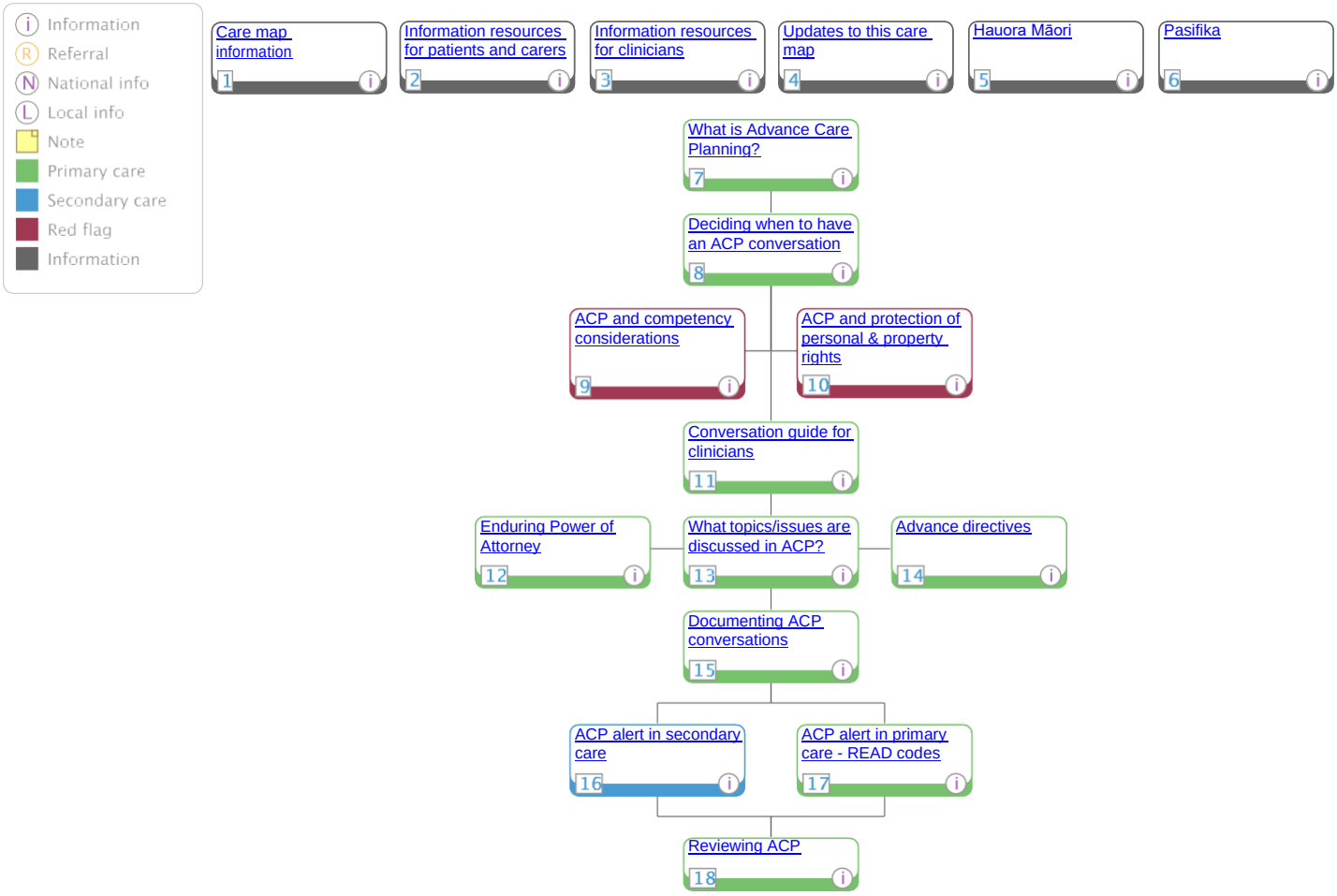
Advance Care Planning (ACP)

Medicine > General medicine > Advance Care Planning (ACP)



1. Care map information

This care map is designed to be used with people over the age of 18 years who are competent to make decisions.

Advance Care Planning relies on the person being competent to share in the planning process and so needs to be considered early in the care of any person for whom a diagnosis of dementia is suspected.

Definitions:

- **Advance Care Planning [1]:**
  - Advance care planning is a voluntary process of discussion and shared planning for future health care. It involves the person who is preparing the plan, and usually involves family/whānau and health care professionals.
- **Advance Care Plan [1]:**
  - An Advance Care Plan is the outcome of Advance Care Planning. It is formulated by the person and sets out their views about care towards the end of their life. It may also include views about medical care and a wide range of other matters. An Advance Care Plan may include an advance directive.
- **Advance Directive [1]:**
  - An Advance Directive is a statement a person makes about their medical care in the future and becomes effective if a person ceases to be competent to make decisions for themselves. An advance directive is legally binding if made in appropriate circumstances. See 'Advance directives' box for more information.
- **Enduring Power of Attorney (EPA) [1]**
  - Enduring Power of Attorney is a power given by an individual to a person appointed to make decisions on behalf of that individual if, and when they they cannot make, or communicate, those decisions for themselves.

This table highlights the differences between advance care plans, advance directives and EPA.

See Provenance Certificate for full list of references.

2. Information resources for patients and carers

Patient and carer information:

- National Cooperative ACP -resources
- ACP Information Sheet
- A4 ACP wallet card
- Talking about ACP
- ACP Planning Guide
- EPOA pamphlet
- Making the most of your final years
- My ACP
- Thinking about your future health care

Books:

- **In the midst of life** by Jennifer Worth
  - Orion House 2010ISN 978 0 7538 2752 9
- **Being mortal illness, medicine and what matters in the end** by Atul Gawande
  - Profile books 2014 ISN 978 1 84668 5811

Enduring Power of Attorney resources:

- Age Concern

- Office for Senior Citizens

Te Ara Whānau Ora Brochure:

- Te Ara Whānau Ora Brochure

3. Information resources for clinicians

ACP resources

- National Cooperative ACP -**resources**

Healthcare provider information:

- ACP - A Guide for the New Zealand Health Care Workforce
- National Cooperation ACP: How to - 5 steps
- Protection of Personal and Property Rights Act 1988
- Tips for starting a conversation about the end of life

Enduring Power of Attorney resources:

- Age Concern
- Office for Senior Citizens

Education:

- ACP Level 1 e-learning

4. Updates to this care map

Date of re-publication: May 2018

- no change

Date of first publication: March 2016.

This care map has been updated in line with consideration to evidenced based guidelines.
For further information on contributors and references please see the care map's Provenance Certificate.

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.

Local Māori Health Providers
Central PHO Māori Health website

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
- for more information, please refer to the Better Health for Pasifika Communities brochure

Ala Mo'ui - Pathways to Pacific Health and Wellbeing 2010-2014

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 Māori/Pacific Health Providers
Central PHO Pacific Health website

7. What is Advance Care Planning?

Advance Care Planning [1]:

- is a voluntary process of discussion and shared planning for future health care
- it involves the person who is preparing the plan, and usually involves family/whānau and health care professionals
- the process assists the individual to identify their personal beliefs and values and incorporate them into plans for future health care
- may also include views about medical care and a wide range of other matters

An Advance Care Plan:

- is the outcome of Advance Care Planning
- may include an advance directive

Table highlighting differences between advance care plans, advance directives and Enduring Power of Attorney (EPA).

8. Deciding when to have an ACP conversation

Deciding when to have an Advance Care Planning (ACP) conversation [1]:

- ACP is better to occur earlier and within the community setting rather than when a person is in their last year of life or admitted to hospital or an aged residential care facility
- any person over 18 years can make an ACP unless they are already unable to make their own decisions due to disability, illness or injury
- ACP discussions can occur at any time, not necessarily only when a person has been diagnosed with a life-limiting illness
- if a person is well, discussions are likely to focus on what they would want should they have an unanticipated sudden illness or accident
- such discussions would generally be prompted by a specific patient request but could also be recommended by health care professionals or family/whānau members who recognise that a person has care preferences that differ from the mainstream
- the health professional may consider raising the topic of ACP if they wouldn't be surprised if the person died in the next 12 months
- other occasions when it might be appropriate to discuss include:
  - person or their family/whānau/carer enquires about palliative care
  - person has been hospitalised recently for a severe progressive illness or condition or has required repeated admissions for a serious condition (i.e. more than two acute additions to hospital for COPD)
  - person says they want to forego life-sustaining treatment
  - person expresses a wish to die
- some patients will prompt the ACP discussions themselves, but many will expect health care professionals to initiate these discussions
- many patients welcome the opportunity to discuss end-of-life care in advance
- not everyone will choose to participate in ACP

ACP is most easily accomplished when a person is in a stable state of health or when they have had time to adjust to a new illness. Sometimes, however, discussions have to take place when the clinical situation is unstable [1].

9. ACP and competency considerations

Competency and Advance Care Planning:

According to the ACP - A Guide for the NZ Health Care Workforce –"in the context of ACP, competency relates to an individual's ability to make a decision regarding their own health care (that is, competence at decision-making or decision-capacity). At a minimum, decision making capacity requires the ability to understand and communicate, to reason and deliberate, and the possession of a set of values".

ACP relies on the person being competent to share in the planning process and so needs to be considered early in the care of the

person for whom the diagnosis of dementia is suspected (see Dementia Management (Mild) Pathway). A person with dementia does not necessarily lack capacity, however, it should be anticipated that their capacity will fluctuate and decline over time.

The following people may require special considerations:

- people with:
  - mild cognitive impairment
  - intellectual impairment(s)
  - a visual and/or hearing impairment
  - physical impairment(s)
  - speech impairment(s)
- people requiring an interpreter

10. ACP and protection of personal & property rights

Protection of Personal and Property Rights (PPPR) Act 1988 and Advance Care Planning (ACP):

According to the Health and Disability Commission Code of Rights 7(1):

- "services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides or otherwise"

If the person is incompetent, clinicians can lawfully provide treatment to incompetent adults if:

- it is an **emergency situation** and necessity applies
- there is a valid **advance directive**
- there is **another person who is lawfully entitled** to consent
- you act in accordance with **Right 7(4)**
- **court orders**, e.g. Protection and Personal and Property Rights Act 1988 (PPPR Act)

The purpose of the PPPR Act is to assist people who have lost the capacity to make, understand or communicate decisions about their own welfare or property affairs.

The PPPR Act allows people to decide in advance who they would like to make decisions for them if they become incapable of making decisions for themselves. They do this by giving another person an **enduring power of attorney**.

If, however, a person has not given an enduring power of attorney and can no longer make decisions for themselves, family/whānau and others can apply to the Family Court under the PPPR Act to make specific **personal orders** for that person, such as where they will live and who will look after them. Or the Court can be asked to appoint someone - a **welfare guardian** or **property manager** - to make decisions for the person.

The principles of the PPPR Act 1988 are:

- every adult person shall be presumed (until the contrary is proven) to have mental capacity to manage his/her own affairs
- must act in best interest for the patient (patient centred approach and family/whānau)
- person is cared for in the least restrictive alternative or environment (person receives the right care, at the right time and in the right place)
- involvement of the individual person to the extent appropriate (diminished capacity)
- process and regular checks and balance as a safeguard

If an Advance Care Plan and/or valid Advance Directive has been completed these will guide decision making with family/whānau and health professionals when a person loses capacity.

11. Conversation guide for clinicians

Before Advance Care Planning (ACP) is introduced, it is important that the person understands its relevance so that the conversation can be placed in context.

Reaching this level of understanding may involve exploring the person's understanding of their prognosis and general health issue/s. Ideally ACP discussions would first occur when the person is receptive and calm and in a supportive environment (see tips for starting a conversation about the end of life).

The following How to - 5 steps may assist with this:

1. *Preparing:*
   - before having conversations it is important to know about ACP Level 1 e-learning
   - thinking in advance
   - is this okay?
   - combined approach
   - benefit for person/family
   - no decisions today

2. *Talking:*
   - ACP is for everyone but how you raise it will be different depending on who you are talking to
   - understanding:
     - what is your understanding now of where you are with your illness?
   - information preferences:
     - how much information about what is likely to be ahead with your illness would you like from me (e.g. time, what to expect or both of these)
   - prognosis:
     - share prognosis, tailored to information preferences
   - goals:
     - if your health situation worsens, what are your most important goals?
   - fears/worries:
     - what are your biggest fears and worries about the future with your health?
   - function:
     - what abilities are so critical to your life that you can't imagine living without them?
   - trade-offs:
     - if you become sicker, how much are you willing to go through for the possibility of gaining more time?
   - family:
     - how much does your family know about your priorities and wishes?
       - suggest bring family and/or health care agent to next visit to discuss together

3. *Documentation*
   - there is great value in having ACP conversations but unless they are documented they may get lost
   - provide person with family communication guide

4. *Using:*
   - use the information to make decisions around what is important to the person
   - affirm commitment
   - make recommendations to person

Reviewing:

- people may need time for reflection and discussion after they have received this information
- circumstances change and plans need to be updated accordingly
- health care professionals must be sensitive to different cultural perspectives on illness, death and dying and on how end-of-life decisions are to be made, and by whom

Resources:

- National Cooperation ACP: How to - 5 steps
- ACP - A Guide for the New Zealand Health Care Workforce
- National Cooperative ACP - resources

12. Enduring Power of Attorney

Enduring Power of Attorney [2]:

- An Enduring Power of Attorney (EPA) is a power given by an individual to a person appointed to make decisions on behalf of that individual if, and when they cannot make, or communicate, those decisions for themselves.
- There are two types of EPA:
  - personal care and welfare EPA appoints an attorney to make decisions about an individual's personal care and welfare on their behalf
  - property EPA appoints an attorney to manage and make decisions about a person's property

Enduring Power of Attorney information

13. What topics/issues are discussed in ACP?

The Advance Care Planning (ACP) process should empower an individual to make informed decisions about their future care. The content of any discussion should be determined by the individual concerned and, if they do not wish to engage in ACP or conversations about their future care, this preference should be respected.

ACP discussions cover the:

- person's understanding of their illness and prognosis
- types of care and/or treatments that may be beneficial in the future and their potential availability
- person's preferences for future care and/or treatments
- person's concerns, fears, wishes, goals, values and beliefs
- person's preferred place of care (and how this may affect the treatment options available)
- person's views and understanding about interventions that may be considered or undertaken in an emergency (such as cardiopulmonary resuscitation)
- person's needs for religious, spiritual or other personal support
- family/whānau members or others that they would like to be involved in decisions about their care (this may include the appointing of an Enduring Power of Attorney)

14. Advance directives

Advance directive:

- on occasion, the Advance Care Planning (ACP) process of discussion and planning will clarify that the person has very specific preferences for their future treatment
- these can be communicated in the ACP and/or in an advance directive
- an advance directive is a written or oral directive/instruction that enables a person to make choices about possible future health care treatment(s) and becomes effective only when the person loses the capacity to make those choices themselves
- the legal authority of an advance directive rests with its validity, which should be established before it is honoured or given

effect

- there are four legal criteria that an advance directive needs to meet, as follows [1]:
  - the individual was competent to make the particular decision, when the decision was made
  - the decision was made free from undue influence
  - the individual intended the directive or choice to apply to the present circumstances - this criterion is likely to incorporate the requirement that the individual was sufficiently informed at the time of making the advance directive
  - the existence and validity of the advance directive must be clearly established

New Zealand Medical Association - Advance Directive information

15. Documenting ACP conversations

Individuals need to be made aware that a key factor in the success of Advance Care Planning (ACP) is recording and sharing the plan with appropriate others:

- ACP information, like all health information, cannot ordinarily be shared without the agreement of the individual concerned
- ACP discussions should be documented in the person's notes as having taken place
- the record should include the content of the discussions and the plan developed - this level of documentation is in keeping with the obligation on health care professionals to keep full and accurate records of all discussions with patients
- the actual plan can be documented on the National Cooperation ACP forms (My Advance Care Plan) or written within the patient's records or correspondence
- the person should be provided with the opportunity to confirm the accuracy of the record and any disagreements noted
- with the person's understanding and permission, all relevant health care professionals should be made aware that ACP discussions have taken place and should have access, if required, to any plan produced
- a record of who has copies of ACP documents will facilitate future updating and review

Completed copy of ACP:

- person keeps original in a safe place known to family, carers etc (i.e. in a life tube)
- person keeps a card in wallet alerting an ACP exists
- a copy could be sent to the persons lawyer (at their request)
- a copy should be kept at the GP practice (Dashboard alert - that is coded)
- consider if St John needs a copy

NB: This process may change with the advent of electronic tools.

16. ACP alert in secondary care

Recording information and sharing it with primary and secondary care providers and members of multidisciplinary teams is important to maximise the benefits of an Advance Care Plan (ACP):

- a record of who has copies of ACP documents will facilitate future updating and review

An ACP alert should be entered into the MidCentral Health Patient Management System with the following note:

- "This person has an Advance Care Plan that should be considered in health care plans. A copy is available on file, or may be provided by the person or their representative"
- ALERT notification form (**access for MidCentral Health employees only**)
- procedure for entering an ALERT into PIMS (**access for MidCentral Health employees only**)

Notification of ACP should be documented on discharge summary to ensure that the General Practice Team are aware that the person has an ACP.

17. ACP alert in primary care – READ codes

Recording information and sharing it with primary and secondary care providers and members of multidisciplinary teams is important to maximise the benefits of an Advance Care Plan (ACP):

- a record of who has copies of ACP documents will facilitate future updating and review

The following READ codes should be utilised when documenting ACP discussions and plans in Medtech:

- **Advance Care Planning discussions - code 9X3.00:**
  - when ACP conversation is instigated and ACP information provided
- **Advance Care Plan completed - code 9X4.00:**
  - when the person has completed an ACP form or similar
- **Advance Directive/Living Will completed - code 9X.00:**
  - when a person has a completed Advance Directive
- **Enduring Power of Attorney completed - code 9W.00:**
  - when person provides EPA details to clinician
  - use the note field to add details i.e. name of person, named EPA and contact number

18. Reviewing ACP

Reviewing Advance Care Plan (ACP):

- any ACP record should be subject to review and, if necessary, revision
- the possibility and reasons why it may require reviewing should be made clear during the ACP discussions
- processes that ensure review and revision also need to be developed
- a record of who has copies of ACP documentation will facilitate future updating and review
- the ACP can be reviewed at any time according to the person's wishes and as necessary

Consider reviewing or having further discussions about Advance Care Planning:

- if clinical circumstances change
- in the event of a significant life event
- at annual clinical and health assessment
- at comprehensive clinical assessment (InterRAI)
- after hospitalisation
- if there are significant changes to the carer

Advance Care Planning

Provenance Certificate

Overview | Editorial methodology | References | Contributors | Disclaimers

Overview

This document describes the provenance of MidCentral District Health Board's **Advance Care Planning** 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 **May 2018.**

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	Ministry of Health, (2011) Advance Care Planning: A Guide for the New Zealand Health Care Workforce
2	Advance Care Planning Guideline - Capital & Coast DHB

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 update of this care map:

- Kirsten Holst, Physician/Geriatrician, MidCentral Health (Secondary Care Clinical Lead)
- Karen Lowe, Nurse Practitioner Primary Health Care, Cook Street Medical Centre (Primary Care Clinical Lead)
- Liz Elliott, Clinical Advisor Health of Older People, MidCentral DHB (Facilitator/Editor)

The following individuals have contributed to this care map:

- Kirsten Holst, Physician/Geriatrician, MidCentral Health (Secondary Care Clinical Lead)
- Karen Lowe, Nurse Practitioner Primary Health Care, Cook Street Medical Centre (Primary Care Clinical Lead)
- Jayne McNeilage, Clinical Coordinator Social Worker, MidCentral Health
- Bev Flaus, Clinical Nurse Specialist ElderHealth, MidCentral Health
- Elinor Wood, Clinical Nurse Specialist ElderHealth, MidCentral Health
- Jan Waldock, Lead Clinical Nurse Educator, Arohanui Hospice
- Joy Percy, Palliative Care Specialist, MidCentral Health
- Liz Elliott, Clinical Advisor Health of Older People, MidCentral DHB (Facilitator/Editor)

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.