

The Smart Consumer's

guide

to Quality Person-Centered
Nursing Home &
Assisted Living Care



Florida**Pioneer**Network

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Welcome to The Smart Consumer's Guide to Quality Person-Centered Nursing Home & Assisted Living Care

Many people don't think about nursing home and assisted living options until someone they love is in a crisis. They simply don't know where to begin or even what the best questions are to ask.

Informed consumers play an important role in driving demand for a new model of person-centered care. Many long-term care communities were developed based on an institutional, regimented model of care, based on efficiency for the organizations *providing* the care but do not focus on the individual preferences of those *receiving* care.

More than a decade ago, a national movement to re-invent nursing homes started to emerge. This movement is often referred to as the "culture change" movement; a social movement to radically transform nursing homes and other long-term care communities from hospital-like institutions to more humane, home-like models that embrace flexibility and self-determination. Culture change seeks to reinvent nursing homes and assisted living communities so that the voices of elders and those working with them are considered and respected.

The Smart Consumer's Guide has been created to help you determine the level of person-centered care that individual communities offer. It identifies you as an informed consumer who knows what to ask when seeking a place for your loved one to live.

This guide offers key questions to ask in both nursing homes and assisted living communities to determine the level of person-centered care that can be expected. We encourage you to take notes as well. You may not get good answers to all your questions, but in a competitive market place, it is very important for providers to know that we place a high value on our elder's quality of life.

For more information, please visit www.floridapioneernetwork.org

Did You Know?

Florida Pioneer Network is part of a national movement to create models of compassionate, person-centered long-term care, which is often referred to as the "culture change" movement. We educate, connect and support those who, like us, want to move away from rigid institutional models of care to settings where an individual's dignity and choice are preserved; and their voices, and those of their caregivers, are heard and respected.

Person-Centered Values and Principles

- Know each person
- Each person can and does make a difference
- Relationship is the fundamental building block of a transformed culture
- Respond to spirit, as well as mind and body
- Risk taking is a normal part of life
- Put person before task
- All elders are entitled to self-determination wherever they live
- Community is the antidote to institutionalization
- Do unto others as you would have them do unto you
- Promote the growth and development of all
- Shape and use the potential of the environment in all its aspects: physical, organizational, psychosocial/spiritual
- Practice self-examination, searching for new creativity and opportunities for doing better
- Recognize that culture change and transformation are not destinations but a journey, always a work in progress.

(Source: Pioneer Network)

Key Questions for Nursing Homes

Person-centered care allows elders to make their own choices, continue familiar routines and maintain their dignity after moving into the new setting — or in other words, be at home wherever home may be.

While it is true that we all value our independence and autonomy, it is an undeniable fact that many elders will still need nursing home care. There are many options available, and many homes to choose among. Here is a set of questions that was developed by Pioneer Network — the nation’s leading culture change network — to help families determine whether or not a nursing home is engaged in person-centered care.

As you tour the home, notice who is talking to whom. Pay attention to how residents and staff are interacting and communicating. Listen for conversations that indicate people really know one another in a meaningful and personal way.

How is your nursing home involved in culture change and person-centered care?

Listen for: “We have a committee that works on making our place a home for residents who live here. Residents and families serve on the committee. Staff members go to conferences to learn more. Several of our staff (including direct care workers) have visited other places involved in culture change. Staff members have taken training in person-centered care such as Eden Associate training. We have consistent assignment so that our staff can get to know the residents they are caring for including their individual needs and wishes.”

How are you going about transforming your nursing home into a place that is less like an institutional or hospital setting, and more like a home?

Listen for: “We are putting organizational changes into place that give more voice to residents, family members and the people who are closest to the residents, including CNAs. We are meeting regularly as a staff to discuss new and better ways to deliver care to allow residents to shape their day according to their own comfortable and familiar routine.” Keep in mind that pleasing touches like interior decoration, plants and pets are very nice, but building community and accommodating individual choices is what culture change and person-centered care are truly about — even for residents with dementia or other limitations.

How will you get to know my family member?

Listen for: “It is very important for us to really get to know each person who lives here. We have a questionnaire for your family member to fill out that helps us get started. If the person is not able to do this (because of dementia, for example), we want you to help us get to know your family member. Then we will talk together and spend time together. We will learn about his or her preferences, past, favorite activities, and goals and wishes for the future. Everyone on the staff will get to know your family member.”

Do the CNAs/nursing assistants take care of the same group of residents each time they work, or do you rotate the assignments after a period of time?

Listen for: “Consistent Assignment.” “With few exceptions, our caregivers care for the same group of residents each time they come to work.”

Will my loved one be awakened at a set time in the morning or will she have a choice?

Listen for: “Residents may choose to sleep as long as they want without being awakened.”

Did You Know?

There is a difference between nursing home and assisted living care. Technically known as a Skilled Nursing Facility, a nursing home provides 24-hour-a-day skilled nursing care and related services, or rehabilitative services for the injured or disabled; and requires the services of licensed medical professionals.

What is your policy regarding food choices and alternatives?

Listen for: “Let me show you a list of the alternatives we always have on hand if someone does not like the main entree being offered. Do you think your loved one would be satisfied with these? If not, we can usually accommodate her wishes.”

Can my loved one be given a shower/bath when he or she chooses?

Listen for: “Yes. We can accommodate a person’s lifelong pattern of bathing. Plus, we understand about the special needs of persons with dementia. We have many creative ways to keep people clean, so we can adapt to their preferences and comfort and still maintain cleanliness.”

What type of recreational activities are offered here?

Listen for: “We offer a wide variety of meaningful and purposeful activities. Residents have input into what is offered. Many of our activities are also spontaneous. Our CNAs do activities with residents based on what the resident likes to do, including at night for those who are awake. We also have someone here in the evenings and on weekends to engage residents.”

How do you build a sense of community, and give those who live here a voice in the decisions about how things are done?

Listen for: “Residents are part of the home team. We have an active Resident Council. Community meetings, discussion groups neighborhood or household meetings are held weekly with residents, staff and invited family members. Residents have a say in who cares for them.”

How do you meet the special needs of people who have some type of dementia?

Listen for: “We educate our staff on how to best communicate with people with dementia. Because we have consistent assignments, staff know the residents well and can anticipate and meet their needs in flexible, creative ways. We also support and teach staff how to problem-solve difficult situations. Our caregivers are involved in Alzheimer’s Association or other dementia care programs.”

There are many ways a home may choose to put their culture change values into practice. For example, you might hear words like “person-directed,” “resident-directed,” “person-centered,” “neighborhood,” “household model,” “individualized care,” “Eden Alternative,” or “Green House.” Some of these are organizational approaches, some related to a philosophy of care and some are organizations that offer training and staff development. These are wonderful words to hear, but feel free to ask what they really mean in terms of “walking the walk” on a daily basis.

What is the role of family members? Do you have a Family Council?

Listen for: “Family members may visit here any time, volunteer, and participate in our Family Council. Let me provide you with a Family Council meeting schedule. Family members can always speak to any member of our staff to discuss their loved one’s needs and preferences.”

Do you have a rehabilitation team and access to therapists such as speech pathologists, physical therapists and occupational therapists?

Listen for: “We have licensed therapists on staff. We can provide one-to-one therapy, and our therapists also advise us on such things as how to adapt a room or bathroom to best meet individual needs, and how to transfer a resident from chair to bed in the most comfortable way.”

Do you measure the turnover of your staff (defined as the average percentage of staff who stop working at the home each year)? If so, what is the turnover rate for your direct care workers (CNAs, nurse assistants)?

Listen for: Any number under 40 percent. (The national average is 70 percent.)

Do you measure the turnover rate of your licensed nursing staff? If so, what is your turnover rate of licensed nurses?

Listen for: Any number under 30 percent. (The national average is 50 percent.)

Do you measure staff satisfaction? If yes, what do you do with the satisfaction survey results?

Listen for: “Yes. We measure the morale and satisfaction of our staff with a survey and by meeting with them in small groups. We know that if our staff feels respected and supported, they give better care to residents. We use what we learn from the survey to make improvements.” Ask for a recent example.

Do you also measure resident satisfaction each year?

Listen for: “Yes. We measure the satisfaction of our residents by using a survey and by meeting with them in small groups. We use what we learn to make improvements.” Ask for a recent example. Ask residents about this.

Do you measure family satisfaction?

Listen for: “We do. Family opinions are important. However, we understand that our “customer” is the person living here.”

What is your organization’s policy regarding the use of “agency” nurses and “agency” CNAs (people who are brought in from the outside who are not your regular staff)?

Listen for: “Only our own nurses and aides work here. Only in a dire short-staffing emergency do we bring in people from an outside agency.”

What is your mission statement? Is staff able to share the mission in their own words and indicate that it is meaningful to their work?

Listen for: “Our mission statement is....And we try very hard to make our mission not just words but part of daily life for people who live and work here.”

To get a feel of the tone of the nursing home during your “walk-about,” look at the colors (furniture, walls, floors), lighting, real or artificial plants, bird cages and fish tanks, other animals, smells, lighting, signs, elements of privacy, options for sitting alone, conversation areas, and residents’ facial expressions. Are staff and residents interacting in what looks like interest and kindness?

Look at the types of activities that are posted. Check to see if Resident Council and Family Council materials, and ombudsman contact information, are posted in obvious places and at a level where a person in a wheelchair could read them. The last report of the state survey should be available for you to review. Talk to residents and families when you are visiting. Ask them how they feel about the place and if they would recommend it. Remember that if you ask this in the presence of a staff person, individuals may fear sharing negative comments and so may give you an inaccurate impression.

Key Questions for Assisted Living

Did You Know?

Assisted Living is a home for older adults with some combination of on-site supportive services (ranges from personal care, to congregate meals, laundry service, housekeeping, call buttons, etc.). Some provide limited nursing care.

In Florida, Assisted Living Communities and Adult Family Care Homes are licensed by the Florida Agency for Health Care Administration. Options range from small houses where 3-10 residents receive care to larger communities of over 100 residents and everything in between.

What to look for during a tour of the assisted living community

Show up 10 minutes early to sit and observe the general feel of the place and the environment. Talk to residents and families when you are visiting. Ask them how they feel about the community and if they would recommend it. Remember that if you ask in the presence of a staff person, individuals may fear sharing negative comments and so may give you an inaccurate impression. Ask to see the assisted living community's most recent state survey—even if you have already seen it online.

If after the tour, you are sincerely interested in the community, return for an unannounced visit preferably during a meal or scheduled activity. How does the staff handle your surprise visit? Do things look different than they did during the tour? Talk to residents and family members without staff present to find out how they like the community.

This is your opportunity to ask more specific questions about person-centered care and what the assisted living community is doing, if anything, with person-centered care. Listed below are some general and specific things to ask and to listen for in the response. These are not the only “correct” responses, but they will give you a general idea of what you might hear that indicates work toward creating home for residents.

How do you welcome a new resident?

Listen for: “We have a welcoming committee made up of residents and staff that makes a new resident feel special — that everyone is so glad he or she is there. For the first few weeks, a welcoming committee ‘buddy’ stays in close contact with the new resident, making sure that he or she is adjusting well, meeting new people, etc.”

How will you get to know me/my loved one? (or whoever is the potential resident)

Listen for: “It is very important for us to really get to know each person who lives here. We have a questionnaire for the resident to fill out that helps us get started. If he or she is not able to do this (because of memory loss, for example), we want you to help us get to know them. Then we will talk with them and spend time together. We learn about their preferences, their past, what they enjoy doing now and their goals and wishes for the future. Everyone on the staff will get to know them when they move in and on an ongoing basis.”

Do you provide training for your staff on how to provide person-centered care?

Listen for: “Yes, when we hire staff, our philosophy and practice of person-centered care is emphasized in their orientation and we provide training for our staff on person-centered care and other topics. Staff are evaluated on their ability to provide this level of care and attention.”

Are residents involved in developing their individualized care plan so it is based on their needs and preferences?

Listen for: “Each resident (and/or family member if appropriate) participates in the development of the resident’s care plan to ensure that the specific choices and preferences of the resident form the basis for the plan.”

For those residents needing personal care, is the same caregiver consistently assigned to them?

Listen for: “With few exceptions, our caregivers care for the same group of residents each time they come to work.” This is called “consistent assignment”.

How are a resident's sleep and wake times chosen?

Listen for: "Each resident wakes up and goes to bed whenever he or she wants. Breakfast is available for residents whenever they are ready in the morning."

How and when does a resident receive bathing assistance if she or he needs it?

Listen for: "We can accommodate a person's lifelong pattern of bathing. For example, if a resident prefers to shower at night before she goes to sleep, we will assist her in doing so. Plus, we understand about the special needs of persons with dementia. We have many creative ways to keep people clean, so we can adapt to their preferences and comfort and still maintain cleanliness."

What kind of meal service do you offer and do residents have many choices as to what to eat?

Listen for: "A variety of dining choices exist. Multiple menu items are available at every meal. There is a monthly meeting to discuss menus and meal planning, which is open to all residents."

Can residents have a snack or unscheduled meal 24 hours a day?

Listen for: "Yes, snacks are available 24 hours a day; there is a refrigerator and cupboards in the dining room/common area that residents can access." In small homes this may be direct kitchen access with assistance as needed.

What types of recreational activities are offered here? What if a resident prefers an activity that hasn't been offered in the past?

Listen for: "Here is this month's activities calendar. It is important to us that our activities are meaningful and enjoyable to the individuals who live here. We also ensure that staff members engage with residents in spontaneous activities that residents are interested in, whether individually or as a group." Look at the types of activities that are on the calendar. Activities should be diverse. Look for opportunities for residents to be: intellectually thoughtful, physically engaged, involved in the local community, intergenerational, looking into politics, learning something new, engaged in conversation, spiritual, etc. Look for activities that provide assistance to do some things that may have become too hard, such as sewing club, model train club, gardening.

How do you build a sense of community?

Listen for: "Residents and staff are encouraged to get to know each other and develop relationships. This happens one-on-one and in groups. There are informal and formal opportunities for residents to get together with other residents, as well as residents and staff to spend time together. Residents are encouraged to maintain ties with the community outside the assisted living community. Family members and friends are welcome to visit and join in on meals, events, celebrations, etc."

Did You Know?

The movement to transform nursing homes from institutions into homes is much more than pretty wallpaper, new paint in the dining room and a bird in the lobby. It is about elders having control, self-determination, satisfying relationships and a life worth living. It is about striving to create home, wherever your home may be.

How do you give those who live here a voice in the decisions about how things are done?

Listen for: “Residents are part of the team. We have an active Resident Council. (Listen for how the council is used.) The Resident Council runs its meetings and agenda—staff offers support as needed. Town hall meetings and small Neighborhood Council meetings are held with all residents, staff and family members on a weekly basis.” In small homes there is a weekly “kitchen chat” or some such event where anything can be brought up (birthdays, events in the community, etc.) so no aspect of life is overlooked.

Did You Know?

Florida’s Long-term Care Ombudsman Program advocates for residents living in assisted living communities and nursing homes. Ombudsmen listen, mediate, negotiate, propose and facilitate solutions to residents’ concerns and problems. They help residents and families learn about their rights and how to advocate for themselves. Call 1-888-831-0404 or 1-850-414-2323 or visit <http://ombudsman.myflorida.com> to find the Ombudsman for your community.

What is the role of family members?

Listen for: “Family members may visit here any time, volunteer and participate in our activities. Family members can always speak to any member of our staff to discuss their loved one’s needs and preferences.” Some assisted living communities may have Family Councils in which families come together to share ideas and concerns with residents and staff.

How do you meet the special needs of people who have some type of memory loss?

Listen for: “We educate our staff on how to best communicate with people with memory loss. Because we have consistent assignments, staff know the residents well and can anticipate and meet their needs in flexible, creative ways. We also support and teach staff how to problem-solve difficult situations and how to notice subtle changes in residents responses and function.”

Do you measure resident satisfaction each year?

Listen for: “Yes. We measure the satisfaction of our residents by using a survey and by meeting with them in small groups. We use what we learn to make improvements.” Ask to see the survey form and ask residents about this.

Do you measure family satisfaction each year?

Listen for: “We measure the satisfaction of our families by using a survey. However, we understand that our “customer” is the person living here.” Ask to see the survey form.

The Key Questions used in this guide were developed by Pioneer Network (www.pioneernetwork.net) through the support of the Picker Institute, adapted with permission from the work of David Farrell and the California Culture Change Coalition.

Paying for Care

Medicare:

Many mistakenly believe that Medicare covers long-term nursing home care. Traditional Medicare pays only for short-term nursing home stays for rehabilitation following an in-patient hospitalization of three nights or more, assuming other criteria are met. Medicare replacement plans (HMOs) typically pay only for care in nursing homes with which they have a contract.

For further information, see: www.medicare.gov/coverage/skilled-nursing-facility-care.html and www.medicare.gov/what-medicare-covers/part-a/paying-for-nursing-home-care.html

Personal Resources:

Most people in long-term care settings (nursing and assisted living communities) use personal resources to pay for care in the beginning of their stay. As a person's assets are depleted, he or she may qualify for Medicaid assistance.

Medicaid:

In 2011, the Florida Legislature created a new program called Statewide Medicaid Managed Care (SMMC). Those who qualify for long-term care through the SMMC program may receive Medicaid coverage through a managed care plan in a variety of settings, including at home, in adult day care, in assisted living communities, or in nursing homes. For information on eligibility and program specifics for Florida residents, please see: <http://elderaffairs.state.fl.us/doea/smmcltc.php> and <http://www.flmedicaidmanagedcare.com/>.

Long-term Care Insurance:

These insurance policies reimburse policyholders a daily amount (up to a pre-selected limit) for services to assist with activities of daily living. Long-term care policies generally become more expensive to purchase as a person ages, and elders or those in poor health may not qualify for coverage. For more information, see: <http://longtermcare.gov/costs-how-to-pay/what-is-long-term-care-insurance/>

Veteran's Benefits:

Some veteran's benefits, such as the Aid and Attendance Pension, may help pay for nursing home or assisted living care. For more information see: http://benefits.va.gov/pension/aid_attendance_housebound.asp

Get Involved

Nursing homes and assisted living communities in Florida will likely never change unless we are willing to challenge the status quo — so the time to act is now.

While we may not be able to change the fact that the aging of ourselves and our loved ones is an inevitable fact of life, we do not have to accept that the current way of delivering nursing home and assisted living care is the best way or the only way. Nursing homes and assisted living communities around the country are changing. More need to — and it is time for informed consumers in Florida to demand change from them. What can you do?

Replace Fear With Knowledge

Most people react to aging and the idea of living in a nursing home or receiving assisted living care with so much fear that the subject is nearly taboo. Unless we, as a community of informed consumers, confront our fears about aging and nursing homes we will never be able to change the system.

Be a Smart Consumer

If you are looking for nursing home care for a loved one, take along this copy of *The Smart Consumer's Guide to Quality Person-Centered Nursing Home & Assisted Living Care*. The guide includes information that will help you determine the level of person-centered care that is offered in individual settings. Plus, just having the guide with you will signal administrators that you are an informed consumer.

Speak Up and Speak Out

Talk to your friends and neighbors about the need to change the way that nursing homes deliver care. This is a consumer-led movement which is strengthened by many voices speaking as one.

Go Public

Do you know of a group or organization that would host a presentation about person-centered care and Florida Pioneer Network's consumer movement to change nursing home care? Please contact us at info@floridapioneernetwork.org.

Volunteer to Take It On for Mom

Do you want to take an active role in changing the way that nursing homes and assisted living communities in Florida deliver care — for our loved ones and one day, for ourselves? There are many ways that you can help. Visit our website at www.floridapioneernetwork.org to sign up for blog updates or contact us at info@floridapioneernetwork.org.



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