



# Talipes/Clubfoot



## The Parents' Guide



# Contents

	Page
Introduction	3
Who this booklet is for	4
What is clubfoot?	5-6
Why does clubfoot happen?	7
How is clubfoot treated?	8-18
• The Ponseti Method	
• Casting	
• Important points to be aware of	
• Caring for your child during treatment	
• FAQs	
• Tenotomy	
• Boots and Bar	
• What can you do during the boots and bar stage	
• General advice for parents	
Possible further developments	19
What is the long-term outcome?	20
Beyond this booklet	21
Notes	22-23
Acknowledgements	24





# Introduction

## About Steps

Every year in the UK, approximately 2,500 babies are born with a serious childhood lower limb condition. This includes Congenital Talipes Equinovarus, commonly referred to as Clubfoot. 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.

# Who this booklet is for

This booklet is aimed at parents and expectant parents of a child with Clubfoot. We understand that a diagnosis can be upsetting to parents, but we hope that by clearly explaining the condition, treatment, and outcomes, they will feel comforted about the future.

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 are a little further along the journey than you. These trained volunteers are ready to offer advice, support, and practical tips. For more information, please email [info@steps-charity.org.uk](mailto:info@steps-charity.org.uk).

In addition, our Steps Facebook Group is a community of thousands who willingly share their stories, challenges, and solutions.

More factsheets and publications are available from our Helpline on 01925 750271, and from our website [steps-charity.org.uk](http://steps-charity.org.uk). For more information about Steps support services, please email [info@steps-charity.org.uk](mailto:info@steps-charity.org.uk).

## What you should know

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.





# What is Clubfoot?

The medical term for clubfoot is Congenital Talipes Equinovarus (CTEV).

**C**ongenital – present at birth

**T**alipes – refers to the foot and ankle

**E**quino – foot points downwards

**V**arus – heel turns inwards

The term CTEV is rarely used by families, and although you may hear the term 'Talipes' used to describe the condition, most of the practitioners who treat CTEV use the term clubfoot. Clubfoot may affect one foot (unilateral) or both feet (bilateral). Often the calf muscle is less prominent on the affected side.

- The Global Clubfoot Initiative has classified clubfoot into 3 categories:

## 1. Idiopathic clubfoot

is by far the most common and most affected children have no other conditions. It is sometimes referred to as isolated clubfoot or idiopathic (meaning cause unknown) clubfoot.

According to many experts, idiopathic clubfoot occurs in about 1 per 1000 live births in the UK. 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. In the UK the incidence is 1 in 1000 live births.

## 2. Positional clubfoot

occurs when an otherwise normal foot is held in an incorrect position in the womb.

The foot is flexible rather than rigid and this type of clubfoot always corrects itself with time; sometimes physiotherapy is needed using gentle stretches. If a positional clubfoot does not resolve itself, it needs further investigation as it is likely to be an idiopathic clubfoot.

## 3. Secondary or Syndromic clubfoot

occurs in only a very small percentage of cases and is associated with additional chromosomal/genetic abnormalities or syndromes. Further tests may be offered to you by your consultant.

This publication concentrates on the treatment of idiopathic clubfoot.

Some idiopathic feet can be described as 'complex', if they are more resistant to the conventional approach, this may be because the foot has received treatment not in line with the Ponseti method.

Resistant clubfoot is a clubfoot where Ponseti treatment has been correctly performed but there has been no significant improvement. It is often found that this type of clubfoot is not in fact 'idiopathic' after all and is secondary or 'syndromic'. This type of clubfoot is described below.



A foot described as "Atypical" Clubfoot is often swollen, often with a deep crease in the sole and an extended big toe. It can occur on its own, but most often occurs after slippage of a cast.



# Why does Clubfoot happen?

There is **no** known cause for clubfoot. It can occur 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 also become shorter than normal. Tendons are the tough cords that connect muscles to bones.

With clubfoot, the bones of the foot are abnormally shaped and the Achilles tendon (the large tendon at the back of the heel) is tight. In most cases the cause of clubfoot is unknown, but it occasionally runs in the family. 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 born in the UK, and is more common in boys than girls. Worldwide, the annual figure is in the region of 174,000, and approximately 50% are bilateral. 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.

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.

The Ponseti method is regarded as the gold-standard treatment for clubfoot by healthcare professionals in the United Kingdom.

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.

# How is clubfoot treated?

Clubfoot is treated using the Ponseti Method, which 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.

## Positional clubfoot

In cases of positional clubfoot, the foot or feet may *appear* abnormal. This is known as a 'packaging disorder' and is due to the position the feet would have been in while in the womb. Limited space within the womb in the final weeks of pregnancy can restrict a baby from stretching their feet as they grow.

The feet may point inwards and down (below left); Positional Talipes Equinovarus (PTEV) or outwards and up (below right); Positional Talipes Calcaneovalgus (PTCV). Treatment for positional clubfoot usually consists of massage and gentle stretches, directed first by a physiotherapist and then continued at home.



## Atypical clubfoot

Atypical clubfoot is slightly more resistant to routine treatment, but is still correctable. Correction is usually achieved by modifying the standard Ponseti manipulation and casting technique. However, the number of casts may be higher when compared to standard treatment.

It is anticipated that a tenotomy will be performed in the majority of cases of atypical or complex clubfoot. The modified Ponseti method is considered a safe, effective treatment for atypical/complex clubfoot and is thought to significantly reduce the need for later corrective surgery.

# The Ponseti Method

The Ponseti Method is the most successful treatment for clubfoot (based on long-term research) and is the preferred method within the NHS. This technique involves serial casting of the affected foot and leg, followed by time spent in special shoes, known as the 'boots and bar.'



Before treatment



During treatment



4 weeks after treatment

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

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





## Casting

The casting stage, which takes up to a couple of months, involves weekly appointments with a specialist (usually a physiotherapist) 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. More than this may indicate a problem with the correction or that the clubfoot being treated is atypical or complex.



Manipulation and casting of the foot are done very gently so should not hurt your baby.

Many hospitals 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.

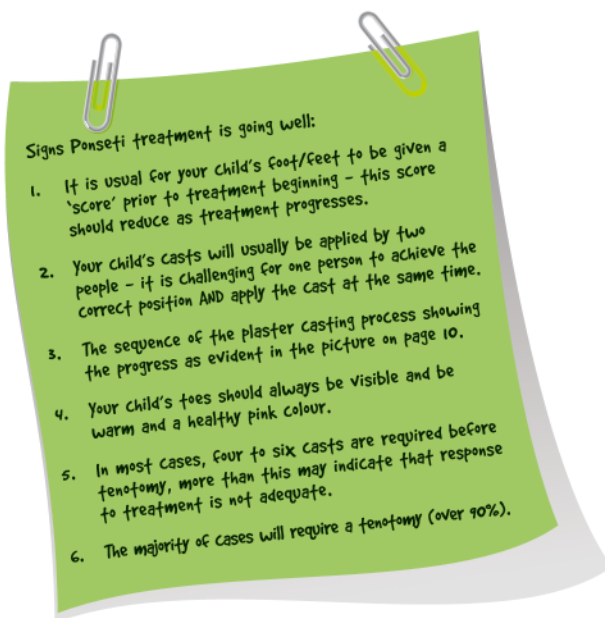
If you live close to the clinic it is possible that you may be asked to remove the plaster cast at home and this depends on your individual clinic. If you are requested to remove the cast at home, you will be given instructions on how to do this and it must be done as close to your appointment time as possible. The benefit of the next cast can be reduced if the previous cast is removed the night before or, in some cases, within a few hours of cast removal.



## Important points to be aware of

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.

- 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.
- 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 casts have slipped and you can no longer see their toes, contact your clinician immediately. 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 will only be able to wear a legless bodysuit/ baby-grow. It is wise to have a good supply of these, along with a few warm blankets to cover them when transporting them home following casting.

Occasionally parents complain of the casts rubbing. If you ask the hospital to put more padding inside at the top this may help. It is also sometimes possible to get padding from your hospital if you need to apply extra at home.

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 as they cannot cut your baby's skin.

## Can my baby wear clothes after the casting?

To enable the cast to dry thoroughly your baby shouldn't wear trousers or a 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?

You will be surprised by how quickly your baby's foot will begin to appear 'normal.' You should see an improvement after each casting appointment. At the start of the casting treatment your hospital 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.

## 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 is usually carried out under a local anaesthetic on an outpatient basis, which means that your baby will not have to stay in hospital overnight. 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.

Your baby may cry before, during or after the procedure, but rest assured that this is unlikely to be due to pain. It's far more likely that they are objecting to being held.



Don't be alarmed if there is some bleeding at the back of the heel, the cast will act as a sponge to the tiny amount of blood produced making it look worse than it is.

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

## Boots and Bar

When the foot is fully corrected, your child will be fitted with special boots attached to a bar (brace), to hold their feet in the most effective position. 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 4/5 years. Regular footwear may be worn at all other times.

The boots and bar must be fitted as soon as the cast is removed as a delay may result in a relapse.

The two most common types of boots supplied are:

- Mitchell boots are suede boots with buckles.
- Markell boots are white leather boots with laces.
- Both are regarded as equally effective in most cases.



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.

The boots and bar stage is crucial and relies on parental compliance. Taking the boots and bars off for only a few hours, 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.

This stage is probably the hardest part of the treatment for parents as feet may well present as being corrected. However, appearances can be deceptive so it is VITAL that boots and bars are worn as instructed.

Your child may object to the boots and bar especially during the first few days. This is not because they cause pain, but because 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.



## What can you do during the boots and bar stage

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.

While there are various other types of braces on the market, none have been proven to provide the results seen with the Markell and the Mitchell boots, and these therefore are the types recommended and used by most Ponseti providers in the UK, except in exceptional circumstances.

### 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 casts and boots and bar, though you may need a little guidance from your midwife or health visitor.

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

### 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.

# General advice for parents

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.
- 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 them safely so that it cannot be ripped off could offer a solution.

# Possible further developments



## Tendon transfer

Occasionally, further surgery is required to rebalance the foot. This minor surgery is known as a tendon transfer. This procedure may involve moving a tendon in front of the ankle to a different position to improve the foot's function. A general anaesthetic is given.

A tendon transfer is typically considered between the ages of 4 and 7 as the need will not be apparent until well after a child has started walking.

The need for this surgery is not related to compliance with boots and bars, but full compliance until the age of 5 decreases the risk of major surgery being required later.

## Relapse

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.

When relapse does occur, it may be necessary for some of the treatment stages to be repeated – for example, your child may have their foot manipulated again and put in a cast.

Ensuring your child continues to wear the boots and bar may be enough to improve their clubfoot significantly. In some cases, surgery may be required following a relapse.

If you are worried that your child is relapsing, it is best to get advice from their treating centre.

# 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 may want to monitor your child until their feet have stopped growing.

A long-term study, following children through to adulthood, specifically looked at the results of the Ponseti Method. This study showed that the use of this method resulted in no greater severity of foot pain or reduced function in mid-life to those born without clubfoot.

## 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."





# Beyond this booklet - support when you need it

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.

## 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, for more information about Clubfoot, its treatment or equipment, please contact or telephone 01925 750271 or email [info@steps-charity.org.uk](mailto:info@steps-charity.org.uk) and remember, you are not alone!

# Notes



# Notes

**steps-charity.org.uk**

**Helpline:** 01925 750271 **Email:** [info@steps-charity.org.uk](mailto:info@steps-charity.org.uk)



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**The National Charity for Lower Limb Conditions**

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