

UK Living Kidney Sharing Scheme

Your questions answered

If you are thinking about donating or receiving a kidney in the UK Living Kidney Sharing Scheme, this information can be used as a guide, but it does not replace a conversation with a living donor coordinator.

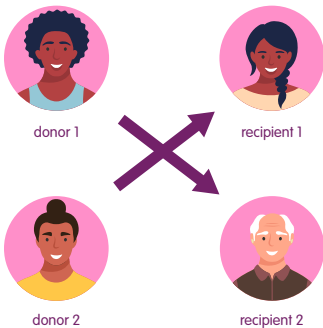
Paired/Pooled Donation

Q1. What is paired/pooled donation?

A1. If you are in need of a kidney and have someone close to you who is willing to donate (a donor) but you are incompatible with each other, because of your blood group or tissue type (HLA type), it may be possible for you to be matched with another donor and recipient pair in the same situation and for the donor kidneys to be 'exchanged' or 'swapped'. Sometimes donor and recipient pairs who are compatible may also choose to donate into the scheme aiming to find a kidney that is better suited for the recipient, either in terms of age or HLA match.

Where two couples are involved this is known as a 'paired' donation and where more than two pairs are involved, this is known as a 'pooled' donation.

2-way exchanges (Paired donation)



3-way exchanges (Pooled donation)

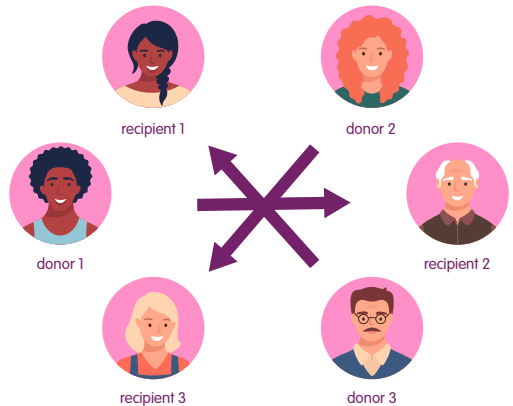


Figure 1. Paired and pooled donation.

Q2. What if there are several potential willing donors for one recipient?

A2. If a recipient has more than one willing donor with different blood groups and/or HLA types, additional donors can be registered with the recipient in the paired/pooled scheme to increase the possibility of a 'match' with another pair. All the potential donors must be fully assessed and willing to do this. If a successful match is identified with one donor, the others do not need to donate.

Q3. What is involved in the assessment of the donor and recipient?

A3. Anyone who wants to give or receive a living donor kidney must be carefully assessed to ensure that it is as safe as possible to go ahead and it is the right decision for them. There are clear guidelines in the United Kingdom (UK) to advise how this should be done.

Q4. How does the process work?

A4. You can be registered in the UK living kidney sharing scheme as a donor-recipient pair when both your assessments are complete.

Four times a year (quarterly) NHSBT performs a 'matching run' between all the donor-recipient pairs in the scheme using a computer program which has been specially designed to work out the best number and combination of potential transplants. If you are a recipient who has chosen to remain on the national transplant list for a deceased donor kidney whilst waiting in the paired/pooled scheme, you will be taken off the list (suspended) once a match has been identified for you. This is important to avoid one part of the swap falling down and everyone involved being disappointed. You will remain suspended unless for any reason your transplant cannot go ahead. If that happens, you will be reinstated on the transplant list as soon as possible.

Your transplant team will advise you about the possibility of choosing an upper age limit and/or specifying a minimum degree of HLA match in another donor. Adding restrictions will mean that fewer donors could be matched to you, but it may be reasonable to do this initially. These choices must be made before the matching run goes ahead as declining a possible swap afterwards means other people also miss out on being transplanted, which causes distress and disappointment. Your living donor coordinator will also check with you before each matching run to make sure that you and your donor wish to register for that particular run to avoid transplants not proceeding after 'swaps' have been identified and all the donors and recipients have been informed.

The disadvantage of the scheme is that not everyone who is registered will find a match. You may wait up to a year before a 'match' is identified and some recipients and donors may never be matched to another pair. This depends upon your individual circumstances and your transplant team will look at other options for you if you have not received a match after three or four matching runs (9-12 months). However, there is no limit to how long you can remain in the paired/pool scheme and the more pairs there are in the scheme, the greater the chance of finding a suitable match for you.

Q5. What happens once I have been matched?

A5. When suitable pairs are matched the transplant centres involved arrange compatibility testing (HLA cross-matching using blood samples) between all the matched pairs as soon as possible. This should happen within 1-2 weeks to confirm that all the transplants can go ahead. If your transplant cannot go ahead for any reason, you will immediately be put back on the national transplant list. As with all living donor transplants the Human Tissue Authority (HTA) must give approval first, and each pair sees a local Independent Assessor (IA) who ensures that

all the legal requirements are fulfilled. Once granted, HTA approval does not need to be renewed unless the circumstances for either the donor or the recipient have changed.

The aim is that all the identified transplants go ahead within 8 weeks after the 'matching run'. However, timings can vary depending on how many pairs are involved and how complicated the arrangements are between all the transplant centres or if, for example, one of the donors or recipients becomes ill. All the donor operations are usually scheduled at the same time on the same day but, in exceptional circumstances, it may be necessary to stagger the operations for practical reasons. In this situation, your transplant team will discuss the plans with you so that you are clear about how the swap will work and any additional risks that there may be for you. As a donor-recipient pair, your operations usually take place in your local transplant centre and the donated kidneys travel between the transplant centres involved. Special transport is arranged to make sure that the kidneys travel as quickly and safely as possible to the recipients. There may be reasons why it is easier or more sensible for a donor or recipient to move to another transplant centre for the operations, which is possible to arrange if everyone agrees.

There is a small risk that an operation may not go ahead as planned, leaving a recipient without a transplant. This is very unusual in living kidney donation but it could happen and it is important to understand when you enter into the scheme that, despite careful preparation during the 'work-up', there is a small chance that it may not be possible to transplant the donated kidney or that it may not work. There are lots of safeguards to prevent this happening and transplant teams work together very closely when they are planning paired/pooled transplants to make sure that all the necessary information is shared and that you are involved in decisions about your donation and transplantation.

Q8. Do I have any special responsibilities once I am registered in the scheme?

A8. By registering in the paired/pooled scheme, you are agreeing that, unless something unexpected happens in the meantime, you commit to going ahead with the donation and transplantation if you are successfully matched. This does not take away your right to withdraw at any time up until the operation but, because this affects other pairs in the scheme, it is important to avoid this happening unless there are exceptional circumstances.

Before each 'matching run', all donors and recipients are asked by their transplant centre to confirm if they wish to be activated (included) in that run. This means that they are fit and willing to participate. Anyone, donor or recipient, who is uncertain about going ahead must be suspended (excluded) from the scheme at this stage. You can be activated and suspended from the scheme as often as you wish, as long as you make it clear before the 'matching run'. If you and/or your donor/s have been unwell, you need to let your transplant team know as soon as possible so that a decision can be made about whether or not you should be included in the next matching run. You must also make sure that your choices about age and HLA types are clear and have been confirmed before each 'matching run' goes ahead.

Q9. Will I know who has given me a kidney, or who my donor's kidney has been given to?

A9. Matched donor and recipient pairs are anonymous to each other prior to the operations in the interests of all the donors and recipients involved. If anonymity is broken prior to the transplant, it could stop all the 'exchange' operations going ahead. After the transplant operations, it may be possible for donor-recipient pairs to meet or contact each other, but only if they all agree that they wish

to do so. The living donor transplant coordinators in all the transplant centres involved can help you to make contact with your donor or recipient after the operations should you all wish to. Some people are more private than others and may not wish to know about or meet other pairs. You should not feel under pressure to do so and, if this is not what you want to do, your privacy will always be respected.

The media are often interested in these types of transplants and may approach you to be involved in news stories, radio and TV programmes and other publicity. The HTA and NHSBT support publicity to raise awareness about donation and transplantation and there is a media policy to guide people which your coordinator can talk you through. If you are asked to be involved in any publicity, please discuss it with your living donor coordinator first so that he/she can advise you. If you are approached directly by the media or wish to offer your own story to raise awareness, particularly before donation or transplantation, please ask for advice before giving any details that may identify your donor-recipient pair, other pairs involved, or the date and locations of operations.

Non-directed Altruistic Donation

Q10. What is non-directed altruistic donation?

A10. This is where a person volunteers to donate a kidney anonymously to someone in need of a transplant whom they have never met and is not known to them. The benefit of this type of donation is that the recipient receives a living donor kidney transplant, which is a great opportunity for them.

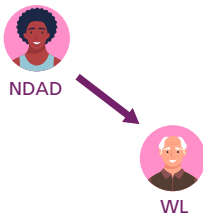
Q12. How does the process work for the non-directed altruistic donor?

A12. For non-directed altruistic donors, the assessment is usually organised by the transplant centre that is closest to where the donor lives but they can choose to contact any transplant centre in the UK from the list on the NSHBT website. When the donor assessment is complete, they are registered as a donor with NHSBT. More information about non-directed altruistic kidney donation is available in this leaflet 'Could I donate to someone I don't know?'

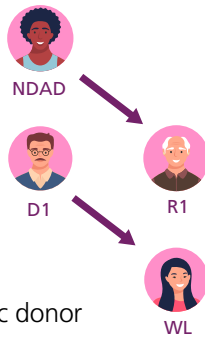
Q13. How do transplant chains work?

A13. Information will be given to all donors about the dates of quarterly matching runs and weeks of surgery so that they can decide which matching run they wish to be included in bearing in mind that they will donate within several weeks after the run and need to give themselves time to recover before resuming their usual lifestyle activities.

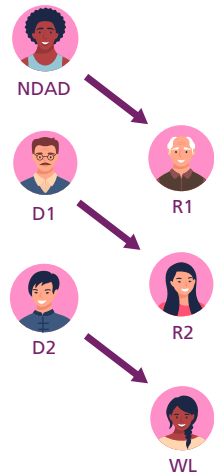
Direct to waiting list



Short chain



Long chain



NDAD = Non-directed altruistic donor
R = Recipient
D = Donor
WL = Patient on waiting list

Figure 2. Non-Directed Altruistic Donation

Q16. Are there any special considerations for non-directed altruistic donors?

A16. Non-directed altruistic donors need to consider that they have no relationship or emotional link with any of the recipients or donors involved in the transplant chain. If the other donors and recipients involved decide not to make contact via their living donor coordinators after their operations, the non-directed altruistic donor may not know how things have gone for them. This may not be a problem but it is important that the donor considers this if they wish to donate.

In terms of special responsibilities, such as anonymity and media publicity, the same guidance applies to the non-directed altruistic donor as to pairs in the paired/pooled scheme.

Further information

For more information on living kidney donation and the UK Living Kidney Sharing Scheme you should contact the living donor coordinator or transplant liaison nurse at your nearest Renal Unit. These can be found on the organ donation website.

Other useful information:

NHS Blood and Transplant

Email: enquiries@nhsbt.nhs.uk

Tel: 0300 123 23 23

Web: www.organdonation.nhs.uk

Human Tissue Authority

151 Buckingham Palace Road, London, SW1W 9SZ.

Email: enquiries@hta.gov.uk

Tel: 020 7269 1900

Web: www.hta.gov.uk

Living Donation, Scotland:

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

Living Donation, Northern Ireland: www.donatelife.co.uk

Charities**Kidney Care UK – Improving life for kidney patients.**

Email: info@kidneycareuk.org

Tel: 01420 541424

Web: www.britishkidney-pa.co.uk

Gift of Living Donation

Exists to promote living kidney donation and raise awareness of organ donation in the African and Caribbean community.

Email: info@giftoflivingdonation.co.uk

Web: www.giftoflivingdonation.co.uk

Give a Kidney

Charity raising awareness of non-directed altruistic donation and supporting donors and potential donors through the process.

Email: giveakidney@gmail.com

Web: www.giveakidney.org

Kidney Research UK

Charity funding research and raising awareness of kidney disease.

Email: enquiries@kidneyresearchuk.org

Helpline: 0300 303 1100

Web: www.kidneyresearchuk.org

Web based kidney health information service for kidney patients, their families and carers, as well as medical professionals and researchers.

Web: www.kidneyresearchuk.org/health-information

National Kidney Federation

Charity run by kidney patients for kidney patients.

Email: helpline@kidney.org.uk

Helpline: 0845 601 02 09 (Monday-Friday, 9am-5pm)

Web: www.kidney.org.uk

Glossary of Terms

Antibodies

Antibodies are produced by the body when it detects something 'foreign'. Their purpose is to remove such substances which can be harmful (e.g. a virus or bacteria), from the body. In general this is a good thing, but it can be a problem in transplantation when an entire 'foreign' kidney is given to someone. If a recipient has antibodies against the donor's blood group or HLA type, that donor's kidney is unsuitable for the recipient as the antibodies will attack the 'foreign' kidney and cause rejection. Blood group antibodies are in the blood from early in life and HLA type antibodies are made if the recipient has previously been in contact with another person's cells through pregnancy (the baby is half of the father), blood transfusion or a previous organ transplant.

Compatible

When the person needing a kidney transplant does not have antibodies to the blood group or tissue (HLA) type of the donor and a straightforward transplant between them is possible.

Deceased donor

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

Donor-recipient pair

A person who needs a transplant and their willing donor who are registered together into the paired/pooled scheme.

Exchange

Matched donor recipient pairs between whom kidneys are swapped.

HLA type

This refers to proteins known as Human Lymphocyte Antigens (HLA) that make up the individual HLA-type of every person. This is often referred to as tissue type. This can be thought of as a 'bar code' which is on the surface of cells. Unless you have an identical twin, then nobody else has exactly the same 'bar code' as you. The HLA-type helps to identify suitable donors for recipients.

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. They interview donors and recipients of living organ transplantation in the UK and submit a report to the HTA.

Incompatible

When someone suitable to donate a kidney cannot give to their loved one who needs a transplant in a direct, straightforward way because they do not match – either they are the wrong blood group or the wrong tissue type.

Living donor kidney transplantation

Kidney transplantation between someone who donates a kidney during their lifetime (living donor) to a recipient who needs a kidney transplant.

Matching run

Kidney matching run carried out by NHSBT, via a computer program four times a year, to identify all paired/pooled exchanges and altruistic donor chains.

UK Living Kidney Sharing Scheme

A scheme that enables kidneys from living donors throughout the UK to be 'swapped' for the benefit of patients waiting for a transplant.

National transplant list

A UK-wide list of patients awaiting a kidney.

NHSBT

NHS Blood and Transplant – 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.

Produced by NHS Blood and Transplant.

Compiled by a sub-group of the Living Donor Kidney Transplantation 2020 Strategy Implementation Group.

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 nhsbt.nhs.uk

Email enquiries@nhsbt.nhs.uk

Call 0300 123 23 23

