

CHARGE Syndrome

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ETIOLOGY

- CHARGE syndrome is a rare disorder that arises during early fetal development and affects multiple organ systems.
- CHARGE syndrome affects approximately 1 in every 10,000 births.

GENERAL CHARACTERISTICS

- The “CHARGE” acronym stands for: **C**oloboma of the eye, **H**ear defects, **A**tresia of the choanae, **R**estriction of **G**rowth and development, and **E**ar abnormalities and deafness
- Individuals with CHARGE often have vision, hearing and balance issues caused by underdeveloped semicircular canals
- In addition to the CHARGE features above, most children with CHARGE syndrome have other features, including characteristic facial features: asymmetric facial nerve palsy, cleft lip or palate, esophageal atresia (blind-ending food pipe) or tracheoesophageal fistula (connection between the windpipe and the food pipe); this may lead to the necessity for a gestational feeding tube or specific food consistency if eating orally
- Most children with CHARGE syndrome have upper body hypotonia (weakness). They are weak, especially in the trunk, and may have sloping shoulders/ kyphosis
- Each child with CHARGE is different, but many, if not all, are strong willed and persevere in spite of their physical or intellectual challenges
- Other coexisting conditions such as Obsessive Compulsive Disorder (OCD) and behavioral challenges can be common amongst individuals with CHARGE



SPECIFIC MODIFICATIONS FOR UNIVERSALLY DESIGNED LESSONS

- Build relationships, get to know the students' visual, auditory and physical needs; their likes and dislikes
- Offer frequent, structured breaks (if necessary); these breaks can be seated, movement or sensory breaks and in consistent, safe, clearly designated areas (i.e. seat or bench, beanbag or scooter)
- Clear beginning and end to activity, finished bins can be used to reinforce the end of an activity
- Use routines to develop sequences, but expand on these routines to continue to develop skill sets, example: modifying consistent warm up slightly to match main content: example: walking/ running to the command of “Ready, Set, Go!” changes to walking lines of tennis court to same “Ready, Set, Go!” command to match a tennis unit
- Encourage and facilitate independence as much as possible in all aspects of their day

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(e.g. helping to set up, clean up, put together a schedule for exercise etc.)

- Plan or design lessons using the correct communication medium i.e. ASL, speech paired with ASL, picture supports if applicable on sequence strips
- Use of Teaching Assistants/ Paraeducators during classes to model, offer specific reinforcement and implement scheduled breaks
- Allow choice making when appropriate through the use of number cards for counting, or choice boards with picture supports
- Collaborate with team members such as OT, SLP, PT to embed sensory strategies into activities i.e. use balls with varying textures, weight etc.
- Certain activities may need to be specifically adapted to accommodate limited range of motion in arms/shoulders often associated with CHARGE syndrome. Try to encourage stretching and oppositional exercises in the thoracic cavity (chest) to alleviate tightness/encourage range of motion



SPECIFIC RESOURCES

www.chargesyndrome.org

www.perkinselearning.org/earn-credits/self-paced/charge-syndrome-self-paced-tutorial

www.rarediseases.org/rare-diseases/charge-syndrome

REFERENCES

- National Organization for Rare Disorders (2021) Online Mendelian Inheritance in Man (OMIM). The Johns Hopkins University. CHARGE Syndrome; Entry No: 214800. Last Edited August 31, 2016. Available at: <http://omim.org/entry/214800> Accessed July 21, 2018.
- U.S. Department of Health and Human Services (2020). Retrieved from: <https://medlineplus.gov/genetics/condition/charge-syndrome/#:~:text=CHARGE%20syndrome%20is%20a%20disorder,genital%20abnormalities%2C%20and%20ear%20abnormalities.>
- European journal of paediatric neurology (Online), European journal of paediatric neurology (2017). Verbeek, R.J. et al. https://www.researchgate.net/publication/317592314_The_neuromuscular_phenotype_of_shoulders_deformities_in_CHARGE-syndrome

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