

# Information for patients and families



Cambridge  
University Hospitals  
NHS Foundation Trust

Together  
Safe  
Kind  
Excellent

# Cambridge Centre for Intestinal Rehabilitation



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## Introduction

Being referred to a specialist centre and coming into hospital can be stressful. Fear of the unknown and loss of control can cause worry, especially when you are already working hard to manage your condition. We hope this leaflet will provide information about what to expect during your stay with us.

We want to make your stay with us as comfortable and stress free as we can possibly make it. Our staff work hard to provide care in line with our values

'Together – Safe, Kind and Excellent' and will always try their best to make sure your stay with us is positive, safe and helpful to you.

We will respect your privacy and dignity, and encourage you to be independent so that you can start your journey to better quality health.

Our unit is a specialist centre, so you may have to wait for a while until a bed becomes available. The waiting list is reviewed on a regular basis.

## What is Intestinal Failure?

Put simply, Intestinal Failure (IF) is when the intestine is unable to function properly. There are several diseases or injuries that prevent it working properly. People with Intestinal Failure may still be able to eat and drink, but cannot absorb enough water and nutrients from the food. Nutrients are the substances in food which keep us healthy. This means that they may become malnourished and dehydrated (not have enough nutrients and water in the body to keep healthy).

For some people, Intestinal Failure may be short term whilst waiting for surgery, but for others it may be life-long. This depends on individual health conditions.





## The team

The Intestinal Rehabilitation team has staff here to support you with Intestinal Failure. Some of the team members are shown in the picture.

Throughout your stay, and as part of your care after you leave hospital, you

will regularly see various members of the team.

Our main ward rounds are on Mondays and Thursdays. A consultant physician, consultant surgeon, specialist nurse, specialist dietitian, specialist pharmacist and Junior Doctors attend the ward rounds.

### Pictures of uniforms worn on the ward and staff roles



**Matron**  
Navy with pale green piping



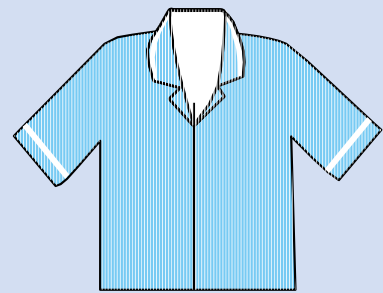
**Ward manager**  
Navy with white piping



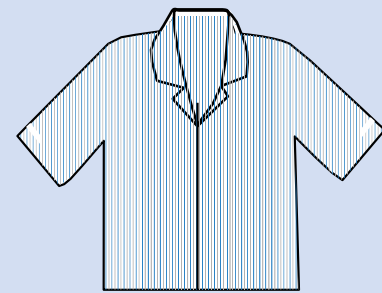
**Specialist nurse**  
Navy with red piping



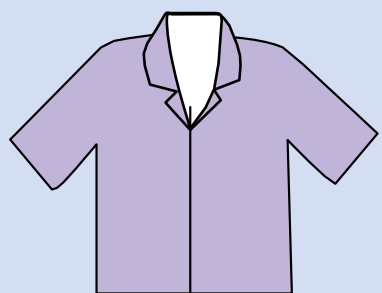
**Junior sister**  
Royal blue with white piping



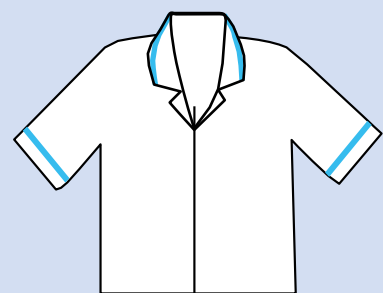
**Staff nurse**  
Blue and white stripes



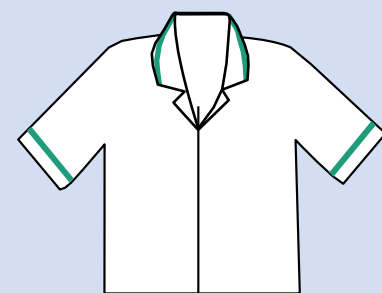
**Health care assistant**  
Grey and blue stripes



**Dietitian**  
Lilac



**Physiotherapist**  
White with pale blue piping



**Occupational therapist**  
White with green piping

## Your stay in hospital

The length of your stay will be discussed with you when you arrive. We expect patients to stay at Addenbrooke's Hospital for assessment and to set up any home artificial nutrition (artificial food, which is specially formulated to provide the right balance of fats, proteins, sugars, vitamins and minerals) you may require. We will keep you updated about when you can expect to go home (be discharged). Your expected date of discharge may change, depending on your health issues.

During your stay with us, part of your assessment may involve an assessment by our Intestinal Rehabilitation surgeons to provide guidance and input on further investigations and treatments.

You may be asked to move to a different location in the unit to allow us to provide the best care to all patients, and so that we can make sure that each patient is cared for safely.

Please try not to bring too many personal belongings with you when you come as this can pose an infection control risk and an issue with storage.

When you arrive on the unit, we will need to do some tests and start your treatment. Some examples of tests and treatments and information about them are given in the next section.

### Tests and investigations

#### Blood testing:

We will need to take blood tests daily to monitor your response to any medications or treatments we have started, and to check your electrolyte (salt) levels. This is especially important if we start parenteral nutrition (liquid nutrition delivered straight into your bloodstream).

#### Reviewing your line:

'Lines' are narrow, flexible tubes which are carefully placed into your body so

that medication and nutrition can be given through them.

If you are referred to our unit with a central line such as a PICC (peripherally inserted central catheter), tunnelled line (Hickman) or Port-a-Cath, we routinely check these to make sure they are safe to use. We will take blood samples from the inside of the line. We will also review the area where the line goes in to your body regularly, to ensure it is healthy. Depending on the line, we may organise an x-ray to check the line tip position.

If you do not have a central line, it is likely that we will arrange for a PICC line to be inserted in the Vascular Access Unit (VAU).

#### What is a PICC line?

A PICC (Peripherally Inserted Central Catheter) is a short-term line inserted into your arm. You may be discharged with this line if you need intravenous (IV) fluids or parenteral nutrition at home.

We may discuss changing this to a tunnelled (long-term) line in future.

If you would like more information on PICC lines please ask for a leaflet.

#### Diagnostic Investigations:

During your assessment we may arrange further investigations to understand your intestinal anatomy, or look for complications such as abdominal collections (areas containing pus) or fistulae (an abnormal connection between the bowel and the skin). The investigations might include x-rays, CT, ultrasound or MRI scans or endoscopic investigations (where a tiny camera is passed into your body on a long, thin, flexible tube). Any investigation and the reason for doing it will be discussed with you in detail before it is requested.

#### Fluid balance monitoring:

Keeping a record of what you are eating and drinking can help us make

sense of your outputs (urine and faeces – pee and poo).

We encourage you to keep a record of this and provide it to the nurses throughout the day so they can update your medical records for us to review.

Upon admission you will be provided with fluid charts. Ideally, we need you to record your intake and output three times a day: morning, middle of the day and evening.

Please note: as part of our assessments we may ask you to be ‘nil-by-mouth’ (nothing to eat or drink), or to reduce the amount you eat or drink, so we can monitor the effect on your output (urine and faeces).

### **Dietary review:**

You will be seen by one of our Intestinal Rehabilitation dietitians on admission, who will assess your current nutritional status (the condition of the body as a result of the intake, absorption and use of nutrition, as well as the influence of disease-related factors). This will include:

- Questions about your current weight and any recent losses or gains, including a desired weight if appropriate
- Taking some measurements on your arm to assess your muscle mass and function
- Discussion about your past/current oral intake including any recent dietary restrictions, followed by education if needed
- Explanation of the Addenbrooke’s Hospital catering system, with additional menus as needed
- Explanation of the role of parenteral nutrition (see below)

## **Treatment**

### **Parenteral (intravenous) Nutrition (PN):**

Parenteral (intravenous) Nutrition is nutrition in its simplest form – it is a liquid that contains all the nutrients you require to meet your nutritional needs (carbohydrates, fats, protein, electrolytes, vitamins and minerals). It is given through a line directly into your bloodstream.

Using this type of nutrition allows us to rest your gut and ensure you are adequately hydrated and nourished.

Having PN does not necessarily mean you cannot eat and drink, but as the amount you take can affect your bowel you may be asked to follow a particular fluid allowance and/or diet. Your dietitian and the rest of the specialist team will explain why and discuss this with you.

### **Enteral Nutrition (EN):**

Enteral Nutrition (EN) is nutrition administered through a tube either into the stomach or part of the small intestine. By doing this we aim to provide nutrition into your gut, bypassing any areas that may be causing problems.

Having a tube does not prevent you from eating or drinking but this will be discussed with you by your dietitian and specialist team.

### **Intravenous (IV) fluids:**

Not all patients require nutrition support (i.e. calories) but may need hydration support in the form of intravenous (IV) fluids. If you need additional fluids in this form, the team will discuss it with you.

### **Stoma care:**

If you have a surgically created opening from either your small or large bowel (a stoma) or a fistula, you will

be referred to the stoma care specialist nurses. They will assess your stoma or fistula and provide ongoing support, management, supplies and training to yourself, your carer and ward staff.

In the lead up to your discharge, the stoma nurses will make a plan with you and other members of the wider team, to ensure that you can be safely discharged and are confident with the care of your stoma/fistula. The stoma nurses will make sure that you are discharged with adequate supplies and know how to obtain more. They will contact your local stoma nurse if you don’t live in our area, and District Nurse if you need support to manage your fistula.

### **Review of medication:**

Your medications will be checked regularly by the Intestinal Rehabilitation team whilst you are in hospital to make sure you are on the most appropriate combination of medicines.

A member of the pharmacy team will see you on admission to discuss any regular medications you take at home. They will make sure these medications are continued in hospital where appropriate.

The ward pharmacist will regularly check the route of administration of your medications (e.g. administered directly into your blood stream/taken by mouth/through a feeding tube), the formulation (e.g. tablet or liquid) and the dose prescribed.

On discharge, the pharmacy team will make sure you are prescribed all the medications you need. The pharmacy team will send a discharge letter to your GP and make sure you leave with a 7-day supply of your medications.

If you have any questions about your medications whilst in hospital, please ask to speak to the ward pharmacist.

### **Physiotherapy / Occupational Therapy:**

We may refer you to physiotherapy or occupational therapy as part of your care so we can get you as fit and independent as possible, especially if you require an operation as part of your future treatment.

### **Psychology review:**

A clinical psychologist who specialises in Intestinal Failure and psychological medicine works with the team. The clinical psychologist works alongside the medical team and provides guidance on how best to support your needs.

You will be offered an initial appointment with the psychologist. This appointment might be during your stay or afterwards as an outpatient, depending on your circumstances. The initial appointment is an opportunity to share more about yourself and what you may be finding difficult in your life since developing an intestinal condition. This will help us to understand how best to support you.

Experiencing intestinal difficulties can have a considerable impact on you and your life. Some of the reasons it may be helpful for you to meet the clinical psychologists include:

- Feeling distressed or frustrated about your symptoms
- Viewing yourself or your body differently
- Struggling to come to terms with changes or losses
- Feeling stressed about your health or wider circumstances
- Losing interest or enjoyment in life
- Difficulties with your social life or relationships
- Feeling overwhelmed by your medical treatment or admission



You may also need support with wider issues, and the clinical psychologist will work with you to understand the nature of your difficulties and to agree a plan of how to address these.

The support offered usually involves attending a set of regular appointments or recommending local support, but this may not always be the case and we will discuss with you what might be the most suitable option for you.

Clinical psychologists provide talking therapies and are not able to prescribe medication. Clinical psychologists are registered with the Health Professions Council.

## Information about the hospital

### Smoking:

Cambridge University Hospitals do not allow smoking or vaping anywhere on site.

We would encourage you to give up smoking to aid your recovery. If you would like to give up smoking, please speak to your ward team, or contact your GP, the NHS Smoke free National Helpline on 0300 123 1044, or your local pharmacist.

### Menu:

If you are able to eat you will be given a menu each day which will give you a choice of meals. In the morning you will be able to select your lunchtime options and in the afternoon your evening meal.

There is a special dietary menu which aims to cater for all religious or cultural requirements. Please let a member of the team know as soon as possible upon your arrival if you would like this. The special dietary menu generally needs to be ordered a day in advance and the housekeepers will assist you with this, however on your day of arrival we will accommodate any special requirements as much as possible.

We aim to provide a relaxed atmosphere at mealtimes, so we have a policy of 'protected mealtimes' on our unit, when visitors are asked to leave. This means that you are able to have your meal in quiet, peaceful surroundings without interruption.

### Meal times:

Breakfast: Flexible  
Lunch: 12:00-14:00  
Evening meal: 17:00-18:00

### Visiting times:

Please ask the ward staff about the visiting arrangements when you arrive. Visiting arrangements might change due to Covid-19 safety measures.

Visitors can check our website, [www.cuh.nhs](http://www.cuh.nhs), for information about parking and charges, including discounts to frequent visiting.

### Wifi:

Wi-Fi is available for all patients and the public on wi-fi name: NHS Wi-Fi

### Hospedia, our bedside system:

All patients have access to Hospedia's easy to use bedside system. This gives access to telephone, films and internet.

Some of Hospedia's services are free, or payments can be made by cash or credit card. To pay with cash, you will need to purchase a Hospedia card from a vending machine in the hospital.

### Other hospital services:

The hospital offers cultural and religious services for those who wish to attend. Information can be obtained by asking a member of staff to contact the chaplaincy, who will come and see you on the unit or arrange for you to attend services or visit prayer room.

There are cash machines, newsagents, cafes/restaurants, a mini supermarket, a hairdresser and bank in the hospital.

## Advice on discharge

We aim to discharge patients early in the morning. We would kindly ask that you make your own arrangements for travel early as the hospital will only provide transport in special circumstances.

If you are to be discharged on artificial nutrition (PN or EN) or IV fluids, the dietitians and specialist nurses will spend time discussing this with you and providing training and materials if needed.

Following discharge you will be reviewed in the Nutrition Clinic after you are discharged. This appointment might be in person, or on video. If further surgical intervention is required you will be seen in a joint surgical clinic. For all appointments, we may ask that you have a blood sample taken beforehand (with your GP or at the hospital) for us to check.

It would be helpful if you could weigh yourself on the morning of the appointment as we will ask for your weight during the consultation.

## MyChart

We would encourage you to sign up for MyChart. This is the electronic patient portal at Cambridge University Hospitals which allows patients to securely access parts of their health record held within the hospitals' electronic patient record system (Epic).

If you are interested in this please let us know and we can provide information, or look on our website: [www.cuh.nhs.uk/visiting-our-hospitals/your-appointment/mychart/](http://www.cuh.nhs.uk/visiting-our-hospitals/your-appointment/mychart/)

## Patient feedback

Your comments, compliments, concerns and complaints will help us to improve the services we provide to our patients. We would like to hear your views so that we can make things better for you and other patients.

We will ask you to complete a survey prior to discharge from hospital using our iPads. If you would like to give feedback or raise any concerns before leaving the hospital, please do not hesitate to speak to your nurse, the nurse in charge or the ward's senior sister. You can also contact the Patient Advice and Liaison Service (PALS) and complaints department at the hospital - phone 01223 216756 or email [pals@addenbrookes.nhs.uk](mailto:pals@addenbrookes.nhs.uk).

If you feel that someone, or a team, has really made a difference to your stay or care, you can nominate them for an award. You can fill in the nomination form on the Cambridge University Hospitals website - [www.cuh.nhs.uk/contact-us/you-made-difference-awards/](http://www.cuh.nhs.uk/contact-us/you-made-difference-awards/) or ask a staff member for a leaflet about the 'You Made a Difference' award.

## Other formats

Help accessing this information in other formats is available. To find out more about the services we provide, please visit our patient information help page (see link below) or telephone 01223 256998. [www.cuh.nhs.uk/contact-us/accessible-information/](http://www.cuh.nhs.uk/contact-us/accessible-information/)

This information is also available on our website with accessibility tools available for it to be translated into audio or written formats in other languages or in a bigger print size: [www.cuh.nhs.uk/our-services/nutrition-and-dietetics/nutrition-and-intestinal-failure/](http://www.cuh.nhs.uk/our-services/nutrition-and-dietetics/nutrition-and-intestinal-failure/)



