

Phantom Limb Pain and Sensation

A Common
Challenge



The War Amps

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About The War Amps

A philosophy of “amputees helping amputees” has been the hallmark of The War Amps since 1918, when the organization was founded by war amputee veterans returning home from the First World War. Today, the Association continues to serve all Canadian amputees by providing financial assistance towards the cost of artificial limbs and a wealth of information about life as an amputee.

The War Amps unique experience and resources have earned it international recognition as a centre of excellence in the field of amputation and as an expert in amputee rights.

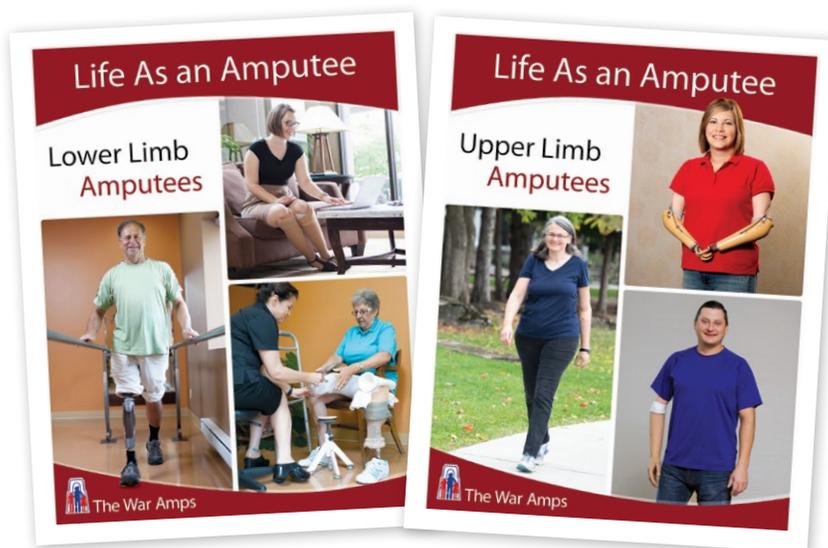
The Association provides a voice for all amputees in Canada and, through our Advocacy Program, works on behalf of individual amputees who have encountered discrimination or red tape in accessing appropriate health care, important financial benefits and/or legal rights.



Read our information booklets for new amputees

If you are about to become an amputee or have recently undergone an amputation, you are entering new territory and may not know what to expect. Our *Life As an Amputee* booklets for lower and upper limb amputees provide a brief introduction to issues surrounding amputation, including information about your clinic team of medical professionals, the rehabilitation process and the reactions you and others may have to your amputation.

These booklets are available at waramps.ca for download, or contact us to receive a printed copy, free of charge.



To find out more about
The War Amps Advocacy Program,
call 1 877 622-2472 or email
info@waramps.ca.

What Is Phantom Limb Pain and Sensation?

Phantom limb pain is a common feeling experienced by amputees in a non-existing body part, such as the arm or leg you no longer have, and should not be confused with pain in your residual limb. It is caused by the brain sending pain signals to limbs that are not there. How it feels differs depending on the person and can vary in frequency – some amputees have mild discomfort while others rate the pain as severe (e.g., a crushing feeling). Even though the feeling is in a body part that is no longer there, it is still very much real and is experienced in the same way any other pain would be, such as if you stubbed your toe.

Phantom sensation is a related but rarely unpleasant feeling that the amputated limb is still there, often experienced as a mild tingling, pressure, or pins and needles. Some amputees experience the feeling that their amputated limb can reach out and grab an item like they used to do, though this is now impossible. Phantom sensation usually decreases over time.

If you are an amputee, whether you were born with limb loss or lost a limb through an accident or illness, it is likely that you have experienced phantom limb pain at some point. For amputees who lose a limb after birth, it is felt by up to 80 per cent of people, mainly within the first year after their amputation surgery, though some people continue to have pain for many years.¹ Those with lower limb amputations tend to experience this sensation more often than upper limb amputees, with 46-90 per cent of lower limb amputees reporting pain.²

Other factors that may influence pain include gender (women tend to experience it more than



men) and whether you had pre-existing pain before the amputation (this indicates a higher chance of experiencing phantom limb pain).³ As well, research has found that phantom limb pain is often felt in several locations of the body instead of just one⁴ and is experienced more intensely in the ankle and foot area.⁵

It is important to note that every person is different and some amputees – including people who may have a higher chance of developing pain – might not experience it at all. Pain often gets better over time, although for a small number of amputees, it can become chronic and make daily living difficult.

¹ Padovani, M.T., et al. (2015). Anxiety, depression and quality of life in individuals with phantom limb pain. *Acta Ortop Bras*, 23(2), 107-10.

² de Boer, R., Paping, M., Kap, B., Geertzen, J. (2017). Residual limb claudication after vascular transfemoral amputation. *Prosthetics and Orthotics International*. 41 (6), 601-604.

³ Subedi, Bishnu, and George T Grossberg. "Phantom limb pain: mechanisms and treatment approaches." *Pain research and treatment*, doi:10.1155/2011/864605.

⁴ Smith, D., Ehde, D., Legro, M., Reiber, G., del Aguila, M., Boone, D. (1999). Phantom Limb, Residual Limb, and Back Pain After Lower Extremity Amputations. *Clinical Orthopaedics and Related Research*, 361, 29-38.

⁵ Mayer, Á., K. Kudar, K. Bretz, and J. Tihanyi (2008). "Body Schema and Body Awareness of Amputees." *Prosthetics and Orthotics International*, 32, 3, 363–82. doi:10.1080/03093640802024971.

What Is Phantom Limb Pain and Sensation?

If you have experienced phantom limb pain, know that you are not alone – many amputees have been in the same situation. Remember that your medical team and The War Amps are here to support you.

Theories About Phantom Limb Pain

Even though phantom limb pain is common, its cause is still not fully known or universally agreed upon. One theory, called the gate control theory of pain, suggests that parts of the spine create a “gate” that allows sensation to travel along the nerves, through the spine and into the brain, where it is registered as pain. Some medical professionals suggest that after an amputation this gate remains open because of the brain reacting to the loss of sensory input from the missing limb. This allows pain to be registered continuously from a body part that is not there.⁶

Another theory proposes that this type of pain occurs because the physical structure of the body has been changed (from losing a limb), which no longer matches the brain’s mapping of the body.⁷ The pain is therefore the absence of the limb that the brain is constantly seeking out.

Some researchers suggest that phantom limb pain is the result of overstimulation of the body and residual limb (the part of your limb remaining after an amputation) instead of the loss of the limb itself.⁸ This overstimulation could be caused by the amputation surgery, stress on the mind and body, and/or the sensitivity of the residual limb.

Unfortunately, medical professionals have yet to agree on a singular reason why and how phantom limb pain happens. With advances in the scientific field happening every year, it may be only a matter of time until more about this condition is understood.

Dispelling the Myths

The complexity of this condition has sometimes led to both doctors and amputees themselves minimizing the issue, which has an impact – often negative – on

understanding the cause of the pain and which treatment to use.

Phantom limb pain was once thought of as a normal part of the grieving process over losing a limb, similar to how some new amputees might have anxious or depressed thoughts because of their amputation that may go away in time. In fact, we now know that this view is incorrect, as amputees who were born missing a limb may also experience phantom limb pain just like those who lost a limb through an accident or illness.

Another myth that used to be widely accepted was that amputees who have persistent phantom limb pain should simply take over-the-counter painkillers such as ibuprofen or acetaminophen with a hot drink to feel better. Unfortunately, due to the complexity of this type of pain, more care is required in most cases.

What Is a Physiatrist?

A physiatrist is one of the most important doctors you will work with as an amputee. They are medical professionals who handle the evaluation and treatment of patients with functional impairments, such as people who lose – or are born without – a limb. Physiatrists have a “whole body” approach to rehabilitation and manage an amputee’s treatments and therapies that other medical professionals, such as physical therapists, will perform.

It is important to work with a physiatrist when seeking out treatment for phantom limb pain. Your family doctor will not have the specialized training to address this condition, but they will be able to provide a referral to see a physiatrist.

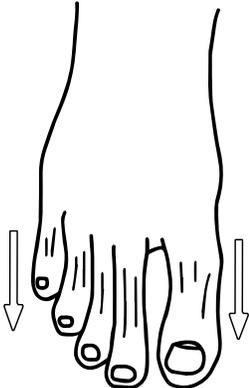
⁶ Feldman, Robert S. (1981). Current theories and treatments related to phantom limb pain. *Orthotics and Prosthetics*, 35(3), 26-30.

⁷ Padovani, M.T., et al. (2015). Anxiety, depression and quality of life in individuals with phantom limb pain. *Acta Ortop Bras*, 23(2), 107-10.

⁸ Ibid.

Common Types of Phantom Limb Pain

Amputees who live with phantom limb pain often experience it in very different ways. While some people may report a mild discomfort in the amputated part of their body, others might describe it like their fingers or toes that are no longer there are being crushed or burned. Below are some of the most common types of pain experienced by amputees, illustrated to show how they are perceived. Though these may appear graphic, we are including these illustrations as they are accurate and validating examples of what phantom limb pain can feel like, as told to us by amputees who have experienced it. Earlier versions of these graphics first appeared in a 1975 issue of The War Amps publication *The Fragment*.



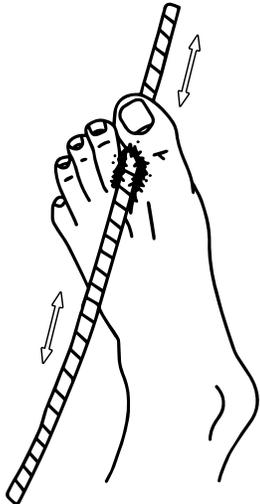
Toes are being stretched



A red-hot poker going through the foot



A hammer smashing the big toe



A rope burn sensation between the big toe and second toe

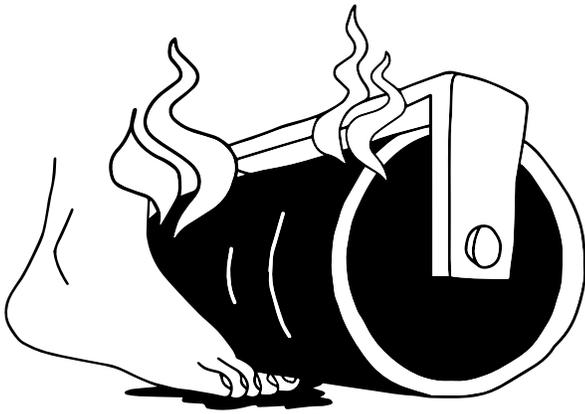


Tightly clenched fist with nails digging into the palm of the hand

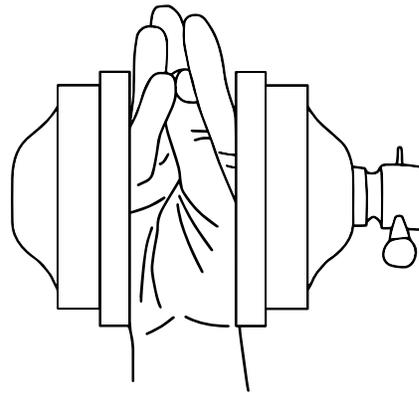


Finger nail is being ripped off

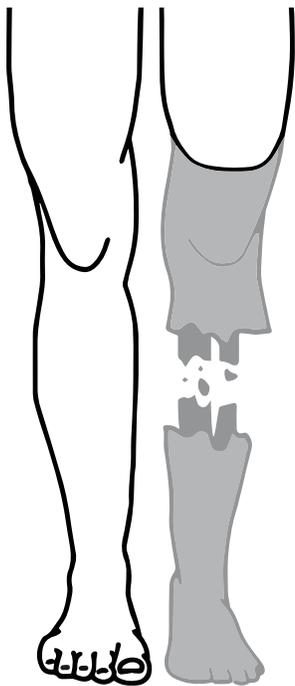
What Is Phantom Limb Pain and Sensation?



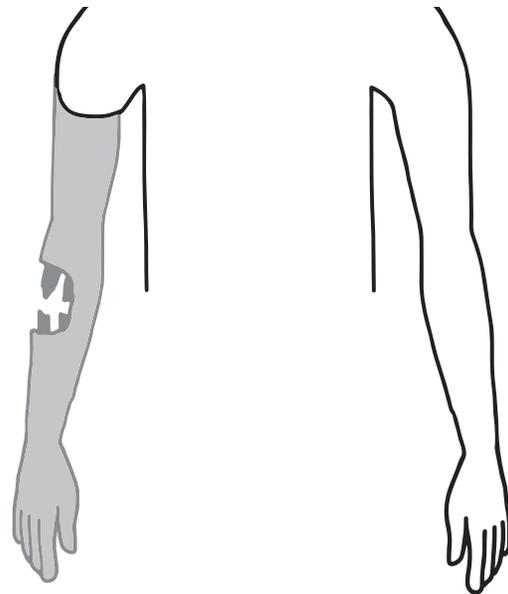
A steamroller running over the front of the foot



Hand being crushed in a press



Broken leg bones in the amputated limb



Broken arm bones in the amputated limb

Tip: When meeting with a medical professional, take a list of questions and make notes during your consultation. This ensures you will not forget an important question, and you can refer back to points shared with you in the future. A family member or friend could also accompany you, if allowed, to handle this during the consult.

Living With Phantom Limb Pain

Dealing with phantom limb pain on a daily basis can be a challenge, especially if you are a new amputee who must handle other aspects of your rehabilitation at the same time. For amputees who experience this type of pain, it can interfere with daily living activities like household chores, caring for children or going to work, and can sometimes be debilitating.

Phantom limb pain can also affect your mental health due to lower levels of quality of life. You may experience conditions such as anxiety or depression if you are not able to live your life as you did before your amputation or the onset of pain. Speak to your doctor or therapist if you are dealing with these mental health concerns; they will be able to help.

Many amputees living with this condition report that there are several factors that can make phantom limb pain worse on a daily basis, including:

- Touching or irritation of the residual limb
- Friction from wearing an artificial limb
- External temperature changes
- Emotional causes (i.e., stress)
- Overfocusing on the amputation

Peer support groups are a valuable resource

Meeting other amputees can help you to feel you are not alone. Friends and family are usually very supportive, but they have not experienced living with limb loss on a day-to-day basis. Your social worker may be able to help you find a support group in your community or online; you can also contact The War Amps for a listing of groups.



It is important to remember that the symptoms of phantom limb pain are very specific to the individual – what might cause issues for one person may not affect another amputee. For example, while some people might find that wearing an artificial limb makes their pain worse, others may actually feel better because it applies pressure to the residual limb and may relieve pain.

Treatment Options

As phantom limb pain is experienced in so many ways among amputees, it can be hard for medical professionals to properly assess and treat it. Unfortunately, some amputees are not able to get the treatment they need to relieve the pain due to the lack of in-depth knowledge about this condition, even



Non-Surgical Treatments

The following non-surgical treatments and techniques are not an exhaustive list of every option available. Many have offered relief to amputees, but it is important to remember that what might work for one person may not help another. Frequent communication with your physiatrist or medical team will allow you to try a variety of treatments to see what works best for your specific situation.

Acupressure and Acupuncture

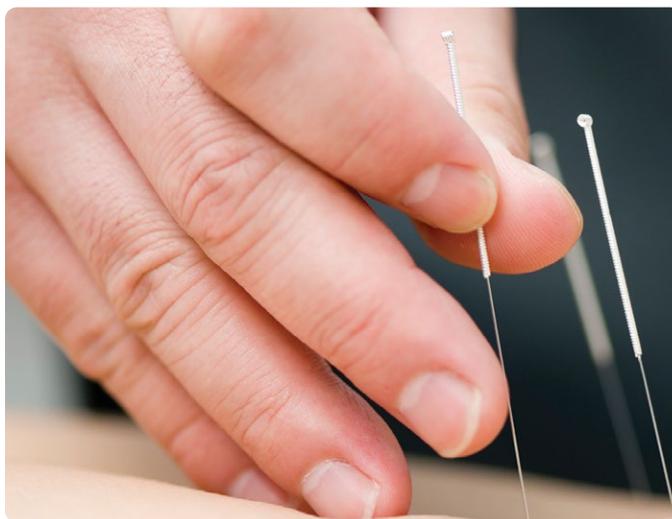
Acupressure and acupuncture are based on traditional Chinese medicine and centred on the concept that energy travels through the body along pathways that can become blocked. In acupuncture, small needles are inserted into the skin at specific points and are manipulated or used with a low electrical current to stimulate the production of endorphins, which relieve pain. Acupressure may appeal to those who are uncomfortable with needles and aims to promote “energy flow” by pressing specific points on the body. Be sure to visit an accredited professional if you are exploring these treatments.

though it is reportedly more common for amputees than residual limb pain.

Your physiatrist may want to “map” out your pain to figure out how it is perceived and where before you start treatment. This can often be helpful, as mapping gives a detailed overview that will help your medical team understand the pain patterns and sources, which can then be matched to other suitable treatment options.

Pharmacological Treatment

Using medication to relieve symptoms of phantom limb pain may be the first course of action taken by your medical team. This might include pain suppressants such as narcotics, corticosteroids and lidocaine, among other medications. Careful monitoring by your doctor is necessary to ensure you are taking the correct dose and to avoid interactions with any other medications you may be taking.



Biofeedback

Biofeedback aims to reduce muscle tension or tightness, which may contribute to any pain you are feeling. Electrodes are attached to the residual limb to detect tension, which then triggers a flashing light or buzzer to provide information on where you can relax your muscle(s) to relieve pain.

Chiropractic Therapy

Visiting an accredited chiropractor for chiropractic therapy involves manual adjustment or manipulation of the spine or other joints to correct misalignments and alleviate pain.

Cold and Heat

In certain circumstances, either cold or heat may help with pain. Using a cold compress or cooling cream/gel (such as Biofreeze®) can numb feeling, while taking a warm bath, applying a heating pad or wrapping your residual limb in warm, soft fabric will help increase circulation. Products with warming qualities such as Rub A535™ or Tiger Balm® may help too.

Desensitization

The nerves in your residual limb can be very sensitive, especially after amputation surgery. Desensitization can reduce nerve sensitivity, pain and discomfort that may contribute to phantom limb pain.



Some amputees have found it helpful to massage their residual limb with a soft cloth or use gentle manual manipulation or vibrations.

Dietary and Herbal Supplements

Some examples of supplements that amputees have found helpful include potassium, magnesium, vitamin B12 injections, juniper berries or Pycnogenol® (a pine bark extract that contains antioxidants). Consult your doctor before taking any supplement or herb, as they can have powerful side effects and may interfere with your existing medication.

Exercise

Exercise increases circulation and stimulates the production of endorphins, which can reduce pain. Many amputees find that moderate, regular exercise can reduce phantom limb pain. Stretching and yoga may also help loosen muscle tightness and tension. If you would like to continue doing certain sports you did before your amputation, discuss with your physiatrist, physiotherapist or prosthetist how to do them safely to limit pain.

Magnetic Therapy

This type of treatment involves using a magnetic field to relieve pain by improving circulation; it may also reduce inflammation and promote healing. The magnets are usually incorporated into bracelets, belts or fabric straps.

Massage Therapy

Massaging the residual limb increases blood flow and circulation, which may alleviate phantom limb pain. This therapy can also help reduce swelling and loosen stiff muscles, as well as provide relaxation. Visit an accredited professional for this treatment; with guidance, it can also be practised on your own.

Meditation

Meditation may help relax tense muscles and lower anxiety levels, as mental tension can worsen pain. By listening to a guided meditation or practising on your own, you can do helpful visualization exercises to make the pain seem remote and to calm your mind.

There are many free and paid apps that can help you with this, as well as online meditation videos or podcasts.

Mirror Therapy

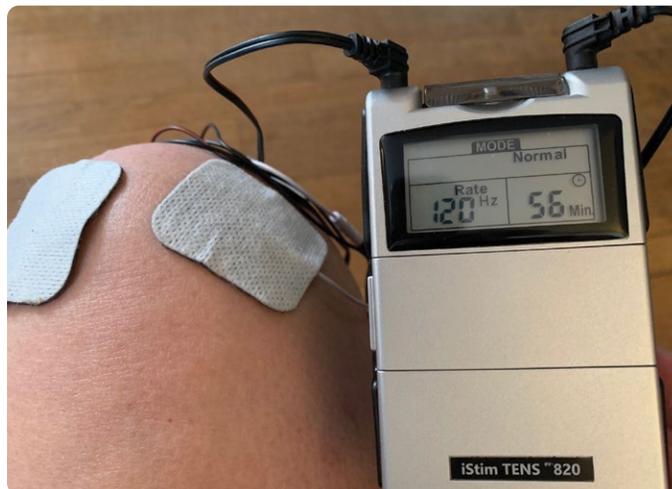
A treatment called mirror therapy may trick your brain into thinking that your amputated limb still exists, therefore reducing phantom limb pain. By placing a mirror lengthwise facing your sound (unamputated) limb, the reflection creates the illusion of two limbs moving together. It also incorporates a technique of muscle tensing and relaxing. In a study, this treatment was found to reduce phantom limb pain after a month of regular practice, largely due to the restructuring that takes place in the brain when presented with this new information.

Shrinker Socks and Shielding Materials

Bandaging and shrinker (compression) socks apply even pressure to the residual limb and may help reduce phantom limb pain. Some shrinker socks contain silver, which may shield the residual limb from barometric changes (a potential trigger for phantom limb pain). Fabrics like Farabloc™ contain thin steel threads that shield the limb and protect nerve endings from electromagnetic waves, which may cause pain. One study found that wearing an electromagnetically shielding liner over your residual limb reduces phantom limb pain significantly. Farabloc™ can be cut, sewn and washed like any other fabric and is available in various sizes.

Transcutaneous Electrical Nerve Stimulation (TENS)

TENS units have pads that attach to the skin and create an electrical current that stimulates the nerves and provides pain relief. Consult your doctor before using this treatment; it should not be used by people with heart disease, heart arrhythmia or those who have a pacemaker.



A TENS unit like this one may be able to reduce phantom limb pain symptoms.

Virtual Reality Therapy

Similar to mirror therapy, virtual reality therapy tricks the brain into believing there are two intact limbs. Using this technology through a headset allows you to “see” your own body with the limb you lost present again.

Surgical Treatment

Revision surgery amputates more of the residual limb in cases of infection, abnormal amputations and where altering nerve endings is important. Undergoing surgery is the last option for treating phantom limb pain because it is more invasive than other methods and could potentially make the pain worse.

Getting surgery does not guarantee a reduction in pain, either – only 35 per cent of amputees who undergo revision surgery feel less pain and 26 per cent of people need four or more revisions before they experience any change at all.⁹

There are other types of surgical treatments, including a tractotomy, injecting muscle relaxants and other pain suppressants, and ablation therapy targeting lesions. These options are less invasive than revision surgery, but they still pose a risk like any surgical treatment and should be weighed carefully by you and your medical team.

⁹ Wood, M.R., Hunter, G.A., Millstein, S.G. (1987). The value of revision surgery after initial amputation of an upper or lower limb. *Prosthetics and Orthotics International*, II, 17-20.

Moving Forward



Despite phantom limb pain being a common condition among amputees, there is still much to be learned and understood. Medical professionals have not been able to agree on only one theory as to why it happens and how to treat it, but there are always new discoveries being made and many options for treatment that may work for you.

Phantom limb pain is an important topic to discuss with your physiatrist, who should take your experiences into account during your rehabilitation in both the short and long term. Remember, you are your

best advocate during your treatment. Talking to your medical team about the challenges you are facing with phantom limb pain will help you get the best and most accurate treatment. This can also help future patients by normalizing and shedding light on this complex condition.

The War Amps is here to help. With more than 100 years of experience assisting amputees, we can provide knowledgeable information and guidance on many aspects of daily living and care. Contact us for more information or visit waramps.ca.

Receive War Amps resources free of charge

The War Amps offers invaluable information about living with amputation through our many resources, which can be sent to you free of charge. Some booklet topics include being an amputee in the workforce, driving with an amputation and daily living aids. Most of our resources are also available at waramps.ca.



Appendix

Technical Terms

The list below explains some of the terms commonly used in the field of prosthetics that relate to phantom limb pain. You may want to keep it handy for future reference.

Acquired amputation

An amputation due to a traumatic injury, or an amputation necessary to treat a disease or illness

AE

An above elbow amputation; also referred to as transhumeral

AK

An above knee amputation; also referred to as transfemoral

Amputation

Removal of all or part of a limb(s) due to injury, disease or illness

Amputee

A person who has had all or part of a limb(s) removed or is born without all or part of a limb(s)

BE

A below elbow amputation; also referred to as transradial

Bilateral amputee

An amputee missing both arms or both legs

BK

A below knee amputation; also referred to as transtibial

Congenital amputee

A person who was born missing part or all of a limb(s)

Desensitization

The process of making the residual limb less sensitive to touch by massaging, tapping, using vibrations or rubbing with a cloth

Edema

Swelling of tissue

Neuroma

A ball of nerve fibres that forms on the end of a severed nerve that continues to grow and can sometimes cause pain

Occupational therapist

A person who works with an amputee to teach them adaptive skills and how to use an artificial limb

Phantom limb pain

Pain experienced by an amputee in a limb or part of a limb no longer present

Phantom limb sensation

Sensation that a limb or part of a limb no longer there is still present

Physiotherapist

A person who works with an amputee in the rehabilitation phase to improve muscle function through exercise and can assist with gait training

Prosthesis

An artificial limb

Prosthetist

A professional who builds and maintains artificial limbs

Rehabilitation

The process of restoring a person who has been debilitated to a functional life

Residual limb

The part of the limb remaining after the amputation

Revision surgery

Surgical alteration of the residual limb to improve function, appearance or pain

Sequelae

Effects of a disease, injury, procedure or treatment

