

# Patient agreement to investigation or treatment

## Living liver donation work-up

**Authors:** Transplant Unit

**Brief description:**

- Thank you for expressing an interest in living liver donation. This form provides information on key points about the assessment process.
- In order to decide whether you are a suitable liver donor it will be necessary to carry out a number of investigations. These include blood and urine tests, scans and other investigations. This is known as the 'work-up'. These tests will take a number of weeks to complete, and will normally involve several visits to hospital.
- Here, we explain some of the aims, benefits, risks and alternatives to having these investigations carried out. We want you to be informed about your choices to help you to be fully involved in making any decisions.
- Please ask about anything you do not fully understand or wish to have explained in more detail.
- If you would like this information in another format or language or would like help completing the form, please ask a member of our staff.

**Please bring this form with you to hospital**

- You will be asked to read this form carefully, and you and your doctor (or other appropriate healthcare professional) will sign it to document your consent.
- All our consent forms are available on the Addenbrooke's website:  
<http://www.addenbrookes.org.uk/consent>
- Guidance for health professionals can be found on the Addenbrooke's intranet site  
<http://nww.addenbrookes.nhs.uk/consent>
- Remember, you can change your mind about having the procedure at any time even after you have signed the form.

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**For staff use:**

Does the patient have any special requirements? (For example: requires an interpreter or other additional communication method)

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.....

## About the assessment process

Below are some key points about the assessment process:

- In order to decide whether you are a suitable liver donor it will be necessary to carry out a number of investigations. These include blood and urine tests, scans and other investigations. This is known as the 'work-up'. These tests will take a number of weeks to complete, and will normally involve several visits to hospital.
- An outline of the tests is contained in the booklet 'living donor liver transplantation – information booklet for potential donors.' You will be given fuller explanations of these tests as they arise.

## Before the investigations

- You will need consultations with a hepatologist (liver doctor), transplant co-ordinators, liver surgeons and a counsellor. It is essential you give full details of any current or past medical conditions or illnesses. Detailed information on the risks, benefits and likely outcomes of donation for both donor and recipient will be given to you.
- We will need to contact your GP to obtain a copy of your medical history and will need to share the results of your investigations with them.
- At any stage, right up to the time of operation, you can withdraw from the process for any reason.

## During the investigations

During the assessment you will need to undergo tests in order to establish whether you are a suitable donor. Listed below are the mandatory tests you will have, there might be a need to carry out additional tests, depending on the results, but we will keep you well informed if this is the case.

### Blood tests:

- The function of your liver
- The ability of your blood to clot
- To see if you are anaemic
- To assess the function of your Kidneys
- To check the level of oxygen in your blood
- For viruses – including Hepatitis B, Hepatitis C, Cytomegalovirus and the HIV virus.
- To exclude any malignancy

**Chest x-ray:** to ensure you have no lung problems

**ECG/Echocardiogram:** to assess the function of your heart.

**Pulmonary function test:** to provide a more detailed assessment of your lungs.

**Scans** to look at the anatomy of your Liver

Depending on the above results you might need a liver biopsy, where a small piece of liver tissue is removed in order to exclude any medical problems.

## After the investigations

- It may be necessary to share the results of these tests with other health professionals.
- As a legal requirement of the Human Tissue Act 2004, once all the investigations and consultations are finished, you and your recipient will meet with the Donor Advocacy Team (DAT – comprising of various independent assessors), who will check that all is in order. They will then apply to the Human Tissue Authority for permission for the transplant to proceed. You will need to produce evidence of your identities and relationship prior to this meeting (see page 4).
- Once a date for the operation is planned, it will be necessary for both the donor and the recipient to attend Addenbrooke's for a day in the week before the operation. This is in order to perform pre-operative checks and ensure both patients are fully prepared. Please feel free to ask any questions at any time.
- You will normally be admitted to the transplant ward (ward C9) the day before the planned operation date. Following the operation, it is expected that you will remain in hospital for a week to 10 days.
- Although we try to accommodate individual circumstances, it is important to realise that no guarantees can be made about the length of time the assessment process will take. Neither can we guarantee a particular date for the operation, but all action will be taken to prevent this from happening.
- If it is anticipated that the liver donor will incur significant financial loss due to travel expenses and loss of earnings; it is possible to apply for a reimbursement to cover some of this loss (within certain limitations). Please ask your living donor coordinator for more information.
- There may be medical reasons that indicate that liver donation is not possible. This does not imply any failing on your part and this will be discussed with you fully.

## Benefits

Individuals who would like to be considered as potential living donor must be in excellent physical and emotional health. This is to ensure that the procedure will be as safe and suitable as possible for you as a donor, but also to ensure that the donated organ is a high quality organ, that will benefit the recipient.

In order to maintain safety for both donor and recipient we will need to carry out the investigations already mentioned.

## Risks

There is a small (5%) chance of discovering an unexpected abnormality during the workup process. These may be incidental findings but some may be important for your future health and may require further investigation. In the event of this happening then the clinicians advising you will discuss the findings with you and whether further investigations are appropriate. They will also inform your GP of any unexpected findings.

Invasive investigations such as liver biopsy, angiography etc. carry a small risk of complications, however each of these tests if required will be explained and consented separately at the time.

## Alternatives

The work up process is commenced on a voluntary basis, and as explained, you don't have to go through the assessment. Currently there are no alternative procedures to a full and comprehensive assessment process if you wish to become a live liver donor.

## Information required from living donor pairs to confirm their relationship

In order to comply with the requirements of the Human Tissue Act 2004, the following evidence of relationship is required.

- Where the proposed transplant is between genetically related individuals, a copy of the birth certificates of donor and recipient are required, and of other relatives where it is necessary to show a relationship, for example grandparent to child. If birth certificates are not available, suggestions of alternative evidence should be submitted, for example family tree, statements from GP/minister of religion/local 'pillar of the community' to vouch for validity of relationship.
- Where the proposed transplant is between a married couple or individuals in a civil partnership, there should be evidence of fact and duration of marriage/partnership (a certified copy of the marriage certificate or civil partnership certificate), numbers and ages of children and family photographs.
- Where the proposed donor and recipient are not related by blood or marriage, there needs to be an explanation of the link between them and the circumstances which led to the offer being made, reasons why the donor wishes to donate, documentary and/or photographic evidence of relationship. This may include marriage certificates, passports, testimonials, affidavits, bills/documents showing proof of living at same address, joint photographs of donor and recipient.
- Photographic evidence of identity, for example: passport or photo driving licence.
- Please ask the transplant nurse/coordinator if you have any questions on this patient information or if you require further information.



We are currently working towards a smoke free site. Smoking is only permitted in the designated smoking areas.

For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169

#### Help with this leaflet:



If you would like this information in another language, large print or audio format, please ask the department to contact Patient Information: 01223 216032 or

[patient.information@addenbrookes.nhs.uk](mailto:patient.information@addenbrookes.nhs.uk)



#### Document history

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Consent form 1

# Patient agreement to investigation or treatment

<b>For staff use only:</b>
<b>Surname:</b>
<b>First names:</b>
<b>Date of birth:</b>
<b>Hospital no:</b>
<b>Male/Female:</b>
<b>(Use hospital identification label)</b>

Responsible health professional/job title

Special requirements .....  
 (For example, other language/other communication method)

**Name of proposed procedure or course of treatment**

## Living liver donation work up

**Statement of health professional**

(To be filled in by a health professional with an **appropriate knowledge of the proposed procedure**, as specified in the Hospital's consent policy)

I have explained the assessment procedure to the patient. In particular, I have explained:

- The intended benefits of the assessment:  
 In order to maintain safety for both donor and recipient we will need to carry out the investigations already mentioned.

- Any serious or frequently occurring risks from the Assessment procedures including those specific to the patient .....  
 There is a small (5%) chance of discovering an unexpected abnormality during the workup process.....

- Any extra procedures that might become necessary during the procedure

Blood transfusion  Other procedure (please specify) .....

I have discussed what the treatment / procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient.

- The following information leaflet has been provided: CF176 .....  
 ..... Version/Date/Ref: Version 2, August 2011 .....

This procedure will involve:

General and/or regional anaesthesia       Local anaesthesia       Sedation

Health professional's signature: ..... Date: .....

Name (PRINT): ..... Job title: .....

Contact details (if patient wishes to discuss details later)

I have offered the patient information about the procedure but s/he has declined information.

**Statement of the interpreter (if appropriate)**

I have interpreted the information to the best of my ability, and in a way in which I believe s/he can understand:

Interpreter's signature..... Date: .....

Name (PRINT): .....

**Important notes: (tick if applicable)**

- The patient has withdrawn consent (ask patient to sign/date here) .....
- See also advance directive/living will

Copy accepted by patient: yes / no (please circle)

**Statement of patient**

<b>For staff use only:</b>
<b>Surname:</b>
<b>First names:</b>
<b>Date of birth:</b>
<b>Hospital no:</b>
<b>Male/Female:</b>
<b>(Use hospital identification label)</b>

Please read this form carefully. If your treatment has been planned in advance, you should already have your own copy, which describes the benefits and risks of the proposed treatment. If not, you will be offered a copy now. Do ask if you have any further questions. The staff at Addenbrooke's are here to help you. **You have the right to change your mind at any time before the procedure is undertaken, including after you have signed this form.**

Training doctors and other health professionals is essential to the continuation of the Health Service and improving the quality of care. Your treatment may provide an important opportunity for such training, where necessary under the careful supervision of a senior doctor. You may, however, decline to be involved in the formal training of medical and other students without this adversely affecting your care and treatment.

**Please read the following:**

**I understand** that I will have the opportunity to discuss the details of anaesthesia with an anaesthetist before the procedure, unless the urgency of my situation prevents this. (This only applies to patients having general or regional anaesthesia.)

**I understand** that you cannot give me a guarantee that a particular person will perform the procedure. The person undertaking the procedure will, however, have appropriate experience.

**I understand** that any procedure in addition to those described on this form will only be carried out if it is necessary to save my life or to prevent serious harm to my health.

**I have been told** about additional procedures which may become necessary during my treatment. I have listed below any procedures that **I do not wish, without further discussion, to be carried out**.....

**I understand** that any tissue (including blood) removed as part of the procedure or treatment will be anonymised and may be used for teaching or quality control, and stored or disposed of in a manner regulated by appropriate, ethical, legal and professional standards.

**I understand** that all research will be approved by a research ethics committee and undertaken in accordance with appropriate ethical, legal and professional standards.

**I understand** that the research may be conducted within a hospital, university, not for profit organisation or a company laboratory.

**Please tick boxes to indicate you either agree/disagree to the points below.**

**Yes**    **No**

**I consent** to storage of tissue including blood, serum and DNA for future reference and use in patient care (for example transplant monitoring).       

**I consent** to storage of information about tissue samples and test results on various computer databases and paper files and sharing such information with other health care professionals, including the Human Tissue Authority and UK Transplant. This may include transmission by email.       

**I consent** to use of unused archived tissue samples (surplus to requirements for patient care) in ethically approved research projects in which individuals' names and identities are coded/anonymised. **If you wish** to withdraw your consent for the use of your tissue (including blood) for research, please contact the Patient Advice and Liaison Service at Addenbrooke's Hospital.       

**I agree** to the use of photography for the purpose of diagnosis and treatment.       

**I agree** to anonymised photographs being used for medical teaching.       

**I consent** to such tests to be made of my blood and urine as may be necessary to establish my suitability to donate part of my liver, including blood tests for the following infections. I understand the reasons for these tests. I understand I will be confidentially informed of the results and future implications of an abnormal result:

- o Cytomegalovirus: Epstein Barr Virus (Glandular fever virus)
- o Hepatitis B
- o Hepatitis C
- o Toxoplasmosis: Human Immunodeficiency Virus (HIV/AIDS virus)
- o Syphilis Varicella Zoster Virus (Chicken pox virus)

**I consent** to genetic and serological based tests to determine the histo-compatibility status (how well matched) of the donor and recipient (in some circumstances such DNA testing can reveal information about the genetic relationship of two or more individuals).       

**I consent** to use of my anonymised medical information and test results in ethically approved research projects, and publication of non-identifiable data in professional forums and journals.

**Please read and tick the following statements:**

- I have read and understood the booklets 'living donor liver transplantation – your questions answered' and the Human Tissue Authority leaflet: 'information about living-donor transplants'.
- I give permission for my General Practitioner to be contacted to gain details of my medical history.
- I have read and understood the section 'keeping transplants safe' and to the best of my knowledge am not aware of any reason why donation cannot proceed safely.
- I undertake to inform the transplant unit if any of these conditions apply to me at any time prior to donation.

**I confirm** that the risks, benefits and alternatives of this procedure have been discussed with me and I have read and understood the above and agree to the procedure (or course of treatment) on this form.

**Patient's signature:** ..... Date: .....

**Name (PRINT):** .....

If the patient is unable to sign but has indicated his/her consent, a witness should sign below. Young people may also like a parent to sign here (see guidance notes).

**Witness' signature:** ..... Date: .....

Name (PRINT): .....

**Confirmation of consent** (to be completed by a health professional when the patient is admitted for the procedure, if the patient has signed the form in advance)

On behalf of the team treating the patient, I have confirmed with the patient that s/he has no further questions and wishes the procedure to go ahead.

Signature Date: .....

Name (PRINT): ..... Job Title: .....