CHOICE

Each resident has the right to exercise choice and have those choices respected. The introduction to residents’ rights in the federal regulations says, *The resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility.* A primary example is the right to reside and receive services with reasonable accommodation of individual needs and preferences. From the **resident’s perspective**, this right means that the facility and staff must allow each resident to direct the patterns of his/her daily life, as well as treatment methods and goals.

From the **staff’s perspective**, resident choice means that the staff needs to think creatively, to see life from the resident’s viewpoint when a request is made or a preference is stated. Instead of saying, “No,” or, “We can’t do that because. . .,” the staff should say, “Let’s see what we can do.” Staff and residents can brainstorm together and then take action. Exercising choice means considering ways to accommodate residents’ preferences and decisions. Staff have a responsibility to help residents exercise their rights, even when staff feel that helping is not their duty. Examples are staff helping a resident to smoke or not interfering when a resident visits with persons whom the staff feel are not appropriate choices of friends. The law challenges the facility to focus on meeting the needs and desires of each individual resident, not on maintaining the customary routines of the institution.

There are some other important dimensions of exercising choice. Making a choice is not a time-limited event. If a resident says she does not care what clothing she wears that day, the person’s choice does not mean that she will never have a clothing preference. An individual’s choice and preferences may change. After a person has been in the facility awhile, or if her condition changes, she may make different choices than the ones previously stated. **Exercising choice is a continual process.**

THE NURSING HOME REFORM ACT

There are two key provisions in the federal law (Nursing Home Reform Amendments of the Omnibus Budget Reconciliation Act of 1987 or OBRA ’87) that establish the foundation for resident choice as well as other provisions: **Quality of Care** and **Quality of Life**.

- **Quality of Care** says 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

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1 The Nursing Home Reform Amendments is also referred to as the Nursing Home Reform Law or as OBRA ’87.
written plan of care.

- **Quality of Life** says a nursing facility must 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.

There is the same underlying theme in each of these provisions: facilities must be responsive to the particular preferences and needs of each individual resident. Building on that premise, the residents' rights provisions follow the Quality of Life section in the law. Residents’ rights are like the directions for achieving quality of life. If facilities follow these directions and fully implement residents' rights, they will be promoting quality of life for each resident.

Residents’ rights also have implications for quality of care requirements. Since residents’ rights and quality of life are related, what factors do residents consider important for quality? In 1985, the National Citizens’ Coalition for Nursing Home Reform asked 450 residents in 15 cities across the country what quality meant to them. Studies since then continue to support the importance of these same factors to residents. A few central issues were poignantly and consistently identified. Many of these were incorporated as provisions in the Nursing Home Reform Law. They include the following:

- Kind treatment by staff,
- Respect for residents' dignity and being treated as adults,
- Opportunities for choice and input in care and services, particularly related to food, activities, and personal schedules,
- Privacy.

**Basic Themes**

The residents' rights listed in the federal law, and therefore all of the regulations that follow from them, embody four basic themes.

The four themes are:
1. Communication
2. Choice
3. Decision-making
4. Participation

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The following examples illustrate how these four themes encompass residents’ rights.

1. **Communication**

   Effective, on-going communication between residents and staff is essential to fulfilling residents’ rights. A resident may say, "I don't want this food." What does this mean? It could mean that the resident is refusing a special diet, or it could be the resident's way of saying that the food is unpalatable because it is cold, bland, or is food that the resident has never liked. There may be a different, unrelated problem behind the refusal of the food. When residents exercise their right to say, "No," staff need to ask questions and observe until they fully understand what the resident is really expressing. Even residents who are not very articulate or who have some degree of memory impairment can express choices.

   Specific examples of rights pertinent to communication include residents’ rights to:
   - Be fully informed of his or her rights and all rules and regulations governing resident conduct and responsibilities, orally and in writing, in a language the resident understands;
   - Participate in planning his or her care and treatment; and
   - Voice grievances without discrimination or reprisal AND have prompt efforts by the facility to resolve these.

2. **Choice**

   Explained above.

3. **Decision Making**

   Each resident has the ability to exercise his/her own rights unless that individual has been adjudicated incompetent according to state law. To exercise decision-making, residents need full information to be able to make a truly informed decision. They need accurate information about alternatives and the consequences, short- and long-term, of the decisions they are considering. Decision-making is the implementation of exercising choice.

   Another aspect of resident decision-making is being in an environment that is truly encouraging and supportive. Residents need to feel free to make their own decisions without fearing that they will be declared incompetent or discharged if their decisions differ from what professionals recommend or from what their family wants. Once a decision is made, residents need to know that their choice will be respected. One of the requirements of the Nursing Home Reform Law is that nursing homes must protect and promote the rights of each resident.
A few specific examples of rights in this area are a resident’s right to:
- Manage his or her financial affairs;
- Work or not work; and
- Choose a personal attending physician.

4. Participation
Residents are to participate in planning their care and treatment and to participate in:
- Resident groups if they so choose;
- Social, religious, and community activities;
- The survey process; and
- The administration of the facility.

Even residents with a diagnosis of dementia can participate in planning care and exercising choice. If a resident’s preference cannot be honored, the staff needs to engage in problem solving with him/her to find a solution that is as close as possible to what the resident wants. Residents need to be familiar with the grievance process in the facility and have confidence that the process will work. Facilities are required to assure resident and advocate participation in the administration of the home.

These four themes—communication, choice, decision making, and participation—embody the approach, attitude, and philosophy of implementing residents’ rights. They have to be continuously exhibited.

Note: See the Resources Section for a copy of the federal regulations related to Residents’ Rights.

**THE BASICS OF INDIVIDUALIZED QUALITY CARE**

Consumer Fact Sheet No. 16

April 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).

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**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:

<table>
<thead>
<tr>
<th>Problem</th>
<th>Goal</th>
<th>Approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incontinence</td>
<td>Will become independent in toileting</td>
<td>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*).</td>
</tr>
</tbody>
</table>

*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:

<table>
<thead>
<tr>
<th>Need</th>
<th>Goal</th>
<th>Approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>I need assistance with using the bathroom</td>
<td>I want to regain my independence in using the toilet so that I may go home.</td>
<td>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*).</td>
</tr>
</tbody>
</table>

*CNA=Certified Nursing Assistant, N=Nursing; PT=Physical Therapy; OT=Occupational Therapy; ST=Speech Therapy; D=Dietary
Three examples of Basic Quality of Care Practices follow: Toileting, Hydration, and Mobility

TOILETING

Basic Quality of Care Practices for Toileting

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

Your Mom and You

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

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:

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

*CNA=Certified Nursing Assistant, N=Nursing; PT=Physical Therapy; OT=Occupational Therapy; ST=Speech Therapy; D=Dietary
Tips for Monitoring the *Individualized Care Plan for Toileting/Continence*

- Be vigilant that your mother is toileted on *her individualized* schedule rather than someone else’s schedule (e.g. on her lifelong schedule every 3-5 hours, rather than every two hours, which does not help your mother and wastes staff time).

- Be especially watchful on evenings, nights, weekends, Mondays and Friday, and holidays, when there may be less staff. If the facility is short staffed, or staff is poorly monitored, then they may tell a resident that she must use a brief (diaper). This is both a quality of care and quality of life issue. The indignity of soiling herself and the feelings of helplessness may be the cause of depression.

- Provide your mom with her special soap and skin creams. Also provide the easy-open, sanitizing hand wipes. Check remaining quantities to see if they are being used.

- Check that the call bell is on her left side so she can request help until she can use her right side.

- Staff shortages can cause staff to withhold fluids so the need to toilet is less frequent. Does she drink her tea when pills are passed, at lunch, and between meals?

- Telephone the charge nurse at odd hours (e.g. 1a.m); ask about the number of available staff on duty. Keep a record of who you spoke to and what was said.

- While visiting, check that the call bell is on the left side and monitor the timeliness of staff assistance to the toilet. Ask your mom if she ever has to wait too long for assistance to the bathroom. Incontinence causes wet skin and clothing, which may lead to skin breakdown and pressure ulcers.

- When possible, vary your visit times to avoid staff from becoming too familiar with your arrival times (some staff members are inclined to give care only when the family is expected to visit).

- If you help your mother to the bathroom, be sure you are aware of her current transfer, ambulation, and assist ability. This is to avoid the possibility of injury to your mother or yourself. When in doubt, always ask.
HYDRATION
(getting enough to drink)

Basic Quality of Care Practices for Hydration

- Most residents should drink about eight glasses of fluid a day.
- Fluids that the resident likes should be available, within reach, 24 hours a day. At mealtime, fluids should be served at a temperature that is safe and is according to the resident’s preference.
- If a resident cannot remember to drink, then staff must remember and assist with drinking throughout the day according to the resident’s lifelong routine.
- If a resident cannot drink, then staff must assist at meals, between meals, and at night as needed.
- If a resident needs to relearn how to drink, then staff must teach her and take responsibility for providing the rest of the fluid through IV, 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:

<table>
<thead>
<tr>
<th>Need</th>
<th>Goal</th>
<th>Approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistance with drinking an adequate amount of fluids</td>
<td>Gain independence in hydration</td>
<td>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).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>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).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Monitor and record independent hydration (eight glasses/64 ounces/2000cc per 24 hours) for one week to assure ability to hydrate independently (N).</td>
</tr>
</tbody>
</table>

* CNA=Certified Nursing Assistant , N=Nursing; PT=Physical Therapy; OT=Occupational Therapy; ST=Speech Therapy; D=Dietary
Tips for Monitoring the *Individualized Plan of Care* for Hydration

- Make sure the large handled cup is at the bedside on the left side until your mother is able to reach with her right side, then reverse bedside table to force use of her right hand.

- You and your family members agree to bring your mother’s favorite iced tea mix. You follow-up to be sure your mother is having this drink.

- Families should see residents drink fluids at meals three times a day, between meals when pills are passed (usually 4-8 ounces), and before bedtime at the very minimum.

- Check your mother’s skin, eyes, and mouth for increased dryness, especially on Mondays, Fridays, weekends, and holidays. Report any signs of dryness to staff.

- Notice and report the presence of any skin changes/irritations/breakdown, as well as the presence of strong, dark, odorous, or small amounts of urine.

- Advise the staff of the amount of fluids that were taken during your visit so that it can be calculated in the 24 hour total (I & O).
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:

<table>
<thead>
<tr>
<th>Need</th>
<th>Goal</th>
<th>Approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistance with keeping joints mobile</td>
<td>Prevent contractures</td>
<td>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).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>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).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>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).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Assess right hand contracture for possible need of splint; provide instructions for application (OT).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Assess ability to do active exercises independently on both sides in one month, 3/14/05 (N/OT/PT).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>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).</td>
</tr>
</tbody>
</table>

* CNA=Certified Nursing Assistant, N=Nursing; PT=Physical Therapy; OT=Occupational Therapy; ST=Speech Therapy; D=Dietary
Tips for Monitoring the *Individualized Care Plan for Mobility*

- Ask your mom if the certified nursing assistants (CNAs) are assisting with the active ROM to her left side at 10:00 a.m. and 8:00 p.m.

- Ask CNAs to describe and demonstrate the active exercise program to you. They may not know how to do them.

- Visit your mom on Mondays, Fridays, evenings, weekends, and holidays to be sure ROM is occurring as scheduled each day. (PT and OT programs are usually closed on weekends and holidays and nursing staff is often reduced).

- Help your mother take responsibility for these exercises as soon as possible. Encourage your mother to do ROM exercises on her own as much as she can, adding more as her strength and flexibility improve.

- If your mom is leaning to her right side when she sits in a chair, ask the staff for help in repositioning her. She should be supported on her right side so that it looks even with the left (e.g. good body alignment should be maintained as much as possible).

- If a hand splint or hand roll is being used, remove and check your mom’s hand for cleanliness, an unpleasant odor, and skin irritations.
**Tips on How to be a Proactive Partner in Care**

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

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

- Participate in the IDT care planning conference. Ask for one if you have unanswered concerns. If the professional jargon becomes too confusing, suggest using an “I” Care Plan format (described on the next page).

- Know the specific goals as outlined in the Care Plan.

- Be aware of any changes in the Plan of Care; ask the staff to keep you informed.

- Monitor the steps of the Plan of Care as outlined; address lack of implementation immediately.

- Physical, Occupational, and Speech Therapy are only parts of the Care Plan. Assure the basics of 24 hour care are covered on the plan, including nutrition, hydration, toileting, activities (not just bingo), mobility to support the goals of the therapy.

- When possible, make frequent telephone calls to the nursing facility. Avoid calling at times of high activity for example, the change of shifts, meal times and medication pass times.

- Know your rights under the law. Individualized care identifies both what and how care is to be provided.

- Remember, care and services are provided to maintain current abilities and attain those abilities lost by a resident’s condition. Abilities should decrease only if a new disease occurs, there is an irreversible progression of the condition, or a resident refuses care. In this nursing home the cause of your mother’s hand contracture, incontinence, and dehydration was directly related to her lack of** Basic Quality of Individualized Care.**
A Best Practice

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

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

<table>
<thead>
<tr>
<th>Need</th>
<th>Goal</th>
<th>Approaches</th>
</tr>
</thead>
</table>
| I need to keep my left side strong| Long-Term Goal: I want to return to my home for my birthday on June 1st.  
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). |
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

This consumer fact sheet is part of the National Citizens' Coalition for Nursing Home Reform’s Maryland Family Council Project. Funding for this fact sheet was made possible by a grant from the State of Maryland Department of Health and Mental Hygiene, Office of Health Care Quality. 

NCCNHR is a nonprofit membership organization founded in 1975 by Elma L. Holder to protect the rights, safety and dignity of America’s long-term care residents.
Sample In-Service
Sensitivity to Residents’ Situations

This exercise is designed to sensitize staff to residents’ feelings of powerlessness, loss, and lack of choice.

Ask each staff member to complete the exercise on the following page. After each one has made their choices, conduct a discussion exploring how their life would change, what they would have to give up, and how they would feel about moving into the facility. During the discussion, remind staff that residents should be encouraged to:

- Air grievances and suggestions;
- Discuss concerns with staff, i.e. discussing menu preferences with the dietitian;
- Participate in care planning; and
- Get involved with the resident council.

Now have staff get in groups of 2, 3, or 4 people. These are now “roommates” and each group is to come up with one set of seven items to “keep.”

Follow exercise with discussion:

- How hard was this exercise?
- Did anyone have to give up something they really wanted to keep?
- Would they be compatible with their new roommates?

After discussing the exercise, ask participants how they can help residents with their adjustment to nursing home life and how they can return power and control to residents.

Adapted with permission from the Missouri State Long-Term Care Ombudsman Program
FANTASY EXERCISE

Imagine that you are an 80-year old person. Safety, social, nutrition and housekeeping needs are no longer being met in your present residence. You have some family, some close friends, and much the same likes and dislikes as you do at your current age. You, your doctor, and others whose judgment you respect have come to think you need the help you could get living in a nursing home.

In this fantasy situation, pretend you must move into a facility and can keep only seven of the privileges listed here. Place a check mark in front of the seven that are most important TO YOU. If the most important things to your happiness are not listed, you may add two choices by writing them in the space marked “other”. These will be included in your final list of seven.

____ The privilege of doing gainful activities daily, similar to what you did in your home or apartment.
____ The privilege of taking frequent trips, and visiting friends and family outside the facility.
____ The privilege of keeping pictures of your family and small, treasured mementos.
____ The privilege of bringing favorite pieces of furniture from your home or apartment.
____ The privilege of defining your own schedule, i.e. making noise, staying up late, not getting dressed in the morning, etc.
____ The privilege of entertaining friends in sufficient space and privacy.
____ The privilege of keeping and preparing food in any way you please.
____ The privilege of keeping a pet.
____ The privilege of monitoring your own health; to keep, take, or refuse medications.
____ The privilege of making totally independent decisions, with yourself and your close family and friends as the only people's opinions to consider.
____ The privilege of determining how you will spend your time: leisure, rest, work, alone, with others, etc.
____ The privilege of continuing relationships with friends who live in their own homes.
____ The privilege of having space and supplies to work on your hobbies.
____ The privilege of grieving for loss of home and independent living status.
____ The privilege of receiving considerate, respectful care, with your privacy and need for independence respected.
____ The privilege of living in an environment where it is okay to talk about and discuss your fears and feelings about aging, life, and death.

OTHER_______________________________________________________________

_______________________________________________________________

________

Adapted with permission from the Missouri State Long-Term Care Ombudsman Program
Sample In-service Training Exercise

**What I Will Be Like When I’m 85 years**

**Directions:** Write about what you will be like when you are 85 years old. Include information about your personality; what you think will be important to you; what your interests might be; what you will like to do with your time; how you will relate to others; etc.

Name: ___________________________ Age: ____ Date: __________

Shared by: Bonnie Ruggles-Ruechel, National Association of Activity Professionals
**EXAMPLE**

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

I want my caregivers to know:

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

The way I like to awaken & begin my day:

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

The way I relax and prepare to sleep at night:

I am a terrible sleeper. Don’t worry if I am up several times, reading, puttering and checking e-mails.

Activities I enjoy:


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 (homemade); 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:

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Foods that I enjoy:

For comfort:

For fun:

Other:

Things I do not like:

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Things that calm or soothe me:

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Stories
Choice

Long-term care ombudsmen, activities professionals, and others submitted the following stories and others related to residents exercising choice.

For the two years that Mrs. B had been a nursing home resident, she repeatedly told the ombudsman that she wasn’t happy and wanted to go home. But she wouldn’t let the ombudsman discuss this with her son, whom Mrs. B said was her guardian and had placed her there. But when her nursing home and other bills were delinquent because her son was failing to pay, Mrs. B finally asked for assistance. To deal with the guardianship issues, the ombudsman referred the case to a Georgia Legal Services attorney, who found that the guardianship proceedings were still pending, and that Mrs. B’s son was not her guardian after all. Having no legal barriers to moving back to her own home, Mrs. B was assisted in arranging in-home services. Today Mrs. B is living in her own home. She reports to the ombudsman that she feels in control of her own life again.

Submitted by: Becky Kurtz, Georgia State Long-Term Care Ombudsman

Although facility residents frequently wish to live in a community setting, some do not. Mr. R has lived for many years in an intermediate care facility for the mentally retarded (ICF/MR). When the facility began to reduce its size, facility staff identified Mr. R as a good candidate for community placement. Mr. R’s family called the ombudsman for assistance. When the ombudsman visited Mr. R, he told her repeatedly and consistently that he did not want to be forced to leave. Together with a Georgia Legal Services attorney, the ombudsman advocated for Mr. R’s wishes to be honored. Today, Mr. R continues to live in the place of his choice. He tells the ombudsman that he is pleased to remain in the place that has become his home.

Submitted by: Becky Kurtz, Georgia State Long-Term Care Ombudsman

After her stroke, Mrs. B received therapy in a nursing home. Her condition dramatically improved, so she started talking to her family about wanting to leave the facility. Her family, worried that Mrs. B couldn’t manage on her own, insisted that she stay. When the ombudsman met her during a routine visit, Mrs. B explained her frustration at staying in the facility when she felt she could manage in a less restrictive environment. The ombudsman provided Ms. B and her family information about the array of long-term care options, and they decided on a personal care home where the ombudsman continued to visit.
Several months later Mrs. B told the ombudsman that she didn’t need the level of services provided by the personal care home. Again, the ombudsman provided Mrs. B and her family information on options and services in the community. Today, Mrs. B has her own apartment. She reports to the ombudsman that she is doing well on her own and is proud to show her family how self-sufficient is.

Submitted by: Becky Kurtz, Georgia State Long-Term Care Ombudsman

A Long-term Care Ombudsman had a 96-year-old resident at a facility in Central Illinois. This resident was in a wheelchair and determined to return home. Mrs. S talked to Long-term Care Ombudsman about how beautiful her house was and that she needed to get home to take care of it. Mrs. S was alert and once again determined to go home. The Long-term Care Ombudsman talked to Mrs. S about help at home. She made it clear to Long-term Care Ombudsman that she would not need help. She talked about the wonderful neighbors she was ‘blessed’ with. The Long-term Care Ombudsman asked about cleaning and scrubbing floor, that maybe Mrs. S could have someone once a week to clean. Mrs. S graciously declined help stating she would put a wet rag on the floor and move it with her feet. After many conversations with the resident and resident and the facility, social service director was the biggest hurdle, a cab was called and the resident returned home. She called the facility the next day to let them know everything was fine and was happy to be home. Mrs. S was able to live her final days (6 months) the way she wanted, in her own home. This case taught me to ask the question, just because a person is over the age of 80 or 90 why do people assume they can no longer make decisions for themselves. This is my favorite success story.

Submitted by: Pat W., Long-term Care Ombudsman

While visiting a Nursing Home in Seward, Alaska last July, I noticed an elderly Alaska Native woman sitting on the floor in the hall crying. I asked staff about her and they told me her name was Mrs. P and she was a new resident. She lives in a remote Alaska village called. They told me that she was there because her grown daughter had recently been killed and she “lost it”. The husband and family couldn’t deal with her so they brought her to Seward where she was admitted to the nursing home. She had reverted back to only speaking in her native language of Yupik, and there was no one to “translate”.

I went over to her and sat down on the floor next to her. She was crying and I could understand that she was saying “I want to go home” over and over. I visited with her for a while and she began to say things to me like “I’m hungry”. We went to the dining room and she sat down and ate some crackers. She took me into her room and we sat on the bed and she continued to cry. I told her that I would help her go home. She seemed to understand.
Over the next few months, with the help of the Social Worker from the home, we began a plan to return Mrs. P to her village. Soon after she was sent to Seward, her husband realized that he needed her back home! They are in their 80’s but, as a lot of native elders are doing, they are raising small grandchildren. The youngest “adopted” grandson was only a year old.

I visited Mrs. P several more times and she began to talk to me about her family – in what little English she could. She showed me a calendar and pointed to the dates all of her children were born and to the dates that 3 of them had died. She had lost two other children to accidental deaths. I continued to tell her that we were working on getting her back home but we wanted to make sure she was “healthy” enough. She began to eat better and to participate in her “recovery” with the help and encouragement from the home.

Finally, in December – before Christmas – a date was set to send her home. Because she could not travel unescorted, the Social Worker from the home, and I both traveled with her to her village. What an experience for us! It was the middle of winter and needless to say, the “big” plane only takes you so far! We had to take a small puddle jumper to the village – where we were offloaded onto a “runway”. No building, no taxi, no nothing – just a dark, windy knoll. Mrs. P was picked up by her husband, (who was never very warm to either of us). We managed to bum a ride from another family and were told to “get in the back” (that would be the bed of the pickup truck). So we did. We were quite wet and cold by the time we got “checked in” at the Atco construction trailer (no “hotels” in the village). I guess once Mrs. P got home she gave Mr. P a piece of her mind – because the next thing we know, a young girl shows up at the “trailer” and says her grandmother wants us to come to their house and eat supper! So again – we climbed into the back of a pickup truck and off we went!

The story of our “time” in Mountain Village is a most interesting tale – like us being “snowed in” and having to wait for a flight out of there! I could elaborate a lot more on the “details”, but that is not the most important point of this writing……

The entire experience was such a life enriching one for both myself and Susan (the social worker)! The empowerment of this tiny, meek, tearful little woman to stand up and to do what she needed to do in order to return to her village – the smiles we shared – the non-verbal communication that passed between us – she and I singing “You Are My Sunshine” to each other while sitting in the airport – not to mention the chance to work so well with another agency to attain a positive outcome for an elder – were just AWESOME!

Submitted By: Julie Bailey, Assistant Long Term Care Ombudsman, State of Alaska

When working in a facility, there was a male resident who would go to bed at 10:30pm every evening after watching the evening news on television. He would
be in bed for 2 or 3 hours sleeping, but then would wake up. He was a teacher for 35 years and was an avid reader, especially Children’s Literature. Children’s Literature was one of the subjects he taught. He wanted to get up and read. He had his own supply of books, so staff would make sure he had the proper lighting and a comfortable chair or prop him up in bed so he could read. He would read for 30 minutes or sometimes for a couple of hours and then was able to go back to sleep. Reading seemed to be the way to get this gentleman to go back to sleep, otherwise he was awake for the rest of the night.

Submitted by: Bonnie Ruggles-Ruechel BS, ACC

At every Resident Council meeting, the residents were asked if there was anything they would like to have done in their life and had not been able to do. A lady in her late 60’s, who was a retired army nurse, said “Yes, I always wanted to play Bridge”.

As Activity Director, I contacted the local technical college and made arrangements for a lady to come and teach residents how to play Bridge. We had four tables, twelve people in all, including some activity staff, who took Bridge lessons. The class met once a week for six weeks. The instructor kept the lessons as basic as she could.

When the six lessons were finished, the activity department held a graduation party for the class. We had a meal and each resident was presented a graduation certificate for his or her completion of the course. This certificate was framed so the resident could hang it up in their room.

After, all this was done, there were still four ladies who continued to play Bridge. The lady who requested this, passed away six weeks later. She was able to fulfill one on her dreams, before she passed away.

Submitted by: Bonnie Ruggles-Ruechel BS, ACC

In looking at ways to offer choices to residents at Life Care Center of Pueblo, 2 years ago a “Sleep In, Eat Late” program was started.

Instead of the usual 7:00 a.m. to 8:30 a.m. breakfast, the residents were able to choose their breakfast time between 8:30 a.m. and 10:00 a.m. In the beginning, there were 6 residents participating in the new program. Now, there are 20 to 24 residents that enjoy sleeping longer.

One of the residents, now 96 years old, had not been much of a participator in group activities in the Center, but strongly stated how she minded getting up for such an early breakfast. When the new breakfast program was offered, she was the first the embrace the “Sleep In” with much joy.
She has not missed one breakfast and is always thrilled to order her omelet with “everything but bell peppers”. She became comfortable with the new breakfast group and now serenades everyone before she leave the dining room. She has become acquainted with the other residents in their group and now has begun attending other group function at the Life Care Center of Pueblo. Having the choice of sleeping later and taking small steps in socializing, the 96-year-old resident has become more social in her everyday life.

Submitted by: Renee Risoli, Social Services Director, Life Care Center of Pueblo, Colorado
Long-term care ombudsmen, activities professionals, and others submitted the following stories and others related to residents exercising choice.

When Mr. H’s company bought CC Center, it was anything but! [Mr. H is the Administrator]. This 123 - bed nursing home received deficiency packed surveys year after year. As far as the public was concerned it was the residency of last resort: high staff turnover, unanswered concerns of residents and families, odors, all the long-term care horror stories. At one point in it’s history, the Administration asked the Director of Nurses not to attend Care Plan Meetings because it was so difficult for her to be nice to the families! The citizens who lived here were hopeless and so I was not too thrilled at the prospect of another company buying this residence to change the wallpaper and “clean house” (cut staff.) Boy, was I wrong…what a difference today!

The first thing I noticed was that the building was clean inside and outside and the perpetual odor was gone. All the citizens who live there were obviously receiving help attending to their personal care. Residents and staff were smiling more often and the staff – even though busy - was actually friendly. The staff of the “old guard” had slipped away, Mr. H told me he had 55% staff turnover in the first 3 months. I believe this was due in part to his “room to room” management style instead of the “mostly behind the desk” style of his predecessors. I all but stopped hearing from disgruntled families who used to paper the facility with complaints and kept the state hotline number on their speed dial. Their concerns were being heard and addressed promptly by Mr. H and his staff. The residents receive consistent visits to ask, “what do you miss?” One by one each resident’s normal individual routine is being learned and adopted into practice. The staff is utilizing the care planning process to accomplish this, of course, but mostly it has been through personal visits with each resident in their room.

The old smoking porch is now a pleasant place for smokers and everyone else too. The screened in porch between two wings now has raised planters with seasonal flowers (and a tomato plant or two); it overlooks a previously neglected outside area that is beautiful with a large flowerbed around a big pecan tree. There are new residents as well: squirrels, pigeons and songbirds!

Now there are refreshment stations in the common areas of the home where the citizens, their visitors and family can help themselves to coffee, juice and water. The people really like this because it allows them the opportunity to be hospitable as they would if they were in their own home. An old therapy room was converted into a rather authentic, great Movie Theatre with a huge screen and projector. When the movie is playing it’s dark in there!
You wouldn’t know that this Nursing Home shares its street with a six-story high-rise building for single families operated by the local Housing Authority. So, at first glance, the neighborhood is not the first place people would choose to look for a care facility. But, the quality of this nursing home excels above the homes located in higher tax brackets elsewhere in town. Above the newer buildings and more costly decoration— it’s the quality of life and quality of care that really matter. The turnaround has been incredible—I am so pleased to submit their success! …with hope to spark another!

Submitted By: Patrice V. Berry, Regional Ombudsman, Texarkana, TX

Mrs. J came to live at H Home a couple of years ago. She was a determined soul, outspoken and always pushing us on. She didn’t sit by the sideline and tell us what to do; she jumped right in and became one of the team as we found ourselves on the culture change journey.

Mrs. J ran restaurants all her life. She enjoyed the activity kitchen but wanted to do things on a bigger scale. She was willing to go to sanitation class and did well. With the kitchen staff at her direction and the activity director as her support she planned the menu and prepared supper. We had paprika chicken on rice, fried cabbage, green beans, cottage cheese with pears, home made rolls and tapioca pudding. It was a great meal. After we had eaten Mrs. J critiqued the kitchen staff and shared changes that might help the kitchen be more efficient.

Mrs. J had respiratory problems and soon was on oxygen that meant she could not be near flames. Hospice was now involved with Mrs. J’s care. She never gave up. She continued to make homemade soup, cookies and other foods in the activity kitchen for special occasions with staff support.

Mrs. J served on the food committee, the welcoming committee and the marketing committee. She was always ready to share the story. She, along with a group of other residents met with a class, spoke at a seminar, and was featured at the first meeting of the St. Louis Pioneer Coalition. Mrs. J was always gracious to those that came to H Home to learn more about our journey. She wrote the President and the Governor to encourage them to “come see.” Mrs. J would tell you she sat the state surveyors down and her hospice workers to “set them straight about culture change.” She was an advocate because she was experiencing culture change first hand.

Mrs. J, even though on hospice, decided she wanted to put together a cookbook and redecorate her room. The room is nearly finished and the gathering of recipes has begun but Mrs. J has been called away by God.

Mrs. J lived every minute of her life. Always helping and serving others even as she took her last breath. What if she had not lived at a home that was on the journey? Would she have had the opportunity to serve, to be productive, to share with others and to be in control of her daily life?
The other residents are planning a memorial for Mrs. J. It is an activity that is occurring from the heart. "Mrs. J is portable," says the family, and "her date book is open."
Submitted by: Marcia Haslett, NHA, Hitz Memorial Home, Alhambra Il.

Since its journey to culture change began nearly four years ago, PEC Center has been credited with a number of creative innovations. Adopting a philosophy of resident-centered care has allowed PECC to view industry-standard activities in a new light, one that serves our purpose of promoting choice and independence for our residents.

An early feature of PECC's culture change strategy was the establishment of "neighborhoods of care", a division of the facility into three physically distinct areas. Each neighborhood has a unique name chosen by vote of the residents who live there. We saw that as each neighborhood developed its own personality the interests of those residents could no longer be effectively served by one facility-wide Resident Council. This led to the creation of Resident Councils for each neighborhood of care.

Once the neighborhood Councils were established participation by the residents increased dramatically. Soon, the Council Presidents and members of the neighborhood were driving the Council meetings. Reports by department heads continued, of course, but the smaller groups encouraged fuller participation and more spontaneous contributions by residents.

Some things were carried over from the days of one large Council, but adapted for the new circumstances. Formerly, one staff member was chosen by the Resident Council to be honored as Employee of the Month. With advent of neighborhoods of care, consistent staff assignments were emplaced, thus enabling each neighborhood to grow to know and bond with the staff that much better. The neighborhoods continued the tradition of electing an Employee of the Month, and now each month three PECC staff members are recognized. Since the residents and staff are more familiar with one another, the honor has gained value in the eyes of the staff.

Building on this foundation, the facility's administration adopted what we believe is a unique practice: since the culture is changing toward as much resident choice and empowerment as possible, each Resident Council now has a role in hiring. Prospective employees are still interviewed by the appropriate managers, but whenever possible the Councils are brought into the process. (If the schedule of interviews doesn't allow that, the Council President is invited to interview the candidate.) We believe that engaging the residents themselves in the hiring of the staff who will help care for them benefits everyone. The residents have important input into the makeup of the staff while prospective employees are able to get acquainted with the people they will be caring for.

So far this seems to have been a positive change for all. Residents express far more satisfaction with staff than before, and new staff enter the neighborhood with a head
start in understanding the culture of the neighborhood to which they are assigned. Complaints from the neighborhoods to administration about staff have become unusual, while new staff find it easier to feel "part of the family" and at home on the neighborhood. Most importantly, we believe this innovation gives our residents real control of the quality of their lives at PEC Center.

Submitted by: Dean Barnett, staff, PECC, Pueblo, Colorado.

At a facility in Peshtigo, Wisconsin, one of the items requested when the resident council officers met in executive session a couple of days before the regular meeting was that all council officers have a copy of the minutes of the meeting (all the meetings).

Loose-leaf notebooks were purchased for all the officers (President, Vice President, Secretary and Treasurer). The activity director typed the minutes from each meeting and after they were reviewed by the officers for corrections, a copy was given to them for each of their binders. This was kept in the officers’ room so they could reference it at any time. The policy and procedures for Resident Council included each officer having a binder in their rooms.

Submitted by Bonnie Ruggles-Ruechel, BS, ACC, NAAP

As Mr. M approaches nearly nine decades of living, he yearns for one last moment soaring through the skies. On Saturday, June 10th at 9:00 a.m., former mayor donated his time, plane and talent as a pilot to take Mr. M on his dream flight. Mr. M, a resident, was a U.S. government employee, fighting forest fires from 1944 - 1948. For his final six months with the government, he was a fire jumper (parachutist).

Throughout the years, as Mr. M worked in sales, as a custom wheat cutter, ranch hand and logger, he remembered his years as a paratrooper for the fire fighters. After his stint with the government, he returned to the Haven area and, married his sweetheart, Mrs. M. He then farmed in partnership with his dad until he retired. But the love of flying never left Mr. M. He and Mrs. M traveled after retirement and saw all but two of the states but he didn’t fly. Shortly after Mrs. M passed away, Mr. M moved to the nursing home and tabled his dream of one more flight.

But, one day, Mr. M told a social worker about his hope of another chance to soar. And the social worker began a campaign to fulfill Mr. M’s wish. "Once I started telling people about it, the plan just came together," she said. "A fellow-social worker, our staff and administration really got with the program and put a plan together."

The plan included the former mayor as a pilot, Mr. M’s nephew as transportation for Mr. M to get to the airport and lots of cheerleaders throughout the facility, working on the logistics of getting Mr. M in the air. A CNA accompanied Mr. M on his flight to assist. During the flight, Mr. M entertained the passengers with stories about his smoke jumping days and about his high school wrestling championship where he earned the
nickname, “Smiling Fritz.” It was a day of dreams come true for Mr. M and a day of new memories and excitement.

"Our staff really put it all together," stated the nursing home CEO. "It's just another example of the dedication and determination of our staff to provide a nurturing and life-focused environment for our elders."

Submitted by: Kimberley Moses-Stevens, Independent Living/Marketing Coordinator, Kansas