CMV & Me: Information for Transplant Patients

What is cytomegalovirus (CMV)?

CMV is a common virus infecting people of all ages. It belongs to the family of herpes viruses. CMV does not usually cause serious problems in healthy people, but it is the most important serious infection affecting transplant patients.

CMV can be described as either an infection or a disease. CMV infection means that there is CMV reproducing; or making copies of the virus. CMV disease means that the virus has caused damage to an organ and is causing symptoms to occur.

As a transplant recipient, am I at risk for CMV? How can I get CMV?

It is estimated that 50-80 percent of the population in the United States has been infected with CMV. Once CMV infects a person, it stays dormant in his or her body for life. Most people do not have signs or symptoms, but the virus can reactivate when the person's immune system is weakened.

Transplant patients may already have been exposed to CMV before their transplant. It is also possible for a transplant patient to receive a donor organ that has been infected with the virus. In rare situations, a transplant patient may become infected with CMV either as a result of contact with the virus within the community or after receiving blood that is CMV positive.

Will I be tested for CMV before my transplant? Will my donor also be tested for CMV before the transplant occurs?

Transplant patients are screened for CMV both before and after the transplant occurs, and donors and donor organs are tested before transplantation. As part of their transplant evaluation, patients have blood samples drawn to determine if they have the virus.

If I test positive for CMV, will I have to wait longer for my transplant?

CMV status will not delay your transplant. However, there may be more of a risk for potential organ transplant recipients if they are CMV negative. This is because they run the highest risk of receiving a primary infection either from receiving a CMV-positive organ or from the community while their immune system is at its weakest.

It is preferred that a CMV-negative patient receive a CMV-negative organ, but this is not usually possible. When CMV-negative patients receive a CMV positive organ, most transplant centers will note the patient as high-risk. Due to better antiviral medications and protocols, we lessen the risk of getting CMV if patients are treated with antiviral therapy for longer periods of time. When an organ becomes available, the best possible decision will be made for each potential recipient based on many factors, with CMV status as only one of those factors.

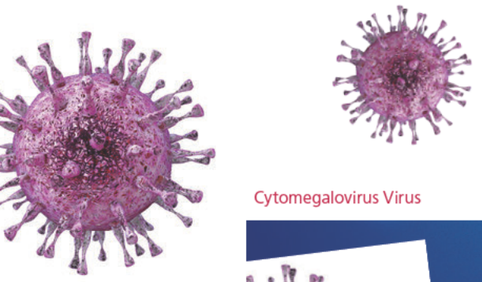
CMV & Your Immune System

Patients with weakened immune systems, including transplant patients, may develop more serious complications from CMV infection, including, but not limited to these:

- Gastrointestinal disease
- Pneumonia
- Hepatitis

Your healthcare provider may administer either blood or urine tests to determine if you have CMV. A tissue biopsy can also confirm the diagnosis.

A CMV infection may occur more than once. Because CMV stays in a person's body for life, it is possible for someone to have more than one infection. If a person's immune system is weak, the chances of a CMV infection reoccurring is greater.



Cytomegalovirus Virus

CMV & Infection

How long after an organ transplant can I get a CMV infection?

A CMV infection may occur during the first month after a transplant, but it is also possible for a reactivation of the patient's pre-existing CMV infection to develop after this time period. This is one reason why it is so important to stay in close communication with your transplant team and follow treatment plans exactly as directed.

How do I know if I have a CMV infection? Can my healthcare provider test me for CMV?

Healthy adults with a CMV infection may experience mild illness. Symptoms of CMV may include, but are not limited to the following:

- Fatigue
- Joint stiffness
- Loss of appetite
- Fever
- Swollen glands

Can CMV affect my transplanted organ? Can it affect my overall health?

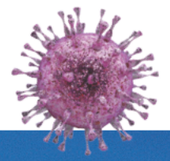
CMV may cause serious disease in multiple organs and lead to infection if left untreated. It may also cause injury to the transplanted organ and, in some cases, organ rejection.

Is CMV preventable and how is it treated?

Once CMV is in the body, it stays there for life. CMV can be treated with the use of medications. These medications can be given either as a precaution to high-risk patients (before possible infection) or when a CMV-related infection is confirmed. It is very important for transplant patients to stay in close communication with their transplant team and follow treatment plans exactly as directed.

What should I do if I think I have a CMV infection?

If you think you may have a CMV infection, you should see your health are provider, listen carefully to his or her instructions, and take all medications exactly as directed.



Healthcare Provider Visit CMV Question Checklist

Before & After Transplant

Working closely with your doctor and transplant team is an important step in the transplant process. The questions below are meant to serve as a guide to help you discuss your individual plan with your transplant team.

Before Your Transplant

- What types of healthcare providers will be part of my transplant team?
- What medical tests will I need before the transplant?
- Will I be tested for CMV? Will my donor be tested for CMV?
- What other kinds of tests will we have?
- What will happen if I test positive for CMV? What will happen if my donor tests positive for CMV?
- If my donor tests positive for CMV, will he or she no longer be permitted to donate the organ?
- If I test positive for CMV, will I need to take medication before my transplant?

After Your Transplant

- What steps will I need to take to help prevent my transplanted organ from developing a CMV infection?
- Will I be tested for CMV after my transplant? What kinds of tests will I have?
- What will happen if I test positive for CMV after my transplant?
- What medication will I need to take so I can minimize my risk for developing a CMV-related infection? How often do I need to take my medication?
- What might happen if I do not take my medication as directed?
- How will I know if I have a CMV-related infection? What should I do if I think I have a CMV-related infection?
- What else can I do to help protect myself against CMV?

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Tips for Families & Caregivers

One of the most valuable things you can do as a caregiver is to offer support. You can help by ensuring your loved one does these things:

- Sees his or her doctor or transplant team regularly.
- Takes all of his or her medicine as directed by doctor or nurse.
- Seeks prompt medical attention for any signs or symptoms of CNV infection.
- Stays informed about his or her health.
- Asks doctor or transplant team any questions about his or her health or the health of the transplanted organ.

Screening Donors for CMV

In some cases, living donors who have donated an organ to a loved one may feel guilty about the possibility of passing on CMV. Prior to the transplant, the doctor and transplant team will screen the live donors and determine the risk of transplanting a donated organ that is CMV-positive. With the help of a doctor or transplant team, this situation will be closely monitored.

Helpful Resources

Listed below are sites you and your caregivers may find useful.

- www.itns.org/index.php
- www.cdc.gov/cmv/ index.html
- www.nlm.nih.gov/medlineplus/ency/article/000663.htm

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REFERENCES: This information is provided by Genentech, a member of the Roche Group. | Jointly developed by the International Transplant Nurses Society and Genentech, a member of the Roche Group.

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