



Phantom limb pain

This leaflet is for amputee patients and aims to increase your understanding of phantom pain, including what can be done to manage it.

Understanding phantom pain

All pain sufferers benefit from knowing more and understanding the hows and whys of pain.

- It can give meaning to your symptoms.
- Make phantom pain less threatening.
- Resolve misunderstandings.
- Provide explanations.
- Allow for problem solving, giving you freedom to make changes that can improve your pain.

The difference between phantom sensation and phantom pain

Phantom sensation:

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

- It may feel normal in size, shape and sensation.
- Some people may only be able to feel some parts of their limb rather than the whole limb.
- Some people may have a range of sensations such as itching, aching or squeezing.

Generally, the feelings or sensations are not painful and can be managed using simple techniques. For example, rubbing your operated leg (residual limb) or the remaining limb in the same area that you can feel the phantom sensation.

The phantom feelings in your leg will feel real so it is very easy to think your leg is still there, and try to stand up on it. Therefore, it is important that you focus when standing or transferring, or you may fall, especially if you have just woken up.

Phantom pain

For some amputees, the phantom limb may feel shortened or is in an awkward position and can feel painful. The pain can be described as a burning, tingling, aching, itching or cramping sensation, or even a more painful sharp, stabbing or shooting pain.

This phantom pain is very real and can be debilitating leading to a variety of responses which can cause possible bouts of:

- Anxiety and depression.
- A deterioration of physical and mental health.
- A delayed ability to adapt to being an amputee.

Phantom pain can be triggered by many things such as:

- Increased stressful emotions, thinking about the amputation or seeing others in pain.

Compassionate

Aspirational

Resourceful

Excellent

- By physical triggers, such as referred sensations.
- By changes in weather or temperature.

All pain experiences are normal and they are a response to what your brain judges to be a threatening situation.

The brain receives many messages or inputs from all over the body. The brain then interprets these messages as to whether an action or output needs to take place. These messages are not painful; they may be danger messages. The brain then needs to interpret these danger messages as to whether pain is the response that is needed to help to protect us.

Pain is not only an interpretation of these danger messages but it also involves many thoughts and emotional contributions. Pain is just one of many responses our brain makes to defend ourselves.

Why do we feel that the phantom limb is still present – be it painful or not?

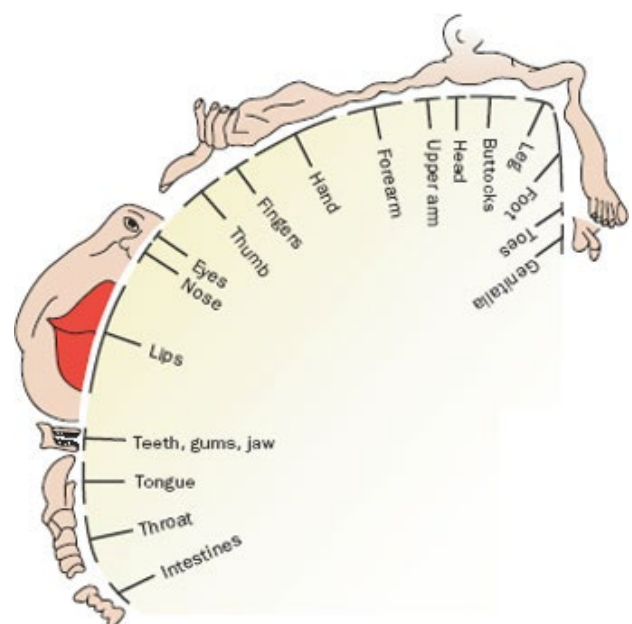
Different parts of our bodies have different amounts of sensory connections to the brain. Those parts with lots of sensory connections are more sensitive and can feel 'more'. This is mapped out on the 'virtual body' diagram (right), which shows how we feel certain parts of our body. As you may notice in the diagram the body has quite a distorted appearance, so the lips, hands, face and feet are huge while parts of the body with fewer sensory connections to the brain appear smaller.

Phantom pain is the result of a form of brain remodelling (also called remapping or smudging) – when the brain adjusts the sensory connections. Remapping or smudging is normal for the brain, it is how we learn, how we adapt.

For example, when you first put on a ring, you are initially very aware of its presence on your finger, but after a while you get used to it. It has become remapped onto the virtual body and you are no longer aware of it.

During the past 20 years, researchers have used a number of theories to explain phantom limb pain. Three of the most prominent are:

- 1) Following an amputation there has been a faulty remodelling of the neurons / nerves in the brain.
- 2) There is a dispute between the messages being sent and then received back between the brain and the missing limb. The nerves in the residual limb can be sensitive to various stimulations, including swelling, pressure from a poorly fitting prosthesis, knocking or bumping the residual limb. The nerves are also sensitive to chemical changes in the body, so it can be triggered by stress as your body releases a chemical hormone (Cortisol).
- 3) There are vivid memories of where the leg used to be or how it felt.



The brain is full of nerves which are interconnected and distributed throughout the brain. These networks are created through experiences and are called *neurotags*.

Neurotags are only activated when they receive a certain amount of input and this is called a threshold. These can come from our senses, experiences, expectations, beliefs and so on, to trigger a response or output.

Neurotag outputs can be many things, for example the smell of freshly baked bread and what that might evoke in you. This could be salivation, a grumbly tummy or a smile.

Another output may be pain. Remember, pain is only felt when the brain interprets messages it is receiving as being a threat to the body. Neurotags can become sensitised where the threshold level is reduced and therefore needs less input to be triggered. In some cases, just thinking about something can trigger an output.

Understanding what is happening to you can help. Fear of the unknown is powerful, but so too is knowledge. The fact that the brain is forever changing and adapting means that we have the power to change it. This knowledge alone may be enough to trigger a change.

What can be done?

If you are suffering from phantom limb pain, then please inform your doctor or prosthetist or therapist and they can then refer you for treatment.

Examples of interventions are:

- A review of your medication to try and dampen down your over sensitive neurones.
- A review of your prosthesis to ensure a good fit and comfort, which may then reduce your stress.
- A course of acupuncture may be appropriate in helping to manage your pain.
- A look at your lifestyle – for example stresses, smoking, diet, exercise – how these may be impacting on your pain and how to go about making some changes.
- Or it may require some brain retraining to normalise your sensitised neurotags of pain.

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 any triggers.

Everyone is different and everyone's pain experience is 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 best work for you.

Please be aware that patience, perseverance, commitment and time will be required.

Further reading

Explain Pain – David Butler and Lorimer Moseley.

The Graded Motor Imagery Handbook – David Butler, Lorimer Moseley, Timothy Beames and Thomas Giles, Noigroup publications.

www.bodyinmind.org

www.nhs.uk/Conditions/Amputation/Pages/Complications.aspx

Contact details

Gail Murray, Amputee Physiotherapist
Level 1, Battle Block Outpatients and Therapies,
Royal Berkshire Hospital, London Road, Reading RG1 5AN
Tel: 0118 322 5339 / 8545

Information courtesy of The Amputee Rehabilitation Department, Queen Mary's Hospital.

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

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