

Dementia Care in the Community

*A FAITH-BASED GUIDE TO COMPASSIONATE
CARE, SUPPORT, AND INCLUSION*














Supporting Individuals, Families, and Congregations Living with Dementia

Developed by: The Long Term Care Community Coalition




NursingHome411.org

Contents

1. Sample Caregiver Support Meeting Agenda
2. Fact Sheet – Compassionate Dementia Care: Tools and Tips for Families and Care Teams *
3. Fact Sheet – Community-Based Dementia-Friendly Initiatives 
4. Fact Sheet – Understanding and Responding to Dementia-Related “Behaviors”
5. Fact Sheet – Communication Tips for Dementia Caregivers *
6. Fact Sheet – Care Planning for Individuals Living with Dementia 
7. Fact Sheet – Informed Consent to Dementia Care & Services *
8. Fact Sheet – Effective Dementia Care Navigation
9. Fact Sheet – Engaging Activities for Individuals Living with Dementia *
10. Fact Sheet – Supporting Nutrition and Hydration for Individuals Living with Dementia *
11. Fact Sheet – The Benefits of Therapy Services for Individuals Living with Dementia *
12. Fact Sheet – Non-Pharmacologic Approaches to Dementia Care 
13. Fact Sheet – Pain Assessment Tools for Individuals Living with Dementia
14. Fact Sheet – Pain Management for Individuals Living with Dementia 
15. Fact Sheet – Home Safety for Individuals Living with Dementia *
16. Fact Sheet – Preventing Pressure Ulcers & Urinary Tract Infections *
17. Fact Sheet – Psychotropic Drugs: Risks, Benefits, and Questions to Ask *
18. Fact Sheet – Palliative & Hospice Care for Individuals Living with Dementia: What Families Need to Know *

Legend

- Fact sheets marked with a  icon include an accompanying micro-learning module. Find them at nursinghome411.org/dementia-care-in-the-community.
- Fact sheets marked with an asterisk (*) include an accompanying Care Card. Find them at nursinghome411.org/dementia-care-in-the-community.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

Sample Caregiver Support Meeting Agenda (30 Minutes)

Welcome & Opening (5 minutes)

- Welcome participants
- Brief introduction
- Set a supportive, confidential tone

Check-In (5 minutes)

- Invite participants to briefly share how they are doing
- Offer an optional guiding question (e.g., “What has been most challenging this week?”)

Learning Component (10 minutes)

- Introduce one LTCCC toolkit resource (fact sheet or mini-module)
- Highlight 2-3 key takeaways
- Keep language simple and practical

Group Discussion (7 minutes)

- Ask open-ended questions:
 - ⇒ What stood out to you?
 - ⇒ Does this reflect your experience?
- Encourage sharing, but allow people to pass

Resource Sharing & Wrap-Up (3 minutes)

- Share relevant care cards or additional toolkit resources
- Encourage participants to explore the toolkit
- Thank participants and invite them back

Facilitator Tips:

- Keep the conversation supportive, not clinical
- Allow silence – people may need time to share
- Avoid giving too much information at once
- Focus on connection as much as education
- Follow up with participants if possible

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

COMPASSIONATE DEMENTIA CARE: TOOLS AND TIPS FOR FAMILIES AND CARE TEAMS

FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

Quality of life and quality of care are deeply connected. Every person – regardless of cognitive or physical challenges – deserves to live with dignity, respect, and as much independence as possible.

This tip sheet shares simple, practical strategies for family caregivers, home health aides, and assisted living staff to help ensure individuals living with dementia receive compassionate, high-quality care. In addition, you'll find information on dementia care training and support programs that can help strengthen your skills, improve care quality, and support your own well-being. For more information and resources, please visit our website, <https://nursinghome411.org/dementia-care-in-the-community>.

Why Person-Centered Care Matters

Dementia affects how a person thinks, communicates, and engages with the world. When caregivers understand and support each person's unique needs, routines, and preferences, it can reduce distress, improve cooperation, and enhance the individual's comfort and dignity. Research also shows that person-centered care improves mood, reduces behavioral challenges, and may even reduce hospitalizations.

Care Practices That Support Quality of Life

Care in the home and assisted living settings should follow key principles that respect and support the individual's needs, preferences, and abilities. Caregivers should aim to:

- ⇒ **Create a safe, familiar, and comforting environment.**
- ⇒ **Engage individuals in meaningful activities** tailored to their interests, history, and current abilities.
- ⇒ **Honor personal routines and preferences**, including cultural and spiritual practices.
- ⇒ **Communicate clearly and calmly**, using visual cues, gentle tone, and simple language.
- ⇒ **Promote independence** by encouraging the person to do as much as they can for themselves, even if it takes more time.
- ⇒ **Ensure consistency in caregiving staff** to reduce anxiety and build trust.
- ⇒ **Involve the individual and their family in care decisions** whenever possible, respecting their voice and choices.

The Value of Training & Support for Caregivers

Caring for someone with dementia can be rewarding, but the right training can make a big difference.

- ⇒ **Caregiver-friendly training programs** offer practical, easy-to-understand tools for communication, managing challenging behaviors, and daily care routines.
- ⇒ **Support services** like respite care, counseling, and caregiver support groups can help reduce stress and prevent burnout.

Dementia Care Training Providers

There are numerous programs available from both for-profit and non-profit providers. Following is a small sample. Please note that inclusion below does not indicate endorsement.

In addition, the Alzheimer's Association has a training and certification program and recognizes a range of programs. For more information, visit

<https://www.alz.org/professionals/professional-providers/dementia-care-training-certification>.

Caregivers As Partners in Care Teams. (<https://carepartners.ucsf.edu/>)

- Caregivers As Partners in Care Teams (CAP-CT) is a national training program from the University of California at San Francisco. It is designed to equip healthcare professionals with the skills and confidence to actively involve family caregivers in patient care. By integrating caregivers into care teams, the program aims to enhance patient outcomes, reduce hospital readmissions, and improve overall satisfaction for both patients and their caregivers.
- Cost: Free

Health Resources and Services Administration (HRSA) Training.

(<https://bh.w.hrsa.gov/alzheimers-dementia-training>)

- The federal Health Resources & Services Administration has a wide variety of dementia training materials and learning modules for both professional and family caregivers.
- Cost: Free

Activated Insights. (<https://activatedinsights.com/training/>)

- Activated Insights Training offers user-friendly online courses for senior living and home-based caregivers to enhance skills, build confidence, and support regulatory compliance.
- Cost: \$125

CARES® Dementia Basics™ Online Training Program. (<https://hcinteractive.com/>)

- CARES® is an award-winning, evidence-based online dementia care training program that teaches the 5-step CARES® Method™ alongside best practices from the Alzheimer's Association.
- Cost: \$199

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

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.

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.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

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

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

INFORMED CONSENT TO DEMENTIA CARE & SERVICES FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

Personal autonomy – the ability to make choices about one’s own life – is important to everyone. A diagnosis of dementia does not diminish a person’s desire to have control over their decisions, especially those related to health care and daily life. In fact, as cognitive abilities change, maintaining a sense of autonomy can become even more essential to a person’s dignity and well-being.

Cognitive impairment can make it more difficult for individuals to fully understand options, express preferences, or make complex decisions. This may lead family members or professionals to step in and make choices on their behalf. While often well-intentioned, this can unintentionally undermine the individual’s rights and preferences.

This fact sheet offers practical guidance on understanding and applying the principles of informed consent in dementia care. For additional tools and resources, visit nursinghome411.org/dementia-care-in-the-community.

What is Informed Consent?

Informed consent is a foundational principle in care. It ensures that individuals understand and agree to the care and services they receive. For people with dementia, this means actively involving them—alongside their families—in conversations about their care. It’s not only respectful but also essential for person-centered, values-based care.

- **Informed** = Providing the information on a plan of care or proposed treatment in a way that the recipient can understand. Information includes the risks and benefits of the proposed treatment as well as the risks and benefits of alternative treatments.
- **Consent** = The individual or their designated surrogate makes the final decision, regardless of whether those decisions align with the care provider's recommendations.

WHAT IS INFORMED CONSENT?

“Informed consent is an ethical concept—that all patients should understand and agree to the potential consequences of their care—that has become codified in the law and in daily practice at every medical institution.”

- [A Practical Guide to Informed Consent](#)

How Does This Align with Professional Standards of Care?

Professional care standards emphasize the importance of informed consent to ensure that individuals' right to make decisions over what care they will or will not receive is honored. This approach involves actively partnering with people living with dementia and their families to help them make well-informed decisions based on the individual's preferences, values, and health goals, promoting autonomy and tailored care outcomes.

Best Practices for Supporting Autonomy

- **Start with Respect:** Assume capacity. Always begin by involving the individual in decisions to the greatest extent possible.

- **Simplify Communication:** Use clear, simple language, visuals, or other tools to help explain choices.
- **Offer Support, Not Substitution:** Instead of making decisions *for* someone, make decisions *with* them whenever possible.
- **Know Their Values:** Understanding what matters most to the individual can guide care that aligns with their goals.
- **Involve Trusted Others:** Family members, friends, and advocates can help bridge communication and support informed choices.
- **Document Preferences:** Advance care planning and documented preferences help ensure care reflects the person's wishes, even if decision-making becomes more difficult.

Legal Documents

Legal documents can play a crucial role in ensuring that the wishes and values of a person with dementia are honored as the disease progresses. They also empower trusted individuals to make decisions on their behalf when the person is no longer able to do so. For a helpful overview of key documents—such as powers of attorney, living wills, and other tools that support future planning—visit the Alzheimer’s Association’s Legal Documents page at <https://www.alz.org/help-support/caregiving/financial-legal-planning/legal-documents#power>.

Tips for Putting Informed Consent into Practice

- **Include the Individual.** Support the person with dementia in participating in care planning. Ask providers to explain options in clear, simple terms.
- **Respect Preferences.** Advocate for care that honors the individual’s values, goals, and dignity. Make sure their voice and priorities are central in all decisions.
- **Be Informed.** Learn about the person’s health conditions, treatments, and care options so you can support informed, values-based choices.
- **Ask Questions.** Speak up! Ask about risks, side effects, alternatives, and long-term outcomes. The more you know, the better you can support informed decisions.
- **Work as a Team.** Promote collaboration among the individual, family members, and care providers. A shared approach leads to more personalized and respectful care.
- **Honor the Right to Choose.** The individual (or their representative if they have designated one) has the final say. **Any decision that directly affects the patient's physical or mental functioning or has more than minimal risk is subject to informed consent.** Even if a provider disregards informed consent protocols, the individual should always feel empowered to reject a proposed treatment or advocate for one not offered.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

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.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

ENGAGING ACTIVITIES FOR INDIVIDUALS LIVING WITH DEMENTIA

FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

Dementia can significantly impact an individual's ability to engage with the world around them. However, activities tailored to the individual's abilities and interests can improve quality of life by providing opportunities for social interaction, physical movement, cognitive stimulation, and emotional expression.

This fact sheet highlights several appropriate and beneficial activities for individuals living with dementia and tips for how to implement them. For additional resources and information, visit our website at <https://nursinghome411.org/dementia-care-in-the-community>.

Music Therapy

What it is: Music therapy uses music as a tool to improve mental, physical, and emotional health. It can take many forms, from singing and listening to live or recorded music, to interactive activities like drumming or using small instruments.

Benefits:

- ⇒ **Emotional Well-being:** Music has the power to evoke memories, reduce anxiety, decrease agitation, and improve mood. It can bring comfort and joy to individuals with dementia, even when verbal communication becomes difficult.
- ⇒ **Cognitive Engagement:** Listening to familiar songs or participating in sing-alongs stimulates memory and cognitive function. Music also helps with attention, focus, and recognition.
- ⇒ **Physical Movement:** Active participation in rhythm-based activities, such as clapping or moving to the beat, can improve coordination and motor skills.
- ⇒ **Social Connection:** Group music activities encourage social interaction, creating a sense of belonging and reducing feelings of isolation.

Tips for Implementation:

- Select music that aligns with participants' personal tastes and backgrounds.
- Avoid sensory overload.
- Create a calm and inviting atmosphere, possibly dimming the lights and ensuring comfort for all participants.
- Consider working with a music therapist for more structured sessions. A list of board-certified music therapists can be found at www.cbmt.org.

Adaptive Dance

What it is: A movement-based activity adapted for individuals with dementia focusing on gentle, rhythmic movement that suits a wide range of mobility and coordination levels.

Benefits:

- ⇒ **Physical Movement:** Enhances flexibility, coordination, and balance.
- ⇒ **Emotional Expression:** Offers a therapeutic outlet to reduce frustration or agitation.
- ⇒ **Cognitive Stimulation:** Encourages mental engagement by following patterns and responding to music.
- ⇒ **Social Interaction:** Fosters community and reduces isolation through group participation.

Remember: The goal of these activities is not perfection—but **connection, joy, and purpose**. Small, thoughtful adaptations can go a long way in helping someone living with dementia feel included and empowered.

Tips for Implementation:

- Ensure a clutter-free, safe space to minimize fall risk.
- Use calming, upbeat music that's familiar but not overwhelming.
- Keep the sessions short (15-30 minutes) to maintain energy and interest.

Art and Creative Expression

What it is: Engaging in art activities such as painting, drawing, or crafting to support self-expression and cognitive engagement.

Benefits:

- ⇒ **Self-Expression:** Helps individuals convey emotions, thoughts, and memories that may be hard to communicate with words.
- ⇒ **Cognitive and Motor Skills:** Stimulates brain activity and helps maintain hand-eye coordination.
- ⇒ **Emotional Release:** Provides comfort, boosts self-esteem, and promotes a sense of accomplishment.
- ⇒ **Social Interaction:** Encourages cooperation and communication in group settings.

Tips for Implementation:

- Use safe, easy-to-handle materials and tools
- Provide large-print instructions and simple designs.
- Encourage freedom of expression without focusing on results.
- Try to avoid projects that may be too childlike; instead, incorporate adult-appropriate themes.
- Display finished works in art shows or community exhibits to celebrate creativity.

Getting Started: 3 Simple Ways to Begin Today

- Play a favorite song during breakfast and clap along together.
- Try a 5-minute seated stretch or gentle dance in the living room.
- Set up a drawing station with large-print designs and washable markers.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

SUPPORTING NUTRITION AND HYDRATION FOR INDIVIDUALS LIVING WITH DEMENTIA

FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

Proper nutrition and hydration are essential for individuals living with dementia. They support brain function, physical health, and overall quality of life. Malnutrition can accelerate cognitive decline, while key nutrients help preserve memory, muscle strength, and mobility. Staying well-hydrated helps prevent complications such as infections, constipation, and confusion. However, dementia can create many challenges that make it harder to eat and drink regularly and safely. Cognitive, physical, and behavioral changes may affect a person's appetite, ability to recognize food, or swallow safely.

This fact sheet outlines common challenges related to nutrition and hydration and offers practical tips to support comfort, health, and well-being. For more resources, please visit our website, <https://nursinghome411.org/dementia-care-in-the-community>.

Common Challenges

- **Cognitive Changes:** As dementia progresses, individuals may forget to eat or drink, not recognize food, or feel confused during meals. These cognitive impairments can lead to missed meals or dehydration.
- **Physical Difficulties:** Using utensils, chewing, or swallowing may become difficult due to motor skill loss (apraxia) or swallowing difficulties (dysphagia), which can increase the risk of choking or aspiration.
- **Loss of Appetite:** Appetite may decline due to changes in taste or smell, medication side effects, depression, or illness. This can lead to weight loss, lower energy, or malnutrition.
- **Dehydration:** People living with dementia may not feel thirsty or they may forget to drink fluids. Dehydration can exacerbate cognitive decline, cause urinary tract infections, and lead to serious health complications.

Tips to Support Nutrition and Hydration

- **Create a Calm Mealtime Environment:**
 - Serve meals in a quiet, well-lit space with minimal distractions.
 - Keep table settings simple and uncluttered.
 - Use plates and utensils that contrast in color with the table to help with visibility.
- **Encourage Participation and Independence:**
 - Allow the person to help with setting the table or choosing meals.
 - Offer finger foods or adaptive utensils for easier self-feeding.
 - Provide gentle assistance as needed while still promoting dignity and independence.

- **Offer Nutritious, Appealing Foods:**
 - Provide a balanced diet with fruits, vegetables, whole grains, and lean proteins.
 - If appetite is low, offer small, frequent meals and high-calorie snacks.
 - Use herbs or flavor enhancers to improve taste if food seems bland.
- **Monitor Swallowing and Food Texture:**
 - Watch for signs of difficulty swallowing (e.g., coughing, pocketing food in the cheeks of the mouth).
 - Modify food texture (e.g., soft, pureed foods or thickened liquids) if needed.
 - Consult a healthcare provider or speech-language pathologist for a safe feeding plan.
- **Promote Regular Hydration:**
 - Offer drinks frequently - even if the person doesn't ask.
 - Use preferred beverages (e.g., flavored water, juice, or warm broth).
 - Provide easy-to-hold cups or straws to support independent drinking.
 - Consider offering hydrating snacks like fruit, gelatin, or popsicles.
- **Screen for Malnutrition and Dehydration:**
 - Monitor weight, appetite, and energy levels regularly.
 - Involve healthcare professionals in routine screenings.
 - Keep a food and fluid log if intake becomes a concern.

By being proactive and supportive, caregivers can help individuals with dementia stay well-nourished and hydrated, enhancing comfort, safety, and quality of life.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

THE BENEFITS OF THERAPY SERVICES FOR INDIVIDUALS WITH DEMENTIA FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

Therapy services can be very valuable for people living with dementia, helping them maintain their independence and improve their quality of life. By addressing physical, cognitive, and communication abilities, therapy services can help people with dementia adapt to their condition, delay decline, and sustain a greater sense of autonomy. However, accessing these services can be challenging due to systemic barriers, funding limitations, and gaps in caregiver and professional understanding of dementia care.

This fact sheet outlines different types of therapy services, potential barriers to accessing those services, and steps families can take when advocating for services for their loved ones. For more resources, please visit our website, <https://nursinghome411.org/dementia-care-in-the-community>.

Therapy Services

Therapy services include:

- **Physical Therapy (PT)** can help individuals improve mobility, strength, and balance, which reduces the risk of falls and other injuries. Maintaining physical abilities can enhance independence in daily activities, like dressing, bathing, and moving around.
- **Occupational Therapy (OT)** can address memory, attention, and other cognitive skills. OT can improve health, well-being, and overall quality of life by supporting the ability to participate in activities. This can help individuals stay engaged and maintain independence.
- **Speech and Language Therapy (SALT)** can assist with language and communication challenges. Speech and language therapists can also help with swallowing difficulties.

Common Barriers to Access

Families may encounter several challenges when trying to secure therapy services for their loved ones in assisted living facilities and other home and community-based settings, including:

- **Misconceptions About Dementia and Rehabilitation:** There is a widespread mistaken belief that therapy services are not beneficial for people with progressive conditions like dementia, leading to under-referral or denial of services for individuals with a dementia diagnosis.
- **Systemic Gaps in Assisted Living and Home Care:** Assisted living and home-based settings may not routinely incorporate rehab services, focusing instead on basic personal care. This can limit the ability of individuals to access and benefit from rehabilitation therapies.

- **Lack of Dementia-Specific Rehab Expertise:** Rehabilitation therapists are not always trained in dementia-specific techniques.
- **Communication Difficulties:** People living with dementia may struggle to understand the need for rehabilitation services, leading to resistance.
- **Resource Constraints:** Lack of proper equipment and dedicated rehabilitation spaces restricts the delivery of effective therapy. Assisted living and home care agencies may be more focused on meeting daily basic needs, with limited resources, including staff, allocated for specialized rehabilitation.
- **Restrictive Policies:** Use of physical or chemical restraints (such as antipsychotic drugs) or concerns about falls may prevent individuals from participating in rehabilitation.

Tips for Family Members and Loved Ones

Get involved! Engaging with staff, attending care meetings, and encouraging participation in therapy services can improve outcomes.

Ask questions, such as:

1. What types of therapy services would best support my loved one's needs?
2. How are therapy goals set and measured?
3. How often are goals (and progress toward goals) reviewed?
4. How can we monitor progress?

Request regular assessments: Ask for ongoing evaluations of your loved one's physical and cognitive abilities to determine if they are eligible for therapy services. Inquire about whether physical, occupational, or speech and language therapy is available and appropriate.

Encourage person-centered care: Therapy services should be tailored to the individual's abilities and needs. Activities should be meaningful and aligned to the interests of the individual.

Monitor and communicate progress: Family members play a crucial role in observing changes in their loved one's physical and cognitive abilities. Sharing observations with the care team can help tailor therapy services to achieve better outcomes.

Interdisciplinary collaboration: Advocating for care teams to communicate and work together effectively can lead to better rehabilitation outcomes.

Advocate for more resources: Families can push for improvements in staffing levels and access to appropriate equipment. Request that staff receive training in dementia care and effective communication strategies to better support residents during rehabilitation.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

NON-PHARMACOLOGIC APPROACHES TO DEMENTIA CARE

FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

Supporting a person living with dementia means more than addressing symptoms – it means understanding the individual behind the condition. While changes in behavior, mood, and cognition are common, they are often responses to unmet needs or environmental challenges, not signs of a psychiatric disorder that require medication.

Non-pharmacologic approaches prioritize dignity, safety, and personhood. These strategies focus on adapting the environment, improving communication, and providing meaningful engagement to prevent or reduce distress. Evidence shows that such approaches are often more effective – and far safer – than psychotropic medications, especially antipsychotics, which carry serious risks for older adults.

This fact sheet outlines practical, compassionate strategies that can be used to support individuals living with dementia through person-centered care that respects their needs, abilities, and preferences. For more information and resources, please visit <https://nursinghome411.org/dementia-care-in-the-community>.

The Value of Non-Pharmacologic Approaches in Dementia Care

People living with dementia may experience behavioral symptoms (e.g., agitation, aggression, vocalizations) and psychological symptoms (e.g., anxiety, depression, hallucinations, delusions). These may stem from physical discomfort (such as pain or infection) or emotional distress (such as boredom, fear, or changes in routine). Except in emergencies, the standard of care is to address these needs without medication whenever possible.

Professional Standards of Dementia Care

Professional standards prioritize non-pharmacologic strategies as a first-line approach in dementia care. These methods help maintain cognitive function, support emotional well-being, promote independence in daily activities, and reduce so-called “behavioral and psychological symptoms of dementia” (BPSD).

These approaches are especially helpful for individuals in assisted living or at home. For family caregivers, they provide practical, low-risk, evidence-based tools that can reduce reliance on medication and improve outcomes. By prioritizing these approaches, care providers can enhance quality of life, support cognitive functioning, and mitigate BPSD, all while minimizing the potential adverse effects associated with medication use.

Common Non-Pharmacologic Approaches:

Note: Non-pharmacologic interventions such as cognitive stimulation, reminiscence therapy, and music therapy have been shown to improve quality of life and, in some cases, cognitive function. Effectiveness can vary based on the individual and their care setting.

Non-pharmacologic care – like all care – works best when it is tailored to the individual’s unique history, preferences, and strengths.

Psychological and Behavioral Therapies:

- ⇒ **Cognitive Stimulation Therapy:** Group-based sessions involving puzzles, games, and mentally engaging activities.
- ⇒ **Reminiscence Therapy:** Uses photographs, music, or videos to evoke positive memories and encourage engagement. This can be used in a group or individual setting.
- ⇒ **Validation Therapy:** Emphasizes empathetic communication and emotional validation through active listening and gentle cues.
- ⇒ **Pet Therapy:** Interaction with animals for comfort and emotional connection.
- ⇒ **Bright Light Therapy:** Exposure to natural light to support sleep and regulate circadian rhythms.

Social and Sensory Interventions:

- ⇒ **Aromatherapy:** Use of essential oils to promote calm and stimulate the nervous system.
- ⇒ **Massage Therapy:** Gentle physical touch to reduce anxiety and foster emotional connection.
- ⇒ **Music Therapy:** Involves listening to familiar, personalized music to stimulate memory and reduce stress.

Physical and Functional Activities:

- ⇒ **Occupational Therapy (OT):** Provided by trained professionals, OT supports participation in daily activities and adapts environments to reduce stressors and enhance safety.
- ⇒ **Walking:** Gentle, regular walks—indoors or outdoors—can improve mobility, reduce agitation, and provide sensory stimulation.
- ⇒ **Household Tasks:** Activities like folding laundry or watering plants promote physical engagement and a sense of purpose.

Tips for Non-Pharmacologic Care

- Learn what brings comfort or joy to the individual, such as music, a tv show, scents, pets, or favorite memories.
- Introduce one approach at a time and see how your loved one responds.
- Keep a journal to track which activities improve mood or behavior.
- Be patient and flexible; some approaches may take time or need adjustments.
- Involve the individual in activities they enjoy or have a history with—even small successes can make a big difference.
- **Get support!** Don’t hesitate to ask a dementia care specialist, occupational therapy, or social worker for help customizing approaches.

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>.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

PAIN MANAGEMENT FOR INDIVIDUALS LIVING WITH DEMENTIA **FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING**

Pain is a serious concern for older adults—especially those living with dementia. Dementia can affect a person’s ability to explain or describe their pain. For example, a person living with dementia may not be able to say *where* it hurts or *why* they’re uncomfortable. Instead, they may communicate their pain in ways that are hard for caregivers and family members to understand. This often results in underdiagnosed and undertreated pain, with avoidable health and quality-of-life consequences.

This fact sheet offers insights and practical tips for identifying, assessing, and addressing pain for individuals living with dementia. For more information and resources, please visit our website, <https://nursinghome411.org/dementia-care-in-the-community>.

Why Pain Often Goes Unrecognized in Dementia

- **Communication Barriers:** Advanced dementia affects memory, language, and judgment, making self-reporting of pain difficult or impossible.
- **Pain Shows Up in Other Ways:** People living with dementia may express pain through non-verbal signs, such as restlessness, aggression, resistance to care, refusing to eat, or becoming withdrawn, rather than saying they’re in pain.
- **Limited Staff or Caregiver Training:** Care staff or family caregivers may not know how to recognize these signs or may mistake them for “acting out” rather than a medical or environmental issue.

What Can Happen When Pain Goes Untreated

Comfort is a basic human need and pain, when left unaddressed, robs individuals of comfort, dignity, and quality of life. For people living with dementia, untreated pain can have especially serious consequences. Its impacts can include:

- **Emotional Distress:** Persistent pain can lead to sadness, anxiety, irritability, and disrupted sleep, all of which may be misinterpreted as “behavioral problems.”
- **Physical Decline:** Pain often limits mobility, leading to muscle weakness, reduced activity, and a loss of independence.
- **Social Withdrawal:** Individuals in pain may stop participating in activities they once enjoyed and withdraw from social interaction.

Recognizing and treating pain—especially in those who may struggle to express it verbally—is essential to compassionate, person-centered dementia care.

Best Practices for Managing Pain in Dementia

The best approach to pain management starts with **careful observation** and **non-drug strategies**, followed by medications only when necessary.

Remember:

1. All “behaviors” are a form of communication.
2. People with dementia have **not** lost their ability to feel pain and suffer if it is not treated.

Following is an overview of current standards of practice for assessing and addressing pain in individuals with dementia.

1. Use a Specialized Pain Assessment Tool

Utilize validated pain scales designed for people with dementia, like the PAINAD scale, which considers behavioral cues like facial expressions, vocalizations, and body movements alongside verbal reports (if possible) to accurately assess pain level. Visit <https://nursinghome411.org/dementia-care-in-the-community> for the PAINAD scale and other useful resources.

2. Try Non-Pharmacological Approaches First

- **Identify and address underlying clinical issues:** A thorough examination by a healthcare professional can help determine if a medical condition is causing the pain. Common sources include back pain, arthritis, joint stiffness, constipation, or more serious conditions such as cancer or heart disease.
- **Identify and address environmental causes:**
 - Identify if there are certain places, times of day, noises, or activities that trigger upset.
 - Adjust lighting, noise levels, and room temperature to create a calming environment.
- **Physical therapy or massage:** Gentle exercises, stretching, and massage can address musculoskeletal pain.
- **Cognitive stimulation activities:** Engaging in familiar activities to distract from pain.
- **Music therapy:** Soothing music can be calming and music that the individual has enjoyed in the past can be pleasing and distracting from discomfort.
- **Behavioral management techniques:** Positive reinforcement, redirection, and reassurance to address pain-related behaviors.

3. Medication Options (When pain is severe and not alleviated by non-pharmacological interventions.)

- **Acetaminophen:** Often the first and safest option.
- **Nonsteroidal anti-inflammatory drugs (NSAIDs):** Use with caution due to potential side effects like stomach irritation, especially in older adults
- **Opioids:** Should be used only if pain is severe and other treatments aren't working. Monitor closely for side effects like confusion or drowsiness.
- **✗ Note:** Antipsychotic drugs are NOT appropriate treatments for pain or for typical "behavioral symptoms" of dementia (like restlessness, agitation, or shouting).

4. Important Medication Safety Tips

- **Start low, go slow:** Begin with the lowest effective dose and increase only if needed.
- **Regular monitoring:** Watch for side effects and monitor if the medication is helping.
- **Team-based planning:** Involve different care professionals – doctors, nurses, therapists, and family – to develop and adjust the care plan.

The goal, whenever possible, should be to reduce (and, if possible, eliminate) the use of medications, especially opioids, antipsychotics, and other potentially dangerous drugs.

Pain doesn't have to be a part of aging or dementia. With the right tools, training, and attention, caregivers can help improve comfort, reduce suffering, and support a better quality of life for the individual.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

HOME SAFETY FOR INDIVIDUALS LIVING WITH DEMENTIA **FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING**

Home should be a place of comfort, familiarity, and dignity – especially for someone living with dementia. As dementia progresses, everyday spaces can become confusing or even dangerous, but small changes can make a big difference.

This fact sheet offers practical, person-centered tips to help caregivers and families create a safer, more supportive environment – whether at home or in assisted living. By adapting the space to meet changing needs, individuals living with dementia can maintain independence and continue to thrive in the place they know best. For more resources, please visit our website, <https://nursinghome411.org/dementia-care-in-the-community>.

How Dementia Affects Safety

Dementia can impact thinking, movement, behavior, and sensory perception, leading to increased safety concerns:

- **Judgment:** Difficulty using household appliances or managing routine tasks safely.
- **Orientation:** Confusion about time and place can result in getting lost, even in familiar surroundings.
- **Behavioral Changes:** Feelings of fear, suspicion, or agitation may arise.
- **Physical Ability:** Difficulty with balance can increase the risk of falls.
- **Sensory Changes:** Vision, hearing, and temperature sensitivity may be altered, making it harder to perceive hazards.

Home Safety Tips

To prevent accidents and create a safer environment, consider the following strategies:

1. **Evaluate the Environment**
 - Regularly check high-risk areas such as garages, basements, and workrooms where tools, chemicals, and cleaning products are stored.
 - Remove clutter and tripping hazards like throw rugs or cords.
 - Review your home safety setup every few months and adjust as needed.
2. **Kitchen Safety**
 - Use appliances that turn off automatically and secure stove knobs to prevent dangerous usage.
 - Keep medications, toxic plants, and other hazardous items out of reach.
 - Use labels with pictures or words on cabinets to support independence.
3. **Bathroom and Bedroom Safety**
 - Install grab bars in the bathroom and consider adding non-slip surfaces to reduce the risk of falls.

- Keep the bedroom organized and ensure that furniture is secure to prevent tipping.
- 4. Lighting and Visibility**
- Place additional lighting in hallways, bathrooms, and stairways to avoid disorientation, especially at night.
 - Install night lights and motion sensor lights in key areas like hallways and entries to make navigating the home safer.
- 5. Doors, Windows, and Wandering Prevention**
- Install locks on doors and windows that are out of sight to prevent wandering.
 - Use secure storage for keys and ensure that locks inside the house are removed to avoid entrapment.
- 6. Emergency Preparedness**
- Have emergency contact information (e.g., local police, hospitals) easily accessible.
 - Ensure that smoke detectors, carbon monoxide alarms, and fire extinguishers are functional, and replace batteries regularly.
- 7. Medication and Chemical Safety**
- Store medications in a locked cabinet and consider using a pill organizer to ensure proper dosage.
 - Keep harmful chemicals, such as cleaning supplies or pesticides, securely stored away.
- 8. Garage and Outdoor Areas**
- Limit access to dangerous tools, such as lawnmowers or snow blowers.
 - Ensure chemicals like gasoline or paint are stored in safe, out-of-reach locations.
- 9. Support Independence**
- Maintain a balance between ensuring safety and encouraging independence.
 - Create spaces for social interaction and activity to prevent isolation.

Note: Maintaining a safe home requires energy and attention. **Caregivers need care, too.** Take breaks, seek support, and consider respite services. A well-supported caregiver is essential to a safe and stable home environment.

Additional Support Services

- **Dementia Care Coordinators:** These professionals assist with evaluating the home for safety hazards and providing resources for caregivers.
- **Medical Alert Programs:** Enrolling in medical alert services can provide peace of mind by offering emergency support if needed.
- **In-Home Community Services:** Home care aides, nurses, and meal delivery services can help with daily tasks, allowing caregivers more time for self-care.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

PREVENTING PRESSURE ULCERS & URINARY TRACT INFECTIONS FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

Individuals living with dementia face a higher risk of developing pressure ulcers (also called bedsores) and urinary tract infections (UTIs), due to factors like reduced mobility, incontinence, and cognitive impairment. Because they may have more difficulty expressing pain or discomfort, these issues can go unnoticed until they become serious.

This fact sheet explains the risks, early warning signs, and practical strategies to help prevent pressure ulcers and UTIs and support better health, comfort, and quality of life. For more information and additional resources, please visit: <https://nursinghome411.org/dementia-care-in-the-community>.

Pressure Ulcers (Bedsores)

What They Are

Pressure ulcers are injuries to the skin and underlying tissue caused by prolonged pressure, especially over bony areas like the heels, hips, backside, and elbows. They are categorized in stages based on severity, from mild redness to deep wounds involving muscle or bone.

Risk Factors

- Limited mobility or being bedridden
- Medical conditions that affect circulation
- Poor nutrition or dehydration
- Incontinence
- Cognitive impairment (unable to express discomfort)
- Infrequent skin checks

Preventing pressure ulcers and UTIs not only avoids pain and medical complications—it also reduces hospital visits and improves comfort and dignity for people with dementia.

Prevention Strategies

1. **Reposition regularly:** Turn or reposition individuals at least every two hours to relieve pressure on vulnerable areas.
2. **Use Pressure-Relieving Devices:** Special mattresses, seat cushions, and heel protectors can help reduce prolonged pressure.
3. **Keep Skin Clean & Dry:** Cleanse skin gently with mild soap and lukewarm water. Moisturize to prevent dryness and cracking.
4. **Support Good Nutrition and Hydration:** A balanced diet rich in protein, vitamins, and fluids strengthens skin and speeds healing.
5. **Check Skin Daily:** Look for redness, swelling, or sores - especially on heels, hips, shoulders, and backside.
6. **Incontinence Management:** Promote continence through regular toileting, appropriate diet, and communication. For individuals using incontinence briefs, change wet or soiled pads promptly and protect the skin with barrier creams as needed.

- 7. Encourage Movement:** Light exercises or guided range-of-motion activities can improve circulation and reduce pressure ulcer risk.

Urinary Tract Infections (UTIs)

What They Are

UTIs are infections in any part of the urinary system, including the bladder, urethra, and kidneys. They are common among people with dementia, especially those who are incontinent or unable to manage toileting independently. UTIs can worsen confusion, cause significant discomfort, and lead to serious complications if untreated.

Risk Factors

- Incontinence or difficulty with toileting
- Immobility or limited communication
- Poor hydration
- Use of urinary catheters (indwelling or intermittent)
- Inability to follow hygiene routines
- Limited access to bathrooms

Prevention Strategies

1. **Promote Hydration:** Encourage frequent fluid intake to help flush bacteria from the urinary tract. Offer water, juice, and broth.
2. **Establish a Toileting Routine:** Prompt regular bathroom trips and offer assistance when needed. Maintain a consistent schedule.
3. **Practice Good Hygiene:** After incontinence episodes, clean the genital area gently using warm water and mild soap. Always wipe from front to back to prevent the spread of bacteria.

When to Seek Medical Help:

For pressure ulcers (bedsores), contact a healthcare provider if you notice redness that doesn't fade after relieving pressure, swelling or warmth in the area, pain, an open sore or blister, or skin that appears dark or blackened. Any signs of infection - such as pus, a foul odor, or fever - should be addressed promptly to prevent complications.

For urinary tract infections (UTIs), seek medical help if the individual develops a fever or chills, experiences pain or burning during urination, or if their urine becomes cloudy, dark, or bloody. A sudden increase in confusion, agitation, or unusual behavior can also signal a UTI. Pain in the lower abdomen or back may also be a warning sign.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

PSYCHOTROPIC DRUGS: RISKS, BENEFITS, AND QUESTIONS TO ASK FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

When someone is living with dementia, they or their family may be told that psychotropic drugs – such as antipsychotics, antidepressants, or sedatives – can help manage so-called “challenging behaviors” like agitation, wandering, or resistance to care. But while these medications may seem like a quick solution, they often come with serious risks and rarely address the underlying cause of the behavior.

This fact sheet is designed to help families, caregivers, and advocates better understand the role of psychotropic medications in dementia care. It explains the potential benefits and dangers of these drugs, especially antipsychotics, which are frequently overprescribed despite warnings from health authorities. It also offers critical questions to ask when medication is recommended. For additional resources and information, visit <https://nursinghome411.org/dementia-care-in-the-community>.

What Are Psychotropic Medications?

Psychotropic medications are drugs that alter brain function and can affect a person’s thoughts, emotions, or behavior. In dementia care, these medications are sometimes prescribed to try to manage behavioral expressions or emotional changes, such as:

- Aggression or agitation
- Anxiety or depression
- Hallucinations or delusions
- Sleep disturbances

While these drugs may sometimes offer short-term relief, they do not treat the root causes of “challenging behaviors” and carry significant risks.

Common Types of Psychotropic Medications

Type	Why It’s Prescribed	Common Risks
Antipsychotics	To manage aggression, severe agitation, hallucinations	Sedation, stroke, Parkinsonism, higher risk of death
Benzodiazepines	For anxiety or sleep problems	Falls, confusion
Antidepressants	For mood symptoms or depression	Confusion, dizziness, falls
Mood Stabilizers	For mood swings or irritability	Drowsiness, worsened cognition

Weighing the Benefits and Risks

Potential Benefits

While psychotropic medications are not a first-line treatment for most dementia-related behaviors, there are limited situations where they may offer relief or support:

- **Managing Severe Distress or Safety Risks:** There may be times when these medications may be used temporarily to help de-escalate a crisis when an individual poses an immediate risk to themselves or others. Once the crisis is over, the standard of practice is to implement non-

pharmacological approaches to address the individual's symptoms and undertake gradual dose reduction of the medications.

- **Supporting Sleep in Specific Cases:** Certain medications can help reduce severe sleep disturbances or nighttime agitation when non-drug approaches have not been effective.
- **Treating Coexisting Mental Health Conditions:** For individuals with pre-existing conditions such as depression or anxiety, psychotropic medications – particularly antidepressants or anxiolytics – may continue to play a helpful role under close supervision.

Risks to Consider

- **Increased Risk of Falls:** Psychotropic drugs can cause side effects like dizziness, sedation, and impaired coordination, significantly raising the risk of falls and related injuries in older adults.
- **Worsened Cognitive Function:** These medications may contribute to or worsen confusion, disorientation, and memory loss. This can impair a person's ability to walk safely and navigate their surroundings, further increasing the risk of accidents.
- **Higher Risk of Stroke:** Certain antipsychotic medications have been linked to an increased risk of stroke, particularly in older adults with dementia.
- **Aggravation of Behavioral Symptoms:** While intended to reduce behaviors like agitation or aggression, psychotropic medications can sometimes intensify these symptoms or trigger new behavioral issues.
- **Increased Risk of Death:** Some psychotropic drugs—especially antipsychotics—carry the FDA's most serious warning, a **black box warning**, due to their association with higher mortality rates in older adults with dementia.

Questions to Ask the Doctor:

- Why is this medication being recommended?
- What specific symptom or behavior are we trying to address?
- Have non-drug approaches been tried first? What were the results?
- What are the alternative treatments?
- What are the potential side effects, and what should we watch for?
- How will we know if the medication is working?
- What is the planned duration of use?
- When will we review its effectiveness and safety?
- Is there a plan to reduce or stop the medication over time (tapering)?

What You Can Do as a Caregiver:

- **Trust your instincts.** Speak up if something doesn't feel right or if you notice concerning changes.
- **Stay organized.** Keep an up-to-date medication list, including doses and reasons for use.
- **Observe closely.** Monitor for any changes in mood, behavior, movement, or alertness and share your observations with the care team.
- **Advocate for regular reviews** to assess whether the drug is still effective, monitor for side effects, and determine if continued use is necessary.
- **Explore alternatives.** Learn about non-drug strategies and ask for support in implementing person-centered approaches to care.

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

PALLIATIVE & HOSPICE CARE FOR INDIVIDUALS WITH DEMENTIA: WHAT FAMILIES NEED TO KNOW

FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

When a loved one is in the later stages of dementia, families often have questions about comfort, care, and what to expect. Navigating these decisions can be emotionally difficult and overwhelming, especially when trying to balance medical needs with personal wishes. Palliative and hospice care can provide important support during this time, focusing on comfort, dignity, and quality of life. These services help manage symptoms and ease stress for both the individual and their family.

This fact sheet provides an overview of palliative and hospice care for individuals living with dementia. Early planning and open communication with healthcare providers can help families make informed decisions about care access the right resources. For more resources, please visit our website, <https://nursinghome411.org/dementia-care-in-the-community>.

What is Palliative Care?

Palliative care provides relief from symptoms and emotional stress at any stage of a serious illness, including dementia. It helps people live as comfortably and meaningfully as possible—while continuing with other treatments, if desired.

What Does Palliative Care Offer?

- **Purpose:** Focuses on symptom management, emotional support, and improving overall quality of life.
- **Who Provides It:** A multi-disciplinary team of physicians, nurses, counselors, and spiritual advisors (if desired).
- **Where It's Offered:** Available in the home, long-term care facilities, outpatient clinics, and hospitals.
- **Who Qualifies:** Anyone with a serious illness, including Alzheimer's disease and related dementias.

What is Hospice Care?

Hospice care is a specialized type of palliative care for individuals nearing the end of life. It focuses on comfort rather than curative treatment, helping people live their final months with dignity and as little pain as possible.

What Does Hospice Care Offer?

- **Purpose:** Focuses on alleviating pain and managing symptoms to ensure the individual is as comfortable as possible.

- **Who Provides It:** A multi-disciplinary team of physicians, nurses, counselors, and spiritual advisors.
- **Where It's Offered:** At home, in hospitals, long-term care settings, or dedicated hospice facilities.
- **Care Approach:** Curative treatments are discontinued to prioritize comfort and quality of life.
- **Who Qualifies:** Individuals with a life-limiting illness and a life expectancy of six months or less (if the illness follows its typical course).

Why These Services Matter for People Living with Dementia

- **Symptom Relief:** Helps manage pain, agitation, anxiety, and other distressing symptoms.
- **Comprehensive Support:** Multi-disciplinary teams provide care coordination, emotional support, and spiritual guidance.
- **Family and Caregiver Support:** Provides caregiver education, respite care, and grief counseling.

Start the Conversation Early!

Early planning helps ensure that care reflects your loved one's values and wishes. Talk with healthcare providers about options, ask questions, and revisit decisions as circumstances change.

How Do I Know When It's Time for Palliative or Hospice Care?

- **Palliative Care:** Appropriate at any stage of dementia to improve comfort and reduce stress—often alongside other treatments.
- **Hospice Care:** Appropriate in the advanced stages, when curative treatments are no longer helping and the focus shifts to end-of-life comfort.

Commonly Asked Questions

Q: Can my loved one still live at home while receiving hospice or palliative care?

A: Yes. Both types of care can be provided in the home or in assisted living.

Q: Is it too early to ask about palliative care?

A: No. It's never too early. In fact, starting palliative care early can improve comfort, reduce hospital visits, and help families plan with less stress.

Q: Can my loved one get palliative care even if they're still active?

A: Yes. Palliative care is not only for end-of-life. It can begin at any stage of dementia to manage symptoms and improve quality of life.

Q: Does accepting hospice care mean my loved one will die soon?

A: Not necessarily. While hospice care is designed for individuals with a prognosis of six months or less, some people live longer, especially when they receive good symptom management. Hospice can even be extended if needed.

Q: What if we change our minds about hospice care?

A: Hospice is a voluntary service. You can stop hospice at any time if your loved one's condition improves or you choose to pursue curative treatment again.