The process

From problem to treatment

Does your child with autism spectrum disorder (ASD) struggle with a problem behavior? Does it affect your family? Do you feel overwhelmed by the treatment options? And does the thought of medicating your child concern you?

Autism Delaware posed these concerns to four local health-care professionals:

- an expert on child mental health, pediatric psychiatrist Karl W. McIntosh, MD
- an expert on the nervous system in a child, pediatric neurologist S. Charles Bean, MD
- an expert on child development, developmental pediatrician Rhonda S. Walter, MD
- an expert on patient-centered health care, nurse practitioner Veronica Wilbur, PhD, FNP-BC

All agreed that the first thing you need to know is whether the problem is related to ASD or something else.

How do I start?

Begin researching possible doctors. When you have several who may meet your needs, make an appointment with each. Then, write a list of questions to ask. The goal is to find out what you can expect from each health-care professional.

Here are some questions to consider:

- Have you worked with patients on the spectrum before?
- How comfortable do you feel around people with ASD?
- Can you point our family in the best direction to meet our unique needs?
- Do you recommend therapy, and if so, what type?
- If a medication is needed, will you be available to help our family through the process for finding the best drug and dosage for our child?

The best-case scenario for you and your child is a team of medical experts proficient in ASD, including a primary health-care provider who can make treatment referrals (such as a doctor, nurse practitioner, and physician's assistant). Also consider a pediatric psychiatrist for prescriptions plus a psychologist, counselor, or licensed clinical social worker who can work with the child on the problem behavior. Each health-care professional should be able to build a long-term relationship with the child.

At this point, your focus is squarely on your child as an individual living with ASD in your home, so you are the expert on your child's needs. This level of attention needs to extend to every other setting your child is part of, too. You need to gather data about your child's behavior in each setting and be able to note any differences.

And it's your job to share this with your assembled team of medical experts.

"You need to be able to talk to the team, so you need to document your concerns as you go," recommends Heidi Mizell, Autism Delaware's resource coordinator. "Organize the information in a way that works best for you." Mizell endorses the care notebook handed out at workshops hosted by Delaware Family Voices. For a schedule of upcoming care notebook workshops, visit delawarefamilytofamily.org.

A first appointment with each medical expert needs to be considered a fact-finding mission. "Clinicians need to gather data so they're aware of prior indications, behaviors, and so on," notes Rhonda S. Walter, MD, a developmental pediatrician at Nemours/Alfred I. duPont Hospital for Children for 23 years. "Everyone on the child's treatment team needs to talk to each other. Be sure to tell your clinicians about all the supplements and treatments you want to try, too."

"Parents can help improve communication by providing the specific names, addresses, and phone and fax numbers of everyone on the team," adds S. Charles Bean, MD, a long-time pediatric neurologist at Nemours.

Once the team has determined that the problem is ASD-related, make sure your child is receiving appropriate services. "The number-one rule," continues Bean, "is 'Do not delay!' If your child is under the age of three, get services as soon as possible. Even if you're unsure of the diagnosis, it's better to err on the side of early treatment. Children with autism need

Are you having a problem carrying out this process?

The process noted here is a best-case scenario. If you find a shortage or lack of resources, contact Autism Delaware. We can help you find a resource or help advocate for one.

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The process (continued)

help working on core symptoms involving socialization, communication, behavior management, and education.

"It's also important to support the family," says Bean. "With a child with special needs, a family needs help dealing with multiple other things. Family training is needed to promote the carryover of the work done in school, and services need to extend to daycare and post-21 programs [for when the child ages out of the school system]. And all of this needs to grow with the child's needs."

Finally, the child needs a thorough physical, and the child's medical history needs to be recorded. Here, Karl W. McIntosh, MD, offers two more top goals. "Number one," lists the child and adolescent psychiatrist with Concord Behavioral Health, "is get information on how the behavior was handled in the past; and number two, evaluate what the person can and cannot do."

Treating the behavior

All four of our experts also agree that a behavior problem should be treated with behavioral therapy. Examples include cognitive behavioral therapy (CBT), applied behavior analysis, and verbal behavior therapy.

"Try therapy first," suggests nurse practitioner Veronica Wilbur, PhD, FNP-BC, associate professor and chair of the doctor of nursing program at Wilmington University, "and know what the specific behavior is you want to address. If social communication is impaired by fear, for example, is the child reacting to a particular situation in which he or she cannot process the stimuli adequately? And if the child exhibits erratic behavior, how different is it from his or her usual behavior and how is it impacting social interaction?"

Wilbur suggests that the parents create a diary of the problem behavior that includes what is being seen and when. Here are some questions to answer in the diary:

- What is the situation in which the behavior takes place?
- How often does the behavior occur in which situation?
- Is the situation familiar or unfamiliar?
- Is the behavior new? If not, how long has the behavior been going on?
- If the child takes a while to calm down, how long does he or she need?

The answers to these types of questions will point treatment in the correct direction for the individual child.

"There's no silver bullet for anyone in psychiatry," explains McIntosh, "and all change provokes anxiety, whether you have autism or not. During times of transition and stress, a teenager with autism suffers the same as a teenager without autism. The key is to recognize the social-emotional differences. I've worked with bankers who needed two years before they could say what they needed and kids with autism who needed only two weeks.

"I don't use CBT for a person with autism," says McIntosh of his individualized 18-year practice in psychiatry and child and adolescent psychiatry. "Nature has to be sculpted. Instead, we practice how to be in the room."

Deciding to medicate

If behavioral therapy alone is not enough, physicians may recommend behavioral therapy with a complement of medication. "The goal," defines Bean, "is not only to reduce unwanted behavior but also to make the child more available for learning. A medication may help overcome a behavior block that's stopping the child's advancement. You need to make sure the medication is not interfering with the behavior program and learning."

"Medication is an adjunct to everything else," agrees Walter. "You need to get everything else in a row before turning to medication.

"The ideal time to consider meds," suggests Walter, "is before a symptom gets out of hand. Target the symptom that is interfering most with your child's life, and think about using meds if the child's symptom is stopping the day-to-day flow of family life."

Some questions to consider are

- How is the symptom interfering with the child's education and development?

Tool kits!

Autism Speaks offers a tool kit for parents considering medication. The kit provides help through the decision-making process.

For parents who have already decided to medicate, Autism Speaks offers *ATN/AIR-P Autism and Medications: Safe and Careful Use.*

Both can be downloaded at autismspeaks.org. Click on Family Services; then, Tool Kits.

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The process (continued)

- How is the symptom affecting behavior and causing stress in the family?
- Is it causing a true distress in the child, like agitation or discomfort?
- How could a medication enhance the child's development, education, or behavior?

Start low, and go slow

The process for finding the best drug and dosage involves a long-term strategy of trial and error—because no one standard exists for ASD treatment. "[W]hile the Food and Drug Administration (FDA) has approved two drugs for treating irritability associated with the autism, it has yet to approve a medicine for treating autism's three core characteristics" (autismspeaks.org/what-autism/treatment/medicines-treating-core-symptoms). For more, see *Why it's prescribed* on the next page.

For more on standards for ASD treatments, see *We need a standard.*

"Always treat the mood first," notes McIntosh. "Then, adjust as needed. In my opinion, if you look at the symptoms over time, you'll find this will improve functionality and communication. If the benefits and limits are clear, you can determine a drug's effectiveness.

"From the pharmacologic standpoint," continues McIntosh, "the process is observational. You have to observe people to figure out the best course of treatment. If you're dealing with anxiety, you need to educate parents to know what it looks like.

"Meds work when a relationship exists between the physician and the family," adds McIntosh.

"Start low, and go slow," advises nurse practitioner Wilbur about medicating children with ASD, "because a drug can have the opposite effect on a child than intended." However, as long as the parents understand this phenomenon, there's no need to panic when a child starts a new drug, because with only one dose in the body, it's not concentrated enough to bring on a side effect.

"You need to take a drug about a week for a side effect to surface," explains Wilbur, "and a side effect tends to ease after two weeks. It may even go away." (For an explanation on the difference between a side effect and an allergy, see the box following this article.)

The other important point to remember, notes Bean, is the drug may fix the problem now, but the problem—and the drug's effect in the child's body—may change over time.

"The reason," explains Bean, "is autism is not just one thing; it's a spectrum with different levels of cognitive

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A double-edged sword

"Medication is like a double-edged sword for someone with autism," says S. Charles Bean, MD. "Drugs don't always work as expected; they could have the opposite effect of what you want and make the situation worse." Here are two examples:

Antipsychotics and tranquilizers—In her book *Asperger's Syndrome and Sexuality* (Jessica Kingsley Publishers, London: 2006), Isabelle Hénault cites a 1992 study that suggests antipsychotics and tranquilizers can affect sexual function in males with a *DSM-4* diagnosis of Asperger's syndrome. The possible side effects were erectile dysfunction and delayed ejaculation (P. Alarie and R. Villeneuve, *L'impuissance: Évaluations et Solutions,* Editions de l'Homme, Montréal: 1992).

This is important because, according to Dave Hingsburger in *Hand Made Love: A Guide for Teaching about Male Masturbation*, "a number of behaviors or attitudes lead to problematic masturbation, including... masturbation that does not end with ejaculation... [and] injury occurs from masturbation (due to overly intense stimulation) (Newmarket, Diverse City Press: 1995)."

Stimulants—When a child without ASD is diagnosed with attention deficit hyperactivity disorder, a stimulant is usually prescribed to help the child concentrate. But for a child with ASD who's over-fixated inside, notes Bean, stimulants can induce anxiety and magnify the inability to concentrate.

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The process (continued)

abilities; therefore, it's a strong determiner of the medication's ability to work."

Parents should ask whoever is prescribing the medication to detail the possible side effects. Parents should also read the package insert that comes with the prescription.

"The handout can be scary," admits Wilbur. "Rather than be overwhelmed by all the information, look for the possible side effects that are most common, like weight loss or gain, nausea, headache, insomnia or drowsiness."

Once the medical expert makes sure the family understands the range of both positive responses and side effects, the parents' job is to follow how the child responds to the medication. "The doctor needs to explain what the medication does and doesn't do," sums up McIntosh, "so the parents know what to look for. They need the tools to be able to observe the child's behavior at home."

Why it's prescribed

According to the Autism Speaks website, relief for autism's core symptoms—communication difficulties, social challenges, and repetitive behavior—cannot be found consistently through medication (autismspeaks.org/what-autism/treatment/medicines-treating-core-symptoms).

"It's hardly surprising that few medications are available," says Autism Delaware's clinical director, Susan Peterson, PhD, BCBA-D, "considering that two core symptoms are communication difficulties and social challenges." Instead, other symptoms are addressed, such as irritability, anxiety, depression, repetitive and self-injurious behaviors, and co-diagnoses like ADD and ADHD.

Irritability—Two FDA-approved antipsychotic drugs are prescribed for children (aged 6 or older). The belief is that, by relieving irritability, sociability is improved while reducing tantrums, aggressive outbursts, and self-injurious behaviors. "However, both medicines tend to produce significant weight gain and diabetes risk. Therefore, their use requires close monitoring" (autismspeaks.org/what-autism/treatment/treatment-associated-psychiatric-conditions).

Anxiety—The FDA has approved several selective serotonin reuptake inhibitors (SSRIs) for people without ASD—but not for adults or children with ASD. "Some studies suggest that antianxiety medications are less effective, overall, in those with autism than with other groups. It may be that the biological root of autism-associated anxiety may be different from that of anxiety in the general population. As such, individuals with autism may respond best to tailored treatments" (autismspeaks.org/what-autism/treatment/treatment-associated-psychiatric-conditions).

Depression—Like anxiety medication, depression medication has not been studied in adults or children with ASD. Unlike it, "[s]ome research suggests that individuals with ASD are at increased risk of side effects from antidepressants. The most common side effects include sleepiness, agitation, increased irritability, restless leg syndrome, and gastrointestinal problems…. [I]t may take several trials of different medications to find one that works well with minimal side effects. Dosing needs to be carefully tailored to the individual as well" (autismspeaks.org/what-autism/treatment/treatment-associated-psychiatric-conditions).

"Antidepressants and antianxiety medications are also given for sleep disturbances and obsessive-compulsive disorder," adds Nemours' pediatric neurologist S. Charles Bean, MD. "And alpha-agonists are prescribed for sleep, agitation, inattention, and tics as well as anxiety."

Repetitive and self-injurious behaviors—An opiate antagonist (approved for opioid and alcohol addictions) eases these behaviors in some children and adults with ASD. "Dopamine blockers," continues Bean, "are prescribed for self-injurying behavior and internal stresses, but they have more side effects."

ADD and ADHD—Conditions that can be co-diagnosed with ASD—attention deficit disorder or attention deficit hyperactivity disorder—are often treated with stimulants. Because of the stimulant's physiological actions in the body, notes Bean, side effects often occur and can include decreased appetite, irritability, emotional outbursts, and sleep disorders. Usually prescribed to address the inability to concentrate, a stimulant can further provoke anxiety and the inability to concentrate.

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We need a standard

Every child is a unique individual with his or her own set of traits and motivations. Every autism diagnosis is as unique as the spectrum. And no one coordinated approach or community standard exists for autism spectrum disorder (ASD).

Yet a study published October 21, 2013, in *Pediatrics* (the American Academy of Pediatrics' online journal site), notes the prevalence of prescriptions filled for children with ASD: "Among 33,565 children with ASD, 64 percent had a filled prescription for at least one psychotropic medication, 35 percent had evidence of a psychotropic polypharmacy (two or more classes), and 15 percent used medications from three or more classes concurrently" (pediatrics.aappublications.org/content/early/2013/10/16/peds.2012-3774.abstract).

Because these numbers stand in contrast to the lack of evidence proving effectiveness and appropriateness of drug therapy in children with ASD, the study concluded that a standard of care needed to be created.

Side effect vs. allergy

A side effect, reads the fifth edition of the *American Heritage Dictionary of the English Language,* is "an undesirable secondary effect of a drug or therapy." An allergy is "an abnormally high sensitivity.... Common indication of an allergy may include sneezing, itching, and skin rashes."

A life-threatening allergy reaction can occur quickly. Called anaphylaxis, it can include hives, itching, flushing, and swelling of the lips, tongue, and roof of the mouth. According to the website *epipen.com,* "The airway is often affected, resulting in tightness of the throat, chest tightness, and difficulty breathing. These reactions can also be accompanied by chest pain, low blood pressure, dizziness and headaches."

If you have any concerns about either side effects or allergies, call your doctor.

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