Life after liver transplant

Your guide to life after liver transplant

BRITISH LIVER TRUST

Raising awareness, transforming lives

Contents

"If you have any problems or worries, talk to your transplant team. Lots of people have a few bumps along the road, most of the time they can be sorted out. The sooner you let your team know about any issues, the better."

Katie Quist, Lead Nurse Liver, Royal Free Hospital

This booklet will help you understand more about life after liver transplant and give you advice on what you can do to give your new liver the best chance of success. 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 www.britishlivertrust.org.uk/transplants

The British Liver Trust thank Gilead for their kind donation to support the development of this booklet. Gilead have had no influence in the initiation, development or editorial content of this project.

What to expect from your transplant team after a liver transplant

After you've had a liver transplant and been sent home from hospital, you'll need to return for regular appointments at the liver transplant centre. For the first 2 to 3 months, these will probably be once a week. You'll then go less often as you recover – usually every few months, and then once a year.

Your transplant team is made up of a team of specialists that may include surgeons, hepatologists (specialist liver doctors), liver transplant coordinators, a dietician, pharmacist, social worker and a psychiatrist or specialist addictions nurse. The team members may be different to those you saw before your liver transplant.

Your transplant doctors will check your general health and how your liver is working at your check-up appointments, as well as if you have any complications from your surgery. If you have any questions during your recovery, such as what you can and can't do, contact your transplant team. They are there to help you and can offer advice and support to help you get on with life after liver transplant.

What to tell your medical team

Let your transplant team know if there are any changes to your health or you get any new symptoms. These could be a warning sign of complications such as those on pages 6 and 7.

If you have complications you may have:

- a fever
- extreme tiredness
- yellow-looking eyes and skin (jaundice), this can be hard to notice on black or brown skin
- pain in your tummy
- itchy skin
- tremor (trembling or shaking)
- blurred vision
- chills or feeling very hot
- a really bad headache
- diarrhoea
- vomiting
- shortness of breath
- chest pain
- not peeing much, or at all, or very dark pee

Ask your transplant team what else to look out for.

It's important to tell them how you are recovering and how you are getting on with taking all your medicines. The team is there to support you. If you had a liver transplant to treat alcohol-related liver disease and are finding it difficult not to drink, for example, it's important to tell your team so they can give you the right help and support.

What to expect from your transplant team after a liver transplant (continued)

Complications

There are some potential complications of liver transplant that you'll need to be aware of that may happen after you get home.

- **Infections**

Infections happen in around 2 out of 3 people who have a transplant. The immunosuppressant medicines you are taking make it much harder for your body to fight them off. Infections could be bacterial such as E. coli, viral such as cytomegalovirus (CMV), or fungal such as Candida.

Finding and treating infections quickly and stopping you getting them where possible is an important part of your transplant team's job. Look out for symptoms such as fever and shivers and tell your transplant team if you think something is wrong.

You might be given antibiotics or other medicines to stop you getting an infection in the first place. This is called prophylaxis. You can read more about medicines to stop you getting infections on pages 15 and 16.

- **Bile duct problems (biliary complications)**

The join between the two bile ducts (the duct coming out of the donor liver and your duct) may leak. Or scar tissue may cause a narrowing around the ducts and affect the flow of bile. This is called a biliary stricture.

They can usually be treated during an endoscopy so most people won't need surgery. Your doctor uses a very long and narrow tube (endoscope) with a light and camera to look at your liver. They can often repair the problem at the same time, for example by using a small tube called a stent to hold the bile duct open.

Less often you may get a more serious complication called ischemic cholangiopathy. This happens when the bile ducts aren't getting enough blood, possibly due to a blood clot.

- **Disease recurrence**

Sometimes your liver disease can come back after a transplant and damage your new liver. The chance of this happening depends on the type of liver disease. If it can't be treated, you may need to have another liver transplant. Ask your liver transplant team for information.

- **Rejection**

Your body might attack your new liver because it's not a part of you. Your immunosuppression medicines help stop this happening. It's important to remember that rejection isn't all or nothing. If your body starts to reject your liver this can usually be stopped. So it's important to tell your team straight away if you think something is wrong.

Living with immunosuppression

You'll need to take medicines after your operation to lower your immune system and reduce the chance of your body rejecting your new liver. These are called immunosuppressants and you'll usually need to take them for the rest of your life.

Most people take 2 or 3 different immunosuppressants. Your transplant doctors and liver pharmacists will tell you which types of immunosuppressant you'll take and give you detailed information about how to take them. It is very important to follow these instructions.

If you have any problems with your medicines, your team may be able to make changes to your immunosuppression medicines, so make sure you tell them.

If you miss any doses or are struggling to remember to take your medicines, tell your liver transplant team straight away. They may be able to help. For example, they might be able to change the time you take them, so it coincides with something you'll do every day (eg mealtimes or going to bed). There are also smartphone apps that you can use to remind you when to take your medicines and how much to take.

For detailed information about what medicines you need to take after a liver transplant, including tips on how to remember to take them, read our medicine planning chart and instructions.

Risks

Immunosuppressants may give you some side-effects, such as headaches, shaking (tremor), or a rash, but it depends on which medicine you take.

Immunosuppressants can also cause more serious problems, such as:

- increase your risk of some cancers, such as skin cancer
- put you at higher risk of infections
- weaken your bones
- damage your kidneys.

The information on diet, vaccinations and screening on pages 10 to 13 will help you manage these risks. And your transplant team will give you advice and monitor your health to check for any problems.

Sun safety

Protect your skin from too much sun, in the UK as well as abroad. Spend time in the shade, cover up with clothing, and use a high factor sunscreen with good UVA protection.

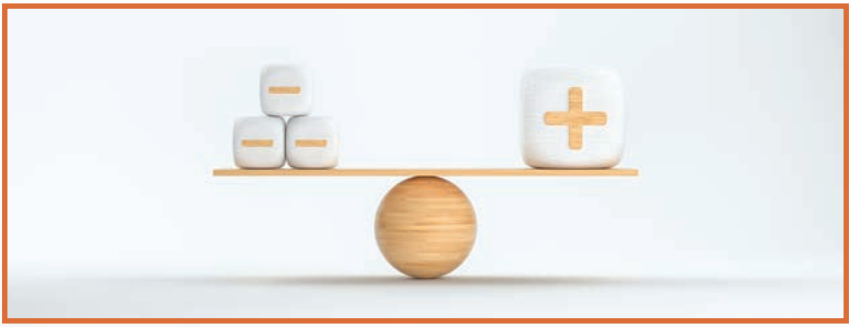
Living with immunosuppression (continued)

Your diet

You may need to make some adjustments to your diet when you take immunosuppressants. Your team can give you information on foods to avoid or have less of. For example, grapefruit can affect how well some immunosuppressants work. So ideally don't have any, and never within two hours of taking your medicines.

Immunosuppressants lower your immunity, so it's best not to eat unpasteurised milk or cheeses, or raw or undercooked meat, fish and seafood.

Particularly during the first three months after your transplant, it is important that you avoid eating foods that may contain bacteria such as listeria, salmonella or E.coli. You might be more vulnerable to food poisoning and there can be problems while you are on high doses of anti-rejection drugs.



Foods that could contain listeria and other bacteria include:

- unpasteurised milk
- unpasteurised cheese and soft cheese such as feta, brie, camembert and blue vein cheese
- pâté
- live yoghurt
- food that contains raw egg, such as home-made mayonnaise
- soft serve ice creams
- refrigerated smoked seafood and fish
- shellfish
- unwashed salads
- deli meats

It's common to put on weight after a liver transplant. This can be a side effect of your medicines, but can also happen if your appetite improves with your health. It's important to eat well and keep to a healthy weight as it will help you to recover from your liver transplant. Your dietitian may advise you to cut down on foods that are high in salt, cholesterol, fat or sugar. If you need help with losing weight or are unsure about what to eat, ask your transplant team for advice.

Living with immunosuppression (continued)

Vaccinations

Make sure you have any vaccinations your GP offers you, such as the flu and COVID jabs. Catching flu may affect the success of your liver transplant so it's even more important to get it.

The timing of vaccines after a liver transplant is important. If you are due any vaccines, let your liver transplant team know so they can advise you.

The only vaccinations you can't have after a liver transplant are live vaccines. These are vaccines that contain a weakened form of the virus that causes a disease. Your immune system won't be able to cope with this.

If you're unsure about taking a vaccine and if it's live or not, ask your transplant team or GP.

"It took several months to recover energy and for the brain fog to dissipate and I'd say I didn't declare myself as completely back to normal until a full two years on, but I regard my transplant as an operation that happened once and life now is great."

Natasha was put on the liver transplant waiting list when doctors realised her liver was so large it was covering her heart.

Screening

Taking immunosuppressants can make you more likely to pick up certain infections so you may need to be screened for these at your check-ups. Or if you had an infection such as viral hepatitis before your transplant, your new liver will be screened to check for the virus.

Accept invitations from your GP to take part in national screening programmes, such as for breast and bowel cancer. This is especially important for cervical cancer screening, sometimes called a smear test.

Some immunosuppressants increase the risk of getting a virus called human papillomavirus (HPV) that can lead to cervical cancer. So it's a good idea to take part in screening, which helps prevent it from developing. Women are invited every few years, depending on their age. Trans men can be screened too. If you are registered as male with your GP you won't be invited automatically. Ask your GP, or a local sexual health or family planning clinic, to arrange cervical screening for you.

Your medicines

You'll need to take a number of medicines to keep you well after a liver transplant. Your transplant team will let you know how long you'll need to take these for.

Here is a summary of medicines but you may need to take more. The instructions for how to take your medicines may vary – check what you need to do with your transplant team. Read the patient information leaflets for information about your medicines too, including information on potential side-effects.

If you forget to take any of your medicines, contact your transplant centre straightaway.

Immunosuppressants

Purpose: to stop your body rejecting your liver.
Example of medicines:
Tacrolimus (Adoport), cyclosporin (Neoral), mycophenolate
How to take: As capsules, twice a day.

- Swallow tacrolimus and cyclosporin with a drink (preferably water), ideally on an empty stomach or at least an hour before a meal, or 2 to 3 hours after a meal.
- Take mycophenolate with food.

Special instructions:

- Don't take tacrolimus or cyclosporin on the day of any clinic appointments until after you've had blood tests.
- Do not have any grapefruit, and never within two hours of taking your medicines.

Steroids

Purpose: to stop your body rejecting your liver.
Example of medicines: Prednisolone
How to take: As tablets, once a day. Take them with food.
Special instructions:

- Your dose you are prescribed may change over time. This will need to be a gradual change – don't stop taking them unless your transplant team has told you to stop.

Antibiotics

Purpose: to reduce your risk of getting a bacterial infection.
How to take: Follow the instructions your transplant centre gives you.

Antiviral medicines

Purpose: to reduce your risk of getting a viral infection.
Example of medicines: Valganciclovir
How to take: Follow the instructions your transplant centre gives you on how often to take antiviral medicines. Take them with food.
Special instructions:

- If you handle broken tablets, wash your hands straight away.

Your medicines (continued)

Antifungal medicines

Purpose: to reduce your risk of getting fungal infection.
Example of medicines: Nystatin
How to take: As liquid drops, four times a day.
Drop the liquid in your mouth and rinse it around your mouth before you swallow.
Special instructions:

- Don't eat or drink anything for 15 minutes after you take it.

Antihypertensives

Purpose: to lower your blood pressure as some immunosuppressants can raise this.
How to take: Follow the instructions your transplant centre gives you.

Anti-acids

Purpose: to protect your stomach because some immunosuppressants can irritate your stomach lining.
Example of medicines: Ranitidine and Omeprazole
How to take: As capsules or tablets, twice a day.

Painkillers

Purpose: to ease any pain in the first few months after your operation.
Example of medicines: Paracetamol and tramadol
How to take: As capsules or tablets, four times a day.
Special instructions:

- Tramadol – don't take more than the recommended dose, and take the capsules whole (don't break them in two or chew them), with a drink, not with food.
- Paracetamol – don't take more than the recommended dose, and take care not to have with any other products that contain paracetamol (such as cold medicines).

Anticoagulant medicines

Purpose: to thin your blood to prevent clots.
Example of medicines: Heparin, warfarin and aspirin
How to take: Heparin is an injection that you have twice a day after your operation. Then you move on to taking warfarin tablets once a day. Aspirin is in the form of tablets that you take once a day, with food.
Special instructions:

- Take warfarin at the same time every day. Don't eat cranberries or drink cranberry juice, tea, or alcohol. You'll need to have a blood test every week while you take warfarin. You will also be given a medical alert card which you should carry with you all the time.

Your medicines (continued)

Other medicines

You may need to take other medicines to control health conditions, such as statins or beta blockers for heart disease. Or medicines to lower your blood sugar levels if you live with diabetes as immunosuppressants can raise this.

Do not take any medicines without speaking to your transplant team first to check they are suitable for you. This includes prescribed and non-prescribed medicines, ones you buy at the chemist, and any herbal remedies.

Side-effects

All medicines can have side-effects, some more troublesome than others. The potential side-effects are listed in the patient information leaflet for each of your medicines. If you notice any side-effects, let your transplant centre know.

How to take your medicines

It may feel overwhelming to take all these different medicines but it's important to keep you well. Your doctors or pharmacist will let you know how to take them, when and how often. Follow their instructions. You might find it helpful to write down some notes – you could use the space below. And put reminders in your phone.

For detailed information about what medicines you need to take after a liver transplant, including tips on how to remember to take them, read our medicine planning chart and instructions.

Notes

Name of medicine: .....
Time(s) to take it: .....
Dose (one tablet or more?): .....
Potential side-effects: .....

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Life after liver transplant

A liver transplant is a major operation and the recovery process can be long (up to a year). You'll be supported by a range of specialist health professionals during your recovery, and going forward. Most people are eventually able to return to most of their normal activities after a liver transplant, and have a good quality of life.

Here's roughly how long it will take to get back to some activities.

Activity	Time after your operation
Light exercise	Straight away. Walk a little every day and as you recover, go for longer.
Moderate exercise (for example, jogging, swimming or cycling)	8 weeks. But don't play any contact sports such as rugby.
Drive	Around 3 months. Check with your surgeon.

Go on holiday	At least 6 months. You'll need to wait at least this long to go out of the country and it may be longer depending on your recovery. You can go on a staycation in the UK sooner than this. Always check with your transplant team and arrange your trip around your check-up appointments.
Return to work	It will depend on your individual circumstances. If you worked before your liver transplant, you can usually go back within 3 to 6 months after your operation. But it depends on your job and how physical it is. Check with your transplant team.

Common questions about life after liver transplant

Here are some common questions about life after liver transplant. Ask your transplant team if you have more.

Can I drink alcohol after liver transplant?
If you had a liver transplant because of alcohol-related liver disease, you'll have committed to life-long abstinence from alcohol. A donor liver is likely to be more easily damaged by alcohol than your own liver. So even if you didn't have a liver transplant for this reason, you should still take care to only drink a little, if you decide to drink at all.

When can I have sex after liver transplant?
You can have sex again as soon as your wound has healed and you feel ready.

Can I have a baby after liver transplant?
Many women have successful pregnancies after a liver transplant. It's best to seek advice before you get pregnant.

Some medicines, such as mycophenolate, have been linked to problems with pregnancy when taken by the mother or father. So it is important to have safely changed to a different drug first.

When you get pregnant you will need extra monitoring and specialist care.

Can I contact my donor's family to thank them?

Yes, you can write a letter, which can go to your transplant centre, which will pass it on. Or the Donor Family Care Service team can do this for you.

Can I claim benefits?

If you can't work due to your liver condition, you may be able to claim benefits. Contact the Department for Work and Pensions and if you need help navigating the application process, there are a number of specialist charities and organisations, such as Citizens Advice.

Support

It can be a long road to recovery after liver transplant and there will likely be challenges along the way. There are a number of support services online that can help you through this time.

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

And 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.

Useful words

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

Bile – a yellowy green fluid that helps your body to digest foods that contain fat and cholesterol. It's made in your liver and stored in your gallbladder.

Bile ducts – tubes that connect your liver to your gallbladder and small bowel.

Jaundice – a symptom of liver damage that makes your skin and eyes look yellow. It can be harder to see on brown or black skin.

Immunosuppressants – medicines that lower your immune system to prevent it attacking your new liver.

Statins – medicines to reduce the amount of cholesterol in your blood that help treat heart and circulatory disease.

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.

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/recovery
Information on recovering from a liver transplant.

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

We would like to thank:

- Our patient focus group, reviewers and case studies.
- Katie Quist, Lead Nurse Liver, Royal Free Hospital.
- Paul McKie, Specialist Social Worker (Liver Transplant & Liver Transition), King's College Hospital.
- Louise Hogg, Advanced Clinical Pharmacist (Hepatology), Leeds Teaching Hospitals NHS Trust.
- Doug Thorburn, Consultant Hepatologist, Royal Free Hospital.
- Ruben Sanchez Aldehuelo, Consultant Hepatologist, Hospital Universitario Ramon y Cajal, Madrid.

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

"After my operation a scary episode of acute rejection threatened my progress but was quickly sorted out with some high dose steroids, and I was released two weeks post-transplant.

Then it was getting to grips with an array of new medicines (around 15 pills per day), learning to walk, wash and sleep with my various appendages, and satisfying my enormous steroid induced appetite.

Fast forward 10 years and I'm on two types of immunosuppressant medications. My main side effects are occasional tremor, insomnia, and frequent urinary tract infections – all of which are a small price to pay for otherwise feeling really healthy.

From a former PE-avoider, I now love to exercise and be active! I'm determined to make the most of the life I have been given."

Anna had a liver transplant in 2012, as a biology student, and now works in clinical research in the NHS

Website: www.britishlivertrust.org.uk
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TP-LAT/08/22