

Consumer Fact Sheet

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

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

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

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

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

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

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

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

Assessment and Care Planning

The Resident Assessment and Care Plan Process:

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

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

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

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

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

Developing an Individualized Care Plan:

The Care Plan, by law, *is initially prepared with participation to the extent practicable of the resident or the resident's family or legal representative.* The initial care plan must be complete by the 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.

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

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

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

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

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

Toileting, Hydration, and Mobility

Toileting

Basic Quality of Care Practices for Toileting:

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

Your Mom and You

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

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

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

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

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

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

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

HYDRATION

(getting enough to drink)

Basic Quality of Care Practices for Hydration:

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

Your Mom and You

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

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

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

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

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

Mobility

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

Your Mom and You

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

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

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

Tips for Monitoring the *Individualized Care Plan* for Mobility

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

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

Tips on How to be a Proactive Partner in Care

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

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

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

A Best Practice

First Person Care Plans:

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

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

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

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

Tips for Moving Toward an “I” Care Plan

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

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

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

Residents' Rights Week Packets from previous years are available through the Consumer Voice. Visit www.theconsumervoice.org.

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

The Consumer Voice Consumer Fact Sheets available at

http://www.theconsumervoice.org/public/50_156_434.cfm include:

Abuse and Neglect

Assessment and Care Planning

Consumer Guide to Choosing a Nursing Home

Culture Change in Nursing Homes

Individualized Assessment with Behavior Symptoms

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

Physical Restraint Free Care

This consumer fact sheet is part of the National Consumer Voice for Quality Long-Term Care'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.

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

© 2011 National Consumer Voice for Quality Long-Term Care, 1001 Connecticut Avenue, NW • Suite 425 •
Washington, DC 20036 • Phone: 202.332.2275 • Fax 202.332.2949 • Email info@theconsumervoice.org

