

ATTENTION DEFICIT HYPERACTIVITY DISORDER AND TUBEROUS SCLEROSIS COMPLEX

IF MY CHILD HAS TSC, DO I NEED TO WORRY ABOUT ADHD?

Attention Deficit Hyperactivity Disorder (ADHD) is a common neurobehavioral disorder. Approximately 3 percent to 5 percent of school age children have symptoms of ADHD that interfere with academic performance. ADHD may be even more common in children with tuberous sclerosis complex (TSC). As many as 25 percent to 50 percent of children with TSC have some of the signs of ADHD. ADHD often accompanies epilepsy and learning disability, and the symptoms of ADHD are usually present in children with autistic spectrum disorders. Perhaps a third of the children with TSC plus epilepsy or TSC plus learning disability will have evidence of ADHD. Though ADHD is not diagnosed in the child with autistic disorder, many children with autism are hyperactive and inattentive.

WHAT ARE THE SYMPTOMS OF ADHD?

The main symptoms of ADHD are hyperactivity, impulsivity and inattention. The hyperactivity and impulsivity usually appear first, often beginning prior to the school age years. Inattention may not be recognized until elementary school. The child with hyperactivity fidgets and squirms, can't stay seated, runs when he should walk, is noisy and excessively talkative, and is often described as constantly on the go. The impulsivity is seen as trouble waiting turns and frequent interrupting. The teenager with hyperactivity and impulsivity feels restless and moves quickly from one task to the next frequently failing to complete projects. The child with inattention has trouble concentrating and is easily distracted, makes frequent careless errors, appears not to listen and seldom completes work, is disorganized and tends to procrastinate, and is forgetful and frequently loses books, homework or clothes. While most people have some of these symptoms some of the time, the person with ADHD has many of these symptoms most of the time.

HOW IS THE DIAGNOSIS MADE?

The criteria for the diagnosis of ADHD are found in the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition* (DSM-IV). It lists nine symptoms of inattention and nine of hyperactivity and impulsivity. To make a diagnosis of ADHD, there must be six or more symptoms of either inattention or hyperactivity/impulsivity present for at least six months. The symptoms should have begun prior to age 7, cause significant evidence of impaired functioning in at least two settings, and cannot be better explained by another diagnosis. If the child has both inattention and hyperactivity-impulsivity, the diagnosis will be ADHD, combined type. If there is inattention but not hyperactivity-impulsivity, the diagnosis is ADHD, predominantly inattentive type. The inattentive type of ADHD is more common in adolescents and adults with ADHD.

The diagnosis of ADHD is made by physicians-including family practitioners, pediatricians, neurologists and psychiatrists-and by psychologists. The physician can also prescribe medication if that is needed for treatment of the child. The psychologist can do further testing to assess learning problems. Child and adolescent psychiatrists are specialists in behavioral disorders and are a good resource if there are questions about the diagnosis.

At this time, there are not specific laboratory tests for the diagnosis of ADHD. The diagnosis is based on the history from the parents and the child's teacher. The professional doing the evaluation will ask about symptoms of both ADHD and other behavioral and cognitive disorders that may accompany or mimic ADHD. Specific questionnaires, such as the Conners Parent Rating Scale and Teacher Rating Scale or the ADHD Rating Scale-IV by DuPaul et al., may be used to help with assessment and to follow response to therapy. Some professionals may use computerized tests such as the continuous performance test to look for evidence of ADHD. Neuroimaging and specialized neurophysiological tests are helping us to better understand ADHD, but are not used routinely for diagnosis.

ARE THERE OTHER PROBLEMS THAT MIGHT LOOK LIKE ADHD?

It is important to be careful in making a diagnosis of ADHD. Almost everyone has occasional problems with forgetfulness, lack of concentration or difficulty sitting still. Some children are temperamentally more active and enthusiastic than the average child. If there is no impairment, the child should not be given a diagnosis of ADHD.

Some children with learning disabilities may appear to have trouble concentrating or paying attention because they

have given up listening to lessons they do not understand or because they have to concentrate so hard to learn that their attention wears out faster. Their failure to complete tasks may be a sign of not knowing how to do the work instead of a sign of inattention. Other children may be bored by work they have already mastered and thus appear inattentive and are disruptive. Learning difficulties can be determined by psychoeducational testing.

Children that are depressed or anxious may have trouble concentrating, sleeping, and have agitation that results in excessive movements. Children with sleep disorders may be fatigued and drowsy during the daytime thus appearing inattentive. Children that are living in a chaotic home and children that are being abused may look distracted and fail to concentrate on schoolwork.

Seizures can sometimes be confused with ADHD. Absence seizures and complex partial seizures may cause repeated episodes of brief loss of attention. If a child has TSC, seizures are always a possibility. Chronic headaches from increased intracranial pressure due to a giant cell astrocytoma can cause lethargy and inattention and should not be confused with ADHD.

Children with TSC may have difficulty paying attention without the other behavioral problems of ADHD. There are several brain networks that control different types of attention. Cortical tubers or heterotopias may disrupt these pathways. A comprehensive neuropsychological assessment may help define the type of problems with attention.

ARE THERE OTHER BEHAVIORAL OR COGNITIVE PROBLEMS THAT ACCOMPANY ADHD?

A child with one behavior problem may well have other troubles. Children with ADHD are at risk for oppositional defiant disorder (ODD), conduct disorder, anxiety disorder, depression, bipolar disorder, Tourette syndrome and learning disability.

Children with ODD refuse to obey, frequently annoy others and are often easily annoyed. They are angry children who have frequent temper tantrums. In comparison, the children with conduct disorder get into trouble for major violations of the rules. They are aggressive towards others, destructive, steal and lie, are truant from school and run away from home. Approximately 30 percent to 40 percent of children with ADHD have ODD or conduct disorder. The children with both ADHD and ODD or conduct disorder are the ones at risk for developing substance abuse or delinquency.

Approximately 20 percent to 25 percent of children with ADHD will have additional problems with anxiety or depression. Fearfulness or excessive worrying suggests anxiety, and sadness or irritability characterizes childhood depression. Bipolar disorder is uncommon but almost all the children who develop bipolar disorder before their teenage years will have symptoms of ADHD. Grandiosity (ostentation), a decreased need for sleep, hyper sexuality, racing thoughts, severe irritability and rapid mood swings are symptoms of bipolar disorder.

Perhaps 25 percent of children with ADHD will have specific learning disabilities. Treatment of the ADHD will not be sufficient to improve their academic performance. These children will require special educational programs to help them learn.

WHAT CAUSES ADHD?

ADHD is caused by a combination of genetic and neurological problems. ADHD definitely is a familial disorder. If a parent has ADHD, approximately half of their children will have symptoms of ADHD.

The evidence for neurological involvement comes from new imaging techniques such as PET scanning and functional MRI. These studies show that patients with ADHD have less activity in the frontal lobes than people with no evidence of ADHD. This is consistent with psychological studies that show problems in executive functioning, tasks that involve the frontal lobes. The executive functions are important in planning, self-control and analysis of behavior, tasks that are difficult for the child with ADHD.

HOW DO YOU TREAT ADHD?

The two methods for treating ADHD are behavioral and medical. Usually both are required for the child with significant problems. Psychosocial treatments involve the child, parents and the school system. The first steps are modifications in the school and training of parents. Basic modifications in school might include reducing distractions, frequent reminders to stay on tasks, help with organization, rewards for attention and concentration and extra time for tests. Parent management training instructs the parents on establishing structure in the child's environment, using effective discipline for impulsive behaviors, rewarding attention, reducing oppositional behavior, promoting positive parent-child interaction and often relaxation techniques to help deal with the parents' stress.

If the child has alienated other people by his impulsive or disruptive behaviors, social skills training may be needed. Some children will benefit from cognitive training in organization, planning and social responses. If the first modifications in the school setting are not successful, the child may need smaller classes or one-on-one instruction. An individualized educational plan is essential for the child with severe ADHD. Many children with severe ADHD will qualify for special educational services under the **Individuals with Disabilities Educational Act** or section 504 of the **National Rehabilitation Act**.

Medication is helpful for the child with ADHD. Parents worry that these drugs are addictive, but truth is that appropriate use of stimulants may help prevent later substance abuse. Parents also expect that their child will be off medication by adolescence. This may happen, but some teenagers and adults may find that stimulants continue to be beneficial and stopping medication leads to difficulties at school or work. Finally, the response to medication cannot be used to determine the diagnosis. Children with ADHD and children without ADHD may have an increase in attention span on stimulants.

The stimulants are usually the first drugs used to treat ADHD. Examples are methylphenidate (Ritalin, Concerta), dextroamphetamine (Adderall, Dexedrine) and pemoline (Cylert). These drugs work in almost 80 percent of children with ADHD. The medication takes effect within 30 minutes. The duration varies by the medication used from an average of four hours for regular Ritalin or Dexedrine, to six hours for Adderall, to 10 to 12 hours for Concerta. The main side effects are decreased appetite and trouble sleeping. Some children complain of headaches, stomachaches, depression or irritability.

If the stimulants are not effective or cause unacceptable side effects, antidepressants can be used. These include the tricyclic antidepressants (desipramine, nortriptyline) and bupropion (Wellbutrin). The antidepressants are effective in 60 percent to 70 percent of children with ADHD. Tricyclic antidepressants may cause dry mouth, constipation, lethargy, increased heart rate and increased blood pressure. Bupropion causes the same side effects as both the stimulants and the tricyclic antidepressants. In high doses, bupropion has caused seizures.

Clonidine and guanfacine have been used to reduce hyperactivity and to promote sleep. They are less effective for improving attention. The main side effects are lethargy, fatigue, and decreased blood pressure.

For the child with TSC and ADHD, extra care must be taken in choosing a medication. Bupropion can lower the seizure threshold. There is a minimal risk of increase in number of seizures with the tricyclic antidepressants. Stimulants do not seem to cause seizures as long as the dose is appropriate. If there is a history of heart problems in TSC, tricyclic antidepressants and clonidine must be used cautiously. The tricyclics can affect cardiac conduction and clonidine can lower the blood pressure.

DO CHILDREN OUTGROW ADHD?

In the past, we thought ADHD disappeared during adolescence. Better follow-up studies have shown that is wrong. Though 30 percent to 40 percent of children with ADHD will improve significantly, approximately half to 60 percent will continue to have some symptoms of ADHD, and an additional 10 percent to 15 percent will have more severe problems. Adults with ADHD do not have the obvious hyperactivity seen with childhood ADHD. Adults more often have restlessness, trouble attending, distractibility and disorganization. They will respond to many of the same therapies used successfully to treat childhood ADHD.

ADHD AND TSC

The symptoms of ADHD and the criteria for the diagnosis of ADHD are the same for children with TSC and children unaffected by TSC. The symptoms of ADHD are more common in children with TSC. Inattention in children with TSC may be caused by ADHD, seizures, central nervous system tumors and hydrocephalus, and by cortical tubers disrupting CNS pathways involved in attention. Children with TSC and epilepsy are at risk for autistic disorder. Autistic disorder may cause hyperactivity and inattention but should not be mistaken for ADHD.

Children with ADHD and TSC are at risk for other problems. Learning disabilities are more common in the child with TSC. Anxiety and depression may accompany a chronic illness and may be more common in children with TSC than unaffected children. The therapy for ADHD is the same in children with TSC with certain cautions. Drugs that lower the seizure threshold and drugs that affect the heart must be carefully monitored. (See the Fact Sheet "Psychopharmacology and the Child With TS".)

One organization that may be helpful in providing additional information is:

Children and Adults with Attention Deficit Disorder (CHADD)

499 NW 70th Avenue, Suite 109
Plantation, FL 33317
(800) 587-3700

Written by David W. Dunn, M.D., and William G. Kronenberger, Ph.D., from the Indiana University School of Medicine.

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