

Paediatric Infectious Diseases, St Mary's Hospital

# Congenital Cytomegalovirus



## Information for patients, relatives and carers

### What is cytomegalovirus?

Cytomegalovirus (CMV) is a common virus, which belongs to the same family of viruses as the glandular fever virus. CMV is usually harmless, and rarely causes problems in healthy people. Once infected with CMV, it stays in our bodies long term, but our immune system usually keeps it asleep (the virus is there but not active). CMV is the most common infection to pass from a mother to baby in the womb. If a pregnant woman gets CMV, sometimes it passes to the baby, and if it causes problems for the baby this is called congenital cytomegalovirus.

### How does it spread?

CMV is spread through direct contact with bodily fluids of someone who has the virus. CMV can be passed through saliva, blood, breast milk, tears, urine, poo and sexual fluids. During pregnancy, CMV can pass to the unborn baby across the placenta. Spread of CMV can be reduced through careful hand washing and avoiding bodily fluids.

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## What are the symptoms?

In most healthy adults and children, CMV does not usually cause any symptoms or long-term health effects.

Some people with CMV may develop a mild glandular fever type illness, with symptoms including, fever, sore throat, rash, extreme tiredness, swollen glands and an enlarged liver or spleen.

A blood test can tell if you have an active CMV infection or have picked up CMV in the past.

## Signs in a newborn

Most babies with congenital CMV will have no obvious signs or symptoms at birth, but up to 10% may develop hearing loss and/or developmental problems over time. All babies who fail the newborn hearing screening test should have a CMV test, before 21 days of age.

Some babies may have signs of CMV infection at birth. These can include, premature birth, low birth weight, lots of very small red or purple spots (called petechiae), larger (2-8mm) red or purple dome shaped spots (called blueberry muffin rash), a head significantly smaller than other babies (microcephaly), enlarged liver and spleen, yellow skin (jaundice), scarring or inflammation at the back of the eyes.

More than half of children with signs and symptoms of CMV at birth, will have long-term problems such as hearing loss or developmental disabilities.

## How could CMV affect my pregnancy?

In the UK we do not routinely screen women for CMV in pregnancy, but if you are diagnosed with CMV during pregnancy, you should have additional scans to detect any signs of CMV in the unborn baby. You may be offered an amniocentesis (taking some fluid from the sac around the baby) to see if your baby has been infected.

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You may be offered antiviral treatment, which may reduce the risk of CMV infection of the baby or the severity; this should be discussed with your obstetrician.

## What will happen once my baby is born?

A saliva, urine or blood test can confirm whether the virus is present, and the baby has congenital CMV. The samples must be taken before 21 days of age. Further tests will be carried out by your doctor, including blood tests, brain scans, hearing and eye tests.

No vaccine for CMV is currently available, but some are in clinical trials. Newborns with symptoms of congenital CMV infection may be given antiviral medication (valganciclovir), which may improve hearing and developmental outcomes. You can ask for our information leaflet to find out more about the valganciclovir treatment.

## Is my baby infectious to others?

A baby with congenital CMV will intermittently have the virus in saliva and urine for some months, but this usually gets less over time. Passing the virus on can be reduced through careful hand washing and avoiding bodily fluids.

A baby with congenital CMV will not be infectious to others if they are on valganciclovir treatment, as this puts the virus to sleep. When the treatment is finished, they are no different to any other infant/toddler who all may have CMV in saliva or urine from time to time.

You and your baby can attend baby groups and soft play just like any other family, the usual hand washing rules apply to all. You do not need to tell anyone about your baby's CMV.

## Long-term follow-up

All children born with congenital CMV should have their hearing and development regularly monitored. This includes regular hearing tests until 5-6 years of age, and assessment by a paediatrician for the first few years, to check their development. Ongoing support from the multi-disciplinary

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developmental team (physio, speech and language, psychology, paediatrician, etc) may be required for some children.

## Who can I speak to for more advice?

If you have any questions, please contact the Family Clinic Specialist nurses' (phone 07500835509) or the department of Paediatric Infectious Diseases 02033121013.

If your baby has a diagnosis of CCMV you can also have support from CMV Action. They cannot give you medical advice but can support you and help you contact other families.

**[www.cmvaction.org.uk](http://www.cmvaction.org.uk)**

**Freephone 0808 802 0030.**

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## How do I make a complaint about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at [imperial.pals@nhs.net](mailto:imperial.pals@nhs.net) The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY

Email: [ICHC-tr.Complaints@nhs.net](mailto:ICHC-tr.Complaints@nhs.net)

Telephone: **020 3312 1337 / 1349**

## Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team: [imperial.communications@nhs.net](mailto:imperial.communications@nhs.net)

## Wi-fi

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[www.imperial.nhs.uk](http://www.imperial.nhs.uk)

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