# Living Well with a Long-Term Health Condition:

### 3. Managing Anxiety and Worry

#### Why this leaflet?

This resource is intended for people who are living with, or have recently been diagnosed with, a long-term health condition. Living with a long-term condition can bring challenges, which might make people feel anxious, stressed or worried. It explains what anxiety is and why it can be more common among people living with a long-term health condition. There are some tips and advice about how to cope with it within this leaflet. You may need to adapt things slightly to your own health needs. If you have concerns about anything or how to adapt things to your own particular needs, please ask your GP or your health care professional.

Anxiety is common in people who are living with on-going health problems. It can make you feel nervous and uneasy focusing your mind on your worries. This can be stressful and tiring. It is important to remember that these thoughts and feelings are normal and that there is hope. There are lots of things you can do that will make a difference, and help is at hand if you need it. Overcoming anxiety will help you to cope better with your treatment. It will help you to get back to doing the things you enjoy and value. This booklet contains lots of information and advice. You might find it helpful to read it in small chunks, or with a family member or friend.

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#### What is anxiety?

It is common to have worries and fears when you are living with an on-going health problem. For example, you may have experienced shock when you were diagnosed, been unsettled to learn that your condition needs to be managed rather than cured, and worried about what could happen in the future. All of these reactions are understandable and may affect how you think, how you feel and what you do. Anxiety can affect your mood and behaviour. Anxiety can also give you physical symptoms which can be confusing because these anxiety symptoms can feel like the symptoms of your condition and may even make those symptoms worse.

#### Signs of anxiety

Everyone experiences the symptoms of anxiety slightly differently, but these are some of the most common experiences.

#### You might feel:

- Tense, anxious, nervous
- Uneasy, on edge, jumpy, panicky
- Unreal, detached, out-of-it
- Hot, sweaty, shaky
- · Aching or tense muscles.

#### You might also experience:

- A pounding heart, fast breathing, tingling and numbness
- Stomach churning, nausea, needing to use the bathroom urgently
- A racing mind, trouble concentrating, mind going blank, brain fog
- Constant worrying and imagining the worst
- Wanting to avoid things that you need to do.

#### **Causes of anxiety**

Anxiety is a normal reaction to threat, sometimes called the 'fight or flight' reaction. This alarm system developed thousands of years ago to keep us safe from danger, like predators. When triggered, it makes your body get ready for a fight or for running away (e.g., by making your heart beat faster and your muscles tense up).

This worked really well when there were dangers like predators around, or when we had to hunt wild beasts for food. Unfortunately, it is less helpful for modern day threats. Things like money worries or fears about the future can trigger this 'fight or flight' response. In reality in these situations, it is more useful to be able to think clearly, not necessarily prepare for physical dangers.

The physical symptoms of anxiety (e.g., racing heart, sweating, shaking) can be very unpleasant. They can even be frightening and make you think that something bad is about to happen, like having a heart attack or collapsing. These anxiety symptoms are real physical symptoms in your body and are not 'all in your head'. Thankfully, they are not dangerous, just unpleasant, and will go away by themselves over time.

Other things can trigger anxiety or make it worse. It doesn't help to avoid the situations that make you anxious. And it helps to make sure your thoughts are realistic and based on fact rather than your imaginings. Although it might feel tempting to ask for reassurance from friends or family sometimes that can make things worse because it makes you concentrate more on the anxious thoughts and anxiety rather than other things which can be more helpful.

## Common causes of anxiety in people with health conditions

Research has shown that Unpredictability, Uncertainty and Unfamiliarity can make anxiety worse. Unfortunately, all of these experiences are common for people living with long-term health conditions and it is therefore not surprising that anxiety can be a frequent experience. Here are a few common examples of where unpredictability, uncertainty and unfamiliarity can make people with long term health conditions more vulnerable to anxiety.

- Anxiety about treatment. For example, you might have worries about the side-effects of the medication you take, the way you have to take it (e.g., injecting yourself) or about procedures, like operations or scans.
- **Fear of pain.** You might get worried about pain you may feel or worrying about pain in the future. This pain may be a symptom of your condition or may be part of your treatment or rehabilitation.
- Anxiety about the future. You might have worries about your health, your
  recovery from flare ups, your return to work or education, or your finances. All
  of these things can be affected by living with a long-term health condition. You
  may also have concerns about what it means for you as a person to have
  these difficulties now and in the future. You might have concerns about being
  dependent on others, for care or for money.
- Anxiety about getting out and about. It is common for people with health problems to worry about what could happen when they go out and about. For example, you might worry about being jostled or bumped into, particularly if you have balance, mobility, or pain problems. It is also common to worry about getting tired or not being able to stand in queues, for example.
- Anxiety about medical emergencies. For some people with certain conditions, such as heart conditions, it is common to worry about whether you are near a hospital or whether an ambulance could get to you quickly, even if you have never needed these services before.
- Anxiety about other people's reactions. Depending on the condition you
  are living with, you may have to cope with visible signs of your condition such
  as skin problems, hair loss, having mobility aids, scars from surgery or
  changes to your weight and shape. As a result, you may feel differently about
  your appearance. You might be worried that other people will stare at you or
  ask personal questions. You might be worried about whether your partner will
  still find you attractive and how this could affect your personal or intimate
  relationships.

#### Factors that keep anxiety going

Anxiety can be kept going by vicious cycles of thoughts, feelings, and physical feelings.

#### **Thoughts**

Anxiety can affect the way you think, making you imagine the worst or making it difficult to think logically, which can in turn increase anxiety. Although these thoughts can seem very believable, remember that not all thoughts are true all of the time.

Anxiety often makes people look out for other things that might go wrong. This can make you notice worrying things in your body, and in your environment more, that might even seem to confirm the anxious thoughts you have. For example, you might notice symptoms that you fear are 'not right', which trigger worry, that you would usually ignore/not notice if you were not feeling anxious. Remind yourself that these symptoms may be part of the 'fight or flight' reaction, which are harmless, rather than always a sign of serious illness.

The following leaflets in this series might help you:

- What is the Mind-Body Link?
- Making Your Thoughts Work for You

#### Choices and behaviours – the problem with avoiding

Avoiding the things that you feel anxious about is very common. This is often because anxiety is unpleasant, and you want to avoid those feelings or thoughts. This avoidance can seem quite helpful in the short term because often it keeps the feelings of anxiety at bay. However, in the long term it can make anxiety worse, and it can become much harder to tackle those problems that you have put off.

Avoiding things that make you feel anxious may also reduce your confidence because you miss out on chances to find out that you can cope, even when times are hard. Sometimes the avoidance can have unwanted side-effects on your long-term condition. For example, avoiding doing things that have been recommended by your health professional because they are hard or painful can make your health seem worse and reduce your fitness.

#### Worrying about the symptoms of anxiety

The physical symptoms of anxiety are unpleasant and can be scary. Often, they really can make the symptoms of a long-term health condition feel worse. It can also be difficult to work out whether the symptoms you are experiencing are a result of the long-term health condition itself, or a result of anxiety, or a combination of both. Being worried about experiencing these symptoms again in the future can also make worry worse.

It can be difficult for either you or your health care professional to work out how best to treat or to manage your anxiety symptoms. It is always helpful try to manage symptoms of anxiety as best as possible. It can improve your quality of life and help you to feel more in control of your situation.

#### Managing anxiety

Here are some ideas for how to break these vicious cycles of anxious thoughts, emotions and physical sensations. It isn't always easy to manage anxiety and does take some time and patience. You may need to practice some of these things before you feel you are getting any benefit. It is also worth trying out different suggestions until you find something that works for you. Try taking things one step at a time too – it is always best to work on one thing at a time.

The problems that are causing the anxiety won't necessarily go away but using some of these strategies should make problems/challenges feel more manageable and less overwhelming. It may give you more confidence to cope with other challenges in the future, as you can practice the successful strategies again. It may also give you more energy and confidence to enjoy the things you are able to whilst living alongside your health condition.

#### **Understanding your anxiety**

Understanding the main causes or what most often triggers your anxiety is a really good first step. Try to record the times when you feel most anxious in a diary or somewhere on a computer or phone. It can be helpful to ask yourself some questions:

- "What was happening just before I became anxious?"
- "What was running through my mind?"
- "What did I do to manage how I was feeling?"
- "Was this helpful in the short term? (e.g., leaving the situation)"
- "Are there any downsides to this strategy in the long run? (e.g., missing out on something I wanted to do)"
- "Is there anything else I could have done?"

Understanding things is a way of coping in itself. It can help reduce those feelings of uncertainty and unfamiliarity. Once you understand what is happening better you can start figuring out how to manage them as best you can.

Sometimes there can be a feeling of underlying anxiety a lot of the time and that can be very draining and preoccupying. If this sounds like it is something you are experiencing, try making a list of the things you are worrying about and work on one thing at a time. If this is difficult or overwhelming, you can ask someone you trust to help you make the list and organise them.

#### What you can and can't control

It is always important to work out what you can really control or change, and the things that you actually have very little or no control over. And there will always be things in between where you might have some influence over the outcome, but there might be lots of other things affecting the outcome too.

It can be very helpful to think about problems in this way. For each thing you are worrying about, it can help to then write down what you can control and what is beyond your control – you can then focus on the things that you can control and take steps to reduce your anxiety. If there are things happening to you or around you that you have no control over, it is important to find ways of looking after yourself in the best way possible. Some of the ideas in the rest of this resource might help you. Otherwise, it can feel frustrating if you feel you aren't getting very far. Not surprisingly the anxiety then feels worse.

#### Taking care of yourself

Try to eat a well-balanced diet. Take regular exercise if you are able and as you have been advised by a healthcare professional. Think of an activity which is manageable and enjoyable for you. You might need to take this quite slowly and build up gradually. Eating well and keeping active can help to reduce the stress and physical tension which often accompany anxiety.

Allow yourself enough time for sleep and rest. If you are not sleeping well, try not to worry and focus on building a good sleeping routine. Having a regular bedtime, and allowing time to wind down before bed, can help.

The following leaflet within this series might help you:

Your Sleep

#### Talk to someone

When you are feeling anxious you might not feel like talking about it. You might even want to avoid topics that make you feel anxious. However, talking to someone you trust about how you are feeling can really help. It can be useful to tell someone how they can help you, so they can offer the support that you need. You might want to let them know that they can help you just by spending some time with you and listening. They may also be able to help you put some of the other ideas in this booklet into practice.

#### **Tackling problems**

When you are anxious, it can seem like everything will go wrong, and you might feel quite overwhelmed. This is a way of gaining some control by breaking down problems into steps.

- 1. Make a list of all the problems which are troubling you.
- 2. Pick out one thing that you can do something about and circle it. Do not pick the hardest one to start with.
- 3. Now make another list of everything you can possibly do about this problem. What can you control? What is manageable for you?
- 4. Pick out the option you would like to try first and circle it.

- 5. Write down how you will be able to tell if it's working.
- 6. Write down how you will put this option into practice. Break it down into steps if you need to.

The following leaflet within this series might help you:

Problem Solving

#### **Practicing relaxation**

Learning how to relax your mind and body can really help you to manage anxiety. You can try out different things until you find one (or more!) that works for you. Different things might help you relax in different situations. For example:

- Listen to relaxing music or 'white noise' like the sound of the sea. There are
  lots of relaxation Apps available. It is worth trying out a few until you find one
  that works for you. You can download free relaxation apps to your phone, use
  Google to find files to download to your PC or MP3 player or buy a CD (these
  are widely available)
- Spend five minutes practicing breathing from your stomach. Rather than breathing with your upper chest, try to breathe deeply so that your belly rises and falls gently.
- Try using meditation, or prayer if faith is important to you.
- Imagine being in a peaceful scene, such as a beach or a woodland. Notice what you can see, hear, touch, taste, and smell.
- Gently tense and relax different muscle groups in your body until your body feels physically relaxed, skipping any areas where you have pain if necessary.
- Try not to rush around during the day. Leave plenty of time for your planned activities.

#### Balance your awareness of your body

Being aware of your body can help you to make wise choices, for example, you might want to speak to your GP about a new symptom you are experiencing. But being over-aware can make it hard for you to focus on other things. This can mean you miss out on fully enjoying the good things in life. Being over-aware can also cause you unnecessary worry and distress, which can make your symptoms feel worse. It can help to put your feet flat on the ground and simply notice how it feels. You can also try focusing on your surroundings: name 5 things you can see, 4 things you can feel, 3 things you can hear, 2 things you can smell, and 1 thing you can taste.

#### **Practice mindfulness**

Mindfulness is about paying attention in a particular way and being fully present and accepting of the current moment. Mindfulness suggests you take a curious and non-judgmental attitude towards whatever you are experiencing in the 'here and now',

rather than focusing on the past or the future. It can help you become less caught up with difficult thoughts, feelings, and sensations by helping you to just notice them instead of trying to get rid of them or push them away.

#### Try these simple steps:

- Focus first on your breath. Pay attention to the natural rhythm of your breath.
- Notice the rise and fall of your chest and stomach. Notice how the breath feels coming in and out of your nose. Pay attention to any changes in your breath.
- Use all of the senses, touch, sight, smell, hearing and taste to pay attention what is around you.
- Don't be concerned if you notice your mind has wandered off. This is normal.
   When this happens, just gently bring your attention back to the breath and to your senses.
- Thoughts, feelings and sensations will continue to come up and try to grab your attention.
- Instead of pushing them away, or judging them as bad or a nuisance, just observe them, as if they were leaves on a stream or cars driving by outside.
- Then bring your attention gently back to the breath.

Practicing mindfulness might feel strange or difficult at first, but with repeated practice it feels more natural. As you become more skilled at using mindfulness, it can help you be less bothered by difficult or painful thoughts and feelings about life or the health problems you face. It can also help you be less affected emotionally by unpleasant physical symptoms.

#### **Face your fears**

Have you noticed that something specific makes you anxious often? Although it is a very difficult thing to do, facing your fears is one of the most effective ways to overcome this anxiety. Ask yourself the following questions:

- "What am I avoiding or not doing anymore because of anxiety?"
- "What is the worst thing that could happen if I went ahead and did the thing I am worrying about?"
- "If this did happen, what is so bad about that and how would I cope?"
- "What makes me think this would definitely happen?"
- "Are there any other possible outcomes? (e.g., Could something good come of it? Do I have something to gain?)"

When you are facing your fears, your predictions about what will happen are often much worse than what actually happens when you go for it. Even if something bad does happen, like people staring, or an increase in your pain, maybe you'll get a chance to find out you can cope despite these challenges.

If you do decide to start facing situations that make you anxious, make sure you give yourself credit afterwards. For example, you might say to yourself "Well done. That was hard but you did it". It might help to write down times when you have successfully dealt with situations that made you anxious, so you can remind yourself in the future of what helped. Also, plan some kind of reward for yourself for afterwards. This can be anything you enjoy like a favourite meal or a DVD. This will help you to continue facing you fears until the anxiety goes down gradually over time.

Remember to share your achievements with those around you. Their encouragement will build your confidence for the next time you are coping with anxiety.

#### **Further reading**

- Manage Your Mind by Gillian Butler and Tony Hope
- Overcoming Anxiety by Helen Kennerley
- Living Well with a Long-Term Health Condition <u>Problem Solving</u>
- Living Well with a Long-Term Health Condition <u>Making Your Thoughts Work</u> for You

#### **Next steps**

- Plan a time to use the ideas in this leaflet
- Share the ideas with someone who can support you
- If some of these ideas are new to you may want to try working through the ideas in this resource (and the other resources in this series) small steps at a time
- If you have tried the ideas in this leaflet and you have not seen any improvements, talk to your healthcare professional about getting further support.

#### Kings Patient Advice and Liaison Service (PALS)

This is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleden Wing, near the main entrance on Bessemer - staff will be happy to direct you.

Their website can be found here: PALS – King's College Hospital NHS Foundation Trust (kch.nhs.uk/patientsvisitors/help-and-support/pals).

Tel: 020 3299 3601 Fax: 020 3299 3626 Email: kch-tr.pals@nhs.net

#### **Providing feedback**

We welcome your feedback on this series of leaflets, please use the QR code or the link below to access a short survey. <a href="https://forms.office.com/e/R86s27ggfa">https://forms.office.com/e/R86s27ggfa</a>



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