

# **Medical Problems, Treatments, and Professionals**

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Raising a healthy child is one of the most difficult - and rewarding - challenges any parent can tackle. For parents of children with autism, the rewards are just as great as for other parents. The difficulties, however, can be more daunting because you have to take autism into account in almost all decisions you make about your child's medical well-being. For example, how will your child react to having her teeth cleaned? Can she handle a flu shot? Is it more important to take care of these problems now, or is it better to avoid any additional stress for the present?

All children have a chance of developing any number of diseases or conditions. Parents of "normal" children are rarely informed of all the possible diseases their children *might* get. But when your child has autism, doctors often tell you the statistics for your special child. This may seem insensitive and unfair, but the fact is, children with autism are simply more likely to develop certain medical problems. And because these medical problems can sometimes cause developmental delays and behavior problems, early detection and treatment are crucial.

As a parent, you can help your child by learning the basic facts about medical conditions so that you can spot problems in the early stages. You can also help your child by learning to ask the right questions and to communicate well with doctors so that you can jointly make important decisions about your child's medical care.

This section outlines some of the common medical conditions and potential problem areas you should look out for, and also includes tips on how best to work with medical professionals to ensure optimal care for your child. First though, because your child's autism and the medications sometimes used to treat its symptoms can contribute to other medical problems or affect the way your child interacts with medical professionals, this chapter discusses the medical treatment of autism itself. It reviews the medications occasionally prescribed to reduce behaviors common in children with autism, and explains their benefits and risks.

## **Medical Treatment of Autism**

Although we do not yet know the causes of autism, medicine has made important strides in treating some of its symptoms.

Medications can sometimes be very helpful in reducing or eliminating problem behaviors. Because medications may also produce harmful side effects, though, it is essential to weigh their risks against their benefits. In addition, you should be aware that some treatments are still new or experimental and carefully consider any controversy surrounding them in discussions with your doctor. This section reviews the medications most commonly prescribed for children with autism and the important considerations involved in selecting and using medications.

### **Medications**

The medications used to treat children with autism, like all medications, have their benefits as well as their limitations. Unfortunately, no medications have yet been developed that "cure" autism. Rather, medications are sometimes used to treat specific symptoms when they interfere with education or pose a potential danger to the child. For example, medication may be prescribed to treat a self-abusive behavior

like severe head banging or to treat behavior like continual hand flapping, which can interfere with education.

The medications most often prescribed to treat autism are called *neuroleptics*, or "major" tranquilizers, and include a number of medications that affect the brain in specific ways. Among the most commonly used major tranquilizers are thioridazine (Mellaril™), chlorpromazine (Thorazine™), and haloperidol (Haldol™).

Do not confuse these major tranquilizers with the "minor" tranquilizers such as Valium™ and Librium™, which adults commonly take to manage anxiety. The "major" tranquilizers act in a different way, and are most frequently used for adults with severe psychiatric illnesses. One of the ways they work is by reducing the activity of *dopamine*, a chemical in the brain that acts as a *neurotransmitter*, or messenger, between nerve cells. In children with autism, dopamine appears to regulate certain problem behaviors - for example, self-injury and stereotyped, or purposeless, repetitive movements. Major tranquilizers may increase the attention span of children with autism and make them more able to learn.

Because each medication has a range of side effects, it is important to balance the potential benefit of the medication against its risks and to be prepared for any side effects you may observe. Whenever medication is prescribed, your child's doctor should review the possible benefits, risks, and side effects with you, other people who help care for your child, and the school staff.

Probably the most common side effect of the major tranquilizers is sedation or sleepiness. A child may become overly sedated after the medication is used and may be unable to benefit from her educational program. In that case, there is little point to using the medications in the first place. Other side effects of the medications include problems in movement. Sometimes children will develop peculiar postures or muscle spasms around the head and neck; these side effects can often be controlled by the addition of another type of medication to some extent, all major tranquilizers produce dry mouth, constipation, blurred vision, and other effects most commonly associated with allergy medications or over-the-counter cold preparations. Less common side effects include changes in the function of the liver, effects on blood cells, restlessness or agitation, sensitivity of the skin to the sun, and true allergic reactions. Often side effects are dose related - that is, they are more common with higher doses of medication - but sometimes individuals have side effects even on low doses of medication.

After a drug is stopped or has been administered for a long period of time, other side effects may emerge. For example, a child may develop unusual head and body movements, which usually disappear some weeks or months after the drug is stopped. The most worrisome side effect of these drugs, however, is a condition known as *tardive dyskinesia*. Tardive dyskinesia typically occurs only after very long periods of treatment. In tardive dyskinesia, movements of the face - grimaces or tongue protrusion - are accompanied by unusual movements of the body and hands. Probably such movement problems reflect changes in brain sensitivity to neurotransmitters. Because this condition is sometimes irreversible, it is important that the doctor prescribing the medications continue to see your child periodically to monitor the medication.

Given the potential side effects of these medications, it is important that they be used only when necessary. Before starting your child on medications for behavior problems, you and her teachers should review your child's educational and behavioral program to determine whether changes in the environment or program might produce enough improvement to make medication unnecessary. For example, sometimes a change in classroom activities or daily routine may help reduce behavior problems.

When medications are unavoidable, it is essential that they be used sensibly, in the lowest effective dose, and for the shortest possible period of time. This means that your child must be monitored closely while she is taking medication. To make monitoring easier, the prescribing doctor - who may be a psychiatrist,

developmental pediatrician, or other specialist - may want to do a physical examination and laboratory studies before starting medication. This enables the doctor to compare behavior before and after medication and to get a "baseline" against which any adverse effects of the medications can be measured. As a parent, you can help monitor your child by providing the doctor with behavioral records from the school and by continuing to observe your child closely.

The choice of medications and dosages depends on several factors. For example, children who are more agitated do better with a more sedating medication. Otherwise less sedating medication is generally used. Typically a low dose of medication is prescribed to begin with, and then adjusted depending on the child's response. Sometimes children have trouble with one medication, but do well on another. Because of the risk of long-term side effects and the need to monitor the usefulness of the medications, you and your physician may decide to reduce or stop the medication during certain periods. In some emergency situations, such as when the child's head banging is so severe as to pose the risk of serious injury, higher doses of medications may be prescribed. Once the behavior is under control, the medication can be gradually reduced.

The use of these medications should not be undertaken lightly. Often, though, these medications can greatly help your child adjust and respond well to an educational program. A good working relationship between you, your child's physician, and the school staff will help to ensure that your child is treated for the shortest period of time with the lowest possible dose of medication.

Aside from the major tranquilizers, there are other drugs available for children with autism, but their usefulness has not been proven as conclusively. In addition, the response of children with autism to other types of medications is more unpredictable than their response to the major tranquilizers or in comparison to the responses of children without autism. For example, stimulant medications are sometimes used for children with attention span problems and "hyperactivity," but when these same medications are prescribed for children with autism with similar behaviors, their behavioral problems often become worse, not better.

Minor tranquilizers such as Valium™ and Librium™ may sometimes make children with autism more agitated. The usefulness of some experimental medications remains to be proven conclusively. Some researchers have suggested that special diets or large doses of vitamins and minerals (particularly Vitamin B6 and magnesium) may improve the behavior and functioning of the child with autism. These treatments remain controversial, however, since the results of research studies have been rather mixed. At present, it seems possible that some children do respond positively to these treatments, while others respond negatively. Probably the majority of children have little response to them.

In general, it is important to realize that education, rather than medication, offers the best chance for improving problem behaviors in children with autism. Parents should not engage in new or experimental treatments if their child's education is adversely affected.

## **Medical Problems Associated with Autism**

As you read about the medical problems that children with autism can have, remember that not every child with autism has the medical problems covered in this section. These conditions are mentioned because of the special difficulties they present for children with autism or because children with autism have higher chances of developing them than children in the general population. It does not mean that your child *will* have these problems, but that she might. And remember, also, that in medicine, forewarned is forearmed.

The most common medical problems and issues linked with autism are: 1) seizures; 2) accidents and injuries; 3) infections; 4) dental problems; and 5) nutrition problems. This section describes these problems and explains their treatment.

## **Seizures**

For reasons that are unclear, children with autism are more likely than other children to have seizures. Seizures occur in about one in four children with autism, more commonly in those who are mute or have lower IQs. Often, but not always, these seizures do not develop until adolescence.

Seizures are caused by abnormal electrical activity in the brain and disturb the normal functioning of the nervous system. They can produce a temporary loss of consciousness or temporary changes in behavior such as unusual movements, loss of bladder or bowel control, or staring spells. Children with autism can have several of the various types of seizures, depending on the area of the brain where the abnormal activity occurs.

Seizures can sometimes be triggered by environmental factors, or *stimuli* - for example, by rapidly blinking lights. They may also be more common in certain situations - for example, when a child has not had enough sleep. In addition, younger children sometimes develop seizures in connection with high fevers, but these seizures usually do not persist.

Seizure disorders are diagnosed by taking a detailed medical history and by doctor examination, as well as by use of an EEG (electroencephalogram). EEGs record electrical activity in the brain and help the doctor pinpoint where the seizures are originating. Their results are not always conclusive, however. Sometimes people with obvious seizures may have normal EEGs between episodes. Similarly, some people with autism who do not have seizures may have abnormal EEG patterns.

Medicine has advanced a great deal in treating seizure disorders, but cannot always entirely eliminate seizures in every child. In treating seizures, a number of different *anticonvulsant* medications are prescribed. Depending on the type of seizure, one or more medications may be used. The level of the medication in the blood often is monitored carefully and the dosage adjusted so that as little medication as is effective is used. Since these medications sometimes produce side effects such as drowsiness, changes in the blood, and gum swelling, it is important to work closely with your doctor or a neurologist. It is also important that all medical professionals involved in your child's care know exactly which medications he or she receives.

## **Accidents and Injuries**

Even if your child did not have autism, you would probably take care to accident-proof your home as soon as she was able to get around by herself. You would cover electrical sockets, put locks on cabinets containing poisonous cleaning supplies, and store knives and scissors where prying fingers could not reach them. As the parent of a child with autism, you will need to take these precautions and more. Children with autism, and especially younger children with autism, sometimes have a combination of poor judgment and good motor skills that can lead them into dangerous situations or places.

To provide a safe environment for your child, you should periodically check both your home and your child's school for hazards. Check not only for obvious hazards like open stairwells, but also for less obvious hazards like ill fitting window screens that could easily be jarred loose. In addition, try to keep your child's habits in mind. For example, if your child tends to mouth objects indiscriminately, as many

children with autism do, make sure that lead-based paint is not used anywhere at home or at school. In addition, some of the precautions you might take with small children without disabilities make good sense for your child with autism. This can include installing plug covers, door latches, and stair gates; placing cleaning supplies and medicines out of reach; and using an intercom to listen to your child when she is in her room.

Because accidents do happen, keep a well-stocked first-aid kit in your home and make sure that you, your family members, and your babysitter all know how to use it. As further insurance, post emergency numbers prominently near every phone.

Besides protecting children with autism from unsafe environments, sometimes you must also protect them from their own self-injury. Although self-injury occurs infrequently, when these behaviors are severe they can cause physical injury or interfere with your child's education. Self-injury is most common in children with autism who are more severely retarded. Among children with autism, self-injury can range from repeated scratching or gouging of skin and eyes, to self-inflicted bites or severe head banging. Serious damage can result either from the injury itself or from complications like infections. Head banging, for example, can result directly in serious injuries such as skull fractures, while scratching or biting may lead to infections.

Sometimes these behaviors may actually be connected with other medical problems. For instance, head banging may reflect the presence of pain from an ear infection. For this reason, you and your child's doctor should search carefully for any underlying problem that may be contributing to your child's behavior. Unfortunately, these problems can sometimes be difficult to treat. A minor skin problem, for example, may lead to scratching, which results in infection, which causes further irritation and more scratching.

A variety of methods, including medicine, protective equipment, or applied behavior analysis (behavior modification) can be used to control self-injury. Often two or more of these methods are used together. These methods call for the involvement of parents, school personnel, and physicians.

### **Treatment of Injuries**

The treatment of your child's injuries is much the same as for other children, with a few exceptions. For example, children with autism may sometimes require casts rather than bandages when it is important that an injury be protected from further damage and when the child is unable to leave the injury alone. On the other hand, when an injury is minor, sometimes it may make more sense to avoid extensive treatment; for example, avoiding sutures (stitches) for a wound if they are not really needed. You always need to consider that your child may not do what is in her own best self-interest.

### **Infections**

Infections are a natural part of growing up. In children with autism, these illnesses can be harder to diagnose correctly, because your child may not cooperate with the doctor, particularly when she is ill. Furthermore, infections may go unrecognized for some time unless your child is able to complain of pain or discomfort or a dramatic change in her behavior suggests a medical problem. Accordingly, your observations of your child can often be invaluable in helping the physician reach a diagnosis. Signs of infection can include marked changes in your child's behavior or her appearing ill.

Repeated ear or tonsil infections can be a problem. Decisions regarding possible treatments depend on the

particular circumstances. For example, with chronic ear infections, tubes can be placed in the eardrum to reduce further infections, but you must decide whether the potential benefits outweigh the risks and stress involved in hospitalization and anesthesia. In general, you will have to weigh the potential benefits of any medical procedure against the risks to your child's emotional well being. Usually, it is best to make these decisions jointly with a physician who knows your child very well and who understands his or her special needs.

Sometimes medical procedures must be done. You really have little choice, but as this section explains later on, you can try to make the procedure as simple as possible. Your child, like every child, needs her childhood immunizations, periodic laboratory studies of blood and urine, and other aspects of "routine" medical care. In addition, immunization against one type of hepatitis, a form of liver infection common in institutional settings such as residential centers for the mentally retarded, may be appropriate. Ask your pediatrician for his advice.

### **Dental Care**

All children need to take care of their teeth in order to avoid serious problems such as infected teeth and gum disease. Proper dental care may be even more important for your child if she is on one of the seizure medications like Phenytoin (Dilantin<sup>TM</sup>) that sometimes cause gum changes. Unfortunately, achieving good dental hygiene for your child can be especially difficult. She may not be interested in tooth brushing or other aspects of routine dental care. For example, she may not like having things put in her mouth or may resist when you try to brush her teeth. In addition, she may become panicky when visiting a dentist's office.

If your child does not cooperate with the dentist, you may have to interview potential dentists to find one willing to adapt his procedures to your child's special needs. You can also take steps to minimize your child's anxiety and discomfort - chiefly by helping your child to become familiar with the professionals involved. In rare instances when your child is very uncooperative and has significant dental problems, general anesthesia may have to be used.

At home, you should take care to teach good dental hygiene along with other skills of daily living. And just as you would with any child, you should use fluoride in the drinking water or in the toothpaste to help prevent tooth decay in your child.

### **Nutrition**

Children with autism often have eating habits and other problems that can jeopardize good nutrition. Some are extremely fussy about the foods they will eat. They may eat the same foods over and over again and resist new foods, or may not tolerate certain food textures. In addition, they may have frequent mealtime temper tantrums. Sometimes these problems can approach a self-inflicted malnutrition that causes other health and development problems. For example, a child who refuses to eat dairy products may not develop strong bones and teeth.

In contrast, other children with autism are compulsive overeaters. Since children with autism may also be less physically active than other children, they may gain excessive amounts of weight. In addition, some medications, particularly certain of the major tranquilizers described previously, may encourage weight gain.

Whatever your child's problems with food are, you may want to have a nutritionist do a complete nutritional assessment of your child. By talking with you, observing your child, and analyzing tests and medical records, the nutritionist can often uncover behavioral and medical reasons, as well as dietary reasons, for your child's nutrition problems. The nutritionist can also evaluate your child's need for vitamin and mineral supplements, and determine whether she is taking any medication that might affect her appetite or nutritional needs. After completing the assessment, the nutritionist will develop a plan to improve your child's diet and her independent feeding skills. By following this plan and the behavior modification suggestions you will find in this manual, you can help to ensure that your child's nutritional needs are met.