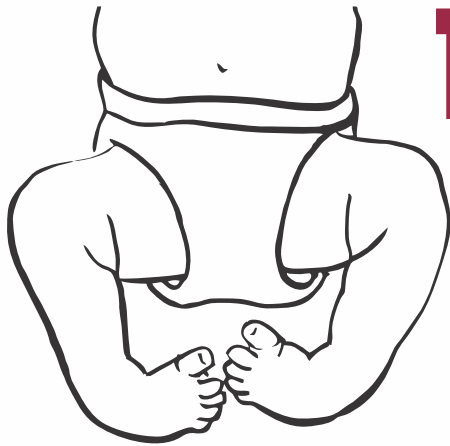


Ponseti for Parents[©]



1

INTRODUCTION

2



CASTING

3



BRACING

4



FOLLOW-UP



Ponseti for Parents[®]

Parent adviser manual

Foreword

This manual is intended as an educational tool for parent advisers interacting with families in clubfoot clinics.

The STEPS Ponseti for Parents[®] programme informs and encourages the families of children born with clubfoot. It provides information about clubfoot and the treatment, what to expect, and how important their involvement and commitment is to ensure a successful outcome.

Recent studies, and anecdotal reports we have received from clubfoot clinics, indicate that family support and education with a positive message, helps parents to follow the treatment guidelines, and reduces recurrence.

The material is informative and practical. There are many visual references to make it simpler to convey the content.

Each stage of treatment is colour-coded, so it is easy to access and refer to while the parent adviser talks to families.

We hope that you will find this to be a valuable resource and support for the families of babies born with clubfoot.

Warm regards,



Karen Moss

(STEPS founder and Executive Director)

References:

1. Ponseti, Ignácio V. *Congenital Clubfoot: Fundamentals of treatment*. Oxford University Press, January 1996
2. Pirani, Shafique, Lynn Staheli, & Edward Naddumba. *Ponseti Clubfoot Management: Teaching Manual For Health-Care Providers In Uganda*. Global-HELP Organisation, 2008
3. Lohan, Iris. *Treatment Of Congenital Clubfoot Using The Ponseti Method: Workshop Manual*. Global-HELP Organisation, 2011.
4. Staheli, Dr. Lynn, Dr. Ignacio Ponseti, et al. *Clubfoot: Ponseti Management. 3rd edition*. Global-HELP Publication. Global-HELP Organisation, 2009.
5. Ponseti International Association website, various articles. <www.ponseti.info>
6. South African clubfoot information website. <www.clubfoot.co.za>
7. Morin, M., D. Hoopes, and E. Szalay. *Positive Communication Paradigm Decreases Early Recurrence in Clubfoot Treatment*. *Journal of Pediatric Orthopedics*, 34:2, March 2010
8. Nogueira, Monica Paschoal MD PhD, Mark Fox, and Jose Morcuende MD PhD. *The Ponseti Method of Treatment for Clubfoot in Brazil: Barriers to Bracing Compliance*. *Iowa Orthop Journal* Oct; 33: 161-166
9. Morgenstein A, Davis R, Talwalkar V, Iwinski H Jr, Walker J, Milbrandt T. *Randomized Clinical Trial Comparing Reported and Measured Wear Rates in Clubfoot Bracing Using a Novel Pressure Sensor*. *Journal J Pediatr Orthop*. 2014 Apr 29.
10. Haft GF, Walker CG, Crawford HA. *Early clubfoot recurrence after use of the Ponseti method in a New Zealand population*. *J Bone Joint Surg Am*. 2007 Mar;89(3):487-93

NOTE: This manual is used in conjunction with Ponseti for Parents leaflets that are given to families for take-home information:

Patient Handout 1: *Introduction and casting*

Patient Handout 2: *Bracing*

FOR THE PARENT ADVISER

THE PARENTS' ROLE

Parent support is crucial to achieve a good result for clubfoot treatment.

If parents do not understand or follow the instructions, problems can occur, and the possibility of recurrence or relapse is high.

It's important to explain to parents how important their role is for a successful outcome.

They are a key part of the team that ensures their child will walk on straight and flexible feet.

The treatment is tougher on the parents than the child.

They feel guilt and sadness about what their child has to go through, and think that perhaps they did something wrong to cause it. They worry that the child will be in pain. They feel anxiety about the outcome for their child.

Reinforce and confirm that nobody is to blame for the child having clubfoot.

Explain the steps of treatment carefully. Make sure that they understand the treatment and the importance of these instructions.

Parents may feel overwhelmed by the new information.

They worry that they cannot cope with what is required. You can reassure them that this treatment does not hurt the child, a well-fitted brace on a corrected clubfoot should not be painful, and in time it will be a part of their daily routine.

YOU WILL MEET WITH THE PARENTS AT DIFFERENT STAGES OF TREATMENT:

FIRST CONSULTATION

- Explain clubfoot
- Explain how the Ponseti treatment works, and how long it takes
- Emphasize that their cooperation is very important for success
- Reassure them that although it will be hard for them, their child will not experience pain and the treatment is successful
- Describe the outcome to reassure them:
 - Successful for over 90% of cases
 - Child will be able to walk and run on strong, functional and pain-free feet
- Give them the introductory leaflet to take home – ***Patient Handout 1: Introduction and casting***

CORRECTION PHASE – CASTING AND TENOTOMY (USUALLY 4-8 WEEKS)

- Explain cast care – keeping them dry, checking circulation in the toes, etc
- Explain the tenotomy and why the cast must be kept on for longer.

MAINTENANCE PHASE – BRACING (USUALLY 4 YEARS)

- Emphasize the wearing of the brace is non-negotiable
- Explain the brace wear schedule
- Explain that although the foot looks straight, it can turn back in if the brace is not worn
- Explain that the child needs a few days to adjust to the brace, some crying is normal
- Reinforce that the brace should not be removed if the child cries
- The brace should be part of the routine from the start.
- Put the brace on with the parent and ask them to practice with you.
- Explain how to check for the correct position of the heel inside the shoe
- Give them the brace leaflet to take home – **Patient Handout 2: Bracing**

Emphasise that they should come to the clinic if there is any sign of problems described in the introductory and bracing leaflets

FOLLOW UP, OUTCOME

- Explain that follow up appointments are important to check on the fit of the brace, to look for signs of relapse or other changes
- Encourage them to come to regular check-ups as prescribed and to follow all instructions
- Emphasize that they should come to the clinic if there are problems with keeping the brace on
- Encourage them to talk to the doctor or other clinic staff about their concerns

OLDER CHILDREN, COMPLEX CASES, RELAPSE

There are some patients who may need additional or modified information.

- Late referral, recurrence, resistant clubfoot (approximately 10% of cases), complex and syndromic clubfoot often require more support and detailed information
- These patients need a specialist team to diagnose and specify treatment, and in most cases the treatment takes longer, requiring more specialised and intensive support for the families
- In less than 10% of patients the treatment fails because the foot is complex or resistant. Some of these cases can still respond well but a very experienced doctor must do the treatment
- Recurrent clubfoot is most often because the child is not wearing the brace as instructed. The foot can be treated again and more information given about the brace wear

To help with communication of information, clubfoot can be classified as:

- a Untreated clubfoot** – Under 2 years old
- b Neglected clubfoot** – Untreated clubfoot after 2 years old
- c Corrected clubfoot** – Corrected by Ponseti treatment
- d Recurrent clubfoot** – The foot starts to turn in again (supination), the heel stretch reduces, child on tiptoes (equinus)
- e Resistant clubfoot** – Stiff clubfoot, often seen with syndromes, e.g. arthrogryposis
- f Complex clubfoot** – Usually to describe clubfoot treated by a method other than Ponseti and needing more treatment

EFFECTIVE COMMUNICATION WITH PARENTS

According to studies 40-80% of medical information given to patients is forgotten immediately. The more information that is given, the less is remembered. Also about half of information that is remembered is incorrect.

Medical information given to parents needs to be:

- Remembered + Understood in order for them to have = Satisfaction with the treatment = Adherence
- Simple and specific instructions are remembered better than general statements
- We have colour-coded the book, so the treatment explanation is categorized different phases
- Visual communication aids are especially effective in low-literacy patients
- The manual and leaflets are well-illustrated
- A combination of spoken (Clinic) and written/visual information (Leaflets) is best



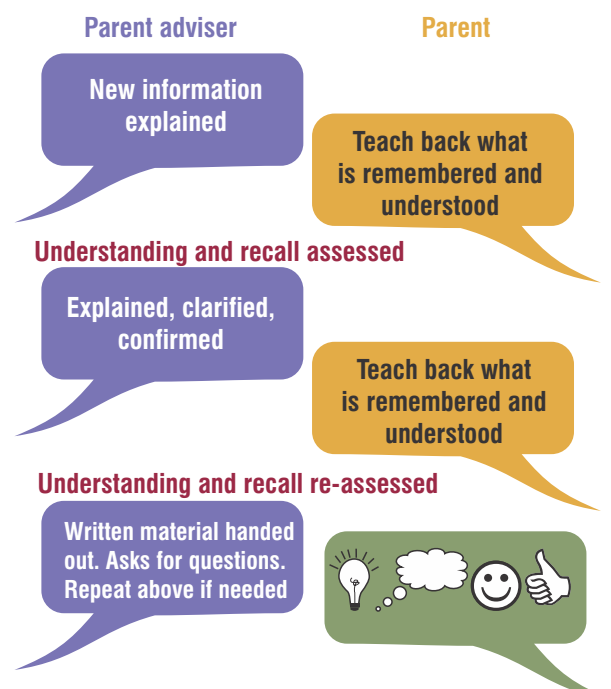
Overview of Ley's model on the interactions between patient-related factors and therapy adherence, Roy PC Kessels, PhD

The 'Teach-back' Method

Teach-back confirms that you have explained the information in a way that the parent or caregiver understands clearly. You confirm this by asking the parent to explain it back to you. This feedback can also help clinic staff find the best ways to communicate the information.

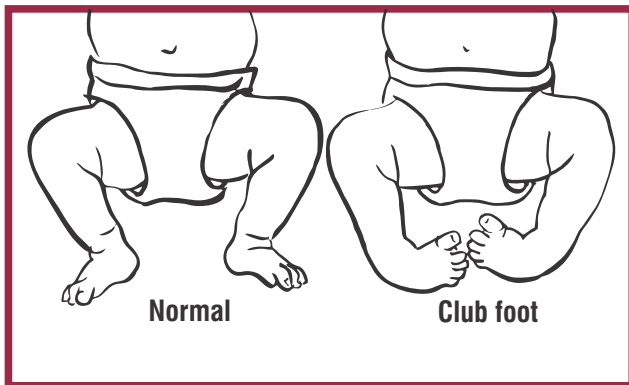
Tips for 'Teach-Back':

- Start slowly
- Plan your approach
- Listen more, talk less
- Use the correct questions: 'What are you going to do when you get home?', 'Show me how you would put on the brace.'
- Assess the memory and understanding
- Clarify anything that needs more explanation
- Repeat the Teach-back method until you are satisfied the parent understands
- Use the take-home leaflets, and show images in the manual as a visual reference.



FIRST CONSULTATION

CLUBFOOT DIAGNOSIS AND TREATMENT



WHAT IS CONGENITAL CLUBFOOT?

- The foot points downward and it is twisted inward so that the top of the foot is almost where the bottom should be
- The foot is stiff and cannot be brought to a normal position
- One or both feet can be affected
- 'Congenital' clubfoot means that the child is born with the condition
- The medical name for clubfoot is Talipes Equinovarus

WHAT CAUSES CLUBFOOT?

- Clubfoot is no-one's fault
- Your baby's clubfoot is not caused by anything you have done, or have not done while pregnant
- Doctors do not yet know the cause of congenital clubfoot
- Sometimes clubfoot can run in families, sometimes it is an isolated case
- Sometimes clubfoot is linked with other conditions, but this is very rare
- Most children with clubfoot are otherwise healthy

HOW IS CLUBFOOT TREATED?

- **The Ponseti method** is the treatment of choice
- This treatment corrects the position of the foot slowly and gently, so that your child will have a foot that functions well and looks normal, with no pain

WHEN DOES THE TREATMENT START?

- Treatment can start at 7 – 10 days old
- Ideally, when the child is 2 weeks old, they should have their first casts applied
- If your baby is older but not walking, treatment is still very effective
- If your child is walking, the treatment can still be successful, but it can take longer as the foot is less flexible and some older children may need additional surgery

OVERVIEW OF THE PONSETI TREATMENT FOR CLUBFOOT

The description below is the standard procedure for babies with congenital clubfoot. If your child is older, or has other health problems in addition to clubfoot, the treatment plan may differ.

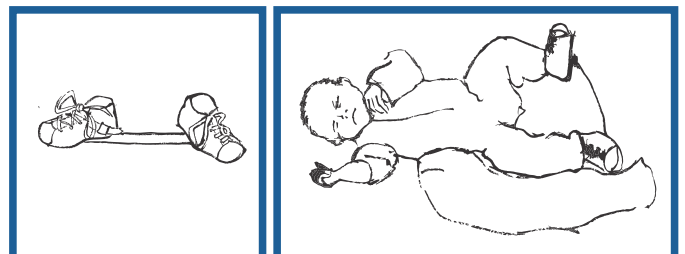
WHAT DOES THE TREATMENT INVOLVE?

The treatment has two parts:

1. Correction Phase (CASTING & TENOTOMY)



2. Maintenance phase (BRACE)

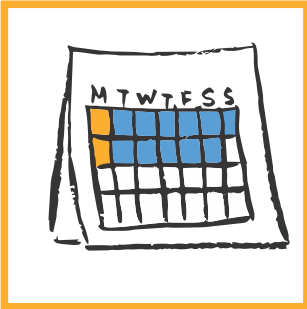


CORRECTION PHASE

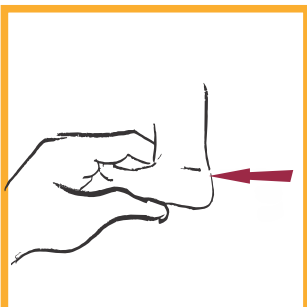
CASTING



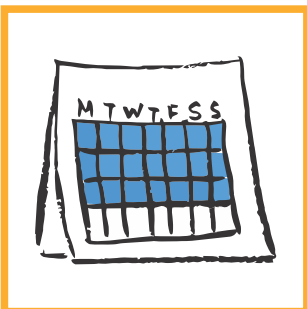
- The foot is gently manipulated and full leg plaster casts (POP) are applied to hold the foot in position and stretch the ligaments and tendons
- The cast is removed every 5 to 7 days, then the foot is manipulated again and another cast (POP) applied until the bones are in the correct position
- The position of the foot will change quickly
- For young babies starting treatment by 2 weeks of age, it usually takes 4 to 6 casts to correct
- For children under 6 months old, it should take a maximum of 8 casts over a period of two months, changed weekly
- For older children and complex clubfoot, it can take longer to correct the foot and more casts may be needed



TENOTOMY AND FINAL CAST



- Most children will need the tenotomy, which is a minor procedure usually done with local anaesthetic
- Children need the tenotomy because their heel (Achilles) tendon is short and tight and it pulls the heel up
- If it is not corrected the child will walk on tiptoes
- Some doctors use general anaesthetic for older patients
- After the tenotomy a final POP cast is applied and left on for three weeks
- During this time the tendon regenerates in the lengthened position and the foot can be bent up easily towards the front of the leg (dorsiflexion)
- If your baby is unhappy after the tenotomy, it is fine to use some paracetamol (Calpol, etc.) as you would after vaccinations



FOR HOME REFERENCE: Patient Handout No. 1: *Introduction and Casting*

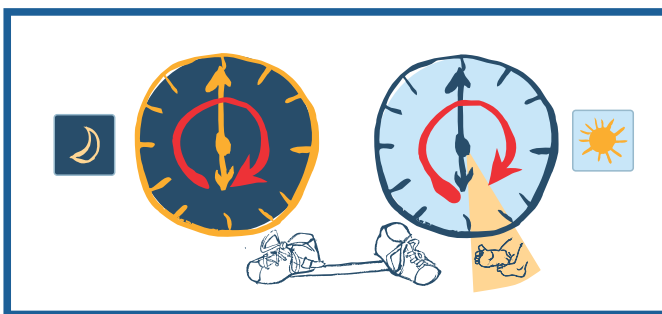
MAINTENANCE PHASE

BRACING

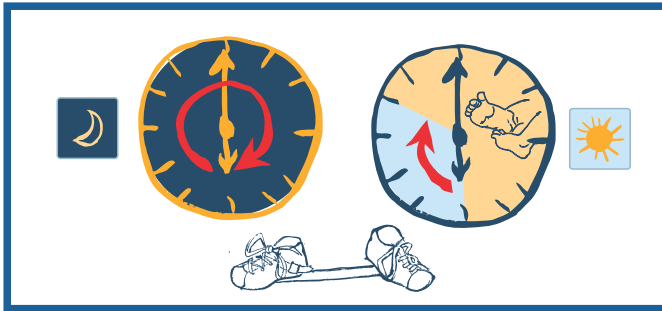
- The bracing is a critical part of the treatment.
- You and your family play an extremely important part in this phase.
- Immediately after the last cast is removed, your baby will start to wear the clubfoot brace (two shoes attached to a bar).
- Both feet are put in the shoes even if your child only has one clubfoot.
- Even though your baby's feet will look normal, they can turn in again if you do not use the brace.
- If the foot turns in again more casts are needed, and sometimes surgery if the child is older.
- **It is very important to make sure that your baby wears the brace as you are told:**

BRACE TIME SCHEDULE

To achieve the best result from treatment, the instructions need to be followed closely. It will depend on the child's age, but the standard brace wear schedule is as follows:



First 3 months: Brace worn for 23 hours every day. It comes off for one hour for bath time.



After 3 months of full-time brace wear: The brace wear is gradually reduced by 2 hours per month - when your baby is sleeping (day naps and night-time).

NOTE: Keep the brace on for at least 14 hours until your child starts to walk.

Once your child is walking: 12 hours of brace wear (night time when sleeping) is recommended until your child is 4 years old.

REMEMBER: Be consistent. Have a routine from the start and your child will adapt to the brace. Wearing the brace is good and is part of the treatment.

FOR HOME REFERENCE: Patient Handout No. 2: *Bracing*

HOW LONG WILL IT TAKE?

The schedule below is typical for a newborn of about 2 weeks old

CASTING

WEEK 1

WEEK 2

WEEK 3

WEEK 4

WEEK 5

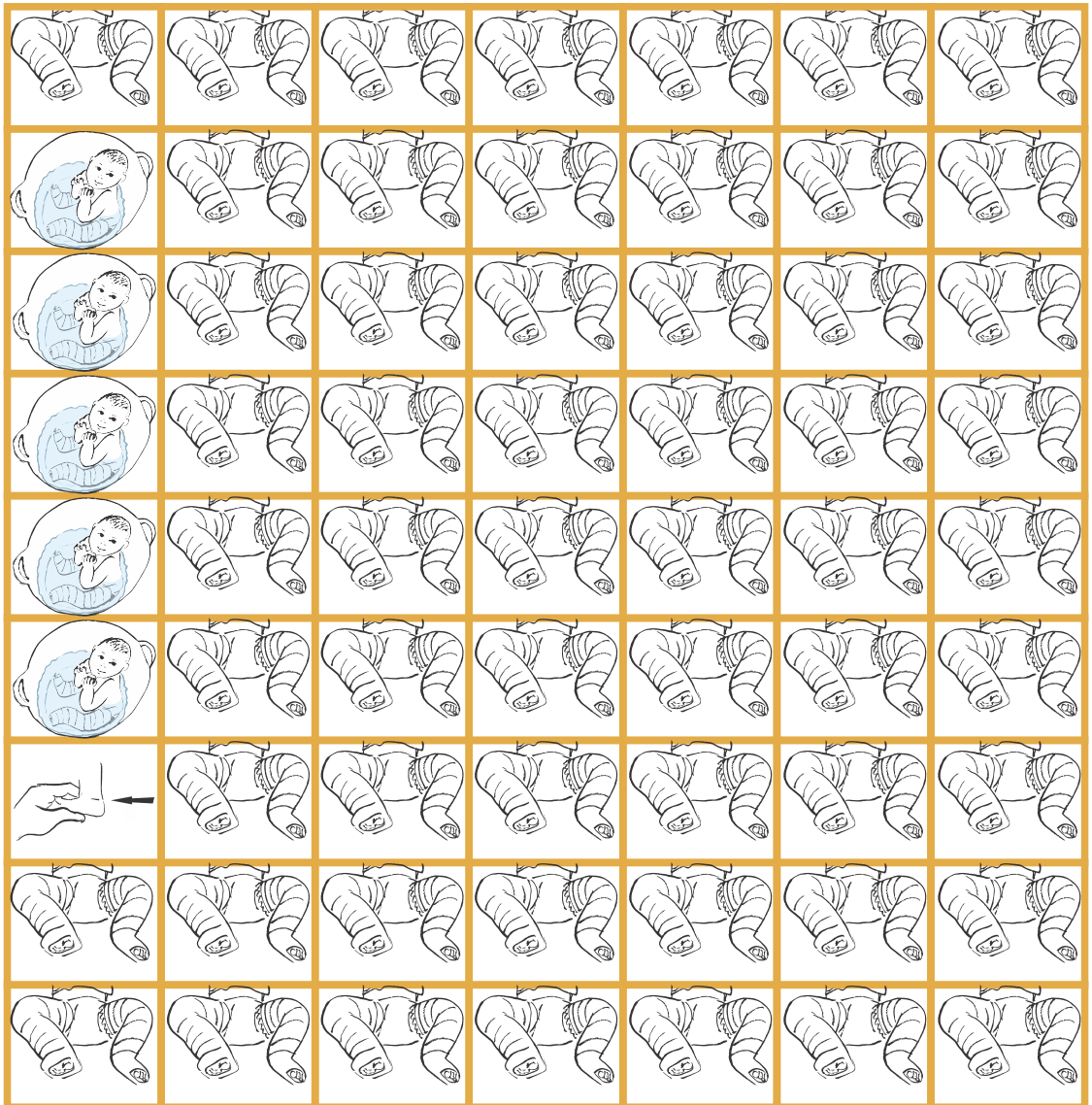
WEEK 6

TENOTOMY + CAST
(90% of cases)

WEEK 7

WEEK 8

WEEK 9



BRACE
(initial phase)

MONTH 1

MONTH 2

MONTH 3



**23 HOURS
A DAY**

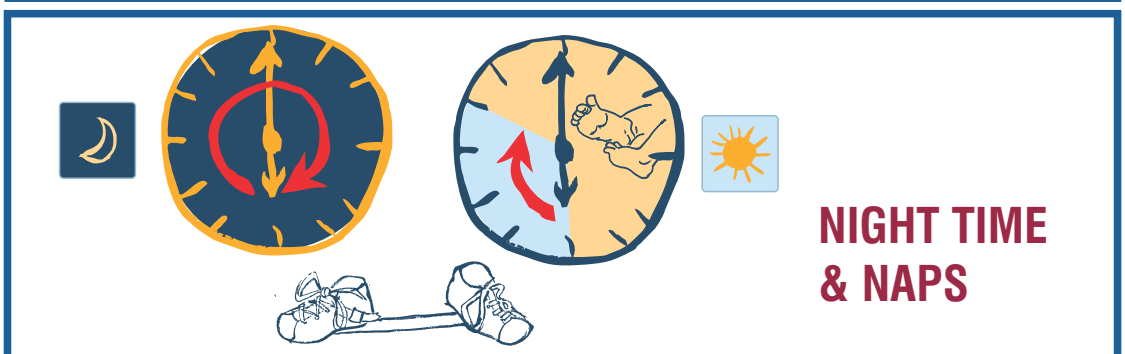
BRACE
(continued maintenance)

YEAR 1

YEAR 2

YEAR 3

YEAR 4



**NIGHT TIME
& NAPS**

INSTRUCTIONS AND ADVICE FOR THE CORRECTION PHASE

WILL THE MANIPULATION AND CASTS HURT MY BABY?

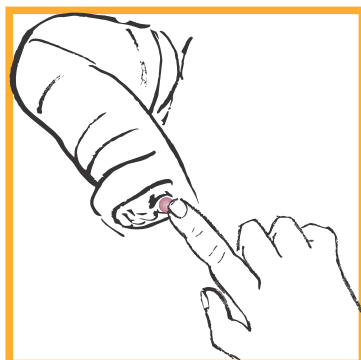


- The manipulation is very gentle and will not hurt your baby
- If your baby is upset during casting, it can be because they don't like having their legs held, or because they don't like having their clothes removed
- To help with this you can comfort your baby. Bring your baby to the clinic hungry and feed during the casting. You can also play, sing, and use noisy or shiny toys as distraction
- You will be able to feed your baby during the casting, they may tell you the best place to stand and how to hold your baby
- Your baby may be restless for a few hours after casting. The casts are heavy until they are completely dry. You can roll up a small towel and put it under your baby's knees to help support the weight of the cast

CAST CARE AT HOME



1. Keep the cast clean and dry
2. Do not bath your baby while in casts - lay your baby on a towel, use a soapy cloth to wash, rinse off and dry with a towel, without wetting the cast
3. Check for cracks or breaks in the cast
4. Rough edges at the top of the cast can be padded with some cotton wool to protect the skin from rubbing
5. Do not put powders or lotion inside the cast
6. Cover the cast while your child is eating and drinking
7. Prevent small toys or objects from being put inside the cast
8. For nappy leaks wipe the cast as clean as possible with wet wipes (do not use water or a wet cloth)
9. You should always be able to see your baby's toes
10. Toes should be normal skin colour and feel warm
11. Press the toes a few times a day to check if they are warm, and make sure that the colour comes back quickly afterwards
12. Your baby should be able to move the toes while in the cast, both freely and when you touch them
13. In cold weather you can put socks over the casts to keep the feet warm
14. You can roll up a small towel and put it under the knees to help support the heels when your baby is in a car seat or carrier, or sleeping



CAST CARE AT HOME (continued)

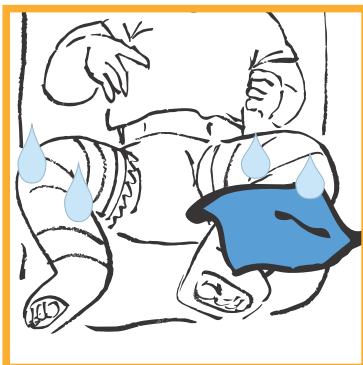
If you notice any of these, or are worried, call your doctor or go to the clinic immediately.



1. High fever
2. Increased swelling above or below the cast
3. Fluid or bad smell from inside the cast
4. Toes are cool or cold
5. Toes are not normal skin colour.
6. You cannot see the toes, they have slipped back into the cast
7. The cast is cracked or soft
8. Swollen toes
9. Cast is too tight around top of leg
10. Your baby kicks the cast off



REMOVING THE CAST



- Some clinics will remove the cast when you arrive. Some will ask you to remove it yourself. The cast should only be taken off the day of the appointment, not the night before
- The foot can start to turn in after removing the cast, which is why it shouldn't be too long between the last cast being removed and the next one applied
- Wet the cast and wrap with a damp towel, then cover with a plastic bag until the plaster softens
- You should find a knob of bandage near the knee where you can unwind and remove the cast
- Adding some vinegar to the water before wetting the cast helps to soften the plaster faster
- If you remove the cast at the clinic, they will give you a container with warm water to sit your baby inside so you can wet the casts and soften them before removing



FOR HOME REFERENCE: Patient Handout No. 1: *Introduction and Casting*

INSTRUCTIONS AND ADVICE FOR THE MAINTENANCE PHASE

WILL THE BRACE HURT MY BABY?

- The brace should not hurt your baby
- Do not remove the brace if your baby cries, this will make it more difficult to keep it on in future
- The first few days are very important to establish the brace routine
- Your baby needs to get used to wearing the brace, it takes 2 – 7 days for most babies to adjust
- Your baby needs to get used to moving and lifting both legs at the same time
- You can play with the bar while it is on, move it up and down, bend and straighten the knees to show your baby how to move the legs together
- When your child is used to the brace, they can move freely and reach milestones like crawling and walking just like any other child
- **Do not stop using the bar if you have problems.** Clubfoot can recur without the bar. Go to your doctor or clinic and ask for help

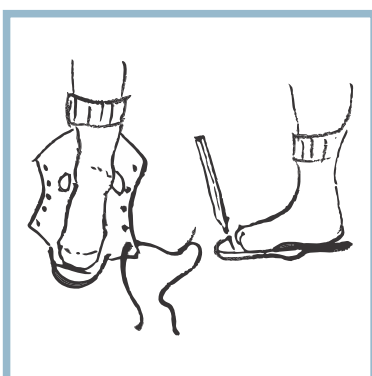
FITTING THE BRACE

1. It is important to put the brace on correctly and it must be worn daily for the amount of time the doctor says.
2. The shoes **must** be worn with the bar for the brace to work
3. It takes time to get used to putting on the shoes, but be consistent and soon it will be part of your routine

BRACE TIPS



- The skin on legs and feet should be clean and dry
- Do not put cream or lotion on the feet
- Plain cotton socks without stitching or patterns are most comfortable
- Socks with rubber grips on the bottom can help prevent slipping inside the shoe
- Some children are more comfortable without socks, especially in hot weather
- Open the shoe up completely the first time so you can see that the foot is correctly positioned
- Fit the shoe on the affected or more severe foot first
- Bend the knee and apply a bit of pressure while you put on the shoe. This helps to keep the heel down and the foot in the right position
- When fitting for the first time, draw a line on the inside of the shoe at the edge of the toes



BRACE TIPS (continued)

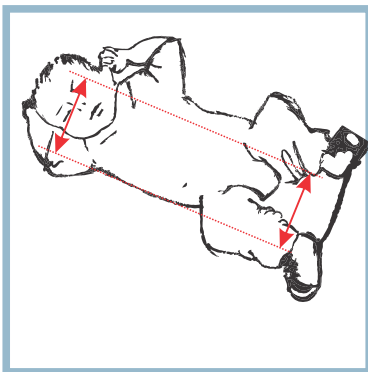


- Always check that the heel is right at the back of the shoe and touching the bottom before tightening the straps or doing the laces up
- Keep your thumb pressed down across the middle of the foot to keep it down securely while you do the laces or tie the straps
- Fasten the shoes laces or straps securely
- Holding the shoe firmly with one hand, pull the leg upwards to make sure that the foot is not moving inside the shoe. If it does, lace the shoe tighter
- You should still be able to see the line you drew in front of the toes. If you can't the heel has slipped up. Remove the shoe and start again
- Keeping the knee bent helps to get the heel down
- Check again that the heel is still down and far back enough in the shoe. Most shoes have a small hole at the side of the heel so you can check easily
- Check that you can see all the toes, and they are straight
- Don't be afraid to redo it until you get it right. After a while, it will become so quick and easy and part of your routine

Do a demo on a child showing how to put the brace on. Check shoe, toes, heels etc.

Ask the patient's caregiver to show you how they put on the brace, and guide them, if needed, to increase confidence

PROBLEMS WITH THE BRACE

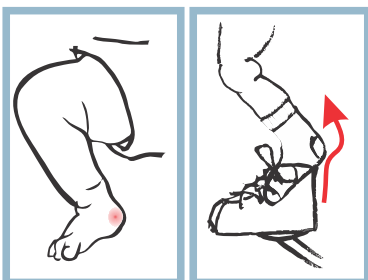


After the first few days of adjustment, your child should be wearing the brace without problems.

It is important to note any changes and contact your doctor or go back to the clinic as a problem with the brace can mean that:

- Width of brace is too short
- Shoes are too small
- Foot is turning again or not well corrected

SHOE FITTING, BRACE ADJUSTMENTS



If the shoe does not fit correctly, it can cause problems. Contact your clinic immediately if you see:

- Red pressure marks or bruises on the feet
- Open pressure sores or blisters on the feet
- Foot slips out of the shoe even when you have tightened it correctly

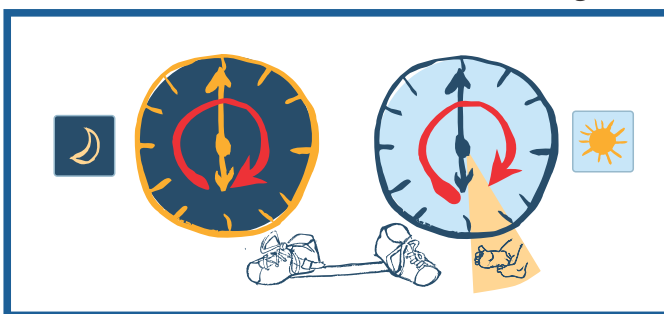
SLEEP DISTURBANCES

After the first period of adjustment, most children sleep well in the brace. If, after adjusting to the brace, your baby is upset or not sleeping, but is not sick or teething, etc., there are a few things to try:

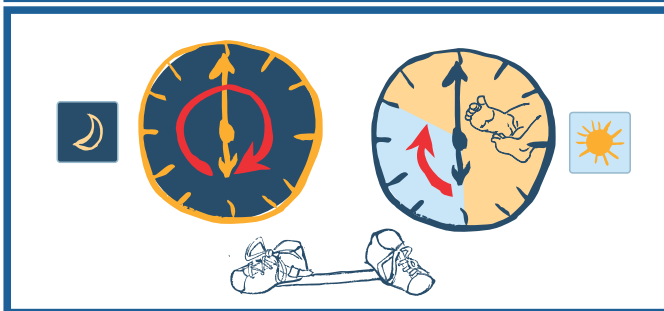
- Check that that the shoes are still the correct size.
- The bar may become too narrow because your child has grown, if you have an adjustable bar, widening it slightly may help, or you may need to get a bigger bar
- Make sure that loose bedding is not getting tangled in the brace; a sleeping bag or light blanket is best
- Pad the side of the cot if the brace is banging on it and waking your baby
- Move your older child to a camp cot if they need more room for the brace

HOW LONG WILL MY BABY HAVE TO WEAR THE BRACE?

Most babies wear the brace until the age of four.



First 3 months: Brace worn for 23 hours every day. It comes off for one hour for bath time.



After 3 months of full-time brace wear: The brace wear is gradually reduced by 2 hours per month - when your baby is sleeping (day naps and night-time). By the time your baby is weight bearing (cruising), brace wear is at least 12 hours.

WHAT CLOTHES CAN MY BABY WEAR, DO I NEED SPECIAL EQUIPMENT

- While your baby is in casts, footless leggings and all-in-one suits are best
- While in the bar, it's easier to use pants that have poppers so you can change the nappy and remove clothes without having to remove the bar. Dungarees are good, and girls can wear dresses or skirts
- Most car seats and strollers/prams will work, as long as you can still secure the middle strap. The wider ones are best

FOR HOME REFERENCE: Patient Handout No. 2: *Bracing*

WHAT HAPPENS IN THE FUTURE?



Regular check-ups to make sure that the brace fits and the feet are still looking good. Any type of shoes or barefoot is fine for when your child is not wearing the brace.

Your baby will grow up with straight and flexible feet and be able to run, walk and play like any other child.

A small number of children will have more resistant clubfoot that can come back as the child grows and need more casting or sometimes surgery. This is why the regular clinic visits are important.

WHO CAN I TALK TO ABOUT CLUBFOOT?

Many clinics have a clinic assistant who will explain clubfoot and the treatment. At clinic days you will meet other parents who have babies and children in different stages of treatment, you can talk to them or join a parents support group.

For information on Southern African Ponseti contact:

www.steps.org.za

www.clubfoot.co.za

www.ponseti.co.za

It is important to remember that you, the parent, are the most important part of the treatment. This cannot be done without you making sure your child is at every appointment. The casts need to be changed once per week and the brace needs to be worn every night.

If you need help or support during the treatment, please contact your clinic or a parents support group for advice and help.

GLOSSARY OF TERMS

This glossary of terms is designed to be a quick guide to the medical terms.

| | |
|--|--|
| Abduction: | The movement of a limb away from the midline of the body |
| Achilles Tendon: | The tendon that joins the bone of the heel to the calf muscle. |
| Anterior: | At or towards the front. |
| Anterior Tibialis Tendon Transfer (ATTT): | A procedure usually only performed around age four for children with continual relapse problems. To prevent further relapses, the tendon of the tibialis anterior muscle is transferred (pulled across and attached) to the third cuneiform (bone of the foot). This makes the foot plantigrade and prevents relapse. |
| Arthrogryposis: | Distal arthrogryposis type 1 is a disorder characterized by joint deformities (contractures) that restrict movement in the hands and feet. The characteristic features of this condition includes permanently bent fingers and toes (camptodactyly), overlapping fingers, and a hand deformity in which all of the fingers are angled outward toward the fifth finger (ulnar deviation). Clubfoot (syndromic) is also commonly seen with distal arthrogryposis type 1. |
| Bilateral clubfoot (BCF): | Both feet are affected. |
| Calcaneus: | Heel bone, the larger of the two bones forming the ankle joint |
| Complex clubfoot: | This clubfoot is shorter, broader and has a deep crease across the sole. It is more difficult to treat, and usually requires modified casting |
| Congenital: | A condition that is present at birth. |
| Deformity: | A distortion of any part of, or the body in general, different in size or shape |
| Dorsiflexion: | In clubfoot treatment, dorsiflexion is the ability to bend at the ankle, moving the foot upward in the direction of the shin. |
| Eversion: | Sole of the foot turns outwards |
| Genetic: | Refers to genes, and inherited traits or conditions. |
| Heel cord: | <i>See Achilles tendon.</i> |
| Idiopathic: | Medical term that means of unknown cause. Clubfoot is idiopathic in most cases, unless it is linked to a syndrome (in the minority of cases) |
| In utero: | When the baby is in the mother's womb. |

| | |
|--|---|
| Inversion: | Sole of the foot turning inwards |
| Ligament: | A short band of tough, flexible, fibrous connective tissue that connects two bones or cartilages or holds together a joint. |
| Maceration: | Skin softened by soaking. Maceration can occur if a child's skin becomes wet under the cast. The skin breaks down and it is painful. |
| Manipulation: | Manually stretching the clubfoot in specific positions to achieve correction before casting. |
| Metatarsus adductus: | Condition that looks similar to clubfoot but only the forefoot is turned in, the ankle is not twisted. Typically not treated with casts, it is usually outgrown as the child gets older. |
| Neurogenic clubfoot: | <i>See Syndromic Clubfoot.</i> |
| Orthotist: | An orthotist is trained to make orthotics such as braces or splints to support limb function. An orthotist working with will often fit the brace that is used after clubfoot correction. |
| Paediatric Orthopaedic Surgeon: | A doctor specialising in children's orthopaedics. |
| Percutaneous: | In surgery it refers to a procedure that punctures the skin rather than using the 'open' approach that exposes tissue. A 'percutaneous tenotomy' forms part of the Ponseti method and can be done using local anaesthetic only. |
| Physical therapy: | Some doctors prescribe physical therapy to assist with tight tendons in correct clubfoot. Parents can be taught stretching exercises to be done on their baby to increase flexibility and prevent relapse. |
| Plantigrade: | Walking evenly on the sole of the foot. |
| POP: | Plaster of Paris. |
| Positional clubfoot: | Not considered a clubfoot by doctors, this is when a baby is born with the foot turned in, but it is flexible and can be easily pushed into the correct position. Caused by position of the baby in utero, it usually self-corrects without any treatment. Also called "postural" clubfoot. |
| Posterior: | At or towards the back |
| Pressure sore: | A sore that develops from a long period of too much pressure on the skin. In clubfoot treatment, it is usually due to casts being put on too tight, or the brace shoes not fitting correctly – either due to incorrect measurement, or the clubfoot is not completely corrected. |

| | |
|----------------------------------|---|
| Pronation: | The inward roll of the foot during normal motion and occurs as the outer edge of the heel strikes the ground and the foot rolls inward and flattens out. Moderate pronation is required for the foot to function. With excessive pronation, the foot arch flattens out and stretches the muscles, tendons and ligaments underneath the foot. |
| Recurrence: | In clubfoot treatment, refers to a recurrence of the symptoms. The foot turns in and children put weight on the outside of the foot when walking. Recurrence requires recasting, brace wear and sometimes surgery. |
| Serial casting: | The term used for the repetitive casting process that is used in the Ponseti method. A cast is applied and removed after five to seven days. This is repeated until the clubfoot is corrected. |
| Supination: | The opposite of pronation, it is the outward roll of the foot during normal motion. A natural amount of supination occurs during the push-off phase of running as the heel lifts off the ground and the forefoot and toes are used to propel the body forward. |
| Syndromic clubfoot: | This is a rare form of clubfoot that is associated with a syndrome. It is more difficult to treat. Some syndromes and conditions that can include clubfoot are arthrogryposis, spina bifida, tethered cord, Down syndrome, Ehler Danlos syndrome, and cerebral palsy. Some are also referred to as teratologic, neuromuscular or neurogenic clubfoot. |
| Talus: | Anklebone, the smaller of second the two bones forming the ankle and heel joint |
| Tenotomy: | A minor surgical procedure that clips the Achilles tendon (heel cord) to lengthen it and drop the heel. The cast is left on for three weeks to allow the tendon to heal. No stitches are required. |
| Tibia: | Shin bone. |
| Tibialis Anterior tendon: | Dorsiflexes and inverts foot at the ankle |
| Unilateral clubfoot: | Only one foot is affected by with clubfoot. |
| Valgus: | Directed away from the midline of the body. |
| Varus: | Directed towards the midline of the body. |

References:

1. *The Iowa Orthopaedic Journal*, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1888384/>
2. *Oxford English dictionary*
3. *Clubfoot: Ponseti Management* (Global Help books)
4. *Genetics Home Reference* <http://ghr.nlm.nih.gov/condition/distal-arthrogryposis-type-1>
5. *Merriam-Webster's Medical Dictionary*

Ponseti for Parents[®]

Copyright © 2014 by Steps Charity

Printed in South Africa

First Printing, 2014

ISBN 978-0-620-60445-1

Ponseti for Parents[®]

STEPS Charity South Africa

13 Chesterfield Road

Oranjezicht

Cape Town

8001

SOUTH AFRICA

Disclaimer

This clubfoot manual for parent education is not designed to and does not provide medical advice, professional diagnosis, opinion or treatment. This manual provides general information for educational purposes only. The information provided in this manual is not a substitute for medical or professional care, and you should not use the information in place of a visit, call consultation or the advice of a Ponseti healthcare provider. STEPS is not liable or responsible for any advice, course of treatment, diagnosis or any other information you obtain through this manual.

STEPS developed the **Ponseti for Parents**© programme to support families with vital information and advice to ensure successful treatment.

Parents and caregivers are extremely important in achieving good results, as they are the ones who take the child to the clinic, deal with cast care at home, check for any problems, make sure the brace is on properly for 23 hours a day in the first three months of wear and then commit to their child sleeping in the brace until age four.

STEPS designed this as a multi-media parent education programme for weekly clubfoot clinics:

- **STEPS** identifies advisers in clinics who can be trained to understand the different stages of treatment and how to advise and support parents. The Ponseti for Parents© parent adviser manual provides information about clubfoot and the treatment, what to expect, and how important their involvement and commitment is to ensure a successful outcome
- The take-home leaflets are informative and practical, and repeat the message from the parent adviser. There are many visual references to make it simpler to absorb the content.
 - The first time parent gets a take-home leaflet that has basic information on clubfoot, a treatment overview, and the casting phase
 - The second take-home leaflet is for the start of the brace phase and explains brace fitting, routine, and the importance of following instructions to prevent recurrence
- The parent information DVD can be shown in clinic waiting rooms which will convey the same messages given by the parent advisers and the leaflets
- There is a poster designed for use in child health clinics, ante natal clinics, and immunisation centres, etc. This will help to raise awareness that clubfoot can be treated, a simple explanation of how it is treated, and where to go for help

STEPS is committed to supporting parents and the Ponseti for Parents© programme is our contribution to achieving the best outcome for children with clubfoot.

Endorsed and approved by Steps medical director: Dr Jacques du Toit

