

Disaster Preparedness

HOME AND COMMUNITY-BASED SERVICES
FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS



alzheimer's 
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A TOOLKIT FOR
THE AGING NETWORK


INTERNATIONAL

HOME AND COMMUNITY-BASED SERVICES FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS



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This project was funded by the U.S. Administration on Aging under contract number GS-10F-009L MOBIS, Delivery Order No. HHSP2332004001143U. This report is a product of the Alzheimer's Disease Demonstration Grants to States National Resource Center developed by the Alzheimer's Association. The statements contained in this document are solely those of the authors and do not necessarily reflect the views or policies of the U.S. Administration on Aging.

About This Toolkit: Disaster Preparedness

Home and Community-Based Services for People with Dementia and Their Caregivers

A disaster can happen anytime, anywhere, and any place to anyone. To prevent unnecessary hospitalization or nursing home placement, disaster preparation is critical for older adults, caregivers, and families taking care of loved ones. **This toolkit outlines actions states can take to empower caregivers to make informed decisions about the special needs of people with dementia at a time of emergency or disaster.**

The Disaster Preparedness Toolkit:

- Shows how disaster preparedness plays a critical role in decreasing institutional care.
- Provides reasons for states and caregivers to engage in disaster preparedness.
- Provides an array of resources that are model programs or unique examples for state officials or caregivers to use when developing their own program. Many of these programs are funded by the U.S. Administration on Aging through the Alzheimer's Disease Demonstration Grants to the States (ADDGS) Program.
- Summarizes key actions states and caregivers can take when preparing for emergencies or disasters. For states, these key actions are:
 1. Facilitate coordination among state and local emergency management offices and the Aging Network.
 2. Develop special needs registries identifying people who may need help before a disaster.
 3. Provide specialized education on disaster preparedness to people with dementia and their caregivers.
 4. Provide dementia training to first responders, law enforcement, emergency medical technicians, and firefighters.
 5. Include persons with dementia and caregivers in the development and planning process of state and local emergency plans.

For caregivers, these key actions are:

1. Create personal disaster plans.
2. Plan and prepare.

This toolkit provides information on promising practices, with hyperlinks to material available on the Internet.

Promising Practices: Disaster Preparedness

Home and Community-Based Services for People with Dementia and Their Caregivers

Why Engage in Emergency or Disaster Preparedness for Persons with Dementia?

- Disasters can be categorized as four types of events: natural (hurricanes, earthquakes, floods, tornados, lightning, extreme heat/cold); man-made (large fire, terrorist attacks, explosions, hazardous materials accident); technological (nuclear, utility, and computer failures); and public health emergencies (epidemics).
- Alzheimer's disease is a devastating degenerative disease that causes memory loss, poor judgment, personality changes, and severe functional limitations. According to the Alzheimer's Association's *2008 Alzheimer's Disease Facts and Figures*, an estimated 5.2 million Americans have Alzheimer's disease. By 2050, that number may grow to 16 million. At age 65, one in eight persons has some form of dementia and by age 85, nearly one-half experience Alzheimer's or a related dementia. To be effective, disaster preparedness programs need to accommodate the needs of this growing population.
- Because dementia affects cognitive ability and judgment, effective emergency preparedness must involve caregivers in addition to local and state governmental entities. The impact of Hurricane Katrina on persons with dementia and their caregivers illustrates how the elderly are disproportionately impacted by disasters—of confirmed fatalities resulting from Katrina, 64 percent were age 65 or older. The necessary evacuation and displacement created circumstances that resulted in persons with dementia being lost for days, living without vital medications. During emergency situations, people with dementia experience exacerbated symptoms due to anxiety, fear, and confusion. At the same time, family caregivers, unable to locate a cognitively impaired loved one can experience fear and uncertainty about their family member's fate.
- Most disasters, except for hurricanes, do not give advance warning. Caregivers can find themselves unexpectedly unprepared to assume full responsibility for a loved one suddenly discharged from an assisted living or other residential facility. While any type of disaster causes unavoidable disruption, careful preparation by family caregivers and state and local authorities can mitigate the devastating effects on this vulnerable population.

What Are Dementia-Capable Services?

To be dementia-capable, emergency service personnel and providers must be:

- skilled at identifying people with Alzheimer's disease,
- knowledgeable about the kinds of services that can help people with dementia and their caregivers, and
- capable of providing linkages to other agencies and community organizations that can help.

Disaster Preparedness

Lessons learned from past disasters indicate that when families and state emergency management offices are prepared to address the needs of people with disabilities, such as people with dementia, the impact of a disaster can be diminished. The [Administration on Aging](#) Web site contains a great deal of useful information and contacts on disaster preparedness. In order to be prepared for emergencies, states and caregivers can perform several key activities:

States

1. Facilitate coordination among state and local emergency management offices and the Aging Network.
2. Develop special needs registries identifying people who may need help before a disaster.
3. Provide specialized education on disaster preparedness to people with dementia and their caregivers.
4. Provide dementia training to first responders, law enforcement, emergency medical technicians, and firefighters.
5. Include persons with dementia and caregivers in the development and planning process of state and local emergency plans.

Caregivers

1. Create personal disaster plans.
2. Plan and prepare.

Promising Practices for Each Key Activity: States

1. Facilitate coordination among state and local emergency management offices and the Aging Network

A well-coordinated and dementia-capable system between state and local emergency offices and the Aging Network will not only save lives but will also ensure that the special needs of individuals and caregivers are addressed during all phases of a disaster. The following are helpful guides to a coordinated system:

- *Administration on Aging Emergency Assistance Guide* offers a comprehensive set of technical assistance materials to help the Aging Network and others prepare and plan for the management of major emergencies or disasters.
- [Disaster Planning for Older Adults in Palm Beach County, Florida](#) is a report that details how local, state, and federal agencies can coordinate services with the Aging Network.

2. Develop special needs registries identifying people who may need help before a disaster

Special needs registries list people who may need assistance before, during, and after a disaster. Registries are especially effective for those with dementia who live

alone. Local area agencies on aging and other community service providers are likely to have ready-made registries based on their client lists. For example, clients who receive home-delivered meals are more likely to have a limited ability to evacuate during a disaster.

During an extended power outage in Wayne County, Michigan, the Office of Services to the Aging utilized its client lists to provide shelf-stable food to seniors and to conduct well-being checks with homebound seniors.

3. Provide specialized education on disaster preparedness to people with dementia and their caregivers

People with dementia and their caregivers can be educated on potential disasters and appropriate planning and response through a variety of methods. Among these methods are special newspaper editions, videos, pamphlets, community presentations, and coordination with organizations which serve senior citizens. Below are examples of educational materials on personal disaster preparedness:

- [Get Ready Now](#) pamphlet by the U.S. Department of Homeland Security
- [Caring for Someone With Dementia in a Disaster](#) by the Federal Emergency Management Agency (FEMA)
- [Just in Case](#) video by Aging in Stride

4. Provide dementia training to first responders, law enforcement, emergency medical technicians, and firefighters

First responders—consisting of law enforcement, firefighters, emergency medical technicians FEMA personnel, and Red Cross workers—are generally involved in providing direction and assistance, especially during the first part of the disaster/emergency. Providing these first responders with dementia education will ensure they have the appropriate knowledge and tools to work effectively with individuals who have dementia. Educational trainings provided annually as part of a regular training schedule can ensure that new and seasoned personnel are familiar with the special needs of people with dementia. States can provide dementia education to first responders in the following ways:

- Collaborate with the local [Alzheimer's Association chapters](#).
- Develop a booklet on working with seniors and people with disabilities. The New Mexico Department of Health, in collaboration with other local agencies, created a booklet entitled, *Tips for First Responders*, that specifically addresses working with seniors and individuals with multiple types of disabilities.
- Incorporate dementia training into annual law enforcement trainings. The Florida Department of Law Enforcement, in partnership with the Alzheimer's Association, incorporated a section on emergency preparedness and response within the state-funded law enforcement training program.

5. Include persons with dementia and caregivers in the development and planning process of state and local emergency plans

Including caregivers and persons with dementia in the development of state emergency plans will ensure that accommodations for persons with dementia will be included in the plans.

- A report from the Western University of Health Science in California, [Serving and Protecting All by Applying Lessons Learned](#), details many suggestions and reasons underscoring the importance of including those with dementia and other disabilities in the planning process.

Promising Practices for Each Key Activity: Caregivers

According to several organizations' disaster guides ([FEMA](#), [Red Cross](#), and [The AGS Foundation for Health in Aging](#)), it is essential that individuals and families take steps to create their own personal disaster plans that will allow them to survive for up to 3 days without assistance from state or local governments or first responders. States and local governmental agencies can work with citizens, the Aging Network, and other community services to encourage and promote appropriate disaster planning for persons with dementia and their caregivers.

1. Create personal disaster plans

The most important thing every family can do is create an individual or family emergency plan. Disasters are difficult for everyone, but for persons with dementia, they can be especially challenging. Structure, consistency, and calm surroundings are ideal for persons with dementia; yet, during a disaster, it is all but impossible to provide this type of environment. With careful planning, however, many problems can be avoided or at least mitigated. Below are four key personal planning strategies:

- Plan ahead. Educate yourself about potential disasters in your area. Know the specific hazards that threaten your community. Reach out to local emergency management offices, the local area agency on aging office, or the local single points of entry such as [Aging and Disability Resource Centers](#) to learn about community services, evacuation plans and area. To locate your area agency on aging office, visit the [Eldercare Locator](#).
- Craft a communication plan. Share your personal disaster plan with friends and family. Make sure you share your plan with someone who lives in a different area of the country.
- Create a disaster kit. When putting your disaster kit together, consider what you need to survive on a daily basis including water, food, and medication for a minimum of 3 days. Place items for the kit in a backpack or bag that is easy to carry. Keep the kit in an accessible location.

Several organizations have created personal disaster plan templates and guides. Examples of these materials can be found below:

- *Just in Case* guide by the Administration on Aging
- [*Disaster Preparedness for Seniors by Seniors*](#) by the Red Cross
- [*Preparing for Disaster for People with Disabilities and other Special Needs*](#) by FEMA and the Red Cross
- [*Emergency Preparedness: Taking Responsibility for Your Safety*](#) by the County of Los Angeles, Office of Emergency Management
- [*Disaster Preparedness for People with Disabilities*](#) by the Red Cross

2. Plan and prepare

Caregivers and families will need to take extra steps to ensure the safety of the person with dementia. For example, when faced with an evacuation, leave as early as possible to avoid long travel times. Additionally, you should include in the emergency pack important calming objects that can help a disoriented person with dementia feel calmer in unfamiliar circumstances.

- The Alzheimer's Association [*Disaster Preparedness Fact Sheet*](#) provides specific information and tips on facing disasters for those affected by dementia.
- The Red Cross and Prepare.org offer suggestions for [emergency preparedness for people with cognitive disabilities](#).
- Easter Seals' [*s.a.f.e.t.y. first*](#) suggests emergency preparedness considerations for individuals with special needs.
- The Centers for Disease Control and Prevention provides a Web site, [*Emergency Preparedness & Response: Agents, Diseases, and Other Threats*](#), that offers information on many threats, including pandemic flu.
- Depending on the stage of dementia, some individuals will be able to participate in and organize their own emergency plans. However, because of the progressive nature of the disease, involvement of a caregiver, family member, or other designated person is essential.
- An article from Caregiver.com, [*Before It's Too Late: Planning for an Emergency*](#), provides emergency information designed for caregivers.

Other recommendations for planning and preparation include:

- Identification. Every person with dementia should have identification. Caregivers should ensure that their loved one is enrolled in [MedicAlert® + Alzheimer's Association Safe Return®](#) to assist with identification and reunification if the person with dementia becomes lost or separated from them.
- Evacuation. Regardless of one's medical condition, everyone should preplan to evacuate if needed. The safest choice is to stay with relatives or friends. If these options are not available, caregivers should relocate to a special needs shelter that accommodates individuals with dementia and their caregivers.

Emergency public shelters also provide a safe place to stay; however, caregivers must recognize that public shelters are frequently local schools and may not have facilities to accommodate the special needs of a person with dementia, such as incontinence or the need for privacy. FEMA has developed [*Caring for Someone with Dementia in a Disaster*](#), which offers tips if you are relocated and provides information on creating a safe environment.

- Hospitalization. In case of hospitalization, the North Carolina ADDGS program developed a brochure, [*Hospitalization Happens*](#), designed to relieve stress by helping families prepare for both interrupted and planned hospital visits.
- Assisted Living Facility. Caregivers are advised to contact the administrators of their loved one's assisted living facility to determine how disasters are handled, including whether the assisted living facility coordinates evacuations, the method of evacuation, and where residents will be taken. Evacuation may be considered the responsibility of the residents or family members.

Additional Information

The Administration on Aging has developed eight toolkits in this series that focus on different aspects of providing home and community-based services to people with dementia and their caregivers. These online toolkits are available at the [AoA's Alzheimer's Program Website](#). Toolkit titles include:

1. Consumer-Directed Care
2. Disaster Preparedness
3. Resources for Individuals and Families
4. Serving African American Families
5. Serving Asian and Pacific Islander Families
6. Serving Hispanic Families
7. Single Point of Entry Systems
8. Supporting Family Caregivers