Your Questions Answered

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Introduction

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 be very dangerous to unborn babies. In fact, congenital CMV is one of the most common causes of birth defects in the UK.

Despite this there is very little awareness of CMV and the facts are often misunderstood. This can make it stressful and confusing for families coming to terms with a diagnosis and planning how best to support their children.

At CMV Action, we understand. We have all been there before.

We are a registered charity (1147633), run by families affected by CMV. In this booklet we bring together the latest research evidence and facts to answer the questions that families, and the professionals who work with them, really want answered.

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 would like to send a big thank you to all the families and professionals who have been involved in producing this booklet. 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.
The basics about the virus:

What is CMV?
CMV, or Cytomegalovirus, is a common virus that can infect people of all ages. Once CMV is in a person's body, it stays there for life. Most healthy adults and children will have no signs or symptoms and no long-term effects from CMV. It can, however, be very dangerous to unborn babies. Congenital CMV is one of the main causes of children being born with permanent disabilities.

Who is at risk of CMV?
One of the highest risk groups is pregnant women who contract CMV as it can cause a number of birth defects in the developing baby. Others at risk include people with low immune systems e.g. chemotherapy patients, transplant patients and people who are HIV Positive.

Is congenital CMV a rare condition?
No! CMV is the most common infection at birth. As many as 1 in 150 newborn babies are born with congenital CMV. The majority of these will not have any symptoms. However, around 1 in 1000 babies born in the UK every year will have permanent disabilities as a result of CMV – around 900 children every year. As CMV is a relatively unknown condition, it is a common misconception that it is rare. It is in fact more common than Down's syndrome, Toxoplasmosis, Spina Bifida or Cystic Fibrosis.

What is the difference between CMV & 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 or long-term health problems. The main ways of catching CMV are:
- Person-to-person contact: CMV is spread from one person to another by close and prolonged contact with bodily fluids such as urine, saliva, blood, faeces, tears, breast milk, semen and cervical secretions. You can catch CMV by kissing, sexual intercourse, sharing eating and drinking utensils, and sharing mouthed toys. You cannot catch CMV by merely being in the same room with someone.
- Mother to newborn baby: CMV is commonly transmitted to newborns through the mother's breast milk or the process of giving birth. Babies who catch CMV this way do not seem to have any problems.
- Transplants and transfusions: CMV may be spread to organ and bone marrow transplant recipients and to patients who receive a blood transfusion from a donor with an active or past CMV infection. CMV can be a particular risk to these patients as they have reduced immune systems.
- If CMV is transferred from mother to unborn baby during pregnancy, this is known as congenital CMV (or cCMV).
What are the different types of CMV infection?

Congenital CMV can occur in three ways:
- Primary infection: when a woman is infected for the first time in pregnancy.
- Reinfection: when a woman is reinfected with a different strain of CMV. This type of infection can produce the same symptoms and problems as a primary infection.
- Reactivation: when a woman’s existing CMV infection reactivates. This does not cause as much harm as primary infection or reinfection.

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. While there is an active infection in the body, CMV will be excreted or shed in bodily fluids. However, after 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 for one strain, she can still get reinfected with a different strain. The body will fight the virus and produce new antibodies just as with a primary infection.

Like other viruses in its family, it is possible for any strain of CMV to reactivate (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 viral shedding may reoccur.
Transmission

How is CMV spread?
CMV is found in bodily fluids, including urine, saliva, blood, mucus and tears. Up to a quarter of young children shed CMV, which means it will be in their bodily fluids. Pregnant women who have young children or work with young children should be especially careful. Pregnant women should be extra vigilant with hygiene, e.g. washing hands.

Is it safe to breast feed my baby?
CMV is frequently transmitted via breast milk and term babies acquiring CMV by this route are generally completely unaffected. This is a natural and normal route of transmission of many viruses.

Congenitally infected infants, whether symptomatic or not, may become reinfected with the maternal strain but this is thought not to be significant. The risk of ‘reseeding’ with a new virus is outweighed by the fact that mothers will also be passing on their antibodies to both the CMV and a multitude of other bugs. The benefits of breast milk are numerous and well documented and if a mother wishes to breast feed her baby she should be encouraged to continue.

Should I continue to breast feed if my baby is being treated with anti-viral medication?
Ganciclovir therapy given postnatally is of proven benefit if started in the first month of life. Reinfection via breast milk if a baby is on ganciclovir is unlikely.

If I have a baby with congenital CMV, would my next baby also have congenital CMV?
There is little information about the risks of having a second child with congenital CMV but the risk of having a second baby with CMV symptoms as a result of your original virus reactivating is actually very low – around 0.01% or 1 in 10,000.

There is still a risk of being reinfected with a different strain of CMV and it is therefore important that all pregnant women practice simple hygiene precautions even if they have had CMV before. There have been a few reports of mothers who gave birth to more than one baby with congenital CMV however these cases are extremely rare. That said, parents of a baby with congenital CMV are advised to wait a year from delivery before trying for another baby to reduce this risk even more.
My child has congenital CMV, are other people at risk of CMV infection from him/her?
Yes, when they are shedding the virus, but no more so than from any other healthy adult or child who carries the CMV virus. Around 50-80% of the population in the UK will carry the CMV virus. Therefore those who are most at risk of harm from CMV, including pregnant women, should follow the basic hygiene precautions listed in the ‘prevention’ section to reduce the risk of infection.

Should my child’s nursery or school take special precautions?
Around a quarter of young children will already be carrying the virus. There is therefore no need to treat your child any differently from any others. All nurseries should ensure that staff are practicing good hygiene precautions with all children. This means washing hands after changing nappies, not sharing cups and cutlery and washing toys regularly.

Any pregnant women working in school and nursery settings are at particular risk and need to be extra careful. Unfortunately very few schools and nurseries have heard of CMV. Our support volunteers at CMV Action would be happy to talk to any professionals that work with your child to make sure they are fully informed.
## Symptoms

### What are the symptoms of 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, fatigue, and swollen glands. CMV has more serious symptoms in people who have a weakened immune system such as transplant recipients and chemotherapy patients.

### Will all children born with CMV have symptoms?
There is a huge range between cCMV children as to how severely they are affected and many children will have absolutely no problems at all.

Most children born with CMV will not show symptoms at birth. These cases are called ‘asymptomatic’. Most of these children will not have any problems but around 15% of them go on to develop a hearing loss over time. Very rarely they may go on to have developmental or learning difficulties.

Some children will be born with obvious symptoms of CMV such as a small head size (microcephaly), little red spots (petechiae), jaundice, enlarged liver and spleen, hearing loss or calcium deposits in the brain. These cases are called ‘symptomatic’. Some of these children will go on to develop other problems such as physical and motor impairment, seizures, ADHD, Autism, developmental differences and learning delays or visual impairment.

Overall around 1 in 5 children with congenital CMV will have permanent problems. Of these, only around one third will be those who were obviously ill at birth. In the other two thirds the problems will have emerged over time and may not have been immediately obvious. This is what makes it such a hidden burden.

The approximate composition of congenital CMV babies in the UK:

<table>
<thead>
<tr>
<th>Symptomatic</th>
<th>Asymptomatic</th>
</tr>
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<tbody>
<tr>
<td>10%</td>
<td>90%</td>
</tr>
<tr>
<td>600 babies</td>
<td>4400 babies</td>
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### Source
Will my child’s hearing loss get worse?
The most common disability associated with congenital CMV infection is hearing loss. It is progressive (worsens over time) in around half of cases. Therefore you need to have regular follow-ups with an audiologist to monitor any changes.

If your child is diagnosed with congenital CMV early enough (before they are 4 weeks old) then they can be treated with antiviral medication such as ganciclovir and valganciclovir. This may help to stop hearing loss from getting worse.
How do you prevent CMV during pregnancy?
CMV is spread from person to person via bodily fluids, e.g. blood, saliva, urine, tears, etc. CMV infections are common in toddlers and preschool age children and the virus is frequently transmitted in family or group day-care settings.

Pregnant women can reduce the risk of infection by following a few basic hygiene precautions:

• Avoid sharing dummies, cutlery, drinks or food with anyone.
• Avoid kissing babies, toddlers and small children directly on the mouth. Kiss them on the forehead or cheek instead.
• Wash your hands with soap and water, especially after changing nappies or coming into contact with any bodily fluids.
• Wash any items that have been contaminated by bodily fluids with soap and water.
• Use condoms during sexual intercourse even after conception.

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. Nobody is immune from all strains of CMV.

Why haven’t I heard of CMV before?
At the moment there simply isn’t enough public awareness of CMV, and so most people have never heard of it. One of the aims of CMV Action is to raise awareness amongst pregnant women and healthcare professionals about the risks of congenital CMV and the simple hygiene measures that can prevent it.

Is there a vaccine against CMV?
There is no licensed vaccine against CMV at this time. However, research is being conducted on the safety and effectiveness of different experimental CMV vaccines.
Testing

How do I know if I have CMV?
Most CMV infections are not diagnosed because the infected person usually has few or no symptoms. A blood test can tell a person if they have CMV or have had a previous infection. However, if you have had a previous infection it is still possible to get infected from a different strain or reactivation in future pregnancies. It is therefore important for all pregnant women to follow simple hygiene precautions to reduce their risk.

How do you make a diagnosis of congenital CMV infection?
A saliva, urine or blood test can confirm whether the CMV virus is present (saliva and urine are most reliable). The sample must be taken within the first three weeks of a baby’s life to be sure that it is a congenital CMV infection i.e. the baby caught it whilst in the womb. Otherwise they may have caught it during or after the birth, which won’t cause any long-term problems.

If your child tests positive for the CMV virus when they are more than 3 weeks old this may still indicate that they were born with congenital CMV. Every baby in the UK has a small blood sample taken when they are a few days old. This blood sample is called a Guthrie card and they are stored for around 5 years (even longer in some areas). If your child tests positive then your doctor should try and retest their Guthrie card to confirm whether it was definitely a congenital infection.

Should I find out if my child is still shedding the virus?
Most children with congenital CMV will shed the virus (which means it will be present in their bodily fluids) through toddler and preschool age. Infants and children who catch CMV after they are born will also shed CMV. The virus will affect each child differently and the length of viral shedding can range from just a few months to eight years of age, and possibly longer.

It is not necessary to keep checking if your child still has the virus active in the urine or saliva because its presence does not appear to influence or predict problems. Furthermore, schools, teachers and therapists should not require your child to be tested for CMV shedding before being accepted into a programme. A quarter of all small children will have CMV and your child should not be treated any differently. Your child should not be denied access to nursery or education because of the diagnosis of congenital CMV infection. If you have any problems then our support volunteers at CMV Action will be happy to help and advocate on your behalf.

You should be aware that your child may pose a risk to pregnant women and warn them to take hygiene precautions. However your child is not a special case and any other small child a pregnant woman comes into contact with could pose just as much of a risk.

Is it possible to screen for CMV in pregnancy?
Researchers are investigating treatments to reduce the risk of a mother with an infection transmitting CMV to her baby. For now we need to focus on the simple hygiene measures that can prevent catching the virus in the first place.
Treatment

Is there a treatment for congenital CMV?
Antiviral drugs, such as ganciclovir and valganciclovir, can be used to treat symptomatic newborns, including babies who have hearing loss but no other symptoms. Other options, such as hearing aids and cochlear implantation, are available to manage the impact of CMV. All options should be carefully discussed with your baby's doctor and individualised to your baby's needs. The information in this section may help you in this process.

Should we treat asymptomatic babies?
Most of the babies born infected with CMV are "silently" infected or asymptomatic and do not have any symptoms of their infection at birth. However, up to 15% of these asymptomatic newborns may have hearing loss; sometimes it is detected by newborn hearing screening and sometimes it is detected only by careful follow up. The hearing loss in asymptomatic newborns is usually only in one ear but it can involve both ears. The involved ear also characteristically progresses to have a severe or profound level of hearing loss over months or years. Even one-sided hearing loss can influence your child's speech and language, behaviour, and school performance. However, these babies do not appear, at this time, to have significant problems with their IQ or school performance, provided their hearing loss is identified early and they receive appropriate speech and language interventions or hearing aids.

Most doctors do not recommend antiviral treatment for asymptomatic newborns because it is not possible to accurately predict which children will develop hearing loss and which children will retain normal hearing.

Most doctors do not recommend antiviral treatment for asymptomatic infants and children who develop hearing loss or hearing loss progression because controlled clinical trials to prove the effectiveness of treatment have as yet not been performed in these groups. However, some experts have used and advocate treatment with an antiviral medication in some of these children with documented hearing loss, with the goal of maintaining as much hearing as possible.

What are the benefits of antiviral treatment?
Babies with severe or life threatening CMV disease should receive antiviral treatment with the goal of reducing the amount of active virus thus allowing your baby to control the infection with his or her own immune system.

Antiviral treatment should be started if CMV has affected the central nervous system and caused hearing loss, eye disease or abnormalities detected on the brain scan. Severe bone marrow disease which includes low blood counts (white blood cells, red blood cells or platelets) will also require treatment. Other diseases such as oesophagitis, colitis, and hepatitis with jaundice may improve with treatment, but there are no controlled trials to tell us for sure.

For newborns with congenital CMV who have hearing loss, a recently published multi-centre controlled clinical trial (Kimberlin, et al in Journal of Paediatrics, July 2003) showed treatment with ganciclovir was beneficial, and may help your baby retain normal hearing or slow progression of his or her hearing loss for 6-12 months, maybe longer. Some babies who receive ganciclovir will have improved head size. However, there is no evidence, at this time, that treatment with ganciclovir will improve your baby's IQ or school performance.
Transmission

What are the risks of antiviral treatment?
The most common side effect is a decrease in the blood count and infection fighting cells. In some instances kidney and liver function can also be affected. Close monitoring of white blood cell counts, kidney and liver function is therefore necessary during the course of treatment. There may be unexpected long-term effects of treatment, especially on growth and development, and this issue is currently being studied.

How is treatment given?
Treatment of newborns with ganciclovir is a challenging procedure. It usually requires 6 weeks of medicine given through a central intravenous line. The usual dose is 6 mg per kg per dose, and a dose is given over a one-hour infusion every twelve hours. If your baby is premature or has problems with kidney function, your doctor may adjust the dosage of the medication. Also, most doctors will require your baby be in the hospital for the entire length of treatment. However, under special circumstances it may be safe to administer treatment at home. Your baby will be examined at least every week or more often if your doctor feels it is necessary. Blood and urine tests will be performed to make sure the level of CMV is reduced. During the course of treatment, bone marrow function, kidney and liver function will also be closely monitored.

In some circumstances, it may be possible to administer valganciclovir which is an oral treatment. This treatment is given twice a day for six weeks and can be given at home by parents. During the treatment course, blood and urine levels will be taken to ensure the level of CMV is reduced.

Bone marrow, kidney and liver function will also be closely monitored and the baby will be reviewed regularly in the outpatient department. The decision to start valganciclovir is dependent upon the severity of the baby’s symptoms and the collective opinion of the medical team looking after the baby.

Other treatment options for congenital CMV Infection
Whether or not your baby receives antiviral medication as a newborn, remember that careful follow up to identify progressive hearing loss is important. If their hearing worsens over time it is important to consider other treatment options, such as hearing aids or cochlear implants as early as possible. Speech and language therapy can also help children with hearing loss acquire necessary language skills.

Occupational and physical therapy may help rehabilitate children with motor disabilities. Seizures should be controlled with anti-convulsant medications.
Management

When a diagnosis of congenital CMV has been made, what type of follow-up is recommended?

All children born with congenital CMV should be monitored regularly. This is even the case for children born without any symptoms as often the problems only develop over time. They should have a full range of tests after they are born or when congenital CMV has first been diagnosed:

- Blood count, platelet count and liver function tests
- Brain scan
- Hearing test
- Eye test

After this, their growth and development should be regularly monitored:

- All children born with CMV should have a hearing assessment every 3-6 months until age 3 and then yearly until 6 years old. This is particularly important as hearing loss is often progressive and may get worse over time.
- All children born with CMV should have a clinical assessment by a paediatrician at around 1 year old to check that their development is as expected.
- Those children more severely affected should have an additional paediatric assessment at 6 months and neurodevelopmental assessment at 1 year.
- Children born with symptoms of CMV should have an annual eye test until the age of 5.

Unless your doctor has advised you otherwise, children with congenital CMV infection should receive the routine immunisations recommended for all children.

My child has been diagnosed with congenital CMV, what can I expect for their future?

As with any child, it is difficult to predict what the future holds for a child with congenital CMV. At CMV Action we understand just how difficult a diagnosis of CMV can be for your family. The early days following diagnosis can be bewildering and upsetting. And as your child gets older they may face new challenges as a result of the virus.

Our dedicated team of support volunteers are all parents of children with congenital CMV. They are on hand to talk to you about your experiences, point you in the direction of further information or put you in contact with parents facing similar issues.

Whilst other parents can offer a wealth of advice and support, we recommend that you discuss any concerns about your child’s health with their doctor.

What support is available?

It is important for you to know you are not alone and that many people can help you and your family. CMV is a misunderstood virus and the latest factual information about this virus is available for you, your family and friends, teachers and health professionals.

A parent-to-parent support network has also been established. The support network is a database of families from all across the country who have a child with congenital CMV. Families join for a variety of reasons but they mostly want support and advice from other families with similar experiences.

For more information and support: call us on 0845 467 9590 email us info@cmvaction.org.uk visit www.cmvaction.org.uk
For more information about CMV, our parent-to-parent support network or other services please contact CMV Action:

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Glossary

Acquired Infection
Infection with CMV that occurred sometime after birth.

Antibody
Immune substance in the serum portion of the blood that helps fight off and control the infection or disease. There are at least two types of antibodies, IgG and IgM, produced in response to a CMV infection.

CMV IgG
Antibody made at the time of first infection. It persists throughout life after a CMV infection.

CMV IgM
Antibody made early at the time of the first infection with CMV. It usually disappears within 12 to 18 weeks and, therefore, can be used as indication of a recent infection in healthy individuals.

Congenital Infection
Infection passed from mother to unborn child prior to birth. It is documented by isolation of the virus from a bodily fluid, such as urine, collected in the first 3 weeks of the baby’s life.

Immunity
Body’s ability to resist infection based on the production of antibodies and white blood cells.

Infection
Entry of an agent, such as the virus called CMV, into the body. Usually there is production of an immune response. Infection may or may not be associated with disease.

Primary CMV Infection
The first time someone catches CMV infection.

Reactivated CMV Infection
A type of recurrent CMV infection. It is a prior infection that has become active again, usually causing viral shedding and rarely causing symptoms of infection and viral shedding.

Reinfection
A type of recurrent CMV infection. It is a repeat infection with a new strain of the CMV virus. Its consequences are unknown at this time.

Seronegative
Antibody (IgG) absent or negative in serum (non-immune).

Seropositive
Antibody (IgG) present or positive in serum.

Virus Shedding
Presence of the virus active in body fluids, such as urine, saliva, breast milk, semen and cervical secretions. Virus shedding can be detected by a viral culture. It also may be called virus excretion.