

Your Way!

How to Find Dignity and Choice in a Nursing Home



A Consumer Education Project funded in part by the Retirement Research Foundation

Joint Project between the The Retirement Research Foundation and



to educate the Nursing Home Consumer in Illinois

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Your Way! - How to Find Dignity and Choice in a Nursing Home

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Table of Contents

Introduction	5 6
The Changing Culture in Nursing Homes	9
Process for Achieving Your Way!	13
Defining Nursing Home Services	15
Defining Care Services	17
Evaluating My Care Needs	21
How Do You Pay the Nursing Home Bill?	25
Taking Care of You and Your Loved Ones Needs	29
Explaining the Your Way! Questionnaire	32
Your Way! Questionnaire	39
Nursing Home Comparison Sheet	46
In My Area What Now?	47
Resources	
A Note About Advanced Directives	ii
Illinois and National Resources	iv
Acronyms and Commonly Used Terms in Health and	
Nursing Home Care	X
Resident's Rights	xvi
My Personal Directions for Quality Living	xviii
Illinois Pioneer Coalition Membership Information	XX

Introduction

From the moment we are born we are aging....

How do you envision your life as you age?

What happens to your aging vision if something happens to you or your loved one that requires more care then you can give at home? No one wants to go into a Nursing Home but many times this becomes our only option.

By the year 2020, 12 million older Americans will require long-term care services. Nursing Homes provide the most common institutional setting for older people with over 90% of institutional elders in the United States living in Nursing Homes.* These statistics show that there is a very strong potential that you or one of your loved ones will be one of these individuals needing Nursing Home care at some point in their lives. With this being said, how do you make this important life choice? How can you make sure that personal needs are met and that quality care is provided? It is your right to get the care you deserve and have continued quality of life even though you are sick and needing nursing care.

The purpose of this packet is to help make the process less complicated by educating the potential Nursing Home consumer. It provides information on what questions to ask and what to look for when making this important life decision. Remember, this consumer we are talking about is **YOU** – it is all of us!

For easy reference, the materials provided with in this packet can also be accessed on line at www.illinoispioneercoalition.org.

^{*}According to SeniorCare Marketplace statistics

Need Help Now?

This package has been designed for individuals who have time to sort through information to make an educated decision regarding what Nursing Home is right for them.

If you find yourself in the situation where you have to act now and do not have the time to do a lot of research, the information below should help give you a quick guide.

So, the decision has been made that my loved one needs 24-hour Nursing Home care. How can I make a quick, educated decision about where to go?

First, make several copies of <u>The Changing Culture in Nursing Homes</u> located in the next section of this packet beginning on page 7, so these will be handy for you to distribute. Use this to help convey what type of Home you want for your loved one.

Next, communicate. Give everyone you talk to a copy of <u>The Changing</u> <u>Culture in Nursing Homes</u> so they know what is important to you.

- Talk to the Hospital Social Worker or Case/Care Manager to discuss options.
 - They will know the Nursing Homes located within your community. They are not allowed to tell you which place to go to, but they can give you a list of Nursing Homes and they should be able to tell you the services that these Homes offer.
 - Have them assist you in figuring out how you will pay for the Home. (Review <u>How Do You Pay the Nursing Home Bill?</u> located in this packet on page 25 for assistance on what you may be eligible for.)
- Talk to your doctor.
 - Why is Nursing Home placement being recommended? Use the
 <u>Evaluating My Care Needs</u> sheet located on page 19 if you feel this
 will be useful in sorting through this question. Make sure that the

- Homes you look at offer the care needed and that 24-hour Nursing is really what is needed.
- o What are the doctor's opinions about Homes in the area?
- Your doctor may not go to Nursing Homes, so find out if she/he
 has any respected colleagues that go to any Homes.
- If your doctor does go to a Nursing Home do not feel obligated to have to go to that Home. No matter where you choose doctors will be available to follow your care.
- Talk to the hospital staff. They see many people coming and going from the Nursing Homes to the hospital. They probably have some opinions about what Homes they think provide good care.
- Use social media. This may be one of the best ways to get opinions from others who have been in the same situation that you find yourself in right now. When people have knowledge about Nursing Homes, they typically welcome the opportunity to share this information.
- Talk to anyone else who may have some knowledge about Nursing Homes in the geographic area you are looking at. This includes clergy, friends, co-workers, etc. Consumer referral can be the best way to gain information.

Call all the Nursing Homes that you think will be a good match for you based upon:

- Services
- Feasibility for visiting
- ❖ Information that you have received from all the networking you have done.
- Tell the Home that you need to decide quickly and that you want to make sure that they can take you based upon your financial requirements/payment options and services needed. Share these with them right up front.
- Ask them: Do you engage in Culture Change? If they do not know what that is, ask them:
 - o Will my loved one always have the same staff carrying for him/her?
 - Will my loved one be able to choose what time he or she wants to go to bed, when he or she wants to eat, and when he or she wants to have a shower or a bath?

Eliminate Homes based upon their answers to the above questions. If
they ask you more questions about what you are talking about, applaud
the inquiry and direct them to the Illinois Pioneer Coalition website at
www.illinoispioneercoalition.org Do not even bother to visit the Homes
that answer "no" to these questions.

Finally, visit the Nursing Homes that knew what you were talking about regarding Culture Change or answered the questions above with "yes" responses.

- Use the <u>Hour Way!</u> <u>Questionnaire</u> included in the packet beginning on page 41 when touring and interviewing the Home. If you have any questions as to why the particular questions have been selected, refer to <u>Explaining the <u>Hour Way!</u> <u>Questionnaire</u> on page 33. (It takes approximately 1 hour to tour and complete the questions for each Home that you visit.)</u>
- Get a copy of the Public Health Inspection Report from the Home and review it. Know that most Homes have areas that need improvement listed on these reports. That does not mean that it is a "bad" Home. Just make sure you are aware and comfortable with your findings. Do not hesitate to ask the Home about your concerns.
- Review <u>Taking Care of You and Your Loved Ones Needs</u> on page 29 to assess for the importance of these ideas as well.
- Observe, ask questions and trust your "gut"! Remember you are the customer and deserve to have dignity and choice throughout the decision-making process to ensure that you have things ...

Your Way!

The Changing Culture in Nursing Homes

The need for Nursing Homes arose about 50 years ago out of the requirements for hospitals to discharge the chronically ill person to focus on acute care needs instead. Because of this, today's Nursing Homes were typically created as "homes for the aged" to care for this

chronically ill older adult. Many Nursing Homes were built like hospitals and organized to run in a similar manner. As a result, Nursing Homes became regimented and tasks and schedules became their main focus.

Today, daily life in many Nursing Homes is still organized around predetermined schedules where the tasks become the focus of care, <u>not</u> the person that is being cared for. Because the emphasis is primarily on quality of care and not on quality of life, the patient's life, (or resident's), often lacks choice, meaning and purpose. The result is that there is little sense that the Nursing Home is "home" for the person living there.

Culture Change

There is a movement in the Nursing Homes industry to transform this institutional approach of care delivery into one that is person-centered and directed. The culture envisioned is one of a community where each person's capabilities and individuality are affirmed and celebrated. This movement, referred to as *Culture Change*, promotes quality of care and quality of life simultaneously, making each inseparable and equally important. The results are better functional and behavioral outcomes for individuals and greater satisfaction with care by the elders who live in the

homes, their families and caregivers (Rader & Tomquist, 1995). These positive results were shown even when older adults had complex chronic conditions.

Each person is an individual and has different needs and wants. A Culture Change Home will respect this and adapt their care and services so that you can have the same quality of life that you had previous to needing Nursing Home care.

With Culture Change the voices of individuals needing care and those working closest with them always come first. It involves a continuing process of listening and changing routines and organizational approaches in an effort to individualize and de-institutionalize the care. This is also referred to as person-directed or person-centered care where 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 Nursing Homes occurs through meaningful relationships where caregivers and staff really know the people that they care for so individuals can continue to live a meaningful life and feel "at home" wherever they are.

Key Components of Culture Change

Nursing Homes that practice a Culture Change philosophy treat the person as an individual and respects his/her personal wishes, needs, and choices. The care provided honors personal habits, cultural preferences, and values. The caregivers see the person as a complete being who has thoughts, feelings, physical and spiritual needs. This occurs through consistent and trusting care giving relationships which promote physical and emotional comfort while keeping the person involved with family, friends and his/her social network.

What Does Culture Change Look Like?

The chart below illustrates some of the differences between traditional Nursing Home care and care at a Culture Change Home. More specific examples of Culture Change are included in the *Explaining Your Way!*

Questionnaire located on page 33.

Traditional Care Person-Centered Care Residents are told when to wake up, Residents wake up, go to bed, eat, and bathe when they choose to. go to bed, eat, and bathe based upon institutional schedules and set Staff alter their work routines to routines honor the resident's preferences. Residents frequently have different The same staff take care of the care staff. The staff do not know the same residents; they know each residents well so they are not familiar other and caring relationships with their preferences. Residents develop. Staff ultimately provide often feel unknown, insecure and better care and residents feel more scared secure, content and happy.

The Illinois Pioneer Coalition

The Culture Change movement has been supported nationally since 1997 when a coalition of prominent professionals in long-term care began to advocate for person-centered care. These "pioneers" of social change established a not-for-profit organization called the Pioneer Network. The Pioneer Network has become the national umbrella organization for the Culture Change movement and was the catalyst for encouraging change in Illinois.

The Illinois Pioneer Coalition (IPC) was organized in October 2002 and currently serves as the Culture Change advocate for the State. In 2008 The IPC became a 501-3c organization recognized by the long-term care community as a source for education and training on person-centered care practices. Nursing Homes throughout the State have been provided with

training on Culture Change and how to "do it better". Some Homes have been more progressive than others in embracing the practice ideas shared through these training sessions. While it is the IPC's mission to educate as many Homes as possible, not all Homes have welcomed the idea of change. It is our belief that when the consumer demands care practices to be individually driven, then the motive for change at the provider level will grow. It is through this packet for you, the consumer, that we are continuing to encourage change to occur. The materials provided are designed to help you better understand what you should be looking for so that you can make an informed and educated decision about which Nursing Home is right for you. In turn we are hoping that the Nursing Home providers respond to the demands of the new educated Nursing Home consumer thus accelerating the rate of Culture Change in Illinois.

The Illinois Pioneer Coalition commits to these principles and values:

- Know each person.
- Each person can and does make a difference.
- Relationship is the fundamental building block of a transformed culture.
- Respond to spirit, as well as mind and body.
- Risk-taking is a normal part of life.
- Put person before task.
- All elders are entitled to self-determination wherever they live.
- Community is the antidote to institutionalization.
- Do unto others, as you would have them do unto you.
- Promote the growth and development of all.
- Shape and use the potential of the environment in all aspects: physical, organizational, and psychosocial / spiritual.
- Practice self-examination, searching for new creativity and opportunities for doing better.

Process for Achieving

Your Way!

Step-By-Step Process for Determining Which Home is Right for You

The process below outlines how to best decide which Nursing Home will be right for you. Tools are provided within the packet to help with each step along the way. There are also reference tools at the end of this packet which provide further information if needed. All of these tools are also online at www.illinoispioneercoalition.org

1. Decide on the care needs for the level of care that is appropriate for you/your loved one.

Tool: Care Needs Evaluation

2. Decide on payment source.

Resources sheet: How Do You Pay for Long Term Care?

3. Assess Personal Needs:

Resource Sheet: Taking Care of You and Your Loved Ones Needs

4. Select up to 4 homes (recommended) to research and visit.

Tool: Facility Information Sheet

5. Conduct Internet Research on the Homes.

Tool: Facility information sheet

Resource Sheet: Important Websites

- Federal Website for quality review:
 <u>www.medicare.gov/nursinghomecompare</u>
- State Website for quality review, including annual inspection results:

http://www.idph.state.il.us/webapp/LTCApp/listing.jsp?facilityid=6014294

6. Make appointment and visit the Nursing Home.

Tool: Your Way! Questionnaire

- ➤ Recommended to visit 2 times with one of those times in the evening or weekend.
- 7. After you visit all the homes that you are considering, compare homes to each other.

Tool: Facility Comparison Sheet

Defining Nursing Home Services

Nursing Homes provide care for individuals who need 24-hour nursing care without being in a hospital. A doctor supervises this type of care and the Illinois Department of Public Health regulates these facilities. Paying for Nursing Home Services depends on the type of care required and is briefly explained below. (For more detailed information, refer to "How Do You Pay the Nursing Home Bill?" located on page 25.)

Other commonly used terms for Nursing Homes are:

- Long Term Care Facility
- Nursing Facility or
- Convalescent Home

- Rehabilitation Center
- Center

Old People's Home

Specialized Services provided by Nursing Homes

Certain Nursing Homes may provide specific types of care. Some of these require special licensing and some of these do not. The same facility may carry a variety of different licenses. The type of licensed Nursing Home care that focuses on the aging adult are described below.

Skilled Nursing Care is nursing and rehabilitative care that is prescribed by a physician and is delivered on a daily basis by skilled medical personnel such as nurses or therapists. Skilled care is generally provided to assist patients during recovery following hospitalization for treatment of acute conditions. Another term you may hear for this is **Rehabilitation Center**. Medicare Part A will pay up to 100 days of skilled care if the individual qualifies. But, because skilled care is so narrowly defined, Medicare payments will usually last for only a short time, and are temporary. Nursing Homes providing these services have a Skilled Nursing Care license. You may find that some hospitals have a Skilled Unit in their hospital. These

Units are licensed just like a Skilled Nursing Home and are held to the same standards as the Nursing Home.

Intermediate Care is provided for patients who are recovering from acute conditions but do not need continuous care or daily therapeutic services. Intermediate care is provided by skilled professionals such as registered or licensed practical nurses, and therapists, under the supervision of a physician. Medicare Part A does not cover intermediate care in these Nursing Homes. A Nursing Home providing these services have an Intermediate Care Services License. Medicaid will pay for Intermediate Care services if the individual is eligible. Not all homes accept Medicaid so if you think the person is eligible for Medicaid assistance, look for a Home certified for this program. For more information on qualifying for Medicaid assistance, visit:

http://www2.illinois.gov/hfs/medicalprograms/brochures/pages/hfs 3191.aspx

Dementia Care in Illinois may also be referred to as a **Special Care Unit**. This is a specific license provided by the State and additional criteria must be met in order for a Nursing Home to designate itself as such. You may find that Alzheimer's or Dementia Care is also provided in a non-certified Home but they are not allowed to advertise themselves as a Special Care Unit Facility since they do not have to abide by the Special Care Unit criteria. Many times, you will find a Nursing Home that has this license designates a Special Care Unit in the Home, meaning that it is separate from the rest of the facility. This Unit may have doors that have alarms or locks on them so that the individuals living in the unit do not wander off the unit without staff supervision. This is done to help assure safety for the dementia care individual.

If 24-hour nursing care isn't what you think you need, then there are other options that are explained in the next section of this packet,

<u>Defining Care Services:</u> What level of care should I be looking for?".

Defining Care Services: What level of care should I be looking for?

Is Nursing Home Care my only choice?

Ask your doctor, nurse, hospital discharge planner and/or other social service professional to explain all the possible options for care so that you can decide which ones fit your situation. Remember, though, that these professionals have limited information and work for the organization or company and not for you. Hospitals are pressured to get you or your loved one out of the hospital quickly which may not lead to finding the best place for the follow-up care which you need and deserve.



Knowing this, an educated you is your best resource. The information in this section is intended to provide you with basic definitions of care options to assist in fully investigating the right place for you or your loved one.

The State of Illinois has developed a comprehensive booklet titled <u>State and Federal Programs for Older Adults</u> that can be accessed at: http://www.state.il.us/aging/1news_pubs/publications/state-federal_book.pdf. This booklet features more details on the programs listed below as well as other valuable resource information.

Home Services offer in-home assistance such as in-home aides or nursing care, and sitter services. This help may be for long or short periods and it is completely up to the patient to decide. Home Care Agencies provide <u>non-medical</u> care, also known as personal care service, in the home environment under the direction of a licensed Registered Nurse (RN). Home Services agencies charge for their services by the hour or accept

private insurance. In some cases, Medicaid may pay for services rendered if the individual meets eligibility requirements.

- Contact your local Area Agency on Aging for more information on this at http://www.state.il.us/aging/2aaa/aaa map.htm or call the Senior Hotline at 1-800-252-8966 or 1-888-206-1327 (TTY)
- For a listing of agencies, visit https://data.illinois.gov/ and click on IDPH Home Services Directory

Home Health Care agencies provide nursing, home health aide, physical therapy, occupational therapy, speech therapy and social work services in the person's own home. These services are under the direction of a physician and are usually provided to help the patient recover from an illness, injury, disease or exacerbation of a chronic condition. Medicare part A will typically pay for these services after a hospitalization.

• For more information, visit https://data.illinois.gov/ and click on IDPH Home Health Agencies Directory

Assisted Living Facilities are defined differently by each State. In Illinois if a person requires total assistance for two or more Activities of Daily Living (i.e. bathing, dressing, eating mobility, toileting) they are not eligible to live in an Assisted Living environment. Before admission a physician must complete a thorough assessment which documents the cognitive, physical and psychosocial condition of the individual. Personal and health-related services must be available to all residents 24 hours a day. It is not required that Nursing Care be available, but it may be provided by the Facility or by an outside home health agency. Residents must be able to administer their own medications, or they must be given by licensed personnel. However, non-licensed staff can supervise residents when taking their medicine and make sure that the medication's instructions are followed.

For a listing of agencies, visit https://data.illinois.gov/ and click on IDPH Assisted Living and Shared Housing Licensed Establishments Listing

Supportive Living was developed by the State of Illinois as an alternative to Assisted Living for low-income older persons and persons with disabilities under Medicaid. The Illinois Department of Healthcare and Family Services has obtained a "waiver" to allow payment for services

which are not routinely covered by Medicaid such as personal care, homemaking, laundry, medication supervision, social activities, recreation and 24-hour staff. The resident though is responsible for paying the cost of room and board at the facility.

- For more information, contact the Illinois Department of Healthcare and Family Services, Bureau of Long-Term Care at 217-782-0545.
- For a list of Supportive Living Facilities, visit http://www.slfillinois.com/operational.html

Continuing Care Retirement Community (CCRC), also called Life Care Communities, are communities that include independent living residences, (small housing units such as cottages, condominiums /apartments), an assisted living facility and a nursing home which are located on the same campus. CCRCs and their residents establish a business arrangement through a legal contract specifying exactly which supportive services, nursing care, other healthcare, and housing will be provided for residents. Options also vary on the "ownership" contingencies in these communities.

- For more information, contact the Department on Aging Senior Help Line at 1-800-252-8966, 1-888-206-1327 (TTY).
- For a listing of Communities, visit http://www.ccrcdata.org/

Retirement Center is a term that has no definition in regards to Medicare or Medicaid. You may hear this term in regards to a community where social services and activities are provided for senior citizens who generally do not require ongoing health care. They may be used when describing CCRCs due to the Independent Living portion of these communities.

Hospice services are available to individuals who are terminally ill and have a life expectancy of six months or less. The goal is to provide comfort for terminally ill patients and their families, not to cure illness. A physician's certification is required to qualify an individual for the Medicare Hospice Benefit. The physician also must re-certify the individual at the beginning of each six-month benefit period. If you qualify for hospice care, you will have a team of doctors, nurses, home health aides, social workers, counselors and trained volunteers to help you and your family cope with

your illness. Depending on your condition, you may get hospice care in a hospice facility, hospital, or nursing home.

- For more information contact Illinois Hospice and Palliative Care Organization at 1-888-844-7706 or visit www.il-hpco.org.
- For a listing of agencies, visit https://data.illinois.gov/ and click on IDPH Hospice Directory

Respite Care means the provision of intermittent and temporary substitute care of frail or disabled adults 65 years of age and older in the absence of the primary care-giver. The purpose is to provide a "rest" or respite to the primary caregiver so that they can continue to provide care in the home after the respite is provided. Respite care can be provided in the home, in a day care setting during the day, overnight, or a long-term care facility such as a Nursing Home or Assisted Living/Supportive Living Facility. If the individual is receiving Hospice Care under Medicare, Medicare will cover respite care for up to five days.

- For more information on the Caregiver Support program and services, contact the local Area Agency on Aging or the Department on Aging Senior Help Line at 1-800-252-8966, 1-888-206-1327 (TTY) or e-mail: aging.il.senor@illinois.gov
- Also visit <u>www.state.il.us/aging/1caregivers/caregivers-main.htm</u> or <u>http://www2.illinois.gov/hfs/medicalprograms/brochures/pages/hfs</u> <u>3191.aspx</u>

Adult Day Care designed especially for older adults who want to remain in the community but cannot be home alone during the day due to physical, social or mental impairments. Adult day service facilities may provide health monitoring, medication supervision, personal care, recreational and therapeutic activities. The service also offers respite care to family members who serve as caregivers.

 For more information contact the Illinois Department on Aging Senior Help Line at 1-800-252-8966, 1-888-206-1327 (TTY) or visit www.state.il.us/aging

Evaluating My Care Needs

The decision for Nursing Home placement never comes easy. Many times, the catalyst for Nursing Home care comes after a catastrophic event brought the individual to the hospital or from the realization that the individual requires a higher level of care then what can now be provided for at home, (perhaps due to an advancement of a diagnosis, changes in care givers, safety issues, etc.).



When the realization that the individual can no longer live independently, a decision must be made about the best alternative for care. This may or may not mean Nursing Home care. There are other types of care services available in Illinois, but determining which type of care is needed can be very overwhelming. Please refer to <u>Defining Care Services:</u> <u>What level of care should I be looking for?</u> on page 15 for further information.

The question, "Does the individual require 24-hour care?", needs to be looked at critically. If the answer is not clear, a <u>Care Needs Evaluation</u> to help with placement determination has been included to help sort this out. These questions will assist with the decision-making process. The intention is to help provide guidance with this decision and use of this form is not meant to replace recommendations made by your Healthcare Provider. You may also want to refer to this form when talking to the Care Facility to make sure that you and your loved one's needs will be met.

Care Needs Evaluation

List all the Diagnosis that the Individual has:								
Vision and Hearing					No			
Does the individual have vision issues?								
Describe:								
Does the individual have hearing losses?								
Describe:								
Which of the Following Describes the Mobility Condition of the Individual?								
	Yes	No		Yes	No			
walks independently			should be using a cane or walker but doesn't					
occasionally needs assistance/ seems unsteady			uses a walker					
uses a cane			uses a wheelchair					
has had a recent fall			has had a fall that caused an injury					

Which of the Following Describes the Cognitive Condition of the Individual?						
	Yes	No		Yes	No	
has no noticeable memory problems			occasionally is forgetful			
frequently forgets things such as locking the door, turning off the stove, medication, etc			frequently forgets information about friends, family, news events, etc			
gets confused			wanders during the night			
has difficulty solving problem			gets lost			
Which of the Following Describes the Social and Emotional Condition of the Individual?						
	Yes	No		Yes	No	
has lots of friends and sees them regularly			has lots of friends but doesn't see them regularly			
doesn't have many friends			is involved in activities			
seems depressed			outside the home			
seems lonely			seems impatient			
seems stressed			seems angry			
Which of the Following Describes the Transportation Abilities of the Individual?						
	Yes	No		Yes	No	
has a car and can drive it			has transportation through friends			
has a car and cannot drive it			has public transportation available			
has a car and shouldn't drive it			uses private for-pay transportation			
doesn't have a car			needs transportation			

From Your Observations, Evaluate the Individual's Performance in These Areas

Activity	Can Do Independently	Needs Some Help	Needs a Lot of Help
Rising from a seated position			
Getting out of bed			
Getting in or out of a car			
Preparing a meal			
Eating a meal			
Toileting			
Bathing			
Getting dressed			
Personal hygiene			
Doing laundry			
Using the telephone			
Taking medications			
Paying bills			
Keeping track of finances			
Shopping			
Home maintenance			
Household cleaning			

How Do You Pay the Nursing Home Bill?

When a person enters a Nursing Home one of the biggest concerns is how to pay the bill. Nursing Homes provide food, housing, laundry, social activities, personal care and medical care 24 hours a day. This is expensive. The person admitted is responsible for the bill, so how can this be paid for?



There are several different options to help pay or defray the cost of Nursing Home Care. Becoming educated on this will help you navigate your care choices and assist with your decision process.

Personal Savings and Income

One way to pay for Nursing Home Care is from personal savings and income. If this is an option, find out the projected monthly cost of care and what happens once the savings runs out. (The average daily cost in Illinois is \$167-\$206 per day.) Medicaid may be available if personal savings or income run out, but not all homes accept Medicaid. If you will be using private funds to pay for care, you may want to find out if the home is Medicaid certified and if it is possible to receive Medicaid after funds diminish. (See the information on Medicaid below)

Insurance

Some people may have some type of insurance which may pay some of the bill. Most medical insurance is "hospitalization" insurance and does not cover, or has very limited coverage, for nursing home stays. Even "Nursing

Home insurance" may or may not cover the bill depending on the reason for being in the Nursing Home, the treatment and the terms of the policy. Talking with the insurance company directly is your best way to find out what you are eligible for.

Medicare

Medicare is one of the most frequent methods of paying for short term Nursing Home Care. Medicare is a Federal health insurance program which helps defray many of the medical expenses of most Americans over the age of 65. Under Medicare the first 20 days may be covered in full. From days 21-100, Medicare will pay a portion of the cost of care if you continue to require skilled services. You must pay part of the cost (called the "co-pay") of your stay. These days will be covered only if the person was in the hospital three midnights immediately before entering the Nursing Home and the resident needs certain skilled care or if treatments are showing improvement in the individual's condition so continuation of treatment is valuable. Medicare stops paying when the treatment ends or the 100 days are used. (55 days was the average length of stay that Medicare paid in 2007.)

Visit www.medicare.gov for more information on Medicare

Medicaid

For those who have limited income, Medicaid may be an option. Medicaid is a joint federal-state health care program for people with a low income. The program is administered by each state and the type of services covered differs. In Illinois a person must apply to the State of Illinois through the Department of Health and Human Services to obtain Medicaid eligibility. There are strict criteria that must be met in order to qualify for Medicaid. The state will not pay bills more than three months prior to the date of application. Not all Homes are Medicaid certified and some who are may require a person to pay privately using up their own funds before switching to Medicaid.

Visit <u>www.medicaid.gov</u> and go to *Illinois* in the drop box provided on the right side of the screen for more information.

Veterans Administration

If your loved one is a Veteran, there may be assistance through the Veterans Administration, (VA). A person who served in the active military, naval, or air service and who was discharged or released under conditions other than dishonorable may qualify for VA health care benefits. In order to access these benefits, the Veteran must first apply for enrollment. In Illinois, the Nursing Home must have a contract with the VA in order to accept payment for the Nursing Home stay through the Veterans Administration. Homes that have VA contracts are limited. The VA can provide more information on which Homes in your area have such a contract.

To submit an application for enrollment, call 1-877-222-VETS (8387) or call any VA Health Care Facility or VA Regional Benefits Office or go to www.1010ez.med.va.gov/sec/vha/1010ez/ to fill out an application online.

Wartime Veterans' Improved Pension Program is a program that provides financial assistance to wartime veterans and/or their surviving spouses who reside in long term care or assisted living facilities. Many American wartime veterans are unaware that they may be entitled to this pension benefit, which can pay out over \$1,500 per month. An application must be completed and other criteria must be met in order to be eligible for the program. The application is over 30 pages long and must be completed accurately, or you must start the whole application process over.

The American Association for Wartime Veterans (AAWV) helps complete these applications for free. Visit: www.usawarvet.com or call 1-800-850-4947.

Other Resources Available to Assist with Financial Questions

With all this information you may still find that you have more questions. The information in this section of the packet is intended to help educate you and your loved one on your choices. For additional information talk with your hospital caseworker or social worker, local Area Agency on Aging or Ombudsmen.

There is also a National program called the State Health Insurance Assistance Program (SHIP) that may be very helpful. This is a free counseling program where trained counselors provide answers to questions related to Medicare, Medicare Supplement Insurance, Medicare Advantage, Medicaid, long-term care insurance, prescription coverage and low-income assistance. Each state has a SHIP program.

- You can find the Area Agency closest to you by going to: www.aoa.gov or calling the Eldercare Locator number at 1 (800) 677-1116
- For more information on the Long-Term Care Ombudsman Program, contact the Senior Helpline: 1-800-252-8966, 1-888-206-1327 (TTY) or visit http://www.state.il.us/aging/1directory/ombudsmen.pdf for the Statewide directory.
- You can find the SHIP program in your state by going to the website: www.healthassistancepartnership.org or calling: 1 (800) MEDICARE

Taking Care of You and Your Loved Ones Needs

Multiple things should be looked at prior to deciding upon which Home is right for you. There are things that should be addressed which are not part of any check sheet but may affect the emotional adjustment for your loved one and for yourself. These include conversations with your loved one regarding the future and the effect that facility dynamics can have on the overall quality of life for both of you. Within this section we try to address some of these to help you feel more assured that the right decision is being made.

Moving into a Nursing Home can be very hard on both the individual and the family. This is not easy... sometimes just recognizing that may help. But what else can be done?

Involve the individual in the decision process to every extent possible. The only way to *find dignity and choice* is by involving the person in the conversation. The individual has been making decisions for him/herself throughout their adult life. Now is not the time to change that. Very personal choices are being made - shouldn't he/she be involved in these conversations to every extent possible?

Suggestions:

- Provide reassurance that you can be depended upon to act in his or her best interest and that you will be there for support.
- Have open discussions about his or her wishes, abilities and options. Be honest about what is reasonable and what isn't. Use the support of healthcare professionals to keep these conversations honest.
- Help your loved one maintain a sense of control by providing support and guidance in making empowered decisions.

• Share your own feelings and respect your own needs in relation to your loved one's expectations of you - be honest about your time and energy limits.

Being honest with yourself and your loved one will really help in dealing with the emotional side to this decision process. With that being said though, there are other things that may also produce stress and anxiety, particularly as time goes on.

The issues below are those "non-checklist" items that may ultimately affect the quality of life experience. By considering these upfront, we hope that you will be a more informed consumer to assure that you achieve "way," and find that dignity and choice which you and your loved one deserve.

Location of the Home can have a large influence on the quality of life for the individual. Think about location in terms of the impact on both the individual and on visitors.

Consider....

What type of community does your loved one prefer? Rural? Urban? Is it important for the individual to remain in their Community? Who will be visiting the individual? Think about the location in regards to family, loved ones and friends being able to visit easily and frequently.

What about Ethnic and/or Religious Culture of the individual? Think about religion, language, diet, etc. If the individual living in the Home has a strong connection to any of these, this will be very important.

Consider...

There are Homes that specialize in the specific needs and desires of ethnic and/or religious cultures. Does the individual's needs impact diet, meaningful engagement, ability to communicate easily with others, etc.? If these needs are not met, what effect will this have on the individual?

Visitation: According to the Federal and State regulations, there should be no limitations in regard to visiting times in a Nursing Facility unless it has an adverse effect for the client. Even though this is mandated, some

Homes provide better for this than others. If you desire or require "off" times for visiting, make sure that the facility will fully accommodate this for you.

Consider...

When will you be visiting? Perhaps due to work schedule, other life commitments, etc. you want to visit late at night; will you be able to do this readily? Do the doors lock at a certain time of night? How will you get in? Will this be okay? Particularly if sharing a room, is there a place where you can visit so that you don't disturb the roommate?

Doctor Visits: Who will follow the individual's care once admitted to the facility? Will your doctor continue to see you or will you be assigned to a staff doctor? Although you have the right to continue with your own physician, not all physicians follow their patients into Nursing Home settings.

Consider...

Will your doctor follow you at the Home? If you have appointments outside the Home, how will you get to appointments? You may have to pay for a transportation or depend on family or friends to take you to appointments outside of the facility. Is this something that you are willing to do?

Other Miscellaneous Considerations:

- What is the Smoking Policy?
- Will you be going out of the facility for visits? What is the home visit policy? (Many times, with Medicare stays there are policies regarding this.)



Explaining the Your Way! Questionnaire

Definitions

When a person moves into a care facility, it becomes their Home. Thus, when "Home" is used in this document we are referring to Nursing Home.

The term "Resident" is frequently used in Nursing Homes to refer to the person living in the facility. This is another term used for patient, client, etc.

How to Use the Questionnaire

This questionnaire is designed to help you assess the quality of life and care that a Home provides. Use it when you do a visit. It includes general questions that should be asked by all prospective residents and/or their families and is designed to help sort out what is important to you and/or the potential resident, generate conversation, and discover the philosophies and procedures of the Home (the things that determine what it may be like to actually live there).

A couple of other important notes about the questionnaire:

- The value of these questions is going to vary from person to person. Some questions will be very important to you; other less so. The decision on the best home for you is an individual one.
- Observations are a key part of this evaluation and decision process. The answers to these questions are going to be based on your personal

judgment and the more observant you are, the better your judgment. Try to keep the questions that are most important to you in mind throughout your whole tour and interview.

• You will notice "bonus" questions throughout the questionnaire. These questions refer to practices that are permitted by regulators, but are not featured in many Homes in the State thus far. If the Home you are visiting features any of these practices, you may find that they are more advanced than others in becoming a "person-centered" care Home.

Explanations of Questions

The Questionnaire has been broken into sections. Below we have conveyed the reasoning behind why the questions in each section are being asked.

Care Practice:

How staff care for the individual is of utmost importance. When thinking about what is important for you, reflect on what life is like at home and expect that for your life - or your family member's life - in a Nursing Home. Some of the things that influence life at "Home:"

- When staff cares for the same individuals every day, relationships develop naturally and staff are better able to understand the needs, preferences and expectations of the persons in their care.
- Some Homes hire "agency staff" to fill in when they do not have enough employees to cover a shift. Agency staff members typically do not know the residents well, if at all, because they do not work at the same Nursing Home all the time. Thus, the practice of contracting out for staff is not considered a practice of person-centered care.
- We are all individuals and have our preferences. The time one goes to bed at night and wakes up in the morning is an example of a very personal and very important lifestyle preference. When that choice is not available the entire day can be affected. In a Nursing Home, we

should expect to be able to get up and go to bed when we want to, just as we do in our own homes.

- Call bells or lights are used by the residents to signal to staff that they need assistance. You may observe call lights over the doorways of the residents' rooms or hear signals going off in the rooms or the hallways. It should be the responsibility of all staff to respond to these signals not just the Nursing assistant or the nurse. If lights or bells are going off for an extended period of time, it may be a sign that staff are not very responsive to the resident's needs. The only way to measure this is to look, listen and observe.
- As with any job, certain people are more suited to work in this field than others. If people enjoy what they are doing, they are going to do a better job. This is just a fact of life!

Environment:

How the space around us looks can affect how we feel about the place and how we feel when we are there. When thinking about our own homes, there are probably certain things or aspects which are important in defining that space as our home. A big piece of this is simply having a place of our own. What defines "home" for you? Here are some things to consider.

- There should be no limit to when a resident can have visitors. Doors may
 be locked for safety at a certain time but a buzzer or doorbell should
 available so a resident can have visitors whenever they like.
- Having comfortable places to go, to relax or visit is important. This
 includes outdoor spaces for most of us. Your room should be your
 personal space but people also want to be able to visit outside of the
 room in a comfortable, inviting space.
- As we age, environment can play a big role in our safety. Bathrooms, hallways, and common spaces should be evaluated for safety and accessibility.
- Paging systems and other overhead speakers usually are not used in a home environment. In a Nursing Home, paging systems are set up for

staff convenience. Having to listen to people talking to each other through an overhead paging system can be annoying and can cause problems with concentration and sleep. Person-centered/directed homes will use their phone system, pagers, or the like to talk with each other so that residents do not have to hear communications between staff members.

Dining:

Dining is not just about consuming food. It is an opportunity for socializing as well as for enjoying the pleasures of a meal. Fortunately, institutional dining can be an easy thing to change with a little effort.

- Think about how we dine at home. For the most part, we eat at our own preferred mealtimes or when we are hungry; we do not eat off of trays; and everyone seated at the table receives their food at about the same time. These things should not change when you are living in a Nursing Home.
- Many Culture Change Homes have changed their dining service to provide a better experience. Examples:
 - Restaurant Service staff take meal requests based upon menu choices and serve it to you at your table.
 - Buffet Style Food is available on a steam table and you can either go to the steam table and request what you want or staff can take your order and get it for you.
 - Family Style Platters or bowls of food are placed on each table and you can take what you want.

Everyday Life:

How we spend our time is a very personal choice. What is important for one may not be important for another. Although this is a fact of life, having a good quality to our day is still very achievable while living in a Nursing Home. When asking the questions in this section, think about them from the point of view of the person who will be living in the Home. Be specific about the individual's preferences for daily life and see if those preferences will be available when living in the Home. This includes all aspects of daily life which are important to the person, including those related to work or hobbies, recreation, social life, leisure, and private time, etc.

Culture Change:

The questions in this section allow you to assess the Home's awareness of and commitment to person centered/directed care. Some Homes will be further along than others in accepting and implementing the practices of Culture Change. Some will need to make changes and others may need to maintain or improve changes they have already made.

How do we know if a Home is interested in changing and/or improving? One indicator is communication. A Home that values information from residents, families and staff and provides regular opportunities for communication is usually a Home that is interested in improving. Below are some communication-related ways a Home demonstrates its focus on person-centered care.

- Generates opportunities for conversations by conducting meetings with families, residents and staff.
- Measures staff, family and resident satisfaction thoroughly and regularly.
- Uses Resident Questionnaires to get to know the residents better and "I"
 Care Plans where the care of the resident is expressed in his/her voice to
 promote a deeper understanding of why the care practice is important
 (i.e. I have been a diabetic my whole life, but I am still able to have
 desert with my meal. I have done this my whole life and know how to
 regulate my sugar.").
- Involvement in the Illinois Pioneer Coalition (which promotes personcentered/directed care).

- Conducts neighborhood meetings where everyone who lives on the same floor or unit discusses whatever they would like. This practice helps build a sense of community between the facility and the residents.
- Provides a Family Council where family members meet, discuss issues and make recommendations. This practice helps build a sense of community between the facility and the families.
- Distributes and explains the Home's mission statement
- Talks to residents and their families and asks them their opinions about the Home.
- And most importantly, follows through on the information received: changes policies or procedures when necessary, trains staff adequately and regularly provides feedback or updates to residents, staff and families.

Other Important Questions:

- Staff turnover is another method of measuring staff satisfaction. The national average of turnover for Nursing assistants in Nursing Homes is 66%. If staff is satisfied, the turnover rate is usually below 40%.
- The longevity of the Administrator and the Director of Nursing can be an indicator regarding the stability of the Home.
- Staff to resident ratios should be compared against each other. There are no state specific regulations for the number of caregivers to residents because the type of care that is provided by the facility or the type of care that an individual resident may need will affect this ratio. It is important though to compare this number from Home to Home keeping in mind the acuity of the care that is being provided in the home.
- The Illinois Department of Public Health surveys each Home on an annual basis. Legally the written survey must be available to all people all the time. You should always ask to see the survey for any home you are considering.

When looking at the surveys, keep in mind the following:

- Nursing Homes are reviewed at least once a year by the State. There are many items, both large and small, which are reviewed during this annual review. Thus, it is very rare to have a survey with absolutely no violations. Deficiencies are meant to make the Home aware of opportunities for improvement. It is how they respond and react to the deficiency that is important so do not be afraid to talk with the Home about their survey and ask them what they did to improve upon the deficiency.
- Look carefully at the items that were rated deficient and consider the importance of each one, the number of residents affected by each and the number of total deficiencies.

Supplemental Questions for Specific Concerns

We have also included questions at the end of the questionnaire that may be more specific to individual needs of care such as therapy services, Dementia/Alzheimer's care, etc. Not all of these questions will pertain to you or your family members. Adapt them for your own use and use at your discretion.

Your Way! Questionnaire

Summary Sheet for Nursing Home Questions

Directions:

Nursing Home Comparison Number:

- Make copies of this form for each Nursing Home that you are going to visit for a tour.
- Number each Nursing Home so that you can correlate this number on the <u>Nursing Home Comparisons Summary Sheet</u> on page 49. Make sure you place this number on the top of each page so that you can easily keep track of the information.

Name:		
Address:		
Phone:		
Contact:		
Notes		
	No.	
	Nursing Home	
Evaluation Area	Score	Comments
Evaluation Area	(number of "yes" responses in	Comments
	each category on the attached Questionnaire)	
Care Practices	Questionnaire)	
Environment		
Dining		
Everyday Life		

Culture Change	

Your Way! Questionnaire

Nursing Home Comparison Number:									
<u>Care Practices</u>									
Questions	Yes	No	Comments						
Is the same Nursing Assistant consistently assigned to care for the Resident?									
➤ When the regular Nursing Assistant is not scheduled to work, is a substitute Assistant consistently assigned to care for the Resident?									
Is the same Nurse consistently assigned to care for the Resident?									
When the regular Nurse is not scheduled for work, is a substitute Nurse consistently assigned to care for the Resident?									
Do all the staff work for the Nursing Home and not for an outside agency?									
Can Residents decide when to go to bed and wake up in the morning?									
Can Residents get a bath or shower as often as they would like?									
> Can Residents select between a bath or shower?									
Will the staff meet with the Resident, and/or the family, to discuss concerns whenever they would like?									
Observations	Yes	ON	Comments						
Do the Residents look well cared for?									
Do you observe that Nurse call bells or lights are not ringing or flashing for excessive periods of time?									
Do you observe staff smiling and saying hello to Residents, each other and visitors?									
Care Practice Totals									

Nursing Home Comparison Number:									
<u>Environment</u>									
Questions	Yes	Z	Comments						
Is visiting time unrestricted?									
Does the Home have a garden/outdoor space that the Residents can access without staff and is wheelchair accessible?									
Is there space available for families and visitors to visit in private besides just the Resident's room?									
Can Residents decorate their own rooms with bedding and pictures?									
Bonus: Can Residents bring in their own furniture to decorate their room?									
Observations	Yes	Z	Comments						
Do the Resident rooms look pleasant and comfortable?	•								
comfortable? Is the Home free of objectionable odors as you walk									
comfortable? Is the Home free of objectionable odors as you walk through the hallways?									
comfortable? Is the Home free of objectionable odors as you walk through the hallways? Does the Home appear clean? Are hallways uncluttered so that people and									
Is the Home free of objectionable odors as you walk through the hallways? Does the Home appear clean? Are hallways uncluttered so that people and wheelchairs can move about freely? Ask to see where Residents bathe. Does this space									

Nursing Home Comparison Number:							
<u>Dinin</u>	g						
Meal time Hours: Breakfast: Lunch:			Dinner:				
Questions	Vec	Z	Comments				
Are meal times for at least 2 hours?							
Can Residents eat a full meal any time between these hours?							
If someone doesn't want to eat at the time of the meal, can they eat later?							
Is there restaurant, buffet, or family style type of dining?							
Can Residents select from at least two choices for their main entre?							
Can families/visitors dine with the Resident if they choose? (at a cost or for free)							
Are snacks and drinks available 24-hours a day at no additional cost?							
Observations	Ves	Z	Comments				
Are Residents eating without trays?							
Are Residents sitting at the same table served their food about the same time?							
Are Resident's mealtime requests provided in a prompt manner?							
Do staff give individual assistance to those that need it?							
Is there a pleasant aroma in the dining room?							
Sample the food. Does it taste good?							
Does the dining room have a comfortable feel to it?							
Dining Totals	S						

Nursing Home Comparison Number:								
<u>Everyday Life</u>								
Questions	Yes	oN	Comments					
Are Resident birthdays celebrated on the actual date and not just at a group celebration every month?								
Do children come into the Home to interact with the Residents?								
Is there a store, gift shop or cart available where Residents can purchase items?								
Are there outings into the community?								
Do Residents have access to a computer and internet?								
Will the Home accommodate specific daily interests of the individual such as religious, educational, and <i>fun</i> things?								
Does the Home have any pets?								
Bonus: Are Residents allowed to bring their own dog or cat to <i>live</i> with them in the Home?								
Bonus: Do Residents have access to washers and dryers to do their own laundry if they would like?								
Observations	Yes	oN	Comments					
Are Residents smiling?								
Are families smiling?								
Look at the Activity Calendar. Are there a variety of activities being offered?								
Are programs offered in the evenings?								
Are programs offered on the weekends?								
Everyday Life Totals								

Nursing Home Comparison Number:	Nursing Home Comparison Number:							
<u>Culture Change</u>								
Questions	Ves	No	Comments					
Are you a Culture Change Nursing Home?								
Have Staff have received training in culture change and person centered/directed care?								
Other then Resident Council, do you hold meetings where the Residents/families provide suggestions and ideas.								
➤ Do you measure staff satisfaction?								
Do you measure Resident/family satisfaction?								
Culture Change Totals								
What other things do you do to consider your Home?								

Nursing Home Comparison Number:	
Other Important Questions	
Questions	Response
What is your percentage of Nursing Assistant Turnover?	
How long has the Administrator worked here in this position?	
How long has the Director or Nursing worked here in this position?	
How many Residents does each Nursing Assistant care for during a shift?	
How many Residents does each Nurse care for during a shift?	
How many violations did you receive on your last survey? Ask to see the report.	
Whom do I go to if I have a problem:	

Supplemental Questions for Specific Concerns						
Concern	Notes					
Therapy services: • Types of therapy offered ○ Physical ○ Occupational ○ Speech • Number of days per week treatment offered • Hours of service						
Physician: Expected number of visitsHow selectedCan my own physician follow me?Transportation for appointments						
 Room selection: Private verses shared rooms Maximum number of Residents sharing rooms How are roommates decided upon? 						
 Special Services you may require such as: Dialysis treatment Alzheimer's/dementia care Psychiatric Skin Care Chronic Pain 						

Your Way! Nursing Home

Nursing Home Comparisons Sheet

Use the table below to compare the Homes that you have visited. Some of the questions asked are going to have more value and meaning for one person over another, so don't just make your decision based upon the overall score.

In order to make the right decision for you or your loved one, you need to decide what is important to you personally.

Nursing Home	Home 1	Home 2	Home 3	Home 4	Comments
Care Practices:					
Environment:					
Dining:					
Every Day Life:					
Culture Change:					
Nursing Assistant Turnover percentage:					
Longevity of the Administrator:					
Longevity of the Director of Nurses:					
Number of Residents each Nursing Assistant cares for:					
Number of Residents each Nurse cares for:					
Number of violations on the last survey:					

I Did Not Find Homes Doing Culture Change in My Area... What Now?

What if you visit several Nursing Homes in your area and none of them meet the criteria for Culture Change which you are looking for? Or what if you find a "good" 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 the movement is still young and growing, Culture Change is not occurring in all Homes throughout the State. This is the reason for educating you, the consumer.

The Culture Change movement is still new and changes take time. We need more advocates to spread the word and help promote this change. Consumers can create the demand for this new type of long-term care. Steve Shields, a Culture Change leader and Nursing Home CEO/owner in Manhattan, Kansas, gives this example in his community of about 100,000 people: The Culture Change model has been embraced by all the Nursing Homes in Manhattan, a direct result of consumer awareness and the demand for this type of care.

If you are in this difficult situation where you cannot find a Nursing Home which provides person-centered/directed care in your area, you need to speak up!



The more that the Nursing Homes 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.

So How do I Advocate for Person-Centered/Directed Care for My Loved One?

First, use the information in this packet to make an informed decision and seek out the best Home based upon your individual needs. Next, help the staff to get to know your loved one. Share who the resident is by bringing in pictures, sharing life history and daily routines. Put the information in writing so that all staff working each shift have access to this. Join the Family Council. If there is no Family Council, inquire about starting one. (Federal and State regulations support the creation of Family Councils when family request it; for more information visit the National Consumer Voice for Quality Long-Term Care at www.theconsumervoice.org or talk with the State's elder care advocate, the Ombudsman at www.state.il.us/aging/1abuselegal/ombuds.htm.) Get involved in the care being received. Do this by attending the Care Meetings which are scheduled on a regular basis (typically within the first week to 30 days of admission depending on the type of care being received and then at least every three months thereafter). Do not be afraid to ask questions. Remember you are the consumer and deserve to be informed.

How Can I Support Increased Awareness to This Cause and advocate for Culture Change?

- Share what you have learned with others. Talk to your family, friends and community members about Culture Change and what you have learned. Help breakdown the belief that there is nothing that can be done to change the long-term care system. If Consumers demand; systems will change!
- Visit Nursing Homes in your community. Share the <u>Hour Way!</u>

 Questionnaire and tell them this is what you want for your loved ones and your community. Tell them Homes across the State are doing this and they WILL be left behind if they ignore this. Direct them to the Illinois Pioneer Website for more information.

 (www.illinoispioneercoalition.org)

- Talk with your family about your wishes prior to the "crisis" moment. A
 good resource for this is found in the Resource Section of this packet, <u>My
 Personal Directions for Quality Living</u>. This can also be accessed on The
 National Consumer Voice for Quality Long-Term Care website,
 <u>www.theconsumervoice.org</u>)
- Become a part of the Illinois Pioneer Coalition.
 - Regional Coalitions of the Illinois Pioneer Coalition exist throughout the State of Illinois. Consider joining a local coalition so that you can keep abreast of what is going on in our State. The website has more information on the location of these coalitions.
 - Membership is available so that you can be updated on what is occurring throughout the State and keep current on trends in the Nursing Home Community. Refer to the membership application in the Resource section of this packet or visit www.illinoispioneercoalition.org for more information.
- Join the IPC's Facebook page "like" us to show your Facebook friends you care.
- Join the National Campaign for Nursing Home Reform's Advancing Excellence to show Nursing Homes in Illinois that Illinois Citizens care and are demanding change. (www.nursinghomequalitycampaign.org)
- <u>DON'T</u> do nothing! At some point someone you care about *will* need Nursing Home Care whether you like it or not. Advocate for change now, so that you can have it...

Your Way!

Resources

The following resources have been included in this packet to assist the consumer in navigating the long-term care path.

- A Note About Advance Directives: What You and Your Family Should Know
- Illinois and National Resources: Agencies and Organizations
- Acronyms and Commonly Used Terms in Health and Nursing Home Care
- My Personal Directions for Quality Living blank form and sample
- Long Term Care Resident Rights
- Illinois Pioneer Coalition Membership Application

A Note About Advanced Directives:

What You and Your Family Should Know

Everyone has the legal right to accept or refuse treatments. This may include decisions such as a machine to help you breathe or an attempt to restart your heart. Helping your loved ones understand the kind of care you want is an important gift, if for some reason, you are no longer able to make decisions. If you have shared your wishes for care in advance, you can help relieve the stress and worry that making medical decisions for someone else can cause.

It is important to complete the documents that share your wishes with family members and your healthcare team so everyone understands the kind of care you want before a medical crisis occurs.

Advance directives are the legal documents and **advance care planning** is the process that allows you to make your wishes for care known to others.

Power of Attorney for Healthcare-Advance Directive should be completed by everyone over the age of 18. This document allows you to choose the person you want to speak for you regarding healthcare decisions when you cannot speak for yourself. In Illinois, this person is called an "agent" or patient representative. The agent makes decisions only if you are not able to make your own decisions, as determined by your doctor. The person you choose to be your agent should be someone you trust; someone who is willing to make decisions based on your wishes – no matter what his or her preferences might be. It is important to talk to your agent about your beliefs and fears about care, including what is important to you. You

should also talk to your doctor about your wishes. You do not need a lawyer to assist you in completing the Power of Attorney for Healthcare – Advance. It can be completed by a social worker or other healthcare professional help you complete the form.

According to the **Illinois Surrogacy Act**, if you have not named someone as your agent using a power of attorney for healthcare form and an emergency occurs the healthcare team must locate someone else to make decisions on your behalf. This law requires the healthcare team to try to contact relatives and others following a certain order until they locate someone willing and available to make medical decisions for you. Since this may not be the person you prefer they may not know your wishes. This is why it is important to complete the Power of Attorney for Healthcare so that your life decisions are followed.

There is a new form issued in March of 2013 called the **Uniform Do-Not-Resuscitate (DNR)/POLST Advance Directive**. This form allows you to request or forbid cardiopulmonary resuscitation (CPR) to try to restart your breathing and heart should your heart and/or breathing stop. The form also allows you to request all treatments, or limit treatments or comfort care following an emergency. The POLST form is an advance directive in accordance with Illinois law. It is <u>not</u> intended to replace a Power of Attorney for Health Care form. It should be used in addition to the Power of Attorney form. If you have not completed a POLST and you already have a DNR form, it is still valid. For more information on the POLST form, go to www.POLST.org.

Illinois and National **Resources: Agencies and Organizations**

Administration on Community Living - ACL: (Previously called the Administration on Aging)

Federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of older Americans and people with disabilities across the lifespan. Eldercare Locator Service is a free national service, providing written information about long-term support options in general and connecting the elder to resources in their own community. 1 (800) 677-1116

www.eldercare.gov.

Advancing Excellence Campaign – AE Campaign

National campaign to promote quality in Nursing Homes across the country. Provides tools for the providers to work on specific quality issues as well as the opportunity for the consumer to take action and sign up to show support for public commitment to quality in longterm care.

www.nhqualitycampaign.org

Affordable Care Act - ACA

Federal Legislation that expands Medicaid coverage to millions of low-income Americans www.medicaid.gov/AffordableCareAct/Affordable-Care-Act.html

Aging and Disability Resource Centers - (ADRC)

These centers provide free information to consumers and their families to about the full range of long-term service and support. 1 (800) 677-1116 www.adrc-tae.org

Alzheimer's Association -

Mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Website offers resources to assist in fulfillment of this mission.

800-272-3900 www.alz.org/illinois/

Area Agency on Aging - AAA

Area Agencies have the primary task of planning and coordinating services and programs for older people in their respective areas. Illinois is divided into 13 Planning and Service Areas (PSAs). The general website will direct you to information on where to find service in your community.

www.state.il.us/aging/

Centers for Medicare and Medicaid Services - CMS (formerly HCFA)

Agency within the US Department of Health & Human Services responsible for administration of several key federal health care programs including Medicare (the federal health insurance program for seniors) and Medicaid (the federal needs-based program) www.cms.gov/

For information geared more to the consumer such as information on Medicare part A & B, Open Enrollment, etc., visit: www.Medicare.gov

Chicago End-of-Life Coalition

A multidisciplinary group of healthcare providers and interested residents from throughout the Chicago area who share a conviction that people should expect excellent care at the end of life, and that healthcare institutions should be able to meet that expectation. Website has information on where to find support services and other end-of-life resources.

www.cecc.info/

Healthcare and Family Services - HFS (formerly IDPA)

State agency dedicated to improving the lives of Illinois families through healthcare coverage and child support services. Website contains information to assist in long-term care navigation in Illinois www2.illinois.gov/hfs/

Illinois Department of Human Services – DHS

Created to provide Illinois residents with streamlined access to integrated services, especially those who are striving to move from welfare to work and economic independence, and others who face multiple challenges to self-sufficiency.

www.dhs.state.il.us/

Illinois Department on Aging - IDoA

IDoA helps older people live independently in their own homes and communities. By working with Area Agencies on Aging, community-based service providers and older people themselves. Goal is to improve quality of life for current and future generations of older Illinoisans.

www.state.il.us/aging/

- Care Giver Support Program: www.state.il.us/aging/1caregivers/crc.htm
- Senior HelpLine
 Monday Friday, 8:30 a.m. 5:00 p.m. CST
 Toll-free within Illinois: 1-800-252-8966, 1-888-206-1327 (TTY);
 Outside of Illinois: 217-524-6911
- Elder Abuse Hotline: 1-866-800-1409, 1-888-206-1327 (TTY). 24-hour hotline to report suspected abuse of the elderly in IL

Illinois Department of Public Health – IDPH

www.idph.state.il.us/

- Booklet on "How to select a Nursing Home a reference and check sheet for the potential nursing home resident and his/her family" from the State of IL can be accessed at: www.idph.state.il.us/public/books/nhtoc.htm
- Information on Nursing Homes' annual inspections
 http://www.idph.state.il.us/webapp/LTCApp/listing.jsp?facilityid=6014294

Illinois Department of Veterans Affairs -

Internet site developed to help the Illinois Veteran navigate the many federal, state, and local resources and benefits available to veterans. www2.illinois.gov/veterans/

Illinois Long-Term Care Ombudsman Program

Regional Ombudsmen advocate on behalf of residents and their families in long-term care facilities. The ombudsmen also intercede on behalf of individuals and groups to ensure that they receive the benefits and services to which they are entitled and that their rights guaranteed by law are protected and enforced.

Senior HelpLine: 1-800-252-8966, 1-888-206-1327 (TTY)

Website: www.state.il.us/aging/1abuselegal/ombuds.htm

Joint Commission on Accreditation of Health Care Org. - JCAHO

An independent, not-for-profit organization that certifies health care organizations and programs in the United States. Joint Commission accreditation and certification is recognized nationwide as a symbol of quality that reflects an organization's commitment to meeting certain performance standards.

www.jointcommission.org/

Legal Assistance Foundation - LAF

Not-for-profit organizations that provides free civil legal services to low-income persons and senior citizens

Land of Lincoln Legal Assistance Foundation, Inc. Serves 65 counties in central and southern Illinois.

www.lollaf.org/

Legal Assistance Foundation of Metropolitan Chicago Serves Chicago and Suburban Cook County www.lafchicago.org/

National Consumer Voice for Quality Long Term Care – formerly National Citizens Coalition of Nursing Home Reform (NCCNHR)

Advocates for public policies that support quality care and life and empowers and educates consumers and families while promoting the critical role of direct-care workers and best practices in quality-care delivery.

www.theconsumervoice.org

National Council on Aging

BenefitsCheckUp is a comprehensive online resource for locating financial assistance programs that may help you pay for medications, health care, utilities, meals and other expenses.

www.benefitscheckup.org

Nursing Home Compare

An Internet site that allows you to look at how Nursing homes perform on clinical and staffing quality measures. Allows you to search by city or zip code www.medicare.gov/NursingHomeCompare/

Nursing Home Complaint Hotline

The Department of Public Health operates a Central Complaint Registry to record and investigate complaints regarding hospitals, nursing facilities, home health agencies, and the treatment of patients.

1-800-252-4343, 1-800-547-0466 (TTY); if out-of-state, call 1-217-785-0321 www.idph.state.il.us/healthca/nursinghometestjava.htm

Office of State Guardian - OSG

Provides adult guardianship services to eligible wards when a probate court appoints the office as legal guardian. They will also provide basic information and advice about adult guardianship and be able to suggest viable alternatives to adult guardianship or help find ways to make guardianship work better for an individual.

www.gac.state.il.us/osg

Pioneer Network

The focal point of the national long-term care culture change movement who provides resources and training to the Nursing Home providers on a National Level.

www.pioneernetwork.net

Quality Improvement Organization - QIO

Teligen is the Medicare contracted Quality Improvement Organization (QIO) for the state of Illinois, (formerly called The IL Foundation for Quality Health Care). Through quality improvement efforts and education, Teligen ensures that the Medicare beneficiaries throughout Illinois receive appropriate, high-quality Medicare care in both inpatient and outpatient settings.

Consumer Hotline: 1-800-647-8089

http://www.telligenqio.org/.

State of Illinois -

Official site for all information from the State of IL www.Illinois.gov



Acronyms and Commonly Used Terms in Health and Nursing Home Care

A

ADL – Activity of Daily Living ADON – Assistant Director of

Nursing

AMA – Against Medical Advice AL – Assisted Living

APS – Adult Protective Services AROM – Active Range of Motion

B

b.i.d. – twice daily BP – Blood Pressure

C

CHF – Congestive Heart Failure CNA – Certified Nurse Assistant;

COPD – Chronic Obstructive also referred to as a Nursing

Pulmonary Disease Assistant, Nurse's Aide

Culture Change – also referred to as CV – Cardiovascular

Person Centered or Person Directed CVA -Stroke

Care

CW – Caseworker

D - H

DON – Director of Nursing DON – Determination of Need

DX – Diagnosis EENT – Eyes, Ears, Nose and Throat

FOIA – Freedom of Information Act Hx – History

I-K

ICF – Intermediate Care Facility

ICF-MR – Intermediate Care Facility for the Mentally Retarded ICF-DD – Intermediate Care Facility for Developmentally Disabled

IOC – Inspection of CareIV – Intravenously

L

LPN – Licensed Practical Nurse

LTC – Long Term Care

LSC – Life Safety Code LTCO – Long Term Care Ombudsman

\mathbf{M}

MDS – Minimum Data Set

MMSE – Mini-Mental Status Examination MI – Mentally Ill

N - O

NH – Nursing Home NSG – Nursing

NSG – Nursing

NP – Nurse Practitioner

OT – Occupational Therapy

P

PA – Physician Assistant

POA – Power of Attorney

PROM – Passive Range of Motion

PTA – Physical Therapy Assistant

PC – Phone Call

PRN – As Needed

PT – Physical Therapy

Px- Physical Examination

Q

q. – every

q.h. – every hour

q.o.d. – every other day

q.d. – every day

q.i.d. – four times a day

R

R – Resident

RD – Registered Dietician

RAI – Resident Assessment Instrument $RN-Registered\ Nurse \qquad ROI-Release\ of\ Information \\ Rx-Prescription \\ \hline S \\ SHL-Sheltered\ Care\ Facility \qquad SLF-Supportive\ Living\ Facility \\ SNF-Skilled\ Nursing\ Facility \qquad SSA-Social\ Security \\ Administration \\ SSD-Social\ Services\ Director \qquad SSI-Supplemental\ Security\ Income \\ ST-Speech\ Therapy \qquad Std.-Standard \\ \hline T-Z$

TIA – Transient Ischemic Attack (mini-stroke) t.i.d. – three times a day W/C – wheelchair

Residents' Rights: An Overview



Residents' Rights are guaranteed by the federal 1987 Nursing Home Reform Law which requires Nursing

Homes to "promote and protect the rights of each resident" and places a strong emphasis on individual dignity and self-determination. This Nursing Home Reform Law requires each Nursing Home to care for its residents in a manner that promotes and enhances the quality of life of each resident. They must do so by ensuring dignity, choice, and self-determination.

Below provides a synopsis of the 1987 Nursing Home Reform Law.

The Right to Be Fully Informed of:

- · Available services and the charges for each service
- Facility rules and regulations, including a written copy of resident rights
- Address and telephone number of the state Ombudsman and state survey agency
- State survey reports and the Nursing Home's plan of correction
- Advance plans of a change in rooms or roommates
- Assistance if a sensory impairment exists
- Informed in a language they understand (Spanish, Braille, etc.)

The Right to Complain

- Present grievances to staff or any other person, without fear of reprisal and with prompt efforts by the facility to resolve those grievances
- To complain to the ombudsman program
- To file a complaint with the state survey and certification agency

The Right to Participate in One's Own Care

- Receive adequate and appropriate care
- Be informed of all changes in medical condition

- Participate in their own assessment, care planning, treatment, and discharge
- Refuse medication and treatment
- · Refuse chemical and physical restraints
- · Review one's medical record
- Be free from charge for services covered by Medicaid or Medicare

The Right to Privacy and Confidentiality:

- Private and unrestricted communication with any person of their choice
 - o During treatment and care of one's personal needs
 - o Regarding medical, personal, or financial affairs

Rights During Transfers and Discharges

- Remain in the nursing facility unless a transfer or discharge:
 - o is necessary to meet the resident's welfare;
 - is appropriate because the resident's health has improved and s/he no longer requires Nursing Home care;
 - o is needed to protect the health and safety of other residents or staff;
 - is required because the resident has failed, after reasonable notice, to pay the facility charge for an item or service provided at the resident's request
- Receive thirty-day notice of transfer or discharge which includes the reason, effective date, location to which the resident is transferred or discharged, the right to appeal, and the name, address, and telephone number of the state long-term care Ombudsman
- Safe transfer or discharge through sufficient preparation by the Nursing Home

Right to Dignity, Respect, and Freedom

- To be treated with consideration, respect, and dignity
- To be free from mental and physical abuse, corporal punishment, involuntary seclusion, and physical and chemical restraints
- To self-determination
- Security of possessions

Right to Visits

 By a resident's personal physician and representatives from the state survey agency and Ombudsman programs

- By relatives, friends, and others of the residents' choosing
- By organizations or individuals providing health, social, legal, or other services
- Residents have the right to refuse visitors

Right to Make Independent Choices

- Make personal decisions, such as what to wear and how to spend free time
- Reasonable accommodation of one's needs and preferences
- Choose a physician
- Participate in community activities, both inside and outside the nursing home
- Organize and participate in a Resident Council
- Manage one's own financial affairs

My Personal Directions for Quality Living

To my caregivers paid and unpaid: Name:_____ I am recording my personal preferences and information about myself, in case I need long-term care services in my home or in a long-term care facility. I hope this information will be useful to those who assist me. Please always talk to me about my day-to-day life to see what it is that I want and enjoy. However, the information below may provide some help in understanding me and in providing my care. I want my caregivers to know: The way I like to awaken & begin my day: The way I relax and prepare to sleep at night: Activities I enjoy: Things that I would like to have in my room:

Foods that I enjoy:

Things I do not like:
I become anxious when:
Things that calm or soothe me:
Things that make me laugh:
Religious Preferences:
Other:
At the end of my life, I would like:
For more information about me please talk to:
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www.nccnhr.org.

My Personal Directions for Quality Living (Sample)

To my caregivers paid and unpaid:

Name:_	Alice H. Hedt	
Date:	June 16 2011	

I am recording my personal preferences and information about myself, in case I need long-term care services in my home or in a long-term care facility. I hope this information will be useful to those who assist me. Please always talk to me about my day-to-day life to see what it is that I want and enjoy. However, the information below may provide some help in understanding me and in providing my care.

I want my caregivers to know:

I have led an active and busy life, raising three children (born in four years) and working as an advocate for nursing home residents. My family and friends are very important to me. I enjoy traveling and talking with people who have different life experiences and viewpoints. I have been married for over 30 years. I particularly enjoy singing in choirs and spending time outdoors by water or in the mountains.

The way I like to awaken & begin my day:

I enjoy (need) coffee and like to start my day quietly, read the paper, have a quiet devotion time, and then have breakfast while watching the news on TV.

The way I relax and prepare to sleep at night:

I am a terrible sleeper. Don't worry if I am up several times, reading, puttering and checking emails.

Activities I enjoy:

I have led an active and busy life, raising three children (born in four years) and working as an advocate for nursing home residents. My family and friends are very important to me. I enjoy traveling and talking with people who have different life experiences and viewpoints. I have been married for over 30 years. I particularly enjoy singing in choirs and spending time outdoors by water or in the mountains.

Things that I would like to have in my room:

- *My favorite reclining chair- it has heat and vibrates, and an afghan.*
- Pictures of where I have traveled.
- *The books I have had with me all of my adult life.*

- I would very much like a window with a bird feeder and flowers.
- Art posters on the wall Matisse, O' Keefe

Foods that I enjoy:

For comfort: mashed potatoes and gravy, macaroni and cheese (home-made); egg biscuits. For fun: watermelon, white sheet cake with vanilla icing, caramel ice cream sundaes - the ones from MacDonald's are cheap and good; caramel corn

Other: I enjoy most ethnic foods, especially Thai, Mexican and Vietnamese; I like to drink different kinds of green tea and Merlot.

Things I do not like:

Crafts. Food that is really spicy. Prejudice. Chin hairs – please pluck mine!

I become anxious when:

I feel pressured to do things that I don't think I should do.

Things that calm or soothe me:

Talking with close friends; music; massage; talk radio (especially the game shows).

Things that make me laugh:

Children – especially my granddaughter and God children; old movies; funny stories.

Religious Preferences:

While I have been a Lutheran my whole life and my husband is a Lutheran minister, I am very open to most spiritual experiences and worship opportunities.

Other:

I like lotions and soaps that smell good, especially lavender. I enjoy all kinds of music and I like projects—coordinating activities, etc. I prefer sleeping on my left side and need a pillow that is comfortable to me because I have some neck pain. I need my glasses.

At the end of my life, I would like:

To have a few family and friends with me. I do not want to be alone when I die. It would be very nice if someone would read hymns, psalms, and poetry to me. Please see my living will and advanced directives. I would like for Pastor Wiggins to provide spiritual support if he is available.

For more information about me please talk to:

My husband Fred; my children – Matt, Melissa and Bethany; my friends, especially Beverly, Sue, Rosemary, Marj, Cilla and Nancy.



Illinois Pioneer Coalition Membership Application

Please Print Legibly

I.	Select Membership type Membership is good for one year from the date payment is received			
		Individual - \$50 pe Name	er year	
		Address		
		Phone		
		Email		
		Facility - \$150 per Facility Name	year	
		Contact Person		
		Facility Address		
		-		
		Facility Phone		
		Facility Fax		
		Email		
		Trade Association Business Name	/ Vende	er - \$300 per year
		Contact Person		
		Business Address		
		Business Phone		
		Business Fax		
		Email		
		Liikii		
II.	Make chec	k payable to:	Illinois	Pioneer Coalition
III. Mail this form and check to: IPC Membership Services				
				P.O. Box 165
				Gibson City, IL 60936



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