

Are you on edge?



A booklet for people coping with the stress and worries of limb reconstruction

Anxiety is common in people who have experienced serious injuries. 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 during recovery, 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 and recovery. It will help you to cope better with the effects of limb reconstruction on your life, helping you get back to doing the things you enjoy and value.

It is normal to have worries, concerns and anxiety following a serious injury. The accident itself may have shocked you, leaving you feeling upset. Having limb reconstruction can also be a very difficult experience which may affect how you think, how you feel and what you do.

Mark's story describes some common experiences associated with having a limb reconstruction frame. You may recognise some of them.

Mark is a 29 year old man who had a motorcycle accident six months ago. He had a serious leg injury and was treated with a limb reconstruction frame. At first he was just glad he did not lose his leg. However, as time went on he began to feel more and more stressed and on edge.

He started to dread having his pin sites cleaned and the frame adjusted because it was so painful. He would get stressed just thinking about it. He worried that others would notice him shaking and sweating and think that he was weak and pathetic.

During his treatment, Mark got a bad pin site infection. After this, he started looking out for signs of infection several times a day, getting very worried if he noticed any changes like redness or soreness. Sometimes he had frightening thoughts like, "This treatment won't work". It helped a bit when the doctors reassured him that everything was OK but sooner or later the worrying thoughts cropped up again.

Mark also noticed that he was very irritable out in public. He worried that people would bump into him, hurting his leg, or that he wouldn't be able to find places to stop and rest. However, the worst part for him was people staring, making him feel embarrassed, self-conscious, and angry. He started avoiding going out as much as possible.

Although Mark hadn't told anyone, he was bothered by the weight he had gained and by how the frame looked. He was avoiding undressing in front of his girlfriend and was starting to worry about what would happen to their relationship. On top of this, when he thought about the future, he feared that he wouldn't be able to cope.

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 things (e.g. busy places, social events, new things, situations where you have felt anxious before, the place where you had your accident)

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.

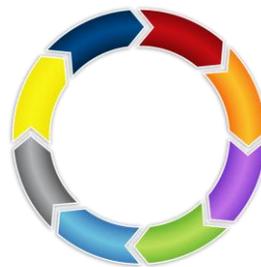
Common causes of anxiety in limb reconstruction



- **Anxiety about treatment.** For example, you might have worries about having a major operation or about looking after your frame (e.g. pin site care and frame adjusting)
- **Fear of pain.** You might get worried about the pain you expect to feel as part of your treatment and rehabilitation
- **Anxiety about the future.** You might have worries about your recovery, your health, your return to work or education, or your finances. You might also worry about whether you will be able to get back to your old self.
- **Anxiety about getting out and about.** It is common for people with limb injuries to worry about being bumped into, getting tired or not being able to stand in queues, for example.

Anxiety about other people's reactions. 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 the frame. For example, you might have worries like "If Mum is looking after me, does that mean I'll lose my independence?" or "Will my friends forget about me because I won't be out in the pub or playing sport?"

What keeps anxiety going?



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

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.

Mark got very anxious about his pin site infection and started to think that his treatment would fail. This stressed him out even more. As it turned out, he only had two infections in total and his treatment went mostly to plan. His prediction turned out to be untrue.



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 a sign of serious illness.

Mark started experiencing tightness in his chest and a pounding heart during pin site cleaning. There were heart problems in his family and he feared it was the start of a serious heart problem. He started to watch closely for any signs that his heart was not right and he began noticing more and more symptoms. Now he was really worried. A check up at his GP revealed that he had a healthy heart. His GP said his symptoms were most likely anxiety, triggered by the pin site care, which would not do him any harm.



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.

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, if you are working with a physiotherapist, ask for their advice. 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 resist any temptation to have a few alcoholic drinks at bedtime or to rely on caffeine during the day. This will only make you feel worse in the long run.

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 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. 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.

<i>Thinking Style</i>	<i>Example</i>
Thinking the worst	"This treatment isn't going to work. I'll get all the complications the doctors talked about"
Mind reading	"They think I'm weak and pathetic because I get so tense and shaky before having my pin sites cleaned"
Predicting the Future	"I'll never get back to normal at home or at work"
Overgeneralising	"I've had one infection so far. That means I'll get lots of infections"
Jumping to Conclusions	"The Doctor spent a long time talking about the risks of my operation. That must be because I am very a high risk patient and things will almost definitely go wrong for me"

The examples above 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, like an infection, 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 was having painful treatments and told you they were stressed and tense, would you think he was weak and pathetic? Probably not. 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 focusing your attention on your breath
- 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.



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.



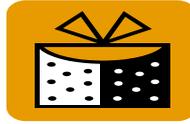
Mark was avoiding going out because he thought he wouldn't be able to find places to rest and thought people would stare. However, not going out was affecting his fitness, his relationship and his mood.

With some encouragement from his girlfriend he decided to take the risk of all these things happening and went out. While it was a challenge to find places to sit down, he discovered he could cope. While some people did stare, most people did not seem to notice him. He also figured out that smiling at people who stared or asking them "Have we met before?" worked better than looking at the floor and feeling embarrassed.

Afterwards he told his family that it wasn't easy to get about with the frame but it was not as bad as he feared. He decided that, on balance, it was worth it to continue going out. Soon afterwards he was planning the next trip. He was still apprehensive but told himself "I've done it once. I can do it again".

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.



Coping following an accident

Most people who are involved in accidents or other traumatic events will be distressed and upset in the days, weeks and even months afterwards. However, you might be feeling particularly on edge or numb, avoid things that remind you of what happened and experience nightmares or flashbacks. If you are still experiencing these symptoms six weeks after the event, with no signs of improvement, you may have post-traumatic stress disorder (PTSD). Speak to your healthcare professional about getting the support you need if you think you might be affected

Further reading

Manage Your Mind by Gillian Butler and Tony Hope
Overcoming Anxiety by Helen Kennerley



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.



**Written by Dr. Claire Doyle, Clinical Psychologist and Dr. Jane Hutton,
Consultant Clinical Psychologist**