



## **CHADD and the National Resource Center on ADHD**

### ***Ask the Expert Chat Series***

**September 16, 2010 – Increasing Awareness and Decreasing Stigma of ADHD**

**Moderators – NRC Staff**

**Expert – Marie Paxson, immediate past president, CHADD**

**Moderator 1:** We will begin shortly. Just to remind everybody, this is a moderated chat. All questions go to the moderator for review. We will do our best to post as many of your questions as possible . . .

In recognition of ADHD Awareness Week, today's Ask the Expert chat is "Increasing Awareness and Decreasing Stigma of ADHD." We are excited to announce that our expert this afternoon is CHADD's immediate past President Marie Paxson . . .

Marie Paxson of West Chester, PA, is the mother of two grown children with ADHD. She has spent years advocating for people living with the disorder. Paxson's knowledge of ADHD stems from both her professional and personal experiences. Over the years, she has been on the receiving end of many myths, misconceptions, and judgmental remarks . . .

Sometimes these were handled with diplomacy, sometimes not. It can be difficult to know which approach to take in awkward situations. This chat will discuss how and when to correct untrue remarks and when it is best not to respond. Working together we can increase awareness about ADHD and help shatter the myths and misconceptions surrounding it.

Thank you Marie for joining us! Now for our first question.

**John:** Right off the bat, thank you for your time on this activity. As a person recently diagnosed with adult ADHD, I am often faced with the question from friends / family like, "You didn't have a problem as a kid, why do you have this now?" What is the best way to frame a response to this comment?

**Marie Paxson:** Facing stigma is a really tough situation. There are so many people who don't understand ADHD very well. Depending on how old an adult is now, the diagnosis may not have been very common back then. Baby-boomers for instance, they certainly had the symptoms, but didn't receive accurate diagnosis and treatment.

The trick is to balance whom to tell about your ADHD and how to say it in a way that gives them a better understanding. Can you let me know the type of stigma you are dealing with? Rude comments, or refusal to help you, etc?

**John:** they just don't believe ADHD exists

**Marie Paxson:** One thing that comes to mind is that a lot of people have many supports in place during childhood. They have less responsibilities and manage fewer details. So in some cases, their childhood ADHD was easier to manage.

It is really hard to deal with naysayers, isn't it? One thing I often have to decide is if it is worth my time and energy trying to convince them. Or should I use my time and energy to help manage how ADHD is affecting my family?

We all know people who have strong political views that are different from yours and will not listen to any other points of view. Would your time be better spent managing your ADHD or your child's ADHD instead of trying to convince someone who will never hear you? Can you limit the amount of time you have to spend with people like this? Can you shorten the duration of mandatory visits? i.e., stop in for dessert at holidays instead of the entire afternoon or meal? Or are these people you are required to spend a lot of time with? Can you "counterbalance" these relationships with an equal amount of supportive people?

The questions I just posed are the questions I ask myself when I'm deciding whether to respond to naysayers.

**Anadder:** Hi Marie, I'd love to know what to say to a parent who in essence says, "Well others have been successful with ADHD, why haven't you been successful?"

**Marie Paxson:** I think the general public doesn't understand that ADHD has "severities." They tend to only understand the type of ADHD that they've been exposed to. I.e., some people have mild ADHD and no co-occurring conditions. Others have a severe case of ADHD and very limiting co-occurring conditions. I like to use analogies or show similar situations. If you know the person has been affected by any of these conditions, it can highlight the individuality of those with ADHD.

Diabetes – some people manage their illness with diet and exercise, others need an insulin pump installed in their bodies. Asthma- some people occasionally use an inhaler. Others need to be hospitalized. Arthritis – some people can do yoga and take nutritional supplements while others with arthritis are in a wheelchair. Cancer – some cancers can be managed with “watchful waiting.” Others require aggressive treatment or surgery.

Sometimes it can be helpful to point out that people with ADHD have the same rate of having successful lives as the rest of the population. And each individual defines success in their own unique way.

**c2cwith3:** Rude comments are what I have a hard time dealing with. I had a "friend" say, "Of course your house is quiet! You drug all your kids!" How do you deal with that?

**Marie Paxson:** Now that is rude! Sometimes I like to use the "compassion" in my response. No one likes to be thought of as uncompassionate. And compassionate doesn't necessarily mean that one agrees or approve of something, just that they are taking a non-judgmental stance.

Perhaps point out that your child has a documented medical condition that is being helped by medication. You can point out that using the word "drugs" in that fashion is very stigmatizing. Not to mention that a true friend wouldn't want your life to be any more difficult.

**Sarah:** how best to handle a child's teacher who doesn't believe in ADHD and thinks your child's actions are purposeful?

**Marie Paxson:** That is such a tough situation. I have heard of parents who have education of the teacher about ADHD put into the student's IEP. Would it be possible for another teacher to speak to this teacher? The message might be more easily accepted.

And of course you always have the option of speaking to the principal or special education/learning support teacher in the building. Because while not alienating the teacher can be important, your child's education is more important than his/her hurt feelings.

**Moderator 1:** To learn more about communicating with your child's school, please see our [What We Know Sheet #4: Educational Rights for Children with ADHD in Public Schools](#).

**Hania:** Our 13 year old son has started medication this summer and it is almost miraculous. Obviously we are concerned about the long term effects. Is it true that children have to stay on medication the rest of their lives? Or is that a rumor?

**Marie Paxson:** I'm so glad your son is responding well to treatment. ADHD treatment is so individualized; it is hard to give a general answer to that question. There are adults with ADHD who are so grateful that they have found help through medication that they can't envision being successful without it.

There are others, especially with milder symptoms, who use the medication to focus on learning the skills they need to be successful and can discontinue use of it. The teen years are challenging with or without ADHD and I know that drivers with ADHD often need treatment to remain safe on the roadways.

**Moderator 1:** To learn more about Managing Medication for Children with ADHD, please see our [What We Know Sheet #3](#).

**Jc:** Hi Marie. I struggle as to whether to tell people my sons have ADHD. I hide the fact that I have to give my younger son medicine and actually lied to a friend that it was an iron supplement. My husband does not think we should share with family and friends. What do you suggest? Tell or not tell? I don't

want my kids to be treated differently, but I want them to know they have a disorder and we are working on it every day.

**Marie Paxson:** I struggled with this also. I think when children are younger it is somewhat easier to disclose. Then when they became teens I felt they were entitled to their confidentiality and they could choose whom to tell and whom not to tell.

I've heard both sides of this issue. On the one hand, some experts feel that keeping a child's ADHD contributes to stigma. I've heard author Robert Tudisco, a special education attorney, say that going to school meetings and saying things like "is my child's info kept confidential?" or "are the IEP's kept in a locked file cabinet?" makes children think they have something shameful. I've also heard psychologists say that during a treatment session a teen will answer their cell phone with "dude, I'm in therapy. Can I call you right back?"

So some people are more comfortable than others. When you disclose you may be surprised at how many people are also affected by the disorder and would like to talk to you about it. But if you are holding back, then you must feel that you are dealing with some potentially judgmental people.

I guess I've been surprised a few times about how my children's peers reacted to my family's ADHD. Once they let my son use a dictionary during a Scrabble game because they knew that spelling was difficult for him. Who would have thought of that - an accommodation for a board game, LOL.

**Jen:** Do children sometimes outgrow ADHD? I was told my son would outgrow his around the teenage years.

**Marie Paxson:** Many experts believe that 70 percent of children with ADHD will have symptoms into adulthood. The hyperactivity component often subsides with adolescence, but they still have the disorder.

So you would want to be mindful that your child may still need help and support with schoolwork. And some kids' physical hyperactivity subsides but they are verbally impulsive, which can cause trouble for them.

**Moderator 1:** Before our next question, you should know that the NRC produces a series of Information Sheets and all of these "[What We Know](#)" Sheets are found at [www.help4ahdh.org](http://www.help4ahdh.org), in the "[About ADHD](#)" section, including our [WWK #20A](#) and [#20B](#) on ADHD and Teens.

**Machalea:** Recently, when my neighbor saw my two elementary-aged kids riding their bikes, he said that if more kids played outside, there would be fewer diagnoses of ADHD, which is caused because kids watch TV too much. My older son has ADHD. I chose not to say anything because this neighbor is not involved in my child's health, welfare or schooling.

**Marie Paxson:** There have been some studies indicating that children with ADHD see improvement when they participate in outdoor activities. The book "Spark" by John Ratey looks at the effects of exercise on the brain, which would include ADHD.

And although the book isn't about ADHD, *Last Child in the Woods*, by Richard Louv, makes a strong case for unstructured outdoor activities being important for child development. ie, pickup games of baseball vs. organized sports. Or building a fort from fallen branches vs. being indoors with Legos. that sort of thing.

And even if it didn't help a child's ADHD, with all of the anti-obesity campaigns and work that is being done, exercise is certainly beneficial for general health.

**Regina:** Wondering if you have used a good "one-liner" when others say things like, "ADD is just an excuse!" or "Everyone is ADD!"

**Marie Paxson:** Not a particular witty remark or any snappy comeback. But I've tried to win people over to my point of view. I might say something like, "I probably would have said something similar BEFORE my child (or self, spouse, friend, etc.) was diagnosed with ADHD. I feel very differently now."

Or I might acknowledge their perspective before I try to change their mind; something like, "I know it sometimes seems that way. But look at the number of organizations that have determined that ADHD is real. Real science Defines ADHD as real disorder: <http://www.help4adhd.org/en/about/science>.

One phrase I've heard regarding the "excuse" accusation: "ADHD is an explanation, but not an excuse." This demonstrates that while there may be occasional slip-ups and glitches, that the person is actively managing their disorder and doing the best they can.

And sometimes I say something along the lines of, "how fortunate that you aren't affected by the disease and have the luxury of disbelief" (I mean, really, I know people who have physical illnesses that I don't completely understand and it would never occur to me to question or criticize how they are coping with it).

**Mi\_Mi:** I am a mother of 2 teens with ADHD and I myself was diagnosed at the age of 45. I worked in Pharmaceuticals and even sold ADHD medications to Pediatricians and Family Practice Drs. I am amazed at the lack of understanding of proper treatment of ADHD. How can we change this with the medical professionals?

**Marie Paxson:** I know what you mean. Luckily CHADD and other organizations have programs for medical and mental health professionals at our conferences and workshops. In some ways it may have to come from the grassroots. Parents are encouraged to ask pediatricians if they are following APA (American Pediatric Association) guidelines for treating ADHD. Even if the doctor isn't sure what they are, he/she might now go back and look it up.

AACAP (American Academy of Child and Adolescent Psychiatry) has a "practice parameter" for ADHD on their website that can be downloaded. You might want to see if your doctor is familiar with this. Or even bring it with you on your medical visit.

To be fair, I don't think that doctors are intentionally unknowledgeable about current information on ADHD. I just think that they are required to know so many intricacies about so many illnesses and conditions.

**c2cwith3:** I have 3 boys and all are ADHD. One is also bipolar. Is there something I am doing wrong that caused them all to be ADHD? I feel very, very judged when someone finds out that all 3 are ADHD.

**Marie Paxson:** I'm sorry that you are receiving so many negative messages. No, you did not cause this. ADHD tends to run in families, but that is the only reason that you have more than one child with the disorder. I get so irritated with those who think this is caused by poor parenting. This is a brain-based disorder and that is why our children act the way that they do.

One of the ways to be an effective parent is to educate yourself and your children about ADHD. Most of us are loving, caring parents, but love isn't enough. We need specific parenting techniques and strategies that we can use on a daily basis.

The parenting strategies that are used for children with ADHD can look very different than methods used on children without the disorder. In addition to learning these techniques (CHADD has a parenting class program called "Parent-to-Parent as well as 200 local support groups around the nation) surround yourself with supportive people.

**Moderator 1:** Want to receive well-rounded comprehensive knowledge about ADHD? Parent to Parent courses offered in local communities and online, provide educational information and support for individuals and families dealing with ADHD and learning to navigate the challenges of ADHD across the lifespan. [Learn more about Parent to Parent!](#)

**Baby:** Autism receives so much attention, but ADHD doesn't. How can this be changed?

**Marie Paxson:** I think this has something to do with ADHD being a "hidden" disability. Often those who have autism behave in a manner that signals that they have special needs, so people feel more sympathetic towards them. And the general public realizes from the get-go that those with autism will be impacted their entire life. The autism community doesn't have to constantly explain that it is a lifespan condition.

CHADD is working hard to change the public's perspective of ADHD. This disorder can have serious consequences if left untreated (substance abuse, traffic accidents, teen pregnancy, interaction with law enforcement). But if we highlight the dark side of this disorder too much, it can send a message that ADHD is "bad," or worse, that those who have it are bad. It is a really delicate balance.

And those with ADHD don't want to be seen as not sympathetic to those with autism. The game of "my disease is worse than your disease" has no winners. CHADD networks and interacts with leaders of the autism community because we have so many things in common. When I was running a chapter near Philadelphia, we often had people who came to us because their child was diagnosed with ADHD, and then received an autism diagnosis later. So some people with autism have ADHD as a co-occurring condition and vice-versa.

**Moderator 1:** We have ten minutes left. Marie will move through as many questions as possible. If we are unable to get to your question please contact one of our Health Information Specialists on ADHD by calling 1-800-233-4050 between 9 AM- 5PM EST or by clicking on the "Ask A Question" link on the top of our website: [www.help4adhd.org](http://www.help4adhd.org).

**Sarah:** My spouse doesn't want to treat our ADHD child because he doesn't think ADHD is real (He doesn't want him to carry a "label" for the rest of his life). It creates so much strife in our household b/c I am trying to do what the doctor says and he doesn't want to believe that our child has the disorder. What do I do to increase his awareness of ADHD so we can help our child?

**Marie Paxson:** I hear this a lot. I think this has to do with people being afraid of labels. Sometimes with good reason. But the truth of the matter is that the child has ADHD whether we acknowledge it or not. Often the best route to go is to have a 3rd party try to educate your spouse. Most likely he/she is tired of hearing it from you (sorry).

So you could try to have someone he/she respects talk this over. Or go to a well-regarded professional. Or introduce some reading material on the subject. Not to be crude, but when I was a new mom and wanted my husband to read articles on parenting (he prefers sports and woodworking), someone told me to take all of the magazines out of the bathroom and replace it with the baby books ;)

You could also "bargain" for open-mindedness on this topic in exchange for the same deal on the topic of your spouse's choice. for instance, your spouse will read some literature or articles on ADHD for a specific amount of time and in exchange you will do the same for the topic of his/her choice. And no, I didn't read any woodworking articles ;) but I would have if it were necessary!

In short, I think you will need some carefully-chosen allies for this issue. I admire your commitment to help your child even though it is causing stress on the home front. I've heard adults with ADHD lament that they didn't have enough parental buy-in for their childhood ADHD symptoms and that is not the case with your family.

**Moderator 1:** Missed part of the chat? Past chat transcripts are available to CHADD members as a benefit. Learn more about [joining CHADD!!!](#)

**Moderator 1:** This will be our final question.

**Sharon\_R:** My daughter is a senior in high school and hopes to attend college next year. In general, what feelings do college professors hold regarding accommodations for students with ADHD? Is there anything I can tell her to help her with facing this stigma on her own?

**Marie Paxson:** I have heard both positive and negative stories about ADHD in college. The good thing is that there are more services available because you are paying for them.

One of the best pieces of advice is to choose a college with a strong Disability Office and get signed up for services (there is paperwork involved) because a strong Disability Service department can make all the difference in the services that are delivered. It's also a place to go for assistance when a student needs help with either the system or with an individual professor.

**Moderator 1:** Thank you Marie for all your insightful advice. Together we can make a difference to increase awareness of ADHD! Your answers have given us the confidence to do this appropriately at the source of misinformation. Being able to spread awareness is an important part of ADHD awareness week. Thank you for helping us all learn how we can participate.

If you have a question that was not answered today, please contact us online (National Resource Center's Web site at [www.help4adhd.org](http://www.help4adhd.org) ) or by phone (800-233-4050) between 9AM and 5PM EST and one of our health information specialists will respond.

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