

## Amputee Rehabilitation

This factsheet describes the process of rehabilitation after childhood amputation due to septicaemia. This includes the fitting of prosthetic limbs (prostheses). Prosthetic limb (prosthesis) fitting takes place in a centre which is likely to be separate from the hospital where your child was treated when they were ill. The centres are called prosthetic and amputee rehabilitation centres (PARCs).

This factsheet describes what you need to know about caring for your child after amputation and what to expect during the appointments at your local PARC. It also describes the types of limbs that may be available for your child initially and over time as they become stronger, more skilled and used to wearing them.

Children who have lost limbs as a result of septicaemia often need more specialist care compared to those with limb loss as a result of other causes. For example, excessive skin scarring can cause blistering and sores to develop in the area between the residual limb and prosthesis. Additionally, some children will need to undergo revision surgery if they experience bone growth problems which will mean that they may be unable to use their prosthesis for periods of time.

The aim of a prosthetic limb is to assist the child by minimising their disability and the resulting impairment and maximising their participation in all activities they wish to do. This will help them to become as independent as they want to be and to achieve all their personal goals.



Figure 1: Edward lost 4 limbs to meningococcal septicaemia aged 7

Prosthetic limbs can be very useful, but sometimes they are not appropriate. Their use will depend on the activities that your child wants to do.

There are a lot of situations when using a limb can get in the way. Prosthetic limbs don't allow the user to feel sensation like skin does, so in certain circumstances they can be detrimental. This is especially true for young children and babies where the texture of a material is part of learning about their environment, such as feeling the different textures of fleece or cardboard.

It must be stressed that most children use artificial limbs that are useful to them; this is why most children with lower limb amputations use prosthetic legs but many children with upper limb amputations choose not to use prosthetics. Never force a child to use a prosthesis, it can become a focus of frustration for the parents and the child and cause a rift between them. Encouragement is the best way forward with positive reinforcement. As stated earlier most children will use the artificial limbs that are useful to them!

An example of encouragement may be to put their favorite toys onto a play table that they have to stand up to get to. The child desires the toys and can better play with them using both arms and their prosthetic leg for support and of course lots of positive verbal reinforcement.

There are many advantages to be gained from using prosthetic limbs, but it is important to go into the limb fitting process with realistic expectations. It will take time and practice for your child to learn to use their new prosthesis confidently. Prosthetic limbs will need to be replaced from time to time to keep up with their growth. Rehabilitation involves a lot of hard work at building strength and co-ordination skills, which means that there will be lots of appointments at the PARC. The rewards from all this hard work will more than pay off in the long term because prosthetic limbs can allow amputees to walk, run, grasp objects and have the freedom of mobility without the use of a wheelchair.

### How will I find out whether prosthetic limbs are suitable for my child?

In some circumstances staff from the PARC will come to visit your child whilst they are still recovering in hospital. This may not happen in all cases however and you may find that the first time you meet the staff is when you attend the PARC for an assessment to see if prosthetic limbs will be suitable for your child.

The initial appointment is likely to last between 1 and 2 hours and if prosthetics are thought to be suitable for your child, you will be given lots of information about how your child will be treated over the coming years. It is a good idea to take a copy of My Journal with you so that you can make notes during this appointment.



Figure 2: Charlotte lost her limbs to meningococcal septicaemia aged 2, but doesn't let this deter her from joining in with drawing

The staff that you are likely to meet during the appointment will include some or all of the following:

- **Consultant in Rehabilitation medicine** – this doctor will be responsible for the overall care of your child and will oversee your child's rehabilitation, making sure they get the best possible treatment
- **Prosthetist** – responsible for casting, fitting and adjusting your child's prosthetic limbs
- **Technician** – responsible for making the prosthetic limbs
- **Occupational Therapist (OT)** – responsible for helping your child learn how to use their prosthetic arms and legs so that they can carry out day to day tasks and participate in hobbies
- **Physiotherapist** – responsible for helping your child to walk and balance in their prostheses by improving muscle strength and co-ordination
- **Clinical nurse specialist** – will show you how to care for your child's residual limb and help if there are any difficulties with pain or skin breakdown
- **Counsellor/psychologist** – may work with you and your child to help them come to terms with their disability
- **Social worker/care manager** – can give advice regarding benefits and other financial matters, and be involved with plans for discharge from the acute hospital.

## When will my child be fitted with their prosthetic limbs?

If the initial assessment at the PARC suggests that your child would benefit from using a prosthetic limb, a series of limb fitting appointments will be made. In some cases, if it is agreed that a child is ready for prosthetic rehabilitation immediately, the team may start the limb fitting the same day.

Factors that are important for wearing a prosthetic limb and that can delay the provision of a prosthesis:

- Sometimes children are not ready to wear a limb because they are finding it difficult to come to terms with being an amputee. Patience and understanding from everyone really help here. There are no time limits but just remember that maintaining the limbs, the skin and the range of movement and strength of muscles, is essential to give the child the best opportunities for limb use.
- The age of the child is very important. If the child is not at walking age yet (under 9 months) then a cosmetic limb is usually supplied at first.
- The skin on the residual limb will need to have healed sufficiently to take weight. If skin has not healed very well it can lead to a delay in provision of a prosthesis. A daily skin care routine is very important. Tips on how to care for scarred skin is available from the factsheet 'Skin scarring after septicaemia'.
- The range of movement of the joints is very important;
  - Leg: if the joints cannot straighten fully this can make fitting a prosthetic limb quite difficult because the socket has to make up for the lost movement which makes the prosthesis heavier and harder to use. There are limits to how much range of movement can be lost before the prosthesis will not work, for knees and hips this is about 30°.
  - Arms: if the elbow joint does not flex fully, it can limit how useful the arm will be, as the elbow needs to flex to near the normal range so that for example the prosthetic hand could hold a spoon and the spoon could reach the mouth.
- Muscle strength: it is essential that muscles are strong enough to do the job that we want them to do. So if someone is sitting in a chair they do not need to be strong, but

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if they are going to stand then the muscles need to be stronger and if they are needed for walking or running then the muscles need to be stronger still. For the first 2-3 weeks after the amputation surgery the wound is healing, both in terms of the skin on the outside and the muscles on the inside (where they are stitched to each other and to bone). It is important not to do any muscle building work in this period as it can put undue stress on the healing tissue. During this time the main aim is maintaining range of movement. After 2-3 weeks, putting more weight through the limbs and building muscle strength becomes more important.

- Fitness: this is also very important because walking with a prosthesis takes more energy. Prosthetic limbs are not as energy efficient as legs and they do not generate power, so the remaining muscles have to make up for this. As your child moves through the rehabilitation process then fitness becomes more important.
- Infections: these can be very painful and must be treated early to prevent interference with rehabilitation and reduce pain. Your consultant in rehabilitation and/or GP will need to treat infections quickly. Early treatment will prevent the infection from spreading deeper into the tissues.
- How the bones have been affected by the acute illness can also affect the timing of rehabilitation and the fitting of prosthetics. More information about this is available from another factsheet in this series entitled 'Bone growth problems after septicaemia'.

## What does limb fitting for a new prosthetic arm or leg involve?

The limb fitting takes place over a series of appointments with approximately 1 week intervals between appointments.

### Appointment 1 - Cast and Measures

This initial appointment usually involves taking a cast and various measurements from your child so that the socket of the prosthetic limb can be made to fit exactly. A cast of your child's residual limb is taken by wrapping it in bandages soaked with plaster of Paris whilst pressing down firmly on the areas which are able to support the most weight. When it is dry it is taken off and you have a perfect impression of the residual limb. This is then filled with Plaster of Paris. After this has dried the original plaster bandage is removed to make a plaster model (positive impression) of the residual limb.



**Figure 3: Lyndon gets re-measured for a new socket after a growth spurt. He lost his limbs from septicaemia as a baby**

By adding plaster to some areas of the model the prosthetist can stop the socket pressing into certain parts of the residual limb and by removing plaster they can make the socket press more. The purpose of this is to make the contact between the prosthetic and residual limb as comfortable as possible and for your child's weight to be supported by the strongest part of their residual limb.

If your child has extensive skin scarring, they may also be measured for silicone or gel liners to protect the skin and any skin grafts that they have. These liners should be worn over the residual limb to prevent rubbing between the residual limb and the socket.

The socket is then made by applying layers of materials such as polypropylene and carbon fibre over the positive impression. Polypropylene is usually used for the first socket as the residual limb can vary in shape initially and this material can be adjusted easily using heat.

## Appointment 2 - Fitting

The purpose of the next appointment will be to test the fit of the socket. If your child has been prescribed silicone or gel liners, they will be asked to test the fit of the socket whilst wearing the liners.

This stage may need more than one appointment to get the fit of the socket right. Just like when buying a new pair of shoes it is important for a prosthetic limb to fit well to avoid rubbing and discomfort. Encourage your child to communicate with yourself, the prosthetist and the consultant about the fit of the socket so that the prosthesis can be as comfortable as possible and your child will want to use it.

Once the socket has been fitted, the prosthetist can arrange for the complete prosthesis to be assembled ready for the final fitting.

## Appointment 3 onwards – Final fitting, adjustments and practicing using the prosthesis

At this appointment your child will have the chance to try on their new prosthesis in its entirety. The prosthetist will check that the limb fits as well as it can. Over the next few weeks and months the focus will then be on helping your child to use the limb effectively.

The initial fitting appointments for new amputees will be exhausting and can be uncomfortable. This is especially relevant for children being fitted with prosthetic legs for the first time and your child will need plenty of breaks. There will be support available during the appointment from the physiotherapist and/or occupational therapist. It is likely that there will be some discomfort even if the socket is a good fit if it is the first time your child has tried weight bearing or wearing a prosthesis. This discomfort will reduce over time as your child gets used to wearing and using the limb.



Figure 4: Lyndon practicing walking with a new pair of legs

## What sort of prostheses will my child be fitted with?

The type of prostheses that your child will be fitted with will depend on the location and level of the amputation as well as:

- **Age** - young children will need small, simple prostheses which are in line with the rest of their body. They will need to be a lighter weight and simpler to use the younger and smaller the child. As children become more co-ordinated and have the strength to support heavier prostheses, they may use limbs with more advanced technology. Prosthetic technology is much more advanced for adults than it is for children, but whether your child is suitable for adult prosthetics is more dependent on their size and weight rather than their actual age.
- **The presence of other amputations** - children with multiple amputations may be tried with different types of prostheses at different times to see what works well for them. Babies may be fitted with cosmetic arms to try and get them used to wearing a prosthesis from an early age, but the emphasis may change to wearing prosthetic legs once they start to try and stand.

The types of prostheses that your child needs are likely to change over time as they grow and their interests and aspirations change. The two main types of prosthetic limbs are cosmetic and functional:

**A cosmetic prosthesis** is designed to look as natural as possible. Cosmetic legs can be used to disguise the fact that a leg is missing when your child is in a sitting or lying position to complete an appearance. Cosmetic below knee prosthetics can take body weight, but through knee and above knee prostheses tend to be composed of only dense foam which will buckle under pressure.

**A functional prosthesis** will help your child to do something such as walk or grip. Some can be designed or adapted for specific activities such as running, horse-riding, riding a bike or swimming.



**Figure 5: Olivia lost her arm below the elbow and legs below the knee aged 2**

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## Upper limb prosthetics

Many prosthetic clinics will offer provision of cosmetic upper limb prostheses as soon as possible for young children (3 – 8 months of age). A cosmetic prosthesis is designed to look as natural as possible rather than be functional. For example, a cosmetic arm will disguise the missing arm, but will have no active moving parts so your child won't be able to grip anything with it.

The advantages of wearing a cosmetic arm from an early age are that it can get the child used to wearing it and can introduce your child to two handed activities such as clapping early on. It is also thought that babies who have worn prosthetics from an early age are more likely to accept future more functional limbs than a baby who has never worn a prosthesis.

There are three main levels of cosmetic finish for both upper and lower limb prostheses:

1. An off-the-shelf cosmetic cover that has very few surface features of a hand or foot.
2. An off-the-shelf high definition cover (costs a few hundred pounds) which looks quite realistic up to a few feet away.

3. Bespoke high definition silicone limb covers (up to a few thousand pounds). These look exactly like the original limb but are heavy and have poor function, especially in lower limb prostheses because the silicone cover can split if the limb is moved too much. As the covers are so expensive to manufacture

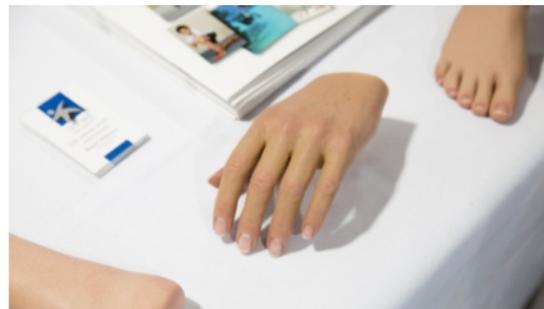


Figure 6: An example of high definition silicone prosthetic covers

they are not available as standard on the NHS, but can sometimes be prescribed in special circumstances. Usually this is because of the psychological effects of being an amputee.

By the time your child reaches 12 to 24 months they may start to be fitted with a functional prosthetic arm. The type will depend on the level of the amputation that they have.

**Trans-radial amputation** is the removal of an arm below the elbow. The prosthesis for this type of amputation will consist of a rotatable moving hand or hook attached to a socket shaped to fit the residual limb. There are several options:

- **Split hook prosthesis** - this is a very functional device which allows the child to carry out fine motor tasks such as building a Lego structure as well as gross motor tasks such as holding a book. The split hook opens and closes via a strap that is worn over the opposite shoulder. The child operates the split hook by moving their arm in such a way that they pull against the strap. This is known as a body powered system



- **Mechanical hand** – it is possible to swap the split hook on a body powered system for a mechanical hand. Although the hand may look more acceptable than the hook, because it comes with a cosmetic cover the grip may be slightly weaker



- **Myoelectric prosthesis** – an advantage of this device is that it can be operated without the use of straps. This means that the child can put it on and take it off themselves, but it will be slightly heavier than a body powered split hook prosthesis because it contains a battery and components which power the opening and closing mechanism. Young children can wear a battery pack around their waist to reduce the weight of this type of prosthesis. It takes a certain amount of skill to use this type of prosthesis because the opening and closing mechanism is controlled by the child flexing specific muscles in their residual limb. Sensors in the prosthesis detect electrical energy generated when a muscle contracts and act as a switch to send power to the hand.



**Trans-humeral amputation** is the removal of an arm below the shoulder. The prosthesis will need to consist of a socket connected to an elbow joint so that the user can position their prosthetic hand/hook. There is limited choice in commercially available children's elbow mechanisms. The main options are:

- No moving elbow at all
- A friction elbow which is positioned by manually moving it
- A hand operated locking elbow which is manually maneuvered into position and locked by pushing a button

- A body powered elbow where a body harness is used to bend and lock the elbow. This requires quite complex movements so it can be difficult for children to operate.
- An electronic elbow which has powered options. These are very heavy, only come in adult sizes, are difficult to use and are very expensive.

It is harder to operate a prosthesis with an elbow mechanism than one without and the elbow increases the overall weight of the arm. For this reason, many children wear a cosmetic prosthesis with a friction elbow or just have it fixed into a natural position. The types of hands that can be fitted are the same as those mentioned for below elbow amputees.

Over the shoulder harnesses are often used to hold prosthetic arms in place. Alternatively, silicone sleeves can be used to hold the prosthetic limb in place without requiring a harness.

### Lower limb prosthetics

Babies can have a non-functional cosmetic limb from 3 – 6 months of age, but children will not be fitted with functional legs that they can walk and stand in until they start to try and pull themselves up. This is usually at around 9 -12 months of age.

#### Everyday walking limbs

**Trans-tibial amputation** is the removal of a leg below the knee. A walking limb consists of a socket attached via adapters and lightweight tubes to an ankle joint and prosthetic foot. The type of foot is dependent on your child's size and weight and this will need to change as your child grows. It is best to move to adult feet as soon as possible because the range is much greater (usually size 4 upwards for most feet).

**Trans-femoral amputation** is the removal of a leg above the knee. The walking limb consists of a socket attached to a knee joint. The knee is then connected to the prosthetic foot via adapters and lightweight tubes.



Figure 7: Walking legs for above and below knee amputees

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Very young above knee amputees may start off wearing legs that don't bend (see section on stubbies below) and then move on to a leg with a knee. There are many different types of knee available and your child's prosthetist will prescribe the type of knee which will suit your child's clinical needs. Some knees may be too bulky for very young children so the type of knee your child uses will change as they grow.

There are also various different types of feet and as with the knees, the type of foot your child needs will change over time as they grow taller and heavier, and as their activity levels change.

In the early stages and during periods of rapid growth, your child is likely to have quite a simple prosthesis because it will need replacing so frequently. The emphasis in the early stages will be more focused on getting your child's balance, posture and walking gait as natural as possible by helping them develop their strength rather than on more complicated movements.

### Stubbies

Stubbies, shorties or SNAPs (short non-articulating pylons) are sockets with either feet or rubber pads on the end. They are typically used where both legs have undergone trans-femoral amputations or knee disarticulation (through the knee amputation).

The advantages of these are that they are much lighter than normal walking prostheses because there are no heavy knee joints and they can be easy to take on and off. It is also easier to balance in them because the wearer is closer to the ground. This means that if a child falls over they are much less likely to hurt themselves. Walking in stubbies takes more energy than walking on prostheses with knees that bend, but many children find them convenient for use around the home or for walking short distances.

### Sports limbs

There are many different types of sports prostheses such as limbs with flipper attachments for swimming, running legs with have carbon fibre blades which act like springs to help propel the wearer forwards as they run and special feet for taking part in sports such as skiing.

Sports prostheses are not supplied routinely on the NHS but in certain circumstances they may be funded. Some sporting limbs can be



**Figure 8: Carbon fibre blades help store energy to make sporting activities easier**

considered as performing a dual purpose because all running components have to be waterproof which means they can be used as shower limbs and also as limbs for getting to and from the pool or on the beach. The dual-purpose nature of these limbs can help justify their provision on the NHS.

### How does a prosthetic leg stay on?

Different methods are used to attach the prosthetic leg and this is known as the suspension. The type of suspension used will differ from child to child and will depend on whether your child has amputations on both legs or just one, the level of their amputations and the amount of scarring your child has. Some of the ways that prostheses attach are:

#### Below knee amputation

**Cuff suspension** – these sockets use a leather or cuff strap to hold the prosthesis in place.

This is the most basic, but also most dependable, method of holding a leg on. However, there are disadvantages; the strap can crease behind the knee causing discomfort and there can also be an amount of pistoning. This is where the prosthesis pulls away from the leg slightly during the swing phase (when the leg is swinging through), then gets pushed back on when the limb hits the ground and weight is taken. This can lead to rubbing and sores.

**Supracondylar suspension** – in these cases, the socket is shaped to fit the bone. For example, a socket can be made which gets narrower above the knee to hold the prosthesis in place. This is an excellent way of holding the limb on but can be tight to fit and **cosmetically, the top of the socket is very evident through the clothing covering the knees.**

**Suction** – this type of system consists of a silicone or gel liner and a one way valve in the socket. A liner is a snugly fitting silicone or gel sleeve that rolls over the residual limb. Many children who have lost limbs as a result of meningococcal septicaemia benefit from wearing liners because they prevent rubbing between the delicate skin and the socket. They are also good for keeping scar tissue supple and moisturised. Inserting a liner-covered residual limb into the socket and applying body weight expels excess air through the valve keeping the prosthesis attached.

**Locking liner** – this type of suspension involves a silicone or gel liner with a pin at the end.

The pin locks into the socket of the prosthetic leg to keep it in place. A button on the side of the prosthesis releases the pin and allows the prosthesis to be removed.

The main problem with liners is that the residual limb spends a long time in a confined, dark, moist space which is an ideal environment for bacteria and fungal spores to grow. Regular washing and drying of the residual limb, and the liner is vital in reducing the risk of infection.

Liners are total contact sockets, so the end of the residual limb takes some weight. This can rule out their use in a number of patients.



Figure 9: Example of a locking liner

**There is no single best suspension method for everyone; it is whatever is best for your child.**

### How will my child learn to walk on their new prosthesis?

When your child is first discharged from hospital, they may need to use a wheelchair. If this is the case, the initial focus of the physiotherapist in the PARC will be to make sure that your child is able to get in and out of their wheelchair safely.

In the early stages there will be a focus on keeping all of the body's joints healthy and moving as freely as possible. It is important to avoid joint contractures from developing in the early stages and so the physiotherapist will give you lots of exercises to do to prevent them from developing. More information about this is available from the factsheet 'Amputations including loss of fingers, toes and limbs'.

If your child is a single limb amputee, then whilst your child's first prosthesis is being made, the physiotherapist will focus on helping your child to practice standing and supporting themselves on one leg. For children who have had both legs amputated the physiotherapist will focus on helping your child to weight bare and balance on their residual limbs providing that their wounds have healed sufficiently.

Once the new prosthesis has been delivered, your child will have a series of appointments to practice using it. At first, your child will be asked to practice standing in the prosthesis. Once they are confident with this, they will be asked to take some steps whilst wearing the prosthesis with the aid of parallel bars or a walker.

A prosthetist and physiotherapist will be involved in fitting the prosthesis. The prosthetist will be looking at the way your child walks to see if the height and other aspects of the limb are correct and allow your child to move with a natural gait. The physiotherapist will be working

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on improving the strength of your child's muscles and balance to help them walk and stand in the prosthesis.

Once your child has shown that they are able to safely use the prosthesis, you will be able to take the prosthesis home and practice walking there. The physiotherapist will provide information about a range of exercises that will help your child develop strength and movement allowing them to get the best use from their prosthesis.

As well as seeing a physiotherapist at the PARC and at the hospital, it is likely that you will also be assigned a community physiotherapist or OT who will come and visit the family and work with your child at home and in the school or nursery setting. You may be loaned equipment that you can use at home to help with the exercises such as:

**Standing frame** – this is a frame that will support your child in the standing position. It is more likely to be used for amputees who have lost both legs as it allows them to get gradually used to weight bearing in the prosthesis.

**Walker/crutches** – whilst your child is learning to walk in their prosthesis, they may need additional support from a walker or crutches.

It takes considerably more energy for an amputee to walk on prosthetic legs compared to the energy it takes for a non-amputee to walk. Those with higher level amputations use more energy walking on prostheses than those with lower-level ones, and amputees who have lost both legs will use more energy than amputees who have lost one leg. This means that some amputees will always need to alternate their time between a wheelchair and using prostheses to walk. Amputees who have lost part of one limb may find that they do not need to use a wheelchair at all once they have become used to walking with their prosthetic leg.

## What problems might my child encounter when wearing their prostheses?

Your child may encounter some problems when wearing their prosthetic limbs. Some of the particularly common ones are:

**Discomfort** – the residual limb can temporarily swell throughout the day and changes in size can cause the socket not to fit as well as it should. Children are also likely to have growth spurts which can affect the comfort and fit of the socket. Unusual bone growth caused by septicaemia can also cause problems, these are discussed in more detail later in this factsheet.

**Rubbing** – if skin rubs against the inside of the socket, it can cause sores to develop. This will be painful and increase the risk of infection. It is important to get in touch with the rehabilitation team as soon as any rubbing occurs because the problem will only get worse. Your prosthetist should be able to make some adjustments to the prosthesis and the rehabilitation consultant will be able to help with pain relief.

**Sweating** – this can be particularly problematic when liners are being worn. Excessive sweating inside the liner can be uncomfortable and lead to infections. It is important to wash and dry the liner at least once a day. There are ways of treating excess sweating, for example, by using special antiperspirants on the area. Make sure you tell your rehabilitation consultant if your child has problems with this.

**Infections** – the inside of the socket can get very warm and be an ideal breeding ground for bacteria which can then go on to cause infection. You should let your rehabilitation consultant know as soon as possible if any part of the residual limb becomes, red, itchy or painful. The consultant will be able to prescribe medication to treat any infections.

It is important to discuss any discomfort that your child has whilst wearing their prosthesis with the PARC as soon as possible because the problem is likely to only get worse over time. Problems with comfort as a result of swelling can be overcome by changing the number of socks worn in the socket throughout the day and addressing problems as soon as they arise will prevent more serious problems such as sores and blisters from developing. Likewise, if the discomfort is as a result of your child having outgrown their socket, the sooner you talk to the PARC about this the sooner they can get a new socket made for your child.

### Is there anything we can do to reduce the likelihood of these problems occurring?

Yes. The skin of the residual limb should be kept as healthy as possible by following a daily hygiene routine which your child should be encouraged to participate in and take ownership of. It should start as soon as the wounds allow and become a daily activity after that.

- **Washing and drying** the residual limb every day will help to prevent infection. It is also important to wash any silicone or gel liners every day and replace socks daily.
- **Massaging** the residual limb daily after washing and drying using an aqueous cream will help flatten out any lumpy scar tissue, keep the skin soft and stop skin from sticking to the bone under the residual limb.
- **Moisturising** the skin regularly will help to keep it supple and soft.
- **Observing** the residual limb every day can help you spot problems early on. Check the skin for signs of fungal infections, little cysts, blisters, sores and rubs by looking for any sore, red or broken areas, or other changes in appearance. Using a mirror is essential to examine the parts of the limb that you cannot see directly. If you notice anything that you are concerned about, call the rehabilitation team at the PARC for advice.

### What problems might unusual bone growth cause and how can it be treated?

Unusual bone growth in the residual limb can cause pain, infection of the surrounding tissue and poor fitting of prostheses. Problems like these can usually be resolved with surgery but the exact treatment will depend on the nature of the bone growth problem. Some of the more common problems that children experience are outlined below.

- **Overgrowth of bone**

It is possible for residual bone to grow faster than the surrounding muscle and soft tissue. This causes bone to push into the skin at the end of the residual limb which can be painful, increase the risk of infection and cause problems with wearing prosthetic limbs. This type of bony overgrowth needs to be treated surgically and children with this problem are likely to need revision surgery. This involves re-trimming of the bone and revision of the soft tissue covering the end of the residual

limb. This can be necessary up to every 2 to 3 years until they reach adulthood but often is a lot less frequent than this.

- **Bone growth at an unusual angle**

The residual part of amputated bone may grow at an angle if the growing parts of the bones (growth plates) were damaged during the initial illness. Bone growth at an angle within the residual limb can cause problems when fitting prosthetic limbs and may need surgical correction to improve your child's ability to use prostheses successfully.

- **No bone growth**

Damage caused by the initial illness can stop bones growing altogether. This can be particularly problematic if children are affected at a very young age and require high level lower limb amputations. If the residual limb was short in the first place and does not lengthen as your child grows, there will be very little for the prosthetic limb socket to attach to. This will impact on mobility when using prosthetic limbs. The problem can be overcome by surgically lengthening the remaining bone.

There is a possibility that the bones in non-amputated limbs were damaged during the acute illness and the rehabilitation consultant and orthopaedic surgeon will be monitoring your child for signs of this as they grow. More detailed information about the treatment of bone growth problems is available in separate online factsheets called 'Bone growth problems after septicaemia' and 'Information about external fixators'.

### Will my child be able to do all the activities that other children do?

Children are remarkably resilient. Even children who have had parts of all four limbs amputated are able to get involved with physical activities such as running and swimming. Many parents report that their children come up with imaginative and innovative ways to take part whether that is with or without the aid of prostheses.



Figure 10: Charlotte and Amber enjoying a game of catch

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## **I have heard of other parents raising money for getting private provision of prostheses? Should I do the same?**

Many parents complain of there being a postcode lottery when it comes to NHS prosthetic services and we often hear that this is one of the main reasons why people fundraise for private provision. However, there is no reason why your child should not be provided with perfectly adequate limbs from the NHS.

The following section outlines what you are entitled to with regards to your NHS prosthetics provision. This information may help you to get the best from your local NHS service. If for any reason you are unsatisfied with the service that your local PARC is providing you should try to discuss the reasons behind this with the team who are treating your child. If this does not resolve the issue, then you are entitled to seek a second opinion and you can change your service provider.

We strongly encourage you to try and resolve issues with your local provider before seeking provision from an alternative NHS centre or going privately. As children are growing, they will need to attend multiple appointments at the PARC and will be provided with many different limbs throughout their childhood to keep pace with the changing shape of their residual limb and increases in height and weight. Children can also put their limbs through rough treatment which can lead to more frequent replacement of parts resulting in high expense if you have opted for private provision. If you choose to change to an alternative NHS provider, you will need to consider the increased travel times and cost to reach the centre.

### **What should my NHS service provide?**

All child amputees should be seen at a tertiary PARC. A tertiary centre should<sup>1</sup>:

- be led by an experienced consultant in amputee rehabilitation who specialises in prosthetics
- have socket manufacture and limb assembly services on site
- have a team of clinicians including a prosthetist, physiotherapist, OT and counsellor who all have experience in the management of children

- provide combined clinics with an orthopaedic surgeon, plastic surgeon and pain management specialist where appropriate to deal with limb surgery including revision and reconstruction, and pain management

Your PARC will prescribe prosthetic limbs and liners for your child to use, and they will also arrange sessions with a physiotherapist and/or OT to help them develop the skills and strength necessary to use the prostheses.

The PARC should be working to specific rehabilitation goals which have been agreed between you, your child and the PARC. These goals should be reviewed and amended regularly as your child grows and becomes more confident and skilled at using their prosthesis. For example, if a child has had both legs amputated an initial goal may be for them to walk a certain distance in their prosthetic legs with the aid of a walker. Eventually as they become stronger and more used to wearing their limbs this may progress to walking in their prostheses unaided.

Currently different PARCs have different prescription policies. As every centre is different, it is difficult to specify exactly what you can expect. However, every centre should have a set of prescription guidelines setting out the range of components that can be used for patients including:

- types of sockets, joints, socket liners, cosmetic covers
- provision of second limbs, sports limbs and shower legs
- provision of high-definition silicone

### How can I get the best from my NHS service?

Good communication is really important. Children who have lost limbs as a result of septicaemia often have other problems which can make prosthetic rehabilitation more **complex than usual**.

**Communicating with the amputee rehabilitation consultant** - this is essential as they are the leader of the multidisciplinary team. They look holistically at your child and should have a wide breadth of knowledge to ensure all your child's needs are being met. They will prescribe the components of your child's prosthesis and will also refer on to other services such as orthopaedics or plastic surgery if necessary. If you have any concerns about your child's care, it is essential to discuss them with the consultant.

**Communicating with the prosthetist** - a comfortable socket is one of the most important things to get right when fitting prosthetic limbs. A comfortable fit will determine whether or not your child will be happy to wear them.

When attending fitting appointments, it is vital that you encourage your child to say if they are experiencing any discomfort when they try on the socket. Likewise, if your child's socket becomes uncomfortable at any point in between appointments, you should speak to your PARC as soon as possible. Try to get as much information from your child as possible about the discomfort they are feeling. Ask them exactly where the pain is and whether the pain starts after they have been wearing the limb for a while or if it is always there. The more information your child's prosthetist has to work with, the more likely it is that they will be able to solve the problem.

**Multidisciplinary team meetings** - your child may need to have corrective operations to their residual limb which can temporarily affect whether they can use their prostheses. If your child has any planned operations, it is a good idea to ask for a joint meeting with staff from the PARC and the medical team who are responsible for operating on your child. This type of appointment is called a multidisciplinary team meeting and it will be useful for efficiently planning your child's prosthetic rehabilitation and recovery following the operation.

**Communicating your child's needs** - the PARC will be working with you and your child to reach specific goals which will change over time. As your child's rehabilitation goals progress and they become used to wearing prosthetic limbs, they may need to change the type of prosthesis they have so that new activities can be tried.

If you find that the prosthetic limbs provided by the centre are holding your child back it is a good idea to discuss this with the prosthetist so that alternatives can be investigated. Explain what your child is unable to do in the prosthesis that they currently have, so that the prosthetist can try to address this problem. For example, if your child is unable to run in their current prosthesis and this is frustrating them because they are unable to take part in games at school you should try and explain to the prosthetist exactly how your child is restricted by their current limbs so that the problem can be addressed.

The NHS does not support the provision of running limbs as a standard NHS service for children. However, your PARC should have a clearly defined policy for the provision of running legs which includes a process for funding in exceptional cases. There are cases where running legs have been funded on the NHS.

Children have more energy than adults and while many adults don't run as part of their normal daily routine, most children do. Some centres get around the problem of being unable to supply running legs for children by prescribing hybrid legs which are suitable for both walking and running. It is important to communicate to your prosthetist what your child wants to achieve from their prosthesis rather than simply asking for a specific type of limb. Your prosthetist can prescribe limbs that will help your child reach their rehabilitation goals, but they cannot prescribe a limb on the basis of a parent or a child simply wanting one!

If your child has had amputations of the arm and they would like to take part in a particular activity such as playing tennis, riding a bike, or painting, the occupational therapist can work closely with your child and develop simple arm attachments or tools to help your child achieve these goals.

Maintaining good communication about your child's changing needs and aspirations with the rehabilitation team is the best way to get the most from your NHS prosthetics service.



Figure 11: Sofia lost her left leg below the knee aged 2 and got her first running leg six years later aged 8

## Further sources of information and support

A wide range of information and support is available to children who have lost limbs and their families. Some useful organisations to contact are listed below:

### **Limb Power**

A charity assisting in the rehabilitation of amputees that provides opportunities in recreational and competitive sports and arts.

**Website:** [www.limbpower.com](http://www.limbpower.com)

**Email:** [kiera@limbpower.com](mailto:kiera@limbpower.com)

### **Limbless Association**

A charity providing information and support to the limb-loss community of all ages and backgrounds.

**Website:** [www.limbless-association.org](http://www.limbless-association.org)

**Helpdesk:** 0800 644 0185

### **Reach**

A charity that provides information, support and guidance for families with children who have upper limb deficiencies.

**Website:** [www.reach.org.uk](http://www.reach.org.uk)

**Helpline:** 0845 1306225

### **Steps Worldwide**

A charity that values and supports individuals, families and carers affected by a lower limb condition.

**Website:** [www.stepsworldwide.org](http://www.stepsworldwide.org)

**Helpline:** 01925 750271

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1. The Working Party of the British Society of Rehabilitation Medicine. *Amputee and Prosthetic Rehabilitation – Standards and Guidelines (3rd Edition)*. 2018 [cited 2021 August]; Available from: <https://www.bsrn.org.uk/downloads/prosthetic-amputeerehabilitation-standards-guidelines-3rdedition-webversion.pdf>.