



Dementia, Caregiving and Transportation

Dementia describes a set of symptoms associated with the progressive decline of an individual's cognitive function, often becoming severe enough to interfere with everyday activities. The most common form of dementia is Alzheimer's disease, although dementia can be caused by a number of conditions, such as a stroke or traumatic brain injury (Alzheimer's Association, 2015).

While symptoms of dementia can vary greatly, individuals with dementia may experience challenges with one or more of the following:

- **Memory**
- **Communication and language**
- **Ability to focus and pay attention**
- **Reasoning and judgment**
- **Perception and processing of visual information**
- **Physical mobility**

A dementia-friendly community focuses on the inclusion of people with dementia. Dementia-friendly communities educate community members, including service providers, about dementia to help them understand that dementia is more than a diagnosis. Everyone has a role to play by recognizing that people living with dementia are a part of the community and supporting their independence, value and inclusion.

It is important to create networks that allow individuals living with dementia to be supported in their homes and communities as they age. Most family caregivers (78 percent, according to the National Alliance for Caregiving, 2015) either provide or arrange transportation for their loved ones, but they may not always be able to transport them where and when they need, or want, to go. In such situations, it is essential for caregivers to become knowledgeable about the transportation options available in their community and identify the services most suited to their loved one's needs.



Someone in the world develops dementia every 3 seconds. It is estimated that 50 million people were living with dementia worldwide in 2017. (*Alzheimer's Disease International, 2017*)

Transportation Tips for Caregivers

Know your loved one's transportation needs. What are their most important destinations? Can your loved one still travel independently? How could transportation services support you as a caregiver and help your loved one feel less isolated? Determine which locations (such as medical appointments) you would like to provide transportation for your loved ones.

Find out who can help. The local public transit agency, Area Agency on Aging, Aging and Disability Resource Center or Center for Independent Living can help. Ask if a mobility manager or travel counselor is available.

Identify the transportation choices most likely to meet your loved one's needs.

If the person living with dementia is unable to travel independently, ask about transportation programs that offer assistance, such as help getting from the door to the vehicle or someone to stay with the rider at the destination. Find out the cost of a ride and if financial help is available. Other caregivers, friends and family members may also have useful information to share from their own experiences.

No matter what transportation option is chosen, there are a few things you can do to increase your loved one's safety and comfort. Create a travel kit, as described in this brochure. If needed, find out if a personal care attendant or family member can travel with your loved one.

Get to know the drivers and make sure they get to know your loved one.

Drivers often get to know and develop friendly relationships with their passengers. Consider giving the driver your telephone number so you can be contacted if there are concerns.



The Role of Transportation Providers

Transportation drivers and providers who are aware of the challenges that individuals living with dementia and their caregivers face are better able to recognize dementia symptoms and ensure a safe and enjoyable trip for all riders.

Drivers' observations can be critically important for assuring the safety and well-being of all passengers, and can be

important in determining the strengths and supporting the needs of the riders they transport. While a driver is unlikely to know all of their passengers well, they see some individuals every day or every week. Drivers may observe patterns of behavior or detect sudden changes in behavior that are cause for concern and indicate that an individual is in need of extra assistance.

Clues that an individual is confused and may need extra assistance include:

- Difficulty remembering familiar activities, such as forgetting how to pay the bus fare or signal a stop
- Becoming lost in familiar places or forgetting their final destination
- Asking the same question over and over again
- Expressing frustration towards the driver or other passengers
- Finding it difficult to follow directions
- Becoming confused about time, people and places



Dementia-Friendly Tips for Drivers



Always provide good customer service: Something as simple as a friendly face can help a person living with dementia feel at ease if they are experiencing confusion relating to where they are going, how to pay the fare or how to alert you of a stop.

Give clear, concise and simple directions: Individuals with dementia may have difficulty dealing with unexpected or stressful situations, such as navigating a route change, recognizing a change in the bus stop location, or managing a delay in bus arrivals or departures. Provide information clearly and succinctly. You may need to repeat yourself if it is noisy.

Respond to questions: If an individual is confused, they may ask what stop is next or ask for assistance in providing payment, especially on a vehicle that is unfamiliar to them. They may ask several times for clarification and direction. Drivers can be helpful by responding to the questions calmly and helping create a comfortable atmosphere for riders.

Remind passengers of the overall bus route and name a few upcoming stops: If an individual seems confused, ask if the confusion is related to a destination and whether they have an address written on a piece of paper. Direct them to safely take a seat near the front of the bus. Let them know you will alert them when you arrive at their stop.

Be patient: Older adults with dementia may become frustrated because of fear, overstimulation or difficulty in expressing their thoughts. Elevated stress levels resulting from confusion can sometimes be conveyed as agitated behavior. If an individual appears frustrated, it is important for the driver to be patient, understanding and sensitive to their needs. Acknowledge what the passenger is saying by listening, responding politely and repeating critical information.

Let passengers know that you are willing to help them: Maintaining eye contact and using simple language can help mitigate the passenger's frustration. Please keep in mind that their frustration is likely not directed at you but rather at the situation.

Report problems to a supervisor: Most transit agencies and transportation providers have policies and procedures to address overall safety concerns and customer care. The tips provided here are meant to help drivers better serve passengers living with dementia. Find out whether dementia training is available for drivers.

Putting Together a Travel Kit

A travel kit can support safe and comfortable travel for a person living with dementia.

At a minimum, the travel kit should include:



A small bag with an ID tag attached, packed with travel kit items



Identification, preferably a picture ID, with the name, address and telephone number of the traveler



A fare card or the exact fare needed to get to the destination and return home



The traveler's destination, including the full address and telephone number

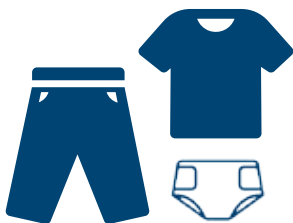


Emergency numbers, including the name and telephone number of the traveler's main caregiver and primary physician



Prescription medication that may need to be taken during the trip

Optional items may include:



Incontinence products (and possibly a change of clothing)



A cell phone (if the traveler is used to having one)



Eyeglasses if the traveler needs them for reading

Other items to include for the traveler's comfort:



A snack and bottle of water, especially for someone who is diabetic



A sweater/jacket/shawl or small blanket



A book or puzzle

The Destination Cards included in this brochure can be detached, photocopied and included in a travel kit.

Destination Telephone:

Destination Telephone:

Destination Telephone:

Destination Address:

Destination Address:

Destination Address:

WHERE I'M GOING

WHERE I'M GOING

WHERE I'M GOING

ABOUT ME

ABOUT ME

ABOUT ME

My Name:

My Name:

My Name:

My Phone Number:

My Phone Number:

My Phone Number:



**EMERGENCY
PHONE NUMBERS**

My Personal Contact:

My Primary Doctor:

My Caregiver:

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PHONE NUMBERS**

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Resources

A number of community agencies and national organizations have a vested interest in supporting dementia awareness and ensuring that people with dementia can live in their homes and communities for as long as possible.

The Alzheimer's Association is a national organization devoted to enhancing care and support for all those affected by Alzheimer's and other dementias. The Alzheimer's Association has a 24/7 Helpline (800-272-3900) and local chapters in communities across the country that run support groups, awareness events, and educational workshops on Alzheimer's disease and dementia. To learn more, visit www.alz.org.

Area Agencies on Aging (AAAs) provide home and community-based services, administer family caregiver support programs and promote healthy aging. To find the AAA in your community, visit www.n4a.org.

Aging and Disability Resource Centers (ADRCs) serve as single points of entry into the system of home and community-based services. To find an ADRC in your community, visit www.adrc-tae.acl.gov.

Dementia Friendly America is a national movement designed to effectively support and serve persons who are living with dementia and their family and friend care partners. To find out more, visit www.dfamerica.org.

Eldercare Locator is the only national information and referral resource to provide support to consumers across the spectrum of issues affecting older Americans. The Locator (800-677-1116) is available Monday – Friday, from 9:00 am until 8:00 pm, Eastern time. Visit eldercarelocator.acl.gov for assistance.

Centers for Independent Living (CILs) provide peer support, travel training and independent living skills training. To find a CIL in your community, visit www.ilru.org.

Title VI Native American Aging Programs support healthy aging and often provide educational and awareness programs for older American Indians, Alaska Natives and Native Hawaiians. To learn whether a Title VI program is in your community, visit www.n4a.org.

Community-Based Adult Day Health Care Centers or other providers of health and social services may also be good resources to consider. Visit www.nadsa.org to learn more.

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National Aging and Disability Transportation Center

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Who We Are

The National Aging and Disability Transportation Center (NADTC) is a program funded by the Federal Transit Administration and administered by Easterseals and the National Association of Area Agencies on Aging (n4a) with guidance from the U.S. Department of Health and Human Services, Administration for Community Living.

The **National Association of Area Agencies on Aging (n4a)** is a 501(c)(3) membership association representing America's national network of 622 Area Agencies on Aging (AAAs) and providing a voice in the nation's capital for the more than 250 Title VI Native American aging programs. The mission of n4a is to build the capacity of its members so they can better help older adults and people with disabilities live with dignity and choices in their homes and communities for as long as possible. www.n4a.org

Easterseals is the leading non-profit provider of services for individuals with autism, developmental disabilities, physical disabilities and other special needs. For nearly 100 years, we have been offering help, hope, and answers to children and adults living with disabilities, and to the families who love them. Through therapy, training, education and support services, Easterseals creates life-changing solutions so that people with disabilities can live, learn, work and play. www.easterseals.com