






Be REDy Booklet

for caregivers

Autism & Wandering

Education, Prevention & Response

BIG RED SAFETY BOX®

NATIONAL AUTISM ASSOCIATION

One Park Avenue, Suite 1
Portsmouth, RI 02871
877.622.2884
nationalautism.org

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Nearly Half of Children with Autism Wander from Safe Settings.

If you are receiving this toolkit, chances are you are a caregiver for someone diagnosed with an Autism Spectrum Disorder (ASD) who may be at risk of wandering or bolting away from a safe environment.

Because people with ASD have challenges in areas of sensory processing, impulse control and bodily autonomy, it is critical for parents and caregivers to understand ways to keep loved ones with autism safe.

As such, we are pleased to provide you with this Be REDy Booklet. In it, you will find prevention tips, resources, and tools designed to help keep your loved one safe. Our three *Be REDy Pals* will also help guide you with quick tips & insights.

Please remember that regardless of any tools you may have in place, if your loved one's diagnosis interferes with their ability to recognize danger or stay safe, it is critical that you maintain close supervision and security in your home.

We hope you'll find this booklet helpful. If you need more information or additional assistance, please visit us online, write us at naa@nationalautism.org or call 877-NAA-AUTISM.

With hope,

Wendy Fournier

President, National Autism Association

In This Booklet, You Will Find a:

- Prevention Checklist
- Swimming Lessons Tool
- Root-cause Tool
- Tracking Technology Tool
- Sample Letter Set
- Social Story Template
- Caregiver Resource List
- Family Emergency Plan
- Calming Cards Tool
- Emergency Profile Sheet
- Quick Tips Sheet

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About Autism & Wandering

Wandering/elopement is the tendency for an individual to leave the safety of a responsible person's care or safe area, which may 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 exiting the house when the family is not aware. This behavior is considered common and short-lived in toddlers but may persist or re-emerge in those with autism. ***According to research, nearly half of children with autism are at risk for wandering away from a safe setting.***

Because people with autism are vulnerable to dangerous situations including drowning, traffic incidents, becoming trapped hot cars, etc., it's important to take critical precautions. ***Be aware that drowning fatalities remain a leading cause of death, along with traffic injury.***

Wandering/elopement is typically a form of communication, often occurring to get to something of interest or away from something bothersome, usually noise, commotion, fears/phobias, and demands. These impulses and incidents can increase with added anxiety and stress, especially if the individual has challenges with coping, calming, or regulating their emotions. ***Early signs of exit-seeking behavior can start in toddler-hood. They include social/demand avoidance, moving to a different area of building or home unnoticed, bolting when upset, and seeking out water or other quiet places.***

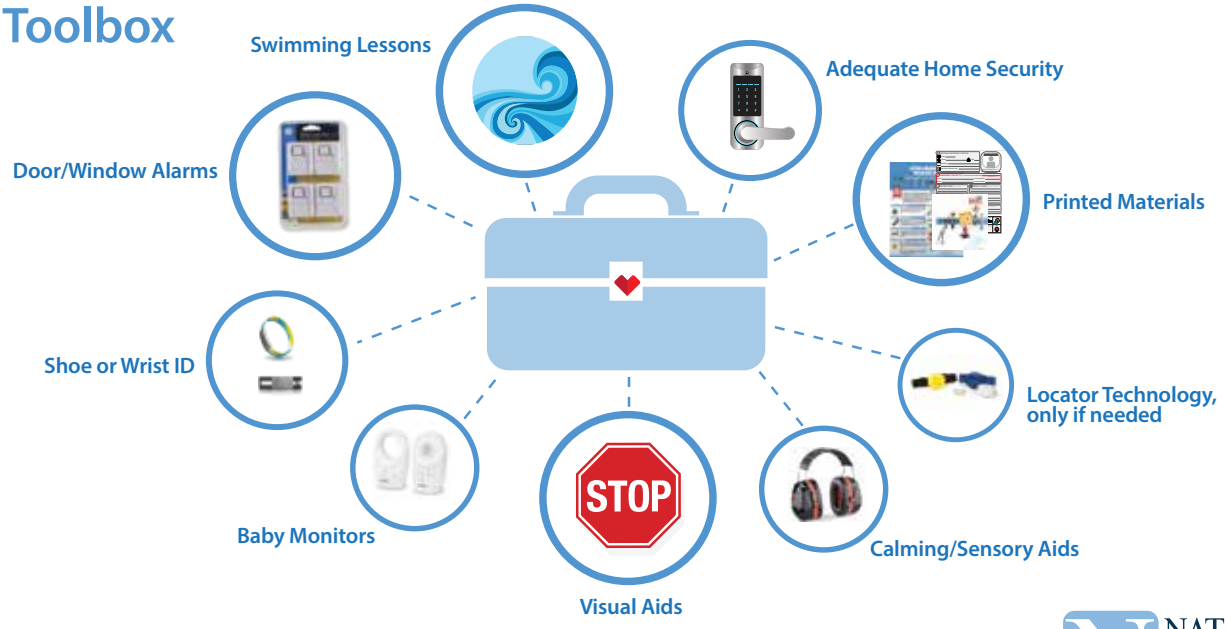
Prevention Checklist:

- *Secure home, outdoor gates, garage door*
- *Identify & Address Triggers*
- *Teach Safety/Coping & Pursue Forms of Communication*
- *Enroll in swimming lessons*
- *Secure wearable identification and/or locative technology*
- *Alert relatives, school & neighbors*
- *Alert local first responders*
- *Speak with your loved one's doctor*
- *Create Emergency Plan*
- *Stay extra vigilant during transitions, parties, vacations, new moves, visits, & noise/stress/commotion*

If Your Loved One is Missing:

- **Remain Calm**
- **Call 911**
- **Search Nearby Water First**

Safety Toolbox



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Swimming Lessons

Whether it's bathtime, swimming, jumping in puddles or simply splashing around at the beach, water-play remains a common favorite activity among kids with autism. Unfortunately, water also carries significant risk for those who wander off. According to NAA research, the leading cause of death in autism-related wandering cases is drowning. Therefore, it's extremely important to enroll your child into swimming lessons as early as possible.



Ways to find swim lessons in your area:

- Ask your local swim facility, such as YMCA, to provide swimming lessons that can accommodate your child's unique needs.
- Safe Splash Swim School has 100+ U.S. locations and provides swimming lessons specifically for those with autism and other special needs (safesplash.com)
- Google 'Special Needs Swimming Lessons' + Your City, State.
- Search for a swim school in your area that is a member of the United States Swim School Association. The association teaches a course internationally that trains swim instructors how to teach swimmers with special needs.



- *Children with autism will go straight to water regardless of its temperature or type.*
- *Even if your child does not seem to like bathtime or swimming at the pool, natural water sources may be perceived differently. These include ponds, lakes, fountains, rivers, canals, even waste water.*
- *Teaching your child how to swim can help lower risk, but does not eliminate risk, so it's important to stay vigilant.*
- *If you own a pool, fence your pool and use gates that self-close and self-latch higher than your children's reach. Remove all toys or items of interest from the pool when not in use.*
- *Neighbors with pools should be made aware of these safety precautions and your child's tendency to wander.*

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Root-Cause Scenarios

It's critical to seek out the root cause of a child's wandering behavior – *why* is the child wandering/bolting? What do they want/not want? Wandering behaviors usually have a trigger or reason. To help with this, a Board Certified Behavioral Analyst (BCBA) can assess your child. Once you identify the reason or trigger, strategies can be created to prevent wandering incidents and teach your child about dangers.



Sample Scenario: Child Loves Water

Emily loves playing in water. On walks, she often wants to go look at the pond and cries when passing it in the car.

Strategy: Allow water time in an adult-supervised setting. Try scheduling consistent "water play" each day, or at the same time each week. Schedule around times easily recognized, such as after dinner or school. Make sure the child sees that each water-play activity has an end time and is "all done." Swimming lessons each week can also act as water-play. Be sure to take a picture of the swim instructor and place this into the schedule. Knowing what to expect may satisfy your child's desire to reach water, as well as give him/her a tool to communicate their desire with a trusted adult instead of attempting to reach a destination on their own.







Use pictures of your child enjoying safe water-play, and visuals to communicate settings that are unsafe.

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Sample Scenario: Unique Fixation

Alex loves road signs, especially highway exit signs. He often cries or reacts to signs when passing them on the highway. He verbally stims on highway exit numbers. He will leave home or school to find his item of interest.

Strategy: Allow the child to explore fascinations in an adult-supervised, safe setting. Try to find ways to incorporate the focus/fascination into daily activities so the child knows when to expect it. Use drawing time, pictures, games and other creative ways to satisfy the child's need to touch or explore items of fixation.







Create ways for your child to explore an item of focus through their own creativity. Use visuals to communicate settings that are unsafe.

When Anxiety/Triggers Cause Bolting:

Exit-seeking behavior can be goal-directed (to get to something of interest) or a panic response to escape something bothersome or traumatic, such as:

- Noise & commotion
- Transitions or disruption in routine
- Uncertainty & worries about social situations
- Fears and phobias
- Sensory oversensitivity and overstimulation
- Too many demands or expectations
- Being prohibited from using self-calming techniques, such as repetitive behaviors, stimming, or hyper-focusing on favorite topic
- Disorganization in communication/response (rushed to respond to a question)
- Arguing, fighting, crying nearby
- A repeated demand that escalates, such as needing to correct homework

Use Calming Strategies:

- *Give time & space*
- *Allow modifcations ('It's okay to not sit at the Thanksgiving table')*
- *Allow self-calming (stimming; time alone)*
- *Write down look-forwards (favorite foods or topics; upcoming event)*
- *Deep breathing (4-7-8 breathing) and Stretching/Yoga*
- *Drawing, Coloring, Reading*
- *Taking a bath or shower*
- *First/Then Strategies*
- *Progressive Muscle Relaxation for Stress and Insomnia (PSM)*

Use Calming Tools:

- *A safe 'escape' area they can choose to go to, such as an indoor tent*
- *Noise-canceling earmuffs and/or Sunglasses*
- *Weighted Blanket*
- *Fidget tools*
- *White Noise Machine*
- *Legos or Puzzle*
- *Lava Lamp*
- *Essential Oils*
- *Visual Schedules, calendars and/or Social Stories*
- *'Look-forward' Lists*
- *Written Explanation of OCD/Anxiety (To Promote Self-awareness)*

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Tracking & Locator Technology

There is a wide range of tracking devices available. However, there is not one solution that is appropriate for everyone. Some children will wear a wristband, some will not. Some need a waterproof device, some do not. Some areas do not have reliable cellular service, which is vital for many of these units. There are simply too many variables in products, and a wide scope of individual needs for our children for us to make specific recommendations.

Families should thoroughly research the features of personal locating devices before deciding on which is best for their child. *Always remember, personal safeguards do not replace adequate adult supervision.*

Important Considerations:

- Battery Life - does the unit have to be charged? If so, how often? Is your loved one's exit-seeking behaviors too severe to be unprotected during the charging process?
- Water Resistance - can the unit be worn when bathing, showering, swimming?
- Efficacy in water – will the unit transmit a signal under water?
- Is the unit removable by the wearer?
- Is geofencing/perimeter notification available?
- Cellular service in your area - will the unit work in the area of your home, school, etc?
- Does the system involve trained emergency response personnel?
- Is the manufacturer accessible in case you have critical questions or challenges? Are they interested in your child's specific needs?
- What are the costs involved -- are there monthly fees?

Device Options

For radio frequency units that run through law enforcement, visit projectlifesaver.org or safetynettracking.com to see if service is available in your area.

For GPS units that are operated by caregivers and purchased through retail methods, visit angelsense.com or similar retailer.





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Awareness Letter for Schools, Neighbors, etc.

This is a resource to provide to your child's school, IEP team, local aquatics facility, homeowners association, etc., as needed.

To Whom It May Concern:

Similar to wandering in people with dementia, people with autism spectrum disorder (ASD) may wander or bolt from a safe environment. Unfortunately, many cases end in tragedy. Because people with ASD have challenges in areas of sensory processing, impulse control and bodily autonomy, it is critical for all of us to understand ways to keep those with autism safe.

According to a study published in Pediatrics, 49% of children with autism wander/elope from safe supervision. This is at a rate nearly four times higher than their unaffected siblings, indicating it is not an issue of bad parenting. It is, however, a growing crisis in need of awareness, understanding and hyper vigilance.

From 2011 to 2016, accidental drowning accounted for 71% of reported wandering deaths in those with an autism diagnosis. Many children and teenagers with autism have little understanding of danger and are unable to respond to their name when called. Dangers associated with wandering/elopement include drowning, getting struck by a vehicle, falling from a high place, and hyperthermia.

Individuals with autism often leave a safe environment to get to something of interest, or away from something, such as loud noises or bright lights. It has become so common in our community, it was assigned the medical diagnostic code Z91.83.

With challenges in areas of language and cognitive function, it can be difficult to teach children and adults with ASD about dangers and ways to stay safe. As such, our organization respectfully requests your help in allowing, or providing, resources and safeguards that could potentially save a child's life. This may include offering swimming lessons to special-needs children, allowing fencing to go around an at-risk child's home, covering the cost of locator technology, tightening security around nearby water and pools, informing parents of any wandering incidents on school grounds or other non-home settings, and providing close and constant adult supervision.

We are grateful for your commitment to those with disabilities. Should you have questions, you may reach us at 877.622.2884 or naa@nationalautism.org.

Sincerely,

Lori McIlwain

Lori McIlwain
Co-founder, National Autism Association

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Sample Physician Letter

This is provided as an example only for your child's physician.

NAME OF CHILD (DOB XX/XX/XX) carries a diagnosis of Autism, which poses certain cognitive challenges and safety risks. NAME currently attends NAME OF SCHOOL in NAME OF TOWN.

NAME has a history of wandering from safe environments, including a YEAR incident where NAME wandered from LIST INCIDENT. According to Centers for Disease Control (CDC), Wandering places children and adults with autism spectrum disorders (ASDs) in harmful and potentially life-threatening situations—making this an important safety issue for individuals affected and their families and caregivers.

If given the opportunity, NAME will wander from safe environments. NAME'S wandering tendencies include goal-directed elopement, which means NAME will seek out items of interest, specifically roads and bodies of water. NAME'S history also includes fleeing incidents following a meltdown or escalation trigger.

It is for these reasons, and NAME'S history of elopement, that NAME now has a medical diagnosis of Wandering In Diseases Classified Elsewhere (Medical Code Z91.83). To ensure NAME's safety, it is medically necessary that NAME have close and constant adult supervision at all times, and that proper safeguards are in place. Safeguards may include architectural barriers, door alarms, visual prompts, and a school-wide response protocol.

A Functional Behavioral Assessment should be done to help identify root causes of NAME's elopement behaviors. NAME must never be left unattended by any adult for any reason. Leaving NAME unattended poses serious safety and health risks.

Sincerely,

(Doctor's Signature)

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A Multi-Layered Approach is Best.

A multi-layered approach to prevent, and respond to, wandering emergencies is necessary to achieve optimal safety for your child. This includes making every attempt to educate your child on self-help skills including swimming, making every attempt to educate them about safety and potential dangers by using social stories, language, prompts, or any communication mechanism best suited for their individual needs. It's important that caregivers work to understand what is causing, or contributing to, the wandering or bolting behaviors so that any triggers may be addressed or eliminated.

The most important thing is that the at-risk child or adult is learning to keep themselves safe, while proper safeguards and adult supervision are also in place to help ensure their safety.

No matter what prevention strategies are put into place, parents should never allow themselves to feel a false sense of security Although certain safety-product retailers may market their items with words like "go relax" and "have peace of mind," please know that these benefits are secondary to the overall goal of safety.

Resource List

General Resources:

National Autism Association: nationalautism.org
National Center for Missing & Exploited Children: missingkids.org

Swimming Lessons:

YMCA Listing: nationalautism.org
Safe Splash: safesplash.com

Service Dogs:

4 Paws for Ability: 4pawsforability.org
Autism Service Dogs: autismservicedogsofamerica.org
Assistance Dogs: assistancedogsinternational.org

Safety & Security Products:

Vivint Home Security: vivint.com
NAA's Big Red Safety Shop: nationalautism.org
Project Lifesaver: projectlifesaver.org
SafetyNet Tracking: safetynettracking.com
AngelSense GPS: angelsense.com
RoadID: roadid.com
MedicAlert: medicalert.org

For First Responders:

Reverse 911: achildismissing.org
Project Lifesaver: projectlifesaver.org
SafetyNet Tracking: safetynettracking.com
National Center For Missing & Exploited Children: 1-800-THE-LOST

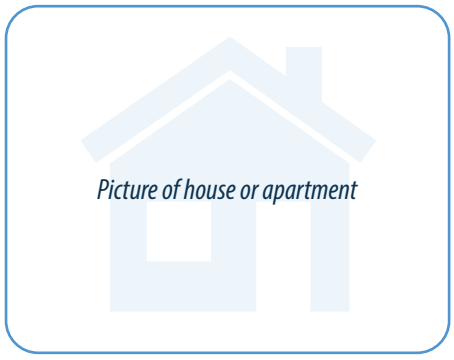
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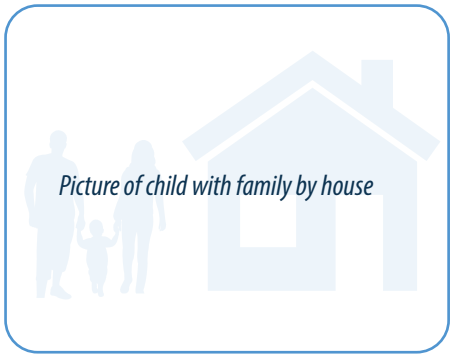
Social Story: *Staying In My House*

Customize with your own images.

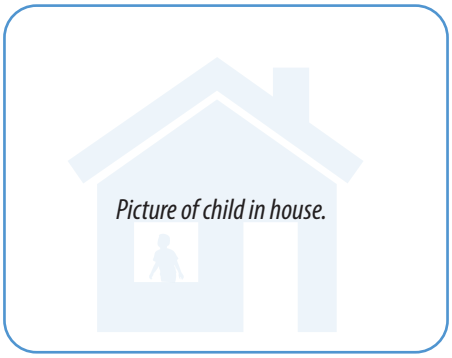
My Name Is: _____



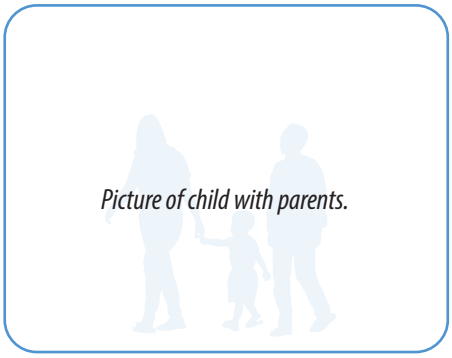
This is my house.



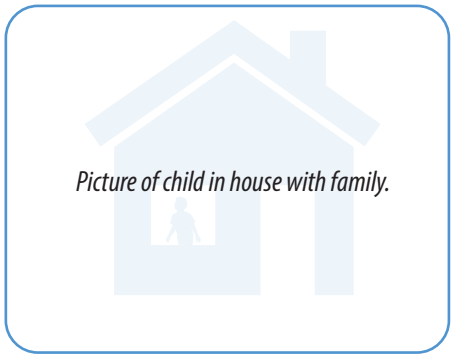
I live in my house with my family.



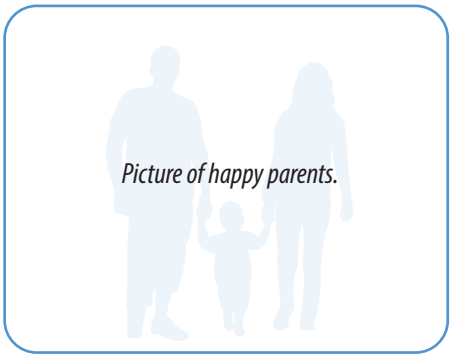
It's important for me to stay in my house.



When I stay in my house, my parents will know where I am.



Staying in my house will keep me safe.



Mom & dad will be happy that I am safe.

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Cut out these Calming Cards, or use them as a guide to customize for your child/adult.

1



HAPPY!

Everything's Okay!

2



WORRIED

I Can Try To:
- Take 5 Deep Breaths
- Sing a song in my head
- Play with my fidget toy
- Ask for time and space
- Tell my mom or dad why I am worried

3



SAD

I Can Try To:
- Take 5 Deep Breaths
- Sing a song in my head
- Play with my fidget toy
- Make a 'favorite things' list
- Color or draw
- Ask for time and space
- Tell my mom or dad why I am sad

4



ANGRY

I Can Try To:
- Do 4-7-8 Breathing*
- Take time and space
- Take a shower or bath
- Play with my fidget toy
- Color or draw
- Look at a list of my favorite things
- Tell my mom or dad why I am angry

***Breathe in for 4 seconds, hold breath for 7 seconds, exhale for 8 seconds; repeat**

Annually (or more frequently) complete and share with school staff, family, friends, neighbors, caregivers, police, fire, and rescue professionals.

PERSONAL EMERGENCY PROFILE

DATE: _____

NAME: _____ AGE: _____

ADDRESS: _____

PHYSICAL DESCRIPTION: _____

PLACE PHOTO HERE

TRACKING FREQUENCY # (If applicable)

EMERGENCY CONTACT(S)

IF LOST, MAY BE FOUND AT: _____ (Likely places to go)

NAME: _____ PHONE NUMBER: _____

NAME: _____ PHONE NUMBER: _____

RESTRICTIONS (Allergies and diet)

MEDICAL NEEDS (Diagnosis, health concerns)

SIGNS OF ESCALATION (Changes in behavior that show increased or decreased anxiety, anger, etc. Recommendations for do's and don'ts.)

LIKES (Attractions, favorite things, hobbies, interests, foods, drinks, verbal exchanges, etc.)

DISLIKES (Triggers, sensitivities, fears, things to avoid, foods, drinks, verbal exchanges, etc.)

Symbols aid understanding and communication for everyone. Show and point to symbols when talking with a rescued person.

eat	drink	cold	Mom	Dad	call home	go home	deep breath
Yes	pain	safe	lost	Add personal message here	Add personal message here	Add personal message here	No

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Family Wandering Emergency Plan

Make sure your family has a response plan in case of a wandering emergency. Before an emergency happens, sit down together and decide where to search, how you will get in contact with each other, and what you will do in an emergency situation. Keep a copy of this plan.

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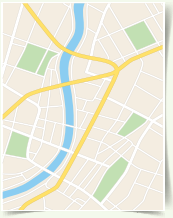
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Helpful Tips



Inform Others

Fill out the alert form found in this booklet and provide it to trusted family members, neighbors, and search partners.



Identify Threats

Identify threats before-hand, especially nearby ponds, lakes, pools, canals, water plants, etc., & nearby busy roads.

Mark's Search Team



Create Group

Create a Group Contact for family members, neighbors, and search partners, and assign it a name so you can easily text everyone at the same time.

Create an Emergency Plan

- Set a meeting with your family & trusted neighbors
- Inform them of your child/adult's tendency to wander/bolt & provide the alert form
- Assign each willing family member & neighbor a location to search
- Assign one emergency contact to stay with your younger children during emergencies
- Create a group text and easy group name
- Provide the group text with a snapshot of their agreed search location (below)
- Plan a mock drill as if it were the real emergency plan
- Update or reassess the plan as needed

If your child/adult with autism is missing, call 911 immediately & Search Water First.

Search Locations

List the main places your child/adult may likely go, especially nearby ponds, lakes, pools. Be specific. Search these areas first, and stay there until police arrive. If you've assigned search partners, make sure they know which location is assigned to them and visit it ahead of time.

Example: the pond on Maynard Road;
Smith's pool on Ralph Street

Search Partners

Before an emergency happens, assign at least five willing search partners who will commit to searching for your child/adult. Make sure they are close by, and understand your loved one's likes/dislikes/fears, their search responsibilities, and assigned location they should stay at until police arrive.

Example: Neighbor Stacie, 919-555-1616
Older Sibling's Name, 919-555-0808

	Assigned to	Name/Number
1.		
2.		
3.		
4.		
5.		

Our Group Name is: _____

Snap a picture of this section & text it to your group.

AUTISM & WANDERING PREVENTION TIPS

Promoting Safety In the Home & Community





Similar to wandering in people with dementia, people with autism spectrum disorder may wander or elope from a safe environment. Because people with ASD have challenges in areas of sensory processing, impulse control and bodily autonomy, it is critical for parents and caregivers to understand ways to keep loved ones with autism safe.

Prevention
Education
Response

Install Home Safeguards



Install secure locks (exterior doors), home security system or door/window chimes; fence yard; secure gates; keep garage opener out of reach; use baby monitors and visual prompts like simple stop signs.

Secure Personal Safeguards



Have wearable identification on your child; Temporary Tattoos are great for field trips and other outings; Check with local law enforcement to see if they offer Tracking Devices.

Create Community Awareness



Alert trusted neighbors, and introduce them to your child; fill out an alert form for local police, include a current photo and unique characteristics, likes, fears, and behaviors; alert the school, and bus drivers.

Remain Hyper Vigilant



Stay on extra high alert during warmer months, holidays, vacations, camping trips, transition periods, outdoor gatherings, a recent move to a new home or school, visiting an unfamiliar setting, public outings.

Initiate a "tag, you're it" system during family gatherings and transitions. Tag one responsible adult to closely supervise your child for an agreed-upon period of time.

Identify Triggers/Teach Self-help



Be aware of any known triggers that could prompt fleeing (loud noises, bright lights, fears, etc.) and work towards teaching your child safe alternative ways to respond.

For an individual who demonstrates bolting behaviors due to fear or stress, etc., use aids, such as noise-cancelling headphones, and teach calming techniques using favorites topics or items.

Teach Safety Skills



Enroll your child into swimming lessons. Final lessons should be with clothes and shoes on.

Use social stories to teach individuals with autism ways to stay safe, and use favorite objects or tools to demonstrate when it's outside time versus inside time.

Pursue forms of reliable communication, and seek a therapist who can help with impulse control and purposeful motor skills.

Call 911



Remain calm and always call 911 immediately if an individual with ASD is missing; law enforcement should treat each case as "critical." Law enforcement agencies are encouraged to contact the National Center for Missing & Exploited Children at 1-800-THE-LOST (1-800-843-5678) for additional assistance.

Search Water First



Immediately search areas that pose the highest threat first, such as nearby water, busy streets, train tracks, and parked cars.

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- REMEMBER -

IF A CHILD OR ADULT WITH AUTISM IS MISSING, SEARCH WATER FIRST



#WANDERINGPREVENTION
#AUTISMSAFETY
#SEARCHWATERFIRST

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