

Supporting People with Learning Disabilities to Develop their Advance Care Plans



A Guidebook for Supporters

Acknowledgements

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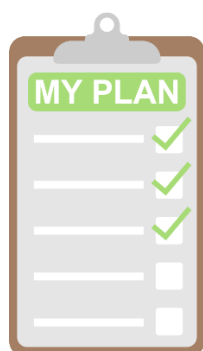
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Purpose of this booklet



This booklet will be of most use to those who are supporting people with learning disabilities to develop their advance care plans, including:

- General Practitioners, Practice Nurses, and other health professionals
- The families and whānau and loved ones of people with learning disabilities
- Learning disability service provider organisations
- People with learning disabilities themselves, who want to find out more or support others in developing their Advance Care plans.

Advance care planning is increasingly well-utilised in Aotearoa New Zealand. However, it can be difficult to access for people with learning disabilities and, as a consequence, people are often excluded from developing their own plans. We aim to change that by describing processes and strategies that people with learning disabilities may find helpful, and by introducing a range of resources and materials that can assist in the planning process.

We recommend that everyone who is supporting someone with their advance care plan should read this booklet and complete the training 'Supporting People with Learning Disabilities with their Advance Care Plans'.

At present this training is available by contacting Nic McKenzie at nicmckenzie5@gmail.com. In future we aim to make this available more broadly.

What is advance care planning?

For most people, advance care planning is a positive and beneficial process. It is a way of recording what is important to us at the end of our lives, and our explicit preferences for future medical care (and other more holistic wishes). It is a gift to our loved ones to help guide decision-making when we are no longer able to make our wishes known.

Although the approach to advance care planning differs from place to place, it is generally accepted that high quality plans include content related to:

- What is important to the person in their current life (their values and beliefs). This ensures that the intent of the person's end of life care decisions can be understood and honoured by those responsible for implementing the plan.
- Things that the person wants to do before they die (personal life goals)
- How and where the person wants to be cared for while living and dying (including treatment preferences)
- What the person wants to happen when they are dying and after they die (such as where they want to die, care of their body after death, cultural or spiritual protocols, funeral and burial arrangements)
- Legal and financial matters (such as a Will, appointment of an Enduring Power of Attorney, and Advance Directives).

Advance care planning leads to improved outcomes at end of life, greater patient and family satisfaction, and reduced stress for surviving family members. Having a plan makes it easier for families and others to know what a person would want if they become unable to speak for themselves. Research shows that people's wishes are much more likely to be followed when a plan has been made (around 80%), than when it has not (around 30%).



"Talking about death doesn't bring death closer. It's about planning for life. Without communication and understanding, death and terminal illness can be a lonely and stressful experience, both for the person who is dying and for their friends and family." (Dying Matters Coalition and the National Council for Palliative Care)

Pro-active planning

We recommend the pro-active development of plans, where possible, while people are young and well. Pro-active discussions are often easier to have, as there is less pressure to make decisions quickly or to confront existing serious illness. These early discussions can then be revisited with less anxiety when people do become unwell later in life.

The rights of people with learning disabilities

People with learning disabilities in Aotearoa New Zealand have the same rights as everyone else, including the right to make the decisions that are part of an Advance Care plan.

 <p>Health and Disability Commissioner Te Toihau Hauora, Hauātanga</p>	<p>The Code of Health and Disability Consumers' Rights protects people's rights to:</p> <ul style="list-style-type: none"> • Be fully informed • To make informed choices and give informed consent • Effective communication that meets their needs • Services of an appropriate standard.
 <p>CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES</p>	<p>Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (which Aotearoa NZ has ratified) recognises people with learning disabilities as capable of acting under the law, and acknowledges their right to exercise that legal capacity to make decisions and have their decisions implemented.</p> <p>The UNCRPD rejects the idea that only some people have legal capacity, or only some of the time.</p>

What does this mean for advance care planning?

These rights require that all people who choose to engage in developing an advance care plan must be supported to learn and understand the relevant information (in whatever way is necessary), to communicate their choices, and to have these acknowledged and acted upon.

NZ law says that everyone is presumed to have legal capacity, **unless proven otherwise**. 'Testing' people's capacity, or the competence of decisions, should only be carried out in exceptional circumstances, where there is specific concern. Having a learning disability isn't automatic grounds for concern, or to initiate testing.

Only some of the decisions in an advance care plan are legally binding and require a legal definition of decision-making competence. These are; directives and refusal of treatments; appointment of an EPOA; a legally-binding Will. There are many aspects of the advance care planning process that people can contribute to (such as description of values, worries and concerns, preferred place to live when unwell, and funeral wishes) without requiring the level of decision-making competence that is needed for legally-binding decisions.

Decision-making competence

What is decision-making competence?

Having decision-making competence means that a person understands the 4Cs:

- **C**ontext
- **C**hoices
- **C**onsequences
- **C**onsistency



Can **C**ommunicate their decision (in whatever way they are able to)

Decision-making competence is specific to each decision and situation.

In order to act on the decisions recorded in a person's advance care plan, the healthcare professional needs to be confident that each decision is relevant to the person's current situation, that they understood the options and consequences, and would not have changed their mind. Where there is doubt surrounding any of this, the integrity of the plan may be questioned.

It is therefore important that people are supported well in the decision-making process, and that care is taken with complex decisions.

Supporting Decision-Making

- 1) If the person has a general understanding of planning, choice-making, concepts of death/ageing, and is interested in advance care planning (after learning about it), start. You can scope this out through discussion, or by using the 'End of Life Planning Scale' to check existing knowledge. If not, start with learning about planning, making choices, and death and dying. [The Talking End of Life website \(www.caresearch.com.au/TEL/\)](http://www.caresearch.com.au/TEL/) provides excellent information about how to do this, and has been specifically developed for people with learning disabilities and their support teams.
- 2) Build competence – provide learning opportunities for every decision. Making decisions is collaborative, interdependent, and relational, and is not something that people (any people) do on their own. It is therefore ok for a person to have support and guidance (not coercion) to help them make decisions that are right for them. The 'Learning About It' section of this booklet provides additional guidance on how to do this.
- 3) Support the person to make all the decisions that they can.
- 4) For decisions where the 4Cs can't be met, ascertain and record the person's will and preference (when this is clear) and record this too. See the next section for more details on this process.
- 5) Record how decisions were made. This adds credibility and creates confidence about the process. The information can then be used to guide the checking of decisions (if needed).

When decisions need to be made inter-dependently

There may be times when a person needs support to make a decision inter-dependently (rather than independently), either for a specific section of the Advance Care plan, or for all of the plan. In these instances, the aim should shift to a Supported Decision-Making approach, aiming to identify and document the person's 'will and preferences': what we can identify to be their wishes or preference; their values; their concerns; priorities.

Make sure to:

- Include the person in every aspect of decision-making, as actively as is possible, alongside their family/whānau, guardian (if there is one), and support team.
- Keep the focus on what the person would want, not what others think is best. Ask questions such as "What do you know about X's wishes, priorities, preferences?" and "What have you seen or heard?". Share examples from the person's life that illustrate these.
- Record not only the outcome of discussions but how information was collected, and whose preferences are being recorded – it is important for health professionals to know if the decisions recorded are not the person's own decisions.
- Remember that a person's decision-making competence can change – revisit the decisions once the person has had time to learn about the topic.

Documenting 'will and preference'



My funeral / tangi


Location and Officiant: Nic's local church with Paul Munroe to officiate. Paul is a family friend and would speak from a personal standpoint to honour Nic's life.

Type of Service: She'd want a typical church service. She loves seeing photos of people on a big screen at funerals – we think she'd want that too.

Coffin: Nic once commented how much she liked someone's pink coffin, so we think she'd like this, with pink flowers, as this is her favourite colour.

Songs: Morning has Broken, Amazing Grace – she hates the organ, so please just play piano or guitar instead.

After the Service: Nic always enjoyed the social aspects of funerals and we know she'd appreciate it if her friends were able to come to her home afterwards to share food and drinks, and talk about her life. She'd want there to be sausage rolls and chocolate eclairs – her favourite foods.



How I made these choices:

The family discussed Nic's funeral and have made choices that we think Nic would like, based on how she has responded at previous funerals – what she smiled at and was relaxed about. She has favourite songs she likes to sing, and people who are close to her, so we think she'd like to incorporate this in her funeral – it's our best guess about what she'd want.

Record the person's 'will and preferences' in any way that works, including:

- In the easy-read advance care plan template, but being careful to note that the decisions are based on the person's will and preference or is the wish of someone else. This will not be able to be added to the formal on-line advance care plan.
- Health professionals could make an 'Advance Care Planning Progress Note' – it won't be formally recognised as an advance care plan, but is accessible to health professionals on-line (in the South Island).
- During hospital admissions, health professionals could also instigate 'serious illness conversations' and record decisions on the 'shared goals of care form'.

Barriers to advance care planning



There are some common barriers that prevent people with learning disabilities from starting and/or successfully completing their own advance care plans. These are important to understand, so that they can be addressed.

Other people's assumptions

People with learning disabilities are frequently not told when they are dying, because others assume and worry that they will either not understand or not cope with knowing. This immediately excludes them from making any contribution to the health and care choices that are being made, resulting in a lack of choice and control at the end of their lives.

Others may assume, without first supporting the person to learn, that the person does not have the knowledge or ability to plan and make competent decisions. This again results in the person being excluded from planning.

The person's own knowledge/experience

When people's knowledge and experiences are limited, they may not have enough background information to make the decisions they are being asked to make. This does not mean that they cannot learn this information.

Limitations in support:

In most cases, health professionals are best placed to provide the health and treatment information, but may not be comfortable or sufficiently experienced to do so in a way that meets the person's communication and learning needs, nor have enough time to do so. Conversely, disability professionals with skills in person-centred planning are probably best placed to meet the person's communication and learning needs (and may see the person more regularly), but may not have sufficient medical knowledge to provide accurate information about health and treatment options.

Research shows that this dis-connect can result in the plan either never being started, being incomplete (missing information), or ending up as 'best interest' plan, rather than directly reflecting the person's own decisions.

Inaccessible/complex materials that the person can't read or make sense of

Text-heavy documentation can be hard for people to read and understand. These barriers are significant, and need to be addressed so that people with learning disabilities can effectively take part in advance care planning.

What do we need to do differently?



Research has demonstrated that it is possible, and not always difficult, to address the barriers described in the previous section. This results in people with learning disabilities successfully developing their own advance care plans.

The process and materials discussed and recommended in this booklet are evidence-based, and have been developed in response to research involving people with learning disabilities.

What do we need to do differently?

- **Presume competence** (unless proven otherwise). Openness and honesty with sharing diagnostic information (for those with life limiting conditions) is an important first step.
- **Use a trained 'Guide'** (facilitator/navigator) to support each person through their planning process, to ensure that communication and learning needs are met, and to facilitate the involvement of family and whānau, health professionals, and disability professionals.
- **Adapt the process to suit the person.** Every person with learning disabilities is unique, and has different support preferences. A one-size-fit-all approach is unlikely to be successful.
- **Support people to learn** about their health and their options (building knowledge), using accessible materials and resources, before making decisions.
- **Proceed at a pace that suits the person** (usually over several weeks or months). This can be significantly slower than usual.
- Support the person to **record their decisions, in a way that they can make sense of** and understand.
- **Share the plan** so that it can be implemented when necessary.

The remainder of this booklet focuses on implementation of the above recommendations, which are the key to success for people with learning disabilities.

Sharing Diagnostic Information

If the person has a life-limiting condition, start by making sure that they are aware of their diagnosis and what that means. Openness and honesty are key.

Good resources to help with sharing diagnostic information and other bad news with people who have learning disabilities include:

	<p>Open Future Learning - Training on breaking bad news is available at http://www.openfuturelearning.org/</p>
	<p>Aotearoa Serious Illness Conversation Guide – this is a general guide for health professionals on having conversations about serious illness. https://www.myacp.org.nz/serious-illness-conversations</p>
	<p>Books Beyond Words series - https://booksbeyondwords.co.uk/bookshop?category=Health This series of books are pictorial (no written words), enabling the story and language can be adapted to each individual. Titles include “Am I Going to Die?”, “When Somebody Dies” “Getting on with Cancer”, and “Anne has Dementia”. Look under the “Health” and “Grief” sections of the publisher’s website.</p>
	<p>How to Break Bad News to People with Intellectual Disabilities: A Guide for Carers and Professionals’, by Irene Tuffrey-Wijne. This book offers unique and adaptable guidelines that can be used by practitioners to ease the process of breaking bad news to people with intellectual disabilities. It provides effective tips and support that will help social workers, counsellors and caring professionals relay all types of bad news as sensitively and successfully as possible.</p>
	<p>IHC Library – https://ihc.org.nz/library-page The IHC Library is the single biggest source of materials on learning disability in Aotearoa New Zealand. Anyone can become a member, and resources are posted to anywhere in New Zealand free of charge. There is an online catalogue that can be searched for titles. Most of the above resources can be borrowed from the IHC Library.</p>

Identifying and utilising a Guide



Earlier in the booklet we discussed the benefits of having a Guide to support people. We recommend that a Guide is identified for all people with learning disability who would like one. It is a role that needs to be negotiated amongst those involved.

Although the Guide could be anyone from a person's network, the skills and attributes required are most likely to be met by someone from their family or whānau, personal networks, or disability service.

What Does a Guide Do?

The way that a Guide operates can be flexible and there are no specific rules. Some things that a Guide might do are:

- Introduce advance care planning to relevant people with learning disabilities and their family and whānau.
- Co-ordinate with others. For example, ensure input from health professionals for discussions about medical or treatment decisions, and involve family members in discussion (when the person asks for or consents to this).
- Lead (or delegate) the learning/thinking/decision-making/recording of the plan, or offer guidance to others who are involved in supporting the person. This may include directing others to resources, and checking to see what assistance they need.
- Ensure that all aspects of the plan are as fully developed as is possible.
- Ensure that the plan is signed off by a health professional.
- Ensure that the plan is stored and shared according to the person's wishes.

Who is best suited to be the Guide?

Consider who fits the mould. We recommend that Guides have the following attributes/skills:

- Skilled in working in partnership with people with learning disabilities to develop person-centred plans.
- Able to adapt teaching methods and communication to meet the individual needs.
- Has time to connect with the person regularly over a period of weeks or months, as the planning process may take some time.
- Has read this guidebook and attended the training 'Supporting People with Learning Disabilities with their Advance Care Plans'.
- Comfortable talking about death and dying, but does not need to have in depth health/medical knowledge.
- Confident in liaising with other professionals (health and disability) and/or the person's family and whānau members.
- Able to be objective and support the person without leading them to decisions.
- Be trusted by the person.

Initiating advance care planning



Introducing the topic of advance care planning can sometimes feel challenging, whether someone has a disability or not. Some of the reasons are that:

- We worry about upsetting people, or making them think they are sicker than they are
- We don't know exactly what to say
- We wonder if the timing is right
- Other people need to be present
- It can be difficult to find (uninterrupted) time
- It can be uncomfortable to talk about death and dying

However, many people are grateful when someone else brings it up, because they have been thinking about it anyway, and starting the conversation makes people feel that others do care about what is important to them. Of course, some people may not want to talk and that's OK.

Tips for introducing advance care planning conversations:

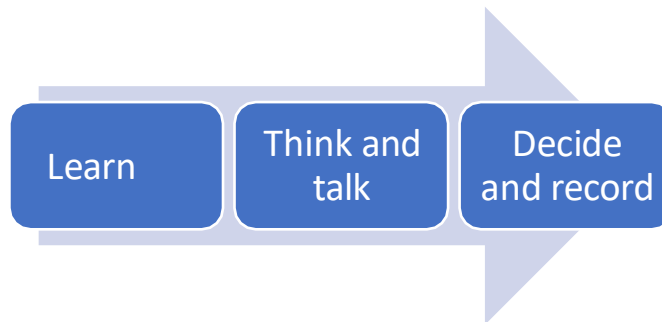
- Avoid leaving the conversation until it's urgent
- Be gentle, sensitive and empathetic
- Make sure the person is ready (their agenda not yours).
- Don't give up if people aren't ready/interested the first time. Repeat discussions can help. Providing some information for people to take away and think about may help. Try sharing the easy read pamphlet 'What is advance care planning?'.
- Be prepared – have all the information (and resources) you need. Use accessible materials, uncomplicated (but direct) words, and short sentences – practice how you will do this.
- Create the right environment.
- Make sure the right people are there (including someone to help share the message in an accessible way).

Conversation starters:

Someone with a new diagnosis	"I know you've got a lot going on. Your [condition] might make you think about the future. Let's talk about what's important to you"
Someone with chronic illness:	You have [condition]. If you get really sick, we want to follow your wishes. Can we talk about that?
Someone with an end stage condition:	[Make sure you have explained what is happening with their health, and the person is clear that they are dying] "We want to do the right things for your health. Now is a good time to talk about what you want."
Someone who is well:	"We are talking to people about this booklet [show the plan template]. It's about making plans for the future. You can say what you'd want if you got really sick. It makes sure we follow your wishes."

Teaching content and options

For each decision / content area:



Tips for Teaching:

- Make sure that you have a good understanding of all of the content yourself. You may like to read some of the resources suggested later in this book. This is particularly important for complex topics and those that have legal standing, such as resuscitation, treatment options, organ donation, enduring power of attorney, and wills.
- Remember that what you usually do in the advance care planning process (and that usually works for others) might not work.
- Prepare for the planning process to take several sessions.
- Plan each session in advance, preparing so that you know exactly how you are going to explain and teach any concepts:
 - Address one content area at a time (such as burial vs cremation) and make that decision, before moving on to another content area.
 - Start simple, and add information in small chunks as appropriate.
 - Allow time for the person to process information – leave pauses in the conversation, and wait after asking questions.
 - Check understanding regularly. Ask the person to tell you what they know, and encourage them to ask questions or tell you if they don't understand.
 - Avoid metaphors (“when your tank is running low”) and euphemisms (“pass away”). Be direct and say what you mean.
 - Repeat and revisit each topic as often as needed.
- Individualise your approach to match the person's learning needs and preferences – find out what helps them learn and understand. Consider the following:
 - Easy read versions of information.
 - Images and visual resources. Google images and www.photosymbols.com (featuring people with learning disabilities) are both great places to search.
 - Videos that demonstrate particular concepts or options.
 - Discussions with friends and family who can share actual experiences - for example, talking to someone who has lived in a rest home, or has been intubated.
 - Reflecting on experiences from television or real life (such as funerals, resuscitation, organ donation) and identifying what was good or not so good about them.



Support the person to talk about their options with other people they trust:

- Support the person to introduce the topic to people they trust. People who know the person well can often add really rich and detailed information, and help the person to clarify their thinking.
- They might like to share the easy read plan, show what they've been talking about, share a pros and cons list (or develop one as part of the conversation), or watch videos on the topic.
- Share resources (and explain how to use them. Repeating things can be helpful. Don't expect other people to know what to do with the resources without an explanation.
- Guide the process as needed. You may like to share the 'Guidebook for Supporters' with them. This will help them to understand the process and contribute in a useful way. If they show an interest in learning more, you could also direct them to this on-line course. The more people who know about Advance Care Planning, the better!
- Reinforce that decisions must be the person's own, and that everyone else should remain impartial and objective.

Recording the plan



Recording decisions is important. This needs to be done in a way that is meaningful to the person. This enables them to confirm what they have chosen, revisit their decision, and change their mind in the future if they want to.

Start with an accessible template

We recommend using a plan template that is produced in easy-read format, provides lots of space for writing or drawing, adding pictures and photos, and that specifically includes all of the key content that an Advance Care plan should include.

We recommend using ‘My plan for a good life, right to the end: An easy-read advance care plan’.

My plan for a good life, right to the end

Easy read advance care plan

1

This template was co-produced by people with learning disabilities in Aotearoa New Zealand.

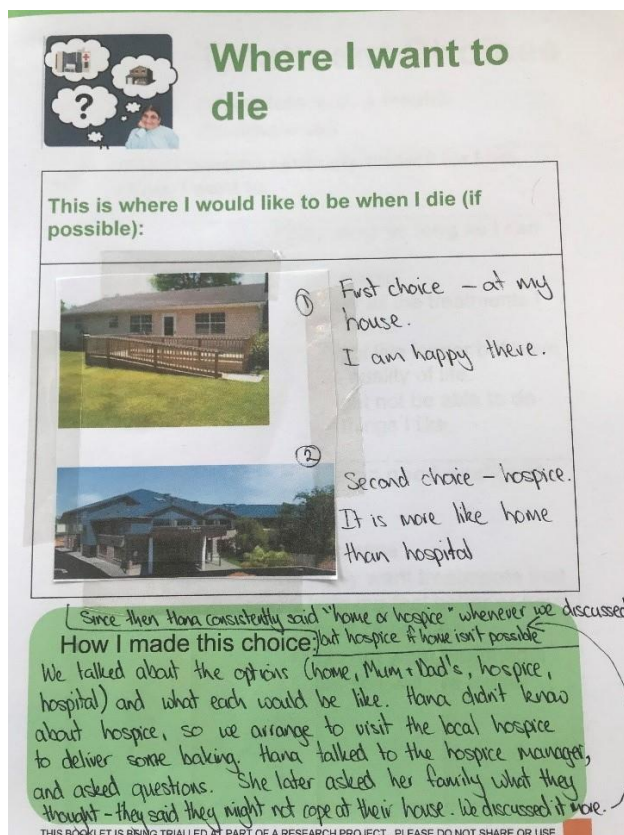
It aligns with the Te Tāhū Hauora Health Quality & Safety Commission’s ‘My Advance Care Plan and Guide’ so will have some familiarity to health professionals.

The alignment with ‘My Advance Care Plan and Guide’ means that the plan details can be loaded on-line and accessed by any health professional who needs to use it. Health professionals may also attach a copy of the paper plan to the electronic health record.

Importantly, this template includes a place to record, HOW decisions were made. This information helps health professionals have confidence in the decision-making process, and enables the process to be replicated if decisions need to be checked.



Tips for using 'My Plan for a Good Life, Right to the End: An Easy Read Advance Care Plan':

- Record people's decisions in any way that works for them – writing, pictures, photos, or real objects stuck onto the page. Make sure to use the person's words.
- Make sure that the person can tell from the page what the decision was. If not, try another way.
- Add extra pages if needed – some people need a lot of space to make their decisions clear.
- Add enough detail to the 'Process followed to make this choice' sections. This gives credibility to the process, and will help health professionals if/when they need to check that the person has made an informed choice.



In this example, Hana has used photos to illustrate her choices. Her support person has written short sentences in Hana's words, to explain her choice.

In the "Process followed to make this choice" section Hana's support person has recorded the process of how the decision was made.

<input checked="" type="checkbox"/>		<p>I'm not sure</p> <p>This means:</p> <ul style="list-style-type: none"> The doctor can decide, with help from my loved ones
<input type="checkbox"/>		<p>None of these</p> <p>This means:</p> <ul style="list-style-type: none"> I want something else Follow my directive(s)

How I made this choice:
 Hana and her manager, Mark, visited for an appointment. I explained what the options meant in her circumstances. Her health is fine at the moment. She found it difficult to decide, and said she might feel differently if she had a specific health issue. She then left + discussed with her family. Mark reports that they used the pictures above and made pros/cons lists for each option. Hana felt undecided + said she trusted the Drs to choose. She'd want to consult the Drs because uncertain. Dr P. Rashid

In this example, Hana has ticked the box to indicate her treatment preference.

Her GP, Dr Rashid, has recorded how Hana made her decision.

Alternative templates

Some alternative templates may suit some people. A variety of alternative options are listed below. It is worth noting that all of these options were produced overseas, so do not align with New Zealand's standard 'My Advance Care Plan and Guide'.

- Living Well: Thinking and planning for the end of my life' - <http://hsaonlinelearning.org/product/living-well-thinking-and-planning-for-the-end-of-your-life>
- Glancing Back, Planning Forward - www.tcd.ie/tcaid/accessibleinformation/planningtool.pdf
- When I Die - http://www.pcpld.org/wp-content/uploads/when_i_die_2_0.pdf
- Make an audio recording (well suited for people who have visual impairments)

Checking Decisions



Checking a person's decisions is important. Healthcare professionals need to be sure that the decision has been made without coercion, and that the person understands and is happy with their choice.

Checking should be undertaken with the same degree of rigour that is applied to people without learning disabilities. Checking should not turn into "competence assessment" unless there is a specific cause for concern.

Tips for checking decisions:

- Identify what process best helps the person to make decisions. This should be recorded in their plan.
- Find out how the person came to their specific decision – use that as a guide to help you revisit and check the decision.
- Explore the options again (teach and discuss). Not remembering the decision doesn't necessarily invalidate the decision. Many people will struggle with a question such as "tell me what you decided about treatment options", but may be able to respond if you say something like, "this part is about what you want to happen if you get very sick. These are the choices (show them visually from the easy read plan template or learning materials)...let's look at them all again. Tell me which one you want. Tell me which ones you don't want", "what do you think about (X option)?"
- Use whatever aids are necessary – pictures, signing, Talking Mats – to help the person understand, show/tell you, and explain what their choice is.
- Be direct, use short sentences and uncomplicated words/concepts.
- Allow plenty of time between questions and answers.
- Look for stability of decisions and a rationale that is meaningful to the person.

When there are concerns or conflicts



If there are concerns or conflict about the competence of decisions, most Te Whatu Ora districts will have access to experts who can assess competence. These assessments should relate specifically to the decision being questioned, and should be carried out in a way that meets the person's communication needs.

Sharing the plan



An advance care plan is only useful when it can be implemented. This is much more likely to happen when the plan is shared with those who need it, stored where it can be found, kept up to date, and referred to when someone becomes seriously unwell.

To ensure that this occurs:

- Encourage sharing of the plan with those who may need it. This could include:
 - Healthcare team members, such as General Practitioner, Practice Nurse, medical specialists
 - Family and whānau
 - Partner or close friends
 - Enduring Power of Attorney
 - Service Providers.
- Store the plan safely and securely (with consent from the person).
- In disability services, only record on file what you have consent to record (i.e. location of the plan, EPOA, treatment choices, directives).
- Encourage reviews of the plan when health, circumstance, or wishes change. Consider linking reviews to usual person-centred planning cycles.
- When the time comes, advocate for implementation.

Useful teaching resources

You may find the following resources useful in explaining content and options, and for ensuring that you understand a topic well before teaching it to someone else.


Before starting – sharing diagnostic information

Resources	Potential Use
Breaking Bad News	Open Future Learning http://www.openfuturelearning.org/ provide on-line training modules related to the topic of sharing bad news. These are based on Irene Tuffrey-Wijne's book How to Break Bad News (https://uk.jkp.com/products/how-to-break-bad-news-to-people-with-intellectual-disabilities?_pos=1&_sid=e39ad1eb0&_ss=r).
Books Beyond Words series	The Books Beyond Words series (www.booksbeyondwords.co.uk/bookshop?category=Healthseries) features books that are pictorial only – no words. They can be used as needed to help explain health (and other) situations, including diagnosis and prognosis. Titles include Am I Going to Die, Ann has Dementia, Getting on with Cancer, When Dad Died, When Mum Died, When Somebody Dies.

Blue section: what matters to me

Resource	Content
Memory Tree website – cultural and religious views on death and dying.	<p>The Memory Tree website (https://www.amemorytree.co.nz/customs.php) provides examples of how death is traditionally viewed in various cultures and religions. Use this information to help you guide a conversation or prepare appropriate visual images to use.</p> <p>Please note, none of this information should be considered as the single source of truth – it is important to explore what each individual person wants, which may or may not follow what is usual for their culture or religion.</p>
The person and their personal networks	The person themselves and their personal networks will be able to provide the best guidance on cultural and faith-based rituals or requirements.

Green section: why I'm making a plan, what I want to do before I die

Resource	Content
Love to know – website. How to Explain Death and Dying	The Love to know website has a section called How to Explain Death and Dying (www.lovetoknow.com/life/grief-loss/explaining-death-dying-youth), which provides information on how to explain death and dying to young people at various stages. Although the people you support are not children, some of this could be helpful.
Advance care planning website	Tō tātou reo advance care planning, Aotearoa New Zealand's advance care planning website (www.myacp.org.nz) provides various resources that explain what advance care planning is about, and why it is useful.
'Dying isn't as bad as you think' video	The 'dying isn't as bad as you think' video (www.youtube.com/watch?v=CruBRZh8quc), featuring Dr Kathryn Mannix, explains why it is important to talk about death and dying, using real/concrete language, and what death and dying is actually like. It explains what happens at the time of death, and leading up to it, to help allay fears.
Bucket list booklets 	There are plenty of bucket list journals (things I want to do before I die) available in bookstores or on line. Some people may enjoy recording their bucket list in a book, and then updating it with reflections following the activity. These can be a good way to help people focus on living their life.

Orange section – making choices, knowing about my health, important people, people to make decisions if I can't

Resources	Potential Use
Talking End of Life website video on choosing someone to help with decision-making	A large portion of this video (www.vimeo.com/238692750) talks about choosing someone to make decisions on your behalf when you can no longer make them yourself. A guide/supporter could watch this with the person, and discuss afterwards.
Public Trust information on Enduring Power of Attorney	This site has information about Enduring Power of Attorney (www.publictrust.co.nz/products-and-services/enduring-power-of-attorney/personal-care-epa), including a video you could watch with the person you support. Some of the language is a little complex, and it moves quite quickly, so you may need to watch several times, or stop the video at intervals and talk about what you've watched.

Ministry of Social Development website - Enduring Power of Attorney form and information	The Ministry of Social Development website has a lot of information and videos about EPA and answers to frequently asked questions. Some of this is quite complex, but it is a good place to look for information – a support person can then translate this into less complex language for discussion. www.superseniors.ms.govt.nz/finance-planning/enduring-power-of-attorney/index.html
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Grey section: treatment options, resuscitation, advance directives

Resources	Potential Use
Healthcare professionals	Each person’s healthcare team will be able to provide detail on treatment options and expected outcomes, and any other details that may contribute to decision-making.
Brain Activity After Cardiac Arrest	The Very Well Health website (https://www.verywellhealth.com/brain-activity-after-cardiac-%20arrest-1298429) has some useful reading about cardiac arrest and how CPR may or may not help.
Hato Hone St John’s First Aid Resuscitation video	This video from Hato Hone St John’s (www.stjohn.org.nz/first-aid/first-aid-library/resuscitation) discusses and demonstrates (on a model) HOW to do CPR. You could view the demonstration aspect of this video with the person you support, to show what is involved in CPR.
Health and Disability Commissioner website – information about Advance Directives	Government information about Advance Directives in New Zealand (www.hdc.org.nz/your-rights/about-the-code/advance-directives-enduring-powers-of-attorney). You could share this with the person you support, and explain it to them in uncomplicated language.

Yellow section: after I die, organ donation, caring for my body, my funeral / tangi, burial vs cremation, messages for loved ones, documents

Resources	Potential Use
Diagram to show organs	<p>Search on line for something like ‘line drawing of human organs’ to find a good simple diagram of the human body and its organs. You could print and adapt this as needed.</p> <p>Use the diagram to explain what organs are, and then identify where they are in the person’s body and what they do.</p> <p>Use the diagram to show which organs the person is would agree to donate (or not donate), either by circling, ticking, or colouring green (donate) or red (do not donate). This could be added to their plan.</p>
Frequently Asked Questions information about donating your body to medical science	<p>Use these web pages from University of Otago and Auckland University are good sources of information about donating a body to medical science:</p> <ul style="list-style-type: none"> • https://www.otago.ac.nz/anatomy/bequests/how/index.html • https://www.fmhs.auckland.ac.nz/en/sms/about/our-departments/anatomy-with-medical-imaging/bequests/procedures.html#:~:text=At%20the%20time%20of%20death%2C%20your%20family%2C%20attending%20doctor%20or,your%20GP%20or%20treating%20doctor
Organ donation process	<p>The Organ Donation NZ website (https://donor.co.nz/facts-and-myths/) is a source of good information about donating organs in Aotearoa New Zealand.</p>
Videos on organ donation from the Talking End of Life programme	<p>The Talking End of Life resource was developed specifically to help support workers learn how to discuss end of life issues with people with learning disabilities. There are two videos on organ donation on this site – an animation (www.vimeo.com/239579283), and a discussion (www.vimeo.com/238692222). Select the one most appropriate to the person you support. The first is a short animation, and the second is more complex.</p>
Talking End of Life website videos - funerals	<p>This video (www.vimeo.com/239579151) from the Talking End of Life website is a very short and basic animation that introduces a European style funeral.</p> <p>This more in-depth video (www.vimeo.com/238690001) features a person with learning disability and a support person. They attend a funeral and gravesite, and talk about funeral wishes and burial and cremation.</p>

	This video (www.vimeo.com/238681435) also features a person with learning disability and a support person. It shows speeches and memorial aspects of funerals.
Talking End of Life website videos on burial and cremation	This short animation (www.vimeo.com/239578802) explains burial in simple terms. This short video (www.vimeo.com/239578956) explains cremation in simple terms.
Talking End of Life website – video About remembering someone who has died.	This video (www.vimeo.com/238681435) explores some aspects of remembrance, mainly within a funeral setting.
Talking End of Life website – video about who will have your things after you die	This video (https://vimeo.com/238691363) is an introduction to making a Will. It features a person with learning disability and a support person talking about who will have his things after he dies. Watch this with the person you support to start a conversation.