

UK Living Kidney Sharing Schemes

Your questions answered



- Paired/Pooled Donation
- Non-directed Altruistic Donor Chains

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This document provides information if you are thinking about donating or receiving a kidney as part of the UK Living Kidney Sharing Schemes, which include:

- Paired/Pooled Donation
- Altruistic Donor Chains

If you are thinking about donating or receiving a kidney, we want you to know as much as possible about what is involved for you and what choices you may have. This information can be used as a guide to help you, but the scheme is quite complicated and your Coordinator will discuss this with you face-to-face in more detail to help you understand the options.

You will find a glossary on Page 14 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 to help you.

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'.

For example, I need a transplant and my sister is willing to donate one of her healthy kidneys to me but she is the wrong blood group for me. However, it may be that her kidney might be a good match for Mrs Blogs (somewhere else in the UK) who also needs a transplant and that Mr Blogs (who can't donate to his wife because of his blood group) has a kidney and blood group that would suit me very well. The paired scheme allows a computer programme within NHSBT to 'match' couples in this situation and enable the two donated kidneys to be 'swapped' meaning that I would receive the donated kidney from Mr Blogs, whilst his wife, Mrs Blogs, would receive my sister's donated kidney. In both pairs the person in need of a kidney receives a transplant they would not otherwise have had.

Where two couples are involved this is known as a 'paired' donation (see *Figure 1*) and where more than two pairs are involved, this is known as a 'pooled' donation.

The person who is donating a kidney does not do so until there is a suitable kidney identified for their relative / friend, so they will only donate if their friend/relative will also be receiving a transplant at the same time.

Sometimes donor and recipient pairs who are compatible may also choose the paired/pooled scheme aiming to find a kidney that is better suited for the recipient, either in terms of age or HLA match. This is particularly useful if the person with kidney disease is not yet requiring dialysis, so there is time to try to find a more suitable transplant. For example, a younger recipient is likely to need more than one transplant in his/her lifetime so a younger donor with a closer HLA match may be preferred to give the best possible chance of the transplanted kidney working for a long time and to lower the risk of developing antibodies. Antibodies make it more difficult to find another suitable transplant in the future.

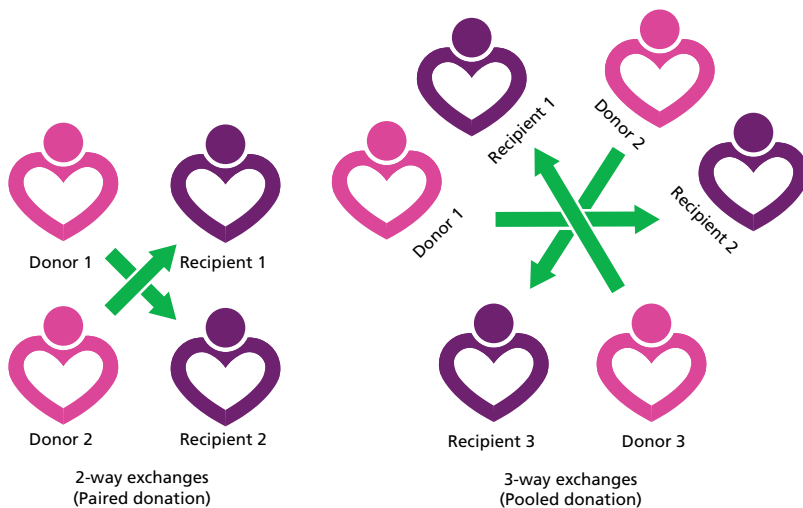


Figure 1. Paired and pooled donation.

Q2. Who is eligible for the paired/pooled scheme?

A2. Any donor and recipient pair who are considering living kidney donation are eligible for the scheme. However, apart from the example described (see Answer 1), most *compatible* pairs prefer to donate and receive directly. The process is usually more straightforward and there is greater flexibility to plan the transplant when other pairs are not involved.

If you are a recipient who is incompatible (not a match) with your donor, paired/pooled donation is usually the best option to go for first – a compatible transplant is nearly always more straightforward and more successful than an incompatible transplant. Removing antibodies from the blood can be quite complicated and the recipient has to undergo more treatment to make a transplant possible. Your transplant team will discuss the possible options that are suitable for you in detail. Almost all people remain on the national transplant list for a deceased donor kidney when registered in the paired/pooled scheme.

Q3. What if there are several potential willing donors for one recipient?

A3. 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.

If the transplant cannot proceed for any reason with the 'matched' donor, it may be possible for one of the other donors to be considered for an alternative match with a different pair or to re-enter the scheme the next time round. In these circumstances, it is realistic to assess and register a maximum of 2-3 donors per recipient in the scheme. This will be discussed with you by the transplant team.

Q4. What is involved in the assessment of the donor and recipient?

A4. Anyone who wants to give (donor) or receive (recipient) 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. You will be given information that explains the assessment (work-up) process and you will have plenty of opportunity to ask questions and discuss your own particular situation with the transplant team looking after you. In paired/pooled donation, the assessments for both the donor and recipient are usually arranged by the transplant centre where the recipient is being cared for. Please read 'Could I be a living kidney donor?' for more information about being a living kidney donor.

Q5. How does the process work?

A5. You can be registered in the paired/pooled scheme as a donor-recipient pair when both your assessments are complete. (See Answer 4.)

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. (See Answer 8.)

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.

Q6. How do I know that I will get a good kidney?

A6. Every person that has been entered into the paired/pool scheme as a possible donor has already been fully assessed in the same manner as your potential donor. All transplant centres in the UK follow the same guidelines to decide if someone is healthy enough to donate and nobody will be registered unless the transplant team is happy that they are suitable. This is unlike a deceased donor, where there is limited information available about the person's health and quality of their kidneys before transplantation.

Q7. What happens once I have been matched?

A7. 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.

Please see *Answer 14* for more information on the procedure if a non-directed donor is included in the chain.

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 (see *Answer 5*) 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 kidney whom they have never met or heard about and is not known to him/her. The benefit of this type of donation is that the recipient of the transplant receives a living donor kidney transplant from a healthy donor, which is a very good option for the patient. Non-directed altruistic donors usually donate into the paired/pooled scheme to create a 'chain' of up to three transplants (see *Answer 13*) unless there is a patient with higher priority on the national transplant list. If the donor cannot be matched to a recipient to initiate

a chain, the kidney is donated to the most suitable recipient on the national transplant list, using the same national allocation scheme that is used for deceased donor kidneys.

Q11. Who can be a non-directed altruistic donor?

A11. Any adult can volunteer to be considered as a non-directed altruistic donor (over 18 years of age in England, Northern Ireland and Wales, over 16 years of age in Scotland). Anyone wishing to volunteer or find out more should contact the living donor coordinator in their closest transplant centre. You can also find more information about donating a kidney to someone you don't know by visiting the organ donation website.

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?'

Altruistic Donor Chains

Q13. What are altruistic donor chains?

A13. This is when a non-directed altruistic donor donates into the UK Living Kidney Sharing Schemes instead of directly to the national transplant list. The donated kidney is matched to a recipient in the scheme and, in turn, the donor registered with that recipient donates to another recipient and so on, as shown in figure 2. The chain ends when the last donor donates to a recipient on the national transplant list. In this way, it is possible to 'trigger' up to three transplants from a single non-directed donation. This creates the maximum number of transplant opportunities for patients.

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 (see Answer 5). Donor-recipient pairs who are registered in the paired/pooled scheme are told about the possibility of being matched in an altruistic donor chain instead of a usual 2-way (paired) or 3-way (pooled) exchange.

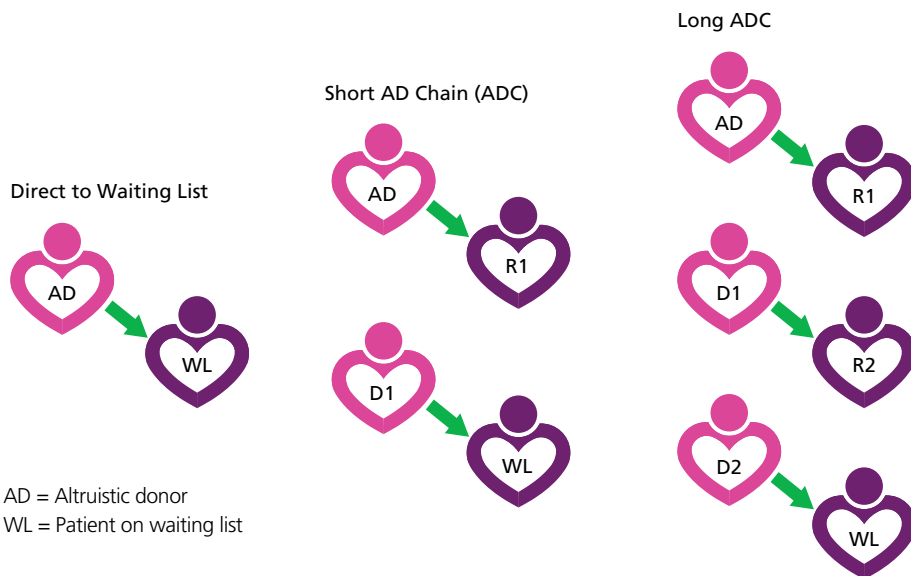


Figure 2. Non-Directed Altruistic Donation

Q14. What happens when a recipient in the paired/pooled scheme is identified in an altruistic donor chain?

A14. If a recipient in the paired/pooled scheme is matched in an altruistic donor chain, the process is the same as previously described (see Answer 7). If compatibility testing with all the matched donors and recipients shows that the transplants can go ahead, HTA approval for the paired/pooled donors and recipients will be needed and a date for the operations planned (usually within 8 weeks). Again, donors and recipients usually stay in their local transplant centres and kidneys are transported to the recipient transplant centres. All the donor operations are usually scheduled at the same time on the same day but, sometimes it may be necessary to stagger the operations on different days for practical reasons and to avoid unnecessary delays in scheduling transplant dates. In this situation, the non-directed altruistic donor nearly always donates first,

to start the chain. Your transplant team will discuss this with you so that you are clear about how the swap will work and any additional risks that there may be for you.

Q15. What happens if an altruistic donor donates directly to the national transplant list?

A15. The allocation of a kidney from an altruistic donor works in just the same way as it would for a kidney from a deceased donor. Visit www.kidney.org.uk for more information.

Q16. Are there any special considerations for altruistic donors?

A16. Non-directed altruistic donors need to think about the fact that they have no relationship or emotional link with any of the recipients or donors involved in the transplants that may follow their donation. This means that they do not experience the pleasure of seeing a loved one benefit from a transplant as they would if they knew the recipient. If the other donors and recipients involved decide not to make contact via the living donor coordinator after the donation and transplantation 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 thinks about this when deciding to donate.

A non-directed donor also needs to decide if they wish to donate to the paired/pooled scheme to create an altruistic donor chain or 'opt out' and give directly to the national transplant list instead. 'Chains' create more transplant opportunities for patients who are waiting so it is important to make it feasible for as many altruistic donors as possible to have the chance to enter a matching run rather than donate directly to the national transplant list. However, all donors are free to decide what is best for their circumstances and how 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 (see Answer 8).

Further information

We hope that this information will help you to decide if you want to take part in the UK Living Kidney Sharing Schemes so that you can discuss your decision in detail with your transplant team.

To help you make a decision that is right for you, we suggest that you read this leaflet together with any other information that you have been given about living donor kidney transplantation, including the Human Tissue Authority (HTA) leaflet '*Information About Living Donor Transplants*', which is available from your living donor coordinator or from the HTA website www.hta.gov.uk.

For more information on living kidney donation 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

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

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.

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**