Pain Management

This Fact Sheet provides important—and practical—information you can use to get the help you need to manage 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. This Fact Sheet will give you information to cover a variety of situations.

It is important to remember that pain can be caused by an ill-fitting prosthesis, so maintain a good fit at all times. Many of these tips are questions for you to ask yourself. The answers will give you more information about your condition, treatment, and pain management. Remember: You have a right to ask questions and to understand your options.

Long after surgical wounds have healed, most amputees still feel pain in their amputated limb and in the part that is now missing. Pain that feels like it comes from a missing limb, finger or toe, is called “phantom pain.”

Sensations in the missing limb aren’t always painful. It is common for an amputee to still feel his or her missing limb. Sensations such as movement, touch, pressure, itching, posture, and heat and cold can still be felt although the body part is no longer present.

Despite their names, phantom pain and phantom sensations are very real to the amputees who have them. They are physical, not psychological or all in your head. There is still much to be learned about phantom pain. Dr. Douglas Smith, medical director of the Amputee Coalition of America (ACA), has written several articles about pain. The most recent is a series of articles titled “The Phantom Menace.” The series can be found in the ACA online library catalog or you can call ACA for a copy.
Why is managing pain important?

“Pain is a thief. Pain robs the person in pain of the chance to enjoy being alive…”

Pain can 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 suffer. Pain can cause you to lose your appetite, which can lead to weakness. Pain that is not treated can also cause depression and feelings of hopelessness. Many people think that pain is an unavoidable part of limb loss. Your condition may cause pain — but pain can and should be treated. There are many options available 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. Only you know how much pain you feel, and where it hurts. But 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 team member in your care.

Remember:

- You are not a “bad” patient if you tell your doctor you have pain. You are not bothering him or her if you speak up. 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 when you ask for pain relief; in fact, you are being strong.
- Most side effects from pain medicine can be managed as long as you tell your doctor about them.
- If you feel your pain is not being adequately relieved, tell your doctor right away. Your doctor may:
  - reassess your pain carefully
  - prescribe a different medication, adjust the dosage, use a combination of drugs to relieve your pain
  - refer you to a pain specialist.
• 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 useful to look more closely at your beliefs.

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 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. Pain after surgery or after breaking a bone are examples 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 the pain may last
• Most importantly, how the pain 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. Doctors disagree on when to say that pain is no longer acute and has become persistent. Generally if the pain is still present three to six months after it began, it is considered persistent.

**Phantom Pain and Residual Limb Pain**

Most amputees experience pain in their residual limb or as “phantom pain,” which feels as if it is in the part of their limb that is missing.

Residual limb pain is believed to come from injuries to nerves at the amputation site. At the ends of these injured nerve fibers, **neuromas** are formed. Neuromas, which are 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.

**Getting the Most from a Doctor’s Appointment**

Feeling nervous before going to the doctor is very common. This makes 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. Do whatever you need to do to understand. Following are some suggestions to help you prepare for a doctor visit:

- 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 is really going on and 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 with your doctor and any other professionals treating you for pain. Your doctor needs to know what kind of pain you are feeling and how bad it is. Then, he or she can prescribe the most effective treatment program for you.
Some people find it difficult to talk about their pain. Others have trouble finding the right words to communicate how the pain feels. Many people don’t know what to tell the doctor, or what questions to ask about their pain. 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.

1. **Where is the pain?** Your pain may be in more than one place; list all the painful areas. 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?** Is it aching? Throbbing? Burning? Sharp? Dull? The list below includes some of the words frequently used to describe pain. If you don’t find a word that describes what you feel, use the most descriptive words you can find.

<table>
<thead>
<tr>
<th>Aching</th>
<th>Sharp</th>
<th>Dull</th>
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<tbody>
<tr>
<td>Burning</td>
<td>Crushing</td>
<td>Pins &amp; Needles</td>
</tr>
<tr>
<td>Sore</td>
<td>Stabbing</td>
<td>Prickling</td>
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<tr>
<td>Pounding</td>
<td>Throbbing</td>
<td>Shooting</td>
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<tr>
<td>Crampy</td>
<td>Knot-like</td>
<td>Deep</td>
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<tr>
<td>On-the-surface</td>
<td>Stretching</td>
<td>Pressing</td>
</tr>
<tr>
<td>Tight</td>
<td>Pinching</td>
<td>Tender</td>
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<tr>
<td>Electric</td>
<td>Pulsing</td>
<td>Gnawing</td>
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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 say simply that they “hurt.” Be aware that those words alone may not communicate all the information you want your doctor to have.

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 tell him how much you hurt. He or she may be able to help you, though, by asking you to use a pain rating scale to “measure” your pain.
**Numbered pain rating scales** ask 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. 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).

![Numbered pain rating scales](image)

**Figure 1**

**“Faces” pain rating scales** are helpful for people who have trouble speaking or understanding how to respond to the 0 to 10 scale. 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 stay 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).

![“Faces” pain rating scales](image)

**Figure 2**

At each appointment, your doctor should ask you to rate your pain using the same kind of scale each time, and record your pain level. Examples of a numeric pain rating scale and a scale that uses faces are printed here so you can become familiar with them.

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. Keep track of what does and doesn’t work for your doctor, for yourself, and for caregivers who want to help you.
A pain diary is another tool to help you keep track over several days of changes in your pain. What makes it better or worse? What medication(s) have you used? How are your treatments working? Use the same scale to rate your pain each time. Take the diary to your doctor’s appointments. It 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 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 something else.

How to Find a Pain Management Specialist

Each person’s pain is different. The ACA recommends that you consult with a qualified pain management physician. Choose one near you who offers a complete pain management program.

To find the right doctor, start with your family physician or surgeon. If they cannot help you, ask them to check with your local hospital or medical center. Many anesthesiologists become trained in the field of pain management. Frequently, they will work with other physicians, nurses, therapists, and medical professionals. Together they will offer a variety of treatments. These types of practices are often the best way to deal with the complex pain issues of amputees.

Neurologists, internists, and rehabilitation physicians may also have advanced training in pain management. The key is to find someone with the proper training. You need someone who is willing to involve other healthcare providers who may be needed to treat your particular problem.

Some pain centers offer only one type of treatment, such as acupuncture or manipulation. Some may treat only a special type of complaint such as headaches or back pain. Remember that it may be difficult to find someone with pain management experience, so it is important that you:

- Ask questions
- Check staff credentials and training
- Check their experience in handling phantom pain
- Be sure you understand what medicines you might be given, what to expect, and their side effects
• Ask about alternative treatments and how they might be appropriate
• Finally, always ask about fees and insurance reimbursement.

Treating Pain after Amputation

Post-amputation pain is very complicated and can be difficult to treat. A number of therapies may be right for you, including the following:

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

From this list you can see that the professionals involved can range from 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.

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:

• Speak to your healthcare professional or a case manager to express your concerns
• Always 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
• Ask what other options are available for you to try to help 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 special 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, amputation or limb loss related agencies, and organizations. 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. 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 nearly as possible with referrals to fellow amputees who have experienced similar limb loss and are of comparable age.

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 list 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

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
- The right to have your pain thoroughly assessed and promptly treated
- The right to be informed by your doctor about what may be causing your pain, possible treatments, and the benefits, risks and costs of each
- The right to participate actively in decisions about how to manage your pain
- The right to have your pain reassessed regularly and your treatment adjusted if your pain has not been eased
- The right to be referred to a pain specialist if your pain persists
- The right to 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.


**For complete documentation, please see the original version of this fact sheet.**