



Serious illness conversations: Reference guide for health care professionals

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Acknowledgements

The majority of the content of this guide was drawn from Ariadne Labs. 2016. Serious Illness Care Program: Reference Guide for Clinicians.

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, et al. The Hui Process: a framework to enhance the doctor-patient relationship with Māori. New Zealand Medical Journal. 2011; 124:1347).

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 Commission.

Key ideas for successful discussions about serious illness care

Principles

- The serious illness conversation will reflect the patients 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 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 and participation by significant others/whānau throughout the SICC process and conversation.
- Consider others in the multi-disciplinary team that may be useful to have as part of the serious illness conversation ie: Māori health worker, allied health staff.
- Seek connection with the patient through whakawhanuatanga.
- Give a direct, honest prognosis when requested by the patient. Present prognostic information as a range.
- Allow silence and other reflective practice ie: 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.
- Utilise the 3-step health literacy guide when providing information: Ask, Build, Check (<https://www.hqsc.govt.nz/.../health-literacy-booklet-3-steps-Dec-2014.pdf>).

Do not:

- Talk 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 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. Use 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 ad-lib.

1. Serious Illness Conversation Guide

The backbone of this training, the Serious Illness Conversation Guide, 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 prognosis, exploring key topics, and closing and documenting the conversation.

2. 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 scenarios.

For patients, families and whānau

Pre-visit letter – see Appendix A 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 family and 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 family, whānau and friends about the same topics you bring up with them in your conversations. Like the clinician materials, the whānau communication guide suggest language for the patient to relay information to their family, 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 patient/whānau and/or remind them that it is available.

How the Serious Illness Conversation Guide is organised

Serious Illness Conversation Guide Aotearoa

Stage	Patient-tested language
SET-UP	<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>
ASSESS	<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>
SHARE	<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>Allow silence, explore emotion</p>
EXPLORE	<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>
CLOSE	<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 a meaningful and successful conversation.

Preparing for the conversation

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.

Cultural Safety and Unconscious bias

Cultural safety is based in attitude change. If safe attitudes are held by the practitioner they will be able to work with the continuum of people and cultures within their care. For Māori this may mean whānau members that can provide karakia or spiritual safety, or others that have more experience navigating the health care system and advocate on behalf of the patient and their whānau.

Attached as **Appendix B** is the paper by C Lacey et al - The Hui Process: a framework to enhance the doctor-patient relationship. New Zealand Medical Journal 2011; 124:1347. This paper describes a method of integrating cultural competency practice, specific to Māori, in the doctor-patient relationship

As clinicians we cannot claim to be experts in the culture or realities of others. We can, however, become experts in reflecting on our own culture and attitudes that inevitably shape our practice. Respect and humility lay the foundations for a mutual exchange where the locus of control sits with the patient and their whānau. The practitioner that accepts that their own reality is no more valid than anyone else's, will be the practitioner that can navigate the serious illness conversation.

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 practice
- understands their own assumptions, biases and stereotypes that are held 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

A unconscious bias training resource is being developed by the Commission (expected release date November 2019) will assist you to examine attitudes and stereotypes that affect your understanding, actions and decisions in an unconscious manner. In the interim, here are some resources to support you to assess your bias - www.oranui.ac.nz and <https://www.tolerance.org/professional-development/test-yourself-for-hidden-bias> (Project Implicit).

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 and 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 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.

Prior to 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 ahead, 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 patient/whānau-centred 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 A.

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 the clinical team are here to share their expert clinical knowledge.
- Acknowledge those that are in attendance. Allow time for introductions firstly of those in attendance and then the clinical team.
- Apply the practice of whakawhānauatanga to find familiar ground during introductions to assist with connections (refer to the 'hui process').
- 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.
- Consider engaging a social worker, Māori health clinician/support or other clinician to provide extra support to you or to the whānau in difficult situations.
- Wrap up with an acknowledgment of the whānau importance and appreciation of their engagement in the discussion. Invite someone to close the meeting with a karakia, if applicable.
- Encourage patients and whānau to discuss these issues further and always leave them with a number to contact and clarity around the next steps.

Initiating the conversation with a patient

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

How to initiate the conversation - Mihi and Whakawhanaungatanga

Please refer to the ‘hui process’ for further information.

Welcome the patient and whānau. Offer to start with a karakia, if appropriate. Here is one you could use:

Tu tawa mai I runga (I summon from above)

Tu tawa mai I raro (I summon from below)

Tu tawa mai I roto (I summon from within)

Tu tawa mai I waho (and from the surrounding environment)

Kia tau ai te mauri tu (The universal vitality and energy to infuse and enrich all those present)

Te mauri ora kit e katoa (Unified, connected and blessed)

Haumi e

Hui e

Taiki e!

Invite the patient and 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 name, role in patient’s care and include a personal connection or self-disclosure. The connection should draw on your understanding of Te Ao Māori and relevant patient and whānau beliefs, values and experiences including the patient’s whenua (land) connections, whānau involvements, use of te reo.

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

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	<p><i>“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?”</i></p> <p><i>“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.”</i></p> <p><i>“We want to help you stay in control of decisions about your care, and to support your whānau if</i></p>

		<i>they are asked to be involved in making difficult decisions on your behalf.”</i>
Ask permission	Give the patient control	<i>“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.”</i>

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 patient’s perspective on his/her 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, careful titration of discussion to avoid overwhelming the patient with anxiety, extra emotional support, and ongoing discussion¹.

Discussing information preferences

Clinicians regularly hesitate to provide prognostic information out of concern that it may be harmful to the patient. Patients frequently describe frustration that they cannot get information that they want and need about 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 also to avoid giving information that is not wanted or will be harmful. Knowing that you are providing information that is wanted by the patient will help you feel more confident in opening this part of the conversation¹.

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 hear news they are not expecting and not wanting. It is often useful, when a patient says she 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?”

¹ Bernacki R, Paladino J, Neville BA, et al. Effect of the Serious Illness Care Program in Outpatient Oncology: A Cluster Randomized Clinical Trial . *JAMA Intern Med*. Published online March 14, 2019;179(6):751–759. doi:10.1001/jamainternmed.2019.0077

Bernacki R, Paladino J, Neville BA, et al. Effect of the Serious Illness Care Program in Outpatient Oncology: A Cluster Randomized Clinical Trial . *JAMA Intern Med*. Published online March 14, 2019;179(6):751–759. doi:10.1001/jamainternmed.2019.0077
<https://www.atsjournals.org/doi/full/10.1164/rccm.200806-969OC>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3530838/>

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 titrate 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 the illness.

Discussing prognosis with patients is valuable for several reasons:

- It allows patients and 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 patients to make more informed decisions about medical treatments.
- Patients are generally overly-optimistic about 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	
<p>Key ideas</p> <p>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 for heart, lung, and kidney disease. Patients do not expect precision, but they expect to be given time to prepare for what may come.</p>	<p>Using the time based prognosis</p> <ul style="list-style-type: none"> • Provide prognostic information as a range, without providing too much specificity: Days to weeks, weeks to months, months to years • Acknowledge prognostic uncertainty: <i>“It could be shorter or longer”</i>

Functional prognosis	
<p>Key ideas</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</p>	<p>Following the use of the functional prognosis prompt and pause to allow the patient to process what you have just said, you could</p> <p>Provide information on what is likely and not likely to prove: <i>“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.”</i></p> <ul style="list-style-type: none"> • Support hope:

<p>improve in the future – helps patients understand what their lives will be like in the future, and allows them to make trade-offs that align with their values.</p>	<p><i>“I think we can get you well enough to go home and to spend time with your whānau.”</i></p> <ul style="list-style-type: none"> • Affirm commitment to optimising function: <p><i>“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.”</i></p>
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Unpredictable prognosis	
<p>Key ideas</p> <p>For conditions like advanced heart and lung disease, which can remain stable, slowly deteriorate over time, or bring sudden and life-threatening crises, these scenarios should be communicated to patients. This allows them and their families/whānau to consider their values and preferences within this context, and to prepare.</p>	<p>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 these strategies</p> <ul style="list-style-type: none"> • Provide clear information about potential trajectories: heart disease is unpredictable. <p><i>“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 by some difficult decisions.”</i></p> <ul style="list-style-type: none"> • Use hypotheticals: <p><i>“If your heart failure were to suddenly worsen, you may feel very short of breath and you might need to be hospitalised.”</i></p> <ul style="list-style-type: none"> • Hope for the best, plan for the worst: <p><i>“Even though this is difficult to think about, I am hopeful that you will have a lot of good time ahead and that doing some planning together can help you have a safety net, in case things don’t go as we hope.”</i></p>

The 'wish/worry/wonder' framework

I wish... I worry... I wonder...	
<p>Key ideas</p> <p>'I wish' allows for aligning with the patient's hopes.</p> <p>'I'm worried/concerned' allows you to share your worries.</p> <p>'I wonder' is a subtle way to make a recommendation.</p> <p>Note: NZ consumer testing found many people have a more positive response to the word 'concerned' than the word 'worried'.</p>	<p>Try this strategy</p> <p>Align with patient's hopes, acknowledge concerns, then propose a way to move forward:</p> <p><i>"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."</i></p>

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 expression, body language, the use of psychological defences, and affective expressions (tears, flushing, etc.)
- Anxiety can also be reflected in the clinician's affect. 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 the patient and whānau's anxiety. Pausing before starting this conversation to settle yourself, practicing the Guide, and developing your skills will lower your anxiety, and lead to less stressful and more effective conversation.
- Strong emotion tends to impair cognitive processing.
 - Recognising and acknowledging the patient's (and whānau's) emotions, and allowing the patient and whānau time to process them, allows the patient/whānau to move forward into cognitive processing of the information and making a plan.
 - If the patient is in a crisis (medical or other life crisis), capacity for dealing with anxiety might be diminished. If possible, delay a serious illness conversation until the crisis has passed. If not possible, recognise that you will have to proceed especially gently.
- Difficult conversations should be carefully "titrated" to keep the patient and whānau's anxiety within a manageable range.
- For a number of people feeling connected is one of the strongest antidotes to anxiety. Expressions of empathy (e.g., "*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 whānau some element of control allows the patient to self-titrate anxiety-producing discussion (e.g., "*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.

Talking about family 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 has 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 his/her 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.”

Time to make a plan - poroporoaki

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

1. ensuring that you have understood what the patient has told you
2. ensuring the patient and whānau have understood what you have said
3. agreeing 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.

1. Summarise what you have heard	
<p>Key ideas</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>Try these strategies</p> <p><i>“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?”</i></p> <p><i>“I’ve heard you say that _____ (goals) is important to you. You’ve also shared _____ (fears and worries, sources of strength, critical abilities and trade-offs, family considerations).”</i></p> <p><i>“Keeping all of this in mind, and what we know about your illness, I would like to share a recommendation/a few recommendations with you. Would that be ok?”</i></p>
2. State key considerations and recommendations (the proposed plan)	
<p>Key ideas</p> <p>Make recommendations only after you’ve had a chance to explore patient’s values, goals and priorities.</p> <p>Your recommendation may be:</p> <ul style="list-style-type: none"> • Wellbeing based <ul style="list-style-type: none"> - working towards a goal or planning for a life event - pursuit of a hobby or passion - refer to another service who could support wellbeing • Support system based <ul style="list-style-type: none"> - share information 	<p><i>“Given what you have told me about what is important to you, I suggest we...”</i></p> <p>Wellbeing: e.g. arrange 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 _____</p> <p>...make a plan to support your goal of _____ (life event) OR your pursuit of _____ (hobby, passion)</p> <p>Support System: e.g. ...include _____ (your whanau or other significant people) in a further discussion so we can come up with a plan together</p>

<ul style="list-style-type: none"> - invite whānau/support people to the next appointment - involve other support services e.g. social work/Maori health team etc. <p>• Illness based</p> <ul style="list-style-type: none"> - agree a medical plan that supports goals/reflects what is happening with the illness. - E.g. start/stop/continue current treatment <ul style="list-style-type: none"> • consult with a specialist • start/complete documentation • consider shifting the goal of care to focus on symptom management / a palliative approach • revisit the conversation <p>Note: how you make a recommendation can influence the patient's choice and reaction.</p>	<p>...share _____ (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.</p> <p>Illness: e.g.</p> <p>...revisit your treatment plan and discuss whether or not to:</p> <ul style="list-style-type: none"> - start a new treatment(s) - stop current treatment(s) - continue current treatment(s) - consult with a specialist and/or invite a specialist to our next conversation <p>...consider shifting your goals of care to focus more on symptom management and your comfort. Have you heard of hospice/palliative care before?</p> <p>...complete an/some important document(s):</p> <p>advance care plan</p> <p>goals of care document</p> <p>appoint an EPOA</p> <p>OR</p> <p>...revisit this conversation later today/tomorrow/next week/at our next appointment</p> <p><i>“this will help us make sure your care focuses on what is important to you”</i></p>
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If timing is right for a conversation about resuscitation [status]

Key ideas

Discussion of resuscitation status should always follow a broader discussion of prognosis, and values and goals.

Patients are often overly optimistic about the outcomes of CPR.

In-hospital CPR survival, overall:¹

- immediate survival: 30–45%
- survival to discharge: 11–17%.

The above statistics haven't changed in 40 years.

In-hospital CPR survival for cancer patients:²

- overall survival to discharge: 6%
- localised disease: 10%
- metastatic: 5%.

A clinical decision not to offer an intervention like CPR can make patients feel abandoned. Using strong language assures the patient of all the things you will do (eg, intensive symptom control, emotional support for them and their whānau, etc).

Try these strategies

- **Introduce the concept of a resuscitation decision in the context of their values and prognosis:**

"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."

- **Explore patient understanding about CPR:**

"One of the questions we should figure out is whether cardiopulmonary resuscitation makes sense for you. What have you heard about CPR?"

- **Describe CPR:**

- Correct misunderstandings.
- Describe what it is, the risks and benefits, and possible outcomes.
- Share data about possible outcomes (if desired).

"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% – and even those who can be brought back initially have to be kept alive on breathing machines and almost never leave the hospital."

- **Make a recommendation consistent with patient's prognosis and preferences:**

"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 you have as much time as possible with your whānau, and on getting you home."

- **Check for patient agreement:**

"How does this plan sound to you?"

- **Emphasise the care that will be provided to the patient:**

"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."

- **Do not say "We will just give you comfort care."**

- **Do not offer CPR if it's not clinically indicated:**

Inform patient they are not a candidate for CPR because it will not be effective and ask them to affirm your decision.

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:

Kia whakairua te tapu

Kia wātea ai te ara

Kia turuki whakataha ai

Kia turuki whakataha ai

Haumi e

Hui e

Tāiki e!

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.

Managing the conversation – 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 patients on track	
<p>Key ideas</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 time frame, if reminded.</p>	<p>Try these strategies</p> <ul style="list-style-type: none"> • Acknowledge that this is a tough conversation, and gently bring patient back to topic: <i>“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.”</i> • Remind patient of time constraints: <i>“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.”</i> • Interrupt gently: <i>“Mrs. Smith, I wonder if we could get back to my question about your priorities if time is getting short.”</i>
Managing your time	
<p>Key ideas</p> <p>Some questions can be effectively handled by other members of the team, but <i>prognosis should not be delegated</i>.</p> <p>The conversation can still be effective when spread over several visits.</p>	<p>Try these strategies</p> <ul style="list-style-type: none"> • Delegate some questions to other members of the team, as appropriate. • Consider going through two questions per visit. • Make sure everyone documents the discussion.
Documenting the conversation	
<p>Key ideas</p> <p>Avoid using the computer while talking to the patient.</p>	<p>Try these strategies</p> <ul style="list-style-type: none"> • Make notes on the guide if you need to remember specific things patient says. • If you must document while talking, make frequent eye contact with patient.

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.

Patient says: 'I don't want to talk about it'	
<p>Key ideas</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.</p> <p>Many patients are unsure about receiving information. They may want it but be scared of what they will hear.</p> <p>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"> • 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. • Patient needs more support (eg, from a family/whānau member) to address these issues. • This is a bad time because of other difficult events/stressors (eg, symptoms, other life stressors). • Patient has an anxiety disorder that makes it difficult to tolerate the anxiety of a discussion. 	<p>Try these strategies</p> <ul style="list-style-type: none"> • Explore patient's reasons for not wanting to discuss this: <i>"Help me understand the reasons you would prefer not to talk about this."</i> • Elicit information about how patient thinks about planning for the future: <i>"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."</i> • Ask about the positives and negatives of discussing these issues. • Remind patient that the aim is to initiate discussion, not to make decisions. • If patient is unsure, acknowledge or name the ambivalence – also how difficult the situation is: <i>"I hear you saying you know it is important to do some planning and also that you worry this process will be too overwhelming."</i> • If patient expresses intense anxiety about dying, explore specifics or consider referral to palliative care. • Use 'I wish' statements (eg, <i>"I wish that things were better so we didn't need to talk about this"</i>) • Inform patient that you will bring this up at a subsequent visit; delaying the conversation until more support is available can help. • Acknowledging patient stress and a plan to return to these issues later can be helpful. • If patient expresses more global anxiety, explore patient's experience of anxiety in a non-threatening way and consider mental health referral: <i>"Do you often find yourself overwhelmed with worries?"</i>

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 patient focus on additional hopes beyond survival.

Consider strategies to reduce anxiety (eg relationship building, encouragement of including 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 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 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 patient 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 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."

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 patient's condition is stable, let them know that decisions are not urgent and encourage them to talk with their whānau.

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.

Try these strategies

- **Reassure patient 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."

Let patient know you will bring this up again.

- **Encourage discussion with whānau:**

"These can be difficult decisions and it can be useful to involve your whānau. I'd encourage you to talk about it with your whānau and then we can discuss it again at your next visit."

- **If patient is declining rapidly, acknowledge this and focus on providing care aligned with patient wishes:**

"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."

Patient expresses intense emotion (tears)

Key ideas

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.

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'.

Titration based on patient responses with gentle guidance allows forward movement without the patient being overwhelmed.

Sometimes, backing off is a good temporary strategy. Stay calm.

Patients are often frightened of alienating their health care team by crying – acknowledging the emotion and staying present in the conversation can mitigate this.

Most people feel better when they have a chance to express feelings.

Try these strategies

- **Allow silence for patient to express feeling.**
- **Name the feeling.**
- **Provide non-verbal support.**

(Eg, eye contact, open body language, nodding and non-verbal encouragers, providing tissues or putting a hand on a shoulder.)

- **Ask patient to describe what the tears are about:**

"Help me understand what is making you so sad/upset/scared."

- **Explore feelings:**

"Tell me more."

- **Express empathy:**

"I am sorry that this is so sad/upsetting/scary for you."

- **Provide support and encouragement:**

"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."

- **Obtain permission to proceed:**

"Can we see if we can talk a bit more about this?"

- **Negotiate where to next:**

"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?"

- **If emotion is very intense and persistent, explore whether a mental health referral would be helpful.**
- **Avoid giving false or premature reassurance to contain patient distress.**
- **Avoid offering information that is not explicitly sought.**

Patient expresses anger

Key ideas

Stay calm.

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.

Try these strategies

- **Acknowledge the anger, being careful not to minimise or change the intensity:**

“You sound very angry.”

- **Explore what is making patient angry:**

“Tell me what is making you angry?”

- **Acknowledge the anger non-defensively. Empathise with patient’s situation if appropriate:**

“I can see you are really angry and are feeling let down that the chemotherapy hasn’t worked as we had hoped it would.”

- **‘I wish’ responses can be helpful:**

“I wish this cancer had responded to the treatment too.”

- **As patient talks about the reasons they are angry, look for ‘transition’, ie, a point where the anger reduces and other feelings become more prominent. These might be feelings of sadness or loss.**

- **Once other emotions are present, acknowledge and explore these.**

- **Allow patient an opportunity to explore what it means to them to be talking about these end-of-life issues:**

“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?”

- **Encourage patient to say what is on their mind:**

“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.”

Patient is reluctant to stop 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 disease-modifying treatment.

Patients may not want to stop treatments that are directed at their underlying disease because they fear loss of 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 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 patient understanding, as this information may be counterintuitive to patients.

- **If clinically indicated, make a clear, direct recommendation against further disease-modifying treatment.**

- **Reassure patient 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 priorities for your care become managing your symptoms.”

- **Don’t say you can reconsider disease-modifying treatment later if you can’t.**

Talking about family involvement

Key ideas

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

Family/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 has 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 his/her 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 A - Preparing the patient for the conversation: A script for a pre-visit conversation or letter

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 or letter that you can adapt to your own style:

At your next appointment, [Dr's name] would like to talk with you about your illness and some of the things that are particularly important to you, so 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 whanau before your appointment with [Dr 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 whanau?

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 having 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 B – Hui Process

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