

WHĀNAU GUIDE

Kaitiakitanga Assisted Dying Pathway

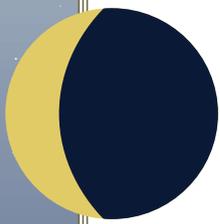
Prepared by Dr Tess Moeke-Maxwell on behalf of the Waerea study, 2026.

Below are suggestions to help whānau navigate the Kaitiakitanga Assisted Dying Pathway.

Terminal illness & Palliative Care

- Māori adults who have been clinically advised they have an incurable terminal illness have the right to palliative care (holistic care of hinengaro (mind), tinana (body), wairua (spirit) and whānau (family, including extended family) at the end of life.
- Palliative care also includes caring for bereaved whānau.
- Palliative care is provided at home, in hospitals, aged residential care facilities, and hospices. Anyone involved in caring for a person at the end of life including medical specialists, G.Ps, district nursing and community hospice nursing, provide palliative care.
- Palliative care continues if a person chooses to have a natural death and when they are accepted for an assisted death.

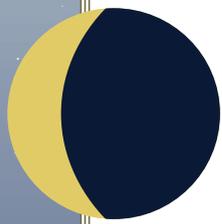




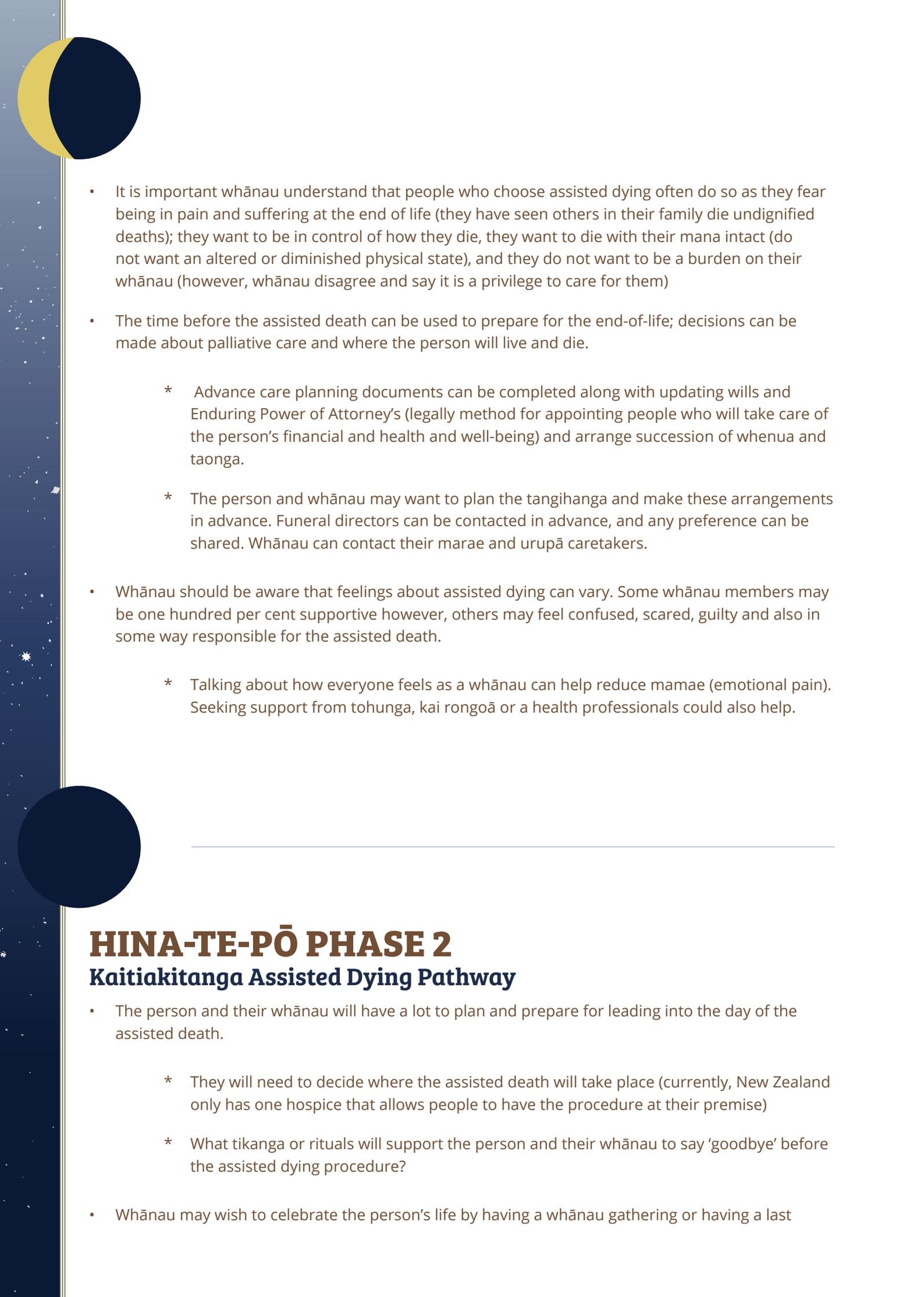
HINAURI | PHASE 1

Kaitiakitanga Assisted Dying Pathway

- Māori adults who have an incurable terminal illness want to exercise their mana motuhake (autonomy and independence) and maintain their mana (status, power, prestige) until the moment they die.
- Māori adults who have an incurable terminal illness who wish to hasten their death have the legal right under the End of Life Choice Act (2019) to request an assessment for a medically assisted death.
- The person with a terminal illness should consider being assessed as soon as possible; the assessment can take up to three weeks to complete.
- The assisted dying date can be extended for up to 12 months if the person feels well enough.
- Healthcare professionals are not allowed to raise assisted dying with a person. The person needs to speak to their GP or another healthcare provider if they want to discuss having an assisted death. They will refer them to the Assisted Dying Service, or they can contact the service directly themselves.
- For information about assisted dying, contact the Assisted Dying Service; Phone: 0800 223 852 (call back service) or email: AssistedDying@tewhatauora.govt.nz
- If a GP or another healthcare provider puts a referral in to the Assisted Dying Service, the person should ask them to advise them when they have done it (to avoid delays).
- An assisted dying assessment will be arranged with an assisted dying Attending Medical Practitioner (assisted dying doctor). This meeting will take place wherever the person is at the time (home, hospital, hospice, for example).
- At this meeting, the doctor will need to check that the person meets the legal criteria for an assisted death. They will also check that the safeguards are in place. For example, they will need to be certain that the person is not being coerced (forced) into having an assisted death. They will stop the process if they suspect coercion.
- If the assisted dying doctor assesses that the terminal person meets the assisted dying criteria they will arrange a second interview by a different doctor (Independent Medical Practitioner) on another day.
- The person with an incurable terminal illness will be assessed by an Independent Medical Practitioner on a different day. They will confirm whether the person meets the eligibility criteria to have an assisted death.
- In some cases, a third assessment may be arranged with a psychiatrist to determine whether the person is of sound mind to make the assisted dying decision.
- In cases where the person is deemed eligible for an assisted death the person chooses their assisted dying date. In cases where the person is declined, they could be invited to reapply at a later stage when their illness progresses, and it is more likely they will meet the criteria.



- People accepted for an assisted death will need to carefully consider the timing of the assisted dying date and the place where the assisted death will take place.
- The person should make sure the date does not clash with special events (birthdays, anniversaries or extraordinary events).
- Whānau are important kaitiaki (guardians)
- Whānau can help their whanaunga (relative) who has the incurable terminal diagnosis find information about assisted dying and they can attend the assisted dying assessments if the person wants this.
 - * The person does not have to tell their whānau but it can cause mamae (emotional pain) if whānau are excluded from being involved.
- Whānau may be more familiar with the term 'euthanasia.'
- Whānau should become familiar with the EoLC Act's (2019) safeguards and assisted dying criteria as this will help to prepare them for the assisted dying assessments and could help reduce disappointment if a person is declined, for example.
 - * Contact www.health.govt.nz to locate assisted dying information.
- Whānau provide loving support when they attend the assisted dying assessment. Whānau can ask questions after the assessment or discuss any concerns they have when it is over.
- During the second assessment the person and their whānau could ask the assisted dying doctor or assisted dying nurse to see a photograph of the needle and medication (if this is the administration method being used) to avoid feeling surprised or distressed at the time of the procedure.
- Being together as a whānau and holding hui (meetings) will provide everyone with an opportunity to discuss what assisted dying is and it will enable them to develop an understanding about why the person with a terminal illness has chosen this end-of-life option. Whānau can also ask questions:
 - * The www.poukāpura.co.nz website has information and resources to help Māori whānau discuss assisted dying together, as a whānau.
 - * The person who has a terminal illness and their whānau can consider whether they will share information about the assisted death with others or keep it private. Who will be told and who won't be told?
- Whānau can consider how they will care for everyone on the Kaitiakitanga Assisted Dying Pathway; people with incurable terminal illnesses may have special needs (disabilities, for example) and there may be whānau members who have unique needs (children, or people with mental health problems, for example).

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- It is important whānau understand that people who choose assisted dying often do so as they fear being in pain and suffering at the end of life (they have seen others in their family die undignified deaths); they want to be in control of how they die, they want to die with their mana intact (do not want an altered or diminished physical state), and they do not want to be a burden on their whānau (however, whānau disagree and say it is a privilege to care for them)
 - The time before the assisted death can be used to prepare for the end-of-life; decisions can be made about palliative care and where the person will live and die.
 - * Advance care planning documents can be completed along with updating wills and Enduring Power of Attorney's (legally method for appointing people who will take care of the person's financial and health and well-being) and arrange succession of whenua and taonga.
 - * The person and whānau may want to plan the tangihanga and make these arrangements in advance. Funeral directors can be contacted in advance, and any preference can be shared. Whānau can contact their marae and urupā caretakers.
 - Whānau should be aware that feelings about assisted dying can vary. Some whānau members may be one hundred per cent supportive however, others may feel confused, scared, guilty and also in some way responsible for the assisted death.
 - * Talking about how everyone feels as a whānau can help reduce mamae (emotional pain). Seeking support from tohunga, kai rongoā or a health professionals could also help.
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HINA-TE-PŌ PHASE 2

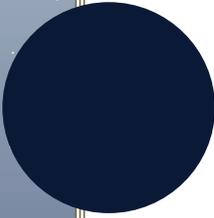
Kaitiakitanga Assisted Dying Pathway

- The person and their whānau will have a lot to plan and prepare for leading into the day of the assisted death.
 - * They will need to decide where the assisted death will take place (currently, New Zealand only has one hospice that allows people to have the procedure at their premise)
 - * What tikanga or rituals will support the person and their whānau to say 'goodbye' before the assisted dying procedure?
- Whānau may wish to celebrate the person's life by having a whānau gathering or having a last



photoshoot, or doing something special, memorable, and healing in the days leading up to the assisted death.

- This is the time when whānau will finalise planning for the assisted dying day and begin preparing arrangements for tangihanga.
 - * What cultural and spiritual support will be used on the assisted dying day and by whom?
 - * What tikanga or resources (including kaumātua, tohunga) are available?
 - * Are their special clothes or taonga the person wants to wear or hold? Are their special karakia, himene (hymns) or songs they want sung?
 - * Does the person and whānau wish to carry out karakia, waiata and other tikanga before, during or immediately following the assisted dying procedure?
 - * Who will convey the person's and their whānau wishes to the assisted dying doctor or assisted dying nurse to prepare them on the day?
 - * Who does the person who has a terminal illness want to be present at the assisted dying procedure?
- Consider how to prepare whānau on the assisted dying day if they have not attended any assisted dying assessments or have not been involved on the assisted dying pathway.
- All whānau who attend the assisted dying procedure should have a good understanding of the assisted dying process and procedure to prepare themselves:
 - * It is important to know that the needle and medication (if this is used) might be bigger than people expect.
 - * It is important to know that the timing of death might be fairly quick (several minutes), and this can feel surprising for people.
- An assisted death may seem more like a sudden death especially if the loved person was talking, walking, singing, or cracking a joke right up until they died.
- An assisted death may appear different from a death caused from natural causes – consider how to prepare whānau for this.
- Some people may prefer not to be present at the procedure.
- Consider how to care for people who may potentially become affected (emotionally upset or distressed) before, during or following the assisted dying procedure.
- Some people prefer to die sitting in a chair or somewhere other than a bed. Make sure their tūpāpaku body is laid flat after the assisted death (before rigor mortis) in preparation for transferring on to a gurney before going to the funeral home.



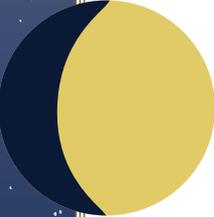
- * Whānau may prefer to wash and dress the tūpāpaku and lay them flat following the assisted death themselves.

- Whānau should be aware that feelings can heighten just before the assisted dying day and on the day of the procedure.

- * Whānau may feel confused, scared, guilty and responsible for the assisted death.

- * Talking about it as a whānau can help.

- * Seeking support from tohunga, kai rongoā or a health professional could help.



HINA-TE-PO PHASE 3

Kaitiakitanga Assisted Dying Pathway

- Whānau should consider whether assisted dying will be a private matter or something that is shared during the person's tangihanga (if they have one) and afterwards.

- Consider how to tell whānau and friends who were excluded from knowing about the assisted death or from attending the assisted dying procedure. How will they be cared for?

- Be aware that the Death Certificate records the cause of death as 'assisted dying.'

- * If you need to produce this document to a civil servant and you do not want them to see the cause of death, you can consider blacking that part out.

- Whānau should be aware that feelings can heighten after the assisted death.

- * Whānau may feel confused, scared, guilty and responsible for the assisted death.

- * Talking about it as a whānau can help.

- * Seeking support from tohunga, kai rongoā or a health professional can also help.

FREQUENTLY ASKED QUESTIONS

Is assisted dying an option for my whanaunga (relative) who has in incurable terminal illness?

Assisted dying may be an option if your whanaunga is 18 years or older, a New Zealand citizen or permanent resident, has a terminal illness likely to end their life within 6 months, is experiencing a serious and irreversible decline in physical capability, is experiencing unbearable suffering that cannot be relieved in a way they find tolerable, and is competent to make an informed decision. They must meet all of these criteria. However, they are not eligible solely because they are of advanced age, have a mental illness, or have a disability.

Is assisted dying the same as palliative care?

There are ongoing discussions among academics and healthcare professionals regarding whether assisted dying comes under the umbrella of palliative care. Palliative care is the care of people who are dying from active, progressive diseases or conditions that are not responsive to curative treatment. It focuses on managing pain and keeping your whanaunga as comfortable as possible. Assisted dying is a separate legal end-of-life care option available to people who meet specific criteria. Your whanaunga can receive both palliative care and assisted dying services at the same time.

Who does my whanaunga tell that they are thinking about assisted dying?

Your whanaunga does not have to tell anyone, but they are encouraged to talk with you and their whānau. As whānau, you can provide important support throughout the process, including attending appointments, providing personal care, and being present on the day. Your whanaunga may be given the opportunity to kōrero with their whānau, but the decision to have an assisted death is theirs alone. No one else can make this decision on their behalf.

Can my whanaunga apply for an assisted death if we are worried, they may die soon?

Yes, they can ask to be assessed. If a healthcare provider tells them not to apply because they do not have long to live, they can still contact the Assisted Dying Service directly to ask whether they can be assessed.

Is assisted dying an emergency service?

Assisted dying is not an emergency service. Applying early gives your whanaunga the best chance of having enough time to complete the process and uphold their wishes.

How long does the assisted dying application and assessment process take?

While the process is officially 4 to 8 weeks, approval is often reached in around 2-3 weeks. Timeframes are similar in both rural and urban areas.

What medication is used in assisted dying?

The specific medications are tightly controlled. Only certain medical professionals involved in providing assisted dying know what the medications are and can access them. Your whanaunga will only be told about them if they are assessed as eligible. They will have a choice about their preferred method of administration of medications.

What should our whānau expect on the assisted death day?

This will depend on when, where, how, and who will be there. It is a personal experience that your whanaunga and your whānau can plan together with the attending practitioner, including choosing tikanga practices such as karakia, music, or storytelling that are important to you all.

How might we as whānau be affected?

Grief is very personal, and people respond differently. How you and your whānau respond may be influenced by many things, including when and how you found out about your whanaunga's decision, your previous experiences with death, and what else is going on in your lives. Some people may benefit from talking with a tohunga, rongoā practitioner or a counsellor. Please note that the Assisted Dying Service does not provide grief counselling or support for whānau. Bereavement, grief, and mental health support services are listed on this website.

Can my whanaunga change their mind about assisted dying?

Yes. Your whanaunga can change their mind and stop the assisted dying process at any point, right up until the medication is administered. No one can make this decision on their behalf, and no one can pressure them into continuing.

Is there a cost?

The assisted dying service is free. Your whanaunga may still need to pay for other aspects of their healthcare, such as regular GP appointments or prescriptions unrelated to assisted dying.

What if we feel our whanaunga's rights have not been upheld?

You or your whanaunga can phone the Nationwide Health and Disability Advocacy Service on 0800 555 050, which is free and confidential. Whānau can also contact the Health and Disability Commissioner to make a formal complaint. Your whanaunga's rights are protected under both the Code of Health and Disability Consumers' Rights and the End of Life Choice Act 2019, outlined in section 2.

Does my whanaunga have to tell their primary healthcare provider they are thinking about assisted dying?

Your whanaunga must raise assisted dying with someone in their healthcare team themselves. A healthcare provider cannot suggest it as an option. If your whanaunga does not have a regular doctor or General Practitioner, or if their healthcare provider does not offer assisted dying services, the provider must explain why and support your whanaunga to find another provider. Your whanaunga can also contact the Assisted Dying Service directly at 0800 223 852 or AssistedDying@tewhatauora.govt.nz, and they can help connect your whanaunga with an appropriate healthcare professional.