

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 22 "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: **Dying**

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



Suggested duration:



20-25 minutes

This guide includes:



Main ideas














Links with other modules












Points to highlight from video




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| <p style="text-align: center;">Talking End of Life ...with people with intellectual disability</p> <p style="text-align: center; color: #c08040;">Teaching how to understand end of life: Dying</p> <div style="display: flex; justify-content: space-between; align-items: center; margin-top: 10px;"> <div style="font-size: 8px;"> </div> <div style="text-align: right;"> </div> </div> | |
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| <p>Welcome to the module about: Dying</p> <p>A person with intellectual disability has the right to know about dying, just like everyone else. [1]</p> <p>This module introduces some key concepts to think about when talking about dying with a person with intellectual disability.</p>  <p>1. Wiese et al. (2015)</p> <p>Go back Slide 2 of 25 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>We want you to get talking!</p> <p>By the end of this module, we hope you will feel more confident about having conversations about death.</p> <p>Through these conversations you can support a person with intellectual disability to understand:</p> <p>"Dying is the period before death when body parts slow down and don't work properly."</p>  <p>Go back Slide 3 of 25 Next slide</p> | <p>We probably all know what death is, but we don't often think very much about what dying is. People with intellectual disability need to understand both dying and death.</p> |
| <p>Every living thing dies</p>  <p>If you look for opportunities to talk about dying, you will start to notice that they are all around.</p> <p>Go back Slide 4 of 25 Next slide</p> | |
| <p>Min-jun</p> <p>Georgia provides drop-in support for Min-jun, a man with intellectual disability.</p> <p>While they are doing the washing up, Georgia notices that the strawberry plant that Min-jun keeps near the window is looking very sick.</p>  <p>Go back Slide 5 of 25 Next slide</p> | |
| <p>What Georgia did</p> <p>Georgia says to Min-jun "It looks like this plant is dying. Do you see how most of the leaves are wrinkly and brown?"</p> <p>Together she and Min-jun scrunch up dead leaves to see how they feel.</p> <p>Georgia points to a healthy plant nearby and says "See how these leaves are soft and green? It's alive and healthy".</p>  <p>Go back Slide 6 of 25 Next slide</p> | <p>Georgia used a couple of helpful teaching skills. <i>She used everyday situations to start a conversation or activity, and Don't just talk about it, do it.</i> More information is in slides 9 to 12 and 23 of the <i>Handy teaching skills</i> module.</p> |

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|  <h3>Think about...</h3> <p>Georgia used a dying plant to talk to Min-jun about the end of life. What are three other things you could use to start a conversation about dying? Type your answer in the box below.</p> <div style="border: 1px solid #ccc; height: 60px; width: 100%;"></div> <p>Go back Slide 7 of 25 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> |
| <h3>Your answers to the 'Think about...'question</h3> <p><small>Georgia used a dying plant to talk to Min-jun about the end of life. What are three other things you could use to start a conversation about dying?</small></p> <p>Go back Slide 8 of 25 Next slide</p> | |
| <h3>Did you get...?</h3> <ul style="list-style-type: none"> • People dying on TV shows • Old or dying animals • An old flower bouquet dying • Signs of ageing in people • A celebrity or known person being diagnosed with a terminal illness  <p>Go back Slide 9 of 25 Next slide</p> | |
| <h3>Repeat ideas and activities often</h3> <p>Later, Georgia and Min-jun are collecting mail from the letterbox. Min-jun's neighbour is sitting on her front porch with her very old dog, Rocky. Georgia thinks this a good opportunity to repeat the ideas she explaining through talking about the strawberry plant. Georgia says to Min-jun "See how Rocky sleeps most of the time now? Rocky used to run around a lot, but he is very old now and is slowly dying. Parts of his body are old and worn out."</p>  <p>Go back Slide 10 of 25 Next slide</p> |  <p>Georgia takes advantage of opportunities to talk to Min-jun what dying looks like. It seems natural and not fake.</p>  <p>Georgia's teaching skill is an example of "Repeat ideas and activities often". See slide 13 of the <i>Handy teaching skills</i> module.</p> |
|  <h3>Think about...</h3> <p>If you had just talked about dying with Min-jun, how could you check his understanding that every living thing dies? Type your answer in the box below.</p> <div style="border: 1px solid #ccc; height: 60px; width: 100%;"></div> <p>Go back Slide 11 of 25 Next slide</p> | |

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| <p>Your answers to the 'Think about...'question</p> <p><i>If you had just talked about dying with Min-jun, how could you check his understanding that every living thing dies?</i></p> <p>Go back Slide 12 of 25 Next slide</p> | |
| <p>Did you get...?</p> <ul style="list-style-type: none"> • What will happen when Rocky's body stops working? • What are some other things that die? • What happens to a tree if someone cuts it down? • Will I die one day? • Will you die one day?  <p>Go back Slide 13 of 25 Next slide</p> | |
| <p>An opportunity for inclusion</p> <p>When people are dying, it is a sad time. However, it can also be an opportunity for inclusion.</p> <p>An example of this can be seen in the case of Claudia.</p>  <p>Go back Slide 14 of 25 Next slide</p> | |
| <p>Claudia</p> <p>Claudia lives in a group home with three other people with intellectual disability. All are in their late 50s.</p> <p>One of Claudia's co-residents, Denise, has heart disease and she is dying. She is being cared for at the group home.</p> <p>All the co-residents have been told that Denise is dying.</p>  <p>Go back Slide 15 of 25 Next slide</p> | |
| <p>Think about...</p> <p>How would you support Claudia to understand what dying is?</p> <p>Type your answer in the box below.</p> <div style="border: 1px solid gray; height: 60px; width: 100%;"></div> <p>Go back Slide 16 of 25 Next slide</p> | |
| <p>Your answers to the 'Think about...'question</p> <p><i>How would you support Claudia to understand what dying is?</i></p> <p>Go back Slide 17 of 25 Next slide</p> | |

| <p>Did you get...?</p> <ul style="list-style-type: none"> • Explain to Claudia how Denise is dying, for example that she's been sleeping more and eating less, and needs people to help her move. • Explain what is happening to Denise by showing Claudia pictures of heart disease on the internet • Involving Claudia in simple care tasks for Denise where possible  <p>Go back Slide 18 of 25 Next slide</p> | | | | | | | |
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| <p>Claudia</p> <p>As the days pass, the disability support professionals (DSPs) in the house explain to Claudia that because Denise is dying, she is eating less, and needs lots more help with personal care.</p> <p>They also explain what is happening to Denise's heart by showing Claudia pictures on the internet. Claudia is involved in simple care tasks for Denise when possible, such as bringing her something to drink.</p>  <p>Go back Slide 19 of 25 Next slide</p> |  <p>People with intellectual disability can better understand what dying is if they're included in the process.</p> | | | | | | |
| <p>Seek help if you are unsure</p>  <p>If you're not sure what you would do in the case of Claudia, or are unsure about anything discussed in this module, please talk about it with someone you trust.</p> <p>Go back Slide 20 of 25 Next slide</p> |  <p>Someone you trust could be your supervisor, a colleague, a friend or family member.</p> | | | | | | |
| <p>Key concepts</p> <p>Dying is the period before death when body parts slow down and don't work properly.</p> <p>You can use a range of everyday situations to start a conversation about dying, including:</p> <ul style="list-style-type: none"> • People dying on TV shows • Old or dying animals • Dying plants • A celebrity being diagnosed with a terminal illness. <p>Involving a client in caring for somebody who is dying is an important opportunity for inclusion and a great way to understand more about dying.</p>  <p>Go back Slide 21 of 25 Next slide</p> | | | | | | | |
| <p>For more information</p> <table border="1"> <thead> <tr> <th>Resource</th> <th>About</th> </tr> </thead> <tbody> <tr> <td>The dying process</td> <td>A resource designed for the general community that explains what happens during the dying process.</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?' and 'When I Die'.</td> </tr> </tbody> </table> <p>Go back Slide 22 of 25 Next slide</p> | Resource | About | The dying process | A resource designed for the general community that explains what happens during the dying process. | 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?' and 'When I Die'. | <p>Click on the links on this page to show participants what these resources look like.</p> |
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| The dying process | A resource designed for the general community that explains what happens during the dying process. | | | | | | |
| 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?' and 'When I Die'. | | | | | | |
| <p>Research supporting this module</p> <table border="1"> <thead> <tr> <th>Reference</th> <th>About</th> </tr> </thead> <tbody> <tr> <td>1. Wise, M., Standiford, R. J., Read, S., Jelles, 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 23 of 25 Next slide</p> | Reference | About | 1. Wise, M., Standiford, R. J., Read, S., Jelles, 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> | | |
| Reference | About | | | | | | |
| 1. Wise, M., Standiford, R. J., Read, S., Jelles, 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. | | | | | | |

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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="272 322 368 398"></div> <p>Print your answers to the Think About questions</p> <div data-bbox="443 322 571 398"></div> <p>Email your answers to yourself</p> <p>Go back <small>Side 24 of 25</small> Next slide</p> | |
| <div data-bbox="193 555 312 689"></div> <p>Congratulations!</p> <p>You have completed the module</p> <p>You can now print a certificate</p> <p>Go back <small>Side 25 of 25</small> Go to home page</p> | |