



amputee
coalition™



Pain Management

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● INTRODUCTION TO
PAIN MANAGEMENT



Pain is a sensation that hurts. It is subjective, meaning that if you are having pain, you are the only one who can feel it and tell others about it. Only you can tell where it is, what it feels like, and if the treatment given for it has worked. Pain can make it hard for you to concentrate on anything except the pain. It can make it hard for you to sleep and hard for you to function when you are awake. It can be depressing, frustrating and overwhelming. However, it is possible to reduce pain and to learn to cope effectively with the pain that remains.

Understanding Types of Pain

People with limb loss experience many different types of pain. Understanding the type of pain you are experiencing and describing it clearly can help you and your healthcare team determine the most effective treatment for decreasing your pain. These terms include:

- **Phantom limb sensation (PLS):** This describes sensations that you might continue to feel in your amputated limb, even though it is no longer there. These sensations may include tingling, pins and needles, itching, temperature changes, pressure, abnormal position and movement. These sensations are not painful; therefore, no treatment is indicated.
- **Residual limb pain (RLP):** This is the pain that originates in the part of your limb that remains. It can be caused by swelling, nerve damage or irritation from your prosthesis.
- **Phantom limb pain (PLP):** When the phantom limb sensations are uncomfortable or hurt, they are called phantom limb pain.

In addition to these types of pain or sensation, there are the pains that you might have experienced before your surgery and the pain that you will experience during normal healing after your surgery.

There are different ways of helping you manage your pain, depending on which type it is. Again, knowing what kind of pain you are experiencing makes it easier for you and your healthcare team to manage that pain – so it doesn't manage you!



Preparing to See Your Healthcare Provider

Here are the things you should do before going to see your healthcare provider about your pain or sensation.

1. Write down your symptoms. When are you experiencing pain? Is it when you are wearing your prosthesis? What were you doing when the pain started? How long does it last? What have you tried to decrease the pain? Does anything help? Keeping track of your symptoms with paper and pen works great. You can also use your computer or smartphone to help. Managemypainapp.com walks you through everything you should be keeping track of regarding your pain. Whatever you use – paper, computer, or smartphone – be sure to take your personal pain record with you to your appointment.

It cannot be emphasized enough how important it is to track your pain. Tracking will likely improve your understanding of your pain so that you will become more effective in coping, and it is a very important communication tool you can use to help your healthcare provider understand why and when your pain occurs.

- 2. Make a list of your key medical information.** This includes any conditions that you have been diagnosed with by any of your healthcare providers and names of all the medications, vitamins and supplements you are taking. It is good practice to keep this list updated and to always bring it to every healthcare provider you see.
- 3. Take a family member or friend along.** Don't leave your companion in the waiting room! Have him or her in the exam room with you. Four ears are definitely better than two when it comes to hearing your healthcare provider!
- 4. Write down questions to ask.** Things like: What are the treatment options? Is there anything besides medication? If medication is prescribed, ask how it works and what the side effects might be. Ask if there is a chance of addiction or dependency if you take it. You might also ask if you should see a specialist. And, be sure to ask if insurance covers it.



The Agency for Healthcare Research and Quality (AHRQ) has an easy-to-use, customized Question Builder that can help you come up with the list of questions you will want to ask your healthcare provider (<https://www.ahrq.gov/questions/question-builder/online.html>).

Next Steps

Once you understand the different kinds of pain you may experience after amputation and have prepared for your appointment with your healthcare provider, you are on your way to managing your pain. It may take some time and patience, but with you and your healthcare provider working together, you can find the treatment plan that will work for you!



PERI-OPERATIVE PAIN MANAGEMENT

The term “perioperative” refers to the period of time that starts when you go to the hospital for surgery and ends when you are discharged. From a pain management perspective, the plan of how your pain will be treated after surgery begins before surgery.

Pain management is important whenever you have surgery. It is even more important when

you have an amputation, because evidence suggests that the better your pain is managed during the time immediately after surgery, the fewer symptoms of phantom pain you will experience.

You have an important role in pain management, from the minute you enter the hospital until the time you leave. You are a

member of your pain management team! Before surgery, you will be giving information about your past experiences with pain management; after surgery, you will be letting your doctors and nurses know how well the pain medications are working.

Before Surgery

When you are admitted to the hospital, you will be asked a lot of questions about pain, including if you currently have pain and if you have been taking pain medication. Be patient! The questions may seem like they are repeated over and over again by the doctors and nurses, but the more information you can give them, the better they will be able to prescribe the best medications for you to use after surgery.

Here is some of the information you will want to give your healthcare team:

- What medications are you currently taking for pain, including non-narcotic medications? Include over-the-counter medications and herbal supplements.
- If you have taken pain medications before, let them know how well they worked. Did you have any side effects that you found particularly unpleasant? Did one medication work better than another?
- Have you ever gone to a doctor who specializes in pain management?
- Are there other things you have done or are doing to help relieve pain? Have you tried cool or warm packs, elevation or TENS (transcutaneous electrical nerve stimulation)? Is there something you do to help you relax when you are having pain?
- The answers to all of these questions will help your healthcare team create a pain management plan that is right for you.

Pain Scale

While you are in the hospital, you will be asked over and over again to rate your pain. The information you give about your level of pain will help the doctors and nurses make sure they are giving you the right amount of pain medication.

There are several different pain scales that can be used, but the two most common are the “Faces” scale that is generally used for pediatric patients and a number scale that asks you to rate your pain from “0 – 10” (“0” being no pain and “10” being the worst possible pain). There is no “right” or “wrong” number for pain. The scales just allow you to tell your healthcare team how much pain you are having and if it is getting better or worse.

Since you will be asked for your “pain number” over and over again, it can seem repetitious and boring. But hang in there – it is all part of helping make sure your pain is managed as well as it can be.

Pain Management After Surgery

There are a growing number of methods to help with pain management after surgery. Some of these are started during the surgery itself and can be continued for several days after surgery; these include:

- Nerve blocks — where an anesthetic or pain medication is injected near a nerve.
- Epidural blocks — where an anesthetic or pain medication is injected just outside the spinal cord but inside the spinal canal.

Another option is a spinal block – where an anesthetic or pain medication is injected into the spinal cord to mix with the spinal fluid. Unlike the nerve block or the epidural block, spinal blocks cannot be continued after surgery.

Narcotic pain medication will also be used for pain management. Generally, these medications are administered through your IV, often through a patient-controlled analgesia

(PCA) pump. Your doctor will order the medication to be given through the PCA, and then you will be able to give yourself doses by pushing a button. No waiting for a nurse to bring you your pain medication!

Non-narcotic pain medications may also be helpful, as are ice packs and extremity elevation.

Some hospitals now have complementary therapies available to help with pain management. Relaxation techniques, massage, aromatherapy, music therapy and acupuncture have all been found to be helpful for some patients. You may want to ask if any of these therapies are available for you to use after surgery.

Leaving the Hospital

As your pain lessens after surgery, you will be transitioned from IV pain medications to pain pills. You will continue to take pain pills after you leave the hospital. The need for these medications will decrease over the first few weeks. You will probably find that ice packs and relaxation techniques continue to be helpful.

LIVING WITH RESIDUAL LIMB PAIN



What is residual limb pain (RLP)? This is the pain that originates in the remaining part of your limb. It can be caused by a variety of conditions related to your surgery or it can be caused by conditions you had prior to your amputation. You and your healthcare team will want to work carefully together to understand the origin and cause of your pain in order to treat it successfully.

Normal Postoperative Pain

After surgery, your postoperative pain will diminish over the first few weeks. After you are discharged from the hospital, you may still be taking pain pills, but should be able

to decrease the number of pills fairly quickly. Methods to decrease swelling will also help reduce your pain, including elastic wraps and residual limb socks, light massage and finger tapping, and cold packs.

Residual limb pain is different from this normal postoperative pain. For example, it commonly occurs after your postoperative pain has ended. It is frequently described as sharp, aching, throbbing or burning in nature. Your entire healthcare team, including your doctors, therapists and prosthetist, will work with you to determine the cause of this pain and decide what treatments might be most effective.

Possible Causes of Residual Limb Pain include:

- Underlying disease process such as skin problems and infection and nerve pain (neuropathy), especially if you have diabetes or circulatory problems
- Surgical trauma, including decreased blood supply to your limb or poor tissue coverage at the end of the bone
- Neuroma formation
- Entrapment of nerves in scar tissue.

Underlying Disease Processes

Key to managing symptoms of pain that have to do with a pre-existing condition like diabetes is to make sure that the condition is managed as well as possible.

For example, if you have diabetes, keep your blood sugar under good control. If you have poor circulation, follow your physician's instructions for diet, exercise and medications.

Managing pre-existing conditions after surgery is as important as ever.



Surgical Trauma

Poor tissue coverage can be caused by the bone at the end of your residual limb not being properly trimmed at the time of surgery, and this can cause pain when you wear your prosthesis. If padding and other methods are not successful, surgery may be required to revise your residual limb so as to decrease your pain and allow you to wear your prosthesis.

Neuromas

A neuroma is a collection, or bundle, of nerve endings that forms under the skin of your residual limb. Think of it like a tangle of hair. It can become very sensitive, especially if the tangle is pressing against your prosthesis.

Because neuromas are made up of nerve endings, possible treatments include medications that help with nerve pain, such as:

- Non-steroidal anti-inflammatory medications
- Specific antidepressants and anticonvulsants that have been found to be effective for nerve pain
- Steroid injections
- Non-medication options include:
- Ultrasound, which is essentially a machine

that uses sound waves to generate heat within a body part. It can help increase blood flow so that inflammation and swelling can be decreased

- Massage, which also helps decrease inflammation and also helps desensitize your residual limb to touch
- Vibration, which creates a mild shaking to contract muscles, and to decrease inflammation and pain
- Percussion/finger tapping at the point of pain, which also helps with desensitization of your residual limb
- Acupuncture, manipulating thin, solid needles that have been inserted into specific pressure points in the skin, which has been helpful for some
- TENS (transcutaneous electrical nerve stimulation), which produces a sensation of mild pins and needles, overriding some of the pain that your body is producing.

Modifying the prosthesis socket to prevent rubbing at the sensitive part of your limb may also be helpful.

Unfortunately, surgery to remove neuromas is not usually successful, because they often just reform.

Heterotopic Bone

Occasionally, excess bone forms abnormally around the end of the amputated limb; this is sometimes called a “bone spur.” The “extra” bone may cause pressure points that interfere with the fit of your prosthesis; this occurs more frequently in children than adults. If the problem cannot be solved with changes to the prosthesis, surgery can remove the excess bone. For children, this is best done after the bone stops growing.

Entrapment of Nerves in Scar Tissue

As your incision begins to heal, your doctor will let you know when you can start massaging your residual limb. This will help to prevent nerves from being “caught” in scar tissue. You will also be taught how to wrap your limb using elastic wraps. This not only helps to prevent scarring but also helps with prosthesis fit.

Managing Pain

No matter the cause of residual limb pain, there are some principles that can be followed to help you manage your pain.

LIVING WITH PHANTOM LIMB PAIN

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 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
- Shingles
- 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



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.



AVOIDING SECONDARY PAIN

Key to preventing secondary pain after limb loss is preventing complications. This means taking meticulous care of your residual limb, your prosthesis and your general health.

Because your residual limb is hidden under your prosthesis, paying close attention to how it looks when your prosthesis is off is very important. Developing habits of twice-a-day inspection and care is very important.

Also important is taking care of your prosthesis, liners and socks.

And what is meant by the term “general health”? This means eating well, getting physical exercise and rest and emotional well-being. It also means managing any health conditions as well as possible. If you have diabetes, this means keeping your glucose levels under good control. And it means maintaining a healthy weight, without swings of weight gain or loss.

General Guidelines for Taking Care of Your Residual Limb

It is hard to overstate the importance of taking care of your residual limb. Your healthcare team will give you instructions, but here are some general rules:

- Wash your residual limb twice a day.
- Use mild, fragrance-free soaps, as they are the least likely to cause skin irritation.
- Use water-based lotions rather than alcohol-based, which have a tendency of drying the skin.
- Wash your liner every night.
- Do not wear a wet liner.
- If your amputation is below the knee, check the hard-to-see area behind your residual limb knee with a mirror.
- Report to your prosthetist the development of any blisters or reddened areas (that don't go away when your prosthesis is off) on your residual limb.



Care for Your Prosthesis

- An ill-fitting prosthesis greatly increases your risk of secondary pain. The socket should be comfortable and practical.
- Always wear shoes with the same heel height as the one your prosthesis was aligned with originally to maintain the right alignment.
- You should check your prosthesis frequently for unusual signs of wear and tear and report concerns as soon as possible to your prosthetist.
- Pistoning and perspiration are two conditions that can cause pain in your residual limb.
 - **Pistoning:** This occurs when the residual limb slips up and down inside the prosthetic socket while walking. This can cause the skin to pull and be damaged. This is generally caused by one of two things: either by trapped air between your residual limb and your socket liner or by weight loss. To prevent trapped air, be sure to put your socket liner on by rolling it on. If you continue to experience pistoning after you have correctly applied your socket liner, contact your prosthetist to have your fit checked. To accommodate weight loss, some sockets can be reduced and/or padded, thicker liners may be used or air bladders may be installed.
 - **Perspiration:** Sweating is normal but can cause heat rash and abrasions. When sweating occurs, you should immediately remove your prosthesis. Dry your liner and skin before putting your prosthesis on again.

Keep Moving

When a group of people with limb loss was surveyed, nearly 50 percent reported pain in their non-amputated limb and 62 percent reported low back pain. This is because after amputation other muscles and joints have to carry extra stresses and loads. These stresses can cause strain, inflammation and further pain. Additionally, low back and hip pain can increase symptoms of phantom pain.

Your physical therapist can help you design an appropriate exercise program. Regular exercise will help you strengthen and retrain your muscles. Besides walking, a good follow-up program may include back extension strengthening and balance exercises – important for helping to decrease the stresses to your low back and hips. You should try and see your therapist once a year or so for gait evaluation. If you slowly develop poor gait habits, it can cause back and/or hip pain.

Weight Management

Maintaining a healthy weight is important for everyone. It is even more important after your amputation. Even a 5-pound weight gain or loss can make a difference in the fit of your prosthesis.

Eat a well-balanced diet and drink plenty of water. Not only will this help with weight management, but it will also help with maintaining healthy skin.

Report any change in your weight to your healthcare provider and prosthetist.

Emotional Well-Being

Emotional well-being is another important part of preventing secondary pain; this is sometimes referred to as the mind-body-spirit connection. Here are some suggestions for how to decrease pain through focusing on your emotional well-being.

- Practice relaxation. We know that tension and stress increase pain. It is estimated that 50 percent of pain can be reduced by relaxation.
- Do things that you enjoy (e.g., hobbies, movies) with people you enjoy being with. Do something new and different every day.
- Get social support. Stay in contact with friends and family, whether in person or by phone/Internet.



ABOUT THE AMPUTEE COALITION

The Amputee Coalition is a national donor-supported, nonprofit health organization serving the over 5.6 million people who have limb loss and limb difference in the United States.

For more information, please call 888-267-5669 or visit [Amputee-Coalition.org](https://www.Amputee-Coalition.org).

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ACKNOWLEDGEMENTS

This project was supported, in part, by grant number 90LLRC0002-01-00, from the Administration for Community Living, U.S. Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

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