End of Life Care

KEY POINTS

- Care during the last hours and days of life should focus on ensuring comfort and dignity
- Physical symptoms can be difficult to control; the best way to ensure they are well managed is to develop a symptom management plan before symptoms occur
- It is often necessary to rapidly increase the doses of morphine and other medications to ensure good symptom control during this phase
- When death is approaching, most individuals look quite similar, despite their underlying medical condition

ASSESSMENT

See comment on page 10

Recognizing When Death is Imminent

- Observations that may help to identify patients who are approaching end of life:
  - Very tired and weak, spend the majority of time sleeping or lying down
  - Little or no oral intake and difficulty swallowing
  - Altered level of consciousness: confused, agitated, restless, or drowsy
  - Changes in pulse, blood pressure, and breathing, cool and mottled extremities
  - Decreased urine and stool output
- Patients with malnutrition will have a more rapid progression to end of life
- Predicting how long a patient will live is very challenging, changes in the patient's condition should guide prognostication. If changes in the symptoms (fatigue, oral intake, level of consciousness) described above are:

- Hourly, death is expected in hours to several days
- Daily, death is expected in days to several weeks
- Weeks, death is expected in weeks to months

- Discontinue vital sign assessments, pulse oximetry, non-essential medications (including IV fluids), and lab and radiological tests (discuss with the family before doing this as they may perceive this as "giving up" on the patient)

- Children are often more resilient and may survive what appears to be the imminently dying phase, because they have less age-related degeneration of vital organs

MANAGEMENT

Ensuring a Good Death

- According to recent studies, patients and family members feel that a "good death" includes:
  - Communication and clear decision-making from health-care providers
  - Adequate pain and symptom management
  - Strengthening relationships with loved ones (resolving conflicts, saying goodbye)
  - Preparation for death

Communication

- It is helpful to provide clear and prompt information about prognosis to the patient and family
  - Use phrases such as "It can be difficult to predict, but I expect that he/she will live for hours to a few days" to provide information about prognosis
- Honesty is preferred so that the family can plan appropriately, e.g. ensure that loved ones are present or have a chance to say goodbye

- Honesty does not lead to a loss of hope, but shows that you are being honest and transparent with the family

Suggested steps and phrases to use when communicating about prognosis in the end of life phase – see Communication chapter for more details

Communication Step	Suggested Phrase
Set up the conversation by introducing yourself and asking permission to proceed	"Can I talk to you about what is happening to your loved one?"
Assess understanding of the illness	"What is your understanding of where your loved one is at with his/her illness?"
Share prognosis in a clear and honest way	"I wish it were different, but I am worried that your loved one is very sick and will not be able to recover from this illness. We do not have any treatments which can cure this problem and I am worried that he/she is not going to live for very long"
Assess goals and wishes	"What is most important for your family at this time, given the information I have shared with you?"
Establish a plan	"I recommend that we focus on providing care which ensures that he/she is comfortable, and he/she can be with those he/she loves"
Close the conversation	"We will be here to treat and support him/her and your family"

Managing Common Symptoms in the Last Hours and Days:

- Guidelines and standardized order sets are helpful to ensure consistent treatment with appropriate doses of medications, and allow bedside clinicians to initiate care
  - Ensure that medications are available at the bedside to quickly

treat common symptoms (such as pain, dyspnoea, and agitation/restlessness) which may arise

- Morphine (or another opioid)
- A short-acting benzodiazepine (e.g. midazolam)

- If symptoms are not well managed, this suffering may be the family's final memory of their loved one, which can cause further distress and a complicated bereavement
- Do not be afraid to rapidly increase the dose of medications to achieve symptom control
- For patients who experience refractory symptoms, palliative sedation can be considered; full details are beyond the scope of this section
- The subcutaneous route is useful in this phase of illness to manage symptoms quickly, but without the trouble of needing to maintain IV access
  - Insert a butterfly needle and secure in place. This can be kept for up to 7 days (provided the subcutaneous site does not have any significant redness or tenderness)
  - **Medications which can be given subcutaneously (at same dose as IV) – see Medications and Appendices for complete details:**
    - Opioids: Morphine, hydromorphone, fentanyl, methadone, oxycodone, diamorphine
    - Sedative-hypnotics: Midazolam, clonazepam, phenobarbital
    - Antiemetics: Haloperidol, metoclopramide, levomepromazine (methotrimeprazine)
    - Anti-secretory agents: Hyoscine BUTYLbromide, hyoscine HYDRObromide, glycopyrrolate, octreotide
    - Antihistamines: Cyclizine, promethazine
    - Miscellaneous: Dexamethasone, methylnaltrexone, naloxone, furosemide

Pain, dyspnoea, and agitation

- These are common symptoms which often require intensive

treatment near the end of life

- Rapidly escalating doses of opioids are appropriate to manage pain or dyspnoea and when used by trained providers
  - This approach will not cause respiratory depression or hasten death when used appropriately
- To facilitate rapid titration: ensure that clinicians are present and medications are available at the bedside

Delirium/confusion

- Delirium in the end of life phase is generally multifactorial and irreversible
  - Causes include the underlying disease process, metabolic and electrolyte imbalances, liver and renal failure, infection, and hypoxia
- Urinary retention is a common and potentially reversible cause, which can be managed with a Foley catheter insertion
- ***Refer to Delirium section for further details***

Weakness/fatigue

- Fatigue is expected as the patient approaches the end of life
- Do not give stimulants (methylphenidate, steroids) to try "to wake the patient up" at this stage of illness
- Gentle repositioning, if the patient tolerates, can help avoid pressure injuries

Decreased oral intake

- Reduced oral intake is a normal part of the dying process and patients do not feel hunger or thirst at this stage
  - Fluids and foods should be provided if desired by the patient, but avoid forcing a patient to eat, which can cause aspiration
- Do not provide parenteral fluids since research shows that this does not improve symptoms, quality of life, or prolong life for palliative care patients who cannot drink

Suggested Guidelines for the Management of Escalating Pain, Dyspnoea, and Agitation in Children

Adapted from the *Interdisciplinary Textbook of Pediatric Palliative Care*

Escalating Pain, Dyspnoea, and Agitation

No ceiling dose exists for symptom management in the last hours or days of life (end of life phase). The correct dose is the dose which relieves the patient's symptoms and does not cause unwanted side effects. Titrate the medications rapidly (over minutes to a few hours)

Loading dose:

For patients already on opioids: Administer a loading dose of opioid equal to 10% of the total dose in the past 24 hours

For patients not already on opioids: Administer IV or Subcutaneous loading dose as follows: Morphine 5 mg, children <12 years: 0.1 mg/kg

Subsequent dosing: Doses may be given q10 mins PRN for end of life symptoms

Escalate dose as follows: (Note: 5 mg is given as an example, actual dose may vary)

First dose: 5 mg, if ineffective after 10 mins, then give

Second dose: 5 mg, if ineffective after 10 mins, notify prescriber

Third dose: 7.5 mg (1.5x starting dose), if ineffective, after 10 mins then give

Fourth dose: 7.5 mg (1.5x starting dose), if ineffective, after 10 mins then give

Fifth dose: 10 mg (2x starting dose)

Once good pain relief is achieved, provide the total dose administered during the titration phase Subcutaneous or IV q4h regularly and as a PRN/SOS dose

Do not use ONLY as needed dosing as this will allow the symptoms to return and will lead to more distress

Pain assessment may be by pain scale or observations of verbal and nonverbal behaviour (crying, grimacing, and moaning)

Continuous infusion instructions

Recommended hourly rate – total opioid administered in the above steps divided by 4

Recommended 24-hour amount of medication – total opioid administered in the above steps multiplied by 6

- Instead encourage families to provide oral care by swabbing the mouth with water and keeping the lips moist with petroleum jelly (Vaseline) or lip balm

Breathing pattern changes

- Breathing will change as the patient approaches end of life, breathing may be slow or rapid and shallow
- Periods of apnoea or increased work of breathing are common, but do not necessarily indicate dyspnoea and so need not be treated unless distressing to the patient

Respiratory secretions

- Patients often have impaired ability to swallow at the end of life, and oral secretions can accumulate in the back of the throat, causing gurgling or rattling sounds
- Generally, the patient is only minimally conscious or unconscious and this does not cause them distress, but family members may find it distressing
- Position the patient on his/her side with the upper body elevated to allow secretions to drain passively
- Discontinue any IV or NG artificial fluids or nutrition that increase secretions
- Avoid mechanical suctioning, as it is not usually helpful and may be distressing to the patient
- *Refer to Respiratory Secretions section for further details*
- **Medications:** (Note: These medications will not work for secretions deep in the lungs (i.e. pulmonary oedema or pneumonia), and are not always effective for upper airway secretions)
  - **Glycopyrronium: 0.2-0.4 mg Subcutaneous q4-6h PRN**
  - **Hyoscine BUTYLbromide: 20 mg Subcutaneous, then 20 mg q4-6h PRN.** Does not cross the blood-brain barrier
  - **Hyoscine HYDRObromide/Scopolamine: 0.4-0.6 mg Subcutaneous q4-6h PRN; OR transdermal patch; replace patch**

every 72 hours

– Note: Hyoscine HYDRObromide crosses the blood-brain barrier and is quite sedating; may increase risk of delirium in end-stage renal failure patients

- **Atropine 1% eye drops: 1-4 drops (each drop contains approximately 0.5 mg atropine) under the tongue q2-4h PRN**

  – Note: Atropine will also cross the blood-brain barrier in patients, and obtund

Incontinence and urinary retention

- Incontinence of urine and/or stool is common
- Change soiled linens promptly, aiming to keep the patient clean and dry
  - A Foley catheter may be helpful, but is not always needed since urine output is minimal and absorbent pads or cloth and plastic can be used
- Urinary retention may occur, and should be suspected in a restless patient with a distended bladder. In this case, a Foley catheter should be inserted
- Urinary retention can be a side effect of opioid medication, which is more commonly seen in infants and young children. A Foley catheter or intermittent catheterization may be needed

Seizures/convulsions

- Seizures can be caused by cancers (primary or metastatic), drug toxicity (e.g. pethidine/meperidine), metabolic or electrolyte abnormalities (hypoglycaemia, hyponatraemia, hypercalcaemia), hypoxia, severe liver failure, infections of the CNS, and epilepsy
  - Treatment is comfort-focused and a full investigative work-up is not necessary.
- For children with a history of epilepsy, if the child can no longer swallow medications, Subcutaneous midazolam or another benzodiazepine should be started

Management

- **Corticosteroids** can be considered for seizures secondary to brain metastasis, to reduce peritumoural oedema
- **Acute treatment (Status Epilepticus)**
- Benzodiazepines are first-line treatment. If the seizure does not resolve within 5 minutes, consider:
  - **Lorazepam 4 mg IV over 2 minutes, OR**
  - **Midazolam 10 mg Buccal/Subcutaneous/IM or IV over 2 minutes**
  - **Diazepam 10 mg PR or IV**
- Can repeat ONCE after 10-20 minutes, if the seizure persists
- If ineffective, consider doubling the dose of midazolam or diazepam or give **phenobarbital**
- Continue regular **phenobarbital** after the seizure stops, to prevent further seizures
- ***Refer to Seizures section for further details***

Counselling Checklist for Family Caregivers at End of Life

Physical Care:

- Moisten mouth with ice chips or a damp cloth soaked in water or fruit juice
- Keep lips moist with balm or petroleum jelly (Vaseline)
- Keep the person clean and dry, use cloths or pads for urinary incontinence
- Give the medications to control symptoms, at the correct times
  - Do not wait until the symptoms are severe, as this will lead to symptoms which are more difficult to control
- Do not force the person to eat or drink, if he or she does not want to eat, this is okay
- Assist the person to change position or turn every few hours to prevent pressure ulcers
- Contact the home palliative care team (or whoever is providing 24-hour telephone support), if pain or other symptoms are not controlled

Emotional and Spiritual Care:

- Tell the person that they are loved and will be remembered
- Ensure that the person has opportunities to discuss any feelings of guilt, worry, or regret
- Pray or connect with spiritual or religious leaders if the person wishes this
- Sit with the person, hold his/her hand and talk to him/her

SPECIAL SITUATIONS

Unsuccessful resuscitation

- During resuscitation, the family should be permitted to be present, as this leads to less anxiety, depression, and second-guessing about the care provided and the competence of staff
- One healthcare provider should to stay with the family, to update them about what is happening, answer their questions, and provide emotional support

Discontinuing fluids and nutrition

- Discontinuing medically administered fluids and nutrition is recommended during the end of life phase
  - Medically provided fluids and nutrition can ethically be withheld or withdrawn if they are no longer in the best interests of the patient, e.g. if fluids are adding morbidity to the process of dying
  - This may be considered when a patient permanently lacks awareness and the ability to interact with the environment, such as a persistent vegetative state or a child with anencephaly
- It is important to counsel patients and families that this does not mean clinicians are "giving up" on a patient, but rather focusing intensely on comfort and support

Discontinuing ventilatory support

- It may be ethically appropriate to discontinue intensive respiratory support (e.g. non-invasive or invasive ventilation) in certain circumstances

- If the underlying cause of ventilator dependence is irreversible, then ventilatory support will not provide a meaningful quality of life and may prolong suffering
- This act of discontinuing ventilator support (or other life-sustaining treatments) is not the same thing as euthanasia or medical assistance in dying
- It is essential to involve the family in the decision to discontinue ventilatory support
  - Involving religious or cultural leaders may also be necessary
- After discontinuation of ventilation, most patients live only minutes or hours; however, there are some patients who may live for a few days or longer
- Clinicians must prepare the family for the possibility that the individual may breathe on his or her own, especially in children, where this is more common

MANAGEMENT

Before Withdrawing Ventilator

- Ensure that family are present if desired
- Turn off all monitors and alarms
- Discontinue all other life-sustaining treatments (e.g. artificial nutrition and hydration, antibiotics, dialysis)
- Remove all unnecessary medical paraphernalia (NG tubes, IV lines, etc)
- Allow any neuromuscular blocking agents to wear off
- Ensure that a rapid acting opioid (e.g. morphine), benzodiazepine (e.g. midazolam or lorazepam), and an agent managing secretions (e.g. glycopyrrolate) are available and drawn up at the patient's bedside
- Give a dose of opioids and benzodiazepine prior to withdrawing the ventilator, to ensure the patient does not feel any discomfort or dyspnoea

Process of Withdrawal

- Ensure that the patient appears comfortable

- Withdrawal by immediate extubation is recommended

After Ventilator Withdrawal

- If the patient appears distressed, symptoms should be immediately and aggressively controlled, by giving morphine and midazolam, every 10 minutes, until distress is relieved
- A clinician should be easily available to answer questions and manage symptoms
- Continuous infusions (IV or Subcutaneous) of medications to manage symptoms can be considered to ensure comfort

Memory Making

- This is especially relevant for parents, but is relevant for any death of a child or adult
- Many times, parents are encouraged to try to quickly forget a child that has died, but this is not recommended as it leads to a more complicated grief for parents
- Having tangible objects to remember their loved one supports family in their grief
- This is especially important in a pregnancy or infant loss, as parents have few tangible memories of their child's short life
- Common memory making activities which can be easily offered to families include:
  - Photographs or videos
  - Prints or molds of hands and feet, locks of hair
  - Linking objects, which provide a physical reminder of the connection between the child and loved one (e.g. a pair of special necklaces or bracelets, one of which is placed with the child and the other with the parent)
  - Personal items, e.g. clothing, baby blanket, small toys, hospital bracelet, birth certificate, bassinet card
  - Memory boxes: items can be stored and looked at when desired
- Some parents may not want to keep any memory items, which

should be respected

- All parents should be offered memory making, since in all cultures, there are some parents who will desire this

After Death Care

- Express empathy with a simple statement such as "I am sorry for your loss"
- Confirm the death by physical examination (absence of heart sounds, palpable pulse, or respirations for 60 seconds)
- Document the date and time of death in the medical record and the cause of death
- Allow the family as much time as they desire to say goodbye and to perform any religious or cultural rituals, as permitted within the limitations of the setting
- During an epidemic (e.g. Ebola), it may not be possible to release the body to the family, so assistance from a psychologist or spiritual support person is important to support the family's bereavement

Supporting Staff who Provide End of Life Care

- Witnessing frequent suffering and death can cause staff burnout, compassion fatigue, and moral distress
- Regular support meetings create a safe space for staff to reflect and express their emotions on providing end of life care
- Staff can reflect on the care that was delivered – what went well, what could be improved
- Senior staff members should attend to demonstrate the importance of seeking support
- Commemorating a patient is also important for healthcare providers, this can be done by having memorial services, attending funeral services, or having follow-up contact with families
- Letters, phone calls, or text messages from staff are deeply valued by families, who often treasure the memories of these small acts of kindness by staff

PITFALLS/CONCERNS

- Avoid giving exact predictions for how long a patient will live, instead, give a range based on how quickly you are seeing changes in energy, alertness, and oral intake:
  - If changes are hourly, death is expected in hours to several days
  - If changes are daily or every few days, death is expected in days to several weeks
  - If changes are weekly, death is expected in weeks to months

PALLIATIVE TIPS

- Do not be afraid to rapidly increase the dose of medications to achieve symptom control during the end of life phase
- Discontinuing IV fluids and nutrition is recommended, as this will reduce symptoms, particularly with respiratory secretions and oedema, and increase suffering
- Provide families with clear and honest information about prognosis using "I wish, I worry" statements
  - "I wish it were different, but I am worried that your loved one is very sick and will not be able to recover from this illness. We do not have any treatments which can cure this problem and I am worried that he/she is not going to live for very long"
- Provide psychosocial and spiritual support which is culturally appropriate

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