

No parent of a child with symptoms of ADHD (hyperactivity, inattention and impulsive words, actions and emotions) likes the idea of giving him or her psychostimulant medications. When both grades and relationships go downhill, most parents will first work very hard to find effective teaching and behavior strategies to get back on course. They worry about "drugging" their child, risking unknown long-term side effects or creating new cast members for "The Walking Dead." Parents tend to believe that medicine

should be used only as a last resort and in the smallest dose possible.

If the problems continue and worsen, however, a time for reconsideration may come. Even the best school and home behavior and learning plans can be sabotaged by the persistent lack of attention and impulsive nature of their son or daughter. Although appropriate educational modifications and behavior therapies developed with the help of qualified teachers and counselors should be in place before medical treatment, there is a price to be paid for waiting too long. Although grades can improve and relationships repaired, the damage to the child's self-esteem may last a lifetime. In these cases, a trial of medication might be a reasonable choice.

The disappointing reality is that 20% to 40% of children do not initially respond to the medications. There may be little or no improvement in symptoms or outcomes, or severe reactions and side effects that cause discontinuation. While stimulants are not a cure for ADHD, they can be the key that opens the doors to effective behavioral and educational therapies when the reasons for this apparent failure are identified and addressed. When ADHD medicines fail, the answers can be found in the following four areas:

- 1. The medication itself
- 2. Adverse side effects
- 3. Coexisting conditions inside the child
- 4. Circumstances outside the child.

#### Problems Caused by the Medication

The two stimulant medications, methylphenidate (Ritalin) and amphetamine (Adderall) are the first line of treatment for children and adolescents with ADHD. Although their chemical structures are different, most patients can take either one although there are some selective responders. The second line medications, atomoxetine, clonidine or guanfacine, are much less effective and associated with significant side effects, such as increased suicidal thoughts, drowsiness and lowered blood pressure and heart rate. Pitfalls in the administration of the stimulants are:

- Not thoroughly educating parents about the expected response, potential side effects or overdose reaction of the medications. Excellent information concerning the medication is available through the CHADD website <a href="http://tinyurl.com/ycc8z8je">http://tinyurl.com/ycc8z8je</a>. The official FDA medication guidelines found at FDA <a href="http://tinyurl.com/mkgxsnz">http://tinyurl.com/mkgxsnz</a> should also be read carefully before starting treatment.
- 2. **Starting the medication at too high a dose**. Although usually not immediately effective, it is always best to start the medication at the lowest dose available to monitor and manage side effects. Better safe than sorry.
- 3. **Not monitoring the response to the medication**. The Parent and Teacher Vanderbilt Assessment Follow-up Forms are an excellent tool to evaluate the reduction of ADHD symptoms, the improvement in grades and relationships, and the presence of side effects or overdose reactions. They are available at the NICHQ website <a href="https://www.nichq.org">www.nichq.org</a>. The form

should be completed *before* medication is started and then repeated for comparison *after* every dosage adjustment.

- 4. Not giving the medication on weekends. Increases in dosage or change in medications should always be done on the weekend so that the parent has the first opportunity to notice positive or negative reactions. Because peak levels of the medication occur at lunch time, the parent will more easily recognize the subtle, dull personality change associated with an overdose that a teacher may miss. Careful monitoring is particularly important when the child alternates time with parents at different houses with different routines after a divorce or separation.
- 5. Not personally talking to the teacher frequently about the child and the monitoring form. It works best if the parent obtains a verbal report from the teachers to supplement the information on the Vanderbilt form, emails both forms to the physician and leaves a voice mail message. Medication adjustments or strategies to deal with side effects can then be accomplished quickly by return phone call. This parent-teacher-physician interaction provides the close communication needed to plan and evaluate new teaching techniques and better behavior modifications.
- 6. **Not including the child in the process.** From the beginning, three things should be asked of the student:
  - Take the medicine regularly for the next six to eight weeks
  - Continue to do their best
  - Give their input on the parent Vanderbilt form concerning symptoms, function and side effects

Although it may be difficult for the child to notice any effect at first because of the low dose, they will always be the most reliable source of information since they are actually taking the medication. If asked, even 1st graders can report on how the medicine helps, when it wears off, what they don't like about it, and when it is too much.

- 7. **Going too fast.** Once the decision to start the medication if made, the temptation is strong to rapidly increase the dose to see results. In most cases, however, it is usually best to wait at least two weeks before making any changes. Although absorbed quickly into the blood stream, it takes some time for the child to adjust to the feeling of medicine both entering and exiting the brain. It is also a mistake to make changes based on what may only have been a few good or bad days at home or school. The goal of the medicine is to achieve a consistent and reliable behavioral response every day regardless of the circumstances.
- 8. Going too slow. Too often both the parent and physician may be hesitant to increase the dose because of concerns of triggering side effects. Once the decision to try any medication is made, however, logic dictates that the correct dose should be given. There is nothing to be gained from giving infant Tylenol drops to a febrile teenager. If bad reactions occur, they will be immediately evident to the parent, child and teacher and quick adjustments can be made. Troublesome side effects that are seen at lower doses often disappear or become acceptable over time.
- 9. **Not considering the timing of the dose.** It is clear that ADHD is not just a school problem —it is a life problem. The duration of the medication effect is important but can vary con-

siderably from medication to medication and child to child. Teachers can provide a more accurate classroom assessment by comparing how the child does before and after lunch. Increasing the dose will usually provide coverage for the entire school day. Untreated ADHD symptoms in the early morning may lead to difficulties getting up and dressed, eating breakfast, finding books and making it to the bus on time. When the medication wears off in the evening there can be problems with homework, participation in sports or family activities, interactions with siblings, dinner and bedtime. It is often helpful to give the medicine before the child gets out of bed or to add a short-acting dose in the afternoon at home.

- 10. **Not regularly contacting the physician.** When medication is discontinued by parents, it usually occurs in the first two to three months and is due to a lack of response or intolerable side effects. Successful ADHD medical treatment requires reliable information from both parents, all teachers and the child. Frequent discussion with the physician about medication, including cost and taste, school issues and counseling can empower the parent to lead their physician-teacher-counselor team effectively.
- 11. **Not trying another stimulant.** If the first stimulant chosen (methylphenidate or amphetamine) is not effective, a trial of the other class is indicated. Younger children who experienced adverse reactions to immediate release medications in the past may do very well with the same drug when delivered in the long-acting form. Because of slight differences in the formulation of the extended-release stimulants, trying a different brand of the same stimulant may do the trick.
- 12. Not adding extended-release clonidine or guanfacine to appropriate doses of stimulant. There is good evidence that adding these alpha-2 agonist medications are safe and can be effective in reducing persistent physical, verbal and emotional impulsive reactions. They are useful in treating all types of tics as well. These medications take longer to work and may cause drowsiness or lowering of blood pressure and pulse.

#### **Problems Caused by Severe Side Effects**

There are a number of key side effects that cause medication failure by discontinuation when present.

1. Weight loss. Stimulants will almost always decrease appetite when the level peaks around lunchtime. Even though mothers try to improve unappetizing school cafeteria fare by packing a favorite food with encouraging notes attached to tempting snacks, most children will lose weight during the first months of treatment. It is reassuring to document that during this time growth rates are rarely affected. Both height and weight should be routinely measured at least every three months and a complete medical evaluation should be performed in any child that shows any evidence of delayed growth.

If stimulant medication actually caused permanent weight loss, the current obesity epidemic in children, adolescents and adults could be quickly ended. Over time the child resumes a normal intake of calories by eating a late dinner, adding a bedtime snack and taking breakfast at home. The medication should not be prescribed if the parent cannot guarantee that the child eats a high calorie, protein rich breakfast every morning at home. Breakfast at school is unreliable because the medicine may dull the appetite early on, the food is unattractive and the friends distracting. Around six months of treatment, the weight stabilizes at the same percentile of the height and tends to remain at that lev-

- el. In all too many cases, the excessive weight gain returns, resulting in obesity and associated health problems.
- 2. Headaches and stomachaches. If the child eats a good breakfast at home every day, not only will the weight stabilize, but headaches and stomachaches will rarely occur. If the child skips breakfast both at home and school and does not eat lunch because of the medication effect, his or her blood sugar levels can drop after this extended period without food. This relative reactive hypoglycemia is the most common cause of afternoon headaches, stomachaches or feelings of jitteriness, lightheadedness, rapid pulse or irritability.
- 3. Insomnia. Although stimulants can affect sleep, in most cases the medication will be long gone from their system before bedtime. The stimulant morning coffee that helps start the day off does not cause sleeplessness at night. ADHD itself is the most common cause for sleep onset difficulties because when the medication wears off, the symptoms of mental hyperactivity and restless physical and emotional energy return. Although not caused by the medication, insomnia will result in treatment failure because of the inattention and irritability caused by persistent fatigue and drowsiness during the day.
- 4. **Irritability.** Like sleep disturbances, irritability is often already present in children with ADHD due to their emotional impulsivity. Occasionally, the stimulant medications may trigger irritable reactions especially during the initial months of treatment. The key to managing the behavior is determining the time it most frequently occurs. There may be difficulties in the morning at home before the medicine kicks in, but more commonly the behavior is seen in the afternoon when the medicine is leaving their system. Parents can almost set their watches by the regularity of the episodes which happen daily around 3 to 4:30 every afternoon. This problem usually improves over time or when larger doses of medicine are given. An afternoon dose of short-acting stimulant may make a difference while families learn to work around the emotional outburst.
- 5. **Tics**. Sudden facial twitches, grimaces or unpredictable but repeated noises, grunts or sniffs are common in children with ADHD. Often there is a positive family history. Although previously believed to be triggered by the medications, more recent research has shown that stimulant treatment can decrease the frequency or severity of tics by decreasing stress. Tics will often change, come and go for unknown reasons and usually resolve as the child ages. Guanfacine ER can be helpful in persistent cases.

### **Problems Caused by Complicating Conditions**

The third reason why medication may fail is the complicating presence of five additional coexisting conditions: anxiety, learning disabilities, oppositional defiant disorder, demoralization and autism spectrum disorder.

1. Anxiety disorders: Generalized anxiety, separation anxiety, panic attacks, school phobia and obsessive-compulsive disorder with rituals and tics may occur in up to 50% of children with ADHD. Early symptoms of separation anxiety can later transform into specific fears and phobias associated with things such as storms, bees or burglars. Devastating social anxiety may eventually develop in teenagers. A strong family history of anxiety or depression is frequently present. Unfortunately, the most common but destructive defense mechanisms of denial and avoidance are often firmly in place. Anxiety clouds the decision for a trial of medication and can exaggerate the presence of side effects for both child

and parent. Although a little anxiety can counterbalance the impulsivity of ADHD, too much often limits the reaction of the child to the most basic responses of freeze, flee or fight. Family disintegration, few friends, falling grades, mountains of homework and missed assignments can so intensify the anxiety that stimulant medication may show little or no effect.

- 2. Oppositional defiant disorder: A personality that can be best described as "sensitive but stubborn" is also present in up to 50% of children with ADHD. Although this may be an admirable trait in some situations, defiance and refusal at home or school is never a good thing. Behavioral modification based on rules, rewards and consequences works better when the medicine prolongs the response time of the child. Taking the time to think can considerably improve the odds of making a good decision. Children with difficult temperaments may still insist on their path even after considering the options. An effective and consistent school and home behavioral plan with specific goals and appropriate rewards can work wonders that medication by itself cannot achieve.
- 3. **Learning disabilities.** The presence of specific learning difficulties in reading, writing, math and organization can also limit the effect of medication. Stimulant therapy often improves handwriting legibility and decreases careless mistakes and messy work. Similarly, ability in subjects that are progressive like math may jump ahead. Division can magically become possible once the missing multiplication skills are mastered.
  - Specific disabilities in reading and executive function, however, will almost always require academic and achievement testing, and the implementation of appropriate educational modifications. Frequent re-evaluation and adjustment of the accommodations is critical for successful medication management. Teaching strategies for children with intellectual disabilities and autism spectrum disorder are essential.
- 4. **Demoralization:** Children and adolescents with ADHD may eventually just give up, stop trying and simply refuse to do the work. Hundreds of "stop that, sit down, no talking, get busy and finish your work, keep your hands to yourself, don't argue, figure it out for yourself, no recess, what is the matter with you?" eventually take a toll in even the most resilient student. When these children with ADHD drop out because of discouragement, depression and more, it is impossible for any amount of medication to get them back.
- 5. Autism spectrum disorder. Recent research has proven that children with ADHD can also have features of autism without an official diagnosis of autism spectrum disorder. The shared characteristics are problems with social interaction, difficulties in communication and unusual restricted and repetitive interests or activities. Although medication cannot change the thought disorder of ASD, it can work to improve attention span, decrease hyperactivity and slow impulsive behaviors providing at least an opportunity for better relationships and learning. When these spectrums collide, special care must be given in the use of stimulants. Therefore:
  - Increases should be made no more than monthly rather than weekly
  - Long acting preparations should always be used to reduce irritability, anorexia and insomnia
  - Side effects should be expected to persist over a longer time
  - Expectations of improvement should be lowered.

#### **Problems Caused by External Circumstances**

The role of the world around the child in reducing the effectiveness of medication is illustrated aptly by a recent patient encounter:

Matthew is an almost 13-year-old who has started middle school about two months ago. He is receiving special education through an Individualized Educational Plan based on academic achievement testing. He is accompanied by his great-grandmother, who babysits him frequently and is a retired school teacher. He is sitting quietly on the examination table playing with his phone and does not stop or even look up when I enter the room. His face is expressionless as he answers all my questions about school, the medicine, and life at home with a monotone delivery of "I don't care." When his grandmother supplies some information about his grades and classes, he snaps sharp answers back to her saying, "That is not true!"

I am uncertain of what I can do because his medications are already at fairly high levels. In the past, both his ADHD and anxiety disorder were well controlled with the treatment regimen. In reviewing his chart, I note that he has also previously failed multiple medications given at appropriate doses and duration of treatment. His physical examination, blood pressure and pulse are normal, and he is tracking on the 50<sup>th</sup> percentile for both weight and height growth. He does admit that he skips breakfast frequently both at home and school. He has no trouble falling asleep but wakens frequently through the night. Neither he nor his great-grandmother can confirm that he regularly takes his afternoon dose of the stimulant because his mother has recently been ill.

She now explains that his mother has rheumatoid arthritis that has suddenly flared up. She is very proud of how Matthew has stepped up to care for her when she has on occasion been unable to get out of bed. She missed his appointment today because her job is in jeopardy due to multiple absences. As I look to Matthew to ask if his worrying about his mother has affected his sleep, he slowly nods his head and his eyes tear up. Now his great-grandmother almost nonchalantly reminds him that the whole household has also been upset since his 21-year-old uncle has moved in with his girlfriend after he recently lost his job. She implies that the problem is related to the opioid crisis currently raging in our Appalachian city.

Instead of changing or increasing his medications, we decide to meet with his teachers as a team to evaluate the medications effectiveness, duration of effect and possible adverse reactions. This will also provide the opportunity to explain his family stresses and discuss possible adjustments to his IEP due to the new academic and social challenges of middle school. We agree to work on establishing a regular sleep schedule and routine breakfast at home.

When Matthew steps out of the room to go to the bathroom, his great-grandmother leans over to me and whispers, "I am really worried because his mother had a huge fight with his grandmother that I think is causing most of his problems." When she states that his mother is seeing a counselor, we agree that Matthew should be included in a family therapy approach.

**In conclusion**, the decision for a trial of medication should be made carefully and can be life-changing for the child and the family. Success will depend on monitoring the administration, managing side effects, dealing with coexisting conditions and understanding the environment in which the child lives.