

# Enterocolitis of Hirschsprung disease

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## What is enterocolitis of Hirschsprung disease?

Enterocolitis means inflammation of the bowel. Enterocolitis of Hirschsprung disease only happens in children who have Hirschsprung disease. It can cause your child to get very sick or even die.

Enterocolitis of Hirschsprung disease:

- Can happen:
  - Before your child is diagnosed with Hirschsprung disease.
  - After your child has a colostomy.
  - After your child has had a pull-through procedure.
- Happens in about 30% of children with Hirschsprung disease.
- Is an emergency!

## What causes it?

Doctors do not know what causes it. It is most likely a mix of:

- A partial bowel obstruction (blockage)
- An infection in the colon
- An abnormal immune system in the bowel wall

## What are the symptoms?

Your child may have one or more of these:

- A distended belly (bloating)
- Diarrhea that is watery and smells very bad
- Constipation (no stools for more than 48 hours)
- Vomiting (throwing up)
- A major change in normal bowel habits
- Fever (temperature of 100.4°F or higher)
- Lethargy (being overly tired) or not responsive
- Cold hands and feet

## When should I call the doctor?

If your child has any of the symptoms listed above:

- Call your child's surgeon (Dr. \_\_\_\_\_). Or call the surgeon on call any time, day or night.
  - Call 404-785-8787 if your child's surgeon is at Children's Healthcare of Atlanta at Egleston.
  - Call 404-785-6895 if your child's surgeon is at Children's Healthcare of Atlanta at Scottish Rite.
- Tell the surgeon that your child has Hirschsprung disease. Then, tell the surgeon your child's symptoms.

**In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.**

# Enterocolitis of Hirschsprung disease, continued

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- If you have already taken your child to a hospital, ask the doctors there to call your child's surgeon or the surgeon on call.
  - Have them call 404-785-8787 if your child's surgeon is at Egleston.
  - Have them call 404-785-6895 if your child's surgeon is at Scottish Rite.

## What happens next?

Your child's surgeon or the surgeon on call may ask you to:

- Give your child a rectal irrigation.
- Take your child to the Egleston or Scottish Rite emergency department (ED) right away (if you live nearby).
- Take your child to the nearest ED (if you live far away). If so, ask the ED doctor to call your child's surgeon or surgeon on call.
  - Have them call 404-785-8787 if your child's surgeon is at Egleston.
  - Have them call 404-785-6895 if your child's surgeon is at Scottish Rite.
- Call 911 for transport to Egleston or Scottish Rite or the nearest ED.

## What is the treatment?

Talk with your child's surgeon about specific care for your child. Some guidelines include:

- Rectal irrigations
- Intravenous (I.V.) fluids
- Antibiotics (if your child has a fever)

## What is the likely outcome?

- Most often, the outcome is good if your child gets treatment right away.
- Your child may have this again and again for a few years. Or it may not happen at all.
- If your child has repeated episodes, it will most often get better after a few years.
- This disease can be fatal (cause death) if not treated **right away**. It is the leading cause of death in children with Hirschsprung disease.

**This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.**

**In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.**