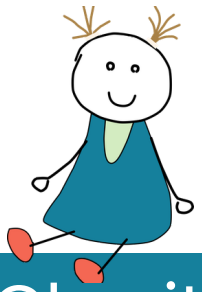
steps

We don't take walking for granted

Planned Amputation, a Parent's Guide



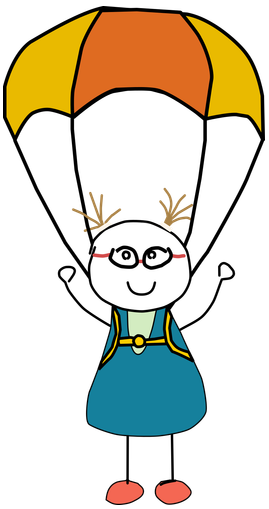
Helpful Information from Steps Charity

Contents

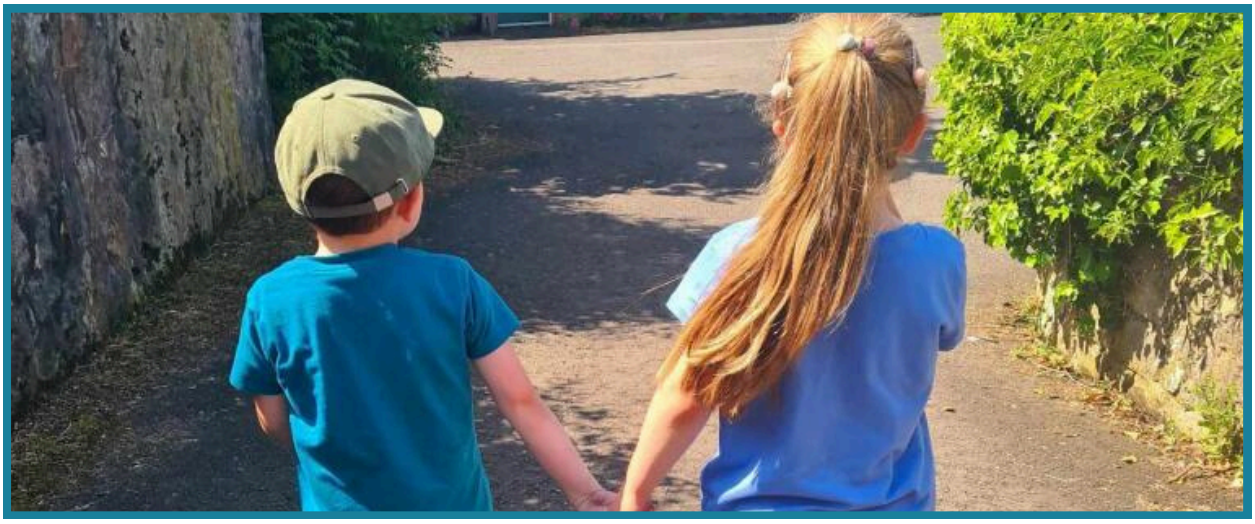
How This Booklet Might Help

At Steps, we understand how a lower limb condition can affect individuals, families, and communities. We are committed to helping people understand these conditions, offering reassurance, and working towards a better future through our partnerships with national health services and research projects.

This booklet is for all parents whose children may require an amputation. It explains why an amputation may be recommended for your child and what amputation and aftercare look like. It cannot tell you everything you need to know about what the future may hold, but we hope it will reassure you. We aim to show that practical help, specialist medical information, emotional support, and signposting to other sources of information are available if needed.



Having this information may help you feel more prepared for the road ahead and better able to ask informed questions about your child's care, treatment, and prognosis.



Help When You Need It

Sometimes being able to contact someone who knows what you are going through can provide much needed encouragement.

Our Family Contact Service can put you in touch with others who have shared a similar experience and can offer advice, support, and practical tips. You can also share your problems and solutions to everyday challenges on our closed Facebook Group for parents.The group is a friendly and safe way of discussing your worries online with other parents, sharing tips, and finding emotional support.

Remember, the Steps team are here to offer information and support in total confidence, and to answer any questions or concerns you may have. This will help you to ask informed questions at hospital appointments or may help to reassure you along the way.

No matter how big or small your concern, please telephone Steps on +44 (0) 1925 750271 or email info@steps-charity.org.uk for support and advice in total confidence.

Social media details and information about how to get in touch with the Steps Family Contact Service can be found on page 26 at the back of this booklet.

About Amputation

What is amputation?

Amputation involves the removal of part or all of one or more limbs of the body and is usually performed to allow better function, or to remove damaged tissues.

When might amputation be considered?

There are a number of conditions or reasons that amputation might be considered as an option for a child. Steps has produced resources explaining specific conditions affecting the lower limbs, their causes and treatment.

When considering treatment options for your child it is important to remember there is not a 'right' or 'wrong' decision. It is based on the beliefs and aspirations of each family and your child's unique circumstances.

A planned amputation allows time to discuss and prepare before the surgery occurs, and consider the long term management and impact. This booklet explains the process for a planned amputation and how you and your child can prepare for this.

Before proceeding you have to feel comfortable that you have spent enough time discussing the issue with health professionals and that you have received all the information and advice you need to make this decision. Sometimes this may take more than one appointment.

In some cases, such as sudden onset of infection, or traumatic injury, a more urgent operation is needed. This is an emergency amputation and may leave less time for you and your child to prepare.

Before Surgery Date

Assessment before surgery

Your child may have a full assessment before they are admitted for amputation surgery, although practices can differ regionally and by circumstance. If needed, the heart, digestive system and breathing function may be checked.

Other assessments that may be conducted before your child has surgery could include:

- Psychological assessment – A child psychologist should be allocated to your case to discuss your child's worries about the procedure and life afterwards and help decide what further support may be needed.

- An assessment of home and school to see what additional support may be needed in these settings.

Again, it is important to allow for variances to provisions depending on treatment centre or region.

Your child may meet their prosthetist, to discuss the type of prosthetic they want, taking into consideration ambitions that they hold in terms of interests and activities. These discussions will form part of their ongoing treatment and may be supported by contributions from a physiotherapist, psychologist, and consultant.

Your hospital may be able to find a child of a similar age with a similar amputation who would be a willing 'buddy' to answer questions that your child wants answered, but feels reluctant to ask a health professional.

Steps operate a Family Contact Service that may be able to put you in touch with others who have been in a similar position, for details see information at the end of this booklet.

Emotional preparation

Some hospitals may offer counselling with a clinical psychologist.

They can advise you on how to manage the emotional reactions of your child. If this service is not available at your hospital you can ask your GP for a referral. You can also seek further information and support from Steps using the resources detailed at the end of this publication.

Talking to consultants

It's important to understand as much as possible about your child's surgery and rehabilitation.

Preparing a list of questions that you want to discuss at your hospital appointments will make it more likely that you get the answers you need. Don't be afraid to ask questions! You may be given a lot of information, so do ask if a handout is available: alternatively, buy a notebook and take notes. Remember to ask about things you don't understand. If you don't ask any questions, your doctor may assume you understand everything.

If possible, bring a family member or a friend with you, for reassurance, and to help you understand and remember the information that you have been given.

Discussing amputation for your child can be a very emotional time. Parents report feelings of guilt, anxiety, and sadness at different times during this journey. All these feelings are normal. Don't be afraid to seek help and support.

Types of amputation

Lower limb (leg and foot) amputations can involve the removal of one or more toes, part of the foot or leg or, in rare cases, the complete removal of the limb. There are many different names for the different types of amputations, including:

• **Partial foot amputation –** Removal of any number of toes or other bones in the foot. This may slightly affect balance. (Depending on which part of the foot is removed there are different names for these amputation including: toe/digital, ray, transmetatarsal, Lisfranc, Chopart, Boyd).

• **Complete foot amputation –** Removal of the foot through the ankle joint (can also be known as a Syme's amputation or, if the heel bone is fused into place, a Pirogoff amputation).

• **Below the knee or transtibial amputation –** Amputation through the shin bone; leaves a stable below the knee stump. Sometimes referred to as BKA.

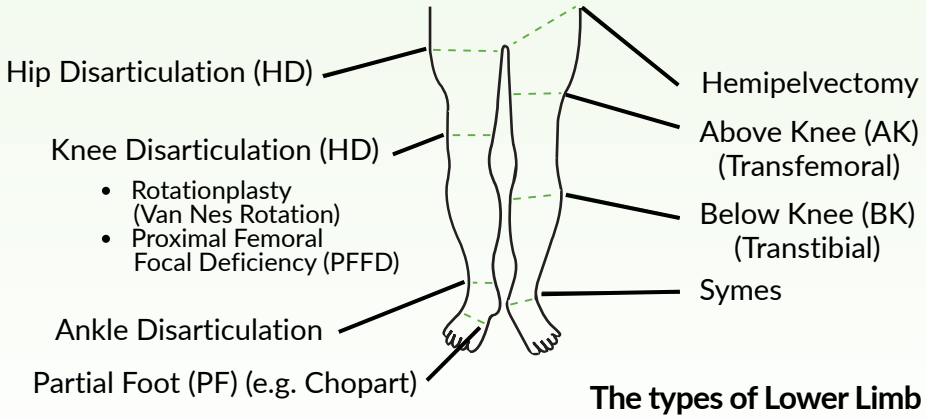
• **Through the knee amputation –** Amputation through the joint, so no bone is cut. Sometimes referred to as TKA.

• **Van Nes rotationplasty –** The knee joint is fused/removed and the ankle brought up to the level of the opposite knee, turned around 180 degrees and functions as a knee joint.

• **Above the knee or transfemoral amputation –** Amputation through the thigh bone. Sometimes referred to as AKA.

• **Hip disarticulation -** Amputation through the joint, without cutting the bone.

• **Hemipelvectomy or transpelvic amputation –** Very rarely performed high-level amputation through the pelvis, that is not usually associated with congenital conditions.



The types of Lower Limb amputation. With thanks to LimbPower

What are the risks of surgery?

Your surgical team will have a great deal of experience performing similar operations and the chances of anything going wrong are very low. All surgery and anaesthesia carry some risk, such as bleeding or infection, but your medical team are trained to deal with complications swiftly and competently.

Complications following an amputation could include pain in the area above the amputation (the technical term for this is residual limb but some people prefer stump or little leg). There may also be pain in the missing part of the limb (phantom limb pain), slow healing and, very rarely, deep vein thrombosis, a condition related to blood clotting in the vein. Very occasionally, additional surgery might be needed to remove thickened nerve tissue that may develop in the residual limb and which can cause pain.

Your team will be able to offer information of risks relevant to your child's condition.

Attending Surgery

Admission for surgery

Usually, your child will be admitted into hospital on the same day that surgery is scheduled to occur. To be 'admitted' to the hospital just means that a bed is assigned to you and often involves lots of forms being completed. As a parent or caregiver, you will be asked to complete a consent form.

Your child going into surgery can be a challenging moment for parents. Everyone reacts and manages their emotions differently, but many people find it helpful to be as prepared as possible for the hospital visits.

Steps have produced a parents' guide, *'Preparing for your child's surgery'*, which explores what to expect and how to prepare for your hospital visit. You may also benefit from talking to other families who have had similar experiences through the Steps Family Contact Service, before your hospital visit.

Returning to the ward

After your child has their amputation, the wound will be closed with stitches and bandaged. There may be a drain to remove excess fluid from the wound. The bandage will stay in place for a few days as the wound starts to heal, to prevent infection. A plaster cast may be applied.

When your child returns to the ward, they will usually be given oxygen and fluids from a drip as they begin to recover. The drip is used to deliver medicines, such as painkillers, and stops your child from becoming dehydrated

Most children recover very quickly. They will only be allowed to sip small amounts of water to begin with, but as soon as they are fully awake, they will be able to eat normally. Your child may also have a catheter fitted so you won't need to worry about toileting for the first few days.

The residual limb will be painful initially and your child will be given pain relief to help with this. Good pain management will be a priority following your child's surgery. It is important you tell the hospital staff if you feel the pain relief is not working, as they may be able to give a bigger dose. A small tube can sometimes be used to deliver pain relief directly to the nerves in the residual limb.

You may notice some swelling around the residual limb. This is known as oedema and is normal. Once the wound has healed, a plaster cast or a compression garment (pad or sock) may be applied to help reduce swelling and may help reduce 'phantom pain.' In the case of a compression garment being used, you will be given a spare to take home, as these must be washed regularly.

Toileting and washing

Getting to the toilet can be tricky if your child is out of nappies. At first, your child may need a bed pan, or in-bed urinals but by the time they are ready to return home, they should, with the help of a wheelchair, be able to get to the toilet either with you or by themselves.

You should avoid getting dressings and bandages wet so, in the first few days following surgery, it's best to clean your child with a damp sponge. Once all dressings are removed and the wound has healed enough, your child will be able to bathe/shower as normal, although they may need a little extra assistance as they adjust to getting about in a new way.

An occupational therapist can support with advice and devices such as bath seats or shower stools to aid this.

Early physiotherapy

Physiotherapy and physical rehabilitation are essential parts of having an amputation. A physiotherapist may visit you and your child to start with some gentle exercises and some hospitals may encourage physiotherapy before the operation, but it's important to allow for variations in practice.

The rehabilitation process will usually start within a few days of surgery (whilst still in hospital), beginning with simple exercises that can be performed lying or sitting down. Your child will learn how to transfer from a bed or seat to a wheelchair and be encouraged to start to move around using the wheelchair at first, to get them used to getting about.

It is very tempting for children to hop to mobilise around the home, but there is a high risk of falls and further injury to the residual limb, as well as possible impact on the healing process. The physiotherapist will teach your child the best and safest way to mobilise around the home.

Going home

The timing of discharge from hospital will ultimately depend on the type of amputation, how well your child has recovered from surgery, and whether there were any complications.

You may have discussions with the physiotherapist or occupational therapist, to help assess your child's home and school environment, although it is more likely that these preparations will be made in advance. It is likely that your child will be provided with a wheelchair to use at home in the first few weeks, to give them time to gradually get used to getting around.

Your child may require visits from the community physiotherapist and a community nurse. You may be passed details for local support groups, possibly including health professionals and local children who have had an amputation. Steps can also help you connect with the community.

On discharge the clinical team will usually provide you with a number to call if you have any questions or concerns, if they don't, don't be afraid to ask.

Aftercare and Life After Surgery

Clinic appointments

Your child will have regular clinic appointments at a rehabilitation centre.

During these visits, he or she will see the doctor, prosthetist and physiotherapist for a check-up, and be given some exercises to learn and repeat at home. Some clinics may offer a hydrotherapy session. Remember, clinic sessions provide opportunities to discuss questions, worries and problems.

Seeing the prosthetist

Following amputation, your child will have an appointment with a prosthetist for the first fitting of their new leg.

The timing of this appointment will depend on your treating hospital and your child's physical ability to wear a prosthesis. The type of prostheses prescribed will depend on the level and type of amputation, and your child's individual clinical needs and circumstances.

Factors which will influence the type of limb your child will have include:

- The type of amputation
- The level of amputation (how much of the limb has been removed)
- The strength of the remaining muscle and the condition of the rest of the leg
- What your child hopes to do with their new leg
- Whether they want the limb to look realistic, are more concerned with function, or would like a specific design
- What products are available to suit your child's clinical needs

It will take time for your child to adjust to using a prosthetic limb and to adjust to finding their own way of moving, walking, and running. They will also have to adapt to the loss of muscle and bone in the amputated leg and get used to their residual limb.

During the initial appointment, your child will be measured and a cast will be made of their residual limb. The cast models the exact shape of your child's residual limb so that a comfortable, well-fitting prosthesis can be made. The first appointment will be quite long, so take some snacks and something to do while the cast is drying.

You will be asked to return for a fitting once the socket has been made. The prosthetist will help your child put the limb on, and ask them to try and walk between hand rails. During this session, the prosthetist will ask your child questions about how comfortable the leg feels and will mark with a pen any areas which are not comfortable and need improvement.

Some adjustments may be made during the treatment session (with the prosthetist taking the limb into the workshop while you wait). Other adjustments will need to be made between sessions, and you will be asked to come back. Often several appointments are required to get a comfortable fit. Your child may find the initial experience a bit tiring, so, if possible, two adult carers attending can provide that extra bit of support needed.

Your child will attend several appointments with the prosthetist to make sure the prosthetic limb fits well and continues to meet their needs. As your child grows, the prosthesis will need to be replaced, which involves making a new cast and carrying out further adjustments.

Your child's medical team will work together and help your child prepare for their prosthetic fitting. They will be taught how to 'desensitise' their residual limb, with a series of massages and actions that will help reduce pain, swelling and fluid build-up.

It is important to consider and discuss with your centre what is available on their prescription list. Not all privately available options are available on the NHS.

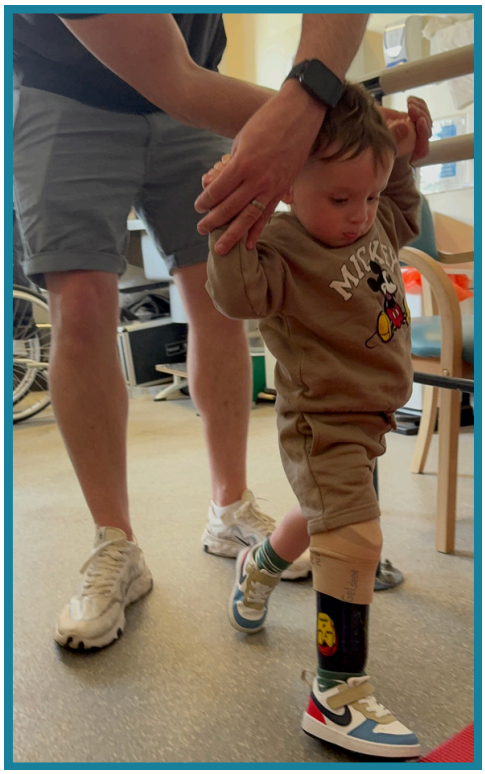
With modern limbs, it is possible to have both a physically realistic, skin tone appropriate prosthesis and one that is highly functional or specialised. Customised legs are available and, in time, your child may be able to use alternative prosthetic limbs such as blades.

The prosthetic service provision in the UK states that "*Children and young people up to the age of 18 years can be prescribed an activity or sports limb if clinically appropriate*". Activity limbs, such as running blades, allow your child to play alongside their friends and move between walking and running easily. Limbs for dignity, such as waterproof 'wet legs' allow your child to shower standing up, supporting their independence. Waterproof limbs also allow them access to water activities, such as getting into and moving around a pool. These options should be discussed with your clinicians when they become relevant.

Prosthetic Physiotherapy

The limb centre physiotherapist will teach you and your child how to perform any exercises that are required to rebuild and maintain muscle strength and flexibility, so your child will be well prepared for the additional physical exertions of using a prosthetic limb.

The limb centre physiotherapist will work with your child and the prosthetist to teach them how to adjust to walking on their prosthesis and help ensure the limb fits and works correctly.



The time it takes to get fully mobile will depend on how your child reacts to the process, the fitting of the prosthesis and compliance with any prescribed exercises. A rehabilitation programme will be tailored to your child's individual needs and may consist of a series of exercises in the gym, massage, residual limb care and sometimes, hydrotherapy. The objective of any programme of rehabilitation is to ensure that your child maintains mobility and strength in both the residual limb and the sound leg.

The physiotherapist will discuss your child's needs and goals at length, and set realistic, achievable targets to work towards at home and during sessions.
It is very important that your child completes the physiotherapy exercises they have been given.

Residual limb care

Residual limb/stump care is a vital part of life following an amputation; while the skin on the base of your foot is designed to take the pressure of weight bearing, the skin of the residual limb is not, and so will need to adjust to being inside a prosthesis socket. The skin and muscles will be subjected to the pressure of body weight from above and the rotational and up and down movements of day-to-day activities. A comfortable, well-fitting socket is the most important consideration for any amputee. Your child will usually have a barrier between the skin and socket, such as a silicone pad or sock to protect the residual limb, although some people find direct (on skin) sockets offer a better fit.

It is important to keep the residual limb clean and dry; wash it with a mild, unperfumed soap and pat dry before fitting a prosthesis. If your child gets very sweaty, the first step is to wash their residual limb more regularly, then talk to your prosthetist. They can offer solutions such as; using Hibiscrub Liquid (an antiseptic) once a week. An emollient cream, such as E45, may be soothing if applied at night, when the prosthesis is not being worn. It is best to consult your clinicians before trying anything new as even talcum powder can cause friction which can damage the residual limb and antiperspirants may clog pores.

It is also important to regularly change anything in contact with the residual limb, such as silicone pads or socks. A periodical wash of these items with an antiseptic is also a good idea, so long as they are well rinsed and allowed to dry thoroughly, and no chemical residue comes into contact with the skin while it is inside the prosthesis.

Encourage your child to be proactive in their residual limb care, check for signs of irritation or infection every day, and contact your doctor if you are worried.

Signs of irritation may include:

- Swelling
- Warm, red or tender skin
- Leaking of pus or fluid
- Your child telling you that they are experiencing discomfort or subtle changes in their behaviour (an uncomfortable child will not always tell you but may show it indirectly with unusual behaviour, either being quieter than usual or being unusually difficult)

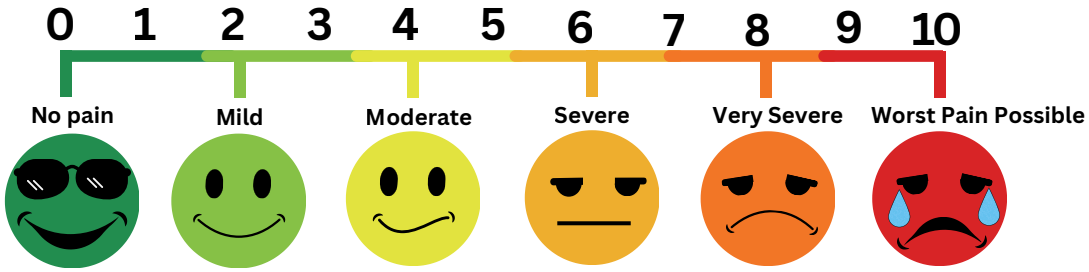
Phantom sensation

Phantom sensation is the feeling of sensation that is not painful, in the part of the limb which has been amputated, and may include sensations such as “being able to wiggle the missing toes”. While this can be distressing for a child or an adult this is not considered an area of concern and you can reassure your child that this is perfectly normal.

Phantom limb pain

Phantom pain is the feeling of pain in the part of the limb which has been amputated.

The symptoms of phantom limb pain can vary from child to child, but can be anything from a ‘feeling’ or sensation of something touching the limb that is no longer present, to a crushing, shooting or burning pain, it may occasionally feel like a cramping or contraction. Some amputees may never experience this phenomenon, and although many do, the symptoms usually ease and become less common after the first year. With young children, who are generally less able to describe pain levels, a feeling and pain chart can be useful.



The causes of phantom limb pain are complex and poorly understood. It is thought that the severed nerve endings may continue to send messages to the brain. The resulting brain stimulation is translated into pain from the missing amputated limb.

Residual limb pain is the feeling of pain in the part of the limb that remains and is above the site of amputation.

Residual limb pain

Many cases of residual limb pain can be linked to physical environmental factors, such as; poorly fitted sockets, residual limb irritation and changes in temperature and humidity. Things like emotional stress, tiredness and strains on other parts of the body, such as back pain, can also cause residual limb pain. Most cases of this are resolved within a year of an amputation, but it is always advisable to talk to your clinicians if your child is experiencing pain.

Nerve damage can also cause residual limb pain, and is often experienced as a "shooting" pain or a feeling like "electricity" passing through the limb. As the nerves heal, nodules, called neuromas, may form on the cut end of the nerve, become irritated and continue to send signals along the spinal cord to the brain. In such cases medication or other treatments may be required to manage the pain.

Treating phantom pain and residual limb pain

In both cases, symptoms will usually ease over time, but there are treatments available to help manage any pain. These will vary from child to child and will depend on the nature of the symptoms. These treatments generally fall into two categories; medications and self-help/complementary techniques. Involving a pain specialist in your child's care will usually be necessary.

Medication

Pain relief medications are given for different types of pain and have various actions which will depend on the age of your child. Medications recommended may include:

- Anti-inflammatory drugs (not steroids), such as ibuprofen
- Steroid injections or local anaesthetics
- Opioids – like codeine or morphine
- Anticonvulsants, to prevent muscle spasms
- Antidepressant 'type' medication such as amitriptyline, which has general effects on the nervous system

Pain management

This is a clinical discipline that focuses specifically on managing pain. The clinical team may prescribe medication as well as "self-management techniques".

Your clinician may recommend massage, desensitisation techniques using different textures on the residual limb, or specific physiotherapy exercises.

Popular interventions for phantom limb pain include Graded Motor Imagery (GMI) and mirror therapy aimed at "retraining" the brain. These techniques can use methods such as phantom sensation (imagining moving missing limb), left/right discrimination (learning to quickly and easily identify images of left and right limb images), and the use of a mirror placed so that when moving the intact limb, it appears that the missing limb is moving. Some people can find this very emotional as they feel they are seeing their amputated limb.

The effectiveness of phantom limb pain management is different for everyone and you should talk to your clinic about what is best for your child.

Additional surgery

In some cases, thickened nerve tissue (neuromas) may develop in the residual limb, or bone can continue to grow (bone spurs). Where these cause pain, surgery may be needed to remove them.

Caring for the remaining leg

It is important to take care of the remaining leg and foot. A well fitted prosthesis on the affected side will normally lead to balanced posture and walking, and the sound limb may even be better protected from undue stress and strain, post amputation. Nevertheless ensure clinicians assess the intact side regularly and report any changes to the skin or sensations in the leg.

Watch out for changes in walking patterns, or your child walking on the side of their foot (rather than the sole).

Choosing the right footwear is essential and an orthotist or podiatrist will be able to give advice on this. They can also give advice on general foot care.

Returning to school

It's important that your child feels well supported when returning to school. Depending on their age, one of their biggest concerns will be how they'll cope at school, particularly, how their classmates will react. Talk to your child's school or nursery teacher and SENDCO (or equivalent). You can do this in advance of their return to school and bring in some books and adapted toys, so they can talk openly with your child and their peers.

It is best for your child to return to school as soon as possible. If the staff at their school have any questions or worries, they should be put in contact with your clinicians for advice. Talk with teachers about your child's return to school and plan well in advance. Your child could use a scrapbook or some pictures to help explain their condition to their peers.

Did you know?

In each of the four nations of the UK there are different names for the person responsible for coordinating additional support needs for children in a school:

- In England and Northern Ireland every school will have a designated Special Educational Needs and Disability Coordinator (SENDCO/SENCO)
- In Scotland the equivalent is an Additional Support Needs (ASN) teacher
- In Wales this role is called the Additional Learning Needs Coordinator (ALNCo).

It is advisable to explain your child's condition to the head teacher and school SENDCO before the child starts school so that any anxieties and potential problems can be identified beforehand. You will need to provide enough information to help the school perform a risk assessment and you may need a letter from the hospital describing your child's adapted needs. This is best arranged before you are discharged. It is also good to have a letter from your consultant pointing out that your child may need additional days off school for hospital appointments, leg fittings and physiotherapy.

Schools are required to regularly update and publish information on their provision for pupils with disabilities and strategies to improve accessibility. Most schools are sympathetic and will make the necessary accommodations.

If you are not satisfied with the provision for your child there are other sources of help and advice such as your local parent partnership service. They can provide, 'accurate and neutral information on the full range of options available to parents.' Be proactive in sourcing the support that you and your child need, and don't be concerned about talking to your child's school. A problem identified early enough can be easier to resolve.

Clothing

It can sometimes be difficult to find clothes, particularly shoes, that fit comfortably and effectively with a prosthesis, especially if the foot on the artificial limb differs in size from your child's remaining foot. If you find that the size of your child's prosthetic foot does not match their remaining foot, ask for one in the right size, as they may not have noticed the difference when fitting! Don't be surprised if the shoe on the prosthetic foot becomes misshapen or the sole wears out faster than on the intact foot.

Modern prostheses are usually slim but sometimes fitting clothes over them can be challenging. Here are a few suggestions to overcome known issues:

- Thicker material in leggings and trousers help resist prosthesis related wear and tear for longer (and is easier to stitch up when the prosthesis does, inevitably, snag).
- Using Velcro on the sides of trousers to aid dressing and adding it to secure sandals and flip-flops to a prosthetic foot can help to stop slippage. If you are using Velcro on the sole of a prosthetic foot, remember to stick the 'hook' side to the foot, as the smoother 'eye' side will slide on hard surfaces when barefoot.
- Tailoring one leg so that it is short over the prosthetic and doesn't cover the knee.
- It is possible to buy 'iron on' patches to reinforce the inside of trouser fabric; this will help prevent the socket rubbing through the material.
- Wearing jeans can be a challenge and finding a pair that will easily slip over a prosthesis can be a case of trial and error. It may help to buy a bigger size, or, in the case of girls, buying a boy's pair and adjusting accordingly.
- Wide-legged 'bootleg' jeans are generally easier to get on, but if your child insists on 'skinny' jeans, then sewing inserts into the seams (when done well) can achieve good results.

- Shoes with laces, such as trainers, are more practical than a lot of slip-on shoes.
- Boots, especially wellies, can be particularly tricky to get over a prosthetic foot. There is no easy answer to the 'wellies conundrum,' aside from cutting the boot on the affected side and slipping the prosthetic foot into a waterproof covering before putting the welly on.
- You can also get zips to add to the side of boots. Waterproof snow or ski boots, which tend to have a gap in the side and a covered zip, for easy fitting, can be practical.

Sport and physical exercise

A child with an amputation can participate in nearly every sport and activity, although, in some cases, slight modifications may be needed. Talk to your child about what interests them and be encouraging. Sports, especially team sports, are fantastic for developing a sense of belonging, improving strength and encouraging positive feelings around body image and confidence. Once your child gets used to getting around, they may feel like trying something new. If, however, they are adamant that they are not interested, do not push them. Let your child decide for themselves what activities and interests they want to develop; an interest in art or music can be just as effective for promoting feelings of confidence and self worth.

Walking, cycling and swimming are all brilliant exercises that require little or no modification. If your child is able to run, specialised 'blades' are available on the NHS. Note that some activities are more tricky for above the knee amputees. Your child will need to learn how to run on their ordinary prosthetic before they will be trained to use a blade.

One family said,
"After amputation they can still do everything they want and be anything they want."

Most amputees don't use a prosthesis while swimming, but it is possible to get a water activity limb (or 'wet leg') for wearing around the pool or for water activities like paddle boarding or canoeing (although you may also choose not to wear a limb for these sports). There are also numerous adaptive sports, such as sitting volleyball, football and wheelchair basketball, suitable for above-knee amputees and wheelchair users.

Your child will not necessarily need a specialised prosthesis; in some sports, they aren't needed at all and your child's standard prosthetic leg will work just as well.

If you would like to know more about what physical activities are available for your child, or about performing, visual and other arts in rehabilitation, please visit the LimbPower website.

Impact on the family

How you respond as a family will depend on many different factors, but don't be afraid to seek help or support.

There are a number of organisations that have been set up for this purpose. Make use of them. For more information, please see the back of this booklet.

Useful books and other media which show amputation

Books

Help! My Child's in Hospital – Becky Wauchope

Paddington Bear goes to the Hospital – Michael Bond

Going to the Hospital: Miniature Edition – Anne Civardi

Just let me put my legs on - Kenzie Le Turley

Goose's Story - Carrie Best

Molly the Pony - Pam Kaster

Other Media

Your Child's General Anaesthetic - Magic Milk and Squidgy Masks (YouTube film)

How to Train Your Dragon (films and series)

National Association of Health Play Specialists (Website with information about the role of play in medical settings)

Who are Steps and How Can They Help?

Steps is the national charity working for all those whose lives are affected by childhood lower limb conditions. Everything we do is about valuing and supporting individuals, families and carers affected by conditions which have an impact on the legs, hips or feet.

Contact Steps (confidential)

Call 01925 750271 with any questions you have or email info@steps-charity.org.uk

Facebook discussion groups (private)

There are two pages for members to join:
Steps Charity - Support Group for Parents
Steps Charity - Support Group for Adults

Family contact support service (confidential)

Connecting parents (or adult caregivers) with other families who have been through something similar. Enquire via our contact number 01925 750271 or email info@steps-charity.org.uk. All our Family Contacts are interviewed and given training before they engage with a family, providing a forum for sharing ideas and consulting other parents on day-to-day questions.

Social media

Steps is active on X (@Steps_Charity), Instagram (@StepsCharity) and on YouTube (StepsCharity)

Please note, external websites are not associated with Steps and Steps are not responsible for their content.

info@steps-charity.org.uk
+44 (0) 1925 750 271
www.steps-charity.org.uk
StepsCharity
@Steps_Charity
@StepsCharity
Steps Charity Groups:
Steps Charity - Support Group for Parents
Steps Charity - Support Group for Adults

Contributors

This Parent's Guide was last reviewed in April 2026.

With special thanks to contributors and reviewers:

Especially Miranda Asher, (Prosthetic Chartered Physiotherapist, Phd, BACPAR chair), The Steps team, Walk:Enabled, The Jones Family.

All other families who contributed input, photographs, and feedback.

Disclaimer

steps
We don't take walking for granted

fieldfisher