

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.

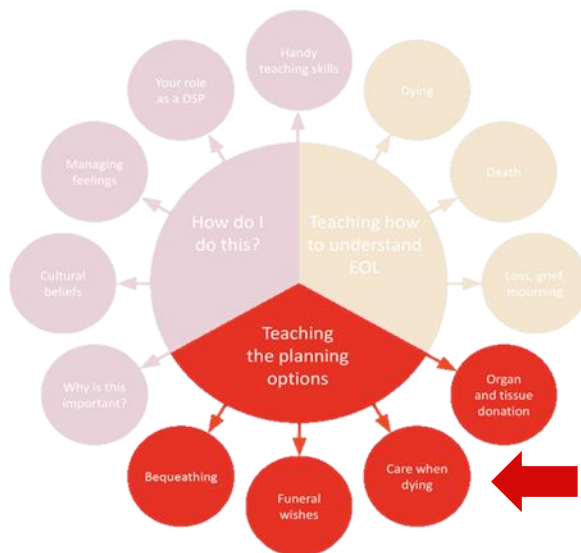
Important information for participants

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: *Care when dying*

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






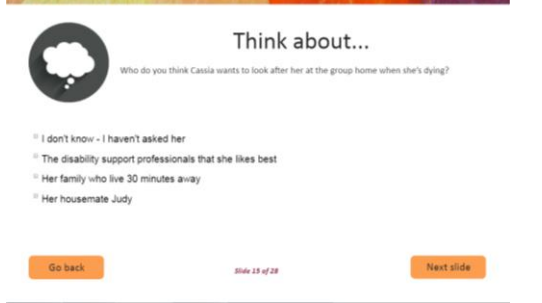


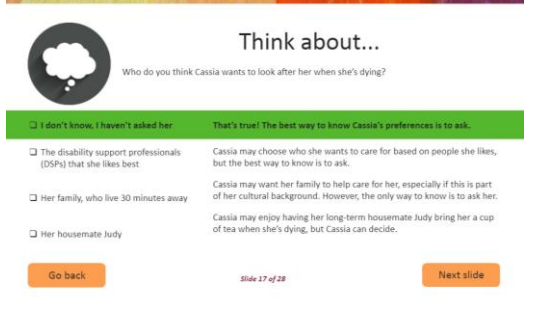

Points to highlight from video







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<p>Welcome to the module: Care when dying</p> <p>After completing this module, we hope that you will feel confident to help a person with intellectual disability understand that:</p> <p>"I can make choices about how people look after me when I'm dying. I can make choices now in case I get too sick to make choices later."</p>  <p>Go back Slide 2 of 28 Next slide</p>	
<p>Why this is important for the dying person</p> <p>Dying doesn't always happen the way people would prefer. Sometimes people die suddenly or need care in a certain way for medical reasons.</p> <p>However, dying can often be made more comfortable for the dying person if things are done the way they like.</p>  <p>Go back Slide 3 of 28 Next slide</p>	 <p>Ask participants if they have examples from their own experience (personal or professional) of a dying person being comforted by having their care preferences honoured.</p>
<p>Why this is important for caregivers</p> <p>People should have the chance to talk about their preferences for care when dying, while they can speak for themselves.^[1,2]</p> <p>By honouring these wishes, caregivers can feel like they've been more respectful to the dying person.</p> <p>Caring for a dying person is the last time that care will be offered, so most people consider it really important to get it right.</p>  <p>1. Bekkema et al. (2016) 2. Tuffrey-Wijne et al. (2007)</p> <p>Go back Slide 4 of 28 Next slide</p>	 <p>When is a good time to talk about care when dying?</p> <p>It is never too late, but it is better to have these conversations <i>in advance</i>, while the person is well, alert and can communicate.</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>Think about...</p> <p>List at least 3 possible things that people might like to choose about how they're cared for when dying. Be as creative as possible. Type your answer in the box below.</p>  <p>Go back Slide 5 of 28 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>Your answers to the 'Think about...'question</p> <p>List at least 3 possible things that people might like to choose about how they're cared for when dying. Be as creative as possible.</p> <p>0</p> <p>Go back Slide 6 of 28 Next slide</p>	
<p>Did you get...?</p> <ul style="list-style-type: none"> • Having favourite things, such as clothes, food, drink, movies or flowers • Skipping family members that are far away • Having family photos where they can be seen • A visit from an old friend • Being cared for by a favourite staff member • Having a way to call someone when help is needed • Receiving comfort when scared or in pain • Going outside to feel the warmth of the sun • A warm bath • Getting hair styled  <p>Go back Slide 7 of 28 Next slide</p>	
<p>Where care is given</p> <p>There are usually some ways you can respect a dying person's wishes about how care is given. Choices about where care is given can be more difficult.</p> <p>Most dying people would like to be cared for at home. [3]</p> <p>For a whole lot of reasons, including the need for medical treatment, many dying people don't get to be cared for at home right up to death. That's okay.</p>  <p>3. Hunt et al. (2014)</p> <p>Go back Slide 8 of 28 Next slide</p>	 <p>Ask participants where they would like to be cared for when dying.</p>
<p>Cassia</p> <p>One of your clients, Cassia, has been diagnosed with cancer.</p> <p>The doctor says that Cassia will need to stay in hospital to receive the best care, but she will die from her cancer eventually even with full treatment.</p>  <p>Go back Slide 9 of 28 Next slide</p>	
<p>Think about...</p> <p>Cassia asks you whether she needs to live in a hospital now. What should you say?</p> <p>Yes you need to live in the hospital so you can stay alive as long as possible</p> <p>No it's not nice in the hospital. You will keep living here.</p> <p>I don't know.</p> <p>How do you feel about hospital?</p> <p>Go back Slide 10 of 28 Next slide</p>	

<p>Your answers to the 'Think about...' question</p> <p><i>Cassia asks you whether she needs to live in a hospital now. What should you say?</i></p> <p>Go back Slide 11 of 28 Next slide</p>	
<p>Think about...</p> <p><i>Cassia asks you whether she needs to live in a hospital now. What should you say?</i></p> <p><input type="checkbox"/> "Yes, you need to live in the hospital so you can stay alive as long as possible." Even if you think its most important for Cassia to get the best treatment possible, she should choose.</p> <p><input type="checkbox"/> "No, it's not nice in the hospital. You will keep living here." Even if you think its most important for Cassia to be in a familiar setting when dying, she should choose.</p> <p><input type="checkbox"/> "I don't know." This is an honest answer but it would be better to open up the conversation so Cassia knows that she can talk about her choices.</p> <p><input checked="" type="checkbox"/> "How do you feel about hospital?" Asking Cassia how she feels is a great way to start a conversation about her choices for care when dying.</p> <p>Go back Slide 12 of 28 Next slide</p>	
<p>Who gives care</p> <p>Another choice that people may have when dying is who cares for them. [1,2]</p> <p>Sometimes a person will choose based on who they like to spend time with.</p> <p>Sometimes a person will have a preference for very deep-held reasons. Think, for example, of a dying woman who has had a long history of abuse by men.</p> <p>1. Bekkema et al. (2016) 2. Tuffrey-Wijne et al. (2007)</p> <p>Go back Slide 13 of 28 Next slide</p> 	 <p>What kind of person would this dying woman want, and not want, to care for her?</p>
<p>Cassia</p> <p>Imagine it is a year after Cassia's diagnosis, and she has chosen to die at her group home.</p> <p>You know that in Cassia's home country of Brazil, family often taken on caring roles when someone is dying rather than relying on paid staff.</p> <p>Go back Slide 14 of 28 Next slide</p> 	

 <p>Think about...</p> <p>Who do you think Cassia wants to look after her at the group home when she's dying?</p> <ul style="list-style-type: none"> <input type="checkbox"/> I don't know - I haven't asked her <input type="checkbox"/> The disability support professionals that she likes best <input type="checkbox"/> Her family who live 30 minutes away <input type="checkbox"/> Her housemate Judy <p>Go back Slide 15 of 28 Next slide</p>	 <p>If Cassia did say she wanted to be cared for by a small group of DSPs she really likes, what practical steps would be needed to make this possible? Discuss DSPs work hours, work schedules (rosters), other clients' needs etc.</p> <p>How would you negotiate with Cassia's family about when and how they would care for Cassia at her group home (assume the family are willing to do this)?</p> <p>Might Judy having a caring role help her to deal with her friend Cassia's illness and eventual death?</p>
 <p>Your answers to the 'Think about...' question</p> <p>Who do you think Cassia wants to look after her at the group home when she's dying?</p> <p>Go back Slide 16 of 28 Next slide</p>	
 <p>Think about...</p> <p>Who do you think Cassia wants to look after her when she's dying?</p> <div> <div> <input type="checkbox"/> I don't know, I haven't asked her </div> <div> <p>That's true! The best way to know Cassia's preferences is to ask.</p> <p>Cassia may choose who she wants to care for based on people she likes, but the best way to know is to ask.</p> <p>Cassia may want her family to help care for her, especially if this is part of her cultural background. However, the only way to know is to ask her.</p> <p>Cassia may enjoy having her long-term housemate Judy bring her a cup of tea when she's dying, but Cassia can decide.</p> </div> </div> <ul style="list-style-type: none"> <input type="checkbox"/> The disability support professionals (DSPs) that she likes best <input type="checkbox"/> Her family, who live 30 minutes away <input type="checkbox"/> Her housemate Judy <p>Go back Slide 17 of 28 Next slide</p>	
 <p>Advance care planning</p> <p>So far in this module, we have looked at choices people can make about care when dying, including:</p> <ul style="list-style-type: none"> How care is given Where care is given and Who gives the care <p>It also important that people with intellectual disability understand that they can make decisions now in case they are too sick to decide later.</p> <p>This is called <i>advance care planning</i>.^[4]</p> <p>4. McKenzie et al. (2017)</p> <p>Go back Slide 18 of 28 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/238692753</p> <p>Go back Slide 19 of 28 Next slide</p>	 <p>Key points for discussion from this video clip are listed below:</p> <p>(00:23) Nick's mother cannot communicate. This is a clear example of why it is important to have conversations and plan <i>in advance</i>.</p> <p>(03:00-03:10) A key feature about appointing an <i>Enduring Guardian</i> is that the person chooses their own trusted guardian, while well (see link on slide 24 for more information about appointing an enduring guardian).</p>
<p>Advance care planning</p> <p>As we saw in the video, advance care planning involves:</p> <ul style="list-style-type: none"> Thinking and talking about what is important in your life Appointing someone you trust as an enduring guardian so that they can make decisions for you about care and medical treatment when you are too sick to do so Saying in advance what medical treatment and other care you do and don't want in various end-of-life situations.  <p>Go back Slide 20 of 28 Next slide</p>	 <p>Saying in advance what medical treatment you want is important, but that situation can change unexpectedly. If so, and the dying person is unable to communicate, the enduring guardian and medical team must decide what to do.</p>
<p>Your role</p> <p>Advance care planning is usually done by the person receiving medical care, together with close family or friends, and medical staff. DSPs may also be involved when appropriate.</p> <p>Your role as a DSP is to make sure that the person with intellectual disability has the opportunity to learn about advance care planning. Then they can decide if they do or don't want to make a plan, just like you or I could.</p>  <p>Go back Slide 21 of 28 Next slide</p>	 <p>Under what circumstances might a DSP be involved in advance care planning?</p>
<p>Seek help if you are unsure</p>  <p>If you are unsure what your role is when talking about care when dying with a client, please talk about it with someone you trust.</p> <p>Go back Slide 22 of 28 Next slide</p>	 <p>Someone you trust could be your supervisor, a colleague, a friend or family member.</p>

<h3>Key concepts</h3> <p>It is important to talk to clients about how they would like to be cared for when they are dying.</p> <p>For a whole lot of reasons many dying people don't get to be cared for at home right up to death. That's okay.</p> <p>Even if a person can not die where they want to, there are usually some ways you can respect a dying person's wishes about how care is given, or who it is given by.</p> <p>Clients may also decide to make an advance care plan to write down their wishes in case they get too sick to decide later.</p>  <p>Go back Slide 23 of 28 Next slide</p>									
<h3>For more information</h3> <table border="1"> <thead> <tr> <th>Resource</th><th>About</th></tr> </thead> <tbody> <tr> <td>Living well, living person-centred: thinking tools with people who have a life limiting illness</td><td>Document designed for people who are dying, including those with intellectual disability.</td></tr> <tr> <td>A Good Death 2</td><td>A guide about end of life care for staff and carers of people with intellectual disability.</td></tr> <tr> <td>Appoint an enduring guardian: NSW Government</td><td>Information and short videos designed for the general community.</td></tr> </tbody> </table> <p>Go back Slide 24 of 28 Next slide</p>	Resource	About	Living well, living person-centred: thinking tools with people who have a life limiting illness	Document designed for people who are dying, including those with intellectual disability.	A Good Death 2	A guide about end of life care for staff and carers of people with intellectual disability.	Appoint an enduring guardian: NSW Government	Information and short videos designed for the general community.	<p>Click on the links on this page to show participants what these resources look like.</p>
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 <h3>Congratulations!</h3> <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>									