NHS
Royal Papworth Hospital
NHS Foundation Trust

Transplantation of hearts from hepatitis C positive organ donors

A patient's guide and consent form

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Introduction

You are being asked to consider whether you would accept a heart transplant from a hepatitis C positive donor. The information in this booklet will help you decide.

What is hepatitis C?

Hepatitis C is a virus that is transmitted in blood and body fluids. 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 thirty 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.

Treatments for hepatitis C have changed greatly over recent years. It is now possible to cure nearly all patients who are infected with the hepatitis C virus. Treatment requires taking tablets for twelve 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 hepatitis C infected heart transplant?

There are not enough donated organs in the UK for all people who need a heart transplant. Due to recent breakthroughs in hepatitis C virus treatment it is now possible to consider using organs from donors infected with hepatitis C for transplantation. These donors are generally younger than average.

What are the risks to me if I receive a hepatitis C infected heart transplant?

The main risk of accepting a heart transplant from a hepatitis C virus infected donor is that you become infected with the virus yourself. You will be offered treatment to cure you of hepatitis C as soon as it has been confirmed that you have been infected. This will minimise the risk of any damage to you.

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

There is a very small chance that the hepatitis C virus may not disappear after the twelve weeks of treatment. 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. With the combination, the chance of not being cured is less than 1 in 2,000 (0.05%). Please discuss any further questions regarding this small chance that you would not be cured with a member of the transplant team.

Whilst all donors are routinely screened for 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 has happened to other patients who have been infected with hepatitis C at the time of an organ transplant?

There have been studies looking at the results of transplanting hearts from hepatitis C virus infected donors into patients who are not infected with hepatitis C. These have mainly taken place in the United States and patients have received treatment for hepatitis C within four weeks of the transplant.

In these studies, all recipients became infected with hepatitis C if the virus was detectable in donor blood. All recipients were then cured of hepatitis C with antiviral treatment. Importantly, the transplanted hearts worked very well, and the overall outcomes were the same as patients who received hearts from hepatitis C negative donors.

How do I know that the heart from the hepatitis C infected donor has not been damaged by the virus?

Hepatitis C can, in rare cases, cause heart damage. The health of hearts that are offered for transplantation is carefully assessed by a series of blood tests, scans and measurements of function carried out on the donor. Only hearts with very little or no known pre-existing damage are used for transplantation. The same precautions will apply to hearts from hepatitis C virus infected donors.

Are there any risks to my family if I receive a hepatitis C infected heart transplant?

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

Until you are cured of hepatitis C, which should happen within the first three to four months after the transplant, we recommend that you do not share your toothbrush and razor blades with anyone. The virus is not transmitted through kissing and saliva. The virus 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 hepatitis C infected heart transplant?

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. Blood tests will be taken on days 3, 7 and 10 and then weeks 2, 4 and 6 after your transplant. If all the virus tests are negative then your transplant organ has not passed on the infection to you.

If any tests are positive for hepatitis C then the doctors looking after you will start you on highly effective treatment very soon after we receive the result. This means that you will be prescribed antiviral tablets that you will need to take for twelve weeks. This will consist of up to three extra tablets a day. The exact number will depend on what treatment the doctors think is best suited to you.

During treatment you will have regular blood tests to make sure that the virus is disappearing from your blood. Once the treatment is finished you will have further blood tests to check that you have been cured. If the virus cannot be detected twelve weeks after the treatment has stopped then you have been cured. If you are not cured by the first course of antiviral treatment, then you will be offered a different antiviral treatment that is highly effective in patients that have not responded to first-line treatment.

It is worth mentioning that these new drugs for hepatitis C have very few side effects and are very well tolerated by patients and there is no interaction with other post-transplantation medications.

What happens to me if I decide not to accept a hepatitis C infected heart transplant?

It is your choice whether you choose to receive a heart transplant from a hepatitis C virus infected donor. If you prefer not to accept an organ from such a donor then you would continue on the waiting list as normal whilst awaiting a suitable organ/donor.

Will I be entitled to compensation if I accept a hepatitis infected heart transplant?

No, you will not be entitled to compensation as the current rules stipulate that you are only entitled if you have unwittingly been infected.

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

PIC 211: patient agreement to PI 211 - Transplantation of hearts from hepatitis C positive organ donors

This form should only be completed after reading ‘PI 211 Transplantation of hearts from hepatitis C positive organ donors’ and discussing this with a member of the transplant team. If there is anything you do not understand, or if you need any additional information please ask.

You may withdraw your consent at any time (even after signing this form). This form confirms you are willing to receive a heart transplant from hepatitis C positive donor.

You will be provided with more information on the day of the transplant and still have the option to decline the offer at any time.

- ☐ I confirm that I have received a copy of the patient information booklet relating to hepatitis C positive organ donors and have had the opportunity to discuss this with a member of the transplant team.
- ☐ I confirm that the risks and benefits of accepting an organ offer from a donor who has hepatitis C.
- ☐ I understand that if I receive a transplant from a hepatitis C positive donor then I will need to have several extra blood tests after the transplant to check whether the virus has been passed to me.
- ☐ I understand that if I develop hepatitis C as a result of receiving a transplant then I will need to have a course of tablet medication to treat this. The treatment is safe and highly effective but in a very small number of patients (less than 1 in 2,000) this treatment may not work.

Patient

Patient signature: ……..……........…....................

Date: ………...

Name (PRINT): ………….......…......................

Healthcare professional

On behalf of the team treating the patient, I have confirmed with the patient that they have no further questions and wish the procedure to go ahead.

Signed: ……………........………….........…......

Date: ………..

Name (PRINT): ………….....................................

Job title: …………...

Contact details

....

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Top copy to be filed in medical notes, carbon copy to be retained in booklet for patient.

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

Statement of interpreter (where appropriate)

I have interpreted the information above to the patient to the best of my ability and in a way which I believe they can understand.

Signed: ……………………..........….....…..........…...............

Date: …………..……………......

Name (PRINT): ..…………………................................

If a telephone / video service has been used, please document the name of the interpreter and company below

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Important notes (tick if applicable).

☐ Patient has advance decision to refuse treatment

☐ Patient has withdrawn consent (ask patient to sign/date here)

Patient signature: ……...………….........…….……..

Date: …………...…

Name (PRINT): ..……………........….....................

Top copy to be filed in medical notes, carbon copy to be retained in booklet for patient.

Where can I find 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 about the new treatments available - you can reach them on **0845 223 4424** and by email: **helpline@hepctrust.org.uk**

There is also a lot of useful up-to-date general information on their website: **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:

britishlivertrust.org.uk/wp-content/uploads/Hep-C-website.pdf

Recommended summary plan for emergency care and treatment (ReSPECT)

ReSPECT stands for ‘Recommended summary plan for emergency care and treatment’. It is a process that helps people to think about what treatment is suitable in an emergency, should they be unable to make decisions at the time.

You can find further details about this in the accompanying leaflet, PI 231 - heart transplant - patient information and consent.

Notes:

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Large print copies and alternative language versions of this leaflet can be made available on request.

View a digital version of this leaflet by scanning the QR code.

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