



Phantom limb pain (PLP) refers to ongoing painful sensations that seem to be coming from the part of the limb that is no longer there. The limb is gone, but the pain is real.

The onset of this pain most often occurs soon after surgery. It can feel like a variety of things, such as burning, twisting, itching or pressure. It is often felt in fingers or toes. It is believed that nearly 80 percent of the amputee population worldwide has experienced this kind of pain.

The length of time this pain lasts differs from person to person. It can last from seconds to minutes, to hours, to days. For most people, PLP diminishes in both frequency and duration during the first six months, but many continue to experience some level of these sensations for years.

People are often reluctant to tell anyone that they are experiencing PLP or phantom limb sensations, for fear that they will be considered “crazy.” However, it is important to report these pains as soon as you begin to experience them so treatment can be started.

What You Need to Remember

- Phantom limb pain/sensation is common for most people after amputation surgery. Symptoms generally improve over time.
- Your phantom limb pain/sensation can be managed so that it does not overwhelm your life.
- The goal of pain management is to reduce pain levels to allow you to get you back to living and enjoying life again.
- Work closely with your healthcare team to create and maintain the pain management plan that works for you.
- When possible, avoid things that trigger your phantom limb pain/sensation.
- Use the Amputee Coalition Web site (amputee-coalition.org) to learn about new therapies and to let others know if a new therapy has worked for you.

About the Amputee Coalition

The Amputee Coalition is a donor-supported, voluntary health organization serving the nearly 2 million people with limb loss and more than 28 million people at risk for amputation in the United States.

For more information, please call **888/267-5669** or visit **amputee-coalition.org**.



Living With Phantom Limb Pain

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What Causes Phantom Limb Pain?

Unlike pain that is caused by trauma directly to a limb, PLP is thought to be caused by mixed signals from your brain or spinal cord. This is an important concept to consider, because the treatment for this pain has differences from the treatment you would receive for other kinds of pain. New therapies for PLP all involve trying to change the signals from your brain or spinal cord.

As with any other kind of pain, you may find that certain activities or conditions will trigger PLP. Some of these triggers might include:

- Touch
- Urination or defecation
- Sexual intercourse
- Cigarette smoking
- Changes in barometric pressure
- Herpes zoster
- Exposure to cold

If you notice any particular thing triggering an episode of PLP for you, let your healthcare provider know. Some triggers can be avoided — for example, you can prevent constipation or stop smoking. For other triggers, you will just have to understand and treat accordingly. You will not be able to prevent the barometric pressure from changing, but you will be able to understand that your PLP might be more severe on days with big shifts in the weather!



Treating Phantom Limb Pain

Treating PLP effectively takes a multipronged approach. Medications of several different categories in combination with non-medication treatments seem to be most effective. This combination of medication/non-medication is similar to treating other painful conditions.

For instance, if you broke your leg, you would expect to take narcotic pain medication, at least for a while. You would also elevate your leg and put ice on it. For PLP pain management, you will take medications directed specifically toward interrupting the pain signals in your brain or spinal cord as well as using certain non-medication therapies, which also work on your brain's interpretation of these signals.

Medications for Phantom Limb Pain

There are many different categories of medications that can decrease your pain. Each of them is thought to work on different kinds of pain sensations. Here are the categories of some of the medications you might be given:

- Acetaminophen and non-steroidal anti-inflammatory drugs (NSAIDs)
- Opioids (narcotic pain medications)
- Antidepressants
- Anticonvulsants
- Beta-blockers
- Muscle relaxants

Some of these medications work best if taken in combination with other medications and if given at certain times of the day. The antidepressants typically used work best if given at bedtime, and are often taken at the same time as the anticonvulsants. Finding the right medications — with the fewest side effects — will require you and your healthcare provider to work closely together.



Non-Medication Treatments for Phantom Limb Pain

Alternative/complementary therapies can be helpful for the reduction of PLP. Here are some of them:

- Acupuncture
- Mirror box therapy
- Biofeedback
- TENS (transcutaneous electrical nerve stimulation)
- Virtual reality therapy
- Imagery
- Music

There are many YouTube videos demonstrating how these therapies have worked for others and how they might work for you.