



# SPAGG

## Coversheet for Specialist Palliative Audit and Guideline Group Agreed Documentation

This sheet is to accompany all documentation agreed by SPAGG. This will assist maintenance of the guidelines as well as demonstrating the governance process undertaken prior to members seeking local approval in their areas of work.

<b>Document Title</b>	<b>Managing chronic breathlessness</b>
<b>Document Date</b>	November 2022
<b>Document Purpose and Intended Audience</b>	To support specialist palliative care clinicians in hospices, hospital trusts and in the community to manage chronic breathlessness.
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<b>References</b>	N/A
<b>Consultation Process</b>	Circulated to SPAGG group for comments and approval
<b>Monitoring</b>	This guideline will be audited by members of the group every 3 years.
<b>Review Date</b> (must be within three years)	November 2025
<b>Approval Signatures:</b> SPAGG chair SPAGG secretary	J. Tomas A. Gray
<b>Date Approved by SPAGG:</b>	
<b>Date submitted to Area Prescribing Committee:</b>	

### Version History

Version	Date	Summary of change/ process
V2	23/1/23	Spelling correction and addition of sodium chloride wording
V3	21/2/23	Editing of relevant services contact information

NEW FOR  
2023



Black Country  
Integrated Care Board

# MANAGING CHRONIC BREATHLESSNESS

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## WHAT IS CHRONIC BREATHLESSNESS SYNDROME?

*“The experience of breathlessness that persists despite optimal treatment of underlying pathophysiology and results in disability for the patient.”*



## Causes of Chronic Breathlessness

- Over 2/3 of breathlessness is caused by cardiorespiratory disease <sup>1</sup>
  - 50% of breathlessness in adults over 40 years old is caused by heart failure, COPD, obesity, anaemia, anxiety or depression
  - The cause of breathlessness is multifactorial in about a third of patients <sup>4</sup>
  - Breathlessness SNOMED code >8 wks 870535009
1. Gillespie DJ, Staats BA. Unexplained dyspnea. *Mayo Clin Proc* 1994;69(7):657-63.
  2. IMPRESS. Breathlessness IMPRESS Tips (BITS) For clinicians 2016 Available from: <https://bit.ly/3wZAQc0>
  3. Sandberg J, Ekstrom M, Borjesson M et al. Underlying contributing conditions to breathlessness among middle-aged individuals in the general population: a cross sectional study. *BMJ Open Respir Res* 2020;7(1).
  4. American College of Radiology. ACR Appropriateness Criteria. Chronic dyspnea—suspected pulmonary origin. 2012.



- Heart failure
- Angina / Ischaemic Heart Disease
- Valvular Heart Disease
- Cardiac Arrhythmias



- COPD
- Asthma
- Interstitial lung disease
- Breathing pattern disorder
- Lung Cancer
- Pulmonary Vascular Disease



- Anxiety
- Depression <sup>2&3</sup>



- Obesity
- Physical deconditioning
- Anaemia
- Long Covid

- Age 18+ Years
- Ongoing breathlessness >8 weeks
- On optimal disease management
- Investigations to consider:- Pulse Oximetry; ECG; CXR; FBC; Lung Function Tests; BNP; ECHO; Other imaging: TFT's, Biochemistry, Iron studies
- Assess Impact of breathlessness symptoms on functional ability and quality of life

The Breathing, Thinking, Functioning (BFT) Model is a tool to help Healthcare Professionals understand, assess and manage chronic breathlessness *Reference: Cambridge BTF: [www.btf.phpc.cam.ac.uk](http://www.btf.phpc.cam.ac.uk)*

	BREATHING	THINKING	FUNCTIONING
DOMAIN	Dysfunctional breathing patterns are common. Breathless patients experience a sense of 'needing more air' and so increase their respiratory rate, using predominantly the upper chest and accessory muscles, further increasing the work of breathing and intensifying breathlessness.	Breathlessness can cause fear and anxiety which in turn can worsen the perception of breathlessness. This can easily lead to panic attacks which in turn can increase the respiratory rate and cause muscle tension, further increasing the work of breathing and the feeling of breathlessness.	Breathlessness leads to inactivity which leads to muscle deconditioning which increases the demand on the respiratory system, and worsens breathlessness further.
INTERVENTION	<ul style="list-style-type: none"> <li>• Breathing techniques</li> <li>• Handheld fan</li> <li>• Airway clearance techniques</li> <li>• Inspiratory muscle training</li> <li>• Chest wall vibration</li> <li>• Non-invasive ventilation</li> </ul>	<ul style="list-style-type: none"> <li>• Cognitive behavioural therapy (CBT)</li> <li>• Relaxation techniques</li> <li>• Mindfulness</li> <li>• Acupuncture</li> </ul>	<ul style="list-style-type: none"> <li>• Pulmonary rehabilitation</li> <li>• Cardiac Pulmonary rehabilitation</li> <li>• Activity promotion</li> <li>• Walking aids</li> <li>• Pacing</li> <li>• Neuromuscular electrical stimulation</li> <li>• Hospice self-management programme if patient end stage/palliative or pulmonary rehab unsuitable</li> </ul>
CONVERSATION	“It is natural to think when you are feeling breathless that you need more air in. In fact this isn't the case -we know that there is plenty of air in your lungs. Try instead to lengthen your out breath, which can make your breathing more efficient and create space for your next breath.”	“Some people say that they're terrified that they are going to die gasping for breath. Although this is an understandable feeling, this almost never happens” (Then give a relevant explanation for a particular patient, for example “At that time, waste gases tend to build up in the blood, making people feel calm and sleepy.”)	“Choosing to make yourself moderately breathless by being active is not harming you. In fact it builds up fitness in your muscles again and can improve your breathing and general health over weeks and months.”

## Non-pharmacological management should be considered for all patients with breathlessness

### GENERAL MEASURES

- Explanation of cause/reassurance/calm manner
- Simple measures such as; keep room cool; use of a fan; open window; relaxation & breathing techniques
- Posture – ideally upright & leaning forward if possible
- Nutritional advice
- Treat depression/anxiety if present
- Encourage social interaction (peer group support; Breathe Easy group; breathlessness management in hospice day unit where appropriate)
- Lifestyle advice and appropriate signposting/referral
- Consider smoking cessation referral & management



For more information please visit the 'How can I manage my breathlessness' website - <https://bit.ly/3U2QhJG>

### SPECIALIST THERAPY

- Consider referral to Physiotherapist/Occupational therapists
- Diaphragmatic breathing technique; pursed lip breathing technique; visualisation techniques to encourage longer expiratory phase
- Relaxation training
- Energy conservation/pacing training/equipment adaptations in activities of daily living & lifestyle expectations
- Strategies to manage other physical symptoms, psychological, social & spiritual needs of patient & family
- Use of Complementary therapy to aid relaxation techniques; such as Palliative Complementary therapy services at e.g. hospices

### Using a handheld fan



- Hold the fan about 6 inches (15cm) from your face or the distance you find most helpful
- Aim the cool air at your cheeks, nose and mouth.
- Either hold the fan still or move it around slightly, whatever you find most helpful.

From Bringing Breathlessness into View - a guide to living well with breathlessness: [hyms.ac.uk](http://hyms.ac.uk)



watch the video

### Surprise question...



**"Would you be surprised if the patient died within the next year ?"**

- If **NO** then consider the following...

- Advance Care Planning
- Gold Standards Framework
- Respect Forms
- Refer to palliative care team

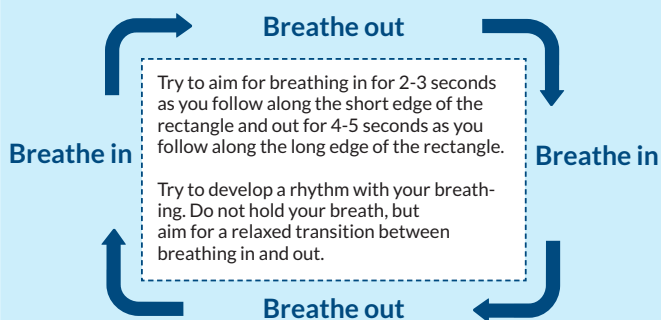


[goldstandardsframework.org.uk](http://goldstandardsframework.org.uk)

### Breathe a rectangle



Breathing should be through the nose, using the diaphragm and done slowly. "Nose, low and slow"



[www.physiotherapyforbpd.org.uk](http://www.physiotherapyforbpd.org.uk)

### MRC Dyspnoea Scale

- Grade 1** Are you ever troubled by breathlessness except on strenuous exertions?
- Grade 2** Are you short of breath when hurrying on the level or walking up a slight hill?
- Grade 3** Do you have to walk slower than most people on the level? Do you have to stop after a mile or so (or after 1/4 hour) on the level at your own pace?
- Grade 4** Do you have to stop for breath walking about 100 yards (or after a few minutes) on the level?
- Grade 5** Are you too breathless to leave the house, or breathless after undressing?

**NOTE: Maximise treatment for underlying disease and liaise with appropriate specialist team**

## Oxygen

- There is no robust evidence base for the use of Palliative Oxygen to relieve breathlessness.
- There is also limited value if oxygen saturation is already >90% prior to starting oxygen therapy.
- If prescribing oxygen 1-2 litres per minute would be usual flow rate, via nasal cannula.
- In palliative care routine monitoring with blood gases is not usually required but use oxygen with caution in patients who are known or have the potential to retain CO<sub>2</sub>.

## Steroids

Steroid treatment may be helpful in patients with COPD, who have previously responded to this treatment. Short term steroid treatment can also be of benefit to patients with malignant obstructive disease (large volume lung tumours or mediastinal lymphadenopathy) prior to treatment with palliative radiotherapy, and in inflammatory malignant lung disease.

Consider the following doses

- Oral prednisolone for exacerbations of known COPD; (30mg od for 5 days)
- 8-16mg Dexamethasone daily for obstructing lung tumours/ lymphadenopathy – prior to radiotherapy.
- Steroids may be worth considering as a therapeutic trial in patients with lymphangitis (typically dexamethasone 16mg per day).
- High dose dexamethasone (16mg daily) can also be used to relieve stridor due to malignant upper airway obstruction (**ONLY PRESCRIBE ABOVE 16mg AFTER SEEKING SPECIALIST ADVICE**).

## Anti-Secretory Medications

In patients with viscous respiratory secretions consider the use of:

- Saline Nebulisers (0.9% Sodium Chloride) 2.5mls PRN up to every 4 hrs
- Carbocisteine 375mg tablets or oral liquid 250mg/5mls
  - Dose 750mg TDS initially to aid sputum clearance.
  - Maintenance dose 750mg BD

There are several options for the management of respiratory secretions in the dying patient. Please see link to West Midlands Palliative Care Guidelines and refer to your local formulary/EOLC guideline for first choice of drug.



## Bronchodilators

In patients with airways obstruction or who have wheeze on clinical examination consider the use of an inhaled bronchodilator, preferably via a spacer device

- Salbutamol inhaler 100-200mcg QDS via Spacer if necessary

## Benzodiazepines

- If patient with breathlessness has low mood and anxiety symptoms please consider commencing an anti-depressant.
- Short acting benzodiazepines may be useful for those patient with marked anxiety/panic attacks associated with episodes of breathlessness.
- There is less evidence for the efficacy of benzodiazepine vs opioid therapy in relieving breathlessness.
- Consider prescribing the following:
  - Lorazepam (scored 1mg blue tablet – Genus brand) 0.5mg sublingual 4–6 hourly PRN
  - Diazepam 2mg–5 mg o.n. regularly for patients with ongoing debilitating anxiety

## Before starting opioids please consider the following:-

- Patient has optimised pharmacological management of underlying condition
- All non-pharmacological management steps have been optimised (see Step 2)
- Consider COPD or heart failure therapy, sputum management, oxygen assessment (if appropriate),
- Ask the question 'Have I missed anything?'

## Opioids can be considered for patients with chronic breathlessness who meet the following criteria

- Patient has persistent breathlessness at rest or on minimal exertion (MRC grade 5)
- Patient has a life limiting diagnosis which is the underlying cause for their breathlessness

## Prescribing opioids for chronic breathlessness:

**First line treatment** recommendation is for **REGULAR OPIOID THERAPY**

Morphine sulfate modified release tablets (MST) 5mg BD

OR

Morphine sulfate 10mg/5mls oral solution – dose 2mg (1ml) QDS

In patients with Renal/Hepatic impairment; Frail Elderly patients or any patient in whom a slower titration is advisable recommendation is:-

- Morphine Sulfate 10mg/5mls oral solution – dose 1mg (0.5ml) bd and careful titration according to clinical response

### Note:

*Opioids cause constipation and may cause nausea therefore it is important to co-prescribe*

- Laxative medication
- Antiemetic for PRN use



## Services in The Black Country

### Dudley

- Physio – Chest Clearance via Respiratory consultant
- Pulmonary Rehabilitation – electronic referral on EMIS
- Action Heart Exercise Referral Scheme – for breathless patients requiring supervised exercise conditioning: direct referral via electronic form on EMIS; Also “Action Health” for cancer referrals requiring supervised exercise conditioning - electronic referral or hard copy referral form (which has to be scanned and emailed to:- [action.heart@nhs.net](mailto:action.heart@nhs.net)) accepted.

The above referrals lead to 12 weeks of supervised, or remote, exercise with Action Heart. Counselling and weight management included.

- Cardiac/Pulmonary Rehabilitation – Stable patients with Heart Failure & Lung Disease, refer to Pulmonary Rehabilitation. Stable patients with Heart Failure & no Lung Disease, refer to Action Heart.
- Oxygen - electronic referral on EMIS
- FAB Group (Fatigue, Anxiety & Breathlessness) - [marystevenshospice.co.uk/our-care/refer/](http://marystevenshospice.co.uk/our-care/refer/)

Lets Get Healthy – Patient refer via website:

[www.letsgethealthy.co.uk](http://www.letsgethealthy.co.uk)  
[www.dudleyci.co.uk/services/lets-get-healthy-dudley](http://www.dudleyci.co.uk/services/lets-get-healthy-dudley)

### Sandwell & West Birmingham

- Patients registered with Sandwell & WB CCG practice and/or a Sandwell resident:
- Please refer patients needing breathlessness management using our Community Contact Centre, where you can access the Cardio-Respiratory services for patients with Heart Failure, COPD, Asthma, Bronchiectasis and ILD.

#### Treatments offered are:

- Pulmonary Rehabilitation
- Onwards referral to Cardiac Rehabilitation (patients with Heart Failure only)
- Individualised Breathlessness management depending on diagnosis/condition
- Chest Physio for patients (for patients with respiratory disease & retaining sputum)
- Long-Covid Clinic

Community Contact Centre number - **0121 507 2664**

Community Palliative Care: Connected Palliative Care:  
call: **0121 507 3611**  
email: [wb-tr.swbh-gm-connected-pc-hub@nhs.net](mailto:wb-tr.swbh-gm-connected-pc-hub@nhs.net)

### Walsall

- General Respiratory Issues:-
- North Locality hub contact: **01922 605750**
- East Locality hub contact: **01922 605442**
- South Locality hub contact: **01922 605752**
- West Locality hub contact: **01922 605764**

Community Palliative Care Physio/OT –  
email: [palliativeahp.team@nhs.net](mailto:palliativeahp.team@nhs.net) **01922 602630**

Community CNS/Consultant –  
email: [palliativecns.team@nhs.net](mailto:palliativecns.team@nhs.net) **01922 602620**

Walsall Specialist Stop Smoking Service **01922 444044**

### Wolverhampton

- Pulmonary Rehabilitation - electronic referral
- Lets Breathe - accessible to hospice patients experiencing breathlessness & fatigue. 4 week rolling program for 6 patients 2 hrs p/wk  
Criteria - already known to Compton Care; GSF green; reversible causes exclude Covid-19 & chest infection.
- Palliative breathlessness management refer via our care coordination team **01902 774570** or via our website  
[www.comptoncare.org.uk/referral-form](http://www.comptoncare.org.uk/referral-form)

Current at date of print - check current services

## Breathlessness Ladder

- Pharmacological Intervention – Opioids
- Pharmacological interventions
- Non-pharmacological interventions
- Identify patients and optimise disease treatment & treat reversible causes



# Managing Chronic Breathlessness

## Quick Links and QR Codes

### Link for Heart Failure



[https://bshpathway.org.uk/about\\_the\\_pathway.html](https://bshpathway.org.uk/about_the_pathway.html)

### COPD



<https://www.blf.org.uk/support-for-you/copd>

### Asthma



<https://www.blf.org.uk/support-for-you/asthma>

### Interstitial Lung Disease



<https://europeanlung.org/en/information-hub/lung-conditions/interstitial-lung-disease/>

### Breathing Pattern Disorder



[physiotherapyforbpd.org.uk](https://physiotherapyforbpd.org.uk)

### Lung Cancer



<https://www.blf.org.uk/support-for-you/lung-cancer/what-is-it>

### Pulmonary Vascular Disease



<https://www.blf.org.uk/support-for-you/pulmonary-vasculitis>

### Anxiety & Breathlessness link



[blf.org.uk](https://www.blf.org.uk)

### Obesity/Physical deconditioning



<https://www.blf.org.uk/support-for-you/breathlessness/causes>

### Long Covid



<https://www.blf.org.uk/support-for-you/long-covid>

### How to use the links

If **viewing as a pdf file** simply click on the link at the bottom of each box to take you to the relevant page.

If **viewing a printed document** use your phone to scan the codes to go directly to the links.

#### TIP:

With so many codes to scan you may find it easier to cover the ones you do not want on phones that are set to automatically scan.