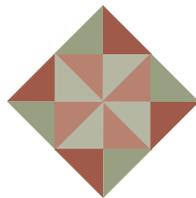


creating | home

A Guide to
Better Care Options
for an Aging America

*Advocating for Change
in How and Where We Age*



Pioneer
Network

Creating Home: A Guide to Better Care Options for an Aging America

*Advocating for Change
in How and Where We Age*

Imagine your own aging...

Will you want choices in where and how you live?

Will you want to be part of a community of people
who care about each other?

Will you act now so that all elders will enjoy a good life?

Will you join the culture change movement
to help create old age in a new way?



creating | home

This booklet was developed by Pioneer Network in partnership with:

- AMDA – Long Term Care Medicine
- American College of Health Care Administrators
- American Health Care Association
- The Coalition of Geriatric Nursing Organizations
- Leading Age, *formerly AAHSA*
- The National Consumer Voice for Quality Long-Term Care



Supported by The Picker Institute, Inc., an international non-profit organization based in Massachusetts that supports research and education in the field of patient-centered care.

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We Are All Aging

From the moment we are born, we are aging. Yet many of us fear our own aging and the dependency and loss of control that may result. Many of us have watched helplessly as our parents, spouses, or other loved ones lose their choice of where and how they receive care. Understandably, at the thought that we might have to move away from our own homes when we need long-term care, we fear losing dignity and privacy. These losses are powerful reasons for change. The present and the past do not have to be the future if we act together now.

“Old age is always a bit older than you are.”

— Jeffrey Love,
AARP

We all want to make our own choices about how and where we live. Some individuals choose to plan ahead and learn about what options are available should they ever need long-term care. Others don't think about residential care options and just say, “I never want to leave my own home.” Many parents tell their children, “Never put me in a nursing home!” But life is usually not that simple; it is important for consumers and advocates to know about long-term care options and how nursing homes and other long-term care settings can be places where we continue to have good lives.

An informed consumer makes better choices. Your choices about how and where long-term care is delivered deserve at least the same level of thoughtfulness as buying or renting a house or apartment. Since we are all getting older, we need to create a vision of meaningful choices and a strategy that will make those choices available.



What Is Long-Term Care?

Long-term care (LTC) is a term used to describe the care needed by someone who must depend on others for help with daily activities. A goal of long-term care is to help people with chronic health problems or dementia live as independently as possible. While many people think that long-term care happens only in a nursing home, in fact, most is given by family caregivers in the persons' homes.

Long-term care involves a variety of services and supports to meet health or personal care needs over an extended period of time, sometimes for the rest of an individual's life. Broadly, that includes care provided in any setting for elders or people with disabilities. These settings include private homes, adult day care, assisted living, or nursing homes. Most long-term care is "non-skilled personal care assistance," such as help performing everyday Activities of Daily Living (ADLs), which include bathing, dressing, using the toilet, transferring (to or from a bed or chair), moving or walking from place to place, and eating. The goal of long-term care services is to help you or your family member maintain functioning and quality of life at a time when a person needs to depend on others to do the things he or she used to be able to do by himself or herself.

Facts about Long-Term Care

Although we like to think of ourselves as always being independent, we are not. Throughout our lifetime we depend on others. This need often increases as we age.

- ◆ About 70 percent of individuals over age 65 will require at least some type of long-term care during their lifetime.

- ◆ 20 percent will need care for more than five years.
- ◆ More than 40 percent of individuals over age 65 will need care in a nursing home for some period of time.

(U.S Department of Health and Human Services, National Clearinghouse for Long-Term Care Information, 2008)

Definition of an Elder

“An Elder is a person who is still growing, still a learner, still with potential, and whose life continues to have within it, promise for and connection to the future. An Elder is still in pursuit of happiness, joy and pleasure, and her or his birthright to these remains intact. Moreover, an Elder is a person who deserves respect and honor and whose work is to synthesize wisdom from long life experience and formulate this into a legacy for future generations.

— Barry Barkan,
Live Oak Institute

Choice and relationships are the most important values in long-term care, but they are often not well supported in the present system, nor are their importance fully understood. However, nursing homes and assisted living communities are taking a leadership position in changing this for the better. This guide will tell you about these changes. It will provide you with information and resources to help you and your family members have conversations about the choices that are available for how and where you age. It will also explain why it is so important to work to protect your choices and your right to advocate for ongoing positive changes for the future.

In this guide, we use terms such as individuals, consumers, and elders to describe those who receive assistance. People of all ages may need supports and services to assist them in their daily lives, but many are elders. When we call older adults elders, it reflects our respect for years lived, contributions made, and wisdom gained. We hope that this guide will help you acknowledge and embrace your own aging and elderhood, and the opportunities and choices that are still to come.

What Is Culture Change?

Have you ever visited a nursing home? What was it like? Did it feel more like a hospital or like a home?

Culture change works to *create home* wherever elders live. The term culture change refers to a *transformation* of services for elders. Culture change focuses on *person-directed care*, sometimes also referred to as *person-centered care*. In this approach to care the voices of individuals needing care and those working closest with them always come first. It involves a continuing process of listening, trying new approaches, seeing how they work, and changing routines and organizational approaches in an effort to individualize and de-institutionalize the care. Person-directed care values include dignity, respect, purposeful living, and having the freedom to make informed choices about daily life and health care. Care is *directed* by and *centered* on the person receiving care.

Culture change in long-term care is about meaningful relationships and service, where caregivers and staff really know the people they care for, so that individuals can continue to live a meaningful life and feel “at home” wherever they are. Part of feeling at home is creating living spaces that are more private, comfortable, and personalized.

Another part of culture change is to support and nurture the staff who help elders and others in care settings or in their own homes. Those who provide the hands-on care in nursing homes are called “certified nursing assistants” or CNAs. Some culture change nursing homes have renamed them “resident assistants.” Caregivers who work in people’s homes are called “home health

“Our society needs an engaged and engaging elderhood because such a life stage offers the best possible refutation of the doctrine of youth’s perfection. Most of us will need to see, with our own eyes, that a valued and valuable elderhood truly exists before we voluntarily surrender our adulthood. As a society, we, perhaps more than any other people who have ever lived, need elders. We need a renewed elderhood that can help older adults become the elders they were meant to be.”

— Dr. Bill Thomas,
www.edenalt.com
July 2009

aides” or “homemaker assistants,” depending on the tasks they perform and the work they do. “Direct care worker” (DCW) is a term that applies to those who provide direct, hands-on care in any setting. It is important that these workers, whatever title they have, feel respected, like their work, and want to continue doing it. The need for these workers is growing as members of the baby boom generation are growing older.

With culture change, true relationships between residents and staff from all job descriptions flourish and a true sense of belonging and community flourish. This includes the meaningful involvement of the residents’ families, friends, and the greater community outside the walls of the building itself.

Why Do We Need Culture Change in Nursing Homes?

Today's "traditional" nursing homes were created about 50 years ago as "homes for the aged." Architecturally, many were built like hospitals and organized to be similarly run. As a result, nursing homes became regimented and task- and schedule-driven. With the advent of federal and state reimbursement for nursing home care (through Medicaid and Medicare), many regulations were written by government agencies to create and oversee better care.

Originating from a focus on illness and dependency, daily life in many nursing homes is organized around predetermined schedules and to-do lists for the staff, who may not know the resident well. Because the emphasis is primarily on quality of care and not on quality of life the resident's life often lacks choice, meaning, and purpose. There is little sense of being "at home."

The culture change movement is working to transform this institutional approach to care delivery into one that is person-directed. The culture envisioned is one of community, where each person's capabilities and individuality are affirmed and celebrated. In culture change, quality of care and quality of life are inseparable and equally important.



What Is Pioneer Network and How Is It Related to Culture Change?

In 1997, a coalition of prominent professionals in long-term care (including providers, advocates, consumers, clinicians, and regulators) began to advocate for person-directed care. They called for a radical change in the culture of aging so that when our grandparents, parents—and ultimately ourselves—need long-term care, we are given the opportunity to have a good quality of life. These “pioneers” of social change established a not-for-profit organization called Pioneer Network, which has become an “umbrella” organization for the culture change movement. This movement is spreading around the country. Its purpose is to improve the quality of life and quality of care for people who need help taking care of themselves, in order to remain as independent as possible.

At the heart of this movement is the goal to change how we *think* and *feel* about elders and our own aging. Aging can be a time of meaningful relationships and opportunities to continue to give, learn, create, and grow. Sadly, Western culture tends to look at old age as a time of just “waiting to die.” Pioneer Network and the growing movement for change sees elderhood as a distinct part of our lives, different from adulthood, with its own challenges and rewards.

The culture change movement consists of thousands of people working at every level and location of long-term care to replace the traditional approach—that is, institutional aging—with an approach that respects each individual.

Having started in nursing homes, since they are the most “institutional” and feared setting, the focus of the culture change movement has now grown to embrace all of long-term care. This move toward self-determination, information sharing, and choice is also occurring in hospitals. (see www.Planetree.org and www.PickerInstitute.org) The term patient-centered care is used when talking about promoting this approach in the hospital setting.

Pioneer Network is a leading advocacy organization for culture change. It also serves as a meeting place for all long-term care professionals, regulators, providers, consumers, and others who are committed to change and to creating environments that are life affirming, satisfying and meaningful.

“Pioneer Network is dedicated to creating the kind of care that each of us wants for our loved ones and ourselves.”

— Bonnie Kantor,
Executive Director,
Pioneer Network

What Is Changing?

Nursing homes that are involved in culture change are moving toward person-directed care. They are working to ensure self-determination, choice, dignity, and meaningful relationships for those who live and work there, as well as involving families and friends to create community. Culture change is causing all types of long-term care settings to focus on person-directed care. However, nursing homes serve as a good example of what is changing because they are often the most institutional long-term care settings.

The chart below illustrates some of the differences between traditional nursing home care and person-directed care.

Moving From Traditional to Person-directed care

| Traditional Care | Person-directed Care |
|---|--|
| Residents are told when to wake up, go to bed, eat, and bathe, based on institutional schedules and set routines. | Residents wake up, go to bed, eat, and bathe when they choose to. Staff alter their work routines to honor residents' preferences. |
| Residents frequently have different care staff. The staff do not know the residents well, so they are not familiar with their preferences. Studies find that residents often feel unknown, insecure, or scared. | The same staff take care of the same resident; they know each other and good relationships develop. This motivates staff to provide better quality care. Studies show that residents feel more secure, content, and happy. |
| Management makes most of the decisions, often without consulting the residents, families, or direct-care staff. | Management seeks input from residents, families, and staff before making decisions that affect their daily lives. Management also trains and supports staff to enable residents to make decisions. |

Person-directed care is appropriate for all residents, even those with some type of dementia, such as Alzheimer's disease. Residents with dementia are often unable to verbalize what they want, like, or don't like. The nursing assistant who consistently works with such a resident knows this information by the resident's body language, behavior, and/or information provided by the family. For example, a person with dementia may not be able to understand that she needs to be clean and, by her words and actions, refuses a bath or shower. A well-trained direct care worker, who knows the person, will have the knowledge, skills, flexibility, and equipment to find new and better ways to pleasantly assist her with washing.

Many people go to nursing homes for short stays to recover from surgery or an acute illness that required hospitalization. Even though they think of themselves as "patients" and not "residents," they too benefit from culture change. For these people, the emphasis of care is on supporting their healing, education, preparation, and choices for the next steps in their recovery.

The "look" of the nursing home is also changing. Many are creating smaller "units," often called neighborhoods. The goal is to create areas that in size and scale look and feel like normal homes, not like big institutional buildings. Forming a neighborhood does not have to include a large remodel or new building. Features of a neighborhood are smaller groups of residents, consistent assignments, and additional resident choice. For example, residents usually dine in their own neighborhood instead of a large dining room that serves the entire building.

In person-directed homes, staff members care for the same people day after day. This is called **consistent assignment** and helps the caregiver get to know each person (resident). Nursing homes with consistent assignment retain the same staff caregivers for many years (have a low turnover rate) and are not likely to use staff from temporary agencies to fill in. In general, agency staff is unfamiliar with the residents and their preferences. Therefore, they cannot meet their care needs as well as consistent staff. Nursing homes with a stable caregiver workforce often provide better care.

Some nursing homes have chosen to build new, or renovate into, separate, self-contained areas where fewer than 25 people live. They are called **households, small houses, or GREEN HOUSES®**. All three can be considered “small houses” and all have their own kitchen, private bedrooms, shared living and dining rooms, and consistent staffing in self-directed teams. They are furnished as a home would be.



In some neighborhoods and all households, GREEN HOUSES®, and other small houses, meal-times look and feel more like family dining because small groups of familiar faces (including staff) eat around a table. Food is often served family-style from bowls, instead of on trays. Living rooms have comfortable chairs and good lighting. Bedrooms are decorated with personal items and furniture. Children feel welcomed by toy boxes or play areas as part of the setting. There is no traditional nurses’ station or overhead paging. Such changes result in closer relationships and a sense of living in a real home with a community of people.

For those long-term care organizations that are not ready to renovate or construct new buildings, it is important that they begin their “culture change journey” by adopting person-directed values and implementing practices that promote choice and meaningful relationships. Then when they are ready to renovate or build new, they will likely not go with the institutional physical environment and replace it with one of the new models.

These neighborhood and “small house” models are operating in a number of states around the country, but availability varies from state to state. Many are affordable and accessible to all people, including those with limited incomes or whose nursing home care is covered by Medicaid (See Definitions for explanation of Medicaid).

It is important to understand that culture change is not just for “high-end” long-term care communities or for people of higher economic means. Culture change is happening in all types of long-term care communities, big and small, including homes caring for people with Medicaid. On average, at least half of the residents in culture changed homes are covered by Medicaid.

How Is It Changing?

There are a number of models of culture change. All share common values of choice, dignity, respect, and relationship, although they may be implemented in different ways. These models are also not the only options for implementing culture change. While some long-term care communities adopt these models, others develop their own.

Here are some examples:

The Eden Alternative

The Eden Alternative was developed in 1991 by Dr. Bill Thomas, a Harvard trained physician and geriatrician, and his wife, Judy. The Eden Alternative is so named because it is an *alternative* to the traditional institutional model of long-term care. Dr. Thomas believes that human beings do better when they are surrounded by the natural world, including not just plants, animal, and beauty, but genuine relationships with people of all ages. The Eden Alternative model is built on alleviating what Dr. Thomas describes as the three plagues of old age: loneliness, helplessness, and boredom. The Eden Alternative has ten principles, which drive how it is implemented in a long-term care community. For more information on the Eden Alternative, please go to: www.edenalt.org

The GREEN HOUSE® Project

“THE GREEN HOUSE® Project creates small, intentional communities for groups of elders and staff to focus on living full and vibrant lives. Each Green House residence is designed to be a home for six to 10 elders, blending architecturally with neighboring homes. The Green House homes are characterized by their vibrant outdoor spaces and pleasing aesthetics both inside and out. Each elder has

a private room or unit with a private bathroom. The elders' rooms allow ample sunlight and are clustered around a shared living room with a hearth, an open kitchen and dining area. The homes are relatively small, allowing many elders to get around without wheelchairs. Safety features are carefully built into each home." For more information on The GREEN HOUSE® Project, please go to www.thegreenhouseproject.org.

The Household Model

The Household model consists of self-contained living areas with 25 or fewer residents, each with their own fully functional kitchen, living room, and dining room. Staff work in multi-disciplinary work teams. LaVrene Norton of Action Pact, Inc. and Steve Shields of Meadowlark Hills Retirement Community in Manhattan, Kansas, one of the first organizations to renovate its health care/skilled nursing facility into households, define households as "Small groups of people sharing house and home while directing their own daily lives through a responsive, highly valued and decentralized self-led service team that is supported by values-driven, resource-bearing, leadership philosophies, practices, policies, and systems." For more information on the Household model, please go to www.culturechangenow.com.

Planetree

"Planetree's holistic approach encompasses body, mind, and spirit. It supports the involvement of family and friends in providing care and empowers individuals by providing information and education. Planetree recognizes the importance of the nutritional and nurturing aspects of food and the healing benefits of an attractive physical environment. Nature, art, music, and space for meditation and prayer are incorporated into this environment." For more information on Planetree, please go to: www.planetree.org

Wellspring Innovative Solutions

"Wellspring primarily focuses on strengthening clinical and managerial skills of staff, empowering residents and frontline staff, and creating a high quality of life for residents. One of the strengths of Wellspring is that it enables nursing homes to affect culture change within their existing physical plant and wherever they are along the continuum of change." For more information on Wellspring, please go to www.wellspringprogram.org.

In addition to these more formalized models, individual long-term care communities implement culture change in their own ways. Resources for providers on their culture change journey can be found at: www.pioneernetwork.net—look for Promising Practices.



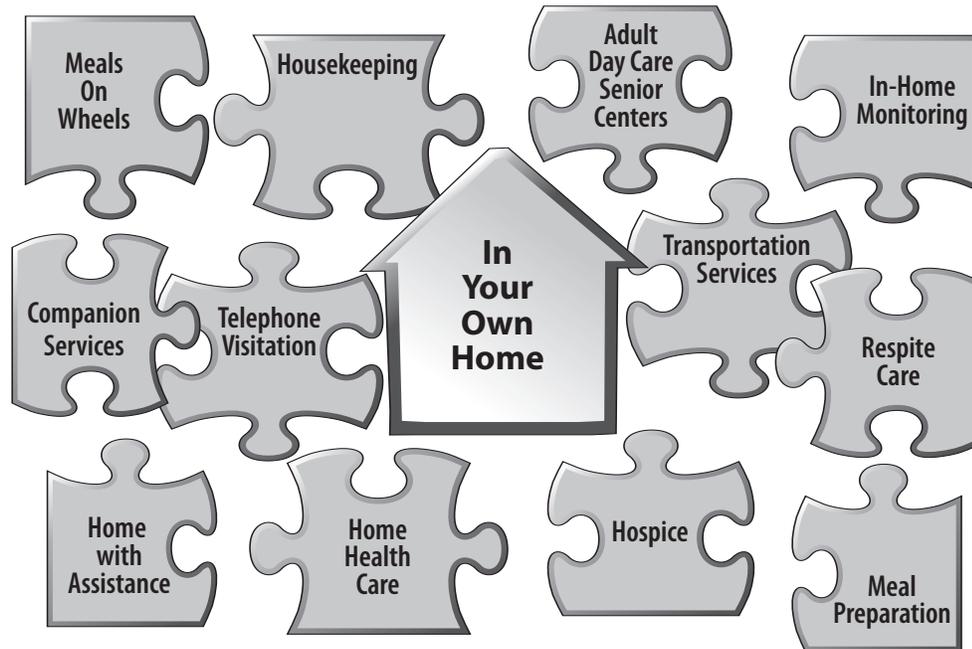
What Are My Choices about How and Where Help Is Provided? Or Is a Nursing Home the Only Choice?

Everyone ages differently. Many elders live independently. Others need help with their physical care and ability to manage in their homes. In the past, a person who needed help had few options outside of their family or a nursing home. But now, because of nursing home cost and consumer demand, a full range of care options and services are more available so that people are able to remain in their own homes longer. If health declines and help is needed that cannot be provided in the home, there are now different types of living arrangements and housing settings available.

Many of us are faced with making long-term care decisions during a time of crisis, when we are under stress. Long-term care is at times a complicated “puzzle.” It helps to spend time learning about all of the options and the “vocabulary” of long-term care before you need it. The illustrations on the next page summarize the options that are currently available.

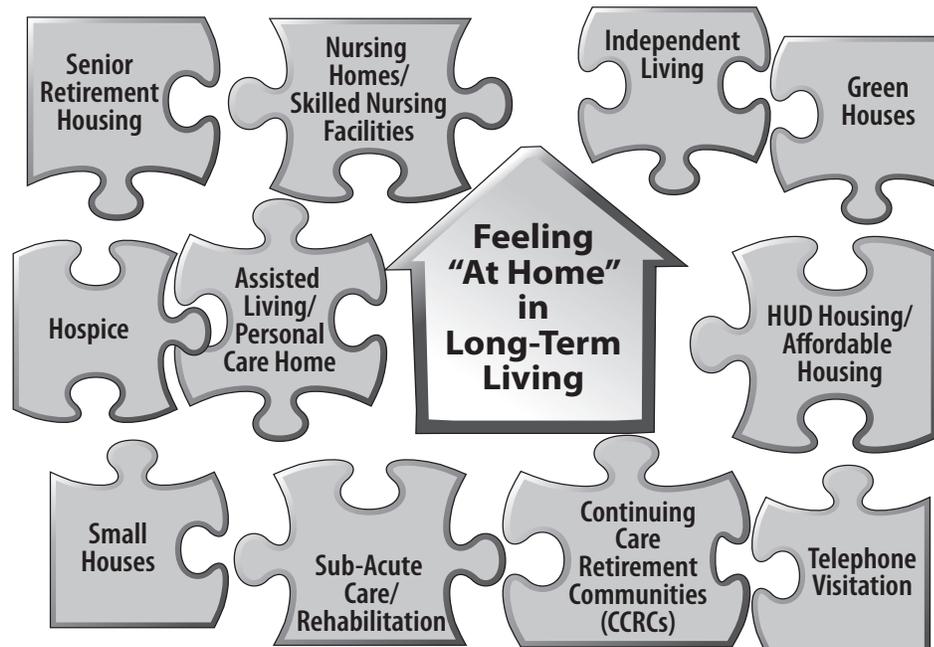
If you are still living in your own home and you need additional help, this illustrates the care options and services that may be available to you:

Options and Services If You Are In Your Own Home



If the time comes when you need, or choose, to move from your home to a different care setting, this illustrates the care options and services that may be available to you:

Options and Services to Help You Feel "At Home" in Long-Term Living



For information about how to access these services and to find out what is available in your area, contact your local Area Agency on Aging. For contact information, call the Eldercare Locator at 1-800-677-1116 or go to www.eldercare.gov.

As mentioned before, culture change and person-directed values are applicable for care delivered in all settings. Although most of the emphasis has been on nursing homes, change needs to happen throughout the array of long-term care services. Providers in various settings, such as assisted living, adult day services, and home care are assessing where they are when it comes to person-directed care. They are exploring how they can do a better job in ensuring that individuals receiving care in those settings have as much control over their daily lives as possible, and the ability to develop meaningful relationships and enjoy life to the fullest extent possible.

See the “Definitions of Common Terms” (page 36) and “Helpful Organizations and Websites” (page 51) at the end of this booklet for details and additional contact information.

What Level of Care Should I Be Looking For?

Recovery from illness, or living with a chronic, progressive condition, varies from person to person. No two people are alike and response to illness as well as treatment is rarely simple. Often there are cycles of being and feeling better and being and feeling worse, moving between multiple care settings, and utilizing a mixture of support services. For example, if someone has had a stroke, he or she has many options for rehabilitation. Here are some possibilities:

home ► hospital ► home with assistance and in-home health care ► home alone

home ► hospital ► rehabilitation in a skilled nursing home ► home with assistance from family members

home ► hospital ► rehabilitation in a skilled nursing home ► move to long-term care in a nursing home or assisted living community

The path taken depends on various factors unique to each individual, including:

- ◆ One's ability to take care of himself or herself without assistance;
- ◆ One's goals for recovery, and where and how those goals will be best achieved;

- ◆ The services, supports and types of settings available in one's area (e.g. home health care, in-home care, adult day services, assisted living, nursing homes);
- ◆ Available resources (e.g. financial, insurance, family and friends, government);
- ◆ Privacy needs; and
- ◆ Spiritual and cultural preferences.

It is important for elders and family members to talk about their preferences and learn about what is available in the area before being faced with a health crisis. Unfortunately, the reality is that most people don't think about long-term care until there is a crisis and a need. Hospital stays are typically very short. Families are given little notice that the person is going to be discharged. If the person is unable to return home and needs to go to a nursing home for rehabilitation, the choice is often limited to where a bed is available. While there is an appearance of choice, that is commonly not the case.

Ask your doctor, nurse practitioner, hospital discharge planner, or other health and social service professionals to explain all of the possible options so that you can decide on the ones that best fit your situation. However, not all health and social service professionals are up to date on the care options in your area. Discharge planners, case managers, social workers, or nurses who work for hospitals or insurance companies work for the organization or company, not necessarily for you. Hospitals are often pressured to get you or your family member out of the hospital quickly, not necessarily to find the best place for follow-up care. There are professional geriatric care managers who (for a fee) help people find care options. Usually, the bottom line is that you or your family members have to be your own care manager by determining what you need and finding the services that are right for you.

How Do I Get Information about Nursing Homes?

If the doctor or other health care provider recommends that a nursing home setting is the best option, ask why he or she is making this recommendation at this time. Also ask why he or she thinks that returning home with help is not an option. Discuss the elder's abilities and needs at the present time and in the foreseeable future. Investigate and discuss all options that are available in your area. If the elder is coming from the hospital, ask to talk with the discharge planner or case manager about options and benefits coverage. Remember that you have choices, and your job is to be the advocate for yourself or your loved one.

Here are some ways to gather information about nursing homes to help you make decisions:

- ◆ Have an honest conversation with the elder about his or her preferences, before assistance is needed. Planning ahead helps the elder (with your help, if needed) make more informed choices. Every time there is a change in condition or a need for assistance, have another conversation to find out about his or her preferences under each new set of circumstances.
- ◆ Contact your Area Agency on Aging or the Eldercare Locator (www.eldercare.org or call 1-800-677-1116) for more information about the services available in your area.
- ◆ Contact your local ombudsman to learn more about the assisted living communities or nursing homes in your area. Every state has a long-term

care ombudsman and there are almost 9,000 volunteer ombudsmen across the country who advocate for residents' rights and quality care, educate consumers and providers, resolve residents' complaints, and provide information to the public. Contact information for state and local long-term care ombudsmen can be found at www.theconsumervoice.org.

- ◆ Visit SNAPforSeniors for a database of senior housing communities in the U.S. (www.snapforseniors.com). It provides information about availability and locations of levels of care on a state-by-state basis.
- ◆ Visit www.PioneerNetwork.net to learn more about culture change and person-directed care and read examples of nursing homes that have changed.
- ◆ Visit the website, Long-Term Care: You Decide (<http://ltc.hsr.umn.edu/index.html>). It has a number of tools your family can use to sort out what would be the best option for you or your loved one.
- ◆ Visit Medicare's Nursing Home Compare website (www.medicare.gov/NHcompare/) to get detailed information about every Medicare- and Medicaid-certified nursing home in the country. It includes the "Five-Star Quality Rating System". This site is also where you will get information about the last government survey (see Definitions) on each nursing home, as well as information about alternatives to nursing homes. Medicare also has a site to get detailed information about home health agencies: www.medicare.gov/HHCompare.
- ◆ Visit The National Consumer Voice for Quality Long-Term Care website (www.theconsumervoice.org), the only national nonprofit organization exclusively representing consumers of long-term care. Download the "Consumer Guide to Choosing a Nursing Home" fact sheet.

After you have done some homework, visit several local nursing homes. Remember, no two homes are alike, and it is important to gather and compare information from a variety of sources. The next section will provide you with guidance on what to ask when you visit nursing homes.

What are Key Questions to Ask the Staff in Nursing Homes to Find Out If They Provide Person-Directed Care?

This Guide has provided you with general information about nursing homes. There is also a need to visit and ask more specific questions about person-directed care and what the nursing home is doing, if anything, with person-directed care and culture change. 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 is your nursing home involved in culture change?

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 attend the state culture change coalition meetings and go to conferences to learn more. Several of our staff (including direct care workers) have visited other places involved in culture change. We have consistent assignment so that our staff can get to know the residents they are caring for, including residents’ individual needs and wishes.”



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 they are not able to do this (because of dementia, for example), we want you to help us get to know them. Then we will talk with them and spend time together. We will 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 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 or he have a choice?

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

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, not only during the day but 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. 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.”

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

“The three plagues of old age are loneliness, boredom and helplessness.”

— Dr. Bill Thomas,
founder of Eden
Alternative and
GREEN HOUSE®

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 things such 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 66 percent.)¹

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 41 percent for RNs and 50 percent for LPNs.)²

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.

^{1,2} American Healthcare Association (AHCA) Survey Nursing Staff Vacancy and Turnover In Nursing Facilities

Do you measure family satisfaction?

Listen for: “We do. Family opinions are important and we consider family a part of the team.”

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? Are 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 people who live and work here.”

To get a feel of the tone of the nursing home during your “walk-about,” Are staff and residents interacting with what looks like interest and kindness? 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. Remember that décor on its own does not equal culture change. Choices and relationships are primary.

Look at the types of resources and 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 latest 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.***

What If There Are No Nursing Homes Doing Culture Change in My Area?

What if you visit several nursing homes in your area and none of them meet the “test” with their answers to the “Key Questions”? Or what if you find a good nursing home, but there is no room available for you or your family member? This is a very difficult situation to be in—to know that things could be better, but not to be able to get it for yourself or a family member. Unfortunately, as this movement is still young and growing, it is not yet the “new normal.” In 2007, fewer than one third of nursing homes said they were involved in and/or committed to adopting culture change (see *Culture Change in Nursing Homes: How Far Have We Come? Findings From The Commonwealth Fund 2007 National Survey of Nursing Homes* at www.commonwealthfund.org). That is the reason we are doing this project and asking for your help.

Long-term care can be changed. It can be different. Many nursing homes are changing and have changed, which proves that it can be done. Remember that culture change and person-directed care are just starting to expand beyond nursing homes into all of the other long-term care settings, including assisted living communities. The culture change movement is still new, and changes take time. We cannot get discouraged about this. This is why we need more advocates to spread the word and help promote change.

Consumers can create the demand for this new type of long-term care. Steve Shields, CEO of Meadowlark Hills in Manhattan, Kansas, a leader in culture change and author of a book, toolkit and business case for the household approach, clearly states that in the future, because of marketplace demand, person-directed care and households will be the only model. All others will not survive. He gives the example, that in his town of about 100,000, the household model is now the only model of nursing home care, a result of multiple factors, but clearly because of consumer awareness and demand.

If you are in the difficult situation of looking for a nursing home that provides person-directed care and there is none available in your area, try some of the education and advocacy suggestions described in the next section of this booklet titled *Suggestions for Education and Advocacy* (page 34). **Keep trying, keep looking, and keep spreading the word. The more that nursing home providers hear consumers asking for it, the faster they will be motivated to make the changes that we all want for our loved ones and for ourselves.**

If your loved one is in a nursing home, helping the staff quickly get to know her/him and you is crucial. Here are some ways to do that: attend care planning meetings; ask questions and share information about who your loved one is, their life history and daily routines. This will allow staff to provide better care for your family member. Putting the information in writing enables it to be shared with the staff who work around the clock. Stay involved and don't be afraid to speak up and be an advocate. A resource for learning more about nursing homes is the book "Nursing Homes: Getting Good Care There" by Virginia Fraser, Sara Hunt, Barbara Frank, and Sarah Greene Burger. Also, consider joining or starting a family council. For information on family councils visit the Family Council Center on the website of the National Consumer Voice for Quality Long-Term Care (www.theconsumervoice.org).

As a society, the future of aging and long-term care is ours to create.

"You must be the change you want to see in the world."
— Gandhi

We have to create the change we wish to see.

Suggestions for Education and Advocacy

What Can I Do Next?

Here are some things you can do with what you have just learned:

1. Share what you have learned with others. One way is to talk to your family and friends about what you have learned. Help break down the often-held belief that there is nothing we can do to change the long-term care system.
2. Visit nursing homes in your community to get a sense of whether they are practicing person-directed care. Use the “Key Questions to Ask Staff in Nursing Homes to Find Out If They Provide Person-Directed Care” found in this Guide. If a nursing home is unfamiliar with culture change, you might share the “What is Culture Change” document in your folder with them.³
3. Talk to your family about your wishes related to housing and assistance. Fill out the form “My Personal Directions for Quality Living”, found in your folder and on The National Consumer Voice for Quality Long-Term Care website (www.theconsumervoice.org), and share it with your loved ones.
4. Host a meeting like this one. If you decide to do so, contact your State Coordinator, whose contact information is in your folder. Or, contact Pioneer Network at 312-224-2574.

³ Participant folder documents from the Creating Home meetings can also be found on the Pioneer Network website (www.pioneernetwork.net) in the Consumer section.

5. E-mail your friends and family the link to the “Advocating for a New Old Age” video that you saw during the meeting. It is available on the Pioneer Network website at www.pioneer-network.net/Consumers/.
6. Get together to participate in a meeting to discuss this Guide to better care options.
7. Become a part of your state or local culture change coalition to help bring about change in long-term care settings in your area. Information about the coalition in your state is available in your folder. To find a coalition in another state, go to www.pioneernetwork.net/Coalitions/Find.
8. Determine if your state has a Citizens Advocacy Group (CAG) and consider learning more about it or possibly joining. Visit www.theconsumervoice.org to find a CAG in your state.
9. Get together again to discuss the contents of Beth Baker’s book “Old Age in a New Age: The Promise of Transformative Nursing Homes.” A copy of the reader’s guide is in your folder. You can use the reader’s guide for your discussion.
10. Consider joining the e-mail list of Pioneer Network so we can keep you informed of culture change news. You can share your email on the meeting evaluation, or go to www.pioneernetwork.net to sign up for email updates.
11. Check the Pioneer Network website (www.pioneernetwork.net) for additional information and upcoming consumer education opportunities.
12. Join Pioneer Network’s Facebook page.
13. Post the Pioneer Network website and video on your Facebook page or other social network.

What does it mean to be an advocate?

Being an advocate means speaking up about something you care about, whether it is for yourself or someone else.

Definitions of Common Terms Used in Long-Term Care and Culture Change

Activities of Daily Living (ADLs): Daily functions such as getting dressed, eating, taking a shower or bath, going to the bathroom, getting into a bed or chair, or walking from place to place. The amount of help a person needs with ADLs is often used as a measure to determine whether he or she meets the requirements for long-term care services in a nursing home as well as government subsidized home- and community-based services. (Also see Instrumental Activities of Daily Living.)

Acute Care: Medical care for health problems that are new, quickly get worse, or result from a recent accident. Acute care has recovery as its primary goal, typically requires the services of a physician, physician assistant, nurse practitioner, nurse, or other skilled professional, and is usually short-term. It is usually provided in a doctor's office, a clinic, or a hospital.

Adult Day Services: Community-based programs that provide meals and structured activities for people with cognitive or functional impairments, as well as adults needing social interaction and a place to go when their family caregivers are at work. (See also Respite.)

Advance Directive: Legal documents that allow you to plan and make your own end-of-life wishes about health care and treatment known in the event that you are unable to communicate. Advance directives consist of (1) a living will and (2) a medical (health care) power of attorney, sometimes called "health care surrogate," depending on the state. (See Living Will and Medical Power of

Attorney). You can create a living will and medical power of attorney form without a lawyer. However, it is very important that you use advance directive forms specifically created for your state so that they are legal. Caring Connections (www.caringinfo.org) provides free advance directives and instructions for each state.

Advance Practice Nurse (APN): These are registered nurses with specialized education and training beyond the basic registered nurse level. Some are called clinical nurse specialists, and some are called nurse practitioners. (See Nurse Practitioner.)

Alzheimer’s Disease: A progressive, degenerative form of dementia that causes severe intellectual deterioration. The first symptoms are impaired memory, followed by impaired thought and speech, an inability to care for oneself and, eventually, death. Onset can be associated with or preceded by depression.

Area Agencies on Aging (AAAs): AAAs coordinate and offer services that help older adults remain in their home, if that is their preference. Services might include Meals-on-Wheels, homemaker assistance, and whatever else it may take to enable the individual to stay in his or her own home. By making a range of options available, AAAs make it possible for older individuals to choose home- and community-based services and a living arrangement that suits them best. (See Eldercare Locator.)

Assisted Living/Personal Care Homes/Residential Care Facilities: A state-regulated residential long-term care option that may have different names depending on the state. Assisted living provides or coordinates oversight and services to meet residents’ individualized, scheduled needs, based on the residents’ assessment and service plans, and their unscheduled needs as they arise. There are more than 26 designations that states use to refer to what is commonly known as “assisted living.” There is no single uniform definition of assisted living, and there are no federal regulations for assisted living. In many states, most assisted living is private pay. Be sure to check with your state about any waiver programs that might be available through Medicaid to pay for the care provided in assisted living.

Care or Case Manager: A nurse, social worker, or other healthcare professional who plans and coordinates services for an individual’s care. This person usually works for an agency or care setting. (Also see Geriatric Care Manager.)

Care Plan: A detailed written plan that describes what is needed for an individual's care and provided by a range of health professionals, including nurses, therapists, social workers, nursing or personal assistants. For those living at home, a good care plan should also list the caregiving activities that family members are able to do, need help learning how to do, and will be doing. "I" Care Plans are written in the first person, as if the person receiving care wrote it her- or himself, and express the desires of the individual for her or his care. Care plans can describe the risks that an individual is prepared to take in exercising his or her autonomous self-determination and choice. Creating the care plan should involve an interdisciplinary team of the care recipient, caregivers, including the nursing assistant, as well as the family as appropriate.

Caregiver: A caregiver is a spouse, family member, partner, friend, or neighbor who helps care for an elder or person with a disability who needs assistance. Caregivers can also be people employed by the care recipient, a family member, agencies, or care settings to provide assistance with activities of daily living (see ADLs) and instrumental activities of daily living (see IADLs).

Case Management: Assistance for families in assessing the needs of older adults and making arrangements for services to help the older adult remain as independent as possible.

Centers for Medicare & Medicaid Services (CMS): With a budget of approximately \$650 billion and serving approximately 90 million beneficiaries, the Centers for Medicare & Medicaid Services (CMS) plays a key role in the overall direction of the healthcare system. With regard to long-term care, CMS is responsible for regulating and paying nursing homes, home health agencies, and hospices for the care of Medicare and Medicaid (in conjunction with the states) beneficiaries.

Certified Nursing Assistant (CNA): A person trained and certified to assist individuals with non-clinical tasks such as eating, walking, and personal care. (See definitions for Personal Care and ADLs.) This person may be called a "direct care worker" (DCW). In a hospital or nursing home the person may be called a *nursing assistant*, a *personal care assistant*, or an *aide*.

Citizen Advocacy Group (CAG): A CAG is a state or regional nonprofit organization dedicated to improving the quality of long-term care. Members of a CAG may include long-term care recipients, their families and friends, citizen advocates, long-term care ombudsmen, and organizations subscribing to the CAG's purpose.

Cognition: The process of knowing; of being aware of thoughts. The ability to reason and understand.

Cognitive Impairment: A diminished mental capacity, such as difficulty with short-term memory. Problems that affect how clearly a person thinks, learns new tasks, and remembers events that just happened or happened a long time ago. Problems that affect cognition. (See definition of cognition.)

Consistent Assignment: Residents receive care from the same caregivers (registered nurse, licensed practical nurse, direct care worker/certified nursing assistant) during a typical work week. Consistent assignments give the caregiver and resident the opportunity to build a close relationship, allowing the caregiver to gain a deep understanding of the resident and allowing the resident to develop a true level of comfort and trust with the caregiver.

Continuing Care Retirement Community (CCRC): A housing option that offers a range of services and levels of care. Residents may move first into an independent living unit, a private apartment or a house on the CCRC campus. The CCRC provides social and housing-related services and might have an assisted living residence and a nursing home, often called the health care center, on the campus. If and when residents can no longer live independently in their apartment or house, they move into assisted living (unless it is provided in their apartment or house) or the nursing home.

Culture Change: The common name given to the national movement for the transformation of older adult services, based on person-directed values and practices, where the voices of elders and those working with them always come first. Core person-directed values are choice, dignity, respect, self-determination and purposeful living. Culture change transformation supports the creation of both long- and short-term living environments as well as community-based settings where both older adults and their caregivers are able to express choice

and practice self-determination in meaningful ways at every level of daily life. Culture change transformation may require changes in organizational and leadership practices, physical environments, relationships at all levels, and workforce models—leading to better outcomes for all involved. While culture change may focus on elders, it improves the quality of life for all care recipients.

Dementia: A general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by structural and physiological changes in the brain. Alzheimer’s disease is the most common type of dementia. It is estimated that 47 to 67 percent of nursing home or assisted living residents have Alzheimer’s disease or a related form of dementia.

Direct Care Staff or Direct Care Worker (DCW): An individual working in a nursing home or assisted living community that provides “hands on” help with activities of daily living (ADLs) to residents. (See Certified Nursing Assistant.)

Discharge Planner: A nurse, social worker, or other professional who coordinates a patient’s transition (move) from one care setting to the next, such as from hospital to nursing home or to one’s own home with home health care and other services. (See “What Level of Care Should I Be Looking For?” on page 23)

Elder Abuse: Any knowing, intentional or negligent act by a caregiver or any other person that causes harm or a serious risk of harm to a vulnerable older adult. The specificity of laws varies from state to state. Types of elder abuse may include Physical Abuse—Inflicting, or threatening to inflict, physical pain or injury on a vulnerable elder, or depriving them of a basic need; Emotional Abuse—Inflicting mental pain, anguish or distress on an elder person through verbal or nonverbal acts; Sexual Abuse—Non-consensual sexual contact of any kind; Exploitation—Illegal taking, misuse, or concealment of funds, property or assets of a vulnerable elder; Neglect—Refusal or failure by those responsible to provide food, shelter, health care or protection for a vulnerable elder; Abandonment—The desertion of a vulnerable elder by anyone who has assumed the responsibility for care or custody of that person. The specificity of laws varies from state to state. (See National Center on Elder Abuse.)

Elder Law Attorney: A lawyer who specializes in the legal rights and issues of older adults and their health, finances, and well-being.

Family Caregiver: Any family member, partner, friend, or neighbor who provides or manages the care of someone who is ill, disabled, or frail. There may be more than one family caregiver involved in a person's care. Sometimes family caregivers are referred to as informal caregivers. This is meant to show that they are different from formal caregivers (professional healthcare workers). But many caregivers do not like the term informal because it incorrectly implies less skill and commitment.

Family Council: Family members of nursing home or assisted living residents who join together to provide a consumer voice and perspective to communicate issues to administrators and work for resolution and improvement. Family Councils can play a crucial role in voicing concerns, requesting improvements, discussing the mission and direction of a nursing home or assisted living community, supporting new family members and residents, and supporting the residence's efforts to make care and life in the home the best it can be. When Family Councils meet independently (without representatives of the nursing home or assisted living community) they are able to speak more freely and openly. Such independent family councils in nursing homes are supported by federal (and some state) legislation.

Geriatric Care Manager: A person with a background in nursing, social work, psychology, gerontology or other human services field, who has knowledge about the needs of and services available for older adults. A geriatric care manager coordinates (plans) and monitors (watches over) a person's care. He or she also keeps in contact with family members about the person's needs and how their loved one is doing. Most geriatric care managers are privately paid and usually not covered by private insurance. Some long-term care insurance companies use care managers to assess the individual's need for services and arrange for the needed services.

Geriatrician: A medical doctor with special training in the diagnosis, treatment, and prevention of illness and disabilities in older adults.

Geriatrics: The branch of medicine that focuses on providing comprehensive health care for older adults and the treatment of diseases associated with the aging process.

Gerontologist: A professional trained in Gerontology. Gerontologists have a Masters or doctoral degree, either in Gerontology, or in another discipline (psychology, biology, social work, etc.) with a focus in gerontology.

Gerontology: The study of the aging process and individuals as they grow from midlife through later life including the study of physical, mental and social changes; the investigation of the changes in society resulting from our aging population; the application of this knowledge to policies, programs, and practice.

Health Care Practitioner: A professional providing medical, nursing, and other healthcare related services.

Home Health Aide (HHA): A person trained to provide basic health care tasks for older adults and persons who are disabled, in their home. Tasks include personal care, light housecleaning, cooking, grocery shopping, laundry and transportation. Tasks may also include taking vital signs (such as heart rate and blood pressure) or applying a “dry dressing” for certain kinds of wounds. They are supervised by a registered nurse when they are employed by a home health agency.

Home Health Care: Services given to patients at home by registered nurses, licensed practical nurses, therapists, home health aides, or other trained workers. Certified home health agencies often provide and coordinate these services. These services, provided on a short-term basis and ordered by a physician, are usually covered by Medicare and Medicaid. With Medicaid, there are differences in coverage between states.

Home- and Community-Based Services (HCBS): Services provided in an individual’s home or a setting in the community, such as adult day services, senior centers, home-delivered meals, transportation services, respite care, housekeeping, companion services, etc. These services are primarily designed to help older people and people with disabilities remain in their homes for as long as possible. Many states have requested and received “Medicaid waivers” in order to enable low income Medicaid recipients to receive long-term care services in their own homes, adult day care, or an assisted living community instead of moving into a nursing home.

Home-delivered Meals (Meals on Wheels): Meals brought to people who cannot prepare their own meals or are homebound (cannot leave their homes).

Hospice: A program of medical and social services for people diagnosed with terminal (end-stage) illnesses that focuses on comfort, not curing an illness. Hospice services can be given at home, in a hospital, hospice residence, assisted living community, or nursing home. They are designed to help both the patient and his or her family. Hospice care stresses pain control and symptom management. It also offers emotional and spiritual support. Medicare will pay for hospice if a doctor states that a person probably has six months or less to live. Hospice care can last longer than six months in some cases.

Household Model: A small group of residents living within a physically-defined environment that “feels like home” and that has a kitchen, a dining room, and a living room. Staff is consistently assigned so they can develop meaningful relationships with the residents, work in self-led teams, and perform a variety of tasks. The sense of being at home is expressed in recognizing and honoring the rhythm of each individual’s life. For example, there is a wide variety of food accessible to residents around the clock, including breakfast-to-order and on demand. All residents in the household have opportunities to participate in the daily life of the household in a manner and to the extent they choose.

HUD Housing/Affordable Senior Housing: The U.S. Department of Housing and Urban Development (HUD) 202 Program offers subsidized housing and rental assistance for low-income individuals over 62 years of age who meet the eligibility requirements of the federal program. These housing communities often help residents access a variety of healthcare and supportive services as well as transportation.

Incontinence: Loss of bladder (urine) or bowel movement control. This condition can be transient, intermittent, or permanent. Incontinence nurse specialists and physicians can diagnose the kind of incontinence that is present and suggest ways to effectively manage the situation through exercises and timed toileting programs.

Independent Living: A residential location that may or may not provide hospitality or supportive services. Includes rental-assisted or market-rate apartments or cottages. Residents can choose which services they want. There may be an additional fee for some services.

Informal Caregiver: A family member, friend, or any other person who provides long-term care, generally without pay.

In-Home Care: This is often done by family members who become caregivers. Agencies also provide in-home care that is not medical in nature, including help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) or older adults or their families may hire in-home caregivers on their own. (See Definitions). Unlike home health care provided on a short-term basis, these services are not covered by Medicare but may be covered by Medicaid in your state.

Instrumental Activities of Daily Living (IADLs): A series of life tasks necessary for maintaining a person's immediate environment, e.g., shopping for food and medications, cooking, laundering, house cleaning, managing one's medication and finances. An elder may need help with IADLs and not need help with ADLs (See definition of ADL).

Licensed Practical Nurses or Licensed Vocational Nurses (LPN or LVN): LPNs or LVNs have one to two years of technical training. They assist RNs (see definition of Registered Nurses) with data collection, care planning and monitoring residents' conditions. They are licensed to administer medications and treatments, transcribe physician orders, etc. Most of the licensed nurses working in nursing homes are LPNs or LVNs, especially on the evening and night shifts.

Living Will: An advance directive that guides your family and health care team through the medical treatment you wish to receive if you are unable to communicate your wishes. According to your state's living will law, this document is considered legal as soon as you sign it and a witness signs it, if that is required. A living will goes into effect only when you are no longer able to make your own decisions.

Long-Term Care (LTC): A term used to describe the care needed by someone who must depend on others for help with daily needs. LTC is designed to help people with chronic health problems or dementia live as independently as possible. While many people think that long-term care happens only in a nursing home, in fact most long-term care is given by family caregivers in the care recipient's home.

Long-Term Care Insurance: Private insurance designed to cover (pay for) long-term care services provided at home, adult day care, assisted living or a nursing home. There are many long-term care insurance policies with a wide range of benefits. Medicare and Medicare supplemental insurance policies (Medigap) do not pay for long-term care.

Long-Term Care Services: A variety of services and supports to meet health or personal care needs over an extended period of time. This includes medical and non-medical care to people with a chronic illness or disability. Long-term care helps meet health or personal needs. Most long-term care assists people with Activities of Daily Living (ADLs), such as dressing, bathing, and using the bathroom. Long-term care can be provided at home, in an adult day care center, an assisted living community, or a nursing home. In order for state Medicaid programs to pay for home care or assisted living for an individual that meets the income eligibility requirements, the individual must require a level of care equivalent to that received in a nursing home.

Medicaid: The federally- and state-supported, state-operated public assistance program that pays for healthcare services to low-income people, including older adults or disabled persons who qualify. Medicaid pays for long-term nursing home care and some limited home health services, and it may pay for some assisted living services, depending on the state. It is the largest public payer of long-term care services, especially nursing home care. Each state can determine the breadth and extent of what services it will cover above a certain federally required minimum.

Medical Director: A physician who oversees the medical care and other designated care in a healthcare organization or care setting. The medical director is responsible for coordinating medical care and helping to develop, implement, and evaluate resident care policies and procedures that reflect current standards of practice.

Medical (Healthcare) Power of Attorney: The advance directive that allows you to select a person you trust to make decisions about your medical care if you are temporarily or permanently unable to communicate and make decisions for yourself. This includes not only decisions at the end of your life, but also in other medical situations. This document is also known as a “health care proxy,” “appointment of health care agent or health care surrogate,” or “durable power

of attorney for health care.” This document goes into effect when your physician declares that you are unable to make your own medical decisions. The person you select can also be known as a health care agent, surrogate, attorney-in-fact, or health care proxy. With a medical power of attorney you can appoint a person to make health care decisions for you in case you are unable to speak for yourself.

Medicare: The federal program that provides medical insurance for people aged 65 and older, some disabled persons and those with end-stage renal disease. It provides physician, hospital, and medical benefits for individuals over age 65, or those meeting specific disability standards. Benefits for nursing home and home health services are limited to short-term rehabilitative care. There are different parts of Medicare which cover specific services if you meet certain conditions. For detailed information, visit the website (www.medicare.gov) or call for assistance: 1-800-Medicare.

Mild Cognitive Impairment: A transition stage between the cognitive decline of normal aging and the more serious problems caused by Alzheimer’s disease. The disorder can affect many areas of thought and action, such as language, attention, reasoning, judgment, reading and writing. However, the most common variety of mild cognitive impairment causes memory problems. According to the American College of Physicians, mild cognitive impairment affects about 20 percent of the population over 70. Many people with mild cognitive impairment eventually develop Alzheimer’s disease, although some remain stable and others even return to normal.

Nurse Practitioner (NP): A registered nurse with advanced education and training. NPs can diagnose and manage most common, and many chronic, illnesses. They do so alone or in collaboration with the health care team. NPs can prescribe medications and provide some services that were formerly permitted only to doctors. There are a number of types of nurse practitioners (e.g. geriatric, adult, or psychiatric) that work with older adults.

Nursing Home or Skilled Nursing Facility (SNF): A residential care setting that provides 24-hour care to individuals who are chronically ill or disabled. Individuals must be unable to care for themselves in other settings or need extensive medical and/or skilled nursing care.

Ombudsman/Long-term Care Ombudsman: An Ombudsman is an advocate for residents of nursing homes, board and care homes, and assisted living. Ombudsmen provide information about how to find a nursing home or other type of LTC facility and what to do to get quality care. They are trained to resolve problems. An ombudsman can assist you with expressing complaints, but this requires your permission because these matters are held confidential. Under the federal Older Americans Act (OAA), every state is required to have an Ombudsman program that addresses complaints and advocates for improvements in the long-term care system. To find the ombudsman nearest you, visit the National Long-Term Care Ombudsman Resource Center at www.ltcombudsman.org.

Palliative Care: Care that focuses on the relief of the pain, symptoms, and stress of serious illness. The goal is to improve quality of life for patients and families. Palliative care is appropriate at any point in an illness, not just for end-of-life care, and it can include treatments that are intended to cure as well as comfort. It is both a philosophy of care (as is hospice) as well as an approach to caring activities. Palliative care is provided by trained staff in a hospital, home, nursing home, assisted living community or hospice. For more information, visit GetPalliativeCare.org or the National Hospice and Palliative Care Organization (NHPCO) (www.nhpco.org).

Person-Directed Care/Person-Centered Care: An approach to care in which the voices of individuals needing care and those working closest with them always comes first. Core person-directed values include dignity, respect, purposeful living and having the freedom to make informed choices about daily life and health care. It involves a continuing process of listening, trying new approaches, seeing how they work, and changing routines and organizational approaches in an effort to individualize and de-institutionalize the care (e.g., nursing home or assisted living environment).

Personal Care: Non-skilled nursing service or care, such as help with bathing, dressing, eating, getting in and out of bed or chair, moving around, using the bathroom, or any other activity of daily living (ADL) required or desired by the individual needing care.

Primary Care Provider (PCP): This term almost always refers to doctors, nurse practitioners or physician assistants who provide routine care and preventive

care (before people are sick). PCPs diagnose and treat common medical problems, determine how urgent these problems are, and may refer patients to other specialists if needed. PCPs practice in the community, not a hospital or other healthcare facility. Some PCP's follow their patients into the hospital, while others do not. Sometimes a "hospitalist" is assigned to the patient who will likely communicate with your PCP while you're in the hospital.

Provider: A provider is typically a professional healthcare worker, agency, or organization that delivers health care or social services. Providers can be individuals (doctors, nurses, social workers, and others), organizations (hospitals, nursing homes, assisted living communities, or continuing care retirement communities), agencies (e.g., home care and hospice), or businesses that sell healthcare services or assistive equipment (e.g., colostomy care supplies, wheelchairs, walkers, etc).

Registered Nurse (RN): A graduate from a formal nursing education program (three to four years) who has passed a national examination and is licensed to practice by the state board. RNs assess, plan, implement, teach, and evaluate a person's nursing care needs, along with the rest of the healthcare team. In addition, they may do data analysis, quality assurance, research implementation, and research. They work in all types of health care settings and educational programs. In addition to providing care to individuals, RNs also works with groups of people or populations to determine how to promote health and prevent problems on a larger scale.

Rehabilitation ("Rehab"): Services to help restore mental and physical (bodily) functions lost due to injury or illness. Rehabilitation may be given at the hospital or in a nursing home, some assisted living residences, a special facility or the patient's home. The types of services offered generally include physical therapy, occupational therapy, speech therapy, social services, and nursing.

Resident: A person who lives in a residential long-term care setting, such as a nursing home or assisted living community.

Resident Council: Required by nursing home regulation, the Resident Council gives persons living in care settings the opportunity to communicate concerns to administrators, work for resolutions and improvements, and provide feedback

about new programs (e.g., food services). Independent and empowered Resident Councils can play a crucial role in voicing concerns, requesting improvements, supporting new residents and supporting efforts to make care and life in the care setting the best it can be.

Respite Care: Temporary (a few hours or up to a few days) care to offer relief for the family caregiver. Respite care may be given in the elder's home, a community-based setting such as adult day care, an assisted living facility, or a nursing home. It can be scheduled regularly (for example, two hours a week) or provided only when needed. This service can be particularly valuable for family members taking care of persons with dementia.

Senior Centers: Centers that provide services to senior citizens, aged 60 and over. They may offer social activities (like music or crafts), meals, health screenings (such as blood pressure checks, diabetes monitoring), learning programs, creative arts and exercise classes.

Skilled Care/Nursing Care: This level of care includes help with more complex nursing tasks, such as monitoring medications, giving injections, caring for wounds, and providing nourishment by tube feedings (enteral feeding). It also includes therapies, such as occupational, speech, respiratory and physical therapy. This care can be given in a patient's home or in a care setting. Most insurance plans require at least some level of skilled care need requiring the services of a licensed professional (such as a nurse, doctor, or therapist) before they will cover other home-care services.

Subacute Care/Rehabilitation: Care or monitoring after hospitalization in a less intensive and less costly setting, such as a rehabilitation service in a nursing home or in a special unit in a hospital. Subacute care is usually short-term. Check with Medicare to see specifics of how it is covered. (See definition of Medicare.)

Survey (or State Survey): As used in long-term care, the word survey refers to the process a state agency uses to ensure that all nursing homes that receive federal and state funding are in compliance with state and federal regulations, including standards of care. All federally funded nursing homes are surveyed at least annually to ensure compliance with CMS (Center for Medicare & Medicaid Services) regulations. The results of the latest survey must be posted

and readily accessible in all nursing homes and is also available online at Nursing Home Compare (www.medicare.gov/NHcompare/).

Telephone Reassurance Program: A service that provides reassurance calls to check on the safety and well-being of older adults at home. These calls can also offer reminders, such as when to take medication. This type of service may be purchased or volunteer service organizations may provide it.

Transition: A move from one care setting (hospital, home, assisted living, nursing home) to another. Care during transitions involves coordination and communication among patients, providers, and family caregivers. For example, it is critical that there is a way to assure that the proper medication list is communicated from setting to setting.

Turnover: This is the average percentage of staff who stop working at a care setting each year. Virtually all healthcare organizations (hospitals, nursing homes, assisted living, etc.) track and measure the number of staff who stop working (turnover) and the length of stay of staff (retention) in the same or similar jobs. A nursing home or assisted living community with high turnover rates means that new caregivers are constantly being hired and trained.

Visiting Nurse: A term often used for a nurse who visits patients in their homes. The job of a visiting nurse includes checking vital signs (such as heart rate and blood pressure), and assessing physical and mental health and how well the person is functioning at home. The visiting nurse consults with the physician regarding treatment plans, implements the treatment plan, and may educate and train families and other caregivers to perform care tasks. Some, but not all, are affiliated with the Visiting Nurse Association of America agencies.

Helpful Organizations and Websites

Administration on Aging (www.aoa.gov): An agency of the U.S. Department of Health and Human Services. AOA is an advocate agency for older persons and their concerns at the federal level. AOA uses Older Americans Act funds to contract with a nationwide network of State Units on Aging which in turn contract with local Area Agencies on Aging (AAA) to plan and coordinate aging services at the local level.

Advancing Excellence in America's Nursing Homes

(www.nhqualitycampaign.org): A campaign to improve the quality of life for residents and staff in America's nursing homes. The campaign's coalition includes long-term care providers, caregivers, medical and quality improvement experts, consumers, government agencies and other quality-focused organizations. The campaign is designed to strengthen the public trust in nursing home care by focusing on quality improvement and self-regulation. The campaign acknowledges the critical role of nursing home staff and consumers in improving quality of care and quality of life for nursing home residents.

Alzheimer's Association (www.alz.org): The leading voluntary organization in Alzheimer's care, support and research.

The American College of Health Care Administrators (ACHCA) (www.achca.org): ACHCA is a non-profit professional membership association that aspires to be the leading force in promoting excellence in leadership among long-term care administrators.

American Health Care Association (AHCA) (www.AHCA.org): A federation of affiliated state health organizations, together representing more than 10,000 nonprofit and for-profit assisted living, nursing home, developmentally-disabled, and subacute care providers that care for more than 1.5 million older and disabled individuals nationally.

AMDA – Long-Term Care Medicine (www.amda.com): As the professional association of medical directors, attending physicians, and others practicing in the long-term care (mostly assisted living and nursing homes), AMDA is dedicated to excellence in patient care and provides education, advocacy, information, and professional development to promote the delivery of quality long-term care medicine.

Caregiver.com (www.caregiver.com): Caregiver Media Group provides information, support, and guidance for family and professional caregivers. They produce Today's Caregiver magazine and a web site, caregiver.com, which includes topic-specific newsletters, online discussion lists, back issue articles of Today's Caregiver magazine, and chat rooms. Caregiver Media Group and all of its products are developed for caregivers, about caregivers and by caregivers.

Caring Connections (www.caringinfo.org): A program of the National Hospice and Palliative Care Organization (NHPCO), to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. Provides information on advance directives, living wills, and medical (healthcare) power of attorney based on the laws and requirements of your state.

CCAL-Advancing Person-Centered Living (www.ccal.org): CCAL is a national education and advocacy organization focused upon the implementation of principles, research, policies, and programs to foster person-centered living in the community and in assisted living.

CEAL- Center for Excellence in Assisted Living (www.theceal.org): CEAL promotes high-quality assisted living, serves as a convener to bring together diverse stakeholders to discuss and examine issues related to assisted living, helps bridge research, practice, and policies that foster quality and affordability, and maintains an objective national clearinghouse of information and resources about assisted living.

The Coalition of Geriatric Nursing Organizations (CGNO)

(<http://hartfordign.org/policy/cgno/>): CGNO represents over 28,700 geriatric nurses seeking to improve the health care of older adults across care settings and is supported by the Hartford Institute for Geriatric Nursing, located at New York University College of Nursing.

Eden Alternative (www.edenalt.org): An international not-for-profit organization dedicated to transforming care environments into habitats for human beings that promote quality of life for all involved. It is a powerful tool for inspiring well-being for Elders and those who collaborate with them as Care Partners.

Eldercare Locator (www.eldercare.gov): A public service of the Administration on Aging, U.S. Department of Health and Human Services, Eldercare Locator is a nationwide service that connects older Americans and their caregivers with information on senior services. The Eldercare Locator is designed to help older adults and their families and caregivers find their way through the maze of services for seniors by identifying local support resources. The goal is to provide users with the information and resources they need that will help older persons live independently and safely in their homes and communities for as long as possible.

Family Caregiver Alliance (www.caregiver.org): A public voice for caregivers. FCA's pioneering programs—information, education, services, research, and advocacy—support and sustain the important work of families around the country who are caring for loved ones with chronic, disabling health conditions. The National Center on Caregiving (NCC), established in 2001 as a program of Family Caregiver Alliance, works to advance the development of high-quality, cost-effective policies, and programs for caregivers in every state in the country. Uniting research, public policy and services, the NCC serves as a central source of information on caregiving and long-term care issues for policy makers, service providers, media, funders, and family caregivers throughout the U.S.

The GREEN HOUSE® Project (www.thegreenhouseproject.org): A project that supports the development and implementation of small, intentional (“purpose-built”) “Green House communities for a group of elders and staff. A Green House residence is designed to be a home for six to ten elders needing skilled nursing or assisted living care. The purpose is to avoid institutionalizing long-term care

and be a place where elders can receive assistance and support with activities of daily living and clinical care, without the assistance and care becoming the focus of their existence.

Home Health Compare (www.medicare.gov/HHcompare): Developed and maintained by the Center for Medicare and Medicaid Services, this tool provides information about the quality of care in home health agencies all across the country.

LeadingAge, formerly AAHSA: (www.leadingage.org): The members of LeadingAge provide services to individuals and their families every day through mission-driven, not-for-profit organizations and care settings. The 5,700 members of this organization offer the continuum of aging services: adult day services, home health, community services, senior housing, assisted living residences, continuing care retirement communities, and nursing homes.

LongTermCareLiving.com provides consumers with needed information on planning, preparing and paying for long-term care. It includes information on nursing homes, assisted living, residential care, and other types of long-term care. It is sponsored by the American Health Care Association (AHCA) and the National Center for Assisted Living (NCAL).

National Association of Area Agencies on Aging (N4A) (www.n4a.org): N4A is the national umbrella organization advocating to ensure that needed resources and support services are available to older Americans through the Area Agencies on Aging. See definition of Area Agencies on Aging above.

National Center for Assisted Living (NCAL) (www.ncal.org): This is the assisted living component of the American Health Care Association (AHCA). This organization of assisted living providers works to advocate, educate, and network for and with members. It also provides professional development, national lobbying, and quality initiatives for the assisted living provider community. In addition to national advocacy, NCAL supports state-specific advocacy efforts through its national federation of state affiliates. NCAL state affiliates work to create local education, advocate on behalf of assisted living providers, and provide the direct, ongoing support their assisted living members need to improve quality and grow their businesses.

National Center on Elder Abuse (NCEA) (www.ncea.aoa.gov): A national resource center dedicated to the prevention of elder mistreatment. Directed by the U.S. Administration on Aging, the NCEA is committed to helping national, state, and local partners in the field be fully prepared to ensure that older Americans will live with dignity, integrity, and independence, and without abuse, neglect, and exploitation. The NCEA is a resource center for elder rights advocates, health, aging, and social services professionals, APS (Adult Protective Services), law enforcement, legal professionals, public policy leaders, researchers, and others working or on behalf of older individuals who have experienced, or who are at risk for, elder mistreatment.

National Clearinghouse for Long-Term Care (www.longtermcare.gov): This website was developed by the U.S. Department of Health and Human Services to provide information and resources to help you and your family plan for future long-term care (LTC) needs. It is primarily intended as an information and planning resource for individuals who don't yet require long-term care, but it includes information on services and financing options that can be helpful to all individuals.

The National Consumer Voice for Quality Long-Term Care (formerly NCCNHR), (www.theconsumervoice.org): The Consumer Voice's mission is to represent consumers at the national level for quality long-term care, services, and supports. This organization, which has been in existence for more than 30 years, provides information and leadership on federal and state regulatory and legislative policy development as well as models and strategies to improve care and life for residents of nursing homes and other long-term care settings. NCCNHR stands for National Citizens' Coalition for Nursing Home Reform, the former name of this organization. The organization also supports and maintains the National Long-term Care Ombudsman Resource Center.

National Family Caregivers Association (NFCA) (www.thefamilycaregiver.org): National nonprofit organization that educates, supports, empowers and speaks up for the more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age. NFCA reaches across the boundaries of diagnoses, relationships, and life stages to help transform family caregivers' lives by removing barriers to health and well being. NFCA's core Caring Every Day messages are Believe in Yourself, Protect Your Health, Reach Out for Help, and Speak Up for Your Rights.

National Hospice and Palliative Care Organization (NHPCO) (www.nhpco.org): The largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end-of-life care and expanding access to hospice care, with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.

National Long-Term Care Ombudsman Resource Center

(www.ltombudsman.org): Ombudsmen are dedicated to enhancing the lives of long-term care residents. This national nonprofit organization provides support, technical assistance and training to fifty-three state Long-Term Care Ombudsman programs and their statewide networks of almost 600 regional (local) programs. There are also nationally almost 9,000 volunteer ombudsmen. The Center's objectives are to enhance the skills, knowledge, and management capacity of the state programs to enable them to handle residents' complaints and represent resident interests (individual and systemic advocacy). Funded by the Administration on Aging (AoA), the Center is operated by The National Consumer Voice for Quality Long-Term Care, in cooperation with the National Association of State Units on Aging (NASUA).

Nursing Home Compare (www.medicare.gov/NHcompare/): Developed and maintained by the Center for Medicare and Medicaid Services, this tool has detailed information, based on the annual surveys, about every Medicare- and Medicaid-certified nursing home in the country so that you can find and compare homes. The Five Star Rating System for nursing homes can be found here.

Picker Institute (pickerinstitute.org): Picker Institute is an independent nonprofit organization dedicated to advancing the principles of patient-centered care. In cooperation with educational institutions and other committed entities and individuals, Picker Institute sponsors awards, research and education to promote patient-centered care and the patient-centered care movement.

Pioneer Network (www.pioneernetwork.net): The national clearinghouse of the culture change movement, Pioneer Network is a center for all stakeholders in the field of aging and long-term care whose focus is on providing home and community for elders. It believes that the quality of life and living for America's elders is rooted in a supportive community and cemented by relationships that

respect each of us as individuals, regardless of age, medical condition, or limitations. Pioneer Network advocates for elders across the spectrum of living options (which are often dictated by differing levels of assistance needed) and is working toward a culture of aging that supports the care of elders in settings where individual voices are heard and individual choices are respected—whether it is in nursing homes, assisted living communities, adult day centers, private homes, or wherever the elder may live.

Planetree (www.planetree.org) Planetree is a non-profit organization that provides education and information in a collaborative community of health-care organizations, facilitating efforts to create patient-centered care in healing environments. There is a Planetree model for continuing care, made up of ten components that promote healing, person-centered communities.

SNAP for Seniors (www.snapforseniors.com): A web-based senior housing resource and home healthcare listing service in the United States. This resource puts objective information about the nation's 60,000+ licensed senior housing facilities at the fingertips of consumers and their advocates. (See also Nursing Home Compare.)

United Hospital Fund: Next Step in Care (www.nextstepincare.org): The mission of the nonprofit United Hospital Fund (UHF) is to shape positive change in health care for the people of New York. The Fund works to advance policies and support programs that promote high-quality, patient-centered healthcare services that are accessible to all persons across the full spectrum of care. The Next Step in Care campaign is one of the Fund's many initiatives to improve patient care, especially for those most vulnerable. It is taking shape in New York, but is envisioned as national in scope.

Wellspring (www.wellspringprogram.org): The Wellspring Program has assisted nursing homes throughout the country in advancing excellence in their settings by offering education, guidance, and tools to nursing homes to assist in culture change. Wellspring primarily focuses on strengthening clinical and managerial skills of staff, empowering residents and frontline staff, and creating a high quality of life for residents. One of the strengths of Wellspring is that it enables nursing homes to effect culture change within their existing physical plant and wherever they are along the continuum of change. Wellspring is based on the

core principles that care decisions need to take place at the level closest to the resident, a substantial knowledge base is required by all staff to equip them to participate in decision making, and an empowered workforce increases resident and employee satisfaction and reduces staff turnover.

Note: The above Definitions and Resources are not intended as an exhaustive or authoritative reference source but are provided only to inform readers of websites that may provide information of interest. The websites listed above contain information created, published, maintained or otherwise posted by organizations independent of Pioneer Network. Pioneer Network does not endorse, approve, certify or control these websites, nor any commercial product or service referenced therein, and does not guarantee the accuracy, completeness, efficacy or timeliness of information located therein.

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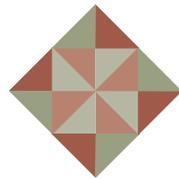
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Pioneer Network

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