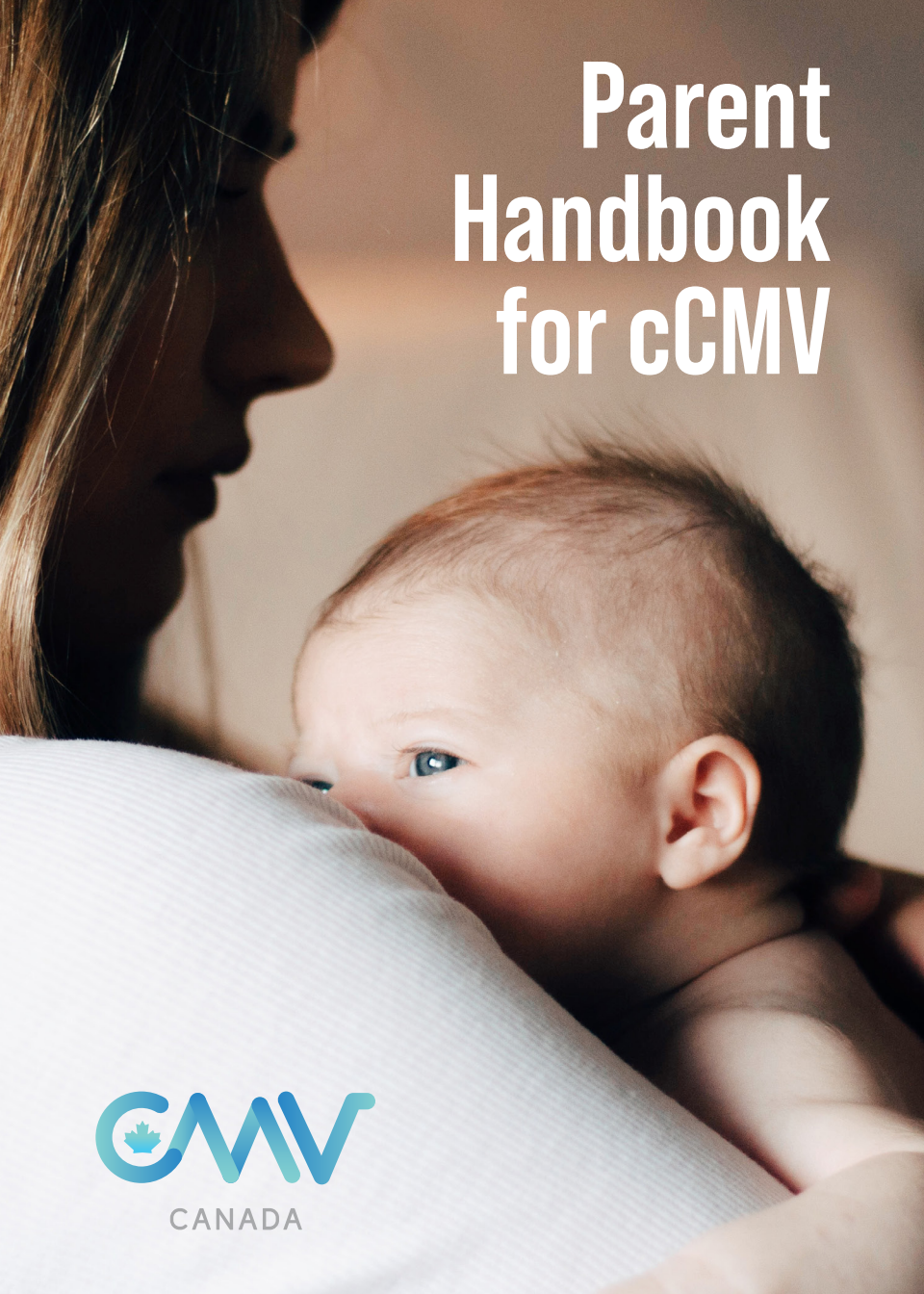
Parent Handbook for cCMV



CMV CANADA

Dear Caregivers,

Receiving a diagnosis of congenital CMV (cCMV) for your child can feel overwhelming and unsettling, stirring many questions and emotions. cCMV affects up to one in every 200 babies, and its impact varies widely. It is important to know that while this diagnosis may feel isolating, you are not alone. Many families have navigated this journey before you, and a supportive community is here to help.

This handbook has been created with you in mind. Inside, you will find answers to some of the most common questions asked by parents in the CMV Canada community. These insights come from the shared experiences of others who have walked a similar path. As you begin to learn more about cCMV and explore your options, we encourage you to stay informed, remain hopeful, and lean on the support around you.

We are here to walk alongside you every step of the way.

With care,

The CMV Canada Community

What is CMV? What is cCMV?

CMV stands for cytomegalovirus. Cytomegalovirus (pronounced site-oh-meg-uh-low-VY-rus) is a common virus. When the virus is passed to a baby during pregnancy, it is called congenital CMV, or cCMV. This means the baby has the virus before birth. If a baby gets the virus from their mother during pregnancy, it can sometimes cause health problems for the baby. However, if someone contracts CMV for the first time as a child or adult, it is usually mild and does not cause lasting effects.

Every year, up to 1 in 200 babies are born with cCMV. It is the most common infection passed from a mother to her unborn baby. CMV spreads from person to person through contact with bodily fluids such as blood, tears, saliva, urine, and breast milk.

How is CMV diagnosed?

Congenital CMV is usually diagnosed by detecting CMV in a baby's urine, saliva, or blood within the first three weeks of life. Testing beyond this time frame can indicate a CMV infection acquired after birth, which is less likely to cause long-term health issues in full-term infants.

In some cases, cCMV may be suspected when a baby does not pass their newborn hearing screening. Hearing loss can be an early sign of cCMV, prompting healthcare providers to recommend further testing, such as checking for the virus in the urine, saliva, or a dried blood spot from the baby's newborn screening.

What does a "positive" CMV screening result mean?

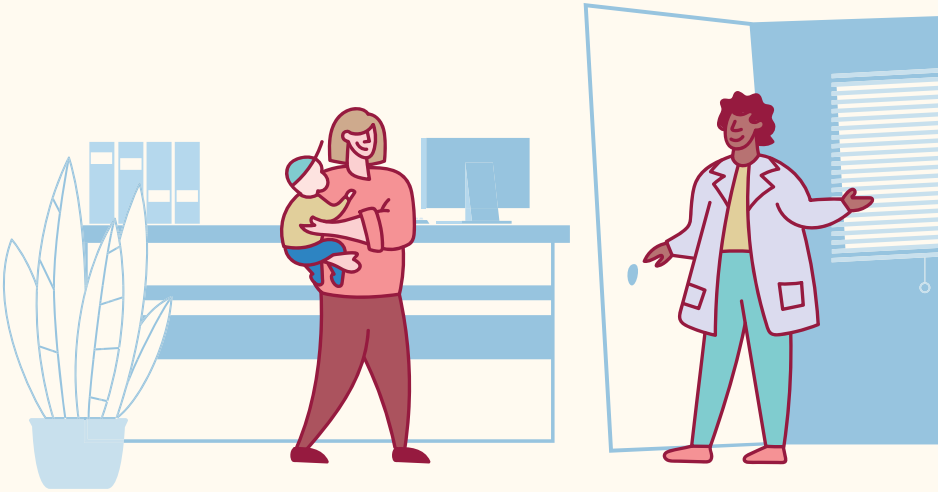
A positive CMV screening result means that your baby likely has a congenital CMV (cCMV) infection. Many babies with cCMV are healthy at birth and will not experience any health problems. However, some babies may develop complications that could affect their health or development. To understand what a positive result means for your baby, a pediatrician or infectious disease specialist will perform a detailed assessment. This evaluation can help identify whether your baby shows any signs of infection and determine if follow-up care or treatment is needed.

What does the assessment for cCMV include?

If a baby has a positive CMV screening result, they will need a follow-up assessment to check for any signs of a congenital CMV (cCMV) infection and to determine the best next steps.

The assessment typically starts with a hearing test (audiology evaluation) to check for any hearing loss, as this is one of the most common effects of cCMV. A pediatrician or infectious disease specialist will also confirm the diagnosis with a urine CMV test and perform a physical exam.

Depending on the findings, the doctor may recommend additional tests, such as blood tests, head imaging, or an eye exam. Eye exams require a referral from a doctor and may take longer to schedule in some areas. These tests help identify whether the baby might benefit from treatment and what kind of follow-up care is needed.



How are babies affected by cCMV?

The effects of congenital CMV (cCMV) vary widely. About nine out of 10 babies born with cCMV will not show any symptoms at birth. This is called a "silent" or asymptomatic infection, meaning there are no obvious signs of the virus, and it often goes undetected without specific testing. However, even with a silent infection, some children may develop complications later on, such as hearing loss, learning delays, developmental challenges, or vision problems.

For the 10% of babies who do show symptoms of cCMV at birth, the following may be present:

- Premature birth
- Small overall size at birth, or small head or brain size (microcephaly)
- Red or purple spots on the body caused by bleeding under the skin (petechiae or purpura)
- Yellowing of the skin and eyes due to high bilirubin levels (jaundice)
- Brain abnormalities, such as calcifications (scarring), white matter changes, cerebral atrophy, malformations, or cysts
- Abnormal muscle tone
- Enlarged or inflamed liver
- Enlarged spleen
- Inflammation or damage to the eyes
- Feeding difficulties
- Seizures

Both silent infections and symptomatic infections can result in hearing loss. Hearing loss may range from mild to severe, affect one or both ears, and can develop shortly after birth or later in childhood. Because of this, regular hearing checks are essential for babies and children with cCMV, even if they appear healthy at birth.

Many children with hearing loss due to cCMV benefit from hearing aids or cochlear implants, which can significantly improve their ability to communicate and interact with the world.

Understanding the Contagion Risk of Children with Congenital CMV

It's natural to worry about whether a child born with congenital CMV (cCMV) might be more likely to spread the virus, especially to other children.

CMV is a common virus that many people, including children, carry at some point without even realizing it. Toddlers and preschoolers, whether or not they were born with cCMV, often shed the virus in their saliva or urine as part of normal childhood infections.

Children with cCMV can and should participate fully in social interactions, daycare, and school without concern about being a greater source of infection than their peers.

However, research shows that babies with cCMV do shed higher amounts of the virus in their urine and saliva and tend to shed it longer and more frequently than non-congenitally infected children. This shedding can continue until at least 6-12 months of age and intermittently thereafter. While this does not mean they pose a unique risk to others, additional information on precautions can be found in the relevant sections of this handbook.

Is there treatment for cCMV?

Yes, there are treatment options available for congenital CMV (cCMV), but they depend on the baby's symptoms and their severity. Newborns who show signs of a significant cCMV infection may benefit from antiviral medications. These medications help slow down the replication of the virus, reducing its impact on the body, but they cannot completely eliminate it.

A physician will assess your baby's condition to determine if antiviral treatment is appropriate. This decision is usually based on factors like the presence of symptoms affecting the baby's overall health, hearing, or development.

Caregivers may also want to discuss follow-up care with their child's physician. Babies with cCMV benefit from regular monitoring of their hearing and developmental milestones. If any concerns arise, support services can be introduced early to address potential challenges and support healthy development.

These services can include:

- **Audiology** for regular hearing evaluations and management of any detected hearing loss
- **Physical therapy** to improve strength, coordination, and movement
- **Occupational therapy** to support daily activities, motor skills, feeding challenges or balance problems
- **Speech and language therapy** to assist with communication and language development
- **Dietitian** to address any nutrition-related concerns
- **Ophthalmology** to monitor vision and eye health
- **Radiology** to assess brain structure and detect abnormalities
- **Infectious disease specialists** for managing and monitoring cCMV-related health concerns

Researchers are also working on developing new treatments and vaccines to improve outcomes and prevent CMV infections in the future.

What type of follow-up is recommended for babies with cCMV?

Babies with a confirmed congenital CMV (cCMV) infection need regular follow-up to monitor their health and development. One of the most important follow-up steps is regular **hearing tests**. Hearing should be checked frequently, especially in the first two to three years of life, and then yearly after that. If any hearing changes are noticed, additional testing may be necessary. For babies with hearing loss due to cCMV, hearing aids or cochlear implants may be recommended to support communication and development.

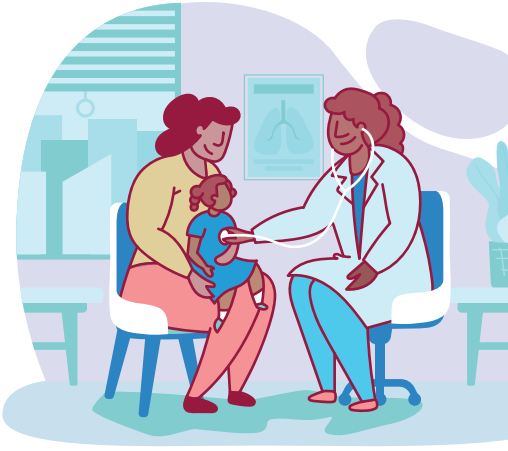
If your baby has other symptoms of cCMV, or if there are concerns about their vision, an **eye exam** should also be performed to check for any eye issues.

In addition to hearing and vision, your baby's overall **growth and development** should be closely monitored. This includes checking for things like:

- Head size, weight and height
- Reaching developmental milestones (such as crawling, walking, or talking)
- Balance problems

Depending on your baby's specific symptoms, additional tests like **blood work** may be needed to check how the virus has affected organs in the body.

It's also important for your baby to continue with their regular **routine check-ups** with their primary care provider, just like other children, to monitor overall health and development.



Can I prevent cCMV?

Although scientists are actively working on a vaccine to protect against CMV, there is currently no vaccine available and no cure for the infection. However, there are steps we can take to reduce the risk of spreading CMV, particularly to protect pregnant women and their unborn babies. Since CMV is transmitted through bodily fluids, these simple precautions can make a big difference:

- Wash your hands thoroughly and often with soap and water, especially after changing diapers or wiping a child's nose
- Avoid sharing food, drinks, or eating utensils with young children
- Do not put a child's pacifier in your mouth
- Kiss young children on the forehead or cheek instead of the lips
- Regularly clean toys, countertops, and other surfaces that may come into contact with children's bodily fluids

How do I cope?

Learning that your child has congenital CMV can bring a wide range of emotions, and every family's journey is unique. It is completely normal to feel overwhelmed as you begin to process the diagnosis and what it means for your family. Many parents have shared experiencing emotions such as:

"Why didn't I know about CMV?"

Sadness
Frustration
Disappointment
Anger
Guilt and Self-Blame
Anxiety
Helplessness

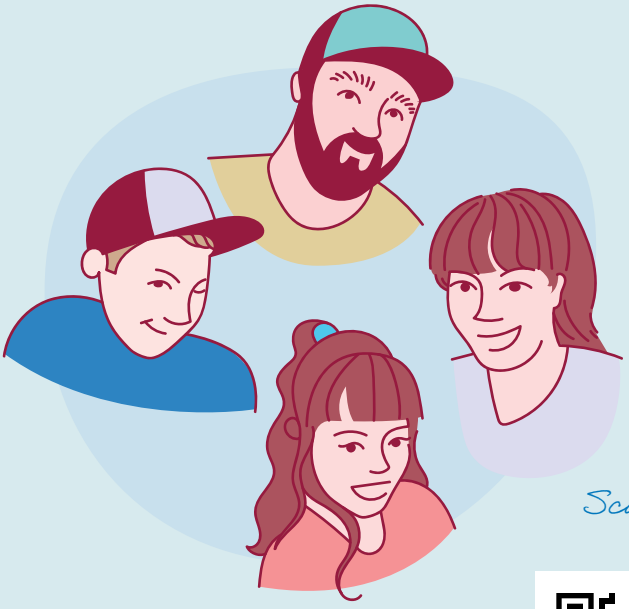
"What did I do wrong to cause this?"

It's not easy, especially after giving birth, to learn that your baby has a condition you may have never heard of before. You might feel overwhelmed, uncertain, or even grieving the life you envisioned for your child. These emotions are normal and valid. If you're feeling this way, know that you are not alone. Connecting with others who understand your experience can provide comfort, hope, and a sense of community. CMV Canada offers regular family support meetings, where you can meet other parents navigating similar challenges.

Remember that it's okay to take things one step at a time. Allow yourself space to process your feelings, seek support when you need it, and focus on the joys and milestones that come with parenting your baby. With time, understanding, and connection, you will find your way forward.

The Robinson Family Innisfail, Alberta

Before Lisa and T.J. received the diagnosis of a severe fetal infection at 23 weeks into their second pregnancy, cCMV was a risk they had never heard of. Thanks to early detection and exceptional medical care, their daughter Georgia was born much stronger than doctors had anticipated. Although she faces challenges due to the neurological effects caused by cCMV, Georgia continues to surpass expectations and bring joy to everyone around her.



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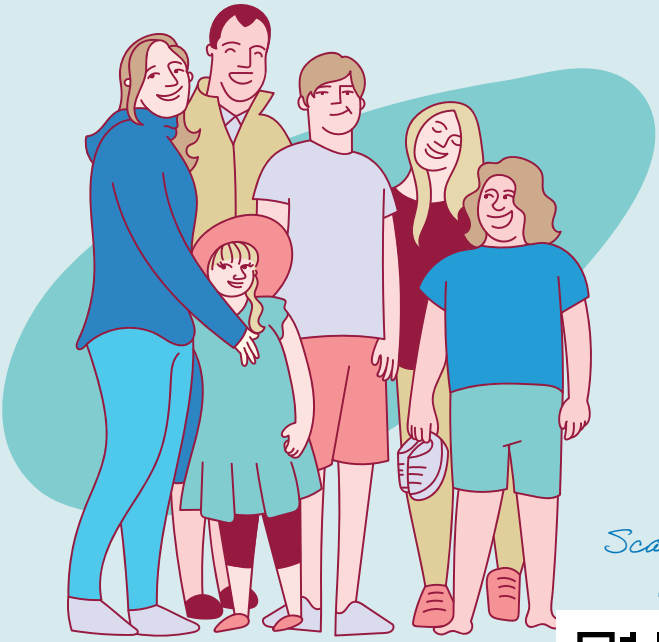
The Tétrault Family Winnipeg, Manitoba

Rob and Michelle Tétrault first learned about cCMV when their son Alexandre's infection was detected during a late ultrasound. Without this discovery, his condition might have gone unnoticed. Early diagnosis gave them the chance to begin treatment and start therapies that made a remarkable difference in Alexandre's development. Today, Alexandre is thriving.



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The Jones Family Ottawa, Ontario

William and his daughter, Francesca, have a unique place in Canadian history as part of the pilot phase of Ontario's groundbreaking universal newborn cCMV screening program. Francesca's congenital CMV infection was identified through this program shortly after birth, allowing for early interventions that made a world of difference. Francesca was born with profound hearing loss due to cCMV. Thanks to the early detection and timely treatments, her family was able to access the resources and therapies needed to support her development. Today, Francesca is a happy and energetic child who thrives on chatting and laughing with her parents, embodying the transformative power of early diagnosis and intervention.

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Navigating Resources and Support

Finding the right resources and support can make a big difference when raising a child with congenital CMV (cCMV). There are many places to turn for help:

Medical Support:

Your healthcare team, including pediatricians, infectious disease specialists, and audiologists, can provide guidance on your child's case. Early intervention services can also help your baby reach their developmental milestones.

Community Connections:

Connecting with other families who understand your journey can be a source of comfort and strength. Facebook groups like **CMV Mommies** and **CMV Family Support** offer online spaces to share experiences, advice, and encouragement. CMV Canada also hosts regular family support meetings via Zoom, where you can meet other parents, exchange tips, and feel part of a supportive community

Online Resources:

Reliable websites, such as those from CMV organizations, can provide up-to-date information and helpful tips for managing your child's needs.

You are not alone in this journey

A supportive community of parents, healthcare providers, and advocates is here to help you navigate this path and celebrate your child's growth and achievements.

About the Canadian CMV Foundation

The Canadian CMV Foundation is a national charity dedicated to preventing congenital CMV and improving the quality of life for those affected. We focus on raising awareness, supporting families, advocating for change, and championing innovative research.

Have you or a loved one recently received a CMV diagnosis? Would you like to connect with someone whose child has been treated for CMV? Reach out to us at **info@cmvcanada.com**. We are here to help.

Most people are not familiar with CMV, including 91% of women.

Increasing awareness of CMV and how to prevent it is one of our key goals.

Now that you know, you can share this knowledge with others.

CANADA