Pain Management and the Amputee

by Partners Against Pain & NLLIC Staff

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Pain Management

This fact sheet provides important and practical information you can use to get the help you need to manage your pain. In many instances pain will decrease over time; however, in some cases it may be necessary to take more aggressive steps to control pain. The information contained within this fact sheet is provided to give you the information you'll need to cover all eventualities. One of the most important things to remember is that pain can be caused by an ill-fitting prosthesis, so maintenance of a good fit at all times is imperative. Many of these tips are questions for you to ask; the subsequent answers will give you more information about your condition, about treatment, and about pain management. Remember: you have a right to ask questions and to understand your options.

Long after surgical wounds have healed, as many as 80 percent of all amputees still experience pain in their residual limb and in the part that is now missing.[1] When an amputee has pain that feels like it comes from a missing limb, finger or toe, this type of pain is usually called *phantom pain*. However, some may only experience *phantom sensations*, which are not always painful. It is common for an amputee to still feel his or her missing limb intact. Sensations such as movement, touch, pressure, itching, posture, and sensitivities to heat and cold can still be felt although the affected body part is no longer present.

Despite the labels, *phantom pain* and *phantom sensations* are very real to the amputees who experience them; they can be physical and/or psychological. While there is still a lot to be learned about phantom pain, at present there is much speculation and theory. Dr. Douglas Smith, medical director of the Amputee Coalition of America (ACA), has written several articles about pain for the ACA, the most recent being a series of articles titled "The Phantom Menace," which focuses on phantom pain and the conventional and alternative ways to approach it. The series can be found in the ACA online library catalog or can be requested by contacting the ACA.[2]

Why is Managing Pain Important?

"Pain is a thief. Pain robs the person in pain of the chance to enjoy being alive…"[3] Unrelieved pain can completely change your quality of life. It can make it hard to sleep, to work, to socialize, and to perform daily activities such as housework. Relationships with friends and relatives may become strained. Ongoing pain can leave you with no appetite, which can lead to weakness. Pain that is not treated can also cause depression and feelings of hopelessness.[4] Many people think that pain is an unavoidable part of limb loss. Your condition may cause pain, but it can and should be treated. Luckily, there are many options available today to manage pain effectively.

You Are the Expert

The most important part of good pain control is the role *you* play. Remember that nobody understands your pain the way you do; and only you know how much pain you feel and where it hurts.[4] You may have to help your doctors, nurses, friends and family understand your pain, and you or a caregiver may have to *ask* for the help you need. Learning to communicate with your doctors, nurses, friends and family will help you become an active participant in your care.

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Knoxville, TN 37915-2566
www.amputee-coalition.org
acainfo@amputee-coalition.org
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Remember:[5,6]

- You are not a "bad" patient if you tell your doctor you have pain, nor are you bothering him or her. Doctors want to make you feel as comfortable as possible and improve the quality of your life. They cannot do this unless you share your experience of pain with them.
- Coping with unrelieved pain can be exhausting and can keep you from enjoying friends, relatives, and other activities. You are not being weak to ask for pain relief; in fact, you are being strong to ask for help.
- If you feel your pain is not being adequately relieved, tell your doctor right away. Your doctor will reassess your pain carefully and might prescribe a different medication, adjust the dosage, use a combination of drugs to relieve your pain, or refer you to a pain specialist. Most side effects from pain medicine can be managed as long as you tell your doctor about them.
- Pain does not necessarily mean your condition is getting worse.
- Some cultures, and even some families, have very individual beliefs about pain and its meaning. When you have severe pain, it may be important to look more closely at your beliefs.

Types of Pain

There are two types of pain: *acute* and *persistent*. What makes them different is how long they last. Acute pain tends to be severe and lasts a relatively short time. It is a signal that the body is being injured, and most of the time the pain goes away when the injury heals.[7] Pain after surgery or after breaking a bone is an example of acute pain. If you are going to have any kind of procedure related to your condition, make sure to ask your doctor ahead of time:

- How much pain to expect?
- How long it may last?
- Most importantly, how it will be managed before, during and afterward

Persistent pain can last for long periods of time, even years. It can range from mild to severe.[8] Doctors disagree on when to say that pain is no longer acute and has become persistent, but generally, if the pain is still present three to six months after it began, it is considered persistent.[9]

Phantom Pain and Residual Limb Pain

As stated earlier, as many as 80 percent of all amputees experience pain in their residual limb or as "phantom pain," which feels as if it is in the part of the limb that is missing.[1]

Residual limb pain is believed to derive from injuries to nerves at the site of the amputation. At the ends of these injured nerve fibers, neuromas are formed. These bundles of nerve fibers may send out pain impulses in a random fashion, or they may give off pain signals when trapped by other tissue, such as muscle.

In contrast, phantom pain is thought to originate in the brain itself. When the part of the brain that controlled the limb before it was amputated no longer has a function, other areas of the brain fill in.[10] As mentioned before, Dr. Douglas Smith, the ACA medical director, has written a series of articles titled "The Phantom Menace," which can be found in the ACA online library catalog or can be requested by contacting the ACA.[3]

Getting the Most from a Doctor's Appointment

Feeling nervous or anxious before going to the doctor is very common. It can make it hard to remember what happened during the visit. Even though you think you are listening carefully, you may not hear everything the doctor says. Remember that you are an active participant in your care—so do whatever you need to do to understand. Following are some suggestions to help you prepare for a trip to the doctor and to get the most out of the time you have there.

- Prepare before you go.[2] Write out your questions ahead of time and bring them with you.
- Bring someone along to help listen and take notes. Speak openly and honestly with the doctor or nurse.
- Let them know how much information you want to have.
- Work toward mutual trust and respect.
- Report what s really going on. Don't leave anything out! Don't leave until all your questions have been answered!
- There is no such thing as a silly or dumb question!
- Ask for explanations of words or concepts you don't understand.
- Keep asking questions until what you want to know is clear.
- Repeat back to the doctor what you think you have heard.
- Make sure you've had time to share all the information you wish.
- Do not let anyone make you feel rushed. It's your appointment!
- Insist on privacy. Important discussions should take place in a private place, not in the hallway or at a reception desk.
- Be willing to reschedule another visit if more time is needed. The management of chronic pain often is time consuming and a treatment plan evolves over time.

How to Talk with Your Doctor about Pain

Talking openly about your pain should begin in conversation with your doctor and any other professionals treating you for pain.[4,11] Your doctor in particular needs to know what kind of pain you are feeling and how bad it is so that he or she can prescribe the most effective treatment program for you.[4]

But some people find it difficult to talk about their pain at all; some have trouble finding the right words to communicate how the pain feels.[4] Many people don't know what to tell the doctor, or what questions to ask about their pain. While your doctor may ask you some of the following four questions, reading them here and thinking about how you would answer them will help when you get to your appointment.[12]

1. Where is the pain? Your pain may be in more than one place; list all the painful areas.[8] You may even want to draw a simple picture of your body and mark or color the areas where you feel your pain.

2. What does the pain feel like?[9] Is it aching? Throbbing? Burning? Sharp? Dull? The list below includes some of the words frequently used to describe pain.[4] If you don't find a word that describes what you feel, use the most descriptive words you can find.

Aching	Burning	Cramping	Crushing	Deep	Dull
ElectricGnawing		Knot-like	On-the-surface	Pinching	Pins & Needles
Pounding	Pressing	Prickling	Pulsing	Sharp	Shooting
Sore	Stabbing	Stretching	Tender	Throbbing	Tight

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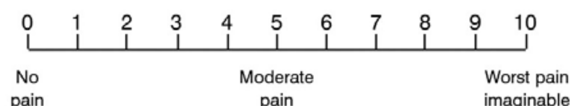
Be sure to tell your doctor or nurse if you use words other than "pain" to describe this unpleasant sensation. For example, some people describe it as discomfort or as being uncomfortable or that they simply "hurt." Just be aware that those words alone may not communicate all the information you want your doctor to have.[4]

3. How much pain are you feeling? Descriptive words tell the doctor what the pain *feels like*, but the doctor also needs to know *how much* pain you are feeling. There is no blood test, visual test or foolproof way to measure pain. The doctor will rely on you to describe how much you hurt. Your doctor may be able to help you, though, by asking you to use a pain rating scale to "measure" your pain.

- **A numeric pain rating scale** asks you to rate your pain by picking a number from 0 (no pain) to 10 (worst pain imaginable) that best indicates how bad the pain feels to you.[5] The doctor will write down the number in your chart and compare it to the number you select next time; this way you will both be able to see how your pain level is changing (see figure 1).



From: Acute Pain Management: Operative or Medical Procedures and Trauma, Clinical Practice Guideline No. 1. AHCPR Publication No. 92-0032: February 1992; Agency for Healthcare Research & Quality, Rockville, MD; pages 116-117.

Figure 1

- **"Faces" pain rating scales** are helpful for children, and for people who have trouble speaking or understanding how to respond to the 0 to 10 scale.[10] There are several different scales that use a series of faces with expressions from smiling (0 = no hurt) to tearful (10 = hurts worst). It is important to stick to the scale—exaggeration of pain or the scales used to rate pain make it extraordinarily difficult to judge the success or effects of treatments (see figure 2).

From Wong DL, Hockenberry-Eaton M, Wilson D, Winkelstein ML, Schwartz P, eds. *Wong's Essentials of Pediatric Nursing*. 5th ed. St. Louis, MO: Mosby; 2001:1301. Reprinted by permission.

Figure 2

The most important part of having your pain rated using a scale is your honesty. You shouldn't "play it down" and say your pain is a level 3 when it is a level 7. You may not get the treatment you need.

4. What makes your pain better? Or worse? You may have found ways to make your pain feel better, like using heat or cold or sitting or lying in certain positions.[12] Keep track of what does and doesn't work for your doctor, for yourself, and for caregivers who want to help you.

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A *pain diary* (see figure 3) is another tool to help you keep track of changes in your pain over several days, what makes it better or worse, what medication(s) you've used and how your treatments are working. Use the same scale to rate your pain each time. Taking the diary to your doctor's appointments will provide a good deal of information to help evaluate your pain treatment plan. No matter what causes the pain, or makes it feel better, keeping a careful record is a helpful way to communicate with your doctor. However, these diaries aren't meant for everyone. If you find a diary makes you concentrate more on the pain, you might want to try another option.

Date __/__/__

Were there changes in your medicines today? (please explain)

0	1	2	3	4	5	6	7	8	9	10
no pain		mild		moderate		distressing		horrible		unbearable pain

Time	Pain Rating 0–10 Where is the pain?	What were you doing?	Did you take medicine? What? How much?	After 1–2 hours, what is your pain rating?	Other problems, comments

Figure 3

How to Find a Pain Management Specialist

Treating post-amputation pain often involves using a variety of techniques, interventions and medications, as well as involving help from several different healthcare professions. Each person's pain should be addressed individually. Therefore, ACA highly recommends that you consult with a qualified pain management physician who offers a comprehensive pain management program near you.[12]

Although the best place to start is with your family physician, internist, or surgeon, they cannot always help in the area of chronic pain. If they are unable to handle your pain problems, ask them to check with the department of anesthesia at your local hospital or medical center. Many anesthesiologists today go on to do further postgraduate education, specifically in the field of pain. Frequently, they will direct a staff of other physicians, nurses, therapists, and medical professionals who together offer a variety of treatments. These comprehensive or multidisciplinary types of practices are the best way to deal with the complex pain problems of amputees.[13]

Not all pain management specialists are anesthesiologists. Other types of doctors such as neurologists, internists, and rehabilitation physicians may also have completed advanced training in this field. The key is to find someone with the proper training — one who has access to and is willing to involve all the professionals who may be needed to treat your particular problem.[13]

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Some pain centers offer only one type of treatment, such as acupuncture or manipulations, and treat only a specific type of complaint such as headaches or back pain. Although phantom pain is important, you must remember that in the field of pain management, extensive experience in treating it is still relatively uncommon; therefore, don't be afraid to ask questions. Ask about credentials and training, as well as their experience in handling phantom pain. Be sure you understand what medicines you might be given, what to expect, and their side effects. Inquire about alternative treatments and how they might be appropriate. Always ask about fees and insurance reimbursement.[13]

Treating Pain after Amputation

Post-amputation pain is very complicated and can be very difficult to treat.[13] There are a number of options that are appropriate for pain management, including, but not limited to:

1. Proper prosthetic fit
2. Physical therapy, exercises, transcutaneous electrical nerve stimulation (TENS) units and related treatments
3. Relaxation and stress management techniques
4. Biofeedback, cognitive and behavioral therapy
5. Non-steroidal anti-inflammatory drugs (NSAIDs)
6. Adjunctive medicines, including antidepressants and neuroleptic agents
7. Oral opioid analgesics
8. Muscle relaxants

As you can see, a wide range of professionals are involved in this list: your prosthetist, physical therapist, psychologist, psychiatrist, family doctor, anesthesiologist, physiatrist, internist, orthopedic and neurosurgeon, as well as the technicians and other professionals who may be involved. Ask them to explain the various interventions that are available to you.

If you do experience pain or discomfort, tell your doctor, nurse, prosthetist, physical therapist or other caregiver right away so your doctor can take steps to relieve your pain.[6]

When Pain Medications are Recommended

The physician should determine the best approach to manage pain based on its cause. In circumstances where there is no way to treat the cause of the pain specifically, or if it will take time for the treatment to take effect, the physician may consider prescribing specific medication for pain relief.

Questions to Ask Your Doctor or Pharmacist about Taking Your Pain Medicine[8]

- How much medicine should I take? How often should I take it?
- If my pain is not relieved, can I take more? If the dose should be increased, by how much?
- Should I call you before increasing the dose?
- What if I forget to take the medicine or take it too late?
- Should I take my medicine with food?
- How much liquid should I drink with the medicine?
- How long does it take the medicine to start working? (called "onset of action")
- Is it safe to drink alcoholic beverages, drive, or operate machinery after I have taken pain medicine?
- What other medicines can I take with this pain medicine?

- What side effects from the medicine are possible and how can I prevent them?

Types of Pain Medicine[13]

For mild pain, your doctor may recommend acetaminophen and other NSAIDs, including aspirin and ibuprofen (see Step 5 above). Most of these are available without a doctor's prescription. NSAIDs, when used alone, have a limit to their pain-relieving effect; therefore, taking a higher dose than specified may not be recommended. And even though aspirin is an excellent pain reliever, it too has its limitations. So, even though these are available without a prescription, your medical team will still need to monitor you.

For moderate to severe pain, your doctor may prescribe opioid pain medication, which requires a prescription (see Step 7 above). Examples of opioids are morphine, fentanyl, hydromorphone, oxycodone and codeine. Opioids can be taken by mouth (pill or liquid), as a suppository, by injection or absorbed through a patch on the body. Unlike NSAIDs, most opioid pain relievers don't have a limit on their ability to relieve pain. Usually, the higher the dose, the greater the pain relief. Your doctor will be careful, of course, to ensure your dose is appropriate to manage your level of pain.

As with any treatment for pain, if these medications aren't helping you, your healthcare team will try an alternative. Sometimes your doctor may prescribe nonopioids along with these opioids to treat specific types of pain, such as using NSAIDs along with opioids to treat bone pain.

There is a risk of abuse or addiction with opioid pain relievers. Drug addiction is characterized by compulsive use, use for non-medical purposes, and continued use despite harm.[14] If you have abused drugs in the past, you may have a higher chance of developing abuse or addiction again while taking an opioid pain reliever. The development of addiction to opioid analgesics in properly managed patients with pain has been reported to be rare. However, data is not available to establish the true incidence of addiction in chronic pain patients.

Today, the U.S. Drug Enforcement Administration (DEA) is working closely with many of the country's leading health organizations — such as the American Medical Association, the Oncology Nursing Society, the American Pharmaceutical Association, the American Cancer Society and others — to make sure that laws about opioids do not become barriers that keep patients from getting the pain relief they need.[15] The laws are there to help prevent drug abuse. Our government and many committed healthcare professionals are working together to make sure that laws and access to proper pain relief are kept "in balance."

Non-drug Therapies for Pain

Non-drug therapies are often helpful in relieving pain when used alone or in combination with your pain medication. It is important to discuss with your physician what type(s) of non-drug approaches may be most appropriate for your specific condition. Here is a list of the most common additional therapies.[4]

Heating pads or **cold packs**, applied to specific muscle areas, can provide relief from pain. Heating relaxes the muscles, while cold refreshes the area.
Deep muscle relaxation works by allowing the amputee to release tension immediately; however, learning relaxation skills will take time.
Therapeutic touch concentrates on massaging the body's energy field alone. Some believe that massaging the energy field that surrounds the body corrects imbalances in the energy.
Distraction therapy claims that turning a person's attention away from a painful activity can make him/her more comfortable.
Massage therapy can work by massaging the external, outer mechanisms of pain to the primary, root cause.
Music therapy is the prescribed use of music and musical interventions to restore, maintain, and improve physical health and well-being.
Acupuncture is a traditional Chinese practice of puncturing the body at specific points to cure disease or relieve pain.
Deep breathing helps with the ability to cope, to control stress, and relax the patient.
Hypnotherapy involves relaxation and concentration. During a "trance," the patient focuses on things he/she wants to experience instead of pain.
Biofeedback uses special machines to learn how to relax specific muscles in the body to reduce tension.
Guided imagery focuses and directs the imagination. It is the way people can use their imagination in order to heal.
Transcutaneous electrical nerve stimulation (TENS) provides relief of pain by applying electrical stimulation to the skin.

Advocate for Your Own Care

An advocate is someone who is informed, educated, empowered and who acts on his/her own behalf, or on behalf of someone they are caring for. You can be your own best advocate for pain relief and for care of other symptoms related to your illness or its treatment.[6] Many of the tips in this fact sheet may be useful to you in advocating for your needs.

What to do if Your Pain is not Being Managed

If you've done all your homework, asked all your questions, shared your own information honestly and your pain is still not being adequately managed:

- First, speak to your healthcare professional or a case manager to express your concerns.
- Secondly, bring your diary, if you decide to create one, to doctor's visits to show the impact that pain is having on your quality of life.
- Finally, ask what other options are available for you to try to find relief.

If you still feel you are not receiving adequate care, ask your doctor to refer you to a pain specialist. These doctors have received specialized training in managing pain.

Remember: You Are Not Alone

The Amputee Coalition of America (ACA) is a national, nonprofit amputee consumer educational organization representing people who have experienced amputation or are born with limb differences. The ACA includes individual amputees, amputee education and support groups for amputees, professionals, family members and friends of amputees, and amputation or limb loss-related agencies and organizations.

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The ACA has regional representatives located across the United States who are experienced support group leaders and can offer referrals to the amputee support groups nearest you.[16] The ACA has created and maintains a database of trained and experienced amputee peers who are willing to communicate by phone, fax, e-mail, postal service or (when possible) to make in-person visits. Amputees are matched as closely as possible with referrals to fellow amputees who have experienced similar limb loss and are of comparable age. (See ACA contact information at the end of this fact sheet.)

There are many resources in your community that can provide guidance and support. Your hospital social worker and/or nurse educator are both valuable sources of information as well as people who will listen if you need to talk.

In addition to the ACA, there are other organizations that can be helpful (see Internet Resources below). Many of these have local chapters you can contact. All of these Internet sites are full of information to help you and your loved ones learn to effectively manage pain and live your life to its fullest.

The American Pain Foundation Pain Care Bill of Rights[17]

As a person with pain, you have the right to:

- Have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists, and other healthcare professionals.
- Have your pain thoroughly assessed and promptly treated.
- Be informed by your doctor about what may be causing your pain, possible treatments, and the benefits, risks and costs of each.
- Participate actively in decisions about how to manage your pain.
- Have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.
- Be referred to a pain specialist if your pain persists.
- Get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.

Although not always required by law, these are rights you should expect and, if necessary, demand for your pain care.
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Internet Resources

Request a referral by your family physician to a local pain clinic or anesthesia department at your local hospital. Call your county society of anesthesiologists and ask for a list of pain management specialists in your area.

- American Academy of Pain Management http://www.aapainmanage.org
- American Pain Foundation http://www.painfoundation.org/
- American Pain Society http://www.ampainsoc.org
- American Society of Anesthesiologists http://www.asahq.org
- Amputee Coalition of America (ACA) 900 East Hill Ave., Suite 285 Knoxville, TN 37915 888/AMP-KNOW (267-5669) http://www.amputee-coalition.org
- International Association for the Study of Pain http://www.iasp-pain.org/
- The Mayday Pain Project http://www.painandhealth.org/

- National Library of Medicine http://www.nlm.nih.gov/
- PainNet http://www.painnet.com/
- The National Foundation for the Treatment of Pain http://www.paincare.org
- National Institutes of Health http://www.nih.gov/
- Pain and Policy Studies Group http://www.medsch.wisc.edu/painpolicy/
- Worldwide Congress of Pain http://www.pain.com/. This site has a listing of pain specialists according to state, as well as offering consumer information and permitting users to "Ask the pain doc" questions.

** The contents of these sites are solely the responsibility of the authors and do not necessarily represent the official views of the ACA/NLLIC. The use of trade names is for identification only and does not constitute endorsement by the ACA/NLLIC.

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