

COPING WITH TRAUMATIC INJURY AND DISEASE OF THE LIMBS

Traumatic injury and disease that affects the limbs can be life-altering and temporarily overwhelming. You may have questions about what to expect and where to turn for help.

TESTIMONIALS

After my accident, I had so many questions. My first priority was survival – beyond that, I wondered, how would my life ever be the same? Could I possibly ever return to the life I had dreamed of?

When my wound became infected, I was told it was 'my leg or my life.' Having the ability to speak to a peer visitor helped take the fear out of what I was facing.

She answered my questions and became a real mentor for me as I recovered both physically and emotionally.



"When I got sick with meningitis and my leg had to be amputated, my family and I were scared for my future.

We needed to understand what to expect and what questions to ask. No one should go through this alone."

- Nick Roumonada

At Hanger Clinic, we are dedicated to Empowering Human Potential through unparalleled clinical care and educational programs designed to assist individuals in getting back to their lives.

YOUR JOURNEY

Your journey is unique. Not every person who experiences limb trauma or disease travels the same path. Your road to recovery may include:

- Single or multiple surgeries
- In-patient or out-patient physical and occupational therapy
- Counseling for mental health, coping, stress management, or enhanced quality of life
- · Recovery time in the hospital, a rehabilitation or skilled nursing facility
- · Appointments with surgeons, your primary care physician, orthopedic specialist, and prosthetist

The end goal for anyone experiencing this journey is to lead a life of independence, freedom and happiness.

Throughout these pages, you will find common concerns and questions shared by many people who have experienced limb trauma or disease. At Hanger Clinic we hope to provide valuable information, resources and support to help you navigate your road to recovery and your return to the life you love.



Hospital Stay – The length of your hospital stay will be determined by many factors including your overall health, the severity of your injury or disease, outside complications like infection and neuromas, and the possibility of multiple surgeries.

Questions for your health care team: Based on the state of my limb, how long do you think I'll be in the hospital? Will multiple surgeries be necessary? How can I avoid potential complications with healing? What goals should I work on to speed up my recovery? Will I need help at home after discharge with my personal care or daily life? How do I make sure I have the support I need at home after discharge?

Wound Care and Avoiding Infection – Keeping your limb(s) on the path to healing means properly caring for your wounds to avoid infections like methicillin-resistant Staphylococcus aureus MRSA/Staph. Your risk of infection is directly related to the severity of your limb injury, so proper treatment and protection of the incisions is critical. Your health care providers will properly clean, dress, and protect your wounds in the hospital. To help prevent infection, follow your care providers' instructions, wash your hands thoroughly with anti-bacterial soap before touching your limb, and make sure you understand the preventative measures you can take while recovering in the hospital.

Questions for your health care team: Can you teach my care giver (loved one, friend, etc.) and me how to properly care for my wound at home? How should my limb look and feel as it heals? Is redness normal? What signs should I look for that might indicate infection?





Pain Management – Depending on the state of your limb, you may feel different sensations and pains associated with your injury or disease. Some people describe the pain as burning sensations, pin pricks, throbbing pulses, or electrifying jolts. Sharing the type of pain you are experiencing with your physicians can help them determine the best course of treatment to make you comfortable.

With limb trauma or disease that results in amputation, phantom limb sensations and phantom limb pains are common after surgery. They can be felt in the part of the limb that was amputated. Although the limb is no longer there, the nerve endings at the site of the amputation still send signals to the brain. These sensations and pains can be guite concerning while you are experiencing them, but they do often diminish over time. There are many therapies and remedies that can help you cope with pain.

Questions for your health care team: How do medications work to ease my pain? What are the possible risks or side effects of these medications? What are some alternative therapy options for dealing with limb pain?

EMOTIONAL HEALING

Common Responses to Limb Trauma

Losing the mobility and functional ability that you are accustomed to can be extremely distressing and difficult. It is important to remember that healing, both physically and emotionally, is a process. Facing the challenges ahead will get easier with time, but the initial shock of dealing with limb trauma or disease can be allconsuming. You are not alone. Many individuals who have dealt with limb trauma experienced a flood of emotions while recovering, including anxiety, helplessness, isolation, anger, fear, irritability, extreme sensitivity, strained relationships, and Post Traumatic Stress Disorder (PTSD). Questions like, "Will my life ever be the same? Will I ever walk correctly again? Will this affect my ability to work?" all seem very daunting while lying in a recovery room.

Understand that these feelings are normal, and they do not have to be permanent. Many people experience varying levels of grief and depression during this trying time and these feelings will come and go, especially as you begin to set goals and make strides toward your recovery. Anxiety will be replaced by confidence, a sense of hopelessness will be replaced by hope, and low self-esteem will be replaced by pride as you begin to heal your life. Take time to adjust and anticipate that this may be a difficult time in your life, but also a time of growth, change and transformation. Take care of yourself physically and emotionally, knowing that each small step you take brings you closer to reclaiming your life.



If, at any point, you feel that you need support in managing your feelings of grief or depression, reach out to your health care team and ask for help.

Coping with the Stress of Change

Be patient with yourself, your family, and your care team. Ask for support from loved ones and friends. Find ways to communicate and express your feelings through talking, journaling, or a creative means of expression that works for you. The more you work through your feelings, the closer you move toward healing. Tell loved ones how they can support you. Find ways to interact with others, through social media, support groups, or peer visitors. Engage in wellness-promoting behaviors such as healthy eating, suitable activity, mental stimulation, and proper rest. Reduce stress through meditation, breathing exercises, massage, acupuncture, guided imagery, or enjoying a good book. Establish or reestablish positive routines so you have something to look forward to daily. Avoid numbing yourself with alcohol or drugs as those behaviors hinder your healing process and ability to cope with your challenges head-on. Finally, seek support and inspiration from others who have been where you are now. There are many local or national resources that are available and specific to your circumstances. Remember that your mental and emotional well-being play a significant part in your overall recovery. Be kind to yourself.

Resources to Help with Emotional Healing

- AMPOWER Peer Support: The AMPOWER program's mission is to strengthen and empower those with limb
 loss or limb difference through peer support, education, and community. If your limb trauma or
 disease resulted in amputation, go to HangerClinic.com/AMPOWER for information on connecting with peer
 support and resources.
- **EmpoweringAmputees.org** is a password-protected, private community for individuals and families affected by or considering amputation. The community is made up of over 7,000 amputees, family members and care providers sharing their personal experiences with limb trauma, disease, loss and recovery.
- The Trauma Survivors Network (TSN) is an excellent resource for individuals and families dealing with major injury or illness. To contact the TSN National Administrator call 800-556-7890.
 E-mail: admin@traumasurvivorsnetwork.org
 - The TSN Recovery Assessment is designed for patients who are recovering from a traumatic injury. It will help you understand your strengths and available resources, as well as identify problems or challenges you may face in your recovery. Assess yourself at www.traumasurvivorsnetwork.org/recovery_assessments
 - The TSN NextSteps Program is based on the principles of self-management. This approach recognizes that YOU play the most important role in your recovery. NextSteps guides and supports you to be active and in control of your recovery. It uses techniques that have been scientifically proven to increase your self-confidence and ability to advocate for your own needs. NextSteps empowers you to be an active self-manager of your health and your life. www.traumasurvivorsnetwork.org/pages/nextsteps
- Mental Health America has an online tool that screens for depression, anxiety and PTSD.
 Grief, depression, and PTSD are common in those who have experienced limb trauma or disease.
 The symptoms of depression can make it hard to function. Be aware that there are effective treatments for both depression and PTSD. Learn more at MentalHealthAmerica.net/mental-health-screening-tools.
 If you think you may be depressed, talk to your physician about where to turn for help.

Questions for your health care team: Where can I find local resources for dealing with my emotions? Who can I speak to in the hospital about the way I'm feeling? Are there peer support programs that can help me? Can you refer me to a therapist who specializes in helping people recover from trauma or disease? Does this hospital host any support groups?

Phases of Recovery

- Safety and Stabilization: Identifying which areas of your life need to be stabilized and how that will be accomplished will be helpful in moving toward recovery.
- Remembrance and Mourning: This phase involves the important task of exploring and mourning the losses associated with the trauma and providing space to grieve and express emotions.
- Reconnection and Integration: This phase requires the creation of a new sense of self and a new future. You become ready to take concrete steps towards empowerment and self-determined living.

For more information visit: Trauma-Recovery.ca/recovery/phases-of-trauma-recovery/ and PsychCentral.com/lib/the-5-stages-of-loss-and-grief/



Understanding the different phases you may experience and fully engaging in your recovery can bring unexpected benefits. As you gradually embrace your healing, you begin to develop inner strength, self-awareness, compassion for others and surprisingly, a greater ability to experience joy and peace like never before.

COMMUNICATING WITH YOUR CARE TEAM

During your recovery, many different physicians, nurses, and other health care professionals will be dedicated to your care. Take advantage of your time with these individuals to address your questions and concerns. Keep a notebook nearby to jot down questions as they come to you and have it handy during meetings and appointments.

Surgeons – You may interact with trauma surgeons, orthopedic surgeons, vascular surgeons, and plastic surgeons during your stay in the acute care setting.

Questions for your surgeon(s): What can I expect for my recovery in terms of treatment, time in the hospital, medications, and home care? What are the benefits of this procedure with regard to pain relief, function, and mobility? Will this surgery solve the problem? Will any more surgeries be required in the future? What type of care will I have to provide for myself at home?

When will I be able to return to my regular activities (work, lifting, driving, and exercise)? What can I do to help with my recovery? Will I need physical therapy? Will you refer me to a physical therapist and/or occupational therapist? Will I see you again after I'm released or do I continue on to a different physician? Can I contact you with questions after I'm released?

Case Manager – While in the hospital, you may be assigned a case manager. A case manager combines quality, efficiency, and resource management in the delivery of patient care and is often responsible for coordinating discharge plans and care pathways that ensure the best outcomes for patients.

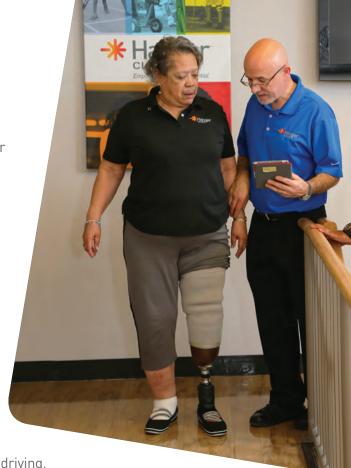
Questions for your case manager: Does my discharge plan include home health services, skilled nursing facility placement, and a referral to in-patient or out-patient rehabilitation services? Will you help me obtain insurance authorizations for services? If you are not the one to help me with questions related to insurance coverage, can you help me find the person who is?

Social Worker – Hospital social workers use case management skills to help patients and their families address and resolve the social, financial, and psychological problems related to their health conditions.

Questions for your social worker: Can you help me understand my care pathway (acute, sub-acute, home care) and the kinds of resources available to assist me? Can you help me arrange for resources/funds to finance medications, durable medical equipment, and other services I might need? Can you help me find a therapist or counselor who can assist me with dealing with my emotions? Can you tell me what my next steps are once I'm discharged from the hospital? What appointments will I need to make? When and with whom? Can you help me understand my insurance coverage and my responsibilities for payment?

Physical Therapists (PTs) – PTs help people with physical injuries regain range of movement and control their pain. They help people who have lost motor function due to accidents or illness to create a plan for rehabilitation which typically involves stretching, strength training, exercises, and physical manipulation to facilitate recovery.

Questions for your PT: Do you take my insurance? Do you specialize in treating individuals with my condition? What are the typical recovery times for people with my condition? How can I get the most out of my physical therapy?





Occupational Therapists (OTs) – An OT is a health professional who plays an integral part in helping individuals regain their ability to perform daily living and work activities to live life to the fullest.

Questions for your OT: What should I expect from you as my OT?
What assistive devices might I need? What do I need to change in my home in order to return to my daily living activities? How often will we work together? What is your plan to help me return to independence? Can you assist with resources and information on vocational rehabilitation?

Orthotists – An orthotist is a clinician who designs, fabricates, and fits braces or other orthopedic appliances prescribed by physicians. Often, customized braces can restore mobility and function for individuals who have experienced limb trauma or disease.

Questions for your orthotist: What types of braces are available? When and how often should I wear the brace? What can I expect from this brace? If I'm considering amputation after a lower limb injury, are there any bracing options that could help me move better and reduce my pain?

A detailed list of questions can be found at:

HangerClinic.com/new-patient/Pages/Choosing-a-Orthotic-Provider.aspx

Prosthetists - A prosthetist is a clinician who fabricates and fits artificial limbs and similar devices prescribed by a physician. If your limb trauma or disease results in an amputation, you will work with a prosthetist to choose the best prosthetic device to restore you to function and mobility. Unlike your surgeon or physical therapist, you will continue to see your prosthetic provider throughout your lifetime. It will be important to have a provider you can develop a good rapport with and that you truly believe has your best interests in mind.

Questions to ask your prosthetist: How much experience do you have with fitting individuals with similar residual limbs? What are my options and choices? How long will this process take? Will you or someone in your office assist me with insurance authorizations?

For a detailed list of questions, see the "Questions to ask your future prosthetist" document included in this package. A list of questions can also be found at:

HangerClinic.com/new-patient/Pages/Choosing-a-Prosthetic-Provider.aspx



Starting a personal, free webpage on CaringBridge.org allows you and your family to share health updates with the people who care about you.

FINANCIAL RESOURCES

Financial Concerns – As a result of your limb trauma or disease, you may qualify for short-term or long-term disability. It will be important for you to understand the necessary steps to secure your financial health. Ask your case manager or social worker about disability resources prior to being discharged from the hospital.

Social Security – The Social Security and Supplemental Security Income disability programs are the largest of several Federal programs that provide assistance to people with disabilities. Learn more at: SSA.gov/disability

US Department of Education and Vocational Rehabilitation – This program provides grants to states to support a wide range of services designed to help individuals with disabilities prepare for and engage in gainful employment consistent with their strengths, resources, priorities, concerns, capabilities, interests, and informed choice. Each state has different programs through the USDE and Vocational Rehab. For more information visit:

ED.gov/about/contacts/state and search by state or conduct a general Google search for "Vocational Rehab Programs" by your city and state.

For general inquiries call: 1-800-USA-LEARN (1-800-872-5327).

Disibility.gov - Disability.gov is the federal government's website for comprehensive information about disability-related programs, services, policies, laws, and regulations. The site links to thousands of resources from many different federal government agencies, as well as state and local governments and nonprofit organizations across the country.Learn more at: Disability.gov/

Insurance – Navigating through your health insurance statements and hospital bills is confusing and can be a struggle. Be persistent and try to stay calm when seeking answers to your questions. You may be telling your story for the tenth time, but the person listening is hearing it for the first time. When calling your insurance company record the date, time, and the name of the representative with whom you are speaking. Take notes on the information you receive so you can refer back to them later. Some insurance companies will assign a case manager to your care while others will not. Identify an advocate, family member, or friend who is willing to help you review statements, track payments, and get answers to your insurance questions. The Amputee Coalition has an Insurance Coverage and Reimbursement Guide that can be ordered online at: Store.Amputee-Coalition.org/Merchant2/merchant.mv

The Affordable Care Act – The new Affordable Care Act (ACA) is an extension of the Medicaid program which helps cover the uninsured who fall above the poverty level, but still cannot afford health insurance. The ACA Exchange is a nationwide network of health insurances where uninsured individuals can secure coverage through either a private health plan or through Medicaid. The hospital social worker or case manager can refer you to someone who can help you navigate through the website to learn more about your coverage options. Learn more at: Healthcare.gov





THRIVING AGAIN

Returning Home, Returning to Life - The time it takes to resume life as usual following limb trauma or disease is different for everyone. For a while, you may need to rely on friends and family to assist you at home. You will likely have many follow-up appointments with physicians and therapists. For your convenience, try to schedule multiple appointments into a single day so that you are not traveling back and forth from home to appointments daily.

Modifications to the home – If your mobility has been impaired as a result of your limb trauma or disease, you may need to make temporary or permanent modifications to your home. Tips and tricks for making life easier at home can be found at: HangerClinic.com/new-patient/ampower/ed-resources/Pages/Amputee-Home-Adaptations.aspx





THE HANGER CLINIC **ADVANTAGE**

Coping with Traumatic Injury and Disease of the Limbs

Hanger Clinic is committed to helping all patients reach their full potential by providing access to resources which are designed to help those who have undergone traumatic injury and/or disease discover their path back to living life to its fullest.

With Hanger Clinic's nationwide network, patients will receive the same excellent care across the U.S. that they receive close to home.

For over 150 years, our clinicians' commitment to the individuals they serve has been second to none.



* To learn more, visit HangerClinic.com



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EmpoweringAmputees.org