

## Advice Leaflet for Amputees with Phantom Limb Pain

### **Aims of this leaflet are to:**

- Explain the difference between phantom limb sensation and phantom limb pain
- Provide explanations as to why you get phantom limb pain
- Give you strategies to help alleviate pain

### **Phantom Limb Sensations (PLS)**

Phantom limb sensations are variable and the majority of all amputees will experience different feelings. They are normal feelings of the whole or of part of the limb that is no longer there. They can trick you into thinking that your limb is intact and complete and so put you at higher risk of falling when you try to move and walk so therefore it is important to concentrate at all times during activities to move safely as you have been taught by your Physiotherapist to be safe and reduce the risk of falling.

### **Phantom Limb Pain (PLP)**

Over half of all amputees suffer Phantom limb pain which are distressing sensations appearing to originate in the limb that is no longer there. The nature of the pain may be burning, tingling, itching, stabbing, cramping or shooting pains. The intensity goes from mild to severe and whilst common it is very distressing but it can be managed with medications from your GP and which specific thinking exercises with the Physiotherapist.

### **How The Brain Manages Normal Feelings and How We React To Pain.**

In the normal situation, feelings such as touch, pressure, temperatures and pain pass from our muscles and skin along our nerves in our limbs passing up through our spinal cord up to our brain. The brain then decides if this feeling is safe or harmful. If the incoming feeling is deemed to be harmful, our brain has an automatic reflex to send messages to the rest of the brain so that action is taken to reduce any more harmful situations. Imagine treading on a drawing pin the brain quickly feels a sharp and harmful sensation in the foot and so the leg muscles quickly respond with a reflex to withdraw the foot up and away from the pin to reduce the pain and save harm. If however the incoming feeling is that of warmth and comfort from slippers then there is no reaction and the limb stays rested and relaxed.

### **What Is The Cause Of PLP?**

Whilst the brain remains intact following an amputation, part of the brain becomes redundant as there are no messages from the absent limb. Following a foot amputation there will be no normal feelings from your foot on the floor or a slipper being put on or walking on a soft carpet. There is just a situation of pain and soreness from surgery and a fear of how to cope in the future. Whilst the rest of the brain remains active throughout, the redundant part of the brain can be invaded by sensations from other parts of the brain and body. It is this invasion into the redundant part of your brain that is believed to be the cause of the horrible feelings and PLP in the limb that is absent.

Most patients who have an amputation will have had pain both before surgery and after the surgery. This memory of pain can be a trigger for PLP. The limb can be felt in painful and awkward distorted positions and be felt to be stuck. Early pain relief tablets (analgesia) can help to reduce distress and can minimise the pain felt in the future. It is important to discuss with the Doctor just where your pain is felt and the nature of your pain to help the doctor identify whether it is pain from your remaining tissues from the surgery or indeed Phantom pain from the part that is no longer there.

### **How to Manage PLP?**

- Use of specific nerve medications aimed at relieving phantom limb pain (ask your GP)
- A review of your prosthesis to ensure appropriate use and fit (ask at the Limb fitting Centre)
- A review of lifestyle factors such as smoking, diet, alcohol, exercise and factors causing stress.
- Graded Motor imagery (GMI) exercises (explained below)

### **Graded Motor Imagery Exercise; A simple explanation of the theory behind it.**

<http://www.gradedmotorimagery.com/> or <http://www.noigroup.com/page/noiuk>

Graded Motor imagery is an effective treatment approach for some people to reduce the distressing pain from a part of the body that is no longer there. This pain is real; it is not imaginary but it can be reduced by using your imagination in a series of ways so tricking the brain into believing the limb is still there using 3 stages

- Left/Right discrimination (knowing left from right side)
- Explicit motor Imagery ( thinking of movement without a limb)
- Mirror Therapy (tricking the brain using a reflection of a limb in the mirror)

## HOW YOU CAN HELP YOURSELF TO REDUCE YOUR PAIN; Putting GMI into Practice

Here are 5 stages of imaginary exercises to practice; starting with stage 1. Progress slowly and don't worry if you experience a small increase of pain initially; with time it should reduce. If you progress too fast, there may be a worsening of your pain so revert back to stage 1 and work through slowly again. Practice 3/4 times every day for 10/15 minutes each time.

### **Stage 1: you need to relearn the body has 2 equal sides on the left and the right.**

**Following amputation it is common to feel very awkward, asymmetrical, one sided with overwhelming caution to protect the amputated side. There are no normal spontaneous movements; every activity is planned and thought through for safety. Movement is one sided with favouring of the remaining side and the tendency to forget there is another side to yourself. Therefore the aim of stage 1 is to relearn there are both left and right sides of the body. Try the following suggestions:**

- Look at simple pictures of limbs on the internet, in magazines or books and decide whether they are left or right images. Draw circles around the left limbs.
- If you have an Apple or Android phone, you can download the "Orientate free" app which is a game for amputees to play to practice left and right discrimination. <https://itunes.apple.com/gb/app/orientate-free/id479540062?mt=8>
- You could purchase recognise flash cards or create pictures of limbs and practice separating them into left and right piles. <http://www.noigroup.com/en/product/btrfc>

### **Stage 2: – you need to start watching others moving normally to appreciate how the body moves so effortlessly and symmetrically.**

If you have had a leg amputation try to imagine people walking, playing football, dancing. Don't think of yourself, just look at others. See them having fun.

### **Stage 3: start thinking of how you used to move, walk, run, swim and be active. Think of pleasurable activities you used to enjoy.**

- Start with simple movements; imagine walking or climbing stairs.
- Imagining your intact limb moving such as bending down and standing up, stretching up onto tip toe, moving sideways.
- Progress to imagine moving your amputated limb with the same movements as above.
- Try imagining simple movements in different environments such as on the beach or on snow. Try to imagine the different environments clearly, such as the different smells and sounds.

### **Stage 4: Start thinking of specific activities that include the part of the limb that is not there.**

- Imagine different activities you used to with the limb that is not there now. Bend and stretch the knee, move the foot up and down, wriggle the toes.
- Imagine specific tasks such as putting on slippers, or making a cup of tea if you have lost an arm.
- Imagine hobbies and sporting activities and practice specific movements required for that sport that you have done in the past – football skills, golf stances, dancing steps.
- If you suffer phantom pain with your phantom limb being frozen or stuck such as curled toes, try to imagine doing the opposite movement, such as straightening your toes. Practice unlocking and unfreezing them.

### **Stage 5: Mirror Therapy - use a mirror to replace the limb and see it move.**



Mirror therapy should be completed once you have gone through stages 1-4 and is when a mirror is placed to create the illusion of 2 intact limbs. This is something that your physiotherapist will complete with you initially and show you how to complete. You should try to complete simple exercises with the intact limb and try to imagine that these movements are occurring in your amputated limb. Try to ensure that the whole of the limb is present in the mirror. Practice simple exercises such as bending and straightening the knee, or curling and straightening your toes.

## **Further Information**

Further information on PLP and motor imagery can be found using the resources below:

- <http://www.noigroup.com/page/noiuk>
- [http://www.noigroup.com/documents/The Graded Motor Imagery Handbook ebook.pdf](http://www.noigroup.com/documents/The_Graded_Motor_Imagery_Handbook_ebook.pdf)
- [www.bodyinmind.org](http://www.bodyinmind.org)
- <http://www.nhs.uk/conditions/amputation/Pages/Introduction.aspx>
- [www.britishpainsociety.org](http://www.britishpainsociety.org)