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.

Department of Gastroenterology
Patient Information
Waiting for your transplant

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If you are listed for a small bowel or multi visceral transplant

Once everyone is happy that you are a suitable candidate and that you are ready to be listed on the national organ register, your coordinator will call you. Your details will be held on a national data base ready for you to be matched with a suitable donor.

Once you are listed you must be prepared for a call at any time of the day or night by your coordinator or a member of their team. It is wise to have a bag packed ready with toiletries and other personal items that you might want whilst in hospital.

If you do wish to be temporarily removed from the list for a holiday or other personal reasons, you must inform your coordinator immediately. Patients are sometimes removed from the list due to infection or illness; this will be explained to you and the reason for it. Hopefully you will be relisted as soon as possible.

Any break in compliance, i.e. taking illicit drugs, not coming to appointments, not taking medications correctly or going against medical advice could put your place on the transplant list at risk.

You may have to wait for over 12 hours before finding out if it is possible for the transplant to go ahead. Once the retrieving surgeons have seen the organs at the donor hospital and decided whether they are suitable for transplant, they will let the recipient transplant coordinator or the transplant ward know if the transplant is going ahead or if it is cancelled and you should be sent home. This is often called a false alarm and unfortunately may happen more than once before you are transplanted.

Donors

Organ donors are people who have voluntarily signed up to the organ donor register and have stated that they would wish for their organs to be used for transplantation in the event of their death.

Donors for small bowel and multi visceral transplants are called “heart beating” or “brain stem dead”, this means that they have been declared dead in a hospital while attached to a ventilator (artificial breathing machine) and have no chance of recovery. Consent is given by the next of kin for organ removal and transplantation.

You will know minimal details of your donor but after your transplant you may like to write a thank you letter to the donor’s family telling a little bit about yourself and how the transplant has improved your life. This letter will be passed on to your donor’s family by the coordinator.
If you are called for transplantation

You will be called by a transplant coordinator when suitable organs become available. This can happen at any time of the day or night, so you must always be contactable on the phone number that you have given your coordinator. If needed, your coordinator will arrange for you to be transported to the hospital where the transplant ward team will be expecting you.

Once at the hospital you will have bloods taken, an ECG of your heart and maybe some other test to get you prepared for theatre. The surgeon and an anaesthetist will come and see you on the ward and explain to you that although suitable organs have been identified there are some final tests that are necessary to do before they are absolutely sure that they are the correct organs for you.

Because timing is very important you will be prepared for theatre and may well be taken to the operating department to wait for the final confirmation that your transplant is going to take place. We do understand that this is a very anxious time for both you and your family and we will try and keep you as fully informed as possible. One relative will be allowed to wait with you at this time. The average time taken for a small bowel transplant is approximately 12 hours. During this time your relative can wait for you in the ITU (intensive care unit) relative’s room and if at all possible a member of the team will give them a progress report.

Whilst listed you will be expected to:

Give three monthly blood samples for tissue typing lab
It is essential that we receive these samples three monthly, you can have the blood taken at your GP or local clinic and we will provide boxes for you to send them back to us in. Failure to comply with this may result in you being suspended from the waiting list until we receive the sample.

Attend regular local clinic or joint clinic appointments
This is required to check your progress whilst listed. Although you will be under the care of the Addenbrooke’s transplant team we work very closely with your referring hospital and these will continue to be your lead clinicians. We work very closely together and seeing them on a regular basis prevents so many trips to Addenbrookes.

Blood tests
It will be necessary to have your blood tested monthly to ensure you remain well enough for transplantation, this can be done at your GP surgery or local hospital. This will be your responsibility to arrange but the transplant team will be happy to assist and will monitor your blood results.

Inform your coordinator of any illnesses or admissions to hospital
The team needs to be able to contact you 24 hours a day in case an organ offer is made for you, therefore please ensure that we always have an up to date address and telephone number. It is essential that you inform your coordinator of any line infections, line changes or blood transfusions.