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An introduction to organ donation

Organ donation saves lives. When people donate their organs and tissues for transplant, they can save or improve someone else's life. In the UK, around 6,500 people are waiting for a transplant. Without organ donors, our doctors and nurses can't help them. The stats speak for themselves:

- Three people die every day due to a shortage of people willing to donate organs
- Half a million people die each year, but only around 5,000 people die in circumstances where their organs can be donated

Source: [NHS Blood and Transplant \(https://www.organdonation.nhs.uk/news-and-campaigns/organ-donation-campaigns/\)](https://www.organdonation.nhs.uk/news-and-campaigns/organ-donation-campaigns/).

Some people forget to sign up to the NHS Organ Donor Register (ODR). Others don't feel comfortable with the idea. Whilst many are simply confused. This guide provides you with all the information you need to make the decision on whether to be an organ donor.

Waiting for a transplant explained

Organ transplants are one of the most important achievements of modern medicine. A surgeon's ability to remove healthy organs from a person and transplant them into someone else, whose organs have failed or been injured, is life-saving.

As amazing as transplant are, they don't happen as often as they could. Not everyone is signed up with the NHS ODR, and many relatives aren't willing to donate organs on their loved one's behalf. This means there's always a long waiting list for transplants.

But what does it mean to wait for a transplant? It's a nerve-racking time. Average waiting times can vary, depending on the organ and whether you're a priority patient. Figures from 2015 show that 6,856 patients were on the active waiting list for a transplant. Of these:

- 3,194 have waited less than a year
- 1,584 between 1 and 2 years
- 905 between 2 and 3 years
- 454 between 3 and 4 years
- 208 between 4 and 5 years
- 139 between 5 and 6 years
- 91 between 6 and 7 years
- 281 more than 7 years

Source: [NHS Blood and Transplant \(https://www.organdonation.nhs.uk/news-and-campaigns/news/nhs-blood-and-transplant-reveals-nearly-49-000-people-in-the-uk-have-had-to-wait-for-a-transplant-in-the-last-decade/\)](https://www.organdonation.nhs.uk/news-and-campaigns/news/nhs-blood-and-transplant-reveals-nearly-49-000-people-in-the-uk-have-had-to-wait-for-a-transplant-in-the-last-decade/).

There are even some people too ill to be placed on the waiting list.

Although there were more organ transplants in the UK than ever before in 2015/16, waiting for a transplant is still difficult. For some organs, the outlook is worse than others. The average waiting times for different organs is shown the table below:

Average waiting times on the transplant list in the UK

	Adult	Child
Kidney	1,022 days	316 days
Heart (non-urgent)	1,033 days	357 days
Lung	233 days	-
Liver	137 days	74 days

There's an urgent heart scheme and super urgent liver list for some patients. This is for those in desperate clinical need of a transplant.

The call for a transplant could come at any time, so patients are normally told to have a bag packed and be ready to go into hospital at short notice. But that bag could be in your wardrobe for days, or even years.

When a donor organ becomes available, a computer generates a list of potential patients. There are strict guidelines about who the organ will be given to. Children and young adults are given priority, as it's more likely they'll have longer-term benefits. For older adults, a scoring system is used. It's based on things like:

- How long you've been on the waiting list
- How well matched the donor is in terms of tissue type, blood group and age

Patients on the transplant list shouldn't give up hope. It's important to carry on living life as normal. But that isn't easy. As you'll see shortly, those waiting feel like their lives are on hold and can suffer health problems in the meantime.

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How important is organ donation?

In 2015, a 14-hour film titled "The Wait" was released. It captures a day in the life Simon Howell, a patient waiting for a kidney. The film shows his ongoing struggle, as his day is broken up by four life-saving sessions of dialysis. Simon describes his unbearable fatigue and his family live in constant uncertainty about the future. "I'm in limbo," he says. Only an organ transplant can change that.

At the launch of the film, Sally Johnson, NHS Blood and Transplant Director of Organ Donation and Transplantation, asked people to imagine how they'd feel if someone close to them was waiting for a transplant. "I'm sure we'd all hope an organ would be available to help someone we love – so shouldn't we all pledge to be organ donors so more lives can be saved?"

When you die, your organs could help someone else to live

Waiting too long for a transplant can have severe consequences. In 2015, 466 patients died before they could get a transplant. A further 881 were removed from the transplant waiting list. That's why organ donation is so important – it changes people's lives for the better.

The UK has one of the lowest rates of consent for organ donation in Europe. It reached a high in 2015 at 62%. But it's not enough. You can help.

What it means to register for organ donation

Your organs and tissues can only be used if you want them to be. Joining the ODR lets the right people know you give legal consent for your organs to be used, should you die. You might not want to think about that, but it's important to make your wishes known.

In the UK, around 22 million people have signed onto the ODR. They've made their decision to donate organs and tissues after their death for transplantation. The list is confidential and only used by medical staff to determine if someone wanted to donate.

Amazingly, one donor can save or transform up to nine lives. Many more patients can be helped by the donation of tissues. Transplants are life-changing.

How to register

- Fill in an [online form \(https://www.organdonation.nhs.uk/register-to-donate/\)](https://www.organdonation.nhs.uk/register-to-donate/) – it takes less than two minutes
- Call the NHS's 24-hour donor line on 0300 123 23 23

You've also got the choice to join when you register:

- For a driving licence
- To a GP surgery
- For a European Health Insurance card

When you register, you'll get a donor card. Every day, around three people die who could have benefited from a transplant. Make the difference, and become an organ donor today.

Do you want to donate all organs and tissue?

All

Some

Please select which organs and tissue you wish to donate:

Kidney



Corneas



Heart



Lungs



Liver



Pancreas



Small bowel



Tissue



If you'd like to donate some, but not all of your organs, you can choose this option when registering.

How to make a living donation

You can also become a living kidney, liver or tissue donor. To do this:

- Contact your [local kidney transplant centres](https://www.odt.nhs.uk/transplantation/kidney/kidney-transplant-units/) (<https://www.odt.nhs.uk/transplantation/kidney/kidney-transplant-units/>).
- Contact your [local liver transplant centres](https://nhsbt.dbe.blob.core.windows.net/umbraco-assets/1620/contact-details-for-liver-transplant-centres-july-2016.pdf) (<https://nhsbt.dbe.blob.core.windows.net/umbraco-assets/1620/contact-details-for-liver-transplant-centres-july-2016.pdf>).
- Email: enquiries@nhsbt.nhs.uk (<mailto:enquiries@nhsbt.nhs.uk>).
- Call the National Tissues Referral Centre on 0800 432 0559
- Email: national.referral.centre@nhsbt.nhs.uk (<mailto:national.referral.centre@nhsbt.nhs.uk>).

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Types of donation

Confused about the organ donation opportunities? Let us help.

Donation after death

When you die, you can donate the following:

- Kidneys
- Heart
- Liver
- Lungs
- Pancreas
- Small bowel
- Corneas
- Tissue

This will help someone when their organs aren't functioning properly and they need a transplant. Remember: you can only help if you join the ODR.

Living donation

Living donation is the alternative to waiting for an organ from a deceased donor. Those signed up will be assessed to see whether it's safe for them to donate, and whether their organ is a match for the patient. Living donors could be strangers, family or friends. You can donate:

- **Kidneys.** A healthy person can lead a normal life with one kidney. Around a third of kidney transplants in the UK are from living donors.
- **Liver.** You can give part of your liver to someone with liver failure who needs a transplant. Liver transplant operations are performed on patients with end stage liver disease, primary liver cancer, and children with metabolic diseases.
- **Tissue.** Living donors can donate bone and amniotic membrane – that's part of the placenta. If your baby is delivered by caesarean section, doctors can use it in eye surgeries to help wounds heal fast. You can donate your femoral head if you are having a total hip replacement. Other donated bone is used to restore health and mobility.

How will I know if I'm suitable to be a living donor?

Before you can be a living donor, you will undergo several tests. These check you're fit and healthy enough to donate. The process involves doctors, coordinators, psychiatrists and independent assessors. You'll have a Living Donor Coordinator to guide you through the details.

As a potential donor, you'll be subject to a psychological assessment. Being scared or feeling guilty about doubting your decision is normal. But doctors must ensure you're of sound mental health. Going through a living donation is emotional, and the impact on you has to be acceptably small.

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Are you eligible to be an organ donor?

Anyone can sign up to the organ donation register. Age isn't a barrier – people in their 70s and 80s have become donors and saved lives. In the UK, the oldest living person to donate a kidney was 85. Most medical conditions aren't barriers to donation either.

An introduction to organ donation in the UK

Organ donation has been a priority in the UK for some time. In 2008, the NHS Blood and Transplant department created a new team. They were responsible for increasing the rate of organ donation to 50% by 2013. The group hit its targets.

Encouraged by this success, the NHS is keen to continue improving. The UK Strategy 'Taking Organ Transplantation to 2020' has a target of increasing consent rates to 80% by 2020. The UK wants to match the best countries in the world.

We're a long way from meeting the target, though. Since 2013, donation consent has only increased from 57% to 62%. Four out of ten families who were approached didn't agree to donation taking place. To increase rates, there are two areas of focus. Donation rates remain a major goal, but the NHS also wants to do the following:

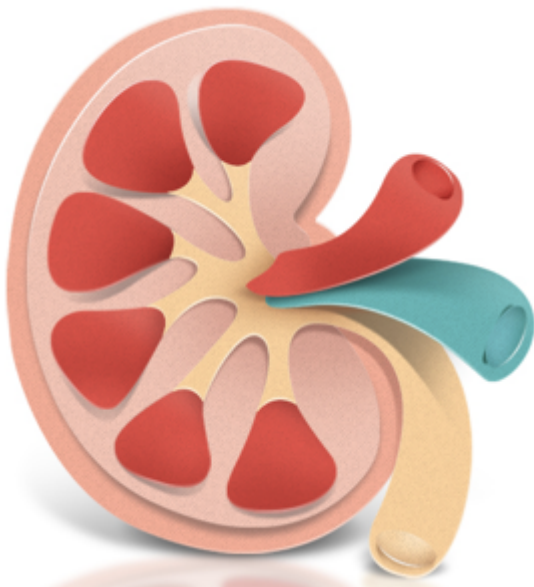
- **Improve consent rates.** The UK has one of the highest family refusal rates. Refusal means a loss of potential donation – so there's a need to encourage people to discuss their plans with family and friends.
- **Address misconceptions.** The NHS believe organ donation should be a social responsibility and a mark of good citizenship. But there are common misconceptions. For example, older people think their organs aren't 'useful', whilst some believe their religion stands in the way of being a donor. The myths need to be busted.

The vital organs and their functions

Kidney

Your kidneys filter all the waste from your blood, turning it into urine. If a kidney stops working, harmful fluids build up and your blood pressure can rise.

Kidneys are dark red, and roughly fist-sized. They sit below the ribcage towards the back of your body. You can live with one kidney as the other will grow to compensate.



Pancreas

Found in your abdomen, your pancreas produces insulin to control blood sugar levels in the body. When a pancreas isn't working, blood sugar levels rise and can cause diabetes. It's also responsible for producing chemicals to help with digestion.

It's possible to live without a pancreas if you take insulin and enzyme supplements.

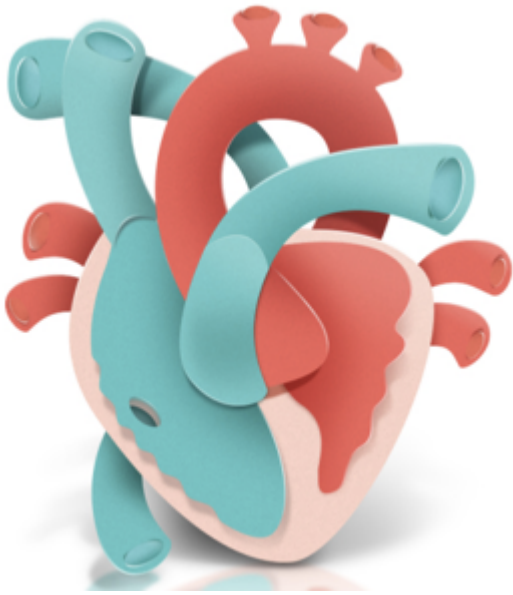
Liver

The liver is the largest internal organ. As part of your digestive system, your liver produces bile to clean out your body. It helps get rid of toxins and regulates blood sugar levels.

If your liver isn't working properly, you can feel tired and sick, have a loss of appetite, or pass brown urine.

Heart

The heart pumps blood around your body, carrying vital oxygen and nutrients. Without a heart, your body wouldn't get the oxygen it needs.



Lung

Your lungs breathe in air, absorbing oxygen and transferring it to the rest of your body. These organs are also responsible for clearing carbon dioxide from your blood. It's possible to have a single or double lung transplant, or a simultaneous heart and lung transplant.

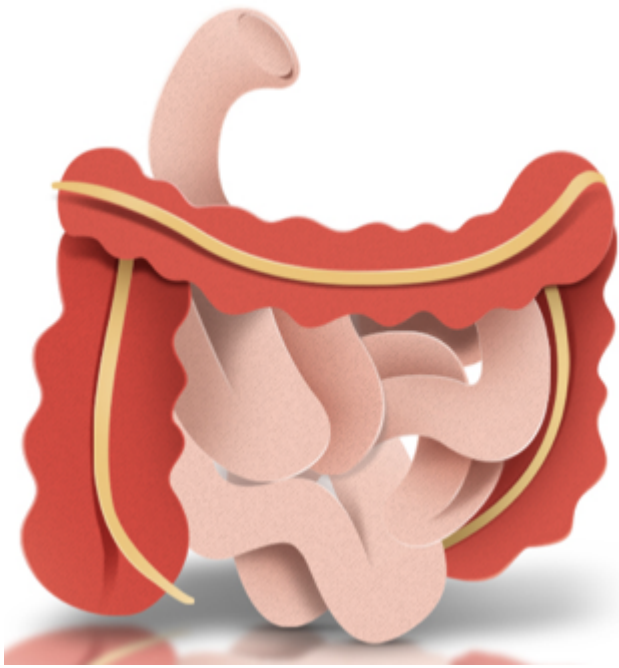
Corneas

The cornea lets light into your eye. Without them, you wouldn't be able to see.

Small bowel

Your small bowel absorbs the nutrients and minerals from food, before passing it on to the bowels. Around 90% of the food we eat enters the blood through the wall of the small bowel through highly specialised cells.

Without it, you can't digest food and would need to get nutrition in another way – through a drip, for example.



Tissue

Tissue is a group of functioning cells. A donation of tissue could be skin, bone or heart valve.

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Key restrictions on organ donation

There's not a lot to stop you from donating. In fact, very few medical conditions will mean you can't sign-up to the organ donation register. The only restrictions are:

- Creutzfeldt-Jakob Disease (CJD)
- Organs that risk transmitting an infection or cancer

Otherwise, a decision will be made whether to use your organs and/or tissue based on strict medical criteria. For example, it's possible to donate organs that have been affected by cancer in the past. Surgeons are trained to balance the risk of using an organ against the risk of a patient dying because they don't have the transplant.

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What happens to your organs after death (if you didn't register)

When you die, your family are asked to support your decision to donate organs and tissue. If you don't register, your family will still be asked to decide on your behalf. A team of donation and transplant specialists will ask what they think loved one would have wanted.

Almost 90% of families agree to organ donation if they knew their loved one's wishes. Less than 50% agree if they never had the conversation. That person could have signed up to the ODR, yet their organs won't be donated because their family didn't know.

It's a huge burden for families to decide, especially at such a difficult time. But when a family says no, someone waiting for a transplant may miss out. The NHS say family refusal is the biggest obstacle to organ donation. Whatever your choice, discuss it with your family. Making your wishes clear reduces the stress for them. Death can be uncomfortable to talk about, but it will become easier.

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FAQs on organ donation

Being an organ donor is a generous decision. Understandably, people want to have all the facts before making such an important choice. Donating organs and/or tissue should be something you choose to do and feel comfortable with. Here are the answers to some common questions:

- **Does organ donation affect arrangements for viewing the body?**

Doctors remove all organs and tissue with great care. Surgical incisions are carefully closed and covered. Arrangements for viewing the body after donation are the same as immediately after death.

- **Does it stop you having an open-casket funeral?**

Being an organ donor doesn't stop you having an open-casket funeral. No-one will see any difference, as you're clothed for the burial.

- **Can you donate your organs if you're under 18?**

Yes. Minors should tell their parents of their organ donation wishes. Parents can then give consent should the worst happen. There are always children on the transplant waiting list. These patients usually require smaller organs than an adult can provide. Having child donors improves this situation.

- **Am I too old to donate my organs?**

It's down to healthcare professionals to decide to use your organs or tissue. They make these decisions based on a medical assessment – not age. As such, there's no age limit for donating.

- **Does the UK buy or sell any organs?**

It's illegal to buy or sell human organs and tissues in the UK.

- **Will my organs be used for research?**

Doctors can only use your organs and tissue for medical or scientific research with permission from your family.

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Organ donation around the world

Most people agree organ donation is a good thing, but the process is different all around the world. Let's take a closer look at how countries deal with organ donation.

How other countries treat organ donation

In December 2015, Wales made organ donation opt-out. Unless you make it known you don't want your organs to be used after death, they will be. This is only if you've lived in Wales for more than 12 months and are over 18 years old.

This was the first such move in the UK, predicted to increase the number of organs available by 25%. In the first six months after the policy was introduced, the Welsh government said 60 organs were transplanted. Just 3% of people opted out.

A UK Department of Health spokesperson said: "We're watching how the change in Wales impacts on donations and continue to work hard to build on the significant increase in organ donations achieved in recent years."

Elsewhere in the world, organ donation and transplant rates vary (see table).

In Brazil, they chose a hard opt-out system in 1997. Eight years later, they returned to the previous opt-in process. But why?

The country faced problems as families weren't allowed to overrule the system, enabling doctors to remove organs when family members knew the deceased would have objected. Brazil had ignored the possibility people weren't well-informed enough.

In France, there's a soft opt-out organ donation system – like Wales. Consent is presumed, but the deceased's family has the final say. This helps to balance respect for family rights and the burden of decision.

It's a similar process in Spain. The country is often considered the gold standard for organ donations. In 2016, 4,818 transplants were performed in Spain. For every one million people, the country has 43.4 people who have donated.

To keep refusal rates low, better awareness about the importance of organ donation is needed. This is where the UK can improve.

Source: [International Registry in Organ Donation and Transplantation](http://www.irodat.org/img/database/pdf/NEWSLETTER2016_SecondEdition.pdf)
(http://www.irodat.org/img/database/pdf/NEWSLETTER2016_SecondEdition.pdf).

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The benefits of an opt-out system for organ donation

Organ donations are an emotional experience. Donors, living or deceased, offer an amazing gift. Anything a country can do to support more donations is beneficial. An opt-out system promises just that – more donors and more transplants. That's because unless there's evidence that a person didn't agree to transplant, their organs would be available. To break it down, here are the key benefits:

- [Experts have said](https://www.bmj.com/content/340/bmj.c2188) (https://www.bmj.com/content/340/bmj.c2188) almost 300 extra operations could be carried out a year if people were asked to 'opt out'
- There's reduced emotional pressure on families to decide
- It overcomes the issue of people 'forgetting' to sign up to organ donation, or not making their wishes known

What's more, advances in medical science mean the number of people whose lives could be saved by a transplant is rising. Opt-out offers a way of keeping up.

An [independent report from the Organ Donation Taskforce](https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/4245/organsfortransplantstheorgandonortaskforce1streport.pdf) (https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/4245/organsfortransplantstheorgandonortaskforce1streport.pdf) considered the potential impact of an opt-out system for organ donation in the UK. Key findings included:

- Huge range of strong views and opinions on this matter
- Everyone agrees there is an urgent need to do something to help the thousands of people in need of transplants
- Current system isn't doing enough to support the high level of public support for organ donation
- Warnings of the potential for provoking those with anti-donation feelings
- Need to address the low awareness of the ODR. The register needs to be publicised, so people know it's easy to sign-up

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Religion and organ donation

There are many misconceptions about organ donation. For example, people think it's against many religious beliefs. That's not the case. In fact, the major religions in the UK support organ donations and transplant. This includes:

- Christianity
- Islam
- Judaism
- Buddhism
- Hinduism
- Sikhism

In 2014, Pope Francis [described the act of organ donation](http://www.donorrecovery.org/2014/10/pope-francis-supports-organ-donation/) (<http://www.donorrecovery.org/2014/10/pope-francis-supports-organ-donation/>), as "testimony of love for our neighbour." Unsure about your faith's position on donation? Simply ask your religious leader. The UK is increasingly multicultural. Community leaders are there to help with decisions. But ultimately, it's a choice you should make yourself.

Addressing the need for organ donation amongst ethnic minority communities

In the UK, black, Asian, and other minority ethnic (BAME) people are under-represented as organ donors. The NHS need more donors because:

- Some blood and Human Leukocyte Antigen (HLA) types are more common among ethnic groups
- Some ethnic groups are more likely to develop medical conditions that need blood, organ or tissue donations
- People who need bone marrow are more likely to find a match with someone with a similar ethnic background

Currently, BAME patients have to wait much longer than white patients. For a kidney transplant, it's around a year longer. It's all down to the lack of suitable organs. According to NHS Blood and Transplant, only 67 of 1,364 deceased donors in the UK were from the BAME community in 2015/16. During that time, 1,686 patients from the BAME community were waiting for an organ transplant.

It's time for change. We hope the following transplant life stories will encourage people from all backgrounds and cultures to register as organ donors.

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Organ donation life stories

People choose to donate their organs for different reasons. Some people may have had a personal experience change them. Others do it instinctively. But everyone who signs up could change someone else's life. It's a selfless choice and one with huge benefits for a patient's life.

Top tips from the experts

Faced with the potential of organ donation, people have a lot of questions. The advice of experts offers great support to people and groups.

- US Transplantation Expert Andrew Cameron on the risks and recovery for a living organ donor

Just like any other major surgery, there are risks and a period of critical recovery time for transplantation surgery. But living donation doesn't change life expectancy. Most donors will go on to live a healthy life after recovering from surgery – which takes around six to eight weeks. Here's what you can expect:

- For kidney donors, the remaining kidney will enlarge slightly because it has to do the work of two healthy kidneys

- For liver donors, the liver regenerates and regains full function

Specific donor-related risks should always be discussed with your transplant team.

Source: [Johns Hopkins Medicine \(https://www.hopkinsmedicine.org/health/articles-and-answers/ask-the-expert/living-organ-donation-answers-from-transplantation-expert-andrew-cameron\)](https://www.hopkinsmedicine.org/health/articles-and-answers/ask-the-expert/living-organ-donation-answers-from-transplantation-expert-andrew-cameron).

- Dr Rafael Matesanz, medical director of the Organizacion Nacional de Trasplantes in Madrid, on Spanish organ donation

Spain has the most impressive deceased organ donation rates in the world. It's been this way for some time. Dr Rafael says the country's success over the last 20 years is down to being prepared in intensive care.

Spain has doctors acting as transplant coordinators in intensive care at every hospital. They take a lead role in spotting potential donors. These doctors can approach the patient's family and prepare them for the option earlier on.

"Most donors are lost not because the family refuses but because potential donors are not detected adequately," said Dr Matesanz.

Source: [BBC \(http://www.bbc.co.uk/news/uk-wales-34932951\)](http://www.bbc.co.uk/news/uk-wales-34932951).

- Adnan Sharif, a consultant nephrologist at Queen Elizabeth Hospital in Birmingham, on UK organ donation

Adnan Sharif points out that most deceased organ donors in the UK were never registered. In 2014, 59% of the 1,320 deceased donors weren't registered. "Therefore, having more names on the register with an opt-out system does not automatically translate into more organ donors," he said.

Source: [Science Daily \(https://www.sciencedaily.com/releases/2015/10/151020191703.htm\)](https://www.sciencedaily.com/releases/2015/10/151020191703.htm).

Organ donation is a necessity. Whether the UK sticks to an opt-in system or not, there's something you can do now to help improve the situation. With the details of this guide, you can make your own decision. Register to be an organ donor and share your wishes with family and friends. Just one donor can save or transform up to nine lives. Many more can be helped through the donation of tissues.

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Useful links & further information

Interested in becoming an organ donor? Find out more with these useful links:

NHS Blood and Transplant: About donation

<https://www.organdonation.nhs.uk/about-donation/>
(<https://www.organdonation.nhs.uk/about-donation/>).

International Registry in Organ Donation and Transplantation

<http://www.irodat.org/> (<http://www.irodat.org/>).

The potential impact of an opt out system for organ donation in the UK

http://webarchive.nationalarchives.gov.uk/+http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_090312
(http://webarchive.nationalarchives.gov.uk/+http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_090312).

NHSBT Organ Donation: 2013 research

https://nhsbt-dbe.blob.core.windows.net/umbraco-assets-corp/4254/nhsbt_organ_donation_public_behaviour_change_strategy-2.pdf
(https://nhsbt-dbe.blob.core.windows.net/umbraco-assets-corp/4254/nhsbt_organ_donation_public_behaviour_change_strategy-2.pdf).

Consenting to organ donation

<http://www.healthtalk.org/peoples-experiences/organ-donation-transplant/organ-donation/consenting-organ-donation> (<http://www.healthtalk.org/peoples-experiences/organ-donation-transplant/organ-donation/consenting-organ-donation>).

Organ spotlight

<https://www.organdonation.nhs.uk/about-donation/organ-spotlight/>
(<https://www.organdonation.nhs.uk/about-donation/organ-spotlight/>).

Could I be a living liver donor?

<https://nhsbt-dbe.blob.core.windows.net/umbraco-assets/1517/27709-234mv-could-i-be-a-living-liver-donor.pdf> (<https://nhsbt-dbe.blob.core.windows.net/umbraco-assets/1517/27709-234mv-could-i-be-a-living-liver-donor.pdf>).

How Spain became the world leader in organ transplants

<https://www.thelocal.es/20170111/how-spain-became-world-leader-at-organ-transplants>
(<https://www.thelocal.es/20170111/how-spain-became-world-leader-at-organ-transplants>).

Organ Donation Scotland

<https://www.organdonationscotland.org> (<https://www.organdonationscotland.org>).

Organ Donation Northern Ireland

<https://www.organdonationni.info> (<https://www.organdonationni.info>).

Organ donation rates for transplants still too low in UK, says NHS

<https://www.theguardian.com/society/2016/sep/01/organ-donation-rates-for-transplants-still-too-low-in-uk-says-nhs> (<https://www.theguardian.com/society/2016/sep/01/organ-donation-rates-for-transplants-still-too-low-in-uk-says-nhs>).

Human Tissue Authority: Body donation FAQs

<https://www.hta.gov.uk/faqs/body-donation-faqs> (<https://www.hta.gov.uk/faqs/body-donation-faqs>).

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