Liver transplant assessment

Your guide to being assessed for a liver transplant

BRITISH LIVER TRUST

Raising awareness, transforming lives

Contents

"While it may feel quite overwhelming to have lots of tests, it's so valuable to make sure a liver transplant is the right treatment for you."

Katie Quist, Lead Nurse Liver, Royal Free Hospital

This booklet will help you understand more about the liver transplant assessment and give you advice on how to prepare and what the process will involve, as well as what the decision will mean for you. Your doctor is the best person to speak to about your own assessment, as they know your medical history.

To help you prepare for appointments, see the range of other information we have on liver transplants at britishlivertrust.org.uk/transplants

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What is liver transplant assessment?

Liver transplant assessment is a process to see if a liver transplant operation is possible, and the best treatment option for you. You'll need to have this assessment before you can be put on a waiting list for a liver transplant.

A team of liver transplant specialists will assess you to see if a liver transplant will be a safe and effective treatment for you. The process can vary between liver transplant centres but it will involve having a number of tests over about 2 days. The assessment checks if you are well enough to have the operation, and if it will improve your condition. It also helps your team work out how soon you need a transplant if you are approved.

You may be admitted to hospital to have these tests as an inpatient (where you stay in hospital throughout the process) or you may be able to have them as an outpatient. This means you stay at home but come into hospital for appointments to have the tests.

A multidisciplinary team (MDT) of specialists will assess the results of your assessment tests to make a decision. The team may include surgeons, hepatologists (specialist liver doctors), anaesthetists, intensive care specialists, liver transplant coordinators, a dietician, social worker and a psychiatrist or specialist addictions nurse.

Who can have a liver transplant assessment?

You may be considered for liver transplant assessment if you have:

- End-stage liver disease (cirrhosis)
- Some types of liver cancer, mainly hepatocellular carcinoma (HCC)
- Acute liver failure (when your liver suddenly stops working properly)
- Liver disease that can't be managed or seriously affects your quality of life.

If you want to know if transplant could be an option for you, ask your doctor.

The liver transplant operation

What happens

A liver transplant is an operation to remove a diseased liver and replace it with a healthy one. This can involve a whole liver, a reduced liver or a split liver. A reduced liver is when only a part of the liver is used. And a split liver is when either a right or left lobe is used (the liver is divided into two main lobes – the larger right and the smaller left).

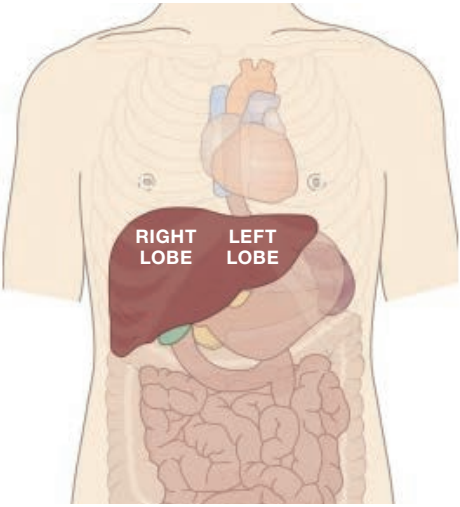
Benefits and risks of the operation

There are benefits and risks for you to consider before you have a liver transplant. While you will get a new liver that will hopefully work well and give you a longer and better quality of life, there's a chance you'll have some problems during, or after the operation. These may include bleeding, infections, or your body may reject your new liver and see it as something it needs to attack.

Your doctor will explain the benefits and risks of a liver transplant to you so you can make an informed decision about whether to go ahead. Make sure you ask questions if you're unsure about anything so you understand what a liver transplant operation involves, and what you'll need to do afterwards to give your operation the best chance of success.

For detailed information about the operation, including benefits and risks, read our booklet Your guide to having a liver transplant operation.

Your liver is on the right side of your tummy, just under your ribs. It works like your body's factory and carries out hundreds of jobs that help keep you alive and well.



Your liver:

- turns digested food from your gut into all the different chemicals your body needs
- breaks down toxins, alcohol, drugs and other harmful substances
- helps control the amount of sugar in your blood
- makes the chemicals that help your blood clot.

Life after a liver transplant operation

A liver transplant is a major operation and the recovery process can be long (up to a year). It's important to understand the commitment that you need to make to your own health after the operation.

You'll need to take medicines for the rest of your life to prevent your immune system from reacting to your new liver. And you'll have regular appointments with your doctor to check that your liver is working well. Although these will also be life-long, they should become less frequent with time.

You'll be supported by a range of specialist health professionals during your recovery and afterwards. Most people are eventually able to return to most of their normal activities after a liver transplant and have a good quality of life.

For detailed information about what to expect after a liver transplant, read our booklet Your guide to life after a liver transplant.

Support

Support is an essential part of the transplant process. Your transplant team will need to make sure that you have this in place before you're considered for a liver transplant. If you'd like a family member or carer to be involved in your liver assessment, your transplant team will ensure they feel included in the conversation. They may hold online education events for patients and their family and carers, for example.

Let your transplant team know if any of you have any questions or concerns. Transplant units have services available to help you. While these can vary by centre they usually include:

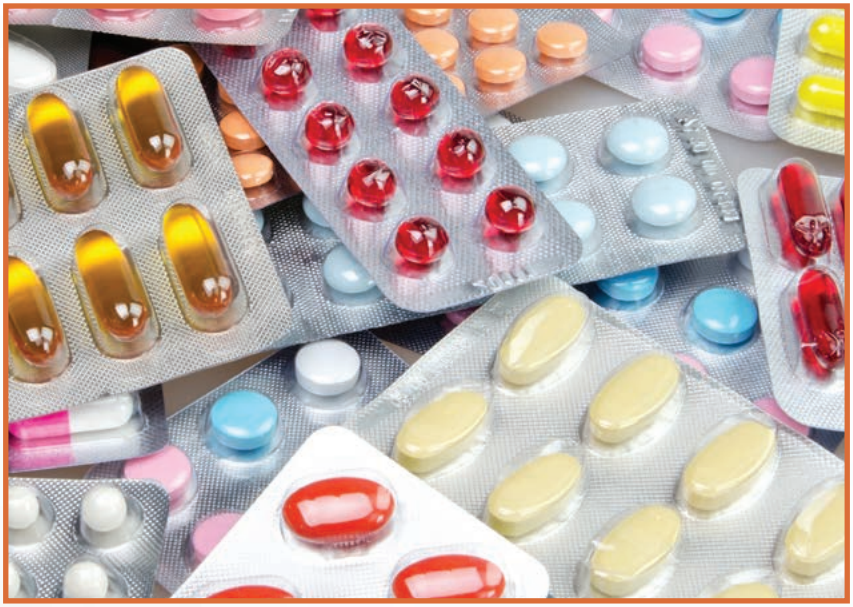
- **Social workers**
- **Physiotherapists**
- **Occupational therapists**
- **Dieticians**
- **Pharmacists**

We have information for family and carers, which gives tips and advice and how to access support in our booklet Your guide to supporting someone through a liver transplant.

What to bring

When you go to hospital for a liver assessment, whether as an inpatient or outpatient, take along any medicines you're currently taking and any written communication about your liver disease or previous test results. If you have any other conditions, it's a good idea to bring any medicines you take or information from your doctor. Bring anything that will help you answer questions about your health.

If you're having your tests in hospital as an inpatient, make sure you have everything you'll need for about 2 days.



What to pack

- [ ] Toiletries
- [ ] Comfy clothes, separate tops and bottoms are a good idea to make it easier to examine your tummy
- [ ] Underwear
- [ ] Nightwear
- [ ] Magazines and books (anything to keep you busy while you're waiting in between tests)
- [ ] Water bottle
- [ ] Medicines (including any information about them)
- [ ] Letters from your doctor
- [ ] Mobile phone and charger (ideally a 3m charger so it can reach your bed from the wall socket)
- [ ] Pen and paper so you can write down any information your transplant team give you, and note down questions you have for them

Questions to ask before your assessment

Ask as many questions as you want to help you understand the process and what it means for you. Here are some examples and space for you to add some more:

- Where will I have the test and how long will it take?
- Is there anything I need to do to prepare for this test?
- Can I drive home after the test (if an outpatient)?
- What will the test result mean?
- Will I need to have the test again?

Your questions

What happens in a liver transplant assessment?

You'll have a number of tests to help your doctors decide if you are able to have a liver transplant. These will assess your liver and general health and find out whether your body can cope with the operation and whether a transplant is the best option for you. Your doctors will also assess your mental health because a liver transplant is major surgery that you need to be able to cope with both physically and mentally.

The tests

- **Scans**

You will have **CT** and/or **MRI scans**. These will give detailed images of the inside of your body, including your liver, which will help to check everything looks right for surgery or if there are any potential problems. If you have liver cancer, scans will check where it is, and if it has spread out of your liver.

You may also have an **ultrasound** to check the blood vessels going to your liver to make sure the surgery can go ahead. A clinician will move a probe over your liver area to send sound waves through your skin, which are reflected and sent to a computer to turn into pictures.

- **Blood tests**

You'll have some blood tests to check your general health and find out if there is anything that could cause a problem with a liver transplant. For example, you'll be screened for a range of viruses, including human T-lymphotropic virus (HTLV) and hepatitis. If you have an infection, this may need to be treated or clear before you can be considered for a liver transplant. You may need to have a number of samples taken (usually up to 12).

- **Chest X-ray**

A chest X-ray will be part of the assessment. It allows your doctors to see if your heart and lungs are working well and you're fit enough to have an operation.

- **Lung function tests**

You may have lung function tests, such as a spirometry, to see if your lungs are working well enough to have the operation. In a spirometry, you'll blow into a device to measure how much air you can breathe out in one forced breath.

- **Electrocardiogram (ECG)**

You'll have an ECG to check if you have any problems with your heart. A clinician will attach leads to your chest, arms and legs, which are connected to a machine that measures the electrical activity in your heart.

Fitness tests

You'll have some tests to see how physically fit you are and how well your heart copes when it has to work hard, like during the operation. Make sure on the day of your test that you wear something you can move in that won't restrict you.

Different centres test this in different ways, for example you might be asked to cycle as hard as you can on an exercise bike. Or they may ask you to climb some stairs. You might do the fitness test while having your heart monitored for example with an ECHO (see below).

You want to push yourself as hard as you can on this test but don't worry, just do your best. **It's a good idea to practise while you are waiting for your assessment by doing some physical activity every day.**

Echocardiogram and cardiopulmonary exercise test

You'll have an echocardiogram (ECHO) to check the size of your heart and how well it pumps blood to see if there are any problems. A clinician will move a probe over your heart area to send sound waves through your skin, which are reflected and sent to a computer that turns them into pictures.

In an ECHO and cardiopulmonary exercise test (CPET), you'll do some vigorous activity, such as a session on an exercise bike while having the test. This is so your doctors can compare your heart action when it's working hard to when it's at rest. You may need this test if you have risk factors for heart disease, or are over 50.

- **Kidney function tests**

You may need to give samples of blood and urine to check how well your kidneys are working. Kidney problems are common if you have liver disease.

- **Coronary angiography**

You may need a coronary angiography, for example if you have coronary disease. It will help your doctors understand how healthy your arteries are and whether there are any problems that could make a liver transplant too risky. A doctor will inject a dye into your arteries and take an X-ray.

- **Endoscopy**

An endoscopy can find out whether the tiny veins in your food pipe (oesophagus) and stomach are damaged or bleeding (variceal bleeding). During an endoscopy, your doctor will pass a very thin tube with a tiny camera down your throat and into your stomach, usually under local anaesthetic.

Psychological assessment

A psychologist, psychiatrist or addictions nurse specialist will ask you questions about your health and life, including if you take drugs or drink alcohol, and how much. It's important to answer all the questions as truthfully and fully as possible.

The purpose of the assessment isn't to test you and there aren't any right or wrong answers. The team will only want to understand your individual circumstances so they can offer you the support you need to give you the best chance of having a successful liver transplant.

Psychological assessment will also make sure that you'll be able to cope and adjust to life after your operation. For example, you'll need to remember to take medicines for the rest of your life and attend regular healthcare appointments.

Visit our website to watch a video about being assessed for a liver transplant britishlivertrust.org.uk/transplants

Understanding what's involved

The assessment period is a good opportunity to ask questions so you understand what a liver transplant operation involves, and what you'll need to do after it to give yourself the best chance of a good recovery.

The assessment decision

After all the tests are complete, which will usually take around 2 days, a multidisciplinary team of specialists will meet to decide whether a liver transplant is the best treatment option for you. You will usually have your decision within a week and it will fall into one of the following categories:

- You will be put on the waiting list for a transplant.
- You need a transplant but need to have more tests to make sure it will be safe. You'll get a final decision after these tests are done, which is usually after a few weeks, but it will depend on the type of test.
- A liver transplant isn't suitable for you right now. You may have some other form of treatment first and see if you improve, or you may need to work on your fitness or change your alcohol or drug use. You can then be assessed again, usually in a few weeks.
- A liver transplant isn't an option for you, which your transplant team will explain.

The transplant assessment must show that your life expectancy with a liver transplant will be more than your life expectancy without one, and that you'll have a better quality of life.

Questions to ask about the decision

- Will I be added to a waiting list – if so, when?
- Can I just repeat any specific tests that ruled me out for a liver transplant or will I need to have a whole new assessment?
- What are my treatment options if I'm not approved for a liver transplant?
- Can I get a second opinion on my transplant assessment?
- What will happen next?
- Who can I speak to about my results?

What happens next

If you're eligible for a liver transplant

If the transplant team decide you're suitable for a liver transplant and need one soon, they'll ask if you want to be placed on the waiting list. This is a list of everyone in your local area who needs a liver transplant and donors are matched to these.

If you're well enough, you can stay at home while you wait to be matched to a donor. Be prepared to get a call at any time to say that a liver is available. You'll then need to go into the liver transplant unit and may have your operation.

Your options if you're not eligible

If you are not approved for a liver transplant, your transplant team will ask you:

- to have regular check-ups to monitor your condition – the assessment can be repeated if your condition changes
- if you want a second opinion – another transplant team can do an assessment to see if they agree with the original decision

Depending on your health and the liver condition you have, there may be treatments to help control your symptoms. And there are people you can talk to, to support you and help you going forward.

For advice on planning for your future if you're not approved for a liver transplant, including getting emotional support, read our booklet Thinking ahead.

Understanding donors

Most livers used in liver transplant operations come from donors who have died. But sometimes a portion of a liver may be taken from a living donor. People who donate part of their liver can live a healthy life with the liver that's left.

A donated liver may be a whole liver, a reduced liver or a split liver.

- A **whole liver** is exactly as you'd imagine, the entire liver.
- A **reduced liver** is when only a part of the liver is used. This is more common in liver transplants in children.
- A **split liver** is when either a right or left lobe is used. Usually, the larger right lobe transplants are used for adult recipients, and the smaller left lobe is used for children, or an adult with a small body size.

A healthy liver is the only organ in the body that can re-grow a lost part, which is why a living donor can donate part of their liver.

The donor liver

There will be some choices to make about the donor liver before you sign a consent form to have a liver transplant.

If your donor liver is from a person who has died, it will most commonly be after brain death or, less often, circulatory death.

- Donation after brain death (DBD) means the person has been declared dead through brain testing.
- Donation after circulatory death (DCD) means the person was declared dead after their heart stopped beating. This can potentially have more risk because the supply of blood, oxygen and essential nutrients to the liver is interrupted when the donor's heart stops beating. However, livers can be preserved in what's called a perfusion machine and this technology is developing. You might like to ask your transplant team what they use in your centre.

There are other risks to consider. Some livers are likely to work for longer than others, for example because of health problems the donor had. It's also possible for diseases to be passed to you through a donor liver. All donated livers carry some risk, but generally this is much lower than the risks of your liver disease.

Your transplant team will talk you through your choices and explain what these could mean for you. This is your personal choice and they will support you whatever you decide to do.

How you're matched to a donor

DBD livers are matched to people using a set of criteria called the Transplant Benefit Score (TBS).

The TBS takes into account 7 characteristics from the donor, like their age and existing health conditions, such as diabetes, and blood group. These are matched with 21 characteristics from you including your age and health conditions, and other things that were measured in your transplant assessment. Ask your transplant team to go through the criteria with you.

When a DBD liver becomes available it will go to the person with the highest TBS score. But the final decision to accept the organ still rests with you and your transplant surgeon.

DCD livers are matched to people by transplant teams based on things including your blood group, size, weight, need and waiting time.

The waiting list isn't like being in a queue where everyone is seen in a set order. The liver is matched to the person who needs it most at that time and who will get the most benefit from that particular liver. The right liver goes to the right person at the right time.

Waiting for a transplant

It can be a nervous time waiting for a liver transplant but there are some things you can take control of so you're prepared when the call comes.

Take care of yourself

If you're at home waiting for a liver transplant, try to keep yourself in the best of health so you're ready for the operation when it comes. If you need advice or support, speak to your transplant team.

- Make sure you attend all your hospital appointments, including consultations and scans. You'll also need to go to your GP to have monthly blood tests so your transplant coordinator can update your transplant waiting list records.
- Take all your medicines as instructed. And speak to your team before starting any new medicines, including ones prescribed by a doctor as well as ones you buy over the counter.
- Eat a well-balanced diet. Your hospital can give you advice or visit our website to read or download information about eating well for a healthy liver.
  britishlivertrust.org.uk/balanced-diet
- Do some regular physical activity. This will make sure you're as fit as possible before your operation and will do better after it. Pick something you enjoy or ask your team for ideas.
- Don't smoke. If you smoke it will affect the chances of your surgery being a success.
- Don't drink alcohol or use drugs.

Waiting for a transplant (continued)

Be ready

Make sure you organise things in advance so you're ready for when the call comes. Here are just a few suggestions – ask your transplant team for more.

- Keep your transplant team up to date. Make sure your transplant coordinator has your current contact details and if anything changes, let them know. Also tell them if anything changes with your personal life or health, such as if you get an infection, or you take any new medicines.
- Talk to your transplant team about how you will get to hospital when you get the call to have a liver transplant. You may wish to make your own way to hospital. If you need hospital transport this should be available but you'll need to let your team know in advance.
- Pack your things so you have a bag ready to grab and go.
- Arrange childcare, pet care, or other responsibilities. Have some plans set up with someone who can help at short notice.
- If you work, let your employer know your situation and that you may need to take leave at short notice.

Questions to ask

- How long will I be on the waiting list – could I be taken off it for any reason?
- How much notice will I be given if a donor is found?
- Can I eat or drink anything before I come into the transplant centre? – what if I had just eaten before the call came through?
- Do I have a good chance of a new liver for my circumstances?
- What support is available while I'm on the waiting list?

What to expect from your transplant team

You'll have a regular review with your transplant team, every 6 weeks or so, while you're on the waiting list to check your health and that a liver transplant is still a safe and effective option for you. You'll have some of the tests again as part of these reviews.

You'll go into hospital as an outpatient to have some health checks. They'll keep you updated about your health and if there's anything you need to do. For example, if you get an infection, it's important to get treatment.

Talking to others who are in a similar situation or who have already had a transplant can be helpful. Some hospitals have their own support groups or mentors.

"I love the British Liver Trust support groups, because the people there know what it's like, what you are going through. You can ask anything, find out if someone else has had the same thing happen, or ask what to expect. Just knowing someone is there and someone will answer your question is a huge relief. It's a big part of helping me to cope."

Elsbeth has recently had a liver transplant.

Being taken off the waiting list

Sometimes you can be taken off the liver transplant list, and this may be temporary or permanent. This can be for a number of reasons.

You may wish to temporarily take yourself off the list if you have a family function, such as a wedding, to attend, or want to go on holiday. Your transplant team will allow you to take a break but it's important to let your transplant coordinator know how long this will be for.

If you have alcohol-related liver disease and your transplant team has advised you not to drink but you do, you must contact your addictions nurse or transplant centre for advice. If you don't tell your team what is happening and are found to be using alcohol, you'll usually be removed from the waiting list at that centre.

Sometimes you may be offered a second opinion at another centre. If you're able to demonstrate that you have since made changes to support lifelong abstinence, you could be given another chance. The most important thing is that you're open and honest with your team so they can support you in the best way possible.

If your condition gets better or worse you might need to be removed from the list while your need for a transplant is reassessed. This can also happen if you develop a related condition, such as a new liver cancer.

If you get another unrelated health condition, you may be removed temporarily. Your transplant team will talk things through with you in your reviews.

This can be a very difficult and anxious time. There are a number of support services that can help you. We have a helpline, online community and a range of support groups to help answer questions, share experiences, or just listen. britishlivertrust.org.uk/support

There are other organisations that can provide mental health support such as Mind and Samaritans. See the information on useful websites at the end of this booklet.

What happens when a donor is found

Once a donor is found for you, your transplant team will contact you. This can be at any time, day or night. You'll need to go to the transplant centre straight away, but safely.

While you may be excited a match has been found, all organs from donors carry some degree of risk so this must be balanced against the benefits of having the liver transplant, and the risks of waiting for another donor. Your surgeon will make the final decision on whether the liver is the right match for you.

For detailed information about what will happen next, including what will happen when you arrive at hospital, read our booklet
Your guide to having a liver transplant operation.

Useful words

Acute liver failure – when your liver suddenly stops working properly.

Balanced diet – A diet with the right amounts of all the different nutrients your body needs to stay healthy.

Chronic – An illness that lasts a long time (more than six months) and possibly for the rest of a person's life.

Cirrhosis (also known as end-stage liver disease) – A serious stage of liver disease where the liver has a lot of damage and scar tissue. This means it can no longer repair itself or grow new cells properly.

Hepatocellular carcinoma (HCC) – cancer that develops in the liver itself.

Transplant Benefit Score (TBS) – a scoring system used to match donor livers to patients. Read more on page 23.

British Liver Trust information and resources

Scan the code or visit **britishlivertrust.org.uk/transplants** to read and download all our information about liver transplants for patients. This includes detailed advice on having a liver transplant and life after a liver transplant, as well as questions to ask your doctor about transplants.

Useful websites

NHS Blood and Transplant liver transplant resources
www.nhsbt.nhs.uk/organ-transplantation/liver
Information about transplant centres and care and support.

NHS nhs.uk/conditions/liver-transplant/who-can-have-it/
Information on liver transplant assessment.

Samaritans samaritans.org/ or call 116 123 for free.
Samaritans are there to listen to whatever is troubling you, no matter how big or small. You can call, text or email them 24 hours a day, every day.

Mind mind.org.uk/
Information, advice and support for anyone who is having a problem with their mental health.

Special thanks

All our publications are reviewed by medical experts and people living with liver disease. We welcome your comments on this booklet, please email publications@britishlivertrust.org.uk

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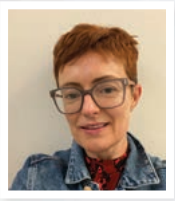
About the British Liver Trust

The British Liver Trust is the leading UK charity for all adults affected by liver disease. We are entirely funded by donations, including gifts in wills. Our mission is to transform liver health by improving awareness, prevention, care and support.

Make your gift online today at
britishlivertrust.org.uk/donate



"It's more than just scans and tests - the assessment team spend time looking at the quality of your life.

Emotional, mental and physical wellbeing are critical to the operation as well, so time spent with the dietician and physio play a part in the diagnosis and they offer great support.

It is all about ensuring you are as healthy as possible ahead of the surgery to give yourself the best chance of recovery."

Lou, who has Budd Chiari syndrome, has been assessed for a liver transplant.

Website: britishlivertrust.org.uk
Nurse-led helpline: 0800 652 7330
Online community: healthunlocked.com/britishlivertrust
Office: 01425 481 320 **Email:** info@britishlivertrust.org.uk

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