



Emergency Preparedness: Expecting the unexpected when living with ALS.

Michelle Fredrick, PT, ATP

Manager, Equipment and Assistive Technology
The ALS Association

ALS
ASSOCIATION

Education@ALS.org
800-782-4747

What IS an Emergency?

SERIOUS,
UNEXPECTED,
& often
DANGEROUS
situation requiring
IMMEDIATE ACTION

Types of Emergency Situations

1

Personal Emergencies

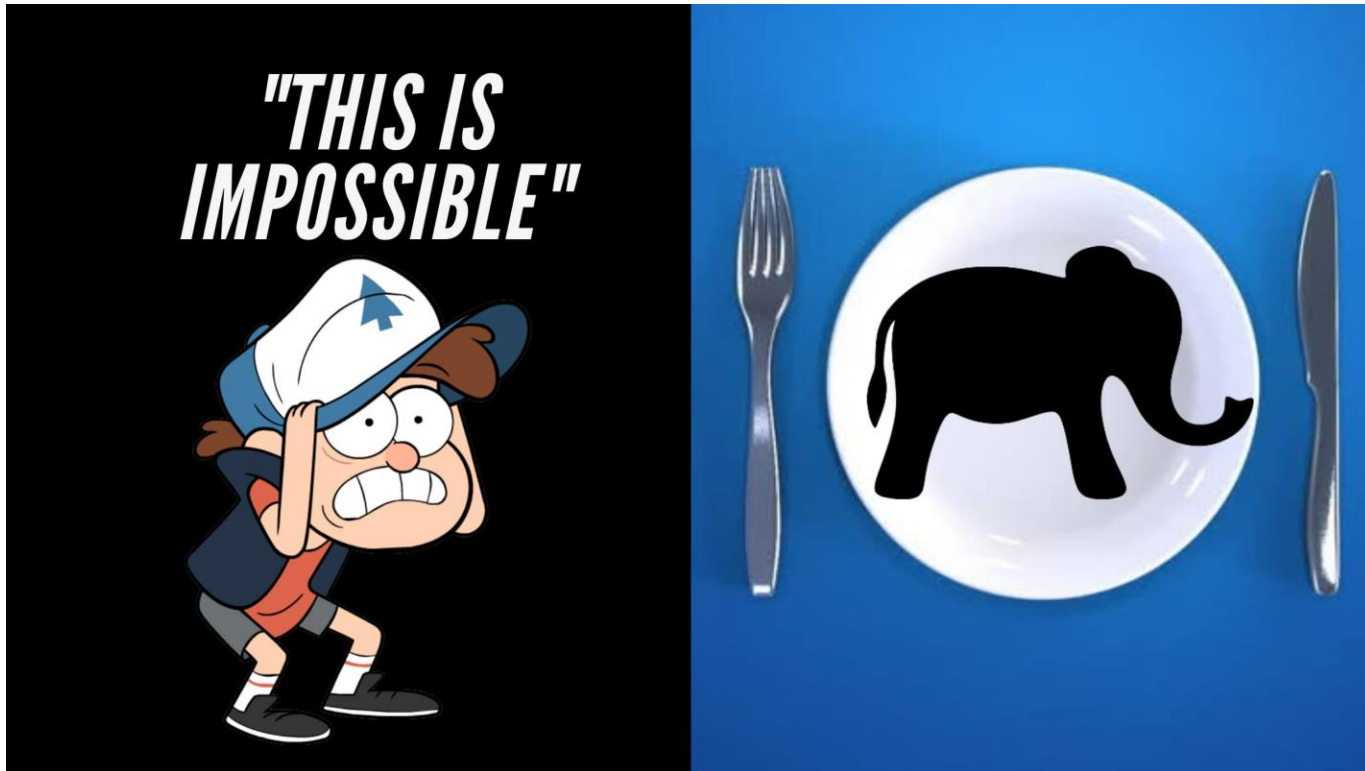


2

Community Emergencies



It can feel like a lot...



- You are about to get a lot of information
- But you can tackle it one task at a time!

Should you need to “GO” in an emergency....



- Hospital
- Home evacuation
- Community evacuation

Prepare a “GO-Bag”



Ready for EVACUATION or
going quickly to the
HOSPITAL

Information

Medical Information List
(details next slide)

Insurance Card copies

Advanced Directive Info

Information

ID / bank account /
insurance policy info

Equipment/Supplies

Communication board

Nutrition and respiratory
supplies, medication

Glasses/cash/credit card

Extra phone battery

Community

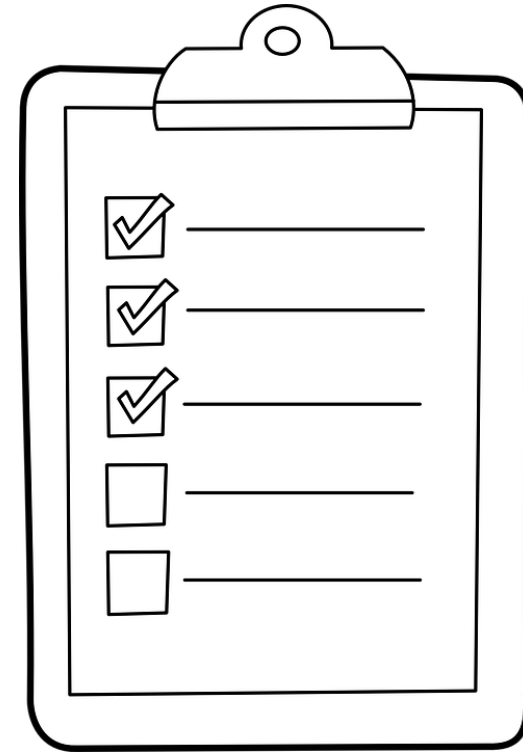
Support network contact
info

In Case Of Emergency
List

--who to contact if you
can't communicate

Medical Information List....

- Medical conditions
- Medicines (names, dosages, instructions)
- Allergies, blood type
- How you communicate
- Adaptive devices/Assistive Technology/Durable Medical Equipment used
- Your ability to: Lie flat, swallow pills, and any other special instructions re: your care
- List of providers and their contact info (physicians, pharmacy, RT, OT, PT, SLP, SW, etc.



ALS Association Tools



Medical Information Packet

Download or order a printed copy

- ALL of the info from previous page
- plus some specific info for health care/hospital providers
- letter board

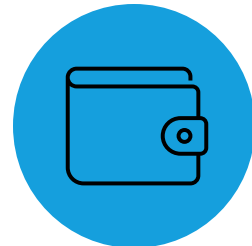


Key Medical Information Card

Download or order a printed copy

- ALS dx, physician and emergency contacts
- limited info for health care providers
- letter board

*Also available as an App: search **ALS Key Medical Information** in the Apple App Store or Google Play



<https://www.als.org/navigating-als/resources/medical-information-materials>

Prepare a “GO-List”



Of vital things that don't fit in your “Go-Bag” (keep in your go bag?)

Equipment

Mobility
Shower/toileting
Communication
Daily living aides

Equipment

Respiratory
-especially your mask!
Feeding Pump
Backup batteries/
chargers for powered
equipment

Supplies

Medication/nutrition/etc.
that need refrigeration
Items that have too
limited supply to store in
the Go-Bag

Community

Identify who in your
network could locate
and bring supplies that
get left behind.
Photos of equipment &
photos of settings

Bonus points: Laminate and attach to each device instructions for assembly, operation

If you have COMMUNICATION challenges....

- Plan how you will communicate with unfamiliar help if you don't have your communication device
 - Remember YOU might be the one calling 911 for someone else
 - Carry a printed card and/or store/record some info on your phone to inform first responders and others about your needs
- Store communication aides in all emergency kits (paper and writing materials, copies of a word/letter board, pre-printed phrases)
- Make sure your emergency health info card/packet explains your best method of communication
- Have a backup power source ready if you use a communication device, computer, laptop, tablet, etc. for communication



If you have MOBILITY challenges.....



- Keep mobility aides close at hand
- Know how to instruct someone how to assist you if you need to leave your devices behind
- Keep your Go-Bag in an easy-to-access place
- Have extra batteries or alternative charging options for power wheelchairs
- Keep an extra manual or transport wheelchair as backup if possible
- Add a tire patch kit to Go-Bag if wheelchair tires aren't puncture-proof
- Keep instructions with equipment
- Keep a list of serial numbers of your equipment

If you have RESPIRATORY challenges....

- Secure equipment so it doesn't fall/get damaged (bag, etc.)
- Have backup/alternative power sources prepared
- Test back-up batteries/alternate power sources on a schedule
- Know how long batteries will last
- Show your support network how to operate and safely move your equipment. Attach laminated instructions
- Register with your utility/electric company for prioritized power restoration
- Consider a generator or other backup power supply



Should you need to Evacuate your Home...



- Periodically review and update a plan for exiting home that matches your movement abilities.
- Practice! (2x/year OR if there is a change: physical status, home layout, caregivers involved, etc.) Include caregivers!
- If possible, store a back-up wheelchair and other equipment with a neighbor or other off-site location for quick access.

Should you need to Evacuate your Community...

- Listen to radio or television for location of emergency shelters. Note those that are accessible to people with physical disabilities.
- Wear appropriate clothing, including sturdy shoes.
- Take your emergency supplies (go bag + go list).
- Confirm on arrival that the shelter can meet your needs.
- Inform your support network of your location and status.



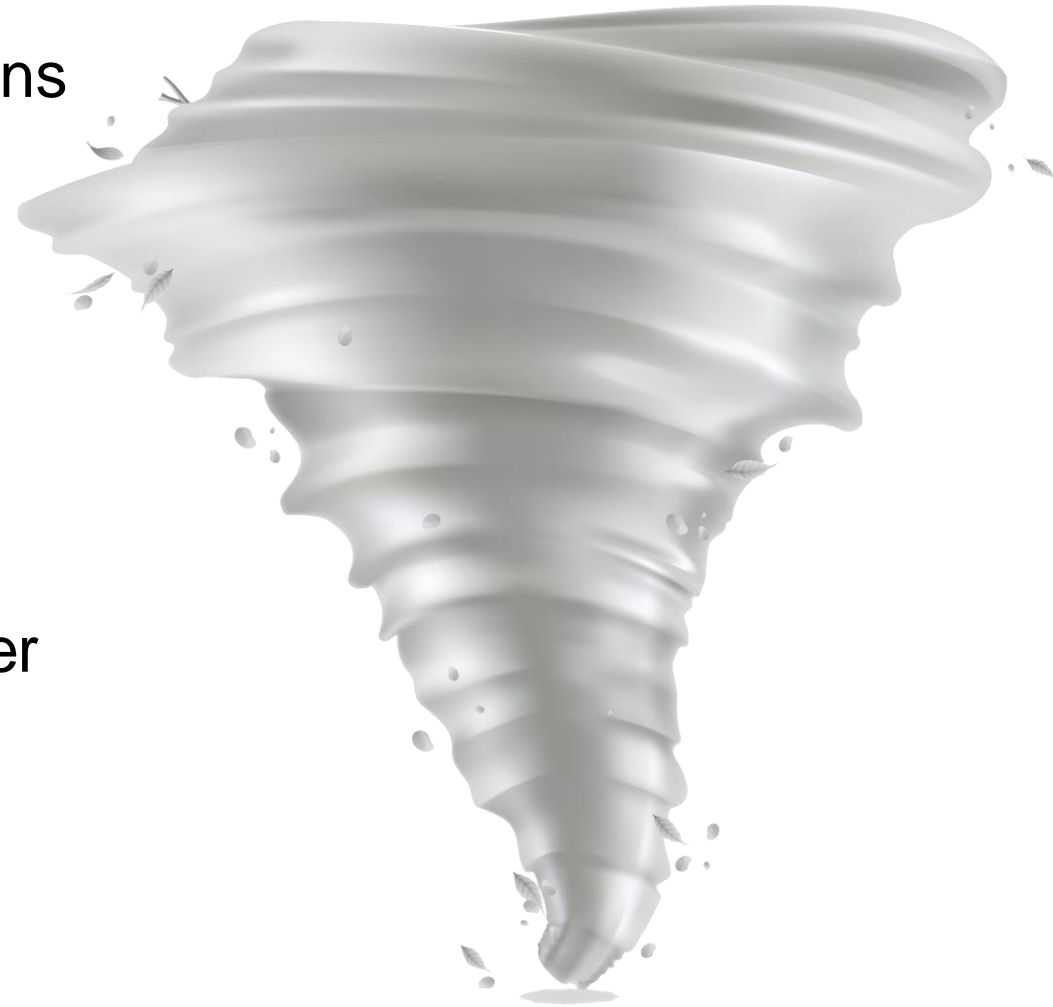
Should you need to “STAY PUT” in an emergency...



- Shelter-in-place
- Weather
 - Tornado/winter weather

In case you need to Shelter-in-place.....

- Identify and practice a plan for different situations
 - Where will I go, and how will I get there?
 - What supplies do I need for an hour/day/longer?
 - Where to store them so I can access?
 - May need to reassess seasonally
- Know how to connect and start a back-up power supply for essential medical equipment.

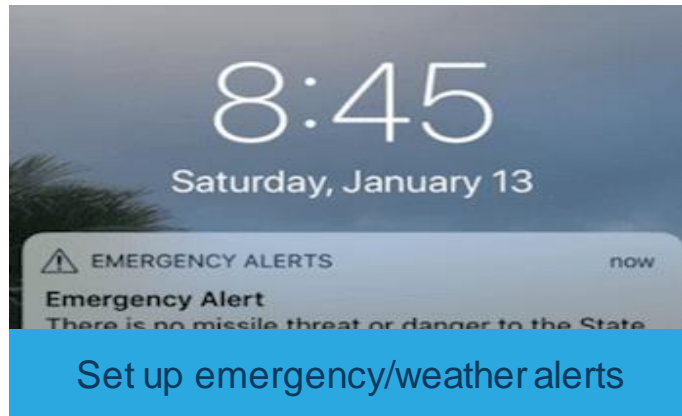


TO DO LiST

1. SO
2. MANY
3. THINGS



What could I do in 5 minutes.....pick one



What could I do in 15 minutes.....pick one



Call local emergency responders



Call local/county emergency preparedness office



Contact electric service provider

Do what you can, one thing at a time

