

TURNER SYNDROME

Background

Turner syndrome (TS) is a genetic condition affecting only females. It is characterized by short stature, failure to begin puberty, infertility, heart defects and certain learning disabilities. Signs and symptoms affecting bone development and growth may be subtle and develop slowly while others are suspected prenatally as they affect the developing heart and kidneys. Other physical signs are evident at birth or during infancy. As the child ages, no growth spurts occur at expected developmental times.

Medical conditions are often associated with the heart, thyroid, or kidney(s). This could include congenital heart defects, hypertension, and urinary tract infection. People with TS are also at high risk for metabolic syndrome including central obesity, insulin resistance (pre-diabetes), high blood pressure, high cholesterol and type II diabetes.

An individual with TS often has a cognitive profile that includes normal intelligence and verbal capabilities but weaknesses in the areas of visual-spatial, executive, and social cognitive function. This includes variables in things like nonverbal communication, slowed response times and immaturity. A child may have trouble recognizing social cues and maintaining personal boundaries. Things like facial expressions are also easily misinterpreted. Issues of spatial awareness and abstract concepts make certain subjects particularly challenging. Spatial awareness can also affect spelling, punctuation, mapping, understanding time, changing point of view, and even drawing and handwriting.

While there is no cure for TS, treatments aim to manage the symptoms and complications. The primary treatment for nearly all girls with TS includes hormone therapies. Growth hormone therapy is usually given as a daily injection to increase height during early childhood to the teen years. Estrogen therapy is usually started around the age of 11 or 12 to begin puberty. A girl with TS may have numerous health care specialists involved with her care depending on what medical and developmental issues she may experience.



Top Takeaways for School Considerations

Turner syndrome (TS) is a chromosomal abnormality affecting females. The main symptom is short stature.

Delays in physical growth and sexual development may lead to issues with low self-esteem, anxiety, and depression.

Students with TS may have normal intelligence but often experience difficulties with visual-spatial and executive functioning. Girls with TS also have a higher rate of an attention-deficit/hyperactivity disorder (ADHD) diagnosis.

Students with TS are prone to recurrent ear infections. Hearing loss and sensitivity to noise could require coordination and planning (e.g., alarms, announcements, assemblies).

Most students with TS respond well in a structured and well-ordered day. It is helpful for them to know the daily schedule and some may find a sudden change to routine difficult.

Girls with TS are highly verbal but may struggle with understanding social relationships. They may be rigid and inflexible towards behaviors of others. Social cues and facial expressions are often misunderstood.

Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnosis of social isolation, impaired physical mobility, impaired swallowing, low situational self-esteem, and ineffective breathing patterns
- Current diagnosed health condition including date of diagnosis, progress of disease process and other chronic health conditions
- Current medication and treatment orders (consider schedule, equipment needs and side effects)
- Student-specific triggers, avoidance, or intervention strategies
- Elimination interventions and equipment needs
- Use of specialized equipment, adaptive equipment, and orthotics
- Skin check, pressure relief techniques
- Consider emergency care plan(s) (ECP) and emergency evacuation plan(s) (EEP) as related to medical needs in the school setting, and staff education/training, as appropriate

Discussion Starters for Educational Team

1. Has the school staff been trained to implement the student-specific emergency plan?
2. Would the student benefit from evaluations or assessments in any of the following areas: physical therapy, occupational therapy, speech and language therapy, assistive technology, adapted physical education, functional behavior, psychology, hearing and vision?
3. Would the student benefit from additional academic support and/or modified education (e.g., copies of notes, extra time, reduced workload, simplified instructions, alternative formats for presentation of material, 504/IEP)?
4. Can strategies be implemented to assist the student with executive function (e.g., plan, prompts, organizers, agendas)?
5. Does the student need additional adult support to access the academic curriculum in the least restrictive environment?
6. Would schedule flexibility support the student?
7. Does the student need support with gross or fine motor skills in the classroom?
8. Does the classroom environment support the student's needs and/or equipment? (e.g., desk/seating options, ability to reach objects, flash pass for bathroom or nurse)

Resources

Kennedy Krieger Institute: Neurology and Neurogenetics Clinics
kennedykrieger.org

Turner Syndrome Foundation
turnersyndromefoundation.org/

Turner Syndrome Support Society: How to help your child survive and succeed at school: A Guide for Parents and Teachers
tss.org.uk/downloads/TSSS%20education%20booklet.pdf



Scan QR code or visit KennedyKrieger.org/Redirect for more information.