Toolkit for Respiratory Palliative Care

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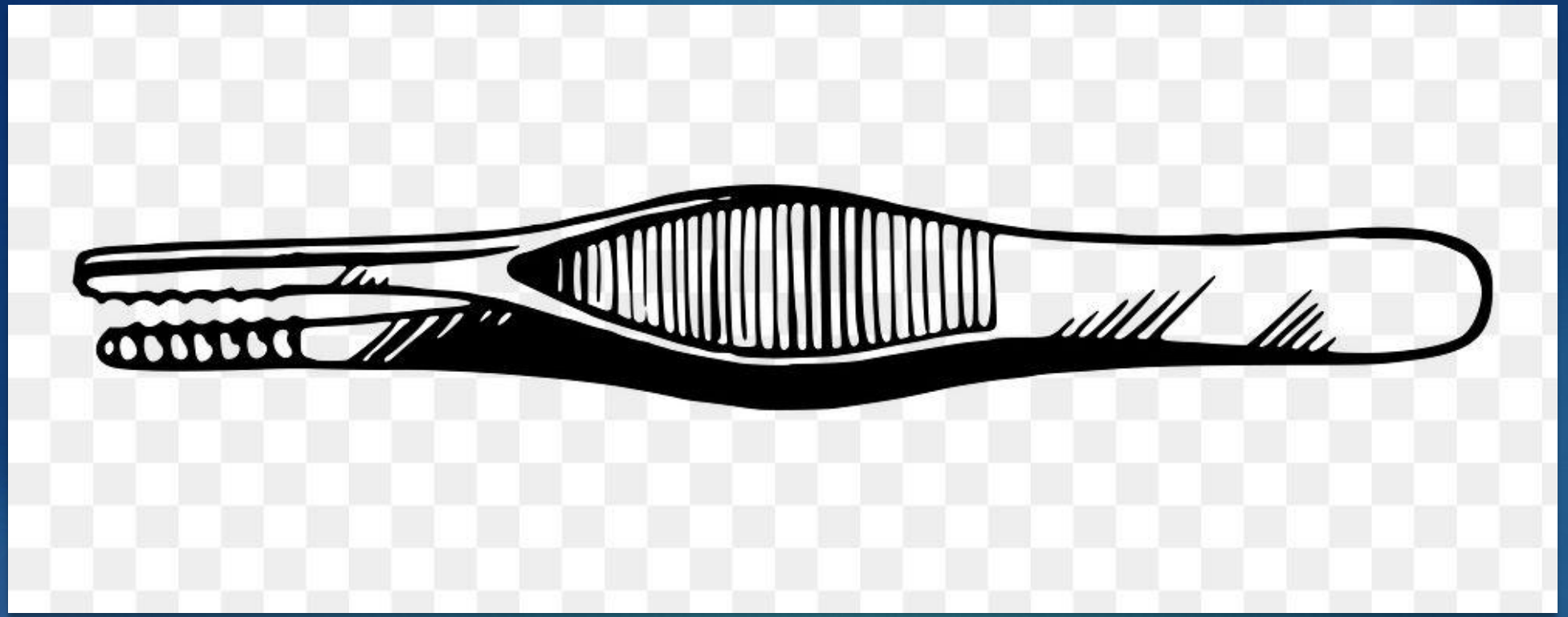


Tool One

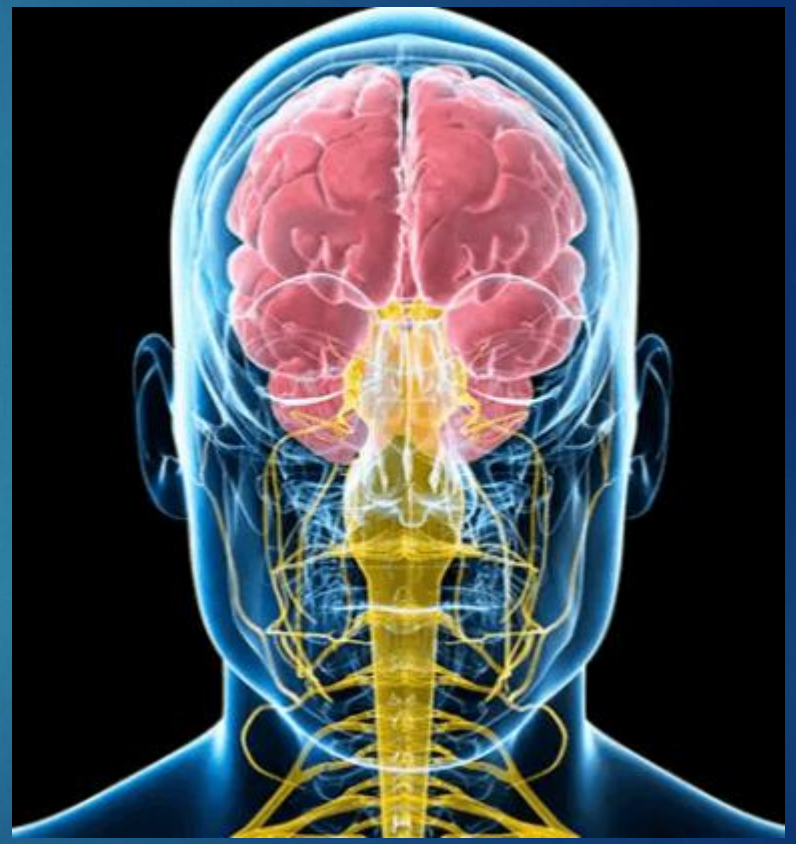
UNDERSTANDING BREATHLESSNESS

Clinical Definition

- Breathlessness is a **subjective experience**
  - Influenced by physiological, psychological, social and environmental factors
- Not a single organ experience

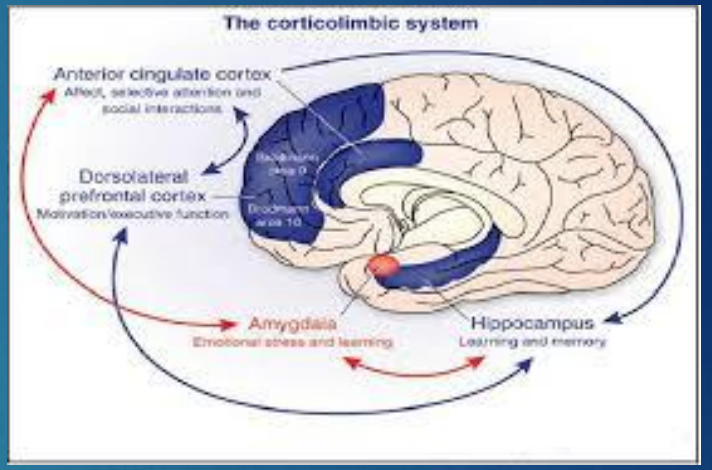
Mechanistic Framework: mismatch

- Brainstem-determined ventilatory **demand** vs mechanical **supply** from lungs/chest wall
  - Mismatch generates the symptom
- **Hypoxia is not the dominant driver** in most chronic cases



Neuroscience of Breathlessness

Breathlessness is not just a signal from the lungs- it is interpreted and amplified in the cortico-limbic system where sensation, emotion, and attention meet.



This is why dypsnoea feels frightening, overwhelming and sometimes' out of proportion'.

Why this matters clinically?

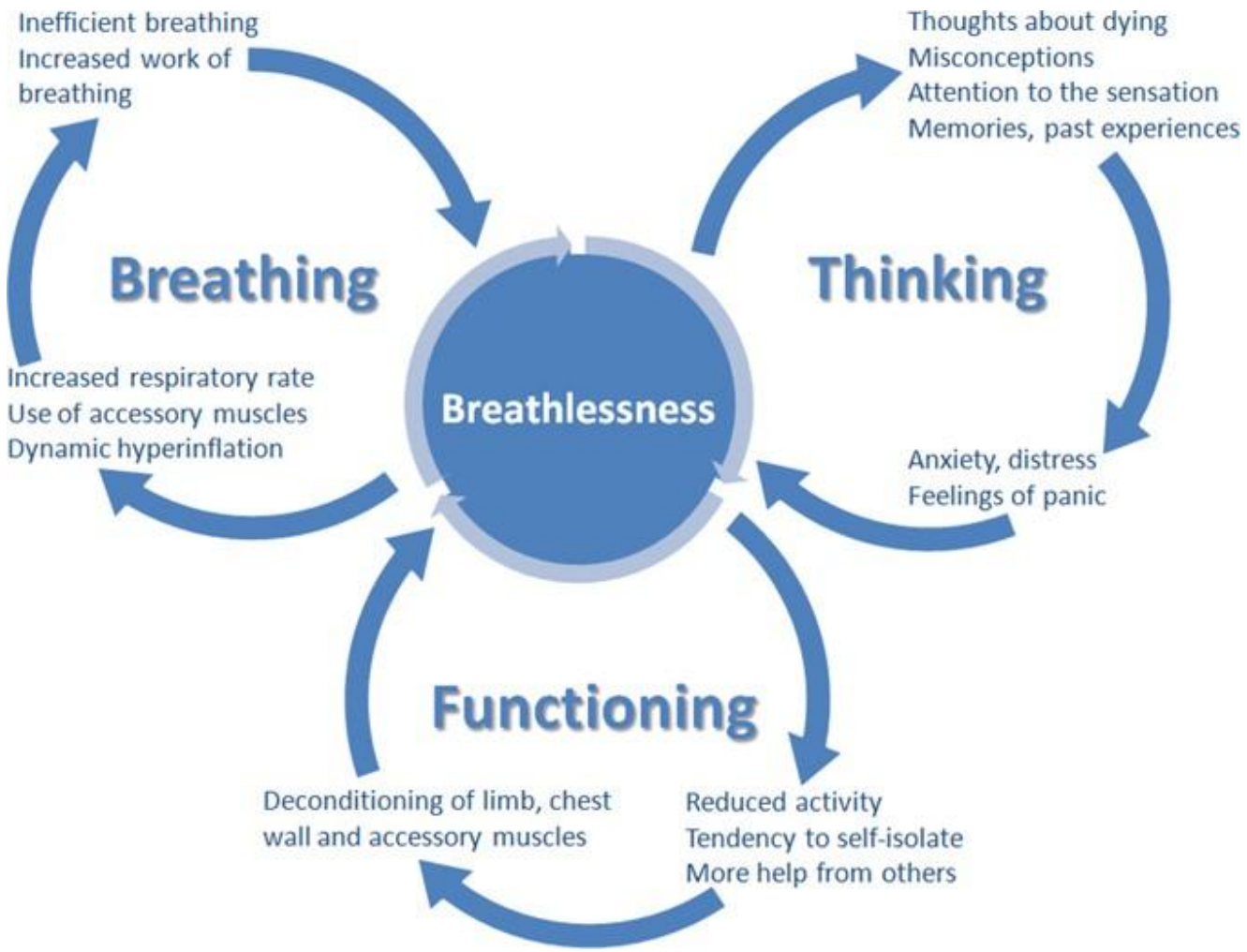
- When this system activates strongly:
  - Breathlessness feels scary
  - The sensation becomes louder
  - The person becomes hyper-aware of every breath
  - Anxiety increases ventilatory demand, worsening mismatch
  - Even mild exertion can feel overwhelming

Tool Two

BREATHLESSNESS ASSESSMENT

Breathlessness assessment

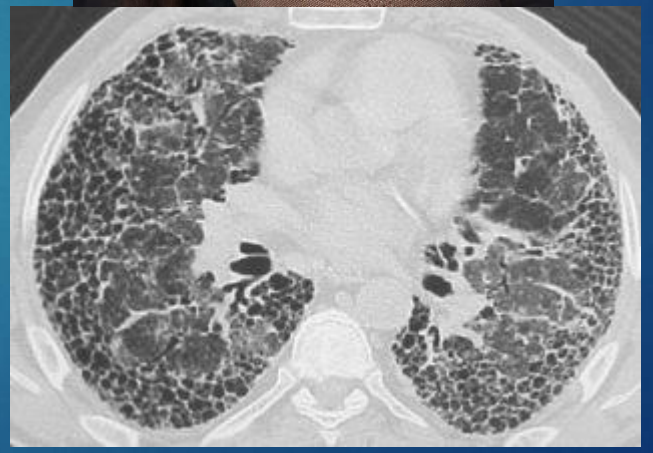
- Similar to the concept of ‘total pain’, one can consider ‘total breathlessness’
- Breathlessness appears to be really complex, more than just receptors and muscle stretch



The 'BTF' model – Spathis et al

Case example: Mr BW

- Mr BW is a 78-year-old NZ European man who has recently been diagnosed with Idiopathic Pulmonary Fibrosis, on a background of progressive breathlessness on exertion over the last 12 months.
- He has just been given the bad news that his prognosis is around 2-3 years.
- He is finding the breathlessness difficult to manage and is petrified of choking to death, so much so that he has avoided going out of the house in case something happens with his breathing.



Case example: Mr BW

- The 'thinking' domain is most prominent for Mr BW, and spending some time exploring his thoughts around breathlessness and reassuring him around the choking feeling would be worthwhile.
- His fears of breathlessness are impacting on the 'functioning' domain – his fear of going out of the house will be leading to deconditioning, which in turn worsens the breathlessness and so on….

Anxiety and depression

- Anxiety disorders quoted as prevalence of up to 40% in COPD
- 3x higher than the general population (14%)
- ? anxiety associated with increase relapse rates after exacerbations and possibly worse survival

In practice….

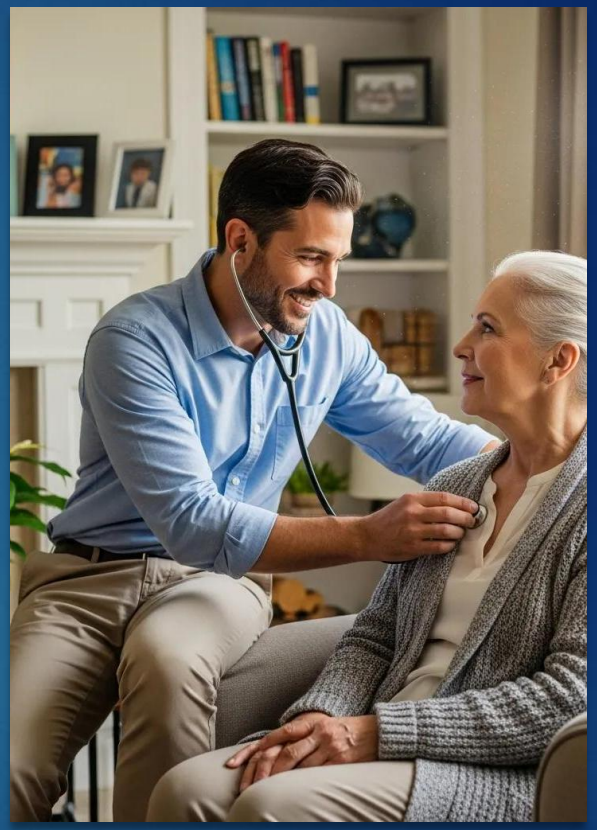
- Take an anxiety history
  - What precipitates it?
  - What makes it better/worse?
  - Is their anxiety pervasive?

In practice….

- Consider dedicated anxiety management
  - Explain what is happening and why they are experiencing anxiety
  - Is an SSRI needed?
  - Respiratory psychologist or psych consult review
  - If you need a benzodiazepine, target the duration of action to the duration of anxiety….

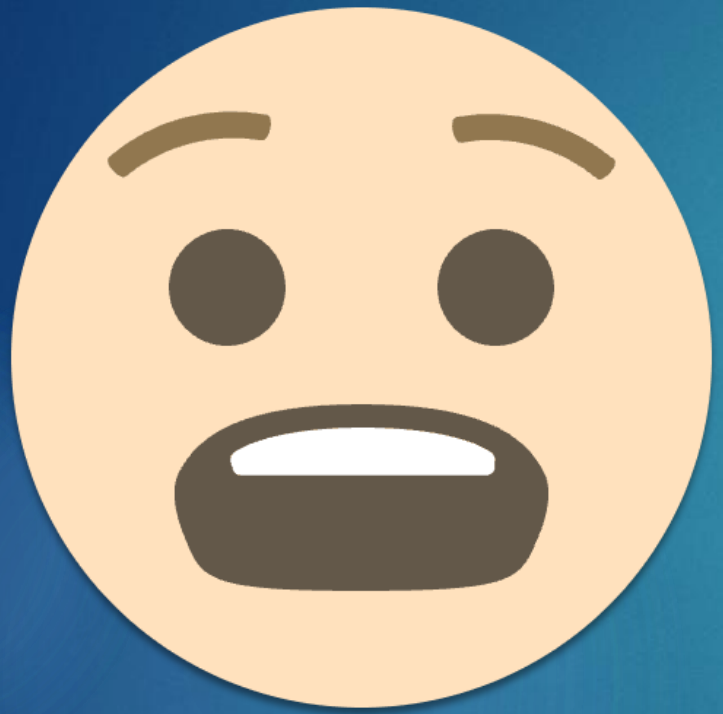
Respiratory Psychologist Tips!

- Give COPD patients 10-15 seconds of time to get breath back
  - Tell them to take their time
- Start to slow your breathing yourself in a slightly exaggerated way and often breathing will synchronise (2 mins)
- You have made a strong connection with the patient!



Tool Three

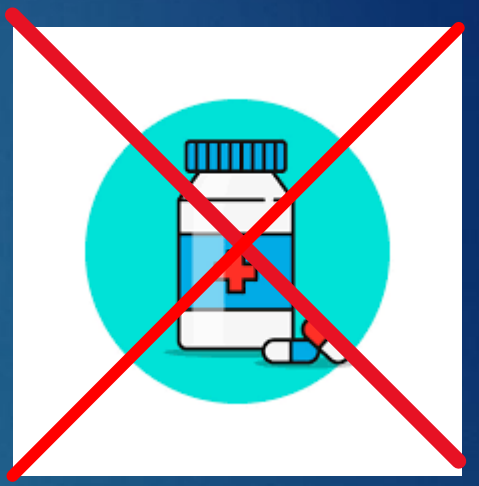
BREATHLESSNESS MANAGEMENT



In chronic breathlessness… the drugs do not really work…..

Pharmacological Limitation in Chronic Breathlessness

- Pharmacotherapies rarely modify the **mismatch + behavioural + affective** components; residual dyspnoea persists after disease optimisation.
- **Oxygen**: no superior symptom relief vs. air in **non-hypoxic** patients



Pharmacological Limitation in Chronic Breathlessness

- **Opioids/Benzodiazepines**: **selective** roles (refractory or end-of-life dyspnoea; severe anxiety at end of life); not first-line for chronic dyspnoea

What does work?

- **Tell patients they will not die during a breathlessness episode**
  - Single biggest thing ANY health professional can do
  - Some necessary nuance re acute episodes

Breathing retraining
Positioning
Fan/facial cooling
Chest wall vibration

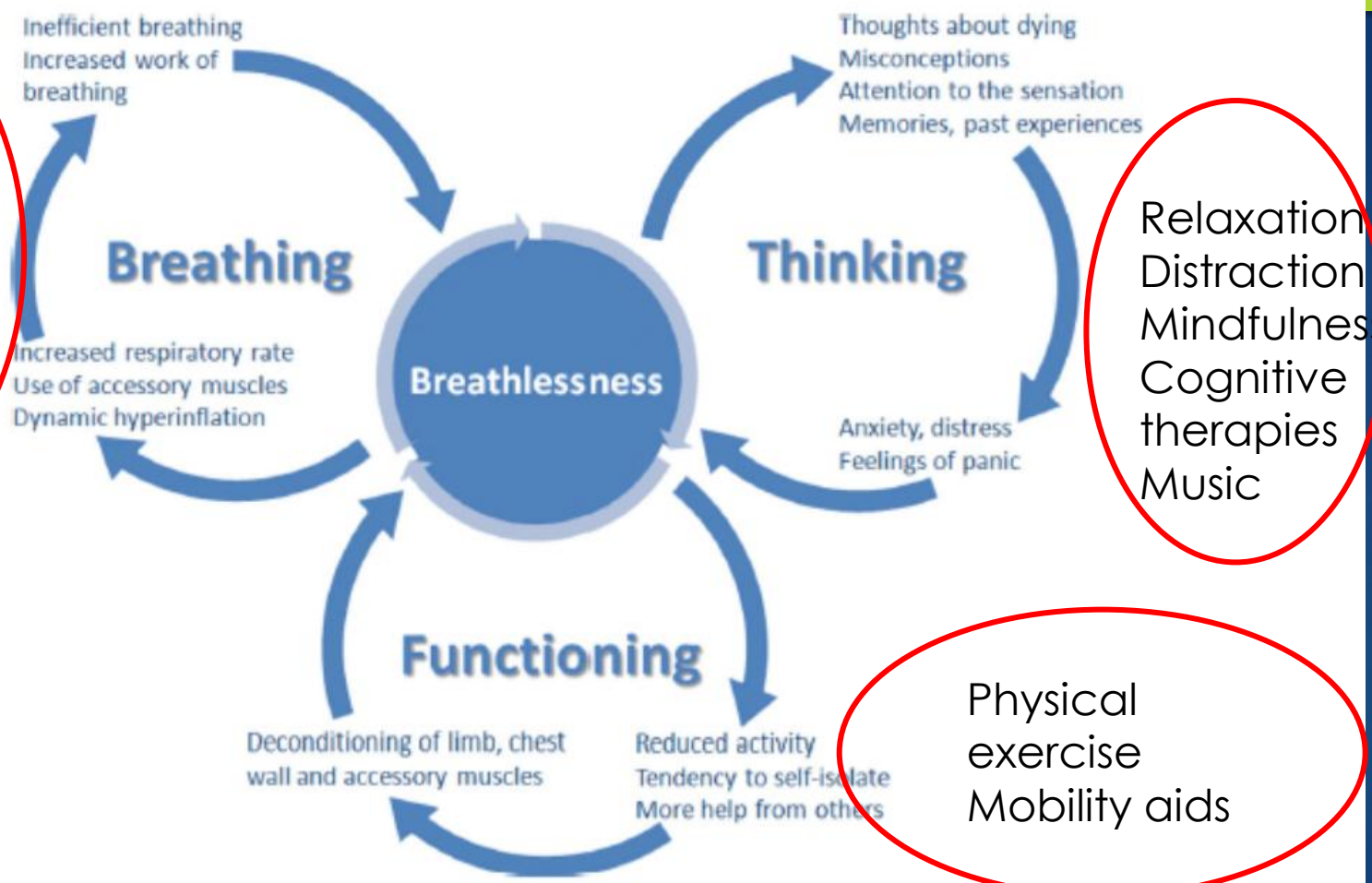


Fig. 1 The Breathing, Thinking, Functioning clinical model

Relaxation
Distraction
Mindfulness
Cognitive therapies
Music

Physical exercise
Mobility aids

Spathis et al. The Breathing, Thinking, Functioning clinical model: a proposal to facilitate evidence-based breathlessness management in chronic respiratory disease. Primary Care Respiratory Medicine (2017) 27:27

Non-Pharmacological Core Interventions - breathing

- **Breathing:** forward-lean positions, handheld fan, breathing control, pursed-lips/recovery breathing, airway clearance, inspiratory muscle training, chest wall vibration.

Hand-held fan

- Cool air blowing across the face and nasal mucosa reduces the sensation of breathlessness
  - Stimulation of 2nd and 3rd branches of trigeminal nerve
  - Simple, portable, inexpensive
  - Gives patients sense of control
  - Gives carers something to do

- **Warning- not all fans are equal!**

Non-Pharmacological Core Interventions - thinking

- **Thinking:** myth-busting, clinician reassurance, brief CBT techniques, relaxation/mindfulness, acupuncture.

Cognitive behaviour therapy

Addresses the ‘thinking’ cycle

- Take the thought to court!
- Downward arrow techniques
- Encouraging ‘small’ acts of bravery
- Challenging that ‘little’ voice
- Staying in the moment
- Breathlessness Recovery Plan

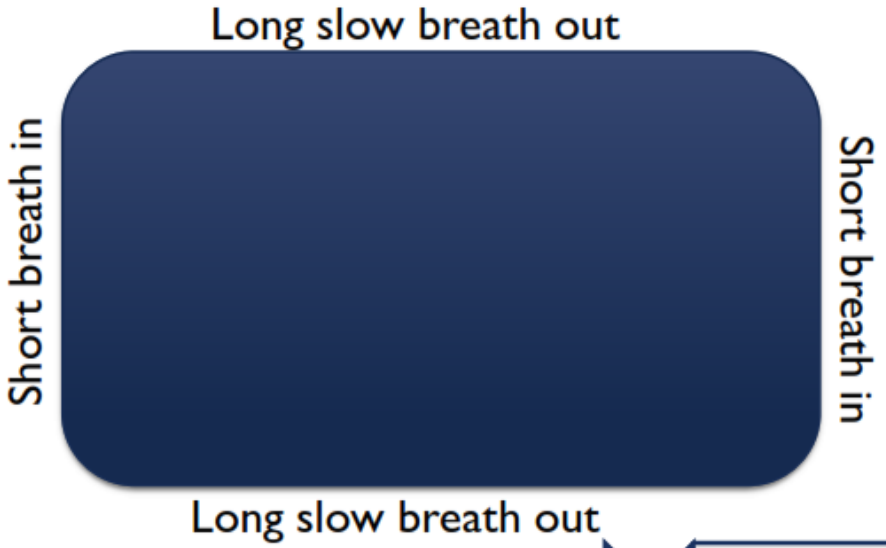
Non-Pharmacological Core Interventions - functioning

- **Functioning:** graded exercise, energy conservation, walking aids, pulmonary rehab.

Physical activity, exercise and diet

- Step counter/pedometer
- Encourage walking to toilet
- Move things away from easy reach!
- Nutrition assessment
  - Refer to dietitian
- Pulmonary rehab

IN THE MOMENT[1]



When breathless, remember the 3 Ps

Pause
(stop what you are doing)
Position
(get into a position that relieves your breathlessness, lean forward, drop your shoulders)
Purse lips
(smell the roses, flicker the candle)

And use your fan!

- Stop — Stop what you are doing
- Drop — Drop your shoulders
- Flop — Flop (lean) forward

1. Booth S *et al.* 2014. Managing breathlessness in clinical practice . Springer, London.

Breathlessness Intervention Clinics

- Multicomponent breathlessness services improve **dyspnoea mastery and health-related quality of life**; recent RCT shows benefit in COPD outside Europe;
- Models are acceptable and safe.

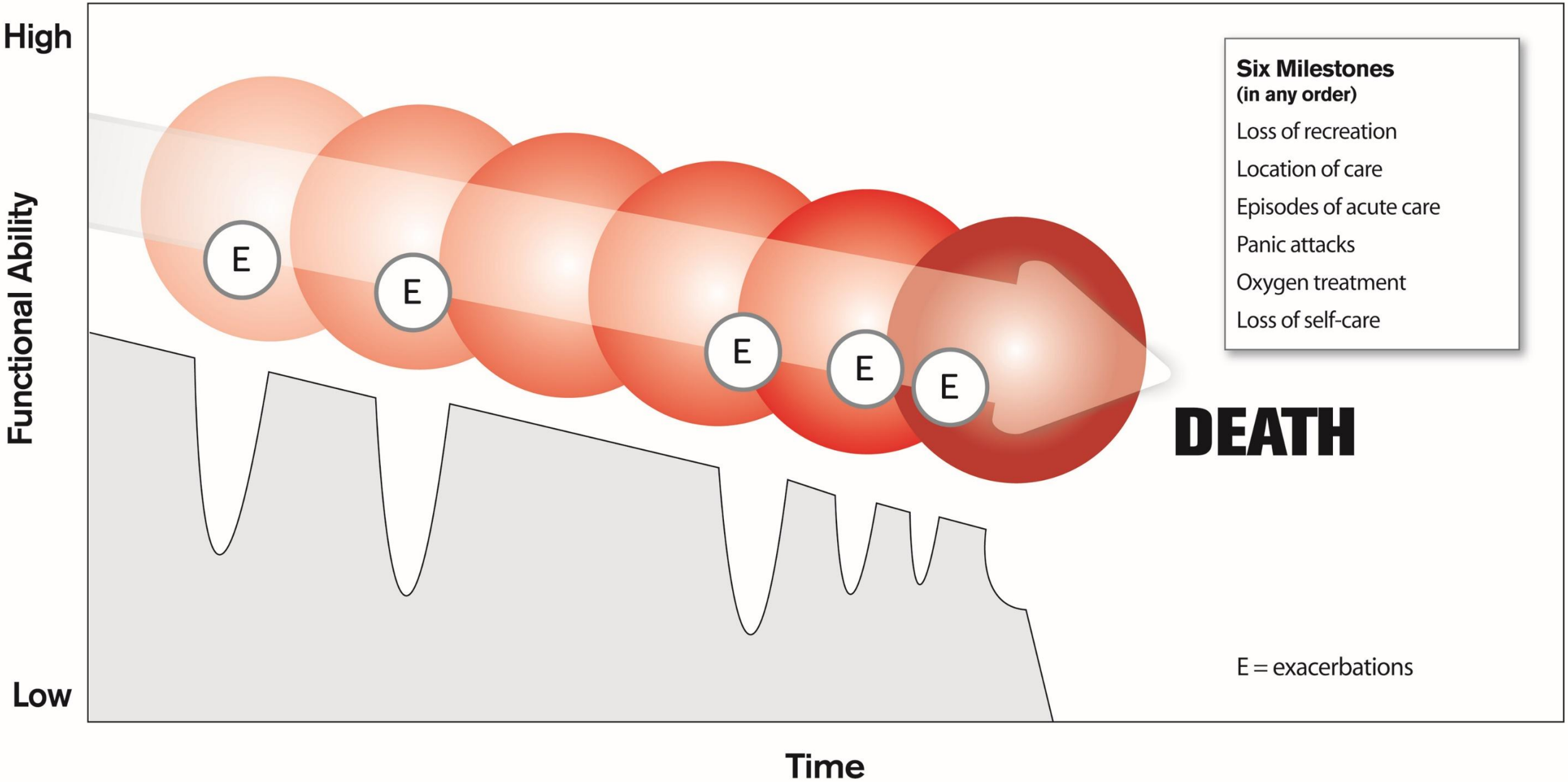
Tool Four

PALLIATIVE CARE APPROACH

The upshot is….

- People have stopped searching for a transition point
- Hedge your bets both ways
  - ‘best case/worst case’
  - ‘I hope that…. But I am worried that…’

Trajectory of Chronic Obstructive Pulmonary Disease



The Three Triggers for Palliative Care Approach

1. Mannix question

   Is this person sick enough to die?

2. Choice/ need

   Asking about a palliative approach

3. Clinical indicators….SPICT tool

THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT™)

Te Kahu Pairuri o Aotearoa hospice New Zealand

The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems. The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

...uk) for information and updates.

Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Review current care and care planning.

- Review current treatment and medication to make sure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family/people close to them. Support carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, share, and review care plans.

Ways to start the conversation

Have you given any thought to the future?

I see you were in hospital recently, I am getting worried about your health…

Shall we book an appointment to do some planning as I can see you are not as well as last year?

Tool Five

PLANNING FOR THE DEATH

Important to know

- People with chronic refractory breathlessness do **NOT** 'choke to death'
- In the last hours or days of life, the picture is one of 'normal dying'
- In COPD or those with hypercapnia, the memory is affected and people will be unaware of what is happening to them

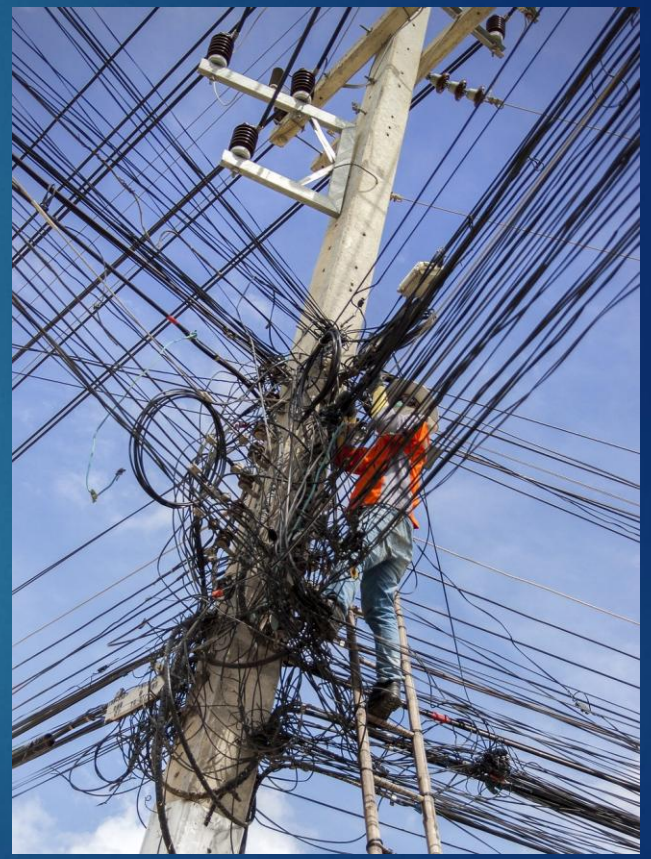
Place of death

- Will depend on the disease:
- Lung cancer – more predictable, more likely to die at home or hospice
- Chronic illnesses such as COPD – more likely to die during an exacerbation, in hospital

Dying at home with chronic respiratory disease

- ‘I don’t want to go back to hospital’

- Takes dedicated planning and open conversations
- May involve Specialist Palliative Care team
- Drug availability, nursing and family availability, rapidly changing scenario
- May be best transferred to some form of inpatient environment, with a clear plan for palliation



Māori world view at end of life

- Discuss with whānau/family about the last days of life both before the end of life and during the dying process.
- Ask whānau/family to document their preferences in the plan of care.
- End of life care should be:
  - inclusive of whānau/family
  - culturally informed
  - relevant
  - well-supported by health professionals

https://www.hqsc.govt.nz/resources/resource-library/care-during-the-last-days-of-life-pairuri-palliative-care-frailty-care-guides-2023/

Case example: Mr JH

- Mrs JH, a 63 year old Māori woman, has severe COPD and has had 5 hospital admissions in the last year
- She received BiPAP on the last two occasions.
- She is adamant she never wants to return to hospital and certainly never wants to have ‘that mask treatment’ ever again.
- She lives alone, her daughter lives 2 doors down and provides frequent support, her son is also in town.

Case example: Mrs JH

- Mrs JH consistently expresses a desire not to return to hospital when she next has an exacerbation, she understands the implications of this decision and fills out/publishes an Advance Care Plan.
- You discuss with Mrs JH and her daughter the options around what to do at the next exacerbation, what might be expected to happen and what dying at home might look like.

Case example: Mrs JH

- A detailed Acute Plan is created with Mrs JH and her whānau/family and lodged on the electronic health record; Hato Hone/St John are notified.
- She deteriorates further the next winter with multiple chest infections. She is now mostly bedbound and needing help with all ADLs
- May need-parenteral medications and drug orders placed in the house in case of acute deterioration.

Any questions?