

# 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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