

*Adapted from the 2014 edition of the Amputee Coalition
publication First Step: A Guide for Adapting to Limb Loss*

Nothing is quite as bewildering or scary as the unknown. That's why one of the most frustrating aspects of limb loss is trying to understand what lies ahead on the road to recovery.

Some of most common questions include:

When will I receive my first prosthesis?

How long must I wrap my residual limb?

When will I walk again?

How long does phantom pain last?

The usual "one-size-fits-all" response is something like, "Well, that depends," or, "Everybody is a little different." But in today's world, where our lives are measured by calendars, clocks and coffee spoons, we want something more. We want a date, the number of days, weeks or months.

Are We There Yet?

The hard truth is that we all march to a different drummer; not everyone progresses at the same pace. A date is nothing more than a goal, a target that everyone likes to have so that we can measure our progress. Most folks are content to accept whatever timeframe is offered by their physician, physical therapist and prosthetist. The trouble with such goals is that if we fall short, we all feel a small sense of failure, whether real or imagined. We wonder what we did wrong. Unfortunately, recovery time after limb loss can be unpredictable because there are so many variables unique to each person, and rehabilitation doesn't come with a crystal ball.

So what are the common signs or milestones that tell us we're on the road to recovery? There are several, and though the timeframe for reaching each may vary, almost everyone will reach their goals and eventually get to the place they want to be. Like any journey, the anticipation of getting to where we want to go always makes the trip seem longer than it actually is.

Making the decision

One of the hardest decisions a person will ever face is the one to have a limb amputated. Few people actually have the decision made for them because most people are required to give their consent. Although it's difficult to weigh the concerns and agree to adopt a life with an uncertain future, many people have said that once they made their decision, there was a great sense of relief. Once the decision was made, they could begin to look to the future.

Getting out of bed

The day after your surgery is one of the most difficult to get through. It's painful. It's sad. And it's scary. The "simple act" of getting out of bed and starting the process of rehabilitation takes a tremendous amount of courage. Typically, just

sitting on the edge of the bed and moving over to the chair is a painful but very important beginning.

Walking with an assistive device

As the old saying goes, the journey of a thousand miles begins with a single step. Even if you have upper-limb loss, getting out of bed and walking is an important first step. Learning to walk while in the hospital is not an easy task, but it will help improve your mobility around the house and will make getting back to your way of life much easier. However, many people are not ready to walk just after surgery because of weakened muscles or other medical conditions; in their case, it is not practical. If this is the case for you, don't worry; your time will come.

Meeting family and friends for the first time

Once you get home, you may have difficulty with having your family and friends around. Most people are not themselves during this time. You may feel uncomfortable because your body has changed, the residual limb is painful, and you may require considerable assistance. Family and friends may also feel uncomfortable. They may find it hard to strike a balance between being helpful and being bothersome. Also, choosing the right words in conversation can be awkward. It's up to you to set the tone. Be yourself; don't be afraid to ask for what you need, and let them know what you can do for yourself. If someone says something awkward, laugh it off and realize that no harm was intended. Accept their support and establish your independence.

Accepting a peer visit or joining an amputee support group

Asking others for help can be very difficult for some people. However, accepting a visit from a peer visitor or another amputee can not only be comforting but can help you find the answers to many questions you may have. If knowledge is power, then getting in touch with an Amputee Coalition-certified peer visitor or support group can be a critical milestone.

Restoring physical conditioning

From the first day after surgery, you should be striving to increase your cardiovascular endurance, strength, balance and flexibility. Even if exercise was not a significant part of your life before, it must be now. The sooner you can rise from a chair on your own, walk moderate distances with an assistive device, and maintain your standing balance, the sooner you will be ready for prosthetic fitting. Moreover, you will begin to notice that everyday activities, such as moving around the house, getting in and out of the car, and going places in the community, will be much less demanding.

Reducing residual-limb swelling

Using compression dressings will help reduce the swelling and create a "stable limb." In other words, the swelling will not increase and decrease as much throughout the day. This is a key milestone; once the residual limb is stable, the pain will typically decrease enough to begin the fitting process for the prosthesis. For some people, however, their residual limb may always fluctuate in volume or swell because they tend to retain fluids or have a secondary condition that causes swelling. If this is a problem for you, it just means that you will have to continue using a compression wrap when you're not wearing your prosthesis.

Meeting your prosthetist

For many people, finding the right prosthetist is a process that takes some time. Because your prosthetist could potentially be a lifelong caregiver, it is important that you take the time to explore your options and interview several prosthetists. You need to discuss what your prosthetic needs and options are and make several decisions about

components, socket design and other issues that you are probably not very familiar with. Taking the time to ask questions, talk to other amputees and do a little research on your own can really help with the decision-making process.

Receiving your first prosthesis

There is something unique about receiving your first prosthesis. Many folks will tell you that there is a sense of turning the corner. There is a quiet excitement because you feel that once you receive the prosthetic limb, your life will be whole again. You'll be able to go on walks with your spouse, dance or use both arms. Sometime during the fitting process, however, it will strike you just how difficult it is to use a prosthesis in the beginning. Although it's easy to let yourself become disappointed, you have to understand that with time and practice, you will become increasingly skilled at using your new prosthesis.

Learning to use your prosthesis

Regardless of whether it is an upper- or lower-limb prosthesis, prosthetic training takes time. Unfortunately, many people only learn the basics, just enough to do simple tasks with their prosthetic arm or to walk a little. Seeking a physical or occupational therapist who specializes in prosthetic training is just as important as finding a qualified prosthetist. Far too many people fall short of their prosthetic potential simply because they don't receive proper training. Learning how to use a prosthesis correctly can reduce the amount of effort required and increase your functional ability. Once you have mastered the use of your prosthesis, everything else will tend to become just a little bit easier.

Getting back to work

For many people, retirement seems to be a logical option after the loss of a limb. But this must be a considered decision, not one made simply because of limb loss. Several studies have shown that most people with limb loss can and do return to work, regardless of the level of amputation or number of limbs amputated. If you are a leg amputee, the main difference may be the amount of standing and walking that you can do compared to before. Work is a positive experience, and for many of us, it provides a sense of worth and contribution to the community. Getting back to work should be a goal. You may have to make some adaptations, but, for most people, the minor accommodations are well worth being able to get back to the job.

Getting back to leisure activities

Returning to activities that you once enjoyed is one of the most significant milestones. Again, some accommodations may have to be made, but they will be worth it. Sharing your leisure interests with other people with limb loss is a great way to overcome any obstacles and to make a few friends with common interests.

Accepting your new body

One of the most difficult milestones to overcome is the overall acceptance of limb loss. A gentleman with multiple amputations once said that for him to return to work, sports and life, he had to let go of the notion that he would still be able to do things the way he once did. Only after he stopped trying to do things as a "two-legged" person and learned how to do them with the body he now had was he able to move on and embrace life. The key for many people with limb loss is to stop focusing on the part of their body that they have lost and to focus on the whole of the person that they are. In short, be comfortable with who you are and continue to live life to the fullest.

Remember, there are no timeframes for reaching each milestone because everyone is different. Set short-term goals that you can reach within a reasonable time while keeping your eye on your long-term goals. Don't become impatient

and so focused on the milestones along the road to recovery that you miss all of the other things that life has to offer. Think of each step as an event in itself. Then, after some time, look back and see which ones you've completed. You might find that you are farther along than you thought.

It is not the intention of the Amputee Coalition to provide specific medical or legal advice but rather to provide consumers with information to better understand their health and healthcare issues. The Amputee Coalition does not endorse any specific treatment, technology, company, service or device. Consumers are urged to consult with their healthcare providers for specific medical advice or before making any purchasing decisions involving their care.