

Amputations including loss of fingers, toes and limbs

This factsheet describes why amputation of fingers, toes or limbs may be necessary in very severe cases of meningococcal septicaemia. It also describes what to expect during the initial recovery and rehabilitation period and the support available for your child and family.

Most children with amputations as a result of meningococcal septicaemia will also have significant skin scarring. More information about skin scarring is available from a separate factsheet called 'skin scarring after septicaemia'.

Having a child hospitalised with such a severe life threatening illness is a very frightening time for the whole family. From not knowing whether your child will make it through, to finding out that they will survive but require amputations, you will probably find that the months your child is in hospital are an emotional rollercoaster.

It is important to remember that you are not alone. Specialist staff at the hospital will support your child and the rest of the family through each stage of illness and rehabilitation. If you contact the meningitis charities, they can offer information, support and put you in touch with other families who have been through a similar experience.

What is septicaemia?

Septicaemia is blood poisoning caused by large numbers of bacteria multiplying in the blood. The body has to try to fight the growing number of bacteria and at the same time fight the toxins that the bacteria release which make the person feel so ill.

Why might amputation be necessary after septicaemia?

The bacterial toxins attack the lining of blood vessels and they start to leak, causing the rash of septicaemia, which can develop into larger purple areas of skin. At the same time, blood clots also form making it even harder for blood to carry oxygen to all areas of the body.

To maintain circulation to the vital organs (the brain, liver, kidneys, heart and lungs) the circulatory system reduces the blood supply to the extremities such as the hands, feet and the surface of the skin. When skin loses blood supply, it is starved of oxygen so that patches of it can eventually blacken and die. This most often happens to tissue on the fingers, hands,

toes and feet because the blood has further to travel to reach these areas. In cases of severe illness, whole digits and entire limbs will need to be removed or amputated.

If my child needs amputations will it happen straight away?

No, amputations are only done if the tissue has not survived and every attempt to save the limb will be made. However, tissue that has died can become a threat to the child as the chemicals released from the dying tissue can cause more harm.

What treatments will my child get?

The first priority in treating children with septicaemia is life-saving antibiotics, which are given through a drip. The sickest children need to be transferred to a paediatric intensive care unit (PICU) so that they can be monitored closely and looked after by specialist nurses and doctors. The PICU staff will explain the care and treatment that is being given.

Once your child is medically stable the treatment priority may then be to help damaged tissue to heal. Depending on the extent of the damage, areas of dead tissue may be cut away (debridement) or part of a limb may be removed (amputation). As time goes on it gets easier to distinguish dead tissue from healthy tissue, so surgeons may wait a while before operating to make sure they don't remove more than they need to.

A paediatric orthopaedic and plastic surgeon will carry out the amputation operation under general anaesthetic. The surgeons will be trying to preserve as much of the limb as possible. This means that they will amputate at the lowest possible level whilst making sure that there is sufficient healthy tissue to allow the residual limbs to heal as well as possible. A prosthetist (professional responsible for fitting artificial limbs) will ideally consult with the surgeon before the amputation operation to make sure that the level of amputation is suitable for the fitting of a prosthetic limb in the future.



Figure 1: Blackened fingers following septicaemia



Figure 2: Blackened toes following septicaemia

If your child's fingers or toes are affected then the doctors may decide not to remove them surgically, but allow the blackened digits to fall off naturally (auto-amputate). This will ensure that as much healthy tissue is preserved as possible. This process can take some time, so it is possible these auto-amputations will happen when you are back at home.

It can be very distressing to see your child's body damaged by septicaemia, but it is important to remember that the way your child looks in hospital during and immediately after their illness will not be the same as when their body has had time to heal.

What is an amputation level?

The amputation level describes the location at which the body part is amputated.

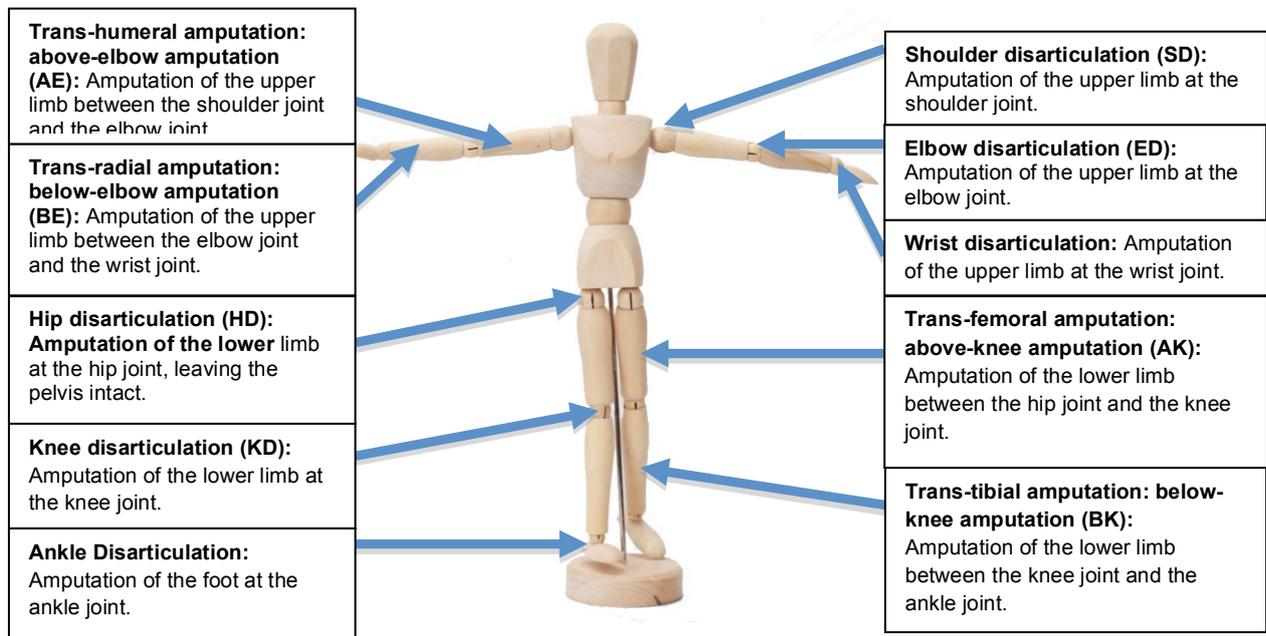


Figure 3: Diagram of some of the main amputation levels

It is also possible for just parts of the hand or foot to need amputation (known as a partial foot or partial hand amputation).

What happens after my child has had the amputation operation?

Your child will have dressings applied to their wounds to encourage healing and prevent infection. These dressings are likely to be changed two or three times a week for the first couple of weeks under general anaesthetic in the operating theatre.

Your child may have several debridement operations (removal of skin and dead tissue) at the same time as the dressing changes. Because the difference between dead and healthy tissue becomes more apparent over time, removing unhealthy tissue in stages allows the surgeons to preserve as much healthy tissue as possible.

If a large amount of skin was damaged it may be necessary for your child to have reconstruction surgery. This will take place after the initial amputation has healed. The procedure involves moving healthy skin and muscle from elsewhere in the body to cover the end of the residual limb and provide cushioning. It is important for the skin to heal well because if the soft tissue at the end of the limb is very fragile then it may tear or blister easily when your child wears prosthetic limbs. This can be problematic not only because it will be painful and discourage your child from wearing their prosthetics, but also because it can be a source of infection.

The surgeons treating your child will do their best to make sure the condition of the skin on residual limbs is as good as possible. Caring for scars correctly can also significantly improve the strength of this skin. More information about skin scarring and how best to care for scars is available from a separate factsheet called 'skin scarring after septicaemia'.

Will my child be in any pain?

There will probably be some pain after surgery. The nurses and doctors will aim to keep your child as comfortable as possible whilst they are in hospital, assess your child's pain and choose the most appropriate treatment to help manage it. This might mean that they are provided with intravenous pain killers to start with and then switched to oral pain killers once the pain lessens.



Figure 4: Tilly Lockey in hospital before amputation of her hands

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It is likely that your child will also be supplied with painkillers when they return home from hospital. These painkillers should be taken as directed to ensure your child remains comfortable and in as little pain as possible.

What happens once the amputations start to heal?

It will take time for wounds to heal, so during their hospital stay children will also be undergoing rehabilitation to make them as mobile and independent as possible. There will be a whole team looking after different aspects of your child's care whilst they are in hospital which may include some or all of the following:

- Plastic surgeon
- Orthopaedic surgeon
- Specialist nurse
- Occupational Therapist (OT)
- Physiotherapist
- Pain specialist
- Psychologist

There will be an emphasis on preventing joint stiffness (known as contractures) from developing whilst your child is recovering in hospital. Contractures are caused by structural changes in the soft tissue such as scarring or long periods of inactivity causing normally elastic or stretchy tissue to be replaced by stiff, fibrous inelastic tissue. Joints next to the amputation site tend to develop contractures if the remaining limb is not exercised or stretched out soon enough after the operation. Contractures most often occur as a result of the patient keeping the residual limb in a comfortable flexed position.

A physiotherapist or OT will carry out one or more of the following whilst your child is in hospital to help prevent contractures from developing:

- Exercises and stretches to keep the joints mobile
- splinting (applying a splint to hold the area in a stretched position)
- scar massage (once the area has healed)

How long will my child be in hospital?

Many children who are severely ill will spend considerable time in PICU whilst they become medically stable and will then be moved to a paediatric ward to have amputation and debridement operations and for associated healing and recovery time. Most children with amputations following meningococcal septicaemia return home from hospital within three months. In some of the more complex cases where children require multiple amputations the hospital stay may be longer.

What support is available when we return home?

Parents often feel overjoyed when the time comes to bring their child home from hospital, but also feel anxious because doctors and nurses will no longer be on hand to answer questions. Support will still be available when you return home.

Before your child is discharged home from hospital, staff should ensure the following¹:

- Adequate pain control has been established and you understand when and how the prescribed medication should be given
- Arrangements have been made for wound care
- Your child will be safe and as functionally independent as possible (this is age appropriate, so young children, who still require lots of input from their parents when it come to daily activities such as washing and dressing, may be discharged earlier than older children such as teenagers who will want and need a greater level of independence)
- You have been provided with a written exercise programme to prevent contractures
- You have been instructed and are comfortable with giving your child scar massage to help prevent contractures
- A housing assessment has taken place to ensure that your home is safe for your child and that arrangements have been made for adaptations if they are required
- If your child is to use prosthetic limbs, you should be referred for assessment and ongoing care at a disablement services centre (more information about prosthetic limb fitting is available from our 'prosthetic rehabilitation' factsheet)
- You have contact details for the ward should you need their advice

For the first year following your child's initial illness it is likely that much of the focus will be on skin and soft tissue healing, physiotherapy and OT to prevent contractures and to keep your child as mobile as possible.

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Your child's physiotherapist or OT will advise you on how to help your child continue the exercises and how often splints should be worn. It is important for your child to continue with these treatments at home because if contractures develop they can cause permanent joint stiffness, pain, problems with gait (walking pattern) when wearing prosthetic limbs and make walking very difficult and tiring.

At home it may be difficult to get your child to do the prescribed exercises because they can be uncomfortable. Talk to your specialist health visitor (if you have one), physiotherapist or OT about this. They will have plenty of useful suggestions about how to help your child engage with their individual stretching and exercising routine.



Figure 5: Sofia Crockatt, unilateral below knee amputee, practices her long jump skills at her weekly athletics club

More information about contractures and caring for scarred skin is available from our 'skin scarring after septicaemia' factsheet.

Will my child be given prosthetic (artificial) limbs?

Your child will be assessed to see if prosthetic limbs are suitable for them. Many amputees use prosthetic limbs to help with mobility and daily living. Whether prosthetics are appropriate and the type that your child may use in the future will depend on the amputation location, level and whether they have any other amputations or disabilities.

The fitting of prosthetic limbs takes place in a separate centre called a disablement services or limb fitting centre. The level and the type of the amputation plus the location of skin scarring can determine the most suitable type of prosthesis for your child, so it is beneficial to have the input from a prosthetist at an early stage.

Limb fitting won't begin until the scars on your child's residual limbs have healed sufficiently. If your child is very young, limb fitting for functional lower limbs may not take place until they start to try and pull themselves up although cosmetic limbs are usually provided as soon as the skin can tolerate them because this helps the child get used to wearing a prosthetic limb.

There are many advantages to be gained from using prosthetic limbs. They can allow amputees to walk, run and grasp objects and have the freedom of mobility without the use of

a wheelchair. However, 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 limbs confidently. Limbs will need to be replaced frequently as your child grows and your child will need to work hard at building strength and co-ordination skills which means that there will be many appointments to attend.

More information about prosthetic limb fitting and rehabilitation is provided in a separate factsheet called 'Amputee rehabilitation'.

Will we need any special equipment when we return home?

Wound management (dressings and pressure garments) - some children may still have unhealed wounds when they are discharged from hospital. A community nurse can carry out the dressing changes in your home or you may do this yourself. The dressing kit can be supplied when your child leaves hospital and prescriptions for any further dressings can be provided by your GP.

Children with extensive skin scarring may be prescribed pressure garments to help with skin healing. More information about caring for damaged skin following septicaemia is available in a separate factsheet called 'Skin scarring after septicaemia'.

Wheelchair/crutches - Some children with minor amputations and who are old enough may be discharged from hospital with crutches. Minor amputations refer to amputations involving the toes and part of the foot, but if the child cannot take weight through their leg (i.e there is no heel that can take weight safely) then crutches should not be used because it will only be a matter of time before the child falls or slips and could land on the end of the amputation stump which would be very painful and detrimental to the scar.

Under no circumstances should children be allowed to hop until they are used to being an amputee, it will lead to a fall as outlined above.

If your child has lower limb amputations and is of walking age it is likely that they will be assessed for a wheelchair by NHS wheelchair services. Children with below knee amputations will have a support board fitted to the chair to keep the leg elevated. This helps prevent contractures by keeping the knee straight rather than staying in the flexed position. The physiotherapist or OT will make sure that your child is able to get in and out of their wheelchair safely.

Most children will have a manual wheelchair when they are first discharged from hospital, but some children with upper and lower limb amputations may need a power wheelchair to help them move around independently. Children must learn how to control a power chair so they are usually supplied at a later date.

Home adaptations - in some circumstances it may be necessary for the family home to be adapted to make daily activities such as washing, dressing, toileting and eating manageable for your child. For example hand rails next to the toilet and bath can improve access and it may be necessary to install a ramp to allow wheelchair access to the home. Many adaptations may not take place until a child reaches age 3 or 4 because up until then it is considered that parents would carry their child and help them with daily care.

An OT should visit the family home and will make recommendations if adaptations are necessary¹. Some home adaptations may need to be accessed through a social worker. More information about how social workers may be able to help is available from our online factsheet 'Social work and community support'.

What follow up appointments will we need to attend?

You will need to attend regular follow up appointments with the various professionals who were involved in the treatment of your child whilst they were in hospital. For convenience, many hospitals will arrange multidisciplinary reviews for your child so that clinicians of differing specialities attend one appointment to review your child's progress. The initial appointments will mostly focus on how well your child is healing. The physiotherapist will assess the range of movement that your child can achieve around their joints. The plastic surgeon will assess how well your child's skin and soft tissue is healing. Further treatment will be considered if scars are restricting movement of the joints, or areas of skin are not healing very well.

Your child will have regular follow up appointments with an orthopaedic surgeon throughout their childhood. The orthopaedic surgeon will be monitoring your child for any signs of unusual bone growth which could cause problems in the future. Unusual bone growth can occur in the amputated limb or in the remaining limbs if blood supply to growing parts of the bones (growth plates) was interrupted during your child's initial illness. They will monitor:

- the rate of bone growth
- the angle of bone growth

Follow up appointments are an opportunity to discuss any concerns that you have with the professionals. If you have any concerns do not be afraid to discuss them and take the opportunity to ask any questions that you have.

A member of staff from the local disablement services or limb fitting centre may have visited your child in hospital to make an initial assessment on their suitability for rehabilitation with prosthetic limbs. More information about prosthetic limb fitting and rehabilitation is provided in a separate factsheet called 'Prosthetic rehabilitation'.

Children who have had toes or a partial foot amputation may need to attend follow up appointments with an orthotist who can provide specially adapted footwear.

Children who have had fingers or partial hands amputated may continue to have follow up appointments with a hand therapist. This is a specialist OT who uses exercises, splinting or massage to maximise the function of the remaining hand.

When will my child be able to return to school?

It is important for children to return to school as soon as they are well enough and if it is safe for them to do so. If your child needs a wheelchair, the school will need to be wheelchair accessible. If necessary the local OT, school nurse or specialist health visitor will help the school to prepare for your child's return and can also speak to teachers to help them understand what your child's needs are likely to be and anticipate any problems they are likely to face when they return.

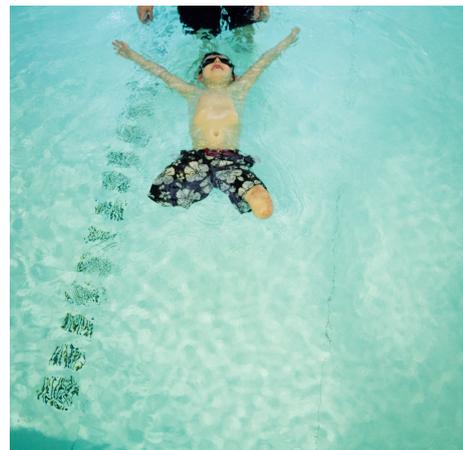


Figure 6: Bilateral amputee Robbie Jones enjoying a swim. Robbie lost his legs to meningococcal septicaemia at 21 months of age.

In some circumstances the school will provide a learning support assistant to help your child. They can help with tasks such as; daily physiotherapy, getting from class to class if this is required and taking notes if your child is no longer able to grip a pen.

It is likely that your child will need to attend many outpatient appointments at the hospital while they recover. It can be helpful to discuss upcoming appointments with their teachers to try and make sure that important events in the school calendar aren't missed.

Adjusting to a changed appearance and physical ability

It can be difficult for older children with amputations to adjust to their life with limb loss. They may become very frustrated by their physical limitations and they can also be self-conscious about looking different. Young children on the other hand often seem to cope quite well and you may find that you feel more distressed about their injuries than your child seems to.

The charity Changing Faces can help both children and parents come to terms with an altered appearance.

It is a challenge to handle other people's reactions effectively, but if you learn to do this then you can help your child to manage if they encounter any staring or questions about their appearance as they grow up and become more self-aware.

Many people find themselves wondering what sort of future their child will face with amputations. It may be encouraging to know that a research study, which followed up children with limb amputations as a result of meningococcal disease showed that most go on to live full and valuable lives. The study found that children are able to use effective strategies to overcome their physical impairments and report a good quality of life years after their illness².

Further sources of information and support

Changing Faces

Changing Faces is a UK charity for people and families who are living with conditions, marks or scars that affect their appearance. They give practical and emotional support to adults, children and their families.

Website: www.changingfaces.org.uk

Email: support@changingfaces.org.uk

Freephone Helpline: 0300 012 0275

Steps

STEPS is the leading voice of lower limb conditions. Everything they do is about valuing and supporting individuals, families and carers affected by clubfoot, hip dysplasia or any other lower limb condition.

Website: <http://www.steps-charity.org.uk/>

Email: info@steps.org.uk

Tel: 01925 750271

Reach

Reach is an association for children with upper limb deficiency. Reach provides the means by which parents and professionals can bring together experiences, information, support and guidance.

Website: <http://www.reach.org.uk>

Email: reach@reach.org.uk

Tel: 0845 1306 225

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