



FAMILY MEMBER RIGHTS AND DECISION MAKING¹

Family Member Rights

When residents are not able to exercise their own rights, family members who are guardians or legally considered to be the resident's representative can exercise the resident's rights. This applies to many, but not all, family members.

As relatives of a resident in a nursing facility, federal regulations provide family members with the rights and protections listed below.* However, in instances where the family's wishes are contrary to the resident's wishes, and the resident has the legal capacity to make decisions, the facility must uphold the resident's decision.

- Unless the resident exercises her right to privacy and does not want to notify or include her family, as a family member, you have the right to:²
 - Participate in the development of the resident's care plan;
 - Be notified when there is -
 - an accident involving the resident
 - a significant change in the resident's condition
 - a need to alter treatment
 - a change in room or roommate
 - a change in residents' rights
- Before transfer or discharge, the facility must provide written notice of the proposed transfer or discharge to the resident and, if known, a family member or legal representative. Prior to transfer (due to hospitalization or therapeutic leave) the facility must provide written notice of the state and facility bed-hold policies to the resident and, if known, family member or legal representative.
- Residents may receive visitors at any time of day or night. Family members have the right to form family councils in which they come together to work for improvements in the quality of care and quality of life of their loved ones. They have the right to meet in the facility with the families of other residents in the facility.

**Unlike nursing homes, assisted living facilities (also known as board and care homes) do not have federal requirements; therefore, assisted living facilities regulations vary by state and the federal regulations mentioned in this section only apply to family members with relatives in a nursing home.*

¹ Much of this material has been adapted from the book, **Nursing Home Care in Suburban Cook County: A Family Caregiver's Guide**. Developed by Robyn Grant for the Suburban Cook County Ombudsman Program in Illinois and shared with the National Long-Term Care Ombudsman Resource Center.

² State Operations Manual. Appendix PP- Guidance to Surveyors for Long-Term Care Facilities. Centers for Medicare & Medicaid Services (CMS). Interpretive Guidelines 483.20(k)(2) and 483.10(b)(11).

Decision-making Authority

Residents often execute a health care and/or financial power of attorney (POA) document. The resident or “grantor” designates an “agent” or “attorney-in-fact” (often a family member) to act on their behalf. The “powers” granted by the “grantor” depend on the type of power of attorney document. For example, a durable power of attorney means that the document is still valid when the grantor lacks the capacity to make decisions. If a resident lacks decision-making capacity and does not have an advance directive, state law will determine who has decision-making authority.

A POA does not automatically give the agent the right to make decisions for the grantor. The type of decisions an agent can make for the grantor depends on the powers stated in the POA and the capacity of the grantor. For example, if the POA is limited to financial decisions, the agent does not have the authority to make health care decisions. The agent should have a copy of the POA document and a copy should be in the resident’s chart.

Even if a resident has dementia or a limited capacity to make decisions, there may be times when she is able to indicate her preference in a particular situation. At those times, regardless of an individual’s legal authority, it is important to honor her preference whenever possible. Additionally, if a resident lacks the ability to make decisions or has been adjudged incapacitated by a court of law, she still has the right to be informed and be consulted regarding her preferences.³

Regardless of a POA document, family members should advocate to ensure their loved one’s voice is heard and her wishes and choices are respected.

- Make sure she is not left out of a conversation. If this happens bring attention back to the resident by asking her a question pertaining to the conversation. Do so repeatedly if necessary. Serve as a model to others.
- Encourage your loved one to speak up about her needs and preferences. You can do this by saying, “What do you think, Mom?” or “What would you prefer?”
- If staff members or other individuals are making decisions for the resident, say, “Let’s find out what Mom thinks.”

³ State Operations Manual. Appendix PP- Guidance to Surveyors for Long-Term Care Facilities. Centers for Medicare & Medicaid Services (CMS). Interpretive Guidelines 483.10(d)(3)