

**LONG  
TERM  
CARE**

**COMMUNITY  
COALITION**

# **SUPPORTING DEMENTIA CARE IN FAITH COMMUNITIES**

**Long Term Care Community Coalition**

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

# The Long Term Care Community Coalition

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

# Training Goals

- ▶ Understand the caregiver experience within your community
- ▶ Learn what is included in the LTCCC Dementia Care Toolkit
- ▶ Practice how to use and share the toolkit resources in real situations
- ▶ Leave with a simple, actionable plan to support caregivers

# Why This Matters

- ▶ Many caregivers are already part of your congregation - often quietly balancing caregiving, work, family, and spiritual life
- ▶ Without support, caregivers may experience burnout and isolation
- ▶ Faith communities can play a crucial role in reducing that isolation

# The Gap We're Addressing

- ▶ Caregivers often don't know where to find clear, trustworthy guidance
- ▶ Information online can feel overwhelming or too clinical
- ▶ Faith leaders are trusted - but may not feel equipped with dementia-specific knowledge
- ▶ The toolkit provides simple, practical guidance for real situations

# Introducing the LTCCC Toolkit

- ▶ Free, online resource available at [NursingHome411.org](http://NursingHome411.org)
- ▶ Designed for caregivers, families, and community members
- ▶ Available in English and Spanish
- ▶ Focused on real-life caregiving situations

- Webinars & Events
- Dementia Care Toolkits**
- Family Resource Center
- Abuse, Neglect, & Crime Reporting Center
- Resident Advocacy Tools
- Fact Sheets
- Assisted Living

LEARNING CENTER >



## Dementia Care Toolkits

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### Dementia Care Toolkits



The **Long Term Care Community Coalition's Dementia Care Toolkits** are designed to support quality, person-centered care for individuals living with dementia—whether in a nursing home or in the community. Use the links below to explore fact sheets, care cards, and other resources tailored to different care settings: **Nursing Homes** and **Private Home & Assisted Living**.

Thank you to the Fan Fox and Leslie R. Samuels Foundation, Inc. for supporting both of these projects and enabling us to make these resources freely available to the public.

NURSING HOMES

PRIVATE HOME AND ASSISTED LIVING

# How the Toolkit is Organized

- ▶ **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
- ▶ Designed so you can choose what works best for your setting

# Fact Sheets: What They Provide

- ▶ Clear explanations of common dementia care challenges
- ▶ Written in plain language - no medical background needed
- ▶ Useful for both individual learning and group teaching
- ▶ Topics include:
  - Care planning
  - Engaging Activities
  - 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.

# LONG TERM CARE COMMUNITY COALITION

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## 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*

## 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://bhw.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/>)

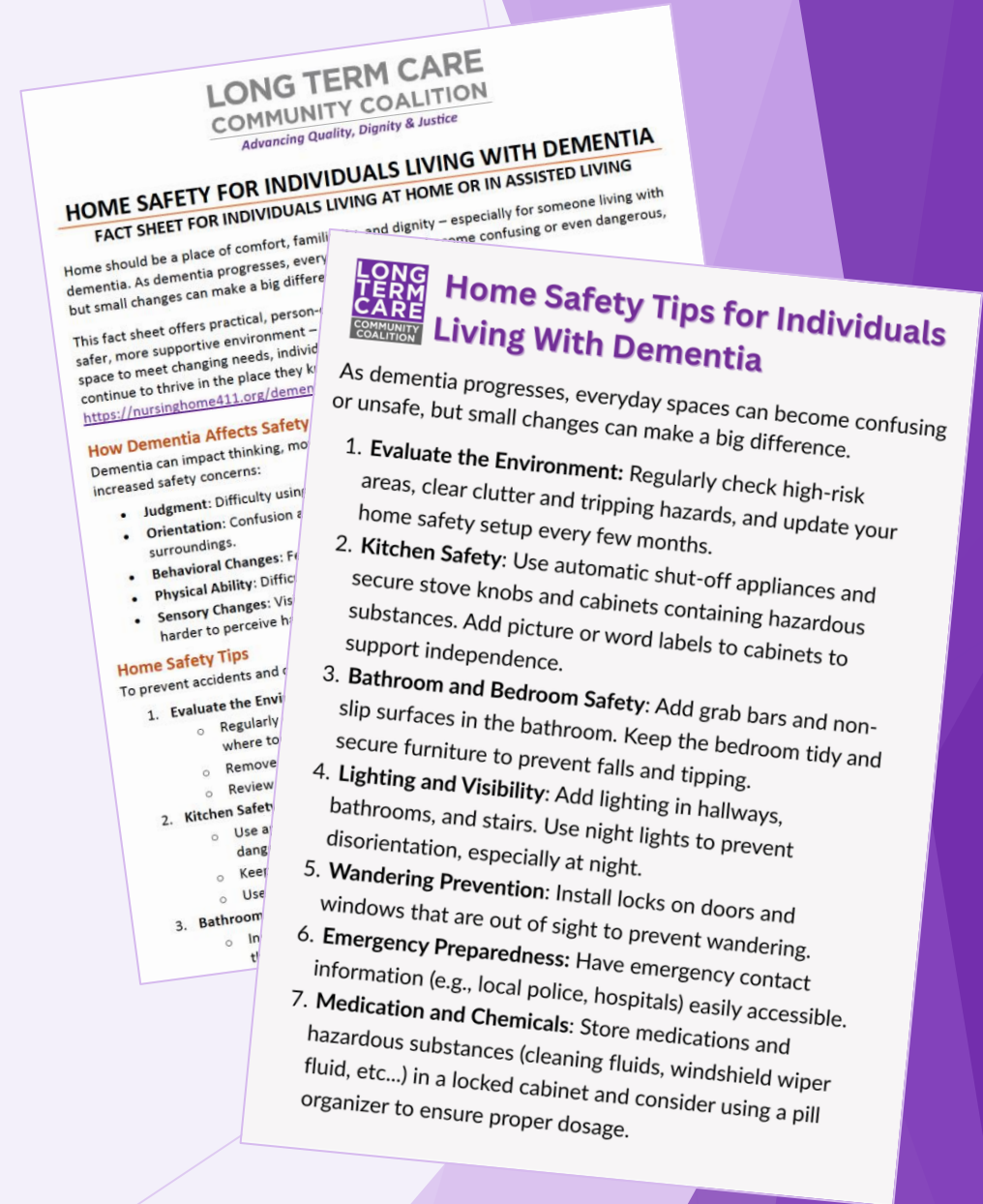
- CARES® is an award-winning, evidence-based online dementia care training program that teaches the 5-step CARES® Method™ alongside best practices from the Alzheimer's Association.
- Cost: \$199

# How You Might Use Fact Sheets

- ▶ Share during a pastoral visit or caregiving conversation
- ▶ Use as handouts in a support group or workshop
- ▶ Email or print for caregivers needing guidance
- ▶ Use one sheet as the focus of a 15-30 minute session

# Care Cards: What They Provide

- ▶ Short, focused tips for specific caregiving challenges
- ▶ Designed for moments of stress, confusion, or uncertainty
- ▶ Easy to print or keep on a phone
- ▶ Provide immediate, actionable guidance



# How You Might Use Care Cards


- ▶ Share directly with a caregiver in a moment of need
- ▶ Review together during a conversation
- ▶ Highlight one card per week in your communications
- ▶ Use as a quick follow-up after a discussion

# Mini-Modules: What They Provide

- ▶ Short educational videos on key dementia care topics
- ▶ Designed for flexibility - watch alone or in groups
- ▶ Reinforce and expand on fact sheet topics
- ▶ Help build confidence among volunteers and leaders

# 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 You Might Use Mini-Modules

- ▶ Show during a small group or caregiver session
- ▶ Pause to discuss key points
- ▶ Assign as optional learning for volunteers
- ▶ Combine with fact sheets for deeper understanding

# 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

# Leading a Simple 30-Minute Session

- ▶ 5 min: welcome and check-in
- ▶ 10 min: review a fact sheet or mini-module
- ▶ 10 min: group discussion and sharing
- ▶ 5 min: share care cards and next steps

# What This Looks Like in Practice

- ▶ Start with empathy and acknowledgment of caregiving challenges
- ▶ Use one resource - not too many at once
- ▶ Encourage sharing without pressure
- ▶ End with something practical they can take with them

# Supporting Caregivers One-on-One

- ▶ Use toolkit during pastoral care or support conversations
- ▶ Offer a specific resource instead of general advice
- ▶ Follow up with additional materials
- ▶ Help caregivers feel informed and less alone

# Simple Ways to Share the Toolkit

- ▶ Add link to bulletins, newsletters, or website
- ▶ Mention during announcements or sermons
- ▶ Send directly to individuals who may benefit
- ▶ Introduce gradually - one resource at a time

# Community Announcement Sample

## Dementia Care Resources for Our Community

Across our community, many individuals are quietly caring for loved ones living with dementia. Caregiving can be both meaningful and challenging - and having the right information and support can make a difference.

The Long Term Care Community Coalition (LTCCC) offers a free Dementia Care in the Community Toolkit designed for caregivers, families, and community members. This resource includes:

- ▶ Plain-language fact sheets on dementia care, communication, and safety
- ▶ Quick “Care Cards” with tips for everyday caregiving situations
- ▶ Short educational materials and links to additional trusted resources

These tools are practical, easy to use, and available in English and Spanish.

Explore the toolkit: <https://nursinghome411.org/dementia-care-in-the-community>.

# Building a Sustainable Approach

- ▶ Start with one conversation or small group
- ▶ Train a few leaders or volunteers
- ▶ Integrate into existing ministries
- ▶ Build awareness over time

# Reflection

- ▶ Who in your community could benefit from this?
- ▶ What is one resource you could share this week?
- ▶ What is one small step you can take?
- ▶ What feels realistic to start with?

# Next Steps

- ▶ Explore the toolkit yourself
  - [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
- ▶ Reach out to LTCCC for support
  - [info@ltccc.org](mailto:info@ltccc.org)
- ▶ Additional resources available through LTCCC

Thank you!



Questions?



Comments?

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