

## Preparing for a Medical Emergency While Living with ALS

According to the [World Health Organization](#), some 40 percent of patients experience harm in ambulatory and primary care settings with an estimated 80 percent of these harms being preventable. In recognition of [Patient Safety Awareness Week](#), we want to provide you with important resources and tips to help keep you and your loved ones safe in the event of a medical emergency.

People living with ALS will likely experience complications related to the disease that warrant a visit to the hospital at some point in their journey. At the same time, they are not immune from other injuries or medical issues—people with ALS can still get sick or possibly hurt themselves in ways unrelated to the disease. Making the conscious choice to be prepared can make all the difference.

### Developing a Proactive Medical Emergency Plan

Being proactive and putting a plan in place before an emergency happens can help provide piece of mind for everyone. First responders and emergency personnel may not be aware of an individual's condition, or familiar with how to treat them.

- If you're unable to communicate or otherwise explain your health challenges, it's difficult to ensure the safety of your treatment. Using a service like [smart911.com](http://smart911.com) or reaching out to your local fire department to build an emergency health profile will help prepare emergency personnel before they reach your door.
- Another option is to apply to [NORD's MedicAlert Assistance Program](#). NORD and MedicAlert Foundation [recently announced a new program](#) to help provide protection to people with a rare disease, including people with ALS, in emergency situations. Through MedicAlert's emergency response center, patient's emergency health profiles are relayed to first responders 24 hours a day, seven days a week, providing detailed critical information including medical conditions, medications, treatment protocols and emergency contacts.
- Keep an emergency supply (also known as a "go bag") kit in your home, car, workplace or anywhere you may spend your time. Include such items as food, feeding supplies (formula if you have a feeding tube), water, a first aid kit, adaptive equipment, communication board and batteries. And always remember chargers for everything!
- Ask to go to the hospital where your clinic is located if possible and have a prepared letter from your neurologist saying that your caregiver must be with you to aid in communication or mobility.
- Ask to bring your own respiratory equipment or feeding tube formula for comfort and consistency.
- 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).

## How to Prevent Misunderstandings in the Hospital or Emergency Room

In the event of a visit to a hospital or emergency room, it's best to contact your clinic coordinator and let them know your loved one has been hospitalized. You and your caregiver are your best advocates for your care and treatment and understanding the nuances ALS symptoms present can make all the difference. If there are issues, contact the hospital ombudsman for additional support.

- Be sure you and your caregiver have assembled a comprehensive file of your medical information. A [Medical Information Packet](#) allows you to provide critical information regarding specific issues related to ALS care, and how your issues can most appropriately be addressed. Compile a list that contains the names and numbers of your doctors, your medications, dosage instructions, and any existing conditions. Make note of your adaptive equipment, allergies, and any communication difficulties you may have.
- When a person with ALS arrives at a hospital or emergency room, they may face additional obstacles with hospital staff who may not fully understand how ALS affects a person's breathing, speech and movement. Consider bringing this [Hospital Communication Sign](#) with you, and post it at the head of your bed or other prominent location to aid in communication about your care with hospital staff.
- Be sure to let everyone know you have ALS up front. Since slurred speech is not uncommon in people with ALS, hospital staff may assume that the patient is under the influence of drugs or alcohol.
- It is possible that hospital staff will attribute breathing issues or respiratory problems to a lack of oxygen. However, most of the time this is not the case and giving a person with ALS oxygen can be dangerous. Make sure you let staff know if you use any sort of breathing machine.
- Because weakened respiratory muscles is a typical symptom of ALS, it can be dangerous to lie a person with ALS on their back as it could cause CO2 retention. Remind staff of this, especially prior to any procedures such as an MRI. In extreme cases, weakened muscles might also be a red flag for hospital staff to examine the spinal cord, which is unnecessary and hazardous.

While developing and implementing a proactive plan for medical emergencies may take some time and energy, it will help to provide piece of mind to everyone involved and help to ensure you receive the proper care when you need it most.

**For more information and resources to help you and your family prepare for a medical emergency, visit [als.org](https://www.als.org) [HERE](#).**