NHS

North West Coast
Strategic Clinical Networks

SYMPTOM CONTROL, PALLIATIVE CARE & REFERRAL GUIDELINES FOR PATIENTS WITH CHRONIC RESPIRATORY DISEASE

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Contents

Introduction

These guidelines have been prepared for the use of health care professionals, to support the delivery of palliative care for patients with advanced chronic respiratory disease. They are intended to be used only in that context, and are written presuming a proper use of professional knowledge, skills and discretion, and are not a substitute for that, or for direct advice from local respiratory or palliative care specialists. If local formularies opt for a specific choice of drug, these should be adhered to.

Palliative care is all about teamwork, and advice might also be taken locally from nurses, pharmacists or others, but prescribing decisions remain the responsibility of the individual prescriber.

Drug dosages and guidance are appropriate for use in primary care, or by other health care professionals outside specialist respiratory or palliative care. Consultants (and sometimes others) in those specialties may use dosages, combinations or drugs outside these guidelines.

These guidelines are designed to be used by healthcare professionals. If you are a patient or a relative of a patient, you should recognise that these guidelines are not a substitute for a healthcare professional's judgement in an individual case. They are simply intended to inform decision-making. If you have any questions, please speak to one of the doctors, nurses or other professionals involved in your (or your relative's) care, as the authors and publishers of these guidelines cannot comment on the care of individual patients.

Palliative care is defined by the World Health Organisation as**:**

> "……an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early intervention and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".
>
> [*Sepůlveda et al 2002*]

It is our responsibility as health professionals to ensure that access to palliative care is equitable across all patient groups (regardless of diagnosis), based on symptom burden (both physical and psychological), social and spiritual care needs. Patients with end-stage respiratory disease are likely to encounter significant physical, psychosocial and spiritual needs, and are therefore likely to benefit from a holistic, palliative care approach. It is recognised that those living with severe COPD experience health-related quality of life comparable to, or worse than that of those with advanced non-small cell lung cancer. [*Habraken et al 2009*].

Most palliative care is delivered by non-specialists (community or hospital teams for whom delivery of palliative care is not their sole practice). This guideline aims to support those healthcare professionals in meeting the specific needs of patients with advanced respiratory disease.

Estimating Prognosis and Advance Care Planning

Estimating prognosis is challenging in advanced respiratory disease, and a holistic, palliative care approach should be based on clinical need rather than prognosis.

Estimating when patients may be in the last year of life can be helpful when considering commencing advance care planning discussions, and also to guide decision making when adding patients to Gold Standards Framework Registers (or similar). The most common non-cancer respiratory illnesses encountered in palliative care are COPD (chronic obstructive pulmonary disease and interstitial lung disease (ILD or pulmonary fibrosis).

If two or more of the following GSF prognostic indicators apply to a patient with **COPD**, this suggests that a patient may be entering the last year of life:

- Disease assessed to be severe (e.g. FEV1 <30% predicted)
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level, or confined the house
- Signs and symptoms of right heart failure
- Combination of other factors e.g. anorexia, previous ITU/NIV, resistant organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

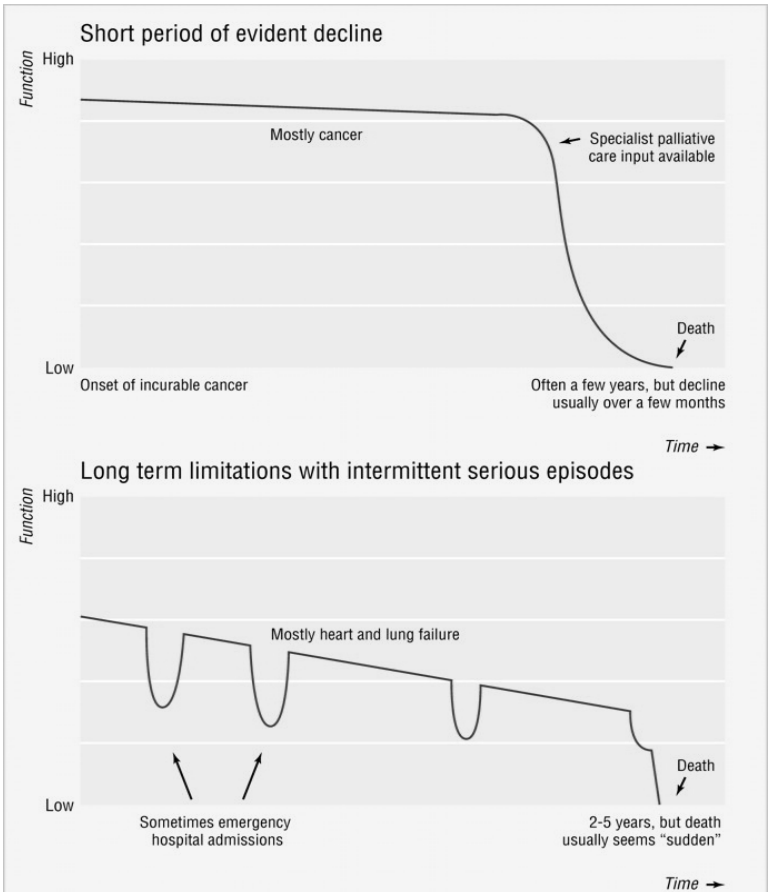
For patients with **interstitial lung disease (ILD)** (pulmonary fibrosis), it is important to be aware of the subtype of ILD, as this impacts significantly on prognosis. The prognosis for those with idiopathic pulmonary fibrosis (IPF) is significantly shorter than for those with other forms of the disease [*Flaherty et al 2002*], with a median survival from diagnosis of approximately 3 years. [*BTS 2008*]

The SPICT Supportive and Palliative Care Indicators Tool (SPICT) is used by some areas within the Network to support the identification of patients with advancing disease who may have unmet supportive and palliative care needs. It provides specific indicators for advanced respiratory disease and is freely available online:

http://www.spict.org.uk/the-spict/

The disease trajectory for patients living with severe non-malignant respiratory disease is different from those with cancer (Fig.1), in that they are likely to experience a slow decline in respiratory and functional capacity punctuated by sudden, unpredictable exacerbations. It is difficult to predict which exacerbation will result in death, and patients often make a near-full recovery, even from severe exacerbations. It is therefore important that the process of advance care planning commences early in the patient's illness if it is to inform care towards the end of life. There is evidence that patients with severe COPD would welcome the opportunity to talk with healthcare professionals about their future care. [*MacPherson et al 2013*]

Figure 1: Disease Trajectories



Adapted from Murray, SA et al 2005, and Lynn and Adamson, 2003.

Advance care planning can be defined as:

> *'the voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. If the individual wishes, their family and friends may be included. It is recommended that with the individual's agreement this discussion is documented, regularly reviewed and communicated to key persons involved in their care.'*

This discussion may lead to:

- An **Advance Statement (AS)** describing wishes and feelings, beliefs and values about future care. It is not legally binding, but if the patient loses capacity it would be taken into account when 'best interest' decisions are made. An AS can either be verbal (the patient may feel that having the conversation is sufficient) or more formally documented.

  Topics covered may include the patient's views on non-invasive ventilation; future hospital admission; where they would be wish to be cared for if very unwell; where they

would wish to die and DNACPR decision-making. It is also useful to understand and document what would matter most to that person if they were very unwell or dying, for example the presence of certain family members; spiritual care; wishes for after death care.

- An **Advance Decision to Refuse Treatment (ADRT).** This can be verbal; however, it must be documented if the patient wishes to refuse life-sustaining treatment. An ADRT is legally binding if valid and applicable to the situation at that time.

Detailed guidance on advance care planning is available in the 'Advance Care Planning Framework for Cheshire & Merseyside Palliative and End of Life Care Network' document (published in 2015), which is available online on the NWC SCN website.

Referral to Specialist Palliative Care

Estimating prognosis is challenging in advanced respiratory disease, and all specialist palliative care referrals should be based on clinical need rather than prognosis.

Patients with advanced respiratory disease and their family/carers should have access to a full range of services offered by multi-professional specialist palliative care teams including where appropriate referral and admission to hospice services [*NICE COPD Guidelines 2010*]. Patients should be referred to specialist palliative care services according to the Cheshire & Merseyside Palliative & End of Life Care Network referral criteria:

Referral can be made by health and social care professionals for:

- Patients with advanced, progressive, incurable, malignant and non-malignant disease who have complex physical, psychological, spiritual, social or carer needs
- Where the above patient and/or family needs are unable to be met by health professionals in the current care setting and may be met by a specialist palliative care service
- Where the current health professionals require support and advice of the specialist palliative care service for e.g. patients dying with complex needs, challenging ethical dilemmas or complex communication issues

The aim of specialist palliative care intervention is to increase patients' understanding of their illness, facilitate future care planning, and optimise holistic symptom management through a multi-professional team approach, including both pharmacological and non-pharmacological measures. Support for families and carers is also an important element of specialist palliative care services. The profile of the intervention may need to be different to that offered to patients with a cancer diagnosis (due to differing disease trajectories), and should be 'tailor made' on an individual basis following an initial assessment. This may include inpatient, outpatient (e.g. clinic or day therapy attendance), and community services.

Specialist palliative care interventions may sometimes be brief, but should be responsive and

timely. There should be recognition that patients may be discharged back to the referring team if the needs identified on referral have been appropriately addressed, with the option to re-refer should this become necessary in the future. However, some patients with complex needs may require continued access to specialist palliative care services over the longer term.

Symptom Control

General notes

- Symptom control should continue in conjunction with active respiratory management for as long as such active measures are considered appropriate.

- In the event of sudden or unexpected deterioration, always consider potentially reversible causes for this (e.g. infection, pneumothorax, pulmonary embolism).

- In the case of the more uncommon respiratory diseases (e.g. interstitial lung disease, bronchiectasis), close liaison with specialist respiratory teams is recommended, to ensure that standard respiratory management is optimised as appropriate.

- A 'holistic' approach should be adopted, encompassing physical, social psychological and spiritual assessment which responds to priorities identified by both the patient and the health professional, respecting patient choice, past life experience and current situation.

- It is important to consider the meaning of a symptom to the patient, for example, as breathlessness or pain worsens, do they assume "I am getting worse?" Are there particular things that worry or frighten them which need to be addressed?

- All interventions should be underpinned with open, sensitive, solution focused communication with not just the patient but also the people who care for them.

- A multidisciplinary and multiprofessional team approach to symptom control is of great importance.

Breathlessness

Standard Respiratory Management: Inhaled Therapy

Bronchodilator therapy should be prescribed in accordance with NICE and local guidance (e.g. Pan Mersey COPD Inhaled Drug Therapy Guidelines).

www.panmerseyapc.nhs.uk/guidelines/documents/G17_flowchart.pdf

Ensure inhaler technique is optimised, and if a metered dose inhaler is used then a compatible spacer device should also prescribed, either Volumatic® or Aerochamber plus®.

Bronchodilators may not be part of standard management in some conditions, e.g. interstitial lung disease. However, a trial of inhaled or nebulised bronchodilators may still be worthwhile.

The majority of patients with COPD will be prescribed an inhaled or nebulised short-acting $beta_2$ agonist (SABA) bronchodilator e.g. salbutamol or terbutaline for use as required. An inhaled or nebulised Short-Acting Muscarinic Antagonist (SAMA) bronchodilator (e.g. ipratropium bromide) can be used as an alternative for those patients who do not tolerate or have limited benefit with a SABA.

Patients with severe COPD (FEV_1< 50%) with persistent dyspnoea and/or frequent exacerbations are likely to be prescribed a combined Long-Acting $Beta_2$ Agonist and Inhaled Corticosteroid LABA/ICS e.g. Symbicort®, DuoResp® or Fostair®. (Seretide accuhaler® is also available but it is no longer deemed a first choice option due the potential increased risk of severe pneumonia) [*Suissa S et al 2013*]. Alternatively, a Long-Acting Muscarinic Antagonist (LAMA) may be used (e.g. Tiotropium, Glycopyronnium, Aclidinium and Unmeclidinium). Patients should not be co-prescribed a SAMA and a LAMA.

The next step in inhaled therapy is to combine the use of LAMA and LABA agents with inhaled corticosteroids. Combination Long Acting Muscarinic Antagonist and Long Acting Beta Agonist LAMA/LABA e.g. Aclidinium with Formoterol (Duaklir Genuair®), Indacaterol with Glycopyrronium (Ultibro Breezhaler®), and Umeclidinium with Vilanterol (Anoro Ellipta®) are options for patients who would otherwise be treated with separate inhalers.

For photographs of commonly prescribed inhalers, please see Appendix 1.

Nebulised bronchodilators are of additional benefit to some patients with obstructive lung disease. Nebulised salbutamol can be added in alongside other respiratory therapies if subjectively beneficial to the patient. Nebulised ipratropium bromide can be tried as an alternative to a LAMA inhaler, but many patients gain more benefit from the inhaler than nebulised therapy.

Table 1: Standard doses of commonly prescribed inhalers

	Inhaled	Nebulised
Salbutamol (SABA)	100 – 200 micrograms q.d.s. +/ or p.r.n.	2.5 – 5mg q.d.s. +/ or p.r.n.
Terbutaline (SABA)	500 micrograms q.d.s. +/ or p.r.n.	5 - 10mg q.d.s. +/ or prn
Ipratropium bromide (SAMA)	20 – 40 micrograms 3-4 times daily. Max q.d.s.	250 – 500 micrograms 3 - 4 times daily. Max q.d.s.
Tiotropium (LAMA)	Handihaler® 18micrograms o.d. or Respimat 5micrograms o.d. (2 sprays of 2.5 micrograms)	Not available
Glycopyrronium (LAMA)	44 micrograms (Seebri Breezhaler®) o.d.	Not available
Aclidinium (LAMA)	322 micrograms (Eklira®, Genuair®) 322 micrograms b.d.	Not available
Umeclidinium (LAMA)	55 micrograms (Incruse® Ellipta®) o.d.	Not available
Formoterol (LABA)	12 micrograms b.d. (can use up to 48mcg/day; dependent on individual products licensing) Easyhaler® 12 micrograms/dose, Atimos Modulite® 12 micrograms/dose; licensed up to 48 micrograms/day	Not available
Indacaterol (LABA)	150mcg o.d. (Onbrez® Breezhaler®) Can increase up to 300 micrograms/dose if some benefit, but still symptomatic)	Not available
Budesonide/Formoterol (ICS/LABA)	Symbicort 400/12 micrograms Turbohaler® **FEV1 <50%** One puff b.d. DuoResp® 320/9 micrograms Spiromax® **FEV1 < 50%** One puff b.d.	Not available
(Beclometasone/Formoterol) (ICS/LABA)	Fostair® 100/6 micrograms **FEV1 <50%** Two puffs b.d.	Not available
Fluticasone Furoate/Vilanterol (ICS/LABA)	Relvar® 92/22 micrograms Ellipta® **FEV1 < 70%** One puff o.d.	Not available
Fluticasone prop/Salmeterol (ICS/LABA)	Seretide 500/50 micrograms Accuhaler® (dry powder) **FEV1 <60%** One puff b.d.	Not available
Aclidinium + Formoterol (LAMA/LABA)	Duaklir Genuair® (dry powder) 340/12 micrograms. One puff b.d.	Not available

Indacaterol + Glycopyrronium (LAMA/LABA)	Ultibro Breezhaler® (dry powder) 85/43 micrograms. One puff o.d.	Not available
Umeclidinium + Vilanterol (LAMA/LABA)	Anoro Ellipta® (dry powder) 62.5/25 micrograms. One puff o.d.	Not available

Tiotropium should be used with caution when patients' creatinine clearance < 50ml/min. and should also be withheld if patients are commenced on Ipratropium nebulisers.

Glycopyrronium use with caution when patients Creatinine Clearance <30ml/min.

Aclidinium can be used in severe renal impairment (no renal restrictions).

Standard Respiratory Management: Additional Measures

Theophyllines can be helpful in reducing breathlessness and wheeze in some patients with obstructive lung disease (e.g. COPD, bronchiectasis, asthma). They are effective in some patients, but others find little or no benefit. A three months trial is often worthwhile to assess for a subjective response. It is advisable to start at a low dose, with careful titration if there is a good response to treatment. Plasma theophylline levels require monitoring (especially if high doses are prescribed), in view of the narrow therapeutic window.

Surgical management can be considered in a carefully selected, small group of patients with advanced emphysema to improve symptoms of breathlessness. Options available include bullectomy, lung volume reduction surgery and non-surgical lung volume reduction (e.g. bronchoscopically placed endobronchial valves or coils). Patients with advanced emphysema should have a high resolution CT scan of their chest to evaluate for the suitability of these treatments. In the presence of large bullae or heterogeneous emphysema, there may be surgical treatment options available. Referral for an opinion in secondary or tertiary respiratory services would be advised if this had not already been considered.

When involved in the care of patients awaiting lung transplant, it is vital that therapeutic changes (especially regarding use of corticosteroids) are discussed with the transplant team at University Hospital South Manchester.

Palliative Management of Refractory Breathlessness

Pharmacological

Opioids form the mainstay of pharmacological management for refractory breathlessness. The use of low-dose opioids for refractory breathlessness in advanced disease has been shown to be safe and effective, including in patients with type 2 respiratory failure. [*Ekstrom et al, 2014*] It is important that they are used alongside non-pharmacological measures (described in the following section). Some patients will not benefit from opioid therapy at all, so it is essential that their benefit and side effects are reviewed regularly. Opioids should be discontinued if there is no perceived benefit following dose titration as detailed below.

When taken regularly, the full effect of opioid therapy may not be felt for several days, so titration should be carried out weekly in patients who are stable (more rapid titration may be appropriate in the last days of life). Some centres use opioids on a p.r.n. basis initially, which may help patients to gain confidence with their use. However, regular administration is likely to be most effective.

It is crucial that opioids are prescribed in accordance with NICE guidelines (i.e. with concurrent regular stimulant laxative e.g. senna 15mg nocte for the duration of opioid use, and p.r.n. anti-emetic e.g. metoclopramide 10m t.d.s. p.r.n. for the first week of therapy).

Patient compliance should be optimised by taking time to allay fears and misconceptions regarding issues such as addiction, tolerance, or association with the end of life. Written information should also be given to all patients who are prescribed opioids.

Opioid naïve patient

- Commence immediate release oral morphine 2.5mg q.d.s. and 2.5mg p.r.n. (4 hourly, max q.d.s.)
- Titrate regular opioid dose weekly according to response, initially to 5mg oral morphine q.d.s, and then 7.5mg oral morphine q.d.s if beneficial and tolerated.
- The maximum dose of oral morphine that is likely to be helpful for dyspnoea is 30mg/24 hour period. [*Currow et al 2011*].
- Once established a stable dose of immediate release oral morphine, conversion to long-acting morphine could be considered for ease of administration.
- For patients with significant renal impairment (eGFR < 30ml/min), an alternative opioid e.g. oxycodone should be used – **SEEK SPECIALIST ADVICE**.

Patient already taking regular strong opioid for pain

- For breathlessness use an additional p.r.n. dose of strong opioid which is in the range of 25-100% of the 4 hourly strong opioid dose depending on severity of breathlessness.
- For example, if patient is on long-acting morphine 30mg b.d. for pain, the additional range for oral immediate release morphine dose for dyspnoea is 2.5 -10mg p.r.n. titrated according to response.

- Consider increasing the regular dose by maximum of 25-50% if p.r.n. doses are beneficial.

There is little evidence to support the use of benzodiazepines for dyspnoea [*Cochrane Review 2010*]. They may be useful in patients who experience panic or anxiety associated with breathlessness despite optimal opioid use; or in those for whom opioids have proved ineffective. Please see anxiety & depression section (p.25) for prescribing guidance.

Non-pharmacological

Non-pharmacological management of breathlessness plays a crucial role in the palliation of this complex symptom. Referral to a physiotherapist and occupational therapist for consideration of the following techniques is likely to be beneficial. Supporting the patient to take control of their breathlessness is vital. Education into the physiology of breathing is an important part of this.

Hand-held fans

Fans have been proven to be effective in the palliation of breathlessness. [Booth et al, 2006] Hand-held fans are small, lightweight, cheap and safe. They are easy to use and give patients control and independence in the management of their symptoms. Their use should be encouraged early in the management of a breathless episode. Patients should be advised to hold the fan 6inches/15cm away from the face blowing on the cheeks and mouth area (with the aim of stimulating the trigeminal nerve). If the patient is unable to tolerate a fan, cooling the face with a cool mist or cloth is an alternative approach.

Breathing control management.

Education regarding breath control techniques and breathing exercises is useful to improve breathing efficiency, and also enables patients to develop strategies to reduce distress and anxiety relating to breathlessness. This may result in reduced perception of dyspnoea, thus allowing the patient to be more active, comfortably.

Breathing control is "normal tidal breathing encouraging relaxation of the upper chest and shoulders" [*BTS/ACPRC, 2009*]. The important part is normal tidal breathing, not an increased breath. A simple explanation of the role of the diaphragm and breathing accessory muscles can help an individual's understanding of breathing control techniques. People often feel that they should breathe from their chest rather than their abdomen, and it can often take time to work on this. Regular practice will improve their efficiency.

‘Benefits of breathing control

- Deters hyperventilation and its related symptoms by encouraging appropriate tidal volume.
- Promotes efficient use of breathing muscles, encouraging breathing from the diaphragm with relaxation of breathing accessory muscles. This may reduce breathing discomfort, aches in the shoulder region and fatigue.
- Encourages smooth laminar airflow, promoting even distribution of inhaled air.

- Can be relaxing and calming' [*The Cambridge BIS Manual 2011*]

Pursed Lip Breathing (PLB)

There is evidence that pursed lip breathing can be effective in improving ventilation in some patients. PLB can improve exertional breathlessness and physical function [*Nield et al, 2007; Faager et al, 2008*]. PLB has also been shown to lower respiratory rate and speed recovery of breathlessness after exercise [*Garrod et al, 2005*]. Many patients who will benefit from this technique use it instinctively.

Walking aids

The use of a rollator walking frame can increase walking distance in the breathless patient. Referral for a walking aid can be useful as part of the management of breathless patients.

Positioning advice

Upright postures can improve ventilation by maximizing the potential for diaphragmatic breathing. Use of hospital beds and pillow wedges can be useful to aid sleep by assisting the patient to maintain a more upright sleeping posture. Flexed postures can hinder diaphragmatic excursion in all positions. Lengthening groin to shoulders is a good general rule for consideration but needs to be assessed depending on the patient's individual requirements. The forward lean position can be useful in all postures and should be assessed in each individual for tolerance and benefit.

Anxiety management

Anxiety can result in hyperventilation and dysfunctional breathing, and is also likely to increase the patient's perception of their breathlessness. Education regarding the recognition and effect of anxiety is an important part of any breathlessness management package. Exploring the individual's anxieties regarding the meaning and consequences of their breathlessness is crucial, in order to allow discussion and development of strategies for coping with these concerns. Relaxation techniques and CDs are available, but should be used on a regular basis by the patient to improve their effectiveness in reducing anxiety.

Exercise

Breathlessness is unpleasant at best, and terrifying to some patients. It is understandable to want to avoid creating this symptom with exercise. However pulmonary rehabilitation is recommended in COPD management guidelines [*NICE 2006*], and there is evidence to suggest that even those with very severe COPD may benefit from gentle, regular exercise to improve muscle conditioning and efficiency. [*Morris et al, 2009*]

Reassurance regarding exercise and its benefit, and allowing themselves to be breathless is important in order to achieve an improvement in exercise tolerance. Patients often fear that breathlessness is harmful, and hence avoid exertion. The less a person does the weaker they become and the more breathless when they try, which becomes a vicious circle. Encouraging

breathless patients to do gentle, regular exercise can improve muscle conditioning and efficiency.

Complementary therapies

These include relaxation, aromatherapy, acupuncture, visualisation.

Role of the Occupational Therapist: includes guidance re. suitable adaptations to living accommodation; advice regarding equipment (e.g. perching stool); advice regarding fatigue management (e.g. planning and pacing); relaxation techniques.

Role of the Physiotherapist: includes teaching of breathing recovery strategies; advice and support to maintain mobility (e.g. assessment for walking aids); acupuncture; guidance regarding secretion removal techniques; positioning advice.

Use of Oxygen in Advanced Respiratory Disease

Most patients with advanced respiratory disease will have been previously assessed for oxygen therapy and many will already have long-term oxygen therapy (LTOT) for a minimum of 15 hours per day to treat hypoxia. These patients will be known to local Home Oxygen Assessment and Review Services (HOS-AR) who should be contacted directly if further advice or review is required.

LTOT is a treatment specifically for patients with chronic hypoxaemia which can improve long-term survival but it is not a treatment for breathlessness. There is no evidence to support the use of short-burst oxygen therapy for patients whose oximetry or blood gases do not meet the criteria for LTOT. [*Abernethy et al, 2010; Uronis et al 2008; Clemens KE et al 2009; Currow DC et al 2009*]

Evidence suggests that opioids in appropriate doses and non-pharmacological treatments such as fan therapy, pacing, breathing control and psychological support should be offered as first line treatment of breathlessness. When breathlessness continues to be intractable following all other interventions some patients may be considered for oxygen as a palliative measure. Unless the patient is imminently dying, referral should be made to the local HOS-AR service for specialist assessment. [*BTS 2015*]

Oxygen equipment and flow rates

The decision to use either an oxygen cylinder or concentrator will depend upon the patient's needs and hours of use. Oxygen use can quickly escalate in this group of patients resulting in the need for multiple cylinder refills and the risk of oxygen running out leading to panic and distress. If oxygen is to be used for more than 1hour in total over 24hours it can be more cost effective and convenient to prescribe a concentrator. In most areas ambulatory oxygen can only be prescribed by specialist oxygen teams on a Part B HOOF (Home Oxygen Order Form) so appropriate referral should be made.

Oxygen can be administered via nasal cannulae or an oxygen mask. It is usual to provide nasal

cannulae as this tends to be better tolerated and patients can continue to eat, drink and talk with oxygen still in place. Flow rates will usually be between 2-4l/pm however patients with advanced respiratory illness such as interstitial lung disease (ILD) can require much higher flow rates and additional equipment. In these cases advice should be sought from specialist oxygen teams or the patient's respiratory team. Some patients with high respiratory rates (e.g. ILD) or very high perception of breathlessness may not have their needs met adequately by nasal cannulae and it may be necessary to use a mask and venturi system. As flow rates via nasal cannulae and oxygen masks are not equivalent, advice should be taken before switching between interfaces. Patients who are at risk of developing hypercapnia may also need assessment with blood gases.

Humidification of oxygen is not necessary at flow rates of 4l/pm or less. Patients who require higher flow rates particularly above 8l/pm may benefit from humidification however currently only cold water humidifiers are available from the oxygen supplier. These systems are largely ineffective and can be reservoirs for infection therefore are not routinely recommended.

Assessment of risk

It is the responsibility of the person undertaking the assessment to identify risks and put control measures in place to minimise the likelihood of harm *before* oxygen is prescribed. The most common risks associated with home oxygen are fire, burns or explosion or trips and falls if long tubing is supplied. The likelihood of problems are significantly increased if patients or others in the property smoke, have a history of substance misuse, have cognitive impairment which may be related to certain medications as well as organic causes, or have mobility or visual impairments. Full education and written information regarding the risks and health and safety advice must be given to the patient and /or carers. In some cases where the risks potentially outweigh the benefits it is not appropriate to prescribe oxygen.

The oxygen supplier will carry out its own risk assessment at installation and most Fire and Rescue services (FRS) now routinely visit patients following oxygen installation. However those patients considered at higher risk should be specifically referred to FRS for early review and sometimes before oxygen is installed.

Prescribing oxygen

Wherever possible, oxygen assessment and prescription should be done by the local HOS-AR service. If this is not possible either because the patient is in distress and in the last few days of life or the HOS-AR service is not available, oxygen can be ordered by non-specialist health care professionals using a Part A HOOF. A patient home oxygen consent form (HOCF) must also be signed to permit data sharing with the oxygen supplier.

The completed HOOF must be faxed to the current regional oxygen supplier Air Liquide on 0870 863 2111.

Follow up assessment and review

HOS-AR services will regularly review all patients who commence oxygen therapy unless it is

clinically inappropriate to do so i.e. patient death is imminent. Non-specialist prescribers who complete a Part A HOOF should inform their local HOS-AR team and discuss the appropriateness of review.

Cough

Intractable cough is a challenging symptom, which is present in up to 80% of patients with advanced respiratory disease. [*Elkington H et al, 2005*]. Frequent coughing can have a significant impact on quality of life due to its impact on sleep, oral intake and willingness to engage in social activities. Frequent paroxysms of coughing may also result in additional symptoms such as vomiting, pain and urinary incontinence.

It is important to rule out reversible causes for cough (e.g. infection, drug-induced, gastro-oesophageal reflux disease, post-nasal drip) prior to commencing palliative measures.

Cough can be classified into productive or 'wet', and non-productive or 'dry'. In patients with 'wet' cough, interventions to aid expectoration are most appropriate (see Sputum section on p.18 for further guidance). Anti-tussive agents may be used for patients with 'dry' cough, as detailed below:

- **Peripheral anti-tussive agents**:
    - Simple linctus 5 - 10 mls p.r.n. 3 - 4 times daily (limited evidence for use, but anecdotally can be helpful, and safe).
    - Sodium cromoglicate 10mg inhaled q.d.s. via spacer device (limited evidence from one small RCT in patients with lung cancer, but safe and included in APM guidance). [*Moroni et al, 1996; Wee B et al, 2012*]

- **Central anti-tussive agents**:
    - Codeine linctus (15mg/5ml) 5 -10mls q.d.s. or p.r.n.
    - Low dose oral morphine solution (10 mg/5 ml) starting dose 2.5 mg (1.25mls) p.r.n., increasing to q.d.s. and 4 hourly p.r.n.)
    - Gabapentin 300mg t.d.s. increasing to 600mg t.d.s. [*Ryan et al, 2012*]
    - Baclofen 10mg t.d.s. or 20mg o.d. (*N.B. Avoid sudden withdrawal due to risk of severe psychiatric reactions*).

Management of Sputum

If sputum increases in amount or changes in colour, it is important to exclude infection and consider whether antibiotics and steroids are indicated (depending on the patient's primary respiratory diagnosis). Management of difficulty in expectorating or high volume sputum includes:

- Mucolytics (use with caution in patients with a history of peptic ulcer disease) e.g. Carbocisteine (Mucodyne®) at starting dose of 750 mg t.d.s. reducing to maintenance dose of 750mg b.d. once satisfactory

response obtained, i.e. reduction in cough and sputum production. Capsules (375mg) and liquid (250mg/5ml) available.

- Sodium Chloride 0.9% nebules 2.5 – 5mls q.d.s. or as required may ease expectoration.

- Chest physiotherapy

- 7% hypertonic saline can be of benefit to help with sputum clearance in patients with bronchiectasis. It can cause significant bronchoconstriction, therefore patients require assessment by a respiratory specialist prior to initiation.

- Azithromycin can be used to reduce exacerbation frequency or sputum volume in patients with COPD or bronchiectasis. It is used for its anti-inflammatory rather than antibacterial activity. This treatment should only be initiated following specialist respiratory assessment. It is usually prescribed at a dose of 250mg three times a week, but can also be used daily.

- Intravenous antibiotic therapy can be considered to reduce sputum volume in patients with a high bacterial load in their sputum. A sputum sample to assess for the presence of infection is useful in selecting appropriate patients.

Pain Management

Pain is experienced by the majority of patients with advanced respiratory disease. Approximately one third of patients with COPD report “significant pain”, although it is often under-assessed. [*Blinderman et al, 2009*] A thorough assessment of pain is necessary in order to identify and reverse the cause and select the most appropriate analgesic regimen.

Potential causes of pain in advanced respiratory disease include:

- Lung parenchyma e.g. chest infection
- Musculoskeletal e.g. rib fracture, costochondritis, muscle sprain, intercostal muscle fatigue
- Pleural disease e.g. pneumothorax, effusion
- Vascular e.g. pulmonary embolism
- Co-morbidity or drug-induced e.g. osteoporotic vertebral collapse secondary to steroid treatment; angina; osteoarthritis pain
- Surgical e.g. post-thoracotomy

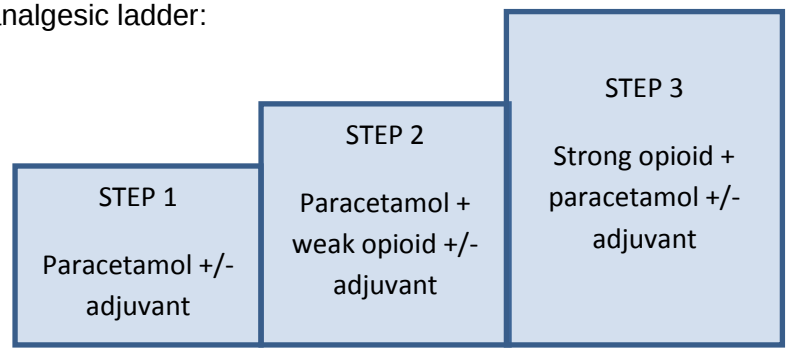
A comprehensive pain assessment involves determining the physical characteristics, whilst understanding the impact of pain on functional status, psychosocial factors and spirituality.

The principles of pain management:

1. Identify and treat any reversible cause

2. Use a multidisciplinary approach
3. Involve patient and carers in decision making and set realistic goals
4. Consider non-pharmacological interventions e.g. massage, relaxation, psychological support including cognitive behavioural therapy, TENS machine
5. Use WHO analgesic ladder to initiate and titrate analgesia
6. Review effect after each change in treatment

WHO analgesic ladder:



STEP 1: For mild pain commence regular paracetamol at a dose of 1g q.d.s. If commencing a NSAID, use ibuprofen 400mg t.d.s. and consider a test-dose prior to initiation if there is a high risk of bronchospasm. (*N.B. Avoid NSAIDs in patients with renal impairment; gastro-intestinal bleeding or cardiovascular disease*).

STEP 2: For moderate pain consider the addition of a weak opioid, such as codeine phosphate at a dose of 30 - 60mg q.d.s.

STEP 3: For severe pain, which has failed to respond adequately to steps 1&2, consider commencing a strong opioid. Offer the patient a regular oral sustained-release morphine (e.g. MST®, Zomorph®), with rescue doses of oral immediate-release morphine (Oramorph®) for breakthrough pain. For patients with no renal or hepatic impairment a typical starting schedule is 10mg modified-release morphine twice daily with a breakthrough dose of 2.5 - 5mg immediate-release morphine p.r.n. All patients should be prescribed a regular stimulant laxative on commencing strong opioids, and a p.r.n. anti-emetic as transient nausea is common during the first few days of opioid therapy. [*NICE 2012*]

It is important to monitor the response to morphine prior to dose titration, and to avoid increasing the total daily dose by greater than 50% at any given time. Discontinue dose titration once maximum analgesic effect is achieved with minimal side effects. If the patient develops significant side effects or has hepatic/renal impairment, seek specialist advice as conversion to an alternative strong opioid (e.g. oxycodone) may be needed.

For patients without an oral route, consider an alternative route of delivery such as subcutaneous injection or transdermal patch application.

Management of pain that is not responsive to opioid analgesia may require specialist advice. There are several options available for treating neuropathic pain including tricyclic

antidepressant and anticonvulsant medications. Corticosteroids and anaesthetic interventions may also be considered.

Nausea and Vomiting

In order to provide effective symptom relief, an assessment of aetiology of nausea and vomiting is required. Common causes in patients with advanced respiratory disease include cough, anxiety, pain and constipation. Drugs can induce nausea; for example, opioids, antibiotics and aminophylline. If the patient is on theophylline consider checking blood levels and adjusting the dose. Co-morbidities such as infection, dyspepsia, oral candidiasis and electrolyte imbalance can all contribute.

Assessment involves identifying triggers and associated symptoms. Focused examination and investigation may be necessary. Attempt to reverse any underlying cause and consider non-pharmacological options, for example avoidance of triggers, small frequent meals and use of relaxation techniques.

The principles of initiating an anti-emetic medication are as follows:

- Prescribe a first-line option regularly, according to the most likely cause
- Reassess daily and consider dose titration
- If persistent nausea consider an alternative to the oral route
- If the nausea is not relieved, consider addition or substitution of an alternative first line drug (avoid co-prescribing of metoclopramide and cyclizine, as cyclizine may block the prokinetic effect of metoclopramide)
- If poor response, consider second-line medication and seek specialist advice

First line options:

- Cyclizine inhibits the vomiting centre and is a vestibular sedative.
  Avoid in severe heart failure.
  Dose: 50mg t.d.s. p.o. or 150mg/24h via continuous subcutaneous infusion

- Haloperidol inhibits the chemoreceptor trigger zone and is effective at treating chemical causes e.g. drug-induced nausea
  Dose: 1.5 - 3mg p.o. nocte, or 1.5 - 5mg via continuous subcutaneous infusion

- Metoclopramide is a pro-kinetic medication which relieves gastric stasis, and also has some central effect
  Risk of extrapyramidal side effects - use smallest effective dose for the shortest time necessary. However, if long-term use is required, this is acceptable for patients with a palliative diagnosis.
  Dose: 10mg t.d.s. p.o. or 30mg/24h via continuous subcutaneous infusion

- Domperidone is a pro-kinetic medication, which relieves gastric stasis. It is useful in patients with increased risk of extra-pyramidal side effects, e.g. Parkinson's disease

Dose: 10mg q.d.s. (no subcutaneous preparation available)
Pro-arrhythmogenic, therefore avoid in severe cardiac disease.

Second-line options:

- Levomepromazine is a broad-spectrum anti-emetic and can replace first-line drugs when the cause is multi-factorial. Variable sedation can be an unwanted side effect.
- Dose: 6.25 – 12.5mg o.d. or 6.25-12.5mg/24h via continuous subcutaneous infusion

Anorexia and Weight Loss

Weight loss is common in advanced respiratory disease and is associated with a reduction in quality of life and increased mortality. The aetiology is multi-factorial and occurs as a result of anorexia, (due to dyspnoea, fatigue, low mood, social isolation), and increased pro-inflammatory cytokines which may result in fat loss and muscle wasting. A combination of a reduction in nutritional intake and additional nutritional requirements due to the increased work of breathing places these patients at risk of malnutrition.

A non-pharmacological approach to improving nutrition involves providing dietary advice and helping patients to access regular meals. Positioning is important (i.e. sitting upright at a table rather than in an armchair), and moving to the table approximately 15 minutes in advance of the meal to allow dyspnoea to settle. Meals should be taken small and often, and some patients may find it easier to eat soft food. Nutritional supplements can be useful. If simple measures prove ineffective, consider accessing specialist dietetic support.

A pharmacological approach to stimulate appetite and reduce weight loss may be considered for short-term use (although the evidence of benefit in palliative care patients is limited):

- Corticosteroids: consider a trial of dexamethasone 4mg o.d. for 1 week, followed by a reduction of 2mg per week, then stop.
- A trial of megesterol acetate 80 - 160mg o.d. (This should be used with caution in patients with a history of venous thromboembolism.)

Constipation

Constipation may be triggered by reduced intake of fluids & food, reduced mobility or opioid drugs (strong or weak). It is important to understand the patient's normal bowel habit, and how this has changed.

Non-pharmacological approaches include:

- Increasing fluid intake
- Encourage mobility
- Use of a raised toilet seat, arm rails and footstool to enable use of accessory respiratory muscles and help brace abdominal muscles

Patients on opioids require a regular stimulant laxative to prevent opioid-induced constipation. [*NICE 2012*].

In those with established constipation, it is usually most effective to combine a faecal softener and stimulant laxative. If necessary, an osmotic agent can then be added on a p.r.n. or regular basis.

Faecal softener

- Sodium docusate: 100mg b.d. increasing up to 500mg daily in divided doses.

Stimulant laxatives

- Senna: 7.5 - 15mg nocte, increasing to 15mg b.d.
- Bisacodyl: 10 - 20mg p.o. nocte, increasing to b.d. or t.d.s.
- Sodium picosulfate 5 – 10mg nocte,, increasing to 30mg daily

Osmotic laxatives

- Lactulose solution (3.1 - 3.7g/5ml) initially 15mls twice daily, adjusted according to response
- Macrogols (Movicol®, Laxido® or Cosmocol® sachets) 1 – 3 sachets daily in divided doses. The contents of each sachet should be dissolved in half a glass (approx. 125ml) of water.

Patients with ongoing constipation despite oral laxatives, or who do not have an oral route, may benefit from rectal intervention with glycerine suppositories or bisacodyl suppositories +/- microlax® or phosphate enema.

Naloxegol can be considered for patients with opioid-induced constipation who have had an inadequate response to standard laxative therapy [*NICE TA345*].

Depression & Anxiety

There is a high prevalence (up to 90%) of psychological distress (anxiety and/or depression) in those with advanced respiratory disease. [*Kunik et al 2005*] Psychological symptoms should be screened for and treated, using both pharmacological and non-pharmacological approaches. Appropriate management of depression and anxiety may result in improved perception of physical symptom burden, as well as increasing overall wellbeing and quality of life.

Depression

Non-pharmacological approaches may include cognitive behavioural therapy if available, as this is the first-line intervention recommended by the National Institute for Health and Clinical Excellence for the treatment of mild to moderate depression in patients with a chronic physical health problem. [*NICE 2009*]

Pulmonary rehabilitation (if the patient is functionally able to participate) or gentle (even chair-based) regular exercise, are also likely to be helpful.

Social isolation due to physical restriction may be profound, and is likely to contribute to psychological distress. Mechanisms for relieving this should be explored, for example attendance at a hospice day therapy unit, or local respiratory support groups (e.g. British Lung Foundation Breathe Easy Groups) can prove beneficial.

Pharmacological management of depression includes the following options:

Selective serotonin reuptake inhibitors (SSRIs):

E.g. citalopram 10 – 40mg o.d. (max. 20 mg in patients over 65 years) or sertraline 50 – 200mg o.d.
Useful for mixed anxiety and depression. Gastrointestinal upset common initially.
Please see BNF for details of side effects and interactions.

Mirtazapine: 15 – 45mg nocte

May increase appetite and improve sleep, and does not cause nausea & vomiting.

Anxiety

The initial approach to management of anxiety should be to explore the patient's fears and concerns and address these wherever possible. This is likely to require a multi-disciplinary approach, as factors provoking anxiety may include issues such as financial concerns; fears as to how their illness impacts on family members; uncontrolled physical symptoms or existential distress. Remember also to consider nicotine withdrawal as a cause of anxiety or agitation in inpatients, or those in the last days of life, and consider nicotine replacement therapy as appropriate. Consider referral to a counsellor or specialist palliative care occupational therapist for support with non-pharmacological management techniques such as guided imagery or mindfulness.

If non-pharmacological approaches are not possible, or prove ineffective, consider low-dose citalopram 10mg o.d. for those with an estimated prognosis of greater than 4 weeks.

Benzodiazepines can also be considered, but should be used at the lowest effective dose for the shortest duration possible due to problems of dependency in long-term use, and the caution required in patients with type 2 respiratory failure. [*Ekstrom et al, 2014*]

Drug	Dose	Comments	Pharmacokinetics
Diazepam	2 - 5 mg p.o. p.r.n. up to t.d.s.	• Long acting. • Reduce dosage in frail and elderly.	Onset of action Oral = 15 min Half-life = 25 - 50h;
Lorazepam	500 micrograms - 1 mg sublingually**/**p.o. 4hrly p.r.n. (max. 4mg/24h)	• Some brands of lorazepam tablet will dissolve easily when placed under the tongue. • This is an unlicensed use that results in a fast onset of action. • 1mg tablets are scored, and can be broken in half	Onset of action Sublingual = 5min Oral = 10 - 15 min Duration of action 6 - 72 h Half-life = 10 - 20h
Midazolam	2.5 - 5 mg s.c. 4 hrly p.r.n.	• Short acting • Useful for intractable breathlessness • If the patient is too unwell to take oral medication, midazolam 2.5mg s.c. four hourly p.r.n. can be used as an alternative. • If multiple doses are required then consider administration via 24 hour CSCI at a starting dose of 5 - 10mg.	Onset of action 5 - 10 mins SC Duration of action 5mg < 4 h Half-life = 1 - 4 h

Dry Mouth

The presence of dry mouth may be due to the use of oxygen therapy, other medication (including opioids) or dehydration.
Careful oral examination is necessary to exclude treatable causes e.g. oropharyngeal candida (especially if the patient has recently received antibiotics or corticosteroids).

Management strategies include the following:

- Optimise hydration
- Teeth and tongue should be cleaned at least twice daily with a small/medium head toothbrush and fluoride toothpaste. The mouth should be rinsed thoroughly with water after cleaning.
- Dentures should be removed twice daily, cleaned with a brush and rinsed with water. They should be soaked overnight in water or the patient's usual solution and cleaned with a brush.
- Sipping pineapple juice, or chewing small pineapple chunks
- Ice cubes / ice chips
- Chewing gum to stimulate the production of saliva
- Saliva substitutes - e.g. Oral Balance Gel® or artificial saliva spray
  - Avoid acidic saliva products in dentate patients
  - Be aware that some saliva substitutes are porcine in origin
- Management of dry lips:
  - Commercially available lip salves can be used
  - Water soluble lubricant e.g. Aquagel® can be used safely for patients requiring oxygen therapy
  - **Yellow/white soft paraffin can only be used for patients not requiring oxygen, and who are unlikely to do so**

Financial Benefits

There are many benefits available to support patients and carers when someone is sick or disabled. This list is not exhaustive and patients and families should be guided to specialist websites for further information and advice.

The following information is available from:

https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/benefits-for-people-who-are-sick-or-disabled/

- What help is available
- Disability benefits help lines
- Working Tax Credit
- Benefits for people who cannot work
- Statutory Sick Pay
- Employment and Support Allowance
- Incapacity Benefit
- Severe Disablement Allowance

- Benefits for the extra costs of disability
- Personal Independence Payment
- Disability Living Allowance
- Attendance Allowance
- Benefits for accidents at work and industrial diseases
- Disablement Benefit
- Benefits for people injured in the Armed Forces
- Benefits for carers
- If you need help to claim or collect benefits
- Benefits abroad

Personal Independence Payment (PIP)

Personal Independence Payment (PIP) is a benefit for people aged 16 - 64 years with a long-term health condition or disability. It's being introduced in stages from 8 April 2013, and is gradually replacing Disability Living Allowance (DLA) for people in that age group.

PIP is made up of 2 parts, the daily living component and the mobility component. Each component can be paid at one of 2 rates, either the standard rate or the enhanced rate. If the DWP decision maker decides that the person's ability to carry out the component is limited, they will receive the standard rate. If it's severely limited, they will receive the enhanced rate.

For those deemed to be 'terminally ill', the usual conditions for receiving PIP will not have to be met, and the claim will be dealt with more quickly than other claims. A face-to-face assessment will not be necessary. Terminal illness is defined for these purposes as 'having an illness that is getting worse, and the patient is likely to die within six months'.

Under the normal rules, patients must show that they have limited ability to carry out certain activities for at least three months before meeting the eligibility criteria for the daily living component of PIP. They must also be expected to continue to have these difficulties for at least nine months. Together these are called the **required period condition**. A face-to-face assessment with a health professional may be required.

Patients may also be eligible for the mobility component if they can demonstrate that they have certain difficulties getting around. It is not to meet the required period condition for this aspect of the benefit.

Attendance Allowance

Attendance Allowance (AA) is a benefit for people with care needs who are 65 or over, and are not in receipt of Disability Living Allowance (DLA) or Personal Independence Payment (PIP). AA does not include a mobility component. However, if a person is already receiving a DLA or PIP mobility component when they become 65, they can carry on receiving it. Patients cannot make a new claim for DLA or PIP mobility component after the age of 65.

To be eligible for Attendance Allowance (AA), a person must have had care needs for at least six months (unless terminally ill). Care needs are defined as requiring 'help with bodily functions, for example, washing, getting dressed and going to the toilet.' This help can also include requiring attention to allow participation in social activities, or supervision to stop them from

being a danger to themselves or others. If a person is terminally ill, they are automatically treated as having care needs.

Attendance Allowance (AA) is paid at two rates, a higher rate and a lower rate. The lower rate is paid if the person needs frequent care throughout the day **or** night. The higher rate is paid if the person needs frequent care throughout the day **and** night, or if they are terminally ill.

Free prescriptions

A patient is eligible if they have a continuing physical disability which means they are not able to go out without the help of another person, or if they have one of the other illnesses which entitle them to free prescriptions e.g. diabetes, thyroid disease, stoma and cancer.

http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Prescriptioncosts.aspx

Blue badge scheme

This allows drivers of passengers with severe mobility problems to park close to where they need to go. For more information about the Blue Badge scheme see:

https://www.gov.uk/blue-badge-scheme-information-council

Carer Support

Family members are often supporting a person they love because they are their son, daughter, mother, father, husband or wife. They do not think of themselves as a carer. A carer is someone who looks after a friend or family member who's not able to manage all their needs by themselves.

Being a carer can be both physically and emotionally draining. Carers are more likely to experience physical and mental health problems than people without caring responsibilities. It can place a strain on relationships with other family members, on work and finances.

It is our duty as health and social care professionals to assess the needs of carers, and provide appropriate support. This may include signposting to sources of information (see list of websites below), or to local carer support groups. It is also important to encourage carers to consider their own health needs, and to ensure they are registered with a local GP. Simple messages such as emphasising the importance of the following factors to promote wellbeing can be beneficial:

- **Eating well**
- **Exercise**
- **Getting enough sleep**
- **Psychological and emotional wellbeing**: Being a carer can be extremely stressful. Many carers report negative emotions including guilt, resentment, anger, loneliness. Encourage them to talk to family and friends about how they are feeling and, to ask for help from their GP if necessary. Respite care is an important consideration, and

allows carers time to focus on themselves. Some Hospice at Home services provide regular brief visits for this purpose. Longer-term respite within a nursing home is also available. Services will vary from locality to locality. For further information, see NHS Choices and Carers Trust websites (links below)

- **Balancing work and caring**: Carers have the right to ask to work flexibly if they need to. Altering hours or pattern of work, or working from home, maybe possible. Many larger employers have policies to support this.
- **The financial impact of caring.** Caring often has a financial impact, even if it doesn't directly affect working hours. If carers do need to give up work completely, they may become eligible for benefits such as income support or carer's allowance or for some tax credits.

Carer's Allowance

Carer's Allowance is a benefit for people who are giving regular and substantial care to disabled people in their own homes. Carer's Allowance is a taxable benefit and forms part of your taxable income.

Carer's Allowance is depending on meeting all of the following conditions:

- the carer is aged 16 or over and not in full time education
- the carer spends at least 35 hours a week caring for a disabled person who gets one of the following benefits: Attendance Allowance, Constant Attendance Allowance, the middle or higher rate for personal care of Disability Living Allowance, the daily living component of Personal Independence Payment (either rate) or Armed Forces Independence Payment
- the carer does not earn more than £110 a week after deductions such as tax and national insurance
- the carer is resident in Great Britain at the time of the claim - there are some exceptions, for example, for members and family members of the Armed Forces
- the carer has been in Great Britain for at least 2 of the last 3 years
- the carer is habitually resident in the UK, Ireland, Isle of Man or the Channel Islands
- the care is not subject to immigration control that would prevent them receiving benefits.

There are some exceptions to these conditions if living in another EEA country.

In some cases, carers may meet the conditions for both Carer's Allowance and another benefit, such as Retirement Pension or contributory Employment And Support Allowance. If the Carer's Allowance is either the same as or less than the other benefit, they will receive the other benefit rather than Carer's Allowance. However, if the other benefit is less than Carer's Allowance, they will receive the other benefit and the balance of the Carer's Allowance in addition. The rules are complicated, and it is advisable for the carer to seek specialist advice via Citizens' Advice or a medical social worker. If in doubt, the claim for Carer's Allowance should be made, as this might also allow them to get receive additional amounts in other benefits such as the guarantee credit part of Pension Credit, Housing Benefit.

Carers should be advised to always discuss with the person they are caring for before making a claim for Carer's Allowance, as the patient may lose some of the benefit they get, such as a severe disability addition, if a claim is made.

The following websites provide useful support and guidance for carers:

https://www.carers.org/ - guidance on all issues that may affect carers

http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-assessment.aspx - information on your right to a carer's assessment

https://www.mariecurie.org.uk/help/being-there - information for people caring for someone with a terminal illness, but as relevant to those caring for people with a long term condition, with links to other sites providing information for carers

https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/benefits-for-people-who-are-sick-or-disabled/

http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/breaks-for-carers-respite-care.aspx

Spiritual Care

Spiritual assessment is a crucial element of holistic care; understanding a patient's spiritual care needs is likely to have a positive impact on quality of life. Every person has a spiritual dimension, which may or may not be associated with a specific religion or belief system. It is important to understand what gives a person's life meaning; how they make sense of significant life events; and what coping strategies have proved useful to them during previous life challenges. If a person does have specific religious needs, these should be understood and addressed. The Cheshire & Merseyside Palliative and End of Life Care Network Standards and Guidelines for Spiritual Care (2014) provide detailed guidance in this area, as well as information regarding training resources, and can be accessed via the following link:

http://www.cmscnsenate.nhs.uk/files/4914/0742/3855/Spirituality_Guidelines_-June_2014_FINAL.pdf?PDFPATHWAY=PDF

The following 'Religious Needs Resource' website provides detailed information regarding the religious care needs of those practicing a wide variety of faiths, including at the end of life:

http://queenscourt.org.uk/spirit/

Withdrawal of Non-Invasive Ventilation at the End of Life

Increasing numbers of patients with chronic respiratory disease use non-invasive ventilation (NIV), usually during sleep for control of sleep disordered breathing. This can lead to improved sleep quality, improved symptoms and quality of life, a reduced need for secondary healthcare and through effective control of ventilatory failure improved life expectancy.

All patients who commence NIV for any reason should be aware that it is a therapy like any other. As competent adults they have every right to stop the therapy at any point if it is not helping or becoming a burden.

Most patients particularly those with COPD or obesity related respiratory failure will use the ventilator only at night. As the disease progresses or a distinct acute or chronic illness becomes dominant and they approach the end of life most will choose to stop NIV at some point without any undue problems. They may need the reassurance that such a decision if properly considered is reasonable and then support through effective symptom control.

A smaller number of patients, most commonly those with neuromuscular diseases such as Duchenne Muscular Dystrophy or Motor Neurone Disease will also use the ventilator in the day for relief of symptoms and a very small number may become dependent on it, some using it 24 hours per day. Dependency has no clear definition, but can be thought present when it is felt likely that cessation of ventilator support will lead rapidly to distressing symptoms and death within hours or days. This situation can be difficult for healthcare professionals who may feel their actions are causing the death of the patient. As such the Association of Palliative Medicine (APM), with other groups has produced guidance for professionals. It is clear that a competent adult has the right to ask that ventilation is removed, and that wish should be carried out. Death when it occurs is due to the underlying disease and this situation is not to be confused with euthanasia or assisted suicide, both of which remain illegal. The '*Withdrawal of assisted ventilation at the request of a patient with MND'* guidance has now been published on the APM website, but is relevant to any patient/condition.

Patients dependent on NIV will require pre-emptive medicine in anticipation of symptoms after NIV removal and then close support by the medical team. It is important to recognise that many patients will continue to breathe for many hours or longer after the removal of NIV and death is unlikely to be rapid, unless truly dependent on the ventilator. This can be helpful in separating the act of ventilator discontinuation from death for professionals and family.

There are a very few patients who are ventilated via tracheostomy in the community. In principle the situation when stopping ventilation is no different to using NIV. However many professionals will be unfamiliar with this situation and the support of the long-term ventilation service may well be needed.

All patients receiving community ventilatory support are under a specialist long-term ventilation team. In Cheshire and Merseyside this is based at Aintree University Hospital. They can be contacted if support is needed, there is a dedicated Ventilation Consultant and Physiotherapy team, Monday to Friday; the telephone number for the Ventilation Secretary is 0151 529 8944.

Care in the Last Days of Life

NICE Guideline 'Care of the Dying Adults in the Last Day of Life' (NG31, December 2015) provides detailed guidance regarding assessment and management of patients in the last days of life

It is important to recognise when a patient may be entering the dying phase, and this should be discussed as a multi-disciplinary team. It may be difficult for the health care teams to accept that deterioration does not represent their own failure. It is often more difficult to diagnose the dying phase in patients with end stage respiratory disease than in terminal cancer patients, and active medical management is often appropriate alongside good symptom control. If recovery is uncertain, this information must be shared with the patient (if they wish) and their family.

A patient's care in the dying phase should be supported by a local individualised care plan, guided by the five priorities of care as outlined in 'One Chance to Get It Right' and NICE 'Care of the Dying Adult' (NG31, December 2015). The appropriateness of procedures such as venepuncture, arterial blood gas measurement, and basic nursing observations should be reviewed and clearly documented alongside decisions regarding ceilings of care and DNACPR. As the patient becomes weaker and & has difficulty swallowing, it is appropriate to consider discontinuing non-essential medications. It is also be important to review and discuss as a multi-disciplinary team the need for clinically assisted hydration daily, in discussion with the patient and those close to them. All patients should be supported to eat and drink for as long as possible.

Regular assessment of symptoms and & adjustment of medications, if adequate control has not been achieved, are essential. Respiratory tract secretions may be of major concern to the family but not always distressing for the patient. The patient may be too weak to expectorate secretions. Changing the position of the bed or raising the head of the bed may help. Once the patient is semi-conscious, nursing in coma position will be most useful for drainage of secretions.

Psychological support should be provided for the patient and their family throughout. Spiritual care should be offered in accordance with the patient's cultural and & religious beliefs. Whenever possible, the patient should be cared for in the setting of their choice, with rapid discharge home to die facilitated if this is wished for. The patient may have completed an Advance Care Plan, which will aid in supporting decisions.

The following leaflet provides useful information for carers about what to expect when someone close to them is dying:

http://www.ncpc.org.uk/publication/what-expect-when-someone-important-you-dying

Bereavement support

Bereavement support is an important aspect of care at the end of life. Advice and support for those close to the patient on the next steps following the death of their loved one are vital. This is required both at the time of death and also into the future. Each area will provide a variety of services and referral criteria may vary.

Contact local Specialist Palliative Care, GP or Community Nursing services for advice in relation to the bereavement services available in your area.

Staff can access training in bereavement care via the following website:

http://www.e-lfh.org.uk/programmes/end-of-life-care/

There are also several useful websites providing resources for bereaved caregivers:

https://www.gov.uk/after-a-death/overview

http://www.cruse.org.uk/

http://www.nhs.uk/Livewell/bereavement/Pages/bereavement.aspx

http://www.counselling-directory.org.uk/bereavement.html

http://www.ageuk.org.uk/health-wellbeing/relationships-and-family/bereavement/emotional-effects-of-bereavement/

https://www.bereavementadvice.org/

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Appendix 1

Inhalers for COPD

Provided by: Liverpool Heart and Chest Hospital NHS Foundation Trust | Knowsley Council | NHS Knowsley | Knowsley Community COPD Service – Chronic Obstructive Pulmonary Disease

SABA's




Salbutamol

Bricanyl

SAMA

Atrovent/Ipratropium

LABA/Steroid combination inhalers

Symbicort

Seretide Accuhaler

Relvar

Fostair

Flutiform

Seretide MDI (unlicensed)

LABAs


Serevent/Salmeterol

Oxis/Formoterol

Onbrez

Striverdi

LAMAs


Spiriva Handihaler / Respimat

Eklira Genuair

Seebri

Incruse

LABA/LAMAs

Ultibro

Anoro

Spioloto

Appendix 2: Quick Reference Guide

Patients with advanced respiratory disease experience health-related quality of life similar to, or worse than that of patients with advanced lung cancer.

Symptoms commonly experienced include pain, nausea, constipation, depression and low mood as well as breathlessness and anxiety.

Holistic assessment of patients' needs is vital, addressing social and spiritual needs as well as screening for and treating physical and psychological symptoms.

Prognosis is difficult to predict, so ***advance care planning should commence early***. The following factors indicate a patient with COPD may be in the last year of life (consider suitability for listing on the GP palliative care register):

- FEV1 <30% predicted
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Long-term oxygen therapy
- MRC grade 4/5 (dyspnoea after 100 metres on the level, or housebound)
- Signs of right heart failure
- Other factors e.g. anorexia, previous ITU/NIV, resistant organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

For patients with interstitial lung disease, idiopathic pulmonary fibrosis (IPF) confers a worse prognosis than other subtypes (median survival three years).

Palliative Management of Breathlessness

Rule out reversible causes and optimise standard therapy.
Consider non-drug techniques (e.g. handheld fan, breathing techniques, relaxation techniques)

Opioid naïve patient

- Commence immediate release oral morphine 2.5mg q.d.s. and 2.5mg prn (max q.d.s.)
- Titrate regular opioid dose weekly according to response, initially to 5mg oral morphine q.d.s, and then 7.5mg oral morphine q.d.s if beneficial and tolerated.
- The maximum dose of oral morphine that is likely to be helpful for dyspnoea is 30mg/24 hour period (in divided doses).
- Once established a stable dose of immediate release oral morphine, conversion to long-acting morphine could be considered for ease of administration.
- For patients with significant renal impairment (eGFR < 30ml/min), an alternative opioid e.g. oxycodone should be used – seek specialist advice.

When used in this way, opioids have been shown to be safe and effective, including in patients with type 2 respiratory failure [*Ekstrom MP et al, BMJ 2014*].

Consider p.r.n. benzodiazepines (e.g. lorazepam 0.5 – 1mg sublingually 4 hourly p.r.n. (max 4mg/24h) for episodes of panic associated with breathlessness despite the measures listed above.

Specialist palliative care referral should be considered for patients with uncontrolled physical, psychological, social or spiritual care needs despite initial measures.

Working Party

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