



HMDSN is a voluntary group offering support to parents and carers of children who have Gastrointestinal conditions.

The most common of these problems is Hirschsprung's Disease (HD). Although 'common', it only affects around 1 in 5,000 babies and it is therefore classified as a rare disease.

The Hirschsprung's & Motility Disorders Support Network

HMDSN

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Hirschsprung's Disease



What on earth is Hirschsprung's Disease (HD)?

In simple terms, special nerves cells, called Ganglion Cells, grow in the baby's intestine soon after the baby begins to grow in the womb.

With Hirschsprung's (HURSH-sprungz), these cells do not grow the whole way down the intestine but stop at some point before reaching the bottom. This part of the bowel without cells is called aganglionic.

HD is more common in boys than girls and 1 in every 5,000 babies are affected.

Ganglion Cells!! What are these?

They are cells that allow the bowel to relax and contract, which is necessary to push the pooh down through the bowel.

Without these cells, the pooh cannot pass down the bowel to the baby's bottom as it is too narrow to pass. This then causes an accumulation of pooh, making the bowel swell and the baby looks bloated.

Will laxatives fix it?

No, I am afraid not. The only effective treatment is a surgical procedure called a Pullthrough.

This is where the affected part of the bowel, the aganglionic bowel, is removed and then the good bowel, with the correct amount of cells, is pulled down and attached onto the anus.

After the Pullthrough will my child will be cured?

This is a hard one. No child is ever 'cured' but that does not mean they can't live a 'normal' life. Some children do have problems afterwards. This can be diarrhoea or constipation or periods of both, very severe nappy rash due to the loose bowel motions. In time this does settle down but how long it takes does vary for each child.

Some children never have problems. For others it may take until their mid-teens to gain full control.

For a very small minority, they may never gain control but do not think of this at this early stage, as the vast majority do.

What do I need to be aware of in the early days?

The most severe complication is **Enterocolitis (HEC)**. This can occur both before and after the pullthrough. Children, as they grow older are at less risk to HEC.

Look out for the following symptoms

- **Swollen Tummy**
- **Fever**
- **Foul smelling pooh**

If this goes untreated it can have very serious consequences. If you think your child may have HEC, then **you need to quickly contact your consultant** or go to A & E.

Why have I not heard of HD Before?

Well lets be honest have you talked about your bowel motions? Everyone has them but no one wants to talk about them.

Therefore it is not surprising you have never heard of it, few people have. That is why we call it the 'Secret Disease.'

