



COVID-19 & DEMENTIA

Unique Considerations for the Public Health Community: People Living with Dementia

6/15/20

PEOPLE LIVING WITH DEMENTIA ARE AMONG THE MOST VULNERABLE POPULATIONS DURING A PANDEMIC

Public health and related professionals can use these tip sheets to address the unique risks and challenges of protecting people living with dementia, caregivers, and their families during the COVID-19 pandemic.

The presence of dementia does not increase the risk of COVID-19. However, dementia-related factors — including increased age and high prevalence of other chronic conditions — do increase risk of COVID-19.

Contact tracing requires special consideration for people living with cognitive impairment. And, people living with dementia require unique public health responses whether they **live at home or in the community**, visit **acute care**, or reside in **long-term care communities**. The following tip sheets outline the current landscape, challenges posed by COVID-19 to people living with dementia and their caregivers, and ways public health can protect this vulnerable population.

Immediate action is needed to address people living with dementia during this pandemic. Steps taken now can also be integrated into simultaneous emergency planning should extreme weather, wildfires, and other hazards also occur during the COVID-19 outbreak. Implementing the public health responses in these tip sheets will not only help minimize the negative impacts of COVID-19 on this population and their caregivers, but also support effective and efficient delivery of care, and help protect communities.

EMERGENCY AND DISASTER SITUATIONS CAN EXACERBATE OR COMPLICATE THE UNIQUE VULNERABILITIES ASSOCIATED WITH ALZHEIMER'S AND ALL DEMENTIA.

Loss of Cognitive Functioning May Impact

- » Memory
- » Language skills
- » Visual perception
- » Problem solving
- » Self-management
- » Ability to focus and pay attention

Additional Complications

- » Wandering
- » Anxiety or agitation
- » Communicating through behavior instead of verbally
- » Increasingly dependent on others for care

Dementia is the loss of cognitive functioning (including thinking, remembering, and reasoning) and behavioral abilities (including the ability to care for oneself) to such an extent that it interferes with a person's daily life and activities. Alzheimer's disease and vascular dementia are the leading causes of dementia. The continuum of dementia is associated with the progressive nature of these losses.

Stay Up-To-Date

24/7 Helpline [cdc.gov/aging/covid19](https://www.cdc.gov/aging/covid19)
800.272.3900 [alz.org/publichealth-covid19](https://www.alz.org/publichealth-covid19)

For more information, contact:

[Molly French](#) or [John Shean](#), *Public Health Department*

alzheimer's 
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CONTACT TRACING

Robust contact tracing is necessary to identify and isolate potential new cases of COVID-19. Among adults with COVID-19, those aged 65 years and older are more likely to be hospitalized, be admitted for intensive care, and die. Most older adults living with dementia also have comorbidities that further increase risk for COVID-19, whether they live at home or in the community, reside in long-term care communities, or visit emergency departments and hospitals. Contact tracing guidance from the Centers for Disease Control and Prevention (CDC) identifies cognitive impairment as a special consideration. Beyond memory, dementia often impairs communication, planning, and self-care. Such unique vulnerabilities can affect all aspects of contact tracing.

KNOW THE FACTS

- » Nearly 70% of people living with dementia reside in community settings, and of those individuals, 26% live alone.
- » 30% of older adults with dementia living in the community rely on three or more unpaid caregivers.
- » 95% of people with dementia have one or more additional chronic conditions, and cognitive impairment tends to complicate management and treatment of these other conditions.
- » By age 80, 75% of people with Alzheimer's will be admitted to a long-term care facility.
- » People living with dementia have nearly twice as many hospitalizations annually as those without dementia.

COVID-19 CHALLENGES

Communicating with People Living with Dementia:

- » Persons living with Alzheimer's and other dementias may not understand questions asked by a contact tracer, especially if a caregiver is not present to assist. Dementia may impede accurate recall of recent activities and contacts. Also, effective use of smartphone tracing apps may be problematic.
- » Cognitive and communication impairments may make it difficult for the person living with dementia to directly notify contacts or caregivers.
- » Impaired judgment and reasoning, that can sometimes manifest as paranoia in people living with dementia, may result in suspicion and distrust of contact tracers and hinder cooperation. Cognitive impairment may also increase vulnerability to scams and exploitation from imposter contact tracers.

Planning for Quarantine or Self-Isolation:

- » When quarantine or self-isolation is needed, persons living with dementia may not understand and remember instructions or be able to devise and carry out a plan without support. Special needs related to dementia — including transportation to testing, food or medication access, and management of comorbidities — will need professional expertise.
- » Multiple caregivers may be needed to support self-isolation, quarantine, and (re-)testing. Essential caregivers will need personal protective equipment (PPE) and access to testing themselves.

Supporting Adherence to Plans:

- » Persons living with dementia may have trouble recognizing or describing their symptoms. They may be unable to resolve problems or forget to follow instructions.
- » Because of children, work, compromised immune systems, or other reasons, some caregivers may be unable to directly or consistently assist the person living with dementia during quarantine or self-isolation.
- » Disrupted routines may increase wandering, confusion, disorientation, and delirium for the person living with dementia. Avoidable exposures and injuries may result, and caregivers may experience more strain. Persons with dementia and caregivers may experience acute social isolation.

RESOURCES

Alzheimer's Association	Tips for dementia caregivers	Centers for Disease Control and Prevention	Guidance/resources related to older adults	Association of State and Territorial Health Officials	Contact tracing resources	Alzheimer's Association	Online training for professionals & caregivers
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**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.

PUBLIC HEALTH RESPONSE

Communications and Investigation:

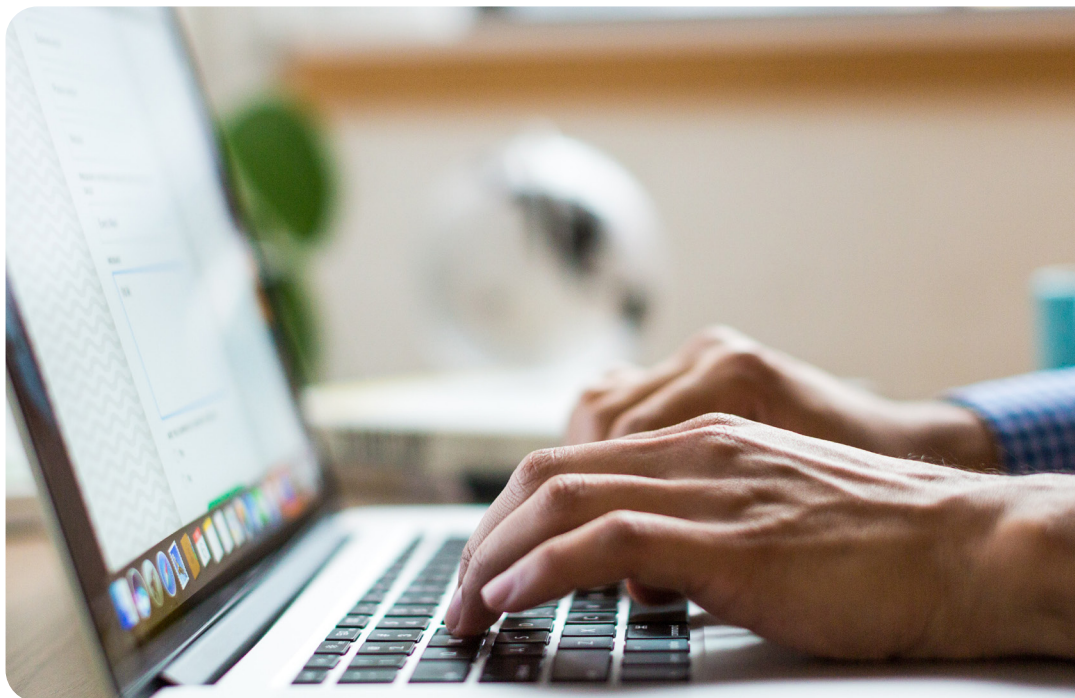
- » Set a standard of involving caregivers when working with a person living with dementia. Engage caregivers in communications, planning, and supporting adherence.
- » Ensure contact tracers are well-trained to identify signs of cognitive impairment, adapt questioning for these individuals, and ask if anyone helps them (e.g., family, friends, and care professionals). The Alzheimer's Association's Communication and Alzheimer's site has tips based on stages of dementia. Training should build awareness of different cultural views of dementia and caregiving.
- » Provide contact tracing teams with the Alzheimer's Association 24/7 Helpline as a source of guidance on communication strategies and information about local programs and services.

Planning for Quarantine or Self-Isolation:

- » Educate contact tracers about involving a variety of caregivers (occasional/regular, unpaid/professional, local/out-of-town) in planning. Tracers should help caregivers to identify what support they themselves need to assist the person living with dementia and also to develop back-up plans, such as for short-term 24-hour care, if caregivers become unable to provide support.
- » Set protocols for contact tracers to notify and coordinate with professional caregivers (such as home health aides).

Adherence to Plans:

- » Provide quarantine and self-isolation support for the unique challenges related to dementia. Case management, instructions or printed prompts, daily phone calls, rides for testing, and "care packages" with food, medications, and supplies are ways to support adherence to plans.
- » Educate professionals who support quarantine and self-isolation to address social isolation as well as dementia-related complications such as disorientation.





HOMES AND COMMUNITY-BASED SETTINGS

Many businesses and community organizations suspended or changed operations because of government emergency orders. Both people living with dementia and their caregivers have been affected by the suspension of adult day services, social events, congregate meals, respite care, peer support groups, community education, physical activity classes, and more. Other services are available through virtual delivery, such as non-urgent primary care, case management, and behavioral health.

KNOW THE FACTS

- » About 70% of people living with dementia reside in community settings, with 26% living alone.
- » 30% of older adults with dementia living in the community rely on 3 or more unpaid caregivers.
- » 95% of people with dementia have one or more additional chronic conditions, and cognitive impairment tends to complicate management and treatment of these other conditions.
- » Nearly one-third of caregivers to persons with dementia provide 20+ hours of unpaid care per week.
- » 6 in 10 people with dementia will wander, which can be dangerous.

COVID-19 CHALLENGES

- » People living with dementia may have difficulty adapting to disrupted routines. Wandering, confusion, and disorientation may increase.
- » Caregivers may receive less or irregular outside assistance, adding to already-high levels of caregiver strain.
- » Risk of exposure to coronavirus increases if hygiene and sanitation practices are inconsistent. People with dementia may not always remember how to thoroughly wash hands, and caregivers may lack the time to sanitize the home. Also, home health and personal care aides may not have personal protective equipment (PPE) to protect themselves and others in the home.
- » Adhering to care plans for other chronic conditions may become problematic. For conditions managed with diet and/or physical activity, persons with dementia may be unable to identify substitutes for scarce special diet materials or canceled physical activity programs. Distant caregivers may be unable to consistently manage medications, monitor health (e.g., blood glucose levels, sleep), and adjust care as needed. Also, cognitive impairment may impede learning how to use telemedicine and other virtual services.
- » Social isolation may be acute among persons and families dealing with dementia, a condition that already tends to isolate people due to stigma, deterioration of communication skills, and many hours spent caregiving.
- » Neglect, abuse, and exploitation may not be detected early if adult protective services (APS) cannot maintain a sufficient workforce of COVID-trained staff.

PUBLIC HEALTH RESPONSE

- » 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. Also, encourage neighbors to offer assistance to neighbors.
- » Distribute the Alzheimer's Association 24/7 Helpline (see callout box) to community members, health care and community service professionals, and first responders to access the latest expert guidance. The Helpline also can direct callers to a wide array of programs and services, including virtual support groups.
- » Coordinate with law enforcement to review, and update as needed, protocol for persons with dementia who are wandering to minimize potential COVID-19 exposures.
- » Offer training and PPE to professional and unpaid caregivers to help reduce potential transmission when providing in-home care and assisting with essential errands.
- » 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.
- » Help community organizations, especially those with ties to underserved populations, to 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.

Alzheimer's Association 24/7 Helpline 800.272.3900

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RESOURCES

Alzheimer's Association

Tips for home-based dementia caregivers

Centers for Disease Control and Prevention

Guidance and resources related to older adults

Centers for Disease Control and Prevention

Portal for health departments

Unless otherwise noted, all facts and statistics come from the 2020 Alzheimer's Disease Facts and Figures report available at alz.org/facts.

alz.org/publichealth-covid19 • cdc.gov/laging/covid19 • Contacts: [Molly French](#) or [John Shean](#), Public Health Department

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EMERGENCY DEPARTMENTS AND HOSPITALS

Many emergency departments (EDs) and hospitals have adopted no-visitor policies to reduce transmission of COVID-19 to patients and frontline health care workers. But caregivers for people living with dementia often are not “visitors;” rather they provide essential medical and emotional support that aids diagnosis and treatment. Specifically, caregivers help reduce fear and anxiety, describe symptoms, assist with communications, avert wandering, detect delirium early, act as advocates, and decipher behaviors related to pain.

KNOW THE FACTS

- » Many hospitalizations among adults aged 65+ with dementia are not for dementia itself, but for a condition often complicated by or resulting from Alzheimer's including diabetes, heart disease, and falls.
- » Among adults aged 65+ with Alzheimer's and other dementias, 23% of hospitalizations were preventable. For African Americans with dementia, 31% of hospitalizations were preventable.¹
- » People living with dementia may not recognize signs of deteriorating health, lack of self-care, or unexpected declines in functioning.
- » Caregivers typically decide if a situation with a person living with dementia can be managed at home. If caregivers are overwhelmed or ill, a manageable event at home may escalate to an ED visit or hospitalization.²
- » Dementia increases risk for delirium and complications associated with delirium.³

Delirium is a state in which a person is confused, disoriented, and not able to think or remember clearly. It usually starts suddenly. It is often temporary and treatable. In contrast, dementia symptoms typically develop slowly and become progressively worse. Many types of dementia are irreversible.

COVID-19 CHALLENGES

Persons living with dementia who are not accompanied by a caregiver may be:

- » Unable to provide essential information (such as name, birthday, health status, and medications), or the information may be inaccurate.
- » More likely to wander or develop delirium without caregiver support.
- » Confused or agitated in new or different environments. They may become unable to describe symptoms or pain, or they may not understand instructions from strangers.
- » Rehospitalized if caregivers are not involved in developing person-centered discharge plans and helping with adherence to treatment plans.

Further, if a caregiver has a sudden, unplanned hospitalization or ED visit, a person living with dementia may be left alone without back-up caregivers being notified. By themselves, individuals with dementia may not recognize they need help or know how to request help. These situations have increased risk for serious injury, illness, or neglect.

PUBLIC HEALTH RESPONSE

- » Avert avoidable ED use by educating families dealing with dementia how to manage health needs during the pandemic. Families will need guidance on how and when to seek emergency care.
- » Promote household safety to reduce falls and other preventable injuries associated with dementia.
- » Educate local hospital systems and Emergency Medical Services (EMS) that caregivers of persons with dementia are essential to quality care and should remain involved during care transitions, including hospital discharge (see resources below).
- » Provide frontline health care workers with tips about how to communicate with persons with dementia and provide person-centered care (see resources below).
- » Ensure hospital systems review and update their emergency plans should a natural or other disaster strike during the COVID-19 pandemic, including how to address the special needs of people with dementia.
- » Establish a community-level protocol between health systems and adult protective services (APS) for situations where persons with dementia are left alone without essential assistance from a caregiver. During admissions, asking “Is there someone at home alone who will need care?” could initiate further inquiry.

RESOURCES

Alzheimer's Association	Dementia behaviors response (Spanish)	Alzheimer's Association	Editable tipsheet for EMS	Centers for Disease Control and Prevention	Allowance for care partner visitation	Hartford Foundation	Resource library for providers, caregivers	Toronto Region Best Practice Initiative	Tip sheet: dementia vs. delirium vs. depression
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Unless otherwise noted, all facts and statistics come from the 2020 Alzheimer's Disease Facts and Figures report available at alz.org/facts.

1. Healthy People 2020. Dementias, Including Alzheimer's Disease.

2. Alzheimer's Association. Reducing Potentially Preventable Hospitalizations for People Living with Alzheimer's and Other Dementias. Policy Brief. 2017.

3. Geriatric Medicine Research Collaborative (2019). Delirium is prevalent in older hospital inpatients and associated with adverse outcomes: results of a prospective multi-centre study on World Delirium Awareness Day. BMC medicine, 17(1), 229. <https://doi.org/10.1186/s12916-019-1458-7>.



LONG-TERM CARE FACILITIES

Long-term care (LTC) facilities, including nursing homes and assisted living facilities, are especially vulnerable to COVID-19 outbreaks due to the concentration of vulnerable older adults — many with some form of cognitive impairment — and the essential need for health care and support workers to commute to and from these facilities. The no-visitor policies currently in place in nursing homes have also been adopted by many assisted living communities and other LTC facilities, so caregivers are unable to provide direct care or emotional support. To help with workforce shortages, some states have relaxed training and licensing requirements for temporary or provisional staff. States also are creating strike or bridge teams for LTC settings with rising or significant outbreaks of COVID-19; members of these teams may have limited knowledge of dementia and person-centered care.

KNOW THE FACTS

- » 48% of people in nursing homes have Alzheimer's or other dementias.
- » Direct-care workers have difficult jobs, and many do not receive the training necessary to provide quality dementia care or have access to personal protective equipment (PPE).
- » In the severe stage of dementia, people often become bed-bound and need round-the-clock care.
- » Some unpaid caregivers continue to help with bathing, dressing, and other activities of daily living for LTC residents living with dementia.
- » Isolation and limited support/ cueing may lead to reduction in eating or drinking. This can create safety concerns, as the affected individual may not recognize food or distinguish between edible and inedible items on a food tray.

COVID-19 CHALLENGES

- » Residents with dementia may have difficulty adhering to social distancing guidelines from other residents. Also, many need hands-on or close-proximity care from staff.
- » Restricted access to LTC facilities may prevent unpaid caregivers, including family and friends, from assisting with direct care and emotional support for persons with dementia. A secondary impact may be increased strain on LTC care providers.
- » Changes in staffing and schedules due to workforce shortages may disrupt the delivery of person-centered care to residents living with dementia. As a result, they may experience more confusion and manifest negative behaviors.
- » Provisional staff and members of strike/bridge teams may have no or little training about dementia and person-centered care.

PUBLIC HEALTH RESPONSE

- » Ensure LTC facilities understand and adhere to CDC and CMS COVID-19 guidance.
- » Improve access to adequate personal protective equipment (PPE), disinfectant, and sanitation supplies for LTC settings.
- » Promote use of the Alzheimer's Association's guidance for LTC professionals, including provisional staff hired due to workforce shortages or members of strike/bridge teams aiding with infection control.
- » Facilitate planning between hospital systems and LTC facilities for evaluation and transfer of potential COVID-19 cases among the LTC population. Include steps for contacting caregivers in these plans.
- » Ensure COVID-19 training for LTC professionals educates them how to cue hand-washing and other hygienic practices, minimize risk for themselves and residents, and monitor co-occurring conditions for persons living with dementia.
- » Ensure LTC facilities review and update their emergency plans for potential natural or other disasters during the COVID-19 pandemic, including how to address the special needs of people with dementia.
- » Ensure LTC facilities maintain communication with appropriate family or other key support individuals, even if done by phone or virtually, during this time of enforced separation.

RESOURCES

Centers for Disease Control and Prevention	Guidance for LTC facility, nursing home management	Centers for Medicare & Medicaid Services	Guidance for LTC facility management	Centers for Disease Control and Prevention	Guidance for retirement communities, independent living	Alzheimer's Association	Tips for professional caregivers
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