Patient Pathways for Lower Extremity Amputees

When it comes to lower limb loss, 54% are caused by vascular disease – including diabetes and peripheral arterial disease, 45% due to trauma and the rest is cancer or congenital. The loss of a leg brings with it a lot of fear, anxiety and concerns for the future. Will I ever be able to return to the things I love? Will I be able to get a job? Will people accept me?

These feelings are natural and normal and in time, you will find that you’ll be able to do all of the things that you used to do, you just might have to do them differently. You may decide to return to work or your vocational interests may change. That will be determined in time. And generally, other people take their cues from YOU. If you accept yourself, others will, too. In order to give yourself the best possible chance at great outcomes, it’s important to understand your care plan and the steps to take to achieve success. There are generally four phases that amputees will go through on their way to independence.

Peri-Operative Phase
The first phase of amputation - Preparing for Amputation:

If your amputation is caused by disease (such as diabetes, cancer, etc.), you will have a scheduled surgery date and surgery plan in place. Prior to your surgery, it is important to as many questions as possible about the planned level of amputation and the options for prosthetic devices.

Ideally, you should meet with 2-3 prosthetists who have experience with the level of amputation that you will acquire. Have prosthetic consultations to find out what kinds of prostheses are available to you and what you can expect once you wounds are healed. When selecting a prosthetist, it’s important to ask:

1. How many prosthetic legs do you fit each year? How many at my amputation level?
2. Do you have experience with high tech microprocessor prostheses?
3. Can I meet one or two of your patients to see a prosthesis in action and ask questions? Or, do you have a peer support program here?
4. Based on my goals, what type of prosthesis do you think would be best for me? Why?
5. What are the advantages and limitations of the different types of prostheses available?
6. What are my options regarding the appearance of my prosthesis? Can it be customized? Will it look exactly like my other leg?
7. If something breaks on my prosthesis, are you able to repair it here or must my prosthesis be sent out?
8. What kind of prosthetic training is available? Do you work with a physical therapist?

Once you have selected a prosthetist, ask your surgeon and prosthetist to consult on your case prior to your surgery. Often times, a prosthetist will be able to share information about the optimal length of the residual limb to make for a successful prosthetic fitting. Understand though, that if your limb is affected by disease, your surgeon may make a decision to amputate more bone and tissue to provide for optimal healing and health.

If possible, meet with another amputee with your level of amputation to discuss your questions and concerns. Often, speaking with someone who has gone through a similar experience helps tremendously as you prepare for surgery.

**Amputations as a Result of Trauma**

If your amputation is a result of trauma, often you do not have the option of preparing for your surgery. You may wake up after a terrible accident to find that you have lost a part of your foot/leg. Chances are, you’ll be flooded with the fear and apprehension, however, know that you have power in this situation, even if you feel powerless at the moment. As you begin to heal and become educated on your options, you can begin to take your health and well-being into your hands and start rebuilding.

To read about stories of lower limb amputation trauma survivors, [click here.](#)

While in the hospital, it’s important to ask questions about your care pathway. Sometimes, your surgeon or nurse will call a prosthetist into the hospital to see you and evaluate your limb. Other times, you’ll be released from the hospital without seeing a prosthetist. Either way, it’s important to understand the next steps and to understand that you have control. You should not sit back and wait for things to happen, but rather you should participate in and drive your recovery and rehabilitation plan. Don’t leave the hospital unprepared. Enlist the help of close family or friends and get answer!

Questions that you’ll want to have firm answers to, prior to being discharged from the hospital include:

1. How do I care for my wound and dressing once I’m home?
2. How will I know if I’m healing properly? What should I look for in terms of infection? Swelling? Muscle contractures? Is there anything I should do / not do to promote quicker healing?
3. What about this pain? (Understand how much and how often you should be taking prescribed medications)
4. Are there exercises and/or techniques I can practice to help deal with desensitization and phantom pain in my residual limb?
5. What about psychological support? Are there therapists who deal with patients with limb loss?
6. Can you provide me with information on peer support? Family support? Groups in the area that are designed to support amputees?
7. Will I be going to a rehabilitation facility? In-patient? Out-patient? Who should I contact to schedule?
8. Will I need physical therapy? Who should I contact? When?
9. If I’m not going to a rehabilitation facility, what are my next steps in this process? See the surgeon in his/her office once healed? See my family doctor to get a prosthetic referral? Make an appointment with a prosthetist?
10. How do I find experienced prosthetists in this area?

**Pre-Prosthetic Phase**

**Preparing the patient for a prosthesis:**

When your questions have been answered and you have been released from the hospital, the next steps include pre-prosthetic training and preparing for your prosthesis. After your wound is healed, you’ll want to make an appointment with the prosthetist of your choice (remember, interviewing different clinicians to gauge experience level and compatibility is critical).

He/she will begin the process of fitting you with a test socket. A socket is the interface of the prosthesis that rests between your skin and the external lamination of the prosthesis. A snug and comfortable fit is critical. In this phase, you must become an excellent communicator. Do not be afraid to tell your prosthetist if the test socket isn’t comfortable. It’s essential that you become very “nit-picky.” Your socket should be snug and secure, but it should not cause you any pain. Do not rush the process in order to get a prosthesis more quickly. It’s important to be patient and understand that this is a process.

While your prosthesis is in check phase (preparatory), you may begin working with an physical therapist for pre-prosthetic training including range of motion/stretching, limb desensitization and muscle strengthening. Ask your prosthetist about whether or not you’ll be needing physical therapy at this phase.
Prosthetic Delivery and Prosthetic Training
Learning to function with a prosthesis:

When your prosthesis is complete, your clinician will call you in for a fitting. During this appointment, you will learn:

1. How to don and doff your prosthesis
2. How to determine if it is on in the correct position
3. How to properly care for your prosthesis, including cleaning instructions.
4. How often to wear your prosthesis in the first few weeks – generally a wearing schedule is determined to gradually work up to full time wear

It might be a good idea to request that a peer support volunteer or another patient wearing the same technology be present at the appointment. He / she can offer tips and tricks with everyday activities like getting up and sitting down, walking down stairs and ramps.

Take your time at this appointment to make sure you understand all of the instructions and information provided to you. Bring a friend or family member along for another set of ears. Don’t be afraid to take notes.

At the conclusion of the appointment, your prosthetist will recommend that you make a follow-up appointment. If anything goes wrong, if you are in pain, or if you have questions prior to that appointment, be sure to call the office right away.

Continue to see your physical therapist during this time to perfect your skills.

Maintenance and Lifelong Care Phase
Reintegration into life:

Once you have achieved independence and operational success with your prosthesis, you’ll move into the lifelong care phase. You should schedule routine follow up appointments with your prosthetist at least once a year. Staying educated on new advancements in prosthetic technology is important, as there may be a new device that could provide you with better function.

Should something break or need adjusting on your prosthesis, call your prosthetist right away and schedule an appointment.

As a general rule, patients can qualify for a new prosthesis every three years, however, if there are significant changes in your health (significant weight loss or gain for example), your clinician can make a request to your insurance provider to accommodate your needs.