



Responding when a person raises assisted dying

A handbook for registered health
professionals

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2021

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About this handbook

This handbook is to help health professionals respond respectfully and appropriately when a person and/or their whānau raises the subject of assisted dying.

Purpose

This handbook is to help health professionals respond respectfully and appropriately when a person and/or their whānau raises the subject of assisted dying. The handbook is not a resource to assess a person's eligibility. It contains an overview of the assisted dying conversation guide and strategies for common scenarios.

The handbook is **not** intended for use with patients.

Background

This handbook was developed in partnership with clinicians and consumers to prepare health professionals for the implementation of the End of Life Choice Act 2019 from 7 November 2021.

The development of this handbook, and the fundamentals embedded in the assisted dying conversations it supports, have been shaped by the principles and articles of Te Tiriti o Waitangi and the Ritenga Māori declaration, and the principles of co-design.

Chapter 1:

Introduction

Health professionals working with patients and whānau may be approached by someone wanting to know about assisted dying. These conversations may take the form of a direct request for assistance to die or a 'testing of the waters' using phrases and euphemisms that suggest a wish to discuss the topic further.

Health professionals may feel uncomfortable or unsure about how to respond in such situations. They may feel inadequately prepared or worried they might say 'the wrong thing'. They may also feel concerned about the legal requirements relating to talking about assisted dying and their responsibilities under the **End of Life Choice Act 2019** (the Act).

If unprepared, health professionals may close down the conversation, leaving the person and whānau feeling unheard, frustrated or worried. Shutting down a conversation before exploring what is prompting the request may also mean the health professional loses the opportunity to understand the reasons the person is asking and explore whether there are also other supportive measures available to relieve any distress and suffering.¹

It is important health professionals are prepared to respond with respect and compassion if assisted dying is raised, regardless of personal views. This handbook is designed to support health professionals when responding to an initial request; it is not intended to be used to assess a person's eligibility. It contains an overview of the assisted dying conversation guide and strategies for common scenarios.

This handbook is NOT intended for use with patients.

¹ Findings from focus groups and co-design workshops held in July 2021.

The End of Life Choice Act 2019

The Act gives competent adults experiencing unbearable suffering from a terminal illness the option of legally requesting medical assistance to end their lives. This is known as 'assisted dying'.

The Act comes into force on 7 November 2021. Until this date, assisting someone to die is a criminal offence under section 179 of the Crimes Act 1961.

The Act defines assisted dying as follows:

assisted dying, in relation to a person, means:

- (a) the administration by an attending medical practitioner or an attending nurse practitioner of medication to the person to relieve the person's suffering by hastening death
- (b) the self-administration by the person of medication to relieve their suffering by hastening death.

Assisted dying is not a replacement for palliative care or health care services more generally. It gives another option to people with a terminal illness in certain circumstances.

Eligibility for assisted dying

The Act gives a person the option to request assisted dying. However, they must meet strict and specific criteria to be eligible. Not everyone with a serious illness will be eligible for assisted dying.

To be eligible, a person **must meet all** of the following criteria:

- be aged 18 years or over
- be a citizen or permanent resident of New Zealand
- suffer from a terminal illness that is likely to end their life within six months
- be in an advanced state of irreversible decline in physical capability
- experience unbearable suffering that cannot be relieved in a manner that the person considers tolerable
- be competent to make an informed decision about assisted dying.

A person cannot receive assisted dying solely because they are suffering from a mental disorder or mental illness, have a disability or are of advanced age.

A person cannot use an advance directive² to request assisted dying. Assisted dying can only be requested by the person wanting the intervention for themselves. It cannot be requested or consented to by an enduring power of attorney for health and welfare.

Both the medical practitioner treating the person and a second, independent, medical practitioner must agree the person is eligible for assisted dying. If either medical practitioner is unsure of the person's competence to make an informed decision, a psychiatrist must also assess the person to confirm their eligibility. If the opinion is reached that the person is not eligible, the process ends.

Providing assisted dying services

The Act outlines the high-level process for providing assisted dying services. This process explains certain steps that include medical practitioners, psychiatrists, pharmacists and nurse practitioners. If you are in one of these professions, you may wish to consider if you are willing to be part of this process.

Some medical practitioners will not offer assisted dying services due to lack of competency (that they don't have the skills or training to offer services) or due to their conscientious objection.

Obligations for medical practitioners (doctors) who conscientiously object

Medical practitioners (doctors) do not have to be involved in providing assisted dying services if they have a conscientious objection.

Regardless of personal beliefs, they should still meet professional standards to ensure continuity of care is maintained for the person and access to lawful medical treatment is not being inhibited.

If a medical practitioner with a conscientious objection is asked by a patient about assisted dying, in addition to their professional duty of care, they have certain responsibilities under the Act. They must:

- inform the person of their objection
- tell the person they have the right to ask the Support and Consultation for End of Life in New Zealand (SCENZ) Group for the name and contact details of a medical practitioner who is willing to participate in assisted dying.

Other health professionals with a conscientious objection can follow these steps but they are not legally required to disclose their conscientious objection.

² An advance directive is consent or refusal of specific treatment that may or may not be offered in the future when the person consenting/refusing no longer has capacity to consent/refuse.

Background to the assisted dying conversation resources

The Ministry of Health has been working with clinical communication experts to develop education resources and conversation tools to help health professionals respond appropriately and respectfully when a person and/or their whānau raises the subject of assisted dying (ie, the initial conversation).

Focus groups with health professionals

In July 2021, virtual focus groups were held with health professionals from around the country to explore how they felt about their ability to respond if a person were to ask about assisted dying, and what tools/resources they felt were needed to support assisted dying conversations.

This is what we heard from the focus groups:

- the majority of participants reported feeling apprehensive and nervous about the Act coming into force
- they were worried about supporting patients and whānau safely, appropriately and respectfully when asked about assisted dying, particularly if they were not supportive of assisted dying or if they conscientiously objected
- they wanted to make sure they gave people the right information and that it was consistent with the messaging shared across the health system
- the legislative requirement that assisted dying cannot be raised by health professionals and must be initiated by the patient creates an extraordinary situation in health – this raised concern with many of the participants in the focus groups for a variety of reasons:
 - some worried they might be caught off guard by the question and their own anxiety or personal views may impact how they responded
 - some were concerned they might panic and jump straight into giving information about the assisted dying process, rather than exploring what is making the person ask about it, and that this might compromise good care
 - some felt this restricted their ability to discuss end-of-life care and options for treatment without being perceived as suggesting assisted dying.

Health professionals asked for tools and learning resources to help them prepare for these discussions and cover the legal requirements of the conversation.

Co-design workshops

Following the initial focus groups, four co-design workshops and two further focus groups involving consumers and health professionals were held in July and August 2021.

The workshops explored how consumers wanted to feel when they raised assisted dying with health professionals. The phrases below reflect some of what we heard:

Acknowledged.

Listened to.

Heard.

It's important that we don't feel rushed.

It's important we feel safe.

Trust is vital.

We don't want to feel uncomfortable.

We need to feel we have rapport.

We need to feel the conversation or responses are non-judgmental.

We don't want to feel embarrassed.

We need opportunities to explore options.

Taken seriously and not fobbed off.

It can feel uncomfortable and scary breaking the ice and bringing this up with somebody.

If you spoke to someone who didn't support assisted dying, you would want to make sure that you were responded to in a way that did not feel disrespectful – you need to feel respected for raising the issue.

'You don't want to do that' needs to be avoided.

We don't want to feel shamed.

We want to be taken seriously and supported.

We would not want to feel 'blocked'.

The language to be used in the assisted dying conversation guide was developed and agreed at the co-design workshops.

This handbook was also informed by what we heard at all focus groups sessions and co-design workshops.

Chapter 2:

Fundamentals of quality assisted dying conversations

The person asking about assisted dying, and their whānau, must be supported during and after assisted dying discussions. This section outlines the fundamentals of what health professionals must do to respond respectfully and appropriately when assisted dying is raised by consumers.

The fundamentals are informed by the three articles of Te Tiriti o Waitangi and the Ritenga Māori declaration:³

- Kāwanatanga – care and treatment is informed equally by the person and their whānau and health care providers in a relationship modelled on shared decision-making, a relationship where power is shared.
- Tino rangatirota – recognising Māori authority and autonomy over their lives, self-determination. Mana motuhake – enabling the right for Māori to be Māori, to exercise their authority over their own lives and to live on Māori terms and according to Māori philosophies, values and practices.
- Ōritetanga – ensuring equity for Māori by undertaking specific actions to ensure access and equitable outcomes, enhancing the mana of people over their life course and contributing to the overall health and wellbeing of Māori.
- Wairuatanga – prioritising Māori world views, values and belief systems (what is important to whānau) into care and treatment planning, in ways that enable Māori to live, thrive and flourish as Māori.

³ Sometimes also called the 'fourth article', the 'forgotten article' or the 'oral article'.

The fundamentals to ensure assisted dying conversations are respectful, safe and person-centric

1. Health professionals are prepared to respond respectfully and appropriately when assisted dying is raised. This requires:
 - a. personal reflection – consider what their own views are about assisted dying and reflect on how those views might impact on how they would respond when assisted dying is raised
 - b. building knowledge – know the facts about the Act including their role and responsibilities; understand the criteria for eligibility; know what their organisation’s policy is on assisted dying and what the organisation expects of them; know who can support the person raising assisted dying if the health professional is unable to; and know where to receive support
 - c. confidence – health professionals can practise responding before they are asked about assisted dying; other members of their team or organisation can help them think about what to say and explore different scenarios that might come up.
2. Assisted dying conversations are culturally safe.
3. Requests to discuss assisted dying are responded to in a timely manner and any obstacles are removed.
4. Assisted dying discussions take place in appropriate environments to maintain the privacy and dignity of the person raising assisted dying.
5. The person asking about assisted dying has those they want to have with them for the initial discussion/s, recognising that the formal assessment process requires that some discussions occur with the patient only.
6. The assisted dying conversation guide is used to support the conversation. The guide is designed to ensure health professionals cover the key aspects of the conversation in an empathetic and evidence-based way.
7. Health professionals seek to understand what is driving the request including exploring the person’s values and needs.
8. The person asking about assisted dying is supported to make an informed decision. Health professionals support the person to consider all options for end of life care and treatment as part of the assisted dying pathway.
9. Assisted dying discussions are documented in the clinical record.
10. Health service providers ensure that governance systems, organisational culture and structures support assisted dying conversations.

Overview of assisted dying resources

For health professionals

1. **Assisted dying conversation guide**

The guide is designed to support an initial conversation in response to a person asking about assisted dying. The focus of the initial conversation is to:

- acknowledge the request
- explore the person's understanding of the Act, their current and likely future health
- understand what has led the person to ask about assisted dying including what their priorities are and what they are worried about
- explain what the first steps in the process are
- make a plan and ensure continuity of care.

The conversation guide is not designed to be used as part of the formal assessment process.

2. **Responding when a person raises assisted dying: A handbook for health professionals**

This document, which is designed to support health professionals to use the conversation guide and navigate the wider aspects of initial assisted dying conversations.

3. Guidance and training resources available on the **Ministry's website** and **LearnOnline**.

For patients and whānau

The Ministry of Health produces information sheets for the public about the Act and how it will be introduced and implemented, which are updated regularly. These can be found on **the Ministry's website**.

Chapter 3:

Overview of the assisted dying conversation process

PREPARE		Personal reflection Build knowledge Gain confidence Have resources at hand
		Person raises assisted dying
RESPOND TO THE PERSON	SET-UP	Acknowledge the request – clarify reason for asking Check if they want anyone else with them
		Person considering it as an option Person looking for general information
		Consider if this is the right time and place to talk Let them know if you do not provide assisted dying services
	ENQUIRE and SHARE	Explore illness understanding Explore understanding of assisted dying State the Act has very specific criteria Let them know they will need a formal assessment
	EXPLORE	What their priorities are What worries them What gives them strength What their whānau know
	CLOSE	Summarise what you have heard Discuss supportive measures If they wish to proceed with assisted dying
		Arrange further discussion/first assessment Tell of options for accessing assisting dying, including list held by SCENZ Group
AFTER		Document Follow-up Debrief

Chapter 4:

Preparing for assisted dying conversations

Health professionals must be prepared to respond respectfully and appropriately when assisted dying is raised. This requires:

- personal reflection – consider what their own views are about assisted dying and reflect on how those views might impact on how they would respond when assisted dying is raised
- building knowledge – know the facts about the Act including their role and responsibilities; understand the criteria for eligibility; know what their organisation’s policy is on assisted dying and what the organisation expects of them; know who can support the person raising assisted dying if the health professional is unable to; and know where to receive support
- confidence – health professionals can practise responding before they are asked about assisted dying; other members of their team or organisation can help them think about what to say and explore different scenarios that might come up.

Self-reflection

Assisted dying is a sensitive topic and may be difficult for some people. When a person talks directly or indirectly about a desire to hasten death it can provoke a strong reaction. It is important to recognise our own feelings and reactions to the topic of assisted dying. Taking time to consider our own beliefs and understand our own preferences can reduce the likelihood of influencing the conversation with our own opinions, values, cultural orientations and beliefs.

Before being asked about assisted dying and needing to respond, it is a good idea to have thought through some of our own thoughts and responses.

Here are some things to consider:

- How do you feel about assisted dying?
- Do you know what matters most to you and your whānau, particularly if your health were to change?
- What tikanga (customs) and kawa (ceremonies) support your wellbeing?
- How does talking about death and dying make you feel?

- What choices would you make for your own future health care?
- What are your views on suffering?
- What do you draw on for inner strength and to sustain resilience?
- Are you able to talk to your whānau about your preferences?

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

The Health Quality & Safety Commission has developed a series of education videos that can help us reflect on our unconscious bias, available on the **Health Quality & Safety Commission's website**.

Build knowledge

- Know the Act – see chapter 1. Refer to the **Ministry of Health website** for more information, and complete the End of Life Choice Act 2019: Overview e-learning module in **LearnOnline**.
- Understand the eligibility criteria – see chapter 1. Refer to the **Ministry of Health website** for more information, and complete the End of Life Choice Act 2019: Overview e-learning module in **LearnOnline**.
- Know your organisation's policies and procedures relating to assisted dying, including roles and responsibilities.
- Know who to rely on for support with these conversations.

Cultural considerations

To effectively support culturally safe conversations, we need to be aware of cultural diversity and to be able to function effectively and respectfully when working with people from different cultural backgrounds. Cultural differences can impact on the quality of communication and impact consumer–health professional relationships. Poor engagement between consumers and health professionals is associated with poor outcomes for both. When having assisted dying conversations with people from different cultural backgrounds, take time to understand their communication and support needs. This will help everyone to form good relationships and have better outcomes.

The Act states that the decision to receive assisted dying must be the individual's. If collective decision-making is important to the person, the function of the wider whānau in that decision-making process should be supported and respected.

Working with whānau Māori

A conversation about assisted dying with people who identify as Māori should ideally begin with an understanding of the person's position within their whānau and community, and of their whānau connection to both place (where people come from and where they currently live) and to people (with whom they are connected and 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 professionals not only to think about Māori who present in terms of cultural context, but also as part of a collective. Like other Indigenous populations worldwide, Māori experience historical, cultural and socioeconomic deprivation that impact 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 tīpuna (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 safe space can be created for therapeutic relationships to develop and mana motuhake (self-determination) to flourish.

The Hui Process

The Hui Process is a method of integrating cultural competency into clinical practice to enhance clinician–consumer relationships in support of Māori health gains.

You may find it helpful to review the following:

- New Zealand Medical Association: **The Hui Process: a framework to enhance the doctor-patient relationship with Māori**

The Hui Process framework

The Hui Process was developed at the University of Otago and draws on mātauranga Māori (traditional knowledge) and practice, and aligns them in a contemporary setting to enhance health professional's ability to work effectively with Māori.

The Hui Process set out below 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 conversations, not only those with Māori.

Using the Hui Process for all consultations will support cultural safety for Māori who raise assisted dying as the kaupapa or reason for the visit.

1. **Mihi – the initial greeting and engagement**
Introduce yourself, describe your role and confirm that the person identifies as Māori. Ask about and agree on the purpose of the consultation. This is when the person might raise assisted dying.
2. **Whakawhanaungatanga – making connection**
Based on traditional Māori protocol, whakawhanaungatanga involves connecting with the person and their whānau on a personal level often through connections with whenua, whānau involvements or the use of te reo Māori. This often requires some sharing of yourself. Include all whānau with the person.
3. **Kaupapa – attending to the main purpose of the encounter**
Here, the focus moves to the clinical task at hand, ie, having the assisted dying conversation. You can use the assisted dying conversation guide to support this.
4. **Poroporoaki – concluding the encounter**
Clearly identify the finishing point of the consultation and make it clear what the next steps are for the person and their whānau, and yourself. There are three parts to the poroporoaki:
 - ensure you have understood what the person and their whānau have said
 - ensure the person and their whānau understand what you have said
 - 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, including talking about assisted dying.

Preparing the environment

Whatever the setting or circumstance, efforts should be made to have conversations about assisted dying in an appropriate environment. Keeping in mind that you may not know that a person will raise assisted dying with you, consider the following for all consultations and conversations:

- ensuring privacy
- if the person wants their whānau to be present, ensuring you have a space that can accommodate that
- ensuring accessibility, for example, ensuring wheelchair access
- setting aside enough time for the discussion so people do not feel rushed
- preventing interruptions.

Familiarising yourself with the assisted dying conversation guide

Refer to *Responding when a person raises assisted dying – Conversation guide for registered health professionals* when reading the following section.

Left-hand side: Conversation flow

This part of the guide will help assisted dying conversations flow and ensure health professionals complete the key steps of a successful conversation in an intentional sequence.

Right-hand side: Suggested language

These words have been co-developed by consumers and health professionals; they are aligned with the conversation flow for easy reference. Using these words will help to ensure a meaningful and successful conversation.

The guide can also support health professionals who do not provide assisted dying services. There may be a number of reasons a health professional does not offer assisted dying:

- they are a nurse or allied health professional and are not able to offer assisted dying under the Act.
- they are a doctor who does not have skills or experience in assisted dying
- they are a doctor with a conscientious objection.

Practise how to respond

- Try saying the words out loud.
- Try role-playing a conversation with a colleague.
- Practise a few times before being asked about assisted dying – this will help to feel more prepared, even though you may not know the person is going to raise the topic with you.

Chapter 5:

Responding when a person raises assisted dying

Initial response when the person raises assisted dying

Treating people and their whānau with respect, integrity and dignity is at the heart of all therapeutic relationships. This chapter discusses how to do that in the context of conversations about assisted dying.

The person will need to raise assisted dying. They may raise it as part of an existing appointment or have made an appointment specifically for this discussion.

If it is not clear that the person is asking about assisted dying, ensure that is what they are asking about before proceeding. You cannot clarify this by asking them whether they want to talk about assisted dying.

A person sharing they 'want to die', 'are ready to die' or 'are ready to join their tīpuna' are examples of what people might say that would need further clarification.

Prompt	Purpose	Suggested language
The person hints or it seems like they might be asking you about assisted dying but it is not explicit	Acknowledge their question Clarify what they are asking about To meet the legal requirements of the Act remember you cannot ask if they are asking about 'assisted dying/euthanasia/assisted suicide'	<i>'Thank you for bringing this up with me. Could you help me understand what you are asking me?'</i> <i>'I do need to be very clear what you are asking me, could you tell me more?'</i>

Using the assisted dying conversation guide

Set-up

When a person raises assisted dying, acknowledge their questions and clarify if they are asking for general information or if they are asking for assisted dying for themselves.

Be prepared to respond to this question even if you do not have a copy of the conversation guide available.

Prompt	Purpose	Suggested language
The person asks you about assisted dying	Acknowledge their question Clarify the reason they are asking about assisted dying	<i>'Thank you for bringing this up with me. Are you asking for general information or do you want to talk about assisted dying for yourself?'</i>

If the person is asking for general information, acknowledge the request and clarify with them how they would like to receive the information. This could be:

- instructions on where to find information online on the **Ministry of Health website**
- printing off information sheets from the **Ministry of Health website** for the person.

Be mindful that some people may not have access to web-based resources. You may need to print them hard copies of the resources for them.

Prompt	Purpose	Suggested language
The person is wanting general information about assisted dying	Provide resources in the most useful/accessible format for the person	<i>'There are a number of resources available which explain assisted dying. Would you like me to give you some information or can I direct you to where you can find information online?'</i>

If the person wants to talk about assisted dying for themselves, before you use the prompts in the conversation guide, consider if this is the right time for the conversation.

Do I have the time for an effective conversation?

The person may have brought this up at the end of a consultation, or as part of another conversation (eg, a serious illness conversation). In order to do the conversation justice, you might need to postpone it until you have some dedicated time. It is important to avoid unnecessary delays, which may have a negative impact on the person receiving appropriate support or being able to access the intervention if that is their wish.

'This is an important conversation for us to have, and I want to make sure we have enough time; can we make an appointment for... /can I come back and see you [this afternoon]?'

Am I able to give my full attention to this conversation?

You may be in a situation where you are liable to be interrupted, or distracted with other things, which means you are unable to be fully present and focused. If this is the case, it might be preferable to arrange another time for this conversation – you may need a few minutes to offload your pager or you may need to arrange an appointment for a future time. Remember to avoid unnecessary delays.

'This is an important conversation and I want to be able to give you my full attention; can we make an appointment for... /can I come back and see you [this afternoon]?'

Am I the right person to be having an assisted dying conversation with them?

People are likely to bring up assisted dying with the health care staff they feel most comfortable with – this may not always be the person who is best placed to have an effective conversation with them. To avoid causing delays and potential frustration for the person, they should not be passed on to multiple people. Find out the best person for them to talk to and arrange for this as soon as possible.

'This is an important conversation and I want to help you talk to the best person to support you; may I suggest talking to your GP/can I arrange for your doctor to come and see you?'

Is the person asking likely able to engage emotionally and cognitively with this conversation right now?

The person asking is not necessarily going to know the extent of the conversation you would intend to have with them (using the conversation guide) or the potential emotional impact on them. For example, they may raise assisted dying following delivery of a poor prognosis, when they may be emotionally drained or less able to think clearly about their priorities. If you suspect the person has a reduced ability to engage with the conversation at this time, explore this with them and support them to decide the best time to talk about assisted dying. If the conversation is to be postponed, remember to avoid unnecessary delays.

'This is an important conversation, and it will involve some exploration. I just want to check that you have the energy to continue now?'

Is this the right environment (or do we have access to the right environment)?

If you are in a shared space, consider if you are able to move to a place with privacy, that will accommodate the person and whānau (if present). If not, you may need to arrange another time and place for the conversation. Remember to avoid unnecessary delays.

'This is an important conversation, and I'd like to be able to offer you some privacy; can I see if I can arrange a room for us? I'll come back to you shortly.'

When you continue the conversation, use the conversation guide prompts. This will help you keep on track while listening actively to the person.

At the beginning of 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.'

If you do not provide assisted dying services, it is important to tell the person early in the conversation. The person can then decide whether they want to continue talking to you. Ensure you also tell the person that you are able to direct them to people who do provide assisted dying services.

Prompt	Purpose	Suggested language
The person wants to talk about assisted dying for themselves and you do not provide assisted dying services	If you do not provide assisted dying services, let the person know at the start of the conversation. You are required to provide the reason you do not provide assisted dying services. This allows the person to decide if they want to continue to have the conversation with you or would like to have it with someone who does offer the service	<i>'I don't provide assisted dying services, because ... only doctors can provide that'</i> OR for doctors <i>I do not have the skills/experience to do that</i> OR <i>I have a conscientious objection ... but I am able to direct you to people who do'</i>

Regardless of whether you provide assisted dying services or not, you should attempt to explore what has prompted the request to talk about assisted dying. Understanding this will inform what additional supportive measures could be offered.

Ask permission to explore what has prompted the request to talk about assisted dying and provide an opportunity to have a support person present.

If the person does **not** want to continue talking to you, please acknowledge that and offer to support them to continue the conversation with someone else.

CHOOSE ONE

'I can put you in touch with someone who does provide assisted dying services'

OR if you are a doctor with a conscientious objection you are required to say:

'The SCENZ Group (Support and Consultation for End of Life in New Zealand Group) holds a list of doctors who provide assisted dying services. You can contact the SCENZ Group via 0800 223 852 to get the name and contact details of a doctor who can help you.'

Prompt	Purpose	Suggested language
You offer assisted dying services or you have told the person you do not offer services	Explain that you do want to understand what has prompted them to ask about assisted dying and ask for their permission to ask some questions	<i>"I would really like to understand what is going on for you. Would it be okay if I ask you some questions?"</i>
	Provide an opportunity for the person to have a support person/persons present A person may decide they do want support or that they would prefer to continue by themselves	<i>'This is an important conversation. Is there anyone else you would like here with you?'</i>

Enquire and share

Assessing the person's understanding of their illness

It is important to gain an understanding of the person's perspective of their illness because this allows a health professional to assess any discrepancies or gaps in the person's understanding and medical reality.

In the context of an assisted dying conversation, a person's and whānau's understanding and expectations of the person's condition and situation may be well aligned with medical realities or there may be discrepancies. If discrepancies exist and it is within your scope of practice, you may wish to add any missing information about current and future health.

Assessing the person’s understanding of assisted dying

There are very strict criteria a person must meet to be eligible for assisted dying. It is useful to understand if the person is aware of the criteria and to let them know they will need to be formally assessed.

“Could you tell me what you know about assisted dying?”

Prompt	Purpose	Suggested language
The person has shared their understanding of the Act	If they demonstrate an understanding of the criteria, confirm that the Act has very specific criteria and that they will need to be formally assessed	<i>‘You’re right, the Act does have very specific criteria and not everyone with a serious illness will be eligible for assisted dying. You will need to be formally assessed to determine if you meet all the criteria’</i>
	If they are unsure or unclear tell them the Act has very specific criteria and they will need to be formally assessed	<i>‘The Act does have very specific criteria and not everyone with a serious illness will be eligible for assisted dying. You will need to be formally assessed to determine if you meet all the criteria.’</i>

You are not required to perform an eligibility assessment as part of this conversation – the formal assessment is part of **section 11 onwards of the End of Life Choice Act 2019**.

Discussing the criteria with the person is complex and should ordinarily be avoided as part of this conversation. You should only discuss the criteria with the patient if that is what the patient wants AND you are competent and confident to do so.

Prompt	Purpose	Suggested language
You have stated that the Act has specific criteria and that they will need to be formally assessed but the person wants to know more about the criteria or about their eligibility from you.	Explain that the criteria is best discussed as part of the formal assessment process, and that they can find out more about the criteria in the Ministry of Health information if they wish.	<i>‘I’m not in a position to be able to go through the criteria with you – this is best done as part of the formal assessment process. However, you can find more information about the criteria in the Ministry of Health information if you wish.’</i>

If the person clearly does not meet the eligibility criteria

During the co-design workshops, consumers told us it is important that these conversations are transparent and health professionals are honest with them. If a person very clearly does not meet eligibility criteria, they wanted to be told early in the process. They did not want health professionals to foster false hope or suggest further assessment if the health professional knows it would not be successful.

If you feel clinically competent and confident to determine that the person very clearly does not meet the criteria, you should tell the person this to avoid the distress of unnecessary assessments and fostering false hope.

Prompt	Purpose	Suggested language
The person is considering assisted dying for themselves and they very clearly do not meet the eligibility criteria	Explain why they are unlikely to meet the criteria	<i>'Currently you do not meet the criteria because you [state criteria]'</i>
	This may be difficult news for the person to hear – allow silence and explore emotion.	<i>'I know this might not be what you wanted to hear.'</i>
	Acknowledge the person's response and let them know that there are other options for care aside from assisted dying	<i>'To help me understand how I can provide the best support for you, given that you don't meet the criteria, I have a few other questions, is that okay?'</i>

Explore

The 'Explore' section of the guide includes four questions to help you learn more about the person's priorities and worries, what gives them strength and how much their whānau know about what is most important to them.

'What are your priorities as you approach the end of your life?'

'What worries you when you think about your health changing?'

'What helps you through the tough times?'

'How much does your whānau know about what is most important to you?'

The person's responses to these questions may help you understand why they are considering assisted dying for themselves and identify applicable supportive measures/end-of-life-care options to discuss in the final part of the conversation process.

Close

Time to make a plan

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

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

Summarise what you have heard

Key ideas

Thank the person for sharing their thoughts with you.

Summarise what you have heard. This supports the person to feel heard and allows you to check you have understood what is important to them.

"I have heard you say ... is really important to you". I have also heard you say you're considering assisted dying."

Discuss supportive measures/end-of-life-care options

Key ideas

Discuss potential supportive measures/end-of-life-care options.

Note: If a person does choose to proceed with the assisted dying process, their assessing doctor must ensure the person understands their other options for end-of-life care. Providing options/additional supportive measures during this conversation may help reduce any symptoms they are experiencing now and support them to meet this requirement when being assessed in the future.

'Keeping that in mind, we can... [discuss applicable supportive measures].'

Supportive measures may include:

- palliative care
- symptom management
- psychological support/counselling
- further medical assessment and consideration of interventions
- referral to another health professional or service
- advance care planning
- further conversation.

If the person might want to proceed with assisted dying

Key ideas

Discuss the next steps in the assisted dying process.

How you approach this part of the conversation will depend on your role, your training in assisted dying or the legal requirements if you are a doctor who has a conscientious objection to assisted dying.

"If you do want to proceed with assisted dying ...

CHOOSE ONE

If you do not provide assisted dying services but you do know who does:

"... I can put you in touch with someone who can provide you with more information and start the formal process"

OR

If you do offer assisted dying services:

"... we can make an appointment to talk more about this and/or start the formal process."

OR

If you do not know who offers assisted dying services or you are a doctor who has a conscientious objection:

"... The SCENZ Group (Support and Consultation for End of Life in New Zealand Group) holds a list of doctors who provide assisted dying services. You can contact the SCENZ Group via 0800 223 852 to get the name and contact details of a doctor who can help you."

Closing the conversation

'How does this approach 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?'

This is a good time to thank the person and their whānau for sharing with you so that together you could arrive at a plan that focuses on what is important to the person.

Chapter 6:

Managing the conversation

Engaging the person and their whānau together during the conversation

Having the person and their whānau present during the conversation offers both opportunities and challenges. Here are some general principles to guide these situations.

- Acknowledge that the person and their whānau are in charge of this process and that you are here to support them in considering the options.
- Acknowledge those that are in attendance. Allow time for introductions, firstly of those in attendance and then you and any other members of the clinical team.
- Apply the practice of whakawhanauatanga 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 the person and their whānau to discuss the issues further and always leave them with a number to contact and clarity about the next steps.

Addressing emotions

To have an effective conversation where the person feels heard and respected, you will need to address any emotions that may arise at any time during the conversation.

Talking about illness, death and dying can be difficult for many people. Talking about assisted dying may add another layer of complexity, and strong emotions may surface and could prevent an effective conversation.

The person may be anxious about raising the subject or be afraid of how the health professional might respond. They may become emotional when talking about their suffering or experience intense sadness when thinking about their future. They may feel angry or frustrated if they feel they have not been heard. In addition, they may have an unrealistic perception of their current and likely future health and their eligibility for assisted dying, which may result in a strong emotional response if they are told they don't meet the criteria for assisted dying.

General principles for managing strong emotion

Health professionals may experience anxiety when talking about assisted dying. The person raising assisted dying and their whānau may also experience anxiety as well as other strong emotions.

- Emotion is manifested through words, facial expression, body language, the use of psychological defences and affective expressions (such as tears or flushing).
- High anxiety in the health professional can raise anxiety levels in the person and their whānau. Being prepared will lower your anxiety level and lead to less stressful and more effective conversations.
- Strong emotion tends to impair cognitive processing.
 - Recognising and acknowledging emotions and allowing the person time to process them allows them to move forward into cognitive processing.
 - If the person is in a crisis (medical or other life crisis), their capacity for dealing with emotion might be diminished.
- Conversations should be carefully 'titrated' so the person is able to keep their emotions within a manageable range.
- Feeling understood and connected are among the most effective ways of managing strong emotion. For example:
 - expressions of empathy (example: 'I can see how hard this is for you to talk about')
 - affirmation of connection (example: 'We will work through these decisions together').

- Offering the person some element of control allows them to self-titrate a discussion that increases their emotion (example: *'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 person 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 person to help support them during and after the conversation.

Communication strategies for managing strong emotion

Person expresses intense emotion (tears)

For example, when talking about their suffering or what they feel is ahead for them

Key ideas

Tears and other strong emotions are natural when discussing serious illness and assisted dying.

When people express strong emotion, it is therapeutic 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 the person's responses, together with gentle guidance, allows forward movement without them feeling overwhelmed.

Sometimes, pausing the conversation is a good temporary strategy.

People 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 their feelings.

Try these strategies

- Allow silence for the person to express what they are feeling.
- Name the emotion you are seeing.
- 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 the person to describe what the tears are about: *'Help me understand what is making you 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; I think it is an important one, and I want to make sure I know what is most important to you, so you receive the most appropriate support.'*
- 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. Do you feel you want to keep talking about this today? Or shall we arrange another 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 person's distress.
- Avoid offering information that is not explicitly sought.

Person expresses anger

For example, if they are told they don't meet the criteria for assisted dying, or if the clinician is a conscientious objector or unable to initiate the assisted dying pathway

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 without defensiveness or judgement can help to surface the underlying emotion that is driving the anger.

Try these strategies

- Name the anger, being careful not to minimise or change the intensity:
'You sound very angry.'
- Explore what is making the person angry:
'Tell me what is making you angry.'
- Acknowledge the anger non-defensively. Empathise with the person's situation if appropriate:
'I can see you are really angry and are feeling let down that you are unable to access assisted dying.'
'I am sorry that I am unable to start the formal process with you; it must be frustrating to have to see someone else.'
- As the person talks about why they are angry, look for a '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.
- Encourage the person 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.'

Other communication strategies

Keeping the conversation on track

Key ideas

People wander when they are anxious or have other high priority issues to discuss.

People jump ahead, or divert the discussion, if they are not aware of what you intend to cover in the conversation.

Moving through the conversation methodically, before coming back to topics that require a more thorough discussion, helps to prioritise.

Try these strategies

- Acknowledge that this is a tough conversation and gently bring the person back to the topic:
'I know this is hard to talk about; it would really help me to understand more of what is important to you.'
- 'Bookmark' topics that require a more thorough discussion:
'It sounds important that we discuss your medication in more detail – is it ok to come back to that?'
- Interrupt gently:
'Mrs Smith, I wonder if we could get back to my question about your priorities?'

Managing time constraints

Key ideas

You may need to arrange another appointment for some dedicated time for this conversation or arrange a second conversation.

By acknowledging the available time at the beginning of the conversation, it helps the person prioritise what they want to discuss.

People usually recognise that there is a limited timeframe, if reminded.

Screening for other things the person wants to discuss, at the beginning of the conversation, reduces the chance assisted dying (or another significant topic) is raised at the very end of a consultation.

Try these strategies

- When available time is inadequate for the conversation:
'This is an important conversation and I'd like to make sure we have enough time – can we arrange another appointment?'
- Signposting the available time:
'In order to make sure we cover what's most important in the time we have, I want us to be aware that we have [15 minutes] together at this time.'

Managing uncertainty

For example, about whether the person wants to proceed with the formal assisted dying process

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

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

Try these strategies

- Acknowledge the person's uncertainty:
'You sound unsure about what you want to do.'
- Empathise:
'That must be really difficult.'
- Explore feelings:
'Tell me how this uncertainty is leaving you feeling.'
- Ask what might help them:
'What do you think might help?'
- Ask if they want to know more about their options:
'Do you feel you need more information about the care and support available to you?'
- Encourage discussion with whānau (if appropriate):
'These can be difficult decisions. I'd encourage you to talk about it with your whānau and then we can discuss it again.'
- Reassure them they do not have to make a decision until they are ready.

Person asks for assisted dying when they are likely in the last days of their life

Key ideas

If the person asks for assisted dying when they are close to the end of their life, this can be distressing for all concerned.

It is important to explore what is behind the request, to try to discover the source of the distress/suffering.

Offer other ways of providing support and relieving suffering. Consider palliative care services if not already involved.

Try these strategies

- Explore:
'Help me understand what is making you ask that today.'
- Acknowledge and empathise:
'It sounds like you've just had enough.'
'I'm sorry you're feeling so awful.'
- Explain assisted dying is not an option for them:
'There are a few steps to the assisted dying process; there wouldn't be time to go through the process before you naturally reach the end of your life.'
- Explore other ways to provide support:
'Can we talk about other ways we can try and improve things for you?'

Person says, 'I'm going to do it anyway'

For example, if they have been told they don't meet the criteria for assisted dying

Key ideas

It is important to explore what they mean and what their intentions are.

Be compassionate, lean in with curiosity.

Acknowledge and empathise with their distress/frustration.

Offer information about end-of-life-care options and interventions that may help relieve their suffering – only after acknowledging and empathising.

Affirm commitment to helping them get the best care possible.

If the person tells you they have an actual plan to take their own life, remember your professional obligations to take steps to prevent this (refer to your regulatory body).

Try these strategies

- Explore their statement:
'Tell me more about that.'
- Empathise:
'It sounds like a distressing situation to be in, to want to take things into your own hands.'
- Align yourself with person by using 'I wish' statements:
'I wish I could tell you what you want to hear.'
- Offer information about alternatives:
'If there was another way to improve your situation, what might that look like?'

Talking about whānau involvement

For example, when setting up an initial or subsequent conversation

Key ideas

Preferences about whānau involvement in an initial assisted dying conversation will vary.

Support the person through exploration to decide when and how they would like to involve their whānau.

Encourage them to consider the benefits for their whānau if they are involved.

Try these strategies

- Explore:
'How involved do you want your whānau to be?'
'At what point should we include your whānau in these discussions?'
'If your whānau has strong opinions that are different from yours, how would you like us to manage that?'
- Encourage the person to involve and prepare their whānau:
'I know these are really difficult issues to talk about, because you care so deeply for your whānau. Involving them in decisions will help them prepare and cope.'

Managing whānau disagreement with the person

For example, about the person's decision to request assisted dying

Key ideas

Be focused and compassionate.

Identify the basis for the disagreement.

Be aware of whānau dynamics.

Maintain the person at the centre of decision-making.

Try these strategies

- Acknowledge, and clarify if necessary, the person's/people's perspective/s:
'I'm hearing you say you don't agree with your mother's decision. Is that right?'
- Explore any underlying emotions:
'What are you feeling as you're talking about this?'
- Empathise:
'This is sounding really hard for you.'
- Gently remind whānau that the decision belongs to the person and:
'I know this is difficult to hear, however the decision is your mother's to make.'
- Negotiate a way forward:
'I know you want what's best for your mother – I'm wondering what we can do to help make this easier for you all?'

When a whānau member asks for assisted dying on behalf of the person

Key ideas

Establish whether the whānau member wants general information or to talk about assisted dying as an option for the person.

Lean in with curiosity.

Find out what has led them to ask.

Find out if it is something they have discussed with the person and how the person feels about it.

After listening, explain that if the person wants to access assisted dying services they will need to raise it with a member of the health care team themselves.

Try these strategies

- Acknowledge and explore:
'I hear you want to talk about the possibility of assisted dying for your mother; can I ask, first of all, what has led you to bring this up today?'
'Is this something you and your mother have discussed?'
 - Acknowledge emotion and empathise:
'It sounds like you're very worried about what's ahead for your mother – that's a hard place to be.'
 - Gently inform the whānau member that the person would need to raise assisted dying themselves if it is something they want to consider.
 - Ask what you can do to support the person and their whānau.
-

Chapter 7:

Actions to take after the conversation

Document

Ensure you document all conversations and plans in the clinical record. Good clinical documentation promotes patient safety and supports continuity of care. This is particularly important in the context of assisted dying, where multiple health professionals may be involved in further conversations and assessment.

Follow up

If, during the close of the conversation, you offer to share assisted dying resources, give the person options for supportive care or suggest referral to another service or health professional, ensure you action these at the end of the conversation. If you are not the person's lead clinician, you may also wish to notify them of the conversation, so they are aware the person has asked about assisted dying.

Using debriefing and self-reflection

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

Questions you might consider including in a debrief

- What are you doing that is working well and what is not?
- How do you know?
- What can you do to improve this experience for people asking about assisted dying?
- How can you support each other?

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

- How did you react? Were you defensive? Upset?
- Why did you react the way you did?
- How did your reaction impact the person and/or their whānau?
- How could you have handled that situation differently?
- How could that encounter influence your next assisted dying conversation?

Self-care

Assisted dying conversations can be challenging and emotionally taxing for many reasons. We may not be prepared for the person to ask us about assisted dying; we are being asked to talk about death and dying, which can be confronting; we may have strong feelings or opinions about assisted dying or the Act, which may be different to those of the person asking; or we may not feel supported in our organisations or by colleagues to have these conversations.

It is important to identify support systems and develop coping strategies that are personally effective.

Consider:

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