

Perthes disease: Surgery information

Information for patients from the Paediatric Orthopaedic Service

The large majority of children who suffer from Perthes disease will not need to have surgery.

Surgery will not:

- Reduce the time for the disease to run its' course (2 to 5 years)
- Decrease the pain your child suffers
- Substitute physiotherapy or exercises
- Reduce your child's limp
- Allow your child to return to sports earlier.

For these and other reasons, some Orthopaedic Consultants will hardly ever operate upon children with Perthes disease.

However, there are those who believe that in certain children (see below) surgery will improve the fit of the ball in the hip socket when the bone reforms.

Surgery will not improve your child's hip in the short term – it is designed to improve the long-term future for the hip.

Surgery will possibly:

- Improve the movement in the hip when the disease has finished
- Delay the onset of arthritis of the hip and need for hip replacement as an adult.

Those children that might have better hips after surgery include:

- Older age of onset (8 years plus)
- Stiffer hips (but might need pre-operative traction)
- Heavier children
- X-rays if the ball starts to move sideways out of the socket (subluxation).

Often the decision for surgery is not black or white and this will be discussed with you and your child in detail, before any firm decisions are made.



Types of surgery

If your child is going to need surgery, then it is very important that the hip has a good range of movement and is not stiff. It may be necessary for them to be admitted to hospital for a period of pre-operative traction to allow the hip to become less stiff.

On the day of surgery, an x-ray will be taken with your child asleep to check the best position of the ball and socket (arthrogram), so it may not be possible to tell you that your child is definitely going to have a femoral or pelvic osteotomy (see below) before they go to theatre.

1. Femoral osteotomy

This operation involves cutting the thigh bone (femur) to try to point the ball into the socket as it reforms. It involves the placement of a metal plate on the bone to hold the bone while it heals. Your child will not have a plaster cast, but will need to use crutches (they may already be using them) to walk very carefully for at least six weeks. The plate may be removed at a much later date if it rubs or causes discomfort.

2. Pelvic osteotomy

This operation involves cutting the bone around the socket to place the socket over the ball as it reforms. It involves placing two metal pins in the bone to hold it while it heals. Your child will then be placed in a plaster hip spica (see information leaflet). After six to eight weeks your child will have a second anaesthetic to remove the plaster hip spica and the metal pins.



After surgery

Your child will need to continue with physiotherapy and hydrotherapy after surgery. Your child will probably limp more after surgery initially due to weakness and the leg having a different range of movement. It will not be possible to judge the success of surgery for many months or even years after surgery since it is not aimed at improving the short-term outcome.

Caring for your child in a hip spica

Your child is going into a hip spica cast

Following surgery, whilst still under anaesthetic, a hip spica cast will be applied to ensure your child's hips/legs remain in the correct position to allow healing to take place. This type of cast is rather like a pair of high waisted plaster trousers. It will encase the abdomen and chest up to nipple line, the hips and pelvis and the legs, either both legs to ankles or the whole leg to ankle on the affected side and to above the knee on the other (1½ hip spica).

Although this sounds very restricting children generally adapt very quickly to being in plaster and find ways of managing to do things. This leaflet aims to give you some information on the care your child will need whilst in plaster and some tips on how to manage your child at home.

Toileting

There will be a cut out in the plaster to allow your child to go to the toilet. Some children are able to sit on a toilet or commode to go to the toilet. For those that cannot, urine bottles and bedpans can be provided for use at home. You will be shown before discharge how best to position you child for toileting. It is important to ensure your child eats a good well balanced diet and drinks plenty of water to prevent constipation. Drinking plenty of water also helps to dilute the urine and minimise the risk of the acidic urine burning the skin. Hygiene is particularly important to prevent sores. You need to keep their skin clean and dry and observe regularly to ensure it is not getting reddened or sore. Wet wipes are useful as they clean the area without getting the plaster too wet.

Feeding

Your child can eat fairly normally, however they may prefer frequent smaller meals to prevent the plaster from feeling too tight. You will need to find the best way of positioning you child, as upright as possible, for meal times. You will be assisted in hospital to find ways of doing this. Their wheelchair or an armchair supported with pillows may be suitable options. A towel draped across the chest or an apron may be useful to prevent crumbs from falling inside their plaster causing irritation. You need to increase your child's fluid intake to prevent constipation and ensure that urine is diluted to reduce the risk of getting sores under the plaster.

Clothing

You will need to split trouser bottoms down the outside seam to get them over the plaster. These can then be fastened by sewing in Velcro along the seams.

Underwear can be split down one outside seam and then ties or Velcro sewn in.

There are also some tracksuit bottoms available that have popper fastenings down the sides which can also work quite well. Overall big and baggy is the way to go for comfort and ease.

Playtime

Your child should be able to continue with some of the leisure activities they enjoy. Some outdoor activities will not be suitable but weather permitting your child may like to go and watch their team-mates. Indoor activities such as arts and crafts, TV/videos, computer games and reading are suitable and should be encouraged to prevent boredom and frustration. Some schools are able to accommodate children in hip spicas but you will need to speak to your child's school prior to surgery. If your child is unable to attend school we can organise home tutoring – if needed please discuss this with the nurse at pre admission clinic. Encouraging visitors, friends and relatives can be a good idea to help stimulate and occupy your child and prevent feeling of isolation from peers. It can also give you some free time!!!

Positioning

You will need to position your child very carefully to ensure your child maximum comfort, to prevent pressure sores and to prevent the plaster from being damaged. Various pieces of equipment may be utilised to assist you in positioning your child. Their position needs to be changed regularly to prevent your child developing pressure sores.

- Bean bags: particularly useful and fairly inexpensive to purchase. The beans mould to the shape of your child's plaster meaning they are well supported and feel comfortable. Bean bags are useful for positioning your child for meal times and during activities.
- Reclining garden chairs: these may be of use to allow your child to sit with the rest of the family for meals or to watch TV etc. A cushion may be needed to support your child's back.
- Pillows/cushions: extra pillows can be utilised to support your child's plaster to ensure their comfort. They can be used under their legs whilst lying on their backs, under their tummy, pelvis, and legs whilst on their tummy, to support them to sit on a chair, and many more ways to suit your child.
- Sleeping: It is useful for older children to have a bed moved downstairs so that you do not have to carry them up the stairs.

You can arrange to have a hospital bed delivered if you feel you need a bed that is able to adjust its height. If you feel you may need a hospital bed please discuss this with your nurse at the pre-admission clinic.

Moving your child

Always wait until you have been shown how to move your child before attempting to do so on your own. We usually encourage the child to help with transfers. You will be shown how to do this by one of the nursing staff or the physiotherapist.

However here are the most important things to remember.

- Protect your back have two people to move your child if they are older
- Never lift your child by the bar
- Always remember to keep your back as straight as possible and bend your knees instead
 of leaning forwards
- Avoid lifting or carrying your child.

On the next page you will see pictures of some of the equipment that is available that can help your child to become more mobile and independent. If you have a particular problem or any ideas, please contact one of the paediatric orthopaedic team. If in doubt please ask, we may have advice or equipment that can help you

Reclining wheelchair/buggy



These can be ordered in advance from the wheelchair service by one of the team.

Monkey pole



These can be useful to help your child move themselves around the bed.

Hoist



This is useful for the older child. An assessment needs to be carried out at home to ensure there is enough room to make it easy to use, as they are quite bulky.

Sliding sheets

These are sheets of material that decrease friction, making it easier to slide your child around the bed or during transfers.

Hire of equipment

You can also hire different items of equipment from the Perthes Association such as hand-propelled bikes and straddle seats for older children. They also do an advice sheet for transporting older children in the car. See below for the Perthes Association contact details.

Useful contacts

Consultant Orthopaedic Surgeon - Mr Cornell Queen Elizabeth the Queen Mother Hospital Ramsgate Road, Margate, Kent

Telephone: 01843 225544 extension 62860

Physiotherapist - Jenny Seggie or Suzanne Gray

Telephone: 01233 616618

E-mail: jenny.seggie@nhs.net or suzanne.gray2@nhs.net

Shirley Bowskill - Plaster Sister

Contact if you have any concerns regarding plaster fit.

Telephone: 01227 864301

Nursing staff

Rainbow Ward

Queen Elizabeth the Queen Mother Hospital

Ramsgate Road, Margate, Kent

Telephone: 01843 225544 extension 62269

Community Children's Nurses

A medical referral is needed for home visits post operative and will be organised by the nursing staff on the ward if necessary. The community nurses are able to organise provision of hospital bed, hoists and monitor wound care

Canterbury office

Children's Assessment Centre, Kent and Canterbury Hospital

Telephone: 01227 766877

Red Cross

Temporary loans of wheelchairs and commodes. Self-referrals accepted. £20 deposit requested.

Ashford branch

223 Quantock Drive, Ashford

Open Monday/Wednesday/Friday -10 to 12pm

Telephone: 01233 620356

· Canterbury branch

Lower Chantry Lane, Canterbury

Open Monday/Wednesday/Friday - 10 to 12pm

Telephone: 01227 766145

Margate branch

Ellington Road, Margate

Open Monday/Wednesday/Friday - 11 to 1pm

Telephone: 01843 223739

· Herne Bay branch

176 Mortimer Street, Herne Bay

Open Monday/Wednesday/Friday -10 to 12pm

Telephone: 01227 365918

Wheelchair Services – A long term loan that requires a medical referral.

• Canterbury office – Wheelchair Service

Trust Headquarters

Littlebourne Road, Canterbury

Telephone: 01227 812393

Aylesham office – Wheelchair Service

New Aylesham Health Centre Queen's Road, Aylesham Telephone: 01304 843777

Perthes Association

PO Box 773

Guildford, GU1 1XN

Telephone: 01483 306637 Email: admin@perthes.org.uk Web site: www.Perthes.org.uk

Steps - Association for people with lower limb abnormalities who can help with obtaining

equipment if surgery is required.

Lymm Court 11 Eagle Brow

Lymm, Cheshire WA13 OLP Telephone: 0871 7170044

Email: <u>info@steps-charity.org.uk</u>
Web site: <u>www.steps-charity.org.uk</u>

In car safety centre can offer advice on suitable car seats or back seat harnesses to accommodate children in hip spica plasters after surgery. They also offer a hire service in some

cases.

Telephone: 01908 220909

Sophia's mums top tips

Information provided by a parent whose child had surgery for Perthes.

Day to day care

- We used lots of pillows and cushions as well as a bean bag to support Sophia in bed. This helped as she was plastered in a lying position.
- We covered the bed mattress in a water proof sheet as using the bed pan some times caused 'accidents'.
- Extra sheets and pillowcases were needed after painting or sticking activities.
- Straws are needed for drinking as drinking in the lying position was difficult.
- Drinking bottles were also useful.
- Baby wipes, tissues and toilet wipes are needed in bulk. We used a lot and found that the supermarket own brands were fine and less expensive than the named brands.
- A tray with an attached cushion is ideal to use for dinner time and also for drawing and painting activities.

Washing and dressing

- I cut up the side of trousers and sewed Velcro to the two sides so they could be pulled on and off easily. It was summer so shorts were perfect.
- Sophia has long hair and this posed a problem as her hair became quite tangled and matted from lying down. I used a child's detangle spray from the supermarket. I sprayed Sophia's hair and brushed it through. It worked really well.
- Plaiting Sophia's hair also helped to keep it tidy.
- I was told that washing Sophia's hair was not important, but I managed to wash her hair in the garden with her head hanging over the edge of our garden hammock, using a jug and bowl.
- Sophia enjoyed having a bed bath. I laid a large towel and used soap and water to wash all her unplastered bits. I then used E45 cream to rub into her legs and arms as her skin became quite dry.

Davs out

We tried to go out every day as it gave Sophia something to look forward to and we were lucky as the weather was good. It really lifted Sophia's spirits and by the fourth week I managed to get Sophia in the car.

The wheelchair folded down and fitted in the car, although I had to put the seats down in the back to fit it in.

I bought a child's travel potty, which folded into a bag. I also took wipes and tissues. If Sophia needed to go to the toilet while we were out, we could pop to the public toilets and use the potty.

Other activities

- Painting by numbers
- Cutting and sticking
- Word searches
- Watching TV, videos and DVDs
- Bingo afternoon with friends with or without little prizes
- Archery set which can be played indoors or outdoors with friends.

I didn't think I would be able to cope being a single parent and having to go to work. But with my family, friends and Sophia's big brother we got through it. Amazingly Sophia remained a happy and positive child throughout. I had been so worried that she would be in pain and feel down, but she didn't. She was so brave and never made a fuss.

I believe that the most important thing was that everyone around Sophia at the time was positive. They treated her the same as before the operation and the hip spica plaster.

If I'm honest we did spoil her a little bit, but she was so brave!!

Sophia's diary

At the hospital

7.15 in the morning

I arrived at the hospital. We went straight to the children's ward. A nurse showed me to my bed, I got undressed and sat on the bed.

The doctor came to see me and told me what he was going to do to my hip. Then a nurse came and put a name tag on my wrist.

The nurse took my temperature. She did this by putting a small machine in my ear. She also took my blood pressure with another machine that clipped to my finger.

I was a bit scared but my mum and dad were with me and it was ok.

The anaesthetist came to see me and said the nurse would give me some medicine to make me sleepy and put some magic cream on my hands to make them feel numb.

The medicine tasted horrible, but I felt sleepy straight away.

9.00 in the morning

I was taken to the operating theatre in my bed and my mum and dad came with me. I was quite sleepy but I remember the anaesthetist putting a needle in my hand but I didn't feel it. I gave my mum a kiss and went to sleep.

12.45 mid day

I woke up in a room and my dad was there. I felt groggy and sleepy but felt no pain. I was taken back to the children's ward where my mum was waiting for me. I kept falling asleep.

3.00 in the afternoon

I woke up properly and felt uncomfortable. Also my tummy hurt. My mum moved the pillows about and propped me up but I could not get comfortable. My legs didn't hurt though, they just felt funny.

I looked at the plaster and was a bit surprised....it looked so big!

Later I wanted to go to the toilet. I couldn't get out of bed because of the plaster so had to go on a bed pan and use a bottle thing. The nurses tried to lift me onto the bedpan but it hurt when I moved. It was horrible and I didn't like it. Once I went to the toilet I felt much better.

I had tummy ache all night and couldn't get to sleep so the nurse gave me some special medicine and it made me fall asleep. Mummy said it was 2.00 in the morning when I finally got to sleep!

I stayed in hospital for two nights and couldn't wait to get home!!

At home

When I got home I felt better. All my friends and family came to see me and I was given lots of presents. Had lots of colouring books, pens, games, and computer games.

I had lots of things to do.

For the first two weeks I didn't like to be moved. I also didn't want to go out. It hurt when I moved or if someone tried to lift me.

To get into the other room or garden I had to be slid onto the special wheelchair then be wheeled about. I was scared to move and I felt safer in my room.

Going to the toilet was much better at home than in the hospital. I could use the monkey bar to pull myself up whilst my mum pushed the bed pan under me.

I had to go back to the hospital on the third week to have my plaster trimmed as it was digging into me in some places. The plaster man had to turn me over onto my tummy which I was really scared about, but once I had done it, it was ok. In fact it was really comfortable and I nearly fell asleep. After he had finished the plaster felt much better and more comfortable.

The very worst part of having a hip spica plaster is the itching! At night it was really bad. I couldn't get to sleep and it was horrible. My mum took me to the doctors and he gave me some medicine called Phenigan lixia which I took at night before I went to bed. It made me sleepy and stopped the itching. Mum also found that putting a fan on helped. After that I slept all night, every night.

After a couple of weeks I didn't feel any pain at all and didn't mind going out in the wheelchair. It was good as I could go out and into the garden.

My mum took me out to the shops every day pushing me in the wheelchair. We stopped off at a café that had seats outside and we had a drink. We even managed to go to a wildlife park, firework display, friend's houses and walks along the sea front.

I was a bit embarrassed going out in the wheelchair at first as I didn't want to see people I knew. After a while I didn't care as it was so good to go out.

I was also scared of going out in the car. I thought it would hurt my legs, or I would get stuck or fall off the wheelchair. My mum persuaded me to try. I got in the front seat which was laid back as far as it would go. My mum put a bean bag on the floor space so I could rest my feet. It was great, we could go anywhere and mum was pleased as she didn't have to walk everywhere!

The good bits of being in a hip spica plaster are that I watched lots of television, played my computer games, ate my dinner in bed every day and didn't have to tidy my room or feed the dog!

Tomorrow I am having my plaster taken off and I can't wait!!

This leaflet has been produced with and for patients

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