Royal Papworth Hospital
NHS Foundation Trust

Transplant and Humanherpes Virus (HHV-8)

A patient’s guide

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What is humanherpres virus?

There are eight types of human herpesviruses that are commonly seen these are:

- Herpes simplex virus-1 (HSV-1, HSV-2).
- Varicella-zoster virus (VZV).
- Epstein-Barr virus (EBV).
- Cytomegalovirus (CMV).
- Human herpesvirus 6 (HHV-6).
- Human herpesvirus 7 (HHV-7).
- Human herpesvirus 8 (HHV-8).

This leaflet covers HHV-8 specifically and it's relevence to transplant patients.

Most people will get herpes viruses as children or young adults. When you first get the virus, your immune system will make proteins called antibodies to attack it. These antibodies will then stay in your blood, looking out for the virus. But unlike most types of viruses, herpes viruses can remain in your body and go dormant, making them undetectable to these antibodies. This is called 'latency'.

When the virus is inactive, it doesn't cause any problems. But if your immune system isn't working properly, the virus can become active again.

What is Humanherpes virus 8 (HHV-8)?

HHV-8 is the newest herpes virus discovered. It is less common in the UK than other herpes viruses. Only about 1 in 20 people in the UK have HHV-8. There is no treatment that will get rid of HHV-8, however there are ways to treat the problems it can cause.

HHV-8 and heart/lung transplants

After your transplant you will need to take strong medicines to suppress your immune system. These will stop your immune system attacking your new organ. The problem is they will also make your immune system less effective at dealing with viruses and other infections.

This means that after a transplant, HHV-8 can come out of hiding if you already have it. If you get it for the first time through your new Heart/Lung, there is a chance the virus will make you ill. In rare cases the virus can then cause serious problems. This can include damaging your new organ, causing your immune system to become over-active or causing rare types of cancer such as Kaposi’s sarcoma and lymphoma.

If you get HHV-8 from a Heart/Lung transplant you will have extra tests and monitoring to look for these problems. This will help to find and treat them early. Some people who get HHV-8 from a transplant will never have any problems from it.

Testing for HHV-8

Organ donors and people having transplants have been tested for other types of herpes viruses for many years.

Since June 2023, all deceased organ donors in the UK have also been tested for HHV-8. A special test is needed for this. This test is more difficult to perform and takes longer than other herpes virus tests.

At the moment the HHV-8 test results come after the transplant has happened, however, this may change in the future as new tests become available.

What are my chances of getting HHV-8 from my transplant?

The new testing programme for HHV-8 has helped us collect data about the virus, how often it is passed on, and how often it causes problems.

Because the virus is quite rare, there have only been a few cases of it being passed on through a transplant. This means it is hard to know exactly what the risks are. This will improve over time as more information is collected. The numbers shown here (June 2023 to December 2024) may go up or down in the future.

How likely is it that my donor had HHV-8?

Around 1 in 20 deceased donors has HHV-8.

How likely is it that I will get HHV-8 from my new heart/lungs?

In a UK case series, the observed transmission rate was 52% (14/27) however this is based on the diagnosis of HHV-8 disease in recipients and not donor or recipient testing pre-transplant.

Some reports suggest that donor transmission events are more frequent in lung transplant recipients than heart transplant recipients.

What happens if I get HHV-8 from my transplant?

If you or your donor are diagnosed with HHV-8, your medical team will monitor your condition closely. However, there are currently no effective treatments for HHV-8 itself or treatments to prevent its transmission. Treatment is aimed at the illnesses it causes.

You will be monitored very closely. This includes:

- Regular clinic visits
- Blood tests
- Monitoring for symptoms (not just for HHV-8 but for other post-transplant risks)
- Other tests if needed

How will we manage the HHV-8 virus if you become symptomatic

If you get an HHV-8-related disease, your medical team can change your treatment quickly. This may include:

- Changing your immunosuppressive medicines (drugs to help prevent rejection)
- Giving you treatment for the symptoms of HHV-8 related disease
- Giving you anti-cancer medicines if necessary

How likely is it that I will die from HHV-8 picked up from a heart/lung transplant?

- Data for heart and lung transplant recipients is limited, and so generalised transplant data must be used at present until a clearer picture becomes available.
- Of the 14 patients who had a diagnosis of HHV-8 related disease, 72% (10/14) patients presented with symptoms of HHV-8. 50% (7/14) of those who had a diagnosis of HHV-8 died (date of findings). Again, we need to consider that these numbers are based on a diagnosis of HHV-8 disease and not testing donors, and so the true infection rate is currently not known.

How should this affect my decision about a transplant?

For any type of medical treatment, you and your medical team should weigh up the risks and benefits. If you are on the transplant list, then you are probably very unwell. Without a transplant the risk of becoming even more seriously ill or of dying is likely to be high.

The risk from HHV-8 if you do have a transplant is low. It is also far lower than for some of the other possible complications of having a transplant. But having a transplant is a big decision. Your medical team will be able to talk to you about all the possible risks and answer all your questions.

The information contained in this leaflet was taken from:

INF1764/1 January 2025

You can view the full report here:

nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/35335/inf1764.pdf

Key points

- HHV-8 is a type of herpes virus.
- In very rare cases, it can be passed on from an organ donor to a person having a heart or lung transplant.
- People who have had a transplant have a higher risk of serious problems caused by the virus.
- It is not possible to find out before a transplant if a donor has the virus, and so there is no option to exclude these donors when considering organs for transplant.
- Testing means that anyone who gets the virus after a transplant can have extra tests and monitoring to look for any problems it may cause.
- There is no cure for the virus, but there are ways to treat the problems it can cause.
- If you are on the transplant list, then it is likely that the risk of not having a transplant is much higher than the risk from the virus.

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