

General Disaster Preparedness

Preparing 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
- **Do not** assume you have been included in emergency plans

Home Safety – Natural Disasters, Emergencies, and Fires

- **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, the 911 system would have a “disability notice” that would alert the responders that a person living at that residence either moves slowly, cannot get out of the house unassisted, or is confined to a second (or higher) floor of the house
- **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/caretakers on an evacuation plan in the event of an emergency**
- Always check and make sure your smoke detectors (and carbon monoxide detectors) are installed, working properly, and have backup batteries
- Have evacuation plans both in the event of a natural disaster, emergency or a fire
- For information about adapted fire safety equipment, go to:
 - <http://www.nfpa.org/public-education/by-topic/people-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
 - a. Certain resources or utilities may not be available and conditions could limit your independence
2. Complete a personal assessment
 - a. 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
 - a. Discuss your special needs with them, including evacuation plans and medical information lists

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
 - a. Include the names and numbers of out-of-town contacts, as well as everyone in your personal support network
5. Compile a medical information list that contains the names and numbers of your doctors, your medications, dosage instructions, and any existing conditions
 - a. Make note of your assistive devices/equipment, allergies, and any communication difficulties you may have
6. Keep **at least a seven-day supply of medications and food** on hand, **ESPECIALLY if you require nutrition through a feeding tube**
 - a. Ask your doctor or pharmacist what you should do if you cannot immediately get more medication or in cases of emergency
 - b. 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 once a month
 - a. Know the location of main utility cutoff valves and learn how and when to disconnect them during an emergency
8. Identify evacuation routes and safe places to go during a disaster
9. Complete a summary checklist to make sure that your personal disaster plan is comprehensive
 - a. Be sure to include your medical needs, evacuation routes, care plans for your service animals, an alternative place to stay, etc.
10. Keep a disaster supply kit in your home, car, workplace or anywhere you may spend your time
 - a. Include items such as food, water, a first aid kit, adaptive equipment, batteries, and supplies for your pets or service animals
11. 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
 - a. Secure or remove furniture and objects that may block your path
12. Show others how to operate your wheelchair or other assistive devices
13. Keep contact information for local independent living centers and other disability services organizations in a safe and easy-to-access place
 - a. <http://www.redcross.org/get-help/how-to-prepare-for-emergencies/disaster-safety-for-people-with-disabilities#Plan-Ahead>
14. 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
15. 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
16. Develop back-up plans for personal assistance services, hospice, or other forms of in-home assistance

17. 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 on 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 alone or 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 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

Emergency Resources and Tools for People with ALS

- There are numerous tools that can help you communicate with and educate first responders about ALS and what to do with someone they are trying to help. The following tools are available to help:
- **Medical Information Packet**
 - Complete online and print (or print and complete) a copy of the Medical Information Packet:
 - <http://www.alsa.org/als-care/resources/publications-videos/medical-information-packet>
 - This Packet allows a person to provide medical information regarding specific issues related to ALS care, and how YOUR issues can most appropriately be addressed
- **Medical Information Pocket “Z” Card**
 - Another helpful tool is the Medical Information “Z” Card provides a brief summary of critical ALS issues, including a mini-letter board, which can be folded and kept in a wallet
 - <http://www.alsa.org/assets/pdfs/Medical-Information-Packet-ZCard.pdf>
- **Rapid Access (low tech) 8 1/2” X 11” printable letter board**
 - Print this out, even if you don’t think you will need it: Medical Information Packet Printable Letter board, Rapid Access, Low Tech Communication Tool
 - <http://www.alsa.org/assets/pdfs/Medical-Information-Packet-EyeGazeBoard.pdf>
- **Key Medical Information Mobile App**
 - The Key Medical Information app provides medical personnel with critical information to care for a person with ALS during an emergency. In addition to medical dos and don’ts, the app provides a communication board and emergency contact fields for users to reference.
 - The app is available in Google Play and the Apple Store and is searchable by “Key Medical Information” or “The ALS Association”
 - If you have trouble locating the app, please use one of the below links, depending on your brand of phone:
 - **Google Play:** <https://play.google.com/store/apps/details?id=org.als.als>
 - Compatibility: Android 4.4 and up
 - **Apple App Store:** <https://itunes.apple.com/us/app/als-key-medical-information/id1262606065?ls=1&mt=8>
Compatibility: Requires iOS 10.2 or later. Compatible with iPhone, iPad, and iPod touch

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, artificial larynx)
- 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/packet explains the best method of communication for you (written notes, pointing to letters/words/pictures, finding a quiet place)
 - See section **“Emergency Resources and Tools for People with ALS”**
- Alternate Power Source
 - Obtain an alternative power source (power converter, batteries) if you use a computer or laptop as a means of frequent 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 an emergency health information card/packet 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 can be plugged into house wiring systems
 - Consult your utility company before you do this
- 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
- 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
 - Ask your power company about the type of back-up 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

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 secured location

- Keep extra aids in several locations, if available
- Emergency Kit
 - 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 motorized wheelchair or scooter, consider having an extra battery available. 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
 - 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
 - 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

Have a "Go Bag"

- Can be used for evacuation or in the event of unexpectedly going to the hospital. Include the following:
 - 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
 - <http://www.operationhope.org/emergency-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 exits

Resources

BE INFORMED: There are various web sites and telephone numbers for preparedness:

- Prepare for Emergencies Now: Information for People with Disabilities:
http://www.ready.gov/sites/default/files/FEMA_Disabilities_R-6_web_june2012.pdf
- Preparing Makes Sense for People with Disabilities and Other Access and Functional Needs:
http://www.fema.gov/medialibrary/media_records/7028
- National Hurricane Center for Hurricane Status: <http://www.nhc.noaa.gov/>

For more information regarding general disaster preparedness contact your local ALS Chapter which can be found at: <http://www.alsa.org/community/chapters/>

Disaster Preparedness Contact List

	Phone Number	Address
Police Department		
Fire Department		
EMS		
Local Red Cross		
Local Emergency Management Office		
Local Public Health Department		
Electric Company		
Gas Company		
Water Company		
Durable Medical Equipment Company		
Physician		
Pharmacy		
Neighbor		
Relatives/Friends		