RESIDENT RIGHTS

If you only read one section of information offered on this website, this is the one you ***must*** read! This is what Our Mother's Voice is saying, loud and clear, to everyone in a position to hear, on behalf of everyone who can't speak out for herself (or himself). This is the change Our Mother's Voice is advocating for in the care provided in nursing facilities across the country.

Moving out of your home and into a congregate living situation means you sacrifice everything about your daily routine, your independence, your familiar surroundings, and many of the little choices that used to be a part of every day. All the things you took for granted and never thought about, now you can't "just do it" because of a rule, or a schedule, or a limitation.

Residents and their families are given a piece of paper with a list of "Resident Rights," but often the true meaning of these rights is not fully understood – by the family or even by the facility staff and management. The Social Worker is typically the staff person with the responsibility of reviewing and explaining these rights to the resident and the family. S/he is also responsible for assisting with ensuring these rights. In cases where the loved one is incapacitated, a "power of attorney," "legal representative," or "family representative" has the primary responsibility of exercising the rights of the nursing home resident on that person's behalf. Other family members should work with that designated representative in addressing questions of resident rights for their loved one. Generally, nursing homes have a standard procedure of working with one primary family member in these cases.

While each state has its own "Bill of Rights of Residents" and its own "Health Licensing Regulations" (or an equivalent of these) which vary from state to state, all should include some reference to freedom from abuse; dignity and respect in treatment of residents; and participation in planning and care. Typically these rules and laws are vague and general, leaving much to interpretation by the surveying agency in determining compliance. Historically, surveyors seem to have been content with even the most minimal efforts which could conceivably be interpreted as approaching the letter of the regulation.

In nursing homes which accept residents whose care is paid by Medicare or Medicaid funding, the regulations are much more specific, and the surveyors are more particular about what they find acceptable. The nursing home may not fully realize that the regulations go beyond just those residents funded by federal programs. According to the Code of Federal Regulations, even if your loved one doesn't receive Medicare or Medicaid funding, as long as the nursing home participates in the federal funding program, the facility must provide that quality of care and services to all residents – not just those receiving the Medicare or Medicaid funds. Here is what the Code of Federal Regulations has to say:

§ 483.15 Admission, transfer and discharge rights.
(b) *Equal access to quality care.*

(1) A facility must establish and maintain identical policies and practices regarding transfer, discharge, and the provision of services under the State plan for all individuals regardless of source of payment;

Our Mother's Voice educates families so they can in turn begin to hold facilities accountable to that standard. It is up to families to advocate for this care; surveyors do not routinely examine compliance with this standard. They are primarily concerned with the services the federal funds are directly purchasing.

Many years ago, the term "Medicaid nursing home" used to conjure up images of poor care and minimal facilities. Those days are largely in the past as far as facilities of any size are concerned. The fact is, facilities that accept federal funding are under periodic examination by government oversight agencies to make sure our tax dollars purchase acceptable care for our loved ones. And those same oversight agencies are there to receive reports and complaints if violations do occur. Our mother's voice spoke when she had complaints, and the regulators listened.

Still, families are often completely unaware of what they have a right to expect from a nursing home – beyond their loved one being clean, dressed, calm, "happy" (often defined as "quiet"), and the facility smelling nice. Our Mother's Voice speaks out to let all families know these facts and understand the true spirit and richness of meaning of these rights, and the quality of life which is present when these rights are fully integrated into the culture of the facility.

A person who lives in a nursing home has a right to a **dignified existence**. But a huge part of that existence has to do with all those things the person gave up when they moved into the facility: their own home, their own routine, their own **choices**, their favorite things. Most families and their loved ones don't realize that even in a congregate setting like a nursing home, one of the basic rights is the right to **self-determination** – to have a say-so about what happens during a routine day, how activities and care services are planned and put in place. Even such "mandated" schedules as meal times, bath times, and bed times can and should be adjusted within reason to accommodate **individual preferences**.

Another basic right which is often misunderstood and undervalued is **communication**. Staff emphasize that families may communicate with their loved one, and they encourage contact. There is another aspect to communication, more crucial to the quality of life of the resident, which staff of many facilities may not have considered: the **resident's communication with staff**. Many times, by the time a loved one must enter a nursing home, the ability to speak or to communicate clearly with words is affected by loss of function or by dementia. But that does not mean that no communication is possible – far from it! People communicate very clearly through their emotions, their eye gaze, their behavior. Those close to them (family AND caregivers) learn to understand and interpret those nonverbal cues, and can respond correctly to meet the communicative intent of their loved one. Some staff of the facility, though, may not notice these behaviors – or if they do, may interpret them as "problem behaviors" or "agitation" and may medicate them away rather than "listening" to their true meaning and

responding accordingly. *This use of medication instead of attending to the communication of the resident is a violation of the rights of the resident.* In nursing homes with excellent reputations, with clean, well-dressed, polite staff, in well-decorated facilities, it is possible to see clean, well-dressed, quiet residents with virtually no active behavior or noisy activity going on. While it is easy to assume from this observation that these homes are well-managed and of good quality, complete evaluation means looking deeper into the use of medications and the practices related to self-determination for each resident. How do staff determine what the nonverbal resident is trying to communicate – or do they consider it "agitation"? What if s/he does not want to bathe at the scheduled time or in the designated shower area? Is that "noncompliance"? What if medication is spit out? Are different methods of administration attempted? Do staff and family discuss possible reasons for all these situations and try to find solutions together? Or do staff have a standard response to this "noncompliance" and simply record the "refusal" if their standard effort fails? Families should ask these questions, but should not rely only on staff's response to provide the complete picture. Observation of how staff handle these situations when they occur is also needed. In fact, federal regulations instruct surveyors to determine that non-verbal residents are provided with alternative means of communication, such as writing or pictures, so that their communication efforts can be "heard".

Behavior IS communication. A resident who is "acting out" is most likely making a serious effort to communicate with staff that "something is not right" with what is happening to them. The federal regulations require that services be provided to meet the needs of those with mental and psychosocial disorders, history of trauma and/or post-traumatic stress disorder, or dementia. If rehabilitative services such as but not limited to physical therapy, speech-language therapy, occupational therapy, and rehabilitative services for mental disorders and intellectual disability, are required in the resident's comprehensive plan of care, the facility must provide them either directly or through contract with other providers.

The nursing home must also allow the resident access to persons and services "inside and outside the facility." Families are typically informed that they have access to their loved one, by way of explanation of this right. Other aspects are not always discussed, and may not even be thoroughly understood by the staff of the facility or the family. For example, access to evaluations and therapies, or alternative treatments, is also part of this right. Sometimes getting specific evaluations, tests, therapies, or other such services for your loved one can be difficult. While there must, by regulation, be a medical need for the service, the family can advocate for that need to the physician, who often then orders the evaluation or service. This process is a part of that right to access.

The Code of Federal Regulations, Section 483.10, lists rights which must be afforded nursing home residents. A facility must protect and promote the rights of each resident, including each of the following rights, briefly annotated here:

Exercise of rights. The loved one, and the family as legally allowed surrogates (check your state laws related to these circumstances) must be able to freely exercise legal and civil rights, without interference, coercion, or reprisal from the facility.

Notice of rights and services. The facility must provide a copy of the rights to the resident, and a list of the services available.

Protection of resident funds. The resident has the right to manage his/her own funds. The facility may charge for certain services but not for others. Funds and charges are closely accounted for.

Free choice. The resident (or legal representative) has the right to choose his/her own attending physician, be fully informed in advance regarding care and treatment and any changes in care and treatment; and has the right to participate in planning, developing, and making changes in care and treatment.

Privacy and confidentiality. The resident is entitled to privacy in personal care & treatment, visitation, communication, meetings, and confidentiality of records.

Grievances. The resident has the right to voice grievances about treatment and to have those grievances resolved promptly.

Examination of survey results. The resident has the right to examine the results of the most recent Federal or State survey performed at the facility and any plan of correction in effect for the facility.

Work. The resident may work for the facility if s/he wants to and the arrangement is thoroughly documented, but may not be required to work for the facility.

Mail. The resident has the right to correspond, send and receive mail, in privacy and unopened, including access to writing materials and postage (at the resident's expense).

Access and visitation rights. The facility must allow immediate access by the resident to: the resident's physician, any representative of the government regulatory agencies governing the facility, the state's long-term care ombudsman, representatives of the state's protection and advocacy agency (or equivalent), any and all family members to which the resident has consented access, anyone providing services to the resident. The facility must also allow the Ombudsman access to resident records (with consent of the resident or legal representative) in accordance with state law.

Telephone. The resident has the right to use the telephone in a reasonable manner, and so that calls cannot be overheard.

Personal property. The resident has the right to keep and use personal property, including items, furniture, and clothing; as space permits and as long as it does not infringe on the rights, health or safety of others.

Married couples. The resident has the right to share a room with the spouse if both consent, when both reside in the same facility.

Self-Administration of Drugs. If the resident's interdisciplinary team has determined that this practice is safe, the resident may self-administer medications.

Refusal of certain transfers.
An individual has the right to refuse a transfer to another room within the institution, if the purpose of the transfer is to relocate —

- A resident of a SNF from the distinct part of the institution that is a SNF to a part of the institution that is not a SNF, or
- A resident of a NF from the distinct part of the institution that is a NF to a distinct part of the institution that is a SNF.

A resident's exercise of the right to refuse transfer as described above does not affect the individual's eligibility or entitlement to Medicare or Medicaid benefits.
(Note: This means that the resident's eligibility for benefits is not affected. Certain services may still be paid by Medicare as well. However, in order to receive Medicare funds for the nursing home care itself, the resident must be in a certified bed. When the period of care covered by Medicare ends, the resident can stay in a certified bed only if there is not another person who is Medicare-funded waiting for the certified bed. The payment for this continued stay in the certified bed will be the responsibility of the resident and not Medicare.)

Can the nursing home make your loved one move? There are legitimate reasons that a facility can move a resident, even if the resident or the family does not want the move. Reasonable efforts to deal with the circumstances in place are usually required, however, unless the resident's condition has improved so that nursing care is no longer appropriate. The Code of Federal Regulations, CFR483.15, speaks directly to this question:

Transfer and discharge requirements.
The facility must permit each resident to remain in the facility, and not transfer or discharge the resident from the facility unless —

- The transfer or discharge is necessary for the resident's welfare and the resident's needs cannot be met in the facility;

(NOTE: **cannot** – NOT that it is ***inconvenient*** to the facility to meet the needs – REMEMBER – THE FACILITY MUST MEET THE NEEDS OF THE RESIDENT. For example, sudden "lack of improvement" after steady progress; "s/he is a danger to other residents;" or "we can't do anything more with her/him" – each require valid clinical assessment, and documentation of all reasonable efforts made to meet the need, to support such a reason that the facility can "no longer meet the needs of the resident". After all reasonable efforts have been exhausted, or if

the facility is not licensed to provide the level of care required by the resident, then transfer may be inevitable.)

- The transfer or discharge is appropriate because the resident's health has improved sufficiently so the resident no longer needs the services provided by the facility;
- The safety of individuals in the facility is endangered;

(REMEMBER – THE FACILITY MUST MEET THE NEEDS OF THE RESIDENT. WHAT HAS BEEN ATTEMPTED BEFORE CONSIDERING REMOVING THE RESIDENT? See first bullet point above)

- The health of individuals in the facility would otherwise be endangered;

(REMEMBER – THE FACILITY MUST MEET THE NEEDS OF THE RESIDENT. WHAT HAS BEEN ATTEMPTED BEFORE CONSIDERING REMOVING THE RESIDENT? See first bullet point above)

- The resident has failed, after reasonable and appropriate notice, to pay for (or to have paid under Medicare or Medicaid) a stay at the facility. For a resident who becomes eligible for Medicaid after admission to a facility, the facility may charge a resident only allowable charges under Medicaid; or
- The facility ceases to operate.

Before a facility transfers or discharges a resident, the facility must

- notify the resident and, if known, family member or legal representative of the resident of the transfer or discharge and the **reasons for the move in writing and in a language and manner they understand.**
- Record the reasons in the resident's clinical record; and
- **Include in the notice the following items:**
  (a)The reason for transfer or discharge;
  (b)The effective date of transfer or discharge;
  (c) The location to which the resident is transferred or discharged;
  (d) A statement that the resident has the right to appeal the action to the State;
  (e) The name, address and telephone number of the State long term care ombudsman

Timing of the notice. Except when circumstances prevent doing so (specifically: endangerment of health or safety of residents*; urgent medical needs of the resident require immediate transfer; improvement of the resident's condition makes earlier transfer possible because the resident no longer requires nursing home level of care), the notice of transfer or discharge must be made by the facility at least 30 days before the resident is transferred or discharged.
(*Facilities may use this "excuse" to involuntarily discharge a "problem" resident. REMEMBER – THE FACILITY MUST MEET THE NEEDS OF THE RESIDENT. WHAT HAS BEEN ATTEMPTED BEFORE CONSIDERING REMOVING THE RESIDENT?)

These are the rights included in the Code of Federal Regulations for participation in the Medicare program for Nursing Facilities. Although not every Nursing Facility accepts Medicare or Medicaid residents, the standard of care represented in these rights and in the other sections discussed here should be the standard families look for when choosing a facility for their loved one. Families should inquire thoroughly into the rights, transfer and discharge practices of the facility before their loved one is admitted. Serious consideration should be given if the facility does not aspire to the standard of these rights. Once the loved one is

admitted, Our Mother's Voice reminds the family to remain vigilant to ensure that these rights and quality of care and services remain in place, for those whose voice has been silenced by age, incapacity, or dementia. Remember: in cases where the resident is not able, due to mental or physical condition, to exercise these rights for oneself, the responsibility for exercising these rights is assigned to a "family representative" or "power of attorney" or "legally allowed surrogate" (usually a family member) on behalf of the resident. That person is then considered to have the same rights as would otherwise be afforded to the resident directly. Our Mother's Voice works to inform that advocate so that the advocate, and other family members as well, can speak out for the resident who cannot exercise their rights independently.

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, 42CFR483.10; 42CFR483.15; and CFR483.40, Center for Medicare & Medicaid Services.