Care during the last days of life
Pairuri (palliative care)

The information in this guide is accurate to the best of our knowledge as of June 2023.

Definition

Last days of life are the hours or days during which death is imminent. *Te Ara Whakapiri: Principles and guidance for the last days of life* and its toolkit offer a guide to care at this time in New Zealand (Ministry of Health 2017).

Why this is important

People require health care from conception to interment (when they reach their final resting place after death). The quality of care during the last hours and days of life directly impacts on the dying person. Just as importantly, the way death and dying is managed impacts the experience of grief for all those left behind (Detering et al 2021).

Implications for kaumātua*

Underpinned by Te Whare Tapa Whā (Durie 1985), *Te Ara Whakapiri* takes a holistic approach to promoting the wellbeing of the person and their **whānau**/family as the end of life nears. From **te ao Māori** (Māori world view) the last days of life is believed to be the time when the person's **wairua** (spirit) moves across the **ārai** (veil) from the physical to the metaphysical realm (Nelson-Becker and Moeke-Maxwell 2020). This is considered a critical aspect of the life phase (Moeke-Maxwell et al 2014).

The individual and cultural preferences for Māori during the last days of life are diverse. It is 'essential that care administered at end of life is inclusive of their whānau/family and is culturally informed, relevant, and well-supported by health professionals' (Moeke-Maxwell et al 2019). For this reason, health professionals must create space for discussion with whānau/family about the last days of life both before the end of life and during the dying process. They should document preferences in the plan of care.

Tikanga

Because the needs of whānau/family will vary, it is best to allow them to lead. The following are some **tikanga** (Māori cultural customs/traditions) that whānau/family may choose to observe (see the *Guide for health professionals caring for kaumātua | Kupu arataki mō te manaaki kaumātua* for more information).

* Kaumātua are individuals, and their connection with culture varies. This guide provides a starting point for a conversation about some key cultural concepts with kaumātua and their whānau/family. It is not an exhaustive list; nor does it apply to every person who identifies as Māori. It remains important to avoid assuming all concepts apply to everyone and to allow care to be person and whānau/family led.

- Gathering together with **waiata** (songs) and **karakia** (prayers/incantations) is a common way in which whānau/family express **aroha** (love, compassion, empathy) at this time.
- Someone stays with the dying person or **tūpāpaku** (deceased) at all times.
- People cannot take food or drink into the room of the dying person or tūpāpaku. Doing so breaches the separation and balance of **tapu** (sacred, restricted, prohibited) and **noa** (ordinary, neutral, unrestricted).
- After the person's death, it is common for mourners to lift the tapu and restore noa by sprinkling themselves with **wai** (water). Have a bowl of water available outside the room containing the tūpāpaku so that **manuhiri** (visitors) can bless themselves after leaving the deceased person's space.
- After the person's death, there will be a time when the wairua must settle. Whānau/family will generally have intuition about when this has happened. After this time, they may wish to wash, prepare and dress their loved one.

After the person's death, the whānau/family may wish to lift the tapu of the room or space where their loved one lived. This process is called a **takahi**. A leader will say karakia while sprinkling the room or area with wai.

Spiritual concerns

Kaumātua may experience spiritual distress in the last days of life. Nelson-Becker and Moeke-Maxwell (2020) provide a helpful table of examples and useful responses (see the **appendix** of this guide).

Assessment

The diagnosis of dying is made only after a clinical assessment confirms that the presenting situation is not reversible. An irreversible situation may be absolute (eg, end-stage disease) or it may occur because the older person is unwilling to consent to treatments (eg, deciding against hospitalisation or invasive treatments). In aged residential care, a registered nurse often completes the first assessment and refers to the primary care provider (general practitioner or nurse practitioner) for support with the diagnosis and management plan.

Care planning

Care focuses on managing the physical and holistic symptoms associated with the dying process, such as the following.

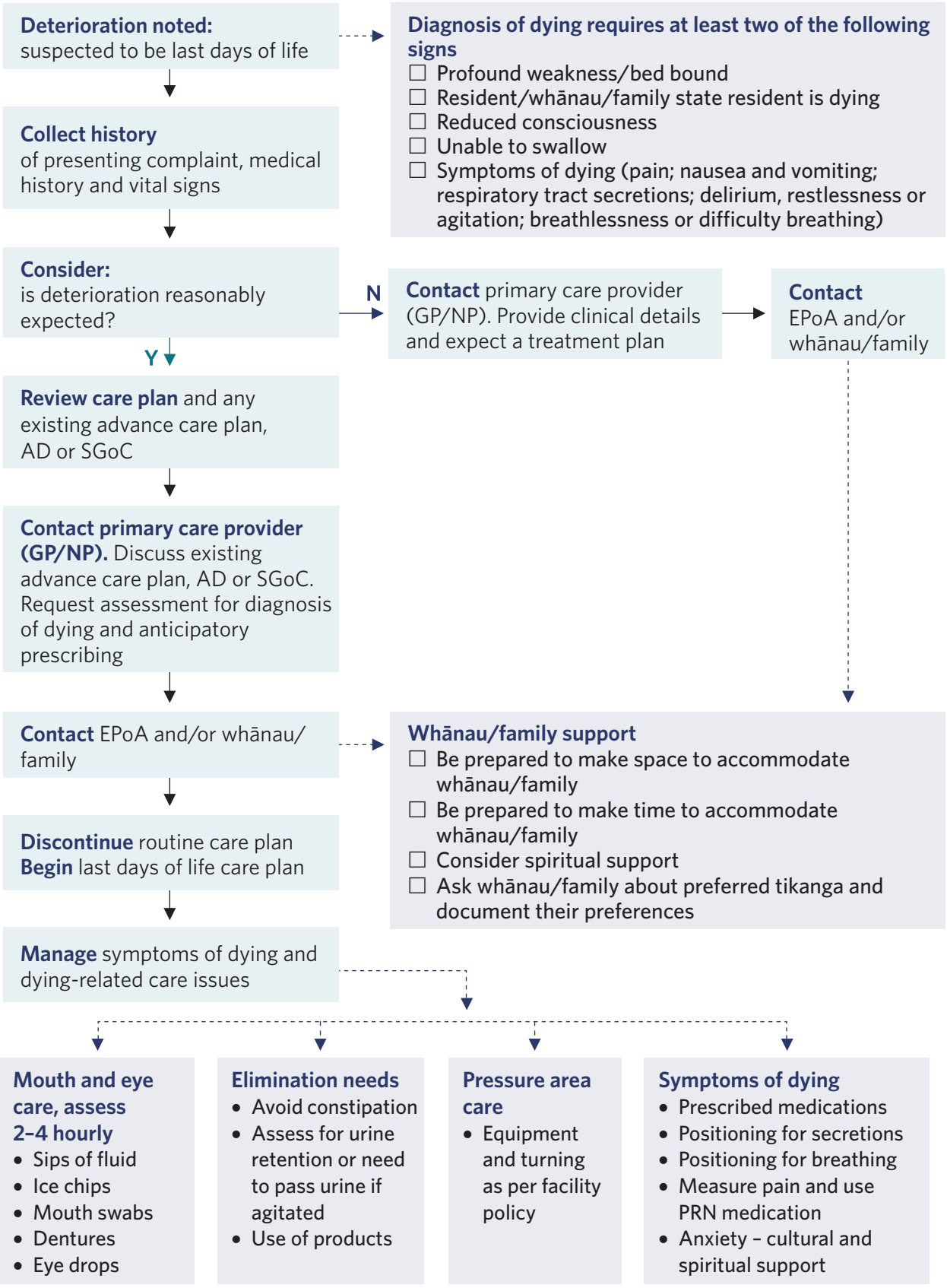
Physical care may involve:

- medication management – making changes to the plan and using anticipatory prescribing
- responding to the common symptoms of dying:
  - pain
  - nausea and vomiting
  - respiratory tract secretions
  - delirium, restlessness or agitation
  - breathlessness or difficulty breathing
- continuing care – responding to mouth care, pressure area care and elimination needs
- environmental management (temperature, noise).

Holistic care may involve:

- guiding loved ones through the dying process
- acknowledging the emotional impact on whānau/family and loved ones
- providing space for gathering
- continuing to provide wairua or spiritual support throughout the process
- accepting the expression of grief in whatever form it takes.

Decision support



AD = advance directive
EPoA = enduring power of attorney
GP = general practitioner
NP = nurse practitioner
PRN = as needed (pro re nata)
SGoC = shared goals of care

References | Ngā tohutoro

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Appendix: Examples of spiritual distress and possible responses

Spiritual concern	Primary condition	Illustration	Response examples
1. Anger toward God or others	Projects anger toward religious figures or clergy, inability to forgive	*Why would God allow this cancer? I've been good*	Listen, encourage sharing of feelings to process them, begin to transform suffering through touching it and dialogue
2. Belief that a miracle will occur	May reflect ethnic or religious group's beliefs and expectations	*I have always done what you ask, God; please do this for me*	Listen, provide realistic support
3. Collective experience of marginalisation during large-scale conditions such as pandemic, war	Scale of personal loss is magnified under unfolding societal conditions	*My loved ones are unable to visit; my needs and the needs of my group are overlooked*	Offer reasonable reassurance, facilitate contact and communication
4. Communication of direct spiritual needs	Majority group culture does not understand or respond to Indigenous needs, as one example	*All whānau/family and health care staff wash their hands when entering/exiting room of the dying to spiritually 'cleanse' spiritual energy*	Work to facilitate requests, ensure tapu (restrictions/sacredness) maintained
5. Despair, desolation	Inconsolable	*No one can forgive me for this*	Ensure safety; explore reasons. Support value and worth; look for avenues of hope

Spiritual concern	Primary condition	Illustration	Response examples
6. Dying away from home, ancestral land	Discusses sense of dislocation, sad	*I want to return home*	Build connections with symbols/objects from home, ask about underlying need
7. Existential concerns	Poses questions about life meaning, what will happen after death, what is the purpose of suffering	*My life has no meaning. What happens when I die?*	May respond with thoughtful questions; share texts from patient traditions if known; proverbs, prayers, songs, poetry for insight
8. Forgotten	Worried that one's death won't matter	*No one will care when I die*	Gently challenge and confront belief; what matters is present life and how one lives it, even if there is no witness
9. Guilt/shame	Deep regrets, lack of self-worth	*I'm so sorry I hurt him. I was never good enough*	Acknowledge feelings and awareness, use cognitive restructuring
10. Isolation or alienation	Shows feelings of loneliness	*I feel so alone*	Problem-solve together and refer for support
11. Immediate spiritual concern	Specific thought, feeling or action related to what is spiritual or a religious community	*I will be judged as a failure by God*	Listen, explore, stay within client/patient belief system
12. Legacy	Worry about how whānau/family may continue after death	*How can I provide for my whānau/family physically, emotionally, spiritually*	Explore whānau/family resilience, explore inter-connecting life tasks separately
13. Loss/grief	Feels deep sorrow loss of good health/home, loss of other support systems	*I don't know how to go on without my sister. I wish I could still walk every day*	Silence for holding space; mindful presence; meditation; breathe together
14. Tapu and noa cultural values	Need to achieve a balance between tapu (restricted, sacred, set apart or forbidden) and noa (safety)	*I am at risk, since tapu may be breached by those who do not understand*	Take cues from whānau/family, learn about cultural values, arrange conditions to facilitate safety
15. Relationship with God/doubt	Does not sense God's presence or presence of the Ultimate	*Where is God now? Why can't I feel him/her?*	Reflect content of thought; summarise change over time – places of challenge and growth
16. Religious or spiritual struggle	Displays deep level of discomfort with spiritual questions which are pervasive	*Why am I feeling this way?*	Accompany; refer to religious or spiritual leaders for specific competencies

Source: Nelson-Becker and Moeke-Maxwell 2020