

Wanders away Doesn't fear danger

Upset by new situations Public outbursts

Can't I.D. self or explain what's wrong

Dangerous obsessions

Crime victim Crime suspect

As parents and caregivers, we may not want to think about possibilities like these. But, there is no escaping the fact that children and adults with autism are at increased risk for many emergencies. Compared to others their age, they are more likely to wander off and may be drawn to bodies of water, tall structures or busy streets. In any crisis, they may be less likely to help themselves.

Because people with autism have no identifying physical characteristics, their disability may not be immediately apparent to others. This means that police, firefighters *and the general public* may expect responses that the child or adult with autism may not be capable of making. In fact, odd behaviors can be misunderstood and actually **lead to** an emergency.

Everyone with autism is different. Individuals may respond differently to the same situation, and what helps one person may not help someone else. You know your loved one's strengths and weaknesses better than anyone, and you are therefore the best person to safeguard him or her. We hope this brochure will help you to identify potential threats to the safety of your loved one and help you not only to prevent, but to prepare for, potential emergencies.

Wandering Off

Wandering is a common and very serious problem. Try door alarms, I.D., and familiarizing neighbors and public safety agencies with your child (see center back panel). Secure pools and teach your loved one how to swim. Look into electronic tracking or a guard dog. Wandering may become less of a problem over time, but it remains one for some adults. Your best defense? Close supervision.

In the Car

Some individuals with autism remove their seat belts. Check baby stores for buckle guards; local schools can recommend what is used on buses. To alert emergency crews, some families use bumper stickers with the words, "I love someone with autism." In an accident, be prepared for the possibility that your loved one may wander off. Medics may need instructions. If a borderline injury, question the necessity of treatment. It could be more upsetting than it is worth.

School Issues

Behavior problems in schools have resulted in police intervention. What was tolerated in a younger child may no longer be accepted when he or she gets bigger. Be sure to address these issues in your child's IEP. It may be your best protection.

School resource officers can learn what is normal for your child, which may help in a crisis. Students may need special protection from bullies – a downside to inclusion. Inappropriate touching of self or others is common, with innocent acts magnified in puberty. Teach your child what is appropriate and what isn't. Rather than trying to eliminate a behavior like masturbation, teach that it is limited to the bedroom.

Fire Safety

It's difficult to predict how someone with autism will act in a crisis. For example, we believe the individual will leave a smoky house, but then he runs into the bathroom and locks the door. This is why advance preparations – especially drills – are critical.

Don't assume what was taught at school will be applied at home. Teach what to do *at home*. Make instructions and drills as simple as you can – for instance, when smoke is seen or smelled, or an alarm sounds, exit to a designated spot, such as a tree.

Try to foresee where your loved one will go if confused or afraid. Any child may try to go to a "safe place." In a real emergency, assign a family member to guard your loved one, who may panic in the commotion or try to go back inside.

Safeguard your home without creating traps. Bars have been put on windows to keep children in, only to entrap them when they *needed* to get out. Use smoke detectors and check batteries. Replace hollow core doors with solid doors, and shut them every night. Use a monitor if closing the door worries you.

Children and adults with autism often lack an understanding of danger. Obsessions with materials like matches need to be taken seriously. Keep them out of sight and reach, and consult a professional about how to change such behaviors.

Some individuals can call 911, while others may turn it into a game. Use your best judgment about teaching this skill. 911 systems can locate users of regular phones, so help *may* be dispatched without details being provided. Calls from cell phones are not as easily traced. (See center back panel about working with public safety agencies.)

Make Sure Your Loved One Wears or Carries Identification

The importance of a bracelet, wallet card or other I.D. cannot be overstated for children and adults with autism. Here's why:

Many cannot speak – or speak well.

Even the person who speaks may be too frightened to answer questions.

The I.D. can state that the person has autism, which may help to explain odd behaviors.

The best person to assist is someone who knows the individual well. The I.D. lists this person(s).

MedicAlert (www.medicalert.org) provides low-cost bracelets and medallions. They are imprinted with the wearer's name, key details (autism, seizures, etc.) and a toll-free, 24-hour number for more information. On file will be contact information, medications, and any other information you want to provide. Stores for runners also have I.D. tags.

If you think your loved one won't wear I.D., try it anyway. Be creative. **Don't give up!** Put a tag on a shoe or belt. Sew information inside a shirt collar. Masking tape works temporarily.

Don't dismiss I.D., thinking it will make your loved one a victim. It's more likely to help than hurt. However, avoid too blatant I.D. – such as "I have autism" in big letters across a T-shirt. But, a shirt with other information on it, like your pager or cell number, may relieve your anxiety on a beach or amusement park trip.

Important! Even with I.D. in place, teach your loved one how to draw attention to it or answer questions.

It's worth the challenge.

Get to Know Your Local Agencies

To prepare for a possible emergency, get acquainted with your local police or sheriff's department, fire department and emergency medical service. Visit a fire station with your loved one or ask for someone to come to your home. Have a firefighter "dress out" so your child can see what full gear looks like. (It can look scary in an emergency.) Ask the fire and police departments to inspect your home and suggest safeguards. Wherever you meet, introduce your loved one and talk openly about the risks you believe he or she faces. Just having public safety agencies know where you live – and that your loved one with a disability lives there too – could be helpful in an emergency.

Contact your community's 911 center. It may have the capability of documenting that someone with a disability lives at your home.

It's a good idea to acquaint neighbors with your loved one's tendencies, especially if wandering off is one of them. Some families prepare flyers with a photo, description, emergency contact information, and details like what may upset, and calm, the individual. If your loved one has odd behaviors in stores, talk to employees where you regularly shop. Tell them about autism. If a behavior may cause problems, like the individual's way of handling items, put it into perspective for them. If you are open and positive, you will probably find that people want to help.

Become an Autism and Informed Response trainer. Parents and caregivers like you have trained more than 2400 emergency responders in South Carolina. The S.C. Autism Society will prepare you, provide materials and even sit in on your first class. Call 800-438-4790 for more information. Parents find this is a great way to teach responders not just about autism, but how it affects *their* loved one. Call soon!

Protecting the Child or Adult with Autism

Information for Parents and Other Caregivers

WHAT YOU NEED TO KNOW

WHAT YOU CAN DO



Autism and Informed Response

Awareness for emergency responders

Funded by a grant from the
S.C. Developmental Disabilities Council