

# Liver Transplant

## Your questions answered

A guide for patients of the Scottish Liver Transplant Unit





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Your questions answered



Liver Transplant “Your Questions Answered”

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# The Scottish Liver Transplant Unit

The Scottish Liver Transplant Unit is situated within the Edinburgh Transplant Centre in Ward 206 of the Royal Infirmary of Edinburgh. The ETC also hosts the national pancreas and islets transplant services as well as the East of Scotland renal transplant service.

The Scottish Liver Transplant Unit (SLTU) opened in November 1992 and is centrally funded by the Scottish Government to meet the needs of people in Scotland who may require a liver transplant. Since it was started SLTU has undertaken over 1800 liver transplants.

ETC has 18 beds in the ward area and twelve in the High Dependency Unit (Ward 215). In addition, there are beds available in the Intensive Care Unit in Ward 118.

This information has been prepared for people attending the Transplant Unit for assessment for liver transplant and for their relatives.

## History of Liver Transplantation

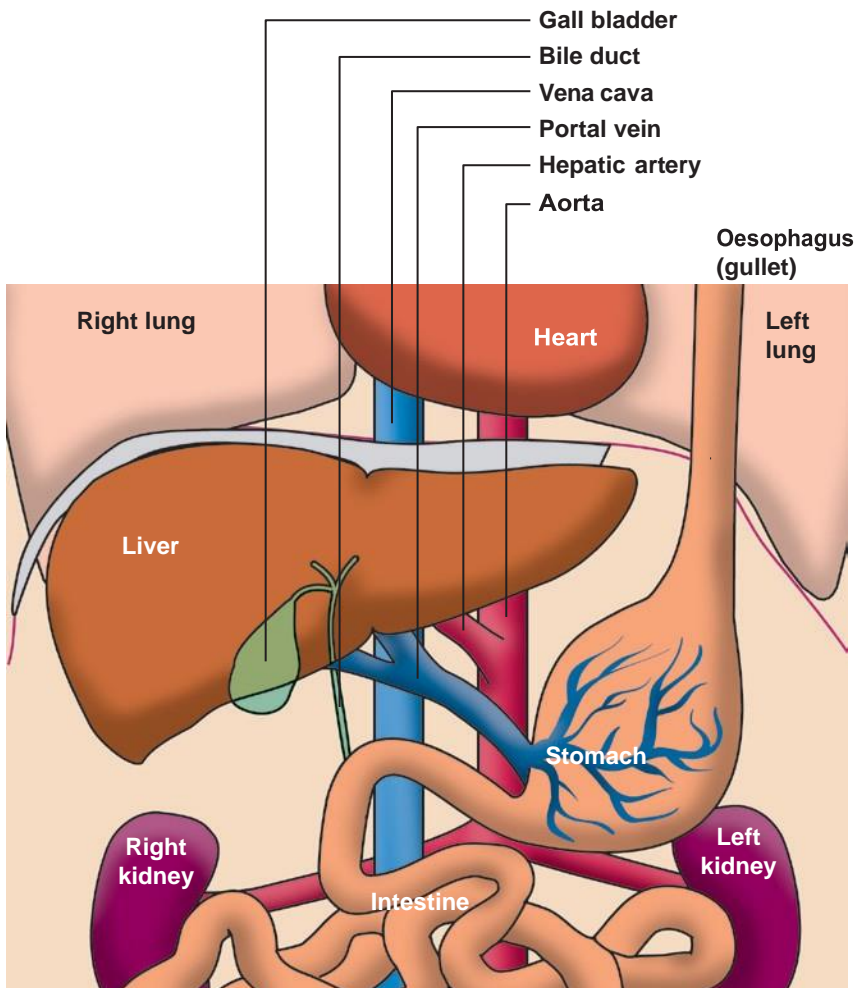
Dr Thomas Starzl performed the first liver transplant in 1963 in the USA. There have been many advances since then and by the early 1980's liver transplantation was widely accepted as a suitable treatment for many patients with advanced liver disease. Improvements in liver transplantation continue to be made as worldwide research leads us to a better understanding and new treatments and techniques are introduced.



# The Liver

## Where is the Liver?

The liver is the largest solid organ in the body. It is in the abdomen on the right side of the body between the diaphragm and the lower rib cage.



*Diagram showing principal organs and vessels relative to the liver*

## What does the liver do?

The liver performs many important functions that are essential for life. These include:

1. Manufacturing new body proteins and blood clotting factors.
2. Producing bile that helps break down fatty foods.
3. Converting food into chemicals necessary for life and growth.
4. Storing essential vitamins, minerals, and carbohydrates.
5. Breaking down drugs and hormones and removing toxins from the blood.

## What happens when the liver becomes diseased?

A healthy liver has a great ability to repair itself and can overcome most harmful things such as viral infection or damage from alcohol, drugs or excess fat. Sometimes the damage is so severe that it causes rapid destruction of the liver cells resulting in acute liver failure. In other cases, there is gradual destruction of liver cells which causes scarring. This scar formation is irreversible and leads to a condition called cirrhosis (chronic liver disease).

Common causes of cirrhosis in adults are chronic hepatitis, sclerosing cholangitis, primary biliary cholangitis, chronic alcohol misuse and non-alcohol related fatty liver disease.

Cancer of the liver, hepatocellular carcinoma (HCC) is another common reason for a liver transplant. Cancer of the liver may occur when the liver is cirrhotic. There are a number of different ways of treating cancer of the liver. A liver transplant can be the best possible treatment if the liver cancer meets certain criteria regarding the size and number of cancer deposits within the liver and if the cancer has not spread anywhere else.

## What are the symptoms of chronic liver disease?

The symptoms are many and varied. You may have experienced some or all of the following:

- **Fatigue** – varying degrees of tiredness which may affect your quality of life.
- **Jaundice** – yellow colouring of the skin and the whites of the eyes caused by a build-up of bilirubin in the blood.
- **Dark urine** – caused by bilirubin in the urine.
- **Pale stools** – difficult to flush away due to high fat content.
- **Pruritus** – a persistent itch all over your body which is often difficult to treat.
- **Weight loss** – the diseased liver cannot properly absorb nutrients from the food you eat.
- **Muscle wasting** – the body will start to break down muscle as a source of energy if it does not get essential nutrients from the food you eat.
- **Tendency to bruise and bleed easily** – caused by the inability of the diseased liver to make enough blood clotting factors.
- **Ankle swelling** – fluid retention.
- **Ascites** – build-up of fluid in the abdomen.
- **Vomiting blood** – blood is not able to flow through the scarred liver easily. This causes a build-up of pressure in the blood vessels of the oesophagus (gullet). If the blood vessels become very swollen, they may burst and bleed into your stomach causing you to vomit. Swollen blood vessels at the bottom of the gullet are known as oesophageal varices.

- **Black stools** – if there is bleeding into your stomach you may also notice your stools are black due to digested blood passing through your system.
- **Mental confusion** – the cause of this is not well understood but is thought to be due to the build-up of toxins in the blood. If it progresses it can lead to coma. This mental confusion is known as hepatic encephalopathy.

## Do all patients with liver disease need a transplant?

Not all patients with liver disease will benefit from a transplant. Other treatments are available to relieve the symptoms of liver disease. A liver transplant is only considered when these treatments are no longer helpful or your liver disease becomes advanced or irreversible. In this situation a detailed assessment is necessary to determine if liver transplantation is now an appropriate treatment option.

# Assessment for Transplant



*Arriving at the Transplant Unit*

## The purpose of the assessment is to:

1. Assess the extent of your liver disease.
2. Ensure all other medical treatments have been considered.
3. Assess your general health and fitness for transplantation.
4. Ensure there are no reasons why transplantation could not take place.
5. Provide you and your family with the information you need about transplant.
6. Find out how you and your family feel about your liver disease and the possibility of transplant.

## Who will I meet in the hospital?

The Transplant Unit is run by a very large team, many of whom are involved in your assessment. These include:

- **Transplant Co-ordinators** – The Transplant Co-ordinators organise your assessment week and provide information about liver transplantation. They support you and your family during the entire transplant process.
- **Nursing Staff** – Throughout your assessment, the nursing staff in the Transplant Unit plan and provide your daily care.
- **Medical Staff**

The **Hepatologist** is a doctor specialising in the medical treatment of liver disease. You will meet a Consultant Hepatologist, their Registrar and the Junior Doctor on a daily basis.

The **Surgeon** is a consultant specialising in liver transplantation and will discuss the operation with you.

The **Anaesthetist** is the doctor responsible for giving you an anaesthetic and monitoring your condition throughout the operation and during your stay in the Intensive Care Unit. As part of the assessment they discuss this with you and will carry out a physical examination.

The **Radiologist** is the doctor who interprets the scans (ultrasound, CT or MRI) that you have.

The **Psychiatrist** is a doctor who specialises in mental health and may be asked to see you as part of your assessment.

The **Alcohol Liaison Nurse** – if the cause of your liver disease was entirely or partly due to alcohol consumption, then you may be seen by a specialist mental health nurse as part of your assessment.

If you have developed liver failure because of damage contributed to or caused by excessive drinking, continued lifelong abstinence from alcohol will be very important for your future health.

We believe you have a responsibility to cooperate as far as further drinking is concerned. Should you be listed for a liver transplant you will be required to sign a formal contract (***Alcohol and Your Liver***) confirming that you agree never to drink alcohol again. You also agree to cooperate with any alcohol rehabilitation programme that is recommended by medical staff.

If you are transplanted this contract still stands and is even more important. You are still committed to lifelong abstinence and you will be followed up by our alcohol liaison nurse in clinic.

### **Other members of the team you will meet:**

- **Social Worker** – One of the social workers will meet with you to discuss your present situation. They will offer you and your family advice and support on personal and practical matters. Referrals to local sources of help and advice can be made.
- **Chaplain** – There are several Chaplains in the hospital. They can be contacted on your behalf. They offer support to you and your relatives and help to meet any religious and spiritual needs you may have as well as being available just to talk.
- **Dietitian** – The dietitian assesses your nutritional state and offers dietary advice accordingly.
- **Pharmacist** – The pharmacist is available to discuss your current medicines and provide information on the drugs you will have to take following a transplant operation.
- **Physiotherapist** – The physiotherapists see you to discuss your present mobility and if necessary, give any advice which might be helpful. They demonstrate and explain the importance of breathing exercises after surgery and the expected rehabilitation that will be needed for discharge home.

- **Occupational Therapist** – The occupational therapist may see you if you are experiencing difficulty in caring for yourself. They can recommend and provide any aids if needed which may help you to regain independence for your discharge.
- **Research Staff** – A number of staff are involved in research associated with liver transplantation. As a result, you may be asked to take part in various research studies. Obviously your cooperation is appreciated, however if you do not wish to take part it will not affect your care in the unit.
- **Support staff** – Language and Interpretation services are available if you need them, including British sign language (BSL).





*Having a CT scan*

## What tests will I need?

During your assessment you will have a large number of medical tests. These are to make sure that you are fit enough for a liver transplant if it is decided that this is the most suitable treatment for your condition.

The number and type of tests that need to be completed during your assessment vary from person to person but usually include:

**1. Complete history and physical examination** – we will speak to you in depth about the course of your liver disease, your symptoms and any other medical problems you may have.

### 2. Blood tests

- To test the function of your liver
- The ability of your blood to clot
- For anaemia
- The function of your kidneys
- The level of oxygen in your blood
- For viruses including Hepatitis B, Hepatitis C, Hepatitis E, Cytomegalovirus (CMV) and HIV
- Tumour markers
- Auto antibodies.



*An MRI scanner*

3. **Chest x-ray**
4. **ECG (Electrocardiogram)** – to assess the function of your heart.
5. **Endoscopy** – enables us to assess the lining of the upper part of your gastrointestinal tract and to look for any signs of bleeding.
6. **CT and MRI scans** – a CT (Computerised Tomography) will be carried out to examine the liver in more detail. In some cases, an MRI (Magnetic Resonance Imaging) scan will also be done.
7. **Pulmonary function tests** – breathing tests which provide a detailed assessment of your lungs.
8. **Echocardiogram** – if further assessment of the function of your heart is needed.
9. **Liver biopsy** – if the cause of your liver disease is uncertain it may be necessary to remove a very small amount of liver tissue to be examined under the microscope to get a diagnosis. This is done on the ward under local anaesthetic using a special needle. Bed rest for a few hours is needed after.



*Having a CPEX test*

**10. Social and psychological assessment** – liver transplantation is a major undertaking and requires total commitment from you and your family/carers. It is important for the team to know that you and your family would be able to cope with all that is involved.

## During your assessment you will...

- Receive a lot of information about the risks and benefits of liver transplantation.
- Have your questions and concerns answered by speaking to all members of the team.
- If possible, meet and talk to someone who has had a liver transplant.
- Be encouraged to discuss the above with your family.

We hope that this will enable you to make an informed decision regarding your treatment should the team decide that a transplant is the most appropriate treatment option.

## Who makes the decision?

Once all your tests are completed, the results are discussed by the team involved in your assessment. The possible outcomes of this discussion are:

- **Transplantation is the best treatment option.** You will be put on the Liver Transplant Waiting List if you have decided that this is what you want.
- **Transplantation is likely to be necessary in the future but at present the risks outweigh the potential benefits.** You will be followed up in our Transplant Clinic or at your local hospital.
- **Transplantation is not indicated.** There are other more suitable treatments available which you can receive at your local hospital.
- **Transplantation is not possible for medical or psychological reasons.** If transplantation is not indicated as a treatment option by the Scottish Liver Transplant Team, you are entitled to a second opinion. This process will be explained if necessary but will probably be a referral to one of the other 6 UK transplant centres.

## Audit and research

Your medical records are stored indefinitely. We will also ask your permission to allow us to pass details about your transplant to the authority which controls transplantation in the United Kingdom, NHS Blood & Transplant (NHSBT). The information we send them allows us to ensure that high standards in liver transplantation are achieved and maintained.

The unit is also involved in research with the aim of improving the outcomes from liver transplantation. You may therefore be approached by a member of staff to discuss your involvement in one of these clinical trials. Your permission **must** be obtained before we can include you in any trial and therefore you will not be included in a trial unless we have discussed it with you in advance.

## Are there any risks from having a transplant?

All organ/tissue donors are assessed to find out if they had any infection or illness that may be passed to patients who receive organ/tissue transplants. Every possible precaution is taken to prevent the transmission of viral infections, cancer or any other potentially life-threatening condition to patients who receive an organ/tissue for transplantation.

Whilst we make every effort to gather this information, we cannot ever give a 100% guarantee that the liver which you will receive is completely free of risk factors.

In the same way, we are very careful in assessing the function of the donor liver before transplant. Because of the shortage of organ donors, we now consider some people to be potential donors who we would not have accepted as donors a few years ago. This means older people and some people where the liver to be transplanted is not functioning perfectly.

The results of transplants from donors like these are still seen to be very acceptable. Therefore, it is felt that the balance of risk is in favour of going ahead with such a transplant rather than leaving a patient waiting on the list.



# The Waiting Period



## What happens if I go on to the waiting list?

Most people are well enough to wait at home until a liver becomes available. Before you go home the Transplant Co-ordinator discusses the arrangements for contacting you and getting you into hospital for the transplant operation.

While you are on the waiting list, we keep in regular contact with you. You will be seen in the outpatient clinic every 4-6 weeks.

It is important that you also keep in touch with us. You must let us know if you are:

- Admitted to your local hospital
- Develop an infection
- Become unwell in any way

It may be necessary to temporarily suspend you from the waiting list until you are well again. If in doubt, phone the Transplant Unit and ask to speak to the Transplant Co-ordinator.

## Where do livers for transplantation come from?

### Donation after Brain Death (DBD)

These are donors who have died following an injury resulting in brain stem death (Heart Beating Donors). This may be as a result of an accident or brain haemorrhage. All organ donors are nursed in the Intensive Care Unit

However, the number of heart-beating donors is far less than the number of patients awaiting transplantation. For patients on the liver transplant waiting list this means that the waiting time is prolonged and there is considerable risk of death on the waiting list. Because of the increasing rate of death on the waiting list a number of measures have been adopted in order to increase the number of organs available for transplantation.

### Donation after Circulatory Death (DCD)

In these donors, death is pronounced after the heart has stopped beating following which organs can be removed for transplantation. Most DCD donor livers function very well however it is recognised that these livers are associated with outcomes that are less successful than those from DBD donors. For this reason, the criteria for selecting suitable DCD donor livers are stricter. New technology to assess and optimise DCD livers before transplant is currently used to allow previously higher risk or unsuitable livers to be transplanted. The surgeon will discuss this with you during your assessment. A liver from a DCD donor may have increased risks when compared to a liver from a DBD donor. However, the risk of staying on the waiting list is often so great that it outweighs the risks of using the liver from the DCD donor.

### Split Livers

If the brain-dead donor is young and previously healthy their liver can often be used to transplant 2 patients. This is because the structure of the liver allows it to be split into two parts both of which can be transplanted. Usually the liver is split for a child and an adult.

With split liver transplantation there can be recognized complications with the blood vessels and the bile ducts of the new liver more than when transplanting a whole liver. However, the overall success rate is comparable to whole liver transplantation.

### **Living donor Liver transplantation**

A healthy relative or close friend may offer to donate part of their liver to you. They would have to undergo a detailed assessment in order to find out if they could donate part of their liver for transplantation. The advantages of receiving this type of transplant are that it may reduce the length of time you are on the waiting list and the operation could be scheduled to suit both you and the donor. The main disadvantage of a live donor liver transplant is that a healthy individual needs to go through an operation that they do not require. A separate booklet covering live donor liver transplant will be given to you and your family if you are put onto the liver transplant waiting list.

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During your assessment week the surgeon and the co-ordinators will discuss the various options for liver transplantation. Not all individuals will be suitable for all types of liver transplantation and this will be discussed with you. If appropriate, you will be specifically asked to consent to split liver and DCD liver transplantation at the time of going on to the waiting list.

The surgical team will consider a number of things relating to both you and the donor before deciding that your transplant should go ahead with the liver that has been accepted for you. All of the above types of transplants have risks, but these risks will have been considered by the surgical team before offering you the liver. At this time the team believe that your long-term survival is better with the liver they have chosen for you rather than you staying on the waiting list.

## How are livers matched?

A liver is matched by blood group, clinical need, and size. During your assessment we will check your blood group and measure your height, weight, and abdominal girth.

In the past donor livers were matched on a centre basis around the country. In 2018 NHS Blood & Transplant (NHSBT) introduced a National Liver Offering scheme. The new scheme allocates livers from donors after brain stem death (DBD) on a national named patient basis to patients on the liver transplant waiting list.

When a liver is available for transplant, an algorithm will consider the donor characteristics and the potential liver recipient characteristics. This uses a scoring system called the Transplant Benefit Score (TBS). The TBS looks at the difference between a patient's need for a transplant and the benefit they are likely to have from receiving the particular liver being offered for them.

The introduction of this system is expected to increase the number of patients' lives that we are able to save and decrease the number of people who die on the waiting list.

## Why do I have to wait?

It is not possible to predict when a suitably matched donor liver will become available and the wait can range from a few hours to many months, even years. This can be a difficult and anxious time for both you and your family. Your concerns can always be addressed to the transplant team at any time, either at clinic or by phone. There is also help from the social work team in the form of the Living on the List support group

## **Can I go away while I am waiting?**

We do not recommend that you go on holiday once you are on the waiting list as it may not be possible for you to get to hospital in time for the operation. If there is an occasion that involves being away from home, it is essential that you discuss your arrangements with the Transplant Coordinator in advance.

## **How will I be contacted?**

The Transplant Coordinator will contact you as soon as a suitable liver is available. In the first instance we will call you at home or try any alternative contact numbers you have given us, e.g. mobile phone/friend/relative.

## **What happens next?**

The call can come at any time of the day or night and you will have to leave for the hospital within a short time (about 1 hour). You will need to plan in advance about arrangements for your children, house, pets, etc. It is useful to have a bag ready with the essential things you need for a stay in hospital. You may wish to come with a close relative or friend. You will be advised about eating and drinking at this time

## **How will I get to hospital?**

You should not drive but a family member or friend may drive you to hospital if they can do so safely. Please consider your travel arrangements during your assessment week. If you need to be in hospital quickly, the Transplant Coordinator will arrange transport for you. This will be discussed with you when you go on the waiting list.



# The Operation

## What happens when I arrive at the Transplant Unit?

The nursing and medical staff meet you when you arrive at the hospital and admit you to the ward. The nurse takes your blood pressure, temperature and pulse. You will have investigations including blood tests, ECG and chest X-Ray. On occasion it may be necessary for you to have a CT scan.

The surgeon will discuss the liver transplant operation again including potential risks and will ask you to sign an informed consent form.

The anaesthetist comes to review you to see how your general condition is since you were assessed. They may prescribe some medication to help you relax before you go for your operation.

The nurses prepare you for going to theatre. You will take a shower and put on a theatre gown.



*In the Theatre*

## Could the operation be cancelled?

Yes, this is a possibility. There are occasions when we are not able to use the donor liver because we discover it is not suitable. This can happen after you have been prepared for the operation. We understand that this can be upsetting. If this situation occurs, the reasons will be explained and you will have the opportunity to ask questions. You will be allowed home when it is convenient for you. You will remain on the waiting list as before.

## Where will my family wait?

Your family may stay with you or use the relatives' overnight room (if available) until the time of your operation. They can continue to use the room whilst you are in theatre. If they live locally, we recommend they go home. On occasion it may not be possible for your family to remain with you due to clinical reasons within the hospital. The nursing staff will keep you informed.

A member of the team will speak to your relatives when the operation is over, either the surgeon or transplant co-ordinator. The intensive care staff will advise you when it is appropriate for you to visit.

The relatives' overnight room may be available for your family during your stay in the Intensive Care Unit unless it is already in use. Alternative accommodation may be available in the transplant flat if it is available. Our social worker may be able to assist with arranging this for you. There are a number of local Bed & Breakfasts around the hospital should you wish to arrange your own accommodation.

## What happens in theatre?

When you get to theatre the anaesthetist will put you to sleep and then you will be prepared for the transplant operation. This involves:

- A tube which passes into the windpipe from your mouth – this is attached to a ventilator to assist your breathing. It remains in

place until you wake up and are able to breathe on your own in the Intensive Care Unit.

- A tube which passes into the stomach through your nose – this is to prevent your stomach becoming distended or bloated during the operation. It remains in place until you are ready to drink fluid.
- Several drips are placed in the veins of your neck and forearms. These are used to give fluid and drugs and to monitor your condition. They remain in place until your condition is stable and you are able to drink fluid on your own.
- ECG electrodes which are placed on your chest to monitor your heart rate during the operation.
- A catheter (tube) is inserted into your bladder which drains urine until you are awake enough to go to the toilet unaided.

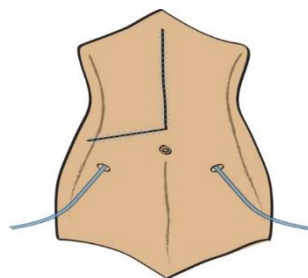
## The Transplant Operation

The transplant operation involves completely removing your diseased liver and replacing it with the donor liver. Your own blood vessels and bile ducts are joined to the blood vessels and bile duct of the donor liver. The operation normally lasts 6-8 hours but may be longer.

You remain anaesthetised after the operation and are transferred to the Intensive Care Unit.

Following the operation, you will have:

- **Abdominal wound** – this is mostly shaped like a long hockey stick. The wound is stapled closed.
- **Drains** – two or three drains are inserted into the abdomen to drain away any fluid or blood that collects around your new liver following the operation. These remain in place until the drainage stops. The drain site may then be covered with a bag or dressing.



*Diagram showing incision and drain site areas*





*In the Intensive Care Unit immediately after Surgery*

# The Recovery Period

## What happens in the Intensive Care Unit (ICU)?

During your time in ICU you will be looked after by a highly specialised team with a wealth of experience of liver transplant patients

Anaesthetists and nursing staff care for you using specialised procedures and monitoring equipment to aid your recovery. There is always a nurse at your bedside caring for you

When you wake up the tubes and drips are still in place. You are unable to talk with the tube in your mouth however it is removed when you are fully awake and the anaesthetist is satisfied you can breathe by yourself. When the tube is removed you can speak again although you will need oxygen through a mask. You may have a sore throat and a hoarse voice.

The physiotherapist helps you with breathing exercises and coughing which are important to prevent breathing problems or chest infections.

Pain is controlled by strong pain killing drugs delivered continuously through a drip (e.g., Fentanyl). Pain control is important to help you breathe deeply and cough, relieve anxiety and to allow you to move freely and to help you recover.

## **May I have visitors in the ICU?**

Yes – Usually visitors are restricted to two. There are strict visiting rules within ICU and visitors must be guided by the nurse in charge

## **How long will I be in ICU?**

The length of stay in ICU depends on your recovery. If there are no complications, you will be transferred to the High Dependency area of the Transplant Unit within 24-48 hours.

## **What happens in the High Dependency Unit?**

You are cared for by the medical and nursing staff from the Transplant Unit. The aim is to have you recover as quickly as possible. You could expect to be sitting up in the chair within 24 hours after transplant. You are still monitored closely but there is less equipment. There will be one nurse for every two patients in HDU.

Pain control remains very important. Pain killing drugs are given through a special drip called a PCA (patient controlled analgesia). This allows you to give yourself a dose of Fentanyl as and when you need it.

The wound and drain sites are cleaned as needed. As the drips and drains are removed you are able to move more freely. When your condition has improved further you will move from HDU to the ward area.

You can have visitors between 2pm– 8pm. This is also limited to two people at a time and they must take off their coats and wash their hands before entering HDU. Visitors must leave the ward during mealtimes.



*In the High Dependency Unit*

## What happens in the ward?

The ward area and its daily routine will be familiar to you from your assessment. A daily blood sample is necessary to show the function of your new liver and the level of anti-rejection drug in your system. The daily ward round pay particular attention to these blood results to decide if further investigation is needed. A liver biopsy may be necessary after the operation to see how well the liver is working and to look for signs of rejection.

The blood results determine the need for further treatments and your length of stay in hospital. This can vary greatly but the average stay after liver transplant is two weeks.

This stage of your recovery involves a lot of hard work on your behalf in preparation for going home and living with a liver transplant. During this period, it is not unusual for your emotions to go up and down. You may find it difficult to cope with your thoughts and feelings but it is quite natural to be feeling this way. Talking about your feelings allows us to reassure you and is very important for your recovery.

You will be supported and guided by the transplant team, many of whom are present on the daily ward round.

**Nurses** – the nurses are involved with your day-to-day care and work closely with you to help you regain your confidence and independence for the earliest possible discharge. They are available to you and your family to discuss any aspect of your recovery and act as a link to the other members of the team.

**Physicians** – Junior doctors do a ward round in the morning and assess your condition on a daily basis. Further decisions about your treatment are made during the consultant ward round later in the day.

**Surgeons** – the consultant surgeon monitors the surgical aspects of your recovery, especially concerning the function of the new liver, wound healing, and care of your drains.

**Anaesthetist** – problems after surgery (such as pain or breathing difficulties) are managed by the anaesthetist throughout the recovery period.

**Radiologist** – an abdominal ultrasound scan is performed by the radiologist routinely 24 hours after the operation. Further information about the new liver may be needed from other radiological investigations e.g., CT scan.

**Transplant Coordinators** – the coordinators follow your recovery on a daily basis and are available to discuss any issues regarding organ donation and transplantation.

**Chaplain** – the chaplain is available on request to offer help and support to you and your relatives throughout your recovery.

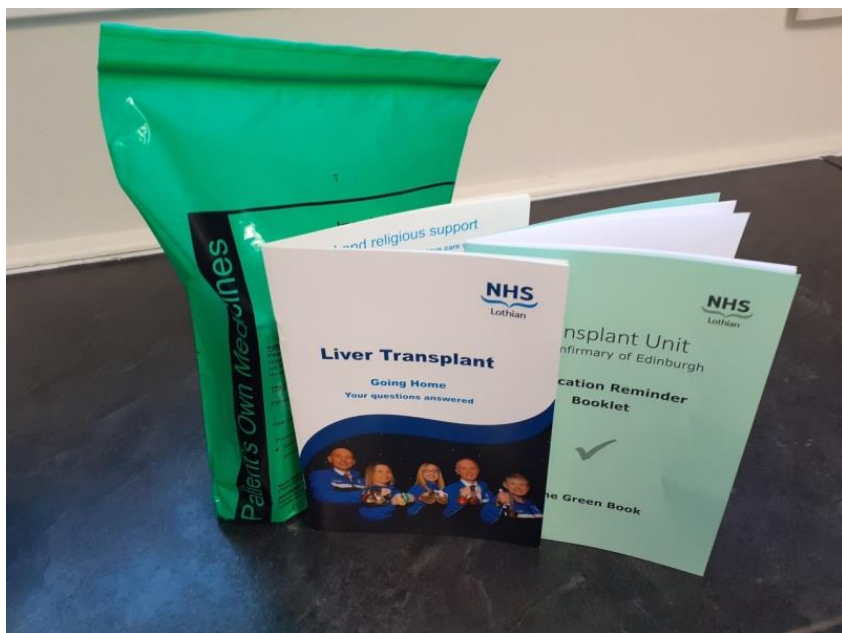
**Physiotherapist** – the physiotherapist assesses your level of mobility and works with you to ensure you are physically fit for discharge.

**Pharmacist** – the pharmacists help you understand the medicines you have to take and why you have to take them.

**Dietitian** – the dietitian discusses your nutritional needs and provides dietary advice.

**Occupational Therapist** – if you are having difficulty caring for yourself the occupational therapist will assess whether you need special aids to help you at home so your discharge is not delayed.

**Social Worker** – the social workers are available to offer emotional support and practical advice to you and your family during your recovery. They will also be available to you following discharge. There is also a 'Living On The List' drop-in group to offer added support to you and your family for the first year after your transplant. Information and dates are available from the social workers. It is a chance to meet informally with other people in similar situations and has trained volunteers who are willing to share their own experiences of transplant and are experienced in listening to and supporting others.



*Preparing for going home*



# Possible Complications

Liver transplantation is a major medical and surgical undertaking and can be associated with significant complications and risks. The risks vary for individual patients depending on a number of factors such as age and general health and the type of liver disease you have. A complication may lead to a longer stay in hospital or may need further procedures including the need for another liver transplant. In the most serious cases a complication can lead to death of the patient.

## During the operation

- Throughout any major operation such as a liver transplant, the heart is stressed and its ability to pump blood around the body may be impaired. This can cause a heart attack, cardiac arrest, or a stroke during the operation. This is why we must carefully assess the function of your heart as part of the assessment for liver transplant.

## Immediately after the operation

- Internal bleeding can occur following the operation. The surgeon will take you back to theatre to stop the bleeding.
- Lung problems may develop which would keep you in ICU longer on the breathing machine until you are able to breathe normally.
- Reversible kidney damage can occur as a result of the operation. The kidneys will gradually recover but dialysis may be necessary for up to six weeks.
- You are most susceptible to infection after the operation. Any signs of infection will be identified and treated with the appropriate drugs.
- Part of the blood supply to the new liver may be cut off and prevent it from working properly. A second transplant may be necessary.
- Very occasionally the transplanted liver does not work at all. It is not known why this happens. The only treatment is an emergency re- transplant.

## First three months

- Acute rejection is a result of the immune system's response to the transplanted liver. It is quickly and easily diagnosed and is immediately treated with high dose steroids.
- You remain susceptible to infection which may need drug treatment as an inpatient.
- Loss of appetite and nausea are common. Your appetite usually returns as you recover but if necessary the dietitian will provide supplements to your diet.
- Bile may leak from the join of the bile duct requiring further tests and treatment.
- Emotional ups and downs can affect you and your family throughout your recovery.

## Long term

- Chronic rejection of the transplanted liver can occur gradually over a long period of time although it is not common. Unlike acute rejection it does not respond to steroids but there are other drugs available that may be helpful. A second assessment and transplant may be necessary.
- Narrowing of the bile duct join may occur causing jaundice. This will require further treatment which may include surgery.
- Certain liver diseases can recur in the transplanted liver. This will require further treatment and possibly a second transplant.
- Anti-rejection medicines can cause high blood pressure which will need to be monitored and treated.
- Gradual long-term damage to your kidneys can be caused by the anti-rejection medicines and by high blood pressure. Your kidney function is regularly monitored by blood tests.

- There is a slightly higher risk of developing cancer because of the effects of the anti-rejection medicines on your immune system. Following advice on cancer screening is essential, for example: skin protection, cervical screening, breast or testicular self-examination.
- Osteoporosis (Weakening of the bones): Liver disease and long-term use of steroids are risk factors for osteoporosis which may need treatment before or after liver transplant.

The possible complications mentioned here will be discussed with you personally during your assessment.

**It is important for you and your family to be aware of these complications and risks but it does not necessarily mean that you will experience all or any of them.**



# Transplant Unit

Royal Infirmary of Edinburgh

## Medication Reminder Booklet



**The Green Book**



# Medications

## How will my body cope with a new liver?

The immune system is our body's natural defence mechanism. It is programmed to recognise and destroy anything unfamiliar. This includes the cells of a transplanted liver as well as the bacteria and organisms that cause infection.

Following a liver transplant, specific drugs are needed to prevent the immune system from rejecting the new liver. These are called immunosuppressants (also known as anti-rejection medications) and you will have to take them every day for the rest of your life.

A combination of the following immunosuppressant medications is prescribed:

- |                        |                              |
|------------------------|------------------------------|
| <b>1. Tacrolimus</b>   | (Adoport, Prograf, Advagraf) |
| <b>2. Ciclosporin</b>  | (Neoral)                     |
| <b>3. Prednisolone</b> | (Steroids)                   |
| <b>4. Azathioprine</b> |                              |
| <b>5. MMF</b>          | (Cellcept, Myfortic)         |
| <b>6. Sirolimus</b>    | (Rapamycin)                  |

All of these drugs will increase your risk of infection. During the first few months after transplantation the need for immunosuppressants is at its highest. This is the time when you are at most risk from infection. The risk decreases when the doses are reduced after several months but it will always remain sensible to avoid close contact with people with infections e.g. chicken pox, flu. You will be monitored very closely for signs of infection and treated if necessary.

Regular blood samples will determine the level of these drugs and the daily dose will be changed if required by the Transplant Unit doctors. If the levels are too low the risk of rejection is greater and the doses are increased. If the levels are too high you may experience more side-effects and the doses are reduced.

You must **never** alter the dose of your immunosuppressants by yourself.

**Failure to take these medications as prescribed can result in rejection of your new liver.**

## What are the possible side-effects?

Like most medicines, immunosuppressants have some unwanted side-effects. Although a medicine is known to cause certain side-effects, it does not necessarily mean that you will experience all or any of them. Other medicines are available to help treat troublesome side-effects.

The following side-effects may be experienced:

- **Tacrolimus** – increased blood sugar/diabetes, headaches, visual problems, shaky hands, aching joints, high potassium, and renal failure
- **Ciclosporin** – high blood pressure, headaches, increased/unusual hair growth, sore or swollen gums, shaky hands, high potassium, and renal failure
- **Prednisolone** – mood changes, increased appetite, weight gain, indigestion, irritation of stomach lining, fragile skin, and thinning of the bones (osteoporosis)
- **Azathioprine** – unusual bleeding or bruising, hair loss, nausea and vomiting, increased risk of skin damage by sun exposure
- **MMF** – diarrhoea, nausea, and vomiting
- **Sirolimus** – diarrhoea, joint pains, skin rash, trouble sleeping, and delayed wound healing

## What other medicines do I have to take?

For the first three to six months after transplantation you need to take the following medicines:

- **Antibiotics** – to reduce the risk of bacterial infection
- **Antifungals** – to reduce the risk of fungal infection in your mouth
- **Antivirals** – to reduce the risk of viral infection
- **Antacid** – to reduce the risk of stomach ulcers and heartburn

## Can I take any other medicines?

Please discuss your current medication with the pharmacist if you need to buy “over the counter” medicines for minor ailments for example, Paracetamol for a headache.

Your GP may wish to contact the Transplant Unit before giving you any new prescription medicines.

## What else do I need to know about medicines?

When you are ready after your transplant you will have the opportunity to participate in the self-medication programme that operates in the Transplant Unit. It is designed to give you practical information about your medicines and inform you of how and when to take them whilst still in hospital. The nursing staff make sure that by the time you are ready to go home you feel confident that you know all you need to about your medications and their possible side-effects. The transplant pharmacist will also counsel you on your medication before you are discharged home.

If you have any concerns about your medicines do not hesitate to ask a member of the team.



# Living with a Liver Transplant

The aim of liver transplantation is to allow you to return to an independent lifestyle with a good quality of life.

## Going home

Everyone looks forward to going home but it can be an anxious time. Your discharge is carefully planned by the team so that you and your family feel confident and well supported at home. You will receive a Discharge Information Pack (Going home booklet) at this time.

## Follow-up Clinic

The purpose of regular follow-up is to see how you are generally. Blood tests are taken to assess your liver function and the level of your immunosuppressants. Initially clinic appointments are weekly. The time between your appointments will increase depending on how well you are, how well the function of your liver is and the length of time since your transplant. Your referring doctor and your GP will also be involved in your follow-up care.

## Exercise

It takes six to eight weeks for the wound to heal but the muscles and nerves take longer to get back to normal. During this time you should avoid strenuous physical activity but gentle exercise is necessary to regain your strength and muscle tone (e.g. walking). In the longer term a liver transplant should not prevent you from participating in any activity or sport that you enjoy, except contact sports which may expose you to injury.

## **Diet and Weight Gain**

After liver transplant you are able to eat a normal balanced diet. It is important to maintain a healthy weight – this can involve some effort as immunosuppressants have a tendency to cause weight gain. Steroids in particular cause this problem through salt and fluid retention – for this reason you should avoid salt whilst on steroids. The dietitian will give you advice on healthy eating and weight loss.

## **Alcohol**

If alcohol is the sole or partial cause of your liver disease, then lifelong abstinence from alcohol is mandatory to safeguard your future health. Many other people also prefer to remain abstinent following a liver transplant. However, if alcohol was not the cause of your liver disease, and you are generally well, you are permitted to drink within the national guidelines.

## **Sex**

There is no medical reason that you cannot have sex when you feel well enough. However, you may find that it takes some time for your sex drive to return and this is quite normal.

## **Contraception/pregnancy**

Female patients of child-bearing age must use appropriate birth control methods as pregnancy should be avoided for at least a year after liver transplant. Male patients who are being treated with Valgancyclovir or MMF should use barrier contraception during treatment and for 90 days after finishing the course. Patients wishing to start a family should discuss this with their transplant team as soon as possible as changes to immunosuppression may be required.

## Driving

You may return to driving from about six weeks after going home from hospital. This will depend on the speed of your recovery.

## Returning to work

You are likely to remain off work for at least three months, but this depends on your recovery and the type of work you do.

## Travel

There is no reason to prevent you from travelling in the UK as soon as you feel well enough but we recommend that you do not travel overseas for at least one year after your surgery. You should contact the Transplant Unit for information on health risks, travel insurance, and medication.

## Any Questions?

Should you have questions or concerns about any aspects of liver transplantation that you wish to discuss with a member of the transplant team please contact us at the Transplant Unit on:

**Transplant Coordinators:** 0131 242 1721

**Ward:** 0131 242 2069

### **Websites you may find useful:**

[services.nhslothian.scot/scottishlivertransplantunit](https://services.nhslothian.scot/scottishlivertransplantunit)

[edinburghtransplant.org](https://edinburghtransplant.org)

[www.odt.nhs.uk](https://www.odt.nhs.uk)

[britishlivertrust.org.uk](https://britishlivertrust.org.uk)

[www.nhsinform.scot](https://www.nhsinform.scot)

[www.gov.uk](https://www.gov.uk) (DVLA)

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Written by Liver Recipient Transplant Co-ordinators, SLTU.

Revised by Liver Recipient Transplant Co-ordinators, SLTU,  
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## Notes

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