

Emergency Preparedness

Guidelines for People with ALS and Their Families

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Emergencies and disasters can strike quickly and without warning, forcing people to leave or be confined in their home. For the thousands of Americans with ALS, emergencies such as fires, floods and acts of terrorism present a real challenge. It is important that people with ALS and their family members make plans to protect themselves in the event of disasters. This needs to be addressed not only at home, but also when away from home, such as at work or on vacation.

In addition, first responders need to know how to work with people with ALS to evacuate them safely and quickly. Emergency planners must ensure that shelters are accessible to people with a variety of disabilities.

Step One: PREPARE

Step Two: Make a Plan

Step Three: Be Informed



Preparation may seem like work --- and it is!

- Preparing does take time and effort, but...
- You can do a little at a time ---the important thing is to start!
- The more you do, the more confident you will be that you can protect yourself and loved ones

Step One: PREPARE

Have a **“Go Bag”** packed in case you need to evacuate or leave your house quickly in an emergency

All “Go Bags” should have:

- A list of personal contacts, family and friends that you may need to contact in an emergency
- Medical insurance cards, Medicare/Medicaid cards, physician contact information, list of your allergies and health history
- If possible, extra medicine or other medical supplies you use regularly
- Extra eyeglasses and/or hearing aids if you rely on these
- Medical alert tags, bracelets or written descriptions of your disability and support needs, in case you are unable to describe the situation



And, if appropriate for you:

- A laminated personal communication board, if you need assistance being understood
- Extra cans of formula if you use a feeding tube
- Copies of current medical prescriptions and doctors orders
- The type and serial numbers of the support devices you use including respiratory equipment
- A list of the local non-profit or community-based organizations that know you or assist people with access and functional needs similar to yours
- If you use a motorized wheelchair, have a light weight manual chair available for emergencies
- Know the size and weight of your wheelchair, in addition to whether or not it is collapsible, in case it has to be transported
- Even if you do not use a computer yourself, consider putting important information onto a portable thumb drive for easy transport
- Battery chargers and extra batteries for hearing aids, motorized wheelchairs or other battery-operated medical or assistive technology devices

Step Two: Make a Plan

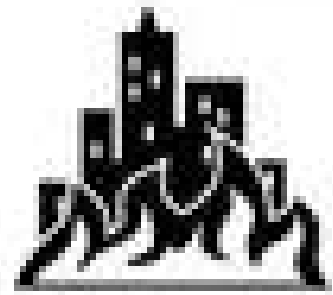
It is **crucial** that people with ALS and their families have a plan in place in case of emergency or disaster. While your go-bag should contain all of your essential materials, it is useless without a plan to back it up!

- 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 hamper your independence.
- Complete a personal assessment. Decide what you will be able to do for yourself and what assistance you may need before, during and after a disaster
- Create a personal support network of 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.
- Make an emergency information 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 network.
- Compile a medical information list that contains the names and numbers of your doctors, your medications, dosage instructions, and any existing conditions. Make note of your adaptive equipment, allergies, and any communication difficulties you may have.
- Keep at least a seven-day supply of medications on hand. Ask your doctor or pharmacist what you should do if you cannot immediately get more. If you undergo treatments administered by a clinic or hospital, ask your provider how to prepare for a disruption caused by a disaster.
 - Install at least one smoke alarm on each level of your home and test once a month. Know the location of utility cutoff valves and learn how and when to disconnect them during an emergency. Identify evacuation routes and safe places to go during a disaster



Step Two: Make a Plan

- 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.
- Keep a disaster supply kit in your home, car, workplace or anywhere you may spend your time. Include such items as food, water, a first aid kit, adaptive equipment, batteries, and supplies for your pets or service animals.
- Make your home or office safer by checking hallways, stairwells, doorways, windows and other areas for hazards that may keep you from safely leaving a building during an emergency. Secure or remove furniture and objects that may block your path.
- Show others how to operate your wheelchair or other assistive devices.
- Keep contact information for local independent living centers and other disability services organizations in a safe and easy-to-access place.
- If you use in-home support services such as Meals-on-Wheels, Life Alert, etc., 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.
- 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.



- Develop back-up plans for personal assistance services, hospice, or other forms of in-home assistance.
- Keep in mind that during an emergency, you may need to explain to first responders and emergency officials that you need to evacuate and shelter 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.

Step Two: Make a Plan

Tips for Specific Needs

For People with Mobility Difficulties

- Store emergency supplies in a pack or backpack attached to your walker, wheelchair or scooter
- If you use a motorized wheelchair or scooter, consider having an extra battery
- A car battery can 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
- Have a lightweight, manual wheelchair available if possible

Evacuation Plan (for home, apartment building, office, hotel, etc.)

- 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. Alert rescue personnel to any areas of vulnerability. 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.

For People with Communication Difficulties

- **Communication:** Determine how you will communicate with emergency personnel if you do not have your communication devices
- **Communication Aids:** Store paper, writing materials, copies of a word or letter board and pre-printed key phrases specific to anticipated emergencies in all your emergency kits, your wallet, purse, etc.
- **Emergency Health Information Card:** Make sure your emergency health information card explains the best method of communication for you
- **Alternative Power Source:** Obtain an alternative power source if you use a computer/laptop for communication

Step Two: Make a Plan

Tips for Specific Needs

For People Who Rely on Respiratory Support Devices

Alternate Power

- Ask your vendor (equipment supplier) about alternative power sources that will sustain you for up to seven days.
- Could you use manually-operated equipment?
- Can your equipment be powered from a vehicle battery? If yes, obtain any hardware necessary for the hook-up.

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 siphon kit on hand in case you need to obtain gasoline directly from your vehicle.
- Some generators can be plugged into house wiring systems. Consult your utility company before you do this.

Test Backups Regularly

- If your backup 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.
- Ask your power company about the type of backup power you plan to use and get their advice.

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 discount 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.

Personal Support Network

- Show your personal support network how to operate and safely move your equipment if necessary.
- Label equipment and attach laminated instruction cards

Step Three: Be Informed

Information is key when a disaster strikes, so stock up early and often. Be sure that you know and contact local organizations which may have more information specific to your area or situation. You can also check you the internet resources listed below.

More Information:

- Prepare for Emergencies Now: Information for People with Disabilities: http://www.ready.gov/sites/default/files/FEMA_Disabilities_R-6_web_june2012.pdf
- Individuals with Disability Access & Functional Needs: <http://www.ready.gov/individuals-access-functional-needs>
- Preparing Makes Sense for People with Disabilities and Other Access and Functional Needs: http://www.fema.gov/media-library/media_records/7028
- Independent Living Resource Center San Francisco: www.ilrcsf.org/resources/publications.shtml
- Patient Provider Communication Website: www.patientprovidercommunication.org/
- United States Society for Alternative Augmentative Communication: www.ussaac.org
- Red Cross: www.redcross.org/museum/prepare_org/disabilities/disabilitiesprep.htm