Information for potential Living Liver Donors

Information for potential living donors
This leaflet provides information to potential donors about the Live Donor Liver Transplant Service at the Leeds Teaching Hospitals.

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Introduction

Your friend, relative or child has been diagnosed with severe liver disease and the doctors looking after him/her have explained that a liver transplant is now necessary. Patients requiring a liver transplant are placed onto a liver transplant waiting list and are regularly reviewed until a cadaver or deceased donor (some one who has died and donated their organs) becomes available.

This information booklet will tell you about the living donor liver transplant programme and the donor assessment procedure. It will identify the risks and benefits of the procedure you should consider. It is important that you read this carefully.

Members of the medical team, including the transplant co-ordinators will be available to explain any aspects which you do not fully understand or that requires further explanation.

When you have read through this information booklet there is a section at the end called ‘What next’? this tells you what to do if you want to be considered as a donor.

What is Live Donor Liver Transplantation?

Most livers available for transplantation are from deceased donors i.e. they come from a person who has died as a result of overwhelming and irreversible brain damage.

In such circumstances it is possible for organs, such as the liver to be donated for transplantation.
These donor livers often come from patients who have died as a result of brain injury from strokes, road traffic accidents etc. The timing of such a donor becoming available is very unpredictable and the quality of these organs, although generally very good, is not always certain.

Your relative will be placed onto this waiting list whatever decision is made over living donor transplantation, and if a suitable, matched liver becomes available then we would use this organ rather than continue with live donor assessment.

However, the fact that the availability of these deceased donor organs is unpredictable has meant that some patients simply cannot wait long enough for such a liver to become available.

In Leeds, at any point in time, there are at least 50 people waiting for a liver transplant, and every year this situation is getting worse. Patients may have to wait for more than a year for a liver to become available and waiting times are getting longer. As a result of this, approximately 1 in 5 patients on the waiting list either die before an organ becomes available or are removed from the waiting list because they become too sick to survive the operation.

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The liver has two important features that make living donation possible.

1. It is much larger than we need (so it has a great ‘reserve’).

2. It can regenerate within weeks if part of it is removed.
Live donor liver transplantation (sometime abbreviated to LDLT) is, therefore the removal of part of the liver of a healthy, living donor and its transplantation into another person with liver failure.

The remaining liver, or remnant in the live donor will re-grow within weeks back to nearly its original size.

LDLT has been carried out in many countries, including the United Kingdom, for over 15 years and is a very successful, well-established means of transplanting livers.

It has three distinct advantages in comparison to waiting for an organ from a deceased donor;

1. It provides a unique opportunity to restore good health to a close friend or relative.
2. It provides a guaranteed high quality organ.
3. The transplant can take place at a specific time before the recipient’s health deteriorates.

However the main disadvantage is that a healthy person, the donor, has to undergo major surgery.
What does Live Donor Liver Transplantation Involve?

As your friend, relative or child is seriously ill from liver disease, your first thought when considering becoming a donor will have been to help him/her recover. This is, of course, a very natural reaction and one that most people will understand.

However, Live Donor Liver Donation is not possible for every potential donor; nearly 2 out of every 3 relatives or friends are unsuitable for a variety of reasons.

This booklet is designed to help you understand the following:

• The living donor assessment, including the risks and benefits.

• The living donor operation itself, including the risks of surgery.

• The long-term outcome of donor liver surgery.

As you read through this booklet you must be clear that:

• Undergoing assessment as a donor, does not commit you to becoming a donor. You can stop the process at any point, right up to the day of surgery.

• We would expect, and indeed require you to discuss this booklet and the whole process with close family members. You do not have to tell your friend, relative or child at the first stage, that you are being assessed as this may rise hopes in the patient who might be dashed if you are found to be an unsuitable donor, or if you decide not to proceed, for whatever reason.
• You as the potential donor and your family must be certain that you are not being pressurised into becoming a donor by any member of the donor team or anybody else, including the patient. If any doubt arises over this at any point in the assessment process then the donor process must stop.

• Your friend, relative or child will already be on the waiting list for a deceased donor liver. Hence your friend, relative or child is not dependent on you for a liver transplant. If no suitable live donor can be found, your friend, relative or child will remain on the waiting list for a deceased donor. Throughout the LDLT process, your friend, relative or child will not lose their place on the deceased donor waiting list, and a deceased donor organ may become available earlier than expected, avoiding the need for live donation.

• Your friend or relative must agree to receive a live donation.

Your safety as a potential donor is the top priority throughout the assessment. The whole assessment may take about 4-5 weeks to complete, particularly if any unsuspected abnormality is discovered which requires further tests.

However, all health care team members must be certain that living liver donation is a safe and appropriate action.
A) The Living Donor Assessment

Individuals who would like to be considered as potential live donors must be above the age of legal consent (18 years), in excellent physical and emotional health. You will be given a medical health questionnaire; this contains several questions about your general health now and in the past.

The medical questionnaire is to see whether you have any contraindications to donation. This could include health issues such as diabetes, cancer, hypertension, recent pregnancy, thyroid disorders, high cholesterol and transmittable infectious diseases, any significant medical problem may exclude you from further evaluation.

A donor must be blood group compatible with the recipient. So the first blood test is identify your blood group, if you do not already know this.

Blood Type Compatibility Chart

<table>
<thead>
<tr>
<th>Blood Type</th>
<th>Can receive a liver from</th>
<th>Generally can donate a liver to</th>
</tr>
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<tbody>
<tr>
<td>O</td>
<td>O</td>
<td>O, A, B, AB</td>
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<td>A</td>
<td>A, O</td>
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<td>AB</td>
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Once you have read through this booklet and discussed its contents and implications with your family, and we have checked your blood group, and your health questionnaire does not exclude you, then we can start the Living Donor Assessment.
Firstly, you will be invited to the live donor clinic to meet with the specialist live donor Transplant Co-ordinator and Consultant liver specialist for live liver donation and a Consultant transplant surgeon. This is the Donor Assessment Team. The specialist live donor Transplant Co-ordinator will lead you through the assessment process. The Donor Assessment Team must agree unanimously that you are medically and psychologically suitable to donate.

The purpose of this appointment is to meet the team and to ensure that you understand all the contents of this booklet, talk about any concerns you have.

We will discuss the risks of live donor surgery, both for the donor and for the transplant recipient. We will also explain to you that if you commence the evaluation process that you can withdraw at any time without further explanation.

The Human Tissue Act 2004 forbids payments of any inducement for the supply of organs. However it does permit payment of reasonable expenses to a donor for travel, accommodation and loss of earnings incurred if directly attributable to the donation of an organ.

The NHS is not legally obliged to make payments. The National Commissioning group (NCG) is the commissioner for live liver donation programme; NCG will be responsible through each liver transplant centre for the re-imbursement of donors. There is a set maximum limit that each donor can claim. The transplant co ordinator will give you information about this scheme at the beginning of your assessment.

If you still want to proceed with assessment, then you would be put forward to Stage 1.
Stage 1
This first stage is to ensure that your liver is suitable to split for transplantation. You will be asked to sign a consent form for the tests and investigations required for the donor assessment. The potential risks associated with the assessment will be explained to you. A CT/MRI scan will look at the detailed anatomy of your liver and assess the feasibility of safely removing part of your liver for transplantation, and to estimate the weight of your liver. Your scans will be evaluated by a team of Consultant Surgeons to ensure the donor operation can be performed safely.

Blood tests will be taken at this stage; these include a test to see how your liver and kidneys are functioning, tests to exclude the presence of any undiagnosed cancer, and tests for viruses that can be transmitted between donor and recipient. A test for HIV (the virus that causes AIDS) will be included in these tests, you will have signed a consent form for this test to be carried out, and you will be offered appropriate counselling if this or other tests come back with a positive result. The blood tests may include a test to identify your genetic make up.

Very rarely as part of this assessment process, we may find a previously undiagnosed illness; in this case you would be referred to an appropriate specialist.

The results of these tests will be carefully considered by the specialists looking after you.

The team must be certain that the partial hepatectomy (the name given to the operation whereby part of your liver is removed) will be technically possible and safe for you as the donor.
At the end of your operation there must be enough liver left behind for you to survive and sufficient to transplant into your relative, friend or child for them to survive.

**Stage 2**

Once your CT/MRI has been evaluated by the team of Consultants, and it is thought possible to remove part of your liver safely, you will be asked if you want to proceed along the assessment pathway.

In some circumstances liver biopsy may be necessary. This test involves a small needle being inserted into the liver to remove a small amount of liver tissue. A liver biopsy carries with it a risk of bleeding from the liver (rare), penetration of other organs (rare) and very rarely death (1 in 10,000 cases).

We will also contact your General Practitioner (GP) to inform them of your ambition to donate part of your liver and to ask their opinion as an independent professional.

**Stage 3**

In stage three we will look at your general fitness to undergo surgery and anaesthesia. The donor team must be sure that you are both medically and psychologically suitable to donate.

You will meet again with the Consultant liver specialist, a Consultant Anaesthetist to ensure that you are fit for anaesthesia and to explain the options of pain control post operatively. You will undergo test to look at your heart (ECG), and lungs (Chest X-ray and Lung function tests).

In stage 3 you will also meet with a psychiatrist and social worker and undergo assessment by them.
This psychological/social assessment will help you to consider the family, emotional, financial and physical stress of undergoing donor surgery.

Becoming a living donor should not affect your Life Insurance Policy but might affect other insurance policies such as health insurance, mortgage policies etc. Potential donors should check their own policies, discuss their intention with the companies involved and try and get their companies view in writing. We would also recommend that you discuss your intention to donate with your employer.

The psychiatrist will review in depth your reason for volunteering to donate, your family support and ensure you understand the process and have not been pressurised by any member of the medical team or anyone else into becoming a donor. Undergoing surgery at a time when a close family member, friend or child is unwell inevitably results in stress for the whole family. The psychiatrist will explore how you have considered the impact of becoming a donor with your family unit, as well as yourself.

The psychiatrist will also help you explore issues about unfavourable outcomes of surgery, for example, what happens and how you would feel if the transplanted liver failed? It is important that all prospective donors understand that the long-term success of a transplant operation can never be guaranteed. Potential donors must consider the possibility of transplant failure.

The transplant co ordinator is responsible for your journey through the assessment pathway. They will discuss with you at each stage of the assessment process, including what occurs on the day of surgery and post donation.
They will give you as much information as possible so that you can make an informed decision about donation.

At the end of this stage then you will meet with the Donor Advocate Physician, this is an independent senior medical doctor who is responsible for reviewing your medical assessment ensuring all medical risks are minimal, this is a quality control system.

**Stage 4**

You will meet with and Independent Assessor (IA). This person is independent of the transplant and donor team. This person acts on behalf of a government body called the Human Tissue Authority (HTA).

The HTA governs all live donor transplant activity in the UK. This person will verify your claimed relationship with the person who you want to donate to.

You will be asked to provide evidence of your relationship, evidence to prove you are who you say you are, for example, your birth certificate, passport, marriage certificate, photographs etc.

The transplant co ordinator will help you do this.

When the IA is satisfied with all the evidence he/she collected they will liaise with the HTA to seek permission for the liver donor transplant to go ahead. The HTA will look at the evidence and then let the donor team know of their decision.

This can take up to 10 working days from the date of the application submission.
Stage 5 - MDT & Independent Assessor (IA)

Whilst your application to proceed with live donor transplantation is with the HTA, the donor team will meet to review your case and consider setting a date for surgery with the liver transplant team. The transplant team will do their best to commit themselves to this date but it may be necessary to postpone the live donor operation at short notice if a deceased donor organ transplant has to be performed on another patient on the same day.

During all these stages and up until we allocate a date for live donor transplant your friend, relative or child will remain on the deceased donor waiting list.
Donor Evaluation Process

Initial Evaluation
Donor Information Booklet given
Medical Questionaire
Blood Group Check
Live Donor Clinic to meet with Donor Assessment Team, proceed to:

Stage 1.
Blood Work Up
CT/MRI Liver

Stage 2.
Possible Liver Biopsy
Contact GP

Stage 3.
Full Clinical Assessment.
Full Psychological Assessment.
Social Assessment.

Stage 4.
Independent Assessment (IA)

Stage 5.
Multidisciplinary Case Review
Donor Surgery date set
B) The Living Donor Operation

The surgeon performing the operation will explain the procedure to you in detail. The description outlined below is only a basic outline of the procedure.

1. Donor Liver

The liver lies underneath the ribs on the right hand side.

After anaesthesia is established the operation begins with and a midline incision from the bottom of the sternum to the umbilicus, sometimes this is extended to the right of the umbilicus.
2. Donor Liver Removal

It is possible to split the liver in different ways, the type of surgery depends upon whether the transplant recipient is an adult or child or on the size of the donor liver.
3. Donor Liver (Right Hemihepatectomy)

The donor operation that removes segments 5,6,7 & 8 of the liver is known as a right hemihepatectomy, this operation removes approx 60% to 70% of the entire liver.

This is the most common type of live donor hepatectomy in adult to adult live liver transplantation.
4. Donor Liver (Left Hemihepatectomy)

The donor operation that removes segments 2, 3 & 4 of the liver is known as a left hemihepatectomy, this operation removes approx. 40% of the entire liver.

This type of donor operation is usually undertaken when an adult donates to a child or an adult with a large liver donates to an adult.
5. Donor Liver (Left Lateral Sectionectomy)
The donor operation that removes segments 2 & 3 of the liver is known as a left lateral sectionectomy, this operation removes approximately 20% of the entire liver.

This type of donor operation is usually done when an adult donates to a small child.
6. Post-operative care
The donor surgical procedure takes around 3 to 4 hours. When surgery is complete you will be transferred to a High Dependency Unit.

The following day, depending on your condition you will be transferred to the Liver Transplant Unit.

All donors will be on our Enhanced Recovery after Surgery Program. Donors can start eating and drinking as soon as they feel able too. Until then you will be given fluids via a ‘drip’ into a vein. Over the next few days the various drainage tubes placed during surgery, like your bladder catheter, and stomach tube, will be removed.

You will have various blood tests and maybe an ultrasound scan during this recovery period.

Some patients may develop mild jaundice after surgery which resolves without any treatment. Occasionally this may persist and ultrasound scan and other tests will be done to rule out any complications.

Most patients are discharged from hospital between 5 - 7 days post-op.

Live donors are given a blood thinning injection daily after surgery; this reduces the likelihood of complications from a blood clot forming. This daily injection continues for six weeks following surgery. Most patients learn to give this injection to themselves and do so at home without difficulty.

It is important to be physically active after surgery in order to reduce the risk of forming clots.
Donors are advised to avoid air travel, prolonged car journeys for 4 weeks after surgery. If a long car journey is necessary during the first 3 months after surgery, then we advise you to stop the car every hour and walk around for 15 minutes to promote blood flow to the legs. **A daily walk is advised after discharge to help build up stamina.**

Most complications are soon after surgery, but some may appear after discharge home. Patients must contact the liver unit if they develop new abdominal pain, redness around the wound, yellow skin, fever, cough or shortness of breath or any other medical concern.

A follow-up clinic visit will be arranged for 4 weeks after discharge.
What are the risks and potential complications of the operation?

The assessment process continues right up to the point of your liver being examined at the time of surgery to check it is still safe to proceed. If an unexpected finding or a reaction to anaesthesia occurs, then surgery will not proceed. This is rare but can occur in anything up to 5% (1 in 20) of such surgical procedures.

The risks associated with the procedure can be divided as **Anaesthesia risk (1)** and **Surgical risk (2)**.

1. You will need an anaesthetic for your operation. During your assessment the anaesthetist will explain the anaesthetic and post operative care procedure. But you will need a number of special drips and tubes. These may include:

   - **An arterial line** - a small drip into an artery in the wrist, this is used to monitor your blood pressure. The main complication is damage to the artery. This is an extremely rare complication, but has potentially serious consequences including the need for repair of the artery.

   - **A central line** - this is a drip through the vein in the side of your neck which passes down into your heart. This is used for monitoring pressures during the operation, and to give drugs. There are small risks associated with insertion of this line; these include bleeding, puncture of lung and infection. Central lines are used commonly, and serious complications are rare.
• **Epidural catheter** - this is placed between the bones of your back for pain relief and to control your blood pressure and minimise blood loss during the operation. There is a small risk of complications with this procedure, the most serious is permanent nerve injury resulting in loss of sensation or partial paralysis, this may occur once in every 30,000 cases. Infection is also a rare complication.

2. Any abdominal surgery causes pain and discomfort and carries a risk of bleeding, infection, and injury to nearby organs. Other infections include pneumonia, urinary tract infection and skin infection. The commonest surgical complication after donor surgery is:

• **Bile leak** - this is because bile can leak from the cut surface of the divided liver. This occurs in 5-15% of the procedures and may require a further procedure afterwards (usually done in the X-ray department), but may require further surgery.

• **Deep vein thrombosis / pulmonary thrombosis** - patients having operations on their abdomen are at risk of developing blood clots in their legs and lungs while they are in bed recovering. These are potential serious complications. However you will wear special stockings during and after surgery to help prevent this complication, and you will be encouraged to get up and around as soon as possible. You will also be given a small injection of heparin once a day after your operation to prevent this possible complication.
• **Insufficient liver** - very rarely (less than 1:200) cases removing part of the liver leaves insufficient healthy liver and causes liver failure in the donor. If the donor’s liver does not recover; the donor may require an emergency transplant. The purpose of all the tests performed prior to surgery is to minimise the chance of this happening.

• **Death** - every step is taken to minimise the risk to you as a donor having surgery. However, it is impossible to eliminate every risk. It is estimated that the risk of dying from this type of surgery is between 1:200 and 1:500. This must be carefully considered and discussed with your family.
C) The Long-Term Outcome of Living Donor Operation

The following long-term outcomes of this type of surgery should be considered:

- Most donors are fit to return to work after about 4 to 8 weeks depending upon their type of work. And return to heavy manual work and normal sporting activities by three months. However, this does vary from person to person.

- Your abdominal scar will fade over time but will always be visible and a small number of people complain of long term wound pain.

- This surgery may affect your healthcare insurance in the future; you need to discuss this with your provider.

- Patients will be reviewed in the outpatient department early after discharge home and regularly reviewed in the first year. After that we would expect patients to be followed up life long, this will mean an annual telephone clinic consultation.
What Next?
If you have read and understood the contents of this information booklet and you have any questions please read the FAQ leaflet, however if you have any further questions please contact a member of the donor assessment team.

If you feel you have understood and discussed this with those concerned and want to proceed further you can:

- Fill in a health questionnaire and return to the transplant co-ordinator. You can request a health questionnaire from the live donor office or download from our web page
- Get your blood group checked, either at GP or we can arrange.
- Telephone the transplant co-ordinators on 0113 20 66913 to make arrangements for an appointment at the live donor clinic.

Leeds Live Donor Liver Transplant Program
- Telephone: 0113 20 66913
- Fax: 0113 20 64127
- Email: juliejeffery@nhs.net or k.mcgoohan@nhs.net
- twitter: @ liveliverdonor
- facebook: https://www.facebook.com/LeedsLiveDonorLiverTransplant
- Web: http://www.leedsth.nhs.uk/a-z-of-services/live-donor-liver-transplant-program/