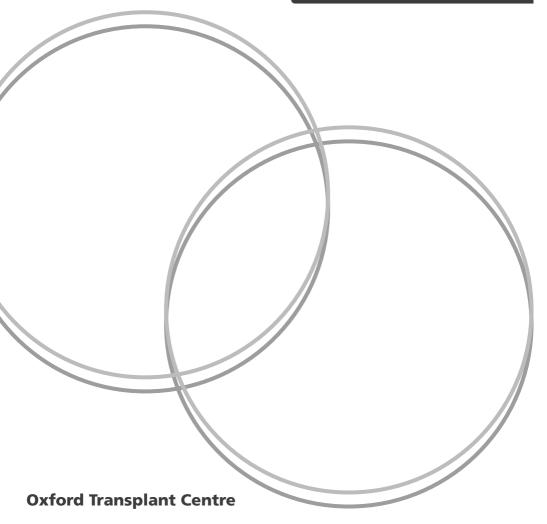


## Transplant Waiting List: Hepatitis C Donor Organ

Information for patients



This leaflet has been written for you to help you decide whether or not you would accept a transplant from a hepatitis C virus infected donor.

The benefits of using this potential supply of organs for people on the UK transplant waiting list has been endorsed by the UK transplant community. It is now being rolled out across UK transplant units. If you still have any questions after you have read this leaflet please speak to a member of the transplant team.

## What is hepatitis C?

Hepatitis C is a virus that is transmitted through blood and body fluids. The hepatitis C virus lives in the liver and blood of infected people. It can cause inflammation and scarring of the liver. The scarring can be severe, although it usually takes 30 years for the scarring to become life-threatening in people who have not had a transplant.

Severe scarring may develop more rapidly in people who have had any transplanted organ and are taking drugs that suppress their immune system.

Treatments for hepatitis C have changed enormously over recent years. It is now possible to cure nearly all people who are infected with hepatitis C. Treatment requires taking tablets for 12 weeks. Once the virus is fully treated it does not come back and does not affect your long term health.

# Transplants from hepatitis C infected donors

There are not enough donated organs in the UK to transplant into all people who may need them. Due to recent huge 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 and may be healthier, with lower blood pressure and less heart disease or other medical conditions. This means their donated organs may be of higher quality than an older person.

Transmission of certain viruses from the donor to the recipient is already part of the recognised but acceptable risks of organ transplantation. This move to expand the donor pool to include donors with hepatitis C has followed a national consultation process.

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

#### What are the risks to me?

The main risk of accepting a transplant from a hepatitis C virus infected donor is that you may become infected with the virus yourself. This is true for other viruses too (such as the herpes virus), some of which are more difficult to treat than hepatitis C.

You will be offered treatment to cure you of the hepatitis C virus as soon as is has been confirmed that you have been infected. This will minimise the risk of any damage to your liver.

If the hepatitis C virus infection is not treated, you could become jaundiced (yellow) and may develop a rare severe inflammation in your liver (called fulminant cholestatic hepatitis). In the longer term (about 3 to 6 months) the hepatitis C may also start to cause damage to your transplanted organ. There is a very small chance that the hepatitis C virus may not disappear after 12 weeks of treatment (see page 6). 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 have been shown to be highly effective in curing people whose hepatitis C treatment has failed with other drugs.

96 to 98% of the people who have not responded to the first treatment will be cured by this medication. It is very unlikely that we won't be able to cure the hepatitis C. Only 1 person in 2,500 will not be cured.

Please speak with your transplant doctor or surgeon if you have any further questions about the treatment of hepatitis C.

## Why are we now using hepatitis C donated organs?

There have already been several studies looking at the results of transplants from hepatitis C virus infected donors into people who are not infected with hepatitis C. These have mainly taken place in the United States, but there are also other transplant units in the United Kingdom that are already using donated organs.

Patients who received treatment for hepatitis C within 4 weeks of the transplant were then cured of hepatitis C. Importantly, the transplants then went on to work very well.

The outcomes for the people who received an organ from hepatitis C infected donors were the same as those for people who received transplants from donors without hepatitis C.

#### **Screening before transplantation**

Hepatitis C can, in rare cases, cause kidney damage. The health of organs that are offered for transplantation is carefully assessed by a series of blood and urine tests, which are carried out on the donor. Only organs with very little or no known pre-existing damage are used for transplantation.

#### What are the risks to my family?

The risks to your family are very small. Transmission of the hepatitis C virus is mainly through infected blood and body fluids. Until you are cured of hepatitis C, which should happen within the first 3 to 4 months after the transplant, we recommend that you do not share your toothbrush or razor blades with anyone.

The virus is not transmitted through kissing and saliva. However, it can be transmitted through sexual intercourse, so we recommend that you or your partner uses barrier contraception (condoms) until you are told that you have been cured of the virus. The advice for any organ transplant is that you should not attempt to conceive a baby within the first year. You will be given more information about this.

### What will happen if I receive a hepatitis C infected transplant?

After your transplant you will have a specific and very sensitive blood test to look for the presence of the hepatitis C virus in your blood. We will do this as part of your routine blood tests.

If any of the tests are positive for hepatitis C we will prescribe you specific antiviral medication. You will need to take this for a total of 12 weeks.

The exact dose will depend on what treatment the doctors think is best for you. During the treatment you will have regular blood tests to make sure that it is working and the virus is disappearing from your blood.

When the treatment is finished you will have further blood tests to check that you have been cured of the virus. If the virus disappears from your blood and cannot be detected 12 weeks after the treatment has stopped then you have been cured. If the first course of treatment does not work, you will be started on a second 12 weeks course of a different medication.

These new drugs for hepatitis C have very few side effects and are generally very well tolerated. Your transplant team will talk to you about side effects.

### Where can I get more information?

#### **British Transplantation Society**

Information about transplantation. Website: <u>www.bts.org.uk/british-transplantation-society-statement-on-consultation-to-review-policy-on-organ-donation-copy</u>

#### **Oxford Transplant Centre**

Information about the Oxford Transplant Unit. Website: <u>www.ouh.nhs.uk/services/departments/renal/transplant</u>

#### **NHS** website

Information about kidney transplants. Website: <u>www.nhs.uk/conditions/kidney-transplant</u>

If you have any further questions, please speak to a member of the transplant team.

#### **Further information**

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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