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CLUB FOOT



Practical Advice — From one parent to another

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Front cover photographs:

Harrison's right leg in plaster in his high chair.

Harrison playing, wearing his Mitchell Boots and Bar.

Website: www.steps-charity.org.uk

Finding Out Your Baby Has Clubfoot/Talipes

My name is Sharon and I had my second baby in June 2007—Harrison. To our shock he was born with a problem with his right foot. This had not been picked up on any previous scans during my pregnancy. On the maternity ward we were told "don't worry, a bit of physiotherapy and it will be sorted". We were so worried about him. Especially when we returned home and our GP did not know anything about his condition. We ended up in a local hospital booked in for physiotherapy. They took one look at his foot and we were told it was a bit more complicated than it had first appeared. To cut a long story short, we were fortunate that a friend of a friends little boy had club foot too.

*All she told us was: 1. not to worry, it could be fixed,
2. to look up Ponseti treatment online and
3. to contact STEPS!*

We did all of that, and two years on Harrison's foot looks fabulous.

If you found out at a scan about your baby's clubfoot you will probably be more prepared for the treatment than I was. Although you probably spent the rest of your pregnancy worrying!

If you found, as I did at birth, it is traumatic. I now know that there is fantastic treatment available, fantastic advice available through STEPS and some fantastic friends to be made through STEPS Discussion Forum to get you through it!

I hope some of the advice, that follows will be of use to you. There is a lot of light at the end of tunnel!

*Best wishes
Sharon*

Ponseti Treatment – The Parents' Guide

There are various leaflets available through STEPS to give you an idea of what the Ponseti treatment is all about and why you would choose it. There's also a great DVD to watch to give you an insight into what the treatment involves.

However, this leaflet is different. It's here to give you, the parent/carer, practical advice. It is not written or endorsed by medical professionals. It's written by a mum, based on information gained through the experience of caring for a baby with clubfoot/talipes. It is also based on information from other mums looking after babies with clubfoot/talipes.

This leaflet is based on you choosing the Ponseti method of correction for your child.

The tips in this leaflet may or may not work for you and your baby, but it's a collection of the best ideas out there to make your lives a little less stressful when looking after your new baby. I hope you find it useful and that some of the recommendations here work. You will hopefully end up in no time at all with a baby with beautiful feet.

What to Buy?

The only special things you need are clothes without feet in them. So sleeping suits that are footless (or cut the feet out of a normal one!) and any trousers need to have poppers on the underneath – dungarees always have poppers so they are ideal. (Though you do get a bit sick of your baby only wearing dungarees after a while!!!!)

High chairs ideally need the centre strap to be undoable or detachable so that when they are in 'boots and bar' they can still use it.

Most people don't find it necessary to buy a special pram/car seat etc.. Even a normal Baby Bjorn type sling can be used with the boots on.



Harrison in his high chair wearing Mitchell Boots and bar.

The Plastering Stage

The plastering will be the first thing you encounter with the treatment. The casts should be full length cast up to the nappy line. (Just to make sure they are doing it the Ponseti way....) The plastering will probably be carried out by a physiotherapist and a plaster technician but it varies from hospital to hospital. Sometimes a doctor or consultant does the plastering themselves.

The casts will be put on after the foot has been manipulated as per Dr Ponseti's instructions! The casts put on will be up to the thigh in order to keep the foot in the new position. You should be able to see your baby's toes clearly at all times. I have to say you will probably be amazed how much difference the first cast makes. The casts are put on and taken off weekly, so be prepared for weekly hospital appointments.

Try to get the hospital staff to take the cast off for you. Some won't, so the best way to take a cast off at home is:

Do it just before you leave for the appointment (the baby needs to be in the cast as close to 24 hours a day as possible.) Use a baby bath to soak the cast for a good ten minutes. Use warm water to keep the baby happy. Put in a few spoonfuls of white vinegar, and be prepared to get wet. The cast will start to disintegrate.

It needs to be unwrapped slowly but surely. I always found it was a two-person job. One to hold the baby and one to take the cast off. We're not always that lucky to have two people around though.

Every week as your baby is recast the 'job' gets easier! Most mums find that feeding the baby is the best way to keep them happy and at ease during the process. It doesn't hurt them but I think it just concerns them. Any distractions, such as music, shiny things etc... help to let them be at ease. The more distracted they are the easier it is to get the cast in the right position.

The cast is warm and heavy when it's first done so your baby may need a bit more reassurance than normal (some don't react at all, some scream afterwards) but once the cast is dry it weighs next to nothing and is at a normal temperature.

The baby can't wear trousers/sleepsuit over the cast for the first 24 hours, to allow it to dry. Just a vest is needed and any other clothes or a blanket on the top half in cold weather.

At night, especially when the cast is first done, you may need to put a rolled up towel under their calf to take the pressure off. They may not sleep well or they may not notice it!! Whatever the outcome they soon get used to it and most babies don't even notice it.

Top tip – if you don't want to miss out on bathing time you can buy something from a company on-line called www.limboproducts.co.uk that protects the plaster from getting wet. It comes highly recommended from some mums. Check with your medical team before you buy.

Some parents complain of the casts rubbing. If you ask the hospital to put more padding inside at the top this may help. There is also something on prescription, free from your doctor, called **Mepilex Lite** if you struggle with their normal padding.

Some parents complain of the casts slipping right off. If you think it's slipped, it probably has. Go back to your hospital and get the cast put back on again and again and again! Some children have A-Typical feet (if they have chubby wide feet with a crease on the sole) these feet are harder to treat (but still treatable) so best to go back to your hospital for more advice OR ring STEPS to find a qualified practitioner specialising in this.

A bean-bag can be invaluable at this stage as it takes the weight of the plaster off and keeps them comfy, or a big scatter cushion if it's soft enough.

You will see in between casts that the foot is looking 'more normal' and if the hospital grade the feet at each session, then the grade will be improving (i.e. the number they are graded at will be going downwards towards 0).

Tenotomy

You will be told early on if your baby needs a small minor operation called a Tenotomy. The objective of the operation is to basically give the baby as much flexibility as possible in their foot by releasing the Achilles tendon in the back of the heel. Ninety percent of babies have to have this operation in order to give them maximum flexibility. They may need it on one or both feet.

There are different ways of performing the operation, generally through key hole surgery. There are different ways they will sedate your baby:

Local anaesthetic using anaesthetic cream so they are wide awake.

General anaesthetic so they are asleep.

Your hospital will advise which one they are going to use. It just depends on the preference of the surgeon and the age of the child.

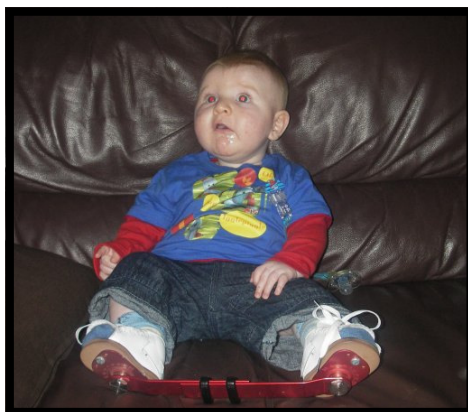
Local Anaesthetic – Generally you will be with your little one for the whole procedure. (However some babies are taken into the theatre with the doctors – depends on your hospital.) It normally lasts about five minutes. It takes about 35 minutes for the cream to numb the area so take things to distract them. Take a bottle in for them to drink and do what you can to comfort them. Afterwards the hospital will advise you how much *Calpol* to give them to ensure they are not in any pain. They may cry but mainly because they don't like being held still! A Steri Strip will be placed over the area that has been cut.

General Anaesthetic – Generally you will not be with your baby for the actual procedure. They will be in theatre for about 45 minutes. The plastering then takes about 15 minutes. You will then get your baby back in plaster casts. Most babies will be asked to drink some milk before they are allowed home and most will be given some Calpol. Some babies may cry, not because of pain but because it is a frightening thing to be in a theatre with lots of strange people! Having a general anaesthetic is quite distressing for the family of any relative, let alone a baby, so get lots of support around you and be strong for your baby.

At the end your little one will be put back into plasters for 3 to 4 weeks that will not be taken off weekly. The casts are generally larger than the ones you will have had before. The casts may take a little longer to remove than the ones you had before but just be patient they will come off.

Whether or not you have had the tenotomy, at this stage your baby's foot/feet will be at some stage graded as 'normal'. That's it - the foot is fully corrected!

You now move onto the hardest part of the treatment . . .



Zack, son of Amy in his Markell Boots and bar.

Ponseti 'Boots and Bar'

Congratulations your baby's feet are now fully corrected. I hate to dampen your spirits but this is probably the hardest part of the treatment AND the most important. I suppose it's relatively easy to correct the feet but now you have to stop the feet from relapsing. The muscle imbalance between the inside and outside leg means your little one constantly wants to bring their foot back to the position it was born in. In simple terms the 'boots and bar' hold the affected foot/feet at a 70 degree angle (if they have an unaffected foot it will be at roughly 30 degrees) in order to constantly stretch the foot in the opposite direction.

Your child will be measured for boots at your hospital appointment. There are several brands of boot. The two most popular are Markells (white leather with laces) or Mitchells (grey suede with straps). There are pros and cons for both types of boot. There are success stories using both types of boot.

The boots need to be worn 23 hours a day for the first three months. This is certainly the hardest part. However some babies wear them without batting an eyelid and others seem to be greatly bothered by them. You'll only know this when it happens.

One mum from STEPS said to me 'make sure you have lots of support around you in the first few days and be prepared for a hard time' and in our case she wasn't wrong! BUT remember lots of parents/carers breeze through this. Bear in mind this leaflet is about giving you the help you need so we assume worst case scenario!

Here's a long list of tips which will accommodate lots of different situations. You certainly won't need all of these!!

General tips:

Use socks that have a 'grip' on the bottom it helps the boots from slipping. Somewhere like Gap is good. If you need a thicker sock Asda do great little thick towelling baby socks.

When the hospital 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 when you are getting to grips with them.

If they don't have straps another good tip is when at the hospital having them fitted put a biro mark on the shoe inside sole where the end of the toes come to. This way you know again where the boot should sit.

If the boots have laces, knot them in the middle so if they come undone you only have to relace them part of the way.

Use the holes at the back of the boot to check the heel is flat. If there is no hole ask the hospital to make one for you!

If you have leather boots smear the inside with Vaseline. They will slip on much easier and are less likely to rub.

Get some clear nail varnish and paint the ends of the straps (if they have suede straps) and you will find it threads through the buckle much easier in the long term. (Remember you'll be putting these on for the next few months.)

Try and get boots that have a detachable bar, particularly if you have an older baby going through this. Much easier getting in and out of the shopping trolley, high chair etc...

Ensure the boots sit at roughly 70 degrees for an affected foot and about 30 degrees for a non-affected foot.

The bar must be as wide as the baby's shoulders. Put the bar on their back across the top horizontally and see if it sits on the outside of their shoulders. If it does, it's fine. If not, extend it as your baby grows. (Ideally get your hospital to do this.)

When you get the 'boots and bar' ask if there are any special tools you need to adjust the boots angle or the bar and take them home with you. Get them to show you how to adjust the boots yourself. Don't get stuck in the event of a problem with either.

If the boots strap snaps or anything else for that matter ring your hospital immediately.

You have one hour a day out of boots. General thought is do it away from bed time and make it fun and maybe bath them then!! Doing it around bedtime means it can be upsetting that they think they are free and then put back into their boots. You will soon find a solution that fits in with your daily routine.

Show them how to kick as they get older in their boots. Normally babies kick with one leg and then the other. Our wonderful babies have to learn how to kick with both legs at the same time. Just show them how and they will soon get it!

Putting boots on:

Everyone does this differently but in summary distract your baby with a toy or food and bend the leg so the heel goes down as much as it can do.

You should always ensure the heel is down as much as possible. The hospital will tell you that this won't happen at first but don't worry, it will over time. My baby took twelve weeks and then suddenly the heel was flat.



Harrison asleep—legs in the air wearing his Mitchell Boots and bar.

Problems to tackle:

The boots keep slipping off: Check they are tight enough (not too tight -remember the tips on the biro marks). Check the socks are not slipping on the sole. Get the hospital or you to pad the inside of the boot, it can work miracles. May need to change brand of boot? Ensure the foot is definitely fully corrected with your hospital as this can cause problems (boots coming off and indeed heel not going flat after a few weeks).

Sore feet and blisters. If sore red patches occur use Compeed or DuoDeam (on prescription) plasters. These act as a second skin and stop the feet from getting sorer. However if the skin breaks at all or a blister develops stop using them immediately as the sore can't breathe, and swap to Mepore self adhesive dressings (on prescription). Use these until the skin has healed and if need be swap back to Compeed or DuoDeam. I can't stress how important this is. So many mums have this problem and if we all knew this up front we wouldn't have had half the amount of problems. Remember you need to do everything you can to keep the boots on 23 hours a day for three months and this will help that journey become a reality.

Sleeping Problems:

Oh yes this can happen. Sleep deprivation is probably the hardest part of the treatment if it happens.

I remember my little one crying for about 24 hours non-stop (no exaggeration) and every day it reduced by an hour. My goodness it was a hard time. Here are some of the tips from parents who have suffered:

Get them to sleep in a sleeping bag (Gro Bag) so that they can't get tangled up in blankets and sheets.

If they continuously knock the bar against the cot bars then pad them (in a safe way so that your little one can't rip the padding off).

If they are a little older and trying to roll over and get stuck, then try tucking the end of the mattress into an oversized sleeping bag. Even tuck a towel in between the cot bottom and the mattress so they can't go anywhere.

A rolled up blanket under their calves will take some of the pressure away from their feet.

Make an appointment to see an osteopath. Seriously! They can pick up whether their body is being 'stressed' by their boots. The boots and bar can weigh about 300g so it's a lot of weight for a little one to have on at night. This can lead to problems which an osteopath can literally solve overnight.

They may, and probably will, adopt very strange sleeping positions. From legs straight in the air, to legs on their head, sleeping on their side with their feet against the cot. All I can say is they must find it comfortable. Nothing to worry about.

They can find themselves on one position and can't move back or get stuck on the bars of the cot. Just put them back into their normal sleeping position and it's sorted.

If feet are overheating use no socks or at least cut the toes out of the socks to let their feet breathe.

Remember the boots and bar **HAVE** to be worn together. If you don't then the treatment will not work and you'll be back in the plaster room.

Once the three months are up the number of hours are substantially reduced. The boots are weaned off them in terms of reducing the number of hours. Your hospital can advise you on this as new information is always appearing, so the rules may change as they learn more about the condition.

Congratulations you made it through the hard part!!



Zac, son of Mandy asleep in his cot wearing Mitchell Boots and bar.

*Please send any old boots and bars you have to **STEPS**, they are sent on to developing countries where they can't afford them.*

General Information that might help:

Walkers and door bouncers are a no no. They teach toddlers to walk on their tip toes and that's bad for a child that has talipes.

If you are worried about having another baby as they might have talipes it's a 1 in 30 chance. In the early days it feels as though you'd never do it again but as with all things it soon disappears and you love their beautiful feet and would go through it again!

Breast-feeding or bottle-feeding? Both can be done with a child in plaster/wearing boots and bar. Your call!

When the numbers of hours are reduced you have to do stretches with your child until they are 5 years old. Get your hospital physiotherapist to show you how.

You may be entitled to some benefits:

Disabled parking permit (Blue Badge). Ring your council and ask them! Some are helpful, some aren't!

Disabled Living Allowance. You are entitled to this if you can show that your child needs substantially more care than a peer does. If you go down this route, as many of us do, don't be surprised if you are rejected at the first hurdle (having filled in a 50-page document!) but appeal, appeal and appeal. If you have to go to tribunal, do it as they may listen to you as you have the opportunity to convince them in person. 'Citizens Advice' offer help with the filling out of necessary forms.

If you are really struggling you can do a self-referral to see a social worker. They will come and assess your baby's needs and may help with child minding to help you go out and do the shopping, provide a care plan to help you, provide an occupational therapist to advise you, etc. They are willing to listen and are not as frightening as you may think they are. Don't just struggle on if you need help, instead ask them - you have nothing to lose but potentially lots to gain.

When you start to buy shoes for your little ones. If you need to go into shoes early Start-Rite do small shoes in specific width measurements. If your child has unilateral talipes then you may have a child with odd sized shoes. If so 'Clarks' will sell you shoes in odd sizes for a 25% supplement on the normal price. If your child has narrow feet try 'ECO' branded shoes.

I don't believe any of the manipulation, plasters or boots and bar causes your baby pain. I think it causes frustration more than anything. So never worry you are hurting your baby. You are doing the best thing you can.

That's about everyone's top tips. Remember some of this will be useful, not all of it. I want you to know that you are not alone. STEPS discussion forum is generally a lifesaver when you are having a wobbly moment or just need to ask advice. Mums/Dads/Carers are there to listen to you. STEPS helpline is there for you too to ask any questions or just for a chat.

Time will fly, you will forget the problems very quickly and you will get there in the end. You will look down one day and see your beautiful child with beautiful feet and wonder what all the fuss was about!

Good Luck on the Journey!

