Steps
We don't take walking for granted

Planned Amputation

The Parents' Guide

Contents

About Steps

Every year in the UK, approximately 2500 babies are born with a serious childhood lower limb condition. Without the correct diagnosis, treatment and support, these children might never walk properly let alone achieve their full potential. That's where Steps come in!

At Steps, we understand how a lower limb condition can affect individuals, families, and communities. So we are committed to helping people understand these conditions, reassuring those affected that the future can be better than the present, and, actively working towards a better future for all those affected.

What Steps do:

From the moment of diagnosis onwards, we are there to help you, by providing the best information that we can, emotional support, and practical advice for the day to day stuff, so that you will feel more confident about the challenges ahead, and your ability to meet them. We do this through our dedicated Helpline, Family Contact Service, trusted publications, and equipment grant schemes.

Nearly all of this is achieved from public donations. We do not charge for our information, but we do hope that if you find our services or publications useful, you will consider supporting us in our work.

Introduction

This booklet is aimed at parents and expectant parents of a child with a lower limb condition or serious illness who may need a planned amputation. Further publications and factsheets are available from Steps and from our website at steps-charity.org.uk, offering support and advice on preparing a child for hospital and attending school.

In addition, we have condition related factsheets that detail specific treatments and associated challenges, providing information to assist care-givers.

We hope that these combined resources will help you to feel better prepared for your child's consultations, treatment and care, and remember, our support services are available to you should you need them.

For more information about Steps support services, please email info@steps-charity.org.uk.

Long-term management of legs of different lengths

When a childhood condition affecting the legs leads to a big leg length difference, operations may be used to help 'equalise' the legs. However, in rare cases, an amputation of the foot and part of the leg may be required because the structure of the shorter leg means that it would be difficult for the child to walk without this intervention. It allows a well-fitting artificial leg, also called a 'prosthesis' to be fitted so that the child can walk despite their condition.

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.

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.

Amputation due to illness

If your child's amputation is related to a sudden, serious childhood illness, infection or injury, you will have less time to prepare for admission and in some cases, the time between the initial diagnosis or event may not leave you or your child any time to prepare.

The timing of your child's amputation will depend on their situation but it is possible that an amputation relating to complications from trauma, burns, or, ongoing treatment for a bone tumour, may allow some time to prepare.

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. Alternatively, you can seek information and support from the resources detailed at the end of this publication or by emailing Steps, info@steps-charity.org.uk.

Assessment before surgery

Your child may have a full assessment before they are admitted for amputation surgery, although practices can differ regionally and through circumstance.

If needed, the heart, digestive system and breathing function may be checked.

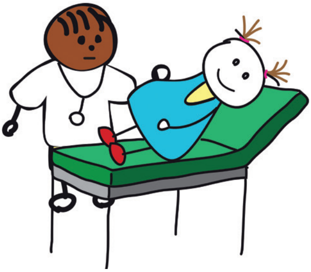
Other things that may be looked at include;

- Psychological assessment – A child psychologist will discuss your child's worries about the procedure and life afterwards and will 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.

Your child will 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 more information, please email info@steps-charity.org.uk, or call the Helpline on 01925 750271.

Admission to hospital

Talking to consultants

It's essential 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. And remember to ask about things you don't understand. If you don't ask any questions, your doctor will assume you understand everything. If possible, bring a family member or a friend with you, as their presence may reassure you, and help you to understand the information that you have been given.

What are the risks of surgery?

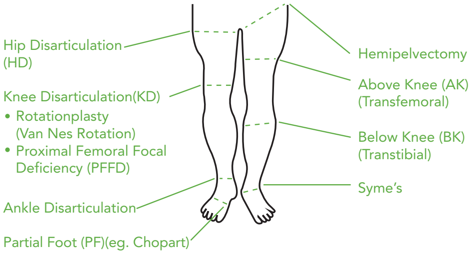
Your surgical team will have a great deal of experience performing similar operations and the chances of anything going wrong are very low. All surgery and anaesthesia carry some risk, such as bleeding or infection, but your medical team are trained to deal with complications swiftly and competently.

Complications following an amputation could include stump pain and 'phantom limb' pain, slow healing and very rarely deep vein thrombosis. Very occasionally, additional surgery may be needed to remove thickened nerve tissue that may develop in the stump and cause pain.

Types of amputation and reconstruction

Lower limb (leg and foot) amputations can involve the removal of one or more toes, to the complete removal of the limb, although this is rare.

- Partial foot amputation – Removal of toes, which may slightly affect balance.
- Complete foot amputation – Removal of the foot through the ankle joint (can also be known as a Syme's amputation).
- Below the knee or transtibial amputation (BKA) – Amputation through the shin bone; leaves a stable below the knee stump.
- Through the knee amputation – Amputation through the joint, so no bone is cut;
- Van Ness 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 /transfemoral amputation.
- Hip disarticulation - Amputation through the joint, without cutting the bone.
- Hemipelvectomy/ 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 http://limbpower.com/

After the 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

Returning to the Ward

When your child returns to the ward, they will usually be given oxygen and fluids from a drip as they begin to recover.

This is used to deliver medicines, such as painkillers, and stops your child from becoming dehydrated. Your child may have a tube coming out from the wound. This is the drain which stops fluid from collecting at the site of the wound and helps healing.

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 stump 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. Note. A small tube can sometimes be used to deliver pain relief directly to the nerves in the stump.

A physiotherapist may visit you and your child and suggest some exercises, but again, it's important to allow for variations to practice.

You may notice some swelling around the stump. This is known as oedema and is normal. Once the wound has healed, a plaster cast or a compression garment (pad) 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 loo can be tricky. At first, your child may need a bed pan, but by the time they are ready to return home, they should, with the help of crutches, be able to get to the loo 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 bath/shower as normal, although they may need a little extra assistance as they adjust to getting about in a new way.

Physiotherapy

Physiotherapy and physical rehabilitation are essential parts of having an amputation.

This 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 be encouraged to start to move around using a wheelchair at first, to get them used to getting about. They will learn how to transfer from a bed or seat to the wheelchair. Following this, they will be introduced to a prosthetic leg by a prosthetist, and they will be taught how to adjust to walking on the prosthesis by the limb centre physiotherapist.

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, stump 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 aspirations at length, and set realistic, achievable targets to work towards at home and during sessions.

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 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 – and, we hope you will be told about Steps!

On discharge the clinical team will usually provide you with a number to call if you have any questions or concerns.

Prostheses - First Fitting

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. In time, they may be able to use alternative prosthetic limbs such as blades. It will take time for your child to adjust to using a prosthetic limb and to adjust to finding their own way of getting around. They will also have to adapt to the loss of muscle and bone in the amputated leg and get used to their residual limb.

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

- The type of amputation
- The level of amputation
- 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

With modern limbs, it is possible to have both a physically realistic, skin tone appropriate prostheses and one that is highly functional or specialised. Customised legs are available, examples include running blades and waterproof 'wet legs' to allow your child to play in water and move about normally beside the pool on holiday.

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. The second stage of fitting a prosthesis involves trying on the new leg and walking practice between hand-rails.

The prosthetist will ask your child questions about the comfort and fit of the leg and will mark up any areas to improve with a pen. This is a time-consuming process and several appointments are often required. The prosthetist will go back into the workshop and you will be asked to come back when the adjustments have been made. It is possible that your child will find the initial experience a bit tiring, so, if possible, two adult carers attending may provide that extra bit of support needed.

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 stump, with a series of massages and actions that will help reduce pain, swelling and fluid build-up.

A 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.

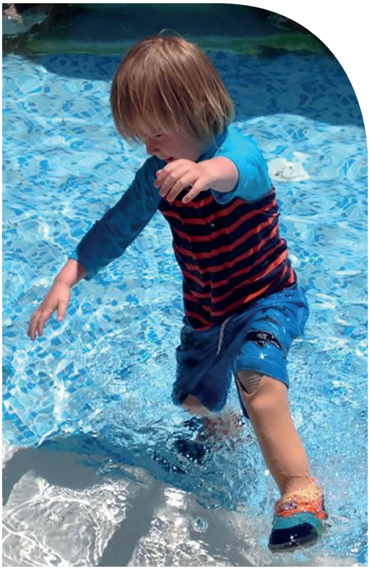
Clothing

It can often 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!

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 prosthetic 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.

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.



Clinic Appointments

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

It is very important that your child completes the physiotherapy exercises they have been given. During the process, 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 provide a hydrotherapy session. Remember, clinic sessions provide opportunities to discuss questions, worries and problems.

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 SEND - Special Educational Needs and Disability Coordinator* (England only), in advance and bring in some books and adapted toys, so they can talk openly with your child and their peers.

The law that applied to SEN in Scotland is called the Education (Additional Support for Learning) (Scotland) Act and aims to make sure that children with additional needs at school benefit from education and reach their full potential. There is also a SEN code of practice for Wales. The protocol for Northen Ireland is contained within the Education (Northern Ireland) Order 1996 (the 1996 Order) and the Special Educational Needs and Disability (Northern Ireland) Order 2005.

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 the physiotherapist/counsellor 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.

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. 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.

Most schools are sympathetic and will make the necessary accommodations.

Each school should publish their disability equality and accessibility schemes as separate documents annually or as part of other school documents and must be able to provide copies to anyone asking for them.

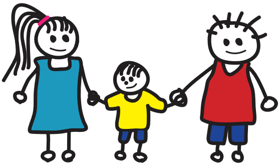
You should discuss your child's difficulties with teachers, head teacher or Special Educational Needs and Disability Coordinator (SENDCO), where available. If you are not satisfied with the provision for your child there are other sources of help and advice such as your local parent partnership service. 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.

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, or email info@steps-charity.org.uk.



Life after amputation

Stump Care

Stump care is a vital part of life following an amputation; the skin of the stump was never naturally made for fitting inside a prosthesis socket. The skin and muscles will be subjected to the pressure of body weight from above, and the rotational and 'piston type' (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 type cover to protect the stump.

It is important to keep the stump clean and dry; wash it with a mild, unperfumed soap and pat dry before fitting a prosthesis. Your prosthetist may suggest using Hibiscrub Liquid (an antiseptic) once a week. It is best to avoid talc. An emollient cream, such as E45 may be soothing if applied at night, when the prosthesis is not being worn.

If your child gets very sweaty, it is best to wash their stump more regularly. Applying antiperspirants to the stump is not recommended when wearing a prosthesis. It is important to also regularly change anything in contact with the stump, such as silicone pads or socks and a periodical wash of these items with an antiseptic is also a good idea, so long as they are well rinsed and dried, and no chemical residue comes into contact with the skin while it is inside the prosthetic.

Encourage your child to be proactive in their stump care, check for signs of irritation or infection every day, and contact your doctor if you are worried. Signs may include;

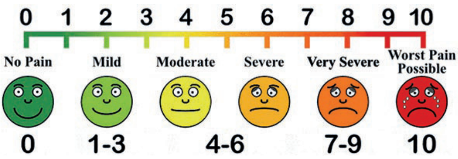
- Swelling
- Warm, red or tender skin
- Leaking of pus or fluid
- Your child; telling you that they are experiencing discomfort or subtle changes in their behaviour (an uncomfortable child will not always tell you but may show it indirectly with unusual behaviour, either being quieter than usual or being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

Phantom Pain and Stump Pain

Phantom pain is the feeling of pain or sensation signals in the limb which has been amputated. This can be very distressing for a child or an adult.

It is not the same as stump pain within the residual leg and the approach taken to address these two situations is completely different.

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.

In cases of stump pain, that is, ‘real’ pain in the end of the remaining part of the limb, a common cause is nerve damage. 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. Many cases of stump pain can be linked to physical environmental factors, such as; poorly fitted sockets, stump irritation, changes in temperature and humidity and things such as emotional stress, tiredness and strains on other parts of the body, such as back pain. Most cases of stump pain are resolved within a year of an amputation.

Treating Phantom Pain and Stump 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 the nature of the symptoms but generally fall into two categories; medications and self-help/ complimentary 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;

- 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

'Self Help'

This is a way of relieving pain symptoms by changing the way you do things or trying new techniques to sooth and relieve pain. Examples of 'self-help' include;

- Ensuring that pain does not come from a poorly fitting socket; and making changes if this is the case
- Massage to improve circulation
- Applying hot or cold items - using heat pads, ice packs or certain skin creams
- A 'TENS' machine (often used during labour), which gives an electric current to reduce pain signals

Some techniques involve an aspect of psychology; imagining the absent limb and pretending to extend the leg, stretch or 'bunch up' toes. Some studies show that this can be quite effective in reducing symptoms. This is possibly because, as discussed earlier, phantom pain may be a result of the nervous system getting 'confused' by signals from the brain to the absent leg not being returned. Picturing the amputated leg and performing imaginary exercises on it, may help the brain adjust. Another technique involves moving the remaining leg, reflected in a mirror. This is known as 'mirror visual feedback'. Your child will be told to watch and exercise their remaining limb inside the mirror box so they can see a reverse mirror image of it. This fools the brain into thinking that the amputated limb is still there. They will then try to imagine moving the limb into a position where it stops hurting. Talk to your rehabilitation centre to explore all the options available to you to help combat your child's phantom limb pain.

Surgery

In some cases, additional surgery may be needed to remove thickened nerve tissue that may develop in the stump causing pain. Surgery may also be needed to remove spurs of bone, which may continue to grow following an amputation, causing additional pain.

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, be vigilant. 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.

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. For more information on art in rehabilitation, visit limbpower.com/index.php/art/arts-rehabilitation.

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 on using a blade.

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 to get about. 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 regular leg will work just as well.

If you would like to know what activities are available in your area, please visit Limb Powers website at Limbpower.com.

Steps Helpline

Our helpline team are here to offer confidential advice and support. They won't tell you what to do, but they will listen to you, and share their knowledge and experience, so that you feel well informed and properly supported.

No matter how big or small your concern please telephone 01925 750271 or email info@steps-charity.org.uk and remember, you are not alone!

Beyond this booklet - support when you need it

Family Contact support service

Often being able to contact someone who knows what you are going through can be the biggest help when facing an uncertain situation. Our Family Contact Support Service can put you in touch with others who have shared a similar experience.

All our Family Contacts are interviewed and given training before they are able to officially engage with another family. In addition, our FaceBook group is a wonderful forum for sharing stories, concerns, and tips about care.

Family Testimonial

Hi there, this is me Lucy with my brother and sister. I'm the little one at the front with the glasses and the cute smile.

This is me at a recent Kuk Sool Won Tournament. KSW is a mixed martial art that I have been doing now for almost two years.

I am the only one in my martial arts school who wears a prosthetic leg. In fact, when we meet with hundreds of Kuk Sool Won students, Instructors and Masters at lots of different Tournaments I am still the only one who wears a prosthetic leg.

From the beginning, in tournaments, I have been treated the same as everyone else. I test and I compete! It's not easy but I just try my best. So far I have earned my yellow stripe. In tournament I compete against boys and girls who have two equal legs and I am proud to say I have always earned a place on the podium. No one feels sorry for me, they judge me fairly.

My hope is to be the first amputee to gain a black belt in KSW.

I was born with unilateral PFFD and Fibular Hemimelia. My mum and dad decided that amputation of my foot would be the best option for me. I call my little leg 'thumper' and everyone in my family loves her!

My message to anyone who wears a false leg like me is to, 'Have a go! Try your best!'

The list below is not exhaustive.

Steps Charity Worldwide (Steps Charity's FB sharing stories on lower limb conditions)

Steps Charity Worldwide (Closed Group – A forum for those affected by a lower limb coindtion or difference)

Fibular Hemimelia Support and Awareness UK (FB Page)

Fibular Hemimelia & Limb Lengthening Awareness (FB Page)

PFFD (Proximal Femoral Focal Deficiency)/ CFD (Congenital Femoral Deficiency) (US based FB Page with active UK members)

SoleMates Community (FB to exchange odd sized or specially adapted shoes)

Finding Help

There are many websites that offer guidance about preparing for amputation, benefits applications, equipment funds, and advice from specialist nurses. These include:

www.amputee-coalition.org Aims to empower people affected by limb loss to achieve their full potential through education, support and advocacy.

limbpower.com aims to help engage amputees and individuals with limb impairments in physical activity, sport and the arts to improve quality of life to aid lifelong rehabilitation

facebook.com/Shoewap/ for people with different sized feet to swap footwear and get advice.

cafamily.org.uk UK based organisation for families and professionals caring for disabled children.

newlifecharity.co.uk UK organisation providing advice and funding for disability equipment.

citizensadvice.org.uk advice on benefit applications and other topics such as discrimination and taking time off work to care for your child

gov.uk/government/publications/equality-act2010-advice-for-schools guide for schools to avoid disability discrimination and help children back into school setting

The Disability Discrimination Act (DDA) and the Disability Equality Duty which was introduced into it in 2005 and updated in 2010 set out the provision schools should make for disabled pupils www.gov.uk/government/publications/equality-act-2010-advice-for-schools

http://www.limbless-association.org/images/Choosing_an_Artificial_Limb.pdf

http://www.limbless-association.org/index.php/information/amputee

limbs4kids.org.au An Australian site for child amputees, lots of useful advice.

Useful books, films and TV shows to prepare for an 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

Film

Your Child's General Anaesthetic - Magic Milk and Squidgy Masks
youtube.com/watch?v=0QfFL2CGkU0

TV

How to Train Your Dragon

Website

The following website provides information about the role of play in medical settings www.nahps.org.uk.

Notes

Important contacts

Questions for consultants

steps-charity.org.uk

Helpline: 01925 750271 **Email:** info@steps-charity.org.uk

Steps Charity Worldwide @Steps_Charity

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