

Emergency Preparedness Considerations for People with ALS and their Caregivers

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Temple Neurosciences

ALS Hope Foundation

Objectives

- Understand the basic safety considerations surrounding emergency preparedness
- Be aware of specific tools that can be used with emergency preparedness
- Recognize special considerations with the ALS population

Emergency Preparedness

- Preparation does take time and effort!
- You can do a little at a time, but the important thing is to start
- The more you do, the more confident you will be that you can protect yourself
- Use this information as a guide
- **Do**
 - Create an individual emergency plan
 - Assemble a “go kit”
 - Check accessibility of local shelters
 - Keep a portable generator or back-up cell phone battery
- **Don't**
 - Think it cannot happen to you
 - Wait until it is too late
 - Leave out those who can assist you in the planning process
 - Forget a flashlight, radio, and two routes for evacuation

Emergencies

- Emergencies can be internal (ex: fire in the house) or external (ex: hurricane)
- Emergencies can happen anywhere, not just at home
 - Work
 - Vacation
 - Mall/movie theater/school/religious services/visiting friends

Emergencies

- Internal
 - Escape
- External
 - Shelter in place
 - Evacuate
 - Early
 - Late
- EMS/Emergency Room Visits

The Nobody Left Behind (NLB) Report

- Funded by the Centers for Disease Control and Prevention
- NLB explored the uncharted area of disability-related disaster and emergency response practices at local emergency management agencies
 - This project sought to determine whether disaster plans and emergency response systems include the health, safety, and survival needs for persons with mobility impairments
- Data from 30 disaster sites around the USA
- A majority of the emergency managers are not trained in special needs populations, which includes persons with mobility impairments.
- There was little to no representation of persons with mobility impairments at the planning or revision stages of the emergency plan.
- A majority of the emergency managers did not know how many persons with mobility impairments live within their jurisdiction.
- Only 21% of the emergency managers are planning to develop guidelines for assisting persons with disabilities.
- **Based on the qualitative findings of the study, beneficial steps for the disability community include persons with disabilities developing individual and disability specific preparedness plans**
 - Create a personal support network (self help team)
 - Do not depend on only on one person as you may be somewhere else besides home when a disaster strikes
- <http://www2.ku.edu/~rrtcpbs/findings/Final%20Report%20NLB%20July%202007.htm>

Internal Threat

- Personal Assessment

- Decide what you can do for yourself, and what you need assistance with (before, during, and after)
- Establish a Personal Support Network
 - Family, friends, neighbors, co-workers
- Show others how to operate your wheelchair or assistive devices
 - Tag all your devices
 - Have instructions on how to use the device attached to it
 - Keep a list of all of your equipment and serial numbers

Internal Threat

- Do a general assessment of the emergency exit or route; have a clear path to an exit and alternate exits
 - If you live in an apartment, ask the management to identify and mark accessible exits and access to all areas designated for emergency shelter or safe rooms
- Basic safety features
 - Fire extinguisher(s)
 - Smoke and carbon monoxide detectors
 - Know where main utility cut-offs are
 - Keep tools you will need near gas and water shut off valves
 - Insurance coverage/inventory home possessions
 - Designate a meeting place

Internal Threat

- Alert local first responders/fire department to your needs
- Emergency Information List
- Medical Information List
- Evacuation Plan
 - Barrier free passages
 - Elevators
 - Alternate egress
 - May need to leave equipment such as power wheelchairs behind
 - Have a manual wheelchair as backup
 - Have brief instructions available
 - Have a “Go Bag”

Emergency Evacuation Aide



Emergency Evacuation Chair



Go Bag



Content suggestions

- Copy of your Medical Insurance Cards
- Medical Card with ALS specific information
- Written list of phone numbers: doctors, pharmacy, and family contacts
- Written list of medications
- 7 days worth of medication
- Written directions on how to communicate with the person with ALS
- Letterboard
- Enteral Nutrition (for those with feeding tubes)
- Advance Directive
- Style/Serial number of medical devices
- Water
- Hand Sanitizer
- Wipes
- Sanitary Products
- Adult Diapers/Urinals
- Phone Charger / Ear Buds
- Socks
- Energy Bars
- Pen and paper
- Cash

Bug Out Bag



- This bag should sustain you for 3-5 days--pack accordingly
 - Clothes, socks, and undergarments
 - Stainless Steel Water Bottle
 - Calorie Dense Food/MRE's
 - Boost/Ensure
 - Eating utensils
 - Enteral Nutrition
 - Extra feeding bags or tubes
 - Blanket, gloves, rain gear, sunscreen
 - Phone Charger (s)
 - Personal hygiene items
 - toothpaste
 - sanitary napkins
 - body wipes
 - hand sanitizer
 - Portable solar charger
 - Adult Diapers
 - Flashlight
 - Medical info / insurance card
 - Medical binder
 - Cash
 - Extension Cord
 - Letterboard / laser pointer
 - Power Wheelchair Charger
 - Photocopies of ID and credit cards
 - Items for infants and toddlers
 - Pet supplies

External Threat

- Preparation
 - Know what disasters are most likely to occur in your area
 - Determine how you will be notified and track the event
 - Know that in major disasters, your Personal Network may be affected, have alternate plans
- Deciding to Stay or Go
 - Plan for both
 - Use common sense and available information
 - Choice may be made for you

External Threat

- Shelter in Place
 - Definitely takes planning
 - General supplies of food and water
 - MRE's or freeze dried meals
 - Emergency supply kit
 - Generator
 - Know how many devices you need to run in order to get the appropriate generator
 - Know battery life of your devices
 - Electric/Power Company
 - Seal area
 - Someone needs to know you are there

External Threat

- Evacuate Early
 - Have a plan of where you will go outside of the area being affected
 - Ensure this place is handicapped accessible
 - Ventilator facilities as an option
 - Transportation
 - What will you take with you

External Threat

- Evacuate Late
 - Emergency response may be delayed or unable to reach you
 - Mandatory Evacuation
 - Shelters
 - Research ahead of time
 - Red Cross/FEMA/Local County
 - Pets
 - What to expect
 - Limited Accessibility/Limited Assistance/Non-Medical Care
 - Crowds/Cots
 - Public Bathrooms
 - Regular food/drink

Communication Considerations

- Make sure your Medical Information Card explains the best method communication for you
- Store writing materials/letter board/key phrases in your emergency kit
- Determine how you will communicate with emergency personnel if you do not have your communication device
- Obtain an alternate power source for electronic means of communication

Mobility Considerations

- Keep mobility aides close at hand so they are there if you need them urgently
- Know how to instruct someone to assist you if you need to leave your devices behind
- Keep your Go Bag in an easily accessible place
- If possible, have extra devices stored outside of the home or area
- Have an extra battery for power wheelchairs, alternative charging options
- Keep an extra manual wheelchair for back-up if possible
- Add a patch kit to the Go Bag if tires are not puncture proof
- Keep instructions with equipment
- Keep a list of serial numbers of equipment

Respiratory Support Considerations

- Secure equipment so it doesn't get damaged from falling
- Have alternate power sources available
- Test your back-up batteries (and alternate power sources) regularly
- Know the duration of the batteries
- Generators
 - Gasoline powered is preferred source for multiple day use
- Utility Company Registration
 - Puts you higher on the list, however there still may be obstacles to getting power restored that will limit a fast response
- Personal Support Network
 - Show how to operate and safely move equipment
 - Label equipment (laminated) with instructions

Emergency Information List

- Personal Contacts
 - Local and out-of-town
- Who to call in case of Emergency
 - Make sure this is written on paper (and laminated) because you may not have access to your electronic device for stored numbers
 - Have physician and pharmacy numbers
 - Home Care Agencies

Medical Information List



- Information about your specific medical needs
- Includes
 - Medical conditions
 - Medicines (Names, dosages, instructions)
 - Allergies
 - Blood type
 - Insurance information
 - Adaptive devices/Assistive technology/Durable Medical Equipment
 - How you communicate
 - Your ability to:
 - Lie flat
 - Swallow pills

Medical Information Packet

- The ALS Association website
- <http://www.alsa.org/assets/pdfs/Medical-Information-Packet-ERHospitalInfoPacket.pdf>
- Allows user to fill out information regarding communication, swallowing, nutrition, mobility, respiratory issues, and others
 - Walks the user through all aspects
 - Laminate these sheets!

ALS Key Medical Information Card

- ALS Association: Information for Emergency Personnel
 - About ALS -> Help for People With ALS and their Caregivers-> Education Materials and Resources-> Medical Information Materials

 My Name is: I have ALS (Amyotrophic Lateral Sclerosis), also known as Lou Gehrig's Disease <input type="radio"/> I have Advance Directives in place	A	B	C	D	E	F	G
	H	I	J	K	L	M	N
	O	P	Q	R	S	T	U
	V	W	X	Y	Z	Space	
	Period	Yes	No	Maybe			
Emergency Contact Person: Telephone Number: Physician Name: Physician Phone Number:							 Intended for informational purposes only <small>ALS Association, 3101 North 1st Street, Suite 100, Tampa, FL 33604-1101</small>

<p>I may slur my words or not be able to speak at all, but I UNDERSTAND what you are saying.</p> <p>Speak to me in a normal voice and ALLOW ME TIME to communicate.</p> <p>My caregiver(s) and I are extremely knowledgeable about my condition, treatment needs, and equipment. Please work with us.</p>	<p>IF I am short of breath and/or have low SpO2, DO NOT give me oxygen unless I have another respiratory condition that requires it. I may need noninvasive positive pressure ventilation to expel CO2.</p> <p>OXYGEN MAY NOT HELP and may mask respiratory failure. My lungs are healthy; my muscles, including diaphragm, are weak. IF I am using BPAP at home, the settings should be the same as those. IF NOT, a BPAP with a pressure of 12/6, backup rate of 10 with titration as needed may help.</p>	<p>LAYING me on my back may be difficult for me because of the possibility of CO2 retention due to diaphragmatic weakness, and aspiration due to poor ability to protect my airway. I may be able if using a BPAP or non-invasive mechanical ventilation.</p> <p>AVOID paralytic or general anesthetics, narcotics or muscle relaxants unless absolutely necessary. If used, the ability to rapidly assist ventilation non-invasively or invasively should be available.</p> <p>IF I have a gastrostomy tube, please use that for administration of "oral" medications.</p>
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Checklist for People with Neuromuscular Diseases

- MDA Website
- <https://www.mda.org/care/resource-list/emergency-resources>

Preparing for Emergencies

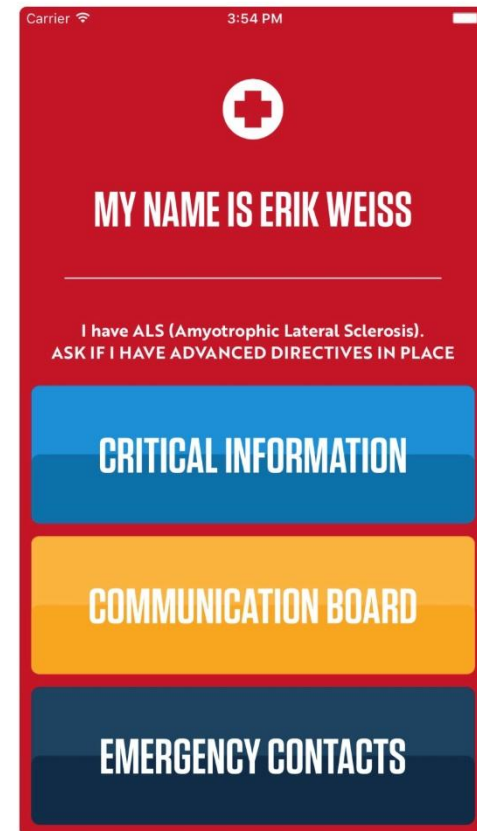


Escape Plan

You may need to evacuate on a moment's notice. Be ready to get out fast.

Key Medical Information App

- Provides critical information to care for a person with ALS during an emergency.
 - Medical information
 - Do's and Don'ts
 - Communication board
 - Emergency contacts
- Available in Google Play and the Apple Store
 - “ALS Key Medical Information”



Key Medical Information App

The screenshot shows a mobile app interface with a red header bar. The status bar at the top shows 'Carrier', signal strength, '3:56 PM', and battery level. The header bar contains a back arrow and the text 'EMERGENCY CONTACTS'. The main content area is white and contains the following information:

ERIK WEISS
February 19, 1986

EMERGENCY CONTACT 1
Elizabeth Weiss - Mother
(312) 584-1226 - mobile

PRIMARY PHYSICIAN
Dr. Charles Park
(630) 542-6385 - mobile
(312) 621-4526 - home

[Edit](#)

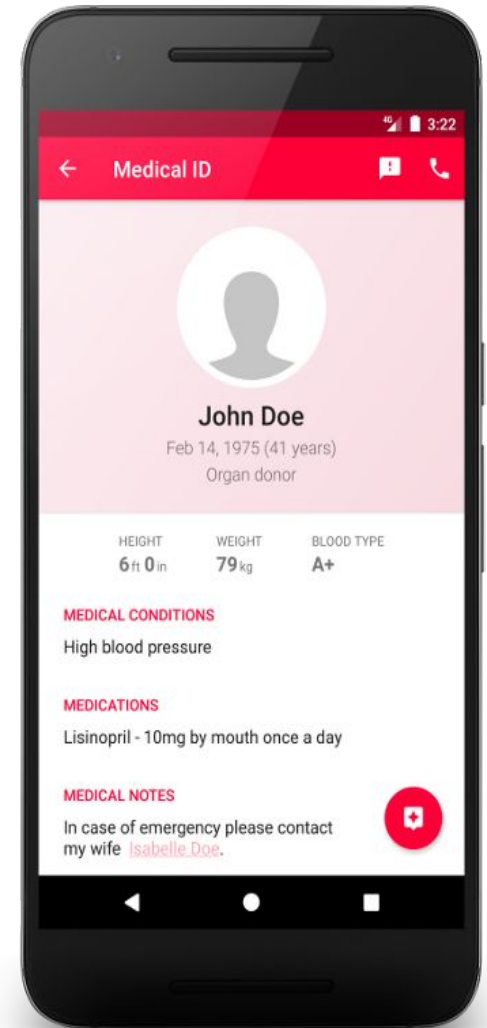
The screenshot shows a mobile app interface with a red header bar. The status bar at the top shows signal strength, '9:41', and '100%' battery. The header bar contains a back arrow and the text 'CRITICAL INFORMATION'. The main content area is white and contains a list of six numbered instructions:

- 1 I UNDERSTAND**
I may slur my words or not be able to speak at all, but I understand what you are saying.
- 2 ALLOW ME TIME**
Speak to me in a normal voice and allow me time to communicate.
- 3 WORK WITH US**
My caregiver(s) and I are extremely knowledgeable about my condition, treatment needs, and equipment.
- 4 DO NOT GIVE ME OXYGEN**
If I am short of breath and/or have low SpO2, DO NOT give me oxygen unless I have another respiratory condition that requires it. I may need non-invasive positive pressure ventilation to expel CO2.
- 5 OXYGEN MAY NOT HELP**
And may mask respiratory failure. My lungs are healthy; my muscles, including diaphragm, are weak. If I am using BPAP at home, the settings should be the same as those. If not, a BPAP with a pressure of 12/6, backup rate of 10 with titration as needed may help.
- 6 DO NOT LAY ON BACK**
Lying on my back may be difficult for me because of the possibility of CO2 retention due to diaphragmatic weakness, and aspiration due to poor ability to protect my airway. I may be able if I'm using a BPAP or non-invasive mechanical ventilation.

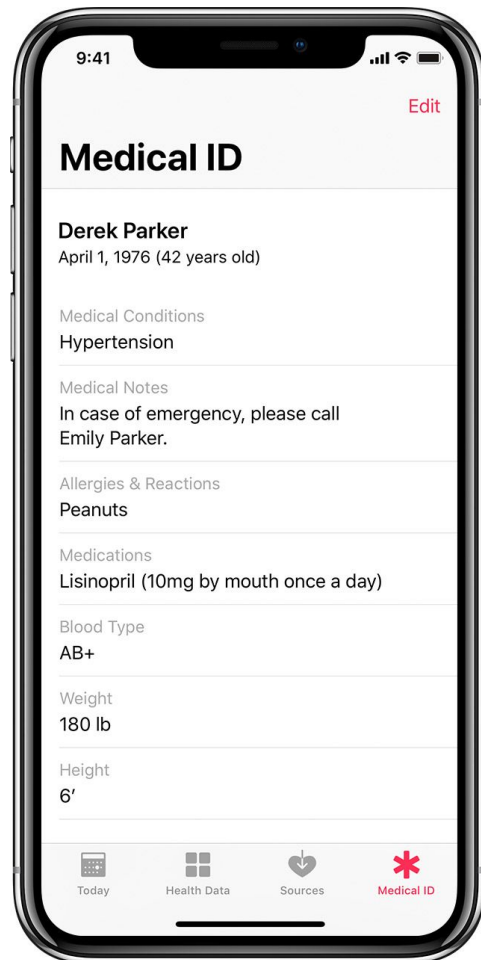
Medical ID App – Android



- Quick access to medical data from lock screen
- Support for multiple profiles (e.g. husband, wife, children)
- In Case of Emergency (ICE) contacts definition and direct call from your lock screen
- Alert feature to send an SMS in one tap (including your location)
- Current location information (address, GPS coordinates)
- Nearby hospitals localization



Medical ID -- iPhone



- Emergency Contacts
- With iOS 11.3 and the Health app, a new beta feature lets you see all your health records — such as medications, immunizations, lab results, and more — in one place
- Even if an iPhone is locked, you can still make an emergency call and check for a Medical ID
- Medical ID helps first responders access critical medical information

Medical ID Bracelets – Regular and “Smart”

- Health ID Emergency Medical ID Bracelet with Smartphone Access
- Medical information is instantly viewed right from your Health ID Band or Card from any smartphone, computer or tablet



EMS/Emergency Room Considerations

SHORTNESS OF BREATH:

If I display shortness of breath or low SpO₂, do not give me oxygen unless I have another respiratory condition that requires it. I may need noninvasive positive pressure ventilation to expel CO₂.

OXYGEN MAY NOT HELP AND MAY MASK RESPIRATORY FAILURE:

My lungs are healthy, but my muscles including diaphragm are weak. IF I am using a BPAP at home, the settings should be the same as those. IF NOT, a BPAP with a pressure of 12/6, backup rate of 10 with titration as needed may help.

LAYING ME ON MY BACK:

May be difficult for me because of the possibility of CO₂ retention due to diaphragmatic weakness and aspiration due to poor ability to protect my airway. I may be able if using a BPAP or non-invasive mechanical ventilation.

AVOID:

Paralytic or general anesthetics, narcotics or muscle relaxants unless absolutely necessary. If used, the ability to rapidly assist ventilation non-invasively or invasively should be available.

If I have a gastrostomy tube, please use that for administration of “oral” medications.

I may slur my words or not be able to speak at all, but I UNDERSTAND what you are saying. Speak to me in a normal voice and ALLOW ME TIME to communicate.

My caregiver(s) and I are extremely knowledgeable about my condition, treatment needs and equipment. Please work with us.

Summary Checklist

- Complete a Personal Assessment
 - What can you do and where do you do it?
- Create a Personal Support Network
 - Who can help you if you need it?
- Gather Information
 - What are the threats and what resources are available?
- Formulate Your Plan
- Put Your Plan Into Place
 - Make the lists, prepare the kit, download the App
- Keep Your Plan Healthy
 - Read Instructions, Practice, Review, Restock

References

- ALS Association
 - <http://www.alsa.org/als-care/resources/publications-videos/medical-information-packet/>
- FEMA
 - Preparing for Disaster for People with Disabilities and other Special Needs
 - <https://www.fema.gov/media-library/assets/documents/897>
- MDA
 - <https://www.mda.org/care/resource-list/emergency-resources>
- NOAA Weather Radio (with alerting capabilities)
 - www.noaa.gov
- Red Cross
 - <https://www.redcross.org/get-help/how-to-prepare-for-emergencies.html>

Questions?

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