Managing the Last Days of Life at Home

The principles in this leaflet are not diagnosis specific; they can be used for any patient who is known to be dying (within the next few days) and the decision has been made to manage them symptomatically.

1. Recognise
Recognising that a patient is coming to the end of their life can be difficult. The clearest signs of approaching death are picked up by day to day assessment of deterioration. In the absence of reversible causes of deterioration in patients with advanced life-threatening disease the following signs and symptoms are indicative of death approaching:
   - Increased weakness and loss of mobility
   - Increasing drowsiness
   - Confusion
   - Decreased ability to take orally

2. Communicate
   - Keep patient (if appropriate), family & carers informed. In particular, consider and explain resuscitation, hydration, sedation and use of medications. Document this discussion.
   - Explain the role of a syringe driver in managing symptoms.

3. Involve
   - Involve the patient and family in the process.
   - The patient’s wishes: does the patient have an Advance Care Plan? Is home the preferred place of death?
   - Consider a Treatment Escalation Plan and Resuscitation Decision Record (TEP-RDR). Inform the patient and/or family of the decision.

4. Support
   - Consider additional support the patient and family might need e.g. chaplaincy, carers, and sitters.
   - Ensure appropriate contact details are given.

5. Plan and do
   - Review current medication and discontinue non-essentials, focusing on comfort care.
   - Prescribe anticipatory/PRN subcutaneous medications.
   - Assess need for syringe driver (SD) to deliver necessary medication and explain this to the patient and/or the family.
   - Update Electronic Palliative Care Co-ordination System for out of hours information.

Goals for the last few days of life:
   - Ensure the patient’s comfort physically, emotionally and spiritually.
   - Make the end of life peaceful and dignified.
   - By care and support given to the dying patient and their carers, make the memory of the dying process as positive as possible.
   - Family, carers and patient (if appropriate) understand the patient is dying and the goals of care.

Common symptoms in the last few days of life and suggested medications:

(See Guidelines for Prescribing for Syringe Drivers in Palliative Care leaflet for more information & dosing regimes)

1. Nausea/Vomiting
   - Regular anti-emetics via Syringe Driver (SD)

2. Pain
   - Opioids, adjuvant analgesics e.g. hyoscine butylbromide for colic, midazolam for muscle spasm, NSAID (PR) for bone pain

3. Respiratory Secretsions
   - Glycopyronium bromide, hyoscine butylbromide, hyoscine hydrobromide,

4. Agitated delirium/restlessness
   - Think of potentially reversible causes for distress: consider urinary retention, constipation, hypercalcaemia, infection, fear
   - Use benzodiazepines (e.g. midazolam and/or sedative antipsychotics e.g. haloperidol/levomepromazine)

5. Breathlessness
   - Consider opioids and/or benzodiazepines

General tips for prescribing:

- The subcutaneous route (sc) is preferable in palliative care patients rather than intramuscular (i.m). Although some of the drugs listed are not licensed to be given sc, they are all commonly used by this route in palliative care.
- The rectal route can be useful for some patients.
- Topical opioid patches should not be started in the terminal stage since it takes too long to titrate against a patient’s pain. If the patient is already established on a patch it may be appropriate to continue with it and add in additional medications via the SD.
- If symptoms are not controlled on usual dose range, please seek advice from the Specialist Palliative Care Team.
- For patients dying with renal failure, alternative medication regimens may be required.
- Substance misuse patients, particularly those on maintenance treatment, require a co-ordinated prescribing approach. Please seek advice from Specialist Palliative Care Team.
- Whilst Hyoscine butyl bromide should be used with caution for patients with cardiac disease and tachycardia, in the context of last days of life it would be appropriate to make a clinical decision based on the risk/benefit.

FOR FURTHER INFORMATION

National Palliative Formulary http://book.pallcare.info
Or telephone:
St Luke’s Hospice Community Specialist Palliative Care Team
Available: 9am-5pm, Monday-Friday
Tel no: 01752 964200
24 hour advice line (St Luke’s Hospice 01752 401172) Calls go through to the Hospice. The Senior Nurse will be able to answer queries or ask the Doctor on call to return your call.
Dr Jeff Stephenson, Dr Doug Hooper & Dr Siomed Evans; Consultants in Palliative Medicine, St Luke’s Hospice, Plymouth, PL9 9XA
Dr Jemma Cooper & Dr Mairead McIntyre, GP Facilitators in Palliative Care

SLH
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