

Surgery to treat your child's bowel for Hirschsprung's disease

Children's Hospital

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Information for Patients

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What is Hirschsprung's disease?

Hirschsprung's disease is a rare bowel condition. It happens in about 1 in every 5,000 newborn babies.

Normally, the bowel squeezes and relaxes to move poo along. This process is controlled by your nervous system. In Hirschsprung's disease, the nerves that control this movement (peristalsis) are missing from part of the bowel, often at the end. Because of this, the bowel cannot move poo properly. This can cause poo to build up and create a blockage.

This can cause constipation. If it is not found and treated early it can sometimes cause a serious bowel infection called enterocolitis. Most of the time we find this out soon after birth and treat it with bowel washouts and then by surgery as soon as possible.

What causes Hirschsprung's disease?

The muscles in the bowel are controlled by nerve cells called ganglion cells. In Hirschsprung's disease, these ganglion cells are missing from some of the bowel. This starts from the opening in the bottom that poo passes through (the anus) through to the bowel. The amount of bowel affected is different for each child.

For some reason, the cells did not grow in that area when the baby was growing in the womb. It is not clear why this happens. There is no way to prevent it.

Hirschsprung's disease is linked to genes which are passed down in families. If you have already had 1 child with this condition, there is a higher chance that another child may have it too.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

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To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

What are the symptoms?

We can often see signs of Hirschsprung's disease soon after the baby is born. Sometimes, the signs do not appear until the child is older.

Signs in a newborn baby:

- Delay in passing of the dark, tar-like poo that healthy babies pass soon after being born (meconium).
- A swollen belly (dilated abdomen).
- Vomiting green fluid (bile).
- Not able to keep feeds down.

Signs in older infants and children:

- A swollen belly and a tummy ache.
- Lasting constipation that does not get better with the usual treatments.
- Not feeding well or not gaining much weight.

How is it diagnosed?

If your doctor thinks your child has Hirschsprung's disease they may ask for them to have an X-ray or a contrast enema. This can show parts of the bowel that look very swollen or parts that look too narrow.

However, an X-ray alone cannot confirm the condition. Doctors also do a procedure called a rectal biopsy. During this procedure, the doctors will take a small piece of tissue from your child's bowel. They will look at this tissue under a microscope to see if the ganglion cells are missing.

Treatment

When your child comes into hospital the first time they may need to:

- take antibiotics if they have enterocolitis.
- stop having milk feeds. They will need to have fluids given directly into a vein.
- have a tube passed through their nose and into their stomach to drain away any fluid and air collecting in it.

All children with Hirschsprung's disease will need surgery.

As your child waits for surgery, they will need to have regular bowel washouts (rectal irrigation) until they have the surgery. To do this we will need to insert a thin tube into their bottom. We will use warm water to soften and drain out stools.

The nurse will teach parents how to do the bowel washouts themselves. This means you will be able to care for your child at home. Most children do well with regular bowel washouts. This helps them to poo and allows them to go home and grow until they can have surgery.

Your child can go back to normal feeds once the bowel washouts have worked and when their tummy becomes less swollen.

If the washouts do not help the poo come out, your child will then need a surgery called an ileostomy. During the surgery, the bowel is brought out through a small opening in the tummy. This opening is called a stoma. Your child will need to wear a bag over the stoma so the poo can go into the bag. The stoma is only needed until your child has surgery to repair the bowel. Then the stoma will be closed.

What happens during surgery?

During the surgery we will need to remove part of the bowel that lacks ganglion cells. The normal bowel is then joined just above the anus.

We can do this as a key-hole surgery where we make small cuts in the tummy or an open surgery where we make a large cut in the tummy. Your surgeon will explain which type of surgery will be best for your child.

Recovery from surgery and discharge information

After surgery, your child will often need to stay in hospital for a few days. We will give them fluids through a drip into a vein. These fluids include food, antibiotics and regular medicine for pain to make them comfortable. This may include having an epidural or a morphine infusion. We will do this until they can manage food and drink. This will also give the bowel time to rest and start to heal.

It is important that your child opens their bowels after surgery and before discharge. In some cases we may give them some medicine to help them do this.

Your surgeon will decide on follow-up visits and any reviews.

The surgical wound will look bright pink and should heal by itself. It will have a certain amount of swelling and may have a small amount of oozing.

Contact your consultant, specialist nurse or Ward 10 if the wound:

- starts to bleed.
- becomes red and or more painful when touched.
- starts to discharge pus.

At first they will probably have a sore bottom when they poo. It can help to:

- leave their bottom open to the air whenever possible.
- use baby oil to gently clean their bottom.
- use nappy cream after each change.

Call your surgical team or your specialist nurse if your child has problems like a swollen tummy, a fever or foul-smelling diarrhoea.

After the operation your child may have:

- **Constipation.** They may need treatment like high-fibre diet rectal treatments and oral medication (laxatives).
- **Hirschsprung's associated enterocolitis (HAE).** This is an infection of the bowel. The signs and symptoms of this are:
 - a swollen tummy (distended abdomen)
 - a high temperature (above 38 degrees)
 - stools which smell foul
 - vomiting
 - lack of energy/ tiredness (lethargy)
 - not wanting to feed as normal

HAE is a medical emergency. If your child is showing symptoms of this you need to contact your consultant, specialist nurse or discharging ward right away. If your child is unwell please go the children's Emergency Department.

Some children may have food intolerances after surgery. You can continue as before but if you have any worries please talk with your specialist nurse or consultant.

Your child should recover well and their bowels should work normally after surgery. Some children may still need bowel washouts or medicine to help them poo.

Life after surgery

Most children with Hirschsprung's disease do very well. They usually grow up to live normal healthy lives.

After surgery, most children can poo normally and their bowels work well. They may take a bit longer to be toilet trained.

A small number of children may have problems controlling their bowels (incontinence). This can last until they are a teenager and be very distressing. Your surgical team will continue to manage this.

