



A Resource Paper:

QUALITY CARE IN ANY SETTING: USING OMBUDSMAN KNOWLEDGE TO HELP CONSUMERS

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TABLE OF CONTENTS

The Role Of The Long-Term Care Ombudsman Program...	4
Ombudsmen Can Help Consumers Learn About Quality Care...	5
The Long-Term Care Ombudsman Program’s Knowledge Base...	6
Summary...	8
Appendix...	9
Good Care Prevents Poor Outcomes	
How Do You Know When Preventive Care Is Needed?	
Rehabilitative/Restorative Care to Increase Function	
The Basics of Individualized Quality Care	
Advancing Excellence: Goal #1 Reducing Pressure Ulcers	
Ombudsman Guide to Good Practice	
Office of the Ohio State Long-Term Care Ombudsman, Client Rights Comparison	
Quality Care Practices, Selected Resource List	

QUALITY CARE IN ANY SETTING: USING OMBUDSMAN KNOWLEDGE TO HELP CONSUMERS

Long-term care ombudsmen (LTCO) have knowledge about quality of care that can help long-term care consumers regardless of where the consumer lives. Skilled ombudsmen know the importance of hydration, nutrition, mobility, basic hygiene, and skin care, among other basic care fundamentals. The basics of good care practices are the same regardless of the setting or the care provider.

Since the Long-Term Care Ombudsman Program began, LTCO have used their knowledge about good care practices to address issues on behalf of residents in long-term care facilities. Ombudsmen know what to observe and how to listen for indicators that care practices may need to be improved. With the expanding range of options for long-term care services, LTCO have basic knowledge that can help consumers¹ regardless of the setting.

This paper is intended to:

- help LTCO recognize the knowledge and resources about quality of care that they have, and
- be alert for opportunities to share key information about quality of care with consumers.

There are three major sections in this resource paper:

- The Role of the Long-Term Care Ombudsman Program,
- Ombudsmen Can Help Consumers Learn About Quality Care: Examples,
- The Long-Term Care Ombudsman Program's Knowledge Base.

THE ROLE OF THE LONG-TERM CARE OMBUDSMAN PROGRAM

When consumers contact the LTCO program for assistance in selecting a facility, LTCO typically provide information about the available range of options such as assisted living facilities, board and care facilities, nursing homes, or in-home services. Ombudsmen suggest tips on what to observe and what questions to ask when visiting a facility. Some of these tips relate to quality of care. Ombudsmen routinely refer consumers to other sources of information related to quality of care such as the facility specific information available on the Centers for Medicare & Medicaid Services website or on a facility's survey report.

With the expansion of home and community based care options, LTCO are seeing some individuals move from one care setting to another or back home with supportive services. Ombudsmen may visit the same individual in more than one type of setting over the span of a few weeks or months. Because of the transitions that consumers experience, it is appropriate for LTCO to include information and resources about good care practices when providing information about long-term care facilities or other options for care.

Ombudsmen have many educational tools and resources about good care. These are useful for ombudsman education and can help LTCO talk with consumers and providers about care practices. Four examples of LTCO tools are:

- "Using Resident Assessment and Care Planning As Advocacy Tools: A Guide for Ombudsmen and Other Advocates,"
- "Nursing Home Quality Initiative Training Curriculum Manual for Long-Term Care Ombudsman Programs,"
- "Care Matters: Choice, Accountability, Rights, Empowerment," and
- "Giving Voice to Quality."

One of the challenges of the LTCO role is to be knowledgeable in many areas related to long-term care. Many times, LTCO resolve issues by asking key questions and by getting the responsible experts to respond to the resident's needs.

¹ In this paper, consumers means residents, potential residents, and/or their family members.

Ombudsmen are not required to be experts in all areas of quality care. As a resident advocate, LTCO need to know enough to ask questions when symptoms of poor care are present and to know some good care practices to prevent or address a range of typical conditions.

Ombudsman knowledge about quality of care can benefit consumers in non-institutional settings as well as individuals living in facilities. Ombudsmen particularly understand the importance of individualized care planning in the provision of quality care. Some type of care planning is essential to quality across the spectrum of long term care services.

In talking about quality care, LTCO need to:

- be aware of their knowledge and share a few tips with consumers as opportunities arise,
- be aware of the limits of their knowledge such as understanding several factors related to malnutrition but not all of the complexities that may be contributing or that may address the situation, and
- be prepared to refer the consumer to printed materials or other resources on various aspects of quality of care.

OMBUDSMEN CAN HELP CONSUMERS LEARN ABOUT QUALITY CARE: EXAMPLES

What can I do?

- 1.** When you talk with consumers about long-term care settings, services, and options, listen for opportunities to share information about good care practices.

Example: A caller says that her dad's nightly roaming is getting worse so she and her mother have been trying different ways to keep him in the bed. The caller wants to know about assisted living facilities and nursing homes near her dad's home. She believes that he will soon need to be in another setting because home care is rapidly becoming more difficult.

In addition to giving the caller the requested information about facilities, you ask a few questions about her father's behavior. Your questions prompt the caller to think about why her dad is roaming at night and what calms him. You share information about care issues that can result from immobility (being restrained) such as skin irritation, pressure sores, broken bones or death when individuals try to free themselves, and agitated behaviors. You offer to send the caller information about other approaches to care and other resources. You explain to the caller other sources of information or support such as the Alzheimer's Association and services provided by the aging network, case management, caregiver support, or Aging Disability Resource Centers, that can provide more detailed information about home care.

This approach takes more of your time on the phone; however, if the father moves into a nursing home you already have begun educating the daughter about why restraints are not good care.

- 2.** Provide information to consumers about good care as opportunities arise during your normal LTCO activities.

When you give presentations for family councils or community groups, possibly as part of a community education series for caregivers, include information about good care. The training guide for "Nursing Homes: Getting Good Care There" has a few sections that may be used to address this topic: resident assessment and care planning, the seven most common problems with care, and good care is restraint free. Some handouts for consumer education from the book are in the appendix of this paper.

- If you have handouts relevant to nursing homes, talk with consumers about how to apply the information about care in other settings. If they are not dealing with a nursing home, who do they talk with when questions arise?
- Empower consumers to know what early signs to observe that may indicate problems with care, what questions

to ask, and who to ask, in whatever setting care is provided.

- Use other resources such as the goal specific consumer fact sheets from the Advancing Excellence Campaign² or use “Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes, Phases 1 and 2.” Talk with consumers how to use the information in knowing what good care practices are, making observations, asking questions, and gaining ideas for care planning.
- Remember, good care principles apply regardless of the setting, even in a hospital or a house. By educating consumers, you may help prevent problems or at least help an individual to receive timely and appropriate treatment.

3. Provide information to consumers about what to do if there are issues with care outside of a facility.

Example: During a facility visit, you see a resident and her daughter who tell you that the resident is moving back home with support from a transition program. They are pleased and say that the care manager assured them that the resident will receive the services she needs to continue to do well. You encourage them to expect good care, offer to send them information about what to observe and who to contact if they encounter problems. When you return to the office, you select a few pertinent resources and the information about rights, appeals processes, and where to go with questions and problems, and mail these to the daughter who gave you her address.

As a LTCO you have foundational knowledge to share without presenting yourself as someone with clinical expertise in a range of medical or complex care issues. If you have many years as a LTCO, you may not realize how much you know about quality of care that is not common knowledge for everyone.

What can my LTCO program do?

1. Include links to information about quality care practices and organizations on your LTCOP’s website. Make it easy for consumers to learn about quality care, what to look for, and where to go for more information.
2. Join coalitions and/or participate in task forces or meetings with other organizations such as disability rights groups, in-home providers of long-term care services, paraprofessional health care worker organizations, Alzheimer’s support groups, culture change coalition, the LANE³ in your state, state gerontology association, to learn and contribute to dialogue about quality of care and good care practices in any setting.

THE LONG-TERM CARE OMBUDSMAN PROGRAM’S KNOWLEDGE BASE

Where do I start?

1. Stay informed about quality of care and good care practices and enable all LTCO in your program to be knowledgeable in these areas. If you are a new LTCO, learn about good care. Basic care topics include care planning, continence care, hydration and nutrition, basic hygiene, and disease-specific good care. As previously mentioned, there are many resources about quality of care and good care practices. A number of these are specific to your role as an ombudsman or are tools for LTCO to use in educating others. Some of the resources include training guides.
2. Begin with the resources listed in the appendix. Two primary resources for LTCO and consumers are “The Seven Most Common Problems in Care—How Can You Help?” Chapter 4, in *Nursing Homes: Getting Good Care There*, and “The Basics of Individualized Quality Care,” Consumer Fact Sheet No. 16 by NCCNHR. Information about quality of care and good care practices is integrated throughout the national curriculum for basic LTCO training, “Equipping Long-Term Care Ombudsmen for Effective Advocacy”.

² For fact sheets and more information about the Advancing Excellence Campaign, go to: <http://www.nhqualitycampaign.org/>

³ The Advancing Excellence Campaign supports statewide coalition of stakeholders called Local Area Networks of Excellence (LANEs). The LANE in each state supports participating nursing homes in achieving their goals. http://www.nhqualitycampaign.org/lanes_definition.htm

Many other resources are on the National Long-Term Care Ombudsman Resource Center's web site as well as links to additional resources and information about quality of care, www.ltombudsman.org.

3. Refresh your knowledge of the good care areas contained in the Nursing Home Reform Law (OBRA '87). Fourteen areas are specified for quality of care in nursing facilities:

Activities of daily living	Vision and hearing	Pressure sores
Urinary incontinence	Range of motion	Mental and psychosocial functioning
Naso-gastric tubes	Accidents	Nutrition
Hydration	Special needs	Unnecessary drugs
Antipsychotic drugs	Medication errors	

The Resident Assessment Protocols (RAPs)⁴ are a tool to help facilities identify residents who are at risk for specific care issues and intervene to prevent problems and to help treat problems in order to improve the resident's condition. The RAPs contain information about quality care and good care practices that can be educational for LTCO as well as for facilities and consumers. There are eighteen RAPs based on the fourteen areas of care specified in the law.

Delirium	Cognitive loss	Visual function
Communication	ADL function/rehabilitation potential	Urinary incontinence and indwelling catheter
Psychosocial well-being	Mood state	Behavioral symptoms
Activities	Falls	Nutritional status
Feeding tubes	Dehydration/fluid maintenance	Dental care
Pressure ulcers	Psychotropic drug use	Physical restraints

An additional federal resource is the Guidance to Surveyors. Although this information is designed for use by nursing home surveyors, the narrative content, definitions and probes contain basic information about good care practices. The Guidance to Surveyors is a resource for education and advocacy for LTCO.

4. Check out available information and resources to learn more and to gain ideas. Begin with the NORC website, www.ltombudsman.org and the NCCNHR website, www.nccnhr.org. There are some excellent information sheets on the NCCNHR site that provide a succinct overview and others that apply good care practices to specific areas of care. Each of these web sites has a section on culture change and/or quality initiatives. The NCCNHR site has more resources developed for consumers and the NORC site has more resources developed for LTCO. The information for consumers is beneficial for LTCO also.
5. Participate in teleconferences and online training opportunities related to quality care and good care practices. NCCNHR and NORC offer conferences that are directly applicable to LTCO work.
6. Join the Advancing Excellence Campaign and participate in the Local Area Network for Excellence (LANE) in your state.

<http://www.nhqualitycampaign.org/> This campaign is “an unprecedented coalition [that] includes long-term care providers, caregivers, medical and quality improvement experts, government agencies, consumers and others... building on the success of other quality initiatives, including Quality First, the Nursing Home Quality Initiative

⁴ In October 2010, the MDS 3.0 goes into effect. At that time, RAPs will be replaced by Care Area Assessments (CAAs). CAAs are similar to RAPs in that they cover the majority of areas known to be problematic for residents and will trigger additional assessment and care planning. The CAA process is different from the RAP process in that it does not require a specific assessment tool or protocol but rather permits the use of CAA resources and/or other current evidence-based or expert-endorsed resources. NORC will release an updated version of this document when the MDS 3.0 goes into effect.

(NHQI), the culture change movement, and other quality initiatives.” There are succinct fact sheets for consumers on specific good care practices related to the campaign goals. The fact sheets are excellent resources. The fact sheet on pressure sores is in the appendix of this paper.

7. Participate in a culture change coalition if there is one in your state. The coalition will increase your knowledge and will offer opportunities for dialogue about good care practices. You can contribute a perspective based on your work with a range of facilities, residents, and families.

8. Check out other online resources such as the Pioneer Network’s website which contains several video clips, resources, and links related to culture change and to culture change coalitions in various states. <http://www.pioneernetwork.net/>

The CMS website contains information on quality care. One section provides an overview of initiatives and links for additional information. <http://www.cms.hhs.gov/NursingHomeQualityInits/> Refer to the resource list in the appendix for additional sources of information on specific good care practices.

9. Learn about consumer rights, including appeal rights and processes, for non-facility-based long-term care services. The LTCOP already has information about rights and appeals in nursing homes, assisted living facilities and board and care facilities. Most LTCOPs also have some knowledge about rights and appeals for hospice services, home care services, and hospitals although the information may not be compiled into one reference resource. You may have dealt with issues with the quality care provided by a home care agency to an assisted living resident. Pull this information together as a quick reference. The Ohio LTCOP is one program that has developed a chart showing differences in client rights by type of setting. This chart is included in the appendix.

10. Maintain resources about quality in your office that can be given to consumers, and know referral sources for more specific information about quality care practices. Better yet, put the resources on line or link them to resources that are available on other sites. Don’t reinvent the wheel when there are already excellent resources about pain, restraints, care planning.

11. Maintain a list of experts who can give you and consumers information about quality care. Nurses, pharmacists, and others that you can call on to get specific information.

SUMMARY

Long-term care ombudsmen have knowledge and information about quality care that can be helpful to consumers regardless of the setting in which care is provided. With the increasing options for long-term care services and with individuals moving from one setting into another, it is important for LTCO to share information with consumers about quality care, good care practices, and indicators that intervention may be needed. For example, LTCO knowledge about good skin care is applicable to caring for individuals in their own homes, in assisted living apartments, in hospitals, or in nursing homes. If consumers know what to look for, when to question, and where to go with their questions, problems may be addressed before severe problems develop.

All LTCO can share information with consumers, regardless of whether the LTCO program is serving home care clients. As LTCO speak to caregivers, conduct public education programs, and answer calls about selecting a facility, they can use these opportunities to provide information about quality care. Sharing information about quality care is a matter of realizing that LTCO knowledge applies across different types of care settings and being alert to opportunities to empower others to identify and seek quality care.

APPENDIX

GOOD CARE PREVENTS POOR OUTCOMES

From *Nursing Homes: Getting Good Care There*, Appendix 6

Preventable Poor Outcomes	Preventive Care
Bladder or bowel incontinence due to immobility or poor memory	Nursing home staff must take resident to toilet, according to individualized care plan and upon resident's request
Use of urinary catheter due to inadequate toileting	Toilet as noted above. Use of restorative care. Use adult incontinent brief only as adjunct to toileting. Residents shouldn't be told to relieve themselves in their clothing because incontinent brief is on. Catheters can be used appropriately only when: obtaining sterile urine specimen; removing urine from bladder in the event of nerve damage; and trying to heal a skin wound
Malnutrition/dehydration due to immobility, inability to understand or remember	Provide nourishing food that resident enjoys. Assist with eating, per care plan. Family and friends can help, especially if resident takes a long time to eat.
Tube feedings because staff is too busy to help residents feed themselves	Same as above. Never accept "she takes too long to eat" as adequate reason for tube feedings. Inserting a tube through the nose into the stomach, or directly into the stomach, is an uncomfortable invasive procedure that seriously diminishes quality of life. You should ask, <i>Would I want to endure that?</i>
Resident poorly dressed and groomed. Mouth and foot care poor due to busy staff, poorly trained staff, or poor staff supervision	Staff should help resident to groom and dress as needed. Clothes should be clean, though spills can occur during meals and activities. Staff should help keep mouth clean, free from food. Feet should be kept clean and dry; use lotion to soften skin; toenails should be filed.
Pressure sores due to: immobility; poor nutrition; poor fluid intake; incontinence	See that staff change position at least every two hours; two people should move heavy, immobile resident to avoid friction against body sheets. Prevention equipment includes: sheepskin booties on heels and elbows; special mattresses; special cushions in wheelchairs. Encourage resident to eat and drink; toilet as needed, keeping skin clean and dry; place pillows between knees, ankles, arms and body; help residents out of bed daily.
Contractures due to immobility	Staff should perform range-of-motion exercises for each joint from neck to toes at least daily. Help residents out of bed daily. Position resident in bed or chair with pillows/foam rolls between knees, ankles, arms and body. Residents should not be tilted to one side in a chair.
Decreased independence; loss of ability to dress, groom, eat, toilet, etc. Caused by lack of restorative services, treatments.	Staff should provide assistance to promote independence. If resident can eat alone, but takes a long time, staff should not try to feed the resident to save time.
Drug interaction due to: too many drugs, wrong types of drugs, and too high dosage.	Staff should reassess drugs to see why they are administered and how they affect residents. Look for: drop in blood pressure that causes residents to fall when they try to stand; dry mouth or skin; poor appetite; upset stomach; vision change; excess urination; restlessness; personality change.
Inability to see or hear due to: lost/broken hearing aids or lost/dirty/broken eyeglasses.	Staff should ensure hearing aids/eyeglasses are operating and kept in safe place.

How Do You Know Preventive Care is Needed?

From Nursing Homes: Getting Good Care There, Appendix 6

At-Risk Residents Are:

Immobile (unable to move without help) due to: injury, disease, drugs' or restraints

Non-communicative or unable to be understood due to injury or disease

Demented or unable to remember due to injury, disease drugs

Preventable Poor Outcome

Pressures on coccyx (small triangular bone near end of spine), hips, heels, shoulders. Contractures forcing resident into fetal position, curled up with rounded back and bent knees. Bladder and bowel incontinence and possible use of catheter. Malnutrition or poor diet. Dehydration or insufficient fluids.

Bladder or bowel incontinence and possible use of catheter. Also can result in malnutrition, dehydration and decreased ability to eat, dress, walk and perform other activities of daily living.

Same as above. Also, decreased mobility unrelated to disease, plus increased risk of accidents.

Rehabilitative/Restorative Care to Increase Function

Fro

m: Nursing Homes: Getting Good Care There, Appendix 6

Care Problem	Rehabilitative/Restorative Care	Who Requires Care?
Incontinence	Bowel and bladder training. Staff should visit with resident every two hours to check whether resident is clean/dry, or needs to go to the toilet. Staff also monitor frequency/amount bladder and bowels excrete. Food and fluid intake also measured.	Residents who can regain control of bladder and bowels, but do not have a bladder infection, severe memory loss, nerve damage to bladder, or bowel disease.
Immobility	<p>Physical therapy (PT) department schedules regular sessions until no further improvement possible. Resident then transfers to preventive maintenance program. Resident learns to stand; pivot; transfer from bed to chair; walk; and use canes, crutches, walkers and wheelchairs.</p> <p>Restorative range of motion exercises: Over time range of motion may increase</p>	<p>Residents who lost movement due to falls, broken hip, stroke, improper restraint use, or accidents.</p> <p>Resident who has start of contracture due to poor care in past</p>
Unable to dress and groom oneself	Occupational therapist (OT) suggest changes in clothes, grooming equipment such as Velcro closures if resident can't button clothes. Breaks down each task so it can be relearned step by step, teaches nurse how to follow through with program	Residents whose loss of function is due to injury or poor care.
Ability to communicate	<p>Speech therapist evaluates problem and does exercises to improve speech. When speech cannot be regained suggests other communication devices: pencil, paper, electronic devices. Teaches staff to follow through when therapist not there.</p> <p>Audiology services evaluates residents hearing and prescribes appropriate devices-staff must keep devices in good working order and be sure it is not lost.</p> <p>Optometrist prescribes glasses. Staff must help to keep devices in good working order and be sure they are not lost.</p>	Residents who have lost hearing or speaking ability due to injury disease or lost equipment
Unable to eat or drink independently	Occupational therapy: Same as above but emphasis on special equipment such as plates with high rim, tableware with built up handles. Dietary: providing appropriate foods: thickener in liquids if unable to swallow, finger foods for those unable to remember how to use a fork and knife. Teaches staff how to follow through. Speech therapist: assesses swallowing ability and suggests changes in foods, positioning for eating and drinking.	Resident who has lost function due to injury, disease, poor care.

THE BASICS OF INDIVIDUALIZED QUALITY CARE

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 NCCNHR).

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

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

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

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

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

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

ASSESSMENT AND CARE PLANNING

The Resident Assessment and Care Plan Process

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

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

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

assessment information is the foundation for the care planning process.

Developing an Individualized Care Plan

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

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

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

Here is an example of what you may find:

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

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

NCCNHR (formerly the National Citizens' Coalition for Nursing Home Reform) 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.

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

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

*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:

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

NCCNHR (formerly the National Citizens’ Coalition for Nursing Home Reform) 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.

		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, nasogastric, or stomach tube.
- A resident is assessed by Occupational Therapy and, if needed, given special equipment such as a large handled/weighted cup to foster independence in drinking.
- Fluids are the right consistency to promote safe swallowing (e.g. thin liquids, thickened liquids, jello, puddings), to avoid the possibility of liquids going into the lungs, causing a condition called *Aspiration Pneumonia*.
- Staff monitor the amount of fluid taken every 24 hours and monitor for signs of dehydration (e.g. dry, flaky skin, poor skin tension, dry, cracked lips, dry mucous membranes in mouth, increased irritation, restlessness or confusion, and the presence of strong, odorous, dark colored urine).
- Staff should also keep track of the amount of urine passed each 24 hours (this is referred to as "I & O", Intake and Output, the monitoring of the amount of fluids taken in compared to the amount of urine passed out).
- Staff monitors the progress of a resident to drink independently and changes the care plan as often as needed to reach that goal.

Your Mom and You

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

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

* 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

Basic Quality of Care Practices for Mobility

- Any part of a resident’s body that moves independently upon entering the nursing home must be maintained by the resident or staff.
- If any part of the body cannot be moved independently, then staff must move it for the resident (e.g. move each joint in each finger).
- Active and passive range of motion (ROM) exercises are done at least twice a day to prevent loss of mobility (e.g. if your mom is able to move her left arm above her head on the day of admission, that ability is maintained by active range of motion).
- Passive ROM is done *for* a person until active ROM is achieved (e.g. if your mom is not able to lift her arm above her head on the day of

admission, then that ability is attained first through passive ROM and then active ROM).

- Active ROM is done with a resident or independently by a resident.
- A resident who can walk without assistance should maintain that ability.
- A resident who does not need a wheelchair on admission should not use one.
- When a resident is sitting or lying down, alignment of the body (so that the two sides look equal) is accomplished by use of pillows, bolsters, towel rolls, and wedges.

Your Mom and You

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

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

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Tips for Monitoring the *Individualized Care Plan* for Mobility

- Ask your mom if the certified nursing assistants (CNAs) are assisting with the active ROM to her left side at 10:00 a.m. and 8:00 p.m.
- Ask CNAs to describe and demonstrate the active exercise program to you. They may not know how to do them.
- Visit your mom on Mondays, Fridays, evenings, weekends, and holidays to be sure ROM is occurring as scheduled each day. (PT and OT programs are usually closed on weekends and holidays and nursing staff is often reduced).
- Help your mother take responsibility for these exercises as soon as possible.
- Encourage your mother to do ROM exercises on her own as much as she can, adding more as her strength and flexibility improve.
- If your mom is leaning to her right side when she sits in a chair, ask the staff for help in repositioning her. She should be supported on her right side so that it looks even with the left (e.g. good body alignment should be maintained as much as possible).
- If a hand splint or hand roll is being used, remove and check your mom's hand for cleanliness, an unpleasant odor, and skin irritations.

Tips on How to be a Proactive Partner in Care

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

- Work closely with the nurse and CNAs to provide important details of your mother's life (e.g. toileting schedule, preferred drinks, usual appearance of body and skin).
- Participate in the IDT care planning conference. Ask for one if you have unanswered concerns. If the professional jargon becomes too confusing, suggest using an "I" Care Plan format (described on the next page).
- Know the specific goals as outlined in the Care Plan.
- Be aware of any changes in the Plan of Care; ask the staff to keep you informed.

- Monitor the steps of the Plan of Care as outlined; address lack of implementation immediately.
- Physical, Occupational, and Speech Therapy are only parts of the Care Plan. Assure the basics of 24 hour care are covered on the plan, including nutrition, hydration, toileting, activities (not just bingo), mobility to support the goals of the therapy.
- When possible, make frequent telephone calls to the nursing facility. Avoid calling at times of high activity for example, the change of shifts, meal times and medication pass times.
- Know your rights under the law. Individualized care identifies both *what* and *how* care is to be provided.
- Remember, care and services are provided to *maintain* current abilities and *attain* those abilities lost by a resident's condition. Abilities should decrease only if a new disease occurs, there is an irreversible progression of the condition, or a resident refuses care. In this nursing home the cause of your mother's hand contracture, incontinence, and dehydration was directly related to her lack of *Basic Quality of Individualized Care*.

A Best Practice

First Person Care Plans

In the previous sections we have outlined the *Basic Quality Practices* in three areas of care and how they can and should be individualized for the resident. As illustrated, care plans tend to be very clinical, written in language that residents and CNAs do not understand. Try suggesting the use of an “*I*” *Care Plan* written in the words you and your mother would

use. You will notice that a resident “problem” becomes a “need” and the “intervention” is changed to “approaches.” This language turns the whole thought and planning process around so that it is the resident who identifies her own particular goals. Clarity is further enhanced when the resident's own words and phrases are used. Let's look at mobility in an “*I*” *Care Plan*.

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

Need	Goal	Approaches
I need to keep my left side strong	Long-Term Goal: I want to return to my home for my birthday on June 1 st . Short-Term Goal: “I	“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

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

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Tips for Moving Toward an “I” Care Plan

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

If you are interested in learning more, NCCNHR has several publications that may be of interest. For a publication list, call 202.332.2275 or visit www.nccnhr.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 NCCNHR. Visit www.nccnhr.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 NCCNHR to use its Maryland work as the basis for this booklet.) [Cost 5 for \$10.00]

NCCNHR Consumer Fact Sheets available at http://www.nccnhr.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 - a NCCNHR tool for person-directed care

Physical Restraint Free Care

Residents' Rights

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.¹

FAST FACTS: Pressure Ulcers

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

What is a pressure ulcer?

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

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

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

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

What is the best care for preventing pressure ulcers?

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

What can consumers do?

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

Advancing Excellence in America's Nursing Homes is a national campaign to improve the quality of care and life for the country's 1.5 million people receiving care in nursing homes. Find out if your nursing home is part of the Advancing Excellence Campaign. To sign up or get more information, go to www.nhqualitycampaign.org.

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

What should you see staff doing to treat pressure ulcers?

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

How can residents and families help?

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

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

Whom should you go to ask questions?

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

OMBUDSMAN GUIDE TO GOOD PRACTICE

Adapted from the Louisiana Long Term Care Ombudsman Resource Manual
Developed by Sara S. Hunt, MSSW and reviewed by Sarah G. Burger, R.N., M.P.H.

The following pages contain some helpful suggestions on how to recognize several conditions commonly found among residents. Many of these symptoms can be observed by the ombudsman representative (LTCO) without invading an individual's privacy.

This section is intended to provide guidance for the LTCO's observations. Residents, their family members, and caregivers may have other ways of identifying these problems and may take more direct action to address the problems.

The information gained through observation, questions, and listening form the basis of addressing a resident complaint or initiating a discussion about your observations with a resident, family and/or the nursing home staff and administrators.

A. PHYSICAL CONDITIONS

PERSONAL HYGIENE

Personal hygiene (cleanliness) is conducive to good health and positive self-esteem.

Problem Indicators

- ❖ Body odors
- ❖ Dirty skin
- ❖ Dirty, matted, or unkempt hair
- ❖ Dirty clothes

LTCO's Response

- ❖ **Observe**
 - How does the resident look?
 - How do the resident's clothes look?
 - Is there any evidence of a recent incontinence episode?
 - Is the resident's appearance always like this?
 - Is today's appearance an exception or a chronic state?
 - Has the resident just eaten? If so, are there any problems with getting food or drink into the mouth?
- ❖ **Question**
 - What is the resident's bath and grooming schedule?
 - Is there a medical reason for the body odor?

- Who takes care of the resident's grooming needs?

NAIL CARE

The aging process can make it difficult to care for one's fingernails and toenails. Toenails can become thicker and harder to reach. Both toes and fingers can ache and become less easily manipulated if nails are neglected.

Problem Indicators

- ❖ Very long and /or thickened nails
- ❖ Difficulty in walking
- ❖ Complaints about fingers and toes aching
- ❖ Scratches on the body
- ❖ Difficulty in manipulating objects with the hands

LTCO's Response

❖ **Observe**

- How do the resident's nails look?
- Does the length of the nails interfere with picking up or using objects?
- How well does the resident walk?
- Are the nails clean?
- Is there evidence of scratching and breaking or irritating the skin?

❖ **Listen**

- Does the resident complain of hands or feet aching?
- Does the resident comment on nail care?

❖ **Question**

- Ask the resident and/or caregivers, who cuts nails?
- How often are nails trimmed?

SKIN CARE

Elderly skin is susceptible to dryness and is easily torn or bruised. Abrupt onset of generalized itching can be a sign of certain diseases. The scratching that often follows severe itching can lead to infection or long term skin irritation. Good skin care is important for maintaining general health.

Problem Indicators

- ❖ Scaling or flaking skin
- ❖ Scratching or complaints about itching

- ❖ Dryness
- ❖ Rash
- ❖ Changes in skin appearance
- ❖ Growth or changes in appearance of warts or moles
- ❖ Itching or burning feet

LTCO's Response

❖ **Observe**

- How does the resident's skin look?
- Are there any observable differences in the resident's skin today versus other days?
- Does the resident frequently scratch himself/herself?
- Are there a number of scratches, cuts, or bruises on the resident?
- Do you see skin care lotion in the room?
- Do you ever see anyone applying lotion to the resident's skin?

❖ **Question**

- Does the resident's skin itch?
- Does anyone rub lotion on the resident's skin?
- Has a nurse or physician looked at this mole/wart?
- Is there any explanation for this rash?
- Has a nurse or physician looked at this rash?

Information About Treatment

- ❖ Moisturizers, especially those containing petrolatum or lanolin, can be helpful in keeping the skin lubricated.
- ❖ Avoid using highly-perfumed products on the skin.
- ❖ Use mild soap for skin and for laundry.
- ❖ Some fabric softeners can cause skin irritation and itching.
- ❖ Abrupt onset of generalized itching may be a sign of disease.
- ❖ Any sudden changes in the skin should be examined by a nurse and/or physician.

BEDSORES / DECUBITUS ULCERS / PRESSURE SORES

Sores or ulcers are caused by the lack of blood circulating to some part of the body, because of unrelieved pressure of the body on bed or chair. They tend to occur on the lower spine, side of the hips, and on heels, although they can be found any place on the body.

Problem Indicators

- ❖ Red or pink spots over pressure areas
- ❖ Ulcers

LTCO's Response

❖ **Observe**

- Are there red spots or ulcers on the resident's skin?
- Does the resident remain in one position for an extended period?*
- If a resident is always in bed, is the bed clothing usually wrinkled?*
- Is there a lack of cleanliness from causes such as soiling or excessive perspiration?*
- Does the resident have problems with circulation?
- Is there fluid within reach? Is the resident able to drink it?

❖ **Question**

- Has a nurse or a physician looked at this spot or ulcer?
- How often is the resident repositioned?
- Is the resident's skin checked carefully everyday?
- If a bedsore is present, is it being treated?

Note: These questions indicate factors that can contribute to the development of bedsores. As a LTCO, your ability to detect the presence of bedsores is very limited. Your advocacy role can best be fulfilled by ongoing observation of these factors and of the care afforded to residents who are in bed or sitting for prolonged periods.

Information About Treatment

- ❖ As with any problem, prevention is the best treatment. Proper nutrition and adequate hydration (sufficient fluid intake) are important to maintenance of good skin care. These two things also help the healing process should a pressure sore occur.
- ❖ Special devices are designed to keep pressure off discolored skin and bedsores. Foam wedges and pillows are used for positioning. Egg crate or other pressure relieving mattresses or cushions are used in bed and chair.
- ❖ Lambskins are soft and allow the air to circulate next to the skin.

- ❖ Large foam mattress mats are designed expressly to prevent bedsores.
- ❖ Generalized back rubs can improve circulation and add comfort. Do not massage skin over bony prominences for it may injure the skin.
- ❖ Cleanliness and Freedom from Pressure Are the Most Important Factors in the Prevention and Cure of Bedsores.
- ❖ *No One Method May Be Entirely Satisfactory in Prevention or Treatment.*

DEHYDRATION

This condition is the lack of adequate fluid in the body. It is a crucial factor in the health of older people.

Problem Indicators

- ❖ Dry or inelastic skin
- ❖ Confusion or hallucinations
- ❖ Licking the lips
- ❖ Dry mouth
- ❖ Dizziness or lightheadedness
- ❖ Flushing
- ❖ Rapid pulse
- ❖ Fever
- ❖ Sunken eyes

LTCO's Response

❖ **Observe**

- Is there fresh water available to the resident?
- Does the resident need assistance or encouragement to drink?
- Does the resident drink the fluids served at meal time?
- If assistance is needed, is it given?
- During times of increased temperature in the facility, such as during a heat wave or air conditioning problems, are residents encouraged to increase their fluid intake?

❖ **Question**

- Is the resident thirsty?
- Is the resident on medication that causes some of these symptoms, such as a diuretic?
- Does the resident consume adequate amounts of liquids in a day?
- If the resident needs to increase fluid intake but refuses to drink water, what will the resident drink? Is that drink available?

- If dehydration is suspected, has a nurse or physician checked the resident for this possibility?

MALNUTRITION¹

Malnutrition is a condition resulting from inadequate nutrition. It can occur due to a range of factors such as: depression, unable to eat without assistance due to functional limitation (e.g. stroke) or dementia, loss of appetite, decreased sense of taste due to side effects of medication, diminished absorption of nutrients due to physical decline of endocrine system, poorly fitting dentures; insufficient saliva which aids in breaking down food in the mouth, diminished swallowing ability known as peristalsis, inadequate assistance with eating by staff.

Problem Indicators

- ❖ Loosely fitting clothes
- ❖ Cracks around the mouth
- ❖ Pale lips and mouth
- ❖ Complaints that dentures no longer fit
- ❖ Confusion
- ❖ Skin breaking down: red spots, bruises, tears

LTCO's Response

- ❖ **Observe**
 - How does the resident look: skin, mouth, fit of clothes?
 - Has there been a change in the resident's appearance during your last several visits?
 - Can the resident feed herself? If she needs assistance, does someone help her?
 - How much of her meal does the resident eat?
 - Does it take a long time for the resident to eat? Is she rushed through meals, unable to finish her food?
 - Does she eat snacks during the day?
 - Does she seem uninterested in food?
 - Does she say that she is hungry between meals?
 - Does she appear to have difficulty swallowing, e.g. chokes or turns head to the side to swallow?

¹ This section is excerpted from the Illinois Ombudsman Program Curriculum and from *Nursing Homes: Getting Good Care There*. S Burger, G Fraser, S Hunt, & B Frank. Impact Publishers. California. 1996.

❖ Question

- What does the resident say about your observations?
- What does the resident say about her appetite and eating?
- What does the resident like to eat? Does she receive it?
- What makes eating an enjoyable experience for the resident?
- Are snacks offered to her? If so, does she eat them? What are they?
- If her dentures don't fit, what is being done to remedy this problem?
- Has the staff talked with the resident about meeting her nutritional needs?
- Does the resident's care plan address her ability to eat and benefit from her nutritional intake?

STROKE

A stroke is a sudden lack of blood to some part of the brain causing that part not to function. It is often the result of arteriosclerosis, a hemorrhage, or a blood clot. The medical term for stroke is *cerebrovascular accident*. Strokes can be disabling or fatal. Early treatment followed by rehabilitation minimizes stroke deficits.

Problem Indicators

- ❖ Sudden, temporary weakness or numbness of face, arm, or leg
- ❖ Temporary difficulty in speech
- ❖ Loss of speech
- ❖ Trouble understanding speech
- ❖ Brief dimness or loss of vision, particularly in one eye; double vision
- ❖ Unexplained headaches or a change in headache pattern
- ❖ Recent change in personality and mental ability
- ❖ Inappropriate emotional responses and fear
- ❖ Paralysis on one side of the body

LTCO's Response

❖ Observe

- What can the resident do?
- Does the resident understand verbal or written communication?
- Can the resident speak well enough to express needs and ideas?
- How does the resident communicate?
- How do others communicate with the resident?
- To what does the resident respond? (color? textures? speech? written messages? music?)

❖ **Question**

- Is the resident receiving any therapy directed toward rehabilitation of stroke-related impairments?
- Are there any “communication tips” for interacting with this resident?
- Can the resident use a story board?
- What is normal for this resident in terms of emotions and speech?
- Are there other things that could be tried to assist the resident in either regaining a degree of functioning or greater independence?
- Would an occupational therapy consultation be helpful? Has the resident had one?

❖ **Visit**

- Be present for and with the resident.
- Be patient as you interact with the resident.
- Keep trying to communicate. Do not give up because communication is tiring or frustrating for either of you.
- Offer honest praise or encouragement when appropriate.

DRUG-RELATED ISSUES

In the elderly, drugs may have especially toxic and undesirable reactions because of elders’ reduced metabolic activity and altered central nervous system reaction. The number and frequency of interactions and side effects for a predominance of drugs increase with age. Over-medication and adverse drug interactions are common drug-related problems among the elderly. A number of drugs that are often prescribed for the elderly have side effects that produce behavioral and/or psychological changes.

Problem Indicators

- ❖ Hallucinations
- ❖ Paranoia
- ❖ Confusion
- ❖ Tremors
- ❖ Lethargy
- ❖ Sedation, drowsiness
- ❖ Depression
- ❖ Muscle tics
- ❖ Delirium
- ❖ Restlessness

LTCO's Response

❖ **Observe:**

- Do you notice any recent changes in the resident's functioning or mood?
- Is there an apparent cause to explain these changes?
- Do these changes persist for more than one week?

❖ **Question**

- Can the resident tell you why he/she is “blue,” restless, weepy, or any other symptom you notice?
- Has there been a change in medication?
- Has a nurse or a physician seen the resident?
- Has a pharmacist recently reviewed the resident's medications?
- What are the side effects or interaction effects of the resident's medications?
- Have the resident's medications been given as prescribed?
- If drugs seem to be the problem, is there another way to achieve the same effect without the specific medication(s) in question?

B. Psychological Conditions

DEPRESSION

Depression is a mood disorder characterized by very low spirits. It is often overlooked in the elderly because it may manifest itself in less conspicuous ways than in younger populations. It covers a variety of symptoms that are also indicative of other conditions. Depression may exist along with dementia. *Depression in the elderly is generally responsive to treatment.*

Problem Indicators

- ❖ Impairment of memory and attention
- ❖ Sadness
- ❖ Loss of energy/apathy
- ❖ Helplessness
- ❖ Exaggerated quietness
- ❖ Boredom
- ❖ Changes in appetite
- ❖ Early morning fatigue
- ❖ Constipation

- ❖ Pacing
- ❖ Insomnia
- ❖ Frenzied activity
- ❖ Self-neglect
- ❖ Hypochondriasis

LTCO's Response

❖ **Observe**

- Has there been a recent change in the resident's behavior or mood?
- Was this behavior/mood characteristic of the resident prior to institutionalization?
- Does this change persist over a number of days or weeks?
- Have there been any changes in the resident's environment or caregivers or other relationships?
- How are others responding to the resident?
- Has anyone listened to the resident, allowed the resident to discuss what is on her mind?

❖ **Question**

- What is the resident feeling?
- Have there been any recent changes in the resident's environment, condition, treatment regime, or relationships?
- How long have these changes been occurring?
- Has a nurse or a physician seen the resident to assess these changes in mood or function?
- Is the resident receiving counseling or any other treatment for this condition?
- Has the resident had a recent physical examination? Medication review?
- Has the resident been encouraged to pursue meaningful activities or to exercise?

❖ **Listen**

- What is the resident expressing?
- What is the resident seeking?
- What is the resident really saying? (*Read between the lines, then check with the resident for accuracy of interpretation.*)
- Does the resident express any suicidal thoughts? *If so, report them immediately.*

ALZHEIMER'S DISEASE AND RELATED DISORDERS

Alzheimer's disease is a progressive, irreversible, neurological disorder that affects an estimated four million American adults and anywhere from 50%-70% of nursing home residents. It is the most common form of dementing illness and usually has a gradual onset.

Problem Indicators

- ❖ Decline in intellectual functions
- ❖ Decline in ability to perform routine activities
- ❖ Impairment in memory, especially recent memory
- ❖ Confusion
- ❖ Personality change
- ❖ Behavior change
- ❖ Difficulty finding words, finishing thoughts, or following directions

LTCO's Response

❖ **Observe**

- What are the resident's abilities?
- What problems is the resident having in daily functioning?
- When did these problems begin?
- Have these impairments been gradually developing or has there been a sudden onset?
- What does the resident do?
- What does the resident say?
- How do caregivers respond to the resident?
- Is there anything in the environment that could explain these changes?
- What kind of care does the resident receive?
- Is the resident expected to fit into the environment or is the environment responsive to the resident's needs?

❖ **Question**

- Have you noticed any changes in your _____? (Use your observations or what the resident says, to fill in the blank with this question.)
- When did these changes begin?
- Has anything in the resident's treatment regime changed?
- Is there a physical cause for these problems, such as a recent illness or move?
- Has a physician examined you since _____ began? (Fill in the blank with the specific change or problem that you are pursuing.)
- Have all other potential causes of these changes, particularly reversible ones, been

considered and eliminated?

- If the resident is restrained, what is the goal? What was tried to reach the goal prior to using the restraint? What happened? What is the plan for reducing and eliminating the restraint?

❖ **Visit**

- Spend time visiting this resident even though your conversations may not make sense to you all of the time.
- Pay attention to the resident's non-verbal cues (body language) and emotional state.
- Pay attention to what caregivers tell you about the care this resident receives and reports of changes in functioning.
- Report any changes in behavior/functioning you see to the nurse. Infections can go undetected and untreated in individuals who are confused or who cannot verbally express their needs. Sometimes the only clues are sudden, unexplained changes in behavior or functioning.

Information About Treatment

Effective treatment for dementia depends on caregivers knowing the details of the person's life and maintaining that daily rhythm, e.g. time of arising, bedtime, bathing habits, toileting habits, food and drink likes and dislikes and times of consumption, lifelong work, religious observances, and first language spoken.

**Office of the Ohio State Long-Term Care Ombudsman
Client Rights Comparison²**

NURSING HOMES; RESIDENTIAL CARE FACILITIES	NURSING FACILITIES*	ADULT CARE FACILITIES	HOME CARE
ORC 3721.13	42 CFR Part 483	ORC 3722.12	42 CFR Part 484
Post and Provide (3721.12)	Inform Orally and in writing Upon admission & during stay (b)(1)	Post and provide (3722.13)	Provide/Hotline
Post Statement of Deficiencies (3721.12)	Examine survey results & plan of correction; Posted in place readily accessible (g)		
Access to Advocates, etc. (3721.14)	Access to advocates, etc.; ombudsman access to records with permission (k)	Access to ODH, resident rights advocate, ombudsman (3722.15)	
Grievance Committee (3721.12)			
Safe & Clean Environment (1)	Safe & clean environment (483.15 (h))	Safe & clean environment (1)	
Dignity, Freedom from Abuse, Neglect, Exploitation (2)	Freedom from abuse, corporal punishment, involuntary seclusion (483.13 (b))	Dignity (2), freedom from abuse, neglect, exploitation (15)	
Appropriate Services without Discrimination (3)	Accommodation of needs (483.15 (e))		
Response to Requests (4)			
Clothing & Linen Changes (5)	Clean bed and bath linen in good condition (483.15 (h))		
Identity of Physician, other Caregivers (6)	Identity of physician and way of contacting (b)(8)		
Choice of Physician (7)	Choice of physician	Retain services of	

² The state laws and regulations cited in this table apply only to Ohio residents.

NURSING HOMES; RESIDENTIAL CARE FACILITIES	NURSING FACILITIES*	ADULT CARE FACILITIES	HOME CARE
ORC 3721.13	42 CFR Part 483	ORC 3722.12	42 CFR Part 484
	(d)(1)	any health or social services practitioner (13)	
Participate in decisions, including giving or withholding informed consent for treatment (8)	<p>Make choices about his life (483.15 (b)(3))</p> <p>Informed of health status/ condition (b)(3)</p> <p>Informed and participate in care planning (d)(2),(3)</p> <p>Refuse treatment (b)(4)</p>	Refuse treatment or services (14)	Participate in planning care or treatment
Access to records (8)	Inspect & purchase copies - Written request & 24 hour notice (b)(2)	Examine records (18)	
Withhold Payment for Physician Visits if not Provided (9)			
Confidentiality of Records (10)	Confidentiality of records (e)	Confidentiality of records (19)	Confidentiality of records
Privacy during Care (11)	Privacy during medical treatment (e)		
Decline Participation in Research (12)	Refuse to participate in research (b)(4)		
Freedom from Chemical and Physical Restraint (13)	Freedom from physical restraint or psychoactive drugs not medically required (483.13 (a))	Freedom from physical restraint (16)	
Choice of Pharmacy (14)		(Retain any health practitioner (13))	
Civil Rights, Voting (15)	Exercise as resident & citizen (a)(1)	Legal rights (17)	

NURSING HOMES; RESIDENTIAL CARE FACILITIES	NURSING FACILITIES*	ADULT CARE FACILITIES	HOME CARE
ORC 3721.13	42 CFR Part 483	ORC 3722.12	42 CFR Part 484
Access to Vocational, Educational, and Other Programs (16)			
Consume Alcohol (17)			
Use Tobacco (18)			
Retire and Rise (19)	Self-determination and participation (483.15 (b))		
Observe Religious Obligations; Participate in Community Activities (20)	Interact with the community; Participate in social, religious, community activities (483.15 (b),(d))	Practice religion of choice (3); Participate in community activities (10)	
Private and Unrestricted Communications (21)	Private communications (e)(1), (i), (j), (l)	Private and unrestricted communications (9)	
Share Room with Spouse (22)	Share room with spouse (n)	Share room with spouse (22)	
Room Doors Closed (23)			
Personal Clothing and Possessions (24)	Description of manner of protecting funds (b)(7) personal clothing and possessions (m)	Personal clothing (5) and property (6)	Property treated with respect
Informed of Rate; Notice of Rate Change (25)	Mcd recipients: Informed of items covered & not covered, with rates & changes Each: services, charges, changes (b)(5),(6)	Informed of rate; Notice of rate change (20)	Charges, coverage, changes no later than 15 days after HHA aware
Monthly Itemized Bill (26)			
Manage Financial	Financial:	Statement that	

NURSING HOMES; RESIDENTIAL CARE FACILITIES ORC 3721.13	NURSING FACILITIES* 42 CFR Part 483	ADULT CARE FACILITIES ORC 3722.12	HOME CARE 42 CFR Part 484
Affairs (Also 3721.15) Financial Records (27) Interest Bearing Account, Conveyance, Notice of Balance (3721.15)	freedom from exploitation Manage financial affairs (Also 3721.15) Financial records (27) Interest bearing account, conveyance, notice of balance (3721.15)	resident may complain to survey agency re: abuse, neglect, misappropriation (b)(7) Manage financial affairs (c)(1) Financial records (c)(4) Interest bearing account, conveyance, notice of balances (c)	Freedom from abuse, neglect, exploitation (15) Manage financial affairs (4)
Access to Property (28)			
Notice of Room Change (29)	Notice of room change ((b),483.15 (e))		
Conditions for Transfer or Discharge (30 and 3721.16)	Admission, transfer, discharge rights (483.12)	Conditions for transfer or discharge (3722.14)	
Voice Grievances (31)	Voice grievances/prompt efforts to resolve (f) Exercise rights free of interference, etc. (a)(2)	State grievances (11)	Voice grievances; HHA must investigate and resolve
Change in Status Reported to Sponsor Within 12 Hours (32)	Change reported within 24 hours (b)(10)	Change in status reported to sponsor (21)	
Protected Outdoor Areas; Adequate Indoor Space (3721.14)	Private space for resident or family groups (483.15 (c))	Use common areas (7)	

NURSING HOMES; RESIDENTIAL CARE FACILITIES	NURSING FACILITIES*	ADULT CARE FACILITIES	HOME CARE
ORC 3721.13	42 CFR Part 483	ORC 3722.12	42 CFR Part 484
	Refuse to perform services; perform services by choice under certain conditions (h)		
Self-Administration of Drugs with Physician Order - RCF Only (3701-17-14)	Self-administration of drugs (o)		
		Engage in or refrain from activities (8)	
		Visit facility prior to admission (12)	
Sponsor May Act (3721.13 (B))	If resident adjudicated incompetent, legally appointed person may act (a)(3)	Sponsor, Dir. of ODH, Dir. of ODA, RR Advocate may act (3722.12 (C))	Family or guardian may exercise if patient incompetent
Waiver Void (3721.13 (C))		Waiver void (3722.12 (C))	
Cause of Action (3721.17 (I))		Cause of action (3722.12 (D))	
	Post and provide information about Medicare and Medicaid benefits (b)(9)		
		ADDED THROUGH RULES: Not Locked In Not Locked Out Not Isolated or Having Food or Services Withheld	

* Indicates federal citations (column 2) applicable in all states:

- 483.10 Resident Rights
- 483.12 Admission, Transfer, and Discharge Rights
- 483.13 Resident Behavior and Facility Practices
- 483.15 Quality of Life

QUALITY CARE PRACTICES, SELECTED RESOURCE LIST

Consumers, Advocates, Ombudsmen

“The Seven Most Common Problems in Care—How Can You Help?” Nursing Homes: Getting Good Care There. Read the book or at least this chapter. Use the training guide to share the information with others.

http://www.ltombudsman.org/uploads/NHGCT_Teaching_Guide_w_App_07.pdf

The following resources are available on the NCCNHR web site: <http://www.nccnhr.org/> “The Basics of Individualized Quality Care,” Consumer Fact Sheet No. 16. NCCNHR. (On web site, look under Family Member, Fact Sheets.)

Restraint Free Care: Although the following resources contain some data and laws specific to California, the majority of the information is generic and applicable in all states. (On web site, look under Family Member, Family Councils, California Voices Project.)

“Restraint Free Care in California. A Guide for Residents, Their Families and Friends to Understand and Promote Restraint Free Care in California Nursing Homes.” NCCNHR.

“Restraint Free Care in California. A Training Guide to Equip Long-Term Care Ombudsmen and Consumers to Understand and Promote Restraint Free Care in California Nursing Homes.” NCCNHR

Centers for Medicare & Medicaid Services and State Department of Health

“Changes Idea Sheet” for specific areas of care includes background information, typical issues, barriers, nursing home regulatory support and ideas for making changes. Rhode Island Department of Health website, under Nursing Homes, then Individualized Care Pilot (ICP). Several resources are available including the change ideas,

<http://www.health.ri.gov/nursinghomes/>

This information is also available on the Quality Partners of Rhode Island’s website, under nursing homes, then individualized care, <http://www.qualitypartnersri.org/>

“Guidance to Surveyors.” Appendix PP. *Survey Interpretive Guidelines*. Centers for Medicare & Medicaid Services, Baltimore, MD.

http://www.cms.hhs.gov/manuals/Downloads/som107ap_pp_guidelines_ltcf.pdf

“Resident Assessment Protocols, Appendix C.” The Minimum Data Set 2.0 Manual. Centers for Medicare & Medicaid Services, Baltimore, MD.

http://www.cms.hhs.gov/NursingHomeQualityInits/20_NHQIMDS20.asp#TopOfPage

Clinical and Disease Specific

Consumer Fact Sheets related to specific care topics included in the Advancing Excellence Campaign goals.

http://nhqualitycampaign.org/star_index.aspx?controls=consumer

“Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes, Phases 1 and 2.” This booklet contains a brief description of selected care issues followed by a concise list of good care practices to try in order to address an individual’s needs. It was developed by the Alzheimer’s Association’s Campaign for Quality Residential Care. http://www.alz.org/alzheimers_disease_publications_quality_care.asp

“Nursing Home Care of Individuals with Multiple Sclerosis: Guidelines and Recommendations for Quality Care.” These guidelines include clinical practice information, practical tips, and best practices with regard to nursing and daily care, rehabilitation, psychosocial needs, and cognitive issues

<http://www.nationalmssociety.org/download.aspx?id=523>

There are two more guidelines pertinent to LTCO work. (1) “Assisted Living for Individuals with Multiple Sclerosis: Guidelines and Recommendations.” Topic areas addressed in this set of guidelines include resident life, clinical issues, rehabilitation issues, and staffing and training. (2) “Serving Individuals with Multiple Sclerosis in the Home: Guidelines and Recommendations for Home Care Providers and Personal Care Assistants.” Areas discussed in this document include clinical issues and symptom management, assessment, primary health care needs, daily care issues, safety, emotional and family issues, rehabilitation, and wellness and community integration. <http://www.nationalmssociety.org>

“Try This: Best Practices in Nursing Care to Older Adults”, is a source of succinct educational information and demonstrations on selected good clinical care practices. Find this set of resources and additional videos and narrative information on numerous care topics applicable to practice in hospitals, nursing homes, and assisted living on the website of the Hartford Institute for Geriatric Nursing, New York University College of Nursing. <http://www.consultgerirn.org/resources>