Te Ara Whakapiri

Symptom management in the last days of life

Holistic care recommendations and anticipatory prescribing flow charts

SOUTH ISLAND ALLIANCE
best for people, best for system

South Island Alliance, December 2020. Review December 2022.

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.

Introduction

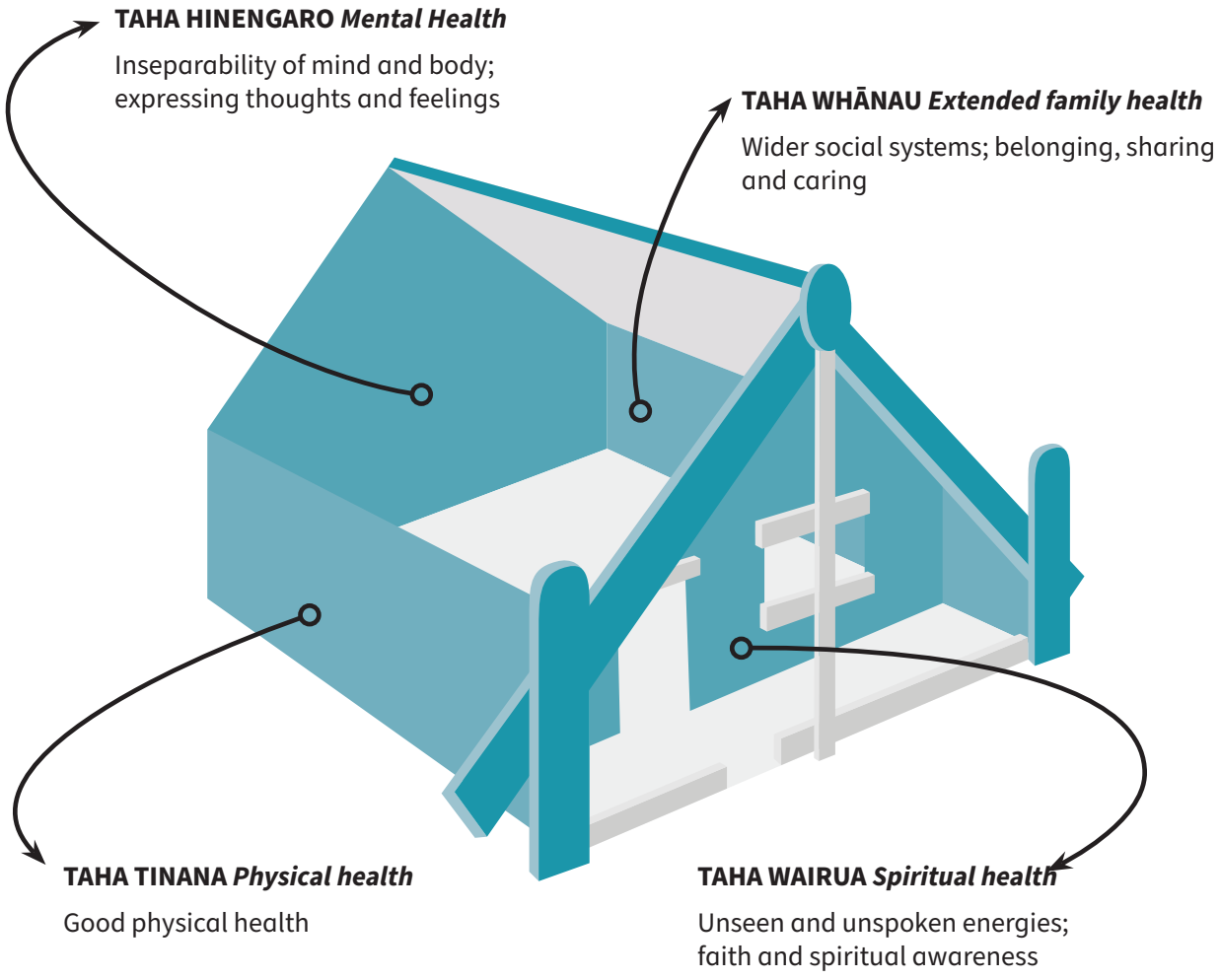
This document encompasses advice, suggestions and best practice wisdoms, aimed to optimise care for patients in their last hours and days of life. It focuses on five main physical symptoms that often require attention as people die; pain, agitation/delirium/restlessness, nausea/vomiting, dyspnoea/breathlessness and excessive respiratory tract secretions. It provides both holistic care recommendations and anticipatory prescribing flow charts for each symptom. There are a myriad of considerations that are integral to the provision of holistic (whole person) care.

Quality care of the dying demands knowledge, skill, compassion and courage. It requires us to be open and attentive to the unique needs and preferences of each person and their whānau both when things are straightforward, and when they are not. In addition to physical symptoms, we will be faced with psychological, social, spiritual and extended family preferences and concerns. If these are neglected, the patient's care will be compromised along with the experience of their loved ones.

Te Whare Tapa Whā

Māori philosophy toward health is based on a holistic health and wellness model called Te Whare Tapa Whā (see below). It recognises that health is underpinned by four dimensions that represent the basic beliefs of life and each wall is necessary to the strength and symmetry of the building. Attention to all four of these dimensions is essential at the end of life, and is why this model was chosen to provide the framework for Te Ara Whakapiri.

Care of the dying is both a responsibility and privilege. Te Ara Whakapiri is designed to help everyone get it right, every time.



Source: Durie (1998); Te Ara (2015)

Holistic care recommendations

Holistic care recommendations for each of the five main symptoms will provide carers (both professional and family) with useful tips, insights and suggestions to aid the person as they are dying. They will enhance confidence (knowing what to do is as important as knowing what medications to give) and will ensure better efficacy from medications and clinical interventions. 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 essentially a pharmacological framework for uncomplicated (normal) dying. These are intended to be used when symptoms have not previously been challenging to manage. There is one flow chart for each symptom except pain, where there is an additional chart for patients with significant renal impairment (as morphine cannot easily be used in advanced kidney disease). Underpinning the flow charts is the understanding that advice and support is always available from specialist palliative care services (e.g. Hospice) if and when needed. Normal dying should be within the capability of all services and organisations but when complexities arise, it is absolutely okay to ask for help. Contact details for the local specialist palliative care service are included on the flow charts for easy reference.

To supplement this document there are a range of other Te Ara Whakapiri resources available

- Recognising the dying patient flow chart
- Medical management planning – general principles
- Baseline assessment and preparation for dying (for completion by registered health care professionals)
- Ongoing care of the dying person (to guide and document the persons progress if they are dying in a health care facility)
- Home care in the last days of life (to guide and document the persons progress if dying in a private home)
- Discharge checklist (to be used when discharging a dying person from hospital or Hospice)

Additional resources

HealthPathways

- Community HealthPathways (localised to each DHB)
- Hospital HealthPathways (localised to each DHB)
- Allied Healthways (Canterbury only) - www.canterbury.alliedhealthways.org.nz
- Healthinfo - www.healthinfo.org.nz

Palliative Care Handbook

- www.hospice.org.nz/resources/palliative-care-handbook/

Hospice New Zealand

- www.hospice.org.nz/

CareSearch

- www.caresearch.com.au/caresearch/tabid/3429/Default.aspx

Holistic care recommendations for pain

Background

› Pain is strongly influenced by factors including emotional, spiritual and existential issues
› Anxiety, uncertainty and fear all worsen the experience of pain

Non-pharmacological care is extremely important

› Listen to the person's experience. Being with them and acknowledging their pain can help reduce it
› Ensuring the person is positioned comfortably, and repositioned when required, will help reduce stiffness and muscular aches
› Regular position changes are necessary to provide pressure relief
› Distraction can help reduce pain by helping the person to relax. Distraction therapy comes in many forms, e.g. guided audio, TV, music, reminiscing
› Heat and/or coolness can often help ease pain, e.g. by applying heated or chilled packs. Care should be taken with the temperature to prevent burning
› Massage or touch can be beneficial. Something as simple as a gentle hand massage can be comforting
› Prayer, mindfulness and meditation can be beneficial in reducing pain or existential suffering, depending on the person's spiritual or cultural perspectives

Refer to: Pain in patients with no/limited prior pain
Anticipatory prescribing flow chart for the last days of life

Pain in patients with renal impairment
Anticipatory prescribing flow chart for the last days of life

Pain in patients with no/limited prior pain

Anticipatory prescribing flow chart for the last days of life

eGFR > 30mL/min or renal function not known and no expectation of significant renal impairment

NO → If eGFR <30mL/min see **Pain in patients with renal impairment**

YES

Is the person already taking morphine, oxycodone or transdermal fentanyl?

YES

Morphine/Oxycodone

- Convert to 24 hour dose via CSCI*
- Prescribe PRN dose of morphine or oxycodone Q1 hourly via subcutaneous line. Occassionally doses may be charted Q30 minutes PRN
- Recommend a maximum of 8 PRN doses/24 hours

Fentanyl

- Continue with transdermal fentanyl
- Prescribe fentanyl Q1 hourly PRN via subcutaneous line (occasionally Q30 minutes) to a maximum of 100 mcg (2mLs). Maximum of 8 PRN doses/24 hours

See calculations

NO

Prescribe morphine 2.5–5mg Q1 hourly PRN via subcutaneous line (consider lower dose for frail elderly eg. 1–2mg Q2 hourly)

Review within 12 hours
If pain occurs/persists, convert to 24 hour dose via CSCI*

Review within 24 hours

Morphine/oxycodone

If pain persists and three or more PRN doses have been required

- Increase the opioid in CSCI by the total additional dose required in the last 24 hours
- Increase the PRN dose accordingly
- Review again within 24 hours

If pain is incident pain only (e.g. on turning), continue with current CSCI dose and give PRN dose via subcutaneous line prior to activity

Fentanyl

For advice regarding titration and conversions, discuss with hospice or palliative care team

Calculations

Morphine/oxycodone

To CONVERT from oral morphine to subcutaneous morphine: subcutaneous dose = 1/2 oral dose

To CONVERT from oral oxycodone to subcutaneous oxycodone: subcutaneous dose = 2/3 oral dose

To CONVERT to 24 hour *continuous subcutaneous infusion (CSCI): total (regular + PRN) subcutaneous doses required in last 24 hours

To CALCULATE PRN subcutaneous doses (morphine or oxycodone): prn dose = 1/6 total 24 hour dose, Q1 hourly prn

Fentanyl

- For patients established on transdermal fentanyl the subcutaneous PRN dose is roughly equivalent to the **hourly** transdermal dose, to a maximum of 100 mcg (2mLs) e.g. 25 mcg/hr patch = 25 mcg subcutaneously PRN Q1 hourly

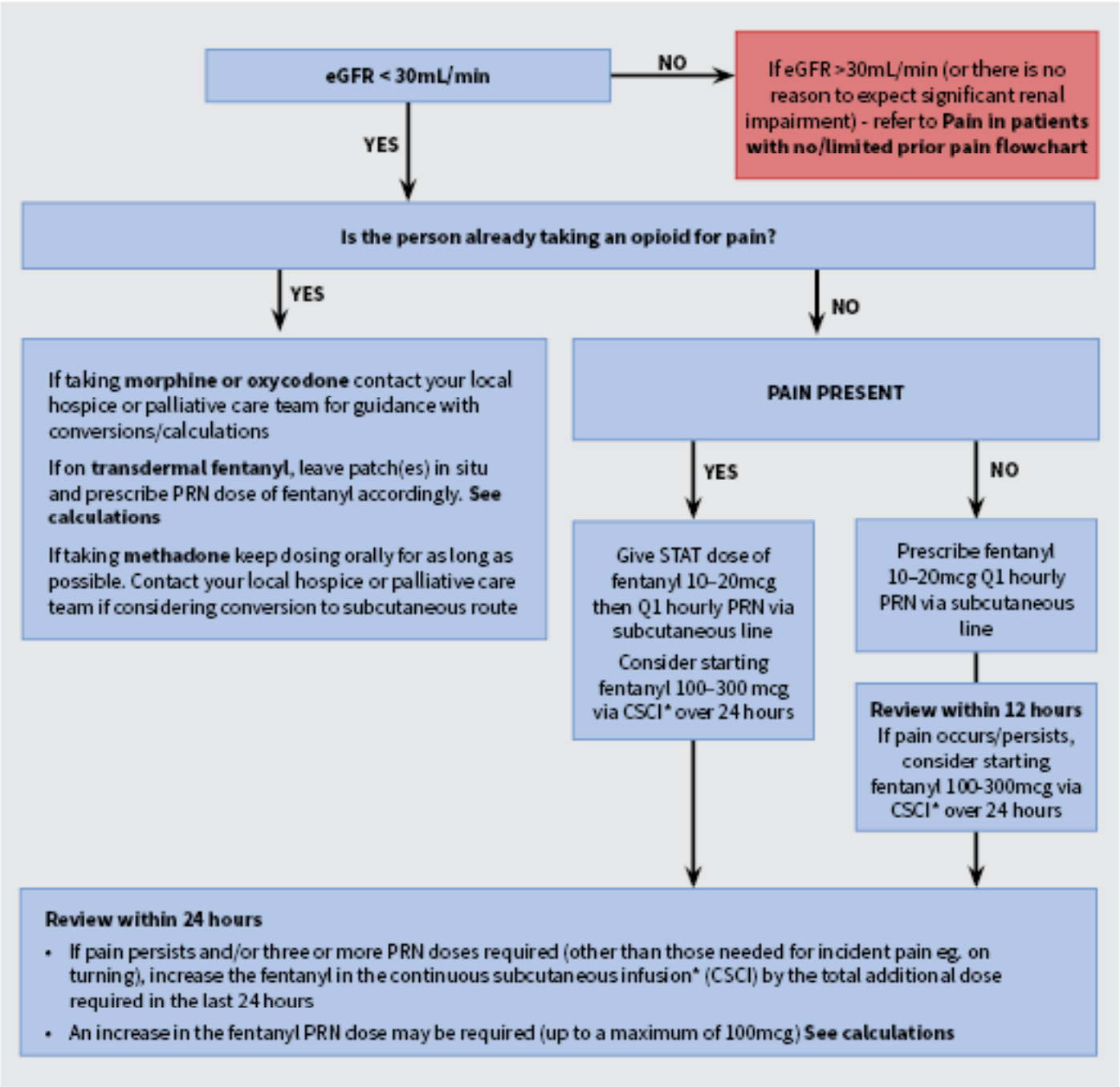
If symptoms persist or support required, contact your local hospice or palliative care team.

Anticipatory prescribing ensures that in the last hours and days of life there is no delay responding to a symptom if it occurs. Please refer to the Te Ara Whakapiri Holistic care recommendations for further information.

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.

Pain in patients with renal impairment

Anticipatory prescribing flow chart for the last days of life



Fentanyl calculations

- For patients established on transdermal fentanyl, the subcutaneous PRN dose is roughly equivalent to the **hourly** transdermal dose, to a maximum of 100 mcg (2mLs) e.g. 25 mcg/hr patch = 25 mcg subcutaneously PRN Q1 hourly
- For all other advice regarding titration and conversions, discuss with hospice or palliative care team

If symptoms persist or support required, contact your local hospice or palliative care team.

Anticipatory prescribing ensures that in the last hours and days of life there is no delay responding to a symptom if it occurs. Please refer to the Te Ara Whakapiri Holistic care recommendations for further information.

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Holistic care recommendations for agitation, delirium and restlessness

Background

› Changes in consciousness and behaviour are common in the hours and days before death
› Some behaviours can be explained by cultural or spiritual norms (e.g. talking to spirits)
› Agitation and restlessness during the last days of life is distressing for everyone
› The cause of delirium is often multifactorial
› Delirium can be difficult to manage and is usually irreversible in the dying phase
› Terminal restlessness is often a 'pre-death event'
› Multiple investigations in a dying person are usually best avoided, although some causes can be treated e.g. pain, urinary retention, dehydration

Non-pharmacological care is extremely important

› Surround the person with familiar voices, pictures and belongings
› Involve the family/whānau in care. Suggest a roster so someone familiar is with the person if at all possible
› Provide a low-stimulus environment, e.g. low-level noise and lighting
› Consider urinary retention and toilet as appropriate
› Maximise bed comfort. Regular changes of position can be helpful
› Gentle mouth cares are essential, if tolerated
› Avoid too many blankets as this can cause overheating
› Ensure safety by lowering the person's bed and providing sensor mats
› Consider use of close observation (sitter)
› Explore use of gentle massage, aromatherapy
› Consider whether providing music or turning on the radio would be helpful
› Offer spiritual/religious guidance or support, as per the wishes of the person and their family/whānau

Refer to: Agitation, delirium and restlessness
Anticipatory prescribing flow chart for the last days of life

Agitation, delirium and restlessness

Anticipatory prescribing flow chart for the last days of life

AGITATION/DELIRIUM/ RESTLESSNESS PRESENT

IF CONSCIOUS
Use haloperidol as first-line.
Haloperidol 0.5mg STAT via subcutaneous line then 0.5–1mg Q1 hourly PRN via subcutaneous line (maximum dose 5mg/24 hours).

Review within 6 hours
If ineffective change to midazolam 2.5mg STAT via subcutaneous line then 2.5–5mg PRN Q30 mins via subcutaneous line

IF UNCONSCIOUS
Use midazolam as first-line.
Give Midazolam 2.5mg STAT via subcutaneuos line, then 2.5–5mg PRN Q30 mins via subcutaneous line

Review within 6 hours
If ineffective change to levomepromazine (Nozinan™) 6.25mg STAT via subcutaneous line and 6.25mg PRN Q4–6 hourly via subcutaneous line

If multiple PRN doses have been necessary, consider converting to continuous subcutaneous infusion (CSCI).
Possible options include:

- Haloperidol only - 3mg/24 hours (max dose 5mg/24 hours)
- Midazolam only - 10–30mg/24 hours (max dose 60mg/24 hours)
- Haloperidol + midazolam
- Levomepromazine (Nozinan™) only - 12.5 –25mg/24 hours (max dose 50mg/24 hours)
- Levomepromazine (Nozinan™) + midazolam

Continue PRN subcutaneous doses as above.

AGITATION/DELIRIUM/ RESTLESSNESS ABSENT

Prescribe PRN haloperidol and/or PRN midazolam.
Haloperidol 0.5mg Q2 hourly PRN via subcutaneous line (max dose 5mg/24 hours).
Midazolam 2.5mg Q30 mins PRN via subcutaneous line (max dose 20mg/24 hours).

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

Pre-exsisting conditions

- In conditions such as dementia with BPSD (Behavioural and Psychological Symptoms of Dementia), many of the routinely used medications cannot be given subcutaneously so alternatives need to be prescribed.
- For patients on large doses of background anxiolytics, higher doses of benzodiazepines may be required at the end of life.

If symptoms persist or support required, contact your local hospice or palliative care team.

Anticipatory prescribing ensures that in the last hours and days of life there is no delay responding to a symptom if it occurs.
Please refer to the Te Ara Whakapiri Holistic care recommendations for further information.

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.

Holistic care recommendations for nausea/vomiting

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 are continued

Non-pharmacological care is extremely important

› Provide a well-ventilated room, circulating fresh air from a fan or open window
› Try to eliminate sights and smells that cause nausea
› Prioritise mouth care as poor oral hygiene will make nausea impossible to control
› Ensure constipation and/or faecal impaction is identified and managed
› If the person is still eating, offer small amounts of bland foods, fluids and snacks at room temperature
› It may be helpful to establish a favourite food or drink that could provide pleasure in small quantities. This is something that the family/whānau can bring in
› Be careful with offering food or fluid if the person is unable to swallow as this may cause distress. Ensure the patient is in an upright position if possible to minimise choking and reduce the risk of aspiration. Providing small tastes may still be possible and welcome
› Help family/whānau understand that a decreased need for food and fluids is a totally natural and normal part of the dying process
› Providing sips of lemonade, ginger ale, peppermint tea or another fluid of choice can help
› Distraction therapy such as reminiscing, music, TV, radio etc. can help relieve stress and give a sense of wellbeing

Refer to: Nausea/vomiting
Anticipatory prescribing flow chart for the last days of life

Nausea/vomiting

Anticipatory prescribing flow chart for the last days of life

Is the person taking one or more anti-emetic?

YES

Convert oral anti-emetics to subcutaneous. Administer either as regular bolus doses via subcutaneous line or via CSCI* e.g.

- haloperidol 0.5 – 1mg nocte or BD or 2 – 5mg/24 hours
- and/or metoclopramide 10mg TDS/QID or 30 – 60mg/24 hours
- and/or Cyclizine 100mg – 150mg/24 hours (cyclizine is generally not recommended to be given as a subcutaneous bolus)

Ensure a subcutaneous PRN anti-emetic is also prescribed

No

Prescribe an anti-emetic via subcutaneous line e.g.

- haloperidol 0.5mg Q4 hourly PRN (maximum dose 5mg/24 hours)
- and/or metoclopramide 10mg Q6 hourly PRN (maximum dose 40mg/24 hours)

If effective, consider converting to 24 hour dose via CSCI*. Possible options include:

- Haloperidol only
- Metoclopramide only
- Haloperidol +/- metoclopramide +/- cyclizine

Ensure a subcutaneous PRN anti-emetic is also prescribed

Review within 6 hours

If nausea/vomiting persists, change to Levomepromazine (Nozinan™) 3.125mg–6.25mg Q4–6 hourly PRN via subcutaneous line.

- If effective convert to *continuous subcutaneous infusion (CSCI), max dose 25mg/24 hours
- Ensure subcutaneous PRN Levomepromazine (Nozinan™) is also prescribed

If symptoms persist or support required, contact your local hospice or palliative care team.

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Holistic care recommendations for dyspnoea/breathlessness

Background

› Dyspnoea is a subjective symptom and can be extremely distressing
› Experience of dyspnoea does not always correlate with the physical signs
› For unconscious people, the health care professional will be reliant on relevant physical clues and input from the family/whānau to assess the level of distress i.e. tachypnoea (fast breathing), tachycardia (fast heart rate/pulse) laboured breathing and cheyne-stokes respiration may not necessarily be an indication of distress, unless accompanied by signs such as sweating, grimacing or agitation

Non-pharmacological care is extremely important

› Provide support with pillows. Supporting arms on pillows helps release tension in the shoulders as does head and neck support
› Open a window or use a fan with a gentle flow of air across the person's face
› The use of non-restrictive light bed linen can be helpful
› Plan nursing interventions to ensure a balance between rest and activity so as not to exacerbate breathlessness
› Distraction therapy such as relaxing music of the person's choice can be very effective
› The use of massage or touch can be beneficial. Something as simple as a gentle hand or foot massage can be very relaxing
› Oxygen at the end of life is usually unnecessary and can safely be discontinued
› Reassure family/whānau that changes in breathing are normal in the last hours/days of life and that care now focuses on monitoring for, and responding to, signs of distress

Refer to Dyspnoea/breathlessness
Anticipatory prescribing flow chart for the last days of life

Dyspnoea/breathlessness

Anticipatory prescribing flow chart for the last days of life

eGFR > 30mL/min or renal function not known and no expectation of significant renal impairment

NO → If eGFR <30mL/min use opioids with caution and ensure subcutaneous midazolam is available PRN (see below)

YES

DYSPNOEA/BREATHLESSNESS PRESENT

Is the person already taking morphine or oxycodone?

YES

CONVERT morphine/oxycodone to 24 hour dose via CSCI*.

Prescribe PRN dose of morphine/oxycodone Q1 hourly via subcutaneous line

see calculations

NO

Morphine is the gold standard

Prescribe PRN morphine 2.5–5mg Q1 hourly via subcutaneous line (consider lower dose for frail elderly eg. 1–2mg Q2 hourly)

Review within 6 hours

If dyspnoea persists, and opioid dose(s) were helpful, increase (or initiate) the opioid in CSCI* by total PRNs required in previous 24 hours. Increase the PRN dose accordingly.

see calculations

If the person is still dyspnoeic, consider adding midazolam 5–15 mg /24 hours via CSCI, plus 2.5mg PRN Q1 hourly via subcutaneous line

YES

DYSPNOEA/BREATHLESSNESS ABSENT

Morphine is the gold standard

Prescribe PRN dose of morphine 2.5–5mg Q1 hour via subcutaneous line (consider lower dose for frail elderly eg. 1–2mg Q2 hourly)

If dyspnoea/breathlessness occurs, change to PRESENT guide

Calculations

To CONVERT from oral morphine to subcutaneous morphine: subcutaneous dose = 1/2 oral dose

To CONVERT from oral oxycodone to subcutaneous oxycodone: subcutaneous dose = 2/3 oral dose

To CONVERT to 24 hour *continuous subcutaneous infusion (CSCI): total (regular + PRN) subcutaneous doses required in last 24 hours

To CALCULATE PRN doses (morphine or oxycodone): PRN dose = 1/6 total 24 hour dose, Q1 hourly PRN

If symptoms persist or support required, contact your local hospice or palliative care team.

Anticipatory prescribing ensures that in the last hours and days of life there is no delay responding to a symptom if it occurs. Please refer to the Te Ara Whakapiri Holistic care recommendations for further information.

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Holistic care recommendations for excessive respiratory tract secretions

Background

› This is commonly referred to as the ‘death rattle’
› It is experienced by dying people who are too weak to cough or are unconscious. These people are no longer aware of or 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 to listen to

Non-pharmacological care is extremely important

› Raise the head of the bed and turn the person slightly to one side or tilt their head. This can help lessen the noise. Small changes of position will often make a big difference
› Reassure the family/whānau that the changes in secretions are part of the normal dying process
› Explain that the person is unconscious and therefore unable to cough or clear their throat. They are usually unaware of the sensation or noise (similar to when people snore in their sleep)
› The family/whānau might appreciate some background music
› If the secretions are malodourous, the use of aromatherapy can be very helpful
› Provide regular mouth and lip care. The family/whānau may like to help with this
› If the person needs to remain on oxygen and thick secretions are a problem, consider humidification
› Suctioning is not normally used at the end of life. Occasionally oral suctioning can help clear loose secretions out of the mouth but deep suctioning is best avoided as it can exacerbate secretions

Refer to Excessive respiratory tract secretions
Anticipatory prescribing flow chart for the last days of life

Excessive respiratory tract secretions

Anticipatory prescribing flow chart for the last days of life

IT IS IMPERATIVE THAT REPOSITIONING AND FAMILY EDUCATION/SUPPORT ARE PRIORITISED.

Anti-cholinergic medication may not alleviate this symptom.

Prescribe
Hyoscine butylbromide (Buscopan™) 20mg
Q2 hourly PRN via subcutaneous line (maximum of 120mg/24 hours).

↓

SECRETIONS PRESENT

↓

Consider stat dose and assess effect.

↓

Review within 6 hours:

If symptoms persist and initial dose(s) were helpful, consider hyoscine butylbromide (Buscopan™) 40–80mg over 24 hours via continuous subcutaneous infusion (CSCI).

If hyoscine butylbromide (Buscopan™) is ineffective, do not persist as it causes excessive dryness.

If symptoms persist or support required, contact your local hospice or palliative care team.

Anticipatory prescribing ensures that in the last hours and days of life there is no delay responding to a symptom if it occurs. Please refer to the Te Ara Whakapiri Holistic care recommendations for further information.

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