SPECIALIST PALLIATIVE CARE REFERRAL

GUIDELINES AND SYMPTOM CONTROL FOR

PATIENTS WITH END STAGE CHRONIC RESPIRATORY DISEASE

MARCH, 2011

REVIEW DATE: MARCH, 2014
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>3-4</td>
</tr>
<tr>
<td>Management of Chronic Respiratory Diseases</td>
<td>5</td>
</tr>
<tr>
<td>Referral guidelines to Specialist Palliative Care for patients with End Stage Respiratory Disease</td>
<td>6</td>
</tr>
<tr>
<td>Symptom Control Guidelines</td>
<td>7</td>
</tr>
<tr>
<td>• General notes</td>
<td>7</td>
</tr>
<tr>
<td>• Breathlessness</td>
<td>8-9</td>
</tr>
<tr>
<td>- Pharmacological</td>
<td>10</td>
</tr>
<tr>
<td>- Non pharmacological</td>
<td>10</td>
</tr>
<tr>
<td>• Cough</td>
<td>10-11</td>
</tr>
<tr>
<td>• Management of sputum</td>
<td>11</td>
</tr>
<tr>
<td>• Use of oxygen in patients with End Stage Respiratory Disease</td>
<td>11-13</td>
</tr>
<tr>
<td>• Pain</td>
<td>13-14</td>
</tr>
<tr>
<td>• Nausea &amp; vomiting</td>
<td>15</td>
</tr>
<tr>
<td>• Anorexia</td>
<td>15</td>
</tr>
<tr>
<td>• Cachexia</td>
<td>16</td>
</tr>
<tr>
<td>• Constipation</td>
<td>16-17</td>
</tr>
<tr>
<td>• Psychological Issues</td>
<td>17-18</td>
</tr>
<tr>
<td>• Dry mouth</td>
<td>18</td>
</tr>
<tr>
<td>Financial benefits</td>
<td>18-19</td>
</tr>
<tr>
<td>Spiritual care</td>
<td>19</td>
</tr>
<tr>
<td>Terminal Respiratory Failure – The Last Few Days of Life</td>
<td>20-22</td>
</tr>
<tr>
<td>Carer/ Bereavement support</td>
<td>23</td>
</tr>
<tr>
<td>References</td>
<td>24-25</td>
</tr>
<tr>
<td>Members of the Working Party</td>
<td>26</td>
</tr>
</tbody>
</table>
Introduction

These guidelines have been prepared for the use of health care professionals, particularly in primary care, as guidance in the palliative care of patients with severe 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 choice of drug for cost efficiencies, 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 indeed drugs outside these guidelines (rarely have doses in excess of those in British National Formulary (BNF) volume 59 been incorporated into these guidelines).

If you are not a health care professional – e.g. you are a patient or a relative of a patient – you should recognise that these guidelines are not a substitute for a doctor’s professional judgement in an individual case. They are simply intended to inform that doctor’s decision making. From your point of view, while they provide a reasonable basis on which to base a discussion, they are not rules for the doctor to follow. 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”.

Sepúlveda et al (2002)
The key principles underpinning palliative care are identified by Tebbit (1999) in the document “Palliative Care 2000” from the National Council of Hospice and Specialist Palliative Care Services as:

- “A focus on the quality of life which includes good symptom control.
- The whole-person approach, taking into account the patient`s past life experience and current situation.
- Care which encompasses both the person with life-threatening disease and those that matter to that patient.
- Respect for patient`s autonomy and choice (eg over place of care, treatment options, access to specialist palliative care).
- An emphasis on open and sensitive communication, which extends to patients, informal carers and professional colleagues”.

Chronic respiratory disease is the 3rd most common cause of death, accounting for 16% of all deaths (89,000 deaths per year). It causes 13% of adult disability, of which the greatest cause is chronic obstructive pulmonary disease (COPD) (Edmonds et al 2001).

Studies have shown that patients with endstage respiratory disease have unmet physical, psychosocial and spiritual needs and would greatly benefit from the holistic palliative care approach (Claessens et al 2000; Gore et al 2000; Hill & Muers 2000; Edmonds et al 2001).
Management of Chronic Respiratory Diseases

Guidance for the management of COPD in adults in primary and secondary care has been produced by the National Institute for Clinical Excellence (NICE) (2010) and by the British Thoracic Society (BTS) (available at www.britthoracic.org.uk). The Department of Health is soon to publish COPD Strategy which has an End of Life Care chapter.

Local and national guidelines are available for the management of other diseases such as asthma and diffuse parenchymal disease (BTS Guidelines available at www.britthoracic.org.uk)

Regardless of the underlying diagnosis, by the time end-stage is reached symptom control will be essentially the same. Where appropriate, disease-specific treatment should continue alongside symptom control.
Referral guidelines to Specialist Palliative Care for patients with end stage respiratory disease

(All at the discretion of the referrer and in conjunction with clinical assessment)

These are intended as guidelines not as rigid criteria.

- The patient has had a diagnosis of chronic respiratory disease confirmed within the last two years by a specialist respiratory physician, within the last two years and attempts to optimise therapy, including pulmonary rehabilitation where appropriate, have been made.

- Ideally the patient has knowledge and understanding of their disease, is aware of the reason for referral to Specialist Palliative Care and does agree to this. Where for any reason the patient is not aware of their diagnosis, it may be advisable to discuss with the local Palliative Care physician at the time of referral.

- Two or more of the following should also apply:
  - The patient has uncontrolled physical or psychological symptoms despite optimal tolerated therapy.
  - Dyspnoea which impacts on activities of daily living to a degree deemed unacceptable to the patient between exacerbations, despite maximal tolerated therapy.
  - The patient makes increasing use of emergency treatment for infection and/or respiratory failure.
  - The patient has an anticipated life expectancy of 12 months or less.

Ideally, if a patient is being referred to hospice services, they should be aware that, dependent on local policy, resuscitation facilities and such treatments as intravenous aminophylline, intravenous antibiotics and blood gas interpretation are generally not provided within the hospice setting.
Symptom Control Guidelines

General notes

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

- In the case of the more rare respiratory diseases, close liaison with Specialist Respiratory teams is recommended, to ensure that, whilst appropriate, active management is optimised.

- The holistic approach to symptom management should be applied wherever possible, considering physical, psychological, social and spiritual aspects.

- 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?

- The multidisciplinary team approach to symptom control is of great importance. The management of dyspnoea may include involvement of physiotherapy and occupational therapy, to explore means by which a patient’s independence may be maximised and some degree of control retained, as well as by medical and nursing interventions.

- Optimum palliation of the symptoms depends on compliance with medication.

- In the event of deterioration of symptoms, exclude a treatable precipitant, eg chest infection, anaemia.
Breathlessness

Pharmacological

- Inhaled or nebulised bronchodilators
  - β-agonists eg Salbutamol, Terbutaline
  - Antimuscarinic bronchodilators eg Ipratropium bromide, Tiotropium
  - Combination preparations eg Combivent®

Bronchodilator therapy should be optimised in accordance with NICE guidance. Optimal doses include:

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<th>Inhaled</th>
<th>Nebulised</th>
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<tr>
<td>Salbutamol</td>
<td>100 – 200 micrograms</td>
<td>2.5 – 5mg QDS +/- or PRN</td>
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<tr>
<td></td>
<td>QDS +/- or PRN</td>
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<tr>
<td>Terbutaline sulphate</td>
<td>500 micrograms</td>
<td>5 10mg QDS +/- or PRN</td>
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<tr>
<td></td>
<td>QDS +/- or PRN</td>
<td></td>
</tr>
<tr>
<td>Ipratropium bromide</td>
<td>20 – 40 micrograms</td>
<td>250 – 500 micrograms</td>
</tr>
<tr>
<td></td>
<td>3-4 times daily</td>
<td>3 4 times daily Max</td>
</tr>
<tr>
<td></td>
<td>Max QDS</td>
<td>QDS</td>
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<tr>
<td>Tiotropium (Long acting)</td>
<td>Handihaler 18 micrograms OD or Respimat 5micrograms OD (2 sprays of 2.5 micrograms)</td>
<td>Not available</td>
</tr>
<tr>
<td>Combivent®</td>
<td></td>
<td>1 nebul 3 – 4 times daily</td>
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- Please note: Inhaled Tiotropium should be withheld if patients are commenced on Combivent® or Ipratropium nebulisers.

British National Formulary Volume 59, March 2010

Bronchodilators may not be effective in some diseases, eg pulmonary fibrosis. However a trial of inhaled, or occasionally nebulised, bronchodilators may still be worthwhile in such conditions.

Prescriptions for inhaled longacting β2 bronchodilators (LAB) eg. Formoterol or Salmeterol or combination LAB/corticosteroid inhalers eg, Symbicort® or Seretide® should be continued. Use of a spacer device eg.
Volumatic® should be advised also with compatible devices.

- **Sodium Chloride 0.9% nebulas 2.5 mls 5 mls as required** to ease expectoration, and aids with dry nasal passages, which anecdotally may help to relieve breathlessness. This needs to be reviewed regularly and discontinued if no response or benefit is claimed.

- **Benzodiazepines**
  - **Sublingual lorazepam 500 microg 1mg PRN to max 4mg in 24 hours**
    - especially if an element of anxiety is present. Although not licensed to be taken sublingually, the oral tablet formulation can be administered by this route to achieve a more rapid symptomatic relief.
  
  - **Diazepam 2mg po PRN to maximum tds, increased if necessary up to a maximum total dose of 15 - 30mg over 24 hours in divided doses**, can be considered as an alternative.

    These doses of benzodiazepine should be halved in elderly and debilitated patients. Monitor for excess drowsiness in such patients.

- **Oral morphine sulphate solution (10 mg/5 ml) – commencing at initial low dose of 2.5mg (1.25mls) qds + PRN as needed to a maximum of 3 4 hourly**. If PRN medication is required more frequently it would be appropriate to seek advice from Specialist Palliative Care. Ensure when a dose increase is intended that the calculated dose is safe for the patient – this would normally be not more than 50% higher than the previous dose. Prescribers should be familiar with the following:
  - Starting dose
  - Frequency of administration
  - Standard dosing increments
  - Symptoms of overdose
  - Common side effects.

  - Rapid release morphine (either oral morphine solution or Sevredol® tablets) is often more effective for control of dyspnoea than sustained release (MST®, MXL®, Zomorph®)
  - Morphine is excreted renally. If renal impairment or failure is present, use a lower dose initially & reduce the frequency to bd or tds if using an immediate release preparation (depending on response). It may be advisable to consult the local Specialist Palliative Care Team.

In patients who are already taking strong opioids, such low doses of oral morphine can still be effective for dyspnoea. In these patients it is essential to confirm any recent opioid dose, formulation, frequency of administration and any other analgesic medicines prescribed for the patient. This may be done through discussion with the patient/patient’s representative, the prescriber or with medication records.
Some patients may need to take different doses for dyspnoea and breakthrough pain. Good communication between clinical teams is essential.

- **Oxygen** See section “Use of Oxygen in End Stage Respiratory Disease

Consider possible causes of breathlessness other than endstage respiratory disease such as coexistent heart failure, pleural effusion, pneumothorax, pulmonary embolus.

**Non-pharmacological**

- Fan
- Breathing control management
- Anxiety management
- Occupational therapy – adaptations, lifestyle adjustments
- Physiotherapy – breathing recovery strategies, maintaining mobility/walking aids, acupuncture
- Complementary therapies, including relaxation, aromatherapy, acupuncture, visualisation
- Psychological support

Some of these can be accessed through Specialist Palliative Care services.

**Cough**

- If related to difficulty expectorating – **Sodium Chloride 0.9% nebules 2.5 – 5 mls PRN to 12 hourly as needed**, which anecdotally may ease expectoration.
- Symptomatic relief **Simple linctus 5 mls – 10 mls PRN 3 – 4 times daily**.
- Cough suppressants
  - **Codeine linctus (15mg/5ml) 5 mls – 10 mls PRN to max QDS.**
  - Low dose oral morphine solution (10 mg/5 ml) starting dose **2.5 mg (1.25mls) PRN to 3 – 4 hourly as needed**. This may also help dyspnoea & pain. If PRN medication is required more frequently than this it would be appropriate to seek advice from the Specialist Palliative Care Team.  
  - **Methadone linctus (2mg/5ml) initially 2mg nocte, increasing to bd if necessary.**

- Ensure that when a dose increase is intended that the calculated dose is safe for the patient. This would normally be not more than 50% higher than the previous dose.

- Prescribers should be familiar with the following:
  - Starting dose
  - Frequency of administration
  - Standard dosing increments
  - Symptoms of overdose
  - Common side effects
In these patients it is essential to confirm any recent opioid dose, formulation frequency of administration and any other analgesic medicines prescribed for the patient. This may be done through discussion with the patient/patient representative, the prescriber or with medication records.

In the event of acute infection, it may not be advisable to use cough suppressants (see NICE guidance).

- **Physiotherapy**
  - Positioning
  - Acupuncture

### Management of Sputum

If sputum increases in amount or changes colour, exclude infection and consider antibiotics. Ensure adequate oral fluid intake, where appropriate, to liquefy secretions.

- **Mucolytics in patients with a history of peptic ulceration these should be used with caution**
  - **Carbocisteine (Mucodyne®) capsules** at starting dose of **750 mg tds** (2 capsules tds) reducing to maintenance dose of **750mg bd** (2 capsules bd) or **Carbocisteine (Mucodyne®) oral liquid** (250mg/5mls) at initial dose of **750 mg tds** (3 x 5mls tds) reducing to **750mg bd** (3 x 5mls bd).

  - **Mecysteine hydrochloride (Visclair®)** 200mg qds for 2 days then 200mg tds for 6 weeks, then **200mg twice daily**.

  These should both be reviewed 4 to 8 weeks after initiation and reduced to the maintenance dose if benefit is felt. If the patient feels no benefit, then it should be stopped.

- **Sodium Chloride 0.9% nebulus 2.5mls– 5mls as required**, which anecdotally may ease expectoration.

In the event of acute infection it may not be advisable to use cough suppressants (see NICE guidance).

- **Physiotherapy**

### Use of Oxygen in End Stage Respiratory Disease

Almost all patients with end stage respiratory disease will previously have
been assessed, and been found to require long term oxygen therapy (LTOT).

The guidelines for requirement for LTOT are well documented for both COPD and pulmonary fibrosis.

Whenever oxygen is being prescribed for home use, patients and relatives must be aware that it is essential they refrain from smoking in the same room as the oxygen cylinder. Risk assessment is needed regarding any safety hazard that may be present, for example trip hazard from oxygen giving set.

However, oxygen can also be used for the palliation of disabling dyspnoea, not relieved by other treatments, in those patients who do not meet the requirements for LTOT. Oxygen for palliation can be ordered from primary or secondary care. Formal assessment, including measurement of blood gases, or follow up, may not be required in patients who are in the terminal phase of their illness. When ordering oxygen (using a Home Oxygen Order Form – HOOF), two decisions need to be made:

1. For how many hours per day does the oxygen need to be used? Patients who do not meet the criteria for LTOT may use oxygen on an ‘as required’ basis although a specific time in hours needs to be stated on the HOOF form, e.g. 4 hours. Initially they will be supplied with oxygen cylinders. However, if they regularly use more than 180 litres of oxygen per day, the oxygen company will provide them with an oxygen concentrator and a cylinder as ‘back up’.

2. What flow rate (Litres/minute) is required?

There are no strict criteria to be met as far as the flow rate is concerned. In COPD patients, care must be taken to avoid carbon dioxide retention if at all possible, although in patients who are terminally ill this consideration is overridden by the need to palliate symptoms. If pulse oximetry is available, it is reasonable to provide oxygen at a flow rate sufficient to keep the SaO₂ around 92%, or as near to this as possible without causing significant side effects (such as dry upper airways due to high flow rates, or headaches due to carbon dioxide retention).

Patients with pulmonary fibrosis often have very low oxygen saturations and desaturate still further on exertion. They frequently require high flows of oxygen and may need two or more concentrators installing at home to provide this. In Liverpool and St Helens & Knowsley and Wirral there are oxygen assessment services linked to the Liverpool Heart and Chest Hospital, Aintree Chest Centre and the Royal Liverpool, Broadgreen University and Wirral Hospitals if advice or assessment is needed.

Ambulatory oxygen devices may be warranted by patients who require oxygen to remain ambulatory. The number of these patients is small, but some of these devices, such as liquid oxygen, are extremely expensive and research has shown that, even when provided to patients, they are seldom used. It may therefore be advisable to discuss the appropriateness of such oxygen supplies with the respiratory team looking after the patient.
Across Merseyside and Cheshire, all home oxygen is supplied by Air Products. Their fax number, to where completed HOOFs should be sent, is 0800 214709; telephone number is 0800 373580. For non emergency supply the response times for the company are set as follows:
- Within 24 hours for patients awaiting hospital discharge
- Within 3 **working days** for all other patients.

However, oxygen can be ordered as an emergency request when it will be delivered within 4 hours (including weekends and Bank Holidays). The tariff for emergency oxygen delivery is 9 times higher than that for non-emergency supply.

The supplier invoices the PCT, therefore the PCT Home Oxygen Service Lead must be informed of the order. The GP must be informed of the order if they have not been the prescriber.

In some areas, fire and advocacy services will do a home risk assessment.
**Contact numbers:**
- **Merseyside:** 0800 7315958 Ref 244
- **Cheshire:** 01606 868656

Further information about the Home Oxygen Service is available on the British Thoracic Society website (www.britthoracic.org.uk).

**Pain**

- Need to consider psychological, emotional & spiritual aspects as well as physical – pain may be affected by patient’s mood and what the pain signifies to the patient (eg progression of their illness).

- Importance of other team members – including physiotherapist, occupational therapist, district nurse, specialist nurses, social worker, psychologist, chaplain, pharmacist.

- Need full assessment of pain, site, possible cause etc. Remember to consider other causes and pathologies in addition to respiratory disease.

- Analgesic ladder (WHO):
  
<table>
<thead>
<tr>
<th>Step</th>
<th>Medication</th>
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<tbody>
<tr>
<td>STEP 1</td>
<td>Paracetamol +/- adjuvant</td>
</tr>
<tr>
<td>STEP 2</td>
<td>Paracetamol + weak opioid +/- adjuvant</td>
</tr>
<tr>
<td>STEP 3</td>
<td>Strong opioid + paracetamol +/- adjuvant</td>
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**Notes:**
For STEP 3:

- Commence oral morphine solution (10 mg/5 ml) at dose of 2.5 mg (1.25mls) PRN up to a maximum of 3 4 hourly. Low dose oral morphine solution may help breathlessness as well as pain. If PRN medication is required more frequently than this it would be appropriate to contact the local Specialist Palliative Care Team for advice.

- Ensure that when a dose increase is intended that the calculated dose is safe for the patient. This would normally be not more than 50% higher than the previous dose.

- Prescribers should be familiar with the following:
  - Starting dose
  - Frequency of administration
  - Standard dosing increments
  - Symptoms of overdose
  - Common side effects

In these patients it is essential to confirm any recent opioid dose, formulation frequency of administration and any other analgesic medicines prescribed for the patient. This may be done through discussion with the patient/patient representative, the prescriber or with medication records.

In patients who are already taking strong opioids, low dose oral morphine solution may also help breathlessness as well as pain (refer to Breathlessness page 8)

Some patients may need to take different doses for dyspnoea and breakthrough pain. Good communication between clinical teams is essential.

- If pain is continuous, regular oral morphine solution may be required. It may be appropriate to consider commencing a regular longacting preparation such as MST Continus® or Zomorph® twice daily 12hourly or MXL® once daily with additional PRN oral morphine solution available for breakthrough pain.

- Reduce dose and frequency in renal impairment. If renal function is markedly impaired, contact the Specialist Palliative Care team for advice regarding alternative opioids.

- Antianginal medication would be most appropriate if pain is angina.

- Pleuritic pain may necessitate intercostal blockade. Refer to local Pain Specialist.

- Neuropathic pain – refer to local Specialist Palliative Care Team for advice.

For symptom control in the last 48hrs, Morphine or Diamorphine may be given subcutaneously via syringe driver – see page 22.
Nausea and Vomiting

Consider potential causes of nausea & vomiting as this may guide selection of the most appropriate antiemetic. Common possible causes include medication and constipation, secondary to analgesia (see below). If aminophylline or theophylline are potential causes of nausea or vomiting in a patient, blood levels must be checked. (The product literature or Pharmacist should be consulted to clarify the appropriate time to check levels in relation to when the medication is taken, as this varies between products).

- If constant nausea with renal impairment or renal failure,
  Haloperidol 1.5 mg 3 mg nocte orally
  Cyclizine 50 mg tds orally

  Avoid cyclizine if coexistent heart failure as it may worsen this.

- If related to meals, early satiety, vomiting of undigested food,
  Metoclopramide 10 mg tds orally
  Domperidone 10 mg tds orally

If the antiemetic being used is not helping to ease nausea, it may be advisable to stop it and commence an alternative rather than adding a second. Wherever possible, polypharmacy should be avoided.

It may also be advisable to consider an alternative route to the oral route. If nausea is not controlled within 24 hours with oral medication, alternative routes, such as subcutaneous or intravenous, should be considered.

- Persistent/severe nausea & vomiting (side effects – unpredictable sedation)
  Levomepromazine (Nozinan ®) 6.25mg – 12.5mg PO daily or 6.25mg – 12.5mg /24hrs SC

Anorexia

Corticosteroids

- Dexamethasone 4 mg daily each morning for 1 week, then reduce to 2mg daily for 1 week, then consider stopping or reducing gradually.
- Prednisolone 10 – 15 mg each morning daily for 1 week, then half the dose for a further week, then consider stopping or reducing gradually.

Megesterol acetate 160 mg daily. Should be used with caution in patients with a history of thromboembolism and with conditions that may be worsened by fluid retention eg cardiac failure, hypertension, renal dysfunction.
Cachexia

Patients with chronic respiratory disease may have poor appetite and lose significant amounts of weight. Poor appetite is exacerbated by breathlessness, fatigue, drug reactions, renal impairment and depression. The combination of reduced nutritional intake and increased requirements place the patient with chronic respiratory disease at risk of malnutrition. An unintentional weight loss of 10 per cent in 36 months is indicative of malnutrition.

Dietary advice can be confusing to this group of patients. Especially those with coexistent heart disease may follow low fat or “diet” programmes which may be too low in energy for their changing needs. Patients who increase their nutritional intake and prevent further weight loss or increase their nonoedematous weight may have an improved sense of well being and improved body image.

There may be family expectations relating to food intake and this can make mealtimes stressful. In general, patients should be given permission to eat as much or as little of what ever they want and encouraged to have small frequent meals and snacks. Many patients may be following a no added salt diet, based on previously given dietary advice. If they are struggling with the palatability of a no added salt diet this can be relaxed to improve intake. Patients may need assistance with cooking and shopping. Use of oral nutritional supplemental drinks may be appropriate. Referral to dietician for advice would be beneficial.

Constipation

- May be triggered by reduced intake of fluids & food, immobility, weak or strong opioids (NB consider prophylactic laxatives when commencing these).

It may be necessary to use a faecal softener, a stimulant laxative or a combination product of the two.

Doses given below are those in the BNF, but higher doses may be needed in palliative care patients.

Faecal softener

- **Sodium docusate** up to 500mg daily in divided doses.
- **Lactulose solution (3.1 - 3.7g/5ml)** initially 15mls twice daily, adjusted according to the patient’s needs.
- **Movicol® sachets 1 – 3 sachets daily** in divided doses usually for up to 2 weeks. The contents of each sachet should be dissolved in half a glass (approx 125ml) of water. Maintenance dose 1 – 2 sachets daily.
- **Magnesium hydroxide 30 – 45mls at night when required.** This may be useful in resistant cases and may also help to relieve coexisting gastric symptoms. However, care is needed in patients with moderate or severe renal impairment.
Stimulant laxatives

- **Senna** 2 – 4 tablets, or 10 – 20mls of syrup usually at night. Initial dose should be low then gradually increased.

Combination of softener and stimulant

- **Codanthramer (dantron and poloxamer)** 1 - 2 capsules or 5 mls – 10mls of solution (25/200 in 5mls) at night.
- **Codanthrusate (dantron and docusate)** 1 – 3 capsules, usually at night, or 5 mls –15 mls of suspension at night.

The use of these is licensed in terminal illness.

In resistant cases magnesium hydroxide may be useful (this may also help to relieve coexisting gastric symptoms).

**Psychological issues**

- Low mood
- Insomnia
- Anxiety
- Fatigue & lethargy

- Medication should be considered including:-

**Antidepressants**

**Low Mood**
Avoid tricyclic antidepressants if coexistent cardiac disease in view of cardiotoxic sideeffects.

*Sertraline 50 mg once daily* is a suitable firstline agent except for management of coexistent anxiety and depression in which case **Citalopram** would be appropriate. For depression, **Citalopram 20mg daily** should be commenced, whilst for panic disorder the appropriate dose would be **Citalopram 10mg daily**, increased after 7 days to 20mg daily.

*Mirtazepine*, commencing at an initial dose of 15 mg nocte, increasing according to response, is another alternative especially if nausea or poor appetite are associated problems.

- **Night sedation**

**Insomnia**

eg **Lorazepam 500 microg 1 mg nocte PRN**

**Temazepam 10mg nocte PRN**.

- **Anxiolytics**

**Anxiety/Agitation**

**Lorazepam 500 microg 1 mg sublingual PRN** (maximum 4mg in 24 hours in divided doses).
Diazepam 2 mg po PRN to tds, increased if necessary up to a total dose of 15mg 30mg in 24 hours in divided doses). These doses should be halved in elderly and debilitated patients.

- Remember to consider nicotine withdrawal as a cause of agitation and consider nicotine replacement as appropriate.
- It is important to explore underlying issues and deal with these where possible applying a holistic approach involving appropriate members of the MDT.
- It may be valuable to explore what a patient thinks is preventing them from sleeping, what makes them anxious, why they feel low.

**Dry Mouth**

May be due to oxygen therapy, other medication or dehydration.

- Ice cubes
- Pineapple juice/ chunks
- **Oral balance gel** requires ‘ACBS’ on a prescription when being dispensed by a community pharmacist.
- **Saliva orthana** oral spray, Glandosane, BioXtra, Salivese, Salivix – these are only licensed for dry mouth due to radiotherapy or Sicca syndrome and require ‘ACBS’ on a prescription.

Consider underlying treatable causes eg oral thrush (especially if risk factors such as recurrent antibiotics, corticosteroids).

**Financial Benefits**

- Disability Living Allowance (DLA) (if<65 years, need help getting around, help with personal care or help with both)
- Attendance Allowance (AA)(if >65 yrs, if need help with personal care, usually for more than 6 months)

Special rules for DLA or AA high rate of allowance are applied if prognosis is less than 6 months. For a patient to claim this, the DS1500 and relevant sections, including the mobility component of the Disability Living Allowance application, should be completed. If a patient is eligible under the special rules, they do not require help for more than six months to be entitled to Attendance Allowance or DLA personal care component.

A patient is eligible for free prescriptions if their GP agrees they have a continuing physical disability that means they cannot go out without the help of another person.
Travel abroad should only be considered with full insurance for people with endstage respiratory disease and difficulty may be encountered when seeking this. Advice regarding suitable companies can be obtained from BACUP and from the Hospice Information Service (Myers, 2009).

Advice about travelling abroad with controlled drugs is available on the website www.aintreehospitals.org.uk and advice about air travel for patients with respiratory disease is available on the British Thoracic Society website on www.britthoracic.org.uk.

The Citizens’ Advice Bureau (CAB) is a useful resource for advice and information regarding practical issues including finance. The Disability Helpline (0800 882200) may also be useful.

**Spiritual Support**

This should be assessed for all patients. See Spiritual Care guidelines within Merseyside and Cheshire Palliative Care Audit Group Standards and Guidelines 2009 www.mccn.nhs.uk
Terminal Respiratory Failure – The Last Few Days of Life

When opioid medicines are prescribed, dispensed or administered, the healthcare practitioner concerned should confirm any recent opioid dose, formulation, frequency of administration and any other analgesic medicines prescribed for the patient. This may be done, for example, through discussion with the patient/patient representative, the prescriber or with medication records.

Ensure that when a dose increase is intended, that the calculated dose is safe for the patient eg. for oral Morphine or Oxycodone not normally more than 50% higher than the previous dose.

Prescribers should be familiar with the following characteristic of that medicine and formulation:

- Usual starting dose
- Frequency of administration
- Standard dosing increments
- Symptoms of overdose
- Common side effects

In palliative care it is recognised that higher than normal doses may be required.

- There needs to be agreement within the team about the patient’s condition.
- It may be difficult for the health care team to accept that deterioration does not represent their own failure.
- It is important to recognise patients who appear to be approaching the terminal phase of their illness. It is often more difficult to diagnose the dying phase in patients with endstage respiratory disease than in terminal cancer patients.
- In patients with endstage respiratory disease, improvement may be achieved with medication – a reversible precipitant such as a chest infection may be present.
- If recovery is uncertain, this needs to be shared with patient & family.
- As the patient becomes weaker & has difficulty swallowing, it is appropriate to consider discontinuing nonessential medications. Those which provide symptomatic benefit should be continued.
- Essential medications such as analgesics, antiemetics and anxiolytics can, if appropriate, be converted to subcutaneous doses given continuously over 24 hours via syringe driver, with as required doses available if needed.
- Such inappropriate invasive procedures as venepuncture and checking of temperature, blood pressure etc. should be discontinued.
• It is important to establish the inappropriateness of ventilation, including noninvasive ventilation, & cardiopulmonary resuscitation. It may also be necessary to discuss with the patient & family the stopping of intravenous hydration.
• Regular assessment of symptoms & 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 semiconscious, nursing in coma position will be most useful for drainage of secretions.
• Psychological support of the patient & family are very important. Good, clear but sensitive communication is of paramount importance.
• Spiritual care in accordance with the patient’s cultural & religious beliefs is important.
• Ideally, whenever possible, the patient’s terminal care should be facilitated within the setting of their choice, and in accordance with the wishes of the patient and family at home. Use of the documents “Preferred Priorities for Care” (available at www.endoflifecareforadults.nhs.uk/eol/ppc.htm and “Gold Standards Framework” (available at www.goldstandardsframework.nhs.uk may promote this.
## Symptom control in the last 48 hours

### Breathlessness

**Morphine** at initial dose of 2.5mg 5mg sc or **Diamorphine 1 – 2.5mg sc PRN to 4 – 6 hourly**, if not on oral opiates. If patient is already on oral morphine or other strong opioid, seek advice of Specialist Palliative Care Team regarding appropriate starting dose of diamorphine or morphine.

If effective, consider commencing a syringe driver with diamorphine or morphine. Dose is dependent on the amount of oral strong opioid and sc diamorphine or morphine required in the previous 24 hrs.

If the patient is breathless and anxious, consider **midazolam 2.5mg sc stat**. If effective, this can be repeated or given in a syringe driver with diamorphine or morphine if appropriate. The dose is dependent on the patient’s requirements in the previous 24 hrs.

### Pain

**Morphine 2.5mg – 5mg sc** or **Diamorphine 1mg – 2.5mg sc PRN to 4 – 6 hourly**, if not on oral opiates. If patient is already on oral morphine or other strong opioid, seek advice of Specialist Palliative Care Team regarding appropriate starting dose of diamorphine or morphine.

If effective, consider commencing a syringe driver with diamorphine or morphine. Dose is dependent on the amount of oral strong opioid and sc diamorphine or morphine required in the previous 24 hrs.

### Agitation, terminal restlessness

Exclude precipitating factors such as urinary retention, faecal impaction, pain, uncomfortable position in bed, and address these appropriately.

**Midazolam 1.25 mg – 5mg sc 4hourly PRN.** If repeated doses are required, consider commencing a syringe driver with the dose dependent on patient’s requirements in the previous 24 hours.

Diamorphine or morphine alone are not appropriate.

Consider nicotine withdrawal as a possible cause of agitation.

### Nausea and vomiting

**Haloperidol 5 – 10mg sc over 24 hours** via syringe driver.

**Cyclizine 150 mg sc over 24 hours** via syringe driver. Use with caution in patients with co-existent heart failure

**Levomepromazine 6.25mg – 12.5mg** sc over 24 hours via syringe driver.

### Retained secretions

**Glycopyrronium 200 micrograms – 400 micrograms sc stat** or **600 micrograms – 2400 micrograms (2.4mg) over 24 hours** via syringe driver to total maximum of 2.4mg over 24 hours

**Hyoscine hydrobromide 400microgram sc stat** or **1200 micrograms – 2400 micrograms sc over 24 hours** via syringe driver to total maximum of 2.4mg over 24 hours.

If secretions are poorly controlled despite these measures contact the Specialist Palliative Care Team for advice.
**Carer/ Bereavement support**

Contact local specialist services for advice.

Helpful web address: [https://elearningforhealthcare.org.uk](https://elearningforhealthcare.org.uk)
References and Useful Resources

AddingtonHall J (1998) “Reaching out: Specialist Palliative Care for Adults with NonMalignant Diseases”, National Council for Hospice and Specialist Palliative Care Services and Scottish Partnership Agency for Palliative and Cancer Care, Land and Unwin (Data Sciences) Limited, Northamptonshire.

Aintree University Hospitals NHS Foundation Trust website www.aintreehospitals.org.uk.


British Thoracic Society website at www.britthoracic.org.uk


Gold Standards Framework website www.goldstandardsframework.nhs.uk


Liverpool Care Pathway for the Dying Patient website www.mcpcil.org.uk/liverpool_care_pathway

Merseyside and Cheshire Palliative Care Network Audit Group, ´Standards and Guidelines (4th Edition) 2010

Merseyside and Cheshire Cancer Network Website www.mccn.nhs.uk
Myers K (2002) ＂Flying home or on holiday: helping patient to arrange international travel.  ＂


National Council for Palliative Care (2008) ＂A Fresh Approach: Palliative and End of Life Care for People with Chronic Respiratory Disease. ＂

National Council for Palliative Care ＂Difficult conversations, communicating with people with Chronic Obstructive Pulmonary Disease about the End of Life.


National Institute for Clinical Excellence (2010) Clinical Guideline 12 ＂Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care. ＂

Preferred Priorities for Care – document and guidance for health care professionals available at www.endoflifecareforadults.nhs.uk/eol/ppc.htm

Royal College of Physicians (1999) ＂Domiciliary oxygen services: Clinical guidelines and advice for prescribers. ＂


Tebbit P (1999) ＂Palliative Care 2000 Commissioning through partnership. ＂National Council for Hospice and Specialist Palliative Care Services, Land and Unwin (Data Sciences), Northamptonshire.

## Working Party

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