The Royal Children's Hospital Melbourne

COLORECTAL AND PELVIC RECONSTRUCTION SERVICE

Hirschsprung Associated Enterocolitis

Information for families

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Colorectal and Pelvic Reconstruction Service (CPRS)
Information for families

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About this booklet

The Colorectal and Pelvic Reconstruction Service (CPRS) at The Royal Children's Hospital Melbourne (RCH) is leading the way in colorectal and pelvic care in Australia.

We aim to deliver the highest quality clinical care to children and families with colorectal and pelvic conditions. We play a vital role in increasing the awareness, understanding and knowledge of these conditions in the community, and work collaboratively to educate health care professionals.

This booklet has been developed to support parents, carers and children who have colorectal and pelvic conditions. The CPRS seeks to establish a healthy relationship with all families, as we believe this enables the best care possible. The content of this booklet has been developed based on the extensive clinical experience of the authors and the most recently published evidence for this clinical condition.

This CPRS booklet has been categorised into different stages of your child's journey, which allows you to read the information that is important to you at the time. Some parts may appear repetitive. This is because some of the information is relevant throughout different periods of your child's care.

Everyone learns differently. Some people like to read instructions, some like to learn by having information explained to them, and many like to do both. Make sure you tell the members of the CPRS team if you are finding any information in this booklet difficult to understand.

Hirschsprung associated enterocolitis (HAEC)

Children diagnosed with Hirschsprung disease are at risk of developing an infection known as HAEC.

This infection leads to inflammation of the large bowel, and may cause your child to become unwell quickly.

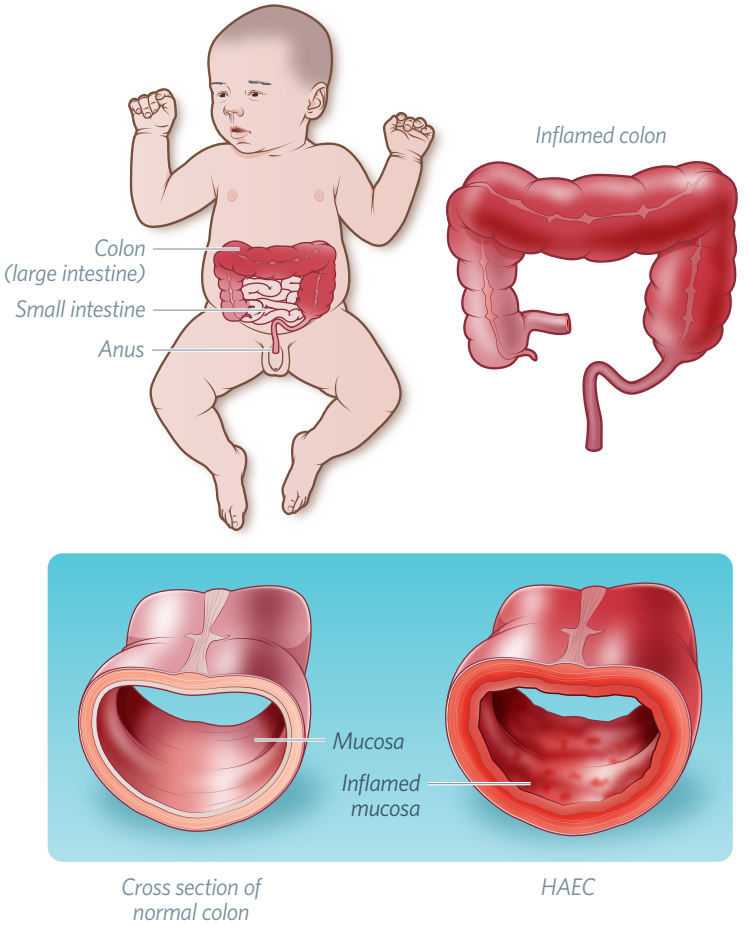
It is important to know the signs and symptoms of HAEC, and the care associated with this condition.

HAEC — what causes it?

Infection and/or inflammation of the bowel in children with Hirschsprung disease may be caused by:

- Obstruction of the bowel (this may occur before the pull-through procedure, as well as after the pull-through procedure)
- Infection from viruses and/or bacteria (children with Hirschsprung disease are more prone to these infections)

Hirschsprung-associated enterocolitis (HAEC)



Cross section of normal colon

HAEC

HAEC — risk factors

There are a number of factors that may increase your child's chance of developing HAEC, including:

- Undiagnosed Hirschsprung disease — a delay in the diagnosis of Hirschsprung disease may increase the likelihood of presenting with HAEC
- Down syndrome — children with Down syndrome who have Hirschsprung disease have an increased risk of HAEC, even after their pull-through procedure
- Long-segment Hirschsprung disease — the risk of HAEC is greater when longer sections of the large bowel are affected

HAEC — signs and symptoms

It is important that you and your child's carers are familiar with the signs and symptoms of HAEC, as it may present in a number of ways.

- Abdominal distention (swollen tummy)
- No stools (constipation)
- Explosive watery stools (diarrhoea)
- Vomiting
- High temperatures
- Lethargy
- Poor feeding
- Rectal bleeding

HAEC — treatment

Treatment for HAEC will vary, depending on the severity of your child's symptoms. If your child is experiencing any of the signs and symptoms of HAEC it is extremely important to seek medical assistance immediately.

Mild cases of HAEC may be treated with oral antibiotics and bowel washouts (rectal). In some cases, washouts may begin at home, with the support of the CPRS team.

An x-ray of your child's abdomen may be taken to assess their large bowel for the accumulation of stool (poo) and gas. You may also be asked to bring in a sample of your child's stool, if you are doing washouts at home.

A blood test may also be performed to check your child's electrolytes (salts).

In serious cases, your child will be treated with intravenous antibiotics through a drip, bowel washouts and bowel rest (no eating or drinking). This will require a hospital admission for up to five days.

In rare circumstances, surgery may be required to treat HAEC.

The CPRS team will provide you with a HAEC alert card and a letter to explain your child's condition. These will outline the suggested treatments for HAEC, and the contact details for the CPRS team. It is important to carry this alert card with you at all times.

If your child experiences any of the above signs or symptoms, please contact the CPRS Clinical Nurse Consultants on 03 9345 6970 or at **colorectalnursingcnc@rch.org.au** or present to your local Emergency Department.

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