Public Health: Caregiving and Hurricane Preparedness
Janelle J. Christensen, PhD., M.P.H.
Objectives

1. Identify **unique concerns** when caring for someone with ADRD during disasters (at home, and in a skilled nursing facility).

2. Identify the **costs and benefits** of nursing home evacuation versus sheltering in place during a hurricane.

3. Cover **regulations and best practices** for staff and resident safety when evacuating and sheltering in place during a storm.
Questions

1. What is the most difficult decision that caregivers need to make in the face of a hurricane?

2. What are **two** differences between caring for a person with ADRD in the community versus in a skilled nursing facility during a hurricane?

3. What are **four** topics that professionals can cover with community-dwelling caregivers to better prepare them for hurricanes and disasters?
Nurses as Caregivers

- How many of you have cared for someone with ADRD in a long-term care facility?
- How many of you have provided care for someone with ADRD in your own family in your own home?
- How many of you have provided this care during a hurricane, blizzard, or under threat of a wildfire?
- How many of you advise or interact with families providing care (informal caregivers) for someone with ADRD in their homes?
Alzheimer’s Disease and Related Disorders (ADRD)

- What are some public health concerns related to ADRD (in general)?

- What public health concerns might be most prominent during a natural disaster?
Overview

1. Establishing the problem(s)
   - Disaster planning challenges for Long Term Care (LTC) and people with ADRD

2. Considerations and Solutions for Community Dwelling Caregivers

3. Considerations and Solutions for LTC Facilities
Hurricanes and the Elderly

• Over 64% of Hurricane Katrina deaths were over 65 years old (even though they made up less than 12% of NOLA’s population).

(Brinkly 2006; Brunkard et al. 2008; Jenkins et al. 2008).
Depressing HHS study finds gaps continue to exist in nursing home emergency preparedness...they are overall woefully unprepared” MAY 16, 2012
REGINA PHELPS, RN, BSN, MPA, CEM

Can this be prevented?
Hurricane Sandy

A map showing the thousands of LTC facilities in the path of Hurricane Sandy. October 29, 2012 by Long-Term Living staff
“Nursing Home Is Faulted Over Care After Storm”

New York Times Headline on November 12, 2012: By MICHAEL POWELL and SHERI FINK

Promenade nursing home in Rockaway Park, Queens, NY

Can this be prevented?
“My patient is not dead, my patient is not dying, all she needs is oxygen!”

Can this be prevented?

“Terri Johnson screams as she seeks help for Dorothy Duvic at the Morial Convention Center in New Orleans in the aftermath of Hurricane Katrina on Sept. 1, 2005. Johnson was an in-home caretaker for Duvic.”

(Melissa Phillip : Houston Chronicle)
Alzheimer’s Disease and Related Disorders (ADRD)

- An estimated **5.4 million** Americans had a diagnosis of Alzheimer’s disease or a related disorder (ADRD) in 2011
- 1.4 million unpaid caregivers providing for their needs
- Most people with ADRD live and die at home.  
  - 46% die at home, 35% at hospital, 19% in a nursing home (Callahan et al., 2012)
- 450,000 people with ADRD live in Florida

(Alzheimer’s Association 2011)
Disaster Preparedness as Risk Reduction

- Disaster planning and mitigation save lives.  
  (Tengs et al. 1995)

- There is very little literature on disaster planning for people on ADRD and for their caregivers who live in the community.

- Households with an older adult (65+) less likely to evacuate for a hurricane.  
  (Solis et al., 2009; Cherry, 2010; Christensen et al., 2012)

- 57% of the general US population reported that they had absolutely no emergency preparedness plan.  
  (2007 FEMA Citizen Preparedness Review)
## Disaster Planning: Community Dwelling Caregivers versus Skilled Nursing Facilities

<table>
<thead>
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<th>Community Dwelling</th>
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<tr>
<td>Expected to have disaster plan: <strong>57% of general population does not have a plan</strong></td>
<td>Required by law to have Comprehensive Emergency Management Plans in Florida. <strong>Varies state to state.</strong></td>
</tr>
<tr>
<td>Can use special needs shelters, regular shelters if no other option. <strong>Special Needs Shelters vary from county to county.</strong></td>
<td>Required to have mutual aid agreements with “like” facilities. Cannot use Special Needs Shelters. <strong>Varies state to state.</strong> (Brown et al., 2008)</td>
</tr>
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<td>Unknown training.</td>
<td>Trained staff (depending on evacuation drills). <strong>Varies facility to facility.</strong></td>
</tr>
<tr>
<td>Unknown support systems.</td>
<td>Ideally supported by Emergency Operations Centers (EOC). Emergency Power Restoration</td>
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# Risk Analysis: To Evacuate or Shelter?

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<td><strong>6. Case load</strong></td>
<td>NA</td>
<td>Census/Number of people with ADRD</td>
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<td><strong>7. Stage of Dementia</strong></td>
<td>Type and Stage of person with ADRD</td>
<td>?</td>
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<td><strong>8. Training</strong></td>
<td>Unknown</td>
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Community Dwelling Caregivers

- Diverse group of people
  - Mostly female
- May not have training on caregiving or ADRD
- Variation in literacy levels and access to information
1) People may lack information about risk or how to prepare for it (access);
2) They may not understand the information or how to use it (comprehension);
3) They may not have the means to properly prepare (socio-economic factors);
4) They may not trust the people or entities that are providing them information about risk (risk perception).

(Sorensen and Vogt Sorensen 2007)
1. Managing stress induced behaviors during disasters.
2. Safe Return enrollment.
3. Caregiver specific disaster kits.
4. Know your evacuation options!

(Differences between Special Needs Shelters and Regular Shelters)
1. Stress and Behavior Management

- Changes in the environment (putting up hurricane shutters or evacuating to an unfamiliar place) can be confusing and disruptive for people with dementia.

- You might see some stress-related behaviors that you might not normally see.

- Behaviors vary over course of disease.
1. Stress Related Behaviors, cont.

Stress Related Behaviors

- Depression
- Anxiety
- Wandering
- Increased Stubbornness

Irritability and Aggressiveness
- Social Withdrawal
- Mood Swings
- Distrust in others
- Changes in Sleeping Habits

Research has shown that: 1) **music therapy**, 2) **touch (massage) therapy**, 3) and **exercise** are can help people with dementia reduce stress (and stress related behaviors).

 Especially prominent in early to middle stages ~
“Refusal to Evacuate”
(Christensen, 2012)
1. Different stages of dementia require different disaster plans

It was very difficult, though, because [my husband] didn't want to go. I had to fight with him to get him out of the house. That was my big problem because I couldn't reason with him. He was totally resistant. At the hotel, he spent the whole time in the bed. Not happy... Both of those hurricanes made landfall just about ten miles from here.

-Caregiver, Wife describing husband in stage 4-5 of Alzheimer’s Disease
<table>
<thead>
<tr>
<th>Stage 1 -- Normal adult</th>
<th>No functional decline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 2 -- Normal older adult</td>
<td>Personal awareness of some functional decline.</td>
</tr>
<tr>
<td>Stage 3 -- Early Alzheimer's disease</td>
<td>Noticeable deficits in demanding job situations.</td>
</tr>
<tr>
<td>Stage 4 -- Mild Alzheimer's</td>
<td>Requires assistance in complicated tasks such as handling finances, planning parties, etc.</td>
</tr>
<tr>
<td>Stage 5 -- Moderate Alzheimer's</td>
<td>Requires assistance in choosing proper attire.</td>
</tr>
<tr>
<td>Stage 6 -- Moderately severe Alzheimer's</td>
<td>Requires assistance dressing, bathing, and toileting. Experiences urinary and fecal incontinence.</td>
</tr>
<tr>
<td>Stage 7 -- Severe Alzheimer's</td>
<td>Speech ability declines to about a half-dozen intelligible words. Progressive loss of abilities to walk, sit up, smile, and hold head up.</td>
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</table>

(Reisberg et al. 1988)
Now I think it is easier because, since she was diagnosed, we have found the right balance of medications and she is not as anxious as she used to be. Her disease has progressed so she is more forgetful. I think she would be OK if we had to evacuate. She will be confused maybe, but not resistive (sic).

-Caregiver, Adult Daughter speculating on mother who is now in stage 6
1. Gentle Responses to Stress Related Behavior, cont.

<table>
<thead>
<tr>
<th>Potential Problem Behaviors During Disasters</th>
<th>Caregiver Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Increased stubbornness&quot;- refusal to evacuate</td>
<td>Don’t argue. Entice with other options (dinner, visiting family). Make preparations (pack) or throw out food when they are not in the room to <strong>avoid confrontation</strong>.</td>
</tr>
<tr>
<td>Time disorientation-</td>
<td>Use their perceived time/era to direct them to evacuation or preparation activities (for example, “we need to go pick the kids up from school” or “we have to make the cruise ship, so let’s hurry and get packed”).</td>
</tr>
<tr>
<td>Spatial disorientation-Wandering- Becoming lost</td>
<td><strong>Enroll in Safe Returns.</strong> Locks on doors. Alert neighbors of PWD’s condition. Walking can be healthy and reduce anxiety if the PWD is supervised during this activity.</td>
</tr>
<tr>
<td>Anxiety induced behaviors- Violence</td>
<td>Don’t argue and remain calm. Take submissive posturing (head down, hands up). Start <strong>singing</strong> a familiar song and encourage the PWD to join you. Try helping the PWD get <strong>regular exercise</strong>. Give a soft massage to the PWD hand or neck once they are calm.</td>
</tr>
</tbody>
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Solutions for Community Dwelling Caregivers

1. Managing stress induced behaviors during disasters.
2. Safe Returns enrollment.
3. Caregiver specific disaster kits.
4. Know your evacuation options!

(Differences between Special Needs Shelters and Regular Shelters)
2. Caregiver Disaster Preparedness and Kit

• Safe Return enrollment.
1. Managing stress induced behaviors during disasters.
2. Safe Returns enrollment.
3. Caregiver specific disaster kits.
4. Know your evacuation options!

(Differences between **Special Needs Shelters** and **Regular Shelters**)

**Solutions for Community Dwelling Caregivers**
3. Specific Disaster Kit

• Everyone should have a box set aside with supplies that are designated ONLY for a disaster.

• It should be easy to pick up and carry in case you have to evacuate.

• Most of these supplies can be purchased at discount stores such as the Dollar Tree at a low cost (a dollar an item).
3. Caregiver Specific Disaster Kit:

- Keeping cool and hydrated
  - Battery powered fan
  - Wash cloth/instant ice pack
  - Drink with electrolytes (sport drink)
  - Water
3. Caregiver Specific Disaster Kit

• **Communication**
  - Crank/battery powered radio
  - Door hanger

• **Medications**
  - Refill before a storm

• **Paperwork**
  - Home insurance
  - Medical papers
3. What do you need to stay comfortable?

- Sanitary (incontinence) supplies (if necessary)
  - Pads
  - Wet-wipes
  - Gloves
  - Hand sanitizer
- Stress Reduction Activities (for different stages)
  - Cards, puzzles, art supplies
  - Folding laundry
  - Making music
# 3. Caregiver Disaster Kit As Disaster Education

<table>
<thead>
<tr>
<th>Backpack</th>
<th>Batteries</th>
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<tbody>
<tr>
<td>Crank radio with flashlight</td>
<td>Large Zip-lock bags for medical documents</td>
</tr>
<tr>
<td>Door Hanger</td>
<td>Basic First-Aid Kit</td>
</tr>
<tr>
<td>Medications! Refill Early</td>
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<td>Instant Icepack</td>
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<tr>
<td>Hand sanitizer</td>
<td>Wash Cloth</td>
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<tr>
<td>Wipes w/ reminder label</td>
<td>Battery powered fan</td>
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<td>Activities: Early: Cards</td>
<td>Wash Cloth</td>
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<td>Activities: Early: Crossword Puzzle Book</td>
<td>Gatorade</td>
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<tr>
<td>Activities: Late: Colored pencils</td>
<td>Water bottle (3 gallons per person per day!)</td>
</tr>
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<td>Activities: Late: Tactile Ball</td>
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Solutions for Community-Dwelling Caregivers

1. Managing stress induced behaviors during disasters.
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(Differences between Special Needs Shelters and Regular Shelters)
4. Know Caregiver Resources

- If your home isn’t safe, where?
- Friends or family?
- Hotel?
- Shelter?
  - Special Needs Shelter or “regular” shelter?
2. Special Needs Shelters

- Ambivalence and confusion about who should use them.
  - Confusion on the county levels about who is eligible. People with dementia are frequently excluded from these services.
  - Most caregivers **do not know that they exist or that they are different from regular shelters**, even after reading the informational pamphlet.
  - ACC staff unclear on who qualifies.
2. Special Needs Shelters

• Explicit exclusion of people with dementia, as described in previous slides.
• Implicit exclusion of people with dementia, by not providing appropriate services:

*I cannot imagine any of my folks being in a special needs shelter. The special needs shelters up here are not dementia specific. It can be so crazy...*

-ACC Staff Member
2. Special Needs Shelters

- Run by county EOC
  - Regular shelters are run by American Red Cross
- Has physicians and nurses on staff
- It has auxiliary electrical power, is wind resistant, and not flood-prone
- “Last resort”
There was a police officer who was taking care of his mother who had Alzheimer’s disease and his aunt [who] had emphysema. They [the special needs shelter] took the aunt [with emphysema], but wouldn’t take his mother [with dementia]. What was he going to do? He had to work during the hurricane.

-Alzheimer’s Community Care, Administrator
Eligibility Criteria for Special Needs Shelters.

(1) A person shall be eligible for access to a special needs shelter if:

(a) They are a person with special needs;
(b) Their care needs exceed basic first aid provided at General Population Shelters; and
(c) Their impairments or disabilities:
   1. Are medically stable; and
   2. Do not exceed the capacity, staffing and equipment of the special need shelter to minimize deterioration of their pre-event level of health.

(2) Special needs shelter may choose to accept persons with care needs that exceed the criteria stated in subsection (1).

(3) Determination as to the capacity (either in skills or assets) of the special needs shelter is made by the local emergency management agency and the county health department or their designees.

Specific Authority 381.0303(6)(a) FS. Law Implemented 381.0303(6)(a) FS. History–New 11-21-07.
We went to a [regular] shelter located in a school. I thought, “oh my God!' It was totally unacceptable. There were kids running around. It was crowded. You had to bring your own bedding and I couldn't let him (the person with dementia) sleep on the floor. It was loud and chaotic. It just wasn't well organized at all. Also, they don't take pets and we have cats. We took one look at it and we realized it wouldn't work so we just turned around and came home.

-Caregiver, Wife
1. Does this person need a **medical treatment that requires electricity**? (For example, is this person on O2, use a C-pap machine or is he or she on **dialysis**?)

- **Yes**

  2. Does this person have a disease that causes **dementia**?

    - **Yes**
      - 3. Does this person **have a caregiver** to assist with daily needs, medications and safety management?

        - **Yes**
          - Encourage them **NOT to go to SpNS. Use Regular Shelter if needed.**
        - **No**
          - Sign up for SpNS

    - **No**
      - 4. Does this family **have a safe location to go**?

        - **Yes**
          - Encourage them **NOT to go to SpNS. Use safe location.**
        - **No**
          - Sign up for SpNS

- **No**

  Encourage them to **sign up for SpNS**.

---

A **“Safe Location”** is a building that is **not in a flood or evacuation zone**, is made of **cinder block**, has hurricane shutters or high impact glass, preferably with **access to a generator.**

Also consider the level of **social support** available to this family. If they do not know anyone in the area, consider the SpNS shelter.
1. Managing stress induced behaviors during disasters.
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(Differences between Special Needs Shelters and Regular Shelters)
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Long Term Care and Hurricanes

• Most difficult decision for nursing home administrators is whether to evacuate or shelter in place.
• Both options carry risks.
Long Term Care and Hurricanes

Decision: Evacuate or Shelter-in-Place

Internal Factors
- Staff
- Resident Acuity
- Physical Structure

External Factors
- Nature of Event
  - Rural
  - Urban
  - Metropolitan
- Location of Facility
  - In the Zone
  - Hurricane Evacuation Zone
  - Storm Surge Zone
  - Flood Zone
- Time
- Scope

Destination
- Transportation
- Supplies

Emergency Management Guide for Nursing Homes
Decision Makers

- Nursing Home Administrator or Designee
- Facility Owner
- Facility Corporate Representative
- Local or State Office of Emergency Management Representative
- Governor of the State
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<td><strong>Dietary:</strong></td>
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<td><strong>Non-perishable food &amp; supplies</strong></td>
<td>One-week, s. 59A-4.110(4), FAC</td>
<td>7-10 days</td>
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<td><strong>Drinkable water supply</strong></td>
<td>3 gallons per resident per day during and after a disaster which is defined as 72 hours, 59A-4.133 (18), FAC</td>
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<td>1 gallon per staff member per day during and after a disaster which is defined as 72 hours, 59A-4.133 (18), FAC</td>
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<td><strong>Essential supplies</strong></td>
<td>72 hours, s. 59A-4.126 (2)(b), FAC and AHCA Form 3110-6006, March, 1994</td>
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Hurricane Sandy

A map showing the thousands of LTC facilities in the path of Hurricane Sandy. October 29, 2012 by Long-Term Living staff
Disaster Cycle

Kampur 2012 and FEMA, 2012
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