TUBEROUS SCLEROSIS COMPLEX

Background

Tuberous sclerosis complex (TSC) is a genetic disorder that causes the growth of non-cancerous (benign) tumors throughout the body. The areas most often affected include the brain, heart, lungs, kidney, eyes, and skin. Symptoms widely vary depending on the location and manifestation caused by the tumor. Skin growths and changes in skin pigmentation and texture may be the most visible symptom of TSC.

Tumors that form on surfaces and layers of the brain can cause the most substantial impact. Neurological conditions like seizures, developmental delay, and intellectual disability can range from mild to severe impairment. Lesions can also form in the brain ventricles and potentially block the flow of cerebrospinal fluid, leading to behavioral changes, nausea, and headaches. Some children may require the placement of a shunt to reduce the intracranial pressure. Heart and kidney tumors can disrupt blood flow to these vital organs and cause complications such as abnormalities in the heart's rhythm and potentially kidney failure.

There is no cure for TSC but treatment is symptomatic and supportive. Medications can help treat brain and kidney tumors, while others can help control seizure activity. Surgery is sometimes used when tumors are blocking vital organs and disrupting function.

Top Takeaways for School Considerations

Tuberous sclerosis complex (TSC) causes the growth of benign tumors throughout the body. Tumors growing in the brain can cause disruptive neurological symptoms. Delays range from mild learning disabilities to severe impairment of cognitive abilities.

TSC is the leading genetic cause of seizures. A large percentage of students with TSC will also develop autism spectrum disorder.

Other health impairments affecting the heart, lungs, and kidneys may require monitoring and considerations for activity precautions (e.g., high blood pressure, shortness of breath, cough, chest pain).

Students with TSC may experience higher rates of mental health conditions such as anxiety, depression, aggression, and self-injurious behavior.

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Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnosis of risk for injury, impaired thought process, risk for unstable blood pressure and impaired gas exchange

- 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)

- Assessment of implanted medical device (consider location, date of surgical placement, and device specific information)

- Use of specialized equipment, adaptive equipment, and orthotics

- 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. Can rest breaks, safe spaces or reduced stimulation times be built into the student's schedule?

Resources

Kennedy Krieger Institute: Tuberous Sclerosis Clinic
kennedykrieger.org

Teacher's Guide: Educating a child with Tuberous Sclerosis Complex
citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.666.378&rep=rep1&type=pdf

Tuberous Sclerosis Alliance
tsalliance.org/pages.aspx?content=2

Tuberous Sclerosis Association
tuberous-sclerosis.org/

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

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