CMV: WHAT TO EXPECT

A guide to the diagnosis, treatment and management of congenital CMV

CMV Action
Tel: 0808 802 0030
Email: info@cmvaction.org.uk
Web: www.cmvaction.org.uk

Spring 2016

CMV Action
EDUCATE • VACCINATE • ERADICATE

A GUIDE TO THE DIAGNOSIS, TREATMENT AND MANAGEMENT OF CONGENITAL CMV

A diagnosis of congenital CMV in your newborn baby can be confusing and upsetting. This document sets out the key points from the clinical guidelines currently available for the diagnosis, treatment and management of congenital CMV. 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 of 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 be different in different local areas. This document has been checked by medical experts and references to clinical guidelines can be found at the end of this document.

Making the diagnosis – what doctors will look for

If congenital CMV is suspected, your baby's doctor will look for certain signs of CMV infection. These are not unique to congenital CMV and some babies will not show all these signs.

Some children 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).

Most babies will not show any symptoms at birth, this is called 'asymptomatic'. If congenital CMV is suspected, doctors should still carry out tests to confirm a diagnosis. Your baby may also be referred to a paediatric infectious diseases consultant whilst these tests are being carried out or once congenital CMV has been confirmed.

Making the diagnosis – what doctors will test for

A saliva, urine or blood test taken within the first three weeks of life can confirm that your baby was born with congenital CMV. Ideally, at least two of these tests should be carried out, and the sooner after birth that these are done the better, so treatment can begin immediately, if appropriate. In order to confirm a diagnosis, doctors should carry out the following tests:

What may be tested?	Why?	How may this vary locally?
Saliva swab	This is the quickest and easiest way to test whether the CMV virus is present in your newborn baby and is very reliable.	Saliva testing is not available in all areas.
Urine sample	A urine sample from your baby in the first three weeks of life is the most accurate form of diagnosis. Ideally a urine sample and saliva swab test will be taken to confirm congenital CMV.	Collecting urine samples from babies is not easy. Not all clinics have the special bags and pads and time to do this when you have an appointment with the doctor.
Blood test	A saliva or urine test is the best way to confirm whether the CMV virus is present. However, blood tests can also be useful.	Should be widely available.
Newborn blood spot card	Every baby in the UK has a small blood sample taken when they are a few days old. This blood sample is stored on a card. Some symptoms of congenital CMV infection, such as hearing loss, may only develop as a child gets older. For any child aged older than three weeks, a saliva or urine test won't tell whether any CMV they have now was there when they were born. Going back to the newborn blood spot card can sometimes confirm this. If it is positive it is likely that a baby has congenital CMV. However if this test is negative, then it does not rule out CMV infection before birth.	Local policies vary on how easy it is to retrieve dried blood spot cards.

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. In some cases it can help doctors to identify children who may be most at risk of developmental or hearing problems in the future. Some children may also have visual impairment caused by a brain problem rather than an eye problem. This isn't always easy though. The doctor will decide on the most appropriate kind of scan (ultrasound, CT or MRI) and discuss the results.
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).
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.

Treatment for congenital CMV

Antiviral drugs, such as ganciclovir and valganciclovir can be used to treat newborn babies and should be started within the first month of their life. Some drugs are given intravenously (in the bloodstream), others are given orally (in the mouth). This guidance is for babies who are full term – born after 32 weeks of pregnancy. The main benefit is to reduce the severity of hearing loss associated with congenital CMV infection. 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 part of their treatment. They will be closely monitored for any side effects and risks. The length of treatment will be discussed with you and will depend on many factors. 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.

Side effects of treatment

The most common side effect of anti-viral treatment is a decrease in infection fighting white blood cells which means your baby may be more susceptible to other infections. In some instances kidney and liver function can also be affected by these drugs. Doctors will monitor your baby very closely during treatment and will check on: white blood cell counts, platelet count, kidney and liver function. 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.

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-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. If your child is affected by hearing loss, they may be offered cochlear implants or hearing aids. 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.

- 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.

- Children born with symptoms of congenital CMV should have an annual eye test until the age of five.

If your child has not been offered these follow up tests, you should ask your doctor to make the referrals to the relevant specialists.

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

On-going support

There are many professionals who may be involved in the care of your child.

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	Dieticians 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.

If you want to know more about treatment and support, contact CMV Action on:

0808 802 0030

or email:

info@cmvaction.org.uk

CLINICAL REFERENCES

1. Fifteen minute consultation: Diagnosis and management of congenital Cytomegalovirus, Shah T, Luck S, Sharland M, Kadambari S, Lyall H. Arch Dis Child Educ Pract Ed 2015 Accepted
2. The first set of evidence-based UK guidelines for the detection and treatment of congenital Cytomegalovirus were published in 2011. Kadambari S, Luck S, Williams EJ, Griffiths PD, Sharland M. Evidence based management guidelines for the detection and treatment of congenital Cytomegalovirus. Early Hum Dev. 2011 Nov;87(11):723-8
3. Boppana, S.B., S.A. Ross, and K.B. Fowler, congenital Cytomegalovirus infection: clinical outcome. Clin Infect Dis, 2013. 57 Suppl 4: p. S178-81.
4. Kimberlin, D.W., et al., Valganciclovir for Symptomatic congenital Cytomegalovirus Disease. New England Journal of Medicine, 2015. 372(10): p. 933-943.
5. Gwee, A., et al., Ganciclovir for the treatment of congenital Cytomegalovirus: what are the side effects? Pediatr Infect Dis J, 2014. 33(1): p. 115.

NOTES

CMV Action

EDUCATE • VACCINATE • ERADICATE

Registered charity number: 1147633

0808 802 0030

info@cmvaction.org.uk

cmvaction.org.uk

@cmvactionuk

/CMVAction