The Christie
NHS Foundation Trust

Colorectal and peritoneal oncology centre (CPOC) department

Surgery for small bowel neuroendocrine tumours

Introduction

Small bowel neuroendocrine tumours (NETs) are rare bowel tumours. They start in the neuroendocrine cells of the small bowel. They often develop slowly and don't always have specific symptoms.

What are neuroendocrine cells?

Neuroendocrine cells are part of our neuroendocrine system. Neuroendocrine cells don't form an actual organ. Instead, they are scattered throughout other organs like the oesophagus, stomach, pancreas, intestines, and lungs. They make hormones which control how our bodies work.

The digestive system is large and has more neuroendocrine cells than any other part of the body.

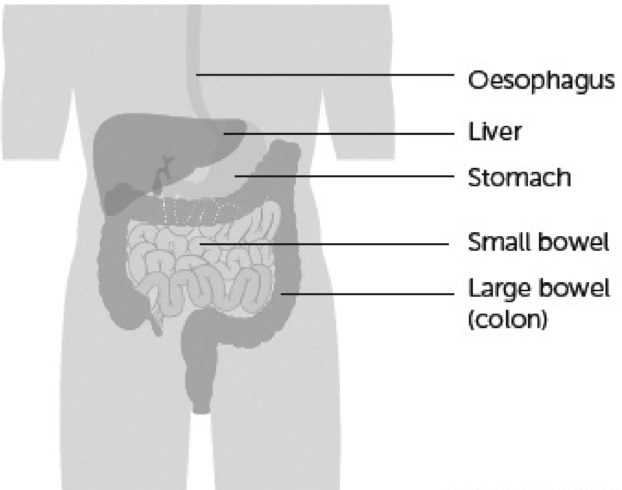
What is the small bowel?

The small bowel makes up most of the digestive tract. It is about 6 metres long, but it is folded up so that it fits inside the abdomen.

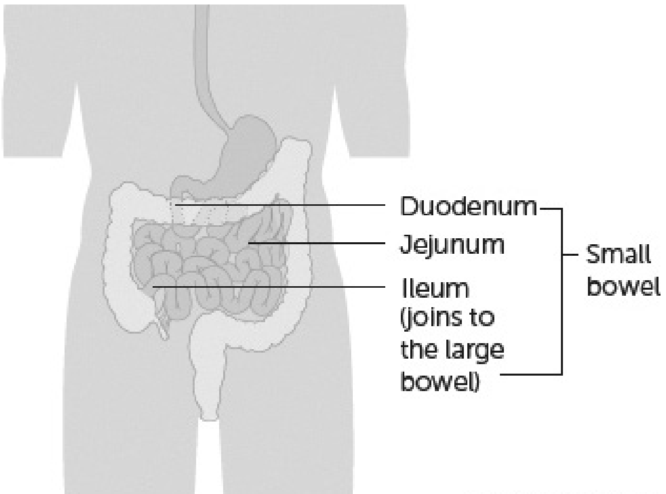
It has 3 sections:

- duodenum – the top part of the small bowel, which connects to the stomach
- jejunum – the middle part
- ileum – the lower part, which connects to the large bowel (colon)

Right at the end of the ileum, just before it joins to the colon, is a small pouch called the appendix.



Cancer Research UK



Cancer Research UK

How common are small bowel NETs?

Small bowel NETs are rare cancers and occur in 1:500,000 people.

What happens during the operation?

The type of surgery you have depends on the size of the tumour, where it is and whether it has spread to other parts of the body.

You might have surgery to remove all of the tumour(s) or surgery to only remove part of the tumour(s) called debulking surgery. It is likely you will have open surgery. This means having a large cut in your tummy (abdomen). During the operation, your surgeon might also remove the nearby lymph nodes.

Some people might have keyhole surgery. Keyhole surgery is also called laparoscopic surgery. Surgeons use a laparoscope to do it. This is a narrow telescope that lights and magnifies the inside of your body, which your surgeon can see on a TV screen. To do this type of surgery your surgeon makes a number of small cuts through your skin. They put the laparoscope and other small instruments through these to carry out the surgery.

Are there complications with this operation?

Risks of this operation are small and much less likely to affect you than the risk of doing nothing. However, this is a major operation and some people (1 in 200 people) do not survive the surgery. This risk is dependent on your other health issues.

There are sometimes complications. These may include:

- Bleeding
- Infection
- A leak from the anastomosis (the join where the bowel is connected back together)
- Injury to other organs within the abdomen (for example, the large intestine, ureter, or bladder)
- Deep vein thrombosis (blood clots in the veins in the legs)
- Pulmonary emboli (blood clots in the lungs)

Will I need to have a stoma (bowel bag)?

It is unlikely that you will need a stoma. However, sometimes it is not possible to join the bowel back together again, so the end of the bowel is brought out onto the abdomen (tummy) to form an opening outside the body, known as a stoma. A stoma bag is then fitted around this opening to collect your bowel contents.

The stoma may be permanent or temporary.

If you need a stoma or it is possible that you may need a stoma, you will be seen by a stoma nurse. These specialist nurses are skilled in caring for patients who have a stoma and will be able to answer any questions you may have.

Preparation for surgery

You will have investigations and tests to prepare you for your operation. These are to confirm the diagnosis, to see how far the disease has spread, and to assess how fit and well you are for the proposed treatment.

You will be asked to come along to a pre-operative assessment clinic where you will meet a nurse who will check you are medically prepared for your operation.

You will have a MRSA (Methicillin Resistant Staphylococcus Aureus) test before your admission to hospital. This involves taking a simple swab of your nose, throat and perineum (seat area). This is a routine procedure carried out on all patients who are admitted to The Christie for surgery. You can get more detailed information about MRSA from the infection control team, or ask one of the nurses.

We may ask you to have some pre-operative tests to assess your fitness prior to the surgery. This would include a breathing test (pulmonary function) and an echocardiogram (ultrasound scan of your heart). You may also be asked to have a cardio-pulmonary exercise test (CPX) where you will be asked to ride on a stationary bike while breathing into a face mask.

The Christie has an online surgery school which can help you get ready for surgery and will also provide information for post-surgery. You can find this on **www.christie.nhs.uk/surgeryschool**.

If you are particularly anxious about your surgery we have a complementary therapy team who you can be referred to for ‘hypno calm’ prior to the operation. Please ask your CNS if you would like a referral.

If you are a smoker, it would benefit you greatly to stop smoking or cut down before you have your operation. This could reduce the risk of chest problems as smoking makes your lungs sensitive to anaesthetic. If you need help/support in stopping smoking we have a smoking cessation team you can contact **0161 956 1215** or **07392 278408** or you can contact your GP.

Before you come into hospital for your operation, try to organise things ready for when you go home. If you have a freezer, stock it up with easy-to-prepare food. Arrange for relatives and friends to do your heavy work such as changing your bedding, vacuuming and gardening and to look after your children if necessary.

How long will I need to be in hospital?

You will stay in hospital for as little time as necessary, usually for between 7 and 14 days. Your surgeon or specialist nurse will discuss with you daily achievements which you should try to meet.

What should I expect after surgery?

Immediately after the operation (within the first 5 – 7 days), you will need:

- Admission to the oncology critical care unit (OCCU) for 24 to 48 hours
- Oxygen through a face mask
- A drip into a vein in one of your arms to give you fluid
- A catheter (tube) in your bladder to drain away urine
- Medication to deal with pain from the incision. This may be given as an epidural (where the medicine is given through a fine tube in your back) or through the drip.
- A tube in your nose to stop you from vomiting
- A drip into a vein in your neck to give you artificial feed (called TPN)

Later (the following day or so), you will need to:

- Move around as soon as possible with help from the nursing staff on the ward and the physiotherapy team

Visiting times

When in the OCCU it is open visiting but only 2 – 3 visitors are allowed at the bedside at one time. Once on the ward, visiting is 2:00pm – 8:00pm and meal times are protected (12:00pm – 1:00pm and 5:00 – 6:00pm).

Leaving hospital and coping at home

After you leave hospital, if you have any new concerns or problems (for example, severe abdominal pain, a raised temperature or bleeding) it is important to contact your own doctor (GP) or the hospital. You will be given contact numbers for your key worker (colorectal specialist nurse) when you leave hospital.

Recovery time after your operation varies from person to person. You may find it takes several weeks to feel better. You can expect a gradual improvement over the next 6 – 12 weeks.

Please follow these general advice points:

- You should not attempt to drive, lift or move heavy objects, do heavy housework (for example vacuuming, changing the beds) or start digging the garden until a minimum of 6 weeks following your operation.
- Getting back to work will depend on what type of job you do. Please ask if you are unsure. The ward should provide you with a sick note, please ask before you go home. Your GP can then supply you with further sick notes.
- Getting back to normal activities and exercise will depend on you. It is safe to gently increase your levels of physical activity providing it is comfortable to do so.

Follow up after surgery

Your clinical nurse specialist (CNS) will contact you once you are discharged home to check you are recovering well. We will then see you in The Christie outpatient clinic 4 – 6 weeks following your stay in hospital and you will then be reviewed at regular intervals.

Support

We know that people who have had a cancer diagnosis can be affected in a variety of ways. For some people there will be physical concerns while others may have emotional or spiritual needs. Practical and financial worries can come to the fore during cancer investigations and treatment and these can put significant strain on people. Most people want to be well informed and involved in decision making but people’s information needs vary too. Everyone is an individual and has their own concerns and needs.

Your CNS is there to support you throughout your journey and if you have any questions/concerns or would just like to go through things again please do contact them on the number provided below. If appropriate and with your consent, we can refer you to a trained counsellor. We have a counsellor and a consultant psycho-oncologist who specialise in problems relating to cancer. If you feel you may be helped by these services please talk to your CNS to discuss a referral.

We hold regular health and wellbeing events in the auditorium at The Christie to support patients with a cancer diagnosis. Please ask your CNS for the date of the next event.

Consent to treatment

The colorectal and peritoneal oncology team will discuss the treatment that is recommended for you and explain how it will affect you.

We will ask you to sign a consent form agreeing to accept the treatment that you are being offered. The basis of the agreement is that you have had The Christie’s written description of the proposed treatment and that you have been given an opportunity to discuss any concerns. You are entitled to request a second opinion from another doctor who specialises in treating this cancer. You can ask your own consultant or your GP to refer you.

Your consent may be withdrawn at any time before or during this treatment. Should you decide to withdraw your consent then a member of your treating team will discuss the possible consequences with you.

The colorectal and peritoneal oncology centre (CPOC)

The colorectal and peritoneal oncology centre has an international reputation for treating advanced and early colorectal cancer, appendix tumours, peritoneal tumours, anal cancer and tumours within the pelvis.

If you have a query regarding our service, please contact **0161 446 8051** or visit The Christie website **www.christie.nhs.uk/cpoc**

The service will provide:

- ongoing advice and support for patients, their partners and families
- information and advice about treatment and treatment options
- a point of contact should problems arise
- a link with other health care professionals involved in your care at home and in hospital
- referral to specialist services.

Who can contact us?

Any health care professional who needs information or advice and any patient coming for assessment or treatment can contact the service themselves. They can also be referred by another health care professional.

We are happy to speak to partners, friends and family, providing the patient has given consent.

If you know the name of your consultant, please contact their secretary directly.

Consultant	**Secretary**
Professor S T O'Dwyer	0161 918 2189
Mr M S Wilson	0161 446 3366
Professor A G Renehan	0161 918 2189
Mr C R Selvasekar	0161 918 2310
Mr O Aziz	0161 918 2057
Mr H W Clouston	0161 918 2391
Mr J Wild	0161 918 7352
Miss R Fish	0161 918 2391
Mr P Sutton	0161 918 2057

Clinical nurse specialists:

Rebecca Halstead (lead)
0161 918 7096 or 07766 780952 rebecca.halstead@nhs.net

Rachel Connolly
0161 918 7001 or 07785 725629 rachel.connolly2@nhs.net

Lisa Wardlow
0161 918 7183 or 07826 892213 lisa.wardlow@nhs.net

Amanda Coop
0161 918 2097 or 07824 373785 amanda.coop@nhs.net

Fax: 0161 918 7078

If your key worker is not available, please leave a message on the answering machine with your name, date of birth and telephone number. All messages will be responded to as quickly as possible, but this may not always be on the same day.

If you have any problems after your operation, please contact The surgical oncology ward on 0161 446 3860.

Further information

For information about the colorectal and peritoneal oncology centre visit **www.christie.nhs.uk/cpoc**

Christie information

The cancer information centre at The Christie in Withington stocks a wide range of booklets free to patients, their families and carers and offers a free confidential service for anyone affected by cancer. Contact: **0161 446 8100**.

Complementary therapy and smoking cessation

There is an outpatient drop-in service at The Christie on Tuesday and Thursday from 4pm. Contact directly by calling **0161 446 8236**. For smoking cessation telephone **0161 956 1215** or **07392 278408**.

Maggie's centre

The centre provides a full programme of practical and emotional support, including psychological support, benefits advice, nutrition and head care workshops, relaxation and stress management. Maggie's Manchester is directly across from The Christie on Kinnaird Road. Contact Maggie's on **0161 641 4848** or email **manchester@maggiescentres.org**

Macmillan Cancer Support

This is a national charity offering advice and support. Call the freephone helpline **0808 808 0000** (Monday to Friday, 9:00am to 8:00pm) or if you are hard of hearing, use the textphone **0808 808 0121**. Macmillan Cancer Support publish booklets which are free and available on their website **www.macmillan.org.uk**

Hospital chaplaincy

Situated in department 57, on the first floor above the dining room, and next to the education centre. We have a Christian chapel, a Muslim prayer room and a multi-faith quiet space. If you would like someone to visit you on the ward please ask a member of staff.

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard. If you would like to have details about the sources used please contact **the-christie.patient.information@nhs.net**

For information and advice visit the cancer information centres at Withington, Oldham or Salford. Opening times can vary, please check before making a special journey.

Contact The Christie Hotline for
urgent support and specialist advice

The Christie Hotline: 0161 446 3658

Open 24 hours a day, 7 days a week

January 2021 – Review January 2024
CHR/CPOC/1430/08.12.20 Version 1

The Christie Patient Information Service
Tel: 0161 446 3000   www.christie.nhs.uk