Non pharmacological management of breathlessness in practice

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Guys and St Thomas’
The challenge of breathlessness
Background

• FAB group at STC
  • 6 sessions: breathing; exercise; pacing/OT; diet; sleep; CBT
  • On average people only attended 3 sessions and the majority of people didn’t manage all 6

• Cambridge BIS study day
St Christopher’s

• 3 week group not 6 weeks
• Begin and end with assessment by a therapist
• An outpatient only service (inpatients should be referred for individual physiotherapy)

GSTFT Oncology Service

• Refined patient booklet and Tool kit of fact sheets
• Cont. to deliver on one to one basis & one day Lung living Well programme event 5 times a year
• Close links with established Pulmonary rehab service
• Aiming to develop 3 week group model
The Cambridge Breathlessness Intervention Service (CBIS)

- Dr Sara Booth, Dr Anna Spathis and others
- [http://www.cuh.org.uk/breathlessness](http://www.cuh.org.uk/breathlessness)
Breathlessness

The vicious cycles

Breathing

- Inefficient breathing
- Increased work of breathing
- Breathe faster
- Use of wrong muscles
- Over-breathing

Thinking

- Unhelpful, unrealistic thoughts & images
- Anxiety, Distress, panic

Functioning

- Muscle weakness
- Body gets deconditioned
- Move about less

Thinking

- Unhelpful, unrealistic thoughts & images
- Anxiety, Distress, panic

Adapted from - Sara Booth, Cambridge BIS
GOAL

• Help individuals to feel more in control of their breathing and be as independent as possible

• To alleviate the distress of dyspnoea in a manner that most enhances the person's quality of life
Dyspnoea at rest

Non-pharmacological interventions are the most effective interventions currently available to palliate breathlessness in the mobile patient

Booth et al 2011

Dyspnoea on exercise

Terminal dyspnoea
## Key Non Pharmacological Breathlessness Management

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<tr>
<th>Breathing</th>
<th>Thinking</th>
<th>Functioning</th>
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<td>Breathing techniques</td>
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<td>Handheld fan</td>
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<td>Airway clearance techniques</td>
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<td>Singing therapy</td>
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<td>Activity pacing / energy</td>
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<tr>
<td>Inspiratory muscle training</td>
<td>Acupuncture/Acupressure</td>
<td>conservation</td>
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<td>Chest wall vibration</td>
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<td>Nutritional supplements</td>
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<td>Non-invasive ventilation</td>
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<td>NMES</td>
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<tr>
<td>Cough</td>
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1-2: Inhale
1-2-3: Exhale

Relaxation techniques
CBT techniques
Mindfulness
Self-hypnosis
Acupuncture/Acupressure
Pulmonary rehabilitation
Exercise/activity
Walking aids
Activity pacing / energy conservation
Nutritional supplements
NMES
The vicious cycles

Breathing

Thinking

Functioning

Breathlessness
1. Educating Breathing
Importance of position
2. BREATHING CONTROL

3 R’s

- **RISE**—tummy rises as you breathe in
- **RELAX**—relax the tummy—relax the breath out
- **REST**—don’t rush into the next breath—wait for it to come

**Practical tips:**
- Position and posture
- Relax shoulders, upper chest
- Notice tummy rise and fall
- Float air in, relax breath out
- Out breath longer than in breath
- Practice
3. WHAT TO DO WHEN BREATHLESS & IN AN ATTACK
Recovery breathing (4 F’s)

- **Fan**
- **Forward lean**
- **Flop**
- **Focus on out breath**

Practical tips:

- Explain: ‘you don’t need more air in, you need to empty your lungs, which will make space for the next breath’
- ‘Lengthen’ out breath in hyperinflation or hyperventilation, ‘relaxed’ out breath in restrictive lung conditions and lung cancer
- Purse lip Breathing
### The fan

<table>
<thead>
<tr>
<th>Study</th>
<th>Outcome</th>
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<tbody>
<tr>
<td><em>Liss and Grant 1988</em></td>
<td>Increase in breathlessness after nasal anaesthesia in COPD patients receiving air or oxygen via nasal cannulae</td>
</tr>
<tr>
<td><em>Booth et al 1996</em></td>
<td>Oxygen and air both reduced breathlessness at rest in advanced cancer, but no difference between air and oxygen</td>
</tr>
<tr>
<td><em>Galbraith et al 2010</em></td>
<td>Crossover RCT showing reduction in breathlessness with fan in 50 patients with advanced disease</td>
</tr>
</tbody>
</table>

“...tiny but so effective... brilliant... definitely it does seem to work”
Visual

Calming hand

- SIGH OUT
- INHALE GENTLY
- EXHALE GENTLY
- STRETCH HAND AND THEN RELAX
- RECOGNITION
Be still... Be calm
Drop the shoulders
Slowly sigh Out... and ...out
Hear the sigh ‘Haah’ ...Soft and quiet
Feel control returning
Peaceful and safe.

Jenny Taylor
St Christopher’s Hospice
in End of Life Care Journal (2005)
TOOLS FOR MANAGING BREATHLESSNESS ATTACKS

- Stop activity
- Cold compress
- Open window / Fan
- Support / space from carer
- Other tips

- Laminate action plan in case feels panic – 4F’s
- Leave CD with the narrative of a short BC / relaxation technique
- Pictures...
The vicious cycles

Breathing

Breathlessness

Thinking

Functioning
Thinking matters

• Difficulty breathing can cause strong emotional responses
• Panicky, anxious or miserable thoughts worsen the breathing and add tension
• Fight or flight response builds up tension
• Ask for help – thoughts matter – help is available.
Panic mechanism

- Adrenaline response; ‘fight or flight’
- Physiological vigilance enhances symptom awareness
- Spiral of breathlessness and panic
- Overwhelming sense of terror
- Instinctive strategy enhances respiratory compromise
- Panic memory reinforced
THE COPING SPIRAL

FEELING OF RELAXATION AND CALM

That's MUCH better, I knew I could cope if I tried...

Keep Calm

Let go tense muscles.
Again, sigh slowly:
Out – Out – Out...

I'm beginning to relax, and my breathing is becoming calmer...

Relax shoulders

Sigh slowly:
Out – Out – Out...

I'm beginning to regain control, and I feel better already...

The First Symptoms of Anxiety

Breathing Faster
Body tense

I'm beginning to feel anxious, but I know what to do, and I WILL get through this...

Here I am in a situation that is worrying and distressing me...
Ways to manage thoughts and feelings

• Relaxation and massage, mindfulness, social support and talking, imagery, exercise, distraction and music

• Explore thoughts- these aren't facts, share them and find out how true they are.

• For severe anxiety and panic – CBT.

• Breathing techniques to move, pace and regain a sense of control.
Looking after yourself

• Stretch neck and shoulders
• Relaxation
The vicious cycles

Breathing

Thinking

Functioning

Breathlessness
Functioning
Correct the Spiral of disability

Cardiorespiratory Diseases

Breathlessness

Increased Work of breathing

Inactivity

Muscle Deconditioning

Fatigue

Weakness
How to break the cycle of weakness

• Exercise
• Make a habit of activity/exercise
• Pacing, planning, prioritisation
• Find the right level of exercise and activity for YOU
How much to do

• Breathing is deeper and faster
• Can still talk
• Able to control breathing
Seated exercises – x10

1. Holding your hands out in front of you, squeeze and release your hands
2. Bend your elbows and touch your shoulders then lower.
3. Starting with your hands on your shoulders, raise both arms towards the ceiling together or one at a time.
4. Rotate your shoulders– forwards, up, back then down both together or one at a time
5. Raise your heels then your toes alternately
6. Lift one leg at a time and rotate the ankle 5 times in each direction
7. Lift one leg at a time, marching in the chair
8. Stand up then sit down
Overview of approach

• Initial assessment
  1. Reversible contributors
  2. Existing coping strategies
  3. Expectations and priorities

• Management using BTF approach
  ❖ Establish which of the B, T, and F vicious cycles predominate
  ❖ Explain the perpetuating vicious cycle(s) to the patient/carer
  ❖ Use this to provide rationale and focus for initial management

4. Breathing
5. Thinking
6. Functioning
Practical management of breathlessness

• Week 1 – Breathing
• Week 2 – Functioning
• Week 3 - Thinking

“we may not take away your breathlessness completely but we can help it have less impact on your life”
Summary of the Non Pharmacological approaches

• Breathlessness education
• Breathing exercises
• positioning of ease
• Airway secretion clearance techniques
• Hand held fan
• Calming hand
• Walking aids
• Poem – jenny taylor
• Cough management
• Exercise and activity
• Pacing
• Distraction techniques
• Relaxation CD - self hypnosis therapy & mindfulness
• Crisis plan
• Support Careers
Explanatory analysis suggests it was not only the *provision* of these interventions that was important; *how they were delivered was key to their impact*. The data suggest they were delivered through the provision of knowledge, with specialist expertise, which increased patients’ and carers’ confidence. For example, some reported receiving handheld fans from other clinicians but identified the way BIS delivered this intervention as different: BIS explained how and when to use the fan and how it might work, so legitimising what at first appeared an unlikely effective intervention.
Results

BIS reduced patient distress due to breathlessness (primary outcome: \(-1.29; 95\% \text{ CI } -2.57 \text{ to } -0.005; P = 0.049\)) significantly more than the control group; 94\% of respondents reported a positive impact (51/53). BIS reduced fear and worry, and increased confidence in managing breathlessness. Patients and carers consistently identified specific and repeatable aspects of the BIS model and interventions that helped. How interventions were delivered was important. BIS legitimised breathlessness and increased knowledge whilst making patients and carers feel ‘not alone’. BIS had a 66\% likelihood of better outcomes in terms of reduced distress due to breathlessness at lower health/social care costs than standard care (81\% with informal care costs included).

Conclusions

BIS appears to be more effective and cost-effective in advanced cancer than standard care.
An Integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised control trial

- 105 patients randomised to early palliative care integrated with respiratory services
- Cancer, COPD, ILD

- Significant benefit in primary outcome, a component of quality of life, 16% better in early palliative care group
- Significant survival benefit
- No difference in costs

Higginson et al Lancet Respiratory Medicine, Dec 2014; 2(12): 979-987
DOI:10.1016/S2213-2600(14)70226-7
Managing breathlessness: a palliative care approach

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ABSTRACT
Breathlessness is an important and common symptom globally, affecting patients with a variety of malignant and non-malignant diseases. It causes considerable suffering to patients and also their families, and is a significant cost to healthcare systems. Optimal management of the symptom should therefore be of interest and importance to a wide range of clinicians. Best practice in the management of breathlessness consists of both non-pharmacological and pharmacological interventions as evidenced by recent randomised controlled trials of multidisciplinary breathlessness support services. As well as providing evidence for integration of early palliative care into respiratory services, these revealed that patient distress due to breathlessness can be significantly reduced and better outcomes can be achieved at lower cost than standard care.

many of these will be precipitated by breathlessness. One to four per cent of primary care encounters are also related to breathlessness. Although trajectories of breathlessness vary depending on the underlying aetiology, as disease advances, the prevalence and intensity of breathlessness increases with up to 78% of patients with lung cancer, 88% of those with congestive heart failure and 95% of patients with chronic obstructive pulmonary disease (COPD) experiencing breathlessness at the end of their lives. Prevalence also increases with age: a large Australian study reports breathlessness prevalence at 6.7% in those under 35 years, 9.8% in those aged 50–64 years and 16.9% in those aged above 65 years.

This article summarises the available evidence on the aetiology and clinical management of breathlessness in advanced disease to help clinicians improve their care of this highly symptomatic group.
THE NON-PHARMACOLOGICAL MANAGEMENT OF BREATHTHNESS

Jenny Taylor

The non-pharmacological management of breathlessness has an important adjuvant role in the treatment of breathlessness at the end of life. This article will describe elements of breathing control techniques used by physiotherapists that can be modified and implemented effectively by nurses in all care settings. Positioning, relaxation, and energy-conservation measures are also supportive evidence-based strategies that can be adopted by nurses in their role as key members of the clinical team. Results of a small audit carried out at St Christopher’s Hospice are presented. These showed that anxiety and panic play a more significant role than was assessed initially in a proportion of patients referred for breathlessness management. Understanding the mechanism of panic will equip the nurse to provide appropriate support. Patients are often desperate to retain some personal control even at this stage in their disease and will respond positively to self-help measures when supported by the nurse. All quotations used in this article have been taken (with permission) from patients referred for physiotherapy intervention for breathlessness management.

Declaration of interests: none

KEY WORDS
Anxiety
Breathing control
Breathlessness
End of life
Non-pharmacological strategies
Nursing role

Breathlessness, especially in the acute terminal phase of a disease, is one of the most difficult symptoms

This article will explore the supportive strategies, both practical and psychological, that nurses can employ when confronted with this very distressing and frightening clinical picture.

Context
Breathlessness in terminal cancer, heart failure and end-stage respiratory disease is managed by pharmacological and non-pharmacological means. Pharmacological measures, including medications such as opiates and anxiolytics, make a significant contribution to the alleviation of symptoms, but have a tendency to cause side-effects such as respiratory depression, constipation or excessive drowsiness.

risk of reducing respiratory drive. There is potential for it to be used inadvisedly by the patient because of psychological dependency and a misunderstood perception of oxygen as ‘life support’. Oxygen therapy can restrict movement and has a consequent psychosocial impact on quality of life. Additional concerns are fire hazard, community provision and cost.

It is not the purpose of this article to explore these pharmacological treatment methods. This information can be found elsewhere (e.g. Meek et al, 1999; Sykes et al, 2004), but they have been mentioned briefly for completeness. The key to optimum management of symptoms is
Keys to success

• Early intervention
• Attention to detail
• Manage expectations
• Health coaching approach
• Careful explanations including evidence
• Know when not to talk about breathlessness
• Compassionate challenging of misconceptions
• Encourage practice: a daily (non-drug) ‘medicine’
Quotes

“Nothing has changed about my disease, but everything has changed about how I can help myself cope with it”

“My anxiety had taken away any power that I might have to cope with my breathlessness – I’m now in control”

“Its such a relief not to be told keep calm and just take a deep breath; Neither works when I panic, now I understand why”

“I was so frighten before”

“I was a victim – now I have some tools to help myself”

“I didn’t believe anything could help me but this did – The CALMING HAND is my favorite”

“Its things like dressing sitting down, breathing in for 1 step and out for 2 steps that helps me”
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<th>Description</th>
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<tr>
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<td>20 patients Cancer Uncontrolled</td>
<td>Improved breathlessness, distress, functioning</td>
<td>Corner 1996</td>
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<tr>
<td>Nurse led OP clinic</td>
<td>119 patients Cancer RCT</td>
<td>Improved breathlessness, depression, performance status</td>
<td>Bredin 1999</td>
</tr>
<tr>
<td>Kings’ Breathlessness Support Service (AHP/medical OP/home)</td>
<td>105 patients Mixed RCT</td>
<td>Improved mastery of breathlessness</td>
<td>Higginson 2014</td>
</tr>
<tr>
<td>Cambridge Breathlessness Intervention Service (AHP/medical OP/home)</td>
<td>53 patients Cancer RCT, phase 3</td>
<td>96% benefited, reduction in distress from breathlessness</td>
<td>Farquhar 2014</td>
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## Key References:

### Evidence: non-pharmacological

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