

CHARGE: Where to begin

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What is CHARGE syndrome?

(Smith, Centre, Smith & Blake, 2010)

C - coloboma of the eye: there is a cleft, or the eye fails to close during the developmental of the eyeball.

H - heart defects which vary in severity treatment- surgery or ongoing observations.

A - choanal atresia: blocking or narrowing of the nasal passage by bone or cartilage.

R - retarded growth which occurs in most children, but the delays vary.

G - genital hypoplasia which is typically seen in males.

E - ear abnormalities such as atypically shaped external ears and a degree of hearing loss.

How is communication impacted?

- Abnormalities in the face can often cause many problems in communication, which causes something as simple as smiling to not develop until about the age of three (Peltokorpi & Huttunen, 2008).
- Children with **CHARGE syndrome** could have a hard time processing symbolic language which could be due to physical abnormalities, substantial hospitalizations or a sensory deficit (Thelin & Fussner 2004).
- It is harder to develop language because the children also typically lack the environmental input that they would receive through vision, hearing and other sensory impairments (Swanson, 2011).

Prevalence

(Smith et al., 2010)

- Estimated to affect 1 in 15-20,000 babies born.
- According to the data collected, more than 90% of children with **CHARGE syndrome** are affected with hearing impairment.

Communication opportunities

(Swanson, 2011)

Spoken Language

- Approximately 40% of those with **CHARGE syndrome** use this as their primary mode of communication (Thelin & Fussner, 2005).

Manual

- Hand-under-hand or coactive signing is when the caregiver sits behind the child and the child's hands rest on top of the caregivers.
- Tactile sign is when the caregiver and child sit face-to-face, and sign to one another hand-under-hand.

Visual symbols & Voice output

- Picture Exchange Communication Board (PECS)
- Voice Output Communication Aids (VOCA's)

Gestures

- Hand and arm gestures are primarily used by children in the presymbolic stage.

Total communication

- Includes voicing, sign, gestures, pictures, etc.
- Is the most common form of communication for children with **CHARGE syndrome**.
- Chosen by many parents when communicating with their child.

Tips to support the child

- Observe the child to see if they are making communication attempts (Smith, Smith, Blake, 2010).
- Support the child's fatigue, stress, anxiety and function difficulties (Deuce, 2017).
- Communication bubble (Griffin, Davis & Williams, 2004).
 - 1-2 feet surrounding the child
 - If outside of this, the communication does not exist.
- Have a communication shelf in the child's environment (Griffin, Davis & Williams, 2004).
 - An object represents each part of the child's day.
 - When the activity is completed the child places the object to represent that in a box.
- Provide the child with a visual/ tactile calendar to layout his/her day (Deuce, 2017).
- Photographs, Picture Communication Symbols (PCS) and object symbols can be used to communicate between peers (Swanson, 2011).

Stay in touch!

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