

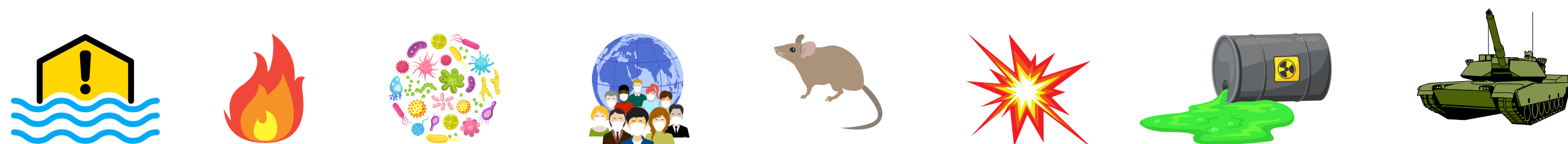


# Emergency Preparedness Toolkit for People Living with ALS/MND

International Alliance of ALS/MND Associations

## BACKGROUND

Emergency situations occur every day. They are caused by many things, such as natural hazards (e.g., flooding, fire), diseases and pandemics (e.g., COVID-19), pests (e.g., rats) and human activities (e.g., fire, explosions, spills, war).

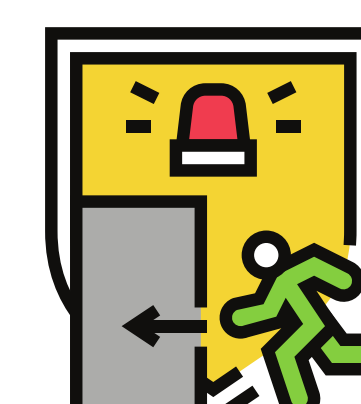


These situations are especially difficult situations for people living with ALS/MND and their families. Being prepared is critical.

Emergency preparedness is also aligned with the Fundamental Right People living with ALS/MND (PALS) to have the right to the best quality of life possible. This planning will help PALS and their caregivers (CALS) be ready for their unique needs and circumstances in the event of an emergency.

Thinking about what type of emergency might happen is a necessary building block to developing an emergency preparedness plan. Consider questions like:

- What are the risks in your area?
- Is it possible to eliminate the hazard?
- How can we reduce the risk or the likelihood of that event taking place?
- Am I or is the organization at risk? What can we do to reduce the consequences?
- How can we share the cost or the pain of the event with others?



## RESOURCES FOR INDIVIDUALS

In the immediate aftermath of a disaster, it is common for specialized services and rehabilitation to support persons living with chronic disability to be cut back or de-prioritized. Therefore, it is important to consider the unique needs of a person living with ALS/MND in the event of an emergency.

Some of the most important things for PALS and CALS to consider when assessing personal risk and making preparedness plans include availability or access to:

Electricity/generator/batteries	Ambu Bag
Water	Emergency medication kits (and instructions)
Support network details	Nutrition and supplies
Communication capabilities	Breathing/ventilator support (BiPAP)
Mobility/transportation	Accessible shelter
Alternates for power sources, pharmacy, caregivers, medical professionals, etc.	Care for your pet(s)

Several resources are available in the [Emergency Preparedness Toolkit](#) on the Alliance's website, including forms, checklists and videos to help people living with ALS/MND and their caregivers get started. These can be printed and shared with your support network and should be updated regularly.



Medical Emergency Card  
**I HAVE ALS/MND.**

EMERGENCY INFORMATION FOR MEDICAL PERSONNEL

NAME:  
D.O.B.:  
HOSPITAL:  
PHYSICIAN:  
EMERGENCY CONTACT DX-ALS/MND:  
EMERGENCY CONTACT NUMBER:

Important! My caregiver(s) and I are extremely knowledgeable about my condition, treatment needs, and equipment. Please work with us. Having my knowledgeable caregiver(s) with me during my hospitalization is very important to me.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS  
**EMERGENCY PREPAREDNESS TOOLKIT**

The unique needs of a person living with ALS/MND are important to consider on any given day, and even more so in the event of an emergency. Please consider this list of items in preparing your plan.

**WHERE TO START?**

- ☐ Understand emergencies that could happen near you.
- ☐ Complete a personal ability plan.
  - What you will be able to do.
  - What helps will you need before, during and after an emergency?
- ☐ Build your support network.
- ☐ Prepare a list of emergency contacts.
- ☐ Collect all medical information:
  - Medications
  - Medical conditions
  - Special equipment
  - Allergies
  - Health insurance information
- ☐ Communication difficulties instructions
- ☐ Medication supplies
- ☐ Emergency supply kit (home and car)

Figures 1 &2. Examples of downloadable assets from the [Emergency Preparedness Toolkit](#).

## RESOURCES FOR ORGANIZATIONS

It is important to determine the organization's critical business functions in terms of services it provides its members on a regular basis and during a disaster situation.

- Keep the plan simple with checklists and review its content with stakeholders.
- Consider how the organization's staff and community volunteers will function and be supported, as they too are experiencing an emergency.
- Develop partnerships with other organizations and local disaster management agencies who have complementary capabilities so that all aspects of need can be managed in the event of an emergency.

Some high-level elements of an organizational emergency preparedness plan include:

1. **Plan administration:** Who is the emergency plan for? Include internal and external stakeholders.
2. **Introduction:** Define the purpose and scope.
3. **Impacts to consider:** Community, staff, communications, operations, facilities, finances
4. **During the emergency:** Identify immediate and short-term priorities
5. **Response evaluation:** Evaluate the actual vs. ideal performance, and identify gaps and lessons to update emergency plan.

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For more information on this project and others please contact us at [alliance@als-mnd.org](mailto:alliance@als-mnd.org) or visit us at [als-mnd.org](https://als-mnd.org).