Cytomegalovirus (CMV) is a type of virus in the herpes family—the kind of viruses that also causes chicken pox, shingles and cold sores. It’s a common virus and most people in the US (about 2 in 3) have the virus by the time they turn 40. It can infect people of all ages, and is the most common virus passed onto a pregnant woman’s unborn baby. Almost all gay and bisexual men are infected with CMV, and more than 3 out of 4 people with HIV carry the virus.

Once a person gets CMV, it stays in his/her body for life. But most of the time, it doesn’t cause disease. This is because a healthy immune system keeps it under control in most people. Although CMV disease was a major cause of death earlier in the epidemic, it’s seen much less often now due to today’s potent HIV treatment. However, among those with HIV, having CMV is a major risk of sometimes difficult CMV disease.

How is CMV spread?
CMV is easily passed from person to person through close contact with body fluids, such as saliva, semen, vaginal fluids, blood, urine, tears and breast milk. You can get CMV when you touch these fluids and then touch your eyes, nose or mouth. People can also get CMV through sex and breastfeeding, but rarely from blood transfusions and organ transplants.

Contact with the saliva or urine of young children is a major cause of CMV infection among pregnant women and other children. For these women, 1 out of 3 of them will pass it onto their unborn babies. This contrasts with women who already have CMV before their pregnancy, because less than 1% of them pass CMV onto their unborn babies.

How do you prevent infection?
You may already have CMV, and your doctor can test for it. However, people can take steps to lower their risk of infection, even though it’s nearly impossible to avoid in everyday life. Washing your hands often and well and using condoms during sex may help prevent CMV infection.

CMV is common in young children so being careful around them will help prevent infection. This may be nearly impossible to avoid while parenting, in households with children, day care centers and schools. However, some suggestions include:

- Washing your hands after contact with children; after contact with their saliva, tears or urine; or after contact with objects that they’ve touched such as cups, pacifiers, utensils, toys and diapers. Refraining from touching your eyes, nose and mouth in these situations is important, as well as not sharing food or drinks with them.

How can you tell if you have infection?
When a person is first infected with CMV, it typically doesn’t cause symptoms. If they are present, symptoms might include fatigue, swollen glands, fever and sore throat. Since these are flu-like symptoms, most people don’t know when they get CMV.

Several tests can find CMV, including blood or urine culture tests, blood tests to find either the virus or its antibodies, and body tissue samples. If the test comes back positive, it means you have CMV infection. Read page 2 for more information on CMV disease.
How do you prevent disease?

While most people with HIV also have CMV, not all will develop CMV disease. People with very low CD4s are most at risk for the disease, but there are medicines that can help suppress CMV and prevent its disease.

The most effective way to prevent CMV disease is by getting the best care you can for your HIV. This keeps your immune system intact and increases CD4s. If your immune system shows signs of damage like CD4s below 50, taking preventive therapy is an important decision to make.

CMV disease most often affects the eye in people with HIV. So seeing an experienced eye doctor, called an ophthalmologist, can help prevent CMV retinitis.

Finally, the drug Cytovene (ganciclovir) is used to prevent CMV disease in people with CD4 counts below 50 or with other signs of weakened immune systems. Talk with your doctor about the pros and cons of using the drug because of its side effects, lack of proven benefit, cost and risk for developing resistance to it. Some people who start preventive therapy can stop it once their CD4s go back above 100–150 and stays there beyond 6 months.

How can you tell if you have CMV disease?

CMV disease most often affects people when their CD4s fall below 50. You may also be at risk if you have a slightly higher count (50–100) and have had at least one other opportunistic infection. A blood test can measure the level of CMV though it doesn’t always mean there’s active disease.

CMV disease can be found in almost any part of the body, sometimes in more than one place at a time. In people with HIV, CMV seems prone to infect one or both eyes. If you think you have symptoms, talk to your doctor as soon as possible.

DISEASE OF THE EYE

CMV retinitis is damage to the back of the eye (retina) and it remains the leading cause of blindness. Symptoms include blurred vision, blind spots or floating spots in the affected eye. Even if treatment is successful, any damage can be permanent. Left untreated, CMV retinitis will lead to blindness.

DISEASE OF THE COLON

CMV colitis is the second most common CMV disease in people with HIV. Symptoms include diarrhea, weight loss, loss of appetite, pain in the stomach or chest, blood in the stool, diarrhea and fever. These are common for many different conditions in HIV disease, which can make it difficult to diagnose. Disease in the upper gut is called CMV gastritis.

DISEASE OF BRAIN & NERVES

Infection of the brain is called CMV encephalitis. Symptoms include dizziness, headaches, seizures, personality changes and nervous system problems. Death can occur within weeks or months.

Infection of the nerves is called polyradiculopathy. Symptoms include numbness, pain and tingling in the legs, feet, arms and hands, and the loss of muscle, urinary and bowel control, which are common symptoms of other OIs.

DISEASE OF THE THROAT

CMV esophagitis affects the throat. Symptoms include difficult and painful swallowing, chest pain, fever, mouth sores and hiccups.

DISEASE IN NEWBORNS

Congenital CMV is the most common infection in newborns. About 1 in 10 babies born with it have symptoms such as a rash, low birth weight, small head, jaundice, and large spleen and liver.
How do you treat disease?

Treating CMV disease happens in 2 stages: induction and maintenance therapy. Induction therapy is used when the disease first appears and usually takes 2–3 weeks. Maintenance therapy is used to prevent it from returning.

Treatment depends on the type of CMV disease as well as how severe it is. People with CMV retinitis can take medicine by mouth, implants in the eye (ocular implants), injection or IV line, and may be given more than one drug at a time. Because several of the drugs are given by IV, they may impose changes in a person’s lifestyle. These medicines can interact with many drugs, including some HIV drugs and common drugs like NSAIDs. Learn about possible drug interactions by reading the package insert of your prescription or talking to your doctor or pharmacist.

GANCICLOVIR (CYTOVENE)
Ganciclovir can be used to treat all forms of CMV disease. It’s given by IV or as a pill. For induction therapy, it’s given by IV twice a day for 2–3 weeks. For maintenance, it’s given either by IV once a day for 5–7 days per week or by capsule 3 times a day. Possible side effects include low red blood cells, nausea, diarrhea, vomiting, fever, stomach pain, loss of appetite, confusion, dizziness and headache. Ganciclovir should be refrigerated and kept out of direct light.

Ganciclovir is given by IV at treating CMV disease. The side effect for ganciclovir is low neutrophils, which are important cells for fighting bacterial infections. For foscarnet, it’s kidney toxicity.

FOSCARNET (FOSCAVIR)
Foscarnet can be used to treat all forms of CMV disease, given by IV. For induction therapy, it’s given 2 or 3 times a day for 2 or 3 weeks. For maintenance, it’s given once a day. Possible side effects include kidney damage, low red blood cells, nausea, diarrhea, vomiting, fever, stomach pain, loss of appetite, confusion, dizziness and headache. Foscarnet should be refrigerated and kept out of direct light.

Ganciclovir and foscarnet are equal at treating CMV disease. The side effect for ganciclovir is low neutrophils, which are important cells for fighting bacterial infections. For foscarnet, it’s kidney toxicity.

VALGANCICLOVIR (VALCYTE)
Valganciclovir is the only approved oral treatment and is as effective as IV ganciclovir for treating CMV retinitis. For induction therapy, it’s given as two 450mg tablets twice a day for 3 weeks. For maintenance, it’s given as two 450mg tablets once a day. Possible side effects include low red or white blood cells, low platelets, nausea, vomiting, diarrhea, constipation, stomach pain, loss of appetite, thirst, fever, constipation, headache, back pain, leg swelling and trouble walking or sleeping.

Oral therapy does not cause neutropenia. It also avoids other complications like sepsis that can occur when using an IV.

CIDOFOVIR (VISTIDE)
Cidofovir is used for CMV retinitis and may be effective for other forms of the disease. It’s given by IV with probenecid (to help prevent kidney damage from the cidofovir). For induction therapy, it’s given once a week for 2 weeks. For maintenance, it’s given once every 2 weeks. Possible side effects include kidney damage or failure and low white blood cells.

Cidofovir is taken once a week, but its serious side effects makes it less desirable to use. It’s more often used when the other therapies are no longer suitable due to resistance, failure or side effects.

GANCICLOVIR IMPLANT
This implant is only used for CMV retinitis and does not prevent disease in the other eye. It’s a pellet that’s surgically implanted and changed about every 6 months, releasing drug over time. Possible side effects include low white blood cells as well as discomfort from surgery and some loss of clear vision, both of which are usually temporary.

FORMIVIRSEN (VITRAVENE)
Formivirsen is used to treat CMV retinitis for patients who have failed other therapies. It’s given as a shot into the affected eye. For induction therapy, it’s given every other week for 2 doses. For maintenance, it’s given once every 4 weeks. Possible side effects include minor pain, redness or swelling of the eye.
What about resistance?

One of the concerns with some of the drugs used to prevent and treat CMV disease is the issue of resistance. CMV can become resistant to the drugs, which then makes it harder for them to control the disease. As well, resistance to one drug may lead to developing resistance to the others. Ganciclovir is one of the drugs that CMV can develop resistance to rather easily, as well as foscarnet and cidofovir.

Concerns for children

Preventing congenital CMV helps prevent the type of disabilities that may occur after birth and during a child’s lifetime. Although most babies born with CMV grow up with normal health, some with symptoms at birth are more likely to have permanent disabilities and symptoms that get worse. These can include hearing and vision loss, mental disability, and liver and spleen problems, among many others. If a newborn is found to have congenital CMV, it’s advised to get his or her hearing and vision tested regularly. Babies infected after birth are not at risk for disabilities.

How can I get the medicines to treat CMV?

CMV medicines are available by prescription through a health provider. Most states also cover these drugs through their ADAPs (AIDS Drug Assistance Programs). To see if you’re eligible for your state’s ADAP and to find out if these therapies are covered by it, contact your state department of public health, state Office of AIDS, or state ADAP. Information is also available through the AIDS Treatment Data Network at 1-800-734-7104, or visit www.atdn.org and click on “Access Project.” People who can’t otherwise afford the drugs can sometimes get them through the manufacturers’ Patient Assistance Programs.

- Ganciclovir insert: 1-800-843-1137
- Valganciclovir: 1-800-443-6676, www.rocheusa.com
- Cidofovir: 1-800-226-2056
- Foscarnet, Foscavir: 1-800-488-3247

Concerns for pregnant women

If you’re pregnant or plan to become pregnant, a CMV test can help you know how careful you must be to prevent CMV infection. If the test is positive, there’s little chance that your unborn baby will be harmed by CMV — unless your infection occurred in the few months before your pregnancy. If the test is negative, the best way to protect unborn babies from CMV is by using good hygiene before and during pregnancy.

If your doctor finds that you had a new CMV infection during pregnancy, this does not mean that your unborn baby is infected. In many cases, you can have CMV without it spreading to the baby. However, CMV drugs would not be used because they have serious side effects and are not approved for pregnant women. The only way to know if a newborn has CMV is by testing within the first 3 weeks after birth.

What research is being done on CMV?

Currently, scientists are working to develop a vaccine and other methods that prevent CMV infection, especially for an unborn baby, although so far it hasn’t shown enough protection. Scientists are also working to develop new medicines that may be more effective, cause fewer side effects, can be used in pregnant women, and are not as prone to resistance as the currently approved drugs.