Live Donor Liver Transplantation

DONOR INFORMATION
Introduction

You may have a friend, relative or child that has been diagnosed with severe liver disease and the medical team 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 deceased donor (someone who has died and donated their organs) becomes available. However, there are not enough deceased donor organs to meet the needs of the listed liver recipients.

You may be an Anonymous /Altruistic donor who wants to donate a gift of a liver lobe to some in need of a liver transplant.

This information booklet has been written to provide all individuals considering live
donation with further detail 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. The liver donor transplant coordinator and members of the live donor team will be available to explain any aspects which you do not fully understand or that require further explanation.

What is Live Donor Liver Transplantation?

Most livers available for transplantation are from deceased donor i.e. they come from a donor 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.

If you have a relative on the liver transplant waiting list whatever decision you make regarding living donor transplantation does not affect them being considered for an appropriate deceased donor organ. However, the fact that the availability of these deceased donor organs is unpredictable. The waiting time for deceased donor liver transplantation
ranges from days to months to years, this is dependent the availability of donor organs and the health status of the recipient. This has meant that some patients simply cannot wait long enough for such a liver to become available. Sadly some of the patients waiting on the deceased donor list will either die or become their health deteriorates to a point at which they can no long be considered for transplantation.

The option of living liver donation reduces the risk of health deterioration and death for patients who need a liver transplant. With live donor liver transplantation (LDLT), the recipient receives a high quality organ for transplantation before the recipients health severely deteriorates.

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

- It is much larger than we need (so it has a great ‘reserve’).
- It can regenerate within weeks if part of it is removed.

Live donor liver transplantation (LDLT) is, therefore the removal of part of the liver of a healthy, living donor and it is 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. LDLT has three distinct advantages in
comparison to waiting for an organ from a deceased donor:

• It provides a unique opportunity to restore good health to a patient who may be a relative or close friend.
• It provides a guaranteed high quality organ.
• 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?

Live Donor Liver Donation is not possible for every potential donor; about 1 out of every
3 potential donors is 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 the information in this booklet
with close family members. You do not have to tell the person who you are wishing to donate to 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 and the donor team must be certain that you are not being pressurised into becoming a donor by any member of the transplant 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.

The potential transplant patient is most likely already on the waiting list for a deceased donor liver. Hence, they are not entirely dependent on you for a liver transplant.
If no suitable live donor can be found, the potential transplant recipient will remain on the waiting list for a deceased donor. Throughout the live donor assessment process the potential liver recipient’s position on the deceased donor list will not be affected.

The intended recipient must agree to receive a live donation.

Donor safety is our first priority. The whole assessment can take about 4-5 weeks to complete. Donation will not be offered if the live donor team believe that the potential harm outweighs the benefit. The final decision to perform the living donor transplant rests with the donor healthcare team.
A. The Living Donor Assessment

Individuals who would like to be considered as potential live donors must be in excellent physical and emotional health. Generally over 18 years of age (special exceptions to this may be considered).

You will be given a medical health questionnaire; this contains several questions about your general health now and in the past. Potential donors have a responsibility to honestly and fully report any and all health concerns, issues, and /or behaviours that might affect their candidacy or pose a health risk to a potential organ recipient.

All information obtained during the assessment is strictly confidential and will not be shared. 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 in nearly all circumstances 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 liver from</th>
<th>Generally can donate to</th>
</tr>
</thead>
<tbody>
<tr>
<td>O</td>
<td>O</td>
<td>O, A, B, AB</td>
</tr>
<tr>
<td>A, (Non-A1)</td>
<td>A O</td>
<td>A, (O), AB</td>
</tr>
<tr>
<td>Blood Type</td>
<td>Can receive liver from</td>
<td>Generally can donate to</td>
</tr>
<tr>
<td>------------</td>
<td>-----------------------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>B</td>
<td>B, O</td>
<td>B, AB</td>
</tr>
<tr>
<td>AB</td>
<td>O, A, B, AB</td>
<td>AB</td>
</tr>
</tbody>
</table>

Both blood type and donor medical history must be provided prior to proceeding with a donor evaluation.

You will be invited to the live donor clinic to meet with the specialist live donor assessment team, this is usually a live donor liver transplant coordinator, a consultant liver surgeon and a consultant liver physician.

The Donor Assessment Team must agree unanimously that you are medically and psychologically suitable to donate.

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

Disclosure

We will discuss the risks and benefits of live donor surgery, both for the donor and for the transplant recipient.

Potential donors must communicate directly with us regarding questions/concerns. We will not communicate with third parties (family members, friends, recipients, etc.). We will also explain to you that if you commence the evaluation process that you can withdraw at any time without further explanation.

Blood group testing may discover misattributed paternity, you will be asked to
sign a form expressing your wishes regarding disclosure of this information to you. The transplant recipient will also be given the same information and opportunity of expressing wishes of disclosure.

Financial Considerations

We will explain the donor re-imbursement scheme. 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 NHS England is the commissioner for live liver donation programme; they will be responsible through each liver transplant
## Menu

### Initial Evaluation
- Donor Information
- Medical Form
- Blood Group Check
- Live Donor Clinic

### Stage 1
- Blood Work-Up
- CT / MRI Scan

### Stage 2
- CT /MRI Scan review
- Liver Biopsy * if needed
- Contact GP

### Stage 3
- Full Clinical Assessment
- Psycho-Social Review
- Independent Donor Physician
- MDT Case Review

### Stage 4
- Independent Assessor (Human Tissue Authority)
centre for the re-imbursement of donors. There is a set maximum limit that each donor can claim.

If you would still like to proceed with assessment at this point you would be put forward to Stage 1

**Donor Advocate Team**

The donor advocate team is a group of people some of whom you will see as part of your assessment. The team’s main purpose is to protect and advocate for the donor’s best interest. Independently, but in collaboration with the donor assessment team the donor advocate team will make recommendations regarding the evaluation process; educate you about the medical, psychological and financial implications of donation; help to determine your suitability
(an acceptable medical risk); ensure free (autonomous) informed consent; provide emotional support and follow-up; and ensure continuity of care throughout the entire donation process. Members of this team are the live donor liver transplant coordinator, social worker, psychiatrist and independent physician.

**Stage 1.**

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.

This first stage is to ensure that your liver is suitable to split for transplantation, this is determined by two scans:
A CT 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.

A MRI scan will look at the bile ducts and blood vessels going to and from 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 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 makeup. When this test is conducted on a donor and recipient, who believe they are genetically related, the results may suggest that there is no genetic link. You will be asked to sign a form to register your wish to have or not have this information disclosed to you. The recipient will also be given this opportunity.

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 live donor assessment team. 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 the liver recipient for them to survive.

Stage 2.

When the CT and 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 a 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).

**Psychological/Social Assessment**

The 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, or the transplant recipient does not ‘take care’ of the portion of liver donated?

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 live donor liver 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 this point in time the donor team will meet to review your case and consider setting a date for surgery with the liver transplant team. The donor and 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.

**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.

For Anonymous/Altruistic donors you will be asked to provide evidence of your identity and the IA will ask you about your motivation to donate.

For individual wanting to donate to a relative or friend the IA will verify any claimed relationship with the person who you want to donate too. 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 live donor liver 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.

B. The Living Donor Operation

The target date for surgery is always subject to change. If the donor surgery is cancelled or delayed we re-schedule the surgery as soon as possible. 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.
Menu

Doner Liver
After anaesthesia is established the operation begins with an incision across the top of the abdominal wall. Surgery begins with a careful examination of the internal structures including an intra-operative ultrasound and an x-ray of the bile ducts. Occasionally at this point despite satisfactory pre-operative tests, we find a pattern of blood vessels or bile ducts that would make the transplant unusually risky for the donor or recipient. In this situation we do not proceed with the donor surgery and the incision is closed. This happens in about 3-5% of donor surgeries. Once the donor anatomy is confirmed suitable the recipient is sent to the operating theatre. The donor liver tissue is divided as described below; this procedure takes between 4 and 8 hours.
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 approximately 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 4 to 8 hours. When surgery is complete you will be transferred to a High Dependency Unit. Live donors are cared for by the live donor team which includes surgeons, transplant co ordinator, physicians, pain specialists and nurses.

The following day, depending on your condition you will be transferred to the ward.

We strive to minimize post-operative pain which is managed either by patient controlled analgesia pump (PCA) or epidural. After 2 days oral pain relievers are prescribed.

Most donors can start eating and drinking as soon as they feel able to post-op. Any
drainage tubes inserted during the surgery (intravenous drip, bladder catheter) are gradually removed over the first few days.

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 as soon as possible after surgery in order to reduce the risk of forming clots; you will be given information regarding this.

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.

The remaining liver segments grow and resume normal function within a few weeks after donation. Most complications are
soon after surgery, but some may appear after discharge home. Patients are given details of who they should contact if they develop new abdominal pain, redness around the wound, yellow skin, fever, cough or shortness of breath or any other medical concern. We will discuss these again as part of your discharge teaching.

A follow-up clinic visit will be arranged for 4 weeks after discharge. The remainder of the follow-up care is provided by telephone consultation, electronic questionnaire and at your family doctor, unless you need to see the live donor team in person.

Most donors are off work for 6-12 week period while recovering from surgery, this will depend upon the nature of their employment.
What are the risks and potential complications of the operation?

Liver donation is associated with risks no matter how carefully the donor surgery is performed. It is vital that persons considering donation have a good understanding of the nature of this surgery, the benefits, and the risks. Risks are discussed frequently during the assessment and are carefully reviewed during visits with the live donor team. Some of the risks of live donation are outlined below.

About 30% of live donors will experience complications. Most of these complications are mild and transient (temporary); however some can be serious and life threatening complications.

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

**Anaesthesia**
You will need an anaesthetic for your operation. 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.

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 will 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 extremely 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 is may occur once in every 30,000 cases. Infection is also a rare complication.

**Surgical**

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 1 in 200 and 1 in 500 depending upon the type of surgery. This must be carefully considered and discussed with your family.

The surgery is performed through a large upper abdominal incision; this may result in a mild permanent weakness in the abdominal wall and or a small patch of numbness beneath the incision just above the umbilicus (navel).
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.

This surgery may affect your ability to obtain health or life insurance in the future; you need to discuss this with your provider.

No matter how carefully the liver transplant is performed, there is the potential that the liver transplant recipient may die during or after the transplant surgery. If this happens,
the donors will know that they have done everything possible to help a loved one. Nonetheless, potential donors should consider carefully how you might respond to the stress of dealing with the recipient’s death.

What Next?

If you have read and understood the contents of this information booklet and you have any questions please do not hesitate to contact a member of the live donor assessment team. If you feel you have understood and discussed this with those concerned and want to proceed further you can:

• Get your blood group checked, either at GP or we can arrange this at Leeds
Teaching Hospitals

• Fill in the health questionnaire and return to the transplant co ordinator

• Telephone the transplant co ordinator office to make arrangements for an appointment at the live donor clinic; telephone 0113 206 6913 or email live-donor-clinic@leedsth.nhs.uk