

DDH - developmental dysplasia of the hip

A Parents View

DDH - A little love and help at the start

I'm not sure what my expectations were, but I found it scary, it's upsetting, it's un-nerving - and that's just the parents! You will hear this a million times, but children are resilient more than we give them credit for. It took 9 days for my daughter to re-learn how to crawl with a SPICA cast on, 5 days to go backwards and 3 to spin around and she is only 14 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, let's 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), understand what is going on, so when the doctors say we might have to do blah, you know which blah they're talking about. I emailed it 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, pass it on. Inside it, there is a list of possible equipment that you might need.

The most important being a car seat, a pram and a blue badge.



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 and are in stock so I can walk away with it today?'**

With a slightly baffled look - too much information.....can not compute...at you and then at your child and a AHA moment will happen.

2 hours later.....we had a pram and a newly educated shop assistant.

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 doctors note/hospital appointment, have my daughters 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 wont 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 got a grant or not.

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 go!

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 its a fabric highchair that fits nearly all the chairs in 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/ 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 Ltd 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 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. Its 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, crinkly paper and a renewed interest in the fp* ball that encourages you to 'roll with me' and the front of the fp* walker...you know the one... hello puppy calling, do you want to play a game, lets clap hands together as we learn our abc's (I might be paraphrasing here) Fisher Price Toy.

Final message from one Mummy to others

YOU GOT THIS. Cry, rage, head band if you need to, but **YOU'VE GOT THIS.** Don't get upset in front of your baby, as in their eyes you are God, and if you are upset then their world is ending and they will be upset too. Cuddle them, make them smile and giggle, this is just a blip, they wont remember - you will but they wont. They will amaze you every day and they learnt to problem solve issues like how can I reach remote? can I spin on here? how do I balance on this rocking caterpillar?

You are loved and there's a whole community out there waiting for your questions, you are not alone and yes, you really do need that cake!

Take care xx

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 Holt

Paediatric Orthopaedic (August 2017)

If you have any comments about this leaflet or the service you have received you can contact :

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If you would like this information in another format or language contact the above.

Potřebujete-li tyto informace v jiném formátu nebo jazyce, obraťte se prosím na výše uvedené oddělení

Jeżeli są Państwo zainteresowani otrzymaniem tych informacji w innym formacie lub wersji językowej, prosimy skontaktować się z nami, korzystając z ww. danych kontaktowych

ਚ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਪ੍ਰਾਚੂਰ ਜਾਂ ਭਾਸ਼ਾ ਵਿੱਚ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ,
ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਉਪਰੋਕਤ ਵਿਭਾਗ ਵਿੱਚ ਸਾਡੇ ਨਾਲ ਸੰਪਰਕ ਕਰੋ।

اگر آپ کو یہ معلومات کسی اور فارمیٹ طرزبان میں درکار ہوں، تو
برائے مہربانی مندرجہ بالا شعبے میں ہم سے رابطہ کریں۔

"إذا احتجت الحصول على هذه المعلومة بشكل مغاير أو مترجمة إلى لغة مختلفة فيرجى منك الاتصال بالقسم
المذكور أعلاه"