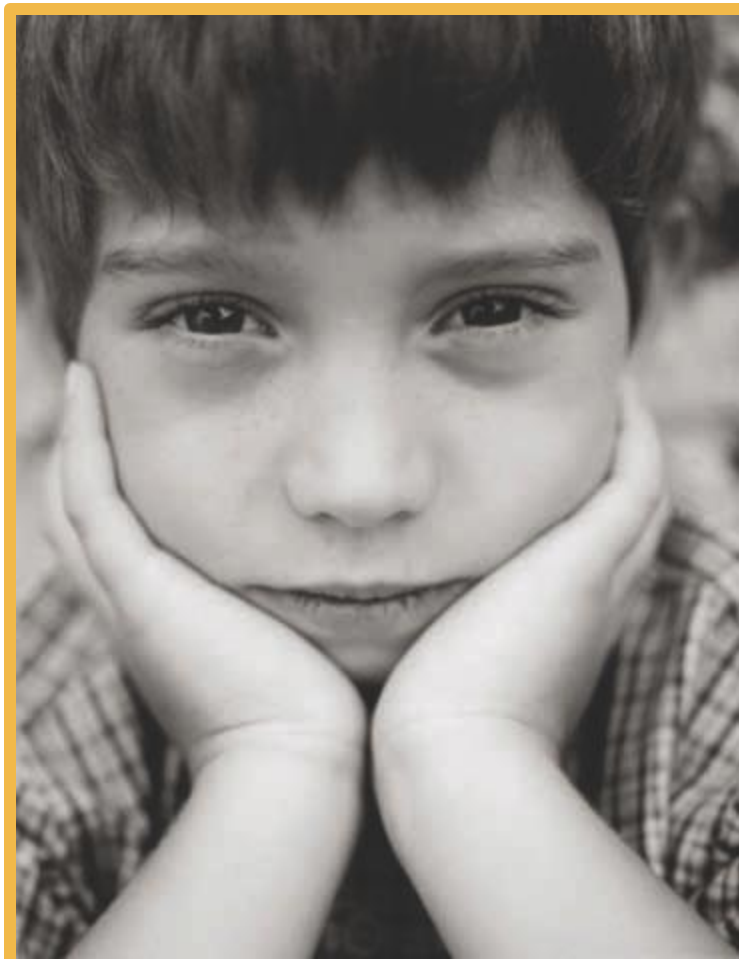


Autism: Should My Child Take Medicine for Challenging Behavior?



A Decision Aid for Parents
of Children with Autism
Spectrum Disorder



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This toolkit has been created as an electronic form- it can be completed on your computer (internet connection not required). You may enter and track your responses by clicking on the checklists and within boxes labeled “open text.” You may also navigate through the document by clicking on hyperlinks. **DON'T FORGET** to save the document to your computer and / or print out for you and your provider’s reference. Additionally, you may choose to print and complete the document with pencil / pen.

HOW CAN A DECISION AID HELP YOU?

A decision aid can help you work with your child’s health care provider when making important medical decisions. There is not always one “right” choice. The decision aid can help you understand the possible risks and benefits of different treatments. It will help you decide what is most important to you and your family and help you choose an option. *The goal for a decision aid is to help you work with your child’s health care provider to choose a treatment that matches your needs and values.*

IS THIS DECISION AID FOR YOU?

- ✓ Are you thinking about having your child with autism* take medicines for challenging behavior?
- ✓ Has your child’s health care provider suggested medicine?

This decision aid has been designed to help you decide whether to have your child take medicine.

➤ This decision aid is for you if...

- You are a parent or caregiver of a child with autism who also has challenging behavior
- You want more information about medicines that are used for behavior
- You want to be part of the decision about treatments for your child

Some families might use this decision aid to help them after a professional has suggested medicine as a treatment option. Other families might use this decision aid before meeting with a health care provider to talk about medicine. Sharing information from this decision with a health care provider can be helpful. It might help you tell about your values and about your child’s behavior.

➤ Using this decision aid can help you...

- Learn about autism and common problem behaviors
- Learn about the possible benefits and possible risks of medicine
- Make clear what is important to you in making a decision about medicine
- Make a decision about whether to have your child take medicine for behavior

**For the purposes of this decision aid, the term “autism” will be used to describe children with all types of Autism Spectrum Disorders, including Autistic Disorder, Asperger Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).*

Terms of Use

This decision aid contains general information only. It is not intended as medical advice. It is important that you work with your child’s health care provider to determine your child’s individual medical needs.

WHAT ARE THE OPTIONS?

1. Treat problem behaviors with medicine.
2. Don't take medicine. Try other ways to improve behavior.
3. Treat behavior issues with a combination of medicine and other treatments

Key Points of This Decision Aid

➤ **Educational and behavioral therapies are the main treatments for children with autism.** Medicines should be considered only after these therapies have been used. Educational and behavioral therapies should be continued even if medicine is added as a treatment

➤ **Medicine does not cure autism.**

➤ **Medicine might help with challenging behaviors,** such as hyperactivity, tantrums, sleep problems or anxiety. This may make it easier to join into family life, community activities or school programs. This might make your child feel more comfortable or be able to learn better. Medicine does not help every child with autism. Even when it helps, medicine usually does not eliminate the problem behavior completely. Also, not every problem behavior can be treated with medicine.

➤ **It is important to try only one new treatment for behavior at a time.** This helps families and the health care team to know which treatments are helping and which treatments are causing problems.

➤ **Medicines have side effects.** Some children are able to take them without problems. The type and the seriousness of the side effects depend on the medicine chosen and the child's response. There are several groups of medicine used. ([CLICK HERE to Review the Medication Table](#) on page 16)

➤ **Medicine costs money.** The cost will depend on the type of medicine and whether you have insurance that pays for some or all of it. You can try medicine for a while to see if it helps. Sometimes the benefit is worth the cost to you.

➤ **Working together with a health care provider is important.** If you decide that your child should take medicine, learning about the medicine will help to reduce risks. It is important that you feel comfortable talking with your health care provider. He or she needs to know about the other treatments that have been tried or are currently being used. Sharing information from your child's school team and other people who work with or care for your child will also help. ([CLICK HERE to read Question Prompt List](#) on page 20)

Frequently Asked Questions:

What is autism?

[CLICK HERE to read "What is Autism"](#) on page 13

What medicines are used to treat children with autism?

[CLICK HERE to read about "Medicines Used"](#) on page 15

What are the side effects of these medicines?

[CLICK HERE to read about "Side Effects"](#) on page 15



Why might your health care provider recommend medicines?

[CLICK HERE to read some of the "Reasons"](#) on page 15

What can you do to help your child without taking medicines?

[CLICK HERE to read about "Non-Medicine"](#) options on page 17

COMPARING THE OPTIONS

	Take medicine (for behavior)	Don't take medicine (for behavior)
<p>What is usually involved?</p>	<ul style="list-style-type: none"> You learn about the medicine. You learn what symptoms it can help with. You learn what side effects to watch for. You give medicines every day. You talk with the school team, health team, and others who work with your child to see how well the medicines are working. You watch your child for side effects. You meet with your health care provider regularly. 	<ul style="list-style-type: none"> You can work with your health care provider and others to determine if health problems or other factors might make behavior worse. You can consider other ways to teach desired behavior and reduce problem behavior. You can find other ways to reduce family stress. You can ask family or friends to help you. You can find respite or other community supports to help your child and family.
<p>What are the Benefits? (Pros)</p> 	<ul style="list-style-type: none"> Your child might be less irritable. Problem behaviors might improve. Your child may function better at home, school, and in the community. Your child and family might sleep better. Your child may fit in better with other children. You might feel that you are doing everything possible for your child. 	<ul style="list-style-type: none"> You avoid cost and possible side effect of medicines. You won't have to feel worried about using medicines. You avoid the uncertainty of trying medicines. If behaviors continue to be a problem, you can always try medicines later. You may find other treatments for problem behavior.
<p>What are the Risks? (Cons)</p> 	<ul style="list-style-type: none"> Medicine will not cure autism. Medicine may not help every child with autism. Medicines can cost a lot. Your child might have side effects from the medicine. 	<ul style="list-style-type: none"> Problem behavior might cause stress for family, school, and child. Behavior may continue or get worse. Your child may not be able to be included in as many family, school, or community opportunities. Your child may not do as well in school. Your child may have more difficulty with other children.

Are you interested in what other families decided to do? Many other families have faced this decision. These personal stories may help you.

[CLICK HERE to read Personal Stories](#) on page 18

CONSIDERING PERSONAL BENEFITS AND RISKS

If you are thinking about medicine for your child, it is important for you to name what behaviors cause the most problems. Medicines do not help with all types of behaviors. Medicines are usually used only when behaviors are causing severe problems. You might want to ask others who spend time with your child to tell you what behaviors they see.

✓ **Mark behaviors that are a problem for your child**

Behaviors and Symptoms that might get better with medicines

<input type="checkbox"/>	Hyperactivity (high activity level, "on the go", restless, fidgety)
<input type="checkbox"/>	Short attention span
<input type="checkbox"/>	Impulsivity (acts without thinking)
<input type="checkbox"/>	Irritability (testy, grouchy, oversensitive)
<input type="checkbox"/>	Aggression
<input type="checkbox"/>	Hurts himself or herself
<input type="checkbox"/>	Tantrums
<input type="checkbox"/>	Repeating thoughts (thinks about the same thing over and over)
<input type="checkbox"/>	Repeating behaviors
<input type="checkbox"/>	Sleep problems
<input type="checkbox"/>	Tics
<input type="checkbox"/>	Anxiety (too many fears, worries a lot)
<input type="checkbox"/>	Depression (low mood, sad)

Behaviors and Symptoms that are not usually helped

<input type="checkbox"/>	Does not follow directions
<input type="checkbox"/>	Refusing behaviors (flopping, running)
<input type="checkbox"/>	Slow learning
<input type="checkbox"/>	Not talking, low communication skills
<input type="checkbox"/>	Poor social skills

Other behaviors or symptoms not listed above:

You might want to print this out for your records

It is important to talk with your health care provider. You will want to know if he or she thinks medicines might help. You will want details about the medicines that might be used. Some families find it helpful to write down questions to talk about with their health care provider. [CLICK HERE to read Question Prompt List](#) (on page 20) for a list of questions you might want to ask.

CONSIDERING PERSONAL BENEFITS AND RISKS (CONTINUED)

Medicines are usually used only when behaviors are causing a serious problem for your child. Behaviors can cause problems for your child in different ways, though. This might help you think about how behavior is affecting your child and family.

	Leaning toward choosing medicine	Don't know	Leaning away from medicine
Behavior Improvement?	My child's behavior is not getting better with non-medicine treatments.	My child's behavior is getting a little better with non-medicine treatments.	My child's behavior is getting better with non-medicine treatments.
Learning?	My child's behavior is making it very difficult for him/her to learn.	Behavior is making it a little difficult for my child to learn.	Behavior is not a problem for learning at all.
Problems at school?	My child's behavior is causing a lot of problems at school.	My child's behavior is causing a little problem at school.	My child's behavior is not causing problems at school.
Family stress?	My child's behavior is causing a lot of family stress.	My child's behavior is causing a little family stress.	My child's behavior is not causing any family stress.
Outings?	My child's behavior makes it very difficult to take him to stores, church and other places/ activities. I rarely take him/her out.	My child's behavior makes it a little difficult to take him/her out, but I still do it.	I can take my child out easily.
Bothersome to self?	My child's symptoms bother him/her a lot. He/she seems unhappy, uneasy or uncomfortable.	My child's symptoms bother him/her a little OR I don't know if they bother him/her	I do not think my child's symptoms bother him/her.
Other? (open text)			

You may want to share the information above with your child's health care provider. You or your child's teachers might be also asked to fill out behavior rating forms. This will help your child's team to know more about the behavior problems.

CLARIFYING PERSONAL VALUES

➤ **First consider some of the reasons FOR giving your child medicine:**

	Very important to me ★★★★★	Slightly important to me ★★★	Not important to me ★
I think my child may feel better.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think that problem behaviors might improve.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicine might help my child might do better at school.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicine might help my child might do better at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think our family might have less stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child and our family might sleep better.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child might make friends with greater ease or might join in activities with other children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can deal with side effects of medicine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I want to know that I am doing everything possible for my child, even if it means having him or her take medicine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are there other reasons FOR using medicine that have not been listed? (open text)			

➤ **Next, consider some of the reasons for NOT giving your child medicine:**

	Very important to me ★★★★★	Slightly important to me ★★★	Not important to me ★
I am worried my child might have side effects.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am worried that there might be long- term side effects of medicine that have not been discovered yet.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am worried that problem behaviors might not improve.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The cost of medicine will be hard for my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think that other treatments are better for my child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will feel bad about having my child take medicine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If I choose to have my child take medicine, I may feel uncomfortable if family or friends disagree with my choice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicine will not cure my child’s autism.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking medicine would be very hard for my child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don’t want my child to rely on medicine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are there other reasons for NOT using medicine that have not been listed? (open text)			

WHICH WAY ARE YOU LEANING?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEANING AWAY FROM MEDICINE		UNCERTAIN		LEANING TOWARDS MEDICINE

WHAT DO YOU NEED TO FEEL MORE READY TO DECIDE?

<input type="checkbox"/>	Review Facts → CLICK HERE to review the <u>7j</u> on page 13
<input type="checkbox"/>	Review Options → CLICK HERE to read about Comparing Options on page 5
<input type="checkbox"/>	Get More Support → From Whom? _____
<input type="checkbox"/>	Take more time to think about the decision.

Other (open text):

Questions (open text):

Concerns (open text):

Remember: The goal of this decision aid is to help you sort through your personal values and preferences so that you can communicate them to your provider

WHAT ARE MY OPTIONS?

➤ Now that I have reviewed the information, what are my options?

<input type="checkbox"/>	I could work with my child's health care provider and have my child take medicine to treat behavior or emotional symptoms.
<input type="checkbox"/>	I could discuss medicines and other treatment options more with my health care provider before making a decision.
<input type="checkbox"/>	I could discuss medicines and other treatment options more with my partner and family before making a decision.
<input type="checkbox"/>	I could decide not to have my child take medicines now and think about this option again in ____ months.
<input type="checkbox"/>	I could decide against using medicines for challenging behaviors.

➤ How sure are you about your decision?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NOT SURE AT ALL		SOMEWHAT SURE		VERY SURE

Use this box to list questions, concerns, and next steps:

** You might want to print this out for your records**



Remember:

The goal of this decision aid is for you to choose a treatment that matches the needs and values of your child and family.

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ADDITIONAL INFORMATION

FREQUENTLY ASKED QUESTIONS ABOUT AUTISM

➤ What is autism?

Autism is a general term used to describe a group of developmental disorders known as Pervasive Developmental Disorders (PDD) or Autism Spectrum Disorders (ASD). Disorders in this group include Autistic Disorder, Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) and Asperger Disorder

Many people refer to this group as Autism Spectrum Disorders (ASD). In this decision aid, the term autism is used to refer to this whole group of disorders.

People with autism have symptoms or difficulty in three areas:

1. Social interaction
2. Language as used for social communication
3. Repetitive interests or behaviors

Children with autism have a wide range of learning and thinking developmental skills. Some people have average skills. Some people have higher abilities in some or all areas. Others have a lot of difficulty with thinking and learning.

Daily activities of children with autism vary with each child. Autism symptoms, thinking and learning ability, behaviors, and other medical factors can affect daily functioning.

While all children with autism have problems in three main areas, appearance and severity of symptoms is different in each child;
No two children with autism are exactly alike.

➤ What is the cause of autism?

The exact cause of autism is not known. Some children have autism as part of a genetic disorder such as Fragile X, Tuberous Sclerosis or Angelman's syndrome. Being exposed to certain diseases or chemicals during pregnancy has also been linked to autism. For most children the cause is not known. Scientists think that there are many factors. Important factors include genetics, either on their own or when combined with exposure to environmental factors.

Current measures show that **1 in every 110 children have autism**. Autism is more common in boys than in girls.

➤ Is there a cure for autism?

There is no known cure for autism. Autism is a life-long condition. Improvement in skills is expected over time, with treatment. Some children may improve enough to no longer have an autism diagnosis.

➤ **What might the core symptoms of autism look like?**

Social	<ul style="list-style-type: none"> • Less eye contact, use of gestures or facial expression • Difficulty understanding the emotions, feelings of others • Difficulty playing with same age children • Problems making and keeping friends • Less sharing of interests with others
Communication	<ul style="list-style-type: none"> • Lack of speech • Slow to learn speech • Unusual speech (repeats things, speech sounds unusual) • Difficulty making conversation • Less imitation and pretend play
Repetitive Behavior	<ul style="list-style-type: none"> • Repeating activities or movements (rocks, spins, flaps hands, flicks fingers) • Uncommon, strong, limited interests (often talks about same topic or plays with same item, knows a great amount of information on topic) • Plays with parts of toy rather than the toy as a whole (i.e. spins wheels of toy car)

➤ **What are the long-term outcomes for children with autism?**

Early diagnosis and treatment are very important. Outcomes vary and are hard to predict. Some children develop good language skills and others remain nonverbal. Some children attend their neighborhood school and learn easily. Other children need help in school and have difficulty learning. As adults, some people may live by themselves, get married, and hold a job. Other people might need supports such as living with another adult who can assist him or her. Outcomes are affected by communication and learning skills, behavior, and health. Some children show so much improvement with time and treatment that they are no longer diagnosed with autism.

➤ **Are there common health and medical problems?**

Yes, common problems include:

- Seizure disorder
- Poor nutrition
- Gastrointestinal disorders
- Sleep problems
- Tic disorders
- High rate of accidents and injuries
- Mental health disorders (anxiety, depression, mood disorders)

Would you like more information about autism, diagnosis and treatment?

Link to www.autismspeaks.org/whatisit/index.php

MEDICATIONS AND SIDE EFFECTS

➤ Medicines used

Medicines can't cure autism. But they can help children with certain problem behaviors. They can reduce hyperactivity, anxiety, and irritability, and can improve attention. It is important to be clear about what symptoms are causing problems. This will help your health care provider know if medicine can help your child.

Medicines do not help every child with autism. Even when they help, medicines usually do not eliminate the problem behavior completely. Also, not every problem behavior can be treated with medicine.

There are many different medicines used. The chart below lists types of medicines and behaviors (target symptoms) that the medicine might help with.

➤ Side effects of medicine

Side effects are different for each group of medicines. Some side effects are mild and get better after a few weeks of taking the medicine. Other problems are more severe and may cause the child more problems. Sometimes side effects mean the medicine must be stopped. The chart below lists common side effects for each type of medicine.

Some medicines have an alert (called a black box warning) from the Food and Drug Administration (FDA) about side effects.

For more information on side effects and black box warnings:

www.accessdata.fda.gov/scripts/cder/drugsatfda/

It is important to have regular visits with your health care provider while taking these medicines. It is also important for the family to know about and watch for side effects from the medicines.

➤ Common reasons medicine is recommended

Medicine may be recommended when children have behaviors or symptoms that are moderate to severe and are not getting better with other treatments. Your health care provider may recommend medicine if:

- Problem behaviors put your child at risk of harming himself or others
- Behaviors are causing difficulty and stress for your family at home
- Behaviors are causing learning problems
- Behaviors are making it difficult for the school team to work with your child
- Your child is not able to do activities in the community because of behavior

➤ **Table of standard medication choices & potential side effects**

Medicine Type	Target Behaviors	Possible Side Effects	
Stimulant Medicines			
<ul style="list-style-type: none"> • methylphenidate (Ritalin, Metadate, Concerta, Methylin, Focalin, Daytrana) • mixed amphetamine salts (Adderall) • dextroamphetamine (Dexedrine) • lisdexamfetamine (Vyvanse) 	Hyperactivity Short attention span Impulsive behaviors	Common: Problems falling asleep Less appetite Irritability/emotional outbursts	Less common: Anxiety Depression Repeating behaviors/ thoughts Headaches Diarrhea Social withdrawal Changes in heart rate Tics
Alpha Agonist Medicines			
<ul style="list-style-type: none"> • guanfacine(Tenex,Intuniv) • clonidine (Catapres, Catapres TTS, Kapvay) 	Hyperactivity Short attention span Impulsive behaviors Sleep problems Tics	Common: Sleepiness Irritability	Less Common: Aggression Less appetite Low blood pressure Constipation
Anti-Anxiety Medicines			
<ul style="list-style-type: none"> • fluoxetine (Prozac) • fluvoxamine (Luvox) • sertraline (Zoloft) • paroxetine (Paxil) • citalopram (Celexa) • escitalopram (Lexapro) 	Depression Anxiety Repeating thoughts Repeating behaviors	Common: GI problems (nausea, vomiting, constipation, low appetite) Headaches Problems falling asleep Sleepiness Agitation Weight gain	Less common: Seizure Thoughts of harming self Suicide Serotonin syndrome
Second Generation/ Atypical Antipsychotics			
<ul style="list-style-type: none"> • risperdone (Risperdal) • olanzapine (Zyprexa) • quetiapine (Seroquel) • aripiprazole (Abilify) • ziprasidone (Geodon) 	Irritability Aggression Self-injury Tantrums Sleep problems High activity level Repeating behaviors Tics	Common: Sleepiness Drooling Increased appetite/ weight gain	Less common: High blood sugar, diabetes High cholesterol Tardive dyskinesia (abnormal movements) Quetiapine – eye side effects Ziprasidone- heart side effects
Medicines For Seizures and Mood Problems			
<ul style="list-style-type: none"> • carbamazepine (Tegretol, Carbatrol) • valproic acid (Depakote, Depakene) • lamotrigine (Lamictal) • oxcarbazepine (Trileptal) • topiramate (Topamax) 	Seizures Mood problems Aggression Self-injury	Common: Sleepiness Nausea / Vomiting	Less common: Dizziness Rashes Memory problems Hepatitis Liver failure Pancreatitis Bone marrow suppression Tremor

BESIDES MEDICINE, WHAT ARE THE OTHER OPTIONS?

Some of the most important ways to treat challenging behavior do not involve medicine. Some of these things you can do yourself. You might need help for other things. You might be able to get help from your child's health care provider or school team. You might also be able to get help from local psychologists or social workers. If your child has a community helper or a service coordinator, ask that person.

Try some of these things:

- **Try and see what is causing the behavior.** Sometimes treating a health problem or changing a daily routine can improve behavior.
- **Work with your health care provider to find and treat health problems that might be part of the behavior problem.** For example, children who have pain from a tooth problem or from a stomach problem might have more tantrums. Children with allergies or constipation might be irritable. Children who do not sleep well at night might have problems with attention during the day. Treating these types of medical problems can help with behavior.
- **You can work with a behavior specialist** to figure out reasons for some behaviors. Some children have tantrums to get out of something that is hard to do. Some children hit other people as a way of telling them something when they are not able to talk. Sometimes the adults around children encourage problem behaviors without meaning to. A behavior specialist can help with ways to teach children better behaviors.
- **You can work with a child psychologist.** Some children with autism benefit from counseling or treatments such as Cognitive Behavioral Therapy (CBT). These treatments might help with anxiety, depression, social skills, and other difficulties. A psychologist can also help parents to learn ways to help their child. Some families find that working with a psychologist also helps them cope better.
- **Make a daily schedule.** Children have better behavior when they know what to expect. You might need to use pictures to help your child understand the schedule.
- **Get help in caring for your child.** Every parent needs a break sometimes. Finding good caregivers can be difficult. If respite care is available, use it. You can also ask for help from friends and family. Sometimes caregivers can be found through churches, colleges, and local disability agencies.

PERSONAL STORIES FROM FAMILIES

Other parents have faced a similar decision. Their experiences may help you. Here are some of their personal stories.

*“Having my son try medicines was a very hard decision for me. The thing that helped most was having a trusting relationship with our nurse practitioner. **We tried medicines slowly and carefully.** He did not have much response to medicines initially. He gained weight on one medicine and I was just not comfortable. We recently started a new medicine and it has been working very well. He is much less moody and irritable. His outbursts and aggression at school have gotten much better. I am feeling much more comfortable now. I am happy with my decision.”*

(Parent of Andre, age 10)

*“Medications are not for us. There is not enough information about using them for children and we worry about long-term side effects. **We are working on behavior with the school and our doctors and that is best for us.** We want to wait until there are more answers about medicine and autism.”*

(Parent of Nina, age 7)



*“We tried different things for years before we thought about using medicine. We had decided we were a “non-medicating family”. We tried special diets, vitamins, special school programs and tutoring. I am glad we did not jump into using medicine. But, when his sleep problems and hyperactivity were more than we could handle, our doctor suggested a medicine trial. **It was the right time for us,** and I trusted her. Talking to other parents helped us, too. Our son started to sleep and so did we. He is more settled at school and can be involved in activities.”*

(Parent of Tommy, age 11)

*“My son turned 8 and he was too big for me to keep him safe. He would pull me into a parking lot or traffic. I got scared. I couldn’t take him anywhere. I couldn’t even get him from the car to the house. It was so bad that I had him signed up to move into a group home. It was very sad for me. **Trying medicine was a good option. For our son, it helped.** I found I could handle him. His meltdowns were not so big. Now he is happy and he is living at home with me and my husband. He is still hyper, but we’re living with it.”*

(Parent of Andrew, age 9)

*“Our son has to take seizure medicine to control seizures, so there was no choice about that treatment. It has made us very cautious about using other medicines. **We want the medical and school teams to monitor medicines closely** with us to be sure we are not missing side effects. It is a lot of responsibility.”*

(Parent of John, age 13)

*“We have thought about medicine, but have decided against it so far. Our family tends to be suspicious of medicines and we worry about the stress of extra appointments and the routine of having to give medicines every day. We have found other things to help with his behavior. When he was younger, he was on a special diet that I think helped a lot with his behavior. He also had an aide at school that helped him understand the expectations. As he has gotten older, counseling and spending time with adults in our church community has been helpful. **We still think about medicine to help with our son’s behavior, but it is not the right option for us now.**”*

(Parent of Amir, age 11)

*“We avoided medicine until he was 5. We could deal with his behavior at home. When school started there were more issues with attention and being disruptive. Medicine has helped a little bit with his ability to pay attention. **For me it is really important to stay focused on what symptom are we targeting.** It is hard because there is no medical diagnosis that mandates medicine. I just want to help him do as well as he can.”*

(Parent of Luis, age 6)

QUESTIONS FAMILIES SHOULD ASK THEIR PROVIDER(S)

Sometimes it is helpful for families to write down questions they want to ask their healthcare providers. Below are some common questions and a blank space where you can take notes.

1. Information about the medicine:	Notes (open text)
What medicines might help with my child's behavior problems?	
What are the behaviors (target symptoms) that the medicine might help with?	
How long will it take the medicine to work?	
What are the possible side effects and how common are they?	
Are there FDA advisories for this medicine?	
Are there blood tests or other tests that need to be done before the medicine can be started?	
Are there blood tests or other tests that need to be done after the medication starts?	
When and how will we decide if the medicine is helping?	
Other questions you are thinking of:	

2. Care of child while taking medicine:	Notes (open text)
Is there information about the medicine that I can take home to look at?	
Can you write instructions for me?	
Who do I contact if my child has problems or I have worries?	
What else should my family or school team be doing to help with behavior?	
What happens if my child takes too much medicine or misses a dose?	
Are there foods, medicines, vitamins or supplements that affect this medicine?	
How do I explain the medicine to my child and to my family?	
Should I tell the school about the medicine?	
How often will my child need to come back to the clinic? Who will we see for follow-up visits?	
Other questions you are thinking of:	

3. Next Steps	Notes (open text)
If the medicine is helpful, how long would we continue the medicine?	
What happens if this medicine does not help?	
How quickly can the medicine be stopped if we do not like the effects?	
Other questions you are thinking of:	