

CMV: YOUR QUESTIONS ANSWERED

A guide for families affected by CMV

CMV Action

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Spring 2016

CMV  **Action**
EDUCATE • VACCINATE • ERADICATE

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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 pose serious problems to unborn babies. In fact, congenital CMV is the most common non-genetic cause of inner ear hearing loss and a major cause of childhood disability.

CMV IS THE
MOST COMMON
INFECTION
PASSED FROM
MOTHER TO BABY

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

Spring 2016

Cytomegalovirus (si-to-MEG-alo- vi-rus)

THE BASICS ABOUT THE VIRUS

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 who become infected will have no signs or symptoms and no long term effects from CMV. It can however pose serious risks to unborn babies if a pregnant woman catches it for the first time. Congenital CMV is when a baby has been infected before birth. It is one of the leading causes of hearing loss in children and one of the main causes of childhood disability.

This section gives some basic information about what CMV is, who is at risk and the difference between CMV and congenital CMV.

Who is at risk of CMV?

Contracting CMV infection during pregnancy poses a risk to the developing baby, as some of these babies are born with permanent health problems. Others at risk include people with low immune systems, for example people on chemotherapy, or who have had a transplant or who are HIV-positive.

Is congenital CMV a rare condition?

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. Congenital CMV causes more birth defects and childhood deaths than Down's Syndrome, Toxoplasmosis (from cat poo) or Listeriosis (from soft cheese).

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. Congenital CMV is when CMV infection is transferred from the mother to the unborn baby during pregnancy. Some babies infected in this way will be born with birth defects.

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 who is infected.
- **Mother to unborn baby**
CMV can be transmitted to the developing baby across the placenta, causing congenital CMV.
- **Mother to newborn baby**
CMV can be transmitted to newborns through the

mother's breast milk or the process of giving birth. It is rare for full-term babies who catch CMV in this way to have problems. However, premature babies or very low birth weight babies can be affected.

- **Transplants** CMV may be spread to those receiving organ and bone marrow transplants. The virus can be a particular risk to these patients as their immune system is compromised or weakened.

- **Transfusions** Patients who receive a blood transfusion from a donor with CMV infection may acquire CMV themselves. However, donor blood is routinely treated in the UK to reduce these risks and CMV negative blood is recommended for some at-risk groups. People who have a normal immune system are unlikely to have health problems as a result of CMV infection.

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 (protective proteins) 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 against one strain of CMV, she can still get re-infected with a different strain. The body will fight the virus and produce

new antibodies just as with a primary infection.

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 active 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.



CMV can be transmitted to the developing baby across the placenta, causing congenital CMV

TRANSMISSION

You can't catch CMV from simply being in the same room as someone with the virus. It is spread through bodily fluids, so the chance of catching it through casual contact is very low. However, pregnant women need to take care, particularly if they work with young children or have very young children at home. This section explains how CMV is spread, how it is transmitted to an unborn baby, gives information about breast feeding and outlines the risks of your child passing on CMV if they are infected.

How is CMV spread?

CMV is found in bodily fluids, including urine, saliva, blood, mucus and tears. It is spread through close contact with bodily fluids. The main way pregnant women catch CMV is from small children's saliva and urine. So women who work with children, or who have a family already, need to be especially careful during pregnancy. There are some simple measures that can reduce the chance of catching CMV infection, these are described in the **Risk Reduction** section.

How long does the virus stay on surfaces?

The CMV virus survives on different surfaces for different periods of time. For example, it survives at least 15 minutes on hands, longer on plastic and shorter on wood.

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.

Is it safe to breast feed my 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. It is thought that this does not cause further problems. The benefits of breast milk are numerous and well documented and if you wish to breast feed your baby you should be encouraged to continue.

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.**



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



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

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.

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

If your child was born with congenital CMV and still has an active infection then others can catch it through close contact with their bodily fluids.

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

There is little information about the risks of having a second child with congenital CMV.

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. In general, women are advised to wait a year from delivery before trying for another baby to reduce this risk as far as possible.

However, there is still a risk of being re-infected 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.

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.

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.

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 their urine or saliva because its presence does not appear to 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.

Can CMV be transmitted through egg or sperm donation during fertility treatment?

There is little evidence on this. CMV has been identified in sperm, but the risks of transmitting CMV through donor sperm have not been quantified. It is not known whether CMV can be transmitted via egg donation and whether the risks are greater or less than with sperm donation. Despite a relatively low risk, congenital CMV infection from donated sperm cannot be ruled out.

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.

RISK REDUCTION

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

How can I reduce the risk of infection whilst I'm pregnant?

There are ways you can reduce the risk of infection whilst you are pregnant. Although it may be hard to avoid all possible exposures to CMV, by making a few recommended changes, you can help protect your unborn baby from infection.

DON'T SHARE



- 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 or give them a big hug.

WASH WITH CARE



- Clean your hands after touching 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 15 to 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.



Does hand sanitiser reduce risks?

If you cannot get to a sink, then alcohol based hand sanitiser is a good alternative. While it won't completely remove the CMV virus, it will render it non-viable. Wet-wipes are not effective at removing or de-activating CMV.

Can I reduce my 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.

These guidelines note that it is preferable to recruit CMV negative donors, who have never had the infection. However, when there aren't enough CMV negative donors (because most people catch CMV at some point in their lives), CMV positive donors should be used with CMV positive recipients. As the evidence is not clear cut, the recommendation about whether to use a CMV positive donor should be a matter of clinical and personal judgement.

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.

I am a nursery worker and am pregnant. Am I 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 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. 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.

DIAGNOSIS AND MANAGEMENT IN PREGNANCY

Diagnosis of CMV infection during pregnancy usually follows an abnormal scan or test. This can be confusing and stressful. However, it does not necessarily mean that the infection has been passed on to your baby or that they will be affected by the virus. This section aims to explain how doctors diagnose CMV during pregnancy and where you can go for further support.

FOR NOW WE NEED TO FOCUS ON THE SIMPLE HYGIENE MEASURES THAT CAN REDUCE THE RISK OF CATCHING THE VIRUS IN THE FIRST PLACE

How do I know if I 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.

A blood test can tell if you have an active CMV infection or have had a previous infection. However, if you have had CMV before, it is still possible to catch a different strain. It is therefore important for all pregnant women to follow simple hygiene precautions even if they have had CMV before – nobody is 'immune'.

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 develop normally and available tests are not able to distinguish between infections that would seriously affect the baby and those that would not. Neither are there any treatments proven to reduce 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.

Researchers are investigating treatments that could be effective in pregnancy. But for now we need to focus on the simple hygiene measures that can reduce the risk of catching the virus in the first place.



CMV ACTION WORKS WITH MIDWIVES TO RAISE AWARENESS OF THE VIRUS AND TO SUPPORT WOMEN THROUGH THEIR PREGNANCY

www.cmvaction.org.uk/healthprofessionals

I am pregnant and have been diagnosed with CMV: what does this mean for me and my baby?

Being diagnosed with CMV infection when you are pregnant can be very stressful. However, it does not necessarily mean that your baby has the virus. Of all the women who catch CMV for the first time during pregnancy, only around a third will pass it to their unborn baby.

You may have additional scans or an amniocentesis (taking some water from the sac around the baby) to see if your baby has been infected. 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.

Some babies do have more severe symptoms when they are born. Diagnosis in pregnancy can help to ensure that your newborn baby is diagnosed quickly and gets the support that he or she needs.

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 **Further Support**).

Is there any treatment for CMV infection in pregnancy?

Some small-scale studies have investigated a treatment called 'Hyperimmune globulin (HIG)'. This aims to reduce the risk of transmission from mother to baby and to reduce the severity of symptoms in babies that have been infected. However, the amount of evidence available is limited and the effectiveness and risks of this treatment have not been confirmed. A larger-scale study is currently under way.

HIG is therefore not offered in the UK or other countries as routine practice. Some private practitioners in other European countries offer this unproven treatment.

DIAGNOSIS AND SYMPTOMS 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 and will not develop any as they grow older. Others may have no obvious signs at birth, but may go on to develop hearing loss as a result of congenital CMV. A small number of babies born with the most serious symptoms may develop learning, developmental and physical disabilities.

This section explains the obvious symptoms of congenital CMV at birth and how a diagnosis will be made. It gives information about monitoring hearing loss and details some of the more serious health impacts of congenital CMV.

How will my baby be diagnosed?

A saliva, urine or blood test can confirm whether the CMV virus is present (saliva and urine tests are the most reliable). Ideally, two samples should be collected. 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, i.e. your 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 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.

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 Dried Blood Spot or Guthrie card and they are stored for around five years. This can help confirm whether it is a congenital infection.



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

Will all children born with congenital CMV have problems?

There is a huge range in the severity of problems that children with congenital CMV experience and many children will have absolutely no problems at all.

Most children born with congenital CMV will not show symptoms at birth. This is called 'asymptomatic' infection. Most of these children will not have any problems but around 15% of them will go on to develop 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 congenital 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. Some of these children will go on to develop other problems such as cerebral palsy, seizures, ADHD, autism, developmental differences and learning delays or visual impairment.

Overall around one in every five children born with the virus will have permanent problems such as hearing loss or developmental disabilities due to the infection.

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) for around half of children infected. Therefore, you need to have regular follow-ups with an Audiologist to monitor any changes.

If your child is diagnosed with congenital CMV before they are four weeks old then they can be treated with antiviral medication. This may help to stop hearing loss from getting worse.

What problems might emerge over 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

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, and when diagnosis is made.

This section sets out the treatment currently available for babies diagnosed in the first few weeks of life, including the benefits and risks of this treatment.

TREATMENT
OPTIONS
SHOULD BE
INDIVIDUALISED
TO YOUR
BABY'S NEEDS

Is there a treatment for congenital CMV?

Anti-viral drugs, such as ganciclovir and valganciclovir, can be used to treat babies with symptoms of congenital CMV. Ganciclovir is given intravenously (into a vein through a 'drip') and would be the drug used for babies who are not able to take all of their feeds by mouth, for example, in premature babies. Valganciclovir can be given by mouth and would be used for babies who are feeding normally. Treatment options should be carefully discussed with your baby's doctor and individualised to your baby's needs.

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 should be started before four weeks of age. 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, up to 15% may go on to develop hearing loss. This usually only affects one ear, but may involve both ears.

Anti-viral treatment for asymptomatic newborns is not recommended because it is not possible to accurately predict which children will go on to develop hearing loss. There is currently no evidence that anti-viral treatment is of benefit for children who develop hearing loss later in childhood. However, a study is currently being carried out to understand more about this.

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

What are the benefits of antiviral treatment?

Anti-viral treatment may help to prevent hearing loss or 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. In a recent research study, a small positive benefit was seen in babies who received six months of valganciclovir treatment compared to six weeks of treatment.

What are the risks of antiviral 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 a reduction in the number of platelets in the blood (the cells that help the blood clot). The liver can also be affected in some cases. Blood tests are required to closely monitor the blood cells and function of the liver. If these side-effects do happen, then anti-viral medication may have to be stopped for a while.

The decision to start anti-viral treatment is not straightforward. 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 options for anti-viral treatment and length of treatment with a doctor who has experience in treating babies with congenital CMV, such as a paediatric infectious diseases specialist.

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.

This section sets out the tests that should be offered soon after birth, further tests that will be carried out in the first few years of their life, and gives details of other support available if your child has more complicated health impacts as a result of congenital CMV.

My baby has been diagnosed with congenital CMV, what type of follow up should we expect?

All babies born with congenital CMV should be carefully assessed for any symptoms at the time of diagnosis. All children should continue to be monitored regularly, this is also the case for children born without any symptoms, as some problems only develop over time.

When babies are first diagnosed with congenital CMV the following tests are normally done:

- Blood tests to check the blood count (red blood cells, white blood cells and platelets), kidney and liver function and the amount of CMV virus in the blood;
- Brain scan.
- Hearing test.

- Eye test.

After this, all children should be regular monitored:

- Babies who receive anti-viral treatment will have blood tests every few weeks whilst on treatment.
- All children born with congenital CMV should have a hearing assessment every three to six months until the age of three and then yearly until six years old. This is particularly important as hearing loss is often progressive and may get worse over time.
- All children born with congenital CMV should have 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 born with symptoms of congenital CMV

should have an annual eye test until the age of five.

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

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. 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 diseases specialist.

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.

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.

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. 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.

CMV Action

For information, the latest research and support about CMV

Tel: 0808 802 0030

Email: info@cmvaction.org.uk

Web: www.cmvaction.org.uk

DURING PREGNANCY

ARC

ARC is the only national charity helping parents and healthcare professionals through antenatal screening and its consequences.

Tel: 0845 077 2290 or

0207 713 7486 from a mobile.

Email: info@arc-uk.org

Website: www.arc-uk.org

Tommy's

Offers support for miscarriage, premature birth and still birth.

Tel: 0207 398 3400

Email: mailbox@tommys.org

Website: www.tommys.org

PREMATURE BABIES

Bliss

Offers confidential advice and support to new parents of premature and sick babies.

Helpline: 0500 618 140

Email: ask@bliss.org.uk

Website: www.bliss.org.uk

SUPPORT FOR PARENTS OF CHILDREN WITH SPECIAL EDUCATIONAL NEEDS AND DISABILITIES

See CMV Action's website for a full list:
www.cmvaction.org.uk/get-support

Cerebra

Supports families of children with brain related conditions – including a sleep service, grants and emotional support.

Tel: 0800 328 1159

Email: info@cerebra.org.uk

Website: www.cerebra.org.uk

Contact a Family

For families of disabled children. Offers support and information.

Tel: 0808 808 3555

Email: helpline@cafamily.org.uk

Website: www.cafamily.org.uk

Independent Advice Support Service Network (formerly Parent Partnership Service)

Provides local information, advice and support for parents of children with special educational needs. See website for details of local groups and support.

Website: www.iassnetwork.org.uk

Kids

National charity providing information, support and a network of play centres/activities and groups for disabled children and young people.

Contact via the website

Website: www.kids.org.uk

National Autistic Society

Provides information, support and services for people with autism and their families.

Tel: 0808 800 4104

Email: [via website](mailto:via@nas.org.uk)

Website: www.nas.org.uk

National Deaf Children's Society

Dedicated to creating a world without barriers for deaf children and young people. Offers information, support, events and groups.

Tel: 0808 800 8880

Email: helpline@ndcs.org.uk

Website: www.ndcs.org.uk

Cochlear Implanted Children's Support Group (CICS)

Voluntary group run by parents in the UK to provide support at before, during or after a child's cochlear implant.

Tel: 020 8876 8605

Email: info@cicsgroup.org.uk

Website: www.cicsgroup.org.uk

Portage

The Portage service offers home education and support for pre-school children with special educational needs and disabilities. See their website for details of local support.

Tel: 0121 244 1807

Email: parents@portage.org.uk

Website: www.portage.org.uk

Sense

Sense is a national charity supporting and campaigning for people who are deafblind and those with sensory impairments.

Tel and textphone: 0300 330 9256 or 020 7520 0972

Email: info@sense.org.uk

Website: www.sense.org.uk

Sibs

Provides support and information for siblings of disabled people. Young Sibs is just for younger brothers and sisters of disabled children. See the website for contact details.

Sibs Website: www.sibs.org.uk

Young Sibs: www.youngsibs.org.uk

