



Steps

We don't take walking for granted

Perthes' Disease Handbook



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 the story of one little boy who has experienced 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.

Reaching Out: Your Steps Family

Sometimes when things feel a bit tricky, it helps to talk to someone who understands. At Steps, we have a lot of ways to help the whole family. We have a **Family Contact Service**, which means we can connect parents (or adult caregivers) with other families who have been through something similar. They can share advice, be supportive, and give helpful tips.

If you ever feel a bit unsure or have questions, adults can call our Steps helpline. It's an amazing team who know a lot and can help you with all your questions. Parents and caregivers can call them at **01925 750271** or send them an email at **info@steps-charity.org.uk**. Calls are confidential so the team can help with any worries and will keep everything private.



We also have a special group on **Facebook**. There you can talk about your questions and problems with other parents. It's a safe and friendly place to share your feelings and get support and advice.

Remember there are no stupid questions, if you have a worry or a question it is important to ask. No matter how big or small your concerns are, give us a call, send an email, or start by following us on social media.

Steps is here to help you!

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.

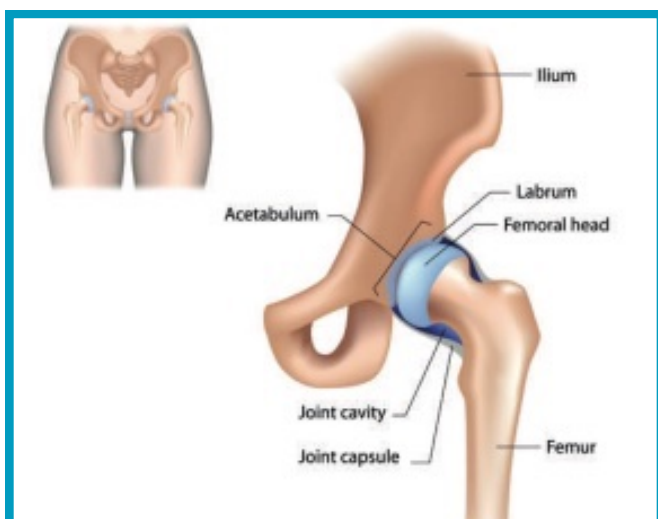
What is Perthes' Disease?

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).



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 your hips can be treated.

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 may recommend this if the joint seems particularly stiff or if there is something on your X-rays that causes concerns. 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 from your consultant.

If you are already a teenager when Perthes' first shows up it's a bit different than when you're younger. Healing 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 one 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 might 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. They might give you gentle activity, or 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.

LATEST NEWS

Doctors throughout the UK will soon lead the world in completing a national study where they fairly compare 'Surgical Containment' to 'Optimised Non-Surgical Containment', which is an evidence-based package of care involving physiotherapy, activity restriction and pain management. 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 in stage 3 or 4 (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.

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 doctor's advice for 'containment through activity' can help keep the ball in the socket. If this method isn't enough, then other forms of containment to stop the ball starting to escaping from the socket can be used. 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.

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).



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, which might change the shape of the hip.

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

If you are even younger (under 5) your hip has a better chance of keeping a nice round shape.

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 X-rays are taken every 3-4 months in the early stages of the disease. Lying both with your legs straight and with your legs in a frog leg position.

Remember that treatment doesn't always mean surgery, especially as different countries have different processes. 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 like a little window in the front and back, these should also 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. 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. 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, hippotherapy with horses?

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.



Noah's Story

Noah was a little boy who loved playing football. But early on in his life he was sick with an illness that meant he had to be very careful about getting bumped, grazing, or cutting his skin. He had to stop playing his favourite sport, football, for a while. After many months of being very careful and seeing the nurses every day, he was well enough to be allowed to get back on the football pitch. Hooray!

Noah was back on the pitch, showing that he didn't just love football, he was really good at it! So good that Everton Football Club signed him up for the development centre where they train young footballers who might one day become professionals.

Noah learned new skills and was developing every week. Noah was asked to play a year above by his grassroots team in a tournament. He showed all the new skills he had learned, playing well and scoring the winning goal in the semi-final.

Then, in the final, he scored the goal which won his team the cup!

But after that winning goal, Noah felt a lot of pain in his hip. At first everyone thought it was from playing so hard, but it just didn't get better. Noah's parents took him to see a nurse. There, for the first time, they heard the word "Perthes".

The nurse sent the family to Alder Hey hospital, where Noah had X-rays and an MRI and Mr Bruce (the specialist) agreed it was Perthes' and explained what this meant. Noah's mum says that Mr Bruce, "Described the hip joint as an ice cream cone and the hip joint as a scoop of ice cream on the top. Showings us Noah's X-ray he said the ice cream is melting and this is what is causing your pain."

Noah was 7 years old, was advised to stop playing football (to protect was left of the ice cream), again, and that he would need surgery. He needed a Varus Osteotomy (to put the femoral head back into the hip socket) as soon as possible, to give his hip the best chance of healing in a nice shape. It was a tough decision for his parents but seeing Noah's pain get worse over the next few weeks, his parents said, "We had to do what we could to help our boy."



Unfortunately for Noah, his surgery got cancelled a few times due to Covid. Finally, on his older sister's 13th birthday, Noah was able to have his operation.

His mum took him to the hospital and they talked to the anaesthetist (the person who makes sure you are asleep during surgery). Noah's earlier illness had involved so many needles he did not want to see any more of them, so they decided to use a special mask (with gas and air). Noah would be fast asleep before any needles were used. Mum says, "Knowing this, Noah arrived at theatre, jumped on the bed, put his hands behind his head and said, 'Let's do this'."

After a very long surgery, mum met Noah in the recovery room. He was now wearing a Spica Cast (you can read about this on the Steps website too). The operation and the cast meant that Noah had to learn special ways to move out of his bed into the wheelchair and how to go to the toilet. It also meant that he couldn't go upstairs to his bedroom, the hospital dropped off a special bed and Noah's parents set up a cozy bedroom in the living room. For 12 weeks Noah, his mum, and his dad all slept downstairs, pretending they were camping under the stars.

When the cast could finally be removed, Noah stayed at the hospital and did exercises with the physiotherapist and did more movement therapy in a warm pool. He kept getting stronger, could walk more and used his wheelchair less.

Noah's family have had support from the Steps network and have since supported others through Steps. "As a family, we are grateful for the support received from Steps during our journey and the other families we have met over the years."

Now, four years later, Noah is doing great, but he is still recovering (his femoral head is 90% regrown).



Noah's family say it has been emotional for the whole family "He still has good and bad days and the pain, he still gets, but we can manage this through heat packs and baths. He is back playing football and being able to play and have fun."

Most importantly Noah's family want him, and us to know that, "He has been through a lot and is a total inspiration to us all."

To read more stories like Noah's, visit www.StepsWorldWide.org

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 needs time to talk about how they are feeling, with each other and, with the medical professional. We know it's a lot of new information all at once, 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.

- Family Contact Service (confidential)

Connecting parents (or adult caregivers) with other families who have been through something similar. Enquire via our helpline **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.

- Facebook discussion groups (private)

There are two pages for members to join

Steps Charity Worldwide - Support Group for Parents

Steps Charity Worldwide - Support Group for Adults

- Helpline (confidential)

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

- Social media

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



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


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

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Steps Charity Worldwide - Support Group for Parents
Steps Charity Worldwide - Support Group for Adults



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We don't take walking for granted

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