

Emergencies and disasters can strike quickly and without warning, forcing people to leave or be confined in their home. For the thousands of Americans living with ALS, emergencies such as fires, floods and acts of nature present a real challenge. We recognize how important it is that people living with ALS and their family members have the resources they need to make plans to protect themselves in the event of a disaster.

While we are not a disaster response organization or direct care provider, we have assembled the following information and resources to help you and your family plan and prepare. Should you need non-emergency help, call or email us at 1-877-568-4347 or info@alsnc.org.

PLEASE NOTE: This guide has many resources to help you plan **before** the storm.

Preparation Takes Time and Effort

- The important thing is to start preparing – you can do a little at a time. The more you do, the more confident you will be that you can protect yourself when the time comes.
- Keep this guide and your emergency materials together in a notebook. Print all relevant information you may need in an emergency ahead of time in the event of lost power or internet access.

Home Safety – Natural Disasters, Emergencies and Fires

- **Do not** assume you have been included in emergency plans.
- **Call your local fire department and other first responder organizations and report to them that a person living with ALS resides in your home. Make sure they understand any specific medical needs (e.g. tracheostomy, ventilator-dependent, feeding tube, mobility issues).**
 - In the event of an emergency or disaster, the 911 system would have a “disability notice” through the Computer Aided Dispatch (CAD) that would alert the responders that a person living at that residence needs additional attention immediately. The address also appears on EMS computers during 911 calls, serving a double purpose.
 - ➡ ○ **You MUST notify LOCAL EMS ahead of time!**
- Register with your local utility company.
- Ask your local fire department and other first responder organizations if they have any personnel or volunteers that could come to your home to work with you and/or your family/caregivers on an evacuation plan in the event of an emergency.
- If you have a service provider coming into the home (home health, palliative or hospice care, respiratory therapy company, etc.), talk to them about their emergency plans.
- Always check and make sure your smoke detectors (and carbon monoxide detectors) are installed, working properly and have backup batteries. Change batteries in the spring and fall.
- Have evacuation plans in the event of a natural disaster, emergency, or a fire. Make sure you have communicated these plans with your family and/or caregivers.
- For information about adaptive fire safety equipment, go to:
- <https://www.nfpa.org/Public-Education/Fire-causes-and-risks/Specific-groups-at-risk/People-with-disabilities>

Disaster Preparedness for People with Disabilities

1. Know what kinds of disasters could happen in your area and consider what your environment might look like after one occurs.
 - Certain resources or utilities may not be available, and conditions could limit your independence.
2. Complete a personal assessment.
 - Based on a given disrupted environment, your capabilities, and your limitations – Decide what you will be able to do for yourself and what assistance you may need **before, during and after a disaster**.

3. Create a personal support network – including family, friends, relatives, neighbors, roommates and co-workers who could assist you at a moment's notice.
 - Discuss your special needs with them, including evacuation plans and medical information lists. (See the Emergency Medical Services Information document included in this binder for special needs listed)
4. Make an emergency information and contact list so others will know whom to call if they find you unconscious, unable to speak, or if they need to help you evacuate quickly.
 - Include the names and numbers of out-of-town contacts, as well as everyone in your personal support network.
5. Organize your medical information in one place that is easy to access.
 - Include the names and numbers of your doctors, your medications, dosage instructions and any existing conditions.
 - Make note of your assistive devices/equipment, allergies, special nutritional requirements, and any communication difficulties you may have.
6. **Keep at least a 7-day supply of medications and food on hand, *ESPECIALLY* if you require nutrition through a feeding tube.**
 - Ask your doctor or pharmacist what you should do if you cannot immediately get more medication or in cases of emergency.
 - If you undergo treatments administered by a clinic or hospital, ask your provider how to prepare for a disruption caused by a disaster.
7. Install **at least** one smoke alarm on each level of your home and test them at least once a month.
8. Know the location of main utility cutoff valves and learn how and when to disconnect them during an emergency.
9. Identify evacuation routes and safe places to go during a disaster.
10. Complete a summary checklist to make sure that your personal disaster plan is comprehensive.
 - Be sure to include your medical needs, evacuation routes, care plans for your service animals, an alternative place to stay, etc.
11. Keep a disaster supply kit in your home, car, workplace or anywhere you may spend your time. Include items such as food, water, a first aid kit, adaptive equipment, batteries and supplies for your pets or service animals.
12. Make your home or office safer by checking hallways, stairwells, doorways, windows and other areas for hazards that may keep you from safely leaving any dwelling during an emergency.
 - Secure or remove furniture and objects that may block your path.
13. Show others how to operate your wheelchair or other assistive devices.
14. Keep contact information for local independent living centers and other disability service organizations in a safe and easy-to-access place.
15. If you use in-home support services (Meals-on-Wheels, Life Alert or other support services), work with them to personalize emergency preparedness plans to meet your needs so you can keep in touch with them during and after an emergency.
16. Work with local transportation and disability services (e.g., Paratransit, Independent Living Centers) to plan ahead for accessible transportation if you may need that for evacuation or other reasons during a disaster.
17. Develop back-up plans for personal assistance services, hospice or other forms of in-home assistance.
18. Keep in mind that during an emergency, you may need to explain to first responders and emergency officials that you need to evacuate with your family, service animal, caregiver or personal assistance provider so they can provide the support you need to maintain your health, safety and independence.

Deciding to Stay or Go:

- Depending upon your circumstances and the nature of the emergency, the first important decision is whether you stay or go.
 - You should understand and plan for **both** possibilities.
 - Use common sense and available information to determine if there is immediate danger. In any emergency, local authorities may or may not immediately be able to provide information on what is happening and what you should do.
 - You should monitor television and/or radio news reports for information or official instructions as they become available.

- If you're specifically told to evacuate or seek medical treatment, do so immediately.
 - If you require additional travel time or need transportation assistance, make these arrangements in advance.
- Whether you are at home or elsewhere, there may be situations when it's simply best to stay where you are and avoid any uncertainty outside.
 - Consider what you can do to safely shelter-in-place with family, friends, or neighbors.
 - Consider how a shelter designated for the public would meet your needs.
- There could be times when you will need to stay where you are and create a barrier between yourself and the potentially contaminated air outside.
 - This process is known as "sealing the room". Use available information to assess the situation. If you see large amounts of debris in the air or if local authorities say the air is badly contaminated, you may want to take this kind of action.
 - For more information about "sealing the room" visit <https://www.ready.gov/shelter>

Evacuation

- There may be conditions in which you will decide to get away or there may be situations when you may be ordered to leave.
 - Plan how you will get away and anticipate where you will go.
 - Choose several destinations in different directions so you have options in an emergency.
 - Ask about evacuation plans at the places where you spend time including work, school, community organizations and other places you frequent.
 - If you typically rely on elevators, have a back-up plan in case they are not working.

Tips for People with Communication Disabilities

- Communication
 - Determine how you will communicate with emergency personnel if you do not have your communication devices (augmentative communication device, word board, etc.).
- Communication Aids
 - Store paper, writing materials, copies of a word or letter board and pre-printed key phrases specific to anticipated emergencies in all of your emergency kits, your wallet, purse, etc.
- Emergency & Medical Information Form
 - Make sure you keep updated written records of your medical information. This should include a list of any diagnosis' you have been given, names and contact info for your healthcare providers, medications and dosages, and any specialty equipment or devices you require. It should also explain the best method of communication for you (written notes, pointing to letters/words/pictures, finding a quiet place).
 - Maintain a written list of your emergency contacts including how to contact them.
- Alternate Power Source
 - Obtain an alternative power source (power converter, batteries) if you use a computer or laptop as a means of frequent communication.
- Communication Checklist
 - Determine your ideal method of communication in the event of an emergency and be prepared to use it.
 - Store communication aids in all of your emergency kits (make sure to have a Rapid Access Communication System in place. This could include a letterboard, laser pointer or other communication system that does not rely on electricity).
 - Make an emergency health information packet (see the Medical Information Packet in the Medical Section) and be sure to include your communication needs.
 - Store batteries or chargers for communication equipment.

Tips for People with Life-Support Systems

- Secure Equipment
 - Secure your life-support equipment to prevent damage from falling. If you use a chain, make sure it is welded (not bent).

- Alternate Providers
 - Determine which facilities/providers can serve you if your home system becomes inoperable or your current provider is unable to assist you.
- Alternate Power
 - Ask your vendor about alternative power sources that will sustain you for *up to seven days*.
 - Use manually operated equipment if you can.
 - If your equipment can be powered from a vehicle battery, obtain any hardware necessary for the connection.

Generators

- For all-day use over several days, a gasoline-powered generator is the preferred alternative power source. Test it periodically and operate it only in an open area to ensure good ventilation. If you store an adequate gasoline supply, make sure you do so safely. Keep a syphon kit on hand in case you need to obtain gasoline directly from your vehicle.
- Some generators are built with an option for remote monitoring. With this feature, an alert can be sent to you directly, and/or to a generator service provider. This helps ensure your generator is operational when you need it.
- Consult your utility company before you select or set up a generator that can be plugged into house wiring systems.
- Test Back-ups Regularly
 - If your back-up power system relies on batteries, be aware that stored batteries require periodic charging, even if they are unused. A charging routine must be strictly followed.
 - Test your alternative power equipment regularly to ensure it will function in an emergency.
 - Know the working duration of any batteries that support your system and make sure you are comfortable in using those batteries if needed.
 - Ask your power company about the type of back-up power you plan to use and get their advice.
 - Understand that if you do lose power, your battery is intended to give you time to get to a safe place that has power and is not intended for long-term use.
- Oxygen Users
 - Ask your provider if a reduced-flow rate may be used during a disaster to prolong the life of the system.
- Record the reduced flow numbers on your equipment so you can refer to the values when needed.
 - Be aware of oxygen safety; avoid areas where gas leaks or open flames may be present.
 - Post "Oxygen in Use" signs.
 - Keep the shut-off switch for oxygen equipment near you so you can get to it quickly in an emergency.

Utility Company Registry

- ➔ • Many utility companies keep a list of names of people dependent on life-support systems and tag their meters.
 - Registering for this service may qualify you for a discounted rate; contact the customer service department for more information.
 - Never count on your power being quickly restored.
 - Utility personnel may not be able to reach you right away after a major disaster.

Tips for People with Mobility Concerns

- Storage
 - Store emergency supplies in a pack or backpack attached to your walker, wheelchair or scooter.
 - Store needed mobility aids (canes, crutches, walkers, wheelchairs) close to you in a consistent, convenient and secure location. (Keep extra aids in several locations, if available.)
- Keep a pair of heavy gloves in your supply kit to use while wheeling or making your way over glass and debris.

- If you use a power wheelchair or scooter, consider having an extra battery available. A car battery may be substituted; however, it will not last as long as a wheelchair's deep-cycle battery.
 - ➡ ○ Ask your vendor if you can recharge your batteries (in the event of a power outage) by connecting jumper cables to a vehicle battery or using a special converter that plugs into your vehicle's cigarette lighter.
 - If you do not have puncture-proof tires, keep a patch kit or can of "seal-in-air" to repair flat tires and/or keep an extra supply of inner tubes.
 - Store a lightweight, manual wheelchair, if available.

Evacuation Plan for People in Wheelchairs

- Arrange and secure furniture and other items to create barrier-free passages in your home and office.
- If you spend time above the first floor of an elevator building, plan and practice using alternate methods of evacuation. If needed, enlist the help of your personal support network.
- There will be instances where wheelchair users will have to leave their chairs behind in order to evacuate safely.
 - If you cannot use stairs, familiarize yourself with lifting and carrying techniques that will work for you. If you live upstairs, consider purchasing an evacuation stair chair.
 - Alert rescue personnel to any areas of vulnerability. (This may be done when notifying local EMS/Fire Department of condition and equipment.)
 - For example, the traditional "fire fighter's carry" may be hazardous for people with respiratory weakness.
 - You need to be able to give brief instructions regarding how to move you.

Have a "Go Bag"

- Complete the Medical Information Packet (in the Medical Information section) and place it in bag.
- Can be used for evacuation or in the event of unexpectedly going to the hospital. Include the following: (some may be put on thumb drive for easy, safe access)
 - Current medications and list of all medications, including dosages.
 - Health forms.
 - Copies of insurance cards.
 - Communication board.
 - Liquid nutrition/feeding tube supplies.
 - Respiratory equipment supplies.
 - Glasses.
 - Cash/travelers checks.
 - Important family documents such as copies of insurance policies, identification and bank account records in a waterproof, portable container. You can use the Emergency Financial First Aid Kit (EFFAK) developed by Operation Hope, FEMA and Citizen Corps to help you organize your information.
<https://community.fema.gov/PreparednessCommunity/s/emergency-financial-first-aid-kit>

Determine Your Evacuation Options When Traveling

- If you have difficulty using stairs, ask for a guest room on a lower floor.
- Let registration staff know that you may need assistance in an emergency and let them know the type of assistance you may need.
- Check exit routes on the back of guest room doors and familiarize yourself with the exits and exit maps.
 - Track the escape route, note the number of doors between your room and the emergency exit.

Resources

Important Phone Numbers:

Emergency: 911

American Red Cross: 866-438-4636

FEMA: 800-621-3362

NC DOT Statewide Road Closures: 511

Disaster Distress Helpline: 1-800-985-5990 (a resource available 24 hours-a-day, seven-days-a-week, 365-days-a-year. This national hotline is dedicated to providing immediate crisis counseling for people who are experiencing emotional distress related to any natural or human-caused disaster.)

Website Links:

North Carolina Emergency Management: www.readync.gov

National Hurricane Center for Hurricane Status: www.nhc.noaa.gov

People with disabilities emergency preparedness:

Ready.gov: www.ready.gov/disability

American Red Cross: www.redcross.org/get-help/how-to-prepare-for-emergencies/inclusive-preparedness-resources.html

FEMA Emergency Preparation Brochure: https://www.fema.gov/pdf/library/pfd_all.pdf

Disaster Assistance: www.disasterassistance.gov

To order or print the following: Medical Information Packet, Key Medical Information Card, File of Life Card, Social Distancing Door Sign, or Hospital Communication:

<http://www.alsa.org/als-care/resources/publications-videos/medical-information-packet/>

Apps:



FEMA (Federal Emergency Management Agency)



Emergency Alerts – American Red Cross

Additional Resources:

Find Open Shelters –

- FEMA: Search for open shelters near you by texting SHELTER and your zip code to 4FEMA (43362). Example: Shelter 01234. (Standard text message rates apply)
- Red Cross-Find an Open Shelter: <https://www.redcross.org/get-help/disaster-relief-and-recovery-services/find-an-open-shelter.html>

Register yourself and your family with the Red Cross as safe: www.redcross.org/safeandwell

Prepare your pets for disasters: <https://www.ready.gov/pets>