



## *Dementia, Caregiving and Transportation Toolkit*

NATIONAL AGING AND DISABILITY TRANSPORTATION CENTER

The **Dementia, Caregiving and Transportation** toolkit was adapted from **NADTC's Winter 2017-2018 [online course](#)** which provided an in-depth look at transportation needs and concerns experienced by family caregivers, particularly caregivers of individuals with dementia, and offered guidance on community approaches for connecting transportation and caregiver networks.

NADTC recognizes the vital role of caregivers in providing transportation to older adults and people with disabilities, while acknowledging the challenges of providing ongoing care. It is important to help caregivers and individuals learn about how to access information about community transportation services, the range of transportation options that may be available, and important considerations for matching transportation options and specific care needs, particularly for individuals with dementia.

If older adults or people with disabilities don't have access to public transportation or don't know how to use it safely, they risk a loss of independence, isolation, and increased dependence on family and friends for everyday errands and essential medical or personal appointments. Based on the work showcased in the NADTC course, we believe that transportation challenges faced by caregivers of individuals with dementia can be helped by bringing together transportation and caregiving programs to develop community-specific solutions.

### KEY FACTS

- Nearly 60% of people with dementia live in their own homes and communities.
- 44 million caregivers in the U.S.
- On average, 78% of caregivers provide or arrange transportation.
- Nearly 9 in 10 Asian American caregivers help with transportation, compared to 78% of White caregivers and 72% of African American caregivers.
- Despite need for support, only 23% of caregivers have used transportation services.

*Sources: Dementia Friendly America; AARP & National Alliance for Caregiving: Caregiving in the U.S. 2015*

The written and video materials in Sections 1 and 2 were developed as a comprehensive review of the issues. However, the individual presentations as well as the two sections may be viewed independently.

# SECTION 1: Family Caregiving and Community Transportation: Understanding Shared Interests, Challenges and Opportunities for Collaboration

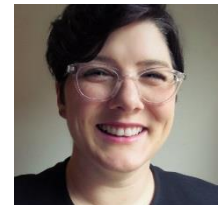
This section covers information about four topics: an overview of family caregiving; the Dementia Friendly America initiative; community transportation services in rural areas serving people with disabilities; and the role of transit and paratransit in meeting the needs of people with dementia and their caregivers.

## Section 1 Materials

### 1 Presentation by C. Grace Whiting, Interim CEO, Chief Operating Officer, National Alliance for Caregiving, Bethesda, MD

[Video Link](#); [PowerPoint Link](#)

*This presentation provides an overview of family caregiving and the work of the National Alliance for Caregiving and explores the relationship between caregiving and transportation.*



### 2 Presentation by Nora Super, Chief, Programs and Services, National Association of Area Agencies on Aging, Washington, DC

[Video Link](#); [PowerPoint Link](#)

*This presentation provides an in depth look at [Dementia Friendly America](#) and [Dementia Friends USA](#) - two initiatives that are raising awareness about dementia and fostering dementia friendly communities across the country.*



### 3 Presentation by Billy Altom, Executive Director, Association of Programs for Rural Independent Living (APRIL), Little Rock, AK

[Video Link](#); [PowerPoint Link](#)

*This presentation focuses on making community connections in order to meet the transportation needs of people with disabilities in rural communities.*



### 4 Presentation by Steve Yaffe, Transit Services Manager, Department of Environmental Services – Transportation Division, Arlington County, VA

[Video Link](#); [PowerPoint Link](#)

*This presentation covers the role of transit and para transit in addressing the mobility needs of people with dementia and their caregivers.*



## SECTION 2: How to Connect Family Caregiver Groups and Community Transportation for Mutual Benefit: Case Example and Step-by-Step Instructions

This section consists of a videotaped meeting on dementia, caregiving and transportation convened by Dementia Friendly Prince George's County, Maryland, with guidance and assistance provided by NADTC.

Dementia Friendly America and Dementia Friends (which includes a chapter in the county) are part of a global movement that focuses on engagement of the entire community and changing the way people think, talk and act about dementia.

NADTC worked with Dementia Friendly Prince George's County (Maryland) to reach out to, and work with, the local transportation network for the purpose of developing training on transportation targeted to local caregivers of individuals with dementia and the broader community. The training included discussion of transportation needs and transportation resources that community members may access to address those needs.

### 1 Setting the Stage: Panel discussion

#### [Video Link](#)

*Video includes:*

- Introduction and Remarks by Gloria Lawlah, Former Maryland Secretary of Aging
- Panel Discussion Participants:
  - Moderator: Virginia Dize, NADTC Co-Director
  - Bonita Spikes, Person living with dementia
  - Gwendolyn Graves, Care partner
  - Sara Fought, Coordinator of Village Rides, Jewish Council for the Aging of Greater Washington
  - D'Andrea Walker, Associate Director of Transportation, Prince George's County
  - Malcom Augustine, Board Member, Washington Metropolitan Area Transit Authority



### 2 Developing a Path: Report outs from focus group discussions

#### [Video Link](#)

*Video includes:*

- Introduction by Dr. Claudia Thorne, State Coordinator, Dementia Friends Maryland
- Group Report Outs
  - Topics covered:
    - *What destinations need transportation support?*



- *What types of transportation are used?*
- *What support needs have to be addressed to ensure safe travel?*
- *What makes transportation “dementia friendly?”*
- *What is the impact on families and caregivers?*

### **3 Connecting Family Caregiver Groups and Community Transportation for Mutual Benefit: Step by step instructions on planning your own transportation and caregiving meeting**

**Presentation by Virginia Dize, Co-Director, [National Aging and Disability Transportation Center, Washington, DC](#)**

[PowerPoint Link](#)

*This presentation offers step-by-step instructions for planning a community event involving caregivers, transportation providers and Dementia Friends groups to develop community transportation solutions for individuals with dementia and their caregivers.*



## **Supplemental Materials**

- Conference Summary: [Addressing the Mobility Needs of Individuals with Dementia and their Care Givers in Prince George's County, Maryland](#)
- NADTC Brochure: [Dementia, Caregiving and Transportation](#)
- [Transportation Questions for Focus Groups for Dementia Caregivers and Persons with Dementia](#)
- [Resources/Supplemental Reading](#)



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. NADTC's mission is to increase accessible transportation options for older adults, people with disabilities and caregivers nationwide.

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