



# Talipes/Clubfoot



## The Parents' Guide



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# Introduction

Parents are often distressed when they find out that their baby has talipes or clubfoot as it is also known. Life can suddenly feel overwhelming and be filled with worries and unanswered questions: Is it our fault? What is talipes/clubfoot? Will our child walk? What can be done for our new baby?

It may be helpful to remember that it is absolutely normal to feel like this.

## Support when you need it

We understand that this can be a very difficult time. If you have questions, concerns or simply feel you would like someone to talk to - please do not hesitate to contact us - we will be happy to help.

Please call our helpline on **01925 750271** or email [info@steps-charity.org.uk](mailto:info@steps-charity.org.uk) to request a copy of our Clubfoot – The Ponseti Method DVD or ask about our other services.

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 service can put you in touch with others who have shared a similar experience and can offer advice, support and practical tips. Please contact our helpline

for details. Our online discussion forum is another fantastic resource for helpful tips and practical advice written by parents who are coping with a child affected by talipes/clubfoot. You can also share your problems and solutions to everyday challenges.

Talipes/clubfoot is usually an easily treated condition although the final outcome will in part depend on your child's response to treatment and parental support in complying with the boots and bars stage. However, most children are treated successfully and eventually your child should have pain free functioning feet and be just as active as any other child.

# What is Talipes/ Clubfoot?

The medical term for Talipes 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, it is usually diagnosed as ‘talipes’ but is commonly referred to as Clubfoot. It may affect one foot (unilateral) or both feet (bilateral). Often the calf muscle is less prominent on the affected side.

Clubfoot can be classified into 4 categories:

## Congenital

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. Idiopathic clubfoot occurs in about 1 to 2 per 1000 live births in the UK.

## 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 usually corrects itself with time, sometimes physiotherapy is needed using gentle stretches.

## Complex or Atypical

clubfoot refers to feet which are more resistant to routine treatment but are still correctable, using a slightly different casting technique. Atypical feet are short and chubby with a deep crease across the sole. The big toe may also stick out at an odd angle to the other toes.

## Syndromic

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

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

# Why does Clubfoot happen?

Clubfoot 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. In 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 20 times more likely to have another child with the condition.

Clubfoot affects one baby in every 1000 born in the UK and is twice as common in boys than girls. In around 50% of the cases both feet are affected.

In a small number of cases clubfoot may be associated with other conditions, so your doctor will examine your baby thoroughly, not simply the feet. Ideally all babies with clubfoot will be referred for a scan of their hips as part of the thorough assessment.



## How is Clubfoot diagnosed?

Clubfoot can often be detected in an unborn baby using an ultrasound scan although it is not possible to determine the severity of the condition at this stage and it cannot be treated before birth. However, sometimes it is only discovered at birth as the feet are visibly turned inwards. Whether or not it has been detected before or after the birth, the treatment remains the same.

“At the hospital, we were given a copy of a Steps leaflet and recommended we made contact. From then on we felt like we had another family member supporting us. Steps told us everything we needed to know and more besides and gave us great, frank, personal advice.”

# Treating Clubfoot

A technique called the Ponseti Method is the main treatment for clubfoot. An increasing number of orthopaedic specialists (bone specialists) use the Ponseti Method and it is available in many clinics. However, not all hospitals provide the service.



Before treatment



During treatment



4 weeks after treatment

The Ponseti Method is successful in treating more than 9 out of 10 cases of clubfoot. Long-term results are also very promising compared to previous surgical treatment methods.

Certainly within the first few months of treatment you will need to travel to the hospital on a weekly basis so it is worth bearing this in mind when deciding which hospital you request.

**“I will never forget the day when my son took his first steps. He walked across the room and hugged me. I’m sure that moment is a treasured memory for every parent but for a parent of a child with clubfoot it is extra special.”**



# The Ponseti Method: Overview

“Parents of infants born with clubfeet may be reassured that their baby, if otherwise normal, when treated by expert hands will have normal looking feet with normal function for all practical purposes. The well treated clubfoot is no handicap and is fully compatible with normal, active life.” Ignacio Ponseti, M.D. (Ponseti International Association – [www.ponseti.info](http://www.ponseti.info))

The late Dr Ignacio Ponseti from Iowa, developed the Ponseti Method, a minimally invasive treatment for clubfoot.

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. A plaster cast is then applied from your baby’s toes to their groin to hold the foot in its new position.

The casts will be changed weekly at each appointment and your baby’s foot is corrected a little more each time. A minor operation, known as a tenotomy, is usually required to release your baby’s achilles tendon.

When the foot is fully corrected, your child has to wear 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 and then just at night and nap times up to the age of 4/5years. Regular footwear may then be worn at all other times.



Photograph courtesy of Mr M Uglow, Consultant Orthopaedic Surgeon, Southampton

# The Ponseti Method: Casting Stage

The 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.

The casting stage which takes a couple of months, involves weekly appointments in which a specialist (usually a physiotherapist) manipulates your baby's foot gradually correcting the position of the foot.

On average 5 to 6 casts are required. Your baby may need to have a few more or a few less, depending on the severity of the condition.



A plaster cast is then applied from your baby's toes to their groin to hold the foot in its new position. The toes should be exposed and clearly visible.

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

Most hospitals will allow you to bottle/breastfeed your baby while casting is being done.

This helps as the baby is then more relaxed. You may be allowed to bathe your baby at the hospital when they take the cast off and before they apply the new one.





# The Ponseti Method: Tenotomy/Tendon Surgery

Following the casting stage, your specialist will decide whether your baby needs to have a small operation (tenotomy) to release the tight tendon at the back of their heel (the achilles tendon).

A tenotomy is often recommended when the heel has not stretched down fully (usually after the fourth or fifth cast) and 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 heelcord 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 be assured that this will not be due to pain, but probably because he/she objects 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 and will look worse than it is. Bleeding up to the size of a 20 pence piece is acceptable, more than this should be checked by the hospital.

One in three children will require further surgery when they are between 2 and 7 years of age. This may involve moving a tendon in front of the ankle to a different position to improve the foot's function. (tendon transfer). It is not possible to predict if a tendon transfer is needed until after the child has started walking.

# The Ponseti Method: Boots and Bars

When the foot is fully corrected, your child must wear special boots attached to a bar (brace) to hold their feet in the corrected position. These must be fitted as soon as the cast is removed – a wait of only a few days might result in a relapse.

There are mainly two types of boots supplied by the hospital:-



## Mitchell boots

which are suede boots with buckles.

## Markell boots

which are white leather boots with laces.

Either type of boot works equally well in the majority of cases.

The boots are worn for 23 hours a day for the first 3 months 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.

This is a crucial part of the treatment and relies entirely on the parents' 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. Remember that the casting will correct the feet but it is the boots and bar that maintain the correction long term.

## Important note:

When wearing the boots and bars at night and nap time, parents should aim for 12 hours overnight and set up an evening routine, for example: bath, boots, bottle, bed.



# Relapse

Talipes is never 'cured', rather the position and function of the feet are maximised by the treatment. Sometimes, clubfoot can reoccur. This is known as a relapse and it is estimated to occur in 1 or 2 out of every 10 cases. Relapses are more likely if the treatment method described in this booklet is not followed exactly.

When there has been a relapse, it may be necessary for some of the treatment stages to be repeated - for example, your child may need to have their foot manipulated again and put in a cast.

In some cases, ensuring that your child continues to wear the boots and bar may be enough to improve their clubfoot significantly. However, in other cases where there has been a relapse, surgery may be required.

Continuing with the boots and bar up to the age of 4/5 years reduces the incidence of a relapse to 5% (there is a 30% risk of relapse if stopped at 3 years of age). 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.

## What is the long term outcome?

Most children do well with treatment and there will be no problems going to school and taking part in a full range of sporting activities. There has only been one long term study following children through to adulthood and this was specifically to look at the results of the Ponseti Method. This study showed that the use of this method resulted in no greater severity of foot pain in mid life to those experienced by people without clubfoot.

Following treatment, the specialist will probably monitor your child until their feet have stopped growing.

# General Care Advice

Even though you may be upset to learn that your baby has clubfoot, please be reassured that treatment should not hurt your baby. This is not to say that they won't protest strongly during examination and treatment.

Caring for a child throughout treatment can be challenging at times so don't be afraid to ask for help from friends, family, hospital and of course Steps. Our helpline team are available to offer confidential advice and help with any concerns you may have no matter how big or small, so please do get in touch on [01925 750271](tel:01925750271) or email [info@steps-charity.org.uk](mailto:info@steps-charity.org.uk)

Quote from an adult born with clubfoot treated with surgery and now in pain.

“So to any parent needing support during their child's corrective procedure, I say do it with love. Think long term and think positively about all the things they will be able to do and not have to go through. From my perspective, this type of treatment is a quick fix and will avoid years and years of all things unnecessary. It might seem hard on a new born baby and a lot to cope with, but it's an investment in your child's future.”



# Plaster Cast Care Advice

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 – it is easily damaged. Plasters dry best when they are exposed to the air.

The plaster cast can either be removed in clinic or at home. If you are requested to remove the cast at home this must be done as close to your appointment time as possible. Relapse may occur if removed the night before or in some cases within a few hours.

It is important to follow all of the instructions below carefully to ensure your baby is happy and safe, and the treatment is 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.
- Your baby's toes change in appearance and become cold.
- The plaster becomes loose, cracked or crumbly. Keep the plaster dry at all times.

# Frequently Asked Questions - Casting

## 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 any advice but in general if you use a baby bath to soak the cast for a good 10 minutes with warm water the cast will start to disintegrate. Every week as your baby is recast the process will get easier and most mums find that feeding is the best way to keep your 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/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. We would also suggest 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 whilst 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 will generally 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 this can vary.

The edges of the plaster are often 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 can slip down inside the plaster which can irritate the baby's skin.



Some babies can have disturbed sleep patterns during treatment especially when the first cast is applied. Try altering their 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 overnight 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.

## How will I know the casts are working?

You will be surprised how quickly the foot is looking 'normal' and 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 as the feet improve.



Before treatment



4 weeks after treatment

# Boots and Bars Advice

This stage is probably the hardest part of the treatment as your child's feet will now look corrected but it is VITAL that the boots and bars should be a non-negotiable part of your child's routine to prevent a relapse.

Your child may object to the boots and bar especially during the first few days. This is not because they are painful, but because they are something new and different. Children can vary, some don't seem to mind the boots and bar whilst others seem to object to them. However, if your child is completely inconsolable and you believe that they are in pain, contact your hospital right away.

Play with your child in the boots and bar. Your child will be unable to move his/her legs independently so you can teach them that they can kick and swing their legs simultaneously with the boots and bar on. You can do this by gently flexing and extending their knees by pushing and pulling on the bar.

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.

Your child may adopt a very strange sleeping position. Baby sleeping bags will help with padding and will keep the baby from pulling at the straps and laces.

If blistering occurs this usually indicates that the boot has not been fitted tightly enough. Make sure the heel stays down in the shoe. If it continues to slip and the blisters show no sign of healing, contact your hospital.



Please contact our helpline on [01925 750271](tel:01925750271) or email [info@steps-charity.org.uk](mailto:info@steps-charity.org.uk) to request advice on clothes, socks, etc.

## 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 talipes, you'll be so engrossed in the development of the feet that you risk missing out on other small details, so taking photos helps you to think about the whole development of your baby"



## "Superheroes"

As night time fell and it was time to sleep  
She was tucked up in bed, not making a peep,  
After a bath and a story, milk and a kiss,  
Her adventures in dreamland she didn't want to miss!  
On with the first boot, then with the other,  
She smiled at her mommy and pulled up the covers,

For Jaime was a special girl who wore boots and a bar,  
So she could jump really high and run really far,  
So she could hop and skip and dance all day  
And be a "superhero in my dreams" she would say.  
A superhero? I hear you shout  
What's this superhero business about?

You see, every night when she closed her eyes,  
She'd dream that her boots made her fly through the skies,  
She'd surf on the water and ski on the snow,  
And fly higher and higher - to space she would go!  
She'd see mountains and rivers, deserts and trees,  
Fly with birds and aeroplanes over the seas....

And as morning approached and she'd stir in her bed,  
She'd remember her dreams and what her mommy always said.  
"That special girls and boys who wear bedtime shoes  
Will grow up big and strong and be whatever they  
choose..."

So to all you "superheroes" who wear their boots at night,  
You are amazing and fantastic, oh and  
super, that's right!

Poem by Rachel Gessey, mum to Jaime



# Glossary of terms

Abduction	Moving away from the midline of the body
Achilles tendon	A large tendon connecting the calf muscles to the heel bone
Adduction	Moving towards the midline of the body
Anterior	At or towards the front
Atrophy	Wasting – usually of the calf muscle
Bilateral	Affecting both sides
Calcaneum (or Os Calcis)	The heel bone
Calcaneus	Describes the posture of the hind foot when in an upwards position (opposite of equinus)
Dorsal (dorsum)	Top of foot
Dorsiflexion	Bending the ankle so the foot points up
Epiphysis	The growing section of a bone
Eversion	Turning the sole of the foot outward
Fibula	Bone on the outer side of the leg below the knee
Idiopathic	Cause unknown
Inversion	Turning the sole of the foot inward
Lateral	The outer edge
Metatarsal bones	The five bones of the foot between the tarsal bones and the toes



Metatarsus varus or Metatarsus adductus	Inward turning of the metatarsal which gives a pigeon toed appearance
Orthosis	Splint or support
Orthotics	Department dealing with splints and appliances
Plantar	Relating to the sole of the foot
Plantar flexion	Bending the ankle so the foot points down
Plantigrade	Walking normally on the whole sole of the foot
Plantar surface	Sole of the foot
Pronation	Foot rolls inwards
Supination	Foot rolls outwards
Tarsal Bones Metatarsal	Bones in the foot between the ankle joint and the bones
Tenotomy	The surgical cutting of a tendon
Tibia	Shin bone (next to fibula)
Unilateral	Affecting one side
Valgus	Directed away from the midline of the body
Varus	Directed towards the midline of the body

**steps-charity.org.uk**

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

 Steps Charity Worldwide  @Steps\_Charity

Steps registered charity number 1094343

Company number 4379997

Externally reviewed August 13 and republished July 2016

Steps is the national charity working for all those whose lives are affected by childhood lower limb conditions

**Acknowledgements:**

Steps wishes to thank:

**Mr Guy Atherton MA FRCS, Consultant Paediatric Orthopaedic Surgeon, Bristol Royal Hospital for Children.**

**Mr Simon Barker BSc(Hons) FRCSEd, Consultant Paediatric Orthopaedic Surgeon, Royal Aberdeen Children's Hospital.**

**Mr Mike Uglow FRCS (Tr&Orth), Consultant Paediatric Orthopaedic Surgeon, University Hospital Southampton.**

**Denise Watson, Paediatric Orthopaedic Physiotherapy Practitioner, Chelsea & Westminster Hospital London.**

**Mr Fredrick Dietz, MD University of Iowa Hospitals and Clinics.**

**Mr Manoj Ramachandran, Consultant Paediatric and Young Adult Orthopaedic Surgeon, Barts and the London Children's Hospital and The Royal London Hospital.**

**Ms Clare Carpenter, Consultant Paediatric Orthopaedic Surgeon, University Hospital of Wales.**

**Mr Mike Benson, Steps Trustee and Orthopaedic Advisor.**

**NHS Trust and all the parents who provided feedback and photos for the production of the Talipes/Clubfoot leaflet.**

**We don't take  
walking for  
granted...**



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 give with confidence