

Dementia & Transportation

Plus Dementia Friendly Calculator

HIGHLIGHTS

Challenge of Dementia

Introduces dementia as an illness that affects many

Dementia and Transit

Describes the general effects of dementia on driving and using transit options

Dementia and Driving

Discusses how dementia impacts driving

Dementia and Options

Discusses how dementia impacts transit options and creates challenges to transit providers

Transportation Challenges

Relates warning signs to transportation impact

Friendliness Calculator

Offers a method of calculating the dementia friendliness of transit options

FOR MORE INFORMATION

Please visit the numerous fact sheets and exercises in addition to the planning, implementation, and evaluation sections of the TurnKey Kit.

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 nonspecific 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 TRANSIT

Dementia's effect on cognitive functioning can have a negative impact on personal travel. As it progresses, it eventually affects the ability to drive because of diminished functioning in judgment, multitasking, reaction times, and spatial skills making it difficult to physically drive and navigate a vehicle. When people with dementia no longer drive, they 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 to 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. This 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. On average, people with Alzheimer’s disease live between three and 11 years after diagnosis, but some survive 20 years or more. The degree of impairment at diagnosis can affect life expectancy.²

DEMENTIA AND 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, friends, and 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 the following: 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.

DEMENTIA AND 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 identifies 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, be confused regarding the destination, and have difficulty communicating with the driver, which makes it difficult to use even the most supportive options.

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

Transportation Options

Family members: live nearby as 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

Volunteer Transit: paid and volunteer driver services

Other Options: low speed vehicles, walking

² www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

TRANSPORTATION CHALLENGES

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),

Warning Signs	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.³ In 2000, the Beverly Foundation identified the 5 A’s of Age-Friendly Transportation, and in 2012, the Foundation adapted its 5 A’s to reflect criteria for dementia friendliness. These criteria are described in the illustration below.⁴

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.

³ 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.

⁴ 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-FRIENDLY TRANSPORTATION CALCULATOR

Identifying the “dementia friendliness” of transportation options available to persons with dementia can be challenging. 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 a transportation option 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 care 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 ongoing 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

0	5	10	15	20	25
Just Starting	Out of the Garage	On the Road	Chugging Along	Getting Close	Passenger Friendly