Are you struggling?

A booklet for people living with the effects of limb reconstruction

Depression is common in people who have experienced serious lower limb injuries and limb reconstruction with a frame. Depression can make you feel hopeless and see things negatively. It is important to remember that these thoughts and feelings are part of depression, 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, which you can read in small chunks by yourself, or with family members and friends.

Overcoming depression will help you to get on with living your life, doing the things which are important to you, and taking care of your health and recovery.
Living with the effects of limb reconstruction can be hard. You may be in pain, have trouble getting about and be unable to do everything you would like to do. You may also be worried about the future, have concerns about how your body looks and have difficult decisions to make about treatment. You may be fed up with coming to the hospital and with having to rely on health professionals and family members. All of this can get you down. Most people will have days when they feel really fed up. If you are feeling this way most days for several weeks, it may be that you are depressed and will find this booklet particularly useful.

If you think you might need more help than a booklet like this can provide, speak to your health professional about the other options which are available.

**What are the signs of depression?**

You might feel...
- Sad, low, tearful, guilty, lonely, despairing, overwhelmed or numb
- Fed up and irritable, and snap at those closest to you
- Tired all the time
- Preoccupied and find it hard to enjoy things
- Restless and unable to settle to anything
- Hopeless about the future

You might also...
- Find it hard to get out of bed and to get going
- Have trouble with your concentration or memory
- Eat and sleep more or less than usual
- Stopping seeing people and doing things you enjoy
- Be harsh on yourself and think that you are not good enough
- Think negatively about the world in general
- Have thoughts about harming yourself

Some of these signs might be hard to tell apart from the symptoms of your health problem, or side effects from your medication.

If you think you are in danger of acting on thoughts of harming yourself, do ask for help, from your GP, other health professional, or at A&E.
What causes depression?
Depression is often triggered by a stressful event or situation, such as physical illness or injury. Some people seem to be more vulnerable to depression than others. This can be explained by differences in the chemistry of the brain and the body, (such as your hormones), or differences in the way we think about life and cope with stressful situations. What happens to us early in our lives can make us more vulnerable to depression later on.

Once depression has started, it can be kept going by vicious cycles of thoughts, feelings and choices.

Depression makes it hard to get going, so you might not feel like doing the things that will help you. It is important to make a commitment to do them anyway.

Depression makes you think negatively, so you might believe nothing will make a difference, or that you are not worth bothering about. Remember that these thoughts are part of the depression and are not true.

Depression also tends to make your thoughts go round and round in circles. You might hope this will help you find some answers. On the other hand, being lost in thought makes it hard to take positive action.

Depression often makes you harsh on yourself, so you might blame yourself for things which are part of the depression, such as problems with concentration. If your injury was the result of an accident, you may unfairly blame yourself for this too. Punishing yourself wastes energy which you could use in more positive ways.

Think about how you might encourage someone else, such as a child, to carry out a difficult task. Shouting at them wouldn’t help. In fact, it would probably
upset or angry, and make them less likely to carry on with the task. Gently, but firmly, encouraging them would work better. You can do this for yourself, too. For example, you might calmly say to yourself:

_You can do this. Just keep on going and you’ll get there._

This booklet offers some ideas for breaking 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 lift your mood, as well as improving your physical well-being. It may also improve how you feel about your body and how it looks.

![Salad](https://via.placeholder.com/150)

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.

**Talking to someone**

When you are depressed, you might not feel like talking, but telling someone you trust 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.

**Planning how you spend your time**

You might find it helpful to draw up a plan for the week ahead, including:

- Things you need to do, such as picking up children from school.
- Things which are important to you and will give you a sense of achievement.
• Things which you might enjoy. This might include things you have enjoyed in the past and new things you would like to try.
• Time spent with people whose company you like.
• Time to rest.

It’s good to start gradually and build up what you are doing over time.

Pace yourself realistically, taking into account both the limitations of the frame and your depression. For example, you might need to take things more slowly and take frequent breaks. Think about what might get in the way of you doing something, and plan ways round these barriers.

Give yourself credit for what you do, even if it seems quite small.

**Tackling problems**
When you are depressed, it can seem like everything is going 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.
Depression and thinking
When we are depressed, negative thoughts tend to pop into our minds. It is useful to recognise these and to remember that they are part of the depression, not helpful and generally not true.

These are some of the kinds of thoughts that are most common in depression, with examples:

Predicting the future  I’m always going to feel this bad.
Thinking the worst  This set back means I’m never going to recover.
Mind reading  She must think I’m a complete idiot.
Taking things personally  The nurse was quiet today. I must have done something to annoy her.
“Should” thoughts  People on the bus should see that I’m struggling and offer me a seat without me needing to ask.
Overgeneralising  I didn’t know the answer to that question. I am so stupid.
Dismissing the positive  I did well in physio today but it’s probably just a one off. Things are still pretty bad.

Useful questions to ask yourself, with examples
Is there any evidence against this thought?
When you feel very bad, physically or emotionally, it is easy to imagine that it will go on for ever. However, you might remember that you have had bad times like this in the past, and that things have got better. You might also know 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?
The nurse might have been quiet because something completely different was on her mind.

How helpful is it to think this way?
You might think it’s reasonable to expect someone to offer you their seat on the bus, when it seems obvious you are in pain. However, standing there getting more and more wound up, and more and more tense, will not help. It will probably be more helpful to say something like *I’m sorry to bother you, but standing gives me a lot of pain. Please could someone let me sit down?*

What would you say to a friend?
It’s unlikely you would tell a friend he was stupid just because he got one question wrong. You might say it was a difficult question, or that it was on a subject that he didn’t know much about.

In particular, depression can make you think more negatively about your health problem and recovery. For example, on days when your pain is particularly bad or when the frame is limiting what you are trying to do, you might think that you can’t cope and that it is just going to get worse.

All of this thinking, and the sadness and fear that might go with it, can happen without you really noticing. It can then make you focus more on the pain or the complication, making it feel worse, and making the negative thoughts even stronger. To break this cycle, it can help to notice these thoughts, and to ask yourself the questions above.

Recognising your good qualities and what you achieve

Depression makes it hard to notice and remember good things. It is a bit like wearing distorting glasses, which make the difficult aspects of life and the mistakes you have made very clear, but make it hard to see the good things.
We all make mistakes, and it is important to learn from them, rather than punishing ourselves for them, and to give ourselves credit for our strengths and achievements. One way of doing this is to make a list of your good qualities and things you:

- Achieve and have done, even though they were difficult
- Are good at and know a lot about
- Can help others with

You can include compliments you have been given and anything that shows you have been appreciated. Perhaps consider the kind of things you might encourage a friend to write on a job application if they wanted to show off their best qualities.

Don’t set the standard too high. For example, being a good listener does not mean you need to be ready to listen to your friends’ troubles 100% of the time, even if you are feeling really low or in pain.

Keep your list, so that you can look back at it when your negative thoughts are strong. You can add to it over time.

**Specific challenges**

**Problems after 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.

**Concerns about how your body looks**

Having limb reconstruction can have an impact on how you look and how you think and feel about your body. For example, you may have noticed changes in your body as a result of being less active and have concerns about how the frame and your limb looks. You may have had to change how you dress because
of the frame and might be fed up with people staring and asking personal questions. These issues can get you down and affect your confidence and relationships.

Earlier we saw how depression can show us the negative side of things but hide the positive. This might make you focus on your imperfections and think that others are doing the same. For example, you might think "The frame is the only thing people see".

Try to challenge these negative thoughts, which probably are not true, and pay some attention to your good qualities and achievements. Finding ways to manage staring, such as smiling or raising your eyebrows at people who stare, or having a short prepared phrase for people who ask personal questions, may help you cope with other people’s reactions.

*Getting the help you need when you need it*

It can be hard to ask for and accept help, particularly when you are not used to it. This is particularly true for men but can be true for women as well. You might have thoughts like “Everyone is sick of helping me with my pin site care” and “I should be able to do this myself”.

Try asking yourself what you would do if a friend or loved one needed your help because of an illness or injury. Maybe if the shoe was on the other foot you would be happy to help. You might even feel good about it.

*Dealing with set-backs and complications*

Complications and set-backs in your treatment, such as pin-site infections, can be extremely challenging. As well as this, depression can make you view these complications as a sign that the treatment will not work and that things will continue to be difficult without a clear end in sight.
If you notice this happening, try to focus on all of the challenges you have already overcome in your recovery. If it is your first set-back, ask your medical team about other patients who have overcome similar difficulties so you can be reminded that there is hope.

Finding a way to ask for practical or emotional support from friends, family, or your healthcare professionals may help.

Further reading
The following books were written by experts on depression and are good places to find further advice.

*Feeling Good: The New Mood Therapy* by David Burns (published 2000)
*Overcoming Depression: A guide to recovery with a complete self-help programme* by Paul Gilbert (published 2009)
*Mind Over Mood: Change How You Feel by Changing the Way You Think* by Dennis Greenberger and Christine Padesky (published 1995)
*Overcoming Depression and Low Mood: A Five Areas Approach* by Chris Williams (published 2009)

The next step
Choose where you will start with putting the ideas in this booklet into practice. Write this down, and keep it somewhere where you will see it, such as on your fridge or in your wallet. Set a date when you will review how you are doing and think about what to do next. Remember to be patient, to take one step at a time, and to be realistic about what is manageable. Be kind and encouraging to yourself, and give yourself credit when you take a step forward. Good luck!

Written by Dr Jane Hutton, Consultant Clinical Psychologist & Dr Claire Doyle, Clinical Psychologist, King’s College Hospital, July 2012