

Are you on edge?

A booklet for people coping with the stress and worries of living with health problems

Anxiety is common in people who are living with on-going health problems. It can make you feel nervous and on edge, focusing your mind on your worries. This can be stressful and tiring. It is important to remember that these thoughts and feelings are common 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. 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.

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.



It is normal to have worries, concerns and anxiety 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 would be managed rather than cured or worried about what would happen in the future. All of these reactions are understandable and normal and may affect how you think, how you feel and what you do.

Andrew's story describes some common experiences associated with living with health problems. You may recognise some of them.

Andrew is a 48 year old man who has been living with back pain from an old sports injury for about 10 years. Like many of the men in his family he has high blood pressure and slightly raised cholesterol. However, recently at a routine check-up his GP told him he has 'borderline diabetes'. His GP gave him leaflets about these conditions which listed all the things he was at risk of including stroke and heart attack. The leaflets also talked about how important it was to exercise and to eat healthy food. Andrew left the appointment in a daze, not sure if he had taken it all in.

Andrew knew he was meant to exercise but his back pain often got in the way. In fact, he would start to get stressed just thinking about the pain he expected to feel. Also, exercise made him breathless and made his heart pound and he couldn't help thinking he might be doing himself more harm than good.

When he started to think about what these problems might mean for his future as a father, a husband, an employee and as a man, he would feel overwhelmed. Feeling this way sometimes seemed unbearable so he would go to the pub and have a few pints to block it all out, even though the next day he would feel guilty about it.

What are the signs of anxiety?

You might feel:

- tense, anxious, nervous
- 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 & numbness
- stomach churning, nausea, needing the loo urgently
- a racing mind, trouble concentrating, mind going blank
- constant worrying & imagining the worst
- wanting to avoid.

What causes 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 predators around. 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, even if it is not that helpful for solving the problem.

The physical symptoms that go with 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.

Avoiding situations which trigger anxiety, mistaking these anxious thoughts for facts and looking for reassurance from others are some things which can keep anxiety going and even make it worse.

Common causes of anxiety in people with health problems

- **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) or about procedures, like operations or scans
- **Fear of pain.** You might get worried about pain you expect to feel. 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. You may also have concerns about what it means for you as a person to have these difficulties now and in the future.
- **Anxiety about getting out and about.** It is common for people with health problems to worry about being jostled or bumped into, particularly if they 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, heart conditions for example, 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. You might be bothered by people staring or asking personal questions.

You may also have concerns about your family’s, friends’ or partner’s reactions to your condition. For example, you might have worries like “If my daughter is looking after me, does that mean I’ll lose my independence?” or “Will my partner still find me attractive even though I have changed physically?”

What keeps anxiety going?

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

Thoughts

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

Andrew's own father had died unexpectedly from a stroke when Andrew was a teenager. Andrew started to have unpleasant images of this happening to him and had the thought "That will happen to me too!". These thoughts made him feel panicky and often his heart would race and head would start to feel fuzzy.

Anxiety often makes people look out for other things that might go wrong. This can make you notice more worrying things in your body and in your environment. For example, you might notice symptoms that you think are 'not right', which trigger worry. 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.

When Andrew's heart raced and head felt fuzzy he became frightened. He thought this may be a sign that something bad was about to happen, like a heart attack or stroke. To be safe, he kept a close eye out for these symptoms. He was glad he decided to be on the lookout because he started to notice more and more signs and symptoms.

Choices and behaviours

Because anxiety is unpleasant, you probably want to avoid it. This is understandable! Avoiding things that make you feel anxious works in the short term. However, in the long term it can make anxiety worse. This is because you do not get the chance to find out whether your fears come true.

It also reduces your confidence because you miss out on chances to find out that you can cope, even when times are hard. It can have unwanted side-effects. For example, avoiding activity can make certain health conditions worse as you lose fitness and strength, and avoiding doctors' appointments because they make you feel anxious may mean you are not getting the treatment you need.

When Andrew noticed symptoms he believed were suspicious, he made sure to stop what he was doing. Understandably, he believed this was keeping him safe because the symptoms went away when he rested. However, this got in the way of the exercise he was meant to be doing and when he went back to his GP for a follow up his blood pressure reading had not improved.

Also, his wife pointed out that going to the pub when he was stressed and overwhelmed might help him in the short term but was unlikely to be any good in the long run.

This booklet will offer some ideas for how to break these vicious cycles. This won't be easy, and it will take some time and patience. Take things one step at a time.

Taking care of yourself

Try to eat a well-balanced diet. Take regular exercise if you can. Think of an activity which is manageable for you and which you might enjoy. 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, but try not to worry if you are not sleeping well. Having a regular bedtime, and allowing time to wind down before bed, can help.

Try to not to have alcoholic drinks at bedtime or to rely on caffeine during the day. This will only make you feel worse in the long run as both can disrupt good quality sleep.

Talk to someone

When you are feeling anxious you might not feel like talking. 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. 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.

Understanding your anxiety

Understanding what triggers your anxiety is a good first step. Try to record the times when you feel anxious in a diary. 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)”

Once you know what your trigger situations are, you can start figuring out how to manage them better.

Anxiety and thinking styles

Your thoughts about a situation affect how you feel. For example, if you heard a bump in the night and thought it was your cat, you might feel annoyed but roll over and go back to sleep. However, if you believed it was a burglar you might feel scared and anxious and perhaps call the police.

Below are some common thinking styles linked to anxiety. Often these thoughts are not true and trigger ‘false alarms’ of the ‘fight-flight’ system.

Thinking style	Example
Thinking the worst	I will get all the complications it is possible to get and lose my independence sooner rather than later.
Mind reading	My doctor thinks I am a lost cause and dreads me coming in for appointments.
Predicting the future	I will definitely end up in needing 24-hour care.
Overgeneralising	That high blood pressure reading today means my blood pressure is out of control.
Jumping to conclusions	The doctor spent a long time talking about the risks of my medication and treatment plan. That must be because I am very a high risk patient and things will almost definitely go wrong for me.

The examples on the previous page show how anxiety can make you think more negatively about your health problem and recovery. All of this thinking, and the worry that goes with it, can happen without you really noticing.

To break this cycle, it can help to notice these thoughts, and to ask yourself the following questions.

Useful questions to ask yourself

Is there any evidence against this thought?

When you feel very bad, physically or emotionally, it is easy to imagine that the worst will happen or that you won't be able to cope. However, you might remember times in the past when you coped during hard times. Reminding yourself of these times might help you think of things you can do that will help you feel a little better.

Is there anything I can do about this problem?

Have you ever tackled difficult problems before? You might be able to draw on your own experiences or the experiences of friends and family to come up with a plan to deal the problem.

Is there another way of thinking about the situation?

For example, the doctor may have been talking about all the risks because it is part of her job to tell each patient what could go wrong. It might not mean that she is more worried about you compared with other patients. Asking others for their views on a situation may also help.

How helpful is it to think this way?

For example, if you have had a setback or become particularly unwell it might have really got you down. Focusing on these setbacks will just make you feel more worried and disheartened. Instead, focus on how you have managed to overcome setbacks in the past and pay attention to any signs that things are improving.

What would you say to a friend?

If a friend or loved one was struggling with lots of health problems and told you they were stressed and tense, what would you advise them to do? Would you say kind, compassionate things to them and show them you understand their struggles or tell them to pull their socks up?

Try to take this kinder attitude towards yourself and try not to fall into the trap of being much harder on yourself than you would ever be on others. This is not fair on you and probably not helpful.

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 you can do something about and circle it. Don't pick the hardest one to start with
- 3) Now make another list, of everything you could possibly do about this problem
- 4) Pick out the option you would like to try first and circle it
- 5) Write down how you will put this option into practice. Break it down into steps if you need to
- 6) Write down how you will be able to tell if it's working

Learn to relax

Learning how to relax your mind and body can help you to manage anxiety. You can try out different things until you find one that works for you. For example:

- Listen to relaxing music or 'white noise' like the sound of waves crashing. You can download free 'White Noise Apps' to your smart phone, use Google to find audio files to download to your PC or MP3 player or buy a CD (these are widely available).
- Spend five minutes practicing abdominal breathing. Rather than breathing in your upper chest, try to breathe deeply so that your belly rises and falls gently.
- Try using prayer or meditation practices.
- 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

Being aware of your body can help you to make wise choices, 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 what you can see and hear in the world around you.

Practice mindfulness

Mindfulness is about paying attention in a particular way. It invites you to 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.
- 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.
- 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.

As you become more skilled at using mindfulness, it can help you be less bothered by difficult or painful thoughts and feelings about the health problems you face. It can also help you be less affected emotionally by unpleasant physical symptoms.

Facing your fears

Although it is a very difficult thing to do, facing your fears is one of the most effective ways to overcome 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 it?”
- “If this did happen, what’s so bad about that?”
- “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.

Andrew told his GP about the suspicious symptoms he was having, like a racing heart and shortness of breath when he did exercise or got stressed. His GP told him that these were normal symptoms that happen when people exercise, particularly when they have not exercised in a long time, and when people get anxious. She also pointed out that the more he avoided exercise the worse the breathlessness and other health problems would likely become.

Andrew decided to take one flight of stairs at work the next day instead of using the lift all the way. As he climbed the stairs, he started to feel breathless and his heart began to pound. When he had the thought “Something bad is about to happen!” he focused on his GP’s advice and kept going slowly. When he reached his floor, his symptoms went away after a few minutes and he discovered that nothing bad happened after all. Over the next few weeks he worked up to taking the stairs all the three floors.

Andrew and his wife decided together that instead of going to the pub when he felt overwhelmed, stressed or worried that they would sit down together and talk about his concerns. This wasn’t always easy as Andrew didn’t see himself as much of a ‘talker’ but he decided he was willing to try it out.

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”. 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 your fears until the anxiety goes down gradually over time.

Further reading

- Manage Your Mind by Gillian Butler and Tony Hope
- Overcoming Anxiety by Helen Kennerley
- Leaflet about ‘Problem Solving’ from the IMPARTS Leaflet Collection
- Leaflet about ‘Managing Sleep Problems’ from the IMPARTS Leaflet Collection.

Next steps

- Plan a time to use the ideas in this leaflet
- Share the ideas with someone who can support you
- 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.

King's 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 Hambleton Wing, near the main entrance on Bessemer - staff will be happy to direct you.

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