Liver transplantation:
What does it mean to me and my family?
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Disclaimer
This information booklet is to be used in conjunction with discussions and education by the staff on the Liver Unit.

Be aware that the information given may alter due to protocol amendments and more importantly, because of the individuality of your care.

Acknowledgments
Thanks go to the many Liver Unit staff as well as patients and their families who over many years have contributed to the development of this book.

Caroline Stanton and Pete Ashcroft

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Introduction

Welcome to the Liver Unit

Liver transplantation is a recognised form of treatment for some patients in the final stages of liver failure. The liver transplant programme in Birmingham started in the early 1980s and we have now done more than 3,500 transplants. There have been many advances in practice during that time.

The phrase “liver transplantation” may cause you to feel many different things, from initial fear and anxiety through to excitement and relief. Reading this book will help to answer some of your questions so that you can make that final decision about going forward for liver transplantation. It will supplement the information given to you by the various members of the Liver Unit team who will be involved in your care.

During your liver transplant assessment you will have the opportunity to find out all you need to know about liver transplantation. You will be able to meet other patients who have already had a liver transplant. You will meet members of the Birmingham Liver Support Group’s Hospital Visiting Team who will talk to you about their experiences and are available to answer your questions. (See ‘Support groups.’)

It is important that you use this opportunity to find out all that you can about liver transplantation. Some patients find it helpful to keep a diary which can help you to remember what investigations you have had and who you have spoken to. You can write down questions that you want to ask the staff next time you see them.
About this book
This book is given to all patients who come to the Queen Elizabeth Hospital Birmingham (QEHB) for liver transplant assessment. It is yours to keep, regardless of the outcome of your assessment. Please keep it safe and make it available for your loved ones to read as well. Many patients tell us that they found the book an invaluable source of information throughout the assessment and transplant process and that they still refer to the book for information and advice many years after their transplant.

We can only provide one book per patient. However, we can send you an electronic copy via email if you have a home computer.

Finding your way around
Do not hesitate to ask a member of staff if you feel lost. Maps and guides are available from the information desk in the main entrance (atrium) and on the Trust’s website: www.uhb.nhs.uk.

Accommodation – The Relatives’ Wing
Up to two relatives can stay on the hospital site whilst you are an inpatient or if you need to stay overnight for outpatient assessment. There are a limited number of rooms in Nuffield House. The accommodation managers can be contacted on 0121 371 4524. Please call between 08:30-16:30 weekdays.

Provisional bookings can be made prior to admission but rooms cannot be guaranteed.

You are advised to phone on the morning of admission to check availability. Most rooms are twin. There are bathroom facilities, a kitchen, and residents’ lounge with a TV. Unfortunately, it is not possible for children under the age of 16 to stay in the accommodation. The charges are as follows:
• £20.50 for one person per night
• £30.50 for two people sharing, per night
Please note these prices are subject to change
If no room is available, or if you prefer, there are a number of local B&Bs and reasonably priced hotels. Ask the accommodation officer or the transplant coordinators for a list of these.

Social issues

Transplant assessment is carried out either as an inpatient on ward 726 or as an outpatient. Inpatient assessment usually means at least a week (possibly longer) in hospital. Outpatient assessment involves two visits to the QEHB: one for a day and one for two days. If you go onto the waiting list there will also be regular clinic visits and possibly hospital admissions. This can be a costly process involving time off work, transport, parking and accommodation fees for patients’ relatives, as well as telephone and food costs. The Liver Unit has a social worker (see ‘Contacting the hospital’) who may be able to help with these issues and others relating to your needs at home and claiming benefits. The transplant coordinators can refer you to a social worker if you ask them.

Everyone needs help and support through this difficult time. If possible, ask family and friends for assistance, especially during the time of the transplant. You may find them helpful in fielding telephone calls, preparing your house for your return home, caring for pets or for transport to hospital for visits and so on.
Contacting the hospital

Telephone enquiries

It is recommended that you select one or two people to act as ‘spokespeople’ who can pass on information to the rest of the family. The wards are limited to the amount and detail of information that can be passed on via the telephone, in order to maintain patient confidentiality and privacy.

Direct telephone numbers:

<table>
<thead>
<tr>
<th>Service</th>
<th>Telephone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Queen Elizabeth Hospital Birmingham (Main switchboard)</td>
<td>0121 627 2000</td>
</tr>
<tr>
<td>Ward 726 direct line</td>
<td>0121 371 7260</td>
</tr>
<tr>
<td>Ward 726 staff base 1</td>
<td>0121 371 7261</td>
</tr>
<tr>
<td>Ward 726 staff base 2</td>
<td>0121 371 7262</td>
</tr>
<tr>
<td>Critical Care Unit (Area A)</td>
<td>0121 371 6325 / 6324 / 6328 / 6330</td>
</tr>
<tr>
<td>Liver Outpatients</td>
<td>0121 371 4414</td>
</tr>
<tr>
<td>Dietitians</td>
<td>0121 371 3428 / 3489</td>
</tr>
<tr>
<td>Social work</td>
<td>0121 371 4593</td>
</tr>
<tr>
<td>Bereavement Care</td>
<td>0121 371 2450</td>
</tr>
<tr>
<td>Liver transplant coordinators: 08:00-16:00</td>
<td>0121 371 4528</td>
</tr>
<tr>
<td>On-call via switchboard 16:00-08:00</td>
<td>0121 627 2000</td>
</tr>
<tr>
<td>Accommodation</td>
<td>0121 371 4524</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>0121 627 2389</td>
</tr>
</tbody>
</table>
Website and email addresses

You can access the information about the Liver Unit on the Trust’s website: www.uhb.nhs.uk. Select A-Z of services and click on Liver Unit. The liver transplant coordinators can be emailed at: lrtc@uhb.nhs.uk

PALS (Patient Advice and Liaison Service)

PALS works in partnership with patients and staff to help improve services to patients. They are situated just down the corridor from the information desk at the main entrance. Ask at the information desk for directions. PALS are there to:

• Provide advice and support to patients and carers
• Listen to your comments, compliments and concerns, suggestions or queries
• Help resolve any problems that you may have, as quickly as possible
Pre-transplant

Transplant assessment

The purpose of transplant assessment is to evaluate your general level of health and fitness, investigate the progress and severity of your liver disease and consider treatment options. One of these treatment options may be a liver transplant. The assessment includes evaluation of your heart, lungs and kidneys as well as your liver, and will also look for any other diseases that you may have. It also considers how you as an individual would cope with having a liver transplant and what kind of support you have at home to help you through it. At the end of the assessment, one of several conclusions may be reached:

1. You may be put on the transplant waiting list, and then wait for a liver to become available
2. You may decide that you do not want a liver transplant
3. We may advise that a liver transplant is not appropriate and that other treatments may be more effective
4. We may feel that liver transplantation is not technically possible; in this case you would not go on the waiting list. We can refer you to another liver transplant unit for a second opinion if you are not happy with this decision
5. You may want to go home to think through your options and reach a decision later

The assessment involves having a number of tests or investigations and meeting members of the team who will be assessing your needs and giving you information about liver transplantation. The assessment process is described in more detail a little later on in this booklet.
Liver unit staff

The doctors

A large number of doctors will be involved in your care on the Liver Unit including surgeons, anaesthetists and physicians. The doctors work as a team. Each patient has a designated consultant but you will meet other consultant surgeons and hepatologists on your transplant journey. You could fill in the names of the doctors that you see below.

My consultant hepatologist is:

The consultant hepatologist I saw in my assessment was:

The consultant surgeon I met in my assessment was:

The consultant anaesthetist I met in my assessment was:

The surgeon who did my transplant was:

The consultants are supported by medical and surgical registrars and house officers. Doctors from all over the world visit the Liver Unit to undertake research and work in a medical capacity. The Queen Elizabeth Hospital Birmingham is a teaching hospital and medical students may come to see you as well.

The liver transplant coordinators

The liver transplant coordinators are a team of specialist nurses who will guide you through your transplant journey. They will guide you through your assessment and they are there to support you whilst you are waiting; it will be one of them who calls you on the phone when a
suitable donor for you has been found. They will work with you whilst you are in hospital at the time of your transplant and see you in the clinics during the first three months afterwards. You can contact them for help and advice at any time no matter how long ago your transplant was. They work as a team and you may meet several coordinators as you go along. Write their names below if you wish:

The coordinator I met in my assessment was:


The coordinator who called me in for my transplant was:


Other coordinators I have met:


How to contact the liver transplant coordinators

For routine calls during office hours it is advisable to call after 10:00.

Telephone the secretary to the transplant coordinators on 0121 371 4528 (08:00-16:00) weekdays. Out-of-office hours and weekends via switchboard 0121 627 2000: ask for the on-call liver transplant coordinator.

The nurses

The senior nurse for the Liver Unit oversees nursing across the Liver Unit including Ward 726, the outpatient department and the work of the specialist nurses.

There is a large team of nurses working on ward 726 and in the outpatient department. Jay Ittoo is the ward sister for ward 726 and Maria Round is the sister in the liver outpatients department. Some of the nurses have more experience than others; some of the nurses will be students and others will be unqualified nursing assistants. If you are unhappy with your care, or if you want to compliment the nurses, ask to speak to the nurse in charge or the senior nurse.
The chaplain

The chaplaincy service covers all the major religious denominations but their main interest is in you as a person, with all the emotions, hopes, fears and concerns that are common to most patients. If you want to see a chaplain please ask the nurse who is looking after you. If you want religious support for your own faith, the chaplain will be able to contact an appropriate person.

Clinical trials coordinators

The clinical trials coordinators are specialist nurses who are trained in research and liver disease. Transplantation is at the forefront of medical science and research projects are regularly undertaken on the Liver Unit. The clinical trials coordinators may meet you and your family to discuss the possibility of your inclusion in a research project, ensuring that you understand what the project entails.

In order to improve standards of care we often survey patients’ opinions about the care that they receive on the Liver Unit. You may be asked to participate in surveys of this nature by members of the team or researchers. If you decide not to participate in a survey or research project the standard of care that you receive is not affected.

All research trials and studies are approved and regulated by an independent Research Ethics Committee as well as the Trust’s Ethics Committee. Your participation is entirely voluntary and you are entitled to withdraw at any time.

The dietitians

As part of your assessment you will be reviewed by a dietitian who will talk to you about your diet and assess your nutritional needs. They can give you a tailor-made plan for your nutrition taking into account your own particular circumstances. You may need to take nutritional supplement drinks to help maintain your nutrition. There are a wide range of supplements available and the dietitian will advise which are best for you.

If necessary, arrangements to review your progress can be made when you are seen in liver outpatients. Please speak to your dietitian to
arrange this.

Your dietary needs will be different after a transplant and you may need further advice from the dietitian. If you wish to speak to a dietitian please ask the nurse looking after you or the transplant coordinators who will contact them.

**The pharmacist**

After your transplant you will be taking different tablets, some of which you will have to take for the rest of your life. The pharmacist will explain the benefits of these drugs and their side effects. Following your transplant you will meet the pharmacist who will talk through your tablets with you and your carer.

**The physiotherapist**

Physiotherapists will work with you after your transplant by helping you to deep breathe and cough, and to build up your strength and regain your mobility. Physiotherapy is extremely important, especially immediately following the transplant, to keep your chest clear. You will be shown how to support your wound to make coughing easier. The sooner you are able to get up and about the sooner you will be able to go home.

**Clinical Nurses in addiction psychiatry**

Call via the Queen Elizabeth Hospital Birmingham’s switchboard or on 0121 371 4528.

Where alcohol or other recreational drugs are a key feature of your liver disease you will be seen by one of the clinical nurses in addiction psychiatry. They will assess your understanding of your disease and will plan any support that you may need.

If you are receiving, or have ever received, care or treatment for mental health issues they will ensure that you are well prepared and appropriately supported for transplant. They may also want to see you with your family and may need to follow you up in clinic both before and after transplant. They may wish to see you along with a consultant psychiatrist.
The social worker
You can see a social worker during your transplant assessment or afterwards if you wish to. They are there to help you with claiming benefits, housing issues, reclaiming transport costs and other financial concerns. You can contact the social worker directly (see ‘Contacting the hospital’), or you can ask the transplant coordinators who will refer you to them. The social worker will be involved in the planning of extra help from your local social services department if that is required.

The ward clerks and clinic receptionists
The ward clerks can be found in the ward reception area. Your relatives will probably speak to the ward clerks when making enquiries about your condition on the telephone. They will also help you with doctor’s sick notes, appointments for outpatient clinics and general enquiries. The clinic receptionists will also help you in making your next outpatient appointment.
Information about the liver and liver disease

The healthy liver

The liver is the largest organ in the body. It is located in the upper right hand side of the abdomen (from the waist, up and sheltered by the lower ribs and across to below the heart). A healthy liver is smooth and firm, similar to liver seen at the butchers. It is supplied with blood from two different sources, as can be seen in the diagram. The liver filters blood supplied from the portal vein, blood from the artery supplies the liver cells with oxygen.

The healthy liver can grow new cells to replace damaged ones. This is called regeneration. However, damaged livers (as in cirrhosis) do not regenerate normally. If the liver is too damaged (nearly three quarters) it cannot function properly and the individual will start to experience some of the symptoms of liver disease.

The liver has many functions, some of which are listed here:

- Processing digested food from the intestine
- Manufacturing bile, an important substance for digestion of fat
- Breaking down food and turning it into energy
- Producing heat for the body
- Controlling levels of fat, amino acids (protein) and glucose (sugar) in the blood
- Helping combat infections in the body
- Neutralising and destroying drugs and toxins, including alcohol
- Making enzymes and proteins which are responsible for chemical reactions in the body, for example those involved in blood clotting and repair of damaged tissues
Diagram of liver anatomy and placement in the body

- Vena cava
- Aorta
- Liver
- Gall bladder
- Bile duct
- Hepatic artery
- Portal vein
The unhealthy liver

When the liver becomes damaged by disease, it is unable to properly carry out these functions. Because the liver has so many functions the signs and symptoms of liver disease are widespread. Some patients experience many symptoms whilst others may have very few. The symptoms can also change as the condition of the liver fluctuates. The list below shows some of the effects of liver disease:

- Fever
- Jaundice (yellowing of the eyes and skin)
- Bruising and difficulty in stopping cuts from bleeding
- Loss of appetite – nausea and vomiting
- Weight loss and muscle wasting
- Pruritus (itching skin)
- Ascites (fluid in the abdomen), and oedema (fluid on your legs and hands)
- Tiredness
- Loss of concentration – confusion – change in personality (encephalopathy)
- Disordered sleep pattern
- Changes in your stool (pale or black or diarrhoea)
- Dark urine
- Spider naevi (red spots on your skin)
- Caput medusa (veins that show up on your tummy)
- Palmar erythema (reddening of the palms of your hands)
- Fetur hepatis (smelly breath)

There are many causes of liver disease. You are probably aware of your own diagnosis already. If you are uncertain please ask the doctors or liver transplant coordinators. You can find information about the causes of liver disease at: [www.liverfoundation.org](http://www.liverfoundation.org).
The assessment

The assessment is a medical, psychological and social evaluation. You will have many blood tests and investigations; you will also be asked questions about your health, and your home and social situation. The aim is to establish if a liver transplant is the right treatment for you, at the right time, and to minimise the risks associated with it. You will also be given information to help you understand about liver transplantation so that you can decide if it is a treatment that would suit you.

Investigations

During your assessment you will have a number of investigations. Some of these tests may have been performed at your local hospital, however, it is likely that we will want to repeat them. You may not need all of the tests described below but most patients have: chest X-ray, ECG, abdominal ultra-sound scan, blood tests, echocardiogram, ward spirometry and pulse oxymetry. After you have gone onto the waiting list you may have a bone density scan. (See below and ‘Osteoporosis’.)

Investigations you will have

Blood tests

The doctor or nurse will take blood, usually from your arm. Many tests are carried out on your blood. These can help to confirm the cause of your liver disease, how poorly your liver is and if you have any other diseases. The tests include:

- Liver function tests
- Urea and electrolytes (kidney function tests)
- Full blood count and clotting (gives further information about how well your liver is working)
- Virology (to check your hepatitis A, B, and C, HIV and CMV status (See ‘Virology’ and ‘Glossary’)
- Cancer markers and other disease indicators
• Alcohol level (this can be taken randomly at any clinic visit or on being admitted to hospital, particularly where alcohol has been a feature of your disease)

Chest X-ray
To look at your heart and lungs.

Echo cardiogram
This is a study that involves using sound waves to see the heart and how it is beating. It is a simple and pain-free scan where gel is applied to the chest and an ultrasonic probe is moved across it.

Electrocardiogram (ECG)
This study records the natural electrical activity of the heart. It involves having stickers placed on your chest, wrists and ankles and is pain-free.

Pulse oximetry
This tests how much oxygen is getting into your body. A small probe is clipped onto a finger and within a few seconds a reading will appear on the monitor.

Ultrasound
This test occurs in the Imaging department. You may be asked not to eat or drink anything except water for six hours before as food and some drinks prevent the gall bladder from being seen. Gel is applied to your tummy and an ultrasonic probe is moved over the skin and allows the technician or doctor to see your liver, its blood vessels and bile ducts; any cysts or tumours; the kidneys, gall bladder, pancreas and spleen.

Virology
Blood will be tested for infection and viruses including HIV and Hepatitis A, B and C. All potential transplant recipients are tested for these routinely. You may need vaccination against Hepatitis A or B, which will be given to you whilst you are at the hospital or by your GP after you leave. (See ‘Vaccinations.’)
Ward spirometry

This is a breathing test carried out by the doctors or transplant coordinators to test the strength of your lungs. You will be asked to blow hard into a tube. You will be given three attempts, and the best of the three is recorded.

There are other tests that you may need. The doctors or transplant coordinators will tell you if you need extra investigations and why it is felt they are needed. These are listed and explained below. There are procedures that are not mentioned here: for these there are leaflets available on the ward and in clinic. You can also ask the doctors, nurses or liver transplant coordinators if you have any questions about your tests. Remember this is a full list of possible tests and you may only need the tests listed above.

Investigations you may have

Angiography

This investigation looks at the blood vessels in your liver or elsewhere. It takes place in the Imaging department and is done by doctors. Your written consent will be obtained after doctors have explained the procedure and answered any of your questions. You will be starved before the procedure and given antibiotics. A line is passed into an artery in the groin, arm or neck. Contrast is injected through the line and X-rays are taken which will show any blockage or narrowing of the blood vessels in the liver. Sometimes the procedure is a little uncomfortable, and medication can be given to help you relax. After the procedure you may have more antibiotics and you will be asked to rest on your bed for four hours to allow healing of the site where the line was put in. Your blood pressure, pulse and the wound site will be monitored.

Arterial blood gases

This is a test to see how much oxygen is carried in your blood. The doctor will take blood from the area on your wrist where you can feel your pulse. This is a sensitive area and sometimes there may be some discomfort, although this is a quick test.
Biopsy
The removal of a small piece of tissue from the body. (See ‘Glossary’.)

Bone scan (Dexa scan)
This test is to determine how strong your bones are, as sometimes with age and liver disease they can become weak due to a disease called osteoporosis. An X-ray machine is passed over the area that is of interest (usually the hips and pelvis) to determine any problems. Most patients will have this test after they go onto the waiting list to screen them for osteoporosis. (See also ‘Isotope bone scan’.)

CT scan or CAT scan
This is a scan that uses a computer to create a picture of the body. You will be asked to lie still for the scan and you will pass through a large metal hoop. Some patients may be given an injection of contrast which will enhance the picture, or you may be asked to drink a mixture which will also enhance the picture depending on which organs need to be viewed.

Exercise ECG
This study records the electrical activity of your heart when you are exercising. The ECG leads will be placed on your chest, wrists and ankles and you will be asked to walk on a treadmill. When you feel uncomfortable or breathless you can tell the doctor and technician who will stop the study.

Electroencephalogram (EEG)
This study records the natural electrical activity of the brain. It involves having tiny stickers applied to your scalp and is pain-free.

Endoscopy
This investigation looks at the oesophagus (gullet) and stomach to look for ulceration, inflammation and varices. (See ‘Glossary’.) Your written consent will be obtained after discussions with a doctor who will explain the procedure and answer your questions. You will be told
not to eat for six hours before so that your stomach is empty. Whilst you are in the endoscopy room, a local anaesthetic may be sprayed on the back of your throat. You may be given an injection which will make you feel sleepy. Afterwards you will go back to the ward on your bed. If varices are found they may need to be treated. This will be done using either Sclerotherapy (injecting the varices to remove them) or Banding (supporting the varices with a band around the vessel so that the varices cannot bleed).

**Diagnostic ascitic tap**

If you have ascites the doctor may take a small amount of the fluid out using a needle and syringe. This would be sent to the laboratory for examination. If you have severe ascites these may be drained (paracentesis) whilst you are on the ward.

**Isotope bone scan**

This is a bone scan that involves injection into a vein of a radio isotope tracker which is taken up by the bone and then X-rayed. You may have this scan for a number of reasons and this would be explained by the doctors beforehand.

**Lung function tests**

These tests are performed in the Lung Investigation Unit and help the doctors and anaesthetists understand how well your lungs are working. They supplement the ward spirometry tests if needed.

**MRI (Magnetic Resonance Imaging)**

MRI is similar to CT. It uses magnetic forces to see through the body. You will lie on a scanning table with your arms at your sides. The scanning table slides into a large circular magnet. For clear pictures you will be asked to lie very still and possibly to hold your breath for a short time. You will be asked whether you have anything metal in or on you, such as a pacemaker or staples in a wound. Some patients may find the procedure claustrophobic. If you think that you may feel uncomfortable, discuss this with the nurse or doctor who will be there during the test. There are some procedures that can be performed whilst you are
having an MRI such as angiography. You will be informed about any procedures before they are done.

**MRCP (Magnetic Resonance Cholangiopancreatography)**

This is a special test of the liver and bile ducts using MRI (see above). There is no special preparation for it.

**Myocardial perfusion scan**

This test shows how well your heart works when it is under stress by looking at the blood supply to the heart muscle. It may require two separate sessions, possibly on different days to do the test – one at rest and one with your heart being made to work a little harder. To make your heart work harder you can be injected with a drug which will make it beat faster. For both sessions, the test involves an injection of a radioactive substance (so that it can be seen in the body by the equipment). The radioactivity is the same amount as that received when you have an X-ray.

**Percutaneous liver biopsy**

This is usually performed on the ward. The doctor will explain how the biopsy will be taken and ask you to sign a consent form. Local anaesthetic is applied to an area on your side over your liver. This area is then cleaned and a special needle is inserted to take out a small sample of liver. After the biopsy you will be asked to rest on your bed for four hours, and then be allowed to sit upright for another two hours. Your blood pressure and pulse will also be monitored as will the wound site for any bleeding.

**Swan-Ganz catheter (right heart catheter)**

Sometimes it is important to look closely at the heart and lungs. To do this, the doctors will arrange for you to have catheter passed through a vein in your neck or near your collar bone. Local anaesthetic is applied to the area of your neck or collar bone and a very thin catheter is inserted. It will pass down the vessels into the chambers of the heart. Once in position, the catheter allows for measurements of the heart’s functions. After they have taken their readings, the doctors will remove
the line and apply a small dressing to the wound. You will need to lie on your bed for several hours afterwards.

**Transjugular liver biopsy**

Sometimes a percutaneous liver biopsy cannot be performed due to ascites or because it takes a long time for the blood to clot. The biopsy can then be performed by passing a catheter via a vein in your neck. The doctor will explain the test and ask you to sign a consent form. You will be given antibiotics before and after the biopsy. The test takes place in the Imaging department. Local anaesthetic will numb the area of the neck and sedation can be given to help you relax. The doctors will pass a small needle into a vein in your neck. A thin wire passes through the vein and a small sample of liver is taken. After the biopsy you will be asked to lie on your bed for four hours, and then be allowed to sit up for another two hours. Your blood pressure and pulse will be monitored and the neck wound will be watched for bleeding or bruising.

**Venogram**

This study is very similar to an angiogram and the procedure is the same. The veins in and around the liver will show up on the X-ray.

**People who you will meet**

You will meet many people during your assessment. These will include:

**Consultant hepatologist:** Your medical consultant (physician) will assess the severity of your liver disease, manage your treatment and make recommendations as to whether you should have a transplant or not.

**Consultant surgeon:** The surgeon will assess the technical aspect of the transplant operation and explain how the operation is performed. He will also explain about organ donation and that you might receive a ‘whole liver’; or a ‘split liver’ (see ‘Glossary’ for terms and diagrams). The split liver is usually shared between a child and an adult. He will also explain the potential complications and side effects of the transplant and ask you to sign a consent form for liver transplantation. Signing the consent form does not commit you to having a transplant.
or mean that you have been added to the waiting list. It is a formality which is best undertaken at this time or at a later date if you prefer.

**Registrar and house officers:** These doctors work with the consultants carrying out the day-to-day care on the ward. They will talk to you about your liver disease, examine you, take blood and arrange the tests and investigations that you may have.

**Consultant anaesthetist:** The anaesthetist will assess the ability of your heart and lungs to cope with the transplant. They will talk to you about the day of surgery and the Critical Care Unit. (See ‘Anaesthetic assessment’.)

**Liver recipient transplant coordinator:** You will meet a transplant coordinator during your assessment. The coordinators will guide you through the assessment process and answer any questions that you may have. They will arrange to talk to you and your family (carer) at length about going on the waiting list, what happens at the time of the transplant, the operation and the care that you will need afterwards. It is important for your carer to attend this talk as they need to understand the care that you need and the risk of transplantation, just as you do.

**Liver support group:** The group is made up of former transplant patients who give up a little of their own time to come into the hospital and talk to you about their personal experience of liver transplantation and to answer your questions. Patients often tell us how helpful it was for them to meet the Support Group members.

**Dietitian:** If the doctors are concerned about your nutrition you may be referred to a dietitian who will meet you to discuss your diet and any supplements that you may need.
Other people you may meet

**Social worker:** A social worker is available to help with arranging support both before and after your transplant. If you are entitled to receive benefits they may be able to help you with this. You can phone them directly or speak to the transplant coordinators if you want to meet the social worker.

**Clinical nurses in addiction psychiatry:** These nurses will assess your needs and any support you may require after transplantation. You may meet these nurses at assessment if alcohol or other recreational drugs are a feature of your liver disease. Alcohol consumption may affect your health before or after the transplant, and therefore you may need support to remain alcohol free. Any patient (regardless of the cause of their liver disease) may be seen by one of the nurses if there are particular psychological issues such as depression or anxiety that they may be able to help you with.

**Other specialist doctors:** If you have health issues other than those associated with your liver disease, or if the tests which you have identify potential problems with your heart or lungs, you may meet specialist doctors such as cardiologists (heart doctors) or oncologists (cancer doctors). The liver doctors will let you know if they are planning to involve these other specialists in your care.

**Clinical trials coordinators (research nurses):** You may meet the research nurses if there are research studies underway which they think you may be able to help with. Remember, your involvement in these trials is completely voluntary. If you decide not to participate in a survey or research project the standard of care that you receive is not affected. (See ‘Clinical trials coordinators’.)
Anaesthetic assessment

All assessment patients are reviewed by the anaesthetist. You may meet the same anaesthetist or a different member of the team on the day of your transplant. The transplant operation puts enormous strain on your body. The assessment process allows the anaesthetist to decide if you are fit enough to undergo the operation and, if so, to make plans to tailor the anaesthetic to your individual needs.

The anaesthetist will consider the results from your heart and lung tests and ask you a number of questions about your general health and fitness, about any drugs that you are taking and any allergies that you may have. They will want to know about any previous anaesthetics and operations – particularly if you had any difficulties. He may wish to examine your heart and lungs, mouth and airway. If your teeth are in poor shape he may recommend that you have some dental treatment before you are put on the waiting list or whilst you are waiting for your transplant.

The anaesthetist will discuss procedures that are necessary for you during and after the transplant operation. This will include central lines, arterial lines, blood transfusions, pain relief, epidurals (see ‘Glossary’) and ventilation on the Critical Care Unit (see ‘Critical Care Unit’). It is also your opportunity to ask any questions you may have.

Going onto the waiting list

Towards the end of your assessment a decision will be reached about whether or not you should be placed on the waiting list for a liver transplant. If it is felt that a transplant is the right treatment for you and if you want to have one, you will be added to the waiting list. Some patients do not feel ready to go on the waiting list straight away. If you feel you need time to think things over before going onto the list that is not a problem. You can call us when you have made your decision or come back and discuss it with your consultant a few weeks later, if you wish. We will not add you to the list until you feel ready.
Categories of waiting list

You could be listed as either ‘urgent’ or ‘priority’ – this will depend on the severity of your liver disease. The severity of your liver disease is determined by your UKELD score (see ‘Glossary’). Patients with a high UKELD score are listed as ‘priority’ whilst patients with a lower UKELD score are listed as ‘urgent’.

Patients with a high UKELD score are likely to be quite unwell and therefore need a transplant as soon as possible. These patients may potentially be kept in hospital until a liver becomes available. Most patients will be on the ‘urgent’ category – these patients will normally be well enough to be at home whilst waiting for their transplant. Sometimes you may become poorly enough to have to stay in hospital before your transplant. If you do become more poorly it is likely that your UKELD score would increase and you would then become a ‘priority’ patient.

Being ‘suspended’

Sometimes you can become poorly with infections or have other treatments that would leave you unsafe for transplant until you are better. In this situation you would be taken off the waiting list temporarily (suspended) until you are safe to transplant.

Listing of patients with a tumour

If you are being transplanted because you have a tumour you may be placed on the priority list even though your UKELD score is likely to be quite low. This will depend on the size of your tumour and other factors which the transplant coordinators and surgeon will discuss with you when you go on the waiting list.

It does not happen very often but sometimes a patient with a tumour will have to be taken off the waiting list because their tumour has become too big. The chance of this happening is less than 5% (1 in 20). This is because the risk of the cancer spreading to outside the liver would be too great. The size of your tumour is monitored every three months by an ultrasound or CT scan when you come to clinic. (See also ‘Transplantation for liver cancer’.)

32 | Liver Transplantation
Listing for alcoholic liver disease

If alcohol is a key feature of your liver disease you may have random blood alcohol levels taken. If you are found to have a positive blood alcohol test you will be taken off the waiting list.

Listing does not guarantee a transplant

Unfortunately, since we cannot predict how long a person will wait for their transplant, it is possible that you may become too sick to have a transplant or may die before a liver becomes available. 199 adult patients were added to the list in 2011 and 23 were removed because they died whilst waiting for their transplant or because they became too sick. (12% or 1 in 8). Being on the waiting list therefore is not a guarantee of having a transplant.

Matching of donor and recipient

When a liver becomes available, patients are considered from both the urgent and the priority list depending on blood group and size. When there are two or more patients of the same blood group and size that would be suitable for a particular donor liver, their position on the priority or urgent list would determine who had the transplant, priority patients being considered first. Some donor livers, however, may be unsuitable for a sick patient on the priority list but would be suitable for a patient on the urgent list. In this event a patient from the urgent list would be chosen. Length of time on the waiting list would also be considered, all else being equal.

The ‘super urgent’ list

There is a special category of the waiting list called ‘super urgent’. This is reserved for people who have previously been well who suffer a sudden and catastrophic liver failure; they may only have a few days to live due to their condition. In an effort to find them a donor liver as quickly as possible these patients take priority over patients on the ‘priority’ and ‘urgent’ waiting lists, not just in Birmingham but in all of the transplant centres in the UK.
Your old liver

After your old liver is removed at transplant it is taken to the laboratories and looked at to confirm the disease that you were diagnosed with. Sometimes small sections are stored for research. The doctors will ask you to sign a consent form for permission to do this. Research into the causes of liver disease may involve taking cells from these samples of your old liver and growing them for short periods to allow experiments on them in the laboratory. When the research is completed the samples will be disposed of in an appropriate manner. (See also ‘Research into liver disease’.)

Vaccinations

If required, we recommend that you are vaccinated for hepatitis A and B. This will be discussed with you by the transplant coordinators and involves a course of vaccinations which can be started at the end of your assessment and completed by your GP. The vaccinations do not delay you being placed on the waiting list.

Osteoporosis

Most patients who are added to the waiting list will be started on supplements to help prevent osteoporosis. This is a disease which causes the bones to gradually become weakened and we know that it can occur in patients with chronic liver disease. You will probably have a bone density scan (see ‘Investigations’) soon after you are added to the waiting list. After your transplant the supplements may be continued as you are still at risk of osteoporosis, this time because of the anti-rejection medication.

NHSBT (NHS Blood and Transplant)

The transplant coordinator will need to know your height, weight and girth (waist) measurements in order to help find a suitable donor for you. They will also ask you to sign a consent form to allow them to send your
personal details to an organisation called NHSBT. This is an NHS-funded organisation that manages the national organ donor register, issues donor cards and also manages the recipient register. When you go onto the waiting list you are added to the recipient register. For this to happen, you will be asked to give written consent. The transplant coordinator will give you a booklet which explains all about NHSBT.

Transplant for cancer or viral Hepatitis

Transplant for liver cancer

If you have a tumour (cancer) in your liver this will be discussed with you during your assessment. Because we cannot say how long you will have to wait for your transplant there is a small risk (less than 5% or 1 in 20 in 2011) that your tumour could become too big or may spread beyond the liver. In these circumstances you would have to be taken off the waiting list. Whilst you are waiting for your transplant, the size of your tumour will be monitored every three months by an ultra sound, CT or MRI scan. You will be sent an appointment letter about four weeks before the scan is due.

The aim of the transplant is to try to cure your cancer and treat the underlying liver cirrhosis. An absolute cure, however, cannot be guaranteed. There is the risk of your cancer returning either in your new liver or somewhere else in your body.

After your old liver is removed it is closely examined in the laboratory. As soon as the results of this examination (histology) are known (four to six weeks after your transplant) the surgeon will discuss it with you. It can provide additional information as to the likelihood of your cancer returning.

If it is felt that your cancer has become too big it will not be possible to offer you a transplant. There are other forms of treatment that may be suitable for you such as TACE (transarterial chemoembolisation), RFA (radio frequency ablation) and chemotherapy. These treatments will not cure you of your cancer but they may help to control its progress. These treatments will be explained to you by an oncologist (cancer doctor), surgeon or specialist nurse. Your treatment may take place at
the Queen Elizabeth or at your local hospital – this will be decided by you and your oncologist.

Some patients will have TACE or RFA whilst they are waiting for their transplant to help control the size of their tumour. (See ‘Glossary’.)

**Transplant for viral Hepatitis**

**Hepatitis B**

If you are being transplanted because of hepatitis B you will be given oral anti-viral medication to reduce the level of hepatitis B virus in your body. These oral medicines are called Lamivudine, Tenofovir, Adefovir and Entecovir. You will have one or sometimes two of these medicines for the rest of your life. The doctors will decide the best treatment for you.

The hepatitis B virus mainly lives in your liver cells and is removed from your body at the time of transplant. However, the virus also circulates in your blood and could infect and damage your new liver so, after your transplant, it is very important that you continue with the anti-viral medication which prevents the virus damaging your new liver.

You will also be given hepatitis B immunoglobulin; also know as HB Ig. This contains human anti-bodies which protect the body against the hepatitis B virus. In hospital this will be given at the time of the transplant as an infusion directly into a vein, and for the first three days afterwards. Once you have gone home you will receive HB Ig in the liver outpatients clinic as a subcutaneous injection (the HB Ig is injected just under the skin with a small needle). The hepatitis specialist nurses will teach you how to give this injection yourself as you will need to have one injection every week for the first year.

After the first year, your liver consultant will explain to you if you need to continue with these injection or just the oral tablets. Used like this these drugs are effective at keeping the virus at very low levels and this will prevent damage to your liver.

After an initial appointment with the surgeons you will be seen in the Post Transplant Hepatitis Clinic by your consultant hepatologist and the hepatitis clinical nurse specialist (Sally Bufton and Katrina O’Donnell, contactable via liver outpatients or on 0121 371 4600/4603).
**Hepatitis C**

Hepatitis C is a little more difficult to manage after a transplant. Although most of the virus is removed at the time of your transplant, it will still be in your blood and other body fluids. At the moment there are no treatments available to stop the virus from infecting your new liver, however if the virus comes back aggressively your doctor may speak to you about starting anti-viral treatment. New anti-viral drugs are being developed all the time and it is hoped that eventually they will be able to control the level of hepatitis C virus. After your transplant your doctor will discuss any new treatments that may be suitable for you.

**Waiting list deaths and removal from the list**

It is important for you to understand that if you are accepted onto the waiting list your transplant is still **not guaranteed**. You need to wait for a suitable donor. The number of donor livers available for transplant is not enough to satisfy the demand. This means that each year more than 1 in 5 (22%) of those people who are listed for a liver transplant do not receive a transplant either because they become too unwell and have to be taken off the waiting list, or they die whilst waiting for a transplant.

Clearly this can make waiting very stressful. You will see the doctors in liver outpatients each month whilst you are on the waiting list. You will probably not see a transplant coordinator in clinic whilst you are waiting but if you want to see a coordinator ask the clinic nurses to contact them, or phone them directly. If you are concerned about the length of time that you have been waiting or have any questions about this, make sure that you mention it to the doctor, or ask to speak to the transplant coordinators.

Remember, the liver transplant coordinators are only a phone call away if you need to discuss any concerns that you may have.
Preparation for listing

Before you can be placed on the waiting list, it is important to ensure that you and your family are aware of the complications and side effects associated with transplantation. The liver transplant coordinators will ensure that you and your carer have attended a teaching session with the coordinator and that you have been seen by the surgeon and anaesthetist. See the check list below. **You will not be added to the waiting list until this is complete.**

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<tr>
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<tbody>
<tr>
<td>Attended coordinator teaching session with family</td>
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<tr>
<td>Height, weight and girth taken</td>
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<td>UK Transplant – Use of Data consent form signed</td>
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<td>Seen by anaesthetist</td>
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<td>Seen by surgeon</td>
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<td>Consent for surgery form signed</td>
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<tr>
<td>Vaccinations given or letter for GP given</td>
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<tr>
<td>Contact numbers given to LRTC</td>
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The following is a check list of all the areas of information that you should have covered before you are listed for transplant. There is space for you to tick and date against each area if you wish to.
## Issues of organ donation

<table>
<thead>
<tr>
<th>Source of organs and infection screening, types of donor (DBD / DCD), marginal donors (DCD, Hep C + B core ab+ ve, older donors, liver ‘quality’)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Categories on waiting list (super urgent, priority, urgent, suspended)</td>
</tr>
<tr>
<td>Changing category and removal from list</td>
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<tr>
<td>Allocating an organ based on blood group, size and condition</td>
</tr>
<tr>
<td>Types of transplant (whole and split)</td>
</tr>
<tr>
<td>Feelings about donation and receiving – being able to write a letter</td>
</tr>
</tbody>
</table>

## The Liver

Anatomy of the liver, the immune system

## Practicalities of the transplant

<table>
<thead>
<tr>
<th>Waiting on the list and monthly clinic visits</th>
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<tbody>
<tr>
<td>Contact and transport for transplant</td>
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<tr>
<td>Potential liver offer and cancellations</td>
</tr>
<tr>
<td>Last-minute check (ECG, chest X-ray, bloods)</td>
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<tr>
<td>Care for relatives (before, during and after transplant)</td>
</tr>
<tr>
<td>Transplant lines, tubes and drains</td>
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<tr>
<td>‘Open and close’ if tumour</td>
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<tr>
<td>The transplant operation</td>
</tr>
<tr>
<td>Critical Care (ventilator, renal dialysis, monitor, the team)</td>
</tr>
<tr>
<td>Issues of organ donation (continued)</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Critical care complications (hepatic artery thrombosis, primary non-function, early dysfunction, breathing, lungs, heart, kidneys, prolonged stay in Critical Care, further surgery)</td>
</tr>
<tr>
<td>High dependency and ward care (walking, eating and drinking, learning medication, deep breathing, pain control)</td>
</tr>
<tr>
<td>Complications (rejection, infection, surgical complications – bile leaks and strictures, medication side effects)</td>
</tr>
<tr>
<td>Home (5-10 days), who to call if ill at home</td>
</tr>
<tr>
<td>Clinics (twice weekly, then monthly) with surgeons then physicians</td>
</tr>
<tr>
<td>Referring hospital and GP shared care</td>
</tr>
<tr>
<td>Medication side effects and complications (diabetes, renal failure, cancers, high blood pressure, headaches, tremors, osteoporosis)</td>
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<tr>
<td>Looking after yourself (dentist, sun, cancer monitoring, relationships and contraception, diet, alcohol)</td>
</tr>
<tr>
<td>Driving, exercise, holidays</td>
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<tr>
<td>Three-month protection from infection, vaccinations</td>
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<tr>
<td>Post-mortem examinations, consent, explanted liver and research</td>
</tr>
<tr>
<td>Recurrence of original disease</td>
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</tbody>
</table>
Section 2

Waiting and transplant

**Being on the waiting list**

Most people are well enough to wait at home for their transplant. This can be quite a stressful and anxious time. You will be aware that sooner or later you will be called in for your transplant but you don’t know when that will be; it may be in a few days or not for several months, possibly even longer than that. You will need to have a plan of what to do when you finally get ‘the call’, how you will get to the hospital, who you need to call to let them know and so on.

Whilst on the waiting list it is important to look after yourself. You must try to eat a healthy diet and follow the advice that you may have been given. Exercise as best as you can, make sure that you see the doctor if you need to, and visit the dentist regularly. If you have any major dental work, such as a tooth extraction, please inform the transplant coordinators. **If you smoke, try to stop if possible.** You can ask the liver transplant coordinators, nurses or doctors, or your GP, for advice about stopping smoking. Sometimes the doctors will insist that you stop smoking before you are added to the waiting list.

Because waiting can be a stressful time, try to enjoy treats and special occasions. It is permitted to have holidays away (on the UK mainland only) **but you must inform the transplant coordinators if you plan to go away.** An alternative plan for contact and travel may need to be arranged. (See ‘Holidays’ on the next page.) Remember that your partner or carer will also be feeling this stress. This is an equally difficult time for them so the advice given above should apply to them also.

**Clinic**

You will be expected to visit the liver outpatient clinic every four to six weeks whilst you are waiting for your transplant. This is important so that the doctors can see how you and your liver are doing. It is important to tell the doctor if you have been ill or if your condition has worsened since your last visit.
**Sickness**

If you become ill whilst on the waiting list, it is important to tell the transplant coordinators. This is so that they can speak to the doctors and make sure that you get the right treatment. It is also important, as you may need to be suspended from the waiting list until you are better. This is because it would be too dangerous to transplant you whilst you were ill with an infection or because you have had another treatment.

Some reasons why you could be suspended:

- Dental treatment – tooth extraction, etc (see ‘Dental care’)
- Recent Sclerotherapy – the injection of varices to prevent them from bleeding. You do not need to be suspended if you have had banding of varices
- Infection e.g. of your ascites, of your chest
- For a short period following TACE or RFA

If you are admitted into hospital you or your family must inform the liver transplant coordinator.

When you are well again, you will be placed back on the waiting list. As you will be selected for transplant by your blood group, size and condition – there is no change to your ‘place’ on the waiting list.

**Holidays**

If you feel well enough you can go on holiday whilst you are waiting for your transplant. We would recommend that you stay on the UK mainland. If you go abroad you will be suspended from the waiting list as you cannot return to the hospital in time for your transplant. You must discuss travelling abroad with your medical consultant. He may advise you that it would be best not to miss the opportunity of a transplant.

If you go away from your home for a few days, it is important to tell the liver transplant coordinator. They need to know:

- Where you are going
- How you can be contacted whilst you are away
• How you will get to the hospital if called and how long it will take
• When you will return from your break

Contact
The liver transplant coordinator will ask for your contact details. If these change whilst you are on the waiting list, i.e. if you move house or change your mobile phone number, you must inform the transplant coordinators. They will also ask you to list the phone numbers of a few people, family or friends, who could be contacted if it is not possible to contact you directly. Make sure that these contact people know where you are and how long you will be out, e.g. if you are going to the cinema, out for a meal or shopping.

Transport
• Know the route to the hospital
• Make sure that you have a robust plan as to who will drive you to the hospital when you are called
• Never travel by public transport – it may not travel when you want it, or take you to where you think it is going
• Drive sensibly and within speed limits. You will always have time to travel safely
• If you encounter any road problems, e.g. traffic jams, which may cause a significant delay, contact the liver transplant coordinator on 0121 627 2000

The ‘call’
The liver transplant coordinator will contact you when a donor liver becomes available. Please remember that, despite getting to the hospital, this can sometimes be a false alarm and that the transplant might be cancelled. (See ‘Reasons for cancellation’.) This will be very disappointing. However, it is essential that it is treated as the ‘real thing’. Be prepared to leave home and set out for the hospital within an hour of the call. If you are going to have a split liver transplant or if
your liver is from a non-heart beating donor the coordinator will tell you at this time. They will also tell you which ward to go to and check your estimated time of arrival.

Be prepared

• A suitable donor liver could become available at any time during a 24 hour period, 365 days of the year. It is important and will be less stressful for you if you are fully prepared

• Have a bag packed with your pyjamas, a few day clothes (elasticated waists e.g. track suit trousers or shorts, t-shirts and shoes) and toiletries. Your carer’s bag will also need a few food supplies and an alarm clock (for early morning calls). Try not to bring too much as the ward has only limited space to store things whilst you are in theatre and on the Critical Care Unit. How much you bring will depend on your own circumstances, how far away you live and whether your carer is planning to stay in Birmingham until you are well enough to go home

• Consider writing a checklist of things to do before you leave

• Please do not bring in a lot of money or other valuables, such as laptops, credit cards or jewellery

• Keep paper and pen by your telephone to take instructions that will be given to you by the liver recipient transplant coordinator

• Ensure that you have made arrangements for child care, care of pets or for the support of elderly relatives if required

• Leave your home safe and secure

• On arrival in hospital, go to the ward as directed by the transplant coordinator
Checklist

- Come to clinic every four to six weeks
- Tell the coordinator if you are:
  - Ill (requiring medical treatment from the doctor)
  - If you have major dental work (tooth extraction, etc)
  - Admitted to hospital (for whatever reason)
  - Go on holiday or take a break away from home
- Always tell contact people where you are
- Always have transport available to take you to the hospital
- **Remember that the call may be a false alarm**

It is your responsibility to ensure that you are contactable 24 hours a day, to inform the transplant coordinators of any changes in your circumstances and to ensure that you attend the outpatients department in Birmingham for your regular appointments.

Accommodation for carers at the time of transplant

We cannot guarantee that a room will be available in Nuffield House at the time when you come in for your transplant. Rooms are in great demand and it may be better for your relatives/carers to consider staying in a local B&B or hotel. A list of these is available from Ward 726 or the transplant coordinators.
Your donor liver

Your donor liver will come from someone who has died and it is a very special gift. Families that give consent for their loved one to become an organ donor make a very brave decision at a very difficult time. The death may be due to a number of causes such as trauma, a brain tumour or a stroke. However, the donor will be in hospital in an Intensive Care Unit and their breathing will be supported by a machine called a ventilator.

There are two different types of donor: donors with brain death (DBD) and donors with cardiac death (DCD). We feel that it is important for you to understand the difference between these two types of donor as this will help you understand how a particular donor is chosen for you.

Until 2004 all donors in the UK were donors with brain death (DBD). Unfortunately the number of donor was falling and the number of people waiting for a transplant was increasing, hence more and more people were dying whilst waiting for a transplant. Donation from people with cardiac death (DCD) is not new; it is common practice in many parts of the world. In this country DCD donation is now considered in order to make up the shortfall in donors. Although it has helped, it has not solved the problem completely and there are still too few donor organs available to satisfy the need.

Donors with brain death (DBD)

This type of donor has been diagnosed as having suffered ‘brain stem death’. The brain stem is an area at the centre of the brain that passes information from the brain to the rest of the body. This information includes control of basic life processes such as breathing and consciousness. The patient will be on a ventilator machine which breathes for them: without it they would not breathe for themselves. Very stringent tests are performed to diagnose brain stem death and once this is confirmed the patient’s family will be asked if they would consider organ donation. Because of the support of the ventilator the patient’s heart will continue to beat and their organs (heart, lungs, liver and kidney for example) will remain in a suitable condition to enable donation to occur. The donor will go to the operating theatre with
a beating heart, hence this type of donor is sometimes referred to a ‘heart beating donor’.

**Donors with cardiac death (DCD)**

Donors with cardiac death will also be in an Intensive Care Unit but have not been diagnosed with brain stem death. Doctors will have assessed the patient’s condition and reached the conclusion that recovery, either due to brain damage or other injuries, is impossible. Because death is inevitable the doctors will discuss with the patient’s family the possibility of withdrawing the life support treatment. Following this decision the patient’s family will be given the opportunity to consider organ donation. The patient will be taken off the ventilator machine. If they were on drugs to help support their heart and blood pressure these will be stopped. Soon after withdrawal of treatment the patient’s heart will stop beating and death will occur.

Because treatment can be withdrawn in a controlled manner and at a suitable time, organ donation can be considered. If the patient’s family give consent for donation and the patient is suitable to become an organ donor the surgical team and operating staff can be prepared. This allows the patient to be transferred to the operating theatre very soon after they have died. Because the patient’s heart has stopped beating before they are taken to the operating theatre, there is the potential for damage to occur to the liver due to lack of oxygen. Keeping this time as short as possible minimises the damage to an acceptable level. This type of donor is sometimes referred to as a ‘non heart-beating donor’.

**Matching of donor and recipient**

Around 140 adult transplants are carried out each year in Birmingham. In 2011 there were 146 adult transplants of which 37 were from DCD donors (25%, or 1 in 4). Whatever the type of donor, DBD or DCD, their family will have given their consent for organ donation. The potential donor is then screened for infections and other illnesses. Their blood will be tested for viruses such as HIV, hepatitis B and hepatitis C. The family will be asked if there is any reason to believe that their relative is at risk from these types of infection. The donor’s medical
history will be examined to look for any incidence of cancer. Although the screening is very thorough, there is **no absolute guarantee** that the donor liver will function properly, or that illness or infection could not be passed on.

The donor of a liver that comes to Birmingham may be in any one of around 80 hospitals which fall within our ‘zone’: Liverpool, Stoke, Coventry or Bangor, for example. When a donor liver is offered, the surgeon will assess who is the most appropriate recipient, or in the case of a split liver, recipients. The decision will depend on many factors and includes the blood group and size (small recipients therefore may wait longer) and shape of the donor, together with an estimate of the ‘quality’ of the liver. When the liver arrives in Birmingham it will be looked at by the consultant surgeon. If there are any specific issues about the liver being offered to you, the surgeon will discuss this with you before your operation begins.

**Most livers are likely to work from the very start whereas others may take a few days to settle down. A very poorly recipient may not be able to cope with this settling in period.**

The consultant surgeon will decide if the donor liver is suitable for transplantation. You (the recipient) will be taken to theatre and the transplant operation will begin. Not all transplant patients will be deemed suitable to receive a liver from a donor with cardiac death (DCD). This will be discussed with you in detail by a consultant surgeon during your assessment when you give consent for the operation.

When you are called in for your transplant you will be informed by the transplant coordinator if you are going to receive a liver from a DCD donor. This is because there are implications for the amount of time that you will need to get to hospital and the time at which you go to theatre for your operation, also because there is a much higher risk of cancellation when the transplant is from a DCD donor. These issues will be discussed with you in more detail by the transplant coordinator during your assessment.
Living donation

As explained earlier, there is a shortage of organ donors in the UK. The shortage continues despite the introduction of DCD donation. Because of this shortage, one in five patients who are added to the waiting list will die before a donor organ suitable for them becomes available. In order to overcome this risk some patients will enquire with us about ‘living donation’. This is where a part of the liver from a relative or close friend is used for transplant.

Living donation is possible because the liver (unlike other organs in the body) has the ability to regenerate. Over a period of two to three months the donor’s own liver will grow back to approximately its original size and the part which was transplanted will grow as required for the recipient. Not everyone who might wish to become a live donor will be considered suitable; neither will all recipients be considered as suitable for a live donor. Such decisions would be made for medical, psychological or social reasons. Even though a person may wish to become a live donor the recipient must also agree to this form of donation. There are many advantages to live donation, including a decreased waiting time, but it is important to remember that the donor will undergo major surgery and this is not without some risk. Live donation is an important alternative that you and your family may wish to consider. If you have someone who is interested in donating part of their liver to you, then please contact the liver transplant coordinators.

Writing to the donor family

You may have many different feelings about your transplant, from relief to fear. You may well feel sad for the person who has died and for their grieving family. It is important to remember that organ donation is something positive that can come out of what is otherwise a tragic event: this can bring a lot of comfort to the bereaved family. Whatever your thoughts are now, you may feel differently after your transplant. After your transplant you may wish to write to the donor’s family. There is no rush to do this: in many ways it is better to wait until you are out of hospital and well on the road to recovery before you write. This also allows the family time to come to terms with their loss and to grieve.
Ask the liver transplant coordinators for information about how to go about writing to the donor family.

**Coming in for your transplant**

Once you have arrived at the hospital, the staff will need to check that you are well enough to have your transplant. Tests that may be ordered include:

- A chest X-ray – to look for infection
- An ECG – to look at your heart before the transplant
- Your temperature – to check for infection
- Blood tests – to check for infection and how your kidneys are working
- Blood will also be taken to allow for blood products to be prepared for your operation
- You will be asked to not eat or drink anything for six hours before your anaesthetic
- The nurses will check your pulse, temperature and blood pressure
- The doctor will examine you and take blood
- You will have a chest X-ray and an ECG. If you have ascites the doctor may take a specimen of this to look for possible infection
- You may need medication or treatment overnight. This may mean having an intravenous drip of fluid, platelets or blood plasma
- An hour before your anaesthetic, you will be asked to change into your theatre gown and support stockings. The nurse will check that you are wearing a name band and will apply tape to any jewellery that you cannot remove
- The on-call doctor will confirm that you have signed the consent form for the operation. If you have not signed a consent form the consultant surgeon will obtain your consent before you go to theatre
- You may be seen by the anaesthetists before you go to theatre. They will look at the results from your blood tests: if these are suitable, you
may be offered an epidural for your pain relief post transplant (See ‘Glossary’)

- The donor liver will be checked by the surgeons before you are taken to theatre. If you have been offered a ‘split liver’, the doctors will need to see if it can be divided. If it cannot be divided then only one patient (usually the most ill) can be transplanted

- You will go to theatres on your bed or on a theatre trolley or, if you prefer, you can walk. Your carer can accompany you to the theatre reception area

Reasons for cancellation

Even though you have been called into hospital for your transplant we cannot be certain that your operation will go ahead. In 2010 more than one in every three transplants was cancelled (39%). There are several reasons why your transplant may be cancelled:

**You are not well enough.** This is one reason why you need to come into hospital as soon as possible once we know there is a suitable donor for you. If you were not well enough to have your transplant we would have time to bring in a ‘back-up’ recipient.

**The liver could not be split.** Either you or the child who is sharing your donor liver will be the ‘priority’ patient. In the event that the liver cannot be split, the priority patient will have their transplant and the other patient’s transplant will be cancelled. If you are called in for a split liver transplant the coordinator will inform you at the time if you are the priority patient or not.

**The liver was not suitable.** The donor liver is likely to be coming to Birmingham from another hospital. The surgeon may wish to see the liver to be certain that it is of a suitable quality before you go to theatre. As the liver is unlikely to arrive until shortly before your transplant is due to start, if it is not suitable, your transplant may be cancelled just minutes before you were due to go to theatre.

**The liver was diverted to a sicker patient.** Very occasionally a patient is called in for transplant and their liver is diverted to a patient who
has been placed on the super urgent waiting list. (See ‘Going onto the waiting list’.)

**There was no Critical Care Unit bed.** Before you are called in for transplant we ensure that a bed is available for you in the Critical Care Unit. Whilst every effort is made to ensure that this bed is kept for you, due to unforeseen circumstances it can very occasionally be lost.

**A donor with cardiac death (DCD) did not proceed.** This is the most common reason for cancellation of transplants. When the transplant is from a DCD donor and treatment is withdrawn it is necessary for the donor’s heart to stop beating within a certain time period. If this period is exceeded the donation will not go ahead. In 2010 there were 28 transplants from DCD donors but a further 36 transplants were cancelled for this reason. So if you are called in for a transplant from a DCD donor the chances of your transplant being cancelled are greater than 50%. The chances of cancellation with a DBD donor is much smaller than this.

If your transplant is cancelled this will be a great disappointment to you. You may well have had a long journey followed by a sleepless night. You will experience all of the emotions of knowing that you are about to have your transplant and undoubtedly you will be stressed. If you are cancelled we can only apologise and ask you to understand that your presence in the hospital was essential as you cannot afford to miss the opportunity of a transplant.
The day of your transplant

The transplant coordinator will meet you approximately one hour before you are due to go to theatre. Depending on how you feel you can either walk, or go on a theatre trolley to the operating theatre. One or two people can come with you into the theatre reception area where you will be met by a theatre nurse. The nurse will check that you have a name band on your wrist and that you have signed the consent form. Your family will be able to wish you well and then you will be taken through into the operating theatre.

In the anaesthetic room

In the anaesthetic room there will be one or more anaesthetists and one or more operating theatre assistants (ODAs). The ODA will attach some monitoring to keep you safe whilst you are put to sleep: a blood pressure cuff on your arm, ECG leads on your chest and a pulse oximeter on your finger.

The anaesthetist will place a cannula (venflon) into the back of your hand or into your arm through which they will give you drugs to put you to sleep. You will probably be given some oxygen to breathe via a face mask at this point. The anaesthetist will then inject the drug through the cannula. You may feel a cold sensation as the anaesthetic drug travels up your arm and a metallic taste when it reaches your mouth. You will drift off to sleep within a few seconds.

In a few cases, where veins are difficult to find, or patients are particularly scared of needles, it is possible to put patients off to sleep by breathing gas through the mask. This takes longer than the injection to achieve its effect and for this reason the injection is usually preferred.

Once you are asleep the other tubes and lines are inserted. (See ‘Glossary’ for further explanation.) These are:

- Endotracheal tube
- Nasogastric tube
- Central line
- Swan-Ganz catheter
• Arterial line
• Epidural (not everybody)
• Urinary catheter

Blood and blood products

The use of donated blood and products derived from donated blood is routine and frequently essential during liver transplantation. All blood and blood products are thoroughly screened prior to you receiving them. During your operation it may be necessary to give you blood (red blood cells) and other blood products (plasma, platelets and cryoprecipitate). The anaesthetist closely monitors the ability of your blood to clot, and the amount of red blood cells you have, to ensure you are not given products that you don’t need.

Use of aprotinin

If there is significant bleeding during the transplant the anaesthetist may use a drug called aprotinin. Aprotinin works by strengthening the blood clot that is formed naturally and reduces overall blood loss by around 40%. This is associated with a similar reduction in transfusion of blood and blood products. Because this drug is unlicensed for use in liver surgery the surgeon will discuss it with you when you give consent for the transplant operation and the transplant coordinators will give you written information about it.

In the operating theatre

A team of surgeons, led by a consultant, will undertake your transplant operation. This will take between six and eight hours, although it could be longer or shorter. Whilst surgeons are removing your old liver, other surgeons will start to prepare the donor liver. If you are having a split liver transplant the ‘split’ will be taking place at this time.

The transplant operation, step by step:

1. The surgeons will make a wound across your abdomen, above the navel but below the ribs, from your right side and over towards the left
2. The removal of your old liver will take two to three hours. The portal
vein, hepatic artery, bile duct and vena cava are clamped and cut to allow removal of the old liver.

3. It takes three to four hours to put the donor liver in. The vena cava, portal vein and artery are reconnected and the clamps are then taken off the vessels to allow your blood to flow into the new liver. This is called reperfusion.

4. There is a pause to ensure that there is no bleeding from any of the blood vessels.

5. The donor bile duct is connected to your bile duct or in certain circumstances the Roux-en-Y is done (see ‘Glossary’), and the gall bladder is removed (the gall bladder is sometimes removed when the liver is prepared prior to transplantation).

6. A drain is placed in the abdomen below the wound to allow any extra blood or fluid to drain away.

7. The wound is closed.

After your old liver is removed it is closely examined in the laboratory. As soon as the result of this examination (histology) is known, (four to six weeks after your transplant) the surgeon will discuss the findings with you in clinic. Sometimes small sections of your old liver are kept for research. The rest of your liver will be incinerated.
Care of your loved ones

Once you have gone to the operating theatre the transplant coordinators will support those who came to the hospital with you. They will make a plan as to how best to support them, for example, by helping them to get a room in Nuffield House if needed, or making sure that they know the location of the Critical Care Unit. They will check that they have their correct mobile phone numbers as they may need to contact them if there are changes to the plan.

If your partner/carer cannot be at the hospital during your transplant, then the liver transplant coordinator will contact them by telephone if you wish them to. It is important that the transplant coordinator knows how to contact your next of kin in case of an emergency.

When your transplant is finished you will be taken to the Critical Care Unit. The transplant coordinator will have made a plan as to how best to support your partner/carer at this time. This may include meeting with the surgeon to discuss how the surgery went and how well the transplanted liver is working. If your partner/carer cannot visit at this time the transplant coordinator will speak to them on the phone and make sure that they know how to contact the Critical Care Unit should they wish to.

After your transplant

The Critical Care Unit

After your transplant, you will be taken to the Critical Care Unit where you will be monitored very closely. You will have one nurse looking after you all of the time. There are specialist doctors in the Critical Care Unit called Intensivists, who will be involved in planning your care, along with the liver physicians and surgeons.

The amount of time that you spend asleep (sedated) after your transplant will depend on how long your transplant has taken and how well you were before it. Some patients (those who are relatively young and fit) may be woken a few hours after their operation finishes, while other patients will remain sedated and on a ventilator (see ‘Glossary’) to
support their breathing until the morning after the day of the transplant.

**Waking up after your transplant**

After your sedation is stopped you will start to wake up. As you wake you may become aware of a tube in your mouth (endotracheal tube) which is attached to the ventilator helping you to breathe. (See diagram.) As you awaken you will become less dependent on the ventilator; doing more and more of your own breathing. This process is called ‘weaning’ (see ‘Glossary’). As soon as the doctors and nurses are confident that you will be able to breathe without the help of the ventilator, the endotracheal tube will be removed. This is painless although it may make you cough. Some patients find that they have a sore throat for a few days after the endotracheal tube is removed.

**Physiotherapy**

After the tube is removed you will need extra oxygen. This can be given either through a light plastic mask (oxygen mask) or two small prongs that sit under your nose (nasal specs). It is very important to breathe deeply and to cough to clear secretions from your chest at this time. The physiotherapist will teach you how to do this without it causing you to hurt too much. You may be given an ‘incentive spirometer’ (see ‘Glossary’) to occasionally breathe through; this will help you to focus on deep breathing. The physiotherapist will also help you to move into different positions in the bed to help you to breathe better, usually on your side or sitting up.

**Pain relief in the Critical Care Unit**

Relieving pain is important. If you are in pain you will not be able to breathe properly or move properly and this will delay your recovery. Your pain relief in critical care will be morphine given through your central line or the epidural. (See ‘Glossary’.) Everyone’s experience of pain is different and **you must tell the nurses** if you feel too uncomfortable; they may be able to increase your morphine or give you other pain killers via the nasogastric tube. Most patients no longer need morphine by the time they are transferred to the ward a day or so later; here you will have regular pain killing tablets. (See ‘Medication’.)
Sleeping in the Critical Care Unit

Your medication may cause you to have very vivid dreams and/or nightmares. Sometimes these dreams seem to happen in the day and are called hallucinations. Hallucinations can be disturbing, however, the doctors and nurses are aware that they can happen and will make sure that you are safe.

Complications

There are complications and side effects of transplantation that could keep you on the Critical Care Unit longer than expected. Please remember that the majority of people do not have these problems. However, they are listed here for your information. It is important that you understand these risks before you give your consent for the transplant:

Your donor liver not working at all (Primary graft non-function)

After the donor liver is removed from the donor it is packed in ice for transfer to Birmingham. During this period the liver cells stop working. Once the liver has been ‘plumbed in’ to you, the recipient, and your blood starts to circulate through the liver, the liver cells will start to work again. Unfortunately, and for reasons not fully understood, sometimes the liver cells will not start working. This is called ‘primary graft non-function’. It is a rare but very serious complication which would mean that you needed a second liver transplant very quickly. The surgeon and transplant coordinator will explain the risks of this to you during your assessment.

Your donor liver not working well (Primary graft dysfunction)

This is very different from ‘primary graft non-function’. Sometimes a donor liver is just a little slow at settling into your body and does not work as well as it should at first. You will probably remain in the Critical Care Unit, possibly sedated and on a ventilator, until the doctors feel that your liver function has picked up sufficiently.
Your lungs not working well (respiratory failure)

If you have been ill for quite a while before your transplant your muscles may be weak. You may already have had problems with your lungs before your transplant (i.e. from smoking), or you may develop a chest infection. These and other factors can make it harder for you to breathe without the help of a ventilator following your transplant. The process of learning to breathe again without the support of a ventilator is called ‘weaning’. If the doctors feel that it will take quite a long time for you to wean from the ventilator you may need a tracheostomy – this is a breathing tube that is placed directly into your windpipe through the neck. It will make the process of weaning more comfortable for you as you no longer have the endotracheal tube in your mouth. You will be given a general anaesthetic when the tube is placed.

Your heart not working well (cardiac failure)

The transplant is very strenuous for your heart, which has to work very hard throughout the operation. This, and/or the complications described above, can put strain on the heart and powerful drugs need to be given to support it. You would remain in the Critical Care Unit until these drugs are no longer required.

Your kidneys not working well (renal impairment)

Before transplant, your kidneys may be affected by your liver disease. As the heart has to work so hard during the operation blood supply to the kidneys may be reduced. Together, these problems can cause your kidneys to stop working temporarily after your transplant. It may take several weeks for your kidneys to recover, during which time you will require renal dialysis. Whilst you are in critical care you would be on a kidney filter machine (see ‘Glossary’). Once you are well enough to leave the Critical Care Unit you would have renal dialysis (see ‘Glossary’) every few days or so until your kidneys are working again.

You may still feel the effects of your liver disease

Liver disease may cause encephalopathy (see ‘Glossary’). After your transplant your donor liver has a lot of ‘catching up’ to do to clear up the toxins which cause encephalopathy. Because of the strain on your
You may get an infection

Whilst every effort is made to try to prevent infection, you are very vulnerable immediately after the transplant. This is because of the strain on your body caused by the surgery; the drips and drains that puncture your skin, and because you are given drugs to prevent rejection which in turn reduce your body’s ability to fight infection. If you develop an infection it is likely to prolong your stay in critical care as your body will struggle to fight the infection and recover from the surgery.

You may have complications from the surgery including:

Bleeding

Several blood vessels have been cut and reconnected to your donor liver. (See ‘Operation, step by step’.). This can sometimes cause bleeding after the operation. The ‘stab drain’ (shown in the diagram of the patient in critical care) is in place to show if this is happening. If bleeding continues you may need a blood transfusion whilst in the Critical Care Unit. Usually the bleeding will stop after a short time though occasionally a patient will need to be taken back to the operating theatre to repair the problem.

Bile leak and bile flow problems

The bile duct has also been cut and re-sewn. Here too there is the potential for a leak to occur. Once again, this problem is rare but may mean a return to theatre to repair the bile duct. Sometimes a small needle will be put through the skin to drain away any bile which has leaked. The drain will remain for a while until your own body has repaired the leak. If there is a blockage in the bile duct (due to obstruction or narrowing) bile will be unable to flow properly through the bile duct. This may potentially require surgery or placement of a stent. (See ‘Long-term considerations’.)
Hepatic artery thrombosis

This would be a serious complication. The artery supplies the liver with oxygen which is essential for the liver cells to remain healthy. A hepatic artery thrombosis is a blood clot in the artery. This stops the flow of blood containing oxygen to the liver and the liver cells die. If this occurs within three weeks of your transplant you would need a second liver transplant as soon as possible and would be placed on the super urgent waiting list. (See ‘Going onto the waiting list’.) The doctors and transplant coordinators would speak to you at length and explain the implications of having a second transplant.

Open wound

Sometimes the new liver may be a little too big and be a bit ‘squashed’ inside your abdomen, and it might be difficult for the surgeon to close your wound with stitches. This is rare but, if it does happen, then a special dressing is applied and you would be kept asleep on the ventilator until the tissues are less swollen. You would return to theatres within a day or two for the wound to be properly closed.

Wound problems:

There are several reasons why wound healing can become a problem:

• Your anti-rejection medicine can sometimes slow the healing process
• Your wound becomes infected
• If you have a lot of ascites this can leak through the wound slowing the healing process
• If you are poorly nourished

(See ‘If your wound is slow to heal’.)

Most people have none of these problems and stay in critical care for only two or three days. If you do have problems your stay in critical care will be longer. Serious complications can lead to you staying in critical care for a prolonged period. If this happens it becomes increasingly difficult for your body to get better – although not impossible. You could be in critical care for several weeks before you are well enough
to go to the ward. The nurses, dietitians and physiotherapists all work with you to help you get better. The dietitian will help to feed you by using the nasogastric tube or giving you nutritious fluids which can be given through the ‘triple lumen’ line. (See ‘Diagram of patient in Critical Care’.) The physiotherapist will help you to breathe by helping you to cough and to clear secretions from your chest. They will also help you to exercise and to regain your mobility as your muscles may become weak if you are in bed for a prolonged period.

If you experience severe complications you will need a great deal of support from the machines in critical care. You may be on a ventilator (breathing machine) to support your breathing; you may be on a kidney filter to support your kidneys and you may be on powerful drugs to help support your heart. Clearly this would be a very critical time for you and your family and friends would be very anxious. The doctors and nurses are available for them to speak to and to keep them informed of your progress. If family/friends are calling the Unit by phone for information it is recommended that you nominate one or two people as the main contact. Too many people calling can cause messages to become confused. Nurses will only give limited information over the phone because of confidentiality.

**Summary of the risks of liver transplantation**

Statistics are about groups of people rather than individuals and therefore they can sometimes be misleading. During your assessment the surgeon, hepatologist and anaesthetist will discuss with you the potential risks of transplantation and try to summarise how high or low the risks are for you as an individual. However, as a guide, the table below outlines the percentage chance of occurrence of the known complications of liver transplantation.

<table>
<thead>
<tr>
<th>Known potential complication of liver transplantation</th>
<th>Percentage of patients who experience this problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bleeding requiring a blood transfusion in critical care</td>
<td>30%</td>
</tr>
<tr>
<td>Condition</td>
<td>Rate</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Renal failure requiring temporary support (dialysis / CVVH)</td>
<td>30%</td>
</tr>
<tr>
<td>Acute rejection</td>
<td>20%</td>
</tr>
<tr>
<td>Potential need for a re-transplant (all causes)</td>
<td>10%</td>
</tr>
<tr>
<td>Biliary leak / stricture</td>
<td>13%</td>
</tr>
<tr>
<td>CMV infection at 3 months or more post transplant</td>
<td>6%</td>
</tr>
<tr>
<td>Hepatic artery thrombosis</td>
<td>4.8%</td>
</tr>
<tr>
<td>Bleeding requiring return to theatre</td>
<td>4%</td>
</tr>
<tr>
<td>Chronic rejection</td>
<td>less than 3%</td>
</tr>
<tr>
<td>Primary graft non-function</td>
<td>2.7%</td>
</tr>
<tr>
<td>Biliary stricture requiring reconstruction surgery</td>
<td>1.2%</td>
</tr>
</tbody>
</table>

Figures are from the QEHB database

Because there may be some damage to a DCD (donor with cardiac death) liver through lack of oxygen, there is a difference in the survival rate and the incidence of post operative complications experienced by DCD liver recipients when compared to DBD (donor with brain stem death) recipients. (See ‘Your donor liver’.)

<table>
<thead>
<tr>
<th></th>
<th>DCD recipient</th>
<th>DBD recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survival at 1 year post transplant</td>
<td>85%</td>
<td>90%</td>
</tr>
<tr>
<td>Survival at 3 years post transplant</td>
<td>78%</td>
<td>83%</td>
</tr>
<tr>
<td>Length of hospital stay post transplant</td>
<td>12 days (average)</td>
<td>11 days (average)</td>
</tr>
<tr>
<td>Incidence of primary graft non-function</td>
<td>2.7%</td>
<td>3.4%</td>
</tr>
<tr>
<td>Incidence of hepatic artery thrombosis (HAT) by 3 years post transplant</td>
<td>9.6%</td>
<td>2.9%</td>
</tr>
<tr>
<td>Incidence of biliary complications (in the absence of HAT)</td>
<td>18.8%</td>
<td>6.2%</td>
</tr>
</tbody>
</table>
Death

Unfortunately a small number of patients will develop serious complications and despite the best efforts of the doctors and nurses they will die. This is very rarely a sudden event and there is usually time to start to prepare a patient’s family/friends for this tragic outcome. Needless to say this is a very difficult time for family and friends; the doctors, critical care nurses and transplant coordinators will try to support people through this time and ensure they are as informed about events as much as possible. The hospital chaplain can be contacted if you wish.

If your loved one is very poorly following a liver transplant and there is the possibility that they may die this can be particularly difficult for the families of liver transplant patients as you may be a long way from home. Therefore we would recommend that you try to have other family or friends come to Birmingham to help support you through this difficult time.

When a person dies in hospital their next of kin may be asked to give permission for a hospital post-mortem examination. This may help to answer any questions that might remain as to the cause of death. It is important to try to determine why each patient has died in order to try to prevent the same thing happening to someone else. Sometimes, due to circumstances about the death, a post mortem is a legal requirement decided by the Coroner.

Following the death the patient’s family will need to collect a Death Certificate from the Bereavement Care Service in the outpatient department and the death will need to be registered at Birmingham Register Office. Written information will be provided by the Critical Care Unit/ward on how to do this and Bereavement Care within the hospital will help support the family at this difficult time.

Many post-transplant patients have asked whether it is possible to donate organs and tissues in the event of their death. This may be possible, and your family should enquire at the time if that is your wish.
Diagram of patient in the Critical Care Unit

- Nasogastric tube
- Triple lumen
- Swan-Ganz
- Site of T-tube (Split liver only)
- Stab drain
- Arterial line
- Pulse oximeter
- Venflon
- Urinary catheter
Moving to the ward

Once you are well enough to leave the Critical Care Unit you will be transferred to the liver ward. You will not need to be monitored as closely now and your arterial line will have been removed; ECG leads and pulse oximeter may also be removed. You may still require a little extra oxygen through a face mask or nasal ‘specs’. Once you are able to walk around a little, your urinary catheter can be removed. You will probably be in one of the four-bedded bay areas at first. After a few days here you may be moved into a single-bed room. You will now be able to get in and out of bed unaided and will be starting to walk more and eat and drink more. The nurses are there to help you as required but they cannot do this without your cooperation.

There are **four aspects of care** that you yourself will be responsible for as the doctors and nurses cannot do these things for you:

1. Deep breathing
   As explained earlier, you will be expected to do breathing exercises regularly. You will need to take a deep breath and hold it for at least three seconds. You should do this about five times every hour. You will also be asked to “huff” as if you were going to create a mist on a mirror. This will help you to cough, which is important to reduce the risk of developing a chest infection by clearing the secretions off your chest. You may also be given a small device to occasionally inhale through called an ‘Incentive Spirometer’ which will help you to keep your chest clear.

2. Mobilising
   You will be expected to sit out of bed for most of the day and you will be encouraged to walk a little as soon as you are able. This may be difficult at first due to the urinary catheter and central line; however the nurses and physiotherapist will help you. The nurses will help you put on special supportive stockings (TED stockings) which can be removed when you are walking regularly. Mobilising as soon as you are able is important for several reasons:
   - It will reduce your back pain
   - It will help to prevent constipation and reduce ‘wind pain’
• It will reduce the chance of getting a chest infection
• It will reduce the chance of getting a deep vein thrombosis (see ‘Glossary’)
• It will maintain functional range of most of your joints and help strengthen your muscles

3. Eating and drinking
After your transplant it is important that you eat well; your body needs protein and calories to help it heal and for you to regain your strength. The doctors will tell you when you can start eating. You will start on sips of water and gradually build up to a normal diet. You will be encouraged to drink nutritious supplements (e.g. Ensure, Enlive, Fortimel). With your new medication, food and drinks may taste different, so you may no longer like your favourite foods.

If required the doctors will refer you to the dietitian who will give you advice about what you can eat. Your friends/family can bring food in for you; however, your own food cannot be prepared or heated in the hospital. Due to your new medication, you may find that you are on a restricted diet; foods that are high in potassium (if your kidneys are not working well), or sugar (if you have become diabetic following your transplant) may not be permitted. If diabetes is a problem following your transplant you will be seen by the diabetic specialist nurses who will talk to you about diet and how to manage and monitor your blood sugar levels.

4. Self-medication
Immediately after your transplant you will be taking a lot of new medication (see ‘Medication’). You will remain on some of this medication for the rest of your life. Before you are ready to go home we need to be certain that you know which tablets to take and when to take them. You will be given a ‘drug card’ with this information on. Each time the nurses give you your tablets you can check them against the card. Before long, the nurses will be asking you which medications you are expecting to take and when. You will also see the pharmacist who will talk to you about your medication, the possible side effects and any special instructions. If you are worried about remembering
which drugs to take the pharmacist will provide you with a box which contains your tablets arranged for each day of the week.

The number of tablets that you need to take will change almost daily whilst you are in hospital and this can be confusing. It is important therefore that you and/or your carer have a thorough understanding of your medication.

Removing the lines and monitoring equipment

The Swan-Ganz catheter will usually be removed the day after your transplant. The catheter is inserted through a larger tube called a Swan Sheath – this is likely to be removed two or three days after your transplant.

The nasogastric tube is likely to be removed one or two days following your transplant. If you had a Roux-en-Y (see ‘Glossary’) this may be longer. If your nutrition is poor and you are having difficulty eating the tube may be replaced by a very narrow tube through which you will be given a liquid feed directly into the stomach.

The stab drain will be removed three to five days after your transplant. The amount of fluid coming out of the drain will most likely be small enough by this time for the tube to be removed; it will be replaced by a small bag (MC2000 bag) which will collect any further fluid that drains. This can be emptied as required. Sometimes patients go home with this bag and it is managed by the district nurse until the fluid stops draining completely.

The arterial line will be removed before you leave the Critical Care Unit.

The urinary catheter will be removed as soon as you are able to get out of bed to use a commode or urine bottle, provided your kidneys are working normally.

The central line is likely to be removed three to five days after your transplant. If you need intravenous fluids or antibiotics it may be a little longer.

The ECG leads will be removed when you are transferred to the ward or soon after.
Pain relief on the ward

Effective pain relief is important; it allows you to breathe properly and mobilise more quickly, helping you to get better sooner. You will be given pain relief regularly on the ‘drug rounds’ and also you can ask for extra pain relief in between times if you feel you need it. Some pain cannot be relieved with tablets alone.

Back pain can be a problem after a transplant, especially if you suffered with back pain before your transplant. This can sometimes be difficult to control but usually improves when you are more mobile and able to walk.

‘Wind pain’ is caused by the bowel being slow to start working. Gases build up causing discomfort and pain. Walking will help to relieve wind pain. Peppermint water can also help. The nurses can give you some if you ask.

Sleeping on the ward

Sleeping in hospital can be difficult. This can sometimes be made worse by having different medications and the stress of having been unwell. Some patients tell us that they experienced very vivid dreams and/or nightmares. Sometimes these dreams seem to happen in the day and are called hallucinations. Hallucinations can be disturbing, however the doctors and nurses are aware that they can happen, and will make sure that you are safe.

If you are slow to recover

Problems that can be slow to resolve and lead to a longer hospital stay are listed below:

1. Extra fluid around the body which can be seen:
   • In your legs and hands as oedema
   • Around the tummy as ascites (this is more common if you had a lot of ascites before your transplant)
   • On the right side of your chest as a pleural effusion (because of irritation to the diaphragm during surgery)
• These problems are usually resolved naturally in time. Sometimes the doctors will use medication as well

2. **If your wound is slow to heal:**
   There are several reasons why your wound may take time to heal:
   • Because of the medication that you are taking (especially the steroids as they slow down the healing process
   • Because of ascites. If you have a lot of ascites this can leak through the wound. The nurses will apply a bag to collect the fluid. It will dry up naturally within a few days or weeks
   • Because of infection. To reduce the risk of infection, the dressing is taken off your wound quite soon after the transplant. If the wound becomes red or inflamed, the doctors will examine it and the nurses will take a swab of the wound to look for bacteria. If the wound is being treated suitably then you can be sent home and the district nurse can come in to clean and re-dress the wound as required
   • Poor nutrition – if you are not getting enough protein in your diet healing will be slowed down

3. **Biliary problems**
   See ‘Complications’ and ‘Biliary stricture’.

4. **Poor mobility**
   If your early recovery was slow due to complications in Critical Care, or if you were extremely sick prior to your transplant, it will take you longer to regain your strength and independence. Rehabilitation can sometimes be very slow.

5. **Acute rejection**
   See Rejection below. Acute rejection is common and can be treated. Some patients will experience several episodes of acute rejection and this will inevitably delay your discharge home

6. **Side effects of your medication**
   See ‘Side effects of your medication’
7. Psychological disturbance
Either as a side effect of your medication, the stress of a slow and difficult recovery, or for reasons unknown, you may experience personality changes, confusion, depression or other psychological problems which can sometimes need medical treatment and be slow to resolve.

Transfer to your local hospital
If your recovery has been slow and you are not well enough to go home, but your liver condition is stable, you may be transferred to your local hospital to complete your recovery. If this happens, the liver transplant coordinator will speak to the doctors and nurses at the local hospital, giving them advice on how to care for you and phoning the hospital regularly to see how you are getting on. You may occasionally be brought by ambulance to Birmingham for an outpatients appointment.

Carers and loved ones
The time whilst you are in hospital recovering from your transplant can be very demanding for your partner/carer, family or friends. They may feel that they want to be at the hospital the whole time but are unable to do so due to other commitments. The cost of accommodation and travel can cause financial hardships. It is important during this time that your carer feels comfortable with the demands placed upon them. Many other carers have found that it helps to ask other family and friends to take on tasks such as ‘telephone duty’ or ‘transport duty’ in order to help. Your carer may need time away from the hospital and we may recommend that they take a break and go home for a few days, or go shopping or sight-seeing in Birmingham to take their mind off things a bit. If they are not staying in the hospital, travelling to and fro can be very tiring and we may recommend that they take a day off from visiting occasionally, to allow them to rest and to catch up with things at home. It’s important that they look after themselves as they need to be as fit as possible to look after you once you have gone home.
Rejection

There are two types of rejection, acute and chronic.

**Acute rejection** is the body’s normal reaction following a transplant. It happens in around 20% of patients and can occur as early as six days after transplant but can occur at any stage. Many patients are still in hospital when it occurs and it is very quickly picked up on your daily blood tests. To confirm acute rejection you would have an ultrasound scan and then a liver biopsy. Acute rejection is easily treated with extra steroid tablets.

Some patients will have more than one episode of acute rejection. Other patients have acute rejection after they have gone home. In this case you may develop symptoms such as a high temperature, jaundice, diarrhoea, vomiting and feeling generally unwell, though there are other reasons why you might have these symptoms; an infection for example. A blood test can determine if your symptoms are likely to be caused by rejection. If so you would need to come back into hospital to have the acute rejection confirmed and treated.

**Chronic rejection** is seen in less than 3% of patients and generally occurs over a longer period of time and after the first three months. Sometimes a change in anti-rejection medication can control or even stop chronic rejection, however, sometimes the liver can become badly damaged and another transplant is required.

Medication

After your transplant you will need to be on medication for the rest of your life. This medication is called immunosuppression. It works by reducing your body’s natural defence system (immune system). Your immune system attacks ‘foreign bodies’ such as bacteria and viruses. The new liver will be seen by your body as being ‘foreign’ and your body will automatically try to attack it. This is called rejection. Although the donor liver is ‘foreign’ to your body it is, after all, a liver, and therefore it is not as ‘foreign’ as a bacteria or a virus. To prevent rejection from happening, the doctors will prescribe immunosuppression (also known as anti-rejection) medication which
will suppress the immune system. The immune system will still be able to attack bacteria and viruses (though not quite as efficiently) but it will not attack the liver. This prevents damage to the liver by your immune system. The medication is specific to each patient and the amount given may vary, even daily, at first.

Below is a list of ‘dos and don’ts’ about your medication. However, taking your medication should not become an all-consuming issue. Taking medication should be like brushing your teeth, a part of your daily routine that is done automatically.

**Dos**

- Even if you have had a transplant for years, there is always the possibility of the liver being rejected. Always take the medication that you have been prescribed. If you miss a dose don’t panic. Do not take a double dose when you realise you have missed one previously.

- Always carry your drug card with you and show it to your doctor or dentist (the transplant coordinators will give you this after your transplant).

- Always check any new medication that you may be prescribed or buy over the counter for suitability or interactions with your other medication. Your local pharmacist will do this for you. If you have any concerns, you can contact the Pharmacy Department at the Queen Elizabeth Hospital Birmingham on 0121 627 2000 and ask to bleep 1345.

**Don’ts**

- Do not take your Prograf, Neoral or Sirolimus before you come to clinic (even if the appointment is in the afternoon). Bring the medication with you to clinic, so that you can take it after your bloods have been taken.

- Do not eat grapefruit or food with grapefruit derivatives, pomegranate juice or Earl Grey tea if you are taking Prograf or Neoral as this can increase the level of the drugs in your body. Levels could become too high.
• Do not take herbal or Chinese medications, particularly St. John’s Wort, as they interact with some of your medication

• Do not take a ‘double dose’ of your medication if you miss a dose – if in doubt contact the liver transplant coordinators

• Do not take non-steroidal anti-inflammatory pain relief such as Neurofen/Ibuprofen or Volterol/diclofenac. The description on the side on the medication box may use the term ‘non-steroidal anti-inflammatory medication’. These drugs may affect your kidney function

• Do not take aspirin (even ‘baby aspirin’) unless prescribed by the Liver Unit doctors

• Do not drive cars or work machinery if you feel dizzy after taking your medication

• The side effects of the medications do not always occur but are listed for your information in the Appendix. If you develop side effects do not panic, it may be possible to reduce or change your medication and, as your body gets used to the medication, the side effects are likely to reduce

It is your responsibility to make sure that you always have enough medication and that you do not run out. Bear in mind that you might need extra supplies over holidays such as Christmas, or Easter or if you go on holidays abroad.

Do not leave it till the last day before you re-order your tablets. Your pharmacist may have to order some of your drugs and this could take several days.

You must take your medication as prescribed. If you do not, your body could reject the donor liver. If your liver is rejected because you do not take your medication it is likely that you would not be offered another transplant.

If you have problems with remembering to take your medication the liver transplant coordinators and pharmacists will be happy to help and suggest strategies which can help you to remember to take your tablets.

If you do not like taking your medication because it makes you feel ill with side effects, then please tell the Liver Unit doctors or the liver
transplant coordinators. The doctors will try to adjust your medication to make it more suitable for you.

**Early side effects of medication**

When you start your medication, your body may respond with some side effects. Everyone is different, and it is impossible to predict if you will have side effects or not. The potential side effects, and how they are treated, are listed here:

**Diabetes**  
The medication might make your body unable to process sugar – this is called diabetes mellitus. After your transplant the nurses will monitor your blood sugar every few hours by taking a small drop of blood from your fingertip. You may need to be given tablets or insulin to lower the amount of sugar in your blood. If this happens you will be seen by the diabetic specialist nurse who will teach you how to give your own insulin. You will also be taught about which foods you can and can’t eat. You may remain diabetic forever. Sometimes, as your steroid tablets are reduced, the diabetes improves and you can switch from insulin to tablets to control your blood sugar.

**Kidney problems**  
Occasionally the kidneys are affected and they do not work as efficiently as normal. The doctors may need to adjust your anti-rejection medication or give you other drugs to help the kidneys. You may also need to avoid certain foods for a while. The coordinator or dietitian will discuss this with you if it happens.

**High blood pressure**  
If the medication causes you to have high blood pressure you will need to take tablets to control it. Your blood pressure is monitored in the clinic and by your GP if necessary.

**Headaches**  
A few patients suffer with very bad headaches. These usually improve after a time.
Tremor
Some patients find that their hands are shaky. This is often worse in the mornings and improves as the day goes on. This will usually improve with time as your body becomes accustomed to the medication.

Nausea
You will be taking a lot of new tablets which are strange to your body. Some patients will experience nausea, though this is likely to improve with time.

Diarrhoea
Some tablets can potentially cause diarrhoea. If you develop diarrhoea you should inform the nurses or transplant coordinators as there may be other reasons for developing diarrhoea which would need to be investigated.

Psychological disturbances
You may experience personality changes, confusion, depression or other psychological problems which can sometimes need medical treatment and be slow to resolve.

Altered taste
Some patients tell us that food taste differently after their transplant; you may no longer like your favourite foods, or you may find eating difficult as food now seems bland.
Section 3

Going home

You may experience a mixture of feelings when you are told that you are ready to go home. You may feel relieved and excited, but you may also feel apprehensive and anxious about how well you will cope. The liver transplant coordinator will speak to you and your partner/carer before you go home to discuss these and other issues.

Before you go home we will want to be certain that:

• You know all your tablets and are confident about what to take and when to take it
• You have been given two weeks supply of tablets to take with you
• You are eating and drinking well enough
• You are able to walk around well enough to cope at home. This will include being able to climb stairs
• You have a letter for your GP to book a district nurse to manage any wound which may still require attention and to show him what tablets you are taking
• You have an appointment to come back to clinic

The transplant coordinator will inform your GP that you are going home.

Getting home

It is important that you plan for going home, preparing your transport and having suitable clothing for the journey. If you came into hospital for your transplant by hospital transport this can be arranged again to take you home, otherwise it will be your family/carers responsibility to get you home.

Table of tablets (See back cover)

Call the transplant coordinator if you have any concerns about medication. Some of the tablets you are taking may affect your ability
to drive. Discuss this with your consultant when you are ready to resume driving.

**Your responsibilities**

If you are ready to go home you are ready to start to take responsibility for your own care. Here is a list of things that you need to do:

- Visit your GP, or arrange for him to visit you at home. Your GP will need to see you when you first arrive home because he may need to visit you at a later stage if you are unwell. If this happens he will be able to identify any changes in your condition

- Your GP also needs to know what tablets you are on. It is your GP’s responsibility to prescribe them for you. There are some tablets which at first your GP may not be able to prescribe. If there are tablets that your GP cannot prescribe they will be provided for you in the liver clinic. **You will need to tell the doctors in clinic that your GP will not prescribe them**

- If you have no means of transport of your own you will need to book hospital transport to bring you to Birmingham for your clinic visits. **It is your responsibility to organise this.** Hospital transport will normally only be available for the first six weeks following transplant

**If you live in the West Midlands or Warwickshire:**

Call transport on 0121 627 2098 (they will answer, though it may take some time).

**If you live outside the West Midlands or Warwickshire:**

Contact your GP to organise transport. If he is unable to do this call transport on 0121 627 2098 (they will answer, though it may take some time).

**If you live in Wales:**

We are aware that some GPs will not organise your transport. If so contact transport on 0121 627 2098 (they will answer, though it may take some time).

- If you are unwell at anytime you must contact the liver transplant coordinators. They will advise you what to do.
• If it is more than three months since your transplant and you are admitted to hospital (for whatever reason) please contact the Queen Elizabeth Hospital Birmingham on 0121 627 2000 and inform your consultant’s secretary or the Liver Unit medical registrar on call. This will enable us to advise your local team as required

Clinic

You will be expected to attend liver outpatient’s clinic in Birmingham within a few days of being discharged home. You will then be expected to attend the Outpatients clinic weekly for four to six weeks, depending on your condition. As you get better, these appointments are extended to fortnightly and then monthly. After three or four months the clinic visits reduce to three monthly, six monthly and eventually to yearly visits. For the first three months you will be seen by the surgeons and the liver transplant coordinators, and then you will be seen by the physicians as you had been before the transplant.

The importance of clinic visits cannot be stressed enough. It allows the doctors to see how well you are recovering, monitor your liver and kidney function and check the level of anti-rejection medication in your blood. It is also your opportunity to ask questions and to tell the doctors and the coordinators if you have any problems or concerns.

• You will have blood taken (remember not to take your immunosuppressive medication before you have had your blood taken, even if it is an afternoon appointment – see ‘Medication’)

• You will be weighed

• You will have your blood pressure taken

• You must bring your drug card with you. If changes are made the doctor will write this down on the drug card

• Bring an overnight bag with you, in case you are admitted to the hospital

We know from our experience that the first three months are crucial for the long-term success of a liver transplant. If you feel unwell after you have gone home you must contact the transplant coordinators:

• If you have diarrhoea and/or vomiting
• If you have a high temperature
• If you become jaundiced
• If you have problems with pain

The transplant coordinators will discuss your symptoms with the doctors and together we will make a plan of how best to deal with them. This may include:

• An earlier clinic appointment
• A visit to the GP
• A visit to you by the GP
• Admission to your local hospital
• Advice from the transplant coordinators over the phone

Although you are still being seen in Birmingham it is important that your local consultant also sees you. If you do not hear from them you should arrange for an appointment for about one month following your transplant. Your consultant here in Birmingham will write to inform them about your condition and how your transplant went.

Your GP

You will need to see your GP within a few days of being discharged home. You will be given a letter to give to them which tells them what has happened to you whilst you have been in hospital and what medication that you are on. Your GP will prescribe your medications. If your GP is unable to prescribe any medication, it is important that you tell us when you come to clinic so that we can prescribe it for you or arrange for your local hospital to provide it. Your local chemist may not stock some of your medications, so they may take several days to order.

Rest

You and your partner/carer are likely to be very tired after the ordeal of having a transplant. For the first few days, you might find it easier not to have many visitors. At first you may find that you need a short nap in the afternoon.

You may find that you still have some of the vivid dreams or nightmares
that you may have had in hospital. Some people may feel slightly frightened of going to sleep. You may find that your carer is also having bad dreams. This is often due to the stress of what you have both been through. It is good to talk about the dreams, however silly they may seem. Remember that this is normal and that you are safe.

**Exercise**

Although it is important to rest, it is also important to take exercise. Walking is good exercise. A gentle walk around the garden or the neighbourhood each day is suitable. Gradually increase the amount of exercise over the weeks. Cycling is another good form of exercise. Swimming in public baths is not recommended until all wounds are **completely** healed due to the risk of infection. Once you are fully fit, if you are a keen sports person there is now the opportunity to enter the Transplant Games. You can log on to the website for more details [www.tsagb.org.uk](http://www.tsagb.org.uk).

**Diet**

After your transplant, a high protein diet is needed to help with wound healing. Dietary restrictions necessary before transplant, e.g. reduced salt or fat, are not likely to be required. The dietitians, nurses and transplant coordinators will advise you about your specific dietary requirements, as there may be foods which you should avoid, especially if you have dietary needs for other reasons e.g. diabetes. Sometimes, perhaps a month or so after transplant patients may start to put on more weight than they would wish, there are many reasons for this and you should discuss this with the doctors if you are concerned. You **must not** eat grapefruit or grapefruit products, pomegranate juice or Earl Grey tea as they interact with your medication. **Alcohol should not be drunk** until you have discussed it with your Liver Unit consultant.

Some patients will require a low potassium diet for a period after the transplant often due to the effect of the tablets on their kidneys. If this is the case the doctor will discuss it with you in clinic. Guidelines for a low potassium diet are as follows:

**Protein foods** such as fish, meat, cheese, milk, eggs and pulses are fine to eat as usual.
**Starchy foods** such as bread, rice, pasta and cereal are a good source of slow release energy and are not high in potassium.

**Please note – you do not need to follow the low potassium diet described below unless it has been requested by your doctors.**

**Foods to limit:**

**Drinks:** coffee, fruit juice

**Fruit:** oranges, bananas, grapes, dried fruit, avocado

**Vegetables:** mushrooms, spinach, baked beans, jacket potatoes

**Miscellaneous:** chocolate, nuts, crisps, toffee, fudge, liquorice

The water used to cook potatoes and vegetables should be discarded. Potatoes should be cut into small pieces and boiled in a large volume of water.

The transplant coordinators will be happy to discuss this and any other enquiries with you. If required they can refer you to the dietitian.

**If you are ill at home**

The liver transplant coordinators can be contacted at any time, day or night if required. They are available to give you advice about what to do if you are unwell. Often people just need reassurance, though you may also be advised to see your GP, or have your GP come out to see you, depending on how unwell you are. It is a good idea to have a thermometer at home so that you can check your temperature if you feel unwell. The coordinator may well ask if you have a temperature or not.

The coordinator will discuss your symptoms with the doctors and call you back. You may be asked to have blood taken by your GP the following day or to come to clinic sooner than planned. If you are very unwell there is always the option of phoning for an ambulance so that you can be admitted to your local hospital if need be, though this does not happen very often. **If you are admitted to your local hospital you or your carer must inform the transplant coordinators.** If it is fairly soon after your transplant you may well be transferred back to Birmingham.
**Risk of infection**

You are particularly vulnerable to infection during the first few months following your transplant. This is because you are still recovering from your surgery and you are still taking steroid tablets. It is recommended that you try to avoid contact with people who have coughs and colds. However this is not always possible, as the people you live with may catch a cold. If you catch a cold and have difficulty shaking it off or if you develop a chesty cough, you should visit your GP and inform the doctors when you come to clinic. If you come into contact with other infections, shingles or chicken pox for example, contact the transplant coordinators for advice. You should not use the public swimming baths until your wounds are fully healed.

**Cytomegalovirus CMV**

Cytomegalovirus (CMV) is a member of the herpes virus family and is very common; between 50-80% of adults in the UK are infected with CMV. If your donor was CMV positive you will be taking an antiviral tablet (Valgancyclovir) for the first three months following your transplant. When this is due to stop you will have blood taken in liver outpatients to check for levels of the virus in your blood. After you stop taking valgancyclovir there is a small chance that you could develop CMV infection. If you do develop CMV infection you may feel unwell with a flu-like illness for a week or so. Occasionally patients develop a more serious infection and need to be treated with intravenous antiviral medicine in hospital.

**Getting used to being at home**

Arriving back home and recuperating after your transplant can cause emotional as well as physical upset. You may feel as though you are on something of an ‘emotional rollercoaster’. This may be a due to a combination of lack of sleep, anxiety about being back at home, disappointment in how the transplant has gone, the size of your wound scar, niggling pain, the process of starting to feel well again (which may be the first time for a long while), frustration with loved ones (who have also been under a lot of stress), and so on. Do not be alarmed if you experience high and low periods, swings of mood between great
happiness and depression, and maybe tearfulness that you cannot control or explain.

Remember that your body has experienced a major crisis which has both physical and emotional effects, and a period of adjustment is natural and necessary. Another reason to feel upset can be the knowledge that you have survived, when others have not. This feeling can be worse if you know other patients who have died whilst they were waiting for a transplant, or after their transplant. You may also have strong feeling of grief for your donor and their family.

**Care for your loved ones**

Whatever the relationship, husband, wife, partner, friend, it is important to remember that the loved ones of patients who have had a liver transplant have also been through a highly emotional and stressful experience. Whether they sat next to you at the bedside throughout your hospital stay or not, they will have been worried about you. They may have spent many days travelling to and fro from home to Birmingham. They may have had to manage the home and family as well as trying to juggle work and visit you in hospital. They also have a period of adjustment to go through. Now that you have had your transplant you may not be as reliant upon them as you were. It is important that you and your partner talk through your experience together and that you continue to support one and other.
Long-term considerations

Biliary stricture

Patients whose bile duct is joined directly to the donor bile duct can sometimes develop a narrowing of the bile duct (stricture) at the site of the connection. This can often be treated by placing a small plastic tube (a stent) into the bile duct to keep it open. Occasionally however stents can become problematic, for example due to recurrent infection, or blockage and you will be asked to come into the Queen Elizabeth to have this area of the surgery rebuilt. This is called a biliary reconstruction and you would expect to be in hospital for a week to 10 days following the surgery. (See ‘Roux-en-Y’ and diagram near the back of the book.)

Risks of cancer

Because you are taking anti-rejection medication you are at increased risk of developing some cancers, especially of the glands, the skin, gullet and bowel. You should ensure that you monitor your body for these and other potential cancers and seek early treatment if you are concerned. There does not appear to be any increased risk of cancer of the lung or breast.

• Skin cancer – see care of your skin below
• Breast cancer – see sexual health below
• Cancer of the testes – see sexual health below
• Cancer of the cervix – see sexual health below
• Prostate cancer – men who find they are having difficulty passing urine should discuss this with their GP
• Cancers from smoking (mouth, throat, and lungs for example) – if you need advice and support to stop smoking please ask the liver transplant coordinators, nursing staff or doctors
• Bowel cancer – after your transplant your bowel habit will be disturbed. However, if later on you notice blood, mucus or other abnormal bowel habits please seek advice from your GP or tell the Liver Unit doctors
• **Lymphoproliferative disease** – this is a rare cancer of the bone marrow which can occur due to your medication (approx 2% following liver transplant). It is diagnosed by blood, and other tests, and can be treated

**Kidney failure**

Your kidney function is monitored each time you come to clinic. Your anti-rejection medication affects your kidneys and in the long term there is a risk of severe kidney problems, possibly even kidney failure requiring dialysis or kidney transplantation. This can be minimised by close monitoring of blood levels of anti-rejection medication and adjustment to your medication if required. It is one reason why you continue to be seen in liver outpatients regularly for the rest of your life. Some medication can make your kidney function worse (for example Ibuprofen) and therefore you need to check with your pharmacist, the coordinators or doctors before starting new medicines.

**Recurrence of your original disease**

Liver transplant is not always a cure for your underlying disease. With some conditions there is the possibility that your new liver will become damaged in the same way that your old liver was. Conditions where there is the possibility of recurrence of the original disease are: hepatitis B and C (see ‘Transplant for viral hepatitis’), Transplant for any form of cancer (see ‘Transplantation for liver cancer’), PBC, PSC, auto-immune hepatitis (AIH), NASH and cryptogenic cirrhosis. If you have any questions about this please speak to the doctors or transplant coordinators. **Patients transplanted for alcoholic liver disease would not expect be offered another transplant in the event of recurrence.**
Sexual health and related issues

After a long illness and/or major surgery it is not uncommon for people to feel undesirable or to lack sexual drive. This is perfectly natural as limitations in your health can affect your ability give and to receive sexual pleasure.

- You may feel unhappy with your ‘body image’
- You may have feeling such as fear, sadness or anger
- You may feel more/less dependent on your partner and this may affect your relationship
- You may still be experiencing some physical pain or discomfort
- You are in the process of returning to normal strength and fitness

It is important to continue with normal loving contact such as touching, kissing and cuddling. Often relatives of transplant patients feel afraid to touch or to kiss their loved ones when they are on the Critical Care Unit or in hospital, however there is no reason why you should not do this. It is important that you respond to your personal feeling through this difficult time.

You should resume your sexual relationship whenever you and your partner feel ready to do so; it may take a while before you feel ready for this. Men may experience problems with impotence and women may find that their menstrual cycle is irregular. Most often these problems will resolve in time. If you are at all concerned you should talk things through with your GP or with the Liver Unit doctors.

Contraception

Irregularities in your menstrual cycle do not necessarily imply lack of fertility therefore it is important that you take contraceptive precautions.

- **Hormonal contraception** – the pill (combined or progesterone only), contraceptive injections, or the Mirena ‘coil’ intra-uterine system. These forms of contraception carry a risk of vascular complications and should not be used without first consulting your Liver Unit doctors

- **Intra-uterine devices** – the ‘coil’. These devices carry a risk of infection
and should not be used without first consulting your Liver Unit doctors

• **Barrier methods of contraception** – condom, female condom and diaphragm are all suitable forms of contraception

Sexually transmitted diseases (STD)
As you are taking anti-rejection tablets which may make you more susceptible to infection you should be extra vigilant about the risks of sexually transmitted disease. If you have several sexual partners, or have casual sex, you should always use a condom. Some sexually transmitted diseases are not obvious and you may not be aware that you or your partner has them. If you experience symptoms such as discharge, bleeding or itching or if you feel you are at risk of STD then you must visit your GP or genito-urinary clinic.

Pregnancy
Women should discuss family planning issues with the Liver Unit doctors. We advise that you do not become pregnant for **at least one year** following your transplant. If you do become pregnant **you must** inform the Liver Unit doctors, this is because:

• Some anti-rejection medicine can potentially cause foetal abnormalities

• Pregnancy may affect the levels of medication in your blood

• It is important to monitor liver function during your pregnancy

You **should not breast feed your baby** as some anti-rejection drugs are present in breast milk. Discuss this with your Liver Unit doctors.

Some illnesses which lead to liver transplant are hereditary, for example Wilson’s disease and Haemachromatosis and it may be advisable to have children screened to ascertain if they are at risk of developing the disease. Other illnesses, hepatitis B or C infection, for example can be passed on to the unborn baby. If you are uncertain about these sorts of issues please discuss them with the Liver Unit doctors or the transplant coordinators.
In-vitro fertilization (IVF)
There is no reason why women who have had a transplant should not undergo IVF treatment. If you are planning this, please consult your Liver Unit doctors beforehand for advice.

Hormone Replacement Therapy (HRT)
HRT treatment is usually well tolerated in liver transplant recipients and can be considered provided liver function tests are normal. If you are considering taking HRT you should discuss it with your Liver Unit doctors first.

Health screening
You should follow the normal guidelines for breast, cervical and testicular cancer screening, these are:

- **Breast screening** women between the age of 50 and 70 are invited for screening every three years. You should examine your breast regularly and visit your GP if you are concerned

- **Cervical screening** women between the ages of 25 and 49 are invited for screening every three years, aged 50 to 65 every 5 years

- For further information visit: [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)

- **Testicular screening**: men should examine their testicles once a month. If you are concerned you should contact your GP. For more information visit: [www.tcrc.acor.org.uk](http://www.tcrc.acor.org.uk)

Dental care
Care of your teeth and mouth is important to help reduce the risk of infection. It is recommended that you visit the dentist every six months. You need to tell your dentist that you have had a transplant and what medication you are on.

**Antibiotic treatment**: You do not need antibiotic treatment for dental work just because you have had a transplant. For treatments where there is a risk of infection you may need to have antibiotics, if you are allergic
to penicillin you can have ciprofloxacin. Antibiotics such as erythromycin and clarithromycin should not be given as they interact with anti-rejection medication.

**Pain management:** Non-steroidal anti-inflammatories (Ibuprofen etc) should not be taken as they can induce renal impairment. Paracetamol is acceptable up to 3g/day.

Neoral (ciclosporin), one of the main anti-rejection drugs, can cause gum disease, this is more common if you are also taking Nifedipine. Tacrolimus and Mycophenolate have not been identified as causing dental problems.

**Infections in the longer term**

Your immune system is reduced but not to the point that you will catch every infection that comes along. However, sometimes infections can be difficult to overcome and you are more likely to need antibiotics to help fight infection than someone who has not had a transplant. Always seek advice from your GP if you are unwell.

Be sensible in public situations and avoid contact with people who have colds, flu or other infections. It is important however, that you get out and enjoy yourself, using public transport, going to restaurants or to the cinema and so on. If you have any concerns please contact the liver transplant coordinators or speak to the Liver Unit doctors for information and advice.

**Tattoos and body piercing**

There is increased risk of infection (viral and bacterial), though the risk is probably small. We recommend that you do not have tattoos or body piercing without first discussing it with your Liver Unit doctor.
General health and well-being

Coughs and colds

If you go to the chemist to buy ‘over the counter’ drugs for a minor illness such as a cough, a cold, hay fever or constipation you should inform the pharmacist that you have had a liver transplant and what drugs you are taking. They will be able to advise you what you can have. If in doubt, contact the transplant coordinators.

Care of your skin

Because you are taking anti-rejection medication you are at increased risk of developing skin cancer. Make sure that you cover up in the midday sun, use a hat and wear high factor sunscreen (factor 30 as a minimum). This is not only for the sun abroad but here in the UK as well; and also in the winter, when the sun can be surprisingly strong. Take sensible precautions but do not let this spoil your enjoyment of life. Check your skin regularly for warts, moles or verrucas. If you are concerned, have these checked by your GP. Skin cancers are rarely life threatening provided medical advice is sought early.

Extra hair

You may experience extra facial hair quite soon following your transplant. This may be due to the medication. It is important that this hair is not plucked out or treated with laser or electrolysis as it will usually disappear within a few months once the medication is reduced. Suitable treatments may include bleaching the hair with special bleaches, trimming with scissors, or hair removal creams. Be sure to use one which is recommended for use on the face and select ‘sensitive skin’ varieties if possible. It is advisable to test your tolerance of the product by following the directions on the bottle and to apply to a small ‘test’ area first. Hair removers can cause irritation to the eyes, lips, and mucous membranes, so apply carefully. Trained beauty therapists can give suitable advice if you tell them what medication you are on. The liver transplant coordinators and clinic nurses are also available to discuss these issues.
Vaccinations

You may need vaccinations for several reasons. We suggest that you do not have any vaccinations in the first three months after your transplant. However, after three months you may need vaccinations to travel, to prevent flu, or a ‘booster’ to update you or your family members’ immunity.

Winter vaccines: We would recommend that you have the ‘winter’ vaccines, flu and pneumonia. Do not have them unless it is more than three months since your transplant.

Hepatitis vaccines: If you needed the Hepatitis A and/or Hepatitis B vaccines and did not complete the course prior to your transplant you should complete these starting three months after your transplant.

Vaccinations for travelling abroad: Your GP or practice nurse, or the International travel section of the Department of Health (0800 555 7777) will be able to tell you which vaccinations you need if you are travelling abroad.

- Always remember your sunscreen

Listed below are vaccinations you must not receive:

- ‘Live’ vaccinations
- BCG
- Yellow fever
- MMR
- Smallpox

Those who have had liver transplants can safely be given:

- Tetanus toxoid
- Inactivated polio vaccine
- Hepatitis B vaccine
- Hepatitis A vaccine
- Meningococcal polysaccharide vaccine
- Diptheria
• Influenza
• Pertussis (whooping cough)
• Pneumococcal vaccine
• Polio vaccine
• Cholera (in patients over 6 months of age)
• Typhoid (in patients over 1 year of age)

Chicken Pox

The Varicella Zoster virus, which causes chicken pox and shingles, can make a transplant patient very sick. Here are a few guidelines:

• If you have had the disease in the past, the risk of chicken pox infection is very small. A test to check if you have had the disease in the past is often done as part of the transplant assessment

• If you have direct contact (e.g. being in the same room) with someone who has chicken pox and you have never had chicken pox, or are uncertain if you have had it or not you should have blood taken to check for chicken pox immunity. This can be done by your GP but it may take a few days to get the results back. A quicker option may be to ask your GP to fill in a request form and take it the phlebotomy department at your local hospital

• If you have never had chicken pox then you will need some protective treatment. This can be started within ten days of the contact. A drug called Acyclovir is given, although sometimes an injection of Varicella Immunoglobulin is preferred - this can be given by your GP

• If you have been in contact with someone who has themselves been in contact with a person who has chicken pox (indirect contact) the risk is negligible. You are only at risk if you come into direct contact with an infected person
Shingles

The risk of catching the chicken pox virus from someone who has shingles is very small. You are only at risk if you come into direct contact with the skin sores by touching them. If you do have direct contact you should follow the guidelines above for chicken pox.

Alternative medicine and therapies

- **Do not take** herbal or Chinese medications, particularly St. John’s Wort, as they interact with some of your medication
- Homeopathic remedies are not usually a problem
- It is not necessary to take vitamin supplements provided you eat a healthy balanced diet, however, in the accepted dose they will do no harm
- Acupuncture and aromatherapy are not considered to be a risk

Getting on with life

Returning to work

We would normally recommend that you do not return to work until three months following your transplant though some patients, depending on their job, will go back sooner, perhaps just part-time at first. It is very much dependent on your own particular circumstances, however, you should discuss returning to work with your consultant when you are seen in clinic.

Pets

There is no reason why you cannot keep pets after your transplant. Provided they are kept in clean conditions and are well cared for, they do not represent an infection risk. The only pets that need some consideration after your transplant are birds, more specifically pigeons, as they can carry germs that cause lung disease. Please speak to your consultant if you keep pigeons.
Driving

Your medication can affect your concentration and your wound may make some driving actions difficult, for example an emergency stop. When you feel well enough to drive, check with the Liver Unit doctor when you see them in Liver Outpatients. It is advisable on your first drive to take someone with you and drive in a quiet area with few distractions. Also inform your insurance company to make sure that you are suitably covered. You do not need to inform the DVLA in Swansea.

Contact the DVLA if you have:
- Alcoholic liver disease
- A fit following your liver transplant
- Become diabetic

For more information visit www.direct.gov.uk

If you have a Heavy Goods Vehicle or Public Service Vehicle licence, please follow the DVLA guidelines. This is to help you become more confident after an extended period away from driving. The DVLA can be contacted on 0300 790 6801.

Travelling abroad

We advise that you do not travel abroad until at least three months after your transplant. It is strongly advised that you take out medical insurance before you travel. Your insurance is likely to be more expensive than for those who have not had a transplant. Some insurance companies will not provide medical insurance until six months after your transplant.

Here is a check list of things to consider when travelling abroad:
- Check with your Liver Unit doctor before you book
- Make sure that you have adequate medical insurance
- Make sure that you have enough tablets with you, with some to spare just in case
- Carry your tablets with you as hand luggage, in case your bags are
lost or stolen
• Check that you are able to have the recommended vaccinations, if required
• If you are ill whilst on holiday seek medical advice

Publicity
Organ donation and transplantation is often mentioned in the newspapers and on television. Some patients feel so well and happy after their transplant that they want to tell the world about it, and they contact the media to have their story told. If you wish to become involved in something like this we recommend that you contact the transplant coordinators first. They can put you in touch with people who work at the hospital whose job is to work with the media and to provide you with help and advice.

You may also be contacted by the transplant coordinators and asked if you would be willing to participate in a media event. You may be asked if you would be willing to talk to a journalist on the phone, or be interviewed in your home, for example. If you do not wish to participate, please tell the coordinators; they will not be upset, as there will be other patients who may wish to take part who can be contacted instead.

Support groups
Some people gain comfort, support and guidance from like-minded people who have experienced similar situations. Although the Liver Unit staff have a vast experience of liver transplants they have not usually experienced it themselves, either as a patient or a relative. There is great value in talking to patients and carers who have been through transplantation. Even though everybody’s experience is different, they can offer insight into the process that can only be gained from having been through it.

Support groups have many roles. As well as supporting patients through listening and talking they can also offer advice about practical
issues such as insurance. They organise social events and support charities, they help to promote organ donation and transplantation in the media, and they support the Transplant Games. There are local support groups throughout the country. To find out about your local support group, or other information about liver disease and transplantation, contact the British Liver Trust.


More about the Birmingham Support Group

This group (known as the Queen Elizabeth Liver Patients’ Support Group) meets at 19:30 every third Monday in the month, at the Seminar Room at the Queen Elizabeth Hospital. All liver patients, friends and family are welcome. The QE Liver Patients’ Support Group has an important role to play in helping people with liver disease. Patients and their relatives can identify with, and meet people who have had successful transplants. The group comprises of former patients from a wide variety of backgrounds, all of whom are leading full and active lives. Their contribution is greatly valued by the Liver Unit team.

The Visitor Group provide a rota of members who attend the Queen Elizabeth Hospital every Tuesday at 14:00 to speak to the outpatient assessment patients and Wednesday evening at 19:30 for the inpatient assessments and to offer support to other patients.

For further information please contact:
Alan Hyde 01902 679333
Website: www.qehblsg.org.uk

Charitable donations

Some patients have expressed a wish to share some of the generosity they have experienced from family and friends by suggesting to their well wishers that they make a donation to one of the various Trust Funds linked to the Liver Services as an alternative to buying them a gift or sending flowers.

There are various Trust Funds linked to Liver Services that are
administered via the Charitable funds department of the University Hospitals Birmingham NHS Foundation Trust – registered Charity number 1072839. These are:

- Liver Unit Ward and Outpatient Department Fund
- Liver Foundation Trust Fund
- The Sally Painting Memorial Fund

For more information about these funds, or if you would like to make a donation please contact, or send your cheque, payable to the appropriate fund, along with a covering letter to:

Secretary to the liver transplant coordinators, 2nd Flood, Nuffield House, Queen Elizabeth Hospital, Mindelsohn Way, Birmingham B15 2TH.

Your donation will be paid into the appropriate fund and a letter of acknowledgment and a receipt sent out to you with our thanks.

You may also wish to consider a donation to The Donor Family Network. This charitable organisation, run by donor families, aims to support donor families and to promote organ donation. Visit their website at www.donorfamilynetwork.co.uk.

**Suggestions and complaints**

If you have any suggestions or if you wish to make a complaint about the care that you have received, or about your stay in hospital, there is a complaints procedure that can be followed. There are leaflets and posters in the ward areas which guide you through this. The process is in place to help us make changes that can help other patients as well as yourself. Your care will be in no way compromised by any suggestions or comments that you make. You can also drop in to the Patient Advice and Liaison Services (PALS) near the main entrance (atrium) of Queen Elizabeth Hospital Birmingham (new hospital).
Further information

Information and advice for carers

Experience has shown us that support from carers (family and friends) is crucial to the success of a liver transplant. This means that carers need to be involved in the process from the start; the more they understand about liver transplant the better the support they will be able to give. The process of transplantation, from assessment to listing and waiting, through to transplant and recovery is a stressful time for all involved.

What do we mean by carer?

A carer is a person who is able to provide emotional and practical support to the patient throughout the transplant process. This may be one person: husband, wife, partner, grown-up child, brother, sister or a friend; or it may be a group of people.

The role of the carer during transplant assessment

The carer will be expected to attend the Liver Unit with the patient in order to meet the transplant coordinator and other members of the team and for the team to meet the carer. Education and information are essential both for the patient and the carer. A patient will not normally be added to the waiting list until the team are satisfied that there is adequate support for them at home.

The transplant coordinators need to look into the support that is available from family and friends for each patient. This is to ensure that the patient will have adequate support both before and after their transplant. Sometimes the social worker will be involved in helping to put together a suitable support package depending on the needs and wishes of the patient or carers.

- The home situation will be discussed to establish where the patient will stay and who will be in the house to help look after them...
• The social worker will be able to explain what financial help is available

• Transport to and from Birmingham will be discussed: it is the responsibility of the patient and carers to provide transport in the first instance. Other options can be explored if there is no transport available

We are aware that not every patient will have a group of family or friends who are able to act as carers. In this situation we would need to explore other options for support, perhaps a longer stay in hospital after the transplant, for example.

Patients will not be added to the waiting list until the Liver Unit team are satisfied that there is adequate support for the patient and a plan of care and support following transplant has been agreed.

The role of the carer whilst the patient is waiting for transplant

It is essential to contact the transplant coordinators if:
• the patient is unwell
• the GP has prescribed antibiotics for an infection
• the patient has been admitted to hospital
• there is a change in social circumstance
• there is a change in contact numbers
• you are planning a holiday

This can be a stressful time for patients and their carers, not least because we have no way of knowing how long the patient will wait. If you, as a carer are finding it difficult to cope, please contact the transplant coordinators and discuss your concerns, or speak to the doctor when the patient come for their outpatients appointments. (See also ‘Being on the waiting list’.)

The role of the carer at the time of transplant

The period of time when the patient is in hospital for their transplant can be extremely stressful for cares especially if the patient’s recovery is slow or there have been complications. It is important that carers have
someone that they can speak to and discuss problems with, such as friends or family. Remember that the transplant coordinators are there for the carer as well as the patient. Do not hesitate to speak to the coordinator if you need some support or advice.

Carers are not expected to remain in Birmingham for the whole period that the patient is in hospital though some may choose to do so. It is important that carers look after themselves and don’t get overtired. It may be advisable to take a break and return home for a couple of nights to take some ‘time out’. (See also ‘Carers and loved ones’.)

As soon as the patient has been transferred from the Intensive Care Unit plans for discharge will commence:

• We will start teaching the patient and their carer about the medication so that the carer can help with medicines at home
• You will meet with the pharmacist to talk about the patient’s medication
• We will check that the plan for care and support previously agreed is still in place
• You will meet with the transplant coordinator before the patient goes home to agree what support is required and answer any questions that you may have
• Discuss transport options to get the patient home as required

**NB:** Discharge from hospital is dependent on the patient’s blood results – plans that are made for discharge may change once blood results are reviewed.

**Looking after yourself**

It is all too easy for doctors and nurses, and perhaps friends and family too, to focus in on the patient and forget that you, the carer, have also been under a great deal of stress. It is important therefore for carers look after themselves:

• Look after yourself otherwise you may not be fit enough to support the patient when they go home
• Find someone to talk to, a good listener
• Make sure you get plenty of rest
• Take time out for yourself
• Remain optimistic
• Set limits for yourself and learn to say no when things get too much

Sometimes it can be helpful for friends or relatives to come up and stay with you whilst you are in Birmingham (especially on the day of transplant as you can feel lonely and isolated). It may also be helpful to use them to get things ready for when you and your loved one come home. Most people are keen to help in some way or other.

Medication for carers

If you are taking any medication yourself you must bring it with you when the patient is admitted to hospital. Unfortunately the hospital doctors and pharmacy are unable to prescribe or dispense medications other than to the patient themselves. If you forget your medication you will need to either:

• Visit and register with a GP in Birmingham and ask them to prescribe it for you
• Visit the NHS Walk in Centre which is located in Boot’s Chemist, High Street, Birmingham (city centre). Telephone: 0121 255 4500

The role of the carer after the patient has gone home

The patient is ready to leave hospital once they are mobile enough to get in and out of bed, get dressed and go up and down stairs. They will also need to understand what tablets to take and when to take them. It is very useful if you, the carer, are also familiar with the patient’s tablets. It is also important that you know what to do if the patient is unwell. If they are admitted to your local hospital you must inform the transplant coordinators.

You must phone the transplant coordinators if you are concerned about the patient, especially if they have symptoms such as vomiting or diarrhoea, a high temperature, abdominal pain or yellowing of the skin or eyes.
Don’t panic – it is not uncommon for patients to have an occasional problem after going home – this can normally be quickly sorted out either with a visit to the GP, back to liver out-patient’s clinic or potentially an admission to your local hospital or to the Liver Unit in Birmingham.

The patient should get up in the morning and get dressed. They must not lie around in bed all day, even if they don’t feel great. It’s OK to take a nap in the afternoon if they feel tired. They may find it difficult to eat at first and may need to be encouraged to eat properly. They should aim to gradually build up their strength and fitness and do a little bit more each day. Gentle exercise is good but they should avoid strenuous activity for at least three months. They should discuss exercise and fitness with the doctor when they come to clinic.

Arriving back home and recuperating after a transplant can cause emotional as well as physical upset. Both patient and carer may feel as though they are on something of an ‘emotional rollercoaster’. Do not be alarmed. Everyone needs a period of adjustment. (See also ‘Going home’.)

**Tips on how to give support:**

- Try to avoid giving advice or ‘telling’ the patient what to do – encouragement and listening are better
- Don’t be over protective – a gradual return to everyday responsibility will aid recovery
- Don’t try to ‘cheer then up’ as this sometimes has the opposite effect. Comfort and understanding is sufficient
- Do things together, try to think of yourselves as a team
- Don’t give up your own interests and activities – keep a balance between being a carer and being an individual
- Try to be honest and open with each other and say how you feel. Communication is important
- Allow them to go at their own pace and regain their role in life
Research into liver disease

Deaths due to chronic liver disease increased sharply in the UK during the 1990s and are now amongst the highest in Europe; unfortunately there are few effective treatments for most liver diseases. The Birmingham Liver Unit is one of Europe’s leading centres for research into liver disease. A team of clinical and laboratory scientists are working to better understand liver cirrhosis and liver cancer, as well as developing our understanding of how liver transplants function and what makes them survive. In addition we have the expertise and facilities to develop and test new treatments.

We are ideally suited to do this work in Birmingham because we have one of the largest liver transplant programmes in Europe as well as a team of laboratory scientists with internationally renowned expertise in liver disease, hepatitis viruses and liver cancer. Our laboratories are supported by grants from various bodies including the Medical Research Council, Wellcome Trust, Cancer Research UK, the British Liver Trust and by kind donations to the Birmingham Liver Unit’s Liver Foundation Trust. For more information about our research please visit www.bham.ac.uk and search ‘liver’.

Frequently asked questions

Assessment

1) What does transplant assessment mean?
   It is a medical, psychological and social assessment of your health, your liver disease and your needs in order to determine if liver transplant is the best form of treatment of you. (See ‘The assessment’.)

2) How long does the assessment take?
   Those who are assessed as an inpatient can expect to be in hospital for at least five days, Monday to Friday, though it could be longer. If further investigations are required you may need to stay in hospital until these are completed, in these circumstances patients will often go home for the weekend and return the following week. For those
who are assessed as outpatients there are two visits to Birmingham, one for one day and one for two days. These will probably be about two weeks apart. The assessment is normally completed at the end of the second visit, though there can sometimes be delays if extra investigations were required. (See ‘The assessment’.)

3) **What happens if I don’t get on the waiting list?**
   This will depend on why you did not get placed on the waiting list. For some patients it is too soon to consider the transplant option, for others there may be concerns as to your ability to survive a liver transplant. (For more information see ‘The assessment’.)

4) **What if my family can’t get to the hospital for the assessment?**
   Part of the assessment involves your family (or carer) coming to Birmingham to meet the transplant coordinators so that a plan for your care after hospital can be agreed. You will not be added to the waiting list until this has happened. (See ‘Preparation for listing’.)

5) **What tests will I have?**
   All patients have a chest X-ray, ECG, echocardiogram, abdominal ultra sound scan, spirometry, and many blood tests. Other tests may be needed depending on your own particular circumstances. (See ‘Investigations’.)

6) **What if I don’t feel ready to have a transplant?**
   You will not be forced into making a decision. Many patients go home to think about things, or discuss it with their family, before deciding whether to have a transplant or not. (See ‘Going onto the waiting list’.)

7) **What happens if I go on the waiting list?**
   You will be added to list either as a ‘priority’ or an ‘urgent’ patient. (See ‘Going onto the waiting list’.)
Waiting

1) How long will I have to wait?
   It is impossible to say how long you will wait. If you are struggling to cope with waiting please call the transplant coordinators who will talk things through with you. (See ‘Waiting list deaths’ and ‘Removal from the waiting list’.)

2) What if I get very sick whilst I’m waiting?
   You must inform the transplant coordinators if you are admitted to hospital for whatever reason or if your GP prescribes a course of antibiotics. If you are particularly unwell you may be transferred to Birmingham. Sometimes patients are taken off the waiting list temporarily until their condition improves. (See ‘Being suspended’ and ‘Sickness’.)

3) Am I allowed to go on holiday whilst I’m waiting?
   Yes, holidays can be important to relieve the stress of being on the waiting list, provided you are well enough. Holidays must be on the UK mainland only. If you went overseas for a holiday you would need to be suspended from the waiting list and your doctor might advise against this. (See ‘Holidays’, ‘Contact’ and ‘Transport’.)

4) How is the right donor for me found?
   Matching of donor and recipient depends on many factors including; blood group, size, the quality of the donor liver, how unwell the recipient is and length of time on the waiting list. The transplant surgeon assesses the factors and reaches a decision when a donor liver becomes available. (See ‘Your donor liver’ and ‘Matching of donor and recipient’.)

5) How much time do I have to get to hospital for my transplant?
   You should leave home within one hour of being called in for your transplant unless the transplant coordinator says otherwise. You will always have enough time to travel to the hospital safely. (See ‘The call’.)
6) **What if I have no way of getting to hospital for my transplant?**

It is your responsibility to arrange transport to the hospital for your transplant. If you have absolutely no way of getting in you should discuss this at the time of your assessment with the transplant coordinators. (See ‘Transport’.)

7) **What if the transplant coordinators can’t contact me?**

If the transplant coordinator is unable to contact you when a suitable donor for you becomes available you run the risk of missing your opportunity of a transplant. Therefore you must remain contactable at all times. The transplant coordinators will discuss this with you during your assessment. (See ‘Contact’.)

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**Transplant**

1) **What happens when I arrive at the hospital for my transplant?**

You will be seen by the doctors and nurses and checked out to make sure you are free from infections and well enough to undergo the transplant. You will have a chest X-ray and an ECG, blood will be taken to enable the blood bank to prepare blood products for the operation. In the morning you will be seen by the transplant coordinator and possibly the anaesthetist before you go for your transplant. (See ‘Coming in for your transplant’.)

2) **Where does my donor liver come from?**

You donor liver comes from another person. They will have suffered an irreversible brain injury and their heart and lungs will be supported by artificial means on a Critical Care Unit. In 2011 75% of adult transplants were from donors with brain stem death (DBD) and 25% were from donors with cardiac death (DCD). The transplant coordinator will describe the difference between these and how it affects you in detail during your assessment. (See ‘Your donor liver’.)

3) **How long does the operation take?**

Including the time spent in the anaesthetic room approximately five to eight hours. (See ‘In the operating theatre’.)
4) **What are the risks of having a liver transplant?**

The risks of transplantation will be discussed with you in depth by the transplant coordinators and the surgeon during your assessment. The chances of developing complications are listed below (see also ‘Complications and rejection’):

- Biliary leak/stricture 13%
- Hepatic Artery Thrombosis 4.8%
- CMV infection 6%
- Primary graft non-function 3%
- Renal dysfunction requiring temporary support 30%

(See ‘Summary of the risks of liver transplantation’.)

5) **What are my chances of survival after a transplant?**

It is easy to be misled by statistics. Survival rates are dependent on a number of factors, how old you are, how ill you are at the time of your transplant, and the cause of your liver disease to name just a few. However, overall, in the UK one year survival following liver transplant is 88%. Five year survival is quoted as around 75%.

For further information visit: [www.uktransplant.org.uk](http://www.uktransplant.org.uk), [www.optn.org](http://www.optn.org) (from the USA), [www.nhsdirect.com](http://www.nhsdirect.com).

6) **How long will I be in hospital after my transplant?**

The majority of patients are in hospital for 7 to 10 days following transplant. However, if there are complications or if you are slow to recover you may be in hospital for longer. Sometimes, if recovery is slow patients are transferred to their local hospital to continue their recovery before going home. (See ‘Moving to the ward’ and ‘If you are slow to recover’.)

7) **What happens if I die?**

If you are very sick, the doctors, nurses and transplant coordinators will do everything possible to get you better and ensure that your family are kept aware of your condition. If you were to die your family would be asked for their consent for a post mortem examination. The hospital’s Bereavement Officer would help with
making any arrangement and ensuring that your family’s needs are met. (See ‘Death’.)

After transplant

1) What is rejection and will I get it?
Rejection is when the donor liver is ‘attacked’ by your body’s immune system. Anti-rejection tablets prevent this from happening. Approximately (30%) of patients (3 in 10) experience some acute (early) rejection. This often happens whilst still in hospital following your transplant and is treatable. A small number of patients experience chronic (late) rejection; this is often more difficult to treat. (See ‘Rejection’.)

2) What will my quality of life be like after a transplant?
This will depend on many things, such as, why you needed a liver transplant, how old you were at the time of the transplant, if you have any side effects from your medication or not, potential complications following the transplant, how you felt before your transplant, your general outlook on life, the support that you have from your loved ones. Patients who were transplanted for chronic liver disease generally report an increased quality of life following transplant whereas those transplanted for an acute illness report that quality of life is not as good as prior to their transplant. (See ‘Support groups’.)

3) I feel numbness of the skin near my wound, is this normal?
The skin around your wound may be numb or tingle because nerves have been cut when the incision in your abdomen is made to enable the operation. This can feel slightly odd and it may last for several months after your operation.

4) How long will my stitches stay in for?
Your wound will be closed using small metal clips. These are removed 21 days after the operation, either in liver outpatients, at your GPs or by the district nurses.
5) What if my wound is not fully healed before I go home?
   District Nurses can care for your wound at home. The progress of healing can be monitored in Liver Outpatients as required.

6) Will my hepatitis C come back?
   Most of the virus is removed with your old liver, however your new liver will become infected with hepatitis C. You will be seen in the Hepatitis Clinic following your transplant and closely monitored. There is a risk that the new liver will be damaged by hepatitis C, possibly requiring another liver transplant. (See ‘Transplant for viral hepatitis’.)

7) How soon can I go to the swimming baths after my transplant?
   You should not go the public swimming baths until your wounds are completely healed due to the risk of infection. Discuss this with you doctors in Liver Outpatients first (see ‘Exercise’).

8) Do I need a special diet after a transplant?
   You must avoid grapefruit and grapefruit juice, pomegranate juice and Earl Grey tea as these affect the levels of your anti-rejection medication. Some patients need to have a low sugar diet or a low potassium diet due to side effects of their medication. (See ‘Side effects of medication and diet’.)

9) How long will my new liver last?
   There is no time limit on how long your liver will last. However, there are specific conditions which may cause your liver to fail (see ‘Complications’). There are people alive in the world that had transplants 30 years ago. Surgical techniques and anti-rejection medicines are developing all the time and it is impossible to say what the future will hold.

10) Can I take cold remedies from the chemist?
    You should always check with your pharmacist before buying ‘over the counter’ remedies. You should inform them that you have had a liver transplant and what tablets you are taking. If in doubt you can always contact the transplant coordinators for advice. (See ‘Medications and coughs, colds, and so on’.)
11) How soon can I go back to work after my transplant?
We would advise that you do not return to work until three months following your transplant. However, some people may go back to work sooner, perhaps part time initially. It is very much dependent on how quickly you recover following your transplant and the kind of work that you do. You should discuss this with the doctors in Liver Outpatient following your transplant. (See ‘Getting on with life’.)

12) What if there is no one at home to help look after me?
Not everyone has family or friends who can be there to care for them following a transplant. If you have no one to support you, you would be transferred to your local hospital to continue gaining strength and fitness until it was felt that you were able to cope at home. You local hospital would be best place to organise any community support that might be available for you. (See ‘Transfer to your local hospital’.)
List of websites

University Hospitals Birmingham NHS Foundation Trust:
www.uhb.nhs.uk

QEHB, Liver Unit:
www.uhb.nhs.uk/depts/liver

For information on cancer screening:
www.macmillan.org.uk

For information about testicular cancer screening:
www.tcrc.acor.org

For information about the Transplant Games:
www.transplantsports.org

The British Liver Trust:
www.britishlivertrust.org.uk

For information about QEH Liver Patients’ Support Group:
www.qehblsg.org.uk

A liver transplant patients’ support group site:
www.qesupportgroup.org.uk

For information about organ donation and transplantation:
www.nhsbt.org.uk

For general information and statistic on transplantation:
www.nhsdirect.com

For patient education booklets and CDs:
www.itns.org
Glossary

**Allergy**
When the body is very sensitive to something (such as a particular drug) causing the body to react when there is any contact with it.

**Anastamosis**
The joining of two blood vessels together surgically.

**Aorta**
The main blood vessel that leaves the heart taking blood, full of oxygen, to the rest of the body.

**Anaesthetic**
A local anaesthetic is a small injection of a drug that numbs an area of your skin so that a doctor can perform a procedure without hurting you (such as for a liver biopsy).

A general anaesthetic is a mixture of medication given through a cannula which puts you off to sleep and not feel any pain. This allows doctors to perform bigger procedures (such as an operation).

**Anti-fungal agent**
Medicine that fights fungal infections.

**Anti-rejection medication**
See immunosuppression.

**Artery/arteries**
Blood vessels that take blood from the heart to the rest of the body. As the blood leaves the heart it has oxygen in it to supply the cells with their needs to work properly. This blood is usually bright red. Arteries tend to pulsate, so you can feel it – like the ones in your wrist.

**Arterial line**
A small plastic tube that is placed in the artery in your wrist. It allows for continuous blood pressure monitoring and for regular blood samples to be taken.

**Ascites/ascitic**
Excess fluid in the abdominal cavity (where your stomach, liver and intestines are) which sometimes occurs in liver disease.

**Bacteria**
Germs that may cause disease.

**Bile**
A yellow fluid made by the liver that is stored in the gall bladder. It helps to digest fatty food.
Bile duct
A tube that allows bile to pass from the liver into the digestive tract.

Biliary leak
After transplantation, the bile duct anastamosis can break down causing bile to leak into the abdomen.

Biliary stricture
After the transplant scar tissue can form around the bile duct, or debris can partially block the bile duct, preventing bile from leaving the liver.

Biopsy
See liver biopsy.

Central line
See ‘Intravenous catheter’.

Cholangitis
Inflammation of the bile ducts.

Cirrhosis
Scarring of the liver causing liver damage. There are many different causes for this.

Cytomegalovirus (CMV)
A virus that is common in a large proportion of the population and can affect patients who have had transplants, making them feel very poorly; this is called CMV disease.

Deep vein thrombosis (DVT)
A clot that forms in a vein, usually in the leg. This can happen when people are in bed for long periods of time.

ECG leads
Wires that join stickers on your chest to a heart monitor.

Encephalopathy
Drowsiness, irritability and personality changes which may occur as a result of liver disease. It can eventually lead to a coma.

Endotracheal tube
A plastic tube that is passed through your mouth and into your wind pipe and connected to a breathing machine (ventilator). It is passed when you are asleep under general anaesthetic, and is removed when you are able to breathe on your own.

Epidural
A small tube passed into the spinal area. Anaesthetic is then passed continuously through the tube giving pain relief for some transplant patients.

Full blood count
A blood test that looks at how many blood cells you have.
Gall bladder
This is a pear-shaped sac that lies under the liver. It stores bile until the body needs to digest fatty food. Some people have this sac removed if there are stones in it (gallstones). The gall bladder is removed during transplantation, because it does not heal very well. The bile will then flow straight into the digestive tract and help to digest fatty food. The body can cope with having the bile delivered this way with no need for further treatment.

Haematemesis
The vomiting of blood which may be fresh (bright red) or stale (resembling coffee-ground particles).

Hepatic
Relating to the liver.

Hepatic artery
A small blood vessel which delivers blood from the heart to the liver. This blood contains oxygen which the liver cells need to keep working.

Hepatic artery thrombosis
This is a rare complication of liver transplantation. It is a blockage of the hepatic artery, which is a vessel that supplies the liver with oxygen that allows the cells to work. If this happens it is most likely to happen in the first 48 hours after the transplant, but can happen at a later time (although this is even rarer). It is treated by another liver transplant, and the doctors and liver transplant coordinators will discuss this with you.

Immunosuppression
The medication used to prevent your body from attacking the donor liver.

Incentive spirometer
A small plastic device that the patient inhales through occasionally which helps to expand the lungs and aid deep breathing and coughing post transplant.

Intravenous catheter
A small plastic tube that goes into a vein. This allows the doctors to give fluids, blood or medication. Sometimes it is placed in your arm (venflon), sometimes it is placed in your neck (central line).

Jaundice
Yellowing of the skin and eyes due to bile not being removed from the body.
Kidney filter machine
A machine which filters the blood when the kidneys are not working properly. This is called CVVH (Continuous veno-venous haemofiltration). It is not as efficient as renal dialysis.

Liver function tests (LFTs)
A blood test that helps the doctors assess how well the liver is working.

Liver biopsy
A small piece of tissue removed from the liver for examination.

Lymphoproliferative disease
This is a form of cancer that can occur as a result of the immunosuppression drugs. It is rare (around 2%) and can sometimes be treated.

Melaena
Black stool caused by partially digested blood from bleeding in the oesophagus.

Nasogastric tube
A tube that is passed through your nose and into your stomach. It is needed to:
1) feed you if you are unable to eat because you are too unwell.
2) release acid and air from your stomach that may otherwise make you feel sick.

Oedema
Fluid that collects around the ankles, feet, legs, fingers etc.

Osteoporosis
This is a disorder of the bones that can be caused by liver disease. The bones become brittle as they lose their density. This can be treated with extra medication prescribed by the doctor.

Paracentesis
This is the drainage of ascites by inserting a needle through the skin into the fluid within the abdomen. Fluid drains into a bag over a period of several hours. Patients may have fluid (albumin) given into a vein during the procedure to support blood pressure.

Piggy-back
A surgical technique that is sometimes used to connect the new liver. The surgeon will discuss this technique with you.

Pleural effusion
Fluid that collects above the diaphragm in the cavity around the lungs causing breathlessness.
It is fairly common after liver transplant and is due to irritation to the diaphragm as a result of the surgery. The fluid is usually reabsorbed by the body in its own time.

**Portal vein**
A blood vessel which takes blood to the liver from the gut. This blood contains the absorbed products of digestion from the intestines and waste from other cells of the body. The liver cleans this blood before it returned to the heart.

**Primary graft non-function**
A rare complication after liver transplant when the donor liver does not work. It is necessary to find a new liver very quickly; the doctors and liver transplant coordinators will speak to you and your family if this happens.

**Pruritus**
Itching in the skin caused by bile salts not being removed from the body.

**Pulmonary embolism (PE)**
Blockage of an artery in the lungs. The blockage could be caused by air or blood. The air could enter during surgery, which is extremely rare, and the blood clot could occur if you are immobile for a period of time, which is why the nurses will encourage you to get out of bed quite quickly after your transplant.

**Pulse oximeter**
A machine that recognises how much oxygen is in your blood. This is a painless procedure as the probe is slipped over your finger or toe.

**Reduced liver**
When the donor liver is cut down to size to fit in your body. The other part of the liver would not be used for anybody else.

**Rejection**
The human body’s response to having something it does not recognise inside it. The body’s defence system attacks the ‘foreign’ object. The immunosuppression medication that you take after your transplant will prevent this from happening. Despite the medication, some early (acute) rejection is common. If you have rejection, you may feel unwell or the doctors may find that your blood tests have become abnormal. It is diagnosed by a liver biopsy, which is done after you have had an ultrasound. Acute rejection is treatable by
increasing or changing your medication. A very small group of patients may develop rejection that is not treatable, (chronic rejection) and they may need to have another transplant.

**Renal dialysis**
A machine is used to ‘wash’ the blood when the kidneys are not working properly.

**RFA (radio frequency ablation)**
In radio frequency ablation (RFA) a needle electrode is inserted through the skin and directly into the liver tumour guided by ultrasound, CT or MRI scan. High frequency electrical currents are then passed through the electrode creating heat that destroys the abnormal cells.

**Roux-en-Y**
A method of connecting the bile duct to the gut. The surgeon will discuss this technique with you (see diagram).

**Splenomegaly**
A large swollen spleen. This is common in patients with chronic liver disease.

**Split liver**
It is sometimes possible to use a donor liver for two people. Before the liver is used it is checked to see if the position of the vessels allows it to be split. Extra vessels can be created from other tissue from the donor and the liver is shared usually between an adult and a child. If the liver cannot be split, it is offered to the sickest patient. Potential side effects of splitting a liver include a slightly greater risk of bile and/or blood leaking from the surface where the split occurred, and slightly greater problems with the vessels.

**Swan-ganz catheter**
See ‘Investigations’ section.

**TACE (transarterial chemoembolisation)**
Treatment of a liver tumour to reduce its size by injecting chemotherapeutic drugs directly at the tumour via the hepatic artery. A catheter is inserted into the femoral artery and guided into position using X-rays.

**U and Es**
Urea and electrolytes. This is a blood test which gives information about how well your kidneys are working.

**UKELD score**
A calculation to demonstrate the severity of liver disease. It looks at
bilirubin, sodium, creatinine levels in the blood as well as INR (blood clotting). Patients with a UKELD score of 54+ are added to the priority waiting list.

**Urinary catheter**
A soft flexible plastic tube that is placed into your bladder to allow accurate measuring of urine output. This is important after a transplant as the kidney can be affected, it is also helpful if you are asleep under anaesthetic, or are not able to move about very much.

**Varices (varix-singular)**
Enlarged veins in the oesophagus, which can be a side effect of liver disease.

**Variceal bleed**
When the varices bleed.

**Vena cava**
The large vein which returns blood to the heart. It passes behind the liver and the liver is connected to the vena cava via the hepatic veins.

**Venflon**
See ‘Intravenous catheter’.

**Ventilator**
This is a machine that helps you to breathe when you are under general anaesthetic. As you start to wake up, the machine recognises when you take some of your own breaths and allows for it.

**Virology**
A blood test that determines if you have been exposed in the part to viruses such as hepatitis B and HIV.

**Weaning**
As you wake up from your anaesthetic you will start to take some of your own breaths and become less dependent on the ventilator. The process of reducing your need for the ventilator is called “weaning”.

**White blood cells**
Cells in blood that help the body fight infection.

**Whole liver**
A donor liver that is not reduced or split.
Appendix of medications

Name: Azathioprine Imuran
Tablet strengths: 25mg, 50mg
Action of the drug: Immunosuppression – to prevent rejection of the liver
Expected length of time on drug: Life
Possible side effects: Stomach upsets; reduces white blood cells
Special instructions: Take with food

Name: Basiliximab (other name: Simulect)
Tablet strength: Given in hospital only
Action of the drug: Immunosuppression – to prevent rejection of the liver used in first few days post transplant in specific patients
Expected length of time on drug: Two weeks
Special instructions: Only used in hospital as a special infusion

Name: Co-codamol (other name: Kapake)
Tablet strength:
Action of the drug: Pain relief
Expected length of time on drug: As required
Possible side effects: Drowsiness, constipation
Special instructions: This medication contains Paracetamol (beware if taking other medications). Do not take more than 8 tablets in 24 hours or more than 2 tablets at a time. Beware using machinery and driving motor vehicles due to potential drowsiness
Name: Co-trimoxazole (other name: Septrin)
Tablet strength: 480mg
Action of the drug: Antibiotic – prevents certain types of chest infection
Expected length of time on drug: 3 months
Possible side effects: Nausea and vomiting
Special instructions: Take on alternate days

Name: Daclizumab (other name: Zenapax)
Tablet strength: Given in hospital only
Action of the drug: Immunosuppression – to prevent rejection of the liver, used in first few days post transplant in specific patients
Expected length of time on drug: Two weeks
Special instructions: Only used in hospital as a special infusion

Name: Fluconazole (other name: Diflucan)
Tablet strength: 50mg
Action of the drug: Prevents fungal infection
Expected length of time on drug: About 8 weeks
Possible side effects: Stomach aches

Name: Lansoprazole (other name: Zoton)
Tablet strengths: 15mg, 30mg
Action of the drug: Prevents acid release into stomach
Expected length of time on drug: At least 3 months
Possible side effects: Diarrhoea, nausea
Name: Mycophenolate (other names: Cellcept, MMF)

Capsule strengths: 250mg, 500mg

Action of the drug: Immunosuppression – to prevent rejection of the liver

Expected length of time on drug: Life

Possible side effects: Stomach upsets, diarrhea, reduces white blood cells, bone marrow cancer

Special instructions: Do not take before blood samples are due to be taken

Name: Neoral Names: Ciclosporin, CyA

Capsule strengths: 25mg, 50mg, 100mg

Action of the drug: Immunosuppression – to prevent rejection of the liver

Expected length of time on drug: Life

Possible side effects: Headaches, tremors, can affect kidney function tests, can raise blood pressure, can increase blood sugars, and can cause certain cancers

Special instructions: Do not take before blood samples are due to be taken. Do not eat grapefruit

Name: Nystatin Nystan

Medication: Yellow liquid

Action of the drug: Prevents fungal infections

Expected length of time on drug: about 8 weeks

Possible side effects: nausea

Special instructions: Take after meals. Rinse medication around mouth and then swallow
Name: Paracetamol
Tablet strength: 500mg
Action of the drug: Pain relief
Expected length of time on drug: When needed
Possible side effects: Liver failure if overdose
Special instructions: Maximum 8 tablets in 24hrs and 2 tablets at one time. Remember other medications can also contain Paracetamol such as cold remedies – so always read the labels of ‘over the counter’ drugs

Name: Prednisolone (other name: Steroids)
Tablet strength: 5mg
Action of the drug: Immunosuppression – to prevent rejection of the liver
Expected length of time on drug: 3 months unless you have been on this drug before your transplant or your diagnosis needs further steroid treatment
Possible side effects: Increases appetite, weight gain, fluid retention, indigestion, increase in blood sugars, osteoporosis
Special instructions: This drug is a steroid. Take with food. Do not take enteric (red sugar) coated tablets. You will be given a small blue card (called a Steroid Card) that you will need to carry with you at all times

Name: Sirolimus (other name: Rapamune)
Tablet strengths: 1mg, – can also come as 2mg sachets of powder.
Action of the drug: Immunosuppression – to prevent rejection of the liver, used in some patients with chronic rejection. Expected length of time on drug: several months
Possible side effects: Stomach upsets, diarrhoea, can affect kidney function tests, can cause certain types of cancer
Special instructions: Do not take before blood samples are due to be taken. Mix sachet contents with half a glass of orange juice or water,
ensure all taken by refilling glass with water or orange juice. Do not use any other fluids other than orange juice or water

Name: Tacrolimus (other names: Prograf, FK, Advograf)
Capsule strengths: 0.5mg, 1mg, 5mg
Action of the drug: Immunosuppression – to prevent rejection of the liver
Expected length of time on drug: Life
Possible side effects: Headaches, tremors, can affect kidney function tests, can raise blood pressure, can increase blood sugars, and can cause certain cancers
Special instructions: Do not take before blood samples are due to be taken. Do not eat grapefruit, pomegranate juice, Earl Grey tea

Name: Tramodol (other names: Tramake, Zydol)
Capsule strength: 50mg
Action of the drug: Pain relief
Expected length of time on drug: As required
Possible side effects: Drowsiness, constipation
Special instructions: Beware using machinery and driving motor vehicles due to potential drowsiness. Maximum of 8 capsules in 24 hours and no more than 2 capsules each time. You can take medication containing Paracetamol if you have used this medication

Name: Valganciclovir (other name: Valcyte)
Capsule strength: 450mg
Action of the drug: Prevents cytomegalovirus infection
Expected length of time on drug: 3 months
Possible side effects: Nausea, diarrhoea, abdominal pain
Special instructions: Your dose may be changed
Information for patients taking Prograf (tacrolimus)

The dose of tacrolimus is carefully adjusted to your needs: too much will cause toxicity and too little may result in rejection and even failure of your liver graft.

There is a new form of tacrolimus called Advograf. This is a once a day preparation (slow release). You should not take Advograf unless it has been prescribed for you by the doctors on the Liver Unit in Birmingham.

There are other tacrolimus preparations available. You must not take any of these unless they have been prescribed by the doctors on the Liver Unit in Birmingham.

Some medicines will interact with tacrolimus so you should always check before taking new medicines (this includes over the counter medicines).

Some of the more commonly taken medicines that interact with tacrolimus are listed below.

You should not take any of the following without first checking with the Liver Unit:

<table>
<thead>
<tr>
<th>Non steroidal anti-inflammatory drugs (painkillers)</th>
<th>Antibiotics;</th>
</tr>
</thead>
<tbody>
<tr>
<td>E.g. aspirin (except low dose aspirin prescribed by your doctor)</td>
<td>• Erythromycin</td>
</tr>
<tr>
<td>• Ibuprofen (‘Nurofen’, ‘Brufen’)</td>
<td>• Clarithromycin</td>
</tr>
<tr>
<td>• Diclofenac (‘Volterol’)</td>
<td>• Rifampicin</td>
</tr>
<tr>
<td>• Naproxen (Naprosyn)</td>
<td>• Synercid</td>
</tr>
<tr>
<td>• Drugs used to treat high blood pressure such as nicardipine, nifedipine and diltiazam</td>
<td>• Chloramphenicol</td>
</tr>
<tr>
<td>• Diuretics (water tablets) such as amiloride</td>
<td>• Telithromycin</td>
</tr>
<tr>
<td>• Danazole</td>
<td></td>
</tr>
<tr>
<td>• Omeprazole</td>
<td></td>
</tr>
<tr>
<td>• St. John’s Wort</td>
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</tbody>
</table>

Remember to: avoid grapefruit juice, pomegranate juice and Earl Grey tea.
Liver surgery: Piggy-back technique

Donor vena cava attached to front wall of recipient vena cava
Liver surgery: Roux-en-Y technique

- Liver
- Stomach
- Bile duct
- Bowel
- Anastomoses
Liver surgery: Split liver

- Right side of liver
- Vena cava
- Portal vein
- Bile duct
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<th>Action of the drug</th>
<th>Possible side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valganciclovir 450mg 3 months</td>
<td><img src="image1.png" alt="VGC" /></td>
<td></td>
<td>Prevents CMV infection.</td>
<td>Nausea, Diarrhoea, Abdominal pain</td>
</tr>
<tr>
<td>Co-trimoxazole (Septrin) 480mg 3 months</td>
<td><img src="image2.png" alt="OK VGC" /></td>
<td>Take on alternate days.</td>
<td>Antibiotic – to prevent certain chest infections.</td>
<td>Nausea, Vomiting</td>
</tr>
<tr>
<td>Pravastatin 40mg (to start 3 months after transplant)</td>
<td><img src="image3.png" alt="40" /></td>
<td>Take at night</td>
<td>To control cholesterol</td>
<td>Muscle pain, Muscle Tenderness, Weakness, Chest pain, Fatigue, Ring GP straight away</td>
</tr>
</tbody>
</table>

### Alternative Anti rejection

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Picture</th>
<th>Special instructions</th>
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<th>Possible side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ciclosporin (Neoral) 100mg Life</td>
<td><img src="image4.png" alt="100 mg" /></td>
<td>Do not take before blood sample is taken on a clinic day. Avoid grapefruit.</td>
<td>Immunosuppressant – to prevent rejection of the liver.</td>
<td>Headaches, Tremors, Can affect kidney function, Rise in blood pressure, Can cause certain cancers, Can increase blood sugars, Excess body hair</td>
</tr>
<tr>
<td>Ciclosporin (Neoral) 50mg Life</td>
<td><img src="image5.png" alt="50 mg" /></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ciclosporin (Neoral) 25mg Life</td>
<td><img src="image6.png" alt="75 mg" /></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mycophenolate (Cellcept) 500mg Life</td>
<td><img src="image7.png" alt="500mg Cellcept" /></td>
<td>Take with food</td>
<td>Immunosuppressant – to prevent rejection of the liver.</td>
<td>Stomach upsets, Reduced white blood cells, Rise in blood pressure, Headaches, Tremors</td>
</tr>
<tr>
<td>Mycophenolate (Cellcept) 250mg Life</td>
<td><img src="image8.png" alt="250mg Cellcept" /></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicine</td>
<td>Picture</td>
<td>Special instructions</td>
<td>Action of the drug</td>
<td>Possible side effects</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>---------</td>
<td>-----------------------------------------------------------</td>
<td>----------------------------------------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td><strong>Tacrolimus</strong> 5mg (Prograf)</td>
<td></td>
<td>Do <strong>not</strong> take before blood sample is taken on a clinic day. Avoid grapefruit.</td>
<td>Immunosuppressant – to prevent rejection of the liver.</td>
<td>• Headaches • Tremors • Can affect kidney function • Rise in blood pressure • Can cause certain cancers • Can increase blood sugars • Nausea</td>
</tr>
<tr>
<td><strong>Tacrolimus</strong> 1mg (Prograf)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Tacrolimus</strong> 0.5mg (Prograf)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Azathioprine</strong> 50mg</td>
<td></td>
<td>Take with food.</td>
<td>Immunosuppressant – to prevent rejection of the liver.</td>
<td>• Stomach upsets • Reduced white blood cells • Rash • Aching joints • Dizziness (call transplant co-ordinator)</td>
</tr>
<tr>
<td><strong>Azathioprine</strong> 25mg</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Prednisolone</strong> 5mg</td>
<td></td>
<td>Take with food. <strong>Do not</strong> take enteric (red) coated tablets.</td>
<td>Immunosuppressant – to prevent rejection of the liver.</td>
<td>• Increased appetite • Weight gain • Fluid retention • Indigestion • Increased blood sugars</td>
</tr>
<tr>
<td><strong>Nystatin</strong> 2ml (short term)</td>
<td></td>
<td>Rinse around mouth, then swallow. <strong>Do not</strong> eat or drink for 30 mins after taking</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Lansoprazole</strong> 30mg</td>
<td></td>
<td></td>
<td>Prevents acid release into stomach.</td>
<td></td>
</tr>
<tr>
<td><strong>Lansoprazole</strong> 3 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Some of the tablets you are taking may affect your ability to drive. Discuss this with your consultant when you are ready to resume driving. Call the transplant co-ordinator if you have any concerns about medication.