



## Appendix 4

# Frequently Asked Questions (FAQs) for people with upper limb amputations

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*These FAQs are specific to trauma or acquired upper limb amputations. FAQs specific to congenital limb absence will be addressed in another document.*

## Pre-amputation Stage

### Will the amputation site be sore? Can the pain be controlled?

Yes. The amputation site will be sore post amputation due to the surgery that is involved.

During amputation surgery, skin, muscles, nerves and bones are severed and individuals can experience a range of different pain sensations.

Pain however is individualised. Pain can be managed through medication as well as non-pharmacological interventions: electrical, physical, psychological and cognitive. Your rehabilitation team will monitor your pain and collaboratively work with you to find the optimal approach. This may involve other personnel with appropriate expertise: anaesthetists, pain specialists, psychologists, physiotherapists etc.

Everybody experiences pain differently and one amputation cannot be compared to another. Likewise, management of pain will be different for each individual and may require a variety of management options.

### What can I do to prepare for the amputation(s)?

If you are having a planned amputation or know in advance that you will require an amputation for any part of the hand, arm or upper arm, it is important to build up stamina/your endurance and maintain strength in the unaffected arm as well as in the remaining parts of the arm to be amputated. This will help with your post amputation rehabilitation.

Where possible, ensuring a physiotherapist, physical therapist or exercise physiologist is part of your rehabilitation team is important. They will create an individually designed pre-amputation strength program for your specific condition and potential amputation.

### Who will be involved with my treatment from amputation through to receiving my prosthesis?

There will be a wide variety of trained professionals involved with your treatment, rehabilitation and lifelong care. These professionals may include surgeons, nurses, anaesthetists, and rehabilitation personnel such as a rehabilitation physician, physiotherapists, occupational therapists, psychologist and/or social worker.

If you decide to wear a prosthesis your team will include your prosthetist.

Amputee peer support groups can also provide a wealth of support during your amputation and lifelong journey. Having a good support system such as family and friends will also be helpful during your amputation and rehabilitation journey.

It is important to note that in some low-income countries, some of these professionals may not be available. If you require assistance with your rehabilitation journey, firstly ask your hospital rehabilitation personnel for advice or information. Secondly you could talk to a peer support group that you can access locally and/or remotely for their experience of the rehabilitation journey in your geographical location. They will also know which services should be available as part of your health system or those that are private services.

# Post-amputation and Pre-Prosthetic Training Stage

## ***Hospital questions***

### **How long will I be in hospital?**

Hospital stays vary depending on the severity and if there are any complications with your amputation(s). Consulting your surgeon and rehabilitation team for a realistic timeframe is recommended.

## ***Amputation questions***

### **Why this level of amputation?**

Your level of amputation will be determined by a number of factors depending on the reason for your amputation.

If you have suffered trauma or disease, the level of your amputation will be determined by the amount of tissue that has been damaged or affected.

The opportunity to salvage functional joints and existing innervation (functional nerve supply) around the amputation site will also be highly relevant.

## ***Pain questions***

### **How long will the amputation site(s) be painful?**

Pain varies for every individual. For some it may be weeks to months and for some people they experience some level of pain or uncomfortable sensation throughout their life. See the question about pain management and ensure you consult your rehabilitation team for pain management options.

### **What pain relief can I have?**

Pain relief immediately following an amputation can be managed by a variety of medications and nonpharmacological interventions. It is important that the type of pain you are experiencing is understood and that you consult your rehabilitation team to ensure that the best form of treatment is prescribed. You may be referred on to a pain specialist for further consultation.

For longer term pain i.e. years after an amputation you may have experienced many types of pain and trialled many pain management options. If your pain is persisting, consult your rehabilitation team who may refer you onto a pain specialist to determine alternative options to help manage your pain.

It is important to note that many amputees may have some sort of pain long term and may require multiple pain management techniques.

## What is phantom limb pain? Can it be controlled? How long does it last?

Pain and phantom sensation after amputation are common problems. There are three types of sensory phenomena that can occur after amputation:

- phantom sensation
- phantom limb pain
- residual limb pain.

**Phantom limb sensation** is an amputee's sense that the amputated limb is still present and includes non-painful sensations such as itching. It occurs in nearly all people with amputations and may in some individuals resolve with time, while in others it may remain for the long term. The important thing to understand is that it is very common, is perfectly normal, and is NOT a psychological phenomenon to be treated. If it is very unpleasant (e.g. the hand is twisted in contorted postures or feeling crushed) it is best described as phantom limb pain and treated as such.

**Phantom limb pain (PLP)** is pain in the limb that is not there.

Phantom limb pain (PLP) may not commence immediately post amputation but may arise a week or two later. Your rehabilitation team will be very alert to its presence and treat it appropriately, aiming to control it as much as possible. This generally requires medication – specific anti nerve pain agents, as well as strong analgesics including narcotics if necessary.

If your PLP is resistant, a pain specialist or your anaesthetist may recommend more invasive techniques. It is important to try to control PLP early and keep it under good control.

Non-pharmacological techniques may also be used to treat PLP including mirror box therapy, and graded motor imagery. Discuss therapy options with your rehabilitation team.

Using a prosthesis is felt to be positive in controlling PLP. PLP may gradually become less severe or even resolve for some individuals, although it can persist long term in others.

Psychological techniques may be helpful in managing PLP in the longer term, but PLP is NOT a psychological phenomenon.

**Residual limb pain (RLP)** is pain felt in the residual limb:

1. Early after amputation RLP is generally related to the cause of amputation and the many structures which have been directly affected by surgery and which are still healing.
  - a. A common complaint is marked hypersensitivity of the skin to touch. This responds best to “desensitisation” – touching, handling, bandaging and other techniques which hand therapists know about.
  - b. Occasionally a sharp shooting pain occurs when a single point is touched – this may mean that a nerve has become caught up in scar tissue, and may need a limited surgical revision to free it up.
2. RLP which develops later (more than a month or more) is different.
  - a. Poor socket fit is very common and the prosthetist should be alerted.
  - b. Sometimes when soft tissue cover is tight over cut ends of bone (especially in partial hand amputations) the skin may break down and a minor revision to shorten the offending bone may be needed.

- c. Children are particularly prone to bony overgrowth (at the cut end) which can cause skin breakdown and may need surgical revision.
- d. Neuromas occur when nerves try to regrow often forming a mass of tangled nerve endings which may be irritated when pressed or touched causing a shooting pain. The first approach is to ensure the socket is fitting properly and not pressing on the area. Occasionally a limited surgical revision is necessary.
- e. A range of other causes of RLP occur – skin breakdown, muscle and tendon injuries, nerve injuries, joint injuries, and even injuries closer to the body (e.g. shoulder, neck) can cause referred pain felt in the limb. These may need to be investigated and appropriate therapy instituted.

Consult your amputee rehabilitation team and/or prosthetist for assistance.

### **Is it painful to wear a device?**

When wearing your device for the first time your residual limb and skin may take some time to adapt and during that period, you may experience discomfort, skin irritation and strain on the body. Working collaboratively with your prosthetist will be key to ensure your device isn't too tight and to building up your skin tolerance. Ensure that your device isn't too tight or too loose and ensure you work with your prosthetist to get the right fit for you. Understanding and catching these 'niggles' early will help prevent further issues and complications in the future.

### **Will I be able to feel anything with a prosthesis on?**

Sense of feel is defined in a variety of ways.

“Proprioception”, in some countries known as kinaesthesia, is your body's ability to sense movement, action, and location, to know where your body is in relation to its environment and other objects. It is present in every muscle movement you have. Without proprioception, you wouldn't be able to move without thinking about your next step. A body powered prosthesis can help a user perceive how much force they are using when grasping an object via the cable/harness system.

“Proprioception” is different from the actual sense of touch which differentiates between different, surfaces, texture and temperature.

Whilst not yet easily available there are researchers currently developing externally powered prostheses that can detect a sense of feeling through pressure sensors to mimic the sensation of touch through vibrations. This does not allow for discrimination of hot or cold and will not be available in all prostheses.

Use of vision is instrumental in grasping and releasing objects because of the lack of actual sensation in the prosthesis.

## ***Prosthesis/device and cost questions***

### **When can I get my device(s)?**

If you choose to wear a prosthesis or use assistive devices, your definitive (final) prosthesis/device will be fitted once your amputation site has healed, swelling has reduced, and the skin robust enough to tolerate the socket.

### **How long will my recovery be before I can be fitted with a prosthesis?**

Normally 4-8 weeks post amputation is when a prosthesis can be fitted. This will depend on the extent of the injury and if there are any skin grafts or burns which may require additional healing. If the injury is traumatic in nature, there may need to be revisions to your amputation that will require additional surgery.

Normally staples or stitches will be removed about two weeks post-surgery and shrinker management can begin. A shrinker is like a very elasticated sock that fits over your stump. Shrinker management is a way to help shape the limb and reduce any oedema (swelling caused by accumulation of fluid) so that the stump is the optimum shape and size for fitting a socket and prosthesis. Please note it can be difficult in some cases to find a small enough shrinker for the upper body and alternative bandaging may be used.

### **What type of prosthesis or device will I be given?**

The type of device you will receive will be decided between you and your prosthetist based on your functional needs.

The type of device you receive will also be dependent on the type of technology available within your country and in some cases dependent on the type of funding available.

When you are without an arm or hand, there are many tasks that you will have to do differently. There are 6 options that you will be presented with regarding prosthetics. They include:

- Not using a prosthesis
- Passive functional prosthesis (aesthetic restoration)
- Body powered prosthesis
- External powered prosthesis
- Hybrid prosthesis (combination of body powered and external powered)
- Activity specific prosthesis

More information about the types of prosthesis available for upper limb amputations can be found in the [Service User Guide](#).

### **What devices or prostheses are available?**

It is important for you to understand what is available within your country or geographical location and what will be functionally appropriate for you. You will need to consult your local prosthetist and hospital or health system.

## How will my prosthetist and rehab team decide what type of prosthesis is best for me?

It has been said that no single prosthetic device is capable of addressing the multiple deficits associated with upper limb loss. Normally starting with a body powered device (see *What type of prosthesis or device will I be given?*) will provide the user with a lighter system that will more easily accommodate the volume changes experienced in the early stages of prosthetic fitting.

Advancing to an external powered prosthesis (see *What type of prosthesis or device will I be given?*) is only appropriate once the volume of the residual limb has stabilised. In a sense, a body powered prosthesis is like a slip-on shoe that can more easily accommodate volume change by adding socks whereas an external powered prosthesis needs to fit like a tight Italian dress shoe so that the electrodes that operate the hand or elbow have intimate contact with the skin.

## How do devices stay on?

Upper limb prostheses have a socket that attaches onto the arm designed specifically for your level of amputation. The socket and materials used should create a snug fit that enables functionality and allows ultimate control based on the type of prosthesis you have been prescribed. It is the 'snug fit' itself that holds the prosthesis on.

If you are also using other assistive devices, these may be attached to the residual limb in a variety of ways that may include a socket or a simpler system, such as a Velcro strap.

If you have a significantly high amputation (through shoulder amputation) you may have less options available due to the complexity and lack of stump remaining. It is important to consult your prosthetist about prosthetic and assistive device options.

## How heavy will my device(s) be?

The weight of your device will depend on the type of upper limb prosthesis you are prescribed as well as the materials of which it is made. Generally speaking, the more complex the device, the heavier it will be, and battery powered prostheses with powered hands will be heavier than body powered prostheses.

If weight is an inhibiting factor for you, then make sure you work with your prosthetist to choose the right type of device for you (pending country availability). This may not be a prosthesis but rather assistive devices.

## What will the cost of my prosthesis be?

Prices will vary based on technology and type of upper limb prosthetics available in your country or geographical location.



## **Independence questions**

### **What can I do to help myself?**

There is a wide range of support that you can utilise to help adapt to your limb loss.

- Maintaining your rehabilitation program
- Staying active within your limitations and maintaining a nutritious diet
- Reaching out to a peer support group in your country (see [www.ic2a.world](http://www.ic2a.world))
- Engaging with a psychologist to help with your mental health and adaptation to limb loss

## **Prosthetic training stage**

### **What will I be able to do with my device(s)?**

A picture often paints a thousand words but can be deceiving. Remember that a prosthesis does not give you a sense of feeling and that you will be relying on your vision to pick up and grip objects.

A body powered prosthesis (see types of prosthesis question) will have limitations when fully extended and when used close to the mouth or closer to the body. The harness that operates the body powered prosthesis operates most efficiently somewhere between these two extremes. There will be limitations or potential difficulty when performing tasks at and above head height.

Externally powered prostheses (see types of prostheses question) are heavier, and may or may not require the use of a harness for suspension, and control should be used in combination with a body powered component in a hybrid-style prosthesis.

### **What will I NOT be able to do with my device(s)?**

Wearing your prosthesis will not bring back your sense of touch and feel. You may have imperfect fine motor control. For example, it may be harder to pick up small objects. You may also find that some tasks that you could do single handedly now require both hands/ arms or you may have to change doing some tasks to your unaffected arm.

Some recreational or household activities can still be performed but you may require some alternative assistive devices or to change hands to perform the task for example playing a musical instrument, playing sport, doing the ironing or tying up your hair.

### **How long will it take to learn to use my device(s)?**

Each person adapts differently to their device. Some individuals may adapt within days or weeks, others may take time. This may also be dependent on the level of trauma or type of amputation you have experienced and the complexity of the technology involved in your device.

No two people's bodies or situations are the same, so take things at your own pace and think about how much the device is helping you and how much potential you think it might have to help you.



You may feel that you are more functional without a prosthesis. This is not uncommon. It is therefore important that you discuss the various options with your prosthetist and rehabilitation team.

### What sort of advanced training is needed?

Advanced training involves performing bimanual (both hands) tasks as opposed to unilateral (single hand) tasks which you will usually learn in the early fitting stages. Often in the early stages of fitting, changes in the volume of your residual limb will affect how your prosthesis performs, but by the time the volume of your stump has settled, you can progress to working on more complex functionality.

The rehabilitation team you are working with may have challenges with doing training if you have not followed up with your prosthetist to ensure that you have an optimal fit.

Advanced training may include knowing when a body powered system is better than an external powered system for a specific activity (see *What type of prosthesis or device will I be given?*). Practising bimanual activities can show you that stabilizing objects with a prosthesis and performing fine motor activities with your unaffected side and/or an assistive device are often more efficient.

Remember that there is not necessarily a wrong or right way of doing something. Rely on your rehabilitation team to demonstrate some skills and then, if you think they are useful for you, adopt and adapt these accordingly to suit your lifestyle.

## Every stage

### Support questions

#### Can I talk to someone about how I feel about the amputation(s)?

Yes! Talking with other upper limb amputees and/or joining a peer support group can help you understand your feelings about your upper limb loss and learn how to live with limb loss and function in the best possible way. Peer support groups can be found via [www.ic2a.world](http://www.ic2a.world). If you can't find one in your country or region contact the IC2A team who will be able to assist in finding support for you.

It is however important to remember that everyone is different. You may also find a personal psychologist or counsellor more helpful at certain times, particularly those trained in trauma and upper limb loss. You can ask your rehabilitation team and/or treating hospital to assist with a referral to a psychologist or counsellor.

#### Can I talk to someone who is the same as me?

Yes! Many countries have amputee/peer support groups. Go to [www.ic2a.world](http://www.ic2a.world) to see if there is one that is based in your country. If there isn't one, please contact IC2A and they can put you in touch with someone to support you.

Peer support groups can be helpful at various stages of rehabilitation. Some people find it useful straight after amputation and others may not be ready to discuss their amputation until the advanced rehabilitation or return to vocational or recreational skills. Peer support

groups will however have other upper limb amputees available for any stage of the rehabilitation journey.

## **Prosthesis questions**

### **Does everyone use a prosthesis?**

No. Some may choose not to use a prosthesis but rather utilise either a variety of adaptive devices or just their residual stump(s) or use a prosthesis for certain activities. It will depend on your goals and functional needs. You need to find the best option for you! Ensure you consult your prosthetist to find out the best options for you.

Talking to someone who has a similar amputation to you may also help you to work out the best options for your type of amputation.

### **What if I can't use the device(s) I am given or I am having difficulty using it?**

Please tell your prosthetist so that they can reassess your function and needs and help you with training and/or find a different solution that works for you.

### **What happens if I need a new device?**

Contact your prosthetist for a review.

### **Will I have the same prosthesis forever?**

No. It is important to have regular reviews with your prosthetist to ensure that the device is still fitting you appropriately, that your function is maintained and that the device or any part of it hasn't become worn out, which can be dangerous.

Initially you may require regular reviews as you adapt to your new device, but then once the right fit and function is found for you these reviews will become less frequent.

### **If better devices become available, will I be offered them?**

Not necessarily, but if you are interested in finding out about something you have heard about, you should ask your prosthetist about it.

Bear in mind that not all new devices or new technologies are suitable for everyone. In some cases, a simpler prosthesis, other assistive devices or no prosthesis, may be the most suitable option for you. Climate (cold, heat, humidity), function required, serviceability and distance to a limb fitting facility may influence what works for you.

Consulting with your prosthetist will help provide you with the options most suited to you and your amputation.

## **Cost questions**

### **Who will provide my device(s)?**

Usually, a prosthesis is prescribed by a prosthetist. See below who might pay for it.

### **Will I have to pay for my device(s) if so, what is the cost?**

Each country has a different funding or payment system that may vary from requiring the individual to pay for the prosthesis and assistive devices through to the device being paid for by the healthcare system. Pending how your amputation occurred, sometimes an insurance company or employer may pay for the prosthesis and devices.

To find out what system is used in your country, and if you are required to pay for the device yourself or where you might get assistance, please discuss with your prosthetist or healthcare system.

The level of technology for upper limb prosthetics will vary country to country. Please consult a prosthetist within your country to determine your options.

## **Adaptations to home or workplace questions**

### **What adaptations will be required at work and home?**

This will depend on the level of amputation, other conditions you may have, trauma associated with your amputation as well as your level of independence. You may require a consultation with an occupational therapist who will carry out a home and/or work assessment to see what changes need to be made to enhance your function. For example, you may require adaptations to your car to be able to continue driving or you may require bathing or hygiene accessories like a shower chair and grab/handrails to be able to wash independently.