

How CHARGE Syndrome Impacts Participation at School and Home

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Deafblind Physical Therapy Team

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Objectives

1. Learn how CHARGE syndrome can affect gross motor development
2. Identify areas of support that students with CHARGE syndrome often need
 - a. Understand the ways that PTs in various settings can help support those needs
3. Review the purpose of school-based physical therapy services
4. Discuss important considerations regarding equipment

Dive into Senses

& how they can impact
balance

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Sensory Systems

- Give us information about the world and about our bodies
- Each system has unique receptors that send information to the brain
- Different receptors react to light, sound, vibration, touch, stretch



Sensory Systems

Systems that affect balance

- Vision
- Vestibular
- Somatosensory - touch and proprioception

All systems work together in a complex dynamic process

- Multiple senses verify or refute information
- The brain is the processing center

What does all that have to do with movement?

Lots to consider

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Motor Development in CHARGE

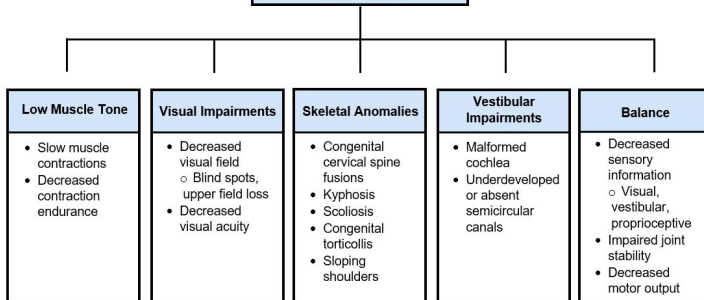
Sensory impairments often lead to motor impairments

- Less motivation to move around without sensory input
- Less information for motor learning and balance

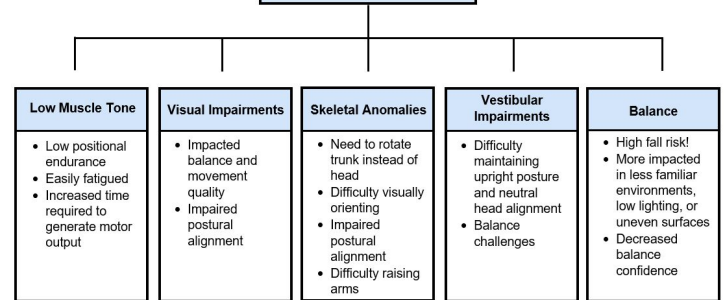
Key Points

- Balance confidence is key!
- Be patient! It's okay if skills take a little longer

Physical Characteristics of CHARGE Syndrome That Affect Gross Motor Performance



Impact of Physical Characteristics of CHARGE Syndrome



Additional Considerations

Conditions that PTs may not directly address in IEP goal areas but need to be aware of when providing services:

- Deafblindness - supporting environmental access and communication strategies
- Osteoporosis - time spent in standing and equipment use, exercise prescription, fall risks
- GERD - positioning considerations
- Constipation - increased motility with movement, GI discomfort
- Cardiopulmonary factors - monitoring of vital sign responses during exertion

Areas that PTs lead the CHARGE on!

Positioning, Endurance, and Balance

Positioning Support

Maintaining posture is hard work!

- PTs can help with:
 - Frequent positional changes
 - Use of positioning equipment
 - Interventions to address range of motion limitations and bony anatomy



Endurance

Low tone, balance challenges, and impaired coordination increase the energetic costs of movement!

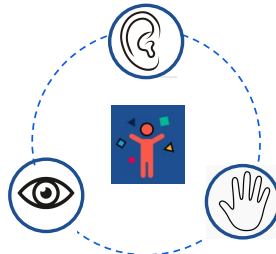
- PTs can help with:
 - Activity planning
 - Managing energy levels
 - Positioning
 - Environmental modifications



Balance

All parts of the balance system are affected by CHARGE

- PTs can help with:
 - Teaching compensatory strategies
 - Practicing safe falling
 - Improving balance confidence
 - Equipment and bracing use
 - Other safety measures



Practical Application

The challenges we see

| | | | |
|--|--|--|--|
| | Small steps and caution while walking / negotiating stairs | | Flopping to the floor |
| | High intensity sensory seeking (stomping, rocking, spinning) | | Difficulty transitioning into/out of a chair or onto/off the floor |
| | Getting tired quickly and needing rest breaks often | | Abnormal posture / position |

Practical Application

| | | |
|--|---|--|
| | Small steps and caution while walking | <ul style="list-style-type: none"> Slow transitions between locations May need human guide or hand-held assist |
| | High intensity sensory seeking | <ul style="list-style-type: none"> Increased time needed for sensory activities in order to feel centered and participate |
| | Getting tired quickly and needing rest breaks | <ul style="list-style-type: none"> Need planned routes between destinations |
| | Flopping to the floor | <ul style="list-style-type: none"> Need to make walking easier or more fun |
| | Difficulty transitioning from chair or floor | <ul style="list-style-type: none"> Need extra support like chair or bench to put hands on |
| | Abnormal posture / position | <ul style="list-style-type: none"> Need appropriate seating or bracing Changes in position throughout the day |

Teamwork Makes the Dream Work!

Other Team Members Play an Important Role

- Orientation & Mobility - Safe navigation strategies
- Occupational Therapy - Proprioceptive and vestibular sensory input
- Adaptive Physical Education - Adapted sporting activities
- & many more! Working as a collaborative team helps to generalize skills across settings and people
 - Family, caregivers, and friends
 - Classroom teachers, teaching assistants, paraprofessionals, interveners
 - Community programs and recreational activities

We can all work together!

Making the connection
between home and school

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School-Based PT Definition

- Primary purpose is for **educational access**
 - Physical access to school environment and activities
- Educational model, not rehabilitation model
 - Funded through district instead of insurance
 - Ongoing services instead of episode of care to address injuries or operations
- Focus on promoting independence
- More than just mobility!
 - Positioning support, equipment and bracing needs, consultation services, etc.



Service Delivery

- Least Restrictive Environment
 - Consultation vs. Direct Services
 - Push-in vs. Pull-out Services
 - Group Therapy vs. Individual Therapy
- School Progression
 - Early school years - more likely to be direct, individualized, and higher frequency to address gross motor development
 - Later elementary/high school - more likely to be in group setting or lower frequency to fine-tune balance skills
 - Transitional age - more likely to be consultative to address healthy lifelong exercise routines and recreational/leisure access

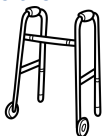


Equipment

- Who pays?
 - District vs. insurance
 - Medical doctors provide prescriptions
- What is the PT's role?
 - Assessment
 - Writing Letters of Medical Necessity (LMNs)
 - Adjustment and modifications
 - School vs. home equipment

Equipment

All equipment needed throughout the school day should be written into the IEP



Mobility



Seating/Positioning



Transportation



Recreation

- Grants and equipment share programs are available!
- CHARGE syndrome foundation has a recreational sport equipment grant!

PTs are here to support your child!

Thank you for coming!

Questions?

References

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