amputee coalition™

First Step

A Guide For Adapting to Limb Loss

2024 EDITION | VOLUME 8

First Step

2024 EDITION
VOLUME 8

PREPARING FOR YOUR JOURNEY

Meet your healthcare team and learn about the steps of your journey.

RECOVERY AND REHABILITATION

Get back to life and discover your new normal.

LIVING WELL WITH LIMB LOSS

Learn about the skills, tools, and resources available to help you thrive.

Published by amputee coalition™

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OUR MISSION

We envision a world where our community thrives. Our mission is to support, educate, and advocate for people impacted by limb loss and limb difference.

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INTRODUCTION

Welcome, community member.

First Step is your guidebook to navigate your limb loss or limb difference journey. Chapter by chapter we walk you through the process, from preparing for surgery and choosing a prosthetic device to managing pain and staying healthy. There are even specific sections just for parents, children, and caregivers.

You can read through **First Step** like a book or flip straight to the chapter you need. We try to touch on as many topics as possible, and while this publication isn't meant to go in depth on every subject, you can always learn more about specific questions from the Amputee Coalition, the National Limb Loss Resource Center®, or your healthcare team. Throughout **First Step**, you will read the personal stories of people just like you who made the same journey you're starting now. In the back of this booklet, you will find additional resources including a glossary of medical words and phrases you may hear, helpful checklists for meetings with your healthcare team, and more. We hope **First Step** will become your go-to guide throughout your journey.

The Amputee Coalition wants to welcome you to the limb loss and limb difference community. Even if you've never thought about us before today, you are joining a diverse and vibrant community of people who know exactly what you're going through – because we've been there, too. We've lost limbs, we've been born with limb differences, we're healthcare providers, caregivers, volunteers, advocates, family and friends. And we're here to support you.

The Amputee Coalition is the nation's leading organization on limb loss and limb difference. We're the largest non-profit, non-partisan organization dedicated to supporting you to live well with limb loss and limb difference. We're community focused and community driven, so we're excited to get to know you! As you become the expert in your own health care, we want you to learn from our experience and we want to learn from yours.

We hope you will get involved. You can connect with other members of our community through the Amputee Coalition's social media channels or at one of our events. Through our Certified Peer Visitor Program, you can spend time with others in your area who have made the same journey you're starting now. And, you can even advocate for change by sharing your story of limb loss or limb difference with our leaders and lawmakers. Everything we do is made possible by you, our community.

This is the first step of your new journey. Your life may be changing, but you're still you, and we're here to help.

Let's take this **First Step** together!

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PERSONAL STORY

DENISE HOFFMANN

> **“Being able to try out prosthetic devices has changed my life, allowing me to find the right prosthesis for me. Now I encourage every person new to limb loss and limb difference to advocate for themselves for this same opportunity.”**
>
> **DENISE HOFFMANN**

My name is Denise Hoffmann, and at the age of 12 I was diagnosed with metastatic bone cancer in my left femur. My surgery required the removal of my knee and all of my femur (except for the femur head), leaving me with an allograft and fused knee. Four years later the cadaver bone and allograft snapped, and I had to have three more surgeries. Then they found another break during my freshman year of college. Knowing I didn’t want an unpredictable life of surgeries, I decided to have an above-the-knee amputation that moved my tibia up to replace the failing cadaver femur from my original surgery. I became a pediatric nurse, and I worked with the same doctors and nurses at the children’s hospital where I had received my cancer treatment. There, I met my husband and we keep very busy raising our three teenage girls.

I am excited about the advances in prosthetic devices technologies. One of the things I never liked about the process of getting a new prosthesis was that you couldn’t test the costly device that you would be using every day.

That all changed for me six years ago when many manufacturers and prosthetists began to allow patients to try prosthetic devices before purchasing. I finally received a prosthesis that felt comfortable, required less energy to use, and gave me the most natural gait I had ever had since being an amputee. My favorite benefit was to be able

DENISE HOFFMANN

to use my new prosthesis for water activities (a limitation that I had felt for years). I'll never forget the first day that I was able to go down a waterslide with my girls, when I became a participant and not a bystander. Being able to try out prosthetic devices has changed my life, allowing me to find the right prosthesis for me. Now I encourage every person new to limb loss and limb difference to advocate for themselves for this same opportunity.

While prosthetic technologies have advanced, not all insurance companies have advanced their coverage of them. My insurance actually doesn't even have prosthesis coverage at all, but that didn't stop me from fighting to have the best life possible. After multiple denials over many months, I finally got the phone number of my insurance case manager. When I called, I told her the story of my life as a mother of young children, my activity level, my work as a nurse, and the limitations of not having a prosthesis. Two days later, my prosthesis was approved. The key to receiving my prosthesis was working closely with my healthcare team to have thorough documentation for my insurance claim, as well as being my own advocate by personally telling my story to the insurance company case manager.

Your Journey

There are many roads that bring each of us to the limb loss journey. Some people may begin their journey suddenly due to infection or an accident. For others, it may be planned as a way to manage health challenges, such as diabetes, vascular disease, or cancer. And some people welcome it if they suffer from chronic pain. No matter where your journey begins or why, we all follow a similar path. This guide will explain what milestones will come along your path, and it will offer tips, insight, and information to help you get the best care for you.

BYOA: **Be Your Own Advocate**

At the end of each section you may find boxes titled "BYOA". These boxes highlight ways you can advocate for the best care for you. We hope these boxes will educate, inform, and empower you to take the reins of your rehabilitation journey.

Personal Stories

Throughout this guide, we share the personal stories of others who have made the journey through limb loss and limb difference. We hope you'll see yourself in them. At each stage of your journey, you can learn from their experiences and see the possibilities for a full life after recovery.

How to Communicate with Your Healthcare Team

Whether this is your first major healthcare experience or your hundredth, communicating with your healthcare providers can be intimidating.

Many of us grew up with the idea that we're supposed to do whatever our doctors tell us without question, but times have changed. Now, healthcare providers - like doctors, surgeons, physical therapists, occupational therapists, social workers, and prosthetists - are trained to involve you in decisions about your care and treatment. In learning to be an advocate for yourself or others, it's important to remember that no one knows how you feel but you. You are the expert of your own body.

Advocating for yourself means communicating your thoughts, feelings, and wishes to your healthcare team. It requires you to share candid information and experiences about your medical condition. While all of this may be new, and perhaps uncomfortable at times, it is a crucial part of being active in your own care. Your healthcare team's ability to create the best treatment plan for you depends on open, honest communication between both of you. Science has provided many wonderful medications and tests, but nothing replaces what your healthcare team learns from you.

One way to be your own advocate is to use the patient communication skills training system called PACE. Each letter in the word PACE stands for an action you can use to convey that you are knowledgeable about your health condition and want to know more.

PACE stands for:

Present detailed information
Ask questions
Check your understanding of information
Express concerns about the recommended treatment

Using the PACE system will help you:

- Be better prepared for your visit
- State your concerns clearly and honestly
- Provide a complete description of how you are feeling and what you are experiencing
- Ask questions about your treatment and rehabilitation
- Express concerns or problems about treatments that have been recommended

Present Detailed Information

Presenting information includes describing new issues you're having or changes in how you're feeling as well as information about your lifestyle that is affected by your limb loss. It's often hard to share all of your concerns in an appointment. But it's important to share concerns right away so you and your healthcare team have enough time to address them. Be prepared to share your medical history and a list of all the medications, vitamins, minerals, and herbs you are taking.

You can use the **Medical History Worksheet** found in the Appendix. Also be prepared to share which activities you enjoy, what your goals are, and what you were doing before your limb loss. All of this information will help your healthcare team better understand you, your lifestyle, and your goals.

Ask Questions

Think about questions to ask your healthcare team before your appointment. That will help you decide what information is most valuable for you to get during your visit. Some important questions include: What are my options? What are the risks and benefits? How likely are those risks and benefits? What will happen if I do nothing?

Check Your Understanding of Information

It is a good idea to confirm your understanding of information provided by your medical team, such as instructions for physical therapy exercises or how to clean a liner.

There are three ways you can do this:

1. Ask them to repeat or clarify information that is unclear. For example, "Do I have to take all of this medication even if I start to feel better?"

2. Repeat aloud what they have just said.
3. Summarize your understanding of what was just said. For example, "What I hear you saying is that I should do this exercise twice daily for twenty repetitions on each side, correct?"

Sometimes individuals can be shy about checking their understanding, but doing so is very important. It shows your medical team that you are interested in getting complete and correct information. Also, you are more likely to remember the information, especially if you summarize what the provider has told you in your own words. Don't hesitate to ask the provider to spell medical terms, draw a picture, or write down information for you. This is part of their job. If you are concerned about checking information the provider gives you, consider asking for permission to record the visit, take notes, or ask someone to accompany you to the appointment.

Express Concerns about the Recommended Treatment

You may experience problems following a treatment prescribed by your healthcare team. For example, medications may have side effects that interfere with activities you enjoy. Let your healthcare team know if something isn't working for you. They may be able to make changes to the treatment plan to find the care that is best for you.

Unfortunately, people can unknowingly hurt themselves by changing or not following the treatment plan without talking with their healthcare team first. The best course of action is always to be honest with your team. Express any feelings about your treatment, goals, and values so they can develop a plan that meets your needs.

Don't hesitate to:

- Explain how you are doing following the treatment.
- Express your willingness and desire to change the treatment to better meet your needs.

Adjusting to limb loss takes time and can be emotionally draining. Good communication can make your journey much easier.

Know Your Insurance

Knowing and understanding your insurance coverage for surgery, rehabilitation, and assistive technologies can help you make informed decisions about your healthcare journey. Surgery and rehabilitation coverage often follow traditional in-network and out-of-network benefits. Unfortunately, many insurance plans have strict limits on prosthetic care and other assistive technology coverage. Discussing your care plan with your healthcare team will help you understand your insurance coverage for your specific needs.

Here are a few tips to help you learn what your coverage, exclusions, and out-of-pocket payments may be. All of these may not apply to your insurance policy. Therefore, it is best to contact your insurance company if you have questions or concerns.

1. Ask for a copy of your insurance policy summary of benefits and read it. Check what your coverage is for surgeries, physical and occupational therapy, inpatient rehabilitation, and prosthesis coverage.
2. Be aware of anything that refers to annual or lifetime limits or caps. This could be in dollars, or it could be in language. Examples include things such as "one prosthesis per lifetime," or "will cover the cost of the prosthesis" up to a certain dollar amount if you have a grandfathered plan or prosthetic coverage isn't considered an essential health benefit in your state.
3. Find out if a prosthesis is considered to be durable medical equipment (DME) under your insurance plan. If so, research the full scope of your DME benefits.
4. Look for any exclusions. For example, exclusions of specific types of prosthetic devices, such as microprocessor or myoelectric technology. Exclusions could also reference ultra-hazardous activities or exclude coverage for damage to a device that could be considered abuse.
5. Be aware of your out-of-pocket maximums, which indicate the most you would have to pay in a given year for health care, as long as the services you receive are covered by your plan. This amount can vary greatly depending on the level of coverage you have and if you have an individual plan or a family plan that covers multiple individuals.
6. If you receive your insurance through your employer, reach out to your employer's Human Resources Department. They can be an important resource when navigating your insurance coverage. You can also contact member advocates within your specific insurance company.

Your Health History

Effective communication is the key to getting the most out of your care. Going to see your doctor, therapist, prosthetist, or other medical professional these days can feel like sitting for an important test. Take time to prepare. Think about what is most important to communicate. Come prepared with notes and lists. These will increase your chances of leaving appointments well-informed and satisfied with your care.

Documenting and sharing your or your loved one's medical history with all the members of your healthcare team is necessary for thorough communication of your past and current medical conditions. By having all of your pertinent health information readily available, the team can make the most appropriate recommendations for you.

A medical history is made up of several different pieces of information that come together to tell the story of your past and current health. These pieces of information come from many different sources. By compiling them into one document or folder, you can make sure these important records are easily accessible to you, your support system, and your healthcare team. One of the more common ways is to use a healthcare journal. This is simply a notebook, binder, or online file where you keep all of your pertinent information.

Some key items to include are:

- Physician's contact information
- Pharmacy contact information
- Living Will and/or Durable Power of Attorney for Healthcare Decision Making
- List of allergies
- List of medications
- Surgical history with dates of procedures
- Past and current treatments and therapies
- A timeline can be helpful when explaining symptoms and medical procedures
- Activities of daily living that you're engaged in Information Regarding Health, Mobility, Pain, and Other Challenges or Accomplishments.

In the Appendix you will find the **Medical History Worksheet** which include these same items. This particular worksheet was created to document your or a loved one's new journey as a person living with limb loss or limb difference.

As your journey continues and your care evolves, it is important to keep your records up to date. This will help you communicate the most current information to your healthcare team during follow-up appointments.

When discharged from the hospital, ask the staff to explain the treatment(s) using the PACE system outlined earlier. Find out why a test or treatment is needed and how it can help. If you had a test, and you haven't heard back from the doctor, don't assume that no news is good news. Ask about the results. Ask if the treatment is based on the latest medical studies and evidence.

During your appointments, take notes while your healthcare provider is talking or bring a cell phone or voice recorder if they do not mind you recording (make sure to ask first!). For important appointments, it's also a good idea to bring a support person to help you remember important details and ask questions, and to help you record the advice and information afterward. Whenever possible, ask for written instructions for any medications or other treatments prescribed. When picking up a prescription, make sure it's the right medicine and dosage. Double-check the label. If you have any questions about the directions on medicine labels, ask.

In the Appendix you will find the **Follow-Up Appointment Worksheet**. It is recommended that you make copies of this worksheet before you write on it so you can use it more than once. Be sure to write the date of your appointment each time you use it so that you can track your healthcare team's instructions.

Remember, these sheets can be filed in a folder with other medical documents to form a detailed personal medical history record. These hard copies can also be scanned into an electronic file to share with your healthcare team or for your own recordkeeping if you prefer.

Tips to Get the Most Out of Your Appointments

- Arrive early, and bring plenty of patience.
- Make a list in advance of the appointment of all the things you wish to discuss.
- Bring a family member or friend if they're available. It can help to have an extra set of ears to pick up on information and instructions. Having someone who can take notes and act as a scribe can be helpful. It is also helpful to have someone along when you receive a new diagnosis or learn of complications that can provide support.
- Be upfront and honest about your lifestyle choices including diet, alcohol intake, smoking history, drug use, physical and emotional health, supplements taken, and alternative treatments. By outlining these lifestyle choices up front, your providers are able to see the big picture. Do not hide information from your providers or they may not be able to help you make the best decisions to meet your goals. You must be willing to have these conversations in order for your healthcare team to best assist you.

- Use the PACE system outlined earlier and ask questions. If you do not ask questions, your provider may assume you understand and don't need additional information. Be sure to ask any Who, What, When, Why, and How questions you might have. Ask about any medical terms used that you do not understand. Ask about treatments as well as your general diagnosis.
- Be persistent. If you do not understand, ask for clarification. It helps to repeat the information and ask, "Is that correct?" If you are feeling rushed or uncomfortable, let them know. And never be afraid to seek a second opinion.

Considerations for Kids

It can be challenging for children and adolescents to advocate for themselves with adults, and especially with doctors. Encourage your child to make eye contact with doctors and express their concerns directly. If the doctor looks at you when talking about the child, use eye contact to redirect the doctor to look at your child. If the doctor speaks only to you, ask your child, “what do you think?” Talk to your child ahead of time about being prepared for the visit. Explain how PACE works and use the tips above to help them feel better prepared.

BYOA: **Be Your Own Advocate**

Use the **Medical History, and Follow-Up Appointment worksheets** in the Appendix to communicate your ongoing diagnoses, treatments, and needs with all of the members of your healthcare team. This will help you feel better prepared and ready to engage actively with your team.

STAGES OF YOUR JOURNEY

CHAPTER 2

Stage 1: Preparing for the Road Ahead

- Your Clinical Care Team
- Your Community Resource Team

Stage 2: Surgery

- Causes of Limb Loss and Limb Difference
- Before Your Surgery
- Day of Surgery
- After Your Surgery
- Discharge from Hospital

Stage 3: Rehabilitation

- What to Expect in Rehabilitation
- A Few Considerations to Keep in Mind

Stage 4: Device Decision Making

- Is a Prosthesis Right For Me?
- Elements of a Lower-Limb Prosthesis
- Lower-Limb Prosthesis Selection
- Elements of an Upper-Limb Prosthesis
- Upper-Limb Prosthesis Selection
- Assistive Devices
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Stage 5: Rehab With Your New Device

- Your First Prosthetic Device
- Learning to Use Your Prosthetic Device
- Prosthetic Maintenance and Getting Back to Living
- Educational Questions for the Prosthesis User

PERSONAL STORY: AUTUMN JONES

My name is Autumn Jones, a below-the-knee amputee who struggled with depression, shame, and the inability to use any of those aforementioned coping skills when faced with limb loss.

During my hospitalization, I was overcome with grief, loss, shock, and disbelief. Most days I replayed what I should have, and could have, done to save my foot from being amputated. Hearing my care team refer to what used to be a perfectly pedicured foot as a 'stump' led to my very first panic attack. I had a team that provided excellent physical care, but mentally I felt completely alone. Thankfully, I was able to lean on the one coping mechanism I believed would help. I picked up my journal and I wrote in it everyday for months.

One month after my amputation, I wrote an entry titled "What I Needed from My Team After My Amputation."

My list included:

- Mental health evaluation by a social worker or therapist
- Grief counseling
- Support group information
- A peer visitor (to see and feel that there was life after loss)
- Information on insurance and grants for a prosthesis
- Questions to ask my prosthetist
- Literature detailing what my next several months as an amputee would look like
- That list became the first step in my quest to improve this experience for future amputees.

"During my hospitalization, I was overcome with grief, loss, shock, and disbelief...A mental health evaluation would have confirmed my thoughts and feelings were normal." - AUTUMN JONES

A mental health evaluation would have confirmed that my thoughts and feelings were normal. Support group information would have allowed me to meet other amputees who were familiar with challenges regarding self-image, learning how to drive, and getting used to people staring. Having a peer visit would have provided me with a cheerleader and advocate to communicate with beyond my own friends and family. And, knowing what to ask my prosthetist may have prepared me more when it came to things like limb shrinkage, prosthetic foot options, and the unforeseen challenges that come with learning how to walk again using a prosthesis. Recently, I proposed these recommendations to a surgical care team and reaffirmed my commitment to become a Certified Peer Visitor to ensure that no amputee in my community has to move through this journey alone.

STAGES OF YOUR NEW JOURNEY

Your new journey living with limb loss typically has five stages that progress from your surgery to when you might begin to feel more comfortable with your "new normal."

Stage 1:

Preparing for the Road Ahead

In Stage 1, you may meet your surgical team and rehabilitation teams. This can help you plan for your rehabilitation and prepare for a prosthesis or other assistive device, should this fit with your goals.

Stage 2:

Surgery

In Stage 2, you will prepare for, undergo, and recover from your surgery at a hospital or surgical center.

Stage 3:

Rehabilitation

In Stage 3, you will work with your healthcare team to recover from surgery and begin physical rehabilitation.

Stage 4:

Device Decision Making

In Stage 4, you may work with your healthcare team to decide if a prosthetic device is right for you.

Stage 5:

Rehab With Your New Device

In Stage 5, you will continue your rehabilitation. If you have a prosthesis, you will begin rehab with your device to learn how to use it properly and safely.

Stage 1:
Preparing for the Road Ahead

- Your Clinical Care Team
- Your Community Resource Team

Your Clinical Care Team

Your clinical care team is the team of healthcare professionals who care for you throughout your journey. Keep in mind that the number of team members you work with will depend on your individual situation, healthcare needs, and insurance coverage.

Patient

You are the center of your healthcare team. You have the opportunity to shape your recovery plans and steer your rehabilitation team in the direction that meets your goals. Each of the other team members is a specialist in their field. Their success, and yours, relies on your active communication and participation in your recovery and rehabilitation.

Surgeon/Physician Assistant/Nurse Practitioner

A surgeon will perform your amputation surgery. They may come from a variety of specialties depending on your cause of amputation, including orthopedic surgeons, trauma surgeons, vascular surgeons, and others. They may work with a physician assistant or a nurse practitioner who is a trained mid-level provider, who can assist the surgeon before and after surgery with pain control, follow-up visits, and referrals for physical therapists, occupational therapists, or physiatrists. Other surgeons may also be available to help with reconstruction of your limb, such as a plastic surgeon or a vascular surgeon, who repairs blood vessels.

If you know about your surgery in advance, consider asking your surgery team to consult with a physiatrist and a prosthetist about your amputation. This may help to ensure that your amputation level and residual limb are in the best possible shape to accept a prosthesis when you are ready, if that's part of your care plan.

Primary Care Provider (PCP)

Your primary care provider will continue to provide you with general medical care. Even though you now have different specialists working with you, it's important to keep seeing your primary care provider on a regular basis for health maintenance and preventive care.

Your PCP will also be vital to some of the medical documentation you may need to support you in your recovery and readjustment.

Mental Health Professionals

Mental health professionals offer counseling and support services for patients and their families during your journey. They can help you work through the emotional journey of limb loss or limb difference. In addition to providing counseling services, mental health professionals may be able to connect you with community and vocational resources.

Physical Therapist (PT)

Your physical therapist will work closely with you to focus on strength, balance, and walking. They may also recommend equipment like shower chairs, braces, walkers, canes, and wheelchairs. Physical therapists also can help you prepare for working with prosthetic devices. Your physical therapist may collaborate with your prosthetist to define your needs for a prosthesis or other assistive device. You will find the **PT/OT Interview Questions** in the Appendix.

Occupational Therapist (OT)

Occupational therapists typically work with individuals with upper-limb loss, but can also be valuable for people with lower-limb loss depending on individual health conditions and needs. An occupational therapist helps you learn new methods to complete necessary daily tasks. The occupational therapist ensures you are equipped to manage activities of daily living, including skills for independent living, getting a handle on regular work and household activities, and participation in recreational activities. An occupational therapist may also recommend special tools you can use to make your life easier.

Prosthetist

A prosthetist is trained to provide you with care related to your prosthesis. Your prosthetist will help you decide if a prosthesis is right for you and, if so, will work with you to find the right prosthesis and components to meet the goals outlined in your care plan. They will evaluate, measure, create, and fit the prosthesis to you. Throughout your journey, they will continue to help you use your prosthesis and maintain comfort for your activities. Community Connections, a database available through the Amputee Coalition's website can help you find a prosthetist in your area: nllrc.Amputee-Coalition.org, you will find the **Prosthetist Interview Questions** in the Appendix.

Rehabilitation Doctor

Your limb loss rehabilitation team will likely be led by a physiatrist, when available. Also known as rehabilitation doctors or physical medicine and rehabilitation physicians (PM&R), physiatrists have broad medical training that allows them to diagnose, assess, and manage issues that produce temporary or permanent impairment. They develop and oversee individual rehabilitation, care, and pain management plans for their patients, with the goals of enhancing performance and decreasing pain. The following is an overview of some of the major players that are likely to be a part of your community resource team. These are the people who help you while you are in the hospital or rehabilitation facility, and when you return home. Your team may differ from another individual's team based on your activities of daily living and goals for your journey.

BYOA:

Be Your Own Advocate

Encourage your healthcare team to communicate about your needs. Ask your prosthetist to meet with your surgeon before amputation. Sometimes the residual limb can be shaped in specific ways to have a more comfortable fit with a prosthesis. Build your team by taking an active role in facilitating communication between team members. In the Appendix you will find specific interview questions for your PT, OT, and prosthetist.

COMMUNITY RESOURCE TEAM

Some of the care team outlined in this section will be in your life for a short time; others will be lifelong members in your recovery and readjustment. Whenever possible, be your own advocate and research your options in advance. If you are going to work with someone for a long time, it's important to make sure they will work well with you. To request a Certified Peer Visitor, please visit the Amputee Coalition's website.

Patient Advocate

Patient advocates can be professionals who specialize in navigating the healthcare system. Patient advocates too can be a family member or close friend you trust to help you navigate your care. Navigation of care can include scheduling appointments, transportation, maintaining health records, and working to help you feel comfortable with your healthcare decisions.

Caregiver

A caregiver can be a professional who is hired to assist you with activities of daily living (showering, cleaning, shopping, etc.), or can be a family member (parent, brother, sister, etc.) who helps you live your best life. Many people think of a caregiver as someone who is with you all the time, but you can determine how much assistance you need or want. Patients often refer to their caregiver as a friend because they know their caregiver wants the best for them.

Discharge Planner/Social Worker

This nurse or social worker reviews your plan of care during your hospital stay and prepares for items you will need after discharge, such as equipment, follow up appointments with providers, home health, or prescriptions. This person regularly communicates with your insurance company regarding acuity of care and obtains authorization for continued treatment.

Case Manager

Case managers may act as discharge managers in the hospital, but others work in the community or directly for an insurance carrier to help you manage your needs and navigate the healthcare system.

Peer Visitor

A Peer Visitor is an individual outside of your immediate family or healthcare team that provides support and a listening ear, but not medical advice. A peer is someone who has a similar or shared experience. Peer visits can happen in person or over electronic communication, like email, phone, or text. The Amputee Coalition runs the Certified Peer Visitor training program to connect individuals and caregivers with a peer visitor who understands and has experienced limb loss or limb difference or has experience as a caregiver. To request a Certified Peer Visitor, please visit the Amputee Coalition's website.

PERSONAL STORY: BRIAN MARQUEZ

My name is Brian Marquez and I'm a congenital below elbow amputee. I've been wearing prostheses since I was three months old. Now, at 26 years old, prosthetic devices have become an important part of me and my growth.

For a large part of my life, being an amputee with a prosthesis was a mixed bag of emotions. The constant questions, bullying, and looks would always make it difficult for me to want to go out in public. I'd always make sure to cover up my arm so others wouldn't notice. It wasn't until I got a little older that I met someone else with a limb difference and I was shown exactly how normal (and, frankly, cool) being limb-different can be! Through these friendships I've learned to be more confident in my body and how it was made. I even often go out in public without my arm now! It's such a freeing experience.

With this confidence in who I am and what I can do (which is everything and anything, by the way), I use a lot of my time working with various charities and teaching kids that it's phenomenal to be unique!

Recently, my limb-different friends and I created a comic book featuring limb-different superheroes called Super-Abled Comics.

The goal of the comic is to show kids that, no matter your difference, you can still be a hero. I think it's a great message for people to read. Outside of working with children, my career involves me making video games and reviewing them for accessibility, because it's important that when we create entertainment for all we keep those with disabilities in mind. I spent a lot of my life trying to hide who I was, but when I realized that nothing I can do will change 'ME', I learned to accept and love every inch of myself. That ultimately made me confident and excited to be a part of this loving community of limb-different individuals.

" For a large part of my life, being an amputee with a prosthesis was a mixed bag of emotions. The constant questions, bullying, and looks would always make it difficult for me to want to go out in public. I'd always make sure to cover up my arm so others wouldn't notice. It wasn't until I got a little older that I met someone else with a limb difference and I was shown exactly how normal (and, frankly, cool!) being limb-different can be! Through these friendships I've learned to be more confident in my body and how it was made. I even often go out in public without my arm now! It's such a freeing experience." - BRIAN MARQUEZ

Stage 2: Surgery

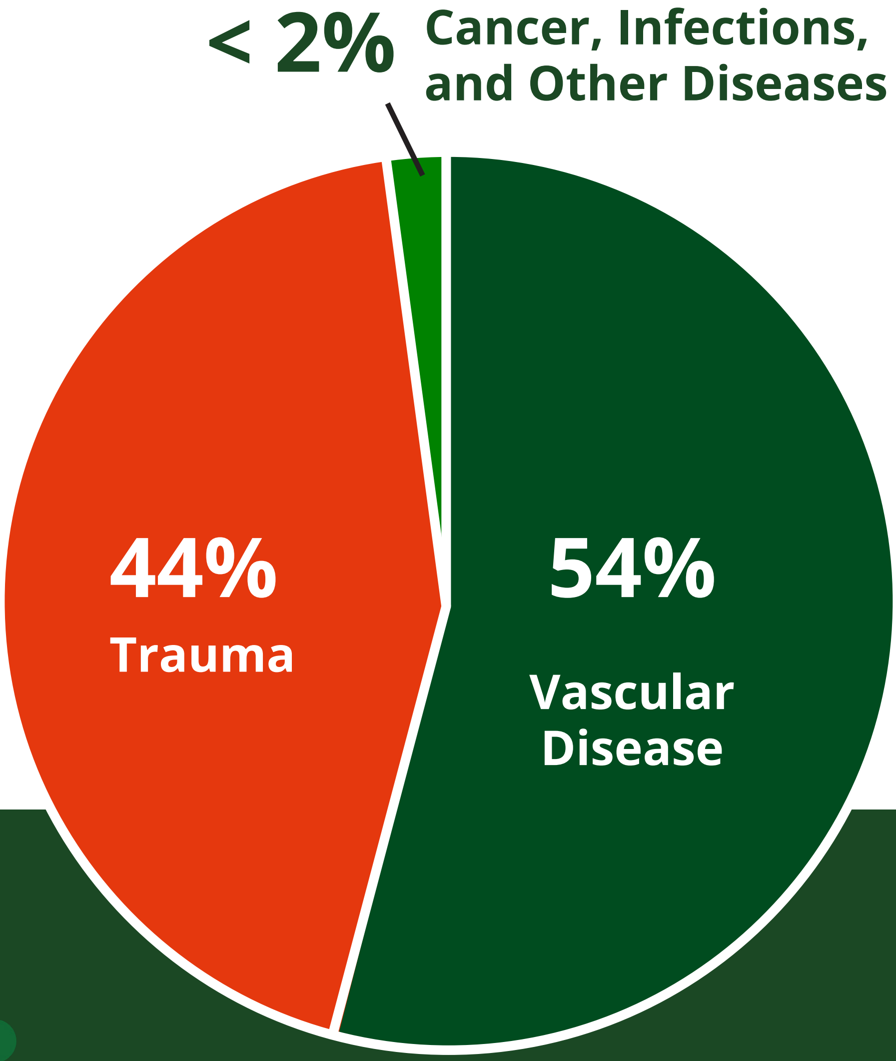
- Causes of Limb Loss
- Before Your Surgery
- Day of Surgery
- After Your Surgery
- Discharge from the Hospital

Causes of Limb Loss

While anyone could experience limb loss for any number of reasons, there are three main causes:

- Vascular disease
- Trauma
- Cancer

Limb loss can be the result of an emergency or it can be planned. The decision to undergo amputation surgery should be discussed, if possible, with your healthcare team and your support system.



Before Your Surgery

Meet With Your Clinical Team

If your surgery is planned, discussing the details with your healthcare team – including your surgeon, physiatrist, therapists, and prosthetist – can help you feel more comfortable and prepared for surgery. Here are some questions that you can ask your clinical care team during a pre-surgery meeting:

- Is amputation the best solution for me?
- What type of surgery is recommended?
- What experience do you have with amputation surgery?
- How long will my surgery last?
- What are the major risks of my surgery?
- What steps will you take to minimize those risks?
- Will I have pain after my surgery, and for how long?
- How will my pain be treated after surgery?
- When can I put weight on my residual limb?
- Will I be able to use a prosthetic device? If yes, when can I start wearing a prosthetic device? If no, what other options might I expect in assistive technology support?
- Can you refer me to someone who has been through a similar amputation?
- Will I have stitches or staples that will need to be removed after surgery?
- How long will I have to stay in the hospital?
- What does the rehabilitation process look like?

Remember, you can get a second opinion with another surgeon, physiatrist, therapist, or prosthetist. You should be comfortable with your care team, and they should be willing to listen to your needs and help you understand your journey.

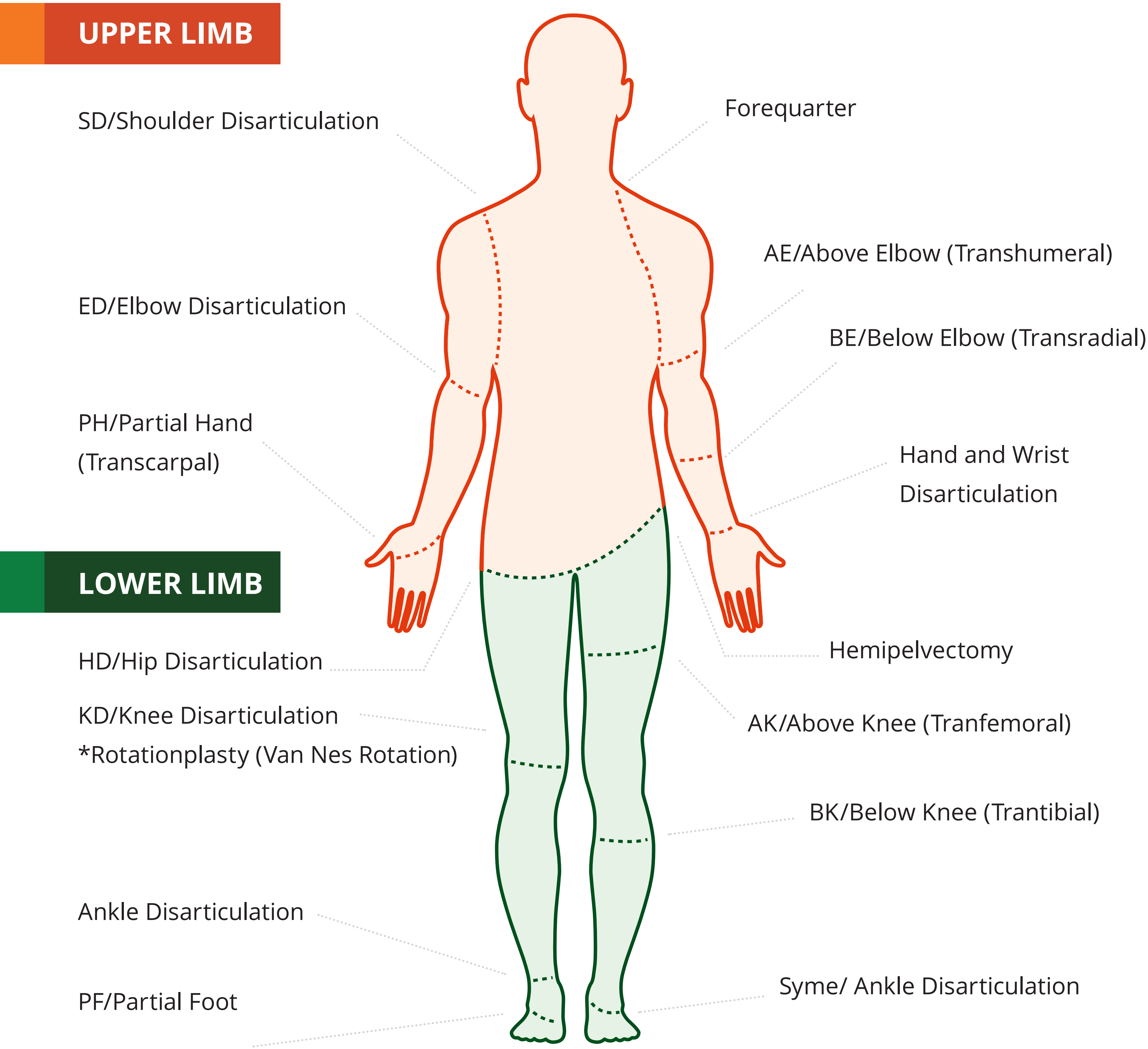
Types of Amputation Surgery

There are many different types of amputation surgeries. Here are the correct names for some of them:

- **Transtibial:** an amputation that goes through the bone or calf below the knee (tibia), also known as a below-knee amputation (BKA) or below knee (BK)
- **Transfemoral:** an amputation that goes through the bone or thigh above the knee (femur), also known as an above-knee amputation (AKA) or above knee (AK)
- **Syme/ankle disarticulation:** an amputation through the ankle joint
- **Partial hand:** an amputation through part of the hand
- **Partial foot:** an amputation through part of the foot
- **Knee disarticulation:** an amputation through the knee joint
- **Transradial:** an amputation that goes through the bones of the forearm below the elbow (radius)
- **Transhumeral:** an amputation that goes through the bone or upper arm above the elbow (humerus)
- **Elbow disarticulation:** an amputation through the elbow joint
- **Hip disarticulation:** an amputation that removes the entire leg including the top of the thigh (femur)
- **Hemipelvectomy**: an amputation that removes the entire leg and a portion of the pelvis, also called a transpelvic amputation or "hemi"
- **Shoulder disarticulation:** an amputation that removes the entire arm
- **Forequarter amputation:** an amputation that removes the entire arm and a portion of the scapula and clavicle
- **Wrist disarticulation:** an amputation through the wrist
- **High-level amputation:** this typically refers to both hip disarticulation or hemipelvectomy, but can also reflect shoulder disarticulations
- **Bilateral:** removal of left and right portions of either the arms or both legs at any location
- **Quadruple:** an amputation of all four limbs, sometimes called a quadrimembral or "quad"
- **Trimembral:** an amputation of any combination of three limbs, also called "tri"

TYPES OF AMPUTATION SURGERY

Your surgeon will discuss the best type of surgery for you. Then, your prosthetist will work to find the most effective prosthetic device for you.



Special Considerations for Parents

When a child is born with a limb difference, the word “amputation” may be frightening. As parents, you and your family have to learn about the surgical and prosthetic device options to prepare your child for a high quality of life.

BYOA: **Talk to Your Surgeon about TMR Before Surgery**

Nerves want something to do. If they are cut and left unconnected, they will feel pain. Targeted Muscle Reinnervation (TMR) connects amputated nerves to nearby muscles. Reconnecting these nerves may prevent pinched nerves, phantom limb pain, or chronic nerve pain. You can find out if TMR is right for you by talking with your healthcare team before surgery.

Day of Surgery

Arriving to the Hospital/Surgery Center for a Planned Surgery

Your surgery will be scheduled at a hospital or surgery center. The day before to your surgery, the hospital or surgery center will contact you with the time you should arrive. They also will provide instructions for the night before surgery, including rules for eating and drinking, medications, skin care, and what to bring with you. Don't be afraid to ask questions if any directions are confusing or unclear.

When you arrive to the hospital or surgery center on the day of surgery, you will change from your street clothes into a hospital gown. A nurse will help prepare you for surgery. An anesthesiologist, a doctor trained to help you stay asleep during the surgery and decrease pain during and after surgery, will meet with you and discuss their role. If you have had any complications during past surgeries, be sure to let your know anesthesiologist know (i.e, decrease in oxygenation levels, nausea when waking from surgery, history of sleep apnea, allergies, or history of past drug addictions). Your surgeon will talk with you and answer any last questions you may have about your amputation surgery. Don't be afraid to ask questions – your surgeon is there to help you.

The Operating Room

Your amputation surgery will be performed in an operating room. After meeting with the anesthesiologist and your surgeon, you will be taken into the operating room. At this time, your family and friends will have the opportunity to stay in the waiting room. In the operating room, the anesthesiologist will give you medications to help you sleep through the operation and reduce pain during the procedure. Because you will be asleep, you will not see, hear, or feel anything during the surgery.

The average amputation surgery lasts approximately one to three hours, depending on the type of amputation and any other complicating health conditions. For example, a below-knee amputation (BKA) may take 1.5 hours, while an above-knee amputation (AKA) may take 2.5 hours. Before you go under anesthesia, your surgeon will help you understand how long your surgery will take.

The Recovery Room

Immediately following surgery, you will be taken from the operating room into the recovery room (also known as Post-Anesthesia Care Unit), where you will wake up from surgery and receive pain medications, as needed. Nurses will be by your bed to talk with you, help with your comfort, and assist with initial recovery as you wake up. If you experience pain, discomfort, or nausea, notify your nurse or doctor immediately.

If your surgeon is okay with you eating and drinking, you may be able to have ice chips, water, or juice while in the recovery room. It is very common for patients to feel thirsty after surgery.

Your Hospital Room

After waking up in the recovery room, you will most likely be taken to a hospital room. You can ask your surgeon or the nurses if you will have a private or shared hospital room after surgery.

Your family and friends will be able to visit you in your hospital room in accordance with hospital policies. Don't worry if you are tired after surgery, you will likely need lots of rest. It is normal to rest and sleep after surgery.

The length of your hospital stay depends on whether your surgery was planned or unplanned, and what the cause of surgery was. For example, if you had surgery because of an infection or trauma, you might need to stay in the hospital for a longer time to receive medications for infection and to monitor your recovery. If you had amputation surgery due to cancer, your hospital stay might be for a shorter time once imminent threats have been removed and initial recovery is under way. Ask your doctor how long they think you will stay in the hospital at your pre-surgery appointment.

After Your Surgery

Pain

You probably have some concerns about managing pain after surgery and during rehabilitation. Surgery is a significant physical trauma. Immediately after amputation surgery, you will likely experience postsurgical pain from having your skin, muscle, and bone cut. This pain can be quite intense and it's important to try to stay with or ahead of pain.

Pain control after amputation is crucial. Pain can slow your recovery and result in a longer hospital stay. Be sure to inform your nurse or surgeon if the pain you are experiencing is not tolerable. To help your clinical care team understand your pain, you will most likely be asked to rate your pain on a scale of 0-10, with 0 being no pain and 10 being the worst pain you have ever experienced. (See page 37).

Everyone experiences pain differently. Pain tolerance levels are different from patient to patient, so it makes sense that each patient's pain control options will differ. Depending on your needs, controlling your initial post-operative pain may only require repositioning yourself and a cold pack, or it may require medications, massage, or other techniques.

While in the hospital, your surgeon or other member of the clinical care team will likely prescribe medications as well as other pain management solutions.

Medications can be very effective at reducing or eliminating pain. Traditional pain medications – anti-inflammatory agents, acetaminophen, muscle relaxers, and narcotics – work well for pain from a physical injury. Nerve pain, however, often does not respond well to traditional pain medications. Instead, nerve pain is often treated with anti-seizure medications or anti-depressants. These types of medications work by changing the chemistry of the nerve to stop the pain or by blocking pain signals to the brain. Some people who have nerve pain or sensations after limb loss will opt to remain on a pain medication for the rest of their lives.

Nerve pain often occurs immediately after surgery in a mild form. If not treated early, it can actually become more intense as healing occurs. It may be difficult to communicate exactly where the pain is coming from.

You should be comfortable with your medications. If you have any questions about medications or recommendations, don't be afraid to ask your nurse or physician. Be persistent. It's part of their job to answer your questions.

Your residual limb may be quite swollen after surgery, and some level of swelling can be expected, sometimes up to a full year after surgery. Your clinical care team may prescribe an anti-inflammatory drug to help reduce the swelling. If you feel like the swelling is contributing to your pain, be your own advocate and ask about anti-inflammatory options available without a prescription for when you leave the hospital.

The big muscles of the residual limb can react to pain by spasming, which can generate additional pain. If this is the case, your surgeon may also prescribe a muscle relaxer.

Medication options other than narcotics exist. Your care team may prescribe mild pain relievers, such as acetaminophen, which can be used in combination with the medications described above. You can also use other methods to manage pain such as breathing exercises and compression. For more information about pain and pain management, turn to **Chapter 3 – Pain.**

By the time your sutures or staples are removed, your pain should be well controlled, and any narcotics, anti-inflammatory drugs, and muscle relaxers can be steadily withdrawn based on your doctor's recommendations and your own feelings. A limb that is healing well should become less painful and more comfortable.

Wound Healing

Initially, you will likely have sutures or staples at your amputation site to help close your surgical wound. These are usually removed between two and four weeks after surgery, depending on your healing process. Your surgeon, physician assistant, or nurse practitioner will decide when it is best to remove your sutures or staples.

While in the hospital, a member of the clinical care team will help with dressing changes, if needed. Dressings are usually changed daily. Depending on the condition of your residual limb, and the reason for your amputation surgery, dressing changes may happen more or less frequently. The type of dressing can also vary. After your surgery, your surgeon will talk with you and your family and friends about your wound healing.

Wound healing can be affected by other medical conditions or procedures. If you are going through chemotherapy and radiation, your wound healing may be slower than usual. Likewise, if you have complications from vascular disease, your healing process could take more time due to slower flow of oxygenated blood to the healing site. Your healthcare team will advise you on the best recovery plan for you.

Below are some barriers to wound healing that slow the healing process:

Swelling

Swelling at the incision site and residual limb can slow healing. Minimize swelling by elevating the site of the surgical incision, applying compression, or using ice packs. Make sure you follow directions from your clinical care team with regard to swelling. If you notice redness or increasing pain or drainage at the incision site, notify your surgeon immediately, as this can be an early sign of infection.

Smoking

Smoking slows healing. Tobacco use also increases your risk for heart attack, stroke, and blood clots. It is best to stop smoking before your surgery. If you have any questions or concerns about quitting smoking, ask a member of your healthcare team. There are many different programs that can help you quit smoking.

Vascular Disease

Vascular disease, which includes diabetes and peripheral arterial disease, is the leading causes of adult amputation and high blood sugar levels can significantly slow healing. If you have diabetes, monitor your blood sugar levels carefully. After surgery, it is common for blood sugar levels to be elevated. If you have insulin-dependent diabetes, you may have to adjust the amount of insulin you use after surgery. It is also important to limit the number of sugar-sweetened beverages you consume after surgery, as this can slow healing.

Poor Nutrition

Poor nutrition can slow healing. Some patients may be undernourished or malnourished prior to amputation surgery. Dietary supplements, in addition to hospital meals, may be provided to help with wound healing.

Pressure Ulcers

Pressure ulcers, also known as bedsores, are wounds that occur from being under pressure for extended periods of time, usually over bony portions of the body, like your hips or tailbone. Alert your healthcare team to any discomfort you experience, especially in areas not related to your surgery, to help prevent these types of ulcers from developing.

Patients who have undergone an amputation or partial amputation of a lower-limb are at greater risk for developing pressure ulcers on the lower back or hips. Your nursing team will examine these areas frequently to ensure that you do not experience skin changes. Changing positions frequently, staying hydrated, and using special mattresses for high-risk patients may help prevent these types of pressure ulcers from occurring. If you notice a discolored or darkened area on your skin, this may be a sign that a pressure ulcer is forming. Notify members of your care team if you notice this or if normal color doesn't return to the area within half an hour.

Blood Clots

To reduce the possibility of blood clots in the deep veins, known as deep vein thrombosis (DVT), your physician may temporarily place you on an anticoagulant drug, otherwise known as a blood thinner. Leg elevation, early mobilization, and drinking plenty of water (four to six glasses per day) may also help prevent lower-limb blood clots.

The most significant complication related to lower-limb blood clots is the development of a pulmonary embolism (PE), in which a blood clot travels from your legs to your lungs. **Symptoms of a PE include shortness of breath, chest pain, or cough. If you develop any of these symptoms, seek emergency medical attention immediately.**

Pneumonia

Individuals who have a pre-existing lung disease (such as emphysema or COPD) should work with their healthcare team to prevent pneumonia after surgery. Your team will discuss breathing exercises with you and may recommend the use of an incentive spirometer, a device that measures how deeply you can inhale, to maximize lung function. Early mobility to a chair and participating in physical or occupational therapy can also help prevent lung complications after surgery.

Contractures

A contracture is the tightening of soft tissues that limit joint motion. A contracture occurs when muscles and soft tissues become stiff and fibrous from lack of movement. Contractures can make it difficult to wear your prosthesis, make it difficult to walk, and increase the need for an assistive device like a walker.

Most contractures are caused by not moving joints enough. After a lower-limb amputation, lying in a hospital bed with the head of the bed up and the hips bent up or pillows under the knees may cause contractures at the hips and knees. Similarly, lying in bed with the elbow bent up and resting on the chest most of the time may result in a contracture at the elbow.

Contracture Prevention

Prevention is the best approach for dealing with contractures. There are different types of exercises for different levels and location of limb loss. If you have not received information about contracture prevention, stretches, or exercises, ask your healthcare team which are best for you.

Contracture Management

Contractures can develop at any time, so it’s important to listen to your body. Once they develop, contractures are extremely difficult to stretch out. Therapists can manually stretch a contracted joint, and, in some cases, your therapist might recommend a static splint, a spring-loaded dynamic splint, or serial casting to stretch out a contracted joint. Serial casting is a process in which a series of casts are applied to the contracted joint. Each cast stretches out the joint more than the previous one.

Serial casting works more easily with ankle, knee, wrist, and elbow joints. It does not work as easily for hip and shoulder joints. The process is lengthy, uncomfortable, and restrictive. Other techniques to deal with contractures use heat or ultrasound treatments in conjunction with prolonged stretching.

It takes a lot of time and hard work to stretch a contracted joint. Stretching can help, but activity and exercise are even more important for maintaining joint range of motion, especially when you are limited to bed or wheelchair activity. Some studies have indicated that at least five to six hours of activity per day is required to maintain normal joint motion, regardless of time spent stretching every day. A physical or occupational therapist can be very creative in developing an exercise and activity program in a restricted setting.

Discharge from the Hospital

Your surgeon, along with other members of the clinical care team, will work with you to determine when you are ready to be discharged from the hospital. You may be discharged to your home, an in-patient rehabilitation facility (IRF), or skilled nursing facility (SNF). If you are returning home, you will be given instructions for wound care, pain management, follow-up appointments, and when to call for help. If you do not feel comfortable returning home after your surgery, ask to speak to a hospital case manager so that you can discuss your discharge options. A rehabilitation facility will provide you with daily intensive therapy to prepare you for a successful return home. Data has shown that being discharged to a rehabilitation facility or skilled nursing facility can improve overall outcomes. It's important to communicate and be your own advocate during your discharge. If you are being discharged to a rehabilitation facility, your surgeon will work with the rehabilitation facility and case manager to ensure the proper resources (physical therapy, occupational therapy, etc.) are available to you during your rehabilitation. Typically, you receive less therapy when you are discharged directly to your home. Be sure to ask questions prior to your discharge to find out what your options are, what your insurance covers, and what setting will best help you to reach your goals.

PERSONAL STORY: RYAN BAHR

My name is Ryan Bahr, and I am a right below-knee amputee. I was born with bilateral club feet, with the right foot worse than the left. After six surgeries from 1995 to 2012, and living with daily pain, I had four options for my right foot: remove parts of tendons that could be the source of my pain; revision of previously fused ankle joints; an artificial ankle; or below-knee amputation. Immediately, I knew what I wanted. I elected to have a below-knee amputation on January 14, 2014.

Growing up, I always knew that I wanted to become a medical provider, whether a nurse anesthetist, surgeon, or physician assistant (PA). In 2017, I started applying to PA programs. Each PA program has a set of technical standards they use in helping to determine whether a candidate can fulfill the roles and responsibilities of a PA student and graduate from the program. Unfortunately, some schools worried about whether I could complete their program because I am an amputee.

After applying to many programs, I was told by three that they did not feel I could complete their program due to the physical nature of PA school. I didn't let those programs stop me from advocating for myself.

In November, 2017, I was accepted into a PA Program, class of 2020! While attending orientation, a classmate asked me, "How are you going to do this with a fake leg?" At first, I was taken aback because I knew that I had worked hard to get into PA school. I looked at my classmate and said, "Just like you," and walked away.

After that experience, I knew that I would have to advocate for myself and be the voice of change for future students who are, by the world's definition, "disabled." I met with several members of the PA program to discuss how my experience could be used to help future students like me. In our class on "Health, Justice, and Society", I shared an article about another disabled healthcare provider to discuss the fact that not everyone is the same. Just because your friend, colleague, or patient is not like you, because they may have a "disability," that person can still become who or what they want.

I will be graduating with a Master of Health Science and will take the national board exam to become a certified physician assistant. Throughout my second year of PA school, I have completed rotations at various healthcare facilities and with various medical providers. Yes, there are times when I have to take a break from standing for prolonged periods, and may have to modify the way I participate in treating patients, but I have not let my disability define me.

Throughout my PA education, I have shared my story with patients. One told me, "You have worked hard to get where you are today. Now you have motivated me to keep going and share my story with others." After I graduate, I hope to have opportunities to continue to share my story and improve opportunities for future students like me.

Since my amputation, my life has changed for the better. When people ask if I regret making the decision to amputate my right foot, I tell them that I would have done it sooner and I never look back. My amputation does not define who I am, but has helped shape me into who am today.

"Growing up, I always knew that I wanted to become a medical provider, whether a nurse anesthetist, surgeon, or physician assistant (PA)." - RYAN BAHR

Stage 3: Rehabilitation

- What to Expect in Rehabilitation
- Coming Home From the Hospital
- A Few Considerations to Keep in Mind

What to Expect in Rehabilitation

When your surgeon feels you are medically stable after surgery, you may be discharged home, or more likely to an in-patient rehabilitation facility (IRF). At the IRF, your clinical care team, as described earlier, will focus on many things.

It is important for you to be engaged with your team and learn as much as you can about your medical circumstances, your limb healing, recovery exercises, and benefit versus risks for using a prosthesis or other assistive technology.

You have to outline your goals with your medical team. These goals can include independence, safety, mobility, or education on limb loss and limb difference. Remember, you are the center of your rehabilitation team as you navigate this journey successfully.

As you begin your rehabilitation, protecting your residual limb will be a top priority. This means keeping the skin healthy, preventing the limb from rubbing against or bumping into surfaces, or taking unnecessary risks during rehabilitation and recovery. While this may feel like you're being held back, the cautious pace of this phase helps you achieve your recovery goals and allows you to connect with your prosthetic device or other assistive devices outlined in your care and recovery plan.

Coming Home from the Hospital

Before you're discharged to go home, you will be trained on what your new mobility will be like.

During this phase of rehabilitation, you will discuss with your healthcare team which assistive devices will be the most helpful for your mobility and safety. They will train you how to use them to navigate everyday environments. Candid conversations with your team, especially asking questions or expressing concerns, is vital to your success. Remember: this process is about you.

To learn more about which assistive devices you may use, turn to **Chapter 2, Stage 4: Device Decision Making.**

A Few Considerations to Keep In Mind

Protect the limb when moving. If your rehab team recommends you wear a brace or cover over your limb, it's important to follow their recommendations. Typically, these devices help prevent the limb from touching other surfaces. The limb protector should be comfortable, so speak with your team if you feel it is difficult to keep on.

Be mindful of your limb at all times. When getting up from a chair or moving into bed, carefully put down the healing limb so as not to accidently hit it on a surface.

Know your limits. A phrase you should remember is "just because you feel like you can do something, doesn't mean you should." In other words, patience is vital. Testing your limits could have dire consequences, as a fall or injury at this phase of recovery could potentially prevent the functional use of a prosthesis and prolong your recovery. It is better to work with your rehab team to design goals that are both fulfilling and meaningful to you, while still being safe and low risk.

Don't forget about your sound limb. While you may be excited to get around and push your limits, remember not to exceed the limits of your sound limb(s). Your rehabilitation team will want to make sure that all of your limbs are healthy and strong, which includes reducing repetitive stresses. You may be frustrated if you are asked to limit how much you hop on one leg, but know it is for good reason to preserve the health and strength of your sound limbs.

Work with your healthcare team. Your physical therapist or occupational therapist may work to address the swelling and shape of your residual limb. Physical therapists and occupational therapists work closely with the other members of your healthcare team, including your prosthetist, to ensure that your compression garments are effective and coordinated with your exercise and recovery program.

Ask, ask, ask. The best thing you can do at every phase of your journey is ask questions. Why am I doing this? What is the benefit? What purpose does it serve? By asking questions and receiving answers, your rehab plan becomes more purposeful and defined. Remember, you are the star of the team. Without you, there would be no rehab plan!

Considerations for Your Child

Healthy, active children heal more quickly than adults. Parents may be amazed how active and energetic their child is just a few days after the surgery. At times, it is difficult for parents to keep their child still to allow healing. An active child is not as likely to develop contractures as they move and play throughout the day. Work with your child's healthcare team to determine the right balance of activity and rest for your child.

PERSONAL STORY: ALEX JOHNSON

My name is Alexis and I am an above-knee amputee. I had osteosarcoma when I was 15, and after three years of chronic pain and multiple surgeries I made the decision to amputate. Now I'm 27 and a medical student.

My first year after my amputation was hard because I was still learning so much about prostheses. In the beginning, I didn't know what to do. I saw eight different prosthetists at one company and none of them could fit me properly. When I got my sockets, they were terrible. I wondered, "What have I done? Why did I choose amputation?" They didn't fit right and I just kept falling. Every time they made my socket, they made it too short. I have a very short femur and a lot of soft tissue, so the socket needs to be longer so it can hold more of the soft tissue.

I finally found a prosthetist at a different company and we worked well together. I've learned to become a huge advocate for my socket, dealing with insurance and knowing what I want and what I like, but it took a while. It just takes time. You've got to meet someone with whom you gel.

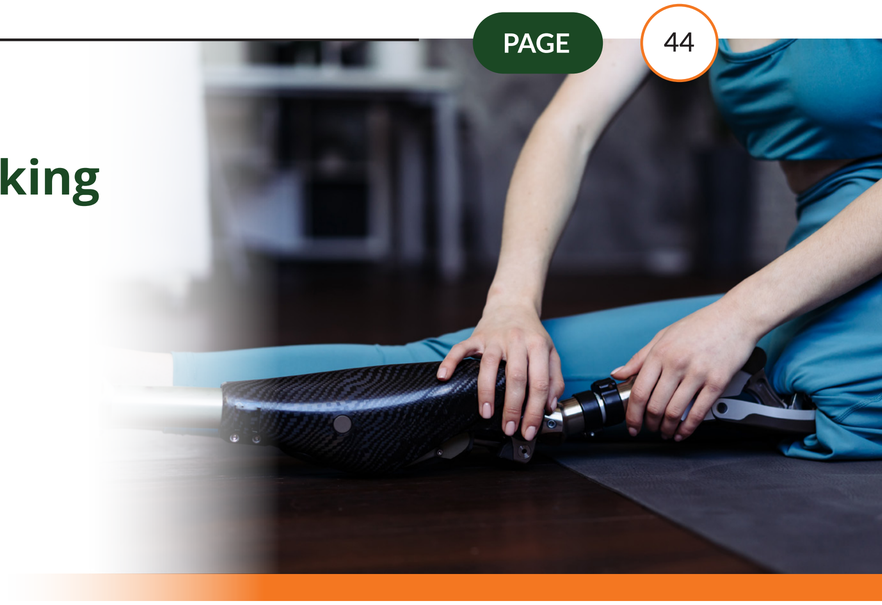
Another thing I learned over time was the importance of watching my weight. I know we don't like to talk about weight in our culture, but I've learned to watch my weight because, if I gain weight, my leg doesn't fit.

I wish I would have been more educated about different prosthetic devices. I wish I would have gone to see how a socket is made, how they make it for each person, and "prosthetist shopped" like I "doctor shopped". I didn't know that you could have different prosthetists. I didn't even know there were different types of knees. I didn't know anything about cutting stuff to relieve medially, or other specific terminology...I just had no idea.

> **“I wish I would have gone to see how a socket is made, how they make it for each person, and ‘prosthetist shopped’ like I ‘doctor shopped’.”** - ALEXIS JOHNSON

I thrived after I found a prosthetist who understood what I needed. I did a swim triathlon and played sitting volleyball. I work out every day and I like the elliptical. I can do a ton of stuff and walk really well. Sometimes, my socket annoys me but that’s just part of it. I feel much happier.

So, I think if I would have known the process, it would have been a hundred percent more helpful because I feel like it took me three years to figure it out and become educated on prostheses. It was a lot of trial and error that I could have avoided if I was educated.



Stage 4: Device Decision Making

- Is a Prosthesis Right For Me?
- Elements of a Lower-Limb Prosthesis
- Lower-Limb Prosthesis Selection
- Elements of an Upper-Limb Prosthesis
- Upper-Limb Prosthesis Selection
- Assistive Devices
- Insurance Considerations

Is a Prosthesis Right For Me?

It's an exciting new world as technology for prosthetic devices accelerates. Dancers, runners, bikers, rock climbers, and many more kinds of athletes are raising the bar for activities. Some movies and advertisements feature leading characters with notable prosthetic limbs.

Many people who experience limb loss aren't going to be a Paralympic athlete or a motivational speaker. Most people just want to be able to live independently and successfully. You may just want to be able to walk to your mailbox, go grocery shopping, sit on the floor with your grandkids, or go out to movies or dinner with friends. Whatever your quality of life, the decision to wear a prosthesis is entirely up to you.

There is a wide range of prosthetic devices to choose among, from cosmetic prostheses to various body-powered devices to microprocessor devices. Some people, like those with high-level limb loss or limb difference, such as hip disarticulations, hemipelvectomies, or shoulder disarticulations, prefer not to wear prosthetic devices for long periods, if at all. If you have a lower-limb amputation, you will need to consider what other types of mobility devices you'll use to get around if a prosthesis isn't a consideration.

If you have an upper-limb amputation, an occupational therapist can work with you to accomplish activities of daily living, working activities, and recreation with or without a prosthesis. Upper-limb prosthetic devices can be fitted with different components to suit different activities. Other adaptive and assistive devices can be similarly helpful when the prosthesis is doffed (taken off or removed). If you have a lower-limb amputation, you'll want to consider which assistive devices are best for you: a wheelchair; a scooter; rolling walker; forearm crutches; or traditional crutches. The amount of energy it takes to move around using a prosthesis with an above-knee amputation can be more than three times higher than for someone with a below-knee amputation. High-level amputations have larger and heavier prosthetic devices that include three joints (hip, knee, ankle for lower-limb and shoulder, elbow, wrist for upper-limb), so moving around takes a lot of energy.

As a person with limb loss or limb difference, you may wonder how you will do things. There are many different factors to consider when choosing which device is the right fit for you, or if using a prosthetic device is the right choice for you. It is important to include all of the members of your healthcare team when making this decision.

Consider your overall health, your cognitive abilities, the level of your limb loss or limb difference, and the condition of your residual limb. Your motivation, goals, and desire to use a prosthetic device are also important factors in deciding the right option for you. Additionally, you will need to know what your insurance covers, what it doesn't cover, and what are your options for paying out-of-pocket costs.

Some people decide a prosthesis is not right for them; others use a prosthesis part-time; still others use a prosthesis in combination with other assistive devices, like a cane or walker.

There will be times that wearing the device full time isn't practical (due to pain, fit, comfort, etc.). Using a combination of assistive devices will help improve your independence, mobility, and activities of daily living. Remember that hopping is not recommended since it can damage your sound limb.

Use PACE communication tools to learn which prosthesis or other assistive device options may be best for you. It is important for you to communicate clearly with your team to get the right combination of devices to enhance your quality of life.

ELEMENTS OF A LOWER-LIMB PROSTHESIS

Liner

Lower-limb prostheses have the following common components:

- Socket/Rigid Outer Frame: provides structural integrity and safety
- Soft Inner Liner: interfaces between the socket and limb
- Socks: helps to adjust for swelling or volume fluctuation
- Suspension Mechanism: holds the limb to the rigid outer frame
- Pylon/Alignable System: helps to match the length and angle of the other limb
- Knee Joint: for above the knee amputation
- Ankle Joint/Foot: provides the ability to step
- For those who have an osseointegration procedure, the socket, inner liner, and socks are removed replaced by a connection point to the rod protruding from the residual limb.

Socket

The socket is one of the most important parts of the prosthesis. A well-made socket ensures comfort, prevents skin irritation, and provides better control over the prosthesis. If your socket is uncomfortable, you are less likely to wear your prosthesis. Your prosthetist will custom design and fabricate a socket to fit your residual limb. They should work with you to find a comfortable fit and offer design options to suit your lifestyle.

Liners and Socks

The socket connects your residual limb to the rest of the prosthetic components. An additional layer, called a liner, fits over your residual limb and provides a barrier between your skin and the socket. The liner provides cushion, comfort, and a better fit for your socket. A prosthetic sock is usually worn over the liner and can help manage residual-limb volume changes. These socks come in different sizes, materials, and thicknesses, also called plies. You will have to experiment with different sock ply combinations to figure out what works best for you.

TYPES OF SOCKETS

Suction Socket

Incorporates a cushioned silicone liner, a suspension sleeve, and a supportive carbon fiber outer frame with valve. Can be used with a silicone liner with suspension sleeve, a seal-in liner, or no liner at all (skin fit).

Vacuum-Assisted Socket

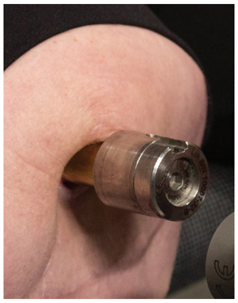
Incorporates a liner, suspension sleeve and an air evacuation pump. The system creates a vacuum between the liner and the socket wall, which holds the prosthesis onto the residual limb. Designed to be used with a vacuum suspension system.

Dynamic Suction Socket

Incorporates a thin, bio-elastic socket and a supportive carbon fiber outer frame. This type of socket strengthens the muscles in the residual limb by allowing them to fire freely into their own compartment within the socket.

Dynamic Socket

Designed with adjustable panels that can be tightened or loosened.



Osseointegration

Direct connection between human bone and artificial implant. Osseointegration implants a metal anchor directly to the bone of a residual limb to which a prosthesis is attached (abutment).

Suspension Systems

When a prosthesis is well-suspended, it feels lighter and can be more easily controlled. A well-suspended socket also helps to reduce skin issues on the residual limb. The type of suspension system that will work best for you depends on several factors, such as your activity level and the shape of your residual limb.

TYPES OF SUSPENSION SYSTEMS

Lanyard

Uses a strap to pull the liner into the socket. The lanyard also connects the socket near the top edge to reduce rotation and shear.

Pin Suspension

Uses a silicone liner with a pin at the end. The pin is pushed into a lock in the bottom of the socket, keeping the prosthesis from falling off. Unlike a suspension sleeve, this liner is worn underneath the socket.

Suction

Uses a soft liner, a one-way valve, and sometimes a sealing sleeve to create suction. Inserting your liner-covered limb into the socket and applying body weight as you stand expels air through the valve and creates suction.

Vacuum Suspension

Uses sub-atmospheric pressures to suspend the residual limb inside the socket. Vacuum suspensions, manual or electric, provide even adhesion of the residual limb to the entire interior surface of the socket for stability and reduced friction and shear.

Prosthetic Knees

Prosthetic knee joints are used in above-knee prostheses and are meant to replicate the function of the human knee. The type of prosthetic knee used in your prosthesis will depend on your activity level, weight, strength, residual limb length, and individual preference.

TYPES OF PROSTHETIC KNEE JOINTS

Single-Axis Knee

A knee joint that moves around on only one axis. Can be constant friction (only moves at one speed) or can be hydraulic or pneumatic (can move at variable speeds).

Polycentric Knee

Also called a “four-bar” knee, this knee joint has multiple axes. Can be constant friction (only moves at one speed) or can be hydraulic or pneumatic (can move at variable speeds).

Microprocessor Knee

This knee joint uses feedback from sensors to adjust joint movement in real time with an onboard computer (microprocessor). The microprocessor controls the speed and ease with which the knee reacts while the user is walking. They also sense when you trip or stumble, and will increase stability.

Combined Knee/Ankle Systems

Prosthetic devices with coordinated knee and ankles can increase stability and make it easier to walk on uneven or sloped surfaces. Knee/ankle systems use a combination of hydraulic and microprocessor control. They are typically recommended for more active individuals with above-knee amputations.

Prosthetic Feet/Ankles

The type of prosthetic foot and ankle that is incorporated into your prosthesis depends on your activity level, functional ability, and lifestyle.

TYPES OF FEET/ANKLES

SACH (solid ankle cushioned heel)

The most basic prosthetic foot. It has no moving parts but instead uses a soft heel to absorb impact.

TYPICAL USER:

People who do a limited amount of walking with little variation in speed.

Single-Axis Foot

This type of foot has a single ankle joint that allows the foot to move up and down.

TYPICAL USER:

People who need stability.

Multi-Axis Foot

This type of foot has two or more joints that allow the foot to move up and down and side to side. Multi-axis feet allow for walking over uneven ground.

TYPICAL USER:

Individuals who need a lot of foot movement for activities like hiking, golfing and dancing.

Dynamic-Response Foot

This type of foot stores energy as the foot touches the ground and releases energy when the foot leaves the ground. Dynamic response feet provide a sense of push-off for increased balance and more natural walking.

TYPICAL USER:

Individuals who are more active.

Activity-Specific Foot

These types of feet are designed for specific activities, such as swimming, running, skiing, or other activities.

TYPICAL USER:

Individuals who participate in a specific activity.

Vertical Shock

This type of foot reduces the amount of force transferred from the foot to the socket by compressing and/or rotating under your weight.

TYPICAL USER:

Individuals who enjoy high-impact activities.

Hydraulic Ankle

This type of ankle provides greater range of motion in the joint to enable both low- and high-activity users to walk with more stability.

TYPICAL USER:

Individuals who want extra stability on declines for activities like hiking and golfing.

Heel Height Adjustable Ankle

This type of ankle can be manually adjusted from a flat heel, for walking barefoot or in sandals, up to two inches, for walking in boots and heels.

TYPICAL USER:

Individuals who want to adjust their ankle height to wear a variety of shoes.

Microprocessor Ankle

This type of ankle uses a microprocessor to control the flow of hydraulic fluid. It typically has an even greater range of motion than the hydraulic ankle. It is programmable for different ankle resistances as well as for shoes with heel heights up to two inches.

TYPICAL USER:

Individuals who want extra stability on declines or the ability to adjust the ankle to wear a variety of shoes.

Lower-Limb Prosthesis Selection

To prescribe the prosthesis best suited to you, your primary care provider or physiatrist should work with your prosthetist and other members of the rehabilitation team to establish what you could do prior to your amputation, your current function, and what is anticipated that you'll be able to do with a prosthesis.

Step 1: Understanding Function

Your ability to function well in your environment (home, work, school, recreation) is important to determine which device will be best for you, as are developmental milestones for a child with limb difference.

Step 2: Assessing K-Levels

K-levels are a rating system created by Medicare and used by most insurers to indicate a person's rehabilitation potential. The system is a rating from 0 through 4, which indicates a person's potential to use a prosthetic device. Your K-level designation is important because it is the driving factor in the decision for which prosthetic components to provide and the payment for them. Your healthcare team will work together to determine what you have the potential to do with a prosthesis.

K0

K0 LEVEL

Does not have the ability or potential to ambulate or transfer safely with or without assistance. A prosthesis does not enhance quality of life or mobility.

FOOT/ANKLE ASSEMBLIES:
Not eligible for prosthesis
KNEE UNITS:
Not eligible for prosthesis

K1

K1 LEVEL

Has the ability or potential to use a prosthesis for transfers or ambulation on level surfaces at fixed walking speeds. Typical of the limited and unlimited household ambulator.

FOOT/ANKLE ASSEMBLIES:
External keel, SACH feet or single-axis ankle/feet
KNEE UNITS:
Single-axis, constant-friction knee

K2

K2 LEVEL

Has the ability or potential for ambulation with the ability to traverse low-level environmental barriers such as curbs, stairs or uneven surfaces. Typical of the limited community ambulator.

FOOT/ANKLE ASSEMBLIES:
Flexible-keel feet and multi-axial ankle/feet
KNEE UNITS:
Single-axis, constant-friction knee, microprocessor knees

*Some K2 users may be eligible for microprocessor knees due to the safety they provide.

K3

K3 LEVEL

Has the ability or potential for ambulation with variable cadence. Typical of the community ambulator who has the ability to traverse most environmental barriers and may have vocational, therapeutic or exercise activity that demands prosthetic use beyond simple locomotion.

FOOT/ANKLE ASSEMBLIES:
Flex foot and flex-walk systems, energy-storing feet, multi-axial ankle/feet or dynamic response feet, microprocessor ankles
KNEE UNITS:
Fluid and pneumatic control knees, microprocessor knees

K4

K4 LEVEL

Has the ability or potential for prosthetic ambulation that exceeds basic ambulation skills, exhibiting high impact, stress or energy levels. Typical of the prosthetic demands of the child, active adult or athlete.

FOOT/ANKLE ASSEMBLIES:
Any ankle/foot system appropriate
KNEE UNITS:
Any ankle/knee system appropriate

Step 3: Recommendation on Specific Components

Components for lower-limb prostheses include different types of suspension systems, from a simple sleeve socket, which slips over the residual limb to form a snug fit, to a passive- or active-suction system, which use air pressure to suspend the residual limb in the socket. There are also different kinds of prosthetic knee joints, from a single-axis mechanical device to microprocessor knees with an onboard computer to improve gait and reduce falls.

Different kinds of ankles and feet are available, depending on your needs.

Many prosthetic manufacturers provide trial programs to help you get the best components for your needs. It is important to tell your prosthetist about your goals, work life, and hobbies. When selecting a device, consider functionality and lifestyle choices, the ability to adjust for wearing boots or heels, or the ability to choose a split toe shell that allows an individual to wear sandals, or wanting to use your device for water activities.

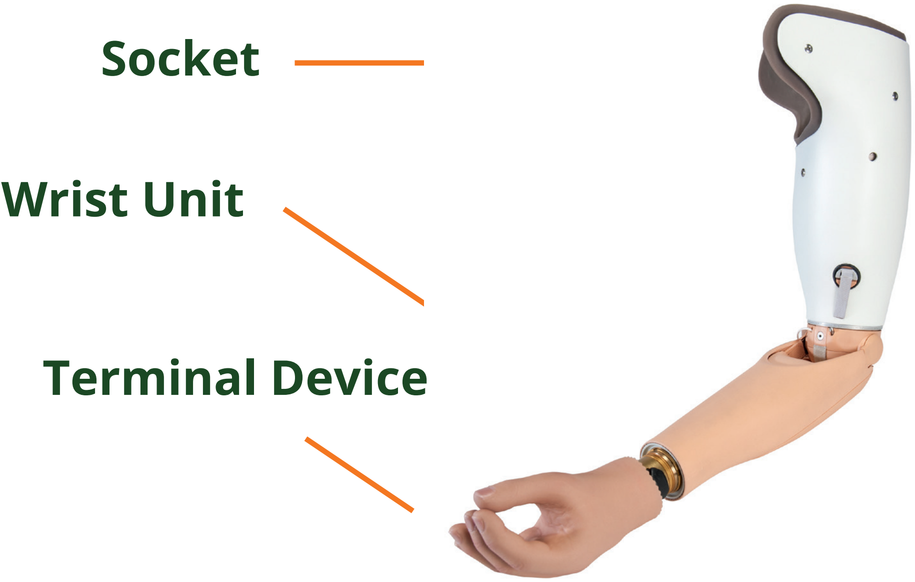
These are all things you should communicate with your prosthetist to help determine the best components for your needs.

Step 4: Decisions on Prosthetic Rehabilitation

The importance of good rehabilitation for safe and effective prosthesis use cannot be stressed enough. If in-patient rehabilitation is available, it will generally be a more intensive program as you will receive daily physical and occupational therapy. Otherwise, outpatient services remain crucial. No matter how you do it, rehabilitation is necessary for success.

Self-advocacy and patient advocacy become crucial at this stage. You will have to work with your healthcare team and insurance company to determine what resources are available to you.

ELEMENTS OF AN UPPER-LIMB PROSTHESIS



Myoelectric Prosthesis

Upper-limb prostheses have the following common components:

- Socket/Rigid Outer Frame: provides structural integrity and safety
- Socks: help to adjust to swelling or volume fluctuation
- Control Mechanism: helps drive the prosthesis, and can be body powered, myoelectric, or a hybrid
- Suspension Mechanism: holds the limb to the rigid outer frame
- Terminal Device: helps grasp and release, modular components can be used to meet specific goals
- Above-elbow amputations additionally have an elbow joint component to allow for bending and angling to enable reach in multiple directions. For those with an upper-limb osseointegration procedure, the socket and harness are replaced by a surgically implanted metal abutment.

Upper-Limb Prosthesis Design Options

There are many different types of upper-limb prosthetic devices. The most common types are functional aesthetic, body powered, myoelectric, hybrid, and activity specific. Except for functional aesthetic devices, upper-limb prostheses incorporate one or more control systems, which allow the user to operate the components of the prosthesis. The type of control system used in your prosthetic device will depend on a variety of factors, such as your functional level, functional needs, personal preference, and insurance coverage.

TYPES OF UPPER-LIMB PROSTHETIC DEVICES

Functional Aesthetic

CONTROL SYSTEM:

None. Generally worn for cosmetic purposes and designed to look like your missing biological limb.

Body-Powered

CONTROL SYSTEM:

Cable and harness system that requires you to use your body movements to pull the cable and make the terminal device (a hand, hook, or prehensor) open and close.

Myoelectric

CONTROL SYSTEM:

Operates using battery power and muscle activity. In a myoelectric-controlled system, electrodes are placed on the surface of the skin. The electrodes detect signals from the muscles, which in turn control the operation, speed and direction of the prosthesis.

Hybrid

CONTROL SYSTEM:

Combines body power and myoelectric control.

Terminal Devices

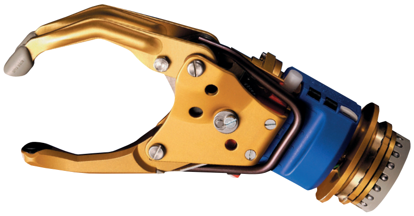
The terminal device is found at the end of the prosthesis and can be used to grasp objects, provide aesthetic value, and perform other tasks. There are terminal devices available for body-powered, myoelectric, and hybrid prostheses.

Hooks

Allow you to hold and squeeze objects between two split hooks.

Prehensors

Consist of a thumb-like component and a finger component that may resemble a lobster claw, pliers or a bird's beak.



Artificial Hands

Designed to function more like a human hand. Most prosthetic hands make use of a pinching or squeezing function, using the thumb and first two fingers. Others have individual powered digits and adjustable grip control.

Activity-Specific

Available for a wide variety of recreational activities such as swimming, golfing, hunting, fishing, playing baseball, and weight-lifting – just to name a few.

Wrist Units

A wrist unit attaches the terminal device to the forearm of the prosthesis and allows the user to adjust the position of the terminal device. Multiple wrist units are available:

- Quick disconnect units are helpful for those who use multiple terminal devices and need to switch quickly and often.
- Flexion wrist units can help users reach midline, which makes activities such as toileting, eating, shaving, and dressing easier.
- Friction wrists allow users to change the rotation of the wrist.

Upper-Limb Prosthesis Selection

You will typically discuss prosthesis decisions after the skin of your residual limb is completely healed. Early prosthesis fitting following amputation has been shown to improve outcome and functional use, especially in individuals with upper-limb loss.

Step 1: Understanding Function

Your ability to function well in your environment (home, work, school, recreation) is important to determine which device will be best for you, as are developmental milestones for a child with limb difference.

Step 2: Assessing Functional Needs

You will be assessed for your readiness and need for a device based on your muscle strength to control a prosthesis, intended use (heavy work, fine work, no reach/grasp function), comfort, skin condition, insurance coverage and cost restrictions, and desire to use the device. Please note that K-Level criteria, which apply to lower-limb prostheses, do not apply to upper-limb prostheses.

Step 3: Recommendation on Specific Components

Upper-limb prosthetic components range from aesthetic, where the arm looks more lifelike than body-powered hooks or terminal devices, to myoelectric devices, which use sensors to detect muscle changes in your residual limb to signal movement and pre-programmed grip patterns.

Step 4: Decisions on Prosthetic Rehabilitation

The importance of good rehabilitation after amputation for safe and effective prosthesis use cannot be stressed enough. If in-patient rehabilitation is available, it generally will be a more intensive program as you will receive daily physical and occupational therapy. Otherwise, outpatient services remain crucial. No matter how you do it, rehabilitation is necessary for success.

Self-advocacy and patient advocacy become crucial at this stage. You will have to work with your healthcare team and insurance company to determine what resources are available to you.

Assistive Devices

Assistive Devices for Lower-Limb Loss

You will most likely use several assistive devices during your recovery and rehabilitation process. As your strength improves and your confidence grows, you may need assistive devices less. If you use a prosthesis, you may progress to the point where you rarely need an assistive device. As you get older, you may come back to using one or more assistive devices.

Using an assistive device is not a weakness. Assistive devices enable people to be more functional. Even if you use a prosthesis full-time, you may still need to use an assistive device, such as crutches or a cane, when:

- Getting up in the middle of the night
- Showering/bathing
- Swimming

Wheelchairs

There are two primary types of wheelchairs: manual and motorized. Manual wheelchairs are propelled by the user. They generally weigh less than motorized wheelchairs and may be collapsible for easy transport. Motorized wheelchairs are battery powered. They are heavier than manual wheelchairs and require special equipment to transport.

Your physical therapist can help you choose the wheelchair that is most appropriate for you. Wheelchairs can be customized to meet your individual mobility needs and goals. Before selecting a wheelchair, assess your needs and type of assistance you expect from the wheelchair. Consider your body strength, whether you plan to transport the chair, and what types of activities you wish to perform in the chair. Some prosthesis users will use a wheelchair to save energy on activities that traditionally require a lot of walking, such as shopping or going sightseeing.

Your physical therapist should teach you wheelchair skills, such as going up and down ramps (with your new balance point so you don't tip), going up and down stairs and curbs, getting in and out of the car, and other activities that may be difficult at first.

Keep in mind that if you regularly use an assistive device, you will want to keep an eye out for other issues that may develop. If you sit for long periods of time, you may develop hip contractures. Or if you overuse an upper extremity, you may develop rotator cuff issues or carpal tunnel syndrome. "Push-assist" chairs can help with these. Be sure to talk with your healthcare team about the best ways to prevent overuse and injuries.

Walker

A walker provides stability for standing and walking by providing four points of contact around the individual to widen their base of support. A walker can be used with or without a prosthesis.

There are two basic styles available: rolling and non-rolling.

- Rolling walkers have wheels and can move more freely. However, because they move more freely, they can cause instability when you are first learning how to walk with a prosthesis.
- Non-rolling walkers allow for increased stability, but they don't allow for a natural walking pattern and can disrupt gait training. Your healthcare team may begin rehabilitation with a non-rolling walker and transition to a rolling version as appropriate for you.

Cane

A cane provides a third point of support during standing and walking. Your therapist may recommend that you use a cane for additional support and stability while you learn to walk with a prosthesis. Cane choices vary depending on the amount of support needed:

- Hemi-Walker is the most supportive type of cane. It is lighter than a walker, but does not provide as wide a base of support as a full walker.
- Quad-Cane is a four-pronged cane that provides a smaller base of support than a hemi-walker. Quad-canes are often used during the rehabilitation process to increase confidence and stability during early walking activities.

Crutches

Crutches offer the user three points of contact with the ground and a very stable base when the individual is upright. They may be used with a prosthesis, but they are more often used without one. The type of crutch a person uses depends primarily on personal preference, but if you will be using crutches without a prosthesis for a long period of time, consider using forearm crutches. Forearm crutches reduce stress on the armpit area, as well as the shoulders, arms, and wrists. Crutch users should also be aware that lighter-weight, ergonomically designed, and custom-made options are available. Specialized tips with gel inserts to absorb shock help reduce stress on the body. Using crutches helps many people with lower-limb loss increase their ability around the home and in the community.

Assistive Devices for Individuals With Upper-Limb Loss

There are a variety of tools and items that can help individuals with upper-limb loss or limb difference manage tasks with greater ease and efficiency, regardless of whether or not they use prosthetic devices. Many of these items are available through medical supply stores. Others can be found in local department and/or hardware stores. This is not an exhaustive list of options, but it should give you a good start to making your home and life more accessible.

Dycem and rubber/silicone matting are great for keeping items from sliding on a surface or getting a better grip when holding objects and opening jars. Shelf or rug liners can also be used for these purposes.

Suction cups are great for stabilizing objects such as cutting boards or small appliances. Some tools can be purchased with a suction cup base.

Coban is a self-sticking textured material that can cover slippery surfaces in order to obtain a better grip. It comes in rolls and can be reused multiple times.

Velcro can be used to replace fasteners, create a pull-tab, or organize cords. It comes in a variety of colors and strengths and is available at grocery, craft, and hardware stores, as well as many different department stores. Most types of Velcro are self-adhesive.

Cylindrical foam tubing can be used to cushion and enlarge grips on tools and eating utensils.
It is available in a variety of different diameters and in sheets. Pipe insulation purchased from a hardware store can be used for the same purpose.

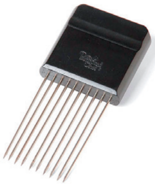
Knobs can be a challenge to grasp and to turn. Smaller knobs can be replaced with larger knobs or winged knobs to make door, drawers and appliances easier and more efficient to access.

A **Button Hook** can snare buttons and help you pull them into a buttonhole. The hook end can also snare a zipper so that you can pull it up or down.

One-Handed Rollers are great for pushing out dough. They have a long roller at one end and a short roller at the other to accommodate different contours and sizes.

A **rolling pizza knife** can be used for more than just pizza. It can also be used to cut bread and softer fruits and vegetables.

A **mandolin** can be used to slice a variety of fruits and vegetables. An egg slicer can be used to cut foods such as cheese and berries.



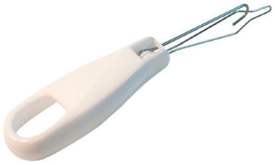
A **holding pick** can be used to stabilize foods while cutting.

A **bath mitt** can be used to wash your body, help you bathe a child, wash and dry dishes, and dust and wash windows. Bath mitts are available in many different styles and textures that will suit a variety of tasks.

A **rocker knife** is another great alternative for cutting and chopping. The rocking action saves energy and easier on your joints.

Whenever possible, use **electric tools**, especially can openers, shavers, and food processors.

Body scrubbers can help you get to hard-to-reach places while showering. You can use your residual limb or mount on the shower wall with suction cups. You can make a larger body washer by sewing several small scrubbers onto heavy-duty netting.



Zipper pulls can be attached to zippers on many garments, such as jackets and boots, to make them easier to fasten.

Scissors can be used to cut many foods, including meat, poultry, and fish.

Tongs are helpful for many tasks, from serving food to getting to hard-to-reach places.

Insurance Considerations

Lower-Limb Loss

The K-Level system, discussed earlier, classifies the functional level of individuals with lower-limb loss and helps determine eligibility for prosthetic components. This system is used to ensure that prosthetic devices and components are appropriate and meet individual medical needs.

Your healthcare team will likely perform various tests and evaluate your short- and long-term goals to determine your K-Level. Your previous activity level, the condition of your residual limb, your daily activities, and any other ongoing medical conditions will be factors in their decision. You will likely be required to have in-person evaluation with your healthcare team so that they can generate the proper documentation required to support the need for your recommended prosthetic components.

Upper-Limb Loss

While upper-limb prosthesis determination does not utilize K-Levels, the same process must occur. The determination for an upper-limb prothesis will likely include your:

- coverage for different types of devices;
- previous and current medical condition;
- grip needs to accomplish activities of daily living; and
- secondary health conditions that may limit use of certain devices.

Insurance Decision

Your healthcare team will likely submit a claim outlining the devices and components that meet your medical needs, supported by proper and thorough documentation. Your insurance provider will review the claim, request further documentation if needed, determine your level of coverage, then approve or deny the request.

Appealing an Insurance Denial

Due to the relatively high initial cost of prosthetic devices, be prepared for a denial. Often insurance companies use the denial process as a way to protect against potentially fraudulent claims or to try to reduce their financial burden. Insurance company decisions can be appealed. “No” does not necessarily mean “No.” Don’t give up, and understand your options in the next steps!

If your initial claim is denied, then you should talk with your medical team and consider filing an appeal. You may need to provide further documentation to prove the medical necessity of your appeal. Typically, your providers will work to file an appeal on your behalf. You can connect with a Patient Navigator from the Amputee Coalition’s Resource Center to assist you with filing your appeal.

Work with Human Resources

If you receive your plan through an employer, work with your Human Resources (HR) department. How do you work with HR? Pre-emptively. Make your employer aware of your prosthetic needs and ask if they might be able to consider a plan that would provide adequate and appropriate coverage. Within your current coverage, HR can often help you navigate your current plan, or even help you with the appeals process in certain instances.

Work with Your Healthcare Team

Communicate your needs, lifestyle, activity level, goals, work, and hobbies with your healthcare team. Their assessments and thorough documentation of your specific needs are crucial in the claims process in order to prove medical necessity. This is another reason why self-advocacy and sharing your information is vital for prosthesis determination.

How to Write an Appeal Letter

In certain instances, you may be asked to provide additional information to your insurer. In an appeal letter, it's important to include your name, insurance plan and ID number, reason for the denial, and why the device is necessary for your recovery based on your medical needs. Be polite and courteous; use please and thank you. Specifically, explain your activities of daily living, such as using stairs in the home, walking up ramps in driveway, or taking care of small children. Think through your daily routine and document those items that are frustrating or difficult for you. Explain your work environment and the necessity of certain functions you need a prosthesis to perform. Explain hardships that occur every day when a prosthetic device is not provided, and ask for a timely approval of your device. Make it personal, giving as much detail of your daily life and activities as possible. You may even include photos or videos of the above interactions to help further personalize your story.

Ask your prosthetist or the Amputee Coalition for resources, like studies that have documented the benefits of device use, to support your claim for a device.

Often, insurance coverage for internal and external devices are different. Know what your insurance company's coverage is for a knee or hip replacement surgery (these are internal prosthetic devices). Request the same coverage for your external prosthetic care. Keep a copy of your letter and documents. Mail all of your documentation in a certified letter to your insurance claims department for receipt confirmation.

Follow Up

If neither you nor your prosthetist have heard back from your insurance company in a timely manner, contact your insurance company and ask to speak with a patient advocate or case manager. Have a copy of your letter and documentation handy.

Ask if there has been a review of your appeal. If it has not yet been done, ask when you can expect a response or when you can follow up again. If it has, ask if there is any other documentation needed, or what you can do to facilitate the approval. You can reiterate your activities of daily living, the necessity to return to work and remain engaged in your community, the benefits of having this specific device, the daily hardships you encounter without your device, or hardships with an aging or antiquated device.

The Amputee Coalition offers an Insurance and Reimbursement Guide that provides more in-depth information about coverage criteria necessary for prosthetic reimbursement.

Insurance Coverage and Access

The Amputee Coalition is committed to guaranteeing equal insurance coverage for people living with limb loss and limb difference. That means treating limb loss care, rehabilitation, and prosthetic devices like any other benefit within an individual's insurance policy, including eliminating arbitrary caps and restrictions on prosthetic device coverage. We believe medical decisions must be made by you and your healthcare team, not by insurers. So far, we have successfully enacted laws in more than 20 states to improve coverage, and we're working on the rest. We're also working with Congress to pass a comprehensive federal law.

BYOA: **Advocate for Change**

With your help, we can improve the lives of millions of Americans living with limb loss and limb difference. We offer numerous opportunities for you to get involved in advocacy each year. Visit our webpage to sign up to become an Advocate or Certified Lead Advocate today.

PERSONAL STORY: MIKE ST. ONGE

My name is Mike and I became a quadramembral amputee in January 2000 due to sepsis. My left arm is very short below the elbow and my right is amputated through the elbow. I lost both of my legs just below my knees. Recovery was a year-long process. I spent five months in the hospital, then another six months in rehabilitation.

Early on, I realized that my devices needed to be comfortable and dependable because I was so reliant on them. I spent about two months with just my upper-limb prostheses trying to figure out what they could accomplish versus just using my residual limbs. It was not long before I came to realize that I could do most tasks one-handed with my left arm. After that, I stopped using my right prosthesis.

I did some research and experimented with different types of hooks, such as a heavy- duty work hook and a voluntary closing hook that closed when you applied force. I finally settled on a 555 stainless steel hook. It was robust enough and had fingers that easily grasp round objects like my favorite bottled beverage.

Then along came myoelectric hands with the individual articulating fingers. Trouble. I really coveted some of the features, so I talked to vendors and wearers alike. How durable were the fingers? What happens if I popped one of them off? How long does it take for repairs? How tolerant is it to water?

I have to admit, I was enamored with the different grip patterns they could offer, especially the trigger finger for spray bottles. Ultimately, I decided that a hook is best for me. Like an old dog that knows how to stay on the porch, hooks were reliable, durable, consistent, and, if I broke something, I could fix it by myself. Now don't get me wrong, I like those myoelectric hands. I think they're great. But I'm rough around the edges and hard on my equipment. I respect and admire what is being done to advance the field of upper prosthetics. But, for me and my needs, it's the tried and true body-powered hook.

> **"Ultimately, I decided that a hook is best for me. Like an old dog that knows how to stay on the porch, hooks were reliable, durable, consistent, and, if I broke something, I could fix it myself."**
>
> - MIKE ST. ONGE

Stage 5: Rehab With Your New Device and Without

- Your First Prosthetic Device
- Learning to Use Your Prosthetic Device
- Prosthetic Maintenance and Getting Back to Living
- Educational Questions for the Prosthesis User
- Insurance Considerations

Your First Prosthetic Device

Once you and your healthcare team have determined the best prosthetic device for your journey, you may be eager to start using a prosthesis. But the process takes time.

Measure, Casting, or Scanning

It is important to understand that the casting and fitting process for your first prosthesis can take multiple visits over several weeks.

For someone new to limb loss, the casting and fitting process can usually start after swelling of the residual limb is under control, and the incision site has healed. On average, this is usually four to six weeks after surgery. Your surgeon and prosthetist will work together to determine when it is right for you to begin the casting and fitting process. Don't rush this process. If your residual limb is not ready, you may further delay your recovery.

To connect a prosthesis to your residual limb, a socket must be fabricated. The socket is an essential element of your prosthesis, as it is fit to your specific residual limb and should have a comfortable fit.

To fabricate a socket unique to your residual limb, your prosthetist will take measurements of your residual limb. Measurements can be taken using plaster casting, fiberglass casting, or laser scanning. Your prosthetist will help you decide the best way to measure your residual limb, and different prosthetists may use different techniques.

Test Socket

After measurements of your residual limb are taken, a temporary "test" or "check" socket will be fabricated. Usually, the temporary socket is clear, and allows your prosthetist to see how your limb fits into the socket, and if there are any pressure spots. Once the temporary socket is fabricated, other components of your prosthetic device will be added to allow you to begin standing and walking, or using your arm and hand.

As you begin standing and walking or using your arm and hand, the temporary socket and components of your prosthetic device will be adjusted and modified to help you feel more comfortable using the prosthetic device, and to prevent pain or discomfort in the residual limb. Don't be discouraged if many adjustments or modifications are needed to make your prosthetic device feel right to you. Everyone's residual limb is different, and your prosthetic device is unique to you!

Final Prosthesis Fitting

During your final prosthesis fitting, your prosthetist will make final adjustments for fit, comfort, and control. They will also fit and adjust your prosthetic components. To determine whether adjustments are needed, your prosthetist will ask you to walk in your new prosthesis. If needed, your prosthetist will adjust the components to allow you to walk better. It may take several weeks to find the right fit.

It is crucial to communicate how the prosthetic device feels. Does it feel like it's pushing you backwards? Forwards? If you don't hold your knee in place, does it drift into a bend? Once you have your first prosthetic device, you will work with your healthcare team to learn how to use it.

Learning to Use Your Prosthesis

The first thing you will learn is how to don and doff (put on and take off) your prosthetic device. This can include putting on your liner, which protects your skin, and then the prosthetic device. Individuals with lower-limb loss or limb difference may then begin walking for the first time. Individuals with upper-limb loss or limb difference may focus on learning how to strengthen their residual limb to begin using their new prosthesis for activities of daily living.

Many basic skills must be learned before and during early use of your prosthesis. These can include changing footwear, learning residual limb volume management techniques, getting dressed, maintaining the prosthesis, sockets, and liners, and, most importantly, inspecting and managing the skin integrity and overall health of your residual limb. Like any other skill, using a prosthesis can only be mastered with regular practice over time. If you ask other individuals with limb loss, many will tell you that it can take months or even years to become a proficient prosthesis user, and there always are opportunities to learn and improve.

For people with a lower-limb amputation, early weight-bearing activities, balance, sensory reintegration, and muscle re-education often happen before walking activities, and continue once walking activities have begun. Finally, gait training (learning how to walk) on the prosthesis begins. Experienced prosthesis users may make walking with, and using, a prosthesis look easy.

For many, though, walking is a journey, and takes time. Don't get discouraged if you have difficulties taking your first step. As your body gets used to wearing a prosthesis, and you strengthen your residual limb and surrounding muscles, walking will become easier. Likewise, for people with an upper-limb amputation, rebuilding strength and establishing grips and function can take time but will become easier if you stick with it.

Stretching

Stretching during this phase focuses on the hip muscles and knee muscles for those with lower-limb loss, and the chest, shoulder, and remaining muscles in your residual limb for those with upper-limb loss. Much like how you need to work hard to prevent or reduce contractures, you also need to make sure you are stretching on a daily basis so that you can maintain an efficient gait. Stretching is important for long term health and well-being.

Strength

Now that you have your prosthesis, you can begin strengthening activities that weren't possible or allowed previously. Activities like squatting, bridging, and resistance exercises can now be done while wearing the prosthesis, allowing you to increase your strength to counteract the demands of the prosthesis. Likewise, swinging, gripping, and performing upper-limb-resistant exercises can be performed now. Strengthening typically focuses on the hip musculature and core, as a strong hip and mid-section can better control the placement of the prosthesis. For upper-limb amputees, it is important to work on strengthening your neck, shoulder, and shoulder blade with range of motion exercises. Good posture and alignment are important for upper extremity prosthesis use.

Balance

Most important of all is balance. Prosthesis wearers are at a higher risk of falls regardless of the reason for amputation or limb difference. Balance can be thought of in a few ways: standing on both feet; standing on just one leg; and transitioning between legs. For the purposes of gait training, all three types of balance must be developed. It is okay not to have perfect balance on your prosthetic leg, as this is not always possible based on the technology of the prosthetic components.

However, you want to test your balance limits, develop an understanding of your fall risks, and minimize the likelihood of falls occurring through balance training.

Gait Training

To learn how to walk with the prosthesis, it is necessary to perform gait training. Gait training is a fancy way of saying "learning to walk efficiently while minimizing your risk of falling." This means that gait training isn't just about walking, it is about making sure each step helps you conserve energy, and that the steps you take are safe and not going to contribute to falling or other health conditions from poor form. Walking is made up a combination of different components: balance, strength, flexibility, and awareness. Therefore, to develop a good gait, we need to make sure that the balance, strength, and flexibility are there.

Gait training is very helpful for people with lower-limb amputations, but people with upper-limb amputations and those with limb difference can also benefit greatly from gait training to improve form and reduce future complications. Gait training in children should be based on age, developmental abilities, and medical conditions. Most certainly, play is incorporated to encourage your children to come up and down into standing, cruise, and walk. Age-appropriate play activities also are used during upper-extremity prosthetic training.

Making Your Prosthesis Your New Partner

Newer prosthesis wearers must learn to trust the prosthesis. The prosthesis is new to many individuals with lower-limb loss, and as such they have not had a chance to build confidence in it. Is the prosthesis going to hold me? Will it collapse? Can I be sure I am safe? These questions are commonly encountered for newer wearers, and for some it can be the limitation that prevents effective prosthesis use. Thus, to better prepare yourself for the daunting experience of taking your first steps on your prosthesis, here are some guidelines to consider.

You Can Trust Your Prosthesis: Your prosthesis is designed to hold your body weight, so it will not collapse underneath your weight if you are utilizing it properly.

Your Prosthesis Takes Instruction From You: How you use the prosthesis determines how it reacts. For instance, many above-knee prosthetic legs will only begin to bend at the knee joint if the weight is carried over the toe. In other words, the knee of a prosthesis is intuitively designed to follow the lead of what a "normal" gait cycle should look like.

Build Your Confidence: Before walking on the prosthesis, you should practice standing, weight-shifting, stepping, and otherwise balancing on your prosthetic leg. This portion is usually performed securely in the parallel bars with a physical therapist nearby. These exercises help build your confidence, so that when you take your first step you can trust your body and prosthesis.

Falls Happen: Know that whether you've experienced an upper- or lower-limb loss, you may fall. Do not let this discourage you! There are some things you may not be able to control (a lump or divot on the ground) that can easily throw you off balance. One of the first things you should learn in your physical rehabilitation is how to fall safely to reduce risk of injury.

Don't Be Afraid to Speak Up! Self-advocacy is important here just like it was in the other phases. It is normal to not feel secure on your limb, and it takes time to build confidence. Communicate with your prosthetist and physical therapist about your feelings, concerns, and what is working or what is not working. You are not alone. You can move past this phase, together with your rehab team.

Prosthetic Maintenance and Getting Back to Living

Throughout the rehabilitation process, you and your medical team will talk about your goals so you can get back to activities you participated in before your amputation. Do you enjoy golfing, running, swimming, or biking? Do you enjoy cooking, going to the movies, or going out to community events? Do you want to learn how to do a new activity? There are many different devices and components to help you achieve your goals and get back to living the life you want.

Moving through the phases of physical rehabilitation ultimately prepares you to return to work, leisure, and recreational activities. Your prosthetic care will be ongoing, but once you are in the prosthetic training phase, you will visit your physical therapist and prosthetist frequently. As time goes on and your rehabilitation goals are met, those visits will start to decrease. Your body will continue to change, and you may need minor adjustments or repairs from time to time. Also understand that the first year, or more, your residual limb will continue to change, and it is up to you to remain diligent in communicating to your prosthetist when your socket isn't fitting well and needs adjustment.

Prosthetic devices are like anything else mechanical – eventually, they wear out or break and need to be replaced. New components may be introduced. Talk with your prosthetist regularly and stay informed about how new technologies may benefit you and when you may be eligible with your insurance provider to receive a new prosthetic device.

TYPICAL WEAR AND TEAR OF PROSTHETIC COMPONENTS

	GENERAL LIFESPAN	REPLACEMENT SIGNS
Prosthetic Liners	Varies	Looks stretched out or is thin, doesn't fit well due to limb changes
Prosthetic Socks	12 Months	Looks stretched or is frayed
Sealing and Suspension Sleeves	Varies	No longer provides adequate suspension, is torn or stretched out
Harnesses	Varies. Check once per year.	Has frayed, torn or broken straps or broken fasteners
Prosthetic Socket	Varies. If your socket is causing discomfort, your prosthetist can modify the fit through the use of pads and other techniques.	If you have experienced significant weight gain or weight loss, or if your socket is causing skin breakdown or open wounds
Prosthetic Feet, Knees and Terminal Devices	Five Years	Can be replaced sooner if they experience catastrophic failure or if you have a significant increase or decrease in activity level

Special Considerations for Upper-Limb

Many therapists will recommend a progressive wearing schedule so that you can build tolerance to the socket. It can take time to get used to the weight and the length of your device, not to mention the feel of the harness. Studies show that if you choose to use an upper-limb prosthetic device, you will be more successful if you get used to the device quickly. The longer it takes, the more likely you may be to reject the device.

Prosthetic Socket Management

- Where should my leg feel the pressure in the socket?
- What does the liner do?
- What is the difference between the liner and the socks?
- How often should I clean the socket?

Sock Management

- Name the different types of socks and how many I should wear?
- What is the proper way to put on my socks?
- How should I wash and dry the socks?
- What do I do when my leg feels loose in the socket?
- What do I do when my leg feels tight in the socket?
- Why is it important always to carry extra socks with me when wearing my prosthesis?

Skin Care

- What is the importance of checking my skin regularly?
- How long should areas of redness last on my skin?
- What do I do when I have an area of skin breakdown?
- For more information, use the **Follow-Up Appointment Worksheet** in the Appendix.

BYOA:
Understanding Your Prosthesis and Communicating Your Experience

The previous questions may help you understand your prosthesis and communicate your experience to your healthcare team. Caretakers for children or older adults might also find these questions helpful as you learn more about the prosthesis together.

PAIN

- Understanding and Talking About Pain
- Types of Pain Associated with Amputation
- Pain Management
- Tips for Dealing with Pain
- Alternative Pain Management

CHAPTER 3

PERSONAL STORY: MARION HILLIARD

My name is Marion and I became a below-knee amputee at the age of 47 in a work-related accident. I was the manager of a tree service when I got pulled into a wood chipper by the leg. My left foot was cut off by the machine before someone put the machine into reverse. In three seconds, my entire life changed.

As I laid in my hospital bed, the surgeon and his team gave me my options, none of which I wanted to hear. I was told that I would never be able to return to my profession and passion for tree climbing. But I was determined to find a way back to supporting my family and doing what I loved.

One of the first steps toward my goal was to embrace that I was an amputee. Attending the Amputee Coalition conference, I learned there were many resources to help me with activities and programs, like First Swim, First Run, and First Climb. They're some of the best avenues to find help and encouragement because they're a community of amputees finding their way back to living a full life.

My second step was to study more about the mechanics of tree work and tree climbing. I started attending climbing competitions to gather information on the use of equipment and techniques. I even had my wife volunteering and, although she wasn't thrilled to know that I was thinking about climbing again, she became my biggest fan and advocate.

One of the first things I had to come to terms with was how my body felt and how to deal with pain. As I began my journey back, I realized phantom pain is very real and unpredictable, and it would strike out at me with no warning.

I made up my mind that pain wasn't going to stop my journey, but I realized I couldn't push my residual limb too far. I learned that when I wore my prosthetic leg for long periods of time, I was jeopardizing my skin. That can be a major setback if a wound breaks the skin. I came to understand the need for me to rest my limb and to remove my device, keep my leg dry, and keep my skin healthy. I knew that my skin was vital in me being able to wear my prosthesis.

Two years after my accident, I returned to the job I love. Most of the time, people have no idea that I am an amputee until I return to ground level and pull up my pant leg, showing off my prosthetic leg. My job as a tree care specialist is challenging and exhilarating, but most of all I love the excitement that I bring to others as they watch me climb.

"One of the first things I had to come to terms with was how my body felt and how to deal with pain. As I began my journey back, I realized phantom pain is very real and unpredictable, and it would strike out at me with no warning." - MARION HILLIARD

Understanding and Talking About Pain

People with limb loss experience many different types of pain. Understanding and describing the types of pain you are experiencing can help you and your healthcare team determine the most effective pain management plan for you. Pain is something different to everyone. What may be a high level of pain for one person may be a low level of pain or not register for someone else. There can also be emotional aspects for pain, which are hard to define.

When you experience pain, only you can feel it, tell where it is coming from, describe what it feels like, and communicate whether the treatment is working. Since pain is largely subjective, you will be asked to rate the intensity of your pain on a scale of 0 to 10, with 0 being no pain at all and 10 being the worst pain imaginable. Providing this information to your healthcare team will help your physicians prescribe the correct pain medication in the correct amount.

ACTIVITY TOLERANCE SCALE

Wong-Baker Facial Grimace

No Hurt	Can Be Ignored	Interferes With Tasks	Interferes With Concentration	Interferes With Basic Needs	Bed Rest Required
No Pain	Mild Pain	Moderate Mild Pain	Moderate Severe Pain	Severe Pain	Worst Pain Possible

Verbal Descriptor

●	●	●	●	●	●	●	●	●	●	●
0	1	2	3	4	5	6	7	8	9	10

Healthcare providers refer to pain as being either acute or chronic. Acute pain is temporary. It typically has a clear cause and goes away as the cause improves or heals. Chronic pain lasts for a longer period of time or may be permanent.

Describing Your Pain

You may tell your healthcare team that you are in pain, and they may ask you to describe it using words like:

- Sharp
- Aching
- Throbbing
- Twisting
- Pinching
- Tingling
- Shooting
- Stabbing
- Electrical
- Pins and needles

It is important to communicate your pain to your healthcare team because managing pain is an important part of recovery. If not treated early, pain can become more intense and even hinder the healing process. You should work with your healthcare team to determine what medications may be best for you. It is always a good idea to discuss past history with medication addiction prior to starting a pain management program with your healthcare team.

Types of Pain Associated with Amputation

Post-Surgical Pain

Pain is expected after amputation surgery. Post-surgical pain is typically acute and will diminish over the first few weeks after surgery. Traditional pain medications can help provide pain relief until healing occurs. Methods to decrease swelling, including elastic wraps or shrinkers, residual limb socks, light massage, finger tapping, and cold packs, may also help to reduce pain.

Residual Limb Pain

Residual limb pain originates in the part of the limb remaining after amputation surgery. Residual limb pain is different from normal post-surgery pain and commonly occurs after post-surgery pain has ended. It is frequently described as sharp, aching, throbbing, or burning. Residual limb pain can be caused by a number of things:

- Surgical trauma
- Swelling
- Neuroma formation (a ball-shaped mass of nerve cells)
- Bone spur formation
- Nerve damage
- Entrapment of nerves in scar tissue
- Irritation from your prosthesis
- Conditions you had prior to your amputation

Phantom Limb Sensation and Phantom Limb Pain

After limb loss, it is common for individuals to experience phantom limb sensation and phantom limb pain. Phantom limb sensation is when you feel as if your amputated limb, or part of your limb, is still there.

Some people who experience phantom limb sensation after surgery worry it's all in their head. However, these sensations are common and normal. Phantom limb sensations occur because the nerves leading from the amputated limb to the brain are still there. As a result, messages from these nerves essentially "trick" the brain into thinking that the limb is still present. Phantom limb sensations may include tingling, pins and needles, itching, temperature changes, pressure, or abnormal position and movement. Phantom limb sensations may be uncomfortable, but they are not painful, so no treatment is advised.

A phantom limb sensation that is also painful is called phantom limb pain. Phantom limb pain is a type of nerve pain. It most often occurs soon after surgery and may persist well beyond the time when you have recovered from surgical pain. The painful sensation can last anywhere from a few seconds to several days. Some people have chronic, persisting phantom limb pain that is not limited to days. Phantom limb pain is most frequently felt in the fingers and toes and is often described as burning, twisting, electrical, or like pins and needles. For most people, phantom limb pain diminishes in frequency and duration during the first six months after amputation surgery. However, some people continue to experience phantom limb pain for years. It is believed that nearly 80 percent of the amputee population worldwide has experienced phantom limb pain.

Secondary Pain

Complications following amputation surgery can be another source of pain. The best defense against secondary pain is preventing complications. This means taking meticulous care of your residual limb.

If you use a prosthesis and your limb is healed, you should not expect to experience pain as a result of wearing a prosthesis. Your prosthesis should fit and be comfortable. If you are experiencing pain when using a prosthesis, tell your prosthetist so they can improve fit and function. Painful sensations resulting from poor prosthetic fit can be caused by things like pressure sores and blisters. It is important to pay close attention to how your residual limb looks when your prosthesis is off. It's good practice to inspect your residual limb twice a day. It is also vitally important to take care of your prosthesis, liners, and prosthetic socks, so be sure to talk with and follow directions from your medical team and the manufacturer of your prosthesis about how to care for these items.

You can also avoid secondary pain by taking care of your general health. This means eating well, exercising, getting plenty of rest, and taking care of your emotional well-being. Drinking plenty of water and staying hydrated is also very important. Manage any health conditions as well as possible. If you have diabetes, keep your blood sugar levels under control. Maintain a healthy weight and try to avoid large weight gains or losses.

Pain Management

Pain management is most effective with a comprehensive approach. Your entire healthcare team, including your physician, therapists, prosthetist, and mental health professionals, should work with you to determine the cause of your pain and form an organized and focused treatment plan.

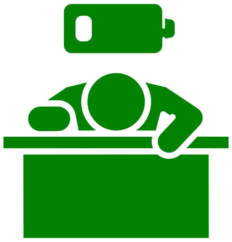
Medications can be very effective at reducing or eliminating pain. Traditional pain medications – anti-inflammatory agents, acetaminophen, muscle relaxers, and narcotics – work well for pain from a physical injury. Nerve pain, however, often does not respond well to traditional pain medications. Instead, nerve pain is often treated with anti-seizure medications or anti-depressants. These types of medications work by changing the chemistry of the nerve to stop the pain or by blocking pain signals to the brain. Some people who have nerve pain or sensations after limb loss will opt to remain on a pain medication for the rest of their lives.

Nerve pain frequently occurs immediately after surgery in a mild form. If not treated early, it can become more intense as healing occurs. It may be difficult to communicate exactly where the pain is coming from.

Remember that you are the most important member of your healthcare team. Report any pain or discomfort you are experiencing to your healthcare providers as soon as it starts so they can work with you to address the issue before it gets worse.

Work with your healthcare team to develop strategies for dealing with the type of pain you are experiencing. Keep in mind that traditional pain medications may be appropriate for some types of pain but not for others. Below we offer pain management techniques in addition to medications.

Pain and anxiety often make it hard to sleep. Lack of sleep slows healing, worsens pain, and lowers mood.



Chronic pain and exhaustion can lead to depression, anger, and anxiety that slow healing and make it harder to sleep.

Pain, depression, and lack of energy may make it harder to be active. Lack of exercise can worsen pain and may make it harder to sleep.

Find ways to regulate your sleep such as a nightly ritual of reading or watching a short TV program, going to bed at the same time every night, avoiding caffeine after 3 p.m., and limiting light and technology when ready for bed. Guided meditation has been useful for many people to help them feel more centered and less reactive. Guided meditation recordings can be found in many free apps for your smart phone and on YouTube. Maintaining a steady course of controlling your mood and regulating your sleep will help you feel like your pain is under control, too.

Opioids

Opioid medications may be an important part of your recovery and pain management – but not the only part. Talk with your healthcare team about which medications may be right for you. Ask any questions or express any concerns you may have about your medications and learn about them. Alert your healthcare team to any changes in your pain levels or effects from medication. Be your own advocate to make sure you get the care that is best for you.

Tips for Dealing with Pain

Medication is not the only option for dealing with pain. There are some physical techniques you can try to help manage your pain.

- Begin to exercise as soon as your surgeon allows it. Standing, walking, and stretching improve your general health and they interrupt pain signals.
- Desensitization techniques may help alleviate pain. Desensitization techniques include massaging, squeezing, brushing, tapping, and wrapping your residual limb. Ask your physical therapist to demonstrate these techniques.
- Know your triggers. You may find that certain activities or conditions, such as touch or changes in the weather, trigger phantom limb pain. Some triggers can be avoided. For others, you will just have to understand and treat accordingly.
- Wearing your prosthesis may help alleviate pain. Some people are pain free while wearing their prosthesis, but once they take it off, painful sensations begin. Compression can help reduce swelling and alleviate pain and abnormal sensations. Wearing a shrinker may help alleviate pain.
- Keep a pain journal. Keeping track of your symptoms and pain triggers to share with your healthcare team may help them find the right treatment for you.
- Tension and stress can increase pain. It is estimated that as much as 50 percent of an individual's pain can be reduced using relaxation techniques.

Even if you have supportive family and friends, joining a pain support group may help you find new ways to cope with your pain.

Alternative Pain Management

There are many alternative techniques and therapies to help with pain management that do not require medication. Below are a few ideas you may consider.

Targeted Muscle Reinnervation (TMR)

Nerves want something to do. If they are cut and left unconnected, they will feel pain. Targeted Muscle Reinnervation (TMR) connects amputated nerves to nearby muscles. Reconnecting these nerves may prevent pinched nerves, phantom limb pain, or chronic nerve pain. You can find out if TMR is right for you by talking with your healthcare team.

Alpha-Stimulation

Alpha-stimulation may help to relieve post-surgery pain through painless electrical stimulation. It can be used on its own or in conjunction with physical therapy, medication, and other forms of pain management.

Acupuncture

Acupuncture is when hair-thin needles are inserted into the skin at specific points around the body to reduce pain. Not everyone is a good candidate for acupuncture. Talk with your healthcare team before pursuing this therapy.

Mirror Therapy

Mirror therapy involves placing the affected limb behind a mirror. The mirror is positioned so that the sound limb appears in place of the hidden limb. When you move your sound limb, the reflection tricks your brain into thinking that movement has occurred in your phantom limb without pain.

Biofeedback

Biofeedback is a treatment technique that trains people to control body functions, such as breathing, skin temperature, blood pressure, and heart rate. Teaching people to control muscle spasms and blood flow in their residual limb may reduce or eliminate some phantom limb pain sensations.

TENS

TENS (transcutaneous electrical nerve stimulation) therapy uses low-voltage electrical currents for pain relief. Electrical currents are delivered via a small, battery- operated device connected to several electrodes. The electrodes are placed on the skin around the painful area.

Virtual Reality Therapy

Virtual reality therapy places an individual in an immersive virtual environment, similar to a video game, and given an avatar with four intact limbs. The individual then has their avatar perform tasks using the avatar’s limbs. This virtual activity has been shown to reduce and eliminate phantom pain for some people.

Imagery

Imagery is a guided relaxation technique that uses your imagination to create a thought or an image to distract you from your pain symptoms.

Music

Listening to music that makes you feel calm or relaxed may help reduce pain symptoms.

Pain can make it difficult or impossible for you to sleep and function when you are awake. Living with chronic pain can be lonely, frustrating, and overwhelming, and may lead to depression or despair. Understanding pain won't make it go away, but it can make the pain easier to tolerate and address.

With a comprehensive pain management approach, it is possible to treat and reduce your pain and learn how to cope effectively with the pain that remains.

BYOA:

Medications Aren't Always the Best Answer

There are many different techniques for managing pain. Medications aren't always the best answer. Work with all the members of your healthcare team to find the treatment that is best for you. You can learn more about comprehensive pain management techniques on the Amputee Coalition's website.

Special Considerations for Kids

Children often express pain differently than adults. Sometimes it can be seen in changes in behavior and mobility. A child who has been using a prosthesis may begin to avoid using it, not bear weight on the limb, or not allow their limb to be touched. Since children are still growing, they experience different secondary conditions than adults. Parents are the best judge of their child's pain.

STAYING HEALTHY

- What is Self-Management?
- Skin Inspection
- Hygiene
- Knowing Normal vs. Abnormal
- Secondary Conditions

CHAPTER 4

What is Self-Management?

Life after limb loss requires adapting not only to changes in how we get around, but also in how we care for ourselves and our families. This means we need to accept certain new responsibilities, such as vigilant skin hygiene, and learn how to recognize when something is wrong. This chapter focuses on the things you can do to ensure you are doing everything possible to avoid developing unwanted secondary complications, such as skin breakdown, wound formation, or pain.

Self-management can be defined as the knowledge and skills required to care for the residual limb and how to know when to seek help. Each of the major areas of self-management are described in the following section, with instructions on how to perform the necessary skills correctly. If you do not understand the information presented or are concerned that it conflicts with what you have been told, please speak with your healthcare team for the care that is best for you.

Skin Inspection

Inspecting your skin is one of the most important aspects of self-management you can perform. Whether or not you are in a prosthesis, the skin of your residual limb requires numerous daily inspections to ensure its integrity. When you first start wearing your prosthesis, skin inspections should be performed more frequently. As you adapt to your prosthesis, skin inspections can become less frequent as your residual limb adapts to the environment of the prosthetic socket and liners. Ask your prosthetist for a wearing schedule and skin inspection schedule when you receive your prosthesis. Here are the things you want to be vigilant about:

Skin Abnormalities

Blisters, scratches, ingrown hairs, and any other abnormality of the skin should be identified as soon as possible and communicated immediately to a member of your healthcare team. Depending on your specific situation, it may be recommended that you not wear your prosthesis until the abnormality has healed. A general rule when trying to determine if it is safe to wear your prosthesis: "If the limb looks off, take the prosthesis off!" In other words, it's always better to err on the side of caution and speak to a healthcare professional than to try to solve the problem yourself, which can prolong your recovery and ability to get back to wearing your device.

Discoloration Over Bony Area

When you take off your prosthesis, redness over bony areas or skin discoloration may be signs the prosthesis does not fit correctly. Treat any issues immediately since skin over bony areas is more susceptible to breakdown and possible infection. Then consult with your prosthetist right away.

Rashes

Rashes can come in many different forms and look different depending on your skin type. The most common type of rash found on a residual limb is a fungal rash. Keeping your residual limb and liner clean and dry helps prevent this. Much like the skin abnormalities mentioned above, it is an indicator to speak with a healthcare provider.

Bruising or Swelling

Bruising or swelling at the end of your residual limb can be a sign of an ill-fitting socket. Notify your prosthetist if this occurs in order to avoid further damage to your limb.

Blisters

Difficulties with donning or doffing a liner or socket are a common cause of blisters. Blisters are either filled with clear liquid or cloudy liquid. If clear, they should not be popped but simply covered with a dressing. This will allow for it to pop on its own and start to heal quickly. Cloudy fluid that could indicate a possible infection, in which case it should be examined by a member of your healthcare team. Clean blisters should be washed with gentle soap and water as described earlier.

Surgical Site

If you still have sutures or an actively healing wound, you typically will not be in your prosthesis. You still need to examine the residual limb numerous times a day and be vigilant of the surgical site. You may have some discharge, which can present as a light pink or red and bloody discharge. A surgical site that is healing normally does not have pus, foul-smelling liquids, deep red or cloudy blood. If your limb's discharge is changing, getting heavier, or if you are at all concerned, reach out to your healthcare team and have it evaluated. Remember, no one will know your limb as well as you do!

Covering and Treating the Wound

The science of wound care is much better understood than it was years ago. Wounds heal best when they are kept covered. Leaving it open to the air can cause inflammation and stall healing. Open wounds, cuts, or blisters should be kept covered at all times except during cleansing.

Simple abrasions or cuts usually can be treated without too much trouble. However, the location of the cuts may be important. If the cut is on the end of your residual limb or the area where you bear weight in your socket, it may heal more slowly. In this case, it is important to stay out of your prosthesis as much as possible. A simple cut or abrasion should be washed at least daily with soap and water, then have a water- or honey-based gel applied and a cover dressing. Our skin normally has bacteria on its surface and open wounds do as well. Open wounds are not sterile and do not require gloves for the majority of care. You should wash your hands with soap and water before applying any ointments, creams, or other topical treatment to your wound.

Although topical over-the-counter antibiotics like Neosporin, Bacitracin, and triple antibiotic ointments are readily available, they are not a great choice for regular use. A day or two may suffice. These topical agents often cause rashes due to allergic reactions to the ingredients. These rashes can be quite challenging to treat and lead to delayed healing. If your cut isn't improved after a week of these treatments, please see your prosthetist or wound-care provider.

In advanced wound care, antimicrobial agents such as silver or honey are used to combat any surface bacteria. These can be found in the wound-care aisles of pharmacies such as CVS, Walgreens, and Rite Aid. Silver and honey have been used for millennia in wound care, and you can find them listed as a Silver Gel or a Honey Gel in most pharmacies or online.

Types of Bandages

Once the cut or abrasion has been treated with a topical gel, apply a cover bandage. Although gauze is a common wound dressing, it not ideal a cover bandage. Gauze traps bacteria and keeps it pressed against the wound. Gauze fibers can become stuck on the wound and removal can be quite painful. Other dressings are able to absorb drainage and shrink, which lowers inflammation and allows easy removal without pain or trauma.

Foam dressings are made from layers of polyurethane and are designed to keep fluid away from their skin. They may have an adhesive border which is used to keep it in place. Therefore, tape is not necessary. The adhesives in tape are quite harsh and strip the top layer of cells away from the wound and surrounding area. This can cause increased irritation and pain. Modern foam dressings with an adhesive border use a silicone adhesive which allows for easy removal without pain or trauma to healthy skin. The other main advantage to these dressings is they are not very bulky and can be used with your liner and socket. If the dressing is very bulky, socket fit becomes an issue and other problems can arise.

Hygiene

While everyone has different standards for hygiene, after losing a limb hygiene becomes mandatory to avoid complications. Here are some typical recommendations for care of your skin and prosthetic components:

Residual Limb Care (After Surgical Site Has Closed)

Unless instructed otherwise, use warm water with fragrance-free soap. Be sure to clean any skin folds you may have, including by the healed surgical site. Do this daily. A few notes about soap and bathing:

- Soap does not need to be antibacterial/ antimicrobial
- Avoid soaps with fragrances/perfumes
- Liquid soap is usually easy to apply
- Baby wipes are very useful for a quick cleaning of your residual limb
- Do not immerse your limb in a bathtub until your provider gives you permission. A shower is fine as the water will wash away the soap easily.

It's very important to apply lotion or moisturizer to your limb within fifteen minutes of getting out of the shower to lock in moisture and prevent dryness or cracking. Pick a gentle lotion, such as Aquaphor or Eucerin, that doesn't have a lot of fragrance or chemicals that can cause allergic reactions.

Silicone Liner Care

Your liner should be washed according to the manufacturer's recommendation. Typically, this involves using the same fragrance-free soap and warm water. The part that needs daily cleaning is the inside of the liner since it touches your skin. Use a lint-less cloth, like a microfiber towel, to scrub the inside of the liner and remove any dead skin cells, hair, and sweat. To dry the liner, you should use the recommended liner tree provided to you when you received your prosthesis. If you do not have this device, you can dry the liner with another lint free cloth, turn it right-side out so that the gel portion is on the inside, and lay it flat to dry overnight. Never dry the liner with the silicon exposed to the air, as it can cause cracking. Also never fold it over a coat hanger as it can cause breaks in the silicone. Let the liner dry overnight. Never don a wet liner as it creates an environment for fungus and bacteria to grow.

Knowing Normal vs. Abnormal

Skillful self-management is recognizing when something is wrong. Much of what was discussed in the skin inspection section falls under this heading. Your residual limb is skin like any other part of your body, but instead of it being exposed to the environment or clothing, it is generally maintained in a compressive garment, a liner, or a prosthesis. Because of the intimate relationship between the residual limb and the socket, you need to be vigilant about how your limb looks, feels, and smells to prevent unwanted complications. Some typical situations that you may face are:

Pressure vs. Pain

It is normal to feel pressure when you are wearing your prosthesis, especially in the areas you are bearing weight. In the beginning this sensation may be uncomfortable, so it may register as pain. However, this pressure should be distinctly different than the pain you experience when injured. Pain is sometimes a way of letting your body know that something is causing you harm. If you feel pain in your residual limb, that is different from the sensation of the pressure of the socket. If you experience pain, or have a question about the pressure, it's important to speak to your healthcare provider. Even if you are unsure, it is better to seek assistance than potentially injure your limb.

Proper vs. Improper Fit

A proper fit for your prosthesis is essential to being able to function to your fullest ability. Every prosthetic socket has a different suspension system, and many use socks. Socks are a way to take up space in your socket after your residual limb shrinks (a normal process after amputation). If you find the prosthesis is fitting too loosely, you may be able to try adding socks 1 ply at a time. Your prosthetist should be able to provide you a number of different socks depending on your specific suspension method. If the fit is too tight, try removing socks. Regardless, only adjust socks to the point you are able to achieve a snug, comfortable fit. If you are unable to do so, then it is best to contact your prosthetist and leave the prosthesis off.

Normal vs. Abnormal Discoloration

As described earlier, you need to pay close attention to any discoloration. In individuals with lighter skin, the area may appear reddened. In individuals with darker skin, it may appear darker than the surrounding skin area. It is normal to have uniform discoloration after removing your prosthesis, liners, or compressive garments. The discoloration should be evenly distributed throughout the skin that was in contact with the socket and should fade after about 15-20 minutes. If the discoloration lasts longer than 20 minutes, or if the discoloration is unevenly distributed, then it indicates a potentially improperly fitting component. A follow-up visit with the prosthetist is recommended in this situation.

Sound From Your Prosthesis

A normally functioning prosthesis should be nearly silent although this depends on the components of the prosthesis. If you hear noises like beeping (indicating a possible battery or microprocessor issue), grinding, squeaking, or cracking, then you should call your prosthetist immediately to limit potential long-term damage and ensure safety. These are all signs that the prosthesis requires repairs or replacement.

No one knows your body as well as you. Be vigilant about identifying things that do not look, feel, smell, or sound normal. There will be issues that are outside of your control. You will need to advocate for yourself by reaching out to your healthcare team. Do not be afraid or concerned that you are "bothering" someone. The healthcare providers work to serve you and want to keep you healthy and free of unwanted complications.

Secondary Conditions

Back, Hip, and Knee Problems

Back, hip, and knee pain caused by the stress and strain of walking with an improper gait or using a prosthesis or crutches are sometimes even more of a problem for people with limb loss than other types of pain.

Upper-limb loss can shift your center of balance and lower-limb amputation causes a change to a person's center of gravity, disrupting the symmetry of the back and hips. This puts stress on the joints and causes the muscles in the lower back and sound limb to be used abnormally. This often leads to chronic pain, spasms, strain, and bursitis. The knee joint on the unaffected limb may develop issues over time due to overuse.

What You Can Do:

Ensure your prosthesis fits well and is aligned correctly. Continue doing the exercises and stretches as instructed by your physical therapist. Improving balance and strengthening the core can help to relieve back pain over time. Learn about good body mechanics to avoid as many problems as possible. Remember, hopping on your sound limb can cause long-term problems.

Shoulder and Wrist Problems

Crutch users may experience pain in their shoulders and wrists over time as remaining joints are stressed due to overuse. Arthritis, muscle strain, carpal tunnel syndrome, and nerve damage can occur over time.

What You Can Do:

Long-term crutch users should be aware that lighterweight, ergonomically designed, and custom-made options are available. Specialized tips with gel inserts to absorb shock help reduce stress on the back, shoulders, elbows, and wrists. Skid-resistant tips also improve safety. Be sure to replace the tips when they wear down. Regular stretching and exercises to encourage mobility and flexibility of shoulders and arms will build upper body strength and reduce the risk of injury. Alternating between various mobility devices, if possible, can help over-stressed joints heal.

Bone Density and Muscle Loss

Bone density and muscle loss can be problems for anyone who is inactive. After amputation, some of the muscles that remain are not used as often as they were previously. This muscle disuse can lead to shrinkage or atrophy. Bones also need to be stimulated through muscle activity or bearing weight to avoid becoming brittle (osteoporosis).

What You Can Do:

One of the best ways to develop strong bones is through weight-resistance training. Weight-resistance training has the added benefits of improving overall health, building self-esteem, and improving body image. Your physician may also recommend the use of specific medications or nutritional supplements.

Weight

Maintaining a healthy weight is important for everyone. It is even more important after your amputation. Even a five-pound weight gain or loss can make a difference in the fit of your prosthesis and in your overall mobility.

What You Can Do:

Eat a well-balanced diet and drink plenty of water. Not only will this help with weight management, but it will also help with maintaining healthy skin. Report any change in your weight to your healthcare team and prosthetist.

Maintaining Wellness of Your Sound Limbs

Much of your care and focus will likely be on your residual limb, but you may instinctively rely on your sound limbs more than before, so it is important to care for them too.

For lower-extremity limb loss, it is natural to become more dependent on your sound leg. You might find yourself hopping on it, putting all of your weight on it when sitting, using only that leg to go up or down stairs, using only the sound leg when squatting to pick up something off the floor. Recent research has shown that it is very common for a person with a lower-extremity limb loss to develop arthritis in the hip and/or knee in their sound leg.

If using a prosthesis, consciously try to put as much weight on the device as you do on your sound leg when performing activities. These are good habits to get into to maintain the health of your sound limb. Additionally, if you have limb loss as a result of diabetes or cardiovascular disease, it is even more important to examine your sound limb daily to ensure you do not have any wounds or signs of infection such as redness, pain, discharge. If you find anything of concern, seek care as soon as possible.

For upper-extremity limb loss, it is not uncommon to use the sound side to accomplish many tasks. This overt use of one body part can lead to overuse syndrome, muscle or soft tissue damage, and nerve impairment. In addition, it is common to use other body parts for snaring, grasping, and supporting objects. When you use your trunk for these purposes, you are likely to contort, rotate, or elevate the body into unusual positions that can cause fatigue as well as muscle pain. It is common for many people with upper-limb loss or congenital difference to use the foot to grasp objects, particularly small items from the floor. While this allows us to avoid having to bend over, extreme use of the toes for these purposes can lead to osteoarthritis and bony changes that impact shoe fit. Using body parts in unintended ways can also compromise safety. Remember these tips to maintain your health in the years to come.

BYOA:
Wound Care

If your wound or cut is deeper than the skin surface, please contact your prosthetist or a wound care provider as soon as possible for them to see it in person. It is always ideal to start advanced wound care quickly rather than to wait for several weeks as this can cause the wound to stop healing and have more bacteria build up on the surface. Also, if you develop systemic signs of infection, such as redness, pain, or swelling on your residual limb, fevers and chills, or elevated blood sugars in a diabetic patient, please see a healthcare provider as soon as possible. And remember: never take a bath with an open wound!

YOUR EMOTIONAL JOURNEY

CHAPTER 5

- Grieving After Limb Loss
- The Road to Emotional Recovery
- Accepting Your New Body
- Strategies for Achieving a Positive Body Image
- Redefining Relationships and Intimacy

PERSONAL STORY: MARION HILLIARD

My name is Posie and I had an above-knee amputation in 2011.

On November 19, 2010, my husband of 41 years died suddenly at 64. We had just celebrated our anniversary and made so many plans for the future. I was devastated.

A month later I couldn't put weight on my leg. I went right to the doctor and he discovered that I had a MRSA infection in my knee where I had a knee replacement. I was septic and he couldn't save my leg. He amputated my left leg above the knee on January 5, 2011.

Without my husband I felt lost, but my four kids were right there to support me and help make the decision to amputate. I had just turned 62 and, once again, I didn't know what the future would hold for me.

As I lay in rehab, I had some major decisions to make. I could either let this destroy me or I could see this as an opportunity to go on, grow, and become something positive. I had some goals in mind. I worked hard at physical therapy and there were challenges, but I was determined to walk again and get back my life. I would make my husband proud and honor his memory. In time I realized that this had been a gift from God to see myself and others differently and to share this gift with others. It took the focus off of me and onto others. I learned a new appreciation for life.

I started a support group for amputees with my prosthetist. I became a Certified Peer Visitor for the Amputee Coalition and I became a Lead Advocate and joined other amputees to lobby for insurance fairness for amputees with our legislators.

I returned to my life as an amputee with resolve and purpose. I returned to skiing, which I had done as a member of the

National Ski Patrol for most of my life. My husband and I had spent every winter skiing, so getting back to the sport we loved had a special significance for me. Now I participate in many adaptive sports in my area, such as cycling, kayaking, tennis, and waterskiing, and I have even taken up sled hockey and surfing.

I came to realize that, by the grace of God, I had lost my leg and had been given a new life, and the possibilities were endless. I never once saw my amputation as a loss. The real loss was losing my husband, but by losing my leg I came to realize that I didn't have to see this as the end but rather as a beginning. I have six beautiful grandchildren and two great-grandchildren, and I spend as much time with them as I can. Looking back doesn't change the past, so I look ahead to what the future holds for me.

> **"As I lay in rehab, I had some major decisions to make. I could either let this destroy me or I could see this as an opportunity to go on, grow, and become something positive. I had some goals in mind. I worked hard at physical therapy and there were challenges, but I was determined to walk again and get back my life."**
>
> - POSIE MANSFIELD

Grieving After Limb Loss

It is natural, after an amputation, to experience a wide range of emotions. Some common emotional reactions may include shock, feelings of loss and grief, and changes in your body image. Shock is a natural emotional reaction. No matter how prepared you may have been for the surgery, or even if it was desired, adjusting to the realization that the limb is gone and that everyday life has been altered can take some time and be a continuous process. Feelings of loss are also common. It is certainly acceptable to grieve over the loss of your limb and for how it effects your life. A change in body image is another emotion you may feel. First you may struggle with accepting it within yourself, and later you may wonder how others see you.

Losing all or part of a limb is a life-changing event that can cause grief and lower self-esteem. A part of you has been irreversibly lost, so you should give yourself time and permission to mourn that loss.

Grieving is different for everyone. Your past experiences, your age, the site and level of your limb loss, your ongoing individual circumstances, your support mechanisms, your coping history, and the cause of your limb loss are all factors for how you will cope. A loss is a loss regardless of how it occurred. Grieving may begin prior to surgery with anticipatory grief. Future grieving may be triggered by an event, such as a birthday or anniversary of the limb loss, by a memory, activity, or even by a sight or smell.

Remember that grieving is a normal and expected part of recovery. There is no right or wrong way to grieve as it is an individual process. It is normal for you to feel uncertain about the future. You may be asking:

- How is this going to affect my ability to do the things I used to do?
- Will my friends and family be able to support me through this?
- What are people going to think of me?
- When will I walk again?
- How will my health be affected?
- Will I be able to go back to work?
- Will I be able to manage in my home environment?
- How do I move forward after this?
- What will my future hold?

Five Stages of Grief

There are five classic stages of grief Individuals do not necessarily go through every stage, and not necessarily in the same order; rather, it can be much like riding a roller coaster, full of ups and downs. For example, someone with a traumatic limb loss may experience a longer phase of the denial stage, whereas someone who suffered from a long-term illness or disease may feel a sense of relief and not go through the denial stage. You may grieve and re-grieve over the course of your lifetime. The important thing is to recognize what stage you are in and understand what may help you to cope.

STAGES OF GRIEF

Denial and Isolation

Avoidance, Confusion, Fear, Numbness, Blame

1

Anger

Frustration, Anxiety, Irritation

2

Depression

Overwhelmed, Helpless, Lack of Energy

3

Bargaining

Struggling to Find Meaning, Reaching Out to Others, Desire to Tell Your Story

4

Acceptance and Hope

Finding Meaning, Exploring Options, Having a New Plan, Empowerment

5

The five stages are defined as:

- **Denial and Isolation:** This isn't happening to me...
- **Anger:** Why is this happening to me?
- **Bargaining:** I promise I'll be a better person if...
- **Depression:** I don't care anymore.
- **Acceptance and Hope:** I'm ready for whatever comes.

The truth is that we are all different. Our strength, endurance, circumstances, and ages are different. We heal both physically and emotionally at varying paces. The circumstances that led to your limb loss are unique to you. With so many different variables, recovery time after limb loss can be unpredictable. Everyone progresses through rehabilitation and recovery at their own pace.

The Road to Your Emotional Recovery

Response to amputation may depend upon your specific cause, type, and timing of amputation. Your age, personality, coping skills, and stage of life can also influence how you feel. Cultural, religious, and family beliefs may also be factors. Your support system and the response of friends, family, and significant others also will affect how you feel.

Even if you chose it, a loss is still a loss, regardless of how it occurred. The important thing to remember is that you are not alone on this journey. There are several avenues for support that are available for you along the way.

Counseling

Counseling can help you and your family sort through your reactions to your amputation. It can assist you in clarifying your feelings about limb loss and adjusting to life changes. Counseling can help you develop realistic expectations and goals for your future. There are several types of professionals you can seek for this support, including clinical social workers, professional counselors, clergy, or psychologists. Remember, sometimes it can take a bit of work to find the person most helpful to you. Do not feel discouraged if you feel the first person you meet with is not the right fit. This is a personal decision and may take some research on your part.

Support Groups

Joining an amputee support group is a great way to get peer support. Participating in a support group offers an opportunity to connect with a group of people living with limb loss. Being with people who understand what you are experiencing can be very empowering. A support group provides a safe forum for discussions about life as a person living with limb loss, a variety of education programs, and, on occasion, social events! Some groups may be just for you. Others may include family members. You can find information about support groups on the Amputee Coalition's website or by calling the National Limb Loss Resource Center®.

Online support can be extremely helpful for your emotional recovery. Online support groups allow you to share information, gain insight, and hear advice from others who are going through similar experiences. While participating in online support groups is great for making connections and helping you cope, support groups are not the same as group therapy sessions. The information you receive should not be considered medical advice. Always seek the counsel of a trained medical or healthcare professional for anything related to your medical, rehabilitation, and psychological needs.

Participating in support groups connected to or supported by recognized national organizations, like the Amputee Coalition, can help to increase your safety in person and online. Although messages to the Amputee Coalition's social media accounts and AC Connect (our online community forum) are moderated by Amputee Coalition staff, for information and resources, please contact the National Limb Loss Resource Center® online or by calling our toll-free phone line.

Certified Peer Visitors

Asking others for help can be difficult. If you do not know anyone who has a limb difference, limb loss can feel isolating. Accepting a visit from an Amputee Coalition Certified Peer Visitor can provide connection and encouragement. They will understand the journey that you are on now. You can contact the Amputee Coalition to arrange for a Certified Peer Visitor in your area to meet with you. A Certified Peer Visitor has gone through specialized training, and they often are someone with a similar type of limb loss as you. Visit the Amputee Coalition's website to learn more about the Certified Peer Visitor program.

PALS (Promoting Amputee Life Skills) Program

The PALS program is an individual online course that empowers those with limb loss by teaching coping skills, problem solving, and goal setting. You can learn more about the PALS program by visiting: **PalsAmputeeLifeSkills.org**

Spiritual and Religious Support

Spirituality and religion may help you understand major changes in your life by being attentive to mind, body, and spirit. Spiritual and religious perspectives and practices may provide a context in which anxieties about physical and mental functioning may be faced, felt, and understood. Patients who are spiritual may use their beliefs to cope with illnesses, pain, and life stresses.

PERSONAL STORY: LISA STRUBE

My name is Lisa and I had an above-knee amputation when I was 18 as a result of a traumatic accident. As a person with limb loss, I struggled with body issues and sharing with others that I had a disability. Connection and intimacy are the best things I have experienced as a person. However, getting to a place where I could open up and trust someone was a challenge.

I always had a bubbly personality and it was exhilarating dancing close to someone or touching someone's hand. But I forgot about that after my limb loss because of how much emotional turmoil I was in.

Eventually, I decided to date when I was ready.

I did get the "It's not you, it's me," line from a few people I dated. Of course, that was never easy to deal with. I wasted so much time being afraid of rejection, so I had to get over it.

Over time, I learned to value myself and I knew that there was someone out there who would accept me as I am. I got to a place where I wanted to meet someone and I knew that I had to be honest about my limb loss. There was much that I missed during those years I chose to remain alone. Then, one day, I met him and my life changed forever.

David and I met on a dating app and I knew he was special right away. When we hung out, he would ask if I wanted to remove my prosthesis so I could be more comfortable. He loved me with no makeup and messy hair. I could tell him things and he would remain nonjudgmental and kind. This man was special, and I trusted him.

He told me how much he loved my body and would gently touch my stump. I knew he really did love me and accepted me. Never had I been able to be completely myself around someone. Our connection was strong and we were able to have fun together. I must have done something right because David asked me to marry him a year after we started dating. All the bad dates and heartache were worth it to find this amazing man.

Is limb loss hard? Yes. Can you still live an incredible life? Absolutely. Are there people out there who will accept you? You betcha. Trusting someone is scary, and there are risks. But these risks can bring love into your life that can be better than you have imagined, and that is definitely worth it.

> **“ Over time, I learned to value myself and I knew that there was someone out there who would accept me as I am.**
>
> **I got to a place where I wanted to meet someone and I knew that I had to be honest about my limb loss. There was much that I missed during those years I chose to remain alone.”**
>
> - LISA STRUBE

Accepting Your New Body

One of the most difficult roadblocks to overcome on the journey to emotional recovery is acceptance of your new body. The key for many people is to shift focus from the lost limb to the whole person. Your amputation doesn't define you. Learn to be comfortable with who you are and continue to live your life to the fullest. There are resources, support mechanisms, and a whole community out there to help you. Remember, everyone's journey is different. Short-term goals can help you accomplish long-term goals. Think of each step as an event in itself. Soon you may find yourself further along than you thought.

In the hospital, or even once you're home, having your family and friends around may feel awkward. You may feel uncomfortable because your body has changed. You may be in pain. You may require assistance early in your recovery. Your family and friends may find it hard to strike a balance between being helpful and being bothersome. Choosing the right words in conversation can be challenging for everyone dealing with new and unfamiliar circumstances.

You can set the tone. Let your family and friends know how you feel about your limb loss and what you need from them. Do not assume they know how best to support you. Let them know you can still do things for yourself, but do not be afraid to ask for help. It is important to accept support from your family and friends while also establishing your independence.

Body Image and Self-Esteem

Limb loss and limb difference may result in significant body image issues and concerns. You may not want to look in the mirror, and you may worry how your body appears to others.

It's important to understand that you can overcome these individual perceptions to feel more comfortable with your body. Acceptance is important. The support and guidance of your healthcare team can improve your ability to adjust.

Lower-Limb Loss

You are probably familiar with being told to "stand tall" or "walk with your head held high" as a means of asserting your confidence. After being fit with a prosthesis, however, you initially may experience balance issues, your steps may be slower, you may be tired and have less energy, or you may be less sure of yourself. If you don't use a prosthesis, using other devices, such as a wheelchair or crutches, may create body image challenges. With time and practice, as your mobility improves, your confidence will improve.

Upper-Limb Loss

The hand is an intimate, multifaceted tool. It is responsible for precise actions, from threading a needle to lifting heavy materials. Our hands also play a major role in our social interactions. We greet people, express our emotions, provide comfort, and communicate with our hands. Since our hands play such a large role in physical and social lives, the loss of an upper-limb often presents psychological challenges. As you learn adaptive techniques, with or without a prosthesis, your confidence will improve.

Strategies for Achieving a Positive Body Image

Fortunately, there are many ways to improve your self-image and accept your new body.

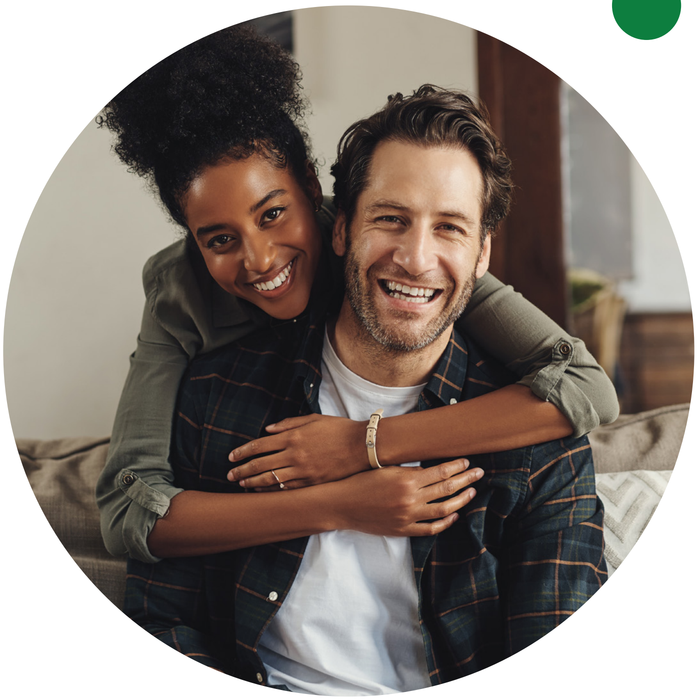
Finding meaning in your experience can help promote a positive body image. During the recovery process, people learn not to define themselves by their limb loss. You are still the same person you were before.

How you act toward yourself with friends and family helps guide how they interact with you.

Social interactions after limb loss can be challenging, especially for those who are shy. By sharing experiences and insights, you will begin to realize that you are not alone.

Redefining Relationships and Intimacy

The quality of our relationships is determined by how we respond to life. Having healthy physical relationships and activity after limb loss can be valuable for many. Few things make us feel more vulnerable than being naked in front of another person. Add limb loss to the equation and those feelings can be even more complicated. Your body has changed, and your responses to physical activity may have changed. You may be afraid that your partner will not accept or be comfortable with your residual limb. You may not see yourself as physically attractive or worry you may not be able to satisfy your partner.



Some people with limb loss and limb difference have expressed concern about keeping or finding someone to love and accept them. These concerns are normal. However, it is important to understand that you are still desirable.

Changes to your physical appearance may make it more difficult to engage in personal relationships. It is important to communicate honestly about your feelings and your fears. Talk to your partner about how your changed body looks, feels, and works. Things that aroused you before your limb loss may no longer provide the same sensations. You may even experience pain in your residual limb during physical intimacy. Take the time to rediscover and explore yourself with and without your partner.

If you are in a long-term partnership or marriage, you may close yourself off from your partner. Initially, this is understandable. It may be difficult to be intimate immediately after amputation due to discomfort and pain. This may subside with time. Remember that your loved one is also adjusting to your limb loss and needs to be able to express their feelings as well. While it may be awkward and uncomfortable at first, the process of rediscovery can be exciting for both of you.

Establishing new relationships can be daunting. Relationships are powerful factors in our emotional and physical well-being. Love and intimacy make us feel whole. Losing a limb might alter how you function, but it does not eliminate your desire for love, affection, and closeness. Open communication can help prevent hurt feelings and misunderstandings and is likely to strengthen and increase meaningful relationships.

Talking through the mechanics of physical activity with your partner also may be helpful. The discussion might be uncomfortable at first, yet it may be exactly what you both need. Instead of focusing on performance, allow yourself to experience the moment for what it is. If you experience challenges, you may want to consult with a medical professional to support your physical or emotional needs. You may need to get ideas and advice from a rehabilitation professional about positions to adapt for limitations in mobility. If you feel comfortable talking with other individuals with limb loss, they also may be able to provide useful intimacy tips.

Some common questions about intimacy include, “Should I leave my prosthesis on or take it off?” “When is it best to let someone you’re dating know that you’re living with limb loss?” The truth is these types of questions are normal and different for everyone.

If you find it difficult to deal with body image or insecurities, cognitive behavioral therapy might be a good option. A therapist can help you reassess how you think about problems and stop negative judgments in favor of more constructive ways of looking at your body. Self-esteem and personal independence foster confidence in all aspects of life, including relationships. Forming an unhealthy emotional dependence on your partner can have a negative impact on your relationship.

Recovering physical function is just as important as any other aspect of functional rehabilitation after limb loss. For a person who loses one or more limbs as an adult, regaining a sense of self confidence may be a valuable component to successful rehabilitation and healthy reconceptualization of body image.

If you need help locating resources, contact the National Limb Loss Resource Center®.

Special Considerations for the Older Adult

Although limb loss in older adults can be lifesaving, mental and emotional healing may take considerable time and requires strong support of family, caregivers, and guidance from their healthcare team.

BYOA:

Your Emotional Journey

Your emotional journey after limb loss is ultimately up to you. If needed, seek professional counseling and guidance. Your attitude and outward communication will guide how others interact with you.

LIVING WELL WITH LIMB LOSS AND LIMB DIFFERENCE

- Transportation
- Driving
- Vehicle Modifications
- Living in Your Home
- Going Back to Work or Starting a New Career
- Going to School – First Time or Returning
- Events and Activities
- Advocacy
- Sports and Recreation
- Travel

CHAPTER 6

Transportation

For new amputees, getting back to driving may take some time. There are many different kinds of transportation services available. Transit agencies provide curb-to-curb paratransit service to individuals unable to use regular public transportation, as mandated by the Americans with Disabilities Act. This type of transportation service is typically wheelchair-accessible vans or taxis, and the services can be run by private, nonprofit, or public organizations. The transportation costs are usually free or low cost. To find out about paratransit in your community, contact the Amputee Coalition, your local Area Agency on Aging, or your local Center for Independent Living.

Driving

Driving an automobile provides a great deal of independence and personal freedom. Having limb difference or limb loss of one or more extremity does not mean that you have to give up this independence. Driving is still possible!

Here are some tips you might find useful when getting back to driving:

- Adjust the driver's seat all the way back, enter the car, then adjust the seat for driving. This allows plenty of leg room for those with lower-extremity limb loss to enter and exit the vehicle. Some models with power seats allow this to happen automatically. Likewise, the additional space can allow for greater movement for those with upper-limb loss to get settled in.
- Adjust the steering wheel down so that your upper legs can reach it. Having the steering wheel close means your legs can help hold the wheel steady or provide needed friction in steering through a turn.
- When parking on an incline, park facing downhill so you will not have to fight the weight of the door while trying to exit the vehicle.
- When parking where there are multiple places to choose from, consider parking in such a way that others do not have room to park next to the driver's side door. When parking in a lot where spaces are tight, hug the passenger side tight to the line to allow more room to enter and exit the driver's side door. Watch out for concrete poles like those found around gas pumps. These make for trouble (and unexpected repair expenses) when opening car doors.

Vehicle Modification

Depending on your type of limb loss and the type of prosthesis you use, you may prefer to purchase a wheelchair-accessible vehicle or convert an existing vehicle to add

accessible features and controls in order to drive again. Many people with limb loss and limb difference continue to drive their vehicles without making any changes at all.

There are a number of modifications that can be made to cars, vans, and other vehicles to make them accessible, including:

- Mechanical hand controls
- A left-foot accelerator
- Reduced-effort brakes and steering systems
- Power transfer seats
- Lifts and ramps

Those with a right lower-leg limb loss may require a special accelerator, while those with an upper-limb amputation may be best suited by a steering ring or ball. Those with a bilateral lower-extremity limb loss should be considered for hand controls, and foot controls even exist for those with bilateral upper-limb amputation. Vehicles now have readily available options for adaptive cruise control (also called autonomous cruise, intelligent cruise, or radar controlled), blind spot detection, and lane departure warning, all of which make driving safer as well as accessible for those with disabilities.

If you are uncomfortable adapting to driving after limb loss, consider working with an occupational therapist or a certified driver rehabilitation specialist. They will conduct a thorough evaluation of your needs, identify applicable adaptive equipment, and provide you with information on purchasing an accessible vehicle. The evaluation process includes a clinical pre-driving assessment and on-the-road training. You will need a prescription from your physician to begin the process.

All states require a valid learner's permit or driver's license to receive on-the-road training. You cannot be denied the opportunity to apply for a permit or license because you have a disability. However, there may be limitations based on your use of adaptive devices or other medical conditions. Check with your state's Department of Motor Vehicles to determine your options.

If finances are a concern, there are resources that can provide financial assistance for wheelchair-accessible vehicles and adaptive equipment. Check with the following organizations to see if they provide financial help or grants for accessible vehicles or vehicle modifications:

- State vocational rehabilitation department
- County social and human services programs
- Charitable organizations and churches
- Veterans Administration (for U.S. military veterans with limb loss)

In certain instances, Medicare will pay for adaptive equipment. If your limb loss is work related, check with your insurance company about its workman's compensation policy. A number of vehicle manufacturers offer rebates for individuals with disabilities who require vehicle modification. Having a prescription from your physician for an accessible vehicle or adaptive equipment may exempt your purchase from sales tax. There are also secondary markets for used accessible vehicles just like those for standard vehicles.

Living in Your Home

Your home is the place where you are meant to feel the most comfortable. Before you are discharged from the hospital following amputation surgery, your home should be made as safe and accessible as possible. With limb loss or limb difference, you may need to make some changes or modifications to your home, simple or complex, to make it easier and safer for you to get around and participate in activities of daily living.

An individual with single lower-limb loss may need fewer home modifications than an individual with bilateral lower-limb loss, or an individual with bilateral upper- limb loss. Seemingly simple tasks before your amputation may now take more energy and feel difficult or nearly impossible. Home modifications can make it easier and safer for you to get around your home. If you have questions or concerns about what modifications might be helpful for your lifestyle and activities of daily living, feel free to ask your physical or occupational therapist. They can recommend home modifications that meet your specific needs.

To avoid costly home renovations, consider temporary modifications at first. This will allow you to try those modifications to see if they work for you and your level of limb loss. Once you determine what works for you, you can develop a priority list and proceed with needed permanent modifications. Make sure to follow sound advice when considering a contractor and ask what types of adaptive modifications they have done for other clients.

The **Home Assessment Checklist** in the Appendix can help you prepare. Depending on the type and level of limb loss, as well as overall health status, all of these recommendations may not be appropriate or you may need additional modifications. When considering any modification, think into the future about how you might need a similar modification as you age, then address those concerns from the beginning. For example, say you need to replace your current bathtub-shower combination. For a lower-limb amputee, it may be prudent to consider changing to a roll-in shower with grab bar supports than to replace the fiberglass tub insert. While you may be able to use the tub-shower combination now, it may get much more difficult in the future.

It's important that your home doesn't prevent you from living life on your own terms and as independently as possible. Making a truly accessible home has become easier and less costly in recent times thanks to smarthome technology. These tools can change a person's life by automating thermostats, lights, smoke alarms, door locks, doorbells, robotic vacuum cleaners, garage doors, curtains and blinds, carbon monoxide detectors, motion detectors, security cameras, and ovens.

For more information about making your home accessible, or resources to help fund home modifications, turn to the **Home Modifications/Housing section** in the Appendix at the end of this guide or contact the Amputee Coalition and the National Limb Loss Resource Center®.

Kitchen

- Move items to lower cabinets and shelves for easy access
- Use your kitchen table to prep food from a seated position
- Use a grabber tool to reach lightweight, unbreakable items from a seated position

Entryways and Floors

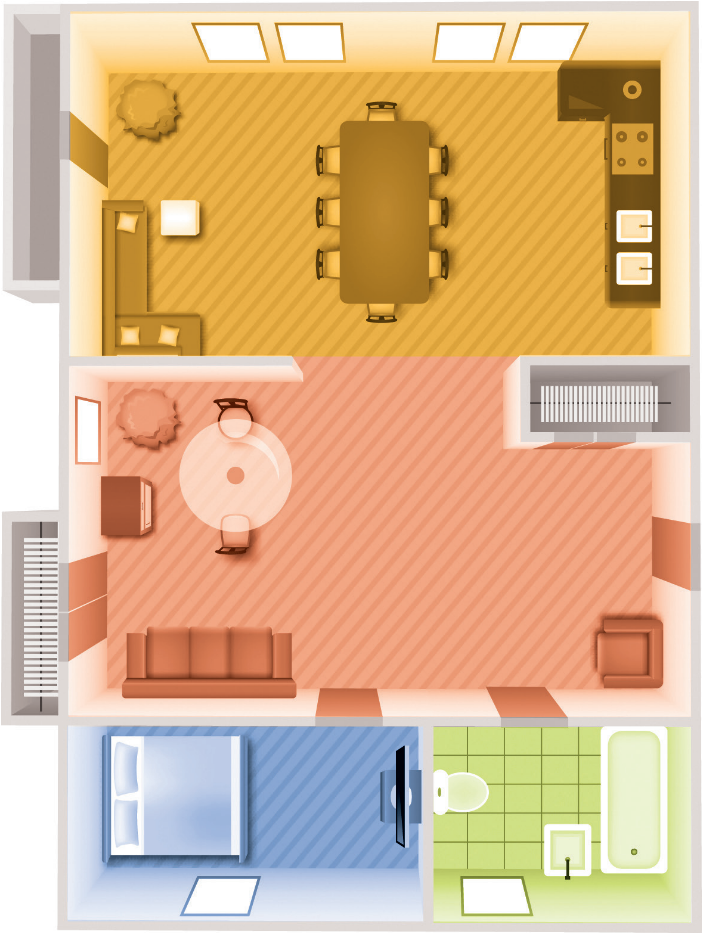
- Install temporary ramps and hand rails to make it easier to get into and out of your home
- Install offset hinges to widen doorways for wheelchair access
- Remove interior doors temporarily if needed for wheelchair access
- Replace doorknobs with lever handles or doorknob extenders
- Install motion-sensor lighting outside and inside the home
- Remove area rugs and floor clutter to minimize trip hazards

Bedroom

- Install temporary bed rails or grab bars to help you get in and out of bed
- Keep wheelchair and crutches within reach of your bed
- If your bedroom is located on the second floor, consider temporarily relocating it to the first floor for easier access

Bathroom

- Purchase a bath chair or shower bench
- Install grab bars in the shower and toilet areas.
- Removable grab bars can be purchased for temporary installations
- Install a night light in the bathroom
- Use pump soap dispensers or install motion-activated soap dispensers
- Place non-slip mats on the floor



Going Back to Work, School, or Starting a New Career

Part of your journey on the road to recovery may include returning to work or school. Several studies have shown the majority of people with limb loss can and do return to work or school, regardless of their amputation level or number of limbs lost. You may need to make some adjustments in this area in order to succeed, and your work environment is obligated under the Americans with Disabilities Act (ADA) to provide reasonable accommodations to facilitate this. ADA employment requirements apply to employers with 15 or more employees.

Getting back to work or school should be a goal. You may have to make some adaptations, but for many people, making minor accommodations are well worth it. If you have a lower-limb amputation, the main difference may be the amount of standing and walking that you can do compared to before. If you have an upper-limb amputation, there may be limitations on some manual activities, but many obstacles can be overcome, especially in today's tech-driven world.

Work or community service also can be a positive experience. These activities can provide you with a sense of pride in knowing you're contributing to your personal and professional communities. Once you are documented as a person with a disability, the ADA requires employers to make reasonable accommodations so that you have an equal opportunity to benefit from the full range of employment opportunities available to others. Use of a prosthesis does not make you ineligible for protection under the ADA.

While employers cannot discriminate against you because of your disability, they do have some flexibility in providing reasonable accommodations. For example:

- Employers can choose among effective accommodation options and do not always have to provide the requested accommodation.
- Employers do not have to provide accommodations that pose an undue hardship.
- Employers do not have to provide personal use items needed to accomplish daily activities on and off the job.
- Employers do not have to make an accommodation for an individual who is not otherwise qualified for a position.
- Employers do not have to remove essential functions, create new jobs, or lower production standards as accommodations.

If your amputation or other serious medical complications prevent you from working, you may qualify for Social Security disability benefits. If approved, you will receive cash payments and, in some cases, medical coverage, which can make a big difference if you are struggling to pay your bills. The Amputee Coalition has published a resource guide, Insurance Coverage and Reimbursement, which provides more information about government programs, such as the Social Security Disability Insurance (SSDI) program. You can request a copy of the guide by visiting the Amputee Coalition's website.

Job training, employment organizations, and state vocational rehabilitation programs are available to help people enter the workforce or shift careers. Contact your state vocational rehabilitation department for more information.

Going to School – First Time or Returning

Whether you are a child in elementary school or an adult in college or graduate school, having a limb difference should not keep you out of the classroom. In fact, your lived experience and story can often make for a strong essay in the application process. Everyone has different goals, and different jobs require different levels of education. There are resources available to assist you with success in education, including the Americans with Disabilities Act (ADA) as it relates to schools and Individualized Education Plans (IEP). There are also numerous scholarship opportunities for individuals living with limb loss or limb difference. The Amputee Coalition even has some limited education scholarships available each year.

Americans with Disabilities Act (ADA) in Schools

The Americans with Disabilities Act prohibits discrimination and poor treatment due to a disability (physical or mental) in employment, state or local government, public accommodations, transportation, and telecommunications. While education is not directly mentioned in ADA, attending school is part of public accommodations, transportation, and telecommunications. That includes needed modifications and adaptations for schools.

If you are attending college, you can request assistance with transportation to buildings that are not close to parking lots or are difficult for you to access due to mobility concerns. The ADA also requires buildings to include access ramps, elevators, and railings in stairways.

Individualized Education Plans (IEP)

An Individualized Education Plan can be developed so that children can attend public schools, including charter schools. IEPs are available from Kindergarten to 12th grade and allow for modifications or assistance with completing education requirements. For example, if a student needs modified requirements in physical education classes, an IEP can be written to provide the school with the student's annual goals, and ways of monitoring progress. If a student needs environmental accommodations to allow for use of assistive devices (crutches, walker, cane, wheelchair, etc.) or a customized desk or chair, an IEP helps to provide guidance to the school. This will ensure that the student can succeed. While IEPs are not available to students beyond 12th grade, colleges are required to provide accommodations and cannot discriminate against accepted students.

Community and Networking

The support of those who have experienced limb loss or limb difference can play a vital role in helping you on your road to recovery and getting back to living your life to its fullest potential. The Amputee Coalition offers support groups, one-on-one conversations with certified peer visitors, and a Facebook page to help provide this support. Visit the Amputee Coalition's website to learn more about these resources, and you can find the Amputee Coalition on many social media platforms.

BYOA:

Advocating for Your Education

The most important factor for success is advocating for yourself or your child. It is important for you to communicate your needs with the school and help them understand what they can do to help you succeed.

Finding Online Support

Online support and connections can be extremely helpful during your new journey. Online groups allow you to share information with and gain insight and advice from others who are going through similar experiences. Participating in an online group can help you feel less lonely, isolated, or judged, and it can provide a sense of empowerment and control over your limb loss. This can help ease stress, anxiety, and depression. Be aware of your feelings while using online groups and communications. If, at any point the group, and/

or any individual make you have any negative feelings, like inadequacy, disappointment in self, jealousy, depression, stress, or anxiety, then discontinue communications with the group and/or individual that makes you feel this way.

While participation in online groups is great for making connections and helping you cope, online groups are not the same as professional therapy sessions. Nor should any information received in an online group be thought of as professional medical advice. Always consult your own healthcare team before carrying out any advice related to your medical, rehabilitation, and psychological needs.

Be Aware Online

As always, we encourage you to use caution when sharing personal information online. Devotees (individuals who express a strong physical interest in amputees and people with limb difference) can be active on social media and websites that are designed for the limb loss community. To discourage unwanted attention, be mindful when posting information and photos online and interacting with people you may not know.

If, at any time, you think you are communicating with an online predator, stop the communications immediately and block them.

You should also be cautious of anyone who attempts to sell a product or service to you online without your consent. Never give personal or identifying information to someone online.

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Certified Peer Visitor Program

The Amputee Coalition's Certified Peer Visitor Program makes sure that no one goes through their limb loss or limb difference journey alone. Launched in 1993, this program has trained thousands of peer amputees, family members, and caregivers to support and encourage others on this journey. Peer visitors believe passionately that support comes in many forms and can make an incredible difference in recovery and rehabilitation.

Please visit the Amputee Coalition's website to learn more about the Certified Peer Visitor Program, including How to Become a Certified Peer Visitor or to Request a Peer Visit.

Events and Activities

The Amputee Coalition hosts a number of events and activities throughout the year designed to provide networking, educational and recreation opportunities to individuals with limb loss or limb difference and their families, friends, and caregivers.

Amputee Coalition National Conference

The Amputee Coalition National Conference is the premier event for the limb loss and limb difference community. It offers several days of networking, education, and adaptive sports and recreation clinics for people with limb loss and limb difference and their families and friends. Education sessions are led by leading experts on limb loss and community members. Clinics offered at the conference are designed to give you the skills to improve your functional ability. The National Conference also hosts an exhibit hall featuring leading manufacturers of prosthetic components and assistive technology, as well as other organizations that serve the limb loss community.

Limb Loss Education Days

The Amputee Coalition Community Days (formerly known as Limb Loss Education Days or LLED) are regional events held throughout the year that bring together people with limb loss and limb difference, their families, and caregivers to connect them with important community resources. LLEDs provide opportunities for you to learn about current community issues and information, try new activities, meet other local amputees, explore local organizations and talk with exhibiting healthcare companies.

Paddy Rossbach Youth Camp

Each year, the Amputee Coalition hosts the Paddy Rossbach Youth Camp. The Youth Camp provides fun and exciting sports, recreation, and social activities for campers with limb loss or limb difference who are between the ages of 10 and 17. The camp experience includes a variety of activities, where every child can set their own personal level of challenge, including:

- Ropes Course
- Fishing
- Canoeing
- Archery
- Team Field Sports
- Sitting Volleyball
- Rock Climbing
- Swimming
- Basketball
- Creative Arts
- Educational Programs

Older campers and trained peer mentors facilitate peer discussion groups to help younger campers learn that they are not alone. All volunteer counselors are also adults living with limb loss or limb difference.
Children often express that camp is the opportunity for them to be themselves amongst their peers without the fear of feeling different.

The Amputee Coalition has also developed leadership training for older campers to prepare them to be camp counselors and leaders in their schools and communities.

Advocacy

Educating lawmakers and insurers about the needs of the limb loss and limb difference community is a crucial part of the Amputee Coalition's mission.

We amplify your voice on issues like improving insurance access and coverage for people with limb loss and limb difference, investing in research for improving care and assistive technology, protecting the guarantees of Americans with Disabilities Act, and improving Medicare and Medicaid coverage.

We work closely with Congress, state lawmakers, and community advocates across the country. We also have long-standing partnerships with the Administration for Community Living, the National Institutes of Health, the Department of Veterans Affairs, the Department of Defense, and other federal agencies.

While we work on a number of different issues, some of our advocacy priorities include investments in community support and research as well as insurance coverage and access.

Investments in Community Support and Research

The Amputee Coalition's work is made possible by a competitive cooperative agreement from the Administration for Community Living (ACL), part of the U.S. Department of Health and Human Services. That funding helps us to provide unique services, such as the National Limb Loss Resource Center®, resources for the community, such as our First Step and InMotion publications, and support for members, such as the Certified Peer Visitor program. We are committed to continuing our close collaboration with the ACL and policymakers so that we can better serve you and achieve new goals.

We also advocate for lawmakers to invest in research. We need more research to understand and measure what it means to live with limb loss, learn what causes limb difference at birth, and develop the next generation of innovative prosthetic devices and other interventions. We also need research to prevent limb loss, from improving safety regulations to curing conditions like diabetes and cardiovascular disease, the leading causes of limb loss.

Insurance Coverage and Access

The Amputee Coalition is working to ensure people living with limb loss and limb difference have access to the care they need to live the life they want to live. That means treating limb loss care, rehabilitation, and prosthetic devices like any other benefit within an individual's insurance policy, including eliminating arbitrary caps and restrictions that may exist on prosthetic device coverage. We believe medical decisions must be made by you and your healthcare team, not by insurance bureaucrats. So far, we have successfully passed laws in more than 20 states to improve coverage, and we're working on the rest. We're also working with Congress to pass a comprehensive federal law. You can learn about your state's status by contacting the National Limb Loss Resource Center®. In addition to coverage in private insurance plans, we also work to improve Medicare and Medicaid coverage and access. Through both regulatory and legislative engagement, the Amputee Coalition is on the front lines fighting to ensure equal insurance access.

Advocacy Forum

Grassroots advocacy is when ordinary people come together to organize their community and educate their leaders about an issue that matters to them. Thanks to your personal stories and grassroots advocacy over the years, Congress has made major investments in the National Limb Loss Resource Center®.

That increased funding continues to help people with limb loss and limb difference, caregivers, and families across the country.

Here is how you can help.

First, reflect on your own story. What has the Amputee Coalition and its community meant to you? If you could only tell your Member of Congress one thing you have learned about living with limb loss or limb difference, what would be most important?

Next, do your homework. Stories are memorable, but they're convincing when they are supported by data. Do you know how many people live with limb loss and limb difference in your state or district? Do you know if your Senator or Representative has a personal connection to the limb loss community? Do you know what their political and policy priorities are so you speak about your experiences in that context?

Finally, get involved. Start small. Take a few minutes to call your Senators and Representative and talk to their staff about why issues like insurance coverage for prosthetic devices matter so much to you. Write them an email or letter. Congressional offices pay close attention to what their constituents say. (And don't forget about your state and local governments, too!) To get you started, the Amputee Coalition has helpful scripts and email templates on their website for free.

The Amputee Coalition believes in the power of advocacy, so consider attending one of the many trainings held across the country every year. Likewise, please consider joining the Amputee Coalition in Washington, D.C., for its Advocacy Forum, when you can bring some good, old-fashioned grassroots advocacy to your Senators and Representatives on Capitol Hill to make a difference for the whole community.

Sports and Recreation

Remaining physically active is a priority for individuals with limb loss. Participating in sports and recreation can improve your health and increase your flexibility, stamina, coordination, and mobility. Physical activity can also increase self-esteem and help improve your body image. Although it may not seem possible at first, you can achieve a healthy, physically active lifestyle with or without a prosthesis.

Physical activity can include everything from walking, running, or rolling to more organized sport activities like sled hockey, amputee soccer, and others. In addition to the multiple health benefits, participating in sports or recreational activities provides a great opportunity for you to meet other people with limb loss, socialize with individuals who share similar activity interests, and help you become more comfortable moving around in your environment with or without a prosthesis.

Whether you prefer individual activities or to flex your competitive muscle, there is an activity suitable for any level of limb loss or limb difference.

Yoga

Yoga is a mind, body, and spirit wellness system that can benefit anyone at any age with any ability. Often when we think of yoga, we imagine a person contorted into an impossible pose that almost no one can do. In reality, yoga is a combination of deep breathing, intentional movements, meditation, relaxation, and life-affirming daily practices.

Cross-Country Skiing

Cross-country skiing is a joy and a workout. There are cross-country skiing adaptations for those with upper- and lower-limb difference.

Downhill Skiing and Snowboarding

Skiing down wintery slopes can be enjoyed by people of all different types of ability, with and without prosthetic devices. Those with upper-limb loss can make use of a single pole, or sport prosthetic hands (terminal devices) designed specifically for skiing or snowboarding. Those with a single-leg amputation can use two skis or a snowboard with their prosthesis, if it is designed for sport, or remove their prosthesis and use just the one ski while holding outrigger crutches that have ski tips.

Cycling and Hand Cycling

Anyone can enjoy zipping around their neighborhood or a track with a variety of cycles and modifications. In some cases, a standard bicycle can be used with modifications for a single arm or leg amputation.

Kayaking

Kayaking can be enjoyed competitively or leisurely by those with upper- or lower-limb difference. Standard kayaking requires three points of contact:

- Your back tight against the seat
- Feet touching foot pedals with a slight bend at the knees
- Bent knees in contact with the side of the boat

Rock Climbing

Indoor and outdoor rock climbing can be performed by people with all different levels of ability and limb difference. For those who only have limb loss in a single limb, you may be able to climb using your other three!

Running

Those with lower-limb difference who want to run at a high level can use specialized prosthetic knees and/or running blades.

> **There are a number of national, regional, and local organizations that offer adaptive sports and recreation experiences for individuals with limb loss.**

Seated Volleyball

Seated volleyball is one of the most accessible sports for those with lower-limb amputation as it requires no specialized equipment. It is also a great sport to play with able-bodied athletes as the rules ensure a level playing field.

Sled Hockey (also called Para Ice Hockey)

Sled Hockey (now referred to as Para Ice Hockey by the International Paralympic Committee) is a great option for those with lower-limb difference who enjoy a high speed, high-contact sport.

Para ice hockey is a modified version of ice hockey where players sit on a specialized sled with two skate blades underneath. Rather than one full-length hockey stick, players have two smaller sticks – one end has metal “picks” to be used for propulsion and the other end has a blade used for passing, stickhandling, and shooting. Otherwise, the rules are

Swimming

For some people living with limb loss and limb difference, getting in the water is one of the most important parts of their rehabilitation and recovery. A warm pool can offer soothing relief from aches and pains as well as an increased sense of balance. It can offer a chance to exercise freely without the burden of prosthetic limbs, and it can bring people together for meaningful social interaction. Regaining the sense of movement can be a defining moment in the recovery process. Be sure to obtain medical clearance from your doctor before getting into the water.

Most people choose to remove their prosthetic device before going for a swim. A prosthesis may allow you to have fun waterskiing, jump in the pool with your kids, or balance out the power of your swim stroke, but there are a few things to consider. If using a prothesis for water activities is a priority, you need to communicate that with your prosthetist.

Tennis

Tennis is a popular adaptive sport. Specialized tennis rackets come in different shapes and sizes to accommodate different types of limb difference. There also are wheelchair tennis leagues in which players use sports chairs for faster turning and movement.

Wheelchair Basketball

To play in many wheelchair basketball leagues you are required to have a lower extremity disability that prevents you from playing standing basketball. You do not, however, have to use a wheelchair for everyday use to qualify!

There are a number of national, regional, and local organizations that offer adaptive sports and recreation experiences for individuals with limb loss. These opportunities are available for just about every sport, activity, level of expertise and budget. Many organizations offer recreational opportunities free of charge to participants.

Ask your prosthetist or therapist about adaptive recreation opportunities in your area. Limb loss does not mean the end of an active life. Advances in prosthetic technologies and rehabilitation care are enabling more people in the limb loss and limb difference community to return to the activities they enjoyed before their amputation, discover new activities, and thrive in their lives after limb loss. For more information, turn to the Resources section in the back of this guide.

Travel

Whether you would like to visit friends or relatives, plan a family vacation, or go to an out-of-state event for work, airline travel will likely be in your future. It may take some extra planning and time, but airline travel is possible after limb loss.

Before You Book Your Flight

To get ready for your trip, speak with your airline representative or travel agent regarding handicapped accessible parking at the airport and the type of restrooms on the airplane.

Ask how you'll be boarding the airplane at each of the airports involved in your trip. If stairs are an issue, you may need another type of airplane or alternative route to ensure you have jet bridges both into the plane from the airport and when you disembark.

Before You Book Your Hotel

If traveling in the United States, ask for a room compliant with the Americans with Disabilities Act. When traveling outside of the U.S., however, accessibility is not standardized in the hotel industry and can easily be interpreted in different ways by hotel employees. Rather than look for wheelchair friendly hotels online, have your criteria and needs ready and deal with the hotel directly. Often, hotel websites will show that they have accessible rooms, but their definitions may differ widely and they may not be designed to meet your needs. You should ask about:

Common Areas

- Designated handicapped accessible parking with a priority location in the parking lot?
- Step-free access (level or ramped) and/or elevator access to main entrance?
- Automated door opening?
- Ground level/lobby level accessible restroom?
- Elevator to above-ground accessible accommodation?
- Level or ramped access to public areas?

Rooms

- Wider entry and bathroom doorways – external 31.5 inches, internal 29.5 inches. Easy to open?
- Mid-height light switches and power outlets?
- Lever-type door handles?
- Maneuvering space on each side of the bed, about 35 inches?
- Roll-in shower?
- Wheeled shower chair and/or wall-mounted shower seat?
- Grab bars in bathroom?
- Raised toilet?
- Lower hanging space in closet?

Neighborhood

- Proximity to markets, restaurants?
- Proximity to health services?

Tips

- Call the hotel directly.
- Keep notes: names, dates, times, topics, what's agreed and confirmation numbers. Take these notes and print outs with you on your trip.
- Ask to talk to someone who is familiar with ADA-compliant rooms because they have been in them.
- Ask questions that will elicit information beyond a yes or a no, such as "Tell me about..."
- Check that you have a credit card guarantee for an accessible room and a confirmation number, not just a request for an accessible room if available at the time of check in.
- Reconfirm your reservation for a guaranteed accessible room a couple of days ahead.
- When you arrive, check out the room before you check in.
- Again, take your notes and print outs with you on your trip.
- In the unlikely event that the hotel does not have the accessible room available for you when you arrive, the hotel will need to find you an accessible room, even in another hotel. "Where will you put us up for the night?"
- In the unlikely event that the complimentary hotel shuttle may not be accessible, the hotel will need to accommodate the service in some other way. "How will you provide alternate shuttle service for us?"
- Be cool, be persistent, use a sense of humor, and your trip will be much more a pleasure than a nightmare.

Packing

- Pack light.
- Ensure you have any tools you need for any assistive devices such as travel crutches for nighttime use or if your prosthetic leg breaks down.
- Consider travel gadgets such as a suction-cup grab bar, a spill-proof travel mug, fanny pack, and fingerless bicycle gloves to protect hands if on crutches or in a wheelchair.
- Make sure you carry your medications and back-up prescriptions with you onto the plane, along with doctors' names, addresses, fax numbers for faxing prescriptions, phone numbers, medical diagnosis, names and dosages of medications you're taking and any allergies you have.
- Photocopy passports, airline tickets, credit cards, any important papers.

Getting Through the Airport

Many airports offer wheelchair assistance once you arrive at the airport and will transport you to your gate, as well as have wheelchair assistance waiting for you at your arrival gate. Besides the added benefit of saving precious time and energy – and having a guide to help you find your way if you're unfamiliar with your airport – the Transportation Security Administration (TSA) often will send wheelchair or disabled travelers through a special entrance that will send you to the front of the line for security checks.

Going Through Security Screening

The Amputee Coalition works with TSA's Disability and Multicultural Coalition to assure that security screening for people with limb loss and limb difference is conducted in a reasonable and appropriate fashion to maintain security as well as dignity and respect. There are several guidelines and restrictions that apply to all passengers, but if you have limb loss or limb difference, there may be additional things to consider:

Give yourself extra time to get your ticket, check your baggage, go through security, and get to your gate. TSA and airlines generally recommend arriving at the airport two hours before your scheduled flight, but it might be a good idea to give yourself an extra hour to account for potentially long lines or additional screening time.

- If you are wearing a prosthesis, cast, or support brace, notify the TSA agent about your device before the screening process begins. Communicate your ability level, as well as any assistance you might need, at this time.
- Passengers with prostheses or support appliances can be screened by advanced imaging technology, or a pat-down. If the standard lane does not have advanced imaging technology, if you cannot hold a proper stance for advanced imaging technology screening, or if you are eligible for expedited screening, you may be screened by a walk-through metal detector.

- You will not be required to remove your prosthesis, cast, sling or support appliance; however, these devices are subject to additional screening, including visual inspection. Screening involving a sensitive area may be conducted in private with a companion or other individual of your choice.
- The prosthesis or support appliance is subject to additional screening, which may include screening of the device and/or hands for explosives and screening by a hand-held metal detector on non-metallic devices. If your support brace alarms for explosive residue, you may

need to remove it for x-ray screening.

- You may voluntarily remove your prosthesis, cast, support brace, sling, or support appliance prior to screening and submit it for X-ray screening. You may also request a private screening at any time.
- Security offices will likely need to see and touch your prosthetic device, cast, or support brace prior to your screening.
- Security officers cannot require you to remove your prosthetic device, cast, or support brace.
- You may have a companion, assistant, or family member accompany and assist you into the private screening area (once they have been screened) and remain throughout the screening process.
- TSA will make every effort to have two security officers of the same gender as the passenger being screened present during the private screening. At any time during the screening process you can request a disposable paper drape for privacy.
- If you are too weak or unstable on your feet to stand for a hand-held metal inspection because of your prosthetic device, cast, or support brace, you may request to sit down after you have passed the walkthrough metal detector. The explosive trace sampling process may require you to lift or raise some of your clothing in order to obtain the explosive trace sample. (Sampling areas can be accessed by you lifting your pant leg or shirt sleeve or by raising your skirt to knee-level.) The security officer should offer you a private screening if clothing will need to be lifted or raised to obtain the explosive trace sample. You will not be required to remove any clothing during the process or remove or display the belt that holds your prosthetic device to your body. Once you are at your gate, let airline boarding personnel know that you may need extra time to board the plane. Sit near the door at the gate so you're called first. TSA has a help line, TSA Cares, to provide guidance to travelers with medical conditions and mobility impairments about what to expect when traveling with a disability (855.787.2227). If you are preparing to travel, you should call at least 72 hours in advance. You will have the opportunity to speak with a representative about any questions or concerns you have. For the latest information traveling with a prosthesis, check the TSA website at **TSA.gov.**

You may also want to contact your airline before you travel to request support navigating the airport, or to find out about how to handle baggage. Many airlines allow for free checked luggage if you check a bag containing durable medical equipment, including a prosthetic device. Keep in mind that bags often get jostled. You can find out more about your options by contacting the airline you're flying before your travel.

Flying can be a challenging experience – especially if it's your first time traveling since your amputation. For additional travel resources to help you prepare for your travel experience, visit the Amputee Coalition's website.

BYOA:

Tips and Tricks for Daily Life

There are many tips and tricks for managing daily life with a limb loss. Many such tips can be found on YouTube videos. Search for a video about the specific question you have. Always remember to check with your healthcare team before taking any medical advice from others.

Special Considerations for the Older Adult

Older adults with limb loss often will need encouragement to continue participation in regular exercise and physical activity once traditional rehabilitation is complete. Providing the patient with community resources, such as those from the Amputee Coalition or a home program with physical activity guidelines – for endurance training, flexibility, strengthening, balance, and walking – will assist the older adult in healthy aging. 'Silver sneakers®' is a free fitness program for older adults and is offered in many community senior centers. Although the exercise programs are not specific for limb loss, being in groups with other older adults can be motivating.

CAREGIVER'S JOURNEY

- Becoming a Caregiver
- First Steps of Caregiving
- Types of Caregiving
- Adapting to New Roles
- Caregiver Burnout
- How to Find Support

CHAPTER 7

This section discusses the caregiver's journey. It provides resources and advice for caregivers, and it may be valuable for those living with limb loss to understand their caregiver's experience and journey.

PERSONAL STORY: JEFF LEWIS

When I coached wrestling and track, I told my athletes, "Whether you think you can or think you can't, you are right." I always say the same thing to new amputees. When I joined my first support group during my amputee journey, a BK (below-knee) amputee shared his story. Ted was an avid outdoorsman, but after becoming an amputee he was told about his limitations. For example, he was warned that if his prosthetic device failed, he could be stranded in the wilderness. In spite of the warnings, Ted hiked the Grand Canyon from rim to rim, an extremely difficult trek for even the most experienced hiker. Just as warned, Ted faced malfunctions and roadblocks but succeeded.

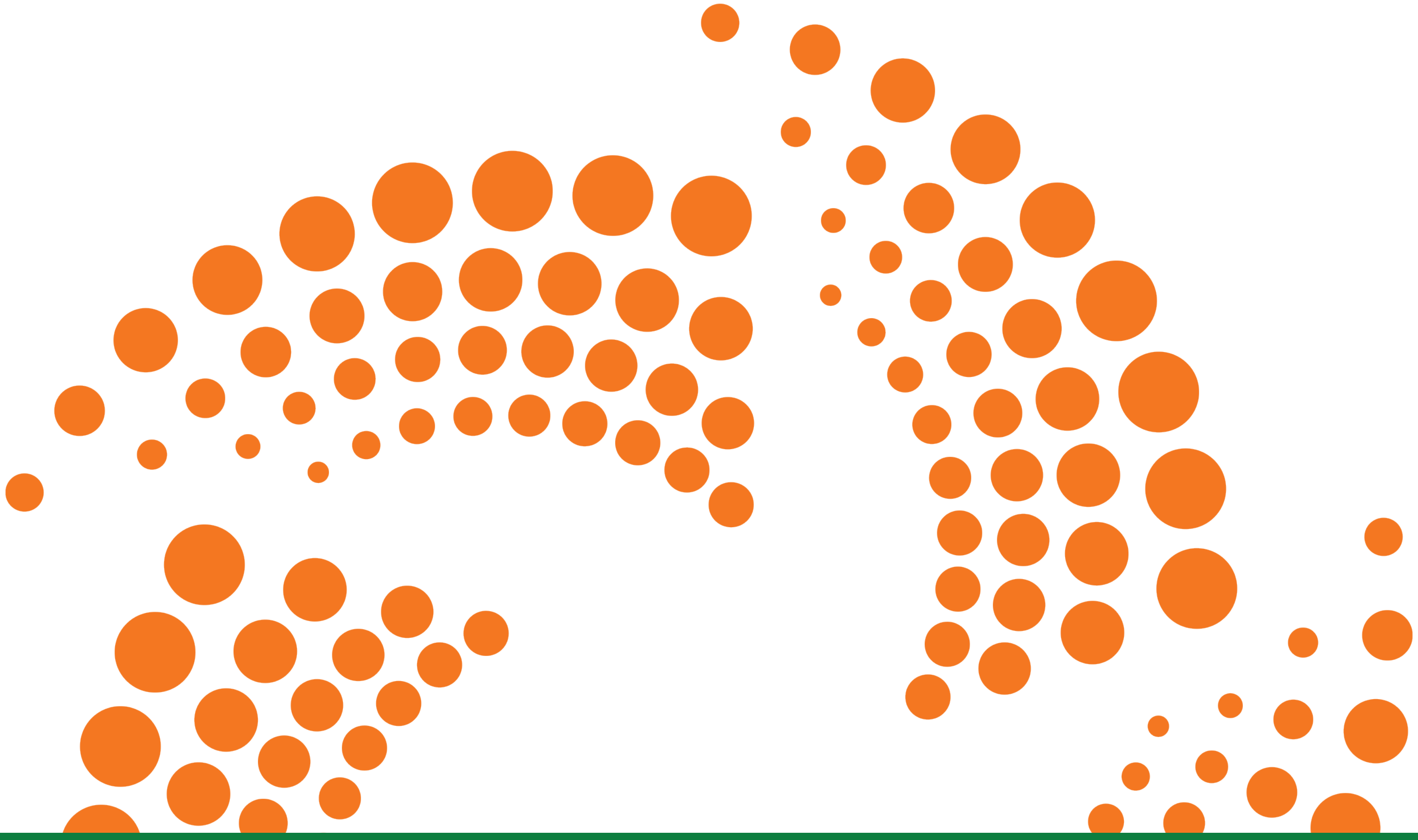
When I awoke from my coma, my wife told me that the first thing I said was, "We have to figure out how I am going to bowl again." But my social worker thought otherwise. "Bowling is impossible for a quadruple amputee," she said, "and golfing even more so. Now, let's get started on your disability paperwork." "Bull manure (edited)," my wife and I blurted in defiant harmony.

Less than nine months later, I was back to work full time until I retired and then continued to work another eight years part time. Bowling and golf? I compete in both and have won dozens of tournaments against fully abled participants. You see, I chose to listen to Ted. Yes, there are many things I can no longer do, like playing my guitar and banjo, but not because someone told me I couldn't.

I choose not to complain about what I can't do; instead, I celebrate the things I can do.

Your journey is ahead. Your life is not worse just different.

> **“ When I awoke from my coma, my wife told me that the first thing I said was, ‘ We have to figure out how I am going to bowl again.’ But my social worker thought otherwise. ‘Bowling is impossible for a quadruple amputee,’ she said, ‘and golfing even more so. Now, let’s get started on your disability paperwork.’ ‘Bull manure (edited),’ my wife and I blurted in defiant harmony.”** - JEFF LEWIS



Becoming a Caregiver

Few people plan to become caregivers. Whether it is a child, a partner, a friend, or a parent, someone in your life may depend on you for help. Caregivers are usually family members, but they also may be friends, neighbors, or even coworkers. Your loved one's experiences affect the entire family system.

According to one survey, 83 percent of caregivers view the experience as a positive one. But caregiving also can be stressful. The lack of experience, available resources, and overwhelming information can be stressful. Depending on the amount of assistance your loved one needs, you may have to reduce the number of hours you can work at a paying job. Likewise, your loved one also may need to reduce the number of hours he or she is able to work or stop working altogether. Children may miss school and other activities while they are recovering from surgical procedures or caring for an older adult. Reduction in family income, coupled with medical costs, may result in financial strain. Caregiving also can cause physical and emotional stress. Roles in your normal family structure may be significantly altered. These are changes to navigate together.

First Steps of Caregiving

Caregiving starts with identifying the needs of the person you're caring for. Some of those needs could include medical needs like going to the doctor or dressing wounds, physical needs like activities of daily living, emotional needs like recovery and readjustment, or living needs like legal or financial challenges.
Here are some questions you might ask yourself and your loved one:

- What type of help does my loved one need right now to live as independently as possible? (Dressing, bathing, lifting, medication management, supervision, companionship, housekeeping, transportation, etc.)
- Who in the family will take charge of caregiving and/or make arrangements for care?
- What types of assistance are expected in the future?
- How much money is available to pay for outside resources?
- Will insurance cover any services?
- Will my job affect the amount of care I can provide?
- How many or what days and times do I most need help?
- What kind of assistance can I provide?
- What assistance are my friends and family members willing to provide?
- Will we be comfortable having a stranger in our home to help us?
- Do we want out-of-home/community care? What kind? How often? How long?

Types of Caregiving

Informal Care

Informal care relies on the assistance of family, friends, neighbors, community, and others who are willing to share some of the caregiving responsibilities. This informal support network can provide assistance with specific tasks (for example, pick up medications, perform certain household chores, walk the dog). They can also provide emotional support and help the person with limb loss maintain a healthy level of social and recreational activity. Making a list of your informal "helper" network, their contact information, and the types of task they can help with will be an invaluable source of support for routine assistance or in times of emergency.

Formal Care

Formal care is home health care, which combines health care and supportive services to help those with limb loss live at home as independently as possible. Home health may be provided by an allied health professional if prescribed by a physician. It also may be a private home health aide who can be hired without a doctor's prescription.

There are two different types of home care available: home health care services and non-medical care services. Nonmedical home care services include companionship, housekeeping, cooking, and many other household activities. Some private insurance and long-term care policies pay for home health care. If not, there may be substantial out-of-pocket costs associated with the different types of care. Nonmedical home care aides can be located through personal referrals or a private home care agency, public health department, or other community organization.

Adapting to New Roles

Some of the emotional stress involved with caregiving can result from the strain of you and your loved one adapting to new roles. When you become the caregiver of someone who has experienced limb loss, your relationship with that person may change. In addition to being a father, mother, daughter, son, brother, sister, wife, husband, or friend, you may need to become a home health aide, service provider, and advocate. At the same time, your loved one is also adjusting to a new role as an individual who may need care and support.

These types of role changes can create feelings of uncertainty, anxiety, resentment, anger, and sadness. You and your loved one may feel as if you have lost the relationship you had before the limb loss. You may feel as if your role as a partner, parent, child, relative, or friend is being neglected, while the care recipient may feel as if their role in the relationship has been minimized. If your loved one was previously the sole breadwinner or main care provider for your family, he or she may have difficulty accepting your care. It can be difficult to ask for or accept help from others if you are used to being independent. Starting with small tasks to ease the transition may help.

All of these feelings are completely normal. However, it's important to understand that role changes do not mean the end of the relationship you had before the limb loss. Remember that you're in this together. You're both learning to live with limb loss. Share your feelings and concerns with each other and keep the lines of communication open. If necessary, seek help from a support group or counselor to better understand your feelings.

Put On Your Oxygen Mask First

On an airplane, the flight attendant tells us when an oxygen mask drops in front of you, you put the mask on yourself first, and then to assist your child or others next to you. Only when we first care for ourselves can we effectively care for others. Caring for yourself is one of the most important — and one of the most often forgotten — things you can do as a caregiver. When your needs are taken care of, the person you care for will benefit, too.

Caregiver Burnout

Caregiver burden can be defined as the strain or load borne by a person who cares for someone else. Many caregivers give up proper sleep, nutrition, recreation, and financial resources to care for a family member or friend. In addition to providing caregiving services and personal commitments of their own, many caregivers also have careers. The caregiver burden begins when the caregiver sees that something has got to give, and the first thing to go is their own well-being.

Family caregivers are less likely to practice preventive health care and self-care. Caregiver stress can take many forms. For instance, you may feel frustrated and angry one minute and helpless the next. You may make mistakes. You might turn to unhealthy behaviors or experience symptoms like:

- Sleep challenges; too much sleep or too little
- Poor eating habits
- Failure to exercise
- Postponement/failure to make medical appointments for yourself
- Feeling overwhelmed
- Feeling alone, isolated, or deserted by others
- Weight change; gaining or losing weight
- Feeling tired most of the time
- Losing interest in activities you used to enjoy
- Becoming easily irritated or angered
- Feeling worried or sad often
- Having frequent headaches or body aches

Caregiving can be an emotional roller coaster. On one hand, caring for your family member demonstrates love and commitment and can be a very rewarding personal experience. On the other hand, exhaustion, worry, inadequate resources, and care demands can be enormously stressful.

Take Responsibility for Your Own Care

You cannot stop the effects of a chronic or progressive illness or a debilitating injury on someone for whom you care. But there is a great deal you can do to take responsibility for your personal well-being and get your own needs met.

As a caregiver you must ask yourself: "What good will I be to the person I care for if I become ill?" The first thing to address is any personal barriers to self-care by identifying the roadblocks.

- Do I feel selfish if I put my needs first?
- Do I have trouble asking for what I need?
- Do I feel inadequate by asking for assistance?
- Do I feel I have to prove I am worthy of affection?

Sometimes caregivers have misconceptions that increase their stress and get in the way of good self-care. Here are some of the most commonly expressed:

- If I don't do it, no one will.
- If I do it right, I will get the love, attention, and respect I deserve.
- Our family always takes care of their own.
- I promised my father I would always take care of my mother.

Since we base our behavior on our thoughts and beliefs, caregivers continually may try to do the impossible or control what cannot be controlled. The result is feelings of continued failure and frustration and a tendency to ignore your own needs. Try reframing caregiving into positive statements such as "I'm good at helping Jan prepare meals." "I can exercise for 15 minutes a day." Remember, your mind tends to believe what you tell it.

Tips for Caregivers

Your support is crucial to the physical and emotional well-being of your loved one. Paying attention to your own needs is very important. The following tips can help you manage the physical and emotional stresses of caregiving:

- Learn and use stress-reduction techniques, e.g. meditation, prayer, yoga, Tai Chi.
- Get proper nutrition.
- Take time off without feeling guilty.
- Participate in pleasant, nurturing activities, such as reading a good book, taking a warm bath.
- Seek and accept the support of others.
- Seek supportive counseling when you need it, or talk to trusted members of your community.
- Identify and acknowledge your feelings, you have a right to all of them.
- Change the negative ways you view situations.
- Be active. Even ten minutes of light exercise

can make you less tired.
- Find ways to connect with friends.
- Join a caregiver support group.
- Know your limits. Your ability to problem solve diminishes when you have more on your plate than you can handle.
- Monitor your physical health by keeping regular appointments with your doctor.
- Monitor your emotional health. Schedule a visit with a professional therapist if you are struggling.
- Get a good night's sleep. Lack of sleep can take a significant toll on your mind and body.
- Establish boundaries. For example, are you comfortable with tasks such as bathing and toileting? If not, talk about what other options are available.
- Address issues as they arise, rather than allowing them to bottle up.
- Put your relationship first. You are still a spouse, child, family member or friend.
- Maintain your personal interests, hobbies, and friendships.
- Consider respite care.

Maintain balance in your family by remembering to take time with other members of your family.

How to Find Support

The Amputee Coalition provides a number of caregiver support programs and resources to reduce isolation and enhance the quality of life for those who care for people with limb loss and limb difference. For more information about any of the following resources and programs, contact the National Limb Loss Resource Center®.

The Amputee Coalition's Certified Peer Visitor Program matches individuals who have provided care for a person living with limb loss with caregivers in need of support. If you would like to request a visit, please visit the Amputee Coalition's website.

The Amputee Coalition booklet "Being a Caregiver" discusses the common themes experienced by caregivers of individuals with limb loss. This booklet is available online and free of charge by contacting the Amputee Coalition's National Limb Loss Resource Center®.

The Amputee Coalition webinar "Caring for the Caregiver" covers how and why people become caregivers, the positive aspects of caregiving, and how to cope with the stress of being a caregiver.

Your local community also may offer resources for caregivers. Check with local churches and community organizations to see if they offer caregiver support programs.

Your support as a caregiver of an individual with limb loss is invaluable. You play a key role in helping your loved one thrive with limb loss. The Amputee Coalition is here to help you and your loved one on this journey. Remember, you are not alone.

Respite care is another type of caregiving service. Respite means a short period of rest or relief. Respite services offers relief for caregivers so they can take a break from the demands of providing constant care. Respite care includes adult day care and home care services, as well as overnight stays in a facility. Respite can be provided a few hours, over a weekend, or even allow you to take a week-long vacation. Many formal caregiver support programs will offer some type of respite care as part of their service package. This respite care might also be provided by your informal caregiving network. You may need to check your insurance coverage to see if you have benefit for respite care.

Additional resources for caregivers can be found in the Resources section at the back of this guide.

Employee Assistance Programs (EAP)

Employee Assistance Programs (EAP) are a benefit your workplace may offer. The type of assistance can greatly vary. Programs generally provide counseling for personal issues such as depression, stress, financial crisis, and illness or death in the family. There are state and federal rules which may address time away from work benefits, protect employability, and may also be available to caregivers. Ask your human resources department for information.

YOUR CHILD'S JOURNEY

- Understanding Your Child's Limb Loss or Limb Difference
- Helping Your Child Understand Limb Loss or Limb Difference
- Watch for Signs of Bullying
- The Decision to Wear a Prosthesis
- Dealing With Body Issues
- 10 Tips for Growing Up With Limb Loss or Limb Difference

CHAPTER 8

PERSONAL STORY: CHARLIE

My name is Ashley and I am a mom to a three-year-old named Charlie. Charlie is our fourth child and a very, active boy who wears a prosthesis on his left leg. Charlie was born with a congenital birth defect that kept his left femur and part of his hip from forming properly. The condition is called Proximal Femoral Focal Deficiency, or PFFD. It is a condition we have planned for since 20 weeks gestation, and every day brings something new.

I remember the days and weeks after our anatomical ultrasound wondering how we were going to care for a child with this sort of physical limitation. It almost makes me laugh thinking about those days. Not because Charlie's condition is funny in any way, but because I spent so much time worrying about his future.

I still have worrisome thoughts at times, knowing how tough this world can be even for those with two feet on the ground. But Charlie

> **" I remember the days and weeks after our anatomical ultrasound wondering how we were going to care for a child with this sort of physical limitation. It almost makes me laugh thinking about those days. Not because Charlie's condition is funny in any way, but because I spent so much time worrying about his future."**
> - ASHLEY, CHARLIE'S MOTHER

surpasses any limitations I innocently place on him. I remember watching him climb up the outside of the staircase before he learned to walk and thinking, “This kid is going to be okay”. He still has mountains to climb.

In the near future, he will undergo a Syme amputation for more mobility and a better-fitting prosthetic. He will need to learn to accept who he is and take comments from others as an opportunity to teach. By no means do I expect life to be easy for Charlie. In fact, I expect just the opposite. But I am hopeful that I can prepare him for all God has intended and he can live the best life possible. It’s the same hope I have for all our children. My father says, “There is no hill too high for a climber” and that’s just what we will teach Charlie to be ... a climber.

Understanding Your Child’s Limb Loss or Limb Difference

Children with limb loss and limb difference must make a lot of physical and emotional adjustments. Physical adjustments depend on the level of the amputation.

Emotional adjustments vary from child to child. For example, emotional and physical adjustments may be needed if the child requires surgery or revisions of their limbs as they grow. It is best to prepare the child, siblings, friends, and teachers about any upcoming surgeries or changes in their journey or assistive devices. Fortunately, there are a number of things you can do to help your child cope with and thrive living with limb loss or limb difference.

Regardless of the cause, limb loss affects the child and the entire family. When faced with a child’s limb loss or limb difference, family members may experience a wide range of emotions, such as fear, worry, sorrow, guilt, confusion, anger, or grief.

When a child is born with a limb difference, parents may think that they did something wrong during pregnancy. This is almost never the case. Congenital limb differences occur for a variety of reasons, many of which are unknown. Parents of a child born with a limb difference may experience tremendous guilt and grief that may last throughout their child’s lifetime.

Parents also can be extremely hard on themselves in cases of amputations that result from trauma. They may second-guess themselves and criticize their decisions in hindsight. Parents may feel as if there was something they did or didn't do that caused or contributed to their child's limb loss. Again, this is almost never the case.

Getting past these feelings can be challenging. It's important for parents to give themselves time to grieve. It is equally important that parents allow their child and other members of the family time to grieve. Helping your child adjust to limb loss also can go a long way toward alleviating feelings of anxiety you may have about your child's future.

If you, your child, or someone else in your family is experiencing chronic sorrow or depression related to your child's limb loss or limb difference, a mental health professional may provide helpful coping strategies.

Perhaps the most important thing you can do for your child is set the tone. Your acceptance of your child's limb loss or limb difference can greatly influence how your child accepts themselves.

Helping Your Child Understand Limb Loss and Limb Difference

Children with congenital limb difference typically begin to notice that there is something different about them around age three or four. They may ask questions about why they are different or believe that their arm or leg will magically grow in fully as they get older. They may feel sad about limbs they never had and wonder, "Why did this happen to me?" or "Why is it so hard for me to do this?" They are likely to feel sad about not having four "normal" limbs. Children with acquired limb loss also may have feelings like these and wish to turn back the clock to a time before limb loss. Fortunately, children recover quickly and often adapt to their circumstances because they aren't constrained by the same societal pressures adults may feel.

There are a number of things you can do to help your child cope and thrive with limb loss or limb difference:

Set the Tone

Perhaps the most important thing you can do for your child is set the tone. Children pick up on your attitudes, actions, and reactions. Let your child know you love them unconditionally. Your acceptance of your child's limb loss or limb difference can greatly influence how your child learns self-acceptance. Likewise, your attitude toward prosthetic limbs or other assistive technology can affect how well your children adapt to their use.

Encourage Reading and Sharing Stories

Reading encourages children's imaginations to grow and opens their world to new people, places, and possibilities. Reading books about difficult concepts, such as limb loss and limb difference, is a safe and familiar way to introduce your child to the topic. When children read books featuring characters with limb loss or limb difference, they are able to identify with the characters and learn new ways to cope with feelings they may be having. Books can give your child the courage to talk openly about limb loss and answer questions from friends and classmates. Contact the Amputee Coalition for resources.

Set Expectations

Have the same expectations regarding behavior and discipline for your child with limb loss or limb difference as you would for any child. Don't limit your child's activities or involvement in school because of limb loss or limb difference.

Encourage Activity

Encouraging your child to try new things. Adaptive recreational and sporting activities will help with their development and will instill a long-term healthy lifestyle. You may find your child does not need any special adaptation. Your child will learn what is possible by trying activities without adaptations.

According to the U.S. Centers for Disease Control and Prevention, childhood obesity has more than doubled in children and quadrupled in adolescents over the last 30 years. Children with physical disabilities may be more prone to leading a sedentary lifestyle than their peers. Children with obesity are at higher risk of developing cardiovascular diseases, diabetes, bone and joint problems, and social and psychological challenges, such as poor self-esteem. Keeping kids moving will provide lasting physical, social, and psychological benefits. Children should be encouraged to play and be as active as possible.

Seek Out Opportunities for Peer Interaction

Limb difference can be incredibly empowering. Seeing other children in the world like them can help reduce feelings of isolation and provide opportunities for emotional growth.

Ask your healthcare providers to introduce you to families and children, or contact the Amputee Coalition to request a Certified Peer Visit from a parent or child who has been through limb loss or has limb difference.

There are many camps specifically for children with limb loss and limb difference throughout the country. Each year, the

Amputee Coalition hosts a Youth Camp for children between ages 10 and 17. This summer camp provides an environment where limb loss and limb difference are the norm. Parents aren't allowed at the Amputee Coalition's Youth Camp, and this provides an opportunity for kids to be themselves with their peers. This also helps break down barriers and gives kids an opportunity to share their experience and feelings with others who are in similar situations and understand what they are going through.

All counselors at the Amputee Coalition's Youth Camp have experience with limb loss and limb difference, and are trained in accordance with Amputee Coalition standards to provide mentorship and guidance for camp attendees. The Amputee Coalition's Youth Camp is free of charge and all costs are covered by the Coalition to make it accessible for all children. For more information about the Youth Camp, or additional local, regional, and national events for children with limb loss and limb difference, contact the Amputee Coalition or talk with your local healthcare providers.

Prepare Your Child for School

Visit your child's school before the school year starts. Meet with the principal, counselors, and teacher to explain your child's limb difference and how it may affect their day at school. It is best for everyone to be prepared, even your child. Simple adaptations, such as adding a railing in the bathroom or stairwell may be needed. Ask your child's counselor or teacher about simple adaptations or an Individualized Education Program (IEP) if your child has greater needs to help them throughout the day. You can read more about IEPs in the "Living Well with Limb Loss" section of this guide.

For children with limb loss or limb difference, the excitement associated with starting a new school year may be replaced with heightened levels of fear and anxiety. Other kids will be curious. They might stare, point, or ask questions. It's difficult for other kids to understand why someone would need an amputation or be born with a limb difference. One way to help your child handle these types of peer interactions is to develop responses to questions that might come up. Simple, factual responses, such as "I was born this way," are often the most effective.

You can also help prevent intrusive staring or repetitive questions by educating your child's teachers and classmates about what it means to have a limb loss or limb difference. The Amputee Coalition has resources available for you to assist with these conversations. You might answer questions about limb loss and prostheses or other assistive devices by doing a show-and-tell. When classmates and friends see children with limb differences engaged in a number of activities, concerns about differences in appearance will diminish.

You also should prepare yourself for any accommodations your child might need to access educational opportunities. Talk with the school about its policies and how it will make those accommodations. For example, your child might need a medical order to request an aide or a note taker.

Watch for Signs of Bullying

Bullying is unwanted, intentional, and repeated aggressive behavior. Bullying can have lasting psychological impact. Children who are bullied are more likely to suffer from depression or anxiety, and miss, skip, or drop out of school. There are four common types of bullying:

- Physical (e.g., hitting, tripping, or pushing)
- Verbal (e.g., teasing or name calling)
- Social (e.g., excluding or spreading rumors)
- Cyber (e.g., sending hurtful messages via text message or social media)

Unfortunately, children with disabilities are more likely to be bullied than their peers. If your child is being bullied, he or she may exhibit some of the following warning signs:

- Unexplainable injuries
- Lost or destroyed clothing, books, electronics, or jewelry
- Frequent headaches or stomach aches, feeling sick or faking illness
- Changes in eating habits
- Difficulty sleeping or frequent nightmares
- Declining grades, loss of interest in schoolwork, or not wanting to go to school
- Sudden loss of friends or avoiding social situations
- Self-destructive behavior, such as running away from home, harming themselves, or talking about suicide

Keep in mind that not all children who are bullied exhibit warning signs. Some kids may want to handle the situation on their own so they can feel in control. Make sure to talk with your child and ask questions to help illuminate challenges they may face.

Dealing with Bullies

Bullying may include things like name calling, public or online humiliation, hurtful pranks, exclusion, shoving, tripping, or hitting Bullying is never okay. Tell your child to try their hardest not to react. A bully's goal is to create an imbalance of power. If the child does not react, it is likely to stop the behavior.

Here are some other tips:

- Walk away when the bully approaches
- Firmly and clearly tell the bully to stop and then walk away
- Avoid the bully
- Hang out with one or more trusted friends; bullies are less likely to engage with groups.

Being bullied can be humiliating. It takes courage for a child to admit they are being bullied. If your child talks to you about being bullied, let them know it is not their fault. Praise your child for doing the right thing in talking with you about it. Ask your child to describe exactly what happened and who was involved, and then talk with your child's teacher or school counselor to see if the situation can be resolved in the classroom. If it is not resolved, put your concerns in writing and contact the school's principal. Be persistent. Talk with your child and school staff members regularly to ensure the behavior has stopped.

Limb loss or limb difference is just one aspect of your child's life – it does not define your child. Focus on the many wonderful things about your child and allow those things to shine.

The Decision to Wear a Prosthesis

You may be wondering whether or not your child should use an artificial limb, or prosthesis. There is no right or wrong answer. Decide what you think will work best for your child. If you decide to get your child a prosthesis, encourage them to do everything possible both with and without the prosthesis. You can observe whether the device helps or hinders your child's progress.

A prosthesis should assist your child's mobility and play. Children with lower-limb loss typically accept their prosthesis since they want to run and play with their siblings and friends. However, a young toddler with a lower-limb loss who is learning to creep and crawl may fuss at first when receiving their first prosthesis as it will slow their crawling and scooting. Parents should be patient as the toddler will learn how to come up and down from sitting, kneeling, and standing using the prosthesis and become less frustrated and fussy the more they practice.

Children with upper-limb differences or loss have different decisions about whether to wear or not wear a prosthesis. The goal of an upper-limb prosthesis is to help with your child's function, from supporting and balancing to holding handlebars and objects. There is no right or wrong answer. Do what you and your child think will be best. It is important for your child to learn activities with and without a prosthesis. The prosthesis should always help your child, never hinder or stop activities. Using the same arm and hand for a long time naturally leads to overuse. Given the weight and function of upper-limb prosthetic devices, their use from a young age can help with long-term adoption. This can help prevent secondary complications associated with over-use syndrome and other conditions related to strain and stress.

When to Begin Prosthesis Use

Early use of a prosthesis typically promotes life-long device adoption. Like the decision to use or not to use a prosthetic device, there is no right or wrong time to begin using a prosthesis. Here are some guidelines that often apply:

- **Infants:** A prosthesis may be provided to your infant depending on the level of the limb loss or difference, developmental milestones, size of your baby, and parents' goals and wishes. A prosthesis could help your child with sitting balance, coming into and out of sitting, grasping, and crawling. It is important to let your child explore their environment and play with and without a prosthesis.
- **Children 3-7 months:** Children often are ready for upper-limb prostheses when they start to sit and use both hands. This happens between the ages of three and seven months. A child's first prosthesis can help with crawling, pushing, and pulling to sit or stand between the ages of six to twelve months.
- **Children 9-16 months:** Children with lower-limb loss are often ready for lower-limb prostheses when they go from crawling to standing. This happens between the ages of nine and sixteen months.
- **Children 1-2 years:** Children are ready for upper-limb functional prostheses (artificial limbs with moving parts) when they are between one and two years of age. This is a time when children start doing more complex activities, such as grasping and handling small objects, like crayons,

Encourage your child to be active with and without a prosthesis, but understand and respect that there may be times when they simply do not want to wear it. Sometimes it's just too hot or uncomfortable. Sometimes kids just want to take a break from their prostheses or feel the regular environment against their skin.

and passing objects from one hand to the other. During this time, a child can learn how to use their muscles to open and close a prosthetic hand.

Encourage your child to be active with and without a prosthesis, but understand and respect that there may be times when they simply do not want to wear it. Sometimes it's just too hot or uncomfortable. Sometimes kids just want to take a break from their prostheses or feel the regular environment against their skin.

When it comes to prosthesis use, the best approach is a balanced one. Younger children who wear an upper-limb prosthesis full time may refuse to wear it sometimes. Remember to talk with your child and identify opportunities to ensure they're making a conscious decision and can identify the reasons they may have removed it. Again, there is no right or wrong. It is the child's and parent's decision.

Children will require new prostheses to keep up with their growth. If your child is complaining of discomfort while wearing the prosthesis or rejecting the prosthesis regularly, it is a good idea to check whether it still fits well or if it is time for a new one.

Youth and Adolescence

Growing up with limb loss or limb difference can be tough. When your child is younger, they may not understand why they are different or why it is harder for them to do some things than it is for others. As they enter adolescence and become teenagers, they may become more aware of their changing body and seek more independence. As with any teenager, they also may become more self-conscious about how they look. Teenage years are hard for everyone, then add in something that makes them "different" like limb loss and limb difference, and there can be additional issues and challenges.

Television shows, movies, magazines, and social media are filled with idealized images of beauty and physical fitness. Many teenagers wonder how they will possibly measure up. Concerns about unattainable expectations may be even more painful in light of the permanent and noticeable fact of a missing limb or limb difference. As a result, teenagers with limb loss or difference may be more likely than their peers to suffer from low self-esteem and negative body image.

Some kids and teenagers may try to hide their limb difference or limb loss. They may look for clothing that hides their limb loss and may avoid social and recreational activities that might expose their legs or arms. Some children may be self-conscious about wearing shorts or worried about finding shoes that look like what other kids are wearing. While they may not be able to change their body, they can change how they see and feel about themselves. Limb loss and limb difference is just one aspect of their life – it does not define who they are.

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10 Tips for Growing Up with Limb Loss or Limb Difference

You have the power to write your own story. From your youth into adulthood, don't let others tell you who or what you can become. Limb loss or limb difference does not define you. The following tips are from other young people with limb loss and limb difference, just like you, and might help you along your journey. Never be afraid to ask for help from someone who has experienced similar things.

1. It gets easier.

Whether you were born missing a limb or lost a limb later, it will get easier as you get older. You'll get used to it, and you'll find most people are more accepting of your difference. In fact, that difference becomes more and more a part of what makes you, you.

2. Your attitude will affect how others perceive and treat you.

There's no getting around the stares and questions. People are going to be curious. The more comfortable, relaxed, and confident you are with yourself, the more others will treat you with respect. A quick, matter-of-fact explanation puts others at ease, and once they know your story, they're likely to stop focusing on your arm or leg.

3. Give yourself permission to feel what you feel.

Being different isn't always fun. No matter how positive and well-adjusted you are, you're likely to have moments when you just don't feel like answering questions. Give yourself permission to feel sad or frustrated. Talk with your friends and family about how you are feeling. Talking about your feelings can help you feel a lot better.

4. Don't limit yourself.

There's nothing you can't do if you're persistent and determined. Whether it's a sport, a hobby, or a job you want, there's a way to make it happen. You may have to do some research and try different approaches, but you can find a way to pursue anything that interests you. Don't sell yourself short by not trying.

5. You have nothing to prove.

As much as it helps to know you can pursue any activity or sport you want, it also can be exhausting to go through life feeling like you have something to prove. Everyone loves stories about people who triumph over adversity and do the impossible. But there's nothing you need to do to "make up for" your difference. All you need to do is be yourself and pursue your own dreams.

6. Tell your family and friends how to support you.

Chances are that your parents, siblings, or friends may try to read your mind and guess how you want to be treated. They may act like nothing is different or they may do a lot of things for you. At different times you're going to need and want different kinds of support. You can help by telling your friends and family how to help. It's especially hard to say something to the people who love you and only want to help, but they will appreciate the direction.

7. Only you can decide if a prosthesis is right for you.

Only you can decide if a prosthesis makes things easier or harder for you. It's different for everyone. You may even find yourself changing your mind at different times or for different activities.

8. Spend time with people who accept you.

Some people will be unable to accept your limb loss or limb difference. They may not want to be your friend or date you because of it. Spend time with people who embrace you. The vast majority of people will not care that you have limb loss or limb difference.

9. Reach out to others.

Whether you're new to limb loss or were born with limb difference, it can be helpful to reach out to other people who know what it's like. The Amputee Coalition Youth Camp is an excellent way to meet other young people with limb loss and limb difference.

10. Laugh when you can.

Humor can be one of the greatest gifts for those who go through life looking different from other people. If you can crack jokes and even learn to laugh at yourself, you will make other people feel at ease and find it easier to get through the natural ups and downs.

NEXT STEPS

- Glossary
- Contributors
- Appendix
- Resources

CHAPTER 9

Next Steps

To our valued community members:

This booklet has been the first step on your journey. We hope it answered questions, offered ideas, and provided you with useful resources. As you take your next steps, you will have new questions and new needs, so we hope you will hang onto First Step as a resource to use again and again. We also hope you will reach out to us. The Amputee Coalition exists to provide you with the resources you need and to connect you to the limb loss and limb difference community and any support or information you need to live well.

We're in this together.

- From the team at the Amputee Coalition

amputee coalition™

Glossary

above-elbow (AE) amputation – amputation through the humerus between the shoulder joint and the elbow joint, also referred to as transhumeral.

above-knee (AK) amputation – amputation through the femur (thigh bone) between the hip joint and knee joint, also referred to as transfemoral.

acquired amputation – the surgical removal of one or more limbs due to complications associated with disease or trauma.

activities of daily living (ADL) – routine activities that people tend to do every day, including eating, bathing, dressing, toileting, transferring, walking, and continence.

ADA – The Americans with Disabilities Act was enacted in 1990 and prohibits discrimination on the basis of disability in employment. To be protected by the ADA, an individual must have a disability or have a relationship or association with an individual with a disability.

advocacy – public support for an idea, plan, or way of doing something, or the process by which an individual or group aims to influence policies or practices.

alignment – the position of the components of a prosthesis relative to one another and the user, or the position of the socket relative to the other prosthetic components of the limb to achieve best function and comfort.

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alignment – the position of the components of a prosthesis relative to one another and the user, or the position of the socket relative to the other prosthetic components of the limb to achieve best function and comfort.

ambulation – the ability to walk from place to place independently, with or without assistive devices.

amputation – surgical removal of all or part of an external body part.

assistive/adaptive device – a product that helps an individual perform an activity or assists with mobility (e.g., wheelchair ramps, hand bars/rails, canes, crutches and walkers).

below-elbow (BE) amputation – amputation of the upper limb between the elbow joint and wrist joint, also referred to as transradial.

below-knee (BK) amputation – amputation of the lower limb between the knee joint and the ankle joint, also referred to as transtibial.

bilateral amputation – amputation of both lower limbs or both upper limbs.

body image – self-perception of one’s body.

body-powered prosthesis – a prosthesis that is powered by the person using their own muscles.

case manager – a professional who helps coordinate insurance coverage, follow-up rehabilitation, prescriptions, social support, and other aspects of recovery.

Chopart amputation – a disarticulation at the midtarsal joint of the foot, leaving a residual limb that is able to withstand weight-bearing without a prosthesis.

comorbidity – coexistence of two or more disease processes.

componentry – the parts that make up a system or device.

congenital limb difference – birth without one or more limbs, or without a part of a limb or limbs.

contracture – the development of soft-tissue tightness that limits joint motion.

contralateral – originating in or affecting the opposite side of the body.

cosmetic cover – an outer, aesthetic covering of a prosthesis, also referred to as a cosmesis.

desensitization – reducing or removing sensitivity in the residual limb by massaging, tapping or applying vibration.

disarticulation – amputation directly through a joint (e.g., hip, knee, shoulder or wrist).

don – put on.

doff – take off.

durable medical equipment (DME) – assistive devices, such as crutches, canes, walkers or wheelchairs. Equipment that helps you complete your daily activities.

edema – a type of localized swelling characterized by an excess of fluid in body tissues. Body parts can swell from injury or inflammation, medications, pregnancy, infections, and many other medical problems.

elbow disarticulation – amputation of the upper limb at the elbow joint.

gait – a manner of walking that is specific to each individual.

gait training – education and instruction to improve an individual's walking pattern.

inpatient – a patient who is admitted to a hospital or other healthcare facility for treatment that requires at least one overnight stay.

K-Level – a rating system used by the Centers for Medicare and Medicaid Services (CMS) and many private insurance companies to indicate the rehabilitation potential of an individual with lower-limb loss.

L-Codes – reimbursement codes used in the prosthetic healthcare industry to identify what services and/or devices were provided.

liner – an interface that rolls onto the residual limb and provides a soft barrier between the skin and the prosthetic socket; used as a suspension system to hold a prosthesis onto the residual limb.

maturation – in prosthetics, the process whereby the shape and condition of the residual limb tissues become stable.

mental health professional – a healthcare professional that offers counseling and support services, as well as community and vocational resources.

microprocessor-controlled knee (MPK) – a type of prosthetic knee joint that is equipped with a sensor that detects full extension of the knee and automatically adjusts the swing phase of ambulation, allowing for a more natural gait. It has the ability to sense when you are in an insecure position—such as when you trip or stumble and will stiffen to provide the support you need to recover.

mobility aid – a device enabling or assisting mobility.

myoelectrics – a technology primarily used to control an upper-limb prosthetic device; electrical impulses generated by muscle contractions are picked up by electrodes to power the prosthesis.

neuroma – a mass of nerve endings in a residual limb resulting from abnormal regrowth of nerves that are severed during amputation.

nurse practitioner (NP) – an advanced-practice registered nurse and a type of mid-level practitioner. NPs are trained to assess patient needs, order and interpret diagnostic and laboratory tests, diagnose disease, formulate and prescribe treatment plans.

occupational therapist (OT) – a healthcare professional trained to teach new methods to complete necessary daily tasks including regular work, household, and recreational activities.

osseointegration – involves implanting a metal anchor directly to the bone of an amputated limb that extends out of the residual limb. A prosthesis is then attached to the metal extension (abutment).

outpatient – a patient who receives treatment at a hospital, clinic, or associated facility but is not hospitalized overnight.
partial foot amputation – amputation of the lower limb below the ankle joint.

partial hand amputation – amputation of the upper limb below the wrist joint.

patient – a person receiving or registered to receive medical treatment; the center of the healthcare team.

phantom limb pain (PLP) – painful sensation that originates in the amputated portion of the limb. Pain that feels like it's coming from a body part that's no longer there.

phantom limb sensation (PLS) – non-painful sensation that feels like it's coming from a body part that's no longer there.

physiatrist – a doctor of rehabilitation medicine who can develop and oversee individual rehabilitation care and pain management plans for their patients, with the goals of enhancing performance and decreasing pain. Also known as rehab doctors, or physical medicine and rehabilitation (PM&R) physicians, and often the amputee rehabilitation team lead.

physical therapist (PT) – a licensed healthcare provider who is educated and trained to help individuals improve or restore mobility or reduce pain in collaboration with other healthcare providers.

physician assistant (PA) – a trained mid-level provider who can assist the surgeon before and after surgery with pain control, follow up visits and referrals for physical therapists, occupational therapists, or physiatrists.

pistoning – undesirable up-and-down motion of the residual limb in the prosthetic socket.

ply – in prosthetics, the thickness of residual limb sock material; the higher the ply, the thicker the sock.

primary care provider (PCP) – a physician who provides general medical care and acts as a gatekeeper to other medical services.

prosthesis – an artificial device that replaces a missing body part, which may be lost through trauma, disease, or a condition present at birth.

prosthetist – an allied healthcare professional trained to provide prosthetic care including patient evaluation, prosthesis design, fabrication, fitting and modification.

pylon – a rigid, usually tubular prosthetic component that fits between the socket or knee unit and the foot.

rehabilitation – care that assists you to get back, keep, or improve abilities that you need for daily life. These abilities may be physical, mental, and/or cognitive (thinking and learning).

residual limb – the portion of the limb that remains after amputation, also referred to as a stump or residuum.

revision – in reference to amputation, the surgical modification of the residual limb.

self-advocacy – the ability to articulate one's needs and make informed decisions about the supports necessary to meet those needs.

shoulder disarticulation – amputation of the upper limb at the shoulder joint.

shrinker – compression garment, sock or liner designed to reduce swelling.

social worker – a professional who offers counseling and support services to patients and their families during the surgical recovery and discharge process and can identify and connect patients with community and vocational resources.

socket – prosthetic interface component; prosthetic container for a residual limb.

sound limb – the intact, or unaffected, limbs that have not undergone amputation.

stubbies – also referred to as foreshortened prostheses. They are custom fitted and are usually made up of standard sockets, no articulated knee joints or shank, with modified rocker bottoms or SACH feet turned backward to prevent the individual from falling. This design allows the person with bilateral lower-limb loss to achieve a lower center of gravity for better balance and stability.

surgeon – a physician specializing in surgery. Surgeons who may perform amputation surgery could be a vascular, orthopedic, or trauma surgeon.

suspension system – a system used to keep the prosthesis attached to the residual limb.

Syme amputation – an amputation through the ankle joint that retains the fatty heel pad portion and is intended to provide end-weight bearing.

targeted muscle reinnervation (TMR) - peripheral nerve transfer procedure that reroutes amputated nerves to motor nerves of nearby muscles for myoelectric prosthetic control, to prevent and/or treat neuroma and phantom limb pain.

Contributors

Ryan Bahr, PA-S

Ryan was born with bilateral club feet and, after having multiple corrective surgeries on the right foot, elected to have a below- knee amputation in 2014. He is a Physician Assistant student at The George Washington University, and will graduate in May 2020. His goal is to work in Pediatrics, specializing in Hematology/ Oncology or Orthopedics.

Linda Bell

Linda lost her right leg and pelvis to an osteosarcoma in 1999. She is a graphic designer and a Certified Peer Visitor, and is active in the amputee community, having attended Blaze Sports Camps, Amputee Coalition Conferences, and Limb Loss Education Days.

Colleen Coulter, PT, DPT, PhD

Dr. Coulter is a board-certified pediatric physical therapist through the American Physical Therapy Association. She is the Team Lead of the Limb Deficiency Program at Children's Healthcare of Atlanta specializing in the treatment of children with upper-and lower-extremity limb differences and amputation. Dr. Coulter serves on the Amputee Coalition's Scientific and Medical Advisory Committee and Upper-limb Society and participates in the Pediatric mobility clinic at the AC Annual Conference.

Marsha Therese Danzig, M.Ed, CIAYT, RYT500

Marsha is a below-knee amputee and Ewing's sarcoma survivor. She founded Yoga for Amputees to help people with limb loss find wholeness through the healing practice of yoga.

Brian Giavedoni, MBA, CP, LP

Brian is a Board-Certified and Licensed Prosthetist at Children's Healthcare of Atlanta. He manages the O&P department and specializes in pediatric complex cases including rotationplasty and congenital limb differences.

Prateek Grover, MD, PhD, MHA

Dr. Grover is Medical Director and Program Director (Amputation Rehabilitation), The Rehabilitation Institute of St. Louis, and Assistant Professor of Neurology - Neurorehabilitation at Washington University School of Medicine. He also serves as the Chair of the Limb Restoration Rehabilitation Networking Group at the American Congress of Rehabilitation Medicine, with focus on patient and professional education, research collaboration, and patient resources and advocacy.

Denise Hoffmann, RN

Denise is a registered nurse whose focus for the past six years has been on patient advocacy and education within the limb loss community; working with Freedom Innovations, the Amputee Coalition, and AOPA. She serves on the Amputee Coalition's Scientific and Medical Advisory Committee, and is also an above-knee amputee of 28 years.

Avery La Fleur, MSW

Avery is a Clinical Care Manager and Educator for individuals with spinal cord injuries at Craig Hospital in Colorado.

Debra Latour, OTD, M.Ed., OTR/L

Debra has a congenital upper-limb difference and is an occupational therapist who specializes in the rehabilitation of adults and children with upper-limb loss/difference. She has authored patented technology, textbook chapters, and continuing education courses for occupational therapy practitioners, and consults to orthotic and prosthetic product research and development. She is Assistant Professor of Occupational Therapy at Western New England University (Springfield, MA), and owner of a consulting practice, Single-Handed Solutions.

Daniel J. Lee, PT, DPT, GCS, COMT

Daniel is a physical therapist who specializes in the rehabilitation of older adults with limb loss. He has authored numerous scientific articles on the subject and speaks nationally on limb loss rehabilitation several times a year. Currently, Daniel is employed as a faculty member in the Department of Physical Therapy at Touro College in Bayshore, NY.

Carol and Jeff Lewis

Jeff is a retired high school teacher, motivational speaker, and quadrilateral amputee of 14 years who enjoys golfing, bowling, and dancing with his wife, Carol. Jeff is a member of the National Speakers Association, is an Amputee Coalition Certified Peer Visitor, and is a co-facilitator of Lively Limbs Amputee Support Group in East Mesa Arizona. Jeff and Carol are past presenters at the Amputee Coalition's National Conference.

Carol Miller, PT, PhD, GCS

Dr. Miller is a physical therapist and Clinical Specialist in Geriatrics. She specializes in promoting health and wellness for adults with limb loss and is a member of the Amputee Coalition's Scientific and Medical Advisory Committee.

Janet Panoch, MA, PhD Candidate

Janet's daughter was diagnosed with osteosarcoma in 2007 and had an above-knee amputation in 2018; Janet's research interests include patient-provider communication and the development of decision-making tools.

Laura Pickoff, MSW, LCSW-C

Laura is a clinical social worker and is Manager of the Case Management Department at the Adventist Rehabilitation Hospital where she has worked closely with the amputee population and co-leads the Amputee Program Team; She is a member of the Amputee Coalition Scientific and Medical Advisory Committee.

Victoria Powell RN, CCM, LNCC, CNLCP, CLCP, MSCC

Victoria is a registered nurse, case manager, and life care planner who specializes in amputation-related care over the lifespan. She has authored textbook chapters and provides regular educational presentations on amputation-related concerns and consults with attorneys, insurance companies, and employers in the care of amputees. She is also a member of the Upper-limb Advisory Council.

Andrea Sherwood, MPO, CPO

Andrea became a prosthetist to help patients achieve the best quality of life possible. Her goal each day is to serve and help patients reach their goals, which requires both good communication and clinical skills.

Appendix

Medical History Worksheet

Demographics

Name

DOB

Height

Weight

Hand dominance

Limb loss and difference related history

Date of surgery

Reason for surgery

Residual limb status

- Skin Condition
- Pain
- Phantom pain
- Contracture
- Use of ACE wraps, shrinker sock or limb protector

Rehabilitation Dates

Assistive devices using

Current Providers

Medical Team Members	Name	Phone
Surgeon		
Physical Therapy		
Occupational Therapy		
Primary Care Physician (PCP)		
Case Manager		
Psychologist/Psychiatrist		
Physical Medicine & Rehab		
Prosthetist		
Other		

Medications (Prescription)

Brand Name	Generic Name	Dosage

Preferred Pharmacy **Phone:**

Medications (OTC)

Over The Counter: Such as Advil, Aleve, Asprin, BC powder, vitamins, supplements, etc.

Brand Name	Used For	How Taken

Medication and Other Allergies

(Such as penicillin, sulfa, codeine, aspirin, NSAIDS, iodine, tape, latex, gelatin, contrast dye etc.)

Surgical History

(Please check all applicable)

- ☐ Tonsillectomy
- ☐ Appendectomy
- ☐ Hysterectomy
- ☐ Gallbladder
- ☐ Thyroid
- ☐ Carpal Tunnel
- ☐ Cataracts
- ☐ Hip Replacement
- ☐ Knee Replacement
- ☐ Gastric Bypass
- ☐ Pacemaker
- ☐ Back Surgery
- ☐ Heart Surgery
- ☐ Hernia Repair
- ☐ Fracture Surgery
- ☐ C-Section
- ☐ Mastectomy
- ☐ Lasik
- ☐ Peripheral Vascular
- ☐ Cosmetic
- ☐ Amputation
- ☐ Other Limb Surgeries
- ☐ Other:

Medical History

(Please check all applicable)

- ☐ ADD/ADHD
- ☐ AIDS/HIV
- ☐ Alcoholism
- ☐ Alzheimer's
- ☐ Anemia
- ☐ Angina
- ☐ Anxiety
- ☐ Arthritis
- ☐ Asthma
- ☐ Atrial Fibrillation
- ☐ Blood Clots
- ☐ Blood Disease
- ☐ Bowel Disease
- ☐ Brain Aneurysms
- ☐ Brain Tumor
- ☐ Cancer: Type
- ☐ Colitis
- ☐ Congestive Heart failure
- ☐ COPD

Medical History Continued

(Please check all applicable)

☐ Coronary Artery Disease
☐ Degenerative Joint
☐ Disease
☐ Depression
☐ Developmental Delay
☐ Diabetes
☐ Drug Abuse
☐ Erythematosus
☐ Fibromyalgia
☐ Gallbladder Disease
☐ GERD
☐ Gout
☐ Hearing Impairment
☐ Heart Attack
☐ High Cholesterol
☐ Hypertension
☐ IBS
☐ Inflammatory
☐ Bowel Disease
☐ Juvenile RA
☐ Kidney Disease
☐ Learning Disability
☐ Liver Disease
☐ Lyme Disease
☐ Meningitis
☐ Mental Illness
☐ Migraine headaches
☐ Multiple Sclerosis
☐ Muscle Disease
☐ Obesity
☐ Osteoarthritis
☐ Osteoporosis
☐ Parkinson’s
☐ Peripheral Vascular
☐ Disease
☐ Pituitary Tumor/Disease
☐ Post-Menopausal
☐ Prostate Disease
☐ Pulmonary Embolism
☐ Reaction to Anesthesia
☐ Renal Disease
☐ Rheumatoid Arthritis
☐ Schizophrenia
☐ Scoliosis
☐ Seasonal Allergies
☐ Seizure Disorder
☐ Sleep Apnea
☐ Spinal Stenosis
☐ Spine Tumors
☐ Spondyloarthropathy
☐ Stomach Ulcer
☐ Stroke
☐ Systemic Lupus
☐ Thyroid Disease
☐ Tuberculosis
☐ Valvular Heart Disease
☐ Visual Impairment
☐ Other:

Family History

(Please check all applicable)

Marital Status: ☐ Single ☐ Married ☐ Divorced ☐ Widowed

No. of Children

Partner's name: Age Occupation

His/her medical condition:

Who lives with you?

Legal Guardianship/Power of Attorney:

Who comprises your support network?

What responsibilities will they take as caregivers?

Parents Living: ☐ Live Nearby ☐ Able To Assist ☐ Siblings ☐ Living Elsewhere

☐ Extended Family

Available support systems?

Would you consider your home life: ☐ Struggling ☐ Strained ☐ Fair ☐ Good ☐ Excellent

Who performs upkeep indoors? Outdoors?

Any immediate repair/maintenance needs?

Transportation:

Valid driver's license?

Type of vehicle(s)

Who lives with you?

Legal Guardianship/Power of Attorney:

Automatic or Manual Transmission?

Current Ability to Drive

Tobacco use: ☐ No ☐ Yes ☐ Formerly

Type: ☐ Cigarettes ☐ Snuff ☐ Chew ☐ Cigar ☐ Vape ☐ E-Cigarette

\# of Years Year Quit? Ever tried to quit? ☐ No ☐ Yes

Illegal/Illicit Drug Use/Abuse: (confidential) ☐ No ☐ Yes

Drug of choice:

Alcohol use: ☐ No ☐ Yes ☐ Formerly

Amount Year Quit # of Years Type Frequency

Caffeine use: ☐ No ☐ Yes ☐ Formerly

Type Amount

Any of Your Pre-Amputation Interests (hobbies/clubs/organizations/ church/recreation)

(Check all that apply)

☐ hunting
☐ fishing
☐ church
☐ crafts
☐ antiques
☐ reading
☐ television
☐ athletic pursuits
☐ golf
☐ gardening
☐ winter activities
☐ water activities
☐ other(s):

What would you consider your pre-amputation activity level to be?

☐ Sedentary ☐ Light ☐ Medium ☐ Active ☐ Athletic

What are your post amputation activity goals?

Education:

Highest grade completed:

☐ GED
☐ High School Diploma
☐ Attend College
☐ College or Advanced

☐ Degree
☐ Vocational School
☐ Specialized Training
☐ Certification

☐ Military Service /Job
☐ Rank at Departure

Vocation:

Current line of work/job title:

Do you like your job: ☐ No ☐ Yes

Length of time at the company:

Length of time in this role:

Physical requirements of your job/attach job description if available.

Has your work status changed as a result of your present illness/injury: ☐ No ☐ Yes

If yes, what is your current work status: ☐ Unemployed ☐ Light duty ☐ Unable to work

Previous Employer, length of employment.

Follow-Up Appointment Worksheet

Date:

Please list any changes in the following:

Medications: Drug Name Dosage

Medical Diagnosis

Therapies or Treatments in care

Home Environment Work

Please list any changes in the following:

Eating

Dressing Toileting

Mobility Transfers

Communication Comprehension

Sleep pattern Transportation

Post Prosthesis Information:

Type of Socket

Manufacturer Name of Arm, Knee, and/or Foot

Socks currently using?

Skin Condition of limb with limb loss/limb difference:

Open wounds, blisters, rashes, abrasions, bruising, swelling, shrinking,

other:

Any pain on limb from socket, explain?

Any pain during specific activities or sitting? Please explain.

Any secondary conditions: pain with any other areas (back pain, pain in sound leg, shoulder,etc.)? Please explain.

Are you using a shrinker sock when not wearing prosthesis?

How many hours per day are you wearing your prosthesis?

Are you using any assistive devices other than your prosthesis?: ☐ No: ☐ Yes

If yes, what other devices are you using, and when?

Are you doing any contracture prevention exercises/stretches?

What is your current exercise and/or physical therapy activities?

Any difficulties with ability to participate in activities, work, activities of daily living?

Physical Therapist/Occupational Therapist Interview

Date

How long have you been in practice?

What are your credentials?

Have you done any continuing education related to the care of individuals with limb loss or limb difference?

How many patients have you/do you typically see with my particular type of limb loss or limb difference?

Do you have any current patients that I might be able to speak with?

How does the process work for a new patient?

Average appointment time?

How many visits?

Do you provide therapy before and after getting a prosthesis?

Do you communicate regularly with your clients' prosthetists, physical therapists, occupational therapists, doctors, and/or surgeons during the rehabilitation process?

Prosthetist Interview

Date

How long have you been in practice?

What are your credentials?

How many patients with limb loss or limb difference do you usually see in a year?

How many patients have you/do you typically see with my particular type of limb loss or limb difference?

Do you have any current patients that I might be able to speak with?

Do you work with specialty prostheses, such as for sports, specific hobbies, or job?

How long does it typically take to receive a prosthesis once the process begins?

How does the process work for a new patient?

Average appointment time?

How many visits?

Do you fabricate in house or outsource your sockets?

Do you have access to all current prosthetic technology?

Can you offer a list of the options available to me, with benefits and drawbacks of each?

What are your work hours?

Do you have on-call hours for emergencies?

How long does it take to get in for an appointment with you?

If my prosthesis fails outside of work hours, what are your protocols?

How many practitioners are in your facility?

Do you work closely with any specific physical therapists, occupational therapists, doctors, or surgeons?

Do you communicate regularly with your clients' healthcare teams during the rehabilitation process?

Do you offer/allow trials of different prosthetic devices?

If so, can I trial them in my home, work, community environment?

Do you accept my insurance?

Do you offer assistance with the insurance claims process?

Do you offer any other new patient resources?

Written Resources, Online Resources, Groups for Specific Hobbies or Sports?

Any local support groups, or Peer Visitors?

Home Assessment Date

Home environment: ☐ City/rural ☐ Own/rent ☐ Live with others?

Condition of home? Size of yard:

Lot vs. acreage?

Type of home:

☐ One story
☐ Two story
☐ Split
☐ Tri-level
☐ Apartment
☐ Frame home
☐ Mobile home
☐ Duplex
☐ Number of floors?

Number of entrances? Which is more accessible:? ☐ Front ☐ Back ☐ Side

Number of steps to entrance:

Driveway surface: ☐ Incline ☐ Smooth ☐ Rough

Garage/carport: Is there space for wheelchair alongside car? ☐ No ☐ Yes

Is garage accessible to the house from a wheelchair? ☐ No ☐ Yes

Are walkway surfaces covered?

Handrails: Present? ☐ One side ☐ Both Sides ☐ Porch

Type of terrain you will need to cross over around the home:

Is there adequate lighting in your home?

Are curbs manageable? Are grade changes manageable?

Is there a ramp? If so, is it sturdy?

Handrails: Present? ☐ One side ☐ Both Sides | Is incline a proper ratio of 1:12?

Bedroom location:

Single ☐ Shared Bed: ☐ Twin ☐ Double ☐ Queen ☐ King ☐ Hospital

Mattress: ☐ Soft ☐ Firm ☐ Adjustable ☐ Tempurpedic ☐

Would a wheelchair fit in the bedroom?

Can a wheelchair be maneuvered in the hallways?

Types of floor coverings?

Electrical outlets accessible?

Bathroom: ☐ Location ☐ Grab bars ☐ Tub ☐ Glass door/curtain

Can you get in/out of tub? Do you have a lift?

Shower stall: ☐ Curtain ☐ Door ☐ Handheld shower

Are you able to use shower stall? Shower chair or bench? Rails?

Sink: ☐ Accessible or required modifications? ☐ Will wheelchair pedals fit underneath?

Toilet: ☐ Accessible or required modifications? ☐ Bidet?

Accessible Mirrors: ☐ Could they be tilted or lowered? ☐ Visible?

Kitchen: ☐ Door swing in/out? ☐ Floor covering? ☐ Wheelchair accessible?

Stove: ☐ Built in? ☐ Wheelchair accessible? ☐ Oven location? ☐ Location of controls?

☐ Gas/electric? ☐ If gas, automatic pilot?

Accessible: ☐ Microwave? ☐ Toaster oven?

Sink: ☐ Wheelchair accessible? ☐ Garbage disposal? ☐ Location of switch?

Cupboards/Cabinetry:

☐ Modifications? ☐ Equipment? ☐ Reachers? ☐ Cupboards below counter top?

Refrigerator:

☐ Hinges on left/right? ☐ Wheelchair accessible? ☐ Location and type of controls?

Kitchen Table: ☐ Wheelchair accessible?

Dishwasher:

☐ Top load/front load/roll out? | ☐ Location and type of controls?

Laundry room:

☐ Location? ☐ Floor covering? ☐ W/C accessible?

Is there an accessible laundry folding area?

Washer: ☐ Top load/front load? ☐ Wheelchair accessible?

Dryer: ☐ Top load/front load? ☐ Wheelchair accessible?

Number of rooms: Accessible by Wheelchair?

Telephone: ☐ Locations? ☐ Accessible? ☐ Emergency dialing system? ☐

Housing: Electrical outlets/light switches accessible in each room?

Environmental Conditions:

☐ Indoors ☐ Outdoors ☐ Temperature variations ☐ Noise

☐ Fumes/odors ☐ Humidity ☐ Dust

Resources

First Step is just one of the resources the Amputee Coalition provides. For more information, check out these additional resources:

inMotion

inMotion is published bimonthly for amputees, caregivers and healthcare professionals. In addition to sharing the stories and perspectives of people living with limb loss and limb difference, inMotion articles reflect the Amputee Coalition's mission to empower individuals with limb loss and limb difference through education, support and advocacy.

Subscriptions are free of charge. Subscribe online at amputee-coalition.org/limb-loss-resource-center/publications/inmotion or by calling 888.267.5669.

Insurance Coverage & Reimbursement: How to Be Your Own Advocate

Insurance Coverage & Reimbursement: How to Be Your Own Advocate provides individuals with limb loss and their caregivers information and resources on advocacy, private insurance and government programs, and the appeals process. To request a copy, call 888.267.5669.

Your New Journey

The Your New Journey folder is designed for individuals facing amputation, those already living with limb loss, or parents who have children with a limb difference. This folder includes helpful information about Amputee Coalition programs and events, brochures about adapting to and living with limb loss, a sample copy of the Amputee Coalition's bimonthly magazine inMotion and an information request form with a return envelope. To request a copy, call 888.267.5669 or visit Amputee-Coalition.org/limb-loss-resource-center/contact-resource-center-request-materials

National Limb Loss Resource Center®

The Amputee Coalition operates the National Limb Loss Resource Center® to connect individuals with limb loss and limb difference, as well as their family members and caregivers to information and resources to help them live well.

The following resources can be accessed online at Amputee-Coalition.org:

- **Resources by Amputation Level**
  Amputee-Coalition.org/limb-loss-resource-center/resources-by-amputation-level

- **How to Find Support**
  Amputee-Coalition.org/support-groups-peer-support/how-to-find-support

- **Events and Programs**
  Amputee-Coalition.org/events-programs

Our resource specialists can connect you to programs, services and other resources available in your community. Contact the Resource Center by phone at 888.267.5669 or submit questions to an Amputee Coalition information specialist online at Amputee-Coalition.org/limb-loss-resource-center/contact-resource-center-request-materials

Publicaciones En Español

Publications Available in Spanish. Many of the Amputee Coalition's educational materials are available in Spanish. To view our selection of materials, visit Amputee-Coalition.org/limb-loss-resource-center/publications/publications-digital-spanish

Materiales Disponibles en Español

Muchos de los materiales educativos de la Coalición de Amputados están disponibles en español. Paraver nuestra selección de materiales, visite https://www.amputee-coalition.org/limb-loss-resource-center/spanish

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 scientific 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.

National Limb Loss Resource Center®

Amputee-Coalition.org/limb-loss-resource-center
Call Toll-Free 888/267-5669, Ext. 1 to speak with an information and referral specialist
8 am-5 pm ET, Mon. - Fri.

ADVOCACY

Amputee Coalition - Amputee-coalition.org

Mobility Saves - Mobilitysaves.org

National Association for the Advancement of Orthotics and Prosthetics - Naaop.org

Patient Advocate Foundation - Patientadvocate.org

ASSISTIVE TECHNOLOGIES

Resna - Resna.org

The Wright Stuff - Thewrightstuff.com

CAREGIVING

Caregiver Action Network - Caregiveraction.org

Eldercare Locators - Eldercare.acl.gov

National Alliance for Caregiving - Caregiving.org

National Council on Independent Living - Ncil.org

USA.gov Caregiver Resources - USA.gov/disability-caregiver

Well Spouse Foundation - Wellspouse.org

CHILDREN

Adventure Amputee Camp

Adventureamputeecamp.org

Camp No Limb-itations

Choa.org/camps/camp-no-limb-itations

Camp No Limits

Nolimitsfoundation.org

Paddy Rossbach Youth Camp

Amputee-Coalition.org/youth-engagement-program-yep/youth-camp

DRIVING AND MODIFICATIONS

Adapting Motor Vehicles for People with Disabilities - nhtsa.gov/sites/nhtsa.gov/files/documents/adapting_motor_vehicles_brochure_810733.pdf

EDUCATION AND SCHOLARSHIPS

Christina Skoski, MD Scholarship - Amputee-coalition.org/events-programs/scholarships/skoski

FinAid - Finaid.org/otheraid/disabled.phtml

Mobility International USA International Exchange - Miusa.org/ncde

U.S. Department of Veterans Affairs - va.gov/education

"25 Great Scholarships for Amputees" - Top10onlinecolleges.org/scholarships-for/amputees

Local Departments of Vocational Rehabilitation also offer varying financial assistance.

EDUCATIONAL/INFORMATIONAL

Americans with Disabilities Act - ADA.gov

Amputee Coalition - Amputee-coalition.org

Limb Preservation Foundation - Limbpreservation.org

U.S. Department of Labor Disability Resources - Dol.gov/odep/topics/disability.htm

EMPLOYMENT

AgrAbility - Agrability.org

Job Accommodation Network - Askjan.org

Lead Center - Leadcenter.org

U.S. Department of Labor Office of Disability Employment Policy - dol.gov/agencies/odep

U.S. Department of Veterans Affairs Vocational Rehabilitation and Employment

Benefits.va.gov/vocrehab/index.asp

U.S. Equal Employment Opportunity Commission - Eeoc.gov

U.S. Office of Personnel Management - Opm.gov/policy-data-oversight/disability-employment

Local Departments of Vocational Rehabilitation also offer employment assistance.

HOME MODIFICATIONS/HOUSING

Habitat for Humanity - Habitat.org

National Resource Center on supportive Housing and Home Modification - Homemods.org

Tunnel to Towers Foundation - Tunnel2towers.org/gmc

U.S. Department of Housing and Urban Development - Hud.gov

INDEPENDENT LIVING

Independent Living Research Utilization - Ilru.org

LIMB/PROSTHETIC DEVICE ASSISTANCE

Amputee Coalition Financial Assistance for Prosthetic Services, Durable Medical Equipment, and Other Assistive Devices

Amputee-coalition.org/resources/financial-assistance-for-prosthetic-services

MAGAZINES AND PUBLICATIONS

Move United Magazine - moveunitedsport.org/news-media/move-united-magazine

Amplitude Magazine Livingwithamplitude.com

InMotion - Amputee-coalition.org/limb-loss-resource-center/publications/inmotion

PEER SUPPORT

Amputee Coalition Support Groups and Certified Peer Visitor Program

Amputee-coalition.org/support-groups-peer-support

SPORTS AND RECREATION

Amputee Coalition Resource for Adaptive Sports Programs

Amputee-coalition.org/resources/adaptive-sports-programs

TRAVEL

Footprints Adventures - Footprintsadventures.org

Society for Accessible Travel & Hospitality - Sath.org

SPLORE Outdoor Adventures - Discovernac.org/programs/splore-outdoor-adventures

TSA - Tsa.gov/travel/special-procedures


amputee coalition
BE MORE ADAPTIVE
EVERYBODY CAN MOVE
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Amputee-Coalition.org