

Phantom limb information

This leaflet offers more information about your phantom limb. If you have any further questions or concerns, please speak to the staff member in charge of your care.

Why do I feel that my limb is still present?

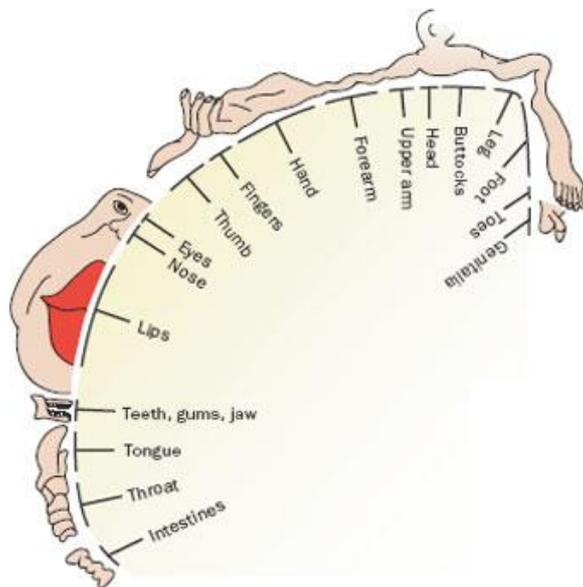
Most amputees are still able to feel their limb after it has been amputated. This feeling is called a phantom limb and is quite normal. What the phantom limb feels like is different for different people, some amputees can just feel the phantom limb, for others it can sometimes feel painful.

There is an area of your brain (called the sensory homunculus or primary sensory cortex), which holds a map of every area of your body.

If you were born with two arms and legs, this information is hard-wired into the map.

Areas which need more sensation (e.g. hands, feet, lips and tongue) have more nerve endings and are a larger part of the map.

The following is what the mental map (sensory homunculus) might look like if it was a picture:



Some parts of the body are shown as bigger than others because of the amount we use them and feel with them.

Other parts of the body are shown as smaller.

When your limb is physically removed, it does not mean that your brain wipes it from your mental map, but as the information coming into this area of the brain has changed, what is felt or experienced is different too.

What's the difference between phantom sensation & phantom pain?

Phantom sensation is felt by most amputees (80%) and is the feeling that the missing limb is still there.

The missing limb may still feel normal in size, shape and sensation, or it may feel different, e.g. you may only feel your toes rather than the whole leg.

You may also have normal sensations such as itchiness or aching.

If the feelings and sensations are not painful, you can try and manage them by rubbing your stump or your remaining limb in the same area where you feel the phantom itch or by trying to move your phantom limb.

Phantom pain may happen if, for example, your phantom limb feels shortened or in a painful position. The pain is very real and can also lead to:

- anxiety and depression
- other physical or mental health problems
- problems adapting to living as an amputee.

Phantom pain can be triggered by:

- stressful emotions e.g. thinking about the amputation or seeing others in pain
- physical triggers
- changes in weather or temperature
- memories of what your limb felt like if it was painful before the amputation.

Phantom pain is complex and may include a wide variety of pain symptoms e.g. tingling, stabbing, burning, aching and many more.

Anxiety, stress, anger and other feelings may make your symptoms worse, e.g. if you feel stressed from new situations like starting prosthetic rehabilitation or waiting to be discharged home.

What causes phantom limb pain?

Phantom pain is caused by a form of brain activity called cortical remapping or smudging.

Remapping happens all the time and is the normal way we learn and adapt. For example, when you first put on a ring you are very aware of it on your finger, but after a while you are no longer aware of it as it has been mapped onto your mind map (sensory homunculus).

All pain is in the brain. When danger is expected, one of the things your brain can do is make you feel pain so that you will do something about it. Sometimes this system can go wrong.

Because you are no longer getting any real feelings from your amputated limb, your brain may be wondering what is wrong and so makes it feel painful so you will do something about it. Your brain has misinterpreted the information as your phantom limb is not in danger.

Researchers have had different ideas to explain phantom limb pain. Three of the main ones are:

- 1) faulty remodelling of the neurons or nerves in the homunculus area of the brain
- 2) mismatched messages sent forwards and back between the brain and the missing limb
- 3) strong memories of where the limb used to be and what it felt like.

What treatments are available?

Phantom pain can settle over time, but if you are suffering from it please tell your doctor, prosthetist or therapist so they can refer you for treatment.

Treatment will help you understand more about what you are feeling and why, so you can:

- understand and explain your symptoms
- feel less threatened by your phantom
- solve misunderstandings
- problem-solve and make changes to help with your pain.

Things your treating team can do are:

- review your medication to try and dampen down over-sensitive neurones
- review your prosthesis to make sure it fits well and is comfortable, to reduce any stress linked to it
- look at your lifestyle e.g. in terms of stress, smoking, diet, and exercise and advise on how these may affect your pain and how you can make changes
- advise on brain retraining to help make your phantom feel normal.

Is there anything I can do to help myself?

Understanding what is happening to you can help. Fear of the unknown is powerful, but so is knowledge. Just knowing this can help trigger change and help with the fear of the unknown.

The brain is constantly changing and evolving, which is how we learn and adapt. Try to think of something you've had to learn as an adult or an experience such as a tooth filling. At first you keep feeling it with your tongue but then your brain adapts to it. Eventually you are no longer aware of it because your brain has learnt that your tooth is not in danger.

Because your brain is always changing and adapting, you have the power to change it and therefore the power to change how it interprets your phantom limb. It can be hard work and takes practice, but with support and guidance you can learn to do this as you can learn other new skills.

Try to feel your phantom limb as a normal limb that can move and relax. You will then have power over it e.g.: feeling your phantom limb on top of the mattress when in bed rather than feeling that it is going down through the mattress.

If you can train your brain to feel your phantom limb in a normal way and in the right place, this can also help you with your prosthesis, as you will be able to feel where you are placing your foot when walking rather than having to look and see where you need to place it.

You will also need to try and control when you feel your phantom leg, e.g. you won't want to feel it at night if you want to get up to use the toilet. This is a common time to have increased phantom sensation and to forget your leg is no longer there and try to stand.

Everyone's pain experience is different so treatment will be personal to you. We will try to work out which type of treatment will be best by assessing and talking with you.

Please be aware that patience, perseverance, commitment and courage will be needed, but with our support treating your phantom can be achieved.

Useful sources of information

Explain Pain is a brain-training book by David Butler and Lorimer Mosely, published by Noigroup www.noigroup.com

www.bodyinmind.org is a website with information about the role of the brain and mind in chronic pain.

Contact us

If you have any questions or concerns about phantom limb sensation or pain, please ask your therapist or contact the amputee rehab gym at Queen Mary's Hospital on 020 8487 6042 (Monday to Friday, 9am to 4pm). Out of hours, please leave a message on this number and we will contact you as soon as possible.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9am and 5pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough Wing (near the lift foyer).

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

Tel: 111