Disaster Preparedness for Community Dwelling Older Adults with Dementia and Their Primary Caregivers

Key Design Elements and Lessons Learned from a Health System Pilot

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Part of the National Alzheimer’s and Dementia Resource Center webinar series sponsored by the Administration for Community Living.
Disaster Preparedness for Community Dwelling Older Adults with Dementia and Their Primary Caregivers: Key Design Elements and Lessons Learned from a Health System Pilot

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DISCLAIMER

The opinions expressed in this presentation are those of the presenters, and do not necessarily reflect those of the Veterans Health Administration.
OLDER ADULTS ARE VULNERABLE TO NATURAL DISASTER(S)

- 70% of the estimated 1,330 victims in Hurricane Katrina were over 60, though they comprised 15% of the area population

(Benson, W,…,(n.d.) Centers for Disease Control, Health and Aging Program)

- Most died in their homes and in the community, with 68 dead found in nursing homes.

GROWING NUMBERS OF DISASTERS AND EMERGENCY EVENTS

--The U.S. experienced the most active and expensive year on record for disasters and emergency events in 2017, with total economic damages exceeding $300 billion dollars.  
https://www.ncdc.noaa.gov/billions/

--Hurricanes, storms, floods, fires, and extreme temperatures touched every region of the country, causing requests for disaster assistance to increase 10-fold over 2016.

THREATS TO HEALTH SECURITY ARE INCREASING

In 2017:

Gulf Coast Hurricanes Harvey and Irma: >80 deaths each in Texas and Florida.

Puerto Rico: Hurricane Maria, > 1,000 deaths estimated. A 6/18 published Harvard School of Public Health study estimated range of 793 to 8,498 deaths.

Northern California Wildfires: at least 44 deaths, with average age of 79 years.

In 2018:

January, 2018

Santa Barbara area Floods/Debris Flow: 21 deaths, including 9 older adults 60+ (2 still missing as of April, 2018)
Santa Barbara floods, January 2018

- Mandatory evacuation orders focused on area in which 7,000 individuals were living.
- Local agencies received 600 calls for help between 3 am and 6 am the time of worst debris flow flooding, from individuals & families trapped in homes.
- 1000 rescued.
- 300 were still trapped in homes days after the debris flow/flooding.

Santa Barbara Independent, January 18, 2018
2018 ALZHEIMER’S FACTS AND FIGURES: AGE DISTRIBUTION OF PEOPLE WITH ALZHEIMER’S DEMENTIA

FIGURE 1
Ages of People with Alzheimer’s Dementia in the United States, 2018

- 85+ years, 37%
- 75-84 years, 44%
- 65-74 years, 16%
- <65 years, 4%

Created from data from Hebert et al. Percentages do not total 100 because of rounding.

Prevalence 17

ACCORDING TO 2014 MEDICARE CLAIMS DATA:

About one-third of all Medicare beneficiaries who die in a given year have been diagnosed with Alzheimer’s or another dementia.

There are disaster response risks for older adults without dementia, including those with mild cognitive impairment (MCI).

The American Academy of Neurology estimates that 15% of people ages 60+ have mild cognitive impairment (MCI). In 2018, that percentage equals 11.6 million people.

MCI is not dementia and is characterized by two subtypes:

a. Amnestic MCI, the primary symptom of which is memory loss.

b. Non-Amnestic MCI, primarily impacts thought processes: symptoms can vary within and between persons with MCI and can include changes in judgment, planning, decision-making abilities, even visual recognition.

MCI can impact older adult individuals’ reaction to and functioning in response, evacuation, and/or recovery.
COGNITIVE AGING

‘Normal’ or age-related changes in cognition or cognitive aging, are thought to impact older adults 60+. Changes can be manifest through one or more of: reduced processing speed, changes in judgement, planning, decision-making, problem solving, learning and/or memory.


When you provide disaster preparedness education/intervention to older adults without dementia or dementia or MCI, BE mindful of potential individual cognitive changes that can occur in older adults.
CAREGIVER ASSISTANCE PROVIDED FOR ACTIVITIES OF DAILY LIVING (ADLS), DEMENTIA PATIENTS VS. OTHER OLDER ADULTS, 2015

Older adults report need for help in evacuating in time of disaster.

25% of 75+ year olds need help evacuating, with over 2/3rds indicating that they need help “from outside the household.”

In the 2000 US Census, 13 million adults age 50 and over reported that they would need help evacuating, and one-half reported that they would need outside help to do so.

Help needed evacuating in event of natural disaster, by age, 2005:

- Age 50-74:
  - Need help evacuating: 13%
  - Among those who need help evacuating, need help from outside the household: 46%
  - Very confident in ability to evacuate: 60%

- Age 75+:
  - Need help evacuating: 25%
  - Among those who need help evacuating, need help from outside the household: 50%
  - Very confident in ability to evacuate: 67%

Source: Harris Interactive® on behalf of AARP, nationwide telephone survey of 1,648 U.S. adults age 50 or older, November 10-20, 2005.

*Difference from 50-74 is statistically significant at 5%.*
ISSUES FOR OLDER ADULTS FACING COMMUNITY DISASTERS

When disaster strikes in communities, older adults have many vulnerabilities:

- Functional capacity limitations
- Chronic disease, including dementia
- Some may no longer drive
- Some may not have cell phones, or may live in areas with spotty cell service
- Some refuse evacuation for a variety of reasons, including fear, pets, home security
- Neighbors who can help may be unaware of individuals’ disabilities
Findings in CA wildfire casualties:

Average Age: 79

Adult range: 50-100 years of age

Many found in ashes of homes, on/or near driveways, or in garage near/in cars.

44 people died in 4 counties, and 6,500 homes and businesses were destroyed.

Northern California wildfires, October 2017
The Northern California wildfire crisis in October 2017 highlighted several emergency notification and response challenges and failures:

- The inability of the 911 dispatch system to handle a “massive” number of calls in a widespread area, and their lack of prepared instructions to help trapped individuals escape a wildfire.

- The need for earlier and more informative community warnings sent through multiple platforms.

- The need for faster evacuations.

Johnson, J. Six months later, emergency upgrades after Northern California fires slow to take effect. The Press Democrat, April 6, 2018.

The concept for the VA disaster kits was developed by former VA researcher Nina Tumosa PhD.

The Dementia Committee at the VA Palo Alto Healthcare System was provided with a kit prototype.

Committee Co-Chair/Clinical Nurse Specialist (BW) identified the disaster kit concept/education as an opportunity to develop a quality improvement project.
An Interdisciplinary Planning Committee was created 8/2010 to develop a disaster kit educational intervention for community-dwelling Veterans with dementia & their caregivers.

Members included:

- The Clinical Nurse Specialist
- A Nurse Practitioner from Home-based Primary Care
- The RN Director of the Adult Day Healthcare Program
- A Geriatrician
- An RN Health Services and Gerontology Researcher
- A Health Science Specialist

--Additional disciplines were consulted: Social Work, Psychology, & Recreation Therapy
GOALS OF THE PILOT

Goals:

1) To develop and disseminate basic disaster kits to community-dwelling Veterans and their primary caregiver(s).

2) To increase caregiver knowledge regarding disaster preparedness elements and planning.

Outcome Measures:

--Distribute 100% of kits to targeted Veterans/primary caregivers over a six-month implementation period.

--Increase caregivers knowledge as a result of preparedness education.
PROJECT PLANNING ASSUMPTIONS

- Disasters of all kinds affect older adults disproportionately, particularly those with special needs.
- Conditions such as dementia complicate disaster response and require targeted planning/supplies, as well as additional time & resources for affected individuals to evacuate, stabilize, and recover.
- Individuals with dementia and their caregivers can benefit from guided disaster preparation and a kit developed with their special needs in mind.
- Sharing contact information with neighbors is key to disaster response—this was a critical issue in recent Northern California wildfire evacuations and survival.
The Pilot Project was designated as a quality improvement project by the VA Palo Alto Office of Research, and approved by the Quality Management Director, September 2010.

The Chief of Staff’s office was kept apprised of the project implementation and progress.

The project team utilized the Plan-Do-Study-Act (PDSA) quality improvement model, a 4-step iterative model used for process improvement.

Outcomes measured through pre/post survey process.

NEXT STEPS: INSTITUTIONAL PROJECT REVIEW, QUALITY IMPROVEMENT MODEL – BASED PLANNING
INITIAL INTERVIEWS WITH CAREGIVERS WERE CONDUCTED TO INFORM PROJECT

- Semi-structured interviews were completed with 16 patients and caregivers were in their homes or geriatric clinic settings.

- Purpose was to identify caregivers’ current knowledge of and engagement in disaster preparedness; responses helped guide/customize kit design.

- A three-question survey was written at a maximum 8th grade reading level, utilizing the Flesch-Kincaid readability and reading level scales (available in MS Word).
BUDGET ESTIMATES AND FUND DEVELOPMENT

- Direct non-labor expenses for the Pilot were estimated at ~$13,000.

- The team sought and obtained donations from Veterans’ service organizations, as well as a Bay Area internet entrepreneur supportive of Veterans (Craig Newmark).

- The VA Geriatric Research, Education and Clinical Center (GRECC), VA Palo Alto Home-based Primary Care, and Palliative Care provided funding support as well.
PRE AND POST-INTERVENTION SURVEY OF KNOWLEDGE AND CONFIDENCE

Assessed belief that preparation is important to respond to a disaster.

Documented:

- Whether caregiver had written contact information/numbers for neighbors.
- Whether caregiver had documented emergency contact information for family members.
- Whether caregiver had a disaster kit in the home.
- Whether disaster kit had at least a 3-day supply of food, water, medication…
PLANNING ELEMENTS-CONTINUED

- Educational material utilized was adapted from California Department of Aging earthquake preparedness material, the Alzheimer's Association, and committee suggestions.

- Distribution of kits/intervention was accomplished through committee staff.

- Pre-Post Survey process completed and data analyzed.
KIT DEVELOPMENT

--Team spent much time discussing rationale for inclusion/exclusion of supplies.

--Several components were not included due to safety concerns (e.g., alcohol-based sanitizer liquid, necklace with whistle).

--Some additional items were placed in the caregiver kits, educational media and emergency radio/flashlight.
<table>
<thead>
<tr>
<th><strong>Veteran's Disaster Kit</strong></th>
<th><strong>Caregiver's Disaster Kit</strong></th>
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<tbody>
<tr>
<td><strong>Items Provided</strong></td>
<td><strong>Items Provided</strong></td>
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<tr>
<td>- cord bracelet whistle</td>
<td>- cord bracelet whistle</td>
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<tr>
<td>- hand sanitizer/face mask</td>
<td>- hand sanitizer/face mask</td>
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<tr>
<td>- Flashing reflector light</td>
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<td>- first aid kit</td>
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<td>- survival and marker</td>
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<td>- safety education handsaw</td>
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<tr>
<td>- photo/ID album (see below)</td>
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<tr>
<td>- Individual photo of the Veteran</td>
<td>- Individual photo of the Veteran</td>
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<tr>
<td>- copy of health insurance cards</td>
<td>- copy of health insurance cards</td>
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<tr>
<td>- completed contact card (inside the photo albums)</td>
<td>- completed contact card (inside the photo albums)</td>
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<td>- copy of healthcare directives</td>
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<td>- Living Will</td>
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<td>- Durable Power of Attorney for Health Care</td>
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**Recommended items to add to both disaster kits**
- Water: one gallon of water per person per day for at least three days (for drinking and sanitation)
- Food: at least a three-day supply of non-perishable food with a flip-top opener or add a can opener if adding canned food
- Medications: a three-day supply of key medications and/or a list of current medications

**Caring for your disaster kits**
- Review every year or when changes occur
- Check the expiration dates of your supplies, replace items as needed
- Replace your medication list with a new list whenever there are changes
- If you are keeping a three-day supply of medications, be sure they have not expired
VETERAN AND CAREGIVER KITS: DIFFERENCES IN CONTENTS

--Crank radio with flashlight for caregiver only.

--DVD from the American Public Health Association on disaster planning in the caregiver kit.

getreadyforflu.org
OTHER ITEMS PROVIDED IN KITS

- hand sanitizer wipes (bottom, left)
- face mask, gloves (left)
- flashing emergency reflector light, (near left)
- notepad and marker (upper near left)
- safety education handouts
- guidance for addressing behaviors during/after disaster; immediate responses to a disaster
- photo album/ID (next pages)
PHYSICAL TOOLS/MATERIAL: TWO KITS

Personal Information

Local Identification/Contacts
DISASTER KIT ELEMENTS

Neighbor/Local Emergency Contact

Picture of PWD / Picture of Caregiver

Additional Contact/Personal Information
EDUCATIONAL TOOLS

Goals:

- Acknowledge existence of caregiver stress
- Minimize learning burden and limit information overload.
- Maximize readability of information

Tools:

- Preparedness information from California Department of Aging, one page Tip Sheet
- Informational CD on community disaster preparedness from the American Public Health Association
DISASTER PREPAREDNESS (continued)

During an evacuation

People with dementia are especially vulnerable to chaos and emotional trauma. They have a limited ability to understand what is happening, and they may forget what they have been told about the disaster. Be alert to potential reactions that may result from changes in routine, traveling or new environments.

- When appropriate, inform others (hotel or shelter staff, family members, airline attendants) that your loved one has dementia and may not understand what is happening.
- Do not leave the person alone. It only takes a few minutes to wander away and get lost.
- Changes in routine, traveling and new environments can cause:
  - Agitation
  - Wandering
  - Increase in behavioral symptoms, including hallucinations, delusions and sleep disturbance.
- Do your best to remain calm. The person with dementia will respond to the emotional tone you set.

Tips for preventing agitation

Reassure the person. Hold hands or put your arm on his or her shoulder. Say things are going to be fine.

- Find outlets for anxious energy. Take a walk together or engage the person in simple tasks.
- Redirect the person’s attention if he or she becomes upset.
- Move the person to a safer or quieter place, if possible. Limit stimulation.
- Make sure the person takes medications as scheduled.
- Try to schedule regular meals and maintain a regular sleep schedule.
- Avoid elaborate or detailed explanations. Provide information using concrete terms. Follow brief explanations with reassurance.
- Be prepared to provide additional assistance with all activities of daily living.
- Pay attention to cues that the person may be overwhelmed (fidgeting, pacing).
- Remind the person that he or she is in the right place.

Helpful hints during an episode of agitation

- Approach the person from the front and use his or her name.
- Use calm, positive statements and a patient, low-pitched voice. Reassure.
- Respond to the emotions being expressed rather than the content of the words. For example, say, “You’re frightened and want to go home. It’s ok. I’m right here with you.”
- Don’t argue with the person or try to correct. Instead, affirm his or her experience, reassure and try to divert attention. For example, “The noise in this shelter is frightening. Let’s see if we can find a quieter spot. Let’s look at your photo book together.”

Take care of yourself

- Take care of yourself by finding a good listener to hear your thoughts and feelings about the event.
- Find moments to breathe, meditate and reflect.

Prepared by The Alzheimer’s Association and distributed by VA Palo Alto Health Care System
The Alzheimer’s Association is the leading voluntary health organization in Alzheimer care, support and research. (Updated November 2007)
Disaster situations increase anxiety for everyone impacted, however, for those with dementia, a crisis can increase agitation.

**Tips for helping decrease anxiety:**
- Reassure the person by holding hands, or offering a shoulder and reassure them that things are going to be fine.
- Find outlets for anxious energy. Take a walk with the person or engage the person in simple tasks.
- Redirect the person’s attention if he or she becomes upset.
- Move the person to a safer or quieter place, if possible. Limit stimulation.
- Make sure the person takes medications as scheduled.
- Try to schedule regular meals and maintain a regular sleep schedule.
- Avoid elaborate or detailed explanations. Provide information using concrete terms. Follow brief explanations with reassurance.
- Be prepared to provide additional assistance with all activities of daily living.
- Pay attention to cues that the person may be overwhelmed (e.g., fidgeting, pacing).
- Remind the person that he or she is in the right place.

**During an episode of agitation:**
- Approach the person from the front at eye level and use his/her name.
- Use calm, positive statements and a patient, low-pitched, reassuring voice.
- Respond to the emotions being expressed. For example, say, “You’re frightened and want to go home. It’s ok. I’m right here with you.”
- Don’t argue with the person or try to correct. Instead, reassure and try to divert attention. For example, “The noise in this shelter is frightening. Let’s see if we can find a quieter spot. Let’s look at your photos together.”

For additional support and tips for assisting someone with dementia during a disaster go to alz.org/co or call 800.272.3900
RECOMMENDATIONS TO CAREGIVERS OF ITEMS TO ADD TO KITS

--One gallon of water per person per day for at least three days. Note: seven day supply is now recommended.

--Three-day supply of non-perishable food, such as Tetra packs, containers with flip-top opener; otherwise add a can opener.

--Three-day supply of essential medications and a list of current medications.

--Eyeglasses; hearing aid batteries; blanket; cash; garbage bags; list of distracting activities for Veteran.
INSTRUCTIONS TO CAREGIVERS ON HOW TO MAINTAIN KITS

--Review kit every year or when changes occur.

--Check expiration dates of supplies; replace as needed.

--Replace medication list with a new list when changes occur.

--Ensure medications have not expired.

--Keep emergency contact information current.
IMPORTANCE OF PHOTO/ID ALBUM

- Maintains key information in one place for caregivers/others.
- Includes a photo of Veteran and caregiver (suggest: service animals/pets also).
- Documents current contact information of neighbor(s) and family.
- Include: Copies of health insurance card(s) and
- Copies of advance health care directives such as:
  --DPAHC (Durable Power of Attorney for Health Care),
  --POLST (Physician’s Orders for Life-Sustaining Treatment),
  --DNR (Do Not Resuscitate)
PRE AND POST SURVEY PROCESS & RESULTS

Caregiver self-survey process utilized

Pre-intervention: Survey was mailed to caregiver before disaster kits distributed (278 mailed, 71 returned)

Post-intervention: Survey mailed to caregivers three months or more after receiving kits (278 mailed, 45 returned)

Results: Intervention shifted knowledge and reported level of preparation from underprepared to prepared, well-prepared, or very well prepared.
LESSONS LEARNED

1. It is essential to include project team members who are knowledgeable about the needs of people with dementia.

2. Understand that clinical personnel have multiple other commitments so factor this into the timeline for developing the program.

3. Family/other caregivers are already stressed—ensure preparedness info is clear, reviewed with caregiver & language accessible.

4. Consider the safety of items placed into a disaster kit for vulnerable populations (i.e., PWD may think an item is food).
LESSONS LEARNED (CONTINUED)

- Behavior management suggestions will change as disease progresses; discuss/modify behavior management activities with caregivers over time.

- Phone follow-up may be an option to determine which person(s) need a home visit for periodically reviewing preparedness elements.

- Some local or state agencies maintain vulnerable population evacuation registries for emergency response purposes; this was not factored in for this pilot but is essential.
COMMUNITY-LEVEL REGISTRIES

Voluntary, available in some cities and/or counties:

- Glendale, California
- Dane County, Wisconsin

Can identify individuals with self-reported special needs:

Form would need to be updated periodically

Data base would need to be accessible in disaster/emergency event situations and part of an organized disaster response process.
LESSONS LEARNED (CONTINUED)

• Project funding needs to be realistic, ongoing, collaborative and coordinated among organizations.

• Disaster planning information from national, state, and local agencies is extensive and can be overwhelming even for those without health issues. Summarize and simplify to educate those vulnerable in the face of disasters.
LESSONS LEARNED (CONTINUED)

--Mobility issues need to be factored in per individual (i.e., discuss residence evacuation plans, including evacuation routes). Individuals may refuse to leave residence.

--According to current evidence, at least seven-day supply kit would be optimal versus a three-day kit.

--Consider collaborating with social network Villages (aging --in-place support organizations) for access to vulnerable populations and assessing needs per community. These organizations maintain information on their members.
LESSONS LEARNED (CONTINUED)

--Include interdisciplinary staff members in team to get an overview from different perspectives.

--It is essential to do a target population/group needs assessment to avoid missing key issues. Be aware of cultural influences impacting disaster response.

--Need to have intermittent outreach to caregivers over time to ensure they are (1) keeping kits maintained, (2) updating instructions as new evidence arises and (3) keeping health/medication information current.
IMPLICATIONS FOR FURTHER INTERVENTIONS/RESEARCH

• Continue to evaluate how current disaster response systems are working to address needs of those with dementia and caregivers: integrated responses?

• Research is needed: How do disaster preparedness interventions assist in preparing dementia caregivers to respond?

• Identify support options for caregivers who need to manage PWD behaviors during extended sheltering following an evacuation and/or disaster.
RELEVANT CONCEPT: HEALTH SECURITY

- Reflects our nation’s strengths and vulnerabilities in measures needed to keep people safe and healthy in the face of an emergency, and tracks how these protections change over time and across U.S. regions.

- Results from the 2018 National Health Security Preparedness Index indicate that though the readiness for disasters, disease outbreaks, and other emergencies continued to improve in 2017, current levels of health security are not optimal.
http://www.getreadyforflu.org/

http://www.getreadyforflu.org/getreadyday/

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