

NURSING HOME RESIDENTS' RIGHTS UNDER THE NURSING HOME REFORM LAW

Introduction

Certain rights are set forth in the United States Constitution for all citizens. Individuals who live in long-term care facilities do not lose these rights when they enter a congregate living environment. In fact, they are guaranteed *additional rights* under state and federal laws specific to their status as residents! These rights are provided for primarily in the following sources:

- Federal Nursing Home Reform Law: *The Omnibus Budget Reconciliation Act of 1987 (OBRA '87)*, as amended, Medicaid Provisions (§1396r), and Medicare Provisions (§1395i-3)
- Federal regulation: *Medicare and Medicaid Requirements for Long Term Care Facilities*, September 26, 1991, 42 U.S. Code of Federal Regulations, (§483).
- State laws

For your information, the residents' rights excerpts from the Medicaid provision of the federal law are included in the Additional Resources section. While many of the rights guaranteed by each of these sources are very similar, it is important that you be familiar with all of them.

A very useful resource for understanding residents' rights is the *Guidance to Surveyors for Long Term Care Facilities*. These guidelines are part of the *Centers for Medicare & Medicaid Services (CMS) State Operations Manual*¹, the document that surveyors use to determine whether a facility has met the federal requirements. Another useful resource is *An Ombudsman's Guide to the Nursing Home Reform Amendments of OBRA '87* by the National Long-Term Care Ombudsman Resource Center.

Resources:

- *Guidance to Surveyors*
- *LTCO Guide to OBRA '87*

Key Provisions

There are two key provisions in the federal law (Nursing Home Reform Amendments² of the Omnibus Budget Reconciliation Act of 1987 or OBRA '87) that establish the foundation for all the other provisions: *Quality of Care* and *Quality of Life*.

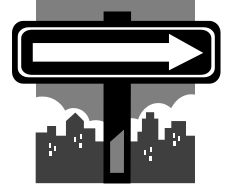
- **Quality of Care** says a nursing facility must provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care.

¹ The full title of this document is the *State Operations Manual, Appendix PP, Guidance to Surveyors for Long Term Care Facilities*, Rev. 5, 11-19-04. The section that covers the survey protocols is, *Appendix P, Survey Protocol for Long Term Care Facilities*, Rev. 1, 05-21-04. In this resource document, the survey protocols are referred to as the State Operations Manual.
http://www.cms.hhs.gov/manuals/107_som/som107_appendixtoc.asp

² The Nursing Home Reform Amendments is also referred to as the Nursing Home Reform Law or as OBRA '87.

- **Quality of Life** says a nursing facility must care for its residents in such a manner and in such an environment as will promote maintenance or enhancement of the quality of life of each resident.

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



Residents' rights also have implications for quality of care requirements. Since residents' rights and quality of life are related, what factors do residents consider important for quality? In 1985, the National Citizens' Coalition for Nursing Home Reform asked 450 residents in 15 cities across the country what quality meant to them. Studies since then continue to support the importance of these same factors to residents.³ A few central issues were poignantly and consistently identified. Many of these were incorporated as provisions in the Nursing Home Reform Law. They include the following:

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

Basic Themes

The residents' rights listed in the federal law, and therefore all of the regulations that follow from them, embody four basic themes. If you learn and remember these four themes, you will understand how to work on the specific rights. You soon will learn many of the specific residents' rights because you will be looking up the exact language of the provisions that apply to an issue you are asked to resolve. The role of the ombudsman is to help residents, their families, and facility personnel understand what these themes mean and how they can be achieved.

The four themes are:

1. **Communication**
2. **Choice**
3. **Decision-making**
4. **Participation**

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

³ Kane, R. *Good (or Better) Quality of Life for Nursing Home Residents: Roles for Social Workers & Social Work Programs*. Presentation for Evaluating Social Work Services in Nursing Homes: Toward Quality Psychosocial Care and its Measurement, Institute for the Advancement of Social Work Research, Washington, DC. December 2-3, 2004.

1. Communication

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

Specific examples of rights pertinent to communication include residents' rights to:

- be fully informed of his or her rights and all rules and regulations governing resident conduct and responsibilities, orally and in writing, in a language the resident understands;
- participate in planning his or her care and treatment; and
- voice grievances without discrimination or reprisal AND have prompt efforts by the facility to resolve these.

2. Choice

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

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

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

3. Decision Making

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

Another aspect of resident decision making is being in an environment that is truly encouraging and supportive. Residents need to feel free to make their own decisions without fearing that they will be declared incompetent or discharged if their decisions differ from what professionals recommend or from what their family wants. Once a decision is made, residents need to know that their choice will be respected. One of the requirements of the Nursing Home Reform Law is that nursing homes must protect and promote the rights of each resident.

A few specific examples of rights in this area are a resident's right to:

- manage his or her financial affairs;
- work or not work; and
- choose a personal attending physician.

4. Participation

Residents are to participate in planning their care and treatment and to participate in:

- resident groups if they so choose;
- social, religious, and community activities;
- the survey process; and
- the administration of the facility.

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

Honoring, upholding, residents' rights is a process; it is not something that is done once, checked off a list, and forgotten because it is a standard that has been met.

These four themes—communication, choice, decision making, and participation—embody the approach, attitude, and philosophy of implementing residents' rights. They have to be continuously exhibited. As an ombudsman, you may be the facility's best model and teacher for implementing residents' rights.