

Phantom limb sensation/pain following amputation

This information leaflet is to help you understand phantom limb pain and ways to manage it.

What is phantom limb sensation or pain?

The causes of phantom limb are unclear. There are three main theories:

- The Peripheral theory: phantom limb sensation/ pain may be the result of nerve endings around the stump forming into clusters, known as neuromas. These may generate abnormal electrical impulses that the brain interprets as pain.
- The Spinal theory: the lack of sensory input from the amputated limb causes chemical changes in the central nervous system. This leads to 'confusion' in certain regions of the brain, triggering the symptoms.
- The Central theory: the brain has a 'memory' of the amputated leg and its link to nerve signals. The symptoms are due to the brain trying to recreate this memory but failing because it is not receiving the feedback.

What is the difference between phantom sensation and phantom pain?

Sensation

This is experienced by nearly all amputees. It is the feeling that the limb is still there after amputation.

Some people may only feel some parts of their limb rather than the whole limb. They may feel a range of sensations such as: itching, aching and pressure.

Generally the sensations are not painful and can be managed with simple techniques such as touching the residual limb or the same area on the remaining limb.

The phantom sensations in your leg will feel real so it is easy to think that it is still there, and try to stand up on it. So it is important to focus when standing up or transferring as there is a risk you may fall.

Pain

For some amputees, the phantom limb may feel shortened or in an awkward position and can feel painful. This is sometimes described as a burning, aching, itching, cramping, sharp, stabbing or shooting pain.

The phantom pain is very real and can at times be debilitating, leading to a variety of responses such as anxiety, depression and difficulty adapting.

Phantom pain can be triggered by many things:

- Experiencing stressful emotions, thinking about the amputation or seeing others in pain
- Physical triggers such as movement of your stump
- Changes in temperature.

What can be done to manage phantom sensation or pain?

If you are experiencing any phantom pain, inform your doctor or health care professional and they can refer you for treatment if needed.

Examples of treatment are:

- A review of the medication you are on. Some medications that you may be given include simple painkillers and anti-inflammatories such as paracetamol and ibuprofen. Anticonvulsants such as gabapentin and pregabalin, or opioids such as codeine or morphine may also be offered.
- Review of your prosthesis (if you are wearing one) to ensure good fit and comfort.
- A look at lifestyle: for example any stress, smoking, diet, exercise and how these may impact on your pain.
- Juzo sock: an elasticated compression sock which helps with swelling and may reduce phantom pain.
- Desensitisation: initially your limb may be sensitive to touch.
 Desensitisation is important to prepare for wearing a prosthetic limb. This can include touching, tapping and rubbing over the end of your residual limb.

- **Distraction:** taking your mind off the pain like reading, listening to music or engaging in a hobby you enjoy.
- Mirror therapy: this is a type of therapy where you move you remaining limb whilst watching the movement in a mirror.

Try keeping a daily log or diary of your phantom limb pain. This can help to see if there is a pattern to the pain or if there are any triggers.

Everyone is different and everyone's pain experiences are different, therefore no single treatment will suit all. By assessing and talking with you we can try to work out which method of treatment will work best for you.

Useful contacts

Occupational Therapy

Royal Sussex County Hospital, Eastern Road, Brighton, BN2 5BE

Phone: 01273 696955 Ext: 67467

Sussex Rehabilitation Centre

(Limb Centre) Brighton General Hospital, Elm Grove, Brighton BN2 3EX

Phone: 01273 242160

Limbless Association

Provide support to amputees and the limb-loss community.

Advice on managing as an amputee and exercise opportunities.

Unit 10, Waterhouse Business Centre, 2 Cromar Way, Chelmsford, Essex CM1 2OE

01245 216670

Helpline: 0800 644 0185 www.limbless-association.org

This leaflet is intended for patients receiving care in Brighton & Hove or Haywards Heath

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