

2021 Trends Report



Photo: ButterFLi, Los Angeles, California

nadtc

The National Aging and Disability Transportation Center (NADTC)

NADTC is a national program funded by the Federal Transit Administration and administered by Easterseals Inc. and USAging, with guidance from the U.S. Department of Health and Human Services, Administration for Community Living.

Our Mission:

To promote the availability and accessibility of transportation options that meet the needs of older adults, people with disabilities and caregivers.

The mission of NADTC is to:

- **Serve** professionals in the fields of transportation, aging, disability, human services and caregiving.
- **Provide** resources and training through an information and referral hotline, website, as well as both distance and online training.
- **Empower** communities across the country to implement or improve innovative transportation programs at the local level.
- **Support** older adults, people with disabilities of all ages, and their families to help them find the best mobility options in their communities to reach their destination of choice.

For more information about NADTC and the services we provide, please visit www.nadtc.org/

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Public Transportation and Passengers with Alzheimer's or Dementia

Background

There are more than six million people in the United States living with dementia and that number is expected to increase to nearly 13 million by 2050. Currently, 70% of people with a dementia diagnosis are living in the community and 25% are living alone. Alzheimer's disease and other dementias have symptoms that affect a person's ability to drive causing them to rely on other forms of transportation to get where they need to go.

With support, people with Alzheimer's and dementia can remain in their own homes and communities and have fulfilling lives. The availability of accessible transportation is a vital factor to make that happen. Public transit providers should build programs that meet the unique needs of individuals living with dementia to ensure they can stay active in their communities for as long as they are able. Transportation providers should incorporate accommodations for individuals with dementia during their planning process. Education and training, communication techniques, travel training and bus buddy programs can all be impactful in providing accessible transportation to people living with dementia.

What is Alzheimer's and Dementia?

Dementia is a generalized term that describes a group of symptoms that affect a person's ability to remember, think clearly and make decisions. It is caused by damage to brain cells and is not a normal part of aging. Alzheimer's disease is the most common type of dementia, accounting for 60%-80% of all dementia cases.



According to the Alzheimer's Association, symptoms of Alzheimer's disease include: memory loss; difficulty solving problems and completing

familiar tasks; confusion with time or place; problems with communication; decreased judgement; and mood and behavior changes. These symptoms impact an individual's ability to use public transportation, including scheduling the ride, getting to the vehicle, paying for the ride, remembering where they are going and how to get back. In the early stages of the disease, symptoms can be mild, and a person may function independently. They will need more help as symptoms become more severe and additional symptoms appear. Accommodations to enable people living with dementia to use public transportation will be needed as their need for support changes over time.

Impact on Public Transportation

As the number of people living at home in their communities who have Alzheimer's or dementia continues to grow, public transit will likely need to expand to serve an increasing number of people potentially eligible for, and using, ADA complementary paratransit services and demand-response transportation. The Americans with Disabilities Act (ADA) requires transit agencies to modify their existing policies and practices, if reasonable and if needed by the person with a disability, for a person with a disability (including people with Alzheimer's or dementia) to take a trip. One possible modification is to provide door-to-door service. An agency may have a curb-to-curb policy; however, if a person with memory loss needs door-to-door service to successfully take a trip, the transit system must modify their policies to accommodate this need. Transit agencies are not required to provide door-through-door service.

Another example might be an accommodation when collecting fares. If a transit agency's policy does not allow bus drivers to assist passengers with fare payment, but a passenger has difficulty figuring out their fare payment, it is reasonable for the driver to assist that passenger by, for example, showing them how to use their ticket or which bills or coins to use. In addition, the transit system could change the payment method.

In 2017, NADTC worked with Dementia Friendly Prince George's County, MD to educate their local transportation network about transportation for individuals with dementia. Focus groups were held to discuss transportation utilization, needs, and recommendations for improving the system for people with dementia. Some of the findings from these focus groups are provided below.

- Place information about transportation services in a central location and broadly disseminate this information in the community and to support groups and senior centers.
- Provide aides to assist drivers in providing door-to-door services.
- Train transportation workers on how to provide dementia friendly services.
- Develop a backup system to family and friends who provide transportation.
- Reduce trip time in scheduling and have frequent communication updates.
- Increase the availability of more affordable transportation options.

[NADTC Dementia Caregiving Transportation Panel](#)

Strategies for Providing Transportation for Persons with Dementia

Understanding Dementia

As a first step in providing accessible transportation to people with dementia, all program staff, including but not limited to drivers, should have a basic understanding of what dementia is, the symptoms of the disease, and what it is like to live with dementia. The Alzheimer's Association offers free, self-paced education programs that can be accessed online, or in-person workshops can be arranged with staff from the Association. Another educational tool is Dementia Friends, which is a one-hour information session, delivered by volunteer Dementia Champions. The Dementia Friends program teaches participants the [five key messages of dementia](#), what it's like to live with the disease, and how to better communicate with someone who has dementia.⁸ Staff who are aware of the challenges faced by individuals with dementia are better able to ensure these riders have a successful experience.



With the growing number of people with dementia, there is an increasing need for drivers to be educated on how to recognize signs of the disease in their passengers. The NADTC [Dementia, Caregiving and Transportation](#) brochure points out that since drivers sometimes see individuals every day or week, their observations can be critically important in assuring the safety of passengers. Changes in behavior such as forgetting to signal a stop or pay the bus fare, asking the same question over and over, or becoming confused about time, people and places are clues that an individual is confused and may need extra assistance.

Communicating with a Person who has Memory Loss

It is essential for transit personnel to learn how to effectively communicate and assist individuals with memory loss. Transit agencies (bus drivers and dispatchers) must ensure effective communication with people with disabilities which includes people who have Alzheimer's disease or dementia. Steps transit agencies might take include:

- providing simplified versions of printed materials, bus routes and fare structure;
- using plain language in conversation;
- teaching all staff to use person-first language – emphasizing the person and not the disability (i.e., person with Alzheimer's; person with Dementia).

Effective Communication When Assisting Passengers with Alzheimer's and Dementia

- Make information available in various formats including print, visual, and auditory
- Provide simplified versions of materials or use simplified language in conversations
- Allow extra time for communication/ conversations
- Provide additional customer service assistance, when needed, for better understanding
- Identify the needs of the passenger and how best to serve them by asking
- Speak directly to passengers, not companions or personal care attendants
- Smile, listen, and show respect
- Emphasize the person, not the disability, by using person-first language
- Have a pen and paper handy to assist with communication
- Speak clearly with a normal tone and speed unless requested otherwise

Brochure: [NADTC: Assisting Passengers with Alzheimer's and Dementia](#)

Additional tips for effective communication from the Assisting Passengers with Alzheimer's and Dementia brochure can be found in the corresponding text box.

NADTC held Office Hours on October 28, 2021 with Heather Comstock, Dementia Care Educator at the HUB on Smith, who presented on innovative approaches to communicate with individuals with dementia. Comstock explains that to help an individual with dementia use public transportation, there must be an understanding of the cognitive challenges the person faces. Just as physical ramps are provided to people who use wheelchairs, "cognitive ramps" should be utilized when serving individuals with memory impairment. By understanding how to effectively communicate with individuals who live with dementia, transportation providers can provide accessible transportation to them.

Challenges

Collaborating with community partners is important when creating a plan for accommodating the needs of people with dementia. Good partners to bring to the table include the Alzheimer's Association, Aging & Disability Resource Centers, Area Agencies on

Aging, and Centers for Independent Living. Since the implementation of the National Alzheimer's Project Act in 2011, a number of organizations and coalitions across the country are working to make communities more livable for individuals living with dementia and their caregivers. These dementia friendly community initiatives are seeking partnership with local organizations that serve people with dementia (such as transit systems) in order to accomplish their mission.

Dementia Friendly America (DFA) offers support for local coalitions and maintains a list of communities who have joined the Dementia Friendly America movement. According to DFA,

one of the key goals for creating dementia friendly communities is to improve the physical environment in public places and systems, including transportation. A partnership between transportation providers and a local dementia friendly coalition can help achieve this goal. Not only can the coalition share insights on the specific challenges someone with dementia faces when utilizing transportation systems, they can also provide dementia training to staff and volunteers who provide the transportation.

People with dementia are at particular risk for being isolated, making accessible transportation of utmost importance. When people are isolated and lonely, their physical and mental health is negatively affected. Researchers warn that social isolation increases the likelihood of mortality by 25%. The Alzheimer's Association stresses the importance of staying socially active as a possible way to delay the onset of



dementia as well as helping individuals with the disease have a higher quality of life.

Recognizing the damage social isolation has on individuals prompted a partnership between the Campaign to End Loneliness and the TransPennine Express, an express train in Great Britain. TransPennine Express designed selected benches at their stations as “chatty benches” to encourage conversation between travelers as they wait for their trains. Building social connections where people gather, including on transit, is important in tackling loneliness.

Travel Training and Bus Buddy Programs

Travel training and bus buddy programs are two methods transit providers use to help new riders learn the skills needed to successfully navigate a transportation system. People who have recently retired from driving may have never used public transportation and might be unsure how to get started. Others might not feel confident in their ability to navigate the system due to memory or other physical or cognitive changes. Offering extra assistance can alleviate these stressors and encourage people with dementia to use available transportation services.

Travel training programs teach new riders the skills necessary to use the transit system such as how to read route maps and schedules, locate bus and train stops, calculate, and pay fares, recognize when the desired stop has been reached and use mobility devices safely on vehicles. Travel Training can be offered by paid employees, volunteers or both and are usually provided free to anyone who needs the training to successfully use the transportation service. Bus buddy

programs go one step further by providing an experienced transit user to ride along with new riders to offer one-one-one assistance during the trip.

Local Examples

Training

Rock County, Wisconsin provides an example of collaboration between two transit systems and their dementia friendly community initiative. Members of the dementia coalition provided training to transit staff and volunteers about the signs and symptoms of dementia, how to approach and interact with an individual with dementia, and how to maintain a dementia friendly environment. After managers, staff and volunteers were trained, the transit systems received a “dementia friendly” certification which lets people with dementia and their caregivers know staff have been trained to accommodate the needs of riders with dementia. New staff are educated by transit management using materials provided by the coalition until they can participate in the coalition’s annual training.

In Oklahoma, Dementia Friendly Tulsa teamed up with the Tulsa International Airport (TUL) to become the first dementia friendly airport in the United States. The effort started by requiring all TUL employees participate in the Dementia Friendly Tulsa (DFTulsa) program. First responder dementia friendly training was provided to airport police officers, and DFTulsa materials were distributed to airport ambassadors and tenants to enhance their awareness of dementia characteristics and ways to interact with passengers. They are also increasing awareness of family-care designated restrooms and their Hidden Disabilities Sunflower Lanyard program. This program, launched in London in 2016, designates a lanyard with sunflowers on a green background to indicate that the wearer has a hidden disability. The lanyard is available to travelers who wish to wear it to discreetly let airport personnel know that they may need additional support, help or a little more time. All these strategies used by the airport could be used by a transit system to enhance the user experience for their customers with dementia.

Travel Training and Bus Buddy



Intercity Transit in Olympia, Washington offers a good example of a Travel Training and Bus Buddy Program. They provide free travel training to anyone who wants to increase their confidence in riding the bus. The program is tailored to meet the specific needs of each rider, teaching them skills such as planning the trip, reading route maps and schedules, making transfers, and ensuring appropriate transit etiquette and safety. Training is provided classroom style or one-on-one while navigating the transit system. A “phase out” method is used in which trainers shadow passengers and follow up with them along the route to track their progress until the rider is comfortable riding alone.

Intercity Transit also offers a Bus Buddy program. Bus Buddies are experienced transit users who ride along with new riders to offer one-on-one, peer assistance, and help them become comfortable using the bus. The Bus Buddy answers questions, shows how to plan a route and make transfers, and helps with online tools. Bus Buddies also organize group trips to participate in community events and other activities. Intercity Transit provides six hours of training to Bus Buddy volunteers before matching them with a rider.

Summary

Alzheimer’s disease and dementia affect many individuals, forcing them to stop driving and leaving them at risk of social isolation. Public transit can play a role in helping individuals with dementia to continue to have a high quality of life, avoid social isolation, and maintain as much independence as possible by implementing strategies to accommodate their unique needs. Training staff and volunteers about dementia and how to effectively communicate with people who have dementia is one important step in providing access to transit services. Collaborating with local partners who participate in dementia friendly community initiatives might be the key to accomplishing this goal. Creating travel training and bus buddy programs will also make public transportation more accessible to individuals living with dementia, especially in the early stages of the disease. Providing easy to read materials and clear signage is another step towards accommodating the needs of people with dementia. Just as transit accommodates people with physical disabilities, individuals with dementia should also be provided the tools and accommodations necessary to utilize public transportation.

References

- Alzheimer's Association: Facts and Figures <https://www.alz.org/alzheimers-dementia/facts-figures>
- Alzheimer's Association: 10 Early Signs and Symptoms of Alzheimer's https://www.alz.org/alzheimers-dementia/10_signs
- Federal Transit Administration: U.S. DOT Announces Reasonable Modification Rule to Improve Access to Public Transportation for Individuals with Disabilities <https://www.transit.dot.gov/about/news/us-dot-announces-reasonable-modification-rule-improve-access-public-transportation>
- Campaign to End Loneliness: Risk to Health <https://www.campaigntoendloneliness.org/threat-to-health/>
- Alzheimer's Association: Stay Mentally and Socially Active https://www.alz.org/help-support/brain_health/stay_mentally_and_socially_active
- Transpennine Express: Our Partnership with The Campaign to End Loneliness <https://www.tpexpress.co.uk/explore-the-north-and-scotland/our-partnership-with-campaign-to-end-loneliness>
- Alzheimer's Association: Educational Programs and Dementia Care Resources <https://www.alz.org/help-support/resources/care-education-resources>
- Dementia Friends USA <https://dementiafriendsusa.org/>
- NADTC: Dementia, Caregiving and Transportation brochure https://www.nadtc.org/wp-content/uploads/Dementia_Caregiving_and_Transportation.pdf
- NADTC: Office Hours: Innovative Approaches to Communicate with Individuals with Dementia <https://www.nadtc.org/event/office-hours-innovative-approaches-to-communicate-with-individuals-with-dementia/>
- National Plans to Address Alzheimer's Disease - <https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-documents/napa-national-plans>
- Dementia Friendly America <https://www.dfamerica.org/>
- NADTC: Two Wisconsin Transit Systems receive Dementia Friendly Designation <https://www.nadtc.org/news/blog/april-2016-news-from-nadtc/>
- Aviation Pros: Tulsa International Airport Set to be the First U.S. Dementia-Friendly Airport <https://www.aviationpros.com/airports/press-release/21213915/tulsa-international-airport-tulsa-international-airport-set-to-be-the-first-us-dementiafriendly-airport>
- Hidden Disabilities <https://hiddendisabilitiesstore.com/>
- Travel Training, Intercity Transit - <https://www.intercitytransit.com/how-to-ride/travel-training>
- Bus Buddy program, Intercity Transit - <https://www.intercitytransit.com/how-to-ride/bus-buddies>

Resources

Alzheimer's Association <https://www.alz.org/>

Dementia, Caregiving and Transportation Toolkit (NADTC) <https://www.nadtc.org/wp-content/uploads/Dementia-Caregiving-and-Transp-Toolkit- FINAL.pdf>

Before You Give Up the Keys (NADTC) https://www.nadtc.org/wp-content/uploads/GivingUpTheKeys_Final_508_AcrobatXI-1.pdf

Administration for Community Living: Aging & Disability Resource Centers

<https://acl.gov/programs/aging-and-disability-networks/aging-and-disability-resource-centers>

Eldercare Locator: Area Agencies on Aging

https://eldercare.acl.gov/Public/About/Aging_Network/AAA.aspx

ILRU: Centers for Independent Living <https://www.ilru.org/projects/cil-net/cil-center-and-association-directory>

Alzheimer's Society United Against Dementia (from England) – Dementia-friendly bus transport

- <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/bus-services>

RTAP Best Practices for travel training - <https://www.nationalrtap.org/News/Best-Practices-Spotlight/Archive-Travel-Training>

U.S Department of Health and Human Services and the National Institutes of Health:

Alzheimer's.gov <https://www.alzheimers.gov/>



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