

TOGETHER WE CAN... ACHIEVE RESIDENT-DIRECTED CARE

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The photos on the front of this packet are of current and former residents of nursing homes who are national leaders on quality of care, quality of life, and residents' rights in long-term care. They are, clockwise from top left – Louise Clark, Belfair, WA; Eduardo Standard, New York, NY; Jackie Coombs, South Issaquah, WA; and Curmet Forte, Washington, DC.

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Together We Can... Achieve Resident-Directed Care

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*Together We Can ...
Achieve Resident-Directed Care*

Section I.

Introduction & Overview

Residents' Rights Week 2005

Together We Can ...Achieve Resident-Directed Care

2005 Residents' Rights Week

by Alice H. Hedt, Executive Director
National Citizens' Coalition for Nursing Home Reform

The right to individualized care is one of the most precious and important provisions of the Nursing Home Reform Law of 1987 because it sets forth a guarantee that applies to each person - the right to individualized care that will help him or her "attain or maintain his or her highest level of well-being – physically, mentally, and emotionally." This year's Residents' Rights packet focuses on this right and delivers an important message, Together We Can....Achieve Resident – Directed Care. Truly, we must all work with one another – residents, family members, advocates, facility staff – to promote this right so that care can be truly resident directed.

Everywhere I go, people are talking about "quality". The nursing home industry has a "Quality First" initiative. The Centers for Medicare and Medicaid has developed a multi-year Nursing Home Quality Initiative that includes involvement by every QIO (Quality Improvement Organization) in the country. The Pioneer Network and the Alzheimer's Association are promoting practices that result in quality while researchers are examining what is a quality experience for residents. With all of this discussion and focus on quality, the 2005 packet reminds us that the care planning process is the lynchpin of resident directed care in all settings – nursing homes, assisted living, as well as board and care facilities. In fact, true quality cannot take place without a vigorous process that involves a variety of players – most importantly, the resident.

This packet contains a wealth of ideas to use throughout the year and particularly during Residents' Rights Week, October 2 – 8, 2005. Our theme, Together We Can...Achieve Resident-Directed Care, reminds us that the real way to respect residents, and promote their rights, is to provide the opportunity for each individual to be fully participative as they are able in the care planning process.

This is NCCNHR's 30th Anniversary. Our Annual Conference, October 16 – 19, will also focus on the Together We Can theme because we believe that working together as individuals and organizations, we can make substantial changes to the resident experience and to the long-term care system. Please consider joining us as we look back on 30 years of advocacy, and look forward to achieving resident-directed care.



PS. I have completed a form in this packet to share with my care givers when I need care. Why don't you complete one as well and use it as a starting point for discussing what quality means to you? I'd love to learn about your experience.

A History of Celebrating Residents' Rights Week

One way to honor residents' rights is by celebrating Residents' Rights Week, the first full week of October. (In 2005, October 2nd - 8th). This is an opportunity to honor residents, ombudsmen, citizen advocates, facility staff and family members who work to respect residents' rights. Setting aside a week to focus on rights is an effective way to make sure that this important topic is never forgotten in your community, facility or state.

Residents' Rights Week is designated by the National Citizens' Coalition for Nursing Home Reform each year to honor residents living in all long-term care facilities, including nursing homes, subacute units, assisted living, board and care, and retirement communities. It is a time to reflect on the importance of the Nursing Home Reform Law of 1987 which promises quality of life and care and residents' rights for *each resident*. During this week NCCNHR also gives special recognition to the work of thousands of individuals who collaborate daily to help assure that dignity, privacy and other basic human rights - often taken for granted in the community - are maintained as an integral part of the lives of residents living in long-term care settings.

Residents' Rights Week originated in 1981 at an annual meeting of the National Citizens' Coalition for Nursing Home Reform. Several nursing home residents in attendance (from NY, MN, WA, IN and DC) decided that it would be special for all residents across the country if time were set aside to celebrate residents and their rights, separate from annual National Nursing Home Week events always held in May. NCCNHR organized a successful petition drive to persuade Congress to designate a "Residents' Rights Day." Senator Claude Pepper (D-FL) and Senator David Pryor (D-AR) responded by introducing a Congressional Resolution for that purpose.

NCCNHR was also successful in making arrangements to take five nursing home residents to the White House to meet with President Jimmy Carter's Special Counselor on Aging, Dr. Harold Sheppard. The residents who attended were Janet Tulloch, Rae Spanover, Joan Knowlton, Ethel Gross and Virginia Caming (all now deceased).

Since 1980, NCCNHR has preserved this tradition, although we have extended the designation to a full week so that facility staff, family members, community advocates and ombudsmen will have flexible opportunities to conduct educational programs and festive events.

Thank you for working to make Residents' Rights Week special and meaningful for all involved. Please remember to share information about your successes so that we can include them in next year's packet. Every resident appreciates each step you take to help promote and maintain dignity and humanity in long-term care services. If you have questions, please call us at (202) 332-2275.

Together We Can ... Achieve Resident-Directed Care
2005 Residents' Rights Week

DEDICATION

In 2005, the Aging Network lost two dedicated long-time advocates, Sharon Zoesch, Minnesota State Long-Term Care Ombudsman, and Howard Hinds, District Long-Term Care Ombudsman with the East Tennessee Human Resources Agency.

Sharon Zoesch was the State Long-Term Care Ombudsman for Older Minnesotans since 1994. Sharon became known as a national expert on long-term care issues for the aging and was a dedicated advocate for the rights of the elderly. Sharon was an active member, and past president, of the National Association of State Ombudsman Programs. Her history of advocacy spanned throughout her life, working with prisoners early on in her career, and with troubled Native American families as a Vista Volunteer. Her husband, Terry, her three daughters, stepdaughter, and a grandson, survive Sharon. Sharon died June 5, 2005. She was 53.

Howard Hinds, District Long-Term Care Ombudsman with the East Tennessee Human Resources Agency and Minister of the West View United Methodist Church for over 29 years, died on May 24, 2005. Howard started his career as the Legal Services Coordinator for the Area Agency on Aging in 1977. In 1981 he added ombudsman services to his job and quickly began the task of creating the first volunteer ombudsman program in East Tennessee. Howard was a true champion for nursing home residents and for the ombudsman program. He also founded the East Tennessee Coalition on Advocacy, Inc., a local citizen advocacy group. Howard is survived by his wife, Anna, a brother and sister, and a cadre of nieces and nephews.

Together We Can... Achieve Resident-Directed Care
2005 Residents' Rights Week

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NCCNHR would like to thank the following individuals and programs that contributed information or resources to this Residents' Rights Week Packet.

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Residents' Rights Week Activity Suggestions

Celebrate Residents' Rights Week (October 2-8, 2005) with one or more of the following activities –

- ◆ Plan a **presentation on care planning** at the October Resident and/or Family Council Meeting
- ◆ Engage in some of the **Getting to Know You Activities** in the Training Materials/Activities Section of this packet.
- ◆ Put up a **Bulletin Board** on Care Planning – have residents include information on their likes and dislikes
- ◆ Have a **family night** that includes activities on care planning
- ◆ **Show the video**, Nursing Home Care Plans: Getting Good Care (see the Resource Section for information on obtaining this free video from AARP)
- ◆ Sponsor your own **Poster Contest** (see the Promotional Materials Section for the Residents' Rights Week Poster). Display the entries around the facility.
- ◆ **Share the materials** in this packet with others
- ◆ **Ask residents how they would like to celebrate Residents' Rights Week 2005!**

Respect Dignity Autonomy Privacy **Together We Can... Achieve Resident-Directed Care** **Residents' Rights Packet 2005**

Whether it's choosing what to eat, when to bathe, or what activities to participate in, long-term care residents have the right to be engaged in the care planning process.

The 2005 Residents' Rights Packet offers examples of how to get involved in care planning as a resident or family member, as well as strategies for facilities and advocates to use to promote a comprehensive and resident-directed care planning process.

The packet includes:

- Residents' Rights Week promotional materials and event ideas
- Stories of care planning successes from across the country
- Materials for ombudsmen, social workers, and others involved in care planning in nursing homes, assisted living, and board and care facilities
- Care plan conference preparation materials developed by national experts
- A new tool to let caregivers know your wishes should you ever need care
- Activity ideas for residents to take part in their care planning
- Training programs/ideas for facility staff
- Fact sheets for Residents and Families
- Much, much more!

Your Residents' Rights Week Poster will arrive in time for Residents' Rights Week!

The winning entry of the 2005 Residents' Rights Week Poster Contest will be reproduced as a 16x20 color poster that will be sent to everyone who has ordered a Residents' Rights Week Packet.

**Together We Can... Achieve higher quality of care and quality of life for
long-term care residents**

Celebrate Residents' Rights Week, October 2-8, 2005!

Promoting Residents' Rights has never been easier! Insert the 2005 packet into your 2003 Residents' Rights Tool Kit and you have a new and comprehensive tool to assist in conducting timely Residents' Rights training sessions. It's not too late to order your 2003 Residents' Rights Tool Kit! The 2003 Residents' Rights Tool Kit, 24/7: Residents' Rights Around the Clock, includes:

- ♦ Educational strategies
- ♦ Activities
- ♦ Posters
- ♦ PowerPoint presentations
- ♦ Readily available materials for year-round effective residents' rights training

Mail/fax pre-payment to: NCCNHR, 1828 L St., Ste. 801, Washington, DC 20036
Ph: 202.332.2275; Fx: 202.332.2949

Order Form

Remember, Residents' Rights Week Packets contain successful practices, activities, and ideas that can be used throughout the year to promote resident respect, individuality, and involvement in the care planning process.

2005 Residents' Rights Packet: *Together We Can... Achieve Resident-Directed Care*

\$25 x Quantity = _____ = \$ _____ S&H: \$5.00 + \$3 for each add'l copy = _____

2004 Residents' Rights Packet: *Spotlight on Quality: Focus on Residents' Rights*

\$10 x Quantity = _____ = \$ _____ S&H: \$5.00 + \$3 for each add'l copy = _____

2003 Residents' Rights Tool Kit: *24/7: Residents' Rights Around the Clock*

\$30 x Quantity = _____ = \$ _____ S&H: \$5.00 + \$3 for each add'l copy = _____

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*Together We Can ...
Achieve Resident-Directed Care*

Section II.

What is Assessment and Care Planning?

Residents' Rights Week 2005

ASSESSMENT AND CARE PLANNING: THE KEY TO GOOD CARE

Consumer Fact Sheet No. 3

1999

Each and every person in a nursing home has a right to good care under the 1987 Federal Nursing Home Reform Law. The law, which is part of the Social Security Act, says that a nursing home must help each resident "attain or maintain" his or her highest level of well being - physically, mentally, and emotionally. To give good care, staff must *assess* and *plan care* to support each resident's life-long patterns, current interests, strengths, and needs. Care planning conferences are a valuable forum for residents and families to voice concerns, ask questions, give suggestions, learn nursing home strategies, and give staff information (such as resident background and daily routine). This requirement in the law is vital to making sure residents get good care.

Resident Assessment

Assessments gather information about the health and physical condition of a resident and how well a resident can take care of themselves. This includes assessing when help may be needed in activities of daily living (ADLs) or "functional abilities" such as walking, eating, dressing, bathing, seeing, hearing, communicating, understanding, and remembering. Assessments also should examine a residents' habits, activities, and relationships in order to help him or her live more comfortably and feel at home in the facility.

The assessment helps staff to be aware of strengths of the resident and also determine the reason for difficulties a resident is having. An example of where a good assessment helps: A resident begins to have poor balance. This could be the result of medications, sitting too much, weak muscles, poorly fitting shoes, or a urinary or ear infection. Staff must find out the cause of a problem in order to give good treatment. Figuring out the cause is much easier with a good assessment.

Assessments must be done within 14 days of the resident's admission to a nursing home (or 7 days for Medicare residents) and at least once a year after that. Reviews are held every three months and when a resident's condition changes.

Plan of Care

After the assessment is completed, the information is analyzed and a care plan is developed to address all the needs and concerns of the resident. The initial care plan must be completed within seven days after the assessment. The care plan is a strategy for how

the staff will help a resident every day. This care plan says what each staff person will do and when it will happen (for example, a 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 they meet their needs and must be comfortable with them.

Care Planning Conference

The care plan is developed by an interdisciplinary team -- nurse, nurse aide, activities and dietary staff, and social worker, **with critical input from the resident and/or family members**. All participants discuss the resident's care at a Care Plan Conference to make certain that all medical and non-medical issues, including meals, activities, therapies, personal schedule, medical and nursing care, and emotional needs are agreed upon and addressed. Resident and family member concerns should be listened to by staff and addressed in the care plan. A good Care Plan Conference takes time. It should not be rushed, and could take at least one hour. Every 90 days after development of the initial plan, or whenever there is a big change in a resident's physical or mental health, a Care Plan Conference is held to determine how things are going and if changes need to be made.

Good Care Plans Should

- Be specific to that resident;
- Be followed as an important guideline for providing good care for the resident;
- Be written so that everyone can understand it and know what to do;
- Reflect the resident's concerns and support his or her well-being;
- Use a team approach involving a wide variety of

- staff and outside referrals as needed;
- Assign tasks to specific staff members;
- Be re-evaluated and revised routinely.

Steps for Residents and Family Participation in Care Planning

Residents and family members have the right to be involved in the care plan conference in order to make choices about care, services, daily schedule, and life in the nursing home. Even if a resident has dementia, involve them in care planning as much as possible. Be aware that they may understand and communicate at some level and help the staff to find ways to communicate and work with them. They can express when they hurt or suffer if they are actively listened to. Participating in care plan conferences is a way to be heard, raise questions, and come to a clear agreement with the facility about how the resident will be cared for.

Before the meeting:

- Ask staff to hold the meeting at a convenient time for you and/or your family member;
- Ask for a copy of the current care plan (if one already exists) so that you can examine each aspect thoughtfully;
- Know about or ask the doctor or staff about your or your loved one's condition, care, and treatment;
- Plan your list of questions, needs, problems, and goals, and;
- Think of examples and reasons to support changes you recommend in the care plan.

During the meeting:

- Make sure the resident is involved and listened to carefully.
- 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 the care plan;
- Find out who to talk to if changes in the care plan are needed, and;
- Find out who to talk to if there are problems with the care being provided.

After the meeting:

- Monitor whether the care plan is being followed;
- Inform the resident's doctor about the care plan if s/he was not directly involved;
- Talk with nurse aides, staff or the doctor about the care plan, and;
- Request another meeting if the plan is not being followed.
- See NCCNHR's "Resolving Problems in Nursing Homes" for additional information.

If you are interested in learning more, the National Citizens' Coalition for Nursing Home Reform (NCCNHR) has several publications that may be of interest. Call 202-332-2275 for a publication list or visit the website at <http://www.nccnhr.org>.

- **Nursing Homes: Getting Good Care There,** Cost: \$11.95
- **Avoiding Physical Restraint Use - consumer booklet,** Cost: \$7.50
- **Avoiding Drugs Used as Chemical Restraints - consumer booklet,** Cost: \$7.50
- *Order both Restraint booklets for \$14***
- **Using Resident Assessment and Care Planning: An Advocacy Tool for Residents and their Advocates,** Cost: \$12

Prices listed do not include shipping and handling.

NCCNHR is a national non-profit membership organization founded in 1975 by Elma Holder to protect the rights, safety, and dignity of America's long-term care residents.

INDIVIDUALIZED ASSESSMENT WITH BEHAVIOR SYMPTOMS

THE MEANING OF INDIVIDUALIZED CARE

The federal Nursing Home Reform Law, passed in 1987, is part of the Social Security Act. It protects each nursing home resident and requires that nursing homes "provide service 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." What this means is that each resident's **individualized needs** must be discovered and addressed.

Mary lived alone for almost 20 years after her husband died. She was fiercely independent and, although frail at 87, was still able to tend her garden. Her daughter, though, began to notice that her mom was not able to remember recent events. Then, her mom forgot to turn off the stove and dinner went up in flames. Some time later, Mary was found 5 miles from her home, lost and disoriented.

Mary went through a battery of tests and was diagnosed with dementia. Her daughter, fearful for her mom, searched for the best nursing home. Within a month, Mary moved to Sunnyside Manor and her daughter felt great relief because her mom was safe and secure.

Unfortunately, her euphoric feeling was short-lived. One month after moving into the nursing home, the daughter was presented with a litany of things her mom was doing wrong. "She wandered into other resident's rooms... she became disruptive and screamed when nurse aides wanted her to go to the TV room...she tried to sneak out the back door."

The next time the daughter visited, Mary was tied in a chair. Staff explained to the stunned daughter that her mom was quite a problem and that today, "she hit the nurse aide." When the daughter demanded that her mom be released from the chair, staff explained that they had a right to protect themselves from her outbursts and that the only other option was to discharge her from the home.

RESIDENT ASSESSMENT PROCESS

The nursing home must carefully and thoroughly assess each resident in order to meet her needs. Many things should be taken into account. A partial list follows:

- Life history, daily routine, strengths, interests, food preferences, and other personal information;
- Functional abilities including walking, dressing, using the toilet and eating;
- Physical or mental conditions that affect a resident;
- Potential for improvement;
- Communication abilities;
- Nutritional status and medications.

A thorough assessment is vital to knowing the resident so staff can care for her in a manner that enhances her quality of life. The assessment must be completed within 14 days of admission into the home, or 7 days for Medicare residents. Thereafter, an annual assessment must take place or be conducted if the resident's condition changes.

DEVELOPING A CARE PLAN

After the assessment is completed, the information is analyzed and a care plan is developed to address all the

needs and concerns of the resident. An interdisciplinary team -- nurse, nurse aide, activities and dietary staff, social worker, **with critical input from the resident and/or family members** -- should work together at a Care Plan Conference to make certain that all medical and non-medical issues are agreed upon and addressed. Resident and family member concerns should be listened to and addressed in the care plan. A good care planning session takes time. It should not be rushed and could take at least one hour. Every 90 days after development of the initial plan, a Care Plan Conference is held to determine how things are going and if changes need to be made.

BEHAVIORAL SYMPTOMS VS. RESIDENT AS PROBLEM

In the preceding story, Mary, the resident, was perceived as the problem. From this negative, blame-the-victim perspective, staff can do little or no constructive problem-solving to address Mary's needs. It is necessary for staff to look at the resident from a new vantage point -- through Mary's perspective. (Mary cannot tell you what is wrong. She expresses much of her distress in behavioral symptoms.)

The *Assessment and Care Plan* should emphasize two main points: the uniqueness of each resident and the staff's responsibility in meeting each individual resident's needs. With these points as the focus, the question can be reframed from "*Why is the resident a problem?*" to "*What do Mary's behavioral symptoms mean (unmet need) and how can staff help her?*"

Mary's symptoms included "aimless" wandering, disruptiveness, and striking other residents and staff. Restraining her will lead to decreased mobility and ability, listlessness, increased agitation, physical problems, and more work for nursing home staff. Instead of using restraints, staff can ask questions which will help find the cause of Mary's behavior and point to appropriate responses. Some potential questions follow with a plausible answer:

Q: Why is Mary wandering? Does Mary have a history of spending time outside? If she enjoys wandering, can staff help her do this safely? Are staff taking her outside for exercise?

A: Mary previously spent many hours outside taking long walks, visiting neighbors and caring for her garden. This is a life-long routine and should be continued. Staff have instead assumed that Mary should sit and watch TV. Mary had not been taken outside at all during her month at the nursing home.

Q: Why would Mary scream? Is there a physical reason for the behavior (pain or infection)? What types of activities did Mary enjoy before the dementia? Is the TV room too noisy?

A: Mary never enjoyed watching TV. She likes to look at the garden from the window in her room. Despite her dementia, she is still aware of her likes and dislikes and these should be respected.

Q: What happened when the nurse aide was hit? Was she trying to get Mary to do something she didn't want to do? Did Mary feel threatened? Are staff trained to work with residents with dementia?

A: The nurse aide yelled at Mary as she approached and Mary felt threatened. It is important for the nurse aide to be gentle and soft spoken in her approach.

WHAT SHOULD BE DONE

Most nursing home staff want to do a good job. It is important that you first approach addresses the issues in a positive, non-confrontational manner. Take the following steps:

- Ask for a Care Plan Conference;
- Make sure the right questions are asked. Use why, when, where, and how questions to help staff think of as many reasons for the behavior as possible;
- Keep the focus on the needs of the resident;
- Know your rights under the law. Residents cannot be forced to leave the home without specific notice and appeal rights; physical restraints cannot be used to treat symptoms treatable by individualized care;
- Monitor implementation of the care plan and address lack of implementation immediately;
- Work closely with aides and professional nurses to orient them to the resident;
- Make sure the resident's doctor is aware of and supportive of the resident's care plan;
- Request outside consultation from the ombudsman, if necessary.

If you are interested in learning more, the National Citizens' Coalition for Nursing Home Reform (NCCNHR) has several publications that may be of interest. Call 202-332-2275 for a publication list or visit the website at <http://www.nccnhr.org>. Prices listed do not include shipping or handling.

➤ **Nursing Homes: Getting Good Care There**
[Cost \$11.95]

➤ **Using Resident Assessment and Care Planning: An Advocacy Tool for Residents and Their Advocates** [Cost: \$12]

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Resident Assessment and Care Planning

KNOW YOUR RIGHTS REGARDING RESIDENT ASSESSMENT AND CARE PLANNING

The 1987 Nursing Home Reform Act includes specific requirements related to resident assessment and care planning. The law says that a nursing home must help each resident “attain or maintain” his or her highest level of well-being – physically, mentally, and emotionally. To provide good care, staff must assess and plan care that will support each resident’s life-long patterns; current interests, strengths, and needs. Care planning conferences are a valuable forum for residents and families to voice concerns, ask questions, give suggestions, learn strategies, and give staff information. This requirement in the law is vital to making sure residents get good care.

What the federal law (PL 100-203) says about assessment and care planning:

Resident Assessment

[42 USC § 1396r (b)(3)]

A nursing facility must conduct a comprehensive, accurate, standardized, reproducible assessment of each resident’s functional capacity, which assessment – describes the resident’s capability to perform daily life functions and significant impairments in functional capacity; is based on a uniform minimum data set specified by the Secretary; uses an instrument which is specified by the State; and includes the identification of medical problems.

Each assessment must be conducted or coordinated (with the appropriate participation of health professionals) by a registered professional nurse who signs and certifies the completion of the assessment. Each individual who completes a portion of such an assessment shall sign and certify as to the accuracy of that portion of the assessment.

Such an assessment must be conducted – promptly upon (but no later than 14 days after the date of) admission of each individual admitted; promptly after a significant change in the resident’s physical or mental condition; and in no case less often than once every 12 months. The nursing facility must examine each resident no less frequently than once every 3 months, and as appropriate, revise the resident’s assessment to assure the continuing accuracy of the assessment.

The results of such an assessment shall be used in developing, reviewing, and revising the resident’s plan of care.

Plan of Care

[42 USC §1396r (b)(2)]

A nursing facility must 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 – describes the medical, nursing, and psychosocial needs of the resident and how such needs will be met; is initially prepared, with the participation to the extent practicable of the resident or the resident's family or legal representative, by a team which includes the resident's attending physician and a registered professional nurse with responsibility for the resident; and is periodically reviewed and revised by such team after each assessment.

What the federal regulations say about resident assessment and care plans:

Resident Assessment

[42 CFR 483.20(a) – (c)]

- The facility must make a comprehensive assessment of a resident's needs, which is based on a uniform data set and describes the resident's capability to perform daily life functions and significant impairments in functional capacity.
- The comprehensive assessment must include the following:
 - Identification and demographic information
 - Customary routine
 - Cognitive patterns
 - Communication
 - Vision
 - Mood and behavior patterns
 - Psychosocial well-being
 - Physical functioning and structural problems
 - Continence
 - Disease diagnoses and health conditions
 - Dental and nutritional status
 - Skin condition
 - Activity pursuit
 - Medications
 - Special treatments and procedures
 - Discharge potential
 - Documentation of summary information regarding the additional assessment performed through the resident assessment protocols
 - Documentation of participation in assessment
 - The assessment process must include direct observation and communication with the resident, as well as communication with licensed and nonlicensed direct care staff members on all shifts

- Assessments must be conducted no later than 14 days after admission; promptly after a significant change in the resident's physical or mental condition; and in no case less often than once every 12 months.
- The nursing facility must examine each resident no less than once every three months, and as appropriate, revise the resident's assessment to assure the continued accuracy of the assessment.
- The results of the assessment are used to develop, review, and revise the resident's comprehensive plan of care.
- The facility must coordinate assessments with any State-required preadmission screening program to the maximum extent practicable to avoid duplicative testing and effort.
- Each assessment must be conducted or coordinated by a registered nurse who signs and certifies the completion of the assessment. Each individual who completes a portion of the assessment must sign and certify the accuracy of that portion. Any individual who willfully and knowingly certifies (or causes another to certify) a material and false statement in a resident assessment is subject to civil money penalties.

Care Plans

[42 CFR 483.20(d)]

- The facility must develop a comprehensive care plan for each resident that includes measurable objectives and timetables to meet a resident's medical, nursing, and mental and psychosocial needs that are identified in the comprehensive assessment. The care plan must describe the services that are to be furnished to attain or maintain the resident's highest practicable physical, mental, and psychosocial well-being; and any services that would otherwise be required under the quality of care provisions [483.25] but are not provided due to the resident's exercise of rights, including his/her right to refuse treatment.
- A comprehensive care plan must be:
 - Developed within 7 days after completion of the comprehensive assessment;
 - Prepared by an interdisciplinary team that includes the attending physician, a registered nurse with responsibility for the resident, and other appropriate staff in disciplines as determined by the resident's needs; and, to the extent practicable, the participation of the resident, and/or the resident's family or legal representative
 - Periodically reviewed and revised by a team of qualified persons after each assessment
- The service provided or arranged by the facility must meet professional standards of quality and be provided by qualified persons in accordance with each resident's written plan of care.

State law and regulations: Note that your state may have additional laws and/or regulations relating to assessment and care plans.

The “Plan of Care” is a “Contract”

This handout is a revised and edited edition from an extensive article written for elder law attorneys by Mr. H. Kennard Bennett. Some of the language has been altered to allow for more generalized understanding by persons who are not attorneys. The context of the material & its message remain the same. Pro Seniors provides this article to help in your understanding of your rights, responsibilities and the importance of active involvement with a loved one living in a nursing home. Please consult an attorney if you need legal advice.

The care of an individual in a nursing home requires a multi-disciplinary approach. The nursing home must be viewed much differently than a hospital. In acute care settings, such as a hospital, the duration of the stay is limited and there is a specific outcome sought. A nursing home is much different, for while there may be (and should be) specific outcomes sought in this setting; they encompass the resident's overall quality of life. Simply put, the nursing home becomes the resident's *home*, and they are usually there for the duration of their life.

Although there are changes underway in the industry, the “institutional model” still predominates in nursing homes; nursing homes often look more like a hospital than a home of any kind, residents usually are in semi-private rooms (like hospitals), and it is not uncommon for the nursing staff and medical staff of a nursing home to view their roles there no differently from that in a hospital.

The standard of care that nursing homes are expected to meet, at a minimum, is set forth in the NURSING HOME REFORM ACT that was part of the OMNIBUS RECONCILIATION ACT OF 1987 (“the NHRA”), which is found at 42 U.S.C. 1395i-3 and 1396r, et seq. The regulations that promulgated the Nursing Home Reform Act can be found at

Volume 42, Code of Federal Regulations, Part 483 (“42 CFR 483”).

The NHRA requires that any nursing facility that accepts Medicare or Medicaid payments (most do) must provide services for each resident to “attain and maintain the highest practicable mental, physical and psychosocial well-being of each resident in accordance with a written plan of care....” What must be brought to bear to meet this standard are the services of specialists in the field of medicine, nursing, therapy, social services, dietary and activities. Moreover, these are not “spot, one time services”; they cover the full twenty-four hours of each day. Ideally, these multiple services should be provided in a somewhat seamless fashion. They must indeed be interdisciplinary, working in union to address the needs of the whole person- a holistic approach. Some experts in the field refer to this as “**psycho-geriatrics:**”

“Psycho-geriatrics represents a holistic approach to adaptation in later life. Thus, the problems and developments of later life must be viewed from a bio-psycho-social perspective, with consideration of socio-economic, spiritual, environmental, psychological and biological factors. Alterations in any one of these areas is likely to impact and affect other areas...”

Simply stated this means that the person needs to be viewed and cared for on many inter-connected levels, from their physical / medical needs, their psychological needs, their need for social contact / activities with people, their ethnic background, their spiritual beliefs and their economic status in society.

In the nursing home setting, this coming to together comes out of the CARE PLANNING process. The NHRA and the regulations stemming from it, specifically require the development of a written plan of care. It is important to note that the care plan is not merely an idea skimmed off the top of some bureaucrat's head in Washington, but rather a tool of time tested, good nursing practices. Care planning first requires good assessment of the individual nursing home resident prior to admission. An assessment determines a resident's abilities in areas known as "activities of daily living" such as walking, bathing, seeing, hearing, or eating, and their assistance needs in each area. The assessment also determines the resident's patterns and preferences in various activities and daily routines. Each discipline should conduct a thorough assessment when a nursing home resident is first admitted. Re-assessments should be made after a hospitalization or upon any other significant change in the resident's circumstances. In essence, the assessment is the gathering of data, ranging from something plainly measurable, such as weight, to something more subjective, like the resident's hobbies and interests.

The Care Plan

Care planning follows the assessment. Without accurate assessment, the care plan will be fatally flawed. Thus, for

example, an erroneous assessment of the resident's work history may lead to inappropriate care planning in the activities department or social services department. If John Doe's employment history shows that he was a jockey, when in fact he never was, he is totally disinterested in horses, then certain planned activities to the horse park could be counter-productive, not to mention confusing to a resident with dementia if those around him keep talking to him as if he *had* been a jockey. (*Based on an actual situation.*)

Armed with detailed, accurate information, a care planning team in a nursing home can begin their work of identifying problems or issues concerning the resident's physical, mental and psychosocial well being. Those problems and issues should be addressed by stating clearly the GOALS to be strived for and the action steps or approaches that should be taken to meet those goals. This, the essence of the plan of care, is precisely the consideration sought by the resident's caregiver / representative when contracting for the services of the nursing home, which is why we say, "The Care Plan is the Contract."

The involvement of the resident, to the extent possible, and the residents' representative in providing information during the assessment stage is vitally important. The resident or representative should be a part of the care planning team; ensuring a meaningful role during the assessment stage of the process will go far in helping to ensure quality care for the resident. Without meaningful involvement of the resident and their representative, disappointments in the quality of care will

likely result or, indeed, serious care problems can develop.

The Law of Care Planning

The NHRA requires that upon admission a "Minimum Data Set" ("MDS") must be developed to serve as a baseline for measuring the progress under a resident's care plan. The MDS includes data on, among other things, the resident's medical history, social history, cognitive abilities, physical functioning, environmental needs, continence, mood and behavior patterns, oral and nutritional status, skin condition, and medication use. Once these are established, a nursing facility must develop for the resident certain "Resident Assessment Protocols" ("RAPs"). These RAPs set forth specific guidelines and protocols for the facility staff to follow to address the needs that were identified by the MDS.

Care plans must be developed following the initial assessment and must be reviewed "promptly after a significant change in the resident's physical or mental condition," or at least once every twelve months.

The initial comprehensive care plan must be developed within 7 days after completion of the assessment. It must be prepared by an inter-disciplinary team defined by the resident's needs and include "to the extent practicable, the participation of the resident, resident's family or legal representative." The care plan is significant, from a legal advocate's point of view, because it defines the standard of care to which the facility can be held accountable. As stated in the regulations:

"(3) The services provided or arranged by the facility must—

- (i) Meet professional standards of quality; and,
- (ii) Be provided by qualified persons in accordance with each resident's written plan of care."

The Relationship Between the Written Admission Contract and the Care Plan

Rarely is a nursing home resident admitted to a nursing home without the resident or his/her representative, signing a written admissions agreement. The nature of these agreements varies from facility to facility, or nursing home chain to nursing home chain, but they are "boilerplate" provisions covering the financial aspects of the resident / facility relationship, such as when the bill must be paid and what happens if it is not paid on time. For the most part, these agreements are forms that are not designed to be the subject of negotiations between the resident and the facility.

They are pieces of paper primarily designed to protect the nursing home. Any attempt to negotiate the written admissions agreement will most likely be rewarded with a blank stare. From the Admission Coordinator and Administrator, followed by a call from the Administrator to the home office or legal counsel, culminating with a pleasant, "Sorry, but we cannot change the terms of this agreement." It is a basic premise that contracts, to be enforceable, must have consideration running between parties to the contract. Nursing home contracts are generally written by lawyers who remember such premises and who are, therefore, careful to include at least a word or two about what the nursing home is going to do for the

resident in exchange for the resident paying their money. This may be as simple as stating that the nursing home shall provide the services required by law, or that the facility shall provide "general nursing care and room and board and other related services...."

The point here is that in even the most draconian (strict/stringent) admission agreements, there remains the obligation of the facility, whether or not it is written in the agreement itself, to provide services in accordance with the law. The law itself has become quite specific in its adoption of "good nursing home practices" to require the provision of interdisciplinary, individualized care in accordance with the written plan of care. Simply stated, the law has been written to enforce good nursing practices that are listed in a written plan of care for ALL residents.

POINTS TO CONSIDER FOR A CARE PLAN CONFERENCE

Developed by:
Robyn Grant, Long-Term Care Advocacy Consultant;
June 2005

(Note: This is not a definitive list!)

Bathing: Is your loved one bathed/showered on days, at times, and in a manner that he or she prefers? Does the frequency of bathing suit him/her? Does he or she receive enough help when bathing?

Toileting: Are staff helping your loved one to the bathroom when s/he needs to go? If your loved one is experiencing incontinence, has a bowel and bladder training program been tried?

Hygiene: Is your loved one kept clean and dry? Are his/her teeth brushed? Or, are his/her dentures clean and in his/her mouth?

Dressing/grooming: Is your loved one dressed in clean clothing that is appropriate to the time of day? Is his/her hair combed? If your loved one is a male, has he been shaved (if that is what he prefers)?

Walking: Does your loved one receive the help he or she needs with walking?

Range of motion (moving the joints): Does your loved one receive range of motion exercises daily?

Positioning: If your loved one spends a lot of time in bed or in a chair, is he or she repositioned at least every 2 hours?

Hydration: Is your loved one receiving sufficient fluids? If your loved one is not able to drink on his or her own or cannot remember to drink, is assistance or cueing provided?

Food: Is your loved one eating well? Is he or she satisfied with the amount of food he or she receives? Are your loved one's food preferences honored? Is your loved one given the help he or she needs to eat? Is your loved one's tray set up for him or her if necessary (food cut up, milk opened, silverware unrolled from napkin, etc.)? Is cueing/encouragement provided if necessary? Has there been any unplanned weight loss? If so, what can be done to address this?

Medications/treatment: Are you aware of all the medications/treatments being given to your loved one? Do any of the medications cause problems or side effects? If so, has your loved one's physician been consulted? Are the medications/treatments having the desired effect? Is your loved one refusing any medications/treatments? If so, what could be causing this? What could be done?

Staff: Are staff friendly? Available when your loved one needs them? Competent? Respectful? Helpful? Kind? Do they know your loved one's needs/preferences? Do they know what care to provide to your loved one and how best to provide it? Is there any staff with which your loved one feels uncomfortable? If so, what is causing the discomfort? How could that be changed?

Activities: Are there any things that your loved one would like to do that he or she is not doing now? Are there any activities that your loved one would prefer not to do?

Room Situation: Does your loved one get along with his or her roommate? If not, what could be done to improve the situation?

Routines/Preferences: Is your loved one allowed to make choices about his/her schedule, how he or she spends her time, what to wear, when to get up and go to bed, when to bathe, etc.?

CARE PLAN CONFERENCE: PREPARATION WORKSHEET

FOR FAMILIES OF LONG-TERM CARE RESIDENTS

Developed by:
Robyn Grant, Long-Term Care Advocacy Consultant;
June 2005

Instructions:

Answer the questions below based on:

- A review of your loved one's most recent assessment (Minimum Data Set – MDS);
- A review of your loved one's current care plan;
- A discussion with your loved one (if possible);
- Your knowledge of your loved one's routines and preferences; and
- Your own observations.

When responding to the questions, remember to include each of the different disciplines involved in the care of your loved one (medical, nursing, social services, dietary, activities and possibly therapy) and all aspects of your loved one's stay in the nursing home. You may also want to think about the questions raised in the handout, "Points To Consider For A Care Plan Conference."

CURRENT ASSESSMENT AND CURRENT CARE PLAN*

1. List any questions you have about your loved one's current assessment and/or care plan.

ADDRESSING YOUR LOVED ONE'S NEEDS

Supporting what your loved one is doing well

2. In what areas is your loved one doing well? (For example, is the resident able to dress him/herself? Is the resident able to walk without assistance?)
3. List any questions you have about any of these areas.

*Ask to review the last completed assessment and care plan a couple weeks before the meeting if you've never seen it or are not familiar with what's on it.

4. What is currently being done to ensure that your loved one continues to do well in these areas?
5. Are these approaches working?
6. Are there any additional approaches that nursing home staff could try?

Assisting your loved one where s/he needs help

7. In what areas does your loved one need help or have problems? (Include new areas that may have arisen since the last care plan conference, as well as ongoing areas. Make sure to identify any areas in which you have observed a decline in abilities or functioning.)
8. List any questions you have about any of these areas.
9. For each area you have identified in #7: What do you think that staff could do to give your loved one the help s/he needs? (This includes approaches that staff are already using that are working and new approaches that you would like staff to consider.)

Supporting your loved one's routines and preferences

10. Identify routines, preferences and interests that are important for your loved one and that have always been a part of his/her daily life (for instance, your loved one might be a "night owl").
11. Does your loved one's day in the nursing home reflect these routines/preferences/interests? (For instance, if your loved one is a "night owl," does staff respect his/her need to stay up at night?)
12. If your loved one's routines/preferences/interests are not incorporated into his/her daily life, what could staff do to make that happen?

ADDRESSING CONCERNS/ISSUES AFFECTING YOUR LOVED ONE'S NURSING HOME STAY

13. Identify any other concerns/issues. (This includes anything that relates to your loved one's life in the nursing home, such as roommate conflicts, relationships with staff, clothing that has disappeared, etc. The care plan is a good time to discuss and resolve problems.)
14. What suggestions do you have for addressing these concerns?

For Long-Term Care Residents:

Things to Think About Before Your Next Care Planning Meeting

It's almost time for your next care-planning meeting. Take some time to think about what information the facility staff needs to know about you to better provide care and services. Below are some questions to ask yourself.

I. Your Life in the Facility

- Are there things you want the facility to know about you that they don't know already? For example:
 - A new hobby or interest
 - Preferences in food or activities

- Are your lifelong routines, preferences, and interests included in your daily life? If not, what can staff do to make that happen?

II. Your Care Plan

- Think about your current care plan. (If you do not have a copy of it, ask for one a few days before your conference.) Is there anything on your care plan you want to change?
 - Is there anything on your care plan you want to change?
 - What change do you want?
 - Why?
 - Are there any specific goals you would like staff to help you accomplish?

III. Concerns

- ❑ What concerns do you have about your care or life in the facility?
- ❑ What can staff do to help with those concerns?

IV. Questions

- ❑ Think about any questions you have that you'd like staff to answer.
For example:
 - Do you have questions about any of the medications you are taking?

V. Attendance at the care plan

- ❑ Is there someone you would like to attend the care planning conference with you? A family member or friend? The long-term care ombudsman?

REMEMBER – THE CARE PLAN MEETING IS ALL ABOUT YOU!!

Be an active participant in the care planning process. Write down, or make a list of, the things you'd like to talk about during your care planning conference. Tell the staff the things they are doing well for you, as well as the areas that you'd like them to change.

The Resident Assessment Process and Care Planning: An Example

An Overview

As you know, the key to achieving quality care for residents is the resident assessment and care planning process. Through an assessment, staff gather information about a resident's life, functioning and needs. This information is used to develop a plan of care focusing on the resident's needs. The resident and family help staff develop this plan. With a proper assessment and care plan that is carried out, the resident receives needed restorative and maintenance services. The result can be a dramatic improvement in a resident's condition.

Still Learning

All facilities are required, by the Nursing Home Reform Law, to provide care to attain or maintain the highest well-being of each resident through use of the assessment and care planning process. Assessment and care planning are an accepted standard of practice. Some facilities are still learning how to conduct assessments and prepare individualized care plans. They're also still figuring out how to help residents and families fully participate in these. Increasingly, consumers like yourself are using assessment and care planning as a forum to ask questions, discuss problems with the care, and identify possible solutions.

The Complete Assessment Process

To help you participate, one example - "Mr. Zentoff" - is followed through the entire process: from the assessment to the care plan. You'll see how Mr. Zentoff's care changes as a result of assessment and care planning. A sample section from the standard assessment form, called the Minimum Data Set (MDS)*, appears on page 53, to show the sort of information

staff will be gathering and reviewing regarding your relative.

As mentioned in chapter 3, the form (MDS) is only one part of the assessment. It leads staff to dig deeper by asking more questions to understand why certain conditions exist. This digging deeper process, or further analysis, is guided by Resident Assessment Protocols (RAPs). In this section, you'll see how the RAPs add to the information on the form (MDS) and help with care planning.

Meet Mr. Zentoff

Mr. Zentoff moves into the nursing home and staff begin to get to know him by asking him and his daughter questions and by observing his abilities. Staff also look at his medical records. This process helps staff complete an assessment form called the MDS. During this process staff learn a lot about Mr. Zentoff.

Mr. Dennis Zentoff, a widower, was admitted to Shady Hill Nursing Facility with diagnoses of diabetes, Alzheimer's disease and a history of high blood pressure. He is eighty years old. He needs assistance with eating, toileting, bathing and has poor balance. The poor balance puts him at risk of falling. He receives a laxative as needed and medicine for high blood pressure.

Mr. Zentoff was a fireman on the evening shift for thirty-two years. After his retirement he kept the same schedule as during his working life. He goes to bed at one o'clock in the morning and gets up at nine a.m. He's used to snacking all day because his meal times never coordinated with his family's when his children were growing up. He has a daughter. His son died twenty years ago. Since his wife died soon after his retirement, he kept to his work day schedule.

He learned to control his diabetes even on that schedule by balancing food, insulin and exercise. For the past eight years he has gotten up at night to go to the bathroom. Otherwise he sleeps well. He was involved in the local boy's club, helping those less fortunate children in his neighborhood. He suffers some loss of

* To obtain a copy of the MDS and a two-page guide, "Assessment and Care Planning: The Key to Good Care," contact The National Citizens' Coalition for Nursing Home Reform, 1828 L St. N.W., Suite 801, Washington, DC 20036 Phone (202) 332-2275, www.nursinghomeaction.org

recent memory which makes it dangerous for him to remain alone. His daughter visits him every week.

You can see how much information about all aspects of Mr. Zentoff's life is collected during an assessment! From this process, staff receive information about Mr. Zentoff's past which help them adapt the facility's routines and environment to support Mr. Zentoff's functioning. By supporting Mr. Zentoff's functioning, staff will also be supporting his quality of life, as you will read in chapter 6.

Wandering Becomes an Issue

While staff are gathering the assessment information, they see Mr. Zentoff wandering around at night. Concerned about his safety, they ask his physician for a sleeping medication. This does make him sleep but his daughter is asking why he seems anxious and lethargic for the first time in his life.

On the MDS form, staff note that Mr. Zentoff walks around the facility at night by marking the MDS under Section E, Mood and Behavior Patterns. Under E-4 Behavioral Symptoms, the staff codes his wandering with a 3 to indicate he wanders daily or more frequently. This triggers staff to look at the Behavioral Symptoms RAP.

If you were Mr. Zentoff's child, you would have questioned the sleeping medication. You'll learn from the information in chapter 5 that sleeping medications are usually restraints. To see how the assessment process guided the staff to discover why Mr. Zentoff wandered all night, read on!

Sample Section of Minimum Data Set (MDS) Form		
SECTION E. MOOD AND BEHAVIOR PATTERNS		
4. BEHAVIORAL SYMPTOMS	(A) Behavioral symptom frequency In last 7 days O. Behavior not exhibited in last 7 days 1. Behavior of this type occurred 1 to 3 days in last 7 days 2. Behavior of this type occurred 4 to 6 days, but less than daily 3. Behavior of this type occurred daily (B) Behavioral symptom alterability In last 7 days O. Behavior not present OR behavior was easily altered 1. Behavior was not easily altered	(A) (B)
a. WANDERING (moved with no rational purpose, seemingly oblivious to needs or safety)		3 1
b. VERBALLY ABUSIVE BEHAVIORAL SYMPTOMS (others were threatened, screamed at, cursed at)		
c. PHYSICALLY ABUSIVE BEHAVIORAL SYMPTOMS (others were hit, shoved, scratched, sexually abused)		
d. SOCIALLY INAPPROPRIATE DISRUPTIVE BEHAVIORAL SYMPTOMS (made disruptive sounds, noisiness, screaming, self-abusive acts, sexual behavior or disturbing in public, smeared/threw food/feces, hoarding, rummaged through others belongings)		
e. RESISTS CARE (resisted taking medications/injections, ADL assistance, or eating)		

Digging Deeper with the Resident Assessment Protocol (RAP)

Each RAP contains three sections of content. Here's how the Behavioral Symptoms RAP would help staff examine Mr. Zentoff's wandering.

I. Problem: describes key characteristics of the problem condition and how this condition affects nursing home residents.

For Mr. Zentoff, staff see that Section I of the Behavioral Symptoms RAP describes the potential dangers of "wandering behavior" and explains why it's important not to use physical and chemical restraints but to find individualized approaches to address "behaviors."

II. Triggers: alert staff to the resident's potential problems or needs.

Triggers guide staff in reviewing the parts of the MDS that trigger the RAP. This section describes symptoms to help staff determine if the resident needs further assessment in this problem area. Triggers relate symptoms to possible causes!

Section II triggers the staff to look at the potential link between medications and behaviors and guides the staff to look for underlying causes and possible solutions.

III. Guidelines: facilitate an assessment of factors that may cause or contribute to the triggered condition. The Guidelines also suggest potential interventions to address the problem.

Section III asks staff to observe the behavior to determine any patterns and to review potential causes of the behavior. Staff knew that Mr. Zentoff's wandering occurred at night. A sleeping pill had been prescribed for this reason before the assessment was completed. Since this RAP asks about changes in familiar routines, staff talked with Mr. Zentoff and his daughter about specific aspects of his daily routine prior to admission. The staff also reviewed the information on the entire MDS, checking for information that might be related to Mr. Zentoff's wandering during the night. If staff can determine how to restore some of Mr. Zentoff's familiar routines, he would no longer need the medication or "behave" in ways that concern staff for his safety.

It's through the RAPs that the process of trial and error begins as the assessment team seeks to determine potential causes of conditions that were identified on the MDS. Once the causes are known, solutions can begin. *Thus, the RAPs are the primary link between the MDS and care planning.*

By the time a RAP is completed, the facility should have information and ideas for addressing the need identified on the care plan. If the review of the RAP indicates a potential for rehabilitation or that a resident is at risk for developing a problem, staff can pick up some ideas to help from the RAP.

The RAPs are also an educational resource for staff and consumers. You might use the RAPs to learn what the facility needs to consider in understanding your relative's condition. The RAPs can give you ideas for approaches to suggest in care planning. The staff, or the ombudsman, can get you the RAPs if you want to read one or more of them yourself. The MDS and RAPs are also available via the Internet on the Centers for Medicare and Medicaid Services web site, <http://www.hcfa.gov>. So, how does this assessment information lead to a care plan? How is this information used on Mr. Zentoff's care plan?

Developing Mr. Zentoff's Care Plan

Look at one example from Mr. Zentoff's care plan: *the need to maintain his ability to walk independently in spite of his unsteadiness on his feet.* Staff put a great deal of thought and discussion into identifying the problem and developing individualized approaches to keep Mr. Zentoff walking independently. The problem identification and the approaches are based on information obtained during the assessment process. Mr. Zentoff's *customary routine* as well as his *preferences* were used to *individualize* the care plan and to guide staff in adapting to his needs.

Mr. Zentoff was included in the care planning process. He indicated to the nurse assistant that he felt adrift in the institution and didn't know what to do with himself. The staff suggested a care planning goal of keeping him safely mobile. Mr. Zentoff agreed with this goal, saying he wanted to be as independent as possible. At the care planning meeting a number of options were discussed including gardening, exercise classes, a walking program or rounds with the security force. He chose the rounds with security; he could use his keen eye to look for fires.

An *interdisciplinary team* was used. A physical therapist was asked to assess Mr. Zentoff's mobility in order to strengthen his unsteady gait and to provide for daily exercise. The therapist decided Mr. Zentoff didn't need therapy but that he did need to be encouraged to walk daily. Thus, Mr. Zentoff went on rounds with the security guard. The latter decision was made with input from the activities director, the nurse, the social worker, physical therapist, nurse assistant on the evening shift, the security guard, and Mr. Zentoff.

Including the *nurse assistant* in the care planning discussion was a key ingredient in the team's ability to develop a successful care plan. Outside of relatives and friends, the evening nurse assistant was the person who knew Mr. Zentoff best. Usually it's the day aide, but Mr. Zentoff was a night owl, so the evening assistant was included. She was the one who knew what his job had been and realized that putting him to bed at 8:00 would be traumatic and against his lifelong habit. Nurse assistants on all shifts were consulted to identify strengths and needs occurring throughout the twenty-four hour period.

If you're wondering what a care plan looks like, see the example below. The care plan might look different in your relative's nursing home because different facilities have various kinds of forms they use for care plans. The form is not important: the information on the form is very important. The care plans in all nursing homes should contain the elements described in the next section. Look how clear Mr. Zentoff's plan for walking is.

Mr. Zentoff's Care Plan for Walking

Need: Maintain Mr. Zentoff's ability to walk

<u>Goal</u>	<u>Approaches</u>	<u>Disciplines</u>	<u>Re-evaluation</u>
Mr. Zentoff will walk the length of the building three times at least five days a week.	Walk on evening rounds with security guard on all three floors at least five times a week. Security guard and Mr. Z. will report to evening nurse assistant.	Nursing Security guards Activities Physical therapy	October 25 (2 weeks)

Elements of This Care Plan

- The care plan *need* is to maintain current functioning. It has a prevention focus.
- The *goal* is specific, measurable and written in a way that anyone can understand.
- The *approach* shows respect for the resident. It's individualized and reflects ideas from many disciplines. The actual days on which Mr. Zentoff is to walk are not specified because he should have choice and flexibility. He might want to walk more often than five times a week. It is clearly the responsibility of the evening nurse assistant to see that the walk is accomplished.
- *Disciplines* (operating departments) involved are spelled out in the plan.
- The date for *re-evaluation* is clear.

Other facilities would individualize Mr. Zentoff's care plan in the following way*:

<u>Need</u>	<u>Goal</u>	<u>Approaches</u>
I need to walk.	I will walk the length of the building three times at least five days a week.	I am used to working at night. The security guard will ask me to walk on rounds with him every evening. I can help him check all three floors of the building. I will be watching for fires on our rounds. We will report to the evening nurse assistant who works with me.

Individualized Care

As a result of the resident assessment process and care planning, Mr. Zentoff receives care tailored to meet his needs and compatible with his lifelong routines and preferences. His care plan guides the staff in assisting him as described below.

Nurse assistants cue him to eat, dress, bathe, and use the toilet before retiring as he has always done. He goes to bed at his customary time and gets up late, missing breakfast. He gets his protein and vegetables at meal times and fills in the rest of his food in divided amounts during the day and evening. He takes only insulin and blood pressure medicines. He doesn't require sleeping pills or laxatives. He gets up, with the assistance of a nurse assistant, to use the bathroom at night. He spends his days socializing with other residents and the staff. Mr. Zentoff goes on evening rounds with the security staff.

* Adapted from a model developed by Susan Misiorski and Lynn MacLean, Apple Health Care, Inc., Avon, Connecticut.

*Together We Can ...
Achieve Resident-Directed Care*

Section III.

Individualized Care

Residents' Rights Week 2005

Residents' Rights Relating to Individualized Care

42 CFR 483

The care plan meeting and care planning are the best ways to help staff individualize care for each resident.

Residents have the right to accommodation of individual needs and preferences

Each resident has the right to a comprehensive assessment of his/her needs

Each resident has the right to care and services to attain or maintain his/her highest practicable level of well-being

Residents have the right to participate in the planning of their care and treatment or changes thereto

Residents have the right to choose a personal attending physician

Residents have the right to be fully informed in advance about care and treatment and any changes in that care and treatment

Residents have the right to be cared for with dignity and respect and in full recognition of their individuality

Residents have the right to choose activities, schedules, and health care consistent with their interests, assessments, and plans of care

Residents have the right to make choices about aspects of their life in the facility that is significant to them

THE BASICS OF INDIVIDUALIZED QUALITY CARE

Consumer Fact Sheet No. 16

August 2005

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 NCCNHR).

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.

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 21st 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.

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*).

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

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

Need	Goal	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*).

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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.

Before the care plan meeting you and your mother think about her routines and review the quality of care basics. Your mother's individualized care plan for the first four weeks might say:

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).

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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, nasogastric, 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 called *Aspiration Pneumonia*.
- 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).

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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

Basic Quality of Care Practices for 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).

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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	Long-Term Goal: I want to return to my home for my birthday on June 1 st . Short-Term Goal: "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).
		"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). "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) "My right hand feels better when I am grasping a big rolled towel" (CNA/N).

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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

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. \$11.95 plus \$3.00 shipping and handling.

Nursing Home Staffing, by Sarah Greene Burger and NCCNHR Staff. 2002. A guide for residents, families, friends, and caregivers. \$7.50 plus \$3.00 shipping and handling.

Residents' Rights Week Packets from previous years are available through NCCNHR. See www.nursinghomeaction.org for pricing and ordering information.

NCCNHR Consumer Fact Sheets available at www.nursinghomeaction.org include:

Resident Rights: An Overview
Care Planning and Assessment
Residents' Rights in Nursing Homes
Neglect and Abuse
Restraints
Involuntary Discharge and Transfer
Assessment and Care Planning: The Key to Good Care
Consumer Guide to Choosing a Nursing Home
Individualized Assessment for Residents with Behavior Symptoms
Access and Visitation in Nursing Homes
Family Involvement in Nursing Home Care
Malnutrition in Nursing Home Residents
Long-term Care Resources on the Internet

Order NCCNHR Consumer Fact Sheets and publications from:
National Citizens' Coalition for Nursing Home Reform

1828 L St. NW, Suite 801, Washington, DC 20036, (202) 332-2275, <http://nursinghomeaction.org>

"I Want To Tell You About My Mother..."

A Guide to Providing Helpful Information to Nursing Home Staff

Developed by Carter Catlett Williams, MSW, ACSW, Consultant

When a person enters a nursing home an important and valuable part of the experience is to talk to staff about herself and what life has been like. However, many individuals may have to rely on their families to give such information for them.

All of us have the stories of our relatives' lives inside us. These stories are so much a part of us and our own lives that we hardly know where to begin. We aren't used to stepping back a little to see our parents' lives in their wholeness. We're more used to exchanging much-loved anecdotes about mother, father, aunt, or uncle, in family gatherings.

To introduce your relative to nursing home staff, helping them know who this person is, is one of the most important things you can do! It will rescue your relative from the limbo of being in strange surroundings where *"nobody knows who I am."* It'll make all the difference in staff understanding your relative's actions and responses because they will know some of the thoughts, feelings, habits and life experiences that lie behind those actions and responses.

But where to start and what to include? There are the easy-to-recite concrete facts that the social worker, or other staff, will request at admission time. Then there is your relative's unique life story that you'll want to be sure the staff knows as well. Both are necessary for staff to come to know your relative. In addition, this is the appropriate time to describe to staff what kind of day makes a good day for this particular person.

To illustrate the type of information you'll want to give staff, look at the following outline. It might give you ideas about other details to include. *Assume your mother is being admitted.*

Facts: Tell about your mother's:

- Birth date and place

- Number of sisters and brothers; where your mother falls in the birth order; number of sisters and brothers still living

Source: *Nursing Homes: Getting Good Care There*, by Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank

Rural or urban childhood
Your mother's ethnic community
Schooling
Marriage and date of marriage
Children
Employment outside of home before and after marriage
Religious affiliation
Hobbies
Date of divorce or widowhood
Living arrangements during marriage and afterwards
Reason for entering the nursing home

Story: A person's story includes hopes, aspirations, and accomplishments, as well as disappointments, losses, and the things that didn't go so well. It includes the person's characteristic ways of handling the ups and downs of life. Here are some suggestions to help you think over your mother's life and tell her story.

What she looked forward to in life: as a child, as a teenager
How much she was able to realize her dreams
If she had a career outside home and family, what the career meant to her
How she and her family coped with the Great Depression of the 1930's
How World Wars I and II affected her life, as well as the Korean and Vietnam wars
What she wanted for her children
Her relationships with her family
Whether religious faith was important to her and how she expresses that: prayer, reading scripture, attendance at church, synagogue, or mosque, volunteer activity, helping others in the community
What she had, and now has, the most fun doing: cooking for the family; hosting family gatherings; gardening; singing; reading; fishing; playing bingo; handwork; going to the movies; sports as a player or spectator; enjoying nature; seeing family and old friends
Whether she likes to crack jokes or enjoys other's jokes
How she handled money
Whether she had pets and what they meant to her
What angers her
What pleases her
What saddens her

Source: *Nursing Homes: Getting Good Care There*, by Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank

What comforts her
Whether she generally has an optimistic attitude or tends to see more
the dark side of things
Her major satisfactions and disappointments
What she values most in life
What you value most about her
To add further richness to your mother's story, collect photographs in
an album for her room and take others to hang on her walls.

What Makes a Good Day for your mother, covering:

Daily schedule

When she likes to get up and go to bed, times of rest and quiet

How she prefers to spend her day

What her mornings and evenings are like at home

Times of her favorite radio and/or TV programs

When and what she likes for snacks

When and how often she likes to go outside

Her usual bowel and bladder patterns

Her patterns with: bathing, eating, and food preferences

The particular things that give her satisfaction and pleasure

Particular foods at certain meals

Careful grooming in the style she prefers

The chance to be alone at least some part of each day

Activities she enjoys: music, movies

Attendance at worship service or other expression of her faith

Where she prefers to place things in her room and at her bedside

How she typically expresses affection and is comfortable receiving
affection: hugs? kisses? touching?

Remember no detail is too small if it's significant to your relative!

- **For Men:** If your relative is a man, the same type of information as previously listed is equally important. In addition, you need to be sure that activities and the response of staff consider things from a man's perspective. More physical outlets or more traditionally masculine pursuits might need to be offered for your relative.

My Personal Directions for Quality Living

Name: *Alice H. Hedt*

Date: *June 16, 2005*

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:

Reading, especially biographies. Going out to eat. Spending time with my friends and family. Movies. Playing some board games. Politics. Manicures, pedicures, massages. Visits – especially from my church family and NCCNHR colleagues and friends. Communicating by e-mail. Learning about other countries and cultures. Concerts. Plays.

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.

This form was developed by the National Citizens' Coalition for Nursing Home Reform to encourage communication between those of us who might need care and those who will be providing the care. Please adapt this tool to express your personal preferences, requests and wishes. Be sure to give a copy to your family members and/or trusted friends and talk with them about what you have written.

**National Citizens' Coalition for Nursing Home Reform
1828 L. Street NW, Suite 801
Washington DC 20036
<http://nursinghomeaction.org> 202-332-2275**

My Personal Directions for Quality Living

Name:

Date:

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:

The way I like to awaken & begin my day:

The way I relax and prepare to sleep at night:

Activities I enjoy:

Things that I would like to have in my room:

Foods that I enjoy:

For comfort:

For fun:

Other:

Things I do not like:

I become anxious when:

Things that calm or soothe me:

Things that make me laugh:

Religious preferences:

Other:

At the end of my life, I would like:

For more information about me please talk to:

This form was developed by the National Citizens' Coalition for Nursing Home Reform to encourage communication between those of us who might need care and those who will be providing the care. Please adapt this tool to express your personal preferences, requests and wishes. Be sure to give a copy to your family members and/or trusted friends and talk with them about what you have written.

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Chapter 1

Individualized Care

You haven't lived 'til you've gone to the toilet on somebody else's schedule!"

— told by a nursing home resident to Carter Williams

YOU'LL RECALL THIS SCENE FROM THE INTRODUCTION:

"Help me... please help me," Rose heard as she hurried to her mother's room. She found her in distress.

"Help me, please," her mother begged. "I've dropped my shoe and I can't reach it. And now I can't get back up."

Rose asked an aide for help, and together they straightened her mother in the chair. As her mother calmed down, they began their daily visit.

On the way home that evening, Rose resolved to talk with the staff about her concerns, as she had on earlier occasions, with help from the local long-term care ombudsman. The staff had responded with some important changes in their approach to her mother's care. Mrs. Beck had lived at the home for six months. Her Alzheimer's disease had progressed rapidly since her admission, and she often acted upset. She had hit staff members, and even spit a time or two - very unlike her mother. Staff confined her to her geri-chair (a wheelchair with a tray in front) for "safety."

Life Before the Nursing Home

Rose recalled telling the ombudsman about her mother's typical day at home. "Mother loved to stay up late with a good book, a warm blanket, and a hot glass of milk. She'd often have a hot bath first and then sit in her favorite chair till one in the morning, reading. She was a late riser, usually not getting up until ten or so. She wasn't much for conversation or activity in the morning. Oh, and her favorite breakfast was a bowl of ice cream!"

Source: *Nursing Homes: Getting Good Care There*, by Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank

INDIVIDUALIZED CARE

Life in the Nursing Home

Rose compared this pattern with life-for Mrs. Beck at the nursing home. Here the routine was to get up at 7, and to be ready for a full breakfast at 8. Next came the procession to the shower so everyone could be dressed and presentable before lunch. Sure enough, incident upon incident documented by staff had occurred in the morning, when Mrs. Beck was too sleepy to be handled and too confused to say "no" in words. So she struck out and was labeled a "behavior problem." Staff, already overworked, didn't have enough time to respond each time she called out for help.

The situation was easily resolved by adapting the daily routine to her mother's needs. The Activities Director arranged for largeprint books, the Charge Nurse adjusted the schedule for bathing and personal care, and the Social Worker helped other staff learn how to defuse situations when Mrs. Beck became upset. "But now here we are again," Rose thought. "Time for another meeting with the staff. We need to get this new situation straightened out." She saw that the aides were so busy "getting the job done" that they had become dulled to such frequent cries for assistance.

Attention to Individuals

You too may have heard someone crying out for help as you visited a nursing home. Perhaps you, like Rose, were told, "Oh, she does that all the time. You can just ignore her." Too often staff are so strained that they draw a mental curtain to tune out the cries.

As a family member, you can talk with staff about ways to respond to your relative that can be soothing for her and can provide the help and human contact she needs.

Hesitant? Of course. It's natural to feel unsure of yourself in such a situation. The staff are working hard, often rushing from one crisis to another without time to question what they're doing. That's why it's so important to call staff attention to situations that they no longer notice. Although staff may be working hard, good

care requires that they have the time to respond to residents' pleas for assistance.

Quality care involves caring for the resident's human spirit as well as her physical health. Nurses, doctors and other health care workers have come to recognize that some of their old approaches to care - restraints, for example actually do more harm than good. For a long time, nursing

homes and state regulatory agencies focused more on immediate efforts to provide "safety," not realizing that short term, stop gap, "safety" measures often have long term negative effects on residents' physical and emotional well-being.

Quality care involves caring for the resident's human spirit as well as her physical health.

What Would You Want if You Were in a Nursing Home?

To examine what good care is, it's important to think about what you would want if you lived in a nursing home. For most people, it's a difficult scene to imagine.

Why? Is the idea of being so sick troubling? Is it fear of dying? Certainly these feelings are natural. But there's something even more unsettling about imagining yourself in a nursing home: *the fear of losing control or independence*. Most people are frightened at the thought of losing their independence as they grow older. Yet some physical and mental decline and increased dependency are inevitable with age.

You may spend part of your own life in a nursing home, so when you think about what nursing homes should be like, pay attention to your own needs and preferences. Doing so will help you better understand what people living in nursing homes are feeling.

Begin by asking yourself, "What if I were to enter a nursing home today? What would I want a nursing home to be like to feel okay about living there?"

Does your image of an acceptable nursing home include being treated with dignity, respect, recognition of your individuality? Would you expect compassion, privacy, choice over aspects of daily life in the nursing home? If so, you share a lot in common with thousands of others across the country who have answered this question.

What Do Residents Say?

As part of a national study, the National Citizens' Coalition for Nursing Home Reform (NCCNHR) asked residents about their views on quality care. Groups of residents in nursing homes in fifteen cities across the United States gave their definition of quality care. The primary factors they listed were:

- treatment with dignity and respect;
- self-determination and the opportunity to make choices about their daily lives; and
- kind, caring staff who regarded them as individuals.

In the years since the study was conducted in 1985, the National Citizens' Coalition has posed the same question - "How would you define quality care if you lived in a

nursing home?" - to advocates, family members, nursing home staff and government officials throughout the country. Consistently, respondents say they want to have their individuality

The basic human need to continue "being who I am" is perhaps the most important need of anyone living in a nursing home.

supported and respected. The basic human need to continue "being who I am" is perhaps the most important need of anyone living in a nursing home.

You might be surprised to learn that *supporting individuality* for each resident has become the standard of care.

In the past, many nursing homes did too little to truly support individuality among residents. Throughout this book, you'll discover how and why this is changing, how staff are helping residents feel more at home. To better appreciate what moving into a nursing home is like from a resident's perspective, read on!

From Home to... Homeless?

The losses most people experience as they go from their own homes into nursing homes are enormous. It's traumatic to make the transition to nursing home life. There are lots of losses that bring about such a move. There are also losses that come because of the move.

Increasing mental and/or physical frailty forces a person to leave the last vestiges of independence and turn to a nursing home - possibly for the rest of his life.

Think about the word "home." What does it mean to you? Do you have warm feelings and images? Are you thinking about family? Security? A place where you can kick your shoes off and be yourself?

Think about how you feel as a guest in someone else's home. Remember what it's like when it's not your kitchen? Not your bathroom? Not your special chair in the living room? Do you breathe a sigh of relief at the thought of the trip's end and your return home?

Multiply that feeling by 365 days a year, and you'll sense the perpetual anxiety and tension - as a permanent "guest" - felt by most nursing home residents. In 1990 nurse Judith Carboni* found a correlation between the experience of living in a nursing home and the experience of homelessness. All the ways that *home* represents connection, safety, security and privacy are not easily available to nursing home residents. Home is an important link to identity - connection to people, places, events in our lives. Look around your home and see all the reminders you've accumulated.

Nursing home residents experience disconnection and loss of identity. Residents may try to cling in their minds to their own identities and their pasts. But, instead of feeling secure, they feel anxious; instead of privacy they feel constantly exposed and vulnerable.

One major loss of the feeling of home is loss of daily routine. We all develop ways of living that provide comfort and help us function - our ways of handling stress, our social outlets, our interests and our pursuits. It could be talking with a friend, watching sports,

"You haven't lived 'til you've gone to the toilet on somebody else's schedule!" things people have been expected to sacrifice when entering a nursing home. Under current standards, however, nursing homes are now expected to support each resident's life patterns. (Reading chapter 2 on residents' rights and chapter 6 on quality of life will show you how things can change.)

"You haven't lived 'til you've gone to the toilet on somebody else's schedule!" That's how one elderly resident described her life in a nursing home to social worker Carter Williams. Residents'

* Carboni, Judith (1990). "Homelessness Among The Institutionalized Elderly." *Journal of Gerontological Nursing*, 16 (7) 32-37.

daily needs become staff tasks. Take a few moments to consider - from a resident's perspective - the basic routine of bathing.

Joanne Rader*, a nurse in Oregon, studied bathing in nursing homes for people with dementia. To begin her research, Rader decided to be given a shower as residents are. Her staff was taken aback by her request. "Oh my, you're brave!" they said. They believed showering her would feel awkward and embarrassing. In fact, it did, even though staff used a skillful and caring manner.

Nurse Rader experienced being wheeled through the hallway with a sheet wrapped around her, then hoisted and handled, sprayed by gushing water, all the time surrounded by cold metal. Throughout, she had the feeling of being exposed and cold and embarrassed. No wonder people with dementia are apt to become agitated during a bath, she mused. Their agitation probably is not so much an inevitable part of nursing home life as it is a predictable reaction to a stressful experience!

Clinicians find that agitation can be soothed if nursing homes are less like institutions and more like home. Nursing homes can be more home-like by respecting residents'

individuality. Home routines can be adapted to accommodate individuals, rather than asking people to fit into institutional schedules for toileting and eating and bathing - for the convenience of staff.

Agitation can be soothed if nursing homes are less like institutions and more like home.

Putting the "Home" Back Into Nursing Home

The 1987 Nursing Home Reform Law, often referred to as "OBRA '87" because it was part of that year's federal Omnibus Budget

Reconciliation Act, motivated many nursing homes to rethink their approaches to care. Born from ardent

Facilities save money by giving good care

concerns and grassroots action by consumers and pioneering health care professionals, the law helped turn the concept of caregiving around. In the days before the law, residents were told to "adjust" to the nursing home's daily routines. Now the law asks nursing home staff to adjust to residents' daily routines.

* Rader, Joanne (1995). "Individualized Approaches to Care." Norwich, CT: *Breaking the Bonds Conference*, June 21.

Although we are a long way from completing this change in thinking but we have made progress. Forward thinking nursing home staff have always approached care in a way that supports individuality. As laws have changed and staff see the benefits of responding to residents' individual needs, many practitioners are learning new approaches to care.

TIP: Administrators of nursing homes who have decided to change routines and accommodate individuals have found they can do so with the same staff and resources and find that it is even more cost effective to do so. The bottom line: *facilities save money by giving good care!* This was documented by

Catherine Hawes of the Research Triangle Institute in 1995.* As professional staff have begun to change practice, there has been an overall improvement - nationwide - in residents' physical and mental functioning. However, nursing homes need enough staff so that staff can take the time to get to know residents as individuals. Working regularly with the same residents also helps staff individualize care.

As consumers begin expecting nursing homes to act differently and supporting nursing homes in new ways of working, change will continue.

The federal law brought a new philosophy based on two very

- important requirements: *Quality of Care* and *Quality of Life*.
- Quality of Care means nursing home residents should get better whenever possible, should maintain the highest possible level of physical, mental, and psychosocial functioning, and at the very least, should not get worse because of the care received from the nursing home.

The *quality of care* requirements include activities of daily living, such as eating, bathing, dressing and walking. They also involve such matters as skin condition, continence, range of motion and psychosocial well-being. In all these areas, *residents should not get worse unless their decline is medically unavoidable*. This means that a

*Hawes, Catherine (1995). Statement for the Forum on Republican Medicaid Proposals to Repeal Access to Affordable Quality Nursing Care. Washington, DC: Democratic Policy Committee (Senators Byron Dorgan, Edward Kennedy, David Pryor, Paul Sarbanes), October 6.

resident who could walk when he entered a nursing home should still be able to walk now, unless suffering a progressive disease that makes it increasingly impossible to walk, or experiencing a new debilitating problem, such as a stroke.

Too often, family members think, or are told, that a resident's decline is the inevitable effect of old age. This may not be true. While some conditions develop as people age and face illnesses, proper nursing and medical interventions can usually stop or slow the decline. Therapeutic and preventive services *do* make a difference. Older people *can* regain their mobility and function after a stroke, a fracture, or other health trauma.

When residents don't get enough exercise or food that's appealing to them, or assistance to continue activities that interest them, they decline. Such declines aren't a natural result of their medical condition, they are the result of *improper care*. They are avoidable, in some cases reversible. (More about quality of care in chapter 4.)

• Quality of Life, as defined in the law, means the nursing home must make reasonable accommodation for the individual needs and preferences of residents. Residents have the right to make choices about their daily schedule, health care, activities and other aspects of life in the nursing home that are meaningful and significant to them.

Just as residents should not get worse physically because of the care they receive, so they should not decline emotionally because of life in the nursing home. In her study, nurse Carboni (footnote, page 12) found that residents responded to a sense of homelessness by retreating into psychic despair, losing touch with the painful present, and exhibiting confusion and withdrawal. The loss of reasoning ability, depression, or other confusion that many residents already experience worsens their sense of homelessness.

The typical effects of depression are social withdrawal, loss of appetite, loss of sleep, confusion, weakness - many of the conditions typically found among nursing home residents. But it's important to remember that - as happens with poor quality of care - such declines don't always result from a resident's medical condition. Rather, they are a resident's natural reaction to losing a

sense of self. These reactions, too, are avoidable, reversible. Attending to a resident's individual needs and making adjustments so she feels at home can help restore emotional wellbeing. (Read chapter 6 to learn about supporting quality of life for your relative.)

Assessment and Care Planning

The main vehicle you have to help your relative is the process of *assessment and care planning*, in which you'll participate in care decisions and helping the home support your relative's preferred life patterns.

Nursing homes must conduct an assessment of each resident. This evaluation is the basis for planning that individual's care. Just as it's necessary to look at a map to plan your route before you head out on a trip, assessment and care planning are meant to give staff direction in working with each resident. (You'll learn more about assessment and care planning in chapter 3.)

Good care planning and assessment can improve nursing home services. That's good practice, and that's the standard of care throughout the nation.

How Are the Standards Enforced... Or Are They?

You might be wondering why you don't see more personalization of care in nursing homes if this is the standard. Nursing homes are still learning how to do things differently, and consumers are still learning to expect better care. Low-staffing makes it difficult for nursing homes to provide the quality care required of them.

The government enforces the quality care standards through regular inspections, called *surveys*, to determine how well each nursing home meets the requirements. Surveyors observe care and ask residents and families about life at the home to determine whether the home meets the standards of practice as defined by OBRA.

The home receives a survey report explaining which aspects of the home are in compliance with the law, and which are not. This report is available in the nursing home so any visitor can review it. Sections of the survey report and information comparing facilities are available on the Internet at <http://www.medicare.gov/Nursing/Overview.asp>.

If a home doesn't follow the good standards of practice, it can be directed to make corrections immediately. The government can also issue fines, stop admissions until problems are corrected, regularly monitor the home to see that the corrections are made, or close the home.

But even with all these enforcement tools at its disposal, the government's ability to hold nursing homes to a good standard of

care remains limited. Surveyors cannot be at the home all the time. They see only a snapshot of daily life when they are there.

What's more, budgetary constraints may make it less likely that government agencies will be able to visit as often and regulate as actively as they have in the past. Indeed, the law itself sometimes comes under attack in the Congress.

And that's where consumer advocates come in. Ombudsmen and families advocating for good care can be just as important in supporting good care as the government's regulatory role. As family members press the standards in the law in discussing care needs and approaches with nursing home staff, the law serves its intended purpose - as a tool for improvement in conditions.

You Are the Link to Better Care

Your first step toward good advocacy is to *continue to relate to your family member as you always have*. Nursing home residents often lose a sense of who they are because no one knows them. You're the link to the past, to your relative's identity. You can reinforce your relative's identity in your interactions with your relative and with staff.

Your second step is to *trust and act on your instincts*. Nursing home care is about taking care of human beings, people who have lived long, full lives and now need help in their last years. Because you know your relative, your insights are as important as the staff's skills. Together, you can help provide the care your relative needs.

It's natural to feel that if you bring concerns to the nursing home staff you will "rock the boat." Perhaps you might think: "This is what nursing homes are like." You might hesitate to speak up because your dad "has to live with the staff after I leave." Yet there are ways of bringing concerns to the staff that can make a big difference. This can be done without putting your parent at risk.

Many nursing home staff will welcome your constructive input. Remember that silence only allows problems to continue. If staff don't know your concerns, how can they address them? Chapter 7 offers guidance on bringing your concerns to the staff.

Third, *know your rights*. Then, you can act. It isn't easy. The perception among many people is that the nursing home knows how to take care of your Mom or Dad. If you determine that the facility isn't living up to your expectations, know that you have a right to voice your grievances, you and your relative have a right

to participate in making decisions about care and daily life, and that you have a right to get help from the ombudsman program if you can't work things out directly with the nursing home.*

Fourth, take comfort in the fact that *laws, regulations and professional standards of good nursing home practice are on your side*. They provide clear requirements for nursing homes to respect residents' dignity and to provide compassionate, individualized care.

Finally, know that the laws work and care is better because of it. Nursing homes have improved their care over time. Through careful assessment, they're identifying each residents' strengths and frailties. They're designing plans of care that support a resident's ability to function. And everyone - staff, residents and families - sees the positive results.

TIPS to Remember

1. Residents in today's nursing home have the same needs you would if you were living in a nursing home - a need for recognition as an individual - a very special individual human being.
2. Without this recognition, residents can feel homeless. This contributes to depression and withdrawal.
3. The best remedy is individualized care where staff get to know each resident and make adjustments in *facility* routines to support life-long *individual* routines.
4. Individualized care is the basic tenet of the standards established by the federal Nursing Home Reform law, and it applies to all nursing homes receiving federal money. It is the new standard of care.
5. Nursing home staff can provide individualized care by assessing each resident and developing a plan of care to meet that person's needs.
6. You can play a role by:
 - Sharing your knowledge of your relative with the nursing home staff; (In Appendix 5 you'll find a list of suggested information to share with staff to help them know your relative.)

* Contact The National Citizens' Coalition for Nursing Home Reform (see Appendix 7) for address of local/state advocacy group in your area.

- Participating in care planning meetings; and
 - Expecting the home to make reasonable accommodations for your relative's individual needs and preferences.
7. Nursing homes need to be well-staffed to provide good care. And government agencies need sufficient resources to enforce the standards of care.

— All laws are subject to change. Regardless of any changes in the federal law discussed in this chapter, these standards are supported in some state laws as well as professional codes of conduct. They are good practice! They represent good care! As a family member you have every right to ask for and expect these practices for your relative.

*Together We Can ...
Achieve Resident-Directed Care*

Section IV.

Training Materials/Activities

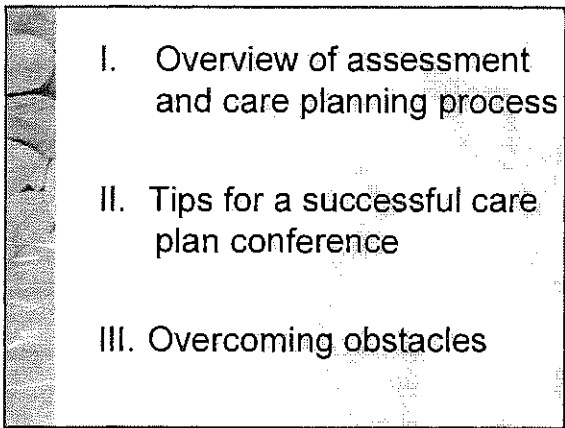
Residents' Rights Week 2005

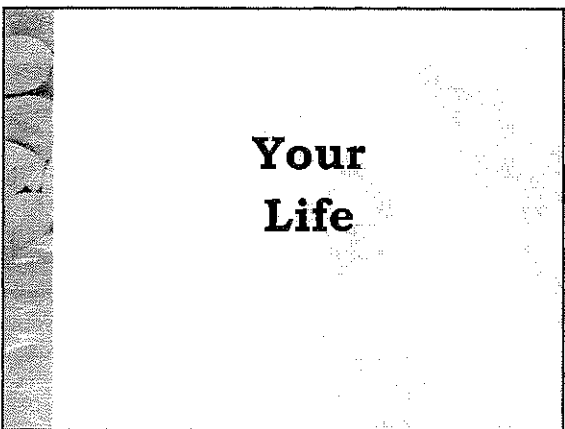
Care Plan Conferences: Making Them Work

Developed by:
Robyn Grant
Long-Term Care Advocacy Consultant
Indianapolis, IN
June 2005

Shared with Permission








Platinum Rule

"Do unto others as they would
have done unto them"

Care Plan


A "road map"

I. Overview of assessment & care planning process



Care Plan Foundation:


The Resident Assessment



Resident Assessment

*Identifies:

- Resident's strengths, abilities
- Areas where resident needs help or has problems
- Resident's routines, preferences



Minimum Data Set (MDS)

Required assessment form

See Family Caregiver Manual p.28

MDS

* Looks at many aspects of a resident:

- * Physical functioning
- * Psychosocial well-being
- * Skin condition
- * Continence
- * Cognitive patterns
- * Customary routines

MDS

- * When is it completed?
- * Who completes it?

What can you do?



- * Share information about your loved one with staff
- * Example:
 - * Resident's life story
 - * What makes a good day for the resident?

Care Plans

*Components:

- *Goals
(needs/problems/concerns)
- *Approaches
- *Target date
- *Responsible department or person

Family Caregiver Guide, p. 50

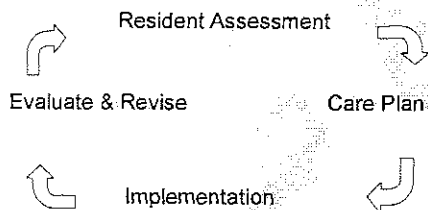
Sample Care Plans: Handouts

Pioneer Practices:

- *"I-Centered" or "Person-Centered"
Care Plans

A Good Care Plan:

- *Has specific, measurable goals
- *Is individualized
- *Is written in language that everyone understands
- *Changes over time!!



Developing a care plan

- *Developed at a care plan conference
 - *Held at least quarterly and upon request
 - *Attended by staff from different departments
 - *Residents and families have the right to participate

News Flash!!

*Resident or family member (if resident's decision maker) is in the driver's seat:

*You can say yes or no!!

What a care plan conference should look like

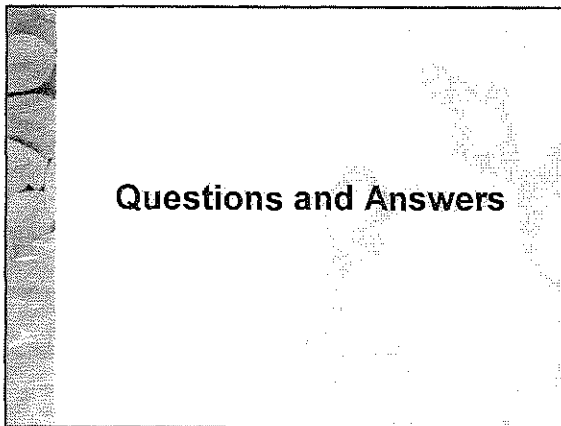
What a care plan conference should look like

*Sharing of information

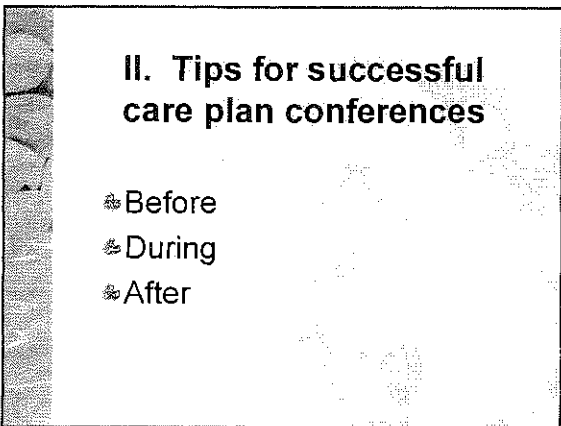
*Dialog - discussion

*Questions

End result: agreement about what will be tried

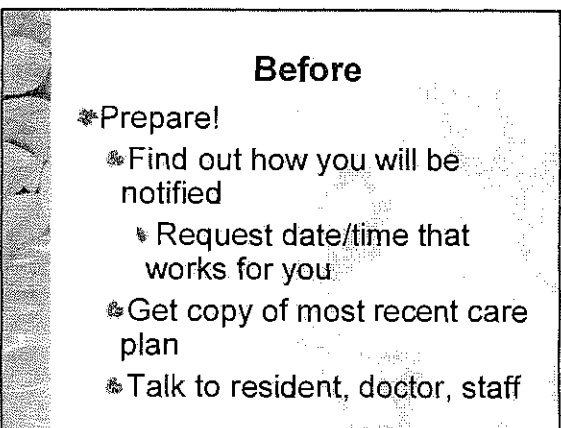


Questions and Answers



II. Tips for successful care plan conferences

- ✿ Before
- ✿ During
- ✿ After



Before

- ✿ Prepare!
- ✿ Find out how you will be notified
 - ✿ Request date/time that works for you
- ✿ Get copy of most recent care plan
- ✿ Talk to resident, doctor, staff

Before

- ✳ Request presence of key staff members
- ✳ Ask for amount of time you think you need

Before

List issues, concerns, questions

- ✳ Complete Care Plan Conference Preparation Worksheet (handout)
- ✳ Share with staff prior to meeting
- ✳ Prioritize if many concerns

During

- ✳ Have someone with you if you can
- ✳ Take notes
- ✳ Try to involve resident if at all possible

During

***SPEAK OUT**

- Ask questions
- Ask for more information, explanation
- Ask staff to explore other ways, approaches
- Make suggestions
- Be open to trying new things (short-term basis)

During

***Ask:**

- How the care plan information will be communicated to direct care staff
- Whom to go to if there are problems

During (Before you leave)

***Make sure you:**

- Understand care plan
- Agree to care plan
- Summarize changes being made

During

**EFFECTIVE
COMMUNICATION!!!!**

**Communication
Suggestions**

Power of "we"

**Communication
Suggestions**

"I" Statements

• 3 ingredients:

- The action
- My response
- My preferred outcome

Communication Suggestions

- Use of "open" questions
- Avoid "WHY"

Communication Suggestions

Reflective Listening

- Paraphrasing
- Summarizing
- Using a tone that shows warmth, interest

Example- Reflective Listening

Your mother is allergic to dairy products, but these products keep showing up on her tray. You have spoken to the food services supervisor. Things get better for a few weeks, but then the dairy products re-appear on your Mom's tray.

**Example -
Reflective Listening**

Administrator Statement

We've had a lot of trouble with our dietary department lately. We can't seem to keep our food services supervisor for more than a few weeks. You have to understand that we're doing the best we can.

**Example -
Reflective Listening**

Possible Family Member Response

You've had a lot of turnover in your dietary department recently, and you are trying to do what you can.

PRACTICE

"There's no way in the world that approach would work with Mom!!

PRACTICE

Why can't staff ever manage to give my mom her medications on time?

PRACTICE

I am sick and tired of finding my mother wet and soiled every time I come in here on the weekend!!

After the care plan conference

- *Get a copy of revised care plan
- *Monitor implementation
- *Keep notes (a journal)
- *Raise concerns if:
 - *not implemented as called for
 - *not working

**Your ideas for successful
care plan conferences
&
Questions and Answers**

**III. Obstacles
to successful
care plan conferences**

Obstacle #1

We only hold care plan
conferences on Tuesdays and
Thursdays at 10:00 am

Obstacle #2

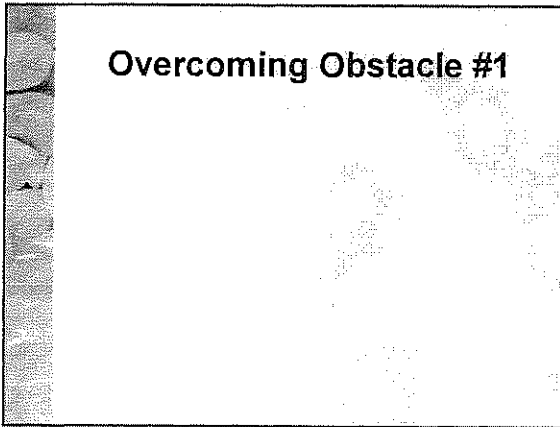
"We can only allow 15 minutes for each care plan conference."

Obstacle #3

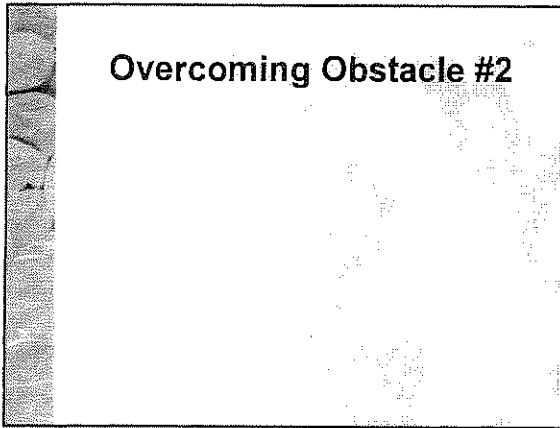
"We can't _____ (for example: give your mother a shower in the morning).
That's not the way we do things here."

Obstacle #4

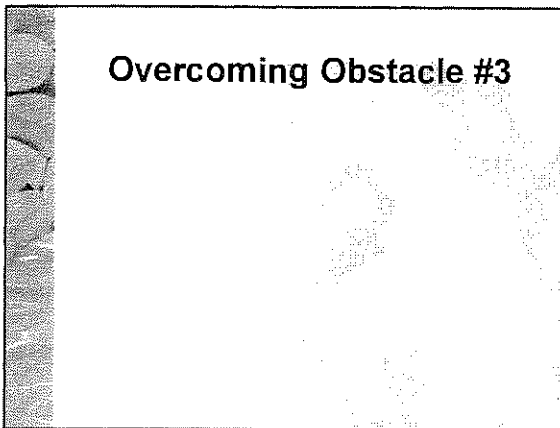
"We know what's best for your mom."



Overcoming Obstacle #1

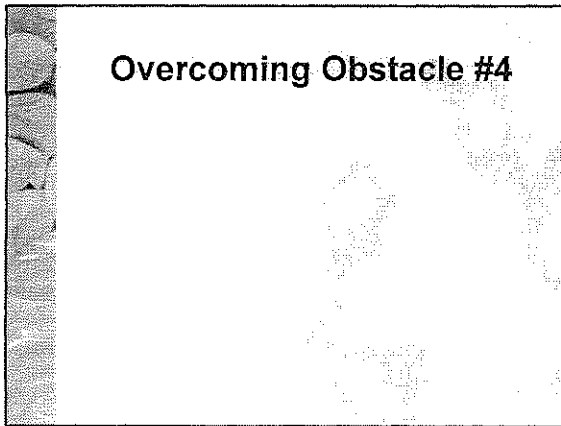


Overcoming Obstacle #2



Overcoming Obstacle #3

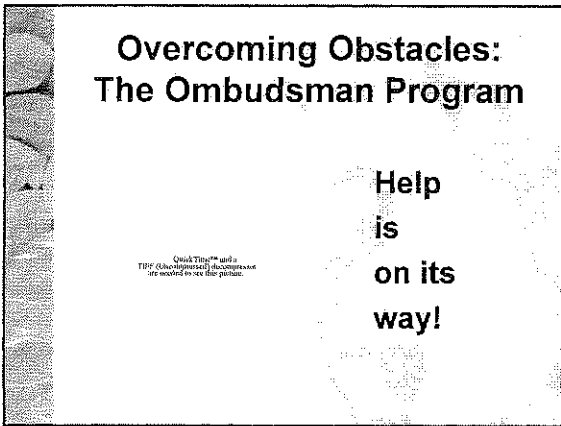
Overcoming Obstacle #4



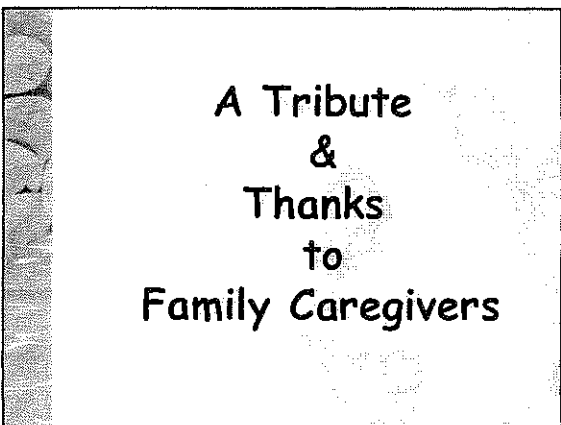
**Overcoming Obstacles:
The Ombudsman Program**

QuickTime™ and a
TIFF (Uncommented) decompressor
are needed to view this picture.

**Help
is
on its
way!**



**A Tribute
&
Thanks
to
Family Caregivers**



Care Plans that Know Each Person

Developed by:
Lynda Crandall, RN, GNP
Oregon Dept of Human Resources
for the
Pioneer Network Conference
August 2004

Shared with Permission

Care Plans that Know Each Person

Pioneer Network Conference
August 2004

Lynda Crandall, RN, GNP
(503)945-5918
Lynda.G.Crandall@state.or.us

Steps to plans that know each person

1. Reframe perspective
2. Change the order of the conversation
3. Act on what you learn

Traditional Approach

- Start with what is "wrong" with the person
 - Assess issues of health and safety
 - Determine what the person can/cannot do
 - Strengths and needs lists
 - Plans that describe how to keep the person healthy and safe

Here is Edward Bear, coming down stairs now bump, bump, bump on the back of his head behind Christopher Robin. It is, as far as he knows, the only way of coming downstairs, but sometimes he feels that there is really another way, if only he could stop bumping for a moment and think of it.

An alternate approach

➤ **Start with how the person wants to live**

- Learn what is important to the person in everyday life first
- Assess issues of health and safety and blend into what is important to him/her

Progression

Problem based plans

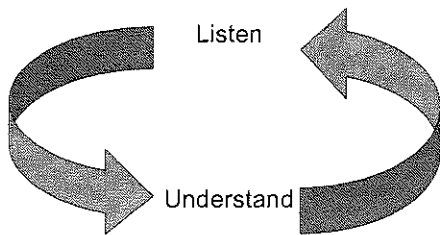


Strength based plans



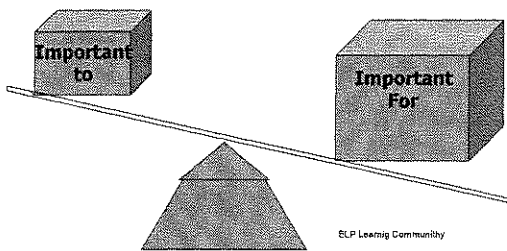
Preference based plans

**What you hear depends on what
you're listening for**

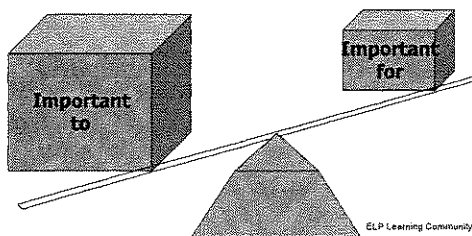


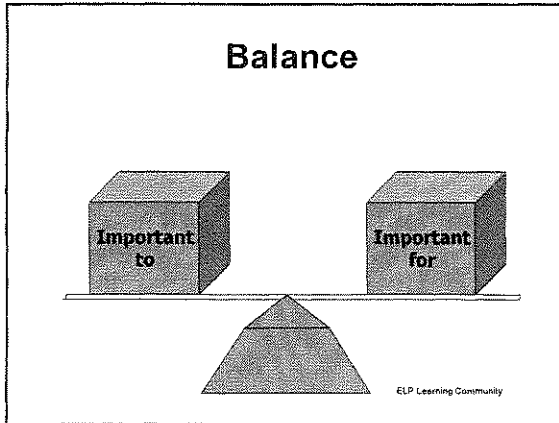
ELP Learning Community

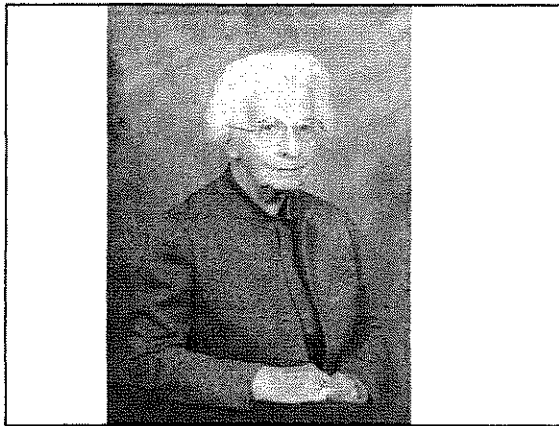
**Health and Safety
Dictates Lifestyle**

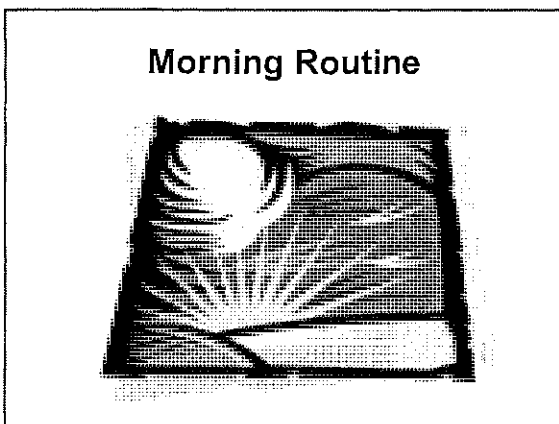


**All Choice,
No Responsibility**









**THE PLAN
IS NOT THE
OUTCOME**

**THE OUTCOME IS
A LIFE
WORTH LIVING**

ELP Learning Community

Beyond paid staff

- Who could/should be included in the process?
- When could/should planning occur in order to accommodate everyone?
- At what point do regulations play a role?

Person centered planning is...

- Finding out what is important to someone
- Learning about what health, safety and risk mean to the person and those who know and care about him/her
- Figuring out how he/she can be supported in having a balance between happy and safe

Language makes a difference

Some examples:

- | | |
|--|--|
| ➤ Planning for someone | Planning with someone |
| ➤ Others are "in charge" | Power is shared |
| ➤ Person is admitted/placed | Person moves in |
| ➤ Care for a person | Support a person |
| ➤ Alzheimer's patient | Person with Alzheimer's |
| ➤ Bedbound person | Person in bed |
| ➤ Wheelchair bound | Person in wheelchair |
| ➤ Health and safety dictate where you live | Health and safety are addressed where you want to live |

Begin with

Important to <i>(person's name)</i>	Important for <i>(person's name)</i>
What else do you need to learn/know?	

Next questions to ask

- What works in the current plan and what doesn't work—a way to learn what needs to stay the same and what needs to change—a bridge to action planning.
- What is the balance between important to and for in current plan and what do others need to know or do a better balance to be achieved?
- Action planning—tied to what is important to and for rather than "by the book" goals

Self determination is what life is about

Choice is about:

- **Preference** (things you like to do)
- **Opportunity** (to do those things)
- **Control** (of when, where and with whom those opportunities will occur)

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In the elder's own words

- Use 1st person only if:
 - He/she actually wrote it
 - He/she dictated it to you
 - You wrote it and he/she checked it over and approves of the wording

Should end with a plan that...

- Is better than what you had
- Describes what has been learned about:
 - What is important to the person in just proportion to what is important for the person
 - What others need to know or do to support the person

Care Plans that Know Each Person

Developed by:
Lynda Crandall, RN, GNP
for the Pioneer Network Conference
August 2004

Ms. Crandall's presentation overviews a collaborative care planning process that blends medical information with the resident's direction on all aspects of their living experience in the nursing home. She helps others learn how to create distinctive, compassionate, and user-friendly care plans that genuinely know each person, and highlights the importance of supportive language.

Lynda Crandall is a Geriatric Nurse Practitioner and was working in a NH when she got her RN notice. She has been in the field 30 years. 3 or 4 years ago she came across the concept of person-centered care, and thought, "how much more can there be to learn?" She thought she was offering lots of choice—am, pm, bath or shower—how much more choice can there be? She thought she understood

Mike Wallace did an interview with mountain climbers from an expedition where several people died. He asked why take the risk. One climber responded "Obviously, you've never seen the view from the top."

Person centered thinking and person thinking planning is conceptually simple, but difficult to implement. If you try to put it into a place without significant regard for relationships, you will not be happy with the outcome.

We need to reframe our perspective. Do not::

- Start with regulation,
- Do not start with best practice (we have lots of them in the research, but they do not take into account the person and how s/he wishes to define health, safety and risk), and
- Do not start with the golden rule -- Rather use the platinum rule: Do unto others as they would have done to them.
- Blend all of those, but don't start with them.

Ms. Crandall first used problem based planning. At one point, she used strength based planning, but it turned out that the strengths were listed but were not used in interventions. Now she uses preference based planning. She notes that in long-term care, we have the luxury of knowing the person before we design an intervention. (vs. an ER where you have to make decisions without that knowledge).

Traditionally	Alternatively
Start with what they can do and stuff they can't do. Put together a plan to keep them healthy and safe make them independent How many people in life are really independent. Answer: zero.	Start with how the person wants to live in their daily life; with what's important to them. Fit health and safety issues into a life.
Make an effort to include direct care workers, but give them the least time or discount what they say.	There's a difference in being interested in something vs being committed to something. Interest means you discuss it and ask questions, but you stop the first day someone calls in sick. Commitment means you make it happen.
Hold care plans on Tuesday and Wednesday and say to families it would be nice if you can come.	Everything is negotiable. Always families are invited and always direct care staff are present and attended to. Negotiate times.

Points to consider:

- To make it work all stakeholders need to be on board, or they become the anchor that holds everyone else back.
- What you hear depends on what you're listening for. Good questions to ask are: Why not? and What if? List the what ifs on a flip chart and then negotiate them out. Often problems are just perceived problems.
- The sequence of how behavior results: Anything you think, you can rethink. First we think about a thing and that moves on into what you feel about a thing; and that moves on into what you do about a thing. What you think is how you feel is how you behave.
- Strike a balance between what's *important to* and *important for* the person. *Important for* – health and safety are important but can't be all consuming or the only thing. *Important for* is health and safety. Many of us who do plans often feel like we are doing them for whom? Say surveyors. The doers do what the checkers check.
When considering *important to*, don't disregard health and safety. We abdicate responsibility when we say anything you want is fine. Michael Smull (ELP Learning Community) says: Happy and dead are incompatible, alive and miserable are unacceptable.

Recommended reading:

Tom Kitwood: *Dementia Reconsidered*

Michael Smull: Essential life style planning on web

- So how do we introduce residents to staff and in what order do we put things in the chart. Example: description of self by medical history or by social history.
- We all want mutually exclusive things—we want a trim, healthy body, but don't want to exercise or diet. Example: resident wants to play bridge, but doesn't want to take Lasix on bridge days because it makes her urinate a lot. Resulted in hospitalization. Find a short term compromise: e.g., move the time of the bridge game; take the Lasix after the bridge game.
- Exercise: Write your name and your morning routine on a blank sheet of paper: On a typical work day, the time you wake up, how you wake up (with alarm, with blaring music; to the smell of fresh coffee), and all the things you do that are important to you (include what brands of shampoo or products if that's important); you can exclude bathroom and sex habits. If you have to deal with kids or pets, include that. Pass it down three people to someone you don't know. This is your new routine. How does it work for you? What's wrong with it?
- An example of why it's important to use platinum rule: the Speaker brushed teeth for other people using crisp, cool water because it's what speaker used. It never occurred to her that someone might want warm water.
- Asking for a routine can give you concrete information. That gives you a lot of information that then lets you "make guesses" between the lines. Make a guess and ask for confirmation. Lots of detail may mean a strong preference for routine. Less detail may mean they didn't have enough time, may mean they're not used to presenting info/ thinking through this way.
- The plan itself is not the outcome. It's okay to have a C+ on paperwork if you have A+ on quality of life. The total reason for doing it is to support a lifestyle that the resident wants to live—one that includes what's important to the resident.

“I” Care Plan

Developed by:
Susan Misiorski
Consultant in Culture Change
New Boston, NH

Shared by NCCNHR with Permission

CASES AND CARE PLAN EXAMPLES

Developed by Susan Misiorski and Lynn MacLean

Apple Health Care Inc. Avon, Connecticut

CASE A

Joe is an 88-year old man with dementia. He has a short attention span. He is very pleasant most of the time. Joe likes to walk around the facility a considerable amount of his waking hours. He is unable to distinguish between areas he is allowed to enter and those which he should not. His ambulation skills are excellent, no assistance is required. Some residents are disturbed by him because he may enter their rooms against their wishes. He prefers to be with staff at all times; he does not tolerate being alone. He and his wife raised 11 children. Joe owned a hardware store and was a respected businessman in town.

TRADITIONAL CARE PLAN

<u>Problem</u>	<u>Goal</u>	<u>Approaches</u>
Wanders due to dementia	Resident will not wander into other resident rooms through next Resident Care Conference (RCC).	Re-direct resident to appropriate areas of facility. Praise for cooperation. Teach not to go into rooms with sashes across the door.
Short attention span	Resident will participate in one group program per week for 15 minutes through next RCC.	Invite to group activities. Praise for participation.

CASE A: INDIVIDUALIZED CARE PLAN
Developed by Susan Misiorski and Lynn MacLean
Apple Health Care Inc. Avon, Connecticut

<u>Needs</u>	<u>Goal</u>	<u>Approaches</u>
I need to walk and I particularly enjoy time with staff.	I will continue to walk freely throughout my home.	<p>I eat breakfast in the DR in my pajamas and robe. After breakfast, please assist me with AM care.</p> <p>I need cueing but give me the opportunity to do as much as I can for myself. After AM care, I want to go to the rec activity or walk with staff.</p> <p>I like to assist staff with writing, folding linen, and stocking shelves. Please let me help you.</p> <p>I like to make rounds with staff and greet fellow residents along the way.</p> <p>I prefer my noon meal in the small DR.</p> <p>I do not like to nap in the afternoon.</p> <p>If weather permits, please take me for a walk outside.</p> <p>Please invite me to staff inservices and meetings.</p> <p>At group activities, I like to sit next to the rec director.</p> <p>I eat my evening meal in the small DR.</p> <p>I like to keep walking in the evening. I go to bed around 11 PM.</p>

CASE B

Developed by Susan Misiorski and Lynn MacLean
Apple Health Care Inc. Avon, Connecticut

CASE B

Fred is an 84-year old man with osteoarthritis. He is very pleasant and social. He frequently visits staff and residents. He ambulates with minimal assistance or moves around the facility independently in a wheelchair. His wife was a resident in the facility, and they shared a room until she passed away 6 months ago. They were happily married for 61 years. They did not have children. Since his wife died, he is in a private room. Recently he began acting out sexually (grabbing at staff and female residents' breasts). He is alert and aware of his actions. He has minimal cognitive impairment and is hard of hearing.

To complicate the situation, the facility received a citation 6 months ago for "failing to protect a resident from abuse" because another male resident was found touching a confused female resident in her genital area within 24 hours of his admission to the facility. This was a Connecticut public Health Code Citation. The staff are afraid of what the Health Department will do if this was to recur.

TRADITIONAL CARE PLAN

Problem

Inappropriate sexual behavior

Goal

Resident will not touch staff or residents against their wishes.

Approaches

Q 15-minute checks to monitor location.

Praise appropriate behavior.

Re-direct and allow time alone in room when sexual behavior occurs.

Private room.

CASE B: INDIVIDUALIZED CARE PLAN

Developed by Susan Misiorski and Lynn MacLean
Apple Health Care Inc. Avon, Connecticut

Needs

I need
companionship.

Goal

I will choose a room-
mate by next RCC.

Approaches

I prefer to have a roommate.

When I'm in my room, I like to watch movies
on my VCR. I especially like action movies.
Please share any you may have with me.

I also like to read books.

I look up words I don't know in my
dictionary. I like to teach these words.

I enjoy wild birds. I have a bird feeder outside
my window. Please leave shades open and
ensure I have bird seed so I can fill the feeder.

When I'm out of my room, I enjoy eating in
the DR.

Please offer me many opportunities to be
around staff and other residents. (I like
games, sports and entertainment.) I may not
talk a lot, but I like the company.

Speak clearly and directly to me, hearing has
become difficult.

Please introduce me to single women who are
also seeking companionship/friendship.

Getting to Know You...

Activity Ideas

Long-term care facilities are their own communities full of people (residents, staff, and visitors) who have had such varied lives and interesting experiences. Getting people together to talk about their lives, interests, jobs, vacations, etc. fosters that sense of community. Who knew that Mr. Smith and Mrs. Jones went to the same high school? And how interesting that Mr. Brown traveled to every continent in his job as an airline pilot. Knowing details about a person's life can make caring for them and communicating with them a much easier task. It will also help to foster positive relationships – even friendships.

Sometimes people need encouragement to share information about themselves and their past experiences, and others just a willing audience who are ready to listen. These activity ideas will work really well for an Activities Director or Social Services staff, or for use during a Resident Council meeting. Through these activities, you can get at individual preferences and learn about individual residents.

On the next couple pages are some ice-breaker game ideas that you can use to get to know residents' likes and dislikes, and hear some stories that they can share with you. You can use most of these activities one-on-one or in small groups; at formal activities or informal gatherings, such as encouraging residents sitting at a table together at dinner to share their favorite vacation memory. Or playing one of the ice-breaker games during a scheduled craft time. Or asking each resident one question as you're helping him or her get dressed and groomed for the day.

Be creative... and get to know each other!!

GETTING TO KNOW YOU...ACTIVITY IDEAS

Activity I. PERSONAL ADVENTURES

Take turns sharing the memorable events of your lives:

- What was the scariest thing that ever happened to you?
- The funniest?
- The best?
- The worst?
- The most embarrassing?
- What have you done that you are most proud of?

Activity II. WHAT IF?

Take turns answering these hypothetical questions and then invent some of your own:

- If you were king or queen of a country, how would you use your power?
- If you could be the best on your block at something, what would it be?
- If you could live any place in the world, where would you live and why?
- Describe your perfect vacation. Where would you visit and who would you want to travel with you?
- If you were stranded on a deserted island and could eat only one kind of food for the rest of your life, what would it be?
- If you could make up a holiday, what would it be and how would you celebrate it?

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Residents' Rights Week 2005

Activity III. FACT OR FIB

Tell residents that you are going to share some information about yourself. They'll learn about some of your background, hobbies, and interests from the 60-second oral "biography" that you will present. When you finish your presentation, tell the participants that you are going to tell five things about yourself. Four of your statements should tell things that are true and that were part of your presentation; one of the five statements is a total fib. This activity is most fun if some of the true facts are some of the most surprising things about you and if the "fib" sounds like something that could very well be true. Tell everyone they can take notes and refer back to them to tell which statement is the fib. Next, invite each resident to create a biography and a list of five statements -- four facts and one fib -- about himself or herself. Then give each person a chance to present the 60-second oral biography and to test the others by presenting his or her own "fact or fib quiz." You can have residents do this part of the activity in small groups.

Activity IV. CIRCULAR FACT OR FIB

Here's a variation on the previous activity: Organize residents into two groups of equal size. One group forms a circle equally spaced around the perimeter of the room. There will be quite a bit of space between people. The other group forms a circle inside the first circle; each person faces one of the people in the first group. Give the facing pairs two minutes to share their 60-second oral "biographies." While each resident is talking, the partner takes notes. After each pair completes the activity, the residents on the inside circle move clockwise to face the next person in the outer circle. People in the outer circle remain stationary throughout the activity. When all residents have had an opportunity to share their biographies with one another, ask them to take turns each sharing facts and fibs with the large group. The other residents refer to their notes or try to recall which fact is really a fib.

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Residents' Rights Week 2005

Activity V. CHAIN GANG

NOTE: This activity can also be used as a staff exercise/team building activity

Learn about each other's hidden talents. Begin by asking the participants "Who can do something really well?" After a brief discussion about some of everyone's talents, pass out paper and ask participants to write down five things they do well. Then provide each person with five different-colored paper strips. Have each participant write a different talent on separate paper strips, then create a mini paper chain with the strips by linking the five talents together. As participants complete their mini chains, use extra strips of paper to link the mini chains together to create one long chain. Have residents hold the growing chain as you link the pieces together. Once the entire chain is constructed and linked, lead a discussion about what the chain demonstrates-- for example, all the residents have talents; all of them have things they do well; together, they have many talents; if they work together, they can accomplish anything; their lives are better when they work together and value each other than when each individual feels alone. Hang the chain in the room as a constant reminder of the talents they possess and the benefits of teamwork.

Activity VI. CANDY SHARE

Pass around a bag of little candies (M&M's work great) and have each person take a few. Don't eat the candies yet! In turn, each person has to tell one thing about him or her for every candy taken. After their turn, they can eat the candy.

Variation: Give each color a category and have the participants share things related to that color. For example: red= tell something about your family, green= tell something that you like to eat, blue= tell something about the work you used to do, yellow = tell what you like to do in your spare time.

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Residents' Rights Week 2005

Activity VII. WHAT IS YOUR FAVORITE...

Test your knowledge about resident's favorite things by spending an evening together creating flash cards. Create two sets of index-sized cards on which to write questions and answers. One set should have questions and on the other set, write what you think will be the resident's answer. The cards are a gold mine of information about the resident's likes and dislikes, and ideas for future thoughtful surprises.

What is your favorite...

... part of the day?	... dessert?	...leisure activity/hobby?
... book?	...movie?	...meal?
...past work?	...restaurant?	...clothing?
...color?	...season?	...section of the country?
...memory?	...flower?	...Sunday afternoon activity?
...quote?	...artist?	...game/thing you did as a child
...song?		

Bonus: What are the three things you would take with you on a desert island?

Activity VIII. GET TO KNOW YOU BINGO

Create Bingo "Cards" by making a table with 9 or 12 boxes. In each box, write a statement, such as: Never been skiing, born in another country, lived in this town their whole life... Each person gets a card. They must then find someone different to fit into each of the categories and get his or her signature on their papers. The first person to fill in all the boxes wins! (See attached sample "card")

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Residents' Rights Week 2005

Get to Know You Bingo
(SAMPLE CARD)

NEVER BEEN SKIING	FAVORITE MEAL IS BREAKFAST	OWNED A PET
TRAVELLED TO ANOTHER COUNTRY	HAS GREAT- GRANDCHILDREN	WENT TO COLLEGE
LIKES TO LISTEN TO MUSIC	LIVED IN THIS TOWN THEIR WHOLE LIFE	LIKES TO DO PUZZLES
HAS BEEN TO THE BEACH	BELONGS TO THE RESIDENT COUNCIL	HAS FAMILY IN ANOTHER STATE

*Together We Can ...
Achieve Resident-Directed Care*

Section V.

Examples of Care Planning and Individualized Care Making a Difference for Residents

Residents' Rights Week 2005

Together We Can... Achieve Resident-Directed Care:
A Care Planning Success Story - #1

ISSUE ADDRESSED: Family Involvement in Care Planning

DESCRIPTION: The Renaissance Gardens at Riderwood Family Council sponsored a three-part monthly seminar series last spring on care plans for skilled nursing residents and service plans for assisted living residents.

During the first seminar a resident-centered planning process model (assess, plan and deliver) was discussed. We later discovered that this model is the same as the generally accepted nursing process model.

During the second seminar characteristics of good plans (needs, goals and interventions) were discussed.

During the third seminar effective ways of participating in the planning conference (before, during and after) were discussed.

Attached is a handout for the third seminar, including a summary of major points discussed during the first two seminars.

SUBMITTED BY: Jim Patton, Chair
Family Council
Renaissance Gardens at Riderwood
3160 Gracefield Road
Silver Spring, Maryland 20904
301-604-6329

Resident Centered Care Plan Process Model

(1) Assess

- Gather information about health and physical condition of resident
- Evaluate how well resident can take care of himself or herself
- Discover resident's habits, activities and relationships

(2) Plan

- Define all of the resident's problems, needs and concerns
- Develop measurable goals for each problem, need or concern with a timetable for attainment
- State a set of specific interventions to be performed by staff in order to help the resident meet each goal

(3) Deliver

- Document each intervention
- Measure progress toward attainment of each goal
- Evaluate the effectiveness of each intervention

Characteristics of a Good Care Plan

(1) General

- Individualized for each resident
- Written in a language that staff, resident and family members can understand
- Agreed to by resident, family member(s) and staff

(2) Needs

- Includes all of the resident's specific medical, nursing, mental and psychosocial needs
- Based on an analysis of an assessment

(3) Goals

- Contains at least one goal related to each need, problem or concern
- States how the attainment of each goal is to be measured
- Provides a timetable for meeting each goal

(4) Interventions

- Describes specific services to be furnished by staff to help the resident meet the goal(s) for each need
- Provides a rationale for why each specific intervention is being done
- Describes specifically what is to be done and when it is to be done
- Assigns responsibility for each intervention to a specific discipline

Care Plan Conference (CPC)

(1) General

- Held after admission, quarterly (SNF), semi-annually (ALF), when there is a change in status or upon request by a resident or personal representative
- Normally scheduled during the morning but can be scheduled at the convenience of a resident or personal representative
- Normally scheduled for a 30 minute time period but can be scheduled for a longer period at the request of a resident or personal representative
- Minimum of 7 days notice given to resident and personal representative
- Attend in person or by conference call

(2) Purpose

- **Report performance** with respect to goal attainment during the prior period
- **Finalize plans** to attain or maintain the resident's highest physical, mental and psychological well-being during the next period

(3) Participants

- **Staff team** including physician, nurse manager, direct care nurse, social worker, geriatric nursing assistant, dietitian, activities director, etc.

- **Resident team** including resident, family member(s), personal representative, friend(s) and any other people the resident requests such as an advocate or ombudsman

(4) Before the Conference

- Review the previous care plan
- Review the resident's chart to identify changes since the last CPC
- Talk to the resident about needs, care and treatment
- Talk to the physician or nurse practitioner, nurses and geriatric nursing assistants
- Obtain a copy of the proposed care plan and compare it with the previous plan
- Evaluate the care plan against the "Characteristics of a Good Care Plan"
- Mark-up the proposed care plan with your changes
- Document your agenda for the CPC

(5) During the Conference

- Sign the sheet indicating that you participated in the CPC
- Ask staff to report on performance with respect to goal attainment since the last CPC
- Suggest changes that you would like to make in the care plan
- Take notes on changes agreed to by staff if the Resident Services Coordinator isn't doing so
- Focus on care plan issues as time is limited to 30 minutes

(6) After the Conference

- Complete the RG CPC survey form
- Obtain a copy of the final care plan
- Monitor implementation of the care plan
- Monitor effectiveness of the care plan

Together We Can... Achieve Resident-Directed Care Planning:
A Care Planning Success Story - #2

ISSUE ADDRESSED: Quality of Life

DESCRIPTION: A retired band director and his wife lived in an apartment on the grounds of a long-term care community. He became ill and had to be admitted to the nursing facility. His financial situation would not allow for the cost of the long-term care facility and for the couple to maintain their apartment as well.

When the husband was discharged from Medicare the situation became critical very quickly. The man was a veteran and had always obtained his medication from the VA, but the facility refused to use the large bottles due to possible med errors and insisted on bubble pack format for meds; the VA did not bubble pack. The wife was distraught because medication costs of nearly \$500 a month was beyond what their budget could handle.

The ombudsman office worked with the facility and family to contact the VA. They learned that the man was 70% service disabled. The ombudsman was able to visit with the person who wrote VA contracts for his area and learned that if the wife was willing to manage weekend care the husband could return to their home on the grounds with 70% coverage for home health for the remainder of the time he lived at home, and of course the medication in the bottles could be resumed. His wife was able to arrange for night and weekend coverage for assistance from the couple's 2 children and their families and the man went home.

The facility was happy as he was very heavy and a difficult transfer, the wife was overjoyed; and no one was happier than the resident! Except - maybe this ombudsman!!!!

SUBMITTED BY: Sue Schuster, LMSW
Regional LTC Ombudsman
1025 Main Street, 1st Flr.
Great Bend, KS 67530
(877)662-8362

Together We Can... Achieve Resident-Directed Care:
A Care Planning Success Story - #3

ISSUE ADDRESSED: Bathing Battle

DESCRIPTION: The Ombudsman received a call from a 78-year-old man who was upset about staff attempting to get him to take a shower late in the afternoons and he was refusing to do so. The Ombudsman talked with the resident and asked him what time would best serve his wants and desires for taking a shower. The resident reported that it would best fit his needs if he were able to shower in the mornings. A Care Plan was developed and specifically addressed the resident's desire to shower in the mornings. This worked for about two weeks, and then the staff reported the resident was complaining again. The Ombudsman was called again and during a conversation, the resident mentioned his like for music. The resident explained that he liked Country Music the most. The Ombudsman asked the resident how he felt about playing country music in the shower and he reported he would love that, "It would be just like at home. I used to do that every day." The Ombudsman met with the treatment team and was able to negotiate the staff placing a radio in the shower room and playing country music for the resident during his showers. It has now been eight months and the resident reports bathing is much more enjoyable, and staff concurs. The resident thanks the Ombudsman every time he sees him for "making it feel just a little more like home."

SUBMITTED BY: Patrick J. Craig, Lead Ombudsman
Pueblo Area Agency on Aging
2631 E 4th Street
Pueblo, CO 81001
(719) 583-6123

Together We Can... Achieve Resident-Directed Care Planning: **A Care Planning Success Story - #4**

ISSUE ADDRESSED: Residents' Rights

DESCRIPTION: A resident was admitted to a continuing care retirement center under skilled Medicare after suffering a hip fracture. The resident had an apartment in the independent living portion of the building and planned to return. The resident appeared very sad. Her husband would visit and become very angry with her. After he left she would cry even more. The staff suggested to the husband that she was depressed and requested to be allowed to approach the physician for an order for counseling. The husband became enraged and called the physician and stated that he absolutely refused to allow any such order.

The facility was frustrated and contacted our office. The ombudsman asked if there had been any mood assessment done upon admission; there had not been due to the emphasis being on the physical recuperation from surgery.

The ombudsman talked with staff about further assessment that might be needed. The staff then asked the resident for permission to have the ombudsman visit with her and her husband regarding the situation. The resident agreed, if she could visit with the ombudsman prior to the ombudsman seeing the husband.

The ombudsman, husband, resident, and facility social worker met, the results of the assessments were shared with the husband and resident and possible interventions were explained. The husband relented when he realized 1) his wife would not be considered "crazy," 2) that incidence of sadness was very normal when an active person was forced to become inactive and had a serious surgery, 3) that Medicare would cover the cost of almost all the necessary professional treatment, and 4) that any medications would most likely be temporary until the resident was able to return to independent living. The team also explained that while the husband was designated as the decision maker when his wife was unable to make her wishes known, at this point she could communicate her wishes and she had indicated that she did want to try whatever could help her feel better. When this was explained the husband indicated he had forbidden the order because he thought he was responsible to protect his wife from being labeled "crazy." He'd thought this was what she would want. For her part, the wife had always done what made her husband happy and did not understand that it was her right to decide on treatment for herself. She needed him to understand the role he could play and for him not to be upset with her decision.

As a result the resident was given a prescription for mood support, a clinical social worker began to visit 1 time a week after the consulting psychiatrist assessed, and the activity and social work departments made a concerted effort to involve and work with the resident. With support from her husband and staff the resident began progressing in physical therapy and she was able to return to the couple's apartment in independent living.

SUBMITTED BY: Sue Schuster, LMSW
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Great Bend, KS 67530
(877)662-8362

Together We Can... Achieve Resident-Directed Care:
A Care Planning Success Story - #5

ISSUE ADDRESSED: Family Involvement

DESCRIPTION: An ombudsman witnessed a positive experience with assessment and care planning practice when she was involved in a care planning meeting with family members of a resident who was moved from an Adult Care Community to a Nursing Home. Those involved were the nursing home team which consisted of physical therapy, nurse manager, aide, dietary, personal care physician, recreation, and the social worker, as well as the resident's spouse who was living in the community with an Alzheimer's diagnosis and out-of-town daughter who was present via telephone. Both the spouse and daughter shared their concerns and personal information regarding the resident which staff was unaware of. The resident was non-communicative and unable to verbalize his wishes. The family shared that he was not a morning person and enjoyed sleeping in. The spouse also shared what foods the resident liked and disliked. The daughter shared concerns regarding medications. The PCP also had concerns and changed many medications which eventually made the resident more alert and improved negative behaviors. The ombudsman witnessed involvement of family in the care planning process resulting in excellent care and quality of life for the resident. It is very important for staff to have knowledge of who the resident was prior to coming to an LTC community. It allows staff to see the person and not the illness.

SUBMITTED BY: Marie Frey
Monroe County Ombudsman Program
1900 S. Clinton Avenue
Rochester, NY 14618
(585)244-8400

Together We Can... Achieve Resident-Directed Care:
A Care Planning Success Story - #6

ISSUE ADDRESSED: Legislative Action

DESCRIPTION: Florida's nursing home residents finally will be able to feel more at home. Governor Jeb Bush has signed into law a bill that allows nursing home residents to arrange their room furniture in whatever way they please. Outdated safety codes had required nursing home beds, like hospital beds, to stick out perpendicularly from the wall with space on both sides.

For years, nursing home residents had ignored the decades-old regulations, while state regulators simply turned a blind eye on the practice. Wall beds opened up more space for residents to make their rooms feel less institutional and a little more like home. But when regulators decided last year to sanction homes that fail to comply with the code, it was enough to drive nursing home residents up the wall.

Seniors drafted petitions and sent letters to their representatives- who actually listened. Starting July 1, wall beds will be legal if residents request them, roommates don't object and they don't interfere with safety or care.

The decision was a clear-cut solution to improve the quality of life for many nursing home residents.

6/16/2005 St. Petersburg Times

SUBMITTED BY: Barbara Hengstebeck
Coalition to Protect America's Elders
3699 Plowshare Road
Tallahassee, FL 32309
(850)216-2727

*Together We Can ...
Achieve Resident-Directed Care*

Section VI.

Promotional Materials

Residents' Rights Week 2005

SAMPLE PRESS RELEASE

FOR IMMEDIATE RELEASE:

<DATE>

CONTACT:

<NAME/PHONE/E-MAIL>

Long-term Care Residents Honored During Residents' Rights Week, October 2-8, 2005
Together We Can... Achieve Resident-Directed Care

<INSERT CITY, AND DATE> Throughout the country, long-term care residents, family members, ombudsmen, citizen advocates, facility staff, and others will honor the individual rights of long-term care residents by celebrating Residents' Rights Week October 2-8, 2005. Designated by the National Citizens' Coalition for Nursing Home Reform (NCCNHR), National Long-Term Care Residents' Rights Week highlights the importance of resident-directed care for the 2.7 million individuals living in the 62,000 nursing homes, assisted living, and board and care homes across the country.

"This year's theme, *Together We Can... Achieve Resident-Directed Care*, again emphasizes the fundamental rights of all long-term residents to be treated with dignity and respect and to maintain quality of life," said Alice H. Hedt, Executive Director of NCCNHR. "Members of the long-term care community nationwide will commemorate the week by holding special events that emphasize the residents' right to self-determination, autonomy, dignity, and quality care."

<INSERT DETAILS ABOUT ANY LOCAL EVENTS INCLUDING WHEN, WHERE AND WHY THE EVENT IS BEING HELD. HIGHLIGHT ANY PROCLAMATION BY AN ELECTED OFFICIAL >

The 1987 Nursing Home Reform Law guarantees nursing home residents individual rights including but not limited to individualized care, respect, dignity, the right to visitation, the right to privacy, the right to complain, and the right to make independent choices. Residents who have made their home in other types of facilities <INSERT NAMES OF OTHER TYPES OF FACILITIES IN YOUR STATE, i.e. assisted living, adult care homes> maintain their rights as US Citizens. Residents' Rights Week raises awareness about these rights and pays tribute to the unique contributions of long-term residents.

The National Long-Term Care Ombudsman Program has worked tirelessly for over 30 years to promote residents' rights daily. More than 8,000 volunteers and 1,000 paid staff are advocates for residents in all 50 states plus the District of Columbia, Guam and Puerto Rico. Authorized under the Older Americans' Act and administered by the Administration on Aging, the program also provides information on how to find a facility, conducts community education sessions, and supports residents, their families and the public with one-on-one consultation regarding long-term care.

<INSERT DETAILS ABOUT STATE OR LOCAL OMBUDSMAN PROGRAM HERE.>

"Residents' Rights Week is an excellent opportunity to re-affirm our collective commitment to residents' rights and to honor long-term care residents. We strongly encourage the community to participate in Residents' Rights Week activities and to visit residents who continue to be important to our communities and society," Hedt said.

<INSERT QUOTE FROM LOCAL OR STATE OMBUDSMAN OR CITIZEN ADVOCACY GROUP>

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Sample Letter to the Editor

Dear Editor:

October 2-8, 2005 is National Long-Term Care Residents' Rights Week, a time to acknowledge the contributions and sacrifices many long-term care residents have made to better our community. This year's theme - *Together We Can... Achieve Resident-Directed Care* - emphasizes the fundamental rights of all long-term care residents to be treated with dignity and respect and to have a say in decisions affecting their care. These rights include freedom of choice, the right to participate in community activities, and the right to have input in their daily schedule. Celebrate and acknowledge these rights through participating in Residents' Rights Week events and calling on your elected officials and local facilities to show their support by attending or organizing activities.

<INSERT DETAILS OF YOUR LOCAL RESIDENTS' RIGHTS WEEK EVENT - BE SURE TO NOTE ANY PROCLAMATIONS FROM ELECTED OFFICIALS.>

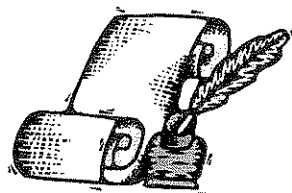
During Residents' Rights Week we recognize our local long-term care ombudsman program staff and volunteers who work daily to promote residents' rights, assist residents with complaints, and provide information to those who need to find a long-term care facility. In this area, the ombudsman program serves <INSERT DETAILS ABOUT THE SIZE OF THE REGION, THE NUMBER OF FACILITIES, AND HOW TO CONTACT THE OMBUDSMAN>

Our community is also served by a citizen advocacy group <INSERT NAME AND CONTACT INFORMATION> that advocates for improved quality of care and quality of life for those who live in long-term care facilities.

As <INSERT NAME OF LOCALITY> celebrates Residents' Rights, I encourage community members to visit someone they know in a long-term care facility, volunteer in a facility, participate in Residents' Rights Week events, or inquire about becoming a volunteer long-term care ombudsman. Your assistance and attention helps to ensure that the voices of long-term care residents do not go unheard and demonstrates to residents that they have not been forgotten.

**** NOTE:** All letters to the editor must include a signature, address, and phone number so that the paper may contact you with any questions. You may also include your affiliation with an organization if you wish. Your phone number and address will not be printed.

If possible, try to link your opening paragraph with something that was recently in the newspaper. For example, "As thousands of World War II veterans gathered this Memorial Day, it is important to remember those veterans and others who currently live in our nations' 62,000 long-term care facilities."



National Long-Term Care Residents' Rights Week 2005 Proclamation

Together We Can... Achieve Resident-Directed Care

WHEREAS, there are nearly 1.7 million individuals living in 17,000 nursing homes; and 1 million individuals living in 45,000 board and care/assisted living facilities in the U.S.; and

WHEREAS, the federal Nursing Home Reform Act of 1987 guarantees residents their individual rights in order to promote and maintain their dignity and autonomy; and

WHEREAS, all residents should be aware of their rights so they may be empowered to live with dignity and self-determination; and

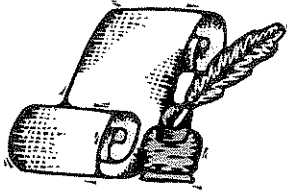
WHEREAS, we wish to honor and celebrate these citizens, to recognize their rich individuality, and to reaffirm their rights as community members and citizens, including the right to have a say in their care; and

WHEREAS, individuals and groups across the country will be celebrating Residents' Rights Week with the theme– "Together We Can... Achieve Resident-Directed Care"– to emphasize the importance of affirming these rights through facility practices, public policy, and resident-centered decision-making that impacts quality of care and quality of life

Now, therefore, I, _____, Mayor of the City of _____, do hereby proclaim October 2-8, 2005 as **National Long-Term Care Residents' Rights Week**, in the City of _____, and encourage all citizens to join me in these important observances.

Signed this _____ day of _____ 2005

_____, Mayor



National Long-Term Care Residents' Rights Week 2005 Proclamation

Together We Can... Achieve Resident-Directed Care

WHEREAS, there are nearly 1.7 million individuals living in 17,000 nursing homes; and 1 million individuals living in 45,000 board and care/assisted living facilities in the U.S.; and

WHEREAS, the federal Nursing Home Reform Act of 1987 guarantees residents their individual rights in order to promote and maintain their dignity and autonomy; and

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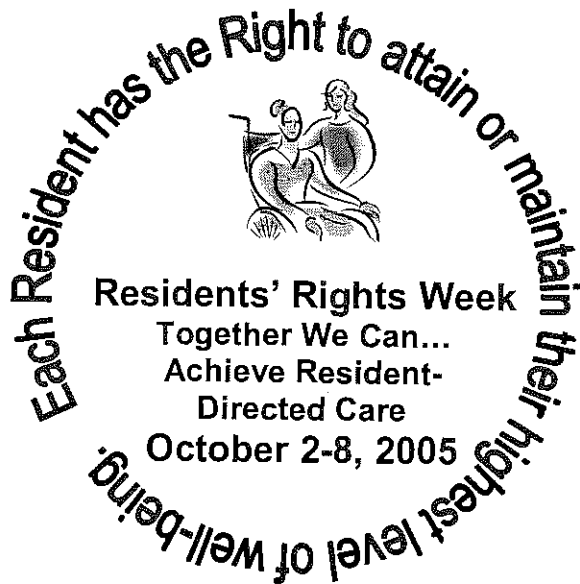
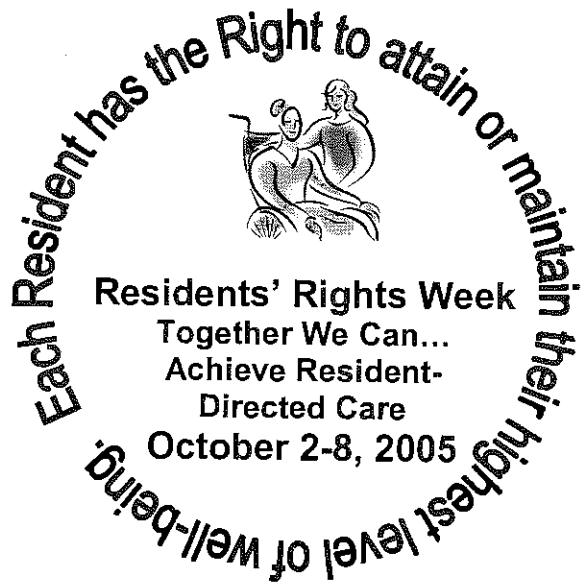
WHEREAS, we wish to honor and celebrate these citizens, to recognize their rich individuality, and to reaffirm their rights as community members and citizens, including the right to have a say in their care; and

WHEREAS, individuals and groups across the country will be celebrating Residents' Rights Week with the theme- "Together We Can... Achieve Resident-Directed Care"- to emphasize the importance of affirming these rights through facility practices, public policy, and resident-centered decision-making that impacts quality of care and quality of life

Now, therefore, I, _____, Governor of the State of _____, do hereby proclaim October 2-8, 2005 as **National Long-Term Care Residents' Rights Week**, in the State of _____, and encourage all citizens to join me in these important observances.

Signed this _____ day of _____ 2005

_____, Governor



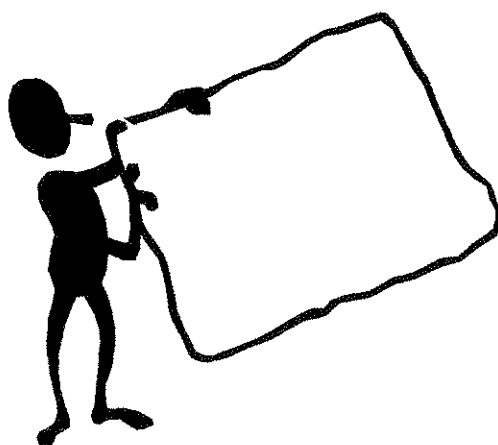
Coming Soon!

The 2005 Residents' Rights Week Poster

There will be one more addition to your Residents' Rights Week Packet!!

The National Citizens' Coalition for Nursing Home Reform (NCCNHR) was pleased to hold a National Residents' Rights Week Poster Contest this year. Residents, family members, activity directors, long-term care staff, and advocates were invited to design and submit poster entries that incorporated the theme "***Together We Can...Achieve Resident-Directed Care.***"

Entries were due August 1st, 2005. A panel of judges will select a winner. The winning entry will be reproduced as a 16x20 color poster that will be sent to everyone who has ordered a Residents' Rights Week Packet.



So check the mail in September for your copy of the Residents' Rights Week Poster.

Posters are a festive and informative way to celebrate this national week, October 2 – 8, 2005, devoted to recognizing long-term care resident's rights.

NEWS RELEASE



P.O. Box 570, Jefferson City, MO 65102

For Immediate Release:

March 22, 2005

Contact:

Nanci Gonder
Office of Public Information
573-751-6062

Ombudsman Program Provides Tips on Care Plans for Nursing Home Residents

Every resident in a nursing home has a right to good care and there are many ways to ensure that good care is delivered. A resident may have a temporary health condition or a chronic disease; either way, his or her care plan and therapeutic needs must be frequently re-evaluated.

“In Missouri, nursing homes must help each resident 'attain or maintain' his or her highest level of well-being - physically, mentally, and emotionally,” said Carol Scott, Missouri State Long-Term Care Ombudsman. This well-being is achieved through assessing each individual and determining his or her diet, and nutritional, therapeutic and skin care needs.

Scott said Missourians should consider the following suggestions about assessment and care planning when working with a long-term care facility.

Good Care Plans Should:

- Be specific to each resident.
- Be written so that everyone can understand them and knows what to do.
- Reflect the resident's concerns and support his or her well-being.
- Assign tasks to specific staff members and use a team approach.
- Be re-evaluated and revised routinely.

Before the care plan meeting:

- Ask for a copy of the current care plan (if one already exists) and examine each aspect thoughtfully.
- Know about or ask the doctor or staff about you or your loved one's condition, care, and treatment.
- Plan your list of questions, needs, problems, goals and examples to support the changes you recommend in the care plan.
- Find out whom to talk to if changes in the care plan are needed, and whom to talk to if there are problems with the care being provided.
- Ask for a copy of the care plan.

-more-

During the care plan meeting:

- Make sure the resident is involved, and listened to carefully.
- Discuss options for treatment and make sure the staff meets with you or your loved ones to discuss your needs and preferences.
- Be sure you understand and agree with the care plan and ask questions if you need terms or procedures explained.

After the care plan meeting:

- Monitor whether the care plan is being followed.
- Talk with nurse aides, staff or the doctor about the care plan.
- Request another meeting if the plan is not being followed.

“To give good care, staff must *assess* and *plan care* to support each resident’s life-long patterns, current interests, strengths, and needs. Care planning conferences are a valuable forum for residents and families to voice concerns, ask questions, give suggestions, learn about care in a nursing home, and give information to staff on a resident’s background and daily routine,” said Scott.

“The right to good care is vital to making sure residents get appropriate care that accommodates their changing needs. Contact the Missouri State Long-Term Care Ombudsman Office at 1-800-309-3282, if you need additional assistance in working with a facility on a care plan or help advocating for resident rights,” added Scott.

Helpful websites on Long-Term Care:

- For information about the Missouri State Long-Term Care Ombudsman Program and/or how to sign up to become a Volunteer Ombudsman, go to:
<http://www.dhss.state.mo.us/Ombudsman/>
- For information on inspection results for long-term care facilities, go to Missouri Department of Health & Senior Services www.dhss.state.mo.us/showmelongtermcare/ Show Me Long-Term Care.
- For information about long-term care, go to www.medicare.gov, the Official U.S. Government Medicare Site, and click on Nursing Home Compare.

Resource for this news release:

- National Citizens’ Coalition for Nursing Home Reform *Assessment and Care Planning*. Retrieved February 2, 2004, from www.nursinghomeaction.org.

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*Together We Can ...
Achieve Resident-Directed Care*

Section VII.

Resources

Residents' Rights Week 2005

Resource List

Bathing Without a Battle

<http://www.bathingwithoutabattle.unc.edu>

The Bathing Without a Battle: Creating a Better Bathing Experience for Persons with Alzheimer's Disease and Related Disorders CD and video package teaches person-centered methods for making the bathing experience more enjoyable for both caregivers and the people they are bathing.

Minimum Data Set & Resident Assessment Instrument

www.cms.hhs.gov/quality/mds20/

The MDS and the Resident Assessment Instrument are the tools developed by the Centers for Medicare and Medicaid Services for assessing a resident's abilities and functional status.

National Citizens' Coalition for Nursing Home Reform

<http://www.nursinghomeaction.org>, 202-332-2275

This site provides up-to-date information on public policies that affect nursing home residents' rights and the quality of nursing home care. Learn how you can make a difference in the care of your loved one in a nursing home and access information on how NCCNHR works to improve care.

National Long Term Care Ombudsman Resource Center

<http://www.ltombudsman.org>, 202-332-2275

Check out this site to learn more about the fifty-two State Long-Term Care Ombudsman Programs, and their statewide networks of 600 regional (local) programs. Access information on training and advocacy opportunities as well as previous Residents' Rights Weeks packets.

Nursing Home Care Plans: Getting Good Care

Video and information kit from AARP. All nursing home residents are entitled to take part in planning for their own care. A care plan is an excellent tool for involving residents and concerned family members in the process of planning care in a nursing facility. This video (15 min. 45 sec.) is

Together We Can... Achieve Resident-Directed Care
Residents' Rights Week 2005

designed to address the issue of the care plan in advocating quality care in nursing homes. To order a copy of this free video kit, send a request in writing to:

AARP Fulfillment
601 E Street NW
Washington, DC 20049

Include the stock number C1642

Nursing Homes: Getting Good Care There (2nd edition) (2002). By Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank. 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. Order from NCCNHR. Price: \$11.95

Contact: National Citizens' Coalition for Nursing Home Reform
1828 L St. NW, Suite 801
Washington, DC 20036

Phone: (202) 332-2275
<http://nursinghomeaction.org>

Pioneer Network

www.pioneernetwork.net, 585-271-7570

The Pioneer Network advocates and facilitates deep system change and transformation in our culture of aging. To achieve this, they:

- Create communication, networking and learning opportunities.
- Build and support relationships and community.
- Identify and promote transformations in practice, services, public policy and research.
- Develop and provide access to resources and leadership.

State Operations Manual – Appendix PP – Guidance to Surveyors for Long-Term Care Facilities

www.cms.hhs.gov/manuals/107_som/som107ap_pp_guidelines_ltcf.pdf

Guidelines for surveyors of long-term care facilities to use in surveying regulatory requirements in nursing homes. Developed by the Centers for Medicare and Medicaid Services.

Together We Can... Achieve Resident-Directed Care
Residents' Rights Week 2005

Using Resident Assessment and Care Planning as Advocacy Tools: A Guide for Ombudsmen and Other Advocates (1992). By Sara Hunt, MSW, and Sarah Burger, RN, MPH. Price: \$12.00. Order from NCCNHR, 202-332-2275.

Websites for more Ice Breaker/Getting to Know You Activity Ideas:

<http://www.education-world.com>

http://ce.byu.edu/yp/youthconf/games/getting_to_know_you.cfm

<http://www.realfamiliesrealfun.com>