amputee coalition™

Beginning Your New Journey

Above-Knee 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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This project was supported, in part, by grant number 90LLRC0001-01-00, from the Administration for Community Living, U.S. Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

What will my life look like going forward?

After an above-knee, or transfemoral, amputation, you probably have a lot of questions. What's next? How will I get around? What will my life look like going forward? There are many people, groups and organizations that can help guide you and your family along the path to recovery. This booklet is just one of the resources available from the Amputee Coalition to help you.

INCIDENCE AND PREVALENCE

Nearly 2 million people in the United States are living with limb loss. Of those, about 1.3 million – 65 percent – have an amputation affecting a lower limb.[1] **More than 580,000 individuals in the United States are living with above-knee amputations.**[1] Each year, an average of 132,723 lower-limb amputation procedures are performed in the United States.[2] Just over 16 percent of those procedures are above-knee amputations.[2]

The majority of lower-limb amputations are due to complications from vascular disease and diabetes. Other major causes of lower-limb amputation include infection and trauma. Only 1 percent of lower-limb amputations are the result of cancer.

FIRST 12 MONTHS AFTER AN

ABOVE-KNEE AMPUTATION

A few weeks 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 transition your care back to your primary care physician or a physical medicine and rehabilitation (PM&R) physician.

WHAT TO EXPECT IN THE FIRST THREE MONTHS

FIRST TWO WEEKS

- Swelling
- Mild to moderate pain
- First physical therapy consultation

TWO TO FOUR WEEKS

- Swelling subsides
- Suture line showing signs of healing
- Minimal drainage
- Pre-prosthetic therapy begins

FOUR TO SIX WEEKS

- Begin outpatient physical therapy
- Begin weight-bearing exercises

EIGHT TO 12 WEEKS

- Continue physical therapy
- First prosthetic fitting

REHABILITATION

The rehabilitation process and timeline after an above-knee amputation are highly individualized. During the first 12 months, you will work with many different healthcare professionals who will help to 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.

Your Role in the Rehabilitation Process

Taking an active role in your recovery is no small task. It will require acceptance, focus, dedication, persistence and patience.

Members of your rehabilitation team will provide you with guidance, recommendations and tools as you recover. But you are the center of your rehabilitation team. You must decide what will work best for you and communicate your decisions openly and honestly with your healthcare providers.

Tell your healthcare team about your goals. If you played golf before your amputation and would like to resume that activity – or if you would like to try a different activity – tell your healthcare providers.

You should know and understand your K level and how it will impact the type of prosthetic device you will be working with. If there are activities you are interested in returning to (golf, running, working, etc.), be sure your physician and your prosthetist are aware of your goals.

MEMBERS OF YOUR HEALTHCARE TEAM

Physician/Physiatrist

Your primary care physician or physiatrist (physical medicine and rehabilitation physician) is the lead physician on your rehabilitation team and manages your rehabilitation care plan. This physician focuses on pain management and medications. He or she is also your main referral source for emotional healthcare, physical therapy, prosthetic treatment, social services, and return-to-work issues.

Physical Therapist

Whether you decide to wear a prosthesis or not, you should start working with a physical therapist as soon as possible after your amputation. You will require weekly visits to your physical therapist for several months to properly prepare you for daily mobility.

Physical therapists can help you:

- Desensitize your residual limb
- Become comfortable bearing weight on your residual limb
- Learn stretching exercises to develop flexibility and range of motion in your knees and hips
- Transfer safely from different positions, such as from a bed or a chair
- Position your residual limb to prevent contractures (see Range of Motion and Flexibility, pg. 12)
- Learn exercises to develop upper-body, core, and sound-side leg strength
- Improve your gait (walking) and balance.

After you select the type of assistive device that will work the best for you, your physical therapist will teach you how to use it safely and effectively.

Prosthetist

A prosthetist is an allied healthcare professional who is educated, trained and certified to design, fabricate and fit a comfortable, functional prosthesis. The relationship you have with your prosthetist will be long-term. It is important to find a prosthetist you are comfortable working with. Initially, you will meet with your prosthetist several times during the first month after surgery. He or she will fit you with an elastic sock, called a shrinker, which will help shape your residual limb for initial prosthetic fitting.

If you decide to be fitted with a prosthetic device, your prosthetist will show you how to put it on (don), take it off (doff), make adjustments, and care for it. After you and your prosthetist reach a comfortable fit with your prosthetic device, visits with your prosthetist will continue to be regular but less frequent.

CHOOSING A PROSTHETIST

Questions to Ask Potential Prosthetists:

1 EXPERIENCE

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

2 REFERENCES

Would any of these people be willing to provide a reference? Ask about the prosthetist and the solution the prosthetist provided.

3 CERTIFICATION

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

4 DEDICATION

Is the prosthetist willing to work with you to find the most appropriate prosthetic tools to use in your daily activities?

Considerations When Evaluating the Quality of a Prosthetic Company:

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 prosthetic care? Does the company have a program for addressing complaints or problems? Do they accept your insurance? If your insurance requires pre-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 care should be rolled into the cost of the prosthetic device. Ask your prosthetist if there are any time limits to follow-up fitting.**

After an amputation, you will see your prosthetist regularly to adjust the fit of your prosthesis. As the swelling in your residual limb goes away, you will not need to see your prosthetist as often. However, it is a good idea to maintain a regular follow-up schedule to address any issues with socket fit and comfort and so your prosthesis stays in good working order.

For additional information on choosing a prosthetist:

- Contact the Amputee Coalition National Limb Loss Resource Center®
- View the brochure, **Working Together for a Successful Outcome**, a collaborative effort of the Amputee Coalition and the American Academy of Orthotists and Prosthetists (AAOP): **Amputee-Coalition.org/resources/a-successful-outcome**

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 can help to ensure you have access to the services you need if they are available in your community.

COMMON ISSUES

Skin Issues

Skin issues are common among individuals with an amputation, especially among prosthetic users. Approximately 75 percent of lower-limb prosthesis users experience skin problems.

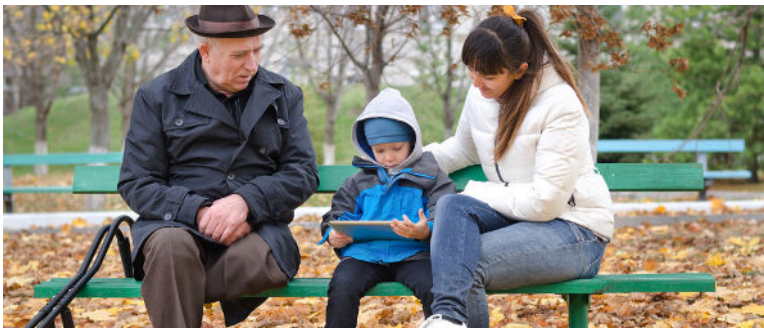
Common Skin Issues Among Lower-Limb Prosthesis Users

- Softening and breakdown of the skin (maceration)
- Pressure sores and blisters
- Irritant contact dermatitis
- Allergic contact dermatitis
- Skin rash (Negative pressure hyperemia)
- Infection of hair follicles in the skin (folliculitis)
- Tender, swollen mass filled with pus (abscess)
- Abnormally dry skin (xerosis)

Some skin issues can be resolved with the use of over-the-counter topical preparations. If you encounter a skin problem that will not go away or heal, contact your prosthetist. Some persistent problems can be resolved with a prosthetic adjustment. Others may require medical intervention.

TIP: Inspect your residual limb regularly using a long-handled mirror to identify skin problems early.

Another common issue individuals with an amputation face is **increased risk of falling.** Your balance is different after amputation. The higher your amputation level is above the knee, the greater your risk is for falling. To minimize your risk of falling, your physical therapist will train you to stand, balance and get around safely with and without your chosen mobility aid. This type of therapy is referred to as **gait and balance training.** It can help to improve your confidence while standing and walking and is an important part of your rehabilitation.



During the first year after your amputation, your residual limb will change size. These **volume changes** are the most pronounced in the first year, but you will continue to experience volume changes throughout your life. Individuals with a lower-limb amputation typically experience two types of residual limb volume changes:

1. The maturation process occurs over the first three to six months of wearing prosthesis
2. Daily fluctuation occurs every day, from morning to night.

TIP: Prosthetic socks can be used to manage volume changes. (See also Sleeves, pg. 17.)

10 TIPS FOR INJURY PREVENTION

1. Be sure your prosthesis fits correctly at all times.
2. Be sure your prosthesis and sound limb are the same height.
3. Use your prosthesis correctly at all times.
4. If you can't or won't wear your prosthesis, assess your risk and have a plan for getting from point A to point B safely.
5. Never hop on your sound-side limb when not using your prosthesis.
6. Be prepared for times when you are not able to use your prosthesis. You should be able to function in your home with or without it.
7. Be aware that medications and/or alcohol can impair your sense of touch, balance, judgment and other bodily functions.
8. Maintain good posture while sitting or standing.
9. Develop close professional and support relationships with your physician, prosthetist, therapist and other prosthesis users so you know where to turn for help if you need it.
10. Use advocacy organizations like the Amputee Coalition to increase your knowledge, support and sense of connectedness.

DESENSITIZATION TECHNIQUES

After amputation surgery, your healed incision site may become hypersensitive to touch and pressure. This can make wearing bandages or a prosthetic device painful. There are four techniques you can use to help make your residual limb less sensitive. Some of these techniques can also help reduce phantom limb sensation. (See also Secondary Conditions, pg. 26.)

For more information on managing phantom pain sensation, contact the National Limb Loss Resource Center®.

1. Massage

Using one or two hands, massage your residual limb using a soft, gentle kneading motion. Massage your entire residual limb. Initially, be cautious over and around your sutured area.

Frequency: 3-4 times daily for 5 minutes.

2. Tapping

Tap your residual limb with your fingertips. Gentle tapping over the suture line is generally OK even before your sutures are removed. Be careful not to tap with your fingernails.

Frequency: 3-4 times daily for 1-2 minutes.

3. Desensitization

Gently run a cotton ball over the skin of your residual limb using a circular motion. When you can tolerate this, progress to a rougher material like a paper towel. When you can tolerate a paper towel, progress to a terry cloth towel.

Frequency: Once daily when you bathe.

4. Scar Mobilization

Place two fingers over a bony portion of your residual limb. Press firmly and, keeping your fingertips in the same place on the skin, move your fingers in a circular motion across the bone. Continue for one minute. Repeat on all of the skin around the bone of your residual limb. Once your incision is healed, you can perform this procedure over your scar.

Frequency: Once daily when you bathe.

RANGE OF MOTION AND FLEXIBILITY

After an above-knee amputation, one of the things your healthcare team will focus on is preventing contractures, a loss of range of motion at one or more of the joints. People with above-knee amputations may have trouble with hip contractures. For some, the hip becomes locked in a forward position. Contractures can be painful. They also can make a prosthetic fitting difficult.

Depending on your overall health and underlying medical conditions, your physical therapist will begin teaching you range of motion and flexibility exercises as soon as possible after your amputation. Among other things, you will work on building and maintaining flexibility in your hips, torso and lower back. It's important to keep up with these activities even after your physical therapy sessions are over. If your needs or medical condition changes, you can revisit your therapist to learn new or revised activities.

KNOWING AND UNDERSTANDING YOUR K LEVEL

Your healthcare team will assess your current activity level as well as your potential functional ability with a prosthesis to determine the most appropriate prosthetic device for you. The K level determination will be initiated by your physician. Be sure your physician has a clear understanding of your goals with a prosthetic device. Communication between your prosthetist and your physician should be encouraged. The Centers for Medicare and Medicaid Services, and most other insurers, use the K Level system to classify functional ability of individuals with lower-limb amputation and determine eligibility for prosthetic components. Medicare uses this system to ensure the prosthetic device you are provided with is medically necessary.

Medicare K Levels[3]

K LEVEL	DESCRIPTION	FOOT/ANKLE ASSEMBLIES	KNEE UNITS
K0	Does not have the ability or potential to ambulate or transfer safely with or without assistance. A prosthesis does not enhance their quality of life or mobility.	Not eligible for prosthesis.	Not eligible for prosthesis.
K1	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.	External keel, SACH feet or single-axis ankle/feet.	Single-axis, constant-friction knee.
K2	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.	Flexible-keel feet and multi-axial ankle/feet.	Single-axis, constant-friction knee.
K3	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.	Energy Storing Energy Return feet (ESER) Microprocessor ankles.	Fluid and pneumatic control knees Microprocessor knee.
K4	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.	Any ankle/foot system appropriate.	Any ankle/ knee system appropriate.

INSURANCE COVERAGE AND

REIMBURSEMENT

Typically, a prosthetic device will be partially covered by your insurance plan. All insurance plans are different, so read your insurance policy and understand what type of prosthetic coverage it provides. Look for annual or lifetime caps on prosthetic coverage as well as any exclusions. Ask your prosthetist if he or she requires a copay and, if so, how much. Be sure to do your homework before switching any health insurance plans. Check with your prosthetic facility before you change your insurance plan. It is essential to advocate for yourself in this process.

For more information about insurance and reimbursement, read the Amputee Coalition's guide, **Insurance Coverage and Reimbursement: How to Be Your Own Advocate.**

It is essential to advocate for yourself in this process.

PROSTHETIC DESIGN OPTIONS

A standard prosthesis is made from a number of different components. These components are connected to a prosthetic socket that fits over your residual limb. The prosthetic socket interface is the most important part of the prosthesis because it connects the wearer to the rest of the prosthetic components. A great deal of expertise goes into fabricating a well-fitting socket. Your prosthetist should work with you to achieve a comfortable fit and offer design options to suit your lifestyle. A poorly fitted socket can lead to pain, sores and blisters on your residual limb. If the socket is uncomfortable, you are unlikely to wear it.

SOCKET DESIGN OPTIONS

There are three basic types of sockets when considering how to design the aspect that allows the user to bear weight. As you read through this section, **make note of any questions you have and consult with your prosthetist about options that best suit your needs.**

Quadrilateral (Quad) Sockets are known for their four district walls or “quad” shape. They generally incorporate a shelf in the posterior aspect for the user to “sit” on while walking. While they can be comfortable, generally they do not offer the best side-to-side (coronal) stability.

Ischial Ramus Containment (IRC) Sockets were designed to stabilize the pelvis and amputated femur during gait. The inner top aspect (wall) of socket cups the ischium, the bone you sit on. By containing this bone, it prevents the socket from shifting from side to side (coronal). While an IRC socket can be less comfortable, it may also offer considerably more control.

Sub-Ischial Sockets are designed to not impinge or contain the ischium. Because they are lower and offer less surface area, this design usually requires some type of enhanced suspension, like vacuum, to allow the user maximum comfort, while still offering the control of an IRC socket.

Not every user has the ability to use this type of design, as control and stability should be equally balanced with comfort.

Design Elements to Socket Design

Flexible Interface/Rigid Frame.
A flexible interface, or soft plastic, is commonly incorporated into the design to enhance the features of the socket. A flexible interface adds areas of flexibility that can allow for improved comfort, adjustability, range of motion and room for the muscle to fire. The flexible interface also contains the soft tissue while the rigid frame supports the weight of the user and attaches the components to the socket.

Dynamic sockets are adjustable with a system to tighten or loosen socket fit. The socket is designed with adjustable panels or straps that can be tightened or loosened. This type of socket allows the user to have some control over their fit should they lose or gain weight or fluctuate in volume from day to day.

Contoured sockets incorporate convex and concave areas to accommodate muscle anatomy. These areas have been reported to allow muscles to fire, help control rotation and help capture the underlying bone, offering more control for the user. This may enhance the feeling of connection between the residual limb and the prosthesis.

SLEEVES

The socket allows the prosthetic device to connect to your residual limb. An additional layer, called a **sleeve** or **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.

Prosthetic **socks** are usually worn over your prosthetic liner and can help to manage residual limb volume changes. These socks come in different thicknesses, or plies. You will have to experiment with different sock ply combinations to figure out what works best for you.

SUSPENSION SYSTEMS

A secure **suspension system** is necessary to keep your prosthesis from falling off. There are a number of suspension systems that can be used to secure the prosthesis on the body:

- A **suction suspension system** consists of a soft liner, a one-way valve, and a sealing sleeve.

- In a **sleeve suspension system**, a suspension sleeve is rolled over the prosthesis, extending onto the skin of the residual limb and sealing off the top of the socket to prevent air from entering or exiting. The sleeve incorporates a valve that releases air as you walk, sit or stand.

- **Pin suspension systems** use a silicone liner with a pin at the end. The pin is inserted into a lock built into the bottom of the socket.

- In a **vacuum-assisted suspension system**, a liner is donned onto the residual limb and a seal is created, where air is not allowed to enter the space between the socket and the liner. A vacuum pump actively draws air out of the area between the liner and the prosthetic socket. The vacuum suspends the prosthesis. Elevated vacuum suspension may improve total contact between the residual limb and the socket, which may offer improved control of the prosthesis.

PROSTHETIC KNEES

The prosthetic knee joint is meant to replicate the function of the human knee. The type of prosthetic knee used for your above-knee prosthesis will depend on your activity level, weight, strength, residual limb length, funding and individual preference. Your prosthetist will be able to review and discuss options that best suit your needs. (See also Knowing and Understanding Your K Level, pg. 13.)

Prosthetic Knee Types

Non-Microprocessor Knees

The **manual locking knee** is the most stable type of prosthetic knee. The knee is locked while walking and must be manually released by the user in order to sit down. While it is safe, the resultant gait is not very normal. The user must circumduct, or swing, the leg wide through swing phase, to clear the toe because the knee does not bend. It is a safe choice for a beginning walker who might lack confidence. It is usually used in the K1 or low K2 population.

A **polycentric knee**, often called a "four-bar" knee, has multiple axes of rotation and is more versatile than a single-axis knee in that it shortens during swing to help the user clear the toe, it tucks under the socket during sitting to create a lower profile, and finally,it gives the user more control over the knee. It is a good option for offering reasonable stability and some voluntary control. It can be used on K1-K4 level users.

A **weight-activated stance braking control knee** is a single-axis, constant-friction knee with a braking mechanism that prevents the knee from buckling when the user has engaged their weight onto the prosthesis. This type of knee is sometimes referred to as a "safety" knee, as it is similar to a locking knee, while offering limited bending during swing. It is typically for the high K1 to high K2 user.

Single-axis, constant-friction knees are basic knees that bend freely, and the speed can be controlled with a screw that slows the knee with friction. Users must rely on their own muscle control for stability. These types of knees are generally used by children. More modern single-axis knees replace the friction control with some type of fluid control. It can be used on K1-K4 level users.

Outside hinges are not commonly used. They are primarily used for knee disarticulation level, as they allow the closest knee center, while offering the maximum voluntary control, or user control. A high K2 to K4 user would use this type of knee.

Fluid controls incorporated into knees allow adjustment of walking speed through the use of liquid or air hydraulics within the knee. This type of knee is typically used by more active patients who vary their walking speeds and do not need assistive walking devices. Most modern **polycentric** and **single-axis** knees now incorporate fluid controls. The fluid can assist in both controlling the swing and stance phase of gait. Adding fluid control will allow the user's gait to be more normal and often offer enhanced stability. Medicare mandates that you must be a K3 or K4 functional level to use this feature.

Microprocessor Knees

Microprocessor-controlled knees (MPKs) use feedback from sensors to adjust joint movement in real time with an on-board computer (microprocessor). The microprocessor controls the speed and ease with which the knee reacts during swing and stance during walking. MPKs incorporate pneumatic, hydraulic or magnetic control, or a combination of these. Because of the reaction time of the microprocessor, the knee has the ability to "instantaneously" react to adjustments in the user's gait, or a potentially dangerous situation. Microprocessor knees have been shown through clinical trials to reduce stumbles and falls, increase gait speed, lower energy consumption and improve quality of life. Microprocessor knees have become the "gold standard" for prosthetic knees at the definitive stage, as they combine the best elements of safety and natural gait. Technically, a user must be K3 or K4; however, a high K2 functional level is also appropriate with good clinical documentation support from a physician to verify the user's ability to become at least a K3 functional level.

Make note of any questions you have and consult with your prosthetist about options that best suit your needs.

Hierarchy of Stability:

In this defined group of non-microprocessor components,
as inherent stability increases, voluntary control decreases.

Hierarchy of Prosthetic Knee
Stability vs. Control

Most Inherent Stability/
Least Voluntary Control

Most Voluntary Control/
Least Inherent Stability

1. Manual Locking Knee
2. Polycentric Knee
3. Weight-Activated Stance Braking Knee (WASB)
4. Single-Axis, Constant-Friction Knee
5. Outside Hinges

Prosthetic Ankles and Feet

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

- **Solid ankle cushioned heel (SACH)** feet are the most basic feet. These feet are rigid and cannot bend. A rubber heel wedge allows for a small amount of ankle movement. SACH feet are typically used by people who do a limited amount of walking with little variation in speed.

- **Single-axis feet** have a single ankle joint that allows the foot to move up and down. Used by people who need stability.

- **Multi-axis fee**t have two or more joints that allow the foot to move up and down and side to side. Used by individuals who need a lot of foot movement for activities like hiking, golfing and dancing.

- **Dynamic-response feet** store and release energy during walking. The full-length foot plate provides a sense of push-off, which results in increased balance and more natural walking.

- **Dynamic response feet** are ideal for more active individuals.

Combined Knee/Ankle Systems

Prosthetic devices with coordinated knee and ankle function can provide the user with increased stability and make it easier for individuals with an amputation to walk on uneven or sloped surfaces. Knee/ankle systems use a combination of hydraulic and microprocessor control and are typically recommended for individuals with a K3-level above-knee amputation.

Finishing Techniques

You can change how your prosthesis looks to suit your personal style. However, it is important to note that covers will add a **significant** amount of weight to your device and can compromise the function of the components. There are a variety of different finishing options available.

- **Cosmetic covers** are typically made of silicone or PVC and are designed to look like a natural limb.

- **Prosthetic sleeves** are Spandex or Lycra covers that slip over the prosthetic socket. They come in a variety of patterns and colors. Prosthetic sleeves can also be used in the laminating process so that the

pattern is permanently adhered to the socket.

- **Fairings** are customizable, removable covers that snap over the prosthesis. 3D scanning technology captures the shape of the sound-side leg, and the fairing is printed using 3D printing technology. Fairings can be customized with any type of pattern or cutouts.

- Designs can be **airbrushed or painted** onto a prosthetic socket, using a process similar to that used to paint automobiles and helicopters.

ASSISTIVE DEVICE OPTIONS

Prosthesis Devices

A **prosthesis** is a tool that can help you regain independence and reach your activity goals after amputation. While your overall health and secondary medical conditions are factors in whether or not you are able to use a prosthesis, the most important consideration is whether or not you want to use one.

Consider the following questions when deciding whether or not you would like to use a prosthesis:

- What do you want to be able to do with the prosthesis?
- What activities would you like to do?
- Do you want to walk or run?
- Do you care about the way your prosthesis looks?

Some people decide that a prosthesis is not for them; others choose to use a prosthesis part-time. Still others use a prosthesis in combination with another assistive device like a cane.

There is no one device that will work for everyone. The key to success is working with your doctor, prosthetist and therapists to address your needs and concerns. Base your decision on what is best for you.

Task-and Location Specific Assistive Devices

Even if you use a prosthesis full-time, there are times when you may still need to use an assistive device (e.g., kneeling walking scooter, crutches or cane), such as:

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

Wheelchair Options

Similar to prosthetic devices, wheelchairs can be customized to meet your individual mobility needs and goals. Before selecting a wheelchair, assess your needs and the type of assistance you expect from a wheelchair. Consider your body strength, whether you plan to transport the chair, and what types of activities you wish to perform in the chair.
Types of Wheelchairs:

- Manual wheelchair
- Ultralight or sports wheelchair
- Motorized wheelchair

Your physical therapist can help you choose the wheelchair that is most appropriate for your lifestyle. Keep in mind that motorized wheelchair use may disqualify you from prosthetic device use.

Assistive Devices

You will most likely use several assistive devices during your recovery and rehabilitation process. As your strength improves and your confidence grows, the amount of support you need from an assistive device will decrease. If you use a prosthesis, you may progress to the point where you don't need an assistive device at all. As you get older, you may come back to using one or more assistive devices.

Progression of Assistive Devices

Less Dependent

More Dependent

- None
- Walking Cane
- Quad Cane
- Single Forearm Crutch
- Single Crutch
- Forearm Crutches
- Crutches
- Rolling Walker
- Walker
- Parallel Bars (used therapeutically)
- Manual Wheelchair
- Motorized Scooter
- Motorized Wheelchair (may disqualify you from prosthetic use)

SECONDARY CONDITIONS

Pain is the most common secondary condition of limb loss. Phantom limb sensation, residual limb pain or back/spine pain affects about 95 percent of individuals with an amputation.

An estimated 80 percent of individuals with an amputation suffer from **phantom limb sensation**. Phantom limb sensation may feel like electrical shocks, burning, cramping, pressure or tingling.

If you are having pain of any kind, talk to your medical provider. While there is no therapy available that claims to cure phantom limb pain, a comprehensive pain management plan can help to address the different kinds of pain you may have and help reduce the likelihood of pain medication misuse or abuse.

Other common secondary problems result from **overuse syndrome** (repeated over-reliance on the sound-side limb). Stress from overuse syndrome can result in osteoarthritis, **osteoporosis** and **back pain.**

TIP: To help avoid or address secondary conditions, maintain regular appointment schedules with your doctor, prosthetist and physical therapist.

For more information and resources on managing pain and/or secondary conditions, contact the National Limb Loss Resource Center®

EMOTIONAL SUPPORT

Limb loss has a significant emotional impact on you and your family. You may experience a range of emotions during the first 12 months after your amputation, and maybe even longer.

Relationships

Limb loss can affect your body image and relationships. Some individuals who have experienced an amputation avoid relationships because they are worried that people won't like them. Some stay away from friends, relatives and strangers due to fear of rejection. These fears are almost always unfounded. Remain involved with people you know, and share your feelings with them.

Body Image Issues and Intimacy

Body image is the way you feel about how you look. When you don't like the way you look or don't look the way you think you are expected to look, it may be hard to accept yourself or be accepted by others.

A negative body image can also limit your intimacy. 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.

If you catch yourself being self-critical, replace those messages with positive ones. When you project yourself as comfortable and at ease with who you are, others tend to be more at ease, too.

Avenues for Emotional Support

Most individuals who have experienced an amputation are well-adjusted and live full and happy lives. Some even say their relationships with family members grew stronger after their amputation.

While friends and family are important members of your emotional support network, it can be helpful to establish friendships with other individuals who have experienced an amputation. People who have experienced an amputation and understand your challenges are in an excellent position to provide you with perspective and hope.

The Amputee Coalition offers many avenues for emotional support:

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

The **Your New Journey folder** describes these programs in more detail.

If you are having difficulty coping or are experiencing significant emotional distress, you should talk with a counselor or mental health professional who can help you to establish healthy coping mechanisms.

HOME MODIFICATION

Your home may need modifications so that you can get around it the way you did before your amputation. Adaptability features are quick changes that can be made to accommodate your needs without having to completely redesign your home.

- Installing grab bars in bathrooms.
- Installing hand rails in entryways.
- Installing swing-out hinges to widen doorways.

If you are purchasing or renovating a home, look for homes or plans that incorporate universal design elements. Universal design uses ergonomic principles to increase efficiency, reduce repetitive stress to the body, and eliminate barriers and hazards to promote safety, independence and dignity. Universal design incorporates some or all of the following features:

- Wider hallways and doors
- Barrier-free entrances
- Adjustable closet rods, shelves and counters
- Touch switches.

VEHICLE MODIFICATION

Almost any type of car, minivan, SUV or truck can be modified so that individuals with an amputation can drive them. Hand controls allow drivers to operate gas and brake controls by hand instead of by foot. In most cases, the original pedals are not affected, so other people can drive the vehicle normally. Left foot gas pedal adaptations for automatic vehicles provide an accelerator pedal to either side of the brake pedal.

If you are considering modifying your vehicle with accessibility controls, you must be evaluated, trained and endorsed by a certified driver rehabilitation specialist (CDRS) before operating the vehicle. Check with your insurance carrier and your state Department of Motor Vehicles to find out more information on any additional requirements.

CONNECTING WITH LOCAL RESOURCES

The Amputee Coalition operates the National Limb Loss Resource Center® to connect individuals with limb loss, their family members and caregivers to information and resources to help them live independently with limb loss. Our resource specialists can connect you to programs, services and other resources available in your community.

National Limb Loss Resource Center®
Phone: 888-267-5669
Web: **Amputee-Coalition.org**

SPECIALTY PROSTHETIC COMPONENT

Lower-limb prosthetic devices are designed to replace the function and/or appearance of your missing lower limb, but they are generally not designed to tackle high-endurance activities like distance running or sprinting. Fortunately, there are a variety of activity-specific feet and legs that can help you take on just about any activity you are interested in. These include:

- Running legs and running feet
- Swim legs
- Biking legs and cycling feet
- Rock-climbing legs and feet
- Shower legs
- Ski legs and feet
- “House” leg – a basic leg just functional enough to get around the house, use the bathroom, etc.

Talk to your prosthetist if you are interested in an activity-specific prosthetic device.

RESEARCH AND DEVELOPMENT

Prosthetic devices and socket technology are improving all the time. Here is just a glimpse at some new and developing technologies and procedures for lower-limb prosthesis users:

- **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.

- Researchers are exploring ways to restore lower-limb function to individuals with spinal cord injury. **Neuroprosthetics** allow for individuals with spinal cord injuries to control prosthetic devices with their mind. Research in this area has implications for future neuroprosthetic devices for individuals with an amputation.

- **Powered robotic foot/ankle devices** may allow individuals with an amputation to walk more naturally, improve their balance, and eliminate compensatory movements that may be necessary with currently available lower-limb prosthetics.

- Research is currently under way to create a more comfortable **prosthetic socket** that improves hip range of motion and connectivity between the residual limb and prosthesis. Researchers are also working on the development of a dynamic prosthetic socket that monitors and adjusts to residual limb volume changes.

- **Phantom limb sensation** research is ongoing. This research could help to improve the quality of life for millions of individuals who have experienced an amputation.

The Amputee Coalition is committed to promoting research that improves the lives of those affected by limb loss.

MORE RESOURCES

This booklet is just one of the resources the Amputee Coalition provides to help amputees live well with limb loss. 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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3. Outcome Measures in Lower Limb Prosthetics. (2005). Proc. of State of the Science Conference, Chicago. Washington, D.C.: American Academy of Orthotists and Prosthetists. Retrieved from **oandp.org/olc/course_extended_content.asp?frmCourseId=ACA066EC-443A-4822-822C-89BC1CBD684E&frmTermId=k-levels.** Accessed January 16, 2016.

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.

SCAN ME

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amputee coalition™

For more information, please contact us at:

601 Pennsylvania Avenue NW,
Suite 420, South Building
Washington, DC 20004

TOLL FREE: 888-267-5669

Amputee-Coalition.org