

Amputation Education

There is no doubt *amputation* will have a significant impact on your life—physically, emotionally, financially, and socially. Regardless of the number of limbs you've lost and at what level, if you want to do the things you did before and live your life like you always have, you're going to have to work harder. And if you want to do new and different things—live beyond your former life—which is what many amputees choose to do, you're going to have to work a lot harder.

Fortunately, there are ways to help minimize the negative impact of amputation on your life. In fact, that's what this guide is all about. Throughout these pages, you will discover a wealth of information and resources to help you deal with your limb loss and regain your life.

Although it might seem unfathomable to you now, when put in different circumstances, human beings can be amazingly resilient. We hope this information aides you in gaining a better understanding of your circumstances.

Benefits of Amputation Surgery

Amputation surgery brings with it a number of potential benefits:

- **Pain relief.** Amputation is often performed because the patient is suffering from complications of diabetes or vascular disease, or because trauma has damaged a limb to the point in which salvage is not possible, all of which can cause considerable pain. Once the surgery is complete and recovery has begun, many patients report significant pain relief.
- **Improved function.** For patients who have a nonfunctional limb or chronic, debilitating pain, amputation can result in improved mobility and function.
- **A second chance at life.** For individuals who have cancer or persistent infection, amputation can be a lifesaving event, preventing the infection from poisoning the bloodstream or the cancer from spreading to surrounding areas.

Risks of Amputation Surgery

No surgery is without risk, and while most complications are not possible to foresee, many individuals who have undergone amputation have expressed some of the following concerns:

Will the surgeon cut off the wrong limb? Hospitals have protocols in place to prevent such errors, and while mistakes are possible, your healthcare team will be vigilant against them. If you have concerns, ask your surgeon to explain the precautions that will be taken to guard against this outcome.

Will there be complications? Patients who smoke or have diabetes, vascular disease, heart disease, and other circulatory issues may be at higher risk for complication or death from limb amputation due to impaired blood flow causing extra strain on the heart. If your amputation is elective, losing weight, ceasing smoking, and beginning a physician-guided exercise program before your surgery may reduce your risk.

Will I die under anesthesia? Although death can occur from anesthesia use, the danger is slight. Studies suggest the number is fewer than 10 per 1,000,000 people. Your anesthesiologist will continuously monitor your vital signs during your surgery and will follow well-established guidelines to minimize risk to you.

Before and During Surgery

Before your surgery, you will likely go through a pre-surgery check-in, after which you will be asked to remove all jewelry and clothing and put on a sterile gown. You will then be brought to the surgical ward and positioned on a surgical table. An intravenous (IV) line will be started in your arm or hand to deliver the anesthesia.

Once in the operating room, your surgeon will decide where to make the incision based on factors such as pulse at the joint near the incision site, skin temperature, and skin color by comparing those factors against a healthy limb.

After the incision is made, your surgeon may determine that the area chosen is too diseased or traumatized to be salvaged, and a new incision point will be selected higher up the limb. A surgeon does NOT make the decision to cut off more of the limb lightly. Maximizing your health and function are the primary goals of amputation surgery, so amputation below a limb area that is not healthy and will ultimately fail to support functionality would not make sense. Ultimately, the surgeon's goal is to conserve as much healthy tissue as medically possible on which to fit a prosthesis.

If you are able to select your prosthetist before your amputation surgery, consider asking your surgeon and prosthetist to consult about your case together prior to your surgery. Your prosthetist may have valuable insight about how much residual limb is optimum for an ideal prosthetic fit.

Once dead tissue is removed and bone is shaped (if necessary), the skin flaps will be closed if the risk of infection is minimal or left open if the risk is significant. With a closed amputation, the incision is sutured completely, although a drain is usually left in for fluid evacuation. A sterile bandage or dressing is then applied. In an open-flap amputation, the skin is held back from the incision to allow for cleaning and removing, if necessary, any infected tissue. The wound may remain open for several days to resolve the infection. When the infection is no longer present, the incision will be closed, and sterile bandages or dressings will be applied.

Postoperative Care

After amputation surgery, you will begin the recovery process, which will include a hospital stay of three to five days or longer, depending on the nature of your amputation and complicating factors. Postoperative treatment will include caring for your amputation site, managing pain, preventing infection, reducing swelling, and preventing contractures and falls.

Initially, your surgical wound will be covered by a dressing. Your wound may have a temporary external drainage catheter tube extruding from it to allow fluid to drain to reduce swelling and encourage healing. Members of your healthcare team will monitor your dressing and ensure your wound is properly cared for.

Depending on the type of wound dressing you have, your residual limb can, and should, be cleaned daily. Thoroughly wash your hands before caring for your wound, and then lightly clean around the wound without rubbing the incision. Saline or wound cleanser should be used. After washing, pat dry with a dry, clean cloth.

Before your discharge from the hospital, you should be able to demonstrate a full understanding of what type of dressing your wound requires and how best to care for and clean it. Should you have any questions, your healthcare team will be able to assist you.

Infection: A healed incision line has a healing ridge with the front and back skin edges sealed. Your incision should be examined daily for signs of infection such as redness of the skin, rising warmth, excessive swelling, increased wound drainage, or wound drainage that looks like pus or has an unpleasant odor. Fever or unexplained pain in the residual limb may be indications of infection deeper in the tissue. If you experience any of these symptoms, consult your physician.

Swelling: Swelling, or *edema*, is caused by fluid buildup in the tissue surrounding the amputation. Swelling in your residual limb is normal after amputation. It is managed with compression wraps, elastic shrinker socks, or rigid dressings, all of which maintain pressure on the residual limb to keep its shape uniform. Without such compression treatment, swelling can leave your limb poorly shaped for fitting a prosthesis. The swelling should reduce significantly within a few weeks, but some degree of swelling may be present for months, necessitating ongoing use of shrinkers.

Contractures: *Contractures* are a shortening and hardening of muscles, tendons, or other non-bony tissue, which causes rigidity. This condition can prevent joints from fully flexing and make stretching muscles virtually impossible. Contractures can be caused by disease, injury, and immobility, such as that which occur with prolonged bed stays after amputation surgery. Once contractures set in, they will limit limb flexibility, so nurses and physical therapists will work to ensure that you do not develop them after amputation.

Prevention is the best solution for contractures. It may be more comfortable to place pillows under your thighs or back or remove your immobilizer, but doing so can increase your risk for contractures. Rigid muscles limit range of motion and compromise prosthesis fitting and use. Avoiding this problem will help you maintain flexibility of your limb and, eventually, achieve a higher degree of functionality.

Postoperative Pain Management

Anesthesia will be used during surgery, so you should neither feel nor recall the procedure. Immediately after and for a few days following surgery, an analgesic (usually an opioid-based medicine) IV drip, or a continuous epidural analgesic will be used to control your pain.

In the initial 24-48 hours after surgery, most patients rate their pain between a seven and a 10 on a scale of one to 10. Your pain rating should be lower to somewhere in the four to eight range over the next several days, and it should be lower even more after 10 days, although pain may persist for two to three months.

Your surgeon may prescribe an analgesic to be taken at home in the first few days or weeks following your surgery. If your pain persists longer than three months, a thorough pain evaluation is needed to determine the cause.

Pain and swelling are normal body responses to trauma, including post-amputation surgery. Pain is a message to your body that something is wrong. While each individual's experience with pain varies, it is indisputable that amputation is very painful. If significant pain continues, other treatments, such as ultrasound, electrical stimulation, and electromagnetic

therapy, are available. *Phantom limb pain* or *phantom limb sensation* may also be present. These feelings are not uncommon, so try not to be alarmed by them.

Psychological Aspects of Amputation

Whether you are preparing for an amputation or have recently undergone surgery, you are likely experiencing a range of emotions. You will have a fairly constant access to a support team that will be able to help you adjust physically, but once that is no longer needed, you will experience another range of emotions as you try to return to your “normal life”—emotions you may or may not be prepared to face. The most emotionally vulnerable time for a new amputee is between six and 24 months after amputation. It is important to have a strong support network of friends, family, mental health professionals, and peers in place prior to surgery.

The first and most important thing to acknowledge is that whatever you are feeling—or not feeling—is okay. Don’t pressure yourself into believing that you must be feeling and/or acting a certain way. You don’t need to put pressure on yourself to be amazingly resilient and well-adjusted to the changes within a specific timeframe. Everyone goes through this process at their own individual pace. Everyone struggles with issues of self-esteem and acceptance regardless of amputation or trauma. So start by taking a deep breath and giving yourself permission to experience and explore all emotions, fears, and anxieties that come up during your transition.

While it’s not possible to cover the multitude of emotions that occur after the loss of a limb, following are some of the emotions you might be experiencing and some coping strategies to try.

The idea of limb amputation can be difficult to wrap your head around. Immediately after amputation, your nerves are still sending out signals, “searching” for the limb they have lost contact with, and your brain is having a difficult time comprehending who you are now. People are socialized to believe that their bodies are integral to their identities. You may even experience the amputation as a loss, and therefore will need to be prepared to mourn that loss like other losses you may have experienced. It’s okay to feel angry or sad about losing the person you were before your amputation. You might feel numb or angry at the world, but you need to pass through certain emotions before you can come to terms with any major life change. The important thing to remember is that your grief experience is your own. You may go through several stages at once or think you are done with one only to circle back to it later on. There is no “right” way to grieve a loss.

5 Stages Of Grief:

- Denial and isolation
- Anger
- Bargaining
- Depression
- Acceptance

Finances and Health Insurance: Be Prepared

Amputation is often the result of a serious medical condition. In some cases, the projected lifetime cost of healthcare associated with amputation can exceed \$1 million per person. When added to the cost of a prosthetic device and related care—not to mention the psychological and physical stresses of limb loss—the financial concerns can be overwhelming.

If you know you're going to have an amputation and have the time to plan and fact-check in advance, anticipate and itemize as many of your expenses as possible. Factor in the cost of remodeling your home with accessibility features and the cost of professional in-home assistance or caregivers, if needed. Individuals with lower-limb loss who opt not to use a prosthesis should research the cost of an alternative mobility aid.

Estimating the Cost of Limb Loss

Cost related to your limb loss will vary depending on the level of your amputation, the type of prosthesis you require, and the material from which it is made. Your cost may additionally vary depending on where you live.

Prosthetic Leg: A prosthetic leg can cost anywhere from \$5,000 to \$70,000. A basic, below-knee prosthesis that would enable you to walk on flat ground could cost between \$5,000 to \$7,000, while one that would enable you to walk up and down stairs could cost \$10,000. A prosthetic device with a hydraulic or mechanical system that allows for movement control can cost more than \$15,000, and a computer-assisted prosthetic leg could cost \$20,000 or more. A technologically advanced microprocessor-controlled prosthetic leg for an above-knee amputee could exceed \$70,000.

Prosthetic Arm: A functional prosthetic arm could cost between \$5,000 and \$35,000. A below-elbow prosthesis typically runs between \$6,000-\$8,000, while a traditional body-powered above-elbow prosthesis costs about twice as much—between \$10,000-\$15,000. A technologically advanced “bionic” arm may exceed \$35,000.

The average cost of a *myoelectric* prosthetic arm also depends somewhat on the level of the limb loss: For the partial loss of a hand, the cost is about \$18,700; for a loss up to the middle of the lower arm, it's about \$20,300; for a loss up to the middle of the upper arm, cost is about \$60,000;

and for a loss up to the shoulder, the cost is about \$61,600 but could exceed \$100,000 for a highly advanced myoelectric prosthetic arm.

Arms that use the *targeted muscle reinnervation* (TMR) surgical procedure to control movement through thought are quite expensive—and not widely available.

Because artificial limbs experience normal wear and tear, they need periodic repair. There may be a few recurring costs associated with limb upkeep including socket fit adjustment, adjustments to components or replacement costs.

Physical Rehabilitation

Physical rehabilitation is a critical part of your amputation recovery process. This therapeutic program can help you manage your pain, care for your scar tissue and residual limb, shape your limb to be fitted for a prosthesis, and strengthen and stretch your muscles to better adapt to living with limb loss. If practiced regularly, the tools, techniques, exercises, and stretches you learn from your physical therapist (PT) will benefit you for the rest of your life.

Ideally, you should have the opportunity to meet your rehabilitation team (including physicians, nurses, and PTs) before your amputation to discuss your treatment. Not only will this meeting allow for better understanding of your surgery, it will also allow you to gauge your comfort level with your team. Without a strong healthcare team, your surgery and rehabilitation will be more difficult, so you should have a high degree of comfort with and confidence in each member.

Pain and swelling of the amputated area may be an initial concern and obstacle to your rehabilitation. Discuss any concerns you have with your healthcare and rehab team and be sure to inform them should your pain or swelling levels change during the course of your rehabilitation.

Scar tissue is another immediate concern for amputees in physical rehabilitation. Suture-line scars, skin grafts, and traumatic scarring may be raised and thick for weeks or months following amputation. At this stage, the scar tissue is not mobile and is prone to tearing so do not stress it excessively. Your therapist should begin to lightly tap and gently massage the skin surrounding your scar tissue soon after your amputation to promote healthy circulation. This also begins to desensitize your tissue, which helps to prepare your residual limb for eventual prosthesis fitting. As your swelling subsides, deep tissue massage will be used to prevent soft tissue from adhering to bone, which tends to occur along the incision line.

While your PT will initially perform these treatments, you will be encouraged to begin touching and massaging your residual limb as soon as possible.

Preparing for a Prosthesis:

As you grow stronger and more confident in your ability, you may be wondering how soon it will be before you can be fit for a prosthesis. Although prosthesis use is a typical goal of amputation rehabilitation, the answer to that question depends on your condition and desires. Not all patients want to wear a prosthesis and those in good health are likely to make the transition more quickly than others, possibly in as few as four weeks. However, a patient is ready for a prosthesis between six and 12 weeks post-amputation. The more diligent you are at doing things like desensitizing your scar and residual-limb tissue, shaping your limb, and strengthening your muscles, the more success you are likely to have with a prosthetic device.

Mobility and Assistive Devices

Physical activity is important for everyone's health, but an amputation makes it even more important. If you have had a lower-limb amputation, you'll be taught how to get around using an assistive device, such as a walker, crutches, a can, or a wheelchair, in the first days after your surgery or as soon as your medical condition allows it. Regardless of what type of mobility device you ultimately decide to use, everyone with lower-limb loss should know how to use an auxiliary device. These devices will help you protect your residual limb and get you moving again.

These types of mobility aids are used by almost every amputee after surgery, and they remain an ongoing part of some amputees' lives, especially those who choose not to use a prosthesis or who use a prosthesis but also need or want additional support at times. Learning to use these mobility devices properly can help you get the greatest benefit from them and avoid the potential problems they can cause.

Potential Problems Caused by Misusing Mobility Devices

Most mobility and assistive devices look easy enough to use, but you might be surprised to know that you need to learn how to use these devices properly. Using a mobility aid incorrectly can cause you additional bodily injuries. The good news is that such injuries are largely preventable.

Using a Prosthesis with One or More Mobility Devices

Even if you regularly use a prosthesis, you might also decide to use one or more additional mobility devices as occasional backups when you have trouble using or wearing your prosthesis. Or you might choose to weave them into your life to allow yourself flexibility in prosthesis use.

Are You a Good Candidate for a Prosthesis?

If you are considering using a prosthesis, it's important to understand that this determination must first be made by your physician. Before your surgery, your primary care physician may test your strength, balance, and coordination. Before and after your amputation, your physician and others on your healthcare team will evaluate your general health and look closely at any medical issues you have that could make extra physical exertion dangerous, as well as any physical damage from conditions like diabetes that would make using a prosthetic device unrealistic. They will assess your mental health, energy, *functional levels*, and at-home recovery resources.

If you are a candidate, your physician will write you a prescription for a prosthesis. Whether or not you pursue this option is up to you.

Medicare K-Levels

K0: No mobility. Patient does not have the ability or potential to ambulate or transfer safely with or without assistance, and a prosthesis does not enhance his or her quality of life or mobility.

K1: Very limited mobility. Patient has the ability or potential to use prosthesis for transfers or ambulation on level surfaces at a fixed walking pace. This is typical of the limited and unlimited household ambulator.

K2: Limited mobility. Patient has the ability or potential to walk and navigate low-level environmental barriers such as curbs, stairs, or uneven surfaces. This is typical of the limited community ambulator.

K3: Basic to normal mobility. Patient has the ability or potential to walk at variable speeds. This is typical of the community ambulator who has the ability to traverse most environmental barriers and may have vocational, therapeutic, or exercise activities that demand prosthetic use beyond simple locomotion.

K4: High activity. Patient has the ability or potential to exceed basic prosthetic ambulation skills and applies high impact and stress on his or her prosthetic device. This is typical of the prosthetic demands of a child, active adult, or athlete.

Preventing and Managing Pain

Pain can be difficult to measure and even more difficult to treat because everyone experiences pain differently. There are varying types of pain and pain intensities, and some people experience pain for longer durations than others. From the pain after amputation surgery to phantom limb pain, you may have to cope with a variety of sensations—from merely unpleasant to possibly debilitating. However, many types of pain can be neutralized through preventative measure, and others are often successfully managed with pharmaceuticals and other means.

Where it Hurts: Pain Areas Associated with Amputation

Our bodies were designed to walk with two legs and to function using two arms. Loss of a limb throws the body out of balance, and people naturally develop compensatory movements to “make up” for the loss of function or balance. Compensatory movements put stress on other parts of the body and, when repeated for long periods of time, can result in muscle strain, joint inflammation and degeneration, and overuse injuries—all of which can cause pain. Following are some of the most commonly reported areas of the body in which people with limb loss report pain:

BACK: Studies have reported that between 62 and 75 percent of individuals with limb loss experience back pain, particularly lower-back pain. Although scoliosis of the spine is a possible culprit for this, in many instances, poor posture, obesity, lack of conditioning, and ill-fitting prostheses are to blame.

HIP: Osteoporosis, osteoarthritis, and degenerative joint disease in the hip appear to affect people with lower-limb loss who use prostheses in greater proportion than the general population, most likely because of the stress placed on the hip by prosthesis use. If you use or plan to use a prosthesis, talk to your physician, physical therapist, and prosthetist about preventive measure you can take. Should you develop any of these conditions, consult your physician for treatment.

KNEE: Particularly for lower-limb may be an issue because of added stress from extra use. In many cases, good prosthetic alignment, proper gait training, and good conditioning can alleviate this problem.

NECK: Although overuse of a prosthesis or a poor-fitting prosthesis may cause neck pain for upper-limb amputees, poor posture or problems with the spine, such as cervical disk disease or disk slippage, may be a more likely cause.

SHOULDERS: Studies have shown that an upper-limb prosthesis can cause shoulder strain, but individuals with lower-limb loss can experience shoulder pain also, particularly when they use walkers and crutches incorrectly. Shoulder pain is usually managed with physical therapy or non-steroidal anti-inflammatory drugs (NSAIDs). Continuing to use walking aids incorrectly or wear ill-fitting prostheses can cause pain to persist and worsen.

Types of Pain Associated with Amputation

While not exhaustive, the following list outlines the types of pain most commonly associated with amputation:

ACUTE PAIN, which begins suddenly and is usually sharp, has a specific cause—such as surgery—and can be remedied by treating the cause. Acute pain may last for just a moment or up to six months, depending on the cause.

CHRONIC PAIN is pain that lasts longer than six months. It may have an underlying cause, such as disease or infection.

ISCHEMIC PAIN is a moderate to excruciating sensation associated with decreased blood flow.

A **NEUROMA**, sometimes referred to as a pinched nerve or a nerve tumor, is a painful mass of nerve fibers formed from severed nerve endings after amputation.

NEUROPATHIC PAIN, also known as nerve pain, is a complex, chronic pain condition caused by nerve irritation, damage, or destruction, and is often described as sharp, stinging, or burning.

PHANTOM LIMB PAIN is the sensation that a missing body part is feeling pain. This pain is often described as burning or shooting but is sometimes described as an achy, squeezing sensation. Up to 80 percent of people with limb loss report experiencing phantom limb pain and 10 to 20 percent of those describe it as interfering with their quality of life.

POST-SURGICAL PAIN is a complex response to tissue trauma during surgery that stimulates hypersensitivity of the central nervous system. The result is pain in areas not directly affected by the surgical procedure.

RESIDUAL-LIMB PAIN may be caused by disease, infection, bony growths, neuromas, sensitive scar tissue, or other underlying factors.

Managing Pain: If pain prevention is unsuccessful, other remedies are available, including medications and noninvasive or minimally invasive therapies. The following are possible pain remedies you may discuss with your healthcare provider:

PHARMACEUTICAL TREATMENTS are possible if physical therapy or other noninvasive procedures prove to be ineffective pain-management techniques, your healthcare provider might prescribe pain medication.

NSAIDS that can be purchased over the counter include ibuprofen (Advil, Motrin); naproxen sodium (Aleve); and the many brands of aspirin.

NARCOTIC pain relievers come in a great variety and must be prescribed by your physician.

ANTIDEPRESSANTS and ANTI-CONVULSANTS, which are normally used to treat depression and seizures, have sometimes been proven effective in relieving pain related to amputation, including phantom limb pain from neuromas.

ALTERNATIVE TREATMENTS may also be effective in alleviating pain after amputation surgery. There are many treatments available and you should discuss these with your healthcare team before beginning any treatments. They include: Acupuncture, involving penetration of the skin with very fine needles; Diathermy, a therapeutic heating of deep muscle and joint tissues; Exercise/physical therapy can help manage pain as well as pain caused by sedentary lifestyle, poor diet and, poor conditioning; Massage therapy, which involves the manipulation of soft body tissues, soothes and stretches muscles and joints and improves circulation; Meditation, a technique involving controlled breathing exercise; Counseling/talk therapy can help to find and alleviate emotional causes of suffering that may manifest themselves physically as pain; Spinal cord stimulation is generally used for people who have chronic pain in their backs and limbs.

No one should have to live in constant or debilitating pain. If you are experiencing pain, contact your healthcare provider to discuss possible treatments right away. There are solutions.