



# The Next Step

The Rehabilitation Journey  
After Lower Limb Amputation

**My Personal Record**

**My Personal Record**

The Next Step is issued to: \_\_\_\_\_

Date of surgery: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

Surgeon: \_\_\_\_\_

Primary care doctor: \_\_\_\_\_

Rehab doctor: \_\_\_\_\_

Nurses: \_\_\_\_\_

Occupational therapist: \_\_\_\_\_

Physical therapist: \_\_\_\_\_

Kinesiotherapist: \_\_\_\_\_

Prosthetist: \_\_\_\_\_

Social worker: \_\_\_\_\_

Psychologist/Psychiatrist: \_\_\_\_\_

Socket: \_\_\_\_\_

Liner: \_\_\_\_\_

Socks: \_\_\_\_\_

Pylon: \_\_\_\_\_

Foot: \_\_\_\_\_

Shoe: \_\_\_\_\_

Knee: \_\_\_\_\_



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# Introduction

It is very important for you and your family to have as much information as possible about all phases of amputation rehabilitation. It will give you a greater level of trust in your team and may improve your outcomes immediately after surgery and through rehabilitation. You are also more likely to have realistic expectations if you understand the recovery time, the processes included in recovery and rehabilitation, and the sequence of events necessary for healing. This handbook will help to guide you through your amputation, recovery, and rehabilitation.

This handbook was written by several clinicians and members of rehabilitation teams in the Veteran’s Administration (VA) and the Department of Defense (DoD) who care for patients who have had an amputation of a lower limb. It is based on the VA/DoD Clinical Practice Guideline (CPG), Rehabilitation of Lower Limb Amputation (2017), that describes the best methods for treating veterans and service members with amputation, and is based on the latest research and expert opinion. This CPG guides rehabilitation teams in providing the best possible care and divides the rehabilitation process into 5 stages:

1. Pre-Operative
2. Post-Operative
3. Rehabilitation
4. Prosthetic Training
5. Long-term Follow-up

This handbook has been divided into five chapters based on these stages of care. This should make it easier for you to find answers to questions you may have, it also helps you learn about what to expect in each phase as you continue to progress through the rehabilitation process. This book is not meant to answer specific medical questions. You should discuss these with your health care provider. It will, however, encourage you to ask more questions and find more answers. It will also provide you with a personal notebook. Use it to write down questions or instructions as you talk with your team, take notes, list reminders or just use it as a personal notebook to capture your own experience as you recover from your surgery and prepare to take your NEXT STEP!

## 0.1 The Rehabilitation Journey

Your journey through amputation rehabilitation will be smoother if you have an understanding of the time needed for recovery. Although each person’s journey may vary in length, many people require between 12 and 18 months.

**Pre-Operative Phase.** Your pre-operative phase starts with the decision to amputate. This phase includes an assessment of your health and function and decisions about strategies that will be applied after the surgery (e.g., pain management and care of your residual limb). During this phase, many topics will be discussed with you including the best level of amputation for your specific condition; your needs for education about your amputation; emotional support; physical therapy and conditioning; nutritional support; and pain management.

**Post-Operative Phase.** Your acute hospital post-operative phase is the time in the hospital after the amputation surgery, and may range from 5 to 14 days. During this phase your medical care will focus on healing your surgical area and prevention of complications. You will learn to care for your amputated limb and begin your physical and occupational therapies. You will receive support from your care team as you adjust to your new condition.

**Rehabilitation Phase.** Your rehabilitation phase begins when you are released from your acute surgical care. This may last up to 6 to 12 weeks after the surgery. The focus of care shifts from surgical and medical issues to rehabilitation. Rehabilitation will focus on maximizing your strength, your ability to take care of your daily activities, and your reintegration to home and community. Rehabilitation at this phase is aimed at improving your function to enable you to achieve your goals with or without an artificial limb (prosthesis).

**Prosthetic Training Phase.** Your prosthetic training phase starts when you receive your first prosthesis. This phase includes training in walking, rehabilitation activities, and emphasis on integration into the community. It also will include vocational and recreational activities that you enjoy.

**Long-term Follow-up Phase.** In this phase, you will move toward greater social reintegration and higher functional training and will become more independent. This phase is not defined by an end-point. Continued assessment and interventions are part of your life-long care. After you have met your major goals for rehabilitation, you will continue

to receive follow-up visits. These are designed to help prevent further amputation and secondary complications as well as promote the care of your residual and non-amputated limbs. In addition, follow-up visits will continually assess your needs for new or different equipment or therapy depending on life changes you may experience. Your team will work with you to accomplish any new goals or solve any new problems that may arise.

## 0.2 Interdisciplinary Team

Your rehabilitation team consists of:

- **You!** Your active participation is encouraged and necessary for your healing. You should feel free to tell your team about your goals and concerns. The team strives to pay attention to your needs and to involve you in the decision making.
- **Family** Your family is important. Their participation is welcomed. They can be trained to assist you in your successful transition home.
- **Surgeon** A surgeon will perform your amputation surgery. Depending on your situation, this might be a vascular surgeon, general surgeon, orthopedic surgeon, plastic surgeon, or a trauma surgeon. Your surgeon has two primary goals when performing your surgery: 1) to remove the diseased, injured, or dysfunctional part of your body; 2) to reconstruct the remaining part of your limb in a way that will promote wound healing and create the best possible residual limb.
- **Physiatrist or Rehabilitation Doctor** prescribes your prosthesis and guides your overall rehabilitation process in collaboration with the whole rehabilitation team. The rehabilitation doctor also prescribes medicines and tests, and consults with your surgeons and other doctors as necessary.
- **Nurses** will care for you from your arrival until your discharge from the hospital. They will monitor wounds for infection, provide pre-

operative and post-operative care, monitor pain medication and assist in the activities of daily living.

- **Occupational Therapists** help with new ways to do daily activities such as dressing, bathing, using the toilet, and cooking. The therapists will order equipment you need for the home, such as grab bars and shower chairs.
- **Physical Therapists** help you with strength, endurance and getting around. Therapists can also help with pain in your residual limb, and help you to use walking aids and wheelchairs. They will create an exercise program to help you prepare for a prosthesis and/or return to previous activities; and help you care for your residual limb.
- **Kinesiotherapists** (present at some VA hospitals) provide exercise programs to enhance your strength, endurance and mobility.
- **Prosthetists** design and fit the prosthesis. You will keep in contact with the prosthetist about any concerns with your prosthesis.
- **Psychologists/Psychiatrists** can help with emotional adjustment and coping.
- **Recreation Therapists** help you with leisure activities—old and new. They also organize community outings and often have lists of local organizations that you may be interested in.
- **Social Workers** can assist by connecting you with VA and community resources for financial, housing, job re-training, and transportation assistance; planning for hospital discharge, and counseling for coping with chronic illness and life changing events.



## 0.3 Coping with Lower Limb Amputation

When someone loses a body part, they naturally experience a variety of emotions. Each person feels and reacts differently depending on their personality and the circumstances of their amputation. Emotions may

include depression, anxiety, sadness, frustration, embarrassment or anger, even though the amputation was medically necessary. Some people feel relieved that a painful limb was finally amputated. Others take it as another one of life's challenges and work to meet the challenge in the best way they can.

**Body Image** refers to the personal view you have of your own body. After amputation, a person's body image changes, because the shape and look of the body is different. This change in your body image is real, and it may take some time to adjust to it. If you have a prosthesis, you will need to get used to seeing your body both with and without the new leg. Changes in your body image may affect your self-image, confidence, and feelings about your sexuality. Additionally, your family, friends, acquaintances, and members of the general public may have reactions to the way your body now looks. The members of the rehabilitation team can help you work through your feelings, regain perspective, and figure out how to respond to others.

There is no right or wrong way to feel after an amputation. This is a very personal experience. Emotional recovery, like physical recovery, is based on your own timetable and other factors. These include age, **sex**, circumstances of your limb loss (trauma, disease, birth), how you coped with problems in your life before your limb loss, support or lack of support from family or friends, cultural values and norms, and socioeconomic factors.



### **What I need to do**

Some suggestions for coping with this experience that you can try:

#### **0.3.1 Physically**

1. Get your rest. Each day, get out of bed, get dressed, and, if possible, go out of the house.
2. Try to get back to doing as many of your usual daily activities as possi-

ble. Work with your rehabilitation team to identify what things you like to do, and how to remove barriers or "roadblocks" to those activities.

3. Make sure you eat well. Eating healthfully can improve your sense of well-being, prevent illness, and provide you with energy when you need it.
4. Get involved in physical and recreational activities that do not cause you pain. Exercise and gentle movement will release endorphins to help decrease depression.
5. Practice deep breathing. This will help relax muscles, decrease pain, and relax and focus the mind.
6. Decrease alcoholic intake. Alcohol is a depressant. Eliminate other drugs that you use to self-medicate. If using prescription drugs, make sure you take them as prescribed.
7. Accentuate your best features; don't focus on the loss. For example, if you have beautiful skin or eyes, a bright smile, a terrific figure or a great personality, this is the time to value your assets.

#### **0.3.2 Emotionally**

1. Spend plenty of time with supportive family and friends.
2. It is common to feel anger, frustration, self-criticism, and sadness from time to time. It may be helpful to make room for these feelings as they come and go. If you find yourself in a low, sad mood all or most of the day for many days at a time, you may be experiencing depression. Tell your doctor or other medical professional whom you trust if you believe you may be depressed.
3. Write about your feelings. You may do this by writing letters or keeping a journal.
4. Assert yourself and communicate clearly. Tell those around you what you need and don't need. For example, you may need to expend less energy on a particular day. Go to a movie or rent a video, especially if the weather is harsh.

5. Tell your loved ones you are experiencing grief and talk about your loss together. This gives your loved ones the chance to express their feelings since they, too, have to adjust to your loss. Don't ignore the problem. Be honest and talk it out. This will give you and yours a greater chance to heal and adjust.
6. Remember, people want to help but often don't know what to do to support you. So ask, ask, ask! You can remain independent — but let go of the controls for now. Allow others to give to you so you can rebuild your energy.
7. Explore the potential benefits of meditation, guided imagery and hypnotherapy.
8. Contact a support group.
9. Laughter is a healer of depression, so add humor. Don't be afraid to laugh at yourself.
10. Get professional help if the depression becomes overwhelming. Everyone needs help at some point in his or her life. You are worth it.
11. Most importantly, know that these feelings may decrease over time. But for now, get support!

### 0.3.3 Mentally

1. Commit yourself to work with the medical staff, physicians, nurses, occupational and physical therapists, prosthetists, and psychologists, even when you don't want to.
2. Do not make big decisions such as beginning or ending a relationship, or buying or selling a house or car, when you are feeling overwhelmed or sad. You may regret this later.
3. Go to a mental health professional for evaluation and medication if necessary.
4. Seek alternative medicine, massage, acupressure, acupuncture and hypnotherapy for pain management, phantom pain, sleeplessness,

anxiety and depression.

5. Replace negative self-talk about your body and life with positive thoughts and ideas.
6. A peer visitor can be an important part of your support system, but is not a professional counselor, therapist, advisor, or problem solver. A peer visitor may be able to relate to your situation, however, so inquire how to arrange a visit.

### 0.3.4 Spiritually

1. Keep your dreams and create a new definition of success. Make goals and objectives for the future, and start small.
2. Accept support from loved ones while remaining independent.
3. Make new rituals/memories thus creating hope for the present and future.
4. If your religion or spirituality is important to you, become more involved with it. The Chaplain/Clergy service is also available as a source of support, regardless of your religious preference.
5. Remember: A part of you is only physically gone or altered; the core of you is still the same.

## 0.4 Introduction Summary

Amputation is an enormous loss and learning to adjust is a process that takes time — so be gentle with yourself. Try not to isolate yourself or withdraw from people. Use your experiences to build new memories and start new traditions to reach your goals. There will be adjustments for your disability along the road to success — but it is still your path. Who you are has not changed. Always remember, you are much more than your physical experience.





# 1 Pre-Operative Phase

## 1.1 What Will Happen to Me?

This is your opportunity to learn about the plans for your amputation and what will happen afterwards. You will meet and talk with several members of your team: your surgeon, your rehabilitation doctor, your physical therapist and your prosthetist before the surgery. They will talk with you about your level of amputation (how much of your leg will need to be amputated), the type of dressing that will be used on the surgical site, healing of the surgical incision, controlling the pain associated with your amputation, the type of therapy you will have after the surgery, and your course of recovery. They should talk to you about your goals as well as what the team would like to accomplish. You will begin the coping and adjustment process.

**K**nowledge about what will happen to you is very important. Make sure all your questions are answered before you go into surgery so you will be as prepared as possible for the next phase. Your team is here for you and your family to help you through this process.



## 1.2 Coping with the Unknown

### 1.2.1 The Emotional Challenge

The loss of a limb is one of the most significant challenges that you will ever encounter. It is different from any other illness or medical condition you may have, because it is a highly visible, physical loss. You are reminded of it each time you get dressed. It has an effect on your mobility and can also impact your activity at work, your hobbies, and your independence.

### 1.2.2 Coping Strategies

Many people find that the more information they have, the easier it is to cope with the idea of amputation before the surgery takes place. Ask questions about the medical procedures, what you can expect in surgery and immediately afterward, what your prosthetic options are, etc. This will help you have a better sense of acceptance going into surgery, which will in turn help you cope with the reality you face after surgery. Each person handles a crisis differently, because every person's life experiences are different. Use what you know works best for you when you are experiencing a difficult situation.

### 1.2.3 Peer Support

You will certainly have some doubts and questions about your or your loved one's future — doubts and questions about working, raising a family, maintaining a relationship, caring for yourself or your loved one, and doing basic daily living activities. Other questions may be more technical or focused on immediate concerns:

- Is the pain terrible?
- How long will I or my loved one be in the hospital?
- Will it hurt a lot after the surgery?
- How does the artificial limb (prosthesis) stay on?

So where do you turn for information, guidance and emotional support to help you through the questions, decisions, choices and alternatives you will face as you enter this new path in life? Who can give you insight and demonstrate that life goes on and can again become happy, full and productive? In many cases, only another person with an amputation who has experienced a similar situation, had similar questions, and faced similar decisions can really provide the answers you need. That is the power of peer support.

Photo by 1st Lt. Ryan Hawley



A peer visit from an Amputee Coalition certified experienced amputee can be most helpful before amputation surgery. A peer can answer your questions regarding such issues as pain, mobility, artificial limbs, adaptive devices, services you may require after your release from the hospital, and local resources that

can help you. A peer visit can also help lessen your feeling of being alone in your situation, because only another amputee can fully understand the amputation experience and recovery process. Peers can help new amputees jump-start their move to a new life by sharing information, by serving as models of success, and by offering understanding and support.

Whether your peer contact comes from an individual or a local amputee support group, the benefits are great. Peers can also serve as a model of success for others involved in the lives of new amputees and provide them with the same knowledge and experience they do amputees. They assist amputees and all of these other individuals while, in turn, helping them also become models of success. That is the power of peer support.



### *What I need to do*

#### **1.2.4 Ask Questions**

Many patients feel a sense of hopelessness and loss of control of their lives after losing a limb. Your treatment is truly a team effort, and you are the central part of that team. You can do a lot to ensure a successful outcome. Ask questions and educate yourself about rehabilitation. Ignorance is the enemy.

- ➔ Talk with your surgeon about the surgery and what you should expect.
- ➔ Talk openly with the amputation care team about your desires and needs. This will help them tailor your treatment to meet your needs.
- ➔ Speak with a prosthetist about your prosthetic options.
- ➔ Meet with your physical therapist and occupational therapist to start conditioning exercises, which can help speed your recovery.
- ➔ Read educational materials that your team recommends.
- ➔ Finally, talk to other people with amputations. There are some questions that your team of therapists will not be able to answer. Sharing your experiences with others will help you conquer the obstacles that you are facing.

### 1.2.5 Preparing for Your Operation

The way you prepare for the operation may affect your ability to heal properly, or may complicate the healing of the wound after surgery.

You should:

- Improve your nutrition
- Stop smoking
- Avoid drinking alcohol
- Take care of your diabetes — control your blood sugar and follow recommendations of your health care team
- Take any prescription medication after discussing it with your doctor

## 1.3 The Surgery

### 1.3.1 Amputation

The word “amputation” is used to describe the removal of all or part of a limb.

Sometimes there can be confusion between the words amputation and disarticulation. You may hear the word “amputation” used more precisely to describe the removal of a limb by cutting through one or more bones and the word “disarticulation” used to describe the removal of a limb by cutting through a joint.

You are going to be part of this decision, along with your surgeons, doctors, prosthetists and therapists. The goal is to restore your limb to a functional level, while maintaining as much limb length as possible.



Your surgeon will explain how much of your limb needs to be amputated and will try to preserve as much of your leg as possible.

The level of amputation will be based upon:

- Your overall general health
- Your to ability to heal
- Best possible length for function and quality of life in the future

### 1.3.2 Level of Amputation

There are many possible anatomic levels of amputation in the lower extremity, and the level chosen depends on the extent of damage or disease in your leg.

The amputation level does affect your rehabilitation plan. The level can determine what rehabilitation is needed prior to prosthetic fitting, the type of prosthesis that may be appropriate, and when prosthetic fitting may begin.

In general, moving from the toes or forefoot up towards the hip and pelvis will increase the complexity of the rehabilitation, and the complexity of the prosthetic device.

#### Forefoot

The forefoot levels are defined as loss of one or more toes, but the metatarsal heads (ball of the foot) remain intact. Loss of toes puts the foot at risk for pressure points, sores and ulcerations. Prosthetic devices and special shoes help improve the distribution of pressure and walking forces. The goal is not to replace the toes, but to improve walking and protect the amputation site and the remaining foot.

## Midfoot

Amputation in the middle of the foot removes the important metatarsal heads (ball of the foot) which takes the weight at the end of each step. The bones in the middle of the foot have irregular shape and surfaces, and the surgeon does try to shape to remaining bone as best they can. A smooth shape is often difficult to achieve.

Prosthetic devices usually have a long footplate that extends past the amputation site to protect the remaining part of the foot and improve walking. Without proper protection, new sores or skin ulcers can lead to failure and more surgery.

After midfoot amputation the prosthetic device may or may not need to rise above the ankle to add stability and control to the remaining foot. Some patients have enough of the foot left to feel stable, but many do not. Many people with midfoot amputation do not want the prosthetic device to rise above the ankle to the calf level, most ultimately walk better with a prosthetic device that adds stability to the heel and the ankle.

## Hindfoot Amputation

Amputation in the back of the foot preserves the heel pad, some of the calcaneus (heel bone). There can be differences in the surgical technique used, what bone or bones are left in the hindfoot, and whether the bones and ankle joint are fused together.

Hindfoot prosthetic devices usually need to extend all the way up the calf to safely transfer the high walking forces from the footplate up to the lower leg. Many hindfoot prosthetic devices now include a proximal tibial socket (near the front of the shin bone), removable and adjustable struts, and wedges to subtly adjust the position of the hindfoot.

After full healing, many hindfoot amputees can do a limited number of steps on the hindfoot without a prosthetic device. Typically this helps

getting to and from the bathroom and in and out of a shower. Excessive walking without a device is not recommended as high pressure points can lead to skin sores, and a single point of contact can lead to increased risk of falling.

## Ankle Disarticulation

Amputation at the ankle level removes all the bones of the foot, but uses the heel pad to cover the end of the tibia bone. This level can be called an ankle disarticulation (removal of a limb by cutting through a joint), or a Syme's Amputation. It is named after the Edinburgh surgeon James Syme (1799-1870). Historically, he performed the ankle disarticulation to minimize blood loss and to avoid having to cut through bone.

A modern ankle disarticulation removes all the bones of the foot and also trims the prominent bone on each side of the ankle (called the malleoli). After ankle disarticulation the heel pad can become very mobile. Some surgeons now prefer a hindfoot amputation over an ankle disarticulation, in many cases, to improve the ability to walk on the heel area.

The ankle disarticulation prosthesis is often very wide and thick at the ankle level in order to contain and protect a mobile heel pad. The ankle level prosthesis also requires a traditional socket that goes up to the knee area. Many patients and families do not think the ankle level prosthesis looks attractive.

## Transtibial Amputation (TT)

When the amputation occurs between the ankle and the knee joint, it is referred to as transtibial amputation. The term "below knee amputation (BK)" is still commonly used, but is not the most current terminology.

Most of these amputations are done in the upper half of the lower leg in order to use some calf muscle to pad the cut ends of the tibia and the fibula. It also allows more space between the end of the residual limb

and the ground to incorporate higher technology prosthetic components. When the amputation is done in the lower half of the calf, there is less soft tissue padding over the ends of the bones, and less space for the prosthetic components.

Transtibial amputation is the lowest amputation level with a functional anatomic knee joint. A functional anatomic knee joint is vital for transfers, for sit to stand, and for the power to step up a curb or stair with the amputated leg. The knee is so important, that extra efforts are often done to save a functional anatomic knee joint if possible.

Transtibial prosthetic devices have a socket, pylon, and foot and ankle components. Suspension strategies to keep the prosthetic in place can include suspension sleeves, straps, liners with pins, liners with suction seal in technology, and vacuum pumps to create suction suspension.

Some individuals, who cannot walk, are still provided prosthetic legs with the goal of improved transfers and improved sit to stand activity. This helps getting into and out of a wheelchair, and getting on and off the toilet.

### **Knee Disarticulation (KD)**

When the leg is removed at the level of the knee joint, it is called a knee disarticulation. Occasionally the term “through knee amputation” is used.

The full length of the femur (thigh bone) is preserved, and the patella (kneecap) may or may not be preserved. The most functional knee disarticulation amputees typically have some muscle padding over the end of the femur, and can tolerate direct weight transfer through the end of the amputation site. This direct transfer of weight at the end of the amputation site is called end-bearing.

This is different from the transtibial (through the shinbone) and transfemoral (through the thigh bone) amputees who cannot tolerate much direct weight transfer at the end of the amputation site, and therefore have limited end-bearing.

Advantages of the knee disarticulation included improved end bearing, longer femur improves strength and control of the thigh, and more balanced thigh muscles especially if the quadriceps and hamstring muscles can be reattached. If significant end-bearing is present, then the prosthetic socket does not need to contain or load the pelvis (ischium), and a lower prosthetic socket is possible. A lower prosthetic socket can be more comfortable, especially when the amputee is sitting.

A visible disadvantage of the knee disarticulation is that the knee joint is lower than the other leg. This is needed because of the muscle padding over the condyles (smooth surface area at the end of a bone), the socket, and the attachment of the prosthetic knee to the socket all take space pushing the knee level distally (away from the body). Often the knee centers can be 1 ½ to 2 inches lower than original level, and the level of the non-amputated leg. This is very visible when sitting, and visible but more subtle when walking.

Patients and families should know that many healthcare providers debate the advantages and the disadvantages of the knee disarticulation. Some have very adamant or emotional point of view. In reality, most knee disarticulation amputees who have comfortable end-bearing, and good thigh muscle strength believe that the advantages of a lower socket and improved thigh control definitely outweigh the disadvantages. If the end of the amputation is very painful, and end-bearing is not possible or painful, then the amputee typically might be better served with revision to the higher transfemoral (through the thigh bone) amputation level. The medical literature is mixed with articles that are strongly supportive, and articles that highlight the disadvantages.

### **Transfemoral Amputation (TF)**

When the amputation occurs between the knee joint and the hip joint, it is referred to as transfemoral amputation. The term “above knee amputa-

tion (AK)" is still commonly used, but is not the most current terminology. In general, the femur (thigh bone) is left as long as possible to still maintain some muscle and soft tissue padding.

Thigh control and balance are dramatically affected with transfemoral amputation. Many patients feel that their thigh is "unbalanced and lacks control". This occurs because the muscles that bring our thigh forward (flexion) and out (abduction) attach at the top of the femur and retain their strength. The muscles that pull our femur back (extension) and in to the midline (adduction) attach distally (away from) and are compromised with a transfemoral amputation.

Many transfemoral amputees state that their thigh rests up and out, and is very weak in moving back and in. Regaining strength and balance of the thigh, and preventing hip contractures that prevent the thigh from normal motion or alignment are vital early goals following transfemoral amputation. If a hip flexion contracture develops, and the thigh is stuck in a forward position, prosthetic fitting and alignment becomes incredibly difficult. Prevention and early therapy on thigh strength and range of motion is very important.

Once the anatomic knee joint is lost, transfers and "sit to stand" become much more difficult. A prosthesis for a transfemoral amputee does not really make transfers easier and can make them more difficult. Commonly, many healthcare teams will require a transfemoral amputee to master three basic skills before moving forward with prosthetic fitting. The three basic skills are:

1. The ability to transfer from bed to chair independently
2. The ability to go from sit to stand, and standing to sitting independently
3. The ability to go up and back in a standard parallel bars using their arms and a one leg gait.

Rehabilitation after amputation is very goal and task focused. The three basic skills are vital to master whether or not a prosthetic leg is used. The reason for emphasis on the three basic skills is to improve core and strength in both arms. Some patients prove mastery of the three basic skills on day one, and others struggle. If prosthetic fitting and prosthetic rehabilitation is attempted before mastery of the three basic skills, success is very unlikely.

Transfemoral prosthetic fitting is more complicated than transtibial prosthetic fitting because of the need to correctly align the patient's center of gravity, the socket, the new knee joint, and the new foot/ankle components. Correct alignment is vital to having a stable system to stand on, and for the sections of the prosthesis to move correctly in walking. More time is required in fitting and aligning the prosthesis, and significantly more time is needed in rehabilitation and training.

### **Hip Disarticulation (HD)**

When amputation occurs up near the hip joint, and there is no femur (thigh bone) or thigh remaining that functions to fit and use a transfemoral prosthesis then a whole new situation arises with a whole new set of challenges. A modified hip disarticulation exists when there may be a small amount of proximal (closer to the center of the body) femur or hip bone left in place but it is not enough to fit into a transfemoral socket. Some surgeons leave a small amount of the femoral hip bone (the ball portion of the hip joint) to fill the void of the acetabulum (the cup portion of the hip joint). There is debate on the whether this improves weight bearing through the amputation site. A true hip disarticulation occurs when all of the femur including the ball portion of the hip joint is removed, but the entire pelvis, including the acetabulum (cup portion of the hip joint) is left intact. In these cases, the cup portion of the hip joint is often filled and padded with a muscle flap.

Hip and pelvic level prosthetic fitting is even more complicated than transfemoral prosthetic fitting because of the need to correctly align the patients center of gravity, the socket, the new hip joint, the new knee

joint, and the new foot/ankle components. Correct alignment is vital to having a stable system to stand on, and for the sections of the prosthesis to move correctly in walking. More time is required in fitting and aligning the prosthesis, and significantly more time is needed in rehabilitation and training.

The prosthetic hip joint cannot be placed where the anatomic hip joint was located. The anatomic hip joint site is filled with muscle or skin flaps and is covered by the prosthetic socket. The best alternative location to the anatomic hip site is usually in front of the socket and not directly under the socket. Placement under the socket makes sitting almost impossible, and placement out to the outside makes wearing regular clothing nearly impossible.

Mastery of the three basic skills prior to prosthetic fitting is vital for the hip and pelvic level amputee.

### **Pelvic Level Amputation**

Once part of the acetabulum or pelvis is removed, then technically the level is called a pelvic level amputation, and is sometimes called a “hemipelvectomy”.

The right and left ischium (the curved bone forming the base of each half of the pelvis) are the parts of our pelvis that we sit on. Differences exist in amputees who still have the ischium on the amputated side. The iliac wing (large expanded portion which bounds the greater pelvis) is the part of our pelvis that contains the abdominal contents. Fitting a pelvic level amputee differs if they have or do not have the iliac wing on the affected side. Finally, the sacro-iliac (rigid joint at the back of the pelvis between the sacrum and the ilium) area connects the back of the pelvis to the lower spine. If the sacro-iliac region is removed, often the nerve roots are damaged or removed, and the normal connection of the pelvis to the spine is lost. Some pelvic level amputees have difficulty or loss of bowel and bladder function.

Pelvic level prosthetic fitting is even more complicated than transfemoral prosthetic fitting because of the need to correctly align the patient's center of gravity, the socket, the new hip joint, the new knee joint, and the new foot/ankle components. Correct alignment is vital to having a stable system to stand on, and for the sections of the prosthesis to move correctly in walking. More time is required in fitting and aligning the prosthesis, and significantly more time is needed in rehabilitation and training.

The part of the leg that remains after your amputation is called the “residual limb.” It is also often called the “stump.” Some members of the team may use any of these names. If you have a preference, let your therapist know.

### **1.3.3 Post-Operative Dressing**

Postoperative dressings are used to protect the residual limb, reduce swelling, and prevent loss of joint motion. There are types of postoperative dressings that are commonly used include Soft Dressings, Vacuum Assisted Closures (also called wound VACs or suction dressings), and Rigid Dressings that include plaster or plastic to help protect the amputation site. The surgeon will decide before the operation, which of these will be best for you. You will have the opportunity to see the surgical incision end of the residual limb when the doctor or the nurse inspects the wound and changes the dressing. The first dressing change may be painful and you should ask for pain medication before it is done.



## 1.4 Managing Pain

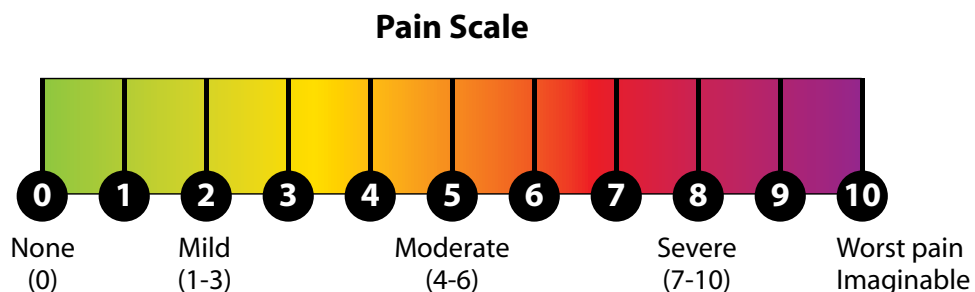
Pain is very common in the limbs of people who require amputation surgery.

The most common types of medicines used to control pain at this phase are narcotic pain medicines that can be administered either through a vein or by mouth. If your level of pain does not require a narcotic medication, your provider may suggest an NSAID (non-steroidal anti-inflammatory drug) or other pain medication instead.

Effective pain management will also help reduce anxiety and distress.

Effective pain management is always a balance between trying to eliminate your pain, and allowing you to be alert enough to participate in your health care. The goal is to control your pain to a manageable level rather than get rid of it completely.

The following scale will be used to assess your pain levels. It ranges from no pain at all (0) to the worst pain you can imagine! (10):



Your psychological state can strongly affect the amount of pain you experience. The more distress you feel the more pain you will feel. Therefore managing stress and anxiety levels is an important part of pain control.

Members of your health care team can help answer your questions and concerns.



### *What I need to do*

When your nurses and physicians ask you about your pain, let them know! You will be asked to rate your pain on a scale of 0 to 10, with 0 meaning no pain, and 10 meaning severe pain.

Let your health care team know if you feel that your pain is not being adequately controlled.

If you are feeling anxious or distressed make sure to let your health care team know. Feel free to ask them to refer you to someone who can help you as you prepare for surgery.

## 1.5 Pre-Operative Phase Summary

- Pay attention to your feelings and use suggested coping strategies.
- Write down your questions and get them answered.
- Set goals for yourself and let your team know about your goals.
- Make sure you are in the best possible health before your surgery.
- Let your physicians and nurses know about any pain you may be experiencing.

**Be strong and positive, and let the journey begin.  
Good luck with your surgery.**





## 2

## Post-Operative Phase

### 2.1 What Will Happen to Me?

During this short period, you will recover from your operation and start to learn how to safely accomplish simple, everyday activities with your new amputation. The main concern during recovery is the healing of the surgical incision and preventing any complications such as stiffening of the joints and infections. You will learn how to take care of your residual limb to help with the healing process.

# T

he rehabilitation team will teach you how to get back to everyday activities that you will need to do when you return home. They will help you learn to move around in bed and perform simple exercises that can prevent stiffening or loss of motion in your joints. They will teach you how to safely get in and out of your bed and begin getting around with a wheelchair. You will also learn how to safely do daily activities that you did before your amputation, such as dressing, bathing, getting in and out of the tub or shower, and getting in and out of your car. There is a lot to learn in this phase and your entire team is here to help you. The secret is to take it one step at a time. This phase typically lasts from about 5 to 14 days. You will stay in the hospital during this time.



### 2.2 Safety — Awareness

Once you wake up you will have to teach yourself that you cannot stand as you used to before the surgery. The rehabilitation team will help and train you how to safely transfer from the bed to a wheelchair, so you can get around (e.g., go to the bathroom). You will usually be provided with a wheelchair until you are evaluated to be safe using crutches or a walker.

After the surgery your balance will be altered, and you have a higher risk of falling. Falling may cause complications that can result in increased healing time, additional surgeries, other injuries, and prolong hospitalization.





### What I need to do

- ➔ You should do something to remind yourself not to try to stand when you get out of bed. For example you may place a chair on the side of the bed where you get up to “remind” you to be careful.
- ➔ Side rails of the hospital bed are also helpful to protect you from falling.
- ➔ Use a wheelchair to move around until you are safe to use crutches or a prosthesis.
- ➔ Don't hesitate to ask for help, even to do simple tasks.



## 2.3 Pain Management

There are different types of pain, and there are different kinds of treatments for each of them.

### 2.3.1 Residual Limb Pain

Residual limb pain is pain in the part of your leg that remains after surgery. This type of pain may be related to the injury that led to your amputation, or the surgery itself. It arises from the bones and surrounding soft tissues and may be described as achy, gnawing or deep. This type of pain will gradually go away as the surgical incision heals and the swelling comes down.

### 2.3.2 Phantom Limb Pain

One of the things that amputees find difficult to understand is how they can feel pain in the area of their limb that has been removed by the amputation. This is called phantom limb pain. It is very common; about 75% of amputees experience this type of pain. It usually happens immediately after surgery but can take 1-2 weeks to develop. There is a lot of

variation in how severe it might be, and how frequently it can occur. In some people it lasts only for seconds during a day, while in others it can be severe and continuous. It is described in many different ways, including, aching throbbing, burning, shooting or electrical.

Phantom pain can have multiple causes. It may originate in the brain, spinal cord, or the nerves that have been severed in the limb.

The good news is that it is usually very manageable, and it rarely limits your function. Many people report that phantom pain gradually goes away or becomes less severe over weeks, months or years.

As with all pain, your level of anxiety and distress can affect how severe your pain is and how it affects your ability to get on with your life.

There are a number of pain medications that can help reduce phantom limb pain. Because it can continue for months, narcotic pain medicines are not part of your long-term pain treatment. Instead your provider is more likely to use a medication like gabapentin or duloxetine hydrochloride. Your physical therapist may employ techniques like mirror therapy or desensitization to help with your pain.

### 2.3.3 Phantom Limb Sensations

Phantom limb sensations are non-painful sensations in the portion of the limb that has been amputated. They are very common and have been described in over 90% of people that have had an amputation. No one really knows what causes them. These may be annoying, but are not painful.

There are many different qualities to these sensations. Some amputees feel tingling, electrical or itching sensations. Others feel that their limb is still present and that they can move or reposition it. Occasionally people with an amputation may feel that their limb is in a cramped or awkward position.

## Post-Operative Phase

These are normal experiences and typically subside with time. Because they do not involve discomfort or pain, they are not treated with medication.



### 2.3.4 How Pain is Managed

It is important to know that in the majority of people with amputations pain can be managed very effectively.

**Narcotic Pain Medicines** - Early after amputation the most common way that pain is managed is through an intravenous line (IV).

**Patient controlled analgesia (PCA)** is a method where you can control the amount of pain medicine you get through the intravenous line by pressing a button. The pump that delivers the medicine is programmed to ensure that the amount of medicine you receive will always be safe. You can't give yourself too much, so don't be afraid to push the button.

As you recover and become more mobile, IV medicines are switched over to medicines that are taken by mouth. This will reduce the risk of infection and allow you to begin to move about your room more comfortably and freely.

To minimize the potential side effects of narcotic pain medicines they are gradually reduced and then discontinued as soon as possible. Common side effects of these medicines are drowsiness, clouded judgment, constipation and breathing difficulties. Be sure to tell your health care team if you experience any of these symptoms.

### Other Pain Medicines

Antidepressant, antiseizure and anti-inflammatory medications may be used in certain situations. Antidepressant medications are sometimes highly effective in the treatment of phantom limb pain for some individuals. In addition, these medications are useful for treating clinical depression, which can worsen the symptoms of phantom limb pain or

increase the frequency of its occurrence.

Anti-seizure medication, such as gabapentin, is now one of the most commonly used medications to treat phantom limb pain. Neurontin seems to decrease the intensity of pain and the number of pain episodes with fewer side-effects than other antiseizure medications.

NSAIDs (anti-inflammatory medications), such as aspirin and other over-the-counter medications, do not directly control phantom limb pain itself, but can help by decreasing the local tissue inflammation that sometimes leads to phantom pain flare-ups.

It is important that you review with your health care team the potential side-effects of all medications (including vitamin, mineral, food and herbal supplements) that you might be taking to treat your pain.

### Pain Management Without Medications

In addition to medications, there are also many other methods of managing pain:

- Massage
- Acupuncture
- Desensitization — is a fancy word for applying other types of sensations to your residual limb. Placing a towel across the end of your residual limb and gently pulling on it, is one type. Local massage, tapping and rubbing are other types.
- Biofeedback, hypnosis
- Nerve stimulators (T.E.N.S.) — this is a device that allows you to apply a low level of electrical stimulation to your limb through pads applied to your skin.
- Elastic bandages and compression socks called shrinkers — these help to reduce pain by decreasing swelling in the tissues, and by providing sensory input to your limb that helps to block pain.

- **Mirror Therapy** — this is a technique that is specifically used to help with phantom limb pain. A mirror is placed vertically between your two legs so that when you look down it appears that your amputated limb is still present. You are actually seeing the reflection of your remaining limb in the position of the amputated limb. Using this tool, you will visualize moving your limb.

Remember managing your anxiety and distress is critical to your overall pain management.



### *What I need to do*

#### 2.3.5 Describing the Pain

Your doctor and your health care team will put together a plan that will control your pain. It is important for you to communicate the location, severity and frequency of your pain.

It is easy to use a number (between 0 and 10) to describe the amount of pain you have. The number 0 will mean no pain and 10 will mean the worst pain you ever had. It can also be helpful to describe what makes the pain worse or better, such as moving into certain positions or making specific movements.

It may be helpful for you to take some notes about your pain, so you can share this information with your health care team.

#### 2.3.6 Treating the Pain

- No single treatment is effective for everyone, and sometimes it's not possible to eliminate the pain entirely.
- The most important goal is to control your pain to the point where you can function and fully participate in your rehabilitation.

- Stress is sometimes connected to pain, so you need to feel comfortable in communicating how you feel and asking for additional help to manage these symptoms.
- It is important to let your health care team know if the medication prescribed is not controlling your pain. Pain that is not controlled can prevent you from fully participating in your therapy program and delay your rehabilitation.
- Make sure to take your pain medicines as they have been prescribed. This is the only way that your health care team will be able to know what effect your pain is having and whether or not changes need to occur in your pain treatment.
- As with all medications make sure that you understand possible side effects that you might experience so that you can report them to your health care provider.



## 2.4 The Residual Limb

### 2.4.1 Post-Operative Dressing

After the operation the residual limb will be dressed to protect the limb, reduce swelling, shape the limb, and prevent loss of motion at the joints.

There are two types of compression dressings: rigid and soft. Rigid compression dressings are made from casting material and will be changed as the swelling in your residual limb decreases. Soft compression dressings are initially elastic bandages applied in a specific way to reduce the swelling at the lower portion of your residual limb. The changing of the dressing may be painful, and you may need to take pain medication prior to dressing changes. These bandages will need to be readjusted several times during the day to maintain proper compression. Members of the rehabilitation team will instruct you in the proper application of these bandages.

### 2.4.2 Healing of the Incision Site

Once the post-operative dressing is removed you will see stitches or staples that keep the incision intact. The stitches/staples will be removed when your surgical team finds that you have healed sufficiently. Your general health can make a big difference on how fast and well the wound will heal. Your diet (what you eat), controlling your blood sugar (if you have diabetes), and not smoking are very important. A wound that is kept clean and dry can avoid infection and heal faster.

### 2.4.3 The Shape of the Residual Limb

After surgery your residual limb may have what you consider an odd shape. It may be much larger at the bottom than the top, or it may have what we call “dog ears.” This is when the limb is somewhat pointed at the ends of the suture line. The swelling in your limb, called edema, is excess fluid due to the surgery. Reducing the swelling will promote better healing, decrease the pain, and will shape the residual limb so it may be fitted with a prosthesis sooner.



#### *What I need to do*

Your role in post-op management includes the following:

- ➔ To make your incision heal faster you should:
  - Eat well — a healthy diet and lots of fluid
  - If you are diabetic, control your blood sugar
  - Make sure that you receive and follow your surgical team’s instructions for keeping the incision line clean
- ➔ Notify a member of your health care team immediately if:
  - your incision line starts to separate
  - you notice increased drainage from the incision

- an odor comes from the incision
- there is redness, swelling, warmth or heat in the area around the incision
- there is increased tenderness of the area
- you feel ill or have a fever
- if diabetic, there is an unexplained elevation in your blood sugar

#### **Rigid Compression Dressing:**

- ➔ Keep the cast dry. Getting the cast material wet can weaken the cast, and damp padding can irritate your skin.
- ➔ Avoid getting dirt or powder inside the cast.
- ➔ Never stick objects inside the cast to scratch your skin. If itching persists, let your nurse know so other measures can be taken.
- ➔ Notify a member of your rehabilitation team if you feel increased pain or numbness that may be caused by swelling or a cast that is too tight.

#### **Elastic Bandage Compression Soft Dressing:**

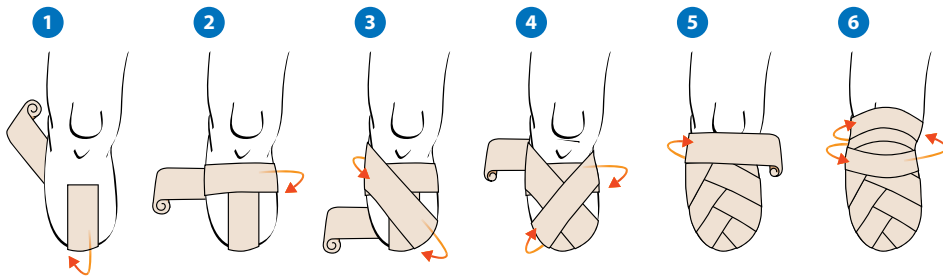
- ➔ Do not pull at your sutures even if the skin around the sutures itches.
- ➔ Notify a member of your rehabilitation team if you notice any tearing or separation of the sutures.
- ➔ Notify a member of your rehabilitation team if you notice that the skin around the sutures is red or swollen, or if you notice any pus draining from the suture area.
- ➔ The bandage needs to be rewrapped several times during the day (usually at least 4-5 times) to maintain proper compression. If instructed by your therapist you may do it yourself.
- ➔ Obtain new elastic bandages if the ones you are using become soiled or lose elasticity.

### Elastic Tubular Bandage

The elastic tubular bandage (a.k.a. an elastic shrinker sock) is a way of applying compression that is often used to reduce swelling to a tender limb. It's easily applied by using the "donning tube." Using the donning tube prevents undue discomfort while putting the bandage on and protects the healing incision. Do not attempt to do this yourself unless you have been trained.

### Wrapping With an Elastic Bandage

The elastic bandage requires skill to apply properly, and if not applied properly can cause problems or be ineffective in reducing swelling. Do not attempt to do this yourself unless you have been trained.



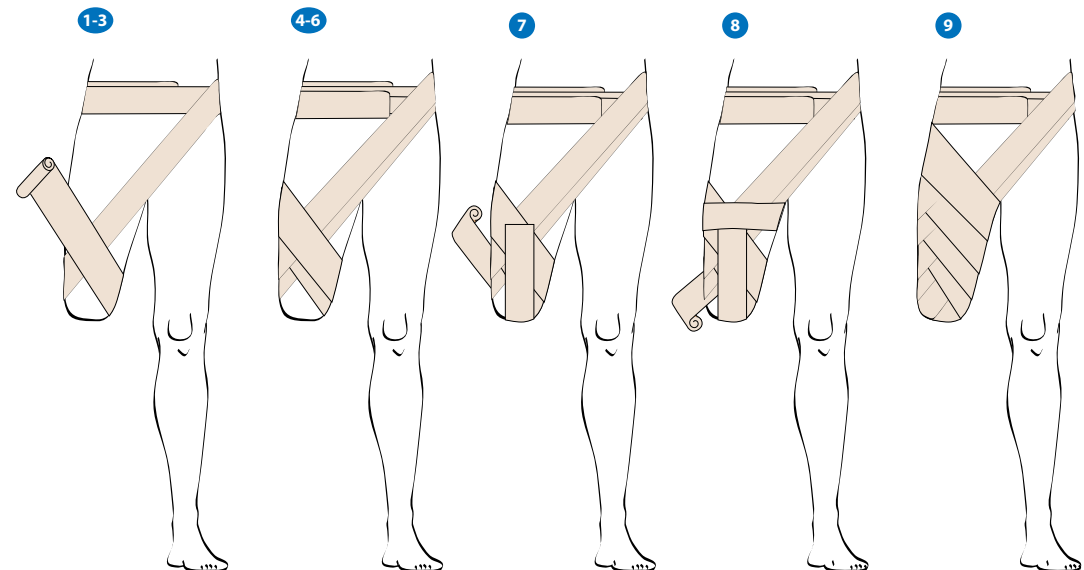
### Below-Knee Amputations

1. Using a 4-inch wide elastic bandage, go over the end of the limb slightly stretching the bandage.
2. Relax the stretch and secure the bandage by going around the limb once.
3. Increase the stretch and go to one side of the center.
4. Decreasing the stretch, go around back.
5. Go up the other side of the center as you increase the stretch again.

6. Repeat this figure eight pattern until the end is securely bandaged and then secure the bandage with Velcro or tape. (Do not secure bandages with pins).
7. If the length below the knee is very short, you will need to make a similar figure eight pattern above and below the joint and then secure the bandage.

### Above-Knee Amputations

1. Use two 6-inch wide elastic bandages. (Bandages can be sewn together.)
2. Wrap around the waist twice.
3. Wrap around the end of the limb.
4. Wrap back around the waist.
5. Wrap around the end of the limb.
6. Wrap around the waist and secure. (This is the anchor for the next bandage.)



7. Take another 6-inch wide elastic bandage and, similar to the technique used for below-knee amputations, go over the end of the limb, slightly stretching the bandage.
8. Relax the stretch and secure the bandage by going around the limb once, then increase the stretch and go to one side of the center.
9. Decreasing the stretch, go around back, and then go up the other side of the center as you increase the stretch again. Repeat this figure eight pattern until the end is securely bandaged, making sure to bandage all of the way up into the groin area. Secure the bandage with Velcro or tape. (Do not secure bandages with pins.)

**Remember: For best results, you must reapply the elastic bandages whenever they loosen.**

### Wearing an Elastic Shrinker Sock

Using an elastic shrinker sock is another way to reduce swelling. These shrinker socks can be used alone or in combination with elastic bandages. If the limb is still very sensitive, it will be more comfortable to stretch the shrinker as it is being put on either by using two pairs of hands or an appropriate-size ring made of a stiff material.

A shrinker is an elastic sock rolled onto the residual limb once the wound from the surgery is healed and the stitches or surgical staples are removed. The shrinker provides more even pressure than a tubular elastic bandage or Ace Wrap.

A shrinker is usually worn most of the day, but your doctor or therapist can let you know the right amount of time for you. In general, the shrinker should be worn anytime you are not in the prosthesis. Make sure you wear a shrinker for at least 8 hours before seeing the prosthetist to ensure proper assessment. You will continue to need the shrinker even after you receive a prosthesis, as a way to keep swelling down. This is

important because a swollen residual limb makes it more difficult to wear your prosthesis.

- If your limb becomes painful, cold or numb from wearing the shrinker, remove the shrinker and consult with the doctor, therapist or prosthetist. You may need a different size.
- A clean shrinker should be worn every day and at night. Follow washing instructions. Have two or more on hand to rotate
- If the shrinker has stretched out and is no longer tight, then it's time to contact your therapist or prosthetist for a new shrinker.
- The shrinker needs to be pulled up snugly against the end of the residual limb.

### Wearing a Silicone Material Liner as a Shrinker Sock

Using a silicone or similar material liner is another way to reduce swelling. These liners come in different thickness, shapes, and materials. They should be used alone and not in combination with elastic bandages. More care should be taken when wearing the silicone liner. Silicone liners can cause excessive perspiration that may irritate the surgical site. If this occurs remove the liner and notify the surgical team.

A silicone liner is a specialized component of the prosthesis that is often used for suspension of the prosthesis. In recent years they have been used post-surgically as a shrinker to control edema and provide some protection to the surgical site. Silicone liners typically have less "stretch" than elastic shrinker socks. They act similar to an elastic shrinker sock but require greater care when applying and during use. Selecting the appropriate size is important and should be the responsibility of the prosthetist.

Similar to a shrinker the liner is usually worn most of the day, but your doctor or therapist can let you know the right amount of time for you. In general, the liner should be worn anytime you are not in the prosthesis

however your doctor may want you to alternate between the shrinker and the silicone liner. If your limb becomes painful, cold or numb from wearing the liner, remove the liner and consult with the doctor, therapist or prosthetist. You may need a different size.

- A clean liner should be worn every day and at night. Follow washing instructions. Have two or more on hand to rotate.
- If the liner has stretched out and is no longer tight, then it's time to contact your therapist or prosthetist for a new shrinker.
- The liner needs to be pulled up snugly against the end of the residual limb.

## 2.5 Motion and Positioning

### 2.5.1 Range of Motion (ROM)

Maximal range of motion (ROM) of your residual limb is most important for successful use of your prosthesis. It also allows you to do your daily activities more easily regardless of whether you use a prosthesis. Muscle and joint tightness that results in loss of motion is called a contracture. It often happens with above-knee and below-knee amputations when people are sitting for long periods of time. A contracture can make prosthetic fitting difficult and sometimes impossible. This will make it difficult to walk.

A combination of ROM assessment, intervention, and education can reduce the risk of contractures. Attention must also be given to ROM of the joints of your non-amputated leg to help you walk better, with less fatigue and less stress on your joints and spine.



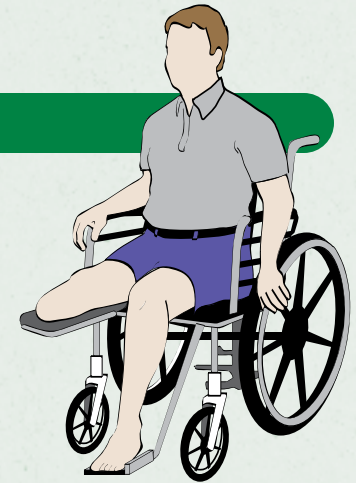
### What I need to do

#### 2.5.2 Prevent Contractures:

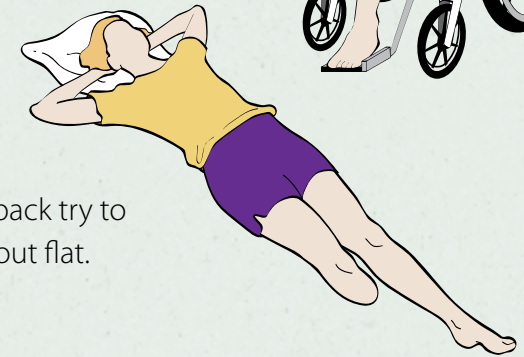
##### Do the Following

##### Below-Knee Amputation

- ➔ Elevate your residual limb on a well padded board when sitting in a wheelchair

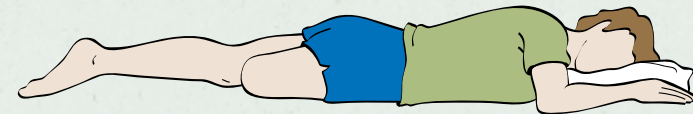


- ➔ When you sleep on your back try to keep your legs stretched out flat.

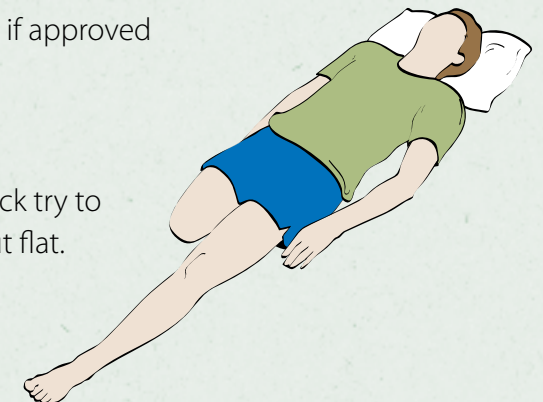


##### Above-Knee Amputation

- ➔ Try to lie flat on your stomach for 15-20 minutes several times a day if approved by your doctor.



- ➔ When you sleep on your back try to keep your legs stretched out flat.

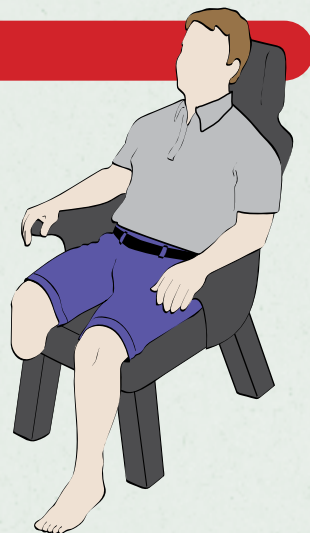




**Do not do the following**

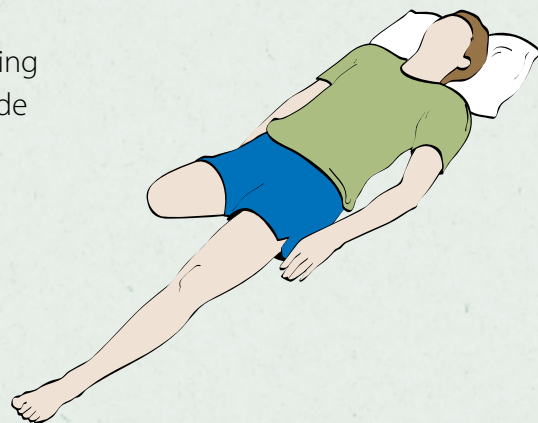
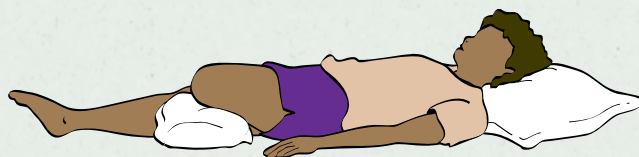
**Below-Knee Amputation**

- ➔ **Do not** sit or lie with your knee bent (flexed) in a chair (including your wheelchair) or on the side of the bed for prolonged periods of time.
- ➔ **Do not** place a pillow under your knee while you are sitting or lying down.
- ➔ **Do not** put weight or pressure on the end of your residual limb.



**Above Knee Amputation**

- ➔ **Do not** sit in the bed for long periods of time.
- ➔ **Do not** lie in the bed with a pillow under your residual limb.
- ➔ **Do not** lie on your back pushing the residual limb out to the side (spreading the residual limb).



**2.6 Physical Rehabilitation**

The aim of rehabilitation is to achieve maximum independence and function. The rehabilitation team will guide you through a program based on your needs and goals. The team will challenge you to improve your mobility, strength and function and identify when you have achieved optimal function with or without a prosthesis, facilitate discharge and develop a plan on on-going assessment and care.

Physical rehabilitation includes assessments and activities that improve the muscles, bones and joints and include range of motion (ROM), strengthening, fitness, and balance.

You will need to strengthen the muscles in your arms, your non-amputated leg and your residual limb. You can lose a great deal of strength by staying in bed for even a few days. This loss of strength will make it more difficult to perform every day activities. Therefore, rehabilitation starts as soon as your doctors clear you to participate.

Your residual limb and non-amputated leg should be strengthened to prevent muscle atrophy (wasting) and to control the prosthesis. Arm strengthening is important for transfers, walking with an assistive device (walker or crutches), and wheelchair mobility. Strengthening of the abdominal and back muscles (core muscles) contribute to stability during transfers and walking.

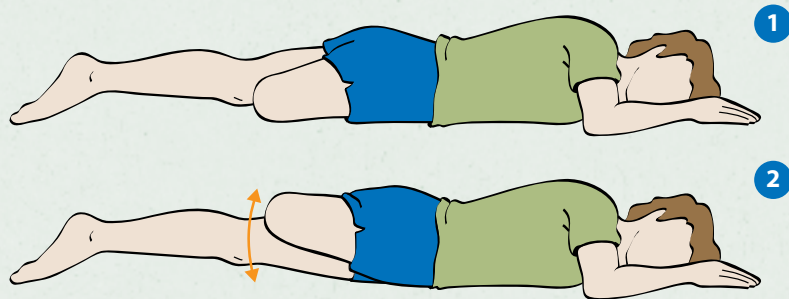


**What I need to do**

- ➔ Your participation in your daily therapy is your responsibility. Your progress can be measured by the amount of time you spend working each day. If something is interfering with your participation, such as pain, notify your team immediately.
- ➔ Perform the exercises on the following pages after your therapist has reviewed them with you:

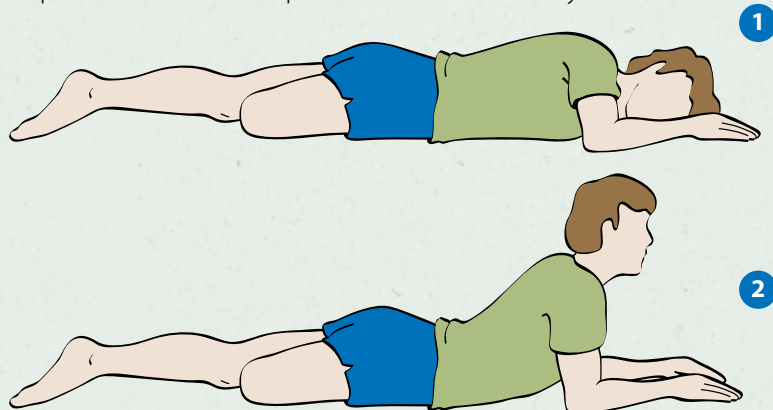
**• Prone (lying on stomach) Hip Extension**

- ▶ Lie on your stomach
- ▶ Keep both legs straight
- ▶ Lift your residual limb off the bed toward the ceiling while keeping your stomach and hips flat on the bed
- ◁ Hold for 5 seconds then lower slowly back to the bed
- ▶ Repeat 30 times and perform 1-2 times daily



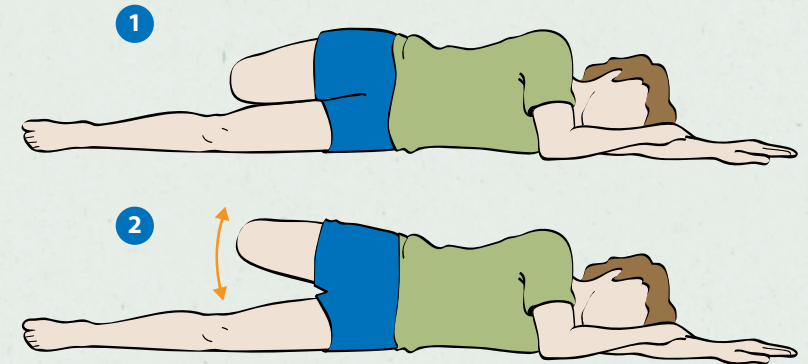
**• Hip Flexor Stretch in Prone**

- ▶ Lie on your stomach with your legs out straight
- ▶ Slowly prop yourself up on your elbows
- ▶ Hold for 10 or more seconds then lower slowly
- ▶ Repeat 3-5 times and perform 1-2 times daily



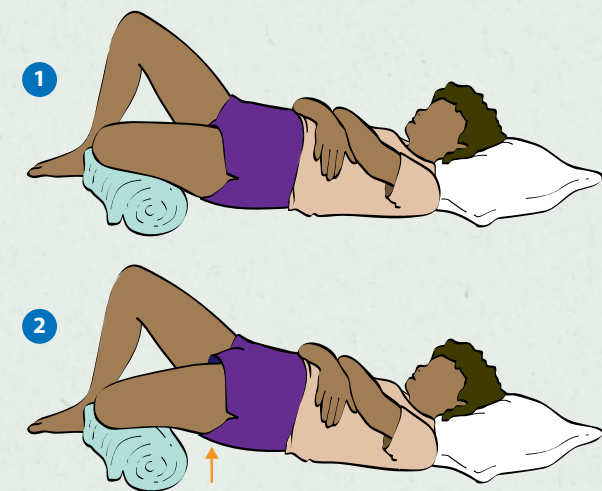
**• Hip Abduction in Sidelying**

- ▶ Lie flat on your non-amputated side
- ▶ Slowly lift your limb toward the ceiling
- ▶ Hold for 5 seconds then lower slowly
- ▶ Repeat 30 times and perform 1-2 times daily



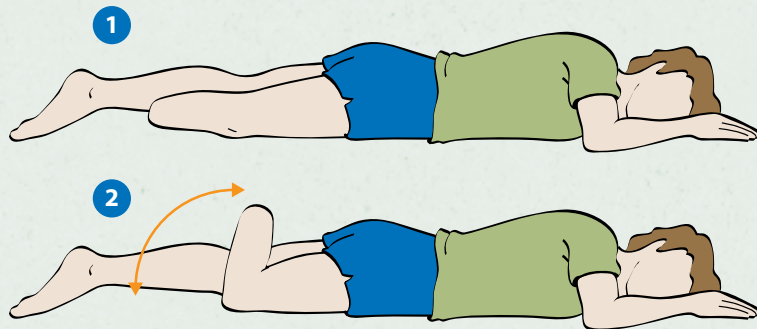
**• Bridging**

- ▶ Lie on your back
- ▶ Place a rolled up towel or blanket under your residual limb
- ▶ Bend the non-amputated leg and place your foot on the bed
- ▶ Push down through your legs, lifting your buttocks and hips off of the bed
- ▶ Hold for 5 seconds then slowly lower
- ▶ Repeat 30 times and perform 1-2 times daily



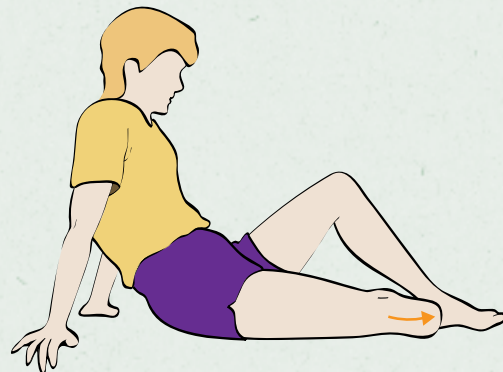
**• Prone Knee Flexion (for Below-Knee Amputations)**

- ▶ Lie on your stomach
- ▶ Keep non-amputated leg straight on the bed
- ▶ Slowly bend the knee of the amputated leg, bringing the end of your residual limb toward your buttocks
- ▶ Hold for 5 seconds then lower, slowly straightening your knee
- ▶ Repeat 30 times and perform 1-2 times daily



**• Quad Sets (for Below-Knee Amputations)**

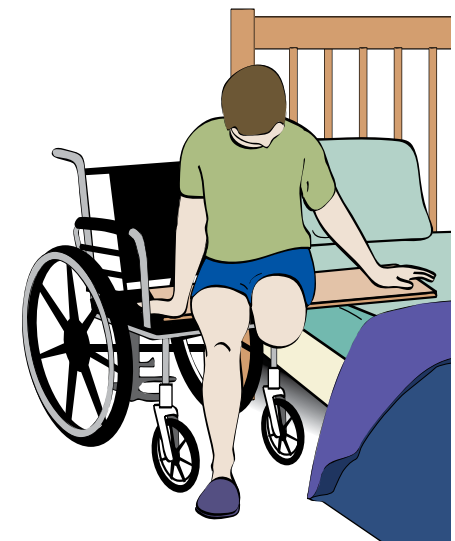
- ▶ Lie or sit semi-reclined on a bed
- ▶ Keep your residual limb straight and bend your non-amputated leg so your foot is on the bed
- ▶ Tighten the muscles on the top of your thigh, straightening the knee of your residual limb
- ▶ Hold for 5 seconds then relax
- ▶ Repeat 30 times and perform 1-2 times daily



**2.7 Functional Activities**

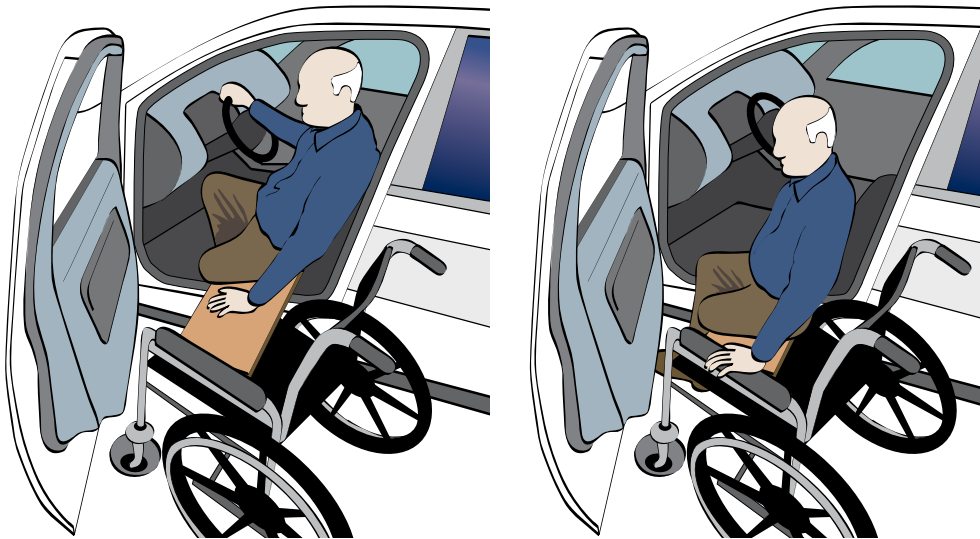
As you gain strength you will start to practice several simple activities such as bed mobility, transfers, and other daily activities to promote and encourage your independence, increase your strength, and reduce your fear of falling. Physical and occupational therapists will teach you the following transfer activities (with or without a prosthesis):

- sit to stand
- bed to chair
- chair to toilet
- chair to tub
- vehicle transfers
- floor transfers



The therapist will also show you how to groom, bathe, and dress yourself to prepare you for your return home. Safe transfers from different surfaces, such as from a wheelchair to a bed or mat, are also emphasized.

Therapists will also assist with any adaptive equipment you may need. This may include a wheelchair, shower bench, walker or crutches, transfer board, and other items to enhance your safety. You should discuss any additional needs with your rehabilitation team, such as grab bars in your shower or near your commode.



## 2.8 Coping Methods

If you are similar to most people with amputations, you were not at your best when the doctor told you that you were going to lose a limb. Chances are that you were acutely ill, injured, hospitalized, and in pain. You may have been weak for some time or confined to your bed for a long period of time.

Post-surgical pain, limited mobility, poor appetite, or poor sleep may make you anxious, sad and fearful. Concerns about your health, your family and your future may feel overwhelming. At times you may feel you are on an emotional rollercoaster. These are all legitimate feelings to have after the ordeal of amputation surgery.



After your initial trauma and throughout your rehabilitation process, you may experience depression, anxiety, flashbacks, resentment, anger, rage, fear, helplessness, hopelessness, and the loss of body integrity. You may express anger in many ways, and it is important to understand that anger is normal. If you are suffering from depression or anxiety, you may benefit from medication, psychotherapy and professional support.

Some patients describe the loss of a body part as similar to the loss of a loved one. However, though a brief period of mourning for the loss of your limb is considered normal, if you find that your grief continues for more than a few months, it will be helpful to seek support from a mental health professional.

While some amount of phantom and residual limb pain is normal, if it interferes with sleep or function, more aggressive treatment should be sought.

Unfortunately, the loss experienced by amputees is not only the physical loss of a body part but also the loss of your former appearance, function, athletic ability, and hobbies. You may, in fact, grieve more for the loss of these functions than for the loss of your limb.

Following an amputation, you may have many concerns. Some people are more concerned about maintaining their physical appearance, while others are more concerned about regaining normal function. You may have fears about social and personal relationships, and you may wonder if your peers and family members will accept you with an amputation. You may also be worried about the impact an amputation will have on employment possibilities and recreational activities.

Some patients are concerned that an amputation will affect overall functioning in some way. You may experience apprehension about falling, concern about not being able to master the use of your artificial limb, and your artificial limb malfunctioning. You may become very frustrated if these problems actually occur, even if only temporarily.



### What I need to do

- ➔ Understand that you may experience many if not all of the feelings described above.
- ➔ Set realistic goals and break them down into small pieces so you can celebrate your successes.
- ➔ Talk to your team about how you are feeling.
- ➔ Ask to talk with a peer visitor who has been through this experience. Most of all, don't try to face this alone.

## 2.9 Discharge from Acute Care

Once your medical condition is stable the team will make arrangements for discharge from the hospital and preparation for the next step in your journey — the Rehabilitation Phase. Rehabilitation following amputation can occur in a variety of settings, regardless of whether you have a prosthesis. Some patients will be best served in an outpatient environment, some may need an inpatient rehabilitation setting, and others may be best served in an intermediate — or long-term care facility.



### What I need to do

Prepare for the next step in your recovery by:

- ➔ Being safe and preventing falls
- ➔ Describing your pain and using several methods to reduce pain
- ➔ Keeping the incision dry and clean
- ➔ Keeping the residual limb wrapped
- ➔ Preventing contractures
- ➔ Exercising to improve ROM and gain strength

Take an active part in your therapy by setting new goals and participating every day. Look forward to discharge and continue to the next step of your rehabilitation.

## 2.10 Post-Operative Phase Summary

- Take special care to avoid falls.
- Be specific in discussing your pain with your health care team:
  - ▶ Where is the pain?
  - ▶ How bad is the pain?
  - ▶ What helps the pain?
  - ▶ What makes the pain worse?
- Let your health care team know immediately if you think you have an infection at your incision.
- Carefully follow your team's instructions on taking care of your residual limb.
- Take an active part in your therapy by setting new goals and participating every day.
- Look forward to discharge and continuing rehabilitation.



## 3

## Rehabilitation

### 3.1 What Will Happen to Me?

During the rehabilitation phase you will make continued progress toward your goals. Now, you and your team will focus on the things that need to happen before you can be considered for a prosthetic limb. These include:

- Edema (swelling) control
- Residual-limb shaping
- Improved cardiovascular conditioning
- Strengthening and range of motion
- Preprosthetic gait training.

## Y

ou will work closely with your rehabilitation therapist during this phase. Your therapist will teach you the necessary techniques to control edema and shape your residual limb. He or she will also work with you on improving your cardiovascular conditioning, especially your upper-body endurance. As your strength improves, your strengthening program will progress to include total body conditioning. The focus will be on specific exercises to strengthen your residual limb to support your body weight when you wear your prosthesis. You will also work to improve your balance and improve your daily activity skills. You may receive additional equipment to help you get around at home and in the community. Your team will talk with you about how to return to your usual activities, such as driving, recreation, work, school, or errands.

In this phase, you may face new challenges in adjustment and new types of pain. Your team will help you work through these problems to maximize your recovery and function.

Your goals are very important to the rehabilitation process. Together with the rehabilitation team you and your family will discuss and establish goals. These goals will help you and the therapists to measure your progress and the final outcome. Also, each team member uses the goals to guide their treatment plan.



### 3.2 Safety — Fall Prevention

You may fall at some point after you have had a lower leg amputation. It may happen in the middle of the night when you get up to go to the bathroom because you don't remember that you're missing a leg. You should also know how to get up off



the floor, and how to call for help if you can't get up. Your therapist can provide you with more individualized recommendations regarding how to avoid falls, or how to get up once you have fallen. It is best to have a safe home that minimizes your risk of falling.



### What I need to do

- ➔ Remove rugs that might slip when you step on them, or make sure that they have an anti-skid mat underneath them. These can be purchased at most stores.
- ➔ Chairs should have arms that make it easy to get up from the sitting position. The legs of the chair should not stick out because you may trip over them.
- ➔ Tables (including coffee tables) also should not have legs that stick out because you may trip over them.
- ➔ Hallways and other commonly traveled areas in your home should be free of clutter. Examples include stacked magazines, newspapers, and appliances.
- ➔ There should be adequate lighting in all of the living spaces of your home. Light sensors in commonly traveled, such as from the bed to the bathroom, can help light up a dark area in the middle of the night so that you don't have to search for a light switch.
- ➔ Have at least one of your phones placed on the floor so if you fall and cannot reach a phone on a higher surface, you can crawl to the one on the floor.
- ➔ Keep a flashlight in the nightstands in your bedroom. This can be very useful in the middle of the night or during a power outage.

The bathroom is an area where you can easily fall. Most bathrooms are small and can be difficult to navigate. In addition, most surfaces are slippery when wet. Some suggestions that can make the bathroom safer include:

- Grab bars in the tub. These should be professionally installed to ensure that they are well anchored to the wall.
- A tub bench or seat can be installed inside the bathtub. These are easily removed. It is a lot easier to wash yourself while sitting down as opposed to standing up.
- A hand-held shower head can be used when sitting on the shower bench. The water temperature can be adjusted while seated.
- Adequate lighting is essential, especially around the medicine cabinet. It is also useful to have a magnifying glass located near your medications. Bottles look alike and can be easily confused.
- An elevated toilet seat will make it easier to get up from the toilet. A toilet seat that is raised above the usual height with the grab bar nearby can be very useful.
- Non-skid mats should be placed in areas where you anticipate water pooling.
- Keep your bedside commode or urinal near your bed.



## 3.3 Pain Management

You may continue to experience some of the pain in your residual limb or phantom limb. These sensations typically get better on their own. Usually by this time your health care team has established a pain management program that is effective for you.





Now that you are exercising and moving about more, you may feel new pain.

Some treatments that were not useful before may become more effective now.



### What I need to do

The ways to manage pain are the same as described in the post-operative section of your book.

- ➔ You should point out to the team any new or old pain and how the treatment is helping you cope with that pain.
- ➔ If pain prevents you from participating in your rehabilitation treatment session it may help if you take pain medication 30 minutes before therapy.

## 3.4 Contracture Prevention

Preventing contractures or tightness in your joints and muscles, developing strength, and improving balance are essential for you to walk with or without a prosthesis. This is done through an exercise program developed for you by your physical therapist or kinesiotherapist. You will be given a copy of the exercises to take home so you can continue doing them when you are not at physical therapy.



### What I need to do

- ➔ Continue to be aware of proper positioning and practice the Do's and Don'ts you learned in Section 2.5.2 on beginning on page 41.



## 3.5 Residual Limb Care

### 3.5.1 Reducing Swelling & Shrinking

Once the staples are removed and the wound is healed you should continue to use the Ace wrap or shrinker to reduce swelling and continue shaping of the residual limb. Covering the residual limb will also provide some protection from injury.

### 3.5.2 Skin Care

#### Inspection of Your Residual Limb

Examine your skin carefully and frequently for signs of breakdown, infection, rashes, or callusing. If you are diabetic or have poor circulation and reduced sensitivity, you must examine your limb throughout the day to make sure you are not developing sores. Diabetics and others with poor circulation have an increased risk for skin irritation. **REMEMBER** - Look at both legs for possible problems.

- Regular inspection of your residual limb may help you identify skin problems early.
- In the beginning, inspect your limb each time you remove your prosthesis. Later on, most amputees find that inspection once a day is enough to identify skin problems early.
- Inspect all areas of your residual limb. Remember to inspect the back of your residual limb and all skin creases and bony areas. Using a long-handled mirror can help.
- Look for any signs of skin irritation, blisters or red marks that do not fade within 10 minutes of removing your prosthesis.
- Report any skin problems to a member of your rehabilitation team.

**Never wait until a problem becomes serious.**

### Daily Care

1. Every day, or more often if necessary, wash your residual limb with a mild or antibacterial soap and lukewarm water. Rinse thoroughly with clean water to remove all soap.
2. Dry your skin by patting it with a towel. Be sure your residual limb is completely dry before putting on your prosthesis. Allow 15 minutes of air-drying before applying your prosthesis. This should ensure that the skin is thoroughly dry.
3. Do not use alcohol-based products on your residual limb; they dry out the skin and can contribute to cracking or peeling.
4. Avoid prolonged soaking in warm bathtubs or hot tubs because this may cause increased swelling in your residual limb.

### If You Have a Prescription or Are Wearing a Prosthesis

1. Do not shave your residual limb. Pressure from the prosthetic socket on “stubble” can cause the hair to grow inward, become painful, and, in the worst cases, even become infected. Never use chemical hair removers on your residual limb.
2. Consult your prosthetist before using moisturizing creams or lotions. Vaseline or petroleum-based lotions degrade some types of prosthetic liners. Only use softening lotions when your skin is at risk of cracking or peeling. If a moisturizing lotion is needed, it is best to apply it at night or at other times when you will not be wearing your prosthesis. Do not apply lotions to any open wound.
3. If needed, applying an antiperspirant roll-on deodorant to the residual limb can help you control odor and perspiration. Do not apply antiperspirant to any open wound.

### 3.5.3 Desensitization

Desensitization is the process of making your residual limb less sensitive. This is important because an overly sensitive limb can affect your ability to wear clothing or your prosthesis. Not everyone will develop this sensitivity, but everyone should work to prevent it.



#### *What I need to do*

To help desensitize your residual limb, do the following:

- Perform desensitization when you are not wearing your compression garment (shrinker, elastic wrap, etc.).
- Perform desensitization for 2-3 minutes twice daily. It may be easiest to do during bathing times.
- Start with a cotton ball and gently rub the skin of your residual limb using a circular motion.
- When you are able to tolerate it, progress to a rougher material such as a paper towel.
- Try to advance to a terry cloth towel or shower sponge.

### 3.5.4 Massage and Tapping

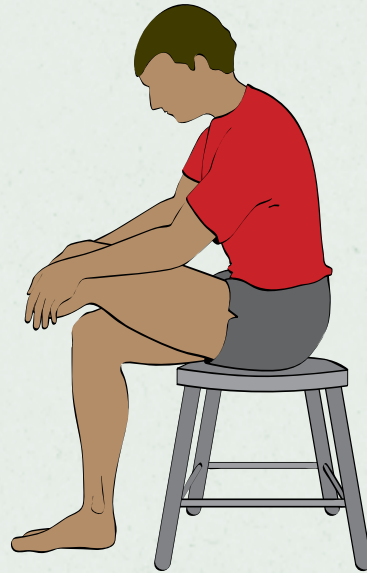
Early massage and tapping of your residual limb will help you to develop a tolerance to both touch and pressure. Both of these can be performed through your compression dressings and when your dressings are off. These techniques may help decrease your sensation of phantom limb pain. Massage also helps loosen scar tissue and promotes circulation.



### What I need to do

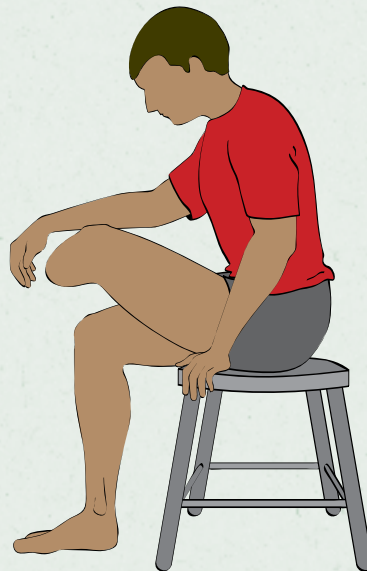
#### Massage

1. Using one or two hands, massage your entire residual limb using a gentle kneading motion. If sutures or staples are still in place, do not massage over them. You may massage around them, but be cautious.
2. Over time—and once your sutures are removed—you can increase the pressure to massage the deeper soft tissues and muscles in your residual limb as well as over your scar line.
3. Perform massage for at least 5 minutes 3-4 times daily. It can be done more often if it helps you in reducing phantom limb pain.



#### Tapping

1. Tap your residual limb with your fingertips, being careful not to tap with your fingernails. Gentle tapping over the suture line is generally allowed even before your sutures are removed (use clean hands!).
2. Tapping should be done for 1-2 minutes 3-4 times daily. It can be done more often if it helps you in reducing phantom limb pain.



## 3.6 Care of the Non-Amputated Limb

### If your amputation is related to diabetes and problems with your circulation:

If you have had a major lower extremity amputation as a result of poor circulation and diabetes you are at a significant risk of requiring an amputation of your remaining limb. Preserving the function of this limb is critical to the maintenance of your mobility and function. You can significantly reduce the risk of an additional amputation if you take special care of this limb. The most common problem, leading to amputation is poor sensation related to diabetic neuropathy. With neuropathy you don't feel when your shoes don't fit well, or when you are getting blisters or sores on your foot. Poor circulation also contributes. Smoking and poor control of your diabetes will increase your risk of neuropathy.

Evenly distributing the pressure on the skin and soft tissues is critical to limb health. Specialized footwear that has an extra deep toe box can help. In more severe cases, a custom shoe may be required. Custom-molded in-shoe orthotics are essential for optimizing the pressure distribution under the foot.

### If your amputation is related to traumatic injury:

Many patients who have had a traumatic injury that is severe enough to require amputation may have also had an injury to their remaining limb. These injuries may impair the function of joints, muscles and nerves. This is particularly common in service members that have been injured in a blast. In some people with amputations their amputated leg becomes their dominant or most functional leg. These injuries may put it at greater risk for wear and tear arthritis.

A complete evaluation of the nerves, bones, muscles, joints, soft tissue and circulation of this limb is necessary to develop a specific rehabilitation plan.



### What I need to do

- ➔ Make sure that you use your eyes or friends' eyes to help you examine the non-amputated foot daily. Look for redness, blisters or sores, cuts or cracking. A long handled mirror can be helpful.
- ➔ Wash and dry your foot properly: Use a mild soap, rinse thoroughly, and dry your skin by blotting or patting, making sure to dry between your toes.
- ➔ Make sure that your toenails are trimmed and your overall foot health is monitored by a health care professional.
- ➔ Never walk barefoot, and make sure that your shoes fit properly. Check your shoes every time you put them on for tears, rough edges or sharp objects.
- ➔ See your amputation team and ask them to evaluate your foot and footwear. Ask them if you need a special insole or orthotic to help protect your foot.
- ➔ Quit smoking and ensure that your diabetes is well controlled.

## 3.7 Equipment Needs

Your rehabilitation team will assess your need for adaptive equipment that may be helpful at home and in the community. Shower chairs, ramps and numerous other types of adaptive equipment will make your home safer for you.

Prior to receiving your prosthesis (if you are a candidate for one), your therapist will issue you an appropriate device for mobility. You should use this assistive device at all times to prevent hopping on your other limb. Hopping on your other limb can injure your joints and/or



muscles that may prevent you from progressing in your rehabilitation. Hopping also puts you at risk for falling.

Falling is a major risk. Falling on the residual limb is very dangerous. An injury to your recently healed, immature limb may have serious consequences for your future mobility. It is a good idea to keep reminding yourself of your amputation, especially when you get out of bed or transfer from one surface to another. Always be aware of your movements to minimize the risk of falls.



## 3.8 Physical Rehabilitation

The goal of the rehabilitation program will now be to complete wound healing, strengthen muscles in all limbs (including the remaining muscles in the residual limb) and maximize your functional level for your daily activities.

### 3.8.1 Range of Motion and Strengthening

Your range of motion is very important in allowing you to perform daily activities more easily. Having good range of motion in the joint(s) of your residual limb will also improve the fit of your prosthesis and help you to walk better. In addition, strengthening the muscles of your residual limb will help you control your prosthesis during all activities. Your therapist will add more strengthening and conditioning exercises as your rehabilitation progresses to help you get in the best shape possible.

As a result of these exercises you will be able to:

- straighten your knee, which is needed to stand and walk;
- bend your knee, which is needed to move from standing to sitting;
- straighten your hip for standing and walking;
- control your prosthetic knee if you have an above knee amputation;
- stabilize your body in standing and walking.

Good range of motion and strength of the residual limb may also prevent or decrease knee, hip and low-back pain.

### 3.8.2 Cardiovascular

You will work on improving your cardiovascular conditioning or fitness level, especially your arm endurance. If you have a leg amputation, you're probably thinking, "I lost a leg. Why do I need to work this hard on my arms?" That's a good question. Remember, you're going to have to use some form of assistive device (wheelchair, walker, crutches) until you can walk well with your prosthesis (if you receive one). It takes a lot of energy to propel a wheelchair or walk with a walker or crutches. If you are fitted for a prosthesis, it can also take a lot of energy to walk. Working on your endurance will help you walk with less fatigue.

### 3.8.3 Balance

You are at an increased risk of falling, because the limb-loss severely impacts your dynamic (moving) and static (standing/sitting) balance. Balance training will increase your confidence to stand and walk with one leg. It is important to acquire the sense of balance, because without it you may not challenge yourself and it will limit your independence and activity.



#### What I need to do

You need to continue doing your ROM, limb and core strengthening exercises during this time. Your therapist will give you exercises to perform at your therapy appointments and at home. If you are having difficulty with any of the exercises or they cause pain, be sure to tell your therapist.

## 3.9 Functional Activities

You will continue to improve your skills in everyday activities. You should

gain independence and practice skills that you were used to doing at home, but may now find challenging. The more you practice, the more confidence you will have.

You may have trouble entering areas of your home after your amputation. Modifications can be made that will help you access these areas. These home modifications all need time to prepare. The team will guide you in the process to offer options. However, no one knows more about your home than you. You should think about, ask questions, visualize how things may or may not work, and together with the team and your family make the necessary changes.



### 3.10 Community Re-Integration

As part of your rehabilitation you will discuss with the team how you will return to your life activities. These may be related to work or leisure, recreation, sports, or hobbies.

The recreation therapist will work with you and with your family to establish goals. This process can include exploration of adaptive leisure equipment, exploration of new leisure interests or opportunities, and increasing awareness of both leisure and community resources. Training may include opportunities to access the community with a recreation therapist to evaluate your comfort and safety with community mobility, planning and alternative transportation options.

The team together with your family members will support you in setting up your goals and evaluating all of your needs. For some activities, there will be specialized, structured training programs such as drivers training, vehicle modifications, and adaptation that will be required for you to return to work.

There are many adaptations that can be made if you would like to resume participation in sports and other hobbies. If you find upright cycling difficult, try a handcycle. If you enjoy downhill skiing, try using adaptive equipment such as outriggers (poles with skis on the ends) instead of poles or a monoski (seated skiing). You should still be able to swim, kayak, fish, and shoot a gun or bow if you enjoyed these activities prior to your amputation. There are many organizations that offer recreational activities and adaptive sports clinics to people with disabilities. Refer to the Resources section in the back of this guide for a listing of those organizations. Most importantly, keep an open mind to new activities that you may now enjoy. Try as many as possible. You may surprise yourself!



### 3.11 Coping Methods

While people often look forward to leaving the hospital, being back at home can be very challenging. When someone is in the hospital, the busy environment, demanding schedule and hospital routines may take up a lot of a person's attention and focus. There may not be a lot of time to think about how life will be different after the amputation. Once someone settles in at home, there may be a lot more time on one's hands, and many activities previously enjoyed may not be immediately possible. There are many reminders of how life used to be. It is very important to have support during this time, and to begin the work of figuring out how to again participate in activities and roles that are important: exercising, parenting, taking care of the home, etc.

This is a time when you may also begin to worry about practical matters such as how your job will be impacted by the amputation, how you will support yourself and your family, and what benefits you are eligible for.

Outside of the hospital, you will face reactions from the community. People will naturally be curious, and some people react more favorably than others. This is a common experience for those who are physically different in any way. This is a time to seek support from people close to

you, and to be in touch with other amputees. Talking with other people who have gone through an amputation can help you recognize that you are not alone, and can give you a place to share stories about your experience. Choosing to spend most of your time alone, or finding reasons not to get out into the community, can be "red flags" that are important to notice and pay attention to. Gradually returning to the outside world is an important aspect of your recovery from an amputation.



#### *What I need to do*

- ➔ Seek support from people close to you, and to be in touch with other amputees.
- ➔ Schedule an appointment with a social worker or other contact person that can guide you about your options to address issues at home, at work, and with family.

### 3.12 Rehabilitation Summary

- Follow your instructions to reduce the swelling of your residual limb.
- Take care of your residual limb daily:
  - ▶ Cleansing
  - ▶ Inspection
  - ▶ Desensitization
- Take care of your other limb daily
  - ▶ Cleansing
  - ▶ Inspection
- Follow your exercise program
- Let your team know about your goals for the future

Make necessary changes at home to regain life and be safe.



## 4 Prosthetic Training

### 4.1 What Will Happen to Me?

During this phase you will become progressively more independent. You and your team will work together to determine whether you will be able to use a prosthesis or whether you will use other equipment to return to your usual activities.

If you are able to use a prosthesis, you will receive an initial prosthesis that best meets your needs. You will need to learn about the different options for prosthetics parts, or components, and work with your rehabilitation team to determine what is best for you. After you receive your initial prosthesis, your therapy will focus on:

- Gait training
- Progressive strengthening
- Balance
- Prosthetic management

Once you have mastered the basics of your prosthetic training, you will progress to more advanced exercises designed to return you to the highest functional level that your amputation will allow.

If you are unable to use a prosthesis at this time, your team will make sure that you have all the necessary equipment for your use at home and in the community to meet your rehabilitation goals.

Much of the information you learned earlier about care of your residual limb, pain control, safety, general health maintenance, and coping with difficulties will be reviewed and reinforced during this phase.

With or without a prosthesis, feel free to push yourself. Never let anyone tell you, "It can't be done." It may not be easy, but you've made it this far, and the only thing that can stop you is your self-doubt.



### 4.2 Pain Management

Residual Limb Pain should be improving throughout this phase of your rehabilitation. The goal during this phase should be to get off of any narcotic medications that may have been previously started. You may still require an NSAID like Motrin or Naprosyn, or medications for your phantom pain such as Neurontin or Cymbalta.

Phantom Pain may continue in this phase of your rehabilitation. Often it is less severe. Many amputees feel that wearing a prosthetic limb reduces the amount of phantom limb pain they experience.

One of the biggest factors that can change the type and amount of pain you might experience at this phase of your rehabilitation is the quality of your prosthetic fit. There have been many innovations in the types of prosthetic components that can improve your overall comfort.

The quality of your prosthetic fit is critically dependent on the size and shape of your residual limb and prosthetic socket. There are many factors that can alter the shape of your residual limb, including the amount



of walking you do, the time since your amputation, your medical status, the medications that you use and the amount of salt in your diet.

Your prosthetist and therapist will help you understand when there are changes in the quality of your fit and things that you can do to adjust the fit. Your prosthetist will also be able to do adjustments to enhance your comfort. If these adjustments are not successful, then a new prosthetic socket will be required. In the

first year after your amputation you may require 3 or more new prosthetic sockets because of rapid changes in the size of your residual limb.

It is important to pay attention to pain in your residual limb related to wearing your prosthesis. If you cannot make adjustments that improve your comfort you should contact your prosthetist. A poorly fitting prosthetic socket can cause skin irritation and can develop into open wounds or ulcers. When this occurs you will often not be able to wear your prosthesis until the wound has healed. This will significantly affect your walking, recreation and work.

Training with the prosthesis may cause pain in joints or muscles in other parts of the body. That is a natural process of your body adjusting to the new way you stand, walk and move using your prosthesis.

Heterotopic Ossification can be a cause of residual limb pain at this phase in your rehabilitation. It is associated with extensive new bone formation near the end of your residual limb. It is much more common after an amputation which has resulted from trauma, especially in blast injuries associated with war. In the early phase, it is seen as swelling and redness near the end of your residual limb, with firm, enlarged tender areas of swelling. Later the swelling, pain and tenderness decrease but new bone formation becomes more prominent. This new bone formation cre-

ates additional challenges for getting a comfortable prosthetic fit. Most patients will be able to be comfortably fit with a custom adapted prosthetic socket. In the unlikely case that this cannot occur, then surgery can be used to remove the areas of boney enlargement.

Neuromas may occur at this phase or later in the rehabilitation. This is a nodular swelling of the nerve at the point where it was cut during the amputation surgery. Neuromas always occur when a nerve has been cut. But they only cause pain if they are particularly large or if the fit of your prosthetic socket causes excessive pressure. In the majority of cases adjusting the prosthesis will allow you to walk comfortably. In some cases the same medications that are used in phantom limb pain can be used to treat neuroma-related pain. In more problematic cases either injections or surgical removal may be necessary.



### *What I need to do*

- ➔ Pay attention to pain in your residual limb. Pain is not a normal part of wearing a prosthesis.
- ➔ Learn from your prosthetist and physical therapist what happens when your residual limb size changes and how it affects your prosthetic fit. That way you can successfully make adjustments to your fit by altering how many prosthetic socks you are wearing.
- ➔ Contact your prosthetist if you cannot successfully adjust your fit on your own.
- ➔ If either you or your prosthetist are unable to successfully modify your prosthetic socket to be comfortable, or if you are concerned that you may have either heterotopic ossification or a neuroma, contact your rehabilitation physician (physiatrist).

**Do not continue to wear your prosthesis if you are having pain, notice open sores or blisters or have red areas that do not go away.**



## 4.3 The Type of Prosthesis

The team will consider and evaluate several factors to determine if prosthetic restoration is appropriate for you. This will be based on level of amputation, condition of your residual limb and the non-amputated limb, your overall health and fitness and—most importantly—on what goals you want to achieve.

If a prosthesis is not appropriate, a custom fit lightweight wheelchair will be your primary form of mobility. In some cases the decision may be reevaluated in the future, and if there are changes a prosthesis may be prescribed.



## 4.4 The Prosthesis

This section is for those individuals that have or will receive a prosthesis.

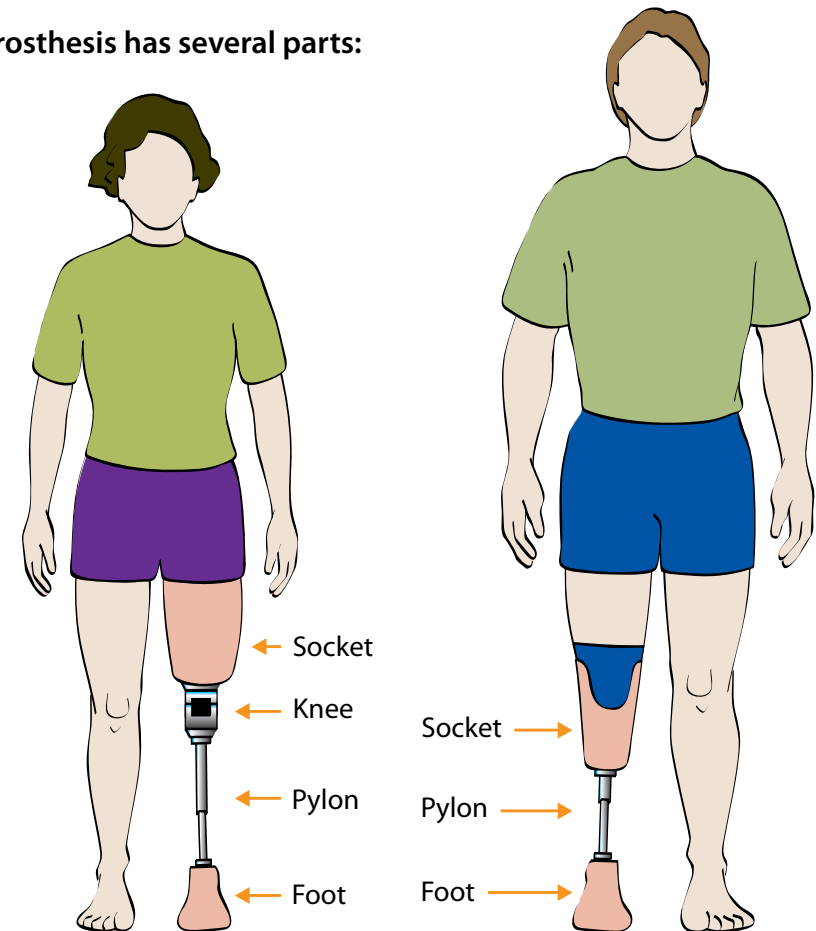
### 4.4.1 Shaping of the Residual Limb

If your clinic team has determined that a prosthesis is safe and appropriate for you, you will be given an appointment to see your prosthetist. As you may know, one of the challenges facing you and the treatment team can be swelling of the residual limb. To the treatment team, this is called edema. Edema will be present to some extent in all cases, and it makes fitting of the prosthesis challenging, but certain measures can be taken to reduce the amount of edema. If you had a rigid dressing and it has been removed, compression of the limb before a prosthesis is provided will prepare you for getting back on your feet. You will use the elastic soft dressing to keep edema from developing. If you have a soft dressing make sure it is reapplied at regular intervals. To review the proper technique for bandaging see the instructions on [pages 36 and 37](#).

### 4.4.2 The Preparatory Prosthesis

A preparatory prosthesis is the first prosthesis that you will be provided. Fitting a prosthesis soon after your suture line has healed helps to combat edema, reduces the possibility of contracture (joint stiffness), and generally improves your overall physical condition. The clinic team may decide to provide you with a temporary prosthesis. This does not happen in every case, but when applied, it is frequently used for several weeks or months. Once the residual limb has stabilized the definitive prosthesis is provided. In some cases, your doctor and prosthetist provide a definitive prosthesis right away. In any case there is a lot to learn about the prosthesis; how to wear it and take care of it, before you can use it to stand or walk.

**A prosthesis has several parts:**



**The Prosthetic Socket** - The socket of the prosthesis is the part that contacts the residual limb. The socket is the basis for the connection between your body and the prosthesis. It provides a means for transferring the weight of your body to the ground through the prosthesis.



The shape of the socket is critical to your comfort and function. The socket must not restrict circulation, yet it cannot be loose. Most sockets cover the entire residual limb. There are several designs available to take maximum advantage of the muscles in your residual limb for control of the prosthesis and for transferring weight to the floor.

Your socket is made specifically to fit your residual limb so that you can put it on and it fits like a hand into a glove. Your prosthetist will create a model of your residual limb in order to fabricate a well-fitting socket. For some patients, the prosthesis can be held in place by “suction”, or a vacuum, provided by a close fit between residual limb and socket. This is known as a suction socket. Variations of socket design include different ways of suspending the limb, providing cushion and comfort to the limb. Your prosthetist and physician will work with you to determine the best choices.

**Socks** - You will likely be issued prosthetic socks with your prosthesis. At least one prosthetic sock is typically worn between the socket and residual limb to provide for ventilation and general comfort. Most prosthetic socks are woven of virgin lamb’s wool, but socks of synthetic yarns are also used. Prosthetic socks are available in varying thickness - most commonly 1-ply, 3-ply, 5-ply, and 6-ply. The higher the number, the thicker the sock. Socks can be used to compensate for residual limb shrinkage if the amount of shrinkage is not too great. The prosthetist can suggest the sock or socks to be used and help you understand when to add or subtract socks. Let your prosthetist know when you begin to use approximately 10-ply of socks as you may need to have a socket adjustment.

**Liner** - You may receive a liner made of silicone or other soft material which rolls onto your residual limb. One function of the liner is to provide suspension of the prostheses. It does so by means of a pin or lanyard built into the liner. Your prosthetist will explain how to apply and maintain it.

**The Prosthetic Knee** - In order to provide the best walking pattern possible and increased safety, your prosthesis may have special components or a knee joint that will limit knee buckling as you roll over the



artificial foot and as you step forward during walking. This feature is common on prostheses designed for a person with an above the knee amputation. This level of amputation is referred to by your treatment team as a trans-femoral amputation.

Your prosthetist will demonstrate to you how this mechanism works. It has various designs intended to provide the most efficient and safe walking pattern for your specific condition. A great deal of effort has been spent over the years developing knee systems but it is still a concern to you and your treatment team. To provide better control of the above-knee prosthesis during standing and walking, prosthetic designers have used mechanical linkages between the socket and pylon that, in effect provide for a moving center of rotation. In some cases they may incorporate hydraulic, pneumatic, magnetic, or microprocessor functions. With advances in technology, sophisticated mechanisms are now available that were not previously. In some cases, with emerging technologies, there can be limitations, including increased weight and reduced durability.

The prescription for your prosthesis will be based on your specific condition and needs.

**The Pylon** – The pylon is the means of attachment of the prosthetic socket to the prosthetic foot. It is a lightweight tube or strut. Most pylons are designed so that the alignment of the foot with respect to the socket can be changed by your prosthetist as needed to optimize your gait pattern. As you begin standing or walking, your prosthetist will adjust the alignment to make your walk as smooth and natural as possible. This process is called dynamic alignment.



**The Foot** – A variety of prosthetic foot designs are available, each having its advantages and disadvantages relative to each patient's situation. Prosthetic feet may have an ankle joint with a significant amount of motion or have less motion and provide more forward momentum when you put weight on the prosthesis. Other options intended to match your specific needs may be prescribed by the clinic team.

**The Shoe** – The shoe is an integral part of the prosthesis. Rubber soled shoes are best. These are widely available and can be inexpensive. Have your prosthetist look at the shoe first if there is a question. Hard heels and leather soles are not advised, because the hard heel doesn't always allow for smooth control when you first step on the prosthesis. Different shoes can be used with your prosthetic foot, as long as the heels of your shoes are all the same height and you discuss this with your prosthetist. The prosthetist will need to know what kind of shoe you will be wearing, so he can order the prosthetic foot with the correct heel height and set up the proper alignment of your prosthesis. An adjustable prosthetic foot or ankle may be appropriate for women who wear different types of shoes with various heel heights. Boots can be accommodated, but may restrict the movement of certain prosthetic feet. Boots are also difficult to put on, and a zipper is often necessary, unless the boot has laces. For the best fit and alignment, it's better to wear a regular shoe in the beginning with the same heel as the boot you will eventually wear.

### 4.4.3 Fitting the Prosthesis

Regardless of the functions provided by your particular prosthetic design, the most important factors in your successful use of a prosthesis are fitting of the socket and achieving proper alignment of the various parts with respect to each other. Fitting and alignment are not simple procedures and will require a great deal of skill on the part of your prosthetist. It will require a great deal of cooperation, patience, and communication on the part of both you and your prosthetist. Teamwork is essential. During prosthetic fitting and alignment, the prosthetist will train you in the basic principles of standing and walking. The fitting affects alignment, alignment affects fitting, and both affect your ability to walk and feel comfortable. Additional training will be carried out by your physical therapist.

### 4.4.4 Putting on the Prosthesis

Putting your prosthesis on is referred to by your rehabilitation team as donning the prosthesis. After the initial fitting you will need to learn how to don your prosthesis independently. Proper donning will improve the alignment and function of your prosthesis and protect your limb from abrasions or bruising. You will need to experiment to determine the method that works best for you.



#### *What I need to do*

- Once the suture line is healed, the residual limb must be washed daily to avoid irritations and infection. A mild soap and warm water are recommended.
- When you are not wearing your prosthesis, you should be wearing your shrinker or compressive sock. You don't wear your prosthesis in bed but you should wear your shrinker.
- The interior of the socket and all items that touch your skin should be kept clean by washing daily with warm water.

- ➔ If you need to use alcohol to clean, use it only on the socket but never on your limb.
- ➔ When prosthetic socks are used, they should be replaced daily or more often in warm humid weather.
- ➔ The socks should be washed as recommended by the manufacturer, typically in warm water with a mild soap and dried well.
- ➔ Lay the shrinker flat to dry (do not use a dryer).
- ➔ The liners need to be washed every day with mild soap and water (no perfume or color to the soap).
- ➔ Prosthetic socks must be applied carefully to avoid wrinkles which can cause skin problems.
- ➔ If your residual limb reduces in size over time you will need to add one or more prosthetic socks to improve the fit of the socket.
- ➔ If you have trouble in obtaining comfort by a combination of prosthetic socks, you should consult with your prosthetist immediately.
- ➔ Your prosthesis should be worn with the appropriate shoe it was designed for. Otherwise it may make you unstable or cause excessive wear on the prosthetic foot, and result in misalignment of the prosthesis.

How much you wear your prosthesis will be determined by your therapist. You will gradually increase the wearing time — with the goal to wear the prosthesis from the time you wake up in the morning until you go to sleep at night.

## 4.5 Prosthetic Education

To achieve an optimal gait and prosthetic function, training in the use of your prosthesis is necessary. Initial training is provided by the pros-



thetist during the fitting process. Physical therapists usually provide the additional training as required. The new prosthesis should be worn initially for short periods and wearing time increased as appropriate for your situation.

A significant problem in obtaining the best possible performance and comfort is excessive weight gain. Fluctuations in body weight are reflected in the residual limb where changes in volume can result in poor fit, discomfort, and consequently

poor performance. A reasonable exercise program and a sensible diet are important factors in the health and well-being of everyone, but even more so with individuals dealing with limb loss.

By following the principles described above and with the help of your treatment team, you should achieve an optimal outcome.



### *What I need to do*

- ➔ Learn how to put your prosthesis on and off (donning and doffing)
- ➔ Learn how to care for the skin of your residual limb
- ➔ Learn to stand with a prosthesis — that involves learning how to shift the weight from one to another and attempt the first steps
- ➔ Learn how to manage and perform sock and liner care
- ➔ With your therapist, practice the exercises that will help you learn to use your limb by progressing from standing, to taking the first steps. More advanced exercises include walking on different surfaces, corners, stairs, and ramps.

### When to Notify a Member of the Rehabilitation Team

- ➔ If you have sores or blisters
- ➔ If you develop calluses or skin discoloration
- ➔ If the skin at the end of your limb feels stiffer or tougher than normal
- ➔ If while walking on flat ground, you feel like you are leaning to one side,
- ➔ If you feel like you are walking uphill or stepping into a hole
- ➔ If your limb feels unusually warm or cold
- ➔ If you are wearing more than 10 ply of socks
- ➔ If your limb has pain or discomfort when it's in the socket
- ➔ If you feel your limb moving up and down in the socket ("pistoning").

#### 4.5.1 Partial Foot

You may have received a partial foot amputation. This may range from a missing toe to loss of the foot. Treatment can include customizing an arch support to provide proper support for the shoe and buoyancy as you roll over the foot. Orthopedic shoes with diabetic or custom inserts may have been provided. A foam or silicone filler is often used to replace the missing segment. In many cases this can be bonded onto a carbon fiber or other type of orthosis. Another option is to provide a custom molded leather lacer or custom high top shoe with a curved sole (rocker bottom). There are many approaches to the treatment of partial foot amputation and your orthotist or prosthetist will guide you on what is most appropriate to your condition.

#### 4.5.2 High Activity or Special Use Prostheses

For individuals with an amputation who have achieved an appropriate level of performance that require a special prosthetic design, there are many options. Examples include ski, swim, climbing, running, and golf prostheses. Other applications are available for bilateral and multilateral amputees. The most advanced emerging technology prosthetic designs in the world are available when appropriate to the functional level of a particular individual.



## 4.6 Residual Limb Care

### 4.6.1 Skin Problems

Always consult with your physician and alert your prosthetist if you have any abnormal skin condition or areas of specific pain.

When you wear prostheses, the skin of the residual limb is especially susceptible to irritation, breakdown and infection as it is stretched, pulled and rubbed by the prosthetic socket. Friction, heat, pressure, shear and moisture within the socket combine to bring about damage to the skin. As with shoes, a properly fitting prosthesis is essential to preventing this painful problem. Unfortunately, swelling, weight fluctuations and muscle changes caused by atrophy, disease, and loss of soft tissue can all affect the size of the limb and the fit of the prosthesis. In fact, the volume of the limb can even change throughout the day as you walk around. Although they will not solve the problem completely, a proper diet, regular exercise, and the maintenance of muscle tone and weight can help minimize these changes.

Skin damage can also result from the use of certain detergents to clean the residual limb and the use of certain kinds of topical medications inside the socket.

Attention to hygiene and skin care is essential. If you wear a prosthesis, your residual limb is encased in a completely or partially airtight socket that does not breathe or allow sweat to evaporate. Sweat is acidic and salty, and when it is allowed to dry, it forms tiny crystals (like sandpaper) on your skin. If this sweat is left on the skin and socket, bacteria can grow. If the skin is broken, infections may occur and can become severe if left untreated.

Always consult with your health care provider or prosthetist if sores or blisters erupt because they could lead to ulcers and serious infections. If you have diabetes or circulatory disease and have anything more than a mild rash, consult your health care provider immediately.

One thing is essential: pay attention to any pain in your residual limb, and if any kind of problem is detected, it should not be ignored.

**Specific skin conditions that can develop on the limb within the socket are:**

- **Infection** - If your skin feels unusually warm, you may have an infection inside the limb, requiring prompt attention. If the limb is unusually cold, this could indicate a circulation problem. Typically, a skin infection occurs in the hair roots. The skin will be tender to the touch when you have an infection. There may be drainage of liquid material. You may have fever or chills, and not feel well.
- **Blisters or irritation** may form at the top of the liner or suspension sleeve. This is usually due to friction and can be avoided by having your prosthetist cut the top in a curved pattern.
- **Knee cap irritation** is usually caused by friction over the knee cap. Remember that pressure and friction can be caused by poor socket fit that needs to be adjusted.
- **Sores or calluses** – may be related to the socket not fitting properly or an incorrect alignment
- **Rashes** – may be caused by bacteria or fungal infection like “athlete’s foot” or exposing the skin to chemical that are used in the cleansing of socks and liners.
- **Abnormal thickening of the skin** – If the tissue at the bottom of your limb feels firm and different from the rest of your limb, it may be edema (swelling) forming because of problems with the suspension or fit.
- **Other skin conditions** that may be caused by wearing the prosthesis include infected hair follicles, nodules, bursa (can sometimes form under the skin, and can range in size).

## 4.6.2 Sweating

Your limb may stop sweating after a period of one to three months, but some do not. Perspiration may increase following an amputation for a couple of reasons. One reason has to do with decreased body surface. You may be perspiring the same amount, but it is concentrated over a smaller body surface. Another reason is that during prosthetic use, your residual limb is encased in a completely or partially airtight socket that does not allow sweat to evaporate. In most cases, daily bathing and the application of an antiperspirant are sufficient to control this. If odor or heavy perspiration continues to bother you, discuss other available treatment options with your physician.

## 4.6.3 Positioning

You are now using your leg and moving and therefore spending less time in positions that cause contractures. Use of the prosthesis and stretching the joints of the limb does not allow contractures. However, when resting, sitting or lying in the bed, continue to practice the positions you learned in the previous chapter.



### *What I need to do*

- ➔ Always consult with your health care team if you have any skin condition or areas of specific pain. If your amputation was due to diabetes or peripheral vascular disease, your team may recommend not to wear the prosthesis until the skin in the area is completely healed.
- ➔ Notify your physician or nurse at once, if any of the skin conditions occur.
- ➔ Bathe your legs daily with warm water and soap.

### **Prosthesis users**

- ➔ If there is skin break or infection, stop wearing your prosthesis until it is resolved.

- ➔ Do not shave the residual limb, because this might cause injury to the sensitive skin.
- ➔ Wash your socks every day with warm water and non-detergent soap. Clean the prosthesis socket every day using a damp cloth and mild soap or alcohol.
- ➔ An antiperspirant applied to the limb at night can be effective in reducing sweating the next day.
- ➔ Test it first on another area to make sure that you are not hypersensitive to the antiperspirant.
- ➔ When resting, sitting or lying in the bed, continue to practice the positions you learned in the previous chapter.

One thing is essential: pay attention to any pain in your residual limb, and if any kind of problem is detected, let your health care team know.



## 4.7 Coping Methods

Participating in physical therapy to learn to use a prosthesis is an exciting and challenging time. You may at last feel as though you are regaining your ability to function more like you did before the amputation. At the same time, prosthetic training is a very physically and emotionally demanding process. Fatigue and physical discomfort

are common after therapy sessions. There will be good days and bad days in therapy, and sometimes it may feel as though you are taking two steps forward, and one back. There are many new things to learn, including re-programming your brain to move your body in ways that are different from how you have done it your entire life. This learning can be tiring and

confusing, and may feel slow. And, once you begin learning to use the prosthesis, you may find that it does not work exactly as you anticipated, or you may have days when it seems to be more trouble than it is worth. Give it time — it is a lot to adjust to, and you may find that with practice you are moving as well as, or better than, you did before the amputation.



## What I need to do

- ➔ Get up every day and challenge yourself with the new skills you learned.
- ➔ See other suggestions to address issues that bother you on [pages 5-9](#).

## 4.8 Prosthesis Training Summary

- Make sure that you understand how to use your prosthesis or other equipment safely. Ask questions if you are unsure.
- Work with your rehabilitation team to make sure that your home has been checked for things that could cause falls. Make sure that you have the necessary equipment to keep you safe.
- Let your health care provider or prosthetist know if you have new pain, or pain that gets worse.
- Let your health care provider or prosthetist know if you have sores, rashes, blisters, or other changes in your residual limb.
- Pay attention to how you are feeling during this new phase and review your strategies for coping.

Photo Courtesy of the Department of Veterans Affairs



# 5 Long-Term Follow-up

## 5.1 What Will Happen to Me?

This phase encompasses the rest of your life. You will set new goals and continue to find new activities and interests. You will also continue to care for your residual limb, your prosthesis, the equipment you have been given, and your other limb. You will manage your pain. You may find that you are facing new challenges associated with aging such as arthritis. There may also be new developments in technology or rehabilitation that will improve your quality of life. Your rehabilitation team will help you as you continue to move forward.

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ou will continue to see your rehabilitation team for the rest of your life. They can help you as you go through those changes associated with continued recovery and life changes. You will have frequent visits at first, because there will likely be changes to your residual limb for 12 to 18 months and you will still be actively adjusting to your amputation.



## 5.2 Pain Management

In the long term, phantom limb pain does not limit your functioning.

With a well-fitting prosthesis, residual limb pain is not a significant problem. Most people will report discomfort rather than pain in the residual limb.

The level of discomfort will vary with your overall activity level.

You must remain aware of pain in the residual limb that suggests that your prosthetic fit or alignment may be declining.

Over many months and years you may begin to experience pain in your joints and muscles. This is caused by long term overuse. Maintaining your mobility as an amputee will put unusual stresses on the rest of your muscles, bones and joints.



### *What I need to do*

- Pursue your life goals and strive to be as active as you can.
- Be aware of what your body and your residual limb are telling you. Modify your activity as you need to, to manage any secondary pain in your muscles, tendons and joints.
- If you are having pain in your residual limb don't ignore it. See your prosthetist or physician. Remember taking care of your residual limb is critical for you to maintain your work, your play, and your role within your family.





## 5.3 Residual Limb

Your residual limb will constantly change shape and contour throughout your life. This will affect the quality and comfort of your prosthetic fit.

Some of the factors that can affect your residual limb are your body weight, your medical status, your diet, your activity level, and for women, pregnancy and your menstrual cycle.

Optimize your body weight and try to keep it stable through regular exercise and a diet that will not cause you to gain or lose weight.

Avoid foods with high salt content, especially if you have heart or kidney disease.

If you are taking diuretic medications, take them as they have been prescribed.

If you have noticed a relatively rapid change in shape of your residual limb especially if you have a history of heart disease or kidney disease, you should see your medical provider as soon as possible.

For women, pregnancy and where you are in your menstrual cycle can also alter your residual limb volumes. If these changes impair your socket fit and your mobility, see your primary care or OB/GYN provider. Sometimes you will need a new prosthetic socket during the interval of your pregnancy and post pregnancy as you return to your normal body weight.



### What I need to do

Continue to take good care of your residual limb. Keep watching for any changes, and report to the doctor any pain, skin breakdown, irritation, or formation of new calluses.

- ➔ Regular inspection of your residual limb using a long-handled mirror will help you identify skin problems early.

- ➔ At first, inspections should be done whenever you remove your prosthesis. Later on, most amputees find daily inspection sufficient for the early identification of skin problems.
- ➔ Inspect all areas of your residual limb. Remember to inspect the back of your residual limb and all skin creases and bony areas.
- ➔ Look for any signs of skin irritation, blisters or red marks that do not fade within 10 minutes of removing your prosthesis. Report any unusual skin problems to a member of your rehabilitation team.

## 5.4 Readjusting and Expanding Your Goals

Throughout your life your interests, personal goals, work goals, and family needs will change. It is important that you periodically ask yourself what your goals are. Rehabilitation is the process of helping you accomplish your goals and needs. This may require changes in your prosthesis and changes in your exercise program and/or some specialized training.



Many of you will have heard of amputees that have accomplished goals that are far beyond what many people without amputations have accomplished.

### It is important to remember:

- The artificial limb (prosthesis) is not the reason they have accomplished these goals. The prosthesis is an assistive device only. These people have incredible underlying abilities that were the primary factors that allowed them to accomplish their goals.
- Accomplishing these advanced goals is not the measure of who you are as a person or whether you are a “successful” amputee.
- Accomplish the goals that are important to you. Your Mount Everest may be climbing the stairs that will allow you to enter your favorite

## 5 Long-Term Follow-up

restaurant with your family, or taking a walk with your grandchild. These all have value.

- For many amputees the accomplishment of their goals does not depend on using a prosthesis. Some will use a power scooter, a conventional wheelchair, or a sport wheelchair.
- Sometimes your medical or residual limb condition may ultimately limit what you're able to accomplish.

You should keep your ongoing regular follow-up appointments with your amputation clinic team.

A comprehensive evaluation by your rehabilitation physician, physical therapist, prosthetist and recreation therapist can help you assess whether or not your goals may be accomplished, and how to modify your goals if they cannot be accomplished. They can also help you identify what you will need to do to accomplish them, and how your amputation team can help you accomplish them.

### 5.5 Specialized Prosthetic Limbs

Specialized prosthetic limbs exist that are specifically focused on certain functional tasks. But remember: in most cases the prosthesis itself is not the tool that enables you to perform a specific function; it is a tool that will help you do something better if your underlying balance strength, endurance, and medical condition will enable you to do it.



**Water Prosthesis** – most prosthetic limbs that are used in day to day walking should not be immersed in water, especially salt water. This applies to bathing and showering as well. If you need to wear your limb

for bathing and showering there are covers for a prosthesis that can protect it from water. There are also prostheses that are made out of components that can be immersed in water. Your occupational therapist can advise you about the best way for you to safely accomplish bathing and showering. If you are interested in doing more advanced water activities such as swimming, SCUBA, water skiing etc. your prosthetist can tell you what components and adaptations can best allow you to accomplish these goals.

**Golf Prosthesis** – many amputees use their day-to-day prostheses for playing golf. In some situations, and depending on how you swing and which of your legs has an amputation, a “rotator” can be put into the prosthesis to help you twist during your golf shot.

**Cycling Prosthesis** – for those with amputations at or above the knee. One of the biggest challenges is getting comfortable on the bicycle seat because of how high the prosthetic socket comes up on your buttock. Also for transfemoral amputees you will need a prosthetic knee that will allow it to “free wheel” during cycling. Some transfemoral amputees use adaptive hand cycles so that they don't even need to wear their prosthesis or deal with the seating challenges. For transtibial prosthesis the amputated limb is very effective at generating power during pedaling. The big problem for you will be to get your knee flexed adequately at the top of the crank cycle. The back upper brim of the socket can limit how much you can flex your knee. Do not modify your prosthesis to accomplish this. This can adversely affect the functional performance of the prosthesis for day-to-day activities. Talk to your prosthetist. He or she can design a specialized prosthesis, in conjunction with some bicycle modifications can allow you to very effectively cycle.





**Running Prosthesis** – Running is possible in a limited way on any prosthesis, but runners who are interested in competitive running or running for exercise on a regular basis will require more sophisticated running prosthetic components. These can be prescribed and fitted by your rehabilitation team.

There are many other types of specialized adaptive devices that enhance participation in other sports such as skiing, snowboarding, hiking, and

climbing. Your recreation therapist and team can assist with exploring other options.

As you approach your rehabilitation team to discuss pursuing some of these higher level goals, it is important to appreciate that they will try to determine whether or not these goals are possible. At times, in borderline situations, they may want you to demonstrate your strong interest by accomplishing specific goals in advance of fitting you with a new prosthesis. At other times in conjunction with a new prosthesis, you will have to participate in an exercise program to enhance your strength, fitness, and balance to be able to accomplish the goals. There may also be additional training that is necessary to learn how to use some of these components.

## 5.6 Secondary Medical Conditions

Someone who has undergone an amputation may have an increased risk of developing secondary complications. Typically these are more likely in individuals who have undergone their amputations at a younger age and who have had to adapt to being an amputee for many years.

This section of your educational materials is not meant to generate additional concern or distress. It is meant to make you aware of these risks so that you can make changes in your lifestyle to minimize or avoid these risks.

### 5.6.1 Diabetes, Circulatory Problems, and Cancer

As in non-amputees, many of these secondary conditions are a result of a poor diet and a sedentary lifestyle. To the extent that limb loss causes an amputee to become less active, it may also increase his or her risk for these problems.

### 5.6.2 Back and Hip Problems

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

Lower-extremity amputation causes a change in the center of gravity, disrupting the biomechanical symmetry of the back and hips. The joints of the lower back and non-amputated limb are stressed and muscles are used abnormally.

Although back problems in amputees are not always related to their gait or their prosthesis, your rehabilitation team can detect many of these problems if you show up to a follow-up visit at the amputation care clinic. Make sure that you have at least one scheduled follow-up appointment within the first year after discharge. Maintain this visit every year. The physical therapists and prosthetists can assist you with any problems that can be eased through proper prosthetic fit, more appropriate components, or gait training. In addition, you should learn about good body mechanics to avoid as many problems as possible.

### 5.6.3 Bone Density and Muscle Loss

Bone density and muscle loss can be problems for anyone who is inactive. After amputation, there are specific muscles that remain but are not

used as they had been, and this leads to shrinkage or atrophy. The bone is normally stimulated when the muscle pulls on it or when we bear weight through the bone. If this does not happen, the bone gets thin (osteoporosis) from not being used.

The primary care provider, the physiatrist and the physical therapist can be especially helpful with these issues, but the best solution is to avoid the problems if possible. Sufficient exercise and proper technique and frequency are important.

### 5.6.4 Obesity

Obesity in America is probably the most serious health hazard we face—and the most costly. Hip and back problems, heart problems, diabetes and various other problems are all affected by obesity or over weight. In some cases obesity may even be their cause

If the amputation has led to decreased activity, weight gain often follows. The obesity causes further stress on the heart and other systems, and weight gain changes the custom fit of the prosthesis.



#### What I need to do

#### Take your Diet and Weight Seriously

- ➔ Many conditions and complications after limb loss can be limited with healthy eating habits. Managing your weight is essential to lengthening the life of yourself as well as the fit of your prosthesis.
- ➔ Apply the skills and principles of proper nutrition. You can apply practical tips for making lifestyle changes to fit your situation. Many practical resources are available for assisting you with adopting good eating habits.
- ➔ Weight loss and weight management are a balancing act! You have to find ways to burn more calories than you take in or you will gain

weight. There are many ways to be active. The secret to success is to find new ways to fit physical activity into your daily life. As you settle into a routine at home, make physical activity choices that work for you, and ones that you will work at every day.

#### Care of the Prosthesis

Your periodic visits to the amputation care clinic will ensure that the prosthetist will be able to check the condition of your prosthesis, and make necessary adjustments and repairs to the socket, and the components. The prosthesis may have been worn out and a replacement or upgrade may be necessary. There may be a time when a new component or a whole new leg may be considered because of changes in your residual limb, or because you have increased your activity and are ready to move on to more advanced challenges. As time passes, there are also new technology developments that you may benefit from.

## 5.7 Ongoing Medical Care



### Diabetes

Diabetes is a very serious illness that can affect many parts of the body — most commonly the brain, heart, kidneys, eyes, blood vessels and nerves. The challenge for the diabetic patient is to cope with the effect of diabetes and maintain

optimal health to avoid any possible complications. Diabetes can put you into high risk for stroke, heart attack, limit your eye sight and diminish your sensation and strength in your remaining limb.

It's most important that you keep your follow-up visit with your primary care provider and your check-up visit with the amputation care clinic. The

health care team can monitor and screen for any complications and start treatment early on to avoid further complications. It is also important to understand how these medical conditions can interact and complicate your life as an amputee.

### Heart Disease

Diabetes and the factors that contribute to poor circulation in your legs can contribute to an increased risk of circulatory problems in your heart muscle. This can cause heart attacks, angina (chest pain), and congestive heart failure. Because walking with a prosthesis can increase the demand on your heart, these conditions can limit your walking endurance, walking speed and walking distance. Also, because of congestive heart failure you can have problems with swelling in your residual limb and remaining leg. Swelling in the residual limb can contribute to poor prosthetic socket fit and pain. This will further limit your ability to use your prosthesis and to walk. It is important to follow the lifestyle instructions mentioned in previous pages to reduce these complications. Also make sure to follow your primary care provider's recommendations in terms of your diuretic use as well as dietary salt restrictions.

### Poor Vision

Because diabetes can contribute to visual problems it can cause balance complications. Your vision is an important tool that helps you keep your balance, especially when you have poor sensation in your remaining limb. See your vision specialist regularly. If you have a decrease in your vision see your primary care provider as soon as possible. If your physician or physical therapist has recommended that you use a cane or crutches to help your balance make sure to follow their instructions.

**Remember: Safety First!**



### Kidney Disease

Diabetes can affect your kidney function. This can complicate your body's ability to balance its fluid status. This can result in problems with swelling in your limbs, and complications with maintaining the best prosthetic fit. This is even more of an issue when you need to have dialysis as part of your treatment. Dialysis can cause very large shifts in fluid volume. This can cause significant changes in prosthetic sock adjustments to maintain your prosthetic fit. Amputees on dialysis will need to pay special attention to dietary restrictions, diuretic medications, and will need to have more frequent and regular visits to their prosthetist to help adjust and maintain their prosthetic socket fit.

### Neuropathy

Diabetes can interfere with normal nerve function. This contributes to poor sensation in your remaining foot. It can also impair your balance and contribute to skin injury on your remaining foot. It has been shown that management of your diabetes with diabetes medications and diet can reduce this risk.

### Risk of Skin Ulcers on Your Remaining Foot

Other sections of this manual have focused on how to best protect your remaining foot. Preserving your remaining limb is probably the most important thing you can do to maintain your mobility for years to come. Follow the foot care instructions that your rehab team and primary care providers have given you.



## 5.8 Physical Rehabilitation

Loss of bone strength (density) and muscle can be problems for anyone who is less active or inactive. After amputation, there are some muscles that will remain but are not used as they had been, and these muscles will shrink over time. Bones also need activity, such as when you walk and bear weight through your bones. If this does not happen, the bone gets thin (osteoporosis) from not being used.

One of the best ways to develop and maintain strong bones and muscles is to do resistance training such as weight lifting. Your general health will benefit. It will also enhance your self-esteem and body image.

Exercising with weights can be done safely at home after learning the proper techniques from your therapist. Basic equipment needed for this activity does not have to be expensive. Resistance training should be a part of your regular exercise program.



### What I need to do

Before beginning any new exercise program, you should talk with a primary care provider. If desired, a physical therapist can help you design an exercise program that fits your needs.

#### As you develop your new skills and routines at home:

- ➔ Set realistic goals. Break goals down into small steps so you can enjoy successes along the way. Goals you set for yourself should be motivating for you, not overwhelming.



Photo Courtesy of the Department of Veterans Affairs

Photo Courtesy of the Department of Veterans Affairs



- ➔ Choose activities you enjoy. Almost everyone faces barriers to getting enough exercise each day, especially when exercise is seen as a big chore. Over time look for a number of activities that can fit into your routine. This way you will have more choices and stay motivated. There are many organizations that offer adaptive sports and other activities that may interest you. Don't be

afraid to try something new! Refer to the Resources section in the back of this guide for the websites of these organizations.

- ➔ Progress slowly and safely with new activities. When setting your exercise goals, make sure you have a plan for monitoring your progress. Post reminders where you see them to remind you of your schedule and mark down the progress made towards completing your goals.
- ➔ Reward yourself! You are more likely to achieve a goal if it is meaningful and rewarding to you.

Safety will always be an ongoing and very important issue with any activity. You must be aware of what risks are involved with your activities. Always consider the safety issues of any environment that is not part of your daily routine, and assess these areas for potential safety hazards.



## 5.9 Coping Methods

You have worked very hard to reach the goals you have obtained, but true rehabilitation has only just begun for you. Life-long care of yourself is necessary to maintain the highest levels of independence and activity. It is realistic for many people to return to activities they value and be able to do many things for themselves. At the same time, most people find that figuring out how to live their lives with the amputation is a gradual process, and requires a lot of practice, trial-and-error, and making small changes in their approach until they figure out what works best.

If you were experiencing stress, sadness, depression, or worry before the amputation, chances are that you may feel these same things afterwards. It is important to realize that the amputation itself is not the only thing affecting how you feel on any given day, and that paying attention to sources of stress or worry in other aspects of your life can improve your general well-being. Also, changes in your life circumstances or social situation (for example, losing a job or getting a new job; getting married, getting divorced, having a child) may present new challenges or may give you new physical tasks you have to do. This may mean that you face more adjustments to your usual way of doing things. As always, working with your rehabilitation team, talking with important, trusted people in your life, and seeking consultation with a mental health professional when needed will help you cope with these developments.



Remember that there may be days when your body is tired, or you are not feeling well. You may need to use your wheelchair or crutches as a backup when using the prosthesis takes too much energy. When you are feeling better, you will be able to resume using the prosthesis.

## 5.10 Sexual activity and intimate relationships

After a limb loss, intimate and sexual relationships can be challenging. There are competing activities and tasks which make it difficult to prioritize intimate and sexual relationships. Additionally, the phase of your recovery and rehabilitation, and how comfortable you are with talking about intimacy, sex, advocating for your desires, and personal needs will also affect your ability to achieve your intimacy and sexual goals. Your ability to communicate and adapt will ensure active participation in intimacy and sexual activities.

Self-advocacy skills, open communication, acceptance, and consideration of your partner's feelings and requests are important to healthy sexual and intimate relationships. Don't hesitate to discuss your sexual and intimate goals with your health care providers and your partner. You will find that communicating intimate and sexual needs will be important in promoting and maintaining healthy intimate relationships and sexual activity.

Self-awareness of your needs and desires will guide your intimacy and sexual activity. Initially consider focusing on intimacy and pleasure goals, versus sexual performance goals. Look for simple ways to maintain intimacy with your partner through such things as: positive affirmations, flirting, sharing time and sharing touch, practicing gratitude, working on a fun project together, or going on dates either inside the home or in the community. Pleasure goals create a more relaxing and fun environment

that promote and nurture intimacy and sexual activity.

Intimacy and pleasure goals focus on the sharing and exploration of touch in a sexual way that makes both partners feel good. External assistance such as sex toys, genital lubrication, and medication can all help assist with enhancing pleasure. Prioritizing intimate relationships can be a strategy to maintain healthy relationships, decrease stress, and improve quality of life post-limb loss.

Sexual performance goals (the ability of the penis to become erect, the vaginal canal to self-lubricate, and achieving an orgasm), are commonly the desired target of sexual success, but can be challenging and sometimes difficult to bring about. To help achieve sexual performance goals, think about planning sexual activity when your pain and/or fatigue are typically at their lowest. Try making modifications and adaptations to your intimate and sexual activities and routines.

Acknowledging your body's signals will ensure your understanding of not only your pain and fatigue patterns, but also enhance your own intimacy and pleasure preferences, and help to achieve satisfying intimate and sexual relationships.



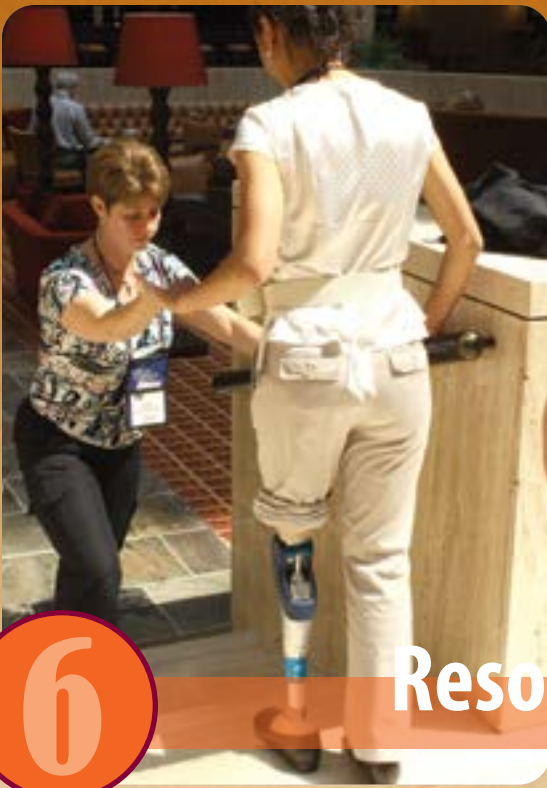
### *What I need to do*

- ➔ Set up new goals for yourself.
- ➔ Discuss these goals with your family, your therapist or good friends.
- ➔ Make sure you do things that you enjoy, have fun and release stress.
- ➔ Remember to check the other suggestions on [pages 5-9](#).

## 5.11 Long-Term Follow-Up Summary

- Set new goals for getting back to your usual activities or advancing your activity level—tell your team about these goals.
- Maintain a healthy life style—exercise, eat well, manage your weight, don't smoke, take care of your other health conditions.
- Take care of your prosthesis and equipment—see your rehabilitation team if you have concerns about your equipment or need repairs.
- Continue to check your residual limb and other limb on a daily basis.
- Follow up with your rehabilitation team on a regular basis.





## 6

## Resources

The following pages list various associations and resources that are online or in print form. You are encouraged to explore the support tools listed here, or perform your own search for additional resources tailored to your interests and needs. The following information offers a starting point for helping you get involved. Having an amputation does not mean the end of an active life. Advances in prosthetics and rehabilitation methods enable more and more amputees to pursue many avenues of an active life, including sports.

Please note that over time some internet addresses may change. However, if you search for the name of a particular organization, you should find the current web site.

## 6.1 Resources

### Department of Veterans Affairs

#### Amputation System of Care

[www.prosthetics.va.gov/asoc/index.asp](http://www.prosthetics.va.gov/asoc/index.asp)

The Amputation System of Care (ASoC) provides specialized expertise in amputation rehabilitation incorporating the latest practices in medical rehabilitation management, rehabilitation therapies, and advances in prosthetic technology. It is a system of care designed to provide Veterans access to the full continuum of care.

Information Available from Amputation System of Care:

- Amputation System of Care
- Traumatic Amputation Fact Sheet

#### Caregiver Support Program

[www.caregiver.va.gov](http://www.caregiver.va.gov)

Caregivers play an important role in the health and well-being of Veterans. The Caregiver Support Program offers training, educational resources, and multiple tools to help you succeed. Please contact the Caregiver Support Line (1-855-260-3274) for advice on being a caregiver.

#### National Veterans Sports Programs and Special Events

[www.va.gov/adaptivesports](http://www.va.gov/adaptivesports)

Veterans of all ages and abilities report better health, new friendships and a better quality of life when participating in adaptive sports. Veterans with disabilities who are physically active simply have more fun! To get started, take some time to review the many sports opportunities available to you by reaching out to your VA clinical team and checking out this website.

Information Sheet: [www.va.gov/adaptivesports/docs/Fact\\_Sheet\\_NVSPSE.pdf](http://www.va.gov/adaptivesports/docs/Fact_Sheet_NVSPSE.pdf)

#### Rehabilitation and Prosthetic Services

[www.prosthetics.va.gov](http://www.prosthetics.va.gov)

VA's Rehabilitation and Prosthetic Services is responsible for the national policies and programs for medical rehabilitation, prosthetic and sensory aids services that promote the health, independence and quality of life for Veterans with disabilities. This includes providing limbs and equipment, home modifications, and many other services.

#### Information Available on Rehabilitation and Prosthetic Services Programs

- Automobile Adaptive Equipment (AAE) Program: [www.prosthetics.va.gov/factsheet/PSAS-FactSheet-AAE-SC-NSC.pdf](http://www.prosthetics.va.gov/factsheet/PSAS-FactSheet-AAE-SC-NSC.pdf)
- Assistive Technology Program: [www.prosthetics.va.gov/factsheet/AT-FactSheet.pdf](http://www.prosthetics.va.gov/factsheet/AT-FactSheet.pdf)
- Clothing Allowance: [www.prosthetics.va.gov/factsheet/PSAS-FactSheet-Benefits.pdf](http://www.prosthetics.va.gov/factsheet/PSAS-FactSheet-Benefits.pdf)
- Driver Training Program: [www.prosthetics.va.gov/factsheet/Driver-Training-FactSheet.pdf](http://www.prosthetics.va.gov/factsheet/Driver-Training-FactSheet.pdf)
- Prosthetic and Sensory Aids Service Benefits: [www.prosthetics.va.gov/factsheet/PSAS-FactSheet-Benefits.pdf](http://www.prosthetics.va.gov/factsheet/PSAS-FactSheet-Benefits.pdf)
- Prosthetic and Sensory Aids Services General Information: [www.prosthetics.va.gov/factsheet/PSAS-FactSheet-What-to-Expect.pdf](http://www.prosthetics.va.gov/factsheet/PSAS-FactSheet-What-to-Expect.pdf)
- Prosthetic and Sensory Aids Service Housing Adaptation Programs: [www.prosthetics.va.gov/factsheet/PSAS-FactSheet-Housing-Adaptation-Programs.pdf](http://www.prosthetics.va.gov/factsheet/PSAS-FactSheet-Housing-Adaptation-Programs.pdf)
- Prosthetic and Sensory Aids Service and Guide Dogs: [www.prosthetics.va.gov/factsheet/PSAS-FactSheet-ServiceDogs.pdf](http://www.prosthetics.va.gov/factsheet/PSAS-FactSheet-ServiceDogs.pdf)
- Prosthetic and Sensory Aids Services Women Veterans: [www.prosthetics.va.gov/factsheet/PSAS-FactSheet-WomenVets.pdf](http://www.prosthetics.va.gov/factsheet/PSAS-FactSheet-WomenVets.pdf)

#### Veterans Crisis Line

[www.veteranscrisisline.net](http://www.veteranscrisisline.net); 1-800-273-8255 and Press 1.

Free, confidential support for Veterans in crisis and their families and friends. The Veterans Crisis Line connects Veterans in crisis and their families and friends with qualified, caring Department of Veterans Affairs responders through a confidential toll-free hotline, online chat, or text. Veterans and their loved ones can call 1-800-273-8255 and Press 1, chat online, or send a text message to 838255 to receive confidential support 24 hours a day, 7 days a week, 365 days a year. Support for deaf and hard of hearing individuals is available.

#### Military Resources

##### TRICARE, Prosthetic Devices and Supplies

<https://tricare.mil/CoveredServices/IsItCovered/ProstheticDevicesSupplies>

#### Computer/Electronic Accommodations Program (CAP)

<http://www.cap.mil/wsm/>

#### Military One Source

<https://www.militaryonesource.mil/>

#### Extremity Trauma and Amputation Center of Excellence (EACE)

<https://health.mil/EACE>

#### Community Resources

##### Amputee Coalition

[www.amputee-coalition.org](http://www.amputee-coalition.org)

National amputee advocate organization, offering books, DVD/videos, and conferences providing support and information. \$30/year membership. Included in membership is the monthly magazine called inMotion, as well a detailed guide for amputees called First Step. Highly recommended. 1-888-267-5669.

##### American Amputee Foundation

[www.americanamputee.org](http://www.americanamputee.org)

#### Amputee sports and recreation websites:

##### Adaptive Adventures

877-679-2770, [www.adaptiveadventures.org](http://www.adaptiveadventures.org)

##### Adaptive Sports Association

970-385-2163, 970-259-0374, [www.asadurango.org](http://www.asadurango.org)

##### Adaptive Sports Center

866-349-2296, [www.adaptivesports.org](http://www.adaptivesports.org)

##### Adventures Without Limits

503-359-2568, [www.awloutdoors.com](http://www.awloutdoors.com)

##### American Amputee Soccer Association

[www.ampsoccer.org](http://www.ampsoccer.org)

##### America's Athletes with Disabilities

800-283-7632, [www.NCHPAD.org](http://www.NCHPAD.org)

##### Challenged Athletes Foundation

858-793-9293, [www.challengedathletes.org](http://www.challengedathletes.org)

**Disabled Sports USA**

301 217-0960, [www.disabledsportsusa.org](http://www.disabledsportsusa.org)

**National Ability Center**

435 649-3991, [www.discovernac.org/](http://www.discovernac.org/)

**National Amputee Golf Association**

[www.nagagolf.org](http://www.nagagolf.org)

**National Center on Physical Activity and Disability**

800-900-8086, [www.ncpad.org](http://www.ncpad.org)

**National Sports Center for the Disabled**

970-726-1540, [www.nscd.org](http://www.nscd.org)

**National Veterans Wheelchair Games**

734-761-7824, [www.wheelchairgames.org/](http://www.wheelchairgames.org/)

**Wheelchair Sports USA**

515-833-2450, [www.nchpad.org](http://www.nchpad.org)

**World T.E.A.M Sports**

617-779-0330, [www.worldteamsports.org](http://www.worldteamsports.org)

**Social clubs for amputees can also be found by searching the internet.**

**Books (not provided or officially endorsed by the VA/DoD)**

- Amputee Coalition, [www.amputee-coalition.org](http://www.amputee-coalition.org), has a detailed guide for amputees called **First Step**. It's free with a \$30/year membership, which also includes the monthly magazine. Many other books are also available from ACA. 888-267-5669.
- **It's Just a Matter of Balance**, Kevin S. Garrison, South Euclid, OH: Print Vantage, 2005. ISBN 0-9773261-0-1. Prosthetist Kevin Garrison tells his story about how he became a below-knee amputee after being diagnosed with cancer as a teenager. He offers hope and inspiration to all amputees young and old.
- **Living With a Below-Knee Amputation: A Unique Insight From a Prosthetist/Amputee**, Richard Lee Riley. Thorofare, NJ: SLACK Incorporated, 2006. ISBN 1-55642-6925. Authored by an amputee and prosthetist, this book covers a spectrum of information on being a below-knee amputee.

- **One Step at a Time: A Young Woman's Inspiring Struggle to Walk Again**, Lenor Madruga. San Jose: iUniverse.com, Inc., c2000. ISBN 0-595-14914-6. On the morning of her 32nd birthday, the author discovered a small, hard lump on her thigh. Within a few nightmarish months, she had barely saved her life — and lost her leg. Now she tells the story of her struggle to return from the abyss of pain, drug addiction, self-torment, and depression that threatened to swallow up her entire life. It is a triumphant story of her determination to dance, drive, swim, water-ski, make love — and do almost everything she used to do before her operation.
- **Whole Again**, by Lee Whipple. The book can be ordered for a tax deductible donation, by contacting The Barr Foundation, 561-391-7601 or [foundation@t-barr.com](mailto:foundation@t-barr.com).
- **The Long Road Home: One Step at a Time**: a Doonesbury Book, GB Trudeau, Kansas City, MO: Andrews McMeel, c2005. ISBN: 0-7407-5385-1. A collection of the Doonesbury strips from a seven-month period, which chronicles the wounding of B.D. in Iraq and his experiences along the road to rehabilitation.
- **Have Crutch Will Travel: The Adventures of a Modern Day Calamity Jane**, Cale Kenney. 1st printed ed., Ltd. Denver, CO: Tell Tale Pub., 2002. ISBN 0-9724303-0-X Cale Kenney had a hemipelvectomy amputation at age 19 as a result of a motorcycle accident. She talks about her accident and recovery, and life since her amputation. Cale has traveled extensively and was one of the first women on the U.S. Disabled Ski Team.
- **You're Not Alone**, John Sabolich, CPO, 1993. Sabolich Prosthetic & Research Center
- **Coping With Limb Loss**, Ellen Winchell, PhD, 1995. Avery Publishing
- **Challenged by Amputation: Embracing a New Life**, Carol S Wallace, 1995. Inclusion Concepts Publishing House

## 6.2 Glossary

- **Adaptive Equipment:** Any equipment that helps you to walk or move around safely
- **ADL:** Activities of daily living.
- **AK:** Above knee amputee
- **Alignment:** The socket is attached to the prosthesis at certain angles. These angles need to be adjusted by your prosthetist and are determined by the position and anatomy of your limb, how you walk, and the characteristics of the artificial foot and or knee.
- **Ambulation:** Walking
- **Assistive device:** Any equipment that helps you walk or helps you with activities of daily living
- **Atrophy:** Diminishing size and strength of muscles
- **Bilateral:** Missing two limbs
- **Biofeedback:** A form of self-hypnosis
- **BK:** Below knee amputee
- **Check socket:** Clear plastic socket made first to see if the socket fits properly
- **Components:** The term used for the different part that make up your prosthesis
- **Contracture:** Tightening of muscles and joints, limiting motion around a joint (knee or hip)
- **Contralateral limb:** The unaffected or remaining limb
- **Desensitization:** Reducing sensitivity of limb by massage or other means
- **Distal end:** End of stump
- **Donning and doffing:** Putting on and taking off a prosthesis
- **Donning tube:** A hollow tube that helps fit an elastic tubular bandage onto your residual limb
- **Edema:** Accumulation of excess fluid in body tissues (swelling)
- **Endoskeletal:** Prosthesis that has a socket attached by a “pylon” or tube to the foot and or knee, and covered with a soft cover
- **Exoskeletal:** Prosthesis that is solid from socket to foot
- **Femur:** The thigh bone
- **Fibula:** The thinner support bone next to the tibia in your lower leg
- **Flexible inner socket:** Flexible plastic sometimes used inside the socket, which can sometimes provide additional comfort
- **Gait training:** Learning to walk with help of the therapist and/or prosthetist
- **Gel Liner:** Silicone type gel sock that goes next to your skin for protection. There are many types and thicknesses.
- **Hard socket:** A socket made of hard materials only
- **Harness:** Straps that keep your arm prosthesis on
- **HD:** Hip disarticulation, amputation of the hip
- **Hemipelvectomy:** Amputation of half of the pelvis
- **Ischial containment socket:** An above knee socket that cups your ischium and help stabilize and control your prosthesis
- **Ischium or ischial tuberosity:** The bone you sit on
- **KD:** Knee disarticulation, amputation of the knee
- **KT:** Kinesiotherapist
- **Laminated:** Type of socket is made from carbon fiber, fiberglass and resin
- **Lateral:** To the side away from the body
- **MAP clinic:** A place where special testing is done to check the way you move or walk
- **Medial:** Toward the mid-line of the body

- **Mirror imaging:** A technique that is specifically used to help with phantom limb pain.
- **OT:** Occupational therapist
- **Orthotist:** A patient care practitioner who makes or fits a wide variety of bracing devices
- **Peer support:** A trained amputee talking to another amputee before or after amputation
- **Phantom limb pain:** Painful sensations in the part of the limb that is no longer present
- **Phantom limb sensation:** Sensations in the limb that is still present
- **Physiatrist:** Doctor who specializes in rehabilitation
- **Pistoning:** The movement up and down in your socket. This will happen when the fit or suspension is not adequate.
- **Plantar flexion:** To point the foot down
- **Proprioception:** The awareness of the position of your body
- **Prosthetist:** pronounced “pross tha tist” The one who makes your artificial limb. Note: The prosthetist is not a doctor but frequently and increasingly has a 4- year college degree in prosthetics or a related field.
- **Prosthesis:** pronounced “pross thee’ siss” (“This pronounced as in the word “thing.”) This is the artificial limb
- **Prostheses:** pronounced “pros thee’ seez.” The plural of prosthesis.
- **Prosthetic:** (adjective) pronounced “pross thet tic” [For example, prosthetic department, a prosthetic knee, prosthetic foot. Your artificial limb is not a prosthetic; it is a prosthesis.]
- **PT:** Physical therapist
- **Pylon:** The “pipe” that goes between the foot and the socket
- **Quad socket:** An AK socket design that has four distinctly sides, and the ischium rests on top of the edge vs. being contained in an ischial containment socket.
- **Residual limb (also residuum):** Technical term for the part of your limb that is remaining (stump)
- **Revision surgery:** Surgery to modify the residual limb
- **Rigid Compression Dressing:** These are usually made from casting
- **ROM:** “Range of motion.” These are exercises materials to improve flexibility and prevent contractures
- **Shrinkers:** Elastic stockings meant to reduce the swelling or “edema” in your limb
- **Socket:** The most important part of the prosthesis, which is custom made to hold your residual limb in place
- **Soft Compression Dressing:** Usually elastic bandage materials that are reapplied often to maintain compression and reduce swelling
- **Stump:** The more common name for the part of the limb that is remaining
- **Socks:** Socks that go over your limb. These come in different thicknesses (ply). The higher the ply, the thicker the sock—usually 1-2 ply, 3 ply, and 5 ply.
- **Suspension:** The way the socket stays on your limb
- **Symes:** Amputation at the ankle joint
- **Tapping:** A technique to decrease the sensitive feelings in a residual limb
- **Thermoplastic:** Type of socket made from a plastic that is heated and formed over the model of your limb (different from laminated)
- **Tibia:** The bone below your knee (shin bone)
- **Transfemoral amputation:** An amputation above the knee
- **Transmetatarsal amputation:** Amputation through the foot
- **Transtibial amputation:** An amputation below the knee

## 6.3 Phases of Recovery Roller Coaster

### Phases of Recovery From Amputation: Role of the Peer Visitor in the Recovery Process

PHASE	CHARACTERISTIC	DESCRIPTION	ROLE OF THE PEER VISITOR
Enduring	Surviving surgery and pain	Hanging on; focusing on present to get through the pain; blocking out distress about future—it is a conscious choice not to deal with the full meaning of the loss; self-protection; may refuse a visit	Silent companion, supporting family
Suffering	Questioning: Why me? How will I...?	Intense feelings about the loss: fear, denial, anger, depression; vulnerable and confused; return to enduring stage; emotional anguish about the loss of self adds to the pain	Listening, empathy, validating, supporting family
Reckoning	Becoming aware of the new reality	Coming to terms with the extent of the loss; accepting what is left after the loss; implications of the loss for future—how will roles change; ongoing process; minimizing own losses in comparison to others' losses	Silent companion, supporting family
Reconciling	Putting the loss in perspective	Regaining control; increased awareness of one's strengths and uniqueness; more assertive; taking control of one's life; self-management of illness and recovery; changed body image; need for intimacy	Silent companion, supporting family
Normalizing	Reordering priorities	Bringing balance to one's life; establishing and maintaining new routines; once again, doing the things that matter; allowing priorities other than the loss to dominate; advocating for self	Validating, additional information, role model
Thriving	Living life to the fullest	Being more than before; trusting self and others; confidence; being a role model to others. This level of recovery is not attained by everyone.	Challenging, recruiting for PV



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