

- Phantom pain patients may suffer from some depression. General support, counselling and pain management programmes may be of value.

WHERE TO GET HELP AND SUPPORT

Limbless Association, www.limbless-association.org Tel. 0800 644 0185
Gives information advice and support. Offers membership with a quarterly magazine.

British Limbless Ex-Servicemen's Association, www.blesma.org
Tel. 0208 590 1124.

The British Pain Society, www.britishpainsociety.org 3rd Floor, Churchill House, 35 Red Lion Square, London WC1R 4SG. Tel. 0207 269 7840
Leaflets available such as: "Understanding and Managing Pain: Information for Patients" & Spinal Cord Stimulation for Chronic Pain : Information for Patients".

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This booklet was compiled by the staff of the Pain Relief Foundation and endorsed by The Walton Centre Pain Team, Walton Center for Neurology & Neurosurgery, Lower Lane, Liverpool, L9 7LJ, UK . www.thewaltoncentre.nhs.uk

The Pain Relief Foundation is a registered charity. If you found this leaflet useful please consider donating to the Foundation. Every donation helps to fund research into the treatment of chronic pain conditions.

Copies of this leaflet are available from The Pain Relief Foundation, Clinical Sciences Centre, University Hospital Aintree, Lower Lane, Liverpool L9 7AL
Registered Charity No. 1156227 Tel. 0151 529 5820, Fax. 0151 529 5821,
Email: secretary@painrelieffoundation.org



Other leaflets in the series:

Trigeminal Neuralgia	Phantom Limb Pain	Shingles & PHN
Arthritis	Low back pain	Pain in Diabetes
Sciatica	Fibromyalgia	Cancer Pain
Pain after Stroke	Complex Regional Pain Syndrome	
Opioids for chronic pain	Chronic Pain and Sex	
Over-the-counter medicines for pain		
Drugs for nerve pain		

Disclaimer: If you have a pain problem which needs treatment you must contact your own doctor. He can refer you to a pain clinic in your area. This leaflet is for information only and should not be treated as a substitute for the medical advice of your doctor. The Pain Relief Foundation cannot offer individual medical advice.



www.painrelieffoundation.org.uk

PHANTOM LIMB PAIN

WHAT IS PHANTOM LIMB PAIN?

- **Phantom limb pain** refers to pain felt in an absent limb. The limb may have been lost because of an accident, or deliberately removed in an operation because of disease. **This kind of pain is the subject of this leaflet.**
- **Phantom limb sensations**, which are not painful, may also be felt in the absent limb.
- **Stump pain** is pain felt only in the stump of the amputated limb.
Amputees often experience all of these at the same time.
- Virtually all amputees have phantom sensations. Three quarters of amputees develop phantom pain. Most of these develop pain in the first few days after amputation. However, phantom pain may start after months or even years. Pain can last for many years, but sometimes it gets better as time passes.
- Phantom pain usually comes in bursts. Only a few people have constant pain. Some have several attacks each day, others less than one a week. Phantom pain is often described as shooting, stabbing or burning. The pain is often felt at the end of the limb, in phantom fingers or toes.
- The missing limb often feels shorter (telescoping). The phantom limb may feel as if it is in a distorted and painful position. The pain can be made worse by stress, anxiety and weather changes.

- Amputation of the arm is common after motorcycle accident injuries where the impact damages the nerves passing from the arm to the neck. This may leave the arm paralyzed and useless so that amputation is necessary.
- Amputation of the leg is commonly done to relieve the pain caused by loss of the blood supply to the leg. The blood supply is lost because of hardening of the arteries (called peripheral vascular disease, PVD). This condition is more common in smokers. Gangrene may develop in the leg and then the leg may **have** to be amputated.
- Traumatic amputations due to war injuries, such as land mine explosions, are common in the armed forces and in war torn countries.

WHAT CAUSES PHANTOM LIMB PAIN?

- **The precise cause is unknown.** Injury to the nerves during amputation causes changes in the central nervous system. It is likely that there is a very important change in the way the brain reads messages coming from the body. Parts of the brain, which controlled the missing limb, stay active. This causes the very real illusion of the phantom limb even though the amputee knows it is not real!

IS THERE ANY TREATMENT AVAILABLE?

- Treatment of phantom limb pain is difficult. Ask your doctor to refer you to a pain clinic if your pain is not improving.

DRUGS

- The usual painkillers, such as ibuprofen and paracetamol, which can be bought at the chemist, have little or no effect on phantom limb pain.
- *Antidepressants such as amitriptyline can sometimes partly help phantom limb pain. These drugs can cause side effects such as dry mouth, drowsiness, constipation or nausea. Therefore they cannot be given to all patients. It may be possible to get the right balance between side effects and benefit so that they are of some help.
- Carbamazepine (Tegretol®) is an *anticonvulsant drug used for epilepsy treatment but it can also relieve nerve pain. Other anticonvulsant drugs, lamotrigine (Lamictal®) and gabapentin or pregabalin (Lyrica®) may also help. It is worth trying them either alone or in combination with other drugs. These drugs can also cause side effects. You may feel unwell, or drowsy or develop a rash.

- These drugs must be taken regularly, for them to work, and not just when the pain is bad. Sometimes more than one drug is needed.
- Some patients may benefit from treatment with strong pain killers such as morphine. Tramadol (Zydol®, Zamadol®) is a milder drug, similar to morphine, which may also help.

**Since this pain is due to specific damage to the nervous system, drugs designed to treat other nervous system disorders, such as depression and epilepsy, can sometimes be very effective for nerve pain.*

STIMULATION THERAPY

- Transcutaneous Electrical Nerve Stimulation (**TENS**) may help some patients. This treatment, using electrodes placed on the stump, causes a tingling sensation, which may reduce the pain.
- **Spinal cord stimulation (SCS)** can be a very effective treatment for phantom pain. An electrical stimulator is implanted under the skin and an electrode is placed next to the spinal cord. The nerve pathways in the spinal cord are stimulated by an electric current. This interferes with the impulses traveling towards the brain and lessens the pain felt in the phantom limb. You will feel a tingling sensation in the phantom limb. This treatment is not suitable for everyone and patients must be carefully assessed.

PROSTHESIS USE AND REHABILITATION

- Phantom pain may be helped by the active use of an artificial limb (prosthesis). Using the limb as much as possible helps lessen the pain. Successful rehabilitation can reduce the amount of pain you experience.

COMPLEMENTARY TREATMENTS

- Vibration therapy, acupuncture, hypnosis and biofeedback may all be used to treat phantom pain, but are often of little help. The pain can sometimes be helped by keeping busy and occupying your mind. Massaging the stump can sometimes help.

MIRROR VISUAL FEEDBACK

- This treatment is still experimental, but has helped in some cases. A mirror is placed so that it reflects the opposite limb so that it looks as if the phantom limb has returned. When the opposite limb is moved the amputee sees the phantom limb move in the mirror. The phantom limb can then also be felt to move. (This is called kinesthetic sensations). If this is repeated many times it may lead to the disappearance of the phantom and the pain.