Congenital Cytomegalovirus (CMV)

Information for Families and Caregivers

DEPARTMENT OF HEALTH

Prepared by

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To obtain this information in a different format, call: 651-201-3650

ACKNOWLEDGEMENT

The content included in this packet was chosen and developed in partnership with the National CMV Foundation and parents whose children have been identified with congenital CMV. The Minnesota Department of Health would like to thank everyone involved for sharing their experiences and insights.

DISCLOSURE

This handout does not provide medical advice. It provides general information about congenital CMV. Every child and family are different and some of the information may not apply to your child specifically. Always check with your child's healthcare provider if you have questions or concerns about their condition.

Updated 5/26

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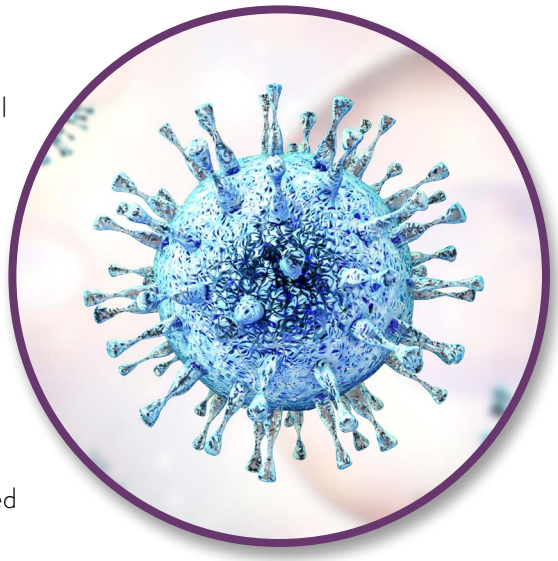
Section 1

About CMV and Congenital CMV

What is CMV?



Cytomegalovirus (CMV) is a common virus that can infect people of all ages. According to the Centers for Disease Control and Prevention (CDC), about 1 in 3 children are already infected by age 5, and more than half of adults have been infected by age 40 in the United States. Once a person has CMV, the virus remains in the body for life and can become active again. It's also possible to be infected with a different strain of the virus.

Most healthy people don't realize they have had CMV because it usually doesn't cause symptoms. When symptoms do occur, they are typically mild and may include fever, sore throat, fatigue, or muscle aches. However, CMV can cause serious illness in people with weakened immune systems.

How do people get CMV?

CMV is passed from one person to another through close contact with body fluids like saliva, urine, blood, semen, tears, and breastmilk.

CMV is found to pass most often among people who live together and among young children in childcare settings. Young children can carry high levels of the virus in their saliva and urine for months after infection. Because of this, young children are a common source of CMV. They can pass the virus to parents and caregivers, even if they appear healthy. Contact with a young child's saliva or urine is a key way CMV is spread, especially to pregnant people.

What is congenital CMV?

CMV may pass through the placenta from a pregnant person to their growing baby. This can happen if they get CMV for the first time or are reinfected during pregnancy. When a baby gets CMV before birth, the infection is called congenital CMV. Most babies with congenital CMV never show signs or symptoms, but some babies may be sick at birth or develop long-term health challenges later.

About one of every 200 babies is born with congenital CMV. This means that as many as 300 babies may be born with congenital CMV in Minnesota each year. Congenital CMV is the most common infectious cause of birth defects in the United States. Congenital CMV is also a common cause of childhood hearing loss.

How do I know if my baby has CMV?

If your baby's healthcare provider has concerns about possible congenital CMV, they may recommend testing your baby. In addition, babies born in Minnesota are tested for CMV as part of the newborn screening program. If a newborn blood screen collected at birth finds CMV, it means chances are high that your baby has congenital CMV. More testing is needed to know for sure.

Congenital CMV infection is most commonly confirmed by testing a baby's urine. To be accurate for congenital CMV, the sample must be collected before a baby is 21 days old. After 21 days of age, it is hard to know if a baby was born with CMV or got CMV after birth (known as acquired CMV). Being born with CMV can lead to long-term health concerns, including hearing loss, in some children. However, getting CMV after birth usually does not cause these issues.

What are the signs and symptoms of congenital CMV?

Congenital CMV affects each baby differently. Most babies do not show signs or symptoms of disease. This is called asymptomatic. When babies do show signs or symptoms of disease, it is called symptomatic.

Asymptomatic congenital CMV

Most babies with congenital CMV do not show signs or symptoms at birth. Most of these children stay healthy and never have health concerns caused by the infection.

Some children born without symptoms will have permanent hearing loss. The hearing loss may range from mild to severe and may be in one or both ears. The hearing loss may be present at birth or may happen later in childhood. All children with congenital CMV should have their hearing tested regularly to catch any changes.

The chance of having some developmental challenges is a little higher for children with asymptomatic congenital CMV than for children without congenital CMV, and a healthcare provider should track their development. Children with asymptomatic congenital CMV may qualify to receive early help to support their growth and development. Please see Section 4 for more information about these early services.

Symptomatic congenital CMV

Some babies with congenital CMV have signs or symptoms at birth. Symptoms can range from mild to severe. Some of the symptoms may be visible and others may be found only by special tests.

Symptoms at birth may include:

- Tiny red, purple, or brown spots on the skin
- Yellowing of the whites of the eyes and skin
- Small head size
- Low birth weight or small size at birth
- Enlarged liver and spleen
- Low level of blood platelets
- Damaged eye retina
- Hearing loss
- Differences in how the brain is formed or developed

Some children born with symptomatic congenital CMV will have permanent hearing loss. The hearing loss may range from mild to severe and may happen in one or both ears. The hearing loss may be present at birth or happen later in childhood. All children with congenital CMV should have their hearing tested regularly to catch any changes.

In addition, children with symptomatic congenital CMV are at higher risk for long-term health concerns and should be followed closely by a healthcare provider.

Long-term health concerns may include:

- Seizures
- Vision impairment
- Motor delay, weakness, or problems with balance
- Intellectual disability

Children with symptomatic congenital CMV may qualify to receive early help to support their growth and development. Please see Section 4 for more information about these early services.

What other tests are possible for my baby if congenital CMV infection is confirmed?

Your healthcare provider may recommend some follow-up tests after a congenital CMV infection is confirmed:

- **Laboratory blood testing** – blood is drawn from a vein to test your baby's liver function and blood cell count.
- **Diagnostic audiology (hearing) testing** – a detailed hearing test. Even if your infant passed their newborn hearing screen, they remain at risk for new hearing loss. They need this extra testing shortly after birth and regularly throughout childhood to identify any changes. Please see Section 2 for more information about hearing and congenital CMV.
- **Head ultrasound or MRI (magnetic resonance imaging) scan** – tests that produce images to look for changes in your baby's brain.
- **Ophthalmology (eye) examination** – dilated eye exam to look for changes in your baby's eyes.

What do follow-up test results mean?

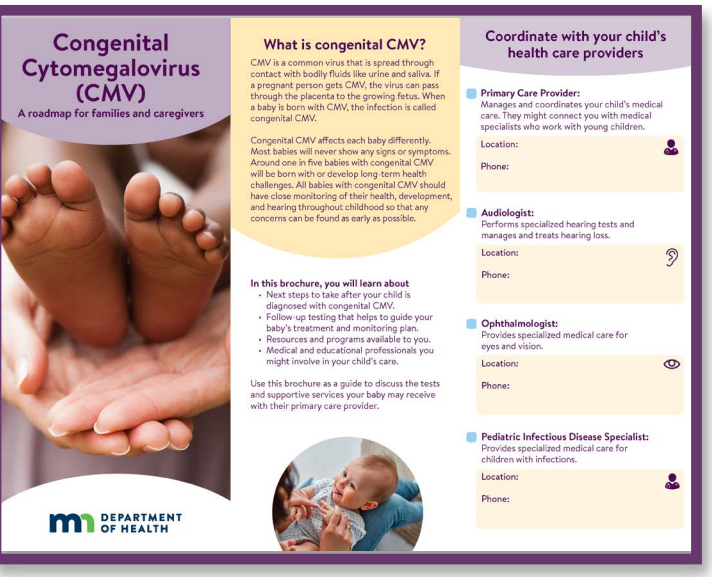
Babies born with CMV can have widely different outcomes, so it is sometimes hard to predict their future health or development. Therefore, your doctor or other healthcare provider may use follow-up tests to: look for signs and symptoms of CMV infection; to find out the level of your baby's disease; and to help guide your baby's treatment and monitoring plan, such as deciding whether your baby should start taking antiviral medicine.

Your healthcare provider should go over test results with you. Be sure to ask any questions you have about your child's test results and about the recommended treatment and monitoring plan.

How is congenital CMV treated?

Congenital CMV is treated based on how it affects your baby. Treatment options include:

- **Manage and watch for symptoms** – All babies with congenital CMV benefit from regular monitoring of their health, hearing, and developmental milestones. Make sure that your child goes to all appointments recommended by their healthcare provider(s). Regular visits are important for managing current health issues and finding new concerns, like hearing loss, as soon as possible.
- **Developmental monitoring and support** – Help Me Grow Minnesota can connect you to information and local resources, like early intervention services, that help your child develop, learn, and grow. Please see Section 4: Growth and Development for more information.
- **Family Support** – Finding out your child has congenital CMV may cause stress or anxiety for some parents. Support from others can help. See Section 5: Parent and Family Support for more information.
- **Antiviral medication** – If your baby has significant symptoms at birth, doctors may prescribe an antiviral medication like valganciclovir. This medicine is usually given for several months. It does not eliminate CMV, but it can help reduce its impact. Your baby's healthcare provider may refer you to a pediatric infectious disease specialist to discuss treatment. It is important that you talk with your healthcare provider about the risks and benefits of antiviral medication.



Congenital Cytomegalovirus (CMV)

A roadmap for families and caregivers

DEPARTMENT OF HEALTH

What is congenital CMV?

CMV is a common virus that is spread through contact with bodily fluids like urine and saliva. If a pregnant person gets CMV, the virus can pass through the placenta to the growing fetus. When a baby is born with CMV, the infection is called congenital CMV.

Congenital CMV affects each baby differently. Most babies will never show any signs or symptoms. Around one in five babies with congenital CMV will be born with or develop long-term health challenges. All babies with congenital CMV should have close monitoring of their health, development, and hearing throughout childhood so that any concerns can be found as early as possible.

In this brochure, you will learn about

- Next steps to take after your child is diagnosed with congenital CMV.
- Follow-up testing that helps to guide your baby's treatment and monitoring plan.
- Resources and programs available to you.
- Medical and educational professionals you might involve in your child's care.

Use this brochure as a guide to discuss the tests and supportive services your baby may receive with their primary care provider.

Coordinate with your child's health care providers

Primary Care Provider: Manages and coordinates your child's medical care. They might connect you with medical specialists who work with young children.
Location:
Phone:

Audiologist: Performs specialized hearing tests and manages and treats hearing loss.
Location:
Phone:

Ophthalmologist: Provides specialized medical care for eyes and vision.
Location:
Phone:

Pediatric Infectious Disease Specialist: Provides specialized medical care for children with infections.
Location:
Phone:

For more information about next steps after a congenital CMV diagnosis, visit:

MDH Congenital CMV Roadmap for families and caregivers (www.health.state.mn.us/diseases/cytomegalovirus/roadmap.pdf)

May I breastfeed if my baby has congenital CMV?

Yes, it is safe to breastfeed a baby who has congenital CMV.

Talk to your baby's health care provider if you are worried about breastfeeding your baby.

Will health insurance cover the costs for all the follow-up tests that my baby's healthcare provider is recommending?

Health insurance coverage for congenital CMV follow-up testing and care varies widely between plans. Some families may have unexpected medical costs because of high deductibles, large co-pays, or limited insurance coverage for specialty care. These costs can create financial stress.

Staying in regular contact with your insurance company can help you understand which tests, treatments, and referrals will be covered and what costs you may need to prepare for. In addition, talk with your child's healthcare provider if you have concerns. Ideally, healthcare providers and families balance clinical guidelines, medical urgency, and financial considerations to determine which tests a baby needs at birth and throughout early childhood.

May my baby go to childcare?

Yes, infants with congenital CMV may go to childcare. CMV infection is very common in babies and young children and the childcare program probably has other children who have CMV. All children can spread CMV, not just those who have been told by a healthcare provider that they have congenital CMV. Children with CMV should not be stopped from going to any childcare setting.

All childcare settings should have regular and good handwashing, hygiene, and cleaning habits. These three things can help lower the risk of spreading CMV.

What should I tell people who ask about getting CMV from my baby?

CMV infection is very common in babies and young children. All children can spread CMV, not just those who have been told by a healthcare provider that they have congenital CMV. It is usually passed from one person to another by contact with body fluids.

One of the most common ways people come into contact with CMV is through contact with young children who recently had the virus. This is because high amounts of CMV can stay in a child's urine and saliva for months after infection. Friends and family members should wash their hands well after changing diapers or touching body fluids (like saliva and mucus) of all children. Friends and family members who are pregnant or immunocompromised and are worried about contact with CMV should talk to their healthcare provider.

What are the chances that congenital CMV could happen again in a future pregnancy?

The risk of having a second child born with congenital CMV is very low. While congenital CMV is common in the general population, repeat cases within the same family are very rare.

Although the risk of congenital CMV in a future pregnancy is already low, taking practical steps to reduce CMV exposure from the urine and saliva of young children could help reduce your risk. Make sure to wash your hands often, especially after changing a diaper or wiping a young child's nose or mouth; avoid sharing food, drinks, utensils, or straws; don't put things in your mouth (like a pacifier or toothbrush) that have just been in a child's mouth; and kiss young children on the forehead instead of the lips to avoid saliva.

If you have questions about your personal risk or would like help to develop a pregnancy plan, please talk with your healthcare provider

Where can I learn more about CMV and congenital CMV?

Contact your healthcare provider for answers to your CMV and congenital CMV questions and visit:

Cytomegalovirus (CMV) and Congenital CMV (www.health.mn.gov/cmv)

National CMV Foundation (www.nationalcmv.org)

Congenital Cytomegalovirus (cCMV) (www.aap.org/en/patient-care/congenital-cytomegalovirus-ccmv)

Section 2

Hearing and Congenital CMV

Why to test your baby's hearing

Congenital CMV can affect the way your baby's ears work. The virus may affect one or both ears. It may change the way your baby hears over time.

Even if your baby passed the newborn hearing screen, they still need regular hearing testing. Speech and language start to develop at birth, so it is important to find any hearing changes as soon as possible. Your baby is learning to communicate with you many months before they start using words. If a baby's hearing changes, parents or healthcare providers often do not know it because many babies with hearing loss still startle to loud sounds and even seem to listen. Follow-up testing is the only way to find hearing loss early. Knowing of any hearing loss will help you and your baby find the best ways to communicate.

When to test your baby's hearing; what the results mean

All babies with congenital CMV should see an audiologist (special hearing doctor) as soon as possible - no more than one month after learning they have congenital CMV. If the test result is normal, or typical, your baby's hearing is normal at that time. Regular testing is needed through childhood, because hearing loss can occur later. Testing is usually done every three months until age 2, every six months from age 2 to 6, and then yearly through at least age 10. Your audiologist will help you schedule testing for your child.

How hearing is tested

A small, special earphone is placed in your baby's ear. It plays sounds and a device measures what happens when the sounds are played. Hearing testing works best when your baby is calm, well-fed, and comfortable. Young babies can be tested while they nap; older babies may need medicine to help them sleep during the test. See the MDH handout, "Preparing for your baby's audiology appointment" on the following pages.

There are more hearing testing methods as your baby grows older. An audiologist can measure how your baby turns their head to sound while they sit on your lap. When your child is in preschool, they may play a listening game with toys.

If your child's hearing changes

Your audiologist will tell you about ways to help your child communicate with you if testing finds they have hearing changes. If you use spoken language, the doctor may prescribe a hearing device to make sounds and words louder to help your child hear them. They will help connect you with early childhood specialists or teachers to help track your child's language development. These professionals know about ways to communicate, including signed languages, and how to access them.

Early Hearing Detection and Intervention (EHDI) Program

The EHDI program helps identify newborns and infants who have or are at risk for having hearing loss and connects families to information and services, including help locating hearing specialists and education resources in their area.

Materials for parents, can be found at (www.health.mn.gov/ImproveEHDI).

Find an audiologist at EHDI Pals (www.ehdi-pals.org).

Preparing for Your Baby's Audiology Appointment

Minnesota Newborn Screening Program

Your baby's audiology appointment

Date (MM/DD/YYYY): _____

Time (AM/PM): _____

Clinic Name: _____

Clinic Phone: _____

What is an audiologist?

An audiologist is a healthcare professional who is trained to diagnose and manage hearing loss in newborns, children, and adults. Someone with hearing loss may be able to hear some sounds while others may hear nothing at all. There are different types of hearing loss based on the specific problem with one or more parts of the ear(s). Complete assessment of both the type and severity of hearing loss by an experienced pediatric audiologist is important to ensure the most accurate plan for follow-up and management of the hearing loss.

Why is my baby seeing an audiologist?

The hearing testing that your baby received at birth/ shortly after birth was a screening test. If a baby does not pass the screening test, it tells us that they need to have further testing by an audiologist. A complete evaluation by an audiologist is the only way to know for sure that your baby is hearing all the sounds importanfor speech and language development.

How long will the appointment take?

Appointments can take 1-3 hours. Sometimes it is not always possible to finish a hearing test in one appointment. If a second appointment is needed, it will be scheduled as soon as possible.

What should I bring with me to my baby's appointment?

- Your insurance card
- A referral if needed
- A current list of medications
- Prior hearing test results and/or evaluations
- Details about any family history of childhood hearing loss
- Names/addresses of individuals where you might want the report sent

What do I need to do before the appointment?

The tests are most easily done when your baby is sleeping. To ensure that your baby is asleep during the testing:

- Do not let your baby nap before the appointment or during the car ride to the clinic.
- Avoid feeding your baby right before the appointment. You will be able to feed your baby at the clinic just before the test.

What will happen during the audiology appointment?

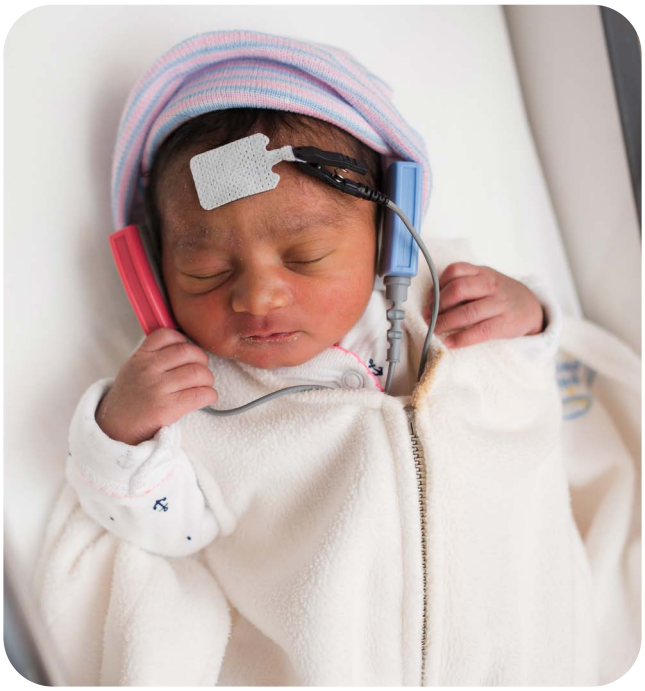
The audiologist will collect information about your baby's medical history, about your pregnancy/labor/delivery with this child, and about family history.

While your baby is sleeping, the audiologist will examine your baby's ears and perform the hearing evaluation. The type of testing performed may include:

- Auditory Brainstem Response (ABR)– Sensors will be placed on your baby's forehead and earlobes to measure the brain's response to sounds. Earphones will be placed on each ear to deliver the test sounds. Your baby will not physically respond to the sounds, but the sensors will be able to measure how well your baby is responding to the various sounds. This test helps determine if any hearing loss is present. If hearing loss is present, it can provide information on what type of hearing loss it is.
- Otoacoustic Emissions (OAE)– A soft rubber tip will be placed at each ear to deliver soft sounds and to measure for an echo that occurs when the ear is functioning normally. This test is usually used in combination with other tests to provide the most accurate diagnosis.
- Tympanometry– A soft rubber tip will be placed at each ear that measures how well the eardrum moves. This test, when used in combination with other tests, can provide some clues about the possible cause of hearing loss.

Will my baby feel any pain?

Your baby will not feel any pain at any point during the testing. Placement of the soft rubber tips and sensors will not harm your baby. Most babies will fuss and wiggle when test equipment is first placed but will calm when held close and swaddled.



Will I get the results of the testing right away?

The audiologist will be able to tell you when the test results will be available and who will be giving you the results. If there are questions about the results, you should contact the audiology clinic.

What if my baby does not sleep through the entire test?

The younger your baby is, the more likely they will sleep through the test, but sometimes an additional appointment is needed. For some older babies, sedation may be recommended by your baby's doctor to help them sleep during the entire time needed for a complete evaluation. To decrease the likelihood of sedation, it is recommended that you make appointments as soon as possible.

What if something comes up, and I need to reschedule my baby's appointment?

It is very important that your baby sees an audiologist. If you cannot make your scheduled appointment, please reschedule the hearing test right away.

Section 3

Healthcare and Financial

Questions about congenital cytomegalovirus for your child's primary care provider

Primary care providers are trained to manage many types of health care needs, including regular checkups; long, ongoing conditions; and illnesses. They may be a doctor, nurse practitioner, or physician assistant, and they may sometimes be called a health care practitioner or clinician.

A primary care provider is usually your child's main health care provider for day-to-day care. They coordinate your child's medical care. They may work in family medicine, pediatrics, or internal medicine-pediatrics.

In addition to getting regular care from a primary care provider, a child with congenital CMV may need to see specialists for more testing and treatment. Specialists are licensed or certified professionals with extra training in one area of medicine or health. Your child's primary care provider will help decide which specialists your child should see and will make referrals for your child to see these specialists, if needed.

Your primary care provider may recommend that your child see one or more of the following specialists:

- **Infectious disease (ID) specialist:** a professional that is an expert in diagnosing and treating people with infections. Pediatric infectious disease specialists have extra training to work with children.
- **Audiologist:** a professional who tests for and treats hearing loss and balance disorders. Some audiologists have special training to work with children and are called pediatric audiologists.
- **Ear, nose, and throat specialist (ENT):** a professional that focuses on ear, nose, and neck disorders, including hearing loss.
- **Neurologist:** a professional who specializes in the brain, spinal cord, and nerves.
- **Ophthalmologist:** a doctor who specializes in eyes and vision care.
- **Early intervention provider:** a support services professional for children from birth to age 3 who have or are at risk for developmental delays.
- **Occupational therapist (OT):** a professional that helps children develop or improve everyday living activities and skills.
- **Physical therapist (PT):** a professional that helps children improve their body's range of motion, strength, flexibility, and movement.
- **Speech-language pathologist:** a professional trained to test and work with children with speech and language challenges.

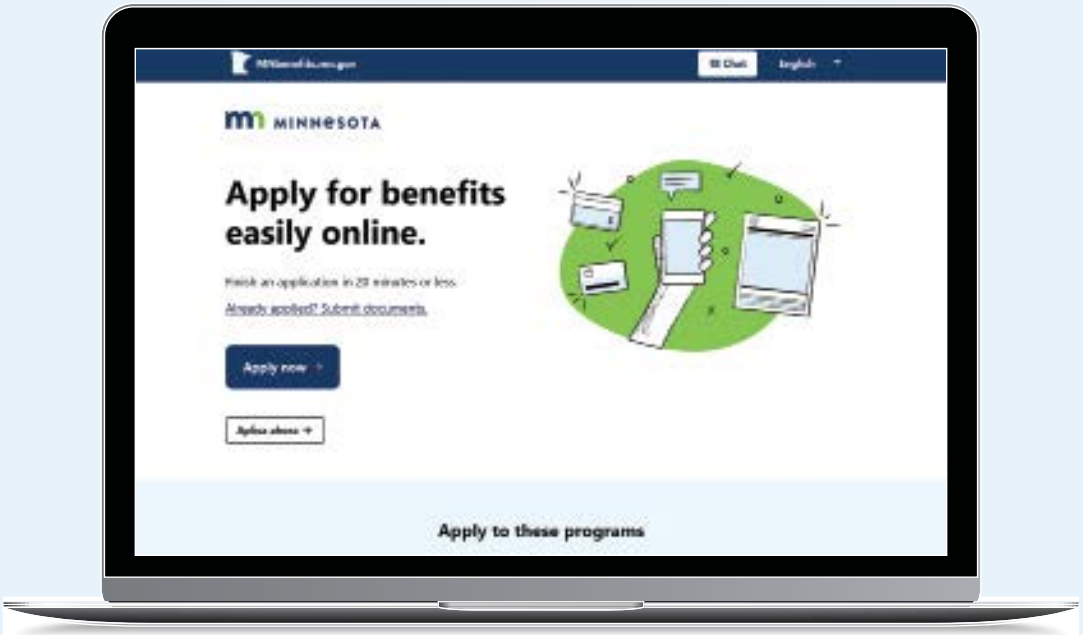
Questions about medical services

Here are some questions to ask your child's primary care provider. Answers to these questions can help you better understand your child's health and the care they may need.

- How much experience do you have treating babies and children with congenital CMV?
- Will my child need more tests because they have congenital CMV? What will these tests tell us about my child's health and development now and in the future?
- What types of treatment will my child need?
- Will you need to see my child more often because they have congenital CMV?
- Should my child see specialists for their congenital CMV? What type of specialists?
- How do I get medical referrals to see specialists if my child needs their services?
- What should I do if I have problems with the referrals or if my insurance company has questions?
- Can your office help me coordinate appointments?
- How do we make sure reports from specialists are shared with you?
- Should my child get all their immunizations on the same schedule as other children their age?
- How often will screening for development and behavior take place for my child? How will I know the results of the screening?
- Can you tell me about early intervention services in my area? Has a referral for services been completed for my child?

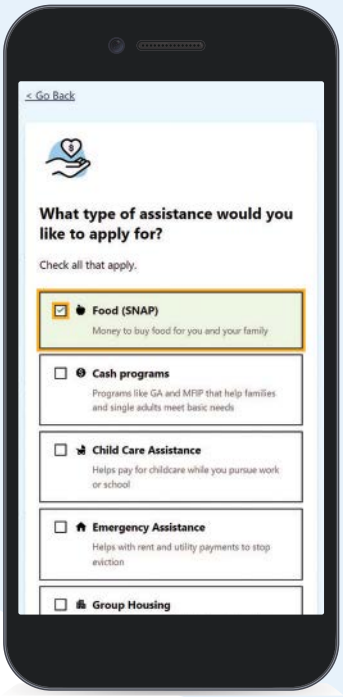
MNbenefits

A safe and easy way to apply for public assistance benefits



Get started today at mnbenefits.mn.gov

Apply from a smartphone any time in less than 20 minutes



- Food assistance (SNAP)
- Cash programs
- Emergency cash assistance
- Housing support
- Child care assistance

MINNESOTA

Pregnancy and parental leave

PREGNANCY AND PARENTAL LEAVE

Minnesota Paid Leave provides paid time off and job protections for most workers during pregnancy, after childbirth or to bond with a child. You may be able to take Paid Leave for:

- pregnancy-related health needs;
- childbirth and recovery;
- bonding time as a birthing or non-birthing parent; and
- bonding after adoption or foster care placement.

If you qualify, you can take up to 12 weeks for your own care and 12 weeks for bonding, with a combined total of up to 20 weeks. Bonding leave must be used within 12 months of the birth, adoption or foster placement. While on Paid Leave, you'll receive part of your normal pay from the state.

Paid Leave may overlap with federal Family and Medical Leave Act (FMLA) protections. If you do not qualify for Paid Leave or FMLA, Minnesota law still provides 12 weeks of job-protected unpaid parental leave. For more information, visit paidleave.mn.gov.

When does the pregnancy and parental leave start?

The following rules apply to both Paid Leave and unpaid leave under Minnesota's Pregnancy and Parenting Leave law:

- Leave must be taken within 12 months of the birth or adoption.
- Employees must request the leave from their employer.
- Employees can choose when the leave will begin.

Employers can adopt reasonable policies about when requests for leave must be made.

Note: Under Minnesota Paid Leave, bonding leave must end within 12 months of the birth, adoption or foster placement. Some of the same rules apply, but eligibility and certification requirements are different. For more information, visit paidleave.mn.gov.

FREQUENTLY ASKED QUESTIONS

What can count against my unpaid pregnancy and parental leave?

If you have paid leave, including sick leave or paid vacation, pregnancy and parental leave can be reduced so the total leave (pregnancy and parental plus paid leave) is not more than 12 weeks. Leave taken for prenatal care may not count against pregnancy and parental leave. If you qualify for both federal Family and Medical Leave Act (FMLA) and pregnancy or parental leave, you only have a right to 12 weeks of leave in total for childbirth or adoption of a child and any other pregnancy-related leave. You may be entitled to additional leave under FMLA for a non-pregnancy related serious health condition. If you have questions about FMLA, contact the U.S. Department of Labor at 612-370-3341 or dol.gov/whd/fmla.

Does Minnesota offer paid family and medical leave?

Yes. Minnesota Paid Leave provides partial wage replacement and time off during or following a pregnancy. Find more information at paidleave.mn.gov.

Pregnancy and parental leave

Does my employer have to continue my benefits during the leave?
Yes. Employees on pregnancy and parental leave are entitled to the same coverage and employer contribution as if they were not on leave.

Do I get my job back when I return from leave?
Yes. You are entitled to employment in your former position or one with comparable duties, hours and pay. You are also entitled to the same benefits and seniority you had before the leave. You may return to part-time work during the leave without forfeiting the right to return to full-time work at the end of the leave. It is against the law for your employer to retaliate, or take negative action, against you for requesting or taking a leave.

DEPARTMENT OF LABOR AND INDUSTRY

Labor Standards • 443 Lafayette Road N. • St. Paul, MN 55155
651-284-5075 • dli.laborstandards@state.mn.us • dli.mn.gov

Notice: This flyer is a brief summary of Minnesota law. It is intended as a guide and is not to be considered a substitute for Minnesota Statutes regarding parental leave laws.
Version 0126

Section 4

Growth and Development

Developmental monitoring and support

Developmental monitoring and screening help track how young children grow, learn, speak, behave, and move over time. Together, they can identify possible developmental delays early and help children and families access the support and services they need as soon as possible.

Help Me Grow Minnesota, Early Childhood Special Education, and the **Follow Along Program** are resources for all Minnesota families and can be supports for your family after learning that your child has congenital CMV.

Help Me Grow Minnesota

(helpmegrowmn.org/HMG/index.html) connects your family to your local school district to talk with people trained in infant and early child development about possible supports and next steps for your child. The services through your local school district are called **Early Childhood Special Education (ECSE)**. You may wonder why the "school" would call you about your baby: This simply lets your family learn about and get services, regardless of immigration and financial status. If you and your school team decide that early childhood special education supports can help your child, you can get this support at no cost.

Parents are important members of your child's educational team. You can ask your school about services that might be available for your child. For example, some parents ask for an educational audiologist to be a member of the school team to help with regular hearing testing.

The Follow Along Program

(health.mn.gov/mnfap) supports you as you follow your child's development, as an infant, toddler, and young child. It helps you know if your child is playing, talking, growing, moving, and interacting like other children of the same age. The program will connect you to a nurse or other local public health staff member if you have questions or concerns. Program staff will share developmental information and activities, connecting you to other supports and services as needed. You can join in this program at no cost, regardless of immigration and financial status.

Help Me Grow: When Parents Know, Children Grow

Some babies and young children need extra help to learn and grow. While all young children grow and change at their own rate, some children experience delays in their development. Special health conditions may affect children's development, too. Accessing early intervention services as early as possible will ensure the best developmental outcomes for these children.

Help Me Grow: Infant and Toddler Intervention are special services and supports for families with children ages birth through two who have developmental delay(s) or certain diagnosed physical or mental conditions or disorders that may result in a delay.

Help Me Grow: Preschool Special Education is for children ages three to five years who meet state eligibility criteria for developmental delay(s) or other disability, and who are experiencing challenges in their learning and development. Children may be eligible if they are not able to learn, speak or play like other children who are the same age.

After a referral is made to Help Me Grow, local early intervention or preschool special education staff will contact the family to determine whether a comprehensive screening or evaluation is needed to determine eligibility.

There are three simple steps to refer a child online:

1. Visit HelpMeGrowMN.org.
2. Click "Refer a Child" button.
3. Fill out form and click "Send this Referral"

To refer a child by phone, call (866) 693-GROW (4769)

Eligible children can receive services in their home, child care setting or school. These services are free to eligible children, regardless of income or immigrant status.

Early childhood specialists will work with eligible children and families to plan the services and supports they need. Services may include:

- Special instruction and other services, such as speech, physical and occupational therapy;
- Ways that a family can support their child's development at home; and
- Connections to community services and programs.

This initiative is made possible through an interagency agreement from the Minnesota Department of Education to the Metro ECSU using federal funding under CFDA number 84.181 Special Education Grants for Infants and Families with Disabilities.

Learn more about your child with Minnesota's

Follow Along Program

- Every few months, you will get a form asking how your child is playing, talking, growing, moving and acting.
- Fill out the form and send it back to us.
- You will get the results with fun activities for you and your child to do together.
- If there are any concerns, we'll get in touch with you and work together on next steps.

For questions about the program or to have an enrollment form mailed to you, call 1-800-728-5420 or email health.cyshn@state.mn.us.

Sign up online today! It's free!
www.health.state.mn.us/mnfap

DEPARTMENT OF HEALTH

Section 5

Parent and Family Support

It is not unusual to feel a range of emotions when you are told your baby has congenital CMV.

You are not alone. These groups may help you find support, resources, and information:

National CMV Foundation

The National CMV Foundation may be able to help your family in several ways. The Foundation can help with:

- Learning more about congenital CMV and the effects it may have on your child's health and development.
- Connecting you with CMV support resources in your state.
- Connecting you with other families experiencing a congenital CMV diagnosis.

Visit National CMV Foundation (www.nationalcmv.org) or email info@nationalcmv.org for more information.

Minnesota Hands & Voices

This group is a community of families with children who are deaf and hard of hearing. It gives parents resources, support, and information they need for better communication and education outcomes for their children. Minnesota Hands & Voices is working with the Minnesota Department of Health to offer parent-to-parent support to families of children with congenital CMV who show signs or symptoms of infection, no matter what the level of hearing. A parent guide will reach out directly to offer support and information after families learn their child has congenital CMV.

For more information about the congenital CMV parent-to-parent support project, email health.cyshn@state.mn.us, or call 661-201-3650 or 800-728-5420 (toll free).
Visit Minnesota Hands & Voices (www.lssmn.org/mnhandsandvoices).

Family Voices of Minnesota

This nonprofit group offers support and information for Minnesota families raising children with disabilities and extra needs. They have peer-led Parent Groups that offer:

- Emotional and informational support from others with lived experience
- Parenting and advocacy tips
- Resource sharing and more.

Visit Family Voices of Minnesota (https://familyvoicesofminnesota.org).

Email: connected@familyvoicesmn.org.

Phone: 866-334-8444, ext. 0.

Section 6

Additional Resources for Families

Here are some additional resources that you may find helpful.

MNSure

MNSure is a marketplace where Minnesotans can shop, compare, and choose health insurance coverage that meets their needs. Coverage options are available for people of all income levels and include Medical Assistance, MinnesotaCare, and Qualified Health Plans. Learn more by visiting the MNSure website (www.mnsure.org), or call the MNsure Contact Center at 1-855-366-7873 for help.

PACER Center

PACER Center (www.pacer.org) is a parent training and information center for families of children and youth with disabilities or special health care needs from birth through young adulthood. Parents can find publications, workshops, and other resources to help families make decisions about education, health care, and other services.

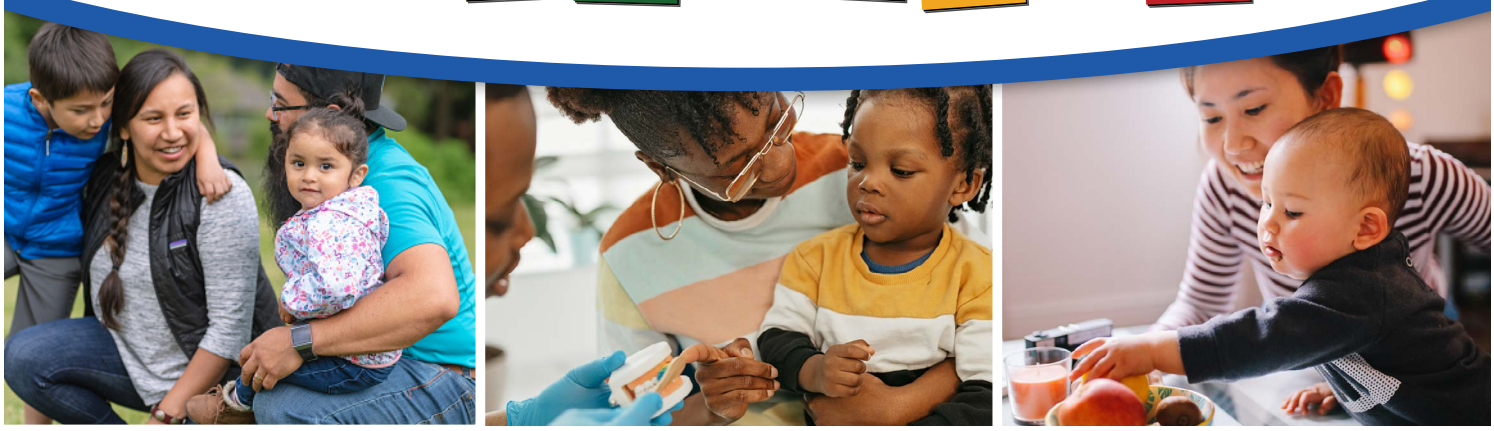
Parent Aware

Parent Aware (www.parentaware.org) is a local service that offers free tools and resources to help families find the quality child care and early education programs their children need to succeed in school and life. Check out their Finding Child Care Guide (www.parentaware.org/wp-content/uploads/2020/08/PA-Child-Care-Guide-English-LINKS_V-6.pdf) to download a family guide in your language.

WIC

The Special Supplemental Nutrition Program for Women, Infants & Children (WIC) is a nutrition and breastfeeding program that helps eligible pregnant women, new mothers, babies, and young children. WIC provides nutrition education and counseling, nutritious foods, and referrals to health and other social services. Visit the MDH WIC Program (www.health.state.mn.us/people/wic/index.html) for more information or to apply for WIC.

help me CONNECT



Find all kinds of resources for your family.

Help Me Connect is an online navigator connecting expectant families, families with young children, and those working with families to programs and services that support healthy child development and family well-being.

- Pregnant and Expecting Families
- Early Learing and Child Care
- Dental and Health Care
- Healthy Development and Screening
- Family Well-Being and Mental Health
- Basic Needs
- Development and Behavior Concerns
- American Indian Families
- Legal Services
- Disability Services and Resources
- Caregiving and Community Support

MINNESOTA

HelpMeConnectMN.org

Postpartum Depression and Anxiety

Postpartum depression, which can last months or years after giving birth, can affect a birthing person's or caregiver's ability to bond with and care for their baby.

If left untreated, it can impact the birthing person's or caregiver's health and may cause sleeping, eating, and behavioral problems for the baby.

When postpartum depression is effectively treated and managed, it benefits the birthing person or caregiver and child's health.

For your baby to feel safe and secure, it is important that you take care of your own needs.

Signs and Symptoms Can Include But Are Not Limited To:

- Persistent sad, anxious, irritable, or "empty" mood
- Feeling guilty, worthless, hopeless, or helpless
- Difficulty concentrating, remembering, or making decisions
- Difficulty sleeping
- Trouble bonding or forming an emotional attachment with the baby
- Persistent doubts about the ability to care for the baby
- Thoughts about death, suicide, or harming oneself or the baby

Depression and anxiety can present differently from person to person. Please contact your healthcare team if you or your loved ones are exhibiting concerning behavior.

Contact for Help

Emergency Hotlines

- For immediate help: **Call 911**
- **988 Suicide and Crisis Lifeline:** Call 988 (formerly the National Suicide Prevention Lifeline) or 1-800-TALK (8255)
- **National Maternal Mental Health Hotline:** Call or text 1-833-9-HELP4MOMS (1-833-943-5746)

Non-Emergency Helplines

- **Mother-Baby HopeLine at Hennepin Healthcare:** (612) 873-HOPE or (612) 873-4673 - the Hopeline is ***not*** a crisis phone line. A mental health professional will call you back within two business days.
- **Pregnancy & Postpartum Support Minnesota:** Call or text 1-800-944-4773, text en Español: 971-203-7773. Support and information provided by peer volunteers 7 days a week.

DEPARTMENT OF HEALTH
CHILD & FAMILY HEALTH

Minnesota Department of Health
Maternal & Child Health Section
PO Box 64975
St. Paul, MN 55164-0975
651-201-3650
health.mch@state.mn.us
www.health.state.mn.us

To obtain this information in a different format, call: 651-201-3650

8/2022

Depression or Anxiety During and After Pregnancy

When Being Pregnant or Having a New Baby Is Not What You Expected

Causes of Depression and Anxiety

There is no single known cause. Parents with a history of depression or anxiety are more likely to struggle during and after pregnancy. Other factors that can increase your risk of experiencing depression and anxiety include:

- Stress (finances, living situation, health)
- Hormonal changes
- Trauma
- Lack of support and social connection
- Baby who is fussy, colicky, or has health challenges

Treatment

The most effective treatment for depression and anxiety can include:

- Therapy or support groups
- Medicine that can be used during pregnancy or lactation (talk with your healthcare provider)
- Social support - family, friends, faith community, parent groups, neighbors
- Public health and home visiting nurses

When Is It An Emergency?

If you feel like hurting yourself or if your loved one speaks of hurting themselves, please contact one of the resources on the back middle panel.

In very rare cases, birthing persons can experience very serious symptoms of psychosis after having a baby. This is a medical emergency and birthing persons should be taken immediately to the Emergency Department at the nearest hospital and should not be left alone with their baby.

Symptoms may include:

- Hearing or seeing things that are not there (often paranoid - being watched or feeling unsafe)
- Being unable to sleep, even when the baby is sleeping
- Speaking or moving at a faster than usual pace.
- Confusion or disorientation
- A personal or family history of psychosis or bipolar disorder

Additional Resources

- **CDC Hear Her Campaign (www.cdc.gov/hearher/index.html)**: provides life-saving messages about urgent warning signs to prevent pregnancy-related deaths
- **Minnesota Help Me Connect (helpmeconnect.web.health.state.mn.us/HelpMeConnect/)**: helps expectant families, families with young children find and connect to services in their local communities that support healthy child development and well-being
- **Family Home Visiting Program (www.health.state.mn.us/fhv)**: home-based service that provides social, emotional, health-related and parenting support and information for families

Things We Can Do

Talk with your healthcare provider or ask a loved one to help you ask for recommendations and get the care you need.

- Talk to a mental health therapist or join a support or parent group.
- Ask your care provider about medicines that can be safely used during pregnancy or while breast/chest feeding.
- Seek out people in your community or faith groups about other support they recommend.
- Ask friends and family for help with child care, chores, errands, or to stop by with a meal.
- Think of small changes you can make to eat healthy, drink enough water, move your body and get rest or sleep.

It may take a combination of the activities above to get the help you need. Be patient with yourself!

Stories From Other Parents

"I love children and couldn't wait to have my own. Then my husband went back to work. I started having thoughts about hurting my baby. No matter what I did, I couldn't stop the thoughts. I lived in fear but kept it a secret." – Isabel

"It has been two months since I saw my doctor, and I feel like a different person. The medicine has helped and my family has been very supportive. I have energy again. I love being a mother." – Malia

This brochure meets the requirements of Minnesota Statute 145.906. For more information, call the Minnesota Department of Health at 651-201-3650 or visit our website at: https://www.health.state.mn.us/communities/mch/

My Postpartum Wellbeing Plan

This postpartum plan is designed to help you think about your mental health and wellbeing, support, and resources you may need during this important time in your and your baby's life. It is your decision if you wish to share this plan with others.

Sleep

Sleep is very important for your health but having a new baby can make getting enough sleep challenging. It is normal for babies to sleep in short stretches, that lengthen as they get older. Your sleep will also probably change after your baby is born but you can try these things to help yourself get needed rest.

- You may need to sleep in 2–3 hour blocks at a time, strung together to get the 7-9 hours you need.
- If you have another person in the home who can help take shifts feeding baby, hand the baby to another adult and go to bed.
- If you cannot get back to sleep after baby wakes, avoid electronics; read, journal, or listen to a meditation instead.
- If it continues to be difficult to get back to sleep after baby goes to sleep, contact your doctor.
- Take advantage of offers for help or ask friends or family to come over to help with baby so that you can nap, take a shower or bath, or get some adult interaction.

Eat Well & Stay Hydrated

- Have available: protein, vegetables, fruit, whole grain foods.
- Have "grab & go" foods available so that you can eat while you are resting or taking care of the baby.
- Have a cup or bottle of water nearby at all times and drink water frequently.

Move & Get Outside

- Check with your healthcare provider if you can begin exercising or making strenuous movements.
- Aim for 30 minutes a day of movement. Start easy! Walk, light housework (cleaning, laundry, cooking) or gardening, a quick trip to the store or get out with other people.
- Try to get outside every day, even if just for a slow walk.

Connect

- Stay connected to supportive family and friends.
- Encourage short visits and be very clear about "visiting hours".

Resources

How Does Being a New Parent Affect Sleep? (www.sleepfoundation.org/sleep-deprivation/parents)

Help Me Connect (helpmeconnect.web.health.state.mn.us)

Nutrition by Life Stage (www.nutrition.gov/topics/nutrition-life-stage)

Minnesota Doula Registry (www.health.state.mn.us/facilities/providers/doula/index.html)

DEPARTMENT OF HEALTH

Minnesota Department of Health
Maternal & Child Health Section
PO Box 64975
St. Paul, MN 55164-0975
651-201-3650
health.mch@state.mn.us
www.health.state.mn.us

08/2022

To obtain this information in a different format, call: 651-201-3650.

Plan Ahead

My best place for relaxing in my home is: _____

Healthy, easy foods I like to eat are: _____

People I can ask for help when I need it:

1. _____
2. _____

Ways to get movement and connect with other people which I could do with a small baby are:

1. _____ 2. _____

Activities I could use help to do (shopping, cleaning, etc.)

1. _____
2. _____
3. _____
4. _____

Just In Case

Having a new baby is a big change.

There are resources available to support you and your baby. If challenges arise, it's good to recognize that and get help.

My early signs that I am feeling bad, depressed or too anxious:

- _____
- _____

It can be difficult to talk about not doing well. If you feel like this, who will you talk to?

_____

What will you say?

_____
_____
_____
_____

Get Help

If it is not an emergency, but I need advice:

- **Provider's office - daytime:**

  _____

- **Provider/clinic after hours:**

  _____

Emergency Hotlines

- For immediate help: **Call 911**
- **988 Suicide and Crisis Lifeline:** Call 988 (formerly the National Suicide Prevention Lifeline) or 1-800-TALK (8255)
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