From Dr. Escudé...

Seizures in People with Intellectual and Developmental Disabilities (IDD)

Seizures in people with IDD can be severe, complex and quite difficult to manage. People with IDD sometimes have limited ability to communicate with words and may communicate through various behaviors. Behaviors that result from a medical illness or a medication side effect may be misinterpreted as a psychological problem, and a person may be started on a psychotropic medication in an attempt to control the behavior which may actually worsen things.

Seizures can present as various atypical behaviors in people with IDD including:

- Disrobing
- Increased agitation
- Failure to “pay attention” in children or “daydreaming”
- Sexually acting out
- Physical or verbal aggression with no antecedent
- Repetitive or ritualistic type behaviors that are short lived
- Rapid eye blinking
- Tantrums
- Falls
- Sudden “sleep”
- Random talking
- Being “hard to reach”

Many seizure medications have side effects and complications that may present as adverse behaviors in people with IDD, such as:

- Medication refusal as the person has learned that every time they take the medication, they feel bad
- Pocketing or “Cheeking” medications because of feeling poorly after taking them
- Refusal to eat due to nausea
- Urinary or fecal incontinence
- Constipation
- Urinary retention
- Agitation and/or Aggression due to the medication or to the ill effects
• Fatigue, especially with sedating medications
• Weight gain or loss
• Scratching one’s self as a sign of a possible allergy even if no rash is present
• Falls due to sedation, dizziness or other balance or cognitive impairment
• Change in cognitive status
• Less verbally interactive
• Tics, dystonic symptoms or muscle twitching, especially with medications known to cause extra-pyramidal symptoms (EPS) or signs of tardive dyskinesia (TD)

General medication prescribing guidelines include:

• Starting low and going slow
• Rule out precipitating factors for increased seizure activity such as constipation or a medical illness before adding or increasing a seizure medication
• Maximize med dosage/level before declaring it a failure
• Slow induction as well as tapering of meds
• Have staff monitor for ANY changes for several weeks when a medication is added or increased
• Once someone has failed 2-3 adequate medication trials, consider surgical options such as a Vagal Nerve Stimulator (VNS)

Other considerations:

• Utilize a neurologist to assist with management of complex seizures and consider an epileptologist where available.
• Utilizing a seizure record for documentation of seizure time, date, length, characteristics and post-ictal symptoms can be extremely helpful.

Thanks for your careful attention to helping those we support live as healthy a life as possible.

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Dr. Escudé has dedicated his career to providing healthcare for people with IDD and other vulnerable populations and teaches on the subject throughout the country.