Emergency Preparedness Considerations for People with ALS and their Caregivers

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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 unchartered 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 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”
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
Getting out of the house, apartment, hotel via an Emergency Evacuation Aide
Emergency Evacuation Chair
HOW TO USE AN EVAC CHAIR
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
    • Will they take pets?
  – Hospital
  – 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
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.
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 (laminate) 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

- https://www.als.org/navigating-als/resources/medical-information-materials

- 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

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**About ALS**: ALS (Amyotrophic Lateral Sclerosis), also known as Lou Gehrig's Disease

**Advanced Directives**

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**Emergency Contact Person:**

- Telephone Number:
- Physician Name:
- Physician Phone Number:

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**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.*

**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.

**OXYGEN MAY NOT HELP** and may mask respiratory failure. My lungs are healthy; my muscles, including the 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.

**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.
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”
**Critical Information**

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.

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**Emergency Contacts**

**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
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 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.
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

• FEMA
  – Preparing for Disaster for People with Disabilities and other Special Needs
  – https://www.fema.gov/media-library/assets/documents/897

• NOAA Weather Radio (with alerting capabilities)
  – www.noaa.gov

• Red Cross
Questions?

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