

The National Citizens' Coalition for Nursing Home Reform (NCCNHR) is a national, nonprofit consumer organization founded to protect the rights, safety, and dignity of America's long-term care residents.

NCCNHR's Mission:

To accomplish quality through:

- Informed, empowered consumers
- Effective citizen groups and effective ombudsmen programs
 - Promoting best practices in care delivery
 - Public policy responsive to resident needs, and
 - Enforcement of standards.

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NCCNHR

National Citizens' Coalition for Nursing Home Reform

**How to Participate in the Care of
Your Loved One During A
Nursing Home Stay**

*Practical Tips For Ongoing
Family Involvement*

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

Since 1999, The Maryland Family Council Project has been providing family members of nursing home residents in Maryland with written information, educational workshops, and educational videos on how to effectively advocate for quality care through the formation of nursing home family councils.

If you would like more information on the Maryland Family Council Project contact:

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**Other Maryland Organizations
You May Want to Contact For Assistance**

State LTC Ombudsman
Maryland Department of
Aging
301 W. Preston Street
Room 1007
Baltimore, MD 21201
tel: 410-767-1100
web:[www.mdoa.state.md.us/
Services/Ombudsman.html](http://www.mdoa.state.md.us/Services/Ombudsman.html)

Alzheimer's Association
Greater Maryland Chapter
1850 York Road, Suite D
Timonim, MD 21093
tel: 410-561-9099 or
800-443-2273
web:www.alzgm.org

Alzheimer's Association
National Capital Area
11240 Waples Mill Road
Suite 402
Fairfax, VA 22030
tel: 703-359-4440 or
866-259-0042
web:www.alz-nca.org

Voices for Quality Care
PO Box 6555, US Postal
Service
St. Charles Town Center
Mall
Waldorf, MD 20603
tel: 888 -600-2375
web:[www.voicesforqualityca
re.org](http://www.voicesforqualitycare.org)

AARP Maryland State Office
200 Saint Paul Place
Suite 2510
Baltimore, MD 21202.
tel: 410-837-4300
web:www.aarp.org/states

More Consumer Resources for Nursing Home Residents and their Families

NCCNHR resources provide long-term care residents and their families with the tools to help them advocate effectively for quality long-term care. Publications address a wide range of issues including: the importance of resident empowerment; family involvement; resident assessment and care planning; staffing; physical and chemical restraints; residents' rights; and more.

To order call 202.332.2275 or visit

www.nursinghomeaction.org.

NCCNHR members receive a 10% discount on all publications

OUR BEST SELLING TITLES INCLUDE:

Nursing Home Staffing: A Guide for Residents, Families, Friends, and Caregivers (2002)

Author: Sarah Greene Burger
\$7.50 + shipping and handling

NCCNHR's nursing home staffing guide helps family members determine whether their loved one's facility provides adequate staffing and helps friends and family members advocate for the staffing that their loved one needs. Beautifully illustrated, this consumer friendly booklet is easy to read.

Nursing Homes: Getting Good Care There

Second Edition 2002
Authors: Sarah Greene Burger, Barbara Frank, Virginia Fraser, and Sara Hunt
\$11.95 + shipping and handling

NCCNHR's classic book includes dozens of specific advocacy strategies, questions to ask, checklists and standards of care for residents, family members, and concerned advocates who seek the best possible care for their loved ones in nursing homes.

Consumer Fact Sheets are Available Free of Charge on:

- Rights of Family Councils
 - Visitation
- Residents' Rights

The Nursing Home Reform Law of 1987 guarantees that each resident must receive and the facility must provide *the care and services to reach his or her highest practicable mental, physical, and psychosocial well being*. Research supports that family involvement during a nursing home stay can help ensure that the facility provides this level of care.

But how can you, as a family member, get involved in the care of your loved one during the stay in a nursing home? When a person is admitted to a nursing home, *family members have the right to be involved with the care of their loved one*, unless he or she states otherwise.

Resident Needs and Wishes Come First!

It is important to remember the role of the family member is to always communicate to the nursing home staff your loved one's needs and preferences. This may be different than what you think is best for your loved one but the resident's needs and wishes should always be respected.

INITIAL FAMILY PARTICIPATION: THE RESIDENT ASSESSMENT AND CARE PLAN

The Resident Assessment

The assessment process is key to understanding what each resident needs to maintain physical, mental, and social function in a nursing home. The resident must have a comprehensive assessment within 14 days of admission to a nursing home and at least once a year after that or anytime there is significant change in the resident's condition. Resident assessment reviews are completed quarterly. The assessment is used to gather information about the health and physical condition of your loved one; her functional abilities such as walking, eating, dressing, bathing, understanding, and hearing; and also examines her habits, activities, and relationships.

Who conducts a resident assessment? Typically an assessment includes:

- The Resident
- Nursing Staff
- Social Services Staff
- Dietary Staff
- Activities Staff
- **Family Members**

Communicating Your Loved One's Story

Introducing your loved one to nursing home staff is one of the most important things you can do. It will make all the difference in staff understanding your relative's actions and responses because they will know some of the thoughts, feelings, habits, and life experiences that lie behind those actions. Use the Resident Assessment to communicate personal habits, such as when she likes to get up in the morning, go to bed at night, if she prefers a bath or shower, and any pertinent health information. Most importantly, this is also the time to share your loved one's unique life story.

Care Plan

Within 7 days of the initial comprehensive assessment a Care Plan Conference is held. At this conference an individualized care plan is developed by an interdisciplinary team consisting of the attending physician, nurse, nurse aide, activities and dietary staff, and social worker. *It is important that the team have critical input from the resident and/or family members.* All participants discuss the strategy for the resident's care in the Care Plan Conference to ensure all medical and non-medical issues are addressed. Participation of residents and family members should be taken into account by a facility when scheduling a care planning conference.

Care plan review conferences are held quarterly or whenever there is a major change in a residents' condition to see if the care plan is working and if it needs to be updated. Families and residents should participate in all care planning conferences because the care plan outlines how the facility will meet the resident's needs.

Family Involvement Checklist

- Did the nursing home complete an assessment within 14 days of admission to the nursing home? Did the assessment include family input?**
- Did the nursing home complete a care plan conference within 7 days of the assessment? Are follow-up care plan meetings held quarterly? Did the care plan conference include family input?**
- Do family visits happen when it is convenient for resident and family members? Are visits comfortable for family members and the resident?**
- Have family members familiarized themselves with key staff including direct care staff (CNAs, RNs and LPNs), social services staff, activities staff, and the administrator?**
- Does the nursing home have a family council? When are the meetings? If one does not exist, are you interested in starting one?**
- Did family members talk with facility staff and/or contact the local ombudsman about concerns related to quality of care and residents' rights?**
- Is there a Citizen Advocacy Group in your city, county, or state? Maryland currently has a state-wide Citizen Advocacy Group, Voices for Quality Care. (See back page for contact information)**

Advocate With Other Residents' Family Members

The 1987 Nursing Home Reform Law guarantees families of nursing home residents the right to form and hold regular private meetings of an organized group called a **Family Council**. Joining or organizing a family council is one of the most effective ways to advocate, not just for your loved one, but for quality care for all residents in a nursing home.

What should I know about family councils?

- The facility must provide a meeting space and a designated staff person to act as a liaison between the group and facility.
- Family councils have the right to meet without staff present unless one is invited to allow family members to voice concerns without reservations.
- A family council has the right to take concerns and suggestions regarding decisions affecting resident care and life in the facility to staff who must act upon the concerns and suggestions.

Advocate With Other Community Members

Contact your Citizen Advocacy Group (CAG). Maryland currently has a state-wide CAG, Voices for Quality Care. CAGs are groups of concerned citizens who work to improve the quality of care for nursing home residents in their locality, state, or region. Many people who help form or join CAGs have had direct experience as family members of nursing home residents.

What role can Citizen Advocacy Groups play?

- CAGs can help family members establish family councils.
- CAGs can support and develop statewide nursing home legislation that promotes improved quality of care for all nursing home residents.
- CAGs can emphasize quality care in nursing homes in the larger community.

What is the purpose of the care plan?

- The care plan is a strategy for how staff will help a resident on a daily basis.
- The care plan clarifies *what* each staff person will do and *when* they will do it.
- The care plan serves as a guide for family members, the resident herself, and staff to discuss the resident's progress.

Tip: Guardianship and Medical Power of Attorney

If your loved one is not able to make personal medical decisions for him or herself, a legal guardian appointed by the court or a medical power of attorney designated before your loved one became incapacitated, has the right to speak on his or her behalf. This includes communicating with nursing home staff about care for your loved one. A family member can play either of these roles.

ON-GOING FAMILY INVOLVEMENT

Visiting

Visits from family members can be an important support for a resident's emotional well-being and can help assure your loved one receives quality care. Visits are an important time to look for changes in your loved one's health and mental status. You should see progress towards meeting the goals in the care plan.

When and how can I visit my loved one?

Under the Nursing Home Reform Act of 1987, residents have the right, and the facility must provide for, immediate access to any resident by immediate family or other relatives of the resident, subject to the resident's consent. There are many ways to visit your loved one. **The resident and family members have the right to decide what your visits entail and when they take place.** Remember to respect the rights of the other residents during your visits.

Tips for visiting your loved one

- Plan your visits around what makes your loved one comfortable. For example, you may want to visit at bedtime to help him fall asleep.
- Plan your visits at times that best meet your schedule, for or example, on your way home from work.
- Visit during meals for mealtime conversation or to help your family member eat.
- It is important to visit at different times of the day and week to see the care your loved one receives at all times.
- Keep a guest book in your loved one's room so visitors and family members can communicate with one another.

Get to Know the Staff

It is important to be familiar with staff members. Know their names and their roles and responsibilities related to resident care.

Who are some of the key staff I should be familiar with?

- **Certified Nursing Assistants (CNAs)** provide 90% of the hands-on care in a nursing home. They take care of the day-to-day needs of residents such as toileting and bathing.
- **RNs and LPNs** organize and manage the care of residents on each unit. They supervise and support the CNAs caring for the residents.
- **Director of Nursing** is in charge of all nursing services for the entire facility.
- **Director of Social Services** manages the social work staff and often leads the care plan process.
- **Director of Dietary Services** oversees the provision of food and, along with the Director of Nursing, implements strategies for preventing weight loss among residents.
- **Administrator** oversees the operation of the entire facility and is responsible for budgetary decisions.

FAMILY ADVOCACY STRATEGIES

Advocate in the Nursing Home

Being an advocate for your loved one means: knowing the importance of and participating in the resident assessment and care plan; knowing the nursing home staff and their roles; monitoring your loved one's care during regular visits; and raising any concerns with staff. **You are the key advocate** for your loved one.

When problems arise how can I effectively advocate?

- Report concerns and problems to staff members as soon as they arise so they can be addressed immediately
- Voice concerns to those directly involved
- If your actions yield no result, report your concern to staff supervisors in writing and in a meeting
- Be assertive, confident, and respectful in your interactions with staff
- Clearly state your concerns and the outcome you would like
- Contact your **local ombudsman** if your concerns are not being addressed by the facility staff. Your local ombudsman advocates for residents of nursing homes. They work to resolve problems of individual residents and help residents and their families and friends understand and exercise the rights of nursing home residents.

Advocacy Tip

Every 12-15 months a nursing home that receives Medicaid or Medicare funding is required to have a **state survey** conducted by the state licensure and certification agency. In Maryland, this is the Office of Health Care Quality. The surveyors must post signs announcing that a survey is in progress. When you see such a sign make it a point to speak with a member of the survey team about quality of life, quality of care, and resident rights at the facility.