Waikato District Health Board

Midland District Health Boards
www.midlanddhbs.health.nz

Living Every Moment
hospice waikato

Te Ara Whakapiri

Care in the last days of life

Inpatient and residential care

Acknowledgement to Ministry of Health for sharing resource

MINISTRY OF HEALTH
MANATŪ HAUORA

New Zealand Government

10/18JB

Introducing Te Ara Whakapiri

The support and care of families/whānau as well as the dying person is a crucial part of last days of life care. It is best delivered by a multidisciplinary team, supporting everyone involved to identify realistic goals of care and contribute to decision-making, whilst also helping them deal with their own distress.

Te Ara Whakapiri - Care in the last days of life, can be used in any care setting to help teams of health care professionals make regular assessments that include reflection, review and critical decision-making in the best interest of the person they are caring for.

The recognition and diagnosis of dying is always complex, irrespective of previous diagnosis or history. Uncertainty is an integral factor in the dying process, and there are occasions when a person who is thought to be dying lives longer, or dies sooner, than expected. **Seek a second opinion or specialist palliative care support as needed.**

Good, comprehensive, clear communication and access to appropriate supports are required to identify and address differences in cultural perspectives in last days of life care respectfully.

All decisions leading to a change in care goals should be communicated to the person where appropriate and to the family/whānau. The views of all concerned must be listened to and documented.

To assist with delivering care in the last days of life, this document includes:

- the ***Recognising the Dying Person Flow Chart***
- a list of principles for general medical management planning (***Medical Management Planning – General Principles***)
- a baseline assessment and care-after-death checklist (***Care in the Last Days of Life***)
- ongoing plans of care ***(ongoing care of the dying person)***
- ***Symptom-management flow charts*** (covering pain, agitation, delirium and restlessness, nausea and vomiting, excessive respiratory tract secretions and dyspnoea/breathlessness).

Additional/optional documents

- the ***Complicated Bereavement Risk Assessment Tool (CBRAT)***
- ***a Transfer of care checklist*** (for people going home to die)

Other information leaflets that may be of help for patient/family/whānau are available, including:

- *What to expect when someone is dying*
- *What to expect when someone dies at home*
- *Te Ara Whakapiri - a guide for family / whānau*

Clinical notes should be used to document significant information from the assessments and care after death to ensure clear communication for all those involved in the delivery of care.

There is also a **staff signature** sheet that helps identify all staff who are using the checklists and plans of care in relation to caring for a particular person.

Recognising the dying person flow chart

Recognition of the person's deterioration

Changes that can indicate dying is starting to occur

- Profound weakness
- Reduced intake of food/fluid
- Difficulty swallowing/taking oral medications
- Bed bound after progressive decline over days and weeks
- Peripheral shutdown (cold hands and feet)
- Poor improvement to medical interventions
- Near-death awareness (stories, travel, visitations)

Changes that can indicate the person is closer to death

- Increased drowsiness/sleepiness, diminished consciousness, delirium, terminal restlessness
- Pallor of nose and top of ears, increased respiratory mandibular movements, relaxed forehead, hyperextension of neck
- Extremities cool, increased cyanosis and mottling of lips and fingers
- Cardiovascular changes (tachycardia, bradycardia, hypotension)
- Respiratory changes (persistent secretions in pharynx / trachea / bronchus, Cheyne-Stokes, apnea, ataxic breathing)

↓

Assessment

Multidisciplinary team (MDT) assessment (lead health practitioner, nursing and allied health, cultural and spiritual support staff)

- Is there a potentially reversible cause for the person's condition (e.g. exclude opioid toxicity, renal failure, hypercalcaemia, infection)?
- Has there been a poor response to medical interventions?
- Is a specialist referral needed (e.g. specialist palliative care or a second opinion)?
- Could the person be in the last days or hours of life?

Clinical decision

The person is NOT recognised as dying
(i.e. not in the last days or hours of life)

↓

Review the current plan of care

Communication

Explain the new or revised plan of care with the person and their family/whānau

The person IS recognised as dying
(i.e. is in the last days or hours of life)

↓

Communication

Agree on the **current plan of care** with the person (where appropriate) and their family/whānau. Focus the discussion on recognising and understanding that the person is dying or approaching the last days of their life

↓

Management

Commence the **Te Ara Whakapiri Plan of Care**, including the **Baseline** Assessment and **Ongoing** Care of the dying patient

↓

Reassessment

A MDT review of the current plan of care should be performed if:

- the person's conscious level, functional ability, oral intake, mobility, ability to perform self-care improves
- the person, their family/whānau, carer or team member expresses concerns about the person's management plan
- it has been three days since the last MDT assessment

↑ (return to Assessment)

Medical management planning – general principles

Purpose

It is essential that:

- **dying** is identified and **recognised** as early as possible, although this can be difficult as signs and symptoms suggesting dying can be subtle (see *Recognising the dying person flow chart)*
- all members of the multidisciplinary team (MDT) understand the **priorities of care**
- the person is assessed and **communication** is unhurried, compassionate and valued for all people involved (the person (if able), family/whānau and staff)
- the person has an **individualised plan of care** that aligns with their stated preferences and needs (if able) and those of their family/whānau
- **dignity, respect and privacy** are provided and maintained
- every effort is made to **optimise symptom management**
- staff are enabled and supported to deliver the **highest standard** of last days of life care.

Principles

The principles of good care at the end of life include:

- **attending** to culture, with clear communications and explanations
- **continuing** any regular medications if withdrawal could cause adverse effects (this may include antianginals, heart failure medications, steroids and benzodiazepines, if dependent)
- **stopping** all non-essential medications (this may include anti-hypertensives, oral hypoglycaemics, diuretics, antibiotics, etc)
- **starting** appropriate medications for existing symptoms as needed (PRN), subcutaneous and oral (if still able to swallow) and, if necessary, via continuous subcutaneous infusion (CSCI)
- **anticipating** symptoms that may occur and prescribing PRN medications (see Anticipatory and Symptomatic Prescribing below) (chart orally if still able to swallow AND as subcutaneous boluses)
- **reviewing** medications at least daily
- **considering** the risks and benefits of administering hydration by parenteral route before commencing or stopping intravenous or subcutaneous fluids.

Anticipatory and symptomatic prescribing

Reviewing prescribed medications

There are five main symptoms that must be anticipated so that care is optimised. Not every dying person experiences these, but some may experience all five. The symptoms are:

- pain
- nausea and vomiting
- respiratory tract secretions
- delirium, restlessness, agitation
- breathlessness/dyspnea.

It is important to anticipate potential symptoms and prescribe accordingly.

Anticipatory prescribing enables health professionals to respond quickly should a symptom arise or when swallowing becomes difficult.

Explain to the person (if able) and their family/whānau the rationale for anticipatory prescribing.

If more than three doses of any prescribed drug are required within the minimum administration period (e.g., if prescribed Q1H PRN and three doses are required in three hours), review and consider whether a continuous subcutaneous infusion (CSCI) would be preferable.

Refer to symptom management flow charts.

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Patient Label

Name: _____ or patient details

NHI: _____ DOB: _____ dd/mm/yy

Address: _____

Last Days of Life Care Plan

Recognition that the person is dying or is approaching the last days of life
Is recognising the dying person flow chart available to support decision making? Yes ☐
The decision to commence the care plan must be made by the lead practitioner responsible for the person's care. The lead practitioner is the person's GP (in community), hospital / hospice specialist or nurse practitioner.
Lead practitioner's name _____ *Designation* _____ *Contact* _____
Named nurse commencing care plan _____
Date care plan commenced _____ *Time care plan commenced* _____

All personnel completing any Te Ara Whakapiri documentation please sign below			
Name (print)	**Full signature**	**Initials**	**Professional title**

Multidisciplinary Team (MDT) review - should take place every three days, 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: .....

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Patient Label

Name: _____ or patient details

NHI: _____ DOB: _____ dd/mm/yy

Address: _____

Assessment

Domain A: Baseline assessment

A.1 Diagnosis: _____

Contributing diagnoses: _____

Ethnicity: _____ Gender: Female ☐ Male ☐ Other ☐ Age: _____

A.2 The person's awareness of their changing condition

Is the person aware they may be entering the last few days of life? Yes ☐ No ☐

A.3 The family/whānau's awareness of the person's changing condition

Is the family/whānau aware that the person may be entering the last few days of life? Yes ☐ No ☐

A.4 Goals of care

Does the person have capacity to make decisions on their own treatment at this moment in time? Yes ☐ No ☐

Has this assessment and priorities of care been discussed, identified and documented with:

The person? Yes ☐ No ☐

Family/whānau? Yes ☐ No ☐

If not, document reasons: _____

A.5 Family/whānau contact

If the person's condition changes, who should be contacted first? Name: _____

Relationship to person: _____ Phone (H): _____ (M): _____

When to contact: At any time ☐ Not at night-time ☐ Staying overnight ☐

Is an Enduring Power of Attorney (EPOA) Personal Care and Welfare in place? Yes ☐ No ☐

Has it been activated? Yes ☐ No ☐ N/A ☐

EPOA name: _____ Contact details: _____

A.5 Advice to relevant agencies of the person's deterioration

Has the GP practice been contacted if they are unaware the person is dying? Yes ☐ No ☐ N/A ☐

(If out of hours, contact next working day.)

Note: *Consider notifying the person's specialist teams, district nursing services, residential care and other agencies involved in their care.*

Domain B: Taha tinana – *Physical health*

B.1 Assessment of physical needs

Is the person: Conscious ☐ Semi-conscious ☐ Unconscious ☐ Unable to communicate ☐

In pain	Yes ☐	No ☐	Able to swallow	Yes ☐	No ☐	Confused	Yes ☐	No ☐			
Agitated	Yes ☐	No ☐	Continent (bladder)	Yes ☐	No ☐	Experiencing respiratory tract secretions	Yes ☐	No ☐			
Nauseated	Yes ☐	No ☐	Catheterised	Yes ☐	No ☐						
Vomiting	Yes ☐	No ☐	Continent (bowels)	Yes ☐	No ☐	Skin integrity at risk	Yes ☐	No ☐			
Dyspnoeic	Yes ☐	No ☐	Constipated	Yes ☐	No ☐	At risk of falling	Yes ☐	No ☐			

Is the person experiencing other symptoms (eg, oedema, myoclonic jerks, itching)? Yes ☐ No ☐

Describe:

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Patient Label
Name: _____ or patient details
NHI: _____ DOB: _____ dd/mm/yy
Address: _____

Assessment - continued

B.2 Availability of equipment

Is the necessary equipment available to support the person's care needs (e.g. air mattress, hospital bed, syringe driver, pressure-relieving equipment)? Yes ☐ No ☐

Provision of food and fluids

- The person should be supported to take food/fluid by mouth for as long as tolerated and appropriate.
- A reduced need for food/fluid is part of the normal dying process.
- For many people the use of clinically assisted (artificial) nutrition/hydration will not be required.

B.3 Is clinically assisted (artificial) nutrition in place? Yes ☐ No ☐

If yes, record route: NG ☐ PEG/PEJ ☐ NJ ☐ TPN ☐

Ongoing clinically assisted (artificial) nutrition is:

Not required ☐ Discontinued ☐ Continued ☐ Commenced ☐

B.4 Is clinically assisted (artificial) hydration in place? Yes ☐ No ☐

If yes, record route: IV ☐ Subcut ☐ PEG/PEJ ☐ NG ☐

Ongoing clinically assisted (artificial) hydration is:

Not required ☐ Discontinued ☐ Continued ☐ Commenced ☐

Consider reduction in rate / volume according to individual need if nutritional support is in place.

Explain the plan of care to the person (where appropriate), and to the relative or carer.

Doctor or nurse practitioner to complete

Review of current management and prescribing of anticipatory medication

B.5 Has current medication been assessed and non-essentials discontinued? Yes ☐

B.6 Has the person's need for current interventions been reviewed? Yes ☐

B.7 Anticipatory prescribing of medication completed (refer to relevant symptom management flow charts):

Pain	Yes ☐	Nausea/vomiting	Yes ☐
Agitation	Yes ☐	Dyspnoea/breathlessness	Yes ☐
Respiratory tract secretions	Yes ☐		

B.8 Have additional treatment and/or care-related issues been discussed with the family/whānau if needed (e.g. food, fluids, place of care, ceiling of care, cardiopulmonary resuscitation)? Yes ☐

B.9 Consideration of cardiac devices:

If a person has a cardiac device (e.g. cardioverter defibrillator (ICD) or ventricular assist device), a conversation should take place with the person and/or the family/ whānau to discuss what can occur in the last days of life, whether the cardiac device should be deactivated and, if so, how and when this would take place.

Has the cardiac device been deactivated? Yes ☐ No ☐ No ICD in place ☐

B.10 Full documentation in the clinical record is required for any issues identified.

Doctor's / nurse practitioner name (print): _____

Signature: _____ Date: _____ dd/mm/yy Time: _____ 24 hour

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Name: _____ or patient details

NHI: _____ DOB: _____ dd/mm/yy

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Assessment - continued

Domain C: Taha hinengaro – *Psychological and mental health*

Assessment of the person's preferences and wishes for care

C.1 Does the person have an advance care plan (ACP) / or other directive? Yes ☐ No ☐

C.2 Has the person expressed the wish for organ/tissue donation? Yes ☐ No ☐

C.3 Has the person expressed a preferred place of care?

No preference ☐ Home ☐ ARC ☐ Hospital ☐ Hospice ☐

C.4 Does the person have a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order in place? Yes ☐ No ☐

C.5 Does the person have any cultural preferences? Yes ☐ No ☐

If yes, describe: _____

C.6 Does the person have any emotional or psychological symptoms or concerns? Yes ☐ No ☐

If yes, describe: _____

Domain D: Te wairua – *Spiritual health*

Provision of opportunity for the person and their family/whānau to identify what is important to them

D.1 If able, has the person been given the opportunity to express what is important to them at this time (e.g. wishes, feelings, spiritual beliefs, religious traditions, values)? (*Refer to the person's ACP for personal wishes if completed)* Yes ☐ Not able ☐

Specify if applicable: _____

D.2 Has the family/whānau been given the opportunity to express what is important to them at this time? Yes ☐

Specify if applicable: _____

D.3 Has the person's own spiritual advisor / minister / priest been contacted? Yes ☐ N/A ☐

Name: _____ Contact no: _____ Date/time: _____

D.4 Are there other needs to address (i.e. access to outdoors, pets, touch therapy, music, prayer, literature, etc)? Yes ☐ No ☐

Domain E: Te whānau – *Extended family health*

Identification of communication barriers and discussion of needs

E.1 Is the person able to take a full and active part in communication? Yes ☐ No ☐

E.2 Have the cultural needs of the family/whānau been identified and documented? Yes ☐ No ☐

E.3 Has the person and/or the family/whānau expressed concern about previous experiences of death and dying? Yes ☐ No ☐

Provision of information to the family/whānau about support and facilities

E.4 Has the family/whānau received information about support and facilities available to them? Yes ☐ No ☐

E.5 Has the *What to expect when someone is dying* information sheet been offered to the family/whānau? Yes ☐ No ☐

If the person is being cared for at home:

E.6 Has the family/whānau received information about who to contact after hours or if the person's condition changes? Yes ☐ No ☐

E.7 Has the *What to expect when someone dies at home* information sheet been offered to the family/whānau? Yes ☐ No ☐

E.8 Has advice been given to the family/whānau on what to do in an emergency? Yes ☐ No ☐

Full documentation in the clinical record is required for any issues identified in this assessment.

Nurse's name (print): _____ Date: _____ Time: _____

Signature: _____ Designation: _____

If the Last Days of Life Care Plan is discontinued, please record here

Date care plan discontinued:

Time care plan discontinued:

Reasons why the care plan was discontinued by MDT:

Decision to discontinue this care plan shared with the person? Yes ☐ No ☐

Decision to discontinue this care plan shared with the family/whānau? Yes ☐ No ☐

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Name: _____ or patient details

NHI: _____ DOB: _____ dd/mm/yy

Address: _____

Assessment - continued

Care after death

It may be appropriate to complete some of this section before the person's death.

Domain F: Taha tinana – *Physical health*

F.1 Verification of death

Time of death: _____ Date of death: _____

Is the person to be buried or cremated? Burial ☐ Cremation ☐ or Other ☐

Name of doctor informed of person's death: _____

Name of funeral director: _____ Phone: _____

Date and time death verified: _____ Who verified the death? _____

F.2 Is the coroner likely to be involved? Yes ☐ No ☐

Has a medical certificate been completed? Yes ☐ Doctor's name: _____

Note: *Relevant members of the multidisciplinary team (MDT) should be advised of the person's death in a timely fashion (e.g., district nurses, hospice, GP/specialist, organ/tissue donation NZ).*

The person/tūpāpaku is treated with dignity and respect.

Ensure the wishes and cultural requirements of the deceased person and their family/whānau are met in terms of after-death care.

F.3 Are valuables to be left on the person/tūpāpaku? Yes ☐ No ☐

Note: *Support the family/whānau to participate in after-death care if they wish to be involved, undertake after-death care according to local policies and procedures and return personal belonging to the family/whānau in a respectful way.*

Domain G: Te whānau – *Extended family health*

G.1 Has the family/whānau been given the opportunity to express spiritual, religious and cultural needs? Yes ☐

Note: *Provide an opportunity to talk with the family/whānau about their spiritual, religious or cultural needs.*

G.2 Has a private space been made available for the family/whānau? Yes ☐

Note: *Respect the family/whānau need for privacy, ensure a private space is available for prayer, karakia or other cultural or spiritual needs and arrange for blessing of the room/bed space as appropriate.*

The family/whānau is provided with information about what to do next.

G.3 Has a conversation been held with the family/whānau to ensure they have adequate information about what to do next? Yes ☐

G.4 Has written material been offered (this may include information regarding local funeral directors, funeral planning, www.fdanz.co.nz, etc)? Yes ☐

Note: *Additional support should be offered at the time of death if needed. This may include a social worker, cultural support and/or chaplain support.*

Domain H: Taha hinengaro – *Mental health*

The family/whānau is able to access information about bereavement support and counselling if needed.

H.1 Was the family/whānau present at the time of death? Yes ☐ No ☐

H.2 If not, has the family/whānau been notified? Yes ☐ No ☐

Name of person notified: _____

Relationship to the deceased person: _____

If no one was notified, explain why not: _____

H.3 Did the family/whānau appear to be significantly distressed by the death? Yes ☐ No ☐

H.4 Was there evidence of conflict that remained unresolved within the family/whānau? Yes ☐ No ☐

If 'Yes' was ticked to either of the last two questions AND/OR the family/whānau expressed distress at being unable to say goodbye, complete the complex Bereavement Risk Assessment Tool (CBRAT)

Note: *Written bereavement information should be offered as available.*

Nurse's name (print): _____	Date: _____
Signature and designation: _____	Time: _____

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Name: _____ or patient details

NHI: _____ DOB: _____ dd/mm/yy

Address: _____

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 (dd/mm/yy)											
	Time (24 hour)											
Domain B: Te taha tinana – *Physical health*												
1. Pain The person is pain free at rest and during any movement.												
2. Agitation/delirium/restlessness The person is not agitated or restless and does not display signs of agitated delirium or terminal anguish.												
3. Respiratory tract secretions The person is not troubled by excessive secretions.												
4. Nausea and vomiting The person is not nauseous or vomiting.												
5. Breathlessness/dyspnoea The person is not distressed by their breathing.												
6. Other symptoms (document fully in clinical notes) The person is free of other distressing symptoms, e.g. myoclonic jerks, itching.												
7. Mouth care The person's mouth is moist and clean.												
Nurse initials each set of entries												
	AM		**PM**		**Night**		**AM**		**PM**		**Night**	
8. 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.*												
9. Mobility/pressure injury prevention The person is in a safe and comfortable environment. Repositioning and use of pressure relieving equipment is effective.												
10. 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.												
11. 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.												

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Patient Label

Name: _____ or patient details

NHI: _____ DOB: _____ dd/mm/yy

Address: _____

Ongoing care of the dying person

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 (dd/mm/yy)						
	Time	AM	PM	Night	AM	PM	Night
Domain C: Te taha hinengaro – *Psychological / mental health*							
12. Emotional support Any emotional distress such as anxiety is acknowledged and support is provided.							
13. Cultural The person's cultural needs are acknowledged and respected.							
Domain D: Te taha wairua – *Spiritual health*							
14. Addressing spiritual needs Religious and spiritual support is offered to the person and to their family/whānau as per the person's wishes.							
Domain E: Te taha whānau – *Extended family health* **(these items refer to the health of the carers, not the person)**							
15. Emotional support Any distress relating to issues such as grief and anxiety is acknowledged and addressed. The need for privacy is respected.							
16. Practical support Advice and guidance are offered according to the needs of the person's family/whānau.							
17. Cultural support The cultural needs of the family/whānau are reviewed and care is mindful of these needs.							
18. Communication Communication is open to address any fears or concerns about the dying process.							
Nurse initials each set of entries							

Management of pain

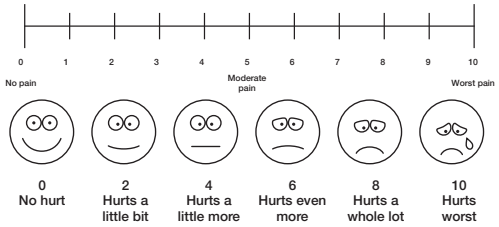
Definition

Pain is; “an unpleasant sensory or emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (International Association for the Study of Pain, 2008).

Assessment tools

Person able to communicate

1. **Use preferred tool for your organisation**
   eg, Wong-Baker FACES™ Pain Rating Scale.



2. **Describe type of pain**

Type of pain	Descriptor
Somatic	Aching, throbbing, gnawing, localised
Visceral	Deep aching, cramping, dull pressure
Neuropathic	Burning, shooting, pins and needs, tingling
Bone	Constant, deep

3. **Document clearly:** Consider the following, assessing their pain using the PQRST format:

P	Palliating factors	“What makes it better?”
	Provoking factors	“What makes it worse?”
Q	Quality	“What is your pain like? Give some words that tell me about it.”
R	Radiation	“Does that pain go anywhere else?”
S	Severity	“How severe is it?” Measured on numbered scale
T	Time	“Do you feel it all the time?”
		“Does it come and go?”
U	Understanding	“What does this symptom mean to/for you?”
		“How does this symptom affect your daily life?”
		“What do you believe is causing this pain?”

Person unable to communicate

Use the preferred tool for your organisation if available. If no tool is available, the Abbey Pain Scale can be used to assess pain in those unable to communicate. (www.apsoc.org.au/PDF/Publications/4_Abbey_Pain_Scale.pdf)

Holistic considerations

Reflect on: Te Whare Tapa Wha principles (Durie 1994)

Emotional considerations:	Fear and anxiety can be both cause and consequence.
Spiritual considerations:	What impact does pain have on the person’s sense of self and their mana/wellbeing?
Social considerations:	Are there any cultural considerations, eg, Māori/Asian/Pacific peoples? How does the pain affect the person’s family/whānau life? And how is this, in turn, affecting the family/whānau’s relationship with their partner/friends?
Physical considerations:	Are there activities or positions that are particularly painful for the person?

Management

1. Involve the person’s family/whānau if the person is happy for them to be involved.
2. Being with the person and believing that their pain exists can help reduce their pain.
3. Helping to position the person to make them as comfortable as possible and helping to reposition them regularly can help reduce stiffness and muscular aches and provide pressure relief. Provide pressure relieving aids.
4. Guided imagery and distraction is a technique that teaches the person to mentally remove themselves from the present and imagine that they are in another place, eg, a favourite vacation spot. It can help reduce some types of pain by helping the person to relax or distract them from unpleasant thoughts. Distraction therapy comes in many forms, eg, guided audio, TV, music, reminiscing, etc.
5. Heat and/or coolness can often help ease pain, eg, by applying heated or chilled wheat packs. Care should be taken to ensure the temperature is suitable and the person will not be burned.
6. Massage or touch can be beneficial. Those giving massage should have an understanding of what is beneficial and what may cause harm. It is important to be aware that some people may not be comfortable with massage or touch.
7. Prayer and mindfulness meditation can be beneficial in reducing pain or existential suffering, depending on the person’s spiritual or cultural perspectives.

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hospice waikato

Pain management flow chart

Morphine is the first-line opioid if eGFR > 45mL/min (unless contraindicated).
Use morphine with caution when eGFR 30 - 45mL/hr.
Use oxycodone with caution when eGFR 15 - 30mL/hr.
If the person is in renal failure GFR < 30 mL/min consider an alternative opioid to morphine/oxycodone, e.g. fentanyl. (See pain management flow chart for patients with severe renal impairment.)

Pain present / **Pain absent**

Is the person already taking oral morphine, oral oxycodone or fentanyl patches?[a.]

YES

1. Continue with fentanyl patches if being used.
2. Convert oral morphine/oxycodone to 24 hour dose (CSCI).[b.]
3. Prescribe PRN dose of morphine Q1 hour for break through pain.[c.]

NO

If there are no contraindications, prescribe morphine 2.5 - 5mg Q1 hour PRN via subcutaneous line.

Review within 24 hours

- If pain is ***escalating*** and three or more PRN doses are required, increase morphine/oxycodone in CSCI by the total additional dose required in the last 24 hours.
- Increase morphine/oxycodone PRN dose.
- If pain is ***incidence*** pain (e.g. turning), continue to give PRN dose via subcutaneous line.

If symptoms persist, contact the hospice or palliative care team for advice.

a. If methadone is being used, please contact the palliative care team for advice.

Morphine/oxycodone calculations

b. To CONVERT from oral morphine/oxycodone to 24 hour CSCI morphine/oxycodone, halve the total 24 hour dose of oral morphine (24 hour total oral morphine = 60mg then prescribe 30mg subcutaneous morphine).

c. PRN doses of morphine/oxycodone: divide 24 hour dose by six and give up to Q1 hour.

Anticipatory prescribing in this manner will ensure that in the last hours and days of life there is no delay responding to a symptom if it occurs.

For increasing medication requirements to manage breakthrough symptoms contact
Waikato Hospital patients: 07 839 8691 or on-call Palliative Medicine Consultant via Waikato Hospital Operator
Community patients: 07 859 1260 (Hospice Waikato), after hours call on-call Palliative Medicine Consultant

Acknowledgement to Ministry of Health for sharing resource

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Pain management flow chart for patients with severe renal impairment (eGFR < 30mL/min)

Morphine and oxycodone have a risk of toxicity in renal impairment (myoclonic jerks, delirium, drowsiness and respiratory depression).

Fentanyl is the safest first-line opioid when eGFR < 30mL/min.

Methadone is an alternative but can be complex to use and should be started only with advice from a palliative medicine specialist.

If person is on a fentanyl patch leave in situ and dose PRN fentanyl accordingly.[a.]

Pain present

- Give a stat dose of fentanyl[a.] 10 - 20mcg via subcutaneous line.
- Consider starting fentanyl 100 - 300mcg via CSCI over 24 hours.

Pain absent

If no contraindications, prescribe fentanyl 10 - 20mcg PRN hourly via subcutaneous line.

If already on fentanyl, this dose will need to be higher.[a.]

Review within 24 hours

- If pain is ***escalating*** and three or more PRN doses are required, increase fentanyl in CSCI by the total additional dose required in the last 24 hours.
- Increase fentanyl PRN dose accordingly.
- If pain is ***incidence*** pain (e.g. turning), continue to give PRN dose via subcutaneous line.

If pain uncontrolled or conversion from standard opioid to fentanyl unclear, contact palliative care team for advice.

a. For patients established on a fentanyl patch the breakthrough dose is roughly equivalent to the ***hourly*** transdermal dose given via subcutaneous line to a maximum of 100mcg (2mL)

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Acknowledgement to Ministry of Health for sharing resource

Management for dyspnoea / breathlessness

Dyspnoea is a very subjective symptom and does not always fit with the physical signs. Studies show that what onlookers see as distressing may not be distressing for the person. When the sensation of breathlessness is frightening, it may be described as suffocating, smothering, laboured breathing or air hunger.

Definition

The mechanism of dyspnoea/breathlessness

There are reported to be three paradigms of dyspnoea.

1. A perceived increase in respiratory effort or work of breathing (in people with **airflow obstruction**, e.g. **COPD** or **bronchiectasis** or a **large pleural effusion**).
2. An increase in the proportion of chest wall strength and respiratory muscles required to maintain homeostasis (in people with neuromuscular disease (**MND**) and **cancer cachexia**).
3. An increase in ventilatory requirements, due to **sepsis**, **anaemia**, **acidosis** or **hypoxemia**.

Assessment

1. Because this is a very subjective experience, the assessment is best based on the person's own report.
2. In severe breathlessness, clinical signs will be visible, such as; increased respiratory rate, excessive use of accessory muscles, gasping/air hunger, pursed lip breathing or arms held fixed down onto mattresses.
3. **For unconscious people at the end of life**, the health care professional will have to rely on relevant physical clues and support from the family / whānau. For example, tachypnoea (fast breathing), tachycardia (fast heart rate/pulse) and Cheyne-Stokes respiration may not necessarily be an indication of distress, unless accompanied by sweating, grimacing, agitation or use of accessory muscles.

Holistic considerations

Reflect on: Te Whare Tapa Wha principles (Durie 1994)

Emotional considerations:	How might it feel for the person to be out of breath all the time?
	How might the person's distress be perceived by those around them?
Spiritual considerations:	What does being breathless mean to the person? How does this affect the person and their perception of self?
Social considerations:	How does being breathless affect the person's lifestyle and the lifestyle of those around them?
Physical considerations:	Are there activities that particularly cause breathlessness but that are meaningful to the person?

Management

1. **Positioning:** Straight and upright - however, it may not be possible for a person to be positioned straight and upright at the end of their life due to weakness. Provide some support with pillows, avoiding horse shoe pillows as people who are small and frail may slip into the hollow space and compress their lungs. Support the person's arms on pillows to help keep their shoulders relaxed and decrease their tension. It is equally important to support the person's head in a good position.
2. **Environment:** A light, airy side room or single room with opening windows. Avoid showering or bathing in very hot water and a humid environment. Offer a gentle flow of air across the person's face from an intermittent fan - the person could hold a fan if they still have the capacity. Dress them in non-restrictive cotton clothing when they are in bed.
3. **Relaxation, anxiety reduction:** Touch may or may not be appropriate. Massage the person's feet and hands if they can tolerate it. Offer the person's choice of relaxing music. Encourage visits from family and friends. Read out loud to the person. Health care professionals should have a calm approach. Avoid using phrases such as 'just keep calm'.
4. **Planning and practice:** Plan what needs to be done and look for efficient ways of doing this. Practice abdominal breathing techniques.

Dyspnoea / breathlessness management flow chart

There is no established evidence that fentanyl oroxycodone is effective in managing dyspnea / breathlessness.

If there is renal impairment, refer to pain management flowchart (eGFR<30) for guidance on fentanyl use.

If the person is already established on oxycodone for pain, it is reasonable to use oxycodone for dyspnoea.

Dyspnoea / breathlessness present

Is the person already taking oral morphine?

YES

1. If not swallowing, convert background oral morphine to 24 hours CSCI.[a.]
2. Calculate PRN dose of subcutaneous morphine[b.] (lower doses may be appropriate for dyspnoea compared with pain dose).

NO

1. Prescribe PRN dose morphine 2.5 - 5mg Q1 hour via subcutaneous line.
2. Titrate requirements for 24 hours.
3. If ≥ 3 PRN doses required initiate 24 hours CSCI.[c.]

Review within 24 hours

If ≥ 3 PRN doses have been given, consider increasing morphine in CSCI by total PRNs required in previous 24 hours.

If the person is still dyspnoeic and anxious, consider adding midazolam 5 - 15mg / 24 hours via CSCI.

If symptoms persist, contact the palliative care team for advice.

Dyspnoea / breathlessness absent

Prescribe PRN dose morphine 2.5 - 5mg Q1 hour via subcutaneous bolus

If dyspnea / breathlessness occurs change to **'PRESENT'** guide.

Morphine calculations

a. To CONVERT from oral morphine to 24 hours continuous subcutaneous infusion (CSCI) of morphine via a syringe driver, halve the total 24 hour dose of oral morphine (e.g. 24 hour total oral morphine = 60mg then prescribe 30mg morphine via CSCI).

b. PRN doses of morphine: Divide 24 hour dose by six and give up to Q1 hour.

c. To INITIATE 24 hour CSCI of morphine via a syringe driver, add up the PRN subcutaneous morphine doses given in the last 24 hours.

Anticipatory prescribing in this manner will ensure that in the last hours and days of life there is no delay responding to a symptom if it occurs.

For increasing medication requirements to manage uncontrolled dyspnoea/breathlessness contact
Waikato Hospital patients: 07 839 8691 or on-call Palliative Medicine Consultant via Waikato Hospital Operator
Community patients: 07 859 1260 (Hospice Waikato), after hours call on-call Palliative Medicine Consultant

Acknowledgement to Ministry of Health for sharing resource

Management of nausea / vomiting

People at the end of their lives can experience nausea and vomiting, which has an adverse effect on the person's physical, psychological and social wellbeing and significantly impairs their quality of life.

Definition

Nausea: A feeling of sickness in the stomach characterised by an urge to, but not always leading to vomit.

Vomiting: The forcible voluntary or involuntary emptying of the stomach contents through the mouth.

Assessment

1. Knowledge of the physiology of nausea and vomiting will promote a rational choice of treatment.
2. History of symptoms and previous management (pharmacological and other) should be continued.
3. Treat reversible causes if possible and appropriate (such as constipation).

Holistic considerations

Reflect on: Te Whare Tapa Wha principles (Duri 1994)

Emotional considerations:	Fear and anxiety can be both cause and consequence.
Spiritual considerations:	What impact does the nausea have on the person's mana and sense of self?
	Are there any cultural considerations, e.g. Māori / Asian / Pacific peoples?
Social considerations:	How is not eatjng affecting the person's family/whānau life? And how is this, in turn, affecting the family/whānau's relationship with their partner/friends?
Physical considerations:	Is there pressure from other people to eat? Does the smell of cooking / food cause the person to feel sick?

Management

Consider exploring the following options for managing nausea and vomiting.

1. Eliminate sights and smells that cause nausea and vomiting, e.g. foods, deodorants, air fresheners, body odour and bowel motions.
2. Provide a well-ventilated room, circulating fresh air from a fan or open window.
3. Help the person dress in comfortable, loose-fitting, cool clothing.
4. Optimise the person's oral hygiene. Consider using ½ tsp baking soda, ½ tsp salt in 250mL water as a mouthwash. Alternatively, there are many different types of mouthwash available.
5. Offer sour candy ice chips made from a lemon/pineapple based juice, ginger ale or fruit as per the person's individual preference and if they are still able to tolerate the taste.
6. Some people may prefer peppermints or peppermint tea.
7. If the person is still eating, offer small amounts of bland foods, fluids and snacks at room temperature.
8. Help elevate the person's upper body when they are eating or drinking.
9. The person may already have a nasogastric (NG) tube on free drainage.
10. Use guided imagery/visualisation , teaching the person to mentally remove themselves from the present and imagine that they are in another place, e.g. a favourite vacation spot. This can mentally block the nausea andvomiting.
11. Use music therapy to relieve stress and give a sense of wellbeing.
12. Use distraction techniques, such as, discussing family routines or providing suitable music or DVDs (e.g. documentaries)
13. Apply acupressure. This can be done by the person or a family member/friend. Acupressure wrist bands are also available.

Some therapies that were used to provide more comfort for the person in the past may no longer be appropriate at the person's end-of-life stage.

Nausea / vomiting management flow chart

Nausea / vomiting present

Is the person already obtaining relief from existing antiemetics?

YES

Continue these parenterally, e.g.

Cyclizine 50mg PO 8 hourly = cyclizine 150mg/24 hours via CSCI

Metoclopramide 10mg PO TDS = metoclopramide 30mg/24 hours via CSCI

Haloperidol 0.5mg PO BD or TDS = haloperidol 1 - 2mg/24 hours via CSCI

NO

Nausea / vomiting absent

Prescribe PRN dose Haloperidol 0.5 - 1mg Q4 hour via subcutaneous line (maximum dose 5mg in 24 hours).

*If nausea / vomiting occur, change to **'PRESENT'** guide*

If the cause of the nausea and vomiting is unknown OR the symptom is not fully controlled, use a broad-spectrum antiemetic, i.e. LEVOMEPROMAZINE (Nozinan®)

Prescribe:

1. Levomepromazine 6.25mg/24 hours via CSCI
2. PRN levomepromazine 6.25mg Q4 hour PRN via subcutaneous line (maximum dose 25mg/24 hours)

If more than two PRN doses given in 24 hours increase to:

1. Levomepromazine 12.5 - 25mg/24 hours via CSCI
2. PRN levomepromazine 6.25mg Q4 hour PRN (maximum dose 25mg/24 hours)

Contact the palliative care team for further advice.

Anticipatory prescribing in this manner will ensure that in the last hours and days of life there is no delay responding to a symptom if it occurs.

For increasing medication requirements to manage uncontrolled nausea/vomiting contact
Waikato Hospital patients: 07 839 8691 or on-call Palliative Medicine Consultant via Waikato Hospital Operator
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Management of agitation, delirium, restlessness

Agitation, delirium or restlessness is extremely common in dying people. The cause is often multifactorial and not reversible. It can be a distressing problem and difficult to manage. The burden of investigations in a dying person is often best avoided, but some causes can be treated (eg, pain, urinary retention, dehydration). Terminal restlessness is often a 'pre-death event'.

Also known as: **terminal agitation, terminal delirium, terminal anguish, terminal distress**.

Definition

Delirium occurring in the last days of life is often referred to as terminal restlessness or agitation. In the last 24–48 hours of life, it is most likely caused by the irreversible processes of multiple organ failure.

Holistic considerations

Reflect on: Te Whare Tapa Wha principles (Durie 1994)

Emotional considerations:	How can emotional issues be identified and addressed at this time? Is there time to address these before the person dies?
Spiritual considerations:	How can feelings of hopelessness and helplessness (by the person and/or their family/whānau) be addressed? Would the person like to see / benefit from a chaplain visiting? How would such a visit affect the person, their perception of self and their lifestyle?
Social considerations:	Is the person safe where they are at the moment? Can they remain there until they die? What other support does the family/whānau need at this time?
Physical considerations:	How can we make this person safe? How is this symptom affecting the person's physical needs?

Management

Treat and/or remove possible causes of pain, for example, by:

1. regularly changing the person's position
2. checking their bladder/bowels to eliminate retention/impaction
3. ensuring their safety
4. involving the person and their family/whānau and providing them with explanations as required
5. using sitters
6. providing a low-stimulus environment, i.e. low-level noise and lighting
7. surrounding the person with familiar voices, pictures, belongings
8. providing gentle massage, aromatherapy, familiar music (volume low)
9. offering spiritual/religious guidance or support (if the person and/or their family/whānau have requested it)
10. lowering the person's bed
11. providing sensor mats
12. helping keep the person's body or room at a comfortable, soothing temperature
13. helping apply smoking or nicotine patch.

Agitation, delirium, restlessness management flow chart

Agitation / terminal restlessness present

Exclude:
- pain
- urinary retention
- faecal impaction
- spiritual distress

If conscious

Use first-line haloperidol *(the goal is to improve clarity)*

Prescribe and give PRN dose haloperidol 0.5 - 1mg Q1 hour PRN via subcutaneous line (maximum dose 5mg/24 hours).

(Do not use in Parkinson's disease)

If unconscious

Use first-line midazolam

Prescribe and give PRN dose midazolam 2.5 - 5mg Q30 min PRN via subcutaneous line.

Review within 24 hours if ≥ 3 PRN doses have been given, consider a CSCI

Maximum total daily dose of haloperidol 5mg/24 hours via a CSCI.

Midazolam 10 - 60mg/24 hours via a CSCI.

If haloperidol and midazolam combination is ineffective, continue midazolam but change haloperidol to levomepromazine (Nozinan®) 25mg/24 hours via CSCI and 6.25mg Q1 hour PRN via subcutaneous line.

Consider contacting palliative care team for guidance.

Agitation / terminal restlessness absent

Prescribe PRN dose of haloperidol 0.5mg Q1 hour PRN via subcutaneous line (maximum dose 5mg in 24 hours).

If agitation, delirium, or restlessness occur, change to 'PRESENT' guide

Anticipatory prescribing in this manner will ensure that in the last hours and days of life there is no delay responding to a symptom if it occurs.

For increasing medication requirements to manage agitation, delirium, restlessness contact
Waikato Hospital patients: 07 839 8691 or on-call Palliative Medicine Consultant via Waikato Hospital Operator
Community patients: 07 859 1260 (Hospice Waikato), after hours call on-call Palliative Medicine Consultant

Acknowledgement to Ministry of Health for sharing resource

Management of excessive respiratory tract secretions

Respiratory tract secretions are generally seen only in dying people who are too weak to expectorate and are no longer able to clear their oral and upper airway secretions. The pooled secretions in the oropharynx and bronchi vibrate as air moves over them. It is audible and is described as noisy, rattling, gurgling and unpleasant. It is often called the 'death rattle'. Excessive respiratory tract secretions have been observed in 23-92 percent of cases and are an indicator of impending death.

Definition

Classifications

- Type I due to salivary secretions.
- Type II due to accumulated bronchial secretions in the presence of pulmonary disease and infections, tumour, fluid retention or aspiration.

Studies suggest that people who develop noisy respirations have the following risk factors:

- Lung cancer
- Brain tumours
- Pulmonary diseases, ie, asthma, bronchitis, bronchiectasis
- Cardiac arrest
- Neuromuscular disorders, i.e. myasthenia gravis, Guillain-Barre syndrome
- Chest infections, ie, pneumonia
- Head and neck cancers
- Cystic fibrosis
- Cessation of steroids in cerebral involvement
- Heart failure

These situations are associated with an increase in oral, bronchial mucous and exudative secretions.

Assessment

1. Consider the person's diagnosis - does the person have the risk factors? Is the breathing noisy and rattly. There are no standardised assessment tools to classify or measure the intensity of secretions, but some research has used subjective noise scores.
2. Consider the distress of the person - are they restless or frowning?
3. Consider the distress of the person's family /whānau and carers - they may be anxious and fear the person is choking to death or drowning. Approximately half of those relatives and friends who witness it, as well as hospital staff, find the noise of respiratory tract secretions distressing.

Holistic considerations

Reflect on: Te Whare Tapa Wha principles (Durie 1994)

Emotional considerations: What does this symptom mean for the family/whānau?

Spiritual considerations: Are there any considerations that need to be taken into account around this time?

Social considerations: How does this symptom affect family /whānau?

Physical considerations:

Management

1. Anticipate problems if the person has the risk factors that increase airway secretions.
2. Reposition the person, often on their side in a semi-recumbent position, to facilitate postural drainage. Or raise the head of the bed and prop up the person with pillows.
3. Carefully assess hydration and reduce or cease parenteral fluids if required.
4. Explain the changes being observed in the dying person to the family and whānau. Communicate with compassion and sensitivity. Reassure the family the reason their loved one is not able to cough or clear their throat is due to their unconscious state - the person is not usually distressed.
5. Use distraction therapy, e.g. music, TV, family talking and reminiscing.
6. Use aromatherapy therapy, eg, any of the following essential oils in an aroma burner or vaporiser: eucalyptus, cypress, ylang ylang, lavender, lemon, lime, cypress, marjoram, cedarwood.
7. Regularly provide mouth and lip care. Wipe away any dribbling with tissues. Use appropriate mouth swabs, e.g. Den Tips® Disposable Oral Swabs, to gently wipe any loose secretions out of the person's mouth if they allow it.
8. If the person has been receiving supplementary oxygen, it may no longer be necessary and can be discontinued. If the person remains on oxygen and thick secretions are a problem, add humidity if the device allows it.
9. Suctioning is not normally used in palliative care. In some hospitals, tracheal aspiration may be performed by skilled personnel, clearing secretions before anticholinergic drugs are started - this remains a complex and difficult procedure.
10. Many studies indicate a need for further research in order to develop 'best practice' standards.

Excessive respiratory tract secretions management flow chart

Secretions present

↓

Explain symptoms to the family and whānau.

Re-position the person.

If persistent and causing distress:

↓

1. Give STAT dose

Hyoscine Butylbromide 20mg

Q2-4 hours via subcutaneous line

↓

2. Prescribe PRN dose

Hyoscine Butylbromide 20mg

Q2 hours PRN via subcutaneous line *(maximum of 120mg/24 hours)*

↓

Review within 6 hours

If symptoms persist and STAT dose was helpful, consider:

HYOSCINE BUTYLBROMIDE

40 - 80mg over 24 hours via CSCI *(Maximum total daily dose of 120mg / 24 hours)*

↓

If symptoms persist, contact the palliative care team for advice.

Secretions absent

↓

Review if the person has known risk factors for excessive secretions (as above).

These situations are associated with an increase in oral, bronchial mucous and exudative secretions.

↓

Prescribe PRN dose

Hyoscine Butylbromide 20mg

Q2 hours PRN via subcutaneous line *(maximum of 120mg / 24 hours)*

↓

If respiratory tract secretions occur change to **'PRESENT'** guide.

Anticipatory prescribing in this manner will ensure that in the last hours and days of life there is no delay responding to a symptom if it occurs.

For increasing medication requirements to manage breakthrough symptoms contact
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