

Congenital Cytomegalovirus

Information for Families & Caregivers



health.mn.gov/CMV

mn DEPARTMENT
OF HEALTH

Prepared by

Minnesota Department of Health
Children and Youth with Special Health Needs

625 Robert St. N.
PO Box 64975
St. Paul, MN 55164-0975

651-201-3650 or toll free 1-800-728-5420
health.cyshn@state.mn.us
www.health.state.mn.us

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 cytomegalovirus. 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 April 2023





Table of Contents

Section 1: About Cytomegalovirus (CMV) and Congenital CMV

Section 2: Hearing and Congenital CMV

Section 3: Growth and Development

Section 4: Parent and Family Support

Section 5: Health Care and Financial

Section 6: Additional Resources for Families

Section

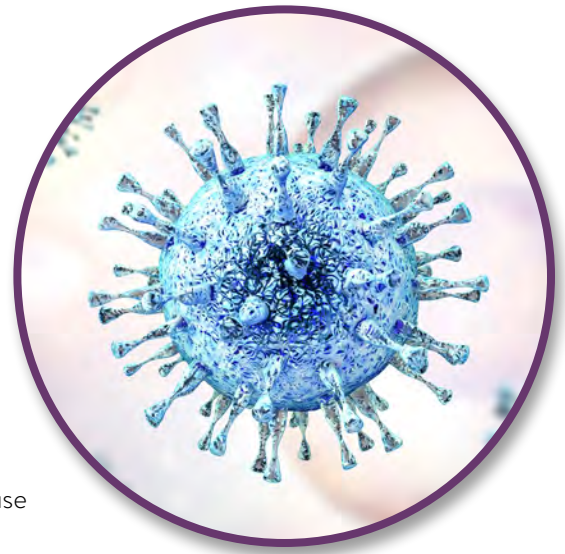
1

About Cytomegalovirus (CMV) and Congenital CMV

What is CMV?

Cytomegalovirus (CMV) is a common virus that can infect people of all ages. One in three children in the United States are infected with CMV by age 5, according to the Centers for Disease Control and Prevention (CDC). More than half of adults have been infected with CMV by age 40. Once CMV is in a person's body, it stays there for life and can reactivate. A person can also be re-infected with a different strain of the virus.

Most healthy people do not know that they have had a CMV infection, because the virus usually does not cause any symptoms. When people first get infected, they sometimes have mild symptoms such as fever, sore throat, fatigue, and/or muscle aches. CMV may cause serious illness for some 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.

The virus is not passed to others at a high rate. However, CMV is found to pass more frequently between people who live in the same house and among young children in child care settings. High amounts of CMV can stay in a child's urine and saliva for months after infection. This makes young children a common source of CMV. Children can pass the virus to parents and caregivers, even if they do not seem sick. Contact with the saliva or urine of babies and young children is thought to be an important cause of CMV infection among pregnant people.

What is congenital CMV?

A pregnant person may pass CMV through the placenta to a growing baby without knowing it. This can happen when the pregnant person gets CMV for the first time or again during pregnancy. When a baby gets CMV before birth, it is called congenital CMV. Most babies with congenital CMV never show signs or have health problems, but some babies may be sick at birth or develop long-term health problems 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 health care 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 cause long-term health problems and hearing loss in some children; getting CMV after birth usually does not cause these things.



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 health care 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 3 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 of congenital CMV infection 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
- Calcifications within the brain

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 concerns early.

In addition, children with symptomatic congenital CMV are at higher risk for long-term health concerns and should be followed closely by a health care 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 3 for more information about these early services.

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

Your health care 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 related to congenital CMV infection.

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 health care 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 health care 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?

Antiviral medication

Most babies with congenital CMV will not need antiviral medicine to treat the infection. Antiviral medicine may improve the hearing and development of some babies with signs of congenital CMV at birth, and it may be recommended for them. Your health care provider may send you to a pediatric infectious disease specialist to talk about different treatments. It is important to talk with your health care provider about the risks and benefits of antiviral medication.

Other options

- **Manage and watch for symptoms.** Make sure that your child goes to all appointments recommended by their health care provider(s). These visits are important for managing current health issues, if any are present. Regular visits are also important to help find new concerns as soon as possible, such as hearing loss.
- **Early intervention.** Help Me Grow Minnesota can connect you to resources to help your child develop, learn, and grow. The program can also connect you with your local school district for evaluation to see if your child can take part in infant and toddler intervention or preschool special education services. Please see Section 3: Growth & Development for more information about early intervention.
- **Family support.** Finding out your child has congenital CMV may cause stress or anxiety for some parents. Support from others can help. Please see Section 4 for family support resources.



.....

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.

.....

May my baby go to child care?

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

All child care 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 health care provider that they have 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 health care provider.



Where can I learn more about CMV and congenital CMV?

Contact your health care provider for answers to your CMV and congenital CMV questions. Visit:

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

National CMV Foundation (www.nationalcmv.org)

Cytomegalovirus (CMV) and Congenital CMV Infection
(www.cdc.gov/cmV/index.html)

A large, light blue circle with a dark blue border is centered in the upper half of the page. The word "Section" is written in a dark blue, sans-serif font to the left of a large, dark blue number "2". Several smaller, light blue circles of varying sizes are scattered around the main circle, some overlapping its edge.

Section

2

Hearing and Congenital CMV

Several light blue circles of various sizes are scattered in the lower half of the page, some overlapping the bottom edge of the main circle.

Why to test your baby's hearing

Congenital cytomegalovirus 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's learning to communicate with you many months before they start using words. If a baby's hearing changes, parents or health care 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 start 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."

Hearing testing changes as your baby grows older. Your 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 at your school or clinic to help track your child's language development.

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, providers, and other professionals can be found at (www.health.mn.gov/people/childrenyouth/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 in the hospital 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 important for 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.

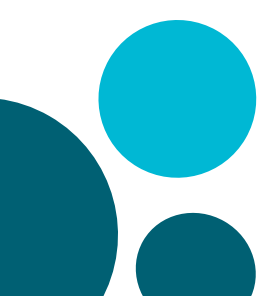
What if something comes up, and I need to reschedule my baby's appointment?

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

Growth and Development





Dear Family,

Congratulations on your new baby!

Today, we want to share three important family resources with you: **Help Me Grow Minnesota, Early Childhood Special Education**, and the **Follow Along Program**. These resources are here to help all Minnesota families and can be supports for you and your family after learning that your child has congenital cytomegalovirus (CMV).

- **Help Me Grow Minnesota** (<https://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 you and your child, you can get this support at no cost.
- **The Follow Along Program** (health.mn.gov/people/childrenyouth/fap) 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 members 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.

Please feel welcome to contact us for more information about these programs or if you have any other questions or concerns. We are here to support you.

A handwritten signature in black ink, appearing to read 'Cat Tamminga Flores'.

Cat Tamminga Flores

Minnesota Part C Coordinator

Minnesota Department of Education

Phone: 651-582-8746

email: cat.tamminga@state.mn.us

A handwritten signature in black ink, appearing to read 'Michele Kvikstad'.

Michele Kvikstad

Early Identification and Intervention Coordinator

Minnesota Department of Health

Phone: 651-201-3723

email: michele.kvikstad@state.mn.us



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





Section

4

Parent and Family Support

It is not unusual to feel surprise, confusion, or a range of other emotions if you are told your child has congenital cytomegalovirus.



These groups may help you find support, resources, and information:

National CMV Foundation

It is the foundation's mission to prevent pregnancy loss, childhood death, and disability due to congenital CMV. Their activities include training local community volunteers, delivering education and outreach, advocating for legislative support, and managing a private CMV family database for those who want to connect with others in their region or state. Each year, the group sponsors a national CMV conference, fundraisers, and other events. Their website has many tips, news items, and other resources for parents and families, childcare providers, and health care providers.

Visit [National CMV Foundation \(https://www.nationalcmv.org\)](https://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, soon 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 651-201-3650 or 800-728-5420 (toll free).

Visit [Minnesota Hands & Voices \(www.lssmn.org/mnhandsandvoices\)](http://www.lssmn.org/mnhandsandvoices).

Family Voices of Minnesota

This nonprofit group offers support and information for Minnesota families raising children with extra medical, physical, behavioral, developmental, or mental health needs. CONNECTED is the group's free parent-to-parent support program that offers:

- One-on-one connection with another parent who has similar experiences or a child with similar needs
- Parent groups for networking, emotional support, and acceptance
- Live chat with other parents who have a lot of experience to share
- Educational webinars

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

Email: connected@familyvoicesmn.org.

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



help me



Connect Families with their Local Communities

Help Me Connect is an online service navigator that helps providers connect pregnant individuals and families with young children (birth-8 years old) with services in their community.

When young families thrive, we all do.

Find Families Services and Resources



Healthy Development and Screening

Parenting programs and Identify concerns early



Developmental and Behavior Concerns

Services for early intervention, special education, and mental health



Disability Services and Resources

Community and family support for children with disabilities



Early Learning and Child Care

Education and child care programs



Family Well-Being and Mental Health

Support the whole family's safety, physical health and mental health



American Indian Families

Resources and supports for American Indians



Caregiving and Community Support

Resources for homeless, immigrants, refugees, teen parents, and other family situations



Dental Care

Find and access affordable dental care



Basic Needs

Help with food, housing, and transportation



Legal Services

Low-cost or free legal services and information



Peacetime Emergency Resources

Support during crises

How to use

1. **Visit:** helpmeconnectmn.org
2. **Select:** A category to see list of services
3. **Enter:** An address to find services nearby
4. **Create:** Favorites for future use
5. **Contact:** HelpMeConnect@state.mn.us for more information



Help Me Connect is an interagency collaboration between Minnesota's Departments of Education, Health and Human Services. This product is made possible using federal funding, 93.434 - ESSA Preschool Development Grants Birth through Five. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Office of Child Care, the Administration for Children and Families, or the U.S. Department of Health and Human Services. Learn more on the [Preschool Development Grant webpage](https://education.mn.gov/MDE/dse/early/preschgr/). <https://education.mn.gov/MDE/dse/early/preschgr/>

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.

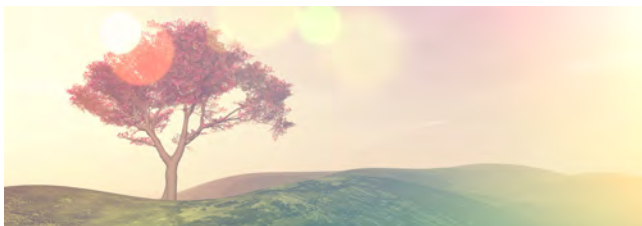
When postpartum depression is effectively treated and managed, it benefits the birthing person or caregiver and child's health.

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.



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

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 \(www.cdc.gov/hearher/index.html\)](http://www.cdc.gov/hearher/index.html): provides life-saving messages about urgent warning signs to prevent pregnancy-related deaths
- [Minnesota Help Me Connect \(helpmeconnect.web.health.state.mn.us/HelpMeConnect/\)](http://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 \(www.health.state.mn.us/fhv\)](http://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? \(www.sleepfoundation.org/sleep-deprivation/parents\)](http://www.sleepfoundation.org/sleep-deprivation/parents)

[Help Me Connect \(helpmeconnect.web.health.state.mn.us\)](http://helpmeconnect.web.health.state.mn.us)

[Nutrition by Life Stage \(www.nutrition.gov/topics/nutrition-life-stage\)](http://www.nutrition.gov/topics/nutrition-life-stage)

[Minnesota Doula Registry \(www.health.state.mn.us/facilities/providers/doula/index.html\)](http://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)
- **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 2 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.



Section 5

Health Care 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 doctors and 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 doctor that is an expert in diagnosing and treating people with infections. Some infectious disease doctors have special training to work with children and are called pediatric infectious disease specialists.

Audiologist: a licensed 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 doctor that focuses on ear, nose, and neck disorders, including hearing loss.

Neurologist: a doctor who specializes in the brain, spinal cord, and nerves.

Ophthalmologist: a doctor who specializes in eyes and vision care.

Orthopedist: a doctor who specializes in treating issues related to bones, joints, and muscles.

Early intervention provider: a support services person 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

Answers to these questions from your child's primary care provider may help you better understand your child's condition and possible care. The answers may also tell you how much experience the primary care provider has with children who have congenital CMV.



Information in this document was adapted from CDC: Questions You May Want to Ask Your Child's Medical Professional on the [CDC: Free Materials About Hearing Loss in Children](http://www.cdc.gov/ncbddd/hearingloss/freematerials.html) website (www.cdc.gov/ncbddd/hearingloss/freematerials.html).

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? How often?

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 must I do if a specialist you send us to then sends us to another type of specialist for more care?

If I have problems with the referrals, or if my insurance company has questions, what should I do?

Can your office help me coordinate appointments?

How do we make sure reports from specialists are shared with you? How will I get copies of all reports from specialists?

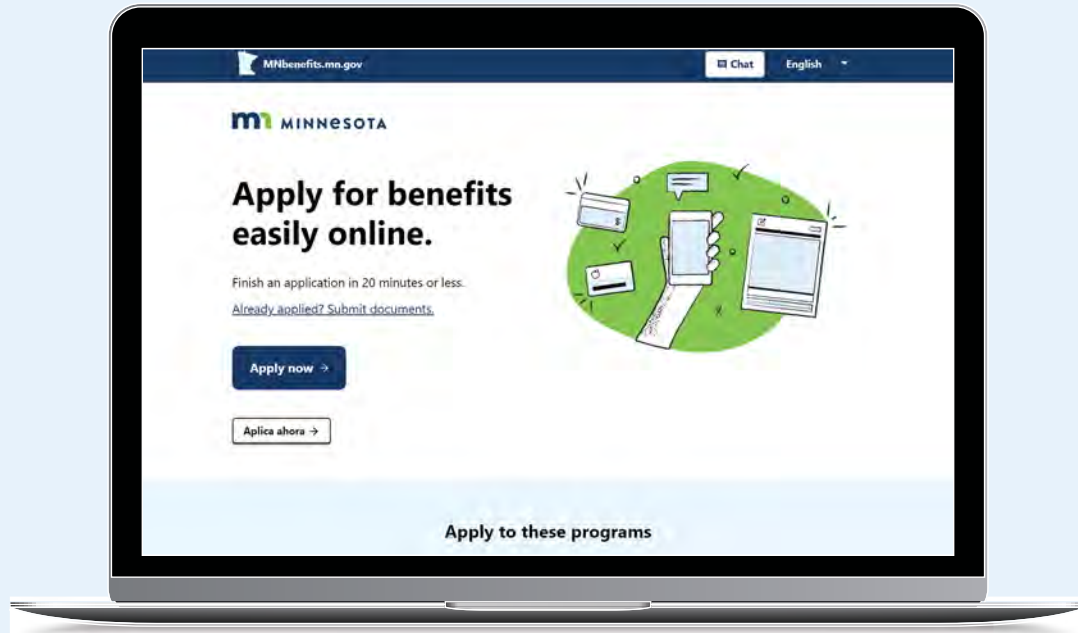
Should my child get all their immunizations on the same schedule as other children their age?

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?

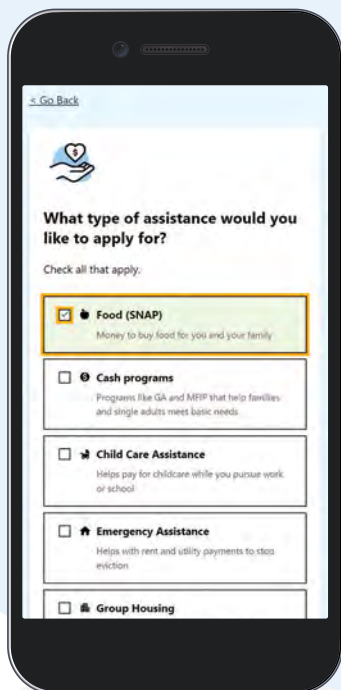
MNbenefits

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



Parental leave laws

PARENTAL LEAVE

Employees may take up to 12 weeks of unpaid leave upon the birth or adoption of their child when:

1. they work for a company with 21 or more employees at a single site, regardless of where that site is;
2. they have been with the company for at least 12 months; and
3. they worked at least half time during the past 12 months.

When does the parental leave start?

- The 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.



FREQUENTLY ASKED QUESTIONS

Can my pregnancy or parental leave count against my paid leave?

Yes. If you have paid leave, including sick leave or paid vacation, the amount of parental leave can be reduced so the total leave (parental plus paid leave) is not more than 12 weeks.

Can my pregnancy or parental leave count against FMLA leave?

Yes. You only have a right to 12 weeks of leave total for birth or adoption of a child and any pregnancy related leave even if you qualify for both FMLA and pregnancy or parental leave.

The federal Family Medical Leave Act (FMLA) requires employers to provide up to 12 weeks of unpaid leave in connection with the birth or adoption of a child or for a serious health condition. 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 www.dol.gov/whd/fmla.

Does my employer have to continue my benefits during the leave?

Yes. Your employer-provided health insurance must be continued during pregnancy and parental leave. You may be asked to pay for this coverage.

Do I get my job back when I return from leave?

Yes. Your employer cannot retaliate against you for requesting or taking a leave. 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.



Labor Standards • 443 Lafayette Road N. • St. Paul, MN 55155
651-284-5075 • 800-342-5354 • 651-284-5099 (Spanish) • www.dli.mn.gov • dli.laborstandards@state.mn.us

Notice: This flier 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 0622



Section

6

Additional Resources for Families



Here are some additional resources that you may find helpful.

MNSure

MNSure (www.mnsure.org) 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 reading the [MNSure Brochure \(www.mnsure.org/assets/mnsure-brochure-english_tcm34-539777.pdf\)](http://www.mnsure.org/assets/mnsure-brochure-english_tcm34-539777.pdf), or call the MNSure Contact Center at 1-855-3-MNSURE (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: A Guide for Families brochure \(www.parentaware.org/wp-content/uploads/2020/08/PA-Child-Care-Guide-English-LINKS_V-6.pdf\)](http://www.parentaware.org/wp-content/uploads/2020/08/PA-Child-Care-Guide-English-LINKS_V-6.pdf) for more information.

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 \(www.health.state.mn.us/people/wic/index.html\)](http://www.health.state.mn.us/people/wic/index.html) for more information or to apply for WIC.





What is MinneStories?

We record and share families' stories about their own, personal experience of being impacted by newborn screening. Through the power of storytelling, we seek to inspire hope and build community through shared experiences.

Why listen?

In an overwhelming and new situation, these stories can help you hear how other have navigated similar paths.

Where can I listen?

You can listen to MinneStories on our website: minnestories.mn.gov





“We have never made the time to sit and talk about [our son’s] hearing loss the way we did yesterday, so it was actually a great experience and pretty eye opening for us.”

-Mother of child with confirmed hearing loss



What is MinneStories?

We record and share families’ stories about their own, personal experience of being impacted by newborn screening. Through the power of storytelling, we seek to inspire hope and build community through shared experiences.

Why would you want my MinneStory?

Every family has a unique store to tell, especially families of children with a condition that can be identified through newborn screening. Your story may be what another family needs to hear to feel empowered, strengthened, and hopeful.

Everyone has a story to tell. We want yours!

Contact us at health.minnestories@state.mn.us

“ I hope that other families can feel at ease after listening to our story, and just stay positive and live your life like normal. ”

Get social with us!

Follow us @mnhealth



#MinneStories