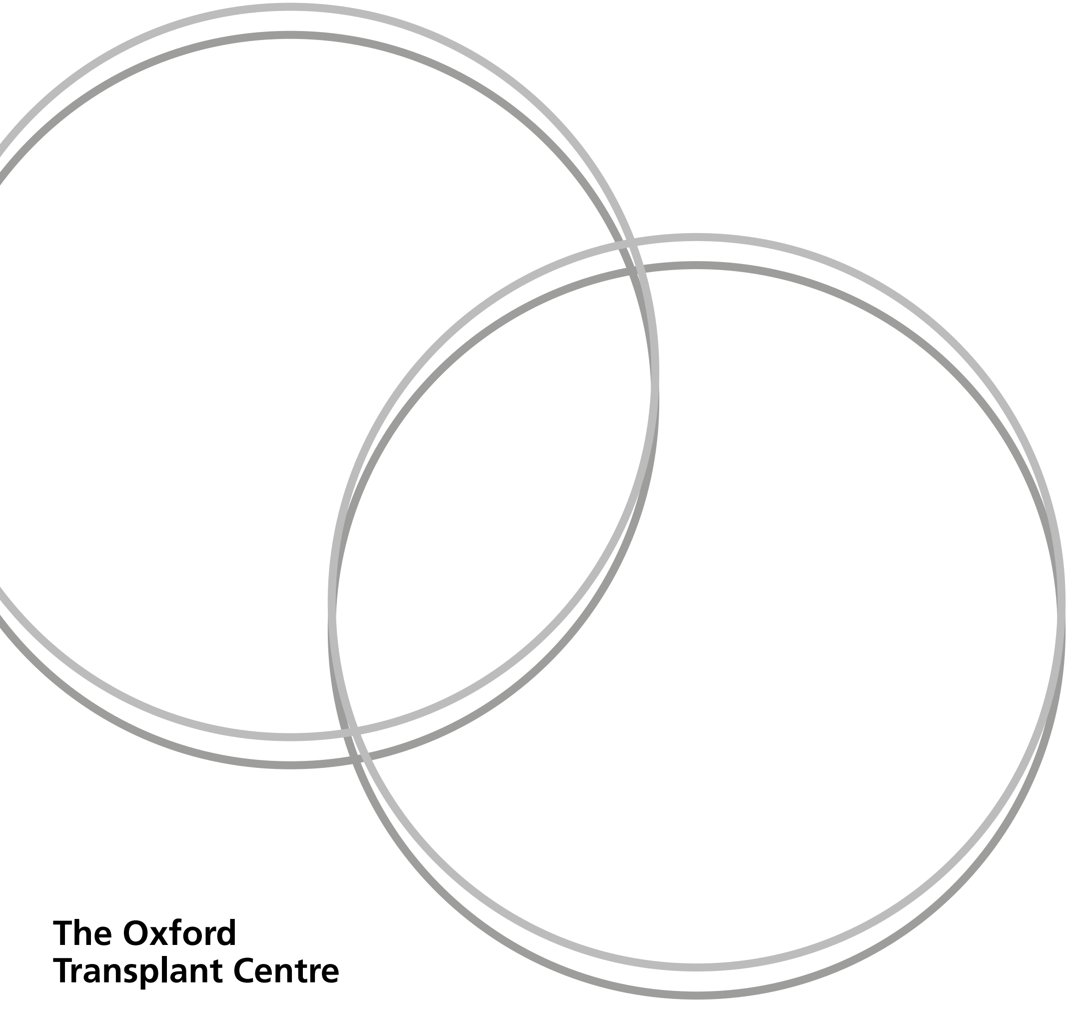
Oxford University Hospitals
NHS Foundation Trust

Intestinal Transplantation

Information for Patients



The Oxford
Transplant Centre

Overview

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

Dr Philip Allan – Gastroenterologist

Mr Venkatesha Udupa – Consultant Surgeon

Professor Peter Friend – Consultant Surgeon

Mr Srikanth Reddy – Consultant Surgeon

Intenstinal Transplant Specialist Nurses

Lisa Vokes – Specialist Dietitian in Intestinal Failure / Transplant

Dr Susan Shaw – Consultant Psychiatrist

Dr Louise Hankinson – Consultant Psychologist

Andrea Devaney – Consultant Pharmacist

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.

CONTACT INFORMATION

The Oxford Transplant Centre

Churchill Hospital
Old Road, Headington
Oxford OX3 7LE

Tel: **01865 225 355**
Tel: **01865 225 356**

Churchill Hospital Switchboard

Tel: **0300 304 7777**

Intestinal Transplant Co-ordinator

Email: **ouh-tr.oxfordintestinaltransplant@nhs.net**

Tel: **01865 228 671**
Tel: **01865 222 990**

Lisa Vokes

Dietitian
Tel: **01865 235 421**

Transplant Ward

Tel: **01865 235 010**
Tel: **01865 235 011**

Renal and Transplant Outpatients (Appointments)

Tel: **01865 225 355** or
Tel: **01865 225 356**

Transplant Pharmacy

Tel: **01865 226 105**

Transplant Nurse Practitioners

Tel: **01865 228 662**

Email: **orh-tr.posttransplantnurse@nhs.net**

Contents

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 the nutrients are 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 surgery to put a donated organ from someone who has died into a person who needs it. Part or all of the intestine can be transplanted. If needed, other organs, such as a stomach, kidney 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.
- The patient has psychological or behavioural issues that would mean that a transplant is not the right treatment for them.

So it is important that each patient is checked by the medical team at the transplant centre to determine if a transplant would be the right treatment for them.

Assessment for transplantation

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

If your consultant thinks a transplant would be suitable for you, they will refer you for an assessment. You will be carefully assessed to see if intestinal transplant is the best choice for you and your disease and your family.

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 organise my assessment?

Your Transplant Co-ordinator is a nurse who specialises in transplant and works directly with the transplant surgeons. They will be the link between the doctors and you. Your Transplant Co-ordinator will contact you to arrange convenient dates for you to come to Oxford for your assessment.

Once a date is agreed, the tests and investigations are arranged. These 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 or sent by email.

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, neck, pelvis and blood vessels, 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).
4. A lung function test / CPET (cardio pulmonary exercise tolerance 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 Practitioner
- Pharmacist
- Anaesthetist
- Consultant Transplant Surgeon
- Transplant Co-ordinator
- Psychiatrist
- Physiotherapist
- Stoma Specialist Nurse

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 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 share a lot of information about transplantation and what is involved and you should 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 as there is a lot of information given to you.

You can contact your Transplant Co-ordinator on:
Tel: **01865 228671/222990**, Monday - Friday 0800-1600

There is an answer phone available at all other times. Please feel free to leave a message and your Transplant Co-ordinator 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 Co-ordinator.

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 and national multidisciplinary teams meet monthly. Your case must be approved at both meetings before you are put on to the waiting list.

Your Transplant Co-ordinator 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 final decision is made.

If you are suitable for a transplant, you will be put on the United Kingdom transplant waiting list. Your Transplant Co-ordinator will arrange for you to sign a consent form to show that you agree to go on the waiting list.

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 Co-ordinator will let you know when this has happened. 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.

- Take regular exercise as this will help maintain your fitness
- If you smoke it is very important to stop – your GP can offer support and advise to stop smoking.
- Let your doctor or Transplant Co-ordinator know if you become unwell, are admitted to hospital or have any changes in your health or medicine. Two weeks following a blood transfusion or an infection you will require a blood test to retest your antibody levels. 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 Co-ordinator 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 tell your Transplant Co-ordinator 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 post the samples back to us 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 ways, including: 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 there is the best chance of success. Neither your doctors nor your Transplant Co-ordinator has any influence over this.

The intestinal offer

When will I be offered an intestine?

Recipient Transplant Co-ordinators work 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 the Recipient Transplant Co-ordinator 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 Co-ordinator (it may be someone you have never spoken to) will tell you exactly what to do. The Co-ordinator 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 medicine. The Recipient Transplant Co-ordinator will let you know what to bring to the hospital and where to go to. They will tell you if you can eat and drink. TPN can continue, if you can travel with it. Otherwise, you will need to stop it to travel. 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.

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, 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 will also be seen by the anaesthetist who will be putting you to sleep for the operation.

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 Co-ordinator 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. This is because we are working against time and 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

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

No. There are three 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 a 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 go ahead.
3. As already mentioned, 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.

Types of donor

Where does the donor intestine come from?

Donor intestines come from somebody who has died. They are donating their organs because they were on the organ donation register and 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 has died and the patient will not survive without a machine to keep them breathing. The organs are retrieved while the donor's heart is still beating. The intestine is removed from the donor and placed on ice to transport to Oxford. A team of surgeons from Oxford will go to the donor hospital to retrieve the organ(s) and bring them back to Oxford.

Can I get cancer or infection from my donor?

All donors are thoroughly screened for cancer and infection and are specifically tested for hepatitis and HIV. 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.

The operation

Where will I have the operation?

The transplant operation takes place in the main operating theatres at the Churchill Hospital. You will be taken to the anaesthetic room once we have confirmation the transplant is going ahead. Surgery usually lasts 8-10 hours, but can last up to 18 hours. If your operation is longer, this does not mean the surgery is going badly. Each operation will be different.

Where does the intestine go?

For most patients who need an intestine transplant, the parts of their own intestine that are no longer working have already been removed.

PMP (Pseudomyxoma peritonei) patients will have their own intestine and as much as possible of the PMP removed as part of the transplant operation.

Each transplant operation is different, because each patient will have a different abdomen, and need different amounts of donor intestine.

The surgeons usually do one of the following procedures:

- Joining the donor intestine to the end of your intestine if you still have some small intestine.
- Joining the donor intestine directly to your stomach.
- If you are having a stomach and intestine transplant, the donor stomach is joined to the end of your oesophagus.

Things can change during the operation. The surgeons may need to remove scar tissue, some of your intestine or make a different connection to make things work.

If any of your intestine or other tissues are removed, they may be sent for testing. If this is likely to happen, it will be discussed with you before the operation.

The end of the intestine is taken to a hole (stoma) made in your abdomen. This leads to the outside of your body (a colostomy or ileostomy). Solid waste from the intestine comes out of the stoma and goes into a bag attached to the outside of the body.

Why do I have to have a stoma?

Depending on how much of your large intestine you have left, the stoma may be temporary. 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 over 24 hours. If the volume suddenly increases it may be a sign of infection or rejection.

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 intestine in great detail and check there is no rejection. This procedure is called a scope.

What happens after the operation?

You will wake up in the Intensive Care Unit. The average stay in ICU is 2-3 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) for medicine, fluids and monitoring equipment (to check your blood pressure, heart rate and how well you are breathing).

The cut on your abdomen will either look like a large “I” or a large upside down letter “Y”. The wound will be stitched and there may be wound drains in place to drain away any extra fluid.

Before you are discharged from the Intensive Care Unit, we need to make sure you can breathe normally without help, you are able to sit in a chair and you do not 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 with transplant patients and are very used to the transplant related medicines and care that you need.

As soon as you get to the ward the 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 their care. Throughout your hospital stay we believe that your recovery is a team effort between the healthcare team, you and your family.

The transplant ward nursing staff will teach 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 medicines. Your nurses will encourage you to mobilise as much as possible.

This reduces the risk of complications such as blood clots and chest infections and will help to get you home faster! 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 have nutrition after my operation?

Within the first 48 hours after your operation you will be started on Total Parenteral Nutrition (TPN). This is sterile liquid food given straight into your blood stream through a drip. This will continue until we are certain that your intestine can cope with liquid feed or food.

Once your new intestine is absorbing enough nutrients and vitamins the dietitian will slowly reduce and turn the TPN off. This usually happens within the first 2 weeks but this can vary from person to person.

You will start off on a light, low fat diet and move on to a normal diet. The transplant dietitian will work closely with you so you are fully aware of what food you can and cannot eat. Sometimes we use tube feeding or sip feeds to help you get off TPN and onto normal diet. Sometimes these need to continue for longer, including after you have been discharged.

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.

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

This varies from person to person and often depends on whether you were eating before your transplant or not. If you have had a restricted diet for many years, 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. Our aim is to get you back to eating normal foods.

Once you are eating again, you will be asked to follow food safety advice to reduce the risk of infection from foods.

Due to the immunosuppressant drugs you will have to take after transplant you will not be able to eat grapefruit or starfruit, as they have an effect on these medications. This will be discussed with you in more detail when the time comes.

How will my pain be controlled?

Many patients with intestinal failure are on large amounts of pain relief, so your pain relief after the operation is adjusted to make sure you have what you need. The final aim is to have you on as little pain relief as possible. After the operation, we use Patient Controlled Analgesia (PCA). This is a pump that you control with a button. This will eventually be stopped and you will move on to taking pain relief by mouth. Making changes to pain medication has to be done in a safe and controlled way because as some medications can affect how well the new intestine will absorb food and drink.

How long will I stay in hospital?

The average length of stay in hospital is 4 to 6 weeks. After being discharged from the ward, if you live a long way from Oxford, may be able to stay in a flat on the hospital site for another 2 to 6 weeks. This is so you can get used to living without TPN and looking after your new intestine by yourself. If necessary, you can have one person stay with you in the flat to help you become more independent.

Will I need blood tests after I have gone home?

Yes. We need to monitor you very closely following your transplant and will be checking on levels such as sodium, potassium and iron.

We will monitor your levels of vitamins and minerals, to make sure you are getting enough nutrients.

Your inflammatory (infection) markers will be closely monitored. If they go up it means there is an infection or inflammation somewhere in your body. If this happens we need to treat you quickly. You may be asked to come back to Oxford for treatment.

Your kidney function will also be monitored because some of the medications can have an effect on your kidneys.

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.

What medicines do I need to take after transplant

Immunosuppressant medications are taken to stop the body's natural defence system (immune system) from attacking and rejecting the transplant intestine.

You will need to have the level of the immunosuppressant medication checked regularly in a blood test to make sure you are on the right dose.

You will need to take the immunosuppressant medication for as long as you have a transplant organ in your body.

As well as protecting your new transplant from rejection, immunosuppressant medications can reduce your ability to fight infections. This means you need to take other medicines that will help to protect you from infections that you could be more vulnerable to.

These are called prophylactic medications or transplant co-medications and are taken for a year. They include medicines called valganciclovir and co-trimoxazole.

Other medicines that you may be required to take more permanently include aspirin and omeprazole.

Dalteparin is a small injection you will need to give yourself every day for at least 6 weeks to prevent blood clots that can harm your new transplant. If you had problems with blood clots that damaged your own intestine before the transplant, you could be on these injections for up to a year. If blood clots are a problem for you, these injections may be changed to a daily tablet that is taken for a long time or even permanently. If blood clots are a problem for you, these injections may be changed to a daily tablet that is taken for a long time or even permanently.

For more information on these medications, please read the booklet: Caring for your transplant. This is available from your Transplant Co-ordinator.

The immunosuppressant dose is different for each person, depending on blood tests immunosuppressant dose is different for each person, depending on and any symptoms or side effects.

As part of the transplant operation an extra medication called alemtuzumab is given, and there is a second dose 24 hours later. This medication lasts for about 3 months and reduces the immune system reaction to the transplant when it is very new. This means you are potentially more vulnerable to infections in the first 3 months

The most common immunosupression medications used in Oxford are Tacrolimus (adoport), mycophenolate mofetil (or azathioprine) and steroids (prednisolone).

Over time, the dose of your immunosuppressants is reduced, but you have to take them for as long as you have the transplant in your body

If you were to stop taking your medication, your transplant can stop working and be rejected. This could make you very ill.

As with all medications there can be side effects, but you may not experience all or any of these. Please speak to your Transplant team if you have problems with side effects as there may be an easy solution. You must not miss doses of immunosuppressant.

Endoscopies and biopsies

What is an endoscopy?

An endoscopy, or ‘scope’, is when a small camera is put through your stoma into the new intestine. This is the best way to monitor for rejection because the Transplant team can look at the new intestine to check on the healing process.

Will I need an intestinal biopsy?

A biopsy is when a small amount of tissue is removed during a scope. This tissue is then studied in the laboratory. As well as having scopes during your recovery, you may need to have scopes and biopsies later on if there is any concern the transplant is not working well.

Once you are home, you may have a scope once a year to monitor your transplant.

Taking biopsies may not happen at every endoscopy and the doctor will inform you if he is going to take one. 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 hospital overnight.

What are the risks of having a biopsy?

As with all procedures there are possible risks with a biopsy, although these risks are very small. There is a small risk of bleeding (2 to 5%). If bleeding did happen, 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 outweighs the small risk of having a biopsy. The transplant team will discuss the risks and benefits of having a biopsy with you if one is needed.

Results and complications

Survival rates

There is continuing study and work on immunosuppression medications and surgical techniques leading to better results for intestinal transplant patients. The number of intestinal transplants done 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%. 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. 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 usually diagnosed by a biopsy or changes in your blood test results. Rejections are usually 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
7. Severe abdominal pain

Infection

As mentioned before, immunosuppressant medicines reduce your body’s natural defence system (immune system) and increase the risk of infection. These infections can be also be more severe.

The intestine naturally contains thousands of bacteria and when this organ is transplanted these bacteria can spread and cause infection.

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 pain, increased frequency or difficulty with passing water
11. Urine that is cloudy or has a foul odour.

After the operation, you will have a line in your neck or groin (a central line), as well as other lines you already have for your TPN.

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 a 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 serious cases the intestine might 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 a few 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, needing another operation or action, such as a drain being inserted. A drain removes either fluid or air that has built up in the area of surgery.

Occasionally your wound edges may come apart after the operation and you may need to go back to theatre and have vacuum pump therapy dressings.

A chest infection can happen after such major surgery. This may prolong your stay in the intensive care unit as it may need treatment with antibiotics. In more serious cases a machine might be needed to help with your breathing for a while and you may need extra oxygen.

You will have a central venous catheter; a line into your neck or groin, in place following the operation, as well as the previous. Due to the immunosuppression medication you will be more vulnerable to line infections. So it is extremely important to have safe line care, using a sterile technique.

Damage

As with all surgery, there is a risk of causing damage to surrounding organs during the operation. This is very rare, but if it does happen you may need further surgery or treatment.

What are the long term complications of transplantation?

Rejection

As above

Infection

As above

Return of the original disease which damaged your intestine

This does not happen to every intestinal transplant patient, but some problems are more likely to return. These include PMP and immune system diseases such as Crohn's Disease.

You are welcome to discuss your own case in more detail with the Transplant team.

High blood pressure

High blood pressure can be a side effect of immunosuppression medication (mainly tacrolimus). Regular monitoring of your blood pressure will be very important and you may need treatment for high blood pressure in the future. Your GP can will manage this if you need it.

Cancer

Cancer is more common in people with transplants due to the immunosuppression medication and certain viral infections that transplant patients are more at risk of.

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 lotions help to reduce the risk of skin cancer.

Women should have their regular cervical smears done as often as recommended by their age group.

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

Renal (Kidney) failure

During the assessment your kidney function will be reviewed. This is because one of the immunosuppressive medications (Tacrolimus) can cause damage to the kidneys. It is therefore important that we continue to monitor the Tacrolimus level to reduce the risk to your kidneys.

Key points to remember

Before your operation

Change of circumstances

Once you have been put onto the transplant waiting list, please tell your Transplant Co-ordinator of any change in your circumstances, e.g. holidays, change of address or telephone number or if you are admitted to hospital.

It is essential that we are able to contact you quickly at any time of the day or night. If we cannot contact you, 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 you have. We will ask you to send us monthly blood samples to check for antibodies that you may have made after the blood transfusion.

Monthly blood tests

These are essential for all patients. It is your responsibility 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 do this at your GP practice. The blood samples to be sent to the hospital by first class post in the envelopes provided. Please send them Monday to Thursday. If they are sent on Friday to Sunday, there will be delays in processing the blood.

24 hour availability

Please do not have answer machines on and make sure you answer any unknown numbers, especially at night, as we may be trying to call you for a transplant. We will not leave a message. Please make sure that mobile phones are on with the volume up and/or buzzer on to get your attention. Make sure that you have given us all the phone numbers where you might be at any time.

Unfortunately the Recipient Transplant Co-ordinator has a limited amount of time to call in a patient for 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

- Because you are at a higher risk of infection 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 a hat and long-sleeved and long-legged clothes that cover your skin if you are likely to be in strong sunlight for any length of time.
- Kidney problems may occur after transplant. If this happens the doctors will adjust your medication and may perform a kidney biopsy.
- **Compliance is key**! Take your medications as instructed and never miss a dose. Before discharge the pharmacist will go through all your new medications and explain what they do and how to take them. You will be given a medicine card to keep with this information. To begin with, the ward nursing staff will help you take the medications. When you are confident with your medications, you will take them on your own, as you will at home.

  Further information is available in the ‘caring for your transplant’ booklet you can get from your Transplant Co-Ordinator.
- We strongly recommend that you don’t take any illicit drugs or marijuana. If you smoke, we recommend that you try to stop. Alcohol can be drunk in moderation.
- Medical management after the transplant will include: adjustment of your immunosuppression medication and biopsies to check for any infection or rejection. We will need to contact

you to make any changes, so make sure your phone is still on and available.

- Pain is common in the first 4-6 weeks after the operation. Pain relief will be given to you as needed. The final aim is to have you on as little as possible or even off pain relief completely!

Clinic Visits

Remember it is **very important** to attend ALL clinic appointments. Please let your Transplant Co-ordinator or the Transplant Nurse Practitioners know if you have to cancel an appointment so that it can be re-arranged.

Please remember to contact your Transplant Co-ordinator 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 Monday to Friday 8:00AM to 4:00PM call the Transplant Co-ordinator on **01865 228 671 / 222 990 or** the Transplant Nurse Practitioners on **01865 228 662.**
3. You need to call Monday to Friday 4:00pm- 8:00AM, or on Bank Holidays, please call the Transplant Ward on:
   01865 235 010 / 235 011

Remember:

Due to the nature of your transplant it is **vital** you to inform the Oxford team immediately of any admissions you have to any hospital. It may be necessary to transfer you to the Transplant Ward at the Churchill Hospital for you to receive specialised care.

Keep a close eye out for signs of infection or rejection.

If in any doubt at any time, please contact us (see above)

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Author: Heather Howe, Transplant Specialist Nurse
Ali Smith, Transplant Nurse Practitioner
Kate Onyett, Transplant Nurse Practitioner
Professor P Friend, Consultant Surgeon
Mr V Udupa, Consultant Surgeon
Mr S Reddy, Consultant Surgeon

October 2021
Review: October 2024
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information

Leaflet reference number: OMI 65264