

Family and carers

Your guide to supporting someone through transplant



BRITISH
LIVER
TRUST

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transforming lives*

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“I’m lucky to have a loving and close family and it is them who did the hard work, supporting, being positive and just being themselves. They were all with me at every step.”

Patrick was diagnosed with liver cancer and had a liver transplant.

This booklet will help you understand more about how to support someone through the liver transplant process from assessment, to life after the operation. It will also give you advice about how to access support for yourself.

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

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Liver transplant assessment

Liver transplant assessment is a process to see if a liver transplant operation is possible for a person, and the best treatment option for them. They'll need to have this assessment before they can go on a waiting list for a liver.

The process can vary between liver transplant centres but it will involve having a number of tests over about 2 days. The person may be admitted to hospital to have the tests or they may be able to stay at home but go to hospital for each test.

Talk to your transplant centre about which option will work best as you may need to drive them to the hospital or go along for the tests (depending on current infection control measures in place) so it will depend on your availability too.



Support is an essential part of the transplant process and the transplant team will need to be satisfied your family member has people to help them before they're considered for a liver transplant. If you would like to be included in the conversation at every stage, ask your family member to request this from their transplant team.

The transplant team will make sure that you get the right information. And they'll give you access to a range of support, including services that offer psychological, social and spiritual/cultural support. There's usually a dedicated transplant healthcare professional who's on the end of a phone 24/7 for patients and carers. And there's ongoing contact with the transplant centre, specialist nurses, and a social worker. You won't be alone getting your family member through this.

Getting the call

Once a matching liver donor is found, your transplant team will contact you. This can be at any time, day or night. Your family member will need to go to the transplant centre straight away. It's probably best that you drive if possible as they may feel anxious about what lies ahead.

It's a good idea to plan for the call in advance. Make sure you have arrangements in place so you can drop everything and go.

For detailed information about liver assessment, including getting on the waiting list and what happens next, read our booklet

Your guide to being assessed for a liver transplant.

Ideas for how to prepare for the call

- Stay close to home so you can get to hospital quickly when the call comes. Your family member can temporarily take themselves off the liver transplant waiting list if you have a family function, such as a wedding, to attend, or want to go on holiday. But it's important they let your transplant coordinator know how long this will be for.
- Have a pet sitter on standby and make arrangements for childcare or other responsibilities.
- Pack a bag for your family member and you. Remember your phone charger (one with a long lead is best).
- Stock up. Fill your freezer so you have meals ready.
- Keep your petrol tank topped up.
- Avoid any unnecessary stress and stops on the way to the hospital.
- If you work, let your employer know about your situation and that you may need to take leave at short notice.



The liver transplant operation

Your family member will have some tests before the operation. The operation can only go ahead once the surgeon and anaesthetist are satisfied that they're well enough to have the operation, and that the donor liver is right for them.

Sometimes, the operation may not be able to go ahead. In fact, it's normal to experience one or more false calls before you have a liver transplant. This can be a difficult time for you all and there are support services that can help you. We have a helpline and online community where you can connect with people who may have been through a similar experience.

britishlivertrust.org.uk/support

If the operation does go ahead, the surgeon will remove the liver and put the donor liver in its place. The operation usually takes about 5 to 8 hours but can be longer. Your transplant coordinator will keep in touch with you throughout the operation. Your family member will recover in the intensive care unit, usually for a few days, until they're well enough to go to a hospital ward. Once on the ward, they will be supported by a range of health professionals to help them recover and prepare to go home. This is usually after a week or two but it will depend on how well they recover.

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

Life after liver transplant

A liver transplant is a major operation and the recovery process can be long (up to a year). Your family member will need to commit to their own health after the operation. This will of course impact you too.

For example, they'll need to take medicines for the rest of their life, which they may need support with. And they'll have regular appointments with their transplant team. To start with, these will probably be once a week for the first 2 or 3 months. They'll then go less often as they recover – usually every few months or once a year. They won't be able to drive for a few months so you may need to take them. If you don't drive, see if there are some public transport options, or book a taxi.



You'll be supported by a range of specialist health professionals during their 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. Remember that this support extends to you too.

Caring for someone can take its toll. You and your family member can get support with your mental health. Speak to your GP, who can refer you. In England and Wales you can also refer yourself into a service.

England (IAPT - Improving Access to Psychological Therapies)

visit nhs.uk/service-search/mental-health

Wales (SilverCloud)

visit nhs.wales.silvercloudhealth.com/signup



“Don’t wait until you’re not coping to ask for help. People are there for you, there’s organisations that are fantastic and they know all about what you’re going through.”

Gill’s husband, Billy was diagnosed with liver cancer and had a liver transplant.

For detailed information about life after liver transplant, including what patients need to do and how soon they will recover, read our booklet

Your guide to life after liver transplant.

British Liver Trust information and resources



Scan the code below or visit
www.britishlivertrust.org.uk/transplants
to read and download all our information
about liver transplants. This includes
detailed advice on having a liver transplant
and life after a liver transplant.

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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Useful websites

Carers UK carersuk.org

Practical and emotional support.

Carers Trust carers.org

Support, services and recognition for anyone living with the challenges of caring.

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.

Carer's Allowance gov.uk/browse/benefits

If you care for someone at least 35 hours a week, you may be eligible for carer's allowance.

For more information about benefits and financial support for yourself or your family member, visit our website.

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



“A liver transplant can affect the whole family and it’s a process you all go through together. It’s important to get the support you need to help someone through what can be a long process.”

Katie Quist, Lead Nurse Liver, Royal Free Hospital

Website: www.britishlivertrust.org.uk

Nurse-led helpline: 0800 652 7330

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