

Gut motility assessment

A close-up photograph of a young child with light brown, curly hair. The child is looking down at a spoon they are holding, which is scooping up a green substance from a yellow bowl. The child is wearing a white shirt and an orange apron with a pink floral pattern. The background is a solid blue color.

Information for families

**Great Ormond Street Hospital for Children
NHS Foundation Trust**

This information sheet explains about the first phase of the assessment process to diagnose gut motility problems and what to expect when your child comes to Great Ormond Street Hospital (GOSH) for assessment.

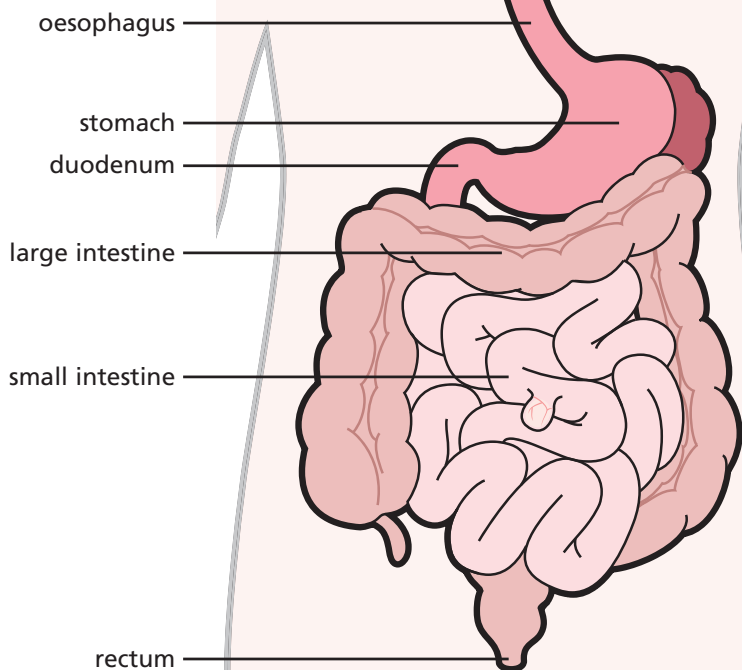
Great Ormond Street Hospital (GOSH) has a large internationally recognised gastroenterology unit. This unit specialises in the assessment and treatment of diseases of the gastrointestinal tract. There are a variety of reasons why children may have gut motility problems. It is therefore important to investigate it thoroughly so that the correct treatment can be offered. GOSH has all the facilities needed for the many investigations, tests and treatment your child may need.

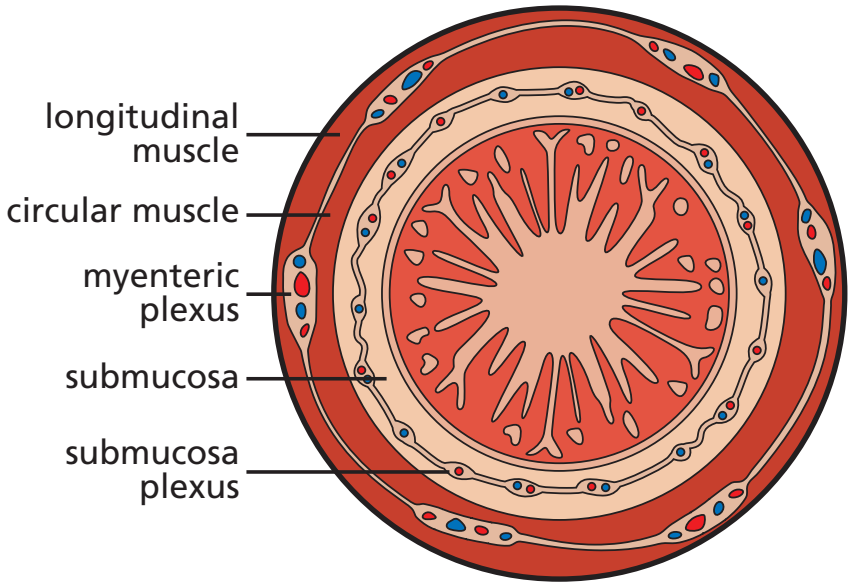
The process of assessment involves an entire team of specialists (multidisciplinary team), some or all of whom you may meet during your child's hospital admission:

- Gastroenterology consultants
- Consultant surgeons
- Clinical nurse specialists
- Ward nurses
- Play leaders
- Dietitians
- Pharmacists
- Social workers
- Psychologists
- Physiotherapists

How does the gastrointestinal tract work?

The gastrointestinal (GI) tract is a complex organ that extends as a hollow tube from the mouth to the anus. Its main function is to break down food so it can be absorbed into the bloodstream and then to expel the waste. The process of moving food through the GI tract involves a complex interaction between hormones (chemical messengers), muscles and nerves, so that food is squeezed rhythmically through the system (peristalsis).





Once food has been processed in the stomach, it empties into the small intestine where the majority of digestion and absorption occurs. Here it is mixed with bile and pancreatic juice containing enzymes (proteins that cause or speed up a chemical reaction). The broken down nutrients are then small enough to pass through the wall of the small intestine, which contains small finger-like structures called villi, and then absorbed by the blood. The blood is carried away from the small intestine through the hepatic portal vein to the liver, where it is filtered, toxins are removed and

the nutrients are processed. The residue then passes into the large intestine, where water is absorbed to form solid faeces (poo).

The entire length of the gastrointestinal tract contains nerves and muscles that work together to move food through from the oesophagus to the anus using peristalsis. If a section of the intestines does not contract these nerves and muscles or they are present but not working correctly, peristalsis cannot occur so food cannot be pushed efficiently to the next part of the tract. This is referred to as a gut motility problem.

There are various types of gut motility problem or dysmotility one of which is the spectrum disorder chronic intestinal pseudo-obstruction (CIPO). There are different types: neuropathic (nerve) motility problems, myopathic (muscle) motility problems or a problem with the pacemaker cells (interstitial cells of Cajal or ICC) which cause the muscle contractions. There may also be a mixture of neuropathic/myopathic motility problems.

There are other types of gut motility problem, such as Hirschsprung's disease.

Chronic intestinal pseudo-obstruction (CIPO) is a condition where the intestines appear to be blocked but in fact nerve and/or muscle problems are stopping food being squeezed efficiently through the gastrointestinal tract. Pseudo-obstruction is a rare condition which can occur at any age but is usually diagnosed in childhood.

The assessment process

When your child is first referred to GOSH, they will be offered an inpatient stay lasting between one and three weeks. During this stay, a doctor will discuss your child's history and carry out a full examination. They will review any previous tests from your local hospital if results are available and make a decision about whether any other tests are needed. A nurse or dietitian may contact you before your child's admission to carry out a pre-admission assessment so their stay is as streamlined as possible.

Diagnosing gut motility disorders is a complex process with many steps so it can take some time to reach a decision. We will do our best to keep you informed of our progress towards a diagnosis.

What tests and scans will my child need?

Your child may need a variety of investigations to diagnose the underlying gut problem and find its cause. Further information about each of these investigations is available on our website. To carry out some of the procedures to inspect the colon, bowel prepared will be needed to empty the gut of any faeces. This will be needed even if the colon is already disconnected by a stoma. The length of time needed to prepare the bowel will depend on your child's current bowel pattern. Some of the investigations that might be suggested include:

■ **Colonic manometry** – This is a test to measure how well the muscles and nerves in the large intestine work. While your child is under a general anaesthetic, a catheter (flexible plastic tube) is inserted into your child's anus and passed up into the large intestine. Once your child has woken up from the anaesthetic, fluid is put into the catheter, which causes

the nerves and muscles in the digestive system to start to move. This movement is detected by sensors contained in the catheter and recorded by a machine.

■ **Antroduodenal manometry**

– This is similar to colonic manometry but looks at the muscles and nerves in the stomach and small intestine. While your child is under general anaesthetic, a catheter is put through your child's nose, into their stomach and then to the small intestine. Once they have woken up from the general anaesthetic, fluid is put into the catheter, which causes the nerves and muscles in the digestive system to start to move. This movement is detected by sensors contained in the catheter, and the movement is recorded by a machine.

■ **Gastroscopy and colonoscopy**

– These are tests which allow the doctor to look directly at your child's GI tract and are also carried out while your child is

under general anaesthetic. To do this test, an endoscope (a thin, flexible tube with a bright light and camera at the end) is passed either through your child's mouth down into their stomach for a gastroscopy or through your child's anus into the large intestine for a colonoscopy.

- **Biopsy** – This is a procedure to take a tiny sample of tissue which can later be analysed in the laboratory. This is carried out during a gastroscopy or colonoscopy using an endoscope. If a 'full thickness biopsy' is required, your child will be referred to the surgeons as this involves taking a larger sample of bowel in the operating theatre.

- **Gastric emptying study** – This is a scan which shows how quickly the stomach passes a liquid or solid into the small intestine. The liquid or solid contains contrast, which shows up well on x-rays.

- **Contrast follow through (upper GI study)** – This scan uses a contrast, a liquid that shows up well on x-rays, to show details of

your child's GI tract. Your child will need to swallow some of this contrast as a drink or in some solid food and then have an x-ray around four hours or so later.

- **Transit study** – This is a test which shows how quickly food passes through the digestive system. Your child will be given some pellets to swallow on three consecutive days and then a few days later have an x-ray to see how far they have travelled through the GI tract.

- **Electrogastrogram (EGG)** – This measures the activity of the nerves in the lining of the stomach, before, during and after food using electrodes (which look like round stickers) stuck to the skin of your child's tummy. It is similar to an ECG test and lasts about four hours.

- **Impedance/pH study** – This is a test which measures the movement of all liquid up and down the oesophagus. This can enable the doctors to see whether your child has either acid or non-acid reflux or a combination of both. A thin

tube – similar to an NG tube – containing a probe is inserted into your child's nostril and down the back of the throat into their oesophagus. The other end of the tube is connected to a recording box. The tube will stay in place for 18 to 24 hours and your child should eat or drink as usual.

- **Ultrasound scan** – This uses sound waves to take pictures of your child's body. The sound waves are of a much higher frequency than normal so you cannot hear them. A jelly is used to help conduct them inside the body. It is the same as the ultrasound scans used during pregnancy.

- **Magnetic resonance imaging (MRI) scan** – This uses a magnetic field rather than x-rays to take pictures of your child's body. The MRI scanner is a hollow machine with a tube running horizontally through its middle. Your child will lie on a bed that slides into the tube.

Your child's intestine will need to be cleared of faeces for all of the procedures looking at the colon.

If they have a stoma already, the disconnected section will need to be cleared as well. We will explain about bowel preparation as how long it will take and how it will be carried out depends on your child's constipation history. In addition to these investigations, other general assessments may be suggested to look at particular areas more closely. These could include the immune system, metabolic system, genetics, bladder, liver and kidneys but will not be needed for every child.

Discussing the results of these tests and scans

The test results will be discussed by the team at GOSH and the doctor who referred your child in a multi-disciplinary team meeting after your child's stay. This may result in further tests and scans or admission for surgery. After the meeting, the team will contact you to explain the next steps to be planned.

What are the options for treatment?

Before you make a decision about any of these treatments, we will discuss the advantages and disadvantages with you and explain why each one has been suggested.

It is difficult to predict which treatment will be most suitable for your child as this is dependent on the results of the tests and scans. However, the options generally include the following, although some may not be suitable for every child.

Diet

A full feeding history forms part of the assessment process. This is important to see which feeds and feeding methods have been tried in the past, how your child tolerated these and what impact they had on their growth and weight gain. As a result of the full feeding history, the dietitian and medical team may suggest altering your child's feed in some way, either in which feed is given or how it is given.

These could include:

- A different milk feed.
- An altered diet, excluding certain foods, such as cow's milk or limiting certain macronutrients, for example fat or sugar.
- A liquid diet.
- An altered method of feeding, such as oral feeding or tube feeding (nasogastric, gastrostomy or jejunostomy).
- Parenteral nutrition, where a solution containing all the nutrients needed for growth is given directly into the bloodstream.

You will be involved in the decision making process about your child's diet and we will give you full training and instructions before you go home. We will also liaise with your local team so you have support when you return home. Booklets for care of nasogastric tubes and gastrostomy/ jejunostomy tubes and about parenteral nutrition are available from the team.

Medication

Your child may need to take medicines to help with gut motility and any associated gastrointestinal problems. There are various different types of medicine, some of which require regular monitoring with blood tests. All medicines have some side effects and the aim of this monitoring is to balance the benefits brought by the medicine with any unwanted side effects. We will make sure you understand fully about the medicine before your child starts taking it. Any medicine prescribed and dispensed through the pharmacy at GOSH will come with an information leaflet.

Surgery

The most common operation suggested is formation of a stoma, where the surgeon brings a healthy part of the bowel to the skin surface and forms an artificial opening (colostomy or ileostomy) through which your child can poo. This can relieve pressure in the bowel (decompression) and allow faeces (poo) to be passed more easily. In CIPO, it is hoped that it prevents further damage to the bowel. If it is indicated that your child will benefit from a stoma, the stoma care nurse specialist will visit you to explain further.

What next?

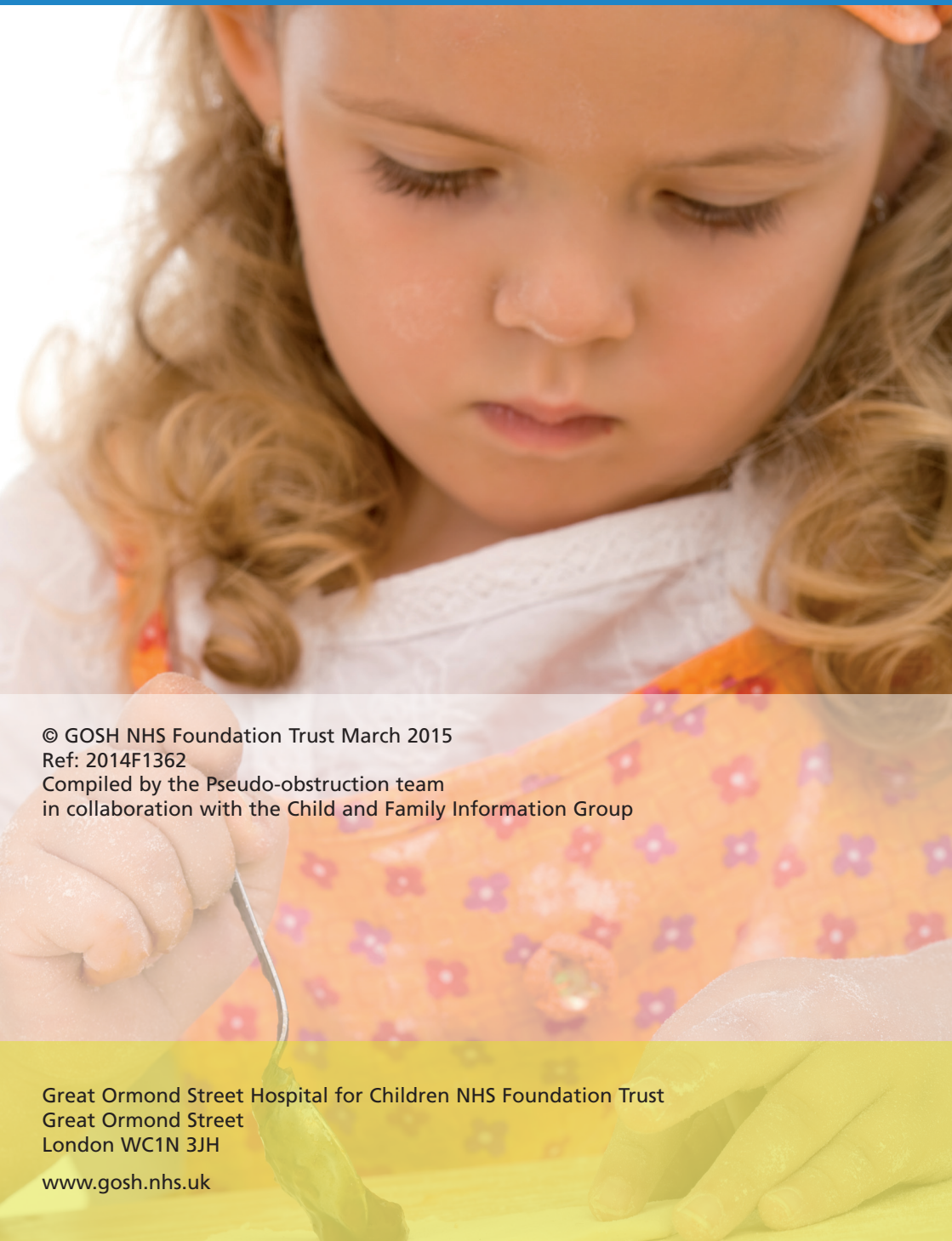
Following discharge after an inpatient stay, we will send a summary of our discussions and results to you, your family doctor (GP), local consultant and any other members of your child's healthcare team. The aim is to work in collaboration with your local team to develop a treatment plan, which may require, further outpatient appointments or inpatient stays.

If your child needs an inpatient admission for formation of stoma, the surgeons and their admission team will contact you with further details. Your child will be under the care of the surgeons for this admission but the Gut Motility team will be kept informed of your child's progress.

Further information and support

The **Hirschsprung's and Motility Disorders Support Network** is an international group offering support to children and families with all types of motility disorder. Visit their website at www.hirschsprungs.info or telephone them on 07935 787 776.

PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy) is an organisation for anyone receiving tube or intravenous feeds. They have a special section for children and young people called Half PINNT. Visit their website at www.pinnt.com



© GOSH NHS Foundation Trust March 2015

Ref: 2014F1362

Compiled by the Pseudo-obstruction team

in collaboration with the Child and Family Information Group

Great Ormond Street Hospital for Children NHS Foundation Trust
Great Ormond Street
London WC1N 3JH

www.gosh.nhs.uk