



**amputee
coalition**[™]



Questions to Ask Your Surgeon and Rehabilitation Team



About the Amputee Coalition

The Amputee Coalition is a donor-supported, voluntary health organization serving the nearly two million people with limb loss and more than 28 million people at risk for amputation in the United States.

This brochure has been adapted from an article appearing in Amputee Coalition's *First Step: A Guide for Adapting to Limb Loss*, Volume 5, published in 2009. The full guide is available by contacting the Amputee Coalition at 888/267-5669 or by visiting amputee-coalition.org.

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Amputation. It's something no one hopes to discuss. However, more than 185,000 amputations are performed annually in the United States because of injury, disease, infection, chronic wounds and dysfunction.

Arms, legs, hands and feet are wonderful parts of our bodies that allow us to interact with our environment. Loss of part or all of a limb forever changes how we move, touch, work and play. But amputation is not a failure. The amputation site becomes the interface with the world by itself or in conjunction with a prosthetic device designed to replace the missing limb.

Surgeons strive toward two primary goals, both of which are critical to the success of the amputation procedure. The first goal is to remove the diseased, damaged or dysfunctional part of the body. The second goal is to reconstruct the remaining part of the limb in a way that will promote wound healing and create the best residual limb possible

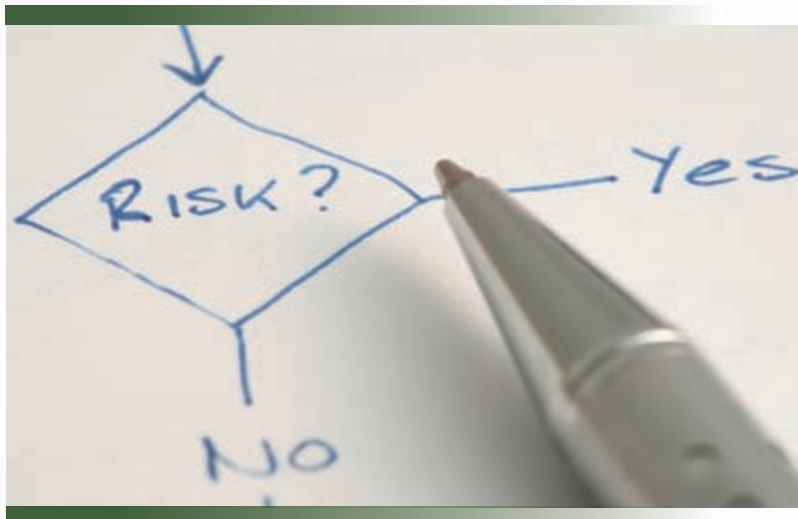
Amputation, recovery and rehabilitation care are part of a team process involving doctors, nurses, therapists, prosthetists and most importantly, the individual facing surgery. This individual, family members and any additional caregivers need to be as well informed as possible about the procedure, recovery, rehabilitation and life after amputation.

Is it an emergency?

When it comes to amputation, the time frame for consultation, consideration and decision making can range from the immediate to years. In cases of trauma, the limb is sometimes lost at the scene of the accident. Sometimes, the person is unconscious and the decision to amputate a limb may have to be made rapidly to save their life. If no family is present, the decision may fall upon healthcare professionals.

In other cases, severe infection may be present and making the individual very sick. In medical terms, sepsis is occurring. Sepsis causes incredible stress on the heart, lungs and circulation, and can cause death if not treated. Treatment can include appropriate antibiotics, surgery to drain or remove infected tissue, and intensive support of the heart, lungs and circulatory system.

Fortunately, true emergencies are rare. There is usually time for discussion, presentation of options and decision making. Frequently, a person may be facing a difficult choice between limb salvage and amputation. Unfortunately, some salvage attempts lead to years of struggling and suffering with a limb that is no longer capable of functioning efficiently or without causing pain. In some situations, the need for amputation is clear, but the individual just needs a day or two to consult with family or to become mentally prepared. Patients should ask their surgeon if amputation is truly an emergency or if the decision can safely be put off for a day or two. If it's safe to wait, the surgeon should consider the request and give the patient the requested time.



Should an amputation be done?

When time and circumstances permit, the physician must explain candidly why injury or disease has significantly limited the person's options. The doctor should convey the nature of the injury or condition and whether it is technically possible to save the affected limb. When we can save the limb, it's usually wise to do so. But predicting the outcome of salvage is not always easy. While it is our natural instinct to want to save every severely injured limb, there are times when this can put the person at increased risk of complications.

Many people may not be aware of how difficult it can be to live with a salvaged limb. They might have heard about the wonders of surgical reattachment of limbs and that badly injured limbs are now routinely saved. But limb salvage and rehabilitation can be a long, difficult and painful process. Salvage can involve several surgeries, and it might mean sacrificing other parts of the body for bone grafts, skin grafts or muscle flaps. Finally, salvage does not necessarily mean "as good as new." Almost always, salvage means limitations. Sometimes those limitations can be a bigger burden to manage than an amputation. The patient should discuss with their surgeon whether salvage is best or whether amputation might be more appropriate.



If time permits, it's wise to seek a second opinion. Amputation is permanent. Seeking the opinions and advice of other physicians, nurses, prosthetists and people with limb loss can be beneficial. People may mistakenly think they're not allowed to go to an amputee support group until after they've lost a limb. Actually, this can be the best place to gain insights into aspects of decision making, surgery, the rehabilitation process, and life with limb loss. Patients who are interested should ask their healthcare provider for information about support groups or call the Amputee Coalition toll-free (888/267-5669) for information about a support group near them.

The way a team plays as a whole determines its success. You may have the greatest bunch of individual stars in the world, but if they don't play together the club won't be worth a dime.

— Babe Ruth

What is meant by amputation level?

Amputation level refers to where on the body the amputation will occur. Level selection and decision making in amputation surgery are not easy. Surgeons try to balance the chance of successful healing with preserving function. We know that higher-level amputations have a better chance of healing, but we also know that the rehabilitation is more difficult and that the result can mean less function. Whenever possible, we do everything we can to preserve as much as possible, especially the elbow or the knee joint.

Over time, surgeons have learned that certain amputation levels tend to function better than others. It's natural to want to save as much skeletal structure as possible, but it's more important to choose a site that will allow the creation of bone shape, muscle and soft tissue padding, and a residual limb with the optimal interface with prosthetic devices. It can be far wiser to choose a higher level of amputation if it will improve the chances of healing and returning to activity.

The patient should ask the surgeon to explain the particular advantages and disadvantages of different amputation levels and why a particular amputation level has been recommended.

What about pain?

Discussions about pain should include the type of anesthesia to be used during the operation, the delivery method of medication in the days immediately after surgery, the medications to be used in the recovery process, and a plan to stop the medication. The patient and their team should also discuss the phenomena referred to as "phantom sensation" and "phantom pain." Phantom sensation is the feeling that all or part of a missing limb is still intact. This occurrence is quite common for many people with limb loss. Most, however, say they do not find it bothersome. Patients who do have difficulty with

phantom pain should ask their healthcare providers about management and coping techniques. It has been hypothesized that the use of certain anesthetics before and during surgery might have a long-term benefit of minimizing phantom pain. Scientific research on this theory has been mixed and not as supportive as initial studies indicated.

Who are these people and what are they doing in my room?

Physiatrists, prosthetists, physical therapists, counselors and peer visitors are all vitally important in presurgery, recovery and rehabilitation. While some surgeons still coordinate the rehabilitative efforts of their patients, a physiatrist is the medical doctor who most often prescribes and coordinates this care. This physician often works closely with the rehabilitative nurse to prescribe treatment and devices and supervises the efforts of the prosthetist and physical therapist. They also can assist in obtaining educational and emotional support from counselors or peer visitors. The patient should know the primary physician who is coordinating his or her care.

When time permits, patients should get a recommendation to carefully interview prospective prosthetists. During the first year following surgery, a new amputee spends a great deal of time with the prosthetist. The amputated limb changes dramatically during this year, and using a prosthesis helps these changes to properly occur. However, a prosthesis that is fit three months after surgery will simply not fit several months later. The residual limb will change, and patients should plan for these changes as their amputation heals and matures. Patients should ask their prosthetist the following questions: How will adjustments be made? When might a new socket be needed? How many visits might be required? What will be covered by insurance? What might I have to pay for?

The same goes for the physical therapist. The patient should ask whether the physical therapist is experienced in working with amputees, what will be done at the therapy sessions, and what is to be done at home between sessions. With the help of the physical therapist, the patient should establish realistic goals and milestones for his or her rehabilitation.

Finally, the patient should ask about support groups and peer-visitation programs. With these programs, patients have the opportunity to talk with other people who have experienced limb loss. The Amputee Coalition has a network of support groups, peer visitor services and other information that can be helpful with these matters.

Contact the Amputee Coalition at (888) 267-5669 to schedule a peer visit or find a support group and other resources.

The essence of success is teamwork with a foundation built on mutual respect.

What can I expect during my recovery?

The first year following amputation surgery is, quite frankly, rough. There are dramatic changes in the shape and size of the residual limb, and a lot of work and fine-tuning is needed to recondition muscles and relearn activities, balance and coordination. Contact with the prosthetist and the physical therapist can be frequent. Therefore, geographic location should definitely be considered when choosing a prosthetist and therapist. Patients will want to know whether their prosthesis will be fairly standard or, because of unique circumstances, more complex to fit. Occasionally, referral to an advanced prosthetics specialist may be recommended.

Visits with a physical therapist are fairly frequent for six months following surgery, which is why it is important to choose someone who is nearby and also experienced with limb-loss patients. Patients should ask about the physical therapy stages, including mobility, injury prevention, reconditioning, postoperative and interim devices, and more definitive prosthetic devices. They should also ask what level of function can be expected and what types of activities can reasonably be worked toward.

During the first year, the best technology is the most appropriate technology. It's natural for a person to want a prosthesis with the latest high-technology components. But a specialized running leg, for example, is simply not the best leg when first learning to walk. Patients should ask members of their healthcare team about appropriate technology and devices that will facilitate rehabilitation, especially in the early stages. Later, as function improves and needs and skills change, a more complex device may be appropriate.

How can I protect my other limbs?

Patients should ask their doctor about measures that can be taken to preserve the health and vitality of their remaining limbs. In cases of vascular disease and diabetes, statistics indicate that people who have had one leg amputated are at risk of losing the other. In cases of trauma or tumors, there also is data to suggest that the unaffected limb will undergo increased wear and tear over the years. Amputation does not change the underlying disease; it only removes the diseased or damaged limb.

So, what can patients do to preserve their remaining limbs? First, if patients smoke, they should stop. And if they don't exercise, they should start. Proper protection and stretching of the back, neck and the remaining limbs are vital. Patients with diabetes should be especially careful about protecting their feet. They should wear properly fitted shoes that allow adequate room for the toes, and they should not walk barefoot.

A good diet that provides proper nutrition, blood glucose level and cholesterol control is also essential. They should also check the bottom of their good foot for unusual bruises or blisters. This should be done every night, usually with a mirror, before going to bed.

How can I work best with my healthcare team?

The essence of success is teamwork with a foundation built on mutual respect. It is equally important for individuals to have realistic expectations for the different healthcare workers' time and expertise. For example, questions about medications may best be taken to a pharmacist. A prosthetist or physiatrist may have the answers about the patient's artificial limb. The podiatrist may best answer questions about foot care. The nature of medical care in the United States has led to more specialization because there is too much information for any one person to master. Patients must, therefore, be skilled at gathering information from many different sources. Patients should ask who is available to help coordinate and supervise the different aspects of their care and take an active role in keeping the different providers aware of all issues.

Patients should make the best use of their and their doctor's time. They should prepare a list of questions in writing before an appointment, and they should listen carefully to their doctor's answers. They may find it helpful to write answers down in a journal, along with their own observations at home, for future reference. Another helpful suggestion is to take family members with them to doctor's appointments. Patients who take a proactive role in their own healthcare will probably be more satisfied with the results. This can be a very difficult time, but active participation in the process is mandatory.



For more information, please call
888/267-5669 or visit
amputee-coalition.org.