

OASIS · AT A GLANCE

Epilepsy and Seizure Safety in Autistic Adults

Seizure types, adult-onset risk, medication interactions, and the safety planning that protects the highest-risk daily activities: bathing, sleeping, cooking, driving. The risk is well-documented; the safety planning often is not.

BY JIM PALASTY · OASIS FOR AUTISM · 10 MIN READ

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IN 5 ADULTS

Approximately one in five autistic adults develops epilepsy by adulthood. The relative risk is many times the general population baseline. The clinical literature is consistent.

How it works

THREE STEPS

Know the signs

Convulsive, absence, focal, atypical. Many seizures in adults look nothing like the stereotyped grand mal. Train the family to recognize all forms.



Neurology + EEG

First seizure or any suspected seizure triggers a neurology referral. EEG, MRI, medication discussion. The workup is standardized.



Safety planning

Bathroom safety. Sleep safety. Kitchen safety. Driving decisions. Each high-risk activity gets its own plan, in writing, before the next seizure.

Safety planning by high-risk activity

Bathroom	Walk-in shower over tub; non-slip floor; door unlocked; person nearby
Sleep	Anti-suffocation pillow; firm mattress; seizure monitor optional
Kitchen	Induction cooktop over gas; supervised cooking; pre-prepared meals
Driving	Per state seizure-free-period law; medical clearance; alternatives
Swimming	Active supervision; never alone; lifejacket; shallow water only
Stairs	Handrails both sides; non-slip treads; supervised in early days
Public	Medical ID; emergency contact in wallet; rescue medication if prescribed

WHAT IT LOOKS LIKE

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Our son had his first seizure at twenty-three. The ER called it provoked and discharged us. The neurologist saw him eight weeks later and ordered the EEG that found the underlying activity. Two seizures and one ER trip happened between the first event and the neurology appointment. We did not know to push for an earlier appointment. We did not know to start safety planning before the diagnosis. We do now. The bathroom door has not been locked in nine years.

THERESA, MARQUETTE

What matters, at a glance

Elevated lifetime risk

Multiple peer-reviewed studies (Tuchman, Spence, Bolton et al.) document epilepsy prevalence in autistic adults at approximately one in five by adulthood, compared with roughly one percent in the general adult population. The risk profile is real.

Seizures are not always dramatic

Absence seizures: brief staring spells, sometimes seconds long. Focal seizures: localized motor or sensory symptoms without loss of consciousness. Many adult-onset seizures look like a moment of confusion, not a convulsion.

Adult-onset is common

Epilepsy in autistic adults can present in early adulthood, mid-adulthood, or later. The risk does not peak only in childhood. New seizure-like events in adults warrant immediate neurology referral, not "wait and see."

Sleep safety matters

Sudden Unexpected Death in Epilepsy is a documented risk; sleep is the highest-risk period for many seizure types. Anti-suffocation pillows, seizure monitoring devices, and bedroom safety planning reduce risk.

Medication interactions

Anti-epileptic drugs interact with psychiatric medications common in autistic adults. The neurologist needs the full medication list. Drug-drug interactions are the source of many treatment-resistant cases.

Driving and water

Driving decisions follow state seizure-free-period laws. Bathing and swimming require active supervision or modified routines. Both are high-impact safety conversations that should happen early in diagnosis.

BRING THESE · CHECK AS YOU GO

☐ Neurology appointment scheduled

☐ Complete medication list compiled

☐ Sleep safety setup complete

☐ Driving status per state law confirmed

☐ Rescue medication protocol (if prescribed)

☐ EEG and MRI ordered

☐ Bathroom safety adaptations made

☐ Kitchen safety reviewed

☐ Medical ID worn

YOUR MOVE

From first event to stable safety plan

1

Any first or suspected seizure: ER first if active, neurology referral within a week, EEG and MRI scheduled.

2

Start safety planning before the diagnostic workup completes. The risk is present even while diagnosis is pending.

3

Implement bathroom, sleep, and kitchen safety adaptations within seven days of the first event.

4

Bring the complete medication list to the neurology appointment. Anti-epileptic drug choice depends on it.

5

Calendar a six-month review for medication efficacy, side effects, and any new safety considerations.

Epilepsy is common in autistic adults. Most of it is treatable. The safety planning that supplements treatment is the difference between a manageable diagnosis and a catastrophic one.

RESOURCES NAMED IN THIS POST

oasisforautism.com · <https://oasisforautism.com>

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