

CMV: CHILDREN AND BABIES

A guide to post-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, CMV can pose serious problems to unborn babies if a woman catches the virus in pregnancy. In fact, congenital CMV (when the infection is passed from mother to baby across the placenta) is the most common non-genetic cause of inner ear 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 when your baby is born 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 bring together the latest research evidence and facts to answer the questions that families, and the professionals who work with them, really want answered.

This publication sets out the key points from the clinical guidelines currently available

for the diagnosis, treatment and management of congenital CMV in babies and children. It gives details of the tests and treatment available and outlines what you can expect from some of the professionals who will be involved in the care your baby or young child. 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

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

Who is at risk of CMV?

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 to unborn babies if a woman catches CMV during pregnancy, particularly if this happens in early pregnancy. Some babies infected in this way (known as congenital CMV when the infection is passed from mother to baby across the placenta) will go on to have life health problems such as hearing loss and developmental difficulties.

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, two or three babies are affected by the CMV virus every day in the UK – almost 1000 babies every year.

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 HIV infection.

2 to 3

babies are
damaged by
CMV every day

More information can be found in our booklet "CMV in Pregnancy" and on our website:
www.cmvaction.org.uk.

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. CMV can be transmitted to newborns through the mother's breast milk or the process of giving birth. However, it does not cause any problems for healthy, full-term babies. A very small number of premature babies may become unwell with CMV; however, this can be treated with medication and is not associated with hearing

or developmental problems. The benefits of breast milk for these infants far outweighs these smaller risks.

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.

There are some simple steps that you can take to reduce the risk of catching CMV whilst pregnant:



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**.

Symptoms and Diagnosis in Babies

Symptoms of congenital CMV in babies are very wide ranging. Most babies born with congenital CMV will have no signs or symptoms at all (known as “asymptomatic”) and will not develop any problems as they grow older.

Others may have no obvious signs at birth, but around 15% may go on to develop hearing loss over time.

Some children will be born with obvious symptoms of congenital CMV (“symptomatic”) and around half of these children will have one or more long-term impairments. These may include hearing loss, cerebral palsy, seizures, ADHD, autism, developmental differences and learning delays, feeding issues or visual or sensory impairment.

Overall, around one in every four children born with the virus will have long-term problems such as hearing loss or developmental disabilities due to the infection.

Making the diagnosis after birth – what doctors will look for

If there is a possibility the CMV virus has been passed on, for example, mother has been diagnosed with a CMV infection in pregnancy, or a baby has failed the new-born hearing screening test, an early diagnosis is essential so that treatment can be considered.

These tests need to be done before the baby is 3 weeks old, to be sure if CMV was caught

before or after birth. If anti-viral treatment is needed, this should be started before the baby is four weeks old. This may help to stop hearing loss from getting worse. If there are signs of CMV infection, your baby’s doctor will test to confirm a diagnosis of congenital CMV (i.e. your baby caught it whilst in the womb). However, some signs are not unique to congenital CMV and some babies will not show all these signs.

Some babies will have very obvious signs of CMV infection. These can include:

- Lots of very small (1-2mm) red or purple spots (called petechiae)
- Larger (2-8mm) red or purple dome shaped spots (called blueberry muffin rash)
- Low birth weight, indicating poor growth during pregnancy
- A head significantly smaller than other babies (microcephaly)
- Enlarged liver and spleen (hepatosplenomegaly)
- Yellow skin (jaundice).

Babies who fail their newborn hearing test should also be tested for CMV infection.



CMV infection is responsible for around **25% of childhood hearing loss**

Making the diagnosis after birth – what doctors will test for

A saliva or urine test can confirm whether the CMV virus is present. A positive test on a saliva sample will normally be confirmed with a urine test, to be sure of the positive result. The sample must be taken within the first three weeks of your baby’s life to be sure that it is a congenital CMV infection, otherwise they may have caught it during or after the birth, which won’t cause any long-term problems for full-term babies. Another reason for confirming the diagnosis within the first three weeks after birth is that treatment needs to begin within four weeks of life.

Further tests once congenital CMV is confirmed

Doctors may carry out further tests to see how your baby has been affected by the infection and whether they should be considered for treatment:

| What should be tested? | Why? |
|--|--|
| Blood count, platelet count & liver function tests | Congenital CMV can cause a reduction in the number of red and white blood cells and inflammation of the liver (hepatitis). |
| Brain scan | Congenital CMV can cause some distinctive changes to the brain which may affect your child as they develop. A brain scan can help doctors to diagnose congenital CMV infection and also consider whether treatment with anti-viral medication is appropriate. In some cases, it can help doctors to identify children who may be most at risk of developmental or hearing problems in the future. The doctor will decide on the most appropriate kind of scan (ultrasound, or MRI, or in some cases both) and discuss the results. |
| Hearing test | Hearing loss is one of the most common symptoms of congenital CMV. This test will be more detailed than the hearing screen carried out on all babies at birth and carried out by audiologist. |
| Eye test | This is to check for any inflammation or scarring on the retina (the light sensitive layer of tissue in the back of the eye). Some children may also have visual impairment caused by a brain problem rather than an eye problem. |

Your baby should be referred to a paediatric infectious diseases consultant if congenital CMV is suspected.

Later Diagnosis

If your child tests positive for the CMV virus when they are more than three weeks old, it can be helpful to test the sample of blood that is collected from all babies in the UK when they are a few days old. This sample is called a Newborn Blood Spot (formerly the Dried Blood Spot or Guthrie test). A positive result will confirm that the infection was caught before birth (a congenital infection). However, this test is not perfect, in that it does not pick up all cases of CMV infection (it picks up 80-90%). Therefore, a negative result cannot fully rule out congenital infection.

Treatment

Treatment for babies and children affected by congenital CMV will depend on many factors, including whether they have symptoms at birth, how serious these symptoms are, whether there is hearing loss, if there are changes on the scans of the brain (ultrasound or MRI), and when diagnosis is made.

Treatment is not recommended for every baby as there is no evidence that it is helpful in all babies.

Antiviral drugs, such as ganciclovir and valganciclovir, can be used to treat babies and should be started within the first month of their life. Ganciclovir is given intravenously (into a vein via a 'drip') and would be the drug used for babies who are not able to take all their feeds by mouth, for example in premature babies. Valganciclovir is given by mouth and would be used for babies who are feeding normally.

The main benefit is to preserve hearing and prevent progression of hearing loss associated with congenital CMV. Also, there may be modest benefits in reducing the impact of congenital CMV infection on the neurodevelopment of the child, in particular improving communication skills. Emerging evidence shows that even when babies have less severe symptoms, treatment can be of benefit. You should discuss all treatment options with your baby's doctor including any risks associated with anti-viral treatment.

Depending on the treatment given and the severity of their symptoms, your baby may need to stay in hospital for the first part of their treatment. They will be closely monitored for any side effects and risks. The length of treatment will be discussed with you; however, it is normally given for a total of six months.

When should anti-viral treatment be used?

Anti-viral treatment is recommended for babies if CMV infection has affected the central nervous system, including their hearing, or a significant effect on other organs. Treatment is normally only recommended to start within the first month of life, as currently we do not have the evidence to support starting treatment later than this. A recent small clinical trial reported that there is no positive effect of antivirals in older babies and children. However, this is an area to discuss with your doctor, as discretion may be used. The goal of anti-viral treatment is to reduce the amount of active virus so that the baby is able to control the infection with his or her own immune system.

Should asymptomatic babies be treated?

Most babies born with congenital CMV are asymptomatic and do not have any symptoms at birth. However, by the age of five, around 15% may go on to develop hearing loss.

Anti-viral treatment is not recommended for all newborns because at present there is no evidence of benefit unless the baby has hearing loss or CMV has affected the central nervous system. There is currently no evidence that anti-viral treatment is of benefit for children who develop hearing loss later in childhood. However, studies are currently being carried out to understand more about this.

What are the benefits of antiviral treatment?

Anti-viral treatment may stop hearing loss getting worse and improve the development of communication. These benefits have been observed in two-year olds whose central nervous system (brain and spinal cord) had already been affected by CMV when they were diagnosed.

Side Effects of Treatment

The most common side effect of anti-viral treatment is a decrease in the number of white blood cells that help fight infection.

Around one in five babies will experience this side effect, most commonly in the first few weeks after starting anti-viral treatment. Less commonly, anti-viral treatment may cause anaemia (1 in 50) or a reduction in the number of platelets (the cells that help the blood clot) in the blood (1 in 100). Although rare, the liver function can also be affected in some cases. Blood tests are required to closely monitor the blood cells and function of the liver.

If any of these tests suggest a problem, then treatment may be stopped or decreased. Your

baby may be prescribed other medication to help improve the number of white blood cells. CMV virus levels will also be monitored during treatment through blood, urine and saliva tests. Your medical expert will help explain the side effects for the dose of medication.

The decision to start anti-viral treatment is not straightforward and will not be appropriate for all babies. The potential benefits of treatment need to be considered alongside the potential side effects of treatment. It is important that you have

the opportunity to discuss the decision about whether to start anti-viral treatment with a doctor who has experience in treating babies with congenital CMV, such as a paediatric infectious diseases specialist. CMV Action can help you find a specialist.

Should I continue to breast feed if my baby is being treated with anti-viral medication?

Yes, you can continue to breast feed if your baby is being treated with anti-viral medication. 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.

Management

On-going management of congenital CMV will depend on how your child has been affected by the virus.

Even for children with no obvious signs at birth, if congenital CMV has been diagnosed they will need to be monitored in their early childhood to check for any symptoms which may develop over time, such as hearing loss.

Long-term follow up

All children born with congenital CMV should have their growth and development regularly monitored. You should be offered:

- A hearing assessment every three to six months until the age of three and then yearly until six years old (NDCS Guidelines). This is particularly important as hearing loss is often progressive and may get worse over time. If your child is affected by hearing loss, they may be offered hearing aids, or in some cases cochlear implants. You should discuss these options with the Audiologist (hearing specialist).
- A clinical assessment by a paediatrician at around one year old to check that their development is as expected. Ongoing follow-up with a paediatrician will be required for some children.

- Children with more severe symptoms should be regularly monitored by a paediatrician while they are being treated, then seen at least annually until the age of two. They should also have a neurodevelopmental assessment at one year. This will help to diagnose any problems with the development of the brain and nervous system.
- Some children will be recommended to have an annual eye test up to the age of five. This will be guided by an ophthalmologist.

Babies who fail their newborn hearing test should also be tested for CMV infection.

I haven't been offered this follow-up, what should I do?

There are no statutory guidelines for treating and managing congenital CMV in the UK, therefore there may be some differences between individual doctors or hospitals. If you are concerned about on-going treatment of your child, you should speak to the doctor looking after your child in the first instance and ask them to make referrals to the relevant specialists. If you have further concerns, you are entitled to ask to see another doctor for a second opinion. The care of children with congenital CMV is usually overseen by a paediatric infectious disease specialist.

UNLESS YOUR DOCTOR HAS ADVISED OTHERWISE, ALL CHILDREN WITH CONGENITAL CMV INFECTION SHOULD RECEIVE THE ROUTINE IMMUNISATIONS RECOMMENDED

Ongoing Support

There are many professionals who may be involved in the care of your child. Please contact CMV Action if you need further advice.

| Title | Area of Expertise |
|--|---|
| Paediatrician | Doctor specially trained for babies and children |
| Infectious Disease Specialist | Doctor who specialises in the diagnosis and treatment of infectious diseases like CMV. These are in the larger hospitals so you may be referred. |
| Neurologist | Doctor who specialises in disorders of the brain, spinal cord, nerves and muscles. Will advise on epilepsy. |
| Audiologist | Specialist in identifying, diagnosing, treating and monitoring hearing loss. They will advise on hearing aids and can refer you to the Cochlear Implant team. |
| Portage/Early years teachers | The team will offer support and advice to disabled children and their families at home. Portage is not available in all Local Authorities. |
| Speech and Language Therapist (SALT) | Speech and Language Therapists provide support for children who have difficulties with communication or with eating and drinking. They will also help with sensory issues and language disorders. |
| Physiotherapist | Physiotherapists help with motor difficulties through movement and exercise. They liaise closely with Occupational Therapists. |
| Occupational Therapist (OT) | Occupational Therapists advise parents and children on equipment that will help with their daily lives. They may also help with sensory issues. They liaise closely with physiotherapists and will help devise suitable programmes. |
| Psychologist | Psychologists study behaviour, thoughts and feelings and advise on how to manage any difficulties. They will advise on behaviour difficulties. |
| Dietician | The dietician will assess nutritional needs based upon your child's medical condition and help with feeding issues. |
| Teacher of the Deaf/Teacher of the Visually Impaired | Teachers with extra specialism in hearing and vision difficulties. |

Frequently Asked Questions

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 congenital CMV can be for your family. The early days following diagnosis can be bewildering and upsetting. As your child gets older, they may exceed expectations or face new challenges as a result of the virus. Our dedicated team of support volunteers have all had experiences of 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.

My child has congenital CMV, are other people at risk of CMV infection from them?

If your child was born with congenital CMV he/she may still have the virus present in his/her saliva and urine for prolonged periods of time. It is then possible for others to catch CMV by contact with your child's saliva or urine. However, simple measures, such as not sharing food or drink and handwashing after contact with saliva or urine, significantly reduces this risk.

Many young children who are otherwise healthy will also shed the virus in their saliva and urine for prolonged periods of time. Therefore, children with CMV should not be treated in a different way to other children.

If I have a baby with congenital CMV, could my next baby also have congenital CMV?

Whilst it is theoretically possible for a pregnant woman to be infected with a different strain of CMV and to pass this onto another baby, this would be an extremely rare event. The risk of having a second baby with CMV symptoms as a result of your original virus reactivating is also very low – around 0.01% or 1 in 10,000. Experts in the UK, have not seen two children with congenital CMV in the same family. However, it is advised that all pregnant women practice simple hygiene precautions even if they have had CMV before.

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 for education settings to treat your child any differently from other children. Any of the children they work with could have an active CMV infection, therefore good hygiene measures are recommended in relation to every child.

All nurseries and schools should ensure that staff are practicing good hygiene precautions with all children. This means washing hands after changing nappies, not sharing cups and cutlery with children and washing toys regularly. These simple hygiene measures have been shown to reduce the risk of catching CMV. If you have any problems with school or nursery because your child has congenital CMV, our support volunteers at CMV Action will be happy to help and advocate on your behalf.

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 much longer.

It is not necessary to keep checking if your child still has the virus active in their urine or saliva because its presence does not influence or predict problems. Furthermore, schools and nurseries should not require your child to be tested for CMV shedding before admitting them. Your child should not be denied access to nursery or education because of the diagnosis of congenital CMV infection and no special infection precautions are required.

If you have any problems with school or nursery because your child has congenital CMV, our support volunteers at CMV Action will be happy to help and advocate on your behalf

Will my child's hearing loss get worse?

The most common problem associated with congenital CMV infection is sensorineural (or inner ear) hearing loss. It is progressive (worsens over time) for around half of children infected. Therefore, you need to have regular follow-ups with an audiologist to monitor any changes.

What problems might emerge over longer periods of time?

There isn't a lot of evidence on this as most studies only track babies' progress for a couple of years after diagnosis. One study followed children for five years and found that all moderate and

serious problems were apparent in the first year of life. Milder problems (e.g. hearing loss in one ear, mild language delay, mild motor impairment that had limited implications for the child) were identified later on.

Families affected by CMV in the UK have a range of different experiences. Some have identified issues, for example around feeding, behaviour and sensory development that became more obvious as their child got older.

CMV Action can put you in touch with other families so you can hear about their individual experiences. Call our helpline 0808 802 0030.

Further Support

It is important to know you are not alone and that there is support for you and your family.

CMV Action can give information and support to you, your family and friends, teachers and health professionals – when your child is diagnosed and in the future. You will be allocated an experienced support volunteer who will tailor their advice to your circumstances. There are also many organisations who can offer advice and information during pregnancy, after birth and to support you and your child throughout their childhood.

For information, the latest research and sources of support about CMV please visit our website, cmvaction.org.uk.

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).

CCMVNET

A group of clinicians across Europe caring for children with CCMV have joined together to establish an international paediatric registry of children with congenital CMV.

The aim of the registry is to learn as much as possible about congenital CMV, to build experience of a large international clinical cohort, which can then be used to design prospective clinical trials of new therapies, and to promote research and education

in CCMV and disseminate useful information about CCMV to the general public, and clinicians. Please see the CMV Action website for further details, or contact CCMVNET at ccmvnet@gmail.com.

