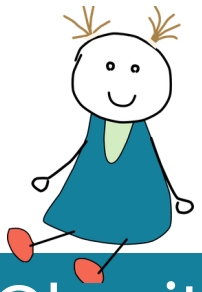
steps

We don't take walking for granted

Perthes' Disease, a Parent's Guide



Helpful Information from Steps Charity

How This Booklet Might Help

At Steps, we know that a leg condition (often called a lower limb condition) can make us feel different, and it can be confusing for us and our families. This little booklet is made for children who have Perthes' Disease, their parents, or any caregivers who need more information.

Steps want to be your helpers and friends during this time. Perthes' might sound like a big word, but we're here to make things a little easier for you and your family.

We understand that sometimes you might feel a bit worried or unsure, and that's okay. We work with doctors and researchers to learn more about how to help kids with Perthes'. We want you to know that we're here to give you lots of information and bucketloads of support.

This little book can't tell you everything, and it can't tell you the future, but we hope it helps. It includes medical information, helpful tips, and stories from a child who also had Perthes'.

If you have questions or if you have any worries, we're here for you. We have lots of ways to support you and put you in touch with other families who have been where you are now.

Remember, you're not alone. We're going to be here with you, helping you understand and feel a bit better.

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 your worries online with other parents, sharing tips, and finding emotional support.

Remember, the Steps team are here to offer information and support in total confidence, and to 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 Steps on +44 (0) 1925 750271 or email info@steps-charity.org.uk for support and advice in total confidence.

Social media details and information about how to get in touch with the Steps Family Contact Service can be found on page 25 at the back of this booklet.

Top Tip:
Talk to other parents of children with Perthes', this can help you feel confident about the future and discuss things that helped them.

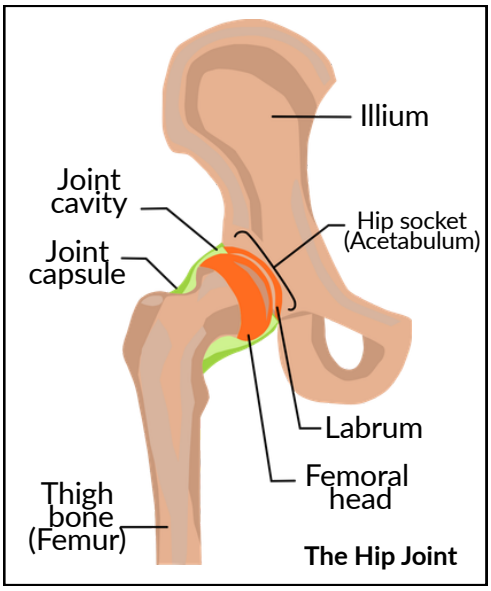
Visit the Steps Website at www.stepsworldwide.org and click 'Get Help' and we can point you in the right direction

What is Perthes' Disease?

Perthes' Disease is the shorter name for Legg-Calve-Perthes' Disease (named after three doctors who helped first spot it and treat it), it is a condition that some children have that can mean their hips don't move or work like other children's do.

You know where the hip is. If someone says, "Put your hands on your hips!" you put both hands on either side of your waist. But what is the hip? The hip is a point where two or more bones meet (a joint) that helps you move your leg. You probably have two hip joints, because there is one for your left leg and one for your right leg.

Look at one of your legs, or someone else's. The bit above the knee, and before the hip, we can call the thigh. Inside the thigh is a big, long bone called the femur. The top of the femur is shaped like a ball, and it fits into the rest of your body at the hip in a bony socket (like a ball sitting in a cup).



The Hip Joint

To understand Perthes' Disease, think of the hip like an ice cream in a scoop. The round part of the hip is like a ball of ice cream. This sits within a socket, which is like the scoop. When the leg moves, the ball moves around in the scoop.

In Perthes' Disease, there is a problem with the blood supply to the ball of the hip joint, which causes it to become soft and change shape, like the ice cream melting.

NB: Have you heard your doctor talk about the "Femoral Epiphysis"? This is just the plate at the very end of the ball part of the femur.

Why do I Have Perthes'?

We are still not sure why some children have Perthes' Disease. It's not because they were hurt or injured, it's not because there is anything wrong with their blood flow in other parts of the body, and there aren't any other common childhood illnesses connected to Perthes' Disease. There is also no evidence that it has something to do with genes (the things that give you your mum's eyes and your dad's nose and make you look like your family). While we do see some patterns, we don't have any evidence that these cause Perthes'.

For example:

- Perthes' is more common in Northern Europe than in other places
- Often children with Perthes' are very energetic and love to race around
- More boys have Perthes' than girls (for every four boys with Perthes', there will be one girl with Perthes')

While we see kids aged anywhere from 2 to 14 years old develop Perthes', it's most common for children to develop it around 5 to 9 years old, when they notice something isn't quite right with their hip.

The good news is that, as time goes by and you get older, the blood vessels in your hip start to grow back and that allows the top of the femur bone to rebuild and grow back. It's a bit like when you break a bone, it isn't fixed overnight but it needs time to grow and heal.

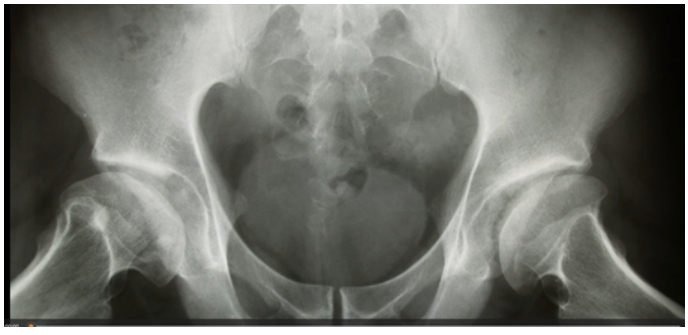
So, it might take a few years, but most kids with Perthes' Disease can get better and be just as active as they were before! Some kids will need an operation, but many will not.

How Can Doctors Tell if I Have Perthes' Disease?

There are a few things that might be a sign of Perthes' Disease, the three most common signs are that you start walking in a way that looks different to other children (limping), that you have difficulty moving your legs properly, or that you feel pain in your leg or hip.

This pain isn't the same for everyone, it may be around your knee or hip or anywhere in the leg. You might feel stiff and achy, and that you can't swing (move back and forth) one hip as much as the other. It can start suddenly, or it can start slowly and begin to hurt more and more each day or week. It's also normal for children with Perthes' to be a little bit shorter than other children their age, which can be another clue.

To find out if it is Perthes' Disease, the doctor will take an X-ray picture, which is completely painless and lets the doctor see your bones. The doctor might take a little sample of your blood to do some tests as well and check for infection. Sometimes they put you in a machine called an MRI (this can be noisy but isn't painful), or perform a bone scan, these scans can see inside your bone and help doctors find out exactly what is happening.



In short: having Perthes' Disease means there is a problem with the blood going to the top of the hip bone. This makes the ball part of the hip bone flatter, making your hip hurt and not work or move the way it should. But this won't last forever and there are ways we can treat your hip.

The Journey of your Hip: Stages of Perthes'

Perthes' Disease isn't something that happens all at once, there are different stages that the tip of your thigh bone and your hip go through. Here they are listed with their technical name and an explanation of what it means and what the doctors might see on the X-ray.

1 Necrosis – Cell structure breakdown

During necrosis something happens to the hip's blood supply that limits the blood getting to the very top of your femur bone. This means the bone cells right at the top are not firm like the rest of your bone but can be a bit squishy. Doctors might take X-ray pictures to see what's going on, but it might look like there are only small changes, or even that there are no changes at all because the soft bone doesn't show up on X-ray. The doctors might also decide to use scanners that can look inside your bone. For you, this can be the time when you start to feel that your hip hurts (due to inflammation), and you might find you are walking differently, or limping.

2 Sclerosis – Hardening and thickening

During sclerosis, the top of the thigh bone becomes very white, as the bone structure (the framework that makes up your bone) changes. The bone is a bit weaker, and because it is right at the top of your leg every time you step on that leg it has to take all the weight of your upper body. This means the weak part at the top of the bone might change shape and can flatten out as it is squished down. Doctors can use the X-ray to see white areas where the bone has hardened.

3 Fragmentation – Unhealthy bone replaced

During fragmentation, new little blood vessels form to help fix the hip. This new blood supply helps take away the unhealthy cells in the bone ready for it to be replaced with new healthy cells and from this comes healthy bone. If the doctor takes new X-ray pictures, the hip might have light and dark patches showing you where old bone is being removed.

4 Healing – New bone formed

The healing stage (also referred to as Re-ossification) is when the new bone grows. It's like the hip is growing a protective shield! The new bone grows from the outside to the inside. This part takes a long time, often 2-3 years, but it's super important as when this stage ends, that is your new hip and its new shape. The shape of the hip and how it fits into the hip bone will influence how things go in the future, the better the fit the less likely further intervention will be necessary.

The fit is influenced by several factors including the extent of the spread of unhealthy bone cells and the age of the child at onset (younger children, particularly those under 5 years old, usually have better results).

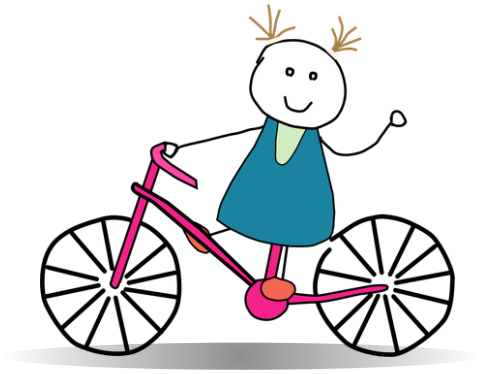
Will My Hip Get Better?

Your hip bone will always regrow.

The doctors will keep asking to look at your hip joint to keep an eye on how it grows and what shape it is. This will help them decide what they need to do to help you be your best.

Lots of kids with Perthes' Disease will just get better, without an operation (where the doctor has to go in and mend something inside your body).

Your doctors will give you advice on the best things to do to help with your pain. For example, making sure you rest when you're feeling pain, soft tissue massages, or doing daily stretches with your family. Steps has some recommended stretches on the website, this daily practice can help you have better hip movement in your leg. Remember to always stretch both legs equally even if only one leg has Perthes' Disease. Please talk to your doctor before starting any new routines



Your doctor may suggest that an operation is the best option. Doctors will often recommend this when the joint seems particularly stiff. This can be a difficult decision for parents and caregivers to make, and every case is different so it is important that you feel you can ask all the questions you need to of your consultant.

If you are already a teenager when Perthes' first shows up it's a bit different than when you're younger. Revascularization can be slower so doctors might suggest an operation straight away, but whatever they suggest you can always ask them more questions to know why they think this solution is best for you.

What Can the Doctors Do?

Once they know it's Perthes' Disease the doctor will have a look at what they think is the best treatment for you.
Although there is a lot of work and lots of research being done on Perthes' Disease and how to treat it, there is not yet an agreement amongst all doctors, surgeons, and clinicians on how to do this best. Doctors have different ideas about how to help, and it will be different for each child.
There are lots of options with different names, some are more common than others. Your doctor might suggest one, or a combination of these done together or at separate times:
Containment: The doctors want to ensure that the soft 'ice cream' on the hip stays in the ice cream scoop. This is called containment, and there are two main types, you may even get a combination of the two.

- **Containment through activity:** This means looking at the hip regularly, both by seeing how your hip moves and through X-rays. The doctor will keep checking that the muscles are not too tight, that your hip can move, ensuring the 'ice cream' keeps smoothing itself within the socket, and that the bone shape is getting better. They might recommend physiotherapy, exercise, or pain management during this time.
- **Containment with surgery**: Surgery may be recommended, especially when containment through activity might not be working. The surgeon will reshape the bone to make the ball fit the socket better. The doctor will talk to you about which on you need
    - Changing either the 'socket' (**Pelvic Osteotomy)**, or the 'ball' (**Femoral Osteotomy)**.
    - Making the 'cup' part bigger, using bone from your own pelvis (**Shelf Acetabuloplasty)**

When you have hip surgery, you night need to wear something called a Hip Spica Cast.
There is more information about these on the Steps website

Other surgery: Your doctors might also recommend some other surgeries to help the hip regrow.

- Loosening the tight muscles around the hip to make it less stiff (**Soft Tissue Release**).
- Controlling how the thigh bone grows (**Trochanteric Epiphysiodesis**).

Pain management: This means finding ways to reduce your pain. Doctors might give you pain relief, or medicine to stop it hurting, or they might tell you things you should and shouldn't do. This might include gentle activity, or using heat pads.

Physiotherapy: This means sending you to a person called a physiotherapist who will show you some things to do that will help you become stronger, move better and control your body better. This might even be in a therapy swimming pool (hydrotherapy pool).

- **Hydrotherapy**: This means swimming in a pool, with a therapist. This is often a warm water pool, and you learn to move your hip in ways that will help strengthen and support it.
- **Stretching and strengthening**: Stretching helps to keep the muscles that move your hip long so that the ball doesn't get pulled into the hip and hurt. Strengthening the muscles around your hip can help with pain too, but also means that you're strong enough to do the things you love. Which can be tricky when your hip with Perthes' Disease doesn't move as well as a hip without.

Weight relief: This means not putting weight through your leg, so can often be bed rest. This is not very common any more as doctors know that too long off your legs doesn't help. But in some cases, whilst in containment, you might have to stay off your feet for a short while.

- **Walking aids**: In some cases, your doctor might ask you to use crutches, a walking frame, or a wheelchair for some time to help give your hip time to heal.

Doctors throughout the UK will soon lead the world in completing a national study where they fairly compare children having surgery and no surgery. Families with other important diseases have found that children in studies usually have closer consultant care and better monitoring than children not in studies (called the 'trial effect'). The study is called the OpNonSTOP (Operation or Non-Surgical treatment of Perthes Disease) study. Keep tuned for updates on the Steps website.

Which Treatment is Best For Me?

The doctors will look at things like your age, what stage of Perthes' you are in, how much movement there is in your hip and other factors in your health. So, everyone will have a slightly different treatment.

If your hip is fragmenting or healing by the time your doctor knows that you have Perthes', then the doctor aims to keep as much movement in the hip as possible. They are working to stop the changes that have already happened in your hip from having a big effect on your movement and stop the changes from causing you pain.

But if your hip has not yet started fragmenting, doctors will focus on containment, aiming to stop the top of your thigh bone (femur head) from moving out of the hip joint (acetabulum). I.e. Keeping the ball/ice cream (femur head) in the cup/scoop (acetabulum).

They will look at how much you can move your hip in all directions, and this will help them decide if an operation is suitable for you.

Everything you do with your leg can push and pull and twist this joint and this might just push that ball out of the cup.

Slowing down and resting more with daily stretches, and following your doctors res advice for 'containment through activity' can help keep the ball in the socket. Where this is not enough doctors might use other forms of containment to stop the ball starting to escaping from the socket. Containment is like putting a shield around your healing bone, helping to protect it, but you will still need to be careful and do what your doctors tell you to do.

Surgery can sound scary, can involve some pain, and sometimes a second operation. But the good news is that your pain will start to disappear, and your hip can heal so you can move better, with less pain and get back to doing the things you love.

Your age when you first develop Perthes' can make a difference:

. For kids who are over the age of 8 when Perthes' starts, the ball will often start to escape the cup, at least a little.

But if you are younger than 7 when your Perthes' first develops this may not happen.

If you are even younger (under 5) then it is less likely that the ball will move out of the socket.

For all ages the doctors will want to keep checking your movements and looking at your hip , until you reach an age when all your bones have grown as much as they are going to (in your teens).

In fact, it is recommended that two different X-rays are taken every 3-4 months, one lying with your legs straight and one lying with your legs in a frog leg position.

Remember that treatment doesn't always mean surgery. It can be a combination of treatments, and it might mean you are asked not to walk (bear weight) for a while.

TOP TIP:

Ask your consultant questions about why they recommend a treatment and/ or what treatment options are. Remember that not all doctors agree on the best treatment as we are still researching what is best. Talk to the Steps community, your own family, other consultants, and do your own investigating to understand the research which is available. The final decision is up to you as a family and the more information you have the more informed a decision you can make.

Surgery can be a big decision and it is worth asking your doctor why they think this is the best course of action. Make sure they are clear about possible long-term complications of both performing and not performing the surgery. Some doctors will be open to trying less invasive methods first if this is what the family prefers. If you find it difficult to talk to your doctor, try and find a team member who can help you communicate, or find a consultant you can build a relationship with.

What is the Hip Spica Cast?

A hip spica cast is like a covering for your hip. It's made from strong materials, similar to what you see when someone has broken their arm, a mixture of plaster of Paris and fibreglass. You'll see lots of white ones, but sometimes they can be coloured and patterned!

Think of it as wearing stiff trousers, but each pair is different, depending on what you need. It can extend from above your belly button all the way down to the ankle, or it can be shorter, there might be a bar across the middle or nothing at all. The cast will usually hold your poorly hip in a fixed position, wider than before, and help your recovery.

It can feel a bit funny at first, but children do get used to it. To help you go to the toilet there's an opening in the front, like a little window, and the back that should help nappy changes. If you don't wear nappies you may still need to use a bedpan (something that looks like a toilet seat with a container that can slip under you in bed) or a special bottle to urinate (wee) into.

This can be difficult to get used to, but the equipment is designed to make it as easy as possible. Now, because of this stiff covering, you might need some different clothes that fit over it and when you ride in a car or a pushchair, you might need a bit more room. Don't worry, the Steps community can help you find carefully designed clothes and equipment that will accommodate the cast.

The cast is there to help your hip get better. If you ever need something specific or have questions, just let the people helping you know – they're here to make things as comfortable as possible for you and remember you can reach out to Steps for advice at any time.

You won't wear the cast forever; you might even need it replaced a few times as it starts to get dirty and wear around the edges. But most clinics will only keep you in a cast for around 12 weeks.

Can I Be Active?

Talking to your doctors is super important when it comes to activity. They might say that for you it's best not to do lots of jumping or high-impact exercise. If you are wearing a brace or cast this might make it difficult to walk for a little while, and your doctor will probably tell you to not walk or stand on the leg while you have containment. But they also want you to be a regular, awesome kid – moving, playing, and having fun!

You always need to listen to the doctor but remember how active you can be, and how active your friend can be, might be different.

Top Tip:

Think about keeping a little diary of your adventures; note down what you do each day, especially if on some days your hip hurts, or if you feel really tired.

If you notice that a day with lots of running or playing makes your hip feel not-so-great the next day, maybe you can spread out the fun across the week.

The clinical team (doctors, physios etc) are like your sidekicks, and they'll help you figure out the best way to keep having awesome adventures while taking care of your hip.

We know this can be confusing, and you might feel lots of emotions bad and good about this. It is important for the whole family to think about your mental health and trying to find new fun activities to do in your free time. And you might be able to do more than you think; swimming is good for your hip, and most doctors will even encourage their patients to swim. But there are all sorts of adapted and seated games, music and arts that you can play, now is the time to try new activities and maybe find a new hobby for life.

Did you know that children with Perthes' are often the sort of kid that loves to be active, and has bursts of energy?
If that's you, just imagine how difficult it would be if you were told you had to sit still all day, so most physios and doctors will recommend finding a balance between activity and rest. Have you tried: swimming, seated boxing, drumming, wheelchair tennis?

What About When I'm Older?

Most children with Perthes' Disease will see their hips get better as they grow. That's because as we grow, so do our hips! The blood flow will get better, and the shape of the cup and ball will change.

What your hip feels like when you're all grown up will depend on how round the end of your thigh bone is once it's finished changing. If it's nice and round, then that's good news and your hip will move well.

But sometimes an operation is needed when children are older to make the bone round. For a few, the bone might stay squashed, or the cup and ball joint might not fit nicely, even with all the doctors' help.

This might mean that they have pain and get a condition called arthritis while they are still young, so they will find that their hip won't move as far as it should (so their high kicks aren't so high) and one day they might need a total hip replacement (a whole new hip). If this is the case the doctors replace the bit of your hip that is not working so well, with a new one.

It's not uncommon for a child to have Perthes' and another diagnosis, commonly either Asthma or ADHD (Attention Deficit Hyperactivity Disorder), so doctors will also likely assess you for these and help you get the support you need.

Fred's Story

When Fred was 3 years old, he started to tell his mum and dad that he could feel a pain in his left leg.

This was frustrating for Fred, as he loved to run around and jump off anything and everything he could find! So, at first, everyone thought it might just be a poorly muscle. But Fred's pain didn't go away, and his walking changed to a limp.

Fred's mum and dad told the doctors, who were very confused. They thought it might be this, and they thought it might be that, but each test came back negative. After several checks, tests, and ideas, they finally found the answer and told Fred and his parents it was Perthes' Disease.

Fred's hip movements were so bad that the doctor told Fred he would need an operation right away. But Fred had to wait for his turn on the waiting list of people needing operations before him. As he waited Fred's hip started to hurt more, and more, and more, until it kept him awake at night. Fred needed some strong painkillers; these made him sleepy during the day as well as at night and Fred didn't like this. Everyone was very happy when finally, they went into the hospital to talk about the operation, but the doctors had changed their minds and thought Fred was too young to have the operation.

Perthes' changed things for Fred and his family, they were a very active family but had to be careful and think about how much walking Fred would be doing every day; going for a walk with the dog, going to a birthday party, or a family gathering; especially when there might be football or trampolining involved. Fred couldn't even have piggybacks from his daddy for very long as it put his hip in a painful position.

This was obviously difficult for Fred and for mum and dad, who didn't like to see their little boy in pain. But the whole family decided to fight "It wasn't going to beat us, and we'd do everything in our power to help him and we have. We are so lucky to have support from our amazing family & friends and Lily has always been the best big sister anyone could ask for."

Fred's mum and dad were helped out by the Steps community, and turned to a specialist surgeon, called Dr. Perry. He helped them learn more and find out what to do next to help Fred. Dr. Perry helped them find the right treatment to get Fred out of pain and back to being a happy little boy.

Sometimes Fred would be fine while he did something, but afterwards, his body would hurt.

Fred's mum says, "Looking back now I think people just didn't understand, it's a rare disease. The other problem was on good days Fred looked like there was nothing wrong."

Over time Fred's hip started to get better, thanks to working hard with Mum and Dad working as a treatment team. Mum was in charge of doing daily exercise, soft tissue release, massage, and physio. Dad worked on strength and, when Fred was strong enough, taught him to ride his bike.

Fred is 10 years old now and he is doing amazingly! His hip has regrown 95% and is the perfect shape and size, so it fits nicely in the socket. After years of not being allowed to play football, he is now able to and is playing for a team! On top of his football games four or more times a week he is also running cross country for his school and taking long bike rides with his dad.

Fred's family want him to know how amazing he is. "He doesn't let anything hold him back."

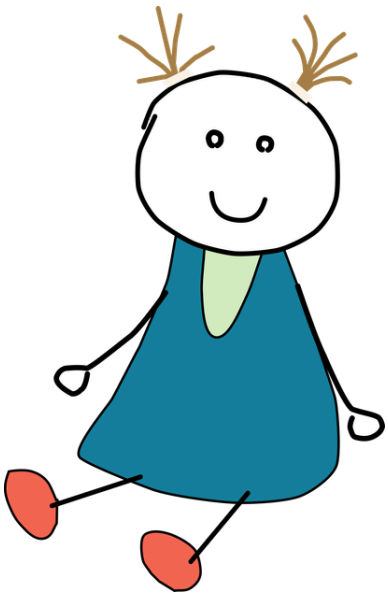
And they also have a message for you.
"We hope Fred shows other Perthes' Warriors out there that there's light at the end of that very dark tunnel when you're first diagnosed.
We're so ridiculously proud of him with how he's dealt with it, and we'll always be grateful to our amazing family, friends and Dr Perry whom have got us through.
Fred's our hero, our Perthes' Warrior."

What Do I Do Now?

Having Perthes' Disease can be different for everyone, depending on your age, how much your hip is affected, and where you live. This means the way doctors help you get better might be different from someone else. It's important for you, your family, and the clinicians to talk together and decide what's the best treatment for you. In the UK, there aren't specific rules for treatment yet, (researchers are working on it!) There are many choices to make, and your thoughts about what should happen and how you want to be treated are important.

Steps can be helpful in this journey. Even though we can't predict the future, talking to other families who went through similar treatments can make things clearer and help you understand how it might affect different parts of your life. The more you know, the better prepared you can be!

After a diagnosis, or even the first indications of a problem, it can feel scary and it's normal to feel sad or worried. The whole family must have time to talk about it with each other and the medical professional. We know it's a lot to understand to start with, but Steps have decades of experience helping families like yours get the information they need to make the journey a lot less scary.



Who are Steps and How Can They Help?

Steps is the national charity working for all those whose lives are affected by childhood lower limb conditions. Everything we do is about valuing and supporting individuals, families and carers affected by conditions which have an impact on the legs, hips or feet.

Contact Steps (confidential)

Call 01925 750271 with any questions you have or email info@steps-charity.org.uk

Facebook discussion groups (private)

There are two pages for members to join:
Steps Charity - Support Group for Parents
Steps Charity - Support Group for Adults

Family contact support service (confidential)

Connecting parents (or adult caregivers) with other families who have been through something similar. Enquire via our contact number 01925 750271 or email info@steps-charity.org.uk. All our Family Contacts are interviewed and given training before they engage with a family, providing a forum for sharing ideas and consulting other parents on day-to-day questions.

Social media

Steps is active on X (@Steps_Charity), Instagram (@StepsCharity) and on YouTube (StepsCharity)

Please note, external websites are not associated with Steps and Steps are not responsible for their content.

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Steps Charity Groups:
Steps Charity - Support Group for Parents
Steps Charity - Support Group for Adults

Remember, you are not alone on this journey. Steps is here to offer a helping hand, a listening ear, and a community that understands. We believe in the strength of shared experiences, and our doors are always open for you. Whether you need information, guidance, or simply someone to talk to, you can reach out to us. Together, we can navigate the path ahead. You are part of a supportive community, and we're here to help you every step of the way.

"It was your videos with Dr. Perry that really helped me help my son when he was first diagnosed. It was because of steps and those videos that gave me clues on what I needed to look for and how best to support my son since there is no cure. I appreciated all the transparency from the videos and I still recommended them to this day."

"Steps have been an absolute lifesaver for me they have provided me with information on Mica's condition and treatment and I have been able to discuss Mica's condition with other families and read how people have coped with the long treatments"

Steps is here to help you like they have helped so many families since their creation in 1975.

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Steps Charity Groups:
Steps Charity - Support Group for Parents
Steps Charity - Support Group for Adults

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