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Te Ara Whakapiri

Principles and guidance for the last days of life

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Mihi

Tuia i runga, tuia i raro
Tuia i roto, tuia i waho …

E rere nei ngā mihi ki a koutou ngā whānau e kaha nei ki te whakaahuru i ō koutou kiri whakahemohemo, te hunga i tuku whakaaro mai, tae atu ki ngā mātanga mohimohi, huri noa i ngā kokonga o Aotearoa. Kei konei te hua o ngā mahi nui o roto i ngā tau, ki te hanga, ki te whakanikoniko i tō tātou whare whakaahuru. Nā koutou, nā tātou, mā koutou, mā tātou ēnei aratohu, ēnei tauākī mātāpono, ka noho mai hei tūāpapa mō te mahi whakaahuru i ō tātou kiri whakahemohemo. Tēnā koutou katoa.

Tuia te taura tangata
Kia mauri tau i te ao, kia mauri tau i te pō
Whakamaua kia tina, hui e, tāiki e!

Acknowledgement

Bind and unite together that of above and that of below
Bind and unite together that of within and that of without …

Acknowledgement goes out to all whānau providing end of life care for their loved ones, to all who have been able to contribute thoughts and ideas to this document, and to all the professional caregivers throughout Aotearoa. Here are the fruits of our deliberations and work over a long period of time, to create and embellish our house of caring. These guidelines, this statement of beliefs and principles have been created by us, created for us, as a foundation for our work in providing end of life care. Tēnā koutou katoa.

Bind and unite the people involved
Creating a settled life force in day, a settled life force in night
Be steadfast in togetherness!

Te ara whakapiri

He aha rā ngā kōrero hei whakaahua i te ara hīkoi o te kiri whakahemohemo me tōna whānau? He aha rā i tua atu i ngā mātāpono taketake o Te Whare Tapa Whā, arā, te taha hinengaro, te taha tinana, te taha wairua me te taha whānau.

Ki te āta mātaihia te ingoa o tēnei puka aratohu, tērā e kitea ēnei mātāpono e whakaatangia mai ana. Ko te noho whakapiri a te kiri whakahemohemo me tōna whānau te āhuru mōwai e tautāwhitia ai ēnei hunga e rua, mai i te tīmatanga o te ara whakahemohemo, ā, mutu noa. Waihoki, ko tā *Te Ara Whakapiri*, he whakakākahu i ēnei mātāpono ki te wairua whakaute me te aroha o tētehi ki tētehi.

The unifying path

How should one truly characterise the experience of a person and their family/whānau at the end of life? In essence, any path or guidance should encompass the fundamentals of Te Whare Tapa Whā, namely the mental, physical, spiritual and social principles.

If we examine the title of this guidance, it is clearly evident that it incorporates these principles. The unification of the person and their family/whānau provides a haven that allows fulfilment of needs suitable for both groups, from the beginning to the eventual end. Furthermore, *Te Ara Whakapiri* conveys these principles alongside the primary values of respect and compassion between one person and another.

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The Last Days of Life Working Group developed *Te Ara Whakapiri: Principles and guidance for the last days of life* in collaboration with the Last Days of Life Governance Group and the Palliative Care Council (PCC).

The authors of this document were the Last Days of Life Working Group members, along with Stephanie Calder (project manager, Cancer Control New Zealand (CCNZ) and David Alsford (analyst, CCNZ).

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2. Hospice New Zealand
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4. New Zealand Nurses Organisation (NZNO)
5. Palliative Care Nurses NZ Society (PCNNZ)
6. Hospital Palliative Care
7. Royal New Zealand College of General Practitioners (RNZCGP)
8. NZ Rural General Practice Network
9. Royal Australasian College of Physicians (RACP)

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Executive summary

Te Ara Whakapiri: Principles and guidance for the last days of life outlines the essential components and considerations required to promote quality care at the end of life for all adults in New Zealand. It also provides examples of useful approaches and tools that will serve as aids for the development of national and/or local resources as part of implementation.

Te Ara Whakapiri is based on an extensive evaluation of the available literature and is informed by local research, ensuring it is applicable to the unique context that is Aotearoa New Zealand. It has been endorsed by key professional health organisations in New Zealand and marks a major step towards ensuring that all health care services across the country are focused on delivering the very best care for people who are dying and for their family/whānau whatever the setting. There are four parts to the document, as follows.

Part A outlines seven overarching principles. These seven principles are underpinned by Te Whare Tapa Whā, a model of care that is concerned with the total wellbeing of the person and their family/whānau.

1. Care is patient-centred and holistic.
2. The health care workforce is appropriately educated and is supported by clinical champions.
3. Communication is clear and respectful.
4. Services are integrated.
5. Services are sustainable.
6. Services are nationally driven and supported to reduce variation and enhance flexibility.
7. Resources and equipment are consistently accessible.

Part B describes three components to care in the last days of life. While being respectful of any cultural, spiritual, religious and family issues that are unique to the dying person, each of these three components is addressed from the perspectives of:

- the person who is dying and their family/whānau
- the health professional(s) providing care
- the specific clinical service or health care organisation (primary palliative care provider and/or specialist palliative care service)
- the wider health system.

1. A comprehensive **baseline assessment** involves identifying the lead practitioner, assessing clinical needs, sensitive and open communication, and clear documentation.
2. **Ongoing assessment** emphasises the importance of developing individualised care plans.
3. **After death care** includes verification of death and the need of the family/whānau for information and privacy.

Underpinning this model of care is the recognition that if a person in the last days of life has a level of need that exceeds the resources of the primary palliative care provider, that provider should refer them to specialist palliative care.

Part C includes two examples of approaches in use within New Zealand that could be adopted or modified for use in other regions.

Part D is a non-exhaustive collection of tools that have been used across the country to assist practitioners in caring for people at the end of life. These are examples only and include guidance on identifying the dying patient plus algorithms to assist with managing the most commonly encountered symptoms.

Te Ara Whakapiri is not a care plan in itself but serves as a foundation document for all policies and procedures concerned with care at the end of life and for all education initiatives. Within a region or district health board, there should be an agreement for consistency and congruence of documentation such that *Te Ara Whakapiri* is applied to local circumstances, resources and needs. It is not intended that examples from Part D or elsewhere are simply uplifted and used without due consideration of implementation and resourcing.

As *Te Ara Whakapiri* is progressively implemented, some tools are likely to emerge that would be suitable for formal evaluation and costing, in advance of widespread adoption in all health care settings. This is needed if incremental, sustainable improvements in end-of-life care are to be achieved in New Zealand.

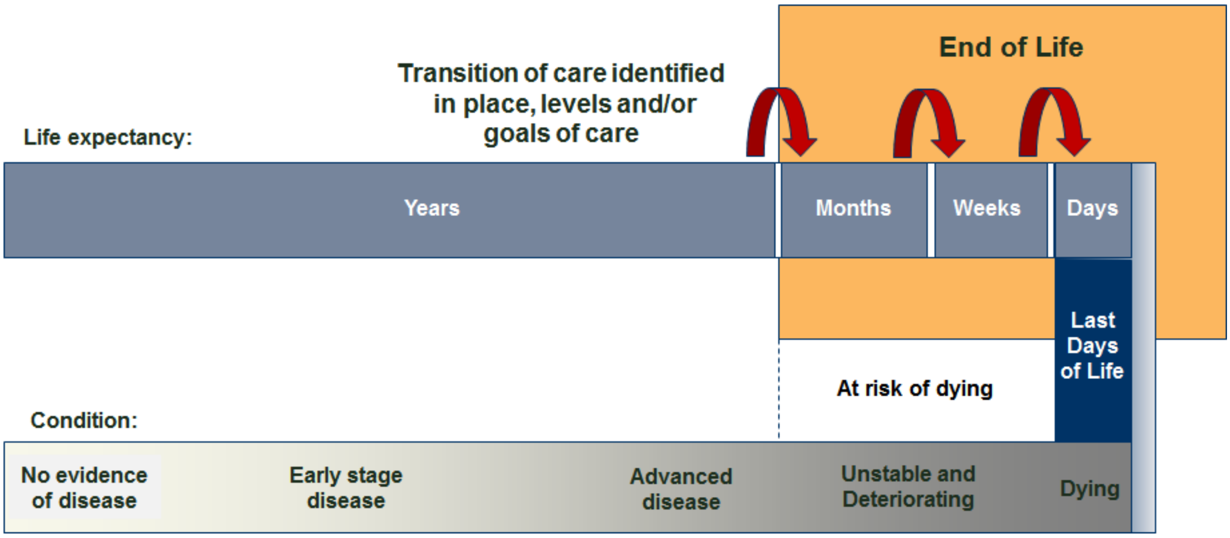
Introduction

Te Ara Whakapiri: Principles and guidance for the last days of life defines what adult New Zealanders can expect as they come to the end of their life. It is a statement of guiding principles and components for the care of adults in their last days of life across all settings, including the home, residential care facilities, hospitals and hospices.

The term 'last days of life' defines the period of time in which a person is dying. It is the period in which death is imminent, and may be measured in hours or days.

Figure 1 represents the last days of life in relation to the end of life.

Figure 1: End of life and last days of life



Source: PCC (2015)

This guidance document has four parts.

Part A: Overarching principles to guide the care of people in their last days of life.

Part B: Components of care that represent the minimum service delivery requirements to ensure quality care for people in their last days of life.

Part C: Examples of approaches that services could use to provide and document care to people in their last days of life.

Part D: Examples of tools that provide practical guidance to health practitioners and services caring for people in their last days of life and their family/whānau.

The seven principles of care set out in Part A are underpinned by Te Whare Tapa Whā model, a holistic approach to care that addresses a person's physical, family/whānau, mental and spiritual health. The components of care set out in Part B outline the practical requirements to achieving quality care for people who are in their last days of life.

The central approach of *Te Ara Whakapiri* is that it will guide the development of individual plans of care that address physical, mental, social, cultural and spiritual issues.

Te Ara Whakapiri addresses the care of adults who are in their last days of life. It is recognised that the trajectory of dying is significantly different for children. In 2014 the Paediatric Society of New Zealand and Starship Foundation developed Te Wa Aroha (or 'time of love'), an advance care planning model of care for paediatric palliative care. Te Wa Aroha is generally more appropriate for the care of children in their last days of life.

The terminology throughout this document is consistent with the *New Zealand Palliative Care Glossary* (PCC 2015). It is suggested that the reader refers to the Glossary if any clarification or elaboration is required.

Background

The Liverpool Care Pathway for the dying patient

The Liverpool Care Pathway (LCP) for the dying patient was an integrated pathway approach to the care of people who are dying, which was developed in the United Kingdom in the 1990s. Its origin was the aim to transfer best-practice approaches used in hospices to other settings. The LCP provided guidance on comfort measures, anticipatory prescribing of medications, discontinuation of interventions no longer necessary, psychological and spiritual care, and care of a dying person's family/whānau, both before and after the person's death. Support materials formed part of the LCP, and included template documents, training for staff and arrangements for auditing and evaluation.

The LCP was introduced in New Zealand in 2005. It included a cultural component appropriate to the New Zealand context. A National LCP Office oversaw the progressive implementation of the LCP in over 350 health care services.

In June 2013, an independent review of the LCP in the United Kingdom identified a number of problems with the model, and recommended that it be replaced by individual care plans for each patient. As a result of the United Kingdom findings, in November 2013 the Ministry of Health commissioned the Palliative Care Council (PCC)[1] to investigate an appropriate new approach here.

Development of the new approach in New Zealand

Accordingly, the PCC appointed a Last Days of Life Governance Group (the Governance Group) in November 2013, and established a Last Days of Life Working Group (the Working Group). These groups were made up of representatives according to their skills and experience, rather than by looking for representation from particular organisations. The Working Group comprised individuals with expertise in palliative medicine, palliative care nursing, aged residential care, gerontology, general practice and last days of life / LCP facilitation. There was also a consumer representative.

The Working Group agreed a comprehensive programme of work to inform the new approach. The process included analysing the United Kingdom review findings and their relevance to New Zealand, conducting a stocktake of services to establish how services were providing care to people in their last days of life in light of the United Kingdom review findings and recommendations, conducting a literature review to investigate best practice and evidence in relation to specific aspects of care and completing a comprehensive survey of family/whānau who had experienced a loved one's last days of life, to establish their perspective.

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[1] The Palliative Care Council of New Zealand was established under Cancer Control New Zealand (CCNZ) in 2008 to provide independent and expert advice and report on palliative care. The CCNZ and thus the PCC were disestablished on 8 August 2015 by the Minister of Health. The work on *Te Ara Whakapiri: Principles and guidance for the last days of life* that was commissioned by the Ministry of Health and undertaken by the PCC was then taken over by the Ministry to the point of publication.

The Working Group identified key stakeholders at the initial stages of the project, and thereafter involved them and consulted with them in a range of ways, including via their participation on the Working Group, Governance Group or PCC, and through presentations to relevant groups and regular updates. The Working Group undertook a broad sector consultation on a draft version of *Te Ara Whakapiri*.

Working Paper No. 5

The Working Group's stocktake of the current provision of care identified certain aspects that required further consideration. The findings are set out in Working Paper No. 5: *Care of Patients in Their Last Days of Life: New Zealand based approaches* (PCC 2014a). Key themes identified by the Working Group relate to:

- **terminology:** the need to clarify terminology used in the last days of life and in relation to death and dying
- **evidenced-based practice:** the need for specific review of evidence regarding culturally appropriate care in the last days of life as well as dementia care
- **diagnosis of dying:** the need for guidance to recognise that a person is dying, emphasising the inherent uncertainties and the importance of sensitive communication with the person and their family/whānau
- **cultural and spiritual considerations:** the need to address cultural and spiritual aspects important to the person dying and their family/whānau
- **workforce issues:** the need to ensure dying people and their family/whānau have access to an appropriate after-hours workforce that is able to make decisions on treatment
- **nutrition and hydration:** the need for guidance on appropriate approaches to nutrition and hydration in the last days of life
- **symptom and pain management:** the need for guidance on symptom management in the last days of life
- **documentation:** the need for guidance on documentation of a dying person's care that is robust enough for data collection and auditing requirements, but that does not take a 'tick-box' approach
- **education and training:** the need to improve the consistency of and access to appropriate education and training about caring for people in their last days of life
- **leadership:** the need for dedicated teams or individuals to support and coordinate the implementation of particular models of care
- **quality indicators and data collection:** the need for any model of care to encompass auditing and regular reviews.

Working Paper No. 7

The Working Group's literature review formed Working Paper No. 7: *International Evidence and Best Practice of Models of Care for People in Their Last Days of Life, Including the Liverpool Care Pathway: A literature review* (PCC 2014b). Internationally, there is minimal robust evidence indicating the effectiveness of the LCP. However, service providers in New Zealand have noted that the standard of care for people and their families/whānau has improved as a result of the LCP.

There is limited international evidence on how the workforce can accurately diagnose or recognise imminent dying. This has been raised as a significant challenge in New Zealand across all health settings. However, some guidance on diagnosis has been developed and implemented with good results, including the Gold Standards Framework Prognostic Indicator Guidance (The Gold Standards Framework Centre in End of Life Care 2011) and the Supportive and Palliative Care Indicators Tool (SPICT™) (NHS and University of Edinburgh 2014).

Working Paper No. 9

The Working Group's investigation of the family/whānau experience of the care of loved ones in their last days of life formed Working Paper No. 9: *Results of a Survey of Family/Whānau Caring for People in Their Last Days of Life* (PCC 2014c). It highlighted two key requirements:

- **a responsive, fully trained workforce**, available any time of the day or night to provide care, advice and compassionate support within appropriate cultural and spiritual mores
- **clear and simple communication**, including advice about when a person is dying, proposed approaches to treatment and care, the use of a care plan, and opportunities for the family/whānau to contribute to care.

Part A: Principles of care for people in their last days of life

Introduction

Excellent care meets the individual needs of a person and their family/whānau (PCC 2014a). The Working Group identified seven principles to achieve excellence and consistency of care for people in their last days of life, across all sectors and in all settings. These are outlined below.

Seven principles

1. **Care is person-centred**. The delivery of care is respectful, individualised and tailored to the person who is in their last days of life. This includes acknowledgement of physical, spiritual, social, mental and cultural factors important to each individual and their family/whānau, and mechanisms to enable these factors to be incorporated into the delivery of care.
2. **The workforce providing care is the right workforce**. An appropriately educated multidisciplinary team provides care, and is supported by clinical leadership. A champion, educator or facilitator leads the implementation of end-of-life care programmes.
3. **Communication is clear and respectful.** Care providers clearly communicate information about the status of people in their last days of life, their care plans and their treatment, to the person and their family/whānau. They create opportunities for the family/whānau to provide input. They support the family/whānau beyond the death of the person.
4. **Services providing care to people in their last days of life are integrated, and move with the person**. Transitions of care are seamless.
5. **Services are sustainable.** Service provision addresses and incorporates governance, auditing processes, evaluation and research.
6. **Services are nationally guided and supported, to improve consistency and reduce unacceptable variation in access, including for geographic reasons**. Services are flexible enough to be able to be provided across all health care settings and to cater for variations in population needs.
7. **Access to resources and equipment is consistent nationally.** Service providers make use of culturally appropriate clinical guidelines to manage symptoms. All people in their last days of life have access to the full range of medications, and staff are available to manage physical and psychosocial symptoms according to best practice and evidence.

These principles are underpinned by a model of care that is increasingly understood and valued in the New Zealand health care environment. This model is known as Te Whare Tapa Whā.

Te Whare Tapa Whā

Te Whare Tapa Whā model of care (Durie 1985) supports these seven principles of care relevant to the last days of life. It is a holistic Māori model of health that compares health to the four walls or cornerstones of a house: all four are required to maintain positive wellbeing. When one of the cornerstones becomes damaged or is missing, the person or a collective may become unbalanced or unwell.

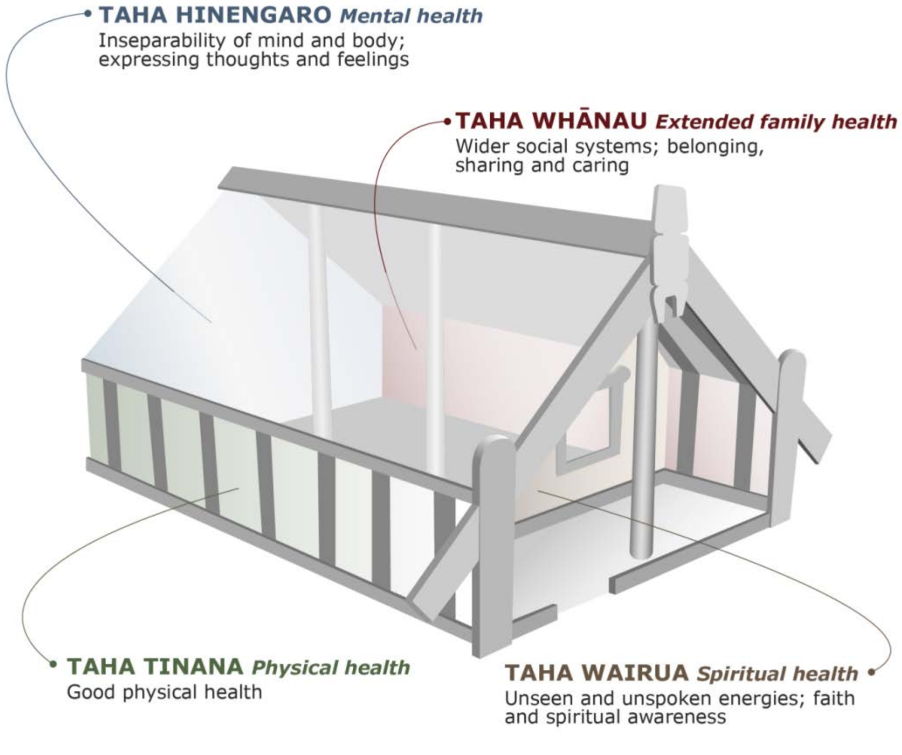
Te Whare Tapa Whā can apply to the total wellbeing of the person as they approach the end of their life, as well as the total wellbeing of their family/whānau.

The four cornerstones are:

- **te taha tinana:** good physical health
- **te taha whānau:** extended family/whānau health and wider social systems; belonging, sharing and caring
- **te taha hinengaro:** mental health, inseparability of mind and body; expressing thoughts and feelings
- **te taha wairua:** spiritual health, unseen and unspoken energies, faith and spiritual awareness.

Te Whare Tapa Whā model is consistent with other frameworks and legislation underpinning quality care, including the Code of Health and Disability Services Consumers' Rights, the Health Practitioners Competence Assurance Act 2003 and competency requirements set out by the Nursing Council of New Zealand and the Medical Council of New Zealand.

Figure 2: Te Whare Tapa Whā



Source: Durie (1998); Te Ara (2015)

Part B: Components of care for people in their last days of life

Introduction

The components of care presented in this section together offer a guide for all services providing care for people in their last days of life, and a platform for auditing and data collection. They are organised into three parts:

1. baseline assessment
2. ongoing assessment of the plan of care
3. care after death.

These components of care expand on the principles of care in Part A, and are informed by the working papers discussed in the Background section (PCC 2014a, 2014b, 2014c).

Te Whare Tapa Whā model provides a framework for using these components to provide holistic care and increase the total wellbeing of people in their last days of life, and it includes their family/whānau. This approach is holistic. Therefore, the components within each of the three parts of this guidance are not presented sequentially or in order of priority, but relative to the dimensions of Te Whare Tapa Whā model.

For the purpose of this guidance, each component of care entails attributes allocated under certain labels, defined as follows.

- **Person receiving care** is the person who has been identified as dying or as approaching their last days of life.
- **Family/whānau** includes the immediate family, extended family, family group and friends of the person identified as dying or as approaching their last days of life.
- **Health practitioner** is a person who is registered with an authority as a practitioner of a particular health profession.
- **Service/organisation** is any organisation or team of health professionals providing health and disability services for the care of people identified as dying or as approaching their last days of life. It includes all primary providers of palliative care and specialist palliative care services.
- **System** encompasses the complex network of organisations that have a role in delivering health and disability services; most notably district health boards (DHBs) and primary health care providers but also including Crown entities and agencies, non-governmental organisations and the Ministry of Health.

1. Baseline assessment

A health practitioner undertakes a baseline assessment when they think a person may be entering their last days for life. This change in condition acts as a prompt to ensure conversations occur with the person and with their family/whānau.

If a person in their last days of life has a level of need that exceeds the resources of the primary palliative care provider, that provider should refer them to specialist palliative care.

Table 1: Baseline assessment summary

Te taha tinana: ***Physical health***	
1.1	Recognition the person is dying or is approaching the last days of life
1.2	Identification of the lead health practitioner
1.3	Assessment of physical needs
1.4	Review of current management and initiation of prescribing of anticipatory medication
1.7	The person's awareness of their changing condition
1.11	Provision of food and fluids
1.12	Availability of equipment to support the person's care needs
1.13	Consideration of cardiac devices
1.14	Advice to relevant agencies of the person's deterioration

Te taha hinengaro: ***Mental health***	
1.5	Assessment of the person's preferences for care

Te taha whānau: ***Extended family health***	
1.6	Identification of communication barriers
1.8	The family/whānau's awareness of the person's changing condition
1.9	Discussion of cultural needs
1.15	Provision of information to the family/whānau about support and facilities

Te taha wairua: ***Spiritual health***	
1.10	Provision of opportunity for the person and family/whānau to discuss what is important to them

1.1 Recognition the person is dying or is approaching the last days of life

Recognising the last days of life can be difficult as signs and symptoms are often subtle. Non-fatal life threatening but recoverable conditions can mimic the last days of life.

Where a health practitioner recognises that a person is in their last days of life, they must ensure that the person and their family/whānau have the opportunity to understand and accept the possibility that death is imminent.

Health practitioners should identify as early as possible that a person is dying, to allow for timely, appropriate care and communication, involving the person (where possible) and their family/whānau. Early identification enables the clinical team to prioritise the provision of comfort and support based on the person's preferences.

There will always be a degree of uncertainty over the timing of a person's death (and there may be a chance that their condition will improve), but this should not preclude anticipatory discussions and the implementation of holistic clinical care.

	Attributes/indicators
Person receiving care and family/whānau	Receive timely and open communication regarding the likelihood of dying soon.
Attending health practitioner	Is confident in using their clinical judgement and experience to recognise when a person is dying or is approaching the last days of life. Is aware that recognising the last days of life allows clinical care to be redirected towards comfort and support while acknowledging the uncertainty about timing and even the possibility of not dying as anticipated. It allows for communication to the family/whānau, giving them time to prepare their thoughts and actions.
Clinical service/ organisation	Ensures that staff can access education and training on recognising the last days of life. Ensures that facilities are configured appropriately to care for people at the end of life.
System (DHB)	Supports health practitioners to become skilled in recognising the last days of life. Ensures that all services/organisations understand their role in caring for people at the end of life.

1.2 Identification of the lead health practitioner

Once it has been recognised that a person is in their last days of life, the health care team should identify a specific health practitioner to lead the care of that person. This decision should be clearly documented. The lead health practitioner will generally not be a specialist palliative care doctor or nurse but will usually be the person's primary health care provider. In the community this will most likely be the person's general practitioner (GP) (or if appropriate, a nurse practitioner). In the acute hospital the lead practitioner will be the person's senior medical officer/consultant. The care plan should also clearly identify who to contact when this practitioner is unavailable. This is important in order to maintain continuity of care 24/7 and to ensure that any changes or concerns are communicated in a timely fashion. On occasions, the lead practitioner may need to be changed. This must be also be documented.

	Attributes/indicators
Person receiving care and family/whānau	Know who is responsible for care, and that someone will be available for support outside of normal working hours.
Attending health practitioner	Follows a clear process for appointing a lead health practitioner or a designated representative. Is aware at all times who the lead health practitioner (or designated representative) is and how and when to make contact. Has access to specialist palliative care support 24/7.
Clinical service/ organisation	Ensures that the lead health practitioner role is supported and that they are committed to the person and their family/whānau. Ensures that lead health practitioners (or designated representatives) are contactable within working hours and out of hours. Ensures access to specialist palliative care support 24/7 according to clear processes.
System (DHB)	Recognises the importance of the relationship between providers of primary and specialist palliative care, and ensures 24/7 availability of specialist palliative care support for all care settings.

1.3 Assessment of physical needs

The attending health practitioner should conduct a baseline assessment to identify the person's priorities of care, symptom management needs and physical care needs (which may include skin integrity, bowel cares, mouth cares and pressure relief). The baseline assessment might include a diagnosis about the person's changing condition and should be documented by the practitioner.

The baseline assessment should include conversations with the person and their family/whānau about factors contributing to the person's changing condition and options for an individual plan of care. The health practitioner should clearly document these conversations.

	Attributes/indicators
Person receiving care and family/whānau	Know that changes are occurring in the person's condition, what these changes are due to, and how their care will be managed as a result.
Attending health practitioner	Understands the importance of the baseline assessment. Discusses options for an individualised plan of care with the person and their family/whānau. Ensures the assessment and any conversations are comprehensively documented.
Clinical service/ organisation	Provides tools for undertaking and documenting the baseline assessment and ongoing evaluation of care.
System (DHB and Ministry of Health)	Ensures the workforce is educated and skilled to provide baseline assessments; if necessary, through workforce development planning.

1.4 Review of current management and initiation of prescribing of anticipatory medication

Doctors and nurse practitioners should prescribe medication for the person as appropriate to address the five most common symptoms experienced in the last days of life. The Working Group recommends anticipatory prescribing, to ensure minimal delay and distress. The five most commonly recognised actual or potential symptoms are:

- pain
- agitation/delirium/terminal restlessness
- respiratory tract secretions
- nausea and vomiting
- breathlessness (dyspnoea).

The health practitioner should regularly review medications and the need for invasive procedures (such as blood tests and X-rays).

	Attributes/indicators
Person receiving care and family/whānau	Where possible, feel supported and encouraged to communicate preferences and priorities regarding care and treatment so that the person can be as comfortable and pain-free as possible.
Attending health practitioner	Includes family/whānau in discussions about management of symptoms and changes in the care plan, if that is the person's wish. Has the skills and knowledge to undertake a comprehensive assessment of the person's current symptoms and to deliver the appropriate pharmacological and non-pharmacological management. This will include, in particular, the five most commonly occurring symptoms at the end of life. Provides education to family/whānau members administering medication. Responds to changing needs and symptoms, and regularly reviews pharmacological and non-pharmacological management.
Clinical service/ organisation	Ensures that there is a framework in place for pre-emptive prescribing and access to appropriate medications. Ensures that staff are educated and trained in management of symptoms in the last days of life.
System (DHB)	Monitors best practice in the management of symptoms in the last days of life, in conjunction with any national programmes for quality indicators.

1.5 Assessment of the person's preferences for care

Clear communication between a health practitioner and a person in their last days of life is fundamental. Health practitioners should clearly communicate all decisions leading to a change in care, and document this conversation. They should assess the person's ability to communicate, and document:

- preferences the person may have to allow a natural death
- whether an advance care plan or advance directive is in place, and whether the person has appointed an enduring power of attorney
- the person's wishes in relation to their preferred place of care and death and the method of disposition after death, such as burial or cremation.

Health practitioners should handle conversations with sensitivity, and include the family/whānau in discussions. Where a person is unable to communicate because of the extent of their deterioration or other factors (such as cognitive capacity), practitioners should hold conversations about preferences with the family/whānau and document the discussion.

	Attributes/indicators
Person receiving care and family/whānau	Are encouraged to talk (for the person, as they are able) about their preferences for care and their wishes for what happens after the person's death.
Attending health practitioner	Makes sure there is an opportunity for conversations with the person and/or their family/whānau about preferences for care and what happens after death, and documents any conversations accordingly. Holds these conversations in a language the person and their family/whānau can understand, with the assistance of an interpreter if needed.
Clinical service/ organisation	Ensures that facilities have private areas in which discussions can take place, and provides access to interpreting services, if required.
System (DHB)	Ensures that all services offer environments that enable privacy for sensitive and compassionate conversations.

1.6 Identification of communication barriers

Health practitioners should identify potential barriers to full communication and provide appropriate additional support. In the case of language barriers, services must offer an interpreter.

Health practitioners should maintain accurate information about an appropriate contact person within the family/whānau; this may not always be the first contact. In some situations, the person or their family/whānau appoints a spokesperson who acts as the key contact. Health practitioners should document:

- the first contact
- whether there is a key spokesperson for the family/whānau, and who this person is
- whether an enduring power of attorney has been or should be activated
- whether there is a valid advance care plan or advance directive that requests specific person(s) are consulted in the event of the person losing competence or becoming unable to communicate.

	Attributes/indicators
Person receiving care and family/whānau	Inform health practitioners of key contacts for family/whānau and any other communication requirements/preferences.
Attending health practitioner	Clearly documents the person's identified key spokesperson, enduring power of attorney and/or first contact. Makes every effort to communicate regularly with nominated people. Ensures that, where there is a valid advance care plan or advance directive, this is honoured
Clinical service/ organisation	Provides support for the person and their family/whānau to make their preferences understood, including through an interpreter if required. Ensures that practitioners record this information accurately and communicate such information in an appropriate manner between services/providers.
System (DHB and Ministry of Health)	Considers and enables appropriate information sharing across care settings, for example through improved electronic records and information technology.

1.7 The person's awareness of their changing condition

Where appropriate, health practitioners should initiate a conversation with the person to explain the changing nature of their condition and the possibility they may be entering into the last few days of life. Practitioners should carefully assess whether the person wants to hold such a conversation, and always respect their views.

Engaging in such conversations can be very difficult. Practitioners should make use of resources such as local policies and guidelines and any training opportunities regarding how to break bad news and hold compassionate conversations.

	Attributes/indicators
Person receiving care and family/whānau	Are informed about any changes in the person's condition, and, if there is a possibility that they may only have a few hours or days to live, are as prepared as possible.
Attending health practitioner	Is skilled, or has access to an appropriately skilled person, to have compassionate conversations that may include breaking bad news. Holds these conversations where necessary, according to the person's wishes. Clearly documents these conversations.
Clinical service/ organisation	Maintains policies and/or guidelines to guide health practitioners in holding conversations about death and dying. Provides training and qualifications in communication skills and compassionate communication, or provides access to such training. Provides or refers staff for support and clinical supervision as required, recognising the impact that caring for people in the last days of life can have on the health of practitioners themselves.
System (DHB)	Recognises the challenges associated with conversations regarding death and dying, and provides support for health practitioners conducting such conversations to acquire the necessary skills.

1.8 The family/whānau's awareness of the person's changing condition

Clear, sensitive and regular communication with the family/whānau is fundamental to the quality of care of people in their last days of life. Where appropriate, health practitioners should hold documented conversations with the family/whānau to communicate the changing nature of the person's condition and the possibility they may be entering into the last few days of life. Practitioners should carefully assess whether the family/whānau wants to hold such a conversation, and always respect their views.

Engaging in such conversations can be very difficult. Practitioners should make use of resources such as local policies and guidelines about how to break bad news and have compassionate conversations.

	Attributes/indicators
Person receiving care and family/whānau	Have time to discuss the change in condition and its implications in a way they understand.
Attending health practitioner	Is skilled, or has access to an appropriately skilled person, to have compassionate conversations that include breaking bad news. Holds these conversations where necessary, according to the family/whānau's wishes. Clearly documents these conversations.
Clinical service/ organisation	Maintains policies and/or guidelines to guide health practitioners in holding conversations about death and dying. Provides an appropriate place to record conversations. Provides training and qualifications in communication skills and compassionate communication, or provides access to such training. Provides or refers staff for support and clinical supervision as required, recognising the impact that caring for people in the last days of life can have on the health of practitioners themselves.
System (DHB)	Recognises the challenges associated with conversations regarding death and dying, and provides support for health practitioners conducting such conversations.

1.9 Discussion of cultural needs

Health practitioners should hold and document conversations with the person and their family/whānau about cultural needs. This conversation could include identification of specific customs, traditions or cultural practices that are important to the person, and how to accommodate them in the plan of care.

Note that it is important for health practitioners to identify a person's ethnicity, because it can indicate particular ways a person may wish to be cared for in their last days of life.

	Attributes/indicators
Person receiving care and family/whānau	Receives, or sees the person receiving, care and treatment in a way that reflects customs, traditions or cultural practices that are important to them.
Attending health practitioner	As part of any baseline or ongoing assessments, provides an opportunity to discuss with the person and family/whānau their preferences regarding customs, traditions or cultural practices, and incorporates them into the individual plan of care. Ensures that cultural needs are honoured, including, where necessary, through referrals to other practitioners, such as Whānau Care or Pacific Island Services. Has an understanding of the key principles of Treaty of Waitangi and its implications in providing health care and support.
Clinical service/ organisation	Ensures that staff have access to education and training in cultural competency. Ensures that staff can access specialised cultural support such as kaumātua and kaiāwhina. Ensures that written resources are available in appropriate languages. Ensures that the service or organisation provides care that acknowledges the key principles of the Treaty of Waitangi.
System (DHB)	Recognises the importance of an appropriate cultural approach to the care of people in their last days of life. Ensures that health practitioners can access education and training in cultural contexts, particularly if they are unfamiliar with the New Zealand setting.

1.10 Provision of opportunity for the person and family/whānau to discuss what is important to them

When a person learns that they are in the last few hours or days of life, the things that were once important to them may well change. It may be helpful to hold a conversation about this with the person themselves, or with their family/whānau. Such a conversation may cover the person's religious or spiritual needs and beliefs. For some, it may involve a re-exploration of their faith; others may feel a need to see a particular person, pet or place, or to have access to particular music, photographs or films.

A conversation about beliefs and values may cover the person's or their family/whānau's wishes as to after death care or funeral arrangements.

	Attributes/indicators
Person receiving care and family/whānau	Have the opportunity to express their thoughts, wishes, needs and beliefs.
Attending health practitioner	Provides an opportunity for conversations with the person and their family/whānau to identify what is important to them, and, where appropriate, their wishes as to after death care and funeral arrangements, and clearly documents such conversations. Where possible, facilitates the wishes and needs of the person and their family/whānau, including through referral to chaplaincy teams or other spiritual providers.
Clinical service/ organisation	Provides access to appropriate services, including chaplaincy and spiritual providers of all denominations. Provides staff with access to education and training on how to have these conversations, and how to access information on provision of care specific to various faiths or religions.
System (DHB)	Promotes an approach to care in which people in their last days of life are able to express their thoughts, wishes, needs and beliefs. Recognises the challenges associated with conversations about death and dying, and provides support and education opportunities for health practitioners conducting such conversations.

1.11 Provision of food and fluids

The provision of food and fluids in the last days of life is an important aspect of care. Health practitioners should hold conversations with the person and their family/whānau about the role of food and fluids at this time, and associated risks. Health practitioners should support the person to continue to maintain an oral intake for as long as is safe and warranted, if they wish to do so.

Health practitioners should make written material available to family/whānau about food and fluid in the last days of life, to ensure that they fully understand the risks and benefits.

	Attributes/indicators
Person receiving care and family/whānau	Can eat and drink if they feel able to do so.
Attending health practitioner	Discusses the benefits and risks of maintaining oral intake with the person and their family/whānau, and supports the person to eat and drink for as long as they are able or wish to do so, including through parenteral feeding if appropriate. Provides the person and their family/whānau with appropriate written resources to support the discussion if needed. Clearly documents an individual plan for fluids and food and reviews it at least daily.
Clinical service/ organisation	Ensures that appropriate written information about the risks and benefits of food and fluid in the last days of life is made available for health practitioners to provide to the person and their family/whānau. Ensures that there is a process for referral to other services that can provide support or advice on this topic.
System (DHB)	Supports the development of resources to provide guidance on the provision of food and fluids in the last days of life. Ideally these resources should be nationally consistent and widely disseminated.

1.12 Availability of equipment to support the person's care needs

People in their last days of life may require specialised resources or equipment; for example, equipment for a continuous subcutaneous infusion (CSCI) of medication, pressure-relieving mattresses, hospital beds or sliding sheets. Services need to ensure such equipment is available.

	Attributes/indicators
Person receiving care and family/whānau	Have access to equipment that helps to make the person's last days of life more comfortable and manageable.
Attending health practitioner	Ensures regular review of the person's care needs, so that necessary equipment may be provided without delay. Is aware of the referral process to other members of the allied health team who can facilitate access to equipment.
Clinical service/ organisation	Ensures that equipment is accessible in a timely manner, irrespective of care setting. Maintains processes for organising and delivering equipment in a timely manner – for example, where rapid discharge home to die is needed.
System (DHB)	Maintains clear processes for accessing funding for equipment required in a person's last days of life.

1.13 Consideration of cardiac devices

If a person in their last days of life has a cardiac device in place such as an implantable cardioverter defibrillator (ICD) or ventricular assist device, health practitioners need to hold a conversation with the person and their family/whānau about what can occur in the last days of life; whether the cardiac device should be deactivated; and, if so, how and when. Practitioners should clearly document such conversations and the plan of care in relation to the device.

	Attributes/indicators
Person receiving care and family/whānau	For the person, is as comfortable as possible and free from distressing symptoms. For the person and their family/whānau, are aware of the rationale for deactivation of cardiac devices.
Attending health practitioner	Ensures that if the person has a cardiac device, they hold and document a conversation with the person and/or their family/whānau about what can occur in the last days of life; whether the device should be deactivated; and, if so, how and when.
Clinical service/ organisation	Maintains a clearly documented process and guidelines about management of cardiac devices in the last days of life, including a pathway to access appropriately skilled staff members (eg, cardiology technicians) and equipment for deactivation.
System (DHB)	Ensures that appropriate information on cardiac devices is available and staff in all care settings have access to skilled health practitioners.

1.14 Advice to relevant agencies of the person's deterioration

It is likely that a number of services or agencies will have been involved in the care of people in their last days of life. Such services could include general practitioners, district nursing services, emergency services and specialist referral teams (such as hospice or cardiology). Lead health practitioners should inform these agencies/services where possible of the change in the person's condition and the expectation that they will die in the next few hours or days. This is important in terms of future appointment-making and the continued care of close family/whānau members, as well as a matter of courtesy.

	Attributes/indicators
Person receiving care and family/whānau	Have confidence that relevant services/agencies will be updated about the person's condition in a timely and sensitive manner.
Attending health practitioner	Where possible, identifies and documents services and agencies involved in the care of the person, and advises them of the change in the person's condition. Has an understanding of the Privacy Act 1993 and its requirements as to the content and method of communication of health information.
Clinical service/ organisation	Maintains processes to ensure that staff can make contact with relevant services and agencies in a straightforward and timely manner. Provides support and education on maintaining privacy of information shared with other agencies and health practitioners, including in terms of the Privacy Act 1993.
System (DHB)	Encourages and facilitates communication between organisations and agencies involved in the care of people in their last days of life, and facilitates communication between them. Provides mechanisms for managing and maintaining the privacy of health care information.

1.15 Provision of information to the family/whānau about support and facilities

The family/whānau of a person in their last days of life needs information about support and facilities available to them.

In a hospital setting, this could include information about car parking, public transport, kitchen facilities, cash machines, telephones, places family/whānau members themselves can sleep within the hospital where available, spiritual supports and chaplaincy services.

If the person is being cared for in their own home, it could include contact details for the district nursing team and specialist palliative care services, after-hours contact details for the lead health practitioner or their designated representative, and information on what to do in an emergency.

Health practitioners should document conversations with family/whānau about available support and facilities.

	Attributes/indicators
Person receiving care and family/whānau	Are provided with clear and timely information about support and facilities available to them.
Attending health practitioner	Provides information to the family/whānau about support and facilities. If the person is being cared for in a private residence, ensures the family/whānau has information about who to contact if the person's condition changes, and how they can make contact. Documents conversations held with the family/whānau about support and facilities.
Clinical service/ organisation	Develops written advice about support facilities available to family/whānau that is tailored to the individual care system.
System (DHB)	Ensures that information resources are of a high standard and are distributed where and when they are needed.

2. Ongoing assessment of the plan of care

Health practitioners should identify the individual care needs of a person in their last days of life, and create plans of care that are appropriate to the person's unique needs and agreed with the person and their family/whānau. Practitioners should undertake ongoing assessment of this plan.

Table 2: Ongoing assessment of the plan of care summary

Te taha tinana: ***Physical health***	**Te taha whānau:** ***Extended family health***
2.1 Development of an individualised plan of care 2.2 Ongoing assessment of the person's care	2.3 Conversations with the family/whānau about the person's changing condition
Te taha hinengaro: ***Mental health***	**Te taha wairua:** ***Spiritual health***
2.4 Provision of ongoing review	2.5 Discussing and addressing changing spiritual needs

2.1 and 2.2 Development of an individualised plan of care and ongoing assessment of the person's care

Health practitioners should develop an individualised care plan for a person in their last days of life, in collaboration with the person and their family/whānau. This plan should address the person's physical, mental, social, cultural and spiritual needs. Practitioners should clearly document the plan, and regularly review it.

Health practitioners should undertake regular assessments of the person's condition, to ensure that they can address changes in a timely manner. Practitioners should allow the person's family/whānau the opportunity to participate in their care.

	Attributes/indicators
Person receiving care and family/whānau	Receives, or sees that the person receives, care according to their unique needs.
Attending health practitioner	Creates a plan of care that is based on discussion with the person and their family/whānau, and offers a summary of the plan to the person and their family/whānau. Ensures that the plan specifies the frequency of ongoing assessments and recognises the needs of the person as central, understanding that needs can change rapidly during the dying process. If appropriate, provides written information to help the family/whānau to understand what changes may occur to the person in their last days of life. Provides the family/whānau with the opportunity to assist with the person's care, and provides support and education if they choose to do so.
Clinical service/ organisation	Recognises the need for frequent assessments at the end of life. Provides processes for staff to clearly document individualised plans of care, including regular reviews, assessments and evaluations of care.
System (DHB)	Supports the creation and implementation of a template for documentation of the individualised plan of care, to facilitate transfer from one care setting to another where necessary. Monitors quality indicators and audits processes and plans of care.

2.3 Conversations with the family/whānau about the person's changing condition

Health practitioners should hold conversations with the family/whānau on an ongoing basis, and particularly when there is a change in the person's condition. Communication should always be clear and respectful.

	Attributes/indicators
Person receiving care and family/whānau	Is promptly informed if the person's condition changes, and is involved in conversations about options for ongoing care.
Attending health practitioner	Holds conversations with the family/whānau when the person's condition changes about options for ongoing care, and documents these conversations.
Clinical service/ organisation	Enables staff to access education and training on how to have these conversations.
System (DHB)	Recognises the challenges associated with conversations about death and dying, and provides support and education opportunities for health practitioners conducting such conversations.

2.4 Provision of ongoing review

Health practitioners should hold ongoing conversations with the person and their family/whānau to ensure that they can address their concerns and wishes. They should review the individual plan of care accordingly.

	Attributes/indicators
Person receiving care and family/whānau	Are allowed to express their wishes and/or concerns.
Attending health practitioner	Holds regular conversations with the person to discuss and address wishes or concerns, and clearly documents these conversations.
Clinical service/ organisation	Maintains policies and/or guidelines to support and guide health practitioners in conducting conversations about death and dying, acknowledging the difficulties associated with these conversations. Provides an appropriate place to hold and document conversations.
System (DHB)	Recognises the challenges associated with conversations regarding death and dying, and provides support and education opportunities for health practitioners conducting such conversations.

2.5 Discussing and addressing changing spiritual needs

Things that may have been important in a spiritual sense to a person at the time of a baseline assessment may change quickly once that person is in the last few hours to days of life. Health practitioners should hold regular conversations to allow the person to convey their wishes regarding their spiritual needs, and address these wishes wherever possible.

	Attributes/indicators
Person receiving care and family/whānau	Have the opportunity to express their changing spiritual needs. Have the support of a kaiāwhina and/or kaumātua of their choice if requested.
Attending health practitioner	Holds conversations with the person and their family/whānau about what is important to them, and clearly documents these conversations. Where appropriate, refers people to chaplaincy teams or other spiritual providers including kaiāwhina and/or kaumātua.
Clinical service/ organisation	Provides access and referral procedures to appropriate services, including chaplaincy and spiritual providers of all denominations, kaumātua and kaiāwhina. Provides staff with access to education and training on how to have these conversations, and how to access information on provision of care specific to various faiths or religions.
System (DHB)	Recognises the challenges associated with conversations regarding death and dying, in particular relating to a person's spiritual needs. Provides support and education opportunities for all health practitioners (including kaiāwhina, kaumātua and chaplains) conducting such conversations.

3. Care after death

Every service that provides care for people in their last days of life should have an individual policy in place regarding the care of people and their family/whānau after death. However, certain elements of these policies should be standard.

Table 3: Care after death summary

Te taha tinana: *Physical health*	Te taha whānau: *Extended family health*
3.1 Verification of death 3.2 Dignity and respect for the person/tūpāpaku	3.3 Provision of information to the family/whānau about what to do next
Te taha hinengaro: *Mental health*	**Te taha wairua: *Spiritual health***
3.4 Assessment of family/whānau bereavement	3.5 Consideration of the spiritual, religious and cultural needs of the family/whānau 3.6 Availability of a private space for the family/whānau

3.1 Verification of death

	Attributes/indicators
Person receiving care and family/whānau	Is supported through the legal process as efficiently and sensitively as possible, so they can proceed with funeral arrangements as soon as possible.
Attending health practitioner	Verifies that death has occurred following clinical examination. Notifies the lead health practitioner of the designated representative. Is familiar with the local policy and accordingly completes the appropriate paperwork, including a medical certificate showing cause of death.
Clinical service/ organisation	Maintains policy and procedures relating to verification of death, including completion of the medical certificate of cause for death (HP4720) and permission to cremate, where required. Ensures that staff are trained and educated to meet legal requirements. Reviews policies and procedures relating to verification of death regularly.
System (DHB)	Ensures that services/organisations are familiar with the legal requirements of after-death documentation.

3.2 Dignity and respect for the person/tūpāpaku

	Attributes/indicators
Person receiving care and family/whānau	Has their wishes and preferences carried out where possible.
Attending health practitioner	Supports the family/whānau if they wish to participate in after death care. Undertakes after death care according to local policy and procedure. Is familiar with the wishes and cultural requirements of the person and their family/whānau in terms of after death care. This may include washing of the person, removing any medical or nursing equipment, and dressing the person in clothes chosen by the family/whānau or in clean gowns. Returns personal belongings to the family/whānau in a respectful way. Informs all health care and social services previously involved in the person's care of the death, as appropriate.
Clinical service/ organisation	Provides staff with education and training on after death care, or provides access to such training.
System (DHB)	Has a process to ensure that services/organisations treat the person/tūpāpaku with dignity and respect at the time of death.

3.3 Provision of information to the family/whānau about what to do next

	Attributes/indicators
Person receiving care and family/whānau	Is aware of the processes that need to occur following the death, including funeral arrangements.
Attending health practitioner	Has a conversation with the family/whānau to ensure they have information about what they need to do next. Provides written material and information if required.
Clinical service/ organisation	Develops written resources to provide information to the family/whānau about what needs to occur following the death, including funeral arrangements.
System (DHB)	Has a process to ensure that information resources are of a high standard and distributed in a timely manner.

3.4 Assessment of family/whānau bereavement

	Attributes/indicators
Person receiving care and family/whānau	Is able to access information about bereavement support and counselling if needed.
Attending health practitioner	Has a conversation with the family/whānau about bereavement support. Conducts a bereavement assessment if the family/whānau wishes to have one, or if the health practitioner considers that one may be beneficial. If the family/whānau has grief needs beyond what the health practitioner can themselves provide, refers the family to other services.
Clinical service/ organisation	Develops a process for bereavement assessment, including documentation.
System (DHB)	Facilitates the development and implementation of comprehensive bereavement and counselling services.

3.5 Consideration of the spiritual, religious and cultural needs of the family/whānau

	Attributes/indicators
Person receiving care and family/whānau	Has the opportunity to express spiritual, religious or cultural needs.
Attending health practitioner	Provides an opportunity for conversation with the family/whānau about their spiritual, religious or cultural needs, and facilitates access to other services where necessary.
Clinical service/ organisation	Maintains a procedure for referral to other services. Provide staff with access to education and training on how to have these conversations, and how to access information on provision of care specific to various faiths or religions.
System (DHB)	Promotes an approach in which family/whānau are able to express their thoughts, wishes, needs and beliefs. Recognises the challenges associated with conversations about death and dying, and provides support and education opportunities for health practitioners conducting such conversations.

3.6 Availability of a private space for the family/whānau

	Attributes/indicators
Person receiving care and family/whānau	Has access to a private space to accommodate needs for prayer or karakia, or other cultural or spiritual needs.
Attending health practitioner	Respects the family/whānau's need for privacy, and ensures that a private environment is available as required.
Clinical service/ organisation	Ensures that private areas are available for grieving families/whānau in all settings.
System (DHB)	Requires services/organisations to provide private areas for grieving families/whānau.

Summary of components of care for people in their last days of life, resources, and communication needs

The following table sets out the components of care according to their relation to the dimensions of Te Whare Tapa Whā.

1. Baseline assessment

Te Whare Tapa Whā dimension	Components of care		Available resources/tools Available either from Part 4 of *Te Ara Whakapiri* (labelled 'A' to 'U') or externally		Health practitioner responsibility The communication needs to be involved in each component
Te taha tinana: *Physical health*	1.1	Recognition the person is dying or is approaching the last days of life	A B	Identifying the dying patient Identifying the dying patient algorithm	–
	1.2	Identification of the lead health practitioner	–		The lead health practitioner is identified and documented. A clear process for contacting the lead health practitioner and their designated representative within working hours and out of hours is provided to the family/whānau.
	1.3	Assessment of physical needs	C	Guideline for developing an individualised medical management plan for end of life: general principles	Baseline assessment is clearly documented in notes, and forms the basis of an ongoing symptom care plan. Options for the individualised plan of care for the person are discussed with the family/whānau.

Te Whare Tapa Whā dimension	**Components of care**		**Available resources/tools** Available either from Part 4 of *Te Ara Whakapiri* (labelled ‘A’ to ‘U’) or externally	**Health practitioner responsibility** The communication needs to be involved in each component
	1.4	Review of current management and initiation of prescribing of anticipatory medication	Nausea and vomiting: D Guideline for developing an individualised medical management plan for end of life: nausea and vomiting E Nausea and vomiting algorithm	Preferences for management are clearly documented and changes are discussed with the person and family/whānau wherever possible. The person and the family/whānau are aware of available medications and have access to medications prescribed. There is clear guidance for family/whānau on use of medications, with written instructions provided as necessary. Current prescribed medications are assessed, and non-essential medications discontinued. As per best practice, any allergies and drug intolerances must be identified and clearly documented.
			Pain: F Guideline for developing an individualised medical management plan for end of life: pain G Pain algorithm H Pain in patients with impaired renal function algorithm	
			Respiratory secretions: I Guideline for developing an individualised medical management plan for end of life: respiratory secretions J Respiratory tract secretions algorithm	
			Delirium/agitation: K Guideline for developing an individualised medical management plan for end of life: delirium, restlessness or agitation L Delirium/agitation algorithm	
			Breathlessness (dyspnoea): M Guideline for developing an individualised medical management plan for end of life: dyspnoea N Breathlessness/dyspnoea algorithm	
	1.7	The person’s awareness of their changing condition	R Breaking bad news flow chart O Rapid discharge checklist for the dying patient	If appropriate, a conversation is held and documented (noting exactly who has been party to the conversation) about the person’s changing condition that clearly conveys the person may only have a few hours or days to live. A conversation is held with all involved parties if transferring the person from one location to another is needed – eg, from hospital to home or hospice.

Te Whare Tapa Whā dimension	**Components of care**		**Available resources/tools** Available either from Part 4 of *Te Ara Whakapiri* (labelled 'A' to 'U') or externally	**Health practitioner responsibility** The communication needs to be involved in each component
	1.11	Provision of food and fluids	Organisation's individual resources on food and fluid in the last days of life	A conversation is held and documented on: • the benefits and risks of maintaining oral intake of food and fluid • requirements for parenteral feeding and fluids.
	1.12	Availability of equipment to support the person's care needs	–	A conversation is held and documented that clearly identifies changes in the person's condition that may necessitate access to specialised equipment.
	1.13	Consideration of cardiac devices	Heart Rhythm New Zealand Position Statement*:* Management of implantable cardioverter defibrillators (ICD) and pacemakers for patients nearing end of life (Heart Rhythm New Zealand 2014)	A conversation is held and documented about the implications of a cardiac device such as an ICD or a pacemaker in the last days of life and the person's or their family/whānau's preference regarding whether it should be deactivated, and how.
	1.14	Advice to relevant agencies of the person's deterioration	–	Relevant services and organisations are notified.
Te taha hinengaro: *Mental health*	1.5	Assessment of the person's preferences for care	Interpreters, if required Organisation's individual resources	A conversation is held and documented on: • language preference • preferences to allow a natural death • advance care plans/advance directives (these must be sighted and complied with if medically indicated) • preferences about place of care and death and for burial or cremation.
Te taha whānau: *Extended family health*	1.6	Identification of communication barriers	Interpreters, if required Example A: Planning for end-of-life care	A conversation is held and documented on: • barriers to communication • who the first contact is • whether there is a key spokesperson for the family/whānau • whether there is an enduring power of attorney in place.
	1.8	The family/whānau's awareness of the person's changing condition	P What to expect when someone is dying (information for family/whānau) Q Supporting care in the last hours or days of life: information for family/whānau/carers R Breaking bad news flow chart	Where appropriate, conversations are held and documented with the family/whānau to indicate the changing nature of the person's condition and the possibility they may be entering into the last few days of life.

Te Whare Tapa Whā dimension	**Components of care**		**Available resources/tools** Available either from Part 4 of *Te Ara Whakapiri* (labelled ‘A’ to ‘U’) or externally		**Health practitioner responsibility** The communication needs to be involved in each component
	1.9	Discussion of cultural needs	S	W.H.Ā.N.A.U: personalising care at end of life	A conversation is held and documented on: • beliefs and family/whānau traditions that may be important • important aspects about the person and/or the family/whānau that the service should know about.
	1.15	Provision of information to the family/whānau about support and facilities	Organisation’s individual resources		The family/whānau is aware of support and facilities available. Documentation of information is provided to family/whānau.
Te taha wairua: *Spiritual health*	1.10	Provision of opportunity for the person and family/whānau to discuss what is important to them	U	Spiritual care assessment tool based on FICA approach	A conversation is held and documented with the person and family/whānau on: • the wishes, thoughts and needs of the person and the family/whānau • considerations for after death care or funeral arrangements • potential referral to chaplaincy teams or other spiritual providers.

2. Ongoing assessment

Te Whare Tapa Whā	Component	Resources	Communication need
Te taha tinana: *Physical health*	2.1 Development of an individualised plan of care	Example A: Planning for end-of-life care Example B: Improving care of the dying guideline	A conversation is held and documented on: • summarising the plan of care • the frequency of ongoing assessments and reassessments • the possible rapidly changing needs of the person • the opportunity for family/whānau to participate in care of the person • available written information resources • the person's wishes and how they are being taken into account.
	2.2 Ongoing assessment of the person's care	–	A conversation is held and documented on changes in the person's condition.
Te taha whānau: *Extended family health*	2.3 Conversations with the family/whānau about the person's changing condition	P What to expect when someone is dying (information for family/whānau) Q Supporting care in the last hours or days of life: information for family/whānau/carers	A conversation is held and documented to ensure that the family/whānau understands what changes are occurring in the person's condition.
Te taha hinengaro: *Mental health*	2.4 Provision of ongoing review		A conversation is held and documented that includes discussion with the person about their wishes, thoughts and feelings.
		O Rapid discharge checklist	A conversation is held with all involved parties should it become apparent that a transfer from one location to another is needed – eg, from hospital to home or hospice.
Te taha wairua: *Spiritual health*	2.5 Discussing and addressing changing spiritual need	U Spiritual care assessment tool based on FICA approach	A conversation is held and documented that provides the opportunity for the person to express their changing spiritual needs.

3. Care after death

Te Whare Tapa Whā	Component		Resources		Communication need
Te taha tinana: *Physical health*	3.1	Verification of death	Local and/or regional protocols		Communication to services involved in post-death arrangements within the service is documented.
	3.2	Dignity and respect for the person/tūpāpaku	–		Health care/social services that have been previously involved in the person's care are aware of the death.
Te taha whānau: *Extended family health*	3.3	Provision of information to the family/whānau about what to do next	Organisation's individual resources		Documentation of information is provided and discussions are had about next steps.
	3.4	Assessment of family/whānau bereavement	T	Bereavement information and assessment	Conversations are held and documented with the family/whānau about access to bereavement support.
Te taha hinengaro: *Mental health*	3.5	Consideration of the spiritual, religious and cultural needs of the family/whānau	U	Spiritual care assessment tool based on FICA approach	An opportunity is provided for conversations with the family/whānau about what is important to them at this time.
Te taha wairua: *Spiritual health*	3.6	Availability of a private space for the family/whānau	–		The service manager is informed that a room may be required.

Part C: Examples of approaches to care for people in their last days of life

Introduction

Nationally, a number of services involved in the care of people in their last days of life have developed guidelines for providing care to people in their last days of life, and for documenting the process.

Examples A and B in this part are two such approaches, produced by Waitemata DHB and Hutt Valley DHB respectively. They are based on local and regional identified needs, but can be adapted by service providers to suit their own needs.

Example A: Planning for end-of-life care

Source: Waitemata District Health Board (2014)

Definition of end-of-life at Waitemata DHB is when death is expected within hours/days during this admission. This includes care during and around the time of death, and immediately afterwards.

End-of-life does not mean ‘no care’; it is a change in focus from active treatment to best supportive palliative care.

As with all clinical guidance, this document aims to support, but does not replace, clinical judgement.

The patient is required to be assessed and a care plan should be developed in line with the patient’s (if able) and family/whānau’s wishes and needs.

Family/whānau contact details	
If the patient’s condition changes, who should be contacted first?	**1st contact:** Name:…………………… Relationship:…………………… Telephone no:…………………… Mobile no:……………………
If the patient’s condition changes, when should they be contacted?	At any time ☐ Not at night time ☐
If the first contact is unavailable, who should be contacted?	**2nd contact:** Name:…………………… Relationship:…………………… Telephone no:…………………… Mobile no:……………………
When to contact	At any time ☐ Not at night time ☐
Next of kin, if different from above	Name:…………………… Relationship:…………………… Telephone no:…………………… Mobile no:……………………

The patient will require daily review by the medical team. End-of-life cares need to be continually reviewed and discontinued if the patient’s condition improves.

Always consider if the Hospital Specialist Palliative Care Team needs to be consulted, to help in patient management, when there are complex symptom management or emotional issues.

Advance care plan

Does the patient have an existing Advance Care Plan or Directive documenting their wishes at end-of-life?	Yes ☐	No ☐	
Is an Existing Power of Attorney for Health in place?	Yes ☐ Name: .... Relationship: .... Contact no:	No ☐	

Recognition of dying

Is the patient aware they are dying?	**Document clearly in clinical notes what was said and by whom.** Date and time of conversation: ....
Is the family/whānau aware the patient is dying? * Both the patient and family/whānau awareness and understanding of the diagnosis are communicated and documented. ***See guidelines on 'Communication'** and **'Breaking Bad News'.***	**Document clearly in clinical notes what was said and by whom.** Date and time of conversation: .... Name of family informed: ....

Preferred place of care

Patient's preferred place of care.	Home ☐	Hospital ☐	Hospice ☐
Family/whānau's preferred place of care. **** If Home, see 'Rapid Discharge Checklist'.***	Home ☐	Hospital ☐	Hospice ☐

Clinical goals – medical staff

Current medications reviewed and non-essential medications discontinued.	Yes ☐	No ☐	
PRN subcutaneous anticipatory medications charted. See ***'Anticipatory Prescribing Guidelines'***.	Yes ☐	No ☐	
Inappropriate interventions discontinued, eg, blood tests, NEWS, routine observations, blood glucose monitoring, oxygen therapy.	Yes ☐	No ☐	
The need for artificial hydration/nutrition is reviewed by the MDT (a reduced need for food/fluids is part of the normal dying process).	Yes ☐	No ☐	
Do Not Resuscitate status recorded on CPR Decision form.	Yes ☐	No ☐	
Implantable cardioverter defibrillator (ICD) is deactivated.	Yes ☐	No ☐	N/A ☐
Organ donation considered and information leaflet given to patient/family/whānau.	Yes ☐	No ☐	

Cultural	
If able, the patient is given the opportunity to discuss their cultural needs, eg, needs now, at death and after death.	**Document clearly in clinical notes what was said and by whom.** Date and time of conversation:......................................
Family/whānau is given the opportunity to discuss their cultural needs at this time, eg, needs now, at death and after death. Refer to appropriate cultural support, eg, Māori Health Service, Asian Support, Pacific Island Support.	**Document clearly in clinical notes what was said and by whom.** Date and time of conversation:...................................... Name of family informed:... Yes ☐ No ☐ Service/s involved: .... Name of person/s involved:... ....
Religious and spiritual	
If able, the patient is given the opportunity to express what is important to them at this time, eg, wishes, feelings, faith, beliefs, values (needs now, at death and after death).	**Document clearly in clinical notes what was said and by whom.** Date and time of conversation:......................................
The family/whānau is given the opportunity to discuss what is important to them at this time, eg, wishes, feelings, faith, beliefs, values (needs now, at death and after death). Offer Hospital Chaplain Service or contact patient’s preferred support person if required.	**Document clearly in clinical notes what was said and by whom.** Date and time of conversation:...................................... Yes ☐ No ☐ Contacted:...
Information and explanation	
Family/whānau given information on facilities available, eg, visiting times, parking, tea and coffee, quiet area, toilets.	Yes ☐ No ☐
Information sheet ***‘What to expect when someone is dying’*** given to family/whānau if appropriate.	Yes ☐ No ☐
Give ***‘Bereavement Information’*** leaflet and list of funeral directors if required.	Yes ☐ No ☐
After death care	
If not already received, give family/whānau ***‘Bereavement Information’*** leaflet and list of funeral directors if required.	Yes ☐ No ☐
Discuss as appropriate with family/whānau viewing of the body/tūpāpaku.	Yes ☐ No ☐
Community providers are notified of the patient’s death, eg, GP, district nurse, hospice. ***See policy and guidelines ‘Death of an In-patient’.***	Yes ☐ No ☐ Contacted:...

Note: CPR = cardiopulmonary resuscitation; GP = general practitioner; MDT = multidisciplinary team; NEWS = National Early Warning Score.

Example B: Improving care of the dying guideline

Source: Hutt Valley District Health Board (2014)

Patient's ID label ....

Improving the Care of the Dying Guideline

Primary diagnosis ....

Associated co-morbidities ....

See end-of-life care guide before you commence.

Prior to instituting ICOD, ensure the following.

- The consultant, along with relevant multidisciplinary members of the team, are in agreement with the diagnosis of dying.
- A family/whānau meeting is arranged (phone contact if this is not feasible).
- Ask family/whānau if they would like to have support/advice from someone in the Māori or Pacific Health Units.
- If the patient is Māori or Pacific – consult with the relevant Unit staff for support and or/advice to health practitioners.
- Consider social worker referral:
  - if requested by patient/family/whānau
  - to assist family/whānau with information/resources
  - to coordinate staff/family/whānau meeting to assist communication and planning
  - where complex psycho-social or health literacy issues are present
  - when the dying person has no identifiable/contactable next of kin.

Family/whānau discussion – *may* include and <u>must</u> be documented in patient notes.

- Active acute medical treatment is no longer in the patient's best interests.
- The goals of care are now optimal symptom management and family/whānau/patient support.
- Is there an existing Advance Plan of Care and/or EPOA for medical treatment? **If YES obtain copies for patient file.**
- Cardio-pulmonary resuscitation is no longer indicated and purple form complete and signed.
- Food/fluids by mouth, if safe to swallow, will be offered for comfort.
- Medications will be rationalised to ensure comfort.
- Most appropriate site of care discussed.
- Specific wishes – religious, spiritual/cultural etc – discussed.
- Other issues identified – eg, health literacy, family/whānau disputes, disagreements.
- Family/whānau carer's wishes regarding contact, ie, any time, during nights etc (document on patient's admission form).

Medical management guidelines

Pharmacological management

- Cease all medications except those essential for symptom management/patient comfort
- Subcutaneous PRN medications written (see suggested algorithms attached)

Discontinue/cancel inappropriate interventions

- IV fluids/enteral feeding/TPN
- Antibiotics
- Routine vital sign recording
- Blood tests
- X-ray imaging
- Deactivate implanted defibrillator (if applicable)
- Other – specify ....

Medical agreement to the care plan

(Consultant or registrar to sign)

....
Name Time/date

Note: If potential patient complexity, eg, severe pain, confusion/agitation, complex psychosocial factors, family/whānau distress, a referral to the Palliative Care Service is advised.

Contact: .... or after hours ph: ....

Part D: Examples of tools and resources to guide the care of people in their last days of life

Introduction

Nationally, some services involved in the care of people in their last days of life have developed tools and resources to support quality care for people in their last days of life and for their families/whānau.

The tools and resources in this part are examples. They can be adapted as appropriate, based on local and regional identified needs.

Table 4: Tools and resources summary

	Te taha tinana: ***Physical health***
A	Identifying the dying patient
B	Identifying the dying patient algorithm
C	Guideline for developing an individualised medical management plan for end of life: general principles
D	Guideline for developing an individualised medical management plan for end of life: nausea and vomiting
E	Nausea and vomiting algorithm
F	Guideline for developing an individualised medical management plan for end of life: pain
G	Pain algorithm
H	Pain in patients with impaired renal function algorithm
I	Guideline for developing an individualised medical management plan for end of life: respiratory secretions
J	Respiratory tract secretions algorithm
K	Guideline for developing an individualised medical management plan for end of life: delirium, restlessness or agitation
L	Delirium/agitation algorithm
M	Guideline for developing an individualised medical management plan for end of life: dyspnoea
N	Breathlessness/dyspnoea algorithm
O	Rapid discharge checklist for the dying patient

	Te taha whānau: ***Extended family health***
P	What to expect when someone is dying (information for family/whānau)
Q	Supporting care in the last hours or days of life: information for family/whānau/carers
R	Breaking bad news flow chart
S	W.H.Ā.N.A.U.: personalising care at end of life

	Te taha hinengaro: ***Mental health***
T	Bereavement information and assessment

	Te taha wairua: ***Spiritual health***
U	Spiritual care assessment tool based on FICA approach

Tool A: Identifying the dying patient

Source: Waitemata District Health Board (2014)

Overview

Purpose

- Identifying that someone is dying is a **process** with significant implications and one that is best carried out by the doctors involved in the patient's care.
- It is important that dying is identified as early as possible, as this can ensure that the appropriate care and communication needed by patients and families/whānau are anticipated and provided. It also allows the clinical team to prioritise the goals of comfort and support based on the patient's preferences.

Scope

This document applies to End of Life Care in the Medical and Surgical Divisions.

Definitions

End of Life Care Definitions, as adopted by Waitemata District Health Board.

End of life

The end-of-life phase begins when a judgement is made that death is imminent (expected within hours–days during this admission). It may be the judgement of the health/social care professional or team responsible for the care of the patient, but it is often the patient or family/whānau who first recognises death is imminent.

End-of-life care

End-of-life care is the provision of supportive and palliative care in response to the assessed needs of the patient and family/whānau during the end-of-life phase. It focuses on preparing for an anticipated death and managing the end of a life-limiting or life-threatening condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the person and the family/whānau to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family (The New Zealand Palliative Care Glossary 2015).

Imminent death

In Waitemata DHB, imminent death is when death is expected within hours–days during this admission (Waitemata DHB End of Life Care Project Steering Group 2013).

Identifying the dying patient

Identifying dying

There may be clinical indicators that a patient is imminently dying. An advanced cancer patient with no chance of a cure may be entering the dying phase if they have been deteriorating over a period of days or weeks and two of the four criteria listed below are present.

The patient is:

- bed bound
- semi-comatose
- only able to take sips of fluids
- no longer able to take oral medication.

Such criteria may not be appropriate in patients who do not have cancer but may still provide a useful guide.

Process of dying

While there may be many different ways of dying, the most common mode of dying involves the following:

- a period of increasing weakness and tiredness resulting in the person spending more and more of their time in bed
- a period of withdrawal with the person spending less time awake and increasing time asleep, decreasing intake of food and medicine, and decreased interaction with others
- a period of unconsciousness with no waking
- cooling of peripheries as the blood circulation is diverted to central processes
- irregularities of heart beat due to metabolic or vascular changes
- stiffness caused by immobility
- breathing patterns change as the person becomes more deeply unconscious and control of breathing is driven by the build-up of carbon dioxide in the system. When the level of carbon dioxide is low, there is no drive to take a breath and so there may be long gaps without breathing. Then when the carbon dioxide builds up in the system, this will eventually cause the body to take several big breaths to expel carbon dioxide. This pattern of intermittent breathing is called Cheyne–Stokes breathing
- difficulties in swallowing often occur in the days or hours before death and may lead to pooling of saliva at the back of the throat. This can cause noisy breathing, often referred to as the ‘death rattle’. This can be very distressing for relatives and carers but is not thought to cause upset for the unconscious patient.

Managing the dying process

Some people die without pain or distress even when death is expected. However, there are five symptoms specifically associated with the dying process. It is important that there is a plan for if/when they arise so that symptom management is optimised. Not every dying patient experiences these symptoms, but some may experience all five.

The five symptoms associated with dying are:

- pain
- nausea and vomiting
- agitation and distress
- respiratory tract secretions
- breathlessness.

Often clinical staff have the skills and knowledge to effectively manage the symptoms of dying. However, there are occasions when the input of a specialist palliative care service will be required, particularly when symptoms prove refractory or difficult to control.

Anticipatory prescribing

- It is important to anticipate potential symptoms, and health care professionals need to be enabled to respond quickly should a symptom arise or when swallowing becomes difficult. Anticipatory prescribing of drugs is important to ensure a patient is not left in pain and distress for a period of time until a drug can be prescribed. It is important to refer to the Waitemata DHB guidelines for developing an Individualised Medical Management Plan for End of Life.
- The Specialist Palliative Care Team should be contacted when there is concern or uncertainty about prescribing for patients at the end of life.
- For further advice regarding anticipatory prescribing or prescribing for symptom management in the dying patient, please see the End-of-Life and Bereavement pages on the Waitemata DHB intranet site.

Conclusion

In providing end-of-life care, it is essential that:

- every effort is made to optimise symptom management
- dignity, respect and privacy are provided and maintained
- the individual needs and preferences of the patient are ascertained and fulfilled insofar as is possible
- communication is optimised for all people involved (patients, families/whānau and staff)
- the patient and family/whānau feel unhurried and valued
- staff are enabled and supported to deliver the highest standard of end-of-life care possible.

Standard of care

The standard of end-of-life care by which we should judge the care that we deliver is whether we would be content if that same care was given to our own family/whānau or to ourselves.

References

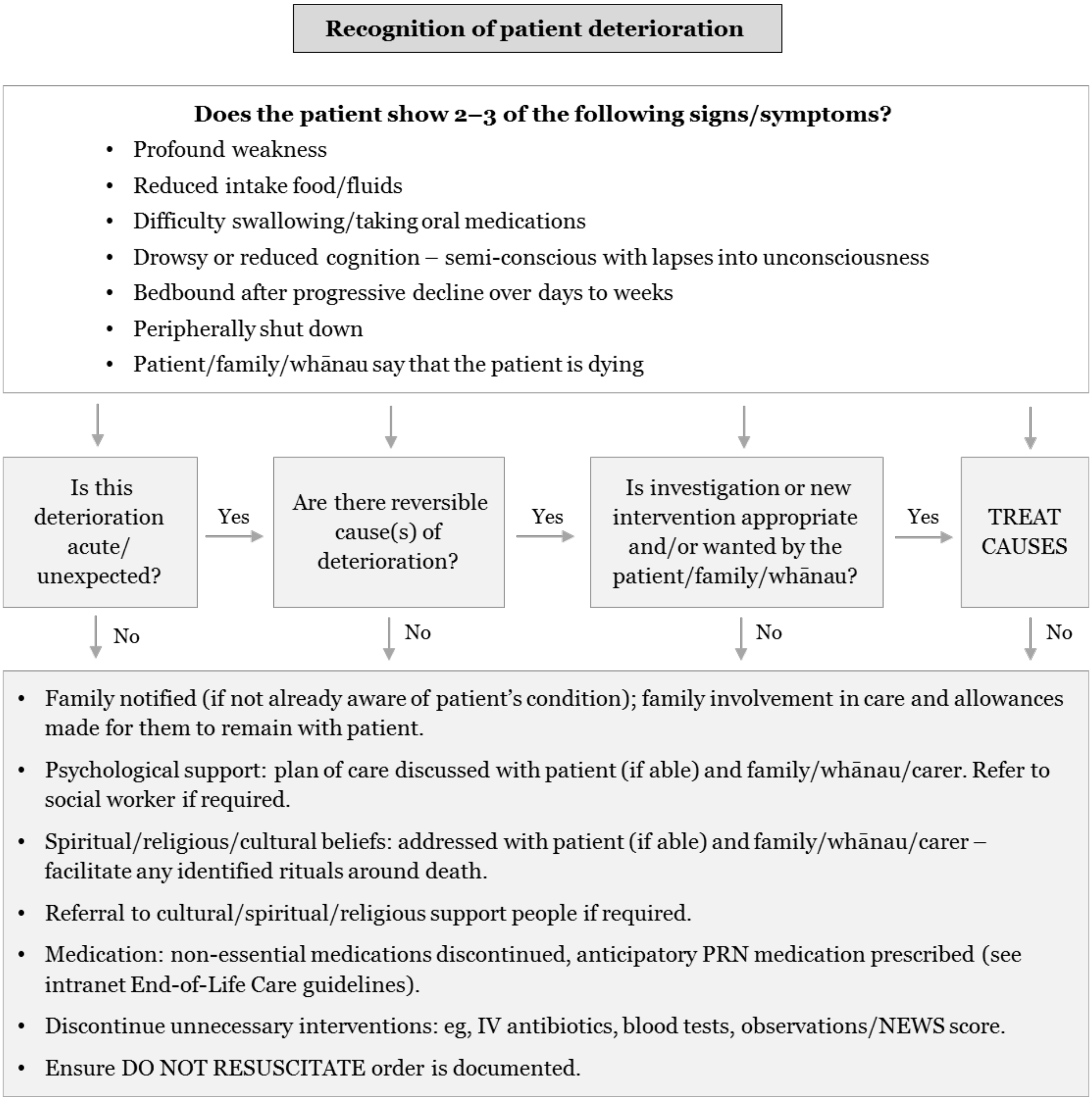
1 Hospice Friendly Hospitals. 2008. When a Patient is Dying booklet. Hospice Friendly Hospitals Programme.

2 Lynn J. 2004. *Sick to Death and Not Going to Take it Anymore!* Berkeley, CA: University of California Press.

3 Murray SA, Kendall M, Boyd K, Sheikh, A. 2005. Illness trajectories and palliative care. *British Medical Journal* 330:7498. doi:10.1136/bmj.330.7498.1007PMCID: PMC557152.

4 Palliative Care Council of New Zealand. 2012. *The New Zealand Palliative Care Glossary*. Wellington: Cancer Control New Zealand. URL: www.cancercontrolnz.govt.nz/sites/default/files/NZ%20Palliative%20Care%20Glossary.pdf

Tool B: Identifying the dying patient algorithm



Recognition of patient deterioration

Does the patient show 2–3 of the following signs/symptoms?

- Profound weakness
- Reduced intake food/fluids
- Difficulty swallowing/taking oral medications
- Drowsy or reduced cognition – semi-conscious with lapses into unconsciousness
- Bedbound after progressive decline over days to weeks
- Peripherally shut down
- Patient/family/whānau say that the patient is dying

Is this deterioration acute/unexpected?

Are there reversible cause(s) of deterioration?

Is investigation or new intervention appropriate and/or wanted by the patient/family/whānau?

TREAT CAUSES

- Family notified (if not already aware of patient's condition); family involvement in care and allowances made for them to remain with patient.
- Psychological support: plan of care discussed with patient (if able) and family/whānau/carer. Refer to social worker if required.
- Spiritual/religious/cultural beliefs: addressed with patient (if able) and family/whānau/carer – facilitate any identified rituals around death.
- Referral to cultural/spiritual/religious support people if required.
- Medication: non-essential medications discontinued, anticipatory PRN medication prescribed (see intranet End-of-Life Care guidelines).
- Discontinue unnecessary interventions: eg, IV antibiotics, blood tests, observations/NEWS score.
- Ensure DO NOT RESUSCITATE order is documented.

Tool C: Guideline for developing an individualised medical management plan for end of life: general principles

Source: Waitemata District Health Board (2014)

Identifying and communicating diagnosis to dying patient

Recognising someone is dying and predicting time of death is difficult. Signs and symptoms suggesting dying can be subtle.

- Last weeks of life are often characterised by progressive physical decline; frailty, lethargy, worsening mobility, reduced oral intake and poor response to medical interventions.
- Last days to hours of life may be characterised by further decline in oral intake, patient entirely bedbound, physical symptoms such as delirium, respiratory changes and cardiovascular changes (eg, peripheral vasoconstriction).

Recognition of dying and communicating this to the patient and family/whānau allows them time to express end-of-life care preferences and attend to important matters before the patient dies.

How you communicate this information is critically important, as is attention to differing cultural attitudes to these discussions.

Expected standard of care

- Inform medical/surgical consultant under whom patient is admitted that patient may be dying.
- Senior medical team member (consultant or registrar) will communicate diagnosis of dying to the patient/family/whānau and to other medical and nursing team members.
- Medical and nursing team will document a personalised care plan incorporating appropriate medical, nursing and allied health interventions. See 'Planning for End-of-Life Care' document.

Medication management: key principles

- Communicate medication plan to your patient and their family/whānau. Clear explanations reduce confusion/anxiety about what is occurring and why.
- Subcutaneous route (subcut) is preferred if patient is unable to swallow.
- Individualise each patient's medication plan according to their need and the risk:benefit ratio of the current or proposed interventions.
- Review your patient and the medication chart daily.
- Stop non-essential medications, those that are no longer conferring benefit, to reduce tablet burden. This may include antihypertensives, oral hypoglycaemics, diuretics, antibiotics etc, depending on the patient.
- Continue current medications if withdrawal could cause adverse effects. This may include anti-anginals, heart failure medications, steroids if steroid dependent, benzodiazepines if benzodiazepine dependent.

- Consider risks and benefits of administration of hydration by parenteral route before commencing or stopping intravenous or subcut fluids.
- Prescribe appropriate medications for existing symptoms as needed (PRN), subcut and orally if still able to swallow and if necessary via continuous subcutaneous infusion (CSCI).
- Prescribe PRN medications (‘anticipatory’ prescribing) for anticipated symptoms that may occur in dying patients subcut (and orally if still able to swallow).

Anticipatory prescribing for asymptomatic patients

- Common symptoms in dying patients include delirium (at times with restlessness and agitation) and accumulation of respiratory secretions. Occasionally dyspnoea, nausea, vomiting or pain may occur.
- Explain to patient and family/whānau that these symptoms may develop and that you are prescribing PRN medications in anticipation of these possibly occurring.
- Reassure patient and family/whānau that pain is not inevitable and may not occur if not already present.
- If more than three successive doses of any prescribed drug are required within the minimum administration period (eg, if prescribed Q1H PRN and three doses are required in three hours), review your patient and consider whether it would be preferable to administer these via continuous infusion syringe driver (NIKI T34).

Prescribing for symptomatic patients: general principles

Some medications can be administered via the subcutaneous (subcut) route, either PRN or via continuous subcutaneous infusion (CSCI), although not all drugs can be mixed together in the same syringe. For most drugs commonly used in palliative care, the oral dose is the same as the subcut dose. Notable exceptions are opioids.

Note: The doses of oral opioids (morphine, oxycodone or methadone) should be divided by 2 to get the equianalgesic subcutaneous dose.

Drug	Indications	Recommended oral:subcut ratio	Comments
Buscopan® (hyoscine butylbromide)	Respiratory secretions Colicky abdominal pain	**Not applicable:** Has extremely low oral bioavailability	Do not use Buscopan® orally for respiratory secretions as it has very low (< 10%) systemic bioavailability when given orally
Buscopan® (hyoscine butylbromide)	Respiratory secretions Colicky abdominal pain	**Not applicable:** Has extremely low oral bioavailability	Do not use Buscopan® orally for respiratory secretions as it has very low (< 10%) systemic bioavailability when given orally
clonazepam	Sedation Seizures Some pain states	1:1	Seldom used as clonazepam can be adsorbed into tubing
cyclizine	Nausea/vomiting	1:1	**Can crystallise with some drugs; check compatibility tables**
dexamethasone	Raised intracranial pressure Several pain states	1:1	**Can crystallise with some drugs; check compatibility tables**
diclofenac	Pain		Seldom used
fentanyl	Pain Dyspnoea	**Not applicable:** Not given orally	Can be used intranasally or submucosally
haloperidol	Nausea/vomiting Delirium	1:1	
hyoscine hydrobromide (Scopoderm®)	Respiratory secretions Nausea/vomiting	**Not applicable:** Not given orally	
ketamine	Pain	**Not applicable:** Seldom given orally	
levomepromazine (Nozinan®)	Nausea/vomiting (4th line) Delirium (3rd line) Sedation (2nd line)	1:1 (or 2:1 for patients on higher oral doses)	
methadone	Pain	1:1 or 2:1 (for patients on higher oral doses)	Divide oral dose by 2 to get subcut dose. For patients on low doses (≤ 20 mg), the 1:1 ratio may be required
metoclopramide	Nausea/vomiting	1:1	
midazolam	Anxiolytic Sedation Seizures	**Not applicable:** Has low oral bioavailability	
morphine sulphate and tartrate	Pain Dyspnoea	2:1 or 3:1	Divide oral dose by 2 (or 3 if patient is opioid toxic)
octreotide	Antisecretory	**Not applicable:** Not given orally	
oxycodone hydrochloride	Pain Dyspnoea	2:1	This is a conservative conversion and some patients may need higher doses

Tool D: Guideline for developing an individualised medical management plan for end of life: nausea and vomiting

Source: Waitemata District Health Board (2014)

Key principles

The key principles in effective management of nausea and vomiting are:

1. use a parenteral route to ensure absorption of the drug: subcutaneous (subcut) route preferred
2. choose **one** drug. Give it regularly, at appropriate doses to **prevent** symptoms (ie, not PRN)
3. choose a second drug and prescribe it PRN for breakthrough symptoms.

Anticipatory prescribing in asymptomatic patients

Use one or more of the following antiemetics.

Antiemetic	Usual dose and frequency	Route	Maximum daily dose	Comments
haloperidol	0.5–1 mg Q4–6H PRN	subcut	5 mg/24 hrs	Do not use in Parkinson's disease/similar disorders Also useful for delirium
metoclopramide	10 mg Q6–8H PRN	subcut	100 mg/24 hrs	Use if prokinetic required Do not use in Parkinson's disease/similar disorders Avoid if bowel obstruction with colicky abdominal pain
levomepromazine (Nozinan ®)	6.25 mg Q4–6H PRN Generally used as a third line antiemetic, especially in ambulatory patients	subcut	25 mg/24 hrs	A broad spectrum antiemetic Can be very sedating in some patients: • avoid if sedation undesirable • not generally recommended for ambulant patients

Symptomatic patients or already on medication for nausea and/or vomiting

If symptoms are well controlled on current oral PRN or regular antiemetic, stop oral antiemetic and continue administration via subcutaneous (subcut) route in anticipation that patient may soon be unable to swallow.

If symptoms are not well controlled:

- review patient, exclude reversible causes and treat reversible causes if appropriate:
  - it may not always be appropriate to attempt to reverse causes in patients at end of life; the burden of treatment may outweigh the benefit
  - it may be appropriate to treat easily reversible causes such as raised intracranial pressure with corticosteroids
- choose the most appropriate antiemetic for the postulated cause:
  - eg, metoclopramide (prokinetic) for gastric stasis; haloperidol for opioid induced nausea

OR

- use levomepromazine (a broad spectrum antiemetic useful for most causes of nausea and vomiting) **provided** that sedation is acceptable to the patient and family/whānau
- administer the chosen antiemetic regularly via continuous subcutaneous infusion (CSCI)
- prescribe a second line antiemetic for PRN use in case the drug you have chosen is ineffective.

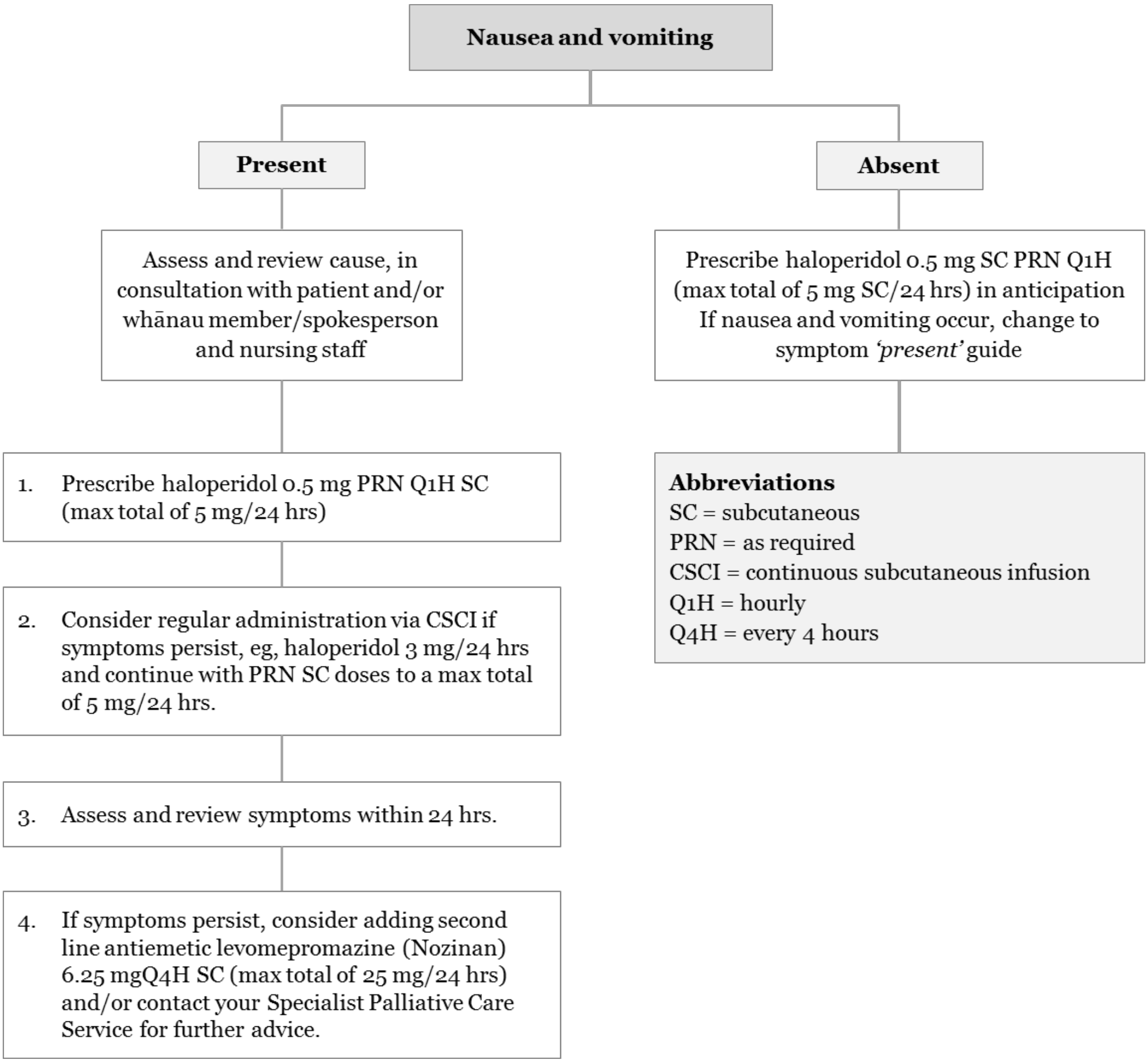
For all commonly used antiemetics, the subcut dose is the same as the oral dose.

The following antiemetics are commonly used subcut.

Antiemetic	Usual PRN dose and frequency	Usual starting subcut dose in CSCI	Usual maximum total daily subcut dose in CSCI
metoclopramide	10 mg Q6–8H	30 mg /24 hrs	up to 100 mg/24 hrs if high dose prokinetic required
haloperidol	0.5–1 mg Q4–6H	1 mg/24 hrs	5 mg/24 hrs
cyclizine	25–50 mg Q8H	150 mg/24 hrs	150 mg/24 hrs
levomepromazine (Nozinan®)	3.125–6.25 mg Q4–6H	6.25–12.5 mg/24 hrs	25 mg/24 hrs

Tool E: Nausea and vomiting algorithm

Source National LCP Office New Zealand (2010)



Nausea and vomiting

Present

Assess and review cause, in consultation with patient and/or whānau member/spokesperson and nursing staff

1. Prescribe haloperidol 0.5 mg PRN Q1H SC (max total of 5 mg/24 hrs)
2. Consider regular administration via CSCI if symptoms persist, eg, haloperidol 3 mg/24 hrs and continue with PRN SC doses to a max total of 5 mg/24 hrs.
3. Assess and review symptoms within 24 hrs.
4. If symptoms persist, consider adding second line antiemetic levomepromazine (Nozinan) 6.25 mgQ4H SC (max total of 25 mg/24 hrs) and/or contact your Specialist Palliative Care Service for further advice.

Absent

Prescribe haloperidol 0.5 mg SC PRN Q1H (max total of 5 mg SC/24 hrs) in anticipation If nausea and vomiting occur, change to symptom *'present'* guide

Abbreviations
SC = subcutaneous
PRN = as required
CSCI = continuous subcutaneous infusion
Q1H = hourly
Q4H = every 4 hours

Tool F: Guideline for developing an individualised medical management plan for end of life: pain

Source: Waitemata District Health Board (2014)

Patients who do not already have pain may not develop pain in the last hours to days of life. It is wise to provide for the possibility that a new event, such as a pulmonary embolus (which is common in patients with malignancy), may cause pain. Review the outcome of your interventions daily.

Note the equianalgesic ratio between opioids

1 mg morphine IV/subcut = 1 mg oxycodone IV/subcut = 10 micrograms fentanyl IV/subcut

Instruct nursing staff to seek medical advice if they have any concerns about the possibility of narcosis before administering an opioid. Signs to look for include respiratory depression (eg, respiratory rate below 10/minute), excessive sedation (which may be due to other causes in dying patients) and pinpoint pupils (abnormal miosis, pupils that fail to dilate in the dark and remain < 2 mm diameter).

Asymptomatic opioid naïve patients: anticipatory prescribing

Patient condition	Drug	Usual dose and frequency	Route	Comments	Maximum daily dose
opioid naïve patients with estimated CrCl ≥ 30 ml/min	morphine	2.5 mg Q30min PRN	subcut	Can use 1 mg in the frail elderly or those with neurological conditions such as motor neurone disease (MND)	no maximum dose/24 hrs
opioid naïve patients with estimated CrCl < 30 ml/min	oxycodone **OR**	2.5 mg Q30min PRN	subcut	Can use 1 mg in the frail elderly or those with neurological conditions such as MND	
	fentanyl Use this if estimated CrCl < 10 ml/min	25 mcg Q30min PRN	subcut	Can use 10 mcg in the frail elderly or those with neurological conditions such as MND **DO NOT DILUTE FOR SUBCUT USE**	

Symptomatic opioid naïve patients

Follow the recommendations in the table above. Review after 6–8 hours. If patient has required ≥ 3 PRN doses, start a continuous subcutaneous infusion (CSCI) with the anticipated 24-hour requirement of opioid. Review daily and adjust CSCI and PRN dose as needed.

In some patients, it may be appropriate to start a CSCI with 5–10 mg morphine (or oxycodone) or 50–100 micrograms of fentanyl over 24 hours without first waiting for response to PRN opioids.

Patients already on opioids (opioid experienced) may be opioid habituated.

If already using a transdermal fentanyl patch, do not alter the strength of the patch. Leave patch at current dose and add the most appropriate additional opioid.

Pain controlled

If symptoms are controlled on oral PRN or long-acting opioids, stop oral opioid and prescribe via subcutaneous (subcut) route in anticipation that patient may soon be unable to swallow.

Divide total daily dose of long-acting regular morphine or oxycodone by 2 to get total daily equianalgesic subcut dose. Administer via continuous subcutaneous infusion (CSCI) over 24 hours.

Divide oral PRN dose of morphine or oxycodone by 2 to get equianalgesic subcut PRN dose.

- PRN subcut opioids can be administered up to Q30min PRN for pain.
- As a guide, an appropriate PRN dose of morphine or oxycodone is one-sixth of the total 24-hour dose in the CSCI.
- If patient requires ≥ 3 PRN doses in 24 hours, consider starting a CSCI with the amount the patient has required in the preceding 24 hours.

Pain not controlled

If symptoms are not controlled on oral PRN or long-acting opioids:

Review patient. Assess the cause of the pain.

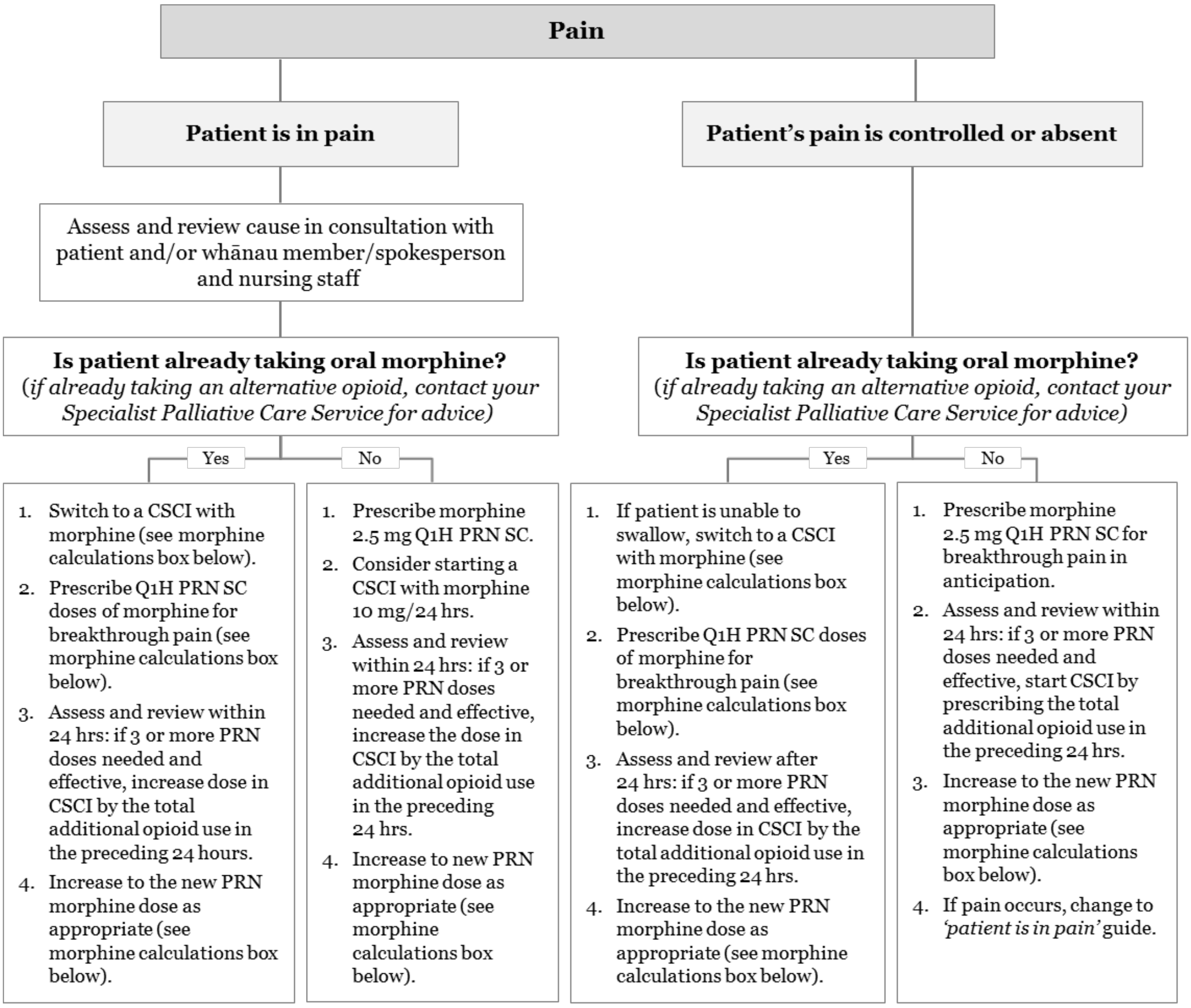
- Simple things may cause pain. Exclude pressure sores, urinary retention and constipation. Drugs may not be required for these conditions.
- Some pains may benefit from medications other than opioids, eg:
  - Buscopan® (hyoscine butylbromide) for colicky abdominal pain
  - corticosteroids (eg, dexamethasone) for headache from raised intracranial pressure or pain from nerve root/cord compression.
- Exclude delirium.
  - Delirious patients may cry out in distress, which may not be due to pain.
  - It is difficult to do an accurate pain assessment in the setting of delirium.

Stop oral PRN and long-acting opioids and prescribe via subcut route. This may improve absorption and pain control.

- **Divide total daily dose of long-acting regular morphine or oxycodone by 2** to get total daily equianalgesic subcut dose. Administer via CSCI over 24 hours.
- **Divide oral PRN dose of morphine or oxycodone by 2** to get equianalgesic subcut PRN dose.
  - PRN subcut opioids can be administered up to Q30min PRN for pain.
  - Review after 6–8 hours. If patient needed **≥ 3** PRN doses, increase the amount of opioid in the CSCI by the corresponding amount. Review daily and adjust CSCI and PRN dose as needed.

Tool G: Pain algorithm

Source: National LCP Office New Zealand (2010)



Pain

Patient is in pain

Assess and review cause in consultation with patient and/or whānau member/spokesperson and nursing staff

Is patient already taking oral morphine?
(if already taking an alternative opioid, contact your Specialist Palliative Care Service for advice)

Yes

1. Switch to a CSCI with morphine (see morphine calculations box below).
2. Prescribe Q1H PRN SC doses of morphine for breakthrough pain (see morphine calculations box below).
3. Assess and review within 24 hrs: if 3 or more PRN doses needed and effective, increase dose in CSCI by the total additional opioid use in the preceding 24 hours.
4. Increase to the new PRN morphine dose as appropriate (see morphine calculations box below).

No

1. Prescribe morphine 2.5 mg Q1H PRN SC.
2. Consider starting a CSCI with morphine 10 mg/24 hrs.
3. Assess and review within 24 hrs: if 3 or more PRN doses needed and effective, increase the dose in CSCI by the total additional opioid use in the preceding 24 hrs.
4. Increase to new PRN morphine dose as appropriate (see morphine calculations box below).

Patient's pain is controlled or absent

Is patient already taking oral morphine?
(if already taking an alternative opioid, contact your Specialist Palliative Care Service for advice)

Yes

1. If patient is unable to swallow, switch to a CSCI with morphine (see morphine calculations box below).
2. Prescribe Q1H PRN SC doses of morphine for breakthrough pain (see morphine calculations box below).
3. Assess and review after 24 hrs: if 3 or more PRN doses needed and effective, increase dose in CSCI by the total additional opioid use in the preceding 24 hrs.
4. Increase to the new PRN morphine dose as appropriate (see morphine calculations box below).

No

1. Prescribe morphine 2.5 mg Q1H PRN SC for breakthrough pain in anticipation.
2. Assess and review within 24 hrs: if 3 or more PRN doses needed and effective, start CSCI by prescribing the total additional opioid use in the preceding 24 hrs.
3. Increase to the new PRN morphine dose as appropriate (see morphine calculations box below).
4. If pain occurs, change to *'patient is in pain'* guide.

If symptoms persist or you require further advice, contact your Specialist Palliative Care Service.
If patient is in renal failure, consider an alternative opioid to morphine, eg, fentanyl.

Morphine calculations

Morphine PO to SC conversion ration = 2:1 eg, 20 mg morphine PO = 10 mg morphine SC. For a switch to a CSCI, halve the **24 hr** doses of PO morphine eg, 30 mg PO BD slow release morphine = 30 mg morphine via CSCI.

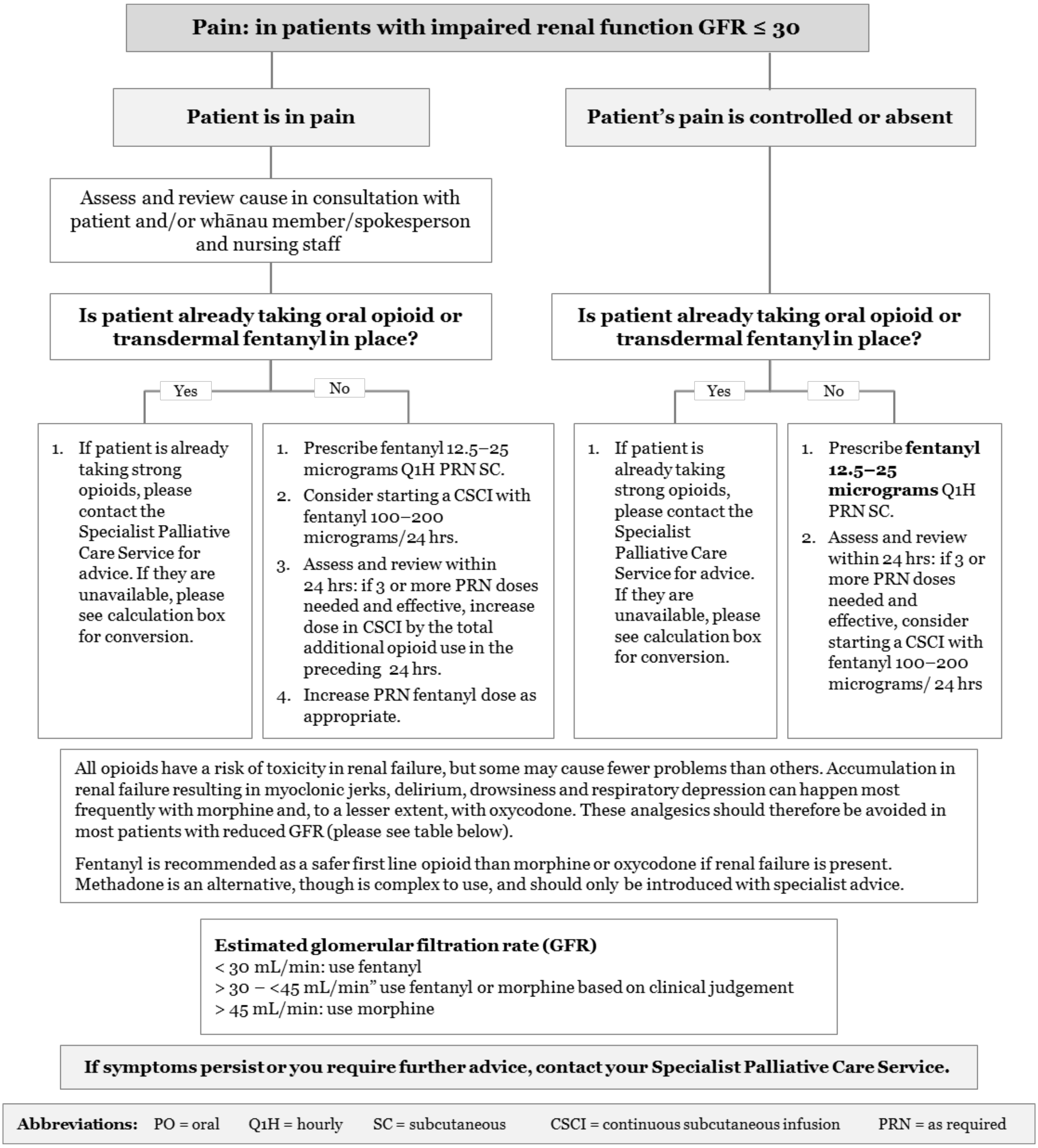
Breakthrough pain doses of SC morphine are 1/6 of the regular SC 24 hr dose given Q1H PRN. For example, 30 mg SC via CSCI requires 5 mg morphine PRN Q1H SC.

REMEMBER THAT IF THE CSCI IS INCREASED, THE PRN DOSE ALSO NEEDS TO BE INCREASED.

Abbreviations: PO = oral Q1H = hourly SC = subcutaneous CSCI = continuous subcutaneous infusion PRN = as required

Tool H: Pain in patients with impaired renal function algorithm

Source: National LCP Office New Zealand (2010)



Pain: in patients with impaired renal function GFR ≤ 30

Patient is in pain

Assess and review cause in consultation with patient and/or whānau member/spokesperson and nursing staff

Is patient already taking oral opioid or transdermal fentanyl in place?

Yes

1. If patient is already taking strong opioids, please contact the Specialist Palliative Care Service for advice. If they are unavailable, please see calculation box for conversion.

No

1. Prescribe fentanyl 12.5–25 micrograms Q1H PRN SC.
2. Consider starting a CSCI with fentanyl 100–200 micrograms/24 hrs.
3. Assess and review within 24 hrs: if 3 or more PRN doses needed and effective, increase dose in CSCI by the total additional opioid use in the preceding 24 hrs.
4. Increase PRN fentanyl dose as appropriate.

Patient's pain is controlled or absent

Is patient already taking oral opioid or transdermal fentanyl in place?

Yes

1. If patient is already taking strong opioids, please contact the Specialist Palliative Care Service for advice. If they are unavailable, please see calculation box for conversion.

No

1. Prescribe **fentanyl 12.5–25 micrograms** Q1H PRN SC.
2. Assess and review within 24 hrs: if 3 or more PRN doses needed and effective, consider starting a CSCI with fentanyl 100–200 micrograms/ 24 hrs

All opioids have a risk of toxicity in renal failure, but some may cause fewer problems than others. Accumulation in renal failure resulting in myoclonic jerks, delirium, drowsiness and respiratory depression can happen most frequently with morphine and, to a lesser extent, with oxycodone. These analgesics should therefore be avoided in most patients with reduced GFR (please see table below).

Fentanyl is recommended as a safer first line opioid than morphine or oxycodone if renal failure is present. Methadone is an alternative, though is complex to use, and should only be introduced with specialist advice.

Estimated glomerular filtration rate (GFR)
< 30 mL/min: use fentanyl
> 30 – <45 mL/min" use fentanyl or morphine based on clinical judgement
> 45 mL/min: use morphine

If symptoms persist or you require further advice, contact your Specialist Palliative Care Service.

Abbreviations: PO = oral Q1H = hourly SC = subcutaneous CSCI = continuous subcutaneous infusion PRN = as required

Tool I: Guideline for developing an individualised medical management plan for end of life: respiratory secretions

Source: Waitemata District Health Board (2014)

Respiratory secretions may develop if patients are unable to clear oropharyngeal secretions. These may generate noisy breathing; however, it is thought this is not unduly distressing to most patients. Often a small volume can generate a lot of noise as air moves across fluid in the airway.

General management

1. Explain symptoms to family and whānau.
2. Minimise patient turns as these disturb fluid and may increase symptoms. Gravity generally ensures that fluid settles and air will move across the top of accumulated fluid, usually without distressing the patient.

Occasionally cardiovascular fluid overload or respiratory tract infection may contribute to respiratory distress. Antisecretory medications are of no use in these situations.

1. If cardiovascular fluid overload is present:
   - a stat dose of frusemide may help
   - stopping IV fluids (or reducing flow rate) may be required.
2. If respiratory tract infection is resulting in copious purulent sputum, a stat dose of an appropriate antibiotic is helpful in some patients.

Anticipatory prescribing in asymptomatic patients

Antisecretory	Usual dose and frequency	Route	Maximum daily dose	Comments
hyoscine butylbromide (Buscopan®)	20 mg Q1–2H PRN	subcut	120 mg/ 24 hrs	Some centres use hyoscine hydrobromide[2] or Scopoderm® patches

Prescribing in symptomatic patients or for patients already using antisecretory medication

Prescribe continuous subcutaneous infusion (CSCI) **and** PRN for breakthrough symptoms. If patient is currently symptomatic, give a stat dose at the same time the CSCI is commenced.

Antisecretory	Usual subcut dose PRN	Usual subcut dose in CSCI NIKI T43
hyoscine butylbromide (Buscopan®)	20 mg Q1-2H	60 mg/24 hrs

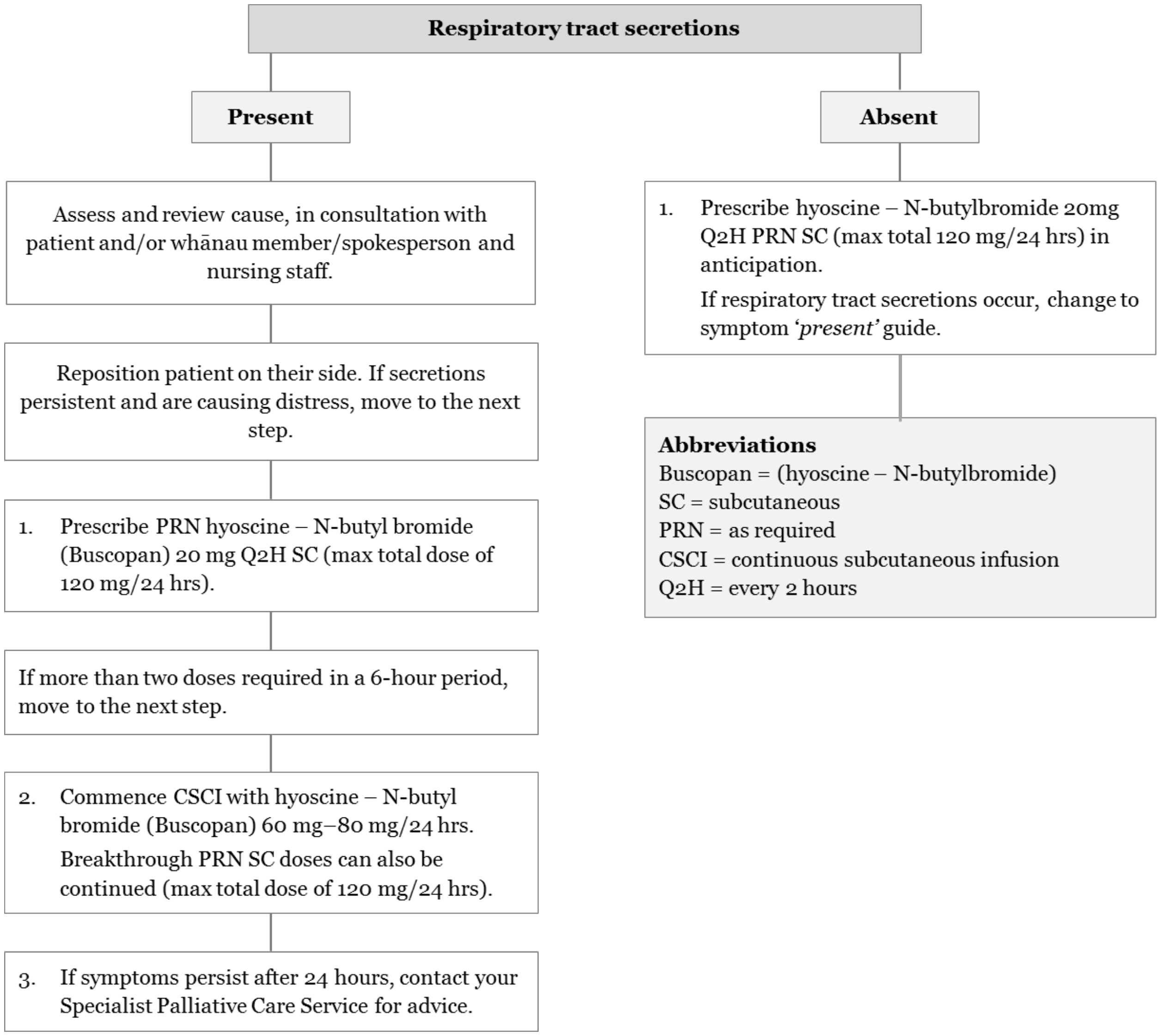
Review after 24 hours: If ≥ 3 PRN doses Buscopan® have been required in previous 24 hours, increase the dose in the CSCI to incorporate patient's actual 24-hour requirement (usual maximum 24-hour dose is 120 mg).

---

[2] Hyoscine hydrobromide, usual dose and frequency 0.4 mg Q2H PRN; can be included in CSCI at a usual starting dose of 1.2 mg/24 hrs; maximum daily dose 2.4 mg/24 hrs.

Tool J: Respiratory tract secretions algorithm

Source National LCP Office New Zealand (2010)



Respiratory tract secretions

Present

Assess and review cause, in consultation with patient and/or whānau member/spokesperson and nursing staff.

Reposition patient on their side. If secretions persistent and are causing distress, move to the next step.

1. Prescribe PRN hyoscine – N-butyl bromide (Buscopan) 20 mg Q2H SC (max total dose of 120 mg/24 hrs).

If more than two doses required in a 6-hour period, move to the next step.

2. Commence CSCI with hyoscine – N-butyl bromide (Buscopan) 60 mg–80 mg/24 hrs.

   Breakthrough PRN SC doses can also be continued (max total dose of 120 mg/24 hrs).

3. If symptoms persist after 24 hours, contact your Specialist Palliative Care Service for advice.

Absent

1. Prescribe hyoscine – N-butylbromide 20mg Q2H PRN SC (max total 120 mg/24 hrs) in anticipation.

   If respiratory tract secretions occur, change to symptom *'present'* guide.

Abbreviations

Buscopan = (hyoscine – N-butylbromide)
SC = subcutaneous
PRN = as required
CSCI = continuous subcutaneous infusion
Q2H = every 2 hours

Tool K: Guideline for developing an individualised medical management plan for end of life: delirium, restlessness or agitation

Source: Waitemata District Health Board (2014)

Delirium, restlessness or agitation is extremely common in dying patients. The cause is often multifactorial. Many causes are not reversible. The burden of investigations in a dying patient is often best avoided.

Readily treatable causes (pain, urinary retention, hypoxia, dehydration, opioid toxicity) should be excluded as treatment may improve comfort in the dying phase.

Anticipatory prescribing in asymptomatic patients

Medication	Usual dose and frequency	Route	Maximum total daily dose	Comments
haloperidol In conscious patients, use first line. The goal is to improve clarity	0.5–1 mg Q2H PRN Start with the lower dose first	subcut	5 mg/ 24 hrs	**Do not use** in Parkinson's disease/similar disorders Also useful for nausea/vomiting
midazolam Prescribe for all patients in case this is needed In unconscious patients, use first line In conscious patients, use second line if haloperidol is ineffective for restlessness or agitation **and** sedation is needed The goal is to manage restlessness or agitation if sedation is necessary. Clarity will not improve and may worsen	2.5–5 mg Q30min PRN Start with the lower dose first Can use 1 mg in the frail elderly, those with renal impairment or those with neurological conditions such as motor neurone disease	subcut	no maximum daily dose	Benzodiazepine-dependent patients may need higher doses Use 15 mg/3 ml ampoules (the concentration is higher than 5 mg/5 ml ampoule, hence volume for subcut administration of a given dose is lower) Also effective for seizures though higher doses may be needed (5–10 mg)
levomepromazine (Nozinan®) Use if midazolam ineffective	6.25 mg Q1H PRN	subcut	25 mg/ 24 hrs	Also useful for nausea/vomiting Can be very sedating in some patients (avoid if sedation is undesirable) Not generally recommended for ambulant patients

If patient is already using haloperidol or midazolam regularly or has required ≥ 3 PRN doses/ 24 hours, start a continuous subcutaneous infusion (CSCI) with the total dose the patient has needed in the preceding 24 hours. If patient is not already on medication for delirium, use guidelines below.

Patient not distressed; sedation not required

	Drug	Usual dose and frequency	Route	Comments	Maximum total daily dose (regular + PRN use)
Prescribe regular **and** PRN haloperidol	haloperidol	1 mg nocte	subcut	or incorporate 1 mg/24 hrs in CSCI	5 mg/24 hrs
Do not use in Parkinson's disease or similar disorders Also useful for nausea and vomiting	haloperidol	0.5–1 mg Q2H PRN	subcut	for breakthrough symptoms	

Review after 24 hours. If ≥ 3 PRN doses haloperidol were required in previous 24 hours, increase dose in CSCI to incorporate patient's actual 24-hour requirement.

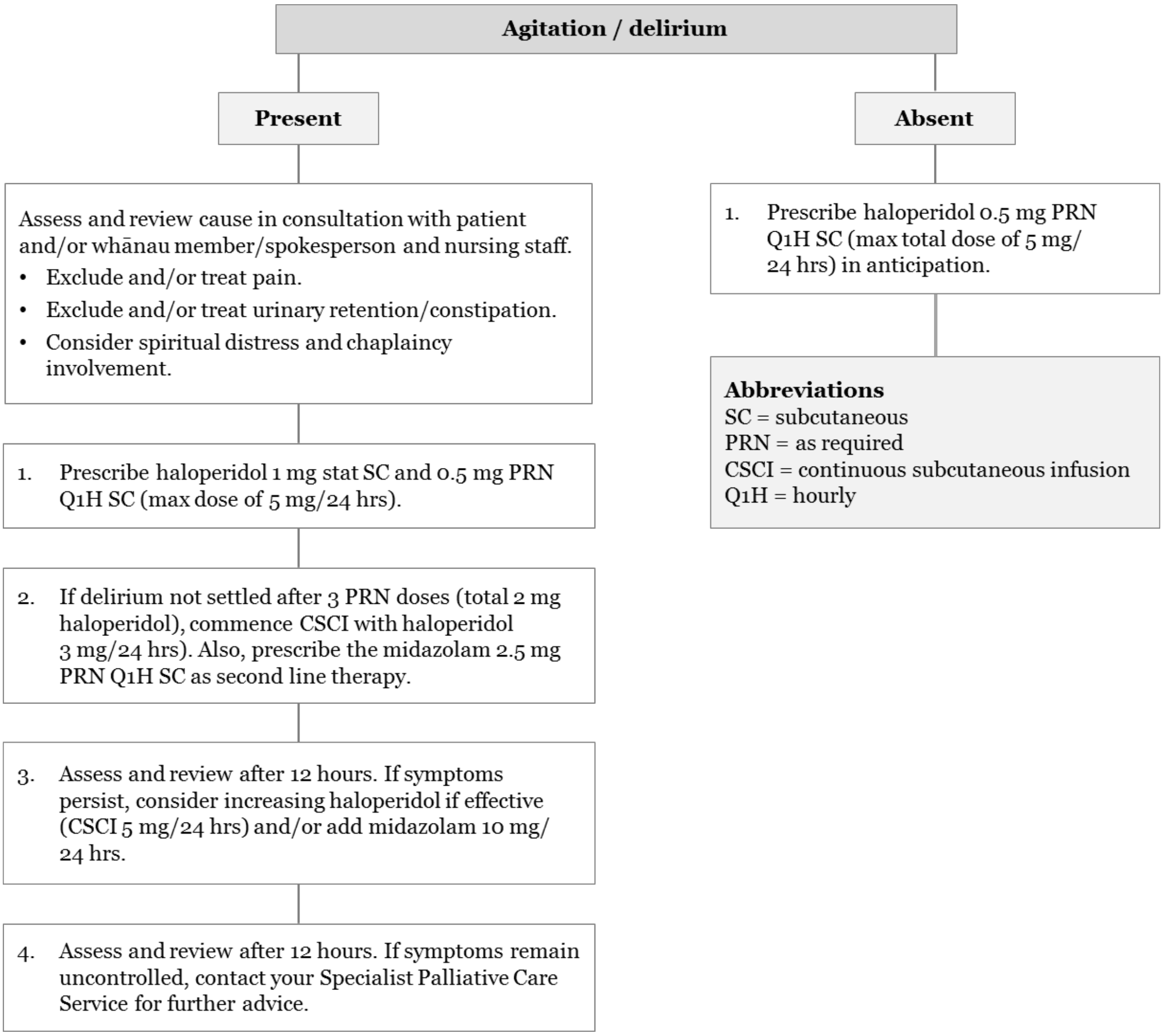
Patient distressed; sedation required

	Drug	Dose and frequency	Route	Comments	Maximum total daily dose
Prescribe regular **and** PRN midazolam	midazolam	10 mg/24 hrs	CSCI	Start with 5 mg/24 hrs in frail elderly or those with neurological conditions, eg, motor neurone disease (MND)	no maximum dose/24 hrs
	midazolam	2.5–5 mg Q30min PRN Start with the lower dose	subcut	Can use 1 mg in the frail elderly or those with neurological conditions such as MND	

Review after 24 hours: If ≥ 3 PRN doses midazolam required in previous 24 hours, increase the dose in the CSCI to incorporate patient's actual 24-hour requirement.

Tool L: Delirium/agitation algorithm

Source National LCP Office New Zealand (2010)



Agitation / delirium

Present

Assess and review cause in consultation with patient and/or whānau member/spokesperson and nursing staff.

- Exclude and/or treat pain.
- Exclude and/or treat urinary retention/constipation.
- Consider spiritual distress and chaplaincy involvement.

1. Prescribe haloperidol 1 mg stat SC and 0.5 mg PRN Q1H SC (max dose of 5 mg/24 hrs).
2. If delirium not settled after 3 PRN doses (total 2 mg haloperidol), commence CSCI with haloperidol 3 mg/24 hrs). Also, prescribe the midazolam 2.5 mg PRN Q1H SC as second line therapy.
3. Assess and review after 12 hours. If symptoms persist, consider increasing haloperidol if effective (CSCI 5 mg/24 hrs) and/or add midazolam 10 mg/24 hrs.
4. Assess and review after 12 hours. If symptoms remain uncontrolled, contact your Specialist Palliative Care Service for further advice.

Absent

1. Prescribe haloperidol 0.5 mg PRN Q1H SC (max total dose of 5 mg/24 hrs) in anticipation.

Abbreviations
SC = subcutaneous
PRN = as required
CSCI = continuous subcutaneous infusion
Q1H = hourly

Tool M: Guideline for developing an individualised medical management plan for end of life: dyspnoea

Source: Waitemata District Health Board (2014)

Dyspnoea is common in end stage disease. Over 50% of patients report this symptom in the last month of life. Dyspnoea is a subjective experience. Visible signs of respiratory distress may not be consistent with patient self-reported distress, which is equally important.

Oxygen may be helpful in hypoxemic patients; however, the need for oxygen should be guided by patient comfort and response rather than solely relying on pulse oximetry. Focusing on treating the 'numbers' may cause heightened anxiety in the patient and relatives. Instead, focus the patient and relatives on comfort.

Patients may find masks, nasal prongs and humidified air uncomfortable. This equipment may be a physical barrier to precious opportunities for communication with family members. Discontinue if not contributing to patient comfort. Midazolam nasal spray may not be appropriate in the dying patient for practical reasons.

Anticipatory prescribing in asymptomatic patients

Patient condition	Drug	Usual dose and frequency	Route	Comments	Max total daily dose
opioid naïve patients with estimated CrCl > 30 ml/min	morphine	2.5 mg Q30min PRN	subcut	Can use 1 mg in the frail elderly or those with neurological conditions such as motor neurone disease (MND)	no maximum dose/24H
opioid naïve patients with estimated CrCl < 30 ml/min	fentanyl **OR**	25 mcg Q30min PRN	subcut	Do not dilute for subcut use This is the preferred drug if estimated CrCl < 10 ml/min Use 10 mcg in the frail elderly or those with neurological conditions, eg, MND	
	oxycodone	2.5 mg Q30min PRN	subcut	Use 1 mg in the frail elderly or those with neurological conditions, eg, MND	
Patients with anxiety associated with shortness of breath	midazolam	2.5–5 mg Q30min PRN Start with the lower dose	subcut	Can use 1 mg in the frail elderly or those with neurological conditions such as MND Benzodiazepine-dependent patients may need higher doses Use 15 mg/3 ml ampoules (the concentration is higher than 5 mg/5 ml ampoule hence volume for subcut administration of a given dose is lower)	

Symptomatic patients or patients already on medication for dyspnoea

If already using an opioid or benzodiazepine for dyspnoea regularly or ≥3 times/24 hrs PRN, then convert to a continuous subcutaneous infusion (CSCI) in anticipation that patient may soon be unable to swallow.

Opioids

Converting current long-acting opioid to subcutaneous (subcut) route

Divide total daily dose of long-acting regular morphine or oxycodone by 2 to get total daily equivalent subcut dose and administer via CSCI over 24 hours.

Converting as needed opioid to subcut route

Divide oral PRN dose of morphine or oxycodone by 2 to get equivalent subcut PRN dose.

- PRN subcut opioids can be given up to Q30min PRN if patient is symptomatic and needs treatment.
- If patient requires ≥ 3 PRN doses in 24 hours, consider starting a CSCI with the amount the patient has required over the preceding 24 hours.

Prescribing as needed opioid for PRN use

Prescribe the same opioid that is in the syringe driver Q30MIN subcut PRN for breakthrough dyspnoea. As a guide, an appropriate PRN dose of morphine or oxycodone is one-sixth of the total 24-hour dose in the CSCI.

- If ≤ 15 mg morphine or oxycodone in the CSCI, use 2.5 mg.
- If > 15 mg morphine or oxycodone in the CSCI, use one-sixth of the total CSCI dose.

Benzodiazepines

Midazolam is the recommended benzodiazepine for subcut use. It is helpful if anxiety is associated with dyspnoea. Patients on oral benzodiazepines should be converted to midazolam if a benzodiazepine is to be used in a syringe driver.

Doses equivalent to approximately 2.5 mg subcut midazolam

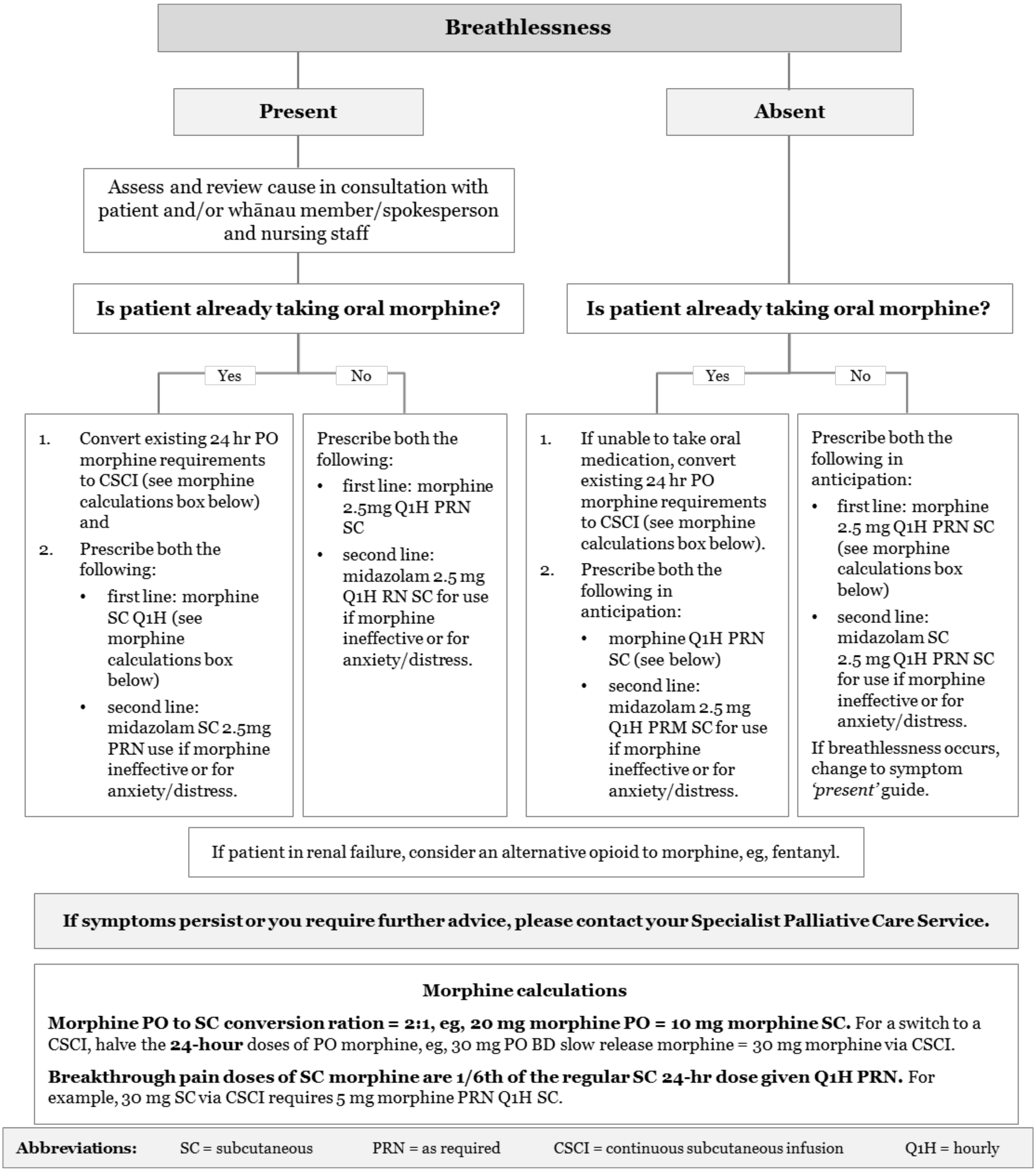
Drug	Dose	Half life
diazepam	10 mg PO/PR	1–2 days
clonazepam	1 mg PO/SC	30–40 hrs
lorazepam	1 mg PO/IV	12–16 hrs
oxazepam	15–30 mg	3–21 hrs
temazepam	10 mg	5–15 hrs
midazolam nasal spray	5 sprays	1.5–2.5 hrs

To convert an oral benzodiazepine or intranasal midazolam to CSCI midazolam, calculate total use of midazolam equivalent in the last 24 hours. This is the 24-hour subcut dose of midazolam needed in the CSCI. Round up or down to nearest multiple of 2.5 mg if necessary. Also prescribe midazolam for PRN use for breakthrough symptoms (as per anticipatory prescribing doses).

Example: Patient has been taking 1 mg lorazepam PO (equivalent 2.5 mg subcut midazolam) + used 7 nasal sprays of midazolam in last 24 hours (equivalent 3.5 mg subcut midazolam) = total midazolam equivalent 6 mg. Round *down* to 5 mg midazolam via CSCI over 24 hours.

Tool N: Breathlessness/dyspnoea algorithm

Source: National LCP Office New Zealand (2010)



Breathlessness

Present

Assess and review cause in consultation with patient and/or whānau member/spokesperson and nursing staff

Is patient already taking oral morphine?

Yes

1. Convert existing 24 hr PO morphine requirements to CSCI (see morphine calculations box below) and
2. Prescribe both the following:
    - first line: morphine SC Q1H (see morphine calculations box below)
    - second line: midazolam SC 2.5mg PRN use if morphine ineffective or for anxiety/distress.

No

Prescribe both the following:

- first line: morphine 2.5mg Q1H PRN SC
- second line: midazolam 2.5 mg Q1H RN SC for use if morphine ineffective or for anxiety/distress.

Absent

Is patient already taking oral morphine?

Yes

1. If unable to take oral medication, convert existing 24 hr PO morphine requirements to CSCI (see morphine calculations box below).
2. Prescribe both the following in anticipation:
    - morphine Q1H PRN SC (see below)
    - second line: midazolam 2.5 mg Q1H PRM SC for use if morphine ineffective or for anxiety/distress.

No

Prescribe both the following in anticipation:

- first line: morphine 2.5 mg Q1H PRN SC (see morphine calculations box below)
- second line: midazolam SC 2.5 mg Q1H PRN SC for use if morphine ineffective or for anxiety/distress.

If breathlessness occurs, change to symptom *'present'* guide.

If patient in renal failure, consider an alternative opioid to morphine, eg, fentanyl.

If symptoms persist or you require further advice, please contact your Specialist Palliative Care Service.

Morphine calculations

Morphine PO to SC conversion ration = 2:1, eg, 20 mg morphine PO = 10 mg morphine SC. For a switch to a CSCI, halve the **24-hour** doses of PO morphine, eg, 30 mg PO BD slow release morphine = 30 mg morphine via CSCI.

Breakthrough pain doses of SC morphine are 1/6th of the regular SC 24-hr dose given Q1H PRN. For example, 30 mg SC via CSCI requires 5 mg morphine PRN Q1H SC.

Abbreviations: SC = subcutaneous PRN = as required CSCI = continuous subcutaneous infusion Q1H = hourly

Tool O: Rapid discharge checklist for the dying patient

Source: Waitemata District Health Board (2014)

Patients with advanced disease require a range of services to ensure their physical, psychological, social and spiritual needs are met effectively and to enable them to live and die in the place of their choice if at all possible. As clinical circumstances can change rapidly, these services need to be particularly well coordinated to prevent unnecessary suffering.

The aim of the rapid discharge checklist is to facilitate a safe, smooth and seamless transition of care from hospital to community for patients who choose to be cared for in their own home for their last days of life.

The procedure relies on:

- hospital staff recognising the priority of the discharge, therefore minimising any potential delays
- patient/carer being aware of and involved in the plan of care
- the hospice/district nurse being consulted re the discharge process
- secondary care prescribing for subcutaneous administration of any regular or anticipatory medications for community use until GP can visit (particularly important if discharge is not within normal working hours)
- GP supporting the discharge.

Checklist	Yes	No	Comment
Does the patient have a preferred place of care?			
Patient/family aware of prognosis			
Family/whānau/carer support decision for discharge			
DNR complete			
Ambulance booked – aware of DNR			
District nurse informed – aware of care needs and discharge date and time. Contact DN Liaison			
GP aware of discharge and arrangements made for GP to visit			
Hospice (if appropriate) is aware of discharge and will review ASAP			
Other MDT members aware if applicable eg social worker, OT, physio			
Reviewed by NASC and individual care package in place			
Reviewed by OT and equipment delivered/ planned eg, electric bed, mattress			
Current medication assessed and non-essential medication discontinued			
Discharge medication ordered: appropriate subcutaneous AND anticipatory medication prescribed			

Checklist	Yes	No	Comment
If patient is being discharged with a NIKI T34 pump in situ, please complete ““ NIKI T34 Discharge Checklist”			
Patient/family understands the discharge medication			
Oxygen arranged if applicable. See Palliative Care Intranet for advice re referral for palliative home oxygen			
Patient/family aware of planned services/visits/ equipment			

Abbreviations: ASAP = as soon as possible; DN = district nurse; DNR = do not resuscitate order; NASC = Needs Assessment and Service Coordination service; OT = occupational therapist.

Tool P: What to expect when someone is dying

Source: Waitemata District Health Board (2014)

Knowing what to expect as death approaches can help make this time less worrying for all concerned.

This information sheet describes the signs and symptoms that can commonly occur when someone is near the end of their life. However, because each person is unique, these signs and symptoms may not all happen in every instance, nor will they necessarily happen in any particular order.

Sleep

In the final stages of illness, most people feel content to stay in bed, and may spend more time sleeping. At times they may not respond to you or may be hard to wake.

Loss of interest in food and fluids

It is common for people to have little interest in eating or drinking. Dehydration is not usually a problem as the body adapts to the reduced intake of fluids.

Ice chips, sips of fluid through a straw, or the use of a sipper cup make it easier to give small amounts of fluids. To help keep the mouth moist, mouth swabs soaked in iced water can be sucked. Lip balm or Vaseline is also useful to prevent dry, chapped lips.

Skin

The nose, ears, hands and feet may feel increasingly cool to the touch. Extra blankets can be used to provide warmth.

Sometimes the skin may look flushed and hot but not feel hot to the touch.

Applying a cool, moist cloth to the forehead may be helpful.

The skin on the hands, feet and underside of the body may become darker.

Breathing patterns

Breathing patterns may change; there can be periods of rapid, shallow breathing or shallow breathing with long spaces in between breaths. These symptoms are very common and do not usually cause distress to the patient.

As the patient becomes too weak to cough and swallow or is semi-conscious, they may develop rattling, noisy or gurgling breathing.

This is caused by a build-up of secretions normally found in the throat and lungs. This is usually more distressing for you than it is for them. Even small amounts of secretions can produce this symptom. Medications may be prescribed by the doctors to help reduce these secretions.

Suctioning is rarely used as it may cause more distress than the gurgling breathing.

Confusion

There may be increasing confusion about time, place and the identity of even close and familiar people.

Displaying a clock can help with keeping track of the time and day. Introduce visitors by name, even if they are well known. Keep familiar objects close by, such as photos or mementoes. The patient may like a pillow or soft blanket from home that is familiar to them. Keep a light on for reassurance if vision is affected.

Restlessness, delirium and agitation

These symptoms usually occur when a patient has become semi-conscious.

Signs include twitching, plucking at the air or at bedclothes, trying to get out of bed even if unable to stand alone and moaning or calling out constantly. Many families find this time difficult because they feel unsure how to help. Restlessness may be due to treatable causes such as constipation or a full bladder, or may be caused by the irreversible effects of their disease.

Keep the person calm by sitting with them and speaking quietly. Quiet music, radio or aromatherapy can be soothing. Always assume they can hear you and they will find your voice comforting.

The doctor may prescribe a sedative.

When death occurs

You may wish to stay at the bedside for a while after death has occurred. Ward staff will help you if you are unsure of what happens next.

If you would like support at any stage from a social worker, chaplaincy service or a cultural service, please ask your nurse or Palliative Care team to arrange this for you.

Tool Q: Supporting care in the last hours or days of life: Information for families/whānau/carers

Source: Waitemata District Health Board (2014)

As the end of life approaches, it can be difficult to estimate how much time is left, but this may now be as short as hours or days.

It can be difficult to absorb lots of information at a time like this, but we will do our best to explain things to you simply and clearly. If you have questions or just want to talk things over with one of the doctors or nurses or the chaplain, please let us know.

Facilities available to you

- There are facilities to make hot drinks on the ward; please ask and we will be happy to show you. There are also toilet facilities available to you.
- Please ask if you would like to stay the night; we will endeavour to make things more comfortable for you.

Medication

Taking tablets and other medication usually becomes more difficult as it becomes harder to swallow safely. We will stop any medication that is not helpful. We will make sure that injections are available if needed, for instance to control pain, nausea/sickness, breathlessness and other symptoms that may occur. They will only be given if and when needed, just enough and no more than is needed to help the symptom.

Reduced need for food and drink

- We will offer help and support with eating and drinking for as long as possible. However, as part of the dying process, most people gradually lose interest in food and drink. When a person stops eating and drinking, it can be hard to accept even when we know they are dying.
- Sometimes fluids given by a drip may be offered, but a drip will only be recommended where it is helpful and not harmful.
- Good mouth care is very important. If you would like to help with this, let us know.

Comfort

We will offer help with personal cares regularly. However, we recognise that it is important for you to have time and space just to be together. This is sometimes a difficult balance to achieve so please let us know if we need to do things differently, for whatever reason.

Feel free to share as much of the physical care as you want, or if you prefer, to provide support by spending time together, sharing memories and news of family and friends.

We understand this may be all very unfamiliar to you. Please let us know if there are any questions that occur to you, no matter how insignificant you think they may be, or how busy we may seem. We want to provide the best care we can.

Tool R: Breaking bad news flow chart

Source: Waitemata District Health Board (2014)

Preparation
Check the patient's notes to assess what has already been discussed
Check who should be present, eg, family, other health professionals
Set time aside with no distractions, eg, pager, mobile phone
Set the scene and ensure privacy

What does the patient know?
'It would help me to know what you understand about your illness. How did it all start?'

Is more information wanted?
'Would you like me to give you more details about your illness?'

Give a warning shot
'I am afraid that it looks more serious than we had hoped.'

Allow patient to refuse information at this time
'It must be difficult to accept this.'

Give explanation (if requested)
A narrative of events may be helpful

Elicit and listen to any concerns
'What are the main things that you are worried about?'

Summarise and plan
'Your main concerns at the moment seem to be ...'

Offer availability and support
Offer follow up discussion, social work referral

Communicate with multidisciplinary team and document
Clearly document conversation in clinical notes

Tool S: W.H.Ā.N.A.U: Personalising care at end of life

Source: Batten et al (2014)

This prompt card provides potential conversation starter questions to guide conversations and includes a background image of Te Whare Tapa Whā (Durie 1985) on one side, as a reminder of the need for a holistic approach to care. On the other side, information is provided to guide conversations to ensure that care for people can be personalised. The card could be laminated and provided to all staff who are involved in the care of people in their last days of life.

'W.H.Ā.N.A.U' - PERSONALISING CARE AT END-OF-LIFE

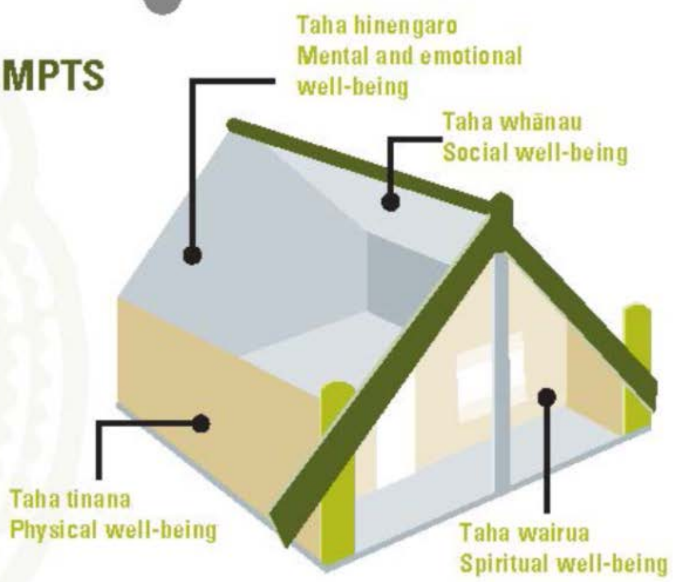
- ✓ **WHO TO ASK?** It may be better to talk with a whānau spokesperson, or with the whānau or family all together
- ✓ **HAVE** *time* and *space* to talk and *offer* thinking time
- ✓ **ASK** - don't assume what's important to you is the same for others
- ✓ **NEED** others to join these conversations? – friends, whānau
- ✓ **AGAIN** - people's needs change, so ask again
- ✓ **UNCOMFORTABLE** asking or responding to these questions? Ask for help – colleagues, chaplains, cultural advisors

SOME USEFUL PROMPTS

What can we do now to help you and those people important to you to feel safe and comfortable?

Do you have beliefs and family traditions that are especially important to you?

What are the important things about you and your whānau that we need to know right now?



Tool T: Bereavement information and assessment

Source: Nurse Maude Hospice Palliative Care Service (2013)

Please print clearly	Place patient label here
Preferred name:	
Date of death:	
Place of death:	

Nature of illness:

Time in NM service:

Family/significant others present at death:

Staff members most closely involved:

Key family and/or significant others for follow-up. Please include children where appropriate.

If there are more than two, please attach another sheet.

1.	Name:		
	Address:		
	Phone (home):	(work):	(cell):
	Email:		
	Relationship to patient:		
	Office use only – Date bereavement letter sent:		

2.	Name:		
	Address:		
	Phone (home):	(work):	(cell):
	Email:		
	Relationship to patient:		
	Office use only – Date bereavement letter sent:		

Comments/information relevant to follow-up, eg, how they are coping, issues they have, children:

Form completed by:

Please print name and designation clearly and complete the other side

The patient was:	
☐ A child or adolescent	☐ The parent of young children
The illness and death:	
☐ The illness was lengthy and burdensome for the family	☐ The patient died from a stigmatised or inherited disease
☐ The death is perceived by the family to be sudden or unexpected	☐ The death was traumatic for the family
The bereaved person/family:	
☐ Is a child or adolescent	☐ Is a young spouse/partner
☐ Is an elderly spouse partner in a long marriage/relationship	☐ Shows signs of poor initial adjustment to the death
☐ Expressed dissatisfaction with their care giving role during the person's illness	☐ Is isolated after the death
☐ Lacks social support or feels unsupported	☐ Feels dissatisfied with help available during the illness
☐ Had an ambivalent or conflictual relationship with the patient	☐ Feels support is antagonistic or unsympathetic
The bereaved person/family has experienced:	
☐ Multiple losses or multiple stressful situations	☐ Mental health problems or has a family history of mental illness
☐ An unusually close partnership, which the death ends	
The family:	
☐ Lacks cohesion	☐ Has poor communication and/or has difficulty resolving conflict
☐ Has few adequate coping mechanisms	☐ Had high emotional distress prior to the death
In your opinion does this person/family need:	
☐ Routine follow-up (letter and information)	☐ Urgent follow-up by bereavement counsellor (must make a referral to counsellor – see form 1852)
☐ Follow-up by bereavement counsellor (non-urgent phone contact)	☐ Not sure (please discuss with counsellor)
Completed by:	**Date:**
To be completed by bereavement counsellor	
☐ No follow-up required. Client advised to contact service if necessary	☐ Follow-up required, enrolled with service
Completed by:	**Date:**

Tool U: Spiritual care assessment tool based on FICA approach

Source: Puchalski and Larson (1998)

Background

The FICA Spiritual History Tool was developed by Dr Puchalski and a group of primary care physicians to help physicians and other health care professionals address spiritual issues with patients. Spiritual histories are taken as part of the regular history during an annual exam or new patient visit, but can also be taken as part of follow-up visits, as appropriate. The FICA tool serves as a guide for conversations in the clinical setting.

Suggested questions

These should be adapted to suit each person and revisited as patient circumstances change.

Faith	What things do you believe in that give meaning/value to your life? **and/or:** Do you consider yourself spiritual or religious? **and/or:** What is your faith or belief?
Importance	In what ways are they important to your life? **and/or:** What influences do they have on how you take care of yourself?
Influence	**and/or:** How are your beliefs/values influencing your behaviour during your illness? **and/or:** In what ways do your beliefs/values help you in regaining your health/wellbeing?
Community	Is there a person or group of people who you love or who are very important to you? **and/or:** How is this supportive to you? **and/or:** Do you belong to a religious/cultural community?
Address	Is there anything we can do to help you while you are with us? **and/or:** Would it help to talk to someone about these issues?

An example of a spiritual assessment in a non-religious person

F	Naturalist
I	Feels at one with nature. Each morning she sits on her patio looking out over the trees in the woods and feels ‘centred and with purpose’
C	Close friends who share her values
A	After discussion about belief, she will try to meditate, focusing on nature, on a daily basis to increase her peacefulness

You can refer to the Chaplaincy Department at any time, but some specific situations may include when:

- one's own belief system prohibits involvement in the spiritual/religious/cultural care of the patient
- spiritual or religious/cultural issues seem particularly significant in the patient's suffering
- spiritual or religious/cultural beliefs or values seem to be particularly helpful or supportive for the patient
- spiritual or religious/cultural beliefs or values seem to be particularly unhelpful for the patient
- addressing the spiritual or religious/cultural needs of a patient exceeds your comfort level
- specific community spiritual or religious/cultural resources are needed
- you suspect spiritual or religious/cultural issues that the patient denies
- the patient or family have specific religious needs e.g. Confession, Holy Communion, Sacrament of the Sick, needs a prayer mat or private space to pray, sacred texts, etc
- the patient's family seems to be experiencing spiritual/emotional pain or trauma
- members of staff seem to be in need of support.

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Appendix 1: References used to develop Working Paper No. 5 and Working Paper No. 7

As outlined in the Background section, the Working Group undertook a comprehensive research and review process to support the development of this guidance. As part of that process, it produced three working papers (PCC 2014a, 2014b, 2014c) that form the evidence base of *Te Ara Whakapiri*.

This appendix presents references for the first two of those documents. Please refer to the working papers for more detail.

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