Palliative Care Guidelines: Lung Disease

Palliative Care in advanced Lung Disease

Introduction
- This guideline addresses the specific palliative and end of life care needs of people with advanced lung disease: chronic obstructive pulmonary disease (COPD) or interstitial lung disease (pulmonary fibrosis).
- Patients with advanced COPD follow an illness trajectory of acute but potentially reversible exacerbations on a background of long term symptoms and progressive decline.
- Patients with interstitial lung disease may have stepwise progression of hypoxic respiratory failure or a sudden, severe exacerbation with a very poor prognosis.

Identification: Does this patient need palliative care?
- Identifying patients with unmet needs improves holistic assessment and care planning.
- Disease specific prognostic tools predict mortality but are less useful for individuals.
- When it would not be a surprise if the patient died in the next 6-12 months, assess the patient and family for palliative care needs.

Clinical indicators of advanced lung disease:
- Cachexia; low body mass index (< 21). Poor or deteriorating performance status.
- Increased hospital admissions for infective exacerbations or respiratory failure.
- Severe airways obstruction (FEV1 < 30%).
- Severe restrictive defect (vital capacity < 60%, transfer factor < 40%).
- Meets criteria for long term oxygen therapy; persistent hypoxia (PaO2 < 7.3kPa).
- Persistent, severe symptoms despite optimal tolerated treatment.
- Breathlessness limiting daily activities between exacerbations, at rest or on minimal effort.
- Symptomatic right heart failure.

Assessment
- Check that current treatment is optimal. (see: Resources)
- Continue treatment of the underlying disease, infective exacerbations, and any co-morbid illnesses in parallel with supportive and palliative care.
- Review any treatments aimed primarily at disease prevention if the patient has a limited prognosis and treatment burdens outweigh benefits.
- Look for common symptoms: breathlessness, cough, fatigue, anorexia, nausea, constipation, depression / anxiety, insomnia, pain (eg. from osteoporosis).
  (See relevant Palliative Care Guidelines)
- Explore patient & family understanding of the illness, management, and care options.

Care Planning
- Inclusion on a palliative care register in primary care ensures regular review/ assessment.
- Agree an anticipatory care plan for future exacerbations/ complications; ensure this plan is sent to out-of-hours services. (Electronic palliative care summary (ePCS), if available).
- If the patient wishes to plan ahead, consider discussing:
  o DNA CPR: Refer to the NHS Scotland Policy “Do not attempt Cardio-Pulmonary Resuscitation”
  o How to appoint a welfare guardian if the patient is worried about future loss of capacity to make decisions. (see: Adults with Incapacity Act)
  o Patient and family’s views about future treatments/care – hospital admission, IV antibiotics, non-invasive ventilation, HDU, ITU.
- When a patient with advanced lung disease has an acute episode of respiratory failure, it can be difficult to decide if they will experience more burden than benefit from intensive, life supportive care.
### Care Planning (continued)

- The alternative is care for the last days of life in a setting that can offer symptom control, nursing care and support for the patient and family.
- Clinicians should assist patients to think about the options for management of future acute exacerbations during a stable period of health.

### Symptom control

- Patients with end-stage lung disease have complex health and social care needs so a multi-professional approach is essential in providing optimal care and support.

**Non-pharmacological interventions:**
- Enhance coping and functional ability using controlled breathing and anxiety management techniques, and by planning and pacing activities.
- Consider any need for equipment/aids, a package of care, or financial / benefits advice.
- If the patient is not hypoxic, a hand held fan can be more effective than oxygen.

**Respiratory disease treatments:** (See: Resources)

- **COPD:** Review current inhalers; consider use of a spacer device or nebuliser.
  - Continue long acting beta agonist and inhaled steroid combinations.

- **Advanced interstitial lung disease:** review immunosuppressants and long term oral steroids.

- **Oxygen:** Long term oxygen therapy guidelines should be followed.

**Medication for breathlessness in advanced disease** (see: Breathlessness guideline)

- Medication is often needed for symptom control in addition to non-pharmacological interventions as the illness progresses.

- **Opioids:**
  - Can improve persistent, severe breathlessness and cough.
  - Give opioids as a therapeutic trial. Monitor patient response and side effects. Titrate the dose.

- **Benzodiazepines:**
  - May relieve anxiety/ panic associated with severe breathlessness, but are less effective than opioids for breathlessness and should be a 3rd line treatment for patients with symptoms unresponsive to non-pharmacological measures and opioids.

### End of life care** (see: Last days of life guideline)

- Plan management of breathlessness in the last days of life with the patient and family.
  - Discuss the option of sedation in the event of increasing distress.
  - Prescribe anticipatory medication, as required, for symptom control.
- Consider using an end of life care pathway (eg Liverpool Care Pathway).
- If the patient is unable to take oral medication, convert to the subcutaneous route.
- Oxygen is only useful if hypoxic; nasal prongs may be better tolerated; a fan or changing the patient's position can help.
- Avoid fluid overload, consider stopping any clinically assisted (artificial) hydration or nutrition. Suction can be distressing and may not improve respiratory secretions.
- Consider a nicotine replacement patch for heavy smokers.

### Practice points

- Starting opioids at a very low dose and titrating carefully is safe and does not cause respiratory depression in patients with advanced lung disease.
- Non-drug measures that maximise patient coping are essential.

### Patient/ carer advice points

- Keep the room well ventilated: open the window, use a fan, and keep the face cool.
- Anxiety /panic are distressing but do not cause harm or worsen patient’s condition.
Resources

Professional

Patient
- Patient leaflet on website: Managing Breathlessness
  Chest Heart and Stroke Scotland http://www.chss.org.uk/
  British Lung Foundation Breathe Easy Support Network http://www.lunguk.org/

Key references

4. NHS QIS Chronic Obstructive Pulmonary Disease Clinical Standards http://www.nhshealthquality.org/nhsqis/7648.html