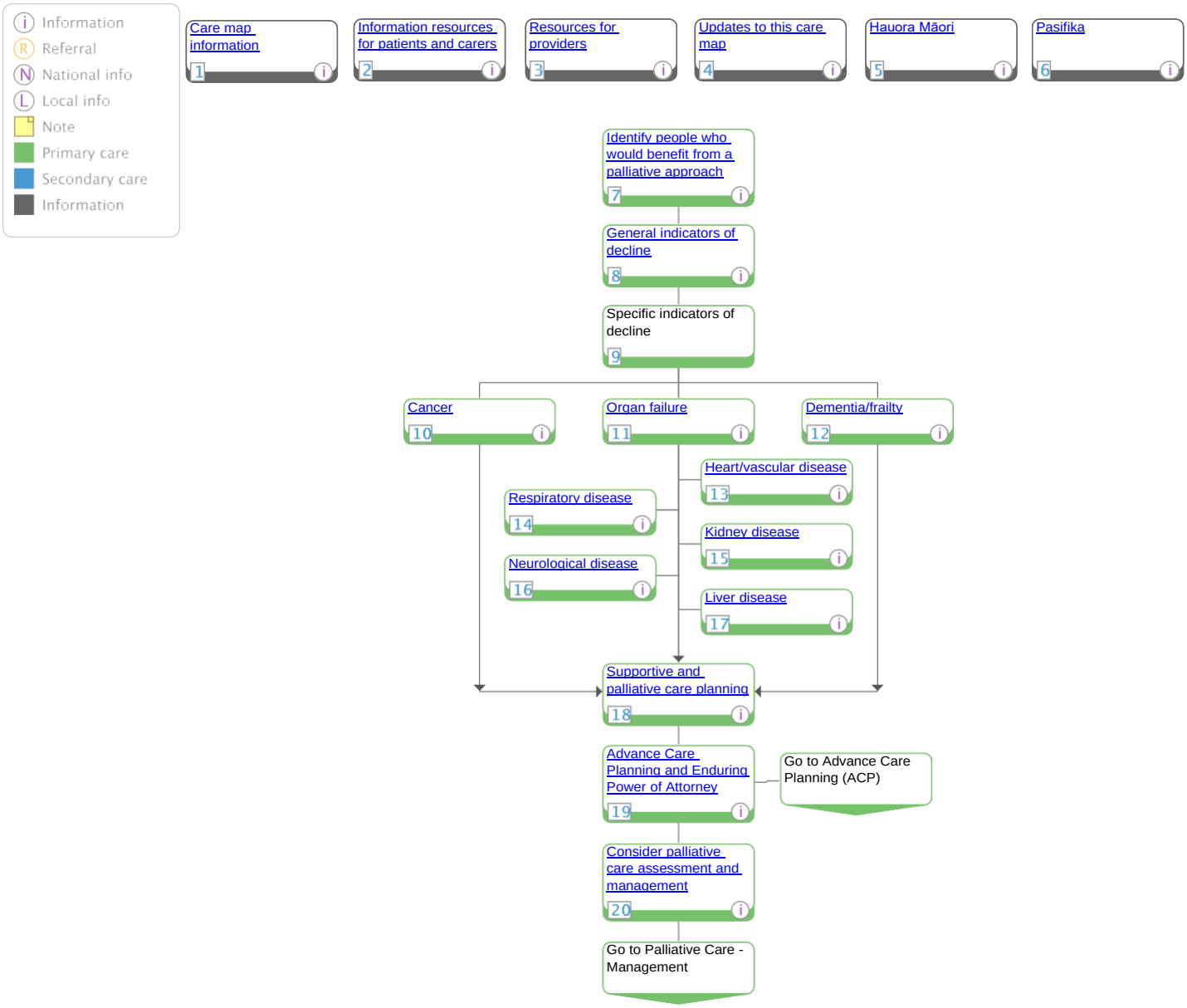
Palliative Care – Early Identification

Medicine > Palliative Care > Palliative Care in Adults



1. Care map information

In scope:

- identification of adults with life limiting illness who would benefit from a palliative care approach

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 patients and their families, and respects the wishes of patients in relation to their treatment and care [1].

The WHO defines palliative care as [2]:

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 a 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 a 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
  - radiation therapy
- includes those investigations needed to better understand and manage distressing clinical complications

A New Zealand specific definition of palliative care is [3]:

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

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 person, but it is often the person or family who first recognises its beginning.

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

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
- What to Expect When You Are Grieving
- Being Prepared for Death - Practical Steps
- Bereavement Support Services and Resources in MDHB
- Advance Care Planning (ACP) pathway
- Enduring Power of Attorney (Ministry of Social Development)

Te Ara Whānau Ora:

- Te Ara Whānau Ora Brochure

3. Resources for providers

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 (ACP) Pathway
- Enduring Power of Attorney (Ministry of Social Development)

Te Ara Whānau Ora:

- Te Ara Whānau Ora Brochure

4. Updates to this care map

Date of first publication: March 2015

Date of re-publication: July 2016

This care map has been reviewed in line with consideration to evidenced based guidelines. No significant changes were made to the pathway following review.

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 (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 further information:

- Hauora Māori

6. Pasifika

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
- Better Health for Pasifika Communities brochure

Additional resources:

- 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
- Central PHO Pasifika Health Service

7. Identify people who would benefit from a palliative approach

Identify factors that should trigger discussions about the end of life:

- 'surprise question':
  - would you be surprised if this person were to die in the next 6-12 months?
  - the surprise question can be applied to years, months, weeks, or days, and trigger the appropriate actions enabling the right thing to happen at the right time

Other factors to consider are:

- people with advanced disease may choose a palliative approach, and not curative treatment
- at the time of diagnosis of a condition which usually carries a poor prognosis:
  - e.g. motor neurone disease
- at a point when there is a deterioration in a chronic illness and the likely diagnosis is measured in months or possibly a year or two:
  - e.g. an acute episode on the background of long-standing chronic obstructive pulmonary disease

Considerations should be made for those with learning disabilities and/or cognitive impairment (see 'Care map information' box).

There are three main trajectories of decline at the end of life:

- people with long-term conditions remain in reasonably good health until shortly before their death, with a steep decline in the last few weeks or months of life:
  - typical of cancer
- people with a more gradual decline, interspersed with episodes of acute ill health from which they may, or may not, recover:
  - typical for people with organ failure
- people are very frail for months or years before death, with a steady progressive decline:
  - typical of physical and cognitive frailty

8. General indicators of decline

Look for two or more general indicators of deteriorating health [4]:

- performance status poor or deteriorating, with limited reversibility:
  - needs help with personal care, in bed or chair 50% or more of the day
- two or more unplanned hospital admissions in the past six months
- weight loss (5-10%) over the past 3-6 months and/or body mass index < 20
- persistent, troublesome symptoms despite optimal treatment of underlying condition(s)
- lives in an Aged Residential Care facility
- needs care to remain at home
- person requests supportive and palliative care, or treatment withdrawal

10. Cancer

Ensure optimal management of underlying disease.

Indicators of advanced condition [4]:

- functional ability deteriorating due to progressive metastatic cancer
- too frail for oncology treatment or treatment is for symptom control

Information and resources:

- Cancer Society
- The National Tumour standards describe the level of service that a person with cancer should have access to in New Zealand. - the standards include care from time of diagnosis through management and support and palliative care
- MOH Cancer Programme
- Central Cancer Network

11. Organ failure

Includes:

- heart / vascular
- respiratory
- kidney
- neurological
- liver

12. Dementia/frailty

Ensure optimal management of underlying disease, see:

- Dementia - Assessment Pathway
- Frailty - Management Pathway

Indicators of advanced condition [4]:

- unable to dress, walk or eat without help
- choosing to eat and drink less
- difficulty maintaining nutrition
- urinary and faecal incontinence
- no longer able to communicate using verbal language
- little social interaction
- fractured femur
- multiple falls
- recurrent febrile episodes or infections
- aspiration pneumonia

Information and resources:

- Alzheimer's New Zealand

13. Heart/vascular disease

Ensure optimal management of underlying disease.

Indicators of advanced condition [4]:

- New York Heart Association (NYHA) Class III/IV heart failure, or extensive, untreatable coronary artery disease disease with:
  - breathlessness or chest pain at rest or on minimal exertion
  - severe inoperable peripheral vascular disease

NYHA classification of Heart Failure:

- Class I -Cardiac disease, but no symptoms and no limitation in ordinary physical activity:
  - shortness of breath when walking, climbing stairs etc.
- Class II-Mild symptoms:
  - mild shortness of breath and/or angina
  - slight limitation during ordinary activity
- Class III-Marked limitation in activity due to symptoms, even during less-than-ordinary activity:
  - walking short distances (20–100 m)
  - comfortable only at rest
- Class IV-Severe limitations. Experiences symptoms even while at rest:
  - mostly bedbound patients

Information and resources:

- Heart Foundation

14. Respiratory disease

Ensure optimal management of underlying disease.

Indicators of advanced condition [4]:

- severe chronic lung disease with:
  - breathlessness at rest or on minimal exertion between exacerbations
- has needed ventilation for respiratory failure or ventilation is contraindicated

Information and resources:

- Asthma and Respiratory Foundation

15. Kidney disease

Ensure optimal management of underlying disease (see CKD Management Pathway).

Indicators of advanced condition [4]:

- stage 4 or 5 chronic kidney disease (eGFR<30ml/min) with deteriorating health
- kidney failure complicating other life limiting conditions or treatments
- stopping dialysis

Information and resources:

- Kidney Foundation

16. Neurological disease

Ensure optimal management of underlying disease.

Indicators of advanced condition [4]:

- progressive deterioration in physical and/or cognitive function despite optimal therapy
- speech problems with increasing difficulty communicating and / or progressive dysphagia
- recurrent aspiration pneumonia; breathless or respiratory failure

Information and resources:

- Parkinson's disease
- Motor neurone disease

17. Liver disease

Ensure optimal management of underlying disease.

Indicators of advanced condition [4]:

- advanced cirrhosis with one or more complications in past year:
  - diuretic resistant ascites
  - hepatic encephalopathy
  - hepatorenal syndrome
  - bacterial peritonitis
  - recurrent variceal bleeds

- liver transplant is contraindicated

18. Supportive and palliative care planning

The person's goals should be central to all care planning.

Agree current and future care goals and management with the person and family. This includes:

- physical
- psychosocial
- spiritual
- cultural

Coordinate care and ensure continuity when transferring to or sharing care with other services.

19. Advance Care Planning and Enduring Power of Attorney

Discuss:

- Advance Care Planning (see Advance Care Planning pathway)
- Enduring Power of Attorney (Ministry of Social Development)

20. Consider palliative care assessment and management

Consider palliative care assessment if symptoms or needs are complex and difficult to manage.

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). *Te Ara Whakapiri: Principles and guidance for the last days of life*. 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, Tararua 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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