Limb Loss Rehabilitation

Patient and Family Guide

WakeMed Rehabilitation

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Why Rehabilitation after Limb Loss is Important

Limb loss is a life-changing event for an individual and their loved ones. A well-coordinated rehabilitation program, provided by a diverse team of experienced limb loss specialists, improves a person's potential for the best possible recovery.

At WakeMed Rehabilitation Hospital, the limb loss team includes the patient and their family, rehab medical staff, case managers, nurses, nursing assistants, physical therapists, occupational therapists, recreational therapists, psychologists, dieticians, and other professionals. All team members work together to help each patient progress toward maximizing their independence, improving their quality of life, and meeting their rehabilitation goals.

The purpose of this guide is to provide you with the information you need to make the best decisions about your care. You are a primary member of the limb loss team and play a vital role in the decision-making process regarding your care and progress toward independence. Our goal is to not only serve your medical and rehabilitation needs, but to also support your social and emotional well-being.

We encourage you and your loved ones to ask questions and provide feedback about your care. We are here for you.

Your WakeMed Rehabilitation Limb Loss Team

What to Expect in Rehab

Your limb loss team will help you develop the skills needed to progress toward caring for yourself, including:

- How to clean your healing wound and provide good skin care
- How to identify early signs of infection, including redness, swelling, increased soreness or drainage from your wound
- How to wrap your leg or apply a shrinker (an elastic sock) to help properly shape your limb and reduce swelling
- How to deal with phantom limb sensation and pain (sensation and pain that you feel in your amputated limb)
- How to position your limb to avoid contractures or tightness of joints
- How to perform exercises to strengthen your limbs after an amputation
- How to move around safely after surgery
- How to manage activities of daily living (like bathing, dressing, and toileting)
- How to develop good eating habits that help the healing process
- How to prevent further complications
- How to adjust emotionally and adapt to your limb loss

Your limb loss team is always available to answer any questions.

Reasons for Amputation

There are three primary reasons an individual may need an amputation.

Disease

Diabetes is the leading cause of amputation in the United States. People with diabetes are prone to developing wounds that do not heal, resulting in amputation. Vascular disease makes up more than half of all amputations annually due to non-healing wounds. Peripheral vascular disease (PVD) and peripheral arterial disease (PAD) are conditions in which blood vessels cannot provide adequate blood supply and oxygen to your limbs.

Trauma and Injury

Traumatic amputations and amputations due to injury account for about 45% of all amputations and are the most common cause of limb loss in people younger than age 50. An injury from an electrical shock, frostbite, car accident, or severe burn can destroy blood vessels and cause tissue death. Amputation is only suggested after all attempts to save the limb have failed or when it is necessary to save your life.

Cancer

Amputation may be recommended to prevent the spread of disease if you have cancer in your limb. Approximately 2% of all amputations are the result of cancer.

Barriers to Incision/Wound Healing

There are several factors that can delay healing.

Smoking

Smoking can negatively impact the healing process. Tobacco use also increases your risk for other medical problems such as heart disease, stroke, and blood clots. Your case manager can provide you with smoking cessation resources if you are interested.

Diabetes

Carefully monitoring your blood sugar is an important part of the healing process. Blood sugar levels are often elevated following surgery. Consistently elevated blood sugar levels can significantly delay healing. Your limb loss team will help you learn how to control and maintain normal blood sugar levels.

Poor Nutrition

Proper nutrition plays an important role in wound healing. You may benefit from a nutrition consult to help you understand how to maintain a well-balanced diet that promotes a healthy lifestyle and wound healing.

Caring for Your Residual Limb

The residual limb is the part of your limb that remains after amputation. Caring for your residual limb is important for your overall health and recovery after surgery. Following the guidelines provided by your limb loss team can help prevent infection and promote healing of your limb for future prosthetic use.

Skin Care

DO

- ✔ DO change your dressing as instructed by your nurse.
- ✔ DO wash your residual limb with mild soap and water after the incision is fully healed and all staples/stitches have been removed.
- ✔ DO use a soft towel to pat your residual limb dry after bathing.
- ✔ DO examine the skin on **BOTH** of your limbs every day using good light and a mirror to see the entire limb.
- ✔ DO alert your limb loss team if you notice any changes to your skin on **EITHER** limb.

DON'T

- ✘ DON'T remove scabs.
- ✘ DON'T soak your residual limb in water (like in a bathtub).
- ✘ DON'T apply any cream or lotion to your residual limb unless recommended by your limb loss team.

PLEASE NOTE: Alert your doctor if you notice the following signs of infection or pressure sores:

- The incision line breaks open or begins to drain (leak fluid) after it has already closed
- Cracks, sores, blisters, rashes, swelling, or increased redness on the residual limb

Skin Inspection

Skin inspection mirror

Inspect your residual limb as well as your non-amputated extremity daily. After surgery, skin inspection should be done whenever dressing changes are performed. Inspect all areas of the residual limb including the back of the limb, skin creases, and bony areas. You will be provided with and instructed in the use of a skin inspection mirror during your rehabilitation stay. You can also take pictures of your limbs to use for daily skin comparisons. This may help you detect any changes. Alert your limb loss team if you have any concerns.

Taking Care of Your Non-Amputated Limb (Sound Limb)

Inspect your sound limb daily. Conditions that impact your amputated limb can also impact your sound limb, potentially leading to another amputation in the future.

Inspect your feet daily for areas of pressure and remember to check between your toes.

A Prevalon boot (heel protector) may be issued while you are in the hospital. This is used to keep your heel suspended off the bed. You also have the option of using pillows under your calf if you are not able to use a Prevalon boot. Continue to inspect your skin even while using a heel protector.

Wear shoes that fit properly in width, length, and depth to prevent blisters or sores that may lead to larger wounds. Your limb loss team can help you obtain diabetic shoes and inserts if needed.

Swelling Reduction and Shaping Your Residual Limb

One of the most important goals after your surgery is to reduce swelling and properly shape your residual limb. The use of a compression wrap or a shrinker helps reduce swelling and assists with shaping your residual limb. Shrinking your residual limb helps decrease phantom pain and sensation. See page 11 Pain Management.

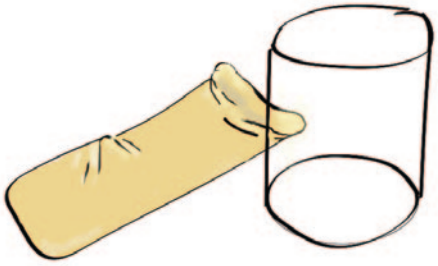
This also helps jump start the healing process and prepare your limb for a prosthesis. Your limb loss team can make recommendations on the best method for you.

Compression Wraps

Your therapist may instruct you or a caregiver on how to apply a compression wrap. We encourage you to practice this process repeatedly so that you become comfortable with the correct application technique.

Shrinker

A prosthetist will measure and fit you for a shrinker once your doctor determines you are ready. Your therapist or nurse will show you how to properly put on the shrinker using a donning tube. A donning tube allows easier application of the shrinker and helps prevent trauma to your incision site.

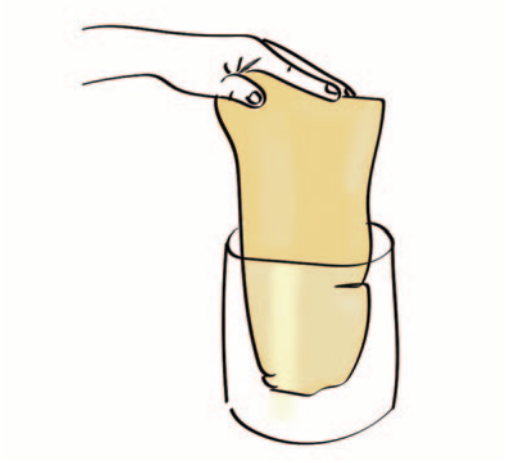


Shrinker with donning device

A shrinker should fit snugly and smoothly with no visible wrinkles. If you experience new or unusual pain or throbbing, remove the shrinker immediately. You should always wear your shrinker, even at night, unless otherwise instructed. Remove your shrinker two or three times a day to check your skin.

As your residual limb begins to shrink, the shrinker may become too large to wear and will begin to slide down. If this happens, ask your prosthetist or therapist to give you a smaller shrinker. Your prosthetist should give you two shrinkers. Put on a clean shrinker every morning after you perform residual limb care. To clean your shrinkers, simply wash them in the sink with mild soap and water and hang them up to dry.

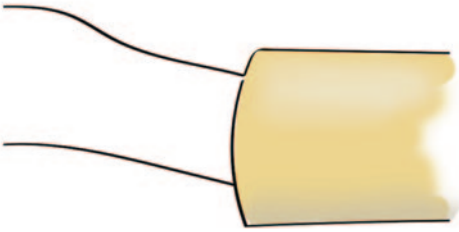
How to Apply a Shrinker Sock Using a Donning Device



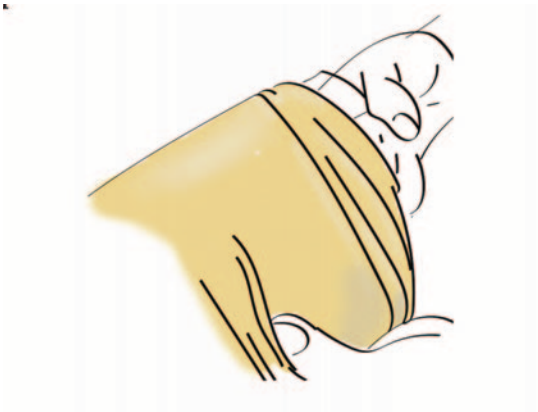
Hold the shrinker sock vertically inside the donning device.

Stretch the shrinker sock over the edge of the device so that it hangs inside the tube.

Pull the edges of the shrinker sock all the way down the sides of the tube until the end of it is flat on top.

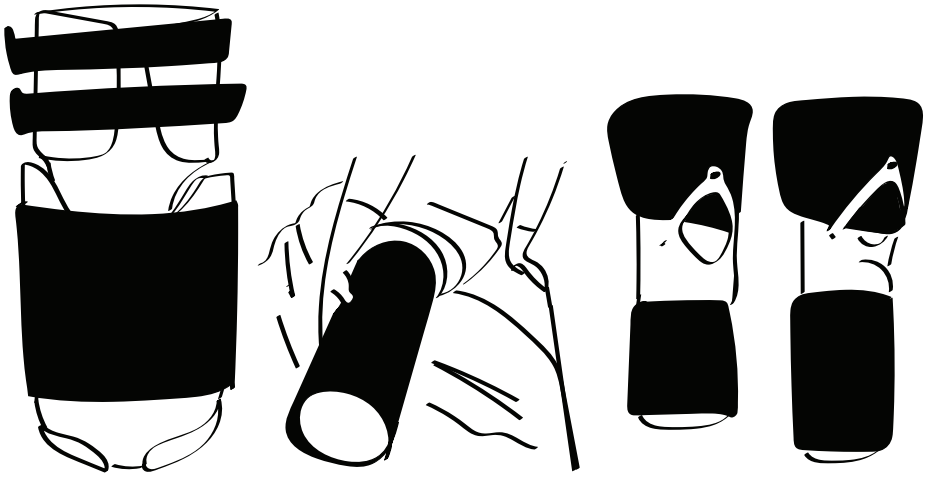


Place the end of the residual limb flush with the end of the shrinker sock.



Slowly and gently, slide the shrinker sock off of the donning device and onto the limb.Once the sock is completely on the limb, set aside the device and smooth the sock from the incision end toward the thigh. Make sure it is smooth.

Limb Protectors



Limb protectors are used to assist in positioning and can provide added protection against accidental injury if you fall or bump into something. Always wear your limb protector when you are out of bed and performing mobility activities. Your therapist will teach you how to put on and care for your limb protector.

Proper Use and Care

- To put on the limb protector, slide the socket over your residual limb and fasten the sleeves and Velcro straps so they are snug but not too tight. You should be able to get a finger under the strap that is just below your knee.
- Loosen the strap when you are lying in bed or reclining in a chair. You should always be able to get one finger under the strap.
- Watch for signs of excessive drainage or bleeding (a small amount of bleeding is not unexpected). If you have excessive bleeding or drainage, alert your limb loss team right away. If you notice just a small amount of bleeding (spotting), keep track of it by describing what you see in a journal. Indicate how much blood or drainage you see and where it is.
- If your foam pad becomes soiled, remove it (if it is removable) and wash it using antibacterial soap. Rinse the pad and lay it flat to dry, gently compressing it with a clean towel to remove excess water. Once it is dry, reapply the pad.

Pain Management

Post-Surgical Pain

After your amputation, you may experience pain in your residual limb. Your limb loss team will help you manage your pain with medications, therapy, and other strategies. Your pain will improve with time as your body heals.

Phantom Sensatory Pain

Many people experience what is known as "phantom SENSATION," a feeling that the portion of your limb that was removed is still there. You may feel itching, twitching, or a sensation that your limb is in a certain position. Phantom sensation is normal and should decrease with time. Your therapists will teach you techniques for desensitization to help reduce phantom sensation.

Some people experience "phantom PAIN" which can be described as a sharp, burning, twisting, or stabbing pain where the limb has been amputated. This pain can be mild or severe. There is not a clear cause of phantom pain. Fortunately, most individuals who experience phantom pain report that the pain lessens with time. If you experience phantom pain, it is important to let your limb loss team know. There are ways to reduce this type of pain.

Helpful Hints for Pain Relief

- Massage your residual limb, gently tapping or squeezing the most sensitive areas. Your therapist will teach you how to do this.
- Use a compression wrap or shrinker to apply pressure to your residual limb.
- Try to be as active as possible. Practice the exercises and stretches your therapists have taught you.
- If you are able and it is safe, change positions to help promote improved circulation.
- Keep a journal of when your pain is most severe and share that information with your limb loss team. You may find that certain activities trigger pain.
- Utilize mirror therapy as advised by your therapists.
- Our recreational therapists can show you alternative methods for pain relief such as using essential oils, tapping, meditation, HeartMath, deep breathing, and healing touch.
- Other alternative methods for pain relief may include acupuncture, TENS, biofeedback, virtual reality, imagery, or music.
- If these techniques are not helpful in pain relief, consult your physician.

Mobility

Early mobility promotes independence and helps prepare you for your prosthesis. Most people with limb loss will use a wheelchair after discharge from rehab and may need a wheelchair at times even if using a prosthesis. Careful consideration must be taken when determining the type of wheelchair that is best for you. The type of wheelchair that you select may impact your ability to receive a prosthesis or limit the type of prosthesis available to you. Your therapist will help you make your decision based on your mobility needs.

There are two main types of wheelchairs:

Manual Wheelchair: Manual wheelchairs require adequate strength and endurance for self-propulsion. They also have handles on the back so that you can be pushed by another person.

Power Wheelchair: Power wheelchairs have a motor, control system, and battery pack that you will need to recharge. They are used by people with less upper body strength or other mobility concerns.

Other Types of Mobility

We discourage “hopping” unless it is necessary for home accessibility. We focus more on mobility and safe transfers from a wheelchair level at the beginning of your recovery. Single leg hopping puts excessive strain on your non-amputated limb. If hopping is necessary, your therapist will teach you how to use an assistive device (walker, crutches) to help reduce the impact on your non-amputated limb.

Safe Transfers

Your ability to move from one surface to another will be impacted by your limb loss. Movement from your wheelchair to another surface is called a transfer. The type of limb loss, your strength and other factors will help determine the type of transfer technique you use. There are also devices (for example: sliding boards or lifts) that can assist you with transferring safely either independently or with assistance.

Here are some important things to know for safe transfers:

- Lock your wheelchair brakes and reduce the distance between the transfer surfaces.
- Make sure both transfer surfaces are stable and do not move.
- Be aware of objects that could scrape against your skin and cause an injury during the transfer.
- If possible, remove armrests or leg rests to minimize barriers.
- Ask for help as needed and explain to the helper exactly what you need them to do.
- Your therapist will train you and your family on how to safely perform transfers based on your ability.

Preventing Falls

There are several factors that put people with limb loss at greater risk for falls:

- **Changes in balance and center of gravity:** Your balance and weight distribution, even when you are seated, will be different because you are missing a limb.
- **Leaning forward in your wheelchair:** When you lean too far forward, your wheelchair can tip over. Ask for help if you need something that is out of reach or use a reacher (your therapist can provide). Always wear your seatbelt while seated in your wheelchair for safety.
- **Desire for independence:** The desire to do things independently, combined with changes in balance and center of gravity puts you at a higher risk for falls.
- **Overconfidence:** When you successfully perform a skill in therapy, you may believe you can perform the skill independently at any time and under any circumstance. It is important to understand your limitations and seek assistance to prevent falls.
- **Phantom Pain/Sensation:** When you are sleepy or taking pain medication, your brain may trick you into thinking the limb is still there. You may try to get up by yourself and fall.
- **Impatience and frustration:** Because most amputations are not planned, the sudden change from walking and being independent to having mobility limitations can cause tremendous frustration. If assistance is not immediately available, it can be tempting to try to get up by yourself before you are ready. Your limb loss team will teach you techniques to help you stay safe and prevent falls.

Exercise

Exercise is one of the keys to regaining your quality of life. It helps maximize your mobility and improve your overall health. Your exercise program begins immediately after surgery under the guidance of your therapists.

Your Daily Activities

A major goal in the recovery process is to regain as much independence as possible. This includes your personal self-care activities like bathing, dressing, and toileting. Your therapists will ask you to try a wide variety of tasks to assess your strength and abilities. Based on their assessment, your therapist will then teach you how to do things as safely and independently as possible.

Preventing Muscle Contractures and Tightness

Muscle contractures can occur when muscles around a joint become tight and do not allow your limb to move freely. With lower limb amputations, muscle contractures typically occur at the hip and knee when the joint is held in one position for a long time. Contractures are painful and difficult to correct. They can also limit your ability to do daily activities and impact the fit and use of your prosthesis.

To prevent tightness in your hips, lie on your stomach when you are in bed as able. Tightness in your hips can come from sitting in a wheelchair for a long period of time. Your therapist can provide you with stretches to help prevent contractures or tightness if you are not able to lie on your stomach.

To prevent knee contractures on your residual limb, keep your knee straight as much as possible. Your therapist will order a special leg rest that will support your residual limb and keep it straight when sitting in a wheelchair. Wearing your limb protector can also help prevent contractures of the knee if you have below the knee limb loss.

Residual Limb Positioning

Helpful tips for residual limb positioning and stretching:

DO

- ✓ DO lie on your stomach 2-3 times each day. Place a pillow under your chest and sound limb to stretch your hip. If you cannot lie on your stomach, lie on your side with your residual limb pulled back as far as it will go. Use a pillow to keep your residual limb pulled back.
- ✓ DO lie on your back with your residual limb close to your sound limb. Do not let your residual limb lie too far away from your body or roll away from your body. Use pillows or towels to help keep your residual limb positioned.

DON'T

- ✗ DON'T hang your residual limb over the side of the bed.
- ✗ DON'T sit in a wheelchair with your residual limb bent or hanging downward.
- ✗ DON'T place a pillow under your hip or knee when lying on your back.
- ✗ DON'T place a pillow between your thighs when lying down.
- ✗ DON'T sit with your legs crossed.

Wearing a Prosthesis

Choosing to use or not use a prosthesis is a personal choice, influenced by your personal goals and other factors. Your limb loss team will assist you with the decision-making process.

Wearing a prosthesis can be important for physical and emotional healing. The process of being fitted for a prosthesis may begin as soon as six to eight weeks after surgery. During your recovery, you will focus on healing, getting stronger, staying flexible and regaining your independence.

Wearing a prosthesis will help prevent swelling in your residual limb and improve your muscle strength and flexibility. Wearing a prosthesis may also lead to greater independence, a sense of accomplishment, and improved well-being.

A prosthesis is a unique piece of equipment designed for each individual with limb loss. No one else will be able to wear your prosthesis. It will be an extension of you. After you and your limb loss team determine the type of prosthesis that best fits your lifestyle and goals, a prosthetist (the person that will build your leg) will work with you to

create your prosthesis. This is a multi-step process including a series of measurements, cast molds, and fittings to ensure the prosthesis can be shaped to comfortably fit your residual limb. Creating a prosthesis requires a great deal of patience, communication and cooperation. The goal is to build a prosthesis that is comfortable to wear and maximizes your mobility.

There are many prosthetic companies in the area. Discuss your options with your surgeon or your limb loss team members.

Once fitted with a prosthesis, you will be encouraged to begin a therapy program focused on improving your mobility using your new prosthesis. WakeMed offers programs in a variety of settings including the Rehabilitation Hospital, Outpatient Rehab and WakeMed Home Health.

Check your skin after wearing your prosthesis to look for signs of poor fit, including redness that does not go away within 20 minutes, blisters, or skin tears. If you see any of these problems, stop using your prosthesis and immediately notify your therapist or prosthetist.

Adapting Your Home

Prior to or immediately following your surgery, you and your caregiver should begin thinking about and planning for potential home modifications. Your limb loss team can offer guidance on the changes needed based on your mobility and equipment requirements. Potential home modifications may include widening doorways and building, purchasing, or renting a ramp. Insurance does not pay for home modifications. Your case manager will help you identify any available community resources.

Checklist for Home

Once you get home from the hospital, it will be important to continue the exercises and stretches you learned from your therapists. You should also follow skin care recommendations for both your residual limb and non-amputated limb.

The following reminders will help you maintain good physical health:

- Make a schedule for yourself so that you can get in the habit of performing your exercises and stretches daily. Perform them the same time each day to stay on track.
- Use your skin inspection mirror to monitor your skin on your residual and non-amputated limbs. Look for signs of infection or skin breakdown.
- Wear your shrinker each night while you sleep.
- Follow the recommendations of your therapists for transferring to the toilet and shower as well as walking recommendations to reduce your risk of falls.

If you have a prosthesis:

- Follow the wearing guidelines for your new prosthesis. Check your skin regularly and contact your prosthetist if you have pain and/or redness that lasts more than 20 minutes after taking off your prosthesis.
- Ask your prosthetist for a prosthetic wearing schedule. At first, you may wear your prosthesis for an hour at a time while sitting. You will increase your wearing, standing, and walking time as recommended by your prosthetist and therapists.
- Wipe out the prosthesis and clean the gel liner as instructed by your prosthetist. When it is hot outside, you may need to clean the liner several times a day. Ask your prosthetist or therapist about other methods to help control sweating.
- Follow the diet recommended by your physician. Healthy eating habits help promote healing and support good skin integrity. Your need for calories will change with your new level of activity. Remember that it is important to maintain a healthy weight to reduce the stress on your sound limb. Notify your prosthetist of any significant weight gain or weight loss to ensure your prosthesis fits correctly.
- Most insurance programs limit the number of outpatient or home health therapy visits per calendar year. Talk to your case manager about how to maximize your therapy visits under your insurance plan.

Adjusting to Life after Limb Loss

Adjusting to life after limb loss is a process, and the road to recovery may not always be smooth. Everyone copes differently depending on age, health status, activity level prior to surgery, attitude toward life, and the type of support available including family, friends, and others who have lost limbs. It is completely normal for someone with limb loss to experience a range of emotions following surgery. Your case manager can help you understand and offer strategies to help you cope with this significant life change.

The Amputee Coalition describes Six Phases of Recovery

Phase 1: Enduring
Surviving surgery and the pain that follows.

Phase 2: Suffering
Questioning the reasons for the surgery. Asking "why me?"

Phase 3: Reckoning
Becoming aware and coming to terms with the new reality of the situation.

Phase 4: Reconciling
Putting the loss of the limb in perspective. Regaining control.

Phase 5: Normalizing
Reordering one's life priorities and establishing new routines.

Phase 6: Thriving
Living life to the fullest and becoming a role model to others.

Coping with Limb Loss

People cope with limb loss in different ways. Thinking through the following information may help you develop a coping strategy and prepare for challenges you may face:

- Was your amputation expected or unexpected?
- What is the level of your limb loss?
- How do you typically deal with stressful events?
- Do you have a good support system and others to talk with openly?
- Will you be able to return to work?
- Will you be able to return to other activities that you enjoyed before your limb loss?
- Do you have the finances available to modify your home so that it is accessible?

Feelings of Grief and Loss

- Feelings of loss, sadness, anger, frustration, and grief are a normal part of recovery.
- The adjustment period immediately following limb loss can feel like a crisis for you and your family. It will not always feel this way.
- Be kind and patient with yourself.

Positive Ways to Cope

- Talk openly and honestly with friends and family about how you feel. If you are unable to do this, consider journaling or writing letters and not mailing them.
- Know that people want to help, but they don't always know how. It is okay to give people specific instructions about what you need. It is also okay to say no to things that you will not find helpful like having visitors when you're not ready.
- Set specific, attainable, and measurable short- and long-term goals for yourself.
- If you are feeling like things are out of your control, focus on ways to feel in charge again. Educating yourself about recovery and advocating for your needs with medical professionals is a great way to regain feelings of control.
- Factor in time to do something you enjoy every day. Maybe it is something small like enjoying a cup of tea or listening to your favorite music. It is important to give yourself opportunities for happiness.
- Think back to other hard times that you have gotten through. How were you able to successfully get through those times? What did you do? Who did you talk with? Use those times as a guide to help you navigate through your adjustment to limb loss.
- Evaluate self-talk. Try to become aware of the things you are telling yourself. Whenever you identify a pattern of negative self-talk, pause and evaluate whether those thoughts are true.
- If you are not ready to talk about your recovery or the circumstances following limb loss, try thinking about how you will respond to questions. It may be helpful to come up with a few responses that you feel comfortable with. It is okay to simply say, "Thanks for asking. I'm not ready to talk about this right now."

Getting Help

If you have feelings of depression or sadness, it is best to seek help early. Consider working with a mental health professional to help you work through this period of adjustment. Here are some ways to connect with a qualified professional in your community:

- If you have private insurance, call the customer service number on the back of your insurance card for a referral. When calling for an appointment, explain the circumstances to the counselor to make sure he/she is a good fit for you. Feel free to ask questions.

- If you have Medicaid or do not have insurance, call Alliance Behavioral Healthcare at 800-510-9132. They are open for referral 24 hours a day.
- If you have Medicare, call your primary care physician for a referral. It may be more difficult to find a counselor that accepts Medicare.

Community Mental Health providers

If you feel depressed and just can't shake it, find help.

- Silver Linings for Seniors – 919-943-3064
- Carolina Outreach – 919-615-1027
- Monarch – 855-986-1763

Limb Loss Support Community

It is important to talk about your feelings after surgery. Share your concerns with your limb loss team. WakeMed offers several support options for patients with limb loss and their families.

Peer Support

Connecting with others who have experienced limb loss can help you understand the recovery process and reassure you that you can live a full life despite your limb loss. Ask your limb loss team how you can connect with a peer supporter.

WakeMed Amputee Group

WakeMed hosts an amputee group, offering support and education on the third Wednesday of each month. If you are interested in getting to know others with limb loss in a group setting, you are encouraged to attend. The group meets in person at WakeMed, or you can join virtually using Zoom. Ask any member of your limb loss team for more information.

Amputee Coalition

The Amputee Coalition is the nation's leading organization supporting the limb loss and the limb difference community. You can find information about additional support groups and online forums at **amputee-coalition.org** or by calling the Amputee Coalition's National Limb Loss Resource Center at **888-267-5669**.

Recreation: Doing Things You Enjoy

Your limb loss team wants you to live a full, active and meaningful life, that includes doing the things you love. Staying active helps you keep a positive attitude, build confidence in your new skills, manage your stress, and improve your social life. If you enjoy sports like golf, basketball, or bowling, you may need to learn adaptive techniques while using a prosthesis or wheelchair. Your therapists will help guide you through this process.

Intimacy and Sexuality after Limb Loss

Intimacy can be intimidating for anyone, but for someone with limb loss, this can be magnified. After an amputation, your body will look different and you may struggle with your own body image. This is normal. It is easy to believe that how we view ourselves is how everyone else views us, but this is far from the truth. You cannot control other people's thoughts or opinions. The only perspective that matters is yours. The key to intimacy with a partner involves self-confidence, trust, and communication.

Intimacy is not just about having sex. Physical intimacy can be in the form of touch, hugging, cuddling, and holding hands. When a person does not experience physical touch with another person for an extended period, it can affect their mood and mental health. Physical touch helps to release a hormone in your brain that boosts mood and therefore is important for your overall mental health. In addition, part of being

intimate involves sharing your thoughts, feelings, interests, and fears in a one-on-one conversation with someone. Open communication can help people feel connected and make it easier to move toward physical intimacy and even sex.

People are innately curious. The power of information is significant and being able to discuss your limb loss and how it happened will help you and your partner connect. Communication can help your partner understand what it is like to have limb loss or limb difference, which can help develop additional trust and intimacy. Being honest about insecurities can further develop trust between you and your partner.

It may be helpful to seek professional counseling, request peer support or engage with the WakeMed Amputee Group to talk to someone with limb loss who can relate to your situation. Your limb loss team is also available and can provide further resources regarding sexuality and intimacy with limb loss.

Resource: Sex and Intimacy after Amputation; by Erin Deegan; Amplitude Magazine; May 1, 2019

Aging with Limb Loss

After limb loss, many individuals return to independence through the use of prosthetics and adaptive equipment. As people with limb loss age, they will generally experience the same decline in physical strength and increased medical needs as the general population. However, aging can also uniquely impact limb loss survivors.

As an individual with limb loss ages, they may experience:

- **Increased medical needs:** An aging adult is more likely to have new medical diagnoses to manage. Individuals with limb loss may have additional diagnoses such as diabetes and neuropathy.
- **Increased falls risk and reduced strength:** Most people naturally lose strength and balance as they age, which creates a higher risk of falling. For those with limb loss, this is magnified due to changes in the center of balance, even when seated. In addition, for those using a prosthesis there is added risk associated with weight bearing that can be more challenging.
- **Skin breakdown:** As we age, our skin naturally becomes thinner and more fragile. Individuals with limb loss are more vulnerable to skin breakdown on their residual limb which could lead to the need for further amputations.
- **Weight gain with age:** It is common to see weight gain in older adults as metabolism decreases. This can affect a person with limb loss even more. Weight gain can increase the amount of stress that a prosthesis adds to the joints and the non-amputated limb. Limb loss increases the amount of energy required for movement. Adding more body weight increases that demand. Weight gain can also affect the fit of the prosthesis which can further reduce mobility and the ability to exercise.
- **Social isolation or depression:** After limb loss, many individuals become isolated due to a lack of independence or changes in life roles. As individuals with limb loss and their caregivers age, they have a higher risk for low mood and depression.

Steps you can take to minimize the impact of aging after limb loss:

- Follow up with your primary care provider on a regular basis and be consistent about managing your medical needs. Closely monitor your blood sugar if you have diabetes and take medications as prescribed.
- Follow up with your prosthetist to ensure your prosthesis continues to fit well. Your prosthetist will evaluate the need for socket adjustments and the need for a new prosthesis as you age.
- You may benefit from a yearly physical therapy evaluation to assess your balance and strength. If needed, ask your primary care provider for a referral to Outpatient Physical Therapy to assess safe mobility.
- Wash your prosthetic liner each day using warm water and mild soap. Make sure your liner is clean and dry before wearing it. Use a skin inspection mirror daily to monitor your amputation site and your sound limb to confirm that your skin looks healthy with no wounds or signs of irritation.
- Aim for a healthy diet with vegetables, whole grains, and protein which will encourage wound healing, decrease the risk of chronic disease, assist with weight management, and provide the energy needed for an active life.
- Join in new activities that promote social stimulation and talk to family or providers if you are feeling down. Stay active in the limb loss community by attending a limb loss support group.

Importance of Self-Advocacy

Self-advocacy is the act of speaking up for yourself, making your own decisions about your life and getting the information and resources you need in a way that you understand. Self-advocacy is very important in the health care setting. Being your own advocate will help you:

- Get the treatment plan that works best for you and your lifestyle.
- Overcome pain by communicating to your health care providers about what is working and what is not.
- Prevent problems before they occur.

What should I do to be an advocate for my health?

- Keep clear records about your medical history. Information about your medical history, current medications and contact information for other physicians or medical professionals that you see will help you stay organized and ensure your current medical provider has a complete picture about your needs.
- Make a list of questions before going to see the medical provider and take notes about things you want to remember during your visits.
- Restate what you have heard the medical provider say before the end of the visit to make sure you fully understand what you need to do.
- Bring a loved one or friend with you to important medical appointments. Four ears are better than two!
- You have the right to choose your medical and prosthetic providers such as your outpatient rehab provider, home health care company and prosthetist. Feel free to interview more than one health care provider before you make your final selection.
- Know what your health insurance will cover and what it will not by contacting your insurance company. Also, ask your medical providers, pharmacists and prosthetists about the costs of medications and devices so you can share them with your insurance company.
- If a non-urgent medical procedure is recommended, ask the physician about risks, benefits and the potential for alternative procedures. Ask for a second opinion if possible.
- Do your research but consider the source. Hospital and university-based websites and other sites like the Amputee Coalition are good sources. Other websites may offer false or misleading information. It is also important to consider the sources of friends and family offering you advice.
- Consider establishing a MyChart account. MyChart allows you the ability to access your medical records, request prescription refills, communicate with providers and schedule appointments. Any member of your team can assist you in signing up at mychart.wakemed.org

Additional Considerations – Upper Limb Amputation

According to the Amputee Coalition, there are nearly 2 million people living with limb loss. Of those, about 700,000 have an upper limb amputation. The needs of individuals with upper limb loss may vary from those with lower limb loss.

Factors that can impact the rehabilitation of an individual with upper limb loss include the level of amputation, the cause of amputation, and the amount of social support at discharge. Talk to your limb loss team about your goals.

Your rehabilitation program will include the following:

- Performing activities of daily living such as dressing, bathing, and toileting
- Developing adaptations to help you accomplish upper extremity tasks
- Caring for your residual limb
- Learning exercises and stretches designed to improve upper limb strength, range of motion, posture, and standing balance
- Exploring assistive technologies and modifications to help you be more independent
- Identifying peer supporters who have experienced upper limb amputation

Your health care team may start the prosthetic process as early as 30 days after the loss of your upper limb. An early start reduces the preference for one-handedness and increases the likelihood of success with your prosthesis.

What to Expect after Your Rehab Stay

Inpatient rehab is only part of your journey after limb loss. You may have started therapy in acute care and will benefit from continued therapy following your stay. There are several ways you can access therapy once you leave the hospital.

- **Home Health** – In-home rehab and nursing services
- **Outpatient Rehab** – Outpatient therapy with access to rehab equipment and services
- **StepForward Program** – Structured, intensive rehab program for patients once they receive their prosthesis. Options for StepForward are available in inpatient rehab, outpatient rehab and home health. Speak with a member of your limb loss team to discuss which setting might be most appropriate for you.

Contact Us

WakeMed Inpatient Rehab – 919-350-7876

WakeMed Outpatient Rehab – 919-350-7000

WakeMed Home Health – 919-350-7990

WakeMed StepForward Program – 919-350-7876

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