Liver Transplantation
Book 1
Information for patients
Section 1 - General Introduction

Introduction
The first human liver transplant was performed in 1963. At first there were many technical problems to overcome with both the surgery and the medication used afterwards.

Since the 1970s however there have been major advances and liver transplantation has now gained widespread acceptance.

It is now possible for patients to resume a near normal life after the operation and the number of patients who have benefited from a liver transplant is increasing rapidly.

Liver transplantation will however not benefit everyone and it is necessary to undergo an assessment process first. This not only ensures that other treatment options have been considered but also ensures that there is a good chance of increasing life expectancy from a transplant.

This booklet is designed to help you understand the various stages of the assessment process.

The complications of the operation are explained to help you understand what this major surgery involves.

Explanation of terms used in this book:
Transplantation: The replacement of your liver by a liver taken from another person.

Donor: The person from whom the liver is taken. The donor is usually someone who has died and who has expressed a wish to donate their liver after death, or who’s family has expressed a wish to donate their liver after death.
At St James’s Hospital we also have a live donor programme which means that a family member or friend could consider donating part of their liver.

**Recipient:** The person who receives the new liver.

**Rejection:** The recipient’s body may recognise the donor liver as "foreign" and react against it, causing damage to the donor liver. This can be treated in various ways.

**Immunosuppression:** The prevention of rejection by giving powerful drugs to stop the body reacting against the new liver. The **immune** system is the body’s way of recognising foreign objects such as infections and new livers. Powerful drugs are used to **suppress** it or dampen down its actions.

**The normal role of the liver**

Your liver is the largest organ in the body. It is found on the right hand side, just below the ribs.

It performs many essential functions to keep the rest of the body working correctly. For example:

- It produces bile and delivers this via fine tubes called bile ducts, into the bowel to help digestion and absorption of vitamins and fats.
- It controls the amount and type of food circulating in your bloodstream.
- It converts damaging substances you eat or which your body makes, into harmless products which can easily be removed from your body.
- It makes clotting factors to stop you bleeding and various other proteins, some of which help you to fight infections.
• It controls the level of several hormones in your blood.
• It metabolises (processes) many drugs.
• It makes most of the proteins that your body needs.
• It stores many important vitamins.
• It helps regulate body temperature.
• It helps provide a defence against infection.

When the liver fails to work properly
There are many different diseases that affect the working of the liver.

Some of them cause gradual deterioration and take many years before they affect the liver severely enough that liver transplantation needs to be considered. These are chronic liver diseases such as cirrhosis.

Others destroy the liver in a very short period of time, often in people who have had no known liver disease beforehand. These are much less common and are called acute liver diseases.

People who suffer from any sort of liver disease can have some of the problems listed on the next page:

• Jaundice (when the skin and eyes go yellow). This can be associated with itching, dark urine and pale stools.
• Increasing tiredness, feeling unwell, feeling cold.
• Loss of muscle strength and weight loss around the face, arms and legs.
• Increasing amount of fluid in the body, causing a swollen abdomen (ascites) and swollen legs.
• Defective clotting of the blood.
• Vomiting of blood from thin walled veins (varices) which develop in the gullet (oesophagus) and the stomach.
• Slowing of mental functions, confusion, excessive sleepiness or coma. This is called encephalopathy.

**Reasons why a liver transplant may be considered**
If you have been assessed as being suitable for liver transplantation this is usually because:

• You have liver failure and there is no alternative to increase your life expectancy and quality of life or,
• You have liver cancer and liver transplantation offers you the best chance of a cure or,
• You have some uncommon symptoms of your liver disease which affect your quality of life to such an extent that the benefits of liver transplantation outweigh the risks.

In addition, your current health is thought to be good enough to mean that you have a better than average chance of being alive five years after liver transplantation (more than 50%).
Section 2 - The Assessment

The assessment process

The assessment will either be as an in patient, or an out patient. This will have been discussed with you by a Transplant Co-ordinator before the planned dates and you will be asked to attend an out patient clinic.

If your assessment is to be done as an in patient you will be admitted to Ward J83 - Bexley Wing.

It is important that you understand this is for an assessment and does not commit either you or us to a liver transplant. A liver transplant must provide you with a good chance of a good outcome and the assessment allows us to advise you appropriately.

In order to discover the type of disease you have, and how it has affected your body, several laboratory tests and X ray studies will be necessary. You may have already undergone some of these tests. Some tests will not need repeating.

Welcome to the liver unit

We have an information leaflet called "Welcome to the Liver Unit" that explains all about staying on the ward. If you have not already received one of these, the ward staff will be happy to give you one on request.

The Liver Unit visiting times are 2pm - 4pm and 6pm - 8pm each day. Outside these times visitors must ask permission from the Nurse in charge. We ask that there are only two visitors per bed. Visitors are asked to leave the ward during the Doctors’ ward rounds if these should take place whilst you are visiting.
This is to maintain patient confidentiality. The ward is run by the Ward Manager and a Junior Sister. They have a team of experienced nurses working with them and most of your enquiries can be directed to them.

The team

Whilst you are undergoing your assessment you will be seen by a Consultant Hepatologist (liver specialist), Liver Registrar, Consultant Transplant Surgeon, Transplant Surgical Fellow, Anaesthetist, Medical Social Worker, Dietician, Substance Misuse Nurse Specialist, Pharmacist, Physiotherapist and Liver Transplant Co-ordinator.

Blood Tests

Blood samples will be taken to determine the type of liver disease you have and how well your liver is working.

Scans of your liver

- Ultrasound - a picture of your liver and its tubes and blood vessels is formed using ultrasound waves. This is painless and has no side effects.
- CT scan - a special Xray which looks in detail at the structure of your liver and nearby structures to help the surgeon with the operation. Not always necessary.
- MRI scan - to check the anatomy of the blood vessels to aid surgery. It looks for tumours and can assess the condition of blood vessels.
- More specialised tests may be needed such as a Hepatic Angiogram or Venogram. In these tests a special dye is injected through a needle into a blood vessel. This outlines the blood vessels around your liver and an Xray is then taken.
If such tests are needed they will be explained.

**Tests on your heart and lungs**
- Chest X ray - this is an Xray picture which looks at your lungs.
- Lung Function Tests - these measure the condition of your lungs. This helps the anaesthetist to judge whether there may be any breathing problems during or after the operation.
- Electrocardiogram (ECG) - a test of the electrical activity of the heart that gives an idea of how your heart will stand up to such a large operation.
- Echocardiogram - this is a form of ultrasound of the heart to check the heart muscle pump function.

**Additional tests**
- Sometimes extra tests are needed if the first tests have shown a potential problem or your medical history means your risk of having an undetected problem is high. Most commonly these are further heart studies like a stress echocardiogram or pressure measurements of your heart or veins.
- CPEX - this is an exercise test which show how your lungs and heart work together.
- A liver biopsy may be needed.

**The assessment team**
The assessment team includes the ward Nurses, Doctors and Consultants.

Following your tests you will then see one of the Consultant Anaesthetists.
A member of the Liver Transplant Coordinator team will see you during your assessment and give you information about the assessment process.

However there will be various other members of staff who will also see you and their contribution and opinion will be sought by the medical team. A Specialist nurse may also speak to you about alcohol or drug use. The Dietician will advise on any special diets we wish you to follow and provide information on healthy eating for people with liver disorders.

All patients who are being assessed for transplant will be referred to the Social Worker. They will discuss home, family situation and care for your needs, this will include help for other family members if you are their main carer.

- Financial worries and advice about depts, mortgage, benefits and travel expenses.
- Employment, college or school problems for you and your family.
- Housing worries including house transfers or housing applications on medical grounds.
- Emotional and practical support for you and your family when you are on The Liver Transplant List.

**The team meeting**

Your case will need to be presented to the full transplant team before a decision is made about a transplant. These meetings are held weekly and provide a wider team discussion about your care. There may several different outcomes of the meeting. Not all patients are suitable for transplant for many different reasons.
Some patients may require further investigations either in Leeds or locally before a final decision can be made.

You will be contacted at home after these meetings either by telephone or letter with the outcome of the meeting. Regardless of the outcome you will be offered the opportunity to meet and discuss the recommendations for your care.

**Other Considerations**

When the transplant team discuss your case they will explain the sort of donor liver you may be considered for. As a result you may be considered suitable for livers from Donation after Brain Death (DBD), Donation after Circulatory Death (DCD) or Living Donors. You may also be considered suitable for a split liver transplant. The recommendations are made by reviewing several factors including:

- Your size and weight. For example, the surgeon needs to consider if your body will cope with a smaller amount of liver in the early stages after the operation.
- Whether you have had previous abdominal surgery and if so does that mean that the operation will take longer? In that case a DCD liver may not be suitable because timing is more critical.
- How urgent is your transplant? If your liver disease is very advanced then we would want to keep the pool of donor livers open as much as possible. This keeps your chances of a transplant as high as possible.
- Do you have active hepatitis C or hepatitis B? Could you therefore be considered for a liver from a donor with these infections as long as liver damage has not occurred?
If you are placed on the transplant waiting list we will explain all the options to you. It is important that you fully understand all the problems and complications that can happen with the different types of donor livers.

Liver transplant surgery is very complex and complications can arise. The rates of some complications differ between the different types of donated livers. The complications are explained in a later section, and are important for you to understand.

Please do not hesitate to ask your Consultant or Liver Transplant Co-ordinator if you have questions about the recommendations for you. Please be aware that if you decide against these grafts the number of donors we can consider for you will be reduced.

The no alcohol agreement
For some people, alcohol is thought to have been a major contributor to their liver disease. If the team decides an alcohol agreement is necessary as a condition of being accepted for transplantation you will be asked to sign this agreement and abide by its terms.

Some people will also be asked to see an alcohol counsellor as a condition of being accepted onto the programme.

If you sign this agreement you are making a pledge to yourself, the transplant team and your donor that you will not drink alcohol again. You are also showing that you understand that transplantation will not be a treatment option for you if you drink alcohol again.
Smoking
Smoking increases the risk of short term complications after surgery, such as Deep Vein Thrombosis (DVT) and wound healing problems. It particularly increases the risk of cancer after transplantation. Stopping smoking may be a condition for you being listed for liver transplant. If you are asked to stop smoking the Substance Misuse Nurse Specialist will help you with this.

Drug use
Drug dependancy like alcohol dependancy is not treated by liver transplantation and can affect quality of life and life expectancy after transplantation. This will always need to be dealt with before you are listed for liver transplant.

If you are thought suitable for a liver transplant
If you are thought to be suitable for a liver transplant and it is something you want to consider, then it is important that you read the rest of this book very carefully. Before going on the transplant list you must understand what waiting for, and having, a transplant involves.

Going on the list
You will be asked to come for an appointment to meet the Transplant Coordinators and the Consultant Hepatologist. You should allow about 3-4 hours for this appointment and it is advisable to bring someone with you. It is also important that you have read all the information in this book before your listing appointment. It may be that you will require an abdominal Ultrasound scan of your liver at this appointment. If this is the case the transplant Coordinators will inform you of the time.
You will need to take only clear fluids for 6 hours before the test.

The Transplant Co-ordinators will explain the procedure of how we contact you and what to do when a donor becomes available. They will supervise your care and support you and your family whilst waiting. They will also keep in touch with you and your family after transplantation.

The Consultant will go through the operation, the complications of liver transplant and more general complications that are associated with any operation. At this point, if you are happy with the information you have been given we will ask you to sign the consent form.

This is why you must have read the information in the rest of this book.

Section 3 - Liver Transplant Surgery & Complications

When you are called in
You will be asked to make your way to the Liver Unit. As storage is minimal please bring only essential items and your medications.

You must not have anything to eat or drink after you have been called to the hospital.

On arrival you will be admitted and examined to assess the current state of your health. You will have blood tests, a urine test and possibly a chest X ray. A close relative or friend may come with you, they may also accompany you to the waiting area in the Operating Theatre. The medical team will contact your relative following the operation.
The operation

A liver transplant is a major operation. The surgery can take anything from 4 - 8 hours or longer if there are other considerations such as special anaesthetic requirements or particular surgical techniques needed because of your liver and blood vessel anatomy, or that of the donated liver.

You will have a large scar across the upper half of your abdomen.

This is necessary as the operation cannot be performed by keyhole surgery. The wound will be closed with metal staples and these will be removed around 14 days after your operation.

During the operation drainage tubes will be inserted around the operation site. These will usually be removed in the first few days after your operation, although it is common to for the fluid to continue to drain for a number of days afterwards - a drainage bag will be applied to the site.

Scars initially look quite red but they fade with time and often become very close in colour to your natural skin colour. Occasionally, in the longer term the scar can show some areas of weakness called an incisional hernia. If this becomes a problem we can look at it at a later date. Your gallbladder will be removed with your old liver. This should not have any serious consequences for you.

For certain conditions, such as Primary Sclerosing Cholangitis, your bowel will be directly attached to the liver so that all your old bile ducts can be removed. This is called a Roux loop. More usually the donated liver’s bile duct is attached directly to part of your old one.
Full liver transplant

Key
- Inferior vena cava
- Portal vein
- Bile duct
- Hepatic artery

Liver

Stomach

Roux loop surgery

Liver
**Split liver transplant**

![Diagram of liver with key: Inferior vena cava (blue), Portal vein (purple), Bile duct (green), Hepatic artery (red)]

**The recovery period**

For you the really hard work will begin when you return to the Liver Unit. The following days will need a lot of determined effort on the part of both yourself and your family. You will need to start gentle exercises to help your recovery.

The physiotherapist will see you every day to help you with deep breathing exercises and increasing your mobility. This will allow your strength to return and decrease the likelihood of complications.

Blood tests will be performed every day to monitor the liver’s function. Further X rays and scans may be carried out, and a needle biopsy of the liver may also be needed.
As soon as the nurses feel your condition has improved they will start the Self Medicating Programme with you and your family.

You will also be encouraged to start reading Book 2 to prepare yourself for returning home. Book 2 gives you information on your medications and life-style after your transplant.

Before discharge you will have an understanding of your new medications and how to enjoy a healthy life post transplant.

The length of stay in hospital varies from patient to patient but is usually around two weeks if recovery has been straightforward.

It is not unusual for patients to go through a period of feeling low. This is entirely natural as you come to terms with a new way of life.

You and your family have come through a period of uncertainty and serious illness.

Your family and the Liver Unit staff will be there to help and support you through this difficult period.

Complications that may arise
All major surgery carries a risk of complications. This is true for the majority of medical procedures. Liver transplant surgery is no exception.

This section tells you the things that might happen, with the chances of the risks happening. It is not intended to alarm you and if you have further questions please feel free to ask a member of the team.
The terminology we have used is explained below:

**Very rare:** Less than one person in every thousand undergoing liver transplantation.

**Rare:** (<1%) Less than one person in every hundred undergoing liver transplantation.

**Uncommon:** (1% to 10%) More than one person in every hundred undergoing liver transplantation.

**Common:** (10% or higher) More than one in ten people undergoing liver transplantation.

### Overall risk with liver transplantation

Nationally the survival rate one year after a liver transplant is greater than 90%. This means that the average patient has a 9 out of 10 chance of being alive and well 12 months after the transplant.

### Common complications after surgery

Pain and discomfort after surgery is to be expected. You will first have a hand held pump containing morphine to help control pain. Later this will change to tablets.

Feeling confused after the operation happens to a variable degree in the first 24-48 hours. It is partly due to the effect of the general anaesthetic wearing off and partly due to either pain or the painkillers used.

If patients have encephalopathy (a form of confusion) due to their liver disease before the transplant, this can take several days to improve. Sometimes confusion is more severe but this is uncommon. It can be related to the drugs used to prevent rejection of the liver (immunosuppression).
Post-operative confusion can be stressful for patients and families; this usually improves.

The bowel can sometimes be slow to work and constipation is common. If the bowel becomes temporarily lazy they can cause abdominal distension and nausea or vomiting. This is called ileus.

There is a risk of chest infection, urine infection and wound infection. You may have to go back to theatre because of bleeding.

**Uncommon complications after surgery**

The donated liver, sometimes doesn’t work. This is called primary non-function, the chances of this is around 2 - 4%. If possible you will be considered for a second emergency transplant. This may not always be available soon enough and is one of the reasons why people may not survive the transplant.

Sometimes the donated liver may take a bit longer than expected to work. This is called delayed function.

Sometimes a blood clot develops in the blood vessel supplying the liver, the hepatic artery. This happens in around 5% of transplants.

This is called hepatic artery thrombosis and if it occurs very quickly after the transplant and you are well enough, you will be considered for a second emergency transplant.

You may develop complications with your bile duct, occurring in around 10 to 15% of cases. These include a stricture or narrowing at the site where your original bile duct is joined to the donated liver’s bile duct.
If this happens you might need to have a procedure called Endoscopic Retrograde Cholangio-Pancreatography (ERCP). This is an endoscopy test with a camera. This allows your doctors to look at the bile duct in more detail and either open up the stricture by stretching it with a balloon, or placing a hollow tube or stent through the stricture to allow the bile to drain. Sometimes surgery is necessary.

Another bile duct complication that can arise is a leak in the bile duct. This may cause a collection of fluid, which may need to be treated with either ERCP or surgery. Complications such as narrowing of the veins going to or from the donated liver may require further surgery, stretching or placement of a tube or stent.

**Rare complications of liver transplant surgery**

Unlike most forms of major surgery, blood clots to the leg (deep vein thrombosis or DVT) and lung (pulmonary embolus) are quite rare after liver transplantation. As they can happen we use blood thinning injections to try and prevent them. Major cardiovascular events during surgery e.g heart attacks are rare, although can occur after transplantation.

**Donor transmitted disease**

It is recognised risk of transplantation that a disease, infection or cancer can be transmitted to you from your donor. We take precautions to keep this risk very low. However information very occasionally becomes available to the team after donation. If this occurs the team will speak with you about this. There are times when we are aware of donor diseases but consider there organs for donation because the risk of disease transmission is known to be low.
If this applies to you, we will discuss this with you before your surgery.

Transmission of cancer from donor to recipient. Very rarely we unexpectedly find out that the person donating the liver had a cancer at the time of their death. Under such circumstances there is a very small chance that this may have been transmitted to you. The risk depends on the position and size and type of the original cancer. Under such circumstances your case will be discussed with the team and then with you to explain what course of action is advisable for your follow up. Some non-infectious diseases or non-cancerous conditions can be transmitted through transplantation. This is rare but can be equally significant for you.

All donors are screened for Hepatitis B and C infection and for HIV infection. Some donors with active Hepatitis C are considered but only under very stringent criteria and only for recipients who already have Hepatitis C infection (see section on extended criteria donors). Donors with known active Hepatitis B and HIV are not considered suitable. However, there remains a very small risk of transmission despite these tests. Under such circumstances you would be advised about appropriate treatment.

**Hepatitis C treatments**

The Consultant responsible for your care will discuss the possibility of treatment for your Hepatitis C whilst you wait for a transplant. If these treatments are suitable for you your viral load will be monitored regularly.

If you have a good response then we would **NOT** consider you suitable for a HCV positive donor.
Section 4 - General Anaesthesia Intensive Care & Complications

About the anaesthetic

Patients who have a transplant will need a general anaesthetic and may need to spend a period of time in the Intensive Care Unit (ICU).

An anaesthetist is a doctor who specialises in giving anaesthetics and looking after patients in the ICU. When the anaesthetist has seen the results of your tests and investigations, they will come to see you and may have some additional questions to ask you at this stage. You will have an opportunity to ask them questions that you may have.

The anaesthetist you see during your assessment will not necessarily be the same one who puts you to sleep for your operation. This is because the anaesthetic team is made up of seven consultants, who share the work equally between them. So, who gives you anaesthetic depends on what day of the week your transplant happens.

When you arrive in hospital on the day of your transplant, you may be seen by another anaesthetist, before you come to the operating theatre.

When you are brought to the operating theatre, you will still be awake and aware of your surroundings.

You will be brought into the main operating theatre and transferred on to the operating table. At this stage, you will be connected to a number of monitors, so that we can observe your heart rate, oxygen levels and blood pressure, while you are asleep.
A drip will be placed into a vein on the back of your hand or your arm. This drip is used to give you some fluids and an anaesthetic drug is injected through it, which will send you off to sleep.

You will require many other drips and tubes to make surgery possible, and these will normally be inserted after you are asleep.

**They consist of:**

**An arterial line**
This is a small drip into the artery in your wrist. This enables us to monitor your blood pressure and the function of your heart on a beat to beat basis.

It also means that we can take regular blood samples without having to stick needles into you.

**A central line**
This is a drip into one of the large veins in the neck. This enables us to give you concentrated drugs which could not be safely given into a small vein in your hand.

It also allows us to monitor the function of the heart.

**Bypass lines**
These are two large tubes. One is placed into a vein in the neck and the other into a vein in the groin.

These are used to divert the supply of blood during the operation so that the liver can be safely removed. They are not always necessary.
**Tracheal tube**

This is a tube into the trachea or windpipe, which is used to provide oxygen and to assist you with your breathing during the operation (it is connected to a life support machine).

**Nasogastric tube**

This is a small soft plastic tube, which passes through the nose and down the throat into the stomach.

This is used to remove excess fluid in the stomach and can also be used for feeding after the operation is over.

Once you are asleep, you may need to be given other drugs to provide pain relief and to keep you asleep for the duration of your operation. The anesthetist will also give you drugs to support your heart and circulation.

You may be given blood transfusions or transfusions of plasma to help blood clotting and to compensate for any blood loss during the surgery.

At the end of the operation, you will be transferred to the intensive care unit. Some patients are woken up before being to being moved to the ICU and others are kept asleep.

The anaesthetist will choose which option is best for you, there are advantages and disadvantages to both choices. It is likely that the final decision will only be made towards the end of your operation.

Up until this stage, we will not know which is the most appropriate option for you.

After your operation you will be kept in the ICU. During this time, you will be closely observed and monitored to make sure
that your circulation is stable, that your kidneys are working well and that the new liver is doing everything that it should. When you are awake and comfortable and your organs are all functioning properly, you will be transferred back to the Liver Unit.

**Is the anaesthetic dangerous?**

Overall, anaesthetics are extremely safe in fit and healthy people. However, anaesthetics have very minor side-effects which though normally well tolerated, may be a problem for those who are extremely sick or who are having complex surgery.

It is common to feel a bit drowsy or nauseated after a general anaesthetic. It is also common to have a sore throat.

Additionally, there is a risk from the various and drips and tubes which you will need. Such complications are generally speaking, not severe, and are rare. They affect around 1 to 2% of patients. They include bruising, damage to blood vessels, or a punctured lung. These side-effects may require additional treatment during surgery.

Because the body is put under a lot of stress during major surgery and transplantation the heart can sometimes develop irregular rhythms called arrythmias.

This is reasonably common but it is uncommon for them to be a problem or continue after surgery and it is rare for them to cause serious problems such as cardiac arrest. Very rarely people develop unexpected allergic reactions to the drugs used for the anaesthetic. However when this does occur it can be serious and sometimes fatal.
Commonly asked questions about the anaesthetic

*What is the risk of this happening to me?*

This is very rare. Estimates have suggested that it occurs in fewer than one in 500 cases, and it may be as rare as one in 10,000 cases. Cases of awareness associated with pain and distress are even rarer.

Patients having a liver transplant receive a combination of anaesthetic drugs and are very closely monitored. The combination of these together means that your risk of being awake during your operation is extremely small.

*Will I experience pain when I wake up?*

Liver transplantation is a very major operation. Surprisingly, although most patients experience some pain, this is generally not as severe as they expect.

Despite the fact that the wound after surgery is quite large, most of the discomfort experienced is in the form of back pain.

*What painkillers will I be given?*

The usual form of pain relief is morphine which is given through a pump. You will control this pump by a button. Each time you press the button, the pump will give a beep and the pump will give you a small dose of morphine.

You can keep pressing the button until you build up enough morphine in your system to make yourself comfortable. After this, the chances are that you will stay comfortable and will only need to use the morphine pump occasionally to top up the morphine in your system.
Can I overdose on the morphine?
No. The pump is set up in such a way that you can’t overdose by pressing the button too often. Use the button as often as you need to make yourself comfortable, and then once you're comfortable simply stop pressing the button.

Can I have an epidural?
Some patients with good blood clotting before their operation may be offered an epidural as an alternative to the morphine pump. This involves a needle being placed in the back near the nerves passing between the spinal cord and the abdomen. A small plastic tube is passed through the needle. The needle is removed and the plastic tube is left in the back near these nerves.

Local anaesthetic can then be pumped down the tube and washed over the nerves to cause numbness. This is continued for a number of hours after surgery, and up to three days, at which point the epidural plastic tube can be removed.

Epidurals have many benefits but they also carry a small risk. The main risk is that of bleeding around the nerves or spinal cord. That is why epidurals can normally only be offered to those patients who have relatively normal blood clotting at the start of their operation.

Will I see my anaesthetist again after the operation?
Your anaesthetist will be involved with your post-operative care on the intensive care unit and may subsequently see you on the Liver Unit. If you require any further surgical procedures at any stage, your anaesthetist (or one of the group of colleagues) will be involved with this.
Further, if there are any questions or issues which you wish to discuss with your anaesthetist after surgery (for example, pain relief) than you only have to ask.

**Intensive Care**

Most patients return from the operating theatre to the ICU. The majority stay in the ICU for between 6 and 48 hours and are then transferred back to the Liver Unit.
As you start to wake up the sights and sounds may be unfamiliar, there will be several machines watching over your recovery making different tones and bleeps. If patients need to stay on the ICU for longer this may be for a variety of reasons. However a prolonged stay on the ICU is uncommon.

Sometimes people need ventilating (help with breathing by a machine) for several days. In this case the anaesthetist may do a mini-operation called a tracheostomy to attach the ventilator directly to the windpipe so you don’t need to have a tube coming out of your mouth.

Sometimes people’s kidneys do not always work at full rate for a few days. In this case a dialysis machine may be used to help your kidneys. This is almost always temporary.

Sometimes further surgery is needed so a return to the ward is impossible.

Muscles commonly become weaker when they are not used for a while, but this usually gets back to normal as you make a recovery.

Infections are common.

Nerve damage is rare.
Section 5 - Complications of Transplantation in General

Infections
The drugs needed after liver transplantation dampen down or suppress the immune system and can make you more prone to infection. These include general infections like those described before, but also infections that would not usually be a problem if you had not needed a transplant, including certain virus infections. The most important of these is Cytomegalovirus infection or CMV. If you have never had this before and you receive a liver from someone who had, then you will be prescribed anti-CMV medication for the first few weeks after transplant. Other infections include fungal infections and again you will be prescribed tablets for the first few days after transplant to try and prevent this.

All hospitals have superbugs such as MRSA, which you may have read about in the newspapers. These are of concern because they are resistant to a lot of antibiotics so treating them can be challenging. However certain antibiotics are very effective. Like most infections, some are serious and some are less so. They tend to be serious in patients who are the most sick or who have been in hospital for a long time.

The number of superbugs in the UK is increasing. The Liver Unit has strict source isolation policies for patients at risk.

According to hospital policy you or your relatives can speak to a member of staff if you have concerns about hygiene on the Liver Unit and please feel free to ask us to wash our hands. There are alcohol gel dispensers at your bedside and at the ward entrance for staff, you and your relatives to use.
Hand-washing technique with soap and water

1. Wet hands with water
2. Apply enough soap to cover all hand surfaces
3. Rub hands palm to palm
4. Rub back of each hand with palm of other hand with fingers interlaced
5. Rub palm to palm with fingers interlaced
6. Rub with back of fingers to opposing palms with fingers interlocked
7. Rub each thumb clasped in opposite hand using a rotational movement
8. Rub tips of fingers in opposite palm in a circular motion
9. Rub each wrist with opposite hand
10. Rinse hands with water
11. Use elbow to turn off tap
12. Dry thoroughly with a single-use towel
13. Hand washing should take 15–30 seconds

Adapted from World Health Organization Guidelines on Hand Hygiene in Health Care

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Other general complications
Although transplantation involves major surgery and all the risks described above, for the majority of patients it is a very successful operation and gives them a new lease of life.

Rejection
Your immune system will recognise the donated liver as being "foreign" ie - not a normal part of you and will try and fight it. This is why you need to take regular medication. However, rejection is quite common in the first few weeks after transplant - up to a quarter of patients may have at least one episode. It can usually be treated, although occasionally it is persistent, in which case increased anti-rejection medication will be needed.

Medication
Please read the information booklet "Liver Transplantation Book 2". This will be given to you in the first few days after your transplant it describes the medicines (immunosuppressants) you will need to prevent your body from rejecting the new liver, and the side effects you might experience. The Liver Unit pharmacist is on the ward most days to discuss your medication with you. A pharmacist or pharmacy technician is usually available in the post transplant clinic.

Medical problems
Certain medical conditions become more common after transplantation. This is partly due to the immunosuppressant drugs. Common ones include: diabetes (either new, or more difficult to control), high blood pressure, high cholesterol, kidney impairment (but true kidney failure needing dialysis is rare).
Weight gain
This can occur after transplantation, sometimes associated with insulin therapy for diabetes, side-effects of other drugs such as steroids, people feeling much better after transplant and eating more, and unexplained in some people. It is important to watch your weight and seek dietician advice early if you have this tendency so that obesity, with its accompanying problems, does not develop.

Cancer
The immune system is important for fighting infection but also has a role in searching the body for cells that might become cancerous in the future. Because your immune system will be suppressed by drugs to prevent your liver from rejecting, there is a small increased risk of cancer. The most common one is skin cancer. Uncommon ones include a particular sort of lymphoma (blood cancer). Both can often be treated.

Smoking greatly increases the risk of cancer developing after a transplant. We strongly advise patients not to smoke after a transplant. The Substance Misuse Nurse Specialist can offer advice.

Recurrence of disease
This is well recognised for many sorts of liver disease. If your original disease comes back into the new liver it may not progress in the same way as previously.

Here are some examples:
If you are being offered a transplant for Hepatitis C and still have active virus at the time of transplant then you will almost certainly get Hepatitis C back in the new liver.
In some people, but by no means all, it can cause cirrhosis again, and sometimes much quicker than the first time round. Occasionally it causes a rapid development of jaundice and inflammation shortly after transplant.

You will be monitored for this with regular liver biopsies and if you weren’t able to go through treatment for the Hepatitis C before your transplant, it may be offered to you afterwards if you are getting scarring on the new liver.

If you were transplanted for liver cancer (hepatocellular carcinoma), there is a 15% overall risk of recurrence.

Liver diseases that recur after transplant include Primary Sclerosing Cholangitis, Primary Biliary Cirrhosis and Auto-Immune Hepatitis.

If you are transplanted for alcohol related liver disease, this should not recur if you continue with life long abstinence.

**New liver disease**
In addition, new liver diseases can occur just as in anyone else. If your liver tests become abnormal after the liver transplant, investigations for new diseases may be performed.

**Living with a Transplant**
There is more information about infections after transplantation, and what to do about them, including chicken pox, in the book *Liver Transplantation: Book 2.* This book also includes advice about medication, general health, holidays, vaccinations, diet and pregnancy after a liver transplant. You will be given a copy after your transplant.
Section 6 - Waiting on the Transplant List

Waiting for a liver
This can be a very difficult time for both patients and their friends and relatives. We do not know how long you will have to wait and it is likely that it will be several months. We advise that you try and carry on life as normally as possible, following your usual routine and continuing your work if possible.

You can continue to see family and friends and could consider taking short break holidays within the UK.

If you want to go away for a few days ring the co-ordinators and discuss where you plan to go and how you can be contacted. It is vital that you can be contacted at all times. This means you also need to let us know if any of your contact details change or if you are admitted to your local hospital.

Outpatient Visits
You will need to be seen about once a month in the Transplant waiting list clinic. This team will be your first "port of call" for queries and letting us know if you are unwell. Transport to and from these visits remains your responsibility other than in exceptional circumstances. If needed please ask one of this team for advice.

The appointments last about half an hour. If you need reviewing by one of the medical team, dietitian or social worker, this will be organised at the same time whenever possible in order to keep your travelling to a minimum.

If you know in advance that you would like to see another member of the transplant team please feel free to phone us beforehand so we can try and arrange this for you.
Please bring a list of the medications you are taking including doses and how often you take them.

Your pulse, blood pressure and weight will be routinely monitored. You will need to have blood tests. You will be contacted by phone if any additional follow-up is needed following review of these results.

If you have any questions it may help you to write them down as it is easy to forget at the time. You might also want to bring someone with you.

The appointment is also an opportunity for you to tell us how you are feeling. We are here to help if you are having difficulties.

**Liver scans whilst waiting**

Most patients on the waiting list will require some form of scan whilst waiting. For patients with cirrhosis the minimum will be an ultrasound scan every six months to look for the development of new nodules in the liver which will need further investigation. Occasionally these turn out to be cancerous.

Some patients will require more frequent scans to keep an eye on their portal vein and cancer patients will require an MRI scan every three months and a CT scan every six months to ensure that their cancer has not grown outside the limits for transplantation.

If you are on the transplant waiting list for longer than one year we will repeat your echocardiogram to ensure that you remain well enough for a transplant.
Becoming more ill whilst waiting

One of the biggest challenges we all face is matching the number of people who would benefit from transplantation with the number of people donating their livers after death for use in transplantation. This means that people are waiting longer and longer for a new liver.

It is important that you are aware that being listed for a transplant does not guarantee that you will receive a transplant. Between 15 and 20% of patients will unfortunately become too unwell or die whilst on the transplant list. Whilst people are waiting it is common for them to become weaker, more prone to infection and develop other complications associated with their liver disease.

If you feel your condition is deteriorating please let us know as it may be necessary to bring your appointment forward or arrange an admission into hospital, either here or locally. If admitted to your local hospital please let us know.

Sometimes people will be temporarily too unwell to transplant. If this happens you will be suspended from the list. You will not lose your place and when well enough will be activated again. Occasionally as people wait longer they actually improve. If we see an improvement we will also initially suspend you.

If you reach a point where you are likely to be better off without a transplant we will remove you from the waiting list. This does not prevent you from being reassessed again in the future if things change.

Unfortunately, with longer waiting times for transplantation, people sometimes become too ill to transplant.
If this is the case we will talk to you about it and remove you from the list. Sometimes a suitable liver does not become available quickly enough. If you deteriorate whilst waiting we will try our best to ensure that your local hospital and GP are aware that you need care centred on ensuring your comfort and make plans with you about your end of life care.

**Carers**

It is very useful for the carer to attend appointments. They can also provide useful up to date information if the patient becomes unwell, is prescribed new medication or is admitted to hospital.

Being the carer or relative of a patient waiting for a transplant is very stressful. Many carers find it very demanding and may need to ask other family members or friends to help out with transport etc.

It may not be possible for them to stay close by during your hospital stay. We would also recommend time away from the hospital allowing them to rest.

**Your general health and well being**

**Alcohol and drugs**

Alcohol and drugs can both cause liver damage. We expect patients to adhere to advice about alcohol.

**Anyone on the transplant waiting list should not drink alcohol.**

Patients placed on the waiting list for diseases in which alcohol has been considered part, or all, of the problem, will be asked to sign a no-alcohol agreement.
Failure to comply with this agreement will lead to permanent removal from the waiting list.

Similarly, evidence of non-prescribed drug use such as cocaine, heroin etc will be viewed as evidence of poor compliance with the expectations of the transplant program and patients will be removed from the waiting list.

**Smoking**

Nicotine is a powerfully addictive agent and giving up smoking can be difficult. However, transplantation is associated with risks including chest infections and an increased risk after transplant of both heart disease and cancer. All of these are increased by smoking.

For this reason we expect all patients to stop smoking when they are listed for liver transplantation and evidence of continued smoking will lead to your suitability being reviewed and possible removal from the transplant list. Nicotine patches can be prescribed by your GP and the hospital has a smoking cessation team which we can contact for you should you wish to see them.

**Nutrition**

**This is extremely important.** At some point during your assessment or early on after being accepted onto the transplant program you will need a nutritional assessment which will involve seeing one of the unit’s dieticians, if the dieticians feel that your nutritional needs are not being met, they may suggest nasogastric feeding.
Protein and calorie supplements will often be needed and all patients with cirrhosis will require calcium and vitamin D supplements which should be obtained by prescription from your GP. The importance of nutrition continues post-transplant.

**Other aspects**

Being unwell can cause a great deal of financial anxiety and additional help at home with general care may be needed.

If not provided this sometimes impacts on your general health. For this reason the Unit has a social worker available for help and advice.

The Specialist Nurse can help if you need advice about alcohol support services and if counselling of this sort has been recommended as a condition of your transplant they can help find somewhere suitable.

If you have ever experienced confusion due to your liver disease (encephalopathy) and been told not to drive please **DO NOT** drive. If you continue to drive against medical advice then we will inform the DVLA as you are a risk to yourself and other road users.

**Patients support group**

The Liver Unit has a support group for patients who have had or who are waiting for a transplant. This group is led and organised by transplant patients and you may wish to make contact with members of the group or come to the meetings.

The contact is **Janet Atherton** and she can be reached by telephone on **01942 704 385** or **Ajantath@aol.com**.
The group meets roughly four times a year, usually on a Saturday morning here in the hospital. A newsletter is produced on a regular basis.

You are very welcome to make contact either for further information or just for a chat with someone who has already undergone a transplant.

**When the call finally comes**

It is wise to have a small bag packed in preparation as the call often comes at unsociable hours of the day or night.

Please bring the minimum you require as storage space is very limited whilst you are in surgery and your relatives may be asked to keep your possessions with them until you are back on the ward.

Bring all your current medication.

Whilst you are in theatre your family may want to return home or they may prefer to stay around the hospital site.

Your family will be informed once you have arrived on the ICU.

**Disappointments**

Sometimes the donor liver is not suitable for you or any transplant. When this happens it is very disappointing for you and your family.

You will not need to stay in hospital and will resume your usual follow-up. It is important to try and stay positive when this happens and the recipient team will always be available to talk to you about this and support you. There is also a possibility that you may be called in on standby.
This means that the liver is intended for use in someone else but for various reasons there is a small possibility that might not be possible in which case it will be offered to you. Usually you will be told if you are being called in on standby.

Rarely unexpected findings such as advanced cancer is found at surgery. Under such circumstances it is unlikely that the transplant will proceed. You will be offered appropriate referrals to cancer specialist teams either here or at your local hospital.

**Section 7 - Where Livers Come From**

*Where livers come from*

Livers are usually donated by someone who has died and who has expressed a wish to donate their liver after death, or where the family has expressed a wish to donate their loved ones liver after death.

At St James’s Hospital we also have a live donor programme which means that a family member or friend could consider donating part of their liver.

Further information on this follows.

*How livers are allocated*

In general livers donated to the Leeds unit are allocated to patients on the transplant waiting list according first to their blood group, secondly their size (trying to get the "best fit") and then to how ill they are and to how long they have been waiting. We may assess patients’ general health at the time of the offer and the sort of liver we have been offered in addition.
For example, some patients will be more suitable for extended criteria livers (this will be discussed with you at your listing appointment) than others.

However, there are some national and regional rules that we have to follow. For example, whilst most patients are transplanted for liver disease that has been present for many months or years (chronic liver disease), a few people develop a rare condition called acute liver failure which can lead to death within days. These patients are given priority nationally over all others.

We also operate a system with two other units in the north of the UK whereby patients meeting certain very stringent criteria are given regional priority over all others.

Extended criteria livers
As the number of candidates for liver transplant continues to exceed the number of donated livers, liver transplant surgeons have extended the number of livers they will consider for donation. These livers are named extended criteria livers as they have a higher risk of primary non-function or delayed function.

Fatty Livers
For example you may receive a slightly fatty liver. Such livers may take a bit longer to work (delayed function) than absolutely perfect ones but eventually do well.

Remember that this can occur with any liver, not just the ones we might call extended criteria.
**Hepatitis B Donors**
Some donors have had past exposure to Hepatitis B, but no evidence of active infection. Their livers can be safely used for transplantation. If you receive such a liver you will be asked to take an anti-hepatitis B drug.

**Hepatitis C Donors**
Patients on the list with active Hepatitis C infection may be considered to receive a liver from a Hepatitis C positive donor if the liver is in good condition. As we expect Hepatitis C to recur in all patients with active infection, receiving such livers does not affect your long-term health prospects.

**Split Livers**
In addition surgeons have looked at how to maximise the good livers we are donated. Very good livers now have to be split (another national rule) so that either 2 small adults or an adult and a child or baby can receive the liver.

This usually works well because the liver eventually grows to fit the recipient. However, for the adult recipient in particular there is an increased risk of complications, particularly bleeding and biliary problems.

This is usually in the first few days or weeks after transplantation, but then settles down and the liver works well.

Surgeons now also consider livers from donors who have died without artificial support to their heart - Donation after Circulatory Death (DCD).

The Leeds unit has one of the biggest experiences of this in the UK.
As people are waiting longer and their risk of dying whilst waiting increases, they will be considered for such livers. There is an increased risk of delayed function and biliary complications with transplantation from such livers.

Some of the biliary complications can occur much later after your transplant. They can be very complicated and difficult to treat. There is a higher risk of this happening with DCD liver transplants. We may need to consider a re-transplant. The risk of using a DCD liver is balanced against not receiving a transplant at all.

**Living donation**

From April 2007 liver transplant units in England have been able to offer transplantation involving living donation, and the Leeds unit has started this. Here someone (usually a relative) offers to donate part of their healthy liver to the person needing a transplant. This is similar to receiving a split liver transplant for the recipient. There is an advantage to the recipient of not having to wait as long and being able to plan the time of transplant to a certain extent. Strict rules apply.

If you would like more information about this, a separate information leaflet is available.

**Further information about living donation**

Please request our information leaflet on this. This details who to contact and what initial tests will be necessary.

For more information about this program please contact **Ms Julie Jeffrey (0113 20 66913)**.
Section 8 - After Discharge & General information

Going home
When the team are happy with your progress, blood results and you understand your medication. You can be discharged home. Occasionally it may be necessary to transfer you to your local hospital before going home.

Once properly home you will come to the transplant clinic.

Transplant clinic
This is held every Tuesday morning. At first you will need to come every week but the frequency of visits will gradually be cut down and by 3-6 months most people are only being seen every 3 months.

Eventually you will be seen at your local hospital in between visits to St James’s Hospital.

Adjusting your medication
You may receive telephone calls to adjust your medication once your blood tests have been seen. It is important that you keep a careful record of these changes so we can check doses with you when we phone.

If you are not confident initially in taking these calls then it is often helpful to ask someone else to take or check the message.

Readmission
Do not be disappointed if you need to come back in to hospital in the early weeks.

This is very common and necessary to ensure all is well.
Usually it is because the liver tests have altered and we need to check there are no blockages or rejection, but sometimes it is because you are not well or another complication needs excluding.

**Transport/ fares**

If medically necessary hospital transport may be provided to bring you to clinic or to hospital for treatment. However this is not freely available and once well enough you will be asked to make your own way to hospital.

If you are claiming any of the following benefits you may be entitled to re-claiming of your travel expenses, please provide proof of entitlement (This is valid for 12 months and proof of entitlement is required annually), receipts (petrol, rail fare, bus etc), attendance voucher (This is a voucher to state that you have attended your appointment- usually obtained from the clinic):

- Job Seekers Allowance (JSA) Income related NOT contribution related.
- Employment Support Allowance (ESA) Income related NOT contribution related.
- Income Support.
- Pension Credits Guaranteed NOT Savings.
- Working Family Tax credit.
- HC2 Certificate Full exemption).
- HC3 Certificate (Partial exemption).

If you do not receive any of the above you may still qualify by filling in a HC1 form based on ‘low income’.
Travel expenses can be backdated up to three months and a HC5 form may need to be completed if you wish to backdate your claim.

**Research**

There is an active program of research going on in this unit.

Some of this research relates to anaesthetics and intensive care, some to medical care including combinations of immunosuppressant drugs, and some to surgical techniques.

All research projects are carefully evaluated through the regional ethics committees. The treatment which we are able to offer patients today is as a direct result of research which has been done over the last 10 years or so, and this research depended very much on the generosity of the previous generation of patients.

If you volunteer to take part in one of the research projects, you may not benefit directly from this yourself, but it is a way of giving something back to the transplant program for the benefit of future patients.

You may be asked if you would like to take part in one of these research projects. Most are co-ordinated by our research co-ordinator, a specialist nurse with expertise in trials who would make the initial approach to you. A full explanation of what is involved will be given.

Nobody is included in the research project, unless they have given their full permission for this beforehand. Participation in any of the research studies is purely voluntary; we are keen that you should take part only if you want to.
If you do not like the idea of taking part in a research project you are under no obligation. You will receive exactly the same quality of care, whether or not you volunteer for a research project.

If you choose to take part in research but subsequently have doubts about this or change your mind, please tell us. We are happy to take you out of a research study at any stage, should you have doubts or concerns about it.

**Accommodation for relatives**
When you are called in for the operation your relatives might want to stay nearby for a day or two. There is a hotel in Bexley Wing which the ward staff can help you to book.

If a room is not available there are a number of bed and breakfast and hotels locally.

**Food for visitors**
There is a general hospital canteen open during normal meal hours and for coffee etc during the day. This serves a mix of hot and cold food.

Throughout the hospital there are smaller food outlets e.g. in Chancellor Wing by the outpatient and A&E entrance and in Bexley Wing. There are several vending machines serving snacks and cold drinks.

The Thackray Museum just next door to the hospital has a nice little café which is open during daytime hours and can make a change from the hospital grounds. The Museum itself may be of interest too.
Section 9 - Contacts & Notes

Contacts Numbers

- Ward J83 - 0113 20 69183
- Intensive Care Unit (Ward J54) - 0113 20 69154
- Liver Recipient Co-ordinators - 0113 20 66585
  An answerphone service is available. Please speak clearly and leave your name and contact telephone number and we will return your call, although this may not be the same day. If your call is urgent please contact Ward J83 - 0113 20 69183
- Substance Misuse Nurse - 0113 20 66315
- Medical Social Worker - 0113 20 64628
- Viral Hepatitis Nurses - 0113 20 65949
- Bexley Wing Hotel - 0113 20 67687
- Appointments - 0113 20 64478

Websites

- www.leedsth.nhs.uk
- www.britishlivertrust.org.uk
- www.uktransplant.org.uk
- www.liverfoundation.org.uk

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