ACHIEVING LONG-TERM SUCCESS WITH YOUR HEALTHCARE TEAM

ACHIEVING LONG-TERM SUCCESS WITH YOUR HEALTHCARE TEAM

Many studies and experts agree that team-based healthcare is the best type of care for people with limb loss. Those who receive coordinated, team-based healthcare are likely to be healthier, happier, and have a better quality of life than those who do not. Even so, team-based care is hard to come by, and you or someone in your family might have to find, create, and manage your team. (For more information, see Your Healthcare Team, pg. 10.)

How often you see each particular healthcare provider after your amputation surgery will vary greatly and will change over time. However, there are certain providers who you are likely to visit periodically or regularly for the rest of your life:

Prosthetist

Your *residual limb* will continue changing for one or two years post-amputation, and this will inevitably require adjustments to your *prosthesis*. You can expect to visit your prosthetist around 15 to 20 times in the first year after your amputation and once or twice a year after that for routine checkups, notes John Peter "Pete" Seaman CP, CTP, a prosthetist at Independence Prosthetics-Orthotics in Newark, Delaware. If you have lifestyle or health changes, you may have to visit your prosthetist more frequently.

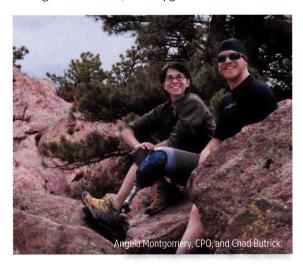
Additionally, you can expect to replace your prosthesis every two to four years, Seaman says. (Author's note: Currently, Medicare will cover a replacement every three to five years, and anything more frequent must be medically justified.)

In 2009, Seaman surveyed 50 lower-limb amputees and found that 62 percent had changed prosthetists more than once over an average period of eight years. Some had changed prosthetists three or even four times. The change was most often due to unhappiness with the fit and comfort of their prosthesis. Some also reported being unhappy with the services provided by their prosthetists. Earlier studies had similar results.

What went wrong? Many in Seaman's study said they wanted better communication with their prosthetic providers, better information about prosthetic options, and more individualized and personalized care, with the goal of having a better fit and improved function.

The study found that a large percentage of these individuals had little or no knowledge about amputations or prosthetics before their surgery, and 82 percent did not interview more than one prosthetist. They simply saw the first practitioner suggested to them.

Seaman's study underscores the importance of interviewing several prosthetists, choosing your prosthetist carefully, and learning as much as you can about prosthetic devices. You have a choice when it comes to prosthetic providers. Being educated about prostheses can help to reduce your anxiety level and allow you to find a prosthesis you can live with over time. As you learn more, you are likely to play an increasingly larger role in selecting your prostheses. (For more information, see Finding the Right Prosthetist for You, pg. 62.)



Primary Care Physician

To maintain general good health and well-being, you will continue seeing your primary care physician. However, you may want to seek out a primary care physician who has knowledge about and experience working with amputees. If your primary care physician does not have this expertise, and you cannot find one who does, you may be able to find a healthcare provider who employs a rehabilitation nurse who has this experience.

Questions to Ask Your Healthcare Provider:

How many of your patients have amputations?

you see patients with limb loss?

Do you coordinate amputee care with other providers?

If you have a medical condition such as heart disease, peripheral vascular disease (PVD), or diabetes, you might need a specialist as your primary care provider unless your condition is very mild. This provider might be a doctor or nurse who regularly treats patients with your condition, someone who is board certified in the specialty, or someone who is part of a treatment team focused on treating your condition.

For example, if you have diabetes, you might consider having an endocrinologist as your primary care provider. If you have PVD, you might seek out a vascular clinic and make that your primary medical "home."



ACHIEVING LONG-TERM SUCCESS WITH YOUR HEALTHCARE TEAM

Physiatrist

A physiatrist is a medical doctor who specializes in physical medicine and rehabilitation. You might have had a physiatrist managing your care when you were hospitalized for your amputation or when you were in an inpatient rehabilitation facility shortly afterward.

A physiatrist who works with amputees will be a specialist who can help you with muscle, skeletal, and neurological problems stemming from your amputation.

Not all physiatrists work with amputees. Physiatrists might specialize in pain medicine, sports medicine, neuromuscular medicine, or other subspecialties. If you need a physiatrist to help with pain, muscle, or bone problems, ask your primary care physician for a recommendation and a referral. Find a physiatrist whose expertise matches what you're looking for.

For a list of physiatrists in your area, visit the American Academy of Physical Medicine and Rehabilitation (AAPM&R) website at www.aapmr.org/patients/findphysician/pages/default.aspx and do a search.

Physical Therapist and Occupational Therapist

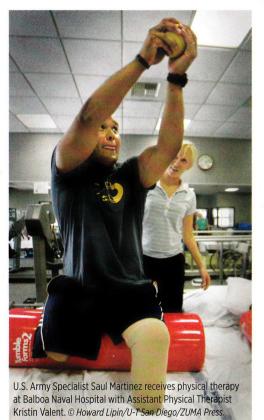
Soon after your surgery, you will be working with a physical therapist (PT)—and most likely an occupational therapist (OT), too—the former to help you regain your strength and get moving, and the latter to help you learn new ways of doing day-to-day tasks.

You are likely to work with one or both of these professionals periodically when you replace your prosthesis or otherwise restructure your mobility system and mobility aids.

Not all therapists have experience with limb loss, so make sure that yours do. It is critical that the PT who helps you with your prosthesis is trained in it, especially if you are getting a high-tech prosthesis.

A PT can also help you start, restart, or reconfigure an exercise program or provide you with training and solutions to help you deal with pain, muscle strains, muscle *atrophy*, bone loss, and body imbalances. Such problems might worsen over time if you don't address them.

For the best results, build a strong team of healthcare providers who communicate well with each other and with you. Good health over the long term is an attainable goal, and with a team you can count on, you can have a long and fulfilling life with limb loss.



References

Feinglass, J, VP Shively, GJ Martin, ME Huang, RH Soriano, HE Rodriguez, WH Pearce, and EJ Gordon. "How 'Preventable' Are Lower Extremity Amputations? A Qualitative Study of Patient Perceptions of Precipitating Factors." *Disability and Rehabilitation* 35, no. 25 (2012): 2158–65. doi: 10.3109/09638288.2012.677936.

Frykberg, RG, DG Armstrong, J Giurini, A Edwards, M Kravette, S Kravitz, C Ross, J Stavosky, R Stuck, and J Vanore. "Diabetic Foot Disorders: A Clinical Practice Guideline." *Journal of Foot & Ankle Surgery* 45, no. 5 suppl (2006): S1–60. hwww.ncbi.nlm.nih.gov/pubmed/11280471

Jones, Chris, CP, Owner and Prosthetist, Rebound Prosthetics. Interviews by Carolyn Cosmos, October 23 and 24, and December 12, 2013.

Konetchy, Cale, CP, Clinical Specialist in Prosthetics, Ottobock. Interviews by Carolyn Cosmos, October 21 and 31, 2013.

Meier, Robert H. III, MD, Physiatrist and Director, Amputee Services of America. Interview by Carolyn Cosmos, October 31, 2013.

Seaman, John Peter. "Survey of Individuals Wearing Lower Limb Prostheses." *Journal of Prosthetics and Orthotics* 22, no. 4 (2010): 257–65. www.oandp.org/jpo/library/2010_04_257.asp doi: 10.1097/JPO.0b013e3181f99672.

Seaman, John Peter, CP, CTP, Prosthetist, Independence Orthotics-Prosthetics. Interview by Carolyn Cosmos, October 21, 2013.

Vigoda, Diane, LCSW, CCM, Team Leader/Counselor, Amputee Services of America. Interview by Carolyn Cosmos, October 24, 2013.

92 Limb Loss Resource Guide

Amplitude Media Group