

Breathlessness and anxiety in adult congenital heart disease (ACHD)

This leaflet explains more about breathlessness and anxiety in ACHD, including useful tips on how to deal with feeling anxious. If you have any questions, please speak to a doctor or nurse caring for you.

Introduction

Not being able to catch your breath can be very frightening. Having ACHD might mean that you worry more than most people about becoming breathless. Being anxious can make breathlessness feel worse, so learning to relax and slow down can help you build your confidence and worry less.

Understanding how anxiety affects your body will allow you to deal with it better and stay safe.

How you can avoid feeling breathless

It is important that you know what is a **safe exercise level** for you. You can learn how to overcome anxiety, which will help with breathlessness.

Over the years you will have learnt what you can do before you feel out of breath. However, this does not mean that you cannot or should not be doing more exercise. In fact, ACHD specialists often encourage patients to do more. Your consultant or nurse can give you detailed advice on how much exercise and which types of exercise are safe for you. Once you have established what is safe for you to do, feeling out of breath should not be so alarming.

"I used to get short of breath and be aware of my heart rate when walking and talking at the same time, or going up a significant number of stairs. These symptoms were affecting my day-to-day life and I was finding myself holding back on certain activities if I felt that it would cause me concern. I have discussed this with my ACHD team and was told that breathlessness is normal after exercise, and that exercise increases my heart rate. I believe that feeling better after exercising has helped me create a healthier lifestyle. I now have a healthier diet and have lost 8lbs over the last 8 weeks – I am near my recommended weight for my height. It is amazing how being able to exercise and not to worry about it has made such a difference to my everyday life."

Person with ACHD

“How much exercise is safe to do will vary from person to person. Generally, the activity should make you breathe more heavily than normal and you may feel your heart beating more quickly, but it should still allow comfortable speech. Once you know your limits, you can confidently exercise safely within them.”

Natali Chung, ACHD Consultant

What you can do to help yourself

Learn ways to deal with the anxiety

Most people who experience breathlessness (because of heart problems or other causes) can experience feelings of anxiety and panic at some point. For some people, this anxiety can be intense and seem overwhelming, but it **can be overcome**. The less anxious you are, the less breathless you will feel, and the easier it will be to cope when you do feel breathless.

You might find it useful to look at this leaflet with a healthcare professional and discuss which of the suggestions might work best for you.

Minds and bodies

Our minds and bodies affect each other in many ways. For example:

- when we are ill, we often feel low in mood
- you might have noticed ‘butterflies’ in your stomach when you are nervous or excited
- you may have seen a child who is no longer troubled by the pain from a grazed knee once they have been given an ice cream or a hug.

Understanding anxiety

The first step to overcoming anxiety is to understand it. Everyone experiences anxiety at some time. It is a normal reaction to feelings of danger and stress.

Anxiety can affect the body in many ways. The physical sensations you experience are not harmful, but they can be unpleasant and frightening, particularly if you do not know what is causing them. It is useful to be able to recognise these sensations so you can learn to work through them. You might want to tick the ones that apply to you on the list below:

- Pain or tightness in your chest
- Fast, shallow breathing
- Fast or pounding heart beat
- Feeling dizzy or faint
- Tense or aching muscles
- Headaches
- Sweating
- Stomach churning
- Needing to go to the toilet
- Trembling
- Pins and needles, or numbness

It is worth remembering that these sensations can be caused by anxiety, but that when they are caused by medical problems, for example a heart condition, they **can be made worse** by anxiety. You will probably feel more anxious at times when your health is worse.

Stress hormones, such as adrenaline, can often be the cause of the feelings of anxiety. These hormones are vital as they allow us to react quickly in emergencies, for example if we need to move quickly to avoid an accident. However, the increased levels of adrenaline might be troublesome when you do not need them.

The good news is that you can learn ways to counteract these feelings.

How anxiety can make breathlessness worse

When we are anxious, we think less clearly. This makes it harder to plan things. When we do not plan things, we tend not to pace ourselves very well and are more likely to get breathless. Thinking less clearly makes it harder to spot our usual triggers that cause breathlessness. It can also lead to a delay in taking action to reduce breathlessness.

Being anxious can make us tense our muscles which we might not realise we are doing. Tension in the muscles around the chest can make breathing feel much more difficult. The higher your levels of anxiety are, the more you tend to focus on not being able to breathe. This makes breathing seem much harder. Anxiety makes us breathe faster and less deeply.

When you are feeling anxious, you might think that it will get worse and worse, but anxiety does go away on its own, unless it is kept going by anxious thinking.

What can help?

Knowing what makes you breathless, and doing something about it. Sometimes it is clear what has made you breathless, such as going up the stairs too fast.

It is good to weigh up all of the solutions you can think of for the problem, and decide which you would like to try. If the first solution you try does not work, you can try another one.

In the case of getting breathless when you go up stairs, you might be able to find ways of doing things differently, such as walking upstairs more slowly or pausing halfway up. In this case, a long-term solution might be building up your fitness so that you find it easier to get up stairs.

Sometimes, there may not seem to be any reason why you are breathless. It may be that something else has caused the problem, such as a thought making you feel anxious.

Noticing your thoughts

How you think about a situation can affect how you feel and what action you take.

Many people with ACHD have very frightening thoughts when they are breathless, such as “I am going to die” or “I am not getting enough oxygen”. This might be an example of what we call ‘emotional reasoning’, which is thinking that if something feels very bad, it must be dangerous. If you have had thoughts like this, the fact you are alive and reading this is evidence that it was not true. It is important to know how to deal with frightening thoughts like this, as well as how to deal with your breathlessness. You could gently remind yourself “This is frightening but I’ve got through it before”.

Some thoughts are unhelpful. For example, if you think “I cannot cope with getting breathless”, you might not do any activity which makes you out of breath. This would leave you less fit and less confident. It would be more helpful to think “It is not nice to be breathless but, if I keep active, I will get more confident and handle the breathlessness. I will also get fitter, so I will not get breathless so easily”.

Another example of an unhelpful thought is “I can feel my heart beating. It is going to go out of control!” This might lead you to feel panicky, breathe rapidly and shallowly, monitor your heart beat, and so build up your anxiety. A more helpful thought would be “I can feel my heart beat, but that is normal. I am exercising within my ‘safe limits’ and so it is fine!”. This would help you to stay calm, and confident that you can control your breathlessness.

Try **not** to think that something might not work very well. For example, many people find that when you ask them not to think about a particular thing, it keeps on coming back into their minds. It is better to notice the thought, and to remind yourself that it is **just a thought**, and not necessarily a true one.

Distraction can help. Depending on the circumstances, you might distract yourself by getting up and doing something else, or talking to someone about a different subject. It can also help to **occupy your mind**. For example, you can think of girls’ names or a country beginning with every letter of the alphabet, or make a list of your top ten films of all time. If you worry a lot, it can help to sit down with a pen and paper for about 20 minutes a day and write down your worries, and put them off for the rest of the day.

Balanced awareness

Being aware of your body can help you to make wise choices. But over-awareness can make it hard to focus on other things. Over-awareness can mean that you miss out on fully enjoying the good things in life. It can also mean unnecessary worry and distress, which can make your symptoms feel worse.

It can help to **put your feet flat on the ground** and just notice how the ground feels underneath your feet. You could also try focusing on what you can see and hear in the world around you.

Learn to relax

Relaxing your mind and body can reduce the feelings of anxiety caused by high levels of adrenaline, and so make it easier to breathe. You may have been shown other exercises to help with your breathing. This one is specifically to help you relax:

- Breathe out first, then just let your body breathe in.
- Breathe as deeply down into your belly as you can, and do this as gently as you can.
- Breathe out first, then let your body breathe in gently through your nose, counting "One... two... three" in your head. Breathe as deeply down into your belly as you can, and do this as gently as you can. Pause a second, then breathe out through your mouth, counting "One... two... three... four". The counting protects you from fast, panicky breathing. Make sure you breathe out for one beat longer than you breathe in.

As you do this, you can keep track of your anxiety. Before you start, rate how anxious you are feeling on a scale of 1-10, where 10 is the worst you have ever felt. After a couple of minutes, rate it again. You will probably notice that it has come down to a more manageable level.

Reduce your stress levels

- Take time to do the things that you enjoy doing, and that help you relax your mind and body. Physical activity, at a level which is manageable for you, can be very helpful.
- Many people find that yoga reduces their anxiety in the long-term.
- Spending time with pets, or people whose company you enjoy, can be very soothing.
- Think about how you can make looking after yourself a priority.
- Learn not to take too much on, and to say 'no' to the things you do not have time for.

Build your confidence

- It is important to be sensible, but not too cautious.
- Doing the things which are most important to you will help you feel more independent and happier.
- If something seems impossible right now, try **breaking it down** into smaller steps and thinking about what help you might need, or how you might do it differently.
- It can help to slow down and do things at a relaxed pace, even if this is not what you are used to.

Know how to explain your situation

- Many people feel awkward or embarrassed about getting breathless in public. However, you can build your confidence with practice. The more confident you get, the less breathless you will be.
- You may worry about not having enough breath to explain what is happening.
- It can help to plan ahead what you can say, for example “I have a heart problem”, or what you can do, for example, point to your chest to show where the problem is.

Your family and friends

- Your family and friends may feel scared when they see you not being able to catch your breath. They might not know what to do.
- It is good to plan ahead for this, and to talk through what they can do to help.
- It is useful to be able to ask for help, but it is also good to build your confidence to do what you can for yourself.

Getting the information you need about your condition

If there is anything you are unsure about, do ask your doctor (or other health professional). Doctors are busy, but your appointment is your time to get the information you need.

Before the appointment, it can help to **write down questions** you would like to ask. In the appointment, it can be useful to **make notes** of the important things the doctor says, or to take someone with you to help you remember what was said.

You might be worried that the doctor will give you bad news, but the more you know about your condition, the more you can do to deal with it.

Useful sources of information

The Somerville Foundation, providing emotional and practical support for people born with a heart condition, **helpline:** 0300 015 1998 (answerphone at weekends), **w:** www.thesf.org.uk

British Heart Foundation have lots of useful information on their website, including advice on coping with breathing problems, **w:** www.bhf.org.uk

Contact us

If you have any questions or concerns about your breathlessness and ACHD, please contact the ACHD nurse specialist, **t:** 020 7188 9712, Monday to Friday, 9am-5pm. Out of hours, please go to your nearest Emergency Department (A&E).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** 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.

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

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.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** 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.

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

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

t: 111 **w:** www.111.nhs.uk

NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: www.nhs.uk

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t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

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