





YOUR PROSTHETIC LIMB MANAGEMENT

UPPER LIMB

Making the most of your prosthesis by actively contributing to your limb centre appointments





LimbPower have consulted with healthcare professionals and amputees to bring you this guide that we hope will enable you to get the most from your visits to the prosthetic service centre, also known as the artificial limb centre. LimbPower hope that this guide will enable you to better understand and contribute to the different treatments and appointment types that are available to you, empower you to care for your residual limb, sound limb and prosthesis, and plan adequately for trips to your prosthetic service centre.

This guide is written for upper limb prosthesis users who obtain their devices through the NHS limb fitting service; however, some of the advice will still be useful for patients who use private prosthetic providers.



Different types of prosthetic service centre

There are 34 prosthetic service centres In England. Prosthetic services in these are provided either by a full NHS model (specifically Gillingham, Preston, Plymouth, and all of Wales and all of Scotland), or in collaboration with one of four private companies Blatchford Group, Opcare, OttoBock and RSL Steeper. Prosthetic services in England are funded by NHS England, and some have a unique contract with one of the commercial prosthetic suppliers. It will really help your prosthetic management if you get to know your local service and how it works.

Here are some questions to ask

- 1. Ask the rehabilitation team to find out who the service provider is (this is the company who runs the limb service) at the prosthetic service centre you attend?
- **2.** Ask who in the multidisciplinary team is responsible for making the decision about which prosthetic components you can have? This can vary from centre to centre.
- 3. Ask if you have been assessed against any outcome measures and what were the outcomes? Prosthetists and therapists use rating systems to indicate a person's rehabilitation potential. Ask what your potential is and how you can move through the rehabilitation process to improve your outcomes.
- Ask your Occupational Therapist (OT) for useful exercises to assist you in your rehabilitation plan.
- 5. Ask your Occupational Therapist how long they expect your rehabilitation to take
- **6.** Ask your prosthetist how long they expect it will take to make your prosthetic socket? For replacement sockets some Limb Centres have guidelines.
- 7. Ask what sports can I do with my prosthesis?
- 8. Ask your limb centre what supporting literature is available Many prosthetic service centers have advice leaflets for care and maintenance of your sound limb, residual limb and your prosthesis.
- **9.** Ask how do I inform someone if I am not happy and who should I speak with to resolve any issues?

Different types of appointments

- 1. Your first visit
- 2. Fitting and delivery of your first prosthesis
- 3. Follow up appointments
- 4. Mechanical or electrical repair
- Socket repair / adjustment / replacement
- 6. Medical review

1. Your First Visit

At your first appointment you will generally be seen by a specialist team of clinical staff that may include a Prosthetist, Doctor, OT, Physiotherapist and other health professionals or students may also be present. The team will discuss your goals and devise a care plan with you to help you meet your goals. The team will endeavour to get the prescription right for a primary (new) patient. At this stage it is very much trial and error and the hands/arms can soon be changed if required.

Many factors affect whether a prosthesis will aid independence. These may include problems or conditions that may affect your sound side arm, such as a stroke, and other factors that may reduce your hand strength or dexterity, or the remaining elements of the affected (limb absent) arm. In addition, factors such as your eyesight and ability to control the muscles within your residual limb will also affect your prescription. If you are going to be fitted with an artificial limb, the prosthetist will then measure your residual limb, and your sound side arm. At this stage they may also take a plaster cast of your residual limb. This may be delayed if there is excessive swelling or unhealed areas or if a specific interface component is required. You may





also be assessed for myoelectric signals, to determine if you would benefit from the use of a myoelectric prosthesis. Please remember that these prostheses can be difficult to control, and will need you to spend some considerable time with an OT performing training exercises and tasks related to the activities of daily living. Please also remember that some of the more complex and expensive devices that you may see on the internet are not currently available via standard NHS prescription policy.

There are different types of prostheses which are custom built to suit your needs so your prosthesis may not be exactly the same as you see other people using. A primary prosthesis will usually have a wrist rotary so the cosmetic hand can be changed by the patient to a functional device such as a mechanical hand or functional appliance.

2. Fitting and Delivery of your Prosthesis

The next appointment will generally be for the fitting of your prosthesis. It usually takes between one to two weeks between appointments although this may vary depending on components selected for the prosthesis and any interim stages required. You will try on the limb and may be fitted with a harness or set of straps if the arm is body-powered. If your device is a myoelectric prosthesis, (primary patient are not generally fitted with a myoeletric arm, as you will need to learn to tolerate the extra weight which comes from wearing a conventional prosthetics), then you will be assessed for control of the device, and will be provided with a rehabilitation plan, and some time with an OT. Once all is satisfactory, the prosthesis is returned to

the workshop for any cosmetic finish to be added. This may take another week or two to finish off, or under some circumstances it may be completed on the day. The timescale is dependent on the work that is needed, and the contractual arrangement within the prosthetic service centre.

You may take your prosthesis home with you, but please follow any advice for limb usage form both the prosthetist and the OT.

3. Follow-up Appointments

During the first year following delivery of your prosthesis, you will be given regular appointments to review your progress.

Your residual limb can change shape and size during this time, so the socket fit may alter. Adjustments to your prosthesis may then be required. If you develop any other problems and wish to be seen in between these dates, you should telephone your prosthetic limb centre to request an additional appointment. Extra socks, cosmetic coverings and other minor items can be posted to you as required.

4. Mechanical or Socket repair

If your appointment is for a repair, it will really help your prosthetist if you can tell them:

- If it is a mechanical failure
- Which component is damaged e.g. the hand, straps etc.
- How did it break?
- What were you doing at the time it broke/stopped functioning?

Don't worry if you don't know all the details, just try to give as much information as possible to help your prosthetist/technician to identify the problem.

If you do know what part (component)

is damaged and needs to be repaired or replaced contact your prosthetist. Parts may need ordering and time could be spared by pre-ordering components prior to an appointment.

5. Socket adjustment / replacement

If your appointment is for a socket adjustment / replacement it will really help your prosthetist if you can tell them:

- Do you have discomfort / pain and if so where on the stump do you feel this?
- On a scale of 1 to 10, with 1 being minimal, to 10 being excruciating, how severe is this pain?
- Has there been any skin redness or tissue breakdown?
- How long have you had the discomfort/ pain?
- Do you know what may have caused this discomfort/pain to start?
- Have you lost weight /gained weight?
- Has the fit of the prosthesis changed?
- Have you changed your habits or activity levels?
- Have you lost the ability to control the prosthesis?

N.B. Some causes of pain may need further examination by the rehabilitation consultant e.g. neuromas, so do tell someone if you are experiencing pain.

Allocate enough time to test the socket and the components properly.

- Make sure that the new socket is comfortable and the electrodes are in the right position to control the device (if myoelectric).
- 2. Try flexing and extending your limb, and make sure that the limb is securely suspended





- 3. Make sure that the socket is comfortable and usable in your home and that you have any devices or attachments that you need.
- **4.** Make sure that you fully understand how to control the device.
- Make sure that you know how to look after any electrical devices i.e. batteries, chargers etc. and where and when they should be used and stored.
- **6.** Make sure that you are happy with the cosmetic cover, and the colour match with your skin on the sound side.
- **7.** Ask if the centre OT can have a look at you using the device.
- **8.** Seek advice on how to keep the skin "glove" clean.

How is your prosthesis working?

- Are you able to perform basic activities with the new prosthesis?
- How is your arm length, is the prosthesis too long or too short?
- Are you happy with the range of motion available? Does the socket dig in at all when you move your residual limb around?

If you are not sure, ask to be referred to the OT or prosthetist.

Give immediate feedback to your prosthetist on any relevant information, especially if the prosthesis is uncomfortable in any way, do not wait until the next visit.

When explaining what's wrong be specific, saying 'it hurts' is the first step, however it is important to expand on why you feel it hurts and explain where it hurts and if you can why it hurts, e.g. 'catching me just there, but only when I'm lifting my arm up.'

The more detail you provide the more informed the prosthetist is. Point, or even mark the spot when it's red and sore.

It is also useful to let your prosthetist know which medications you are currently taking. Take a list of your medication with you that can be dated and added to your clinic notes. This will help the multidisciplinary team with remembering the correct dosage and how to spell any medications.

Remember, using your prosthesis should not be painful, but a period of time building up tolerance to limb wearing is inevitable if you are wearing a prosthesis for the first time.

6. Medical review

The medical (rehabilitation) consultant is your main advocate at the centre and is the prescriber of your prosthesis after consultation with the full multidisciplinary team. If your general health is affected, or if you have any significant form of skin breakdown, or symptoms not directly associated to socket fit, then it is important that you seek the correct medical advice at your prosthetic service centre.

Attend the appointment with notes about any issues you have. This helps the clinical team to structure the appointment appropriately, and with the right people who can help you.

The medical (rehabilitation) consultant is always employed by the NHS and would be your main support in case of issues affecting your satisfaction with the prosthesis, the service provider or the rehabilitation services at the centre in general.

If you want to speed up the rehabilitation



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process and make every visit to your limb centre run smoothly and help the rehabilitation team to do their jobs, get to know your residual limb and share any relevant information with your prosthetist, physiotherapist and rehabilitation consultant. Please see the section below for advice on getting to know your residual limb.

7. General review appointment

Think about what you did before your amputation and what you want to do now.

What is stopping you?

Talk about what you want to be able to achieve rather than what components you want. Don't always be swayed by things that you may have seen on the internet-your prosthetist and clinical team will be able to provide the most appropriate device for your needs. Prosthetists are trained and are constantly being informed of new components or techniques, so it is better to talk to them about your needs and wishes. The prosthetist can then inform you about which component will enable you to do as much as you can.

Research and understand what you want to be able to do. In particular, listen to other amputees, and support groups, particularly those that have a similar level of limb absence as you.





What you need to think about when attending a limb fitting appointment

The three main things to think about are:

Comfort: this is the number one issue affecting amputees ability to be mobile, active, and live a fulfilling life. Comfort is very much linked to the fit of the socket but can also be affected by other factors such as the trim line of the socket and the length and design of the socket. Comfort can also be linked to the use of straps or a harness, or even when your muscles tire if you are using a myoelectric device. It is important to recognise what each element of the prosthesis is there to do, and to report any discomfort quickly to your centre. It is worth noting that leather sockets offer more comfort over bony areas e.g. a short transhumeral. Primary (new) amputees are usually given a supply of stump socks, which you can wear as the primary swelling goes down to help with confort and fit.

Function: this is linked to both you and your prosthesis, and what do you want to be able to do. Keeping active is very important so think about performing activities where possible such as cleaning the house, general exercise, looking after children, joining clubs and classes. Always make sure that you look after any devices, particularly myoelectric devices. Keep them away from dirt, dust and water wherever possible.

Aesthetics (Cosmesis): refers to what the prosthesis looks like? Is this important to you? For some people this is a very important aspect, particularly when they have lost an arm/s. Make sure you are aware what type of cosmetic cover you have, and what you can do to try to clean it. If you feel that the limb is too short or too long, consult your prosthetist. Sometimes, if your stump is very long, it is difficult to get the prosthesis to be as cosmetic as we would like, but ask your prosthetist what options may be available.

Be honest and don't be afraid to question anything you are unsure about or you think feels wrong. This could save another visit to the prosthetic limb centre. If you don't understand ask the OT, prosthetist, physiotherapist or rehabilitation consultant to explain it to you. Ask for take home resources in a format that works for you. Never feel under pressure to make an instant choice about your treatment. If you feel the need to take time to think options over at home, this is okay and your prosthetist will understand.

There can sometimes be a trade-off between comfort, function and aesthetics, so it is really important to know what your priorities are and to explain these to your prosthetist and the clinical team.

Make a list of your goals and priorities. Set yourself specific targets if you can:

- What are your goals and aspirations?
- Are these goals realistic and achievable?
 Discuss with your prosthetist if unsure as everyone is different.

- What did you do before your amputation?
- What would you like to do now?
- What is stopping you, what are the barriers?
- What do you need to do/change so that you can continue with these activities?

Access and dignity

Also think about access to your prosthesis during appointments.

It is really helpful if you are wearing light upper body clothing, so that you can don and doff the prosthesis without embarrassment to you or your prosthetist. Many Limb centres have fitting rooms where you will be with other patients, so think about your dignity. Remember, you will always have the option to request a chaperone.

Don't forget to clean your residual limb, sleeve and socket before an appointment. See the section on hygiene for advice on keeping your prosthesis clean.

Get to know your residual limb (stump)

If you want to speed up the rehabilitation process and make every visit to your limb centre run smoothly and help the rehabilitation team to do their jobs, get to know your residual limb and share any relevant information with your prosthetist, OT and rehabilitation consultant.

Wearing a prosthesis can have an impact on the skin and tissue of the residual limb (Stump). Dealing with residual limb issues quickly will prevent time off from wearing your prosthesis and less time at the limb centre! It is advisable to view any minor irritation as a potentially dangerous



Get to know your residual limb (stump)

Shape of your residual limb	What shape is your residual limb (stump); is it conical, cylindrical or club shaped?
What condition is the residual limb (stump) in?	Is it sensitive to touch? Is it being stretched by the prosthesis? You may find that the scar line is stretched, which needs to be addressed. If you have a congenital absence, there may also be sensitive areas, which the prosthetist will need to be aware of. Your residual limb may also be shaped differently, so be aware that this may affect your prescription options too.
Do you have scar tissue and is this an issue for comfort?	Ask your limb centre for advice on massaging any scar tissue.
What is the firmness of your residual limb (stump)?	Is it flabby or firm? Do you have excess skin or flaps and does this cause you any problems, such as pinching?
What is the condition of the end your stump?	Do you have a bony spur, is the muscle tissue attached or detached, is the bone next to the skin? Does this cause you any discomfort? If you have a bony spur this can make movement painful, so make sure your prosthetist is aware of this and adapts the socket accordingly.
Is your skin sensitive?	Ask your limb centre about ways to desensitize your residual limb (Stump).
Pressure when wearing a suction suspension	The stump is subjected to negative pressure. This can lead to edemas. You can tell you have a problem with negative pressure if you get bruising on the stump which looks like a giant love bite. This means your socket is too tight!
Wearing a prosthesis	During weight bearing uneven loading may cause stress on localised areas of the residual limb (stump) skin e.g. intermittent stretching of the skin, friction from rubbing against the socket edge and interior surface.
Pain, do you experience pain when wearing a prosthesis?	Is this phantom pain in the missing part of the limb or physical pain in the residual limb? / Does the scar tissue hurt? Is the socket causing you pain? What sort of pain and where?
Bacterial and fungal infections	Most upper limb prostheses have a snugly fitting socket in which air cannot circulate freely, thereby trapping perspiration, which can lead to bacterial infection.
Irritatation or allergic reaction	An amputee's skin is vulnerable to the possible irritant or allergic action of the material used in the manufacture of the prosthesis or topical agents applied by the patient himself.
Suspension	Wearing a harness can cause discomfort, particularly under the sound side armpit. Make sure that you check with your prosthetist that the harness is set at the right tension for you – don't just assume that this will be right.
Perspiration and residuum heat	Sweating excessively is not unusual, especially for new amputees where there is an acclimation process when starting to wear a liner. Sweating is a natural cooling mechanism which is less efficient for amputees due to the heat of the residuum (stump) which is encased in a liner, socks and plastic socket. Missing limb reduces the surface area, so this natural cooling mechanism is less efficient.





symptom and to deal with it as early as possible. This is especially true for people with diabetes (see table overleaf).

Check your stump carefully every day for signs of infection, such as: warm, red and tender skin, discharge of fluid or pus and increasing swelling. As we age, the elasticity in our skin reduces and the skin gets thinner which can impact on wearing a prosthesis. Contact your limb centre for advice if you think you may be developing a skin problem.

Hygiene

Ask your prosthetist about stump hygiene, and what are the best ways of ensuring that your socks, liner, socket, myoelectric devices and other components / terminal devices are best and most suitably cared for. Many components have specific criteria that are recommended by manufacturers to ensure that the component or material lasts and performs well so make sure that you are aware of this. Take a pen and paper with you if necessary!

Below are some hygiene basics.

Keep things clean, where possible, particularly anything that will fit directly against your skin

Gently wash your residual limb (stump)
with a non-fragrant soap every evening
(more frequently in hot weather) and dry it
carefully. The stump should not be
washed in the morning unless a stump
sock is worn because the damp skin may
swell, stick to the socket, and be irritated
by friction during walking. If you are going
to wash in the morning make sure the

- residual limb is dry before donning the prosthesis.
- Soaps or detergents that contain bacteriostatic or bactericidal agents in addition to their cleansing action help to reduce the possibility of infection.
- When taking a bath, avoid leaving your residual limb (stump) submerged in water for long periods because the water will soften the skin on your residual limb (stump), making it more vulnerable to injury.
- If your skin becomes dry, use a moisturising cream before bedtime or when you're not wearing your prosthesis.
- Depending on the suspension method some people find wearing one or more socks around their residual limb (stump) helps absorb sweat and reduces skin irritation. Not all prostheses, particularly myoelectric prostheses, allow for the use of socks or liners.
- The size of your residual limb (stump)
 may change as the swelling goes down,
 so the number of socks you need to use
 may vary
- If you have a prosthetic limb, you should also regularly clean the socket using soap and warm water. The best time to cleanse the socket is also at night. Some amputees prefer to use witch hazel, rubbing alcohol or anti-bacterial wipes for the wall of the socket (This is down to personal choice). Don't use rubbing alcohol or anti-bacterial wipes on the residual limb.
- If a stump sock is worn, it should be changed daily and should be washed as soon as it is taken off before perspiration is allowed to dry in it. If the sock does dry with a "dog-ear," a plastic or rubber ball can be inserted into the base of the sock to give it the correct shape.

The amputee can expect mild edema and a reactive hyperemia or redness when first becoming accustomed to the prosthesis. These changes are the inevitable result of the altered conditions that are now forced on the skin and tissues of the residual limb (stump) but be cautious that it is not something more serious. Check the condition of your stump every day!

Get to know your socket

The socket allows the prosthetic device to connect to your residual limb. For some suspension systems an additional layer, called a liner, fits over your residual limb and provides a barrier between your skin and the socket. The liner provides cushion and comfort while providing a better fit for the socket. These liners can be challenging to roll on at first, particularly with one hand, so check with your prosthetist and OT before you consider asking for one.

It is essential that the socket fits correctly. A poorly fitted socket can lead to pain, sores and blisters on your residual limb. The socket suspension options are normally self-suspending (the socket suspends the limb), vacuum and pin lock (with a liner), or a harness (straps).

If your socket doesn't fit or is uncomfortable, or if your harness is ill-fitting, arrange for a review, as it can cause problems with your residual limb which could result in time spent without wearing the prosthesis. Check your socket for cracks or splits, particularly in your socket or components – these can cause failure and breakage over time.

Socket fit self-management. If your socket isn't fitting (too lose) have you tried



adding a prosthetic sock more commonly called a stump sock or a top half sock of a stump sock? Stump socks are an interface material which can be used between the socket and the sleeve. Not all suspension systems allow for the use of stump socks so do ask your prosthetist for more information about whether you can use stump socks to help manage socket fit. Traditional stump socks come in different materials including wool, cotton and synthetics. Sock thickness is measured by the ply rating, most commonly from 1 ply to 6 ply. You can vary the ply number and or number of socks worn to adjust the socket fit. Do you find the fit changes over the course of the day? It is common that the prosthetic socket feels looser as the day progresses as the stump volume/size changes during the day. Always carry a spare stump socks with you so that you can adjust the socket fit throughout the day.

Get to know your componentry – Focus on function not brand

Understand what type of components you have and how they function will help you in your day-to-day activities and will help you when you plan your next prosthetic centre visit, especially if there are activities that you want to be able to do but cannot because of the limitations of your prosthetic components or your socket.

Ask the prosthetist what you are wearing

- What type of socket do you have?
 What are the other options and why was this type chosen?
- What type of suspension do you have and why was this chosen?

Common problems and solutions

If your prosthesis (artificial Limb) is too loose, goes on too easily

- 1. Wear an extra residual limb (stump) sock.
- If you are wearing 3 think residual limb (stump) socks, ring your prosthetic service centre for an appointment.

If your prosthesis (artificial Limb) is too tight

- 1. Decrease the number or thickness of the sock you are wearing.
- 2. Wear your compression sock, often called a Juzo sock for 30 minutes and try again.

If your residual limb (stump) is painful

Contact your prosthetic service centre and ask to speak with a member of the Rehabilitation Team.

If you notice persistent red marks and or blistering on the residual limb (stump) Do not wear the prosthesis (artificial Limb). Contact your prosthetic service centre and ask to speak with a member of the Rehabilitation Team.

If your prosthesis (artificial Limb) clicks or squeaks

Ring your prosthetic service centre for an appointment.

If the strap on your prosthesis is torn or worn

Contact the prosthetic service centre for a replacement. You will need to bring the prosthesis (artificial limb) with you to the appointment.

Stiff lock

Contact the prosthetic service centre and arrange an appointment to have it checked by a prosthetists or technician.

If your prosthesis gets wet and it is not meant to

Remove your shoe and sock and allow the prosthesis to dry naturally. If it is still not working properly contact your prosthetic service centre to get it checked by a prosthetist or technician.

Is your compression sock too loose or too tight

Contact the physiotherapist at the prosthetic service centre and ask for a replacement.

If your prosthesis breaks

Make an appointment at your prosthetic service centre, ask for an emergency appointment. You cannot wait six weeks for a repair.

- What type of sleeve do you have and why you have been provided with this particular one?
- What hand or terminal device(s) do you have and why?
- What elbow joint do you have and why?
- What harness do you have and why?
- What myoelectric hand do you have and why was it chosen?

Get your prosthetist and or physiotherapist to explain it to you (often, outside London especially, amputees may have rehab in a local or district hospital not necessarily the limb centre). It can sometimes take a few weeks to complete the process of re-fitting your socket, which can cause disruption to your life if you do not have a spare prosthesis, so be prepared. Some amputees have a cosmetic limb and an actively-functional limb. If you have a spare prosthesis you may be able to use this when your everyday one is being repaired or refitted which can prevent some of the issues mentioned above.

Different prosthetic service centres have different rules and time frames for re-fitting sockets and carrying out repairs. Do ask your limb centre what their process is and bear in mind that your prosthetist also wants you to be comfortable and of course back to your normal function as soon as possible.



After your visit

You should be able to get back to a normal level of functioning within a few months if you are a new amputee or straight away if you are an established amputee. This new

normal will depend on the location of your amputation as well as your overall health and well-being. Your prosthesis will be a tool to help you do the things you used to.

Remember the prosthetist knows prosthetics, you know your body!

How well you do will depend on your goals, a comfortable prosthetic fitting, follow-up care, and determination.

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fieldfisher

Fieldfisher are delighted to support the LimbPower Advice Sheet and hope that it will ensure that amputees across the UK are able to get the most from the services that are on offer from their prosthetic service centre in order to maximise their rehabilitation. Frequently our clients come to us, unaware of the services that are already available to them through their artificial limb centre. In ensuring this Advice Sheet is made available to all amputees at the outset of their journey we hope that they will be able to make the most of the fantastic support on offer to them.

Fieldfisher have always been at the forefront of supporting the amputee community and we were delighted to sponsor Andy Lewis on his way to winning a gold medal at the Rio 2016 Paralympics. We work closely with the major prosthetic and rehabilitation services in the UK and have working relationships with the world's leading Osseointegration teams in the

Netherlands, Sweden, Germany and Australia. We put rehabilitation at the centre of everything we do. We push for funding under the Rehabilitation Code, early admissions of liability and sizeable interim payments to help put in place the best possible packages for our clients. We frequently take on cases that other firms have refused to take on and the independent directories consistently rank us as top performers in the industry. We have clients all over the UK and are always happy to visit our clients at any location that is convenient for them, understanding that their injuries make it harder for them to travel. If you would like to know more about the services we offer, and the advice we can provide, whether you suffered an amputation as a result of a medical mistake, a road traffic collision or an incident at work, please contact Mark Bowman at mark.bowman@fieldfisher.com or on his direct dial of 0207 861 4043





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