

Successful Communication Methods with Complex Kids

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What is CMV?

A common virus

50-80% of adults have had CMV by the time they reach 40 years old.

Nearly 1/3 children have had it by the age of 5.

80% of children in daycare will catch CMV in the first 2 years.

CMV presents itself as a cold in most cases.

Cyto-megalo-virus

#1 virus transmitted from a pregnant woman to her baby.

#1 reason for non-genetic SNHL in children.

#1 reason for infection-related stillbirths caused by a virus.

- Hearing Loss
- Vision loss
- Developmental/ intellectual disabilities
- Microcephaly (small head or brain)
- Intracranial calcifications
- Lack of coordination
- Cerebral Palsy
- Feeding issues / Failure to Thrive (FTT)
- Sleeping, behavior, sensory issues
- Seizures
- Death (in rare cases)

Asymptomatic CMV

90% of babies every year are born asymptomatic

4-5% will have a hearing loss at birth

10-15% will eventually have a hearing loss

The loss can be progressive into young adulthood and it can fluctuate.

Symptomatic CMV

10% of babies are born with symptomatic cCMV.

Small head size, jaundice, petechiae/pupura (blueberry muffin rash), and/or enlarged liver or spleen.

Approximately 75% will develop a hearing loss later on.

Why these kids?

- Children affected by cCMV gives us such a wide array of disabilities, cognitively and physically.
- While these communication methods may be useful to these families now, things change overnight with cCMV children. These families may need to rethink their communication method to help their child be more successful for future endeavors.
- These children often have multiple other health problems that stem from cCMV and beyond. They have had to get creative and think outside the box on ways to communicate with their children, often combining and changing communication methods.
- While two of these stories we have told over and over, two are new to us. CMV is so complex and their stories have many twists and turns.

Nathan

4 Years Old

Total Communication (Sign Language & Oral)

cCMV (Profound hearing loss, cysts and abnormal white matter in the brain, developmentally delayed, Childhood Apraxia of Speech, and balance issues).

Type 1 Diabetes



Born at 34 weeks

Diagnosed with cCMV at 3 days old in the NICU

Passed his Newborn Screening and another AOE before discharge at 54 days old.

At 6 months old he had a profound loss in his left ear, and severe to profound in his right.

Family started ASL classes at 6 months old

Bilaterally implanted at 12 months old

At 3 years old Nathan made very few sounds, and inconsistently repeated his ling sounds. But loved hearing sounds and would respond to requests. He was diagnosed with Childhood Apraxia of Speech.

Total Communication

- Nathan uses Sign Language (not ASL) and talks using his voice. To achieve this the family has Deaf/hard of hearing role models in the home. They take Sign Language classes taught by a Deaf adult. And attend AVT classes weekly.
- Nathan attends a Total Communication preschool
- At home, Mom and Dad use sign and oral vocabulary
- Using this approach Nathan understands signing and will use it if we don't understand his spoken words
- Making slow but steady progress with vocabulary
- Now putting 4-5 words together and is more vocal about his wants and needs
- Loves singing and signing together



What Worked vs. Wishes of the Past

- Early Intervention
 - Our local programs to help us learn sign language in our home
 - Hands & Voices for helping us find a voice for my son and teaching us our rights for Nathan
 - An amazing TEAM of professionals who are willing to think outside the box
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- I wish we would have been exposed to sign language earlier
 - I wish it wasn't such a fight to combine CI's and sign language
 - I wish we lived in a school district that had more services

Lilly

18 Years Old

Sign Language (deaf/blind approach)

cCMV (Profound hearing loss, clonic-tonic seizures, brain calcifications, oral aversion, anxiety, and sleep disorders).



Born at 38 weeks

Diagnosed at 6 weeks old with cCMV

Passed her newborn hearing screening. At 6 months old her hearing started to deteriorate. By 10 months old she had a profound loss.

Mom started ASL classes at 6 months old

Unilaterally implanted at 3.5 years old

After no progress with speech and Lilly crying while wearing her implants, Mom found out there was an internal failure. CI consult agreed the internal implant was causing her physical pain, and the surgeon was under multiple lawsuits for incorrectly implanting devices.

1.5 years for insurance approval for re-implantation

Refused to wear CIs for 6 months and Mom decided no more and school reported them to CPS.

Sign Language

- At ten years old Mom took an ASL and Deaf Culture class at a local collage and learned about Lilly's rights. Demanded and interpreter.
- Local school suggested the State School for the Deaf. Lilly's eyes lit up during the tours, watching other kids communicate using ASL. She made slow progress, but progress. In the beginning she had 10 signs, 3 years later she had over 100 signs.
- The school went through an administration shift and they didn't feel like Lilly was making the progress they desired to compensate for the services Lilly needed. Lilly went through 24 1/1 aids in 3 years due to constant 24/7 care. Due to her required needs for a 1/1 aid she was removed from the school and placed closer to home.
- Through the years, Mom fought for interpreters and TODs. Lilly lost a lot of progress made, but over the years has found that the deaf/blind approach works best for her attention span and understanding.



What Worked vs. Wishes of the Past

- Now putting 2-3 signs together at a time
- Followed what Lilly wanted (no picture boards or CIs)
- No one suggested to not use ASL with Lilly

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- Wish I would have known my daughter's educational rights much earlier
 - Wish we had more language exposure and acceptance

JT

3 Years Old

Eye Gaze

cCMV (Gross Motor Delay, hypotonia, developmental delay, feeding difficulties, bilateral profound SNHL, asthma, epilepsy, speech and language disorder, CVI)



Born at 41 weeks.

Diagnosed with cCMV at 8 months old via blood spot testing.

Mom had an amniocentesis during her pregnancy. The doctor sent her a letter saying it was negative for CMV. When JT was 8 months old he spent one month in the hospital for seizures. The amniocentesis results were reviewed and showed that Erin's results were actually positive for CMV.

Failed newborn hearing screen but wasn't diagnosed with a hearing loss until 5 months because they were told month after month that there was just fluid in the ears.

Attends a special needs preschool

Eye Gaze



- JT uses an Eye gaze device. Eye gaze control technology allows children with CP or other disabilities, to use movement of their eyes to operate the speech generating device.
- He gets distracted easily but he is able to tell people his wants and needs.
- Struggles with a wandering eye as well that affects the device., although they have found some success with using his peripheral vision



- Finding it a struggle to keep goals on track outside of school, vs in school using this communication device.
- Very thankful for the device as he is still non-verbal and disabled physically making him unable to sign.
- When JT is successful at using the device his face lights up with excitement.
- Recently he was diagnosed with CVI. They were unsure of how this would affect his use of the eye gaze. Luckily his ST had suspected CVI and has been teaching TJ techniques to help with that throughout his therapy.

What Worked vs. Wishes of the Past

- Early and consistent therapy.
 - Therapists who pushed me, as a parent to make me recognize he needed more than I was willing to accept.
 - Correct seating
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- I wish we had known how bad his hearing was earlier.
 - I wish we would have known how his posture issues and lazy eye would impact the Eye Gaze Device
 - I wish our county had speech therapists who dealt with hearing loss.
 - I wish he could sign. Fine motor is very hard and cognitively delayed, we don't know how much he can do.

Axel

3 Years Old

Total Communication with Assistive Technology

cCMV (spastic quadriplegic cerebral palsy, bilateral profound sensorineural hearing loss, calcifications and malformation on the brain, seizures, optic nerve hypoplasia, global developmental delay, motor delay, g-tube, NPO, microcephaly, hyperekplexia)



Induced at 37 weeks for what they thought was
coarctation of the aorta.

Diagnosed with congenital CMV at 2 days old in the
NICU

Failed his newborn hearing screen and was diagnosed
with a bilateral profound sensorineural hearing loss at 1
month old.

Chose to pursue cochlear implants and received first
implant at 6 months old and second implant at 11
months old.

Total Communication



- At 3 years old he is nonverbal and had physical limitations making him unable to sign. He was sent for an assistive technology consult. He was given an Accent 1000 Device with two switch access. While his expressive language was limited, receptively he was understanding what we were signing to him, speaking to him, and modeling to him with a PODD book.



- Axel attends a total communication classroom at in a deaf and hard of hearing preschool.
- Mom and Dad use oral communication and sign language at home.
- We also model language with the AAC device.
- Mom and Dad attend ASL and deaf culture classes.
- Axel will use sign or gestures or his AAC device to get his message across
- Is just starting to put 2 signs together

What Worked vs. Wishes of the Past

- Early intervention
- Having therapists who were all on board with my plan to provide Axel with the tools to chose what communication method works best for him
- Being open minded and know that what works now may not work later and be willing to try new things
 - Hands & Voices who supported our family with all the communication options we chose.
- Supportive team of physicians and therapists who refused to give up and worked together to see Axel as a whole child instead of just their specific focus.

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- Axel does have optic nerve hypoplasia with the possibility that he could at some point lose his vision.
 - The future is unknown.
 - I wish he would have gotten the AAC device sooner. Even If it was just for the purpose of modeling.

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