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

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 Dementia
- 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.

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**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/Neighbours:** 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
**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).

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


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 )**

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<thead>
<tr>
<th>The Road to Dementia Friendliness</th>
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