

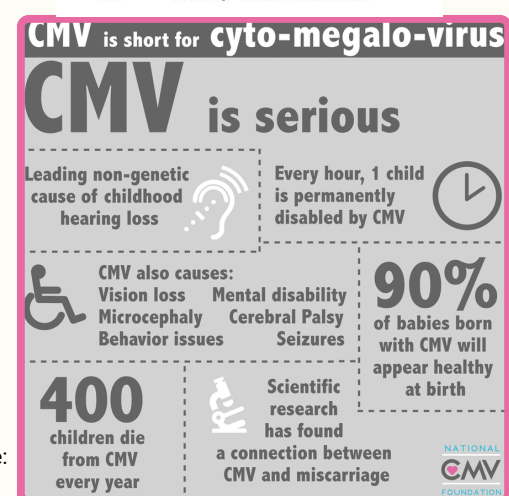
CMV - CYTOMEGALOVIRUS

cCMV - CONGENITAL CYTOMEGALOVIRUS

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Cytomegalovirus [hereafter CMV] is a common widespread virus, it is usually harmless and remains dormant for life. Anyone can contract it and most experience no symptoms or only a mild, flu-like illness with no long lasting effects (NHS, 2023; Abdullah, 2023; CDC 2025). Congenital CMV [hereafter cCMV] is the most common congenital infection worldwide (Jones et al., 2023; Nguyen & Shorman, 2025). Many infants are asymptomatic however may later develop hearing loss or speech and language delay (Rochat et al., 2024).

Image 1: CMV is Serious (Website image: National CMV Foundation, 2025a)



01 PREVELANCE & PROGNOSIS

- Around **1% of all live births result in cCMV** (CDC, 2025) with a global rate of **7 in 1000 births** (NHS Scotland)
- In the UK **1 in 200 babies are born with cCMV - 10 each day** (Tommy's, 2026).
- **1 in 5** of these will experience birth defects and/or complex needs (NHS, 2023).
- **10-15%** develop long term medical or developmental difficulties (NHS Scotland, 2025; Jones et al., 2023; Nguyen & Shorman, 2025).
- **5 in 1000 babies born with cCMV die at birth or within early childhood** (Action Medical Research, 2024).
- cCMV accounts for **25% of childhood hearing loss** and is a major casue of childhood disability (CMV Action, 2022; NHS, 2023; CDC, 2025).
- It is also associated with longer hospital stays, increased medical issues and lifelong therapy needs ((Nguyen & Shorman, 2025: LeWine 2024).
- Pregnant women face increased risk of exposure (NHS, 2023).

02 SCREENING & DIAGNOSIS

The UK National Screening Committee (Tommy's, 2026) and the National CMV Foundation (2025b) do not recommend antenatal or newborn screening with outcomes remaining uncertain (Kalogeropoulou et al. 2025) although this is under US research review (CDC, 2024a). Postnatal testing must take place in the first 3 weeks of life (LeWine, 2024; CMV, 2024a; NHS, 2023). Leruez-Ville et al. (2024) recommend monitoring all high risk children until at least age six, with children receiving neurodevelopmental assessment at 24–36 months. Rochat et al. (2024) report the typical age of diagnosis for key CMV-related conditions:

- **Hearing deficits: mean age 0.84 years**
- **Vision deficits: 1.2 years**
- **Neuromuscular issues: 1.8 years**
- **All qualifying conditions appeared by age 3 years.**

03 BARRIERS TO DIAGNOSIS

Global awareness remains low, contributing to inequity and delayed diagnosis (WHO, 2024; UNICEF, 2026). UK awareness is particularly limited, despite cCMV being more prevalent than Down syndrome or spina bifida (Action Medical Research, 2024). cCMV is a major cause of neurodevelopmental impairment, including hearing loss, intellectual disability and autism (Rochat et al., 2024; NHS Scotland, 2025). Low awareness among families and professionals leads to missed early symptoms and delayed diagnosis (Jones et al., 2023) with persistent lack of awareness contributing to preventable long-term outcomes, underscoring the need for improved health messaging and professional training.

04 TREATMENT & PREVENTION

There is no curative treatment for CMV in pregnancy (NHS, 2023; NHS Scotland, 2024). Antivirals may reduce transmission and weaken infection however only when identified early (NHS, 2023; Leruez-Ville et al., 2024; 2026). Many babies do not require medication, for those that do, treatment depends on symptom type and severity and must be specialist led (LeWine, 2024; NHS, 2023). National CMV Foundation (2025b) and LeWine (2024) strongly emphasise behavioural prevention such as handwashing, avoiding saliva, not sharing utensils and reducing exposure in childcare settings for pregnant practitioners.



Image 2: What is CMV? (Website image: CMV Action, 2022)

05 ALN OUTCOMES

- cCMV is an under-recognised cause of neurodevelopmental impairment (WHO, 2024; UNICEF, 2026).
- Newborns may show prematurity, microcephaly, seizures, neurological impairment, jaundice and sensorineural hearing loss (LeWine, 2024).
- Long-term disabilities include hearing, vision, intellectual, orthopaedic and communication difficulties, and autism (Rochat et al., 2024).
- cCMV is the leading infectious cause of permanent childhood disability, especially hearing loss (Schleiss, 2024; NHS Scotland, 2025).
- Causes developmental delay, growth issues, neurodisability, with hearing loss often progressive (NHS, 2023; CDC, 2025; Kalogeropoulou et al., 2025).

In Wales, ALN is identified when a learner's needs require provision beyond what is ordinarily available, cCMV aligns with this framework due to its associated hearing, communication and neurodevelopmental impacts often meeting this threshold (WG, 2021).

06 IMPACT OF THE ALN

Families report emotional, practical and financial strain, with diagnostic delays contributing to distress (Vandrevala et al., 2020; Greiner et al., 2025a). Long-term needs require multiple services, increasing pressure on routines and finances (Rawlinson et al., 2017).

Wider impact - Annual UK cost: £750 million (CMV Action, 2018)

- **£330 million - NHS, Social Care & Education**
- **£420 million - families and wider economy (lost work, private therapies, specialist equipment)**



In Wales children with cCMV face clear disadvantage due to equity, missed prevention and rising pressures on ALN services. Low professional awareness and delayed diagnosis consistently worsen outcomes (Nice, 2021; CMV Action, 2024; Greiner et al., 2025).

07 INCLUSION

Inclusion recognises all learners as equally valued and entitled to high-quality education. It places responsibility on systems and environments to remove barriers and ensure meaningful participation and fairness (UNESCO, 2017; WG, 2021).

The Salamanca Statement positions inclusion as a systemic responsibility, rejecting segregation and promoting full participation in mainstream education (UNESCO, 1997).

08 BARRIERS TO SUPPORT

Practitioners face major systemic pressures, including limited time, inconsistent specialist support and variation in ALN Code implementation (Norwich, 2023; Murphy et al., 2024; WG, 2025b). Despite legal protections, discrimination persists through deficit-based assumptions and inconsistent adjustments (Murphy et al., 2024; Knight et al., 2023).

09 SUPPORT STRATEGY

Children with cCMV commonly experience ALN and health-related needs, making early identification and sustained monitoring essential (Rochat et al., 2024). NHS Scotland (2025) advises regular audiology reviews to age six and neurodevelopmental assessments for at least two years from six months. These guidelines reflect that hearing loss and neurodevelopmental differences are the most frequent long-term outcomes (CDC, 2024). Given this variability, sign-supported speech [hereafter SSS] is vital for ensuring consistent access to language and learning (Marschark & Knoors, 2024). It provides visual scaffolding that supports comprehension, reduces communication breakdowns and enhances spoken language. Research on SSS shows pairing speech with signs increases communication, social interaction and inclusion (Kravchenko & Boychuck, 2021). SSS is particularly valuable when auditory input is inconsistent. Broadly (2023) states that consistency across settings further strengthens outcomes. SSS also aligns with behaviourist and sociocultural theories of language learning (Skinner, 1957; Vygotsky, 1978) and remains effective despite practitioner challenges (Sin, 2020). SSS supports the ALN Code's focus on removing communication barriers and enabling meaningful participation (WG, 2021). However while SSS is highly effective for fluctuating hearing loss and mixed ALN profiles, for children with profound hearing loss, BSL remains the primary recommendation, with SSS as a supplementary tool (Marschark & Knoors, 2024). In conclusion cCMV is common, preventable and often overlooked, yet early awareness, diagnosis and support can significantly reduce its lifelong impact on children and families.

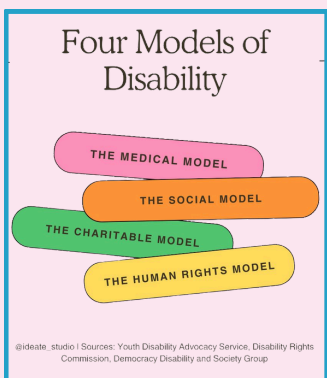


Image 3: Four Models of Disability (Website image: (ide)ate, 2024)