

# A Parents' Guide

When Seizures Are Not the Only Problem —  
Learning and Developmental Issues



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This book is written primarily for families whose children have epilepsy. However, much of the information also applies to children who do not have epilepsy, but who have other diagnoses, including learning disabilities, autism, speech delays, and mental retardation. We hope that this information will be helpful for parents of those children as well.

Each state has different rules and programs for children with health issues or disabilities. Please be sure to discuss these issues and any concerns you may have with your health care provider.





### **Good seizure control — What is next?**

It is common for families of children with epilepsy to focus on seizure control. However, all children with chronic illnesses (such as diabetes, cardiac disease, asthma, cancer, and epilepsy) have a higher risk of associated learning, behavioral issues, and family issues. This is especially true in children with epilepsy. In fact, the families of children with epilepsy are often more stressed and experience more difficulties than do the families of children with other chronic illnesses.

Once the seizures are under control with medications, the families are so happy that they feel they must ignore and simply tolerate the other problems. Families may also feel that their medical team can not assist them with these associated problems (learning, behavioral, and family issues).

On the contrary, families should be encouraged to discuss these issues with their providers and to understand that the earlier the problems are addressed, the sooner a plan can be set in place to solve the issues. Health care providers are very familiar with the diagnosis and treatment of learning and behavioral issues and are not the least bit annoyed by conversations about them. If they are not comfortable solving these problems, they will refer you to the proper person for help.

We will first discuss what issues may be present, then some common diagnoses, and finally how to work with the educational and medical systems to obtain help.

## To whom should I talk about my child’s development?

### Am I worrying unnecessarily?

If you have any concerns at all about your child’s development — no matter how minor — be sure to discuss them with your medical team. It is important to start services and therapies as early as possible, so that your child can reach his or her full potential. There are many warning signs of potential problems.

### Who is helping my child?

The medical team, which consists of doctors, nurse practitioners, physician’s assistants, nurses, social workers, and others, is interested in looking at the whole child, along with his or her environment. This holistic approach involves the immediate family, extended family, friends, the school, the community, and the social setting in which the child lives.

### What kinds of problems might I see?

Problems present themselves differently depending on the age of the child.

#### Main problem categories are:

- Delays in motor development
- Delays in speech development
- Behavioral issues
- Problems with learning
- Problems with attention

These problems may eventually be given a label or a diagnosis. These diagnoses will be discussed in depth later.

## Motor problems

Motor problems may be noted in your baby or child. In young babies there may be an asymmetric Moro or startle reflex — that is, one arm or leg reacts more when startled, or the child moves one hand or leg more than the other. In slightly older infants, there may be subtle delays in meeting developmental milestones — such as rolling over, sitting, crawling, and walking.

#### The developmental milestones for most children are:

Age	Fine/Gross Motor Skills	Social/Verbal Skills
1-2 months	Moves all limbs	Smiles
3 months	Reaches for objects, starts to hold up head, begins to roll side to side	Laughs, babbles, coos
6-9 months	Transfers objects with hands, sits, creeps	
10 months	Crawls, stands with support	Says mama, dada, plays peekaboo
12-18 months	Walks alone	Points to what is wanted
2 years	Runs, climbs	Combines two words
3 years	Copies circle, throws, catches, kicks ball, pedals tricycle, stands on one foot	Knows name, talks in sentences, follows two commands

These are normal developmental ranges. If your child’s development seems different, be sure to discuss it with your medical provider.<sup>1</sup>



As the child becomes older, parents may notice that the child limps, walks on his or her toes or uses one hand more than the other or holds it in an awkward position. Children under the age of two should not show a hand preference. These findings are always abnormal and require attention from your medical team.

### **Speech problems**

There may be problems with speech — either expressive (talking) or receptive (understanding) speech. Expressive speech delays are diagnosed when a child is not using any words, not using sentences, or having articulation problems (sounds garbled or stutters). Receptive problems occur when there is poor eye contact, the child does not smile or laugh, does not respond to his or her name, does not listen or, in toddlers, does not point.

### **Attention problems**

In older children, parents may receive complaints from teachers. The teachers may note that the child is not completing work, is not listening, is not learning at the same pace as the rest of the class, or is having issues with retaining information (memory issues). (This will be discussed in depth later on.)

### **Behavior problems**

In some children, parents and teachers may identify behavioral issues, such as temper tantrums (that are more frequent or severe than what is normally expected at that age), or difficulties with aggression towards other people. These behaviors may include biting, spitting, hitting, kicking, or anger. There may even be withdrawal or symptoms of depression. It is always important to take into consideration normal behavior at each stage of your child's life. For instance, two- and three-year-olds are often "hyperactive" and teenagers may normally be moody and withdrawn from their parents.

### **Feeding issues**

Some children may have feeding problems. In infants, this may be a problem weaning off the bottle, changing to solid foods, resisting new foods or textures, or a monotonous diet. There may be swallowing problems. In older children, these problems are usually behaviors like refusing to eat new foods or certain textures, or eating a limited diet.

## Why do these problems occur?

Of course, the first question asked by many parents is “Why is my child having these problems?”

*The medical team tries to answer this question by asking about the family’s history:*

- Was it a normal pregnancy?
- Were there any problems during the delivery?
- Is there anyone else in the family who has similar problems?

*Certain problems may be caused by:*

- Pregnancy problems
- Birth issues
- Genetic issues
- Metabolic problems
- Brain abnormality
- Unknown
- Familial

In some cases, the history, together with the child’s appearance, may prompt the clinician to order genetic testing. This looks for diseases or syndromes that are caused by defects in the child’s genetic makeup. Often, there is no answer to the question, “Why?”

## What else can cause these problems in a child with epilepsy?

### Double-checking seizure control

Many times, when there are behavioral or learning issues in a child with epilepsy, the medical team will first want to make sure that the seizures are fully controlled. Seizures in sleep, abnormal EEG readings, or recurrent seizures throughout the day may influence learning and cognition. When the child exhibits these symptoms, a 24-hour video EEG may be ordered by the medical team.<sup>2</sup>

## Side effects of the epilepsy medications

When children suddenly develop behavioral problems it is common to think that the issues may be side effects of the medication they are taking to control their seizures. In reality, medications used for epilepsy have fewer side effects than over-the-counter cold preparations. The most common side effects associated with anti-epileptic medications are effects on processing speed and attention. There may be more side effects if the child is on more than one medication. However, all medications do have side effects and it is important to consider these. Every side effect must be listed in the package labeling — even if, in the past, only a few of the people taking the medication experience the side effects. If you think your child is experiencing a side effect, it is important to speak to the medical team before discontinuing the medication. Also, do not assume that every problem is related to a side effect — some symptoms may just be coincidental.

*When a person begins taking medication for his or her seizures, the physician takes several things into account, including:*

1. The effectiveness of the medication for the particular type of seizures (or seizures)
2. Whether or not the medication is available in a child-friendly form (liquid or chewable)
3. How easy the dosing regimen is (once or twice a day rather than three or four times a day)
4. Tolerability (side effects and interactions with other medications)

Health care providers know that behavioral problems are common in children with epilepsy, so we avoid using anti-epileptic medications that may exacerbate existing behavioral problems or create new ones.<sup>3,4</sup>



## What are the diagnoses that are common in children with epilepsy?

*Diagnoses associated with epilepsy include:*<sup>5</sup>

- |                       |                           |
|-----------------------|---------------------------|
| 1. Cerebral palsy     | 4. Learning disabilities  |
| 2. Mental retardation | 5. Speech language delays |
| 3. Autism             | 6. Behavioral issues      |

None of these diagnoses requires medical tests, such as MRIs, PET scans, or CT scans. These tests may, however, be ordered by some medical providers to identify causes of the problems.

## What is cerebral palsy?

Cerebral palsy is a non-specific term used to describe a disorder in muscle function that is characterized by changes in muscle tone (hypertonia or hypotonia) as a result of brain dysfunction. It is present at birth and does not worsen with time. Symptoms may include spasticity (stiffness), involuntary movements (chorea, athetosis), ataxia (balance/coordination difficulties), or a combination of the above. The description of each symptom can be found below.

## Spastic cerebral palsy

There are different categories of spastic cerebral palsy. Sometimes the following descriptive words are used by the medical team:

1. **Diplegia** — the legs are more involved than the arms (most common)
2. **Quadriplegia** — the legs and arms are equally involved
3. **Hemiplegia** — one side of the body is involved, with the arm often more involved than the legs (least common)



## Movement disorders associated with cerebral palsy

1. **Ataxia** — the inability to make smooth, accurate, coordinated movements
2. **Chorea** — continuous random movements
3. **Dystonia** — abnormal muscle contractions that lead to jerking, twisting, spasms, and stiffening at rest or during attempts at movement
4. **Spasticity (hypertonia)** — increased muscle stiffness that worsens with rapid movement and may be associated with increased reflexes and stiffness
5. **Low muscle tone (hypotonia)** — these children appear a little “floppier” or “looser” than usual and may drool, be late walkers, speak late, or articulate poorly

Mild hypertonia and hypotonia may be present without a diagnosis of cerebral palsy.<sup>6</sup>

## What is mental retardation?

Mental retardation is impaired intelligence with significant impairment of learning abilities and skills. The child does not attain full intellectual skills when compared with other children of the same age. This results in significant difficulties in the activities of daily living — like school, hygiene, work, and keeping a house (when they get older).

## How can one tell if a child is mentally retarded?

Testing is done using standardized tests, including the Bayley Scales of Infant Development, the Stanford-Binet Intelligence Scale, and the Wechsler Scales. These determine the child’s IQ (intelligence quotient). The IQ is used as a measure of individual intelligence when compared to that of the general population.

An average IQ is 100, with a range of 90-110. Persons with an IQ of 80 are considered to be of normal intelligence.





### **What are autism and PDD (pervasive developmental disorder)?**

Autism and PDD are disorders characterized by impairments in socialization and communication. They are associated with restricted patterns of interest and usually are first noted around the age of two. There is a lack of social and language development and limited interpersonal interaction. Children with autism and PDD may be easily disturbed by the slightest change in environment and have repetitive self-stimulatory behaviors such as rocking, head banging, or flapping of hands. They also have a limited repertoire of interests and activities. Autism and pervasive developmental disorder are on the same continuum, but PDD has less severe symptoms.

The language of children with PDD and autism may range from none (non-verbal) to difficulties with pragmatic language (carrying on a conversation). Language problems may include use of jargonizing (gibberish), repetitive language, and echolalia (repeating words or phrases). It is very important that any child with speech delays be evaluated to determine that other autistic characteristics are not present.

Diagnosis is made by using standardized scales, such as the CARS (Childhood Autism Rating Scales). Neither autism nor PDD are diagnosed by using MRIs or any other medical test. The only test that may be ordered for children with autism when there is a language regression (loss of language or behavior) is a video EEG (electroencephalogram). This determines whether or not there are abnormal electrical discharges in their brains that may be contributing to the language delays.<sup>7</sup>

## Signs That Autism May Be Present

Poor eye contact

No words by two years old

No pointing by twelve months

Restricted play — lining toys in rows, fixating on parts of toys, same play over and over, sorting toys by color or size

Lack of interest in other children

Excessive interest in twirling objects — fans, etc.

Overly focused on unusual objects — pieces of string, hair, wheels

Abilities beyond what would be expected at their age — reading at a very young age, memorizing train schedules or subway lines

Cannot carry on a conversation

Echoes what other people say or repeats what he or she is saying

Regression — loss of language or behavior

Self-abusive behavior — hitting self, biting self

Self-stimulatory behaviors — flipping light switches on and off, overly focused on water play, watching same videos over and over

No sentences by three years old

Speaking gibberish

Speech not understood by people outside the family

Children with speech delays, autism, and PDD should be evaluated by a professional to determine exactly into which category they fall. Some children who initially are diagnosed with autism or PDD may eventually be left with only a speech delay and/or a learning disability, if they receive early, intensive therapy. Autism and pervasive developmental disorder are treated by early, intensive therapies that focus on socialization and communication.

### *Available therapies include:*

- 1. ABA (Applied Behavioral Analysis or Lovaas or Discrete Trials)** — focuses on teaching children how to learn by using 1:1 intervention to develop skills
- 2. Floor Time or Greenspan** — targets personal interaction to facilitate mastery of skills by integrating therapies for motor, speech, etc.
- 3. TEACCH (Treatment and Education of Autistic and related Communication-handicapped CHildren)** — provides strategies to support the person throughout the lifespan and facilitates autonomy
- 4. PECS (Picture Exchange Communication System)** — helps children spontaneously initiate conversation and understand the function of communication

### **What is an expressive speech delay?**

A speech delay can be either expressive or receptive. Receptive delays are difficulties with understanding language (see section on autism). Expressive delays are difficulties with creating speech and being understood by others. Examples are articulation problems and apraxia. Apraxia is a speech disorder in which articulation is normal but the person has trouble saying what he or she wants to say correctly and consistently.

## What is a learning disability?

A learning disability is present when a child with normal intelligence has a deficit in acquiring the skills needed to perform a specific cognitive task. Learning disabilities are life-long.

### *There are several types of learning disabilities:*

**Dyslexia** is difficulty learning to read despite adequate intelligence, sociocultural opportunity, and conventional instruction. People who are dyslexic may be taught to read accurately, but may never read fluently — that is, smoothly and with good comprehension.

**Dyscalculia** is trouble with arithmetic — particularly calculations, like the multiplication tables, simple addition, and subtraction.

**Dysgraphia** is characterized by writing disabilities. Words may be written wrong, misspelled, or letters may be inappropriately sized or spaced.

**Dyspraxia** is a specific disorder in the form of motor skill development. People with dyspraxia have difficulty planning and completing intended fine motor tasks.<sup>8</sup>

A **nonverbal learning disability** occurs in children who have difficulty understanding visual or tactile information stimuli and then difficulty organizing that information. They often need information presented verbally (by spoken word).

**Sensory integration disorder** (information processing disorder) is a deficiency in the person's ability to effectively use the information the senses have gathered.

### *Several symptoms are:*

1. **Feeding issues:** not eating certain textures
2. **Wearing only certain clothes:** no zippers, no belts, no labels in shirts or pants, only certain fabrics
3. **Resistance to touch:** liking bear hugs but not light touch
4. **Over or undersensitivity to certain smells or sounds**
6. **High pain tolerance**
7. **High or low activity level**
8. **Resistance to new situations**
9. **Toe-walking**

There may also be difficulties with visual or auditory processing. Sensory integration disorder is treated with intense therapy — usually provided by an occupational therapist and/or in a sensory gym.

There are a lot of different learning disabilities, but what is common to all of them is that the child with a learning disability needs to be taught in a different fashion.

## What are behavioral issues?

Behavioral issues can occur in any child with epilepsy, learning disabilities, autism, speech delays and attention deficit disorder.

### *Behavioral issues include:*

- **Hitting others or oneself**
- **Biting**
- **Wandering**
- **Verbal abuse**
- **Spitting**
- **Pinching**

When behavioral issues occur, it is important to consider the child's age. Behavior that is normal at two is not normal at age ten or twelve. Families and the medical team must also consider the child's environment. These problems are treated by using behavioral modification. More severe symptoms may be treated with medications.



## WHAT IS ADD/ADHD?

Attention deficit disorder, with or without hyperactivity, means that the child (or adult) has difficulty paying attention in situations where attention and focusing is needed. It is diagnosed by using rating scales that are completed by the teacher, the parents, and the child (if the child is old enough to do so).

### *Symptoms must:*

1. Have occurred before the age of seven
2. Been present for more than six months
3. Be present in two out of three settings (home, school, in public)

ADD/ADHD is treated with therapy, behavioral modification, and, in some cases, medication. Some families believe that alternative therapies are useful — although these are not proven.

### *These include:*

- Optometric training
- Metronome training
- Vitamins
- Homeopathic remedies
- Biofeedback
- Diet
- Herbs

### *There are several types of attention deficit disorder:*

- ADHD predominantly inattentive type
- ADHD predominantly hyperactive-impulsive type
- ADHD combined type
- ADHD not otherwise specified

*The diagnosis is based on how many of the following symptoms are present:*

#### **Symptoms of inattention**

- Fails to give close attention to details or makes careless mistakes
- Often has difficulty sustaining attention in tasks or play activities
- Often does not seem to listen when spoken to directly
- Often does not follow through on instructions and fails to finish schoolwork, chores, or duties
- Often has difficulty organizing tasks and activities
- Often dislikes or is reluctant to engage in tasks that require sustained mental effort
- Often loses things necessary for tasks or activities
- Often is easily distracted by external stimuli
- Often is forgetful in daily activities

#### **Symptoms of hyperactivity**

- Often fidgets with hands or feet or squirms in seat
- Often leaves seat
- Often runs about or climbs excessively
- Often has difficulty playing or engaging in leisure activities quietly
- Often is “on the go”
- Often talks excessively

#### **Symptoms of impulsivity<sup>9</sup>**

- Often blurts out answers before questions have been completed
- Often has difficulty awaiting turn
- Often interrupts or intrudes on others



ADD/ADHD is never diagnosed by using tests like MRIs, PET scans, or CT scans. However, some researchers are beginning to use these tests to determine how the brains of people with ADD/ADHD differ from those of people who do not have ADD/ADHD. The medical team may order an EEG (electroencephalogram) if the child is reported to have frequent staring spells or episodes of “zoning out.” This test determines if these staring episodes are actually seizures.

## How do I get help for my child?

If you think your child is not developing at the same rate as other children of the same age, you should first alert your child's medical provider. The next step is to ask for a full evaluation. Depending on your child's age, this is done by one of three agencies.

Age	Agency
Birth to 3 years	Early Intervention (called Birth to 3 in some states) — part of the Department of Health
3-5 years	School District — Committee on Preschool Special Education
5-21 years	School District — Committee on Special Education



## Is my child legally entitled to help?

Two federal laws guarantee the rights of children with disabilities to a free and appropriate education. The first is the Individuals with Disabilities Act (IDEA). In order to receive services under this act, the child must require special education and have a learning disability.

Section 504 of the Rehabilitation Act of 1973 is a civil rights act that prohibits public schools that receive federal funds from discriminating against children with disabilities. Under this law, children who have “other health related problems” can receive accommodations. Both laws ensure that children with disabilities are provided with educational, academic and extracurricular opportunities comparable to those received by children without disabilities.

## How can I arrange to have my child receive an educational evaluation?

*The people who can make a referral are:*

- Parents
- Teachers
- Health care providers
- Other professionals in your child's school
- Judicial officers
- The child — if he or she is over 18 and under 21 years old

The request should be made in writing and is called a “referral”. The written request should be addressed to the chairperson of your school district’s Committee on Special Education or to the school principal (see example below).

If the referral is made by someone else, the parent must consent to the evaluation in order to have the child evaluated. The evaluation includes various assessments and tests that determine what your child’s difficulties are and how they affect his or her participation in a regular school program.

Date

Principal Name  
School or District Name  
Address

Re: Student’s Name  
Student’s Date of Birth

Dear...,

I am writing because I have the following concerns about my child’s school performance (or behavior or difficulty with functioning). My child has difficulties with (...).

For this reason, I am requesting a full psychoeducational evaluation. Please let me know as soon as possible when this will be scheduled. My phone numbers are:...

Yours truly,

Name

Try to hand deliver the letter to the school office and have it stamped with the date received. Then, make a copy for yourself. Otherwise, mail via certified mail, return receipt requested.

## How is my child tested?

If your child is under age three, the agency will come to your home to evaluate; if your child is between the ages of three and five, you will be given a list of sites to choose from to decide where the evaluation will take place; and if your child is five or over, the testing will be done at the public school. All testing must be done in your child’s language.

### Tests usually include:

- Physical examination
- Psychological evaluation
- Social history
- Observation of your child in a school setting
- Speech-language evaluation (if warranted)
- Occupational therapy evaluation (if warranted)
- Physical therapy evaluation (if warranted)
- Vocational assessment (for middle to high school aged students, if warranted)

You must be given a copy of the test results — be sure to ask for them.

After the testing, a meeting is scheduled to discuss the results and plan of intervention.

## Should I be worried about my child being labeled?

The most important concern is to get your child the help that he or she needs. Sometimes, the child improves with therapy and the label no longer applies.



## What questions should I ask about the evaluation?

### *Be sure to ask:*

- When will the evaluation be completed?
- What tests will be done?
- What do the tests measure?
- How will the tests be administered?
- Will the evaluation include a parent interview?  
(This allows you time to discuss your concerns)
- Who will do the evaluation?
- How soon will the results be available?

## How is it determined if my child is eligible for services?

In order for a child to receive special education services he or she must have a disability that affects his or her ability to learn.

### *Preschool children may be identified as having:*

- Autism/pervasive developmental disorder (PDD)
- Hearing impairment
- Other health impairment
- Visual impairment
- Deafness
- Deaf-blindness
- Orthopedic impairment
- Traumatic brain injury

### *Children of school age must be identified as having:*

- Autism/pervasive developmental disorder (PDD)
- Emotional disturbance
- Learning disability
- Multiple disabilities
- Other health impairment
- Traumatic brain injury
- Deafness
- Deaf-blindness
- Hearing impairment
- Mental retardation
- Orthopedic impairment
- Speech or language impairment
- Visual impairment



## What happens after the testing is completed?

The usual sequence of events is that an appointment is set up, testing is done, and then a meeting is scheduled to see what, if any, services the child is eligible for. Early Intervention, the Committee on Special Education, or the Committee on Preschool Special Education arranges a meeting with parents. If the child is eligible for services, the Committee on Special Education creates an Individual Education Plan (IEP) that sets goals for the child and determines exactly what services (for how many hours per week) will be provided.

## Where will my child receive services?

Special education services are provided in a variety of settings.

### *These include:*

- **At home (Early Intervention; sometimes additional services when the child enters preschool, or if the child is unable to attend school)**
- **In a center-based program (Early Intervention and CPSE)**
- **At a public elementary, middle, or high school**
- **At a public school if the child is attending a private or parochial school**
- **In a therapeutic setting or private special education school**

In all cases, services must be provided in the “least restrictive environment.” That is, the child must be educated in the setting that is closest to a regular classroom as possible based on the child’s needs. “Least restrictive environment” also means the environment that places the fewest restrictions on the child’s ability to learn.

The range of services begins with education in a regular classroom setting, with “related services.” These may include speech, occupational, physical therapies, and counseling.

One step more restrictive than this is education in a regular setting with push-in services. In this case, a special education teacher co-teaches and concentrates on the needs of the children in the class who have disabilities. School districts may describe this as an inclusion class or a co-teach class.

The next more restrictive placement is in a “special class” — a smaller class with a lower student to teacher ratio. These usually range in size from ratios of 12 students to one teacher to six students to one teacher. There are usually aides in the classroom — so these classes are commonly called 12:1:2 (students:teacher:aides) or 8:1:2 (students:teacher:aides) classes — depending on the ratio of students to teachers to aides.

One step even more restrictive than this is a state-approved private school or a hospital setting (for those with medical or psychiatric diagnoses).

Special school settings may include autism programs (using the therapies listed in the autism section). There are also intensive day treatment programs, therapeutic support programs, and special schools for those with severe dyslexia or emotional disturbances. In some states, these special classes are housed in public schools. They can also be part of a special private school.

Services can be provided for either 10 or 12 months per year. Those children who are eligible for 12-month programs are usually those who would experience significant regression if not in a program during the summer. Regression means that the child would lose what he or she had been taught.

Make sure that you receive a copy of your child’s IEP (Individualized Education Plan), that all interventions and accommodations are listed, and that they are all provided.

## What happens if my child is not eligible for services?

If your child is tested and found not to be eligible for special education, you can ask for section 504 accommodations. A child is considered eligible for 504 accommodations if he or she has a diagnosis that substantially limits the ability to learn. Diagnoses include ADD/ADHD, Tourette's syndrome, tic disorder, anxiety, and cerebral palsy. Section 504 is a federal civil rights act that prohibits public schools that receive federal funds from discriminating against children with disabilities.

### *Services provided under a 504 Plan include:*

- Extended time for testing (usually one time)
- Testing in a separate location
- Questions read and explained
- Questions read and explained by a teacher from that subject area
- Use of a calculator
- Use of a computer
- Resource room
- Use of a scribe
- Waiving of the foreign language requirement
- Peer tutoring
- Taping of lectures
- Typing of homework
- Homework instructions written in planner or on paper by teacher or aide
- Open-book testing
- Multiple choice instead of short answer questions
- Use of dictionary during tests
- Homework modification

This is called a 504 Plan. It must be reviewed annually and usually requires a letter from a physician stating the diagnosis. Make sure that you receive a written copy of the 504 Plan, that all accommodations and interventions are listed, and that they are all consistently provided.



## What if the testing is done and we are still not sure?

Sometimes, a more extensive testing is indicated — this is called neuropsychological testing and is done by a neuropsychologist. A series of tests is performed, taking approximately eight hours and usually scheduled over several days.

### *Testing is done for:*

- Short- and intermediate-term memory
- Attention
- Expressive and receptive language
- Visual-spatial processing
- Comprehension

This extensive testing is usually not performed by the school district unless there is some special indication for it. The testing may be covered by your medical insurance if your child has a chronic disease, like epilepsy, that may be affecting his or her ability to learn.

## What else can I do to make the school day run more smoothly?

You can talk to the teachers and school administration about other accommodations, whether or not an IEP or 504 Plan is in place.

- Extra time to complete work
- Basing grades on effort as well as on achievement
- Marking student's correct answers instead of the incorrect answers
- Modifying homework
- Allowing student to work on homework while at school
- Giving frequent written and verbal reminders about due dates
- Shortening homework assignments
- Allowing extra-credit assignments
- Using a reward system for effort and behavior
- Seating the child near the teacher
- Verbal cues for when the child will be called on
- Organizational strategies — zippered binders, charts, timelines, organizers
- Use of materials that address the student's learning style
- Use of daily or weekly journal to communicate between home and school
- Set of duplicate textbooks (one set to be left at home)
- Frequent parent-teacher meetings
- Schedule meetings for entire team — therapists, parents, aides and teachers
- Email or mail schedule of assignments to parents

## What happens as my child grows older?

Starting in middle school you should begin discussing long-term plans for your child's education. Options include vocational training, community college, and college. In high school, guidance counselors should inform you of the kinds of programs are available for higher education. There may be work-study programs available through the school. Information about vocational schools is available from The National Association of Trade and Technical Schools and the Vocational Information Center. Some trades also provide apprenticeships.

## What accommodations can be made in high school and college?

*Accommodations can include:*

- Additional time to complete tests, coursework, or graduation
- Substitution or modification of courses
- Adaptation of instruction
- Note-takers
- Use of calculators
- Books on tape
- Persons to read for the student
- Use of computers
- Use of scribe
- Use of recorders



### **What happens when my child reaches age 21?**

It is important to talk to your teen and engage him or her in the process. Make a list of his or her strengths and weaknesses — determine if the strong suit is verbal or if your son or daughter should submit a portfolio of work. Look into college early. Rehearse entrance interviews with any child who is applying to a new school or colleges. Update the child's testing. Get letters from teachers and tutors.

If your child has developmental disabilities, education is provided until he or she reaches the age of 21. This may take place in a high school setting or a post-graduate setting, and it is important to check to see what is available in your state.

If the child will attend college, it is important to work with the CSE and the guidance counselor to see what colleges have programs and support services available for students with learning disabilities or other special needs.

On the other hand, as the child enters adolescence (or sooner), it may become apparent that this child will not go to college but will need some training for employment or assistance with the activities of daily life for the rest of his or her life. There are several organizations that can guide you through this process.

The Federal Administration for Children and Families funds organizations that provide family assistance. The actual services are provided by state and local agencies that differ from state to state and include YAI (Young Adults Institute) in New York, New Jersey, and Puerto Rico; and UCP (United Cerebral Palsy) throughout the United States. Many of the agencies offer a comprehensive network of direct services, including job training and placement, residential services, family support services, recreation, and home health services.

For children with more severe impairments, long-term planning should begin early. There should be a clear plan for guardianship in case of parental death. A trust should be set up (if economically feasible) and guardianship should be sought for anyone who will require supervision after they turn 21. Lawyers should be consulted for this. Social security insurance (SSI) is available for those who qualify.

The laws governing IDEA and section 504 accommodations are constantly changing and it is important to keep up-to-date.

## Conclusion

The myths and prejudices associated with our ignorance of epilepsy, learning disabilities, and developmental disabilities are boundless. It is important that we all work together to overcome the stigma associated with these illnesses. Your most important job is to be your child's advocate to ensure that he or she receives all the services that are needed. It is important to "think outside the box" and be creative when asking for help. Just because the school has not provided certain services in this way in the past, does not mean

that they cannot do so now — be persistent. Teach your child to advocate for him- or herself. The earlier the child can speak up and say, "I learn differently. Teach me in a different way," the easier his or her life will be.

Life with a child with chronic medical problems or any kind of disability is a marathon, and not a race. You may be advocating for your child for your whole life. The most important thing to remember is to never give up.



## Other Sources of Help and Information

### Epilepsy

The Charlie Foundation and Ketogenic Diet Status  
[www.charliefoundation.org](http://www.charliefoundation.org)

Epilepsy Canada  
[www.epilepsy.ca](http://www.epilepsy.ca)

Epilepsy Foundation  
[www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

Freeman J, Vining E, and Pillas D. *Seizures and Epilepsy in Childhood*. Baltimore: the Johns Hopkins Press; 2002.

The Hospital for Sick Children  
[www.aboutkidshealth.ca](http://www.aboutkidshealth.ca)

International League Against Epilepsy  
[www.ilae-epilepsy.org](http://www.ilae-epilepsy.org)

Kutscher M. *Children With Seizures: A Guide for Parents, Teachers, and Other Professionals*. Philadelphia: Jessica Kingsley Publishers; 2006.

Wolf SM and McGoldrick PE. *Parents Guide: When The Seizures Don't Stop... Why — and What to Do Next*. Abbott; 2005 — available from your medical team.

### ADD/ADHD

Barkley R. *Taking Charge of ADHD: The Complete, Authoritative Guide for Parents*.

CHADD  
Children and Adults with Attention-Deficit/Hyperactivity Disorder  
8181 Professional Place – Suite 150  
Landover, MD 20785  
301-306-7070  
800-233-4050  
[www.chadd.org](http://www.chadd.org)

Gaynor S. *Beyond Ritalin*.

Hallowell E and Ratey J. *Driven to Distraction: Recognizing and Coping with Attention Deficit Disorder from Childhood through Adulthood*.

National Institute of Mental Health  
<http://www.nimh.nih.gov/healthinformation/adhdmenu.cfm>

## Learning Disabilities

Academy of Orton-Gillingham Practitioners and Educators  
(Orton-Gillingham is a multisensory approach to reading)  
[www.ortonacademy.org](http://www.ortonacademy.org)

International Dyslexia Association  
8600 LaSalle Road Chester Building — Suite 382  
Baltimore, MD 21286  
<http://www.interdys.org>  
800-ABCD123 (222-3123)

LDA — Learning Disabilities Association of America  
4156 Library Road  
Pittsburgh, PA 15234-1349  
412-341-1515  
[www.ldanatl.org](http://www.ldanatl.org)

National Center for Learning Disabilities  
381 Park Ave South — Suite 1401  
New York, NY 10016  
212-545-7510  
888-575-7373  
[www.nclld.org](http://www.nclld.org)

National Institute for Neurological Disorders  
<http://www.ninds.nih.gov/disorders/apraxia>

## Autism/PDD

Autism Society of America  
<http://www.autism-society.org>

National Institute for Mental Health  
<http://www.nimh.nih.gov/publicat/autism.cfm>

Powers MD, ed. *Children with Autism: A Parent's Guide*.  
Second Edition. Bethesda, MD: Woodbine House; 2000.

## Speech-Language Delays

Agin MC, Geng LF and Nicholl M. *The Late Talker:  
What To Do If Your Child Isn't Talking Yet*.

American Speech-Language — Hearing Association  
800-638-8255  
[www.asha.org](http://www.asha.org)

Childhood Apraxia of Speech Association of North America  
412-343-7102  
[www.apraxia-kids.org](http://www.apraxia-kids.org)

<http://www.nicdcd.nih.gov/health/voice/apraxia>

## Sensory Integration Disorder

Ayers AJ. *Sensory Integration and the Child*.

The KID Foundation  
[www.kidfoundation.org](http://www.kidfoundation.org)

Kranowitz CS and Miller LJ. *The Out-of-Sync Child*.

Sensory Integration International (list of therapists)  
[www.sensoryint.com](http://www.sensoryint.com)



## Behavioral Issues

Greene RW. *The Explosive Child*.

## Medications

Drug Information Online  
[www.drugs.com](http://www.drugs.com)

Each pharmaceutical company has a website with information about each medication. See [www.nameofdrug.com](http://www.nameofdrug.com).

## College/Vocational Training

Brown DS. *Learning a Living: A Guide to Planning Your Career and Finding a Job for People With Learning Disabilities, Attention Deficit Disorder, and Dyslexia*. Bethesda, MD: Woodbine House; 2000.

Nadeau KG. *Survival Guide for College Students with ADD or LD*. Washington, DC: Magination; 1994.

Peterson's Guides. *Colleges With Programs for Students With Learning Disabilities or ADD*. 7th ed. Lawrenceville, NJ: Peterson's Guides; 2003.

The Vocational Information Center  
[www.khake.com](http://www.khake.com)

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3. Bourgeois B. New dosages and formulations of AEDs for use in pediatric epilepsy. *Neurology*. 2002;58(suppl 7):S2-S5.
4. Glauser TA. Behavioral and psychiatric adverse events associated with antiepileptic drugs commonly used in pediatric patients. *J Child Neurol*. 2004;19(suppl 1):S25-S38.
5. Pellock JM. Understanding co-morbidities affecting children with epilepsy. *Neurology*. 2004;62(suppl 2):S17-S23.
6. Cerebral Palsy — Ask the Doctor. Available at: <http://www.about-cerebral-palsy.org>. Accessed July 5, 2006.
7. American Academy of Pediatrics Committee on Children with Disabilities. The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics*. 2001;107(5):1221-1226.
8. LDOnline Web site. Available at: [www.ldonline.org](http://www.ldonline.org). Accessed July 5, 2006.
9. American Academy of Pediatrics. *Clinical practice guideline: diagnosis and evaluation of the child with attention deficit/hyperactivity disorder*. *Pediatrics*. 2000;105:1158-70.
10. The University of the State of New York — The State Education Department. *Special Education in New York State for Children Ages 3-21*.
11. Wrightslaw Web site. Available at: [www.wrightslaw.com](http://www.wrightslaw.com). Accessed July 5, 2006.

## Biographies

### *Patricia Engel McGoldrick, NP*



Patty McGoldrick received a master's degree in Public Administration from New York University and a master's degree in Nursing (with certification as a Pediatric Nurse Practitioner) from Columbia University. She is Associate Director of the Developmental Disabilities Center at Roosevelt Hospital and is in private practice with Steven Wolf, with whom she runs several clinics. She is an adjunct faculty member in the Nursing Departments at Columbia University and New York University. She has co-authored several articles and patient guides with Dr. Wolf. She lives in Westchester County, New York with her husband and three children.

### *Steven Wolf, MD*



Steven Wolf, MD, graduated from Albany Medical School and served his residencies in Pediatrics and Neurology at Montefiore Hospital (the teaching hospital for the Albert Einstein College of Medicine). He completed fellowships in Pediatric Neurology and Epilepsy. He is currently the Director of Developmental Disabilities Center at Roosevelt Hospital, the Director of Pediatric Neurology at St. Lukes/Roosevelt Hospital Center, the Director of Pediatric Epilepsy at Beth Israel Medical Center, and the Co-director of the Epilepsy Monitoring Unit at Beth Israel. He is Associate Professor of Neurology and Pediatric at the Albert Einstein College of Medicine. He is in private practice with Patty McGoldrick, NP, with whom he runs several clinics. He serves on the Professional Advisory Committee and the Board of Directors of the Epilepsy Foundation of New York City. He is the author of a textbook, numerous articles, and several patient guides. He resides in New York City with his wife and two sons.

What dose will we start at?

How often will we increase the medication?

What is the maximum dose?

When would we discuss a change in medications?

What are the side effects?

What is the likelihood that my child will have side effects?

Will blood work or other tests be required?

What do I tell the school?

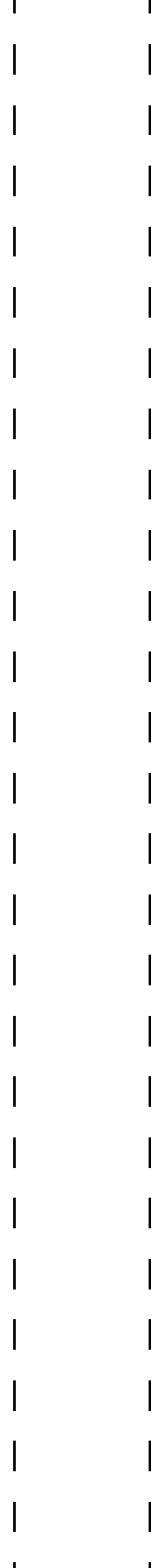
What medications should my child not take with this medication?

Do you have information for me regarding this medication?



Date			
Time			
Duration			
Symptoms			
Brought on by			
Treatment			

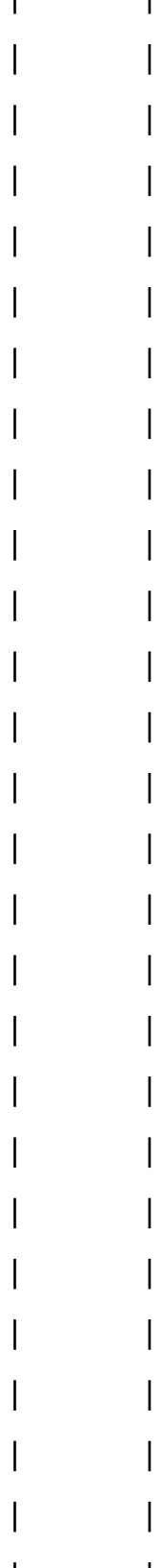
Date	Time	Duration	Symptoms	Brought on by	Treatment



Date	Medication	Dose	# Seizures	Blood level	Side Effect



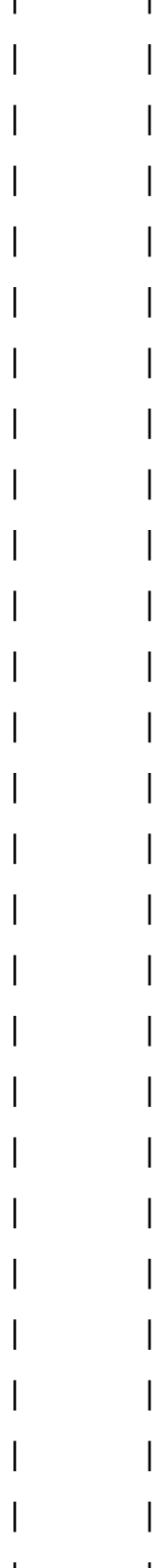
Date	Medication	Dose	# Seizures	Blood level	Side Effect



Doctor	Specialty	Phone	Address	Referred by



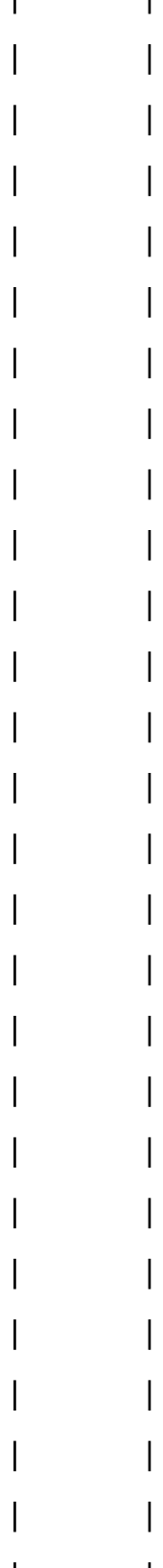
Doctor	Specialty	Phone	Address	Referred by



Name	Type	Phone	Address	Email	Referred by



Name	Type	Phone	Address	Email	Referred by



Name	Address	Phone	Contact	Referred by



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