

# FREQUENTLY ASKED QUESTIONS: AMPUTATION SURGERY

This resource is designed to help you prepare for your amputation surgery. It explains some of the key things about your surgery, care and recovery. The resource also includes suggestions of other information or support that might be useful to you.

These FAQs have been created by researchers with the input of recent amputees, healthcare professionals and amputee charity representatives.

There are two parts to this document. Part One is a series of common questions that patients preparing for amputation have, and their corresponding answers. Part Two is a list of possible questions that you might want to ask your medical team.

This resource has been designed to be helpful to a broad range of people, but every person is different and amputation surgery and recovery are unique and personal to each patient.

#### 1. WHAT IS AN AMPUTATION?

Amputation is the removal of a limb (or limbs) or part of a limb (foot, toe(s), hand or finger(s)). Amputation surgery is used when alternative treatments are not available or have not been successful. Every other possible alternative treatment will be explored with you first. The amputation is described as minor when it involves the removal of a digit (fingers or toes) or a part of a limb (hand or foot). A major amputation is when a whole limb (arm or leg) is removed. Major amputations will be done below or above a major joint, such an elbow or knee. Bilateral amputation involves the removal of more than one limb, either both upper or both lower limbs.

## 2. WHICH HEALTHCARE PROFESSIONALS WILL CARE FOR ME?

Patients preparing for amputation surgery are cared for by a Multidisciplinary Team (MDT). The team is made up of professionals who specialise in amputation care and recovery. The healthcare staff involved in the MDT work together with you as a patient. They will develop your treatment plan and to set recovery goals. Evidence shows that patients being looked after by an MDT have better outcomes.

The people who might be in the MDT are:

- a vascular surgeon,
- a vascular nurse specialist,
- a nurse,
- a physiotherapist,
- an occupational therapist,
- a discharge coordinator.

Other specialists, such as diabetologists (diabetes specialists), interventional radiologists (doctors providing less invasive surgery) and acute pain specialists, might be in your care team.

## 3. WHAT TYPES OF EMOTIONS MIGHT I EXPERIENCE?

Limb loss can create many emotions. Feelings of anger, anxiety, fear, sadness and grief are common for patients who are having amputation surgery. People may still feel these emotions even when they understand that amputation is the best treatment option for them. Recovering from an amputation might involve a mixture of positive and negative emotions. It is important to know that all these emotions are normal and part of the recovery process.

Talking with other people who have had an amputation can help with the feelings you might have. Taking care of how you feel emotionally is important. You can get help and support with how you feel through NHS Talking therapies. You can refer yourself to this service: <a href="https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/">https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/</a>. Some people may need medication to help with their mental health after an amputation. You should speak to your care team or your GP if you are struggling with how you feel. It is perfectly normal to need help with feeling mentally well just as it is with being physically well.

## 4. WHAT WILL HAPPEN TO MY AMPUTATED LIMB AFTER SURGERY?

Not all patients will want to know what will happen to their limb after surgery. Many patients do feel reassured knowing where their limb has gone after surgery. The standard process is that your limb will be incinerated. This process is regulated by the Human Tissue Authority. This means hospitals have to follow certain procedures to ensure that your limb is disposed of appropriately. Some patients may have particular views or beliefs about what they would like to happen to their limb. For example, some patients may wish to have their limb buried or have their undertaker look after it for them until the time of their death. It is not always possible to accommodate individual choices around the disposal of your amputated limb, due to infection or other public health risks. If the disposal of your limb is something you have questions or concerns about, please speak to your care team. You might also find it helpful to discuss this with a hospital chaplain (humanist or religious) or a religious leader from your faith or community.

## 5. WHAT WILL HAPPEN AFTER MY SURGERY? HOW LONG WILL IT TAKE ME TO RECOVER?

After your surgery you will return back to a ward to continue your recovery. It will take time for the effects of your anaesthetic to wear off completely and you will need to rest during this time. The professionals who are caring for you will monitor you and make sure you are recovering well. They will help manage your pain levels and provide oxygen and fluids to you as needed. Your wound will be dressed with bandages, so you will not see your residual limb (the part remaining after the amputation) straight away. Recovery is different for all patients but your care team will want to get you up and out of bed once they feel you are ready. Recovery will involve different stages and everyone's time frames are unique to them. Your care team will work carefully with you to help you adjust and adapt to having had an amputation, both physically and emotionally. It's important to work with them to help recover as best as you can.

## 6. WHAT IS PHANTOM LIMB PAIN AND HOW CAN IT BE MANAGED?

Phantom limb syndrome refers to painful or non-painful sensations felt where your limb was. Non-painful sensations might include the feeling that your limb is still there. The majority of patients who have an amputation report some phantom limb pain. This often occurs immediately after the surgery. People typically describe this type of pain as burning, stabbing or pricking sensations. Management of phantom limb pain will often be through the use of pain relief medications. Your care team will be able to discuss the best way to manage any sensations or pain you experience. If you are concerned about phantom limb pain either before or after your surgery, your care team will be able to help and support you.

#### 7. WHAT HAPPENS AFTER I AM DISCHARGED?

How soon you are ready to go home after your surgery will depend on the type of amputation you have had and your overall health. The occupational therapists at the hospital will do an assessment. They will work with your local authority (social services) to make sure you have the care and support needed for you to return home safely. After an amputation, some people will be able to have a prosthetic limb fitted. The hospital will discuss with you if this is something which will be suitable for you. Depending on your physical health and the type of amputation you have, a prosthesis might not be possible. If you are likely to be having a prosthesis, the Limb fitting centre will contact you to arrange an appointment. This appointment will not happen immediately after discharge. Your care team will give you an idea of the likely timeframe. You will also need to learn to take care of your remaining or residual limb to keep it in good condition and avoid any issues with the wound and scar tissue. Your care team will let you know what you need to do and answer any questions you have about the discharge process. Once patients are discharged from hospitals, many find it helpful to gain support from others who have also had an amputation. Joining an amputee charity or organisation might help you with questions and support.

## 8. AM I ENTITLED TO ANY BENEFITS OR FINANCIAL SUPPORT?

There are several benefits that may apply to you as a result of having had an amputation. These include: Personal Independence Payment (PIP), Disability Living Allowance (DLA), Attendance Allowance (AA) and Employment and Support Allowance (ESA). If you are working you will be entitled to sick pay. If you on a low salary you may be entitled to Income Support and Council Tax Reductions. For more information about benefits or financial help:

- You can use an independent, free and anonymous online benefits calculator to check your entitlement: <a href="www.gov.uk/benefits-calculators">www.gov.uk/benefits-calculators</a>
- The Limbless Association have a helpline which is open 9am-5pm Monday to Friday (excluding bank holidays). You can ring them on <u>08006440185</u> and they will be able to answer questions on welfare rights and benefits information for amputees.

## 9. WILL I STILL BE ABLE TO WORK AND TAKE PART IN SOCIAL ACTIVITIES?

Recovery after an amputation will take time. Amputation might affect your ability to take part in the same work, social and leisure activities that you did before. This might be due to the changes in your mobility or if you are experiencing pain or medication side-effects. You might also not feel like socialising with others due to the negative emotions you are experiencing. Returning to activities you enjoy can have a positive impact on your rehabilitation. It is important not to rush this process and to have manageable expectations about what you will be able to achieve. Some amputee charities organise activities and events specifically for amputees. This might help you to get back to doing the things you enjoy and meeting other people who understand your experience.

If you are planning to return to work after your surgery, your employer will be able support you with a plan for this. The Equality Act (2010) states that your employer should make "reasonable adjustments" to support you in your return to work. You may need support from an occupational therapist to ensure that the correct support is in place for you in your workplace.

# 10. WHAT ARE THE IMPLICATIONS FOR MY RELATIONSHIPS AND HOW CAN MY FRIENDS AND FAMILY HELP ME?

You might be worried about how family and friends will react to your amputation but they often want to do as much as possible to support you. Sometimes friends and family members will not want to let you know how worried they are as they do not want to upset you. As it is common to experience a range of emotions leading up to and after an amputation (such as sadness, anxiety, anger, fear, low self-esteem) this might impact how you communicate with your loved ones. It is important to keep talking with them about how you feel and encouraging them to share how they feel too.

Friends and family members can play an important role in helping you after your amputation. They may be able to provide help with daily tasks such as dressing, showering, preparing meals or providing transport. They might give you emotional support by taking about how you are feeling. You may find it useful to include your family and friends in the planning of your care. Your family or friends can also get support from an amputee charity like the Limbless Association if they would find that helpful.

#### PART2:

## POSSIBLE QUESTIONS YOU COULD ASK YOUR HEALTHCARE PROFESSIONALS

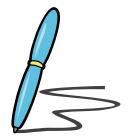


The following list has some ideas about what you might want to ask your healthcare team when having an amputation. The questions have been created from our research. These are things that amputees and healthcare professionals tell us are common concerns for people preparing to have an amputation. Patients' often have lots of questions but sometimes struggle to know who to ask or if they are able to ask certain things. The people caring for you will be used to answering all types of questions. This list is not exhaustive and you may have other things you want to ask. The types of questions you have may change, but you will be able to ask questions at various times and to different health care professionals. You might want to talk with your family or friends about the questions you have. They may have things they want to ask too. There is a space below where you might want to write down your own questions so that you do not forget them.

- Why do I need an amputation? What other treatment options do I have?
- What are the risks and benefits of the surgery?
- Will I need a further amputation?
- How will my pain be managed?
- What will happen about toileting and washing after my surgery?
- How soon after surgery will I be able to go home?
- What rehabilitation will I get and where will that take place?
- Will I be using a wheelchair and if so, who will help me to learn how to use it?
- Will I get a prosthetic limb? And if so, when will that happen?
- What happens if I don't get a prosthetic limb?
- Is there somebody who has had an amputation that I can speak to?
- What care will my residual limb need and who will help me learn about that?
- How do I decrease the risk of falls after an amputation?
- What equipment will I go home with?
- Who do I contact about my amputation if I have any further questions once I am discharged from hospital?

# PART 2: POSSIBLE QUESTIONS TO ASK YOUR HEALTHCARE PROFESSIONALS

Questions I want to ask...



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