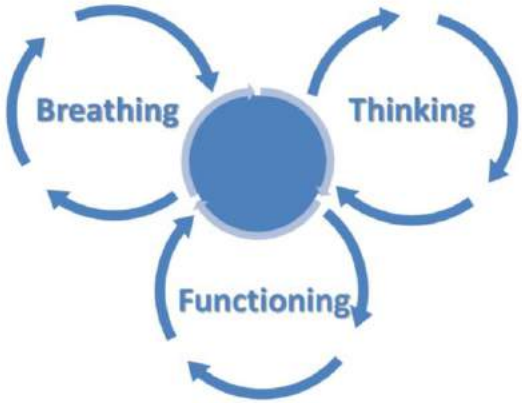
Cambridge University Hospitals NHS
NHS Foundation Trust

Management of breathlessness



Anna Spathis
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Cambridge Breathlessness Intervention Service

Overview

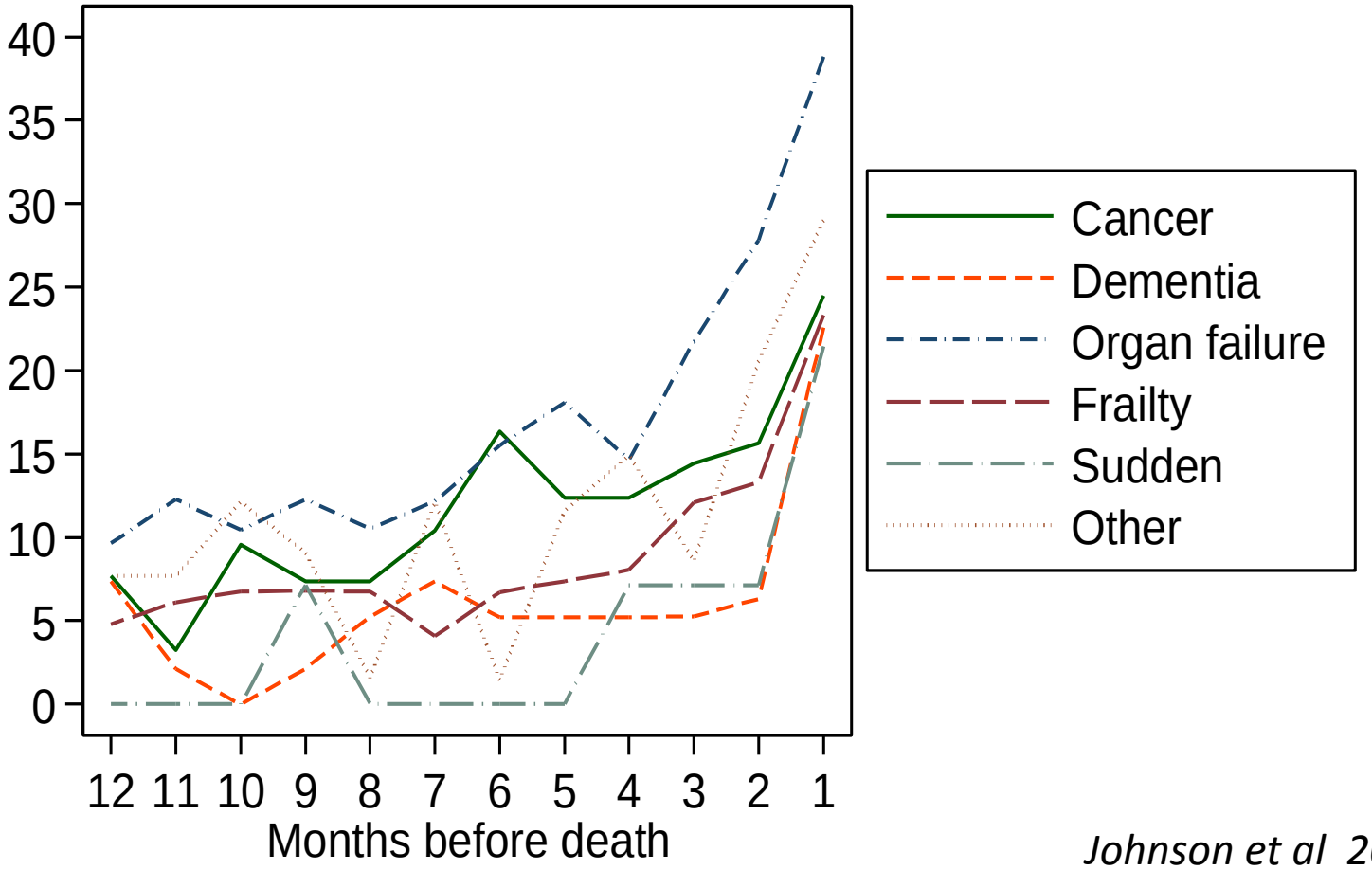
1) What?
   - The size of the problem

2) Why?
   - Management challenges

3) How?
   - Management approaches

Prevalent...

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

…. and distressing

"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.

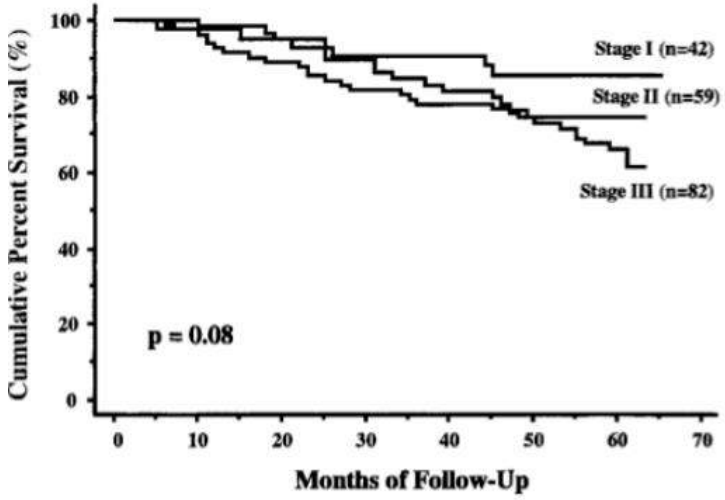
Will I get much shorter of breath? Can I manage it? Is something terrible going to happen?

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

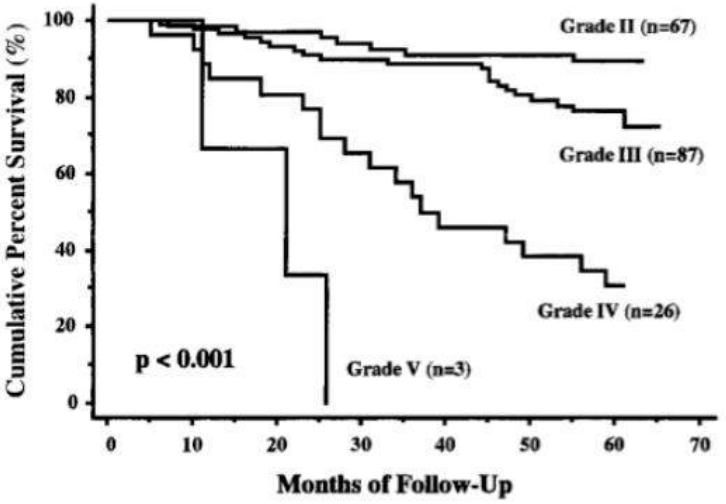
- Poor quality of life
- Psychological morbidity
- Social isolation
- 'Invisible'
- Carer distress and exhaustion
- Long trajectory of suffering

Booth et al 2003, Gysels et al 2008

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



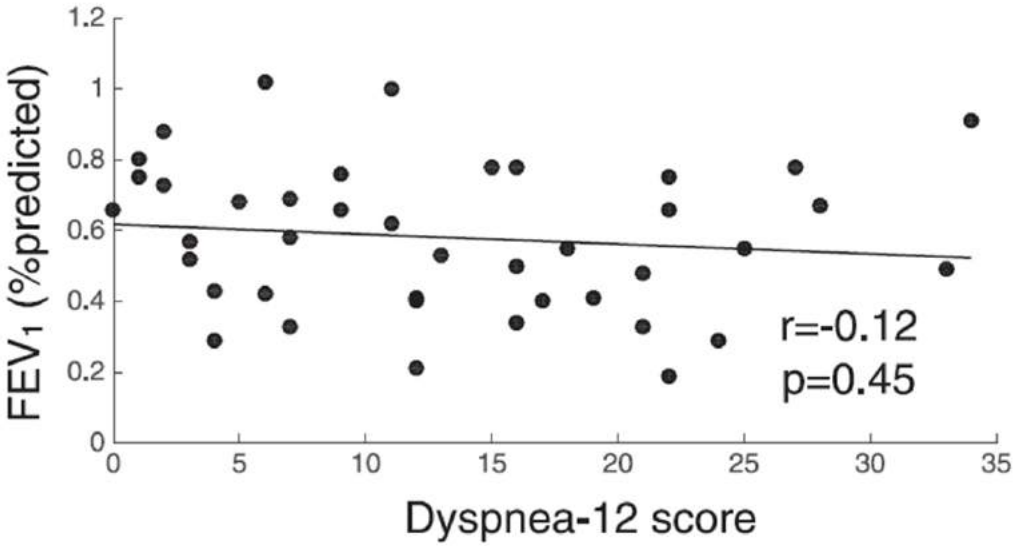
5-year survival according to MRC dyspnea scale

Nishimura et al 2002

Breathlessness: the challenges

1. Breathlessness has little relationship to lung function

2. Little evidence for pharmacological palliation



Current evidence: drug approaches

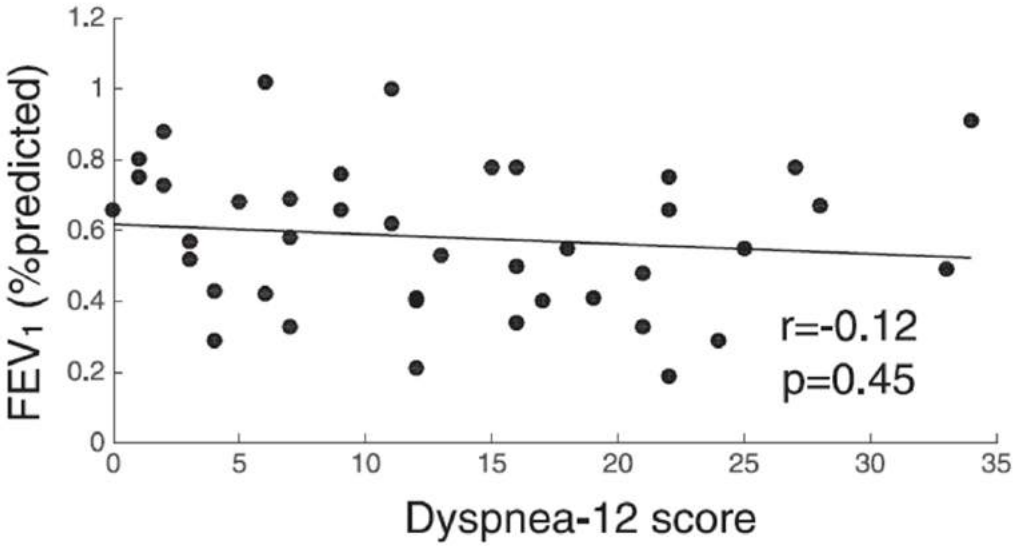
Intervention	Evidence	Clinical recommendations
Opioids *Ekstrom 2015* *Barnes 2016*	• 5-8mm improvement in 100mm VAS • 4.7, 3.0, 2.9 times more N+V, constipation, drowsy • Steady state opioids slightly more effective	• Use if maximised non-drug approaches, or near the end of life. • Start with low dose eg morphine 1mg bd and 1mg PRN.
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.
Oxygen (SBOT) *Uronis 2008* *Abernethy 2010* *Ekstrom 2016* *Bell 2017*	When pO2>7.3kPa: • Only benefit in COPD during exercise; 7mm in 100mm VAS • No benefit in cancer or ILD	• Encourage use of fan instead of oxygen. • Individual clinical assessments. • BTS Home Oxygen guideline 2015: ambulatory oxygen if saturations fall by >4% to <90% during exercise.

Breathlessness: the challenges

1. Breathlessness has little relationship to lung function

2. Little evidence for pharmacological palliation

3. Large number non-pharmacological approaches



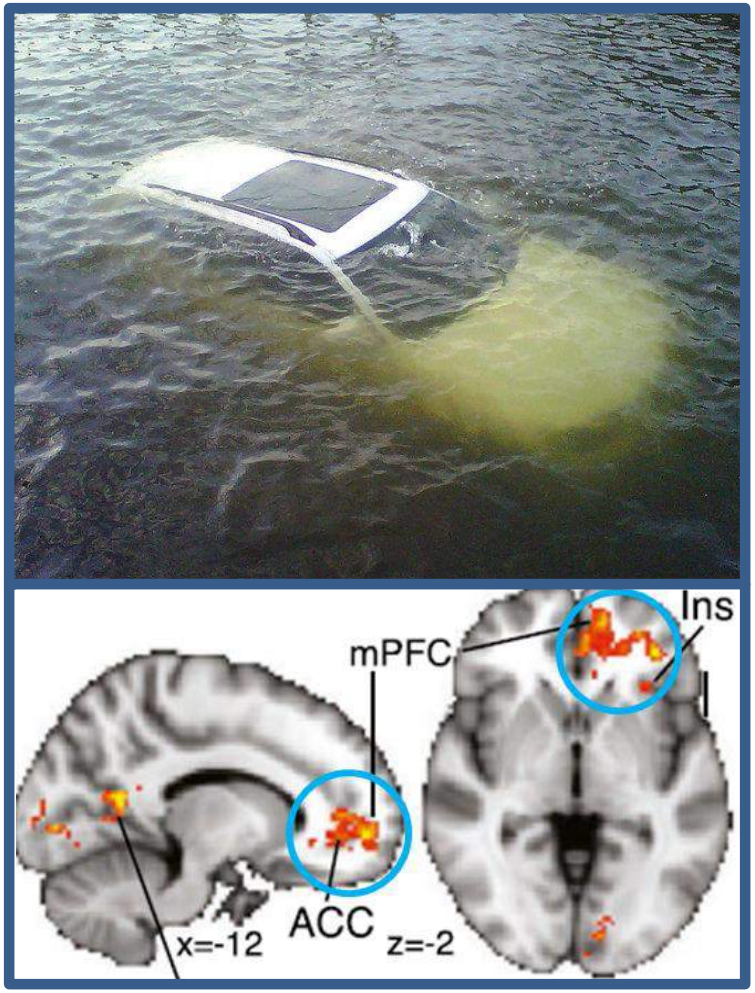
Current evidence: non-drug approaches

Intervention	Evidence strength	References
Pulmonary rehabilitation	++++	McCarthy 2015
Neuromuscular electrical stimulation	+++	Bausewein 2008, Pan 2014
Chest wall vibration	+++	Bausewein 2008
CBT	++	Howard 2014, Livermore 2015
Fan	++	Galbraith 2010, Luckett 2017, Kako 2018
Breathing techniques	++	Borge 2014
Mindfulness	++	Chan 2015, Malpass 2018
Relaxation	++	Hyland 2016, Yilmaz 2017
Walking aids	++	Buasewein 2008
Acupuncture	+	Lau 2008, Feng 2016

Evidence: breathlessness services

Complex intervention	Description	Outcome	Ref
Kings' Breathlessness Support Service (AHP/medical OP/home)	105 patients Mixed RCT	Improved breathlessness mastery, and survival	*Higginson 2014*
Cambridge Breathlessness Intervention Service (AHP/medical OP/home)	53 patients Cancer RCT, phase 3	94% benefited, reduction in distress from breathlessness; cost-effective	*Farquhar 2014*
Cambridge Breathlessness Intervention Service (AHP/medical OP/home)	87 patients Non-cancer RCT, phase 3	92% benefited, non-significant trend in reduction in distress from breathlessness	*Farquhar 2016*
Three or one sessions of a breathlessness service	156 patients Cancer RCT, phase 4	No difference between one and three sessions; single session cost-effective	*Johnson 2015*

Acute threat

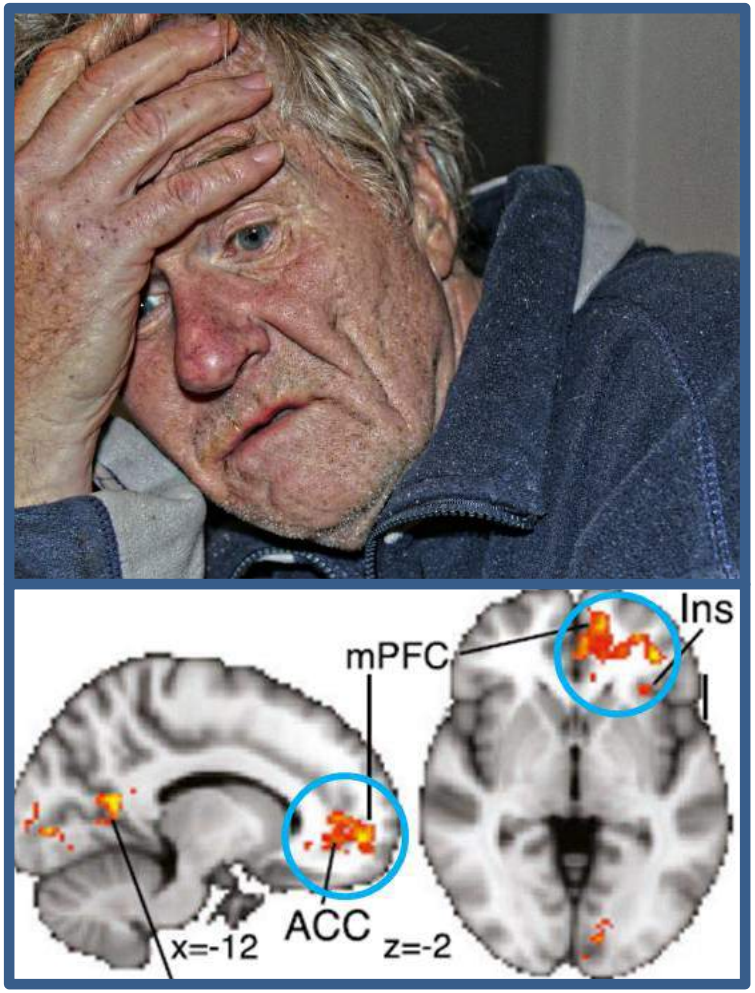


Threat to survival

Emotional response

Avoidance behaviour

Chronic threat

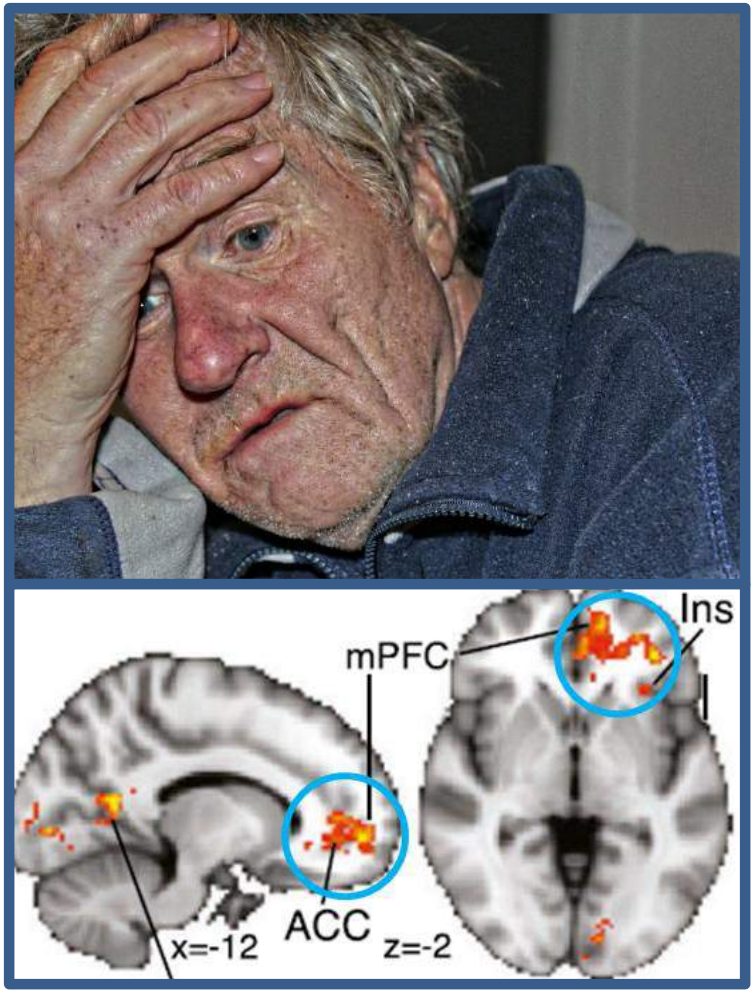


Breathlessness

Emotional response

Avoidance behaviour

Chronic threat

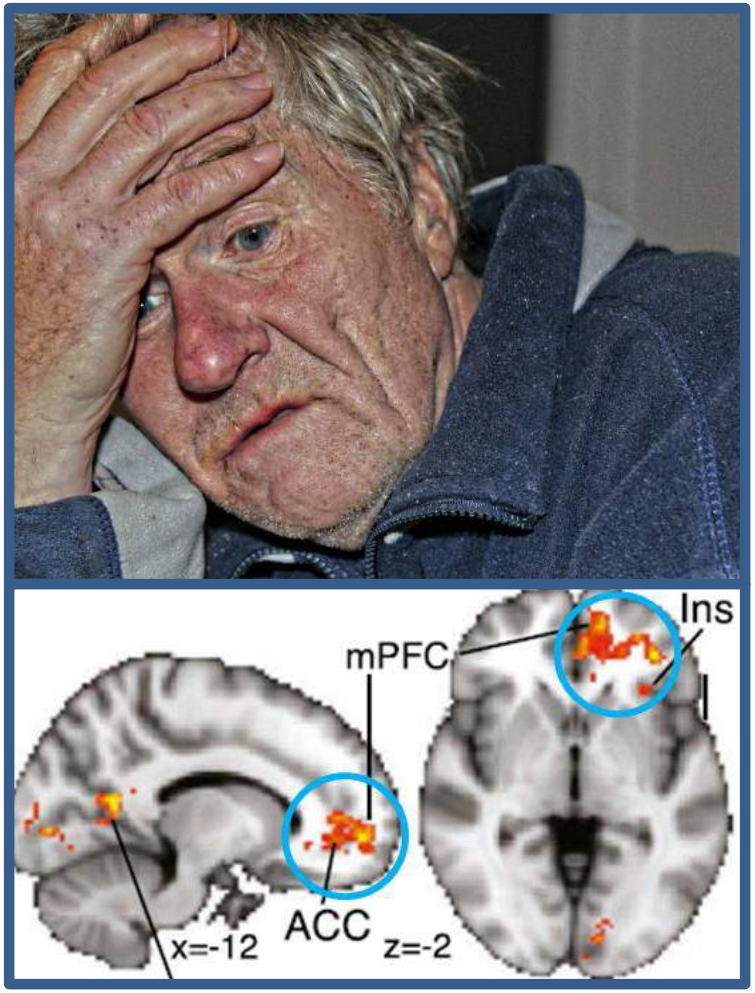


Breathlessness

Emotional response

Avoidance behaviour

Chronic threat



Breathlessness

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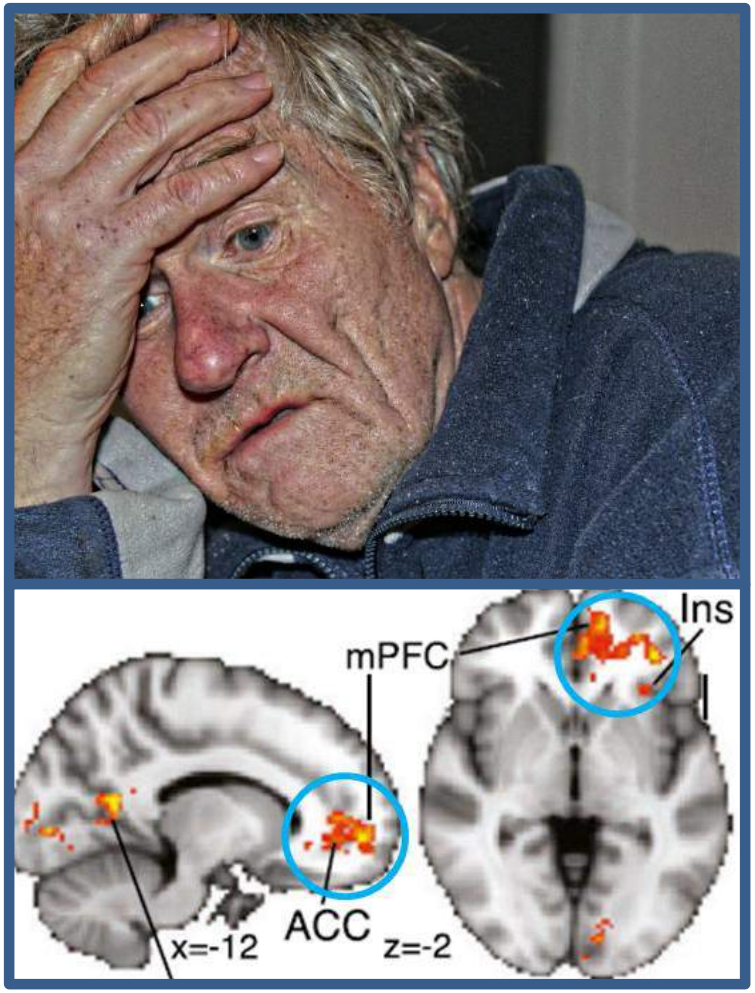
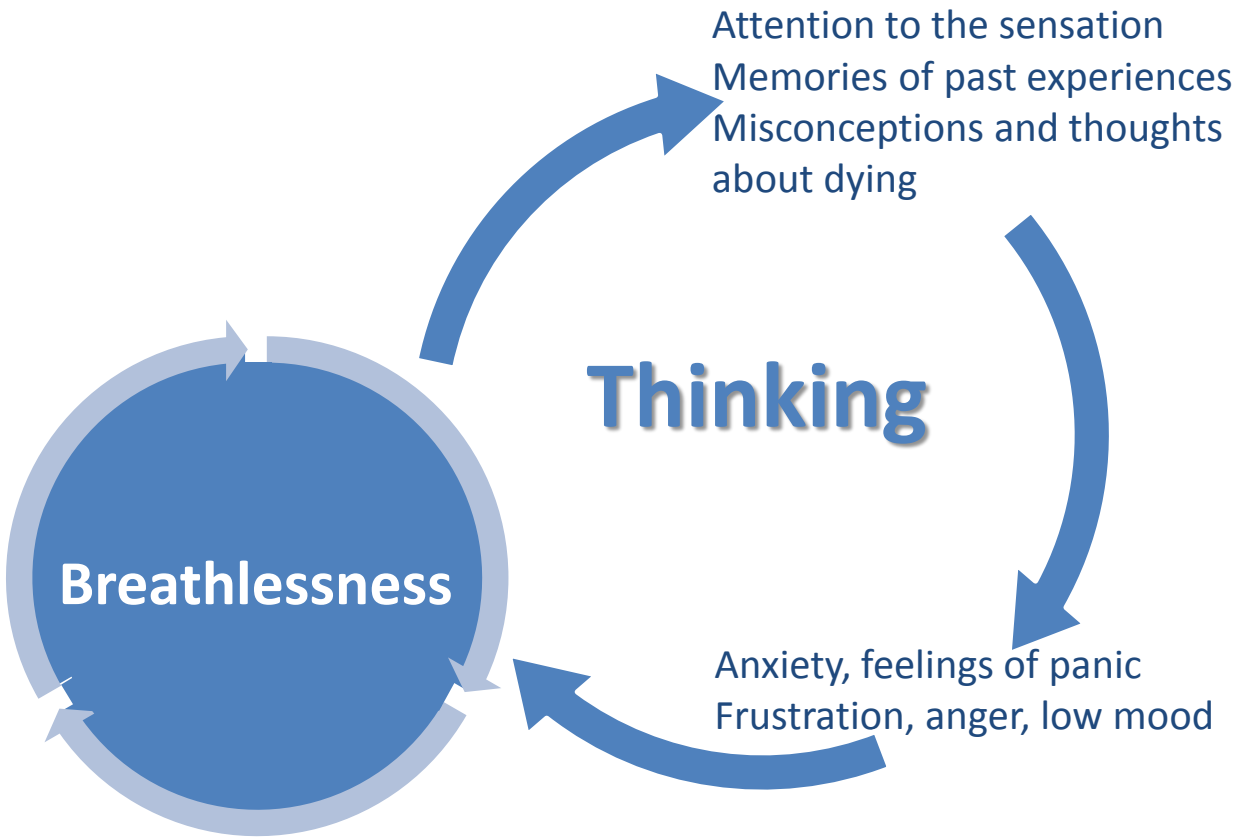
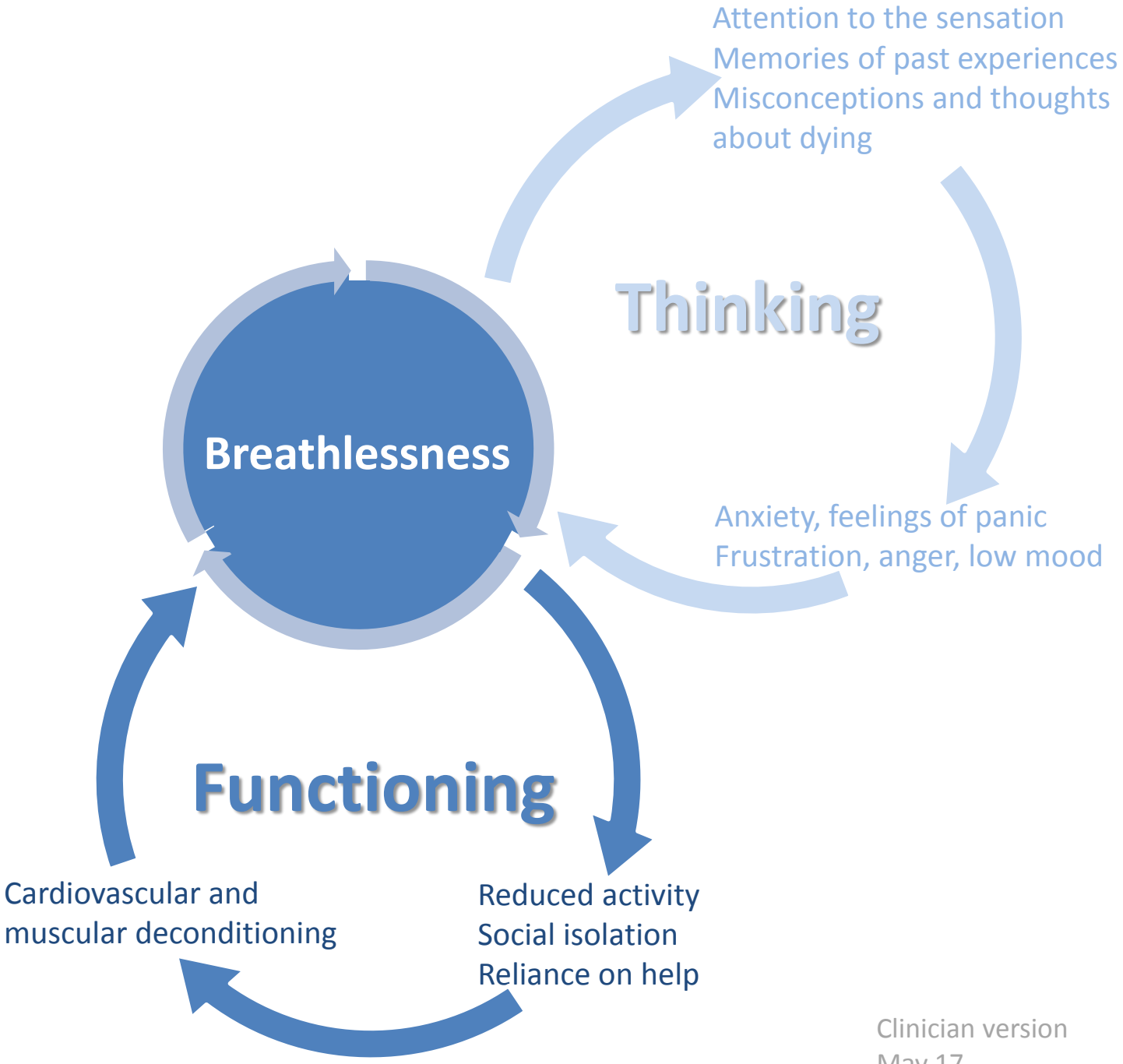


Breathlessness

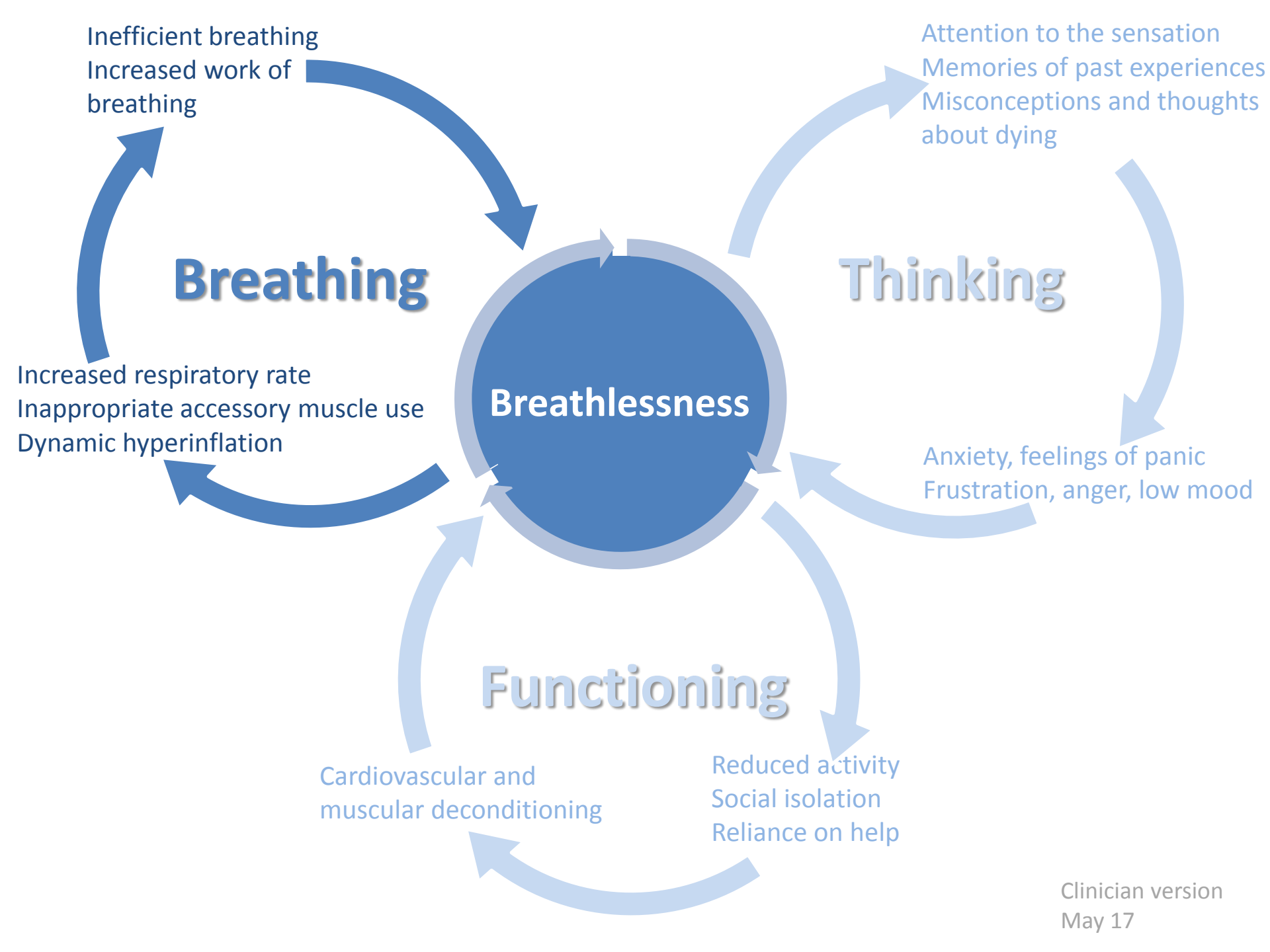
Emotional response

Avoidance behaviour


Attention to the sensation
Memories of past experiences
Misconceptions and thoughts about dying
Thinking
Anxiety, feelings of panic
Frustration, anger, low mood
Breathlessness



Clinician version
May 17



Clinician version
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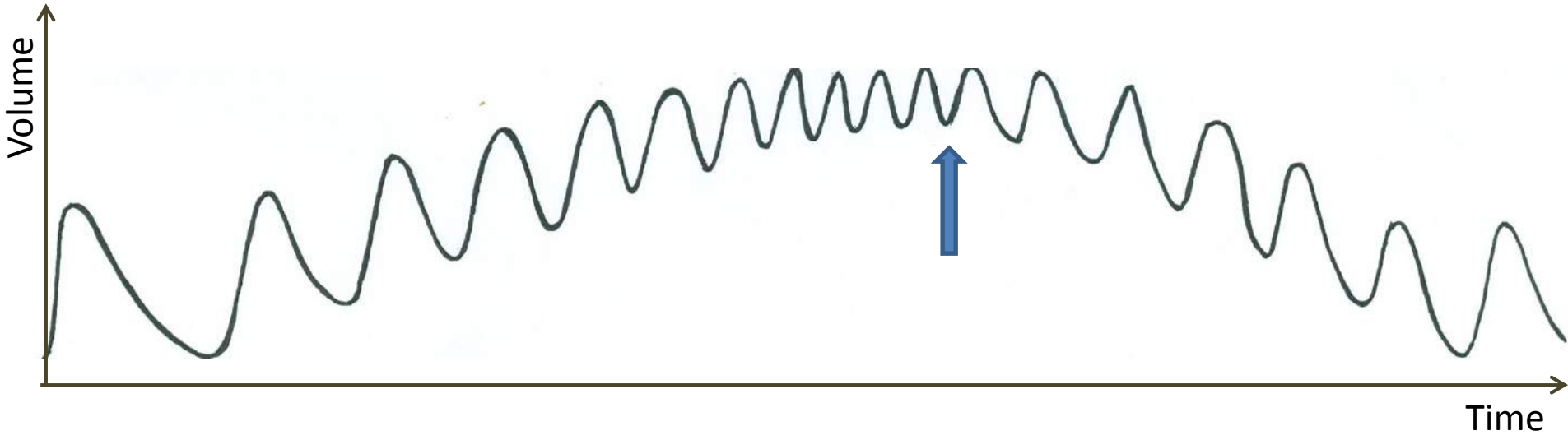
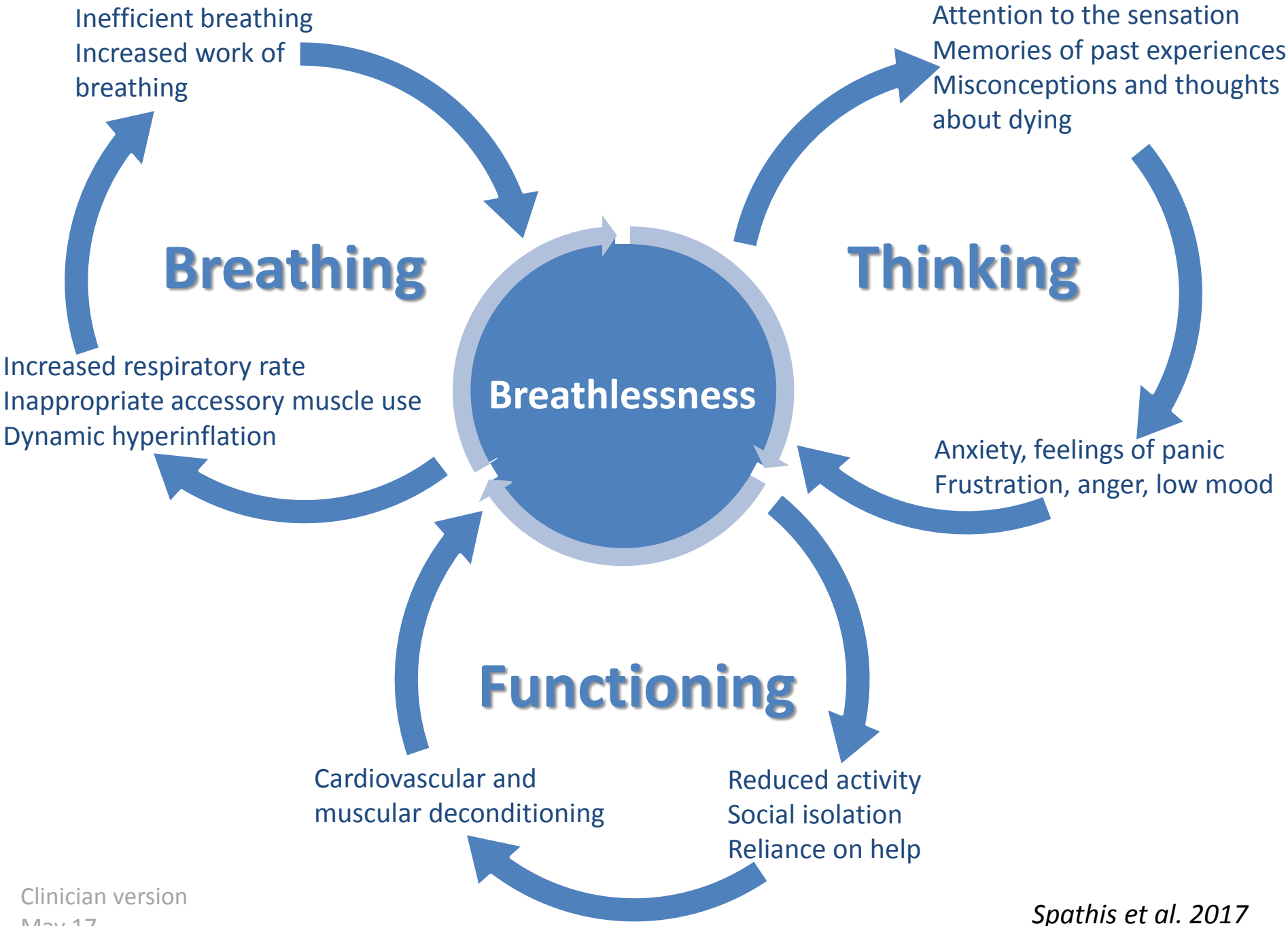
Dynamic hyperinflation



Strong correlation between exertional dyspnoea and end-expiratory lung volume *O'Donnell 2006*



Clinician version
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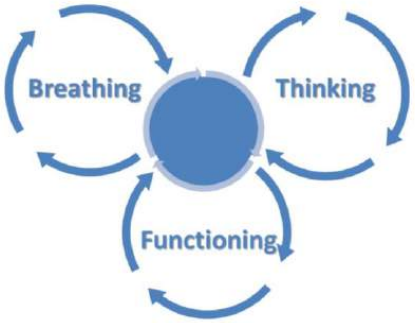
Spathis et al. 2017

BTF model role



1. Making sense
   - Explains breathlessness perpetuation, potential role trigger
   - Understand symptom out of keeping with disease severity

2. Motivation and mastery
   - Explains symptom relief when maximal disease management
   - Provides rationale: small change causing ‘cycle of improvement’

3. Management focus
   - Allows initial focus on predominant vicious cycle(s)

Breathing	Thinking	Functioning
Breathing techniques	Relaxation techniques	Pulmonary rehabilitation
Handheld fan	CBT techniques	Exercise/activity
Airway clearance techniques	Mindfulness	Walking aids
Singing therapy	Self-hypnosis	Pacing
Inspiratory muscle training	Acupuncture	Nutritional supplements
Chest wall vibration		NMES
Non-invasive ventilation		

Mr James (1)

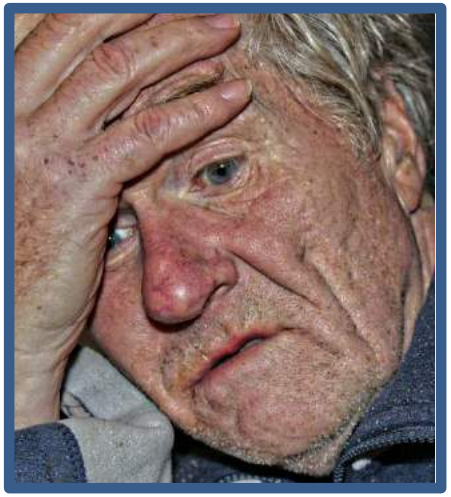
- COPD, stage 3
- Had to retire early from building trade
- Hip/knee pain from osteoarthritis
- ‘Panic’, thought he was dying
- Increasingly housebound since then
- ‘Agoraphobic’, IAPT referral
- Angry, ‘people think I’m loony’
- Excessive use of SBOT
- Initially uncertain about meeting breathlessness service...

“I don’t really like talking about my breathing – it makes it feel worse…”

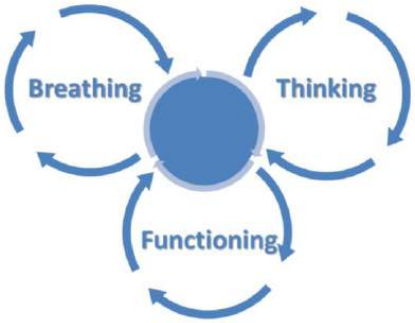
Mr James (2)

- ‘Thinking’ and ‘functioning’ vicious cycles particularly apparent
- Mr and Mrs James engaged by logic of explanation
- Realised trigger panic episode had made things much worse as could not bear thought of it happening again
- Relieved and briefly tearful, ‘I’m not going mad’

“It makes sense. I’m losing all my muscle and I know getting fitter will help… But how can I possibly move around more when I feel like this…



Assessment meeting



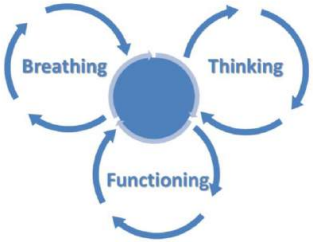
1) Gather information
   - Existing coping strategies
   - Expectations and priorities
   - Trigger event
   - Assess **Breathing**
   - Assess **Thinking**
   - Assess **Functioning**
   - Predominant cycle

2) Initiate management
   - Reinforce existing successful self-management
   - Actively manage expectations
   - Use **BTF model** to help engage
   - Use **BTF model** and patient priorities to focus management
   - Aim for ‘quick wins’ at first meeting

Addressing misconceptions

Breathing
"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."
Thinking
"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.")
Functioning
"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."

‘Breathing’ – example



Recovery breathing

- **F**an
- **F**orward lean
- **F**ocus on the out breath

Practical tips:

- ❖ Proactively 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
- ❖ Use: very breathless, panic, extreme hyperinflation

The 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"

Action plan for breathlessness

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

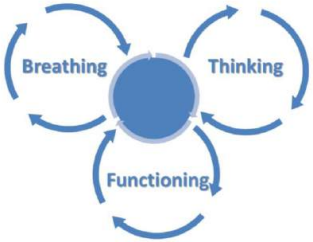
1. **I am going to lean forward and use my fan**

2. **I am focusing on breathing out for longer, gradually longer and longer with each breath out**

3. **I am gently relaxing and softening my shoulders a little more each time I breathe out**

I can do this – I am doing it now

‘Thinking’ – examples



- Address misconceptions about ‘dying gasping for breath’
- Progressive muscular relaxation
- Guided imagery...

Make yourself comfortable

Think about the colour **green**

Concentrate on **green** all around you

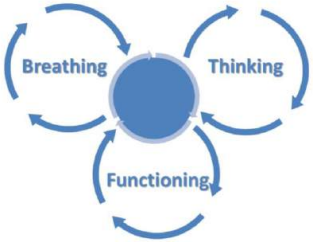
The **green** of spring turf on cliff tops

The damp **green** of misty hillsides

Cricket on a lazy village **green**

Close your eyes and feel the freshness of **green**

‘Functioning’ – example



<u>Pedometer and walking programme</u>

- Record daily and/or weekly steps in a diary
- First week baseline activity
- Aim to increase stepwise each week by 10%
- Continue for 6 weeks

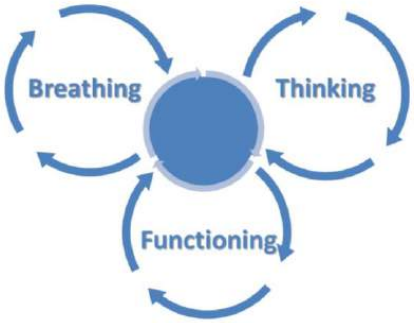
Mr James (3)

- Reinforce existing self-management strategies
- Focus on **T** and **F** cycles, and goal of walking dog around field

- Initial management
  - Explicitly address misconception about dying in a panic attack
  - Laminated action plan in case feels panic
  - Explain that making himself breathless by being moderately active is not harming him
  - Turn to fan before oxygen (SBOT)

- Next visit
  - Start walking programme
  - CD with narrative of short relaxation technique for daily practise

Final points



- BTF model: helps make sense of breathlessness, supports motivation and mastery, and provides management focus
- Support patients to practise non-pharmacological techniques, like a ‘daily pill’
- Enhance resilience, actively manage expectations and know when not to talk about breathlessness

Cambridge Breathlessness Intervention Service
www.cuh.org.uk/breathlessness

Key references

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Cambridge Breathlessness Intervention Service

Referral criteria

- Diagnosed cause of intractable breathlessness
- Optimal medical management
- Would benefit from self-management programme

The team

- 1 WTE Occupational Therapist
- 1.2 WTE Physiotherapists
- 0.2 WTE Consultant in Palliative Medicine
- 0.6 WTE Medical PA
- Access to Clinical Psychologist