



**amputee
coalition**TM



Beginning Your New Journey



Upper-Limb Amputation

WELCOME!

The Amputee Coalition is a national non-profit organization dedicated to supporting individuals affected by limb loss and limb difference. Established with a mission to empower this community through education, support, and advocacy, the Amputee Coalition provides a comprehensive array of resources to enhance the quality of life for amputees.



The organization offers extensive peer support programs, educational materials, and a wealth of information on health and wellness. They actively engage in advocacy efforts to improve public policy and healthcare access for amputees. The Amputee Coalition also hosts events and initiatives aimed at fostering community, raising awareness, and promoting positive change.



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Through their dedicated efforts, the Amputee Coalition strives to ensure that no amputee feels alone and that every individual has access to the tools and support they need to live life fully.



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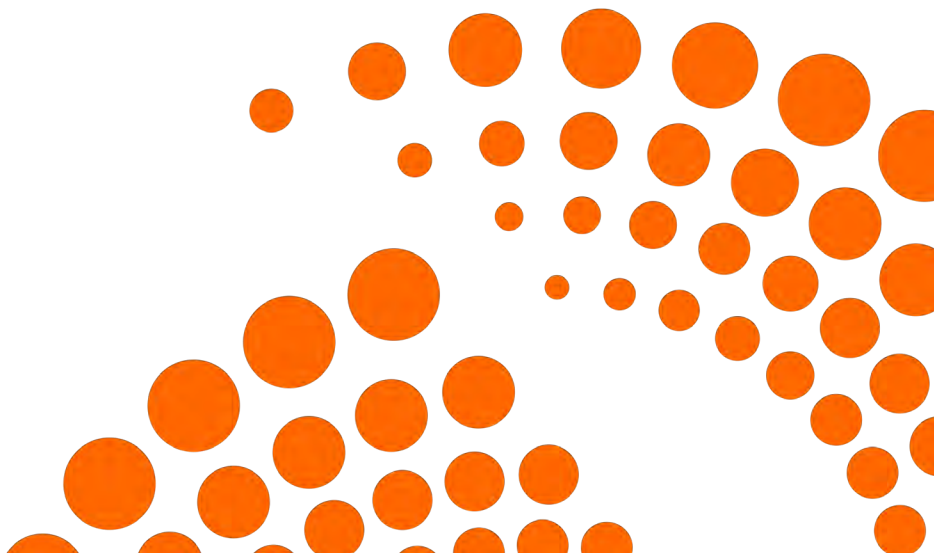


Remember, you are not alone in this journey.



After an upper-limb amputation, your brain is likely racing with questions like “What do I do now?” and “Will my life ever be ‘normal’ again?” This packet will walk you through what you might expect in the first year after your amputation. The topics covered include: rehabilitation, working with your prosthetist, personal care, pain management, prosthetic device options, emotional support, intimacy and relationships, research and resources. As you read through the information, keep a notepad and pen handy. Write down the questions you have. Once you have generated a list of questions, start identifying who might be the appropriate person to pose the question to. If you are at a loss for where to begin, take your list of questions to a healthcare professional. You can also call the Amputee Coalition National Limb Loss Resource Center® for guidance.

Remember, you are not alone in this journey. There are many people, groups and organizations that can help guide you and your family along the path to recovery and rehabilitation. This booklet is just one of the resources available from the Amputee Coalition to help you on your journey to a new normal.



● INCIDENCE AND PREVALENCE

Nearly 2 million people in the United States are living with limb loss.¹ Of these, approximately 700,000 people have an upper-limb amputation.²

Upper-limb amputations account for about 35 percent of total amputations, which is about 10,000 annually.

- The majority of upper-limb amputations are of a finger or a thumb.
- About 9 percent of upper-limb amputations are above-elbow or below-elbow.

It is important to recognize that while the number of upper-limb amputations, compared to lower-limb amputations, is relatively low, the needs of the upper- and lower-limb populations are very different. The upper-limb community is small but tight-knit.

Major Causes of Upper-Limb Amputation

The most frequent causes of acquired upper-limb amputations in the United States are trauma and cancer, followed by vascular complications. An estimated 1,136 children are born each year with congenital anomalies affecting one or both of their upper limbs.³



● FIRST 12 MONTHS AFTER UPPER-LIMB AMPUTATION

During the first 12 months following upper-limb amputation, you will work with a range of healthcare professionals who will help guide your physical and emotional recovery. Some of these professionals will be a part of your life for a short time, and others will become lifelong care providers. **Your rehabilitation care providers should function as a team.** They should communicate with you and each other to help you to recover and regain as much function as possible.



The elements of rehabilitation following an upper-limb amputation are influenced by several factors, including level of amputation, cause of amputation, emotional well-being, and social support.

However, the following should be included in your rehabilitation program:

- Training in Activities of Daily Living
- Development of adaptations to accomplish tasks one-handed
- Care of residual limb to manage pain, swelling and skin care
- Range of motion exercises to prevent contractures and to improve motion of remaining joints
- Exercises to improve strength, posture and balance
- Modifications or assistive technologies necessary to facilitate independence
- Peer support to provide outlets for interacting with others who have experienced an upper-limb amputation.

● REHABILITATION

Recovery and rehabilitation begins with medical care. A few days after surgery, your medical care will transition from suture and staple removal to wound care and pain management. During the first three months, your surgeon will probably transition your care to a physical medicine and rehabilitation (PM&R) physician, also known as a physiatrist. Interest in being fit with an upper-limb prosthesis can be influenced by many things, including emotional readiness. For many people, prosthesis fitting and training occur within the first three months post-amputation. However, some people who initially choose to not use a prosthesis eventually decide that a prosthesis can enhance their quality of life.

During your rehabilitation, be open with your rehab team about any goals you have. The upper-limb prosthesis is commonly referred to as a tool, which is different than a lower-limb prosthesis, which is typically referred to as a “replacement.” Your prosthetist will match you with prosthetic components to accomplish your goals.

Physician/Physiatrist

Your physiatrist is the lead physician on



your **rehabilitation team** and manages your rehabilitation care plan. This physician also focuses on pain management and medications. He or she is your main referral source for emotional healthcare, occupational and physical therapy, prosthetic treatment, social services and return-to-work issues.

Occupational Therapist

An occupational therapist (OT) can help you regain your independence by teaching you how to perform daily activities and self-care with and without a prosthesis. Your occupational therapist should have experience with upper-limb amputations. If you decide to use an artificial limb, or prosthesis, your OT will work with your



prosthetist to create a treatment plan that moves you through pre-prosthetic, interim-prosthetic and post-prosthetic therapy.

Ideally, you will start working with an OT well before your initial prosthetic fitting. The OT's job is to prepare you to tolerate the prosthesis (pre-prosthetic) and teach you how to use it (interim-prosthetic) so that you can live to your fullest potential (post-prosthetic).

Physical Therapist

A physical therapist (PT) can develop an exercise program to help with overall body strength, balance and range of motion issues. Your physical therapist should also have experience with upper-limb amputations. Completing at-home exercises can help you maintain joint flexibility and prevent contracture.

Both your physical and occupational therapists are aware of energy conservation methods to help you develop strategies to prevent overuse injuries.

Overreliance on one arm and/or hand can result in some of the following problems:

- Carpal tunnel syndrome
- Shoulder pain
- Neck pain
- Elbow pain
- Back pain.

Overuse also involves neurologic and vascular implications. The implications of overuse go beyond pain. It is critical to address issues of overreliance or overuse with your rehabilitation team.



Prosthetist

A prosthetist is an allied healthcare professional who is educated, trained and certified to design, fabricate and fit a comfortable, functional prosthesis. It is essential to find a prosthetist who understands the unique issues involved with upper-limb amputation and works at a reputable company with upper-limb expertise.

● CHOOSING A PROSTHETIST

Questions to ask when choosing a prosthetist

Experience

Is the prosthetist trained to work with your type of amputation? How many people have they fit with your amputation level? How many in the past six months? The past 12 months?

References

Would any of these people, who have been fit with upper-limb prostheses, be willing to talk to you about the prosthetist and prosthetic solution the prosthetist provided?

Certification

Is the prosthetist certified by one or both of the national professional certification organizations: the American Board for Certification in Orthotics, Prosthetics and Pedorthics (ABC) and the Board of Certification/Accreditation (BOC)?

Dedication

Is the prosthetist willing to work with you to find the most appropriate prosthetic technology to use in your daily activities? Are they willing and able to show you available upper-limb options and discuss the pros and cons? Make certain they ask and understand your goals with prosthetic technology.

Things to consider when evaluating the quality of a prosthetic clinic

Location

If the facility is too far away, it may discourage you from keeping appointments.

Reputation

How long has the prosthetic company been in business?

Facility

Is the facility clean and accessible?

Services

Does the company have a reputation for quality upper-limb prosthetic care? Does the company have a program for addressing complaints or problems? Do they accept your insurance? If your insurance requires prior authorization, will the company take care of this? How much out-of-pocket expenses will you have to incur? Are there options for payment plans? Is there someone available to help you in case of an emergency?

Unlike other types of medical care,

prosthetic care is not a fee-for-service system. In other words, you will not be charged for each individual office visit. Consultation, evaluation, authorization, fitting, delivery and follow-up should be included in the cost of the prosthetic device. Ask your prosthetist about the length of the follow-up service included in the initial cost. If something does not feel right initially, see your prosthetist as soon as possible.



● WORKING WITH CASE MANAGEMENT

Your hospital or insurance company may assign a case manager or social worker to help coordinate care and insurance benefits on your behalf. Depending on your situation, case managers perform the following services:

- Develop a hospital discharge plan. This involves assessing your condition, needs, abilities and goals and developing a plan to help you achieve those goals.
- Identify appropriate healthcare providers to serve you throughout your rehabilitation process.
- Ensure that healthcare services are provided in a timely and cost-effective manner.

Communicate openly and honestly with your case manager about your needs. This professional is in a position to help ensure you have access to the available services you need.



● TIPS AND TRICKS FOR INDEPENDENT LIVING

There are a number of techniques and adaptive aids you can try to help you complete everyday tasks. Many adaptive aids are available from catalogs, specialty stores or online:

Bathing

- Use wash mitts, pump soap and shampoo bottles.
- Affix a back brush to the shower wall to scrub hard-to-reach areas.
- Sew or pin towel corners so that your residual limb can slip through and “hold” it.

Personal Care

- With a prosthesis: Use large-handled grooming tools or build up handles with foam tubing so they are easier to hold.
- Without a prosthesis: Place cuffs with Velcro closures near the end of the arm to hold grooming tools.
- Use aerosol spray adapters for deodorant or hairspray.
- For toileting needs, try manual or automatic toilet tissue aids for better reach and hygiene.

Dressing

- With a prosthesis: Use button hooks and zipper pulls to fasten clothing, or add Velcro closures.
- Use elastic shoelaces or self-tying Spyrolaces so you don’t have to tie laces, or wear Velcro closure or slip-on shoes.
- Sock starters can make it easier to put on socks.

Eating

- With a prosthesis: If regular-sized utensils are difficult to control, use a three-point hold when wearing a hook terminal device and built-up utensils when wearing a hand terminal device.
- Without a prosthesis: Use a Velcro cuff near the end of the residual limb to hold utensils; angled or longer-handled utensils increase reach; scoop dishes or plate guards help to control food.
- Add crackers to soup to thicken the consistency and decrease spilling.

Household Chores

- For kitchen work, use non-slip cutting boards, one-handed jar and can openers, pan holders, jar tippers for pouring, tab openers for cans, lever faucets, knob turners for controls on appliances.
- Rocker knives are great tools for cutting food with one hand.
- Wheeled push carts make it easier to transport items from one area of the house to another.
- Use Dycem no-slip pads under tableware and bowls to help prevent sliding.

The best teachers you'll find are other people with upper-limb loss. Most people are happy to share the tricks and techniques they've learned over the years.

Special Considerations for Bilateral Limb Loss

People who have lost both upper limbs (bilateral) are almost totally dependent on prosthetic technology, help from caregivers or both. Without prostheses, many individuals with a bilateral upper-limb amputation cannot eat, button a shirt, type, perform personal hygiene or other activities that can be done one-handed.

Early occupational therapy for individuals

with bilateral limb loss will focus on many ways of enhancing functional independence as well as focusing on lower-limb stretching and strengthening and core strengthening. Balance and fall recovery are also addressed.

Tools and Techniques to Help Facilitate Independence

- A universal cuff can slip around the residual limb and hold a fork, spoon or toothbrush.
- Eating utensils that swivel and are easier to grip or provide the appropriate angle can help bring food to the mouth during the initial stages of training.
- Bidets eliminate the need for toilet paper management.

If a bidet is out of your price range, you can use moist, flushable wipes. They can be positioned in the bathroom and easily discarded.

Activities of daily living (ADL) adaptations for toileting aids are available in ADL catalogs; call the Amputee Coalition Limb Loss Resource Center® if you need assistance locating assistive devices.

- Gooseneck clamps and suction cups can hold shower brushes, hair dryers and toothbrushes.

- A “dressing tree” with a system of hooks placed in strategic places on a wooden or PVC stand can make dressing easier.
- A mouth stick enables a person to flip switches, press buttons, type on keyboards, and similar tasks.
- Speakerphones or voice-activated cell phones make communication easier.
- Electronic, hands-free devices can help individuals call for help and control their home environments (lighting, room temperature and appliances).

Do not be afraid to use a device for means other than what it was intended for. For example, salad tongs (specifically set aside for this purpose) can be used to hold wet wipes to assist with toileting. Be creative and use creative thinking techniques regarding the issues you may be having.

● PAIN MANAGEMENT

Many people think that pain is an unavoidable part of limb loss. Your condition may cause pain, but it can and should be treated. Fortunately, there are many options that are appropriate for pain management:

- Proper prosthetic fit
- Physical therapy or occupational therapy
- Exercise
- Transcutaneous electrical nerve stimulation (TENS) units
- Relaxation and stress-management techniques
- Non-steroidal anti-inflammatory drugs (NSAIDs)
- Adjunctive medicines, including antidepressants and neuroleptic agents
- Oral opioid analgesics
- Muscle relaxants
- Mirror therapy.



If you experience pain or discomfort, tell your doctor, nurse, prosthetist, or occupational therapy therapist or other caregiver right away so your doctor can take steps to relieve your pain. The most common types of pain associated with amputation are described in the **Your New Journey** folder.

● PROSTHETIC COMPONENT OPTIONS

Understanding what types of upper-limb prosthetic devices are available and how they function might help you decide whether or not prosthetic device use is right for you. You have five options when deciding whether or not to use a prosthesis:

1. Live without a prosthesis
2. Use a functional aesthetic prosthesis
3. Use a functional prosthesis such as body-powered, cable-controlled, or electric
4. Use combination (or “hybrid”) prosthetic devices
5. Use activity-specific devices.

Keep in mind that a prosthesis is an important tool to help you live the life you want. Base your decision on what is best for you and be aware that your decision to use, or not use, a prosthesis may change as your life circumstances change. Sometimes multiple prostheses or terminal devices will be necessary to enable you to accomplish everything you want to do.

Prosthetic technology offers functional impact in a number of ways.

1. Functional aesthetic prostheses are generally worn for cosmetic purposes



and are designed to look like your missing biological limb. They can help you perform a limited set of basic tasks. To facilitate insurance coverage for these devices the term functional non-articulating should be used.

- 2. Functional prostheses** enable you to perform more complex tasks.
- 3. Body-powered devices** operate similarly to a bicycle handbrake system. They are

controlled by cable and harness systems that require you to use body movements to pull the cable and make the terminal device (a hand, hook or prehensor) open and close.

4. **Electric-powered devices** open and close using battery power. There are multiple control methods that can be used to operate an electric-powered device.

Myoelectric control works through the placement of an electrode on the surface of the skin. The sensor detects a signal from the muscle you intend to use to control the operation, speed and direction of the prosthesis.

5. **Hybrid prosthetic devices** use a combination of body power and electric power to control the elbow, wrist and hand. Hybrid prosthetic systems are typically used by those with above-elbow amputations.

6. **Activity-specific devices.**

7. **Sports and recreation prostheses** help people participate in a variety of activities. Talk to your prosthetist about your goals so you can work together to identify or create solutions that fit your needs.

When choosing between a functional aesthetic or functional prosthesis, consider the advantages and disadvantages of each. Keep in mind that the majority of upper-limb prostheses require a harness, especially for an above-elbow amputation.



● COMPARISON OF PROSTHETIC DEVICE TYPES



Functional Aesthetic Devices

Typical Advantages

- Aesthetically pleasing
- Can provide functional assistance with carrying, holding, and positioning objects
- Lightweight
- Durable
- Easy to maintain

Typical Disadvantages

- No active control of the terminal device
- Limited functional capabilities
- Some do not require a harness

Body-Powered Devices

Typical Advantages

- Lower initial cost
- Lighter
- Easier to repair
- Generally easier to don (put on)
- Offers better tension feedback to the body

Typical Disadvantages

- Mechanical appearance
- Requires a harness
- Can be difficult to use because they rely on the user's physical ability and range of motion of the residual limb

Electric-Controlled Devices

Typical Advantages

- Requires less harnessing than a body-powered device
- Can be built to look more like a real arm
- Strength and body movement are less important
- Provides strong grip force
- Allows for control of more than one function at a time

Typical Disadvantages

- Higher initial cost
- Heavier
- Higher repair cost
- Dependence on battery life
- Insurance pre-authorization can be more challenging

Hybrid Prosthetic Devices

Typical Advantages

- Allows for control of more than one function at a time
- Requires less harnessing than body-powered devices
- Provides strong grip force
- Costs less than prostheses with electric control of the elbow, wrist, and hand

Typical Disadvantages

- Requires harnesses
- Weighs more than body-powered alone
- Higher initial cost and more expensive to repair than body-powered alone

● TERMINAL DEVICE OPTIONS

A **terminal device** is attached to the end of the prosthetic arm through a prosthetic wrist. There are three types of terminal devices for an individual with an upper-limb amputation: **hooks, prehensors** and **hands**. Each type is available for body-powered or electric prostheses, and each has distinct advantages and disadvantages:

1. **Hooks** allow individuals to hold and squeeze objects between two split hooks.
2. **Prehensors** offer many of the same advantages as hooks. They consist of a thumb-like component and a finger component that may resemble lobster claws, pliers or a bird's beak.
3. **Artificial hands** are designed to more closely resemble the human hand.

Most prosthetic hands make use of a pinching or squeezing function, using the thumb and first two fingers. Others have individually powered digits and adjustable grip control.

4. **Activity-specific terminal devices** are designed to help people perform specific activities and tasks. Some common activities include driving, swinging a golf club, throwing a ball or lifting weights.



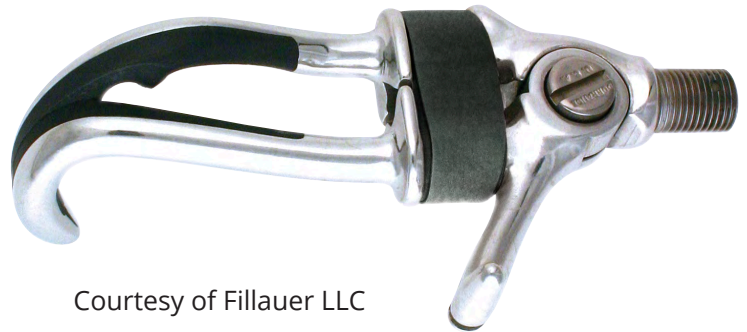
Hooks

Typical Advantages

- Highly functional
- Easy to use
- Able to grasp small objects
- Durable
- Lighter weight
- Lower maintenance and repair costs
- Good visual feedback
- Able to tolerate high heat

Typical Disadvantages

- Mechanical look
- Tips of hooks are more prone to get caught on things
- Decreased grip strength



Courtesy of Fillauer LLC

Prehensors

Typical Advantages

- Highly functional
- Easy to use
- Durable
- Moderate visual feedback
- Do not look as threatening as a split hook
- Not as likely to scratch objects as a split hook
- Not as likely to get caught on things as a split hook

Typical Disadvantages

- Challenging to pick up small items
- Reduced visual feedback compared to split hook
- Not as good for typing



Courtesy of Fillauer LLC

Artificial Hands

Typical Advantages

- Look more like human hands
- Move like natural hands
- Specialized grip patterns
- Stronger grip force

Typical Disadvantages

- Less durable than hooks and prehensors
- Reduced visual feedback
- Higher cost
- Can be more expensive to maintain (depending on type)
- Glove covering hand can stain, get dirty

It is essential to advocate for yourself when dealing with insurance coverage for prosthetic and assistive devices



Activity-Specific Terminal Devices

No single device can perform all of the functions of a human hand. Fortunately, there are many different types of terminal devices that make it easier to perform a specific task or participate in a specific recreational activity. There are various hand tools and kitchen utensils that you can snap onto your device to perform specific tasks. Activity-specific terminal devices have been made for golf, bowling, swimming, weight-lifting, baseball and fishing, just to name a few.

If you are looking for where you can purchase activity-specific devices, call the Limb Loss Resource Center® at 888-267-5669 or visit the Web site at [Amputee-Coalition.org/limb-loss-resource-center](https://amputee-coalition.org/limb-loss-resource-center).

Socket Interface for Upper Limb

The socket is the part of your prosthesis that your residual limb fits into. It connects your residual limb and the rest of the prosthesis. A socket that doesn't fit can cause blisters, abrasions and pain. If the socket is not comfortable, you will be less likely to wear your prosthesis. You should slowly "ease into" a wearing program with your prosthesis and check your skin often after each wearing period. Redness that does not go away in 15 minutes should be brought to the attention of your prosthetist. Your wearing program should be guided by your prosthetist and occupational therapist in the preparatory phase.

The only way your prosthetist will know that something is not comfortable is if you explain what you are feeling. Describe your symptoms with statements such as **"I feel some pinching in this spot"** or **"I feel some pressure in this area right here."**

Fortunately, modern socket interface systems have benefitted greatly from advances in material technology. Flexible materials are making sockets more comfortable and easier to put on and take off.



● EMOTIONAL SUPPORT

Losing a limb can have a significant emotional impact on both you and your family. You will likely experience a range of emotions during your recovery. Remember that your mental recovery is as important as your physical recovery. Take advantage of the opportunity to talk with a counselor and seek peer support to address emotional concerns you have.

Body Image Issues

It is normal for individuals to go through a period of reacting negatively to their body after the amputation. The internal struggle and mental battle is centered around how you see yourself in the mirror versus what your mind believes is attractive. Throughout your life, you have built a concept of your personal perception of beauty and attractiveness, likely centered on what you have seen portrayed in society and in the media. When your perception of how your body looks does not match up to social or personal standards, it may be hard to accept yourself or feel like you are accepted by others.

Be mindful of how you are feeling and keep track of what typically triggers negative

feelings. Speak with a professional if negative feelings start to get out of control. Consider talking with a Certified Peer Visitor through the Amputee Coalition. The process of connecting with your peers can help you normalize your experience.

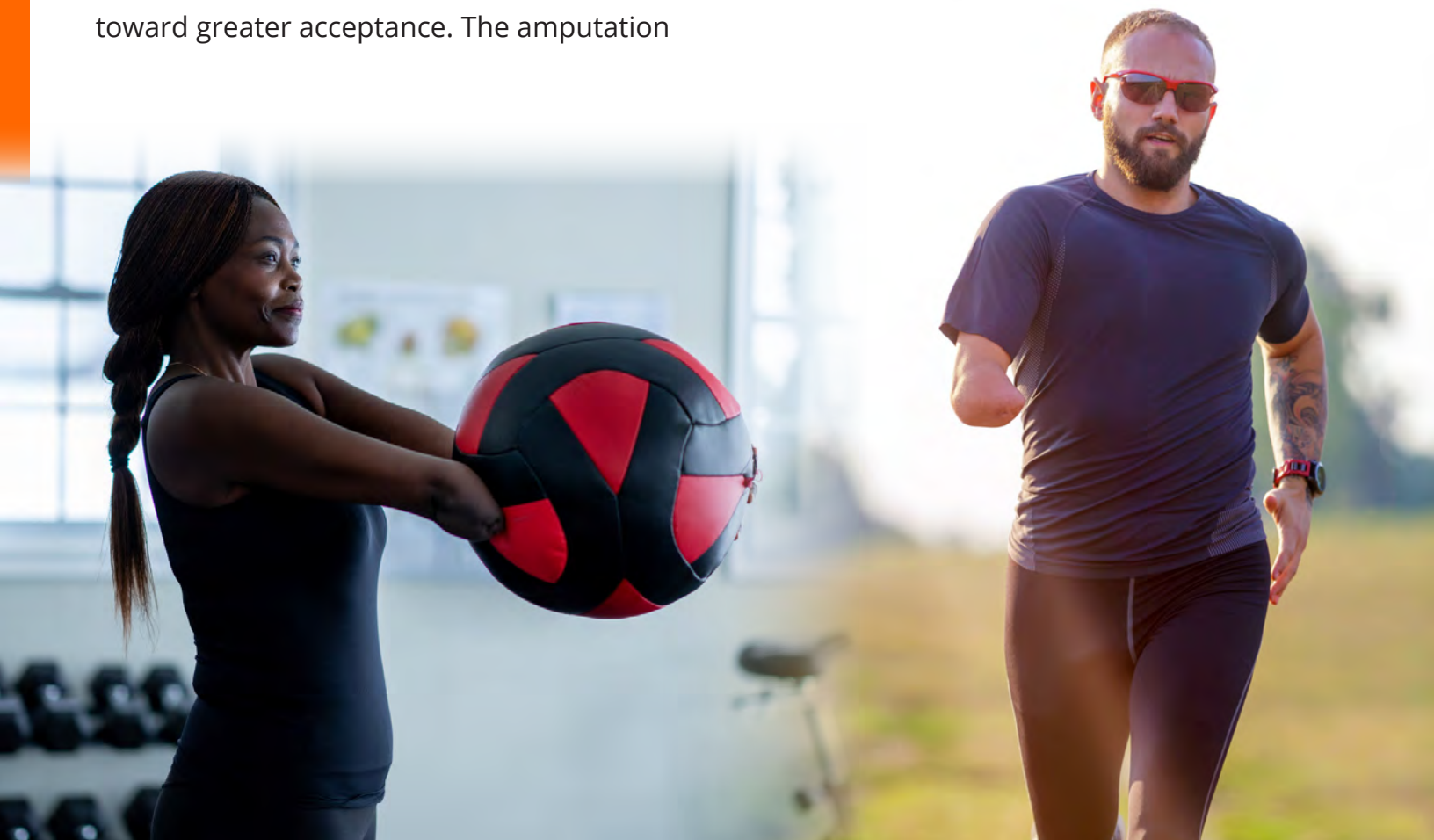
Practice reframing negative thoughts and feelings that negatively impact your sense of well-being. For example, instead of focusing on negative thoughts about how you look, force yourself to say something positive and give yourself a compliment. The next time you have a negative thought about how you look, take a deep breath and stop the negative thought as it enters your mind. Immediately give yourself a positive, uplifting compliment. This process will take time and does not happen easily or quickly. It will take practice and may require the assistance of a professional, such as a counselor or a social worker, to help teach you tools that can be used in similar situations.

You may find yourself concerned about going out in public for fear of stares, insensitive comments, or odd questions from strangers. Do not allow these thoughts and concerns to imprison you in your home.

Take ownership of accepting your changed body and remember that you are in control of your thoughts and how they impact your emotions. While certainly uncomfortable, another individual's ignorance and lack of exposure to difference should not impact your ability to live the life you want to live.

Having recently lost a limb, it may feel as if the amputation has become your identity. Your world is comprised of meetings with doctors, surgeons, therapists and prosthetists. Remember that you were a person with varied hobbies and interests before the amputation and you are still that person. It is important to nurture the relationship you have with yourself and work toward greater acceptance. The amputation

does not need to be the epicenter of your life. Over time, your amputation will become less of the focus and will become a byproduct of your life's experiences. You do not need to be happy about the amputation, but you can work toward accepting the reality of the situation and make a commitment to living a positive life. Keep sight of your goals, both pre- and post-amputation, and keep notes for yourself. What do you need to attain your goals? If a prosthetic device will help you to reach your goals, make note of what it is you want to do and have a very honest conversation with your prosthetist about how your needs might be met with various tools and prosthetic devices.



Intimacy and Relationships

It is helpful to communicate with your partner about any insecurities you have. Talk with your partner about how your changed body looks, feels and works. Talking about your feelings can help alleviate fear of rejection and prevent misunderstandings and hurt feelings. Open communication about insecurities can ease concern, allowing for a strong and healthy intimate relationship to grow and develop.

You may need to take time to re-explore each other and what it means to be intimate together after the amputation. Focus on what brings you pleasure instead of focusing only on how you wish to perform. Being intimate with your partner may require creative thinking about addressing your, and your partner's, comfort. Communication is an essential piece of maintaining a healthy relationship. After talking with one another, you may find it beneficial to discuss specific questions with a healthcare professional.

Consider resources that are available to you, such as books, assistive devices and peer support. If you are having difficulty locating resources, contact the Amputee Coalition National Limb Loss Resource Center® to help guide you in your search.

Avenues for Emotional Support

Individuals with an upper-limb amputation are a small but close-knit community. Fellow individuals with an amputation who understand your challenges are in an excellent position to provide you with perspective and hope.

The Amputee Coalition offers many avenues for emotional peer support:

- Peer Visitor program
- Support and social groups
- Promoting Amputee Life Skills (PALS) course
- Amputee Coalition page on Facebook

The **Your New Journey** packet describes these programs in detail.



● RESEARCH AND DEVELOPMENT

Advances in technology are addressing some of the limitations of current upper-limb prosthetic devices. The following advances are helping to improve the integration and acceptance of upper-limb prosthetic devices, and make prosthetic devices more comfortable, lighter, easier to control and less expensive:

- **Osseointegration** is a method of directly attaching a prosthetic limb to an individual's body through a surgically attached, permanent, bone-anchored titanium implant. Osseointegration eliminates the prosthetic socket. As a result, individuals do not have any of the issues associated with socket wear. However, the procedure comes with a lengthy rehabilitation process and an increased risk for infection. The U.S. Food and Drug Association (FDA) authorized use of a Swedish prosthetic osseointegration implant system for individuals with a lower-limb amputation in 2015.
- **Targeted muscle reinnervation (TMR)** is a surgical technique in which arm and hand nerves are transferred into chest muscle. The nerves grow into the muscle, but they still "think" like hand muscles. As a result, when a prosthesis user thinks about contracting his or her hand, myoelectric sensors pick up the signals, and the prosthetic hand responds. TMR has commonly been performed on individuals with above-elbow amputations.
- **Sensory feedback:** The Defense Advanced Research Projects Agency (DARPA) has awarded contracts to a number of research institutions and universities for Phase 1 of its Hand Proprioception and Touch Interfaces (HAPTIX) program. The goal of HAPTIX is to create a prosthetic hand system that moves and provides touch sensation like a natural hand. By restoring sensory functions, HAPTIX also hopes to reduce or eliminate phantom limb pain.
- **Radio frequency identification (RFID)** tags offer a promising new control method for advanced upper-limb prosthetic devices. RFID tags are made of tiny computerized chips. These chips are programmed with specific triggers that cause a change in prosthesis mode. The user can place these tags anywhere in his or her environment: in a shirt pocket, on

a belt or in another convenient location. When the prosthesis user approaches a tag, it sends the appropriate command to the terminal device.

- **Pattern recognition** is a component of myoelectric prosthetic devices with varying degrees of freedom. It allows an individual to control their prosthesis using muscle contractions. A significant amount of prosthetic device training, both with the prosthetist and at home, is needed to use pattern recognition effectively. Your prosthetist will guide you through simulations and activities to determine the muscles you use to complete various tasks and program the device. Pattern recognition requires isolating one movement at a time. This requires a great deal of training and effort on behalf of the user to ensure the device and muscle contractions are trained to perform the desired tasks. The goal of pattern recognition is to increase control and feedback from the prosthetic device, allowing for longer wear time and a more functional device.⁴
- **3D printing:** With the increased prevalence and affordability of 3D printing, engineers and physicians are able to develop prosthetic devices that are fully customized to the wearer. Consumer

3D printing is leading to a surge in “DIY” assistive devices that can be printed by virtually anyone, anywhere. Such devices are most commonly being used to benefit children who may be embarrassed about missing a limb. This technology is being used today, but it is also still being refined. Remember that any prosthesis should be designed and fit by a trained and licensed prosthetist. Currently, there is limited access to prosthetists or occupational therapists with experience in 3D printed prostheses. Be aware that you may also experience difficulty with insurance coverage of a 3D printed device. A lack of insurance coverage or reimbursement will also impact your ability to meet with a prosthetist or an occupational therapist to adjust the fit or learn how to use the device.

The Amputee Coalition is committed to promoting research that improves the lives of those affected by limb loss. To learn about Amputee Coalition research partnerships or to find an active study seeking participants, visit Amputee-Coalition.org/research.

● RESOURCES

This booklet is just one of the resources the Amputee Coalition provides. For more information, check out these additional resources on our Web site:

Amputee Coalition

Amputee-Coalition.org

National Limb Loss Resource Center®

Amputee-Coalition.org/limb-loss-resource-center

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



References

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● COMMUNITY RESOURCES

Aging and Disability Resource Centers (ADRC)

An ADRC serves older adults, individuals with a disability, caregivers, veterans and family members. This is a “no wrong door” and a “one-stop shop” system where you can obtain information on available long-term services and benefits, regardless of your income.

- Find your local ADRC at: [Eldercare.acl.gov/Public/Index.aspx](https://eldercare.acl.gov/Public/Index.aspx)



Area Agencies on Aging (AAA)

Your local Office on Aging is an excellent resource for in-home and community-based services. Services provided by an Office on Aging vary from benefits screenings to home-delivered meals, transportation and senior centers. Typically, a social worker will work with you to assess your needs and offer referrals to appropriate and available services in your area. The benefit of working with an Office on Aging social worker is that they can stay in touch with you long-term and address your needs as they arise. It is not a service that ends after a certain period of time. Your local Office on Aging is a great first contact when looking for what types of services are available to help an older adult maintain independence and continue to live safely at home.

- Find more information at [AOA.acl.gov](https://aoa.acl.gov).
- You can search for a local AAA by calling 202/872-0888 or visit: [N4A.org](https://n4a.org).



Centers for Independent Living (CIL)

CIL agencies are community-based, cross-disability, nonprofit organizations that are designed and operated by individuals with disabilities. They provide services such as peer support, information and referral, and individual and systems advocacy, as well as independent living skills training.

- Search for your local Center for Independent Living in the ILRU Directory: [ILRU.org/projects/cil-net/cil-center-and-association-directory](https://ilru.org/projects/cil-net/cil-center-and-association-directory)

Vocational Rehabilitation

Vocational Rehabilitation offices help individuals living with a disability to prepare for and find employment. They typically offer job counseling, training, assistive device technology and support services.

- Search for your local Vocational Rehabilitation office at [Askjan.org/concerns/State-Vocational-Rehabilitation-Agencies.cfm](https://askjan.org/concerns/State-Vocational-Rehabilitation-Agencies.cfm).

Local Amputee Support Groups

The Amputee Coalition maintains a network of support groups across the country. Support groups are run by volunteers and vary in the types of programs they provide. Search for a support group in your area: [Amputee-Coalition.org/support-groups-peer-support/support-group-network](https://amputee-coalition.org/support-groups-peer-support/support-group-network).

Virtual Support

If you are unable to locate a support group in your area, or if you are not yet comfortable with venturing out for support, try exploring avenues for virtual support. One of the many benefits of virtual support is that you do not need to leave your home to participate.

Facebook Community

The Amputee Coalition operates a large Facebook group offering virtual support to individuals with limb loss and those who care for them:

Facebook.com/AmputeeCoalition.

Peer Visitation

The Amputee Coalition has a robust community of Certified Peer Visitors across the country. Peer visitation offers tremendous benefit and helps to normalize the recovery process. No one knows what you are going through like another individual who has lived through a similar experience. Call the Amputee Coalition at 888-267-5669 to request a peer visit.

For more information about the program, visit: [Amputee-Coalition.org/support-groups-peer-support/certified-peer-visitor-program](https://amputee-coalition.org/support-groups-peer-support/certified-peer-visitor-program).

● ABOUT THE AMPUTEE COALITION

The Amputee Coalition is a donor-supported, voluntary health organization serving the nearly 2 million people with limb loss and more than 28 million people at risk for amputation in the United States.

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