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PRACTICAL TIPS

These are some things that we learnt along the way. It's either advice gathered from other people or our own discoveries during our experience. We would have appreciated knowing some of these things beforehand and are grateful for the advice we got. We aren't medically trained, these tips are practical advice for other parents, and although every baby is different, most of this should apply in general.

BATHING WITH CASTS ON

Rather don't do it. Even though we were dying to bath Alexander properly, it was really impossible to do with full leg casts on without getting them wet. With the pre-Ponseti treatment the casts he had were only up to the knee (which is almost useless in 90% of cases, as we later discovered), but Dr Ponseti's method is casts right up to the groin. We laid him on a towel, soaped him up with mild baby soap and rinsed him off with a cloth. We took all the chances we got during cast changes to let him soak in a bath for a while.

SOAKING OFF CASTS

You may be asked by your doctor to soak off the plaster casts. We had to do this in the beginning of Alexander's treatment with a non-Ponseti method doctor and also for the last cast, taken off 3 weeks after his tenotomy procedure.

The easiest way for us was to thoroughly wet some long socks a few hours before and roll them onto the casts. At Alex's normal bath time, we would sit him in his bath seat in warm water with some vinegar added (**Tip: vinegar helps to soften the plaster faster**). Then, with his casts completely submerged, squeeze them and start unravelling the bandage bit by bit. Do it carefully, if the bandage tears (it usually does at least once); you have to find the short bit and start working it free all over again.

By the time they were off, the entire bath was murky with plaster of Paris. We would bath him in fresh water, and then apply lots of moisturising cream all over. The exposed skin is quite red and sensitive when it comes out of the plaster and also quite flaky. Alexander would cry a bit when he came out of the bath until he was dressed and the skin covered up again. Just be as gentle and quick as you can and don't worry about the flaky skin, it's the skin that would normally be shed by exfoliation, but hasn't had anywhere to go because of the plaster covering it.

Note: Dr Ponseti doesn't do it this way*, because it has to be done the night before the appointment. He likes to have the casts removed just before he applies the new cast so he can see exactly how the foot has reacted, with no chance for regression overnight. The morning of our appointment, we would soak Alexander's casts in a warm bath with a little vinegar added. (**Tip: The kitchen sink works well if the bath isn't big enough!**) Then wrap the casts with damp towels and cover them with a plastic bag. The nurse would cut off the softened cast when we got to Dr Ponseti's rooms and we would bath him in their sink, to get all the plaster residue off his skin and put baby cream on to moisturize his skin a bit.

*Apart from the tenotomy cast, which is removed three weeks later. We were home already and Dr Ponseti told us that we could just soak it off, it wasn't necessary to have it removed by a doctor or nurse.

AFTER CASTS ARE APPLIED

Your baby may be fidgety and seem uncomfortable. This is usually because the casts are quite heavy when first applied until they dry completely. We would roll up a small towel or towelling nappy and put it under his knees to relieve the pressure on his heels. Within a few hours or so, he was happily swinging his casts in the air – they must develop good abdominal muscles with the extra weight! If your baby's really miserable, a dose of paediatric paracetamol syrup like Calpol or Panado helps.

Don't be too concerned if a tiny baby's nappy leaks a bit onto a cast. We would rub it off as best we could with a wet wipe and leave it. The cast will be removed again in a week anyway.

We were told to check Alex's toes a few times after the casts were applied to make sure that there was enough circulation. The way to do it is to press lightly on the toes, they will go white, but as soon as you remove your finger they will return quickly to their normal colour. If they don't, tell your doctor, the cast may be too tight.

CLOTHING FOR PLASTER CASTS

First of all, ignore all the babygro's (all-in-one suits) with the seamed foot. The casts will not fit through them. If that's all you can find, then buy them a big bigger so that the baby's foot will fit into the length of the leg and you'll have a little pocket of fabric at the end of the cast where the foot was supposed to fit in. The babygro's that don't have a seamed foot section are great and they are usually wide enough to fit over the cast.

During colder weather, we even found that tracksuit pants, and baby jeans, fitted over well, you can stretch towelling socks over the casts to keep the feet warm and dungarees are always useful. Remember that the casts are quite warm, so don't overdress them. In warm weather, Alex would often just sleep in a vest; his legs didn't need any covering other than the casts.

CLOTHING FOR FOOT ABDUCTION BRACE

In the beginning your baby will wear the FAB for 3 months, 23 hours a day. It only comes off once a day for an hour at bath time. Our advice is to avoid all clothing that can't be put on over the head - and if it's pants or dungarees, they should fasten all the way round the inside of the leg with poppers. It's just too much of a hassle to always be removing one shoe to try dress and undress them – and small babies can need several changes through the day. We have a boy, of course if you can dress a girl in dresses, that's easy too.

Also, changing a nappy without the poppers to open up the pants means pulling the pants down - and with your baby's legs held out to shoulder width by the bar, that's not easy. And a bonus for nappy changing with the bar on is that it's so easy to hold it up, keeping both legs out the way. It took us a while to get used to holding two separate feet up again once Alex was out of his FAB fulltime!

GETTING AROUND

Car seats, prams, high chairs need to be checked out carefully, especially for the three-month period of fulltime FAB wear. Check that the car seat is wide enough for the bar width to fit comfortably on it and the same goes for the pram. High chairs with a middle bar between the legs that can't be removed are no-go for a baby wearing a brace. We found that there are products readily available that work well; you just have to be aware of what you need when you go shopping. We used Chicco products – pram, car seat and highchair – and they were all wide enough. **(Tip:**

When your baby is in casts, always roll up a towel and put under the knees - whether for sleeping or sitting. It stops the casts from putting too much pressure on their heels.)

QUESTIONS

Get prepared for these. When we took Alexander out in summer, we would often leave his casts exposed because it was too warm to cover them. Try not to be offended, most people are very worried when they see a tiny baby in casts. If you explain it to them though, they are quickly quite amazed at - and interested in - the treatment. We never let it hold us back from normal activities.

The same goes for the 3 months of full time FAB wear. Although we found that people were usually more comfortable with this. They would comment that their nephew, niece, friend's baby, or even themselves, had worn a brace for something as a baby. It doesn't look as scary as plaster casts can, in fact it's quite zooty looking with the little tasselled leather shoes and anodized red aluminium bar – we called it Alexander's skateboard!

Once your baby is only in the FAB for night time and naps, then there are no more questions, because their feet look absolutely normal and with the Ponseti Method, there's no scarring to make people ask what happened to their feet.

FIRST DAYS OF FAB WEAR

Your baby is going to fuss in the beginning, probably for anything from 2 days to a week, depending on the baby. The reason is usually that they have get used to kicking their heels in tandem instead of any random way like they have in the past.

For the first few days, play with the bar while it's on their feet, hold it up in the air, bend their legs – show them what to do. They will pick it up quickly.

In our case, we would play with Alexander during the day and he would get cross with hit now and again, but generally did OK. Night time was a problem for the first two nights, he would go to sleep as usual, but wake up every hour or two, feel the bar holding his feet, get very angry and start crying.

I discovered that if I put him lying on me, stomach to stomach, he could sleep comfortably a little longer and I think the body contact was comforting for his distress. By the third night, he was sleeping as usual and swinging his bar up and down easily. Then you have to watch out for it crashing down on your knees or arms, it weighs over 400 grams and I've been bruised a few times!

If your baby screams or gets upset for a longer time than expected, make sure that the shoes are fitted correctly, and that there isn't any bruising or blistering occurring. We didn't have this problem, but it can occur for a number of reasons and you need to tell your doctor so the reason can be diagnosed and dealt with.

PUTTING THE SHOES ON

This is quite daunting in the beginning, the first time we did this, it took about twenty minutes, but eventually you're doing it in a few minutes. The most important thing is that the heel doesn't move up and down in the shoe, or your baby will get blisters, so it must be well seated before you do the strap. The strap plays the major role in holding the foot securely, the laces are secondary.

The way that works for us is we either lie Alexander down with his bottle, or sit him on a lap – it depends on his mood. Then make sure that the shoes laces are nicely

loosened up without them coming out of the holes – you can tie a knot in the ends if you're worried about it, but we never did. Then loosen the strap all the way without taking it out of the buckle. Now you can wiggle the foot in, making sure that it is all the way back and in the shoe. Press down firmly on the instep and pull the strap tight. Once the strap is buckled up you can do the laces.

When you take the shoes off, the foot may look a little red in spots. We were told to use thin socks and two pairs for the first two days, which we did and it worked well. If the foot looks purple or blistered in spots, then either the heel wasn't in properly and it's moving in the shoe, or the foot may not be completely corrected and it's uncomfortable for the baby. Check with your doctor as soon as possible if the marks don't go away after a little while or it seems to be getting worse.

MAKING SURE THE SHOES ARE ON CORRECTLY

This is crucial, or your baby may get blisters or sores because the foot is moving around in the shoe too much. When you're new to the shoes, it's sometimes difficult to know if you've got the heel all the way in and to the back of the shoe. What helped us is the first time you put on the shoes, completely unlace them and remove the flap so you can see the whole foot inside the shoe. Push the foot back into the shoes as it can go, you will be able to see easily if the heel is all the way back. Then draw a line (ballpoint pen works fine) just in front of the toes. Make sure when you put on the shoes and lace and strap them that you can see the line. Then you are assured that the foot is in OK. Another tip is to do the strap as tight as you can, then holding the shoe, pull gently on the lower leg. If the toes move at the same time, in a marked way, then you know that either the strap is too loose, or the foot is not all the way in. In a very short time you'll get used to it.

DEVELOPMENTAL MILESTONES

Wearing the casts or FAB will not affect your baby's development. In fact, the FAB can often be a supportive device, allowing them to roll over and sit up unassisted earlier. Alexander started crawling at 8 months and pulling himself and cruising at 8 to 9 months, he does it the same way regardless of whether he is wearing the FAB or not.