

CONTACTS

Contact:

Tracey Prosser

Paediatric Orthopaedic Coordinator
The Geelong Hospital

Ph: 52 26 7062

Mob: 0409 334 744

TRACEYP@BarwonHealth.org.au

For support and to meet other parents of children with clubfoot:
www.AussieClubfootKids.org

AUSSIECLUBFOOTKIDS

An online support network providing parents with information on clubfoot and the Ponseti method, tips on caring for a clubfoot child and contact with other Australian parents facing the same challenges and joys these children bring.

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Barwon
Health

INFORMATION & INSPIRATION
FOR PARENTS OF CHILDREN
BORN WITH

CLUBFOOT

"Parents' of infants born with club feet 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 club foot is no handicap and is fully compatible with normal, active life."

Dr Ignacio Ponseti, M.D.



During winter, while your baby/child is wearing the brace for 23 hours a day ensure long legged body suits snap all the way down both legs so you don't have to remove the Boots & Bar to change their nappy.

Dressing baby in a nighty/dress (yes, even the boys) for bed makes night time nappy changes much easier!

During the casting phase, your baby/child should be able to wear almost anything, just as long as the fabric is stretchy or the fit is loose enough to go over their casts.

Placing a rolled up towel under your babies feet while they sleep might help take the weight of the brace and make your baby/child more comfortable.

Put baby to bed in a sleeping bag/grobag rather than sheets. This will prevent them getting tangled and frustrated as they toss and turn during the night.

If your sleeping baby suddenly starts waking frequently, check the distance between the boots is still shoulder width apart. Remember, as they grow the bar needs to be widened too.

While most children remain in their cot until 2 years or more, many parents find moving their Clubfoot child into a bigger bed earlier helps them sleep better. Do ensure your child is protected from rolling out of bed by using a barrier.

Make putting on the Ponseti Boots & Bar part of your child's bed time routine.

Wrap some padding around the bar or the bars of the cot. This will stop your baby/child being woken up by loud bangs during the night as their bar hits the side as they move around the cot.

HELPFUL HINTS

Giving your baby a bottle, a dummy, or your finger while he/she is having the casts put on will help keep an unsettled baby distracted.

Using disposable nappies is recommended during the casting phase to help prevent any unwanted nappy leaks.

Remember to support the babies legs when they are being held so the weight of the cast does not pull on their little legs.

Use a barrier cream on your baby/child's leg around the tops of the casts to help prevent any rubbing. Note that extensive rubbing may mean the cast is too tight and you should take your baby/child back to the Doctor to have it adjusted as soon as possible.

Remember to support the bar when carrying your little one, so that the weight of the Boots & Bars does not cause feet to slip in the boots.

If the boots are creating blisters on your baby/childs feet, they may not be fitting properly. Check with your Doctor or Physio as soon as possible. Using barrier creams on sensitive areas or padding under the tongue may help.

Cut the toes off the end of socks to keep the feet cool in summer and to also check that all the toes are flat and the circulation is fine.

If your baby/child's foot is slipping, try different ways of lacing the boots, ie. from bottom to top or top to bottom.

As your baby/child learns to kick his feet your might like to protect yourself, your baby and your furniture. Many people find wrapping the bar with foam or padding helps.

During summer, short leg body suits are perfect!



This booklet has been prepared for parents of children that have been diagnosed with clubfoot.

I hope from my experience helping other parents on this journey, combined with the knowledge of other parents who have experienced the Ponseti Method of Treatment, that this booklet will assist you. It is intended to be a guide for you from the time

your child is first diagnosed with clubfoot to the required ongoing treatment for this condition.

In this booklet parents have written about their personal and family experiences when dealing with a child diagnosed with clubfoot.

I would like to thank all the parents who have volunteered their time and personal experiences. My appreciation also to Melanie from aussieclubfootkids.org who devoted her time and skills in preparing this booklet.

Tracey Prosser
Paediatric Orthopaedic Coordinator
GEELONG HOSPITAL
BARWON HEALTH
AUSTRALIA

WHAT IS CLUBFOOT?

Clubfoot C.T.E.V

- Congenital – Present at birth
- Talipes – Referring to foot and ankle
- Equino – Pointing downwards
- Varus - and inwards
- Approximately 1-2 per 1000 births.
- Half of the children born with talipes have both feet affected.
- It is three times more common in boys than girls.

Will My Child be in Pain?

Your baby should not find the condition painful *HOWEVER* it is normal that they may protest at being examined and having plaster casts applied. All casting is done in a gentle manner. No force is applied.

Treatment of my Child's feet using the Ponseti Method

The treatment involves serial manipulation and plaster casting of the clubfoot. The ligaments and tendons of the foot are gently stretched with weekly, gentle manipulations. A plaster cast is then applied after each weekly sessions to retain the degree of correction obtained and to soften the ligaments. Five long leg casts (from toes to the hips) are applied with the knee at a right angle. After removal on the 4th cast the Orthotist will measure for boots & bar bracing.



by pretty quick. During his one hour out of them he would spend almost the entire time kicking and throwing his little legs around, obviously enjoying the freedom.

Living with a clubfoot child has been fairly straight forward for us. Benjamin is our first child, so we did not know any different. Unfortunately he is not a good sleeper and from five months developed a habit of waking every hour needing me to help him back to sleep. During this time we ended up with him in our bed most of the time. Whether or not it was the boots waking him up we will never know, although since he became more mobile at 12 months he sleeps much better.

When he was around 9 months old we switched him to the Mitchell boots. They have been a great success for us. Getting his foot in is easy and being able to clip the bar on and off has made any night time nappy changes much easier. Unfortunately, it didn't make a change to his night time waking habits.

Ben is now 2 and a half years old and apart from still wearing the boots at night you would never know there was ever anything wrong with his feet. There is nothing he cannot do.

We are now expecting our second child who will also be born with clubfoot. While initially disappointed we know this is something we and the baby can handle and that we have so much support from our family, friends and all the members of AussieClubfootKids.org.



Wearing the Markell Boots



Wearing Mitchell Boots

BENJAMIN'S STORY

Our beautiful boy Benjamin was born in July 2007 with Bilateral Talipes. We found out that he had talipes or “clubfoot” at the 18 weeks scan and were devastated that something was “wrong” with our baby. That night we searched and searched the internet for hours, finding out every thing we could on this condition. Thankfully we came across the Ponseti method.

Benjamin started his treatment when he was 10 days old. It was very daunting having those first casts put on. We were amazed at how well our little baby handled it - much better than his parents! There were no tears from him!



Benjamin's newborn feet and first casts

We were lucky to have no trouble with the casts. Every five days we made our trek to the Hospital, had the plaster removed, gave him a bath and some plaster free time, then on with the next cast. Five casts and four weeks later his feet were corrected! Continuing our trouble free run with the treatment so far, we were absolutely delighted when Ben's Doctor decided his feet were flexible enough that he did not need the tenotomy.

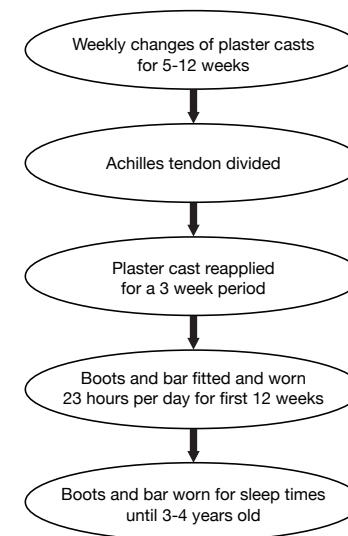
After the fifth and last plaster cast was removed, Ben was fitted with the Markell boots and bars. Once the boots were on, I can honestly say he was not particularly distressed by having to wear them. He did protest at doing the exercises to stretch his Achilles. The first three months where he wore them 23 hours a day went

After the 5th cast a tenotomy is performed. This procedure is done in the outpatient's department plaster room. This is a quick (3-4 second) cut of the Achilles tendon under local anaesthetic. Following the tenotomy, the foot is placed in a long leg cast for three weeks.

Once the cast is removed your child will be fitted with a special orthopaedic device known as the Denis Browne Bar (Boot and Bar) by an Orthotist. ***The boot and bar is worn full time (23 hours a day) for the first three months then at nap time and night time up to the age of four years old.*** It is very important that this routine is followed. Without the bracing the deformity can recur.

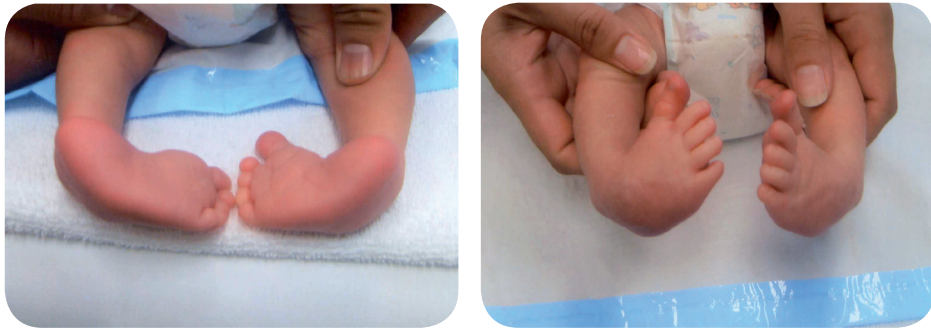
Why is the Ponseti Method so good?

- It does not require surgery.
- Better long term health outcomes for these children. The feet are flexible and mobile after treatment.
- Patients are closely monitored and any follow up action is taken immediately
- Treatment can begin within 48 hours of birth and continues for the first 4 years of life.



KHAILAN'S STORY

When my son was born it was visually apparent that there was something wrong with his feet, we were told that his clubfoot was quite severe but that there was treatment available. I was shocked and fearful at first but at the time I was overwhelmed with the joy of meeting my son for the first time that it was not until I arrived home that the reality of his condition hit me. I was saddened that my child had to go through this hardship so early in his life and fearful for what this would mean for his future. You always hope that your child will be born healthy above anything, so I felt that I had let him down.



Khailan's newborn feet

Awaiting his first appointment for casting I had mixed emotions, eagerness that treatment was to begin and also anxious of how he would react to the treatment. Above all I was most concerned of any pain that he may go through. However Khailan took it all in his stride, if there was any discomfort he didn't show it, he handled the treatment so well, he amazed me with his strength.

The day he had the boots fitted was difficult, it was the realisation that he would have to wear them for an extended period of time, I felt so sorry for him, imagining how uncomfortable it must be. At the beginning I worried that I wouldn't fit them properly, we have had a few ups and downs along the way but now it has become second nature. We still have the occasional days where he is

CORY'S STORY

When we found out that our tiny baby had club foot, we were devastated. Mainly because we didn't know what it was. After a lot of research, and finding out that it was easily fixed, we took it in our stride.

The plaster casts were probably the hardest part for me. As Cory was our second, everything was different, no baths, no easy nappy change, even clothing had to be slightly different to the first. And the looks you get from people, 'why has your baby got plaster at such a young age'. But as time went by, it got easier. The 'Boot and Bar' also take a bit to get used too. But they have changed since we first got them. Much easier.

Cory was never far behind his older brother (and still isn't). His boots haven't stopped him from doing anything, although he sometimes makes out that they do, but all mothers will know, that is called 'laziness'. He can crawl, climb, jump and even walk in his boots. He has recently just started helping do the buckles up. (I just hope he doesn't work out how to undo them any time soon.)

Cory still has just over a year left in them at night but how time has flown. It feels like only a little while ago I was in and out getting plaster on and off.

Probably the best advice I can give is, to take one day at a time. Put the boots into their routine and be consistent. Don't stress too much over it, just remember that we have it better than some others. They learn everything at the same time as other kids. And believe me, it doesn't stop them walking, running, jumping, climbing. It doesn't stop them from doing anything. (Even talking).

Last thing. Ask for help if you need it.
Good Luck.

CONTINUED...

standard procedure to my understanding. He is now 12 months and has had the boots and bar on since the last plaster was removed around the age of 10 weeks or so. He now only wears them for sleep which in his case is about 15 hours a day (including 2 day sleeps). He is crawling, pulling himself to stand and is just starting to cruise around holding on to furniture which is exactly the same time frame as his older sister who does not have a club foot.

All I can add is that having a club foot has not impeded anything I have done in my life. I expect the same outcome for my son.

The piece of advice I would also give is NEVER make a big deal out of it, NEVER exclude your child from any physical activity because of your fear and NEVER talk about it as a disability as it is not so. I understand many people are shocked and saddened for their child and perhaps even themselves when they learn of their child having a club foot. It is no impediment to having a great, active life.



Jack's decorated plaster

very hesitant to have them on and sometimes he will awake in the middle of the night asking for them to be taken off, but overall he is very adaptable and willing.

Khailan reached all the normal milestones of sitting and crawling, all while wearing his boots. He started walking at 11 months old and his feet are still flat on the ground and looking wonderful, looking at his feet now its hard to believe that they are the same feet he was born with. He is now two years old and continues to wear the boots and bars every night without fail, sometimes I even discover him trying to put the boots on himself.

When Khailans treatment first started I had moments when I thought that it wasn't fair that he had to go through what he has, I now feel very positive about his future and grateful that we have the resources available to have the condition treated, it has really put a lot things in perspective. We have kept his casts and boots and look at them as trophies of how far he has come and just how strong he is.

I am extremely proud of my little boy and I am in total awe of my sons courage and resilience through the whole process. We are not quite there yet but we face the remainder of the journey with determination.

Jasmin and Khailan



After the casting phase



Khailan's feet at 15 months old

HARRY'S STORY

We were first told of Harry's clubfoot at his 19wk ultrasound (along with a kidney problem also) - one of the most horrible moments of our lives. We had no idea what Talipes or Clubfoot was, never heard of it. As you can imagine all sorts of horrible images and thoughts came to mind. Fast forward a few hours and we were much calmer after having done some research. Still in a bit of shock that our baby wasn't 'perfect' but feeling more positive about the situation. I wish the sonographers had taken the time to explain what clubfoot really was, they seemed to have the bedside manner of a rock! Over the next few months we did lots of research and discovered the Ponseti technique. We didn't know it at the time but Geelong Hospital is lucky enough to have Ric Angliss and his team treating clubfoot babies with this nonsurgical technique.

When Harry was finally born we were completely prepared for his foot, but to be honest didn't even notice it at first. I remember one midwife saying to us bluntly "did you know about the foot?" Too bad if we didn't I guess... He was healthy and perfect in every way! Harry got his first of several casts a week later and at the time it seemed so wrong to have to put a tiny baby through such an ordeal. In actual fact once the cast was on he really didn't seem to mind, I guess he didn't know any different. I must say we got some strange looks and comments about our newborn baby having his leg in plaster.

Then came the boots. We had heaps of trouble at first. Harry's last cast had slipped and caused his foot to swell like a balloon. He didn't have any heel as such so trying to fit the boots was very difficult and he kept getting out of them. The orthotic people tried to help by putting a couple of heel grips in and made sure the boots were on very tight. The grips were pushing on his 'heel' and caused a pressure sore. When the boots went on he cried and cried until I was in tears too but we knew the boots had to stay on. Eventually it got too much and we knew he was in pain. We took

had to swab the skin from foot to knee with Friars Balsam. This provided the barrier for the sticking plaster that held the side of the splints in place on the leg. Gradually, the foot was moved until it , and the other, good foot, were more or less in a straight line. This took several months.

At 11 months, I had an operation to cut the tendon in the heel. The scar stretched from heel to about half way up the leg (and still does). I was in plaster then for 2 months. Apparently this didn't stop me from standing or trying to walk, but of course, I couldn't until the plaster was removed- then I took off on my own steam almost overnight!

My only recollection of the whole experience remains the "brown boots" that in those days were an integral part of the denis browne orthosis. I still remember my "treat" after I no longer had the wear the boots. Mum and Dad had bought a pair of red, patent, Mary Jane shoes. They were the best things I'd ever seen and the brown boots became a long distant memory!

Also I would like to add that I have never suffered physically from having a club foot and in my teens played a variety of sports including Hockey, Softball, Netball, Swimming and even won a state championships in Rowing!

So when we were pregnant with Jack (our second child), we found out at the 18-20 week morphology scan that we too had a child with a unilateral (left) club foot. However unlike my Mum, I knew exactly what it was, had time to prepare and was offered all sorts of counselling in order to "cope". Before he was even born we knew that he would have plasters, then a tenotomy, then splints until he was around 4 years of age.

The whole process has been relatively pain-free (not sure about Jack but for us!). He went into plaster at 4 days old (first day out of hospital) and continued to have weekly plasters applied until his tenotomy at 7 weeks then another 3 weeks of plaster . Fairly

SUE-ANNE & JACK'S STORY

Our story began 38 years ago when my Mum and Dad had me, their second child...When I was born, Mum noticed something wrong with my foot and when she asked, the Nurse said "Your baby has a club foot", see your GP about it when you get out of hospital. That was her introduction. No explanation, no words of support and certainly no information. Mum can still recall the tears she shed in the shower following my birth and the inevitable question "Will my baby be OK?".



Sue-Anne at 8 months wearing splints with sticking plaster

In those days (and we're talking 1971 here) the process was somewhat more involved and certainly more invasive. I can't tell you what grade of club foot I had, they did not score them in those days, but the first round of treatment began at 9 weeks where I spent 3 weeks in hospital having my "manipulation" as they called it. From Mum's recollection this meant a gradual change in angle of my foot (similar I guess to plastering) except the movement was daily and splints were used. These were heavy metal splints with moveable foot plates (moved with a large screw head) that gradually moved both feet into a better position over this time. When I finally got home, I then had to have a physio change the splints weekly. This was an interesting exercise – at home, Mum

the heel grip off, realising that it was actually causing too much pressure and resulting in the sore. Once the swelling went down and his sore healed the boots were fine. After that initial hiccup it has been smooth sailing. The first 3 months of boots seemed to go on forever, 12 weeks is such a long time for a new baby. We once again got used to the strange looks, the boots are less easy to disguise than a cast. Most people were actually quite intrigued about the whole process when they asked.

Harry is now 2.5 and helps put his boots on before bed, it is part of his routine and he knows nothing else. He can still get around with them on, just a little awkwardly but they don't slow him down! Other than a small scar from his pressure sore his feet look perfect!

Tips I would give to other parents include:

- Listen to the professionals but trust your own instincts too. If I had of realised this earlier Harry's pressure sore would not have gotten as bad.
- A piece of foam wrapped around the bar works wonders for preventing damage to cots (and parents – those things hurt!)
- Be positive about the boots right from the start, particularly in front of the child wearing them.
- Don't be afraid to ask for help or advice. The staff at the DDH clinic are wonderful.
- Talk to other parents, chances are they are going through, or already have gone through what you're dealing with, or maybe you can offer some insight into their situation.
- Think of how lucky you are to have a healthy baby!!

REMI'S STORY

"There is something wrong with your baby's feet, we will need to send you for further tests" we were told at our 20 week ultrasound. That day was such a stand out. I clearly remember standing in the car park crying, shattered that something was wrong with our precious baby. It wasn't until 4 days later we saw our obstetrician we were told that our baby had 'bilateral talipes' - clubfoot. Not knowing anything about this condition we headed home to the internet. We were very eager to see what lay ahead. What a relief- "it was treatable".



Remi's newborn feet

The pictures on the internet were confronting, but when we went on the read that children were walking and leading a normal life we were relieved. I couldn't help think- why us? One in a thousand- we couldn't even win a bottle of wine in a raffle!

We headed to Melbourne for more scans and saw our baby girl waving to us. This was a turning point for us. It was sad to see her little feet, but it was going to be ok.

During the birth of our daughter, Remi, I was feeling very anxious, was everything else ok? Would her feet be the first thing everyone looks at? But she was perfect. On day 3 Rick Angliss visited us at the hospital and reassured us that her tiny feet would function as normal and went in detail about the Ponseti Method.

Remi received her first casts on day 4. This day was extremely sad as my husband and I stood crying, watching her cry. Tracey and Rick were amazing during this time, and I will be forever grateful. After these casts were removed we could already notice the difference, and looked forward each time they were removed to see the difference.

Some comments from people when her legs were in casts were confronting and there were a lot of stares when she was in her boots and bars. Through out this she continued to smile.

Remi is now 9 months old and is crawling, pulling herself up and walking around things. She is still wearing her boots and bars at night time.

We thank Rick, Tracey and the team for the wonderful job they do. Geelong is so lucky to have them and this clinic. Their passion to help children with club feet is truly inspirational. Each step our children take is a credit to them

Sally & Kieron Moore



Remi's feet at 9 months old