Other formats:

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team:

patient.information@addenbrookes.nhs.uk.

Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.
Welcome to the Addenbrooke’s Hospital small bowel and multi-organ transplant programme

This booklet has been designed for patients with small bowel/multi-organ disease who may be considered for transplantation. It provides information about the assessment process and the investigations that will be carried out.

There are many types of treatment for small bowel/multi-organ disease besides transplantation. However, a transplant may be the best choice for some people, when their disease is getting worse or they develop other complications such as liver cirrhosis related to parenteral nutrition (PN) or problems with vascular access.

Before a transplant can be considered you will need to be thoroughly assessed.

This information booklet is designed to give you some basic information on small bowel and multi-organ transplantation. You will probably have many questions about the transplant so please ask any members of the team and they will be happy to help you. You may want to write down any questions to ask us and space is provided for you to do this at the back of the booklet.

The small bowel transplant team at Addenbrooke’s Hospital is made up of gastroenterologists, transplant surgeons, specialist nurses, transplant co-ordinators and dieticians.

Please use this space for any questions you have
After the assessment

Following your period of assessment you will be discharged home or back to your referring hospital. At this point the doctors looking after you (gastroenterologists and surgeons) will collate all the information collected during your assessment. They will then present your case, locally and nationally, to a team of highly experienced doctors, including surgeons and anaesthetists, who will decide what is the most appropriate course of action for your particular case.

Once discussed locally there may be more tests and investigations that are required, you will be kept informed of all these developments by your coordinator. If your transplant team believes that you are a suitable candidate your assessment will be discussed at a national meeting called The National Adult Small Intestine Transplantation Forum (NASIT).

The transplant assessment

You will be admitted to Addenbrooke’s Hospital on ward M4 or G5 for approximately 14 days. You will undergo a number of tests and investigations that will help the medical team to decide if transplantation is the best option for you. It may be necessary to lengthen your hospital stay depending on the number of investigations you require and your general condition during admission, but we will endeavour to get you home as soon as possible.

For patients who are independent with PN we have the use of on-site patient accommodation which can be used instead of being admitted into the hospital for the assessment. The transplant nurse will discuss this option before assessment.

You will have the opportunity to meet the staff on the unit during your assessment. This is a good time to ask any questions that you may have about transplantation and your own particular disease process. We understand that it can be difficult asking questions or you may feel that you are not sure what questions to ask. The transplant specialist nurses will visit you during your stay, go through the process and discuss with you what to expect.

Contacting the small bowel transplant team

Small bowel transplant nurses
Direct line: 01223 34946. There is also an answerphone for messages and we will get back to you within 24hrs between Monday and Friday. Email: add-tr.sbtransplant@nhs.net

Ward M4
Is our Gastroenterology ward where you may be admitted for your transplant assessment. This can be reached via the Addenbrooke’s Hospital switchboard on 01223 245151 or direct line on 01223 256002.
Ward G5
The Transplant Unit is our transplant ward where you may be admitted for transplant assessment.

Nutrition nurses
Can be reached via the Addenbrooke’s Hospital switchboard on 01223 245151 or direct line 01223 216037.

Dietician
Can be contacted via the switchboard on 01223 245151.

A brief guide to the tests that you may be having during your stay and some important information to remember

Blood tests: there are rather a lot of blood tests that need to be taken during your stay as these enable us to have a good understanding of your current condition. We will try and do this as quickly and efficiently as possible.

Micro nutrient study: This is a blood test. Nil by mouth and no TPN for six hours before test

Urine samples: to assess your kidney function you will need to provide a sample of urine for routine testing and we may also need a urine collection over 24hrs. The nurse will give you a collection device for this.

MRSA screen: a swab will be taken from your nose, throat, groin and any other sites that may be susceptible to infection. This is a routine investigation for all patients coming into hospital, if the result is positive you will be informed and the correct treatment will be started.

X-Rays: these will be taken of your chest and abdomen.

Multivisceral transplantation
Multivisceral (multi organ) transplantation is offered to patients who have two or more failing intra-abdominal organs (including the intestines). The transplanted organs include the stomach, duodenum, pancreas, intestine, and liver. In patients with a healthy liver, the other organs are replaced and the liver is saved. The procedure is life-saving for patients with combined abdominal organ failure including those with pre-malignant conditions, such as Gardner’s syndrome, low-grade cancer of the gastrointestinal tract, pseudo-obstruction (abnormal motility of the gut), and those with thrombosed (clotted) veins of the intestine, liver, and spleen.

Modified multivisceral transplantation
This is where the abdominal organs for example stomach, duodenum, pancreas, intestine are transplanted without the liver.
Types of transplantation

Isolated intestine (small bowel) transplantation
Some people are born with or develop irreversible intestinal failure. They become unable to digest food well enough to eat or be fed through a tube, and as a result require intravenous permanent PN. The most common diseases are Crohn’s, blockage of the intestinal blood supply, and abdominal trauma. For these adults and children with the disease limited to the small bowel only, isolated intestine (small bowel) transplantation can be a lifesaving and life-enhancing option.

Ultrasound: this is a quick and painless scan performed to look at your liver, kidneys and central venous access. It will be performed in the radiology department, gel will be put on to your stomach and a probe will be passed over the skin.

Dopplers: this is a scan that looks at the blood flow around your liver and blood vessels in your abdomen.

Bone density test (DEXA): this is a scan to assess the mineral content and strength of your bones. You will be asked to lie on your back and keep still while an x-ray detector (the scanner) comes over the area to be tested. The scan is painless and takes 10-15 minutes. You do not need to do a special preparation for the scan.

CT scan: A CT scan is far more detailed than an ordinary x-rays. It is much more advanced and it is used for taking pictures of virtually any part of your body. A CT scan allows the doctor to inspect the inside of your body such as muscles, organs, large blood vessels, the brain and nerves without having to operate or do unpleasant examinations. It also detects abnormalities in the body such as tumours and abscesses. You may be asked not to eat or drink for few hours before the scan. Depending on what part of your body is being scanned, you may be asked to take a special drink with ‘contrast’ or have an infusion. This helps to give a better picture between organs and tissues on the scan.

Barium enema: this is a special x-ray study of the large bowel (colon and rectum). You will be given a special laxative to help clear your bowel. It is essential that your bowel be empty. Barium is used as a contrast medium to line the bowel and this shows up white on x-rays. During the examination, air can be put into the bowel to distend it, helping it to show up more clearly. Both the barium and the air need to be passed into the bowel through a small soft tube, which is inserted into the rectum (back passage).

Lung Function test: this involves you blowing into a machine which records the amount of air that your lungs can hold.
**Endoscopy:** please do not eat anything six hours before or drink anything four hours before this test. You will be taken to the endoscopy dept on level 3 for this procedure. A flexible camera is used to take pictures and very small samples from your stomach or bowel. You will be offered a short-acting sedation for this procedure if you wish.

**Echocardiogram:** often called an Echo is a test that uses ultrasound to produce an image of your heart. It is a safe and effective way to assess the structure and function of your heart chambers (ventricles and atria), your heart valves and great vessels (aorta and pulmonary artery). It will assess the speed of blood flow and the pumping capacity of your heart.

**Psychologist:** As well as a physical assessment, you will be assessed psychologically by a member of our team. It is important to be honest with the psychiatrist about your hopes and fears of transplantation and also about your coping mechanisms and the support networks that you have in friends and family. This will be critical to your post transplant recovery and life after transplantation as although you will hopefully no longer be requiring PN you will have other medical and personal needs that may be equally as demanding, particularly in the first year immediately post transplant.

**Gastric emptying study:** We will be looking at how your stomach works. **Nil by mouth six hours before. No smoking/caffeine for 24hrs.** Stop all medications that could affect gastric motility i.e loperamide.

**24hr urine collection:** You will be given a collection bottle on the ward.

**Stoma nurse review:** As part of the transplant surgery you will have a stoma formed. The specialist nurses for stoma care will visit you during your stay and discuss this with you in more detail. There are also good support groups for patients with stomas, please ask the specialist nurses for stoma care for more information.

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**If you are receiving parenteral nutrition**

If you are having PN at home, one of the Addenbrooke’s small bowel transplant specialist nurses will call your providing company and arrange for a delivery to be sent to your ward by the Wednesday of your first week, **therefore please bring the first three days’ supply of PN with you from home to the ward.**

On your arrival to the ward the nursing team will meet you and give you a guided tour to show you all the relevant areas that you need to be familiar with.

If you or your carer are happy to administer your PN during your admission, you are welcome to do so but if at any time you do not feel able, please feel free to ask one of the nurses to help you.

**Meeting the specialist dietician**

During your assessment our specialist dietician will come to see you and carry out a thorough examination of your nutritional status and ask you about your PN and dietary needs. Some of the blood tests results will also give us valuable information about your current nutritional status.

**Accommodation for your relative/carer**

Addenbrooke’s Hospital has a hostel in the grounds that is available for patients and their carers or relative. The hostel is free if the patients are staying with the carer/relative. There is subsidised accommodation available for the relative/carer of the patient. Please discuss this with the transplant co-ordinator if your carer/relative would like to use this service. It will need to be booked in advance and arrangements made for the key to be collected on the day of arrival.