

**LONG  
TERM  
CARE**

**COMMUNITY  
COALITION**

# **SUPPORTING CONSTITUENTS LIVING WITH DEMENTIA**

**Long Term Care Community Coalition**

**[nursinghome411.org](http://nursinghome411.org)**

# The Long Term Care Community Coalition

- ▶ **LTCCC:** Nonprofit, nonpartisan organization dedicated to improving care & quality of life for the elderly & adult disabled in long-term care (LTC).
- ▶ **Our focus:** People who live in nursing homes & assisted living.
- ▶ **What we do:**
  - ▶ Policy analysis and systems advocacy;
  - ▶ Data resources & analyses;
  - ▶ Education of consumers and families, LTC ombudsmen, and other stakeholders;
  - ▶ Home of two local LTC Ombudsman Programs in the Hudson Valley, New York
- ▶ **Website:** [www.nursinghome411.org](http://www.nursinghome411.org)
  - ▶ Range of free resources on nursing home and assisted living care

# Training Goals

- ▶ Introduce the Dementia Care in the Community Toolkit
- ▶ Provide practical ways to connect families with trustworthy information and support
- ▶ Prepare staff and interns to recognize common dementia caregiving challenges
- ▶ Support community outreach and constituent service efforts

# Why This Matters

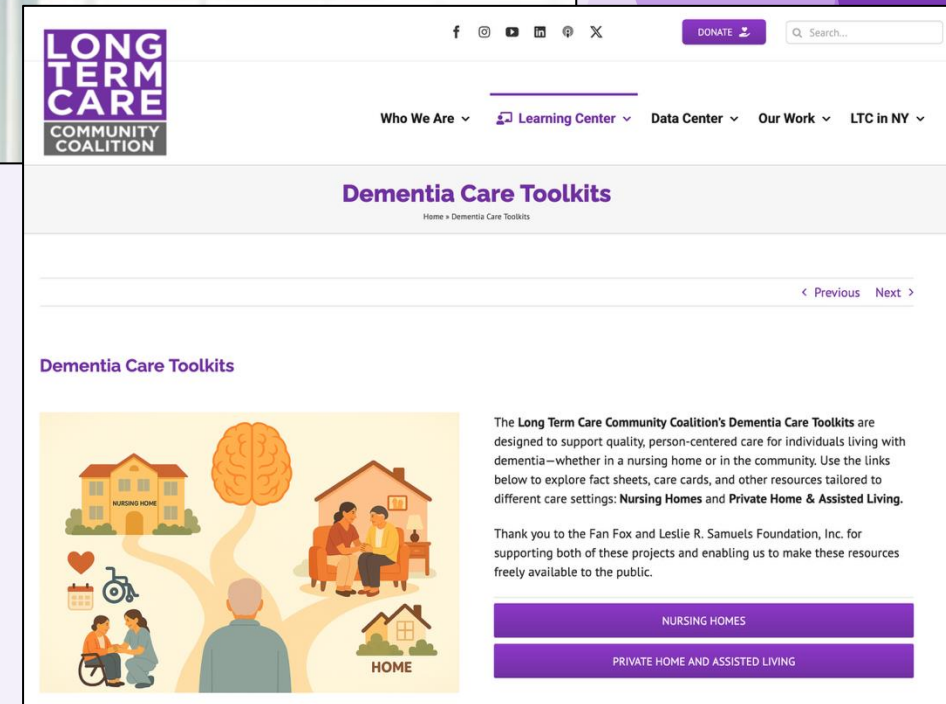
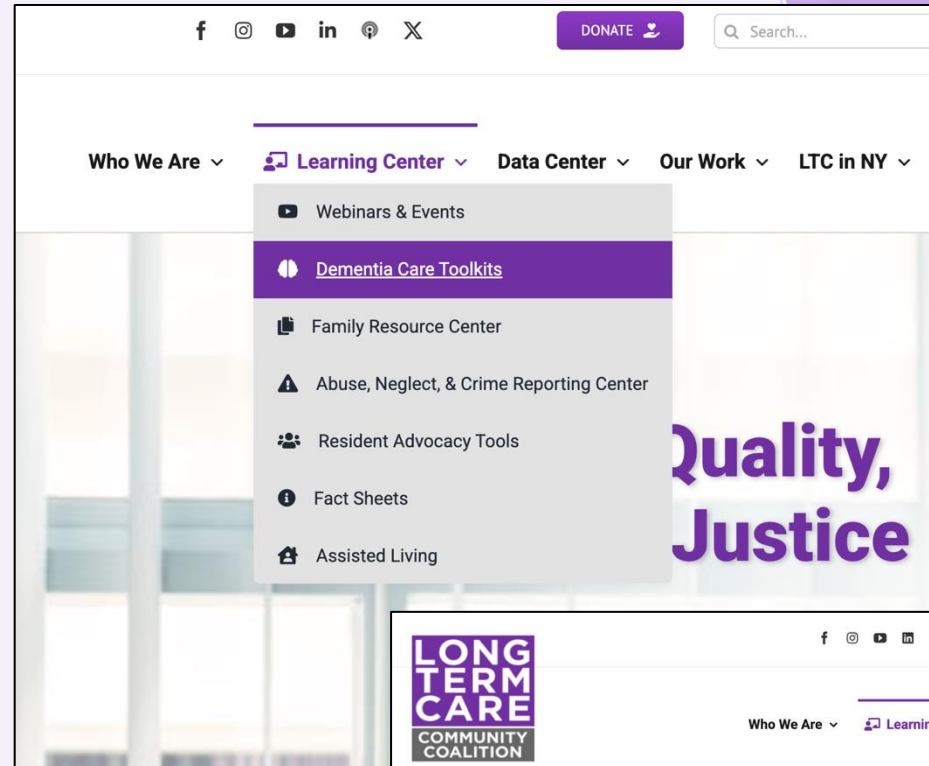
- ▶ Many constituents are balancing work, caregiving, and financial stress while supporting a loved one living with dementia
- ▶ District offices frequently receive calls about home care, assisted living, nursing homes, and caregiver crises
- ▶ Families often need help understanding next steps, available services, and care options
- ▶ Legislative offices can play an important role by connecting families to trusted resources

# Introducing the LTCCC Toolkit

- ▶ Free, online resource available at [NursingHome411.org](https://NursingHome411.org)
- ▶ Available in English and Spanish
- ▶ Designed for both family and professional caregivers
- ▶ Supports people living at home or in assisted living

# Accessing the Toolkit

- ▶ Visit [nursinghome411.org](https://nursinghome411.org)
- ▶ Accessible via phone, tablet, or computer
- ▶ No login or subscription required
- ▶ Easy to share



# What's Inside the Toolkit

- ▶ **Fact Sheets:** provide deeper but user-friendly information on dementia topics
- ▶ **Care Cards:** quick, practical tips for real-time situations
- ▶ **Mini-Modules:** short videos for learning and group discussion
- ▶ **External resources** for deeper learning

# Fact Sheets: What They Provide

- ▶ Clear, plain-language guidance on dementia and caregiving
- ▶ Designed for family members and caregivers
- ▶ Topics include:
  - Care planning
  - Home Safety
  - Pain Assessment Tools
  - Preventing Pressure Ulcers and Urinary Tract Infections
  - Understanding and Responding to Dementia-Related “Behaviors”
  - Palliative and Hospice Care: What Families Need to Know
  - Psychotropic Drugs: Risks, Benefits, and Questions to Ask

## COMMUNITY-BASED DEMENTIA-FRIENDLY INITIATIVES

### FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

Living with dementia can present daily challenges, but communities can make a difference. Dementia-friendly initiatives (DFIs) are local efforts to create safer, more supportive, and more inclusive environments for people living with dementia and those who care for them. By raising awareness, improving access, and promoting dignity, these initiatives can help individuals stay connected, active, and valued in the places they call home. DFIs are transforming the way we think about dementia care—by focusing on dignity, inclusion, and support.

This fact sheet explains how dementia-friendly initiatives and other community supports can improve quality of life, reduce stress, and promote dignity and connection. For more resources, please visit our website, <https://nursinghome411.org/dementia-care-in-the-community>.

### Why Dementia-Friendly Initiatives Matter

Dementia-friendly initiatives (DFIs) offer real benefits for individuals living with dementia and those who support them. Communities that adopt DFI principles often see:

- **Reduced Hospital Visits and Delayed Institutionalization:** Individuals in DFI communities often stay in their homes or assisted living settings longer and avoid unnecessary hospital visits.
- **Enhanced Quality of Life:** DFIs contribute to improved physical health, social interaction, and overall well-being.
- **Reduced Caregiver Stress:** By offering social support and resources, DFIs can help ease the emotional and physical demands of caregiving.

### Key Elements of Dementia-Friendly Initiatives

- **Awareness and Education:** DFIs often include community training and education programs to increase understanding of dementia, enabling communities to recognize symptoms, respond supportively, and reduce stigma.
- **Supportive Environments:** DFIs work to create accessible, welcoming public spaces. This includes physical adaptations to make areas dementia-friendly, such as clear signage, safe walking paths, and accessible transportation.
- **Community Engagement and Social Inclusion:** DFIs foster social programs to reduce isolation for people with dementia and to support meaningful community involvement. Programs like [memory cafés](#), [adult day centers](#), and social groups provide safe spaces for socializing.
- **Caregiver Resources and Support:** DFIs offer resources to assist caregivers, including support groups, training, and respite services to help manage the emotional and physical demands of caregiving.

### Examples of Dementia-Friendly Models & Resources

- **Dementia-Friendly Communities (DFCs):** These are towns, cities, or organizations that commit to becoming inclusive and supportive for people living with dementia. They may include training for public employees, adapting local businesses, or offering special community events.
  - **Memory Cafes** are a great example. These are social gatherings designed for individuals with memory or cognitive changes and their caregivers, providing a supportive environment to connect, socialize, and engage in fun, interactive activities like music, dance, or arts. [Find a Memory Cafe near you.](#)
- **Dementia Friendly Neighborhoods or Villages:** Some communities are designed specifically for people living with dementia. They provide safe, enclosed areas where individuals can walk freely, connect with others, and live independently as possible.

### Examples of Community Resources

- **Adult day programs** offer structured activities, social engagement, and supervision in a safe environment—giving individuals stimulation and caregivers valuable respite.
- **Area Agencies on Aging (AAAs)** connect families to local services such as transportation, meal delivery, home modifications, caregiver support groups, and care coordination.
- **In-home support services**, including personal care aides and skilled nursing, allow individuals to remain safely in their homes while receiving necessary assistance.
- **Memory cafés and dementia-friendly community initiatives**, promote inclusion, reduce stigma, and foster social connection.

### Resources

- **Adult Day Centers:** This resource from the Alzheimer's Association provides information on the benefits of day centers, types of services offered, and tips on selecting a center.
- **Federal Resources for People with Alzheimer's Disease and Related Dementias:** [Alzheimers.gov](#) provides information and links to a variety of resources, including "Tips for Living Alone With Early-Stage Dementia" and the Eldercare Locator to get connected to services in your community.
- **Dementia Friendly America (DFA):** DFA is a national initiative launched in 2015 that aims to foster communities across the U.S. that are informed, safe, and respectful for individuals living with dementia and their care partners. See [DFA's Community Toolkit](#).
- **Dementia Friendly Communities Guide:** This comprehensive guide is designed to assist communities in creating environments that support individuals living with dementia and their caregivers. It outlines a step-by-step approach to developing dementia-friendly initiatives, emphasizing the importance of community involvement, awareness, and tailored strategies to meet local needs.

## **CARE PLANNING FOR INDIVIDUALS LIVING WITH DEMENTIA**

### **FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING**

Effective care planning is essential to ensuring that individuals living with dementia receive the support they need to maintain their highest quality of life and well-being. A person-centered approach to care planning identifies an individual's unique needs, preferences, and goals while outlining the services and supports necessary to address them. For those with dementia, this process must consider cognitive, emotional, physical, and social well-being.

This fact sheet outlines strategies for implementing a respected, evidence-based framework to enhance person-centered care, address common challenges, and support the well-being of individuals with dementia and their caregivers. For additional resources and information, visit our website at <https://nursinghome411.org/dementia-care-in-the-community>.

#### **What is Person-Centered Care Planning?**

A **person-centered care plan** focuses on the individual's unique needs, preferences, and values. Understanding "what matters most" to the person living with dementia is the foundation of this care. The goal is to align care practices with their personal priorities—enhancing comfort, reducing stress, and fostering engagement in activities that are meaningful to them.

#### **A Useful Foundation for Person-Centered Care Planning: The 4M Framework**

Current professional standards for dementia care planning emphasize an approach that addresses what are called the "Four Ms": What **matters** to the individual, **medication** usage and management, **mentation** (mental health), and **mobility**.

This **4 M Framework** focuses on aligning healthcare decisions with what matters most to older adults:

1. **What Matters:** Focuses on understanding the individual's goals, preferences, and what is most important to them. This ensures that care plans align with the individual's priorities, improving quality of life.
  - **Example:** If an individual values routine and a quiet environment, the care plan would prioritize creating a consistent daily schedule and a calm, familiar setting.
2. **Medication:** Emphasizes safe prescribing practices, avoiding medications that may cause harm or interfere with the older adult's cognitive function, mobility, or overall well-being.
  - **Example:** An individual with dementia may be on multiple medications for chronic conditions. Regular medication reviews should be done to minimize polypharmacy and adjust medications that may interfere with cognitive function or mobility.

3. **Mentation (Mental Health):** Supporting cognitive and emotional well-being by preventing, identifying, and managing common conditions in older adults, such as dementia, delirium, and depression.
  - **Example:** If the individual enjoys music, incorporating music therapy sessions that reflect their taste can help stimulate cognitive engagement and emotional well-being.
4. **Mobility:** Encourages maintaining or improving physical function by promoting regular movement, which helps prevent falls, increase independence, and improve overall health.
  - **Example:** If an individual values their independence, the care plan may include daily walks or exercises that promote strength and balance, tailored to their mobility level.

#### **Common Challenges in Implementing Person-Centered Plans:**

Implementing person-centered plans can present challenges for individuals living with dementia, their families, and care providers. These challenges include insufficient meaningful activities tailored to individual needs, a lack of empowerment and support for care staff, limited opportunities to build strong relationships with caregivers, a shortage of tools to track care quality, and the emotional, physical, and financial burdens placed on unpaid family caregivers.

#### **Tips for Addressing These Challenges:**

1. **Advocate for meaningful activities.** Individuals, their families, and care providers can work together to ensure that engaging and personalized activities are incorporated into daily routines, based on the individual's interests and needs.
2. **Empower care staff.** Good training and supports, including opportunities to get to know the individual and become familiar with their unique preferences, needs, and abilities, can result in a better experience for the individual as well as their caregivers.
3. **Families can collaborate with providers** to ensure that reliable tools are used to assess and track care quality, identify practices that are – or are not – working, and make changes as necessary to meet the needs of the individual with dementia as they evolve.
4. **Families are encouraged to seek support for themselves** by utilizing respite services, joining caregiver support groups, and exploring financial assistance or counseling options to ease the emotional, physical, and financial toll caregiving can take.

# LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

## UNDERSTANDING AND RESPONDING TO DEMENTIA-RELATED “BEHAVIORS”

### FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

When an individual living with dementia shows signs of upset, distress, or other behavioral changes, it can be difficult to know how to respond. These changes, commonly referred to as Behavioral and Psychological Symptoms of Dementia (BPSD), are common. While these symptoms can be distressing, they often have underlying causes and can usually be addressed without medication.

This fact sheet provides practical steps and gentle, effective strategies to help caregivers, families, and community-based care providers respond to these behaviors with compassion, patience, and understanding. For more resources, please visit our website, <https://nursinghome411.org/dementia-care-in-the-community>.

### What are Behavioral & Psychological Symptoms of Dementia (BPSD)?

People living with dementia often experience changes in mood and behavior. These behaviors are not “just part of dementia” and can often be reduced by understanding and responding to the person’s needs. They may include:

- Aggression or agitation
- Hallucinations or delusions
- Anxiety, depression, or apathy
- Restlessness, pacing, or wandering
- Verbal outbursts or resistance to care

#### The Most Important Thing to Remember:

Behavior is  
communication.  
Behavior is *not* a disease.

### Key Points to Know

- **Medications are rarely the first or best option.** Antipsychotic drugs should only be considered a risk when a person is at immediate risk of harming themselves or others. Even then, they should be used for a short time and closely monitored.
- **Not all symptoms need medication.** For example, hallucinations that don’t bother or upset the person often do not need to be treated at all.
- **Most behaviors have a cause.** These symptoms may be a sign that the person is in pain, confused, overwhelmed, or having an unmet emotional, social, or physical need.
- **Non-drug approaches usually work better.** These include changes in daily routine, communication style, environment, and meaningful activities. For more information, see [LTCCC’s fact sheet on non-pharmacologic approaches to dementia care](#).

### Steps for Addressing BPSD

- **Obtain details about the person’s behaviors** (nature, frequency, severity and duration) and risks of those behaviors, and discuss potential underlying causes with the care team and (to the extent possible) resident, family or representative;
- **Identify potentially remediable causes** of behaviors (such as medical, medication-related, physical, functional, psychosocial, emotional, environmental);
- **Implement non-pharmacological approaches** to care to understand and address behavior as a form of communication and modify the environment and daily routines to meet the person’s needs;
- **Implement the care plan consistently** and communicate across shifts and among caregivers and with the resident or family/representative (to the extent possible); and
- **Assess the effects of the approaches**, identify benefits and complications in a timely fashion, involve the attending physician and medical director as appropriate, and adjust treatment accordingly.

### Non-Pharmacologic Approaches to Address BPSD

Effective care for someone experiencing BPSD starts with understanding their unique needs, preferences, and routines. Following are some examples of approaches that might be taken, depending on the specific needs of the individual:

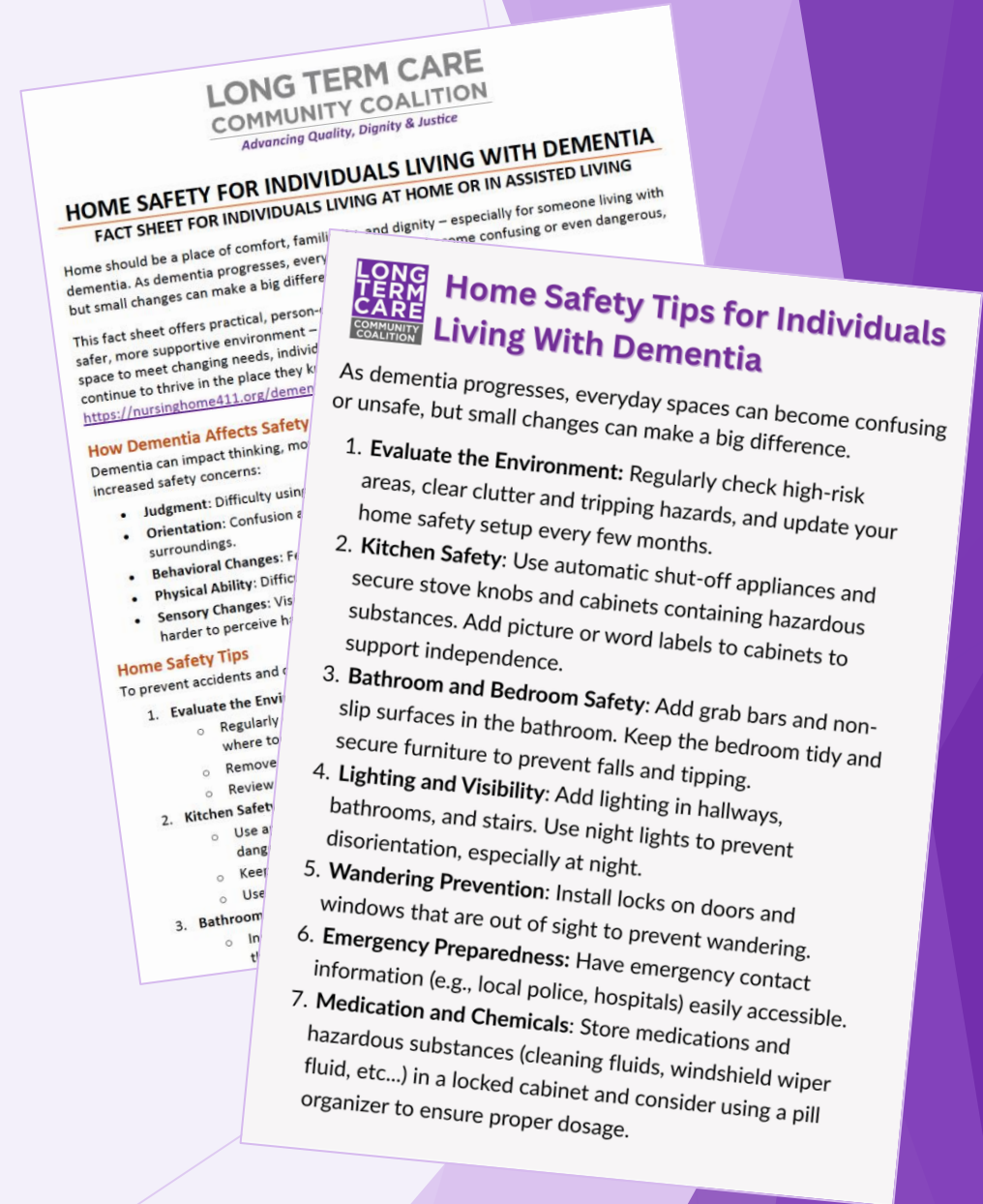
- **Clinical:** Check for any physical discomfort that could be contributing to behavioral changes. Pain, hunger, a need to use the bathroom, or reactions to medications are common causes that can often be resolved with simple care adjustments.
- **Environmental:** Too much noise, bright lights, or unfamiliar surroundings can be overwhelming. Creating a calm, home-like space—whether at home or in assisted living—can reduce confusion and stress.
- **Staff Training:** Make sure caregivers—whether family members or staff—receive training on dementia-friendly care such as:
  - Communication strategies and how to prevent or respond to resistance to care (like during bathing or dressing);
  - Person-centered approaches to care;
  - Understand how dementia affects behavior and how to respond with empathy and patience.
- **Activities:** People living with dementia—whether at home or in assisted living—benefit greatly from being involved in meaningful, engaging activities, regardless of their physical or cognitive abilities. Activities like music and art therapy, light exercise, and time with animals (including real pets or comforting stuffed animals) can help reduce anxiety, improve mood, and promote connection. The key is to choose activities that are tailored to the person’s interests, preferences, and abilities.

# How Legislators Can Use Fact Sheets

- ▶ Provide constituents and families with trusted guidance during emotionally challenging situations
- ▶ Support conversations about behavior changes, safety concerns, and care planning
- ▶ Help constituents and families better understand dementia-related symptoms and communication changes
- ▶ Reinforce recommendations around home care, assisted living, and next steps

# Care Cards: What They Provide

- ▶ Quick, easy-to-read tips for everyday caregiving situations
- ▶ Designed for real-life moments when immediate guidance is needed
- ▶ Mobile-friendly - can be saved or accessed on a phone
- ▶ Focus on simple, actionable strategies



# How Legislators Can Use Care Cards


- ▶ Provide quick, easy-to-share tips for families experiencing stress or crisis situations
- ▶ Offer mobile-friendly resources constituents can save directly to their phones
- ▶ Use during community events, caregiver outreach, and constituent meetings
- ▶ Share practical guidance families can use immediately at home

# Mini-Modules: What They Provide

- ▶ Short, focused educational videos
- ▶ Designed for busy caregivers with limited time
- ▶ Cover key caregiving topics in a simple, approachable way
- ▶ Can be watched individually or shared in group settings

# Fact Sheets

These fact sheets provide practical, easy-to-understand guidance to help individuals and families navigate dementia care in home and assisted living settings, supporting informed decisions and better quality of life.

Fact sheets marked with a  icon include an accompanying micro-learning module. Click on the link to the fact sheet to view the fact sheet and the video.

Care Planning for Individuals Living with Dementia 

Community-Based Dementia-Friendly Initiatives 

Compassionate Dementia Care Tools and Tips for Families and Care Teams



Engaging Activities for Individuals Living with Dementia 

Effective Dementia Care Navigation

Home Safety for Individuals Living with Dementia 

Informed Consent to Dementia Care & Services

Listening Beyond Words: Tips for Dementia Caregivers 

Non-Pharmacologic Approaches to Dementia Care 

Pain Assessment Tools for Individuals Living with Dementia

Pain Management for Individuals Living with Dementia 

Palliative and Hospice Care: What Families Need to Know 

Preventing Pressure Ulcers and Urinary Tract Infections 

Psychotropic Drugs: Risks, Benefits, and Questions to Ask 

Supporting Nutrition and Hydration for Individuals Living with Dementia

The Benefits of Therapy Services for Individuals Living with Dementia

Understanding and Responding to Dementia-Related “Behaviors”

# How Legislators Can Use Mini-Modules

- ▶ Use brief videos to introduce key dementia care concepts to constituents and families and caregivers
- ▶ Support staff education and reinforce person-centered care practices
- ▶ Provide flexible learning tools during support groups, trainings, or outreach efforts
- ▶ Encourage discussion around challenging caregiving situations and available supports

# External Resource Library

- ▶ All of the fact sheets and care cards are based on professional standards and expert research. The Toolkit page provides a curated list of these external resources for those looking to dig deeper.

## External Resources

The external resources include tools, guides, and research from trusted organizations to help families and caregivers deepen their understanding of dementia care and find support for navigating home and assisted living settings.

Care Planning

Dementia Appropriate Activities

Dementia Care Navigation: Tips and Tools for Caregivers

Dementia Care Trainings

Dementia-Friendly Initiatives

Home Safety

Hospice and Palliative Care

Informed Consent

Miscellaneous Research

Non-Pharmacological Approaches

Nutrition and Hydration

Pain Assessment

Pressure Ulcers and Urinary Tract Infections

Psychotropic Drugs

Therapy Services

# Easy Ways Offices Can Use the Toolkit

- ▶ Add the toolkit link to your district office website or resource page
- ▶ Include toolkit materials in follow-up emails related to aging, caregiving, or long-term care
- ▶ Share resources through newsletters, social media, and community outreach
- ▶ Equip staff and interns with trusted information to support constituent conversations
- ▶ Partner with local organizations serving older adults and caregivers

# Suggested Staff or Intern Orientation Agenda

(can be done in-person, via video conference, or hybrid)

- ▶ Overview of dementia caregiving challenges facing constituents
- ▶ Introduction to the LTCCC toolkit and available resources
- ▶ Review common constituent concerns related to long-term care
- ▶ Watch a short mini-module video together
- ▶ Discuss referral strategies and community outreach opportunities

# Discussion Questions

- ▶ What caregiving concerns do constituents contact your office about most often?
- ▶ What dementia-related situations create the greatest stress for families?
- ▶ How can district offices improve resource-sharing and caregiver outreach?
- ▶ What community partnerships could strengthen support for caregivers?

# Implementation Ideas

- ▶ Add toolkit resources to constituent service materials
- ▶ Highlight caregiver resources during Older Americans Month and caregiver awareness campaigns
- ▶ Share care cards and fact sheets at community events and senior fairs
- ▶ Include dementia resources in district newsletters and websites
- ▶ Use materials to support conversations with local aging and long-term care organizations

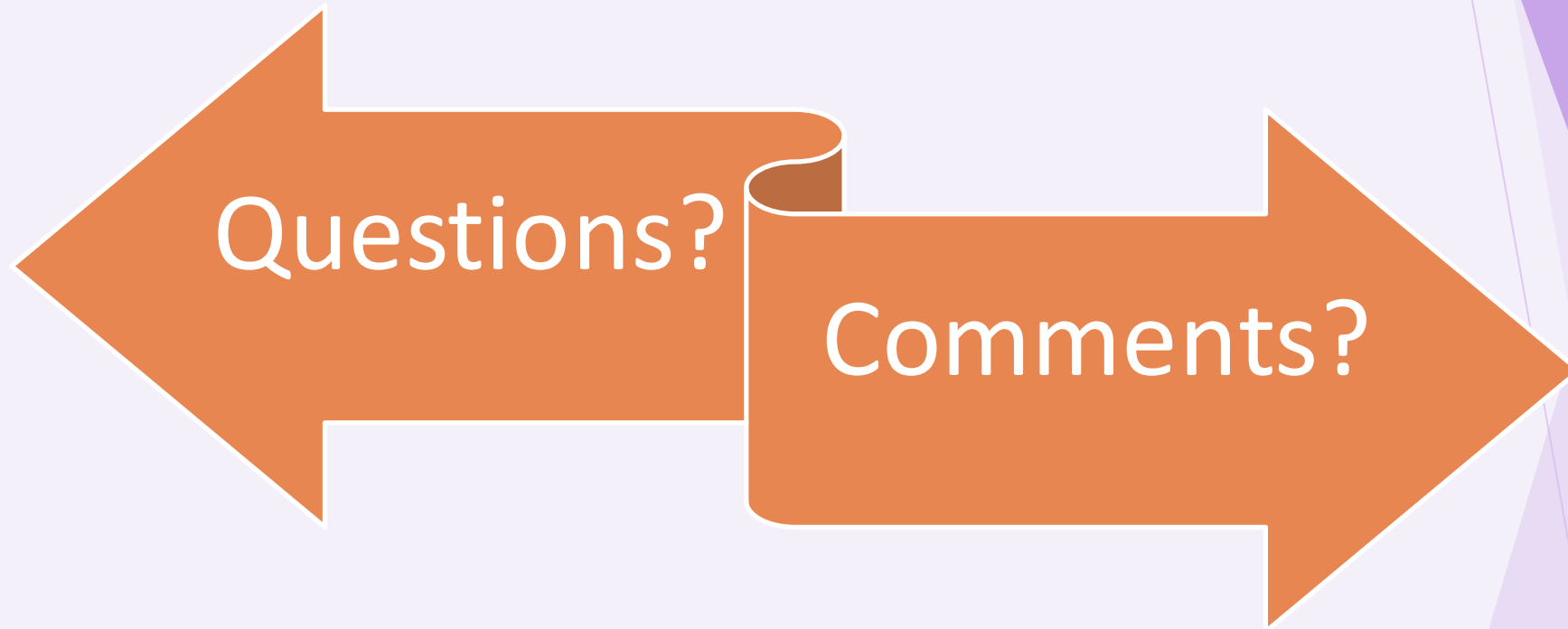
# Key Messages for Legislators & Staff

- ▶ Dementia caregiving affects families across every community
- ▶ Caregivers are often overwhelmed and unsure where to turn
- ▶ Behavior changes are common and often misunderstood
- ▶ Trusted educational resources can reduce stress and improve safety
- ▶ Small acts of support and connection can make a meaningful difference for constituents

# Next Steps

- ▶ Explore the toolkit
  - [Nursinghome411.org/dementia-care-in-the-community](https://nursinghome411.org/dementia-care-in-the-community)
- ▶ Add the toolkit to your office's constituent resource materials
- ▶ Share resources with staff, interns, and community partners
- ▶ Identify opportunities for caregiver outreach
- ▶ Visit [www.nursinghome411.org](http://www.nursinghome411.org) for additional aging and long-term care resources

Thank you!



[nursinghome411.org](http://nursinghome411.org)