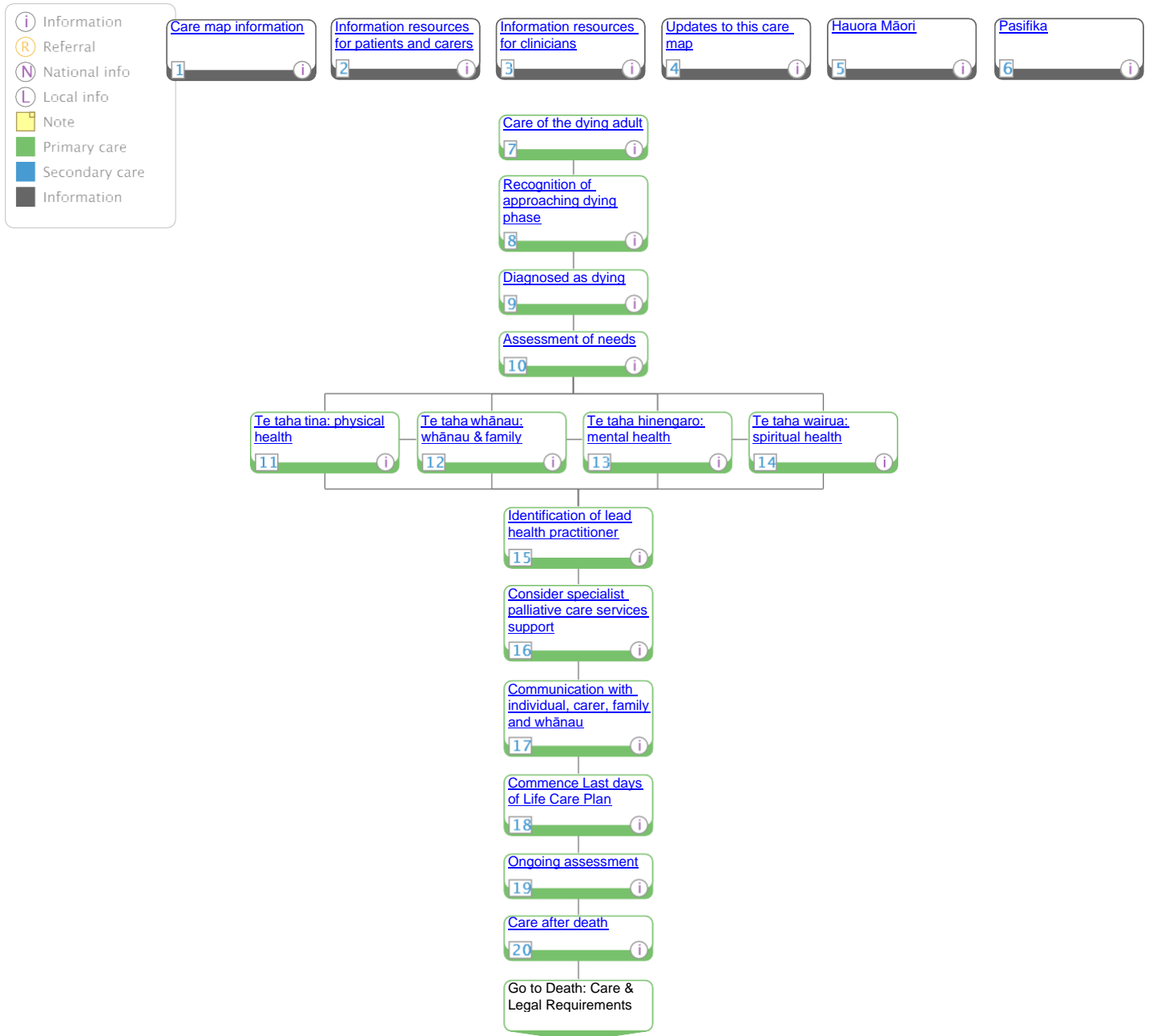


Palliative Care – Last Days of Life

Medicine > Palliative Care > Palliative Care in Adults



1. Care map information

In scope:

- assessment and management of adults who are recognised as being in their last days of life

Out of scope:

- children:
 - for paediatric palliative care contact MidCentral Health Children's Ward Charge Nurse (06) 356 9169 ext. 7073

Definition and principles:

A palliative approach embraces the World Health Organisation (WHO) definition of palliative care. It incorporates a positive and open attitude toward death and dying by all service providers working with people and their families and respects the wishes of people in relation to their treatment and care.

The WHO defines palliative care as [1]:

- an approach that improves the quality of life of people and their families facing the problems associated with life-limiting or life-threatening conditions, through the prevention and relief of suffering by means of:
 - early identification
 - impeccable assessment
 - treatment of pain and other problems:
 - physical
 - psychosocial
 - spiritual

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of a person's care
- offers a support system to help people live as actively as possible until death
- offers a support system to help the family cope during the person's illness and in their own bereavement
- uses an interprofessional team approach to address the needs of people and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

A New Zealand specific definition of palliative care is [2]:

Care for people of all ages with a life-limiting or life-threatening condition which aims to:

- optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs
- support the individual's family, whānau, and other caregivers where needed, through the illness and after death

Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life:

- it should be available wherever the person may be
- it should be provided by all health care professionals, supported where necessary, by specialist palliative care services
- palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or

groups. These include Māori, children and young people, immigrants, refugees, and those in isolated communities

Considerations for people who would benefit from a palliative approach who also have learning disabilities:

- remember that even people with a mild learning disability may understand language in a literal, non-euphemistic manner and therefore anything that is communicated should take account of this
- avoid the use of abstract language in discussions about palliative care approach, e.g. talk about 'dying' rather than 'passing away'
- as the person's ability to concentrate may be impaired it is better to have a number of short, single-focus conversations rather than to try to communicate everything in one session - give the time needed to help the person understand
- take into account the environment in which discussions about a palliative care approach are to be held
- work within mental capacity legislation - to assert the rights of the individual to make important decisions whilst expressing empathy and understanding for the concerns of the family

End of life:

The end of life phase begins when a judgement is made that death is imminent. It may be the judgement of the health/social care professional or team responsible for the care of the individual, but it is often the person or family who first recognises its beginning.

For references see Provenance Certificate.

2. Information resources for patients and carers

Recommended resources for patients and carers:

- [A Guide for Carers](#)
- [Home Nursing Tips](#)
- [Coping Tool for Caregivers](#)
- [Oral Care for Someone who is Dying](#)
- [When Death is near: things to know and do](#)
- [What to Expect When Someone is Dying](#)
- [Talking about dying - child focussed](#)
- [Coping with Bereavement](#)
- [Advance Care Planning](#)
- [Enduring Power of Attorney](#) (Ministry of Social Development)

3. Information resources for clinicians

Information resources for clinicians:

- [Recognising the dying patient](#)
- [Last days of life care plan](#)
- [Oral Care for Someone who is Dying](#)
- [When Death is near: things to know and do](#)
- [What to Expect When Someone is Dying](#)
- [Advance Care Planning](#)
- [Enduring Power of Attorney](#) (Ministry of Social Development)

4. Updates to this care map

Date of publication: March 2017

Please see the care map's Provenance for additional information on references, accreditations from national clinical bodies, contributors, publication schedule, and the editorial methodology.

5. Hauora Māori

Māori are a diverse people and whilst there is no single Māori identity, it is vital practitioners offer culturally appropriate care when working with Māori whānau. It is important for practitioners to have a baseline understanding of the issues surrounding Māori health.

This knowledge can be actualised by (not in any order of priority):

- acknowledging [Te Whare Tapa Wha \(Māori model of health\)](#) when working with Māori whānau
- asking Māori clients if they would like their whānau or significant others to be involved in assessment and treatment
- asking Māori clients about any particular cultural beliefs they or their whānau have that might impact on assessment and treatment of the particular health issue ([see Cultural issues](#))
- consider the importance of whānaungatanga (making meaningful connections) with their Māori client / whānau
- knowledge of [Whānau Ora, Te Ara Whānau Ora and referring to Whānau Ora Navigators](#) where appropriate
- having a historical overview of legislation that has impacted on Māori well-being

For more information about Hauora Māori, [click here](#)

- [Click here for a list of local Māori Health Providers](#)
- [Central PHO Māori Health website](#)

6. Pasifika

[Click here to download the Pacific Cultural Guidelines \(Central PHO\) 6MB file](#)

Our Pasifika community:

- is a diverse and dynamic population:
 - more than 22 nations represented in New Zealand
 - each with their own unique culture, language, history, and health status
 - share many similarities which we have shared with you here in order to help you work with Pasifika patients more effectively

The main Pacific nations in New Zealand are:

- Samoa, Cook Islands, Fiji, Tonga, Niue, Tokelau and Tuvalu

Acknowledging [The FonoFale Model \(pasifika model of health\)](#) when working with Pasifika peoples and families.

Acknowledging general pacific guidelines when working with Pasifika peoples and families:

- [Cultural protocols and greetings](#)
- [Building relationships with your pasifika patients](#)
- [Involving family support, involving religion, during assessments and in the hospital](#)
- [Home visits](#)
- [Contact information](#)

Pasifika Health Service - Better Health for Pasifika Communities

- the Pasifika Health Service is a service provided free of charge for:
 - all Pasifika people living in Manawatu, Horowhenua, Tararua and Otaki who have long term conditions
 - all Pasifika mothers and children aged 0-5 years

- an appointment can be made by the patient, doctor or nurse
- the Pasifika Health Service contact details are:
 - Palmerston North Office - 06 354 9107
 - Horowhenua Office - 06 367 6433
- for more information, please refer to the [Better Health for Pasifika Communities brochure](#)

Additional information:

- Ala Mo'ui - [Pathways to Pacific Health and Wellbeing 2014-2018](#)
- Primary care for pacific people: [a pacific health systems approach](#)
- Tupu Ola Moui: [The Pacific Health Chart Book 2004](#)
- Pacific Health [resources](#)
- [Click here for a list of local Maori/Pacific Health Providers](#)
- [Central PHO Pacific Health website](#)

7. Care of the dying adult

Care for the dying person should follow an appropriate framework that ensures best practice and care for the person- it should involve:

- development of a last days of life care plan
- reviewing the current plan
- continuous assessment and management of presenting symptoms
- care following death

8. Recognition of approaching dying phase

Recognising the last days of life can be difficult as signs and symptoms are often subtle. Factors that may help to [recognise the dying patient](#)

Non-fatal life threatening but recoverable conditions can mimic last days of life

The diagnosis of dying:

- is necessary to ensure the right care is given to the dying person
- requires recognition of the key signs and symptoms of dying
- is an important clinical skill, but can be a complex process
- allows the team to refocus care appropriately for people and their family/whānau

When a person's condition deteriorates unexpectedly, and it is thought they may die soon, they must be assessed by a doctor or a Nurse Practitioner who is competent to judge whether:

- the change is potentially reversible
- the person is likely to die

If the condition is potentially reversible prompt action must be taken to attempt this provided it is in:

- accordance with the person's wishes; or
- their best wishes if they lack capacity to make the decision about treatment at that time

When death is imminent:

- attention should be given to assessing and accommodating the wishes of people, families and other carers
- staff should be trained in best practice on caring for dying people and measures should be in place to ensure that integrated care is delivered

9. Diagnosed as dying

Care for people who are potentially in the last few days and hours should be a continuum, focusing on continually assessing their condition, needs and wishes, and responding appropriately.

10. Assessment of 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.

Te Whare Tapa Whā model provides a framework for providing a holistic assessment [3]:

- te taha tina: physical health
- te taha whānau: extended family/whānau health and wider social systems
- te taha hinengaro: mental health; expressing thoughts and feelings
- te taha wairua: spiritual health; faith and spiritual awareness

Seven principles to achieve excellence and consistency of care:

- care is person-centred
- the workforce providing care is the right workforce
- communication is clear and respectful
- services providing care to people in their last days of life are integrated, and move with the person
- services are sustainable
- services are nationally guided and supported
- access to resources and equipment is consistent

11. Te taha tina: physical health

Te taha tina: physical health [3]

Considerations include:

- assessment of physical needs:
 - baseline assessment to identify:
 - person's priorities of care
 - symptom management
 - physical care needs
 - review of current management and medicines:
 - stopping of unnecessary treatments/medications
 - initiation of prescribing of anticipatory medications for common symptoms including:
 - pain
 - agitation, delirium, terminal restlessness
 - nausea and vomiting
 - breathlessness
- the persons awareness of their changing condition
- provision of food and fluid
- availability of equipment to support the persons care needs
- consideration of cardiac devices

- advice to relevant agencies of the persons deterioration

12. Te taha whānau: whānau & family

Te taha whānau - extended family and whānau health and wider social systems; belonging, sharing and caring [3]

Considerations include:

- identification of communication barriers:
 - there should be effective communication between:
 - all health professionals
 - care workers and agencies
 - the person and their whānau and family
- the family & whānau awareness of the person's changing condition
- discussion of cultural needs
- provision of information to the family & whānau about support and facilities

13. Te taha hinengaro: mental health

Te taha hinengaro: mental health, inseparability of mind and body; expressing thoughts and feelings [3]

Considerations include:

- assessing the person's and family's or carers ability to understand and recognise that the patient is dying and the measures that are being taken to ensure their comfort
- preferences the person may have to allow natural death
- if advance care plan or advance directive is in place
- person's wishes in relation to preferred place of care and death

14. Te taha wairua: spiritual health

Te taha wairua: spiritual health, unseen and unspoken energies, faith and spiritual awareness [3]

Considerations include:

- provision of opportunity for the person and family/whānau to discuss what is important to them

This area takes into account:

- any spiritual or religious traditions that the person may already have
- the need to search for meaning and understanding of their life and circumstances
- the person may have anxiety for themselves or for others left behind
- recognise that the individual may have spiritual needs even if they are not religious

15. Identification of lead health practitioner

Once it is 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
- will not generally be a specialist palliative care doctor or nurse

- in community most likely be General Practitioner or Nurse Practitioner
- in acute care setting most likely to be registrar or consultant
- care plan should identify who to contact when lead health practitioner not available
- important to ensure continuity of care 24/7 and to communicate changes and concerns

16. Consider specialist palliative care services support

Any level of need that cannot be addressed by the Primary Care Team should receive further support or referral as appropriate to specialist palliative care services.

See Arohanui Hospice [Referral Form](#)

17. Communication with individual, carer, family and whānau

Initiate discussion with individual, carer, family and/or whānau and explain the current plan of care and the use of Last Days of Life Care Plan.

18. Commence Last days of Life Care Plan

Commence Last days of Life Care Plan for the dying person.

To mitigate risks of inappropriate use or inadequate end of life care, health professionals should access education and training on quality end of life care alongside the use of the Last Days of Life Care Plan.

[Last Days of Life Care Plan](#) -

- includes ongoing assessments
- provides guidance on:
 - comfort measures
 - anticipatory prescribing of medicines
 - discontinuation of inappropriate interventions, medications and review of treatment regimens
 - psychological and spiritual care
 - care of the family and whānau

19. Ongoing assessment

Reassessment and review of the current plan should be triggered when one or more of the following apply:

- improved:
 - conscious level
 - functional ability
 - oral intake
 - mobility
 - ability to perform self-care
- concerns expressed regarding management plan from either individual, carer, whānau, family or team member

20. Care after death

When death occurs, the relevant professionals, family, whānau or carer should have the necessary guidance on:

- what to do next
- whom to contact
- all relevant contact numbers
- what will happen next

Death should be verified according to local policy and procedure, and relevant procedures for 'laying out' (last offices) should be followed.

The persons:

- death should be communicated across all appropriate health care teams
- family, whānau and carers should receive relevant support and written information about:
 - grief, loss, and bereavement
 - legal tasks, such as collection of the death certificate and registration of death

Palliative Care

Provenance Certificate

[Overview](#) | [Editorial methodology](#) | [References](#) | [Contributors](#) | [Disclaimers](#)

Overview

This document describes the provenance of MidCentral District Health Board's **Palliative Care** pathway. This pathway is regularly updated to include new, quality-assessed evidence, and practice-based knowledge from expert clinicians. Please see the Editorial Methodology section of this document for further information.

This localised pathway was last updated in **July 2016**.

For information on changes in the last update, see the information point entitled 'Updates to this care map' on each page of the pathway.

One feature of the "Better, Sooner, More Convenient" (BSMC) Business Case, accepted by the Ministry of Health in 2010, was the development of 33 collaborative clinical pathways (CCP).

The purpose of implementing the CCP Programme in our DHB is to:

- Help meet the Better Sooner More Convenient Business Case aspirational targets, particularly the following:
 - Reduce presentations to the Emergency Department (ED) by 30%
 - Reduce avoidable hospital admissions to Medical Wards and Assessment Treatment and Rehabilitation for over-65-year-olds by 20%
 - Reduce poly-pharmacy in the over-65-year-olds by 10%
- Implement a tool to assist in planning and development of health services across the district, using evidence-based clinical pathways.
- Provide front line clinicians and other key stakeholders with a rapidly accessible check of best practice;
- Enhance partnership processes between primary and secondary health care services across the DHB.

To cite this pathway, use the following format:

Map of Medicine. Medicine. MidCentral District View. Palmerston North: Map of Medicine; 2014 (Issue 1).

Editorial methodology

This care map was based on high-quality information and known Best Practice guidelines from New Zealand and around the world including Map of medicine editorial methodology. It has been checked by individuals with front-line clinical experience (see Contributors section of this document).

Map of Medicine pathways are constantly updated in response to new evidence. Continuous evidence searching means that pathways can be updated rapidly in response to any change in the information landscape. Indexed and grey literature is monitored for new evidence, and feedback is collected from users year-round. The information is triaged so that important changes to the information landscape are incorporated into the pathways through the quarterly publication cycle.

References

This care map has been developed according to the Map of Medicine editorial methodology. The content of this care map is based on high-quality guidelines and practice-based knowledge provided by contributors with front-line clinical experience. This localised version of the evidence-based, practice-informed care map has been peer-reviewed by stakeholder groups and the CCP Programme Clinical Lead.

1	Hospice New Zealand. (2001). Hospice New Zealand standards for the care of people approaching the end of life. Wellington: Hospice New Zealand.
2	World Health Organization. (2002) National cancer control programmes, policies and managerial guidelines (2nd edn). Geneva: World Health Organization.
3	Palliative Care Subcommittee, NZ Cancer Treatment Working Party (2007). New Zealand Palliative Care: A Working Definition. [Online]. Available from: http://www.moh.govt.nz/moh.nsf/pagesmh/2951/\$File/nz-palliative-care-definition-oct07.pdf .
4	Supportive and Palliative Care Indicator Tool, available http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/SPICTool .
5	Gold standards framework, available on http://www.goldstandardsframework.org.uk/ .
6	MacLeod, R., Vella-Brincat, J., MacLeod, S. (2012). Nurse Maud Palliative Care Guidelines, Guidelines for clinical management and symptom control. 6th ed. Soer Printers. Available on http://www.hospice.org.nz/cms_show_download.php?id=377 .
7	Bellamy, G., Gott, M., Waterworth, S., McLean, C., & Kerse, N. (2014). "But I do believe you've got to accept that that's what life's about: older adults living in New Zealand talk about their experiences of loss and bereavement support. Health and social Care in the Community. Vol 22(1), 96-103.

Contributors

MidCentral DHB's Collaborative Clinical Pathway editors and facilitators worked with clinical stakeholders such as front-line clinicians and pharmacists to gather practice-based knowledge for its care maps.

The following individuals contributed to the original development and review and update of this care map:

- Bridget Marshall, Palliative Care Network Coordinator (Pathway Facilitator)
- Dr Syed Zaman, Consultant Geriatrician, MidCentral Health (Secondary Care Clinical Lead)
- Clare Randall, Chief Executive, Arohanui Hospice
- Nikki Twigg, Palliative Care Coordinator, Arohanui Hospice
- Karen Sherward, Clinical Nurse Specialist, Hospital Palliative Care Team
- Paul Cooper, General Practitioner, Central PHO (Primary Care Clinical Lead)
- Liz Elliott, Nurse Coordinator Practice Development, Health Care Development, MidCentral DHB (Pathway Editor)

The following individuals also contributed to this care map

- Mark Beale, Clinical Director, Medical Services

Disclaimers

Clinical Board Central PHO, MidCentral DHB

It is not the function of the Clinical Board Central PHO, MidCentral DHB to substitute for the role of the clinician, but to support the clinician in enabling access to know-how and knowledge. Users of the Map of Medicine are therefore urged to use their own professional judgement to ensure that the patient receives the best possible care. Whilst reasonable efforts have been made to ensure the accuracy of the information on this online clinical knowledge resource, we cannot guarantee its correctness and completeness. The information on the Map of Medicine is subject to change and we cannot guarantee that it is up-to-date.

Palliative Care: Last Days of Life

Provenance Certificate

[Overview](#) | [Editorial methodology](#) | [References](#) | [Contributors](#) | [Disclaimers](#)

Overview

This document describes the provenance of MidCentral District Health Board's Palliative Care: Last Days of Life pathway.

This localised pathway was last updated in March 2017.

One feature of the "Better, Sooner, More Convenient" (BSMC) Business Case, accepted by the Ministry of Health in 2010, was the development of 33 collaborative clinical pathways (CCP).

The purpose of implementing the Last Days of Life pathway in our DHB is to:

- facilitate better understanding of the principles and practices of care for people in their last days of life
- provide guidance to health professionals in recognizing dying
- encourage appropriate use of resources and efficient use of services
- Promote and provide standardized care plans for last days of life
- Promote and provide resources to support symptom management in last days of life
- promote consistency with New Zealand best practice guidelines Te Ara Whakapiri
- provide easy access to information resources for patients/carers and providers

The scope of the pathway includes use by all health professionals caring for adults who are recognized as being in their last days of life regardless of diagnosis or care setting.

Editorial methodology

This care map was based on high-quality information and known Best Practice guidelines from New Zealand and around the world including Map of medicine editorial methodology. It has been checked by individuals with front-line clinical experience (see Contributors section of this document).

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1	World Health Organization. (2002) National cancer control programmes, policies and managerial guidelines (2nd edn). Geneva:World Health Organization
2	Palliative Care Subcommittee, NZ Cancer Treatment Working Party (2007). New Zealand Palliative Care: A Working Definition. [Online]. Available from: http://www.moh.govt.nz/moh.nsf/pagesmh/2951/\$File/nz-palliative-care-definition-oct07.pdf
3	Ministry of Health. (2015). <i>Te Ara Whakapiri: Principles and guidance for the last days of life</i> . Wellington: Ministry of Health.

MidCentral DHB's Collaborative Clinical Pathway editors and facilitators worked with clinical stakeholders such as front-line clinicians and pharmacists to gather practice-based knowledge for its care maps.

Working group members included:

- Syed Zaman, Consultant Geriatrician, MidCentral Health (Secondary Care Clinical Lead)
- Pauline Blackmore, General Practitioner, Taranaki Health Group (Primary Care Clinical Lead)
- Clare Randall, Chief Executive, Arohanui Hospice
- Jean Clark, Clinical Nurse Specialist Palliative Care, MidCentral Health
- Karen Sherward, Clinical Nurse Specialist Palliative Care, MidCentral Health
- Simon Allan, Director of Palliative Care, Arohanui Hospice
- Karen Lowe, Nurse Practitioner, Cook Street Health Centre
- Bridget Marshall, Palliative Care Network Coordinator (Pathway Facilitator)
- Liz Elliott, Nurse Coordinator Practice Development, Health Care Development, MidCentral DHB (Pathway Editor)

This pathway was distributed widely for consultation and comments received have been acknowledged and taken into consideration in the final document

Disclaimers

CCP Executive Team, MidCentral DHB

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