

# Emergency Preparedness for People with ALS

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 nature present a real challenge. It is important that people with ALS and their family members make plans to protect themselves in the event of a disaster. This needs to be addressed not only at home, but also when away from home, such as at work or on vacation.

## **First Step: Make the conscious decision to be prepared.**

It takes work, but it is worth it! The more you do, the more confident you will be that you can protect yourself when the time comes.

## **Second Step: Make a plan.**

The plan should include:

- 1) Know what kinds of disasters (especially weather/natural disasters) could happen in your area and consider what your environment might look like after one occurs. [Sign up for alerts from FEMA](#) or local weather sources. These alerts can be directly texted to a cell phone, a Facebook or Twitter account, or your home phone number.
- 2) Complete a personal assessment and personal support network of family, friends, relatives, neighbors, roommates, and co-workers who could assist you at a moment's notice. Keep this list handy at all times.
- 3) Make an emergency information list so others will know who to call if they find you unconscious, unable to speak, or if they need to help you evacuate quickly.
- 4) Prepare a medical information list that includes:
  - Names and contact information for medical providers
  - Health insurance information
  - Medications you use
  - Adaptive and support equipment you use
  - Allergies and sensitivities
  - Special care instructions
  - Instructions for getting you out of your home, if necessary
  - The best way to communicate with you if you have communication difficulties

(It is recommended this be on paper instead of a computer data stick/flash drive because there may not be electricity to run a computer to retrieve this information.)

- 5) 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.
  - 6) Identify evacuation routes and safe places to go during a disaster. Remember that in the event of a natural disaster you may be under mandatory evacuation. Should this occur and you do
-

not have accessible transportation, call your local police department and inform them of your situation.

- 7) Keep a disaster supply kit, also known as a “go bag,” in your home, car, workplace, or anywhere you may spend your time. Include such items as non-perishable food, bottled water, a first aid kit, low-tech communication board and/or picture board, adaptive equipment, and batteries. If the person with ALS cannot speak, attach a small recorder (like those found on key chains) to the outside of the bag. The recording should say something like:  
“My name is \_\_\_\_\_. I cannot speak. I communicate by \_\_\_\_\_. In case of emergency, please call \_\_\_\_\_.”
- 8) Show others how to operate your wheelchair or other assistive devices.
- 9) Have an extra battery for a motorized wheelchair or scooter. A car battery can also be used with a wheelchair, but will not last as long as a wheelchair's deep-cycle battery. Check with your vendor to know if you can charge your battery by, either connecting jumper cables to a vehicle battery, or connecting batteries to a converter that plugs into a vehicle's cigarette lighter. **Caution:** Charge only one battery at a time.
- 10) Have a lightweight manual wheelchair for backup.
- 11) Have a patch kit, can of tire sealant (such as Fix-a-Flat), and inner tubes for a motorized wheelchair or scooter with inflatable tires.
- 12) Send/email copies of important documents to your out-of-town contact person.
- 13) Order an adaptor kit if you are using a BiPAP. Respironics (<http://www.respironics.com/>) has a kit that can be used with a car battery and a marine battery.
- 14) 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.
- 15) If you cannot verbally communicate, make sure you always have a Rapid Access Communication System in place. This could include a letter board, laser pointer, or other communication system that does not rely on electricity. You can find more information at [www.patientprovidercommunication.org](http://www.patientprovidercommunication.org).
- 16) Have a converter for your communication device.
- 17) Contact your utility company and fire department before you connect a generator to house wiring. Connecting a generator is specifically prohibited by law in some areas. Evacuating to a special needs shelter may be safer than staying at home with a generator during a disaster.

- 18) Enroll in your electric company's "priority reconnection service," if available. Even with priority reconnection service status, your power could still be out for a long time following a disaster. Individual homes do not have reconnection priority over emergency facilities.
- 19) Have a pet care plan. Shelters do not always accept pets. Contact your local animal shelter.
- 20) For assistance with medical equipment or any other care due to an emergency, please contact your Rocky Mountain Chapter Care Coordinator by phone (866) ALS-3211 or email [info@alsaco.org](mailto:info@alsaco.org).

### **Important Family Documents:**

*Keep these records in a waterproof, portable container*

- 1) Copy of will, insurance policies, contracts, deeds, stocks and bonds
- 2) Copy of passports, Social Security cards, immunization records
- 3) Record of credit card accounts
- 4) Record of bank account numbers, names, and phone numbers
- 5) Inventory of valuable household goods, important telephone numbers
- 6) Family records (birth, marriage, death certificates)
- 7) Copy of Supplemental Security Income award letter

**International Vent Users Network:** For those who have current respiratory support needs, they may find additional information related to urgent medical care environments from the International Vent Users Network: Take Charge Not Chances: <https://www.ventnews.org/tcnc>

### **Third step. Be Informed.**

There are various web sites 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](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](http://www.fema.gov/medialibrary/media_records/7028)

**National Emergency Assistance in Your Community** – There are several different organizations, both public and private, that provide disaster relief assistance to people living in affected areas. The organizations listed below are a few that provide assistance to people nationwide. You should also contact your local, state or county's department of emergency management (or similarly named agency) to obtain assistance information as well.

- National Weather Service - <https://www.weather.gov/>
- Federal Emergency Management Agency (FEMA) - <https://www.fema.gov/>
- Centers for Disease Control and Prevention (CDC) - <https://www.cdc.gov/>

**Members of Congress** – Your U.S. senators and representatives will have staff available to assist you should a disaster or terrorist act affect your area. They will be able to provide you with the latest information about federal resources that are available and often local resources as well. You can contact them by calling the Capitol Switchboard at (202) 224-3121. To identify your members of Congress and obtain their contact information, including locations and phone numbers for local offices, please visit the Advocacy Action Center of The ALS Association and enter your zip code in the space provided.

**The American Red Cross** – The American Red Cross and its local chapters are a helpful resource to contact following a disaster. Information is available by calling 1-800-RED-CROSS (1-8000733-2767) by visiting The American Red Cross website – <https://www.redcross.org/>

**Red Cross of Colorado** - <https://www.redcross.org/local/colorado.html>

- **Mile High Area (Denver)**  
444 Sherman St., Denver, CO 80203 – 303-722-7474
- **Southeastern Colorado**  
1040 S. 8th St., Colorado Springs, CO 80905 – 719-632-3563
- **Northern Colorado**  
1808 N. Boise Ave, Suite 110, Loveland, CO 80538 – 970-226-5728
- **Western Colorado**  
506 Gunnison Ave., Grand Junction, CO 81501 – 970-242-4851

**Red Cross of Utah** - <https://www.redcross.org/local/utah.html>

- **Greater Salt Lake Area Chapter (Regional Headquarters)**  
6616 S. 900 E., Murray, UT 84121 – (801) 323-7000
- **Central and Southern Utah Chapter**  
865 North Freedom Blvd., Provo, UT 84604 – (801) 373-8580
- **Northern Utah Chapter**  
2955 Harrison Boulevard, Suite 204, Ogden, UT 84403 – (801) 627-0000
- **St. George Office**  
476 East Riverside Drive, St George, UT 84790 – (435) 674-4440

**American Red Cross of Wyoming** - <https://www.redcross.org/local/wyoming.html>

5500 Bishop Blvd., Cheyenne, WY 82003 – **Phone:** (307) 638-8906

**State and Local Assistance** – State and local governments provide emergency relief assistance. Check local listings to find the information for your state’s office of emergency management or similarly named agency, or, call your local police or fire department. Many states and localities provide special assistance for the disabled and people with special needs. Contact your state or county office of emergency management (or

similarly named agency) to learn what emergency services may be available for the disabled, including special shelters that will accommodate the disabled, or transportation assistance in the event of an evacuation. *You may need to register in advance for this special assistance.*

**Who to Call in an Emergency or Natural Disaster:**

- Life Threatening Emergency – 911
- The Disaster Distress Hotline – 800-985-5990, <https://www.samhsa.gov/>
- Medical Questions – Call your doctor
- Ventilator Issues – Call your Respiratory Management Provider
- Problems with your Power Wheelchair – Call Your Durable Medical Equipment Provider

The following emergency management departments provide support for local and state agencies for the individual states as listed. Activities and services cover the four phases of emergency management: Preparedness, Prevention, Response, and Recovery for disasters like flooding, tornadoes, wildfire, hazardous materials incidents, and acts of terrorism.

1. **The Colorado Division of Homeland Security and Emergency Management**  
(<http://www.coemergency.com/>)
2. **Wyoming Office of Homeland Security**  
([http://wyohomelandsecurity.state.wy.us/being\\_prepared.aspx](http://wyohomelandsecurity.state.wy.us/being_prepared.aspx))
3. **Utah Department of Public Safety** (<https://dem.utah.gov/> )

**Whom to Contact About Replacement of Important Documents**

Driver’s License Information	<u>Colorado Dept. of Motor Vehicles</u> 303-205-5600 - <a href="https://www.colorado.gov/dmv">https://www.colorado.gov/dmv</a>
	<u>Wyoming Dept. of Transportation</u> 307-777-4800 - <a href="http://www.dot.state.wy.us/">http://www.dot.state.wy.us/</a>
	<u>Utah Division of Motor Vehicles</u> 801-297-7780 - <a href="https://dmv.utah.gov/">https://dmv.utah.gov/</a>
Government Issued ID	Contact the issuing authority
Insurance policies	Your insurance agent or company
Military discharge	<u>Department of Veterans Affairs</u> 1-800-827-1000 or TDD/TTY 1-800-829-4833
Passports	<u>United States Passport Services</u> , - <a href="http://www.passportoffices.us">http://www.passportoffices.us</a>
Birth, death and marriage certificates	Bureau of Records in the appropriate state
Social Security or Medicare cards	Social Security Administration - 1-800-772-1213 <a href="https://www.ssa.gov/ssnumber/">https://www.ssa.gov/ssnumber/</a>

Credit cards	The issuing companies as soon as possible
Mastercard	Contact issuing financial institution
VISA	Contact issuing financial institution
American Express	1-800-441-0519
Discover	1-800-discover (1-800-347-2683),
Titles to deeds	Records department of the area in which the property is located
Stocks and bonds	Issuing company or your broker
Wills	Your attorney
Income tax record	The IRS center where filed, your accountant or 1-800-829-1040
Citizenship papers	Bureau of Citizenship and Immigration Services - 1-800-375-5283