

Phantom Limb Pain

The purpose of this information leaflet is to increase your understanding of phantom limb pain. All pain sufferers benefit from knowing more and understanding the how's 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 the freedom to make changes which 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 their toes rather than the whole limb.
- Some people can have sensations of itchiness or aching.

Generally the feelings or sensations are not painful and can be managed using simple techniques, for example rubbing your stump or the remaining limb in the same area that you can feel the phantom "itch".

What can be done?

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.

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 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.

Everyone is different and everyone's pain experience is different, therefore no one 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, Noigroup publications

www.bodyinmind.org

Phantom Pain

However, for some amputees, the phantom limb may feel shortened or is in an impossible position. For about 80% of amputees their phantom limb can feel painful. The phantom pain is very real and can be debilitating leading to:

- Anxiety and depression
- Deterioration of physical and mental health
- Reduced ability to adapt to being an amputee

Phantom pain can be triggered by:

- Stressful emotions, thinking about the amputation or seeing others in pain.
- Physical triggers such as phantom sensation
- Reduced ability to adapt to being an amputee

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.

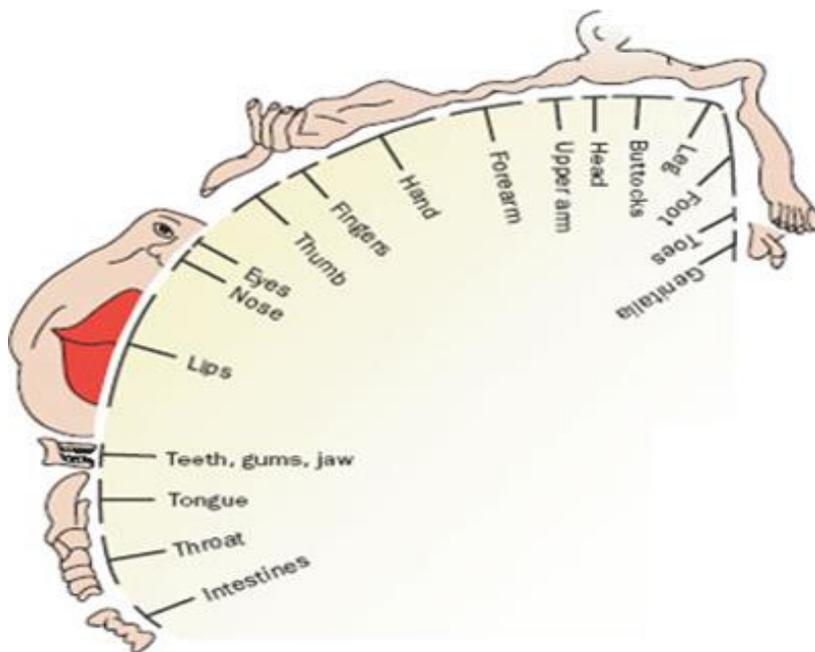
These messages are not painful, they may be danger messages.

The brain then needs to interpretation of 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?

Our body is represented on the surface of the brain in an area called **the sensory cortex**. This representation of the body in the brain is often called the 'virtual body' or 'homunculus'. Below is a picture of what the homunculus looks like:



As you may notice the body has quite a distorted appearance on the homunculus. This is because it represents the amount we feel or use certain parts of our body. So the lips, hands, face and feet are huge. Parts of the body with fewer sensory connections to the brain appear smaller.

Phantom pain is the result of a form of brain remodelling. This is called cortical remapping or smudging. 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 homunculus' hand and you are no longer aware of it.

Phantom limb pain is a complex occurrence that includes a wide variety of symptoms

tingling

itching

burning
aching
stabbing and many more.

During the past twenty years researchers have used a number of theories to explain phantom limb pain.

Three of the most prominent are:

- 1) There has been a faulty remodelling of the neurons / nerves in the brain in the homunculus area.
- 2) There is a dispute between the messages being sent and then received back between the brain and the missing limb.
- 3) There are vivid memories of where the leg used to be or felt like.

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, grumbly tummy, 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.

If you have any questions please contact us at;

**Disablement Services Centre,
Rehabilitation Department
Lower Ground Floor,
Cumberland Infirmary
Carlisle, CA2 7HY
Tel: 01228 814783 Mon – Friday: 08:30 – 16:30**

Transport

Transport is available, if you meet the eligibility criteria Otherwise you will need to make your own way to the DSC. Please phone 0800 032 3240 to book your own transport

Confidentiality

‘The Trust’s vision is to keep your information safe in our hands.’

We promise to use your information fairly and legally, and in-line with local and national policies. You have a right to understand how your information is used and you can request a copy of the information we hold about you at any time.

For further information contact the [Subject Access Coordinators](#)
SACCIC@ncuh.nhs.uk or SACWCH@ncuh.nhs.uk

Feedback

We appreciate and encourage feedback, which helps us to improve our services. If you have any comments, compliments or complaints to make about your care, please contact the PALS team (Patient Advice and Liaison Service) on 01228 814008 between 10.30 and 4.30 Monday to Friday or email PALSCIC@ncuh.nhs.uk.

If you would like this factsheet in another language or format, for example Braille, large print or audio the PALS team will be able to assist you (contact details above)

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