="text-align: center;">One way to talk about death</p> <p>When famous people die suddenly it is often reported on the news. This is a simple and natural opportunity to talk about death to a person with intellectual disability.</p> <p>For example: Adam and Leah are watching TV. The death of famous musician David Bowie flashes up. He says: "Oh did you see that? David Bowie died. What do you think he died of?"</p>  <p style="text-align: center;">Go back Slide 15 of 31 Next slide</p>	<p style="text-align: center;"></p> <p>This example is like the teaching skill "Use everyday situations to start a conversation or an activity" on slides 9 to 12 in the <i>Handy teaching skills</i> module.</p>
<p style="text-align: center;">Another way to talk about death</p> <p>Some people die suddenly, but it is also important to explain that death can happen after a long period of dying. More information about how to do this can be found in the <i>Dying</i> module.</p> <p>At some point, everyone experiences people close to them dying. This can be an opportunity to talk.</p> <p>An example of this can be seen in the case of Anthony...</p>  <p style="text-align: center;">Go back Slide 16 of 31 Next slide</p>	<p style="text-align: center;"></p> <p>Participants can get more information about how to teach about dying, and how people can be cared for when dying in the <i>Dying</i> module.</p>
<p style="text-align: center;">Anthony</p> <p>Anthony has intellectual disability. His mother has cancer and she is dying.</p> <p>Anthony's brother Daniel has told him, but Anthony's disability support professional (DSP) Jenny, is very worried Anthony might not understand what will happen.</p>  <p style="text-align: center;">Go back Slide 17 of 31 Next slide</p>	
<p style="text-align: center;">What did Jenny do?</p> <p>Jenny spoke to Anthony's brother Daniel about her worries. He agreed to take Anthony to some of his mother's medical appointments.</p> <p>Jenny also got a copy of the book <i>When Mum Died</i>. This book can be purchased from Books Beyond Words.</p>  <p style="text-align: center;"><small>© Beyond Words. For current information go to https://booksbeyondwords.co.uk/</small></p> <p style="text-align: center;">Go back Slide 18 of 31 Next slide</p>	<p>There is more information about the whole <i>Books Beyond Words</i> series on slide 28 towards the end of this module.</p>
<p style="text-align: center;">What did Jenny do?</p> <p>Jenny sat down with Anthony and looked through the information.</p> <p>She explained that Anthony's mum is sick and will not get better. She asked questions to make sure that Anthony understood that when his mother dies her body will stop working and she will never come back.</p>  <p style="text-align: center;">Go back Slide 19 of 31 Next slide</p>	<p style="text-align: center;"></p> <p>Using questions to check for understanding is helpful. Eric also does this in the video on slide 11 earlier.</p> <p style="text-align: center;"></p> <p>More ideas about how to do this are given on slides 7 and 8 of the <i>Handy teaching skills</i> module.</p>

<p> Think about...</p> <p>What other things could you do if you were Anthony's DSP? Type your answer in the box below.</p> <div data-bbox="215 309 689 465" style="border: 1px solid #ccc; height: 70px;"></div> <p>Go back Slide 20 of 31 Next slide</p>	
<p>Your answers to the 'Think about...' question</p> <p><i>What other things could you do if you were Anthony's DSP?</i></p> <div data-bbox="215 501 689 772" style="border: 1px solid #ccc; height: 120px;"></div> <p>Go back Slide 21 of 31 Next slide</p>	
<p>Did you get...?</p> <ul style="list-style-type: none">• Discuss with Anthony what he would like to do with his mother before she dies• Encourage Daniel to keep Anthony up to date with what is happening as things change• Support Anthony to visit his mother• Ask Anthony how he is feeling about his mum being sick and dying. Provide support as needed <div data-bbox="518 936 708 1086"></div> <p>Go back Slide 22 of 31 Next slide</p>	
<p> Think about...</p> <p>What would you do if Anthony's family did not want Anthony to be told that his mother is going to die? Type your answer in the box below.</p> <div data-bbox="215 1270 689 1426" style="border: 1px solid #ccc; height: 70px;"></div> <p>Go back Slide 23 of 31 Next slide</p>	
<p>Your answers to the 'Think about...' question</p> <p><i>What would you do if Anthony's family did not want Anthony to be told that his mother is going to die?</i></p> <div data-bbox="215 1464 689 1736" style="border: 1px solid #ccc; height: 120px;"></div> <p>Go back Slide 24 of 31 Next slide</p>	

<p style="text-align: center;">Did you get...?</p> <ul style="list-style-type: none"> • Explain to Anthony's brother Daniel the negative consequences of Anthony not knowing. Use the Why is this important module from this website to help this conversation • Encourage Daniel and his family to include Anthony as much as possible. For example, hospital visits, saying goodbye, attending his mother's funeral • Talk to a supervisor if you are finding the situation difficult to manage  <p style="text-align: center;"> Go back <i>Slide 25 of 31</i> Next slide </p>									
<p style="text-align: center;">Seek help if you are unsure</p>  <p>If you're not sure what you would do about anything discussed in this module, please talk about it with someone you trust.</p> <p style="text-align: center;"> Go back <i>Slide 26 of 31</i> 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>It is important to communicate the following three points when talking to people with intellectual disability about death:</p> <ul style="list-style-type: none"> • When a person dies the body stops working • The dead person will never come back • Death happens to every living thing. This includes me. <p>Tips for communicating:</p> <ul style="list-style-type: none"> • Be very clear in the words that you use • Use real world examples to explain death  <p style="text-align: center;"> Go back <i>Slide 27 of 31</i> Next slide </p>									
<p style="text-align: center;">For more information</p> <table border="1" data-bbox="215 1265 710 1422"> <thead> <tr> <th>Resource</th> <th>About</th> </tr> </thead> <tbody> <tr> <td>Breaking bad news</td> <td>This website contains information and guidelines for caregivers of people with intellectual disability about how to break bad news.</td> </tr> <tr> <td>The Books Beyond Words series</td> <td>Books designed for people with intellectual disability that include only pictures. This allows you to make the story relevant to the client. Topics include 'Am I Going to Die', 'Getting on with Cancer' and 'Anne has Dementia'.</td> </tr> </tbody> </table> <p style="text-align: center;"> Go back <i>Slide 28 of 31</i> Next slide </p>	Resource	About	Breaking bad news	This website contains information and guidelines for caregivers of people with intellectual disability about how to break bad news.	The Books Beyond Words series	Books designed for people with intellectual disability that include only pictures. This allows you to make the story relevant to the client. Topics include 'Am I Going to Die', 'Getting on with Cancer' and 'Anne has Dementia'.	<p>Click on the links on this page to show participants what these resources look like.</p>		
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<p style="text-align: center;">Research supporting this module</p> <table border="1" data-bbox="215 1556 710 1769"> <thead> <tr> <th>Reference</th> <th>About</th> </tr> </thead> <tbody> <tr> <td>Wiese, M., Stancliffe, R. J., Read, S., Jeltz, 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> <tr> <td>McEvoy, J., MacHale, R., & Tierney, E. (2012). Concept of death and perceptions of bereavement in adults with intellectual disabilities. <i>Journal of Intellectual Disability Research</i>, 56, 191-205. doi:10.1111/j.1365-2788.2011.01456.x https://www.ncbi.nlm.nih.gov/pubmed/22803263</td> <td>This study found that some people with intellectual disability only partially understand the concept of death.</td> </tr> <tr> <td>Finlay W. M. & Lyons E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. <i>Psychological Assessment</i>, 13, 319-335. doi: 10.1037/1040-3590.13.3.319 http://dx.doi.org/10.1037/1040-3590.13.3.319</td> <td>This article argues that questions used with people with intellectual disability should be tested to show that they are useful with that population.</td> </tr> </tbody> </table> <p style="text-align: center;"> Go back <i>Slide 29 of 31</i> Next slide </p>	Reference	About	Wiese, M., Stancliffe, R. J., Read, S., Jeltz, 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.	McEvoy, J., MacHale, R., & Tierney, E. (2012). Concept of death and perceptions of bereavement in adults with intellectual disabilities. <i>Journal of Intellectual Disability Research</i> , 56, 191-205. doi:10.1111/j.1365-2788.2011.01456.x https://www.ncbi.nlm.nih.gov/pubmed/22803263	This study found that some people with intellectual disability only partially understand the concept of death.	Finlay W. M. & Lyons E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. <i>Psychological Assessment</i> , 13, 319-335. doi: 10.1037/1040-3590.13.3.319 http://dx.doi.org/10.1037/1040-3590.13.3.319	This article argues that questions used with people with intellectual disability should be tested to show that they are useful with that population.	<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 data-bbox="293 338 400 427"></div> <p>Print your answers to the Think About questions</p> <div data-bbox="485 338 628 427"></div> <p>Email your answers to yourself</p> <p>Go back <small>Slide 30 of 31</small> Next slide</p>	
<div data-bbox="213 591 344 741"></div> <p>Congratulations!</p> <p>You have completed the module</p> <p>You can now print a Certificate</p> <p>Go back <small>Slide 31 of 31</small> Go to home page</p>	