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:
 Coloboma of the eye, Heart defects,
 Atresia of the choanae, Restriction
 of Growth and development, and Ear 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







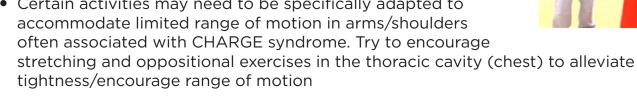


(e.g. helping to set up, clean up, put together a schedule for exercise etc.)

• 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



SPECIFIC RESOURCES

www.chargesyndrome.org

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

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