



**tō tātou reo** 

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 advance care planning

**Serious illness conversations:  
Reference guide for health care professionals |  
He kōrerorero mō ngā tino mate: He aratohu mā  
ngā mātanga tauwhiro hauora**

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**National advance care planning programme**

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HEALTH QUALITY & SAFETY  
COMMISSION NEW ZEALAND  
*Kupu Taurangi Hauora o Aotearoa*

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The strategies to manage anger and denial were largely drawn from The Christie NHS Foundation Trust. 2008. Maguire: Communication Skills Training Unit. *Effective Communication with Patients, Families and Colleagues*.

The conversation structure has been supplemented from the 'Hui Process' (Lacey C, Huria T, Beckert L, et al. 2011. The Hui Process: a framework to enhance the doctor-patient relationship with Māori. *New Zealand Medical Journal*. 124: 1347. URL: <https://journal.nzma.org.nz/journal-articles/the-hui-process-a-framework-to-enhance-the-doctor-patient-relationship-with-maori> (accessed 23 February 2022)).

# Chapter 1: Overview | Upoko 1: Tirohanga whānui

## Purpose of this guide

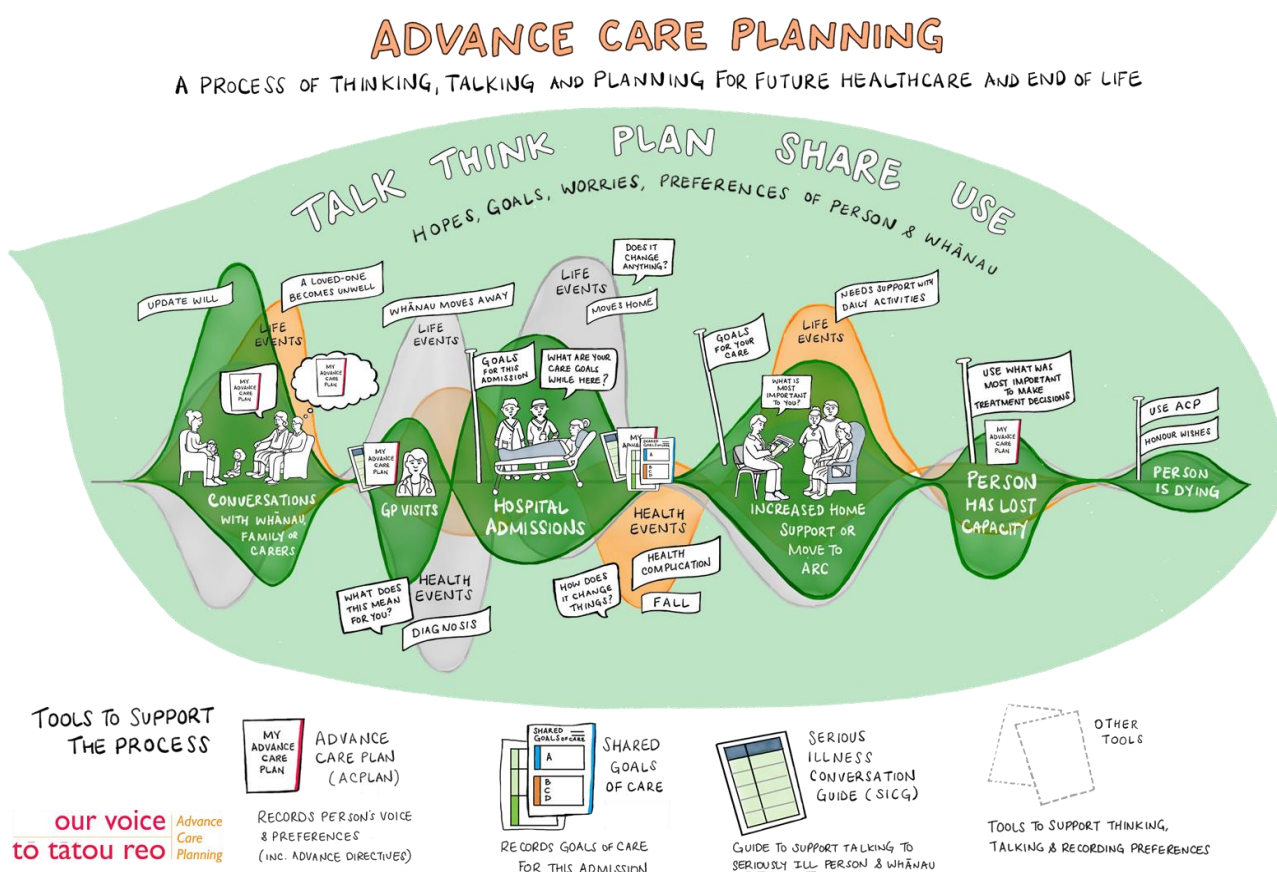
This guide is for your reference in developing communication skills or when preparing for a conversation with a patient and their whānau. **It is NOT intended for use with patients.**

It contains an overview of the tools available to support you in serious illness conversations, ways to start conversations and strategies for common scenarios.

The guide is being continuously reviewed and improved by the Health Quality & Safety Commission (the Commission).

## Serious Illness Conversation Guide and advance care planning

The Serious Illness Conversation Guide (SICG) is a tool to support advance care planning conversations and planning with seriously ill people and their whānau.



This infographic demonstrates that advance care planning is a process of talking, thinking, planning, sharing and using a person's values, hopes, goals, worries and preferences to inform their care and treatment. The relevance and intensity of these advance care planning activities ebbs and flows over time, triggered by either personal or life events for the person and their whānau and/or health events.

## Other tools that support these activities

- **My advance care plan and guide** capture what matters the most to a person, including care and treatment preferences for current and future health, any advance directives and post-death wishes.
- **Shared goals of care forms** support shared decision-making for a specific admission to hospital or aged residential care. Shared goals of care conversations can be supported by using the SICG. The shared goals of care template includes the SICG questions and space to capture the answers.

We recommend watching the video *An Overview of Advance Care Planning in Aotearoa New Zealand*, which can be found on the home page of the Advance Care Planning website [www.myacp.org.nz](http://www.myacp.org.nz). This video will help you understand the process over time and the numerous opportunities for conversations and the tools that you might consider using at different times to support a person and their whānau with their advance care planning.

## Key ideas for successful discussions about serious illness care

### Principles

- The serious illness conversation will reflect the patient's values and beliefs. The clinician will enable an environment that reflects what is important to the patient.
- The serious illness conversation will provide the space to explore with the patient and their whānau, their goals and priorities. These goals and priorities will provide guidance for the clinician on care and treatment pathways.
- The serious illness conversation should provide for mutual understandings of the patient's goals and options for care and treatment.
- Anxiety is normal for both patients and clinicians during these discussions. Recognising this, and acknowledging the part that anxiety plays in what is heard and what is not heard in these conversations, is important.

### Practices

#### Do:

- invite support from and the participation of significant others/whānau throughout the SICG process and conversation
- consider what others to include in the multi-disciplinary team that may be useful to have as part of the serious illness conversation, that is, Māori health worker, allied health staff
- seek connection with the patient through whakawhanaungatanga
- give a direct, honest prognosis when requested by the patient
- present prognostic information as a range
- allow silence and other reflective practices, that is, waiata, karakia, the telling of stories
- acknowledge emotions and explore these when appropriate
- focus on the patient's quality of life, fears and concerns
- make a recommendation ('I have heard you say XX goals and values are really important to you. Keeping that in mind and based on YY medical situation and ZZ treatment options, I suggest that we ...')
- document conversations

- be guided at all times by the patient and their whānau as to the pace and depth of information that is being provided as part of the serious illness conversation
- follow the guide *Three steps to meeting health literacy needs* | *Ngā toru hīkoi e mōhiotia ai te Hauora* when providing information – ask, build, check (see [www.hqsc.govt.nz/resources/resource-library/three-steps-to-meeting-health-literacy-needs](http://www.hqsc.govt.nz/resources/resource-library/three-steps-to-meeting-health-literacy-needs)).

#### **Do not:**

- talk for more than half the time
- give premature reassurance
- provide factual information in response to strong emotions
- focus on medical procedures
- assume that the patient has heard and understood all information provided.

## **Serious illness conversations: overview of resources**

### **For clinicians**

Two resources are available to help you have successful conversations with your patients about serious illness care goals. Practise using these tools and the language within them at least 30 times so you become comfortable with the language and flow. Then, you can feel free to improvise.

#### **1. Serious Illness Conversation Guide**

The backbone of this training, the Serious Illness Conversation Guide (SICG), will help you have successful conversations with your patients. It consists of steps to elicit important information from patients about their goals and values: setting up the conversation, assessing the patient's health understanding and information preferences, sharing the prognosis, exploring key topics and closing and documenting the conversation.

#### **2. *Serious illness conversations: Reference guide for health care professionals* (this document)**

This reference guide will guide you through aspects of the serious illness communication. It provides detailed information about how to prepare for and introduce the serious illness conversation, some suggested language to use and tips for dealing with common patient (and whānau) scenarios.

### **For patients and whānau**

#### **Pre-visit letter (see Appendix 1 for an example)**

This letter is designed to prepare patients for a serious illness conversation with their clinician. It includes topics for patients to think about in advance, reinforces the importance of the conversation, encourages them to engage whānau members, and reassures patients that talking about the future will help them have more control over their care.

#### **Whānau communication guide (still to be developed)**

Designed for the patient's use with their whānau, this guide will help patients talk with their whānau and friends about the same topics you bring up with the patient in your conversations. Like the clinician materials, the whānau communication guide suggests appropriate language for the patient to use to relay information to their whānau and friends

and to continue the conversation by exploring their concerns. When this resource is finalised, we will share it with the SICG community and would encourage you to share with patients and whānau and/or remind them that it is available.

## Cultural safety

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 communications and on the consumer-clinician relationship. 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 the consumer and the clinician.

Chapters 3 and 4 provide guidance to help consumers access and participate in advance care planning and serious illness conversations.

## 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 serious illness conversations can be found in chapters 3 and 4.

## 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, which have evolved over time. Accordingly, we have moved beyond the 3 Ps, and are guided by *Whakamaua: Māori Health Action Plan 2020–2025*<sup>1</sup> to apply the following five principles to our work across the health and disability system.

**Tino rangatiratanga/self-determination:** This provides for Māori self-determination and mana motuhake in the design, delivery and monitoring across the advance care planning programme.

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<sup>1</sup> Ministry of Health. 2020. *Whakamaua: Māori Health Action Plan 2020–2025*. Wellington: Ministry of Health.

**Mana taurite/equity:** This requires a commitment 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. This includes the requirement to be well informed on the extent, and nature, of both Māori health outcomes and efforts to achieve Māori health equity.

**Pātuitanga/partnership:** This requires the advance care planning programme to work in partnership with Māori and develop strong and enduring relationships.

**Kōwhiringa/options:** This principle calls for advance care planning to be provided in a culturally appropriate way that recognises and supports the expression of hauora Māori models of care.

These principles can be utilised as a framework to advance Māori health and support mana motuhake so that members of our indigenous population receive equitable health care and live long, healthy lives.

The advance care planning programme (of which the SICG is a component) is committed to embedding and enacting Te Tiriti o Waitangi by working with Māori to ensure that the advance care planning initiatives are tailored for, and relate with, Māori communities.

In chapters 3 and 4 we discuss tools, resources and offer guidance to enhance your knowledge of te ao Māori (Māori world view) so that we may provide care that supports health gains for Māori and enacts the principles of Te Tiriti.



## **Chapter 2: Serious illness conversation self-awareness | Upoko 2: He kupu kōrero mō ngā tino mate, arokā whaiaro**

Before going ahead and having a serious illness conversation using the guide, there are a number of 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 serious illness conversation. Doing this work first should help us 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**

A targeted advance care planning conversation, using the SICG, can include subjects that can be 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 engaging in advance care planning conversations using the SICG, it is a good idea to have engaged 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.

Some questions to promote self-awareness include the following.

- 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 with males and females differently?
- 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/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.

Refer to the e-learning module called 'Considering your own future health care' for more information about self-awareness and personally engaging in the advance care planning process (available at: [www.hqsc.govt.nz/resources/resource-library/considering-your-own-future-health-care](http://www.hqsc.govt.nz/resources/resource-library/considering-your-own-future-health-care)).

## Understanding our biases and assumptions

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

The key, if we are going to think clearly and make assessments rather than judgements, is to identify when we are falling prey to bias and unconscious distortions. This means understanding *cognitive bias* (our tendency to believe that something is true even if the data clearly says it is not) or *confirmation bias* (where we seek out only information that supports something we already believe and disregard the rest).

The Commission has developed a series of education videos that can help us reflect on our unconscious bias – they are available on the Commission's website at: [www.hqsc.govt.nz/our-programmes/patient-safety-day/publications-and-resources/publication/3866/](http://www.hqsc.govt.nz/our-programmes/patient-safety-day/publications-and-resources/publication/3866/)

## Using debriefing and self-reflection

Debriefing and self-reflection are useful ways of learning from serious illness conversations and of gaining insight into personal feelings and reactions.

Questions you might consider including in a debrief include the following.

- 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 a serious illness conversation?
- How can we support each other?

Reflection following a negative or difficult experience with a person, for example, may involve asking the following questions.

- 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 serious illness conversation using the SICG?

## **A reluctance to engage in advance care planning**

If we feel reluctant to engage in advance care planning or SICG conversations, it is helpful to reflect on why that might be. Questions you might consider when assessing any reluctance include 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 in the SICG that I am uncomfortable with?
- What can I do to overcome my reluctance?

## **Self-care**

Serious illness conversations using the SICG can be challenging and emotionally/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 the following questions.

- What positive support mechanisms work best for me? Am I using them?
- How do I re-energise myself?

## Chapter 3: Supporting Māori health gains | Upoko 3: Te tautoko i ngā painga hauora Māori

The inclusion in health care of Te Tiriti o Waitangi principles, tikanga (cultural protocols), communication strategies and Māori health models, as well as using te reo Māori, have been identified as pivotal to increasing the clinician's ability to work effectively with Māori consumers and their whānau. Below are a few guidelines and resources to strengthen cultural competency so that we can more effectively 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 them in conversations (with the person's permission).
- When planning an advance care planning appointment, always ask the person if they would like whānau or community support.
- 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 engagement of the person and their whānau with 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, a person's education level can affect their understanding of medical terminology, or their financial situation may impact the number of clinic visits that a person attends for completing advance care planning documentation.
- Advocate for a larger Māori workforce that works alongside consumers and their whānau to support Māori health gains.

### 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).

Integrate te reo Māori into your daily practice. This will prepare you for when you work 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

<b>Hui</b>	Meeting
<b>Karakia</b>	Prayer or invocations
<b>Karakia mō te kai</b>	Prayer before food
<b>Karakia tīmatanga</b>	Opening prayer
<b>Karakia whakamutunga</b>	Closing prayer
<b>Kaupapa</b>	The business at hand
<b>Kōrero</b>	To speak or have a discussion
<b>Kupu Māori</b>	Māori word
<b>Mana</b>	A concept with many shades of meaning, including prestige, authority, control, power and influence
<b>Mana motuhake</b>	The ability of Māori to determine things according to their values and what they think is important – Māori self-determination
<b>Mātauranga Māori</b>	Māori knowledge
<b>Mihimihi</b>	Usually held at the beginning of a hui in the form of introductions (The format of a mihimihi includes a welcome (mihi), recitation of your genealogy (pepeha) or where you come from, and who you are in relation to this (whanaungatanga).)
<b>Pepeha</b>	A genealogical statement as Māori, descending from ancestors
<b>Pōwhiri</b>	Rituals of encounter or welcome ceremony
<b>Tangata whenua</b>	The indigenous people of Aotearoa New Zealand
<b>Tautoko</b>	In the context of health, to provide cultural support
<b>Te ao Māori</b>	The Māori world view; acknowledging the interconnectedness and interrelationship of all living and non-living things, strongly influencing every aspect of the culture and contributing to the Māori holistic view of the world
<b>Te reo Māori</b>	The Māori language
<b>Tikanga Māori</b>	Māori protocol or way of being (It's important to remember that tikanga may differ in hospitals, marae, iwi, workplaces, etc. since each rōpū establishes their own tikanga.)
<b>Wānanga</b>	In this context, workshop
<b>Whakapapa</b>	Genealogy (Reciting whakapapa was, and is, an important skill and reflects the importance of genealogies in Māori society in terms of leadership, land and fishing rights, kinship

	and status.)
<b>Whakawhanaungatanga</b>	A te ao Māori process of establishing relationships (It's about making connection, developing relationships through commonality and/or difference. It involves connecting with the consumer and their whānau on a personal level, often through connections with whenua, whānau involvement or the use of te reo Māori.)
<b>Whānau Māori</b>	A term commonly used to denote people who identify as Māori
<b>Whenua</b>	Land (In the context of whakawhanaungatanga, this encompasses ancestral land, mountains and water – ocean, lakes or rivers.)

## Further te reo Māori resources

**Aki Hauora** is a Māori language vocabulary and phrase learning app from the University of Otago. It 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 that can easily be loaded to your phone for some learning fun.

### **Aki Hauora App for Apple**

<https://itunes.apple.com/nz/app/aki-hauora/id1062206292?mt=8>

### **Aki Hauora App for Android**

<https://play.google.com/store/apps/details?id=nz.monkeywise.akihauora&hl=en>

### **The online Māori Dictionary**

<https://maoridictionary.co.nz/>

## Chapter 4: Preparing for the conversation | Upoko 4: Te whakaritenga hei kōrero

### Preparing yourself

As clinicians, we cannot underestimate the role our attitudes, our biases and our preconceptions play in the serious illness conversation. Understanding this and acknowledging and respecting the realities of others will create a space for meaningful conversation about serious illness.

Not many of us can claim to be experts in the culture or realities of others. You can, however, become expert in reflecting on your own culture and attitudes that inevitably shape your practice. Respect and humility lay the foundations for a mutual exchange where the locus of control sits with the person and their whānau. Accepting that your own reality is no more valid than anyone else's will help you navigate serious illness conversations.

For the serious illness conversation to meet its objectives, it is important that the clinician first:

- understands their own cultural values, beliefs and practices and the influences these have on their practice
- understands their own assumptions, biases and stereotypes that they hold about groups of people and how these can shape practice
- can identify power held and how it is used in practice
- critically analyses the diverse realities that influence people's health and wellbeing
- recognises and respects diversity among groups of people.

Please make time to watch the Commission's implicit bias training resources.

The 'Understanding bias in health care' videos are available free from the Commission's website at [www.hqsc.govt.nz/resources/resource-library/learning-and-education-modules-on-understanding-bias-in-health-care](http://www.hqsc.govt.nz/resources/resource-library/learning-and-education-modules-on-understanding-bias-in-health-care) and can also be completed as learning and education modules on <https://learnonline.health.nz>

These will assist you to examine attitudes and stereotypes that affect your understanding, actions and decisions in an unconscious manner.

### Preparing the team for the conversation

Ideally the SICG preparation and conversation will be supported by key members of the patient's health care team. Team communication, whether it takes place in person (ideal) or by email, is critical to consolidating perspectives and arriving at a plan of care for approaching the SICG discussion. Some members of your team may have more training and experience with prognostication and may choose to take the lead on exploring illness understanding and sharing prognosis.

Other members of the multidisciplinary team that may be more familiar to the patient and their whānau might lead other aspects of the conversation. Familiarity can help reduce anxiety.

What you decide about how to carry out these conversations will depend on your patient's needs, who is on your team, what clinical resources you have and your own practice style.

## **Preparing the patient and their whānau for the conversation**

It is generally helpful to explain your plan to discuss serious illness care planning before the visit at which it will actually take place. Informing the patient in advance allows the patient to prepare emotionally and cognitively. Since preparation usually reduces anxiety, giving patients some time to consider the issues tends to be helpful. Preparation also allows the patient to bring along whānau or a friend, if desired.

Many clinicians find that scheduling a designated visit for a serious illness care discussion is useful in allocating appropriate time for the discussion, instead of tacking it onto an already-full clinical visit.

Before the conversation, it is important that one of the team members outlines for the patient how the conversation will take place and who will be involved from the clinical team. The conversation should be framed as being about aligning the patient's values and preferences with the treatment plan and not as an end-of-life conversation, unless the patient is truly at the end of life.

At this stage, the most important thing is to let the patient know that they may invite whoever they wish to participate in the conversation. This may require a different venue if the patient opts to bring extended whānau. Making these conversations open, inclusive and centred around the patient and whānau from the outset sets the scene going forward.

You could use these approaches to prepare the patient and their whānau.

- To reduce patient anxiety, normalise the conversation by saying that this is an approach that is used for all patients with serious illness.
- Emphasise that it is preferable to do this when things are stable, so that there is more time to consider the issues.

Some clinicians prefer to send a letter to patients, outlining the purpose and process of a serious illness conversation. Others prefer to talk with the patient about it before scheduling it. A script or letter that you can adapt to your own style is available in Appendix One.

## **Engaging patient and whānau together at the visit**

Having the patient and whānau present offers both opportunities and challenges. Here are some general principles to guide these situations.

- Acknowledge that the patient and their whānau are in charge of this process and that the clinical team are here to share their expert clinical knowledge.
- Acknowledge those who are in attendance. Allow time for introductions, firstly of those in attendance and then the clinical team.
- Apply the practice of whakawhanaungatanga to find familiar ground during introductions to assist with connections.
- Make it clear at the outset that the language you are using might be unfamiliar and ask people to stop you at any time if you are being unclear – no question is off the table.
- These can be difficult conversations for whānau. Attend to the emotions of whānau, using the same approaches that you would use with a patient – expect emotion, help the whānau member name their emotion/s and respond with empathy and support.
- Encourage patients and whānau to discuss these issues further and always leave them with a number to contact and clarity around the next steps.



## **Cultural considerations**

Find out if there are cultural considerations for which arrangements can be made before the serious illness conversation appointment. Ask whether the person would like to bring someone to provide tautoko (cultural support). Also, remain mindful that some people are reluctant to talk about their care or share intimate details of their lives with professionals of the opposite sex. If possible, the health care professional facilitating the serious illness conversation should be someone with whom the person can communicate comfortably.

Some people value individual decision-making, while 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 it is important to the person, the function of the wider whānau in that decision-making process 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 people (with whom they are connected and their 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 who present in terms of their cultural context but also as part of a collective. Like other indigenous populations worldwide, Māori have and currently experience historical, cultural and socioeconomic deprivation that impacts on their collective and individual wellbeing.

For Māori, identity is a central element to wellbeing and, as a collectivist culture, ideas of self are entwined in tupuna (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 enhance clinician-consumer relationship in support of Māori health gains.

## **Engaging Māori with serious illness conversations**

It is recommended that we use an engagement process that aligns with te ao Māori when engaging Māori in serious illness conversations using the SICG. The Hui Process is such an engagement process.

The Hui Process was developed at the University of Otago and draws on matāuranga Māori (traditional knowledge) and practices and aligns it to a contemporary setting to enhance clinicians' ability to 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 and serious illness conversations, not only those with Māori.

### **1. Mihi – the initial greeting and engagement**

The main focus here is to introduce yourself and describe your role and the purpose for the consultation. At this point, the clinician should confirm that the consumer identifies as Māori.

### **2. Whakawhanaungatanga – making connection**

Based on traditional Māori protocol, whakawhanaungatanga involves connecting with the individual 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. It is important to include all whānau who are with the individual in this aspect of the engagement strategy.

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

Here, the focus moves to the clinical task at hand, that is, having the serious illness conversation.

### **4. Poroporoaki – concluding the encounter**

It is important to clearly identify the finishing point of the consultation and ensure there is clarity around the next steps for the person, their whānau and yourself. There are three parts to the poroporoaki of the Hui Process.

- 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.

## **Preparing the environment**

Whatever the setting or circumstance, you should make the effort to have a serious illness conversation using the SICG in an appropriate environment. Always consider the following.

- Ensure the person's privacy.
- If the person wants their whānau to be present, ensure you have a space that can accommodate that.
- If possible, provide an environment that is familiar to the person.
- Ensure accessibility, for example, ensure wheelchair access if necessary.
- Set aside adequate time for the discussion so people do not feel rushed.
- Prevent interruptions.

## Familiarising yourself with the Serious Illness Conversation Guide Aotearoa

Stage	Patient-tested language
<b>SET-UP</b>	<p>‘We want to make sure you have the best care possible. To do this it would be good to talk about what is happening with your health, what might be ahead and what things are important to you? Is that OK?’</p> <p>‘This is an important conversation. Would you like someone to be here with you?’</p>
<b>ASSESS</b>	<p>‘To make sure we are on the same page, can you tell me your understanding of what’s happening with your health at the moment?’</p> <p>‘In terms of your health, how much information about what might happen in the future would you like from me?’</p>
<b>SHARE</b>	<p>‘This is my understanding of where things are at...’</p> <p><i>Uncertain:</i> ‘It can be difficult to predict what will happen with your health. I hope that you will continue to live well for a long time, but it is possible you could become unwell quickly. It is important we prepare for that possibility.’</p> <p>OR</p> <p><i>Time:</i> ‘I wish this were not the case, but I am concerned that time might be as short as... (express as a range, eg, days to weeks, weeks to months, months to a year).’</p> <p>OR</p> <p><i>Function:</i> ‘I hope that this is not the case, but I am concerned that this may be as well as you will feel and things are likely to get worse.’</p> <p><b>Allow silence, explore emotion</b></p>
<b>EXPLORE</b>	<p>‘What are your priorities if your health does get worse?’</p> <p>‘What worries you when you think about your health changing?’</p> <p>‘What helps you through the tough times?’</p> <p>‘What abilities are so important for you, that you can’t imagine living without them?’</p> <p>‘If your health does get worse, how much are you willing to go through for the possibility of more time?’</p> <p>‘How much does your family/whānau know about what is most important to you?’</p>
<b>CLOSE</b>	<p>‘I have heard you say... is really important to you. Keeping that in mind, I suggest that we... This will help us make sure your care focuses on what is important to you.’</p> <p>‘How does this plan seem to you?’</p> <p>‘I will do all I can to help you get the best care possible.’</p> <p>‘Is there anything you would like to go over again/ask/talk about?’</p>

**Left: Conversation flow**

This part of the guide will help serious illness conversations flow and ensure you complete the key steps of a successful conversation in an intentional sequence.

**Right: Patient-tested language**

These words have been tested with patients; they are aligned with the conversation flow for easy reference. Use these words to help ensure you have a meaningful and successful conversation.

## Chapter 5: Having a serious illness conversation | Upoko 5: Kia kōrerorero mō ngā tino mate

### 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 do that when preparing for and having SICG conversations with people and their whānau.

The ideal time to introduce a discussion of values and goals is when the person is relatively stable and not in a medical or emotional crisis.

### How to initiate the conversation

Welcome the patient and their whānau.

Incorporate mihimihi and whakawhanaungatanga if using the Hui Process.

Offer to start with a karakia, if appropriate. Here is one you could use.

Tūtawa mai i runga.	I summon from above.
Tūtawa mai i raro.	I summon from below.
Tūtawa mai i roto.	I summon from within.
Tūtawa mai i waho.	I summon from the surrounding environment.
Kia tau ai	The universal vitality
Te mauri tū, te mauri ora	Energy to infuse and enrich
Ki te katoa	All those present
Haumi e, hui e, tāiki e!	Unified, connected and blessed!

Invite the patient and their whānau to introduce themselves. Look for connections that you can refer to in your introduction.

Introduce yourself and the health professionals in the room, including their names and roles in patient's care and include a personal connection or share a little about yourself. The connection should draw on relevant patient and whānau beliefs, values and experiences.

Once a connection has been made, you can get down to the kaupapa of the conversation – the serious illness discussion.

### Setting up a serious illness conversation

Use the 'Set up the conversation' prompts to help you remember the optimised sequence of ideas for introducing the conversation with a patient. The table below suggests language that flows from one idea to the next.

Before starting the conversation, acknowledge that you will be using the guide: 'I may refer to this conversation guide, just to make sure I don't miss anything important.'

Prompt	Purpose	Suggested language
Introduce the idea and benefits	Orient the patient State benefit and support	‘Is now a good time for us to talk about what is ahead with your health so we can do some planning and thinking about what this might mean for you and your whānau?’  ‘Talking about it now allows all of us time and space to talk and think these issues through, and to include your whānau in our discussion.’  ‘We want to help you stay in control of decisions about your care, and to support your whānau if they are asked to be involved in making difficult decisions on your behalf.’
Ask permission	Give the patient control	‘Is this OK? If not, we don’t have to do it today, and I will bring it up again for us to talk about later.’

## Exploring illness understanding

Conversations about the future need to start with an understanding of the patient’s perspective on their illness. Do they see it as serious? Do they perceive that it is progressing? What expectations do they have about the future? An understanding of the patient’s perspective on their illness allows the clinician to assess the extent of alignment of patient expectations and medical realities.

Patients and whānau whose understanding and expectations are well aligned with medical realities are usually more prepared for a serious illness conversation. Patients and whānau whose understanding and expectations are significantly more optimistic than medical realities appear to indicate are likely to be at higher risk of future bad outcomes and also will require particular gentleness, carefully measured discussion to avoid overwhelming the patient with anxiety, extra emotional support and ongoing discussion.<sup>2</sup>

## Discussing information preferences

Clinicians regularly hesitate to provide prognostic information out of concern that it may be harmful to the patient. Patients frequently express frustration that they cannot get the information that they want and need about their prognosis from their clinicians. Asking the patient about what kind of information is desired allows the clinician to provide the type of information that the patient wants and needs and avoid giving information that is not wanted or will be harmful. Knowing that you are providing information that is wanted by the patient

<sup>2</sup> Bernacki R, Paladino J, Neville BA, et al. 2019. Effect of the Serious Illness Care Program in outpatient oncology: A cluster randomized clinical trial. *JAMA Intern Med.* Published online March 14, 179(6):751–759. doi:10.1001/jamainternmed.2019.0077

Evans LR, Boyd EA, Malvar G, et al. 2008. Surrogate decision-makers’ perspectives on discussing prognosis in the face of uncertainty. *American Journal of Respiratory and Critical Care Medicine*, 179: 1. URL: [www.atsjournals.org/doi/full/10.1164/rccm.200806-969OC](http://www.atsjournals.org/doi/full/10.1164/rccm.200806-969OC) (accessed 23 February 2022).

Boyd EA, Lo B, Evans LR, et al. 2010. “It’s not just what the doctor tells me:” Factors that influence surrogate decision-makers’ perceptions of prognosis. *Crit. Care Med.* 38(5): 1270–75. URL: [www.ncbi.nlm.nih.gov/pmc/articles/PMC3530838/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3530838/) (accessed 23 February 2022).

will help you feel more confident in opening this part of the conversation.

It is important to recognise, though, that patients may not have thought about what information they want, or about what it would mean if they heard news they were not expecting and not wanting. It is often useful, when a patient says they wants 'all the information', to clarify what that means.

'You said you want to know everything about what is ahead with your illness. Does that include my best judgment about time, or are you more interested in knowing what life will be like for you going forward?'

## Discussing prognosis

Understanding and accepting that a serious illness is likely to end one's life is a process and, ideally, should not have to happen all at once in a crisis. Starting to discuss prognosis early in the trajectory of a progressing illness allows the clinician to present the kind and extent of conversation gently to avoid overwhelming the patient and allows the patient to process, both internally and with whānau, the realities of their illness.

Discussing the prognosis with the patient is valuable for several reasons.

- It allows the patient and their whānau to prepare for the future.
- It can empower them to focus on their most important goals now, rather than at some future time that may or may not occur.
- It allows the patient to make more informed decisions about medical treatments.
- Patients are generally overly optimistic about their prognosis (even when they receive accurate information). This may result in more deferral of personal goals and worse preparation for the end of life.

Because this part of the conversation is difficult for us, we tend to talk too much and beat around the bush.

- Be clear and direct by using the prompts.
- Support hope.
- Be quiet after giving the prognosis.
- Explore how the patient is feeling about what they have heard.

Time-based prognosis	
<b>Key ideas</b> Many patients want our best estimate of how much time they may have given their stage of illness. Cancer may have a more predictable prognosis; less so heart, lung and kidney disease. Patients do not expect precision, but they expect to be given time to prepare for what may come.	<b>Using the time-based prognosis</b> <ul style="list-style-type: none"><li>• <b>Provide prognostic information as a range, without providing too much specificity:</b> Days to weeks, weeks to months, months to years</li><li>• <b>Acknowledge prognostic uncertainty</b> 'It could be shorter or longer.'</li></ul>

Functional prognosis	
<p><b>Key ideas</b></p> <p>For many conditions, it is impossible to predict how much time a patient is likely to have, but it is possible to predict their level of function, which may provide them with useful information for planning and goal setting. Providing functional prognosis – outlining what is and is not likely to improve in the future – helps a patient understand what their life will be like in the future and allows them to make trade-offs that align with their values.</p>	<p><b>Following the use of the functional prognosis prompt and pausing to allow the patient to process what you have just said, you could try the following strategies.</b></p> <ul style="list-style-type: none"> <li>• <b>Provide information on what is likely and not likely to improve</b> ‘I think that your leg swelling may get better, but I think you will still need oxygen, and I’m worried that this may be as well as you feel.’</li> <li>• <b>Support hope</b> ‘I think we can get you well enough to go home and spend time with your whānau.’</li> <li>• <b>Affirm commitment to optimising function</b> ‘We are going to continue physical therapy to give your body the best chance possible to regain some strength. And we’re going to keep looking for other options that can help you feel as well as possible.’</li> </ul>

Unpredictable prognosis	
<p><b>Key ideas</b></p> <p>Conditions such as advanced heart and lung disease, which can remain stable, slowly deteriorate over time or bring sudden and life-threatening crises, should be communicated to patients. This allows them and their whānau to consider their values and preferences within this context and to prepare.</p>	<p><b>Following the use of the unpredictable prognosis prompt and after allowing silence so the patient can process what you have just said, you could try the following strategies.</b></p> <ul style="list-style-type: none"> <li>• <b>Provide clear information about potential trajectories: heart disease is unpredictable</b> ‘With heart disease, people can live well for years, but sometimes things can happen quickly. I think we need to be prepared for a crisis, or sudden event, in which we may be confronted with some difficult decisions.’</li> <li>• <b>Use hypotheticals</b> ‘If your heart failure were to suddenly worsen, you might feel very short of breath, and you might need to be hospitalised.’</li> <li>• <b>Hope for the best; plan for the worst</b> ‘Even though this is difficult to think about, I am hopeful that you will have a lot of good times ahead and that doing some planning together can help you have a safety net, in case things don’t go as we hope.’</li> </ul>



## I wish... I worry... I wonder...

### Key ideas

'I wish' allows for aligning with the patient's hopes.

'I'm worried/concerned' allows you to share your worries.

'I wonder' is a subtle way to make a recommendation.

Note: Consumer testing in Aotearoa New Zealand found many people have a more positive response to the word 'concerned' than the word 'worried'.

### Try the following strategy.

- **Align with the patient's hopes, acknowledge their concerns and then propose a way to move forward**  
'I wish we could slow down or stop the growth of your cancer, and we will continue to look for options that could work for you. But I am concerned that you and your whānau won't be prepared if things don't go as we hope. I wonder if we can discuss a plan B today.'

## Addressing emotions

A key task in serious illness conversations is managing anxiety.

### General principles for managing anxiety

Conversations about serious illness can bring up strong emotions for patients, whānau and clinicians. In talking about serious illness, anxiety is usually the most intense emotion both clinicians and patient/whānau may experience.

- Anxiety is manifested in the clinical encounter through words, facial expressions, body language, the use of psychological defences and affective expressions (tears, flushing, etc.).
- Anxiety can also be reflected in the clinician. High patient anxiety can make the clinician more anxious and is a clue to the patient's state of mind.
- High clinician anxiety can raise anxiety in the patient and their whānau. Pausing before starting this conversation to settle yourself, practicing the SICG and developing your skills will lower your anxiety and lead to less stressful and more effective conversations.
- Strong emotions tend to impair cognitive processing.
  - Recognising and acknowledging the emotions of the patient (and their whānau) and allowing the patient and their whānau time to process those emotions, allows the patient/whānau to move forward into cognitively processing the information and making a plan.
  - If the patient is in a crisis (medical or other life crisis), their capacity for dealing with anxiety might be diminished. If possible, delay a serious illness conversation until the crisis has passed. If that is not possible, recognise that you will have to proceed especially gently.
- Difficult conversations should be carefully measured to keep the anxiety of the patient and whānau within a manageable range.
- For a number of people, feeling connected is one of the strongest antidotes to anxiety. Expressions of empathy (eg, 'I can see how hard this is for you to talk about', 'I wish we

were not in this situation') and affirmation of connection ('We will work through these decisions together') usually reduce anxiety.

- Offering the patient and their whānau some element of control allows the patient to control anxiety-producing discussion (eg, 'How much information do you want me to share with you about what is likely to be ahead?' or 'Would you like to go ahead and talk about a plan today, or is this enough for now?').
- Having a whānau member present can lower or raise anxiety. Ask the patient whether it would be helpful or not.
- Talking 'around' the issue rather than talking directly raises anxiety. Be succinct, direct, honest and gentle.
- Use your team. Engage team members who have a close relationship with the patient to help support the patient during and after the conversation.

<b>Talking about whānau involvement</b>	
<p><b>Key ideas</b></p> <p>Preferences about whānau involvement in decision-making vary a lot.</p> <p>Whānau involvement in decision-making helps them prepare for the patient's death. Preparation is associated with better bereavement outcomes.</p>	<p><b>Try the following strategies.</b></p> <ul style="list-style-type: none"> <li>• <b>Explore options for whānau involvement</b> 'How involved do you want your loved ones to be?'  'If your whānau has strong wishes about your care that are different from yours, how would you like us to decide on your care?'</li> <li>• <b>Encourage the patient to involve and prepare their whānau</b> 'I know these are really difficult issues to talk about, because you care so deeply about your whānau. But involving them in decisions helps them prepare and cope.'</li> </ul>

## Time to make a plan – poroporoaki

There are three tasks in bringing the conversation to a conclusion.

1. Ensure that you have understood what the patient has told you.
2. Ensure the patient and their whānau have understood what you have said.
3. Agree on the next steps.

It is useful to consider what kinds of plans you might recommend following a summary of what you have heard is important to the patient.

<b>1. Summarise what you have heard</b>	
<p><b>Key ideas</b></p> <p>Thank the patient for sharing their thoughts with you.</p> <p>We want to summarise what we have heard so that the patient can feel heard and to check that we have understood what is important to them.</p> <p>Seek permission to provide a plan or recommendation based on what you know about the illness and what is important to the patient.</p>	<p><b>Try the following strategies.</b></p> <p>‘Thank you for sharing with me. I’d like to reflect together on what you’ve shared, to make sure I have understood what is important to you and make a plan for how we might move forward. Is that OK?’</p> <p>‘I’ve heard you say that _____ [goal] is important to you. You’ve also shared _____ [fears and worries, sources of strength, critical abilities and trade-offs, whānau considerations].’</p> <p>‘Keeping all of this in mind, and what we know about your illness, I would like to share a (few) recommendation(s) with you. Would that be OK?’</p>
<b>2. State key considerations and recommendations (the proposed plan)</b>	
<p><b>Key ideas</b></p> <p>Make recommendations only after you’ve had a chance to explore the patient’s values, goals and priorities.</p> <p>Your recommendation may be:</p> <ul style="list-style-type: none"> <li>• <b>wellbeing based</b> <ul style="list-style-type: none"> <li>○ working towards a goal or planning for a life event</li> <li>○ pursuit of a hobby or passion</li> <li>○ referring the patient to another service who could support wellbeing.</li> </ul> </li> <li>• <b>support-system based</b> <ul style="list-style-type: none"> <li>○ sharing information</li> <li>○ inviting whānau/support people to the next appointment</li> <li>○ involving other support services, for example, social work/Māori health team etc.</li> </ul> </li> <li>• <b>illness based</b> <ul style="list-style-type: none"> <li>○ agreeing on a medical plan that supports the patient’s goals/reflects what is happening with the illness, for example:</li> </ul> </li> </ul>	<p><b>Try the following strategies.</b></p> <p>‘Given what you have told me about what is important to you, I suggest we ...</p> <p>For example:</p> <ul style="list-style-type: none"> <li>• <b>wellbeing based</b> <ul style="list-style-type: none"> <li>... <b>arrange</b> for a social worker, palliative care team, community nursing team, chaplain, etc. to meet with you to work out a plan to support you with _____</li> <li>... <b>make a plan to support</b> your goal of _____ [life event] or your pursuit of _____ [hobby/passion].</li> </ul> </li> <li>• <b>support -system based</b> <ul style="list-style-type: none"> <li>... <b>include</b> _____ [your whānau or other significant people] in a further discussion so we can come up with a plan together</li> <li>... <b>share</b> _____ [prognosis, goals, priorities, wishes] with your whānau so they understand the things that are feeling most important to you and/or are aware of things you are worrying about with regard to your future.</li> </ul> </li> <li>• <b>illness based</b> <ul style="list-style-type: none"> <li>... <b>revisit your treatment plan</b> and discuss whether or not to:               <ul style="list-style-type: none"> <li>○ start a new treatment(s)</li> <li>○ stop a current treatment(s)</li> </ul> </li> </ul> </li> </ul>

<ul style="list-style-type: none"> <li>• start/stop/continue current treatment</li> <li>• consult with a specialist</li> <li>• start/complete documentation</li> <li>• consider shifting the goal of care to focus on symptom management/a palliative approach</li> <li>• revisit the conversation.</li> </ul> <p>Note: How you make a recommendation can influence the patient's choice and reaction.</p>	<ul style="list-style-type: none"> <li>○ continue a current treatment(s)</li> <li>○ consult with a specialist and/or invite a specialist to our next conversation.</li> </ul> <p>... consider <b>shifting your goals of care</b> to focus more on symptom management and your comfort. Have you heard of hospice/palliative care before?</p> <p>... <b>complete an/some important document(s), including</b> an advance care plan, a goals of care document</p> <p>appoint an EPOA</p> <p>OR</p> <p>...<b>revisit this conversation</b> later today/tomorrow/next week/at our next appointment.'</p> <p>'This will help us make sure your care focuses on what is important to you.'</p>
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If timing is right for a conversation about resuscitation [status]	
<p><b>Key ideas</b></p> <p>Discussion of resuscitation status should always follow a broader discussion of prognosis and values and goals.</p> <p>Patients are often overly optimistic about the outcomes of CPR.</p> <p>In-hospital CPR survival, overall:</p> <ul style="list-style-type: none"> <li>• immediate survival: 30–45%</li> <li>• survival to discharge: 11–17%.</li> </ul> <p>The above statistics haven't changed in 40 years.</p> <p>In-hospital CPR survival for cancer patients:</p> <ul style="list-style-type: none"> <li>• overall survival to discharge: 6%</li> <li>• localised disease: 10%</li> <li>• metastatic: 5%.</li> </ul> <p>A clinical decision not to offer an intervention like CPR can make patients feel abandoned. Using strong language assures the</p>	<p><b>Try the following strategies.</b></p> <ul style="list-style-type: none"> <li>• <b>Introduce the concept of a resuscitation decision in the context of their values and prognosis</b> 'We've talked about some of the key issues that are important as you get sicker, and I think it would be helpful to get a bit more specific about the types of treatments that do and don't make sense in your situation.'</li> <li>• <b>Explore the patient's understanding about CPR</b> 'One of the questions we should figure out is whether cardiopulmonary resuscitation makes sense for you. What have you heard about CPR?'</li> <li>• <b>Describe CPR</b> <ul style="list-style-type: none"> <li>– Correct misunderstandings.</li> <li>– Describe what it is, the risks and benefits and the possible outcomes.</li> <li>– Share data about possible outcomes (if desired).</li> </ul> <p>'CPR is a procedure for patients who have died in which we use machines to try to restart the heart or breathing. In patients with metastatic cancer, its effectiveness is extremely low – between 2 and 6 percent – and even those who can be brought back initially have to be kept alive on breathing machines and almost never leave the hospital.'</p> </li> <li>• <b>Make a recommendation consistent with patient's prognosis and preferences</b> 'Based on the spread of your cancer, the fact that we have no more treatments to stop the growth of the cancer, and the fact that CPR doesn't work for patients with metastatic cancer, I recommend that we focus intensively on your comfort, on helping</li> </ul>

<p>patient of all the things you will do (eg, intensive symptom control, emotional support for them and their whānau, etc.).</p>	<p>you have as much time as possible with your whānau and on getting you home.'</p> <ul style="list-style-type: none"> <li>• <b>Check for patient agreement</b> 'How does this plan sound to you?'</li> <li>• <b>Emphasise the care that will be provided to the patient</b> 'I want to make sure you know that we will monitor you carefully and arrange for the best possible support for you and your whānau.'</li> <li>• <b>Do not say 'We will just give you comfort care.'</b></li> <li>• <b>Do not offer CPR if it's not clinically indicated</b> Inform the patient that they are not a candidate for CPR because it will not be effective, and ask them to affirm your decision.</li> </ul>
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## Close the conversation

'How does this plan seem to you?'

'I will do all I can to help you get the best care possible.'

'Is there anything you would like to go over again/ask/talk about?'

It is important to allow the conversation to close in the same way it opened. If it started with a karakia, it should conclude with one. Here is one you might use.

<p>Kia whakairi te tapu. Kia wātea ai te ara. Kia turuki whakataha ai. Kia turuki whakataha ai. Haumi ē! Hui ē! Tāiki ē!</p>	<p>Restrictions are moved aside So the pathway is clear To return to everyday activities. Unified, connected and blessed!</p>
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This is a good time to thank the patient and their whānau for sharing with you so that together you could arrive at a plan that focuses on what is important to the patient.

## Chapter 6: Managing the conversation | Upoko 6: Te whakahaere kōrerorero

### Practical challenges

- Time pressures can be a barrier to effective end-of-life conversations.
- Plan for enough time to have a meaningful conversation.
- Use these strategies to make the best use of your time with each patient.

Keeping the patient on track	
<p><b>Key ideas</b></p> <p>Patients wander when they are anxious or have other high-priority issues to discuss.</p> <p>Patients usually recognise that you have an agenda and need to fulfil it within a limited timeframe, if reminded.</p>	<p><b>Try these strategies.</b></p> <ul style="list-style-type: none"> <li>• <b>Acknowledge that this is a tough conversation, and gently bring patient back to topic</b> 'I know this is hard to talk about, but I'd like to see if we can clarify a couple of things about what your worries are about the future.'</li> <li>• <b>Remind patient of time constraints</b> 'I wish we had more time to talk about your new dog, but I would like to get back to thinking about some future planning that I think we need to do.'</li> <li>• <b>Interrupt gently</b> 'Mrs. Smith, I wonder if we could get back to my question about your priorities if time is getting short.'</li> </ul>
Managing your time	
<p><b>Key ideas</b></p> <p>Some questions can be effectively handled by other members of the team, but <b>prognosis should not be delegated.</b></p> <p>The conversation can still be effective when spread over several visits.</p>	<p><b>Try these strategies.</b></p> <ul style="list-style-type: none"> <li>• Delegate some questions to other members of the team, as appropriate.</li> <li>• Consider going through two questions per visit.</li> <li>• Make sure everyone documents the discussion.</li> </ul>
Documenting the conversation	
<p><b>Key ideas</b></p> <p>Avoid using the computer while talking to the patient.</p>	<p><b>Try these strategies.</b></p> <ul style="list-style-type: none"> <li>• Make notes on the guide if you need to remember specific things patient says.</li> <li>• If you must document while talking, make frequent eye contact with patient.</li> </ul>

## Strategies for common scenarios

- Use this content to support your learning in anticipation of a patient conversation, or as follow-up after a challenging interaction.
- **Key ideas** and **strategies** provide a mix of approaches and suggested language.
- The following offer guidance for scenarios that can be challenging for clinicians.

<b>The patient says: 'I don't want to talk about it'</b>	
<p><b>Key ideas</b></p> <p>Exploring why a patient does not feel able to talk about these issues can provide valuable information that helps you provide good clinical care. Many patients are unsure about receiving information. They may want it but be scared of what they will hear. Your remaining calm when you approach these issues with a patient will help them feel that talking about it is possible.</p> <p>There is a 'differential diagnosis' of not wanting to talk about it that includes the following.</p> <ul style="list-style-type: none"> <li>• The patient has intense fears about the future and about dying that are overwhelming – if this is the case, finding a way to gradually introduce the subject may help the patient be better prepared for reality.</li> <li>• The patient needs more support (eg, from a whānau member) to address these issues.</li> <li>• This is a bad time because of other difficult events/stressors (eg, symptoms, other life stressors).</li> <li>• The patient has an anxiety disorder that makes it difficult to tolerate the anxiety of a discussion.</li> </ul>	<p><b>Try these strategies</b></p> <ul style="list-style-type: none"> <li>• <b>Explore the patient's reasons for not wanting to discuss this</b> 'Help me understand the reasons you would prefer not to talk about this.'</li> <li>• <b>Elicit information about how the patient thinks about planning for the future</b> 'I'd like to understand what kind of thinking and planning you would find helpful as we think about what is ahead with your health.'</li> <li>• <b>Ask about the positives and negatives of discussing these issues.</b></li> <li>• <b>Remind the patient that the aim is to initiate discussion not to make decisions.</b></li> <li>• <b>If the patient is unsure, acknowledge or name the ambivalence – also how difficult the situation is</b> 'I hear you saying that you know it is important to do some planning and also that you worry this process will be too overwhelming.'</li> <li>• <b>If the patient expresses intense anxiety about dying, explore specifics or consider referral to palliative care.</b></li> <li>• <b>Use 'I wish' statements</b> (eg, 'I wish that things were better so we didn't need to talk about this').</li> <li>• <b>Inform the patient that you will bring this up at a subsequent visit; delaying the conversation until more support is available can help.</b></li> <li>• <b>Acknowledging the patient's stress and a plan to return to these issues later can be helpful.</b></li> <li>• <b>If the patient expresses more global anxiety, explore their experience of anxiety in a non-threatening way and consider mental health referral</b> 'Do you often find yourself overwhelmed with worries?'</li> </ul>

## The patient says 'I'm going to beat this'

### Key ideas

'Beating this' has many meanings.

Explore them.

Clinicians have the power to reshape the meaning of 'beating' the illness.

Patients who are insistent that they will 'beat' a progressing illness may be using denial as a coping mechanism. We can support a person by checking the strength of the denial and tentatively exploring their underlying concerns and fears. Help the patient focus on additional hopes beyond survival.

Consider strategies to reduce anxiety (eg, relationship building, encouraging them to include whānau members, medication), which may make future discussions less anxiety-producing.

### Try these strategies.

- **Align yourself with patient by using 'I wish' statements**

'I wish I could tell you that we will beat this illness, but I can't. What I can tell you is that we are going to do our best to manage your symptoms and help you focus on the things that are most important for you.'

- **Explore the strength of the denial.**

- **Challenge any inconsistencies in the patient's story**

'You mentioned your condition isn't serious, yet you tell me you have been having chemotherapy.'

- **Check if denial is total by looking for a 'window on the denial**

'Are there ever moments when you think things might not work out?'

- **Some patients want to be seen as fighters by beating their disease. Show respect for the patient's fighting spirit**

'I think you have the capacity to continue to be a fighter no matter what happens with your disease. Let's try to think together about what other things you could fight for if you can't beat the cancer.'  
(eg, by helping loved ones deal with hard realities, by participating in a clinical trial.)

- **Focus on the patient's strengths**

'I can see what a strong force you are for your whānau. I think there is a lot you can do to help them deal with this difficult situation with your illness by helping to prepare them.'

- **Acknowledge the patient's desire to beat their disease, but persist in exploring end-of-life issues and moving the conversation forward**

'We should hope for the best and prepare for the worst.'

## The patient is not ready to make a decision

### Key ideas

Patients need time to absorb and integrate information and to prepare to make decisions.

If the patient's condition is stable, let them know that decisions are not

### Try these strategies.

- **Reassure the patient that there is time to think things through**

'I brought up these issues early so that you would have time to think about what's important to you. I'm not worried that anything will happen in the coming weeks.'



<p>urgent and encourage them to talk with their whānau.</p> <p>For patients who are declining rapidly, sharing information (including the health care professional's concern), and emphasising that decisions are best made soon, may help the patient move forward in considering these issues.</p>	<p>Let the patient know you will bring this up again.</p> <ul style="list-style-type: none"> <li>• <b>Encourage discussion with whānau</b> 'These can be difficult decisions and it can be useful to involve your whānau in them. I'd encourage you to talk about it with your whānau, and then we can discuss it again at your next visit.'</li> <li>• <b>If the patient is declining rapidly, acknowledge this and focus on providing care aligned with the patient's wishes</b> 'I am worried your health is getting worse. Talking today is an opportunity to think through some of the decisions you may be faced with soon.'</li> </ul>
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<b>The patient expresses intense emotion (tears)</b>	
<p><b>Key ideas</b></p> <p>Dealing with emotion is often a precondition for effectively addressing serious illness decisions. Tears and other strong emotions are natural when discussing serious illness issues.</p> <p>When patients express strong emotion, it is therapeutic for you to listen. People value the opportunity to talk through their feelings and to feel heard even if there is no solution or 'fix'.</p> <p>Adjusting the conversation based on the patient's responses with gentle guidance allows forward movement without the patient being overwhelmed.</p> <p>Sometimes, backing off is a good temporary strategy. Stay calm.</p> <p>Patients are often frightened of alienating their health care team by crying – acknowledging the emotion and staying present in the conversation can mitigate this.</p> <p>Most people feel better when they have a chance to express their feelings.</p>	<p><b>Try these strategies.</b></p> <ul style="list-style-type: none"> <li>• <b>Allow silence for the patient to explore and express their feelings.</b></li> <li>• <b>Name the feeling.</b></li> <li>• <b>Provide non-verbal support</b> (eg, eye contact, open body language, nodding and non-verbal encouragers, providing tissues or putting a hand on a shoulder).</li> <li>• <b>Ask the patient to describe what the tears are about</b> 'Help me understand what is making you so sad/upset/scared.'</li> <li>• <b>Explore the patient's feelings</b> 'Tell me more.'</li> <li>• <b>Express empathy</b> 'I am sorry that this is so sad/upsetting/scary for you.'</li> <li>• <b>Provide support and encouragement</b> 'I know this is a hard conversation to have, but I think it is important and that it will help make sure that we have a back-up plan in case we need one.'</li> <li>• <b>Obtain permission to proceed</b> 'Can we see if we can talk a bit more about this?'</li> <li>• <b>Negotiate where to next</b> 'I can see that this is a really tough conversation for you. Are you feeling like you want to keep talking about this today, or does it feel like you might need a break and we can talk more about it next time?'</li> <li>• <b>If the patient's emotions are very intense and persistent, explore whether a mental health referral would be helpful.</b></li> </ul>

	<ul style="list-style-type: none"> <li>• <b>Avoid giving false or premature reassurance to contain the patient’s distress.</b></li> <li>• <b>Avoid offering information that is not explicitly sought.</b></li> </ul>
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<b>The patient expresses anger</b>	
<p><b>Key ideas</b></p> <p>Stay calm.</p> <p>Anger can be a difficult emotion to deal with as it can feel personal. Although it might feel counterintuitive, it is important to give a person the opportunity to express their anger. Responding non-defensively can help to surface the underlying emotion that is driving the anger.</p>	<p><b>Try these strategies.</b></p> <ul style="list-style-type: none"> <li>• <b>Acknowledge the anger, being careful not to minimise or change the intensity</b> ‘You sound very angry.’</li> <li>• <b>Explore what is making patient angry</b> ‘Tell me what is making you angry?’</li> <li>• <b>Acknowledge the anger non-defensively. Empathise with patient’s situation if appropriate</b> ‘I can see you are really angry and are feeling let down that the chemotherapy hasn’t worked as we had hoped it would.’</li> <li>• <b>‘I wish’ responses can be helpful</b> ‘I wish this cancer had responded to the treatment, too.’</li> <li>• <b>As the patient talks about the reasons they are angry, look for ‘transition’, that is, a point where the anger reduces and other feelings become more prominent. These might be feelings of sadness or loss.</b></li> <li>• <b>Once other emotions are present, acknowledge and explore them.</b></li> <li>• <b>Allow the patient an opportunity to explore what it means to them to be talking about these end-of-life issues</b> ‘I am bringing up these issues because I want us both to be prepared for what is ahead. What is it like for you to have me bring them up at this point?’</li> <li>• <b>Encourage the patient to say what is on their mind</b> ‘As hard as it is, I want to learn as much as I can about what this is like for you, including the things that are making you feel angry and frustrated.’</li> </ul>

## The patient is reluctant to stop a disease-modifying treatment

### Key ideas

Once it is clear there is no benefit from evidence-based interventions, it is important to discuss the option of stopping a disease-modifying treatment.

Patients may not want to stop treatments that are directed at their underlying disease because they fear losing the relationship with their team, worsening disease or immediate death.

Poor functional status is a key prognostic indicator of limited life expectancy and warrants a discussion of stopping disease-modifying treatment.

Do not hedge ('Well, it might...'); evidence suggests that patients hear and remember positive but not negative messages.

### Try these strategies.

- **Explore the patient fears about stopping active treatment**  
'Can you tell me what your concerns are about stopping treatment X (eg, chemotherapy, transfusions, etc.)?'
- **Be clear that more treatment may not mean more time**  
'Some studies suggest that stopping chemotherapy may not shorten time, and you may feel better.'  
Check the patient's understanding at this stage, as patients may find this information counterintuitive.
- **If clinically indicated, make a clear, direct recommendation against further disease-modifying treatment.**
- **Reassure the patient that they will continue to receive care**  
'If you choose to stop chemotherapy, you will still be cared for. Rather than focusing on the chemotherapy our priority for your care becomes managing your symptoms.'
- **Don't say that you can reconsider disease-modifying treatment later if you can't.**

## Talking about whānau involvement

### Key ideas

Preferences about whānau involvement in decision-making vary a lot.

Whānau involvement in decision-making helps them prepare for the patient's death. Preparation is associated with better bereavement outcomes.

### Try these strategies.

- **Explore**  
'How involved do you want your loved ones to be?'  
'If your whānau have strong wishes about your care that are different from yours, how would you like us to decide on your care?'
- **Encourage the patient to involve and prepare their whānau**  
'I know these are really difficult issues to talk about, because you care so deeply for your whānau. But involving them in decisions helps them prepare and cope.'

## Appendix 1: Preparing the patient for the conversation: A script for a pre-visit conversation or letter | ĀpitiHanga 1: Te whakarite i te tūroro mō te kōrerorero: He rārangi kupu mō te kōrerorero o mua, he reta rānei

Some clinicians prefer to send a letter to patients, outlining the purpose and process of a serious illness conversation. Others prefer to talk with the patient about it before scheduling it. Here is a script for a letter or conversation that you can adapt to your own style.

At your next appointment, [clinician's name] would like to talk with you about your illness and some of the things that are particularly important to you so that together we can provide the best possible treatment and care. Working with you (and your whānau or others who you wish to include) to establish what is important and how you would like to receive care means that we can plan ahead together.

By planning ahead while you are feeling well, we hope that you will feel less anxious and more comfortable as your illness progresses.

We have put together the following questions for you to consider yourself or with your whānau before your appointment with [clinician's name].

- What would you like to know about your illness and what may be ahead?
- What kind of information would help you make decisions about your future?
- What is most important for you to have a good quality of life?
- What/who supports you as you deal with your illness?
- Are there kinds of medical care that you do not want?
- Have you thought about sharing these thoughts or other aspects of your illness with your whānau?

We suggest identifying someone who can advocate or make decisions on your behalf if you are too unwell. Have a think about who this person might be for you.

Please bring to the appointment whoever you would like to be a part of this important conversation. It's often helpful to have others there so you can continue the conversation together afterwards.

This is just the beginning of an ongoing conversation. We know that you may have other questions or concerns in the future. We will keep being here to support you and answer your questions so that you can make informed decisions and we can provide you with the very best care for you. If you have questions before your visit, please contact: XXX

## Appendix 2: The Hui Process | Āpitiḡanga 2: Te Tukanga ā-Hui

[The-Hui-Process-A-framework-to-enhance-the-doctor-patient-relationship-with-Maori](#)