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Autism Agenda



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Autism & Wandering

Similar to wandering behaviors in the Alzheimer's community, wandering and elopement behaviors in children and adults with autism have led to countless tragedies across the country.

In 2011, a study conducted by the Interactive Autism Network through the Kennedy Krieger Institute found that roughly half, or 49%, of children with autism attempt to elope from a safe environment, a rate nearly four times higher than their unaffected siblings.

It also found that more than one third of children with autism who wander/elope are never or rarely able to communicate their name, address, or phone number. Two in three parents of elopers reported their missing children had a "close call" with a traffic injury. Thirty-two percent of parents reported a "close call" with a possible drowning. Wandering was also ranked among the most stressful autism behaviors by 58% of parents of elopers. Half of families with elopers report they had never received advice or guidance about elopement from a professional.

According to the National Autism Association, in 2009, 2010, and 2011, accidental drowning accounted for 91% total U.S. deaths reported in children with autism ages 14 and younger subsequent to wandering/elopement. Sixty-eight percent of these deaths happened in a nearby pond, lake, creek or river.

There are various reasons someone with autism may wander. More often than not, he/she will wander to something of interest, especially water, or away from something that is bothersome, such as uncomfortable noise or bright lights.

Outdoor gatherings present a unique challenge since it is often assumed there are more eyes on the child or adult with autism. However, heavy distractions coupled with an over-stimulating setting can lead to a child or adult wandering off without notice.

Children and adults with autism wander from all types of settings, such as educational, therapeutic, residential, camp programs, outdoor, public places, and home settings, including relatives and babysitters' homes.

Wandering and elopement tend to increase in warmer months, especially in mid-section areas of the US where home layouts and routines are adapted to accommodate changing weather. Persons with autism are also more likely to play outside or attend summer or day camps during this time.

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NAA has created three digital safety toolkits that can be downloaded here: <http://awaare.nationalautismassociation.org/>

[Caregiver Toolkit](#) | [First Responder Toolkit](#) | [Teacher Toolkit](#)

Take Action in Your Home & Community:

- Download and begin using your Big Red Safety Toolkit today.
- Provide a copy of the First Responder Toolkit to your local police department. Ask them to implement Reverse 911 in your county and read the included Directive from the National Center for Missing & Exploited Children.

Remember: **Search Water First!**

ABOUT AUTISM-RELATED WANDERING

Similar to wandering behaviors in seniors with dementia or Alzheimer's, children with Autism are prone to wandering away from a safe environment. Unfortunately, many cases end in tragedy.

WANDERING DEFINED

Wandering is the tendency for an individual to try to leave the safety of a responsible person's care or a safe area, which can result in potential harm or injury. This might include running off from adults at school or in the community, leaving the classroom without permission, or leaving the house when the family is not looking. This behavior is considered common and short-lived in toddlers, but it may persist or re-emerge in children and adults with autism. Children with autism have challenges with social and communication skills and safety awareness. This makes wandering a potentially dangerous behavior.

Wandering may also be referred to as Elopement; Bolting; Fleeing; Running.

IMPORTANT FACTS

- Nearly half of children with autism engage in wandering behavior
- Wandering occurs across all settings, under every type of adult supervision
- Increased risks are associated with autism severity
- Half of families report they have never received advice or guidance about wandering from a professional
- Accidental drowning accounts for approximately 90% of lethal outcomes

WANDERING DANGERS

Drowning; Exposure; Dehydration; Hypothermia; Traffic Injuries; Falls; Physical Restraint; Encounters with strangers; Encounters with law enforcement.

Source: <http://awaare.nationalautismassociation.org/>

The Importance of Water Safety: Tips and Tools

Water safety is especially critical for children and adults with autism, as many individuals on the spectrum are drawn to water, some of whom are unable to understand the dangers associated with it. Tragically, the leading cause of death among individuals with autism after wandering is drowning.

Autism Speaks has put together some tips to help keep your child safe around water.

1. Start Early

It is never too early to start teaching your child the importance of water safety. Expose your child to water at a young age so he or she can become comfortable around it. Use visuals like picture cards or social stories to teach rules related to water and maximize learning. Be on the lookout for a tendency toward or special interest in water.

You can personalize a story about water safety from Twigtales [here](#).

2. Sign Up for Swim Lessons

The most obvious way to help prevent tragedy around water is to teach your child to swim. Many organizations offer lessons specifically for children with special needs. Check to see if there is an Autism Speaks grant recipient swim program near you [here](#). Remember that special needs swim lessons aren't just about swimming itself, but about how to be safe around water.



Many YMCAs offer special needs swim instruction, so this could be another option to consider. Find the location nearest you. Swim Angelfish is a swim program that has produced some videos with tips and strategies for teaching swimming on their [YouTube page](#). Keep the lessons fun and interactive.

If you aren't aware of any formal programs, see if an avid swimmer or special education teacher in your area can help with lessons.

3. Emphasize the Dangers of Water

Staying safe around water is about more than just the ability to swim. A second component is making sure individuals with autism understand the importance of water safety. Some children and adults with autism are capable swimmers, but their attraction to water can still lead them into dangerous situations - like a river with a strong current, a shallow pool or an unsafe temperature. Make sure the individual understands all of the dangers associated with water.

4. Take Precautions to Prevent Wandering

If your child is drawn to water, take safety precautions to keep him or her away. If you have a pool or live near one, be sure the pool is gated and inaccessible. Put window and door alarms on your home so you know if your child has left unsupervised. Never leave your child unaccompanied or out of your sight near water.

Autism Speaks has many wandering prevention resources.

5. Spread the Word

Let your neighbors know about your child's tendency to wander and his or her attraction to water so they can be on high alert. A flyer with information specific to your child can be very helpful. You can find an example of a Neighbor Alert Letter [here](#).

You may also want to alert first responders in your area. Fill out the [Autism Elopement Alert Form](#) to share information specifically about your child. (https://www.autismspeaks.org/sites/default/files/docs/elopement_alert_form_0.pdf)



Source: <https://www.autismspeaks.org/family-services/safety/water>

RESOURCES FOR CHILDREN WHO WANDER

Resources for children who wander:

AWAARE

AWAARE (Autism Wandering Awareness Alerts Education), was launched by a cooperation of six major autism advocacy groups to increase public understanding of autism-related wandering and reduce the number of fatalities associated with wandering. AWAARE provides safety information, safety guides, and resources to ensure you keep your child safe.

<http://awaare.nationalautismassociation.org/>

Project Lifesaver

Project Lifesaver provides technology and education dedicated to improving safe outcomes for wandering children and adults. From their mission statement: "Project Lifesaver develops public outreach programs to educate others about the issue of wandering, and they constantly work toward developing public policy and effective law enforcement response to help save lives and bring loved ones home." <http://www.projectlifesaver.org/>

Tattoos With Purpose

Starting with the least advanced method but definitely one of the best and least expensive ways of keeping your child safe is Tattoos With a Purpose. Lost and Found Temporary Tattoos are a unique way to help ensure if your child is lost they will be found. Whether you are going to an event where there will be large crowds or you live in an urban area the Temporary Tattoos can help if your child wanders. <http://www.tattooswithapurpose.com/>

EmFinders

EmFinders provides a secure band that is worn 24/7. If a child becomes lost, the registered caregiver calls local law enforcement to file a missing person's report and then calls EmFinders to request remote device activation. Once activated, the band dials 911, provides a message on behalf of the child, and is responded to in the same manner as any other 911 call involving a person in need of emergency assistance. <http://www.asdatoz.com/clear/Emfinders.html>

Lok8u

Nu.m8 created by Lok8u Combines GPS Technology and cell ID technology to locate a missing person to within 10 feet. A child wears a device that doubles as a wrist watch that comes in an assortment of different colors. The 'Safe Zone' feature allows you to easily set your own defined area by time and day. An immediate alert is sent via Text and email to inform you if your child strays outside this area. <http://www.lok8u.com/>

Amber Alert GPS

Designed to work for all children Amber Alert GPS can be especially helpful for children with autism. Amber Alert GPS is about the size of an Oreo cookie. You can put it in your child's bag or you can purchase an arm ankle band to attach to your child. The device uses a combination of GPS and GSM (cell phone technologies) so anywhere your cell phone or a GPS system works the device will work. <http://www.amberalertgps.com/>

Safety Tat

Our proven, award-winning temp-tattoo and labeling solutions not only provide a fun level of security for your little ones, but peace of mind for Moms and Dads as well. And SafetyTat offers a wide range of flexible products to fit your need for literally any occasion. Why leave your child's safety to chance? <http://safetytat.com/>

RESOURCES FOR CHILDREN WHO WANDER CONTINUED...

Safety Net by Lo-Jack

SafetyNet™ technology helps public safety agencies quickly find and bring your loved ones home, providing you with additional protection and peace of mind to keep your loved one safe. When a child goes missing Safety Net works with agencies (usually local fire and police departments) that are trained in using Safety Net to search and rescue a missing child. <https://safetynettracking.com/>

AngelSense

Angelsense provides a GPS and voice monitoring solution to keep children with special needs safe and well cared-for. The solution includes a wearable GPS device - designed to address sensory issues and a friendly app based on smart analytics. Parents use this product to oversee their children daily routine in real time, listen in to make sure they are treated well, get alerts for location changes, locate lost child with live updates, and view pictures of visited locations. www.angelsense.com

FiLIP 2

The FiLIP 2 is a wrist watch, GPS locator, and cell phone that works with an accompanying iOS or Android application. Its modern, light-weight, water-resistant design makes it a top choice in the children's wearables market. FiLIP Technology released this new model in September 2014, making some significant improvements to the original design that make the device much more comfortable to wear on small wrists. <http://www.myfilip.com/about-filip/>

My Buddy Tag

Another wearable children's safety device that utilizes Bluetooth is My Buddy Tag. The My Buddy Tag is an affordable option for budget-conscious parents who want a safety backup plan. It also has a unique feature that alerts parents when the wristband is submerged in water for 5 consecutive seconds. Willie Wu, creator of My Buddy Tag, had this to say: "My Buddy Tag helps prevent accidental drowning. There is no other device out there can also alert you when your child accidentally falls into a pool or lake."

<http://www.mybuddytag.com/>

Alert Me Bands

The only Emergency Contact wristband fully customizable to communicate medical, special needs and allergy alerts.

<http://www.alertmebands.com/product-category/jewelry/>

ifIneedhelp.org

Patches, shoe tags, ID cards, window clings, bumper stickers, dog tags, pins, clips and more.

Social Stories

Create your own stories

<http://awaare.nationalautismassociation.org/social-stories/>

www.Twigtale.com

Emergency Contact App

Provides emergency personnel with actionable information quickly and effectively for more needs-conscious treatment of individuals with autism

ICE4Autism.com

How can I keep my child Safe?

Autism presents a unique set of safety concerns for parents. The advocacy and awareness groups, Unlocking Autism (UA) and the National Autism Association (NAA), have teamed up to provide the following safety information for parents. Not all suggestions listed below are right for every family in every neighborhood. You should carefully consider the best safety options for your individual child.

“We had no idea Louis was out of the house, when we received a call from a neighbor. Thankfully, they were familiar with Lou and knew how to reach us.”

Are You Prepared for an Autism Emergency?

A leading cause of concern for parents with a child with autism is children who run or wander away. In a recent online survey conducted by NAA, an incredible 92% of the parents who responded reported their children were at risk of wandering. This is a problem that must be addressed in every city and town across America. Please review the following information and contact your local first responders to get a plan in place for your child and others who may be at risk in your community.

Wandering can occur anywhere at anytime. The first time is often the worst time. Another concern is preparation in the event that you become incapacitated or injured while caring for a person with autism at home or in the community. If you are concerned that your child may wander, now is the time to get to know your local law enforcement, fire and ambulance agencies. Ask your local 911 call center to “red flag” this information in their 911 computer data base. Should you need help in the future, dispatchers can alert patrol officers about your concerns before they arrive. By providing law enforcement with key information before an incident occurs, you can expect better responses.

Make sure any alterations you make to your home not delay or prevent fire, police, ambulance or rescue personnel from getting to her or him immediately in an emergency.

An ounce of prevention...

You know the expression, “an ounce of prevention is worth a pound of cure.” Following are some tools and ideas to help you plan for and prevent emergencies.

Survey and secure your home

Are there changes you can make to help ensure your child's safety? If wandering is an issue for your family, consider contacting a professional locksmith, security company or home improvement professional to prepare your home. You may find it is necessary to prevent your child from slipping away unnoticed by:

- Installing secure dead bolt locks that require keys on both sides.
- Installing a home security alarm system.
- Installing inexpensive battery-operated alarms on doors and windows to alert you when they are opened. These are available at stores like WalMart and Radio Shack.
- Placing hook and eye locks on all doors, above your child's reach.
- Fencing your yard.

Create an informational handout about your child.

Having a description of and information about your child could be an incredibly valuable tool in ensuring his or her safety. It should be copied and carried with you at all times, at home, in your car, purse or wallet. Include a photo of your child and any important information. Be sure to include your name, address and phone number. Circulate this handout to family members, trusted neighbors, friends and co-workers. The handout will also come in handy if you are in an area other than your neighborhood and need the help of or are approached by the police. This is one item it is important to have before you actually need it.

Alert your neighbors

The behaviors and characteristics of a child with autism have the potential to attract attention from the public. Law enforcement professionals suggest that you reach out and get to know your neighbors.

Decide what information to present to neighbors:

- Does your child have a fear of cars and animals or is he drawn to them?
- Is your child a wanderer or runner?
- Does he respond to his name or would a stranger think he is deaf?

Plan a brief visit to your neighbors:

- Introduce your child or provide a photograph.
- If a neighbor spots your child outside of your yard, what is the best way for them to get your child back to you?
- Are there sensory issues your neighbors should know about?

Give your neighbor a simple handout with your name, address, and phone number. Ask them to call you immediately if they see your child outside the home. This approach may be a good way to avoid problems down the road and will let your neighbors:

- Know the reason for unusual behaviors
- Know that you are approachable
- Have the opportunity to call you before they call 911

Knowing your neighbors and making them comfortable with your child's differences can lead to better social interactions for your child.

Consider a personal tracking device.

Some use a small unit that is put in a child's pocket or backpack and work with your computer or mobile phone so that you can monitor your child's location. Others involve a handheld unit for the parent which tracks the location of the child's wristband. Some units work with local law enforcement and rescue personnel. The tracking distance for the devices varies considerably and ranges from 300 feet for parent monitored units to one mile on the ground and 5-7 miles from the air for those monitored by rescue personnel. Some systems include waterproof tracking devices. Prices range from around \$200 for some parent monitoring units to around \$7,000 for units tied into local rescue personnel. Many local law enforcement agencies have purchased units for tracking residents with autism, Alzheimer's and Down's Syndrome.

Teach your child to swim.

Too often, children with autism are often attracted to water sources such as pools, ponds, and lakes. Drowning is a leading cause of death for a child or adult who has Autism. Be sure your child knows how to swim unassisted. Swimming lessons for children with special needs are available at many YMCA locations. The final lesson should be with clothes on.

Consider a Medical ID Bracelet for your child.

You may want to purchase an ID Bracelet for your child, especially if your child is non-verbal. Include your name and telephone number. State that your child has autism and is non-verbal if applicable.

If your child will not wear a bracelet or necklace, consider a temporary tattoo with your contact information.

Supporting young people online

Information and advice
for parents
and carers



The internet – an inspiring and positive place

The internet is an amazing resource which enables children and young people to connect, communicate and be creative in a number of different ways, on a range of devices. However, the internet is always changing, and being able to keep up to date with your children's use of technology can be a challenge. You may sometimes feel that your children have better technical skills than you do, however children and young people still need advice and protection when it comes to managing their lives online.

Issues that your child may encounter on the internet will vary depending on their age and online activities. We have grouped potential online risks into these 4 categories.



Conduct:

Children need to be aware of the impact that their online activity can have on both themselves and other people, and the digital footprint that they create on the internet. It's easy to feel anonymous online and it's important that children are aware of who is able to view, and potentially share, the information that they may have posted. When using the internet, it's important to keep personal information safe and not share it with strangers. Discuss with your child the importance of reporting inappropriate conversations, messages, images and behaviours and how this can be done.



Content:

Some online content is not suitable for children and may be hurtful or harmful. This is true for content accessed and viewed via social networks, online games, blogs and websites. It's important for children to consider the reliability of online material and be aware that it might not be true or written with a bias. Children may need your help as they begin to assess content in this way. There can be legal consequences for using or downloading copyrighted content, without seeking the author's permission.



Contact:

It is important for children to realise that new friends made online may not be who they say they are and that once a friend is added to an online account, you may be sharing your personal information with them. Regularly reviewing friends lists and removing unwanted contacts is a useful step. Privacy settings online may also allow you to customise the information that each friend is able to access. If you have concerns that your child is, or has been, the subject of inappropriate sexual contact or approach by another person, it's vital that you report it to the police via the Child Exploitation and Online Protection Centre (www.ceop.police.uk). If your child is the victim of cyberbullying, this can also be reported online and offline. Reinforce with your child the importance of telling a trusted adult straight away if someone is bullying them or making them feel uncomfortable, or if one of their friends is being bullied online.



Commercialism:

Young people's privacy and enjoyment online can sometimes be affected by advertising and marketing schemes, which can also mean inadvertently spending money online, for example within applications. Encourage your children to keep their personal information private, learn how to block both pop ups and spam emails, turn off in-app purchasing on devices where possible, and use a family email address when filling in online forms.

There are real advantages in maintaining an open dialogue with your child about their internet use. Not sure where to begin? These conversation starter suggestions can help.

1 Ask your children to tell you about the websites and apps they like to use and what they enjoy doing online.

2 Ask them about how they stay safe online. What tips do they have for you, and where did they learn them? What is OK and not OK to share?

3 Ask them if they know where to go for help, where to find the safety advice, privacy settings and how to report or block on the services they use.

4 Encourage them to help someone! Perhaps they can show you how to do something better online or they might have a friend who would benefit from their help and support.

5 Think about how you each use the internet. What more could you do to use the internet together? Are there activities that you could enjoy as a family?

What can I do right now?

- ☐ Maintain an open dialogue with your child and encourage them to talk to you about their internet use: for example who they're talking to, services they're using, and any issues they may be experiencing.
- ☐ Create a family agreement to establish your children's boundaries, and your expectations, when on the internet.
- ☐ Give your child strategies to deal with any online content that they are not comfortable with – such as turning off the screen, telling an adult they trust and using online reporting facilities.
- ☐ Consider using filtering software to block unwanted content. In addition to filtering, remember that discussion with your child, and involvement in their internet use, are both effective ways to educate them about the internet.
- ☐ Encourage your children to 'think before you post.' Online actions can impact not only yourself but the lives of others. Content posted privately online can be publicly shared by others, and may remain online forever.
- ☐ Understand the law. Some online behaviour may break the law, for example when downloading or sharing content with others. Be able to recommend legal services.
- ☐ Familiarise yourself with the privacy settings and reporting features available on popular sites and services.
- ☐ If your child is being bullied online, save all available evidence and know where to report the incident, for example to the school, service provider, or the police if the law has been broken.
- ☐ Familiarise yourself with the age ratings for games and apps which can help to indicate the level and suitability of the content. Also see if online reviews are available from other parents as these may be helpful.
- ☐ Set up a family email address that your children can use when signing up to new games and websites online.
- ☐ Encourage your children to use nicknames (where possible) instead of their full name online, to protect their personal information, and create strong passwords for every account.
- ☐ Set up a PIN or password on devices to help protect personal information.

Sign up to our Childnet newsletter at www.childnet.com.

Help make sure that your children know how to stay safe online, by using our SMART Rules for primary aged children, or 5 Tips for Teens.

5 SMART Rules for primary aged children:

S Safe: Keep safe by being careful not to give out personal information when you're chatting or posting online. Personal information includes your email address, phone number and password.

M Meet: Meeting someone you have only been in touch with online can be dangerous. Only do so with your parents' or carers' permission and even then only when they can be present. Remember online friends are still strangers even if you have been talking to them for a long time.

A Accepting: Accepting emails, messages, or opening files, images or texts from people you don't know or trust can lead to problems – they may contain viruses or nasty messages!

R Reliable: Someone online might lie about who they are and information on the internet may not be true. Always check information by looking at other websites, in books, or with someone who knows. If you like chatting online it's best to only chat to your real world friends and family.

T Tell: Tell a parent, carer or a trusted adult if someone, or something, makes you feel uncomfortable or worried, or if you or someone you know is being bullied online.

5 Tips for Teens:

1 Protect your online reputation: use the tools provided by online services to manage your digital footprints and 'think before you post.' Content posted online can last forever and could be shared publicly by anyone.

2 Know where to find help: understand how to report to service providers and use blocking and deleting tools. If something happens that upsets you online, it's never too late to tell someone.

3 Don't give in to pressure: if you lose your inhibitions you've lost control; once you've pressed send you can't take it back.

4 Respect the law: use reliable services and know how to legally access the music, film and TV you want.

5 Acknowledge your sources: use trustworthy content and remember to give credit when using other people's work/ideas.

Further advice and resources:

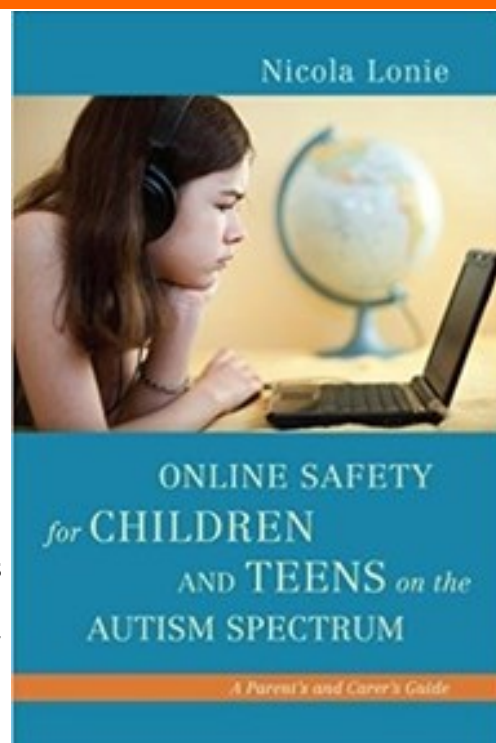
www.childnet.com
www.saferinternet.org.uk



Online Safety for Children and Teens on the Autism Spectrum: A Parent's and Carer's Guide

by Nicola Lonie

Children and teens with autism can be particularly vulnerable to online dangers and this practical handbook explains how you can help your child to navigate websites, chat rooms and social media safely. Providing all the information needed to monitor, educate and guide your child's computer use, the book discusses key concerns such as parental control, social networking, grooming, cyberbullying, internet addiction and hacking. The risks and the warning signs to look out for are clearly explained alongside useful advice and examples from real-life experiences. A Digispeak Dictionary is included that decodes the cryptic language of online slang and there are downloadable forms to help record your child's internet use. The practical solutions in this book will give you peace of mind and ensure that your child can enjoy the educational and social benefits of the internet in safety.



ONLINE RESOURCES FOR INTERNET SAFETY

STAR TOOL KIT: <http://www.childnet.com/resources/star-toolkit>

Through the STAR Tool Kit, Childnet International has developed practical advice and teaching activities related to online safety for young people with autism. STAR stands for key areas the kit addresses:

Safe: Keep your personal information safe (discuss what is considered personal and how to keep it private).

Trust: Not everything online is true (how to search safely and find reliable information).

Action: Always tell someone if anything upsets you online.

Respect: Be kind online.

The tool kit is designed for educators, but parents may find the advice in the guidance documents useful. There is also a "Parents and Carers" section full of resources specific to parents.

NETSMARTZ: <https://www.netsmartz.org/Parents>

Netsmartz offers resources and information for teachers and parents to teach kids about internet-related topics such as file sharing, identity theft, cell phones, cyberbullying, messaging, gaming, inappropriate content, sexting, sexual solicitation, social media, internet safety and privacy. There is content for all ages, including free multi-media videos and presentations, as well as lesson plans for educators.



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VISUALS

EMERGENCY ALERT



Resident with
Autism

**May not respond
to verbal commands**