


Oxford Intestinal Transplant Programme

Your Intestinal Transplant

Patient Information Booklet No. 1

Pre-Transplant



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Contact numbers

The Oxford Transplant Centre

Churchill Hospital
Old Road
Headington
Oxford OX3 7LJ

Tel: 01865 225355/56
Fax: 01865 225616

Churchill Hospital Switchboard

01865 741841

Jonathan Smith

Intestinal Recipient Transplant Coordinator
Jonathan.smith@orh.nhs.uk

Tel: 01865 225478

Mob: 07879 416148

Shirley Lockhart

Transplant Nurse Specialist
E-mail: Shirley.lockhart@orh.nhs.uk
Tel: 01865 857118

June Beharry

Dietitian

01865 221703 or 01865 741166 and ask for bleep 1752

Transplant dieticians

01865 225061

Churchill Hospital Stoma Nurse

Tel: 01865 235367

Transplant Ward

01865 226122

Renal and Transplant Outpatients (Appointments)

01865 225355 or 01865 225356 or 01865 225793

Transplant Pharmacy

01865 226095

Welcome to the Oxford Intestinal Transplant Programme

This information booklet is designed to give you some basic information on Intestinal Transplant. You will probably have many questions about transplant, so please ask any members of the Oxford team and they will be happy to help. It is a good idea to write down any questions you may have. At the end of the booklet there is a section to do this and to make notes if you would like to.

Important points to remember

Change of circumstances

Once you have been put onto the transplant waiting list, please tell your Transplant Coordinator (01865 225478) of any change in your circumstances, such as holidays, change of address, telephone number and if you are admitted to a hospital.

Blood transfusions

Once you are active on the transplant list it is very important that you tell us of any blood transfusions that you receive. We will ask you to send us monthly blood samples to check for antibodies that you may have acquired from any blood transfusion that you may have had.

Monthly blood tests

These are essential for all patients. It is up to you to send your blood samples to the tissue type lab. We will tell you when you have been listed and the tissue typist will send you a pack with blood bottles for you to fill. You can normally do this at your GP practice. They need to be sent to the hospital in the envelopes provided by first class post. Please send them on a Monday, Tuesday, Wednesday or Thursday.

24 hour availability

Please do not have answer machines on, especially at night, as we may be trying to call you for a transplant and we will not leave a message. We cannot give you a pager. Please make sure that mobile phones are on, and that you have given us all the phone numbers where you might be at any time. Unfortunately the Transplant Co-ordinator has a limited amount of time in which to call in a patient for their transplant. If we cannot get hold of you we will call the next suitable person on the list.

Change of mind

If you decide a transplant is not for you please let us know so we can take you off the waiting list.

Intestinal transplant evaluation

Step 1: Referral

Some patients with bowel or multi organ disease may be considered for an intestinal transplant and your consultant has recommended that this may be appropriate for you. Careful assessment now needs to take place to see if intestinal transplant is the best choice for you and your disease. The first step of this assessment will be an appointment with an Oxford Transplant Surgeon, either here at Oxford or at the hospital that has referred you. At this appointment the Transplant Surgeon and you will decide if it appropriate for you to come to Oxford for Intestinal Transplant Assessment.

Step 2: Communication

Your Recipient Transplant Coordinator is a nurse who specializes in transplant and works directly with the transplant surgeons. She/he will be the liaison between the doctors and you! Your Transplant Coordinator will call you to arrange convenient dates for you to return to Oxford for evaluation. Once the dates are agreed upon, the tests/appointments are immediately scheduled. Please remember that it is extremely difficult to reschedule tests once they have been arranged. An itinerary will be posted to your home address if there is time to do so before you come to Oxford.

Step 3: Evaluation

Evaluation is either done as an inpatient or outpatient depending on how well you are and whether we have accommodation available for you. Evaluation involves approximately 5-8 days of testing (or more). We will typically ask for a week of your time to schedule as many tests as possible. Sometimes the days are consecutive but not always – it depends on the availability of departments and the physicians.

A routine intestinal transplant assessment consists of:

1. Blood tests (includes tests for HIV and hepatitis)
2. Diagnostic imaging: Chest X-ray, CT of the abdomen, an ultrasound of arms and legs (to look at your veins) and an ultrasound of your liver
3. Heart testing – which will involve an appointment with a cardiologist (heart specialist), a myocardial perfusion scan, echocardiogram and ECG
4. A lung function test
5. Sigmoidoscopy or colonoscopy (examinations of your bowel)
6. Dental evaluation (usually done by your local dentist)
7. Cervical smear test for all adult females (should be done by your GP).

You will also meet with several people:

- Psychologist
- Gastroenterologist
- Dietitian
- Transplant Nurse Specialist
- Pharmacist
- Anaesthetist
- Consultant Transplant Surgeon
- Transplant Coordinator

The precise tests and people you will meet are adjusted to your individual needs. You may need to have more tests or see other specialists, depending on your past medical history or the results of your evaluation tests.

Step 4: Meeting of the multi-disciplinary team

After evaluation is complete and both the Consultant Transplant Surgeon and you agree that intestinal transplant is the best choice of treatment for you, your case is discussed by the

multi-disciplinary team. The team consists of the transplant surgeons, nurses, gastroenterologists, pharmacists, dieticians and psychologists. A decision is then made about whether you will be confirmed acceptable for transplant.

Step 5: Notification of results

Your Recipient Transplant Coordinator will call you once a decision has been made about your tests. Keep in mind that the multi-disciplinary team may make further recommendations and may need you to undergo more testing.

Remember: Your referring doctor is still in charge of your intestinal related medical needs until you are transplanted. You must have a GP to handle all your non-transplanted related medical issues. You may contact the Transplant Centre and ask your Coordinator about any transplant-related questions.

If you become a candidate for transplant, you will be listed on the United Kingdom Transplant waiting list. Your Transplant Coordinator will be in regular contact with you and explain very carefully what happens when you go on this waiting list. You will then receive a packet in the mail, which contains basic information on being listed and how to send us the blood samples that are required every month while you are on the transplant waiting list.

Please telephone your Recipient Transplant Coordinator at the number listed below if you have any questions about the transplant process:

Recipient Transplant Coordinator: Oxford (01865) 225478

While you are waiting on the list

- Continue to see your GP and your referring specialist routinely: we may want some tests updated on a yearly basis. Your Transplant Coordinator will let your doctors know if this is the case and explain whether they need to be done at Oxford or closer to your home.
- Send in your monthly blood tests to the Oxford Transplant Centre.
- Continue to see your local doctors who take care of your other illnesses (i.e. general practitioner and other specialists).
- Update your Transplant Coordinator on new medications, hospital admissions, procedures, etc. arranged by your other doctors.
- Update your Transplant Coordinator on any changes in address, phone numbers and carers.
- Any break in compliance (i.e. taking illicit drugs, not coming to appointments, not taking medications correctly, going against medical advice) will jeopardize (put at risk) your place on the transplant list.

When you get “the call”

There are Recipient Transplant Coordinators working around the clock to help with your transplant. When you get the call that an organ is available, the Recipient Transplant Coordinator (it may be someone you have never spoken to) will tell you exactly what to do. The Coordinator will ask you some questions, let you know what to bring to the hospital, and where to report, and what time you need to be here. **Please remember you can be called at anytime day or night.**

Once you get to the hospital, the hospital staff will start getting you prepared for surgery. This preparation includes blood tests, starting an intravenous line (a narrow tube going into your vein), a chest X-ray and an ECG of your heart. We will also ask you to read and sign a consent form for the transplant surgery.

You may have to wait for over 12 hours before finding out if the transplant can go ahead. Once the surgeons have seen the organs at the donor hospital, they will let the Recipient Transplant Coordinator know if the surgery is going ahead or if we should send you home – (this is often called a dry run or false alarm).

Dry runs or false alarms can happen frequently. Because we are working against time, everything needs to happen very quickly. This is why you are called in before the surgeons have seen the new organs. We do not know if the organ we accept for you is good enough until the surgeons have actually seen it. Do not be surprised if you are sent home without a transplant. Unfortunately this can happen more than once before getting your transplant.

Please note that under no circumstances should the specific donor information be discussed with the medical staff and/or you. This is to protect the privacy of the donor family.

The transplant operation

How long does the transplant operation take?

On average, the actual surgery lasts 8-10 hours. If your operation is longer, this is not an indication that the surgery is going poorly. Each case will be different.

What happens immediately after the operation?

You will recover in the Intensive Care Unit. The average length of stay is 4-5 days but you may need to stay longer – it depends on how quickly you recover after the surgery. You will have a variety of intravenous access lines (narrow tubes going into your veins) connected to medications, fluids, monitoring equipment, etc. The cut on your abdomen will either resemble large “I” or a large upside down letter “Y”. The wound will be stitched and there may be a wound drain in place to remove excess fluid.

What are the risks?

As with any other operation, there is always a risk of complications and rarely, even death. The surgery is fairly new at Oxford, but the consultant surgeons have had experience with this type of transplant in other hospitals

Unfortunately complications cannot be predicted and can occur at any time.

Complications include (but are not limited to):

- Acute kidney failure (due to new medications)
- Breathing difficulties
- Heart abnormalities
- Infection
- Rejection of new organ
- Blood clots

Recovery and discharge from hospital

After your stay in Intensive Care, you will be transferred to the Transplant ward. The nurses on this ward work specifically with transplant patients and are very familiar with the transplant related medications and care that you need.

As soon as you get to the ward the healthcare staff will start to prepare you for your discharge home. Because you are recovering, it will be important that your relatives are involved in this process. Doctors, nurses, pharmacists, dieticians and your Recipient Transplant Coordinator will all be involved in your hospital care and teach you how to look after your new intestine.

The average hospital length of stay is 4-6 weeks. After being discharged from the ward, if you live a long way from Oxford, you will be expected to stay in our hospital flat for another 6-8 weeks. This is so we can monitor you very carefully and give you treatment quickly if you any problems with your new organs.

Education and your new organs:

Knowing all about your medications, specifically your anti-rejection medication and what they do, is very important to the survival of your new intestine. The transplant pharmacist will give you lots of information on all of your medications. Your Transplant Coordinator and the ward nurses will also give you lots of information to prepare you for discharge from the hospital.

After your discharge from the hospital

Because of your new organs, the surgeons and Transplant Coordinator will monitor you very closely. You will be asked to come to the outpatient clinic at least twice weekly and blood tests may be more frequent than that.

We will also continue to monitor you using the zoom scope for ileoscopy – this may be as often as twice a week in the early months after your transplant. This will continue for four to six months or longer, depending on how well you recover after the surgery and whether you have any relapses. After your scopes are progressing well and there is no rejection or infection, you will have a colonoscopy. We will then arrange for your ileostomy to be closed if this appropriate in your specific case.

Eventually you will have blood tests every couple of months and see your transplant surgeon once a year, unless your condition warrants more frequent monitoring. You should continue to see your General Practitioner for any medical problems not related to your transplant.

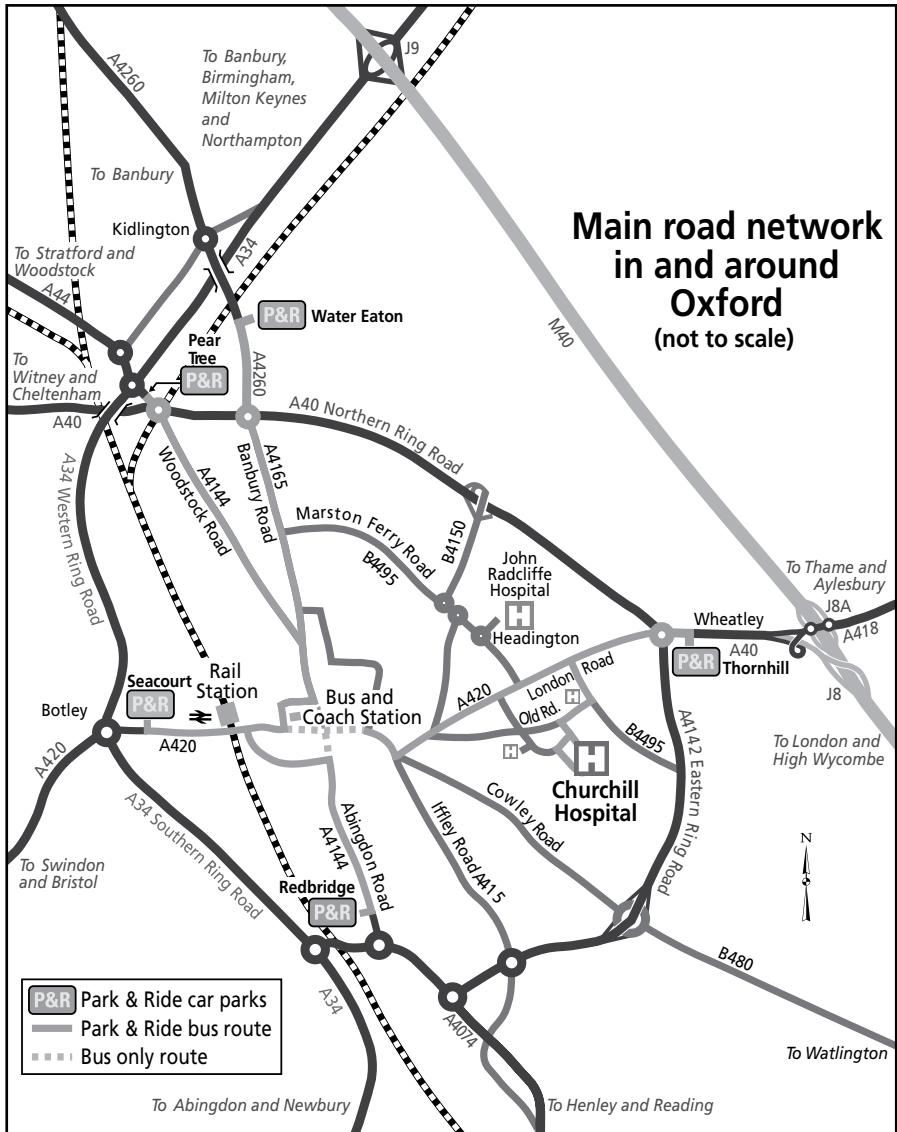
Things to remember

- Give your pharmacist at least 10 days notice for prescription refills. If you live outside the Oxford area this will vary according to local practice. It is good to check on this as soon as you get home as you **do not want to run out**.
- Post-transplant patients are at higher risk of infection due to anti-rejection medications. Immediately after your transplant please avoid crowded areas (i.e. restaurants, shopping centres, parties, etc) for 3 months.
- Cancer is more common after your transplant because of the medications you are taking. To prevent skin cancers use a SPF 50 + sunscreen and suitable clothing.

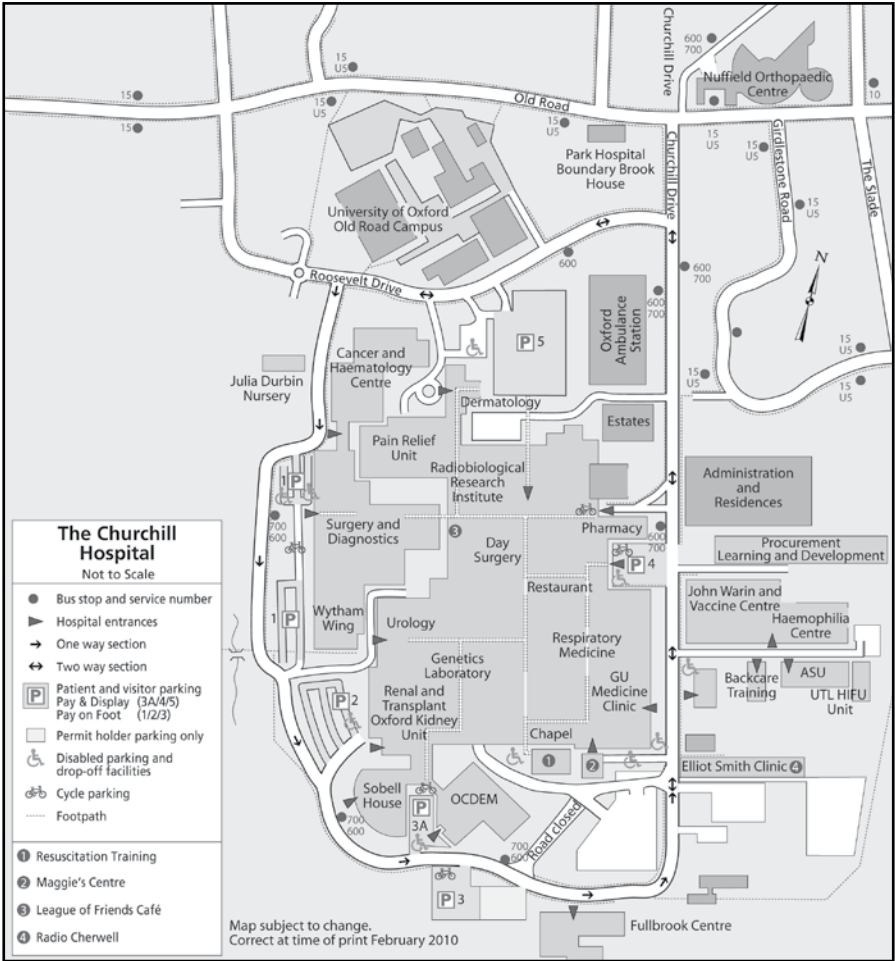
- Kidney problems may occur after transplant because of the prescribed medications. If this happens the doctors will adjust your medication to prevent this happening.
- **Compliance is key!** Take your medications as instructed and never miss a dose.
- We strongly recommend that you abstain from taking alcohol or illicit drugs, and from smoking tobacco and marijuana.
- Your post-transplant medical management includes: adjustment of your anti-rejections pills, diagnostic tests to assess any infection, rejection or blockages in the bile duct, and continuous follow-up
- Pain is common in the first 4-6 weeks after the transplant operation. Pain medication will be given to you as you need it.
- Transplant is performed to improve your life, not disable you. There are cases where complications are severe, limiting the patient's ability to carry out normal daily activities. Our expectation is that you will return to the normal life that you had before your chronic illness: working, enjoying hobbies, and independent living.

Please remember to contact your Transplant Coordinator for any questions that you may have.

How to Find the Churchill Hospital



Hospital Map



If you need an interpreter or need a document in another language, large print, Braille or audio version, please call **01865 221473** or email **PALSJR@orh.nhs.uk**

Jonathan Smith, Recipient Transplant Coordinator
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Oxford Radcliffe Hospitals NHS Trust
Oxford OX3 9DU
www.oxfordradcliffe.nhs.uk