

OVERVIEW

Our Mother's Voice believes that all nursing homes should provide a quality of care and a quality of life that nurture each resident's individuality – mental and physical health, social involvement, spiritual expression, and simple preferences about daily routines and care.

These tenets are the foundation of what each of us considers quality of life. The Centers for Medicare and Medicaid Services recognized this fact when they developed the federal regulations governing long-term care facilities which participate in their federal financial support programs of Medicare and Medicaid. Their regulations strongly support dignity and self-determination for all residents regardless of the level of infirmity or incapacity of the individual resident. Families are provided the right to advocate for their loved ones unable to speak for themselves, through a "family representative" or, in other cases, legal Power of Attorney.

Not every nursing facility participates in the federal Medicare or Medicaid funding programs. In those cases, each state's licensing agency oversees the quality of care provided. These regulations are more general and vague, and less stringent than the federal regulations. In facilities not participating in the federal financial program (Medicare or Medicaid), the federal regulations are important because they set a standard of care for the industry. Many nursing homes that do not receive Medicare or Medicaid funding are voluntarily setting this standard for themselves. Others are slow to do so. Thus, the quality of care provided in facilities varies widely. Families must insist on this standard of care for their loved ones in order for nursing homes to reach this standard. When a family is seeking a nursing facility for a loved one, this fact must be considered paramount, and the search must be diligent, to find the best care. Knowing the goals of the nursing home before selecting a place for a loved one to live is essential.

The quality of care that provides a high quality of life for each resident is described in general terms on this site. Of course, just as each resident is a unique individual, quality of life is defined uniquely for each individual. Our Mother's Voice believes that the only way to achieve the goal of high quality of life in every nursing facility is for consumers – residents and their families – to require it. Historically, "clean, dry, dressed, and fed" was the standard of care accepted by families in our country for their loved ones in nursing homes. That standard is comparatively easy to meet, and so it remained the expectation of the staff as well as the families. In recent years, however, "resident-centered care" or "resident-directed care" is becoming the standard, whether the facility participates in federal programs or not. In some cases, staff accustomed to the old standard may have difficulty adopting this new way of thinking about care. Often those old standards creep back in – especially if the individual needs of the resident mean changing old habits or attitudes. Staff training helps. Time moves change through an organization. But advocacy for one's family member is the catalyst that will move this change forward. Simply waiting for it to occur will mean that change takes longer. Given the limited life expectancy of the nursing home resident, waiting surely will mean that change does not take place in time to impact the quality of life of many current residents.

Our Mother's Voice does not give advice; we provide information. Families should use this information to make their own decisions about their own situation. If the family believes there are concerns that need to be addressed, the information on this site is provided to empower families to advocate for those changes. Following are some generalities about making changes happen which may be of interest.

Each resident has a Social Worker who is the primary point of contact for the family on behalf of the resident. Each nursing home has an organizational hierarchy or chain of command. The Social Worker's job is to assist

the family in understanding the needs and care plan of the resident, and to address family concerns with the staff and care plan team. If working with these staff is unsuccessful, then the administrative hierarchy (Director of Nursing, Nursing Home Administrator, and corporate executive officers) represent the next steps. All these people are charged with responsibility for the well-being of all residents.

Before seeking change, advocates need to be familiar with the regulations in their own state as well as the federal regulations. Links to assist with this task are provided on this site. Knowing which regulations govern the specific facility gives the advocate a strong position from which to make needs known. Identifying specific regulations at issue also helps. If the advocate can name the specific rule the advocate believes is being violated or unfulfilled, then the advocate has a much stronger position.

The advocate must also bear in mind that there are legitimate reasons for certain practices that may seem odd. Regulations are “built” for implementation on a larger scale, and some may seem odd in a given individual situation. Regulations used as an “excuse” for not addressing a need, or as the only reason for a certain practice, however, may or may not be acceptable. Underneath should be something that makes sense. Asking for an explanation is entirely appropriate. The explanation should make sense, even if the family / advocate does not agree with the explanation. The explanation should be supported by facts; and if it is legitimate, discussing it should not make the administration uncomfortable. Receiving those supporting facts may help the family to feel more confident with the explanation.

There are also times when the family may “want” or “wish” a specific outcome for their loved one that is not realistic because of the condition of their loved one. This reality is sad, but it must be faced. If it is the case, there should be supporting facts in medical evaluations and other assessments to substantiate the condition, including ruling out temporary causes (like illness) and other efforts taken to minimize the condition. These supporting facts should withstand questions and requests for further explanation.

Finally, if no resolution is forthcoming, and all other avenues have been exhausted, the regulatory agency charged with oversight of nursing home care in each state has a reporting system by which a family / advocate can make a complaint. The agency then conducts an investigation into the complaint. Again, knowing specifically the violation prior to making the complaint benefits the family member / advocate in making a credible report. Often families are reluctant to report because they fear their family member’s treatment may suffer. Such “retaliation” is illegal. Obviously, resolving questions and concerns in collaboration with the facility staff or administration is preferable. But if there are serious issues which cannot be so resolved, then the family must decide the merits, benefits and consequences of going forward with a complaint outside the organization, such as contacting the regulatory agency. Our Mother’s Voice hopes the information provided on this web site is helpful to families / advocates in making such a determination if it becomes necessary.

Exception: Abuse and neglect concerns are not discussed here. Those concerns are more serious and should be handled according to your state’s laws of reporting. Every facility must post those laws clearly. See “What You Can Do” on this web site for definitions of the terms abuse, neglect, and misappropriation of property.

A CAUTIONARY WORD: Our Mother’s Voice does not give advice, but provides information. The information on this web site is provided to enable families to become strong advocates. For advice, the family should seek counsel from professionals in the field of their specific concern.

FAST FACTS from Our Mother's Voice

Did you know:

- Nursing homes that receive Medicare or Medicaid funding must provide the same quality of services and care for EVERY resident regardless of who pays for the care.
- In a well-run nursing home staff are consistently busy interacting with residents and not just monitoring.
- “Acting out” by a resident is often an attempt to communicate something important. “Inappropriate” behavior often indicates a need for more physical activity or social interaction.
- Physical restraint and medication are not to be used to “control behavior.”
- Nursing homes must offer ongoing activities every day that are meaningful to the residents. And all staff, not just activity staff, are supposed to be responsible for providing activities.
- Residents have the right to receive help if needed to participate in activities. Ambulation, hand-over-hand assistance, verbal and visual prompts.
- Every resident has the right to dignity and choice regarding care, including when and how personal care such as bathing and dressing is provided.
- Standing and walking, even if the resident needs assistance, are essential for health and should be more than to and from the toilet.
- Residents should not be in bed during the day unless their medical condition requires it.
- Excellent and inexpensive training materials are readily available to every nursing home to insure that staff are equipped to give this high quality of care.
- Every nursing home has a social worker whose job it is to help the family see that their loved one's needs are met.
- Family representatives are members of the resident's care plan team, not guests.