

Te Ara Whakapiri

Principles and guidance for the
last days of life

Citation: Ministry of Health. 2017. *Te Ara Whakapiri: Principles and guidance for the last days of life*. (2nd edn). Wellington: Ministry of Health.

First published in December 2015, 2nd edition April 2017
by the Ministry of Health
PO Box 5013, Wellington 6145, New Zealand

ISBN 978-1-98-850224-3 (online)
HP 6571

This document is available at health.govt.nz



MANATŪ HAUORA



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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 whakaatanga 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.

Acknowledgements

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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- Mary Schumacher: chief executive, Hospice New Zealand.

Certain other individuals and organisations provided significant support and advice to the Last Days of Life Working Group, the Last Days of Life Governance Group and the PCC during the development of this guidance. The authors are grateful to:

- the 147 family/whānau members who agreed to participate in a family/whānau survey for the purposes of this document, and who shared their personal journey following the life-limiting illness of a loved family/whānau member or friend
- the organisations and individuals involved in broad sector consultation on the draft document
- Jo Anson, Central Region Cancer Network

- Fiona Bailey, principal advisor, stakeholder engagement, clinical leadership and protection, Ministry of Health
- Lesley Batten, research officer, Research Centre for Māori Health and Development, Massey University
- Victoria Brown, Care Association New Zealand
- Catherine Conland, Presbyterian Support Services
- Helen Colebrook, acting general manager, CCNZ (from 1 February to 2 April 2015)
- Julie Drury, acting programme administrator, CCNZ (until 14 November 2014)
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- He Kupenga Hao i te Reo
- Andrew Lesperance, general manager, CCNZ (until 16 October 2014)
- Heather McLeod, senior analyst, palliative care, CCNZ
- Karla Martin, reference librarian, Ministry of Health
- Kristie Saumure, reference librarian, Ministry of Health
- James Shannon, acting general manager, CCNZ (from 20 October 2014 to 31 January 2015)
- Melissa Toohey, acquisitions librarian, Ministry of Health
- Waitemata DHB End of Life Care Project Steering Group
- Deborah Wise, CNS/team leader, Hospital Palliative Care Service, Hutt Valley DHB.

Endorsements

1. Australia and New Zealand Society of Palliative Medicine (ANZSPM)
2. Hospice New Zealand
3. College of Nurses Aotearoa (NZ)
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.

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 tools from the *Te Ara Whakapiri* toolkit 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.

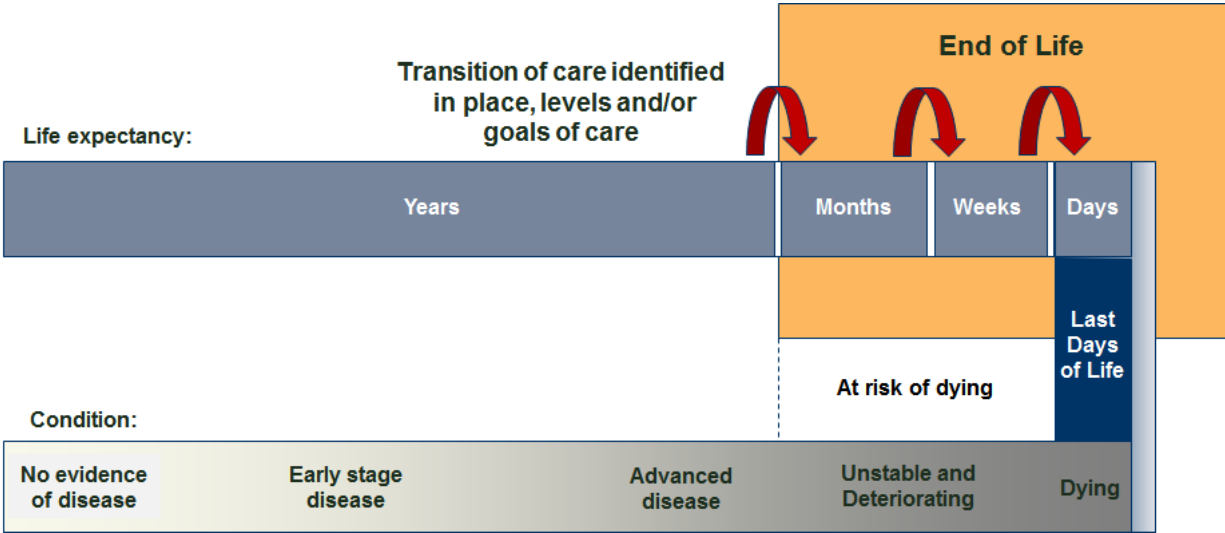
Introduction

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 two 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.

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.

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.

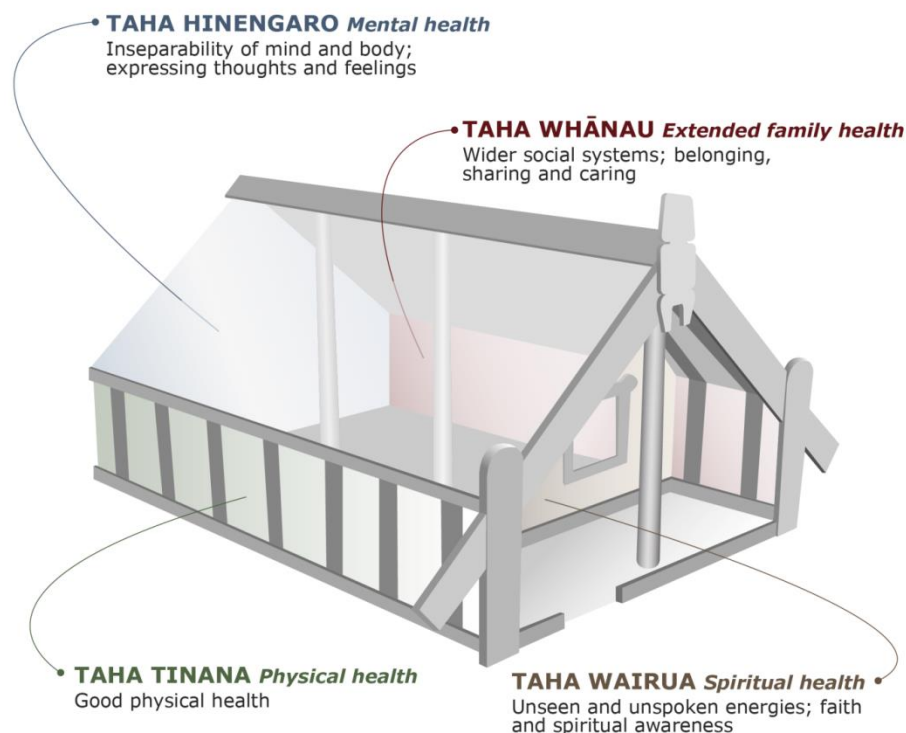
Te Whare Tapa Whā can apply to the total wellbeing of the person as they approach the end of their life, as well as the total wellbeing of their family/whānau.

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: <i>Physical health</i>		Te taha hinengaro: <i>Mental health</i>	
1.1	Recognition the person is dying or is approaching the last days of life	1.5	Assessment of the person's preferences for care
1.2	Identification of the lead health practitioner	Te taha whānau: <i>Extended family health</i>	
1.3	Assessment of physical needs	1.6	Identification of communication barriers
1.4	Review of current management and initiation of prescribing of anticipatory medication	1.8	The family/whānau's awareness of the person's changing condition
1.7	The person's awareness of their changing condition	1.9	Discussion of cultural needs
1.11	Provision of food and fluids	1.15	Provision of information to the family/whānau about support and facilities
1.12	Availability of equipment to support the person's care needs	Te taha wairua: <i>Spiritual health</i>	
1.13	Consideration of cardiac devices	1.10	Provision of opportunity for the person and family/whānau to discuss what is important to them
1.14	Advice to relevant agencies of the person's deterioration		

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	<p>Is confident in using their clinical judgement and experience to recognise when a person is dying or is approaching the last days of life.</p> <p>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.</p>
Clinical service/organisation	<p>Ensures that staff can access education and training on recognising the last days of life.</p> <p>Ensures that facilities are configured appropriately to care for people at the end of life.</p>
System (DHB)	<p>Supports health practitioners to become skilled in recognising the last days of life.</p> <p>Ensures that all services/organisations understand their role in caring for people at the end of life.</p>

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	<p>Follows a clear process for appointing a lead health practitioner or a designated representative.</p> <p>Is aware at all times who the lead health practitioner (or designated representative) is and how and when to make contact.</p> <p>Has access to specialist palliative care support 24/7.</p>
Clinical service/organisation	<p>Ensures that the lead health practitioner role is supported and that they are committed to the person and their family/whānau.</p> <p>Ensures that lead health practitioners (or designated representatives) are contactable within working hours and out of hours.</p> <p>Ensures access to specialist palliative care support 24/7 according to clear processes.</p>
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: <i>Physical health</i>		Te taha whānau: <i>Extended family health</i>	
2.1	Development of an individualised plan of care	2.3	Conversations with the family/whānau about the person's changing condition
2.2	Ongoing assessment of the person's care		
Te taha hinengaro: <i>Mental health</i>		Te taha wairua: <i>Spiritual health</i>	
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	<p>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.</p> <p>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.</p> <p>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.</p> <p>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.</p>
Clinical service/organisation	<p>Recognises the need for frequent assessments at the end of life.</p> <p>Provides processes for staff to clearly document individualised plans of care, including regular reviews, assessments and evaluations of care.</p>
System (DHB)	<p>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.</p> <p>Monitors quality indicators and audits processes and plans of care.</p>

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: <i>Physical health</i>	Te taha whānau: <i>Extended family health</i>
3.1 Verification of death	3.3 Provision of information to the family/whānau about what to do next
3.2 Dignity and respect for the person/tūpāpaku	
Te taha hinengaro: <i>Mental health</i>	Te taha wairua: <i>Spiritual health</i>
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	<p>Supports the family/whānau if they wish to participate in after death care.</p> <p>Undertakes after death care according to local policy and procedure.</p> <p>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.</p> <p>Returns personal belongings to the family/whānau in a respectful way.</p> <p>Informs all health care and social services previously involved in the person's care of the death, as appropriate.</p>
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	<p>Has a conversation with the family/whānau to ensure they have information about what they need to do next.</p> <p>Provides written material and information if required.</p>
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	<p>Has a conversation with the family/whānau about bereavement support.</p> <p>Conducts a bereavement assessment if the family/whānau wishes to have one, or if the health practitioner considers that one may be beneficial.</p> <p>If the family/whānau has grief needs beyond what the health practitioner can themselves provide, refers the family to other services.</p>
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 <i>Te Ara Whakapiri</i> (labelled 'A' to 'U') or externally	Health practitioner responsibility The communication needs to be involved in each component	
Te taha tinana: <i>Physical health</i>	1.1	Recognition the person is dying or is approaching the last days of life	A Identifying the dying patient B 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 <i>Te Ara Whakapiri</i> (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	<p>Nausea and vomiting:</p> <p>D Guideline for developing an individualised medical management plan for end of life: nausea and vomiting</p> <p>E Nausea and vomiting algorithm</p> <hr/> <p>Pain:</p> <p>F Guideline for developing an individualised medical management plan for end of life: pain</p> <p>G Pain algorithm</p> <p>H Pain in patients with impaired renal function algorithm</p> <hr/> <p>Respiratory secretions:</p> <p>I Guideline for developing an individualised medical management plan for end of life: respiratory secretions</p> <p>J Respiratory tract secretions algorithm</p> <hr/> <p>Delirium/agitation:</p> <p>K Guideline for developing an individualised medical management plan for end of life: delirium, restlessness or agitation</p> <p>L Delirium/agitation algorithm</p> <hr/> <p>Breathlessness (dyspnoea):</p> <p>M Guideline for developing an individualised medical management plan for end of life: dyspnoea</p> <p>N Breathlessness/dyspnoea algorithm</p>	<p>Preferences for management are clearly documented and changes are discussed with the person and family/whānau wherever possible.</p> <p>The person and the family/whānau are aware of available medications and have access to medications prescribed.</p> <p>There is clear guidance for family/whānau on use of medications, with written instructions provided as necessary.</p> <p>Current prescribed medications are assessed, and non-essential medications discontinued.</p> <p>As per best practice, any allergies and drug intolerances must be identified and clearly documented.</p>
1.7	The person's awareness of their changing condition	<p>R Breaking bad news flow chart</p> <p>O Rapid discharge checklist for the dying patient</p>	<p>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.</p> <p>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.</p>

Te Whare Tapa Whā dimension	Components of care	Available resources/tools Available either from Part 4 of <i>Te Ara Whakapiri</i> (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: <ul style="list-style-type: none"> 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: <i>Mental health</i>	1.5 Assessment of the person's preferences for care	Interpreters, if required Organisation's individual resources	A conversation is held and documented on: <ul style="list-style-type: none"> 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: <i>Extended family health</i>	1.6 Identification of communication barriers	Interpreters, if required Example A: Planning for end-of-life care	A conversation is held and documented on: <ul style="list-style-type: none"> 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 <i>Te Ara Whakapiri</i> (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: <ul style="list-style-type: none"> • 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: <i>Spiritual health</i>	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: <ul style="list-style-type: none"> • 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: <i>Physical health</i>	2.1	Development of an individualised plan of care	<p>Example A: Planning for end-of-life care</p> <p>Example B: Improving care of the dying guideline</p> <p>A conversation is held and documented on:</p> <ul style="list-style-type: none"> • 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	–
Te taha whānau: <i>Extended family health</i>	2.3	Conversations with the family/whānau about the person's changing condition	<p>P What to expect when someone is dying (information for family/whānau)</p> <p>Q Supporting care in the last hours or days of life: information for family/whānau/carers</p> <p>A conversation is held and documented to ensure that the family/whānau understands what changes are occurring in the person's condition.</p>
Te taha hinengaro: <i>Mental health</i>	2.4	Provision of ongoing review	A conversation is held and documented that includes discussion with the person about their wishes, thoughts and feelings.
			<p>O Rapid discharge checklist</p> <p>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.</p>
Te taha wairua: <i>Spiritual health</i>	2.5	Discussing and addressing changing spiritual need	<p>U Spiritual care assessment tool based on FICA approach</p> <p>A conversation is held and documented that provides the opportunity for the person to express their changing spiritual needs.</p>

3. Care after death

Te Whare Tapa Whā	Component	Resources	Communication need
Te taha tinana: <i>Physical health</i>	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: <i>Extended family health</i>	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: <i>Mental health</i>	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: <i>Spiritual health</i>	3.6	Availability of a private space for the family/whānau –	The service manager is informed that a room may be required.

References

- Batten L, Holdaway M, Allan S, et al. 2014. *Culturally Appropriate End-of-life Care for Māori*. Palmerston North: Massey University/Health Research Council.
- Durie MH. 1985. A Māori perspective of health. *Social Science Medicine* 20(5): 483–6.
- Durie MH. 1998. *Whaiora: Maori health development*. Auckland: Oxford University Press, pp 68–74.
- Heart Rhythm New Zealand. 2014. Heart Rhythm New Zealand Position Statement: Management of implantable cardioverter defibrillators (ICD) and pacemakers for patients nearing end of life. Heart Rhythm New Zealand.
- Hutt Valley DHB. 2014. *Improving Care of the Dying Guideline*. Lower Hutt: Hutt Valley District Health Board.
- National LCP Office New Zealand. 2010. *Liverpool Care Pathway for the Dying Patient (LCP) – Supporting care in the last hours or days of life*. NZ LCP Version 12 (adapted from United Kingdom LCP generic Version 12, 2009). Wellington: National LCP Office New Zealand.
- NHS and University of Edinburgh. 2014. *Supportive and Palliative Care Indicators Tool (SPICT)*. London: National Health Service and University of Edinburgh.
- Nurse Maude Hospice Palliative Care Service. 2013. *Bereavement service*. Document: 1841. Christchurch: Nurse Maude Hospice Palliative Care Service.
- Paediatric Society of New Zealand and Starship Foundation. 2014. Allow natural death/Te wa aroha. URL: www.kidshealth.org.nz/allow-natural-death-te-wa-aroha (accessed 10 September 2015).
- PCC. 2014a. *Care of Patients in Their Last Days of Life: New Zealand based approaches*. Working Paper No. 5. Wellington: Palliative Care Council of New Zealand.
- PCC. 2014b. *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*. Working Paper No. 7. Wellington: Palliative Care Council of New Zealand.
- PCC. 2014c. *Results of a Survey of Family/Whānau Caring for People in Their Last Days of Life*. Working Paper No. 9. Wellington: Palliative Care Council of New Zealand.
- PCC. 2015. *New Zealand Palliative Care Glossary*. Wellington: Palliative Care Council of New Zealand, Hospice New Zealand and Ministry of Health.
- Puchalski C, Larson DB. 1998. Developing curricula in spirituality and medicine. *Academic Medicine* 73(9): 970–4.
- Te Ara. 2015. *The Encyclopedia of New Zealand*. URL: www.TeAra.govt.nz/en/diagram/31387/maori-health-te-whare-tapa-wha-model (updated 23 December 2014).
- The Gold Standards Framework Centre in End of Life Care. 2011. *Prognostic Indicator Guidance*. Shrewsbury: The Gold Standards Framework Centre in End of Life Care.
- Waitemata DHB. 2014. *End of Life Care Guidelines*. Auckland: Waitemata District Health Board.

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.

Care of Patients in Their Last Days of Life: New Zealand based approaches. Working Paper No. 5 (2014a)

Batten L, Holdaway M, Clark J, et al. 2014. Constraints and enablers for culturally appropriate end-of-life care in New Zealand. *BMJ Supportive and Palliative Care* 4(1): A22.

Chan HY. 2013. Institutional policies and guidelines for informed choices and decision making: a review of ACP policies in selected District Health Boards in New Zealand. *BMJ Supportive and Palliative Care* 3(2): 245.

Chan RJ, Webster J. 2011. A Cochrane review on the effects of end-of-life care pathways: do they improve patient outcomes? *Australian Journal of Cancer Nursing* 12(2): 26–30.

Clark J, Marshall B, Sheward K, et al. 2012. Staff perceptions of the impact of the Liverpool Care Pathway in aged residential care in New Zealand. *International Journal of Palliative Nursing* 18(4): 171–8.

Clark JB, Sheward K, Marshall B, et al. 2012. Staff perceptions of end-of-life care following implementation of the Liverpool Care Pathway for the Dying Patient in the Acute Care Setting: a New Zealand perspective. *Journal of Palliative Medicine* 15(4): 468–73.

Dee JF, Endacott R. 2011. Doing the right thing at the right time. *Journal of Nursing Management* 19(2): 186–92.

Di Leo S, Beccaro M, Finelli S, et al. 2011. Expectations about and impact of the Liverpool Care Pathway for the dying patient in an Italian hospital. *Palliative Medicine* 25(4): 293–303.

Forero R, McDonnell J, Gallego B. 2012. A literature review on care at the end-of-life in the emergency department. *Emergency Medical International*: 1–11.

Frey R, Gott M, Raphael D, et al. 2013. ‘Where do I go from here?’ A cultural perspective on challenges to the use of hospice services. *Health and Social Care in the Community* 21(5): 519–29.

Kuper S. 2013. Nurses perspectives on the ‘Liverpool Care of the Dying Pathway’: dead, dying or worthy of resurrection? Paper prepared as part of Master’s Degree, Unpublished.

Mackenzie T, Innes J, Boyd M, et al. 2011. Evaluating the role and value of a national office to coordinate Liverpool Care Pathway implementation in New Zealand. *International Journal of Evidence Based Healthcare* 9: 252–60.

- Marshall B, Clark J, Sheward K, et al. 2011. Staff perceptions of end-of-life care in aged residential care: a New Zealand perspective. *Journal of Palliative Medicine* 14(6): 688–95.
- Melville A, Mitropoulos J, Philpott SJ, et al. 2013. Admission to intensive care for provision of end of life care in Australia and New Zealand: do the patients all die? *BMJ Supportive and Palliative Care* 3(2): 275.
- Neuberger J, Aaronovitch D, Bonser T, et al. 2013. *More Care, Less Pathway: A review of the Liverpool Care Pathway*. London: Department of Health.
- PCC. 2013a. *Deaths in New Zealand: History and projections*. Wellington: Palliative Care Council of New Zealand.
- PCC. 2013b. *Palliative Care in Aged Residential Care: Background and research in New Zealand*. Wellington: Palliative Care Council of New Zealand.
- PCC, Last Days of Life Working Group. 2014a. *Stocktake: Approaches used in New Zealand to care for patients in their last days of life – Liverpool Care Pathway Working Paper*). Wellington: Palliative Care Council of New Zealand.
- PCC, Last Days of Life Working Group. 2014b. *Stocktake: Approaches used in New Zealand to care for patients in their last days of life – other models of care (Working Paper 2)*. Wellington: Palliative Care Council of New Zealand.
- PCC. 2014. *Deaths in New Zealand: Regional and Ethnic Projections 2014–2026*. Wellington: Palliative Care Council of New Zealand.
- PCC. 2014. *Deaths in New Zealand: Place of Death, 2000–2010*. Wellington: Palliative Care Council of New Zealand.
- PCC. 2015. *New Zealand Palliative Care Glossary*. Wellington: Palliative Care Council of New Zealand, Hospice New Zealand and Ministry of Health.
- Taylor AJ, Randall C. 2007. Process mapping: enhancing the implementation of the Liverpool Care Pathway. *International Journal of Palliative Nursing* 13(4): 163–7.
- Thurston J, Waterworth S. 2012. ‘Making sense’: nurses’ experiences of changing practice in caring for dying patients in New Zealand. *International Journal of Palliative Nursing* 18(10): 500–7.

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. Working Paper No. 7 (2014b)

- Ahuriri-Driscoll A, Reid K, Kirk R, et al. 2014. *Understanding the Māori Experience of Palliative Care in Canterbury*. Christchurch: School of Health Science, University of Canterbury.
- Albers G, Van den Block L, Vander Stichele R. 2014. The burden of caring for people with dementia at the end of life in nursing homes: a post death study among nursing staff. *International Journal of Older People Nursing* 9(2): 106–17.
- Amador S, Goodman C, King D, et al. 2014. Exploring resource use and associated costs in end of life care for older people with dementia in residential care homes. *International Journal of Geriatric Psychiatry* 29(7): 758–66.
- Arcand M, Brazil K, Nakanishi M, et al. 2013. Educating families about end-of-life care in advanced dementia: acceptability of a Canadian family booklet to nurses from Canada, France and Japan. *International Journal of Palliative Nursing* 19(2): 67–74.
- Badrakalimuthu V, Barclay S. 2014. Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis. *Age and Ageing* 43(1): 13–19.

- Batten L, Holdaway M, Clark J, et al. 2014. Constraints and enablers for culturally appropriate end-of-life care in New Zealand. *BMJ Supportive and Palliative Care* 4(1): A22.
- Bausewein C, Daveson B, Benalia H, et al. 2011. *Outcome Measurements in Palliative Care: The essentials*. London: Prisma.
- Bellamy G, Gott M. 2012. What are the priorities for developing culturally appropriate palliative and end of life care for older people? The views of the healthcare staff working in New Zealand. *Health and Social Care* 21(1): 121–8.
- Boogard JA, van Soest-Poortvliet MC, Anema JR. 2013. Feedback on end of life care in dementia: the study protocol of the follow-up project. *BMC Palliative Care* 12(1): 29.
- Casarett D, Smith D, Breslin S, et al. 2010. Does nonresponse bias the results of retrospective surveys of end-of-life care? *Journal of the American Geriatric Society* 58(12): 2381–6.
- Chan RJ, Webster J. 2013. End-of-life care pathways for improving outcomes in caring for the dying. *Cochrane Database of Systematic Reviews* (11), Art. No. CD008006. DOI: 10.1002/14651858.CD008006.pub3 (accessed 11 September 2015).
- Clark D. 2012. Cultural considerations in planning palliative and end of life care. *Palliative Medicine* 26(3): 195–6.
- Clark J, Marshall B, Sheward K, et al. 2011. Staff perceptions of the impact of the Liverpool Care Pathway in aged residential care in New Zealand. *International Journal of Palliative Nursing* 18(4): 171–8.
- Clark J, Sheward K, Marshall B, et al. 2012. Staff perceptions of the impact of the Liverpool Care Pathway for the dying patient in the acute care setting: a New Zealand perspective. *Journal of Palliative Medicine* 15(4): 468–73.
- Cormack D, Robson B, Purdie G, et al. 2005. *Access to Cancer Services for Māori*. Wellington: Ministry of Health.
- Costantini M, Ottonelli S, Canavacci L, et al. 2011. The effectiveness of the Liverpool Care Pathway in improving end of life care for dying cancer patients in hospital: a cluster randomised trial. *BMC Health Services Research* 11(13): 1–10.
- Costantini M, Romoli V, DiLeo S, et al. 2013. Liverpool Care Pathway for patients with cancer in hospital: a cluster randomised trial. *Lancet* 383(9913): 226–37.
- Costa-Requena G, Espinosa Val C, Cristòfol R. 2015. Caregiver burden in end of life care: advanced cancer and final stage dementia. *Palliative and Supportive Care* 13(3): 583–9.
- Crowther J, Wilson K, Horton S, et al. 2013. Compassion in healthcare – lessons from a qualitative study of the end of life care of people with dementia. *Journal of the Royal Society of Medicine* 106(12): 492–7.
- Cusarett D, Teno J, Higginson F. 2006. How should actions measure the quality of end of life care for older adults? Recommendations for an International Minimum Data Set. *Journal of the American Geriatrics Society* 54: 1766–71.
- Davies N, Maio L, van Riet Paap J, et al. 2014. Quality palliative care for cancer and dementia in five European countries: some common challenges. *Aging & Mental Health* 18(4): 400–10.
- Davies P, Wye L, Horrocks S, et al. 2011. Developing quality indicators for community services: the case of district nursing. *Quality in Primary Care* 19: 155–66.
- De Gendt C, Bilsen J, Vander Stichele R, et al. 2013. Advance care planning and dying in nursing homes in Flanders, Belgium: a nationwide survey. *Journal of Pain and Symptom Management* 45(2): 223–34.

- Defilippi K, Downing J. 2013. African Palliative Care Outcome Scale. *International Journal of Palliative Care* 19(12): 577–81.
- Department of Health. 2013. *More Care, Less Pathway: A review of the Liverpool Care Pathway*. London: Department of Health.
- Di Leo D, Beccaro M, Finelli S, et al. 2011. Expectations about and the impact of the Liverpool Care Pathway for the dying patient in an Italian hospital. *Palliative Medicine* 25: 293–303.
- Donnelly S, Dickson M. 2013. Relatives matched with staff's experience of the moment of death in a tertiary referral hospital. *QJM* 106(8): 731–6.
- Egan R, McKechnie R, Jobson J, et al. 2013. Perspectives on psychosocial and spiritual cancer support services in New Zealand. *Journal of Psychosocial Oncology* 31(6): 659–74.
- Ekestrom M, Olsson M, Runesdotter S, et al. 2014. Family members' experiences of the impact of the LCP in a palliative care unit and a geriatric ward in Sweden. *International Journal of Palliative Nursing* 20(8): 381–6.
- Ellershaw JE. 2014. The challenges of changing the culture of dying. *Lancet* 383(9913): 207–8.
- Ellershaw JE, Furst CJ, Lunder U, et al. 2013. Care of the dying and the LCP in England: an international perspective. *European Journal of Palliative Care* 20(3): 120–3.
- Ellershaw J, Ward C. 2003. Care of the dying patient: the last hours or days of life. *British Medical Journal* 326: 30–4.
- Frey R, Gott M, Raphael D, et al. 2013. 'Where do I go from here?' A cultural perspective on challenges to the use of hospice services. *Health and Social Care in the Community* 21(5): 519–29.
- Gardiner C, Gott M, Small N, et al. 2009. Living with advanced chronic obstructive pulmonary disease: patients concerns regarding death and dying. *Palliative Medicine* 23: 691–7.
- Goncalves-Pereira M, Zarit SH. 2014. The Zarit Burden interview in Portugal: validity and recommendations in dementia and palliative care. *Acta Medica Portuguesa* 27(2): 163–5.
- Hanson LC, Rowe C, Wessell K, et al. 2012. Measuring palliative care quality for seriously ill hospitalised patients. *Journal of Palliative Medicine* 15(7): 798–804.
- Healthcare Improvement Scotland. 2013. *Palliative and End of Life Care Indicators*. Scotland: Edinburgh: National Health Service.
- Hennings J, Froggatt K, Payne S. 2013. Spouse caregivers of people with advanced dementia in nursing homes: a longitudinal narrative study. *Palliative Medicine* 27(7): 683–91.
- International Collaborative for Best Care of the Dying Patient. 2014. *International Interim Model Integrated Care Pathway (ICP) Documentation*. Liverpool: The Marie Curie Palliative Care Institute.
- Jackson K, Mooney C, Campbell D. 2008. The development and implementation of the pathway for improving the care of the dying in general medical wards. *Internal Medicine Journal* 39(10): 695–9.
- Jansen P, Bascall K, Crengle S. 2009. *He Ritenga Whakaaro: Māori experiences of health services*. Auckland: Mauri Ora Associates.
- Keall R, Clayton JM, Butow P. 2014. Australian Palliative Care Nurses' Reflections on Existential/Spiritual Interventions. *Journal of Hospice and Palliative Nursing* 16(2): 105–12.
- Kisvetrova H, Klugar M, Kabelka L. 2013. Spiritual support interventions in nursing care for patients suffering death anxiety in the final phase of life. *International Journal of Palliative Care* 19(12): 599–605.

- Kross E, Nielson EL, Curtis JR, et al. 2012. Survey burden for family members surveyed about end of life care in the intensive care unit. *Journal of Pain and Symptom Management* 44(5): 671–80.
- Kumar S. 2014. *Buddhist perspectives on end of life care – a conversation with Phra Paisal Visalo*. ehospice. URL: www.ehospice.com/ArticleView/tabid/10686/ArticleId/11687/language/en-GB/Default.aspx (accessed 11 September 2015).
- Leadership Alliance for the Care of Dying People. 2014. *One Chance to Get It Right: Improving people's experience of care in the last few days and hours of life*. London: Leadership Alliance for the Care of Dying People.
- Li Q, Zheng NT, Temkin-Greener H. 2013. Quality of end-of-life care of long-term nursing home residents with and without dementia. *Journal of the American Geriatrics Society* 61(7): 1066–73.
- Lorenz K, Rosenfeld K, Wenger N. 2007. Quality indicators for palliative and end of life care in vulnerable elders. *Journal of the American Geriatrics Society* 55(2): S318–26.
- Ministry of Health. 2014. *Palliative Care and Māori from a Health Literacy Perspective*. Wellington: Ministry of Health.
- Mullick A, Beynon T, Colvin M, et al. 2009. Liverpool Care Pathway Carers' Survey. *Palliative Medicine* 23: 571–2.
- Ngata P. 2005. Death, dying and grief. In: M Schwass (ed). *Last Words: Approaches to death in New Zealand's cultures and faiths*. Wellington: Bridget Williams Books with the Funeral Directors Association of New Zealand.
- NHS. 2009. *End of Life Strategy, Quality Markers and Measures for End of Life Care*. London: National Health Service.
- NHS Scotland. 2013. *Interim Guidance: Caring for people in the last days and hours of life*. Edinburgh: National Health Service Scotland.
- Nicholas LH, Bynum J, Iwashyna T, et al. 2014. Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. *Health Affairs* 33(4): 667–74.
- O'Connor M, Beattie J, Poon Wing Hong E, et al. 2014. End of life care needs of people dying from stroke in Australia, New Zealand and Singapore: a space for palliative care. *Asia Pacific Journal of Health Management* 9(1): 35–44.
- Parry R, Seymour J, Whittaker B, et al. 2013. *Pathways Focused on the Dying Phase in End of Life Care and Their Components*. London: Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care, NHS and the University of Nottingham.
- Pasman HR, Brandt HE, Deliens L, et al. 2009. Quality indicators for palliative care: a systematic review. *Journal of Pain and Symptom Management* 38: 145–56.
- PCC. 2012. *New Zealand Palliative Care Glossary*. Wellington: Palliative Care Council of New Zealand.
- PCC. 2014. *Deaths in New Zealand: Place of Death, 2000–2010*. Wellington: Palliative Care Council of New Zealand.
- Petersen CL. 2014. Spiritual care of the child with cancer at the end of life: a concept analysis. *Journal of Advanced Nursing* 70(6): 1243–53.
- Phillips JL, Halcomb E, Davison PM. 2011. End of life care pathways in acute and hospice care: an integrative review. *Journal of Pain and Symptom Management* 41(5): 940–55.
- Randall F, Downie RS. 2006. *The Philosophy of Palliative Care*. Glasgow: Oxford University Press.

- Rauawaawa Kaumātua Charitable Trust Research Project Team. 2014. *Māori health Literacy and Communication in Palliative Care: Kaumātua-led models*. Wellington: Ministry of Health.
- Raymond M, Warner A, Davies N, et al. 2014. Evaluating educational initiatives to improve palliative care for people. *Dementia* 13(3): 366–81.
- Reinhardt JP, Chichin E, Posner L, et al. 2014. Vital conversations with family in the nursing home: preparation for end-stage dementia care. *Journal of Social Work in End of Life and Palliative Care* 10(2): 112–26.
- Roberts D, Gaspard G. 2013. A palliative approach to care of residents with dementia. *Nursing Older People* 25(2): 32–6.
- Robinson J, Gott M, Ingleton C. 2013. Patient and family experiences of palliative care in hospital: what do we know? An integrated review. *Palliative Medicine* 28(1): 18–33.
- Royal College of Physicians. 2014. *National Care of the Dying Audit for Hospitals, England*. London: Royal College of Physicians.
- Rushton L. 2014. What are the barriers to spiritual care in a hospital setting? *British Journal of Nursing* 23(7): 370–4.
- Schenk A, Rokoske FS, Durham DD, et al. 2010. The PEACE Project: Identification of Quality Measures for Hospice and Palliative Care. *Journal of Palliative Medicine* 13(12): 1451–9.
- Sheward K, Clark J, Marshall B, et al. 2011. Staff perceptions of end-of-life care in the acute care setting: a New Zealand perspective. *Journal of Palliative Medicine* 14(5): 623–30.
- Thurston J, Waterworth S. 2012. ‘Making sense’: nurses’ experiences of changing practice in caring for dying patients in New Zealand. *International Journal of Palliative Nursing* 18(10).
- Tripodoro VA, Berenguer C, von Petery G, et al. 2013. *LCP in Argentina: Time to build the bases to make a difference*. Buenos Aires: Instituto Pallium Latinoamérica.
- Van Soest-Poortvliet M, Van der Steen J, Zimmerman S, et al. 2011. Measuring the quality of dying and quality of care when dying in long term care settings: a qualitative content analysis of available instruments. *Journal of Pain and Symptom Management* 42(6): 671–84.
- Veerbeek L, van Zuylen L, Swart SJ, et al. 2008. The effect of the Liverpool Care Pathway for the dying: a multi-centre study. *Palliative Medicine* 22(145): 145–50.
- Vilalta A, Valls J, Josep P, et al. 2014. Evaluation of Spiritual Needs of Patients with Advanced Cancer in a Palliative Care Unit. *Journal of Palliative Medicine* 17(5): 592–600.
- Watts T. 2013. End of life care pathways and nursing: a literature review. *Journal of Nursing Management* 21(21): 47–55.
- Zimmerman C, Rodin G. 2004. The denial of death thesis: sociological critique and implications for palliative care. *Palliative Medicine* 18(2): 121–8.