Tuberous Sclerosis Complex

Background

Tuberous sclerosis complex (TSC) is a genetic disorder that causes the growth of non-cancerous (benign) tumors in multiple organs, including the brain. The heart, lungs, kidneys, eyes, and skin are often affected. Skin growths and changes in skin pigmentation and texture are often the most noticeable signs of TSC.

Tumors that form on the 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 vital organs and cause complications such as abnormalities in cardiac 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

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

TSC is the leading genetic cause of seizures. Many students with TSC 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.

Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnoses: Risk for injury, impaired thought process, risk for unstable blood pressure and impaired gas exchange
- 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 action plans (EAPs) and emergency evacuation plans (EEPs) related to special health care needs, including staff education/training

Discussion Starters for the Educational Team

1. 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?
2. 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)?
3. Can strategies be implemented to assist the student with executive function? (e.g., plan, prompts, organizers, agendas)?
4. Can rest breaks, safe spaces or reduced stimulation times be built into the student's schedule?
5. Will staff receive education/training to implement the student-specific emergency plan?

Resources

Kennedy Krieger Institute: Tuberous Sclerosis Clinic
kennedykrieger.org/patient-care/centers-and-programs/tuberous-sclerosis-clinic

Tuberous Sclerosis Alliance
tscalliance.org/

Tuberous Sclerosis Association
tuberous-sclerosis.org/

TSA: In Safe Hands- An Introductory Guide to TSC foe Teachers and Educators
tsa.org.au/find-support/resources/in-safe-hands-an-introductory-guide-to-tsc-for-teachers-and-educators/

For more information, please scan the QR code or visit: KennedyKrieger.org/SHNIC

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