



NVTC Fact Sheet 2015

- **Challenge of Dementia**
Introduces dementia as an illness that affects many
- **Dementia & Transit**
Describes the general affects of dementia on driving and using transit options
- **Dementia & Driving**
Discusses how dementia impacts on driving
- **Dementia & Options**
Discusses how dementia impacts on transit options and creates challenges to transit providers
- **Transit Challenges**
Relates warning signs to transportation impact
- **Friendliness Calculator**
Offers a method of calculating dementia friendliness of options

(This fact sheet was modified from a 2008 Beverly Foundation publication)

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nationalvolunteertransportationcenter.org/](http://nationalvolunteertransportationcenter.org/)

Volunteer Transportation & Dementia

The Challenge of Dementia

Dementia is the progressive decline in cognitive function due to damage or disease in the brain beyond what might be expected from normal aging. It is a non-specific illness which can affect cognition including memory, attention, language, and problem solving. Higher mental functions (e.g. memory) are affected first followed by disorientation in time (e.g. day, month, year), in place (e.g. locations of home or travel), and in self-identity (e.g. name).

10 Warning Signs of Dementia¹

- Memory loss
- Difficulty performing familiar tasks
- Problems with language
- Disorientation to time and place
- Poor or decreased judgment
- Problems with abstract thinking
- Misplacing things
- Changes in mood or behavior
- Changes in personality
- Loss of initiative

Dementia and Transportation

Dementia's affect on cognitive functioning can have a negative impact on personal travel. As it progresses, it eventually affects the ability to drive because diminished functioning in judgment, multi-tasking, reaction times, and spatial skills make it difficult to physically drive and navigate a vehicle. And, when they can no longer drive, people with dementia can find it difficult to access travel options that might be available from family members, friends, and transportation services in the community.

Thus, public policy strategies and community action are needed that not only identify at-risk drivers but also assure that the cessation of driving does not mean the cessation of quality of life.

¹ www.alz.org/alzheimers_disease_symptoms_of_alzheimers.asp

Stages of Dementia Dementia goes beyond minor forgetfulness and is heralded by decreasing ability to remember recent events and to concentrate for periods of time. Developed by experts, the “staging” of Alzheimer’s disease patterns provides a useful frame of reference for how *progressive* dementia can unfold over a period of time. The accompanying illustration provides a summary of the common symptom progression patterns that occur in many individuals with Alzheimer’s disease. Such symptoms can vary in their impact. For example, people with Alzheimer’s die an average of four to six years after diagnosis, but the duration of the disease can vary from three to twenty years.²

Stages of Alzheimer’s*

- Stage 1: no impairment**
- Stage 2: very mild decline**
- Stage 3: mild decline**
- Stage 4: moderate decline**
- Stage 5: moderately severe decline**
- Stage 6: severe decline**
- Stage 7: very severe decline**

* B. Reisberg, NYU School of Medicine’s Silberstein Aging and Dementia Research Center

10 Indicators of Driving Decline

1. Easily distracted while driving
2. Other drivers often honk horns
3. Incorrect signaling
4. Scrapes or dents on the car, mailbox or garage
5. Riding the brake
6. Driving at inappropriate speeds
7. Not anticipating potential dangerous situations
8. Bad judgment on making left hand turns
9. Delayed response to unexpected situations
10. Confusing the gas and brake pedals

Dementia & Driving

An individual’s capacity to correctly assess his/her driving abilities decreases with people who have dementia. They may, for example, minimize the complexity of the tasks involved and overestimate their capacities. A variety of indicators of driving decline, ten of which are included in the accompanying illustration, often are noticed by family members and friends, and by driver safety experts. Some people become aware of problems and willingly “give up the keys”. Others feel that driving is their link to independence and continue to drive because they fear the consequences of not driving. Research shows that it is best to reduce driving over time. Strategies for modifying driving behavior

include: driving shorter distances, driving only in familiar areas, limiting driving to daytime, avoidance of difficult left-hand turns, and avoidance of driving in bad weather.³

Dementia & Transit Options

driving is no longer an option. However, when a person with dementia stops driving, it is usually up to the family to find ways to provide the necessary transportation. The accompanying illustration summarizes transportation alternatives that may be available in a community. The ability of a person with dementia to access these options will vary greatly. For example, the person may have difficulty scheduling rides, remembering appointments, handling money, or staying alone in the vehicle or at the destination. Additionally, confusion regarding the destination, communicating with the driver, aggressive behavior, incontinence, and agitation and anxiety may make it difficult to use even the most supportive options.

Experts suggest that it is best to include the person with dementia when planning ahead for the day when driving is no longer an option. However, when a person with dementia stops driving, it is usually up to the family to find ways to provide the necessary transportation. The accompanying illustration summarizes transportation alternatives that may be available in a community. The ability of a person with dementia to access these options will vary greatly. For example, the person may have difficulty scheduling rides, remembering appointments, handling money, or staying alone in the vehicle or at the destination. Additionally, confusion regarding the destination, communicating with the driver, aggressive behavior, incontinence, and agitation and anxiety may make it difficult to use even the most supportive options.

Community Transportation Options

- Family Members:** live near by, caregivers
- Friends/Neighbors:** help with errands, general trips
- Public Transit:** buses, light rail transit, trains/subways
- ADA Paratransit:** for people who have disabilities
- Paratransit:** Dial-A-Ride and other shuttle services
- Private Transit:** taxis, limousines, chauffeur services
- Supplemental Transit (STPs):** paid & volunteer driver programs

² www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

³ www.caregiver.org (Fact sheet on Dementia & Driving)

The accompanying illustration relates the dementia warning signs (identified on page 1) to their impact on the ability of a person with dementia to use any or all of the transportation options (identified on page 2)

Transportation Challenges

Warning Signs and Impact⁴

Warning Sign	Transportation Impact
Memory loss	→ Can't remember ride time/appointment
Difficulty performing tasks	→ Problem making transit arrangements
Problems with language	→ Unable to communicate with driver
Disorientation to time/place	→ Might get lost after transit drop off
Poor or decreased judgment	→ Could have difficulty paying for fares
Abstract thinking	→ May not be able to navigate route changes
Misplacing things	→ Might leave belongings on vehicle
Changes in mood/behavior	→ Could be agitated for no apparent reason
Changes in personality	→ Might become suspicious of driver
Loss of initiative	→ May not want to get in/out of vehicle

Dementia Friendly Transportation

Transportation options can be a lifeline for adults with dementia. Before they stop driving, they and their family members might need to look for other transportation options while they make what is sometimes called “the driving transition”. It is the degree of “dementia friendliness” that will determine whether options will enable them to experience a sense of independence, to get where they need to go, and/or to enjoy an acceptable quality of life.⁴ In 1999, the Beverly Foundation identified the 5 A’s of Senior Friendly Transportation, and in 2008, the Foundation adapted its 5 A’s to reflect criteria for dementia friendliness. These criteria are described in the illustration below.⁵

The 5 A’s of Dementia Friendly Transportation

- Availability:** Transportation services that are available to people with dementia and to their family members... Not only are services offered to them, but they are promoted as supportive transportation and advertised in the community.
- Acceptability:** Transportation services that are acceptable to people with dementia and to their family members... Their special needs are attended to with respect to mainstreaming them into the transit system.
- Accessibility:** Transportation services that can be accessed by people with dementia... Services are easy to use because they offer supportive assistance and get them where they need to go.
- Adaptability:** Transportation services that can be adapted to the needs of people with dementia... Services accommodate their needs for schedule reminders and help at destinations.
- Affordability:** Transportation services that are affordable for people with dementia and their family members... The potential for low-cost operations can enable programs to offer lost-cost services, and to be financially sustainable.

⁴ N. Silverstein, H. Kerschner, and M-H. Rousseau, “On the Road to Dementia-Friendly Transportation”, Alzheimer’s Association Massachusetts Chapter Newsletter, Vol. 26, no.2, Summer 2008.

⁵ As referenced on the Beverly Foundation Fact Sheet Vol.1 (2), the 5 A’s were first identified in a Beverly Foundation focus group study and a subsequent report, Transportation in an Aging Society. Focus Group Project. See www.beverlyfoundation.org (library).

Dementia Friendliness Calculator

Giving up the keys to ensure safety presents challenges. Identifying the “dementia friendliness” of the transportation options available to the person with dementia can be an even greater challenge. To consider the level of dementia friendliness, think of a transit option in your community and check each method that supports people with dementia and/or their family members. Each check equals one point. When you complete your review, add up your score and look at the scoring key to know: (1) where your transit option is on “the road to dementia friendliness”; or (2) how to make transportation dementia friendly.

Availability: The Transportation Service...

- provides transportation to people with dementia
- publicizes service availability to people with dementia
- can be reached by people with dementia
- serves adult day and other dementia support service locations
- does not limit the number of rides for people with dementia

Acceptability: The Transportation Service...

- informs people with dementia about how to use transportation services
- trains drivers to be sensitive to the challenges of people with dementia
- mainstreams people with dementia with other passengers
- accommodates need for demand-response scheduling for people with dementia
- informs family members about availability of dementia assistance

Accessibility: The Transportation Service...

- trains staff in helping new and on-going passengers with dementia
- can provide people with dementia with assistance in identifying destinations
- can provide people with dementia with assistance to and through the door
- can provide people with dementia with assistance at the destination
- trains drivers in methods of helping people with dementia

Adaptability: The Transportation Service...

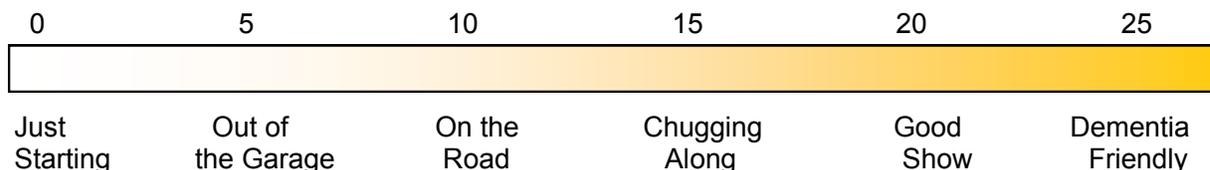
- maintains policy of adapting service to meet needs of people with dementia
- will modify procedures to ease access to services
- can link with other transportation services that are more dementia friendly
- can provide transportation escorts when they are needed
- carries out annual customer survey related to dementia assistance

Affordability: The Transportation Service...

- does not require passengers to handle money
- allows family members/escorts to travel free of charge
- involves volunteer drivers to reduce costs
- accepts donations for transportation services
- secures special funding to provide services to people with dementia

Total _____ (Possible Score = 25)

The Road to Dementia Friendliness



The National Volunteer Transportation Center is an outgrowth of the efforts of each of its founders, especially the Beverly Foundation, to support existing and emerging volunteer transportation programs and services across the country. The Center opened with a database of more than 700 volunteer transportation throughout the 50 states plus the District of Columbia and Puerto Rico. It also includes technical materials related to the planning, organization, and operations of volunteer transportation. Perhaps its most important asset is the wisdom experience, and expertise of its founders who as a group bring the Center a long history of research, direct service delivery, risk management, and insurance, specialized software, and education.