

**LONG
TERM
CARE**

**COMMUNITY
COALITION**

EMPOWERING EMPLOYEES WITH DEMENTIA CARE RESOURCES

Long Term Care Community Coalition

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
 - ▶ Range of free resources on nursing home and assisted living care

Training Goals

- ▶ Understand the impact of dementia caregiving on employees
- ▶ Introduce workplace-friendly dementia resources
- ▶ Facilitate conversations and support sessions
- ▶ Integrate tools into HR, wellness, and ERG programs

Why This Matters

- ▶ Millions of employees are caregivers for someone with dementia
- ▶ Many are balancing full-time work + caregiving responsibilities
- ▶ Often invisible in the workplace
- ▶ Without support, employees may struggle silently

Impact on the Workplace

- ▶ High stress, fatigue, and burnout
- ▶ Frequent interruptions and schedule changes
- ▶ Reduced focus and productivity
- ▶ Workforce attrition

The Employer Opportunity

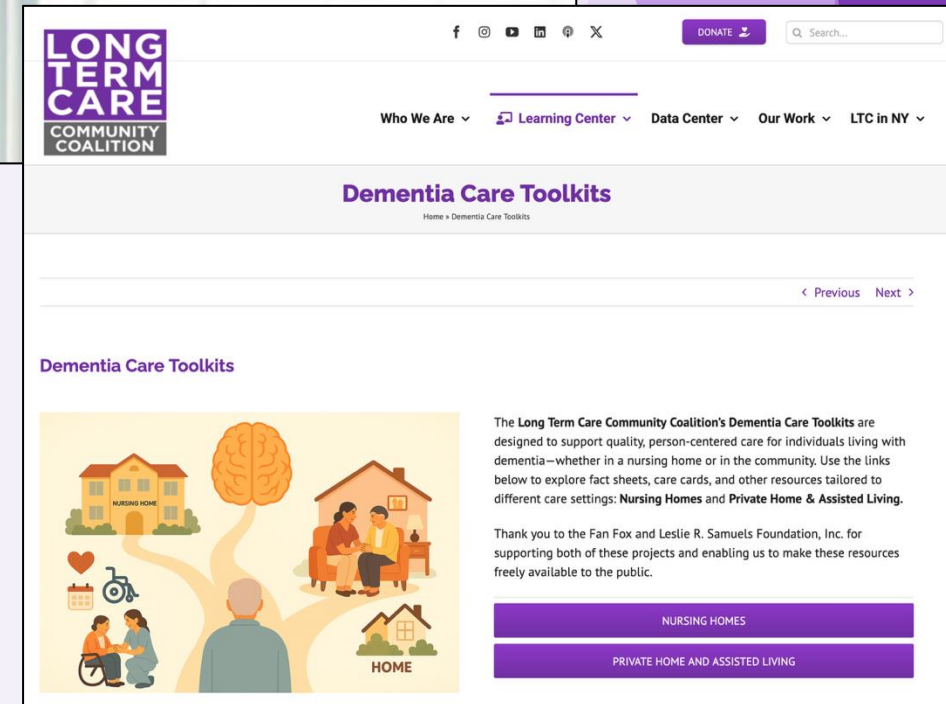
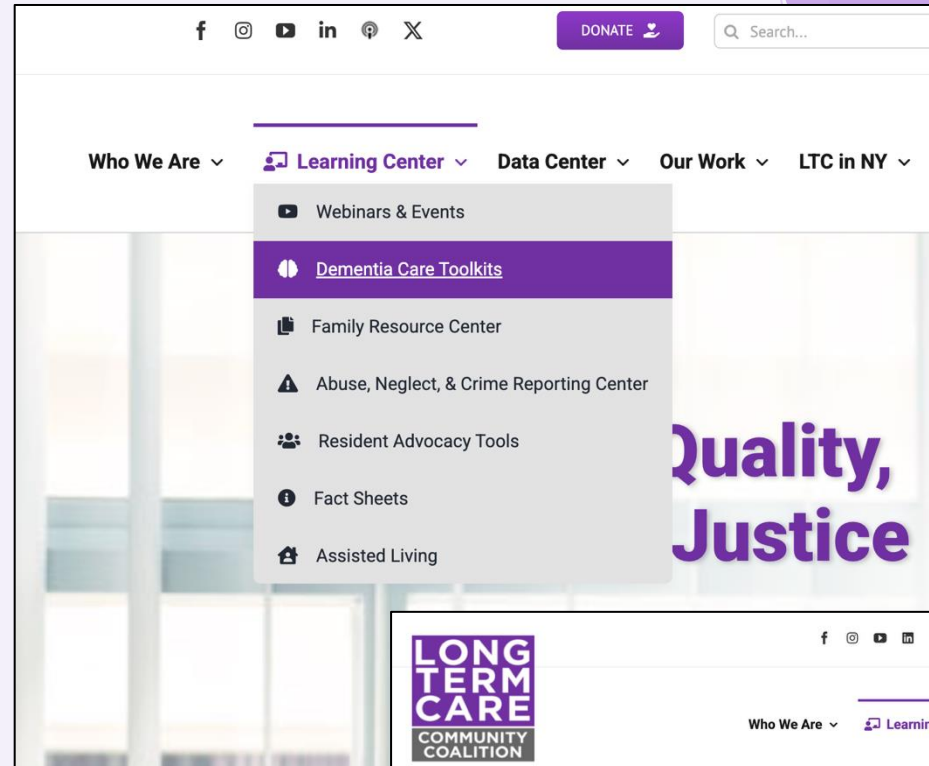
- ▶ Reduce disruptions
- ▶ Strengthen wellness programs
- ▶ Support DEI and family-friendly policies
- ▶ Improve retention

Introducing the LTCCC Toolkit

- ▶ Free, online resource available at NursingHome411.org
- ▶ Designed for caregivers
- ▶ Available in English and Spanish
- ▶ Supports person-centered dementia care

Accessing the Toolkit

- ▶ Visit nursinghome411.org
- ▶ Accessible via phone, tablet, or computer
- ▶ No login or subscription required
- ▶ Easy to share with staff



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 non-professional caregivers
- ▶ Helps employees better understand what their loved one is experiencing
- ▶ 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

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.

**LISTENING BEYOND WORDS:
TIPS FOR DEMENTIA CAREGIVERS**

FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

When a person is living with dementia, behavior often speaks louder than words. What may appear as “difficult” or “bad” behavior – such as agitation, aggression, or withdrawal – is often a response to unmet needs, fear, confusion, or pain. Understanding behavior as a form of communication allows caregivers and family members to respond with greater compassion, patience, and understanding.

This fact sheet offers practical tips to help caregivers and family members understand behaviors and communicate in ways that are respectful, compassionate, and effective. For more resources, please visit our website, <https://nursinghome411.org/dementia-care-in-the-community>.

Dementia is a Disability—Not a Choice

It is crucial to keep in mind that behaviors linked to dementia are not intentional or purposefully defiant. These behaviors are signals of discomfort, confusion, anxiety, or pain. Some common behavioral cues include:

- **Restlessness** = Discomfort, boredom, or pain.
- **Agitation** = Environmental change or confusion.
- **Aggression** = Fear, anxiety, or feeling misunderstood.

Remember:
All “behaviors”
are a form of
communication.

Tips for Before You Start Communicating

Before starting a conversation with someone living with dementia, it's important to create the right conditions for connection. A calm, supportive environment helps reduce confusion and increases the chances of a positive, meaningful interaction.

- **Create a calm environment:**
 - Ensure a quiet space with good lighting.
 - Minimize distractions (e.g., turn off TV or radio).
 - Meet basic needs first (e.g., hunger, thirst, bathroom, pain relief).
- **Plan enough time:**
 - Avoid rushing: Choose a time of day when the person is most alert.
- **Consider language needs:**
 - If the person speaks a different language or uses sign language, involve family members or interpreters if needed.
- **Get their full attention:**
 - Approach the person gently, make eye contact, say their name.

Tips for Talking with Someone Living with Dementia

- **Use simple, clear language:**
 - Keep sentences short and simple.
 - Avoid complex questions or instructions.
- **Be respectful:**
 - Avoid speaking down to the person as if they are a child.
 - Be patient and keep conversations conversational, not interrogative.
- **Include them in conversations:**
 - Don't talk as if the person is not present. Including them helps maintain their sense of identity.
- **Speak calmly and clearly:**
 - Avoid raising your voice or speaking sharply.

When Communications Becomes Difficult:

- **Rephrase, don't repeat:**
 - If the person doesn't understand, try saying it differently. Break down information into manageable pieces.
- **Use humor:**
 - Laugh together about misunderstandings to ease tension, but ensure the person feels respected.
- **Stay calm and positive:**
 - It's important to remain patient and stay calm, even when communication is difficult.
 - A positive and reassuring approach can help the person feel more comfortable.
- **Focus on the person's strengths:**
 - Instead of focusing on what the person with dementia can no longer do, focus on their abilities and interests. This helps foster a sense of dignity.
- **Use reminders:**
 - If needed, use prompts like photos or notes to help the person remember key information, people, or events.

A Note to Remember

Every person with dementia is different. Some tips may work better than others—be flexible and adjust as needed. With patience, empathy, and understanding, you can foster meaningful communication and connection.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

PAIN ASSESSMENT TOOLS FOR INDIVIDUALS LIVING WITH DEMENTIA

FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

Caring for someone living with dementia can be especially challenging when they have difficulty expressing what they're feeling—particularly when it comes to pain. Because individuals living with dementia may have trouble communicating discomfort, family caregivers and professional healthcare providers must rely on other clues to recognize when something is wrong.

This fact sheet introduces three pain assessment tools that help identify signs of discomfort in individuals who cannot verbalize their pain. Using these tools can support timely, appropriate treatment and improve quality of life. For more information and additional resources, please visit our website, <https://nursinghome411.org/dementia-care-in-the-community>.

Important Note: These tools are meant to be used by trained healthcare professionals.

PAINAD Scale (Pain Assessment in Advanced Dementia)

The **PAINAD** tool is designed to evaluate pain in individuals with advanced dementia who cannot verbally communicate their discomfort. It provides a structured method for evaluating pain using five observable indicators.

Indicators Assessed:

- **Breathing:** Normal, labored, or hyperventilation
- **Vocalization:** Moaning, groaning, or silence
- **Facial Expressions:** Smiling, frowning, or grimacing
- **Body Language:** Relaxed posture, clenched fists, or resistance to movement
- **Consolability:** How easily the patient can be comforted or soothed

How it is Used:

The individual is observed during routine care and scored on each of the above five categories to identify whether they are in pain and an intervention would be beneficial.

For More Information: <https://geriatricacademy.com/painad-scale/>.

PACSLAC (Pain Assessment Checklist for Seniors with Limited Ability to Communicate)

The **PACSLAC** is used to identify pain-related behaviors in people with dementia. It includes a wide range of observable indicators across several categories.

Indicators Assessed:

- **Facial Expressions:** Grimacing, frowning, looking frightened
- **Activity Level:** Restlessness, decreased movement, pacing
- **Body Movements:** Guarding, unusual postures
- **Mood and Social Interaction:** Irritability, withdrawal, personality changes
- **Vocalizations:** Moaning, groaning, crying, asking for help
- **Physiological Data:** Increased heart rate, sweating, flushed face

How it is Used:

The individual is observed over a short period, typically during care or activity, by a healthcare professional. Using a 60-item checklist, the observer marks behaviors as present or absent; higher total scores indicate greater pain intensity.

For More Information: <https://pubmed.ncbi.nlm.nih.gov/19098945/>.

ePAT (Electronic Pain Assessment Tool)

The **ePAT** is a mobile app designed for use by trained caregivers or clinicians to assess pain in individuals who are non-verbal. It does this by combining facial recognition technology with behavioral and physiological indicators.

Indicators Assessed:

- **Domain 1: The Face**
 - Cheek raising, tightened eyelids, wrinkled nose, raised upper lip, lip pulling, mouth stretching, parted lips, closed eyes
- **Domain 2: The Voice**
 - Pain-related sounds (e.g., ouch, ah, mm), crying, shouting, howling, sighing
- **Domain 3: The Movement**
 - Restlessness, unusual limb movement, guarding, freezing
- **Domain 4: The Behavior**
 - Social withdrawal, aggression, fear of touch, confusion, distress
- **Domain 5: The Activity**
 - Resistance to care, changes in sleep or routine, prolonged rest
- **Domain 6: The Body**
 - Sweating, flushed or pale skin, fever, rapid breathing, visible injuries

How it is Used:

The ePAT app is used to record a video of the individual's face in order to analyze facial micro-expressions. Then observations are inputted for the five other domains to generate a total pain score and recommended action.

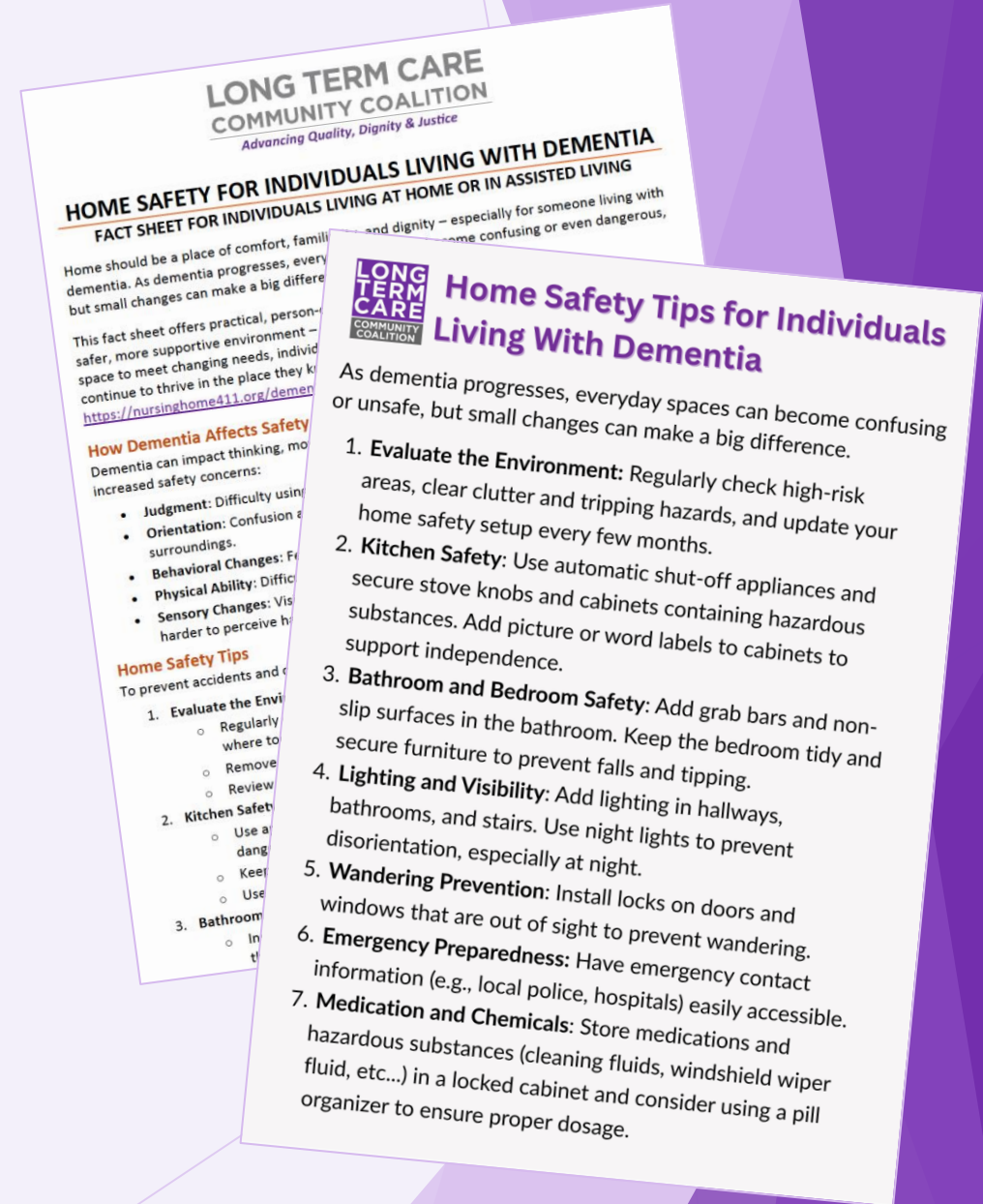
For More Information: <https://journals.sagepub.com/doi/full/10.3233/JAD-170375>.

How Employees Can Use Fact Sheets

- ▶ Learn practical strategies for managing common caregiving challenges
- ▶ Prepare for doctor visits or care planning conversations
- ▶ Better understand changes in behavior and communication
- ▶ Share information with other family members to align care approaches

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 Employees Can Use Care Cards


- ▶ Get quick guidance during challenging moments (e.g., agitation, confusion)
- ▶ Build confidence in responding to difficult situations
- ▶ Keep tips handy on their phone for easy access anytime
- ▶ Share with other family members involved in caregiving

Mini-Modules: What They Provide

- ▶ Short, focused educational videos
- ▶ Designed for busy employees 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 Employees Can Use Mini-Modules

- ▶ Watch short videos when they have time
- ▶ Learn specific skills or strategies for caregiving situations
- ▶ Share videos with family members or support networks
- ▶ Use as a starting point for conversations with others

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

Why Employees Benefit

- ▶ Feel more confident in caregiving situations
- ▶ Reduce crises and emergency situations
- ▶ Improve communication with healthcare providers
- ▶ Better balance caregiving and work responsibilities

Sample Agenda for Session for Employees

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

- ▶ Welcome and self-introductions of participants (if small group)
- ▶ Acknowledge caregiving realities
- ▶ Introduce toolkit
- ▶ Walk through one or two of the resources
- ▶ Show one of the mini-modules
- ▶ Open discussion

Conversation Starters

- ▶ “Does anyone here support a family member or loved one with memory loss?”
- ▶ “What challenges have you faced balancing work and caregiving?”
- ▶ “What support would make a difference?”

Implementation Ideas

- ▶ Add toolkit to intranet
- ▶ Include in HR emails or newsletters
- ▶ Share in employee resource groups or caregiver groups
- ▶ Integrate into employee assistance programs or wellness programs
- ▶ Share a “Care Card of the Month”
- ▶ Highlight during awareness months
- ▶ Offer a lunch & learn

Tips for Reducing Stigma

- ▶ Normalize caregiving conversations
- ▶ Emphasize confidentiality
- ▶ Avoid making assumptions
- ▶ Lead with empathy

Next Steps

- ▶ Explore the toolkit
 - [Nursinghome411.org/dementia-care-in-the-community](https://nursinghome411.org/dementia-care-in-the-community)
- ▶ Share at least one resource this week
- ▶ Plan a conversation or session
- ▶ Additional resources available through LTCCC

Thank you!



Questions?



Comments?

nursinghome411.org