

The Smart Consumer's *guide* to Quality Care

- Nursing Home
- Assisted Living Care
- Home Health Care
- Home & Personal Care
- Hospice Care





Take It On For Mom

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Welcome to The Smart Consumer's Guide to Quality Care Section One: Nursing Home and Assisted Living Care

Many people don't think about nursing home or assisted living options until someone they love is in a crisis and needs immediate placement. Then they simply don't know where to begin the process or even the best questions to ask when seeking help.

Informed consumers play an important role in driving demand for a new model of long-term care: person-directed care. Many nursing homes around the country do not provide person-directed care. Rather they follow an institutional, regimented model of care that focuses on efficiency for the organizations that provides the care for residents but does not include consideration of the individual preferences of residents who receive that care. The focus is almost entirely on medical care and much less on what can be done to make this the individual's home that includes medical services.

In 1997 a national movement to re-imagine how care is provided developed in Rochester. This movement is often referred to as the "culture change" movement. This is a social movement designed to radically transform nursing homes and other long-term care communities and providers from hospital-like institutions to more home-like models, that embrace flexibility and self-determination by residents. Culture change refocuses care so that the individual needs

of the residents and those working with them (including families) are thoughtfully considered and become the primary driver of the care that's provided for that person.

Did you know?

It's The Law! The Nursing Home Reform Act of 1987 requires long-term care facilities that request Medicare or Medicaid funding to provide services so that each resident can "attain and maintain her highest practicable physical, mental and psycho-social well-being." The culture change movement aims to put this law into practice.

The Smart Consumer's Guide was created to help you determine the level of person-directed care provided by nursing homes, in assisted living, and by home and hospice care providers. Section One pertains to nursing homes and assisted living. Section Two begins on page 27 and includes home health care, home/personal care and hospice. This guide identifies you as an informed consumer who knows what to ask and what to expect when seeking a place for your loved one to live.

This section of the guide suggests key questions to ask in both nursing homes and assisted living communities to help determine the level of person-directed care that can be expected. Take notes as your questions are answered; the volume of information may become overwhelming. This will also allow you to review what was said and seen during the first visit to the community. You may not get fully adequate answers to all your questions. It's very important for providers to know that you place a high value on the resident's quality of living experience, not simply on receiving good and safe care.

For more information about culture change in general, please go to www.takeitonformom.com

Did you know?

Take it On For Mom is part of a national movement to create models of compassionate, person-directed long-term care, a primary feature of the “culture change” movement. We educate, connect, and support those who, like us, want to move away from the rigid institutional, medicalized models of care to settings where residents’ dignity and freedom of choice are preserved, and where their voices and the voices of their caregivers are heard and become a part of the entire care provision process.

Person-directed 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, psycho-social, 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*, www.pioneernetwork.net

Key Questions for Nursing Homes

Person-directed care allows a resident to make her or his own choices, to continue familiar routines, and to maintain her or his dignity after moving into the new setting. In other words, person-directed care allows the home to be wherever someone is living.

Regardless of how much one values independence and autonomy, a time may come when a person needs to move to receive professional care. The following is a list of questions developed by the Pioneer Network — the nation's leading culture change advocacy group — to help families determine whether or not a nursing home practices person-directed care.

First, some general suggestions about observations you might make that will set the tone for your questions:

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

SPECIFIC QUESTIONS (It's frequently useful to take notes to help you recall precisely what you saw and heard during your visit).

Did You Know?

There is a difference between nursing home care and assisted living care. Technically known as a Skilled Nursing Facility, a “traditional” nursing home provides 24 hour-a-day nursing care and related services. More recently nursing homes have added rehabilitative services for persons with an injury or a disability. Both major categories of care require the services of licensed medical professionals.

How is your nursing home involved in culture change/person-directed care?

Listen for: “We have a committee that works to make our community truly a ‘home.’ Residents and their family members serve on the committee. Staff members attend training in person-directed care and go to conferences to learn more about culture change and person-directed care. Several of our staff (including direct care workers) have visited other places involved in culture change. We have consistent staff assignment so that our staff can get to know the residents for whom they are providing care and the individual needs and wishes of these individuals.”

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

Listen for: “We’ve made changes that give residents and staff a clear voice about how care is provided, about how residents live

and interact here. We meet regularly as a staff to discuss new and better ways to deliver care that will 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 a community and accommodating individual choices is what culture change truly means. This is especially true for residents who have dementia or other physical or mental limitations.

Do you provide training for your staff about how to provide person-directed care?

Listen for: “Yes, when we hire staff our philosophy about and practice of person-directed care is emphasized in staff orientation. We provide training for our staff in person-directed care, what it is, how to “do it,” and how and why it is our only way of providing care. It’s an on-going educational and skills-enhancement process. Staff is evaluated on their ability to provide this level of care and attention. As needed, retraining and honing of practical skills is provided for the staff.”

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. Residents and family members complete a questionnaire that helps us get started. We want the family to help us get to know our residents. We will talk with residents and spend time together. We want to learn about their preferences, their history, what they enjoy doing now, and their

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 (consistent assignment), or do you rotate the assignments after a period of time?

Listen for: “We have consistent assignment. With few exceptions, our caregivers care for the same group of residents each time they come to work.” 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-directed,” “neighborhood,” “household model,” “individualized care,” “Eden Alternative,” or “Green House.” Some of these are organizational approaches, some are related to the philosophy of care, and some are organizations that offer training and staff development. These are wonderful words to hear. However, ask what they really mean in terms of “walking the walk” on a daily basis in that particular community. How are these philosophies and organizational structures converted into meaningful person-directed care for residents and families?

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

Listen for: “Residents may choose to sleep as long as they want without being awakened. We work with them and family members to find out what was normal and natural for a resident. We make accommodations for residents’ sleep-wake cycles

because not everyone likes getting up at 7 am. We can accommodate meals for a resident who goes to bed very late, sleeps late into the morning and then begins his or her day in the early afternoon.

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 entrée. We can accommodate nearly any request. Throughout the day we ask residents if they want a snack and do our best to make that food available.”

Can my loved one shower/bathe when she or he chooses?

Listen for: “Yes. We can accommodate a person’s lifelong pattern of bathing. We also understand the special bathing needs of a person with dementia. We have many creative ways to keep people clean, so we can adapt to residents’ preferences and comfort and still maintain cleanliness. This may range from sponge baths to showers to spa baths and are offered at times that are best for residents. They may be given daily or less frequently; that’s a decision residents and family members make.”

What types 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, when it’s offered, and how often it’s offered. Many of our

activities are spontaneous. We have someone here in the evenings and on weekends to engage residents. We also have activities at night for residents who are awake later in the evening or into the night. Residents are encouraged to participate in activities but are not forced to do so.

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 team within our community. We have an active Resident Council. Discussion groups and neighborhood or household meetings are held weekly with residents, staff and family members. Residents also have a say in who cares for them.”

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

Listen for: “We educate our staff on how to best communicate with residents who have dementia. Because we have consistent assignments, our staff knows residents well and can anticipate and meet her or his needs in flexible, creative ways. We also teach and support the staff in how to appropriately and creatively problem-solve difficult situations.”

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

Listen for: “Family members may visit any time day or night, may volunteer, and are strongly encouraged to participate in

our Family Council. Family members are encouraged to speak to any member of our staff at any time to discuss their loved one's needs and preferences.”

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

Listen for: “We have many licensed therapists on our staff. We can provide one-to-one therapy as needed. Our therapists also advise us on such things as how to adapt a room or bathroom to best meet the specific needs of a resident. For example, they show us how to transfer a resident from a chair to a bed in the most comfortable and safe manner. We utilize their professional expertise whenever we find an opportunity for our staff to enhance some experience for our residents.”

Did You Know?

Lifespan's Ombudsman program mediates resident care issues in nursing homes and adult homes in Monroe, Ontario, Genesee, Yates, Wyoming, Seneca, Wayne and Livingston counties. Ombudsmen are trained, independent volunteers who are assigned to long-term care facilities. Ombudsmen listen, mediate, negotiate, propose and facilitate solutions to residents' concerns and problems. They help residents and families learn to advocate for themselves. Call (585) 244-8400 to learn more or to volunteer to become an Ombudsman.

Do you measure the turnover of your staff (defined as the average percentage of staff that stop working at the home each year)? If so, what is the turnover rate for your direct care workers (e.g., 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 regularly with them in small groups. We know that if our staff feels respected and supported, they give better care. We use what we learn from the survey and from meeting with staff members to make improvements.” Ask for a recent example.

Did You Know?

Lifespan offers information and guidance for long-term care financing and helps with decisions. Call (585) 244-8400 to learn more.

Do you measure resident satisfaction on a regular basis (at least once a year)?

Listen for: “Yes. We measure resident satisfaction by using a survey and by meeting with them in small groups. We use what we learn to make changes for the benefit of our residents.” Ask for a recent example. If possible, ask residents whether they feel that the staff listens to them and where possible, acts on their suggestions.

Do you measure family satisfaction?

Listen for: “We do. Family opinions are important. We listen to suggestions and where we can, act on them to bring about positive change.”

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: “Our policy and practice is that only our own nurses and aides work here. The only exception to this is when we have a dire short-staffing emergency. Then we bring in people from an outside agency and then have them here for only as long as absolutely necessary.”

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... We try very hard to make our mission not just words, but part of daily life for residents and our staff.”

Did You Know?

New York State publishes a guide to your rights in a nursing home. To learn more about your rights, and other issues related to quality nursing home care, go to www.takeitonformom.com.

And finally a few more general suggestions to help you get a feel for the tone of the nursing home during your “walk-about.” Look at the colors of the furniture, the walls, the floors.

- What types of lighting are used in various areas within the home?
- Are there real or artificial plants within the home?
- Are there bird cages, fish tanks or animals such as dogs or cats anywhere to be found in the home?
- Are there smells other than ones coming from the kitchen?
- What types and sizes of signs are used in the home?
- Is there a sense that privacy is valued and can residents and family gather in private?

- Are there conversation areas or what one might call living rooms or dens?
- What kinds of expressions do you see on the faces of the residents?
- What about expressions on the faces of the staff persons?
- Are staff and residents interacting with what looks like interest and kindness?
- Look at the types of activities that are posted and where these postings are made.
- 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 resident in a wheelchair could read them.
- The last report of the State Department of Health survey should be available for you to review.
- Talk to residents and family members when you are visiting. Ask them how they feel about the place — would they recommend it and why or why not? Try to do this in a private setting without staff present.

Key Questions for Assisted Living Communities

Keep in mind that in New York State, the term “assisted living” can be quite confusing! There “Assisted Living Programs” and “Assisted Living Residences” that are licensed by NYS and regulated by the Department of Health. There are many other communities commonly referred to as “assisted living” that are not licensed and not overseen by the Department of Health. We call these “independent senior housing with services.” Such communities may include one or two meals, housekeeping and activities or other services. Please note that it’s best to seek guidance when attempting to choose among these levels of care.

Did you know?

Lifespan and Eldersource provide information and guidance about housing options for older adults? Eldersource also provides care management and caregiver support. Learn more at www.lifespan-roch.org or eldersource.org or call (585) 244-8400 or (585) 325-2800.

This section refers mainly to licensed assisted living homes, but questions can also be pertinent when selecting other types of housing for older adults.

Who Pays for Assisted Living?

Most often, assisted living is private pay or paid in part by a long-term care insurance policy. Medicaid may pay for care in a licensed Assisted Living Program as determined by eligibility. The private pay rate usually varies from \$2000 to \$5000 a month.

What to look for during a tour of a community.

Try to arrive for your tour ten minutes early. Sit and observe the general feel of place and the interactions between and among residents and between residents and staff. Talk to residents and families when you are visiting. Ask them how they feel about the community. Would they recommend it and why or why not? Try to do this privately as asking in front of a staff person may result in a less than candid response from the resident or the family member. If it's a licensed community, ask to see their most recent state Department of Health survey. (Also available online.)

This is your opportunity to ask specific questions about person-directed care and what the community is doing to enhance their use of person-directed care. Listed below are both general and specific questions to ask during the tour and to listen for in the response of the person giving the tour. These are not the only “correct” responses, but they will give you a general idea of what you might hear that indicates that there is a real focus on the person and on creating a true 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. For the first few weeks, a welcoming committee ‘buddy’ stays in close contact with the new resident making sure that she or he is adjusting well, meeting new people, and in general feeling comfortable about her or his new home.”

How do you get to know your residents?

Listen for: “It is very important for us to really get to know each person who lives here. New residents complete a questionnaire that helps us get started. If she or he is not able to do this (because of memory loss, for example), we want you or the family member to help us get to know him or her. We talk with new residents and learn about preferences, their past, what they enjoy doing now and as much as we can about their goals and wishes for the future. Everyone on the staff gets to know new residents.”

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

Listen for: “Yes, when we hire staff our philosophy about and practice of person-directed care is emphasized in staff orientation. We provide training for our staff in person-directed care, what it is, how to “do it,” and how and why it is our only way of providing care. It’s on on-going educational and

skills-enhancement process. Staff is evaluated on their ability to provide this level of care and attention. As needed, retraining and honing of practical skills is provided to the staff.”

(If applicable to the community)

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

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

(If applicable to the community)

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.’ Only in extreme circumstances do we use persons from an outside agency to work with our residents.”

(If applicable to the community)

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

Listen for: “Each resident wakes up and goes to bed whenever she or he wants to do so. Breakfast is available for residents whenever they are ready to eat.”

(If applicable for the community)

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 or he goes to sleep, we will assist her or him in doing so. In addition, we understand the special bathing needs of a person with memory impairment.”

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

Listen for: “We offer a variety of dining choices. Multiple menu items are available at every meal. There is a monthly meeting open to all residents in which we discuss menus and meal planning.”

(If applicable for the community)

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 with food and snacks 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 for our residents. As you can see we have a wide variety of activities; we consult our residents regularly to find out what group activities they would like to have.” Look at the types of activities on the calendar; they should be diverse. Look for opportunities for residents to be: intellectually thoughtful, physically engaged, involved in the local community, participating in a variety of intergenerational activities, participating in some way in politics, learning something new, engaged in conversation, expanding one’s outlook, and involved in spiritual activities. Be wary of too many activities in which the resident is passive, almost a bystander in that activity. Engagement is critical to continued good function.

How do you build a sense of community?

Listen for: “Residents and staff are encouraged to get to know each other and to develop personal relationships, not just professional staff-to-resident relationships. There are informal and formal opportunities for residents to get together with other residents, as well as for residents and staff to spend time together. Residents are encouraged to maintain ties with the larger community outside this community. Family members and friends are welcome to visit and join us for meals and to participate in our events and celebrations.”

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 and residents run their meetings and develop their own agendas.” In small homes there may be a weekly “kitchen chat” or some event where anything can be brought up (e.g.), birthdays and events in the community.

What is the role of family members?

Listen for: “Family members may visit at any time, are encouraged to volunteer, and may participate in our activities. Family members can always speak to any member of our staff.” 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 impairment. We also support and teach staff how to problem-solve difficult situations and how to notice subtle changes in a resident’s responses and function.”

Do you measure resident satisfaction?

Listen for: “Yes. We measure the satisfaction of our residents by using a survey and by meeting with them in small groups to discuss ‘how we’re doing.’ We use what we learn to make improvements. We specifically discuss how resident suggestions have resulted in changes so each resident understands how seriously we take her or his input.” Ask to see the survey form and if possible 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. When we meet with family members we show them how we’ve responded to their specific criticisms or suggestions, as well as how we’ve responded to the requests of the residents.” Ask to see the survey form.

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

Get Involved

Nursing homes and assisted living communities are not likely to change unless we are willing to challenge the status quo. The time to act is now.

Aging is inevitable. However we can change our current manner of delivering services and care for persons who need our assistance. How we commonly deliver this care is far from the only manner in which care can be delivered. And it is not even the best, the most efficient, or the most effective manner in which to provide care. Person-directed care can deliver care in the most humane and humanizing manner possible... and can do so at a lower cost than the current models of institutionalized care.

Did You Know?

The movement to transform nursing homes and assisted living facilities 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 residents having control, self-determination, satisfying relationships and a life worth living. It is about striving to create home, wherever your home may be.

Replace Fear with Knowledge

Most people react to aging and the idea of living in a nursing home 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 housing options for a loved one, take along this copy of Smart Consumer Guide to Quality Nursing Home/Assisted Living Care. The guide includes information that will help you determine the level of person-directed care that is offered in communities. Just having the guide with you will be an important signal to nursing home and assisted living communities 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 and assisted living communities deliver care. This change 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-directed care and the consumer movement to change nursing home and assisted living care? If so, please contact us at contactus@takeitonformom.com.

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 deliver care? There are many ways that you can help. Visit our website to get more information, further references, and information about upcoming presentations. Contact us at (585) 244-8400 or email us at contactus@takeitonformom.com.

Volunteer to Become a Nursing Home Ombudsman

Lifespan's Ombudsman program mediates resident care issues in long-term care facilities in Monroe, Ontario, Genesee, Yates, Wyoming, Wayne, Seneca and Livingston counties. Ombudsmen are trained, independent volunteers who are assigned to long-term care facilities. Ombudsmen listen, mediate, negotiate, propose and facilitate solutions to residents' concerns and problems. They help residents and families learn to advocate for themselves. Go to www.lifespan-roch.org or call Lifespan at (585) 244-8400 to learn more.

Welcome to

The Smart Consumer's Guide to Quality Care Section Two: Hospice, Home Health Care and Home/Personal Care

When you need care, whether short-term care, long-term care, or end-of-life care, you should have a choice as to where and how that care is delivered. You and your family should be active participants in planning for care as well as in providing that care (to whatever degree desired and possible). One-size-fits-all care that's thrust upon you by a provider agency, the "system," or an insurance provider is far from ideal. What you find when looking for appropriate care may be very different from this philosophy of you "being in charge." It does not have to be that way. This publication is intended to help guide your selection of a provider. We believe that you deserve an active voice in all decisions about care and how that care is provided. In "person-directed" care, the care is focused on what the person needed care desires and how she or he wants to live her or his life.

This section of *The Smart Consumer's Guide* has been created to help you determine the level of person-directed care that hospice, home health care and home/personal care agencies offer. Use of the guide identifies you as an informed consumer who knows what to ask when seeking services for yourself or for a loved one. As you use this guide and talk with potential providers, we encourage you to take notes and be prepared to thoroughly discuss your care expectations.

A Brief Definition of the Terms Hospice, Home Health Care and Home/Personal Care

Hospice

Hospice care is provided for those with a terminal illness and a prognosis of living for six months or less. Hospice care is designed to provide pain and symptom management for persons who have chosen to “let nature take its course” and no longer choose to pursue curative measures to address their disease. The primary goal of hospice care is to make the person as comfortable as possible as she/he completes the final chapter of life. You will often hear hospice care described as “palliative care.” This is not entirely correct. Palliative care focuses on improving the quality of living experience for a person with any serious and chronic disease. The intent is to minimize pain and lessen anxiety so the person is better able to function and to tolerate continuing medical interventions. Palliative care may be used in a variety of settings and is not focused solely on the last months of life. Hospice care is often provided at home, in a hospice care center or in a long-term care setting. It is a means of providing specific types of care and is not “simply” a place in which that care is provided. Hospice care, regardless of the location, is provided by an “interdisciplinary” team of skilled health care professionals who collectively work to address the needs of the person and their family.

Home Health Care

Home health care is provided for people who have continuing rehabilitative and/or recovery needs that no longer need to be provided in a hospital or nursing home. People who are recovering from some type of accident or stroke, have significant wound problems, or need physical, speech or occupational therapy may need this type of care. All services provided by a home health agency are provided by skilled and licensed medical professionals. Home health care may include personal care as described below.

Home/Personal Care

Home care services are non-medical services provided in a person's home. These services are designed to address personal care activities such as bathing and dressing in addition to meal preparation, transportation and housekeeping. Home/personal care services are most often paid for privately or through long-term care insurance. Most home care providers offer a range of "caregiving" services and charge by the hour. This can be arranged through an agency or by locating "private duty" individuals. As you consider having care providers in your home, it is critical to ask the right questions to ensure that the provider's philosophy of care is focused on you as a person, what you need, and how you want those services to be delivered to you.

Questions to Ask Care Providers

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

Listen for: statements that reflect a dedication to working compassionately to meet the needs of the individuals they serve and their families while honoring the person's decisions and choices.

How will you get to know me/my family member?

Listen for: "We believe relationships are the foundation of the care we provide," and statements that indicate a process of understanding the needs of the person and her or his family. All providers should conduct an initial interview/assessment to gather information that will direct how care will be provided.

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

Listen for: "Yes, when we hire staff our philosophy and practice of person-directed care is emphasized in orientation. We provide training for all of our staff about person-directed care and how best to provide this form of care. Staff members are evaluated on their understanding and ability to provide this kind of care and attention on a daily basis to all persons to whom they provide care."

Are we involved in developing the care plan so it is based on our needs?

Listen for: “You are the most important voice in determining your plan of care, and we involve you in the process every step of the way. If you believe or we see there is a need to make changes, we will work together to find an appropriate way to meet your altered needs and to implement these agreed-upon changes. Family members are care partners and are a part of the care team. We value the perspective and input from them. Choices and options are always a part of the discussion.”

How many different staff members can we expect to be in contact with and who is responsible for the overall coordination of care?

Listen for:

(Hospice) You should be assigned one nurse case manager, a social worker, certified nursing aide and chaplain. You might also interface with a physician and a volunteer. Care should be orchestrated by a nurse. It is important to have consistency of care. After-hours care is often provided by a separate ‘on-call’ nurse who works with your primary nurse case manager.

(Home Health Care) You will be assigned one nurse case manager or managing therapist to oversee care provision. After-hours care is often provided by a separate ‘on-call’ nurse who works with your primary nurse case manager. You will have a consistent team of direct care providers helping you.

(Home/Personal Care) “We want you to get to know the people who provide care so we limit the number of people in your home. We have one person or a small team of people helping you.”

How many visits can I expect from the care team?

Listen for:

(Hospice) “A registered nurse will visit at least once a week to address any issues of pain, symptom management and to answer questions. A social worker will visit once or twice a month depending on need. A certified nursing assistant will visit two to four times a week. As an individual needs more assistance with daily activities, the frequency of visits will increase. A physician will visit at least once. Volunteers may provide two to four hours of support a week for companionship and /or respite. A chaplain may visit once or twice a month depending on spiritual needs.”

(Home Health Care) “We determine the level and frequency of care based on the specific health care needs. Insurance also plays a role in the length and number of visits.”

(Home & Personal Care) “Because this is most often a private pay situation, you determine the hours of care.”

How are your team members trained on cultural diversity, communication and compassionate care?

Listen for: “All members of our staff are educated about and knowledgeable in person-directed care principles, enhanced

communication practices, and compassionate care. We work to help our team members understand cultural sensitivity and how to implement best practices in this important care area. On-going training and education is provided throughout the year for all of our team members.”

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

Listen for: “We educate our staff on how to best communicate with individuals who have a memory loss. Because we have consistent assignments, the staff knows the people for whom they provide care and can anticipate and meet the individual’s needs in flexible, creative ways. We also support and teach staff members how to problem-solve difficult situations and how to notice subtle changes in a person’s responses and function.”

If applicable, does your medical director play a role in the provision of care?

Listen for: “Our medical director is involved in practical and direct ways.” Many home health care agencies provide a medical director for home visits. Hospice providers also have medical directors.

How do you work with caregivers who are late or do not show up for their scheduled shift in my home?

Listen for: “We always have back-up plans in place if one of your caregivers is late or is unable to come to your home. We will work to

ensure you've met the person who is coming, but if this is not possible, we will do everything we can as soon as we can to make sure you know about the 'new' person who will be helping you. We also do all we can to inform this "new" caregiver about you and specifically what you need and how those needs are to be met."

How do you handle customer complaints or caregiver conflicts?

Listen for: "We want to hear from you whenever there is a concern about our services or a specific caregiver so we can address those concerns as quickly as possible. Your satisfaction with our support and services is very important to us."

Specifically for Home Health Care Providers

What types of care services are provided by your agency?

Listen for: "Our services include skilled care that is provided by a licensed professional such as a nurse, licensed practical nurse, physical therapist, or occupational therapist, dietitian, social worker, or nurse's aide."

How long will insurance cover your services?

Listen for: a clear definition of covered services, co-pays and expected length of service.

Do you have any affiliate partnerships home/personal care or hospice companies?

Listen for: “We have relationships with other provider agencies that share our philosophy of person-directed care so seamless transitions can be made if care needs change.”

Are your caregivers licensed, bonded and insured?

Listen for: “YES!” You should be certain that the providers in your home are licensed, bonded and insured.

Specifically For Home/Personal Care Providers

What types of services are available?

Listen for: a clear definition of all services provided. Most agencies provide services based on the following:

Companion care includes meal preparation, light housekeeping, and assistance with daily activities such as letter writing, reading, and entertainment. At the companion level of care the caregiver generally does not provide direct, “hands-on” personal care or any sort of care that requires medical supervision.

Personal care includes help with what are called Activities of Daily Living (ADLs). This means assistance with eating, bathing, dressing,

and toileting as needed. This level requires a higher level of training than companion care.

Are your caregivers licensed, bonded and insured?

Listen for: “YES!” You should be certain that the providers in your home are licensed, bonded and insured.

For Hospice Only

Does your medical director play an active or passive role in the provision of care?

Listen for: statements that indicate the medical director is involved in practical and direct ways to provide care. Many hospices have medical directors who make home visits and are available via the nurse case manager.

Does hospice make death come sooner?

Listen for: “Hospice neither hastens nor postpones death and does not deliberately try to shorten or length the dying process. In some cases, hospice care can extend life.”

What happens at the time of death?

Listen for: a clear cut plan for how you and your family will be supported at the time of death. Most hospices provide a visit to

your family by an RN or other staff member at the time of death and then provide ongoing bereavement support.

What happens if the patient's condition improves?

Listen for: “If a person’s condition improves, she or he can be ‘discharged’ from hospice care and return to curative treatment or continue with their daily life as it was before hospice services were started. An individual can return to hospice care at a later time.”

What happens if we decide to seek curative treatment?

Listen for: “A person can go onto and off of hospice care as needed or enter the hospital for certain types of treatment if that treatment leads to an improvement in quality of life.”

Is hospice care limited to a period of six months?

Listen for: In the U.S., many insurance companies, as well as the Medicare hospice benefit, require that a person with a terminal illness has a prognosis of six months or less of further life to start a hospice program. Hospice is not limited to six months. Once a person is admitted to hospice, she or he can remain in hospice for as long as necessary.

Get Involved

While we cannot change the fact that our aging and the aging of our loved ones is a part of life, we do not have to accept that the current way of delivering health care services as being the best way or as the only way. Hospice, home health and home care agencies around the country are changing to become “person-directed.” You can and should have a voice in the discussion about how to most effectively provide the best care in the most appropriate fashion to you or to a loved one.

Speak Up and Speak Out

Talk to your friends and neighbors about the aging services providers in your area. Was their experience truly focused on their care as they defined it or was it a process where they had very little input to the delivery of care? This care change movement is a consumer-led movement which is strengthened by many voices speaking as one. It is time to demand care delivered in a new and more inclusive manner.

Go Public

Do you know of a group or organization that would host a presentation about person-directed care? Please contact us at www.takeitonformom.com.

Volunteer for Take It On For Mom

Do you want to take an active role in changing the way that hospices, home health and home care companies in New York State deliver care for our loved ones and one day, for ourselves? There are many ways that you can help. Visit our website at www.takeitonformom.com or contact us at www.lifespan-roch.org.

Take It On For Mom

New York Culture Change Coalition

Take It On For Mom is an initiative of
Lifespan of Greater Rochester, NY Inc.
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