1. The breathing thinking functioning (BTF) approach

The information given below is designed to help you manage your stable long-term breathlessness. If your breathing is getting worse, or you are experiencing breathlessness as a new feeling, it is important to seek medical advice from your GP.

PATIENT INFORMATION

Introduction

Breathlessness can be a difficult symptom to live with, but there are ways you can reduce its impact on your life. Sometimes, the ways we try to cope can unfortunately worsen the feeling. An important first step is to understand how breathlessness develops. This understanding can then lead to you finding ways to help your breathing.

The breathing, thinking, functioning model

The sudden and distressing sense of breathlessness is very useful when there is an immediate threat to survival, such as suffocation. A threat to survival needs to cause a rapid emotional response, such as terror, that leads in turn to a coping behaviour; such as breathing guicker and deeper, and running away. However, when people have chronic conditions that

affect the heart and lungs, this coping behaviour is less helpful and can cause development of emotions and behaviours that actually make the breathlessness worse.

The control of breathing is complex, and so too are the mechanisms which cause us to feel breathless. How the feeling of breathlessness is created is not yet fully understood. However, we know that breathlessness can impact on our thoughts, the way we breathe, and how we go about our daily activities.

We have highlighted these three areas as 'Breathing', 'Thinking', and 'Functioning'. In each of these areas, specific unhelpful emotions or behaviours develop and lead to three linked vicious cycles that prolong and worsen the feeling of breathlessness. The rest of this leaflet will go through each of these cycles with suggestions of things that can help.



moving and breathing become less fit

Becoming less active Getting isolated Needing help with daily activities



Thinking

Anxiety distress Feelings of panic



1. Breathing

Being breathless can often lead to the development of an inefficient breathing pattern. We feel like we need to 'get more air' so take big breaths in. We tend to pant, with small breaths coming in and out of only the top part of our chest, with our shoulders hunched. The muscles that support breathing (see Leaflet 2), particularly around your neck and shoulders are over-used in an attempt to pull more air in. This increases the effort of breathing and makes it less efficient.

In conditions like chronic obstructive pulmonary disease (COPD), there is not enough time for the lungs to empty when breathing fast. The next breath in starts before the lungs have fully emptied. This causes breaths to stack on top of each other, which makes the chest over-expanded and makes the breathing feel even less comfortable. This leads to an increase in the effort needed to breathe and makes recovery longer.

There are things that can help improve breathing. These include breathing techniques, cooling the face with a fan or cold flannel, and finding a comfortable position.

Things that can be helpful include learning to relax, gradually slowing your breathing, and finding a calm state of mind.

2. Thinking

Feelings of breathlessness almost invariably lead to a sense of anxiety or panic. The areas of the brain involved in the feelings of breathlessness also process our emotions. Feeling anxious or frightened will directly increase breathlessness.

This well-recognised vicious cycle can lead to panic, and faster breathing. When we are anxious it increases muscle tension, which increases the effort of breathing.

3. Functioning

Breathlessness is an unpleasant sensation. Therefore, it is natural to try to avoid it by reducing our activity levels. However, this leads to all our muscles becoming weaker. These weakened muscles use oxygen less efficiently and are not able to do their job as well, which makes the breathlessness worse. Our family and carers try to help by doing the activities that we might otherwise have done, thereby further reducing our activity.

It can help to understand that getting moderately breathless by being active is not harmful and can actually improve breathlessness over the longerterm. Regular exercise or walking more can also help.

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For more information

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2. Hand-held fan

The information given below is designed to help you manage your stable long-term breathlessness. If your breathing is getting worse, or you are experiencing breathlessness as a new feeling, it is important to seek medical advice from your GP.

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Will using a fan help my breathlessness?

When breathless you may instinctively go to an open door or window to 'get some fresh air'. In a similar way, a cool draught of air from a hand-held fan can reduce the feeling of breathlessness. The fan can therefore be seen as a 'portable breath of fresh air'.

The following may also help ease breathlessness:

- A cool flannel or cool water mist spray to the face.
- Opening windows, for example in a car
- Desktop or floor standing fans

How does facial cooling ease breathlessness?

Research has shown that cooling the face with a fan is effective at reducing breathlessness. It is thought that cooling the cheeks, nose and mouth areas sends a message to the brain which reduces the feeling of breathlessness.

How should I use the hand-held fan?

- Adopt a comfortable position that eases your breathlessness.
- Hold the fan approximately 15 centimetres or 6 inches away from the face.
- Aim the draught of air towards your face and move the fan slowly side to side so the draught covers the nose, mouth and sides of the cheeks.
- Use it until you feel your breathing ease.

Fans with three or more rotating blades seem to be most effective as the airflow is stronger. Some people have to use the fan for just a minute, others for 10 minutes, before they feel their breathlessness ease.

The fan can be used at the same time as nasal oxygen. People using face mask oxygen have commented that cooling the cheeks, neck and upper chest with the fan helps to ease their breathing.

When should I use the fan?

You can use the fan whenever you feel breathless. Keep the fan in your pocket when out and about so you have it to hand when needed. Keep a hand-held fan by your bedside so it is in easy reach if you wake at night.

You may find it helpful to use the fan with other breathlessness management techniques such as positioning, breathing techniques, relaxation and mindfulness. Other leaflets in this series provide further details.



Reference

Galbraith S, Fagan P, Perkins P, Lynch, A & Booth S (2010) Does the use of a hand-held fan improve chronic dyspnea? A randomized, controlled, crossover trial. Journal of Pain and Symptom Management Vol 39, Issue 5, pp.831-838.



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3. Breathing techniques to ease breathlessness

The information given below is designed to help you manage your stable long-term breathlessness. If your breathing is getting worse, or you are experiencing breathlessness as a new feeling, it is important to seek medical advice from your GP.

PATIENT INFORMATION

Muscles involved in breathing

The diaphragm

The main muscle of breathing is the diaphragm. This is a large flat sheet of muscle covering the base of your rib cage. As you breathe in, it moves down to help draw the air into your lungs, and your tummy rises. When you breathe out, it relaxes, returning to its natural dome shape, and allowing your tummy to rest back in. The diaphragm muscle does not tire easily.

Breathing accessory muscles

There are many muscles around your neck, upper chest and shoulders with the role of moving your neck and arms. However, when you are breathless, these muscles can pull on your ribs to help with breathing. These muscles are therefore called breathing accessory muscles.

It is normal to use these muscles for short periods of time when very breathless, however; they are not designed to help with breathing for long periods. They require extra energy and effort to use, and fatigue far quicker than the diaphragm.



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When used unnecessarily, these muscles can unhelpfully focus the breathing to the upper chest, making the breathing pattern inefficient. With prolonged overuse they may become tight, stiff and sore.

It is normal to use your breathing accessory muscles when breathless, but also important to relax and 'switch them off' once the breathlessness episode has passed. Try to focus your breathing movement on your tummy (diaphragm) as much as possible and keep your breathing accessory muscles in 'reserve'.

Breathing techniques

Relaxed tummy breathing

When to use

Relaxed tummy breathing may help you recover quicker from breathlessness after activity. It may also help your breathing to settle if you feel panicky. You may wish to use this breathing method with the hand-held fan (Leaflet 2) and a position to ease breathlessness (Leaflet 4).

How it works

Relaxed tummy breathing is sometimes known as breathing control. The aim is to move from fast, upper chest breathing to relaxed, slow tummy breathing. This breathing technique helps to make your breathing as efficient as possible by focusing on breathing from your diaphragm, with the upper chest relaxed.



Breathing from the tummy often does not come naturally. You should therefore practise relaxed tummy breathing when you are not breathless for 10 minutes at a time, at least twice a day. This will help you master the technique.

Before practising, make sure you are in a comfortable position, with your head and back supported and your shoulders and upper chest relaxed. Place one hand on your tummy. Feel the tummy rise and expand as you breathe in and relax down as you breathe out. Breathe gently when practising; there should only be a slight movement of your tummy at rest.

'Breathe low and slow, relax, let go'

If you have a tendency to breathe with small, fast breaths from the top of your chest you may find taking slower, deeper breaths from your tummy helps to ease breathlessness.

Breathe a rectangle

When practising relaxed tummy breathing some people like to imagine a wave, as pictured above. Other people may prefer the image of a rectangle. Wherever you are, there is often a rectangle to be seen, whether this is a book, a TV, computer or tablet screen, a door, window, table top, or even a picture on the wall.







Recovery breathing

When to use

Use recovery breathing when you feel extremely breathless or panicky and you are unable to use relaxed tummy breathing.

How it works

Recovery breathing allows more time for the air to leave your lungs as you breathe out, therefore creating more room for the next breath in. The aim of recovery breathing is to calm your breathing until you can breathe smoothly and quietly from your tummy again. For further information on positions to ease breathlessness see (Leaflet 4).

The 3 Fs of recovery breathing

- Fan
- Forward lean position
- Focus on long or relaxed breaths out

People with chronic obstructive pulmonary disease (COPD), emphysema or asthma may prefer long breaths out, perhaps through pursed lips. People with other conditions may find relaxed breaths out suit them better.

Pursed lips breathing

Some people find breathing in through the nose and out through narrowed lips helps to ease their breathlessness. This technique tends to help people who have conditions such as chronic obstructive pulmonary disease (COPD) or emphysema. People who find this technique beneficial often use it instinctively without realising they are doing it.

Pursed lips breathing helps to support the airways to open, therefore allowing the air to leave the lungs more easily. This creates more room for the next breath in. You can use pursed lips breathing at the same time as relaxed tummy breathing or recovery breathing.

General advice

- Avoid breath holding during activities e.g. climbing stairs or bending
- Try to 'blow as you go', which means breathing out on effort, e.g. blow out when bending, lifting, reaching or standing up from a chair
- Try to avoid rushing
- Try pacing your breathing with your steps e.g. take a breath in and out on each step when climbing the stairs

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4. Positions to ease breathlessness

The information given below is designed to help you manage your stable long-term breathlessness. If your breathing is getting worse, or you are experiencing breathlessness as a new feeling, it is important to seek medical advice from your GP.

When to use

These positions may help you to ease your breathlessness at rest, and after activity. The most commonly used positions are shown, however; you may find other positions of ease which are not pictured. Experiment with and modify different positions until you find what works best for you.

How positioning helps to ease breathlessness

The positions in this leaflet place the arms so the breathing accessory muscles are in a better position to help with breathing. Leaning forward may also improve the movement of your diaphragm, the main muscle of breathing. For more information on muscles of breathing see Leaflet 3.

Resting positions

The following positions may help if you are breathless at rest, or if you are feeling very tired or exhausted.



Make sure you are fully over on your side. Resting your upper arm on a pillow may also help.



Relax down onto the pillows as much as possible. Having your legs apart may also help.



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Positions to ease breathlessness following activity

The following positions may help to ease breathlessness after you have been active. With all positions, try to relax the hands, wrists, shoulders, neck and jaw as much as possible. Experiment with your arm position. Does your breathing feel easier with your hands behind your head or back?

There is no one position which suits everyone, nor one position which people with a particular condition prefer. Experiment with different positions and find what works best for you.



















Use of walking aids

Some people may notice that they are able to walk further and feel less breathless when pushing a supermarket trolley around the shop. Pushing the trolley enables you to maintain a 'forward lean position of ease' while walking.

In a similar way, using a walking frame may enable you to walk further and feel less breathless, as well as providing a portable leaning post when you wish to stop to rest. A walking stick can also provide a portable leaning post. When walking outdoors, people often prefer to use a three- or four-wheeled walker. Some walkers have a seat so you can sit to rest, others may have a handy storage compartment. When using a walker with a seat, always put the brake on before you stop for a rest.



Gutter frame



Rotator frame



Walking stick

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5. Thinking - Managing thoughts about breathlessness

The information given below is designed to help you manage your stable long-term breathlessness. If your breathing is getting worse, or you are experiencing breathlessness as a new feeling, it is important to seek medical advice from your GP.

How the brain responds to breathlessness

We become breathless when we exercise or when we over exert ourselves and it is quite normal to experience breathlessness from time to time. Breathlessness is a very common symptom in longterm conditions such as COPD, heart failure, and cancer.

The fight or flight response

Sometimes, sudden and unusual breathlessness can be a sign that something is wrong. Our brain responds to this by triggering our survival or 'fight or flight' response to manage whatever is going on. This is a very helpful response to help to protect us if we are in a dangerous situation. However, when we are not in a dangerous situation, such as being breathlessness due to a long-term condition, this response is less helpful.

It is normal for our bodies to experience some degree of anxiety. When this happens, the body is preparing itself to react (known as 'fight or flight'). Imagine that you are crossing a road, when you notice a car coming towards you. It is the fight or flight response that helps you to get out of the way. So some feelings of anxiety are useful. When we become anxious, the eyes and ears sense a threat and alert our brain. This then stimulates the adrenal glands to produce adrenaline and release it into our blood. It reaches the heart, lungs, and muscles and causes the reactions needed to help us fight or flee.

Because of your body responding like this when you feel anxious, you might experience some of the following:

Body – tensed muscles, rapid heartbeat, difficulties breathing, chest pains, sweating, dizziness, nausea, dry mouth, blurred vision, or the need to go to the toilet.

Thoughts – unhelpful thinking such as imaging the worst, worrying about looking foolish, worrying about 'going mad'.

Actions – avoiding situations or people which make you feel anxious, poor concentration, aggression, irritability, sleep problems.

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Breathlessness and anxiety

Unhelpful thoughts about breathlessness can often lead to a vicious cycle of anxiety and avoidance, as described in Leaflet 1. When anxiety begins to affect life to an extent that you are experiencing unpleasant symptoms regularly, and unable to do what you want to do, it is helpful to understand the reasons why this is happening, so that you are able to manage these symptoms.

The good thing is that whilst you might not be able to change what is happening in your heart or lungs, you can change the way you think and feel about breathlessness and change behaviours. This, in turn, can help you to do more of the things you would like to do, and feel more in control of breathlessness when it happens.

One person said "I'm in control of what's happening to me, you know, how I feel mentally, not necessarily physically all the time, but certainly mentally I've got a much different attitude".

Some people find it re-assuring to know that usual day-to-day breathlessness on exertion is not harmful. There are ways to manage breathlessness which help you to recover more quickly, or help you not to get so breathless.

Common thoughts about breathlessness

Feeling breathless, or seeing someone you care about being breathless, can be very unpleasant and frightening. If you have had any past frightening experiences of breathlessness, this can also impact on the level of breathlessness you are feeling now. Understanding why breathlessness happens, how the body responds and how you can control these responses can be a very useful way of managing your breathlessness. Talking through your thoughts to help you to understand your body's response can help you to manage your breathlessness.

Breathlessness can also make people feel angry, frustrated, or worried. How does breathlessness make you feel? It is very helpful to talk about how breathlessness makes you feel. This will also help those around you to understand a little more what you are experiencing and will also enable people to help.

Here are some common thoughts or "misperceptions" which people often have about breathlessness with an explanation which may help to relieve some concerns.

Common thought or "misperception"	Alternative Explanation	
"I need more oxygen"	Breathlessness is not always related to the level of oxygen in your blood, and oxygen does not always relieve breathlessness. Using the fan and practising relaxed tummy breathing will help your breathing.	
"I won't be able to get my breath back"	Making yourself moderately breathlessness by being active is not usually harmful and you will recover your breathing.	
"I'm going to pass out"	If you become extremely breathless, you tend to breathe more quickly and shallowly. This is a very inefficient way of breathing and can make you feel light-headed. Practising relaxed tummy breathing can prevent this from happening.	
"I'm going to have a stroke or heart attack"	The fight or flight response can cause your heart to beat faster, tightness in your chest and other symptoms. Understanding the body's response to breathlessness and anxiety can help to take away these worrying thoughts.	





How can I control my anxiety?

Recognise what triggers your anxiety

- Mention how you are feeling to health care professionals
- Try to identify problems and address them one at a time
- Try not to worry about future events, concentrate on the present
- Learn a way of relaxing that works for you
- Use a photo / picture that helps you to think about relaxing thoughts

Thoughts about breathlessness can influence how you feel and behave. Your response to a situation also impacts on how you think and feel. It can be helpful to think about a situation where you felt anxious. Think about what thoughts were going through your mind.

- What feelings did you have?
- What physical symptoms did you notice?
- How did you behave in that situation?
- Then gently ask yourself what could I have done differently?
- Is there an alternative and more realistic thought or response to the situation?

Talking these situations through with a health care professional can help you to change your responses to situations. This can help you to feel less anxious and less breathless. Relaxation techniques can help to manage the physical symptoms of anxiety. There are some techniques to try in Leaflet 6: Relaxation.

Having a plan of action

Many people find it helpful to have a plan of action written down to refer to in times of breathlessness, particularly if you have feelings of anxiety of panic. This action plan may be as simple as a few basic prompts to remind you what to do. It can re-assure you that you have had this feeling before and that you will recover your breathing.

Action Plan for Breathlessness

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

I am going to lean forward I am going to use my fan Focus on gently breathing out

I can do this – I am doing it now I don't need to be frightened – I am OK

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6. Relaxation

The information given below is designed to help you manage your stable long-term breathlessness. If your breathing is getting worse, or you are experiencing breathlessness as a new feeling, it is important to seek medical advice from your GP.

Learning to relax

Breathlessness can often cause anxiety and feelings of panic and Leaflet 5: Managing thoughts about breathlessness, explains the reasons for this in more detail. Anxiety tends to make the feeling of breathlessness stronger, which in turn leads to more anxiety. It is important to remember that breathlessness in itself is not harmful and you will recover your breathing on resting. It is also possible to try to control the level of anxiety you are feeling and relaxation is one way of helping with this. Relaxation is a useful skill that you can learn. This leaflet will go through some ways to help you to learn how to relax.

Preparing for relaxation

Relaxation is not always easy, but the more you practice the easier and more effective you will find it. Try to allow yourself to have some time each day to practice your relaxation exercise. Tell the people with whom you share your home that you will need at least 20 minutes every day to practice relaxation undisturbed. Try to ensure the light and temperature of the room is at a comfortable level.

Positioning

- Check your posture.
- Ensure that your neck, shoulders and arms are as relaxed as possible.
- Sit or lie with your legs uncrossed.
- Try to have your elbows supported at your side on cushions, or on the arm of the chair.
- Let your shoulders and arms sink down into the cushions.

Try to close your eyes. If this is too difficult, choose a spot in front of you, on the wall or floor, and keep your eyes fixed on this point. When you are more relaxed it will be easier to keep your eyes closed.

When you finish your relaxation exercise

- Become aware of the real surroundings by listening to the sounds around you.
- Be aware of how relaxed you feel.
- Start to move very gently by stretching your arms and legs before moving from your position.

Relaxation exercises

These might be something that you can try with a friend or relative together. It might be helpful to have someone read these out to you for the first few times until they become familiar.

A. Visualisation

Visualising a relaxing scene can often help us to feel more relaxed. It could be your favourite place, a walk that you know, a garden, or the beach. It could also be somewhere from your imagination. Somewhere that makes your feel happy and secure, but not places that evoke bad or sad memories. Sometimes visualising colours, and images associated with these colours can also be relaxing. Here are some examples that you might like to try.

Relaxation using colour

- Make yourself comfortable
- Think about the colour green
- Concentrate on green all around you
- The green of spring grass on cliff tops

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Cottage by the sea

First make yourself completely comfortable. Take yourself in your imagination to the garden of a cottage by the sea. You are sitting in a comfortable garden chair with plump cushions. All around you are the flowers of the cottage garden and you have a wonderful view out to the sea. In the distance you hear the rhythmic beating of the waves on the beach below.

After a while, you get up from your chair and walk across the brilliant, sun-warmed grass of the lawn. You make your way down a flight of steps which lead directly onto the wide, smooth, sandy beach. You take off your shoes, and walk over the pale, warm, dry sand down towards the water's edge. Feel the warmth coming from the sand beneath your feet, feel the sand between your toes.

As you get nearer to the sea, the sand becomes smooth, hard and damp. Now you can come to the water's edge. You watch the sparkling foam running up the beach towards you, and you let the warm, shallow water flow around your ankles. You walk along the water's edge, enjoying the rhythmic swish of the waves swirling around your ankles, the sunlight dancing on the water.

Now you turn back towards the cottage. You walk back over the smooth, hard sand, over the pale, powdery sand. You go up the steps which lead back onto the lawn. The grass feels cool and refreshing to your warm, bare, sandy feet. You sit down in your chair again, allow your eyes to close and bask in the warmth of the late afternoon sun.

Enjoy this scene for a few minutes. Then begin to bring your attention back to the room in which you are in. Become aware of the feeling of relaxation that you are bringing back with you. An in your own time open your eyes.

Tranquillity exercise

- Think about the word tranquillity
- Say tranquillity three times in your mind
- Think about a colour associated with tranquillity
- Imagine all the things that 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. ¹

B. Letting go of thoughts

- Spend a few moments taking control of the pace and regularity of your breathing.
- Close your eyes and imagine that you are sitting on the bank of a river.
- You are warm and relaxed, and able to breathe freely.
- You see many leaves slowly drifting downstream.
- When a thought or feeling comes into your mind, try to see this as a leaf and let it drift away from you, and disappear.
- When it's gone, return to gazing at the river waiting for the next leaf to float by with a new thought.
- Try not to think about the contents of each leaf. Just observe it and then let it go.
- Sometimes the same leaf may come up many times or several leaves will seem related to each other, or the leaves may be empty. That's okay.
- Don't allow yourself to be concerned with these thoughts. Just watch them pass in front of your mind's eye.



¹Ref: Thew, M, (2008) 'Portable' Relaxation for Every Day Living' In: Thew, M & McKenna, J. (Eds) (2008) Lifestyle Management in Health and Social Care. Oxford: Wiley Publishing





C. Body scan

- Begin by focusing your attention on your feet, trying to release the tension in your muscles.
- First think of your toes, working up through your ankles to your calves and shins, over your knees and along your thighs.
- Notice how loose your legs feel now.
- Become aware of your tummy and then your chest. Feel the tension flowing out of your body.
- Now think of your shoulders travelling down to your elbows, through your forearms, and into your wrists, hands and fingers.
- Become aware even of your fingertips.
- Notice how loose your arms feel now.
- Next, focus your attention on your lower back and pelvis. Try to release any tension you are feeling here.
- Allow this feeling of looseness rise up your back, to the back of your chest and shoulder blades
- Continuing up into your neck and scalp, to the crown of your head.
- Slowly begin to focus on your forehead and move down to your jaw.
- Imagine that you have a giant paint brush, sweeping over your body, following the same route and creating a feeling of calm and relaxation.
- Feel that every part of your body is relaxed.



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7. Mindfulness

The information given below is designed to help you manage your stable long-term breathlessness. If your breathing is getting worse, or you are experiencing breathlessness as a new feeling, it is important to seek medical advice from your GP.

Mindfulness

When we are worried or stressed, perhaps by a chronic illness, family worries, financial worries, or other difficult circumstances, it is very easy to spend most of the time thinking about the past, dwelling on things that have gone wrong or worrying about the future and being fearful about things that might happen.

The body responds to worry and stress by increasing the production of stress hormones which lead to the fight or flight response as described in Leaflet 5: Managing Thoughts. Increasingly, research has suggested that reducing the level of stress hormones can help us to cope better and feel better. One way of reducing the level of stress that we feel is by learning how to practise a technique called 'mindfulness'.

Mindfulness is when we are able to adopt a 'mindful awareness of the present'. Most people are aware that if they see (or think about) something they enjoy, such as chocolate, even the very anticipation of eating it can bring pleasure. The explanation for why this occurs lies in the internal chemistry of the brain; the experience of pleasure results from chemical changes in the brain.

The change in the chemical reaction in the brain can also reduce anxiety - this is the way that anxietyreducing drugs work. By practising mindfulness we can reduce the amount of stress we feel and the impact of the stress on the brain. However, it does take a bit of practice. There are a range of mindfulness options available, such as books, CDs, websites or apps, such as Smiling Mind which can be used with the same regularity as you might take a tablet. Initially, we would suggest that you chose one and use it twice a day. It is most helpful when you can be in a quiet place and not disturbed. We recommend that you use at a time when you can arrange not to have to answer the telephone and when it is unlikely that you will have to answer other people's needs. It is fine to use it late at night, but if you fall asleep quickly after starting to use it, it will not give you as much training in experiencing the mindfulness that will help you manage stressful situations.

We have found that some people like to use it with their husband, wife, partner, child or carer so that they can both get the benefit from it. You may prefer to use it separately.

After a couple of weeks of using your chosen mindfulness program regularly, you may start to notice that worries or concerns seem to come into your mind without making you feel anxious and disturbed.

You may also find that you start to relax and get more pleasure from the simpler things in your life – music, trees blowing in the wind, a friend's smile. If at the end your chosen mindfulness program you would like to take mindfulness training further, please do not hesitate to ask your GP how you can do this.





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8. Managing your energy levels

PATIENT INFORMATION

The information given below is designed to help you manage your stable long-term breathlessness. If your breathing is getting worse, or you are experiencing breathlessness as a new feeling, it is important to seek medical advice from your GP.

Why do I feel more tired?

Tiredness can be a common symptom in many longterm conditions, especially when you are experiencing breathlessness too. Tiredness makes you feel less motivated to keep active, which means that often you avoid activities. This can lead to you having less energy, which in turn can make you more tired. When this behaviour becomes a habit, the cycle can often be difficult to break. When you have a condition that affects your lungs, the extra effort of breathing uses up more energy. We cannot necessarily take away your tiredness completely, but there are a number of ways in which you can manage it. These, in turn, may help you to continue to do some of the things that you would like to do.

What can I do to help my energy levels?

- Understanding why you have less energy
- Understanding energy levels
- Monitoring energy levels
- Conserving energy
- Keeping active
- Making life easier

Energy levels

Learn to understand your energy levels and try to get to know where your limits lie. Think about how much energy you have to use each day. Some people imagine having a jug of energy, or liken their energy levels to a battery. Consider what you would like to use your energy on, but always leave something in the jar so that it is never empty. Even if you make the best plans, there is always a chance that something unexpected might crop up that uses more energy. So it is always good to keep some energy in reserve. Imagine your energy in terms of having a "jug of energy". Some activities will top up the energy in your jug and other activities will use up the energy in your jug. What would you like you use your energy on? Try to keep 20% of your energy in your jug at all times.

Monitoring your energy

It is often useful to keep a track of the activities that you do within your day and week and monitor how you are feeling at different times. This might enable you to see if there are any patterns and if there are any times of the day and week which are better or worse for you. You can use the weekly diary at the end of this handout for this purpose.

Imagine your energy in terms of having a "jug of energy". Some activities will top up the energy in your jug and other activities will use up the energy in your jug. What would you like you use your energy on? Try to keep 20% of your energy in your jug at all times.



It can be helpful to note down what kind of activities give you energy "energy givers" and what activities drain your energy "energy depleters" and see how many of these activities you do in your day or week. This may also help you to make changes to help with managing your energy.

Try to avoid all or nothing or "boom and bust" patterns of activity. Overdoing it leads the body to require more recovery time. Try to hold back on a good day to enable you to do more on a less good day.



Conserving your energy

It is important to keep a balance between activity and rest and alternate the type of activities that you do in your day so that you are not trying to do too many strenuous things all at once. Use your energy on things that you really want to do so this means deciding on what your priorities are.

It is also important to try not to use up any energy unnecessarily and there are many ways in which you can do this. You might do things in a slightly different way which take less effort, or ask someone else to help. When thinking about how to save your energy, it might be useful to consider the following things.

Planning - Consider which times of the day are best for you and plan activities around this time. Try to space activities out during the week and not concentrate all activities into one day.

Pacing - Slow down your activities as this will take less energy. Slow down when you talk, laugh, eat or cough – these actions can affect your breathing pattern. Break down your activities into smaller tasks that are more manageable. Allow yourself some time each day to try to relax. Remember that it is better to take a little extra time to complete one task and be able to continue, than to finish one task quickly and feel too tired to continue. Prioritising - When you have a fixed amount of energy to use, it is worth having a think about which activities are most important to you. Sometimes it can help to write everything down that you would like to or need to do. Then think about whether these activities are high, medium or low priority for you. When planning what activities you are going to do, concentrate on the high priority things first and then work your way through to the medium priority activities. It might be that you don't get round to doing the low priority activities or ask someone else to do these. You might want to use the prioritising sheet at the end of this handout for this purpose. Positioning - Try to avoid too much bending and twisting which can be tiring. Don't sit or stand in the same position for too long without changing your position. Think about trying to organise your home so that things are easily accessible (for example in the kitchen, have frequently used items to hand). It is less effort to push, pull or slide objects so try to avoid carrying heavy things.

Permission - If you are placing high expectations on yourself, it is worth having a think about allowing yourself to do things in a different way that helps with your energy levels. Try to be patient with yourself and give yourself time to do things. Whilst it is usual to reflect back at times, it is not so helpful to think about the things that you could do or the way in which you could do it before your energy levels were limited. Try to recognise the things that you are achieving.

How active should I be?

Regular exercise has also been shown to help with energy levels and prevents your muscles becoming weaker. It is important to stay as active as you can. This will prevent your muscles becoming weaker. A little regular gentle exercise each day can make all the difference.





How to make your life easier

At home

- Keep things you use frequently downstairs and close to hand
- Have a telephone point close to your bed or armchair
- Consider using a trolley or carrier bag for shopping
- When bathing or shaving, make sure you gather all you need before you start

Walking and climbing stairs

- Pace your breathing to your steps; breathe in over one step, breathe out over the next two steps
- Move at a comfortable pace and avoid holding your breath
- Use walking aids if they help you. You can discuss this with your physiotherapist or occupational therapist
- Stop and rest whenever you need to
- Have resting points at the top and bottom of the stairs
- Use the handrail when climbing stairs, take the steps slowly, one at a time and stop to rest when you feel the need to

Eating and drinking

- Take frequent small meals, rather than one large one
- Eat smaller mouthfuls
- Avoid foods that are difficult to chew, add sauces when possible
- Drink sips of fluid frequently to avoid becoming dehydrated
- Consider using frozen vegetables / mixes or preprepared foods
- Freeze food left over to be used another day
- Try to cook vegetables together to avoid using lots of saucepans
- Use a vegetable basket to drain water rather than lifting heavy pans

Sleeping

- Maintain a comfortable temperature in the bedroom
- Try not to sleep for too long periods get just as much sleep as you need to be refreshed
- Try to get into a routine of going to bed and getting up at the same time
- Try to eliminate noise in the bedroom
- Activity or exercise promotes a balance between activity and rest and may assist with sleeping
- Avoid drinking caffeine based drinks / food before going to bed
- If you are not sleeping at night, try not to sleep during the day. If you need to sleep during the day, try to keep this down to a short nap rather than a prolonged sleep





Weekly diary

List the activities that you have carried out and then rate your level of tiredness on a scale of 0-10 with 0 being not tired at all and 10 being extremely tired.

DAY	ΑCTIVITY	SCALE
MONDAY		
TUESDAY		
WEDNESDAY		
THURSDAY		
FRIDAY		
SATURDAY		
SUNDAY		





Prioritising table

Think about the activities that you do and try to prioritise these into what you consider to be high, medium and low priorities (i.e. put the tasks most important to you in the high priority category).

ACTIVITY	HIGH	MEDIUM	LOW

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