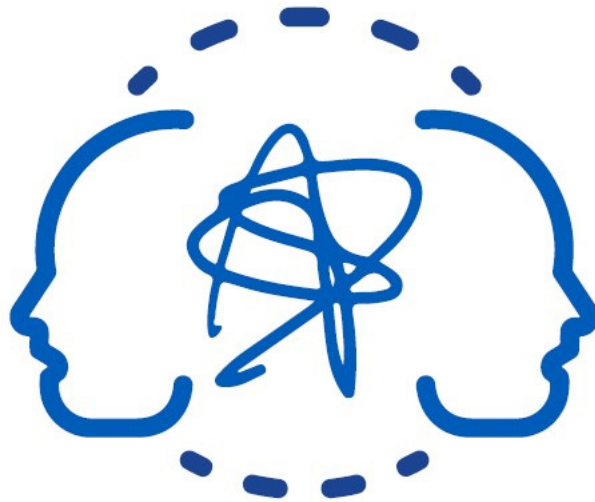


A compassionate approach to understanding breathing difficulties and emotional wellbeing



Contents

Introduction	3
Breathlessness	3
Low Mood, grief and depression	4
Anxiety	5
Breathlessness and Anxiety	6
Relationships	8
Getting help	9
Feedback from people who have used these services	10
Further Support information	10

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Introduction

Living with a breathing condition (such as COPD, asthma, interstitial lung disease, inducible laryngeal obstruction and others) can lead to many difficult feelings. Some people find it hard to cope. They might struggle with feelings such as low mood, worry, anger and fear. Sometimes these feelings can become overwhelming and have an impact on daily life.

This booklet explores common experiences of people living with breathing conditions, suggests some ways of managing these experiences and highlights some of the support that is available when difficult feelings become challenging.

Some parts of this booklet may feel more familiar than others. This is to be expected, as people experience their condition and their emotions very differently. How we describe and experience our physical and emotional health may be impacted by factors such as by the cultures we have experienced for example our families, religion and ethnicity. You may find it helpful to share parts or all of this booklet with someone close to you to help them to understand your experiences and support you.

Breathlessness

It is common to experience breathing problems when living with a breathing condition. Breathing problems not only impact on you physically, but can also lead to changes in your daily lifestyle. Breathlessness can feel overwhelming, frightening and disabling. It can also lead to racing thoughts about what is going to happen. This can make people lose confidence in their ability to cope.

How breathlessness feels...

“Like being under water”

“I feel out of control, gasping for breath. I feel hot and sweaty and try to escape the situation”

“This is it, this is my last breath”

People who experience breathlessness have said that it can make them avoid doing things that might lead to them becoming out of breath. Breathlessness can impact your ability to do activities such as walking, shopping, cooking and washing. It can also mean that people stop doing things that they enjoy, either because they are no longer able to or because they feel scared to do the things they normally would have done. The less we do that we value, the worse we can feel.

Some common feelings that people experience include:

- Frustration
- Sadness
- Irritability
- Isolation
- Anger
- Anxiety
- Depression or low mood
- Panic
- Tiredness

Do you or have you experienced any of these feelings?

You may use other words that would describe how you feel and you might want to note these here.

Low Mood, Grief and Depression

Adjusting to living with a breathing condition can involve feelings of loss. This can be a sense of loss of control over your body, loss of confidence, or threats to your independence. When experiencing loss it is common to grieve. This is a normal process, though people experience emotions in different ways and not everyone will feel the same. There is no right way to grieve but it is more about what you find helpful.

Noticing the difference between grief and depression can be helpful in understanding your emotional wellbeing. With grieving can come intense feelings of sadness, though you may still have moments of happiness. Being low in mood for a long period of time without moments of happiness may be a sign of depression.

Depression or low mood is more than sadness. It can mean losing all interest in things you have always liked to do, spending long periods in bed unable to start your day, and can include overwhelming feelings of despair, fear, and hopelessness. Depression can impact on how you take care of yourself or your ability to function at work or at home. It can also affect your ability to manage your breathing condition and stick to a treatment plan. Some describe depression as a cloak or black cloud that hovers over them.

If you think you are depressed it can be helpful to talk to your GP. They can advise you about treatment options for depression, such as medication and talking therapies. It can also be helpful to talk to your respiratory clinicians, e.g. nurses, consultants and physiotherapists, particularly if your mood is impacting your ability to manage your breathing condition or is triggered by it.

How can I help myself?

1. Make a daily plan by listing some activities that you could do during the day and/or week that are meaningful to you. The more we plan in advance what we would like to do, the more likely we will stick to that plan.
2. Connect with other people – this can help to normalise and validate your experiences and help you to find ways to cope. The British Lung Foundation has support groups where you can connect with other people who have similar breathing conditions.
3. If you are concerned about how you are feeling you could keep a mood diary. This could then be used to start a conversation with your GP or your respiratory team. This can help you to identify any difficulties you are experiencing but can also help you to notice what improves your mood. An example of a mood diary is linked here; https://www.blf.org.uk/sites/default/files/record_your_mood_diary.pdf
4. Setting SMART goals – Remember keeping goals Specific (What specifically am I trying to achieve?), Measurable (How will I measure this?), Achievable (What steps do I need to take to achieve this goal?), Relevant (Is this the right time?), and Timely (Timeframe for the goal). This is a tried and tested way of goal setting.

There are further contact details for support services at the end of this booklet.

Anxiety

Living with a breathing condition is one of many things that can cause people to feel more anxious. This can be because of uncertainty about the future and how your health may be, or worrying about becoming breathless or not being able to do things comfortably. It is also common for people to notice that anxiety caused by daily events (e.g. social situations, events at work, family stress) can lead to their breathing becoming more difficult.

Often one of the first steps in managing anxiety can be to accept that it is normal for humans to feel anxious. We know that our thoughts, feelings, behaviour and our body are all connected. Anxiety is associated with what can be called the body's '**threat system**'. The threat system helps to keep us safe, and when it is triggered, the body goes into the 'fight or flight' response. During this response the threat system overrides our other bodily systems and we experience physical changes. You may experience an increase in heart rate, muscle tension, dilation of pupils, and increased sweating. During these changes, adrenaline is released in our bodies to help us to run away, respond, or even freeze! This is a natural response that we all experience at some points in our lives. Often difficult thoughts and feelings are associated with the threat system, such as those arising from living with a breathing condition like 'Will others judge me for coughing and think I have COVID, this would be embarrassing'.



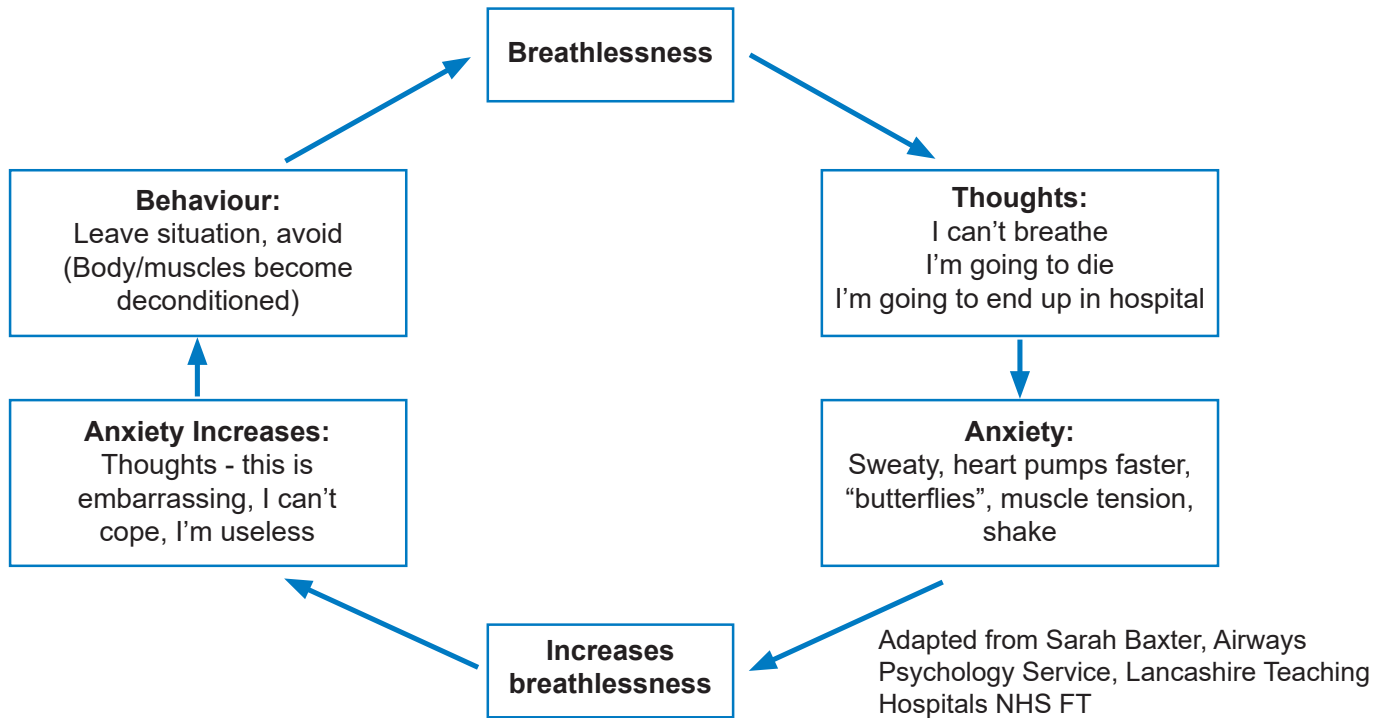
Image: <https://www.atickersguidetolife.com/post/mental-health-awareness-week-panic-disorder>

For some people, the feelings associated with anxiety can remain for longer than is needed, or even when it feels like it is not needed at all. The feelings can start to become unhelpful and get in the way of doing daily activities comfortably.

Breathlessness and Anxiety

Below is an example of how anxiety can affect breathing in a way which has become unhelpful.

This cycle shows how our thoughts, feelings and how we respond to them can impact our lives. It shows how our thoughts can lead us to avoid doing certain things, which can make us feel worse.



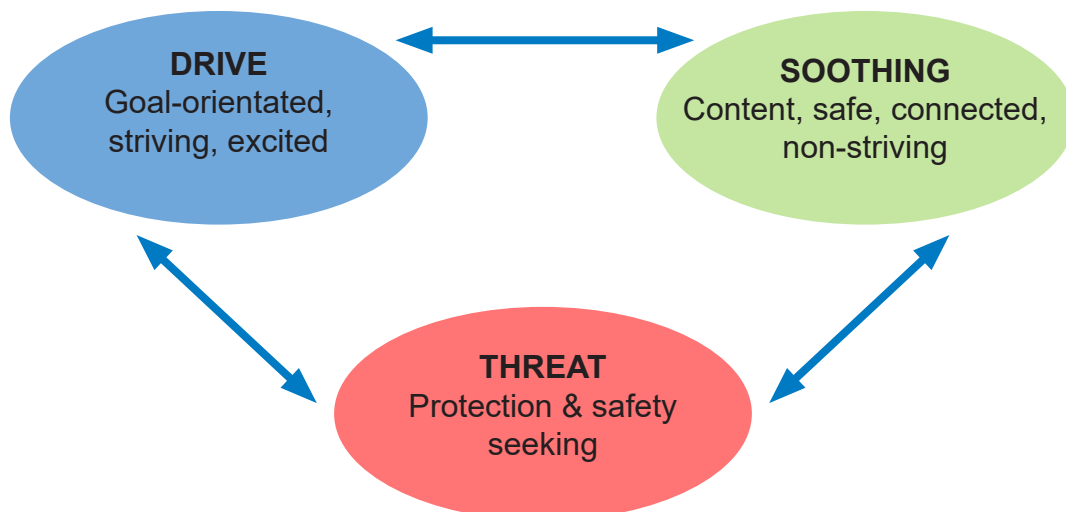
It is natural to avoid a situation that is challenging. But as seen in the vicious cycle above, avoiding challenging situations can have an unhelpful impact on our lives.

You might notice that you have experienced a vicious cycle. It might look similar or different to the one here. When a vicious cycle starts to have an unhelpful effect on your life it can be helpful to get support to find a way out of the cycle.

What can help?

Alongside the 'threat' system we also have 'soothing' and 'drive' systems. These systems can help to explain our emotions and how we can develop skills in regulating them. Paying attention to which behaviours, events or objects activate our different systems can help us in regulating our emotions.

The three systems model (CFT)



The Three Systems Model (CFT) adapted but based on P. Gilbert (2009).
The compassionate mind.

The soothing system helps us to feel safe and socially connected. It is associated with a sense of peace, wellbeing and a calm mind. When we are young children our caregivers help us to soothe. As adults, we learn to self-soothe and to draw upon others to help with this.

When considering what can activate your soothing system, it can be helpful to think about:

- What helps you to feel safe?
- What helps you to feel calm?
- What helps you to feel connected with others or with yourself?

Some people find that the following can help them to feel safe, calm and connected. You might notice other things too:

- Mindfulness (paying full attention to your experience of the world in the present moment)
- Relaxation and grounding techniques
- Spending time with others who you find nourishing
- Doing something kind for yourself or for someone else

The drive system guides us towards things that help us survive and feel good, and is associated with building our motivation, pleasure and excitement. It can help us to seek things we need like food and relationships. It also helps us to achieve our goals like increasing time spent exercising, learning a new skill or to manage feelings of anxiety in order to spend more time outside to do hobbies you enjoy.

When thinking about activating your 'drive system' it can help to consider what is important to us as individuals. Our values can guide us through life. They act as an internal compass and can give life meaning, purpose and help us to make decisions. Where a **goal** may have an end point and change, a **value** can be life long and can be linked to multiple goals through our lives.

Family relations

What kind of relationships do you want with your family?
What kind of mother/father/brother/sister/uncle/aunt do you want to be?

Physical wellbeing

What kind of values do you have regarding your physical wellbeing? How do you want to look after yourself?

Citizenship / community

What kind of environment do you want to be a part of? How do you want to contribute to your community?

Spirituality

What kind of relationship do you want with God/nature/the Earth?

Recreation

How would you like to enjoy yourself?
What relaxes you? When are you most playful?

Marriage / couple / intimate relations

What kind of husband/wife/partner do you want to be? What quality of relationship do you want to be a part of?

Parenting

What sort of person do you want to be?
What qualities do you want your children to see in you?

Friendships / social relationships

What sort of friend do you want to be?
What friendships is it important to cultivate?
How would you like to act towards your friends?



Employment

What kind of work is valuable to you?
What qualities do you want to bring as an employee?
What kind of work relationships would you like to build?

Education / training/ personal growth

How would you like to grow?
What kind of skills would you like to develop?
What would you like to know more about?

Becoming aware of personal values can motivate and guide us in what we want to achieve, which can activate the drive system. When things get in the way of achieving specific goals (e.g. money, time, struggles with physical health/mobility), recognising the values that underpin your goals can help to identify other goals/activities that can give us purpose that are adapted to your current circumstances. For example, a value of 'freedom' may have previously related to the goal of regular long walks, whereas now adjusting this to shorter local walks has helped to maintain a connection to what is important.

Practicing things that activate our soothing and drive systems can make them easier to activate when we need them, helping us to balance our emotions when our threat system is triggered.

Relationships

The changes to your physical health might affect how you feel about yourself, and how you relate to yourself and others. Some examples of changes in how you relate to yourself or to others that may be common for people experiencing breathing conditions or other health conditions can include:

- Feeling unable to care for others in the way that you could previously, and finding it difficult to accept the help of others. Sometimes this can leave people feeling less in control or powerless owing to this change in role.
- Finding it difficult to understand how you feel or to talk about it. This means it can be difficult to express how you feel and what you need from others. Sometimes this causes tension, such as not feeling understood or supported by others when you do not get what you need.
- Setting high expectations for ourselves; when it is understandably difficult to meet these expectations can sometimes lead to frustration, self-criticism and beating yourself up. This may leave you feeling even worse.

It can be useful to become more aware of any unhelpful patterns that you may experience as you may be able to find other ways of responding to how you feel or to the situation instead. Practicing being kinder to yourself, adjusting your expectations of yourself and keeping these flexible, or perhaps letting others know what you are experiencing by talking to them or, writing a letter can be helpful ways of responding.

You might find it helpful to ask yourself these questions if they are relevant to you:

What might help me to accept care from others a little more?

How can I stay connected to other sources of support?



image: www.pexels.com

Getting help

People often find that a good place to start is by talking to those closest to you. This could be family, friends, or other people that support you. Talking to others can help them understand how you are feeling. This can sometimes relieve some of the pressure of difficult feelings related to a health condition.

Talking to others can be important, but finding the words to do this can be difficult. Sometimes it is about **being** together with difficult feelings rather than trying to find the right words. It can help to:

- Share what feels safe
- Suggest how you would like others to respond
- Allow space for you both to share feelings and ideas about what might help.
- Know that it is normal to experience difficult feelings and that they do not always need to be taken away
- Have soothing activities planned around talking e.g. going for a walk or doing something kind for yourself
- It can be helpful for some people to plan in time to sit with important people to talk about something difficult. For others it might be about embracing an unplanned moment that feels right.

Talking to people close to us can sometimes feel like it is not enough. If you would like help from clinicians who are trained in helping to manage the impact of difficult psychological or emotional problems related to your breathing condition the following services may be able to help you:

CHFT Respiratory Psychological Services Telephone number: 01484 343490

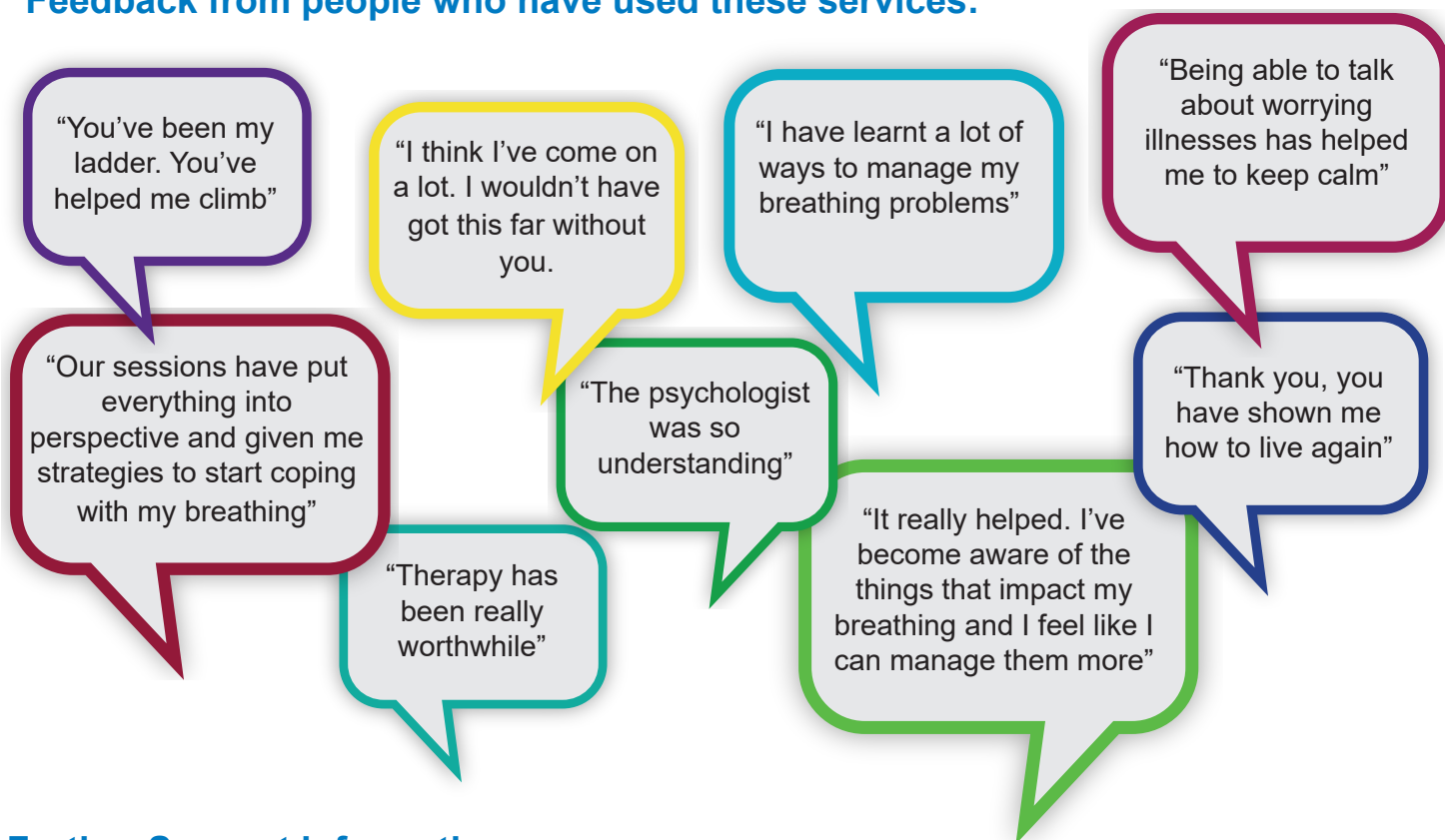
The service offers outpatient psychological assessment, consultation and psychological therapy to patients receiving respiratory care from Calderdale and Huddersfield NHS Foundation Trust.

Huddersfield Royal Infirmary/Calderdale Royal Hospital

This service predominately draws upon:

- Compassion Focused Therapy
- Cognitive Analytic Therapy
- Cognitive Behavioural Therapy

Feedback from people who have used these services:



Further Support information

The services mentioned in this leaflet are unable to offer urgent support. The following services are able to offer immediate 24 hour mental health support, including for people in crisis:

- **Single Point of Access (SPA) for Calderdale & Kirklees SPA call: 01924 316830**

Other important contact details;

- **Emergency Services - call 999** - for immediate significant risk of harm to self or to/from others
- **Samaritans - call 116 123** - 24 hour support and/or Email - jo@samaritans.org - 24 hour support
- **Improving Access to Psychological Therapies (IAPT) Kirklees and Calderdale, call 01484 343700**
- **VITA Minds Calderdale - call 03330 153494**
- **British Lung Foundation; Website <https://www.blf.org.uk/> Helpline call: 03000 030555**

Other useful resources;

- **British Lung Foundation Local Support groups:**
<https://www.blf.org.uk/support-for-you/breathe-easy>
- **Self-help leaflets created by Cumbria, Northumberland & Tyne & Wear NHS Foundation Trust:**
<https://web.ntw.nhs.uk/selfhelp/>
- **Pulmonary Rehabilitation Groups** (more information via the link or speak to your local respiratory team):
<https://www.blf.org.uk/support-for-you/keep-active/pulmonary-rehabilitation>

If you have any comments about this leaflet or the service you have received you can contact :

Respiratory Psychological Services
Huddersfield Royal Infirmary

Telephone: 01484 343490

www.cht.nhs.uk

If you would like this information in another format or language contact the above.

Potřebujete-li tyto informace v jiném formátu nebo jazyce,
obraťte se prosím na výše uvedené oddělení

Jeżeli są Państwo zainteresowani otrzymaniem tych
informacji w innym formacie lub wersji językowej,
prosimy skontaktować się z nami, korzystając z ww.
danych kontaktowych

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اگر آپ کو ہی معلومات کسری اور فارمیٹ طرزبان می درکار ہوں، تو
برائے مہربانی مندرجہ بالا شعبے می ہم سے رابطہ کریں۔

"إذا احتجت الحصول على هذه المعلومة بشكل مغاير أو مترجمة إلى لغة مختلفة فيرجى منك الاتصال بالقسم
المذكور أعلاه"