



Congenital Cytomegalovirus (cCMV) Educational Checklist

What is Congenital Cytomegalovirus?

Cytomegalovirus (CMV) is a common virus frequently contracted by young children and easily spread to adults. Outside of pregnancy, CMV typically presents as a mild illness with no lasting effects. However, when a mother contracts CMV during pregnancy, the virus can pass to the unborn child—a condition known as Congenital Cytomegalovirus (cCMV). This can lead to significant, lifelong developmental, sensory, and neurological impacts for the child.

Purpose of the Checklist

The cCMV Educational Checklist highlights key developmental and educational areas impacted by cCMV and outlines actionable strategies for educational teams. It provides targeted resources to deepen team knowledge and practical tools to support the student, school staff, and family effectively. The educational needs of children with cCMV is a relatively new topic and as resources are published, they will be added to this checklist. The authors are considering this checklist as a living document and are open to suggestions for additions.

Early Signs of cCMV

Many infants with cCMV are born at full term but present with low birth weight and may subsequently experience failure to thrive. Other early clinical signs include jaundice and an enlarged liver or spleen (hepatosplenomegaly) in some. Additionally, while hearing loss is present at birth for many babies, cCMV is uniquely characterized by progressive or late-onset hearing loss, meaning a child may pass their newborn hearing screening and begin demonstrating hearing loss later in early childhood.

The Diagnostic Window & Diagnosis Without Testing

A baby must be tested for CMV within the first 21 days of life to confirm a congenital (cCMV) diagnosis. After three weeks, testing cannot distinguish whether the virus was passed during pregnancy or acquired after birth through breast milk, siblings, or

childcare settings. Because cCMV is often undiagnosed or misdiagnosed early on, many children display symptoms later in development without formal birth confirmation. If cCMV is suspected but unable to be confirmed, this checklist remains a valuable, comprehensive tool to ensure that no developmental, sensory, or educational needs are overlooked, even without an official medical diagnosis.

Preventing Transmission

Protecting against CMV is vital, especially for pregnant individuals. Approximately 70% of healthy children ages 1–3 shed the virus, and children born with cCMV can continue shedding CMV long after birth. To reduce the risk of transmission, the [National CMV Foundation recommends](#):

- Avoid contact with saliva: Kiss children on the forehead or cheek rather than the lips.
- Do not share items put in mouths: Avoid sharing food, cups, utensils, or using mouth to clean pacifiers.
- Maintain hand hygiene: Thoroughly wash hands after changing diapers or wiping a child's nose or mouth.

Supporting Families

- Peer Connection: Sharing [parent stories](#) from the National CMV Foundation can help families feel supported and less isolated.
- Navigating Healthcare: Families often work with medical providers who lack deep familiarity with cCMV. The families may benefit from support in preparing to talk with medical providers.
- Connecting families with your state's Family Engagement Coordinator through your [State Deafblind Project](#) offers crucial regional expertise and support systems.
- Some states have a Deaf/Hard of hearing outreach program. If your state has one, be sure to connect with them and have families connect with them.

Acknowledgements

This checklist was adapted from the [CHARGE Syndrome Educational Checklist](#) (Slavin & Hartshorne, 2019). Sincere thanks to Lily Slavin and Tim Hartshorne for sharing their

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cCMV Educational Checklist

Make a copy of the [cCMV Educational Checklist in Google Sheets](#).



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