*Phrased in clear, conversational language and tested with older adults, the **Preferences for Everyday Living Inventory (PELI)** helps to identify nursing home residents' authentic desires. Staff can use the questionnaire to learn about resident preferences and to personalize and improve the quality of care.*

STEP 1 : FORM A CORE TEAM TO KICK OFF INITIAL EFFORTS

Pilot a roll out of the *PELI* assessment by selecting a **champion** and **team members** who work in social services, therapeutic recreation, life enrichment, community coordination, or nursing at your facility.

Champions or task force members should be:

- ✓ Passionate about honoring resident preference and choice
- ✓ Able to serve as effective leaders
- ✓ Working closely with the employees who will conduct resident interviews
- ✓ Able to develop and use tracking systems such as spreadsheets
- ✓ Willing to identify areas of weakness
- ✓ Eager to seek continuing education opportunities

Consider asking for **self-nominations** or for staff and administration to nominate potential members.

STEP 2: SELECT INTERVIEW QUESTIONS & CREATE INTERVIEW FORM

Team members can use **any of three approaches to decide which *PELI* questions to ask** residents:

1. From the 72 questions in the full *PELI*, select 10-15 to ask in the pilot phase of *PELI* implementation, *or*
2. Focus on the 16 *Minimum Data Set 3.0 Section F* preference items, and ask follow up questions in the full *PELI, or*
3. Have departments divide up the 72 *PELI* questions by discipline and, as a team, decide on the items to ask.

Consider:

- Starting with a **positive focus** and select questions for which you anticipate possible solutions. For instance, asking "How important is it to you to listen to music you like?" may reveal preferences your organization can easily meet.
- Selecting questions on a **topic of particular concern**. In this way, use the *PELI* to gather needed data on preferences that are more challenging to address and to obtain ideas for solutions.
- Creating a paper or electronic document with the 10-15 questions selected by your team to record resident data.

The *MDS 3.0 Section F - Preferences for Customary Routine and Activities* will trigger additional assessment questions when residents say that activities are important, but they cannot do them. If a resident says an activity is **"Important"** or "**Important, but can't do**," the full *PELI* contains follow-up questions that help staff learn more, and devise ways to fulfill the preference through the plan of care.

STEP 3: SELECT & TRAIN INTERVIEWER(S)

Interviewers may be activity professionals, nursing assistants, or social services staff, or volunteers trained to fit your community's needs and resources. Begin *PELI* interviews with long-stay residents, asking questions either in one sitting or over a series of conversations. For residents who are unable to communicate, interview a family member or close friend who can speak on the resident's behalf and who knows his or her preferences well. (Also, see *PELI Tip Sheets: Interview Tips and Working with Proxies*.)

STEP 4: USE ASSESSMENTS TO INFORM CARE PLANNING MEETING

PELI offers a way to discover **each resident's unique interests and passions**. Discussing preference results during care planning meetings helps to create successful care plans and build relationships with residents.

About the Series:

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Preference Based Living

PREFERENCE ASSESSMENT | 2: INTERVIEW TIPS

INTERVIEW BASICS

Forms for the *Preferences for Everyday Living Inventory (PELI)-Mid Level* and *PELI-Full* assessment include brief instructions. This tip sheet offers additional **guidance for training staff and volunteers** who will conduct the *PELI* preference interview. While a full *PELI* interview typically takes 30 minutes in one sitting, a series of three 10-minute interview sessions over several days can accomplish the same goals. *PELI* interviews provide an opportunity to get to know your residents and to **build insight, relationships, respect and trust**.

TRAINING INTERVIEWERS

The champion for *PELI* in your community may serve as a "coach" for those who will conduct preference interviews. **Useful training topics** to consider are:

- ✓ the purpose of *PELI* interviews
- ✓ scheduling procedures
- ✓ materials to have on hand
- ✓ interviewing techniques and tips

Ideally, the champion would first conduct a *PELI* interview with a resident while the trainee observes. Next, the trainee would conduct a resident interview while the champion observes and then privately offers constructive feedback. If staff time for interviews is limited, consider **training volunteers** to conduct preference interviews. Volunteers are likely to find that leading these interviews offers a meaningful and rewarding way to connect with residents.

INTERVIEWING TIPS

Setting & conditions

- ⇨ Select a **comfortable, private** setting.
- ⇨ Sit so that the resident can **see your face**. Minimize glare by directing light sources away from the resident's face.
- ⇨ Make sure the resident can **hear you**. Residents should use their usual hearing aids or other communication devices. If the resident can't hear you, try headphones or a hearing amplifier.
- ⇨ Print the last page from the *PELI*, which is a list of the response options printed in large font; hand it to the resident to use during the interview.

Questions to ask, interactions

- ⇨ If a resident says he or she can **no longer do a particular preference**, say: "I want to know about every activity that would be important to you if you could do it with assistance or support." Select *Important, but can't do or no choice* when the resident indicates that the topic is important, but he or she is physically unable to participate, or has no choice about participating while staying in the nursing home due to nursing home resources or scheduling.
- ⇨ Be careful **not to "put words in the mouth"** of the interviewee.
- ⇨ Give each person **time to collect their thoughts** and explain preferences.
- ⇨ **Offer prompts**, as needed: "Is there anything you'd like to add?" "Can you say more about that?"
- ⇨ Be sure to **thank the nursing home resident**, family member or friend at the end of each interview session. Let them know that the information will be used to help plan their care and daily activities.

Don't approach the preference interview as if it's a task for the interviewer or the resident. Preference interviews are a **meaningful opportunity to personalize care** and focus time and resources that will help residents feel happy, cared for and comfortable with daily life.

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Research supports the positive impact of having family and friends ("proxies") involved in care. They can provide social support for a resident even after transition to a nursing home, and can serve as advocates for individualized care planning. When a resident cannot participate in an interview due to cognitive or communication limitations, a proxy can respond to Preferences for Everyday Living Inventory (PELI) questions, helping to represent the resident's preferences and level of satisfaction.

STEP 1: START WITH THE RESIDENT

Individuals with mild to moderate dementia can still report on their preferences, reliably and consistently. Hard cut-off scores may not always be the best indicator of a person's ability to convey their preferences. We recommend approaching the long-stay resident **three separate times,** on different days, before determining that the *PELI* interview cannot be completed and a proxy is needed.

STEP 2: SEEK A PROXY WHO KNOWS THE RESIDENT & CAN ANSWER QUESTIONS

If a resident cannot participate in a *PELI* interview, it is best to **interview a family member or close friend who knows his or her preferences well** and can speak on the resident's behalf. This person – the proxy – could be the Power of Attorney or other responsible party, but could also be a family member or friend who visits the resident most often.

STEP 3: STEPS TO SUCCESS

- ✓ Decide how you will collect the information. Interviews can take place in person or via phone, video chat, email, postal mail, or a combination.
- ✓ If in person, designate an interview location that is quiet and private. Include the resident in the room if possible.
- ✓ Determine the staff member who will perform proxy interviews and coordinate with the proxy.
- ✓ Schedule the interview at a time convenient for the proxy. (See *PELI Interview Tips* sheet.)

STEP 4: TIPS FOR EFFECTIVELY ENGAGING PROXIES

Invite family members or friends to participate by letter, email, phone call or video chat. During the interview:

- ⇨ Ask the proxy to answer as though the resident has no barriers to pursuing each preference.
- ⇨ Stress that you are seeking **what the proxy thinks the resident would prefer**, not what the proxy prefers.

- ⇨ The **proxy voice is not a replacement for the resident's voice**; it is a complement in the care planning process.
- ⇨ Family/friends can be a great resource to discover interests that can be used to create unique and individually tailored interventions.

Sometimes family and close friends are discouraged by their loved one's condition and believe he or she can no longer pursue past interests. Help the family/friend understand how their input leads to preference-based person-centered goals of care. **Remind the proxy that you would like to understand the resident's preferences so that the care team can devise ways to help the resident fulfill them**.

If the proxy has difficulty answering preference questions, consider simplifying the response options to **Important or Not Important,** rather than using all five *PELI* choices (*Very Important, Somewhat Important, Not Very Important, Not Important at All, or Important, But Can't Do, No Choice*). Encourage the proxy to attend a care planning session, either by phone or in person. When proxies do not attend, track the reasons and engage in a *Plan Do Study Act (PDSA)* cycle to address causes for non-attendance.

WHAT IF THERE IS NO FAMILY OR CLOSE FRIEND PROXY?

If no proxy is available, the direct care workers' experiences and observations may provide insight into the resident's preferences. For example, over several days, staff may be able to determine preferences for daily patterns by being attentive and taking notes when residents are naturally rising or wanting to go to bed. Give new residents a few weeks to get into a routine. Identify a staff member who will use direct care workers' observations to inform care plans.

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PREFERENCE ASSESSMENT | 4: HELPING STAFF ENGAGE

Staff members are the cornerstone of providing individualized, preference-based care. They play the key role in putting this philosophy of care into action. This tip sheet explores ways to build staff commitment and engagement in learning about resident preferences – and most importantly, in using the information to enhance joy and meaning in residents' lives.

STEP 1: HOW TO START THE CONVERSATION WITH STAFF MEMBERS

Engage the staff in a learning circle or team meeting to talk about why it is, or why it may be important, to ask residents about their preferences. Seek examples from staff first. Possible questions to prompt discussion include:

- How do we *honor residents' rights?*
- How do we *provide better care?*
- How do we *promote or support choice or control?*
- How do we *ensure resident satisfaction with care?*

STEP 2: HOW STAFF CAN LEARN ABOUT PREFERENCES

In the learning circle or team meeting, ask: "*How do we know the way a resident likes to live his or her daily life?" "How are we currently assessing resident preferences"? "How do you think we can do it better"?* Staff members learn about resident preferences through a variety of complementary processes, including:

- Through daily interactions and conversations with residents
- Through others: family, friends, and other residents
- Through care planning meetings
- Through formal assessment using the *Preferences for Everyday Living Inventory (PELI)* or *MDS 3.0 Section F. Preferences for Customary Routine*

STEP 3: DEVELOP A PROCESS TO COMMUNICATE INFORMATION ABOUT PREFERENCES

Some ways to integrate preferences into resident care are:

- ⇨ **Involve direct care workers in care planning meetings** – to assist with communicating resident preferences and promote discussions of successful strategies. View care planning as a dynamic, ongoing process.
- ⇨ ***All About Me Board*** – in resident rooms (inside the closet), post the person's preferences and modify as needed.
- ⇨ **Share resident preference information** – in rounds, huddles, clinical records, resident profile cards, "I Care" planning process (story), or on a white board. Once you've learned what a resident likes and dislikes, inform others, as appropriate, so that all can honor those preferences – include *Environmental Services, Maintenance, Nursing, Chaplaincy, Finance, Dining.*

STEP 4: ENCOURAGE STAFF TO HONOR AND FULFILL RESIDENT PREFERENCES

- Staff with more developed **observational skills** may be able to adapt care to resident preferences. Building observational skills can be a focus for hands-on staff training.
- Support staff in **brainstorming** ways to meet residents' preferences. (See *Ensuring Resident Choice* tip sheet.)
- Encourage staff to be **flexible and creative** in developing new strategies to address preferences.

> *"When they started asking how important things were to me, I thought, 'Are you serious?' No one had ever done that before. It feels like they are listening to me and we are 'in this together.'"*
>
> *Felicia – Nursing Home Resident*

STEP 5: LISTEN AND RESPOND TO STAFF CONCERNS

Preference assessment is a new concept for many nursing home staff members. Naturally, they may have concerns and questions about how the process will work. **Engage in honest, ongoing dialogue** about anticipated problems and possible solutions to support culture change and build buy-in. Typical concerns are discussed below. Explore further questions that arise with all nursing home staff members (social workers, recreation staff, dieticians, food workers and nursing). Check in routinely to address issues that surface day-to-day in honoring resident preferences.

Will asking residents about their preferences increase the workload?

When you start asking residents about their preferences, they often report feeling happier, which makes life easier for staff. Residents who feel they are not being heard can become more demanding. Anticipating this dynamic, and **asking residents upfront** about their preferences, **can lighten the load** for staff over time.

Are we raising expectations for care that cannot be met?

It's natural to worry that residents will make impractical, "over-the-top" requests. Yet **most resident preferences are realistic**. Residents are less likely to be anxious, fearful or unreasonable when they know staff members listen to them, pay attention to their choices and respond thoughtfully and creatively. This works best when you know the personalities involved. Talk with residents to work out issues and come up with compromises.

How do you prioritize resident preferences?

At times, it can be challenging to figure out how to meet individual preferences – for instance, when six residents in a household indicate that it is very important to go to bed at 10 pm. If only two staff members are assigned to the group, this preference seems unlikely to be met. However, **empowering staff to connect on the issue and think creatively along *with* residents** can lead to a successful outcome**.** Hold a neighborhood meeting and discuss the bedtime dilemma with residents. Perhaps some will say that their important preference is to be *asleep* by 10 p.m. but they are willing *to get into bed* at 9:30. An alternating schedule also might meet the needs of the majority. When staff and residents collaborate, they can devise inventive ways to fulfill preferences.

What about family members? Don't they add more work?

Residents who are awake, alert and oriented have a right to make their own decisions. Family members often advocate for their loved ones' interests, but they aren't always realistic about the person's needs and preferences. Usually, **talking with families** can resolve differences and lead to an **effective, caring partnership**. However, routinely documenting preferences can protect residents' autonomy in situations where family members try to overrule a resident's wishes.

About the Series:

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BENEFITS OF RESIDENT CHOICE

Choice is a basic right for every person. Research shows that the positive feelings associated with choice and autonomy boost physical and mental well-being among individuals of all ages, and in particular among older adults. Studies indicate that nursing home residents with greater choice about their care experience a deeper sense of purpose and control over their lives and report higher levels of satisfaction, a key indicator of quality. Consumers and their families, provider organizations, and government regulatory agencies increasingly value resident-directed care as an important component of quality.

This tip sheet identifies ways to support and assure that nursing home residents can state their preferences and direct their care as much as possible. This resource reflects best practices among nursing home staff and administrators to overcome logistical and cultural challenges to respect individual preferences for daily schedules, activities and interactions.

CULTIVATING A CULTURE TO ENSURE RESIDENT CHOICE

Organizational leadership sets the stage to create a community that respects and honors resident choice. Key steps are:

- ✓ Make a **top-level commitment** to prioritize and honor resident choice. Communicate this priority to the entire organization.
- ✓ Cultivate a **culture** that empowers residents to voice their opinions, and ensures staff are receptive and responsive.
- ✓ Invest resources in **training all staff** -- including volunteers, activity and social service professionals, nursing assistants, housekeeping, nutrition, transportation and office staff -- to *listen* carefully to residents, *honor* their preferences, and convey *respect* through every interaction. Keep the learning going – at team meetings, invite staff to share examples of how they are meeting resident choices. Celebrate success!
- ✓ Promote understanding that **residents usually are realistic in their requests**. Contrary to popular stereotype, residents generally do not make extraordinary or unreasonable demands ("for surf and turf every night").
- ✓ Empower staff to identify and **overcome obstacles to resident choice** – for example, through flexible scheduling to allow waking and bathing times that align with individual preferences.
- ✓ Empower your **resident council** to find new ways to promote resident choice.

STRATEGIES TO ENSURE RESIDENT CHOICE

Practical ideas that have worked successfully in communities include:

- ➢ Encourage your staff to **use a tool such as the *Preferences for Everyday Living Inventory (PELI)*** to ask residents about their preferences and document the information so that it is available to the full care team (See *PELI Tip Sheets: How to Get Started* and *Interview Tips).* Along with nurses and social workers, encourage certified nursing assistants with consistent assignment to complete the *PELI* with residents.
- ➢ Systematically **incorporate resident preferences and choices into care plans**. For example, use "I" statements when discussing a problem and goal in care planning. Include preferences, such as "I like having coffee with cream

and sugar immediately when I wake up at 6 a.m." or "I don't like to get dressed until I see the newspaper and have breakfast."

- Work diligently and creatively in **partnership with administrators, staff, residents and families** to resolve challenges to meeting resident preferences.
- Offer choices and **activities that are meaningful** to residents and tailored to their strengths and abilities (e.g., it may not be possible to play baseball, but a resident can play on the Wii).
- Start a **Quality Assurance** and Performance Improvement (QAPI) initiative to track organization-wide data about resident preferences and the extent to which they are met. Consider using tools to track progress in matching care to resident preferences, such as the *PELI*, Advancing Excellence Campaign for America's Nursing Homes Person-Centered Care (PCC) Goal, or Match Quality Indicator.
- Invite **resident council** members to share how they would prioritize options for community improvements (e.g., adding a butterfly garden or outdoor thermometer, labeling trees and flowers, and notifying residents when someone in the community passes away).
- **Work with families** to help them understand that residents drive decision-making. While families may disagree with a loved one's choice, the resident is in control. For example, families often want their relative to be more involved in activities, yet the resident may decline to participate (see *PELI Tip Sheet: Working with Proxies).*
- **For individuals whose ability to communicate is limited** due to cognitive or other impairment, encourage family members to weigh in on likely preferences. Also, ask staff to observe residents' responses to care, tasks and activities to identify clues, such as a smile or laugh, indicating that a preference or choice is being honored (see the *EPASS* tool and *PELI Tip Sheet: Working with Proxies*).
- Create PCC huddles for staff to **share positive stories** about their experiences promoting resident choice.
- Create a preferences kiosk for staff, and use flip charts or electronic tools to communicate resident preferences for daily living.
- Create a process for **reassessing preferences periodically**, particularly if the resident is experiencing depressive symptoms, pain, or anxiety.
- Ask staff to bring examples of **preferences that are difficult to fulfill** to team meetings. As a group, brainstorm solutions.

> "We didn't always encourage our residents to tell us what they prefer. We thought it would be too hard to meet their needs. But it turns out we can! We might need to put our heads together to problem solve, but we (residents, staff, and family) recognize we are all better off that way."
>
> *- Director of Nursing, Ohio*

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Preference Based Living

PREFERENCE ASSESSMENT | 6: TOP PREFERENCES ACROSS LTSS SETTINGS

IDENTIFYING TOP PREFERENCES AS A STARTING POINT FOR PLANNING CARE

What are the top preferences of older adults receiving long-term services and support? Do preferences differ by care setting? The answers to these questions can be useful for organizations seeking a starting point to enhance person-centered care in a variety of settings.

This tip sheet highlights top daily living preferences among nursing home residents and older adults who receive home and community-based services. Findings from a recent study reveal areas of shared priorities between the two groups. The findings also highlight the diversity of older adults' preferences and the importance of **asking each individual about his or her wishes for everyday life**. The answers to these questions provide the foundation for person-centered care.

DATA ON TOP PREFERENCES SUPPORT SHARED PRIORITIES

The research is based on responses to the *Preferences for Everyday Living Inventory (PELI)* from two different samples of older adults: 255 individuals living in nursing homes, and 528 receiving home and community-based services. All respondents answered *PELI* questions independently and rated psychosocial preferences items on a scale from "not at all" to "a lot" or "very important."

Ten preferences were rated as important or very important by 75% of nursing home residents as well as by consumers receiving home and community-based services. Most notably, **more than 90% of respondents in each group rated "having regular contact with family" as an important priority**. Having privacy, choosing what to eat and when to bathe as well as having activity options also were important preferences for most in both groups.

Top 10 Preferences:

- Having regular contact with family
- Choosing what to eat
- Going outside
- Having privacy
- Music
- Having regular contact with friends
- Giving gifts
- Traveling or doing things away from here
- Choosing the time to bathe or shower
- Watching or listening to TV

One caveat: This list represents only the top preferences for older adults in the two survey samples. Of course, each person has unique priorities that should be explored and honored to promote a satisfying daily life. (Note that the list above is not presented in rank order.)

PREFERENCE DIFFERENCES: NURSING HOME VS. HOME AND COMMUNITY-BASED SERVICES

An additional analysis highlights nuances in preferences expressed by nursing home residents versus individuals who receive home and community-based services. When researchers looked at the top 10 priorities for each care setting separately, one preference – the desire for **family contact** -- **was at or near the top of both lists**.

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Among nursing home residents only, top preferences focused on:

- **Relationships with staff and those involved in care** -- staff show you respect, staff show they care about you, choose who you would like involved in discussions about your care and choose your medical professional.
- **Personal care** – how to care for your mouth and how frequently to bathe.
- Aspects of the **environment** -- take care of your personal belongings or things and keep your room at a certain temperature.
- **Emotional concerns** – doing what feels better when you are upset.

Top concerns among the home and community-based services group centered on:

- **Activities** -- spending time outside, being active at certain times of the day, music, giving gifts, and traveling.
- Aspects of the **environment** – privacy and keeping possessions in a certain place.
- **Meals** -- choosing what to eat.

This summary of priorities may help providers plan next steps in enhancing person-centered care within and across care settings.

RECOMMENDATIONS FOR PRACTICE

This research suggests that organizations should consider focusing on fostering opportunities for older adults to **connect with family and friends – through visits, email, letter writing and video**. Other priorities might include meeting preferences for meals; activities such as spending time outdoors, enjoying music or creating small gifts for others; privacy; and choice in bathing schedules.

The findings also highlight the diversity of older adults' preferences and the importance of **exploring each individual's priorities for everyday life**, and the need to **capture and be responsive to changing priorities** as people move across settings of care.

Conversations prompted by the *PELI* are an effective way to gather this information. More importantly, these **conversations build and strengthen meaningful relationships among individuals and caregivers** across diverse settings. When people of any age feel that their wishes are heard, understood and respected, this reinforces their sense of connection, competence, independence and quality of life.

Gathering results from PELI interviews can help focus your organization's Quality Assurance and Performance Improvement initiatives. For example, if having regular contact with family, and spending time outside, are key issues for your clientele, a task force might explore: How well are we meeting these preferences? And how might we improve? You can track trends over time to see your progress.

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WHY USE PREFERENCES FOR CARE PLANNING

Using the *Preferences for Everyday Living Inventory (PELI*) to personalize care offers important benefits for residents, families and communities. Understanding and meeting preferences:

- Enhances nursing home residents' autonomy, quality of life and physical and emotional wellbeing.
- Supports more effective and holistic care planning.
- Increases satisfaction among residents and their family members.
- Strengthens trust and communication among residents, family members and nursing home staff.
- Complies with regulations requiring that care plans reflect residents' voices and preferences so that each person can experience a meaningful and enjoyable life.

PREPARING FOR THE CARE PLAN MEETING

A *PELI* interview is just the beginning! The next steps are to **summarize resident preferences for the care team and invite key players to the care planning meeting.** Before the meeting, one or more care team members can review the resident's *PELI* responses and draft simple statements that capture the individual's preferences for team discussion. One approach for these summaries speaks in the resident's voice:

- Personal Care Preferences: Consider my most important preferences, such as *[choosing what clothes to wear]* in order to help me engage positively in care that I can do myself.
- Recreation Preferences: Consider my most important preferences, such as *[doing my favorite activities: reading, painting, gardening]* in order to help me enjoy my leisure time.

Who should you invite to the care planning meeting? **Best practice is to include the attending physician, plus representatives from social services, therapeutic recreation, nutrition services, nursing and a direct care worker**. Of course, always encourage the **resident and family member**, or another person of the resident's choosing, to attend.

Federal regulations now require the input of a direct care worker in the care plan. The Pioneer Network has developed a tip sheet on *Involving CNAs in Care Planning*. This excellent resource discusses ways to help direct care workers prepare for and participate more confidently in care planning meetings. Find the tip sheet at https://www.pioneernetwork.net/wp-content/uploads/2016/10/Involving-CNAs-in-Care-Planning-Tip-Sheet.pdf.

Note that you can **interview direct care workers to gain their perspective before the care planning session**, if they are unable to attend. Ask questions such as: "*Has there been any change in cognition or function of the resident?", or "Mrs. Smith said choosing what clothes to wear was important to her. How has that been going?"*

DEVELOPING CARE PLANS THAT BUILD DIGNITY, PRIDE AND SUCCESS

Each care plan should reflect and honor the individual's unique strengths and wishes. **The aim of the care planning team is to develop realistic, achievable goals that support the resident's priorities and account for their unique needs, challenges and strengths.** Use language that builds dignity and pride – for the resident to review and approve. Key elements include:

- Tailor activities and services to each resident's interests and functional abilities. Well-crafted care plans can reduce stress, agitation, depression and other signs of discomfort.

- Look for ways to solve obstacles in meeting preferences. Think creatively and "out of the box" to support the resident's top preferences and priorities.
- Reassess the care plan at regular intervals or when functional levels change.
- Document the plan clearly and concisely so that team members across shifts can work toward goals consistently.
- Keep care plans open and flexible. Small changes can occur without formal care planning meetings.

To build dignity and promote positive outcomes, use a strength-based care planning approach that addresses functional barriers to preference fulfillment, as shown in the chart below.

Functional barriers to preferred activities	**Strength-based approach**	**Examples of creative adaptations to encourage participation**
Physical: Ability to complete task with previous skills has changed.	Use adaptive equipment or approaches	• Provide large print or audio books • Add raised planters for gardening
Cognitive: Frustration with complex tasks due to decreased comprehension or problem solving.	Simplify tasks. Increase resident's confidence through encouragement and small successes	• Offer two outfits to choose from, not three, in order to ease decision making • When asking a question, allow more time for the client to respond
Social/Environmental: Prefers privacy and/or quieter environment.	Perform tasks one-on-one or in a small group	• Form small groups for individuals with comparable skills or functional levels
Social: Difficulty adjusting to a new environment because prior social supports are less available.	Support adjustment and facilitate social interactions	• Incorporate personal items into the clients' day (e.g., family photos in the room) • Introduce client to peers with similar interests and functional levels
Mental health/social: High anxiety, diminished ability to manage stress.	Provide support at a slow pace in synch with resident reactions (i.e., monitor for positive or negative response)	• Whenever possible, bring preferred activity to resident (e.g., knitting) • Introduce relaxation exercises, such as yoga, meditation and other techniques • Provide opportunities for independent leisure and one-to-one interventions • Develop a peer mentoring program, where residents who successfully manage stress assist others dealing with this issue • Play familiar music in the comfort of the resident's own room. Consider the Music and Memory program (see musicandmemory.org/

STAYING ALERT TO CHANGING PREFERENCES

Keep in mind that **using the *PELI,* and developing preference-based care plans, is an ongoing process, not a one-time task**. Ideally, communities use the *PELI* to assess a resident's preferences and adjust the care plan at quarterly intervals, along with Minimum Data Set 3.0 (MDS) reviews.

Also, **it is important to reassess preferences when the resident experiences a significant change in status**, such as an acute illness or a decline in cognition, or when the resident **loses interest in a preferred activity**. When a resident who has always enjoyed going outside suddenly is no longer interested, explore the reasons. The change may signal a decline in the individual's physical or emotional wellbeing.

CASE EXAMPLES

Case Study A: Mrs. Smith has mild cognitive deficits and arthritis that have led her to feel less satisfied with her favorite activity, knitting. In a discussion with her daughter, she shared that she does not like to knit in large groups.

Client's priorities and strengths	Goal	Supports for goal
Mrs. Smith: I will feel more satisfied with my favorite activity, knitting, when I feel more supported.	I will participate in a smaller knitting group that meets two or three times per week (with more supports).	• Organize a knitting group with a small number of participants. • Offer Mrs. Smith the opportunity to make choices regarding color of yarn or current knitting project. • Adapt the project: use step-by-step tasks, such as winding a ball of yarn for others. • Provide cues in moments of confusion.

Case Study B*:* Mr. Jones has moderate dementia. While he often exhibits pleasant behavior, he also has episodes of aggression, agitation and disrobing. He is 6'4" tall. The care team has become concerned for their own as well as other residents' safety during these periods of difficulty. A conversation with his family about Mr. Jones' preferences revealed that he was an avid wine collector who enjoyed reading about wine and sharing it with others. As one of many interventions, the team developed this plan:

Client's priorities and strengths	Goal	Supports for goal
Mr. Jones: I will feel less agitated and am less likely to experience the urge to disrobe when my hands and mind are occupied with my genuine interests.	I will look at magazines and documentaries on wine to decrease my feelings of agitation.	• Ensure access to wine magazines. • When agitated, provide with conversation about wine, wine magazines or documentaries about wine.

***Case Study C*:** Mrs. Washington, a fully oriented resident who requires physical assistance to move throughout the building, suffers from moderate depression and often refuses to participate in recreational activities. Her interests are keeping in touch with old friends via the computer and interacting with children. The facility only has Wi-Fi access in one part of the building.

Client's priorities and strengths	Goal	Supports for goal
I, Mrs. Washington, am able to pursue my interests with little to no assistance.	By engaging in my preferences of social interaction with old friends and interacting with children, I will have an improved mood.	• Find a young volunteer (who can safely transport her through the building), with whom she can read books or play board games. • Schedule time to use the room with Wi-Fi and interact with friends via email or social media.

Preference Based Living

PREFERENCE ASSESSMENT |

Sexual Orientation and Gender Identity

INTRODUCTION

Person-centered care involves recognizing the whole person we care for and appreciating that each person has multiple identities and is multidimensional. Sexual orientation and gender identity are core aspects of a person. They affect individuals in many ways throughout one's life span. For instance, sexual orientation and gender identity influence a person's sense of self, social connections, interests, health and well-being.

This tip sheet introduces a version of the *Preferences for Everyday Living Inventory (PELI*) that your organization can adopt to address, and raise awareness of, the unmet needs of Lesbian, Gay, Bisexual, and Transgender (LGBT) older adults residing in nursing homes. By including specific questions and response options in the *Rainbow PELI* that pertains to sexual orientation and gender identity we:

- Raise awareness and educate our staff about LGBT inclusion and cultural sensitivity.
- Convey that the care team/provider recognizes and affirms the existence of LGBT individuals and families.
- Provide opportunities for individuals to self-disclose their sexual orientation and/or gender identity.
- Increase our ability to provide competent care and appropriate support to meet the needs of and promote the wellbeing of LGBT individuals and families.

Asking questions that are inclusive helps to heal the history of discrimination that the LGBT community has faced from the medical world. Even if none of the questions are answered or lead to disclosure, asking them sends the message that the LGBT community is recognized and welcomed.

TERMINOLOGY

- Sexual orientation = Describes who one is attracted to emotionally, romantically and/or sexually. It encompasses attraction, behavior and identity.
- Gender identity = A person's innermost concept of being a boy, man, girl, woman, or another gender. One's gender identity may not correspond with one's physical anatomy, or gender assigned at birth. Gender identity does not determine sexual orientation.

The LGBT community uses a variety of acronyms, such as LGBTQIA (Lesbian, Gay, Bisexual, Queer or Questioning, Transgender, Intersex, Asexual). We use the term LGBT in its most inclusive sense to include all non-heterosexual sexual orientations and/or multiple gender identities. Note that labels and terms change over time and resonate differently for people. ***Be sensitive and open to the language and labels individuals use (and do not use) for themselves. Pay attention, and use the terms individuals use to self-identify.***

"COMING OUT" – WHAT YOU NEED TO KNOW

The expression "coming out" refers to the act of disclosing or revealing one's own sexual orientation or gender identity (this includes self-discovery, coming out to one's self). This is an ongoing process. People are unique, and each person has a different coming out experience. Important aspects of this process to consider are:

- Be open to learning about each person as a unique individual with a unique life journey.
- Some people come out only to a few individuals in their lifetime. *Respect this confidentiality*.
- Not everyone self-identifies with a label or wants to be put into a category. *Do not make assumptions about what term or label a person uses to describe their identity.*
- During an individual's lifetime, their sexual orientation and/or gender identity may change.
- *Listen carefully to the words individuals use*, as people may talk in code or drop clues to disclose or "test the waters" to see if it is safe to come out to a certain person or within a certain situation. For instance, someone might say that they are *"part of the family," "a friend of Dorothy," "on the down low," or "have a roommate."*
- "Outing" is when someone reveals another person's sexual orientation or gender identity without permission. Each person has the right to decide whether and how to discuss and reveal their sexual orientation and gender identity. *Respect this decision.*

No one should be forced to disclose their sexual orientation and/or gender identity. It is a privilege to have someone feel comfortable and safe enough to come out to you. But they may not want that information shared with others. Only document on the medical record or disclose to the care team what an individual has consented for you to share.

FOLLOW-UP QUESTIONS FOR THOSE WHO CHOOSE TO DISCLOSE

- Individuals may talk in "code". Don't be afraid to ask them what a "code" word means. For example, say: "I want to make sure I understand you fully, what did you mean by ____?"
- Someone may disclose to you, but not want the information shared with others. If someone discloses, follow up with: "Thank you for sharing. Are you comfortable with my sharing this information with the rest of the care team?"
- Honor the person's request for disclosure. If a person does not wish to share this information with anyone else on the care team, do not document the information in the medical record. Explain that if they change their mind at any point, the information will be used only to ensure the best possible care and support.

IMPLEMENTATION SUGGESTIONS FOR PROVIDERS

- Offer cultural sensitivity training for LGBT older adults as in-service training for staff – *at all levels of the organization.*
- Provide LGBT resources for individuals receiving care and their loved ones.
- Have an LGBT champion within the organization who can support other staff and individuals receiving care.
- Consider creating a Task Force or Employee Workgroup to inspire culture change and educational efforts.
- Consider participating in the Healthcare Equality Index (HEI): http://www.hrc.org/hei
- Display a rainbow flag, poster, brochure, sticker or sign from LGBT organizations, such as Human Rights Campaign, National Resource Center on LGBT Aging, SAGE, PFLAG, Fenway Institute, GLMA, GLAAD, or the National Coalition for LGBT Health. Environmental cues can communicate visually to individuals that the LGBT community is welcomed, recognized, and embraced.
- Build a trusting relationship with the interviewee prior to the *Rainbow PELI* interview.
- Conduct *Rainbow PELI* interviews in a safe space (in a private space).
- Be mindful that this may be the first time the individual is asked about their sexual orientation and/or gender identity, and they may feel uncomfortable. To ease concerns, explain that we ask everyone these questions because we don't want to make assumptions about who each person is. We want to assist everyone to thrive and flourish.
- Remind people that they can ask staff not to document information they share in the interview. The information can always be kept confidential, if that is what they prefer.

WHERE YOU WILL FIND CHANGES TO THE *PELI*

The *Rainbow PELI* adds options to follow-up questions in *the PELI-NH Full* version. For example, if someone says being a member of a club is very important, we added LGBT club and PFLAG as options. Follow-up questions and response options also provide opportunities for an individual to disclose their gender identity and expression. This includes providing a wider range of options for preferred pronouns for each person. We do not want to assume we know someone else's sexual orientation and gender identity.

Do not assume. Let people tell you who they are.

New sexual orientation and gender identity follow-up questions and response options included in the *Rainbow PELI* are:
Q01, Q07, Q20, Q30, Q32, Q34, Q45, Q47, Q48, Q49, Q53, Q54, Q60, Q67, Q68

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