

The use of Hepatitis C infected kidneys in Hepatitis C negative recipients

Introduction

You are being asked to consider whether or not you would accept a kidney from a hepatitis C virus infected donor. This leaflet will explain why this option is being considered for you, and will explain the potential benefits and the potential risks that this may involve. It is important to emphasise that it is your choice whether or not you agree to accept a kidney from a hepatitis C virus infected donor.

What is hepatitis C?

Hepatitis C is a virus that is transmitted in infected blood. It lives in the liver and blood of infected individuals and can cause inflammation and scarring of the liver. The scarring can be severe, although on average it takes 30 years for the scarring to become life-threatening in non-transplant patients. Severe scarring may develop more rapidly in transplant patients taking drugs that suppress the immune system.

Over recent years, developments in hepatitis C treatment mean that it is possible to cure over 95% of people who are infected with the hepatitis C virus. Treatment requires taking tablets for eight weeks. Once the virus is cleared it does not come back and does not affect your long term health.

Why am I being offered a kidney from a hepatitis C positive donor?

There are not enough donated organs in the UK to transplant into all people who may need them. Sadly this means that many people die on

the waiting list. This is especially true for those people who are difficult to transplant because they have a rare blood group or tissue type, or if they have a lot of antibodies in their blood against other people's tissue types. These people often wait a long time for a transplant and are more likely to die on the waiting list. Doctors are therefore trying to find ways to increase the number of organs that can safely be transplanted.

Due to recent breakthroughs in hepatitis C virus treatment it is now possible to consider using organs from donors infected with hepatitis C virus for transplantation. These donors are generally younger than average and may be healthier, with lower blood pressure and may have less heart disease and other medical conditions. Hence their donated organs may be of higher quality than average.

What are the advantages to me of receiving a kidney from a hepatitis C positive donor?

If you agree to accept a kidney from a hepatitis C virus infected donor, you may receive a transplant more quickly. This may be very helpful if you would otherwise wait a very long time for a transplant. Also, because organ donors who are infected with hepatitis C virus are younger than average and are less likely to have other important health issues (like high blood pressure or heart disease), their organs may be of higher quality and therefore more likely to work immediately and may last longer.

What are the risks to me if I receive a kidney from a hepatitis C positive donor?

The main risk of accepting a kidney from a hepatitis C virus infected donor is that you may become infected with the virus yourself.

If hepatitis C virus is **not** treated you may become jaundiced (yellow) and may develop severe inflammation in the liver (fulminant cholestatic hepatitis). In the longer term (three to six months) hepatitis C may result

in kidney injury.

However, you will be tested regularly and offered hepatitis C treatment to cure the virus as soon as it has been confirmed that you have been infected. This will minimise the risk of any damage to you.

Another important risk to consider is the very small chance that the hepatitis C virus may not disappear after the eight weeks of treatment (see below). The chances of this happening are less than 2 in 100 (2%). If this were to happen, you would be offered a different course of tablets that has been shown to be highly effective in curing patients whose treatment has failed with other drugs. These drugs achieve 96 to 98% cure rates. This means that it is very unlikely (1 chance in 2,500) that the transplant team will not be able to cure you of the virus if you are infected.

Whilst all donors are routinely screened for the presence of other infections like HIV or hepatitis B in addition to hepatitis C, the screening tests can very rarely miss infections and there remains a very small possibility that these or other infections could also be transmitted at the time of transplantation.

What is the experience of patients who have been infected with hepatitis C at the time of an organ transplant?

There have already been several studies looking at the results of transplanting kidneys from hepatitis C virus infected donors into patients who are not infected with hepatitis C virus.

These have mainly taken place in the United States and have required that patients receive treatment for hepatitis C very early (within four weeks) after transplantation. These studies show that it is possible to cure every patient of hepatitis C virus after kidney transplantation (100% cure rate).

Importantly, the kidneys then went on to work very well, and the overall outcomes were the same for the patients who received kidneys from hepatitis C virus infected donors as those for patients who received kidneys from hepatitis C virus negative donors.

In the UK, there are already some Transplant Units that accept kidneys for transplantation from hepatitis C infected donors and their results have been excellent, with 100% success of treatment in all patients who were confirmed to have hepatitis C virus post transplantation.

How do I know that the kidney from a hepatitis C positive donor has not been damaged by the virus?

Hepatitis C can cause liver damage, and, in rare cases, kidney damage too. In the UK, livers from hepatitis C positive donors have been used safely for more than 10 years to transplant into patients who already have liver damage caused by hepatitis C virus.

The health of kidneys that are offered for transplantation is carefully assessed by a series of blood and urine tests that are carried out on the donor before and after they die. Only kidneys with very little or no existing damage are used for transplantation. The same precautions will apply to kidneys from hepatitis C positive donors.

What are the risks to my family if I receive a kidney from a hepatitis C positive donor?

The risks to your family are very small. Transmission of the virus is through infected blood.

If you become infected with hepatitis C, we recommend that you do not share your toothbrush and razor blades with anyone until you have cured the hepatitis C. The virus is not transmitted through kissing and saliva. It can be transmitted through sexual intercourse, although it is

rare, so we recommend that you or your partner uses barrier contraception (condoms) until you are told that you have been cured of the virus.

How will I be treated if I receive a kidney from a hepatitis C positive donor?

After your transplant you will have a specific and very sensitive blood test to look for the presence of hepatitis C virus in your blood. The first blood sample will be taken within the first three to seven days of your transplant, then again within the first 14 days, six weeks and the last sample will be taken after three months from your transplant. If the tests remain negative three months after your transplant then your transplant organ has not passed the infection to you.

If any of these tests are positive for hepatitis C virus then the doctors looking after you will start you on highly effective treatment within three to ten days of the result. This means that you will be prescribed some specific antiviral tablets that you will need to take for a total of two months. This will consist of three extra tablets a day. During treatment you will have regular blood tests to make sure that the treatment is working and that the virus is disappearing from your blood.

Once the treatment is finished you will have further blood tests to check that you have cleared the virus. A final blood test will be taken 12 weeks after you complete the hepatitis C treatment, if this is negative you have successfully cleared the virus. We predict that more than 95% of patients will be cured. If the first course of treatment does not work then a second 12 week course of treatment using a different combination of tablets will be used which cures more than 95% of patients whose first course of treatment has not worked. It is worth mentioning that these new drugs for hepatitis C have few side effects (usually tiredness, diarrhoea, headache and nausea) in recent world experience and are generally very well tolerated by patients taking them.

What happens to me if I refuse to accept a hepatitis C infected kidney?

It is your choice whether you choose to receive a kidney from a hepatitis C virus infected donor. If you prefer not to accept an organ from such a donor you will remain on the transplant waiting list as now and you will continue to wait for a suitably matched organ.

Will I be entitled to compensation if I accept a kidney from a hepatitis C positive donor?

No, you will not be entitled to compensation as the current rules stipulate that you are entitled if you have unwittingly been infected. This would not be the case if you knowingly accept a hepatitis C infected kidney.

How do I consent to receive a kidney from a hepatitis C positive donor?

If you are interested or would like to know more, please contact us by phone or email (see below). A member of our team will contact to answer your questions.

To make sure you can be eligible, we will need one extra blood test of your liver and, potentially, an ultrasound scan of the liver. If this is within normal range, you will be asked to sign a check list to make sure that we have given you all the information you require to make this decision. However, if you have pre-existing liver conditions, you will not be eligible for this type of transplantation.

Where can I find out more information?

Please speak first to your transplant team if you have any questions about the information contained in this leaflet. Other sources of information are also available.

The Hepatitis C Trust is the national charity for people affected by hepatitis C and is patient-led. Staff on their confidential national helpline will be able to answer any questions you may have about hepatitis C and provide support and reassurance about the new treatments available. You can contact The Hepatitis C Trust on 0845 223 4424 or 020 7089 6221 and by email helpline@hepctrust.org.uk

There is also a lot of useful up-to-date general information on their website www.hepctrust.org.uk

The British Liver Trust has an excellent publication on hepatitis C that is free to access on the internet. The link to this is <https://www.britishlivertrust.org.uk/wp-content/uploads/Hep-C-website.pdf>

Contacts

If you have any questions or concerns, please do not hesitate to contact the Renal Transplant Team. You can either call us on 020 8725 0107 or email us at stgh-tr.hepcinfo@nhs.net

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

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

Tel: 111

AccessAble

You can download accessibility guides for all of our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.



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