

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 20 "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.

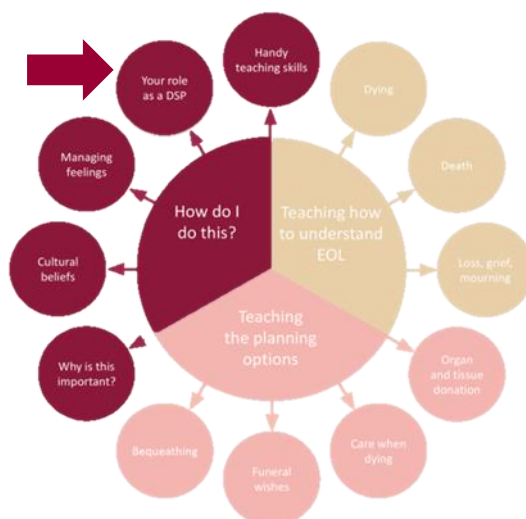
Important information for participants

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: *Your role as a DSP*

This module is mainly intended for disability support professionals (DSPs). 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

 <p>How do I do this? Your role as a DSP</p> <div style="display: flex; justify-content: space-between; align-items: center;"> <div>      </div> <div style="font-size: 0.8em;"> <p>The TEL project is supported by funding from the Australian Government Department of Health under the Public Health and Clinical Research Grants</p> </div> <div>  </div> </div>	
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<p>Welcome to the module: Your role as a DSP</p> <p>Preparing for end of life involves making many decisions. You may feel unsure of your role as a disability support professional (DSP) when one of your clients is making decisions about things like wills, funerals or organ donation.</p> <p>After completing this module, you should be clearer on your role. When it comes to a client making decisions, you're a teacher not a decision maker.</p>  <p>Go back Slide 2 of 23 Next slide</p>	 <p>"You're a teacher not a decision maker" What does this statement mean?</p>
<p>Your role in end of life decisions</p> <p>As a DSP, it is not your role to make decisions about end of life for a person with intellectual disability. Usually, these decisions would be dealt with using person-centred planning processes. You may be involved.</p> <p>Decisions should be made in consultation with others, such as family and trusted friends.</p> <p>Sometimes legal help or medical advice might be needed. [1]</p> <p>1. McKenzie et al. (2017)</p> <p>Go back Slide 3 of 23 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>Your role in end of life decisions</p> <p>Your role as a DSP is to support your client to:</p> <ul style="list-style-type: none"> • Understand end of life [1] • Understand the decisions they could make about end of life • Participate in person-centred planning if they want to make a decision about end of life <p>If your client tells you they would like to decide about something, you should alert the relevant case manager or keyworker so that person-centred planning can begin.</p> <p>To help understand your role in end of life decisions, you will look at two scenarios. The first scenario is about Nick, whose story also appears in the module <i>Care when dying</i>.</p> <p>1. McKenzie et al. (2017)</p> <p>Go back Slide 4 of 23 Next slide</p>	
<p>Nick</p> <p>In the video below, Nick has an advance care planning session after feeling upset about the way his mum is dying.</p>  <p>Having trouble playing this video? Click on this link to view it in Vimeo: https://vimeo.com/238592759</p> <p>Go back Slide 5 of 23 Next slide</p>	 <p>Key points for discussion from this video clip are listed below:</p> <p>(01:25) "you can come up with a plan"</p> <p>(02:26) "Who do you think you'd want to speak for you if you couldn't speak for yourself?"</p> <p>(03:02) What is an "enduring guardian"? Who chooses this person?</p>
<p>Advance care planning</p> <p>In the video, you see DSP Megan explain what an advance care plan is to Nick. Later, you see Nick's advance care plan meeting.</p> <p>You are not shown what happens between these two events.</p> <p>Let's look at three possibilities and think about whether they fit Megan's role as a DSP...</p>  <p>Go back Slide 6 of 23 Next slide</p>	<p>In the video, DSP Megan is present at the meeting (has some involvement) but is not leading the discussion.</p>

<p>First possibility: Megan organises a meeting</p> <p>Megan organises for Nick's aunty and sister to come to a meeting at Nick's house. They do not know what the meeting is about until Megan asks the nurse to explain what an advance care plan is.</p> <p>Is this within Megan's DSP role? Why or why not?</p> <p>Type your answer in the box below.</p> <div style="border: 1px solid #ccc; height: 40px; width: 100%;"></div> <p>Go back Next slide</p> <p style="text-align: center; font-size: small;">Slide 7 of 23</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>Did you get...?</p> <p>No.</p> <p>It is Megan's role to teach Nick about the decisions he can make about care, not start the process on his behalf.</p> <p>If Nick is interested in making an advance care plan, he should talk to his family. He can ask for Megan's support for this, but Megan should not decide for Nick that there should be a meeting.</p>  <p>Go back Next slide</p> <p style="text-align: center; font-size: small;">Slide 8 of 23</p>	
<p>Second possibility: Nick's aunty organises a meeting</p> <p>A week after visiting his mum at the hospital, Nick asks Megan more about advance care planning. Megan tells Nick that his aunty would be a great enduring guardian. Megan rings his aunty later that day and together they organise an advance care planning meeting.</p> <p>Is this within Megan's role? Why or why not?</p> <div style="border: 1px solid #ccc; height: 40px; width: 100%;"></div> <p>Go back Next slide</p> <p style="text-align: center; font-size: small;">Slide 9 of 23</p>	
<p>Did you get...?</p> <p>No.</p> <p>It is Megan's role to teach Nick about advance care planning, not influence his decisions about who his enduring guardian should be.</p> <p>Nick's aunty also isn't the person who gets to decide if Nick will create an advance care plan. Nick should decide.</p>  <p>Go back Next slide</p> <p style="text-align: center; font-size: small;">Slide 10 of 23</p>	
<p>Third possibility: Nick organises a meeting</p> <p>A week after visiting his mum at the hospital, Nick asks Megan more about advance care planning. Megan talks to Nick about what he would like and together they decide to ring Nick's aunty to organise an advance care planning meeting.</p> <p>Is this within Megan's role? Why or why not?</p> <p>Type your answers in this box</p> <div style="border: 1px solid #ccc; height: 40px; width: 100%;"></div> <p>Go back Next slide</p> <p style="text-align: center; font-size: small;">Slide 11 of 23</p>	
<p>Did you get...?</p> <p>Yes.</p> <p>Megan provided information to Nick and let him decide what he wanted to do. She helped him to seek the support of his family.</p> <p>This is a good way to approach a formal document such as an advance care plan, where decisions are written down.</p>  <p>Go back Next slide</p> <p style="text-align: center; font-size: small;">Slide 12 of 23</p>	

<p>Funeral wishes - Caroline</p> <p>Completing an advance care plan is a formal process to write down a client's decisions about care when dying.</p> <p>For other decisions, a less formal option is to complete a ‘My end of life choices’ book (117kb.pdf).</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/238690001</p> <p>Go back Slide 13 of 23 Next slide</p>	 <p>Key points for discussion from this video clip are listed below:</p> <p>Why is it helpful to write down decisions about dying and death?</p>
<p>Think about...</p> <p>Did Anna's actions in the video match her role as a DSP? Why or why not? Type your answer in the box below.</p> <div style="border: 1px solid black; height: 100px; width: 100%;"></div> <p>Go back Slide 14 of 23 Next slide</p>	
<p>Your answers to the ‘Think about...’ question</p> <p>Did Anna's actions in the video match her role as a DSP? Why or why not?</p> <p>Go back Slide 15 of 23 Next slide</p>	
<p>Did you get...?</p> <p>The answer is partly YES and partly NO.</p> <p>The answer is YES because Anna made sure that Caroline understood the decisions she could make about her own funeral. She also encouraged Caroline to share her funeral wishes with family and friends.</p> <p>The answer is NO because it does not appear that Anna involved anybody else in the decision-making process.</p> <p>As a DSP, you should follow the same procedures for end of life decisions as you would for any other important decision your client wishes to make.</p>  <p>Go back Slide 16 of 23 Next slide</p>	 <p>How would these decisions be made at your organisation?</p>
<p>Before person-centred planning</p> <p>To help a client prepare for their own person-centred planning meeting, you could:</p> <ul style="list-style-type: none"> • Make sure that the person understands what they are planning for • Encourage the client to talk to family and friends about their wishes • Take steps to make the planning process meaningful for the client, such as taking photos that represent their options  <p>Go back Slide 17 of 23 Next slide</p>	
<p>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>Go back Slide 18 of 23 Next slide</p>	 <p>Staff can get support and advice from colleagues, not just supervisors.</p>

<p>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>Go back Slide 19 of 23 Next slide</p>													
<p>For more information</p> <table border="1"> <thead> <tr> <th>Resource</th><th>About</th></tr> </thead> <tbody> <tr> <td>Disability services supported decision making: A quick reference guide for disability support workers</td><td>A guide to support people with intellectual disability to make decisions.</td></tr> <tr> <td>Living well: Using person-centred thinking tools with people who have a life limiting illness</td><td>A demonstration of how person-centred planning tools can be applied to end of life.</td></tr> <tr> <td>When I die</td><td>An example of a completed end of life book.</td></tr> <tr> <td>Celebration of life checklist</td><td>A document from Canada that can be used to write down a client's funeral wishes.</td></tr> <tr> <td>My end of life choices book</td><td>A template document to write down end of life choices from Australia.</td></tr> </tbody> </table> <p>Go back Slide 20 of 23 Next slide</p>	Resource	About	Disability services supported decision making: A quick reference guide for disability support workers	A guide to support people with intellectual disability to make decisions.	Living well: Using person-centred thinking tools with people who have a life limiting illness	A demonstration of how person-centred planning tools can be applied to end of life.	When I die	An example of a completed end of life book.	Celebration of life checklist	A document from Canada that can be used to write down a client's funeral wishes.	My end of life choices book	A template document to write down end of life choices from Australia.	<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. McKenzie, N., Mirfin-Veitch, B., Conder, J., & Brundford, 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.12355 https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12355</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>Go back Slide 21 of 23 Next slide</p>	Reference	About	1. McKenzie, N., Mirfin-Veitch, B., Conder, J., & Brundford, 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.12355 https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12355	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>								
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 <p>Congratulations!</p> <p>You have completed the module</p> <p>You can now print a certificate</p> <p>Go back Slide 28 of 28 Go to home page</p>													