

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

Children's Hospital

Information for Patients

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## What is Hirschsprung's disease?

Hirschsprung's disease is a rare bowel condition affecting an estimated 1 in every 5,000 newborn babies.

Normally, the bowel continuously squeezes and relaxes to push poo (stool) along, a process 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. This means the normal movement of the bowel wall that allows the content of the bowel to be pushed forward doesn't work properly. This can cause poo to build up and form a blockage.

This can cause severe constipation and sometimes lead to a serious bowel infection called enterocolitis if it's not found and treated early on. But the condition is usually picked up soon after birth and treated with bowel washouts and then by surgery as soon as possible.

## What causes Hirschsprung's disease?

The muscles of the bowel are controlled by nerve cells called ganglion cells. In Hirschsprung's disease, these ganglion cells are missing from some of the bowel, going up from the opening in the bottom that poo passes through (the anus). The length of the affected part of bowel varies from child to child.

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

A number of genes are linked with Hirschsprung's disease and it does sometimes run in families. If you have had a child with it before, you're more likely to have another child with it.

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**Health information and support is available at [www.nhs.uk](http://www.nhs.uk)  
or call 111 for non-emergency medical advice**

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## What are the symptoms?

Symptoms of Hirschsprung's disease are usually noticeable soon after a baby is born. However, in some cases the disease doesn't present itself until later.

### Signs of the condition in a newborn baby include:

- 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 include:

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

## How is Hirschsprung's disease diagnosed?

If your doctor thinks that your child has Hirschsprung's disease they may request an X-ray or a contrast enema. This may show sections of the bowel looking very bulged (above where the Hirschsprung's disease is), but may also show some narrowing of the bowel.

However, the diagnosis cannot be confirmed by X-ray imaging alone. A diagnosis of Hirschsprung's disease is confirmed by doing a procedure called a rectal biopsy. This is where a small piece of tissue is taken from your child's bowel and examined under a microscope to see if the ganglion cells are missing.

## Treatment for Hirschsprung's disease

Initially when your child comes in to hospital they may need to:

- take antibiotics if they have enterocolitis.
- stop having milk feeds and instead be given fluids 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. This involves inserting a thin tube into their bottom and using warm salt water to soften and flush out trapped stools.

The nurse will teach parents how to do the bowel washouts themselves, so you will be able to care for your child at home.

Your child will be allowed to feed once the bowel washouts have worked and when their tummy becomes less swollen.

Most children will do well on a treatment of regular bowel washouts and will be able to go home and grow until surgery. If the washouts do not help stools to be passed, an operation called a ileostomy may be needed. This involves the bowel being diverted up to the skin through an opening in the tummy. The opening is called a stoma. A bag worn on your child's body is placed over the stoma so stools will pass directly out of the opening into it. The stoma is only needed until your child has surgery to repair the bowel, then the stoma will be closed.

## What does surgery involve?

Babies/ children affected by Hirschsprung's disease will need an operation which involves removal of the part of the bowel that lacks ganglion cells. The normal bowel is then joined just above the anus.

This operation may be done by key-hole surgery, or by open surgery where a larger cut is made in the tummy. Your surgeon will explain which type of operation will be best for your child. The results of both techniques are similar.

## Recovery from surgery and discharge information

Your child will probably need to stay in hospital for a few days after surgery. They will be given fluids through a drip into a vein (until they can manage food and drink), antibiotics and regular medicine for pain to make them comfortable (this may include having an epidural or a morphine infusion). This will also allow the bowel to rest and start to heal.

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

Arrangements for follow-up visits and reviews will be decided by your surgeon.

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 develops problems such as a swollen tummy, a fever or foul-smelling diarrhoea.**

After the operation your child may have:

- **constipation** which may need further treatment such as a high-fibre diet rectal treatments and oral medication (laxatives).
- **Hirschsprung's associated enterocolitis (HAE)**, which 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 either your consultant, specialist nurse or discharging ward as a matter of emergency.**

There is a link to food intolerances after surgery for Hirschsprung's disease. Continue as before but if you have any concerns please discuss these with your specialist nurse or consultant.

Your child should recover well and their bowels should function normally after surgery. However in some cases they may need to continue to have washouts and/ or have medication to help pass stools.

## What is the outlook for children with Hirschsprung's disease?

The outlook for children with Hirschsprung's disease is good, with most growing up to live normal lives as they want to.

Most children are able to pass stools normally and have a normal functioning bowel after surgery, although they may take a bit longer to toilet train. A small number of children have problems controlling their bowels (incontinence), which can last until they're a teenager and be very distressing. Your surgical team will continue to manage this.

## Contact details

Specialist Nurse: 0116 258 5494  
Ward 10: 0116 258 5362 / 5438

## Further information

- [www.nhs.uk/conditions/hirschsprungs-disease/](http://www.nhs.uk/conditions/hirschsprungs-disease/)
- [www.breakawayfoundation.org.uk](http://www.breakawayfoundation.org.uk)
- [www.eric.org.uk](http://www.eric.org.uk)

If you have any questions, write them down here to remind you what to ask when you speak to your nurse/ doctor/ consultant:

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