

Neurodevelopmental Disorders and Epilepsy: Parent Checklist



Red flags that need prompt attention

- Sudden behavior changes or “spells” that might be seizures
- Regression in speech, social skills, or learning
- Severe sleep disruption affecting daytime function
- Aggression or self-injury that puts anyone at risk



Watch for early signs

- Behavior challenges that feel “out of proportion” for age
- Trouble focusing or sitting still
- Speech or language delays
- Social delays, isolation, or trouble with peers
- Learning struggles that persist despite effort
- Sleep problems: hard to fall asleep, frequent waking, daytime sleepiness



Start the evaluation process

- Tell your child's neurologist and pediatrician what you're seeing, with examples
- Ask for referrals for developmental evaluation
- Contact your school district to request an evaluation under “child find”
- If under age 3, self-refer to your state's early intervention program



Prepare for the evaluation

- Write a short developmental history and your top concerns
- Gather school work samples, IEP/504, report cards, teacher notes
- List all medications, doses, and any side effects you notice
- Bring videos of behaviors, “zoning out,” or unusual movements
- Ask which standardized tools will be used and what they mean



Ask about genetics

- Request genetic testing if your child has a history of seizures plus developmental challenges
- Discuss which test is appropriate: chromosomal microarray, whole exome sequencing, or whole genome sequencing



Keep seizure control front and center

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Track medication effects

- Log mood, sleep, attention, appetite, and school performance weekly
- Share side effects with the prescribing doctor; ask if dose or med changes could help
- Change only one variable at a time when possible
- Make sure school and evaluators know about recent med changes



Start therapies that match your child's needs

- Behavior therapy plan in place (ABA-based or developmental approaches like PRT, DIR/Floortime, JASPER)
- Speech-language therapy for communication and social language
- Occupation therapy for sensory regulation, fine motor, self-care
- Social skills practice in groups or structured settings
- Home carryover plan with simple daily practice goals



Support sleep and behavior

- Create a consistent bedtime routine and sleep environment
- Screen for pain, anxiety, or sensory overload when behaviors spike
- Ask about safe sleep and behavior supports, including medication if needed
- Reassess plan if sleep or behavior worsens or school reports new issues



Get school services in place

- Request an IEP or 504 evaluation in writing if not already in place
- Ask for needed services: SLP, OT, PT, behavior support, social skills
- Ensure a Seizure Action Plan is on file with the school nurse
- Add accommodations for attention, processing speed, and transitions
- Include a Behavior Intervention Plan if behaviors affect learning
- If ABA-style support is needed for progress, ask the district about contracting provided



After epilepsy surgery; update supports

- Request a multidisciplinary re-evaluation 6 - 12 months post-op) or sooner if needs change)
- Revise IEP/504 to reflect current strengths and challenges
- Coordinate between neurology, therapists, and school to align goals
- Monitor fatigue, processing speed, and emotional changes during recovery





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Build your care team and your records

- List of core providers with contact info and roles
- Shared goals across medical, therapy, and school teams
- Central binder or digital folder with reports, IEPs, test results, meds list
- Monthly "what's working/what's not" summary to share at appointments



Quick questions to bring to appointments

- Which evaluations should we do first and why?
- How do these results change our therapy or school plan?
- What is the plan for sleep and behavior support?
- Should we pursue genetic testing now?
- How will we measure progress over the next 3 - 6 months



Use trusted resources

- Take our IEP course, read our School and Learning web page
- Print our (Almost) Everything List for funding and services
- CHADD website for ADHD Education
- Reading Rockets for executive function strategies
- Autism Treatment Network sleep resources
- Explore impactful patient advocacy group resources, like the LGS Foundation and TSC Alliance
- Watch videos and webinars on our YouTube channel

