

QUALITY OF LIFE

And if you only read two sections of this website, then this is definitely the second one you must read!

Our mother's voice, through her nonverbal behaviors, told us very clearly that she was not experiencing a decent quality of life when she was admitted to the nursing facility. These were our mother's experiences, through her eyes, and certainly not the way the staff perceived these events. But Quality of Life is not measured through the eyes of others; it is measured through the individual resident's perspective. In no uncertain terms our mother told us that – from her own perspective – the staff did not treat her with dignity when they were performing personal care; they did not consider her preferences when they engaged her in activities; they did not make an effort to keep her engaged in constructive use of time; and they responded to her efforts at communicating her dissatisfaction by physically holding her and moving her limbs, placing her in a wheelchair, and medicating her for “agitation.” From staff perspective, they were seeing that she was bathed and dressed; protecting her from falls; and calming her down when she got upset for no apparent reason. In all fairness to the hard-working staff, they certainly did not intend to infringe on her quality of life. They were just doing their jobs.

Now Our Mother's Voice is spreading the word about what ought to happen.

Here is what the Code of Federal Regulations has to say about Quality of Life:

A facility must care for its residents in a manner and in an environment that promotes maintenance or enhancement of each resident's **quality of life**.

The facility must not only care for, but promote care for residents in a manner and in an environment that maintains or enhances each resident's **dignity** and **respect** in full recognition of his or her individuality. In other words, treating each person as an individual, and not as part of a group one must fit into; not having to do and be just the same as everyone else, or be labeled “unable to participate” or “uncooperative.”

The resident has the right to **self-determination**, and participation in choosing activities, schedules, and health care consistent with his or her interests, assessments, and plans of care.

A resident has the **right** to participate in social, religious, community, and other activities that do not interfere with the rights of other residents in the facility. “We don't have enough staff” is not an acceptable excuse for not providing a way for a resident to participate. Solutions must be sought.

A resident has the right to reside and receive services in the facility with **reasonable accommodation of individual needs and preferences**, except when the health or safety of the individual or other residents would be endangered. Again, “We don't have enough staff” is not an acceptable excuse for not providing reasonable accommodation. Granted, not having

enough staff may put the safety of residents in danger. Often, though, creative use of human resources is a sufficient remedy, without additional staff being needed. The fact is that solutions must be sought.

And, very important to our mother and to many others who are not able to manage their own time independently because of incapacity or dementia, activities are required much more consistently than most families and even staff in many facilities may be aware. The facility must provide for an **ongoing program of activities** designed to meet, in accordance with the comprehensive assessment, the interests and the physical, mental, and psychosocial well-being of each resident. That is EACH resident. It is not sufficient to host an activity and whoever can get to it on their own and do it independently can participate. And, that is ONGOING activities, not an activity most (or some) days, if the activities staff person is working that day. “S/he’s off today” is not an acceptable explanation for an activity not taking place. Other staff are to conduct the activity on days and at times when the activities person is not available.

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. In these facilities, families must seek this standard of care for their loved one in order for these nursing homes to reach this standard. Many nursing homes that do not receive Medicare or Medicaid funding are setting this standard for themselves. Others are slow to do so. Knowing the goals of the nursing home before selecting a place for a loved one to live is essential.

Even people whose understanding of the world around them is blurred by dementia have the right to feel comfortable in their environment. Those with agitation, confusion, and frequent complaints may be “hard to please,” but the Plan of Care is intended to address even these issues in **meaningful** ways. Meaningful is to be and must be defined from the resident’s perspective. In cases where the resident cannot make their perspective known, the family can play a primary role in assuring that staff determine what is meaningful to their loved one. As a member of the care plan team, they (or the family representative) can provide essential input to ensure that their loved one experiences a daily life of quality and meaning regardless of the level of incapacity their loved one may have.

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.

Source: Code of Federal Regulations, 42CFR483.15, Center for Medicare & Medicaid Services.