

Disaster Preparedness and Planning for Populations with Dementia and Other Vulnerabilities

An Annotated Bibliography

August 2016

Introduction

Although some resources relate to multiple different categories, the following disaster planning tools, websites, documents, and other resources are organized into these six categories.

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Underlining is used, sparingly, to flag important points or key resources.

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Emergency/Disaster Preparedness (Regional, State & Local Public Health)

Leading Age. "Disaster Resources." Website, accessed August 2015.

http://www.leadingage.org/Disaster_Resources.aspx

This page is divided into four sections: preparedness, pandemic flu resources, disaster response, and recovery, with a number of outbound links under each. Of interest:

- [National Hurricane Center Tracking/Storm Status](#) -- Get real time status reports on the latest hurricane via the National Hurricane Center.
- [State Emergency Management Agencies](#) -- Find localized information on your state's emergency management website or other digital channels.
- [Map of open shelter locations](#) -- Listing maintained by the American Red Cross in the event of emergency.
- [CMS Hurricane Information and Policy Guidance](#) -- Waivers, public health emergency declarations, Medicare fee-for-service payment and billing policies, information on the Emergency Prescription Assistance Program, and other hurricane-related information.
- [HUD Multifamily Disaster Response Policies and Guidance](#) -- To assist residents displaced by hurricanes, HUD often requests vacancy information be submitted from all Owners and Agents of HUD Insured or Assisted Multifamily Properties. Links also accesses HUD guidance (Chapter 38) and status info.
- [PREPARE - a disaster preparedness program](#) developed by Mather LifeWays Institute on Aging teaches senior living community staff to manage natural disasters and other public health emergencies. The seven-module emergency preparedness program is available as a webinar series, workshop, and toolkit. Check out Mather's [white paper on the Incident Command System: An Introduction for Senior Living and Long Term Care Facilities](#)
- [Super Storms: Preparing for Large-Scale Blackouts](#) -- A white paper created by CNA [insurance] and provided by Aon that discusses scenarios and suggests strategies to protect residents/patients and staff, avoid service interruptions, minimize equipment damage, and reduce liability exposure.
- ["Risk Mitigation in Senior Living: Emergency Preparedness and Protecting a Community from Crippling Failures"](#) chronicles steps to take to prepare in advance for natural disasters. Included in the white paper from LCS are a pre-, during-, and post-emergency checklists; suggested lists of critical supplies; and a list of staffing-related needs.
- [AHRQ Emergency Preparedness Atlas: U.S. Nursing Home and Hospital Facilities](#) - U.S. Department of Health and Human Services (HHS), Agency for Healthcare Research and Quality (AHRQ) resource that can help states and communities with disaster planning and response for nursing homes. Includes case studies and maps for all 50 states to help communities identify local healthcare facilities (hospitals and nursing homes) that could be available and prepared to provide assistance under emergency conditions.
- [Astrodome Analysis: Best Practices for Managing Elderly Disaster Victims](#) -- Baylor College of Medicine's analysis and review of how state and local organizations can implement a triage tool in mass evacuation shelters to assure that seniors receive critical services and direct care -- providing model assessment tool and recommended strategies for use/intervention.
- [Making Community Emergency Preparedness and Disaster Response Programs Accessible to Persons with Disabilities](#) -- U.S. Department of Justice report provides practical and detailed recommendations to address the unique planning, notification, evacuation, and sheltering

challenges for those who work with seniors and other persons with physical limitations, chronic health issues, and/or communications impairments. The Americans with Disabilities Act requires that these programs be accessible.

National Center for Mobility Management. “Emergency Preparedness.” Website, accessed August 2015.

<http://nationalcenterformobilitymanagement.org/by-topic-emergency-preparedness/>

A list of cross-sector resources, including a sample plan, on emergency preparedness for individuals with disabilities and special populations.

- [Preparing Makes Sense for People with Disabilities and Special Needs](#) (Ready.gov, last update 2011). Outlines actions that individuals with disabilities, individuals with special needs, and their caregivers can take to start preparing for emergencies before they happen.
- [Avoiding Disasters for the “Special Needs Population”](#) (Office of Civil Rights, U.S. Department of Health and Human Services, unknown date). Provides information on effective planning, response, and recovery for the special needs population, consistent with federal civil rights laws.
- [Communications with Vulnerable Populations: A Transportation and Emergency Management Toolkit](#) (Transit Cooperative Research Program, Report No. 150, 2011). Describes how to create a communication process to reach vulnerable populations regarding their transportation options in emergencies. Toolkit provides a guiding framework and tools for constructing a scalable, adaptable communication process built on a network of agencies from public, private, and nonprofit sectors.
- [Generic Continuity of Operations/Continuity of Government Plan for State-Level Transportation Agencies](#) (Mineta Transportation Institute, 2011). Offers guidance on how to create state-level transportation agency plans for continuity of operations and continuity of government for use in crisis or emergency situations.
- [Evacuating Persons with Special Needs: Routes to Effective Evacuation Planning Primer Series](#) (Federal Highway Administration, 2009). Explores how to effectively evacuate people who need assistance in leaving an area, particularly people with disabilities, aging populations, people living in congregate or residential care facilities, and those with household pets.
- [Enhancing Public Health Emergency Preparedness for Special Needs Populations: A Toolkit for State and Local Planning and Response](#) (Center for Public Health Preparedness, RAND, 2009). Distills the most relevant strategies, practices, and resources from a variety of sources to identify priority populations and critical strategies. This toolkit is meant to help state and local health agencies improve their current emergency preparedness activities. In addition, community-based and/or non-governmental organizations can use this toolkit to enhance their programming for these populations.
- [The Role of Transit in Emergency Transportation, Special Report 294](#) (Transportation Research Board, 2008). Explores the roles that transit systems can play in accommodating the evacuation, egress, and ingress of people from and to critical locations in times of emergency.
- [Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities](#). An interagency council established by Executive Order to ensure that the federal government appropriately supports safety and security for individuals with disabilities in disaster situations.
- [American Public Transportation Association “Emergency Response and Preparedness Program Resources,” web page](#). Provides resources for transit systems and industry entities to help them prepare for an expected event or in the wake of an unforeseen situation.

- [Community Transportation Association of America, “Emergency Management,” web page.](#) Accessed August 2015. Contains resources to help communities plan transportation services and strategies that can be activated in disaster situations.
- [Planning Framework for the Evacuation of the Transportation Needs Populations in Central Ohio](#) (Mid-Ohio Regional Planning Commission (MORPC), 2012). An evacuation planning framework developed by the MORPC that expressly addresses transportation needs of vulnerable populations in the seven-county area of Central Ohio. Funded through a “Transportation Equity Research Program” grants awarded by the Federal Transit Administration in FY2008 and intended to serve as a replicable model for U.S. communities.

Best Practices for Professional Care Providers (LTC Facilities, Hospitals, First Responders)

Alzheimer's Community Care. "Specialized Disaster Preparedness." Website, accessed August 2015.

<http://www.alzcare.org/disaster-preparedness>

Emergency information and shelter locations in Palm Beach, Broward, Martin, and St. Lucie Counties in Florida, along with a link to a free magazine on disaster preparedness for those with dementia and their caregivers. The organization also offers to work with caregivers on creating a customized preparedness plan.

Aldrich N, Benson WF. "Disaster preparedness and the chronic disease needs of vulnerable older adults," (2008). *Prev Chronic Dis*; 5(1). http://www.cdc.gov/pcd/issues/2008/jan/07_0135.htm

Excerpt: Planning for assisting populations with chronic diseases, especially vulnerable older adults, during a disaster is essential to meeting their special needs. Public health professionals should link with professionals in aging services, emergency planning, and other groups to create a comprehensive system for addressing the needs of older adults during a disaster. Planning, coalition building, and using mapping systems are among the numerous tools and strategies available [for] creating an emergency response system that can rescue and shelter vulnerable populations in disaster situations.

Alzheimer's Association. First Responder Training. Accessed August 2015.

www.alz.org/firstresponders

Excerpt: Free, online Alzheimer's Association First Responder online training program aims to equip law enforcement and other public safety and community partners with information and proper protocols to use when encountering individuals with Alzheimer's disease and other dementias, to keep individuals and communities they serve safer. The program includes a promotional flyer and quick tips sheet. *(Note: This has a module specific to disasters/emergency preparedness that helps first responders with strategies and techniques for helping people with Alzheimer's in a disaster.)*

American Society of Health-System Pharmacists. "ASHP statement on the role of health-system pharmacists in emergency preparedness," (2003). *Am J Health-Syst Pharm*; 60:1993–1995.

<http://www.ashp.org/DocLibrary/BestPractices/SpecificStEmergPrep.aspx>

(Note: This statement was reviewed in 2013 by the Council on Pharmacy Practice and by the Board of Directors and was found to still be appropriate.)

Excerpt: Emergency-preparedness planners at the federal, regional, state, and local levels should:

1. Consult with qualified pharmacists in all areas in which the pharmacist's expertise would contribute to the creation and execution of workable plans;
2. Inform pharmacists, through national and state pharmacy organizations, of plans for deployment of emergency pharmaceutical supplies so that appropriate plans can be made at the local level; and
3. Consult with qualified pharmacists on messages that should be conveyed to the public about the appropriate use of pharmaceuticals in the event of a disaster.

Baker LR. *Disasters and Vulnerable Populations: Evidence-Based Practice for the Helping Professions*, (2015). Book, Springer Publishing Company.

<http://www.springerpub.com/disasters-and-vulnerable-populations.html>

Chapter 6 of this book covers “Older Adults and Disasters” and includes case studies from Hurricanes Katrina, Charley, and Francis, and the Northridge Earthquake. The SWiFT tool is mentioned again, along with a table outlining responder guidelines (sources: CDR, CIDNY, FEMA, SILC, et al). There are mentions of cognitive impairment considerations throughout the chapter, but not much in the way of specifics on dementia or Alzheimer’s. Institutionalized and non-institutionalized/isolated elders are a focus as well.

CDC. “Older Adult Health & Medical Concerns.” Website, accessed August 2015.

<http://www.cdc.gov/aging/emergency/concerns.htm>

The following represents a list of resources (under several subheadings) available online from various organizations, both public and private, on disaster planning for older adults.

Older Adult Health & Medical Concerns

- [We Can Do Better: Lessons Learned for Protecting Older Persons in Disasters](#), via AARP
- [CDC’s Disaster Planning Goal: Protect Vulnerable Older Adults](#), via the Centers for Disease Control and Prevention
- [Disaster Preparedness and the Chronic Disease Needs of Vulnerable Older Adults](#), via *Preventing Chronic Disease Journal*
- [Care of Mentally or Physically Challenged Persons and the Elderly](#), via the World Health Organization
- [Preparedness Information for Persons with Disabilities](#), via DisabilityPreparedness.gov, Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities

Mental Health, including Dementia

- [Caring for Someone with Dementia in a Disaster](#), via FEMA

Chronic Conditions

- [Multiple Chronic Conditions - A Strategic Framework](#)
U.S. Department of Health and Human Services

Recommendations, Best Practices, Pertinent Literature: Recommendations and Best Practices for Planning

- *AGS Special Session, 05/12/2010 - Looking out for Vulnerable Older Adults in Disasters - handouts from these 4 talks available at this site:*
<http://elderlydisaster.pbworks.com/w/page/26338679/Recommendations,%20Best%20Practices,%20Pertinent%20literature>
 1. Ethical issues in disaster planning (Hannah Lipman)
 2. Caring for the frail elderly: use of a geriatric toolkit in disaster preparedness (Judith Ahronheim)
 3. Pandemic preparedness in long-term care facilities (Lona Moody)
 4. Palliative care in health emergencies (Phillip Rogers)
- *AGS SIG Meeting 2011: International Working Group on Seniors and Emergencies: Who, Why, What, Where and When* (Gibson M)
[2011 AGS GIBSON Summary.pdf](#)
[International Working Group on Health Professionals and Continuity of Care \(IWGHP\) Handout 2010 English and French.pdf](#)

- *Canadian Association on Gerontology 2011: Older Adults and Disasters: Are Gerontologists Paying Attention?* (Gibson M, Brown L, Frahm K)
[2011 CAG Disasters and Gerontology GIBSON.pdf](#)
- *H1N1 planning for LTCF*
<http://www3.interscience.wiley.com/journal/122686782/abstract>

Cherry KE (Ed.). *Lifespan Perspectives on Natural Disasters: Coping with Katrina, Rita and Other Storms*, (2009). Book, Springer Publishing Company.

Excerpt: This timely information is invaluable both to mental health service providers and to those tasked with developing age-appropriate disaster preparedness, intervention, and recovery programs. In addition, the book references other deadly storms as well as other major catastrophic events (e.g., the September 11 attacks, the 2004 Indian Ocean tsunami), and includes such topics as: recovery services for the frail elderly, coping and health in late life, preparation and training mental health personnel for disasters. Unique in the disaster literature, *Lifespan Perspectives on Natural Disasters* serves as a research reference and idea book for professionals and graduate-level students in psychology, social work, and disaster preparedness and services.

Commonwealth of Kentucky. *Kentucky All Hazards Long Term Care Planning and Resource Manual*, accessed at <http://www.uky.edu/publichealth/ovargec/emergency-preparedness-training-resources>
Comprehensive planning materials systematically organized.

Kallmyer B, Levine J. “Alzheimer’s Disease and Related Disorders,” (2010). *Geriatric and Mental Health Disaster and Emergency Preparedness*. Book, Springer Publishing Company.

<http://www.springerpub.com/geriatric-mental-health-disaster-and-emergency-preparedness.html>

Excerpt: This book provides a comprehensive overview of the essential information that everyone working, or hoping to work in the field of aging, should know about disasters, emergencies, and their effects on the mental health and well-being of older persons. It provides the reader with evidence-based approaches for identifying and classifying mental health problems, such as Post-Traumatic Stress Disorder (PTSD), depression, and substance use disorders in older adults, which may occur during and post disasters/emergencies. Specific attention is given to the special needs and approaches to the care of at-risk groups of older persons such as veterans and holocaust survivors; older adults who are isolated, dependent, have mobility problems, communication deficits, are cognitively impaired, or have other co-morbidities; elders who use meals-on-wheels, vital medications, or home care; or older persons who are in senior centers, (cont.) nursing homes, or assisted living settings.

Niska RW, Shimizu IM. “Hospital preparedness for emergency response: United States, 2008.” (2011). *National Health Statistics Reports*, no 37. Hyattsville, MD: National Center for Health Statistics.

<http://www.cdc.gov/nchs/data/nhsr/nhsr037.pdf>

Excerpt: This report is a summary of hospital preparedness for responding to public health emergencies, including mass casualties and epidemics of naturally occurring diseases such as influenza.

Revere D, et al. “Public Health Emergency Preparedness and Response Communications with Health Care Providers: A Literature Review,” (2011). *BMC Public Health*, 11:337.

<http://www.biomedcentral.com/1471-2458/11/337>

Excerpt: Health care providers (HCPs) play an important role in public health emergency preparedness and response (PHEPR) so need to be aware of public health threats and emergencies. To inform HCPs, public health issues PHEPR messages that provide guidelines and updates and facilitate surveillance so

HCPs will recognize and control communicable diseases, prevent excess deaths, and mitigate suffering. Public health agencies need to know that the PHEPR messages sent to HCPs reach their target audience and are effective and informative. We conducted a literature review to investigate the systems and tools used by public health to generate PHEPR communications to HCPs and to identify specific characteristics of message delivery mechanisms and formats that may be associated with effective PHEPR communications. We found that detailed descriptions of PHEPR messaging from public health to HCPs are scarce in the literature and, even when available, are rarely evaluated in any systematic fashion. To meet present-day and future information needs for emergency preparedness, more attention needs to be given to evaluating the effectiveness of these systems in a scientifically rigorous manner.

Schwartzberg J. “Recommendations for best practices in the management of elderly disaster victims,” (2009). POGOe - Portal of Geriatrics Online Education via Baylor College of Medicine.

<https://www.bcm.edu/pdf/bestpractices.pdf>

Excerpt: Recommendations for best practices in the management of elderly disaster victims can be used by federal, state, and local government disaster planning teams to help them understand the unique problems faced by frail elder and vulnerable adult populations during a disaster. Recommendations are offered for consideration by these federal, state, and local teams regarding consultation with gerontologists, as well as use of tracking systems, a method for screening and triage and ways to avoid potential harm to frail elders or vulnerable adults. Specifically, the SWiFT screening tool is recommended as a pre- and post-disaster triage tool that can be used to assess and address the needs of this special population. Although the SWiFT tool was initially developed for community elders, its screening capabilities also extend to other vulnerable adults with disabilities and those living in nursing homes or assisted living facilities.

Home & Community-Based Services (Regional, State & Local)

ACT on Alzheimer's. "Action Resources: Local Government: Planning and Emergency Response." Website, accessed August 2015.

<http://www.actonalz.org/planning-emergency-response>

Dementia-Specific Disaster Preparedness resources are included here, along with information for first responders, law enforcement, emergency medical technicians and firefighters.

Alzheimer's Association, New York City Chapter. "With Hope in Our Hearts: New York City after the Storm," (2013). Volume 37, Newsletter. Accessed August 2015.

http://act.alz.org/site/MessageViewer?em_id=67142.0 *Link takes you to eNewsletter, which provides link to article.

Excerpt: Older people in general are often affected disproportionately by disasters (over 70 percent were age 65 or older in confirmed fatalities from Katrina), as there is a greater likelihood that the elderly will have physical limitations, a decline in cognitive function, or limited financial resources, thus making them more vulnerable. This means that in a disaster there are additional risks that must be assessed for older people. This is true whether they are living on their own, living at home with home care, or living in a residential setting such as a nursing home. For people with dementia, regardless of the setting, much will depend on the stage of their illness and on the level of need they have for support or assistance. No matter the stage of their illness, it is important to keep in mind that reactions from people with dementia can be unpredictable and hard to anticipate. Changes in surroundings and routines can be unsettling, as can the heightened activity and excitement in the environment overall, as reflected in television and radio coverage of the events.

Alzheimer's Association, RTI International, U.S. Administration on Aging. "Disaster Preparedness: Home and Community-Based Services for People with Dementia and their Caregivers." Toolkit.

http://www.adrc-tae.acl.gov/tiki-download_file.php?fileId=29143

Excerpt: The Disaster Preparedness Toolkit summarizes key actions states and caregivers can take when preparing for emergencies or disasters. 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, and provides an array of resources that are model programs or unique examples for state officials or caregivers to use when developing their own program.

Bascetta C. "Preliminary Observations on the Evacuation of Vulnerable Populations due to Hurricanes and Other Disasters," (2006). GAO Report and Senate Special Committee on Aging testimony.

<http://www.gao.gov/new.items/d06790t.pdf>

(Note: This testimony is based in part on a prior GAO report, "Disaster Preparedness: Preliminary Observations on the Evacuation of Hospitals and Nursing Homes Due to Hurricanes," GAO-06-443R (February 16, 2006). <http://www.gao.gov/cqi-bin/getrpt?GAO-06-790T>)

Excerpt: In preparing for and carrying out the evacuation of transportation-disadvantaged populations, such as the elderly or persons with disabilities, during a disaster, states and localities face challenges in identifying these populations, determining their needs, and providing for and coordinating their transportation. The elderly are likely to be represented among the transportation disadvantaged because they are more likely, compared with the general population, to have a disability, have a low income, or choose not to drive. GAO has observed mixed efforts at the state and local levels to address the evacuation needs of the transportation disadvantaged. Some emergency management officials told

GAO they did not yet have a good understanding of the size, location, and composition of the transportation disadvantaged in their community. However, GAO also observed efforts in some locations to address the evacuation needs of the transportation disadvantaged by encouraging citizens to voluntarily register with their local emergency management agency, integrating social service providers into emergency planning, and other measures.

Division of Public Health, National Center for Chronic Disease Prevention and Health Promotion, CDC. “Identifying Vulnerable Older Adults and Legal Options for Increasing Their Protection During All-Hazards Emergencies: A Cross-Sector Guide for States and Communities,” (2012). Guidebook.
<http://www.cdc.gov/aging/emergency/pdf/guide.pdf>

Excerpt: This guide aims to equip public health officials, the aging services network, emergency management, and essential partners from other sectors and at all jurisdictional levels with critical information, strategies, and resources to improve the planning for and protection of vulnerable community-dwelling older adults during all-hazards public health emergencies. The guide covers topic areas such as developing plans, partnering and collaboration, using data for action, building registries, using law-based solutions, sheltering, and caregiver preparedness.

Ettner B, and Edmunds M. “Emergency Preparedness – An Overview for Aging and Disability Resource Centers,” (2006). Issue Brief.

http://www.nasuad.org/sites/nasuad/files/hcbs/files/95/4722/Emergency_Preparedness.pdf

Excerpt: This issue brief describes the role of ADRCs in planning for, responding to and recovering from emergencies. It provides checklists and resource information that will assist ADRCs prepare their staff and facilities for emergency situations as well as with meeting the specialized needs of seniors and people with all types of disabilities in crisis situations.

Florida Department of Elder Affairs. “Disaster Preparedness Guide for Elders,” (2013). Elder Update Newsletter: Special Edition.

<http://elderaffairs.state.fl.us/doea/disaster.php>

An extensive guide with two pages of important emergency contact phone numbers, a disaster supplies kit checklist, and disaster planning insights tailored to seniors with hearing loss. It encourages creating a disaster plan for pets. No mention of dementia.

Florida Title XXIX Public Health, Special Needs Shelters, FL. Stat. §§ 381-0303, (2014).

<http://goo.gl/Cq74lz>

Excerpt: County health departments shall, in conjunction with the local emergency management agencies, have the lead responsibility for coordination of the recruitment of health care practitioners to staff local special needs shelters. County health departments shall assign their employees to work in special needs shelters when those employees are needed to protect the health and safety of persons with special needs. County governments shall assist the department with nonmedical staffing and the operation of special needs shelters. The local health department and emergency management agency shall coordinate these efforts to ensure appropriate staffing in special needs shelters, including a staff member who is familiar with the needs of persons with Alzheimer’s disease.

MDC. “When Disaster Strikes – Promising Practices: Older Adults,” (2014). Report.

<http://www.mdcinc.org/sites/default/files/resources/When%20Disaster%20Strikes%20-%20Promising%20Practices%20-%20Older%20Adults.pdf>

A ten-page report from MDC (formerly Manpower Development Corp.) features profiles of model programs: San Francisco’s disaster registry program, Florida’s disaster preparedness and distribution pods, Baylor University/American Medical Association’s SWIFT program, and reports from the AARP Public Policy Institute. This publication is one in an extensive series of 15 “on-the-ground manuals” that cover the following issues and special populations: tourists; sheltering; renters; mobility challenged individuals; individuals with special needs (cognitive impairment is included); mobile home residents; and others. MDC also offers these additional resources and reports on the subject of disaster planning:

- [Integrating Needs and Building Capabilities of Disadvantaged People in Local Disaster Plans](#)
- [A Guide for Integrating Needs and Capabilities of Disadvantaged People into Local Disaster Plans](#)
- [Community Based Vulnerability Assessment: A Guide to Engaging Communities in Understanding Social and Physical Vulnerability to Disasters](#)
- [Before the Storm: MDC's Emergency Preparedness Demonstration Connects Socially Vulnerable Communities with Help](#)

NACCHO. “Improving Preparedness for Community-Dwelling Older Adult Populations,” (2014). White Paper.

<http://nacchopreparedness.org/?p=3122>

Excerpt: To help local health departments (LHDs) address these barriers, NACCHO, with support from CDC, funded three LHDs to implement and test recommendations in CDC’s [Identifying Vulnerable Older Adults and Legal Options for Increasing Their Protection during All-Hazards Emergencies](#).

Developed in 2012, the CDC guide suggests recommendations that can be implemented at the community, regional, tribal, state, and national levels to better identify vulnerable adults and plan for their needs during an emergency. The selected LHDs tested the feasibility of realistically implementing the guide’s strategies by characterizing their community-dwelling older adult populations and determining whether gaps existed that could be filled by additional guidance.

The following are the LHD projects featured in the article.

- *Building an Emergency Registry in Alameda County, CA*
- *Tornado Spurs Laurel County [KY] Health Department to Launch the Community-Dwelling Older Adults Project*
- *Promoting an Expanded Registry in Suffolk County, NY*

(For the full NACCHO Report on Action Options to Improve Preparedness for Community-Dwelling Older Adult Population, [download the issue brief](#). For more information on CDC’s *Identify Vulnerable Older Adults and Legal Options for Increasing Their Protection during All-Hazards Emergencies*, download [the Guide](#).)

Reeve M, Altevogt B, and Davis M. “Regional Disaster Response Coordination to Support Health Outcomes,” (2015). Institute of Medicine, Forum on Medical and Public Health Preparedness for Catastrophic Events. White Paper/Workshop Series Summary.

<http://www.nap.edu/catalog/21713/regional-disaster-response-coordination-to-support-health-outcomes-summary-of>

Excerpt: As many communities within a region will have similar vulnerabilities when considering disasters, a logical step in planning is to establish responsibilities and capacities and be able to work toward common goals to address all-hazards when the entire region is affected. To explore these considerations, the Institute of Medicine’s (IOM’s) Forum on Medical and Public Health Preparedness for Catastrophic Events organized a series of three regional workshops in 2014. [The workshops explored](#)

opportunities to strengthen the regional coordination required to ensure effective medical and public health response to a large scale multi-jurisdictional disaster. The purpose of each regional workshop was to discuss potential mechanisms to strengthen coordination among multiple jurisdictions in various regions to ensure fair and equitable treatment of communities from all impacted areas. The content of each workshop included community planning and engagement, information sharing and management, and issues of surge capacity and health care delivery within the context of a large regional disaster. This summary reflects the discussions from all three of the 2014 meetings and highlights opportunities for improved operational change and alignment. *(Note: A search of the keyword “dementia” in this document did not return any results.)*

Caregiver-Focused

ADEAR, NIA. “Alzheimer’s Disease and Disaster Preparedness,” (2010). Online Article, adapted from Spring/Summer 2010 *Connections* newsletter.

<http://goo.gl/ax5Nnp>

Similar content to *Disaster Preparedness: Alzheimer’s Caregiving Tips* fact sheet (see next item).

ADEAR, NIA. “Disaster Preparedness: Alzheimer’s Caregiving Tips,” (2012). Fact Sheet.

http://www.nia.nih.gov/sites/default/files/disaster_prep-final_12oct19.pdf

A general two-page overview of what to do in the event of an evacuation and are separated from the person with Alzheimer’s. Also, a list of supplies for a disaster kit.

Alzheimer’s Association. “Caregiver/Safety Center.” Website, accessed August 2015.

<http://www.alz.org/care/alzheimers-dementia-safety.asp>

Location services (e.g., SafeReturn, MedicAlert, and ComfortZone) that could be beneficial to caregivers and first responders seeking to assist persons with dementia during disasters.

FEMA. “Helping a Loved One with Alzheimer’s During a Disaster,” (2006). Online Article.

<http://goo.gl/llisQl>

Basic overview of ways to help caregivers prepare to assist persons with dementia during a disaster.

Oliva N, Wexler B, Gullickson G, et al. “Disaster Preparedness for Veterans with Dementia and Their Caregivers,” (2013). Article in *Federal Practitioner*, pages 29-34.

<http://goo.gl/7ryaGV>

Article describing evolution of an educational intervention pilot program at the VA Palo Alto Health Care System that improved natural disaster preparation and response for this population.

U.S. Department of Health and Human Services, Office of the Assistant Secretary for Preparedness and Response, Administration for Community Living. “Disaster Preparedness for Family Caregivers,” (2014). Webinar.

<http://www.phe.gov/preparedness/planning/abc/pages/caregiver-webinar.aspx>

Excerpt: This webinar provides information for those who assist family caregivers in planning for emergencies and disasters. It includes guidance and examples for informing family caregivers on keeping themselves and their loved ones safe in a disaster or emergency by developing personal preparedness plans. The video includes a brief [introduction to preparedness planning for family caregivers](#) and the role of HHS in supporting at-risk individuals and family caregivers, including:

- Lessons Learned from Hurricane Sandy: Challenges of Sheltering in Place for Parents of Children with Developmental Disabilities or Special Health Care Needs Including Autism
- Supporting Older Americans who are Medically Fragile

Ready Houston: *Are You Ready?* (Video)

<https://www.youtube.com/watch?v=A-mImQG834UA>

The 15-minute video seeks to help community residents prepare themselves on how to respond to and recover from the effects of any disaster. The related DVD -- available from

<http://www.readyhouston.tx.gov/> -- contains versions in Chinese, English, Spanish, and Vietnamese both with and without captions.

Personal & Family Preparedness

Alzheimer's Association, AAHSA, AHCA, AHQA, AMDA, NADNA, NCAL. "Planning for a Pandemic/Epidemic or Disaster: Caring for Persons with Cognitive Impairment," (2013). Issue Brief. http://www.ahcanca.org/facility_operations/disaster_planning/Documents/pandemic_dementia_care.pdf

Excerpt: Maintaining operations in a long-term care setting with the expected staffing shortages during a pandemic, epidemic, or disaster would be very challenging. During this time, non-clinical staff may be needed to assist with patient care. This document is designed as a guide for non-licensed staff and lay people who may become involved in direct patient care during a major disease outbreak or disaster.

A section on personal preparedness from CDC's clearinghouse on disaster planning, accessible [via this link](#), includes these resources.

- [Preparedness Resources for Individuals, Families, and Caregivers](#), via the Administration on Aging (AoA)
- [Disaster Preparedness Guide for Seniors, by Seniors](#), via the American Red Cross
- [Disaster Planning Tips for Older Adults and their Families](#), via the CDC Healthy Aging Program
- [Ready.gov: Older Americans](#), via Ready.gov, FEMA
- [Just In Case: Emergency Readiness Older Adults and Caregivers](#), via the Administration on Aging, National Family Caregiver Support Program
- [Older Floridians Handbook: Laws and Programs Affecting Older Floridians](#), via the Florida Justice Institute, Inc., with Carlton Fields and the Florida Department of Elder Affairs
- [Emergency Preparedness for Seniors](#), via Disability.gov, Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities
- [Disaster Preparedness Tip Sheets for Seniors](#), via the California Department of Aging
- [Emergency Preparedness Tips for Those with Functional Needs](#), via the State of Illinois

Christensen JJ. "Hurricane Preparedness of Community-Dwelling Dementia Caregivers in South Florida," (2012). Graduate Theses and Dissertations.

<http://scholarcommons.usf.edu/etd/4010>

Excerpt: The aim of this dissertation is to explore how informal caregivers for people with dementia (PWD), who are community dwelling (i.e., not in nursing homes), prepare and plan for disasters. The research site is a particularly hurricane-prone region of Florida, second only to New Orleans in its vulnerability. An underlying assumption of this research is that caregivers for PWD have to plan and anticipate problems that are unique to their role. The rationale for the study described here is that disaster planning and mitigation save lives (Tengs et al. 1995), but there is little or no literature on disaster planning for the frail elderly and their caregivers.

This work documents the way that caregivers talk about disaster planning and [what they] say they will do if a hurricane strikes and reflects on their past hurricane experiences. Major findings include gaps in the county run special needs shelter services available in Florida for people with dementia. The response and difficulty that caregivers might face can depend on the stage of the disease.

FEMA, AARP, American Red Cross, National Organization on Disability. "Prepare For Emergencies Now: Information for Older Americans," (2014). Brochure.

http://www.ready.gov/sites/default/files/documents/files/olderamericans_quadfold.pdf

Excerpt: This guide outlines common-sense measures [in 3 steps] older Americans can take to start preparing for emergencies before they happen.

The Hartford Center for Mature Market Excellence, MIT AgeLab. “The Calm Before the Storm: Family Conversations about Disaster Planning, Caregiving, Alzheimer’s Disease and Dementia,” (2013). Guidebook.

<http://www.thehartford.com/sites/thehartford/files/the-calm-before-the-storm.pdf>

Focused on caregivers as a key component of an effective disaster plan, this guidebook covers tips on starting a conversation about disaster planning, steps for action, what to do when a disaster is imminent (deciding to stay or go), how to thrive during the time away from home, and the return. A number of checklists and additional resources are also included.

Global Perspectives

HelpAge International. “Older People in Disasters and Humanitarian Crises: Guidelines for Best Practice.” Report.

<http://www.helpage.org/silo/files/older-people-in-disasters-and-humanitarian-crises-guidelines-for-best-practice.pdf>

Excerpt: These *Guidelines for Best Practice* are based on wide-ranging new research from Asia, Africa, Europe, and the Americas and many years of global disaster experience. They aim to help relief agencies meet the special needs of older people in emergencies. While older people are commonly accepted as being a vulnerable or potentially vulnerable group, at present very little is done to meet their particular needs or to recognize their unique capacities and contributions. Humanitarian interventions often ignore older people’s special needs, using systems that discriminate against them and, on occasion, undermine their capacity to support themselves.

The guidelines give examples of key approaches and actions that could help the humanitarian community reduce the vulnerability associated with ageing. They also suggest ways to enhance the capacities and contribution of older people in emergencies.

United Nations Office for Disaster Risk Reduction, HelpAge International. “International Day for Disaster Risk Reduction: October 13, 2014.” Website, accessed August 2015.

<http://www.unisdr.org/2014/iddr/#.VTIsBVxIa9Z>

Review the IDDR Survey on Older Persons and Disasters:

- For older people: [English](#)
- For government disaster management personnel, other agencies, and anyone working in emergencies and DRR: [English](#)

Review the UN World Conference on Disaster Risk Reduction’s extensive list of outcome documents/post-2015 framework for “Disaster Risk Reduction: Building the Resilience of Nations and Communities to Disasters,” here: <http://www.preventionweb.net/posthfa/outcome-documents>