

## Resources for Public Health Officials

Recent natural disasters and public health emergencies, including wildfires, floods, and COVID-19, have reinforced the need for emergency preparedness plans to consider people living with dementia. In particular, these events have often resulted in difficult care transitions for people with dementia, often from evacuations or hospitalizations.

This resource explores some of the key players in dementia care during crises and strategies to support care transitions. Action around care transitions is particularly important for this population, as people with dementia experience a high occurrence of preventable hospitalizations, which represent 23.5 percent of total hospitalizations for individuals with Alzheimer's or other dementia.<sup>1</sup>

This document also identifies broader public health opportunities in emergency planning to help avoid or minimize challenging transitions by anticipating more general barriers to care during community crises.

### KEY PLAYERS IN CARE TRANSITIONS DURING CRISES

Many different stakeholders are involved in care transitions. Even more may be involved during emergency events. Understanding the roles each has during a crisis — and their priorities — can position public health agencies to shape plans, policies, and resources to support people living with dementia and their caregivers.

As one of the most essential stakeholders, any plan to address dementia and care transitions should consider unpaid caregivers. Unpaid caregivers assist with activities of daily living, coordinating care, preventing injuries, and managing comorbidities. Also keep in mind that not all people with dementia may have the support of a caregiver. Nearly 70 percent of people living with dementia reside at home in the community, and of those individuals, 26 percent live alone.<sup>2</sup>

#### Unpaid Caregivers



**Role:** Decision-making during hospitalization and managing wellness after the transition

**Priorities:** Maintaining their own health and well-being as well as that of the person living with dementia

#### Hospitals



**Role:** Acute care and case management during hospitalizations

**Priorities:** Acute care and chronic condition management for individuals directly affected by the emergency and for those with conditions that are exacerbated

#### Primary Care



**Role:** Non-urgent or recurring treatment to manage chronic conditions and diagnose new conditions

**Priorities:** Preventive care and stabilization of and preparation for chronic conditions before crises

#### Skilled Nursing Communities & Residential Care



**Role:** Provision of specialty, place-based care — and addressing other access and other functional needs — for individuals living with dementia and cognitive impairment

**Priorities:** Stabilizing chronic conditions; supporting transitions to acute care settings as clinically appropriate

#### Emergency Management & EMS



**Role:** Provision of emergency services needed, including transportation to hospital

**Priorities:** Continuity of critical services and prioritization and allocation of relief resources

#### Public Health



**Role:** Guidance and education to communities on preparation for crises and available resources for well-being and safety

**Priorities:** Protecting health and well-being of community

**Opportunity:** Promote the role of caregivers in community and individual well-being

## SUPPORTING TRANSITIONS DURING CRISES — ROLES FOR PUBLIC HEALTH

Many of the identified stakeholders include healthcare providers, such as hospitals and EMS, who are directly involved in care transitions during emergencies. Although public health agencies may not provide direct care, they play a broad role in preparing for, and responding to, emergencies in ways that can support or hinder care transitions, and dementia care more broadly.

Ensuring a supportive care environment more broadly for people with dementia during emergencies can help lessen the need for transitions, help transitions go smoothly when they are necessary, and reduce challenges after the transition, such as issues resulting in readmission after hospitalizations. Improved overall care is essential to minimizing additional strain on overburdened health and long-term care systems.

The following represent overarching strategies and policy options that public health leaders can adopt to improve outcomes for people living with dementia and decrease strain on caregivers.

### Broad Opportunities for Public Health

- » **Adopt a “dementia lens” in preparedness and response planning.** People living with dementia are a large portion of the population, including more than 1 in 9 people age 65 and older in the United States.<sup>3</sup> As the leaders in developing and executing preparedness initiatives, public health professionals have a responsibility to make concerted efforts to address the needs of people living with dementia and their caregivers. As a part of developing and reviewing preparedness initiatives and response plans, public health should consider partnering with a specialist or specialty organizations.

Resources: [Alzheimer’s Association First Responder Training](#); [Alzheimer’s Association Local Chapter Locator](#); [Trust for America’s Health Age-Friendly Public Health Systems](#)

- » **Educate and reinforce the essential role of the caregiver.** During any care transition, often the only commonality is the person living with dementia and their caregiver. Public health can play a key role in promoting “continuity of caregivers” during a crisis to help avert unnecessary distress, support effective information sharing, and enable cohesive coordination between care sites, when needed. Public health should educate providers on the different roles of caregivers, and how they can and should be prioritized for support.

Resources: [Alzheimer’s Association Dementia Care Practice Recommendations](#); [Caregiving: A Public Health Priority \(CDC\)](#)

- » **Educate the public health workforce on the prevalence of dementia.** More than 6 million Americans aged 65 and older are living with Alzheimer’s. By 2050, this is projected to reach 12.7 million.<sup>4</sup> Despite the rising prevalence, Alzheimer’s and other dementia can often go undiagnosed, and people with the diagnosis may not be aware of their condition. Public health officials will be better equipped to address the needs of people with dementia when they understand the scope of issue. As a part of this strategy, public health should consider partnering with local Area Agencies on Aging.

Resources: [Alzheimer’s Association Public Health Curriculum and Videos](#); [Area Agencies on Aging](#)

- » **Consider plans and policies that incentivize improvement in quality care.** Public health officials are a respected voice in advocating for use of quality improvement (QI) measures and other policies that support complex care management. Public health should engage or partner with provider societies and advocacy groups to understand complex care management practices that are most impactful or influential during crises.

Resources: [Maintaining Physical and Mental Well-Being of Older Adults and their Caregivers During Public Health Emergencies](#)

### Strategies for Common Crisis Events

Beyond broader public health planning, considering specific emergencies and common disruptions to care can help public health professionals identify and reduce potential triggers for unnecessary care transitions or lessen their impact when they occur.

Public health emergencies can include events such as severe weather, exposure to chemical spills or biological agents, and infectious disease outbreaks, among others. While not all crisis events occur with advance notice, there are many ways to plan for these events in advance. The following table outlines some of these opportunities.

### LEVERAGING PUBLIC HEALTH’S ROLE AS CHIEF HEALTH STRATEGIST

Public health agencies must recognize dementia caregiving as a challenging and unique public health issue — especially during crises. Through their mandate to protect the public’s health, agencies can advance proven strategies to support and maintain the health and well-being of persons living with dementia and their caregivers.

**Alzheimer’s Association 24/7 Helpline 800.272.3900**

*This free service provides confidential support and information to people living with dementia, caregivers, care and emergency response professionals, and the public in over 200 languages.*

<sup>1</sup>-2021 Alzheimer’s Disease Facts and Figures ([alz.org/media/Documents/alzheimers-facts-and-figures.pdf](#)); <sup>2</sup> Ibid.; <sup>3</sup> Ibid.; <sup>4</sup> Ibid.

Crisis Impact	Strategy to Support Care Transitions
<b>Public Health Emergencies (PHEs)</b>	
Need for personal protective equipment (PPE) and hygiene tools for infection control	<ul style="list-style-type: none"> <li>» Offer training and PPE to care professionals and unpaid caregivers to help reduce potential transmission when providing in-home care and assisting with essential errands.</li> <li>» Connect providers and caregivers with supply resources available through health and medical disaster relief non-governmental organizations.</li> </ul>
Reliance on remote care/telehealth technologies	<ul style="list-style-type: none"> <li>» Explore modifications or adaptations to existing dementia-friendly technologies with associated staff or caregiver training.</li> <li>» Evaluate new technologies that become available for inclusivity and usability, including for discharge planning, caregiver education and training, care coordination and case management.</li> </ul>
Impact of interruptions in respite care on caregivers	<ul style="list-style-type: none"> <li>» Ensure caregivers have plans in place for additional support if they become unable to provide care, including situations in which the caregiver has an unplanned hospitalization.</li> <li>» Encourage neighbors to offer assistance to one another.</li> <li>» Work with community partners and community-based organizations to expand access to respite care and resources, such as wellness check-in volunteer programs like Meals on Wheels.</li> </ul>
Interrupted or diminished access to nutrition	<ul style="list-style-type: none"> <li>» Work with caregiving groups, medical societies, and experts in similar fields to develop educational resources (e.g., fact sheets, webinars) on nutritional needs post-hospitalization and how to provide continuity in access to healthy nutrition resources during and after crises.</li> <li>» Develop systems of care that ensure people living with dementia receive adequate nutrition, especially if a caregiver is not present.</li> </ul>
Practice sustained social distancing and isolation to minimize disease spread	<ul style="list-style-type: none"> <li>» Educate care communities on best practices for social distancing and update them regularly as regulations change.</li> <li>» Help community organizations, especially those with ties to underserved populations, use technology to host peer support groups, social events, and more. Such efforts will need to consider user access to devices, broadband, and technical support.</li> <li>» Establish or promote community partners' virtual support groups for caregivers and family members of persons living with dementia to share best practices, tips, and challenges related to care transitions during times of crisis.</li> <li>» Educate caregivers about filling medication prescriptions by mail order or delivery and in greater quantities for both the person with dementia and others in the household.</li> </ul>
<b>Significant Natural Disasters</b>	
Evacuation and potential for separation of individual living with dementia and caregiver	<ul style="list-style-type: none"> <li>» Conduct drills and tabletop exercises outlining courses of action and technologies available to ensure caregivers remain with the individuals they are providing care to and/or develop reunification policies for inclusion in response plans.</li> </ul>

Closed roadways/limited transportation resources affecting ability of care professionals and caregivers to travel to clients	» For crisis events with notice (e.g. hurricanes, wildfires, etc.), encourage community care settings to alter caregiving shifts to allow for caregivers to remain in place, if appropriate, during potential curfews or road closures.
Reduced access to medications	» During a disaster, look to <a href="https://www.rxopen.org">Rxopen.org</a> for info on the operating status of healthcare facilities, including pharmacies and dialysis centers.

## ADDITIONAL RESOURCES

### Partnering with State, Local and Community-based Organizations

- » [Healthy Brain Initiative: State and Local Public Health Partnerships to Address Dementia](#): A Road Map outlining how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers.
- » [State Alzheimer's plans](#): A portal to access state Alzheimer's plans.
- » [Caregiving for People Living with Dementia and How Health Departments Can Make an Impact](#): Brief developed by the Association of State and Territorial Health Officials outlining recommendations for applying public health strategies to caregiver policies.
- » [Needs Assessment Toolkit](#): Offers guidance and resources for state public health agencies on comprehensive needs assessments related to Alzheimer's and other dementias.

### Partnering with Emergency Management Stakeholders

- » [Health Care Coalitions](#): Groups of individual health care and response organizations in a defined geographic region. Coalitions serve as multiagency coordinating groups that support and integrate with public health and medical activities in the context of a crisis. Find your local coalition here: [Health Care Coalition Locator](#).
- » [Emergency Support Function \(ESF\) #8 — Public Health and Medical Services](#): At the federal level, ESFs provide the structure to coordinate interagency support, resources, and capabilities in an emergency response. ESF #8 is a mechanism for coordinating Federal assistance to supplement State, Tribal, and local resources in response to public health and medical care needs. Contact your state and local emergency management agency to learn more about ESF #8 leads in your jurisdiction. Core capabilities of ESF #8 include:
  - » Public Information and Warning;
  - » Critical Transportation (of patients and supplies);
  - » Environmental Response/Health and Safety;
  - » Fatality Management Services;
  - » Mass Care Services;
  - » Logistics and Supply Chain Management;
  - » Public Health, Healthcare, and Emergency Medical Services (e.g., Health Surveillance, Medical Surge, Patient Care, Assessment of Public Health/Medical Needs, Potable Water/Wastewater and Solid Waste Disposal); and
  - » All-Hazard Consultation and Technical Assistance and Support.

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