2013 Webinar Series
State of the Science:
Dementia Evaluation and Management
among Diverse Older Adults and Their Families

Sponsored by Stanford Geriatric Education Center in conjunction with
American Geriatrics Society, California Area Health Education Centers,
& Community Health Partnership

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GERIATRIC EMERGENCY PREPAREDNESS AND RESPONSE (GEPR) WEBINAR SERIES

SESSION TWO: DISASTER RESPONSE: COMMUNITY SHELTERING FOR

PERSONS WITH ALZHEIMER’S DISEASE AND OTHER MEMORY DISORDERS

Presenters
Renee Chase, BBA, Mdiv
Alzheimer’s Association, Greater KY/Southern Indiana Chapter

Jenise Brown, EMT
Louisville Area American Red Cross Regional Chapter & KY Red Cross State Relations Disaster Liaison

Arleen Johnson, PhD
OVAR Geriatric Education Center, University of Kentucky

Betty Shields, PhD-ABD
OVAR Geriatric Education Center, University of Louisville

Melen McBride, PhD, RN, FGSA
Stanford Geriatric Education Center, Stanford University School of Medicine

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“Dementia and Preparedness Planning for Ethnic Elders and Caregivers”

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Our speakers have no financial relationships to disclose and will not discuss off label use and/or investigational use in their presentations.

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Learning Objectives

- Describe the special functional needs of persons with Alzheimer’s disease and other memory disorders during disasters.
- Discuss shelter management for ensuring the safety of persons with Alzheimer’s disease and other memory disorders during disasters.
- Identify resources for disaster preparedness and response for persons with Alzheimer’s disease and other memory disorders.

Renee Chase, MDiv

- Renee Renee is a Community Outreach Coordinator with the Alzheimer’s Association of Greater Kentucky and Southern Indiana. She has a Master of Divinity from Lexington Theological Seminary, BBA in Personnel Management from Texas A & M and Secondary Education Certificate/English Literature Equivalency from University of North Texas.
- At the AD Association, she works with educational teams to deliver quality training to families as well as professional caregivers of people with Alzheimer’s disease, collaboratively designs new curriculum on Alzheimer’s disease, and works with other Association employees and volunteers to raise awareness of Alzheimer’s disease in the community. She is a resource faculty for the OVAR/GEC and has presented numerous trainings on emergency preparedness for persons with memory disorders for statewide and national conferences/webinars.
Janine Brown

- Janine is the Senior Director of Disaster Services for the Louisville Area American Red Cross Regional Chapter in Kentucky; providing disaster support to Red Cross Chapters in Western KY and Southern Indiana; serving as the Red Cross State Relations Disaster Liaison and in the Red Cross’ planning lead for the Red Cross with the Commonwealth of KY.
- In 2010, she was the CEO for the San Joaquin County Red Cross Chapter in Stockton, and before returning to California, Janine was Chapter Solutions Manager for the ARC National Headquarters in Nebraska and Southwest Iowa. She managed growth of services, volunteerism and increased efficiencies.
- She was the Emergency Services Director for Lancaster County Nebraska, ARC Chapter; was on the Governor’s Bio Terrorism Advisory Committee and planning team. She had been the ARC Executive Director for Southwest Nebraska Chapter.
- After graduating from A.A. Stagg High School (Stockton, CA) she continued her education as an EMT/Firefighter and joined the Arapahoe Nebraska fire and rescue squad for 10 years, which ultimately led to her career with the ARC.

Arleen Johnson, MSW, PhD

Arleen is the Director for the Ohio Valley Appalachia Regional Geriatric Education Center, a consortium of the Universities of KY, Louisville, Cincinnati and East Tennessee State University. She has worked with the OVAR/GEC since 1985. She has a PhD in Medical Behavioral Sciences and a Masters in Social Work, both from the University of Kentucky.

Since 1970, she has been a researcher, educator and direct service worker in the field of aging. She helped to develop the national agenda for emergency preparedness for aging and actively participates on the National GEC Collaborative.

Her work is focused on emergency preparedness for rural aging services and long term care providers. She is author of the KY All Hazards Long Term Care Planning and Resource Manual that was designated as a 2010 US Department of Health and Human Services (DHHR) Office of the Assistant Secretary for Preparedness and Response (ASPR) national best practice.
Betty Shiels, MSSW, LCSW, PhD-ABD

Betty is the Institutional Director of the Ohio Valley Appalachia Regional Geriatric Education Center at the University of Louisville, Kent School of Social Work. She received her Masters of Science in Social Work and is completing her PhD in Social Work at the University of Louisville.

Since 1991, she has been involved in research, training, geriatric care management and consulting in the field of aging. She serves on the board of the National Association of Geriatric Education Centers (NAGEC).

Her work is focused on emergency preparedness for long term care providers in Kentucky. She is co-author of the *KY All Hazards Long Term Care Planning and Resource Manual* that was designated as a 2010 US Department of Health and Human Services (DHHR) Office of the Assistant Secretary for Preparedness and Response (ASPR) national best practice.

Melen McBride, PhD, RN, FGSA

Dr. Melen McBride, Associate Director, Emerita, and Ethnogeriatric Clinical Nurse Specialist at Stanford Geriatric Education Center (SGEC), School of Medicine, Stanford University, Palo Alto, CA. She has over two decades of experience in ethnogeriatrics, including use of advance educational internet technology (distance learning, webinars, web-based training) and designed the Cohort Historical Analysis Tool (CHAT) currently in use for graduate students in psychology and nursing programs and has published in these areas and in preparedness and aging.

She represents SGEC in the Geriatric Emergency Preparedness Response (GEPR) Collaborative of six HRSA funded GECs providing leadership (since 2001) to infuse ethnogeriatrics into preparedness training of health professionals. Dr. McBride co-coordinates the SGEC Faculty Development Program in Ethnogeriatrics and Health Literacy.
National Association of Geriatric Education Centers Initiative
Geriatric Emergency Preparedness, Response (GEPR)
Collaborative

- **After September 11, 2001** the National Association of Geriatric Education Center (NAGEC) presented a statement to HRSA about the urgent need for geriatric emergency preparedness training.

- **HRSA responded with a supplemental grant in 2004** to 6 GECs (CA, KY, MO, NY, OH, TX) to provide interprofessional training on bioterrorism and aging; later an “all-hazards” approach was adapted by the group. Initially known as the Bioterrorism Emergency Preparedness in Aging (BTEPA) the group was renamed the Geriatric Emergency Preparedness Response (GEPR) Collaborative.

- **Members were** ~ Consortium of NYGEC, Ohio Valley Appalachia Regional GEC, University of Kentucky, Saint Louis University Gateway GEC of MO & ILL, Stanford GEC Stanford University, Texas Consortium GEC, University of New England, Maine GEC and Western GEC, Case Western University.

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National Consensus

When resources are stretched thin, the needs of vulnerable populations are left unmet in all phases of preparedness.

The Centers for Public Health Preparedness (CPHP), 2007

[http://www.cdc.gov/phpr/cphp/centers.htm](http://www.cdc.gov/phpr/cphp/centers.htm)
Ethnogeriatrics Emergency Preparedness

The functional needs of ethnic elders who have dementia fall into almost all of the Centers for Disease Control’s classifications of vulnerability.

There are many gaps in scientific knowledge about culturally appropriate geriatric preparedness for “all-hazards” events.

*Identifying Vulnerable Older Adults and Legal Options for Increasing Their Protection During All-Hazards Emergencies: A Cross-Sector Guide for States and Communities*


National Association of Geriatric Education Centers Initiative Geriatric Emergency Preparedness, Response (GEPR) Collaborative

- **2010-2015:** continued to offer interprofessional geriatric preparedness programs through the GECs’ HRSA funded educational objectives.

- **2010-2015:** Three members of the GEPR Collaborative formed a national consortium to provide 12 trainings through a Webinars Series on Geriatric Emergency Preparedness hosted by Stanford GEC.

- **Consortium:** Ohio Valley Appalachia Regional GEC, University of Kentucky, University of New England, Maine GEC, and Stanford GEC has offered five sessions; another is scheduled for June and six others on various preparedness response topics in 2014 and 2015.
American Red Cross
Sheltering
A Community Vision

Janine Brown
Sr. Director, Disaster Services
American Red Cross
Louisville Area Chapter, Kentuckiana Region

Who’s job is it?

• American Red Cross?

• Public Health?

• Emergency Management?
Mission

The American Red Cross prevents and alleviates human suffering in the face of emergencies by mobilizing the power of volunteers and the generosity of donors.

Response Guidelines

- Red Cross response occurs in Coordination/Cooperation with Emergency Management but is
  - Mandated by Red Cross policy
  - Based on Red Cross principles and values
  - Vital to keeping commitments to five constituent groups:
    - Clients, Donors, Workers, Partners, Public
Sheltering Cycle

1: Planning and preparedness
2: Opening the shelter
3: Organizing the shelter
4: Operating the Shelter
5: Closing the shelter
6: After action review

Sheltering Considerations and Questions

- Can everyone stay in a congregate shelter?
- Can we meet the diverse needs of everyone in the shelter? (cultural, dietary, health, mental health, children)
- When is someone not suited to staying in a shelter situation?
- How do we determine who stays and who does not?
Partnerships are critical

- Before, during and after the disaster for all ESF 6 Activities such as sheltering, feeding, Bulk Distribution
  - Shelter partners (schools, churches, community buildings)
  - Emergency Management
  - Health Departments
  - Community agencies
  - Pet Partners
  - Feeding Partnerships

Disaster Related Health Needs

- Disaster related injuries and/or illnesses
- Exacerbation of chronic diseases
- Stress related symptoms
- Functional and Access needs clients
- Language translation and/or medical interpreter needs
Registration Phases

Registration
- Registration Form
- Initial Intake and Assessment Tool
- Shelter Resident Information

Reception

Referral
Initial Intake and Assessment Tool

- This tool assesses individuals for functional and access need. It is not a medical form
- Utilized at shelter registration. First 9 questions are asked by registration shelter volunteers or health service volunteers sitting at the registration table.
- Tool is answered per family not individuals.

What are we missing?

What are the challenges?
Client Health Record

- Confidential Health Record utilized by Health Service to document all care provided, including referrals and education
- Documentation should include a statement related to the disaster and their health-related needs (SOAP documentation encouraged). This record continues until health needs are met (several visits may be included)
- S (subjective), O (Objective, A (Assessment), and P (Plan)

Challenges

- Shelter workers are not always trained or able to meet the needs of the whole community.
- We can recognize obvious medical needs but... not all needs are obvious.
- Some clients may be perceived as “difficult” when in reality they are disoriented or have language issues.
- Shelter sites are not all created equal – therefore no two sheltering situations are alike.
- Community resources are not equal
The Bottom Line

If we fail to plan, we plan to fail
But I say....
If we fail to plan together....we plan to fail together

Begin conversations, continue conversations, implement and exercise those conversations.

Reference and Resources
Thank You !!!

Janine Brown
Sr. Director Disaster Services
American Red Cross
Louisville Area Chapter
Janine.Brown@redcross.org
502-561-3641

Preparing for Sheltering Persons With Dementia in Disaster Situations

Renee Chase, M.Div.
Alzheimer’s Association
Greater Kentucky and
Southern Indiana Chapter
Polling Questions

1. Do you have a written plan to meet the specific physical, emotional and cognitive needs of persons with dementia while in a shelter setting?
   Yes
   No
   Don’t know

2. In your agency’s emergency plan, do you have a dementia care training component for staff and volunteers?
   Yes
   No
   Don’t know

Polling Questions

3. Do you have a process for identifying persons with dementia if no caregivers are present and/or the person is alone?
   Yes
   No
   Don’t know

4. Does your agency collaborate with other agencies/entities to provide quality care or support to persons with dementia and their families (whether they shelter in place or are evacuated)?
   Yes
   No
   Don’t know

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Polling questions

- To answer the polling questions, please go to the following link:

https://stanforduniversity.qualtrics.com/SE/?SID=SV_cv7tMUB3fFPCoeN

Assessment

- Due to the nature of intake at a shelter, volunteers have only a short window to assess whether or not a person may have dementia. The best case scenario is that the person has a caregiver with them. However, since many people in the early stages of dementia still live alone, it is likely that one will show up without a caregiver.
Assessment

• Tools
  ◦ Developed after Hurricane Katrina in 2005
    • SWiFT
      • Created and piloted by a team of medical personnel, social workers and protective service employees working in Houston Astrodome
        http://www.dmphp.org/cgi/reprint/2/Supplement_1/S45.pdf
    • Initial Intake Assessment Tool
      • Developed in partnership by Department of Health & Human Services and American Red Cross
        http://www.phe.gov/Preparedness/planning/abc/Pages/initialintakeassessmenttool.aspx

Assessment

• Orientation questions to check cognitive function
  ◦ What is the current month and year?
  ◦ What is the name of this place?
  ◦ What city/town are we in?
  ◦ Who is the current president?
  ◦ About what time of day is it?
So now what?

- FEMA Guidelines

“Shelter operators should provide support services in mass care shelters to accommodate people with disabilities who are not medically fragile but need some assistance with daily living activities unless doing so would impose an undue financial and administrative burden. Such assistance can be provided by medical personnel or trained volunteers.”


So now what?

- Volunteers providing Personal Assistance Services (PAS) for those with dementia should be available in the shelter at all times. Acting as companion/caregiver for a person with dementia requires knowledge of how to interact effectively.

- A good ratio is one volunteer to one or two persons with dementia, depending on the level of need for the people with dementia and the skill of the volunteer.
So now what?

- FEMA provides Operational Tools for providing Personal Assistance Services (PAS) training to volunteers.
- First-line PAS volunteers come from community-based organizations.
- FEMA Mass Care holds contracts with Dynamic Service Solutions Inc. and ResCare to provide additional PAS if there are volunteer shortfalls.

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Impact of a disaster situation

- Due to dementia’s impact on processing information, people with dementia:
  - Are sensitive to trauma
  - Have limited ability to understand directions or explanations
  - May forget instructions
  - Become easily agitated, frustrated or overwhelmed
  - Are prone to wander or hide
Impact of a disaster situation

- Do not leave the person alone.
- Changes in routine and environment can cause:
  - Agitation
  - Wandering
  - Increase in behavioral symptoms such as hallucinations, delusions & sleep disturbances

*It is important that the volunteer companion remain calm. The person with dementia will respond to the emotional tone set by the volunteer.*

Effective care

- 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. Validate the emotions.
- Don’t argue with the person or try to correct. Divert attention.
Effective care

- Avoid elaborate or detailed explanations. Follow brief explanations with reassurance.
- Be prepared to provide additional assistance with 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.

Effective care

- Find outlets for anxious energy.
- Redirect the person’s attention if he or she becomes upset.
- Move the person to a quiet place. Limit stimulation if possible.
- Make sure the person takes medications as scheduled.
- Try to schedule regular meals and maintain a regular sleep schedule.
Addressing behaviors

- When you can see that a person with dementia is beginning to exhibit unexpected behaviors:
  - Aggression: try moving person away from trigger or removing it from the person’s vicinity; use soothing music
  - Anxiety/agitation: use art, music or other activities to engage the person in order to distract and help them relax
  - Confusion: respond with a brief, clear explanation; use photos, pictures and other thought-provoking items to elicit stories of people and places important to the person with dementia

Addressing Behaviors

- Repetition: turn the action or behavior into an activity; answer the person’s question each time she asks; write the answer on a large piece of paper and put it in a prominent place, then refer her back to it when she asks again
  - Suspicion: remain non-defensive; allow the person to express himself; engage the person in an activity, or ask for help with a task
  - Trying to exit building: alert other volunteers that the person has dementia; keep the person active and engaged; use activities & daily tasks
MedicAlert + Safe Return®

- **Process**
  - If a person with dementia in your care wanders away:
    - Call 911
    - A Golden Alert (Silver Alert in some states) will be issued by law enforcement
    - Call 24-hour emergency response line at 1-800-625-3780 to report missing person
    - A community support network will be activated, including local Alzheimer’s Association chapters and law enforcement agencies

MedicAlert + Safe Return®

- If a citizen or emergency personnel finds the person with dementia:
  - The person can call the toll-free number listed on person's MedicAlert + Safe Return ID jewelry.
  - MedicAlert + Safe Return will notify the listed contacts and make sure the person with dementia is returned to where he or she belongs.
A final thought:

- Long before you find yourself trying to care for a person with dementia in a shelter, consider the following:
  - Include family caregivers in your planning process
  - Collaborate with local geriatric and dementia care professionals to put together a team that can provide input on medical issues related to dementia
  - Contact your local Alzheimer’s Association chapter for resources and dementia care training opportunities

Resources

US Administration on Aging (n.d.). *Disaster Preparedness for Persons With Dementia and Their Caregivers: Home and Community Based Services for People With Dementia and their Caregivers*. Retrieved from US Administration on Aging website: 

http://www.ada.gov/pcatoolkit/chap7emergencymgmt.pdf

Resources


The Calm Before the Storm – A guide for caregivers and persons with dementia www.thehartford.com/calmbeforethestorm


The Alzheimer’s Association

The Alzheimer’s Association is the world’s leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer’s disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer’s. Visit www.alz.org or call 800-272-3900.
Q & A

- We now have some time to answer your questions. If you have any questions, please use the “Chat” feature located on the right side of your screen. Please send your chat to everyone if possible.
- After the Q and A, we would like to ask each of the participants to answer the short evaluation questionnaire.

Final Question
Thank You for Participating!