

AMPLITUDE'S GUIDE TO

LIVING

AMPLITUDE

WITH A

LIMB LOSS

AMPLITUDE

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LIVING— AND THRIVING— AFTER LIMB LOSS

AFTER LOSING ONE OR MORE OF YOUR LIMBS, YOUR LIFE WILL CERTAINLY BE DIFFERENT. LIMB LOSS AND ITS ACCOMPANYING ISSUES WILL SIGNIFICANTLY IMPACT YOUR LIFE—PHYSICALLY, EMOTIONALLY, FINANCIALLY, SOCIALLY, AND EVEN CULTURALLY. HOWEVER, THE SUCCESSFUL LIVES OF THOUSANDS OF AMPUTEES WITNESS THAT YOUR LIFE DOESN'T HAVE TO BE OVER AND THAT IT CAN BE GOOD OR EVEN AWESOME.

At first, your mind will be flooded with anxiety and questions that you don't have answers to. You'll wonder how you're going to pay your bills. Whether you'll always have to depend on others. How your relationships will suffer—or if you'll even have relationships. If you'll ever be happy again.

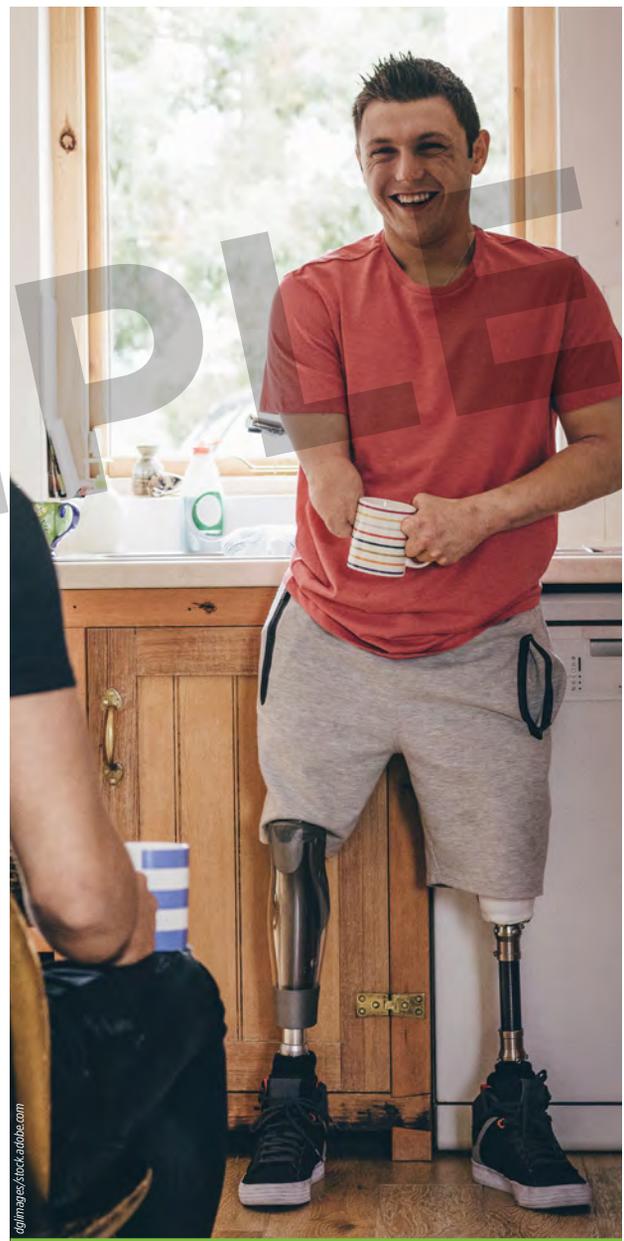
The fact is that if you want to do the things you did before and live your life like you always have, you're going to have to work harder. And if you want to do new and different things—live beyond your former life—which is what many amputees choose to do, you're going to have to work *a lot* harder.

The good news is that there are ways to help minimize the negative impact of amputation on your life, and they are not secret.

Throughout the pages of

this guide, you will discover a wealth of information and resources that will help you regain your life. In addition, *Amplitude* magazine and the *Amplitude* website (www.livingwithamplitude.com), Facebook page (www.facebook.com/AmplitudeMediaGroup), and Twitter feed (@_Amplitude_) offer ongoing information on living and thriving with limb loss. You'll also learn about individual amputees and amputee support groups that are ready to offer you valuable support and knowledge (pg. 34).

Although it might seem unfathomable to you now, human beings can be amazingly resilient and defiant in the face of traumatic circumstances. “Just wait,” they say when people or life tells them they must accept defeat and limitations. “Don't tell me what I can or can't do.”



MANY AMPUTEES ARE PROOF OF THIS.

CARL BRASHEAR, the subject of the movie *Men of Honor*, lost his left leg after a pipe struck his leg during a bomb recovery operation in 1966. In 1970, he became the U.S. Navy's first black Master Diver. Brashear used to say, "It's not a sin to get knocked down; it's a sin to stay down."

JEFF CAIN, KEVIN TREES, AND WILLIAM MALMSKOG pursued demanding careers as a medical doctor, police detective, and firefighter, respectively.

NICK NEWELL became a professional mixed martial arts fighter, and Shaquem Griffin was drafted to play linebacker in the NFL for the Seattle Seahawks. Other amputees are excelling in almost every sport.

AMPUTEE ARTISTS, SUCH AS TOM YENDELL AND HUANG GUOFU, have found ways to draw and paint using their mouths, feet, or residual limbs or prostheses to hold and manipulate pencils, pens, and brushes. (<https://bit.ly/2ljZCcM>, <https://bit.ly/2ljhB35>)

OTHERS, SUCH AS SHAHOLLY AYERS AND EDDIE MCGEE, have become models and actors.

ERIC GABRIEL started a doctoral program after losing his right leg. Before he completed the program, he lost his left leg in 2018. Undeterred, he then went on to complete his program and graduate in 2019 as Dr. Eric Gabriel. He rolled across the stage in his wheelchair to pick up his diploma.



8 TIPS FOR THRIVING AFTER AMPUTATION

- 1 **Believe strongly in your continued potential after amputation.** Thousands of amputees have proven that limb loss does not have to prevent you from going to school, having a job, marrying, having children, participating in sports, and enjoying a full life. You are not defined by your amputation.
- 2 **Set a goal, and work toward it.** Your goal can be big or small as long as it gives you something to strive for. Focus intensely on your goal and move toward it step by step. Break down your large, overwhelming tasks into smaller, more manageable ones and take them on one at a time.
- 3 **Set another goal, and another one, and another one.** Once you've achieved your first goal (perhaps standing again), set another one (perhaps taking your first step). That way, you'll always have something new to achieve. As you accomplish each goal, your self-esteem will grow, motivating you toward greater successes.
- 4 **Accept the support of family, friends, and other amputees.**
- 5 **Keep trying.** Don't give up or take no for an answer.
- 6 **Don't let other people's opinions dictate your destiny.**
- 7 **Research living with limb loss, learn from others, and be willing to consider their advice.**
- 8 **If you fall or get knocked down, dust yourself off, and look for alternate ways to accomplish your goals.** "Fall seven times, stand up eight," advises a Japanese proverb. Even if you fall over and over, if you stand up the last time, you will ultimately succeed.

01

RECOVERY AND HEALTH



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Here are five people who've been through and understand the journey of limb loss that you're now taking. We'll share their challenges and victories, advice, and personal experiences, as well as the thoughts of medical experts.

THRIVING WHILE THREADING THE HEALTHCARE MAZE: YOUR JOURNEY

In 2007, Nikko Landeros and Tyler Carron were just two teens in Colorado coming home from an evening school dance and changing a tire on the side of a road when an SUV slammed into them from behind. Pinned between the cars, "I was conscious the whole time," Landeros says. Carron was knocked out.

Their remaining lower legs couldn't be saved. After amputation surgery, "I was in a dark place. We both were," Landeros says. "What got us through was each other and our families." Adds Carron, "I always had a member of my family with me in the hospital 24/7," and both families were "every day praying for us." Another plus: community support.

Maybe you're an amputee or a relative or friend of a person with limb

loss, or maybe you were born with a limb difference. Maybe you're dealing with disease and expecting surgery and thinking about what lies ahead.

Whatever your circumstance, you may be finding your current journey daunting and your options complex. Read on for information you will need to succeed along the way.

Amputation is a major medical procedure, no question about it, and, whatever stage you're in, your best bet for coping with your surgery, recovery, and rehabilitation is to go into it with as much knowledge as possible. "Do your research," says Lindsay Moorehead, a mother of two who has been a bilateral (two limbs) lower-limb amputee since 2001.

Although it can be difficult asking

questions when you're dealing with serious medicine and health experts, she encourages you to make your questions and needs known. Initially reticent, she learned to speak up "by not having my needs met."

Another lower-limb amputee, college student and athlete Jessica Heims, agrees. She recommends treating the medical people you meet with respect for their hard work, caring, and expertise. However, she stresses that you also need to make sure you communicate clearly, and forcefully if you need to, whatever is going on with your body, what you feel, and what you need. Heims, who attends the University of Northern Iowa, has a below-knee (BK) amputation of one leg due to a condition she was born with.

What else is important for a good journey? We asked the chief medical officer of a busy rehabilitation facility, MossRehab in Philadelphia, to talk about the characteristics of limb-loss patients who make the best recoveries from their amputations. What are they like?

Alberto Esquenazi, MD, a Philly “Top Doc” and a professor of medicine with 36 years of experience, didn’t miss a beat: No matter their type of amputation, health status, or age, “the successful patient is a patient that has a positive attitude and good family (or other) support,” he says.

“I’ve seen patients with a single toe loss who do terribly and patients who are quadrilateral [amputees]—they’ve lost all four limbs—who go on to do amazing things with their lives because they’re determined and have that support.”

We put the same question to prosthetist Chris Jones, CPO, president and co-owner of Rebound Prosthetics in Denver.

Who tends to have a successful rehabilitation? “One key is a good mental state. The other is a good support network. Family and friends are critical,” he says. (See “Your Emotional Journey” and “Calling in the Amputee Cavalry” in the Support and Emotional Well-being chapter.)

Which brings us back to Landeros and Carron. Between the two, they had above-knee (AK), BK, and through-knee amputations. Yet 11 years later, they’d become a knock-about duo on ice hockey rinks and were advising local students about coping. In 2018, they were part of the number one sled hockey team in the world. It won gold medals in South Korea for the United States at the Paralympic Winter Games. They took their prosthetist with them.

Meanwhile, Moorehead found social ties through community work and helping others with limb loss—she became

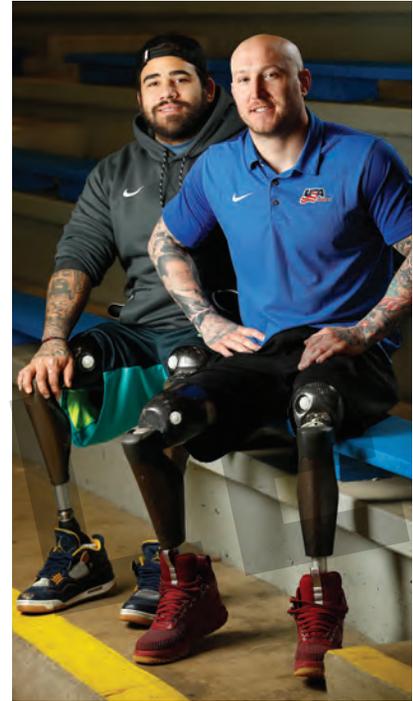
an Amputee Coalition certified peer visitor—and through her full-time and part-time jobs. She’s now busy with a baby daughter who doesn’t sleep much, a helpful spouse, and an adventurous pre-teen son.

In the two years after her son was born, Moorehead says frustrating limb changes caused her to go through ten or 15 pairs of legs. She eventually and reluctantly changed prosthetists. “Advocating for yourself is hard, but I needed legs that fit so I could clean my house and get to my job.” And so she did. (See “Recipe for Success: How to Get the Most Out of Your Post-operative Care” in this chapter.)

Mark Pokras, a Maine wildlife veterinarian and semi-retired professor who had a hip-disarticulation amputation more than 40 years ago, is in a similar situation. His amputation required removal of his left leg to the hip socket to save his life. He’d rejected the prosthesis option, but after he recently discovered his crutches were causing hand damage, he found himself working with David Crandell, MD, amputation program director at Boston’s Spaulding Rehabilitation Hospital.

Due to more recent prosthetics advances, there was a solution for him, and he tried a leg with a computer-controlled microprocessor knee. “Wonderful!” But he can wear it only an hour or two before the “bucket” that cradles his left hip starts causing skin and tissue damage. “I do use it a couple of times a week—I like to push myself.”

For his teaching, lab work, and tromping through fields with colleagues or family, Pokras uses a variety of assistive devices. And in spite of having a good prosthetist he likes, he’s looking for someone closer to home as he tinkers in his garage trying to improve that limb bucket. (For more on Pokras’ mobility strategies, see “Getting Mobile With Lower-limb Loss” in the Mobility and Transportation chapter.)



Nikko Landeros and Tyler Carron
Image by Steve Lundy.



Lindsay Moorehead Image courtesy of Lindsay Moorehead.