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Performance
and Improvement

LIVING WITH BREATHLESSNESS

HANDBOOK



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OVERVIEW

This handbook is here to **support you** following the *Living with Breathlessness* session. You do not need to read it all at once. You can dip in and out, and **focus on the sections that feel most helpful** to you.

There are no right or wrong ways to manage breathlessness. Different things help different people. The aim is to **help you understand your breathlessness** and **try practical strategies** that may help you feel more in control.

HOW TO USE THIS HANDBOOK

Start	with the sections that feel the most relevant to you.
Try	one or two ideas at a time rather than changing everything at once.
Use	the writing spaces to note what works for you.
 Click	on the links for more information.
 Map	out your personalised action plan at the end and choose your next steps.

WHAT IS BREATHLESSNESS?

**Breathlessness is a symptom.
It is not a diagnosis or condition in itself.**

In everyday language, this means **breathlessness is the feeling you get** when your breathing does not feel as though it is meeting your body's needs. It can feel uncomfortable, upsetting or frightening. **Your experience of breathlessness is personal to you.**

A medical definition of breathlessness is:
"a highly subjective, uncomfortable or distressing sensation that occurs when actual ventilation is perceived not to satisfy demand."

People who helped design this intervention described breathlessness in many different ways. There is no single 'correct' way to describe it.



Use this space in the cloud to write down your own words, symptoms or worries



How would you describe your own breathlessness?

“

"It feels like you've been for a run and then never got your breath back"

"It's like you're trying to breathe through a narrow tube"

”

COMMON CAUSES OF BREATHLESSNESS

Many different health problems can cause breathlessness.

People often think breathlessness only comes from the lungs, but other parts of the body can play a part as well.

Around 1 in 10 adults experience chronic breathlessness

Metabolism:

for example complications of diabetes

Heart:

cardiac conditions such as heart failure or atrial fibrillation

Physical

deconditioning:

becoming less fit or less strong over time

Brain and mood:

anxiety, panic and other mental health or mood-related difficulties

Blood and circulation:

for example anaemia or circulatory problems

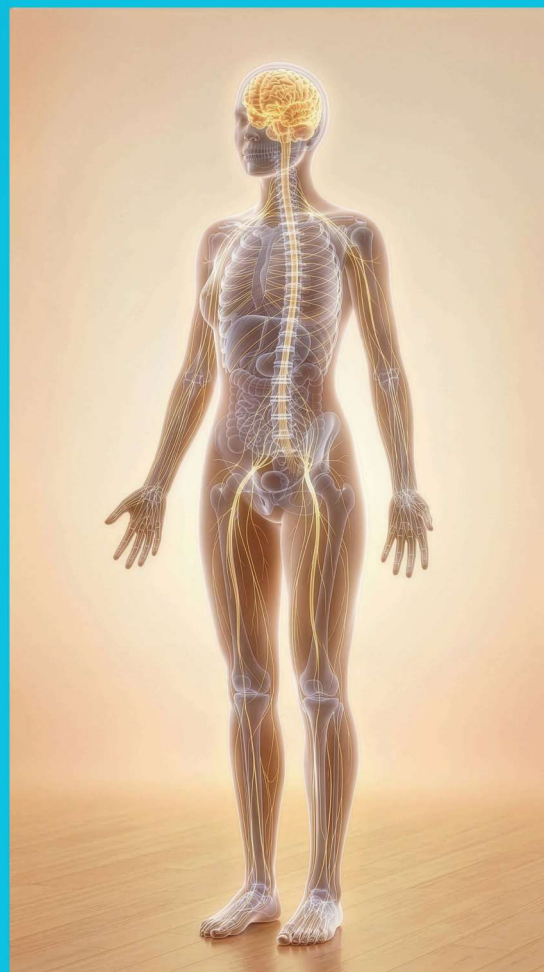
Long Covid

Weight-related factors, including obesity

Muscle, joint or bone problems

Lungs:

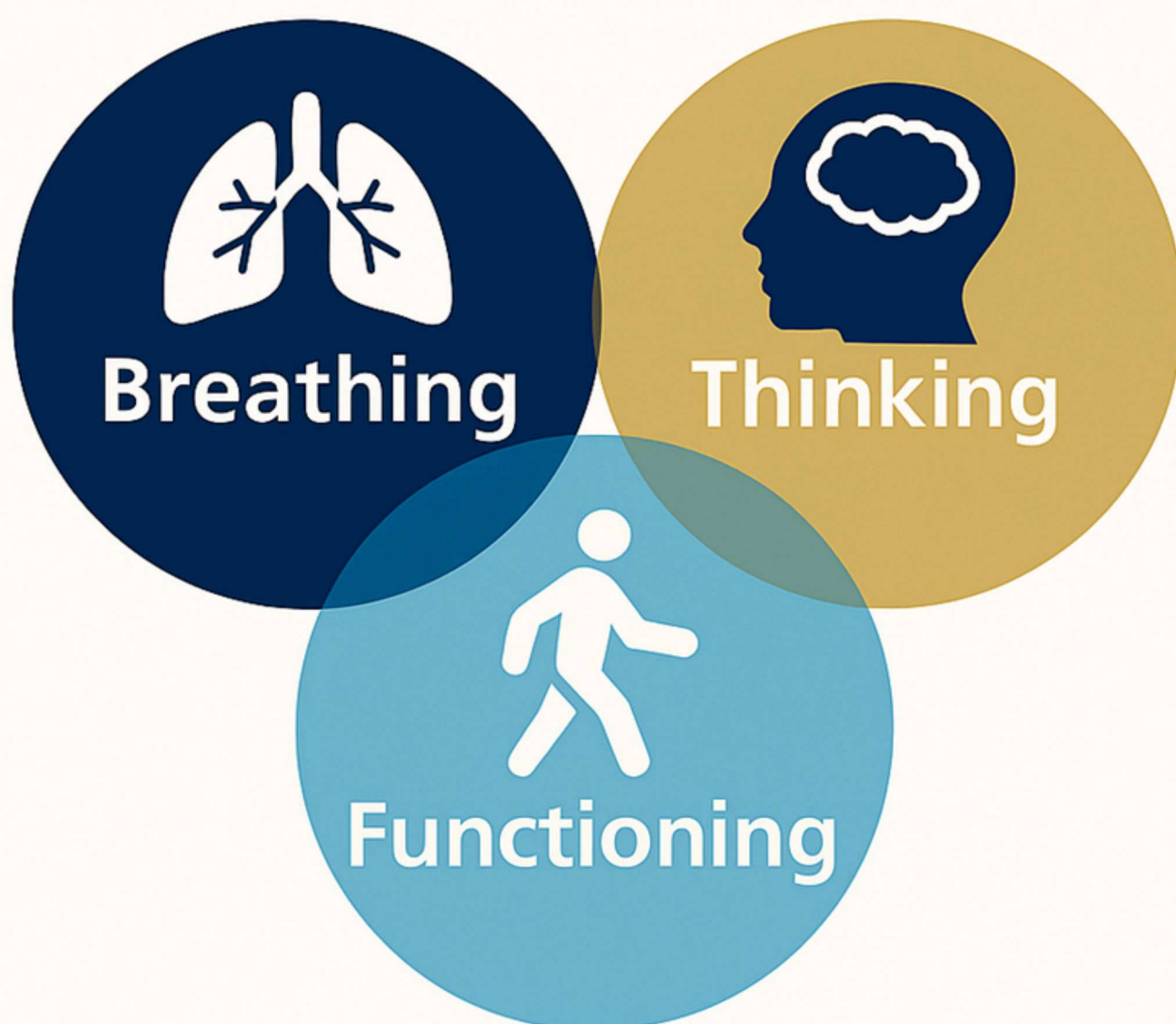
respiratory conditions such as asthma, chronic obstructive pulmonary disease (COPD) and bronchiectasis



For around 1 in 3 people, more than one factor may be causing their breathlessness.

BREATHING, THINKING, FUNCTIONING MODEL

Developed by the Cambridge Breathlessness Intervention Service at Cambridge University Hospitals NHS Foundation Trust. It helps people with breathlessness and professionals make sense of the unhelpful cycles that sometimes happen as a result of the normal emotional and behavioural response to feeling breathless.



This handbook has sections on each of these cycles. You may find one section more helpful than the others or find all of them of value.

USEFUL INFORMATION & SUPPORT



[ASTHMA AND LUNG
UK](#)

information and support for people living with **lung conditions**, including **asthma and COPD**.

Breathing Freely
Your guide to breathing retraining for asthma

[BREATHING FREELY](#)

a free **online course** developed by the University of Southampton to **help people with asthma** retrain their breathing



[PHYSIOTHERAPY
FOR BREATHING
PATTERN
DISORDERS](#)

information, **videos and leaflets** for people diagnosed with a **breathing pattern disorder**



[BRITISH HEART
FOUNDATION](#)

information about **shortness of breath and heart-related symptoms**



[BREATHLESS
INTERVENTION
SERVICE](#)

information about the **breathing, thinking, functioning model** and helpful **information leaflets** on managing each element of the model

NHS Wales apps

Download



COPD

[Google Play](#)
[Apple app store](#)

Asthma

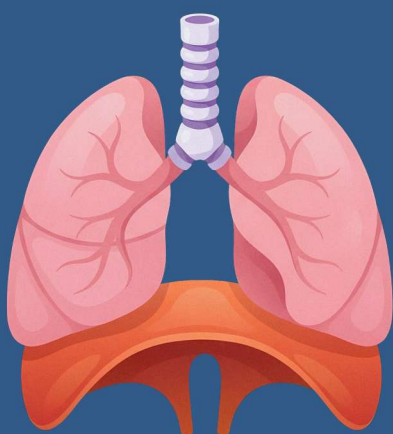
[Google Play](#)
[Apple app store](#)



BREATHING



Efficient breathing uses **very little effort**. It can be called diaphragmatic, abdominal or tummy breathing.



Breathing is an **automatic function**. Even thinking about it changes how we do it.

Our **diaphragm is the most important muscle for breathing**. It is shaped like a dome when relaxed. It attaches to the lower edges of the ribs and spine and separates the chest from the abdomen. It is made up of special muscle fibres that can work continuously without tiring easily.

Most people take between **8 and 12 breaths in a minute** when they are resting.



We should try to breathe **in** and **out** of our noses, if possible. This warms and filters the air.

We have other **muscles in our shoulders and chest** that help us breathe. They are designed to kick in when we need more oxygen for short periods, for example when we are exercising. **They use about 25% more energy** and tire more quickly.



“They’re life-changing and I wouldn’t be able to do anything without them.”

“Concentrating on the breathing strategies helps to calm my mind.”



People who helped design this intervention described how breathing strategies helped them

BREATHING STRATEGIES

1. Diaphragmatic breathing: how to practise

1. Find a **comfortable, supported position**. You might lie on your side in bed, sit upright with pillows, or sit in an armchair.
2. Place one **hand on your tummy** and let your upper chest and shoulders relax.
3. As you **breathe in**, let your **tummy gently rise** under your hand.
4. As you **breathe out**, relax and let your **tummy fall back down**.
5. Keep the **movement gentle**. You do not need to take deep breaths.
6. When this feels easier, practise in **sitting and standing** as well.

The aim is to make tummy breathing your usual relaxed breathing pattern where possible.



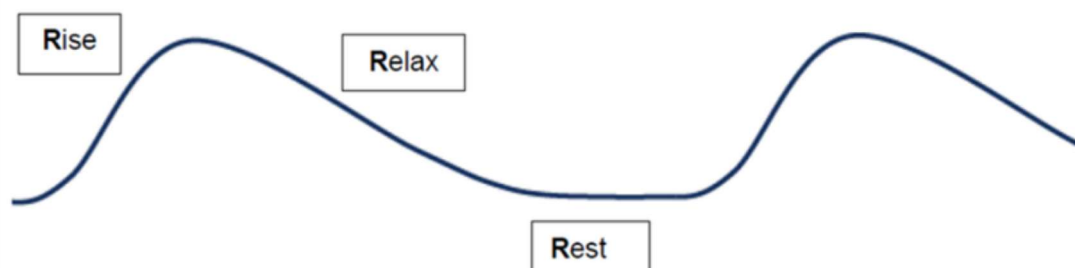
[Diaphragmatic Breathing Technique](#)



It is important we practise diaphragmatic breathing when we are **not feeling breathless**, so that it becomes a natural skill.



The 3 Rs of relaxed diaphragmatic breathing



BREATHING STRATEGIES

2. Three Fs



Facial cooling with
a fan or damp cloth



Flop and drop your
shoulders



Focus on relaxed,
long breaths out

3. Blow as you go

Keep in mind when
you're moving about:



Blow as you
go

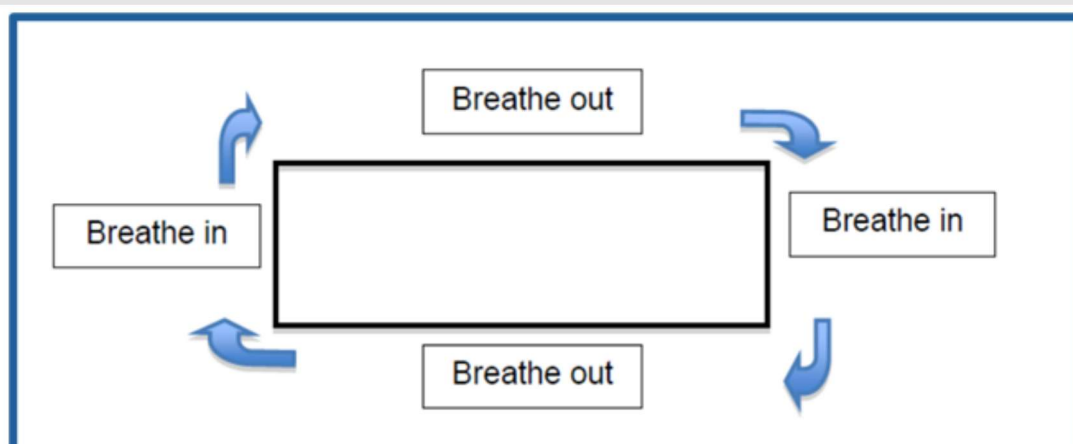
If in doubt,
breathe out

4. Rectangular breathing

Rectangular breathing is a visual technique that may help when you feel breathless, anxious or panicky.

1. **Find a rectangle** around you, such as a book, screen, phone, door, window or picture frame.
2. **Follow the sides** of the rectangle **with your eyes or finger**.
3. **Breathe in** along the short side.
4. **Breathe out** along the long side.
5. **Slow the movement** gradually to help slow your breathing.

Some people find it helpful to count, for example breathing in for 2 and out for 3, or in for 4 and out for 6.

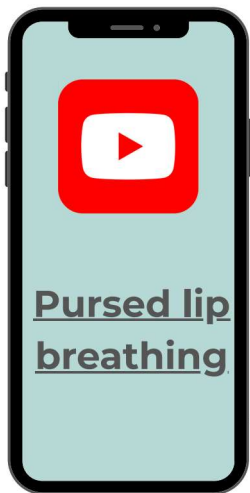
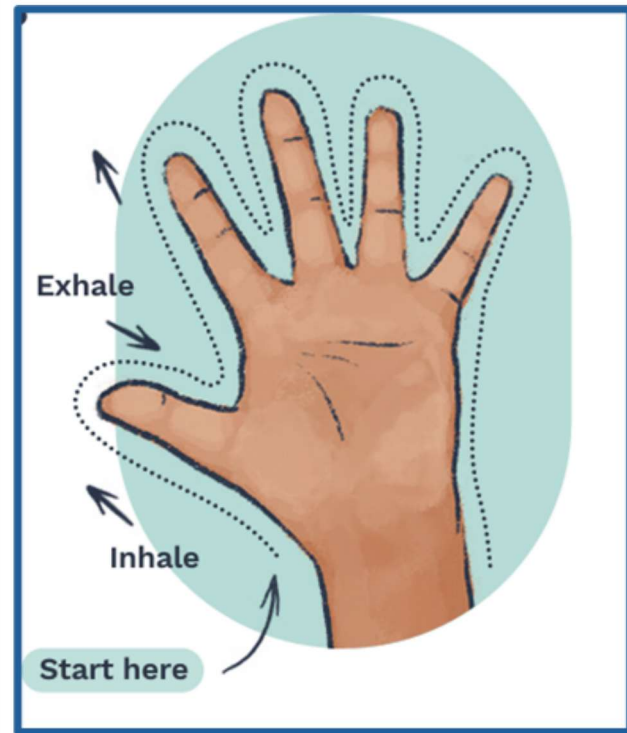


BREATHING STRATEGIES

5. Starfish or hand breathing

This is a tactile technique.

1. Place your **pointer finger** from one hand **at the base of your thumb** on the other.
2. **Breathe in** as you **trace up** the outside of the thumb slowing your breath.
3. **Breathe out** as you **trace down** the inside of the thumb slowly.
4. **Wait** until you feel the need to breathe in. **Inhale**.
5. **Continue** for all fingers.
6. When you get to your little finger **start at the thumb again**.



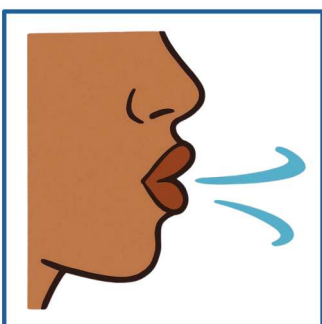
6. Pursed lip breathing

Pursed lip breathing means **breathing in through the nose**, then **breathing out gently through narrowed lips**, as though you are flickering a candle rather than blowing it out.

Some people remember this as:
smell the rose, then flicker the candle.

Breathing out through pursed lips can help slow the breath out and give more time for air to leave the lungs. This can create more space for the next breath in. If breathing in through the nose is difficult, just breathing out through pursed lips may still help.

This technique often helps people with COPD, emphysema or asthma. It can be useful during or after activity. Only do it for as long as it feels comfortable



BREATHING CHECK-IN



On a scale of 0 to 10, how **IMPORTANT** is it for you to practice using effective breathing techniques?

Not important

0---1---2---3---4---5---6---7---8---9---10

very important

What makes you choose this number and not a lower one?

E.g. If you circled 5, what makes you select 5 and not 3?



What would help you get to a higher number?

E.g. If you circled 5, what would you need to get to 7?

On a scale of 0 to 10, how **CONFIDENT** do you feel about using effective breathing techniques?

Not confident

0---1---2---3---4---5---6---7---8---9---10

very confident



What makes you choose this number and not a lower one?

E.g. If you circled 5, what makes you select 5 and not 3?



What would help you get to a higher number?

E.g. If you circled 5, what would you need to get to 7?

MY THOUGHTS: WEIGHING IT UP



What are the good things and not-so-good things about practising breathing techniques?



Good things

Not-so-good things



Practising breathing techniques:
what might get in the way and what could help?



What could get in
the way

What could help



Considering the way forward



Breathing
techniques I
would like to try

How they might
fit into my day



USEFUL INFORMATION & SUPPORT



ACUTE HYPERVENTILATION

Patient information leaflet on **hyperventilation**



TOP TIPS FOR BREATHING WELL

Helping you to **better understand your breathlessness** with **top tips and advice** to support the management of your symptoms.



3 BREATHING EXERCISES TO RELIEVE STRESS

Breathing exercises offer many physical and mental health benefits. **Discover 3 deep breathing techniques** you can use to **feel calmer**.



BREATHLESSNESS - KEEPING ME WELL

Presentations to support breathlessness, and a **demonstration** that **shows breathing techniques** that you might be able use to help with your breathlessness.



ASTHMA + LUNG UK

information is for people who struggle with **breathlessness**, whatever the cause.



UNIVERSITY OF
CAMBRIDGE

**Cambridge Breathlessness
Intervention Service leaflets**



Breathing
techniques for
easing
breathlessness

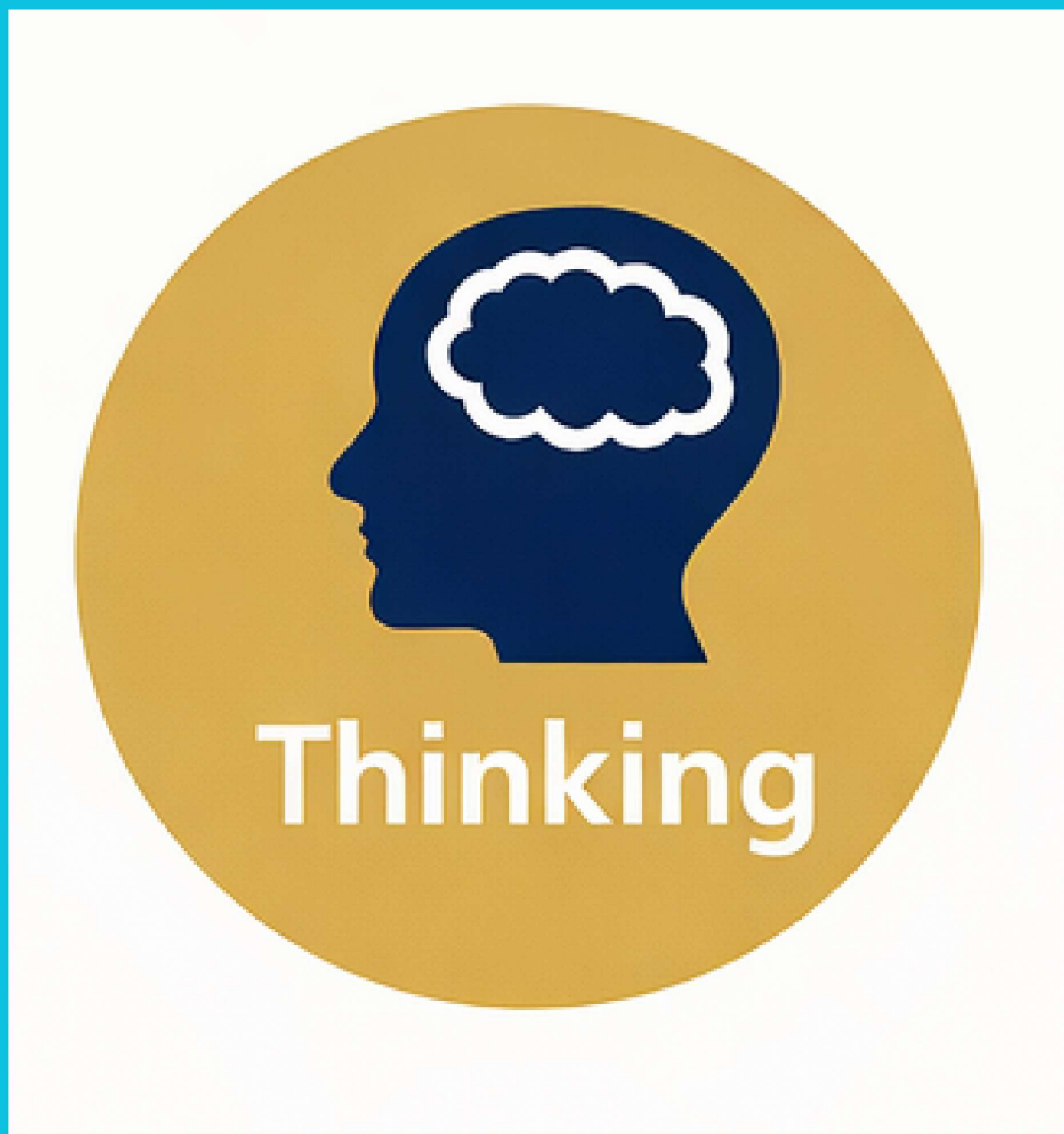


Positions for
easing
breathlessness



Hand-held fans



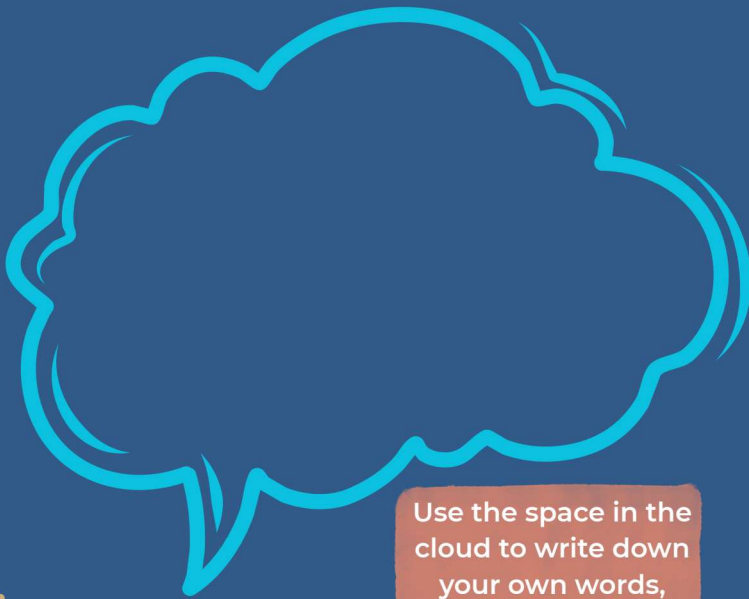


THINKING

Feeling unwell and symptoms like breathlessness can make us feel anxious, scared, stressed, angry or low in mood.

Our **past experiences** influence what we think and how we react in the future. These are perfectly normal responses to the feeling of breathlessness that people describe. Understanding **how and why breathing and thinking affect each** other can help us control how we respond and help us manage it.

What thoughts go through your mind when you are breathless?



Use the space in the cloud to write down your own words, symptoms or worries

People with breathlessness who helped design this intervention described thinking like:

"I need more oxygen."

"I'm going to pass out."

Breathlessness, stress and anxiety can all trigger **a fight or flight response**, resulting in **adrenaline being released** into our bodies.

Adrenaline affects our bodies, how we think and what we do:

- our muscles tense, our heart races, we sweat, feel dizzy or sick, our mouth goes dry, or our vision blurs
- we imagine the worst, worry about looking foolish, or feel like we are "going mad"
- we avoid situations, feel anxious, lose concentration, become irritable, or have trouble sleeping

Breathing quickly and shallowly can **make you feel light-headed** because you breathe out too much carbon dioxide. **Practising diaphragmatic breathing**, or focusing on **a long, slow breath out**, can help stop this.

THINKING

What can help?

- **Notice the early signs** that you are becoming anxious or breathless
- **Use a breathing strategy early**, before the feelings build
- **Practise psychological strategies when you are calm**, so they are easier to use when you need them
- **Ask family or friends to support you** with prompts and reassurance if helpful

1. Reframing unhelpful thoughts

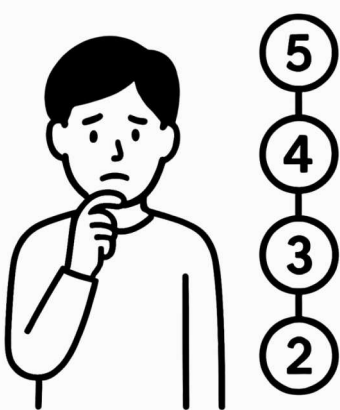


Try to step back and ask yourself what evidence supports the thought. A simple way to remember this is: **catch it, check it, change it.**

catch it

check it

change it



2. Grounding techniques



Grounding helps **bring your attention back to the present moment.**

One example is the **5, 4, 3, 2, 1** technique.

- **5** things you can **see**
- **4** things you can **feel**
- **3** things you can **hear**
- **2** things you can **smell**
- **1** thing you can **taste**

You could also try this 4 minute **“Guided meditation - a short and simple grounding exercise”**. Scroll down to the 3rd video.

THINKING



3. Relaxation techniques

Relaxation can help calm the mind and body.



- **Body scan:** slowly notice and release tension through the body



- **Guided imagery:** picture yourself in a calm, safe place



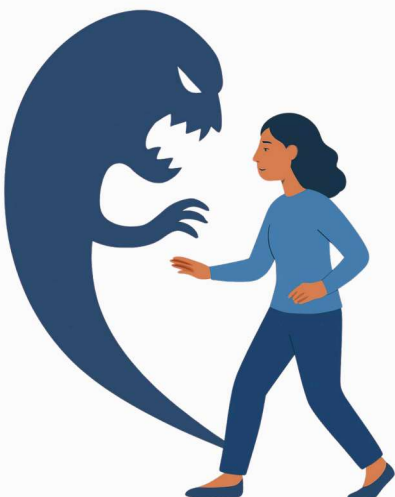
- **Mindful breathing:** gently focus on the breath as it comes and goes

4. Facing fears gradually



Avoiding things that make you anxious may help in the short term, but it **can make your life smaller over time.**

Gradually returning to feared situations can help you **feel more confident** and **more in control.**



THINKING CHECK-IN



On a scale of 0 to 10, how **IMPORTANT** is it for you to practice these techniques to help you manage difficult thoughts or feelings about breathlessness?

Not important

0---1---2---3---4---5---6---7---8---9---10

Very important

What makes you choose this number and not a lower one?

E.g. If you circled 5, what makes you select 5 and not 3?

What would help you get to a higher number?

E.g. If you circled 5, what would you need to get to 7?

On a scale of 0 to 10, how **CONFIDENT** do you feel about using techniques to manage difficult thoughts or feelings?

Not confident

0---1---2---3---4---5---6---7---8---9---10

Very confident



What makes you choose this number and not a lower one?

E.g. If you circled 5, what makes you select 5 and not 3?

What would help you get to a higher number?

E.g. If you circled 5, what would you need to get to 7?

MY THOUGHTS: WEIGHING IT UP



What are the good things and not-so-good things about using techniques to manage difficult thoughts and feelings?

 **Good things**

Not-so-good things 

Practising these techniques:
what might get in the way and what could help?

 **What could get in the way**

What could help 

Considering the way forward

 **Thinking techniques I would like to try**

How they might fit into my day 

USEFUL INFORMATION & SUPPORT



SUPPORT FROM FAMILY AND FRIENDS

Prompts and reassurance from family and friends can help us to implement some of these strategies when we are breathless.



ACTIVATE YOUR LIFE

Free course from Public Health Wales is designed to **help you improve your mental health and wellbeing**



SILVERCLOUD

SilverCloud is an **online course** which offers **support for anxiety, depression,** and much more, all based on **Cognitive Behavioural Therapy (CBT)**.



BREATHLESSNESS SUPPORT

Thinking - **Managing thoughts about breathlessness**



MIND

Mental health information and support, including **resources on anxiety, panic and breathing/relaxation techniques**



FUNCTIONING

Breathing problems can stop us doing the things we want to do. They can also affect our energy levels, making everyday activities more difficult.

Can you think of something you enjoy that you have stopped doing because you are worried how it might affect your breathing or energy levels?



Use this space in the cloud to write down what you have stopped doing

People with breathlessness who helped design this intervention told us they used "if... then..." plans to help them keep doing what was important to them. See page 33.

"If I get breathless or tired when I go shopping with my daughter and granddaughter, then I go and sit and have a coffee and meet them again later."

It can be hard **juggling the various roles and responsibilities** we have at home and at work, as well as staying physically fit. Doing less of the things that are important to us may lead to negative thoughts about ourselves or feelings of low mood and reduced motivation.



Some people find it helpful to think of their **breath or energy levels as a limited resource**, like the charge in a battery or the sand in an hourglass. Once it's gone, it's gone!

It's important to understand which tasks and activities use up our energy, which require very little energy, and what we can do to recharge or refill our reserves.

FUNCTIONING

Using the '4 Ps' on the next page can help us manage our breathlessness and energy levels so we can do as much as possible within our limits and may even be able to increase those limits over time.

All of the Ps overlap and are linked, and one can affect the others. Some Ps may be more relevant to you than others.

Pacing and positioning can help us to:

1. **balance periods of activity** with periods of rest
2. **slow down when walking** so we can walk further
3. **take frequent rests** so we can do things that we otherwise could not do
4. **break tasks down and spread them over a longer period** so we can do things more independently

We can also make sure we are in the **best position to do a task** and **position the things we use regularly** so that we can do as much as possible within our limits.



Permission and perspective can help us to:

- **prioritise** the things that improve our breathlessness or wellbeing
- **give ourselves permission** to not do things that make us too tired, out of breath or feel unwell
- **focus on what we can do**, rather than what we cannot

FUNCTIONING



Physical activity

Research shows **being active** maintains or **improves strength and fitness** and can **help with energy levels**.

Keeping our bodies strong and flexible means it takes less effort and energy to move so we can increase how much we do within our limit.

It's just about **moving more** - at whatever level we can do at the time.

Planning and prioritising

If overwhelmed by thinking about all things we want to do, it can be hard to get started.

Making a list of all the things that are important to us, enables us to prioritise and plan to balance heavy and light activities and rests. We can:

- **Cut out unnecessary tasks** to conserve energy.
- **Spread out activities** through the day.
- **Ask someone else** to do the less important things
- **Prioritise important things** to help mood and motivation.
- **Plan and have contingencies** in place for when we become breathless or run out of energy.



FUNCTIONING CHECK-IN



On a scale of 0 to 10, how **IMPORTANT** is it for you to practice managing your energy day-to-day?

Not important

0---1---2---3---4---5---6---7---8---9---10

Very important



What makes you choose this number and not a lower one?

E.g. If you circled 5, what makes you select 5 and not 3?

What would help you get to a higher number?

E.g. If you circled 5, what would you need to get to 7?

On a scale of 0 to 10, how **CONFIDENT** do you feel about using energy management techniques?

Not confident

0---1---2---3---4---5---6---7---8---9---10

Very confident



What makes you choose this number and not a lower one?

E.g. If you circled 5, what makes you select 5 and not 3?

What would help you get to a higher number?

E.g. If you circled 5, what would you need to get to 7?

MY THOUGHTS: WEIGHING IT UP



What are the good things and not-so-good things about using techniques to manage day-to-day energy?



Good things

Not-so-good things



Practising energy management techniques:
what might get in the way and what could help?



What could get in
the way

What could help



Considering the way forward



Functioning
techniques I
would like to try

How they might
fit into my day



USEFUL INFORMATION & SUPPORT



PHYSIOTHERAPY FOR BREATHING PATTERN DISORDERS

A guide to **optimal breathing** during movement and exercise



ROYAL COLLEGE OF OCCUPATIONAL THERAPISTS

Occupational therapy advice for **managing energy**



KEEPING ME WELL CARDIFF AND VALE UHB- FATIGUE

General advice for **managing fatigue**. Activity diary and fatigue timetable for downloading and completing



CHARTERED SOCIETY OF PHYSIOTHERAPY

Advice on **being active** with a respiratory condition



SUPPORTING SOMEONE WITH BREATHLESSNESS

Advice on **supporting someone with breathlessness to keep active**



NATIONAL EXERCISE REFERRAL SCHEME

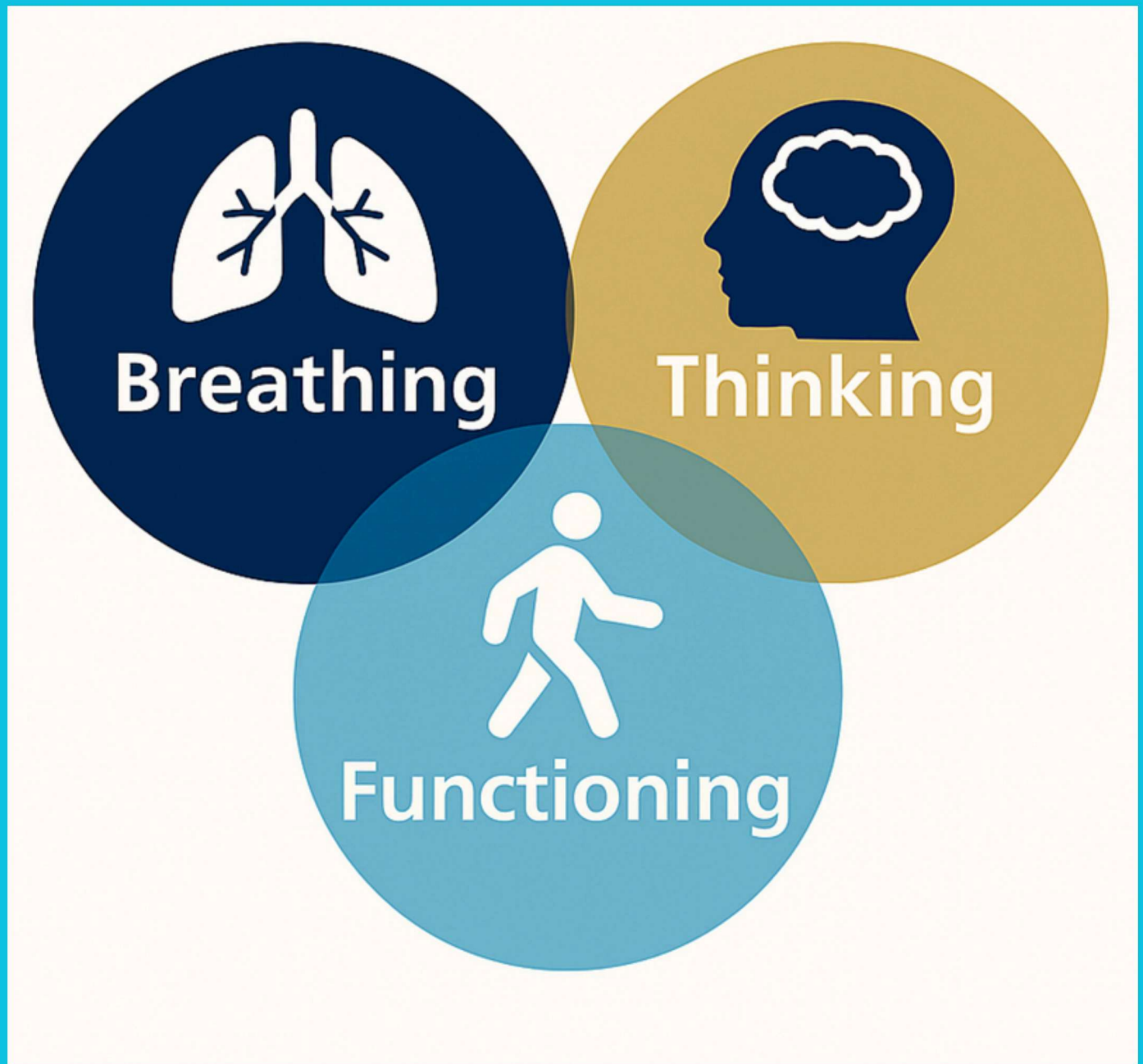
A chronic condition prevention and management programme which aims to **improve the health and wellbeing** of sedentary and inactive adults who are at risk of developing or who have an existing chronic condition.



EDUCATION PROGRAMMES FOR PATIENTS

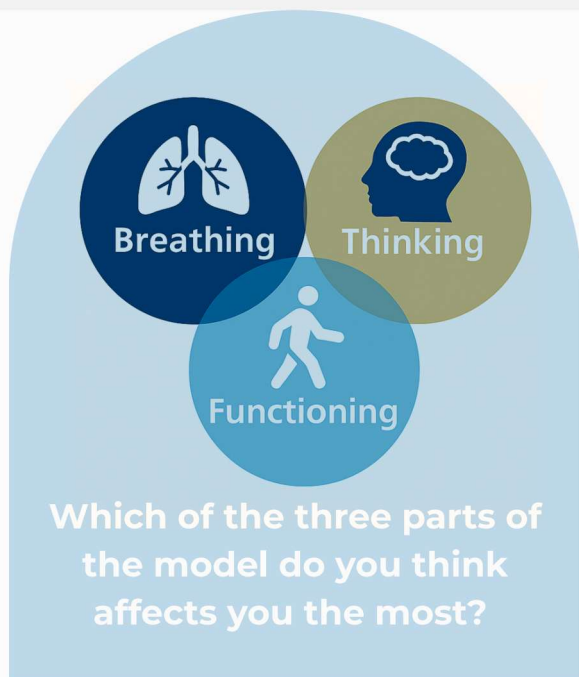
Provide a range of **self-management courses** for people living with a long-term health condition/s, and carers.

GETTING STARTED AND WHAT'S NEXT



IN SUMMARY:

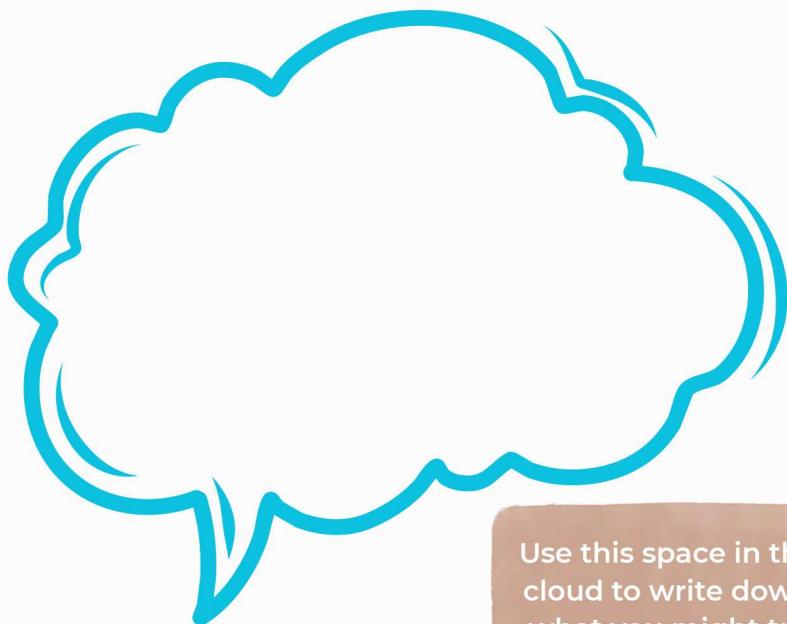
We have looked at some of the things that can make us breathless, explored the breathing, thinking, functioning model and considered some strategies that might help us.



Let's think about **one small change** you can **take away from today**. We'll look at how you might make that change in your life and consider the difference it could make over the next couple of weeks.

Sometimes it can be overwhelming to think about all the changes we want to make or the activities we want to accomplish. They seem too big to work on all at once, which makes it hard to get started.

Is there one small thing that you think might help you?



Use this space in the cloud to write down what you might try

We can **get started** by deciding which steps we are going to work on this week and exactly how we are going to put them into practice.

MY ACTION



plan

This section will help you turn your ideas into a clear, realistic plan. There's no perfect goal. What matters is choosing something that works for you. Select one area of the BTF cycle to get started.

BREATHING | THINKING | FUNCTIONING

WHAT DO I WANT TO ACHIEVE?

What would this area of the BTF cycle help me achieve in my day-to-day life?

(e.g. feel more in control, walk further, feel less anxious)

WHERE AM I NOW?

What am I currently doing towards achieving this (if anything)?

How is this different from what I'd like to be doing?



MY GOAL

Review my progress on:

What am I going to do?

When will I do it?

Where will I do it?

How often will I do it?

How long will I do it for?



START SMALL

What is a small first step I can take this week? How could I build this up over time?

REWARD

If I achieve my aim, I will treat myself with... (material/social/experience)



ONE STEP AHEAD

Making changes does not always come naturally; we might encounter stumbling blocks from time to time - and that is okay. We can increase our likelihood of success by planning for them in advance!

Think of situations that may make it difficult to follow through with your goal - and how you might manage them.

IF...

(anticipated challenge)

E.g. If I am starting a task that might tire me...

THEN I WILL...

(how I will manage this)

...then I will set a break reminder halfway through rather than continuing until I feel exhausted.

What would help you in achieving your goal?

Here are some ideas...

Set a recurring alarm on my phone, or sticky notes on the mirror

Ask my family/friend to remind me or do it with me!

Practise whilst the kettle boils

Keep what you need close to hand (e.g. desk, coffee table)

Add your own!



SUPPORT FROM FAMILY AND FRIENDS

It can be hard for those who have not experienced breathlessness to understand how it feels. However, **family and friends play a vital role in supporting someone with breathlessness.** Feeling confident in how to respond in difficult situations can make a real difference.

Some ways you can help someone with breathlessness:

- **Have some strategies ready** to help them stay calm and manage their breathing
- **Be confident when supporting them**
- Make sure you **look after your own health too!** If you are well you can provide better help and support

If you want to **get an idea of what breathlessness feels like** for the person you support you could try doing the following:

- Take a deep breath in and then breathe out half way. Then breathe in again. Now breathe at that level for a few more breaths.
- **OR**
- Take a deep breath in and hold it as long as you can. What does it feel like?

Now imagine you had to go up some stairs breathing like that. This is what breathlessness can feel like.



“

“By keeping calm, not fussing but being ready to help when asked”

“Learn the signs for when things are getting worse and prompt me to use the strategies that work for me””

People who helped design this intervention described how family and friends can help them manage their breathlessness

USEFUL INFORMATION & SUPPORT



[CARERS WALES](#)

Help for unpaid carers with expert information, advice and support



[SUPPORTING
SOMEONE WITH
BREATHLESSNESS](#)

A source full of **help and advice made for family and friends** of people with breathlessness (sometimes called “carers”). Mainly for people with COPD or cancer, but also resources suitable when supporting people with other illnesses.



[ASTHMA + LUNG UK](#)

Practical help for people caring for someone with a lung condition - from supporting the person you care for, to looking after yourself



[BRITISH HEART
FOUNDATION](#)

Practical help for people caring for someone with a heart condition - care is about you and the person you are supporting



[EDUCATION
PROGRAMMES FOR
PATIENTS](#)

Caring for Me and You (Course for Carers) 6-week course consisting of one 2.5-hour session each week. Helps adults who cares for someone with a long-term health condition to maintain and improve their quality of life through self-management.

LIVING WITH BREATHLESSNESS

This manual has been co-designed as part of the development of an All-Wales Community Breathlessness Pathway led by the Respiratory Network in NHS Wales Performance and Improvement.

It focusses on the things that people who are living well with breathlessness said it would have been helpful for them to know earlier. It aims to provide a foundation of knowledge and skill from which people experiencing breathlessness can then explore and access further support to enable them to live well.

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