Living with amputation

An information booklet for wheelchair users

Produced by SPARAG
In collaboration with FINDING YOUR FEET

SCOTTISH PHYSIOTHERAPY AMPUTEE RESEARCH GROUP
Compiled and updated by members of the Scottish Physiotherapy Amputee Research Group (SPARG) with contributions from Scottish Occupational Therapy Amputee Group (SOTAG) and The National Centre for Prosthetics and Orthotics, University of Strathclyde.

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Scottish charity number
SCO44572
During your hospital stay and throughout your continuing rehabilitation you will come into contact with a number of health professionals.

As you will be receiving a lot of information at this time, it may be helpful to take a note of the names and numbers of the people involved in your treatment.

Surgeon _____________________________________________________

Rehabilitation Consultant ________________________________________

Physiotherapist ________________________________________________

Occupational Therapist __________________________________________

Social Worker __________________________________________________

Clinical Psychologist _____________________________________________
The aim of this booklet is to help you and your family, friends or carers understand more about lower limb amputation and what to expect after your surgery. It will outline your rehabilitation process from the day you have surgery to when you leave hospital and provide you with information about the services available to you.

Who has amputations and why?

Amputation is offered when all other forms of treatment have been tried or considered and is performed because the leg or part of the leg is:-

- So diseased that life is threatened
- So painful it makes life a misery
- So injured that it no longer works as a functional limb

The main reasons for amputation are:

- Circulation problems (e.g. peripheral arterial disease). Problems come from narrowing of the arteries which limits the supply of blood to the legs and feet; this can result in pain or ulceration. If the surgeon cannot repair or bypass the artery and thereby save the leg, it may be necessary as a last resort, to amputate. This removes the life-threatening infection (gangrene) that may have occurred in your feet and legs to limit you from further pain.
- Complications from diabetes
- Poor circulation or severe infection as a result of an accident, injury or complication of a previous surgery (traumatic amputation e.g. road traffic accident)
- A tumour in any of the bones in the leg
- Drug related problems affecting the circulation
- Birth abnormalities
Who will be involved in my care?

The Doctors
You will be under the care of a consultant surgeon on the ward who will have a team of doctors helping them. They will see you regularly while you are in hospital.

The Nurses
The nurses will take care of you from the day of your admission until the day that you leave the hospital. They will be there to help and advise you when moving in and out of the bed, assist with personal hygiene and issuing you with your medication (including pain killers). They are also your link with the other staff involved in your care.

The Physiotherapists
Physiotherapists are involved throughout your rehabilitation programme. They will discuss with you your interests, needs and goals. With this they will build a rehabilitation programme for you. This may involve wheelchair skills, transfers and an ongoing programme to help stretch and strengthen your muscles.

Once you go home, if you require it, you will be referred to outpatient or community physiotherapy.

The Occupational Therapists
Occupational Therapists (OT) are also involved throughout your rehabilitation programme. They will discuss and assess your home circumstances, help you return to everyday activities such as personal care, cooking, and other household tasks.

They may identify a need for any equipment or adaptations to assist you with these tasks. Once you are home, if required, a community or social work OT may also visit. They will assist you with the process for arranging any identified adaptations. They may also, through Re-Ablement or Enablement Services, continue working with you on your return to everyday activities within your home.
Introduction

Discharge Coordinator
The hospital team may have a Discharge Coordinator who helps to remove barriers to allow you to go home as soon as possible.

Podiatrists
Podiatrists are foot care specialists who work both in the hospital and in the local community. They may be involved in planning your care and treatment, as they work with both the diabetic and vascular teams. They can give advice about appropriate footwear and you may have to see a community podiatrist for ongoing care of your remaining foot.
What will happen to me after surgery?

Immediately after your surgery you may feel a little disorientated from the anaesthetic and have:

- an oxygen mask on
- a drip in your arm for fluids and pain killers
- a tube in your bladder called a catheter
- a drain or a nerve catheter in your residual limb.

Whilst pain is unavoidable after any surgery, it is important that if you are experiencing any pain you must tell a member of staff so that the pain can be better controlled.

After your surgery, your amputated leg, also known as your stump, residuum, or residual limb, may have a hard plaster of paris cast or soft elastic dressing. These are to help control swelling, shape the stump and protect the wound.

Approximately five days after your surgery, staff will remove your dressing or cast and the wound will be assessed and re-dressed.
Rehabilitation

Your rehabilitation will begin on the first day after surgery. You will meet different members of the rehabilitation team and they will explain their role and discuss your rehabilitation journey.

The day after surgery, staff may show you how to move around and transfer on and off the bed. This may involve a hoist initially. They will give you a wheelchair in the early stages to help you get about the ward. If you have had a below knee amputation it is very important that you keep your stump supported. You should use a stump board if you have been provided with one; this helps to keep your knee straight and to control the swelling.

It is important that you start exercises as soon as possible after your surgery so that your joints move well and your muscles stay strong. If it is appropriate, you will start going to the Physiotherapy gym.
Initially you may be unsure of how to do everyday activities such as getting in or out of bed, in and out of a wheelchair, on and off the toilet, washing and dressing.

The Occupational Therapist (OT) will teach you how to do these tasks safely and independently. This takes practice. Your OT will tell you about different ways of doing tasks or using equipment to make them easier (e.g. grab rails, raised toilet seats etc).
Will I get an artificial limb?

Not everyone wants, is suitable or is able to use a prosthesis, also known as an artificial limb. The rehabilitation team will work with you to assess if a prosthesis will be suitable for you. Using a prosthesis can be difficult especially if your general health is not good, and for many people using a wheelchair can be the best option.

Your Physiotherapist may use measurement tools to test your balance and ability to carry out functional tasks. Additionally, the rehabilitation team will review your medical history, general health and your specific circumstances – All of these factors can help predict if you will manage with a prosthesis.

If a prosthesis is not suitable for you, your therapist will continue to help you become independent in your wheelchair.
What’s Next?

Attending the gym

Within the gym, you may feel more comfortable in loose-fitting clothes such as tracksuit bottoms, and comfy, well supported shoes such as trainers. Whilst in the gym you will practice transfers (i.e. getting in and out of bed), wheelchair skills and your Physiotherapist will give you an exercise programme.

Wheelchairs

If you are unable to self-propel (i.e. move your wheelchair), you may have an assessment for an electric wheelchair. However, there are criteria that you need to meet for this. You can discuss this with your OT and they can complete a referral if appropriate. If you are getting out and about in your wheelchair but are having difficulty with kerbs and slopes, contact your local wheelchair centre to discuss whether adaptations can be made to your wheelchair to make it easier to push.
What’s Next?

Going home

The team will carefully plan with you when it is safe to go home. Every hospital varies on how long their patients will spend in hospital. This can depend on how quickly you recover from your surgery, the support you have at home and how wheelchair accessible your home is.

Environmental and home visit

If necessary, the OT may arrange to visit your home. This visit helps to identify any problems you may have, such as getting in and out of your home, or any special equipment you may need.

Depending on where you live, the hospital Occupational Therapist may arrange for any required equipment to be delivered to your home, or may contact the community Occupational Therapist at your local social work department.

If you require any adaptations to your home it will be the social work Occupational Therapist who organises this.

Some adaptations, particularly more major ones, are unlikely to be completed before you go home e.g. ramp access or a stair lift. If this is the case you may need to live on the one level temporarily e.g. with a bed and a commode.
What lies in the future?

The aim of rehabilitation is to help you adjust to life following an amputation and to make you as independent as possible, which in turn is better for your health and wellbeing.

Think about your life previously and try to return to as many activities as possible. This may include work, driving, shopping, socialising, hobbies and sports. You may even have the opportunity to take up new activities. If you are finding this difficult talk to your Physiotherapist or OT about the barriers so they can help you find ways to overcome these if possible.

The OT may be able to assist you with work-related activities. They will also be able to give you information on returning to driving.

If you need advice or support in returning to any of these activities or others, there are various useful addresses at the back of this booklet.
Emotions

Almost everybody experiences some emotional reaction when faced with losing a limb. This reaction is a normal part of the process.

You may initially feel numb or in shock, sad or ‘down’, angry or resentful. Feelings vary for each person and talking about your feelings with your friends and family or the staff working with you can help.

Normal (healthy) distress and adjustment to change will often move through a cycle. This can eventually lead to coping with the new situation in the longer term.

Sometimes emotions may become too much to manage with existing supports. If you feel you are not coping, then speak to a member of staff or GP. They can provide advice on how to help you manage your emotions, and may refer you for psychological support. This can involve talking to someone about your difficulties in an effort to introduce positive change.
Phantom Sensations

What are they?

Many people who have an amputation feel that the limb is still there. This is quite normal, it is called a phantom limb. Usually it feels the same length and weight as the original leg but at times you may feel it is in a strange position. You may feel these phantom sensations can be felt in the whole leg or just part of it e.g. one toe or side of the ankle.

These phantom sensations can feel very real and therefore it is very easy to think your leg is still there and try to stand on it. For that reason it is important that you concentrate when standing and transferring to avoid falling, especially if you have just woken up.

The exact cause of phantom sensations remains unknown but it is thought to be due to the change in messages from the nerves in your limb to the brain as your leg is no longer there. The nerves that went into your feet still send messages to the brain even though they have been cut and the brain can respond by sending painful messages as a way of coping with this change.

In some people the phantom feelings can be painful. The pain can be a tingling, burning, itching, cramping sensation or a sharp shooting pain. The cut nerves in the stump can be sensitive to various stimulation including swelling, pressure from your prosthesis, muscle spasms in the leg, knocking or bumping the residual limb, if you are unwell, the temperature, the weather, or sometimes they can come on for no apparent reason at all.
Phantom Sensations

Managing Your Pain

Although phantom pain is very common in people with amputations, please make sure you mention it to healthcare staff if the pain is interfering with your day to day activities.

There are things you can do to lessen the phantom sensation and reduce the pain you may experience, such as touching and massaging the stump.

You can also keep a diary to note if there is a pattern to the sensations and see what brings it on. Like any type of pain, it helps if you do something to take your mind off it. For example, relaxation can be effective at reducing the sensations or doing an activity you enjoy such as reading or watching TV.

There are some medications that can help reduce the pain and other treatments that can help such as using a TENS machine or acupuncture.

You can also ask your Physiotherapist or Occupational Therapist about graded motor imagery or mirror therapy.

Mirror therapy
Ongoing Care

Your stump

Initially the nursing staff or Physiotherapists will dress your wound but after the wound is healed, it is your responsibility to you to look after your stump.

To look after it properly you need to make sure you:

- Wash it every morning and evening with soap and warm water
- Dry your leg thoroughly and do not use any creams or oils unless prescribed or advised by healthcare staff
- If possible, check your stump everyday or more frequently if it is sore. Check the back by using a mirror for any signs of broken skin, redness of blistering. If you cannot check this yourself, it maybe beneficial to ask someone to help you with this
- If any problems develop contact your doctor

Your remaining leg

You also need to make sure you take care of your remaining leg. You need to wash your foot daily and dry it carefully. If you have any problems see your doctor or a podiatrist as quickly as possible.

- Take care when choosing shoes to make sure they fit correctly - preferably natural fibre, seamless, lace or velcro fastening with square toes
- Test the bathwater with your hand before you get in
- Do not wear a sock with elastic tops and never walk barefoot
- Check your foot daily for any cuts or open areas
- Check your nails to make sure there are no ragged edges digging into the toes
- Moisturise the heel and sole of the foot but avoid using it between your toes
- If you have problems with your circulation or diabetes, small cuts are easily infected and can become difficult to heal. If this happens contact your GP or Podiatrist for advice
- Do not be tempted to hop unless you have been advised by appropriate staff, as it can put too much strain on your remaining leg
Ongoing Care

The care of the remaining limb can be divided into 3 main areas:

1. **Immediately after amputation**
   It is vital to protect the remaining limb after amputation. When in bed after amputation there is a possibility of heel sores developing therefore you may be provided with specialist orthotic footwear to use in bed.

2. **Transfers**
   During transfers the remaining leg is in contact with the ground longer than normal so excessive pressure is taken by the foot. You should wear a well-fitting shoe or trainer.

3. **On-going care**
   - The Orthotist may provide you with shoes – follow their advice
   - Wear well fitting, supportive shoes, avoid poorly fitting slippers and walking barefoot
   - Get in touch with your Podiatrist or specialist nurse if you are worried about any change in colour or an open wound appears
   - If the change happens at the weekend or out of hours – contact NHS 24 on 111 for advice
Diabetes

For people who have diabetes, it is very important to keep your blood sugar level well-controlled as it allows healing to occur and reduces the risk of infection.

If you have a lack of feeling in your foot for any reason please pay particular attention to your foot and check it daily. If you are unable to do this yourself ask someone else to check it for you. You can use a mirror to check parts of your foot too.

If you have any questions about your diabetes please ask any health professional. They can speak to the nursing staff who can refer you onto a diabetic nurse specialist.
The National Centre for Prosthetics and Orthotics at the University of Strathclyde requires volunteer patients to assist in the teaching of lower and upper limb prosthetics. During courses, undergraduate students learn about the professional, clinical and technical aspects of patient assessment, casting, socket fitting and alignment. Teaching may take place over a number of morning or afternoon sessions and occasionally for full day sessions at our Glasgow city centre premises. In addition to reimbursement of travel expenses and the provision of refreshments, a small fee is paid for participation.

If you have lower or upper limb absence and think you might be able to help, or would like further information, contact the NCPO administration team by phone on 0141 548 3433 or by email on contact-ncpo@strath.ac.uk
Useful contacts

Scottish Driving Assessment Service
Astley Ainslie Hospital
133 Grange Loan
Morningside
Edinburgh
EH9 2HL
Tel: 0131 537 9192
Email: Marlene.Mackenzie@nhslothian.scot.nhs.uk

Port-ER
Mrs Mel Wade
Secretary Port-ER
50 Littlemead Lane
Exmouth
Devon
EX8 3BS
Email: info@port-er.com
www.port-er.com

Limbless Association
Queen Mary’s Hospital
Roehampton Lane
London
SW15 5PN
Tel: 02087 881 777
www.limbless–association.org

Scottish Disability Sport
Caledonia House
South Gyle
Edinburgh
EH12 9DQ
Tel: 0131 317 1130
Email: admin@scottishdisabilitysport.com

Murray Foundation
A charity supporting those who have encountered lower and upper limb loss
Co-Ordinator: Keith Ferguson
129/11 Gylemuir Road
Edinburgh
EH12 7DL
Tel: 0800 028 2822
Mobile: 07743 780 913
Email: infoatmf@btinternet.com

Edinburgh Limb Loss Association (ELLA)
A support group in Edinburgh and Lothians for amputees
Secretary: Keith Ferguson
Mobile: 07743 780 913
Email: ella.secretary@hotmail.co.uk

Finding Your Feet
A charity supporting lower and upper limb amputees
Skyhub, Skypark 1
8 Elliot Place
Glasgow
G3 8EP
Tel: 0141 258 4868
Email: info@findingyourfeet.net
www.findingyourfeet.net

British Limbless Ex-Service Men’s Association (BLESMA)
Frankland Moore House
185-187 High Road
Chadwell Heath, Romford
RM6 6NA
Tel: 02085 901 124
Email: ChadwellHealth@blesma.org
www.blesma.org

Forum of Mobility Centres
Tel: 0800 559 3636
Email: info@cornwallmobility.co.uk
www.mobility-centres.org.uk
Supporting families affected by amputation and limb difference

Finding Your Feet was set up by Corinne Hutton who had her hands and feet amputated after a battle with Sepsis in 2013. Since losing her limbs, Cor has re-learned how to cycle, run and swim. She has also set a Guinness World Record, become the first female quadruple amputee in history to climb Ben Nevis, completed the London Triathlon, has received numerous awards for her work and is believed to be the first female quadruple amputee to climb Kilimanjaro.

Finding Your Feet understands the challenges and emotions that you and your family face following amputation, and there are a number of ways we can support you through this difficult time. Our in-house Counsellor can offer emotional support or advice either over the phone or in person. We also provide opportunities for individuals and their families to come together; from our Ampu-Teas social club to sporting activities for all ages and abilities, including swimming, cycling, climbing and skiing. Our less active clubs include gardening, crafts and Pilates. Whatever support you feel you need, we will do our utmost to provide it.