# Helping Parents Make Sense of ADHD Diagnosis and Treatment

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## Introduction

The early months of the new school year are often marked by a familiar tale from parents: "The teacher says he can't come back to school until he sees a doctor and gets medication to help him calm down." Parent reactions to this demand by teachers vary from indignation to concern to a desire for a quick fix. Pediatric nurse practitioners (PNPs) are in a key position to help assure that the child suspected of having ADHD receives a thorough and appropriate evaluation and a comprehensive plan of care. Parent support and education through the processes of assessment, diagnosis, and development of an effective treatment plan are critical elements in achieving good outcomes for the child and family (Selekman & Snyder, 2000). Below are answers for questions parents ask frequently.

## Who Gets ADHD?

ADD/ADHD is the most common psychiatric condition diagnosed in children, affecting about 5-10% of all children, or approximately 1.5 million children (Barkley, 1998). It is more frequent in boys (9.2%) than girls (2.9%) (Baren, 2002). Many people are unaware that it affects adults as well, as many as 6 million (Ingram, 1999). Attention deficit with hyperactivity and impulsiveness affects boys more often than girls, but girls are more likely to have the attention deficit disorder without hyperactivity variant (Gaub & Carlson, 1997). Hence, many girls are not diagnosed until middle school or later when learning tasks become more complex.

## What Causes ADHD?

No one gene or structural abnormality of the brain accounts for the diversity of the ADHD spectrum (Castellanos, 1997). Rather it is believed to result from the complex interaction of genetic, biological, and environmental risk factors (Conners, 2003).

About 25% of children with ADHD have a first degree relative with ADHD (Hunt, Paguin, & Payton, 2001). Other genetic risks include the presence of parental mood and conduct disorders, learning disabilities, and antisocial behavior. Parental substance abuse and smoking may also be markers for risk since many adults attempt to improve their sense of well-being via the effects of alcohol, nicotine, and drugs (Beiderman, et al, 1997).

Biological risks also increase the likelihood of ADHD. Among the known associations are maternal smoking and alcohol use during pregnancy, especially during the first trimester (Biederman, et al., 1998). Preterm labor, impaired placental functioning with resultant impairments in fetal nutrition and growth, as well as impaired oxygenation leading to fetal distress and low birth weight, infections of the central nervous system, seizures, and serious head injury are also associated with a higher incidence of ADHD (Saigal, 2000). Preterm infants, especially those with intraventricular hemorrhages, are at greater risk, as well (Seubert, Stelzer, Wolfe, & Treadwell, 1999).

Exposure to heavy metal toxins such as lead and mercury, as well as exposure to carbon monoxide fumes, are known environmental risks for behavior disorders (Conners, 2003). Poor childhood diet, family stress, and living in poverty further increase the risk (Jakovitz & Sroufe,

1987). Newborn illness and stress from the care environment of the NICU also increase vulnerability to the disorder (Gunnar & Barr, 1998). In addition, children with the extremes of easy and difficult temperament appear to be at greater risk for ADHD and a variety of mood disorders (Conners, 2003).

While ADHD is the result of the complex interaction of a variety of risk factors, each individual's outcome is difficult to predict because of the ability of protective factors to modify the negative effects of risk (Conners, 2003). Certainly, access to high quality health care, adequate family resources to access care, and parent investment in the child all ameliorate the negative impact of ADHD.

**What Exactly is the Problem in ADHD?**

Researchers characterize ADHD as a developmentally sensitive disorder characterized by a delay in maturation of the brain's ability to achieve mastery of self-regulation (Hunt, et al., 2001). The three hallmark impairments of ADHD are inattentiveness/distractibility, hyperactivity, and impulsivity (American Psychiatric Association, 1994). Individual children vary in the degree to which each impairment presents.

The behaviors peers and adults perceive as troublesome are the result of actual physiologic differences in brain functions related to learning, particularly in regard to filtering stimuli and selecting relevant information to which to attend, shifting and sustaining attention, as well as linking new and old information, known as working memory (Castellanos, 1997). Not only do children with ADHD have difficulty inhibiting attending to any and every stimulus and controlling inappropriate motor behavior, they also have difficulty modulating their feelings (Hunt, et al., 2001). Hence, they are also vulnerable to mood disorders as well as the social and academic problems of ADHD (Pliszka, 1998). At the heart of the problematic behaviors are deficits in the quantity and function of neurotransmitters, substances produced in the final stage of neuronal development and differentiation (Gualtieri, 1991).

Neurotransmitters and the receptors with which they interact serve both to actively transmit information as well as to selectively repress transmission of information and motor behaviors that would hinder attention and learning (Castellanos, 1997). Children with ADHD appear to lack adequate norepinephrine with which to initiate arousal and to exhaust their dopamine supplies, which help to sustain attention and filter irrelevant stimuli for the current mental task (Hunt, et al., 2001).

**Do Children Outgrow ADHD?**

Researchers find that the behaviors associated with ADHD do change as the child grows older (Biederman, 1998). For example, dopamine levels that help drive the need for exploration peaks at two years of age in normal children, which is developmentally helpful since very young children lay a strong foundation for learning through active exploration (Castellanos, 1997). Dopamine levels decline thereafter, allowing the child to begin the equally important tasks of learning to attend for longer periods of time and to fit into social expectations by bringing their behavior under voluntary and inhibitory control (Biederman, 1998).

A similar process also occurs for children with ADHD, but with a two-year or more delay. Thus, hyperactivity decreases in as many as 50% of children with ADHD as they grow older. However, there is no developmental improvement in attention deficit noted for either boys or girls (Baren, 2002). About 80% of children continue to exhibit symptoms in adolescence, and 85% or more have functional impairments as adults (Barkley, Fisher, Edelrock, & Smallish, 1990).

**Is ADHD a Problem That Really Needs Treatment?**

The majority of researchers and specialists in the care of children with ADHD spectrum disorders strongly recommend treatment for children with these disorders because they consistently result in social and academic failure (Arnold, et al., 1997). Most children experience at least a 2-year delay in social development and at least a 2-3 year delay in cognitive development. One quarter of all affected children also have learning disabilities in reading, written or spoken language, and math. Many have more than one learning disability (Selekman & Snyder, 2000).

Other mood and behavior disorders also co-exist with the ADHD spectrum. Compared to children without ADHD, children with the diagnosis are more likely to suffer from depression (18%), anxiety (26%), oppositional-defiant disorder (35%), conduct disorder (26%), and significant tics (Pliszka, 1998). About 52% of adolescents with ADHD engage in substance abuse and criminal behavior, 15% in antisocial behavior (Baren, 2002). They are at greater risk as well for MVAs (Baren, 2002). Children with ADHD, who are aggressive or also diagnosed with conduct disorder, are at especially high risk for substance abuse (Hunt, et al., 2001). Consequently, it is best to support children with this diagnosis through their delays in CNS maturation with a treatment plan that includes medication, behavior modification, and cognitive assistance (Arnold, et al., 1997).

**How is ADHD Diagnosed?**

There is no lab or imaging test, nor is there a battery of psychological tests, that reliably diagnose ADHD (Leslie, 2002). Rather, the diagnosis rests mainly on history and ruling out other sources for the troublesome behaviors.

There are many causes of inattentive, impulsive, and hyperactive behavior that need to be considered during each child's evaluation (Selekman & Snyder, 2000). In particular, vision and hearing deficits often lead to behavior that suggests inattention and hyperactivity (Leslie, 2002). If the child is unable to hear directions or to see the blackboard or print in books, they cannot follow what they didn't hear, nor can they respond to things they haven't seen. Vision and hearing assessments are integral first steps in evaluating for ADHD.

Other problems may lie in a mismatch between the child's behavioral style and the characteristics and skill level of a particular teacher (Hinshaw, 1992). Clinicians assess for this by looking for cross-setting display of symptoms in reports from reliable informants (Leslie, 2002). If they occur in only one setting, the chances are great that something about the environment or adults in that situation elicits the undesirable behaviors in the child.

Clinicians also need to explore the quality and stability of the home environment, the appropriateness of developmental expectations of the child, and the caregiving skills and commitment of the parents (Murphy & Barkley, 1996). Stress in the home from financial sources, conflict between parents, recent or frequent moves all affect child behavior for the worse. As women delay childbearing, the likelihood of unrealistic expectations for child behavior may increase for partners used to their independent, orderly, career-focused lifestyle (Woodrich, 2000). Even parents who truly want children may underestimate the challenges growing, changing children present to them. Consequently, the initial appointment in primary care should explore these issues as well as provide for a thorough medical history and physical exam.

**Making the Diagnosis**

The DSM IV criteria for ADHD establishes that a child must display 6 out of 9 possible symptoms of inattention or 6 of 9 symptoms of hyperactivity/impulsivity in order to establish the diagnosis (American Psychiatric Association, 1994). In addition, the child must have had symptoms before the age of 7, they must occur in more than one setting, and there must be clear evidence of significant functional impairment in social, academic, or occupational functioning. The symptoms must not coincide with Pervasive Developmental Disorder (PDD) or a psychotic disorder, or be

more appropriately diagnosed as a mood disorder. Most clinicians are hesitant to make the diagnosis of ADHD prior to 6 years of age because of the wide variability in levels of activity that are considered normal in early childhood but that overlap with the symptoms of ADHD.

The history should include a review of the prenatal, intrapartal, and newborn histories for known risk factors (Selekman & Snyder, 2000). The clinician should also review and refine the family history to identify any genetic and behavioral risk factors. A strong social history should identify sources of stress and support in the home. Gaining a sense of the organizational supports the child receives at home is also an important facet of the social history. Is there a schedule for meals and bedtime? How does the parent help the child to transition from one task to another?

The emphases of the physical exam include careful evaluation for the stigmata of inherited disorders, a thorough neurological exam, and developmental assessment (Leslie, 2002). Often minor anomalies that had been dismissed as insignificant lead to consideration of inheritable disorders marked by behavioral disabilities. Chromosomal testing may be indicated.

Thorough evaluations also solicit information from parents, teachers, coaches, and other adults with whom the child spends a significant amount of time. Standardized screening instruments such as the Conners' Parent and Teacher Rating Scales or Vanderbilt ADHD Diagnostic Parent and Teacher Scales help to not only verify the presence of genuine impairments but also to track the child's progress during treatment (Stein, 2002).

**What About Other Problems?**

No evaluation for ADHD is complete until the existence of co-morbidities receives careful consideration (Pliszka, 1998). A strong family history of depression, anxiety, criminal behavior, or substance abuse should prompt evaluation for psychiatric co-morbidities (Murphy & Barkley, 1996). This may be beyond the scope of the primary care professional and require referral to psychiatric specialists (Leslie, 2002). Discovery of developmental delays or neurological abnormalities during the physical exam demand referral to a neurologist. Psychological evaluation for learning disabilities is necessary if there are academic difficulties (Hunt, et al. 2001).

**Is Medication More Effective Than Other Therapies?**

In 1999, a large, randomized clinical trial of three therapeutic regimens reported in the Archives of General Psychiatry showed that medication alone was as effective as behavior modification or counseling alone. However, the best outcomes were achieved with a combination of therapies, with medication, counseling, and behavior modification combined. A valuable lesson learned from this clinical trial was the efficacy of medication plans that covered 12 hours of each child's day, not just the 6-8 hours usually prescribed by non-specialized physicians in the community.

Helping Parents Accept Medications in the Treatment Plan Medication is the aspect of the treatment plan that is most scary for parents, so much so that they often resist and delay use of medication. Clinicians can minimize resistance by sharing information in a clear and supportive way about the negative consequences of not treating ADHD disorders effectively, as well as honest information on the safety profile of the growing number of medications and their formulations from which they have to select (Stein, 2002).

It is also helpful to explain the four classes of medications most often used in treatment and to explain that the drugs within each class are not all the same (see Stimulant Management Chart located at www.nichq.org/resources/toolkit/). Therefore, it will most likely take time to identify the best medication, and then the best dose, that helps the child without causing undesirable side effects (Stein, 2002). Parents often find it reassuring if the clinician carefully adjusts the

medication in small increments and lets the parent know that this is the approach that will be used. If there is information from the history and behavioral profile of the child that suggests one medication over another, it is best to share that information, particularly if undesirable side effects are more likely.

Because of co-morbidities, many children require treatment with more than one drug. The best treatment plan is to minimize polypharmacy as much as possible while achieving good functional outcomes for the child (Hunt, et al., 2001). The Table lists frequently used classes of medications exemplars and specific information about their best use.

**Other Treatment Plan Elements**

Behavior modification strategies often help the child gain control over annoying aspects of their behavior and to master everyday routines through organizational strategies (Stein, 2002). Reward systems for desirable behavior are also effective. There are an abundance of possibilities and resources on the Internet that parents and children can choose from in order to reach success (see the handout ADHD Resources Available on the Internet located at www.nichq.org/resources/toolkit/). The website www.chadd.org has all of its informational materials also available in Spanish.

Tutoring may also be necessary to help a child achieve academic success, as well as structured study schedules (Stein, 2002). Supplemental doses of medication or the use of extended release preparations often help students do their homework effectively.

Behavioral problems may also leave a legacy of low self-esteem for the child and a high level of stress for the parent (Selekman & Snyder, 2000). Therapy as individuals and a family may help parents and children to renew their bonds of affection and their stores of patience and commitment for the long-term treatment of ADHD. Sleep initiation and maintenance problems often leave both the child and the parents at a coping deficit (Hunt, et al., 2001). In addition, care should be taken to assure a regular bedtime routine and to adjust medication to minimize negative effects on sleep (Selekman & Snyder, 2000).

No discussion of treatment would be complete without acknowledging the plethora of herbal, dietary, and alternative treatments parents may try, often in the hope that they will be safer alternatives to mainstream medications (Chan, Gardiner, & Kemper, 2000). To date, none of these alternatives have received testing in randomized clinical trials that have demonstrated their efficacy in children with ADHD, although several are considered safe by the FDA such as valerian and lemon balm.

Primary care professionals need to hold a frank discussion of treatments, especially herbal and dietary supplements that they may already be using or plan to use in conjunction with traditional therapies. A recent survey showed that 64% of 381 parents of children with ADHD had tried or were currently using dietary and herbal remedies (Stubberfield & Parry, 1999). This is critical in order to ensure avoidance of drug interactions that are dangerous to the child (Fugh-Berman & Cott, 1999). This also provides the opportunity to identify safe informational resources to parents while conveying respect for the parents' desire to help their child.

**Follow-Up and Conclusion**
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No discussion of expectations for care is complete without a clear schedule for regular evaluation of the effectiveness of the treatment as it is initiated (Leslie, 2002). This may involve phone contact between the health professional and parent every three or four days, especially as new medications or dosages of medication are trialed. Once an effective medication regimen and

behavior modification program are in place, children require at least one health visit every six months for evaluation and potential modification of the treatment plan (Selekman & Snyder, 2000). Health professionals should also track the acceptability and effectiveness of other therapies implemented, such as counseling and tutoring. Parents may need assistance to identify their ineffectiveness and support to find alternate providers.

## Conclusion

The National Institute for Child Health Care Quality (NICHQ) web site (www.nichq.org) offers health professionals seventeen tools to assist in making the diagnosis of ADHD, structuring and documenting an effective treatment plan, and assisting parents with behavior modification strategies. In addition, the American Academy of Pediatrics (2001) has published guidelines for the diagnosis, evaluation, and treatment of school-age children for ADHD. Together, these resources provide a solid foundation for structuring effective services for at-risk children and their families.

## Tables

Table. Medications Frequently Used in the Management of ADHD and Its Co-morbidities

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