

Rehabilitation for Upper Limb Amputees

Service User Guide

MARCH 2024

Overview

A Best Practice Guide for Upper Limb Amputation Rehabilitation was created as part of the [OneHand](#) project in March 2024. The guide aims to provide a baseline for services providing upper limb amputation rehabilitation and was designed for rehabilitation personnel. You can find the full Best Practice Guide [here](#).

You as upper limb amputees (service users) are the centre of your rehabilitation journey. You and your family or care support also require information about your rehabilitation process. This Service User Guide aims to provide a brief overview of what may be involved in the stages of your rehabilitation following an upper limb amputation. This guide does not cover congenital limb absence. A congenital limb absence guide is being developed.

This Service User Guide therefore aims to inform you, the service user, about key elements of the rehabilitation pathway. In countries where services and personnel are limited, this guide provides you with elements of what could be included in your rehabilitation journey. It aims to encourage discussions with your rehabilitation team to ensure your program is tailored towards your functional needs and goals following limb loss.

Phases of Upper Limb Amputation Rehabilitation

Upper limb amputations are very individualised. The phases and stages you will experience may not always follow a 'straight' pathway. You may have to revisit some of the phases throughout life and this is not uncommon for upper limb amputees. You are encouraged to consult with your rehabilitation team for individualised guidance specific to your amputation, medical history and functional goals.

It is important to note that information about what services and products are available vary from country to country. Your rehabilitation team will be able to inform you as to what is available within your country and health system.



Personnel Involved In Your Rehabilitation

Your rehabilitation journey will be facilitated by a variety of rehabilitation personnel that will include, but not limited to surgeon(s), nursing staff, physiotherapists, occupational therapists, exercise physiologists, psychologists, allied health assistants, pain specialists, peer support (other upper limb amputees) and prosthetists. Some of these personnel may be involved at every stage of your journey and others may only be involved briefly in your journey.

Many amputees have stated that two key services they appreciated being included in their rehabilitation and lifelong journey were psychology services and peer support.

Due to the nature of amputations, psychological support will be offered at every phase of rehabilitation. Psychological support has been shown to assist individuals who have had an amputation, with coping mechanisms to adapt to life without their limb(s).

Peer support will also be offered throughout your rehabilitation journey. Peer support allows you to connect with individuals who have also experienced limb loss. Some countries are yet to have specific peer support groups and personnel; however the International Confederation of Amputee Associations (IC2A) aims to connect amputees around the world with peer support. To find an amputee peer support group in your country or to be connected to peers go to <https://www.ic2a.eu/members/>.



Rehabilitation Phases

Rehabilitation for upper limb amputations generally follows the following phases. Again, it is important to note that some individuals may revisit some of the phases depending on their circumstances.

Phase 1: Pre-amputation phase

Due to the circumstances of your amputation, you may not have had the opportunity to discuss this phase with your surgeon and rehabilitation team. This phase may then need to have been discussed with your family and carers.

If pre-amputation phase is an option for you, the following could be included prior to you having an amputation:

- An initial assessment of your current health status and goals completed by rehabilitation personnel (e.g. surgeon, physiotherapist, prosthetist, psychologist). In this assessment, the surgeon and team will discuss your level of amputation and what your individual rehabilitation process will be following surgery as well as the potential prosthesis(es) or assistive device(s) you may require.
- Information will be provided by the rehabilitation team about the potential function you will have post-surgery and what options are available to support you (e.g. support personnel, assistive devices, other services)
- Psychological support will be offered to help find coping mechanisms to adjust to life without your limb(s). You may not be ready initially for this service but it will continue to be offered and available should you need this service.
- Peer support will be offered. You may not be ready for this support however peer support will continue to be offered throughout your rehabilitation journey. Details about peer support and what is involved can also be found on <https://www.ic2a.eu/peer-support/>.

Phase 2: Amputation phase

Your surgical team will perform the amputation at the level determined as likely to give you the best outcome to ensure the best function, mobility, independence and quality of life based on your need for amputation (e.g. trauma, cancer etc).

You may spend a few days to weeks in hospital following your amputation. Your length of stay in hospital will be dependent on your individual amputation circumstances and should be discussed with the surgeon and in-hospital rehabilitation team.



Phase 3: Initial post amputation phase

Following amputation, the following is usually provided as part of your in-hospital treatment:

- Appropriate wound management and hygiene practices to ensure the best healing outcome for your residual limb(s).
- Information and education on pain management. Some of this education may need to be revisited during other phases of your rehabilitation journey.
- Preparation for pre-prosthetic training which will include some low-level exercises including postural exercises to help your neck, back and shoulders adjust to your limb loss.
- Preparation for fittings for prosthetic and/or adaptive devices (e.g. tools to assist with eating, cutting and other daily tasks). It is important to note that the type of prosthesis you want may not be available within your country and funding system and your prosthetist and rehabilitation team will discuss your options. Your prosthesis choice will however be made with your goals and function in mind.
- Peer support will again be offered during this phase to again help you through your rehabilitation and lifelong journey.
- Psychological support or services will continue to be offered to help you mentally and emotionally develop coping mechanisms to life without your limb(s).

If you don't require or need a prosthesis, this phase will still be focused on postural training and building strength to adapt to the changes in your arm function.

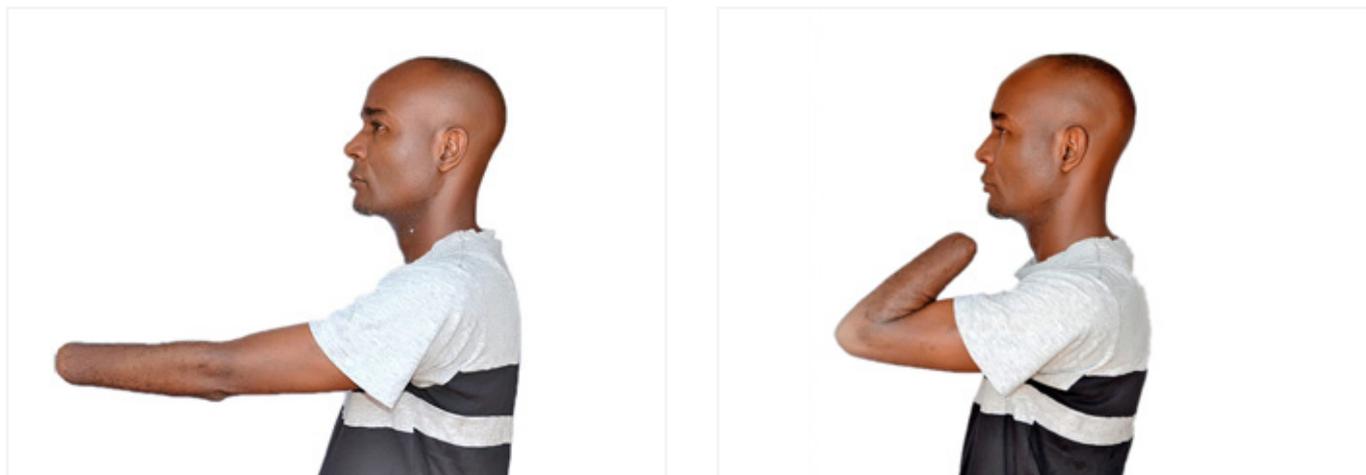
Phase 4: Pre-prosthetic training phase

Depending on the health system in your country, this phase will be delivered as either part of the in-patient or out-patient process. The training program will be designed to help you maintain your strength, function and independence both in your residual limb and unaffected limb(s) and help you to perform activities of daily living with or without a prosthesis.

Should you opt for a prosthesis or adaptive devices, your rehabilitation team will help prepare your amputated limb and body for a prosthesis or assistive devices through a variety of exercises based on your physical ability and strength.

The training program will aim to enable you to adapt gradually to wearing a prosthesis or adaptive device on a regular basis.

If you have had your dominant hand/arm amputated, the exercise and rehabilitation program may also be designed to help you retrain your new dominant hand.



An example of flexion extension exercises for individuals with below elbow amputations.

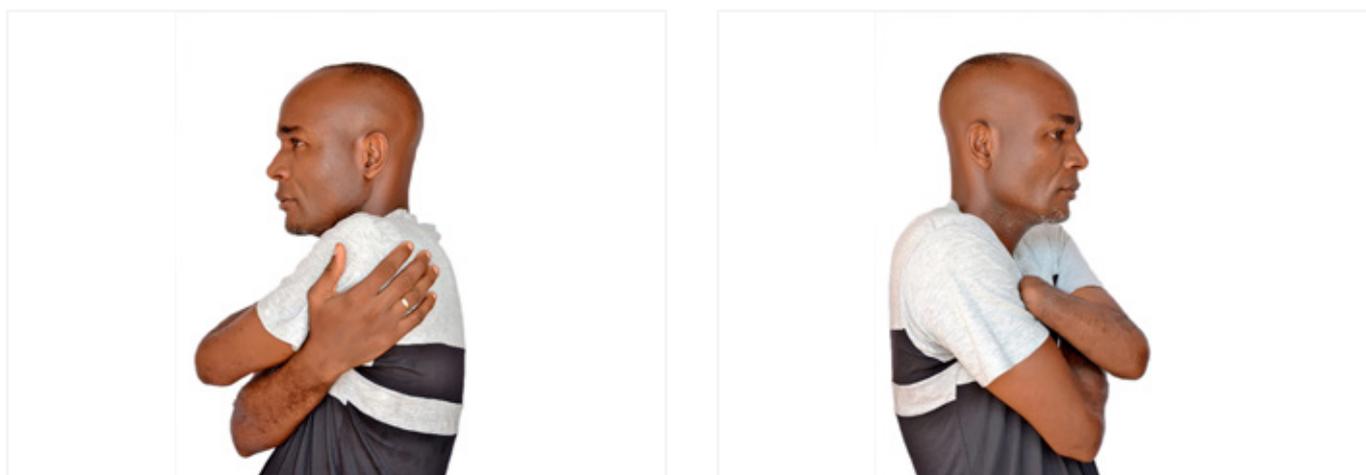
Phase 5: Prosthetic training phase

This phase will predominantly focus on training specific to the type and technology involved in your prosthesis as prescribed by your prosthetist. This phase will also focus on ensuring your residual limb and the rest of your body maintains function.

Should you not require or want a prosthesis, this phase will focus on training for any other adaptive devices you require and ensure that the rest of your body remains functional and strong.

The following will be included in this phase:

- Exercises prescribed will continue to maintain and improve strength in both the affected limb(s) as well as overall body strength.
- The rehabilitation and exercise program will be designed to support your adaptation to wearing a prosthesis. Education will be provided on how to put on and take off (don and doff) your prosthesis appropriately.
- Exercises or activities will be provided to help increase your ability to perform activities of daily living with a prosthesis or assistive devices as well as prepare you for vocational and recreational skills with a prosthesis.
- You may also want to explore new vocational and recreational skills. As part of this phase retraining of skills may be included as part of your program. You may work closely with an occupational therapist to assist with the training of new skills.
- You will be taught how to care for your prosthesis and/or adaptive devices to ensure longevity and appropriate use for all activities you undertake and teach you how to manage skin irritations that can occur with wearing prostheses or assistive devices.



An example of flexion extension exercises for individuals with below elbow amputations.

Phase 6: Lifelong care

This phase is the continuum of care throughout your life.

You may need to revisit some of the phases from 1-5 throughout your life.

Once you have determined your prosthesis you will benefit from having 1-2 yearly reviews with your prosthetist to determine any changes required to the prosthesis, any changes to your stump volume or shape or if your goals and needs have changed and therefore your prosthesis may need to change.

Summary

Overall, the key thing is to remember that upper limb amputation and the associated rehabilitation is an individualised process. The aim of rehabilitation is to maximise your independence and quality of life. It is important to discuss your rehabilitation and changes that may occur in any phase of the rehabilitation process with your rehabilitation team to ensure the best outcome for you, your needs, skills and goals.

Resources

You will have many questions regarding your amputation, rehabilitation and prosthetic or assistive device options. Not all of your questions will have been answered in this Service User Guide.

The following resources however may assist in answering some of your other questions. Amputee associations or peer support groups within your geographical location may also assist with resources to help you on your journey of rehabilitation and limb loss.

1. Frequently asked questions for upper limb amputations
2. Upper limb amputation guidelines
3. Amputee associations around the world
4. Prosthesis options and types

Thank you to the upper limb service users who gave permission to use their photos within this guide and accompanying documents.

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