

CMV IN PREGNANCY

A guide to ante-natal
Cytomegalovirus
(CMV) infection



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Introduction

CMV IS THE MOST COMMON INFECTION PASSED FROM MOTHER TO BABY BEFORE BIRTH

CMV, or Cytomegalovirus, is a common virus that can infect people of all ages. Most healthy adults and children will have no signs or symptoms and no long-term effects.

However, it can pose serious problems if a woman catches CMV during pregnancy, and passes it on to her unborn baby, particularly in early pregnancy. Congenital CMV (when the infection is passed from mother to baby across the placenta) is the most common non-genetic cause of sensorineural hearing loss and a major cause of childhood disability.

Despite this, there is very little awareness of CMV and the facts are often misunderstood. A diagnosis of CMV infection in pregnancy can be stressful and confusing.

CMV Action is a registered charity (1171773), run by families affected by CMV, and by professionals with an interest in the virus. In this booklet we set out the key points from the clinical guidelines currently available for the diagnosis, treatment and management of CMV in pregnancy. We bring together

the latest research evidence and facts to answer the questions that women and their partners, and the professionals who work with them, really want answered.

Research into congenital CMV is constantly developing, so guidelines will change depending on the available medical evidence. Some treatment and tests will also vary depending on local health authorities.

Note: All the information in this booklet has been reviewed by families affected by CMV and by medical experts to ensure it is comprehensive, accessible and accurate.

We review our information regularly so that you can trust that it is always up to date.

If you have any suggestions for the next edition, please email info@cmvaction.org.uk.

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The basics about the virus

Who is at risk of CMV?

CMV can cause a mild flu-like illness, although this does not pose a risk to most healthy adults and children. However, contracting CMV infection during pregnancy (particularly in early pregnancy) poses a risk to the developing baby, and some babies can be born with permanent health problems. Other people who may be at increased risk of significant illness from CMV include those with immune problems, for example people on chemotherapy, or who have had a transplant or who are living with an HIV infection.

What is the difference between CMV and congenital CMV?

Anyone can become infected with CMV. However, most healthy adults and children coming into

contact with the virus will have few, if any, symptoms and no long-term health problems. Congenital CMV is when a baby has been infected with CMV before birth. CMV infection is transferred from the mother to the unborn baby across the placenta in around one-third of pregnancies. Some babies infected in this way will have life-long health problems, such as hearing loss and developmental problems.

CMV is the most common infection passed from mother to unborn baby.

The majority of babies born with congenital CMV will not have any symptoms at birth and will not suffer any long-term problems. However, ten babies are born each day in the UK with CMV and two or three babies of these babies will have long-term problems - that is 1000 babies every year.

2 to 3

babies are damaged by CMV every day

25%

of childhood hearing loss is caused by CMV

CYTOMEGALOVIRUS
(SI-TO-MEG-ALO- VI-RUS)

Transmission

CMV is spread from one person to another by close and prolonged contact with bodily fluids such as saliva, urine, blood, faeces, tears, breast milk, semen and cervical secretions.

CMV can be transmitted to the developing baby across the placenta, causing congenital CMV. Very often pregnant women catch CMV from the saliva of a toddler, therefore care should be taken not to eat leftover food, drink from the same cup, share utensils or kiss on the lips. It can also be caught through contact with urine, so hands should be thoroughly washed after changing a nappy.

What happens in the body during a CMV infection?

When CMV causes an infection for the first time it is called a primary infection. Just as with all infections, the body begins to fight CMV by producing antibodies and immune cells. CMV will be excreted or shed in bodily fluids during this time. However, after the acute infection, the virus remains in the body in an inactive state, usually for life. CMV antibodies will be present for life as well.

There are many different strains of CMV. Even if a woman has antibodies against one strain of CMV, she can still get re-infected with a different strain.

It is possible for any strain of CMV to reactivate or act like a new infection. This type of infection is a recurrent infection and may occur at any time, but especially when the immune system becomes altered or weakened. When reactivation occurs, CMV antibody levels may increase and CMV will be present in bodily fluids (viral shedding).

Are some people immune to CMV?

If you have had CMV before then you will be immune to that strain of the virus. However, there are lots of different strains of CMV and you will not have natural protection against all of these.

There are some simple measures that can reduce the chance of catching CMV infection, these are described on pages 6.

How long does the virus stay on surfaces?

Studies suggest that it can survive on surfaces long enough for people to pick it up. However, direct transmission through person-to-person contact is still considered the most likely way for people to catch it. The CMV virus can survive for at least 15 minutes on hands or other surfaces. Handwashing with soap and water effectively kills the virus.

A lot of small children catch CMV, especially those who attend nurseries. **Women who work with children or who have a family already need to be especially careful during pregnancy.**



The main way women catch CMV is from the **saliva** and **urine** of small children.



CMV is spread through bodily fluids and the chance of getting a CMV infection from casual contact is **very small**.

Risk Reduction

Although clinical trials of CMV vaccines are currently underway, there is no licensed vaccine against CMV at this time.

Without a vaccine, reducing the risks of transmission is the most important thing that we can all do. This section explains the simple hygiene precautions that you can take to prevent the infection spreading.

How can you reduce the risk of infection whilst pregnant?

There are ways you can reduce the risk of infection whilst you are pregnant. Although it may be hard

to do all of these things all of the time, doing your best whilst you are pregnant will reduce the risk of catching CMV. This will be for a relatively short period of time.

- Avoid putting things in your mouth that have just been in a child’s mouth. When possible, try not to share food, cups or cutlery, or put your child’s dummy in your mouth.
- Avoid getting saliva in your mouth when kissing a child.

You can do this by trying to give more kisses on the head, together with a big hug.

- Wash your hands after contact with a child’s urine or saliva. For example, try to make a habit of cleaning your hands after changing a nappy, feeding a child or wiping a child’s nose or mouth.
- Wash your hands well for 20 seconds with soap and water. If you do not have access to soap and water, use hand sanitiser.
- Wash any items which may have been in contact with a child’s saliva or urine.



Avoid putting things in your mouth that have just been in a child’s mouth. When possible, try **not to share food, cups or cutlery**, or put your child’s **dummy** in your mouth.

Wash any items which may have been in contact with a child’s saliva or urine.



Wash your hands after contact with a child’s **urine** or **saliva**. For example, try to make a habit of cleaning your hands after **changing a nappy, feeding a child or wiping a child’s nose or mouth**.

Wash your hands well for **20 seconds** with soap and water. If you do not have access to soap and water, use hand sanitiser.



Avoid getting **saliva** in your mouth when kissing a child. You can do this by trying to give more **kisses on the head**, together with a **big hug**.

Does hand sanitiser reduce risks?

If you don't have access to soap and water, then alcohol-based hand sanitiser is a good alternative. While it won't completely remove the CMV virus, it will render it non-viable. Ordinary wet-wipes are not effective at removing or deactivating CMV.

Are nursery workers more at risk?

People who work in nurseries appear to be at greater risk than health professionals who work with small children in hospital and healthcare settings. This may be partly due to the increased focus on infection control in healthcare settings.

You can reduce your risk by following simple hygiene precautions that are common in hospitals and should already be part of good practice in nurseries:

- Use disposable gloves to change nappies or help children go to the toilet
- Wash hands regularly with soap and water, especially after changing nappies or coming into contact with bodily fluids

- Wash toys regularly, especially after they have come into contact with urine or saliva
- Avoid sharing cutlery, drinks or food with children. Do not put dummies into your mouth
- Avoid kissing babies, toddlers and small children directly on the mouth. Kiss them on the head instead or give them a big hug.

There is no need to stay away from work or move to another setting when pregnant. Everyday contact with children poses no risk. Following the guidelines above should reduce your exposure to their bodily fluids and reduce your risk of catching CMV.

Reducing the risk of CMV infection during IVF

The UK professional body guidelines recommend that sperm, egg and embryo donors should be screened for CMV antibodies. This will show if they have been infected with CMV before or currently have an active infection. People found to have an active infection are recommended to defer donation. Advice from your fertility clinic should always be sought.

The risk of transmission of CMV through egg or embryo donation is negligible, therefore fertility centres may consider the use of eggs or embryos from CMV-positive donors (that is those individuals who have had CMV before) for women who are CMV-negative.

CMV can be found in semen, therefore it is generally recommended that CMV-negative women (those individuals who have never had CMV before) are matched with donor sperm samples from CMV-negative donors. In general, women who are CMV-positive may receive donor sperm from men who have had CMV before.

As the evidence is not clear cut, and practice can vary, the recommendation regarding whether to use a CMV positive donor should be a matter of clinical and personal judgement and should be discussed with staff at your fertility clinic.

Whether donor samples are received from CMV-positive or CMV-negative individuals, CMV can still be caught during pregnancy and therefore all pregnant women are advised to follow the risk reduction measures on page 6.

Diagnosis & Management in Pregnancy

Sometimes there will be a concern about a pregnant mother being unwell during pregnancy, or concerns about the baby's development leading to the mother being tested for CMV infection.

A positive diagnosis can be confusing and stressful. This section aims to explain how doctors diagnose CMV during pregnancy, what this means and where you can go for further support.

How do you know if you have CMV?

Most healthy children and adults infected with CMV have no symptoms and may not even know that they have been infected. Others may develop a mild illness; symptoms may include fever, sore throat, rash and fatigue.

Other symptoms, such as swollen glands, liver or spleen, may sometimes be present. However, these can be symptoms of a wide range of conditions, not just CMV. Always talk to your doctor or midwife if you have concerns.

A blood test can tell if you have an active CMV infection or have had a previous infection. Doctors can diagnose a maternal primary CMV infection (catching CMV for the first time) by testing

for Immunoglobulin M (IgM) and Immunoglobulin G (IgG) antibodies and performing an "avidity" test, which checks how tightly the IgG binds to CMV. By analysing levels of these antibodies and the avidity test, an estimate of the timing of CMV infection can be made. These results will be interpreted by a virologist, as they are not always straight forward. Sometimes your midwife or doctor may ask you to have further blood tests done a few weeks later to help interpret the results of your tests.

The timing of CMV infection is associated with the risk that the baby will be affected by congenital CMV. If CMV infection is contracted in the first trimester, the risk of long-term problems is estimated at less than 1 in 100 and the risk in the third trimester is negligible. Whilst the risks in the later stages of pregnancy are thought to be very low, the studies that report these findings have only followed up infants for the first few years of life, and longer-term studies are yet to report.

As the risks are highest around conception and early pregnancy, it is particularly important that women planning pregnancy or in the early stages of pregnancy take particular care to reduce the risks of catching CMV. See page 6.

Even if you have had CMV before, it is still possible to catch a different strain. It is therefore important for all pregnant women, and those planning a pregnancy, to follow simple hygiene precautions even if they have had CMV before.

Why isn't CMV routinely screened for in pregnancy in the UK?

The UK National Screening Committee has recommended against routine screening for CMV in pregnancy. This is because most babies with CMV are not affected. Also, screening would only detect cases of primary infection and the tests available at present are not able to diagnose secondary infection (infection with a new strain or reactivation of the original strain of CMV).

What does a diagnosis of CMV mean for you and your baby?

Being diagnosed with CMV infection when you are pregnant can be very stressful. However, it does not mean that your baby has the virus, or that they will have problems associated with CMV. Of all the women who catch CMV for the first-time during pregnancy, two-thirds of women will NOT pass it to their unborn baby and most babies who do have CMV remain well.

However, all women who are diagnosed with CMV infection in pregnancy should have additional scans so that any signs of CMV in the fetus can be found. These may include small for gestational age growth, microcephaly (small head) or altered signals in the brain or bowel. You may be offered an amniocentesis (taking some water from the sac around the baby) to see if your baby has been infected. It is recommended that an amniocentesis should take place at least 6 weeks after maternal infection, and after 20 weeks of baby's gestation.



CMV Action works with midwives to raise awareness of the virus and to support women through their pregnancy

It is important to remember that even if the virus has been passed on to your unborn baby, around 4 out of 5 babies born with CMV don't have any health problems at birth.

Treatment for CMV infection in pregnancy

Evidence suggests that the use of a drug called valacyclovir (antiviral treatment) could be helpful in reducing the risk of the CMV infection passing from the mother to her baby during pregnancy or to reduce the risk of severe problems in babies that have been infected.

A recent randomised control trial showed valacyclovir reduced the rate of fetal infection by 71%. You should arrange a consultation with a specialist to discuss this option as evidence is still emerging and practice and guidelines are likely to vary. This treatment is also not suitable in all circumstances.

A treatment called Hyperimmune Globulin (HIG) aims to reduce the risk of the transmission from mother to baby and to reduce the severity of symptoms in babies that might have been infected. However, despite the fact that some small-scale studies reported possible, larger good quality studies have shown that it is not beneficial and in fact it might harm and HIG is therefore not offered in the UK or other countries as

routine practice. Research is ongoing in this area.

Some babies do have more severe symptoms when they are born. Diagnosis in pregnancy can help to ensure that your new-born baby is diagnosed quickly and gets the support that he or she needs. You should see a fetal medicine specialist who will perform a detailed ultrasound of the baby. The fetal medicine specialist might arrange additional ultrasound scans and other tests, such as MRI of the baby's brain in order to look for possible harm caused by the CMV virus. These tests should help the fetal medicine specialist to tell you whether the baby is likely to have problems caused by CMV after birth or not.

CMV Action can give you emotional support during this uncertain time. Organisations such as Antenatal Results and Choices (ARC) can also offer professional support to help you through difficult decisions in pregnancy (see section on Further Support).

When a baby is born

If infection during pregnancy is suspected or confirmed, your new-born will be tested at birth for congenital CMV. It is important that this happens within the first 21 days to confirm that it is congenital rather than postnatally acquired. If the test is negative, your baby does not have CMV. If the test is positive, it is important that your baby is diagnosed as soon as possible to ensure that the appropriate treatment can be commenced in a timely way. This is especially important in terms of reducing the severity of hearing loss associated with congenital CMV infection.

Much more information on congenital CMV infection can be found in our booklet *CMV: Babies and Children*.

Frequently Asked Questions

Is it safe to breast feed your baby?

CMV can be passed through breast milk. However, if your baby is born full term, and you have CMV, they will not develop any problems if you are breast feeding.

Babies who have been infected with CMV in the womb may also be re-infected with a new strain of CMV in the breast milk. This is unlikely to cause further problems. The benefits of breast milk for all babies are numerous and well documented and if you wish to breast feed your baby you should be encouraged to continue.

Some parents are concerned that if they breastfeed, they will

pass the virus to their baby and this will affect the newborn test results. Whilst the CMV virus can be passed through breast milk, postnatally acquired infection will not show up in this test for the first 21 days. This is another reason why it is essential that a baby is tested within the first 21 days to confirm whether there is a congenital infection.

If you have had a recent CMV infection, when can you try to get pregnant?

In general, women are advised to wait a year after active CMV infection before trying for a baby to reduce the risk of active CMV causing infection in the baby.

There is little evidence to guide the

advice on how much time to wait. However, a 6-12-month period is a cautious approach to reduce the risk as much as possible and some women may feel comfortable trying to conceive again prior to this. This advice is the same for women who have had a miscarriage or still birth as a result of CMV.

Further Support

At CMV Action we have supported many pregnant women who have been diagnosed during pregnancy.


We have a group of support volunteers who can talk to you and explain what tests are available and where to go for further advice. We can also put you in touch with others with similar experiences. CMV Action works closely with medical advisors who we contact for specific questions.

CMV Action

For information, the latest research and sources of support about CMV please visit our website, cmvaction.org.uk. You can also read stories and experiences that families affected have shared.

CMV Action has a Facebook page (facebook.com/CMVAction) and a Facebook Family Support Group. Please go to our page to request membership: (facebook.com/groups/335321217452204).

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