Steps
We don't take walking for granted

Hip Surgery and Spica Cast Care

The Parents' Guide

Introduction

At Steps, we understand how a lower limb condition can affect individuals, families, and communities. Our commitment is to helping people understand these conditions, offering reassurance and actively working for a better future, through our work with national health services and research projects. This booklet is for parents with a child going into a spica cast following treatment for DDH or hip stabilisation. It cannot tell you everything you need to know about what the future may hold, but we hope it will reassure you and your child. It is also intended to show that practical help, specialist medical information, emotional support, and links to other sources of information are all available, if needed. This will help you to be more prepared for the road ahead and have information to hand so that you can ask informed questions about your child's care, treatment and prognosis.

Help when you need it

Sometimes being able to contact someone who knows what you are going through can provide much needed encouragement. Our Family Contact Service can put you in touch with others who have shared a similar experience and can offer advice, support, and practical tips.

You can also share your problems and solutions to everyday challenges on our closed Facebook Group for parents. The group is a friendly and safe way of discussing online your worries with other parents, sharing tips, and finding emotional support.

Remember, the STEPS Helpline team are here to offer information and support in total confidence and answer any questions or concerns you may have. This will help you to ask informed questions at hospital appointments or may help to reassure you along the way. No matter how big or small your concern, please telephone our Helpline on 01925 750271 or email info@steps-charity.org.uk for support and advice in total confidence.

Social media details can be found on the back cover.

Contents

Why does Hip Dysplasia happen?

The exact cause or causes of hip dysplasia are not known and it is important to understand that it is not anyone's fault. Even though as parents you may be anxious at discovering your baby has hip dysplasia, he or she will not be in pain. Hip dysplasia does not affect your baby's development such as crawling or walking.

Although many people may think that Developmental dysplasia of the hip (DDH), is a rare condition, it is surprising to know that it is of the most common hip conditions in children affecting 1-3% of all newborns.

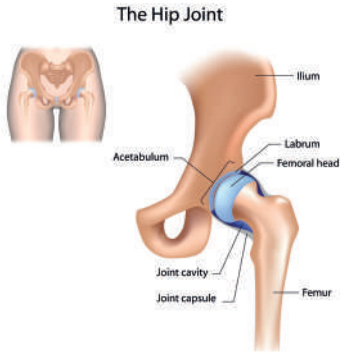
It is widely recognised by health professionals and researchers that hip dysplasia develops around the time of birth. This is because the hip socket is shallower at birth which is a natural occurrence as the feotus grows in the womb and there is limited space for the baby to move. The shallow sockets may allow more flexibility for the baby to pass through the birth canal.
It is also important to know that expecting mothers make hormones that help ligaments relax during the birth. These relaxing hormones can stay in a baby's bloodstream for a few weeks making it normal for babies' hips to be 'stretchier' and looser shortly after birth. As girls usually have more loose ligaments than boys, they are more likely to have hip dysplasia. Statistically they are 4-5 times more likely to have a hip dysplasia diagnosis than boys.

Loose ligaments mean that the hip is easier to be wiggled in the socket and, although in most of the cases ligaments tighten up naturally after birth, approximately 10% does not. If the ligaments around the hip joint are loose, the hip will subluxate. In medicine, a subluxation means that there is an incomplete or partial dislocation of a joint or organ. In hip dysplasia, this is when the ball is no longer centred in the socket.

What is Developmental Dysplasia of the Hip?

DDH encompasses a range of hip joint abnormalities, from mild instability to complete hip dislocations at birth.

The hip joint is called a ball and socket joint. The top of the thigh bone is ball-shaped and fits into a socket on the side of the pelvis. This allows the leg to move both up and down and side to side. For the hip joint to grow normally, the ball-shaped head of the thigh bone needs to be inside the cup-shaped socket. Very young babies' hips are made of soft cartilage which changes into bone over the first few years. For the joint to grow properly the ball and socket have to be held firmly in the right place. It is held in place by ligaments, muscles and a joint capsule.



DDH means the ball and socket do not fit snuggly together: there are varying degrees of severity. If the ball (femoral head) is not held safely in place, the socket (acetabulum) may be more shallow than usual; this is called acetabular dysplasia.

If the ball loses contact with the socket and stays outside the joint it is called a dislocated hip. These are all forms of DDH. One or both hips may be affected.

How can DDH be treated?

For some children, when a splint such as the Pavlik harness has not worked or DDH is not diagnosed until after they are approximately six months old (depending on their overall development), the consultant may recommend surgery. The most common type of surgery is a reduction, a procedure in which the femoral head (ball) is relocated into the acetabulum (socket). Some children may also go on to need bone surgery to correct bony deformities: carefully controlled surgical division of a bone is called an osteotomy.

For all types of surgery, your child will require a general anaesthetic. As part of the procedure to reduce the hip, the surgeon will usually perform an arthrogram (x-ray with dye) first. The arthrogram shows the surgeon the hip structure and whether a closed or open reduction is best for your child (see page 7 for definitions of these terms).

After surgery, your child will be put into a hip spica cast for a minimum of 6 weeks. At around 6 weeks your child will need a review of their hip under a general anaesthetic to check the reduction and the stability of the hip – an x-ray with dye (arthrogram) may be performed under general anaesthetic to confirm the hip reduction.

It is probable that a further period of at least 6 weeks in a hip spica will be needed to allow the hip to stabilise securely.

What other conditions require hip surgery?

There are conditions other than DDH which may require hip surgery and sometime in a hip spica cast; more information is available on these conditions in our series of downloadable publications at www.stepsworldwide.org.uk

What is a hip spica cast?

A hip spica cast is a large plaster cast that can best be described as a 'plaster of paris' pair of trousers. Traditional plaster of paris may be used over wadding, or a combination of plaster of paris and fibreglass material or all fibreglass. Plaster of paris is always white, but, depending on the hospital, the fibreglass plasters can be coloured or even patterned.

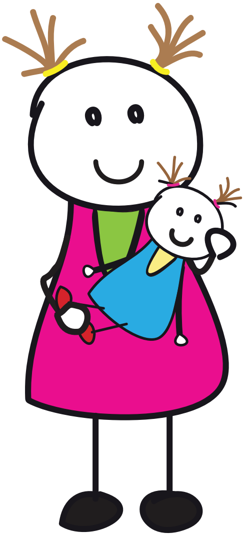
The shape of the spica varies, see photos below, and can extend from the mid-chest down to the ankle, sometimes with a bar across. If the problem is only on one side, following an open reduction, the cast will probably extend to the ankle on the affected side and may stop just above the knee on the unaffected side, but this depends upon the hip stability that will be judged by your surgeon. A 'letterbox' style hole is left in the groin area to allow for toileting.

The purpose of a hip spica is to keep the affected hip in the best position in order for it to develop normally.

Initial procedures

Closed reduction

During a closed reduction, the surgeon gently manipulates the femur (thigh bone) so that the femoral head (the ball) is placed in the socket without making an incision (cut). In order to achieve a stable and tension free reduction, it is often necessary to release the tight tendon in the groin called the adductor tendon. This is achieved by performing a tiny cut (incision) in the groin (adductor tenotomy). Once the femoral head is in place, a hip spica is applied. The time in cast can vary, depending on the severity of the hip dysplasia. The child is sometimes put into a splint after the cast is removed, to maintain correction.



Open reduction

In an open reduction procedure, surgery is undertaken to bring the head of the femur (the ball) into the acetabulum (hip socket). Surgery is performed through a cut (incision) in the groin. Careful release of tight tendons and ligaments is performed to ensure the socket is clear and a tension free reduction of the ball into the socket is easily achievable. The joint capsule is then repaired to aid the maintenance of the reduction.
To complete the open reduction, the surgeon may also need to correct bony deformities and restore normal anatomy by performing a carefully controlled division of a bone (osteotomy – see pages 8-9 for explanation of terms). After surgery is completed, the leg is placed in a position where the hip joint is most stable. This means that the leg may be set at an odd angle in the hip spica cast.

Later treatment; explaining various types of osteotomy

Femoral osteotomy

A femoral osteotomy is sometimes called a rotation osteotomy or derotation osteotomy. The type of surgery depends on the structure of the hip joint and the age of the child.

During the femoral osteotomy the top end of the femur (the thigh bone) is repositioned to give better stability to the hip. The femur is carefully divided surgically just below the femoral neck and rotated to the best position. Some shortening of the femur is also usually undertaken, to reduce the tension in the joint. The femoral osteotomy is then secured in the correct position with a metal plate and screws. The child is then put in a hip spica cast for six to twelve weeks. If metal plates are used, they are usually left in place for at least a year, when the child has a more minor operation to remove them. Some surgeons prefer not to remove the plates routinely, unless any further surgery is required.

Pelvic osteotomy

A pelvic osteotomy is a general term for surgery to reconstruct the hip socket by changing its angle (reorientation) or its volume and is usually only undertaken when other less invasive methods or normal growth will not correct the socket underdevelopment (acetabular dysplasia). The surgeon cuts the bone in the pelvis and moves it to improve the orientation of the hip socket and to improve support for the femoral head. There are many different types of pelvic osteotomy and your surgeon will advise which is the best for your child. One of the most commonly used is the salter osteotomy.

All involve improvement of the position and orientation of the socket and may involve insertion of metal pins and bone grafting from the pelvis. Most young children are immobilised in a hip spica or brace, but older children and teens may be allowed to move around on crutches.

Salter osteotomy

The salter osteotomy may be performed with an open reduction for children who are older than 18 months at the time of their first surgery. It may also be performed as a "stand alone" procedure for residual acetabular dysplasia (poor socket development). A cut is made through the pelvis above the socket where the femoral head sits. The surgeon tilts the acetabulum to correct its angle and inserts a graft of bone (taken from another part of the pelvis through the same incision). One or more pins are inserted through all the pieces of the bone to hold them while they all join together over a few weeks.

Chiari osteotomy

This surgery makes the hip socket deeper and the surgeon slides bone outward to effectively widen the shelf of bone above the femoral head. Steel pins are often used. After the surgery, only partial weight can be put on the leg for three months.

Pemberton osteotomy

This procedure is undertaken to treat acetabular dysplasia where the surgeon cuts the hip bone and tilts the roof of the acetabulum (socket) to correct its angle, filling the gap with a wedge of bone.

Going into hospital

Now that you know your child will be attending hospital, please be reassured that there are several things you can do to make the hospital stay easier.

In the hospital, children benefit when at least one parent stays overnight with them. You can work out a plan with your nurse to allow you to continue caring for your child as much as possible (e.g. bathing, changing clothes and feeding). If you have to leave the hospital at any time, remember to tell your child how long you will be gone for, and make sure that you are back on time.

Children respond differently, depending on the length of stay and the procedures involved. Try and keep to a routine wherever possible, this may be hard but try and keep to their normal bedtimes and habits because this can help them to feel more at home.

We have compiled a 'going into hospital' checklist, which lists some items you and your child might want to bring into hospital to make your stay more comfortable (pages 32/33) and a glossary of useful terminology (pages 30/31).

Communicating with doctors

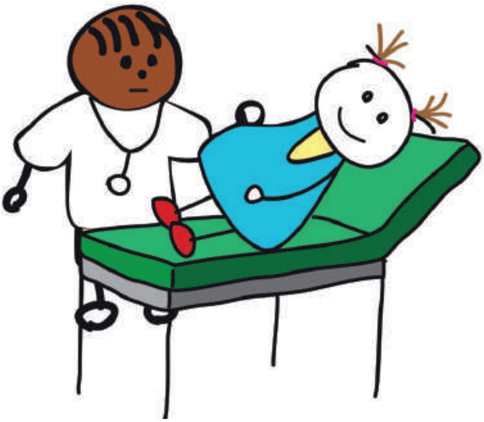
It is important to understand exactly what your child's treatment will be and how it will help your child. Preparing in advance a list of questions or topics that you want to discuss at your hospital appointments will make it more likely that everything is covered.

You should not be afraid to ask questions. Parents often get a lot of information in a short amount of time during a typical visit. If you are not given a handout with the information written down, ask for one, or take notes and ask questions about things you don't understand. If you don't ask any questions, your doctor will likely assume that you understand everything.

Another way to ensure you really grasp what's going on during the appointment is to bring a partner or friend along who can serve as another set of ears. If there are two of you there, you're more likely to get a balanced perspective. You can discuss what you heard afterwards. Also, everyone forgets a certain amount of what a doctor says - having another person there can help you remember key facts.

Getting a second opinion

If you would like to consult with another expert about your child's treatment plan you may ask for a second (or further) opinion. However, it is advisable to first discuss this with your existing consultant and GP in case they wish to clarify any points not fully understood at previous consultations. Getting a second opinion should not offend the original doctor, provided that you stress that you require one so that you have as much information as possible to base your decisions on. Although you do not have a legal right to a second opinion, you do have the right to ask for one.



Going to theatre

It is perfectly normal to feel anxious about your child going to theatre and having an anaesthetic. Anaesthesia is a very safe procedure, but do talk to the doctors and nurses on the ward about any specific concerns you have. Tell them if your child has a cold or has been unwell, as in certain circumstances, it is better to delay the operation and wait until the child is better. Most hospitals allow parents in the anaesthetic room, so that you can reassure your child whilst they are going to sleep. The nurses on the ward will tell you what to expect and explain how long your child will need to go without food.

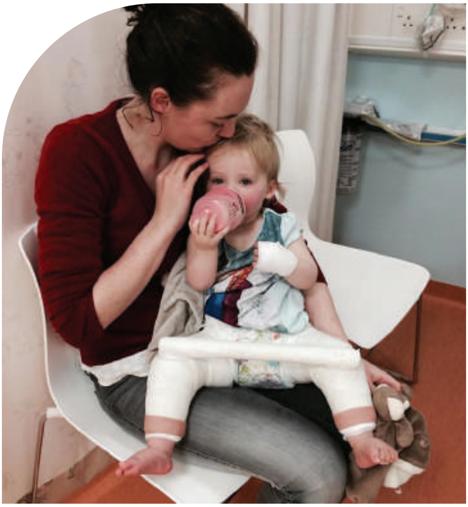
Returning from theatre

Waiting for your child to come back from theatre can feel like forever.

Although it may be difficult, try and occupy your mind to make the time go faster. You will be told when your child is ready to return to the ward. In some hospitals, you will be allowed in the recovery room to be with your child when he/she wakes up. Remember, your child will still be heavily sedated from the anaesthetic, so won't remember much. Try to be calm and reassuring. The sound of your voice will help him/her to settle.

After bigger operations your child may come back from theatre with a drip in the arm or foot. This is used to deliver medicines, such as painkillers and also stops your child from becoming dehydrated. Some children also have a tube coming out from the wound. This stops fluid from collecting at the site of the wound and helps healing.

Most children recover very quickly. They will only be allowed to sip small amounts of water to begin with, but as soon as they are fully awake they will be able to feed normally. After a simple procedure, like a cast change, you may be able to leave the hospital the same day. After a bigger operation, you may be in hospital a few days.



Pain relief

Good pain management is important for your child following surgery. Ask for a copy of your child's pain relief schedule and ensure that relief is administered in accordance with this by hospital staff. This is especially important at night, when your child needs to be given medication and the temptation is there to let them sleep. It is very important that pain medication is given at the correct times, even if this means nursing staff rousing your child gently in order to administer it. When you are discharged from hospital, you may be given some pain relief medication (paracetamol and ibuprofen) to take home with you. These are given just in case your child may experience any pain or discomfort whilst at home. Please follow the instructions on the labels for how much to give and how often. If you find your child is in pain and the paracetamol and ibuprofen are not working sufficiently, then please contact your GP or hospital for advice.

Cast and wound care: when to seek medical advice

It is perfectly normal for your child to feel upset and touchy when the plaster is first put on, especially as they have just undergone surgery.

Extra love, affection and reassurance will usually help to settle your child and make them feel more relaxed. Cuddles are a bit awkward, but you will soon find the easiest way of holding your child.

Useful Advice: Take a photograph of the cast and the skin around the edges of the cast before leaving the hospital. It will help you to communicate with your treating team in case of issues with the cast.

Once your child has been discharged from hospital, if you notice any of the symptoms listed below please seek medical advice immediately by either contacting your GP or hospital ward for advice.

- Severe pain or swelling not relieved by medication or elevating the leg.
- Numbness or "pins and needles" sensation under the cast that does not go away after position is changed.
- If your child's toes/feet are cold to touch and become numb or bluish in colour. Your child's toes should be pink and warm to the touch and they should be able to wiggle them and feel you are touching them.
- Inability to move toes on the casted side, compared to the other side. The spica should 'fit' properly i.e. (the plaster is not too tight or too loose). If concerned get this checked, you will soon have a good idea of what is correct.
- Severe skin irritation or rash around cast edges.
- Cast becomes broken, cracked, loose or soft.
- Unexplained fever above 101°F.
- Any kind of object getting stuck inside the cast.

Wound care: if your child has had an open reduction or osteotomy, when they return from theatre you may be able to see that there is a small dressing in place over the wound in their groin area. This needs to stay in place for 5-7 days at least, but should it fall off before this time, then let one of the nursing staff know and it will be replaced. You should be observing the wound once your child has been discharged from hospital.

You should look for:

- Oozing fluids from the wound such as blood, clear fluid or pus. Pus is only present if the wound is infected.
- Redness to the wound area.
- Your child having a temperature or being 'unwell'.
- An odour, omitting from the wound.
- The wound feeling 'hot' to touch.

In **very** rare cases abdominal pain and vomiting caused by pressure on the mesenteric (gut) arteries, known as "hip spica syndrome" may occur. It is the most serious, but fortunately rare, complication. If caught early, it responds well to removing the abdominal section of the spica but if missed it can cause bowel necrosis (death of the cells in a section of the bowel).

Going home

Toileting

Disposable nappies are preferable for a child in a hip spica as they tend to hold urine better than cloth nappies and there's less chance of moisture seepage. You will need to buy a larger size than usual to accommodate the plaster, with a smaller nappy, with the side tapes removed, pushed up inside the cast. Alternatively, you could cut off the side tapes and use the middle portion of the nappy with popper or tie-on plastic pants.

Frequent changing is needed but some leaks are inevitable. Sleek (may have various other names) - a waterproof adhesive, is usually recommended to help minimise this problem. Sleek is applied round the edges of the plaster, particularly in the nappy area. Sleek can be obtained from the hospital, or most doctors give it on prescription.

A smaller nappy or incontinence pad is usually placed under a larger nappy, which then goes over the spica cast. Every child is different so you will probably have to experiment with various methods until you find the right one for your child. If your child no longer wears nappies, they will require a bed pan or urinal which may be provided by your Local Authority, but if not you can purchase these from a chemist.

For older girls you may also find the Freedom Whiz useful. This is a small portable urinating device, originally marketed to allow females to urinate without removing clothing when away from a conventional toilet (available to buy from Steps).

You many also find that whilst your child is in a hip spica, a urine odour may develop over time. This is normal and is simply due to the length of time that your child is in plaster. In extreme cases, some children may need to return to theatre for the spica to be changed.

There are some deodorisers available which may help mask unpleasant odours. Ask your local pharmacist for advice. Do not apply a deodorant directly onto the skin and be very cautious about applying it to the plaster. Do a skin test first on your baby to check for any reaction.

Washing

The hip spica must **NOT** become wet; if water is absorbed into the spica the plaster will become weak and crack.

It is not possible to bath your child whilst they are in a hip spica, so they will need a thorough wash (top and tail) with a damp cloth at least once a day to keep them feeling fresh.

You are advised not to use skin lotion or powder under the edges of the hip spica as this may cause skin irritation and/or be an inhalation risk. Whilst cleaning the skin daily, it is a good idea to check all the plaster edges carefully for any signs of chafing; these are most likely around the spine and ankles. Great care must be taken round the nappy area to prevent undue soreness.

Hair washing is one of the most difficult problems especially in the younger child who cannot support him or herself. Depending on the length of your child's hair, you may use a wet cloth for hair washing. Cover the plaster with towels and make sure that water does not drip down the plaster.

For longer hair, you could use an inflatable hair washing tray whilst your child is on the bed. These are sometimes provided by your local social services: however, if not they can be purchased from chemists or the internet. A shampoo shield may also be useful to stop soap and water going in the face. Some parents have also found dry shampoo helpful. Most chemists stock this.

Sleeping

Younger children are less likely to be affected by the hip spica cast although 'wind' or colic can be troublesome. A little more time spent in winding a child after a feed, perhaps by moving around with them, is time well spent. Medication can be obtained from your GP if this is a persistent problem.

Children in casts may only sleep for short periods and often become restless and distressed. Disturbed nights can also result from cramp, itching and the inability to turn over.

The recent hospital experiences may make a child feel insecure. Extra reassurance may be needed, and sleeping in the same room or bed as the child need not lead to permanent bad habits. Taking it in turns to do 'night duty' is one way to ensure that you at least get a good night's sleep sometimes.

Practical hints from parents that you may find useful:

- A mattress on the floor avoids the fear of a child failing out of bed awkwardly and gives the opportunity for joining your child if they require a comforting presence during the night (or you could use bed guards to attach to the side of the bed).
- Plenty of pillows under the body and the plaster help to make your child more comfortable. The most vulnerable areas in the spica are the ankles and the waist, particularly around the spine. The plaster edge often digs in here causing greater discomfort, so a flat cushion where the cast meets the spine can alleviate the pressure as your child flexes and moves in the night.

- Some children can wake up distressed which can be very worrying, particularly when a young child cannot explain what is wrong. But for the most part, it is usually cramp. Just massage and flex the ankles and feet.
- Your child may well be too hot. The plaster is like cavity wall insulation and your child may need fewer blankets.
- A lambskin rug or microfiber blanket can help soothe and prevent heat rash.
- If your child is in nappies, raise the head end of the cot on blocks to help urine run down into the nappy and not up the back.

Positioning your child

If your child spends most of their time propped up on pillows or in their pram lying on their back, the pressure of the cast on their spine can cause the skin to become sore. To prevent this you must change your child's position frequently (approximately every 2-4 hours) by turning your child on their side or tummy or if this is not possible, altering the angle they are resting at. Use cushions, pillows and beanbags to make your child more comfortable.

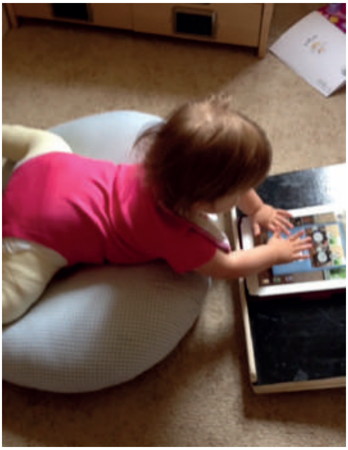
When you turn your child over, you must turn them in the same direction as their unaffected side in case the plaster cracks. When your child is lying on their back place a rolled up towel underneath their ankles to raise their heels off the bed (although be careful not to cause additional pressure from the cast on the abdomen).

In some instances, a bar is placed between the legs of the cast to stabilise the legs, do not use the bar to position or lift your child as it may break.

Although the plaster will feel heavy, your child may be able to move themselves along the floor. Do not leave your child alone especially on a raised surface.

Playtime

Finding ways of entertaining and stimulating your child in a spica cast can be challenging. Many parents use a variety of beanbags for sitting watching television. To offer a change of position, some parents lay their child on their tummy on a bean bag, with a beanbag-bottomed lap-tray in front of them for craft games or jigsaws. A 'hip spica chair' is useful for eating, reading, craft activities and colouring. Parents may find these second hand on the Steps Facebook page or forum. Alternatively, instructions for building a spica chair can be emailed on request info@steps-charity.org.uk.



Clothing

For small babies, babygrows a few sizes larger than usual are probably the easiest type of clothing to deal with, especially those with a full set of leg poppers and open feet. Girls' dresses usually fit over the plaster with no problems, with socks to keep the feet warm.

Boys' clothing and trousers can be more challenging (especially if the spica has a bar) and you may have to adapt clothing with velcro. An adult pair of showerproof 'hiking trousers', cut off at the thigh and secured over the cast with a belt provides good protection during feeding and for unexpected showers while out and about.

If the spica cast is patterned or coloured the cast itself can act like a pair of trousers, just use a pair of shorts or vest with poppers to cover the nappy area. Baby leg warmers are also useful in colder weather.

If the cast comes down to the ankles remember your child's feet can get cold even in warm weather, so they may be more comfortable wearing thick socks or leather soled 'moccasin' style slippers.

Diet and meal times

Your child may no longer fit in their usual high chair, so you may need to find an alternative way of sitting them up whilst eating. It is a good idea to completely cover the whole plaster to ensure it remains clean and to stop food getting inside the cast. It is also useful to use a straw or a cup with a lid to avoid spillages. A toddler booster chair that straps onto a standard dining chair is often a good option for mealtimes and can be also used for games and entertainment at the kitchen table to vary your child's position.

Many parents find that their child's eating habits are unaffected by being in a hip spica although they can get constipated as they are spending so much time lying down. You can help avoid this by ensuring their diet has plenty of fibre and making sure they drink lots of water: never restrict your child's fluid intake. If the problem persists and makes your child uncomfortable, it is best to seek medical advice.

Travel

Getting out and about can be challenging but essential for your own emotional well-being. For the latest information, please refer to the Steps equipment list which lists pushchairs that other parents have found suitable for a child in a hip spica.

Pushchairs

Dependent upon your child's age and shape of the hip spica, they may fit into their own pram/buggy. It may be possible to adapt your existing pushchair by extending straps and using extra cushions, but always consult the manufacturer for advice before making any changes.

Some of the best forms of pushchairs available are the twin side-by-side ones, but these can be expensive to buy unless you can borrow one or buy second hand.

Whatever style of pushchair you use, it is essential that your child is always strapped in securely using the harness provided. If your child's feet stick out at the sides, you will need to take extra care not to bang them going through doorways or other people walking into them.

You will also need to be prepared if it rains, as it's important that the hip spica does not get wet. You may need to be inventive as the waterproof raincover provided with your pushchair may not fit over the cast.

Older children over the age of three will probably require a special lie-back wheelchair such as the 'Chunc'. These may be provided from your hospital or you can also hire them from the manufacturer (**chunc.com**).

Car seats

It is unlikely that your child will fit in their normal car seat, as it has not been designed to be used with children in a hip spica cast.

It is recommended that you do not add any parts to adapt your child's car seat (e.g. cushions), as this could affect their safety in the event of an accident causing injury to your child and invalidate your car insurance. Children in a hip spica are also at a higher risk of injury if they travel in a forward facing car seat, especially if additional cushions have been added.

If your child weighs over 9 kg once in plaster and is under the age of 4 years, they may be able to use a specially modified car seat.

However, this will depend on factors such as position of your child's legs in the hip spica and the age of your child. The car seat can be used as a standard car seat once the plaster has been removed for children up to 25 kg.

For further details, prices and advice you may want to approach the following providers:

In-Car Safety Centre, you can purchase a seat for £220 that has been specially adapted and tested to be safe for toddlers in hip spica. Email: info@incarsafetycentre.co.uk or visit their website www.incarsafetycentre.co.uk or telephone: Milton Keynes: 01908 220909 / Belfast: 028 9074 2052 / Essex: 01702 808313

Maxi-Cosi (part of the Dorel group) have adapted their Opal car seat for children in a hip spica cast and offer a loan scheme for parents who need a seat while their child is in a hip spica. Email the team at uk-consumercare@maxi-cosi.com.

Blue badge parking scheme applies to hip spica casts

If a child is under three and you live in England, Scotland, Wales or Northern Ireland you are entitled to receive a Blue Badge. (Verified on telephone number below with Government Staff January 2016)

For further information visit:
gov.uk/apply-bluebadge

Call;
Telephone (England): **0844 463 0213**
Telephone (Scotland): **0844 463 0214**
Telephone (Wales): **0844 463 0215**

Or contact your local council for details.

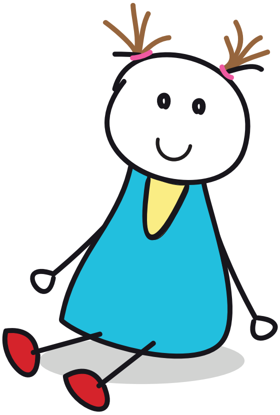
The Blue Badge scheme clearly states:
"A parent or guardian must apply on behalf of a child under the age of three".

The list of bulky medical equipment referred to within the literature includes: *"casts and associated medical equipment for the correction of hip dysplasia."*

Some councils may at first refuse the badge but don't be put off and do appeal against their decision as you are entitled to benefit and it really does help with parking.

Children over three

Throughout the UK anyone in receipt of the higher rate mobility component of the Disability Living Allowance (which is only awarded to children over three) is automatically entitled to a blue badge. At the time of printing DLA only exists for child applicants and remaining provision is covered by PIP (Personal Independence Payments).



Cast removal – what to expect

The hip spica cast may be taken off in outpatients without an anaesthetic, or in theatre under a general anaesthetic, but you will need to check with your hospital to find out their policy.

Children can become upset when the hip spica is removed without anaesthetic and this can also be upsetting for parents as well. Whilst it's not a painful procedure the noise and vibration of the plaster saw, that is sometimes used, may frighten your child. Distraction may help and you are allowed to be near to your child to comfort them.

The plaster technician will try to get through the procedure as quickly as possible. Once the plaster has been removed you may notice your child's skin looks red, flaky and/or scaly. This is perfectly normal and will soon settle down but you may be advised to apply an intensive moisturiser to help remove the dead skin; your GP will be able to prescribe cream for this.

An x-ray is usually taken to ensure that the hip joint is developing satisfactorily and you may also have an appointment with your consultant for a review.

Life after cast

The cast removal is probably the moment you have been waiting for, after weeks or maybe even months of your child in plaster. However, don't be worried if this is not initially the 'happy time' you envisaged and your child appears upset and unsettled without the cast. It can take a bit of time for your child to adjust to having legs again, as their skin will be very sensitive.

You can pick your child up as normal but it is advised to support their bottom and hips.

In some cases, a child may spend some time in an abduction brace following cast removal, in order to keep the hips in a stable position. The length of time in the abduction brace depends on the child's condition and on the individual consultant.

Even though your child may have previously loved bath time, it can take several weeks to get them used to it again, so do not be surprised if they initially get upset when in the water.

Time spent in the cast may also mean that the development of some physical skills seems to have gone backwards, but they will 'catch up'.

Also be aware that your child's legs will not return to the 'normal' position immediately and they may hold their legs in the plaster position. It is a case of waking up the muscles, tendons and joints and reminding them that they can move.

This can take some time and you may be referred to physiotherapy who will discuss some simple exercises which you can do at home with your child. Swimming is also an excellent form of physiotherapy, as it's weightless and your child will often not realise that they are moving their legs. The key to your child mobilising is to let them do it in their own time and do not force or push them to stand or walk.

Childcare and school

Children in treatment for hip dysplasia can continue to go to childcare or school. It is important that your child feels well supported when returning to childcare or school. If your child has a babysitter, nanny or attends a childcare centre, it is important to explain your child's care regarding the cast. It is usually advisable to provide the person responsible for your child's needs with a list of items to be aware of and some useful instructions. Where possible, it would be beneficial to demonstrate a diaper change.

If your child is mobile, make sure that the childcare provider knows that, and understands what your child is able to do. Be sure to tell the childcare provider if your doctor specified any restrictions on your child's movements such as not standing while wearing a spica cast.

If they have any questions or concerns, they should be put in contact with the treating team for advice. Talk with the teachers about your child's return to school and plan well in advance where possible. Your child could use a scrapbook or some pictures to help explain their conditions to the teachers and their peers.

It is advisable to explain your child's condition to the head teacher, nurse and Special Education Needs and Disability Coordinator (SENDCO), where available before the child starts school so that any anxieties and potential problems can be identified beforehand. You will need to provide enough information to help the school perform a risk assessment and you may need a letter from the hospital. This is best arranged before you are discharged. It is also good to have a letter from your consultant pointing out that your child may need additional days off school for hospital appointments. Most schools are sympathetic and will make the necessary accommodations. Each school should publish their disability equality and accessibility schemes as separate documents annually or as part of other school documents and must be able to provide copies to anyone asking for them. You should discuss your child's difficulties with teachers, head teacher or Special Educational Needs and Disability Coordinator (SENDCO), where available. If you are not satisfied with the provision for your child there are other sources of help and advice such as your **local parent partnership** service. They can provide, 'accurate and neutral information on the full range of options available to parents.' Be proactive in sourcing the support that you and your child need, and don't be concerned about talking to your child's school. A problem identified early enough can be easier to resolve.

For further details and information please go to our YOUTUBE channel to view our webinar on Evaluation of Access in School.

Emotional reactions

Hopefully this booklet will help you to cope with the practical aspects of caring for a child in a hip spica. However, dealing with the emotions when you're told that there's something wrong with your child can also be very challenging.

Many of the parents who have contacted Steps have said how much relief they get from being able to express and share their feelings. Hearing how others have reacted helps you realise that you're not on your own and your reactions are likely to be in keeping with those of others in the same situation.

Below are some of the reactions of other parents. They are in their own words and we hope you'll find some comfort in this.

Initially most people feel shock or disbelief.

'It was very difficult at first. We were shocked and then angry, 'Why us?' we asked ourselves. Then finally we were determined that we would win through no matter what.'

It is also hard to prepare yourself for the treatments, which initially to most parents seems like an insurmountable hurdle. The treatment itself is often more distressing to the parents than the child.

"I felt strange that my cuddly little baby had been taken away from me."

"Compared with some other mothers I have had relatively little to deal with, but I do remember feeling overwhelmed and isolated during those first few weeks."

It can be a physically and mentally hard time for parents.

“Because I was tired most of the time I was more irritable with my husband and older daughter. At one stage I almost resigned from my job as I felt that I couldn’t cope with it all.”

However, most parents who have been through all this seem to find their own solutions.

“I know deep down that I will cope with whatever happens, you always seem to find a hidden strength.”

It helps to be able to share one’s feelings, to realise that they are normal and quite justifiable reactions to a very difficult situation. If you want to talk to someone who has been through a similar situation please contact our helpline 01925 750271 or visit our discussion forum on the Steps website www.stepsworldwide.org.uk

Finally, your feelings towards your child do not fundamentally alter and to have your child healthy once again makes your feelings all that more precious.

“I shall never forget the flood of emotion I felt the day the plaster came off and I picked her up and cuddled her close for the first time. She felt so soft and floppy and fragile. I had to learn how to carry her all over again; but it was wonderful!”

Steps host a closed Facebook Group for families to offer each other support and share hints and tips about coping with treatment. To join, visit facebook.com/groups/stepscharity

Glossary of terms for DDH

Abduction	To move a limb or any other part away from the midline of the body
Acetabulum	Cup-shaped socket of the hip bone
Adducted	To move a limb or any other part towards the midline of the body
Arthrogram	X-ray with dye
Bilateral	Affecting both sides
Breech	Position of the baby in the womb, so that it will be delivered buttocks first
Congenital	Present around the time of birth
DDH	Developmental Dysplasia of the Hip
Developmental	Arising in infancy or childhood and dependent on growth
Dislocated	The head of the thighbone is positioned outside the socket and cannot be re-centred (displaced)
Dysplasia	Lack of normal growth, in the hip often refers to under development
Femoral head	Ball shaped top of the thigh bone
Femur	Thigh bone
Gait	Style of walking
Idiopathic	A condition of which the cause is not known
Instability	In the hip refers to a joint which has too much movement

Lax	Loose
Ligament	Tough band of connective tissue that links two bones together at a joint
Orthopaedics	A branch of medicine that deals with bones and joints
Osteoarthritis	Disease of wear and tear in a joint, causes pain and lack of mobility in the joint
Osteotomy	Surgical division of the bone. Please refer to pages 8/9 for explanations
Prognosis	A prediction of a future outcome
Reduction	To restore a joint to its correct position, Closed reduction is done by manipulation. Open reduction is done by an operation
Subluxated	Partial dislocation of a joint, so that the bones are mis-aligned, but still in contact
Tendon	A tough fibrous tissue that connects muscle to the bone
Tenotomy	Surgical division of the tendon
Ultrasound	A technique which uses high frequency sound waves to build up a picture of soft tissue and organs in the body
Unilateral	Affecting one side
X-ray	A technique which uses very low dose radiation to image parts of the body, especially useful for imaging bones

Going into hospital checklist

Things to take into hospital

Hospitals vary on what facilities they provide for parents and children so it is worth checking beforehand what you need to bring and what is allowed. We have listed below some items for you and your child to take into hospital to help make your stay more comfortable.

FOR YOU

- ☐ Books, ipods, magazines – something to keep you occupied
- ☐ Comfortable clothes and shoes and don't forget your PJs
- ☐ Ask about sleeping bags, duvet and pillows as they may not be provided
- ☐ Toiletries, towels, tissues, wet wipes
- ☐ Food and snacks (inc tea, coffee and dried milk) – anything which does not need refrigerating (if you are breastfeeding the hospital may provide meals for you)
- ☐ Insulated cup with lid – hot drinks without lids are not usually allowed on the wards
- ☐ Plate/bowl and cutlery
- ☐ Eye masks and earplugs as the ward can be noisy and bright even at night
- ☐ Plenty of change for payphone/car parking/TV tokens
- ☐ A fully charged mobile phone
- ☐ Breastfeeding pump and bottles (if required)

FOR YOUR CHILD

- ☐ Favourite toys, comforter and books (inc quiet toys to entertain your child at night)
- ☐ Colouring books, paper, washable pens, pencils, crayons
- ☐ Blankets and pillows to make your child more comfortable
- ☐ Food and snacks - anything which does not require refrigeration e.g. Raisins, jars, rice crackers
- ☐ Formula milk (ready made is useful) and equipment e.g. Bottles, sterilizer (if required)
- ☐ Disposable bibs

☐ Baby wipes, cotton wool and toiletries

☐ Nappies and disposable changing mats

☐ Clothes, socks and nightwear

☐ Pram/buggy so you can take your child for a stroll

DDH CONDITION

☐ Nappies to use after cast

☐ Tena Pads to use inside the cast

☐ Gamgee - padded dressing available from most chemists

☐ Sleek tape to waterproof the edges of the cast. Get a supply from the hospital before you leave or ask for a prescription for some more as this needs replacing regularly

☐ Bigger clothes for after cast

Notes

Important contacts

Questions for consultants

Notes (contd)

www.stepsworldwide.org.uk

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