

Caring for a Child with DDH and in a Pavlik Harness

The Parents' Guide



Testimonial

“Lyla started gymnastics aged 3. She took part in her first club competition aged 5, winning a bronze medal for the vault and another for the overall competition. Lyla spent 13 weeks in a pavlik harness with more scans and x-rays than I can count and it has never held her back. Lyla recently started cheerleading and was selected to represent her school in athletics, activities I could have never imagined her doing.”

Emma Malkin
(Mum to Lyla, successfully treated with a Pavlik Harness)






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 / families who want to know more about caring for a child with DDH (Developmental Dysplasia of the Hip) and placed in a Pavlik Harness. It cannot tell you everything you need to know about what the future may hold, but we hope it will reassure you. 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 **+44 (0) 1925 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.

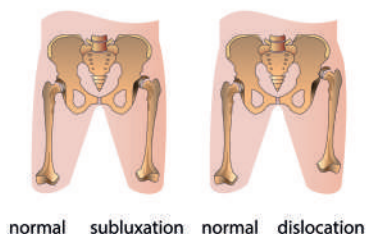
Understanding childhood Developmental Dysplasia of the Hip (DDH)

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 one of the most common hip conditions in children affecting 1-3% of all newborns.

Developmental dysplasia of the hip



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 foetus 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.

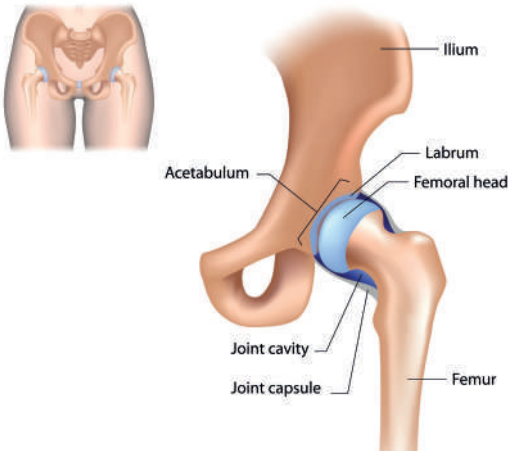
It is also important to know that expecting mothers make hormones that help ligaments relax during the birth. These relaxing hormones can stay in a baby's bloodstream for a few weeks making it normal for babies' hips to be 'stretchier' and looser shortly after birth. As girls usually have more loose 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% do 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)?

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

The Hip Joint



The hip joint is called a ball and socket joint. The top of the thigh bone (femoral head) is ball-shaped and fits into a socket (acetabulum) 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 snugly together: there are varying degrees of severity. If the ball is not held safely in place, the socket 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.

When and how is hip dysplasia detected?

Hip dysplasia in babies is most frequently discovered at the time of the newborn physical examination by physicians, according to national screening pathways. The aim of the screening pathways is to identify all cases of hip instability so that observation and/or early appropriate treatment leads to normal hip development. It is important to understand that 15% of children worldwide are born with some sort of hip instability. The challenge is to differentiate between a hip with instability that will spontaneously correct itself, from a hip with instability that may lead to symptoms and a severe diagnosis.

To date, there is still no consensus as to which programme is best placed to detect DDH. In some countries, there is a universal ultrasound screening, where every baby gets a hip ultrasound soon after birth.

Other national health providers, prefer to apply selective screening programmes, whereby a baby is 'selected' for an ultrasound based on key risk factors. Universal ultrasound screening remains controversial as it might cause overtreatment of neonatal hips which should be avoided particularly if there is a risk that such treatment might harm the baby.

Risk Factors

DDH can happen to any baby but some factors, called 'risk factors', make the condition more likely.

Unfortunately, to date there is no international consensus in deciding what constitutes a significant risk factor. National health systems will apply their own risk factors to determine if there is a need for an ultrasound. The most common risks factors are:

- Breech position in the last three months of pregnancy.
- Breech presentation /Delivery (bottom or feet first).
- Positive Family History such as mother, father, brother or sister, have had a hip problem treated as a child.
- Girls are affected more often than boys, particularly the first born.

Why an ultrasound is necessary to detect hip dysplasia?

An ultrasound helps the doctors to obtain an accurate image of the hips to see if they are well-formed and safely in the right place. It can identify abnormalities of the shape of the ball and socket and see if the ball is unstable - whether it displaces out of the socket. These problems are not always felt when the hips are tested by hand. Sometimes, the ultrasound test may be normal when the physical examination suggested there might be a problem.

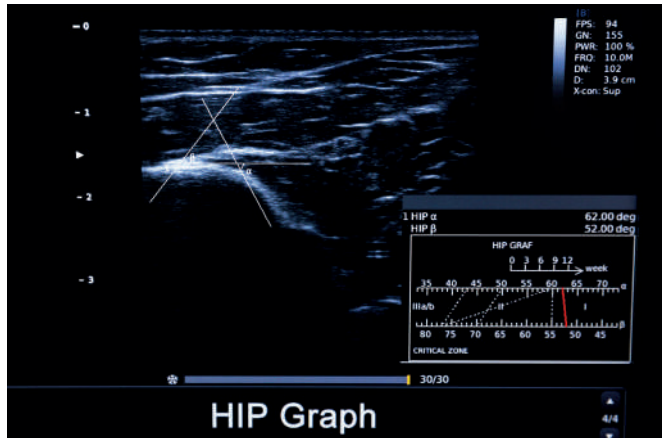


During the ultrasound the doctors will measure certain angles. The Graf method is usually used for the ultrasound classification system for DDH in infants.

This alpha angle is considered normal if it is more than 60 degrees. Mild dysplasia is present when the alpha angle is between 43-60 degrees. Dysplasia is severe when the alpha angle is less than 43 degrees.

Why an ultrasound is necessary to detect hip dysplasia? (contd)

During the ultrasound examination, the hip may also be examined for stability in the same manner as the Barlow test, but the ultrasound is used to see if the hip is unstable instead of relying on the doctor's examination.



Many babies have slightly loose hips so this can be very difficult to interpret. The images can generally show how far out of the socket the hip will move. Of course, this depends on how hard the examiner pushes. In general more than 50% of the ball should remain in the socket. When the number is less than 45% then there is instability. The instability is much more common in newborn infants and the ligaments get tighter with age. Some instability in a six-week old infant is not very uncommon. Sometimes this is treated and sometimes it is observed with a repeated ultrasound study at age three months.

Other imaging methods that may be used for babies or children are x-rays and arthrograms. *

*From the International Institute of Hip Dysplasia



Why does it happen?

When DDH occurs, it is important to understand that a child's hips developed this way on their own. DDH cannot be prevented and it isn't anyone's fault. Even though as parents you may be distressed at discovering your baby has a hip condition, he/she will not be in pain.

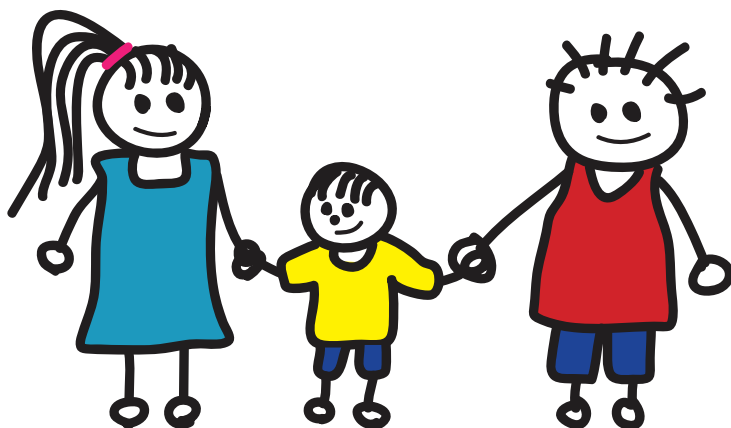
Many babies are born with unstable hips that stabilise soon after birth. With DDH, the problem persists but can be treated successfully with early detection.

About 1 or 2 babies in every 1,000 born will have a hip that is not stable.

Is treatment necessary?

If your baby is diagnosed with DDH, treatment is best started as early as possible. From birth up to 6 months, babies with DDH are usually fitted with a special harness, the most common type being the Pavlik Harness. The baby may need to wear the harness for several weeks or

months and in most cases this will correct the condition. Some babies do not respond to early treatment and some children are not detected until they are older. These cases may be more difficult to treat and surgery may be necessary.



Pavlik Harness Explained



What is a Pavlik Harness?

A Pavlik Harness is a lightweight soft fabric harness. It has a chest strap, two shoulder straps and four leg straps which may be attached to little 'booties'.

For practical advice and Q&A with health professionals please visit our YouTube channel.



Is a Pavlik Harness suitable for all babies?

It is typically used to treat babies with hip dysplasia from birth to 6 months of age.

How does the Pavlik Harness work?

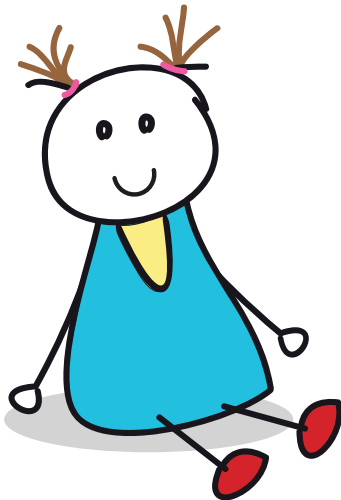
The 4 leg straps are fastened to allow some movement in the legs and to direct them into a position where the hips will be able to develop into a more normal position. It is important

to understand the proper use and fit of a Pavlik Harness. A harness that is too tight can do more damage to a baby's hips, and a harness that is too loose will not hold the hips properly.

How long will my baby have to wear the Pavlik Harness?

The answer to this question depends on the severity of your baby's hip condition and can change over time as your baby's hips improve. As a general rule, it will be worn for 6 to

12 weeks or it could be as long as 6 months. In some cases the consultant may decide to remove the harness sooner if it is not achieving the desired outcome.



Can the Harness be removed during this time?

Your baby will need to wear the harness for 24 hours a day throughout this time. You may be able to remove the harness for bathing for a short period of time, no more than 10 - 15 minutes.

Your consultant will inform you whether you can do this. If your health professional has advised you not to remove the harness, you may spongebath your baby.

Will my child need any special equipment?

- You will not need any special equipment whilst your child is wearing the harness.
- Your child will be able to fit into a normal car seat and pushchair.
- Your child will need to wear larger, loose fitting clothing for comfort.

Is there equipment that I should avoid using?

- Baby door bouncers
- Baby walkers
- Baby slings/carriers
- Swaddling your baby



How will I know if the Pavlik Harness is working?

You will have regular appointments with your consultant or a member of the specialist team, where the harness will be checked to ensure that it is fitting correctly and is still providing the right amount of correction. The regularity of these appointments will vary and again depend on the severity of your baby's hip condition. Ultrasounds and x-rays are also used to see how your

baby's hips are developing.

Between appointments DO contact your hospital if:

- Your baby's feet are constantly slipping out of the booties
- The harness is too loose or too tight
- If your baby has pressure sores or persistent red marks around the shoulders or chest strap
- Your child stops moving their leg/foot.

What happens if the hips do not correct with the Pavlik Harness?

Your consultant will discuss your baby's progress at each appointment. If the hips are not developing in the normal way or remain dislocated despite wearing the Pavlik Harness, the harness will be discontinued. Continuing to use the harness when the hip remains dislocated is very

harmful to the hip. Your consultant will discuss future treatment options with you if appropriate, at this point.

If further treatment is required, please contact our Helpline [+44 \(0\) 1925 750271](tel:+44201925750271) or email info@steps-charity.org.uk for help and advice about the next stage.

What happens when treatment is successful and the Harness is removed?

Your baby may be uncomfortable for a short time and sleeping patterns may be disrupted as they adjust to life without the harness. It is also normal for your baby to hold the frog-leg position for a couple of

days. You can handle your baby as you would normally during this time. Normal activities can be resumed but avoid using doorway bouncers and baby walkers. Swimming is great exercise for your baby at this stage.

Care for a baby in a Pavlik Harness

The first week may seem hard as your baby needs to adjust to the Pavlik Harness. Hang in there, your baby needs this treatment and babies are resilient and can adapt. You will also quickly work out a new routine which will get better with practice. Here are some suggestions to ease the adjustment period:

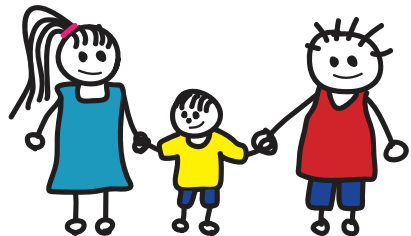


Keeping clean and skin care



Your baby cannot have a bath whilst wearing the Pavlik Harness so you will need to give your baby a sponge wash; particular attention needs to be paid to the neck, shoulders, groin and behind the knees as these can become sore.

Do not be tempted to use cream or talc under the harness as these can clog and cause skin problems. Check for any red areas and if you are worried and you feel concerned the skin is getting worse please seek medical advice immediately.



Nappy changes

For a baby wearing a harness, many parents find disposable nappies easier to manage than cloth. When you change the nappy, lift the baby up under the thighs and try to support the bottom rather than just pulling up on the legs. Don't forget, the nappy always needs to go under

the harness but please take extra care not to dislodge the straps. If the harness webbing gets soiled you can sponge with a mild detergent or scrub with an old toothbrush. However, staining is probably going to be inevitable.

Clothing

Loose fitting clothing, usually the next size up, can be worn over the Pavlik Harness.

Toddler size socks usually fit over the harness 'booties'. However, some babies can get minor skin irritation from the harness straps. A vest can

be used under the harness or safely secure some soft padding around the shoulder straps to stop the problem. Do not put tight trousers or tights on your baby, as this pulls the legs together, which will make the harness less effective.

Breastfeeding

If you are breastfeeding you can continue to do so successfully while your baby wears the Pavlik Harness. You could try curling up next to your baby, underarm feeding or a 'v' shaped pillow to support the baby in the normal position. It can seem difficult at first finding the

right position but eventually you will find a way which suits you both. Feeding may just take a little longer than usual and it is also a good idea to wind your baby more frequently. For further breastfeeding advice and support, please contact your local GP, health visitor or midwife.

Sleeping

Sleeping on the back is always encouraged for the hips. It can take a week or even longer for some babies to adjust to sleeping in a Pavlik Harness. To keep your baby warm at night, you can use the baby sleeping bags in a larger size which fits comfortably over the Pavlik Harness. If your child is inconsolable, maybe the problem is not the harness. Check the same things you would otherwise look for in an unsettled baby: teething, temperature, etc. Do not lie your baby on his/her side as

it is not good for your baby's hips at this stage. It is also not advised to lay your baby face down. Sleeping on the back is always encouraged for the hips.

Loose-fitting clothes should be worn over a harness or splint unless the specialist advises differently. Although babies may like the sensation of being wrapped up tightly or swaddled, this unfortunately is bad for your baby's hips and should be avoided.

Play time & tummy time

Regular play time is encouraged. Older infants sometimes learn to crawl while wearing the Pavlik Harness. This is not harmful. Floor activities, sitting activities and high chair are all encouraged with the harness.

For playing, lay your baby on his/her tummy, back or in a sitting position. As with sleeping, do not lie your baby on their side as it is not good for your baby's hips at this stage.

You can do tummy time with some support under the torso so the hips can stay in the spread position of the harness.



Out and about

Most parents find their babies fit into their usual car seat and pushchair without any problems. Try to avoid long journeys because a car seat usually holds your baby's thighs close together and limits the effectiveness of the harness. If your car seat feels too tight on your baby's legs, then consider purchasing a wider car seat to allow his/her legs to spread apart.





A success story

Ronan born in 2009, Ruth in 2012 and Amelia born in 2015. All treated successfully with Pavlik Harness.

Following his birth in March 2009 Ronan's hips were checked by the midwife as part of the routine hospital discharge procedure. She felt unhappy about his hips however and asked the paediatrician for his opinion - he described the hips as 'clicky' and although he said this didn't necessarily indicate a problem, his hips would be checked again in 6 – 8 weeks. Not entirely happy with this, the midwife asked for a second opinion from a more senior paediatrician who described a 'clunk' when the hips were



examined and said that the hips could be dislocated during examination and would therefore require treatment.

Ronan had an ultrasound scan at 1 week old and went into a Pavlik Harness the following week. I was distraught at seeing my tiny baby in the harness and it took us all a little while to get used to it. Ronan had to wear the harness 24 hours a day. Looking back, I am hugely thankful for the midwife at the hospital, but for her diligence Ronan's hip problem may have gone undetected at that stage. A lot of people told me that it was great that it had been picked up and that he was being treated so early. With hindsight, I can see that they were right but at the time I just wanted to shout at people that there was nothing great about the fact that my newborn needed to be in a harness!



After the harness was finally removed Ronan went back for check-ups every 6 months until at 2 years old, he was signed off completely with healthy hips.



Ronan's sister Ruth was born in January 2012 and although she was given the all clear on her hips, at her newborn check, she was referred for a scan because of her family history. The health visitor had said that she had felt a 'click' however, so

we were anxious to be seen sooner rather than later and made a private appointment for Ruth to be seen by a consultant at 2 weeks old. He said that she had an 'immature' hip but that it may resolve without intervention and asked us to return for a further scan when she was 6 weeks old. This second scan showed no improvement in the hip, and she went into a Pavlik Harness when she was 7 weeks old and was in the harness for a total of 9 weeks, 24 hours a day. Interestingly her harness was much less bulky than Ronan's and the fabric-covered metal buckles had been replaced with plastic and Velcro and it even had little built-in socks! Once she came out of the harness Ruth had 3-6 months follow-up appointments and was signed off with healthy hips at 18 months old.

In October 2015 the youngest of the 3 siblings, Amelia was born. The midwives knew of the strong link to DDH in the family and so Amelia was checked a number of times by a few different

midwives and none of those who checked her could detect a problem. My health visitor couldn't feel a click either but asked for her referral on the basis of family history to be expedited because she was aware that I was anxious to have her checked as soon as possible because of the experiences with her older siblings. Amelia was scanned at 3 weeks old and went straight into the Pavlik Harness. She wore her harness for 12 weeks; this time around the hospital gave us a spare harness and marked the position of all of the straps so when the harness got dirty, as is inevitable with a newborn, we were able to take it off to wash it and swap for a fresh harness. At her last check up in October 2016, the consultant was very pleased with the progress of her hips and had decided to see her once more in October 2017 when she was 2 and was expecting to fully sign her off then.



I am so grateful that my children arrived in the order they did – if either of the girls had been born first, when we had no family history, their DDH could so easily have been missed, but thanks to their brother's early detection, our hip journeys have been short ones. I now have three happy healthy children – no one would ever know they had ever had any hip problems!

We don't take walking for granted...



Babies & Children



Anyone



Families

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