

Could I be a
living liver donor?



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When Geraldine was told by doctors she needed a liver transplant she feared she would face a long wait for a donor organ. But when she mentioned that she was a twin her doctor suggested her sister, Annemarie, could be a match for a living liver lobe transplant.



"I did not think twice about donating part of my liver to my sister when she became ill."

Living liver donor Annemarie

A living liver donor is a person who gives part of their liver to someone with liver failure who needs a transplant (the recipient). This could be a friend or family member, or someone they do not already know.

Living donor liver transplantation has been successfully performed in the UK since 1995.

A liver transplant operation is life saving surgery for patients with end stage liver disease. It is also performed for some patients with primary liver cancer and children with metabolic diseases (affecting the chemical processes within the body). Volunteering to offer part of your liver is a wonderful thing to do, but it is also an important decision and there are many things for you to consider. We hope this information will answer some of the questions that you may have.

You will find a glossary at the end of this leaflet that will explain some of the more technical terms or abbreviations that are used if these have not been explained in the text itself. These are underlined and coloured blue to help you.

Why do we need more living liver donors?

- Approximately 900 people in the UK undergo liver transplantation every year
- At the end of each year around 600 people with liver disease on the UK transplant list are not transplanted and are still waiting for a liver – and the numbers are growing
- Fifteen to twenty percent of patients on the transplant list die or are removed each year whilst waiting for an organ
- Unfortunately there are simply not enough livers donated by people who have died for these patients
- The average waiting time for a liver transplant from someone who has died (deceased donor) is approximately 137 days (4.5 months). For some people with common blood groups such as O the wait can be 244 days (8 months) as there are more blood group O recipients waiting for a transplant. For patients with end stage liver disease, this is a long time.

Donating part of my liver

Could I volunteer to be a living liver donor?

Healthy people who wish to help a loved one or a stranger with liver disease may volunteer to give part of their liver. Volunteer is the key word – this must be something that you choose to do and feel comfortable doing.

Anyone volunteering will be asked to undertake a series of tests so that the transplant team can be absolutely sure that you are suitable to donate. Your health and safety is of primary concern and it is important to be aware from the start that, even if you want to be a donor, not everyone is suitable and you may be unable to donate.

It is also important to remember that even if you do volunteer, you can change your mind at any point in the process – right up to the time of surgery.

Who can donate?

Most often donors are a close relative of the recipient, such as a family member, partner or good friend. However, people who do not know anyone with liver disease, but who wish to donate, can also provide part of their liver for someone on the transplant list. These people are known as non-directed altruistic donors. To find out more about non-directed altruistic liver donation, you can contact the living donor liver coordinators at St. James Hospital, Leeds or King's College Hospital, London where people have already donated in this way, or contact your closest liver transplant centre for further advice. For all other enquiries, it is best to contact the transplant centre where your intended recipient is being assessed for transplantation. You will find direct line contact numbers for the living donor liver coordinators [here](#).

Is there an age limit for donors?

In England, Wales and Northern Ireland, there is no lower age limit specified in law for a person to be considered as a living liver donor. In Scotland, only people over 16 years of age can be legally considered. However, almost all donors are over 18 years old and children are only considered in very exceptional circumstances, with court approval. Children are not considered as non-directed donors.

There is no fixed upper age limit but donors above the age of 45 years will only be considered if they are exceptionally fit and well. Donors are assessed very carefully and your suitability is considered by a team of professionals at the hospital.

How will I know if I am suitable to donate?

You will undergo a number of tests to check that you are fit and healthy enough to donate.

Some people who wish to donate find that they are not able to do so because of the results of the assessment process. Members of the team involved in your assessment will include doctors, coordinators, psychiatrists and independent assessors. They will guide you through the process every step of the way.

What are the tests like?

The Living Donor Coordinator will guide you through the entire process and explain all of the tests that you need to undertake. These are to make sure you are healthy enough to donate and that your liver is working properly. The tests are generally not painful or invasive (but you will be asked for lots of blood samples along the way). They include scans (some including an injection), urine tests, blood tests, X-rays and heart tracing (through wires attached to sticky pads on your skin) and a special test of liver function.

Your test results will be discussed with you when available. If something unexpected is found then some further tests or assessments may also be needed. It is possible that the tests may show a condition or illness that you did not already know about. If this is the case, this will be discussed with you and appropriate referrals and treatment provided.

Donors also undergo a psychological assessment. This is to ensure that you are of sound mental health, because donating part of your liver can be an emotional process, and the risk of any psychological harm to you must be acceptably small.

You will also be assessed by an Independent Assessor, on behalf of the Human Tissue Authority, who is completely independent from your medical team. This is a one-to-one meeting at the end of the assessment process, where you will be asked about your reasons for donating and your understanding of the process. The Independent Assessor is your advocate and ensures you are not being pressurised into donating, or being paid to do so, which would be against the law, and once they are satisfied about your suitability will ask you to sign a declaration. The Human Tissue Authority needs to approve your donation in order for surgery to take place.

The risks

This information does not cover detailed medical questions; it is designed to give you general information about donating a liver based on the advice of medical professionals and currently accepted guidance in the UK, from the research that is available to them. Your healthcare team will discuss risk with you in more detail and on an individual basis, particularly if there are certain concerns about you or your recipient because of your lifestyle, medical history or demographic, as risk must be considered on an individual basis based upon your individual circumstances.

It is also important to note that research in this area is continually evolving and it is not possible to cover every eventuality. Not every possible consequence of donation has been fully researched.

What are the risks for me?

All operations carry some risk and donating part of your liver is no different. There is a small risk of death for the donor: this is estimated at 1 person in every 200 (for right lobe donation) or 1 in 500 (for left lobe donation).

Most complications are minor and include infections (e.g. chest, wound or urine) and, rarely, bleeding, bile leaks or blood clots.

There is also the risk of the liver transplant procedure failing and this may cause emotional distress if things do not work out as expected.

It is very important for you to consider all these risks and discuss them with your coordinator when you are deciding if living donation is right for you. The risks will be explained to you in more detail as you go through the process.

Are there any long-term risks?

It is possible to live a long and healthy life after liver donation, but this does not protect you from other medical problems that you would have developed in any case.

Risk is relative to the person donating and to individual circumstances and we know that some groups of people may need special consideration. In the long term you will be followed up by the transplant team and this will include annual checks and blood tests.

Am I at risk of developing liver failure?

The risk of developing liver failure with left lateral segment donation is very low; however this risk increases with donation of a larger volume of liver such as the right liver lobe. The assessment process will carefully consider the volume of your remaining liver to minimise this risk. If your medical team feel that you are at an increased risk they will clearly advise you against donation.

Will it shorten my lifespan?

It is important to be aware that research is ongoing into the effects of living donation and we do not yet have a completely full picture. Not every possible consequence of donation has yet been fully researched. Living liver donation will only be considered in very fit and healthy individuals. Donors will be carefully followed up in the long term and this has been proven to be beneficial to the donors.

Will I have to change my lifestyle after donating?

No. However, it is important that all patients who have undergone major abdominal surgery avoid weight gain, smoking and excessive alcohol intake. You should be able to lead a normal, healthy life and return to all your normal activities.

Will donating a liver lobe affect my ability to have children?

You can have children after donating part of your liver, although we advise women against trying to become pregnant for at least 12 months following donation. There is not much data available about pregnancy after liver donation but there is no evidence to suggest an increased risk of complications during pregnancy; we know that many previous donors have had successful pregnancies. A man's fertility will not be affected.



The Ahmed family benefited from a life saving mother to daughter living liver transplant in 2014.

Practical considerations

Will I be covered by my health insurance?

You should check with your insurance company prior to donating. The transplant team is always happy to offer help and advice if your insurance company has any specific questions related to the donation and life-long risk for you.

What if I live in a different part of the UK from the person I am donating to?

You can still donate. However, the donor assessment will take place only at the specialist hospital. The donation will take place in the hospital where the person you are donating to is cared for.

What if I live outside of the UK?

You can still donate to a friend or family member but there are some restrictions on donating to people with whom you have not had a close or previous relationship if you are not resident in the UK. Some preliminary tests can be arranged in your own country to see if you could be a suitable donor. You should contact the living donor coordinator in your recipient's transplant centre for further information and advice. If your first language is not English and you are considered to be a suitable donor, translation support is available for you throughout the detailed assessment process.

How long does the donor assessment process take?

The assessment process usually takes 6-8 weeks; it may take more or less time depending upon the hospital you are being assessed at and the types of tests you require. Wherever possible, the assessment process is tailored around your other commitments.

How much time will I need to take off work?

Most transplant centres will try to arrange the tests and investigations before the operation around your work to minimise disruption to your daily life. The recovery period after the operation usually lasts up to 12 weeks, most donors are able to return to work after 12 weeks.

How will I be able to afford time off work?

There is a UK scheme which enables donors to reclaim necessary expenses such as loss of earnings and travel. However, you should first discuss this with your employer and find out what is available under your (their) terms of employment around Statutory Sick Pay. Please talk to your Living Donor Coordinator about expenses at an early stage of the process if you may need to apply to the scheme as there is some information that you will need to read and an application form to complete. Evidence of your earnings and expenses will also be necessary.

Cultural considerations

What are the cultural views on living donation?

The UK is increasingly multicultural. If you have any concerns about living donation contact your Community Association Group or community leaders.

What are the religious views on living donation?

Most religions support living donation as they view it as a gift to a loved one. However, if you have any doubt, you should contact your religious leader or place of worship for support and advice.

How long will I be in hospital?

This varies depending on your individual recovery and type of surgery but the average stay is 6-10 days.

How painful will it be?

When you wake up, you will already have been given strong painkillers to help reduce any discomfort after the operation and you will continue to receive pain relief for as long as you need it in hospital. You will also be given painkillers to take with you when you go home.

Will my liver grow back?

The remaining liver has the amazing capacity to enlarge (hypertrophy) and cope with your individual metabolic needs. This process begins almost immediately and can continue for up to 8 weeks.

Will I need to take any medication after donating?

You will need to take painkillers as mentioned above for a short period of time; however, you will not need any long-term medication as a result of liver lobe donation.

What about follow-up?

We will ask you back to the hospital around 4 weeks after donation so we can check that you are recovering and healing well. The living donor team will be in contact with you every year after your donation so they can make sure that you are still fit and healthy after your donation. This also gives you an opportunity to raise any concerns you may have. If you do not live in the UK, you will be advised how to arrange follow-up in your own country before you return home.

Deciding whether donating is right for you

Do some donors have trouble making the decision?

Donating part of your liver is a very personal decision and is not something everyone feels comfortable with. Only you can decide if it's something you would like to volunteer to do. There are many different reasons why people give a part of their liver. Some people make the decision easily and others go through some soul-searching before deciding. Being afraid of donating part of your liver or feeling guilty about not wanting to donate is quite normal. The only 'right' decision is the one that makes you, the potential donor, feel comfortable. Finding out more information about living donation and talking things over with the medical team and your family and friends may help you make this decision.

Can I speak to somebody who has donated?

Sometimes it is useful to talk to someone who has already been through the process to help you make your decision. The coordinator at your local live donor liver transplant centre can arrange this for you.

What if I decide against being a donor?

Volunteering to become a donor is entirely your choice and the journey between volunteering to donate and actually donating can be a difficult and emotional one. Sometimes people decide that donating is not for them part-way through the assessment process. It is important that you remember that you are free to change your mind at any point along the way. The transplant team wants you to be comfortable with the choice you make and will be supportive and respectful of any decision you make along the journey – even if that means not donating.

Please talk to your coordinator at any point in the process if you are not certain that you wish to proceed with the donation.

Who makes the final decision?

Once all the tests have been completed they are assessed by the donor transplant team. The transplant will only take place if both the donor and recipient are willing to proceed and the transplant team is confident that both donor and recipient are healthy enough to go ahead safely.

Will the transplant be successful?

Living donor liver transplantation is usually very successful and comparable to liver transplantation from deceased donors. However, there is no guarantee that the transplant will be successful and in a small number of recipients the transplant can fail and even require re-transplantation. It is important, before going ahead, to consider how you might feel if the transplant is not successful.

Next steps

What is the first thing I should do if I wish to be considered as a living donor?

Should you wish to be considered as a living donor, you should contact the living donor liver coordinator at your nearest transplant centre or the transplant centre where your intended recipient is being assessed for transplantation if you know where that is. You will find direct line contact numbers for the living donor liver coordinators [here](#).

How is living organ donation governed in the UK?

In England, Wales and Northern Ireland the Human Tissue Act 2004, and in Scotland the Human Tissue (Scotland) Act 2006, provide the legal framework for organ and tissue donation in the UK. The Human Tissue Authority (HTA) regulates the donation by living people of solid organs and part organs. The HTA give approval before any living donation can proceed. All donors will be assessed by an Independent Assessor, who is trained and accredited by the HTA, as a routine part of the evaluation process to ensure that all the legal requirements have been met. The law requires that the donor must fully understand the nature and risks of the procedure and that there is no coercion, pressure or payment involved in the donation of the organ or part organ, which is illegal in the UK.



Donating a liver lobe to a child

The average waiting time for a liver transplant (from a deceased donor) for children is 74 days (2.5 months) but for some children the wait can be between 12 to 18 months.

Where a child is involved, living donors are normally a close relative with parents being the most usual donors. Grandparents or siblings can also be considered depending upon their age, aunts, uncles and other family members or close friends may also be able to donate.

Will I be operated on in the same hospital as my child?

This depends upon where your surgery takes place. Some hospitals look after both adults and children whilst others are exclusively for children. Wherever you are, there will be a team of people caring for each of you. The donor assessment and operation will always be performed in an adult transplant centre. This will be nearby if you and your child are cared for in separate hospitals.

If I am the parent and the donor, who will care for my child whilst I am in hospital?

You will need to plan for the care of your child whilst you are in hospital well in advance and your transplant team can help you to do this. In some families the non-donating parent stays with the child but a grandparent, aunt, uncle, or close family friend may be nominated instead. Whoever it is, it needs to be someone both you and your child feel comfortable with and who understands what is involved in being with your child in hospital. You can speak to your child's doctor or nurse about this and they will be able to give you more information to help you decide. It is important to make childcare arrangements for any other children you may have and for some help at home immediately after you leave hospital. There are people who may be able to help you with this and any other practical concerns you may have.

If I am donating, how long will it take me to recover?

Recovery can take up to twelve weeks, depending upon the donor operation and your individual progress. You will need to rest following discharge from hospital and will need to plan in advance for others to help caring for your child and with day-to-day heavy domestic tasks.

Where can I find out more information or advice on Living Liver donation?

For more information on living liver donation you should contact the living donor coordinator at one of the specialist centres for living donor liver transplantation. You can find a list of these on the NHS Blood and Transplant website.

NHS Blood and Transplant

Email enquiries@nhsbt.nhs.uk

Tel: **0300 123 23 23**

Web www.organdonation.nhs.uk

Human Tissue Authority

Finlaison House, 15-17 Furnival Street, London, EC4A 1AB

Email enquiries@hta.gov.uk

Tel **020 7211 3400**

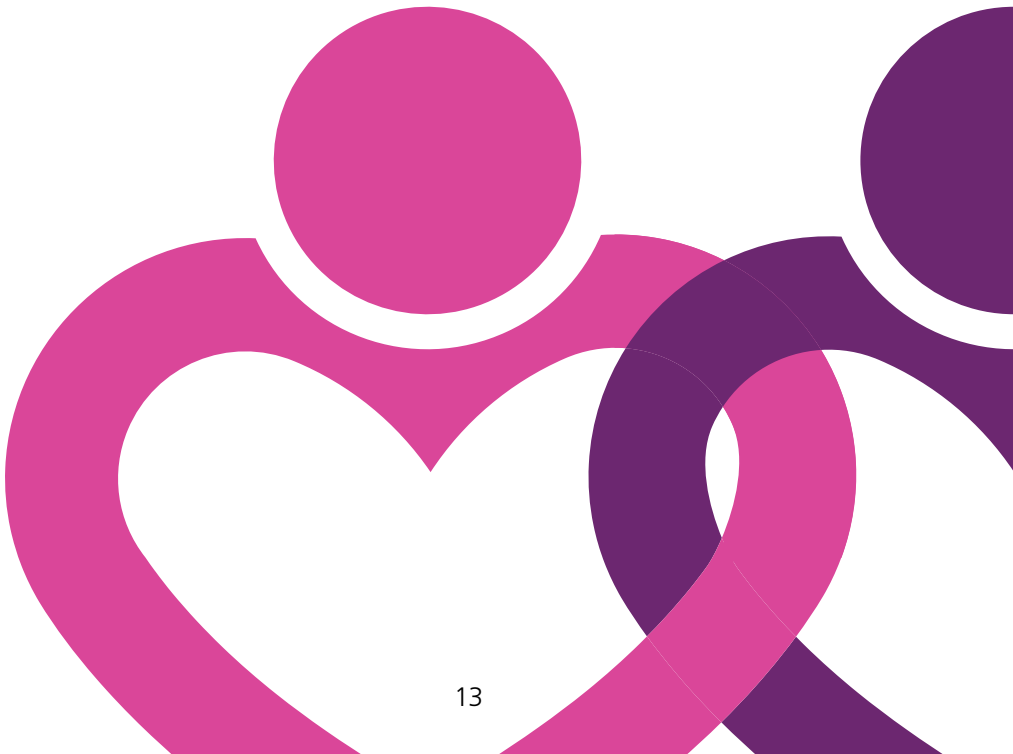
Web www.hta.gov.uk

Living Donation, Scotland:

www.organdonationscotland.org/tell-me-about-living-donation

Living Donation, Northern Ireland:

www.donatelife.co.uk



Glossary of Terms

Deceased donor

A person who donates their organs and tissues for transplantation after their death.

Human Tissue Authority (HTA)

Human Tissue Authority: a regulatory body set up to implement the requirements of the Human Tissue Act (2004).

Human Tissue Act

The Human Tissue Act 2004 for England, Wales and Northern Ireland and the Human Tissue (Scotland) Act 2006 provide the legal framework for organ and tissue donation in the UK. The rules set out by the Human Tissue Authority (HTA) specify certain requirements that must be met before donation from a living donor can take place. All living donor transplant operations must be approved by the HTA following independent assessment.

Independent Assessor (IA)

A trained and accredited person who is independent of the transplant team, who interviews donors and recipients of living organ transplantation in the UK and submits a report to the HTA.

Living Donor Coordinator

A specialist nurse who will be your main point of contact and guide throughout the donation process.

Living liver donor

A person who donates a healthy part (a lobe) of their liver whilst they are alive to someone in need of a transplant.



Transplant List

A UK-wide list of patients waiting for a liver transplant.

NHS Blood and Transplant (NHSBT)

A special health authority of the NHS which is responsible for overseeing the supply of blood, organs and tissues. Within NHSBT the Organ Donation and Transplantation (ODT) Directorate is responsible for ensuring that donated organs and tissues are matched to patients who need a transplant and are used in the fairest way.

Non-directed altruistic donor

A person who donates a healthy organ (part of their liver or one of their kidneys) for transplantation whilst alive but to someone they do not already know.

Recipient

A person with liver disease who receives a liver transplant.

Sources

UK Living Donor Liver Transplantation, BTS/BASL 1st Edition, July 2015.

Guidance for Living Organ Donors on the Human Tissue Authority's Independent Assessment Process, revised June 2015.

Organ donation and religious perspectives, NHSBT, 2009.

NHS Blood and Transplant

NHS Blood and Transplant (NHSBT) saves and improves lives by providing a safe, reliable and efficient supply of blood and associated services to the NHS in England. We are the organ donor organisation for the UK and are responsible for matching and allocating donated organs. We rely on thousands of members of the public who voluntarily donate their blood, organs, tissues and stem cells.

For more information

Visit [blood.co.uk](https://www.blood.co.uk)

Call **0300 123 23 23**