

OGD and proctoscopy for portal hypertension surveillance and endoscopic therapy in children and young people

Information for patients, parents, carers and/or guardians

Your child is scheduled to undergo an oesophago-gastro-duodenoscopy (OGD), also known as a camera test. The Liver Unit at King's College Hospital performs OGDs when there is a diagnosis or suspicion of portal hypertension and/or associated bleeding.

This leaflet aims to provide you with essential information about the procedure, its purpose, and what to expect before, during, and after the OGD and any related endoscopic therapy (endotherapy).

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your name and date of birth and check your ID band. If you do not have an ID band we will also ask you to confirm your address. If we do not ask these questions, then please ask us to check. Ensuring your safety is our primary concern.

What is portal hypertension?

Portal hypertension is a condition where there is increased pressure in the portal vein, which carries blood from the digestive organs to the liver. It can happen due to liver disease or abnormalities of blood vessels related to the liver. This leads to the development of abnormal blood vessels (varices) in the gastrointestinal tract, particularly in the food pipe (oesophagus) and stomach.

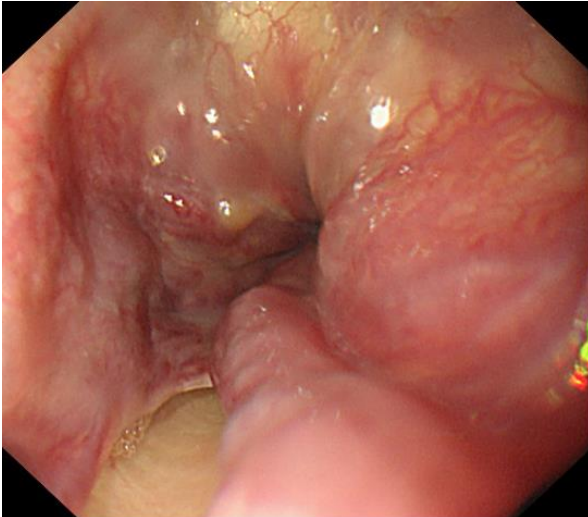
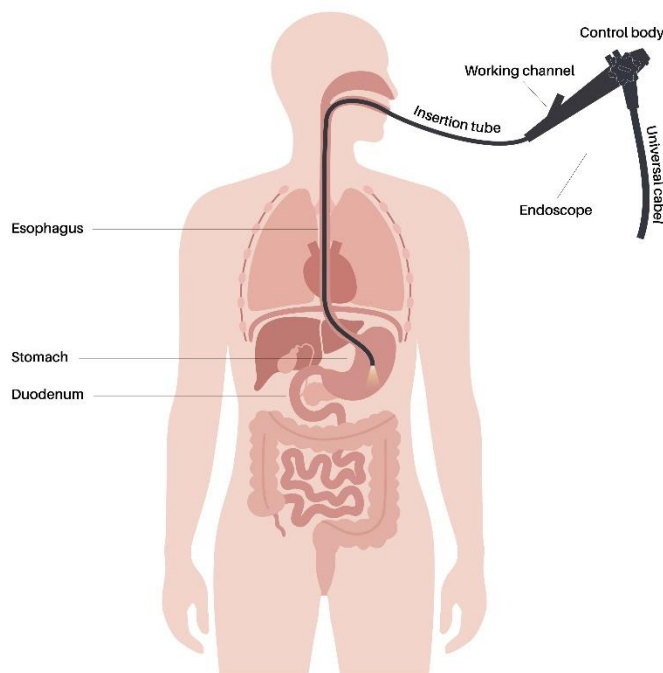


Image shows dilated blood vessels called varices at the lower end of the food pipe

Why do I need this procedure?

The OGD procedure is done to assess and monitor the condition of your child's oesophagus (food pipe), stomach, and first part of small bowel (duodenum) (see image below). It helps identify, evaluate and treat any varices or other abnormalities. We will also perform a proctoscopy (a camera test through the bottom) to look for varices in the rectum (bottom).

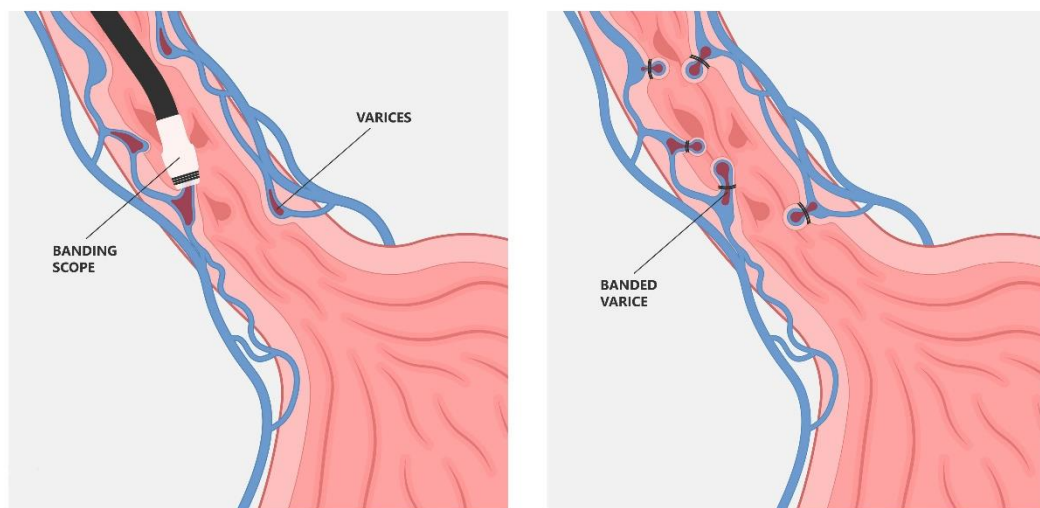


What are the treatment options?

During the OGD procedure, if any varices or abnormalities are detected, a treatment called “endotherapy” may be performed. Endotherapy can treat the varices and prevent complications such as bleeding. The endotherapy technique chosen will depend on your child's condition and the recommendations of the healthcare team. The three common techniques are:

1. sclerotherapy: involves injecting a medication (sclerosant) into the varices to cause scarring, thereby reducing the risk of bleeding
2. glue obturation (also known as glue injection): involves injecting medical-grade adhesive (glue) into the varices to seal them off and prevent bleeding
3. variceal ligation: small rubber bands are placed around the varices to squeeze them and make them close (also known as banding)

Image shows the application of a band on a varix in the oesophagus:



We will discuss the options with you before the procedure. If endotherapy is done, the medical team will inform you after the procedure.

Do I need to prepare for my procedure?

Travel or accommodation

Make necessary arrangements to bring your child to the hospital on the day of admission which may be the day before the procedure.

Fasting

Your child should avoid eating or drinking for a specific period before the procedure, as advised by the healthcare team. This is done to ensure an empty stomach during the procedure. Usual fasting time is 4 hours for infants only on breast milk and 6 hours for all other kinds of food including cow's milk and formula feeds. Clear fluids such as water or Dioralyte may be taken up to two hours before the procedure.

Medications

Inform the medical team about any medications your child is currently taking and allergies. They will provide guidance on which medications should be temporarily stopped or continued before the procedure.

Consent

A member of the medical team will talk you through the procedure, possible risks and complications and ask you to sign a consent form. Your child will be encouraged to take part in this discussion and if over 16 years old can sign the form themselves.

Meeting the anaesthetist

The OGD procedure is performed under general anaesthesia to ensure your child's comfort. The anaesthetist will explain the process and answer any questions you may have. Inform the anaesthetist if your child has any loose teeth or dental implants.

What happens during the procedure?

1. **Anaesthesia:** your child will be given general anaesthesia to ensure they are unconscious throughout the procedure.
2. **Procedure:** a thin, flexible tube called an endoscope (the camera) will be inserted through your child's mouth and gently introduced into the food pipe (oesophagus), stomach, and duodenum (first part of small bowel). This allows the medical team to see inside the digestive system and perform any necessary interventions.
3. **Endotherapy:** if varices or abnormalities are detected, the medical team may perform sclerotherapy, glue obturation, or variceal ligation as mentioned above.

What will happen after the procedure?

1. **Recovery:** Your child will be taken to a recovery area where they will be monitored until the effects of sedation or anaesthesia wear off. They will then be transferred to the ward to recover further.
2. **After care:** The medical team will provide specific instructions on care after the procedure, including any dietary restrictions and medications.
3. **Results:** The medical team will discuss with you the results of the examination and any procedures performed before you go home. They will provide information on the next steps, including any follow-up appointments or treatments required. Follow-up will be arranged based on your child's medical condition

Are there any potential risks and complication?

OGD is generally a safe procedure, but like any medical intervention, it carries some risks, these include:

1. **Pain:** After an OGD, children may experience pain in the throat related to the passage of the scope or bander, pain in the lower chest due to banding and some degree of painful swallowing. Your child can be given painkillers such as paracetamol and can continue this at home, if needed.

2. **Bleeding:** There is a small risk of bleeding, particularly if endotherapy is performed. The medical team will take necessary precautions to reduce this risk. There may be a need for blood product transfusions before or after the procedure.
3. **Perforation:** In very rare cases, a perforation (tear) may occur in the digestive tract. Immediate medical attention is required if this happens.
4. **Difficulty in swallowing:** There may be difficulty in swallowing related to pain, the placement of bands that tends to bulge out the varices, spasm of the lower end of the food pipe or scarring due to injection of a sclerosant. This is usually temporary and soft diet is advised for a few days after the procedure.
5. **Need for emergency procedures:** In case of complications, there may be a need for emergency procedures or emergency surgery.
6. **Infection:** Although rare, there is a small risk of infection related to the procedure. Antibiotics will be considered.
7. **Migration of glue:** There is a very small chance that the glue may move from the injected blood vessel to the blood vessels in other parts of the body (lungs, brain). The effects of this will depend on where the glue moves to but can be serious. This is very rare.
8. **Adverse reactions:** There is a small possibility of allergic reactions to medications or anaesthesia used during the procedure.
9. **Life threatening complications:** While the OGD procedure and endotherapy techniques are generally safe, it is important for you to know that in very rare cases, serious complications can occur, including those that may pose a risk to life. The medical team will take all necessary precautions to minimize these risks and ensure the safety of your child throughout the procedure.
10. **Incomplete procedure:** In the process of reducing risk, the medical team may have to abandon a procedure if it is not safe to continue.
11. **Anaesthesia-related complications:** The anaesthetist will discuss the complications related to anaesthesia when they speak to you.

Are there any alternatives?

Another treatment for portal hypertension and preventing variceal bleeding is the use of a medication called a beta blocker. This medication, (such as propranolol or carvedilol), reduces your child's heart rate and blood pressure in the portal vein, which decreases the risk of variceal bleeding.

The decision to choose endotherapy and/or beta blockers as the treatment option depends on several factors, including the severity of your child's condition, individual patient characteristics, and the recommendation of the medical team. The benefits, risks, and alternatives will be discussed with you by the healthcare professionals involved in your child's care. A few children may require a combination of both endoscopic and medicinal management of their portal hypertension symptoms.

Consent

We must by law obtain your written consent to any procedures beforehand. Staff will explain all the risks, benefits and alternatives before they ask you to sign a consent form. If you are unsure about any aspect of the treatment proposed, please do not hesitate to ask to speak with a senior member of staff.

Who to contact?

Please discuss any questions or concerns with your medical team at each clinic visit. They will be able to provide specific information about your child's individual case and address any uncertainties you may have. They will help you make informed decisions about your child's healthcare. Our primary goal is to provide the best possible care and ensure the wellbeing of your child throughout the process.

If you have any queries or concerns when you are at home before or after the procedure, please contact the clinical nurse specialist and shared care team of the Paediatric Liver Service by calling 020 3299 3774 or emailing kch-tr.livercns@nhs.net

Additional information for children and young people with cystic fibrosis

Depending on your child's condition, it may be necessary or helpful to perform additional procedures under the same anaesthetic. Your team will discuss this with you.

If your child has cystic fibrosis

1. The cystic fibrosis team often requests the anaesthetist and the physiotherapist to take a sample of the airway secretions when the child has a tube to help them breathe during an operation (intubation). This helps them:
 - look for any infection bugs (organisms), as well as see the amount and type of secretions present, which may influence future treatment
 - clear the airways before extubation (removal of the breathing tube), to try and benefit the lungs as much as possible
2. Some saline is put down the breathing tube and the lungs are inflated with oxygen by the anaesthetist while the physiotherapy team use techniques on the chest to release the secretions. The sample is collected with a suction tube down the breathing tube and is sent to the laboratory for analysis. The physiotherapy takes an extra 10 to 20 minutes.
3. After any operation, patients may be sleepy and in some discomfort. This may mean that they are unable to effectively carry out their usual airway clearance techniques. This can slow down their recovery and cause delay to their discharge. In severe situations it may mean they require ongoing support with their breathing in the Paediatric Intensive Care Unit. The aim of the physiotherapy is to minimise the chance this happening and it may continue following surgery.

Sharing your information

King's College Hospital NHS Foundation Trust has partnered with Guy's and St Thomas' NHS Foundation Trust through the King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas' hospitals. King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts share an electronic patient record system, which means information about your health record can be accessed safely and securely by health and care staff at both Trusts. For more information visit www.kch.nhs.uk.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer Road – staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: 020 3299 3601

Email: kch-tr.palsdh@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Communications and Interpreting telephone line on 020 3299 4826 or email kch-tr.accessibility@nhs.net