

Patient Information Leaflet for the Use of Hepatitis C Infected Organs in Hepatitis C Negative Recipients

Introduction

You are being asked to consider whether or not you would accept a kidney transplant from a hepatitis C virus infected donor. The information in this leaflet will help you decide whether or not you would accept a kidney transplant from a donor who has had hepatitis C.

What is hepatitis C?

Hepatitis C is a virus that is transmitted in infected 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 (this severe liver scarring is called "cirrhosis"), 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.

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 12 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 kidney transplant?

There are not enough donated organs in the UK to transplant into all people who may need them.

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 less heart disease and other medical conditions. Hence their donated organs may be of higher quality than average.

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

The main risk of accepting a kidney 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 the hepatitis C virus as soon as it has been confirmed that you have been infected. This will minimise the risk of any damage to you.

If 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 case of untreated hepatitis C infection, in the longer term, this may result in kidney injury

There is a very small chance that the hepatitis C virus may not disappear after the 12 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 2000) that the transplant team will not be able to cure you of the virus if you are infected. Please discuss with your Transplant Doctor or Surgeon if you have any further questions regarding this small chance that you would not be cured by treatment with these tablets.

Whilst all donors are routinely screened for the presence of other blood borne infections in addition to hepatitis C, such as HIV or hepatitis B, the screening tests can very rarely miss infections with these viruses. There is therefore a very small possibility that these or other infections could also be transmitted at the time of transplantation even if the initial screening tests are negative. For this reason, all patients receiving a kidney from a patient with hepatitis C will also have blood tests taken every two weeks (taken at the same time as your other clinic blood tests) to look for these other infections. We will do this for the 12 weeks following your transplant. If your testing for these other viruses is negative, no further testing would be required as the negative tests will have shown that you have not been infected. If any of these blood tests come back with a positive result for another virus, these can be treated very effectively and your transplant team will discuss this with you further.

What has happened to other 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 patients have received treatment for hepatitis C within 4 weeks of the transplant. In these studies every recipient was cured of hepatitis C. Importantly, the transplanted 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.

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

Hepatitis C can in rare cases, cause kidney damage. The health of kidneys from all donors 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 known pre-existing damage are used for transplantation. The same precautions will apply to kidneys from hepatitis C virus infected donors.

Are there any risks to my family if I receive a hepatitis C Infected kidney 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 virus, which should happen within the first 3 to 4 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. Because of some of the other drugs you may have been started on around the time of your transplant, some patients may need to use barrier contraception for a longer period of time after their transplant. If you are not sure whether this relates to you, please ask your transplant team doctor and they will be able to advise you.

How will I be treated if I receive a hepatitis C infected kidney 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.

The first blood sample will be taken within the first 7 days of your transplant, then again within the first 14 days and the last sample will be taken within the first 6 weeks of your transplant. If all the virus tests are negative then your transplant organ has not passed on 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 very soon after we receive the result. This means that you will be prescribed some specific antiviral tablets that you will need to take for a total of 12 weeks. This will consist of either 1 extra tablet or 3 extra tablets a day. The exact number will depend on what treatment the doctors think is best suited to you. Once 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. We predict that more than 95% of patients will be cured. If the first course of treatment does not work then a second 12 weeks 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 very few side effects in recent world experience and are generally very well tolerated by patients taking them.

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

It is your choice whether you choose to receive a kidney transplant 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 hepatitis C infected kidney transplant?

No, you will not be entitled to compensation. Although there is a compensation scheme (Skipton Fund) for patients that have been unknowingly infected with hepatitis C, this would not be the case if you knowingly accept a hepatitis C infected kidney transplant.

Where can I find out more information?

Please speak first to your transplant doctor 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 reach them on 0845 223 4424 or 020 79089 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>.