Navigating the last days of life: a general practice perspective

Navigating the last days of life can feel like an insurmountable challenge; both for people with a terminal illness and for the loved ones who support them. "*Te Ara Whakapiri: Principles and guidance for the last days of life*" is a resource developed by clinicians and published by the Ministry of Health (Manatū Hauora) to assist this process. It outlines key recommendations for providing adults with quality and consistent care during their last days of life, which encompasses all aspects of Hauora wellbeing. The following article aims to contextualise this information for use in general practice and other community settings.

- *We recognise that there are diverse and nuanced scenarios relating to end of life care in the community. This resource is broadly tailored to the setting of a patient receiving care in their home in their last days of life, regardless of the underlying cause, supported by their family/whānau and the general practice and community health care team. Not all recommendations will be applicable for individual patients and their circumstances, and not all general practices will have the resources or capacity to directly provide all of the services listed, e.g. home visits.*
- *This resource is intended to cover the principles of care when a person is in their last days of life; it does not cover all aspects of palliative care and is not restricted to care provided within specialist units such as hospices.*
- *The term "family/whānau" has been used throughout this resource to broadly encompass anyone close to the person, who is not part of their health care team, who will provide care and support in their last days of life.*
- *Some people may choose, and be eligible for, assisted death as per the End of Life Choice Act 2019. This process is not initiated when a person is in their last days of life, therefore this resource does not cover assisted death. Clinical circumstances may mean that some people who have chosen assisted death are not able to give informed consent at the planned time and are therefore unable to proceed, or the application may not have been completed before they entered their last days. This change in plan may be distressing both to the patient and their family/whānau and should be considered in mental health/wellbeing and bereavement assessments. For further resources on assisted dying, see:* ***www.tewhatuora.govt.nz/for-the-health-sector/assisted-dying-service/information-for-health-professionals***
- *This resource does not cover last days of life care in children. For further information on paediatric palliative care, see:* ***starship.org.nz/guidelines/allow-natural-death-te-wa-aroha/****.*

KEY PRACTICE POINTS:

- Recognising that a person is in the last days of life is often associated with an element of uncertainty. This process relies on clinical judgement and previous experience as symptoms/signs may be subtle and variable. Clinical deterioration may also indicate a life-threatening but potentially recoverable condition, however, deciding whether to investigate or initiate treatment depends on individual circumstances.
- Communication with people in the last days of life and their family/whānau should be clear, sensitive and respectful, recognising their individualised needs and including shared decision-making wherever possible
- All decisions relating to end of life care should be documented and considered in the context of any existing advance care plan or advance directive
- The principles of Te Whare Tapa Whā should be used as a framework to guide and deliver individualised care decisions; this not only includes symptom management and physical care, but also consideration of mental/emotional, family/social and spiritual wellbeing. Be conscious that people's perspectives and choices may change as their condition deteriorates. Ensure there is ongoing review and discussion about care options.
- Three key components underpin care for people in their last days of life:
  1. **Baseline assessment** – identify the lead health practitioner and establish contact protocols, including what to do out of hours or if they are unavailable. Assess physical care needs and requirements for symptom management (including anticipatory medicine prescribing). Also identify any mental/emotional, cultural/religious/spiritual issues or needs for both the person and family/whānau. This proactive process helps identify whether the person has a level of need that exceeds the capacity of the primary care provider.
  2. **Ongoing assessment** – support the family/whānau in implementing an individualised care plan that includes regular tracking of the person's condition; this enables all aspects of care to be monitored and addressed in a timely manner (not just physical symptoms)
  3. **Care after death** – equip family/whānau with practical advice on how to recognise when death approaches and what to do when it occurs. Clinical responsibilities include verification of death, assessing the bereavement risk of family members and recognising when further support is required.
- Best practice care for people in their last days of life should ideally be multidisciplinary; family/whānau should be made aware of all support services and facilities available to them

Facilitating a "*good death*" in the community

Death is the inevitable closing chapter in a person's life. There are countless narratives that can lead people to this destination: for some, the possibility of death has been long anticipated due to chronic illness, whereas others may face it unexpectedly. The term "*last days of life*" specifically relates to the period of time in which death is considered imminent (Figure 1).[1] Given the unpredictable nature of human perseverance and diverse pathways leading to death, the duration of this period can vary, and may be measured in hours or days.[1] For many, the concept of having a "*good death*" is highly dependent on how the last days of life unfold, and the manner in which a person dies often persists in the memories of those left behind.[2]

End of life care should ideally be delivered as part of a multidisciplinary clinical service.[3] In New Zealand, an estimated 31% of people die in residential aged care facilities and 22% die in private residences.[4] In these situations, general practices may be tasked with helping people and their family/whānau navigate the last days of life; either as the primary provider of end of life care services or in collaboration with a multidisciplinary team.[4] The general practice team will often work closely with district nurses, aged residential care facility staff, hospice services and in some cases, ambulance services, when providing end of life care.

General practitioners, nurse practitioners and practice nurses are already integrated into the pathways that lead to end of life care; they are often familiar with the patient's history, provide clinical care and support throughout their lifetime and are well positioned to identify those with a life-limiting illness (particularly as people begin seeking more regular care). As New Zealand's population ages, the role of the general practice team within this process will inevitably increase. Terminally ill people should be provided with a consistent standard of care, however, there are considerable challenges that primary care health professionals face when trying to provide end of life care in the community, including:[5]

- Funding and resource limitations
- Capacity and time constraints
- Access to training and guidance

New Zealand-specific guidance is now available

In 2017, "***Te Ara Whakapiri: Principles and guidance for the last days of life***" was published by the Ministry of Health (Manatū Hauora) providing a uniquely New Zealand perspective to guide best practice care of people in their final days of life.[1] Specific aspects of this work were **updated in 2020**.[6]

Te Ara Whakapiri details essential components and considerations, flowcharts and checklists, for providing quality and consistent care for adults in their last days of life, regardless of the setting, e.g. home, a residential care facility, hospice or hospital.[1] It also outlines various overarching principles relating to the delivery of end of life care and the health system(s)

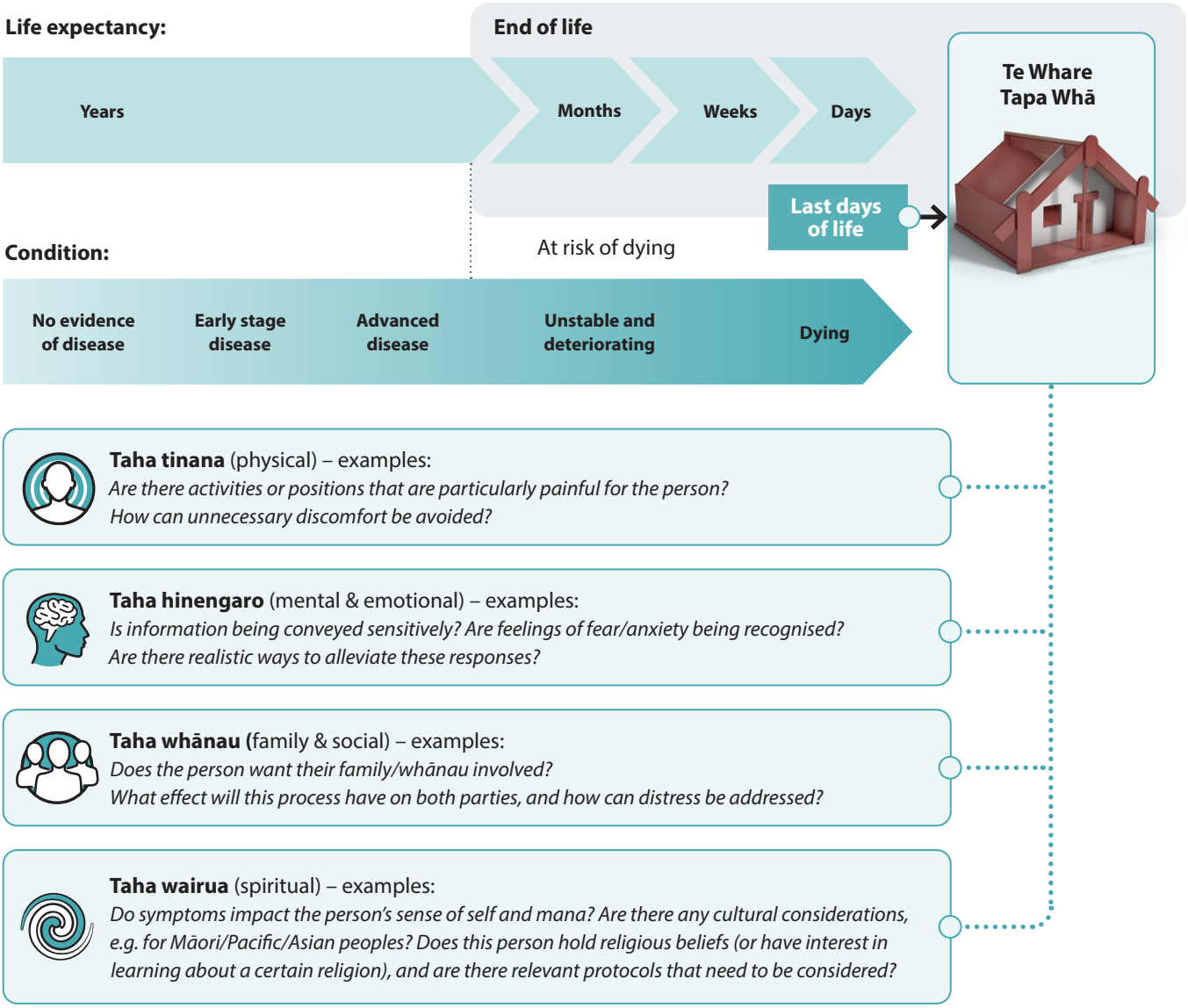


Figure 1. The end of life and last days of life. *Adapted from Te Ara Whakapiri, Ministry of Health – Manatū Hauora.*[1]

facilitating this.[1] While certain concepts are dependent on health policy and system-level action, those most relevant to primary care professionals include that:

Care should meet the individualised needs of the person and their whānau.[1] People in their last days of life may experience physical discomfort, in addition to psychosocial and spiritual distress; factors that are often interconnected.[7] However, no two journeys leading to the last days of life are the same. Each person's unique background gives rise to diverse perspectives, challenges and coping abilities. The universal principles of Te Whare Tapa Whā (Figure 1) can be used as a framework to guide and deliver individualised care across all dimensions of a person's wellbeing.[1,8]

All information relating to the status of people in their last days of life, their care plan and treatment should be communicated clearly and respectfully.[1] Shared decision-making should always be considered; care providers must actively seek input from the person and their family/whānau and create opportunities for them to provide feedback.[1] For further information, see: "Tips for communication with family/whānau".

Details of conversations and decisions should be documented and considered in the context of any existing advance care plan or advance directive(s).[1] See: "A reminder to think ahead: advance care planning".

Family/whānau should also be supported. It is important to pre-emptively discuss with the family/whānau their role, including how they can be involved in care, potentially difficult decisions (e.g. relating to feeding and hydration, discontinuing non-essential medicines) and physiological changes to look for that may indicate impending death (so they can be prepared).[1] Following death, bereavement risk should also be considered, and support arranged if necessary (see: "Assessing family/whānau bereavement risk").[1]

A reminder to think ahead: advance care planning

A patient's transition into the last days of life can be simplified through proactive discussions that prioritise their autonomy and decision-making while they are still competent and have time to carefully consider their options. This process is known as advance care planning and should be strongly encouraged in all patients with a terminal illness, and followed up to ensure it has been completed.

Advance care planning helps to establish the person's preferences and goals for care according to their beliefs, values and lived experience.[9] This approach aims to reduce the burden of decision-making, uncertainty and the likelihood of unwanted interventions at the end of life.[9] Discussions around these topics can be challenging, evolve over multiple consultations and can include the family/whānau if the person wishes.[9] This process may also result in the documentation of specific **advance directives**, particularly if the person has strong views regarding specific medical interventions, or the establishment of an enduring power of attorney (if not already appointed).[9] Advance care plans and advance directives should be signed by the patient and the lead health practitioner, dated and a copy readily available to be shared with any health provider involved in the patient's care;[9] this is especially useful if ambulance services are required or other health providers not familiar with the patient become involved in delivering acute care.

For advance care planning resources (including a template for guiding conversations and documenting preferences, and training material for health professionals), see: **www.hqsc.govt.nz/our-work/advance-care-planning/**

A guide to assist advance care planning with Māori patients and their whanāu has been developed: "He Waka Kakarauri: A model for engaging Māori in Advance Care Planning (ACP) conversations", available from: **www.northlanddhb.org.nz/our-services/a-z/he-waka-kakarauri/?url=/Services/AZ/M%C4%81oriinAdvanceCarePlanningACPconversations.aspx**

Baseline assessment and establishing a care plan

The baseline assessment provides an opportunity to comprehensively evaluate the needs of the patient (Figure 2); if these needs exceed the resources or capacity of the primary care provider, the patient should be referred to a specialist palliative care service.[1]

For a comprehensive checklist covering essential aspects of a baseline assessment for people in their last days of life, **click here**.

Recognising that a person is dying

Clinical judgement and experience is used to determine when a person is approaching the last days of life.[1] However, recognising this transition can be a significant challenge regardless of the care setting as:[1, 10, 11]

- Symptoms and signs can be subtle and may vary depending on the patient's underlying condition(s), e.g. profound weakness, changes in respiratory patterns and mental state, reduced food/fluid intake (see Figure 2 for a comprehensive list)
- Clinical deterioration may also indicate a life-threatening but potentially recoverable condition, e.g. opioid toxicity, infection or hypercalcaemia. The decision to investigate or treat depends on individual clinical circumstances, patient/family/whānau wishes or advance directive(s).

To access the "Recognising the dying person flow chart", click **here**.

As such, there is likely to be an element of uncertainty during this process. In general, the possibility of incorrectly identifying this transition is outweighed by the importance of facilitating timely/open discussions and redirecting care towards individualised comfort and support.[1] This also provides the person and their family/whānau with an opportunity to understand and process the possibility of imminent death.[1] End of life conversations can be difficult depending on the person's history, cultural values, beliefs and attitudes, but are best facilitated using open and honest communication (see: "Tips for communication with family/whānau").[1, 2]

If a person's level of consciousness, functioning/mobility, oral intake or ability to perform self-care later improves after initially deciding they were in the last days of life, a reassessment of the current care plan should be performed to ensure it remains suitable.[10] The person and their family/whānau should also be given an opportunity to express any concerns.

Recognise the person is dying or approaching the last days of life

General features:

- General deterioration, including profound weakness
- Reduced food/fluid intake
- Difficulty swallowing
- Predominantly bed-bound (following progressive decline over days/weeks)
- Peripheral shutdown, i.e. cold hands and feet
- Poor response to treatments
- Changing emotional state, including anxiety, near-death awareness, reminiscing, social withdrawal

More definitive features:

- Increased drowsiness/sleepiness, reduced consciousness or cognition, delirium, terminal restlessness
- Pallor of nose/top of ears, increased respiratory and mandibular movements, relaxed forehead, hyperextension of the neck
- Increased cyanosis and mottling of lips/fingers
- Cardiovascular changes, e.g. tachycardia, bradycardia, hypotension
- Respiratory changes, e.g. persistent secretions in pharynx/trachea/bronchus, Cheyne-Stokes, ataxic breathing

Perform a baseline assessment

Taha tinana (physical wellbeing)

- Identify the lead health practitioner (e.g. the GP) and establish clear lines of communication
- Assess physical needs
- Review current management and consider prescribing anticipatory medicines
- Ensure the person is aware of their changing condition
- Discuss aspects of the persons care, including provision of food and fluids as well as the availability of equipment to support their care needs
- Consider cardiac devices, e.g. ICD or ventricular assist device, and if these should be deactivated
- Advise any other relevant agencies of the person's deterioration

Taha hinengaro (mental wellbeing)

- Assess the person's current mental state and their coping strategies
- Discuss the person's preferences for care, whether an advance care plan/directive is in place and whether the person has an enduring power of attorney (EPA)

Taha whānau (family and social wellbeing)

- Identify any communication barriers; consider involving an interpreter, if required
- Ensure the family/whānau is aware of the person's changing condition
- Discuss family customs, traditions and cultural needs (see below)
- Provide information to the family/whānau about support and facilities

Taha wairua (spiritual wellbeing)

- Provide an opportunity for the person and family/whānau to discuss what is important to them, particularly cultural and spiritual beliefs or practices.
- Incorporate these factors into the care plan, where possible, or co-ordinate access to specialised support, e.g. Kaumātua,Kaiāwhina, Whānau Care/Pacific Island Services, chaplains

Can needs be met with resources/capacity available in primary care?

Yes → **Continue with community-based care**

No → **Refer to specialist palliative care service**

GP = General Practitioner; ICD = Implantable cardioverter-defibrillator

Figure 2. General overview of a baseline assessment for people in the last days of life.[1, 10, 11]

Determine roles and establish clear lines of communication

After determining that a person is likely to be in their last hours or days of life, a lead health practitioner should be identified/documented (if not already designated) and a clear process established regarding when and how to contact them.[1] Ensure contingencies are in place for support both within and outside working hours; a designated alternative contact should be identified, which may include services outside of general practice, e.g. secondary care, palliative care, district nurses, pharmacy, and in some cases paramedicine/ambulance services.

Read more In the community, the "lead health practitioner" will usually be the person's general practitioner or nurse practitioner.[1] The lead health practitioner may liaise with other members of the general practice team (e.g. practice nurses under standing orders) or other health providers (e.g. district nurses, hospice nurses, palliative care clinician) to help support family/whānau in delivering at-home care, e.g. setting up syringe drivers.[12] Arrangements for additional support (e.g. presence of a night nurse or caregiver, volunteer workers) differs across the country – contact your primary health organisation (PHO) or local hospice for further information. **Extended Care Paramedics** (ECPs) are increasingly becoming involved in supporting general practice and hospice teams deliver palliative and end of life care in the community. ECPs are paramedics who have completed additional postgraduate training focused on supporting patients with urgent unscheduled community care needs; currently, these services are mostly based in urban areas, however, work is being undertaken to expand availability into rural and remote settings (e.g. via car-based ECP services).

N.B. People recognised as being in their last days of life may already have been in a hospice or residential care facility before a decision is made to return to their home; in such cases, multidisciplinary support plans and roles may already be established.[12]

The lead health practitioner should in turn identify and document who the key spokesperson and/or first contact is from within the family/whānau, as well as whether there is an enduring power of attorney (and if this has been, or should be, activated).[1] Regular communication with nominated people is essential, particularly if care plan implementation takes place at home.

Establishing a strong working relationship with local palliative care or hospice teams should be a priority in primary care, particularly for general practices with high numbers of older patients. This collaborative approach is particularly important when dealing with patients who have complex needs, as it enables timely discussion and advice to provide the best support possible.

Assess the person's physical needs

There are five main symptoms that need to be proactively considered for every dying person: pain, nausea/vomiting, dyspnoea (breathlessness), respiratory tract secretions and delirium. A physical needs assessment can help identify the priorities of care, providing practical information on which symptoms are most likely to cause the person discomfort and distress, and what additional assistance may be required.[1]

This evaluation may consider:[1, 10]

- **Level of consciousness**
- **Pain severity and type.** Consider physical signs of pain, e.g. facial grimacing, restlessness, tachycardia.
- **Functional status**, e.g. swallowing difficulties, balance problems and falls risk
- **Skin integrity**, e.g. pressure injuries, skin tears, skin dryness, ulceration, infections
- **Gastrointestinal/genitourinary complaints.** Nausea, vomiting and anorexia are common. Abdominal fullness may indicate constipation or urinary retention. Consider catheterisation if not already in place.
- **Respiratory symptoms**, e.g. dyspnoea, respiratory tract secretions, cough
- **Neurological and psychiatric features**, e.g. delirium (which may include agitation and terminal restlessness), confusion, insomnia, fear, anxiety/depression

Not all people in their last days of life are able to communicate information about their physical needs or goals; include family/whānau in discussions, if possible (particularly if they are the ones who will be primarily delivering care).[1]

Discuss symptom management and prescribe anticipatory medicines

People in their last days of life can present with a wide range of symptoms that may change over time; this should be anticipated where possible and a management plan put in place.[1]

Non-pharmacological management strategies should be used as much as possible, particularly if adverse effects of medicines are a concern or if people are wanting to "*die a more natural death*".[13, 14] Examples include setting up a comfortable environment/atmosphere, playing music, using relaxation techniques (e.g. deep breathing), and regularly repositioning the person if possible. However, pharmacological management is invariably required. Anticipatory medicine prescribing is usually implemented for people choosing to die at home to ensure carers can provide timely symptom relief without the need for in-person clinician assessment. Medicine regimens can sometimes be complicated as symptoms may occur concurrently, and the recommended medicines may have overlapping indications (e.g. opioids are used for both pain

and dyspnoea),[6] or interact (e.g. opioids and benzodiazepines may enhance analgesia but can also increase sedation).[15]

Practice point: Prescribing three to five days' of "as needed" medicines for a patient in the last days of life is a reasonable balance between convenience and wastage if the dose or medicine is changed or no longer required. A plan should be established for replenishing anticipatory medicine supplies should the patient continue living beyond this timeframe so there is no interruption in the delivery of symptom relief. Anticipatory medicine prescribing may also assist ambulance personnel or other acute healthcare providers, should they become involved, as they may not always carry the medicines recommended in these resources (see articles below for specific recommendations).

Click on the following links to access further information about managing each of the five main symptoms that can occur in the last days of life. These additional articles include anticipatory prescribing recommendations and flow charts adapted from the Te Ara Whakapiri updates (**www.sialliance.health.nz/programmes/palliative-care/te-ara-whakapiri/**),[6] accompanied by information contextualised for patients choosing to die in the community with the support of their general practice team.

Pain
bpac.org.nz/2023/last-days-of-life/pain.aspx

Nausea and vomiting
bpac.org.nz/2023/last-days-of-life/nausea.aspx

Delirium
bpac.org.nz/2023/last-days-of-life/delirium.aspx

Dyspnoea (breathlessness)
bpac.org.nz/2023/last-days-of-life/dyspnoea.aspx

Respiratory tract secretions
bpac.org.nz/2023/last-days-of-life/respiratory.aspx

N.B. This guidance is intended for patients experiencing an "uncomplicated death". Further secondary care or specialist palliative care input may be required for patients already taking significant opioid doses, with complex medicine regimens, or if symptoms have already been challenging to manage.

Read More. Some medicines or regimens used for symptom management in the last days of life are "unapproved":

During care in the last days of life, the use of some medicines for symptom management involves unapproved ("off-licence") indications, doses or routes of administration (see linked articles above for specific information). Under **Section 25 of the Medicines Act 1981**, authorised prescribers working within the scope of their practice can procure the supply of any medicine for use in patients under their care. This can include unapproved medicines and permits the supply of approved medicines for unapproved uses.

In these situations, the lead health practitioner should first identify whether there is a recognised guideline that endorses routine use:[6, 10]

- **If use is justified under a recognised guideline**, follow the usual process of obtaining verbal consent, including requirements under **The Code of Health and Disability Services Consumers' Rights 1996**, e.g. explain what is being prescribed and why, any safety concerns, and document this in clinical records
  - Written consent may be required if there is minimal evidence to support use, where the evidence for efficacy/safety of medicine use in such a manner is uncertain, or if there is significant risk of adverse effects
- **If routine use is not supported by a recognised guideline**, it may still be justified when used in people in the last days of life if there is still *some* evidence to support a potential benefit (e.g. case studies, peer reviewed textbooks) and it is considered that these potential benefits outweigh possible risks when standard treatment approaches have not provided benefit or are inappropriate. If such criteria are met, documented verbal consent is required at a minimum (although written consent is preferable given the low strength of evidence).
- **If the patient is unable to give consent in any form**, family/whānau are not able to give or withhold consent on their behalf unless they are a welfare guardian or designated as a legal Enduring Power of Attorney (EPA). If no such legal proxy exists in this situation, *the authorised prescriber can still proceed in the best interests of the patient after a discussion with family/whānau*.
- **If an unapproved medicine is used**, ensure **relevant requirements** under **Section 29 of the Medicine Act 1981** are met

Syringe drivers

Subcutaneous medicine administration is often used in the last days of life, including when a person:[16, 17]

- Has difficulty swallowing oral medicines
- Requires a medicine with no oral formulation
- Is too weak or fatigued to reliably take medicines at the prescribed times
- Requires timely onset of action and needs a constant level of medicine for symptom control, i.e. steady plasma concentrations

Syringe drivers are battery-operated pumps that administer a continuous subcutaneous infusion of essential medicine(s).[17] The two syringe drivers currently in use in New Zealand are Niki T34 or the newer model BD Bodyguard T.[18, 19]

Hospice or district nursing services can provide equipment and personnel who can work with general practice teams, patients and their family/whānau to help set up the syringe driver. Depending on the care plan, the family/whānau may sometimes be tasked with changing pre-filled syringes collected from the pharmacy once the driver is set up and instructions are given (if willing and competent).[18] In some regions family/whānau may also be provided with education and support to administer as needed subcutaneous medicines for breakthrough symptoms.

For further information about syringe drivers for clinicians, see:

- **www.health.govt.nz/system/files/documents/publications/syringe-guidelines-jul09.pdf** (N.B. In addition to the Niki T34 device, this resource also discusses the AD Ambulatory syringe driver which is no longer used or recommended in New Zealand)
- **www.caresearch.com.au/portals/10/Documents/NIKI-BodyGuard-pump-handbook-WEB-update-FINAL.pdf** (N.B. This is an Australian resource containing information on both Niki T34 and Bodyguard T devices)

For information on syringe driver competency training, see: **www.hospice.org.nz/education-training/syringe-driver-competency-training/**

For an information booklet about operating syringe drivers for patients and their family/whānau, see: **www.healthnavigator.org.nz/media/5526/syringe-driver-handbook.pdf**

Other considerations for care plans in the community[1]

Discontinue non-essential medicines. Care in the last days of life should primarily focus on relieving symptoms and promoting quality of life. Therefore, continued use of medicines for managing long-term conditions is often no longer necessary (e.g. statins, antihypertensives, urate-lowering treatment[s]); many of these medicines are taken orally (which may no longer be possible), and continuation may increase "pill burden" or cause interactions with medicines introduced for symptom control.[17] Possible exceptions include anticonvulsants or other medicines used to control symptoms, e.g. a diuretic for heart failure, that could impact comfort or cause distress if withdrawn.[7, 20] In some cases, essential long-term medicines may be switched from an oral to subcutaneous route if possible, e.g. levetiracetam, dexamethasone. Most diabetes medicines can be stopped in the last days of life, however, insulin should usually be continued in patients with type 1 diabetes.[21] Discontinuing insulin may be appropriate for patients with type 2 diabetes if they have previously only required small doses to achieve glycaemic control.[21]

For further information on managing diabetes in the last days of life, see: **diabetes-resources-production.s3.eu-west-1.amazonaws.com/resources-s3/public/2021-11/EoL_TREND_FINAL2_0.pdf#page=21**

Food and fluids. People should be encouraged to continue eating and drinking as long as they feel comfortable doing so (including via parenteral feeding, if appropriate). In most cases, people will become gradually less interested or capable of eating/drinking as they approach death, and increasing food/fluid intake is unlikely to prolong life or decrease their discomfort.[22] Trying to compel intake may also cause further distress or result in aspiration, particularly if they have swallowing difficulties.[22] However, some people may find pleasure and comfort from tasting food and derive social/cultural benefits from sharing meals with their family/whānau.[22]

Supportive equipment. Identify whether the person requires access to supportive equipment, e.g. syringe drivers, pressure relieving mattresses/cushions, hoist or electric bed, incontinence products or commodes. Contact your local PHO, allied health or hospice service for more information on funding options or equipment loans. An occupational therapist can assess patient-specific needs if required. In some cases, families choose to purchase equipment themselves.

Oxygen. The use of domiciliary oxygen is not common in the last days of life unless a patient has established hypoxia due to disease, however, a new prescription may occasionally be considered in the dying phase for certain patients (but this may be dependent on local policies and advice). Dyspnoea is primarily managed using pharmacological treatment in the last days of life, supported by non-pharmacological strategies, as appropriate.

Implantable cardioverter-defibrillators (ICDs). In most cases, an ICD should be deactivated as the person approaches death.[23] If not turned off, the device may cause repeated shocking in response to natural arrhythmic patterns that occur close to death;[23, 24] this is likely to be distressing for both the person and their family/whānau. Deactivating an ICD will not cause a worsening of cardiac output.

Cultural, religious and spiritual needs. Identify any specific traditions, customs or practices that are important to the person and consider how these can be incorporated into the care plan. For some, the last days of life are a time when they want to re-explore concepts of faith and cultural links that have not previously been central to their life.

Tailoring last days of life care for Māori

> ***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).[26] Traditionally, whānau assume the role of pou aroha (care stalwarts) during this process, delivering care that:[26]

- 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); and
- 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.[27] The general practice 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.[1] In some cases, people 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:[26]

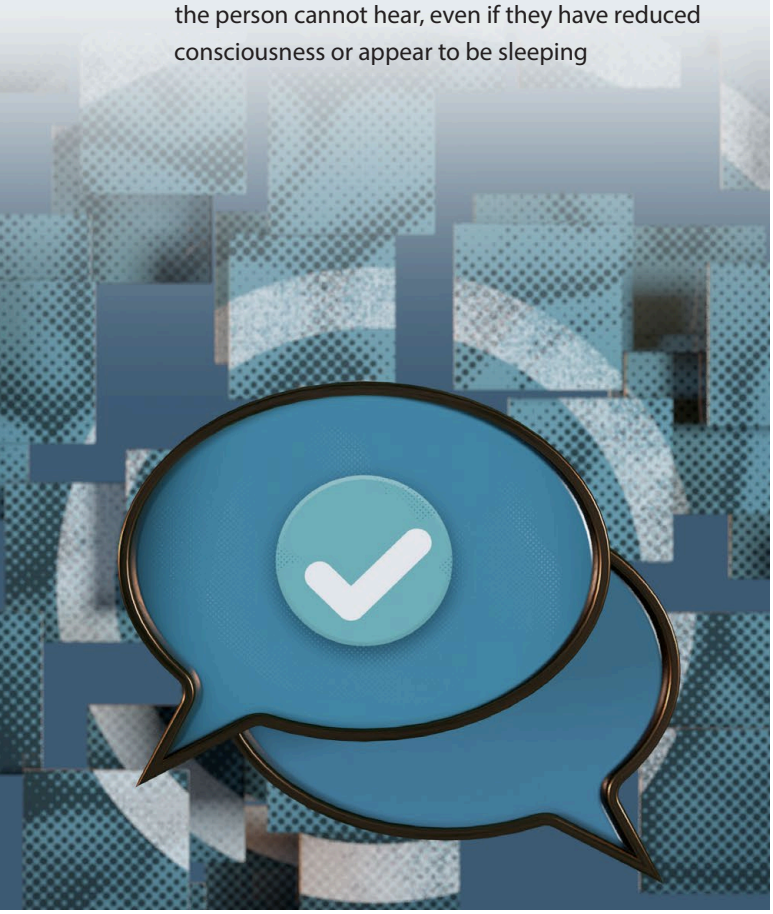
- Using te reo Māori (Māori language)
- Incorporating rongoā (traditional healing) including mirimiri (massage)
- Observing tapu (protocols and practices that govern things that are sacred or restricted)
- Observing noa (protocols and practices that return a state of tapu back to its ordinary state)
- 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)

For further information on providing culturally informed care at the end of life (including sections for both whānau and health professionals), see: **www.teipuaronui.co.nz/**

To access a list of Kaupapa Māori health services, see: **healthpages.co.nz/directory/categories/kaupapa-maori-services**

Tips for communication with family/whānau[1, 5]

- An interpreter may be required if there are language barriers
- Provide opportunities to discuss what is important to the person and their family/whānau, particularly spiritual, religious and cultural needs, including after death occurs (see: "Tailoring last days of life care for Māori")
- Ensure realistic expectations are set, regarding the person's deteriorating condition, needs and possible requirements involved with delivering care at home, e.g. toileting assistance, changes in mental state
- Consider the level of caregiver distress and if they feel capable of being involved in home care; take time to detail their role in managing symptoms, signs of imminent death and what to do once the person has died
- Communicate any changes in the person's condition in a manner tailored to their level of health literacy; be conscious that grief may impair their ability to process information
- Be mindful when talking with family/whānau about the person who is dying; do not assume the person cannot hear, even if they have reduced consciousness or appear to be sleeping



Share information with relevant agencies regarding the person's deterioration. Depending on the patient's clinical history, other health services may already be involved in their care, e.g. oncology, geriatrics, district nursing services, residential care facilities. While it may not be practical or applicable in every situation, these groups should be identified and contacted to inform them of the persons deteriorating condition (particularly if upcoming appointments are scheduled). N.B. Ensure requirements under the **Privacy Act 2020** are adhered to.

Providing a management summary sheet is good practice for supporting acute health providers outside of the usual care team. For example, emergency ambulance services deal with many cases relating to end of life assessment and care support in the community, particularly if unexpected deterioration occurs outside of usual work hours. Extended Care Paramedics are increasingly involved in providing care for these patients in some areas of the country. Completing a brief management summary sheet can be an invaluable resource as this provides clinical context and guidance to assist these acute health providers in making timely decisions about the patient's care (that align with their care plan). In New Zealand, paramedics have a legal obligation to provide care to vulnerable and critically unwell people; deviations from life-preserving obligations can be justified based on additional information available in any given situation, such as the presence of clear advance directives.[25] In the absence of this information, paramedics must apply clinical judgement as to whether they only provide symptom relief or attempt more active interventions, e.g. resuscitation, assisted ventilation.[25] This process can be complicated if the patient is not conscious and there are not clear instructions available regarding their wishes.

For an example management summary sheet, **click here**.

Ongoing assessment and delivery of the care plan

Once the components of an individualised care plan have been established, the next step is to determine the responsibilities of those involved and frequency of ongoing assessment. While New Zealand guidelines state that health practitioners should undertake regular assessments of the person's condition,[1] the practical capacity to do this in-person (i.e. via home visits)

can be a challenge in primary care. In many cases it may be the family/whānau who are providing care and reviewing needs with the support of a community-based nurse (or other health professionals) who will report back to the lead health practitioner.

Te Ara Whakapiri includes a simple home care recording sheet to provide to family/whānau. For access, **click here**.

If they are willing, family/whānau should be encouraged to regularly assess and document symptoms and other aspects of wellbeing so that the need for additional support can be identified and provided early.[1] This information should be reviewed **at least once daily** by a member of the healthcare team.[10] If it is determined that a person's condition is deteriorating or new symptoms have emerged, both they and their family/whānau should be involved in conversations about the options for ongoing care.

Practice point: be conscious of changing perspectives following the baseline assessment.
As people attempt to process the prospect of impending death, their views concerning cultural and religious beliefs may change.[1] Periodically revisit/discuss these concepts and facilitate needs where possible, e.g. by encouraging contact with chaplaincy services or other spiritual providers including Kaiāwhina and/or Kaumātua.

Recognising when death approaches

Being able to recognise impending signs of death is important to ensure the final moments of life are as comfortable and dignified as possible (Table 1).[10] Discussing this information may help the family/whānau to prepare for their loved ones passing, particularly if a healthcare professional will not be present. However, these features do not all occur in every instance or in a specific order.

Care after death

Kua hinga te tōtara i Te Waonui-a-Tāne
The tōtara tree has fallen in Tāne's great forest

Before the person's death, family/whānau should be provided with practical advice on what to do when it occurs. This discussion ensures the person's dignity, respect and wishes will be maintained following death, and allows their loved ones to focus on processing emotions and supporting each other (rather than decision-making).

Key information to provide includes:[10]

- The features to look for that indicate death has occurred (Table 1). It is helpful to note the time of death.
- There is no need to rush – it is okay to spend time with the person after they die. The family/whānau may also want to contact friends or other relatives to come and say goodbye.
- The lead health practitioner should be contacted so the death can be confirmed and a death certificate written. If the death occurs during the night, the family/whānau can wait until the morning before making contact.
- An ambulance does not need to be called; a funeral director will usually arrange collection of the body/tūpāpaku once contacted by the family/whānau. However, there is no legal requirement to use a funeral director and in some cases family/whānau may choose to co-ordinate the funeral themselves. Ensure the family is aware of all **legal** obligations, e.g. confirmation of cause of death and registration of the death.
- Keep the room as cool as possible (e.g. turn off heaters and electric blankets); this will help slow the process of decomposition and is particularly important if the person did not want their body/tūpāpaku embalmed following death
- The person's body/tūpāpaku does not need to be washed. If a decision is made to do this (e.g. for cultural reasons or personal preference), a sponge can be used on the skin/face, medical/nursing equipment removed, dentures and glasses replaced if wished, and the person dressed in favourite clothes. The family/whānau should be advised that the person's body/tūpāpaku will become increasingly stiff over time, so any movement or repositioning should not be excessively delayed.

For more comprehensive information and advice for family/whānau on what to do once a death occurs at home and advice for processing emotions, **click here**

For search tools to help family/whānau find local funeral services, **click here** (Funeral Directors association of NZ) or **here** (NZ Independent Funeral Homes)

To access the Death Documents website (a digital tool enabling practitioners to complete and view the Medical Certificate of Cause of Death and Cremation Forms), **click here**

Table 1. Impending signs of death.[10]

	Description	**Practical advice**(applicable to either health professionals or family/whānau involved in care)
Sleep	People close to death may spend increasing amounts of time in bed or sleeping. It may be more difficult to wake them.	■ Prioritise communication when the person is most alert but never assume they cannot hear ■ Continue talking to them, as appropriate ■ Reassure family/whānau that an increasing need for sleep is a natural part of the dying process and not caused by excessive medicine use
Food and fluids	The person may have minimal interest in eating or drinking. Dehydration is usually not a concern as the body typically adapts to the lower fluid intake.	■ Do not offer food/drink to people if they are unable to swallow ■ Ice chips or a straw/sip cup can help a person ingest small amounts of fluid if required. Mouth swabs soaked in water or fruit juice can also help keep the inside of the mouth moist. ■ Lip balm or moisturiser can be used to prevent chapped/dry lips
Skin	Skin on the nose, ears, hands and feet may feel cooler. Skin can sometimes appear flushed or may become discoloured or blotchy.	■ Apply a cool, moist cloth to the forehead ■ Have an extra blanket available to provide additional warmth, if required ■ Reassure family/whānau that these changes are normal
Confusion	The person may become confused about time, where they are or have trouble identifying familiar people	■ Talk calmly to the person and provide reassurance; identify yourself by name when speaking with them ■ Use a night light ■ Keep familiar objects in the room
Restlessness and agitation	More likely when a person becomes semi-conscious. Signs include twitching, plucking at the air or bed clothes, moaning/calling out constantly and trying to get out of bed (even if unable to stand).	■ Encourage family/whānau to keep sitting and speaking with the person to provide reassurance ■ Consider quiet music, radio or aromatherapy ■ In some cases the cause may be treatable. Consider whether the person needs their position altered, provide mouth care (e.g. ice chips, water spray, lip balm, cleaning teeth) or help with toileting. ■ Clinicians may consider pharmacological treatment, if appropriate, e.g. haloperidol, midazolam
Loss of bowel and bladder control	May occur close to the time of death; often associated with loss of dignity for the person if not sensitively managed	■ Pre-emptively discuss the possibility of these events occurring and options for management ■ Use incontinence products, e.g. pads, pull-ons/wrap-arounds, protection sheets ■ Consider catheter use to drain urine, if appropriate
Noisy breathing	Saliva and mucus may build up if the patient becomes too weak to cough or swallow	■ Reassure family/whānau that this is a normal part of the dying process; it often indicates a transition into deep unconsciousness and is not distressing to the person ■ First-line management should be non-pharmacological, e.g. altering the person's position or turning them on their side if they are congested ■ Clinicians may consider pharmacological treatment, if appropriate
Breathing patterns	Breathing may become more irregular as the respiratory system slows	■ Changes in breathing patterns may be a sign that death is close – notify any family/whānau not present who want to be there at the time of death. However, sometimes these changes may persist for hours or even days before death occurs.
When death occurs	The person will have stopped breathing and be unresponsive. There will be no detectable pulse/heartbeat and facial muscles usually relax, meaning the mouth and eyes may be slightly open. The person's skin will become cooler and paler.	■ There is no need to rush – it is okay for the family/whānau to spend time with the person ■ It is helpful to note the time of death ■ An ambulance does not need to be called ■ At an appropriate time, the lead health practitioner should be contacted (if not present) so the death can be confirmed and a death certificate written. This can be the next morning if the death occurs during the night.

Assessing family/whānau bereavement risk

Once death occurs, the care team's involvement continues as family/whānau may require further support. This might involve an ongoing active role for the general practitioner and/or nurse(s) if the family/whānau are enrolled with the same practice, or if they are not, enquiring whether their needs are being considered by another care provider.

A loved one's death can be one of the most challenging events that family/whānau experience. While many people process grief and integrate their loss, others have significant difficulty adjusting to their bereavement.[28] This challenge can be compounded if there is an abrupt discontinuation of contact with the person's general practice team or lack of follow-up.[29]

It is recommended to discuss bereavement support and ensure a risk assessment is conducted for all family/whānau members who wish to have one (see link below).[1] For family/whānau assessed as being at low bereavement risk, it is usually sufficient to provide written resources (e.g. a brochure or website) and to have a general discussion about the spectrum of emotions that can be experienced. Most will adjust in time with the support of their friends and family/whānau.[28] However, more active intervention(s) may be required for people with multiple bereavement risk factors (e.g. high levels of anger or guilt, a lack of social support).[1] People can be directed to a local bereavement support agency or specialist support, e.g. from a counsellor or hospice bereavement service. Many funeral director services also offer bereavement support.

To access the "*Te Ara Whakapiri Bereavement Risk Assessment Tool*", **click here**.

Further resources:

- Hospice resources for family carers: **www.hospice.org.nz/resources/a-guide-for-carers/**
- He Aratohu mā ngā Kaitiaki (A Guide for Carers – includes information on how to access financial support, if required): **www.msd.govt.nz/documents/what-we-can-do/community/carers/a-guide-for-carers.pdf**
- Further information on financial support:
  - **www.healthinfo.org.nz/index.htm?Financial-support.htm**
  - **www.healthinfo.org.nz/index.htm?Financial-support-for-health-costs.htm#o58197**
- Regional palliative care programmes and funding schemes may be available; contact your PHO or local hospice for further information

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www.bpac.org.nz/2023/last-days-of-life/perspective.aspx

Managing pain in the last days of life

Pain is often feared by people in the last days of life and if not adequately controlled, it can negatively impact their remaining quality of life. Anticipatory prescribing of analgesics enables rapid intervention if pain arises. Morphine is the first-line pharmacological treatment for most patients, supported as much as possible by non-pharmacological pain management strategies.

KEY PRACTICE POINTS:

- Pain is a common symptom experienced by people in the last days of life. The potential for pain should be anticipated and analgesics prescribed so that symptoms may be controlled promptly when the need arises.
- All patients in the last days of life should be regularly assessed for pain. If present, determine the severity, type(s) of pain and whether there is any cause that can be treated, e.g. urinary retention.
  - Pain assessment can be challenging in the last days of life as the patient's level of consciousness fluctuates and communication becomes limited. Consider other ways to identify pain, e.g. by recognising facial expressions or non-specific distress behaviours (e.g. restlessness). Validated scales are also available to assess pain in patients with cognitive impairment.
- Non-pharmacological pain management strategies are recommended (as appropriate) alongside pharmacological treatments. These may include regular repositioning, distraction techniques, e.g. listening to music or reminiscing, use of a hot/cold compress, mindfulness techniques or gentle massage.
- Morphine is the first-line pharmacological treatment for most patients in their last days of life. Fentanyl can be used instead of morphine for those with contraindications or significant renal impairment; however, the dosing regimen can be more complicated and the adverse effects from morphine may become relative, not absolute, in this setting.
  - Where possible, analgesics should be prescribed via the subcutaneous route (convert any oral doses the patient is currently taking)
  - Opioids should also be prescribed and administered on an "as needed" basis for breakthrough pain
- Adjuvant or co-analgesics should be continued for specific indications until swallowing is no longer possible as withdrawal may worsen symptoms, e.g. tricyclic antidepressants or anti-epileptics for neuropathic pain, systemic corticosteroids for pain related to raised intracranial pressure, bisphosphonates or NSAIDs for bone pain; some medicines may be able to be converted to a subcutaneous route, e.g. dexamethasone
- If the patient's symptoms do not respond to appropriate treatment, contact the local hospice or palliative care team for advice

This article is part of a series on managing symptoms in the last days of life. It is recommended to read this article in conjunction with the other articles in the series, particularly: "**Navigating the last days of life: a general practice perspective**".

Pain in the last days of life

Pain is reported to occur in up to three-quarters of people in their last days of life.[1, 2] Managing pain is important during the last days of life as for many people it is their greatest fear, and family/whānau do not want to see their loved one in distress. If pain is able to be successfully managed, a person's overall experience in their last days of life can be improved.[3] Pain should be anticipated and analgesics prescribed accordingly so that if it arises, prompt control is possible.[4]

People may experience pain related to:[5]

- Their terminal illness, e.g. bone pain from cancer metastases, pressure on organs or bones from tumours or metastases, headache due to raised intracranial pressure from a brain tumour or metastases, musculoskeletal pain associated with progressive neurological diseases such as motor neurone disease
- Chronic conditions, e.g. heart failure, multiple sclerosis, chronic obstructive pulmonary disease, arthritis
- Treatment-related adverse effects, e.g. mucositis, neuropathy, infection, lymphoedema, constipation/bowel obstruction
- Other conditions that sometimes occur at the end of life such as pressure ulcers or oral candidiasis

In addition to physical causes, pain can be exacerbated by psychosocial factors, including fear/anxiety and spiritual distress.[3, 6]

Pain assessment

All patients in the last days of life should have regular pain evaluations.[7, 8] However, the assessment of pain in this setting can be challenging as patients become less responsive or begin to experience delirium.*[1, 3] It can also be difficult to assess pain in patients with limited communication due to cognitive impairment.[1, 3]

Pain evaluation usually involves determining:[4, 9]

- **The severity of the pain.** A tool to measure pain intensity is recommended, e.g. verbal descriptor, numerical scale, **Faces Pain Scale**. The **Abbey Pain Scale** can be used to assess pain in patients with limited or no communication.
- **The type(s) of pain present** (see box about adjuvant or co-analgesics):
  - Somatic, e.g. aching, throbbing, gnawing, localised
  - Visceral, e.g. deep, dull, aching, cramping
  - Neuropathic, e.g. burning, shooting, tingling
  - Bone, e.g. constant, deep
- **Whether there is a specific cause that can be treated**, e.g. urinary retention, constipation
- **Any factors that relieve and exacerbate pain**, e.g. body position, movement, temperature, psychological factors, spiritual concerns about the dying process
- **The impact of pain** on all aspects of the patient's wellbeing and functioning

Practice Point: Consider other practical ways to identify that patients with limited communication may be experiencing pain, e.g. by recognising facial expressions or non-specific distress behaviours such as restlessness, moaning, muscle tension.[1, 3, 8] If it is still uncertain whether a patient with limited communication is in pain after an initial assessment, an empiric trial of analgesics may be appropriate.

* For further information, see: "**Managing delirium and psychological symptoms in the last days of life**"

Consider both non-pharmacological and pharmacological pain management options

Making the patient comfortable and pain free is the primary goal in the last days of life. Most commonly this is achieved with the use of analgesic medicines (see: "Morphine is usually the first-line pharmacological treatment"), but non-pharmacological strategies (see below) should be used as well if appropriate.[4, 6, 9]

Ideally, pain management will have been discussed with the patient and their family/whānau prior to the last days of life so that a plan is already in place, i.e. advance care planning, see: **www.hqsc.govt.nz/our-work/advance-care-planning/**.

Non-pharmacological pain management strategies:[3, 4, 6, 9]

- Acknowledge and validate the patient's pain experience, reassure them that every effort will be made to manage their pain
- Minimise exposure to triggers that exacerbate pain, e.g. particular movements or body positions, psychological distress
- Encourage the family/whānau to spend time with the patient which may help to ease their pain
- Regularly reposition the patient (if possible and appropriate). This can be comforting, pressure relieving, and help to reduce stiffness and muscle aches. Provide pressure relieving aids as required.
- Suggest relaxation or distraction techniques depending on the patient's level of functioning, e.g. listening to music or a podcast, watching television, guided imagery (a technique where the person imagines positive images or scenarios, e.g. favourite holiday destination), reminiscing, mindfulness, meditation or prayer (depending on the patient's spiritual or cultural beliefs)
- Use a hot or cold pack
- Gentle massage or touch (i.e. by family/whānau)

- Create an ambient environment, e.g. by lowering lights, setting an appropriate room temperature, aromatherapy

Support the use of other techniques and methods for pain relief that the patient or their family/whānau want to try if they are unlikely to cause harm, e.g. traditional techniques (such as Rongoā Māori, Ayurvedic or Chinese herbal medicines), homeopathy, acupressure/acupuncture.

Morphine is usually the first-line pharmacological treatment

Opioids administered subcutaneously are recommended for patients with pain in the last days of life.[4, 6] Patients already taking opioids orally usually require conversion to a subcutaneous form, i.e. convert oral doses of morphine to subcutaneous doses of morphine (see: "Oral doses should be converted to subcutaneous").

Morphine is the first-line pharmacological treatment for most patients in the last days of life (Figure 1).[4, 6] Oxycodone may be considered for patients who are unable to tolerate morphine.[4] If a patient has significant renal impairment (i.e. eGFR < 30 mL/min/1.73 m^2), the active metabolites of morphine or oxycodone can accumulate resulting in opioid toxicity.[4] Symptoms and signs of opioid toxicity include myoclonic jerks, excessive sedation or confusion, restlessness and hallucinations.[1, 4]

Fentanyl (subcutaneous) may be appropriate in patients with significant renal impairment (Figure 2);[4] however, dosing and administration is more complicated than morphine. Therefore, in practice, morphine may still be used in some patients with renal impairment in the last days of life, particularly if doses are not too high. In the last days of life, contraindications for treatment also become less absolute.

Practice Point: Anticipatory prescribing of "as needed" doses of analgesia is also recommended in patients without current pain (Figure 1); if pain arises the "as needed" dose can be administered and then regular dosing initiated.[6]

Oral doses should be converted to subcutaneous

Many patients entering into their last days of life will already be established on an analgesic treatment regimen, usually with a long-acting opioid (either oral or transdermal). For patients currently taking an opioid orally, conversion to a subcutaneous dose for 24-hour continuous subcutaneous infusion is recommended in the last days of life (Table 1).[4, 6] This is often required as the patient's level of consciousness and alertness is expected to reduce during this period, which makes swallowing no longer possible.[6, 8] If a patient is currently using transdermal fentanyl, patches can remain *in situ* and subcutaneous fentanyl (unapproved route) can be prescribed and administered on an "as needed" basis for breakthrough pain (Table 1).[4, 6]

Table 1. Dose conversion and "breakthrough" dose calculations for subcutaneous morphine, oxycodone and fentanyl.[6]

Dose conversion calculations		
Conversion from	**Conversion to**	**Calculation**
Oral morphine	Subcutaneous morphine	Divide oral dose by 2
Oral oxycodone	Subcutaneous oxycodone	Divide oral dose by 1.5 or multiply by 0.667 (to get two-thirds of oral dose)
Subcutaneous dose	24-hour dose for continuous subcutaneous infusion	Total number of doses (regular + "breakthrough") required in previous 24 hours (excluding doses needed for incident pain)
Opioid conversion guides are available from the New Zealand Formulary: **nzf.org.nz/nzf_70672#nzf_70708**		
An online Australian-based opioid conversion calculator is available from: **www.eviq.org.au/clinical-resources/eviq-calculators/3201-opioid-conversion-calculator**		
Subcutaneous "breakthrough" dose calculations		
Subcutaneous "breakthrough" dose of morphine/oxycodone is equivalent to one sixth of the total 24-hour dose, to be prescribed every hour (occasionally every thirty minutes), as needed		
Subcutaneous "breakthrough" dose of fentanyl is equivalent to the **hourly** dose of transdermal fentanyl to a maximum dose of 100 micrograms in 2 mL		

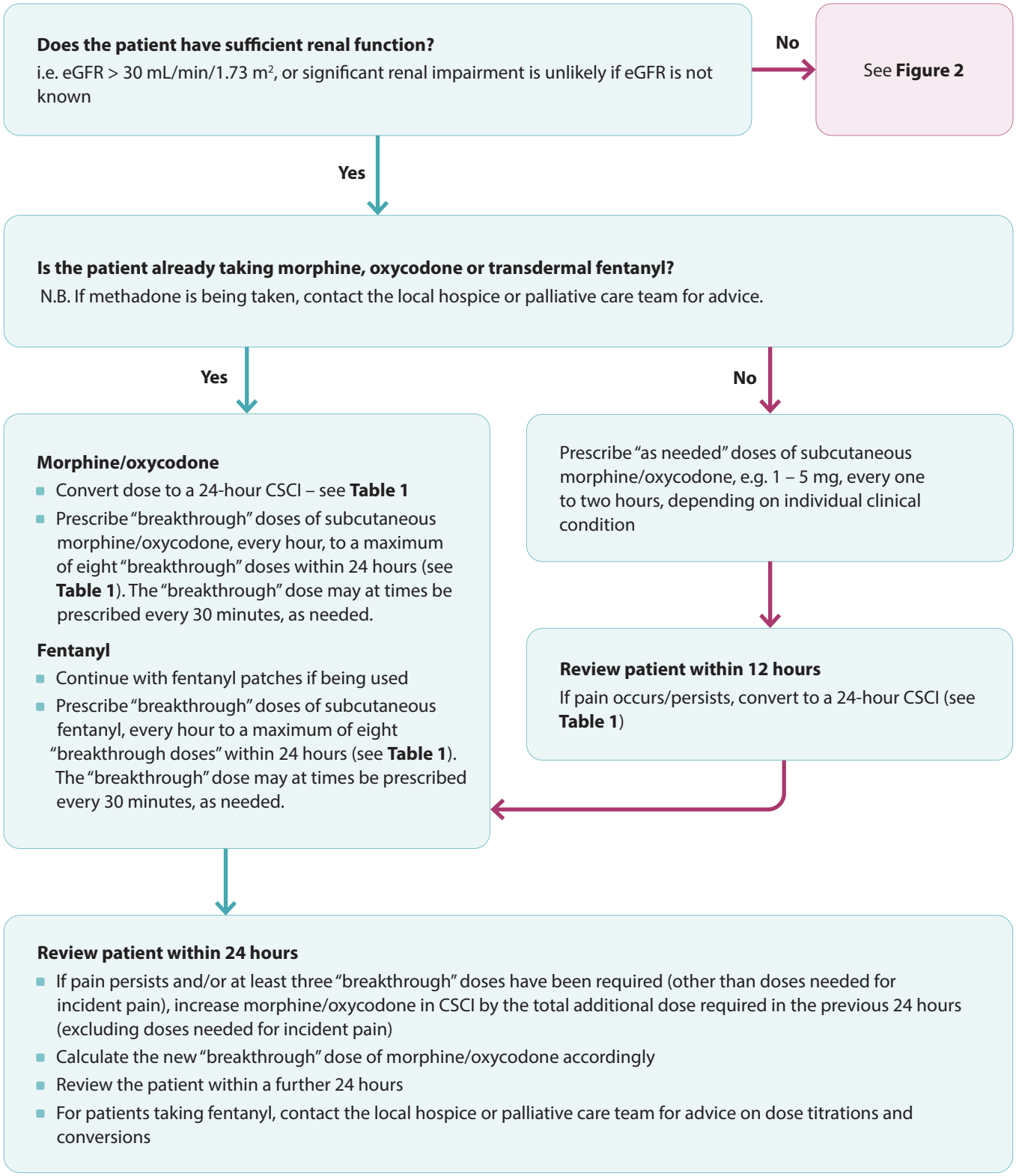

Figure 1. Anticipatory prescribing for pain algorithm for patients with normal renal function in the last days of life. Adapted from *South Island Palliative Care Workstream, 2020.*[6]

CSCI = continuous subcutaneous infusion

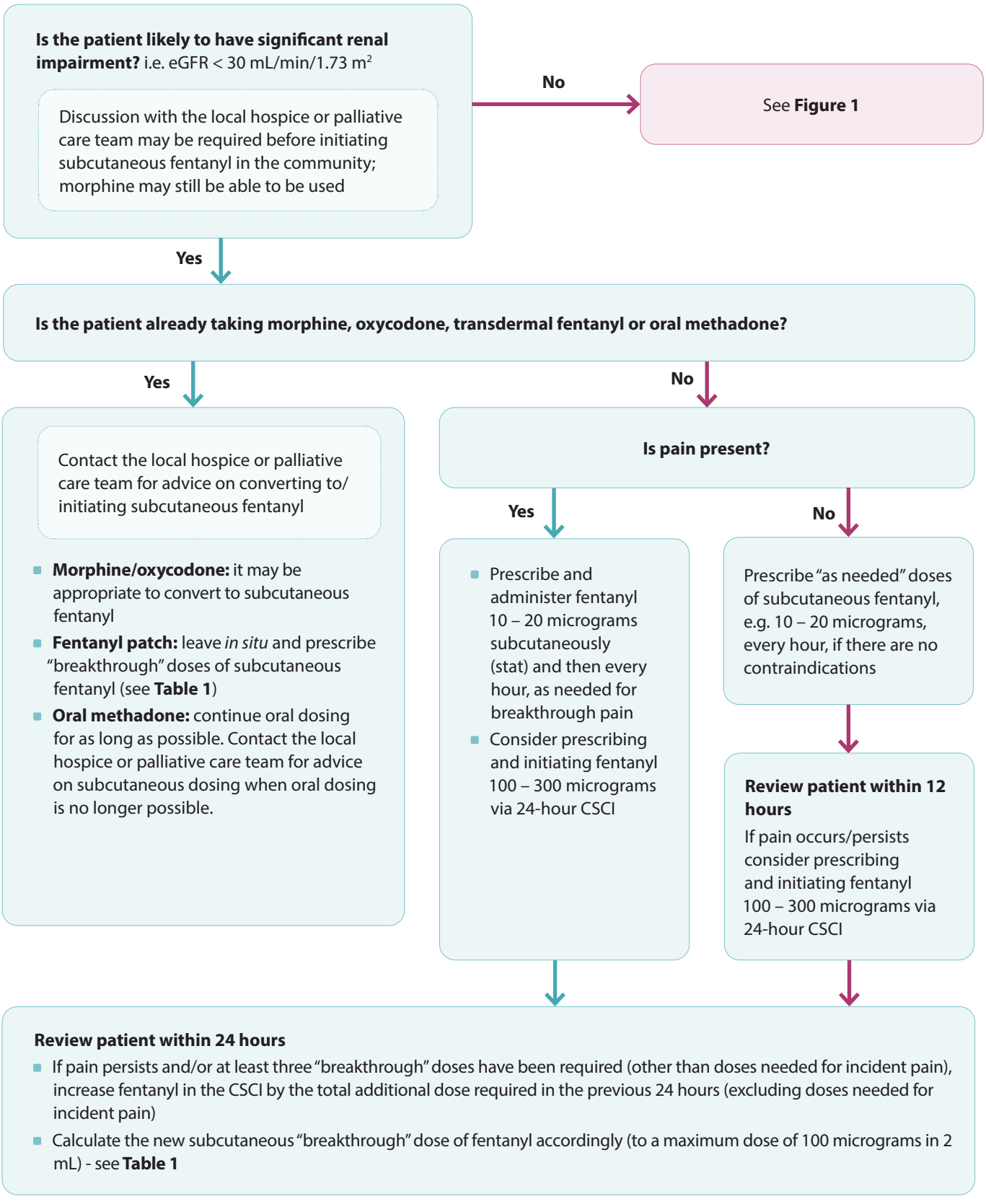

Figure 2. Anticipatory prescribing for pain algorithm for patients with impaired renal function in the last days of life. Adapted from *South Island Palliative Care Workstream, 2020.*[6]

CSCI = continuous subcutaneous infusion

Practice Point: Fentanyl patches take 72 hours to reach steady state and should **not** be initiated in patients who are opioid naïve.[10] The lowest dose fentanyl patch (12.5 micrograms per hour) is equivalent to up to 60 mg of oral morphine.[10]

Prescribe "as needed" doses for breakthrough pain

Subcutaneous morphine/oxycodone doses should also be prescribed and administered on an "as needed" basis for breakthrough pain (Table 1).[6] "Breakthrough" doses are generally one-sixth of the total 24-hour dose and should be prescribed every hour (occasionally every thirty minutes) as needed. A maximum of eight "breakthrough" doses administered within 24 hours are recommended.[6] If the patient has incident pain, e.g. pain associated with movement such as changing position, dressing changes, administer the "as needed" dose prior to the activity.[6]

If pain persists and/or at least three "breakthrough" doses have been required (other than those needed for incident pain) within 24 hours, increase the dose of the opioid in the continuous subcutaneous infusion by the total additional dose required in the previous 24 hours (excluding doses needed for incident pain).[6] A new "breakthrough" dose will now need to be calculated.[6] If pain still persists after a further 24 hours, contact the local hospice or palliative care team.[6]

Adjuvant or co-analgesics should be continued for specific indications until swallowing is no longer possible as withdrawal may worsen symptoms, e.g. tricyclic antidepressants or anti-epileptics for neuropathic pain, systemic corticosteroids for pain related to raised intracranial pressure, bisphosphonates or NSAIDs for bone pain.[3, 8] If the medicine is not being used for analgesia alone it may be able to be converted to a subcutaneous route if it is still required, e.g. dexamethasone. Contact the local hospice or palliative care team for advice if required.

Laxatives are usually only required if constipation is causing discomfort in the last days of life

Almost all patients taking strong opioids experience persistent constipation and are routinely co-prescribed an oral laxative regimen. In the last days of life, however, constipation may not cause symptoms and the benefit from laxatives during this time may be limited.[1, 8] Oral laxatives are ceased once swallowing is no longer possible. Suppositories or enemas are rarely required in the last days of life and they should only be considered if constipation is causing significant discomfort to the patient.[8]

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Managing nausea and vomiting in the last days of life

Nausea and vomiting in the last days of life are often a cause of significant distress for patients and their family/whānau. A range of pharmacological and non-pharmacological interventions can be trialled to minimise the negative impact of these symptoms.

KEY PRACTICE POINTS:

- The causes of nausea and vomiting in the last days of life are often multifactorial and regular review is required to assess severity of symptoms, food and fluid intake, hydration status and any contributing factors
- Modifiable causes of nausea and vomiting should be addressed first, where appropriate, and discontinue preventative medicines that are no longer required, e.g. statins, oral hypoglycaemics
- Discuss non-pharmacological management strategies with the patient and their family/whānau, e.g. maintaining oral hygiene, relaxation or distraction techniques, complementary or alternative remedies
- If pharmacological treatment is required, subcutaneous haloperidol is the preferred first-line option in patients with no contraindications; metoclopramide and cyclizine can also be considered
  - Increase the dose if there is a small but insufficient improvement in symptoms
  - Establish regular dosing early to appropriately manage symptoms
  - Switch to an alternative antiemetic if there is no response to treatment
- Levomepromazine (methotrimeprazine) is the next option for patients with persistent nausea or vomiting despite maximum recommended doses of first-line antiemetics. N.B. Patients may experience sedation even at low doses.
- Occasionally, a combination of antiemetic medicines may be required to provide the patient sufficient symptom relief in the last days of life. Discuss with your local hospice or palliative care team if symptoms are complex.

This article is part of a series on managing symptoms in the last days of life. It is recommended to read this article in conjunction with the other articles in the series, particularly: "**Navigating the last days of life: a general practice perspective**".

Nausea and vomiting in the last days of life

Nausea and vomiting can be particularly distressing and significantly impact quality of life of a person in their final days.[1] Nausea and vomiting commonly occur in people with cancer, heart failure, liver disease or end stage renal disease.[2] Related symptoms include reduced appetite, weight loss, abdominal bloating/distention and constipation.[2]

Nausea and vomiting in the last days of life occurs due to a combination of factors, including:[1–3]

- Gastroparesis, constipation or functional bowel obstruction
- Medicines, e.g. opioids, NSAIDs, antibiotics, anticonvulsants or withdrawal from corticosteroids
- Upper gastrointestinal irritation, e.g. excessive secretions, infection, gastro-oesophageal reflux disease
- Electrolyte imbalances, e.g. hypercalcaemia, hyponatraemia, uraemia
- Anxiety, fear or pain
- Intracranial disorders, e.g. vestibular dysfunction, ototoxicity, raised intracranial pressure*

* Increased pressure inside the skull resulting from brain tumours or metastases, bleeding or swelling can compress structures in the brainstem involved in the vomiting reflex.[4] Common symptoms include nausea, vomiting, headaches and papilloedema, and are often more severe in the morning.[2]

The pathophysiology of nausea and vomiting is complex

The biological pathways that induce nausea and vomiting are complex (Figure 1).[5] The nucleus tractus solitarius (NTS, or vomiting centre) is a cluster of neurons in the brainstem that mediates the vomiting reflex. These neurons receive input from various sources, including:[5, 6]

The cerebral cortex, amygdala and limbic system – sensory input from higher centres relating to cognition and emotion, e.g. sights or smells that induce vomiting

The chemoreceptor trigger zone (CTZ) – located in the medulla oblongata, near the fourth ventricle, sitting outside of the blood brain barrier. This region detects circulating abnormalities, e.g. medicines, bacteria or electrolyte imbalances in the blood and cerebrospinal fluid.

The vestibular system – histamine-mediated signals resulting from inner ear dysfunction, e.g. motion sickness

The gastrointestinal system – mechanoreceptors stimulated by gastric distension and chemoreceptors that detect bacteria, toxins, medicines in the gastrointestinal lumen

In response to information from the above pathways, the NTS sends signals via the vagal nerve to increase gastric contraction and relax the oesophageal sphincter leading to emesis.[6, 7]

The exact pathophysiology of nausea is less well understood but it likely involves the NTS receiving input from similar sites as listed above and then sending signals to the cerebral cortex to produce the sensation of nausea.[5, 6]

Practice point: Clinicians should consider the likely pathophysiology of a patient's nausea and vomiting when deciding on the most appropriate antiemetic to prescribe (Table 1).

Assessing patients with nausea and vomiting

In patients with nausea or vomiting, consider the following factors during the baseline assessment (and ongoing reviews):[1–3]

The onset, duration and severity of symptoms

Potential triggers, e.g. smells from food preparation or those related to bodily functions

Whether any of the patient's medicines (for long-term conditions) are commonly associated with nausea or vomiting

Whether the adverse effects of these medicines outweigh any potential benefit at this stage

The presence of constipation or signs of faecal impaction, e.g. abdominal distension or mass, absence of bowel sounds

Current hydration status and food and fluid intake

The patient's thoughts and emotions concerning their symptoms, e.g. fear, anxiety, anticipation

Management of nausea and vomiting in the last days of life

Discuss with the patient and their family/whānau that nausea and vomiting is not unexpected, why it occurs, and the treatment options that are available for them. Knowing what to expect can alleviate distress. Reassure family/whānau that food and fluid requirements reduce in the last days of

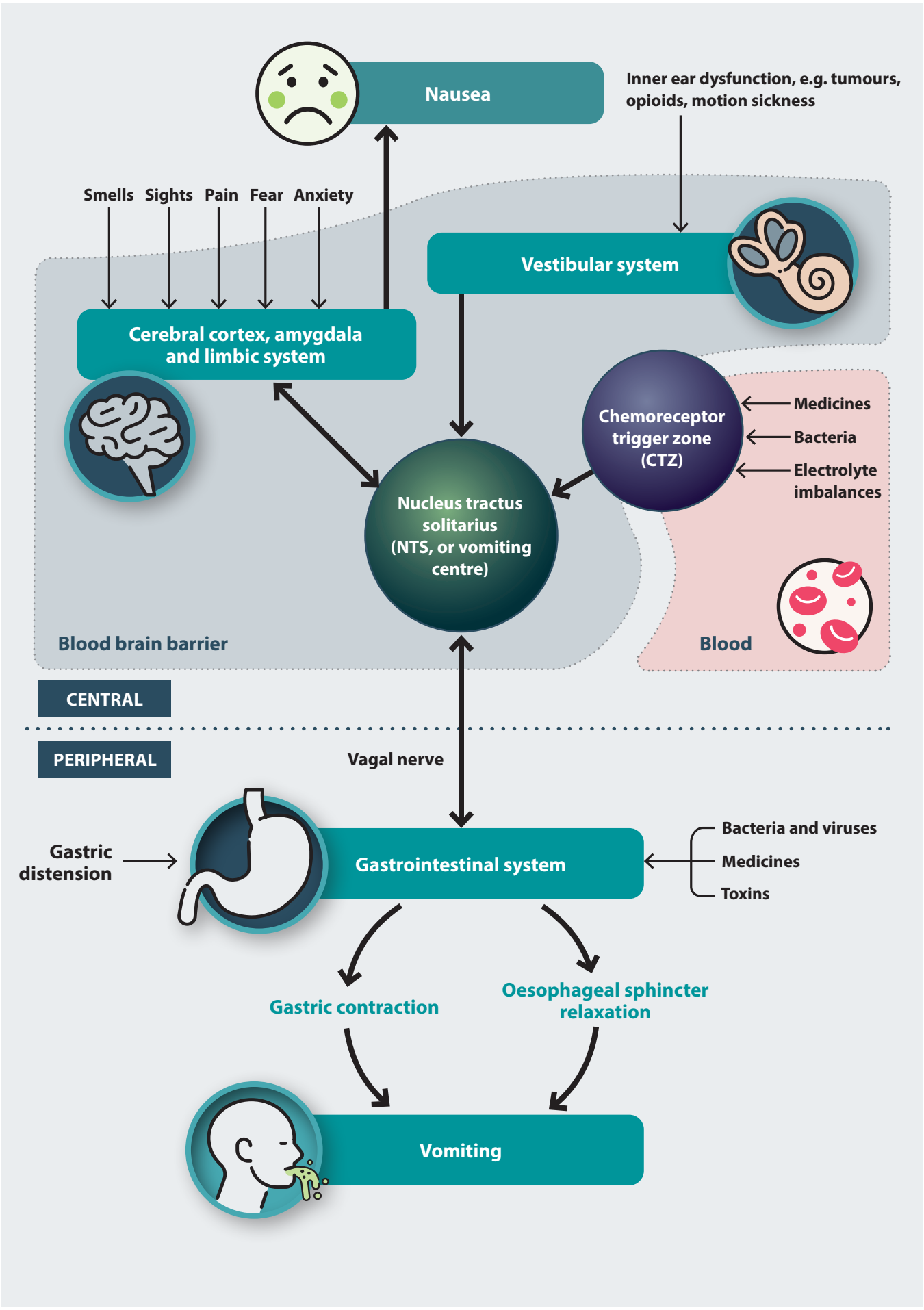


Figure 1. A simplified overview of the pathophysiology of nausea and vomiting.[5–7]

Table 1. Antiemetic medicines for managing nausea and vomiting in the last days of life.

Medicine	Dose	Considerations	Availability
Haloperidol* Dopaminergic (D_2) receptor antagonist (at chemoreceptor trigger zone reducing the effects of circulating abnormalities)[2, 10] In practice, the first-line antiemetic choice as lower adverse effect profile than alternatives, especially in frail or older people Effective for opioid-induced nausea and vomiting, nausea as a result of end stage renal disease or hypercalcaemia[10, 16]	*Patients not currently receiving an antiemetic:* 0.5 mg, subcutaneously every four hours, as needed (usually do not exceed 3 mg/24 hours) *Patients already receiving oral haloperidol should be switched to:* 0.5 – 1 mg, subcutaneously at night, or twice daily, as needed OR 1 – 3 mg/24 hours, via CSCI. Patients whose symptoms are not adequately controlled with 3 mg haloperidol over 24 hours are usually switched to levomepromazine (occasionally a higher dose of haloperidol, e.g. up to 5 mg over a 24-hour period, may be beneficial).	Contraindicated in Parkinson's disease, prolonged QT-interval (gastrointestinal obstruction is a relative contraindication in the last days of life)[8, 16] Avoid in patients with Lewy body dementia due to an increased risk of neuroleptic malignant syndrome[19]	5 mg/mL solution for injection (1 mL ampoules) PSO and prescription
Metoclopramide* D_2 and $5HT_3$ antagonist and $5HT_4$ agonist (at chemoreceptor trigger zone and peripherally promotes gastric emptying and motility)[2, 5] Appropriate for nausea and vomiting caused by gastroparesis, functional bowel obstruction (due to opioid use) and gastro-oesophageal reflux disease[2]	*Patients not currently receiving an antiemetic:* 10 mg, subcutaneously every six hours, as needed (maximum dose 40 mg/24 hours) *Patients already receiving oral metoclopramide should be switched to:* 10 mg, subcutaneously three to four times daily, as needed OR 30 – 60 mg/24 hours, via CSCI[8] however, in practice, patients whose symptoms are not adequately controlled with 40 mg metoclopramide, over 24 hours should be switched to levomepromazine N.B Higher doses of metoclopramide, e.g. 60 mg over a 24-hour period, should be reserved for managing nausea and vomiting that is likely caused by delayed gastric emptying (without obstruction)	Contraindicated in Parkinson's disease, prolonged QT-interval, or if complete bowel obstruction[10, 20] Monitor for extrapyramidal adverse effects, e.g. tardive dyskinesia (more common at doses greater than 30 mg/24 hours) May worsen abdominal cramps in some patients Do not co-prescribe with anticholinergics (e.g. cyclizine, hyoscine butylbromide) if delayed gastric emptying is the clear cause of nausea and vomiting[3]	5 mg/mL solution for injection (2 mL ampoules) PSO and prescription
Cyclizine* H_1 receptor antagonist with anticholinergic actions (at vomiting centre [NTS] and vestibular system)[2] Recommended for nausea and vomiting resulting from raised intracranial pressure (due to brain tumours or secondary metastases), bowel obstruction and vestibular disease[16]	75 – 150 mg/24 hours, via CSCI[16]	Do not co-prescribe with metoclopramide if the likely cause of nausea and vomiting is delayed gastric emptying (without obstruction)[3] Not recommended to be given as a subcutaneous bolus due to injection site reactions	50 mg/mL solution for injection (1 mL ampoules) PSO and prescription
Levomepromazine (methotrimeprazine)† Antagonistic action at dopamine, serotonin, cholinergic and histamine receptors[18] Second-line, broad spectrum antiemetic[16]	3.125 – 6.25 mg, subcutaneously every four to six hours, as needed OR 25 mg/24 hours[8]	Monitor for postural hypotension and excessive sedation[18]	25 mg/mL solution for injection (1 mL ampoules) Only prescription**

CSCI = continuous subcutaneous infusion

* Unapproved route

† Unapproved indication

** Three brands of levomepromazine injections are available on prescription: Levomepromazine (Wockhardt), Levomepromazin-Neuraxpharm (Section 29) and Nozinan (Section 29)

life. Food and fluids should be offered but reducing portion sizes or modifying the consistency may be required (see: "Non-pharmacological management strategies for nausea and vomiting").

Address modifiable causes early

Any modifiable causes of nausea and vomiting should be addressed first:[8]

Long-term medicines associated with nausea and vomiting include cardiac medicines (e.g. digoxin), NSAIDs and anticonvulsants.[2,3] Abrupt discontinuation of corticosteroids can result in adrenal insufficiency which may manifest as nausea.[2] Non-essential medicines should be discontinued (if they have not been already),[3] e.g. statins, oral hypoglycaemics. Possible exceptions include anticonvulsants or other medicines used to control symptoms, e.g. diuretics for heart failure, that could impact comfort or cause distress if withdrawn.[9,10]

Constipation in the last days of life may be caused by medicines, dehydration, reduced food intake, limited movement or bowel obstruction.[11] The benefit of pharmacological treatment may be limited at this time and is often not given, but if constipation is causing significant discomfort and thought to be contributing to nausea and vomiting, pharmacological treatment may be considered. Suppositories (e.g. bisacodyl, glycerol) or enemas (e.g. sodium citrate, phosphate) are preferred as oral medicines may no longer be appropriate.

N.B If constipation is causing distress and treatment is not successful, a rectal examination may be appropriate to rule out faecal impaction or bowel obstruction resulting from a rectal tumour.[10]

Switching opioids in the last days of life may not be practical

Opioids are regularly prescribed for patients receiving end of life care.[12] In some cases, the opioid may be able to be changed or the dose reduced if the usual adverse effects of opioids are intolerable, i.e. nausea, vomiting. However, in the setting of managing a patient in the community in the last days of life, often this is not practical, e.g. due to fixed doses established in syringe drivers, and higher doses needed to manage pain, therefore patients are usually managed by adding an antiemetic rather than withdrawing or changing the opioid. Patients who are vomiting and are currently taking oral opioids should be changed to subcutaneous delivery.[13]

Non-pharmacological management strategies for nausea and vomiting

Patient comfort is the main goal of management for nausea and vomiting. Non-pharmacological strategies to reduce nausea and vomiting include:[1]

- Positioning the patient upright when eating or drinking to reduce the likelihood of choking or aspiration
- Removing sights or smells that are known to trigger symptoms, e.g. certain foods, cooking aromas, deodorants/perfumes, air fresheners
- Adequate ventilation – open windows for fresh air, use of a fan
- Offering small quantities of food if the patient can still eat
  - Some patients may want their favourite food while others may prefer bland foods
  - Provide a variety of fluid options, e.g. water, juice, clear soup
  - Using a straw may make fluid intake easier
  - Offer ice blocks or ice chips if unable to tolerate oral fluids
  - Occasionally, a nasogastric tube may be appropriate for patients with persistent vomiting.[14] Discuss with the local hospice or palliative care team.
- Maintaining good oral hygiene – patients may benefit from regular mouth rinsing, brushing of teeth or cleaning of dentures
  - Mouthwash can be made at home by mixing half a teaspoon of baking soda and half a teaspoon of table salt in 250 mL of water
- Relaxation and distraction techniques, e.g. listening to music, spending time with family/whānau
- Visualisation or guided imagery – allows patients to distance themselves from their symptoms; suggest they imagine themselves in a place associated with happy memories, e.g. favourite holiday spot
- Complementary or alternative remedies for nausea, e.g. ginger ale or peppermint tea
  - Some patients may wish to include Rongoā Māori or other traditional remedies in their care, e.g. bark of the karamu plant (*Coprosma robusta*) for vomiting[15]
- The use of acupressure, either via family/whanau applying pressure to specific points or the use of wrist bands

Pharmacological management of nausea and vomiting

Pharmacological treatments are usually required in addition to non-pharmacological techniques to manage nausea and vomiting (Figure 2). Consider the most likely causes of a patient's nausea or vomiting and the mechanisms of action of available antiemetics when deciding on the most appropriate treatment (Table 1 and see: "The pathophysiology of nausea and vomiting is complex").[10] Patients with multiple possible causes of nausea or vomiting may benefit from a combination of antiemetics;[10] discuss with the local hospice or palliative care team.

Patient is already prescribed one or more antiemetic?

Yes

Convert current oral antiemetic medicines to subcutaneous doses and these can be administered as either regular bolus doses via subcutaneous line or 24-hour CSCI. Examples of subcutaneous antiemetic doses:

- **Haloperidol** 0.5 – 1 mg at night or twice daily (or 1 – 3 mg/24 hours). Patients whose symptoms are not adequately controlled with 3 mg haloperidol over 24 hours are usually switched to levomepromazine (occasionally a higher dose of haloperidol, e.g. up to 5 mg over a 24-hour period, may be beneficial); and/or
- **Metoclopramide** 10 mg three to four times daily (or 30 – 60 mg over a 24-hour period*, however, in practice, patients whose symptoms are not adequately controlled with 40 mg metoclopramide, over 24 hours should be switched to levomepromazine); and/or
- **Cyclizine** 75 – 150 mg, over a 24-hour period†

"Breakthrough" doses of antiemetic medicines should also be prescribed

No

Prescribe (via subcutaneous line) either:

- **Haloperidol** 0.5 mg, every four hours, as needed (maximum dose of 5 mg over a 24-hour period, however, in practice, patients whose symptoms are not adequately controlled with 3 mg haloperidol, over 24 hours should be switched to levomepromazine); or
- **Metoclopramide** 10 mg, every six to eight hours, as needed (maximum dose of 40 mg over a 24-hour period)

Consider switching to CSCI in patients who experience a sufficient improvement in symptoms

Depending on response, patients may require only one antiemetic medicine or a combination of medicines‡

"Breakthrough" doses of antiemetic medicines should also be prescribed

Review the patient within six hours of initiating antiemetic:
For persistent nausea and vomiting in patients taking maximum doses of (or cannot tolerate) first-line antiemetics, clinicians should prescribe levomepromazine (3.125 – 6.25 mg, every four to six hours, as needed). This can either replace or be added to the current antiemetic regimen.

- Consider switching to CSCI up to a maximum dose of 25 mg over a 24-hour period in patients who experience a sufficient improvement in symptoms

"Breakthrough" doses of levomepromazine should also be prescribed.

If nausea or vomiting remains or is worsening, or if additional support is required, contact the local hospice or palliative care team for advice

* Higher doses of metoclopramide, e.g. 60 mg over a 24-hour period, should be reserved for managing nausea and vomiting that is likely caused by delayed gastric emptying (without obstruction)

† Subcutaneous cyclizine should not be given as a bolus dose due to adverse reactions at the injection site

** Cyclizine and metoclopramide should not be prescribed together if the likely cause of nausea and vomiting is delayed gastric emptying

Figure 2. Anticipatory prescribing for patients with nausea and vomiting. Adapted from *South Island Palliative Care Workstream, 2020*.[8, 16]

CSCI = continuous subcutaneous infusion

First-line treatment options for nausea and vomiting

If the patient is not currently taking an oral antiemetic, subcutaneous haloperidol (unapproved route) is an appropriate first-line pharmacological treatment option, unless contraindicated e.g. Parkinson's disease, prolonged QT-interval.[8, 16] Subcutaneous metoclopramide (unapproved route) or cyclizine (unapproved route) are alternative first-line antiemetics for patients who cannot take haloperidol.[8] In practice, haloperidol is preferred in the last days of life as it has a lower risk of adverse effects in people who are frail compared to other first-line options and may have multiple indications, therefore reducing polypharmacy, e.g. it is also used to treat delirium.

Recommended doses:

- 0.5 mg haloperidol, subcutaneously every four hours, as needed (maximum dose 5 mg in 24 hours).[8] N.B. The decision to switch to levomepromazine (see below) is usually considered if symptoms are not adequately controlled with 3 mg haloperidol, subcutaneously over 24 hours.
- 10 mg metoclopramide, subcutaneously every six to eight hours, as needed (usually recommended not to exceed 40 mg in 24 hours)[8]
- 75 – 150 mg cyclizine over 24 hours, via subcutaneous infusion (subcutaneous bolus doses are not recommended due the risk of injection site reactions[17])[16]

Patients who are already taking an oral antiemetic should have their current regimen converted to subcutaneous doses which can be given either as bolus doses or over a 24-hour period using a continuous subcutaneous infusion (Table 1).[8]

Ideally, patients should be reassessed for treatment effectiveness and adverse effects within six hours.[8] It is recommended to convert "as needed" doses to a 24-hour dose for continuous subcutaneous infusion in patients who experience an improvement in symptoms.[8] Additional "breakthrough" subcutaneous doses of the antiemetic should also be prescribed.[8]

Practice point: Ondansetron is not generally recommended to manage nausea and vomiting in patients receiving palliative care as it may exacerbate opioid-related constipation.[2]

Levomepromazine is a second-line treatment option for nausea and vomiting

Levomepromazine* is the most suitable option for patients with persistent nausea or vomiting (unapproved indication) despite taking the maximum tolerable doses of first-line antiemetics.[8] It acts on multiple different receptors, making it suitable for patients with nausea and vomiting due a combination of causes.[10]

The previous antiemetic can be stopped and the patient switched to levomepromazine or it can be added to their regimen if there has been a partial effect from the previous medicine. The recommended initial dose is 3.125 – 6.25 mg of subcutaneous levomepromazine, every four to six hours, as needed (maximum dose 25 mg in 24 hours).[8] If the patient requires more than two "as needed" doses in a 24-hour period, increase the dose.[1] There is a risk of excessive sedation when higher doses of levomepromazine are used.[18]

* Previously known as methotrimeprazine

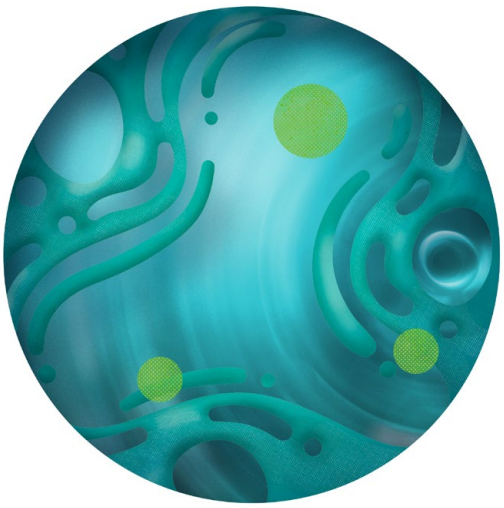
A combination of antiemetic medicines may be required for some patients

Nausea and vomiting often has multiple causes, making symptom management difficult.[3] Patients who do not have a sufficient clinical response to a single antiemetic medicine may benefit from a combination of antiemetic medicines that act via different mechanisms of action (Figure 2).[10] It is recommended to discuss patients with refractory nausea and vomiting with your local hospice or palliative care team.

Practice point: Avoid prescribing anticholinergic medicines (e.g. cyclizine, hyoscine butylbromide) concomitantly with prokinetic medicines (e.g. metoclopramide) in patients with nausea and vomiting attributed to delayed gastric emptying as the anticholinergic effects may reduce the beneficial effects on gastric motility.[3]

Prescribing benzodiazepines for nausea and vomiting

Benzodiazepines, e.g. midazolam, should be considered in patients whose nausea and vomiting may be related to fear or anxiety, e.g. administer beforehand if anticipation of a treatment or procedure is a likely cause of symptoms.[3, 10]



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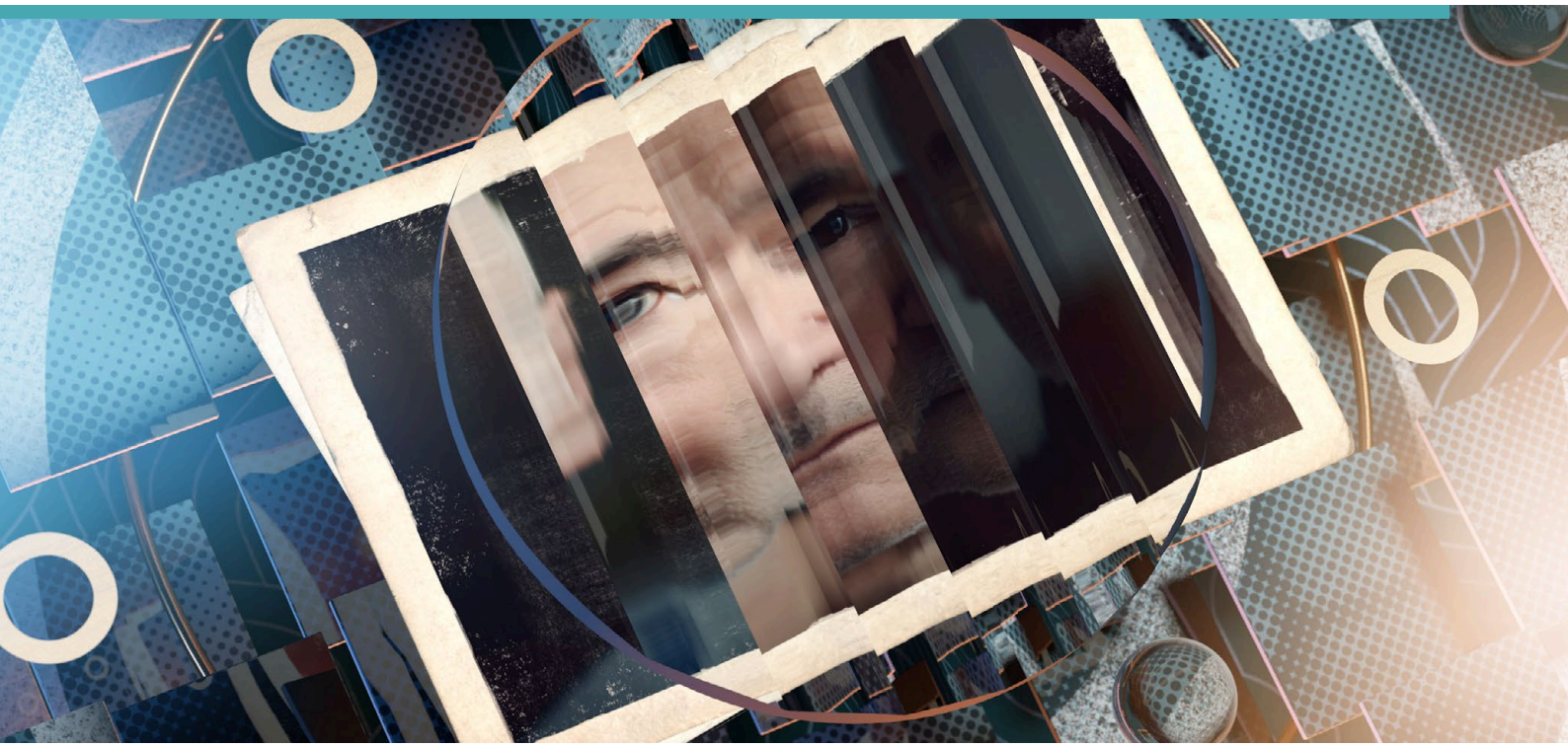

Managing delirium and psychological symptoms in the last days of life

When delirium occurs in the last days of life it is usually irreversible. Pharmacological treatment is only required for patients experiencing significant distressing symptoms, e.g. hallucinations, agitation. Non-pharmacological interventions should be prioritised, and family/whānau can be guided and supported to help with this. Anxiety and other psychological symptoms are also important to consider and manage, as these can exacerbate delirium and other physical symptoms commonly experienced by patients in the last days of life.

KEY PRACTICE POINTS:

- Delirium is a prevalent feature in the last days of life where people experience fluctuations in their attention, cognition, awareness and perception
- The cause is usually multifactorial, involving multiple organ failure and other irreversible factors. However, there are some causes or exacerbators of delirium that can be identified and potentially managed, e.g. pain, urinary retention, infection.
- Non-pharmacological strategies are first-line for patients whose symptoms are not causing distress, e.g. re-orientation cues, creating a safe environment with a comfortable room temperature, a low level of noise and adequate lighting. These interventions may be all that is required to support the patient and their family/whānau.
- If pharmacological treatment is required (e.g. for patients with significant agitation or restlessness), subcutaneous haloperidol or midazolam is recommended first-line based on the patient's level of consciousness
- Psychological symptoms, e.g. anxiety, depression, emotional or spiritual distress, are also common in the last days of life and should be managed as they can exacerbate delirium and other physical symptoms, e.g. breathlessness:
  - General supportive measures and non-pharmacological strategies are first-line
  - Conventional treatments such as cognitive behavioural therapy or antidepressants are unlikely to be appropriate in patients with impaired communication and fatigue, and there is insufficient time for them to have an effect
  - Patients currently taking antidepressants for psychological symptoms should continue to do so until swallowing is no longer possible (if they are providing benefit)
  - An antipsychotic or benzodiazepine may be required for some patients if conservative management is unsuccessful

This article is part of a series on managing symptoms in the last days of life. It is recommended to read this article in conjunction with the other articles in the series, particularly: "**Navigating the last days of life: a general practice perspective**".

Delirium, agitation and restlessness in the last days of life

Delirium occurring in the last days of life (which may include terminal restlessness or terminal agitation) is reported to occur in some form in up to 90% of people.[1, 2] People with delirium typically experience fluctuations in attention, cognition, awareness and perception.[1, 3] There are three types of delirium:[2, 4, 5]

- **Hypoactive delirium** – characterised by drowsiness, inactivity and lack of awareness
- **Hyperactive delirium** – characterised by agitation, hallucinations and restlessness
- **Mixed delirium** – characterised by features of both hypoactive and hyperactive delirium

The cause of delirium in the last days of life is usually multifactorial, involving multiple organ failure and other factors that are now largely irreversible, e.g. hypoxia, metabolic abnormalities.*[4–6] However, some causes or exacerbating factors of delirium can be managed in the final days, such as pain, urinary retention, certain medicines (e.g. opioids, benzodiazepines, anticholinergics) or substances (e.g. nicotine withdrawal) and infection (see: "Managing symptoms of delirium").[7–9] People with pre-existing cognitive impairment are at the greatest risk of delirium.[7] Other risk factors include increasing age, immobility and vision or hearing impairment.[4, 10]

* Delirium that occurs during palliative care prior to the last days of life can often be reversed if this is in line with the person's goals of care, e.g. by correcting metabolic abnormalities, such as hypercalcaemia, hyper/hypoglycaemia and dehydration

Delirium can cause significant distress to the patient and to those supporting them in their last days of life, particularly as this is a time when the patient's cognition, awareness and ability to communicate is highly valued.[4, 5, 11] Provide information and support to the family/whānau, including the likely causes of delirium, potential symptoms and address any questions or concerns they may have.[4, 12] Reassure patients and their family/whānau that this is a normal part of the dying process.

Assessment of delirium

A clinical diagnosis of delirium can be made based on symptom history, pattern recognition and any other relevant information from the family/whānau or carers.[1, 4] Validated tools are available to help assess patients for delirium, e.g. **Confusion Assessment Method (CAM)**, **4AT**.[1, 4] However, these are often not practical or possible to apply in the last days of life, particularly for those with limited communication or fluctuating levels of consciousness.[1, 4, 13]

As a general approach, ask the patient (if possible) or their family/whānau about features of delirium, including any:[1, 4]

- Acute change in mental status and whether this fluctuates throughout the day
- Increase in distractions, disorientation, disorganised thinking or other cognitive changes, e.g. hallucinations, aggression
- Changes in consciousness or activity, e.g. lethargy, stupor, hypervigilance, difficulty sleeping

Repetitive plucking of bed sheets or clothing, groaning and facial grimacing can be signs of delirium in the last days of life.[4, 5, 14] Some patients may also experience auditory or visual hallucinations, which can be distressing for them and their family/whānau.[2, 14, 15] However, these should be distinguished from the positive spiritual visions and experiences that can occur at end of life which are generally comforting and reassuring to patients, and do not require medical intervention.

Managing symptoms of delirium

When deciding on an appropriate treatment plan, consider the patient's emotional, spiritual, social and physical needs.
First consider any reversible causes or exacerbators of delirium, which can be treated.[8, 9, 13] These may include:

- **Pain** – ensure adequate pain relief.[9, 13] For further information, see: "**Managing pain in the last days of life**".
- **Constipation/faecal impaction or urinary retention** – consider use of laxatives/an enema (if possible) or urinary catheterisation if not already in place[14, 16]
- **Medicines,** e.g. corticosteroids, anticholinergics, opioids, benzodiazepines – consider discontinuation or if the medicine is required, lower doses or switching to an alternative medicine[11, 13]
- **Other substances.** If the patient's symptoms are likely caused by nicotine withdrawal, consider use of nicotine replacement patches.[6] A benzodiazepine is often useful for patients with alcohol withdrawal.[17]
- **Infection** (e.g. urinary or respiratory tract infection) – antibiotics may improve the symptoms of delirium if treatment is considered appropriate[4, 10]
- **Psychological causes**, e.g. fear, anxiety or spiritual distress – use non-pharmacological management strategies, considering what interventions (if any) have helped them to overcome this in the past.[7, 13] Antidepressants should not be introduced as there is insufficient time for them to have an effect.[18] For further

information on the management of psychological symptoms, see: "Support the patient's mental health and wellbeing needs".

Prioritise non-pharmacological interventions

Evidence suggests that non-pharmacological interventions are preferable to pharmacological treatments in patients experiencing mild symptoms of delirium.[19, 20] Ideally, non-pharmacological management strategies will have been discussed with the patient and their family/whānau prior to the last days of life so that a plan is already in place (i.e. advance care planning, see: **www.hqsc.govt.nz/our-work/advance-care-planning/**).

Examples of non-pharmacological interventions for delirium:[4, 6, 7, 15]

- Implement safety measures, e.g. lower the bed, use a floor sensor mat, remove nearby potentially hazardous objects
- Regularly reposition the patient
- Gentle mouth care, if tolerated
- Close observation (e.g. by a volunteer "sitter" or family/whānau). Having someone always present can help with re-orientation and reduce the patient's fear/anxiety and feeling of isolation.[3]
- Set an ambient room temperature and consider the patient's proximity to heaters or cold draughts
- Ensure adequate lighting, avoid glare from artificial light or sunlight. Use of a night light may be helpful.
- Maintain a low level of noise in the room and reduce negative distraction, e.g. loud television volume
- Place re-orientation cues, e.g. a clock, newspaper, daily schedules, familiar belongings such as photographs or other personal items
- Access to glasses or hearing aids (if required)
- Suggest relaxation or distraction techniques, e.g. gentle touch or massage, aromatherapy, music or radio
- Spiritual or religious guidance or support (if relevant)

Support the use of other complementary techniques or methods that the patient or their family/whānau want to try if they are unlikely to cause harm, e.g. traditional techniques such as Rongoā Māori, Ayurvedic or Chinese herbal medicines.

Initiate pharmacological treatment as indicated

If non-pharmacological interventions have been inadequate or if the patient is experiencing severe or distressing symptoms, e.g. hallucinations, significant agitation, pharmacological treatment can be initiated.[1, 19]

An antipsychotic (haloperidol) or benzodiazepine (midazolam) administered subcutaneously is recommended first-line for patients requiring pharmacological treatment for delirium, agitation or restlessness, with the initial choice dependent on consciousness level (Figure 1).[6, 15] Benzodiazepines are particularly useful for patients with agitation and anxiety due to their sedating effects, but they can exacerbate symptoms of delirium at high doses.[9, 10, 16] They are also useful for patients whose symptoms of delirium are caused by alcohol withdrawal.[17] Haloperidol is particularly useful for patients who are also experiencing nausea and vomiting as it is the first-line treatment for this in the last days of life; combining indications means fewer medicines are required.

N.B. Some patients, e.g. those with behavioural and psychological symptoms of dementia, will already be taking oral antipsychotics and require conversion to a subcutaneous formulation.[15]

Practice Point: Anticipatory prescribing of "as needed" subcutaneous doses of haloperidol and/or midazolam is also recommended in patients without symptoms of delirium or who do not yet require pharmacological treatment; if symptoms occur/worsen, the "as needed" dose can be administered and then regular dosing initiated (see regimens below).[15]

Haloperidol is recommended first-line for patients who are conscious

If the patient is conscious or semi-conscious, 0.5 mg of subcutaneous haloperidol* should be prescribed and administered stat (subcutaneous injection; unapproved route),[21] with additional doses prescribed on an "as needed" basis, e.g. 0.5 – 1 mg every one to two hours, as needed (to a maximum dose of 5 mg within 24 hours).[15] Ideally, the patient should be reassessed within six hours of initiation to review treatment response.[15]

N.B. Antipsychotics can be associated with restlessness; consider haloperidol as a potential cause if a patient experiences worsening symptoms after treatment initiation.[10, 18] Midazolam can be added early to reduce this effect (or used instead – see below), but do not persist with haloperidol if the patients' distress is worsening.

* Contraindicated in patients with Parkinson's disease and should be avoided in patients with Lewy body dementia[21]

If there has been inadequate response to treatment with haloperidol after six hours:[15]

- **Switch to midazolam** 2.5 mg, administered subcutaneously (stat), and prescribe additional "as needed" doses, e.g. 2.5 – 5 mg, every 30 minutes, as needed; and/or
- **Add levomepromazine**† 6.25 mg, administered subcutaneously, every four to six hours, as needed.

Levomepromazine is a second-line option to haloperidol (with or without midazolam) and is highly sedative. If levomepromazine is used on an "as needed" basis with effect, discontinue haloperidol and convert the daily dose of levomepromazine to a 24-hour dose for continuous subcutaneous infusion, and prescribe additional "as needed" doses.

† Previously known as methotrimeprazine

Midazolam is recommended first-line for patients who are unconscious

If the patient is unconscious, 2.5 mg of subcutaneous midazolam (unapproved indication) should be prescribed and administered stat, with additional doses prescribed on an "as needed" basis, e.g. 2.5 – 5 mg, every 30 minutes, as needed (to a maximum dose of 20 mg within 24 hours).[15] Ideally, the patient should be reassessed within six hours of initiation to review treatment response.[15]

If treatment is ineffective after six hours, add levomepromazine 6.25 mg administered subcutaneously (stat), and prescribe additional "as needed" doses, e.g. 6.25 mg, every four to six hours, as needed.[15]

Practice Point: Patients already established on high dose anxiolytics may require higher doses of midazolam.[15]

Support the patient's mental health and wellbeing needs

Nā koutou i tangi, nā tātou katoa

When you cry, your tears are shed by us all

"Empathy has no script. There is no right way or wrong way to do it. It's simply listening, holding space, withholding judgement, emotionally connecting, and communicating that incredibly healing message of 'you're not alone'" *– Brené Brown*

When caring for a patient experiencing psychological distress, the aim is for them, and their family/whānau, to feel comfortable explaining any fears or concerns.[16] Use communication techniques such as asking open questions, active listening and the appropriate use of silences, speech tone and eye contact.[16]

Identifying the cause of the patient's psychological distress in the last days of life is often difficult as there are usually multiple overlapping causes, such as:[18, 22]

- Fear of pain or other worsening symptoms
- Loss of independence or a sense of burden on carers
- Fear of dying
- Anticipatory grief
- Spirituality concerns
- Contemplating the meaning of life and their purpose
- Concerns about the needs of their family/whānau after they die

Managing psychological symptoms for patients in the last days of life

The initiation of conventional treatments for psychological symptoms, e.g. antidepressants or cognitive behavioural therapy for depression, is not appropriate in the last days of life as there is insufficient time to achieve any benefit, and patient participation will be limited due to fatigue or impaired communication.[3, 18] Patients currently taking antidepressants for psychological symptoms should continue to do so until swallowing is no longer possible (if they are providing benefit).[18]

General supportive and non-pharmacological interventions are appropriate. Additional support may be required for patients with a pre-existing psychological condition.[3] Non-pharmacological strategies may include relaxation or distraction techniques such as listening to music or watching television, aromatherapy, mindfulness-based techniques, reminiscing, spending time with family/whānau or a family pet or therapy animal.[3, 15, 18] Ask about any coping strategies used in the past and whether these could be used again, if appropriate.[7] Patients with spiritual distress may benefit from spiritual or religious guidance or support.[3, 16]

Some patients with insomnia, anxiety or depression may require pharmacological treatment with an antipsychotic or benzodiazepine administered subcutaneously, if conservative management is unsuccessful.[3, 18] Opioid doses should not be increased to sedate the patient.

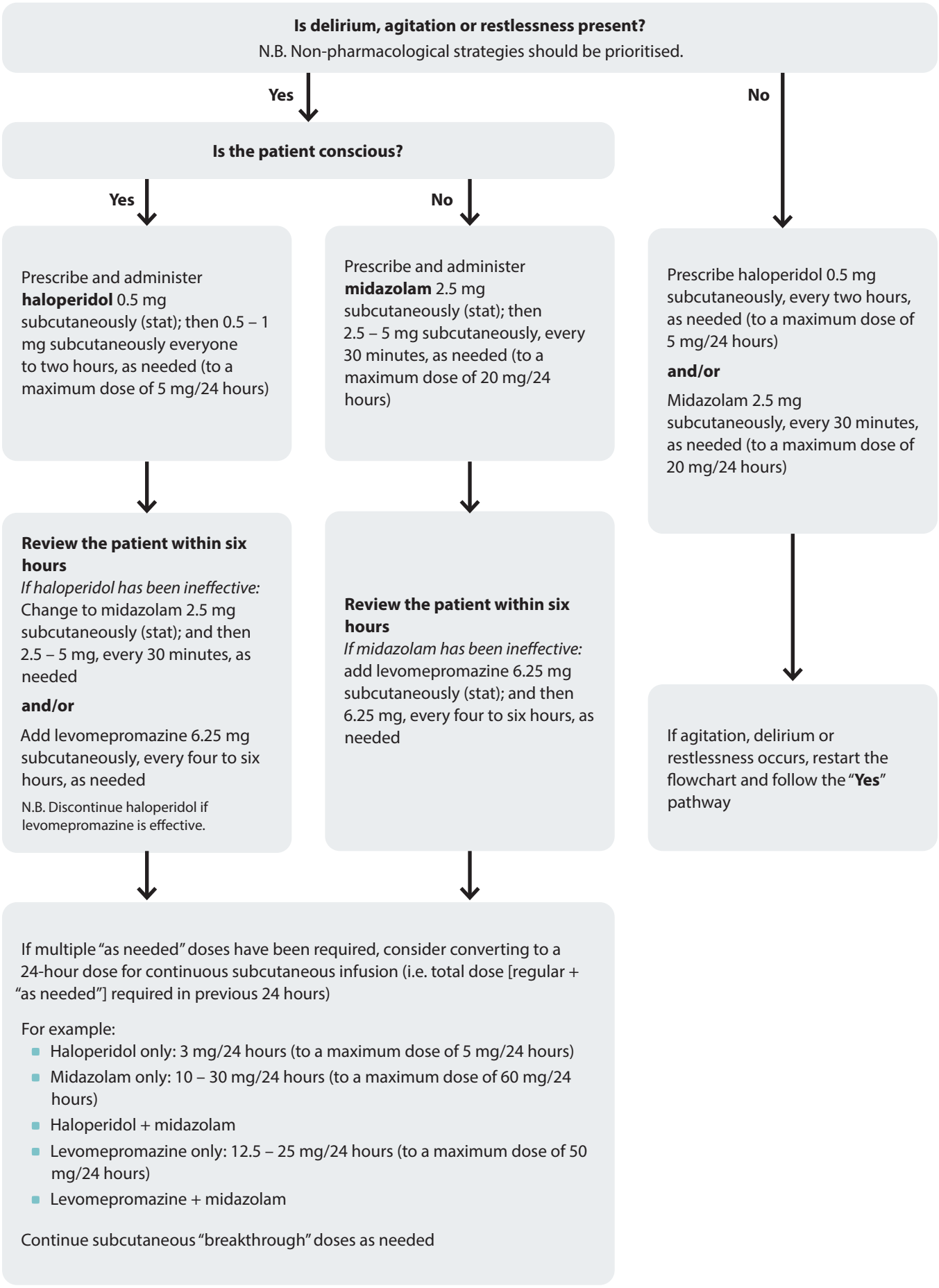

Figure 1. Anticipatory prescribing flowchart for delirium, agitation and restlessness. Adapted from *South Island Palliative Care Workstream, 2020*.[15]

Consider conversion to a continuous subcutaneous infusion

If multiple "as needed" doses of haloperidol, midazolam or levomepromazine have been required, consider converting to a 24-hour dose for continuous subcutaneous infusion, i.e. total (regular + "as needed") subcutaneous doses required in previous 24 hours (Figure 1).[15] Each of these medicines can be used alone for continuous subcutaneous infusion or combination treatment may also be trialled.[15] Continue subcutaneous "breakthrough" doses as needed.[15]

Contact the local hospice or palliative care team for advice if the patients symptoms do not respond to appropriate treatment, or if there is unwanted sedation.[8]

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Managing dyspnoea in the last days of life

Dyspnoea is commonly experienced by people who are nearing the end of life. Once reversible causes have been addressed, management focuses on symptom relief and increasing comfort using non-pharmacological interventions and opioids

KEY PRACTICE POINTS:

- Ideally, the patient's own evaluation of their breathing should be used to assess dyspnoea in the last days of life. For patients with limited or no communication, clinical signs may provide sufficient information, e.g. use of accessory muscles, pursed lip breathing or grimacing.
- Non-pharmacological interventions are paramount and should be used in conjunction with pharmacological treatments, e.g. repositioning the patient upright with pillows to support their head and neck, or arms resting on the back of a chair, increasing air flow around the patient with an open window or fan, relaxation techniques
- First-line pharmacological treatment for patients with dyspnoea is morphine, and subcutaneous administration is the most appropriate route in the last days of life
- There is currently no evidence of benefit for subcutaneous oxycodone or fentanyl in the treatment of dyspnoea but either of these may be trialled if morphine is unable to be used
- Benzodiazepines, e.g. midazolam, can also be used in addition to opioids if symptoms of anxiety are contributing to the patient's dyspnoea. There is no evidence that midazolam relieves breathlessness directly.
- Oxygen is only indicated for patients with dyspnoea and established hypoxaemia due to disease

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Dyspnoea in the last days of life

Dyspnoea (breathlessness) is one of the most common symptoms experienced by people who are nearing the end of life.[1] It should be distinguished from altered breathing patterns and decreasing oxygen saturation that are normal parts of the dying process,[2] and do not require pharmacological intervention on their own. For example, Cheyne-Stokes respiration is a pattern of breathing commonly observed in the last days of life, characterised by alternating periods of hyperventilation and apnoea.[4] It does not require treatment, however, when it occurs in conjunction with dyspnoea and other signs of distress, e.g. sweating, agitation, treatment may be indicated.[2]

The underlying pathophysiology of dyspnoea is complicated, but it is thought to result from three main abnormalities:[3]

1. A perceived increase in work of breathing or respiratory effort, e.g. due to airflow obstruction, associated with conditions such as COPD or bronchiectasis or large pleural effusion
2. An increase in the proportion of respiratory muscles and chest wall strength required to maintain homeostasis, e.g. in people with neuromuscular disease or cancer cachexia/weakness
3. An increase in oxygen requirements, e.g. due to anaemia, sepsis, acidosis or hypoxaemia

These factors induce the sensation of dyspnoea via a complex interplay between chemoreceptor stimulation, mechanical abnormalities in breathing and the perception of those abnormalities by the central nervous system.[3] In some cases, panic and fear relating to difficulty breathing, or "air hunger", may further enhance the patient's physical distress.[3]

In patients receiving palliative care, the initial aims of management are to treat any underlying conditions that may be aggravating their ability to breathe, and therefore reduce the level of dyspnoea.[1] However, as the patient enters their last days of life, the goal of treatment transitions to alleviating the perception of dyspnoea via symptom relief. Treatment should begin with non-pharmacological interventions, then consider the addition of low-dose morphine, and if appropriate, benzodiazepines (if anxiety is a factor in their symptoms).[2,4] An individualised approach is required as treatment effectiveness varies between patients.

Assessing the patient's condition

The patient's own evaluation of their breathing is the most effective tool for assessing dyspnoea.[2] Patients may describe the feeling as not getting enough oxygen with each breath, having to work harder to breathe or chest tightness.[3] Clinical signs indicative of dyspnoea include tachypnoea, pursed lip breathing, gasping or wheezing, increased intercostal accessory muscle use and tachycardia.[2] Chest auscultation may reveal abnormal sounds, e.g. rhonchi or crackles.[5]

As the end of life approaches, the ability to communicate effectively is often lost. In patients who have limited or no communication, look for signs of distress in addition to the symptoms and signs mentioned above, e.g. sweating, agitation and facial expression.[6] Ask family/whānau about any noticeable changes in the patient's condition.

Non-pharmacological interventions for dyspnoea

Non-pharmacological interventions should initially be prioritised for managing dyspnoea in patients in their last days of life.[7] The acceptability and effectiveness of interventions will depend on individual patient circumstances and preference. Ideally, many of these strategies will have been recommended and discussed with the patient and their family/whānau prior to the last days of life so that a clear and agreed upon plan is already in place (i.e. advance care planning, see: **www.hqsc.govt.nz/our-work/advance-care-planning/**).

Non-pharmacological strategies aimed at improving patient comfort include:

Positioning the patient so that their head and torso are elevated.[2] An upright position is preferred* but patients in their last days of life may be unable to maintain this position. Use pillows to support the patient's head, neck, torso and arms.[6] Horseshoe pillows ("tri-pillows") should be avoided due to a risk of increased respiratory difficulty if a smaller patient is incorrectly positioned and sinks into the crevice.[2] Sitting backwards on a chair and leaning forward to lift the arms and support the upper body may also be beneficial if the patient is still mobile.

* Patients with single-sided lung dysfunction may benefit from lying on their side with the affected lung positioned downwards

Optimising the patient's immediate environment.[2] Depending on patient preference, this may include opening curtains and windows to allow light in and fresh air to circulate around the patient.[6] Remind family/whānau to avoid smoking/vaping around the patient. A small fan directed towards the face may be beneficial for some patients as evidence has shown this can reduce the sensation of dyspnoea.[4] Consider a dehumidifier as excessive humidity can worsen dyspnoea.[2]

Interventions to reduce anxiety.[2] For example, relaxation and distraction techniques, listening to music, spending time with family/whānau.[6]

Consider the need for nicotine replacement therapy, e.g. patches, for patients with a history of smoking and who are at risk of withdrawal symptoms.[10]

Complimentary or alternative medicines. The patient or their family/whānau may want to try traditional techniques and methods for symptom relief, e.g. Rongoā Māori, Ayurvedic or Chinese herbal medicines. These should be supported if they are unlikely to cause harm.

Practice point: A person's head is considered tapu (sacred) by Māori, and things that touch the head (e.g. facecloths and pillows) are also tapu by extension.[8] If a pillow has been used to support another part of the body (especially the lower half of the body), it should not be reused to support the patient's head.[8] Different coloured pillowcases can be used to help observe this.

Morphine for dyspnoea

Morphine is the most widely studied and extensively used medicine for the treatment of dyspnoea in patients with a terminal condition.[9] The exact mechanism by which morphine alleviates dyspnoea is unknown, however, opioid receptors are located throughout the respiratory tract and are known to reduce respiratory drive; they may also reduce the sensation of dyspnoea.[9] Anticipatory prescribing of "as needed" doses of morphine is recommended in patients without current dyspnoea (unapproved indication); if dyspnoea arises the "as needed" dose can be administered and then regular dosing initiated.[6]

Initiating opioids for dyspnoea

Opioid naïve patients. Initially low doses may be prescribed on an as needed basis, e.g. 1 – 5 mg of morphine, subcutaneously, every one to two hours, "as needed" (Figure 1).[6] Exact dosing will be determined by the patient's overall clinical condition.

Patients already taking opioids. Many patients in their last days of life will already be taking oral or transdermal opioids for other indications. Convert their daily oral opioid doses to a 24-hour dose for continuous subcutaneous infusion. A further dose for "breakthrough" symptoms can then be calculated by dividing their total 24-hour dose by six.[6] This "breakthrough" dose should be prescribed every hour, as needed and also delivered subcutaneously.[6] N.B. Morphine is normally prescribed two to four hourly, however, in an end of life care setting, doses may be given hourly if required.[10] For patients already using fentanyl patches, see: "Morphine may not be appropriate for all patients".

Review patient response. Ideally, patients should be reassessed within six hours of morphine initiation to review their response to treatment, check for adverse effects and if required, escalate the dose.[6] If there has been mild improvement in symptoms but the patient remains distressed by their dyspnoea, escalate the daily morphine dose by the "total breakthrough" dose in the last 24 hours.[6] A new "breakthrough" dose will now need to be calculated.[6]

Morphine may not be appropriate for all patients

If a patient is unable to take morphine due to an allergy, severe renal impairment or intolerable adverse effects, an alternative strong opioid can be trialled, however, oxycodone and fentanyl have not been as extensively studied for the management of dyspnoea as morphine.[2]

Morphine in patients with renal impairment

In patients with renal impairment, the active metabolites of morphine (or oxycodone) can accumulate resulting in opioid toxicity.[1, 11] Subcutaneous fentanyl is usually the most appropriate option for patients with significant renal impairment (i.e. eGFR < 30 mL/min/1.73 m^2),[6] however, dosing and administration is more complicated than morphine, and contraindications for treatment in this setting become less absolute. Expert opinion is that in patients with severe renal impairment who are imminently dying, small doses of subcutaneous morphine, e.g. 2.5 mg, every six hours, as needed, can be used effectively for dyspnoea with minimal risk of adverse effects.

Oxycodone (unapproved indication) administered subcutaneously is considered approximately dose-equivalent* to subcutaneous morphine,[12] and can be initiated at a similar dose for dyspnoea. Patients already prescribed oral oxycodone for other indications should have their current dose converted to a 24-hour dose for continuous subcutaneous infusion and prescribed further "breakthrough" doses of oxycodone (one-sixth of the total 24-hour dose), as needed (Figure 1).[6]

* This applies to both subcutaneous and intravenous routes (but not the oral route where the ratio of morphine to oxycodone is 1.5:1 or 2:1)[12]

Fentanyl (subcutaneous; unapproved indication) is usually considered first-line for patients with dyspnoea and significant renal impairment, i.e. an eGFR < 30 mL/min/1.73 m^2 (Figure 2);[6] however, dosing and administration is more complicated than morphine. Discussion with the local hospice or palliative care team may be required.

Prescribe 10 – 20 micrograms of subcutaneous fentanyl, every hour, as needed. Patients who are still experiencing dyspnoea 12 hours after the first fentanyl dose should be initiated on 100 – 300 micrograms fentanyl over 24 hours via continuous subcutaneous infusion. After 24 hours the

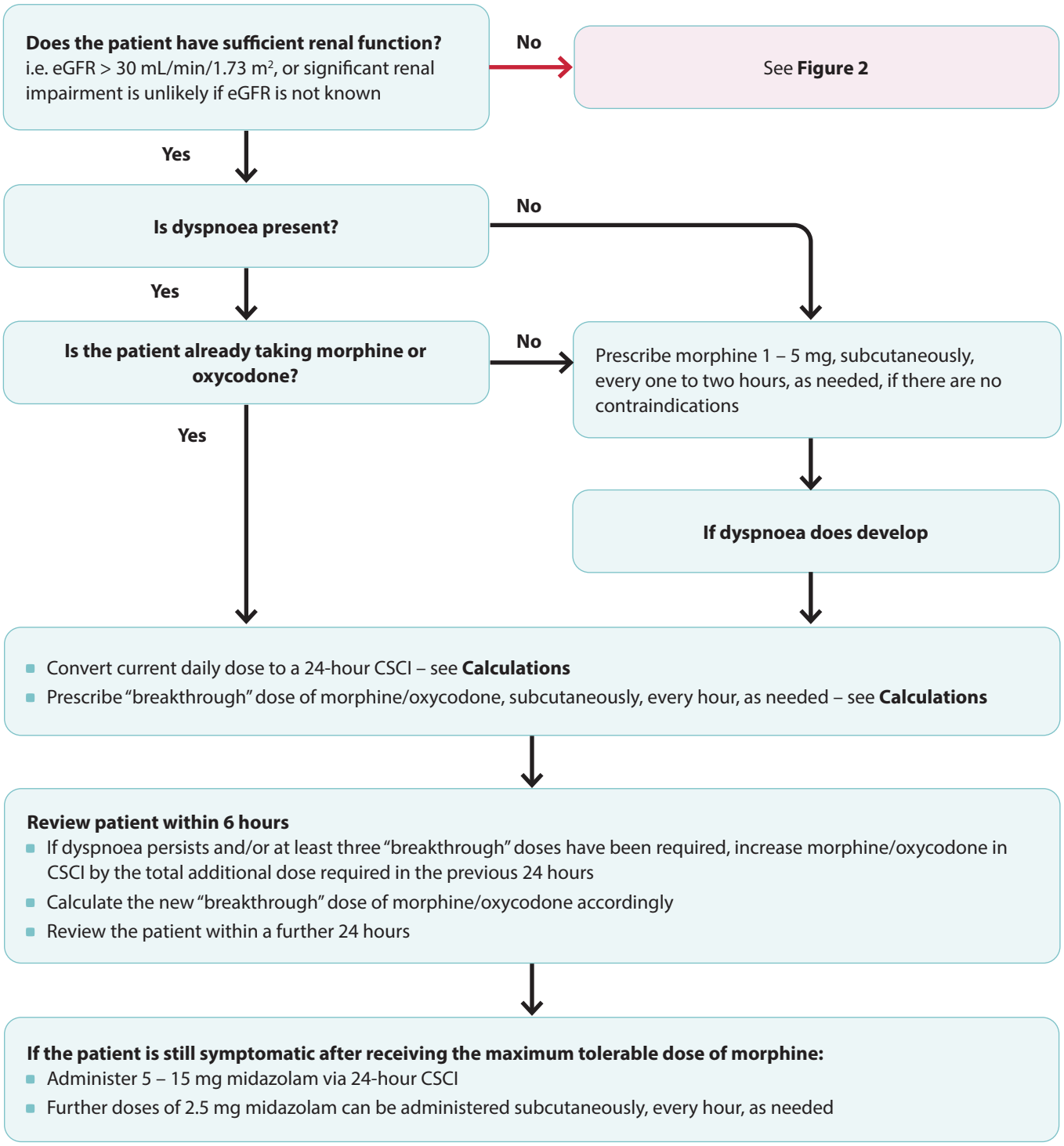
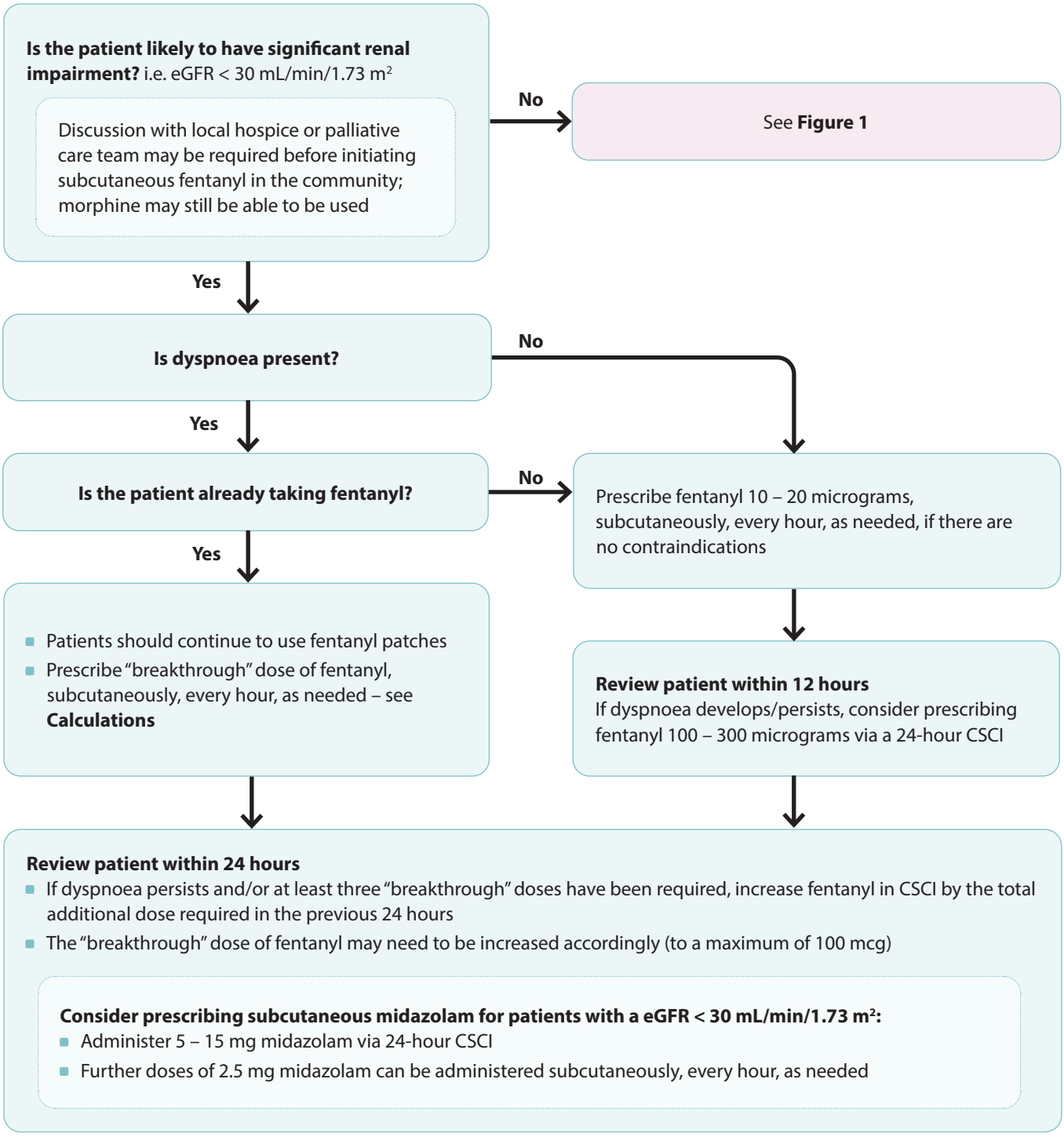


Figure 1. Anticipatory prescribing for patients with dyspnoea (see Figure 2 for an alternative pathway for patients with renal dysfunction). Adapted from *South Island Palliative Care Workstream, 2020.*[6]

CSCI = continuous subcutaneous infusion



If dyspnoea remains or is increasing, or if additional support is required, contact the local hospice or palliative care team for advice

Calculations

- Subcutaneous "breakthrough" dose of fentanyl for patients using fentanyl patches: equivalent to the hourly dose of transdermal fentanyl (maximum 100 micrograms in 2mL)
- Contact the local hospice or palliative care team for advice on dose titrations and conversions for fentanyl

Figure 2. Anticipatory prescribing for patients with dyspnoea and reduced renal function. Adapted from *South Island Palliative Care Workstream, 2020.*[6]

CSCI = continuous subcutaneous infusion

patient should be reviewed; those who require more than three "breakthrough" doses in this period should have their 24-hour subcutaneous fentanyl dose increased by the total "breakthrough" dose.

Practice point: Fentanyl patches take 72 hours to reach steady state and should not be initiated in patients who are opioid naïve.[1] The lowest dose fentanyl patch (12.5 micrograms/hour) is equivalent to up to 60 mg of oral morphine.[1] Patients already prescribed fentanyl patches can continue to use them.[13]

Benzodiazepines for dyspnoea

There is no evidence that benzodiazepines reduce dyspnoea directly,[14] however, they are effective at reducing the associated feelings of panic and anxiety, which in turn may reduce the sensation of dyspnoea.[15] Benzodiazepines should be the next step if non-pharmacological interventions and morphine have not sufficiently relieved symptoms.[14] They can also be considered in patients with reduced renal function,[6] if higher doses of morphine are not appropriate.

Benzodiazepines are usually used in combination with opioids, however, a degree of sedation is inevitable. Doses should be titrated to effect and proportional to the severity of symptoms and patient-related goals.

The recommended dose is 5 – 15 mg midazolam over a 24-hour period via continuous subcutaneous infusion.[6] Further subcutaneous doses of 2.5 mg midazolam can be administered hourly, as needed.[6]

Oxygen for patients with dyspnoea and hypoxaemia

Initiation of oxygen for patients in the last days of life is not commonly required.[7] Oxygen treatment is only recommended for patients with dyspnoea and established hypoxaemia due to disease, i.e. oxygen saturation < 88%.[16, 17] Consider potential adverse effects, e.g. oromucosal dryness, when deciding whether to initiate oxygen as these may outweigh any clinical benefit;[18] discussion with the local hospice or palliative care team may help with decision making. Pharmacological management remains the priority when oxygen is initiated.

While there is not enough evidence to support oxygen treatment for patients with dyspnoea if hypoxaemia is not present,[19] always consider individual patient goals. For example, oxygen therapy may be beneficial (alongside pharmacological measures) in patients who wish to remain at home in their last days of life, if there is clear progressive pathology, e.g. pleural or pericardial infusion.

Patient eligibility for home oxygen is determined by local criteria/policies and in some areas may require authorisation by a respiratory clinician.

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Managing excessive respiratory secretions in the last days of life

Excessive respiratory secretions result when the person becomes too weak to clear their airways in the last days of life. The associated breathing sounds can be particularly concerning for family/whānau, but they can be reassured that it is not a sign of distress or discomfort. The effectiveness of pharmacological treatments is limited and they do not remove secretions already present, so prioritise reassurance of the family and non-pharmacological interventions.

KEY PRACTICE POINTS:

- In patients with excessive respiratory secretions, non-pharmacological interventions include minor positional changes, e.g. upright position with the patient's head to the side, and regular mouth care, e.g. swabbing secretions that accumulate in the mouth
- Prioritise education and reassurance for the family/whānau; explain the causes of abnormal breathing noises and reassure them that the patient is not in distress or experiencing discomfort
- Pharmacological treatment is usually only considered if the patient is unconscious (or semi-conscious) and the excessive secretions are impacting their care or causing distress for the family/whānau. Adverse effects of treatment are common, e.g. worsening dry mouth, therefore it should be stopped if not effective.
- The first-line pharmacological treatment is subcutaneous hyoscine butylbromide:
  - Glycopyrronium bromide is another treatment option
- If the patient's symptoms do not respond to appropriate treatment, contact the local hospice or palliative care team for advice

This article is part of a series on managing symptoms in the last days of life. It is recommended to read this article in conjunction with the other articles in the series, particularly: "**Navigating the last days of life: a general practice perspective**".

Excessive respiratory secretions in the last days of life

In the last days of life, excessive respiratory secretions accumulate in the airways when the person no longer has the awareness or energy to clear the fluid.[1] Inspired (and expired) air passes over the secretions that settle in oropharynx, laryngopharynx and bronchi causing vibrations and a crackling noise, sometimes referred to colloquially as the "death rattle".[1] These sounds can be significantly distressing for the person's family/whānau as they can be misinterpreted as signs of "drowning" or suffocating.[2]

Excessive respiratory secretions can be classified as either Type I, caused by salivary secretions or Type II, caused by the build-up of fluid in the lungs.[3] Type II fluid retention is often the result of pulmonary disease, e.g. COPD, asthma, bronchitis, bronchiectasis, cystic fibrosis and lung cancer.[3] Other contributory factors to excessive respiratory secretions include heart failure, cardiac dysfunction, discontinuation of corticosteroid treatment (for raised intracranial pressure), neuromuscular disorders, e.g. myasthenia gravis, head and neck cancers and brain tumours.[3]

Management of patients with excessive respiratory secretions

Family/whānau can help with the patient's positional changes and mouth care, e.g. providing small amounts of fluid or ice chips, applying lip emollients.[4] Elevating the patient's upper body in bed and positioning their head to the side may reduce breathing noises.[4] In most cases, suction is unlikely to be beneficial, and it can increase secretions and damage the oropharynx/laryngopharynx.[4, 5] Swabbing secretions that accumulate in the mouth with a small sponge may provide some relief.[3] It may be helpful to suggest background music to mask the breathing sounds if this eases distress for the family/whānau.[4]

Reassure family/whānau that the noises made in response to respiratory secretions are not signs that their loved one is in distress, but a normal part of the dying process.[2, 6] Concepts to explain to the family/whānau include:

- Their loved one no longer has enough energy to swallow or cough up the fluid in their throat (or is not aware they need to due to declining level of consciousness)

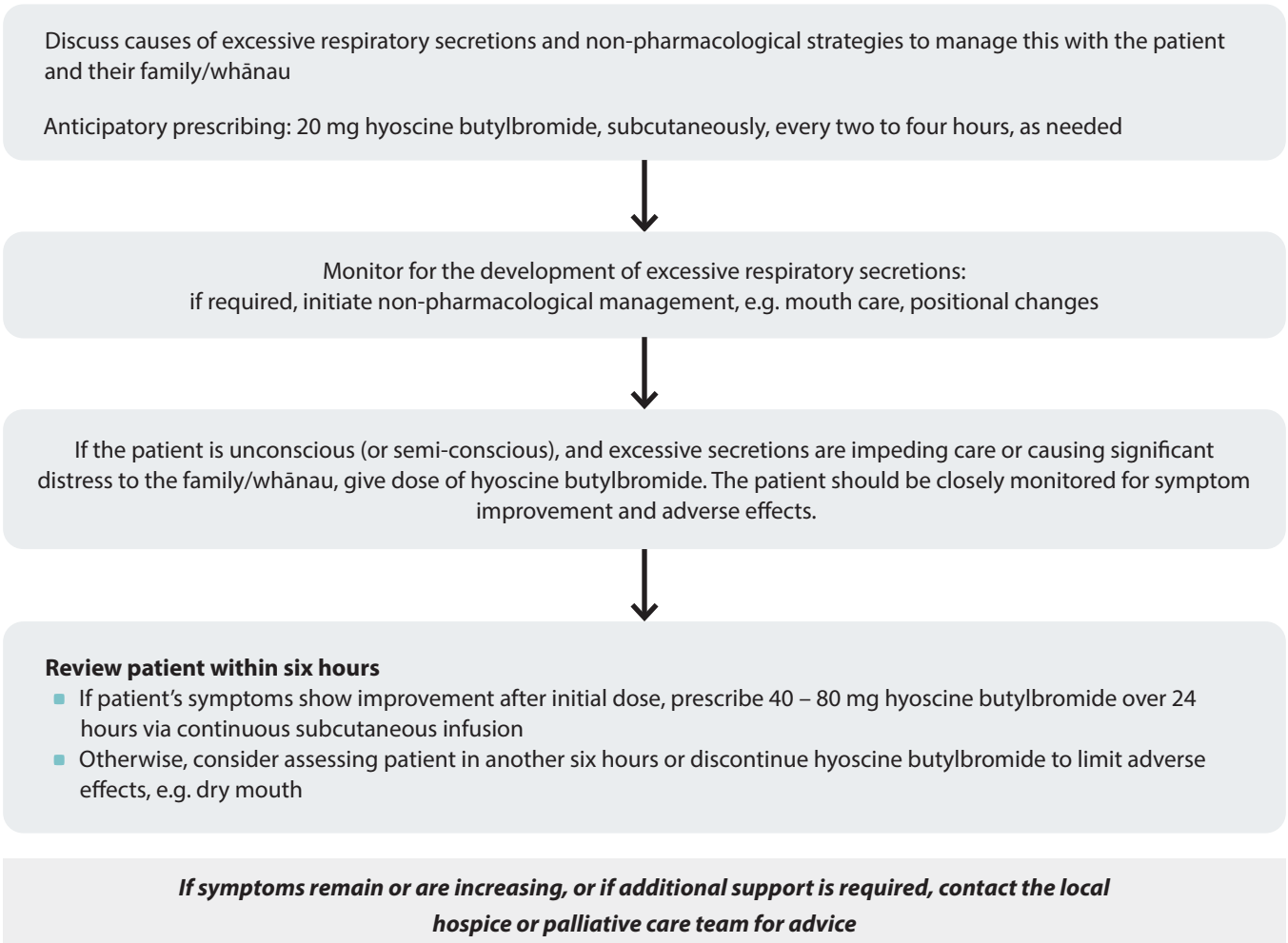

Figure 1. Anticipatory prescribing for patients with excessive respiratory secretions. Adapted from *South Island Palliative Care Workstream, 2020*.[4]

- The noise itself is the sound of air travelling over the pooled fluid (this can be likened to sucking the last of a drink out of a glass with a straw – even small amounts of fluid can make a loud noise)
- Their loved one is not drowning or suffocating
- It often indicates a transition into deep unconsciousness and that death is getting closer
- Medicines will not remove the secretions that are already there; repositioning the person will likely provide more benefit

Support the use of traditional techniques and methods for symptom relief that the patient or their family/whānau want to try if they are unlikely to cause harm, e.g. Rongoā Māori, Ayurvedic or Chinese herbal medicines.

Initiating pharmacological treatment for excessive respiratory secretions

There is limited evidence supporting pharmacological interventions for excess respiratory secretions;[2] they do not remove secretions already present,[7] and only reduce the amount of new secretions forming. Therefore, the benefits of pharmacological options need to be weighed against the adverse effects, and in most cases will often only be appropriate if the patient is unconscious (or semi-conscious).

Hyoscine butylbromide (Buscopan; unapproved indication) is the first-line treatment for patients with excessive respiratory secretions in the last days of life.[5] It reduces secretions due to its anticholinergic action on smooth muscle,[5] however, this mechanism can also cause adverse effects, e.g. dry mouth, constipation and urinary retention.[8] Therefore, patients should be regularly evaluated while receiving treatment, and have mouth care prioritised, even if unconscious.

Give 20 mg, subcutaneously, every two to four hours, as needed (maximum 120 mg daily).[5] Ideally, patients should be reviewed within six hours,[4] although it may take up to 12 hours to see a therapeutic effect.[2] Hyoscine butylbromide should be stopped if the patient shows no improvement after 12 hours.[2] Patients who do show benefit can be switched to a continuous subcutaneous infusion of 40 – 80 mg, hyoscine butylbromide over a 24-hour period.[4]

N.B. Hyoscine *hydrobromide* (Scopoderm TTS) patches are usually avoided in this setting due to a high risk of severe adverse effects, e.g. delirium.[9]

Glycopyrronium bromide is another anticholinergic medicine used to decrease salivary and respiratory secretions.[9] It is an alternative treatment for excessive respiratory secretions in patients in the last days of life (unapproved indication) if hyoscine butylbromide is not available or appropriate.[8] Glycopyrronium bromide can be given as 200 micrograms, subcutaneously, every four hours, as needed.[9] A continuous subcutaneous infusion of 0.6 – 1.2 mg over a 24-hour period may also be considered in patients who show improvement in symptoms.[9]

Practice Point: Adverse effects of anticholinergic medicines need to be considered in the context of the patient's clinical condition and the goals of treatment; some cautions and contraindications for these medicines may not apply to patients in the last days of life, e.g. bowel obstruction (or paralytic ileus), risk of glaucoma, hypertension, tachycardia. Discussion with the local hospice or palliative care team may help with decision making. N.B. Do not prescribe hyoscine butylbromide and metoclopramide together as they have opposing clinical effects.[8]

Regularly review the patient's ongoing care plan and ensure that interventions are current and still appropriate for the clinical condition of the patient.[2] In some situations, limiting or stopping hydration may be considered to reduce the impact of pulmonary oedema or respiratory secretions.

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