Tuberous Sclerosis Alliance

TYPES OF SEIZURES AFFECTING INDIVIDUALS WITH TSC

INFANTILE SPASMS	
What it looks like	Infantile spasms are clusters of quick, sudden movements that typically start between 3 and 18 months of age and almost always occur before 2 years of age. The most frequent and common characteristic is a sudden flexion of the neck (head nod) and all four extremities accompanied by adduction of the arms (movement of the arms towards midline as if the infant is hugging him/herself). Extensor type spasms are less common and are characterized by sudden extension of the neck and lower extremities with extension and abduction (movement of the arms away from midline to the sides). In other cases, the spasms may be subtle, and only abrupt head nods occurring in clusters are noticed. In many cases, infantile spasms are a mix of characteristics.
What it is not	Normal body movements. Colic/gastroesophageal reflux. Startle reflex.
What to do	No first aid, but doctor should be consulted as soon as there is suspicion of changes in the infant's behavior (cranky, restless) and unusual movements are observed, or if there is a regression of development such as cessation of speech or motor skills. If possible, caregivers should videotape the unusual movements so they can be shown to the child's physician.
What NOT to do	Not applicable.
SIMPLE PARTIAL (Also referred to as SPS)	
What it looks like	The major distinction between Simple Partial and Complex Partial (see below) is that there is no alteration in consciousness in individuals with Simple Partial seizures. They may not be obvious to an onlooker. Simple Partial seizures have a diverse range of presentations that include but are not limited to: 1. Involuntary jerking of one part of the body ("focal motor" signs). 2. Behaving out of character because the individual is hearing or seeing things that are not there; feeling unexplained fear, sadness, or joy; feeling tingling sensations; feeling nauseous; looking pale and sweating; appearing to be "drugged" because of pupillary dilatation. Jerking may begin in one area of body, arm, leg, or face. The seizure

	can't be stopped, but the person stays awake and aware. Jerking may proceed from one area of the body to another and sometimes spreads to become a convulsive seizure.
What it is not	Acting out. Bizarre behavior. Hysteria. Mental illness. Psychosomatic illness. Parapsychological or mystical experience.
What to do	No first aid is necessary unless seizure becomes convulsive, then first aid should be used and 911 called if needed. No immediate action needed other than reassurance and emotional support. Medical evaluation recommended.
What NOT to do	Not applicable.
COMPLEX PARTIAL (Also referred to as CPS)	
What it looks like	Usually starts with blank stare, followed by chewing (or lip smacking, swallowing), then random activity. Person appears unaware of surroundings. May seem dazed and mumble. Unresponsive. Actions clumsy, not directed. May pick at clothing, pick up objects, try to take clothes off. May run, appear afraid. May struggle or flail at restraint. Once pattern established, same set of actions usually occur with each seizure. Lasts a few minutes, but post-seizure confusion can last substantially longer. Individual will have no memory of what happened during seizure period.
What it is not	Drunkenness. Intoxication on drugs. Mental illness. Disorderly conduct.
What to do	Speak calmly and reassuringly to individual. Guide gently away from obvious hazards. Stay with person until he or she is completely aware of the environment. Offer to help them get home or to a safe place.
What NOT to do	Don't grab hold of the person unless he or she is in sudden danger (such as a cliff edge or an approaching car). Don't try to restrain. Don't shout. Don't expect verbal instructions to be obeyed.
PARTIAL SEIZURES SECONDARILY GENERALIZED	
What it looks like	Onset may either be a SPS or CPS as described above, which then evolves to a generalized seizure (commonly tonic-clonic as described below).
What it is not	Heart attack. Stroke. Diabetic condition.

What to do	Look for medical identification. Protect from nearby hazards. Loosen ties or shirt collars. Protect head from injury. Turn on side to keep airway clear. Reassure when consciousness returns. Observe how long the seizure (tonic-clonic movement) lasts with a watch or clock. If a single seizure lasts less than 5 minutes, ask subject if hospital evaluation is wanted. If multiple seizures, or if one seizure lasts longer than 5 minutes, call 911. If person is pregnant, injured or diabetic, call for 911 for aid at once.
What NOT to do	Don't put any hard implement in the mouth. Don't try to hold the person's tongue—it can't be swallowed. Don't try to give liquids during or just after seizures. Don't use artificial respiration unless breathing is absent after muscle jerks subside or unless water has been inhaled. Don't restrain.
GENERALIZED TONIC-CLONIC (Old Term: Grand Mal)	
What it looks like	Stiffening (tonic) of limbs/body, and often a cry (caused by air forced through contracted vocal cord). Limbs may be extended, flexed, or each in succession. This phase is followed by muscle jerks, shallow breathing or temporarily suspended breathing, bluish skin, possible loss of bladder or bowel control. Usually lasts a couple of minutes. There may be deviation of the eyes or head to one side. There may be drooling or foaming resulting from lack of swallowing and excessive salivation. There may also be biting of the tongue, cheek, or lip causing bleeding. Normal breathing then starts again. There may be some confusion and/or fatigue lasting minutes to hours followed by return to full consciousness.
What it is not	Heart attack. Stroke. Diabetic condition.
What to do	Look for medical identification. Protect from nearby hazards. Loosen ties or shirt collars. Protect head from injury. Turn on side to keep airway clear. Reassure when consciousness returns. Time the event If single seizure lasted less than 5 minutes, ask the person if hospital evaluation is wanted. If multiple seizures, or if one seizure lasts longer than 5 minutes, call 911. If person is pregnant, injured or diabetic, call 911 at once.
What NOT to do	Do not put any hard implement in the mouth. Don't try to hold tongue—it can't be swallowed. Don't try to give liquids during or just after seizures. Don't use artificial respiration unless breathing is absent after muscle jerks subside or unless water has been inhaled. Don't restrain.
TONIC	
What it looks like	Prolonged stiffening of both upper and/or lower limbs; often occurs during

	sleep, usually lasting seconds. There may be deviation of the head and/or eyes to one side. Lips may turn bluish; breathing may be irregular. Loss of bladder or bowel control may occur.
What it is not	Heart attack. Stroke.
What to do	Turn on side to keep airway clear. Time the event and call 911 if seizure is longer than 5 minutes. Seek medical help if individual has repeated tonic seizures and/or is unresponsive after the seizure has stopped. If this is the first observation of this type of seizure, a medical evaluation is recommended.
What NOT to do	Do not put anything in the mouth during the seizure.
ATONIC (also called Drop Attacks)	
What it looks like	The individual suddenly loses postural tone, which may result in a head nod or jaw drops (milder form), or falling to the ground (stronger form). Consciousness is usually impaired. The individual usually recovers after a few seconds to a minute.
What it is not	Clumsiness. Normal childhood "stage." In a child, lack of good walking skills. In an adult, drunkenness, acute illness.
What to do	No first aid needed unless seizure is severe enough to cause injury. If this is a first-time occurrence, a thorough medical evaluation is recommended.
What NOT to do	Not applicable.
MYOCLONIC SEIZURES	
What it looks like	A sudden, involuntary, brief shock-like muscle contraction that usually involves both sides of the body, with synchronous jerks most often affecting the neck, shoulders, upper arms, body, and upper legs. May cause person to spill what they were holding or fall off a chair.
What it is not	Clumsiness. Poor coordination. Nervous tics.
What to do	No first aid needed, but should be given a thorough medical evaluation.
What NOT to do	Not Applicable
ABSENCE (may be Atypical)	

What it looks like	Stare may begin and end gradually, usually lasts 5-30 seconds and is not generally provoked by hyperventilation. Child may be partially responsive during episode. Eye-blinking or slight twitching movements of the lips may be seen. Children with this type of seizure often have global cognitive impairment; therefore, it may be difficult to distinguish a seizure from the child's usual behavior.
What it is not	Daydreaming. Lack of attention. Child deliberately ignoring adult instructions.
What to do	No first aid necessary, but if this is the first observation of the seizure(s), medical evaluation should be recommended.
What NOT to do	Not applicable.
GELASTIC	
What it looks like	Sudden outburst of laughing or crying for no apparent reason. Usually last for less than one minute. During or shortly after seizure the individual may display some twitching, lip smacking, strange eye movements, fidgeting or mumbling.
What it is not	Intentional laughing or crying, mental illness.
What to do	No first aid is necessary, but if this is the first observation of the seizure(s), medical evaluation is recommended.
What NOT to do	Not applicable
THE FOLLOWING TYPE OF SEIZURE RARELY OCCURS IN INDIVIDUALS WITH TSC	
TYPICAL ABSENCE (Old Term: Petit Mal)	
What it looks like	A blank stare, beginning and ending abruptly, usually lasting 3-20 seconds, most common in children (usually 4 to 14 years old) and usually resolves by 18 years of age. May be accompanied by rapid blinking, some chewing movements of the mouth. Child is unaware of what's going on during the seizure, but quickly returns to full awareness once it has stopped. Typical absence seizures are often provoked by hyperventilation. Children with this type of seizure usually have normal development and intelligence. May result in learning difficulties if not recognized and treated.
What it is not	Daydreaming. Lack of attention. Child deliberately ignoring adult instructions.

What to do	No first aid necessary, but if this is the first observation of the seizure(s), medical evaluation should be recommended.
What NOT to do	Not applicable.

Children with TSC may have mixed seizures such as atypical absence, tonic and generalized tonic-clonic, myoclonic, or atonic seizures. This condition is called Lennox-Gastaut syndrome, and many of these children may have a history of infantile spasms who later transitioned into this syndrome.

References & Resources

Epilepsy Information http://www.epilepsy.com

Thiele EA, Weiner HL (2010) Epilepsy in TSC, In, *Tuberous Sclerosis Complex: Genes, Clinical Features, and Therapeutics,* DJ Kwiatkowski, VH Whittemore, EA Thiele, Editors, Weinheim: Wiley-Blackwell, pp. 187-210

The Treatment of Epilepsy: Principles and Practice, Ed. Wyllie E, Ed. Malvern, PA: Lea & Febiger, 1993

Pediatric Epilepsy Diagnosis and Therapy, 2nd Edition. Pellock JM, Dodson WE, Bourgeois BF Eds. New York, NY: Demos, 2001.

Reviewed and updated by Susan Koh, MD, Co-Director of the TSC Clinic at the University of Colorado, Denver, February 2011.