

Autism and Medicine for Challenging Behaviors: Safe and Careful Use



A Guide for Families of Children with Autism



These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported in part by cooperative agreement UA3 MC 11054, Autism Intervention Research Network on Physical Health (AIR-P Network) from the Maternal and Child Health Bureau (Combating Autism Act of 2006, as amended by the Combating Autism Reauthorization Act of 2011), Health Resources and Services Administration, Department of Health and Human Service to the Massachusetts General Hospital.

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Introduction

This tool kit is for families of children with autism* and other neurodevelopmental disorders who have decided to use medicines to help treat their child’s challenging behavior or manage emotional issues.

*For the purposes of this tool kit, the term “autism” will be used to describe children with all types of Autism Spectrum Disorders, including Autistic Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS).

This tool kit will help **families**:

- ✓ Work with their child’s doctor or nurse to learn about medicines
- ✓ Get the information they need about recommended medicines
- ✓ Ask the right questions
- ✓ Give medicines safely
- ✓ Know if the treatment is working
- ✓ Know if there are side effects and what to do
- ✓ Be confident and informed advocates for their child

This tool kit will help **health care providers**:

- ✓ Explain medicine choices to families
- ✓ Teach families about watching for effectiveness
- ✓ Teach families about checking for side effects and good response
- ✓ Give information about managing common side effects
- ✓ Be clear with families about goals of treatment, possible risks and benefits

Autism: Should My Child Take Medicine for Challenging Behavior?



A Decision Aid for Parents of Children with Autism Spectrum Disorder



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Many children with autism have challenging behaviors or difficulties with their feelings and emotions. Many treatments help. Medicine is one of those treatments, but medicine is not right for every child. It is best to use medicine only after behavioral and educational methods have been tried.

Families who are still deciding about the use of medicine will benefit from another tool kit. The name of the tool kit is “Autism: Should My Child Take Medicine for Challenging Behavior: A Decision Aid for Parents of Children with Autism.” Visit us online at www.autismspeaks.org/atn. [CLICK HERE](#) to download the tool kit

Starting Medicines: An Overview

When thinking about starting medicines it is important to work closely with your child's health care team. It is important to work together with someone who:



- Knows you and your child
- Has experience working with children with autism and behavior difficulties
- Is knowledgeable about the use of medicines in children with autism
- Can help you know the possible risks and possible benefits of each medicine.

Medicines are usually prescribed by a physician or nurse practitioner. Sometimes this is your child's pediatrician or primary care provider (PCP). Sometimes this is a specialist in child development, psychiatry, or neurology.

Sharing your family's values and thoughts helps the doctor or nurse to understand your family. Once you have made a decision to try medicine, it is important to have the right information. This tool kit will help you to give the medicine safely, look for side effects, and know if the medicine is working.

What type of medicine is best for my child?

The type of medicine recommended will depend on the problems or "target symptoms" for your child. Each medicine treats different target symptoms. Your doctor or nurse will think about possible side effects and benefits of the medicine for your child. If there is more than one option, he or she might discuss the pros and cons of those options. When medicine is prescribed, it is usually thought of as a "trial" to see if the medicine helps with the target symptoms. If improvement is not seen, medicine is usually stopped or changed.

How long will it take my child's medicine to work?

How long it takes a medicine to take effect is different for every medicine. Some medicines work within a few minutes. Some can take a month or more to see the full effect. It is important to talk with your child's doctor or nurse to find out how long it will take your child's medicine to work.

What is the right amount of medicine for my child?

The dose of medicine is different for each child. Even with the same medicine, some children do well on a low dose and some children need higher doses. The dose depends on things like the symptom being treated, the child's age and weight, general health and the child's response to the medicine. Most doctors and nurses will start at a low dose and increase slowly until the symptom gets better. This helps to find the dose that is right for the child and to lessen side effects. How fast the dose is changed depends on the medicine. Later in this tool kit is a worksheet that can be used with your doctor or nurse to write down a schedule for increasing the medicine ([MEDICINE ACTION PLAN](#), (page26)).

Starting Medicines: An Overview (cont.)

What are Target Symptoms?

Target symptoms are those problems or behaviors that are causing trouble for the child. It is important to be clear about what symptoms are the biggest problems for your child. This will help you and your doctor or nurse work together to choose the best medicine. Agreeing on target symptoms will also help to measure if medicine is helping.

What are Side Effects? Side effects are negative or unwanted effects of a medicine. Later in this tool kit, you will find more information on [SIDE EFFECTS](#) (pages 9-18), ways to monitor for side effects, and ways to manage common side effects at home. Different medicines have different side effects. For that reason, some medicines have to be monitored much more closely than others.

What does “Off-Label” mean?

Off-label use is when medicine is prescribed for a reason, to an age group, or at a dose that has not been approved by the U.S. Food and Drug Administration (FDA). Off-label drug use is common and legal. Many medicines are known to be helpful to treat an age group or a problem that is different from the condition for which the medicine is approved. It often takes many years to get additional FDA approvals, and drug companies do not always seek them. For this reason, doctors and patients do not have to wait for FDA approval to begin using the drug. Studies of new drugs in children are not common. For that reason, many medicines prescribed to children with autism are “off-label.”

When your doctor or nurse prescribes a drug for your child, ask if it is an FDA approved use, or “off-label.” If the use is off-label, ask what the drug is approved for and for what group of people. Ask about the proof that supports the off-label use. The drug’s website will list the FDA-accepted use and the groups that are approved to take the drug. Trusted websites, such as that of the National Institute of Mental Health (NIMH) (<http://www.nimh.nih.gov/health/publications/a-parents-guide-to-autism-spectrum-disorder/complete-index.shtml#pub5>) are a good source of information about FDA-approved and off-label medication treatment in autism.

Should I tell other people my child is taking medicine?

The decision to tell other people about your child’s medicine use is best made by the family. Talking with your child’s doctor or nurse might help you make this decision. If the medicine has side effects and other people take care of your child, it is important for them to know. However, sometimes it is helpful to try a medication without letting other people know. That way, reports on the child will not be affected by knowing he or she is taking medicine. It is always important to work with school teams and other people who work with your child to know how the medicine affects a child in different situations.

Some families have trouble telling friends or family members that their child is taking medicine. Sometimes important people in a child’s life have strong opinions about the use of medicines. Talk with your doctor or nurse about how to handle this. Often telling others that you are working hard, along with your child’s team, to help your child be his or her best is all others need to hear.

Target Symptoms

Target symptoms are those problems or behaviors that are causing trouble for your child that you would like to be helped by treatment or medicine. For example, the target symptom of a headache may get better with pain relievers.

There are many different possible target symptoms in children with autism. It is important to decide which target symptoms are causing trouble for your child. At this time there are no medicines that treat the core social and communication symptoms of autism. Medicines do not help with thinking and learning problems. However, by helping symptoms that can get better with medicine, a child might behave better in school or therapy, which can help a child to learn better.

Common target symptoms for children with autism are:

- Hyperactivity (high activity level)
- Short attention span
- Impulsive behaviors (acting without thinking)
- Irritability
- Agitation
- Aggression
- Self-injury
- Tantrums
- Repeating thoughts, interests and behaviors
- Sleep problems
- Anxiety
- Depression
- Mood problems
- Tics



Before your child starts a medication, it is important for you to know what symptoms or problems might improve or change with the medicine. Different medicine will help different target symptoms. Some medicines can help with more than one target symptom. Talk to your child's doctor, teachers, and therapists to help decide which target symptoms are causing your child the most problems.

Looking for Medicine Effect

When starting a new medicine, it is important to plan a way to measure how helpful it is. How this is done depends on the child, the family, and the target symptoms. In general, measuring the helpfulness of any medication includes keeping track of the target symptoms in one or more of the following ways:

Frequency – How *often* does the target symptom occur in a specific amount of time?

Examples:

- Number of tantrums each day
- Number of times child wakes during the night each week

Severity – How *severe* is the target symptom?

Examples:

- How hyperactive is the child?
- How severe is the tantrum?

Duration – How *long* does the target symptom last?

Examples:

- How long does the tantrum last?
- How long does it take the child to fall asleep?

We call keeping track of target symptoms “monitoring.” It is important to monitor the target symptoms BEFORE AND AFTER starting medicine.



There are other things that may also be important to monitor, such as medicine dose changes or important events in your child’s life. Life events can change your child’s target symptoms. Life events can make it harder to know if medicines are helping. Important life events might include:

- Going to a new school
- New staff or classmates at school
- Moving to a new house
- Birth of a sibling
- Parent getting or losing a job
- Starting a new therapy or getting a new therapist
- Illness or injury to child or family member
- New person living in house

Make sure you tell your doctor if your child has any of these or other important life events happen.

Ways to Measure and Keep Track of Changes in Target Symptoms:

There are many ways to keep track of changes in target symptoms. You can talk to your child’s doctor, nurse, therapist, or other people who work with him about the best way for your child. Things that are important when keeping track of target symptoms are:

- ✓ **Keep it simple.** How you measure target symptoms needs to be easy enough for you to do it every day.
- ✓ **Write it down.** It is important to record information on paper or computer. At the end of this toolkit are monitoring sheets you can use. You can also make up your own monitoring sheets.
- ✓ **Start monitoring** target symptoms at least 1 week BEFORE starting a medicine.
- ✓ **Continue to keep track** of target symptoms for several weeks or months AFTER starting medicine.

Target Symptom: Sleep Onset
(time it takes for a child to fall asleep)

If your child is taking a medication to help with going to sleep you might write down:

- Time child was put to bed
- Time child fell asleep

Tools To Consider

Calendars or charts: This can be a helpful way to keep track of the frequency of certain behaviors.

Standard behavior rating scales: Some people use standard forms to measure medicine effect. These can be a useful way to get information about the frequency and severity of a child’s problem behaviors and about how things have changed over time. You may have filled out these forms prior to starting medicine. You may be asked to fill them out again at different times during the use of a medicine. Sometimes teachers or even your child will fill out forms.

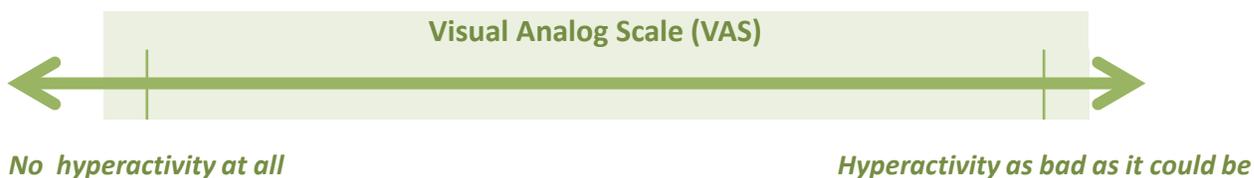
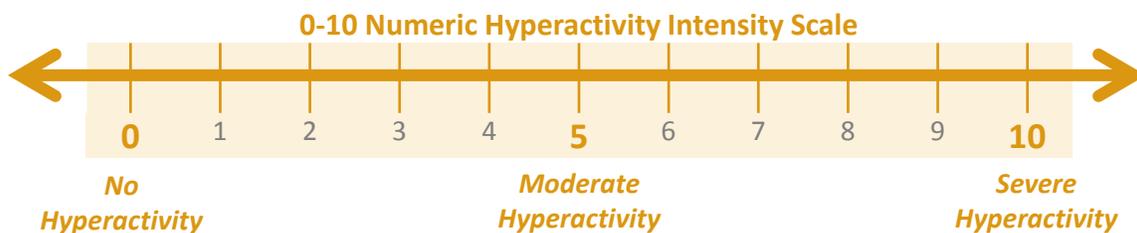
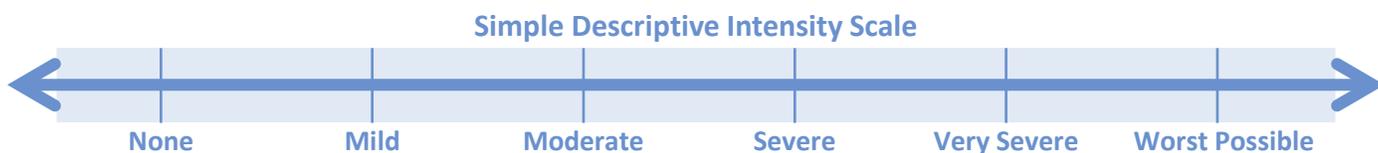
Individual behavior rating scales: Some people use forms that are specific for the child and the child’s target symptoms. See the sample [BEHAVIOR RATING FORMS](#) (pages 27-31). These scales help you keep track of how severe a behavior is or how often it occurs. This will help you to know if things are better or worse.

Target Symptom: Hyperactivity

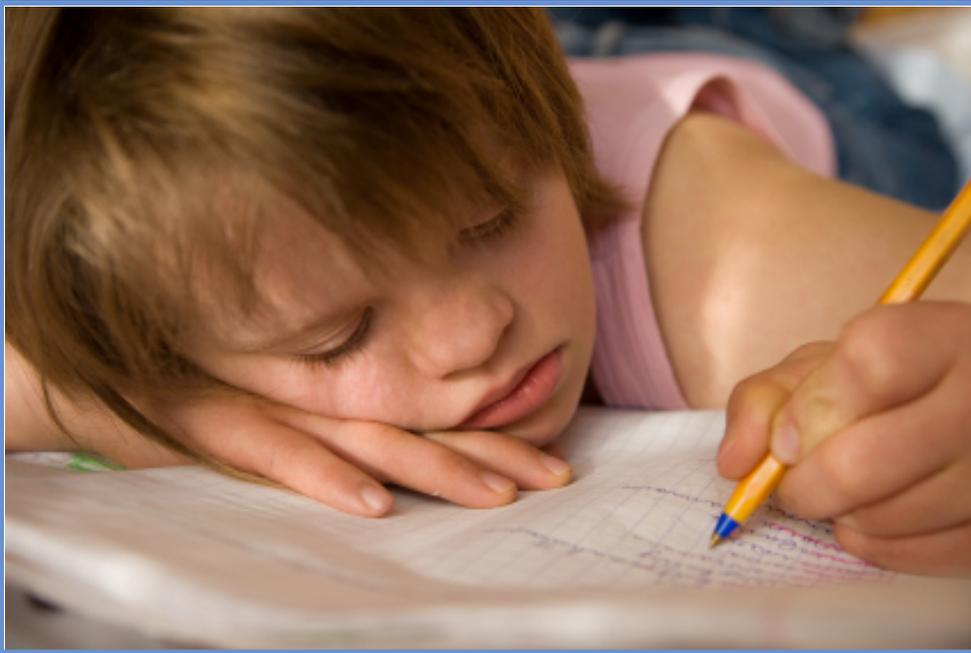
If your child is taking medicine for hyperactivity, you might track :

- How many times child is fidgeting, pacing, or climbing during quiet times
- How many times child got out of seat during dinner
- How many minutes child stayed at table doing homework
- Severity of hyperactivity during certain time periods in the day

Below are examples of scales to measure hyperactivity. You could make a scale for your child’s symptoms



Side Effects



Monitoring for Side Effects

Worry about side effects is one of the main reasons families and health care providers avoid using medicines. All medicines can have side effects. The specific types of side effects are different for each medicine and for each person. The risk of side effects often changes with the medicine dose and other factors.

Things that might affect side effects:

- Other medicines the child takes regularly or occasionally
- Other medical conditions (like seizures or diabetes)
- Other behavioral symptoms (like trouble falling asleep)
- Family or genetic factors



Things your doctor or nurse will do to lower risk of side effects:

1. Use medicines with fewer side effects before using medicines with more common or more serious side effects
2. Start the medicine at a low dose. Increase the dose slowly if needed.
3. Use as few medicines at the same time as possible.

Things families can do to lower risk of side effects:

1. Talk to your doctor, nurse, or pharmacist before using over the counter medicines.
2. Watch for side effects and talk with your doctor or nurse if you notice any.
3. Get information. Having enough information about the medicine is one of the best ways families can lower risk of side effects. It is important that the information is correct. You could get information from:
 - Your child's doctor or nurse
 - A pharmacist
 - Certain, reliable websites on the internet ([RESOURCES](#) - page 32)
 - From parent books about medicines and children ([RESOURCES](#) - page 32)

Monitoring for Common Side Effects (cont.)

Questions to ask:

Some families are worried about asking too many questions or do not know what questions to ask. Asking questions is important. For ideas of questions to ask, see the [QUESTION PROMPT LIST](#) (page 20).

What should I do if I think my child is having a side effect from the medicine?

This depends on how serious the side effect is. Steps a family might take include:

- Review information about the medicine from the doctor or nurse who prescribed it or from the pharmacist.
- Know that most medicine side effects are mild and go away with time. If the side effect is not serious you can:
 - Talk with your doctor or nurse
 - Wait and see if the side effect gets better as your child adjusts to the medicine
 - Try other things that might help, like giving the medicine with food. For information on dealing with [SLEEP](#) and [APPETITE](#) side effects, see handouts in this tool kit (pages 12-15).
- Serious side effects are rare. Serious side effects such as: an allergic reaction, rigid muscles, muscle spasms, heart or blood pressure problems, or severe changes in alertness and thinking, thoughts about hurting self or others, changes in mood mean you should call your doctor or nurse right away. If you cannot talk with your doctor immediately, you should seek emergency care.

Managing Common Side Effects

Some side effects can be managed with some changes at home. The following links give you information on things you can do at home if you child has these side effects:

- [Daytime sleepiness](#) (page 12)
- [Night time sleep problems](#) (page 13)
- [Low appetite/ weight loss](#) (page 14)
- [Big appetite/ weight gain](#) (page 16)



U.S. Department of Health & Human Services



U.S. Food and Drug Administration
Protecting and Promoting *Your Health*

Some medicines have an alert about side effects from the Food and Drug Administration (FDA) called a boxed or black box warning. For more information on side effects and boxed or black box warnings visit:
www.accessdata.fda.gov/scripts/cder/drugsatfda/

Managing Side Effects – Daytime Sleepiness

- Sleepiness during the day is a side effect of some medicines. Often, children get used to the medicine after a few days and the sleepiness goes away.

Things that might help:

- Make sure your child is getting enough sleep during the night. Children who do not get enough nighttime sleep will be more tired during the day. If getting enough sleep at night is a problem, see [NIGHT TIME SLEEP PROBLEMS](#) (page 13) in this tool kit or read the [ATN/AIR-P Sleep Tool Kit](#) online.
- Keep your child active during the day. Plan a daily schedule that includes physical activity and time outdoors with exposure to sunlight.
- Be patient if this is an expected side effect of this medicine. The sleepiness might get better in a few days or weeks.



You should call your child's doctor or nurse if:



- Your child is very sleepy, and is difficult to wake up. This is especially important if he or she just started a new medicine or the dose was increased.
- Your child has other symptoms such as falling when he or she gets out of bed, complaining of dizziness, or symptoms that make you think your child might be sick.
- Sleepiness continues after 3-5 days on the new medicine or new dose. The dose or time given may need to be changed. Depending on the medicine, it might take longer for the sleepiness to go away. Your doctor or nurse will help you to know whether to wait longer.

Managing Side Effects – Nighttime Sleep Problems

Many children have sleep problems. Sometimes sleep problems get worse when a child takes medicines. Sometimes medicines cause sleep problems for a child who does not usually have sleep problems. Some children have difficulty falling asleep. Others wake up during the night or are sleepy during the day.

Step 1:

The first step to helping with sleep is to think about your child's sleep habits. This is very important if your child had sleep problems before medicines started.

Sleep experts suggest these ideas to help your child sleep better:

Daytime:

- Stop naps during the day.
- Eliminate caffeine (chocolate, sodas, tea, coffee)
- Plan activities during the day that will help your child feel tired at night.

Evening:

- Avoid TV, computers, and electronics in the evening. These make it hard to sleep by giving off light that makes the body think it is daytime.
- Avoid other stimulating activities in the evening.

Bedtime:

- Keep the same time for bed each night.
- Keep the same routines before bed each night.
- Make sure you child has a comfortable place to sleep that is the same each night.
- Have you child fall asleep in the same place you want him or her to sleep all night.
- Teach your child to fall asleep alone.

Step 2:

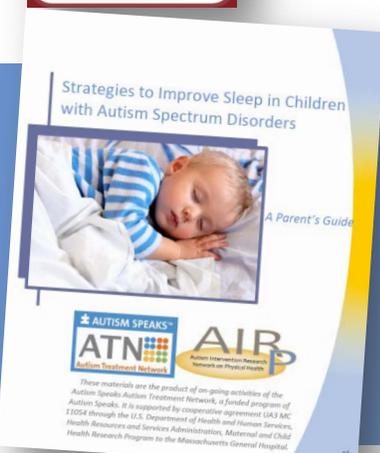
If changing your child's sleep habits does not help, talk with your child's doctor or nurse.

- Sometimes changing the time or dose of your child's medicines can help.
- If sleep is a big problem, the medicine might need to be changed or stopped. It is important to talk with your child's doctor or nurse before doing this.
- Sometimes other medicines such as melatonin at bedtime can help.



You should call your child's doctor or nurse if:

- Your child has big changes in sleep that started with medicine.
- Sleep problems continue even after following the above recommendations.



The above information was taken from the ATN / AIR-P Sleep Tool Kit. Please see the tool kit for more ideas about changing sleep habits and helping children sleep well at night.

[CLICK HERE to download the ATN/AIR-P SLEEP TOOL KIT](#)

Managing Side Effects – Low Appetite

Some medicines used for behavior cause children to have less appetite. The most common medicines causing this side effect are stimulants (see text box for a list). Many families are able to deal with this problem by making changes in eating routines and in the foods the child eats. **Talk to your doctor or nurse if you are worried about your child's weight or growth. He or she can help you to know if weight and growth are a problem.**

Eating Routines:

For many children, minor changes in eating routines or schedules will help a child to eat more. Here are ways eating routines can be changed:

- Plan meals and snacks for when the medicine is not yet working or is wearing off.
- Serve breakfast before giving morning medicines.
- If your child gets a mid-day medicine dose, give it after lunch.
- Consider small but frequent, healthy meals
- Make sure breakfast contains high energy and protein rich foods, which will provide more energy throughout the day. For ideas see: [RECOMMENDED HIGH ENERGY FOODS LIST](#) (page 15).
- At meals, offer solid foods first, to avoid filling up on liquids.
- Use pre-planned mealtimes and snack times. Children often eat more when they have an eating schedule.

Stimulant medications that often decrease appetite:

- methylphenidate (Ritalin, Metadate, Concerta, Methylin, Daytrana)
- dexamethylphenidate (Focalin)
- mixed amphetamine salts (Adderall)
- dextroamphetamine (Dexedrine)
- lisdexamfetamine (Vyvanse)

Food Choices:

For a child who eats small amounts, it is important to make sure that the foods he or she eats are healthy, high in energy, and high in vitamins and nutrients. Protein is digested more slowly than carbohydrates (pasta, bread, cereals) and will provide energy for a longer time. This can be an important way to make sure a child has enough energy throughout the day. Many children with autism are very fussy about what foods they will eat, so families often have to work hard to find healthy, high-energy, nutritious food choices.

These are general ideas that help many children to grow and gain weight while taking medicines that reduce appetite. There are times when families need more help. Make sure you talk with your child's doctor or nurse. Signs you might need more help:

- Steady or constant weight loss or not being able to gain weight
- Child has a very selective diet
- Feeding behavior problems get worse with medicine
- Child has food allergies or is on a special diet
- Child has other medical problems

For children who are losing weight or not gaining enough weight, it can help to add extra calories to the foods the child normally eats.

- Powdered milk (can be added to drinks, milkshakes, puddings, yogurt, soft foods)
- Eggs (add extra eggs to cake mixes, pancakes, and other baked items)
- Nut butters (can be added to milkshakes or blended in other soft foods)
- Instant breakfast drink powders (add to milk, yogurt, shakes)
- Butters and oils
- Cheese sauce

Sometimes, making **small changes can help add calories**, for example:

- From skim milk to 2% or whole milk
- From regular chocolate milk powder to an instant breakfast powder
- From light to whole milk yogurt or cheese



Managing Side Effects – Low Appetite

Recommended Foods

for children not growing or not gaining enough weight due to medicines
 (These foods are high in calories, protein, and other nutrients)

Milk and milk products	<ul style="list-style-type: none"> • Whole milk, cream, half and half • Whole milk yogurt, pudding, cheese, cottage cheese • Powdered nonfat dry milk (added to other foods/drinks) 	<ul style="list-style-type: none"> • Sweetened condensed milk • Sour cream • Ice cream
Meat and protein foods	<ul style="list-style-type: none"> • Any meat, fish, seafood or poultry, but especially high-fat options (chicken or turkey with skin, dark meat, bacon, sausage, 80% or less lean ground beef, bologna, salmon) 	<ul style="list-style-type: none"> • Eggs (scrambled, fried, hard-boiled, and added to other foods) • Nuts and nut butters • Dried beans and pea, hummus
Grains	<ul style="list-style-type: none"> • Breads and rolls with butter, cream cheese, peanut butter or other high calorie toppings • Muffins • Hot cereals made with whole milk or cream 	<ul style="list-style-type: none"> • Pancakes, French toast with butter and syrup • Cheese-flavored crackers, club crackers, other crackers made with fat • Ready to eat cereals with whole milk or cream
Vegetables	<ul style="list-style-type: none"> • Avocados and olives 	<ul style="list-style-type: none"> • All vegetables prepared with oil, butter, cream or cheese sauces
Fruits	<ul style="list-style-type: none"> • All fruits (serve with sugar or cream on top, or with yogurt for dipping) 	
Fats and Oils	<ul style="list-style-type: none"> • Butter, margarine, oil, mayonnaise (use in generous amounts) 	
Drinks	<ul style="list-style-type: none"> • Whole milk and flavored milks (chocolate, strawberry) • Powdered breakfast drinks added to whole milk 	<ul style="list-style-type: none"> • Milk shakes, eggnog • Hot chocolate made with whole milk • Yogurt drinks, especially if made with whole milk yogurt
Other	<ul style="list-style-type: none"> • Barbecue, tartar, or sweet-and-sour sauce • Ketchup • Maple syrup • Cheese spread 	<ul style="list-style-type: none"> • Hummus • Guacamole • Creamed soups



Managing Side Effects – Large Appetite/Weight Gain

Some medicines used for behavior cause children to have more appetite or to gain too much weight. The most common medicines causing this side effect are the antipsychotic medicines listed in the box. Other medicines can also cause this problem. When using medicines that increase appetite, it is important to watch the child's growth. Body Mass Index (BMI) is one way to know if a child's weight is healthy. BMI is tracked on a chart, with healthy numbers in the green range. ([CDC – BMI CALCULATOR](#)).

There are two main ways to prevent or treat weight gain:

1. Reduce calories your child eats
2. Increase daily physical activity, or energy your child uses up

The best thing for most people is to do both. This sheet will help with healthy food choices. Information about [INCREASING PHYSICAL ACTIVITY](#) (page 18).

Antipsychotic medications that often cause weight gain:

- risperidone (Risperdal)
- olanzapine (Zyprexa)
- quetiapine (Seroquel)
- aripiprazole (Abilify)
- ziprasidone (Geodon)

Eating Routines:

- Serve most food only at pre-planned mealtimes and snack times. Overeating and hunger can be managed more easily when children eat on a schedule.
- Do not allow "grazing" or snacking throughout the day. This may result in overeating and high calorie food choices (cookies, candy, chips, ice cream).
- Eat fast foods once a week or less.
- Supervise all food choices.
- Do not allow child to get food without an adult.
- Hide, lock or secure high calorie foods if needed.
- Avoid using food as a reward.
- Tell team at school and others who care for your child about healthy weight and eating goals.

High Fiber Foods:

- Berries
- Pears
- Apples
- Raisins
- Oatmeal
- Popcorn
- High fiber cereals (raisin bran, bran squares)



Mealtimes:

- Serve your child's food on his or her plate in appropriate serving sizes. Avoid buffet style meals. Avoid having serving dishes on the table.
- Give smaller portions. Use smaller bowls and plates to promote smaller portions.
- Allow second helpings only of fruits, salads, and vegetables.
- If your family eats dessert, provide healthy desserts (fruit, low-fat yogurt)

Food choices

- Give protein rich foods at breakfast. Protein gives energy that lasts throughout the day.
- Increase high-fiber foods in child's diet. This creates a feeling of fullness and helps prevent overeating.
- Reduce 100% juice to 4-8 ounces per day and dilute with water.
- Eliminate soda.
- Do not keep high energy snack foods, sodas, and sugar sweetened drinks in the home.

These are general ideas that help many families with slowing weight gain when a child takes medicine. There are times when families need more help. Make sure you talk with your child's doctor or nurse. Children with the following symptoms or situations may need additional help from their doctor, nurse, or a registered dietitian:



- Extreme weight gain, weight gain that continues even with food changes, high Body Mass Index
- Behavior problems that make diet changes difficult
- Problems with blood sugar or cholesterol levels
- Very limited (or selective) diet
- Food allergies, special diets, other medical or genetic problem

Managing Side Effects – Large Appetite/Weight Gain



Replace HIGH calorie foods with LOW calorie foods

	INSTEAD of: 	CHOOSE: 
General	<i>(Foods high in calories)</i>	<i>(Foods lower in calories & higher in nutrients and fiber)</i>
Grains	White pasta, rice, or bread Sweetened cereals	Smaller portions of: Whole grain pasta and rice, whole grain bread Whole grain, high fiber cereals
Milk and Milk foods	Whole milk Regular cheese Regular sour cream Full fat yogurt Ice cream	Fat-free or low-fat milk Reduced-fat cheese Reduced-fat or fat-free sour cream Nonfat or low-fat yogurt
Meat and Other Protein Foods	High fat meats, such as bacon, sausage, or hamburger Poultry with skin Fried meats	Lean meat and fish Chicken and turkey without skin Dried beans and peas cooked without added fat
Vegetables	Starchy vegetables like potatoes or corn Vegetables prepared with butters or sauces French fries	Non-starchy vegetables (broccoli, carrots, celery) Small portions of potatoes, corn, peas, or other starchy vegetables
Fruits	Large portions of fruit juice Canned fruits in heavy syrup	Fresh, frozen, or canned fruit without added sugar or syrup
Fats and Oils	Fried foods Added fats and oils (cream, butter, margarine) Regular salad dressing (more than 1 Tablespoon)	Foods cooked without fats or oils Good: baked, broiled, roasted, steamed, grilled, or boiled Reduced calorie or fat free salad dressings
Desserts and Sweets	Candy Cake Pie Cookies, Ice cream	Fruit Low fat yogurt Low calorie/low fat ice cream Low calorie/ low fat cookies Fruit popsicles
Drinks	Regular sodas and soft drinks Juice and fruit flavored drinks Hot beverages made with milk, cream, syrups	Water Diet sodas Sugar-free drinks

Ways to Increase Physical Activity

For children who gain weight while taking medicine, changes in both diet and activity are important. It is sometimes hard to help children with autism be more active. Here are some ideas to try.

Home/Community:

- Plan outings to neighborhood parks or playgrounds the child enjoys.
- Plan active family time (games of tag, marching, dancing, jumping rope).
- Use fitness videos, electronic games, DVDs and television programs.
- Use rewards for physical activity to establish positive habits.
- Take daily walks. Try walking a family pet or mall walking. Consider a regular route if your child likes routine.
- Encourage your child to be active during quiet activities like watching TV. March, jump, dance or run during each television commercial.
- Investigate use of medical accounts, family reimbursement or health insurance plans for specialized activities, facility memberships or equipment.
- Take advantage of your child's love for routines. Include daily physical activity as part of the before school, after school, and weekend routine.
- Create visual or written daily schedules that include physical activities.
- Talk to family members, sitters, school, day care and community providers that are involved with your child. Ask them to include physical activity in their time with your child.
- Visit community or school fitness facilities, gyms, or pools.
- Join community programs. Many children with autism enjoy swimming, horse riding, yoga, and karate. Many communities have specialized sports programs such as Special Olympics and Challenger Sports.



School:

- Make sure physical education includes energy burning activities.
- Add daily fitness walks in school program for break time.
- Include short spurts of physical activity in school therapies and classroom time.
- Make sure your child participates in daily recess. Do not allow loss of recess to be used as a consequence for negative behavior.
- Participate in school programs such as sports activities and fitness clubs. Ask your school team or Committee for Special Education for needed supports and accommodations.

Getting Help:

All children have different skills, abilities, likes and dislikes. Some children and families need help to increase a child's activity. People who might be able to help:

- Child's doctor or nurse, especially if there are health problems or activity restrictions
- School Physical Education (PE) or Adaptive PE teacher – may help plan more physical activity in the school program each day
- Child's physical therapist – may suggest activities to help your child be more active
- Child's occupational therapist – may suggest other activities to help your child be more active
- Behavior therapists, psychologists – may help with developing routines and reinforcing physical activity
- Community service providers (respite providers, habilitation specialists, service coordinators) – can assist by identifying active programs, or people who could be active with your child
- Friend, neighbor, local teenager or college student – may take child for walks, play in the yard, or participate in activities with a child who needs assistance to join in successfully

MEDICINE TOOLS & RESOURCES



Question Prompt List

Talking to your child's doctor or nurse is one important way to learn about your child's medicine. Some families have a hard time thinking of the right questions to ask. It is often helpful to make a list of questions to ask before an appointment. That way there is less chance of forgetting an important question.

The questions below are the types of questions some families like to ask. They might help you think of the questions you want to ask. You might want to circle or star the questions that you want to ask and add other questions at the bottom. It might be helpful to write down answers to your questions.

Medicine options:

- What are the medicine options?
- Are any of the options likely to work better or have fewer side effects?

About the medicine:

- What are the symptoms that you think the medicine will help with?
- Is the medicine FDA approved for this use or is it "off-label"?
- (If medicine is off-label) What is the approved use of this medicine? What information shows this medicine is effective in children with problems like my child has?

Effectiveness:

- How should we monitor to see if this medicine is effective?

Side effects:

- What are the most common side effects of this medicine?
- How will we monitor for side effects? Observation? Checklists/rating scales? Blood or other tests? Physical examinations?
- What should I do if my child has one of these side effects?
- Who can I talk to if I am concerned about side effects? How can I reach this person?
- Do these side effects usually go away? Will the side effects stay? How long?
- What can be done to help my child deal with these side effects? (like changing the time the medicine is given, giving it with food, etc)?
- Does this medicine ever have severe side effects?
- How would I know if my child is having these severe side effects? What would it look like?
- What should I do if I think my child is having a severe side effect? (Stop medicine? Call office? Go to Emergency room?)

Common Medicines in Autism

Medicine Type	Target Behaviors	Possible Common Side Effects	
Stimulant Medicines <ul style="list-style-type: none"> • methylphenidate (Ritalin, Metadate, Concerta, Methylin, Daytrana) • dexamethylphenidate (Focalin) • mixed amphetamine salts (Adderall) • dextroamphetamine (Dexedrine) • lisdexamfetamine (Vyvanse) 	Hyperactivity (high activity level) Short attention span Impulsive behaviors	Common: Problems falling asleep Less appetite Irritability/emotional outbursts	Less common: Tics Anxiety, depression Repeating behaviors and thoughts Headaches Diarrhea Social withdrawal Changes in heart rate or rhythm*
Atomoxetine (Strattera)	Hyperactivity (high activity level) Short attention span Impulsive behaviors	Common: Sleepiness GI problems (nausea, vomiting, constipation, low appetite)	Less common: Thoughts of harming self, suicide*
Alpha Agonists Medicines <ul style="list-style-type: none"> • guanfacine (Tenex, Intuniv) • clonidine (Catapres, Catapres TTS, Kapvay) 	Hyperactivity (high activity level) Short attention span Impulsive behaviors Sleep problems Tics	Common: Sleepiness Low blood pressure Irritability	Less common: Constipation High blood pressure if stopped quickly
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/ increased activity level Weight gain	Less common: Seizures Heart rhythm problems* Thoughts of harming self, suicide* Serotonin syndrome
Second Generation/ Atypical Antipsychotics <ul style="list-style-type: none"> • risperidone (Risperdal) • olanzapine (Zyprexa) • quetiapine (Seroquel) • aripiprazole (Abilify) • ziprasidone (Geodon) 	Irritability Aggression Self-injury Tantrums Sleep problems Hyperactivity (High activity level) Repeating behaviors Tics	Common: Sleepiness Drooling Increased appetite/ weight gain	Less common: High cholesterol High blood sugar, diabetes Movement side effects** Seroquel –eye side effects Geodon – heart side effects
Seizure Medicines <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: Rashes Sleepiness Nausea, vomiting Memory problems	Less common: Hepatitis, liver failure Pancreatitis Bone marrow suppression Tremor, dizziness

Additional information on specific medicines: <http://www.nlm.nih.gov/medlineplus/druginformation.html>

*Boxed and black boxed warning: Page 22 for more information

**Movement disorder side effects: Page 22 for more information

Common Medicines in Autism (cont.)

Boxed and Black box warnings

 U.S. Department of Health & Human Services

 **U.S. Food and Drug Administration**
Protecting and Promoting Your Health

Some medicines have an alert about side effects from the Food and Drug Administration (FDA) called a boxed or black box warning. For more information on side effects and boxed or black box warnings visit: www.accessdata.fda.gov/scripts/cder/drugsatfda/

Movement Disorder Side Effects

Movement disorders are rare but sometimes serious side effects of some medicines. These side effects can happen right after starting a medicine, with dose increases, after a person has taken the medicine for a long time, or when medicines are stopped. There are several different types of movement side effects, but all include changes in how the child moves his body or muscles. Because these side effects can be serious, families should seek medical care right away if these types of changes are seen. Because children with autism often have movements that they do over and over before starting medicine, it is sometimes difficult to know for sure if new movements are medicine side effects. It is important to work with your child's doctor or nurse to monitor. Things families might see that could be a movement side effect:

- Rigid or stiff muscles, along with high temperature, change in alertness, heart rate or breathing
- Muscle spasms or cramping
- Slowed movements of the body
- Pacing, restlessness, inability to sit still
- Staring episodes, eye blinking, unusual eye closing, unusual eye movements
- Unusual mouth or tongue movements
- Changes in walking, tremors, repetitive movements the child cannot control

Pill Swallowing – Tips for Parents

There are many good reasons for helping your child learn how to swallow a pill. They include:

- It helps to make sure that your child is safely getting the right amount of medicine.
- It allows the doctor or nurse to choose the very best medicine for your child’s condition. Some medicines do not come in liquid or chewable forms.
- Pills often cost less than liquid and other forms of medicine.
- People are more likely to take their medicine if it is accepted and can be taken easily.
- Swallowing medicine in pill form is a useful health related skill

Some things make it harder for children to learn pill swallowing

- Trouble with different tastes and textures
- Active gag response
- Difficulty swallowing
- Feeling scared, worried or anxious about medicine
- Problems with attention or hyperactivity



Best Time to Teach Pill Swallowing

There is not one age or time that is “just right” for learning how to take medicine. Children with autism may need more time or support to learn this skill. Children under age 3 are usually too young. Many school age children are successful. It is important to choose a time that is just right for you and your child. You and your child should not feel pressured. Avoid teaching this skill when your child is ill; for example, when medication is needed for an ear, throat or other infection.

When to get extra help

Some children and families need special help with pill swallowing. If you think that you or your child might need extra help, talk with your doctor or nurse. Types of problems that might indicate the need for extra help:

- Swallowing problems, including gagging or coughing with food and drink
- Severe anxiety or worry about pill swallowing
- Past upsetting experience with choking or with pill swallowing
- Parents who are very worried or who are not able to swallow a pill
- Families where the child responds poorly to parent instructions
- Children with medical, learning or mental health problems that make it difficult for them to learn about pill swallowing from a parent



Pills Swallowing – Tips for Parents (cont.)

Tips for Pill Swallowing Success

- Choose a quiet time when the adult can be calm and patient
- Don't rush
- Get rid of distractions
- Give reassurance and be positive
- No negative comments or nagging
- Smile and laugh with your child
- Give praise for what is going well
- Give choices of drinks and candies for practice
- Try using a straw for the drink
- Try different head positions
- Give choice of sitting down or standing up
- Use pictures to show where the pill goes and how small the pill is compared to esophagus
- Do not hide, trick or call the medicine candy



Steps

1. Use pictures or drawings to show child about swallowing a pill.
2. Swallow a pill in front of your child to show how it is done.
3. Help child to find a comfortable head position.
4. Start with having child swallow only water or a drink.
5. Next, try teaching child to swallow small candies or cake decorations.
6. Move to larger candies when doing well with smaller ones.
7. Make the session short. End the practice session on a successful note, even if it means going back to a smaller candy or just water.

What if my child just is not “getting it” even when we have been practicing and following the tips?

Take a break! Maybe it is not the right time. You can try again in a few months. Talk to your child's doctor or nurse. You may need outside help. The pharmacist or doctor will know if a chew tab or liquid is an option. Some pharmacies can flavor or mix a medicine to make it easier for the child to accept.

More information on pill swallowing:

<http://www.pillswallowing.com> or <http://research4kids.ucalgary.ca/pillswallowing>

Medicine Action Plan

This page is something you and your doctor or nurse might complete together when starting a new medicine. This will help you make sure you have the information you need to give your child his or her new medicine safely.

The following is to be completed by the DOCTOR OR NURSE:

Medicine Name: _____ **Dose:** _____

How to give medicine:

Schedule:

Date: _____	Dose: _____

How long will it take the medication to take effect:

Target Symptoms:

1. _____
2. _____
3. _____

Follow Up Appointment:

	Green Zone:	Yellow Zone:	Red Zone:
Zone	No side effects or side effects that are not worrisome	Mild side effects OR Side effects that do not require a quick change	Serious side effects
Specific side effects (please list)	<div style="background-color: #d9ead3; width: 100%; height: 100%;"></div>	<div style="background-color: #fcf8e3; width: 100%; height: 100%;"></div>	<div style="background-color: #f2dede; width: 100%; height: 100%;"></div>
What should I do?	Keep giving medicine	Keep giving medicine, Call doctor or nurse next business day if side effect is getting worse, lasting long time, or you are worried	Call doctor or nurse right away. Contact through on-call system if it is an evening or weekend.

Behavior Frequency Record #1 – Monthly Chart

This calendar can be used to record how often a target behavior occurs. It will work for behaviors that can be counted, like tantrums, aggression, self-injury, and waking during the night. A monthly calendar works best for monitoring symptoms that do not happen very often. For example, it might be used for a child who has aggression a few times a day or a few times a week. The calendar could also be used to note how many times a child wakes up during the night or how long it takes the child to fall asleep. Behaviors that happen more than 3-4 times each day might be monitored better on a [WEEKLY CHART](#) (page 28). On this calendar you could:

- Make hash marks each time the behavior happens
- Write a time of day the behavior happened
- Mark dates of new medicines or medicine changes

Month: _____

Target Behavior: _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday



Behavior Frequency Record #2 – Weekly Chart

This calendar can be used to record how often a target behavior occurs. It will work for behaviors that can be counted, like tantrums, aggression, self-injury, and waking during the night. A weekly calendar works best for monitoring symptoms that happen many times during the day. For behaviors that happen many times an hour, families might choose a specific hour during the day to monitor. For example, the weekly chart might be used to record tantrums if a child has many tantrums each day. On this chart you could:

- Make hash marks or time each time the behavior happens
- Note how long the behavior continued (if it is something like a tantrum)
- Mark dates of new medicines or medicine changes

Date Started: _____

Target Behavior: _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Target Behavior Severity Tool #2

This is a second tool that can be used to measure severity of behavior. When using this chart, list one target behavior and make an "x" or a line to indicate how severe the behavior is that day.

Target Behavior: _____

Date / Time	Target Behavior					
						
	None	Mild	Moderate	Severe	Very Severe	Worst Possible
						
	None	Mild	Moderate	Severe	Very Severe	Worst Possible
						
	None	Mild	Moderate	Severe	Very Severe	Worst Possible
						
	None	Mild	Moderate	Severe	Very Severe	Worst Possible
						
	None	Mild	Moderate	Severe	Very Severe	Worst Possible

Target Behavior Severity Tool #3

This is a third tool that can be used to measure severity of behavior. When using this chart, list up to 5 target behaviors and make an "x" in boxes 1-5 to indicate how severe the behavior is that day. "1" means the behavior is not there at all or is as good as it can be. "5" means the behavior is as bad as it can be.

Target Behaviors →					
	1 😊	2	3	4	5 ☹️
	<input type="checkbox"/>				
	1 😊	2	3	4	5 ☹️
	<input type="checkbox"/>				
	1 😊	2	3	4	5 ☹️
	<input type="checkbox"/>				
	1 😊	2	3	4	5 ☹️
	<input type="checkbox"/>				
	1 😊	2	3	4	5 ☹️
	<input type="checkbox"/>				
	1 😊	2	3	4	5 ☹️
	<input type="checkbox"/>				
	1 😊	2	3	4	5 ☹️
	<input type="checkbox"/>				
	1 😊	2	3	4	5 ☹️
	<input type="checkbox"/>				
	1 😊	2	3	4	5 ☹️
	<input type="checkbox"/>				

More Information

Books:

Dulcan, Mina (2006). Helping Parents, Youth, and Teachers Understand Medications for Behavioral and Emotional Problems: A Resource Book of Medication Information Handouts, American Psychiatric Publishing, 3rd edition.

Wilens, Timothy E. (2004). Straight Talk About Psychiatric Medications for Kids, The Guilford Press, Revised edition.

Tsai, Luke Y. (2001). Taking the Mystery Out of Medications in Autism/Asperger Syndromes: A guide for parents and non-medical professionals, Future Horizons Publishing.

Internet Resources On Medicines:

MedlinePlus: provides reliable information on specific medicines, vitamins, and supplements. A service of the U.S. National Library of Medicine, National Institutes of Health.

www.nlm.nih.gov/medlineplus/druginformation.html

U.S. Food and Drug Administration • Drugs@FDA: provides information on FDA approval of medications

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

Internet Resources On General Treatments Of Behavior Challenges, Medicine And Non-Medicine Treatments:

American Academy of Child and Adolescent Psychiatry (AACAP): national organization of child psychiatrists and physicians interested in mental health. Provides family information on medicine and non-medicine treatments for behavioral and mental health problems. Provides resources for families on autism and mental health problems. www.aacap.org/cs/forFamilies

Massachusetts General Hospital School Psychiatry program & MADi Resource Center: provides information and resources to families and professionals on diagnosis, medical treatments, non-medical treatments, and educational interventions for children with autism, ADHD, and mental health problems.

www2.massgeneral.org/schoolpsychiatry/index.asp

National Institute of Mental Health (NIMH): provides family and professional information on diagnosis and treatments of autism and mental health problems.

Home page: www.nimh.nih.gov

Autism treatment information: www.nimh.nih.gov/health/publications/a-parents-guide-to-autism-spectrum-disorder/complete-index.shtml#pub5

Internet Resources On Getting Blood Drawn:

ATN / AIR-P Blood Draw Tool Kit: www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/blood-draw-toolkits

Internet Resources On Sleep Problems:

ATN / AIR-P Sleep Tool Kit: www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit

Internet Resources On Pill Swallowing:

North Shore-Long Island Jewish Health System: provides a web-based educational tool for families and professionals to help children learn pill-swallowing. <http://www.pillswallowing.com/>

Alberta Children's Hospital: "Better than a spoon full of sugar: How to swallow Pills". Web based information on ways to teach children to swallow pills. <http://research4kids.ucalgary.ca/pillswallowing>

Oralflo: device that assists some adults and children swallow pills more easily.

<http://www.oralflo.com/index.html>

Acknowledgements

The Autism Speaks Family Services Department offers resources, tool kits, and support to help manage the day-to-day challenges of living with autism (www.autismspeaks.org/family-services). If you are interested in speaking with a member of the Autism Speaks Family Services Team contact the Autism Response Team (ART) at 888-AUTISM2 (288-4762), or by email at familyservices@autismspeaks.org. ART En Español al 888-772-9050.

This manual was written by Lynn Cole, MS, PNP, Patricia Corbett-Dick, MS, PNP, PMH-NP, Linda Howell, RN, BA, and Brianne Schmidt, RD, University of Rochester Medical Center and University of Rochester School of Nursing; Diane Treadwell-Dearing, MD, Baylor College of Medicine, Texas Children's Hospital and Robin McCoy, MD, Oregon Health Sciences University. This publication was edited, designed, and produced by Autism Speaks Autism Treatment Network / Autism Intervention Research Network on Physical Health communications department. We are grateful for review and suggestions by many, including families associated with the Autism Speaks Autism Treatment Network. This publication may be distributed as is or, at no cost, may be individualized as an electronic file for your production and dissemination, so that it includes your organization and its most frequent referrals. For revision information, please contact atn@autismspeaks.org.

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