Postnatal care for babies born with congenital cytomegalovirus (CMV)

Congratulations on the birth of your baby! We understand that you may have lots of questions about being a parent, especially if your child has been diagnosed with congenital cytomegalovirus (CMV). We want to assure you that there is support to help your baby thrive.

What is congenital CMV?

Cytomegalovirus (CMV) is a viral infection that can be passed from a pregnant woman to her developing baby during pregnancy. Congenital CMV means that your baby had this virus at birth. It is one of the most common congenital infections, occurring in about 1 in 200 babies. Most babies with congenital CMV are completely well, but some may have health issues that are present at birth or appear later in early childhood.

Why was my baby tested for CMV at birth?

Babies are not routinely tested for CMV at birth in Australia. Babies are tested for CMV if their mother had a CMV infection during pregnancy or if the baby has some symptoms suggestive of CMV. The most common reason for testing is an infant who does not pass the newborn hearing screening test.

How is congenital CMV diagnosed?

Congenital CMV is diagnosed if the virus is detected in the baby's urine, saliva or blood within the first three weeks of life. If a baby tests positive for CMV after three weeks of life, it might mean that the baby caught CMV after birth, not before birth. If a baby catches CMV after birth, it usually doesn't cause any problems for the baby.

Can I still breastfeed if my baby has congenital CMV?

Yes, breastfeeding is still recommended for babies with congenital CMV. The World Health Organisation recommends babies breastfeed for the first six months of life. Breastfeeding provides many benefits for your growing child including improved visual acuity, cognitive and psychomotor development. It can protect your baby against a range of infections and helps your baby build a strong immune system. Breastfeeding also has many health benefits for you including reduced risk of breast cancer, ovarian cancer and osteoporosis (weak bones). Ask your health care professional if you have questions.

What care will my baby need in the first few weeks of life?

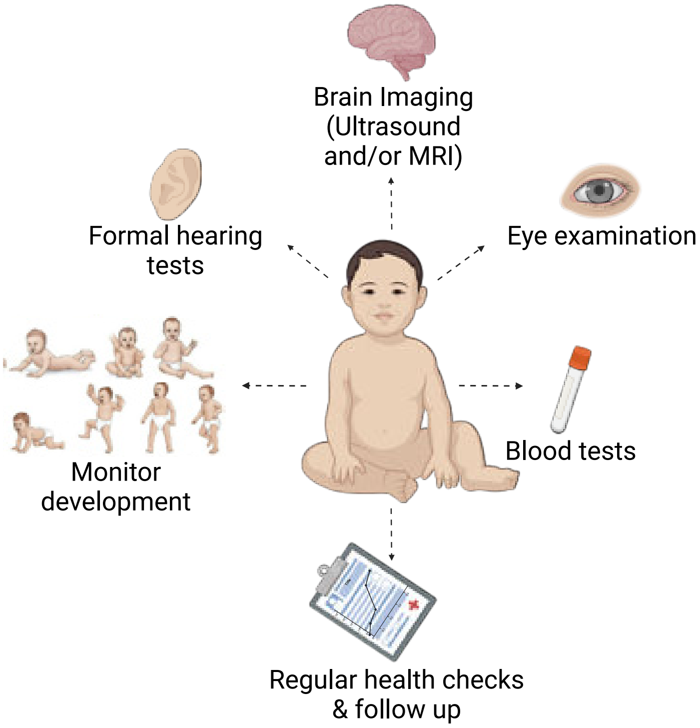
If your baby was diagnosed with congenital CMV, a paediatrician should be involved in your baby's healthcare. All babies with congenital CMV should have regular hearing tests with an audiologist (hearing specialist) in addition to the routine newborn hearing screen. They should also have regular check-ups with a doctor until they are five years of age. These visits may be every three to six months, depending on your child's progress.

What other tests might be recommended?

Depending on your baby's health, their doctor may recommend some of these tests:

- **Eye examination** – This is a physical examination of the fundus (back of the eye) by an ophthalmologist (eye doctor) to check your baby's eyes.
- **Brain imaging** – An ultrasound of your baby's brain to check for any signs of CMV in the brain. If your baby has hearing loss, your baby's doctor may recommend an MRI scan.
- **Blood tests** – These check your baby's blood count, liver and kidney function.
- **Additional testing and treatment** – Your baby's doctor may recommend other tests if your baby has symptoms such as jaundice, an enlarged liver or spleen, or an abnormal rash.
- **Medication** – If your baby has symptoms of CMV, your baby's doctor may recommend treatment with antiviral medication.
  A paediatrician or an infectious diseases specialist should discuss this with you.

Tests that your baby may be offered



Few more important points for parents to consider:

Stay positive and stay informed – While congenital CMV can be a serious condition, most children lead a healthy and happy life. We encourage you to write down your questions and discuss them with your child's healthcare provider. It is important to work closely with your healthcare team to ensure the best possible care for your child.

Self-care – It is important for parents to take care of themselves too. Be sure to take time for self-care and seek support from family, friends, and healthcare providers.

Support and information

Where can I get more information and support?

1. CMV Australia has lots of information resources for families. You can also connect with other families for peer support and advice through this organization. https://www.cmv.org.au

2. Information on congenital CMV from the Childhood Hearing Australasian Medical Professionals (CHAMP) network
https://www.newbornhearingscreening.com.au/wp-content/uploads/2021/02/2101_CCCH_CMV_FAQs_CHAMP.pdf

3. A resource for parents of children with hearing loss from Hearing Australia
https://www.hearing.com.au/HearingAustralia/media/assets/Documents/NSO_1467-Choices-Publication_digital_200121.pdf

4. Aussie Deaf Kids is a source of information and support for Australian families with a child who is deaf or hard of hearing
https://www.aussiedeafkids.org.au/

cCMV Register

What is the CMV Register?

The Australasian Congenital Cytomegalovirus Register (ACMVR) is a confidential database of information about people with congenital CMV. The aim of the register is to understand more about the impact of CMV and to improve the lives of people with congenital CMV through collaborative research. To learn more about the CMV register, please click here.

An initiative of

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