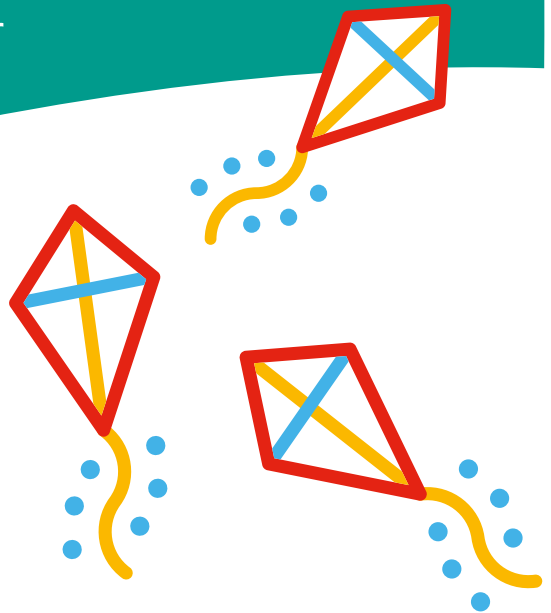


Caring for a hip spica cast

A parent's view

Information for
parents



leeds children's
hospital

caring about children

DDH - A little love and help at the start.

I'm not sure what my expectations were but I found it scary, upsetting, unnerving and that's just us, the parents! You will hear this a million times but children are more resilient than we give them credit for. It took 9 days for my daughter to relearn how to crawl with a SPICA cast on, 5 days to go backwards and 3 days to spin around, and she is only 4 months old.



While all the time, I was panicking and fretting about this, that and the other. It's like having a new born again, you are unsure what to do.

What can they do? Can you leave them? How do they sit up? How do they sleep? How do I pick them up? How do I change their nappy?

You know, that learning curve you had when your baby was born? Yep, that one. Well hello, it's back, new and improved, now with added cast!

OK, lets get organised - the more prep you do up front, the better you will feel.

As soon as you get your operation date, get on this.

Firstly - have a look at: www.steps-charity.org.uk

This charity is ace, you can ring them up and have a chat, they know their stuff.

This is a world of information about childhood lower limb conditions. There are guides for everything. You can stop making stuff up and put your mind at ease (and dare I say it? Yes, I dare, get some sleep). You can understand what is going on so when the doctors explain what might have to be done, you know what they are talking about. I emailed information to my friends and family so they knew what was going on and then, they too, could stop making stuff up and fearing worst case scenarios.

They do a guide called **Steps Parent Guide**. Download it, email it to your friends and family, read it and pass it on. Inside it, there is a list of possible equipment that you might need.

We went the next day for a pram. We walked in, collared an assistant and uttered the words 'My daughter is in a SPICA body cast, what prams do you have that she will fit in? Are they in stock so I can walk away with it today?' After the assistance got over the barrage of questions 2 hours later, we had a pram and a shop assistant with the knowledge to support families who need a pram for a child with a spica cast.

Blue badge and RADAR key

Yep, the disabled one. As your child will be in a cast and you need specialist equipment to help care for them, they are classed as disabled.

Go to your local council website for details. **Don't be put off by the wording.** I applied on Bank Holiday Monday and I got a email back on the Tuesday telling me that we had one. I just had to pop to the local offices with my doctor's note / hospital appointment, have my daughter's photo taken and pay £10. **Easy!**

RADAR key - opens the doors to the disabled toilets, bought mine from Amazon.

Other things....

Day care / Nursery

Double-check and make sure that they are ok with the cast. Some places don't like it and will refuse to take your child. **If they won't take your child, look into getting carers allowance from the government.** If they do take your child, you will have to show them how to change the nappies and provide any equipment that you deem is necessary.

Car seat

Steps-charity do a grant that enables you to buy a car seat that's suitable. Download the forms, fill them out, get them signed and send them back.

I must stipulate, that the grant has limited funding per month and therefore, you are not guaranteed to get it.

MAXI-COSI do a special car seat called the Opal HD, which you can rent for 6 months for £100 (you get £50 back after the 6 months).

All the info you need is here:

www.steps-charity.org.uk/conditions/hip-dysplasia-ddh/hip-spica-car-seat

What we did was, rent the MAXI-COSI and apply for the grant. Then, that way, we had a car seat for 6 months and waited to see if we received the grant.

Prams

On the list of equipment, it gives you the names of the prams that may be suitable for your baby's cast. We had three prams and not one of them was suitable - off to Mothercare we went!

Because the pram we had taken with us wasn't suitable to transport my daughter, I ended up using a wrap, Yep, a stretchy wrap (baby is in permanent frog position and it was very comfy) to go to the car. If you love using wraps and carriers, go to your local sling library (Facebook or Google) where they can help find the best one for you to use.

High chair?

Nope, sorry that's out the window. Have a look at:

www.totseat.co.uk

It's a fabric highchair that fits nearly all the chairs in the world. Ok, so that might be over egging it but it fits most chairs. I bought two - one for home / out and about, and one for day care so I didn't have to remember to pack it or pick it up.

Seating / Sleeping

Bean bags (Dunelm mills), pillows (memory foam) and cushions. If your baby is in a cot, you might want to put it back up to the top to save your back. We used memory foam pillows to find the best position and built on that. We currently have three on the go.

Clothes

Hip-pose Limited have just been bought by Slumbersac. They do specialist clothing for babies being treated for Hip Dysplasia and / or wearing a Pavlik Harness.

www.slumbersac.co.uk/hip-pose-hip-dysplasia-clothing-for-children

Admittedly, it is easier for girls than boys. Girls can wear dresses and skirts for occasions like leaving the house / going to the day care; otherwise, its just a t-shirt.

Steps Charity Worldwide

Hip Hip Hooray - raising awareness for Hip Dysplasia. If you have any questions, you can post on here. The admin team will then post it out to the rest of the group to help with. It's very thoughtful and some of the ideas are just genius.

Toys - I put away all the walking aid toys as I didn't think it was right to remind us what she could do before and it was only upsetting me. So, away with the walking and in with floor puzzles, cars, sorting puzzles, balls, the cat, pegs, magnets, books, the cat again and crinkly paper.

Hello puppy calling, do you want to play a game? Let's clap hands together as we learn our ABC's.

Final message from one mummy to others

This is a difficult and challenging time. You can cry, get angry and cross but you have to work through this. Try not to get upset in front of your baby. If you are upset, they will be upset too. Cuddle them, make them smile and giggle. This is just a blip, they won't remember. You will but they won't. They will amaze you every day by adapting to their situation; for example, How can I reach remote? Can I spin on here? How do I balance on this rocking caterpillar?

There is a whole community out there waiting for your questions. You are not alone and yes, you really do need that cake!

The advice given in this leaflet has been generated by a parents first hand views and practical ideas.

With special thanks to the parents of Jessica.

Paediatric Orthopaedic (August 2017)

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What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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