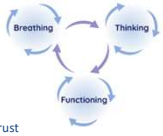
UNIVERSITY OF CAMBRIDGE

Cambridge University Hospitals NHS
NHS Foundation Trust

Practical management of chronic breathlessness

26 May 2023



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Chronic breathlessness

NHS CUH

1) What? **The size of the problem**

2) Why? **Management challenges**

3) How? **Overcoming the challenges**

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NHS CUH

"…a ***subjective experience*** of breathing discomfort that consists of ***qualitatively distinct sensations*** that vary in intensity. The experience derives from interaction among ***multiple*** physiologic, psychological, social, and environmental ***factors*** and may induce secondary physiological and behavioural responses"

*Dyspnoea Mechanisms, Assessment and Management – a Consensus Statement. **American Thoracic Society**. 2012*

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Prevalent…

NHS CUH

Symptoms	COPD (%)	CHF (%)	ESRD (%)	Cancer (%)
Fatigue	32-96	42-82	13-100	23-100
Breathlessness	56-98	18-88	11-82	16-77
Pain	21-77	14-78	11-83	30-94
Insomnia	15-77	36-48	1-83	3-67
Anxiety	23-53	2-49	7-52	3-74

Moens et al 2014

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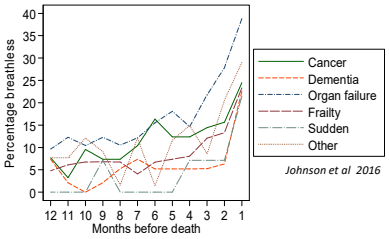
Percentage of participants (age >70) reporting restricting breathlessness at each month during their last year of life, by condition leading to death



Johnson et al 2016

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…and distressing

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"It's like being strangled while you have a big weight pushing down on your chest"

"It's terrible to see it……and you feel so helpless, so useless, so useless, I don't know how you can help really.

Will I get much shorter of breath? Can I manage it? Is something terrible going to happen?

"He says he can't breathe but he has enough air to yell at me"

- Poor quality of life
- Psychological morbidity
- Social isolation
- 'Invisible'
- Carer distress and exhaustion
- Long trajectory of suffering

Booth et al 2003, Gysels et al 2008

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Why is management challenging?

1) Disease-focused approaches alone are often insufficient.
2) Drugs like morphine and oxygen have little evidence of benefit.
3) Many non-drug approaches: how choose, and how engage?

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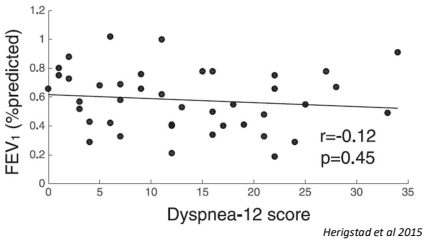
Relationship between breathlessness and a measure of lung function in patients with mild to moderate COPD



Herigstad et al 2015

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Evidence for drug approaches (1)

Intervention	Evidence	Clinical recommendations
Opioids *Barnes 2016* *Vozoris 2016* *Currow 2020* *Ekstrom 2022* *Gaertner 2023*	▪ Recent studies negative ▪ Prior meta-analyses: 5-8mm improvement in 100mm VAS ▪ 4.7, 3.0, 2.9 times more N+V, constipation, drowsiness ▪ Worse outcomes esp. morphine >30mg/24hr	▪ Only use if a) maximised non-drug approaches, or b) near the end of life. ▪ Start with low dose eg morphine 1mg bd and 1mg PRN. ▪ Avoid morphine >10mg/24hrs
Benzodiazepines *Simon 2016*	▪ No significant benefit	▪ Avoid; occasional short term role for acute symptoms eg lorazepam 0.5mg s/l, and in the terminal phase.

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Evidence for drug approaches (2)

Intervention	Evidence	Clinical recommendations
Oxygen (short burst /ambulatory) *Uronis 2008* *Abernethy 2010* *Ekstrom 2016* *Visca 2018*	When pO2>7.3kPa: ▪ Similar benefit from flow of air ▪ Sometimes helpful in COPD and ILD if desaturation on exercise	If pO_2<7.3kPa needs formal oxygen assessment for long-term oxygen therapy (LTOT) If pO_2>7.3kPa: ▪ Encourage use of fan instead of oxygen. ▪ Ambulatory oxygen therapy if saturation falls by >4% to <90% during exercise. ▪ Palliative oxygen therapy only if saturation <92%, and other treatments optimized. Do an individual formal assessment of effect before continuing.
High Flow Nasal Oxygen *Ruangsomboon 2020* *Hui 2021*	▪ Possible benefit in emergency healthcare settings ▪ Very limited evidence	Not recommended unless clear benefit and use is not preventing care in preferred place.

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Evidence for non-drug approaches

Strength of evidence

Intervention	Evidence	Key references
Pulmonary rehabilitation	Consistent, moderately large benefits on dyspnoea, fatigue, emotional function, quality of life, exercise capacity	*McCarthy 2015*
Fan, facial cooling	Most patients perceive benefit from short-term use, both at rest and on exercise	*Luckett 2017, Kako 2018, Swan 2019, Qian 2019, Yu 2019*
CBT	Relief of breathlessness and anxiety in the short-term; inconclusive evidence for long-term impact	*Heslop-Marshall 2018, Yohannes 2018, Williams 2019*
Mindfulness, meditation	Emerging evidence of benefit for breathlessness and other symptoms, including from single 20-min session	*Chan 2015, Malpass 2018, Tan 2019, Look 2021*
Relaxation	Benefit on dyspnoea and well-being; preference for 'thinking of a nice place' and progressive muscular relaxation	*Volpato 2015, Hyland 2016, Yilmaz 2017*
Walking, walking aids	Community-based walking can benefit; also use of rollator	*Vaes 2015, Varas 2018, Lin 2019*
Breathing techniques	Positive impact on breathlessness, most evidence for pursed lip breathing	*Borge 2014, Ubolnuar 2019, Liu 2019*
Acupuncture	Some evidence of benefit in advanced disease	*Feng 2016, Von Trott 2020*

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Overcoming the challenges

1) Development of symptom-focused breathlessness services
2) Development of the Breathing Thinking Functioning (BTF) model

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Cambridge Breathlessness Intervention Service (CBIS)

NHS CUH

Referral criteria

- Diagnosed cause of chronic breathlessness
- Optimal medical management of underlying condition(s)
- Able to benefit from self-management programme

The team

- 1.0 WTE Occupational Therapist
- 1.1 WTE Physiotherapists
- 0.2 WTE Consultant
- 0.6 WTE Administrator

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Diagnosis on referral to CBIS

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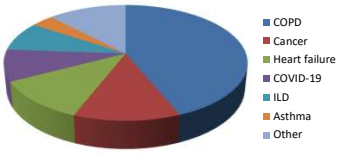

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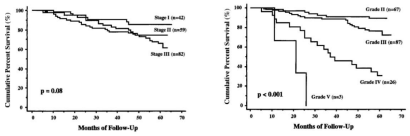
Dyspnea Is a Better Predictor of 5-Year Survival Than Airway Obstruction in Patients With COPD* (CHEST 2002; 121:1434–1440)



5-year survival according to FEV1

5-year survival according to MRC dyspnea scale

Nishimura et al 2002

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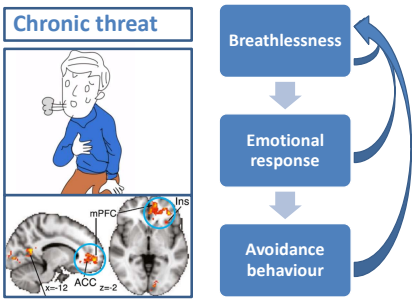

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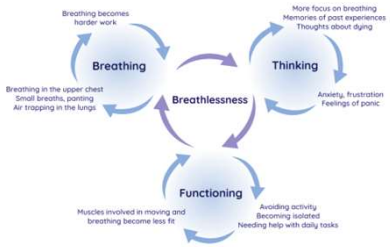

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How can the BTF model help?

NHS CUH

1. **Making sense**
   a) Symptom separate from disease
   b) Perpetuation and role of triggers
   c) Effectiveness of non-drug approaches

2. **Motivating and Managing**
   a) 'Something can still be done'
   b) 'Small changes can make big difference'
   c) Personalised focus on key vicious cycle(s)

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Terry (1)

- Aged 63; stage 3 COPD
- 'Panic' walking along coast path
- Increasingly housebound, sleeping badly, drinking more alcohol
- Repeated hospital attendances, calling for an ambulance at night because of breathlessness
- Overusing cylinder oxygen (2l/min) given after recent admission with chest infection

"I'm so frightened"

"I know there's nothing anyone can do..."

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Assessment

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Reverse the reversible
- Look for and treat reversible causes of breathlessness eg infection, oedema

Gather information
- Experience of breathlessness, and any trigger events
- Existing coping strategies
- Expectations and priorities
- Each of the Breathing, Thinking, Functioning cycles

Outcomes measures
- Breathlessness severity, emotion severity, confidence in self-management

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Measuring your breathlessness

1) How breathless are you these days on a scale of 0-10?

0 1 2 3 4 5 6 7 8 9 10

Not breathless — Worst imaginable

2) How does your breathlessness make you feel? And how [*insert emotion*] do you feel these days?

0 1 2 3 4 5 6 7 8 9 10

Not at all — Worst imaginable

3) How confident are you in managing your breathlessness?

0 1 2 3 4 5 6 7 8 9 10

Not confident at all — Extremely confident

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Management

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General points
- Validate experiences, reinforce own coping strategies, manage expectations

1) Making sense
- Understanding why breathlessness persisting/worse, role of any trigger
- Normalise perpetuating cycles

2) Motivation and mastery
- Can improve breathlessness even if cannot change underlying condition
- Small changes can make a big difference with a 'cycle of improvement'

3) Management focus
- Explain and gently address any misconceptions driving predominant cycle(s)
- Choose techniques that break this predominant cycle(s)

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Breathing	Thinking	Functioning
Breathing techniques	**Muscular relaxation**	**Exercise/activity**
Facial cooling / fan	**Guided imagery**	**Walking aids**
Positioning	**Mindfulness**	**Pacing**
Breathing retraining	CBT techniques	Nutritional supplements
Singing therapy	Self-hypnosis	Inspiratory muscle training

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How to: break the Breathing vicious cycle

An explanation

*It's natural to think, when feeling breathless, that you need to take more air in. In fact this isn't the case - we know there's plenty of air in your lungs. Try to lengthen your **out** breath instead. This makes the breathing more efficient and makes space for the next breath.*

3Fs breathing technique

1. Facial cooling with a handheld fan
2. Forward leaning position
3. Focus on lengthening/relaxing on the out breath a little more each time

Another example

'Low and slow' tummy breathing – let your tummy:

1. Rise
2. Relax
3. Rest

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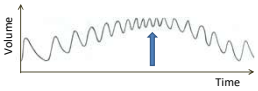
Facial cooling with a fan

Study	Outcome
Liss and Grant 1988	Increase in breathlessness after nasal anaesthesia in COPD patients receiving air or oxygen via nasal cannulae
Booth et al 1996	Oxygen and air both reduced breathlessness at rest in advanced cancer, but no difference between air and oxygen
Galbraith et al 2010	Crossover RCT showing reduction in breathlessness with fan in 50 patients with advanced disease
Luckett et al 2017	Mixed methods analysis of pooled data; 82% benefit, particularly shortening recovery time after activity

"…tiny but so effective… brilliant… definitely it does seem to work"

Forward leaning

Focus on the out breath



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Rectangle breathing

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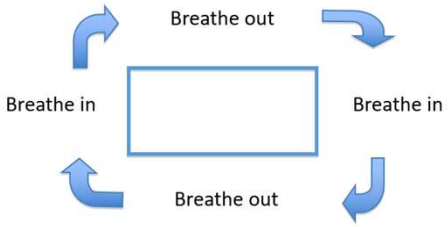

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How to: break the Thinking vicious cycle

An explanation

Many people instinctively feel something bad might happen when they're feeling breathless. Although very understandable, this tends not to happen with usual day-to-day breathlessness.

Other examples

- Muscle relaxation
- Mindfulness
- Meditation
- Relaxation with colour
- Cognitive behavioural therapy

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Think about
the word **tranquillity**.
Say **tranquillity** three times
in your mind.
Think about a colour associated
with **tranquillity**.
Imagine all the things this colour
reminds you of.
Now imagine yourself in a place
that brings a feeling of
tranquillity.
What does it smell like in this
place? What can you hear?
Enjoy this feeling of
tranquillity.

Miranda Thew

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Make yourself comfortable
Think about the colour **green**
Concentrate on **green** all around you
The **green** of spring turf on cliff tops
The damp **green** of misty hillsides
Cricket on a lazy village **green**
Close your eyes and feel the freshness of **green**

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How to: break the Functioning vicious cycle

An explanation

Choosing to make yourself moderately breathless by being active will not harm you. In fact, it builds up muscle fitness again, improving your breathing and general health over weeks and months.

Walking programme

- Measure your steps over a normal week
- Try to make your weekly steps 10% more than the week before
- After eight weeks your activity will have doubled

Other examples

- Pulmonary rehabilitation
- Leaning on a shopping trolley
- Riding a bicycle
- Preparing a meal
- Looking after grandchildren

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Week	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Weekly Total
Week 1 Actual steps								1000
Week 2 Goal + (10%)								1100
Week 3 Goal = week 2 + (10%)								1210
Week 4 Goal = week 3 + (10%)								1331
Week 5 Goal = week 4 + (10%)								1465
Week 6 Goal = week 5 + (10%)								1611
Week 7 Goal = week 6 + (10%)								1773
Week 8 Goal = week 7 + (10%)								1950

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How to: help all the vicious cycles…

My breathlessness action plan

I have had this feeling before – I know it will go away soon

1. **I'm going to lean forward and use my fan**
2. **I'm focusing on breathing out, gradually longer and longer with each breath out**
3. **I'm gently relaxing and softening my shoulders a little more each time I breathe out**

*I **can** do this – I am doing it now*

Other examples

- **Walking in nature**
- **Yoga, tai chi**
- **Singing for breathing**

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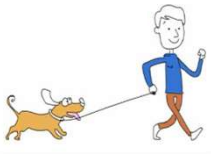
Terry (2)

- Understood the relevance of the Thinking and Functioning cycles, and the impact of the 'panic' trigger
- Encouraged to use his handheld fan for five minutes before turning on the oxygen
- Explained that making himself moderately breathless was not harmful; explored his fear of dying 'gasping'
- Practiced a relaxation technique, muscle clench and release; always after lunch, 'like a daily tablet'
- Pedometer and walking programme; his goal was to walk dog around back field – achieved after seven weeks.

"It is making sense now. I can break those coils… There is something that can be done"

"Strangely, they didn't really talk about my breathing, yet it's feeling better…"



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Associated symptoms

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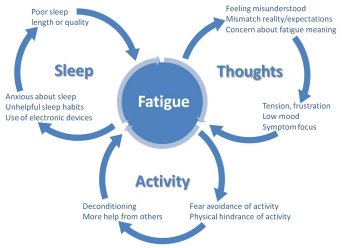

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Balance

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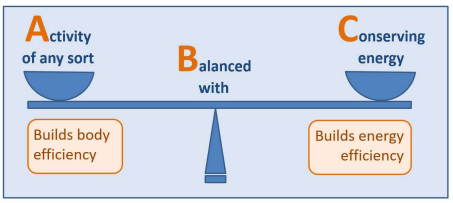
"…on the one hand you're asking me to exercise and, on the other, telling me to pace myself… which is it?"



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Key points

NHS CUH

- Disease management alone is often insufficient to help chronic breathlessness.
- Drug treatments for the palliation of breathlessness are not supported by good evidence.
- Non-drug approaches are evidence-based, brief and can be taught by any interested health professional.
- The BTF model can help people make sense of the symptom and gives a rationale and structure to its management.
- This approach has potential to help associated symptoms.

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