PALCARE
There's no place like home

THE JIMMY S BILIMORIA FOUNDATION

PALLIATIVE CARE
GUIDELINES
FOR A HOME SETTING IN INDIA

CARE IN THE LAST DAYS OF LIFE

INTRODUCTION

This guideline is intended to guide health care professionals caring for patients in the last days of life and their families/carers where a decision is made to continue palliative care. Patients in the last days of life experience significant symptom burden along with psycho-social and spiritual issues. This guideline addresses: recognising dying, communication, shared decision making, maintaining hydration and symptom management (pharmacological measures).

ASSESSMENT

- Assessment must determine the underlying aetiology of symptoms, effectiveness of treatment and impact on quality of life for the patient and family (***refer to the Guideline - Symptom Assessment***)
- Assess for presence of potential reversible causes like infection, opioid toxicity, steroid withdrawal, dehydration, acute kidney injury, delirium, hypercalcemia, hypoglycaemia and hyperglycaemia
- Assess and document patient's physiological, psychological, social and spiritual needs
- Discuss prognosis including patient's goals of care, views relating to further care, preferred place of care and preferences and the views of those important to the person about future care
- Phone calls should be made every 24 hours to assess patients who are terminally ill
- Assessment must include signs and symptoms indicating terminal phase
    - Profound weakness and social withdrawal
    - Loss of interest in food and drink
    - Dysphagia and difficulty to swallow medications
    - Increasing drowsiness and/or refractory delirium
    - Altered breathing patterns (especially Cheyne-Stokes breathing)
    - Progressive fall of blood pressure and/or temperature
    - Coma

MANAGEMENT

Recommendations

- Use a multi-disciplinary approach in the management of patients who are dying

- Initiate treatment of reversible causes, if appropriate for the patient and care setting
- Use good and effective communication to determine the goals of care, place of care and preferences of patient and family regarding end of life care
- Determine a surrogate decision maker/nominated healthcare spokesperson
- Initiate advance care planning with the patient and family at the earliest and review when necessary e.g. patient/family chose aggressive/curative management
- For each symptom in the last days of life, consider non-pharmacological interventions in symptom management, specific to that symptom
- Avoid unnecessary interventions, investigations and monitoring unless it is appropriate
- Review symptoms, medications and stop any medication that does not add to the comfort of the patient
- Explain to the relatives that certain long-term medications are inappropriate as they do not contribute to patient's well-being, comfort (e.g. anti-hypertensives, thyroxine, oral hypo-glycaemic agents, vitamin or iron supplements etc.)
- Routine monitoring of blood pressure and temperature should be avoided in the terminal phase
- Provide rescue medications for management of symptoms during the last days of life (pain, breathlessness, agitation, respiratory tract secretions, and nausea/vomiting) as "if needed medications" ***(refer to the Guideline - Anticipatory Prescribing)***
- Ensure that legible instructions on administration of medications and care are provided to the caregivers
- Plan to facilitate transfer of patient from home to hospice or hospital and back if that is considered
- Continue to provide support to the carers

Communication and shared decision-making

- The doctor along with other appropriate members from the palliative care team should communicate with the patient and those important to patient
- Provide accurate information to patient and those important to patient, regarding prognosis and what to expect in the future
- If there is need and if appropriate, provide contact details of the health care professional nearest to the patient to continue ongoing care
- Ensure that care plan and any future changes in care plan are communicated to and understood by the patient, those important to the patient and other health care professionals (family physician, community nurses; out-of-hours services) involved in the care of the patient
- Provide contact details of members of the team and details of out of hours services

Hydration

- Assess swallowing difficulty and the risk and symptoms/signs of aspiration in a dying patient
- Ensure that the patient and relatives are aware of the risks and benefits associated with oral feeding
- Encourage the patient to continue orally if possible and if he/she wishes
- Continue and emphasise good oral care and including management of dry mouth
- Involve the carers in providing oral care and feeding
- Assess the hydration status (skin turgor, dry mouth, and sunken eyes; only if symptoms indicate dehydration)
- Assess the necessity of starting subcutaneous fluids respecting the patient's goals and preferences
- Consider a trial administration of subcutaneous fluids if the patient has or is likely to develop a distressing symptom secondary to dehydration; e.g. delirium or thirst

Pharmacological measures

The general principles governing the pharmacological management of symptoms in the dying patient are:

- Choose an appropriate route of administration of medication
- If the patient can swallow, then medications should be administered orally
- If patient has difficulty to swallow, then liquid preparations could be considered
- If the patient is unable to swallow, then subcutaneous route is the most appropriate route of administration of medications
- For those patients with a naso-gastric tube in-situ, this route can be used for most medications
- Consider continuous subcutaneous infusion (CSCI) of medications using syringe driver if two or more doses of the 'if needed medications' are administered in 24 hours
- If patient is not on any medication for symptom management, then start with the lowest effective dose for the management of symptom and titrate based on the response
- Pharmacological management along with anticipatory prescribing is necessary for the management of symptoms in the last days of life to alleviate suffering
- **Pain**
    - If patient can take orally then continue and titrate analgesics ***(refer to the Guideline - Pain Management)***
    - If patient is unable to take orally which is most likely the case in the last days of life - they would need opioids (morphine) as continuous

subcutaneous infusion. For opioid conversion ***(refer to the Guideline – Opioids)***

- Tab. Acetaminophen - 1000mg q6h, maximum of 4000mg; can be used safely without dose adjustments (oral, liquid or rectal route)
- Diclofenac suppositories 50 - 100mg q12h, patch 100 - 200mg OD
- Tab. Morphine (dose to be determined by the prescriber) - appropriate dose to be determined by the prescriber (oral, rectal or parenteral)
- If patient had been on transdermal fentanyl or buprenorphine patches they can be continued safely and use appropriate rescue dose of morphine or tramadol for breakthrough pain ***(refer to the Guideline - Opioids for Fentanyl transdermal patch and Buprenorphine patch)***
- For patients with severe renal failure (CKD Stage 4 or 5) ***(refer to the Guideline - Renal failure in last days of life)***

- **Anxiety and distress**
  - Tab. Lorazepam 0.5-1mg S/L OD and prn (frequency may be increased based on the severity)
  - Tab. Diazepam 2.5-5mg PO hsod (up to 2.5mg tid)
  - Inj. Midazolam 2.5-5mg S/C q6h - q8h (or a higher dose as part of CSCI)
- **Breathlessness *(refer to opioids under pharmacological management in the Guideline – Breathlessness)***
  - Tab. Lorazepam 0.5-1mg S/L hsod and prn (frequency may be increased based on the severity) - consider in presence of panic or anxiety
  - Inj. Midazolam 1-3mg q8h and prn
  - In patients with renal failure ***(refer to the Guideline - Renal Diseases in the last days of life)***
- **Noisy respiratory tract secretions (death rattle)**
  - Non-pharmacological measures
    - Explain to the patient's family that this noisy breathing does not distress the semiconscious/unconscious patient
    - Postural drainage - position the patient in lateral position to drain the pooled secretions
    - Avoid using suction to remove secretions from oropharynx as this could be very distressing to the patient
  - Pharmacological measures
    - Medications are most effective when started early
    - Inj. Hyoscine butyl bromide S/C 20mg q8h and prn (Maximum 120mg/24 hours)
    - Inj. Glycopyrronium bromide S/C 200mcg q6h - q8h as required
    - Hyoscine hydrobromide patch 1.5mg/72 hours (if available) can be used once acute secretions are controlled. The patch can be applied behind the ear
- **Nausea and vomiting**

- Haloperidol 1.5-5mg PO, S/C or IV per day in two to three divided doses
- Metoclopramide 10mg PO, S/C or IV q6h - q8h - if prokinetic is useful

- **Delirium**
  - **Restless and confused but not-aggressive**
    - Haloperidol 1.5-5mg PO or SC q4h - q8h
  - **Delirium with paranoia, confusion and/or aggression**
    - Haloperidol 5-10mg S/C or IV every 30 - 60 min until relief then maintenance dose is 50% of amount to achieve control (usually between 1.5-20mg/24 hours divided into one to three doses)
    - Add Midazolam 2.5-5mg S/C stat and q6h prn if agitation persists
- **Anticipatory prescribing -** To improve care at end of life, it is useful if medications for symptom control are made available at home so that they can be administered without unnecessary delay, if required ***(refer to the Guideline - Anticipatory Prescribing)***

Palliative sedation

In case of refractory symptoms palliative sedation can be considered after adequate discussion, consent and consensus among patient/ relatives and staff in the team ***(refer to the Guideline - Severe Uncontrolled Distress)***

General comfort

Good nursing is very important, and relatives can be taught to do this at home. This includes:

- Personal hygiene
- Skin care (particularly pressure areas)
- Oral care ***(refer to the Guideline - Oral Care)***
- Bowel care/ care of stoma
- Bladder care: incontinence pads/catheter if necessary (hyperlink to bladder care)
- Where there is a risk of catastrophic haemorrhage (e.g. arterial blow-out, haemoptysis, haematemesis) then relatives should be warned and prepared ***(refer to the Guideline – Haemorrhage)***

REFERENCES

Adam, J. (2006). The last 48 hours. ABC of Palliative Care (pp. 44-47)

Ellershaw, J. and Ward, C. Care of the dying patient: the last hours or days of life. *British Medical Journal*. (2003); 326:30-34

Hodgkinson S., Ruegger, J., Field-Smith, A., Latchem, S., Ahmedzai, S. Care of dying in the last days of life. *Clinical Medicine*. (2016); 16(3): 254-258

Krakauer, E. L. (2015) Sedation at the end of life. Oxford Textbook of Palliative Medicine (pp. 1134-1142)

Lacey, J. (2015). Management of the actively dying patient. Oxford Textbook of Palliative Medicine. (pp. 1125-1133)

Twycross, R., Wilcock, A., Howard, P. (2014). Central Nervous System. Palliative Care Formulary 5. (pp. 210-384)

Twycross, R., Wilcock, A., Howard, P. (2014). Drug treatment in the imminently dying. Palliative Care Formulary 5. (pp. 819-830)

REFERENCES

Adam, J. (2006). The last 48 hours. ABC of Palliative Care (pp. 44-47)

Ellershaw, J. and Ward, C. Care of the dying patient: the last hours or days of life. *British Medical Journal*. (2003); 326:30-34

Hodgkinson S., Ruegger, J., Field-Smith, A., Latchem, S., Ahmedzai, S. Care of dying in the last days of life. *Clinical Medicine*. (2016); 16(3): 254-258

Krakauer, E. L. (2015) Sedation at the end of life. Oxford Textbook of Palliative Medicine (pp. 1134-1142)

Lacey, J. (2015). Management of the actively dying patient. Oxford Textbook of Palliative Medicine. (pp. 1125-1133)

Twycross, R., Wilcock, A., Howard, P. (2014). Central Nervous System. Palliative Care Formulary 5. (pp. 210-384)

Twycross, R., Wilcock, A., Howard, P. (2014). Drug treatment in the imminently dying. Palliative Care Formulary 5. (pp. 819-830)