


Navigating the last days of life: peer group discussion for general practice

The following questions can be used as discussion points for peer groups or self-reflection of practice. You may choose to focus on specific topics only, or omit certain questions, if time does not permit full discussion.

 It is strongly recommended that the following article is read before considering the questions:

- **“Navigating the last days of life: a general practice perspective”**

The associated articles on symptom management may also help when considering these discussion points:

- **“Managing pain in the last days of life”**
- **“Managing nausea and vomiting in the last days of life”**
- **“Managing delirium and psychological symptoms in the last days of life”**
- **“Managing dyspnoea in the last days of life”**
- **“Managing excessive respiratory secretions in the last days of life”**

Death is an inevitable part of every person’s journey. The idea of what defines a “good death” differs between people and is shaped by their life experiences, beliefs, culture and medical history. How someone transitions through their final days can also vary significantly. Delivering a consistent standard of care that is both individualised yet adaptable is therefore essential.

Hospices and other in-patient palliative care providers in New Zealand work hard to deliver high quality end of life support, however, a significant number of people will spend their final days at home. In these situations, general practice teams may be tasked with being the primary provider of end of life services, often working in collaboration with other health professionals, e.g. district nurses, aged residential care facility staff, hospice services and ambulance services. As New Zealand’s population ages, the need for this care will inevitably increase.

In 2017, **“Te Ara Whakapiri: Principles and guidance for the last days of life”** was published by the Ministry of Health (Manatū Hauora). It outlines the essential components and

considerations required for providing best practice care at the end of life; specific aspects of this work were **updated in 2020**. Key concepts for providing quality and consistent care include:

- Individualising care to meet the needs of the person and their family/whānau
- Clearly and respectfully communicating all information about the person’s status
- Documenting details of conversations and decisions
- Supporting the family/whānau throughout the journey

The principles of Te Whare Tapa Whā can be used as a framework for establishing and delivering an individualised care plan, taking into consideration not only symptom management and physical care (taha tinana), but the mental/emotional (taha hinengaro), family/social (taha whānau) and spiritual (taha wairua) aspects of wellbeing. After identifying the lead health practitioner and establishing contact protocols, a comprehensive baseline assessment is required to establish physical care needs. This process invariably leads to anticipatory medicine prescribing so that carers can provide timely symptom relief without the need for in-person clinician assessment. Symptoms that commonly occur during the last days of life include pain, nausea/vomiting, delirium and psychological symptoms, dyspnoea (breathlessness) and excessive respiratory tract secretions. Non-pharmacological management strategies should also be discussed with the family as an important component of all care plans (e.g. comfortable environment/atmosphere, using relaxation techniques, playing music); this can potentially limit the amount of medicines required and therefore reduce the associated adverse effects. It is important to also identify any cultural, religious or spiritual needs that the patient or family/whānau have and consider how these can be incorporated into the care plan. Other considerations, depending on the clinical circumstances, may include discontinuing medicines used for long-term conditions, providing supportive equipment, co-ordinating the set-up of a syringe driver and arranging for implantable cardioverter-defibrillators to be turned off.

Once a care plan is established, the family/whānau should be supported in its implementation; they 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. This information should be reviewed at least once daily by a member of the healthcare team. Be conscious that circumstances and the person’s wishes can change over time, meaning adjustment of the care plan may be required.

Family/whānau should be equipped with practical advice on what to do when death occurs. Not only does this ensure the person's dignity and wishes will be maintained, but it also helps to reduce the stress experienced by loved ones, allowing them to focus on processing emotions and supporting each other rather than decision-making. Bereavement risk and support should also be considered; 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.

General questions for discussion:

1. Are you or your general practice regularly involved in caring for patients in their last days of life? If not, what are the main reasons? For example, are you not adequately resourced to do so, or do sufficient local resources already exist? Do you expect that demand for this type of care will increase in the future in your community?
 2. End of life care should ideally be delivered as part of a multidisciplinary clinical service. Do you have a working relationship with your local hospice or other community palliative care providers? e.g. district nursing service, residential care, ambulance services/extended care paramedics.
 - If so, what works well and what could be improved?
 - If not, what are some of the barriers to doing so?
 3. An individualised approach is essential when planning the delivery of end of life care; this should ideally consider all aspects of Te Whare Tapa Whā (i.e. the four dimensions of wellbeing). How do you/would you go about prompting and structuring these discussions with patients?
 - There may be occasions when the patient is unable to provide input, and there is a lack of agreement or conflict between family/whānau members regarding specific components of a care plan. How could these difficulties be resolved?
 4. Anticipatory medicine prescribing is invariably required for home-based care in the last days of life so that carers and family/whānau can provide timely relief:
 - Syringe drivers have a significant role in symptom management for people in their last days of life. Are you familiar with the set up and maintenance of models currently available in New Zealand, or would you rely on the expertise of other community palliative care providers? e.g. district nurses.
 - What is your approach to ongoing assessment of need and replenishment of home medicine supplies?
 - Do you find that family members usually understand and are able to follow care instructions, and do they generally feel comfortable about being responsible for administering medicines? How do you address health literacy-related challenges if they are a factor?
 - Some patients or their family/whānau may want to incorporate complementary or alternative medicine(s) to manage symptoms in the last days of life. How do you go about discussing potential benefits and risks? Do you have any examples of complementary treatments that you think are effective for managing symptoms in the last days of life?
5. Non-pharmacological approaches to care are also essential in the last days of life. What general suggestions would you give to family/whānau about creating a comfortable environment for their loved one? Are there any specific examples of a non-pharmacological intervention you find helpful for addressing particular symptoms?
 6. What are some of the key drivers of unplanned hospital admissions for people wanting to die at home? Do you find that identifying and managing these factors helps to reduce the likelihood of unplanned hospital admission? Do you feel confident in recognising when a patient's needs exceed the capacity/resources available in primary care?
 7. How do you help prepare family/whānau for their loved ones passing? What is your approach regarding bereavement needs/risk assessment? Were you aware that standardised tools exist to aid this evaluation, such as the "Te Ara Whakapiri Bereavement Risk Assessment Tool"?

Specific questions regarding symptom management:

1. What symptoms do you find are the most complex to manage in the last days of life and why?
2. Morphine is considered the first-line pharmacological treatment for **pain** in the last days of life, ideally administered subcutaneously. What is your general approach to analgesia in the last days of life? Given that many patients in this context will already be established on an analgesic regimen, can you think of an example where modifying an existing regimen was particularly challenging?
 - Not all patients can tolerate morphine, meaning fentanyl may be required in some cases. How likely are you to prescribe fentanyl in this setting? Do you feel confident in deciding on an appropriate dosing regimen (given that it is typically more complicated than morphine), or would you usually seek advice from a palliative care physician if fentanyl is needed?
3. Opioid use is a common cause of **nausea and vomiting** in the last days of life, yet these medicines are an integral component in the management of other symptoms. What strategies do you have for reducing the nauseating effects of opioids?
 - Can you think of any cases where there have been other specific modifiable causes for these symptoms?
4. The psychological state of patients in their last days of life can vary significantly. In practice, what do you find are the most common symptoms or signs of **delirium**? How confident are you in diagnosing delirium in a dying patient, and distinguishing symptoms from other emotional states? e.g. fear, anxiety or positive spiritual experience.
 - Non-pharmacological strategies are considered first-line for patients with delirium that is not causing distress. What is your threshold for initiating pharmacological treatment, and what medicines do you find work best?
5. How do you go about assessing for **dyspnoea** in patients with limited or no communication in their last days of life?
 - How do you address the potential for respiratory depression in patients requiring opioids for dyspnoea?
6. Noisy breathing caused by **excessive respiratory secretions** – sometimes called the “death rattle” – is common during the last days of life and a normal part of the dying process. How would you explain this to family/whānau to reassure them that their loved one is not suffering? Were you aware that this symptom is generally not treated?



What key learning points did you take away from reading these resources? Did you discover something new? Are there any specific aspects in your current approach to delivering end of life care that you plan on changing?