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**Te whakamahere tiaki i mua i te wā taumaha |
Advance care planning**

Training manual

June 2021

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Document authors: Carla Arkless, Jane Goodwin, Maarie Hutana and Leigh Manson

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Available online at www.hqsc.govt.nz

Enquiries to: acp@hqsc.govt.nz

Document purpose

This manual provides an in-depth view of advance care planning and how it can be incorporated into health care.

It has been written for all health care professionals who are involved in having advance care planning conversations, delivering advance care planning training or implementing advance care planning services.

Please read it in conjunction with the Ministry of Health document, *Advance Care Planning: A guide for the New Zealand health care workforce*,¹ and the National Ethics Advisory Committee document, *Ethical Challenges in Advance Care Planning*.²

¹ Ministry of Health. 2011. *Advance Care Planning: A guide for the New Zealand health care workforce*. Wellington: Ministry of Health. URL:

www.health.govt.nz/system/files/documents/publications/advance-care-planning-aug11.pdf.

² National Ethics Advisory Committee. 2014. *Ethical Challenges in Advance Care Planning*. Wellington: Ministry of Health. URL:

https://neac.health.govt.nz/system/files/documents/publications/Ethical%20Challenges%20in%20Advance%20Planning%20FINAL_pdf.pdf.

Preface

'In some respects, this century's scientific and medical advances have made living easier and dying harder.'³

As health care technologies improve and people with many complex diseases live longer, advance care planning is becoming increasingly important.

There is considerable evidence that advance care planning is poorly undertaken, often happening only at the very end of life when crises occur, when life-sustaining treatments have been instituted despite issues of poor prognosis, and when people are not capable of making decisions about the care they want.

In 2010, the New Zealand Advance Care Planning Cooperative recognised that health care professionals needed better education in advance care planning. The Cooperative developed an advance care planning competency model and based the original training manual, *Advance Care Planning Curriculum Materials*, on the curriculum developed by the Public Information and Advocacy Work Group of the Canadian Strategy on Palliative and End of Life Care.

Following the publication of the original training manual in 2010, the New Zealand advance care planning training programme was developed further, which influenced the re-writing of the training manual in 2015. The training manual has since been revised further in 2021 to reflect the current advance care planning training and resources available.

Available training

- Level 1: four online advance care planning modules⁴
- Advance care planning legal framework video⁵
- Level 1A: one-day advance care planning workshop
- District health board (DHB) advance care planning train-the-trainer training
- Serious Illness Conversation Guide (SICG) training module⁶
- SICG three-hour workshop
- District health board SICG train-the-trainer training
- Implicit bias modules⁷

Available resources

- Advance care planning communication skills manual⁸
- SICG reference guide for health care professionals⁹

³ Field MJ, Cassel CK (eds). 1997. *Approaching Death: Improving Care at the End of Life*. Washington, DC: Institute of Medicine (US) Committee on Care at the End of Life. URL: www.ncbi.nlm.nih.gov/books/NBK233605.

⁴ <https://acp.elearning.ac.nz/login/index.php>

⁵ www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/legal-framework-for-medical-decision-making

⁶ www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/publications-and-resources/publication/4207

⁷ www.hqsc.govt.nz/our-programmes/patient-safety-day/publications-and-resources/publication/3866

⁸ www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/publications-and-resources/publication/4313

⁹ www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/publications-and-resources/publication/4206

Chapter 1: Overview of advance care planning

Introduction

For more information on basic advance care planning concepts, please refer to the Ministry of Health document, *Advance Care Planning: A guide for the New Zealand health care workforce*.¹

What is advance care planning?

Advance care planning is a process of discussion and shared planning for future health care involving the person, their whānau and health care professionals. It gives people the opportunity to develop and express their preferences for future care based on their values, beliefs, culture, hopes and goals; it also gives them a better understanding of their current and likely future health, and the treatment and care options available to them. The process involves conversations, documentation and review. In the context of serious illness, it should also include shared goals of care discussions and documentation.

What is an advance care plan?

An advance care plan is an articulation of what matters most to a person as well as their wishes, preferences, values and goals for current and future care. An advance care plan helps to inform current care and future care including if the person becomes unable to direct their own care.

Advance care plans need to be reviewed and updated regularly, particularly if there is a change in the person's personal circumstances or health.

The role of the health care professional

Historically, advance care planning was not addressed in health care training. This training manual was developed to begin to fill that gap. It recognises the important role of health care providers from all disciplines and in all settings in facilitating advance care planning and of the need to integrate what matters most to a person into the care that is planned and delivered for them.

There are many benefits to encouraging people to engage in advance care planning conversations. It is important to support all people to engage, not only those who are facing a life-threatening condition or those who have a chronic disease, but also people who are younger and in good health. If advance care planning conversations occur before a health care crisis, the person has time to consider their choices and talk with loved ones.

The conversation will be different in different situations; for example, a conversation with someone who is facing inoperable cancer may be quite different from a conversation with someone facing a lifetime with diabetes or someone who is currently well. However, the purpose remains the same: to support the person and their whānau to work through feelings and values in the most respectful and appropriate way. This helps the person and their whānau plan for future care and be more prepared when they may need to make treatment and care decisions in the future. If the person is unable to direct their own care, health care staff and their whānau will have information that can support person-centric decision-making.

This training manual focuses on the various elements of how to prepare for and introduce advance care planning, how to have the conversation and how to engage Māori in advance care planning. There is also an ethical and legal side to advance care planning that needs to be understood (see chapter 4).

Talking about advance care planning

For many people, advance care planning provides an opportunity for people to explore what matters most to them, and express their thoughts, feelings and wishes for their current and future health care. Through advance care planning, people can tell their whānau and their health care team how they wish to be honoured if they become seriously unwell or unable to speak for themselves. Other examples of what could be explored include: the significance of whānau members and the role they play in a person's life; living arrangements and social interaction; spiritual care and wellbeing; and tikanga (protocol) surrounding death.

When health professionals talk with people about advance care planning in the context of serious illness, the Serious Illness Conversation Guide is a useful, evidence-based conversation tool (see chapters 5 and 6).

Ideally, all related information will be documented in an advance care plan. Preferences in the plan might change as the person's health and life circumstances change, especially as it becomes clearer what treatments might be offered and what plans for support need to be made.

The value of advance care planning

For **the person**, the process can provide a sense of control, help to lessen anxiety about what lies ahead and may foster personal resolution.

For **the whānau**, the benefit is in knowing what choices the person would likely have made if they were capable of making decisions about their care and treatment. Having this information can help avoid disputes among whānau because the person's voice can be heard and considered. There are also benefits for whānau after death; they can feel comforted looking back with the knowledge they were able to acknowledge and honour their whānau member's wishes. Advance care planning has been shown to affect the grieving process positively.

For **the health care team**, providers generally feel more comfortable providing care they know is in accordance with the person's wishes; if everyone understands what matters to the person, there is likely to be less anguish and conflict associated with critical decision-making. Advance care planning can help to strengthen the relationship between health care professionals and the people they care for.

Advance care planning is a process

Advance care planning is a process rather than a one-time event. It may involve one or more conversations over time before a person is ready to make any decisions or define goals or preferences. There may be many conversations over the remainder of their lifetime as their health or life circumstances change. People need to know they can change their minds at any time (if they remain competent to do so) about the preferences they have articulated or decisions they have made.

We recommend watching the video ‘An overview of advance care planning in Aotearoa New Zealand’.¹⁰ This will help you understand the process over time, the numerous opportunities for conversations and the various tools you might consider at different times to support a person and their whānau with advance care planning.

Cultural safety and advance care planning

A culturally competent practitioner can contribute to wellbeing by integrating relevant cultural and clinical elements into their practice. Cultural competence requires an awareness of cultural diversity and the ability to function effectively and respectfully when working with and treating people from different cultural backgrounds.

Cultural differences can impact on the quality of communication and impact consumer–clinician relationships. There is evidence that misperception and lack of connection between consumers from non-dominant ethnic groups, such as Māori and Pacific peoples, and health professionals is not uncommon and negatively impacts engagement. Poor engagement between consumers and clinicians is associated with poor outcomes for both. Chapters 3 and 5 provide guidance to support consumer access to and participation with advance care planning.

Health equity and advance care planning

Improving health equity is a national priority, and it is important that our actions as health professionals aim to reduce and dismantle health inequities rather than add to them.

There are disparities in health outcomes between different groups within our population based on age, gender, socioeconomic position, geographical region and ethnicity. In Aotearoa New Zealand, ethnic inequalities between Māori and non-Māori New Zealanders are the most persistent and pervasive inequities in health.

Tools and resources to improve Māori engagement with and access to advance care planning are in chapters 3 and 5.

¹⁰ Available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/publications-and-resources/publication/4215.

Te Tiriti o Waitangi and advance care planning

Te Tiriti o Waitangi is regarded as one of the founding documents of government in Aotearoa New Zealand.

The articles of Te Tiriti o Waitangi have been interpreted and expressed through a set of principles that have evolved over time. Accordingly, we have moved beyond the principles and are guided by *Whakamaua Māori Health Action Plan 2020-2025*¹¹ to apply the following principles to our work across the health and disability system:

- **Tino rangatiratanga/self-determination:** Māori self-determination and mana motuhake are central to the design, delivery and monitoring of the advance care planning programme.
- **Mana taurite/equity:** the advance care planning programme is committed to achieving equitable health outcomes for Māori.
- **Whakamarumarutia/active protection:** this is a call for action, to the fullest extent, to achieve equitable health outcomes for Māori. It includes being well informed on the extent, and nature, of both Māori health outcomes and efforts to achieve Māori health equity.
- **Pātuitanga/partnership:** the advance care planning programme works in partnership with Māori and develops strong and enduring relationships.
- **Kōwhiringa/options:** advance care planning is provided in a culturally appropriate way that recognises and supports the expression of hauora Māori models of care.

The principles provide a framework to advance Māori health and support mana motuhake, so our indigenous population receive equitable health care and live long, healthy lives.

The advance care planning programme is committed to embedding and enacting Te Tiriti o Waitangi by working with Māori to ensure advance care planning initiatives are tailored for, and relate to, Māori communities.

In chapters 3 and 5 we discuss tools and resources and offer guidance to build your knowledge of te ao Māori (Māori world view) so the care provided supports health gains for Māori and enacts the principles of Te Tiriti.

Summary

- Advance care planning is a process of discussion and shared planning for future health care involving the person, their whānau and health care professionals.
- Advance care planning should be incorporated into all aspects of health care and supported by health care professionals from all disciplines.
- Advance care planning benefits the person, their whānau and the health care team.
- Good communication that supports shared decision-making between health professionals, the person and their whānau results in better health outcomes.
- The cultural safety of the person and their whānau is very important in creating an environment of trust, where the person feels safe to participate in planning and shared decision-making.

¹¹ Ministry of Health. 2020. *Whakamaua Māori Health Action Plan 2020-2025*. Wellington: Ministry of Health. URL: www.health.govt.nz/publication/whakamaua-maori-health-action-plan-2020-2025.

Chapter 2: Advance care planning self-awareness

Introduction

Before having advance care planning conversations, there are some things to consider in terms of self-awareness. It is important to recognise our own feelings and reactions to the topics that may come up during a conversation. Doing this work first should help us to avoid influencing the conversation with our own opinions, values, cultural orientations and beliefs. This chapter explores self-awareness.

Engaging in the advance care planning process ourselves

Advance care planning can include subjects that are difficult to discuss. We are asking people to think about their values and what makes life meaningful; to consider circumstances when they may not be capable of making health care decisions; to explore their feelings about death and dying and quality of life; and to potentially discuss these things with their whānau. For some people such a conversation can evoke powerful or uncomfortable emotions. For others it brings a sense of relief that things are out in the open.

Before having advance care planning conversations with people, it is a good idea to engage in the process ourselves, in order to more fully understand the experience of advance care planning and empathise with the people we are supporting to participate.

Here are some things to consider when engaging in our own advance care planning:

- How do I feel about advance care planning?
- Do I know what matters the most to me and my whānau, particularly if my health were to change?
- How do I feel about talking about death and dying?
- What choices would I make for my own future health care?
- What tikanga (customs) and kawa (ceremonies) support my wellbeing?
- What do I draw on for inner strength and to sustain resilience?
- Am I able to talk to my whānau about my preferences?

How personal experiences and values impact advance care planning conversations with others

Self-awareness is a cognitive process of considering our background, cultural identity, where we fit in the community and the world, and how we feel about these things.

Here are some questions to promote self-awareness:

- What did I learn from my whānau about relationships? How does that affect how I deal with whānau members?
- How does my cultural background influence my values? How does that affect how I approach people from cultural backgrounds different from my own?
- What do I think are appropriate gender roles? Do I communicate differently with people of different genders?
- How do I handle criticism or anger?

- In my caring role, how do I deal with people who are being 'difficult' or those exhibiting behaviours that are different from mine?
- When I think about death and dying, what words or images come to mind?

Self-awareness is important because when we have a better understanding of ourselves we are able to experience ourselves as unique individuals and therefore appreciate the uniqueness of others.

Understanding our biases and assumptions

Understanding our biases and assumptions is crucial to clear thinking and working with people and whānau. All of us, no matter our education, intellectual commitment or good intentions, are susceptible to bias. It is part of the human condition.

To think clearly and make assessment rather than judgement, we must identify when we are falling prey to bias and unconscious distortions. This means understanding 'cognitive bias', or our tendency to believe that something is true even if the data clearly says it is not, or 'confirmation bias', which is where we seek out only information that supports something we already believe and disregard the rest.

The Health Quality & Safety Commission (the Commission) has developed [a series of online learning and education modules](#) that can help us reflect on our unconscious bias.⁷

Using debriefing and self-reflection following advance care planning conversations

Debriefing and self-reflection is a useful way of learning from advance care planning conversations and gaining insight into personal feelings and reactions.

Here are some questions you might consider including in an advance care planning conversation debrief:

- What am I/are we doing that is working well and what is not?
- How do I/we know?
- What can I/we do to improve this experience for people engaging in advance care planning?
- How can we support each other?

Reflection following a negative or difficult advance care planning conversation with a person, for example, may involve asking the following:

- How did I react? Was I defensive? Upset?
- Why did I react the way I did?
- How did my reaction impact the person and/or their whānau?
- How could I have handled that situation differently?
- How could that encounter influence my next advance care planning conversation?

A reluctance to engage in advance care planning

If we feel reluctant to engage in advance care planning conversations with others it is helpful to reflect on why that might be through questions like the following:

- Am I avoiding these conversations? Why might that be?
- Have I engaged in my own advance care planning process? What was that experience like for me?
- Are there specific advance care planning topics, issues or questions that I am uncomfortable with?
- What can I do to overcome my reluctance?

Self-care

Advance care planning conversations can be challenging and emotionally or psychologically taxing. Experiencing the emotions of others can take an emotional toll. It is important to identify support systems and develop coping strategies that are personally effective.

Consider:

- what positive support mechanisms work best for me and am I using them?
- how do I re-energise myself?

Summary

- Personal experience in doing our own advance care planning helps when supporting others through the process.
- Identifying personal feelings and reactions helps to reduce the chance of influencing the preferences of others.
- Debriefing and self-reflection are useful tools to support learning and develop insight into personal feelings and reactions.
- Self-care is important because advance care planning conversations can sometimes be emotionally draining.
- Refer to the e-learning module, 'Considering your own future health care',¹² for more information about self-awareness and personally engaging in the advance care planning process, available at: www.myacp.org.nz.
- Refer to the Commission's [learning and education modules on understanding bias in health care](#).⁷

¹² Video can be accessed via the Commission website after registering on the learning management system <https://acp.elearning.ac.nz/login/index.php>.

Chapter 3: Supporting Māori health gains

The inclusion in health care of Te Tiriti o Waitangi principles, tikanga, communication strategies, Māori health models and te reo Māori increase your ability to work effectively with Māori consumers and whānau. Below are a few guidelines and resources to strengthen cultural competency and better support Māori engagement with advance care planning.

How to demonstrate equitable practice

- If unsure, ask people how their name is pronounced.
- Acknowledge the role of whānau as a key health determinant for Māori and actively include whānau in conversations (with the person's permission).
- When making an advance care planning appointment ask the person if they would like whānau or support people involved.
- When whānau and support people are with the person, enquire who they are and how they fit in to the person's life.
- Aim to greet the person and their whānau in their own language and learn a few simple te reo phrases.
- Be aware of the environmental factors that may affect the person and their whānau engaging with health care services.
- Build your knowledge of indigenous belief systems including views on mana, death and dying, reliance upon whānau and karakia (prayer).
- Consider the determinants of health and how they might affect a person's life. For example, education level can affect understanding of medical terminology or financial abilities may impact the number of clinic visits that are attended for completing advance care planning documentation.
- Advocate for a larger Māori workforce that works alongside consumers and their whānau to support Māori health gains.

Use of te reo Māori

Te reo Māori is one of Aotearoa New Zealand's three official languages and is widely used within health care. Te reo Māori is recognised as an important cultural competency and can significantly improve the clinician–consumer relationship because it demonstrates consideration of cultural difference and inclusion of mātauranga Māori (Māori knowledge).

Integrating te reo Māori into your daily practice will prepare you for working with whānau Māori and in turn support Māori health gains. Start with a friendly 'Kia ora' and build up vocabulary over time.

Kupu Māori glossary

Karakia	Prayer or invocations
Kupu Māori	Māori word
Mana	A concept with many shades of meaning including prestige, authority, control, power and influence
Mana motuhake	The ability of Māori to determine things according to their values and what they think is important; Māori self-determination
Mātauranga	Māori knowledge
Pōwhiri	Rituals of encounter, or welcome ceremony
Tangata whenua	The indigenous people of Aotearoa New Zealand
Tautoko	In the context of health means to provide cultural support
Te ao Māori	Māori world view
Te reo Māori	Māori language
Tikanga	Māori cultural beliefs, values and protocols
Whakawhanaungatanga	A te ao Māori process of establishing relationships
Whānau Māori	A term commonly used to denote people who identify as Māori
Whenua	Land; in the context of whakawhanaungatanga this encompasses ancestral land, mountains and water (ocean, lakes or rivers)

Te reo Māori resources

Aki Hauora

This Māori language vocabulary and phrase learning app from the University of Otago is aimed at health professionals and aims to assist learning kupu Māori (words) that are commonly used in the health environment. It is an interactive game which can easily be loaded to your phone for some learning fun.

- For Apple: <https://itunes.apple.com/nz/app/aki-hauora/id1062206292?mt=8>
- For Android: <https://play.google.com/store/apps/details?id=nz.monkeywise.akihaouora&hl=en>

Māori Dictionary

<https://maoridictionary.co.nz>

Chapter 4: Advance care planning and the legal framework

Introduction

Understanding the legal framework for advance care planning is crucial to be able to support and advise people and their whānau on their rights.

The legal framework is described in the Ministry of Health document, *Advance Care Planning: A guide for the New Zealand health care workforce*,¹ in the third Level 1 (L1) online advance care planning module; and in the related video on the advance care planning website.¹³ The National Ethics Advisory Committee document, *Ethical Challenges in Advance Care Planning*,² is also a useful resource.

Code of Rights

Advance care planning is consistent with the Code of Health and Disability Services Consumers' Rights (the Code),¹⁴ which promotes consumer choice and autonomy in planning and receiving health care. Five of the rights within the Code are particularly relevant and applicable to advance care planning:

- The right to dignity and independence (right 3).
- The right to have good care and support that fits your needs (right 4).
- The right to be told things in a way that you understand (right 5).
- The right to be told everything you need to know about your care and support (right 6).
- The right to make choices about your care and support (right 7).

Please familiarise yourself with the details of these rights.

Ethical and legal obligations of health care professionals

Health care professionals engaging in advance care planning need to understand the legal and ethical issues involved. This includes being aware of concerns about the misuse or misunderstanding of advance care plans and/or advance directives. Some key points follow.

- No one should be pressured to have advance care planning conversations, to document preferences or to make future care and treatment decisions. It is a person's right to refuse to engage in advance care planning and it cannot ethically or legally be made a pre-condition for admission to any facility or institution.
- Consent to treatment must be obtained from a competent adult. As long as the person is competent to make their own care and treatment decisions, the fact that the person has an advance care plan or an advance directive, or has appointed a substitute decision-maker, is NOT relevant in determining consent.
- If a person becomes mentally incompetent to make health care decisions and has left prior documented instructions or preferences about care in the event of incompetence, these should be considered when determining what appropriate care and treatment

¹³ www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/publications-and-resources/publication/4224

¹⁴ www.hdc.org.nz/disability/the-code-and-your-rights

would best meet the person's needs. The instructions or preferences do not necessarily provide consent to or refusal of treatment unless they meet the legal criteria for a valid advance directive. Health care professionals must be familiar with the legal requirements for obtaining consent, and with the criteria that make an advance directive legally binding.

Competence

There are two aspects of competence to consider: competence to make treatment decisions; and competence to participate in advance care planning.

Competence to make treatment decisions

Mental capacity (or competence) to make health care decisions is an issue central to advance care planning. Only a competent adult can make current treatment decisions and future treatment decisions (advance directives). Legally, adults are presumed competent unless proven otherwise. Respect for the intrinsic value and dignity of others means that incompetent people must be protected. Declaring a person incompetent places large restrictions on their autonomy and is therefore a very serious decision.

Competence is judged on a specific task or function at a specific point in time. Consequently, the nature of the task or function and the context and level of risk are all relevant in determining competence. This approach provides three possible competency assessment outcomes:

- full/complete competence to consent
- partial competence (the person is competent to consent to or refuse some things, but not others)
- total lack of competence.

Please note that a person may be competent to engage with advance care planning but not competent to make treatment decisions.

Competence for advance care planning

Even if a person is not competent to make current or future treatment decisions, they may still be capable of engaging in advance care planning conversations, and be competent to document their values, goals and what makes life meaningful to them.

Determining if a person is competent

If you are obtaining a treatment decision from a person, you are responsible for determining whether that person is competent or not. You must use your own judgement, based on conversations with the person, to determine whether the person can understand and appreciate the task at hand, be that to articulate what quality of life means to them or to make treatment decisions. If you have doubts about the individual's competence, seek a second opinion, ideally from someone for whom formal competency assessments are part of their role.

The common law test for competence centres on a person's ability to **understand** the relevant information and **appreciate** the reasonably foreseeable consequences of a decision.

To understand: a person must be able to grasp and retain the information relevant to the decision at hand. If doubts about the person's ability to understand arise, the following questions must be explored:

- Has the person been given the relevant information in vocabulary appropriate to their ability to understand, and in a language in which they are fluent?
- Has the person been educated about the illness and the treatment alternatives and been given opportunities to ask questions?
- Does the person understand that there are choices, what each alternative involves and its risks, harms and benefits?
- Can the person remember the information long enough to reach a decision?
- Can the person remember the choices made previously and be consistent in decision-making over time?

Please note that if a person makes a decision that you view as irrational it does not mean the person is incompetent.

To appreciate: a person must be able to grasp how a given treatment will affect them personally. Some people describe appreciation as the person having an emotional understanding of the events and experiences that will result from the decision.

The point is not whether a decision is reasonable, or what you would have chosen, but whether the person had legal capacity as described above to make the decision.

If a person's understanding or appreciation appears uncertain, explore this further with them or involve someone who is experienced in assessing competence formally.

Competency can change over time. Delirium, drugs, fatigue, strong emotions and underlying illness may render a person incompetent; however, the incompetence may only be temporary. Reversible causes must be ruled out and treated, and capacity reassessed. A person's ability to give informed consent and make health care or other decisions may vary from month to month, day to day, or from decision to decision. Different treatments may be offered and accepted or refused as health deteriorates or improves, and people can change their minds.

Informed consent

Health care professionals are responsible for giving the person 'material information' to enable them to make informed health care choices. The 'material information' is all the information that would be required by a reasonable person in the same circumstances and expanded by the person's questions or what a health care provider knows they would want to know.

The 'material information' needed to make informed health care choices includes the risks, harms, benefits and potential benefits of the recommended treatment, of its reasonable alternatives, and of no treatment.

Health care professionals must obtain consent to interventions, which includes advance care planning, from a competent adult. The following are elements of a valid consent.

- It must be voluntary.
- The person must be mentally competent to provide the consent.
- It must be informed (note that the person has a right to refuse information).

The three elements – competence, voluntariness and information – sufficient to meet legal requirements – are also required from an ethical perspective. Both ethically and legally, a discussion is required regarding the goals of treatment, the nature, purpose, risks/benefits of proposed treatments and alternatives to the proposed treatments. The benefits and risks of no treatment should be covered as well. A health care professional should give reasons for recommending one treatment option over others.

The bioethics literature identifies five abilities and conditions to determine capacity to grant informed consent, which closely track the legal requirements:¹⁵

1. Ability to understand information (the informed part) and communicate a decision.
2. Ability to reason (to process information) and deliberate (assess risk/benefits of proposed treatments and alternatives and comprehend the consequences of accepting or refusing treatment).
3. Ability to choose within a framework of personal goals, values and beliefs.
4. The choice is voluntary (no internal or external coercion).
5. Is capable of sustained cooperation (this last item is controversial – not all bioethicists include this capacity).

If the person has appointed a substitute decision-maker, the substitute cannot give consent on behalf of a capable person. In addition, the advance care plan or advance directive cannot be used in place of consent from a competent person. Prior wishes and substitute decision-makers only become relevant when the person is no longer competent.

Consent is more than a form or a formality

Obtaining consent is a process. A signed consent form is not a replacement for the process of obtaining consent. A signed form will not satisfy legal requirements if all the requirements for obtaining an informed consent were not fulfilled. A form may not satisfy your ethical obligations as a health care professional.

Individual autonomy and collective cultures

You may encounter different views of individual and whānau decision-making, and of the importance of individual autonomy. Many people want to make their own decisions about things that are important to their lives, like health care. However, some individuals and some cultures (eg, Māori and Pacific peoples in Aotearoa New Zealand) emphasise whānau or group decision-making over individual decision-making.

While discussing consent to treatment with a competent adult, if the person says they want their whānau to decide, an agreement can be made to include whānau members in the discussion; however, the decision belongs to the competent adult. The person may not want to hear about all the risks, benefits and alternatives, and whānau members may want to discuss them at length, but the consent must ultimately come from the competent person. The consent is still valid even though the person has waived their right to information.

¹⁵ www.mcnz.org.nz/assets/standards/79e1482703/Statement-on-informed-consent.pdf

People with communication difficulties

If the competent adult has difficulty communicating, it is often tempting to talk with the whānau instead; however, to fulfil ethical and legal obligations, you must try to communicate with the person themselves, which may take extra time and resources. For example, you may need to use a communication device or service, or a professional interpreter.

Advance directives

An advance care plan may include one or more advance directives, which are consent to or refusal of specific treatments that may be offered in the future. As with current decisions, a person consenting/refusing in advance in the form of an advance directive must, at the time they make the advance directive, be:

- informed
- competent
- without undue influence (the decision must be voluntary).

If, in the future, a treatment decision is required but the person is not competent to make it, they must also have intended the advance directive to apply in the presenting circumstances.

Valid advance directives are legally binding, and the consent or refusal contained in a valid advance directive must be accepted.

An advance directive needs to be for specific treatment. If an advance directive is not specific enough to function as a consent to or refusal of a treatment it should still be taken into account when decisions are being made because it is an indication of the person's preferences and may provide direction about what they would have wanted.

When working with a person to create an advance directive, ensure the treatments and circumstances are clear and specific.

Example: if a person says they 'don't want renal dialysis', it would be important to support the person to be more specific by exploring with them whether this is 'under any circumstances' OR under limited circumstances. For example, 'If I have become dependent on others for basic needs and my doctors believe there is little chance of this being reversed' OR 'for treatment of chronic renal failure'.

In order to improve clinician confidence in an advance directive, if you are supporting a person to document an advance directive you should document and sign that you believe the person to be competent to make the documented decisions, and that they were informed and without undue influence. This will increase the likelihood that the advance directive will be honoured.

An advance directive should be honoured unless there are reasonable grounds to doubt that the person was competent, informed and acted freely when they made the advance directive, and that they intended it to apply to the presenting circumstances.

Many people will not have strong views about specific treatments they do or do not want in the future and will not therefore include advance directives in their advance care plan.

Enduring power of attorney

An enduring power of attorney (EPA) is an authority given by a person (known as the donor), while they are competent, to another person (known as the attorney) allowing the attorney to act for the person if the person were to become mentally incompetent.

Under the 2007 amendments to the Protection of Personal and Property Rights (PPPR) Act 1988, a medical certificate stating that the person is mentally incompetent is required before attorneys can act in respect of significant matters for that person.

A significant matter means a matter that has, or is likely to have, a significant effect on the person's health, wellbeing or enjoyment of life. Examples are decisions about a permanent change of residence, entering residential care or undergoing a major medical procedure.

There are two types of EPA in Aotearoa New Zealand:

1. EPA for personal health and welfare: the person appoints an attorney to make decisions about their personal health and welfare on their behalf, should they lack competence for such decision-making at some point in the future. There is one main exception to the decision-making authority of an attorney – they cannot refuse standard life-sustaining treatment on behalf of the incompetent person.

Only one person can be appointed to be a personal care and welfare attorney. However, one or more successor attorneys can be nominated to act if the authority of the original attorney lapses.

2. EPA for property: the person appoints an attorney to manage and make decisions about their property. These decisions might concern investment of assets, expenditure and decisions about sale of property. A property attorney may be given the authority to manage property affairs while the person still has competence and to continue to act if they are mentally incompetent, or the attorney may be given the authority to act only once the person loses capacity.

The same person can be both the attorney for personal care and welfare, and property. However, a trustee corporation cannot be a personal health and welfare attorney.

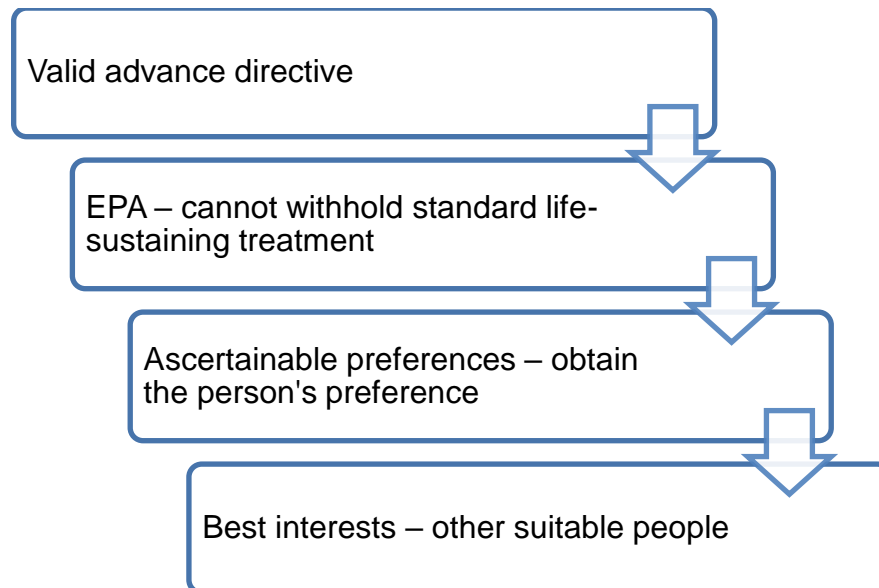
The EPA documentation must be completed while the person has capacity. Both the person and their appointed attorney must sign the document, with both signatures witnessed independently. An attorney must be at least 18 years old, a New Zealand resident, not bankrupt, legally capable and not subject to a personal or property order.

Although whānau may believe they have the right to make decisions on behalf of an incompetent person because of their relationship with them, they do not have this right. This means that, in the absence of a legally authorised EPA, the decision rests with the treating clinician. The views of whānau are clearly important and should be taken into account; however, whānau do not have legal decision-making authority.

Decision-making for an incompetent person

Where a person is not competent to make an informed decision about their health care, there is a specific order in which decision-making rights are determined.

- If there is a valid advance directive that was intended to apply to the current situation, the advance directive will determine consent/refusal.
- If there is no valid advance directive, and there is an activated EPA for health and welfare, the attorney 'steps into the person's shoes' and makes a decision on their behalf based on what the person would have wanted (with one exception, as noted above). A court-appointed welfare guardian can also consent to care and treatment on a person's behalf.
- If there is no valid advance directive and no EPA/welfare guardian, the treating clinician is required to look for the person's 'ascertainable preferences' and to then use those to make the decision based on what the person would have wanted if they could communicate for themselves. To determine 'ascertainable preferences' the treating clinician should look for advance care planning information in the medical record, talk with other clinicians who have previously talked to the person, and talk to whānau about what the person has previously told them about their preferences.
- If there is no valid advance directive, no EPA and no ascertainable preferences, the treating clinician will need to make a decision based on what they believe is in the person's best interests. The clinician should believe the decision is consistent with that which the person would have made if they were able.



If there are legal or ethical uncertainties surrounding the decision-making process, seek advice from other clinicians and your organisation's legal department.

Summary

- Health care professionals have legal and ethical obligations regarding informed consent and refusal of treatments, both in the present and in advance.
- A person must be competent in order to make an informed consent or refusal of treatment, and this competence may vary from day to day or from decision to decision.
- An advance care plan may contain advance directives, which are consents or refusals of specific treatments that may be offered in the future.
- If an advance directive meets the four criteria for validity, ordinarily it should be honoured.
- When a treatment is being offered to a person, the treating clinician must obtain consent before proceeding with the treatment.
 - If the person is competent, consent must come from the person.
 - If they are not competent, look for a consent or refusal to this treatment made in advance by the person (advance directive).
 - If there is no valid advance directive, look for someone who has the authority to consent on the person's behalf (an EPA/welfare guardian).
 - If there is no one with authority, the treating clinician should make a decision based on what they can believe the person would have wanted.
- Refer to the 'Changing the outcomes of future health care' e-learning module available at: www.myacp.org.nz (go to 'Information for clinicians').¹⁶
- Refer to the 'Legal framework for medical decision-making' video at: www.hgsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/publications-and-resources/publication/4224.
- For information regarding the Code of Health and Disability Services Consumers' Rights go to www.hdc.org.nz/your-rights/the-code-and-your-rights.

¹⁶ Video can be accessed via the Commission website after registering on the learning management system <https://acp.elearning.ac.nz/login/index.php>.

Chapter 5: Initiating the conversation

Approaching people and their whānau with respect, integrity and dignity is at the heart of all therapeutic relationships. This chapter discusses how to prepare for this.

The Ministry of Health document *Advance Care Planning: A guide for the New Zealand health care workforce*¹ and the second L1 advance care planning online module contain more information on initiating advance care planning conversations.

When to initiate an advance care planning conversation

A prevailing myth is that only people who are near the end of life, such as the elderly, kaumātua or people receiving palliative care, should engage in advance care planning. The reality is that it is most beneficial to start advance care planning early, before the end of life, when the person has time and space to think about what matters most to them without the pressure of a crisis or worrying decline in their health. Early planning allows the person time to consider their goals and preferences for care and to talk about their wishes and concerns with whānau and health care professionals long before treatment decisions are made.

People of any age can benefit from advance care planning.

The opportunity to talk to a person about advance care planning should be offered in a way and at a time that is most meaningful to them. However, if it is likely a person may die within the next 12 months and no advance care planning has been done, it is important to support the person to start the process. That said, their personal choice whether to engage in advance care planning or not should be respected.

Here are some examples of when advance care planning might be initiated:

- In the primary health care environment, advance care planning might be offered to a healthy person during a routine medical or wellness check.
- In hospital, advance care planning might be offered as part of a shared goals of care discussion, continue throughout the admission and be incorporated into discharge planning, with a request to the practice team to continue the conversation.
- In aged residential care, advance care planning might be initiated as part of the routine care planning process and/or in the process of developing shared goals of care in the first few weeks of admission.

Take into account the person's emotional state when considering the timing of advance care planning conversations. For example, if they have just received a diagnosis of a life-threatening illness, they may be too upset to take in further information. In this situation, if urgent decisions need to be made, a focused discussion about certain aspects of advance care planning may occur, centring on the person's values and goals that will help inform those decisions. A more comprehensive advance care planning conversation is best left for another time.

Who should initiate and facilitate advance care planning conversations

If there is an opportunity to raise people's awareness of advance care planning, health care professionals should do so.

Facilitating advance care planning is not the domain of any single profession. The most appropriate person to facilitate an advance care planning conversation will depend on the circumstances. For example, a doctor may have the best information about prognosis and treatment options, a nurse may know more about the person's needs and goals, a social worker, spiritual care advisor or kaimahi hauora Māori (Māori health worker) may be in the best position to help the person articulate their care preferences.

Advance care planning will most likely involve a number of conversations in different settings over time and as such may be initiated by one health care professional and continued by others.

Factors to consider when initiating advance care planning conversations

The environment

Whatever the setting or circumstance, advance care planning conversations should take place in an appropriate environment. Consider the following.

- Ensuring privacy.
- If the person wants their whānau to be present, ensuring you have a space that can accommodate that.
- If possible, providing an environment that is familiar to the person.
- Ensuring accessibility, for example, wheelchair access.
- Setting aside enough time for the discussion so people do not feel rushed.
- Preventing interruptions.

In a GP practice, privacy should not be an issue; however, allowing time for the discussion can be a challenge. In a hospital ward, finding private space may require some planning ahead. Preventing interruptions will be a challenge in most settings because of the need to be available to others.

Cultural considerations

Find out if there are any cultural considerations you need to factor into the advance care planning appointment. Ask whether the person would like to bring someone to provide tautoko (cultural support). Also, remember some people are reluctant to talk about their care or share intimate details of their lives with professionals of a different sex. If possible, the health care professional facilitating the advance care planning conversation should be someone with whom the person can communicate comfortably.

Some people value individual decision-making and for others whānau make decisions as a group. Legally and ethically in Aotearoa New Zealand it is the individual's decision that is recognised. If the function of the wider whānau in the decision-making process is important to the person, that should be supported and respected.

Developing therapeutic relationships with whānau Māori

Successful therapeutic relationships with Māori begin with an understanding of the person's position within their whānau and community, and of their whānau connection to both place (where people come from and where they currently live) and to people (with whom they are connected and share significant generational links).

Even when whānau appear not to be engaged with things Māori, many can and do respond to Māori processes and/or ways of being. It is important for health care professionals not only to think about Māori that present in terms of cultural context but also as part of a collective. Like other indigenous populations worldwide, Māori have experienced and currently experience historical, cultural and socioeconomic deprivation that impact on collective and individual wellbeing.

For Māori, identity is a central element to wellbeing and, as a collectivist culture, ideas of self are entwined in tūpuna (ancestors), whānau and community, rather than the emphasis being on the individual's needs and aspirations.

Taking the time to greet the person, and all whānau in attendance, is a sign of respect that is imperative when engaging with Māori. In combination with best practice competencies such as karakia (prayer), pōwhiri (rituals of encounter) and whakawhanaungatanga (process of establishing relationships), a physical and spiritual safe space can be created for therapeutic relationships to develop and mana motuhake (self-determination) to flourish. The 'Hui Process', which is discussed in the next section, is a method of integrating cultural competency into clinical practice to improve clinician–consumer relationships and support Māori health gains.

Engaging Māori with advance care planning

When engaging Māori in advance care planning conversations we recommend you use an engagement process that aligns with te ao Māori, for example the 'Hui Process'.

The Hui Process was developed at the University of Otago and draws on mātauranga Māori (Māori knowledge) and practice, and aligns these in a contemporary setting to help clinicians work effectively with Māori.

In a nutshell, the Hui Process is a clinical engagement strategy that is easy to follow and implement, incorporates tikanga Māori and supports Māori health gains. It encapsulates a good relationship approach and could be used to frame all advance care planning conversations, not only those with Māori.

1. Mihi – initial greeting and engagement

Introduce yourself, describe your role and the purpose for the consultation, and confirm that the person identifies as Māori.

2. Whakawhanaungatanga – making connection

Based on traditional Māori protocol, whakawhanaungatanga involves connecting with the person and their whānau on a personal level often through connections with whenua, whānau involvements or the use of te reo Māori. This often requires some sharing of yourself. Include all whānau with the person.

3. Kaupapa – attending to the main purpose of the encounter

Here, the focus moves to the clinical task at hand.

4. Poroporoaki – concluding the encounter

Clearly identify the finishing point of the consultation and make it clear what the next steps are for the person and their whānau, and yourself. There are three parts to the poroporoaki:

- a. Ensure you have understood what the person and their whānau have said.
- b. Ensure the person and their whānau understand what you have said.
- c. Ensure the person and their whānau are clear about the next steps.

This engagement process integrates culturally specific principles of greeting and relationship-building to develop effective therapeutic relationships and provide a physical and spiritual safe space for Māori to engage with health care services.

Kupu Māori

Karakia	Prayer
Kupu Māori	Māori words
Mana motuhake	The ability of Māori to determine things according to their values and what they think is important
Pōwhiri	Rituals of encounter, or welcome ceremony
Te ao Māori	Māori world view
Whakawhanaungatanga	A te ao Māori process of establishing relationships
Whānau Māori	A term commonly used to denote people who identify as Māori
Whenua	Land; in the context of whakawhanaungatanga this encompasses ancestral land, mountains and water (ocean, lakes or rivers)

A full kupu Māori glossary is in chapter 3.

Support services and devices

Before the advance care planning conversation takes place, consider other appropriate supports, such as professional interpretation services, that will need to be arranged ahead of time. Avoid using whānau or community members as interpreters, if possible, as their own views of the situation may colour their translation of the conversation. Professional interpreters should have the necessary knowledge and objectivity.

Some people with disabilities are highly functioning cognitively but cannot adequately communicate verbally. Do not assume that someone who has difficulty communicating does not understand or has nothing to say. Find out what supports they need to make communication possible. Appropriate supports may include interveners for the deaf-blind or computer devices that create speech.

Who should be present?

Some people may prefer to meet one-on-one with a health care professional for all or part of the conversation. Others may want to have one or more whānau members or perhaps a close friend or kaumātua with them. Encourage the person to consider who they would like to be present. Arrange to have the conversation at a time and place that would best support the person and their whānau to attend.

Consider who else from the health care team you might include but check in with the person about this – some people will be comfortable meeting with several health care professionals while others may find being faced with a team of people overwhelming.

Time for reflection

The conversation may take place over several encounters to give the person and whānau time to assimilate, reflect on and discuss the various elements of advance care planning.

Being prepared with appropriate information

Before engaging in an advance care planning conversation, be prepared. Find out the person's state of health, course of illness and relevant medical facts (if appropriate). Having to flip through documentation during the conversation is distracting and can impact on credibility and trust.

The person's understanding

Before advance care planning is introduced, the person should understand the relevance of advance care planning to them so the conversation can be placed in context. To help them reach this level of understanding may involve exploring what they know about their prognosis and general health issues before introducing advance care planning.

Exploring a person's understanding of their current health situation is a key step in the Serious Illness Conversation Guide process; check the guide – it may provide useful language/phrases to help you.¹⁷

Creating an opening for discussion

Reassure the person that advance care planning is an opportunity for them to describe what is most important to them, what they value doing and who they value being; what they are worried/concerned about; and to explore how that should be taken into account as care and treatments now and in the future are planned.

Use simple and clear language, avoiding technical terminology as much as possible.

¹⁷ www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/tools/serious-illness-conversations

Creating an opening for discussion with a person who is well

To encourage a well person to think about advance care planning, an opening might be:

‘You are in excellent health and taking good care of yourself. Now is a good time to think about future health care planning and what would be important to you if your health were to suddenly change (like an accident); we call this advance care planning. Is that something you’ve ever thought about?’

If the person has an advance care plan and/or advance directive, the conversation can focus on what it says, when it was made, whether it reflects current wishes or needs updating, whether it names an EPA, and whether they have discussed the contents with their EPA and whānau. Place a copy in their clinical record if they agree.

If the person is not familiar with advance care planning, you can encourage them to consider it by raising their awareness of why it might be important. For example:

‘You never know what can happen in life. For example, if an accident left you without the capacity to make your own health care decisions, what would you want to have happen? Who would you want to make decisions for you? What would be important to you? Advance care planning helps you think about these questions.’

Give them some take-home advance care planning material and invite them to talk with you next time:

‘I have a [workbook/leaflet] here that you may like to read and give some thought to. On your next visit, we can have a conversation about this, if you like. You may want to write down any questions or thoughts you have and bring them with you. You can ask someone close to you to sit in if you wish. I would like to help you with this, but remember, if you really don’t want to talk about it, that’s okay too.’

Creating an opening for discussion with someone who has a serious illness

A person is considered seriously ill if they have a health condition that carries a high risk of dying and that often negatively impacts their daily function or quality of life.

The Serious Illness Conversation Guide (SICG)¹² can help you navigate an advance care planning conversation with someone who is seriously ill. It is an evidence-based conversation tool that uses patient-tested language, aimed at:

- extending an invitation to participate in the conversation, including a brief explanation of the relevance for the person
- saying why it is important to have the conversation
- checking the person’s understanding of their current and likely future health
- asking permission of the person to share your understanding of their current and likely future health
- providing a prognostic statement to help the person understand:
 - things might change quickly, or
 - this is as good as they are likely to feel, or
 - time is limited
- exploring what matters most to the person by asking the following questions:
 - What are your priorities if your health does get worse?
 - What worries you when you think about your health changing?

- What helps you through the tough times?
- What abilities are so important for you that you can't imagine living without them?
- If your health does get worse, how much are you willing to go through for the possibility of more time?
- How much does your whānau know about what is most important to you?
- summarising the key points and agreeing on next steps.

The SICG and the SICG reference guide for health care professionals are available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/tools/serious-illness-conversations. The reference guide contains an overview of the tools available to support serious illness conversations, ways to start conversations and strategies for common scenarios.

Summary

- Everyone can benefit from advance care planning.
- It is better to initiate advance care planning before the person becomes unwell or nears the end of life.
- Advance care planning can be initiated by any member of the health care team.
- Find out the person's understanding of their current state of health early in advance care planning conversations.
- When initiating advance care planning consider the environment, support services, the person's cultural needs and who should be present, and be adequately prepared.
- For more information on engaging and supporting Māori with advance care planning, see chapter 3.
- For more information on cultural considerations for Asian people, it may be helpful to read the resource *Guidelines for working with Asian patients and their families*.¹⁸
- For more information on initiating advance care planning, refer to the e-learning module entitled 'Talking about advance care planning' at: www.myacp.org.nz (go to 'Information for clinicians' then 'training').¹⁹
- The Serious Illness Conversation Guide supports advance care planning conversations in the context of serious illness. The guide and supporting information can be found at: www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/tools/serious-illness-conversations.

¹⁸ www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/publications-and-resources/publication/4314

¹⁹ Video can be accessed via the Commission website after registering on the learning management system <https://acp.elearning.ac.nz/login/index.php>.

Chapter 6: Having the conversation

This chapter looks at the potential content of advance care planning conversations.

More detail about specific communication behaviours can be found in the *Advance care planning communication skills manual*.⁸

Important considerations

Taking notes

There may be a great deal of information shared during advance care planning conversations, so we advise you to take notes to capture all the important information for documentation purposes. Taking notes also means future conversations can build on, rather than repeat, what has already been discussed. It is courteous to explain the reason for taking notes to the people present.

The person and their whānau may want to take notes too. They may also have brought their own questions in writing. Make sure you deal with those questions as part of the advance care planning conversation.

In some cases, it may be appropriate to make an audio or video recording of the conversation, if that is the person's wish. This may be useful if an important whānau member cannot be present, for example, or if the people present are unable to make notes.

Hearing the person's voice

Everyone is unique, influenced by experience, life circumstances, whānau, society, culture and belief systems. The choices a person makes in advance care planning will be based not just on medical options, risks and benefits, but also on personal values such as what makes life worth living and previous experiences with death and dying. The ways in which medical facts may be interpreted by a person, and the importance placed on various risks and benefits, are deeply personal.

Health professionals engaging in advance care planning conversations should not have preconceived assumptions or predictions about what the person will or should feel or believe. Try to understand the person's viewpoints and perspectives.

Encourage the person to explain how they see things and why certain things are important to them. For some people this may be the first time they have had the opportunity to explore their feelings about what is most important to them in life and how they feel about death and dying. They may even be surprised at the feelings that come up for them. Listen without judgement and help them to articulate their individual preferences to gain an understanding of what is behind those preferences; this will help to ensure the person's voice comes through in the advance care planning.

Active listening

A person can be encouraged to continue talking by using minimal prompts such as nodding or giving verbal encouragement such as, 'Mmm... go on'. Acknowledging and reflecting back to them what they have shared will let them know they have been heard; it will also encourage them to continue and help them to know their views and feelings are valued.

Exploring values and beliefs

Advance care planning conversations are about exploring what matters most to the person and their whānau, what they value doing and who they value being, what quality of life looks and feels like for them and what dying well means to them. Examples of ways to broach this might be:

'It's one of the hardest and yet one of the most important questions we can ask ourselves. What makes life worth living? What matters most to you?'

'What are the things you value most in your life?'

'What does quality of life mean to you?'

'What makes up quality of life for you? Can you think of a situation in which you would consider you would have no quality of life?'

Depending on the person's response, you may wish to explore further, if appropriate.

Someone may fear confusion and loss of independence; others may not worry about these things. People may fear pain, or breathlessness, or some medical treatments. Some people worry about being 'a burden' to whānau.

Again, acknowledging their perspectives without judgement or a need to 'fix' anything will help you capture most accurately what is important to the person.

Involving whānau

Whānau may or may not be present, either because the person has chosen to have the conversation without them, or because they cannot be there despite your best efforts. When it is by choice of the person, it may be that the person finds it difficult to discuss advance care planning wishes and preferences with their whānau. If this is the case, they may allow you or someone else on the health care team to support them to talk with their whānau. Offer them this support.

Having written resources to give to whānau may help. Whānau may wish to meet without a health care professional in the first instance, or after an initial discussion together. Either way, the person should be supported to engage in the most appropriate process for them, in line with their preferences.

Conflict within whānau can occur at times; this is discussed in chapter 6.

Beliefs about life and death

When working cross-culturally, be aware of how personal beliefs, values and culture affect our attitudes and behaviour.

Beliefs about life and death vary considerably among individuals, whānau and cultures, and will affect how people would want to be treated and what would be important to them in the event of serious illness or when they are approaching the end of life. Certain belief systems may impact a person's desire or ability to engage in advance care planning. If the person seems uncomfortable with the advance care planning process but hasn't said why, it might be appropriate to explore this to try to gain an understanding of what might be behind their discomfort.

For example, for many Māori the subject of death is taboo as it is seen as karanga aitua, which is the belief that talking about death will bring it closer. You may need the assistance of clergy or a Māori kaumātua, or someone with the same cultural background with whom the person can communicate comfortably. Understanding a religion or culture requires self-awareness and the acceptance of difference.

Explaining life-sustaining treatment

Advance care planning often involves talking about life-sustaining treatments to some extent, for example, the use of antibiotics for a life-threatening infection, or intubation and ventilation in intensive care. We strongly recommend you do not explore this with a person and their whānau until you have explored the person's priorities and goals, and what they would be willing to go through for more time. The Serious Illness Conversation Guide 'Explore' section has patient-tested language you can use to do this. Once you have a better understanding of what matters most to the person you can make appropriate recommendations around life-sustaining treatment that would support their hopes.

Not everyone may want or be offered all available life-sustaining treatments. There is no value in helping someone decide if they would want a treatment, like intubation and ventilation, if it would never be offered to them or would not support the person's goals and priorities.

For someone who is terminally ill, this part of the conversation may be a simple and straightforward discussion, as any life-sustaining treatment that may be offered is likely to be limited. For someone who is currently well, or in a situation where all possible life-sustaining treatments may be offered at some point in the future, the person may want detail about the various options that may be offered; this may require involving a health care professional with relevant knowledge and experience with such treatments.

If the person expresses a wish for something that would not be offered, talk to them about treatment limitations in their situation and why certain interventions would not be an option for them. If you are unsure about any of these, please involve someone else from the health care team with the appropriate expertise.

Misconceptions about life-sustaining treatments are common. Through hospital-based television shows, many people have gained a distorted view of the possible risks and benefits. On television, hearts are commonly restarted after cardiac arrest in people who are very ill, and people on the brink of death are restored quickly to robust health after administration of some miraculous cure. Part of an advance care planning conversation may

involve correcting misconceptions. It is therefore important to explore the person's understanding of life-sustaining treatments, as appropriate.

The dying process

Advance care planning conversations often include a discussion about dying. Some people may have fears about the dying process; some people may fear being dead. Many people have misconceptions about the dying process. Advance care planning conversations are opportunities to talk about a person's understanding of the dying process, what they might be worried about and what would be important to them at that time.

There are many different beliefs around death and dying. For example, some people believe that to withhold or withdraw artificial hydration or nutritional support constitutes euthanasia or assisted suicide. The alternative and more common view, however, is that artificial nutrition and hydration are medical treatments just like any other, and consequently are subject to the same ethical and legal rules about withdrawing them as other treatments.

It is most helpful, when discussing the withdrawal or withholding of treatments, to keep the discussion in the context of the person's values and goals; in other words, what they would like the health care team to try to achieve for them.

Cardiopulmonary resuscitation

A discussion of cardiopulmonary resuscitation (CPR) in the event of cardiac arrest is also often part of an advance care planning conversation. The term 'resuscitation' can refer to other interventions as well as CPR, and often people mistakenly believe it to mean 'no treatment'. Therefore, be clear that the discussion refers to the heart stopping; interventions in other situations would be a different discussion.

It is also important to know whether there are any treatment limitations for that person; for example, would CPR be medically appropriate for them in all or any circumstances? There is no value in helping a person decide whether they would want CPR if it would never be medically appropriate (for example, for someone with end-stage heart failure). Similarly, if the person's primary goal is to be kept comfortable and to allow the dying process to occur naturally, there is no value in discussing CPR. Instead, the conversation would include clarification that the person understands the implications of their choices, and of the severity of their illness.

There are four general categories when considering CPR as a treatment option:

- People who are likely to benefit.
- People for whom benefit is uncertain.
- People for whom benefit is unlikely.
- People who will almost certainly not benefit – the person will either not recover due to underlying illness or will never be able to experience any benefit.

If the person is likely to benefit from CPR, then talk to them about it. Many people have misconceptions about what is involved in CPR and its likelihood of success, fuelled by what is portrayed in television shows, which is often unrealistic. As before, start with finding out what the person understands:

‘Can you tell me what you understand about CPR? Have any of your health care team talked to you about it before?’

It is not your role to discourage use of CPR, but to be realistic about the severity of the illness that can lead to a cardiac arrest and what is involved in resuscitation, so the person can make informed choices. For example, people are often unaware of the risks of neurological damage, multi-organ damage or the need for life support afterwards. CPR may worsen overall health. The underlying state of health affects the chances of CPR being successful. The level of detail provided will depend on the person’s state of health and desire for information. An example of a fairly detailed explanation follows.

‘If your heart were to stop, you would die. Chest compressions could be performed, and electric shocks could be used to try and restart your heart. Even with CPR, unfortunately, the blood flow to your body is not as good as if your heart were still beating. The longer it takes to restart your heart, the more damage will occur, particularly to the brain. The sicker you are before, the less likely your heart will be able to be restarted at all. If it is restarted, you are likely to need a breathing tube and be on life support afterwards.’

If the person you are talking to is living in their own home and does not want CPR to be performed, the decision should be communicated with others living in the same house. If there is a Do Not Attempt CPR (DNACPR) order, it should be readily accessible.

In some institutions, if no order has been signed, staff have an obligation to perform CPR in the event of a witnessed cardiac arrest. Most health care professionals would try to resuscitate if the person had not specifically rejected CPR.

Interpretation of a person’s preferences and decisions

One of the roles of health care professionals is to interpret, and help people to articulate, their preferences and decisions in such a way as to be meaningful to the clinicians treating them. The person may say something like, ‘I never want to be a vegetable – if I’m ever like that, switch me off.’ This statement may mean different things to different people; therefore, it is important to clarify. You might respond with:

‘What would being a vegetable look like to you?’

‘And what do you mean by “switch you off”?’

Having the conversation in the context of serious illness

We recommend you use the Serious Illness Conversation Guide (SICG) to navigate advance care planning conversations with seriously ill people and their whānau.

Following the invitation to participate, and introduction to the conversation (as outlined in the previous chapter), the SICG prompts you to explore the person’s understanding of their current and likely future health, and then to ask permission to share your own understanding to ensure alignment.

The SICG provides questions using patient-tested language to explore what matters most to the person:

- ‘What are your priorities if your health does get worse?’
- ‘What worries you when you think about your health changing?’
- ‘What helps you through the tough times?’
- ‘What abilities are so important to you, that you can’t imagine living without them?’
- ‘If your health does get worse, how much are you willing to go through for the possibility of more time?’
- ‘How much does your family/whānau know about what is most important to you?’

The conversation is wrapped up by summarising the key points, providing a clinical recommendation and formulating a plan with the person.

The SICG and SICG reference guide for health care professionals are available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/tools/serious-illness-conversations. The reference guide contains an overview of the tools available to support serious illness conversations, ways to start conversations and strategies for common scenarios.

Shared goals of care in hospitals

During an episode of care in an acute hospital setting, decisions may need to be made about what medical treatments will be provided, for example, in the event of deterioration. These decisions need to consider both:

- the person’s preferences, values and goals
- what is medically appropriate.

These conversations are known as shared goals of care conversations.

In the shared decision-making process involved in shared goals of care, the patient’s values are explored and a shared understanding gained of what is important to the patient and what care and treatment options are available. Only then is the goal of care agreed and documented.

Before having the shared goals of care conversation, check whether the person already has an advance care plan. If they do, read and refer to it during the discussion to ensure appropriate continuation of care.

We recommend using the SICG when having the conversation; this will help you discuss the person’s health status and what might be ahead for them, and to elicit their preferences and goals in this context before agreeing on the goals of care for this admission, particularly if the person were to deteriorate. Treatment decisions are then made based on this information and documented ideally on the shared goals of care form.²⁰ Please see chapter 8 for more information on documentation.

Shared goals of care discussions should be facilitated by the appropriate clinician/s and may include other members of multi-disciplinary teams involved in the person’s care. Discussions

²⁰ www.hqsc.govt.nz/our-programmes/advance-care-planning/talking-covid/publications-and-resources/publication/3963/

should happen as early in the admission as possible and with the agreement of the person where they are able to consent. The person, whānau or clinician can begin the discussion.

The shared goal of care decision may be one of the following:

- curative and restorative with all appropriate life-sustaining treatments
- curative and restorative
- quality of life
- comfort while dying.

The decision describes what will be offered if the patient deteriorates.

A similar approach can be used in the community or a long-term care situation, where decisions need to be made about what treatment would be provided to a person in the event of deterioration or acute event. Documentation of these decisions may be different depending on the setting. A shared goals of care form specifically for aged residential aged care is available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/talking-covid/publications-and-resources/publication/4003.

Documentation

All advance care planning conversations should be documented in the clinical record so other relevant health care professionals can continue the advance care planning process if appropriate, and so important information is available to inform decision-making. Details may include, for example, decisions about goals of care, treatment plans, questions or concerns raised by the person and perhaps the need for emotional psycho-social supports, as well as a plan for continuing the process.

The person's values, goals, worries, preferences and any advance directives should be documented and, with their permission, the advance care plan included in their medical record.

The ideal place to document an advance care plan is in the national advance care planning and guide document available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-consumers/publications-and-resources/publication/3212.

The person's values, goals, worries, preferences and any advance directives might be documented in:

- clinic notes
- outpatient clinic letter
- discharge summary
- electronic care plan record
- goals of care forms completed during a hospital admission or as part of an aged residential care admission.

See chapter 8 for more about documentation and sharing of advance care planning information.

Summary

- Find out what the person understands and feels about their health before giving them information.
- Listen carefully to what they are saying.
- Explore if, when and how they wish to involve whānau.
- Always consider cultural, spiritual and religious beliefs.
- Talking about life-sustaining treatments is often part of an advance care planning conversation.
- The level of detail of a discussion about life-sustaining treatments will vary from person to person depending on their state of health, preferences and goals.
- Use the Serious Illness Conversation Guide in the context of serious illness.
- Use the Serious Illness Conversation Guide to support shared goals of care discussions and treatment decision-making.
- Help the person articulate their preferences in a way that will be useful for future decision-making.

Chapter 7: Conflict prevention and management

Advance care planning may, at times, involve some conflict either within whānau or between consumers and the health care team. Usually, any conflict can be easily and simply resolved with appropriate communication before it becomes a significant issue. This chapter discusses how to prevent and resolve conflict. Strategies for managing more complex conflict can be found in the *Advance care planning communication skills manual*.⁸

Conflict may arise in different situations and involve different parties. Some examples follow.

- A competent person and their whānau disagree about engaging in advance care planning.
- A person has a preference for future care that their EPA does not feel able to honour.
- A competent person, or their whānau, wants something that the health care team does not think is appropriate care.
- Members of the health care team disagree over the interpretation of a person's wishes.

It is important to recognise that it is not possible to avoid all conflict. Where possible, however, try to reduce the likelihood of disputes, prevent the escalation of disagreements in the early stages and promote the resolution of conflicts.

Prevention of conflict

The root of many disagreements between health care professionals and consumers is inconsistent information. This can be minimised by having processes in place to transfer, give and receive information effectively.

Clear and unambiguous communication involves finding out the person's perspectives/concerns/understanding, listening carefully, speaking clearly in plain language free of medical jargon and euphemisms, and pausing often to clarify what you have heard and to check what the person has understood.

The way you behave and how that is perceived by the person will impact on what they share with you and how they interpret information you provide. Consider the following.

- Do I seem empathic or impersonal?
- Am I at the same physical level as the people I am talking to or do I tend to stand while they are seated (or lying down)?
- Am I usually rushed or distracted or am I invested in this conversation and the time it will take?
- Do I really listen when people talk about their lives and emotions (as well as their illness and treatment)?

If the person feels they are being genuinely heard, and that their concerns and perspectives are valued, they are more likely to share more, trust you and take on board information from you. If the person is facing a life-threatening illness, they and their whānau may be experiencing significant emotions or stress; if they feel this is acknowledged by you, again they may receive information more effectively and be likely to share more.

Managing differing views

Consider this example: someone, whose health status is deteriorating quickly, is weighing up health care options as part of advance care planning. They have been told that certain treatments are not an option at this point, and why. They disagree with the treatment plan. Getting impatient or pushing a point more aggressively may turn disagreement into anger. To avoid this, try to understand the reason for the disagreement first.

Discovering the reason for disagreement

Here are some questions to consider.

- Have I explored their understanding of their current and future health, their goals and values and what really matters to them first, before giving the information?
- Have I given the information they need to understand the risks/benefits of future care in a way that is meaningful to them? (If not, it may be appropriate to try again.)
- Have I given the information that a reasonable person would need to understand the risks/benefits?
- Do they know that I have heard their disagreement? (If they have a perspective or concerns they feel you haven't heard, they are less likely to be able to engage fully with what you are explaining.)
- Is there something they are afraid of?
- Is this the best time to be having this part of the conversation; are they able to concentrate on this conversation right now or are they distracted? Are the appropriate people present?
- Am I listening more to the whānau or to other health professionals than to the competent person?
- Am I feeling a certain way because the request for care is being presented in a certain way?
- Have I explored if there are spiritual, cultural or other reasons why this person does not agree with the view of the health care team?

Preventing escalation

If you have tried the suggestions above and the conflict is not resolved, seek appropriate support to prevent escalation. Here are some ideas for getting the support you might need.

- A colleague from a different discipline may help to provide additional information or clarity for either you or the person.
- A spiritual or cultural advisor may provide emotional support for the person who has underlying fears, enabling them to move forward with conflict resolution.
- A bioethicist may help to resolve conflict of opinions about appropriate treatment between colleagues.

If a disagreement is escalating, someone with the appropriate skills may need to mediate. Mediation strategies are discussed in the *Advance care planning communication skills manual*.⁸

When the person's request is unable to be met

Although everyone has the right to give instructions, people do not have the right to insist on health care that is not medically indicated. For example, no-one can force a surgeon to try and remove a tumour if the surgeon has assessed that the surgery is impossible or futile. They may, of course, request a second opinion and that request should be honoured if time and resources permit.

These kinds of conversations can be difficult and should involve the person feeling that their choices and their reasons have been heard. Strategies for managing such conversations are addressed in the *Advance care planning communication skills manual*.⁸

Whānau dynamics

Even the most amiable whānau relationships can dissolve under the strain of a situation that disrupts the family system. Avoid labelling whānau who are having a hard time dealing with advance care planning issues as 'difficult' or 'dysfunctional'.

There can be disputes among whānau about carrying out what a person has requested; for example, if they have specified they want to die at home, which whānau member/s will be there to look after them? Who will learn how to give injections? Does everyone understand what kind of care will and will not be given, for example, ventilation or intubation?

Focus on the current situation, the person's needs and the decisions at hand, rather than past disputes. Everyone involved should feel that their perspectives have been heard and taken into account, and that you are not taking sides.

Sometimes grief and distress among whānau about an illness can turn into anger towards health care professionals. Whānau may appear to interfere with delivery of medical care, make extra demands on staff time and see everything as a crisis. Sometimes when someone is dying, whānau do not wish to acknowledge it. They may pretend their loved one is getting better or ask for procedures that they think will 'cure' them. They may avoid their loved one. Whānau members may argue among themselves at the bedside or pass on inaccurate information to other whānau members.

The challenge for the health care team in situations like these is to understand the behaviours and help the whānau cope, where possible. The first step to understanding the behaviours is to listen, not only to what is being said, but also for what is not being said, and understand the motivation and emotion underlying the words. The next step is to acknowledge and validate what is being said and to show empathy. A shared understanding and ability to negotiate a way forward may then be possible.

The health care team must assess its own strengths and limitations in the resolution of whānau conflict. If the situation is beyond the capacity of the team, seek help from a skilled mediator.

When whānau members want to speak for a competent person

Sometimes, for cultural or other reasons, whānau may try to stand between the health care team and a competent person. For example, the whānau may ask that the ill person not be told about a diagnosis and not be consulted on options for care as the disease progresses.

No-one is required to engage in advance care planning; however, everyone is entitled to be informed about their medical condition and given the opportunity for advance care planning. It is not usually acceptable to talk to whānau instead of the competent person. A conversation with the competent person should occur in the first instance, in order to establish what they want to know about their state of health, how much detail they want about their condition and likely progression, and with whom they want the information to be shared. Most people want to be informed directly about their condition; however, in some cultures it is the whānau that receives this information – the competent person should be consulted in the first instance to ensure this is their wish, and if it is, this should be respected.

The whānau can ask to be present for this conversation; however, who attends is up to the person being treated. If there is a problem with communication because of language, make arrangements within the health care team to solve it (for example, seek the services of a professional interpreter or obtain a communication device for a person who has difficulty speaking or hearing).

Similarly, if the whānau objects to wishes that a person makes as part of their advance care planning, the health care team's obligation is to respect the wishes of the person.

Summary

- Clear and consistent communication will often prevent conflict.
- An ability to see the world as it occurs for the person and their whānau will likely result in the building of trusting relationships, and disagreements are more likely to be avoided.
- If the goals of care are agreed upon, conflict is less likely.
- If a person feels their perspectives have been heard, they are more likely to hear the perspectives of the health care team.
- Mediation may occasionally be required if conflict escalates.

Chapter 8: Documentation and the sharing of information

There are different ways you might support advance care planning documentation, depending on the context of the conversation. When an advance care planning conversation has occurred with a health care professional that conversation needs to be referenced and the main points documented in the clinical record. Ideally, when the person is ready to, they will document their advance care plan using the national advance care plan template.²¹ A health care professional would ideally support the person to complete section 6 of the template.

Documenting the information means a person's values, goals, hopes, preferences and advance directives are available to the health care team to support person-centric health care planning and delivery.

The advance care planning document

If a comprehensive conversation, or series of conversations, has taken place, and the person has expressed their values, goals and preferences, for example, suggest that these be recorded in the national advance care plan template. In that way, the person can have a copy and share it with relevant whānau, and a copy can also go in the clinical record and be shared with relevant health care professionals (with the person's permission). When completing an advance care plan, the person needs to be aware that it can be altered at any time by them if they remain capable of making their own health care decisions.

An advance care plan might be completed by the person themselves, or it might involve one or more health care professionals. We strongly advise that the advance directives section be completed with a health care professional with relevant knowledge of the person's care and treatment options.

The clearer and more unambiguous the statements, the more likely they will be interpreted as the person has intended. As discussed previously, the role of the health professional is to interpret the person's statements and ensure what is written will be meaningful to the treating health care team if the information is required in the future. Some things to consider follow.

- Quality of life means different things to different people and therefore needs to be defined by the person in their advance care plan.
- Phrases such as 'being a vegetable' mean different things to different people and need to be defined.
- Different people may have different interpretations of what 'severe' dementia or 'severe' illness means, for example. The parameters need to be defined.

²¹ Available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-consumers/publications-and-resources/publication/3212.

Articulating advance directives

If an advance care plan includes advance directives, these need to be articulated in such a way as to minimise ambiguity and define the circumstances in which a consent/refusal of treatment should apply. It must be clear which specific treatment/s the person is consenting or refusing to receive and in which circumstances they want that consent/refusal to apply.

Here are some examples that might have been written by someone with an advancing neurological disease:

In the following circumstances:	I would like my care to focus on:	I would accept the following treatments:	I would wish to refuse or stop the following treatments:
If the ability to eat or drink by mouth is compromised or absent and this is irreversible	Comfort	Comfort measures	Artificial hydration and nutritional support
If my breathing is compromised	Comfort	Comfort measures	Intubation
If I have quality of life or this is expected to return with treatment. For me quality of life means being able to communicate, feed myself and toilet myself without assistance	Treating reversible conditions, such as infection, with a view to prolonging my life	Antibiotics and other measures to treat reversible conditions	I would wish to stop or refuse such measures if I no longer have quality of life and this is not expected to return with treatment

When assisting a person to define advance directives, ensure the person understands the implications of what they are documenting. In the above example, the person would need to understand that refusing ventilation could result in their life ending sooner than it otherwise would, as ventilation might, in theory, be offered as part of treating a potentially reversible health condition/state.

Decisions may need to be made about what medical treatments will be provided to the person should they deteriorate or have an acute event during a hospital admission or while resident in an aged care facility. This should include decisions about what treatment would be provided in the event of deterioration. These shared goals of care decisions should consider both:

- the person's preferences, values and goals
- what is medically appropriate.

We recommend you familiarise yourself with the principles of shared goals of care.²²

²² Available at: www.hqsc.govt.nz/our-programmes/patient-deterioration/publications-and-resources/publication/4284.

Shared goals of care should be documented on the shared goals of care form. There is a national form for use in hospital settings²³ and one for use in aged residential care settings.²⁴

If someone has an advance directive refusing certain treatments, the shared goals of care must align with this.

Shared goals of care discussions, preferably using the Serious Illness Conversation Guide, can be had by any member of the health care team. Shared goals of care decisions must be made by a doctor or nurse practitioner.

Sharing advance care planning information

The appropriate sharing of advance care planning information is important for two main reasons.

Firstly, advance care planning is a process and there may be more than one health care professional involved. To prevent unnecessary repetition, or beginning the process all over again, relevant information needs to be made available to others involved in the person's care.

Secondly, the information needs to be available to treating clinicians, especially if the person with an advance care plan becomes incompetent, so that what is captured in the advance care plan can be taken into consideration in determining appropriate care and treatment.

There are many health care providers across the country, and they do not all communicate with each other. This makes appropriate sharing of and access to advance care planning information and documents a challenge. Whatever systems or processes are in place in your area, please keep the following things in mind.

- A completed advance care plan is the property of the person.
- Advance care planning documentation needs to be readily available to treating clinicians.
- Ideally all advance care planning documentation should be held in one place within the clinical record with the person's permission.
- Advance care planning notes should be included in hospital discharge summaries, clinic letters or referral letters.
- If someone with an advance care plan transfers from one health care setting to another, the plan should accompany them.
- A person is entitled to change their preferences and amend the contents of their advance care plan. Health care providers must ensure the copy held on record is the latest version.

²³ Available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/talking-covid/publications-and-resources/publication/3963.

²⁴ Available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/talking-covid/publications-and-resources/publication/4003.

Reviewing advance care planning documentation

A competent person may review and alter their advance care plan at any time. If health care professionals have been involved in the process, it would be appropriate to offer a review at certain points in the person's life or illness trajectory. For example:

- following a significant life event such as marriage/civil union, divorce/separation or birth of a child
- following a significant medical diagnosis
- when a major change in health occurs
- when end of life may be approaching.

Summary

- Advance care planning conversations must be recorded.
- Documentation of the advance care planning process should form part of the clinical record and be readily available to treating clinicians.
- Documentation should be clear and usable by the health care team.
- An advance care plan may contain advance directives, which need to be unambiguous and define the circumstances for which they are intended.
- Documentation about treatment decisions, for example, shared goals of care documentation, should align with the person's advance care plan and advance directives.
- Advance care planning documentation must be shared appropriately.
- Advance care planning documentation can be amended by the competent person at any time.
- Health care professionals should offer to review an advance care plan with a capable person at appropriate times.
- Shared goals of care forms and supporting information are available at: www.hqsc.govt.nz/our-programmes/patient-deterioration/workstreams/shared-goals-of-care.

Chapter 9: Developing advance care planning knowledge and skills

Implementing advance care planning into workplaces

Successful implementation of advance care planning requires culture change and a whole-of-system approach. Having clinical staff who are skilled and confident to support people with advance care planning is essential. Training alone will not create sustainable change in practice. We need trained clinicians who can have the conversations and use the information gathered to inform care. This requires the development of a system within district health boards and clinical areas that includes the following key elements.

- Leadership that champions for the programme and sources the people and resources needed.
- A process for identifying people who would benefit from advance care planning.
- Clinicians who are supported to engage in advance care planning conversations with time, training and mentoring.
- People and their whānau who are supported before, during and after advance care planning conversations.
- Conversations that are documented effectively to inform care/treatment that aligns with what is important to the person and their whānau.
- A process for sharing and reviewing plans with the person and other health care providers.
- A process for ensuring what is important to the person and their whānau is used in care planning and delivery.
- A process for reviewing and continuously improving advance care planning and shared goals of care practices.

More information about implementing advance care planning processes into teams and organisations can be found at: www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/implementation.

Keeping a reflective advance care planning log

Keeping a reflective log will help you to reflect on advance care planning conversations and to develop your conversation skills. Here is a suggested format for a reflective log.

- Date and basic demographics of the person and whānau you spoke to – sex, age, ethnic group (do not include the person's name or other identifying information).
- What went well? Why do you think that was?
- What did not go so well? Why do you think that was?
- What might you do differently next time?

You might like to use a spreadsheet, or a journal or diary – choose a format that works for you. Follow your organisation's data security policy and ensure you keep the log confidential and the patient unidentifiable.

Education and training

There are now several New Zealand resources and training opportunities to help health care professionals understand and develop skills in advance care planning.

Level 1 e-learning modules

There are four modules available here: <https://acp.elearning.ac.nz/login/index.php>.

1. Considering your own future health care
2. Talking about advance care planning
3. Changing the outcomes of future health care
4. Clarifying advance care planning processes in your organisation

L1A advance care planning one-day workshops

These one-day advance care planning workshops are being delivered around the country by local trainers, with oversight and support from the national advance care planning programme. Contact your local advance care planning facilitator to find out about workshops in your area, or email: acp@hqsc.govt.nz.

L1A advance care planning train-the-trainer course

This is a two-day course to train people to deliver the advance care planning one-day workshop in their local area. To find out more, please contact your local advance care planning facilitator or email: acp@hqsc.govt.nz.

Serious Illness Conversation Guide online training resources

- 50-minute introductory training video available at: www.hqsc.govt.nz/our-programmes/talking-covid/training.
- 25-minute training video for the aged residential care setting available at: www.hqsc.govt.nz/our-programmes/talking-covid/arc-specific-resources.

Serious Illness Conversation Guide workshops

These three-hour workshops are being delivered around the country by local trainers, with oversight and support from the national advance care planning programme. Contact your local advance care planning facilitator to find out about workshops in your area, or email: SICG@hqsc.govt.nz.

Serious Illness Conversation Guide train-the-trainer course

This is a one-day course to train people to deliver the Serious Illness Conversation Guide workshop in their local area. To find out more, please contact your local advance care planning facilitator or email SICG@hqsc.govt.nz.

Resources

Advance Care Planning: A guide for the New Zealand health care workforce

This Ministry of Health document outlines important information for health care professionals regarding advance care planning processes and practice in the New Zealand context. This training manual expands on the information contained in the Ministry document.

Available at: www.health.govt.nz/system/files/documents/publications/advance-care-planning-aug11.pdf.

Ethical Challenges in Advance Care Planning

This document is produced by the National Ethics Advisory Committee. It explores the ethical challenges that health professionals face in advance care planning, and provides practical assistance for consumers and health care professionals engaged in advance care planning.

Available at:

https://neac.health.govt.nz/system/files/documents/publications/Ethical%20Challenges%20in%20Advance%20Planning%20FINAL_.pdf.

Advance care planning communication skills manual

This manual outlines communication skills and strategies for more complex advance care planning conversations, and for addressing strong emotions and other challenges resulting from difficult conversations.

Available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/publications-and-resources/publication/4313.

Serious Illness Conversation Guide

This Serious Illness Conversation Guide template adapted for Aotearoa New Zealand.

Available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/publications-and-resources/publication/3950.

Serious illness conversations: Reference guide for health care professionals

Available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/publications-and-resources/publication/4206.

Shared goals of care

Information and resources available at: www.hqsc.govt.nz/our-programmes/patient-deterioration/workstreams/shared-goals-of-care.

Resources for aged residential care available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/talking-covid/arc-specific-resources.

Shared goals of care principles for health service providers available at: www.hqsc.govt.nz/our-programmes/patient-deterioration/publications-and-resources/publication/4284.

Video: Legal framework for medical decision-making

Available at: www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/publications-and-resources/publication/4224.

Video: An overview of advance care planning in Aotearoa New Zealand

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