



# VA/DoD Clinical Practice Guideline for the Management of Upper Extremity Amputation Rehabilitation

### **Patient Summary\***

\*Words that first appear in italics are defined in the Limb Loss Definitions section of this summary.

### **Facts About Upper Limb Amputation**

- There are nearly two million Americans living with limb loss, approximately three percent of this population involve loss of one or both upper limbs. [1]
- Nearly 70 percent of upper limb amputations result from trauma. [2]
- From 2001-2014, more than 700 Service Members with some level of upper limb amputation were cared for in one of three military advanced rehabilitation facilities, accounting for approximately 30% of the total number of patients with amputations treated. [3]
- More than 32,000 Veterans have some level of upper limb amputation and this represents 18% of the total Veteran population with amputation that were cared for in the Veterans Health Administration (VHA) since 2000. [3]

# The Care Team Approach

The overall goal of *rehabilitation* after upper limb *amputation* is to optimize your overall health, independence in your daily activities, and your quality of life.

Your rehabilitation *care team* is comprised of doctors, therapists, *prosthetists*, and others working together to provide you a comprehensive treatment program. All members of your care team, including yourself, are important in attaining your personal goals. Your care team also wants to work with you to achieve the goals listed below.

### **Goals of Amputation Rehabilitation**

- Reduce pain in the residual limb
- Reduce phantom limb pain and phantom limb sensation
- Prevent overuse injuries that sometimes occur in remaining limbs
- Improve and maintain physical health
- Become independent and safe in self-care, work, and recreational/leisure activities
- Improve ability to access the community
- Provide support for your psychological and emotional well-being
- Improve your quality of life; address factors that may impact your quality of life
- Facilitate healthy *body image* and self-esteem
- Satisfaction with your independence, your prosthesis and your care team
- Optimize quality of lifelong care





A variety of factors such as your level of amputation, physical condition, diet, social support, emotional well-being and personal motivation impact your recovery following amputation. A comprehensive rehabilitation program that addresses your needs, abilities, and emotional well-being can help you achieve an independent lifestyle. Most upper limb amputation patients are candidates for a *prosthesis*, commonly referred to as an *artificial limb*; however, there are other approaches that your care team can assist with to improve your independence in daily activities without a prosthesis.

### **Expectations for Rehabilitation**

Your rehabilitation should include:

- Training in *Activities of Daily Living (ADL)* such as bathing, hygiene, toileting, eating, dressing and other activities such *as Instrumental Activities of Daily Living (IADL)* which allow you to care for yourself independently such as cooking, cleaning, laundry, shopping, and many others
- Consideration of alternative methods for accomplishing tasks, equipment that may be adapted to ease the difficulty of tasks, and using one-handed techniques
- Care of your residual limb to control swelling, pain, sensitivity, skin care, and shaping
- Range of motion (ROM) exercises to prevent contractures or limitation of motion in remaining joints
- Exercises to improve strength, posture, and balance
- Conditioning exercises for overall health and to help with increased energy needs
- Any necessary modifications or assistive technologies such as hands free phones and computers that may be needed in your home, automobile and work place to facilitate independence in your activities
- Peer support programs which provide an opportunity for you to interact with others with a similar condition, and who face similar challenges, emotions and experiences—this can be in the form of either individual peer support visitors or peer support groups

#### **Pain Following Amputation**

There are several different types of pain that may be experienced after amputation, including:

- **Immediate post-surgical pain** pain experienced after any surgery where skin, muscle, bone, and nerves are cut.
  - Residual limb pain (RLP) pain that occurs specifically in the remaining tissue of the
    amputated limb. It is an expected symptom following amputation. This pain can reappear
    later due to poor prosthetic socket fit, bruising of the limb, chafing or rubbing of the skin,
    and other factors.
  - o **Phantom limb pain (PLP)** pain in the missing part of the limb. It is the most difficult post-amputation pain to manage as it is not well understood.
  - Phantom limb sensations (PLS) non-painful sensory perceptions that the amputated limb
    is still there, thus the term phantom limb. These are common and may be present
    throughout your lifetime.





Associated musculoskeletal pain – pain that occurs in body regions other than the
amputated limb, such as the back, shoulder or opposite limb and may be related to
overuse/compensatory motions or fit and use of the prosthesis. These may be aggravated
by your job, environment, and advancing age.

## Pain management

Due to the variety of pain symptoms following upper limb loss, multiple treatment approaches may result in the best outcome. Medications, as well as other treatment approaches, should be considered. Ask your doctor what medications can be prescribed to help with your pain as well as if there are other appropriate treatment options available. Always follow up with your doctor to assure your treatment regimen is both safe and effective.

### **Phases of Rehabilitation Care**

There are four phases of rehabilitation care that you will progress through following an upper limb amputation. The phases are not defined by fixed points in time. Phases often overlap based on your needs, injury severity, wound healing, pain tolerance, and psychological readiness. Additionally, progression through the phases of care does not necessarily occur sequentially. Phases are repeated as appropriate based on your needs. The four phases are:

- Perioperative
- Pre-prosthetic
- Prosthetic Training
- Lifelong Care

#### **Perioperative Phase**

The Perioperative phase of rehabilitation begins when the decision has been made that amputation is necessary and ends when the residual limb wounds are free of infection, closed, sutures are removed, and you have become independent in self-care activities using one-handed strategies and adaptive equipment. Members of the care team complete assessments of your medical, functional, and psychological status in order to understand your level of function, prepare you for rehabilitation and, ultimately, lifetime care. During this phase, the team provides proper medical, surgical, and psychological management; begins rehabilitation; and works to protect and improve the health of your residual limb.

#### **Pre-prosthetic Phase**

The goal of the Pre-prosthetic phase is to prepare the residual limb for initial prosthetic fitting. During this phase, wound closure and pain control continue to be monitored, ongoing rehabilitation occurs, and continued psychosocial support is provided. You must be medically, surgically and cognitively cleared by the care team for a *diagnostic socket* fitting to occur. The Pre-prosthetic phase ends with the fitting of a





preparatory (temporary) prosthesis. This phase will typically occur in an outpatient or rehabilitation setting.

### **Prosthesis options**

There are up to six prosthesis options you can utilize in various settings:

- No prosthesis
- Cosmetic or passive prostheses
- Body-powered prostheses
- Battery powered prostheses

- A combination body powered and battery powered device
- Activity specific prostheses (e.g., swimming, golfing, etc.)

Different prostheses should be considered to assist you in meeting your functional goals. New goals may require changes to the design of the prosthesis, consideration of a different *terminal device* or warrant the prescription of a completely new prosthesis.

### **Prosthetic Training Phase**

The Prosthetic Training phase marks a turning point in the rehabilitation of the patient who desires a prosthesis. This phase starts upon delivery of a permanent prosthesis and continues until the patient demonstrates successful function during desired activities. This phase involves continued conditioning, functional prosthetic training, return to work and leisure activities, and continued psychological support.

Once the prosthesis is fabricated, ready for use, and a prescription for training is completed, the prosthetist will provide you, your family/caregiver and rehabilitation providers education on:

- Proper terminology related to the prosthesis and its parts
- How the prosthesis works (e.g. prosthetic control strategy)
- Functional and mechanical limitations of the prosthesis
- Any precautions related to the device
- Appropriate care of the prosthesis

In prosthetic training you should focus on:

- Donning and doffing the prosthesis
- Establishing a schedule to wear the prosthesis
- Learning to care for your residual limb and monitoring your residual limb (see Table 2)
- Learning to care of the prosthesis
- Familiarization of components and demonstration of proper and safe use of the prosthesis
- Training to learn how to control the prosthesis
- Functional training with the prosthesis





Report any of the following symptoms:

Ongoing pain in the residual limb or associated with a prosthetic harness

Skin breakdown

Change in the ability to don and doff the prosthesis

Change in limb volume (weight gain or loss)

Change in pattern of usage

### **Lifelong Care**

The last phase of upper extremity amputation rehabilitation is Lifelong Care. This phase typically begins once the initial prosthetic fitting and functional prosthetic training is completed or when a desired level of function and stability from both a medical and rehabilitation perspective has been reached.

During this phase, you should return to your care team for an annual follow-up assessment at least every 12 months. The goal of the Lifelong Care phase is to ensure you continue to maintain functional independence, and the care team should provide any necessary rehabilitation services that you may need, keep you informed about emerging technologies in upper limb amputation rehabilitation, address any changes in goals or health status, and minimize any effects of long-term prosthetic use.

### **Other Resources**

For more information, check out some of the following:

- Amputee Coalition (Knoxville, Tennessee) a non-profit organization that provides numerous resources, outreach, and education for individuals with limb loss. Find out more here: http://www.amputee-coalition.org/
- InMotion magazine (offered by Amputee Coalition, Knoxville, Tennessee) a magazine
  published bimonthly for amputees, caregivers and healthcare professionals. Read the current
  issue here: <a href="http://www.amputee-coalition.org/limb-loss-resource-center/publications/inmotion/">http://www.amputee-coalition.org/limb-loss-resource-center/publications/inmotion/</a>
- Challenge magazine (Disabled Sports USA, Rockville, Maryland) a magazine that provides
  information about adaptive sports to adults and children with disabilities. Check it out here:
  <a href="http://www.disabledsportsusa.org/resources/challenge-magazine/">http://www.disabledsportsusa.org/resources/challenge-magazine/</a>

### **Limb Loss Definitions**

**Activities of daily living (ADL)** – a term generally used to refer to dressing, bathing, grooming, toileting, personal hygiene, feeding and mobility within the home. [4,5]

**Activity specific prosthesis** – a prosthesis designed for a specific activity (e.g. swimming, cycling, kayaking).





**Amputation** – the cutting off of a limb or part of a limb. [6]

**Assistive technologies** – any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. [7]

**Body image** – the awareness and perception of one's own body in relation to both appearance and function. [6]

**Body-powered prosthesis** – an arm prosthesis powered by movement in the upper extremity portion of the body, specifically the muscles of the shoulder(s), neck and back. The motion of these movements is then captured by a harness system that generates tension in a cable, allowing a terminal device (hook or prosthetic hand) to open and close. [6]

**Care team** – a physician-led, patient-centered, multidisciplinary approach to provide a comprehensive treatment plan and ensure lifelong management. specialists involved may include: rehabilitation physicians, anesthesiologists, surgeons (hand specialists, orthopedic surgeons, plastic surgeons), mental and behavioral health specialists, case managers, nurses, occupational and physical therapists, driver rehabilitation specialists, certified prosthetists, recreation therapists, social workers, trained peer visitors, and others.

**Diagnostic socket** – a temporary socket, often transparent, made over the plaster model to aid in obtaining proper fit and function of the prosthesis. [6]

**Donning and doffing** – putting on and taking off a prosthesis, respectively. [6]

Extremity – synonymous with limb, usually referring to an arm or leg. [6]

**Externally powered, or myoelectric prosthesis** – an externally powered prostheses that utilizes muscle electronics. It is a technology used to control the prosthesis via muscle contraction using electrical signals from the muscles to power the prosthesis. [6]

*Hybrid prosthesis* – a prosthesis that combines several prosthetic options in a single prosthesis, usually for individuals who have a transhumoral (AE) amputation or difference. The most common hybrid prostheses are found in upper extremity cases where the device utilizes a body-powered elbow and a myoelectrically-controlled terminal device (hook or hand). [6]

**Instrumental activities of daily living (IADL)** – a broad topic term that includes but is not limited to: home management tasks (e.g., meal planning preparation, clean-up, routine housekeeping, yard work, seasonal home care); laundry; shopping (e.g., community mobility, money management); child care; pet care; work; and individual recreational, leisure or sport activities. [4,5]





**Occupational therapy** – the teaching of how to perform activities of daily living as independently as possible, or how to maximize independence in the case of disability. [6]

**Passive prosthesis** – a prosthesis without active mechanical or electronic parts that usually closely resembles the natural body part it is replacing. Primarily used for aesthetic purposes more so than function but may still assist with pushing, balancing and supporting objects.

**Permanent, or definitive prosthesis** – the definitive prosthetic replacement for the missing limb or part of a limb, meeting standards for comfort, fit, alignment, function, appearance and durability. [6]

**Preparatory prosthesis** – a temporary prosthesis made of lower cost, thermoplastic materials which can easily be modified, is used while the residual limb is still healing and maturing, allows the patient to improve wear tolerance, commence the prosthetic training program, and experiment with different component options to help determine the most appropriate final prosthetic prescription, prior to definitive socket fabrication.

**Phantom pain** – pain in that originates in the amputated portion of the limb. [6]

**Phantom sensation** – this is the feeling that the missing body part is still there. It may involve uncomfortable but not necessarily painful sensations such as burning, tingling and/or itching. [6]

**Physiatrist** – a doctor of rehabilitation medicine who specializes in the comprehensive management of patients with impairments and disabilities arising from neuromuscular, musculoskeletal, and vascular disorders. [6]

**Physical therapy** – a rehabilitative therapy that is concerned with a patient's gross motor activities such as transfers, gait training, and how to function/mobilize with or without a prosthesis. [6]

**Prosthesis** – an artificial limb, usually an arm or a leg, that provides a replacement for the amputated or missing limb. Prostheses is plural. [6]

**Prosthetics** – the profession of providing those with limb loss or with a limb difference a functional and/or cosmetic restoration of missing or underdeveloped human parts. [6]

**Prosthetist** – a person involved in the science and art of prosthetics; one who designs and fits artificial limbs. [6]

**Rehabilitation** – the process of restoring a person who has been debilitated by a disease or injury to a normal, functional life. [6]

**Shared decision making** – the collaboration between patients and caregivers to come to an agreement about a healthcare decision.





**Socket** – the portion of the prosthesis that fits around and envelopes the *residual limb* and to which the prosthetic components are attached. [6]

**Terminal devices** – devices attached to the wrist unit of an upper extremity prosthesis that provide some aspect of normal hand function (e.g., grasp, release, etc.). [6]

**Therapeutic recreation, or recreational therapist** – this mode of rehabilitation provides instruction in returning to leisure activities. [6]

### References

- 1. Ziegler-Graham K, MacKenzie EJ, Ephraim PL, Travison TG, Brookmeyer R. Estimating the prevalence of limb loss in the United States: 2005 to 2050. *Arch Phys Med Rehabil.* Mar 2008;89(3):422-429.
- 2. National Limb Loss Information Center. *Limb loss in the United States: Amputation statistics by cause.*Knoxville, TN: Amputee Coalition of America; 2008. <a href="http://www.amputee-coalition.org/fact-sheets/amp-stats-cause.pdf">http://www.amputee-coalition.org/fact-sheets/amp-stats-cause.pdf</a>.
- 3. Extremity Trauma and Amputation Center of Excellence. Patient care statistics. *HQ US Army Medical Command, JBSA*. Ft. Sam Houston, TX: 2014.
- 4. Radomski MV, Latham CAT. Occupational therapy for physical dysfunction. Lippincott Williams & Wilkins; 2008.
- 5. Fasoli SE, Chen CC. What do clinicians need from a rehabilitation treatment taxonomy? An alternate approach for describing treatment content versus process. *Arch Phys Med Rehabil.* Jan 2014;95(1 Suppl):S74-76.
- 6. National Limb Loss Information Center. *Limb loss definitions*. Knoxville, TN: Amputee Coalition of America; 2008. <a href="http://www.amputee-coalition.org/fact-sheets/definitions.html">http://www.amputee-coalition.org/fact-sheets/definitions.html</a>.
- 7. Technology related assistance to individuals with disabilities act, Public Law 100-407(1988).