# Additional Notes

## End of Life Care: Symptom Management

**What is *Palliative Care*?**[1]

The World Health Organisation defines **palliative care** as, *"An approach that improves the quality-of-life of individuals and their families facing the problems associated with life-threatening illness, through the perception and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*." Life-limiting illnesses may include chronic respiratory conditions, neurological diseases (such as Parkinson's or Alzheimer's), end stage organ failure or cancer.

**What is *End of Life Care*?**

The term 'end stage of life' refers to the point in a person's palliative care pathway when the person begins exhibiting signs/symptoms that suggest that they may be approaching the last week or days of life. End of life care focuses on providing the comfort and support required to adequately meet the physical and psychological needs of the person and their family.

While the physical and psychological presentation of the person will be unique to the individual, there are similar patterns that we can predict and prepare for leading up to and during the end stage of life.

**End of Life Care in the Residential Aged Care Setting:**

An older person in the end stage of life may be diagnosed with dementia, cancer or a number of comorbidities that impact on the level of care they require. This does not necessarily mean that they need to be hospitalised; in fact, the numbers of older people choosing to access residential care in order to effectively manage the end stage of life, is on the rise.

The aim of the staff in the residential aged care setting should be to provide quality care, while managing both the physical and psychological needs of the person effectively, providing a holistic and integrated approach. It is essential that the staff recognise and reaffirm that "dying is a normal part of life and the human experience."

**Discussing & Documenting End of Life Care:**

- The resident should be supported in making decisions about the treatment they wish to receive during their end stage of life.
- This includes non-clinical aspects such as favourite music, pets and all the things that the person considers important to them that may help & support them as part of their end of life care.
- The multidisciplinary team can inform and advise, to assist the resident and/or their family/carers in understanding the choices available to them and the implications associated with these.
- An end stage of life care plan is established in consultation with the GP, multidisciplinary team members (e.g. palliative care team), alongside the resident and any family members, carers or substitute decision-makers they wish to include. *For further information regarding the care plan process, see the ACC course 'Advance Care Planning.'* This care plan should be reviewed regularly, as the expressed wishes of the resident and/or their family/carers may change.

[1] http://www.who.int/cancer/palliative/definition/en/

- You should always consult your national guidelines and any additional policies that your residential facility has in place.

**Physical signs/symptoms:**[2]

As the person's physical health declines, it is essential that care/clinical staff can recognise the signs/symptoms associated with the end stage of life, as this serves as an indicator that the person may have reached the final few days/week of their life.

Signs that the person may be approaching the last week or days of life include:
- An acute event has occurred, requiring revision of treatment goals.
- Experiencing rapid day-to-day deterioration, e.g. profound weakness, confined to bed, declining food or drink, spending the majority of the day sleeping/resting and/or a declining state of consciousness, all of which is not reversible.
- Changes in breathing patterns.
- Increasing loss of ability to swallow.
- Irreversible weight loss.

**What are the common physical symptoms?**[3]

**Pain**
- Pain is often a complication of cancer or attributed to non-healing wounds or pressure ulcers, infection, decreased mobility, constipation or urinary retention.
- The goal in end of life care is to ensure that the older person's pain is effectively treated, so that they remain as comfortable as possible.

**Nausea and vomiting**
- Nausea and vomiting may be present in the end stage of life, related to their condition (e.g. cancer) or as a side-effect of medication.

**Declining oral intake**
- As the older person declines, so will their appetite. They may also find it difficult to swallow food and/or medication, due to physiological changes associated with ageing & their health deterioration.

**Constipation**
- This is often due to the person's decreased oral intake, dehydration or as a side effect of analgesia & decreased mobility.

**Declining bladder function**
- This may impact the older person's production of urine. It is often significantly decreased & becomes increasingly concentrated.
- Retention may be related to medications, bladder spasm or constipation.

**Dyspnoea**
- Dyspnoea, also known as shortness of breath, may be caused by a number of factors, such as pain, a chronic condition, anxiety and/or obstruction.
- The older person's breathing may become shallow and irregular. In the last days, rapid breathing, followed by a temporary cessation in breathing, can be observed. This known

[2] https://www.caresearch.com.au/Caresearch/Portals/0/PA-Tookit/Educational_Flipchart_Introduction_to_a_Palliative_Approach_1.pdf
[3] http://www.palliativecarensw.org.au/pdfs/PCNSW-Signs-Symptoms-of-Approaching-Death-ARTICLE.pdf

as Cheyne-Stokes.

**Terminal agitation/restlessness**

- Terminal agitation and restlessness can often be caused by bowel or bladder discomfort, dehydration, poorly managed pain, or as a side-effect of medications (e.g. opioids).
- The older person may hallucinate, become restless or distressed and be observed mumbling/moaning, twitching and continually trying to reposition themselves.

**Terminal delirium**

- Delirium varies in its presentation - with either hyper or hypo-active symptoms - often caused by infection or metabolic disturbances.
- The causes of delirium are often easily treated but can go unrecognised, especially if a person has dementia. Therefore it is essential for staff to have an awareness of the signs and possible causes of delirium to respond effectively.

**Respiratory secretions**

- Caused by infection, aspiration or the inability to swallow/cough effectively.
- More common in the last hours of life, the person may make a gurgling or rattling sound, due to the air passing through the secretions. This is also known as the death rattle. While not necessarily distressing to the older person, it can be distressing for the family to hear/observe - provide reassurance.

**Dry mouth**

- This can be caused by decreased fluid intake, or as a side-effect of medication, oxygen therapy or heavy mouth breathing.

**Skin breakdown**

- They may develop pressure ulcers - caused by reduced oral intake, nutritional deficiency, poor circulation, inability to reposition one's self & decreased skin perfusion, leading to skin breakdown.
- Their skin may appear mottled (bruised-like), their extremities will become cyanotic & the temperature of their skin will be cooler than normal. This indicates that the body's circulation is shutting down.

**Profound weakness/fatigue**

- The person will become heavily fatigued, drowsy and difficult to rouse, often spending the majority of the day sleeping/resting.
- Remember that the older person can still hear you, even if their response is delayed or diminished.

**What are the common psychological symptoms?**

It is really important when delivering end of life care to look at the whole person and not just the physical symptoms. Sometimes psychological changes occur before a decline in physical health and presentation of physical symptoms. It may be simply that families and care staff will report to you that 'there is something different about them today'.

**Anxiety**

- Anxiety-related symptoms include panic, restlessness, insomnia or shortness of breath, related to poorly managed symptoms e.g. pain, dyspnoea, constipation or urine retention, or as a side-effect of medications.
- It can also be caused by a fear of death, the distress their illness is causing their loved ones or due to loss of control. This can have significant impact on their quality of life in the end stage.

**Depression**

- Depression may cause insomnia, irritability, indecisiveness and a sense of hopelessness.
- They may express guilt over unresolved personal issues or that they are a burden on others. They may also experience the loss of pleasure or interest.
- Sadness is a normal response to the loss that the older person and their family are going through, and does not respond to medication.

**The role of care/clinical staff:**

Care and clinical staff play an essential role when developing and implementing strategies that will effectively manage the person's physical symptoms. These strategies should be individualised to meet the person's presenting symptoms and must be evaluated regularly to ensure that these strategies are effective at achieving the person's desired outcomes and expressed wishes, and support the older person to remain comfortable, while addressing the very real needs of the family.

Refer to the person's advance care directive/plan and end stage of life care plan, being mindful that as the person approaches their last days of life, their expressed wishes or the expressed wishes of their substitute decision-maker, may change.

**Strategies to be implemented:**[4]

**Discontinue non-essential interventions**

Any non-beneficial and/or unwarranted observations, medications, investigations and treatments should no longer be prescribed or administered. The individual and their families may need reassurance that the shift in goals will not reduce the level of attention and care provided to the older person.

**Pain Management**

- The goal is to ensure the older person does not have pain.
- Pain can be verbalised if the person is conscious and staff or family may pick up on important nonverbal cues. Use a pain assessment tool, such as the Abbey Pain Scale and document accordingly.
- The most common medications used to manage pain are:
    - *morphine* (there is no ceiling dose)
    - *hydromorphone* (this is 5 times stronger than morphine)
    - *fentanyl*
- Anticipatory prescribing is designed to enable prompt symptom relief as soon as the person develops symptoms, ensuring timely access to medications. Seek advice from the RN & prescribing GP.
- Pain relief can be prescribed as regular and/or PRN doses for incidental pain.
- Medication are commonly delivered via subcutaneous injection or a syringe driver, which is used to provide a continuous subcutaneous infusion.
- There are often misconceptions around the use of opioids e.g. they create addiction, cause respiratory depression or hasten death. However, when used appropriately, opioids are safe and effective and do not hasten death. The RN may discuss these concerns with the family to alleviate fear.
- Opioids can have side effects such as constipation, nausea and vomiting, drowsiness, dry mouth & confusion.

[4] https://www.caresearch.com.au/Caresearch/Portals/0/PA-Tookit/Guide%20 to the Pharmacological Management of End of Life(Terminal)Symptoms in Residential Aged Care Residents_1.pdf

**Nausea & Vomiting**

- The most common medications used are:
    - *Haloperidol*
    - *Metoclopramide*
- Regular and/or PRN doses can be administered orally or via subcutaneous injection or infusion, as per care plan. Check medications compatibility prior to administering more than one medication through the same syringe.
- Side effects can include increased fatigue, increased agitation, restless leg syndrome and constipation.

**Declining oral intake**

- Offering additional fluids e.g. little sips of water or ice chips.

**Declining bladder function**

- Loss of bladder control will require incontinence aids - ensure all personal hygiene needs are met.

**Constipation**

- A bowel management plan must be in place for any individual on analgesia.
- The most common medications used are laxatives, such as:
    - *Microlax enemas*
    - *Glycerol suppositories*

**Dyspnoea**

- The goal is to ensure the older person is not breathless.
- The most common medications used are:
    - *Morphine*
    - *Hydromorphone*
- Regular and/or PRN doses, via subcutaneous injection or infusion, as per care plan.
- The side effects are the same as that for analgesia.
- Sometimes dyspnoea occurs due to anxiety or panic - offer reassurance.
- Staff may also find repositioning the individual and using pillows effective.

**Terminal agitation/restlessness**

- Non-pharmacological strategies should be prioritised over medication management.
- The most common medications used are:
    - *Clonazepam*
    - *Midazolam*
- Regular and/or PRN doses, via subcutaneous injection or infusion, as per care plan.
- Side effects may include restless leg syndrome, uncontrolled movement, irregular breathing or drooling. Families may find this distressing - provide reassurance and explain that this is a normal symptom in the end stage of life.

**Terminal delirium**

- The most common medication used is:
    - *Haloperidol*
- Regular and/or PRN doses, via subcutaneous injection or infusion, as per care plan.
- Staff may find alternative strategies such as aromatherapy, a quiet room or music therapy to be beneficial to the individual.

**Respiratory secretions**

- The most common medications used are:
    - *Hyoscine butylbromide* - used to dry up secretions.
- Usually administered as PRN doses, topically or via subcutaneous injection or infusion, as per care plan.
- Side effects include blurred vision, drowsiness, dry mouth and urinary retention.
- Regular suctioning is not recommended, as it can cause undue distress without offering significant relief.
- Repositioning e.g. placing the person on their side with the head of the bed lowered, to facilitate drainage of secretions, then elevating the head of the bed slightly, as comfortable.

**Oral care**

- The goal is ensure the older person's mouth remains moist and clean, as this provides comfort and minimises complications. Staff may use a soft toothbrush with toothpaste, sodium bicarbonate mouthwash and regular mouth swabs to clean the mouth.

**Skin Care**

- Pressure area care - repositioning every 2-4 hours and the use of a foam or pressure relieving mattress is recommended.
- Wound care - treatment should focus on providing comfort, easing pain, keeping the wound clean & managing exudate/odour.

**Profound weakness/fatigue**

- Eliminate non-essential tasks & adjust their physical environment to promote rest and relaxation e.g. single room, curtain/screen, lighting, music, etc.

**The role of care/clinical staff:**

Identifying and implementing strategies that meet the psychological needs of the dying person, and their families or carers, are just as important as meeting their physical needs. This may include addressing fear of dying, guilt about past actions and worries about leaving family members behind.

Staff should also be aware of how their own personal values, and cultural and spiritual beliefs/practices inform and influence the care they provide. Staff must not make assumptions or stereotype the individual; rather, they ought to seek out understanding & avoid any judgment or personal criticism of differing views.

**Strategies to be implemented:**

**Offer emotional support to the dying person**[5]

- Good communication is key e.g. active listening - all staff can be involved in this, not just care and clinical.
- Provide opportunities for the older person and their family/carers to express their fears regarding death, loss of control or family concerns, offering sensitivity, reassurance & use of touch, if appropriate.

[5] https://www.caresearch.com.au/Caresearch/Portals/0/PA-Tookit/Educational_Flipchart_Introduction_to_a_Palliative_Approach_1.pdf

- Observe both verbal and nonverbal cues that indicate symptoms of distress.
- Delegate immediate tasks to another staff member, so that you are not interrupted.
- Involve the older person and their family/carers as much as possible with their care, even in their last days. Ensure the approach adopted is reflective of the needs of the person and what they want to know, being mindful not to cause further distress. Use clear language and avoid clinical jargon.
- Access the support of social workers or bereavement counsellors, as appropriate.

**Provide culturally-specific care**[6]

- Offer culturally-sensitive care and ensure opportunities for the dying person and their family/carers to discuss their cultural beliefs, values and practices and any traditions or customs that they wish to partake of.
- Ensuring privacy to conduct any rituals/practices.
- Accessing the support of cultural community leaders.

**Provide spiritually-specific care**

- Provide opportunities for the dying person to discuss their spiritual concerns and any unexpressed grief.
- Ensure privacy for the individual and their family to conduct any religious practices of their choice.
- Access the support of chaplains, pastoral care workers and clergy.
- Support the individual with specific prayers or rituals and ensuring that they have access to any particular religious items, as desired.

**Incorporate alternative therapies that support the person's culture & belief system**

- This may include aromatherapy and the use of essential oils, massage (by a trained professional) or music therapy, among others.



[6] https://www.nhmrc.gov.au/_files_nhmrc/file/guidelines/pc29_guidelines_for_a_palliative_approach_in_residential_aged_care_150609_0.pdf