

Patient agreement to investigation or treatment

Liver transplantation

Authors: Cambridge Transplant Unit

Brief description:

- This is an operation to remove a diseased liver and replace it with a healthy liver. The new liver is removed from either a living donor (often related to the patient) or from someone who has recently died.
- Here, we explain some of the aims, benefits, risks and alternatives to this procedure (operation/treatment). 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.

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 liver transplantation

This is a complex and major procedure to remove a diseased liver and replace it with a new healthy liver. This procedure is generally recommended for patients who suffer from a damaged liver which is not likely to recover satisfactory function. The transplant procedure typically takes six to eight hours to perform; however, if we encounter any difficulties, the operation might take substantially longer.

Before your procedure

- You have been prepared for this procedure by a team of Hepatologists (Dr A Gimson, Dr G Alexander, Dr M Allison and Dr W. Griffiths) with input from surgeons, anaesthetists, psychiatrists, dentists, co-ordinators paramedical staff and nursing personnel. Your name will have been added to the Cambridge Liver Transplant Waiting List. When an appropriately matched liver is available, you will be contacted by phone. At this time, you will be asked to report to ward C9 at Addenbrooke's urgently without any delay. This is because the new liver cannot exist outside the human body for more than a few hours.
- When you arrive, a doctor will see you in C9, quickly go through your medical history again, examine you and take some blood for urgent tests. You will then wait for the new liver to reach Addenbrooke's before you are prepared and taken to the theatre for the transplant operation.
- Very occasionally, the new liver having been inspected will be found to be unsuitable for you just prior to the planned operation. Your operation will then be cancelled. If this should happen, it will not affect your place or priority on the waiting list for another liver.
- This procedure involves the use of general anaesthesia. See below for further details about the types of anaesthesia/sedation we shall use.
- Most people who have this type of procedure will need to stay in hospital for between 10 to 20 days. Sometimes we can predict whether you will need to stay for longer than usual - your doctor will discuss this with you before you decide to have the procedure.

During the procedure

- We will place several lines (tubes) into some blood vessels in your arms and neck. These give you fluids and/or blood, and help us take blood for tests and monitor your condition. In addition, a tube might be passed into your stomach through the nose to decompress (deflate) your stomach. We also place a urinary catheter into your bladder during the operation to drain the urine. A team of surgeons will first prepare the new liver and then carry out the liver transplant procedure in you. The surgeon will make a long curved incision (cut) in the upper part of your abdomen (tummy) and remove the diseased liver. The new liver will then be connected up to the blood vessels and bile duct. Typically, this takes six to eight hours; however, if we encounter any difficulties, the operation might take substantially longer.

After the procedure

- After the liver transplant procedure has been carried out you will be taken to either the intensive care unit on level 3 or the high-dependency unit on ward C9. You might be woken up the same day from the anaesthetic or depending on your condition, the team might decide to keep you anaesthetised and ventilated (placed on a breathing machine) for a day or two in intensive care.
- After this procedure, most people will have a small, plastic tube in one of the veins of

their arm. This might be attached to a bag of fluid (called a drip), which feeds your body with fluid until you are well enough to eat and drink by yourself.

- A nurse will check your pulse and blood pressure regularly. When you are well enough to be moved, you will be taken to a ward.
- Sometimes, people feel sick after an operation, especially after a general anaesthetic, and might vomit. If you feel sick, please tell a nurse and you will be offered medicine to make you more comfortable.
- **Eating and drinking:** Generally you will be allowed to eat and drink a couple of days after the operation.
- **Getting around and about:** As soon as you are able, you will be encouraged to be mobile and carry out deep breathing exercises. This both reduces the chance of getting a blood clot in the leg and also helps you to avoid chest infections.
- **When you can leave hospital:** Most people who have had this type of procedure will need to stay in hospital for at least 10 to 20 days. The actual time that you stay in hospital will depend on your general health, how quickly you recover from the procedure and your doctor's opinion.
- **When you can resume normal activities including work:** When you leave hospital, you should be able to carry out light daily activities at home. However, it might be a few months before you can return to normal active work.
- **Special measures you need to take after the procedure:** You will be given more detailed information about any special measures you need to take after the procedure. You will also be given information about things to watch out for that might be early signs of problems (for example: infection).
- **Check-ups and results:** In the period after the operation, you will be seen very frequently in the Hepatology clinic to check your progress and to make sure your new liver is functioning well.

Intended benefits of the procedure

- Liver transplantation is considered to be a life-saving procedure.
- Most people who have had a liver transplant consider they have more energy and a better quality of life after the operation. They find that most of the symptoms of liver failure, such as jaundice, itching, fluid in the tummy, swelling of legs etc, will gradually disappear.
- After a liver transplant, you can expect a 60 to 70% chance of being alive at the end of a 10 year period.

Who will perform my procedure

- The liver transplant operation will be carried out by an appropriately experienced surgical team led by one or more of the following Consultant Surgeons: Mr Jamieson, Mr Gibbs, Mr Watson, Mr Praseedom, Mr Pettigrew, Mr Huguet and Mr Butler.

Alternative procedures that are available

- Liver transplantation is the only successful form of treatment for non-reversible, end stage liver failure. However, symptoms such as jaundice, itching, fluid overload, etc can occasionally be managed non-operatively, for a limited period of time, with medication.

Serious or frequently occurring risks

- Liver transplantation is a complex and major procedure and there is up to one in 10 risk of death in the first year following it and a very small but real risk of death during the operation itself (one in a hundred).
- Following the operation, there is a small risk (of 2%) that the new liver might not function or a risk (of 4%) that the blood vessels taking blood into the liver might get blocked. This would lead to failure of the liver and we would need to urgently replace it with another liver (a re-transplant) within 48 hours, without which survival is not possible.
- In the event of bleeding or a bile leak, a further operation may be needed to sort out the problem.
- After the operation, there is a 25% risk of acute rejection of the new liver. If this happens, we need to give you some extra treatment with more powerful medications.
- In the longer term, you might develop chronic rejection of the new liver. If this happens you might need to have a further transplant procedure.
- Some liver diseases (ie that caused your original liver failure) can recur in the new liver.
- Most people who have had a liver transplant need to undergo further admissions into hospital in the subsequent months and years. These are necessary so that we can check you, using blood tests, scans, endoscopies and/or liver biopsies.
- As with any other operation, complications can occur, such as wound infections, fluid leaks from drains and wound sites etc. These complications can often be managed with medication, rather than any further surgical procedures.
- We take every effort to screen liver donors for infections and tumours, however, we cannot guarantee that an infection or tumour will not be transmitted from the donor to you, the recipient. The risks are extremely low and the risk of infection is similar to that following blood transfusion.
- You will need to take a number of medications on a long-term basis to prevent rejection of the new liver. This is called Immunosuppression.

Drugs

- It is common for some drugs, particularly the immunosuppressive drugs, to be used in combinations or for conditions for which they were not originally licensed. This is common practice in transplant units such as ours, and such use has been acknowledged by the National Institute of Clinical Excellence. Any new drugs that we use will have been approved by Addenbrooke's Hospital Drug and Therapeutic Committee, or, in the case of clinical trials, by a Research Ethics Committee.

Problems with Immunosuppression

- In order to protect the new 'foreign' liver from rejection by your immune system, you will need to take some powerful immunosuppressive medications. Although these should protect your new liver, they also reduce your immunity; for example, they make you more susceptible to some infections.
- The potential side effects of these medicines include infections, kidney problems, diabetes, stomach upset, wound problems. There is also a higher risk of cancer in patients taking these medications.

- To reduce any side effects, the medical team will try adjust the dose of medications you take, based on your specific condition.
- It is very important that you follow our instructions on when and how to take your medication. If you do not follow the dosage schedule strictly (ie if you miss taking tablets), you run a significant risk of losing your liver without the prospect of a new one.
- Please remember that the Transplant Unit has recommended the liver transplant procedure to you because the team feels that the benefits will greatly outweigh the risks for you.

Information and support

- If you have any anxieties or questions, please feel free to ask any member of the staff. Further information can be obtained from the Transplant Co-ordinators who can be reached through the Addenbrooke's Switchboard on 01223 216 536 or from the Addenbrooke's website www.addenbrookes.org.uk or www.cambridgetransplant.org.uk

Your anaesthesia

General Anaesthesia

During general anaesthesia you are put into a state of unconsciousness and you will be unaware of anything during the time of your operation.

Before your operation

Before your operation your anaesthetist will visit you in the ward, and may have seen you on the ward during your transplant assessment. The anaesthetist who looks after you on the day of your operation is the one who is responsible for making the final decisions about your anaesthetic. He or she will need to understand about your general health, any medication that you are taking and any past health problems that you have had. Your anaesthetist will want to know whether or not you are a smoker, whether you have had any abnormal reactions to any of the drugs or if you have any allergies. They will also want to know about your teeth, whether you wear dentures, have caps or a plate. Your anaesthetist needs to know all these things so that he or she can assess how to look after you in this vital period. Your anaesthetist may examine your heart and lungs and may also prescribe medication that you will be given shortly before your operation, the pre-medication or 'pre-med'.

Pre-medication is the name given to medication (drugs) given to you some hours before your operation. These drugs may be given as tablets, injections or liquids (to children). They relax you and may send you to sleep. They are not always given.

Do not worry if you do not have a pre-med, your anaesthetist has to take many factors into account in making this decision and will take account of your views on the topic if possible. Do not be worried about your anaesthetic. When your anaesthetist visits you before your operation, this is the time to ask all the questions that you may have, so that you can forget your fears and worries.

Before your operation you will be changed into a gown and wheeled to the operating suite into an anaesthetic room. This is an ante-room outside the theatre. The anaesthetist, his or her assistant and nurses are likely to be present. An intravenous line (drip) may be inserted. Monitoring devices may be attached to you, such as a blood pressure cuff or a pulse oximeter. A pulse oximeter is usually a little red light in a small box, which is taped to

your finger. It shows how much oxygen you have in your blood and is one of the vital monitors that an anaesthetist uses during your operation to ensure that you remain in the best of health. You may be given some oxygen to breathe. It is common practice nowadays to allow a parent into the anaesthetic room with children: as the child goes unconscious, the parent will usually be asked to leave.

During your operation

While you are unconscious and unaware your anaesthetist remains with you at all times. He or she monitors your condition and administers the right amount of anaesthetic drugs to maintain you in the correct level of unconsciousness for the period of the surgery. Your anaesthetist is constantly aware of your condition and trained to respond. Your anaesthetist will be monitoring such factors as heart rate, blood pressure, heart rhythm, body temperature and breathing. He or she will also constantly watch your need for fluid or blood replacement. If you have any other medical conditions, your anaesthetist will know of these from your pre-operative assessment and be able to treat them during surgery.

After your operation

After your operation your anaesthetist continues to monitor your condition carefully. You will probably be transferred to a recovery ward where specially trained nurses, under the direction of anaesthetists, will look after you. Your anaesthetist and the recovery nurses will ensure that all the anaesthetic effects are reversed and that you are closely monitored as you return to full consciousness. You may be given some oxygen to breathe in the recovery area, and may find that intravenous drips have been inserted whilst you are unconscious in theatre and that these will be replacing fluids that you might require. You will be given medication for any pain that you might feel, and systems, such as Patient Controlled Anaesthesia (PCA) may be set up to continue pain control on the ward.

You are likely to feel drowsy and sleepy at this stage. Some patients feel sick, others may have a sore throat related to the insertion of the breathing tube during surgery. During this time it is important that you relax as much as you can, breathe deeply, do not be afraid to cough, and do not hesitate to ask the nursing staff for any pain relief, and about any queries you may have. You are likely to have hazy memories of this time and some patients experience vivid dreams. Once you are fully awake you will be returned to the ward, and if you are a day patient will be allowed to go to the waiting area to fully recover before you are accompanied home. Do not expect to feel completely normal immediately!

What are the risks of general anaesthesia?

In modern anaesthesia, serious problems are uncommon. Risks cannot be removed completely, but modern equipment, training and drugs have made it a much safer procedure in recent years. The risk to you as an individual will depend on; whether you have any other illness, personal factors (such as smoking or being overweight) or surgery which is complicated, long or done in an emergency. Please discuss any pre-existing medical condition with your anaesthetist.

- Very common and common side effects (1 in 10 or 1 in 100 people)
Feeling sick and vomiting after surgery, sore throat, dizziness, blurred vision, headache, itching, aches, pains and backache, pain during injection of drugs, bruising and soreness, confusion or memory loss.
- Uncommon side effects and complications (1 in 1000 people)
Chest infection, bladder problems, muscle pains, slow breathing (depressed respiration),

damage to teeth, lips or tongue, an existing medical condition getting worse, awareness (becoming conscious during your operation).

- Rare or very rare complications (1 in 10,000 or 1 in 100,000)
Damage to the eyes, serious allergy to drugs, nerve damage, death, equipment failure.

Please ask if you require this information in other languages, large print or audio format: 01223 216032 or patient.information@addenbrookes.nhs.uk

Potete chiedere di ottenere queste informazioni in altre lingue, in stampato grande o in audiocassetta.

Italian

若你需要本信息的繁體中文、大字體或音訊格式的版本，請要求索取。

Cantonese

તમને આ માહિતી બીજી ભાષાઓમાં, મોટા અક્ષરોમાં અથવા સાંભળી શકાય એવા માધ્યમ (ઓડીઓ ફોર્મેટ)માં જોઈતી હોય તો કૃપા કરીને પૂછો.

Gujarati

تکایہ پرسیار بکے نہ گھر نہ وزانیاریہت دھوی بہ زمانیکی تر ، بہ پیتی گہورہ یانیش بہ شیودی دہنگ

Kurdish

Urdu

آگر آپ کو یہ معلومات دوسری زبانوں میں، بڑے الفاظ کی اشاعت میں یا آڈیو ٹیپ پر درکار ہوں تو براۓ مہربانی اس کیلئے درخواست کریں۔



Addenbrooke's is smoke-free. Please do not smoke anywhere on the site.

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

Document History

Authors	Mr Praseedom, Mr Chris Watson
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Consent form 1

Patient agreement to investigation or treatment

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

Responsible health professional/job title

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

Name of proposed procedure or course of treatment

Liver Transplantation

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

- How it will be performed
- The intended benefits of the procedure
- Any serious or frequently occurring risks including those specific to the patient

.....

- 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:
..... Version/Date/Ref:

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.

Important notes: (tick if applicable)

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

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):

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

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

Statement of patient

Please read this form carefully. If your treatment has been planned in advance, you should already have your own copy, which described 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 tick boxes to indicate you understand and either agree/disagree to the statements below.

- | | Yes | No |
|---|--------------------------|--------------------------|
| I agree to the procedure (or course of treatment) described on this form. | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand that you cannot give me a guarantee that a particular person will perform the procedure. The person will, however, have appropriate experience. | <input type="checkbox"/> | <input type="checkbox"/> |
| I agree that any tissue (including blood) removed as part of the procedure or treatment may be used for diagnosis and audit, stored or disposed of as appropriate and in a manner regulated by appropriate, ethical, legal and professional standards. | <input type="checkbox"/> | <input type="checkbox"/> |
| I agree that tissue (including blood) not needed for my own diagnosis or treatment can be used for the following purposes that could benefit other patients. | <input type="checkbox"/> | <input type="checkbox"/> |
| Teaching | <input type="checkbox"/> | <input type="checkbox"/> |
| Research which may include genetic research | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand that all research will be approved by a research ethics committee and undertaken in accordance with appropriate ethical, legal and professional standards. | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand that the research may be conducted within a hospital, university, not for profit organisation or a company laboratory. | <input type="checkbox"/> | <input type="checkbox"/> |
| I agree to the use of photography for the purpose of diagnosis and treatment. | <input type="checkbox"/> | <input type="checkbox"/> |
| I agree to anonymised photographs being used for medical teaching. | <input type="checkbox"/> | <input type="checkbox"/> |
| 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.) | <input type="checkbox"/> | <input type="checkbox"/> |
| 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. | <input type="checkbox"/> | <input type="checkbox"/> |
| 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. | <input type="checkbox"/> | <input type="checkbox"/> |

.....

Patient's own 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's own 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:**