

## FAST FACTS: Advance Care Planning

*Advancing Excellence in America's Nursing Homes* is a national campaign to improve the quality of care and life for the country's 1.5 million residents. Nursing homes, their staff and consumers can join in this effort by working on the campaign goals designed to improve quality. This consumer fact sheet explains the importance of advance planning for care after a debilitating illness or at the end of life.

### What is advance care planning?

Advance care planning gives you a voice if you can no longer speak for yourself and allows you to plan for and express your wishes about future care. Advance care planning can explain the care you want provided after a serious accident, an illness, or when you can no longer make decisions for yourself.

### What can you do to prepare?

- **Discuss Your Wishes:** Talk with family, friends and caregivers about personal concerns, values and spiritual beliefs regarding end-of-life or emergency care. While this can be hard to do, it is important to discuss things like:
  - What quality of life means to you;
  - What kind of medical procedures you want;
  - What kind of medicines, if any, you want for pain or other conditions you have; and
  - Whether you wish to use hospice care to keep you comfortable at the end of your life.

You might think family members and the doctor already know how you want to be treated at the end of life but a frank discussion allows you to be certain they know what your wishes are. Having a plan in place makes it easier for family members and doctors to carry out your decisions about the level and type of care you want.

- **Plan Ahead:** Make health care decisions ahead of time. This lets you choose the kind of health care you want or don't want. No one has to guess what kind of care you'd prefer at the end of life or after a serious illness or when you are not able to communicate your desires.
- **Identify Your Advocate:** Pick a person to make health care decisions for you when you can't make them yourself. This person is sometimes called a proxy. The person you choose needs to be able to make decisions based on your values and wishes about care. A good proxy is someone who knows you, will likely outlive you and someone you trust. This person only makes decisions for you when you are unable to make them yourself.
- **Review and Update:** Periodically look over your advance care plan and update it when your situation changes or if you change your mind. You should also check in with your designated advocate periodically to make sure they are still able and willing to carry out your plan.



## Why is advance care planning important for residents?

Advance care planning allows you to express your choices, personal concerns, values and spiritual beliefs so that your wishes are known. It can be whatever you want it to be—from aggressive medical procedures to care that keeps you comfortable. Using an advance care plan can relieve family and caregivers of the stress of guessing what kind of care you want at the end of life.

## Why is advance care planning important for nursing homes?

Having information about you and your wishes helps the nursing home respect your choices and provide you with the care you've decided on. Having shared your wishes by talking, choosing someone to speak on your behalf and by writing up a plan, your caregivers will know they are caring for you in the way that you would want.

## What happens if I don't express my wishes through an advance care plan?

The decision to express your wishes is up to you. If you do not have such a plan, family, caregivers and people you may not know will have to make their best guess about the care you would choose. Without a designated person to speak for you, caregivers may not agree about the course of action and may make decisions you wouldn't like.

## What if I don't know what I want?

There are people to help and good information available about advance care planning. Your doctor, nurse, clergy, attorney, Ombudsman or social worker can give you information and share sample documents with you. Your public library will also have information.

## Advance Care Planning Resources

**National Healthcare Decision Day**  
<http://www.nationalhealthcaredecisionsday.org/>, or any of the following organizations:

**AARP: [End-of-Life Planning](#)**  
1-888-687-2277

**Aging with Dignity: [Five Wishes](#)**  
1-888-594-7437

**American Bar Association: [Tool kit for Health Care Advance Planning; 10 Legal Myths about Advance Medical Directive](#)**  
1-800-285-2221

**American Health Lawyers Association: [Guide to Legal Issues in Life Limiting Conditions](#)**  
1-202-833-1100

**American Hospital Association: [Put It In Writing](#)**  
1-800-242-2626

**American Health Care Association: [Having Your Say: Advance Directives](#)**  
[www.longtermcareliving.com](http://www.longtermcareliving.com)  
800-309-3282

**Caring Connections: [Advance Care Planning; Financial Information; Planning Ahead Checklist; Free Brochures](#)**  
1-800-658-8898

**Center for Practical Bioethics: [Caring Conversations Workbook](#)**  
1-800-344-3829

**Medlineplus.gov:**  
[www.medlineplus.gov](http://www.medlineplus.gov), go to "Advance Directives"

**National Cancer Institute:**  
[www.cancer.gov](http://www.cancer.gov)  
800-422-6237

**National Institute on Aging: [End of Life, Helping with Comfort and Care](#)**  
1-301-496-1752



## **FAST FACTS: Resident and Family Satisfaction**

Advancing Excellence in America's Nursing Homes is a national campaign to improve the quality of care and life for the country's 1.5 million people receiving care in nursing homes. Nursing homes, their staff and consumers can join in this effort by working on the campaign goals, designed to improve quality. This consumer fact sheet explains the link between resident and family satisfaction and the quality of care at a nursing home.

### **Why assess resident and family satisfaction?**

- A satisfaction survey is a formal set of questions about the care and services one gets in a nursing home.
- Assessing resident satisfaction is the first step in making changes or improvements in the quality of the care.
- This allows residents the chance to report their experience with care and daily life in the nursing home. The residents rate their satisfaction with the staff and the nursing home. Even many residents with memory loss or dementia can answer basic questions about their care well into the disease.
- Residents will report on areas that are important to them (for example, staff treating them with courtesy and respect) so homes know where improvements need to be made.
- Some nursing homes may choose to survey family members of residents for more information. Surveying family members is very important for residents who cannot respond independently (for example, residents with advanced dementia). The family also can often add information to the resident's viewpoint. Research shows that family and residents' views often differ.
- It is important to keep the focus on each resident and how to improve daily life.

### **What is considered satisfaction survey excellence?**

- The survey should be tested so most residents understand questions the same way.
- The survey should be kept anonymous. Responses should be kept confidential.
- There are several good ways to conduct a survey (for example, face-to-face, mail, or phone).
- The survey method should be adapted to the residents' different abilities to respond to the survey (e.g., blind, deaf).
- Residents with dementia may be able to complete a survey that is given by an interviewer face-to-face. But, they may not be able to complete a mail survey or even a phone survey.
- The survey results should state how many people responded to the survey out of all persons surveyed. The more people who answer the survey, the better the results.
- Survey results from residents should be presented separately from family results.
- The home should conduct the survey on a regular basis (at least annually).

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## **What do satisfaction survey results mean to residents?**

- A high overall satisfaction rating may be a mark of excellence.
- High ratings on items or groups of items important to the resident (for example, being treated with courtesy and respect) are also good indicators of high quality care.
- Survey results showing a high percentage of resident or family willingness to recommend the home to others may be an additional mark of excellence.

## **How do nursing homes use satisfaction survey results?**

The nursing home should be able to explain how and when they will use the satisfaction survey results to make improvements. Consumers can ask these or other questions:

- How do they decide which results to act on?
- How do they set priorities?
- How do they set targets or goals for improvement changes?
- What improvements were made as a result of the survey?

## **What are some questions consumers should ask related to this goal?**

- Does the home conduct a survey of residents and/or family members? If a home is not currently doing a survey, ask if and when they plan to conduct one.
- Ask for a copy of the survey and the results.
- Ask how are surveys conducted (for example, by mail or in-person)?
- Ask who conducts the survey?
- Are the surveys conducted in a way that no one knows who answered the survey?
- Do survey results show a high level of satisfaction overall and in important areas?
- What changes has the nursing home made in response to survey results?
- Have the changes improved the quality of care or daily life of residents? How so?
- Does the state require all nursing homes to do a standard satisfaction survey?
- If yes, ask how this nursing home compares with other nursing homes in the state, area or region?
- If no, do other nursing homes use the same or similar satisfaction surveys to be able to compare the results with this nursing home?



## **FAST FACTS: Pain Management in Nursing Homes**

Advancing Excellence in America's Nursing Homes is a national campaign to improve the quality of care and life for the country's 1.5 million people receiving care in nursing homes. Nursing homes, their staff and consumers can join this effort by working on the campaign goals, designed to improve quality. This consumer fact sheet provides information on how to manage pain effectively and safely in a nursing home.

### **How to recognize when a resident is in pain**

Pain is an unpleasant experience that affects many parts of a person's life. Pain can come on suddenly from an injury such as a bruise or broken bone. It may also be chronic as in a disease like arthritis or cancer. Some people have both kinds of pain.

Pain is difficult to measure and treat. Residents with pain can be depressed, sleepless, restless, distressed or lose their appetite. Treating pain is important. If you don't treat pain, it can make a person's health worse and decrease their activity and quality of life.

### **What is the best care for residents who have pain?**

#### **Consumers should make sure staff ask questions such as:**

- Do you have pain?
- Describe your pain.
- What does it feel like?
- How bad is the pain? Is it pinching, dull and aching or sharp and stabbing?
- Do you have pain all the time?
- Does the pain come and go?
- What makes your pain better or worse?

Consumers should make sure staff monitor residents for signs of pain and observe how residents walk, move from the bed to a chair, eat and go about other daily activities.

Staff should also pay close attention to residents who can't talk or have dementia. These residents may moan, cry or scream when in pain. They may hold or rub a part of the body that hurts. Residents with pain may stop doing activities or change their routines.

#### **Consumers should make sure staff try to find the cause of each resident's pain**

- A physical examination should be done to identify the cause of the pain.
- Tests, including blood tests or x-rays, should be conducted if needed.

#### **Consumers should make sure staff work with residents and families to treat pain**

- Residents, families and caregivers should discuss pain in care planning meetings.
- Pain care planning should include nursing assistants who know the resident well. These caregivers can help identify and relieve pain (see Consistent Assignment Fact Sheet).

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### **Consumers should make sure staff always treat each resident's pain**

- Heat, cold, or massage can relieve pain.
- Drugs are also used to relieve pain. However, most pain drugs have side effects. These include: constipation, loss of appetite, listlessness, drowsiness, or confusion. Pain drugs can cause falls.
- Most side effects can be fairly well controlled. The rule of thumb with pain drugs is to start with the lowest dose and increase the dose slowly.

### **Consumers should make sure staff check frequently to make sure the pain is being relieved**

- Staff should routinely ask residents if they are having pain and also ask residents or family members to report pain.
- Staff should recognize that not all residents will talk about pain or seek treatment for it.
- Men and women may report pain differently and religious beliefs and cultural traditions could affect how people talk about pain.
- Some residents, families and staff worry about drug side effects, addiction and dependency. Others fear bothering the nursing staff.
- Staff should be able to reassure families and residents about managing side effects and fears.

### **What questions should you ask staff about how they manage pain?**

- How do you measure pain? How often?
- Do you keep a written record of each resident's pain?
- How do you involve residents and families in developing the care plan?
- How are you treating the pain? How do you know the treatment is working?
- What changes are made if pain is not relieved?
- What do you do about side effects from pain drugs?

### **Whom should you ask about pain relief?**

The director of nursing and nursing home administrator can answer questions about how staff measure and treat pain. Go to the federal government's Nursing Home Compare Web site (<http://www.medicare.gov/nhcompare>) to find out how well a nursing home manages residents' pain.

## **FAST FACTS: Pressure Ulcers**

Advancing Excellence in America's Nursing Homes is a national campaign to improve the quality of care and life for the country's 1.5 million residents. Nursing homes, and nursing home staff and consumers can join in this effort by working on the campaign goals, designed to improve quality. This consumer fact sheet can help residents and family members understand the importance of preventing pressure ulcers.

### **What is a pressure ulcer?**

A pressure ulcer (a bedsore or pressure sore) is a dark or red area, a break or a deep, crater-like wound in the skin caused by pressure. Pressure ulcers usually develop over bony parts of the body – the tailbone, hips, heels, elbows, shoulders.

Factors that may increase the risk of getting pressure ulcers include:

- Sitting or lying too long in one place
- Sitting in wet clothing or a wet bed
- Not getting enough food and water
- Having many chronic conditions at one time
- Using multiple medications that cause drowsiness, confusion or loss of appetite
- Using physical restraints

Pressure ulcers can be dangerous and painful for a resident, in part because broken skin can allow infection into the body. If untreated, pressure ulcers can deepen and even expose the bone. Deeper ulcers may be hard to heal or may not heal at all. Sometimes, pressure ulcers can lead to serious medical complications and even death.

### **What is the best care for preventing pressure ulcers?**

Some residents have pressure ulcers when they arrive at a nursing home. Residents without pressure ulcers on arrival may develop them later on. Skin changes and pressure ulcers can develop quickly. Routine skin checks are a key to good care.

### **What can consumers do?**

- **Make sure homes have policies in which residents' skin is checked:**
  - Within 24 hours of admission
  - On a regular schedule
  - At least weekly, and more often if they can't get out of bed or reposition themselves
  - Whenever their condition changes
- **Make sure at-risk residents are closely watched by staff, especially those that:**
  - Can't move, don't move often or are restrained
  - Can't eat or drink on their own
  - Are incontinent (not able to control their bladder or bowel)
  - Have active acute medical or psychiatric conditions (e.g., pneumonia, delirium)

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- **Consumers can make sure residents:**
  - Get enough food and fluid
  - Go to the toilet as needed
  - Have their skin gently cleansed
  - Move as much as possible
  - Are turned at least every two hours in bed; every hour while up in a chair
  - Are checked carefully and often for complications of their medications
  - Are turned gently to prevent damage to frail older skin

### **What should you see staff doing to treat pressure ulcers?**

- Certified nursing assistants (CNAs) looking for and reporting early signs of pressure ulcers.
- Licensed nurses (RN, registered nurse, or LPN, licensed practical nurse) describing each pressure ulcer and how it's being treated in the resident's record and checking pressure ulcers daily.
- Nursing home staff using pressure reducing or relieving devices or techniques to protect the bony parts of the body. You should look for staff to be using a pillow to lift heels off the bed or a special bed, mattress or chair cushion that has foam or gel added.
- For residents with dementia, the pain and discomfort from pressure ulcers may lead them to resist care. They cannot say they are in pain the way other residents can. Staff treating patients with these conditions need to pay attention to those signs as potentially communicating pain from a pressure ulcer.

### **How can residents and families help?**

Pressure ulcers are hard to prevent and staff need your help.

- Go to the care plan meeting to be involved in planning your or your loved one's care.
- The less you or your family member can move without help, the more likely a pressure ulcer will develop. If appropriate, inspect the skin yourself when you are helping with care.
- Know the moving or turning schedules and support staff in carrying them out.
- Let staff know if you or your relative is wet, thirsty, hungry or in pain. If your family member has dementia, tell staff how he or she communicates discomfort. Always ask how you can help.
- Be familiar with the medications you or your family member are receiving, including major side effects that can affect alertness, appetite, weight, hydration, mental function, or cause dry or itching skin.

### **Whom should you go to ask questions?**

Ask the CNA caring for you or your family member, the RN or LPN charge nurse on the unit or discuss with the doctor in charge of your or your family member's care. If you still have questions, go to the director or assistant director of nursing, or speak with the facility's medical director.





## **FAST FACTS: Physical Restraints**

Advancing Excellence in America's Nursing Homes is a national campaign to improve the quality of care and life for the country's 1.5 million people receiving care in nursing homes. Nursing homes, their staff and consumers can join this effort by working on the campaign goals, designed to improve quality. This consumer fact sheet provides information on how to avoid the use of physical restraints, which can be harmful to residents.

### **What is a physical restraint?**

A physical restraint is anything that keeps residents from moving around or getting to a part of the body. Residents can't remove restraints easily. Examples include vest and waist restraints, chairs and foam pillows that prevent getting up, bed rails and hand mitts.

### **What do residents and families need to know?**

- Good care avoids the use of restraints.
- Residents, family members or guardians should help plan care to avoid restraints.
- In most cases, restraints should not be used to keep residents from wandering.
- Family and guardians don't have the right to force nursing homes to restrain a relative.
- Restraints can be harmful if used inappropriately.

### **Why can restraint use be harmful?**

- Restraining residents for long periods can lead to poor circulation, constipation, incontinence, weak muscles and bones, pressure sores, poor appetite and infections.
- Restrained residents enjoy life less. Restraints can cause agitation, less ability to do daily activities, less social contact, withdrawal, depression and poor sleep. Injury or death can occur from strangulation on a restraint.

### **What does a restraint mean to a resident?**

Many restrained residents feel like they are being punished. Imagine being in a chair with a tray table that prevents you from rising. You cannot move or stand by yourself, or independently get a drink of water, lie down, or get to the bathroom.

### **Who is most likely to be restrained?**

- Frail residents who have fallen or are unsteady on their feet.
- Residents living with dementia who wander or walk unsafely.
- Residents with very distressed behavior who seem to frighten others.
- Agitated residents who are a danger to themselves or others.

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## **What is good care for residents without restraints?**

### **For unsteady residents and those who wander unsafely, good care is:**

- Having daily care that moves all joints and includes walking with certified nursing assistants.
- Providing safe and pleasant indoor and outdoor walking paths with places to sit.
- Reducing the use of wheelchairs except for transportation.
- Knowing the resident well enough to provide fluids, food, toileting, rest, pain treatment, company and activity without being asked.
- Decreasing the number of medications that cause a resident to walk unsteadily.
- Putting barriers in front of other residents' rooms who do not like wandering visitors.
- Engaging residents in activities based on their past interests and career. Busy residents don't wander and disturb other residents. Some residents need night activities.
- Using low beds so residents can get out of them safely.
- Decreasing noise especially at night. Lack of sleep causes distress.
- Inviting the local Alzheimer's Association in to speak so others can better understand residents with dementia. This helps make their behaviors seem less unusual and threatening.

### **For residents who are distressed and frighten others, good care is:**

- Having staff who understand that some mental and physical conditions, including pain, are so severe that residents may act very distressed.
- Having staff who find and treat the cause of the distress such as infection or pain. These conditions can cause delirium, which can be life threatening.
- Having staff who weigh whether restraints should be used. During a medical emergency, restraints may be an option. However, staff must get an order from the resident's doctor and notify the family or guardians of the situation as soon as possible.
- Carrying out a plan for removing the restraints as soon as possible.

## **How can residents and family help plan care to avoid or reduce restraint use?**

- Ask about and attend care plan meetings.
- Share with staff what things make a good day for residents.
- Share with staff things that upset residents like early awakening, hunger, thirst or pain.
- Work with staff to plan care that keeps residents strong, busy and able to move around the home safely.
- Ask to have the same caregivers four days out of five. Residents are calmer with the same caregiver (see Consistent Assignment Fact Sheet).

## **Whom should residents and family ask about reducing restraint use?**

- If only you or a few residents are restrained, ask the charge nurse (a licensed practical nurse or a registered nurse) on the unit for a care planning meeting to discuss reducing restraint use.
- If the nursing home uses many restraints, suggest to the director of nursing or assistant director of nursing that they join the Advancing Excellence Campaign.
- Find help to reduce restraint use gradually throughout the nursing home at <http://www.nhqualitycampaign.org>.
- Go to the [Nursing Home Compare](http://www.medicare.gov/nhcompare) Web site (<http://www.medicare.gov/nhcompare>) to find out how many residents in your nursing home were restrained.

# Physical Restraint Free Care

August 2007

## Consumer Fact Sheet

### EVERYONE DESERVES DIGNITY AND FREEDOM

Restraint- free individuals can eat, dress and move independently; maintain their muscle and strength; interact with others; and maintain their freedom and dignity.

Physical Restraints	
<p><b>What are Physical Restraints?</b> A physical restraint is any object or device that the individual cannot remove easily which restricts freedom of movement or normal access to one's body. Examples include vest restraints, waist belts, geri-chairs, hand mitts, laptrays, and siderails.</p>	
<p style="text-align: center;"><b>Poor Outcomes of Restraints</b></p> <ul style="list-style-type: none"> <li>• Accidents involving restraints which may cause serious injury: bruises, cuts, entrapment, siderail deaths be strangulation and suffocation.</li> <li>• Changes in body systems which may include: poor circulation, constipation, incontinence, weak muscles and bone structure, pressure sores, agitation, depressed appetite, infections, or death.</li> <li>• Changes in quality of life which may include: reduced social contact, withdrawal, loss of autonomy, depression, disrupted sleep, agitation, or loss of mobility.</li> </ul>	<p style="text-align: center;"><b>Physical Restraints are Used in place of Good Care Because</b></p> <ul style="list-style-type: none"> <li>• Facilities or family members mistakenly believe that they ensure safety;</li> <li>• Facilities fear liability;</li> <li>• Facilities may use them in place of adequate staff.</li> </ul> <p style="text-align: center;"><b>Restraints Are Most Often Used On</b></p> <ul style="list-style-type: none"> <li>• Frail elderly residents who have fallen or may fall.</li> <li>• Residents with a dementing illness who wander unsafely or have severe behavioral symptoms.</li> </ul>

### Physical Restraint Use in the U.S.:

Nationally, over 6% of nursing home residents are restrained. *The Advancing Excellence in America's Nursing Homes Campaign* has set a goal of 5% or less for all nursing homes in the country. In many nursing homes across the country, residents are restraint-free without any increase in serious injuries. It is unrealistic to expect that all falls and injuries can be prevented.

## Federal Law and Regulations

The Nursing Home Reform Act of 1987 (OBRA '87) states the resident has the right to be free from physical or chemical restraints imposed for purposes of discipline or convenience and not required to treat the resident's medical symptoms.

This law also includes provisions requiring:

- quality of care—to prevent poor outcomes;
- assessment and care planning—for each resident to attain and maintain her/his highest level of functioning;
- residents be treated in such a manner and environment to enhance quality of life.

## Restraint Reduction Strategies

Twenty years of experience provide many strategies for safe restraint reduction and elimination. Restraint reduction involves the whole facility, including administrators, nursing directors, physical and recreational therapists, nursing assistants, and housekeeping personnel. Family members and advocates can encourage the facility's efforts, and expect and insist that the facility:

- Complete a **comprehensive resident assessment** that identifies strengths and weaknesses, self care abilities and help needed, plus lifelong habits and daily routines.
- Develop an **individualized care plan** for how staff will meet a resident's assessed needs. It describes the care goals (e.g. safe walking), and when and what each staff person will do to reach the goal. The care team includes staff, residents and families (if the resident wants), and devises the plan at the quality care plan conference. The resident may also invite an ombudsman to attend. Care plans change as the resident's needs change.
- Train staff to assess and meet an individual resident's needs—hunger, toileting, sleep, thirst, exercise, etc.—according to the **resident's routine rather than the facility's routine**.
- Make permanent and consistent staff assignments and promote staff flexibility to meet residents' individualized needs.
- Treat medical conditions, such as **pain**, that may cause residents to be restless or agitated.
- Support and encourage care giving staff to **think creatively** of new ways to identify and meet residents' needs. For example, a "night owl" resident could visit the day room and watch TV if unable to sleep at night.
- Provide a **program of activities** such as exercise, outdoor time, or small jobs agreed to and enjoyed by the resident.
- Provide **companionship**, including volunteers, family, and friends by making the facility welcoming.
- Create a **safe environment** with good lighting, pads on the floor to cushion falls out of bed; a variety of individualized comfortable seats, beds and mattresses; door alarms; and clear and safe walking paths inside and outside the building.

Nursing homes can implement specific programs for reducing physical restraints, including:

- Restorative care, including walking, and independent eating, dressing, bathing programs;
- Wheelchair management program—including correct size, and seat cushion good condition;
- Individualized seating program—chairs, wheelchairs, tailored to individual needs;
- Specialized programs for residents with dementia, designed to increase their quality of life;
- Videotaped family visits for distant families;

- Wandering program—to promote safe wandering while preserving the rights of others;
- Preventive program based on knowing the resident—to prevent triggering of behavioral symptoms of distress;
- Toileting of residents based on their schedules rather than on staff schedules.

#### **Find an Advocate:**

Contact your local or state ombudsman if you have concerns about the care a resident is receiving. An ombudsman is a state-certified advocate for residents of nursing and residential care facilities who is familiar with the local facilities and often with the staff and residents. All conversations with an ombudsman are confidential unless permission is given to use a person's name.

#### **Join The Consumer Voice**

A non-profit membership organization that works to protect the rights, safety, and dignity of America's long-term care residents.

Website: [www.theconsumervoice.org](http://www.theconsumervoice.org)

Phone: 202.332.2275

*The National Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a 501(c)(3) nonprofit membership organization founded in 1975 by Elma L. Holder that advocates for quality care and quality of life for consumers in all long-term-care settings.*

October 2011

## Consumer Fact Sheet

Every person in a nursing home has a right to good care, under the law. The law says the home must help people "attain or maintain" their highest level of well-being - physically, mentally and emotionally. To give good care staff must assess each resident and plan care to support each person's life-long patterns, and current interests, strengths and needs. Resident and family involvement in care planning gives staff information they need to make sure residents get good care.



### What is a Resident Assessment?

Assessments gather information about how well residents can take care of yourselves and when you need help in "functional abilities" -- how well you can walk, talk, eat, dress, bathe, see, hear, communicate, understand and remember. Staff also ask about residents' habits, activities and relationships so they can help residents live more comfortably and feel more at home.

The assessment helps staff look for what is causing a problem. For instance, poor balance could be caused by medications, sitting too much, weak muscles, poor-fitting shoes, a urinary infection or an ear ache. Staff must know the cause in order to give treatment.

### What is a Plan of Care?

A plan of care is a strategy for how the staff will help a resident. It says what each staff person will do and when it will happen (for instance -- The nursing assistant will help Mrs. Jones walk to each meal to build her strength). Care plans must be reviewed regularly to make sure they work and must be revised as needed. For care plans to work, residents must feel like they meet your needs and must be comfortable with them. Care plans can address any medical or non-medical problem (example: incompatibility with a roommate).

### What is a Care Planning Conference?

A care planning conference is a meeting where staff and residents/families talk about life in the facility -- meals, activities, therapies, personal schedule, medical and nursing care, and emotional needs. Residents/families can bring up problems, ask questions, or offer information to help staff provide care. All staff who work with a resident should be involved -- nursing assistants, nurse, physician, social worker, activities staff, dietician, occupational and physical therapists.

#### Inside This Guide:

WHEN ARE PLAN- NING CONFERENCES HELD?	2
WHAT SHOULD YOU TALK ABOUT AT THE MEETING?	2
HOW RESIDENTS AND THEIR FAMILIES CAN PARTICIPATE IN CARE PLANNING	2



## When are Care Planning Conferences Held?

Care planning meetings must occur every three months, and whenever there is a big change in a resident's physical or mental health that might require a change in care. The care plan must be done within 7 days after an assessment. Assessments must be done within 14 days of admission and at least once a year, with reviews every three months and when a resident's condition changes.

## What Should You Talk About at the Meeting?

Talk about what you need, how you feel; ask questions about care and the daily routine, about food, activities, interests, staff, personal care, medications, how well you get around. Staff must talk to you about treatment decisions, such as medications and restraints, and can only do what you agree to. You may have to be persistent about your concerns and choices. For help with problems, contact your local "ombudsman," advocacy group or others listed on the next page.

## How Residents and Their Families Can Participate in Care Planning

Residents have the right to make choices about care, services, daily schedule and life in the facility, and to be involved in the care planning meeting. Participating is the only way to be heard.

### **Before the meeting:**

- Tell staff how you feel, your concerns, what help you need or questions you have; plan your agenda of questions, needs, problems and goals for yourself and your care.
- Know, or ask your doctor or the staff, about your condition, care and treatment.
- Ask staff to hold the meeting when your family can come, if you want them there.

### **During the meeting:**

- Discuss options for treatment and for meeting your needs and preferences. Ask questions if you need terms or procedures explained to you.
- Be sure you understand and agree with the care plan and feel it meets your needs. Ask for a copy of your care plan; ask with whom to talk if you need changes in it.

### **After the meeting:**

- See how your care plan is followed; talk with nurse aides, other staff or the doctor about it.

### **FAMILIES:**

- Support your relative's agenda, choices and participation in the meeting.
- Even if your relative has dementia, involve her/him in care planning as much as possible. Always assume that s/he may understand and communicate at some level. Help the staff find ways to communicate with and work with your relative.
- Help watch how the care plan is working and talk with staff if questions arise.

### **A Good Care Plan Should:**

- Be specific, individualized and written in common language that everyone can understand;
- Reflect residents' concerns and support residents' well-being, functioning and rights; Not label residents' choices or needs as "problem behaviors;"
- Use a multi-disciplinary team approach and use outside referrals as needed;
- Be re-evaluated and revised routinely - Watch for care plans that never change.

*The National Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a 501(c)(3) nonprofit membership organization founded in 1975 by Elma L. Holder that advocates for quality care and quality of life for consumers in all long-term-care settings.*

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## Consumer Fact Sheet

***Individualized care is the right of every nursing home resident. The Nursing Home Reform Law of 1987 requires that residents receive services and activities to “attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care...” Quality of care means what care is provided. The law also requires nursing facilities to “care for its residents in such a manner and in such an environment as will promote maintenance or enhancement of the quality of life of each resident.” An emphasis is placed on dignity, choice, and self-determination for residents. Quality of life means how care is provided.***

**The law requires nursing facilities to provide quality of care in a way that supports quality of life for each resident. When facilities do this they achieve individualized care for each resident. Residents and family members should expect the facility to provide individualized care based on Quality of Care Basics. Read a real resident’s experience in one nursing home and follow how an *Individualized Plan of Care* should be developed. For this example, four areas of care will be used: (1) the assessment and care plan process (the basis for individualized care), (2) toileting, (3) hydration, and (4) mobility. (For more information, see Burger et al “Nursing Homes: Getting Good Care There,” Chapters 4 and 5, available from the Consumer Voice).**

### How One Nursing Home Resident and Her Daughter Can Achieve the Basics of Individualized Care

*Your mother lived independently until she suffered a stroke two months ago. Your need to work prevents you from bringing her to your home for care. Together you made the decision that she would go to a nursing home for rehabilitation. The stroke left her with right-sided weakness (she is also right-handed) and some inability to make herself understood. Based on your mother’s excellent response to rehab in the hospital, her physician thinks she should continue to make progress and return home in eight to twelve weeks.*

*The nursing home staff welcomed your mom. You both felt confident about your decision. Your mom’s roommate was glad for the company and was patient with her slow speech. Your mom asked you to attend the first care planning conference with her. The staff said your mom would receive physical therapy three times a week, and speech and occupational therapy once a week.*

*You’re both pleased with the therapy program, but your mother complained that the nursing staff will not take her to the toilet except as part of the therapy sessions. A fastidious woman, your mother knows when she has to go the bathroom and was determined to use the toilet, not a brief (diaper), bedpan, or commode.*

*At the end of her second month in the facility you noticed that you had difficulty opening your mother’s right hand for the manicure she loved to get. Her skin looked very dry and flaky. Your mom’s spirits seemed to be sinking. In fact, recently she seemed to be getting worse, not better.*

*When you mentioned these concerns to the staff, you were told that this happens to all frail, old people. The nursing staff then suggested speaking with the doctor to obtain an order for an antidepressant. You became really concerned.*

## Assessment and Care Planning

### The Resident Assessment and Care Plan Process:

In order to know what care and services to provide and how to provide them, the law requires a careful and thorough assessment of your mom. Staff needs to learn your mom's strengths and needs. A list of assessment items relating to your mom includes:

- Her life history, daily routines, strengths, interests, food likes and dislikes, and other personal information.  
(Think of this information as the important details about your mother that reflects who she is as an individual, and which will form the basis for planning her care.)
- Her ability to function including walking, dressing, using the toilet, and eating. (The stroke has affected your mom's right and dominant side, so she will need assistance to regain independence.)
- Physical or mental conditions that may affect her ability to recover. (Except for the stroke, she is quite healthy mentally and physically.)
- Her potential for improvement. (Her physician expects her to recover and go home.)
- Communication abilities. (Her speech is slowed.)
- Nutritional status and medications. (She must relearn to feed herself and manage her own medications.)

The assessment is completed by day 7 in a skilled unit (your mother's situation at first); by the 14th day in a nursing facility (long term chronic care); and once a year thereafter, or whenever a resident's condition changes. The assessment is done by the interdisciplinary team (IDT) that includes: the resident, direct caregiver(s), nurse, physician, physical therapist, occupational therapist, speech therapist, activity therapist, dietitian, and social worker. The assessment information is the foundation for the care planning process.

Traditionally, nursing homes have used nursing/medical model care plans. That type of plan is not suited to individualized nursing home care. It is written from the staff perspective rather than each resident's perspective. Here is an example of what you may find:

Problem	Goal	Approaches
Incontinence	Will become independent in toileting	Assist to Bedpan at 6 am, 9am, 12 noon, 4pm, 9pm (or when requests) (CNA) Assess ability to stand and pivot on left leg in one week to transfer to commode or toilet, 2/14/05 (N/PT*).

### Developing an Individualized Care Plan:

The Care Plan, by law, *is initially prepared with participation to the extent practicable of the resident or the resident's family or legal representative.* The initial care plan must be complete by the 21<sup>st</sup> day of her stay, and subsequent care plan reviews are repeated quarterly, or whenever there is a major change in a resident's condition. The initial care plan process begins during the assessment. It is called an *Individualized Care Plan* because each resident's conditions, abilities, needs, routines, and goals are unique, requiring a plan of care (road map for care) that reflects who this individual is. The overarching goal is for your mother to return home and live as independently as possible. There are many little goals along the way. *Care plan goals are all measurable, time limited, and the team member responsible for each is identified.* This simply means that each goal will be clearly identified and stated. Each goal will also list an estimated time for accomplishment, as well as the specific team member(s) responsible in assisting to achieve that goal.

Physical Therapy will help your mother to regain the ability to walk. Occupational Therapy will assist her in attaining independence in dressing, eating, and toileting. Speech Therapy will help to improve her slow speech pattern. But therapy only takes up a few hours each day. The IDT must plan what happens for the rest of the 24-hour period. This plan must support your mother's goal for independence and prevent any harm from occurring. The Plan of Care must then be relayed to each staff member, including the Certified Nursing Assistants (CNAs), so that everyone is consistent in helping your mom reach her stated goals.

Assist to Bedpan at 6 am, 9am, 12 noon, 4pm, 9pm (or when requests) (CNA) Assess ability to stand and pivot on left leg in one week to transfer to commode or toilet, 2/14/05 (N/PT\*).

**Here is an example of an individualized care plan written from a resident’s perspective:**

Need	Goals	Approaches
I need assistance with using the bathroom	I want to regain my independence in using the toilet so that I may go home.	I know when I have to go to the bathroom and will tell you. Please assist me to the bedpan on my usual schedule from home at 6 am, 9am, 12 noon, 4pm, 9pm (and when I request) (CNA). Assess my ability to stand and pivot on left leg in one week. Then help me to the commode or toilet, 2/14/05 (N/PT*).

\*CNA=Certified Nursing Assistant, N=Nursing; PT=Physical Therapy; OT=Occupational Therapy; ST=Speech Therapy; D=Dietary

Three examples of *Basic Quality of Care Practices* follow:

### Toileting, Hydration, and Mobility

#### Toileting

##### Basic Quality of Care Practices for Toileting:

- If a resident can toilet with a little assistance, then assistance must be available as needed 24 hours a day.
- Toileting assistance is given according to a written individualized schedule and whenever a resident asks.
- The number of people to safely assist with transfer/ambulation is clearly stated and are available. This may change as the resident becomes more independent (e.g. two-person assist, one person assist, and staff monitor for safety).
- The toileting equipment is appropriate to the person’s ability, and changes as ability improves (e.g. bedpan, commode, bathroom toilet).
- Each resident has a clearly identified, functional method of asking for assistance (e.g. call bell or other signal device placed for easy use).
- Privacy is assured in toileting so a resident is never exposed (e.g. room door is closed, curtain between beds is pulled, window blinds are closed).
- Toileting hygiene is meticulous to avoid skin irritation/breakdown as well as the spread of infection.
- Night toileting schedule is identified depending on each resident’s preferences and need for uninterrupted sleep (e.g. some residents prefer to remain sleeping and opt to use an adult brief (diaper) at night).
- Nurses/CNAs and others observe the urine for color, smell, and amount as described in the Care Plan.

#### Your Mom and You

Your mom knows when she has to use the toilet, but needs help. Her bladder has always functioned well and she still uses the toilet after breakfast, before lunch, late afternoon, before bed at 9:00pm, and upon awakening. Her routine is to use the toilet five times in a 24-hour period.

Need	Goal	Approaches
Need assistance to the bathroom	Gain independence in toileting	Assist to bedpan at 6am, 9am, 12 noon, 4pm, 9pm (or when requests) (CNA*). Assess ability to stand and pivot on left leg to transfer to commode or toilet in one week, 2/14/05 (N/PT)

		Assist to bedside commode: (same schedule) (CNA). Assess ability to walk to bathroom (15 feet) with assistance in two weeks, 3/1/05 (N/PT).
		With each incontinent episode, assist resident to wash with her own personal soap. After careful drying, apply a skin barrier cream (CNA).
		Monitor skin for redness, irritation, skin breakdown, turgor, etc. (N).
		Weekly skin assessment for redness, irritation, skin breakdown, turgor, etc. (N).
		Place hand washing supplies (sanitizing hand wipes) on left side of the bed within easy reach (CNA/N).
		Place a trash disposal system on left side of the bed within easy reach (CNA/N).
		Two-person assist to bathroom (same schedule) (CNA). Assess ability for one person to assist in one week, 3/8/05 (N/PT).
		One-person assist to bathroom (same schedule) (CNA). Assess ability for independence with cane in two weeks, 3/22/05 (N/PT).
		Monitor safety of self-toileting with the use of quad cane (N).

\*CNA=Certified Nursing Assistant, N=Nursing; PT=Physical Therapy; OT=Occupational Therapy; ST=Speech Therapy; D=Dietary

### Tips for Monitoring the *Individualized Care Plan* for Toileting/Continence

- Be vigilant that your mother is toileted on *her individualized* schedule rather than someone else's schedule (e.g. on her lifelong schedule every 3-5 hours, rather than every two hours, which does not help your mother and wastes staff time).
- Be especially watchful on evenings, nights, weekends, Mondays and Friday, and holidays, when there may be less staff. If the facility is short staffed, or staff is poorly monitored, then they may tell a resident that she must use a brief (diaper). This is both a quality of care and quality of life issue. The indignity of soiling herself and the feelings of helplessness may be the cause of depression.
- Provide your mom with her special soap and skin creams. Also provide
- the easy-open, sanitizing hand wipes. Check remaining quantities to see if they are being used.
- Check that the call bell is on her left side so she can request help until she can use her right side.
- Staff shortages can cause staff to withhold fluids so the need to toilet is less frequent. Does she drink her tea when pills are passed, at lunch, and between meals?
- Telephone the charge nurse at odd hours (e.g. 1a.m); ask about the number of available staff on duty. Keep a record of who you spoke to and what was said.
- While visiting, check that the call bell is on the left side and monitor the

- timeliness of staff assistance to the toilet. Ask your mom if she ever has to wait too long for assistance to the bathroom. Incontinence causes wet skin and clothing, which may lead to skin breakdown and pressure ulcers.
- When possible, vary your visit times to avoid staff from becoming too familiar with your arrival times (some staff members are inclined to give care only when the family is expected to visit).
- If you help your mother to the bathroom, be sure you are aware of her current transfer, ambulation, and assist ability. This is to avoid the possibility of injury to your mother or yourself. When in doubt, always ask.

## **HYDRATION**

*(getting enough to drink)*

### **Basic Quality of Care Practices for Hydration:**

- Most residents should drink about eight glasses of fluid a day.
  - Fluids that the resident likes should be available, within reach, 24 hours a day. At mealtime, fluids should be served at a temperature that is safe and is according to the resident's preference.
  - If a resident cannot remember to drink, then staff must remember and assist with drinking throughout the day according to the resident's lifelong routine.
  - If a resident cannot drink, then staff must assist at meals, between meals, and at night as needed.
  - If a resident needs to relearn how to drink, then staff must teach her and take responsibility for providing the rest of the fluid through IV, naso-gastric, or stomach tube.
  - A resident is assessed by Occupational Therapy and, if needed, given special equipment such as a large handled/weighted cup to foster independence in drinking. Fluids are the right consistency to promote safe swallowing (e.g. thin liquids, thickened liquids, jello, puddings), to avoid the possibility of liquids going into the lungs, causing a condition.
- Staff monitor the amount of fluid taken every 24 hours and monitor for signs of dehydration (e.g. dry, flaky skin, poor skin tension, dry, cracked lips, dry mucous membranes in mouth, increased irritation, restlessness or confusion, and the presence of strong, odorous, dark colored urine).
  - Staff should also keep track of the amount of urine passed each 24 hours (this is referred to as "I & O", Intake and Output, the monitoring of the amount of fluids taken in compared to the amount of urine passed out).
  - Staff monitors the progress of a resident to drink independently and changes the care plan as often as needed to reach that goal.



## Your Mom and You

You noticed already that your mom has very dry skin and seems to be shriveling up before your eyes. Her urine smells strong, another sign of not enough to drink. To effectively address this issue, your mother's individualized care plan might say:

Need	Goal	Approaches
Assistance with drinking an adequate amount of fluids	Gain independence in hydration	Encourage to use both hands and large handled cup filled with iced tea at meals. Put bedside/chair side tea on left side. Hates water, likes iced tea. Assess ability to use right hand in two weeks, 2/21/05 (N/OT/D).
		Encourage use of right hand using large handled cup filled with iced tea. Put bedside/chair side tea on right side. Assess ability for independent drinking in two weeks, 3/7/05 (N/OT/D).
		Monitor and record independent hydration (eight glasses/64 ounces/2000cc per 24 hours) for one week to assure ability to hydrate independently (N).

\* CNA=Certified Nursing Assistant , N=Nursing; PT=Physical Therapy; OT=Occupational Therapy; ST=Speech Therapy; D=Dietary

### Tips for Monitoring the *Individualized Plan of Care* for Hydration

- Make sure the large handled cup is at the bedside on the left side until your mother is able to reach with her right side, then reverse bedside table to force use of her right hand.
- You and your family members agree to bring your mother's favorite iced tea mix. You follow-up to be sure your mother is having this drink.
- Families should see residents drink fluids at meals three times a day, between meals when pills are passed (usually 4-8 ounces), and before bedtime at the very minimum.
- Check your mother's skin, eyes, and mouth for increased dryness, especially on Mondays, Fridays, weekends, and holidays. Report any signs of dryness to staff.
- Notice and report the presence of any skin changes/irritations/breakdown, as well as the presence of strong, dark, odorous, or small amounts of urine.
- Advise the staff of the amount of fluids that were taken during your visit so that it can be calculated in the 24 hour total (I & O).

### Mobility

- Any part of a resident's body that moves independently upon entering the nursing home must be maintained by the resident or staff.
- If any part of the body cannot be moved independently, then staff must move it for the resident (e.g. move each joint in each finger).
- Active and passive range of motion (ROM) exercises are done at least twice a day to prevent loss of mobility (e.g. if your mom is able to move her left arm above her head on the day of admission, that ability is maintained by active range of motion).
- Passive ROM is done for a person until active ROM is achieved (e.g. if your mom is not able to lift her arm above her head on the day of admission, then that ability is attained first through passive ROM and then active ROM).
- Active ROM is done with a resident or independently by a resident.
- A resident who can walk without assistance should maintain that ability.
- A resident who does not need a wheelchair on admission should not use one.
- When a resident is sitting or lying down, alignment of the body (so that the two sides look equal) is accomplished by use of pillows, bolsters, towel rolls, and wedges.

## Your Mom and You

Your mother's right side is weak and special care is needed to prevent permanent damage from a *Contracture*, which occurs because weak muscles tend to shorten or contract. You noticed her curled right hand (remember the manicure?) indicating harm is already occurring. Her individualized care plan might say:

Need	Goal	Approach
Assistance with keeping joints mobile	Prevent contractures	Assist with passive ROM exercises of all joints on right side when dressing and undressing. Assist with active ROM on left side (CNA). Assess ability to participate actively on right side in one week, 2/14/05 (N/PT).
		Position in bed, chair, and wheelchair for good body alignment with pillows, bolsters, and blankets. Use small rolled towel for the right hand (CNA). Assess in one week, 2/14/05 (N/PT).
		Assist with and teach active ROM exercises of all joints on right and left side when dressing and undressing. Assess ability to do these active exercises independently in one month, 3/14/05 (N/OT/PT).
		Assess right hand contracture for possible need of splint; provide instructions for application (OT).
		Assess ability to do active exercises independently on both sides in one month, 3/14/05 (N/OT/PT).
		Position in bed, chair, and wheelchair for good body alignment with pillows and bolsters. Assess for teaching independence in positioning in three weeks, 3/7/05 (N/PT).

\* CNA=Certified Nursing Assistant, N=Nursing; PT=Physical Therapy; OT=Occupational Therapy; ST=Speech Therapy; D=Dietary

## Tips for Monitoring the *Individualized Care Plan* for Mobility

- Ask your mom if the certified nursing assistants (CNAs) are assisting with the active ROM to her left side at 10:00 a.m. and 8:00 p.m.
- Ask CNAs to describe and demonstrate the active exercise program to you. They may not know how to do them.
- Visit your mom on Mondays, Fridays, evenings, weekends, and holidays to be sure ROM is occurring as scheduled each day. (PT and OT programs are usually closed on weekends and holidays and nursing staff is often reduced).
- Help your mother take responsibility for these exercises as soon as possible. Encourage your mother to do ROM exercises on her own as much as she can, adding more as her strength and flexibility improve.

- If your mom is leaning to her right side when she sits in a chair, ask the staff for help in repositioning her. She should be supported on her right side so that it looks even with the left (e.g. good body alignment should be maintained as much as possible).
- If a hand splint or hand roll is being used, remove and check your mom's hand for cleanliness, an unpleasant odor, and skin irritations.

## Tips on How to be a Proactive Partner in Care

It is important, to the extent possible, that you remain involved in monitoring the care that your loved one receives. Below are some important tips for staying involved.

- Work closely with the nurse and CNAs to provide important details of your mother's life (e.g. toileting schedule, preferred drinks, usual appearance of body and skin).



- Participate in the IDT care planning conference. Ask for one if you have unanswered concerns. If the professional jargon becomes too confusing, suggest using an “I” Care Plan format (described on the next page).
- Know the specific goals as outlined in the Care Plan.
- Be aware of any changes in the Plan of Care; ask the staff to keep you informed. Monitor the steps of the Plan of Care as outlined; address lack of implementation immediately.
- Physical, Occupational, and Speech Therapy are only parts of the Care Plan. Assure the basics of 24 hour care are covered on the plan, including nutrition, hydration, toileting, activities (not just bingo), mobility to support the goals of the therapy.
- When possible, make frequent telephone calls to the nursing facility. Avoid calling at times of high activity for example, the change of shifts, meal times and medication pass times.
- Know your rights under the law. Individualized care identifies both *what* and *how* care is to be provided.
- Remember, care and services are provided to *maintain* current abilities and *attain* those abilities lost by a resident’s condition. Abilities should decrease only if a new disease occurs, there is an irreversible progression of the condition, or a resident refuses care. In this nursing home the cause of your mother’s hand contracture, incontinence, and dehydration was directly related to her lack of *Basic Quality of Individualized Care*.

### A Best Practice

#### First Person Care Plans:

In the previous sections we have outlined the Basic Quality Practices in three areas of care and how they can and should be individualized for the resident. As illustrated, care plans tend to be very clinical, written in language that residents and CNAs do not understand. Try suggesting the use of an “I” Care Plan written in the words you and your mother would use. You will notice that a resident “problem” becomes a “need” and the “intervention” is changed to “approaches.” This language turns the whole thought and planning process around so that it is the resident who identifies her own particular goals. Clarity is further enhanced when the resident’s own words and phrases are used. Let’s look at mobility in an “I” Care Plan.

**If the nursing home where your family member resides does not use the “I” Care Plan, you can suggest ways to individualize her care in the interdisciplinary care planning meeting. For instance, it will help staff to know that your mother wants to become stronger; therefore that should be written. Your mother’s strongest time of day should be in writing in the care plan. Ask for a copy of the care plan and rewrite it in the first person with your mother. Let’s look at mobility using an “I” Care Plan.**

Need	Goal	Approaches
I need to keep my left side strong	<b>Long-Term Goal:</b> I want to return to my home for my birthday on June 1 <sup>st</sup> . <b>Short-Term Goal:</b> “I want to be able to go to the bathroom on my own.”	“I want to help the staff move each joint on my left side.” “Please remind me when dressing and undressing to move each joint on my left side.” “Remind me to reach for my tea, which is on my left side until I can use my right side,” 2/14/05 (CNAs/N/OT).

I need to strengthen my right side	I want staff to help me strengthen my right side.	“I want to help the staff strengthen the right side of my body.” “Please help me by moving every joint on my right side until I can begin to do it by myself,” 2/14/05 (PT/CNAs/N/OT).
		<p>“Please schedule my physical therapy early in the day when I am most energetic. I fade in the afternoon,” 2/14/05 (PT/CNAs/N/OT).</p> <p>“I topple over on my right side. This is very uncomfortable. Please put pillows and towels to support my right side so that it looks like my left side when I sit in the chair. Then I can stay out of bed for an extra hour, until four every afternoon, and be up for supper at 6:00p.m.” (CNA/N)</p> <p>“My right hand feels better when I am grasping a big rolled towel” (CNA/N).</p>

CNA=Certified Nursing Assistant, N=Nursing; PT=Physical Therapy; OT=Occupational Therapy; ST=Speech Therapy; D=Dietary

### Tips for Moving Toward an “I” Care Plan

- Share your individual needs and preferences at the care planning conference
- Show how the information will improve care
- Be sure the information is written in the care plan
- Help staff to add personal information if they do not see why it is important

**If you are interested in learning more, the Consumer Voice has several publications that may be of interest. For a publication list, call 202.332.2275 or visit [www.theconsumervoice.org](http://www.theconsumervoice.org). Prices listed do not include shipping or handling.**

**Nursing Homes: Getting Good Care There**, Second Edition, by Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank. 2002. A consumer guide on achieving the best possible nursing home experience for a relative or friend. With clarity and compassion, the authors use everyday language and real-life examples to show that care respecting each resident's individuality, dignity and physical and emotional well-being is within reach. [Cost \$14.95]

**Residents' Rights Week Packets** from previous years are available through the Consumer Voice. Visit [www.theconsumervoice.org](http://www.theconsumervoice.org).

**How to Participate In The Care of Your Loved One During a Nursing Home Stay**, by Jean Badalamenti, 2006. This booklet gives family members practical tips for how to be and stay involved in the care of a loved one while in a nursing home. Using the 1987 Nursing Home Reform Law as a foundation, the booklet outlines the role family members can play including their role in the resident assessment and care planning process, ideas and tips for ongoing visitation with a loved one, and a family members right to advocate for quality care through participation in a family council. (Note: Thanks to the state of Maryland for giving permission for the Consumer Voice to use its Maryland work as the basis for this booklet.) [Cost 5 for \$10.00]

**The Consumer Voice Consumer Fact Sheets available at**

**[http://www.theconsumervoice.org/public/50\\_156\\_434.cfm](http://www.theconsumervoice.org/public/50_156_434.cfm) include:**

*Abuse and Neglect*

*Assessment and Care Planning*

*Consumer Guide to Choosing a Nursing Home*

*Culture Change in Nursing Homes*

*Individualized Assessment with Behavior Symptoms*

*My Personal Directions for Quality Living* - the Consumer Voice tool for person-directed care

*Physical Restraint Free Care*

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*The National Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a 501(c)(3) nonprofit membership organization founded in 1975 by Elma L. Holder that advocates for quality care and quality of life for consumers in all long-term-care settings.*

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## Consumer Fact Sheet

**Quality of care in nursing homes must be addressed from all angles: regulatory, legal, advocacy, and within the nursing home itself. An emerging effort to promote a new way of living and working in nursing homes is known as “culture change.” Culture change involves rethinking values and practices of a nursing home from top to bottom, inside and out. It is not about change for its own sake. It is about change that brings all who are involved in the nursing home culture – staff, management, residents, and families – to a new way of working that creates a humane environment supporting each resident’s life, dignity, rights, and freedom. Culture change is about de-institutionalizing services and individualizing care.**

Providers report that a true commitment to fundamental culture change improves the quality of care and quality of life for nursing home residents and the quality of work experience for staff. From a consumer perspective, it is important to support and advocate for creative approaches with this focus and learn from them.

It is also important to keep in mind that simply stating an organization is pursuing culture change is not enough to ensure high quality care, and that often working towards a new culture can be disruptive in its own way, as organizations seek to redefine work roles in order to put person before task. Consumers must be active partners in this process. We must educate ourselves about all that is involved in this transformation, just as providers and other stakeholders are educating themselves.

The Pioneer Network is an organization working with the Consumer Voice and others around the country to foster the spread of culture change principles and practices. Pioneer principles are used to guide their work.



### Inside This Guide:

PIONEER PRINCIPLES	2
PERSON-DIRECTED PRACTICES	2
BASIS FOR CULTURE CHANGE IN LAW	3
EXAMPLES OF CULTURE CHANGE	3
MORE INFORMATION	3

## Pioneer Principles

- Know each person
- Each person can and does make a difference
- Relationship is the fundamental building block of a transformed culture
- Respond to spirit, as well as mind and body
- Risk taking is a normal part of life
- Put the person before the 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 – yes, the Golden Rule
- Promote the growth and development of all
- Shape and use the potential of the environment in all its aspects: physical, organizational, psycho/ social/spiritual
- Practice self-examination, searching for new creativity and opportunities for doing better
- Recognize that culture change and transformation are not destinations, but a journey, always a work in progress

## Person-Directed Practices

- Establish resident direction in goal setting and care;
  - Re-organize and empower staff, focusing on responsibility, accountability and strong support to direct care workers (resident assistants);
  - Enable resident choice in aspects of daily life significant to the resident, such as time getting up and going to bed; eating; naps; times out-of-doors; favorite pastimes; times and methods of bathing; content of meals and the ways meals are served;
- Emphasize the relationship between the resident and resident assistant as central to quality of life for both; Create opportunities for relationships between hands-on caregivers and residents by using consistent assignment of staff
  - Hold weekly meetings or regular learning circles with staff concerning knowing each resident, team building, and seeking staff's opinions;
  - Give staff a voice in managing their own time and schedules;
  - Accept without judgment the resident's family as part of the community and team;
  - Base toilet use schedule on the individual's bowel and bladder patterns;
  - Teach and model good communication, especially staff listening skills;
  - Mix the presence of children into daily life
  - Welcome and provide for residents' animals for companionship, meaning, and delight;
  - Maintain plenty of living plants inside and out to enable daily contact with the natural world;
  - Encourage creative ideas from staff, residents, and families;
  - Continuously educate staff on culture change;
  - Provide resident assistant training which includes mentorship and support;
  - Use a resident assistant career ladder in which wages are tied to performance and education;
  - Design and organize in-service training to make it person (resident) centered;
  - Support strong, active family councils;
  - Develop small units of 10 to 15 residents;
  - Include child day-care facilities in design.

© Nursing Home Pioneers

## Basis for Culture Change in Law

The Federal law applying to nursing homes, the Nursing Home Reform Law of 1987, requires that each nursing home “care for its residents in such a manner and in such an environment as will promote maintenance or enhancement of the quality of life of each resident.” This requirement emphasizes dignity, choice, and self-determination for residents, as do the principles of the Pioneers. Furthermore, each nursing home is required by law to “provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care which...is initially prepared, with participation to the extent practicable, of the resident, the resident’s family, or legal representative.” This means that a resident should not decline in health or well-being as a result of the way a nursing home provides care.

These provisions of the law require that resident care should be individualized to meet the needs of the resident. Culture change is an attempt to make this part of the law a reality.

## Examples of Culture Change

The implementation of a philosophy of culture change can take many forms depending upon the challenges faced by the organization. Strong models of culture change approaches are illustrated in the work of the early Pioneers, who were brought together for the first time in 1995 by the Consumer Voice. The work of the early Pioneers is spreading beyond first innovators as more and more organizations begin their transformational change journey. There are different strategies for culture change, including the Eden Alternative and the Wellspring approaches. Be sure to ask your nursing home if they are using any culture change techniques.

## For More Information

To learn more about culture change in nursing homes and other aspects of long-term care, contact the Pioneer Network at (585) 271-7570; [www.PioneerNetwork.net](http://www.PioneerNetwork.net); blog: [www.PioneerExchange.org](http://www.PioneerExchange.org); or the Consumer Voice at (202) 332-2275; [info@theconsumervoice.org](mailto:info@theconsumervoice.org); [www.theconsumervoice.org](http://www.theconsumervoice.org).

Other free resources about culture change include:

Quality Partners of Rhode Island, which has training tools and resources to support the “How to Change.” [www.riqualitypartners.org](http://www.riqualitypartners.org); click on the nursing home section.

From CMS, the “Artifacts of Culture Change Tool,” which is helpful in assessing an organization’s status on the culture change journey in addition to provoking ideas about next steps. <http://siq.air.org>.

Eden Alternative tools can be found at <http://edenalt.com/edentols.htm>.

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## Eldercare Locator

**1.800.677.1116**

The Eldercare Locator is a free national service provided by the U.S. Administration on Aging. It is an easy way to find resources for older adults in any U.S. community. Just one phone call or web site visit instantly connects you to resources in your own community. It is a 24 hours/day 7days/week service for information regarding:

- Adult Day Care
- Aging and Disability Resource Centers
- Caregiver Programs
- Case Management
- Elder Abuse Prevention Programs
- Emergency Response Systems
- Employment Services
- Financial Assistance
- Home Health Services
- Home Repair
- Home Modification
- Information and Referral/Assistance
- Legal Assistance
- Nutrition Services
- Personal Care
- Respite Care
- Senior Housing Options
- Senior Center Programs
- Telephone Reassurance
- Transportation
- Volunteer Services

For more information visit [www.eldercare.gov](http://www.eldercare.gov).

The number for Eldercare is **1.800.677.1116**. Be sure to have the city and state or zip code available of where you are seeking services.

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## Filing a Complaint

October 2011

If residents have concerns about their care, they can file a complaint. (Examples of possible concerns include: cold food, conflict with a roommate, call bells not being answered, medication errors, not following through on a care plan, etc.) There are different ways residents can file a complaint.

### You can file a complaint with your ombudsman.

- Residents can file a complaint with the local long-term care ombudsman. Ombudsmen work to resolve complaints on behalf of nursing home residents and ombudsman programs maintain strict confidentiality guidelines regarding the complaints they receive.
- The Ombudsman network has 8,700 volunteers certified to handle complaints and more than 1,300 paid staff. Most State Ombudsman Programs are housed in their State Unit on Aging. Nationally, in 2008 the Ombudsman Program investigated over 271,000 complaints made by 182,506 individuals and provided information on long-term care to another 327,000 people.
- To locate an Ombudsman, go to **<http://www.ltombudsman.org/ombudsman>** and select your state of residence. A list of all Ombudsmen in that state will be listed along with their address, phone number, and areas they serve. You can also locate your local ombudsman by calling the local Area Agency on Aging (AAA) found in the phone book. Facilities are required by law to post the ombudsman's phone number in a prominent place in the facility.

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**You can file a complaint with your state licensing & certification agency.**

- Your state licensing & certification agency will investigate complaints of abuse or neglect in nursing homes.
- Ombudsmen can help residents in filing a complaint with their state licensing & certification agency as they are trained to resolve problems. However, unless the Ombudsman is given permission to share a resident's concerns, these matters are kept confidential.
- To locate the agency in your state go to **<http://www.ltombudsman.org/ombudsman>** and select your state of residence. Your State Ombudsman can also help you locate your state agency. Facilities are required to post the state survey complaint number in the building.

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**Name: Alice H. Hedt**

**Date: June 16 2011**

To my caregivers paid and unpaid:

**I am recording my personal preferences and information about my self, 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 e-mails.*

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.*

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October 2011

## Consumer Fact Sheet

**According to the Nursing Home Reform Act of 1987, all residents in nursing homes are entitled to receive quality care and live in an environment that improves or maintains the quality of their physical and mental health. This entitlement includes freedom from neglect, abuse, and misappropriation of funds. Neglect and abuse are criminal acts whether they occur inside or outside a nursing home. Residents do not surrender their rights to protection from criminal acts when they enter a facility. This information sheet presents resident rights with regard to neglect and abuse, and steps to take if these rights are jeopardized.**

### What are Neglect and Abuse?

**Neglect:** Neglect is the failure to care for a person in a manner, which would avoid harm and pain, or the failure to react to a situation which may be harmful. Neglect may or may not be intentional. For example, a caring aide who is poorly trained may not know how to provide proper care. Examples include:

- Incorrect body positioning -- which leads to limb contractures and skin breakdown;
- Lack of toileting or changing of disposable briefs – which causes incontinence and results in residents sitting in urine and feces, increased falls and agitation, indignity and skin breakdown;
- Lack of assistance eating and drinking -- which leads to malnutrition and dehydration;
- Lack of assistance with walking – which leads to lack of mobility;
- Lack of bathing – which leads to indignity, and poor hygiene;
- Poor handwashing techniques -- which leads to infection;
- Lack of assistance with participating in activities of interest – which leads to withdrawal and isolation.
- Ignoring call bells or cries for help

**Abuse:** Abuse means causing intentional pain or harm. This includes physical, mental, verbal, psychological, and sexual abuse, corporal punishment, unreasonable seclusion, and intimidation. Examples include:

- Physical abuse from a staff member or an intruder or visitor from outside the facility -- including hitting, pinching, shoving, force-feeding, scratching, slapping, and spitting;
- Psychological or emotional abuse -- including berating, ignoring, ridiculing, or cursing a resident, threats of punishment or deprivation;
- Sexual abuse – including improper touching or coercion to perform sexual acts;
- Substandard care which often results in one or more of the following conditions -- immobilization, incontinence, dehydration, pressure sores, and depression;
- Rough handling during care giving, medicine administration, or moving a resident.

**Misappropriation of Property/Funds:** This means the deliberate misplacement or misuse of a resident's belongings or money without the resident's consent. Examples include:

- Not placing resident funds in separate interest-bearing accounts where required;
- Stealing or embezzling a resident's money or personal property, such as jewelry or clothing.

Nursing homes are required by federal law to have intervention strategies and regular monitoring to prevent neglect and abuse. The nursing home must reevaluate these measures on a regular basis.

## Reporting Neglect & Abuse:

It is a violation of State and Federal law for any person, including facility staff, volunteers, visitors, family members or guardians, or another resident, to neglect or abuse a resident.

- Anyone can and should report neglect and abuse. If you suspect neglect or abuse, or if a resident tells you they are experiencing this problem, it is important to believe the resident and REPORT THE ALLEGATION IMMEDIATELY. This will help prevent further suffering by any resident.
- Many states have laws that require the reporting of abuse and neglect. Find out what your state requires.
- Put your report in writing, date it, and keep a copy. Convey as much information as you can about the situation. Remember to include:

**WHO** The name of the victim, including age and address; the name of the facility and the people responsible for the victim's care; the identity of the person who you believe abused or neglected the resident;

**WHAT** The nature and extent of harm and any physical signs of abuse or neglect; any previous incidents; what happened;

**WHERE and WHEN**

The place where the incident happened and time and date of the incident.

Provide as much background information as possible. A thorough report will help the investigator to address the situation quickly.

## Make Your Report to:

- The nursing home's administrator, director of nursing, and social worker
- The state or local ombudsman
- The local police or State law enforcement
- A Protection and Advocacy or Adult Protective Services agency
- The state survey agency that licenses and certifies nursing homes (often in the Health Department)
- A citizen advocacy group, or other church or community group that visits regularly.

## After the Report:

Keep trying until you get the assistance you need.

- Follow up with the resident and facility to make sure the neglect or abuse has stopped.
- Follow up with the person or agency conducting the investigation. Ask for written copies of findings if allowed by law.
- If the perpetrator is charged with abuse or neglect, the charge will be referred to the state licensing authority. If the guilty person is a nurse aide, the charge will be reported to the state nurse aide registry. This registry is used by nursing homes to prevent abusive aides from working with the elderly. Nursing homes are required to check the registry before hiring a person.

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## Ombudsman Information

October 2011

### What is an Ombudsman?

An Ombudsman is an advocate for residents of nursing homes, board and care homes and assisted living facilities. They can assist in finding a facility and how to get quality care. They are also trained to resolve problems and can assist with your complaints. Under the federal Older Americans Act, every state is required to have an Ombudsman Program that addresses complaints and advocates for improvements in the long-term care system. They are trained to resolve problems. If you want, the ombudsman can assist you with complaints. However, unless you give the ombudsman permission to share your concerns, these matters are kept confidential. The Ombudsman program is administered by the Administration on Aging (AoA – [www.aoa.gov](http://www.aoa.gov)).

### A Long-Term Care Ombudsman:

- Resolves complaints made by or for residents of long-term care facilities
- Educates consumers and long-term care providers about residents' rights and good care practices
- Promotes community involvement through volunteer opportunities
- Provides information to the public on nursing homes and other long-term care facilities and services, [residents' rights](#) and legislative and policy issues
- Advocates for residents' rights and quality care in nursing homes, personal care, residential care and other long-term care facilities

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- Promotes the development of citizen organizations, family councils and resident councils
- Long-Term Care Ombudsman efforts are summarized in the National Ombudsman Reporting System ([NORS 2008 data](#)) to include the number of facilities visited, the types of complaints handled and the kinds of complaints filed with ombudsmen.

### **What concerns does an Ombudsman address?**

- Violation of residents' rights or dignity
- Physical, verbal or mental abuse, deprivation of services necessary to maintain residents' physical and mental health, or unreasonable confinement
- Poor quality of care, including inadequate personal hygiene and slow response to requests for assistance
- Improper transfer or discharge of patient
- Inappropriate use of chemical or physical restraints
- Any resident concern about quality of care or quality of life

### **How can I locate my local and state Ombudsman?**

You can go to <http://www.ltombudsman.org/ombudsman> and select your state of residence. A list of all Ombudsmen in that state will be listed along with their address, phone number, and areas they serve.

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## RESIDENTS' RIGHTS: AN OVERVIEW

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April 2011

**Residents' Rights** are guaranteed by the federal 1987 Nursing Home Reform Law. The law requires nursing homes to “*promote and protect the rights of each resident*” and places a strong emphasis on individual dignity and self-determination. Nursing homes must meet federal residents' rights requirements if they participate in Medicare or Medicaid. Some states have residents' rights in state law or regulation for nursing homes, licensed assisted living, adult care homes, and other board and care facilities. A person living in a long-term care facility maintains the same rights as an individual in the larger community.

### Residents' Rights Guarantee Quality of Life

The 1987 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, ensuring *dignity, choice, and self-determination*.

All nursing homes are required "to provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care that... is initially prepared, with participation, to the extent practicable, of the resident, the resident's family, or legal representative." *This means a resident should not decline in health or well-being as a result of the way a nursing facility provides care.*

The 1987 Nursing Home Reform Law protects the following rights of nursing home residents:

#### 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
- Residents have a right to receive information in a language they understand (*Spanish, Braille, etc.*)

#### 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

#### 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

#### Right to Privacy and Confidentiality

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

## Rights During Transfers and Discharges

- Remain in the nursing facility unless a transfer or discharge:
  - (a) is necessary to meet the resident's welfare;
  - (b) is appropriate because the resident's health has improved and s/he no longer requires nursing home care;
  - (c) is needed to protect the health and safety of other residents or staff;
  - (d) 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

### *Advocates for Residents Rights*

Where do you go for help if you're concerned a facility is not guaranteeing the rights of residents? Contact your local or state long-term care ombudsman or, if one exists, your state's citizen advocacy group. The Long-Term Care Ombudsman Program is required by federal law to promote and protect the rights of residents in licensed long-term care facilities. The Consumer Voice can help you locate advocates and ombudsmen in your area. Visit our website: [www.theconsumervoice.org](http://www.theconsumervoice.org) to view a map listing ombudsmen and citizen advocacy groups nationwide.

More fact sheets and publications on how to get good care in nursing homes are available by calling the Consumer Voice at 202.332.2275 or visiting our website at

[www.theconsumervoice.org](http://www.theconsumervoice.org)

**Nursing Homes: Getting Good Care There,**  
\$11.95

#### **Fact Sheets:**

*A Consumer Guide to Choosing a Nursing Home:  
Restraints*

*Access and Visitation*

*Involuntary Transfer and Discharge*

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## The Rights of Resident Councils in Nursing Homes

The 1987 Nursing Home Reform Act guarantees nursing home residents a number of important rights to enhance their nursing home experience and improve facility-wide services and conditions. Key among these rights is the right to form and hold regular private meetings of an organized group called a resident council.

Facilities certified for Medicare and Medicaid must provide a meeting space, cooperate with the council's activities, and respond to the group's concerns. Nursing facilities must appoint a staff advisor or liaison to the resident council, but staff and administrators have access to council meetings only by invitation.

Specifically, the federal law includes the following requirements on resident councils:<sup>1</sup>

- *A resident has the right to organize and participate in resident groups in the facility.*
- *The facility must provide a resident group, if one exists, with private meeting space.*
- *Staff or visitors may attend meetings at the group's invitation.*
- *The facility must provide a designated staff person responsible for providing assistance and responding to written requests that result from group meetings.*
- *When a resident group exists, the facility must listen to the views and act upon the grievances and recommendations of residents and families concerning proposed policy and operational decisions affecting resident care and life in the facility.*

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<sup>1</sup>42 CFR sec.483.15(c); Public Law 100-203, Social Security Act







## The Right to Make a Complaint

### Nursing Home Reform Law of 1987

[Code of Federal Regulations]

[Title 42, Volume 3]

[Revised as of October 1, 2002]

From the U.S. Government Printing Office via GPO Access

[CITE: 42CFR483.10]

[Page 497-502]

TITLE 42--PUBLIC HEALTHCHAPTER IV--CENTERS FOR MEDICARE & MEDICAID SERVICES, DEPARTMENT OF HEALTH AND HUMAN SERVICES--(Continued)  
PART 483--REQUIREMENTS FOR STATES AND LONG TERM CARE FACILITIES--  
Table of Contents  
Subpart B--Requirements for Long Term Care Facilities

Sec. 483.10 Resident rights.

The resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility. A facility must protect and promote the rights of each resident, including each of the following rights:

Pg. 498-499

(b) Notice of rights and services.

(7) The facility must furnish a written description of legal rights which includes—

(iii) A posting of names, addresses, and telephone numbers of all pertinent State client advocacy groups such as the State survey and certification agency, the State licensure office, the State ombudsman program, the protection and advocacy network, and the Medicaid fraud control unit; and

(iv) A statement that the resident may file a complaint with the State survey and certification agency concerning resident abuse, neglect, misappropriation of resident property in the facility, and non-compliance with the advance directives requirements.



Pg. 501

(f) Grievances. A resident has the right to--

(1) Voice grievances without discrimination or reprisal. Such grievances include those with respect to treatment which has been furnished as well as that which has not been furnished; and

(2) Prompt efforts by the facility to resolve grievances the resident may have, including those with respect to the behavior of other residents.