

**LONG  
TERM  
CARE**

**COMMUNITY  
COALITION**

# **EQUIPPING PROFESSIONALS WITH DEMENTIA CARE TOOLS**

**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
- ▶ Prepare professionals to share tools with families and caregivers
- ▶ Support person-centered dementia care practices
- ▶ Provide practical strategies for education and outreach

# Why This Matters

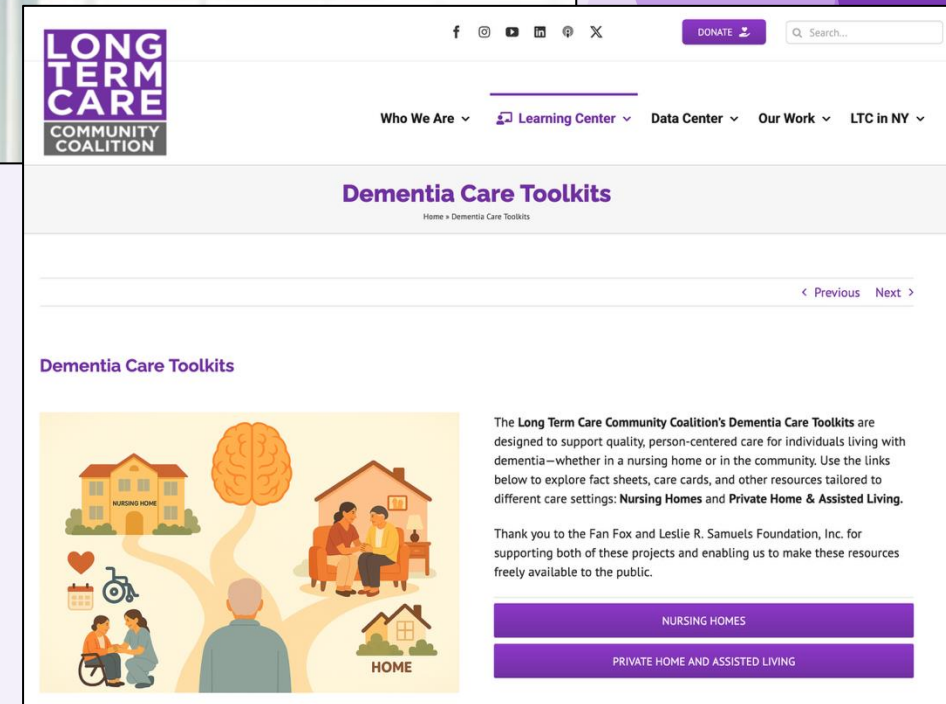
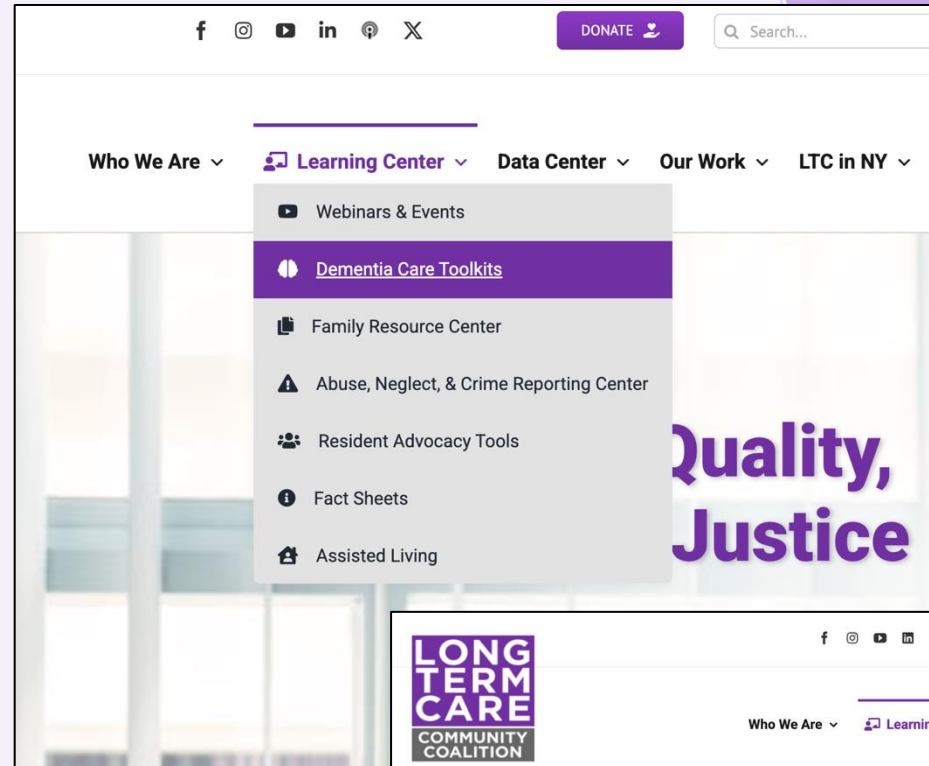
- ▶ Professionals are often the first points of contact for overwhelmed families
- ▶ Families face behavior changes, safety concerns, and caregiver burnout
- ▶ Many caregivers struggle to find trustworthy, practical information
- ▶ Professionals benefit from ready-to-use educational tools

# Introducing the LTCCC Toolkit

- ▶ Free, online resource available at [NursingHome411.org](https://www.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

## **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.

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## EFFECTIVE DEMENTIA CARE NAVIGATION

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

Caring for someone with dementia can be overwhelming. As the condition progresses, families often face challenges in finding the right care, coordinating services, and navigating a complex healthcare system. Dementia care navigation offers guidance and support, helping individuals with dementia and their families access appropriate services, communicate effectively with healthcare providers, and ensure that care is tailored to the individual's unique needs.

This fact sheet describes how dementia care navigation works and how it can help create a more connected, responsive, and person-centered care experience. For more information and resources, please visit <https://nursinghome411.org/dementia-care-in-the-community>.

#### What is Dementia Care Navigation?

Dementia care navigation provides individuals and their families with expert guidance in managing the complexities of dementia care, helping them navigate healthcare systems, coordinate services, and access resources. This support can help ensure timely care, reduce delays, and improve the quality of life for both individuals with dementia and their caregivers. By enhancing communication and reducing confusion, care navigation bridges gaps in fragmented healthcare systems, offering a structured pathway to connect families with needed services. Ultimately, the potential benefits of dementia care navigation are to reduce stress and ensure that individuals with dementia receive personalized, holistic care across all stages of their journey.

#### What is a Dementia Care Navigator?

A dementia care navigator is a trained professional who assists individuals with dementia and their families in navigating the complexities of the healthcare system. They act as a guide, helping to coordinate services, connect families with community resources, and ensure access to timely care. Navigators work closely with healthcare providers to create personalized care plans and assist in making informed decisions, reducing the stress and uncertainty that families often face. By providing ongoing support, they can help ensure that individuals with dementia receive the best possible care at every stage.

#### Benefits of Effective Dementia Care Navigation

Care navigators can serve as a trusted point of contact to:

- Coordinate communication among healthcare providers
- Assist with care planning and decision-making
- Provide education about dementia and disease management
- Support caregivers in their roles
- Connect families with local resources, services, and support networks

Dementia care navigation can help individuals with dementia achieve:

- Improved quality of life
- Fewer emergency room visits
- Better management of daily living needs
- Personalized, compassionate care

Dementia care navigation can help family caregivers by:

- Reducing caregiver stress
- Arranging access to ongoing support
- Assisting with navigating health systems
- Providing guidance in decision-making and planning

#### Resources to Get Started

- Alzheimer's Association's *Dementia Care Navigation Guiding Principles*. <https://www.alz.org/professionals/health-systems-medical-professionals/dementia-care-guiding-principles#Guidelines>
- U. of New Brunswick (Canada) *Implementing a patient navigation program for people with dementia*. <https://www.unb.ca/cric/assets/documents/implementation-resource-toolkit.pdf>

#### **Important Components of Dementia Care Navigation**

*(From the Alzheimer's Association's Guiding Principles)*

1. Be person- and family-centered to ensure collaboration and enhance engagement.
2. Be culturally responsive and address disparities in access to health care and support services.
3. Include well-defined roles and responsibilities for all members of the dementia care navigation team.
4. Address barriers relating to medical, legal, financial, emotional, and other domains facing the person living with dementia and their care partners.
5. Provide coaching, education, and coordination in a manner that is empowering, solution-focused, and strengths-based.
6. Focus on the family unit as defined by the person living with dementia.
7. Ensure that processes and protocols are evidence-based.

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## 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:

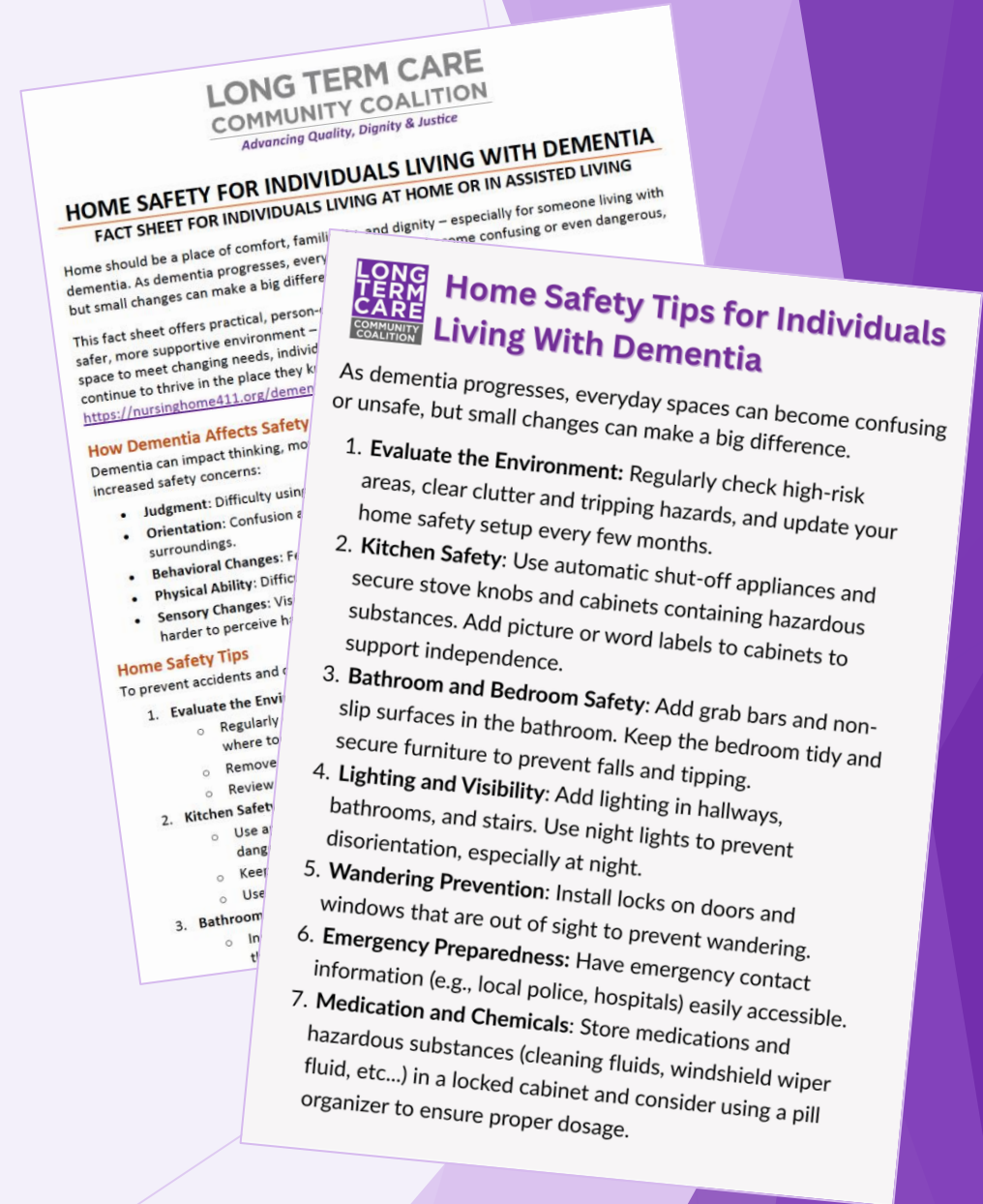
- **Clinical:** Check for any physical discomfort that could be contributing to behavioral changes. Pain, hunger, a need to use the bathroom, or reactions to medications are common causes that can often be resolved with simple care adjustments.
- **Environmental:** Too much noise, bright lights, or unfamiliar 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 Professionals Can Use Fact Sheets

- ▶ Provide families with trusted guidance during emotionally challenging situations
- ▶ Support conversations about behavior changes, safety concerns, and care planning
- ▶ Help 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 Professionals Can Use Care Cards


- ▶ Share quick, practical strategies families can use during moments of stress or crisis
- ▶ Support caregivers managing agitation, confusion, wandering, or communication difficulties
- ▶ Offer easy-to-access tools families can reference at home or on mobile devices
- ▶ Use during consultations, support groups, or caregiver coaching sessions

# 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 Professionals Can Use Mini-Modules

- ▶ Use brief videos to introduce key dementia care concepts to 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

# How Professionals Can Use the Toolkit

- ▶ Share links or PDFs with families after consultations
- ▶ Use care cards during support groups or education sessions
- ▶ Reinforce recommendations already provided to families
- ▶ Support new staff, volunteers, and community partners

# Sample Training Agenda

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

- ▶ Welcome and introductions
- ▶ Overview of dementia caregiving realities
- ▶ Walkthrough of toolkit resources
- ▶ Show a mini-module video
- ▶ Discussion and implementation ideas

# Conversation Starters

- ▶ “What caregiving challenges do families ask about most often?”
- ▶ “What dementia-related situations are hardest for families to manage?”
- ▶ “How can we better support caregivers in the community?”
- ▶ “What resources would be most helpful to share?”

# Implementation Ideas

- ▶ Incorporate materials into staff orientation
- ▶ Use during caregiver support groups
- ▶ Share through newsletters or resource guides
- ▶ Highlight one care card or fact sheet each month
- ▶ Integrate into wellness and community outreach programs

# Key Messages for Trainers

- ▶ Caregiving challenges are common and often overwhelming
- ▶ Behavior is communication
- ▶ Practical education can reduce stress and crises
- ▶ Professionals do not need all the answers - resources matter
- ▶ Empathy and person-centered care is essential

# Next Steps

- ▶ Explore the toolkit
  - [Nursinghome411.org/dementia-care-in-the-community](https://nursinghome411.org/dementia-care-in-the-community)
- ▶ Identify opportunities to share resources in your organization
- ▶ Use the toolkit to support caregivers and staff
- ▶ Check out other resources available at [www.nursinghome411.org](http://www.nursinghome411.org)

Thank you!



Questions?



Comments?

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