Managing Breathlessness 5:
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.

How the brain responds to breathlessness
We become breathless when we exercise or when we overexert ourselves, and it is quite normal to experience breathlessness from time to time. Breathlessness is also a very common symptom in long-term conditions such as chronic obstructive pulmonary disease (COPD), heart failure and cancer.

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 breathless due to a long-term condition, this response is less helpful.

The fight or flight response
It is normal for our bodies to experience some degree of anxiety. When this happens, the body is preparing itself to react, which is 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 the body responds 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 imagining 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.
**Breathlessness and anxiety**

Unhelpful thoughts about breathlessness can often lead to a vicious cycle of anxiety and avoidance, as described in our leaflet ‘Managing Breathlessness 1: The breathing thinking functioning (BTF) approach’. When anxiety begins to affect life to such an extent that you are experiencing unpleasant symptoms regularly and are unable to do what you want, it is helpful to understand the reasons why this is happening so that you can manage these symptoms.

The good news is that while 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. This in turn can help you to do more of the things you would like to do, and help you feel more in control of breathlessness when it happens.

Some people find it reassuring 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 useful way of managing 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 about what you are experiencing and will enable others 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:

<table>
<thead>
<tr>
<th>Common thought or ‘misperception’</th>
<th>Alternative explanation</th>
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<tbody>
<tr>
<td>“I need more oxygen”</td>
<td>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.</td>
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<tr>
<td>“I won’t be able to get my breath back”</td>
<td>Making yourself moderately breathless by being active is not usually harmful and you will recover your breathing.</td>
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<tr>
<td>“I’m going to pass out”</td>
<td>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.</td>
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<tr>
<td>“I’m going to have a stroke or heart attack”</td>
<td>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.</td>
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</tbody>
</table>
How can I control my anxiety?
- Recognise what triggers your anxiety
- Mention how you are feeling to healthcare 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 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 was 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 healthcare professional can help you to change your responses. 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 ‘Managing Breathlessness 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 or panic. This action plan may be as simple as a few basic prompts to remind you what to do. It can reassure you that you have had this feeling before and 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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Useful sources of information

Contact us

Interstitial Lung Disease Service

Phone: 020 7188 8635 (Monday to Friday, 9am to 5pm)
Email: gst-tr.khpildservice@nhs.net

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

Phone: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

Phone: 020 7188 8801 (PALS)  Email: pals@gstt.nhs.uk
Phone: 020 7188 3514 (complaints)  Email: complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch.

Phone: 020 7188 8815  Email: languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

Phone: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

Website: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy’s and St Thomas’ NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

Phone: 0800 731 0319  Email: members@gstt.nhs.uk  Website: www.guysandstthomas.nhs.uk/membership