

# Pain after amputation: a lifelong problem?

By LTC Richard A. Sherman PhD

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### **Pain and the amputee**

For virtually the entire history of modern medicine, doctors thought that amputees rarely had pain problems. The few who did have pain reported it to be in their stumps (residual limbs). Phantom pain (pain which seems to come from the amputated limb) was thought to occur in only one of 200 amputees. Of course, you know that this isn't true. But the medical community didn't know that until just a few years ago when we began sending surveys to military amputees in the United States. We have received over 7,000 survey responses from amputees who told us about their pain problems. The vast majority of them reported that they are bothered by stump pain and over eighty percent reported phantom pain. Although a few reported that their pain went away after the amputation healed, most continued to suffer from pain for the rest of their lives. Some reported that they were pain free after healing but that phantom or stump pain had returned many years later.

Thus, the great majority of you can expect to experience at least intermittent pain for most of your lives. It is important to know what probably causes it and makes it worse as well as which treatments are likely to help so you can minimize the pain. This article gives you an overview of what probably causes most of the pain you experience and the best ways we know of to help it.

### **Pain just after the amputation**

This is probably the largest cut you have ever had. You can expect to feel considerable pain in your stump/residual limb. Traditional pain medications frequently do not affect phantom pain occurring just after an amputation. Morphine delivered by a patient controlled pump (PCA) can be effective in controlling just-post-surgery phantom and stump pain. Epidural analgesia and anesthesia also may be effective. The optimal treatment for acute, post-amputation phantom pain appears to be patience, stress control, and relaxation training. These later treatments are normally provided by the psychologists on the health care team.

Among the vast majority of amputees, pain gradually decreases after the operation until it eventually goes away. Unfortunately, this is not always the case. For a very few people, it remains moderately severe and for many it comes and goes as the body and environment change from both moment to moment and year to year.

## Stump pain

Until they heal, the nerves from the skin and muscles which were either cut or disturbed during the amputation are especially sensitive to chemicals released by bruised or cut tissues. If the stump is bruised significantly, these nerves can become incredibly sensitive to pressure and changes in blood flow within the stump, so considerable pain can be produced by even a minor bump or some changes in position. As healing progresses, the nerves become less sensitive. The stump may remain more sensitive than the rest of the body indefinitely. This is true even though amputees are not more sensitive to pain than non-amputees on other portions of their bodies.

We have survey responses from over 7,000 amputees. Over half of them report that they are bothered by stump pain at least a few times per year. It is incapacitating for a few but is an intermittent, endurable annoyance for most. The pain is frequently affected by the weather and physical exhaustion. Common pain medications and surgery have a mixed record of helping relieve stump pain unless a specific problem can be identified and corrected. The underlying cause of the pain can be exceedingly difficult or impossible to determine so the "trial and error" method of selecting a treatment is sometimes required to find the best remedy. Frequently, nothing helps or the drug side effects are worse than the stump pain.

Occasionally, when cut nerve ends heal, the ends grow into a convoluted ball called a neuroma. This can act like a short circuit in an electrical system and send pain messages to the brain which are not actually related to any damaging event in the stump. Some people develop many neuromas. One or two may be large enough to detect but many are microscopic. We currently do not have the ability to tell which is actually causing the problem. It does not good to take out a large neuroma which can be seen if a tiny one is causing the problem.

A poorly formed or thin pad of skin and other tissues (such as fat) at the end of the stump can cause numerous difficulties. If the stump is not formed well or is not properly wrapped and shrunken, it will hurt when pressure is put on it.

Occasionally the end of the bone in the stump develops tiny spurs which may cause irritation of adjacent muscles and severe pain with movement. This can happen years after the amputation and they may have to be removed surgically.

Your body changes as you age. For example, your blood flow decreases, your skin gets thinner, your muscles and fat pads become smaller. All of these changes effect the way your prosthetic fits and how much physical stress your residual limb can take. This means that a stump which has been pain free limb for decades may gradually become painful and a tried and trusted prosthesis may begin causing problems.

Pain also results from disuse - either just after amputation or years later! If you do not use your residual limb, it will get progressively weaker from lack of exercise, your bones will get softer and easier to damage. This leads to easy bruising as well as pain from the muscles and bones. Your tendons and ligaments will shrink and tighten - which prevents you from standing and moving correctly. These can be very real problems and there is no quick cure for pain resulting from damage to weakened bones and shortened ligaments. Prevention is the best approach. Keep your limb in good physical shape and you will avoid most of the pain problems and disabilities that come with disuse.

## Phantom sensations

Virtually everybody who has an amputation after very early childhood experiences sensations which seem to come from the amputated portion of the limb. This "shadow limb" is called the "phantom" and the feelings coming from it are called phantom sensations. Just after the amputation, the phantom usually feels as though it is the same size and shape as the amputated portion of the limb. Most people feel that they can move and control it as well as they could control the limb itself. The sensations are so real and normal that many young, traumatic, lower limb amputees frequently try to get up and walk away a day or so after their amputations. Phantom sensations normally include all of the sensations you would feel in an attached limb including a sense of position, temperature, itching, and, very occasionally, a ring or other item worn for many years. The phantom frequently rests in the last position the limb was in before it was amputated.

***These sensations are normally not painful and should not be confused with phantom pain.***

One of the most startling and frightening events upon awakening after an amputation is to unexpectedly discover that you can still feel the amputated portion of the limb. The brain and spinal cord contain circuits which cause anxiety to magnify feelings tremendously. These circuits are not under our conscious control and can cause warmth to be experienced as severe burning, tingling to be felt as shocks, etc.

If you have no idea you will seem to be able to feel the amputated limb, it is natural for you to assume that the stress of the amputation has driven you mad. The vast majority of people are not about to tell anyone they have gone nuts - especially not in the strange environment of the hospital ward. This increases anxiety immeasurably. Thus, the failure to warn people of phantom sensations frequently leads to severe anxiety and far more just-post-amputation phantom pain than might be experienced otherwise.

Just after an amputation, nearly everybody feels the entire amputated part of the limb. Most people feel that they can move and control it the way they could when it was attached. As time passes, the limb's shape becomes less vivid and control gradually slips away. For example, a below knee amputee can initially feel the calf, ankle, and foot. Gradually, the foot "telescopes" into the end of the stump so the calf seems to have disappeared. Eventually the ankle may disappear as well. This effect is illustrated in Figure One. For nearly everyone, telescoping does not happen if phantom pain is present. If phantom pain occurs years after the limb was amputated, the phantom usually grows to its original shape and vividness.

Nearly all amputees continue to sense the phantom all of their lives. In addition to the sense of shape, virtually all amputees report various feelings such as itching, warmth, twisting, etc. which seem to come from the limb. Occasionally, the missing limb feels as though it is in a very uncomfortable position. These feelings may change with time of day, fatigue, weather, and other factors. The great majority of amputees report that these feelings are painful at least occasionally.

### **Figure 1.**

Telescoping of a phantom limb over time

(Adapted from an anonymous 1952 US Military report on phantom pain, Reprinted from Sherman Phantom Pain; Plenum Press 1977)

In the basic absence of phantom pain, the phantom gradually shrinks into the end of the residual limb. It becomes less distinct and perceived ability to control position decreases correspondingly. The phantom usually returns to its original level of clarity with phantom pain.



## How you can feel a part of your body which has been amputated - the physical basis for phantom pain and phantom sensations

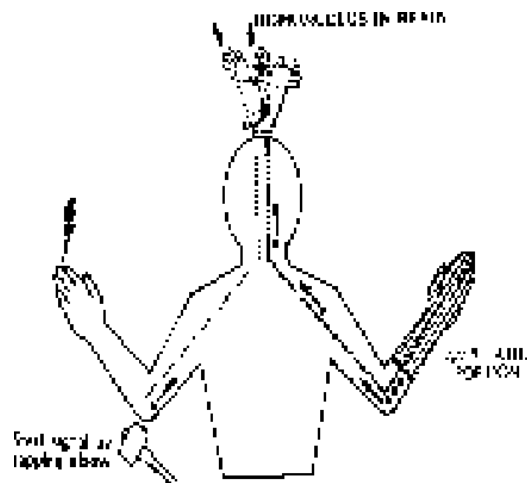
In order to understand how it is possible to feel something that isn't there, it is necessary to understand how the body is "wired" to feel things. Figure Two shows a diagram of how the brain and body are wired together to pick up feelings from your body. The upper rear portion of the brain contains a structure similar to a hard-wired telephone switchboard which is called the sensory (for feeling) homunculus (for "little person"). It is shaped very much like a person and has a place for each nerve coming from your body surface. Thus, if you tap your right little finger, a signal which starts in the nerve endings in the finger runs through your hand, up your forearm, past your elbow, along your upper arm, into your spine, and eventually winds up at the corresponding "right little finger" position in the homunculus. The homunculus is not part of your conscious brain. It is essentially a switchboard which has no way of knowing where the signals reaching it actually started from.

When you bump your elbow, you very often feel pain in your fingers and hand. This is because the nerve which carries signals from your hands and fingers passes just under your elbow and is shocked when you bump your funny bone nerve. The homunculus does not know the signal actually started in your elbow, so it tells the conscious portion of your brain that the feelings came from the fingers and hand. Because it is not under your conscious control, the pain in your hand continues although you know that only your elbow was hit.

### Figure 2

How pain can be felt in a part of the body different than where the pain "signal" started.

When your finger is touched (lightning bolt), a signal travels along nerves past your elbow, through your spine to your brain. The signal goes to a part of your brain (the homunculus) corresponding to your finger. You can send a signal to the same part of your brain by bumping your elbow (hammer) because the brain can't tell where it began. This is why your fingers tingle when you bump your "funny bone". The nerves and brain don't change much after an amputation so you still feel your hand when you start a signal in the stump.



Feelings which seem to come from one part of the body but are actually from another part are called "referred feelings". Pain which seems to come from one part of the body is frequently caused by problems in another part of the body. A common example is a person with a nerve pinched in the low back who feels pain running down the leg instead of in the low back. The signal starts in the back, but since the nerve is supposed to come from the leg, the homunculus reports it (refers it) as coming from the leg. If that leg was amputated, the pain would still seem to come from the same location on the "phantom" because little corresponding change occurs in the homunculus when the leg is amputated and it cannot learn. This system was illustrated on the right side of Figure Two.



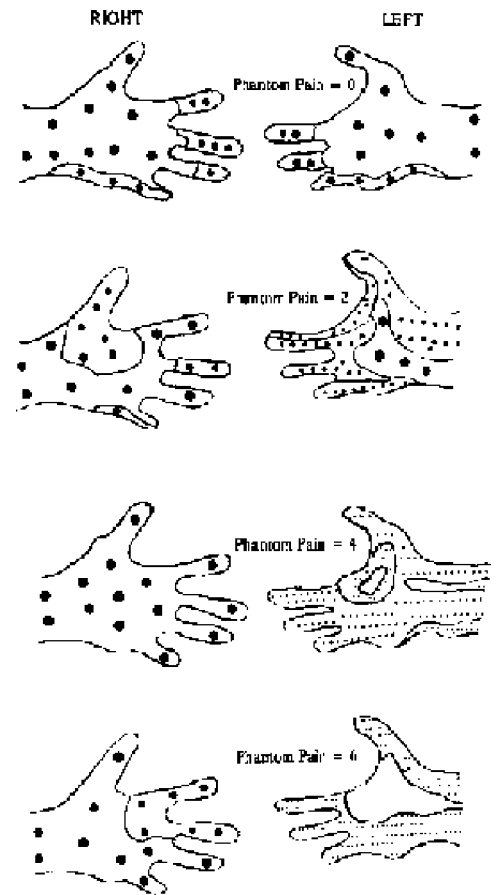
There is no reason to think that those amputees who report phantom pain are either exaggerating normal phantom sensations or have anything wrong with their minds. We have received over 7,000 responses to questionnaires sent to amputees inquiring about problems with phantom pain. Over 80% of the respondents said that they had enough phantom pain to cause them real problems for at least a week every year. Most have episodes of pain which last anywhere from a few seconds per year to several weeks at a time, with several to many episodes per year. Some people have continuous pain which varies in amount from almost none to excruciating over the course of the year. For most, the pain interferes with work, sleep, hobbies, and desired social activities.

About half of the amputees who report phantom pain seem to be able to associate changes or onset of their pain with some change in themselves (such as stump irritation, exhaustion, back pain, or stress) or outside themselves (such as changes in humidity). It is important to note that two amputees who describe their phantom pain as being identical in frequency, severity, and type of feelings may report entirely different events which change the pain. For most amputees, phantom pain is worst just after amputation while the stump is healing. However, it is not likely to go away permanently. A few amputees report that the severity does not decrease after stump healing, but, rather, persists throughout life. Almost none of the respondents to our surveys reported that their phantom pain went away completely with the years after amputation.

Thus, you will probably have some phantom pain. It may be enough to trouble you from a few times per year to almost all of the time. The amount of pain is likely to vary from almost negligible most of the time to severe once in a great while. You may be able to predict what causes your phantom pain to become worse and take measure to avoid the worst of it. Many amputees are afraid to talk about their phantom pain with their health care providers for fear of being thought to be crazy. Some reported that their health care providers either told them outright or strongly indicated that anyone who felt pain in a limb no longer present had mental problems and should see a psychiatrist. This should no longer be the case!

There is NO evidence or indication that amputees are any crazier (or more sane) than people who have not had amputations. Most health care providers have learned that referred pain is a very common problem and that phantom pain is one example of it. They should know that phantom pain has a very real physical basis. Unfortunately, they may not know how to treat it. If you approach a health care provider for treatment and one of the approaches mentioned in this article is not suggested, it may help to show your provider this article as it contains information about the most recent treatments and references to the medical articles demonstrating their effectiveness.

We now know what causes several descriptive types of phantom pain. For example, burning and tingling phantom pain are caused by decreased blood flow in the end of the stump, while cramping or squeezing phantom pain is caused by spasms in the stump. These mechanisms are illustrated in Figures Four and Five. Unfortunately, we do not know what causes shocking or shooting phantom pain yet. Unless the treatment is related to the cause, it doesn't usually work. We also know that a poorly fitting prosthetic causes specific types and locations of phantom and stump pain. This is summarized in Table 1.



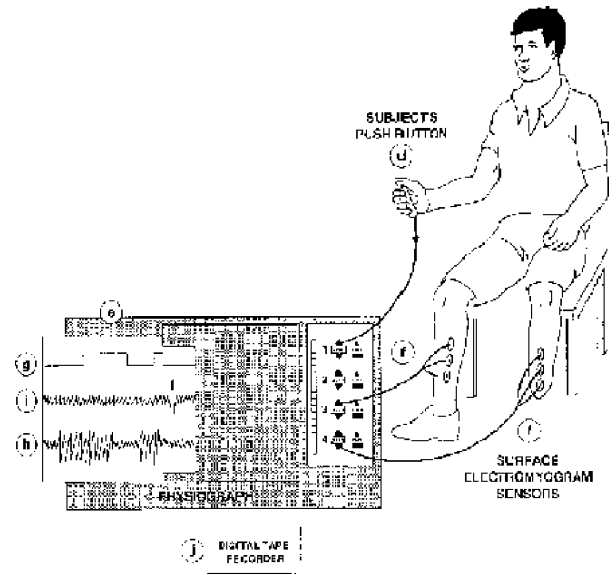
**Figure 4**  
Relationship between burning phantom pain and blood flow in the stump

Redrawn color videothermograms of an amputee missing the index finger on the left hand. Size of dots represent relative warmth at the skin's surface with the largest dots showing the most warmth and blank areas being coolest. Blank areas are essentially the same temperature as the surrounding room. Burning phantom pain intensity is rated on a scale of 0 - 10.

### Figure 5a

Methodology used to establish temporal relationships between change in phantom pain intensity and change in surface EMG of the residual limb.

Both of the subject's limbs are instrumented for recording surface electromyographic (EMG) representations of muscle tension (f). The signals go to a chart recorder (e) where they are displayed with line "i" showing the signal from the intact limb and line "h" showing the signal from the residual limb (stump). The subject presses button (d) when the intensity of phantom pain increases and lets go of the button when the intensity returns to its prior level. The button press signal is displayed on line "g". The entire session is recorded both on paper and by a digital tape recorder (j). (This figure is a revision of one from Sherman and Sherman, 1991 and is used with permission of the American Pain Society).



### Figure 5b

Samples from a chart recording showing surface EMG from the residual limb and "button press" responses to changes in cramping phantom pain intensity made by a bilateral amputee.



Reprinted with permission of Elsevier Publishers from Sherman et al 1992.

Table 1

### Prosthetic problems causing phantom pain

(from Shapiro 1995)

Prosthetic defect	type	nerve entrapped
posterior brim	AK	sciatic
pressure bibula	BK	common peroneal
popliteal bulge	BK	posterior tibial
too many socks	BK	posterior tibial
high lateral wall	AK	lateral femoral cut
high medial wall	AK	ilioinguinal
tight socket	BE	ulnar or median
tight suspension	BE	radial
tight socket	AE	brachial plexus
tight harness	AE	contralateral plexus

Most of the commonly used treatments for phantom pain do not have good long term success rates because they are not related to the underlying causes. In addition to asking the 7,000 amputees discussed above about their treatment experiences, we have surveyed many health care providers, and have carefully reviewed the literature for rates of success of phantom pain treatments upon one year follow-up. All three sources give the same answer. Many treatments offer temporary help but (with exception of those discussed below) even the best usually last only a few months to a year. A few of the thousands of respondents were helped significantly for an extended period of time but each was helped by a different treatment. Surgery, solely for treatment of phantom pain, was not successful in any case. Do not become a victim by permitting an unknowledgeable physician to operate on you!

Unless the treatment is related to the cause, it doesn't usually work. Treatment should begin with a good assessment of the prosthetic fit and a through search for sources of pain referred into the phantom from the back, bladder, etc. Burning ? tingling phantom pain is usually successfully treated by increasing blood flow to the residual limb. Cramping ? squeezing phantom pain is usually successfully treated by decreasing muscle tension and spasms in the residual limb. Specific ways of accomplishing these changes include training you to control your own blood flow or muscle tension, use of muscle relaxing and peripheral blood flow enhancing drugs, and electrical stimulation. If these treatments do not work or if shocking phantom pain is a problem, several medications have recently been shown to have some effectiveness. These include Clonazepam, Mexiletine with Clonidine, and calcitonin. Details on treatment strategies can be found in the recent book on phantom pain referenced below.

There is a substantial incidence of alcoholism among amputees as a direct cause of attempts at covert self-treatment of phantom pain. Drinking alcohol does appear to temporarily reduce awareness of phantom pain for some amputees as it does for other types of pain. However, it is no more effective than other drugs which are probably safer and are definitely easier to control.

### **On the horizon but not here yet**

1. Percutaneously (through the skin) implanted prosthetic holders: Much of stump and phantom pain is clearly caused by problems with the prosthetic socket. If the socket can be eliminated, much of the pain should be eliminated also. The idea of these devices is that weight was meant to be borne by your bones so a strong metal rod is implanted into the end of the bone that is at the bottom of your stump and clamped in place. It has several "arms" that go from the end of the rod protruding from the bone out through your skin to a jig that a regular artificial limb can be attached to. Problems with infections getting into the bones along the device's arms are delaying its wide implementation.

2. Pre-amputation blocks to prevent phantom pain: As the brain and spinal cord seem to have a "memory" for pain which could be related pain in the limb before and during the amputation, it seems logical that blocking any feelings from the limb before amputation should prevent the formation of these memories. Four studies have attempted to do this with mixed results. We'll have to wait for a few more studies to find out if this really works.

### **Further information**

1. Especially for Amputees, their families, and providers: More information about the amputation and recovery processes can be found in the booklet "The amputee's guide" by LTC Sherman and COL Jones published by BLESMA in 1997.

2. Especially for health care providers: More information on phantom pain as well as details on recommended treatments and their rationale can be obtained in the book "Phantom Pain" by LTC Sherman and associates published by Plenum Press in 1997.