

Antibody incompatible kidney transplantation from a deceased donor

This leaflet explains more about antibody incompatible renal transplantation from a deceased donor. It will tell you why you were offered it, the benefits, risks and alternative treatments. It will give you an overview of the process from being referred to our clinic to follow-up after your kidney transplant.

If there's anything not clear for you or you have further questions, please speak to a doctor or a nurse caring for you.

You will have already been given information about the different types of kidney transplants. The aim of this leaflet is to explain more about HLA incompatible renal transplantation from a deceased donor, which is different from 'routine' transplantation in a number of ways.

The transplant team here at Guys and St Thomas' have performed more than 150 antibody incompatible renal transplants, making us the most experienced team in the UK for this sort of transplantation. For many years this kind of transplant was only possible in patients with a living donor, but recently it has become possible for patients on the deceased donor waiting list.

What is antibody incompatible transplantation?

Sometimes a patient waiting to have a kidney transplant has antibodies in their blood that can react against the donor kidney and damage it. Most people develop these antibodies as a result of a previous blood transfusion, pregnancy (for women) or previous organ transplantation.

The antibodies in the transplant recipient are said to be 'incompatible' with the donor kidney; this is known as HLA (human leukocyte antigen) incompatibility. The antibodies are known as anti-HLA antibodies, and they react with proteins (HLA antigens) on the donor kidney. Routine transplantation in these circumstances would result in severe rejection and potential loss of the kidney.

However, it may be possible to remove or suppress these antibodies in a process known as 'desensitisation', which can allow the transplant to take place. Specific treatments, as well as medication, are available to carry out desensitisation.

Why am I being offered antibody incompatible transplantation?

You have been referred to our clinic because you are 'sensitised'. That is, you have previously been exposed to cells or tissue from another person and this has triggered production of a wide spectrum of anti-HLA antibodies. Normally, you would not be offered a kidney if you have antibodies against it. UK National Renal Registry data has shown that the most highly sensitised patients wait twice as long as an unsensitised patient before being offered a kidney from the deceased donor waiting list.

How do you know if antibody incompatible transplantation is right for me?

If you decide you are interested in this option, we will test how much anti-HLA antibody we can remove from your circulation during one session of antibody removal. This is called plasma exchange or DFPP (double filtration plasmapheresis). This will allow us to assess whether we could remove enough antibody on the day of your surgery to enable you to have a kidney transplant.

By measuring the antibodies before and after the test plasma exchange, we will form a list of antibodies which are easily removed; potentially, you could then accept an offer of a kidney which would react with these antibodies, and we could remove them immediately prior to surgery.

In some cases, antibodies remain high after the test plasma exchange, meaning that HLA incompatible transplantation may not be an option.

What will happen next?

After your test plasma exchange we will discuss your results during our multidisciplinary meeting and at your next clinic visit we will explain the treatment options. We will discuss with you your preferences and expectations regarding HLA incompatible transplantation.

If you decide to have an HLA incompatible renal transplant from a deceased donor, we will contact NHS Blood and Transplant (the organisation that allocates deceased donor kidneys) and request that your profile is changed so that you can receive a kidney with previously 'forbidden' proteins (HLA antigens). We hope that this will result in an increased chance of you being offered a kidney via the national allocation scheme.

What are the risks of antibody incompatible transplantation?

There are some risks that are associated with transplant surgery, regardless of whether you are compatible or incompatible with your donor. These risks include the risk of bleeding (both during and after the operation), the risk of wound infection and the risk of death. There is more detail about the risks associated with transplant surgery in chapter 2 of **Your guide to kidney transplantation**. Please ask for a copy of this booklet if you don't have one.

There are additional risks associated with an antibody incompatible transplant, which include:

Rejection

There is an increased risk of rejection after antibody incompatible transplantation. For compatible transplants, around 15% will experience some rejection over the first year. For HLA incompatible transplants this can be 40%.

There are two types of rejection: antibody-mediated rejection, and cell-mediated rejection.

With antibody incompatible transplants, the most common and risky type of rejection is antibody-mediated rejection. The risks are highest within the first month after the transplant. If you have good kidney function for the first month following surgery, the risk of rejection decreases.

An early antibody-mediated rejection can be difficult to treat, and may require more plasma exchange and additional medication. If the rejection does not respond to treatment, the transplant could fail.

Cell-mediated rejection tends to be easier to treat with intravenous steroids.

Bleeding

All surgery carries the risk of bleeding, but when we remove antibodies with plasma exchange, we also remove some of the factors in your blood that are important for making your blood clot. This could increase your risk of bleeding during and after transplantation. It may be necessary to replace these factors before the surgery.

Infections

All transplant patients are at increased risk of infections due to the immunosuppressive medications that we give. For patients who have an antibody-incompatible transplant, we tend to prescribe stronger immunosuppressants, and this may increase your risk of infection. Sometimes these infections can be very serious, and may even be fatal. You will be closely monitored after the transplant for signs of infection.

Patient survival

Although all types of transplant surgery carry the risk of death, this risk is increased with incompatible transplantation (around 5 to 10% potentially). This is partly due to the greater risk of infection associated with taking stronger immunosuppressive medications, which are necessary to help prevent rejection of the donor kidney.

If you have been dependent on dialysis for a long time, you may have other health problems which reduce your ability to survive a major complication, such as a serious infection.

Survival of the transplant

If you are compatible with your donor, there is a 15% risk that your transplanted kidney will stop working within the first five years after transplantation. If you are antibody incompatible, the risk that your donor kidney stops working within the first five years is 30–40%.

Are there any alternatives?

All of this may sound worrying, but the chances are that if you are at the stage of considering an antibody incompatible deceased donor transplant, you do not have any available living donors and your chances of receiving compatible deceased donor transplant within next five years are low due to your sensitisation. You have the option to remain on the national waiting list for a compatible deceased donor transplant.

Antibody incompatible transplantation is risky, but it is often considered better in the long term to be transplanted, even with a high-risk transplant, than to remain on dialysis. Even if you decide to consent for an antibody incompatible transplant there is still a chance, although low, that you'll be offered a fully compatible kidney via the national allocation scheme.

Consent - asking for your consent

We want to involve you in decisions about your care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

How can I prepare for the antibody removal treatment?

In order for the antibody removal procedure to take place (both for the test plasma exchange and the one prior to your transplant) we need to have access to your blood – this is known as vascular access. If you are receiving regular haemodialysis treatment, you will probably already have vascular access which can be used. If you are not receiving haemodialysis, you will need to have a dialysis line inserted. For more information about the procedure, please ask us for a copy of our leaflet, **Having a non-tunnelled haemodialysis line inserted**.

Occasionally people feel tired or light-headed after having plasma exchange. You should eat breakfast or lunch on the day of treatment as this can help to prevent or minimise this feeling. You will also need to arrange for a relative or friend to accompany you home after the test plasma exchange.

What happens during the antibody removal session?

The test plasma exchange will take place on Astley Cooper Dialysis Unit, 5th Floor, Borough Wing, Guy's Hospital, and will be carried out by specialist nurses. Plasma exchange usually takes two to three hours, so you may wish to bring a book, iPod, laptop or tablet with you to help pass the time. You may also wish to bring a snack. If you are receiving regular dialysis, we will dialyse you after the plasma exchange.

You will receive treatment using a machine that is very similar to a dialysis machine. The machine will filter your blood and remove the plasma (the liquid component of blood), which contains your antibodies. The plasma will then be replaced with albumin (a type of protein) or a similar product – this is why we call this **plasma exchange**.

If you are then offered an antibody incompatible kidney and require plasma exchange prior to your surgery it will be organised on Richard Bright ward where we will look after you once you have had your transplant. In some cases, with low antibodies, no treatment will be necessary, despite the antibody incompatibility.

What happens after I have my transplant?

Immunosuppressive medicines

You will be given anti-rejection medication at the time and after your kidney transplant – these are called immunosuppressants, because they work by inhibiting or preventing the activity of the immune system. All patients who undergo kidney transplantation will need to take anti-rejection medication for the rest of the time that the kidney is working. You can read more about these drugs in our booklet, **Your guide to kidney transplantation**. If you have not already been given a copy, please ask us for one.

Patients who are incompatible with their donor usually require higher dose of anti-rejection medication than those undergoing a routine transplant. These usually include **tacrolimus** and **mycophenolate mofetil**. You will also be given some additional medicines prior to the transplant that will further help to reduce the risk of rejection. These will include **alemtuzumab** or **antithymocyte immunoglobulin** which inhibit the cells of your immune system that are involved in rejection.

Alemtuzumab is given by subcutaneous (under the skin) injection during your surgery and a second dose may be given on the first day following surgery. Antithymocyte immunoglobulin is given by intravenous infusion on the day of your transplant and then daily for three days after.

The use of alemtuzumab in transplantation is “unlicensed”. This means that, although it has been used in transplantation for many years, the manufacturer’s licence for the product is for a different condition or range of conditions. More information on the use of unlicensed medicines can be found in our leaflet, **Unlicensed medicines: A guide for patients**. If you have not already been given a copy, please ask us for one.

We hope you have found this leaflet useful. All patients are different and we strongly advise that you discuss your situation carefully with your medical and nursing teams to ensure that you understand the implications for you personally.

Contact us

If you have any questions or concerns, please contact one of the following:

Mr Nizam Mamode (consultant transplant surgeon) **020 7188 1543**

Lisa Silas (advanced nurse practitioner – living donation) **020 7188 5688**

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

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Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

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