

# Intestinal Transplantation



## **OVERVIEW**

This information booklet is designed to give you information on intestinal transplantation. You will probably have many questions, please ask any member of the Oxford team and they will be happy to help. The Oxford team include:

Mr Anil Vaidya – Surgeon

Professor Peter Friend – Surgeon

Mr Srikanth Reddy – Surgeon

Lydia Holdaway – Advanced Nurse Practitioner in Intestinal Transplant

Marion O'Connor – Specialist Dietitian in Intestinal Failure / Transplant

Interest in intestinal transplantation as a treatment for those with intestinal failure began in the 1960's and since then has been continually developing and improving.

In Oxford we have been performing intestinal transplants since 2008.

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.

## **CONTACT INFORMATION**

### **The Oxford Transplant Centre**

Churchill Hospital  
Old Road  
Headington  
Oxford OX3 7LE  
Tel: 01865 225 355/56

### **Churchill Hospital Switchboard**

01865 741 841

### **Lydia Holdaway**

Intestinal Recipient Transplant Coordinator  
Lydia.holdaway@ouh.nhs.uk  
Tel: 01865 226 075

### **Marion O'Connor**

Dietitian  
01865 221 703 or 01865 741 166 and ask for bleep 1702

### **Transplant Ward – Wytham Ward**

01865 235010

### **Renal and Transplant Outpatients (Appointments)**

01865 225 355 or 01865 225 356 or 01865 225 793

### **Transplant Pharmacy**

01865 226 095

### **Transplant Nurse Practitioners**

01865 225 375

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## **SECTION 1**

### **THE INTESTINE AND TRANSPLANTATION**

#### **What is the intestine and what does it do?**

The intestinal tract is part of the digestive tract, which breaks down food into small pieces. The body absorbs these pieces to create energy. The digestive tract is a hollow tube and is divided into several parts. Each part has a special purpose:

- The oesophagus – This is the tube that moves food from the mouth into the stomach.
- The stomach – Mainly stores food before it enters the small intestine.
- The small intestine – This is where most food is broken down and absorbed into the body.
- The large intestine (or colon) – This is where water is absorbed from the digested food and forms solid stools.

The small intestine is about 7-8 feet long in new-born infants and grows to about 20 feet by adulthood. The small intestine is made up of three parts:

- The first part is the duodenum, which is about 12 inches long in adults. It is connected to the stomach. Pancreatic and liver fluids drain into the duodenum.
- The middle of the small intestine is the jejunum, which makes up about half of the small intestine. The jejunum is responsible for absorbing carbohydrates, proteins, vitamins and minerals; these are all taken into the blood stream from the jejunum.
- The lower small intestine is called the ileum. The ileum is between 2-4 meters long. It is responsible for absorbing anything the body needs which the jejunum has not already absorbed.

#### **What happens when it fails?**

The small intestine is the most important part of the digestive system. Most people can live without a stomach or a large intestine, but it is harder to live without a small intestine. Intestinal failure can develop when a person's small intestine does not provide the necessary long term nutrition needed to sustain a normal life. This leads to the need for additional long term nutrition to be delivered through large veins in the body. This is called "Total Parenteral Nutrition" or TPN.

#### **Causes of intestinal failure:**

There are two types of intestinal failure:

1. The small intestine may be too short to digest food correctly. This is called "short gut syndrome".

2. The small intestine or other parts of the digestive tract are not working correctly. This may be called a “motility disorder”.

### **What is transplantation?**

Transplantation is a surgery to put a donated organ from someone who has either died or offered their organ as a living donor, into a person who needs it. Currently we do not perform living related transplants for intestines. A part of the small intestine can be transplanted into a person. If needed, other organs, such as a stomach or pancreas, can be transplanted at the same time.

### **Does everyone with intestinal failure get a transplant?**

No. In some people, potential problems of transplantation may outweigh the benefits. Problems may occur if:

- The patient is not strong enough to withstand the surgery because of other serious illness.
- In some patients (particularly those with tumours) it may not be technically possible to carry out the operation.
- The patient may have serious infections at the time of surgery.

Because of these potential problems, each patient is checked by the medical team at the transplant centre to determine if a transplant would be the right treatment for them.

## **SECTION 2**

### **ASSESSMENT FOR TRANSPLANTATION**

#### **How will I know if I can have an intestinal transplant?**

Some patients with intestinal or multi organ disease may be considered for an intestinal transplant and your consultant thinks this might be appropriate for you. You will now need to be carefully assessed 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 at Oxford or at the hospital that has referred you. The purpose of this first appointment is to decide if it is appropriate for you to come to Oxford for a full clinical assessment.

#### **Who will organize my assessment?**

Your Recipient Transplant Coordinator is a nurse who specializes in transplant and works directly with the transplant surgeons. She/he will be the link between the doctors and you. Your Transplant Coordinator will contact you to arrange convenient dates for you to return to Oxford for your assessment.

Once a date is agreed, the tests and investigations are immediately arranged. The tests and investigations are to check you are fit and well enough to go through the surgery and that a transplant is the right option for you. 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.

#### **What does my assessment involve?**

You may need to be admitted to the transplant ward in Oxford for your assessment. However, if you are well enough and we have accommodation available, this can be done as an outpatient. The tests and investigations will take place over 7-14 days. It is likely you will be asked to be free for a two week period to fit in as many tests as possible. We try to arrange all the tests close together but this is not always achievable.

The intestinal transplant assessment usually consists of:

1. Blood tests (includes tests for HIV and hepatitis)
2. Diagnostic imaging: Chest X-ray, CT scan 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 – about which you will receive a more detailed letter, and an echocardiogram (an ultrasound of your heart - 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:

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

The actual tests you have and people you will meet depends on your own needs. You may need to have more tests or see other specialists, depending on your past medical history or the results of your tests. You will also be shown around the ward and the intensive care unit so you will be familiar with these if you have a transplant.

#### **Can I ask questions at my assessment?**

Yes. All of the specialists you meet will tell you a lot of information about transplantation and what is involved but you should also ask any questions you may have. It might help to write down any questions you want to ask and bring them with you. You may find it useful to bring along a friend or relative for support and to discuss any questions you may have.

You can contact your Transplant Co-ordinator on:

01865 226 075, Monday – Friday 0800-1600

There is an answer phone available at all other times. Please feel free to leave a message and your Transplant Coordinator will get back to you as soon as possible.

You may also like to speak to someone who has already had an intestinal transplant. This can be arranged through your Transplant Coordinator.

#### **How do I get on the transplant waiting list?**

After the assessment is complete, your case is discussed by the multi-disciplinary team, both locally and nationally. The team consists of transplant surgeons, nurses, gastroenterologists, anaesthetists, pharmacists, dietitians and psychiatrists. The team will decide if a transplant is suitable for you. The Oxford multi-disciplinary team meet monthly and the national meeting occurs every other month. Your case must be approved at both meetings before you are put on to the waiting list.

Your Recipient Transplant Coordinator will contact you when the decision has been made. Keep in mind that the multi-disciplinary team may suggest you need more tests before a decision is made.

If it is agreed you are suitable for a transplant, you will be put on the United Kingdom transplant waiting list. Your Transplant Coordinator will contact you to arrange for you to sign a 'consent' form to show that you agree to go on the waiting list.

## **SECTION 3**

### **THE WAITING LIST**

#### **How do I know if I am on the waiting list?**

It takes about a week after signing the consent form to become 'active' on the list. Your Transplant Coordinator will let you know when this has happened. When possible your Transplant Coordinator will call you the day you become active. Being active on the national transplant waiting list means that you could receive an offer of a transplant at any time day or night.

#### **Why do I need to sign a consent form?**

UK Transplant is the organisational body for all transplants in the UK. They hold all the waiting lists and organise the allocation of organs in the UK. They must ask your permission to use your personal information on the waiting list. The consent form lets them know you are happy for them to use your personal information and put your name on the waiting list. They do not use your personal information for anything else.

#### **What should I do whilst waiting for my transplant?**

Carry on as normal but make sure you stay as healthy as you can. Do:

- Take regular exercise as this will help maintain your fitness
- If you smoke it is very important to stop.
- Let your doctor or Transplant Coordinator know if you become unwell, are admitted to hospital or have any changes in your health or medication. You may need to be put on hold from the list if you become unwell, as you might not be well enough to have the surgery. This is called being 'temporarily suspended' from the list.
- Inform your Transplant Coordinator if you travel abroad or are going to be out of contact. Again this will mean you may need to be temporarily suspended from the waiting list.
- Do not forget to inform your Transplant Coordinator when your health improves or you return from holiday so you can be reactivated on the list.
- Send in a monthly sample of blood. This enables us to closely monitor your antibody status, which allows us to match organs to you. We will write to you once you are active on the waiting list and send you the blood bottles and envelopes you require to do this. You will need to arrange your blood tests with the nurse at your GP surgery and then post the samples in the envelopes provided.

**What if I move or change my phone number?**

It is very important that we always have an up to date contact number and home address for you. Transplant calls can come at any time of the day or night and if we are unable to contact you then we would have to offer the organ to somebody else. Make sure your phone is switched on, volume turned up and in working order, especially overnight.

**How long will I wait for an intestine?**

Once you are on the transplant waiting list there will be a period of waiting for a suitable organ to become available. Organs are matched to your blood group and your tissue type. Your tissue type can be affected by the number of antibodies you have. You can develop antibodies through various means; blood transfusions, pregnancies and infections. If you have a high level of antibodies the wait for a matching organ may be increased. If you do not have any antibodies you may receive an offer of an organ relatively quickly i.e. months rather than years. We will discuss your tissue type and antibodies with you.

**Can I reduce the wait for an intestine?**

No. Organs are given to the person who is the closest match to the donor so that there is the best chance of success. Neither your doctors nor your Transplant Coordinator has any influence over this.

## **SECTION 4**

### **THE INTESTINAL OFFER**

#### **When will I be offered an intestine?**

There are Recipient Transplant Coordinators working around the clock accepting offers of organs and coordinating transplant operations. Please remember you could be called anytime, day or night. Think about how you will get to the hospital, especially if you are called overnight. If you are going to need transport it is important your Transplant Coordinator is aware of this. Please also think about what you will do with young children or pets when the call comes. When you are called you will need to come to the hospital as soon as possible as preparing you for surgery must happen very quickly. If you are delayed it could put the chance of your transplant happening at risk.

#### **What should I do when I get the offer?**

A 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 about your general health. It is important for you to inform them if you have any new illnesses and/or medication. The Transplant Coordinator will let you know what to bring to the hospital and where to go to. Do not have anything to eat or drink once you receive the call, unless you need to maintain your blood sugar levels. If this applies to you, you must eat enough to maintain your blood sugar levels. The transplant ward contact number is in the front of this booklet, if there are any problems finding the ward when you arrive at the Churchill Hospital, please call the ward. There is a map of the Churchill hospital at the end of this booklet.

#### **What will happen when I arrive at hospital?**

Once you get to the hospital, the hospital staff will start getting you ready for surgery. This will include blood tests, starting an intravenous drip to keep you hydrated, (as you will be asked not to eat or drink anything), a chest X-ray and an ECG (tracing) of your heart. We will then discuss the surgery again, including the risks and allow you to ask any questions.

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 are common. 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 to you more than once before getting your transplant.

### **Can I ask about the donor?**

As the recipient of a donated organ you are entitled to know the following:

- Age range of the donor
- Gender of the donor
- Type of death (such as a head injury) unless this might compromise the donor's confidentiality
- Whether the donor poses a greater risk to you of spread of infection or cancer

### **If I am called to the hospital, will I definitely receive the transplant?**

No. There are two main reasons why you may not receive the transplant once you arrive at the hospital:

1. We need to assess you and ensure you are currently fit and well enough to undergo surgery and that there have been no significant changes since you were last seen in Oxford. For example we will check that you have not had any new heart problems, put on too much weight or have an infection.
2. When you arrive a blood sample will be taken to ensure the donor organ is an exact match to you. This is called a cross match, if there is a reaction from the sample it is called a positive cross match and the transplant will not be able to proceed.
3. As discussed previously, dry runs can occur if the donor organ is not suitable.

### **If I am called to the hospital, do I have to have the transplant?**

No. It is your choice whether you want to have the transplant or not. But you must be informed that we are unable to guarantee if or when another suitable organ may become available. If you do decline an organ you will be invited to Oxford to re-discuss the option of transplant and ensure you wish to remain on the list. Being on the transplant waiting list is your choice. Should you wish to be removed please ask your referring doctor to inform the Oxford team of this request.

## **SECTION 5**

### **TYPES OF DONOR**

#### **Where does the donor intestine come from?**

Donor intestines come from somebody that has died. They are donating their organs because they were either on the organ donation register or their family have agreed to donation. There are two main types of deceased donors – Donors after Brain Death (DBD) and Donors after Cardiac Death (DCD). For an intestinal transplant the intestine would only come from a DBD donor. These are usually patients who have had an injury to their brain (for example a stroke or head injury) and tests have shown that their brain is dead. The patient will not survive without a machine to keep them breathing and they have lost all senses. The organs are retrieved whilst the donor's heart is still beating. The intestine is removed from the donor and placed on ice to transport it to Oxford. A team of surgeons from Oxford will go to the donor hospital to retrieve the organ and bring it to Oxford.

#### **Can I get cancer or infection from my donor?**

All donors are thoroughly screened for cancer and any infection and specifically tested for hepatitis and HIV, to reduce any risk to you of spread following transplant. We cannot guarantee the screening will pick up all cancer or infections, although it is very rare for the screening process to miss any potential risks. If there are any potential risks to you from the donor, the doctors will discuss this with you and ask if you want to receive the intestine.

## **SECTION 6**

### **THE OPERATION**

#### **Where will I have the operation?**

The transplant operation takes place in the main operating theatres of the Churchill Hospital. You will be taken to the anaesthetic room once we have confirmation the transplant is proceeding. Surgery usually lasts 8-10 hours. If your operation is longer, this does not mean the surgery is going poorly. Each operation will be different.

Please read the booklet provided: Anaesthesia explained

#### **Where does the intestine go?**

The surgeon usually joins one end of the donor intestine to the end of your intestine. Sometimes, the upper end of the donor intestine is joined directly to the stomach.

Sometimes the stomach and intestine are transplanted together. In this case the stomach is joined to the oesophagus at one end. The end of the intestine is taken to a hole (stoma) created by the surgeon leading outside the body (a colostomy). Solid waste from the intestine comes out of the hole and goes into a bag attached to the outside of the body.

#### **Why do I have to have a stoma?**

The stoma, depending on how much of your large intestine you have left, may be temporary. The reason for it is to allow the transplant team to monitor how your body is accepting your new organ. The transplant team will monitor the volume of waste which comes out of the stoma in a 24 hour period. If the volume suddenly increases it may be a sign of infection or rejection. In this case they will review you further.

The stoma is also used to allow the transplant team to see the new intestine. This is done by putting a small camera through the stoma; this camera can zoom in closely and allows the team to see the very small structures inside the intestine to check there is no rejection. This will be done twice a week in the first month and gradually become monthly, three monthly and then will eventually be done once a year if your stoma needs to be permanent. This procedure is called a scope.

#### **What happens to your own intestine?**

The major obstacle with this operation is the removal of your own intestine, as this can be complicated by lots of scar tissues from previous intestinal surgery. The intestine that is removed will be disposed of.

## **What happens after the operation?**

You will wake up in the Intensive Care Unit. The average length of stay is 5-7 days but you may need to stay longer – it depends on how quickly you recover after the surgery. You will have many intravenous access lines (narrow tubes going into your veins) connected to medications, fluids and monitoring equipment (to check your blood pressure, heart rate and how well you are breathing). The cut on your abdomen will either resemble a large “I” or a large upside down letter “Y”. The wound will be stitched and there may be 2-4 wound drains in place to drain away any excess fluid. Before you are discharged from the intensive care unit, staff need to make sure you can breathe normally without help, are able to sit in a chair and no longer need to have your blood pressure or heart rate monitored all the time.

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 used to the transplant related medications and care that you need.

As soon as you get to the ward the healthcare staff will start to get you ready for your discharge home. At the Oxford transplant centre we always aim to include the patient and their family in the care. Throughout your hospital stay we believe that your recovery is a team effort between the multi-disciplinary healthcare team and you and your family. The transplant ward nursing staff will be teaching you how to monitor your blood pressure and temperature, how to measure your urine output, how to monitor how much you drink and how to take your new medications. Your nurses will encourage you to do as much as you are physically capable of doing. This helps reduce the risk of complications such as blood clots and chest infections and will help to get you home as soon as possible. At first, we will help you up to the chair and later help you with walking in the corridor. You will be surprised how quickly you get back on your feet with just a little effort.

### **How will I receive my nutrition after my operation?**

Within approximately 48 hours after your operation you will be started on Total Parenteral Nutrition (TPN), this is nutrition given straight into your blood stream via an intravenous drip. This will continue until we are certain that your intestine can cope with liquid feed or food.

During your operation you will have a narrow plastic feeding tube inserted into your stomach. This feeding tube will have another tube attached inside that will be placed into your intestine. When your intestine is ready we will commence liquid feed very slowly via this tube. Once your new intestine is absorbing enough nutrients and vitamins from the liquid feed your transplant dietitian will slowly reduce and turn the TPN off. This happens usually within the first 2 weeks but this can vary from person to person. Once you are receiving liquid feed and your intestine is absorbing the right amount of nutrition you will be able to start on oral food (food by mouth). You will start off on a light, low fat diet and will progress onto a normal diet. The transplant dietitian will work closely with you at this point so you are fully aware of what food you can and can't eat.

You may need some advice and support managing the stoma if you have not had a stoma before. This will be given by the transplant dietitian and stoma care team. You will also see the dietetic assistant who will order foods for you on a daily basis until you are happy taking a normal diet.

### **How soon after my operation will I be eating a normal diet?**

This can vary from person to person and often depends on whether you were eating before your transplant or not. If you have spent many years restricting diet and fluids, it is likely that it will take some time to build up your food intake again. During this time you will be supported by the transplant dietitian who will advise and support you. Most patients return to a normal diet with no restrictions. Once on an oral diet you will be asked to follow food safety advice to reduce the risk of infection from foods. This will be discussed with you in great detail when the time comes.

### **How will my pain be controlled?**

As part of your assessment you will meet with our pain team to develop an individualised plan of post-operative care for you. Many patients with intestinal failure are on large amounts of pain relief, therefore your post-operative care is designed to suit you. Most commonly we use patient controlled analgesia (pain relief). Pain medication can be altered to suit your needs but this has to be done in a safe controlled manner as some medications can affect how well the new intestine will absorb fluids / food.

### **How long will I stay in hospital?**

The average length of stay in hospital 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 a flat on the hospital site for another 6-8 weeks. This is so we can help you get used to living without TPN and help you look after your new intestine by yourself.

### **Will I need blood tests after my transplant?**

Yes. We need to monitor you very closely following your transplant and will be looking at the contents of your blood to check on levels such as sodium, potassium and iron. We will monitor your the level of vitamins and minerals, to ensure you are getting the right amounts of nutrients. Your inflammatory (infection) markers will be closely monitored. If they go up it tells the team that there is an infection somewhere in your body. If this happens we can treat you quickly. Your kidney function will be monitored, some of the medications you will be on post operatively can have an impact on your kidneys and therefore we need to ensure they continue to work properly.

Initially blood tests will be once a week but this will slow down as you recover and will eventually be on a monthly basis, then every other month and then every 3 months.

You will need to take an immunosuppressive drug (a type of drug which should stop your body rejecting the organ) and have its level monitored for the rest of your life. This will ensure you are taking the correct dose.

**Please read the booklet provided: Caring for your transplant. This is available from your Transplant Coordinator.**

## **SECTION 7**

### **ENDOSCOPIES AND BIOPSIES**

#### **What is an endoscopy?**

An endoscopy is the procedure of putting a small camera through your stoma, into the new intestine. This allows the transplant team to monitor for rejection in the best way by looking at the new intestine to check on the healing process.

#### **Will I need an intestinal biopsy?**

A biopsy is when the surgeon removes a small amount of tissue for examination in the laboratory. After you have had an intestinal transplant, on some occasions the surgeon will want to take a biopsy of the transplanted intestine. We have highly skilled pathologists (a specialist doctor who studies the cause of disease) who will look at this biopsy in microscopic detail to check for any rejection. This will not happen at every endoscopy and the surgeon will inform you if he is going to take a biopsy. It should not cause you any pain or discomfort. If you have been discharged home and are returning to clinic, having a biopsy will not keep you in the hospital overnight.

#### **What are the risks of having a biopsy?**

As with all procedures there are potential risks with a biopsy, although these risks are very small. There is a small risk of bleeding (2-5%). If bleeding were to occur it may lead to you needing a blood transfusion. The risk of a biopsy damaging your new intestine is very small and the benefit of knowing what is going on in your intestines often outweighs the small risk to you of undergoing a biopsy. The transplant team will discuss the risks and benefits of having a biopsy with you at the time.

## **SECTION 8**

### **RESULTS AND COMPLICATIONS**

#### **Survival Rates**

The development of better immunosuppression medications and surgical techniques over the last ten years has led to improved results from intestinal transplant, and continues to do so. The number of intestinal transplants performed increases each year. The Intestinal Transplant Registry collects data for all intestinal transplants and publishes the statistics every two years. Current patient survival at 1 year is now greater than 90%. Long term follow up data in Oxford is not yet available as the programme only started in 2008. Current survival rates, nationally, at 5 years are approximately 50%. This is similar to statistics for patients who have received a lung transplant.

More than 80% of people who have an intestinal transplant gain independence from intravenous feeding can return to eating and drinking as normal.

#### **What are the common early complications?**

##### **Rejection**

Your body's natural immune response is to try and get rid of the new organ. White blood cells are sent in the blood supply by the body to attack the transplanted intestine. Immunosuppressant medication controls this response. However, rejection will occur in about a quarter of all transplants. If you have received more than one organ in your transplant, rejection could affect one or all of the organs. Rejection is diagnosed by a biopsy. Rejections can usually be treated successfully with increased immunosuppression medication but in severe cases it can lead to the transplanted organ being removed.

#### **Signs and symptoms of REJECTION after your transplant:**

1. Increased stoma output and / or diarrhoea
2. Fever / high temperature (above 37.5 C or 99.5 F)
3. Abdominal swelling
4. General tiredness, weakness, fatigue
5. Nausea and / or vomiting
6. Rash on the skin of the body

##### **Infection**

The intestine naturally contains thousands of bacteria. One of the most difficult parts of transplanting the intestine is that when you put it into the recipients' body these bacteria can spread and cause infection. Following a transplant you will be on immunosuppression medication, reducing your body's defence level against bacteria and making you at greater

risk of infections. Therefore, making you more likely to become unwell if the bacteria in the donor intestine spreads.

### **Signs and symptoms of INFECTION after your transplant:**

1. Fever / high temperature (above 37.5 C or 99.5 F or higher), chills or shaking
2. General tiredness, weakness, fatigue or aching (flu-like symptoms)
3. Nausea, vomiting or severe diarrhoea
4. Persistent loss of appetite
5. Pain, tenderness, swelling or leaking fluid from the wound or any part of your body
6. Skin or mouth sores
7. Lumps or blisters
8. Persistent or productive cough, shortness of breath or chest pain
9. Sore throat
10. Burning sensation pain, frequency or difficulty with urination
11. Urine that is cloudy or has a foul odour.

Needing to have another operation following the transplant is a common complication following intestinal transplant, the reason and causes for this can be seen below.

### **Thrombosis**

Thrombosis is a rare complication following transplantation. A thrombosis is when a clot forms in the vein or artery of the new intestine, and it can cause the blood supply to the intestine to stop. If this happens you will have to go back to theatre and in some cases the intestine will have to be removed.

### **Bleeding**

As with all major surgery there is a risk of internal bleeding. This may require a blood transfusion and further operations to stop the bleeding.

### **Leak**

Occasionally a leak may occur at the points where the new intestine has been attached to your own organs. If this is going to happen it should be visible within four days of your transplant surgery. An operation is usually required to repair the leak.

### **Infection from the surgery**

Wound infection can occur after transplantation. This may be deep within the abdomen, requiring a further operation or intervention, such as a drain, being inserted. The purpose of a drain, generally speaking, is to remove either fluid or air that has built up in the area of surgery.

A chest infection can occur following such major abdominal surgery. This may prolong your stay in the intensive care unit as it may require treatment with antibiotics and in more serious cases might mean you need a machine to support your breathing for a period of time.

You will have a central venous catheter, an intravenous line into your neck or groin, in place following the operation, as well as the previous intravenous line for your TPN. Due to the immunosuppression medication you will be more susceptible to line infections and therefore it is imperative to ensure safe line care, using aseptic technique.

### **Damage**

There is a risk, as with all surgery, of causing damage to surrounding organs during the operation. This is a very rare occurrence, but if it does occur you may require further surgery or interventions.

### **What are the long term complications of transplantation?**

#### **Rejection**

As above

#### **Infection**

As above

#### **Recurrence of the original disease which damaged your intestine**

This is not a common long term complication and may depend on what the original disease was. The risks of this will be discussed on an individual basis.

#### **High blood pressure**

High blood pressure can be caused by the immunosuppressive drugs (mainly tacrolimus). Regular monitoring of your blood pressure will be essential and you may need treatment for high blood pressure at some time in the future. Your transplant team will manage this should you need it.

#### **Cancer**

Cancer is more common in people with transplants due to the immunosuppression treatment and types of viral infection. Three of the most common types of cancers to develop are skin cancer, cervical cancer and lymphoma, which is a cancer of the lymphocytes. Lymphocytes are one of the cells that make up the immune system. Careful avoidance of sun exposure and using high SPF, UVA and UVB protection sun screens help reduce the risk of skin cancer. Women should also have cervical smears performed annually.

It is very important you continue to take the immunosuppression medication; as if you do not it is likely you will reject your new intestine.

### **Renal (Kidney) failure**

During your assessment your kidney function will be assessed. This is because one of the immunosuppressive medications can cause toxicity to the kidneys. If you are on this medication (tacrolimus) your renal function will have been reviewed and classed as stable during your assessment but your transplant team will continue to monitor it closely.

## **SECTION 9**

### **KEY POINTS TO REMEMBER**

#### **Before your operation**

##### **Change of circumstances**

Once you have been put onto the transplant waiting list, please tell your Transplant Coordinator (01865 226 075) of any change in your circumstances, such as holidays, change of address, telephone number and if you are admitted to the hospital. It is essential that we are able to contact you quickly at any time of the day or night and if we are not able to do so, you may miss the opportunity of a transplant

##### **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 the blood transfusion.

##### **Monthly blood tests**

These are essential for all patients. It is up to you to send your blood samples to the tissue typing laboratory. We will tell you when you are active on the transplant waiting list and the tissue typist will send you a pack with blood bottles for you to fill once a month. You can normally do this at your GP practice. They need to be sent to the hospital by first class post in the envelopes provided. 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.

#### **After your operation**

- 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 **must not run out**.
- Post-transplant patients are at higher risk of infection due to immunosuppression medications. Immediately after your transplant please avoid crowded areas (i.e. restaurants, shopping centres, parties, etc.) for 3 months.
- Some types of cancers are more common after your transplant because of the medications you are taking. To prevent skin cancers use a SPF 50 +, UVA and UVB sunscreen and suitable clothing if you are likely to be in strong sunlight for any period.
- Kidney problems may occur after transplant because of the prescribed medications. If this happens the doctors will adjust your medication.
- **Compliance is key!** Take your medications as instructed and never miss a dose.
- We strongly recommend that you abstain from taking illicit drugs, and from smoking tobacco and marijuana. Alcohol should be consumed in moderation.
- Your post-transplant medical management includes: adjustment of your immunosuppression medication and biopsies to check for any infection or rejection.
- Pain is common in the first 4-6 weeks after the transplant operation. Pain medication will be given to you as you need it.

Clinic Visits - Remember it is vitaly important to attend ALL clinic appointments. Please let your Transplant Coordinator or the Transplant Nurse Practitioners know if you have to cancel an appointment so that it can be promptly re-arranged.

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

#### **Who to call if you are feeling unwell:**

1. In the event of a life threatening emergency dial 999.
2. For urgent/routine matters during office hours call your named Nurse Practitioner on 01865 225 375 or Transplant Coordinator on 01865 226 075
3. If your call is out of office hours please call the Transplant Ward on : 01865 235 011

#### **Remember:**

Because of the particular nature of your transplant it is very important to inform the Oxford Team immediately of any admissions to hospital. It may be necessary to transfer you to the Transplant Ward at the Churchill for you to receive specialised care.

#### **Signs and symptoms of REJECTION after your transplant:**

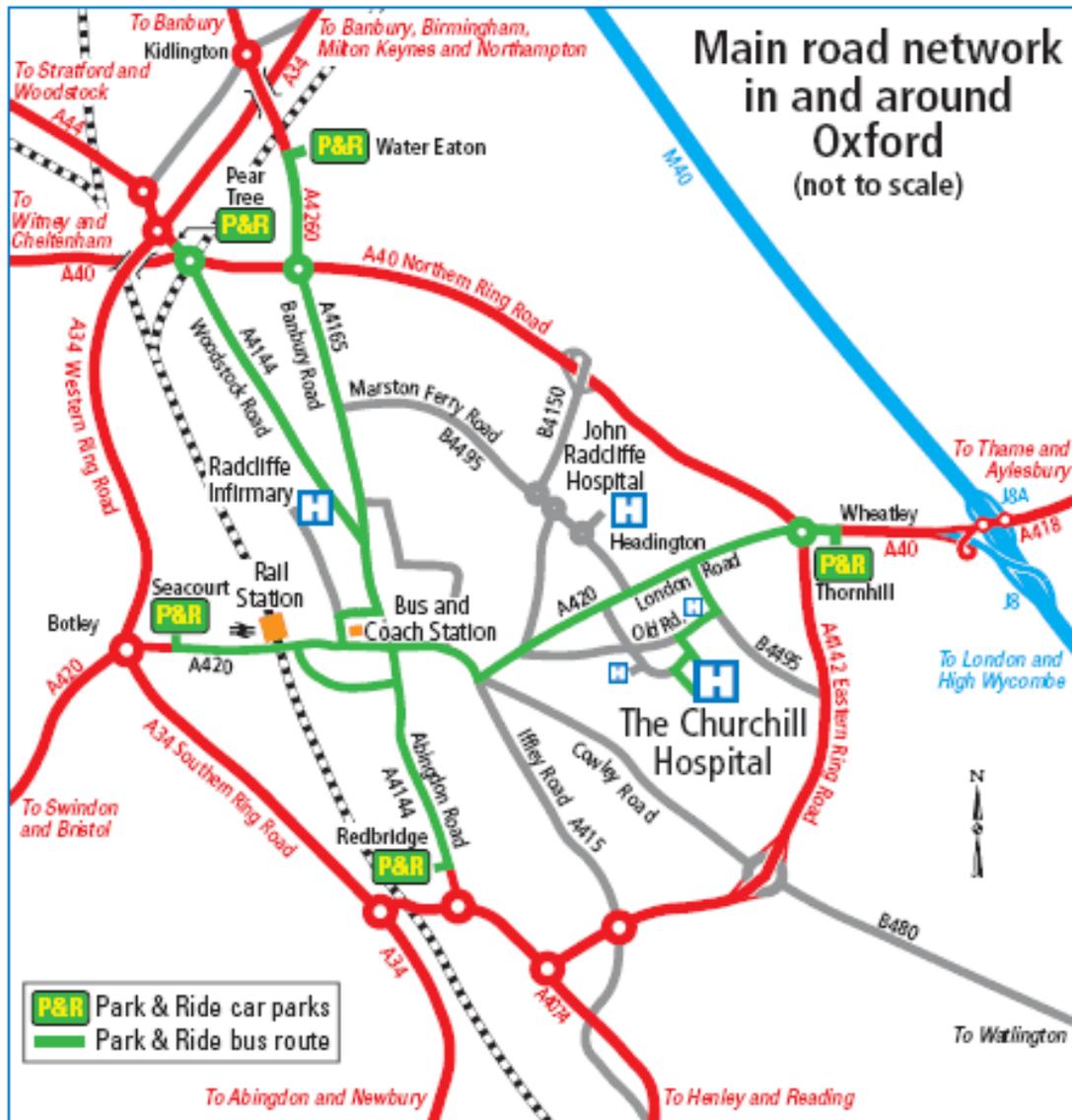
7. Increased stoma output and /or diarrhoea

8. Fever / high temperature (above 37.5 or 99.5 F)
9. Abdominal distension
10. Malaise, weakness, fatigue
11. Nausea and /or vomiting
12. Rash

**Signs and symptoms of INFECTION after your transplant:**

12. Fever / high temperature (above 37.5 C or 99.5 F or higher), chills or shaking
13. General malaise, weakness, fatigue or aching (flu-like symptoms)
14. Nausea, vomiting or severe diarrhoea
15. Persistent loss of appetite
16. Pain, tenderness, swelling or drainage from the wound or from any part of your body
17. Skin or mouth sores
18. Lumps or blisters
19. Persistent or productive cough, shortness of breath or chest pain
20. Sore throat
21. Burning, pain, frequency or difficulty with urination
22. Urine that is cloudy or has a foul odour

## Getting to the Churchill Hospital



## SECTION 11

## **NOTES**

If you need an interpreter or need a document in another language, large print, Braille or audio version, please call 01865 221 473 or email [PALSJR@ouh.nhs.uk](mailto:PALSJR@ouh.nhs.uk)

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