NEW ZEALAND DEMENTIA FOUNDATION

Te Whatu Ora
Health New Zealand

TE ARA WHAKAPIRI

Three tools to help support end-of-life care for aged care residents living with dementia mate wareware

E TORU NGA TAPTAPU, THREE TOOLS. #3



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We started the Dementia End of Life Project project by listening. We engaged with staff across aged residential care, home care, health, mental health, palliative care, Maori health, and general practice in surveys, focus groups, and working groups.

We heard about three key challenges for best practice end-of-life care for aged residential care residents with dementia :

- residents often enter the facility without any prior advanced care planning.
- coordination amongst services, including primary care, can sometimes be difficult
- teams sometimes lack confidence in developing and implementing individual end-of-life care plans.

The project identified three existing evidence-based tools that, when used routinely, can help address these challenges and support high-quality, person-centred end-of-life and palliative care for our residents living with dementia. In short, three tools that every aged residential care facility should know about!

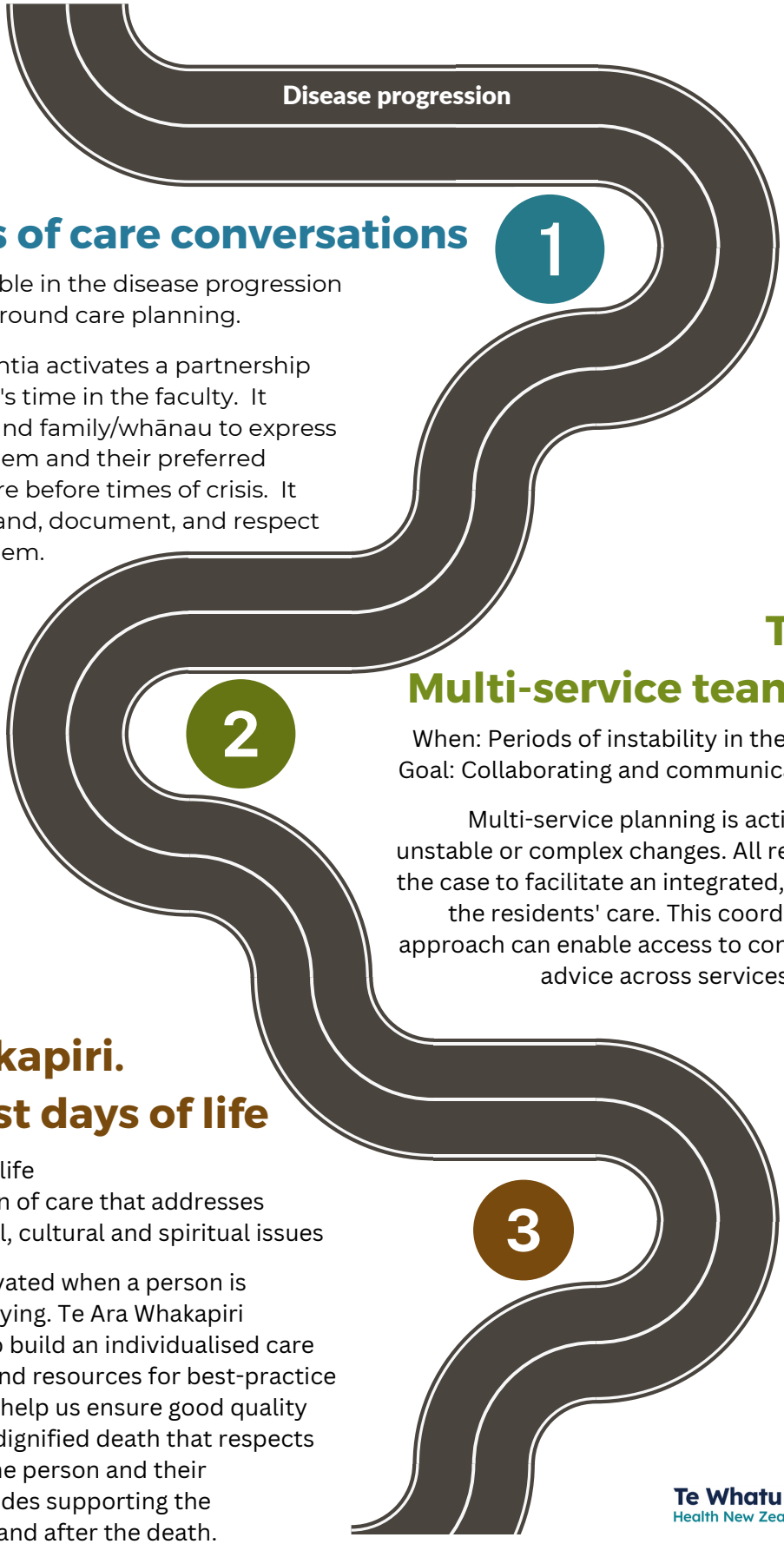
In these *E toru nga tapu tapu / Three tools* booklets we introduce each of the three tools in the context of dementia and aged residential care. We also provide easy access to the tools through a webpage hub:

www.nzdementia.org/3tools

Thank you for your commitment to meeting the unique end-of-life care needs of people living with dementia. We warmly encourage you to find out more and embed any of the tools you are not already using regularly.

Jane Large

Project Leader
Dementia End of Life Project



Talk.

Shared goals of care conversations

When: as early as possible in the disease progression
Goal: early discussion around care planning.

The diagnosis of dementia activates a partnership throughout the person's time in the faculty. It supports the resident and family/whānau to express what is important to them and their preferred achievable goals for care before times of crisis. It can help us to understand, document, and respect what is important to them.

Teamwork.

Multi-service team meetings

When: Periods of instability in the disease progression
Goal: Collaborating and communicating across services

Multi-service planning is activated in response to unstable or complex changes. All relevant teams review the case to facilitate an integrated, holistic approach to the residents' care. This coordinated, collaborative approach can enable access to consultation and expert advice across services for complex issues.

Te Ara Whakapiri.

Guide for last days of life

When: the last days of life
Goal: An individual plan of care that addresses physical, mental, social, cultural and spiritual issues

End-of-life care is activated when a person is identified as actively dying. Te Ara Whakapiri provides a structure to build an individualised care plan and offers tools and resources for best-practice end-of-life care. It can help us ensure good quality end-of-life care and a dignified death that respects what is important to the person and their family/whānau. It includes supporting the family/whanau during and after the death.

Te Whatu Ora Health New Zealand

NEW ZEALAND DEMENTIA FOUNDATION

TE ARA WHAKAPIRI: WHAT IS IT AND WHY IS IT IMPORTANT?

"Te Ara Whakapiri: Principles and guidance for the last days of life" is a national framework that sets out guiding principles for the care of people in their final days of life across all settings, including aged residential care.



Living well with dementia also includes support to die well. End-of-life care for a person with dementia will require skilled person-centred care and a holistic, individualised care plan.

Te Ara Whakapiri is a resource that has been developed by clinicians and the Ministry of Health Manatū Hauora to provide a New Zealand-specific guide to best practice care of people in their last days of life. Te Ara Whakapiri sets out essential components and considerations and provides flowcharts and checklists to guide care for adults in their final days of life.[1,2]

Note: All the links provided in this document are also available on nzdementia.org/3tools

RESOURCE

Te Ara Whakapiri guidelines and toolkit are available to download online

CLICK HERE

POTENTIAL BENEFITS:

- ◯ provision of person-centred and dignified care
- ◯ attention to cultural and spiritual needs
- ◯ attention to detail for symptom management

POTENTIAL BENEFITS FOR FAMILY / WHĀNAU:

- ◯ clear and compassionate communication
- ◯ support for family /whānau
- ◯ care after death

POTENTIAL BENEFITS FOR CARE PROVIDERS:

- ◯ quality end of life care as a higher organisational priority
- ◯ improved documentation
- ◯ improved staff confidence and experience [3]

This booklet provides an introduction to Te Ara Whakapiri in the context of people living with dementia mate wareware in aged residential care and highlights some additional potentially useful resources. This booklet is not intended as a guideline in itself.

TE ARA WHAKAPIRI PRINCIPLES FOR END-OF-LIFE CARE

CARE SHOULD MEET THE INDIVIDUALISED NEEDS OF THE PERSON AND THEIR WHĀNAU.

Each person's unique background and journey give rise to different perspectives, challenges, and strengths. The principles of te whare tapa wha can be used as a framework to guide individualised care across all dimensions of the person's well-being.

DETAILS OF CONVERSATIONS AND DECISIONS SHOULD BE DOCUMENTED.

All these decisions should be considered in the context of any existing advance care plan, advance directives, or shared goals of care conversations.

ALL INFORMATION RELATING TO THE STATUS OF PEOPLE IN THE LAST DAYS OF LIFE, THEIR CARE PLAN, AND TREATMENT SHOULD BE COMMUNICATED CLEARLY AND RESPECTFULLY.

Shared decision-making should always be considered. Care providers must actively seek input from the person where possible and their family/whānau and create opportunities for them to provide feedback.

FAMILY/WHĀNAU SHOULD ALSO BE SUPPORTED.

It is important to have a discussion with the family/whānau ahead of time. This will include

- how they can be involved in care.
- potentially difficult decisions that may arise, such as food and fluid and discontinuing non-essential medicines and
- physical changes that happen when death is close so that they can be prepared

After-death care and support should also be considered.

From BPAC 2003, [2]

LOCAL GUIDANCE

If you are a health professional, you may be able to access a local Last Days of Life Pathway and other palliative pathways on HealthPathways to provide locally adapted guidance and tools consistent with Te Aka Whakapiri.

HealthPathways is a password-protected website that is a key source of assessment, management, and referral information about health services for general practice teams and other community healthcare providers.

Rather than traditional guidelines, each pathway is an agreement between primary and specialist services on how patients with particular conditions will be managed locally. Each region tailors the content of HealthPathways to reflect local arrangements and opinions and offers its own instance of the HealthPathways website to its clinical community.

The HealthPathways website contains integrated patient pathways and information on referrals, specialist advice, diagnostics, GP procedure subsidies and patient handouts - all of which have been collectively agreed upon by local health professionals from across the health system. [4]

HEALTHPATHWAYS

Below is a list of the regions that provide Community HealthPathways. Click on the name to be taken to the website and a contact to register.

- Northland
- Auckland Region
- Midland Region
- Hawke's Bay
- Whanganui & MidCentral
- Wairarapa, Hutt Valley, Capital and Coast
- Nelson-Marlborough
- West Coast and Canterbury
- Aoraki (South Canterbury)
- Southern



PALLIATIVE CARE

Palliative care is a person and family/whānau-centred approach to providing care for someone who has a life-limiting or terminal illness. The aim is to help the person live as fully and comfortably as they can and to support the family/whānau throughout their caring and bereavement. [5]

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
-World Health Organisation

Palliative care

- [ ] Focuses on quality of life
- [ ] Identifies, assesses and treats symptoms such as distress or pain
- [ ] Provides psychological, social, spiritual and practical support
- [ ] Includes not just the dying person but also their family/whanau
- [ ] Regards dying as a normal process
- [ ] Intends neither to hasten or postpone death
- [ ] may be suitable whether death is days or years away, and can coincide with life-prolonging treatments [6]

Providing care in the last days of life

WHAKAPIRI BEING PRESENT

This emphasizes the importance of being present with the person who is dying. It involves physical presence, but also being emotionally present and engaged. This component emphasizes the significance of companionship and support during the end-of-life process.

WHAKARONGO LISTENING

This involves not only hearing the words spoken but also understanding the deeper feelings, concerns, and wishes of the person who is dying and their family/whānau. Effective listening allows for a better understanding of the individual's needs and preferences.

MANAAKI CARING

Manaaki refers to the act of providing care with respect, kindness, and compassion. It involves meeting the physical, emotional, cultural, and spiritual needs of the person who is dying. This component emphasizes the provision of holistic care that acknowledges and respects the person's cultural and spiritual beliefs.

TE ARA WHAKAPIRI

There are 3 key components of care for people in their last days of life

1. BASELINE ASSESSMENT

A comprehensive baseline assessment involves identifying that the person is in the last days of life, assessing clinical and holistic needs, sensitive and open communication with person and their whānau/family, and clear documentation.

2.ONGOING ASSESSMENT

Ongoing assessment emphasises the importance of developing individualised care plans. All aspects of care are monitored and addressed promptly

3.CARE AFTER DEATH

After-death care includes verification of death, respect and dignity for the person who died / /tūpāpaku, and involvement, information, and support for the family/whānau.

[1]

1

KEY COMPONENT ONE

BASELINE ASSESSMENT: STARTS WITH RECOGNISING THE PERSON IS IN THEIR LAST DAYS OF LIFE

The term 'last days of life' or 'active dying' defines the period when death is imminent and may be measured in hours or days. Recognising this phase is complex, and there is often an element of uncertainty:

- Signs and symptoms can vary according to underlying conditions
- Deterioration can also occur due to reversible causes
- Residents may sometimes "recover."
- Some but not all people will go through a noticeable 'pre-active stage' over the preceding 2-3 weeks [1,2]

Commencing a Te Ara Whakapiri care plan has substantial advantages - focusing care on individualised support and comfort for the resident and helping to prepare and support the family/ whanau - that outweigh concerns about uncertainty.

The multi-disciplinary team makes the decision to place a resident on Te Ara Whakapiri in consultation with family/whanau. The care plan is reviewed regularly and as needed (e.g., if the resident's condition changes or the family express concerns about the plan.)

FLOWCHART

The Te Ara Whakapiri toolkit provides a flow chart for recognising the dying person.

CLICK HERE

Advanced dementia mate wareware

It is not always easy to recognise when a person with advanced dementia is approaching the last days of life because they may already have some of the general features that can typically indicate that dying is starting to occur [6], for example:

- profound weakness
- reduced food/fluid intake
- difficulty swallowing
- being predominantly bed-bound [1]

People with advanced dementia may show some of these signs and symptoms for months or even years. However, these symptoms may worsen over two to three weeks or even days or hours [7].

The more definitive signs that death is closer are often more accurate for predicting the final days of people living with advanced dementia mate wareware [6]. These signs include:

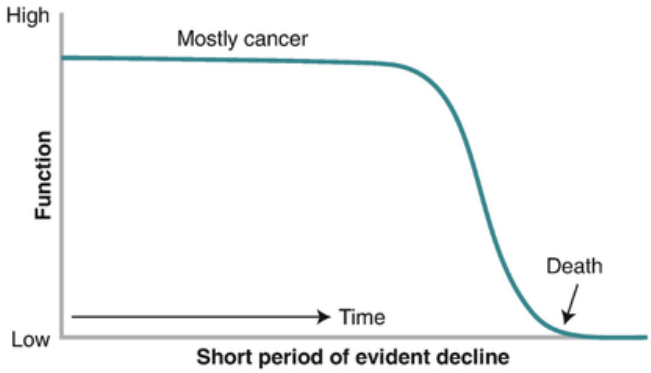
- Noisy gurgling breathing related to the inability to clear secretions
- Abnormal breathing patterns such as irregular (ataxic), gasping (agonal) or Cheyne-Stokes respirations (fast, shallow breathing followed by slow, heavier breathing and moments without any breath at all)
- Agitation, restlessness
- Reduced consciousness when the person becomes unresponsive
- Increased bluish-purple tint to pale skin due to lack of oxygen (cyanosis - this may appear brown on darker skin) and mottling of the skin. [1,6]

A NOTE ABOUT TRAJECTORIES

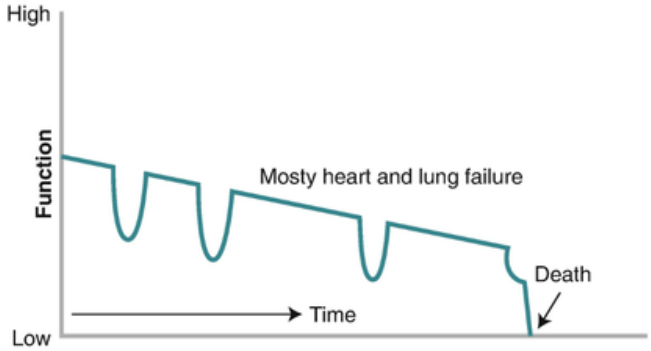
Not all residents living with dementia will die because of advanced dementia; some will die from other causes 'with' dementia.

Three broad trajectories have been described for people with progressive chronic illnesses. Early recognition of a resident's possible illness trajectory can help us anticipate and address their needs in some situations.

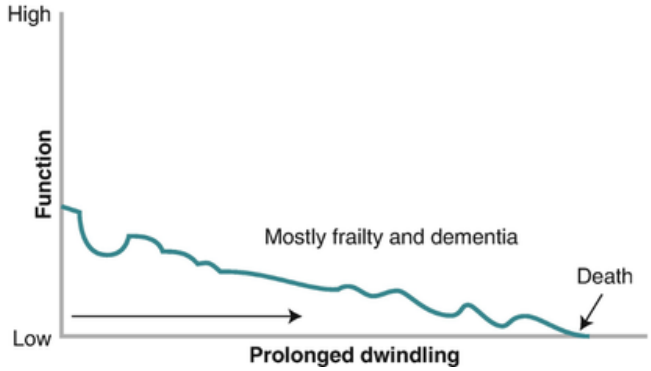
Trajectory



Short period of evident decline



Long-term limitations with intermittent serious episodes



Prolonged dwindling

Example

Mrs Aholima is 69 years old with mild dementia. Mrs Aholima has lung cancer and secondaries in her liver. Over the last month, she has had increasing shortness of breath and fatigue, and her physical mobility has also decreased.

Mr Baxter is an 84-year-old man with mild dementia and heart failure. He has been ill for three years with increasing shortness of breath and finds activity increasingly difficult. He has had three emergency hospital admissions and is worried about further admissions. His decline has been erratic, and his children have gathered more than once in preparation for his imminent death.

Mrs Chen is a 91-year-old woman with advanced dementia, high blood pressure, diabetes, and osteoarthritis. Mrs Chen has been slowly declining in functional capacity and robustness. Following a fall, staff noted that Mrs Chen lost interest in activities and eating. She has recurrent UTIs and trouble swallowing. She is now sleeping for most of the day.

The value of recognising these trajectories is in anticipating residents' probable needs so that the right care can be provided at the right time. It is an 'insurance' approach: what would we need to get prepared if this person was nearing the end of life? [7,8, graph 9]

KEY COMPONENT ONE CONTINUED

BASELINE ASSESSMENT

When the team think a person may be entering their last days of life, a registered staff member undertakes a baseline assessment, with the involvement of a doctor or nurse practitioner. The holistic baseline assessment is based on Te Whare Tapa Wha, as summarised on the next page, p 14. This forms the foundation of the individualised care plan.

Completing this baseline assessment ensures that everyone is on the same page for the individualised care plan and aware of the person's imminent death and what is important to them. It acts as a prompt to have conversations with the person (if possible) and their family/whānau to involve them in assessments and decision-making and to help prepare and support them.

The baseline assessment also helps to identify whether there is a need for specialist palliative input.

The baseline assessment is recorded on a Te Ara Whakappiri baseline form. On pages 15 to 16 we include the adapted version of the form developed by the South Island Alliance.

CHECKLIST

The Te Ara Whakapiri toolkit includes a combined baseline assessment and care-after-death checklist

CLICK HERE

REVISED FORM

The South ISland Alliance provides an adapted baseline assessment and care-after-death form that is a double-sided single page

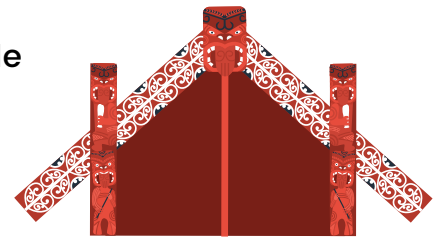
CLICK HERE

GUIDANCE

Te Ara Whakapiri talks through what is involved in each dimension of the assessment and what it looks like when this is well done.

CLICK HERE

The baseline assessment provides an opportunity to comprehensively evaluate the resident's needs. The Whare Tapa Whā model offers a framework to provide holistic care and increase the total well-being of people in their last days of life, including their family/whānau.



Components of baseline assessment

Taha Wairua Spiritual wellbeing

- Provide an opportunity for the person and family/whānau to discuss what is important to them, including cultural and spiritual beliefs and practices.
- Incorporate these factors into the care plan, where possible, or co-ordinate access to specialised cultural or spiritual support.

Taha Tinana: Physical

- Assess physical needs.
- Review current management and consider anticipatory prescriptions.
- If they have the capacity, ensure that the person is aware of their changing condition.
- Discuss aspects of care, including food and fluids, medications, admission to hospital, and equipment.
- Address cardiac devices
- Inform relevant agencies / use multi-service team meetings.

Taha Hinengaro Mental wellbeing

- Assess the person's current emotional state and their coping strategies.
- Discuss the person's preferences for care. If advance care plan and shared goals of care documents are available, use these to inform the care plan. Check whether the person has an enduring power of attorney.

Taha Whānau Family and social wellbeing

- Identify and address any communication barriers.
- Ensure the family/whānau is aware of the person's changing condition.
- Discuss family customs, traditions and cultural needs.
- Provide information to the family/whānau.

[1,2]

Whenua - Land / roots

(Attach Label here or Complete Details)

NAME:_____ NHI:_____

GENDER: ___ DOB: _____ AGE:_____ WARD:_____

SOUTH ISLAND ALLIANCE
best for people, best for system

Te Ara Whakapiri - Care in the last days of life

Baseline assessment and preparation for care after death

Initiation requires consultation with patient, family/whanau and interdisciplinary team

Primary diagnosis:	Ethnicity:
Religion/faith:	Language(s):
Family/whānau spokesperson: Relationship:	
Phone number: Ph any time ☐ Not overnight ☐ Other:	
Enduring power of attorney (personal care and welfare) Yes ☐ No ☐ Activated Yes ☐ No ☐	
Name: Relationship: Phone number:	
Documents in place to guide care decisions (tick as many as apply)	
Do not attempt cardiopulmonary resuscitation (DNACPR) ☐ Shared Goals of Care ☐	
Advance Care Plan ☐ Advance Directive ☐ None ☐ Other:	

These sections can be completed by any registered staff member

Taha tinana – *Physical health*

The person is Conscious ☐ Semi-conscious ☐ Unconscious ☐

In pain	☐	Unable to swallow	☐	Confused/disorientated	☐
Agitated/restless	☐	Incontinent of urine	☐	Experiencing respiratory tract secretions	☐
Nauseated	☐	Catheterised	☐		
Vomiting	☐	Incontinent of faeces	☐	At risk of skin breakdown	☐
Dyspnoeic	☐	Constipated	☐	At risk of falling	☐

Describe any other symptoms: *eg. oedema, sore mouth, myoclonic jerks, itching*

Taha hinengaro – *Psychological and mental health*

The person is aware they are dying (document details/concerns below) Yes ☐ No ☐

Preferred place of death (if known):

Describe any emotional or psychological symptoms, concerns or preferences:

Te wairua – *Spiritual health*

The person has been asked about cultural and/or spiritual needs (document details/concerns below) Yes ☐

A spiritual/religious/faith person of choice has been contacted Yes ☐ N/A ☐ To be done ☐

Name: Contact details:

Describe any cultural and/or spiritual needs, preferences/concerns: *eg. rituals, prayers, music, access to pets*

These sections can be completed by any registered staff member

Te whānau – *Extended family health*	
Family/whānau understand the person is dying (document details/concerns below)	Yes ☐
Family/whānau have been offered written resources *When Death Approaches (or equivalent), Dying at Home (or equivalent)*	Yes ☐
For a person being cared for at home, the family/whānau know who to contact after hours if/when needed e.g. in an emergency	Yes ☐ N/A ☐
Family/whānau have been asked about cultural and/or spiritual needs, preferences or concerns (document details/concerns below)	Yes ☐
Describe any family/whānau needs, preferences or concerns:	

Preparation for care after death			
Preferences for after death have been identified (document details/concerns below)			Yes ☐
Family/whānau are aware of (tick as/when applicable)			
Who, and when, to call after the person dies ☐		The availability of a private space ☐	
When, and how, to contact a Funeral Director ☐		How to stop and remove the CSCI ☐	
Written bereavement information is available to be given as/when needed			Yes ☐ No ☐
Describe any preferences or needs **after death**: *eg. burial/cremation, tissue donation, rituals, prayers, music*			
Items/valuables to be left on the person/tūpāpaku:			
Name and designation (print):			
Signature:	Date:	Time:	

Doctor or nurse practitioner to complete				
Medications reviewed and discontinued as appropriate				Yes ☐
Anticipatory prescribing completed for: (Refer to *Anticipatory prescribing flow charts*)				
Pain ☐	Agitation, delirium and restlessness ☐		Nausea/vomiting ☐	
Dyspnoea ☐	Respiratory tract secretions ☐			
Investigations and interventions reviewed and cancelled/discontinued as appropriate				Yes ☐
Clinically assisted hydration and nutrition reviewed and discontinued as appropriate				Yes ☐
Implantable cardiac defibrillator (ICD) has been deactivated	Yes ☐	To be done ☐	N/A ☐	
Above reviews/plans of care have been discussed with The person ☐ Family/whānau spokesperson ☐ EPA ☐ Other(s):				
Doctor's/nurse practitioner's name and designation (print):				
After hours arrangements:				
Signature:	Date:	Time:		

Adapted from Te Ara Whakapiri, Principles and guidance for the last days of life (Ministry of Health, 2017) by the South Island Palliative Care Workstream. South Island Alliance, December 2020. Review December 2022.

KEY COMPONENT ONE CONTINUED

FAMILY / WHĀNAU NEEDS

Provide opportunities for the person (if possible) and family/whānau to discuss what's important to them, including spiritual and cultural needs for the dying phase and after death. These may change. [1,2]

Communicate changes in the person's condition in a way that they can understand and help to ensure realistic expectations. Discuss relevant aspects of care such as food and fluids, equipment that might be used, care in place rather than in the public hospital, or medication reviews. Be aware that grief can make it hard to process information.[1,2]

People vary in their beliefs about death and dying and how much they want to know. For many, knowing what to expect can help reduce anxiety. Providing written information about what to expect at the end of life can help the family /whānau to prepare and know how to help. Your facility may already have a booklet that you use. If not, we provide a resource written for aged residential care settings.

Let family/whānau know who will be available to talk through questions.

It is recommended to discuss bereavement support and conduct a risk assessment for all family/whānau members who wish to have one. If it appears that there is a high risk, actively direct the person to sources of bereavement support [1,2].

BOOKLET

"When someone you care about is dying in aged residential care: what to expect" is an information booklet for family/whanau.

CLICK HERE

BEREAVEMENT RISK

'Te Ara Whakapiri Toolkit' includes a Bereavement Risk Assessment Tool.

CLICK HERE

TAILORING LAST DAYS OF LIFE CARE FOR MAORI

Ki te wareware i a tātau tēnei tikanga a tātau, arā te tangi ki ō tātau tūpāpaku, kātahi tō tātau Māoritanga ka ngaro atu i te mata o te whenua ki te Pō, oti atu

If we forget our cultural practices, particularly those pertaining to the dead, then our very essence of our existence as Māori will be lost from the face of this earth, to the underworld forever

For many Māori, it is essential that end of life care recognises the importance of whānau and remains grounded in their tikanga (customs) and kawa (protocols). Traditionally, whānau assume the role of pou aroha (care stalwarts) during this process, delivering care that:

- Is informed by mātauranga Māori (knowledge) passed down from tupuna (ancestors)
- Encompasses all principles of Te Whare Tapa Whā (physical, mental/emotional, family/social and spiritual wellbeing)
- Recognises a connection with the whenua (land)

However, Māori whānau, hapū and iwi are diverse in their perspectives and traditions, meaning there is no single template for end of life care. The facility team should consider the individualised cultural needs of Māori and their whānau, discuss what is important to them, and prioritise a plan that facilitates such customs. In some cases, residents and their whānau may benefit from being directed to local Kaupapa Māori health services.

Examples of tikanga/kawa that may be important to Māori in their last days of life

- Using te reo Māori (Māori language)
- Incorporating rongoā (traditional healing) including mirimiri (massage)
- Observing tapu (protocols and practices that govern things that are sacred or restricted)
- Observing noa (protocols and practices that return a state of tapu back to its ordinary state)
- visiting ancestral homes or tūrangawaewae (places where people feel empowered and connected)
- Taking care of personal taonga (treasured objects)
- Including karakia (incantations, prayers, chants)
- Including waiata (songs, singing)
- The presence of Māori Kaumātua (Māori elder) who oversee and provide cultural guidance and support
- Sharing kai (food)
- Observing hygiene principles, e.g. not using a pillow for the head if it has been used elsewhere on the body
- Observing protocols around the removal, retention, return or disposal of any body tissue or substances (no matter how minor they may be perceived, e.g. hair).

WEBSITE

Te Ipu Aronui is a website that provides information on providing culturally informed care at the end of life for both whānau and health professionals.

CLICK HERE

Extract from BPAC Navigating the last days of life: a general pratice perspective [2]

2 KEY COMPONENT TWO
ONGOING CARE AND ASSESSMENT

Following Te Ara Whakapiri, the team develops an individualised care plan for a resident in their last days of life in consultation with the person and their family/whānau. This plan addresses the resident's physical, mental, social, cultural and spiritual needs. The team discusses the family/whānau's wishes to be involved in the resident's care and provides opportunities to participate.

The plan should be documented. The plan should be regularly reviewed by a multidisciplinary team meeting every three days, if the person improves, or if their family/whanau expresses concern about the care plan.

The team regularly assesses the person's condition to ensure they can promptly address changes. A staff member records a retrospective 'overall snapshot' twice a shift for key symptoms and once a shift for the other dimensions. This is recorded on the "Ongoing care of the dying person form", which provides space for 48 hours of notes. For each element, staff note whether the care goals have been achieved without further intervention, there has been a change requiring intervention, or there needs to be an escalation. The resident's progress notes should also include a narrative of the details of changes and interventions.

The revised South Island Alliance version of this form is provided on the following pages.

ONGOING CARE FORM

The South Island Alliance provides a revised form for recording ongoing care.

CLICK HERE

GUIDANCE

Te Ara Whakapiri talks through what is involved in each dimension of the assessment and what it looks like when this is well done.

CLICK HERE

SIGNATURE SHEET

Te Ara Whakapiri toolkit provides a signature sheet for identification of anyone who initials Te Ara Whakapiri documentation.

CLICK HERE

MINISTRY OF HEALTH
MANATŪ HAUORA

Local logo	Patient name: NHI: DoB:

Ongoing care of the dying person

Use the ACE coding below, initial each entry and record details in the progress notes. Seek a second opinion or specialist palliative care support as needed.

A C E codes:	A = Achieved No additional intervention required	C = Change Intervention required and documented	E = Escalate Medical or senior nurse review required and documented

Domains and goals	Date	/ /						/ /					
	Time	0200	0600	1000	1400	1800	2200	0200	0600	1000	1400	1800	2200
Te taha tinana – *Physical health*													
Pain The person is pain free at rest and during any movement.													
Agitation/delirium/restlessness The person is not agitated or restless and does not display signs of agitated delirium or terminal anguish.													
Respiratory tract secretions The person is not troubled by excessive secretions.													
Nausea and vomiting The person is not nauseous or vomiting.													
Breathlessness/dyspnoea The person is not distressed by their breathing.													
Other symptoms (document fully in clinical notes) The person is free of other distressing symptoms, eg, myoclonic jerks, itching.													
Mouth care The person's mouth is moist and clean.													
Nurse initials each set of entries													
			0600		1400		2200		0600		1400		2200
Elimination (bowels and urination) Outputs are managed with pads, catheters, stoma care, rectal interventions, etc. *Note: Observe for distress due to any of the following: constipation, faecal impaction, diarrhoea, urinary retention.*													
Mobility/pressure injury prevention The person is in a safe and comfortable environment. Repositioning and use of pressure relieving equipment is effective.													

Ongoing care of the dying person

Person's name: DoB:

A C E codes:	A = Achieved No additional intervention required	C = Change Intervention required and documented	E = Escalate Medical or senior nurse review required and documented

Domains and goals	Date	/ /			/ /		
	Time	0600	1400	2200	0600	1400	2200
Te taha tinana – *Physical health*							
Hygiene/skin care The person's personal hygiene needs are met. The person's family/whānau has been given the opportunity to assist with the person's personal care.							
Food/fluids Oral intake is maintained for as long as the person wishes. If in place, artificial hydration and feeding is meeting the person's needs.							
Te taha hinengaro – *Psychological / mental health*							
Emotional support Any emotional distress such as anxiety is acknowledged and support is provided.							
Cultural The person's cultural needs are acknowledged and respected.							
Te taha wairua – *Spiritual health*							
Addressing spiritual needs Religious and spiritual support is offered to the person and to their family/whānau as per the person's wishes.							
Te taha whānau – *Extended family health* (these items refer to the health of the carers, not the person)							
Emotional support Any distress relating to issues such as grief and anxiety is acknowledged and addressed. The need for privacy is respected.							
Practical support Advice and guidance are offered according to the needs of the person's family/whānau.							
Cultural support The cultural needs of the family/whānau are reviewed and care is mindful of these needs.							
Communication Communication is open to address any fears or concerns about the dying process.							
Nurse initials each set of entries							

Multidisciplinary team (MDT) review

A multidisciplinary team (MDT) review should take place every three days or if the person's condition improves or if they or their family/whānau express concern about the plan of care.

Reassessment date: _____ Reassessment time: _____ Initials: _____

KEY COMPONENT TWO CONTINUED

ONGOING CARE AND ASSESSMENT: 5 KEY SYMPTOMS

Te Ara Whakapiri provides additional resources for five common physical symptoms that need to be proactively considered for every dying person:

- pain
- delirium
- nausea/vomiting
- breathlessness
- respiratory tract secretions

Holistic care recommendations

These provide carers (both professional and family) with valuable tips, insights and suggestions to aid the person as they are dying. It is important for health care professionals to have a calm approach and to actively support, reassure and encourage family and whānau to be present with their loved one wherever possible.

Anticipatory prescribing flow charts

These flow charts are to be used in 'normal uncomplicated dying' when symptoms have not previously been challenging to manage. Underpinning the flow charts is the understanding that advice and support are always available from specialist palliative care services if and when needed.

Note: If a resident can no longer swallow or needs constant pain relief or other essential medications, a syringe driver can help administer medications. You can contact your local hospice.

The following pages introduce holistic care recommendations and additional resources for each symptom.

RECOMMENDATIONS

"Symptom Management in the Last Days of Life" provides holistic care recommendations and anticipatory prescribing flow charts for the 5 key symptoms in the context of Te Ara Whakapiri

CLICK HERE

HANDBOOK

"The Palliative Care Handbook" (NZ, 9th Ed) has been revised to include clinical guidelines for the care of people living with dementia.

CLICK HERE

MEDICAL

Te Ara Whakapiri toolkit also provides a resource on general pinciples of medical management planning

CLICK HERE

PAIN

- **People living with dementia mate wareware at risk of under-treatment of pain due to their cognitive impairment and communication difficulties.**
- **Pain is often clustered and expressed with other signs and symptoms in people living with dementia, including depression, disrupted sleep, impaired capacity to perform ADLs, distress, and changed behaviour.**
- **Proactive assessment is essential. If possible, it includes self-reporting of pain and if not, a dementia-specific pain tool. [6]**

Background

- A range of factors, including emotions such as anxiety, uncertainty, and fear, strongly influence pain

Non-pharmacological care

- Acknowledge and validate the resident's pain experience. Reassure them that the team will make every effort to manage their pain.
- Minimise movements or positions that cause pain
- Reposition the person regularly and as required to relieve stiffness and pressure, if appropriate
- Facilitate comforting, relaxing, or distracting experiences depending on the resident's level of functioning and preferences, e.g. time with family, music, television, prayer
- Consider using a hot or cold pack under supervision.
- Offer gentle massage or touch (family/whānau may help)
- Create a pleasant environment in the room, e.g. aromatherapy, music, temperature
- Support using other complementary or traditional techniques and methods for pain relief that the patient or their family/whānau want to try if they are unlikely to cause harm. [2,10]

Pharmacological care

See the anticipatory prescribing flow charts in your local HealthPathway, or in the guidance link provided above.

GUIDANCE

BPAC NZ guidance from 2023 on managing pain in the last days of life including prescribing flow charts

CLICK HERE

DEMENTIA PERSPECTIVE

Alzheimers New Zealand has a recorded webinar on pain assessment and person-centred palliative care interventions for residents living with dementia mate wareware.

CLICK HERE

DIRECT CARE STAFF

Caregivers/Kaiawhina are often well-placed to recognise pain. Dementia STARs provides a video presentation or facilitator's toolkit for an education session on pain.

CLICK HERE

AGITATION, DELIRIUM, AND RESTLESSNESS

- **People living with dementia are at significantly greater risk of delirium. Delirium is common among severely ill people, and even more so for people living with dementia.**
- **The impact of delirium or terminal agitation can be profound, with distress, fear, and anxiety for the person living with dementia and their family/whanau. [6]**

Background

- The cause of delirium is often multifactorial. Delirium can be difficult to reverse in the dying phase.
- Terminal restlessness or agitation is anxious, restless, and unsettled behaviour in the final days without other symptoms of delirium. Physical, environmental, and psychosocial factors can exacerbate it.
- Multiple investigations in a dying person are usually best avoided but address causes that can be treated

Non-pharmacological care

- Look for pain and fever.
- Having a calm, familiar person present can reduce feelings of anxiety or isolation. Provide acknowledgement and reassurance.
- Implement safety measures, e.g. remove potential hazards, consider a low bed
- Offer comfort cares if tolerated
- Ensure the environment is relaxing, calm, warm, and peaceful. Minimise noise and 'bustle'.
- Provide familiar and comforting objects from home to promote a sense of comfort and security, e.g., personal bedding, photographs, and books.
- Try playing the person's favourite music in the background for periods of the day. Remove the music if the person appears to be distressed. [2,10]

Pharmacological care

See the anticipatory prescribing flow chart in your local HealthPathway, or in the guidance link provided on the right.

GUIDANCE

BPAC NZ guidance from 2023 on managing delirium in the last days of life including prescribing flow charts

CLICK HERE

DEMENTIA PERSPECTIVE

Dementia Support Australia has a care staff help sheet on managing the symptoms of terminal agitation in dementia

CLICK HERE

BREATHLESSNESS (DYSPONEA)

- **Assessing breathlessness at the end of life can be difficult if the person living with dementia mate wareware is not able to self-report.**
- **It is important to consider whether the person is at risk for dyspnoea. Risk factors include: diagnosis of pneumonia, aspiration, advanced heart disease, or COPD. In particular, there is a high rate of pneumonia in advanced dementia that often causes distress from breathlessness.**
- **Proactively look for signs of breathlessness [6]**

Background

- Breathless is a subjective symptom, and the severity of the perceived experience does not always correlate with the physical signs
- Unlike some other breathing changes associated with the end of life, breathless can be very distressing.

Non-pharmacological care

- Position the resident to elevate their head and torso using pillows to support their head, neck, torso and arms.
- Optimise the resident's immediate environment. Depending on their preference, this might include arranging fresh air to circulate around the resident, a small fan directed towards the face, or a dehumidifier in humid conditions.
- Use interventions to reduce anxiety, such as relaxation and distraction techniques, music, and family/whānau.
- Consider nicotine patches for residents with a history of smoking who are at risk of withdrawal symptoms.
- If the person or family want to try complementary or traditional approaches. These should be supported if they are unlikely to cause harm. [1,2]

Pharmacological care

See the anticipatory prescribing flow chart in your local HealthPathway, or in the guidance link provided on the right.

GUIDANCE

BPAC NZ guidance from 2023 on managing dyspnoea in the last days of life including prescribing flow charts

CLICK HERE

TIPS

PalliAGED (Palliative Aged Care Evidence)offers a Practice Tip Sheet for nurses about dyspnoea.

CLICK HERE

NAUSEA AND VOMITING

- **Dementia itself is not usually a cause of nausea and vomiting.**
- **People living with dementia mate wareware may experience nausea due to a number of reasons including treatment, debility, unrelated conditions, and environmental factors such as overheating or stong odours or flavours [11]**

Background

- Nausea and/or vomiting in the dying phase can significantly impair quality of life
- It is important to identify and treat reversible causes, e.g. constipation, if possible and appropriate
- It is important to ensure existing anti-emetic medications can be continued by having a subcutaneous form ready.

Non-pharmacological care

- Position the resident upright if they are still eating or drinking
- Remove sights or smells that are known to trigger symptoms
- Ensure adequate ventilation – open windows for fresh air, use a fan
- Offer small quantities of food if the patient can still eat. Some residents may want their favourite food, while others prefer bland foods.
- Provide a variety of fluid options if the person can sip or suck through a straw. Offer ice blocks or ice chips if they cannot tolerate oral fluids.
- Prioritise good oral hygiene. Try a mouthwash if the person is able
- Try relaxation and distraction techniques, e.g. listening to music, spending time with family/whānau,
- Be open to using complementary or traditional remedies for nausea, such as ginger ale or peppermint tea, karamu bark, or acupressure wristbands.

Pharmacological care

See the anticipatory prescribing flow chart in your local HealthPathway, or in the guidance link provided on the right.

GUIDANCE

BPAC NZ guidance from 2023 on managing nausea and vomiting in the last days of life including prescribing flow charts

CLICK HERE

BROCHURE

Healthify provides access to a brochure with tips to help nausea and vomiting at the end of life. This is written for a general audience and would be suitable for family / whanau.

CLICK HERE

RESPIRATORY SECRETIONS (DEATH RATTLE)

- **The noise of excessive respiratory secretions is a common sign of imminent death, including for people living with dementia mate wareware. On average, people die within a day of the onset. This can be a sign to encourage friends and family/whanau to try to say their goodbyes. [12]**
- **The dying person is typically unaware of the experience. If this is the case, the priority is to reduce the distress of the family/whanau by providing education and lessening symptoms with care strategies.**

Background

- This is commonly referred to as the 'death rattle'. It occurs in dying people who are unconscious or too weak to cough and can't clear their mouth and airways of secretions.
- Carers (staff and family/whanau) often find this noise disturbing if unprepared.

Non-pharmacological care

- Reassure family/ whānau that the noises are not signs of distress but a normal part of the dying process.
- The person can no longer swallow or cough up the fluid in their throat
- The noise is the sound of air travelling over the pooled fluid (like the sound of sucking the last of a drink with a straw)
- The person is not drowning or suffocating and is usually unaware of the noise (like snoring).
- It is often a sign that they are transitioning into deep unconsciousness and that death is getting closer.
- Repositioning the person on their side and raising the bed head may help.
- The family/whanau can help with mouth care, such as lightly moistened mouth swabs to wipe loose secretions out of the person's mouth.
- The family/whanau may appreciate some background music and aromatherapy scents.
- Suctioning is not usually helpful as it can increase secretions. [2,10]

Pharmacological care

See the anticipatory prescribing flow chart in your local HealthPathway, or in the guidance link provided on the right.

GUIDANCE

BPAC NZ guidance from 2023 on managing excessive respiratory secretions in the last days of life including prescribing flow charts

CLICK HERE

TIPS

PalliAGED (Palliative Aged Care Evidence) offers a Practice Tip Sheet for nurses about dyspnoea

CLICK HERE

3 KEY COMPONENT THREE
AFTER DEATH CARE

Your facility will have a policy about the care of residents and their family/whanau after death. The key elements in the context of Te Ara Whakapiri include:

- Be familiar with the legal requirements of after-death documentation
- Support the family/whānau if they wish to participate in after-death care.
- Treat the person/tūpāpaku with dignity and respect at the time of death.
- Be familiar with the wishes and cultural requirements of the person and their family/whānau in terms of after-death care. This may include washing the person, removing equipment, and dressing the person in chosen clothes.
- Return personal belongings to the family/whānau in a respectful way.
- Have a conversation and provide written resources for the family/ whānau about what occurs following the death.
- Provide information about bereavement support and assess bereavement risk.
- Provide an opportunity for conversation with the family/whānau about their spiritual, religious or cultural needs, and facilitates access to other services where necessary.
- Provide staff with access to education and training on how to have these conversations, and how to access information.
- Respect and facilitate the family/whānau's need for privacy.

Your aged care facility is a special community, and many people may be affected by the death of a resident. In these final pages we move beyond Te Ara Whakapiri to think about after death support for this community.

Supporting staff

Building warm relationships with residents is a fulfilling and meaningful aspect of working in aged residential care. However, when a resident dies, staff may experience a profound sense of loss, and this grief can accumulate over time as more residents die.

To help team members cope with these emotions, it can be beneficial to:
- Acknowledge the emotions of grief
- Talk to a supervisor or colleague
- Engage in self-care activities, such as relaxing, spending time with loved ones, and healthy lifestyle choices
- Seek the assistance of a professional counsellor.

Managers can support their colleagues by providing a safe space to talk about their emotions, listening without judgment, and helping them attend the resident's funeral or tangi if they wish.

It's also essential to allow staff time and privacy to debrief after a resident's death, recognise the loss, and share information about the end-of-life care experience. [13]

Hospice/palliative care liaison staff can be an invaluable resource for staff to discuss their experiences.

AFTER-DEATH CARE FOR MĀORI WHĀNAU

In Te Ao Māori the wairua/spirit will stay close to the tūpāpaku/body until tangihanga/funeral customs have taken place. Being with the tūpāpaku/body and speaking to the wairua/spirit can be comforting. Whānau will draw on their own tikanga (customs) [14], but here are some consideration to be aware of [15].

Where possible, do not leave the body unattended following death.

Be guided by whānau on the cultural and spiritual practices for them at this time.

A karakia should be performed in the area the resident died as soon as possible after the tūpāpaku is removed. From a Māori perspective the room is not spiritually cleansed until an appropriate karakia and cleansing with water has been performed. .

Do not take food or drink into the room following death.

Where possible allow the whānau to take the tūpāpaku/body to a designated area e.g. chapel.

Exiting of Tūpāpaku to designated areas must avoid public corridors and food outlets.

Always transport the Tūpāpaku /body feet first.

Māori protocol and Tikanga Māori should be observed by all staff and vistors for the room where the death occurred and the chapel when it is occupied by the tupapaku/body.

Allow time for karakia.

Offer access to appropriate water and containers for the purpose of spiritual cleansing.

IDEAS TO STRENGTHEN AFTER DEATH CARE

You will already have ways for your team to acknowledge the love and loss of a resident's death for family, residents, and staff. We've collected some simple ideas below. Any of these ideas would be introduced with consideration of the family's wishes and the cultures and capacities of the residents [16,17]

Showing respect



Sometimes staff can provide a quiet guard of honour' as the body is removed. If there are residents who might be distressed by seeing the body being moved, a team member can arrange an activity as this is taking place.



If a staff member isn't on duty when a resident dies, they may often appreciate a message before they return to work.



Have a one-to-one conversation with residents who were friends or neighbours to share the news and encourage them to share memories.



Prepare the room respectfully for the family when they pack up. This might be opening the window, and placing a special quilt, flower, or condolence card on the bed. If the family are interested a spiritual care provider could provide a karakia or prayer, otherwise a staff member can welcome them.



Consider a room blessing to help residents and staff feel at peace with the change of a new resident coming to the room.

Providing meaningful ways to remember the person who has died



Some facilities have a special wall or place for a condolence book for a few days to mark the passing of a resident.



Some places use a memory tree, where people can tie small notes with positive memories of the person.



Let residents and staff know when the funeral, tangi, or other commoration will be held and support transportation to attend.



You might have a symbol to acknowledge the loss, such as butterfly, that can be placed on the resident's door and maybe their usual place at the dinner table.



Some facilities have regular inhouse memorial occasions for all the residents who have died recently.



You might considermailing a sympathy card from your facility on the anniversary of the resident's dealth

SUPPORTING GRIEVING RESIDENTS LIVING WITH DEMENTIA

Like anyone, people living with dementia may respond to bereavement in a range of ways. [18]

When a resident forgets the death



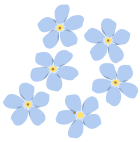
A person with dementia may forget that someone has died. They may ask about them repeatedly. There isn't one right way to respond, it will depend on the individual.



Not understanding may be making the person feel confused and unsupported. For example, they may be aware that the person who has died has stopped visiting them, without knowing why.



For some people, a gentle reminder that the person has died may help. Reminders of the funeral, shown and discussed in a supportive way, may help the person to absorb the news.



People may not recall or understand the loss, but it can still have a strong emotional impact on them, reflected in their behaviour and mood.



If there is a pattern of when the person is asking after the person who died (e.g. at 3pm they always had a cup of tea together) you may be able to pre-emptively arrange a supportive alternative with reminiscence at that time.

Supporting a bereaved resident



Acknowledge feelings and encourage the person to express themselves



Reiminiscence can be helpful afetr a bereavement



Giving the person something that reminds them of the person that died may help with a sense of connection.



consider creative outlets such as music and art that may help people to express their grief



Support faith practices if these bring comfort



Consider other ways to help meet the person's need for attachment such as other relationships, or comfort objects.

WHAT'S IN TE ARA WHAKAPIRI?

Here's a summary of the resources offered by the Manatū Hauora Ministry of Health:

Note: if you are reading a paper copy, visit www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life



TE ARA WHAKAPIRI

- *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.



CARE PLANS

- A baseline assessment and care-after-death checklist
- Ongoing plans of care for health care settings and home care in the last days of life
- A *Discharge Checklist* (for people going home to die)
- Staff signature sheet



MEDICAL MANAGEMENT

- *Recognising the Dying Person* Flow Chart
- Principles for general medical management planning
- Prescribing flow charts for pain, agitation, delirium and restlessness, nausea and vomiting, excessive respiratory tract secretions and breathlessness).



WHANAU

- *When Death Approaches* brochure
- *Dying at Home* brochure
- The *Bereavement Risk Assessment Tool*

RESOURCES AND ACKNOWLEDGEMENTS



OTHER RESOURCES

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Collated in Te Whatu Ora Waiataha Canterbury

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