Steps
We don't take walking for granted

Talipes/Clubfoot

The Parents' Guide

Introduction

At Steps, we understand how a lower limb condition can affect individuals, families, and communities. Our commitment is to helping people understand these conditions, offering reassurance and actively working for a better future, through our work with national health services and research projects. This booklet is for parents with a child diagnosed with Talipes/Clubfoot. It cannot tell you everything you need to know about what the future may hold, but we hope it will reassure you. It is also intended to show that practical help, specialist medical information, emotional support, and links to other sources of information are all available, if needed. This will help you to be more prepared for the road ahead and have information to hand so that you can 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 online your worries with other parents, sharing tips, and finding emotional support. Remember, the STEPS Helpline team are here to offer information and support in total confidence and 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 our Helpline on +44 (0)1925 750271 or email info@steps-charity.org.uk for support and advice in total confidence.

Social media details can be found on the back cover.

Contents

What is Congenital Talipes Equinovarus and why it is referred at times as 'Clubfoot' or 'Talipes'?

Congenital Talipes Equinovarus (CTEV) is a condition which your baby is born with and is easily recognisable from the position of the foot which is turned in and round. The severity of the condition can vary.

Congenital Talipes Equinovarus might sound complicated but, when broken up, it becomes easier to understand.

Congenital – present at birth
Talipes – refers to the foot and ankle
Equino – foot points downwards
Varus – heel turns inwards

Children's orthopaedic specialists rarely use the term talipes when they are talking about CTEV. They usually tend to call the condition Clubfoot. Talipes is usually non-specific.

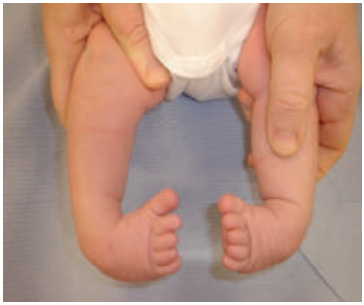
Clubfoot may affect one foot (unilateral) or both feet (bilateral). Often the calf muscle is less prominent on the affected side. In some instances, such as with idiopathic clubfoot, muscle is often thinner and weaker and there is an imbalance of muscles around the foot. The deformity that is the result of this can be corrected sufficiently for the foot to look and function normally though the thinner calf muscle will remain, but the foot cannot be made structurally normal, only treated so that it functions normally.

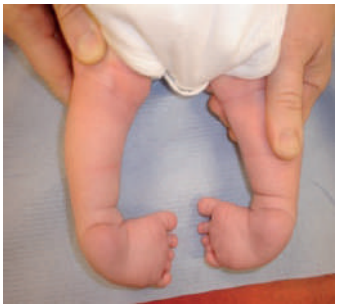
Clubfoot is usually easily treatable, although the outcome will, in part, depend on your child's response to treatment and parental support in complying with hospital advice. Most children are treated successfully and eventually your child should have pain free functioning feet and be just as active as any other child. Treatment should ideally begin in the first week or two of life to take advantage of the elasticity of the ligaments, tendons (soft tissues) and joint capsules, but a delay in starting treatment will not affect the outcome. This could be a factor to consider in cases of prematurity or illness following birth.

Clubfoot can be classified into a number of different categories, here are the most common:

1. Idiopathic clubfoot is by far the most common type of clubfoot. Idiopathic means of 'unknown cause'. It is a structural deformity, whereby there are minor abnormalities of some of the structures in the foot, and this is responsible for the deformity that is seen. It is not flexible or correctable without treatment. According to many experts, idiopathic clubfoot occurs in about 1 to 2 per 1000 live births in the UK. The "Atypical" Clubfoot is a type of idiopathic clubfoot which may be more difficult to treat. It is usually the result of problems with casting e.g., slipping, but can present from birth.

For the purpose of this booklet we will assume that the clubfoot is idiopathic.





2. Positional clubfoot is a foot which falls into a similar position to clubfoot but there is no structural deformity. It will therefore correct spontaneously in most cases, sometimes physiotherapy is needed using gentle stretches.

3. Syndromic clubfoot is a clubfoot deformity that is associated with an underlying medical condition that may have caused the clubfoot e.g., arthrogryposis, spina bifida. They are termed complex when it is clear that they are stiffer and more resistant to conventional Ponseti treatment.

Why does Clubfoot happen?

There is no known cause for clubfoot. Clubfoot occurs when the muscles on the outer side of the leg are weaker than those on the inside of the leg. The tendons on the inside of the leg, the tough cords that connect muscles to bones, also become shorter than normal.

With clubfoot, it is believed that because there are some muscles that are weak, in the developing embryo, the stronger muscles pull the foot into a deformed position, and the cartilage and bones then develop into slightly abnormal shapes and the Achilles tendon (the large tendon at the back of the heel) is tight. If you have had a child with clubfoot, you are more likely to have another child with the condition. Clubfoot affects around 1-2 in every 1,000 babies and is more common in boys than girls. Worldwide, the annual figure is in the region of 174,000, and approximately 50% are bilateral (affecting both feet).

In a small number of cases, clubfoot may be associated with other conditions, so your doctor will examine your baby thoroughly, not simply their feet. There is no evidence of a link between clubfoot and conditions such as Developmental Dysplasia of the Hip (DDH). However, positional clubfoot and some cases of DDH are thought to be caused by the baby's positioning in the womb. These cases are known as 'packaging disorders'. If positional clubfoot presents, orthopaedic specialists may recommend an ultrasound scan of the hips, although practices vary from one hospital to another.

Clubfoot can often be detected in an unborn baby during a routine ultrasound scan, although it is not possible to determine the severity or type of the condition at this stage, and it cannot be treated before birth. Sometimes it is only discovered at birth as the feet are visibly turned inwards.

How is clubfoot treated?

The Ponseti method is regarded as the gold-standard treatment for clubfoot by healthcare professionals. Long term studies have consistently shown good outcomes in the majority of cases. Treated children are no more likely to experience pain than those born without the condition, and studies show that there is no difference in the function of the foot or feet.

The Ponseti Method, is a process of casting followed by bracing of the feet in boots attached to a fixed bar. Most babies will also require a minimally invasive procedure called a tenotomy, which is described later in this booklet.

Positional clubfoot

Treatment for positional clubfoot usually consists of massage and gentle stretches, directed first by a physiotherapist, and then continued at home. Occasionally, babies with more severe positional talipes need a cast and orthotics.

Atypical feet can still be treated by the Ponseti method but by a slightly altered technique. It is important that if your child is found to have, or develop, an atypical clubfoot, that it is treated by a practitioner skilled in using this advanced technique.

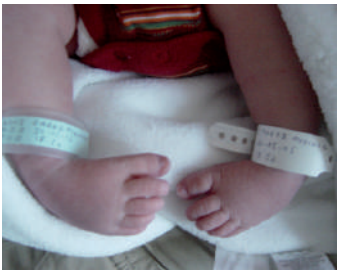
The Ponseti Method

The Ponseti Method usually involves weekly sessions in which a trained Ponseti practitioner (consultant, physio or nurse) or specially trained physiotherapist manipulates your baby's foot with their hands, gradually correcting the position of the foot.

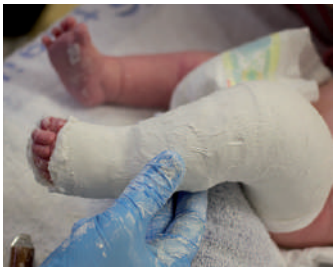
A plaster cast is then applied from your baby's toes to their groin to hold the foot in its new position. The cast will be changed weekly at each appointment and your baby's foot or feet are corrected a little more each time. A minor operation, known as a tenotomy, is usually required to release your baby's Achilles tendon.

This technique involves serial casting of the affected foot and leg, followed by time spent in special shoes, known as the 'Boots and Bar'.

These hospital visits will occur for the first few months of treatment, so this may be a consideration when deciding on a treating centre.



Before treatment

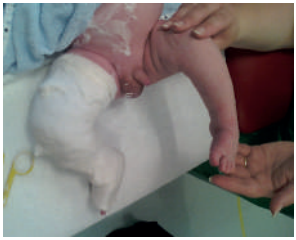


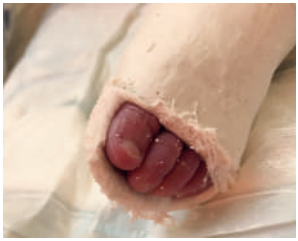
During treatment

4 weeks after treatment

Casting Stage

The casting stage, which takes up on average 5-6 weeks, but can be shorter or a little longer depending on how stiff the foot is, involves weekly appointments with a specialist (trained Ponseti practitioner or a paediatric orthopaedic surgeon) who will manipulate your baby's foot, affecting a gradual correction.





A plaster cast is then applied from your baby's toes to their groin to hold the foot in its new position. It is very important that the toes are exposed and clearly visible (to tell if the cast is slipping).

On average, five to six casts are required, but this may vary. Manipulation and casting of the foot are done very gently so should not hurt your baby.

Many clinics will encourage you to bottle/breastfeed your baby while casting is performed. This can help to relax your baby.

You may be allowed to bathe your baby at the hospital when they take the cast off and before they apply a new one. Please note, that variations do apply.

When the plaster cast is first applied, it takes several hours for the plaster to dry fully. During this time, please take extra care not to disturb the plaster in any way as it is easily damaged. Plasters dry best when they are exposed to the air. The cast is warm and heavy when it's first applied so your baby may need a bit more reassurance than normal, but once the cast is dry it is much lighter.

It is important to follow all the instructions below carefully to ensure your baby is happy and safe, and for the treatment to be successful.

Signs that Ponseti treatment is going well

1. It is usual for your child's foot/ feet to be given a 'score' prior to treatment beginning – this score should reduce as treatment progresses.
2. Usually, the cast will be applied by two people, one to manipulate and hold the foot, the other to apply the cast – it is indeed challenging to achieve the correct position and apply the cast at the same time.
3. The casts progress in a sequence, as shown in the picture.

Key tip before leaving the hospital after casting

Take a photograph of your child's toes position and the skin around the edges of the cast before leaving the treatment room. This will help you to check the positions of the toes over the next few days. It will also help you to communicate with your treating team in case of issues with the cast as they will be able to see a before and after photo of your child's cast.

When at home

- Check your child's toes are of normal appearance and warm.
- Check that the toes are exposed and clearly visible at all times.
- Change your child's nappy frequently to avoid soiling the plaster. You may find it useful to tuck the nappy inside of the top of the cast not on top which should avoid soiling the cast.
- Check the skin around the edge of the cast for any signs of redness or soreness. It is important to contact the hospital immediately if:
    - You cannot see your child's toes. This usually indicates that the plaster has slipped and will no longer be correcting the feet and may cause pressure to the skin at the back of the heel.
    - Your baby's toes change in appearance and become cold.
    - The plaster becomes loose, cracked, or crumbly. Keep the plaster dry at all times.

If your child's cast has slipped and you can no longer see their toes, they 'disappear', contact your clinician immediately as the cast will need to be removed. If you are not able to contact your clinical team immediately it is best to take your baby to the Accident and Emergency for cast removal.

You should not be concerned with the fact that the foot is not in a cast, and it might compromise the treatment. In fact, the foot will probably benefit from a few days out of cast if slippage has occurred. Do not forget, you should always talk to your clinician if you are worried about any aspect of your child's treatment, they will be able to answer your questions and advise on the best course of action.

Caring for your child during treatment

There are no specific clothing requirements for a baby undergoing treatment for clubfoot. However, baby-grows without feet are useful during casting as foot slippage will be visible. Baby-grows are also convenient during the boots and bar stage. Cutting the feet from standard baby-grows works well, so there is no need to buy new ones. Trousers with poppers on the underneath and dungarees are ideal.

During casting, and for the time the cast takes to dry, your baby could either wear a legless bodysuit/baby-grow or you could just leave one leg out of the baby-grow. It would be wise to have a good supply of these, along with a few warm blankets to cover them when transporting them home following casting.

Occasionally some parents have found the cast will rub. If you inform the clinic/practitioner to put more padding inside they will make sure that there is a sufficient enough amount each time. Some babies can have disturbed sleep patterns during treatment, especially when the first cast is applied. Try altering your baby's position at the first signs of wakefulness and inserting a folded towel beneath the legs to take any pressure off.

A beanbag or large scatter cushion can be useful as it moulds to your baby's shape and helps to keep them comfortable. However, do not let them sleep on a beanbag or cushion or use with blankets or covers as your baby can easily overheat.

NB: If the cast is rubbing, slipping or has got very wet, please go back to your hospital and seek medical advice.

Frequently asked questions

How are the casts removed?

The plaster cast can either be removed in clinic or at home. To avoid a relapse, the cast should be removed as close to your appointment as possible. Ask your hospital for advice, but as a general rule, if you use a baby bath to soak the cast for a good 10 minutes with warm water, it will start to disintegrate.

Each week, as your baby is recast, it's likely the process will become easier. Many parents find that feeding is the best way of keeping baby happy and calm. Alternatively, you can try distracting them with their favourite toys or music.
Sometimes a cast cutting saw or plaster knife is used to remove the cast, both of which are perfectly safe.

Can my baby wear clothes after the casting?

To enable the cast to dry thoroughly your baby should not wear trousers/sleepsuit over the cast for the first 24 hours, so don't forget to bring a vest and a blanket to keep your baby warm.

It is also advisable that you bring an old towel to protect your car seat from the wet plaster.

What advice would you give to care for my child while in cast?

You will not be able to bath your baby during the plaster stage so they will need a thorough wash (top and tail) with a damp cloth at least once a day to keep them feeling fresh. You may be allowed to bathe your baby at the hospital when they take the cast off and before they apply the new one – please do check this with your hospital as provisions vary. The edges of the plaster may be protected by a water-resistant tape which also protects the skin from rubbing, but it is still best to clean these areas with baby lotion or wipes. Avoid using talc as it is bad for babies' lungs and can slip down inside the plaster and irritate the skin.

How will I know the casts are working?

At the start of the casting treatment your clinic may have graded your child's feet from 0 to 6 (6 being the most severe). This is known as the Pirani score and this score should gradually reduce with each correction. After the first cast you may wonder why things look worse, this is perfectly normal as you will not be used to the changes taking effect. You will then be surprised by how quickly your baby's foot will begin to appear 'normal.' You should see an improvement after each casting appointment.

Tenotomy

Following the casting stage, a minor operation, known as a tenotomy, is usually required to release your baby's Achilles tendon. A tenotomy is a common procedure and is typically recommended when the heel has not fully stretched down (usually after the fourth or fifth cast); this procedure allows this to happen. The procedure may be carried out under a local anaesthetic on an outpatient basis, which means that your baby will not have to stay in hospital overnight; it may even be carried out in a local clinic. In some cases, a general anaesthetic may be used (useful for wriggling babies!).

During the procedure, the surgeon will make a small cut in your baby's heel cord to release their foot into a more natural position. Your baby's foot and leg will be put in a plaster cast for about 2 to 3 weeks.

Before, during or after the procedure, your baby may be upset and feel a little pain but, rest assured that this is also likely that they are objecting to being held. Any discomfort is very transient, your baby will settle once the cast is reapplied. Do not be alarmed if there is some bleeding at the back of the heel (visible on the outside of the cast), the cast will act as a sponge to the tiny amount of blood produced making it look worse than it is. Your team will advise on how to contact them if you are at all concerned.

Note, your clinic will advise you how much pain relief (if any) to give prior to discharge.

Foot Abduction Braces, commonly known as 'Boots and Bar'

When the foot is fully corrected, your child will be placed in foot abduction braces. The foot abduction braces consist of special boots attached to a bar (brace).

The boots are worn for 23 hours a day for the first 3 months, or longer, and then just at night and nap times up to the age of 4/5years. Regular footwear may be worn at all other times.

Boots and bar are fitted immediately after the final cast is removed.

Failure to comply with the boots and bar protocol is known to be associated with a higher risk of recurrent deformity (relapse).
This is often considered the most important part of the treatment and therefore, as parents and carers, you will have a vital role to play.

The distance between the boots should be shoulder width, and they should be properly fitted to accommodate growth (both in length and width). The boots will need to be changed as your baby's feet grow.

Don't forget, the boots and bar stage is crucial and relies on parental compliance. Taking the boots and bars off or wearing them for only a few hours or without the bar, or overnight, can result in a relapse and may involve repeating the plastering stage, or more serious problems. The casting corrects the feet, but it is the boots and bar that maintains the correction long-term. If bracing is stopped at any point during the treatment the following relapse rates can be expected as follows:

- 1st Year: 90%
- 2nd Year: 70 - 80%
- 3rd Year: 30 - 40%
- 4th Year: 10 - 15%
- 5th Year + - 5%

The boots and bar stage is probably the hardest part of the treatment for parents as the feet may well present as being corrected. However, appearances can be deceptive, so it is VITAL to the success of the treatment that boots and bars are worn as instructed. Some parents describe it as, "short term pain for a long-term gain".

Each child may have different reactions to the boots and bar especially during the first few days. It's usually not due to any pain but that they are new and different. Each child will respond in their own way. Some won't object, and some will. If your child is inconsolable, and you believe they are in pain, contact your clinic. They will be able to advise or reassure you. You should be asked to return to the clinic frequently during the first few weeks after boots and bar fitting all the same, this will be to ensure that there are no problems.

Don't be afraid to play with your child in the boots and bar. Your child will be unable to move his/her legs independently, but they can kick and swing their legs simultaneously with the boots and bar on.

There are many types of boots and bar available and all of them aim to correct the position of the foot. Per the WHO Assistive product guidance these are key specifications that should be present in a FAB (Foot Abduction Brace).

- Fixed bar (width adjustment is an optional feature)
- Boots that hold feet at shoulder-width apart in position of abduction and dorsiflexion (angle adjustment is an optional feature)
- Length of bar: size range to accommodate infants (0–12 months) and children (1–5 years) (e.g. bar width 12–38 cm)
- Bilateral boots: size range to accommodate infants (0–12 months) and children (1–5 years) (e.g. foot bed length 6.4–20.4 cm)
- Abduction angle of boot 30–70 ° (allows for unaffected foot)
- Dorsiflexion angle of boot 10–15 °

https://www.who.int/publications/i/item/9789240020283

Some examples of FABs that are commonly used are:

- Steenbeek Foot Abduction Brace
- Mitchell Brace
- Markell Brace
- Miraclefeet Brace
- Iowa Brace

Padding

By padding the bar, you will help to protect your child, yourself, and your furniture. A bicycle handlebar grip or foam pipe insulation covered in fabric or tape works well as padding for the bar. Specialist 'bar bumpers' are available online and the Steps Facebook Group is a good forum for finding creative ideas and solutions to everyday concerns.

Sleeping

Your child may adopt a strange sleeping position. Baby sleeping bags will help with padding and will keep your baby from pulling at the straps and laces. If blistering occurs, this usually indicates that the boot has not been fitted tightly enough. If it continues to slip and the blisters show no sign of healing, contact your clinic.

Feeding

It is possible to breast or bottle feed fairly easily in both cast and boots and bar, though you may need a little guidance from your midwife or health visitor.

Transport

Generally, parents don't find it necessary to buy a special pram/car seat/baby carrier, as many products will work well with both casts and boots and bar.

Note: It is a good idea to look for a highchair with a detachable or undoable centre strap so that when they are in 'boots and bar' they can still use it.

Parent to Parent Top Tips

Here is some general advice for parents regarding the boots and bar.

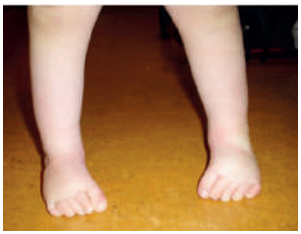
- Socks that have a 'grip' on the bottom help keep the boots from slipping.
- When the clinic fits the boots, make a mark with a biro on the straps (if they have buckles) so you know how tight they need to be in the first days as you get used to taking them off and putting them on again.
- If the boots have laces, knot them in the middle so you only have to re-lace them part of the way when they come undone.
- Use the holes at the back of the boot to check the heel is flat. If there is no hole, ask the clinic if they will make one for you.
- Painting the ends of the straps with clear nail varnish aids easy threading.
- Ask if there are any special tools needed to adjust the boot's angle or the bar and take them home with you.
- Get the clinicians to show you how to adjust the boots yourself.
- It can be helpful to have something to distract your child with (a toy or some food) while boots are being put on.
- You should always ensure the heel is down as much as possible. Note: Your clinician is likely to explain that this won't happen at first but will in time. Tip: take a photograph before you leave the treatment room as it will help you to assess if the boots have slipped.
- If the boots keep slipping off, check they are tight enough (refer to your biro marks). It's also worth checking that the socks are not slipping on the sole.
- In rare cases the foot will slip in the boot if it hasn't fully corrected, so it is important you raise problems with your clinic.
- Sore feet and blisters can be treated with standard medication but do check with your clinic if the blisters form open wounds.
- If your child continuously knocks the bar against the cot, padding it safely so that it cannot be ripped off could offer a solution.

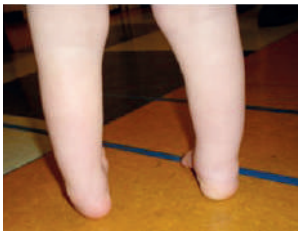
Signs and Diagnosis of Relapsed Clubfoot

The outcomes for children born with clubfoot are overwhelmingly good but, sometimes clubfoot can reoccur. This is known as a relapse. Compliance with the boots and bar nightly until the age of 5 reduces this risk. One of the first signs of a relapse is the loss of dorsiflexion (the movement of lifting the foot upwards).

This happens because of tightness in the Achilles tendon (the large tendon at the back of the heel) and can result in walking on the toes or the inability to place the heels flat on the floor when standing. It may become difficult to get the feet down fully into the boots and bar.

The heel may also start to roll inwards slightly, and the front of the foot may appear to lift more on the inside than the outside as the child is walking, so that the weight is taken on the outside border of the foot.





Untreated relapsing feet may gradually become rigid. It is possible that a Pirani Score will be used to reclassify feet suspected of relapse, but there is no definitive classification to assess relapse.

Treatment for Relapsed Clubfoot

Treatment for relapsing clubfoot will depend on the severity of the relapse. If the relapse is related to problems keeping boots and bar for the recommended time, simply addressing the problem, and following the treatment protocol closely may be enough to correct the feet. For more severe relapses, it is possible that a clinician may need to manipulate the feet and reapply a plaster cast to maintain the correction. This will be followed by a repeat of the boots and bar stage of treatment.

In some cases, surgery to the foot may be required, followed by a plaster cast and again a repeat of boots and bar.

In some cases, a tibialis anterior transfer is required. This is a way of moving one of the tendons on the foot to make it more balanced. The tibialis anterior tendon attaches on the inside of the front of the foot, near the toes. A total tendon transfer will result in the foot being pulled straight. The wounds are stitched and will leave minimal scarring. Stitches are usually dissolvable, but a strong, removable stitch may be used to secure the tendon into its new position. A plaster cast will be worn for approximately 6 weeks following the surgery.

It is important, if you think there is a relapse, to keep the foot in a brace throughout. In the meantime, stretching is really important. If you are able to do effective stretches, especially calf stretches, keep doing so: hopefully, you have been shown how to do these, as well as simple exercises, by a physiotherapist. Exercises to practice may include hopping, walking on heels, balancing on one leg and how to use resistance bands (which help the muscles on the outside of the foot). You will want to keep all the muscle groups strong particularly around the foot keeping it as supple and mobile as possible. Work on strengthening the core and leg muscles and keeping a general fitness is recommended but in a low impact way. Cycling, swimming, yoga, when possible, are all low impact activities the whole family can enjoy together and there are some great online resources for children and families readily available.

What is the long-term outcome?

Most children respond well to treatment and go on to fully participate at school, and in sports activities without issue. Nevertheless, your specialist my want to monitor your child until their feet have stopped growing.

Professor Ponseti published several long-term outcome studies in his lifetime, following children through to adulthood, specifically looking at the results of his method. His studies showed that the use of his method resulted in no greater severity of foot pain or reduced function in mid-life to those born without clubfoot. These studies have been repeated by other practitioners in recent years and also confirm these outcomes.

For more information about clubfoot, it's treatment, clothing and equipment please contact us. Our helpline on: +44 (0)1925 750271 or email info@steps-charity.org.uk.

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 +44 (0)1925 750271 or email info@steps-charity.org.uk and remember, you are not alone!

Parent's top tip

"Take lots of photos, probably even daily. Your child will change so much and so quickly that it will seem like a blur looking back. As the parent of a child with clubfoot, you'll be so engrossed in the development of the feet that you risk missing out on other details, so taking photos helps you to think about the whole development of your baby."

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 closed Facebook group is a wonderful forum for sharing stories, concerns, and tips about care.

Notes

Notes

We don't take walking for granted...

Babies & Children

Anyone

Families

www.stepsworldwide.org.uk

Helpline: +44 (0)1925 750271 Email: info@steps-charity.org.uk

Steps Charity Worldwide @STEPS_Charity

stepscharityworldwide stepscharity

Steps registered charity in England and Wales (1094343), Scotland (SC049759) and also operating in Northern Ireland.
Company number 4379997
Externally reviewed and updated July 2021

Acknowledgements:
Steps wishes to thank all the health professionals and families who provided feedback and photos for the production of this booklet.

fieldfisher