

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

CONSUMER FACTSHEET: INFORMED CONSENT

The right to informed consent is an important one for residents and families to know about (it is hard to exercise informed consent if you don't know you have a right to it!). It is also one of the most important standards related to dementia care and the widespread problem of inappropriate antipsychotic drugging.

Please note: (1) Text in italics is directly from the federal regulations. (2) Numbers in brackets [42 CFR 483.xx] refer to the provision in the federal regulations and are provided for your reference. (3) These standards are applicable to all residents in licensed nursing homes in the United States, whether they are short-term or long-term, private pay, Medicaid, Medicare or have another type of insurance. (4) Where the resident lacks capacity to make decisions and/or has assigned decision-making to someone else, that person takes the place of the resident in exercising these rights.

WHAT IS INFORMED CONSENT?

“Informed consent is an ethical concept—that all patients should understand and agree to the potential consequences of their care—that has become codified in the law and in daily practice at every medical institution.” [From [A Practical Guide to Informed Consent](#).]

THE LAW

I. Right to be Informed of & Participate in Treatment Plan – [42 CFR 483.10(c)]

The resident has the right to be informed of, and participate in, his or her treatment, including:

- *The right to be fully informed in language that he or she can understand of his or her total health status, including but not limited to, his or her medical condition.*
- *The right to be informed, in advance, of the care to be furnished and the type of care giver or professional that will furnish care.*
- *The right to be informed in advance, by the physician or other practitioner or professional, of the risks and benefits of proposed care, of treatment and treatment alternatives or treatment options and to choose the alternative or option he or she prefers.*

II. Right to Participate in Development & Implementation of Care Plan – [42 CFR 483.10(c)]

- *The right to participate in the planning process, including the right to identify individuals or roles to be included in the planning process, the right to request meetings and the right to request revisions to the person-centered plan of care.*

- *The right to participate in establishing the expected goals and outcomes of care, the type, amount, frequency, and duration of care, and any other factors related to the effectiveness of the plan of care.*
- *The right to be informed, in advance, of changes to the plan of care.*
- *The right to receive the services and/or items included in the plan of care.*
- *The right to see the care plan, including the right to sign after significant changes to the plan of care.*

III. Facility Must Inform Resident of the Right to Participate & Support the Resident in This Right – [42 CFR 483.10(c)]

The planning process must—

- *Facilitate the inclusion of the resident and/or resident representative.*
- *Include an assessment of the resident’s strengths and needs.*
- *Incorporate the resident’s personal and cultural preferences in developing goals of care.*

CHECKLIST FOR RESIDENTS, FAMILIES & OMBUDSMEN

The physician (not a delegated representative) should disclose and discuss:

- ✓ The diagnosis, if known
- ✓ The nature and purpose of a proposed treatment or procedure
- ✓ The risks and benefits of proposed treatment or procedures
- ✓ Alternatives (regardless of costs or extent covered by insurance)
- ✓ The risks and benefits of alternatives
- ✓ The risks and benefits of not receiving treatments or undergoing procedures

RESOURCES

- **WWW.NURSINGHOME411.ORG**. LTCCC’s website includes materials on the relevant standards for nursing home care, a listing of antipsychotic drug names and other resources.
- **WWW.THECONSUMERVOICE.ORG**. The Consumer Voice has numerous materials and resources for residents, family members and LTC Ombudsmen.
- **[A PRACTICAL GUIDE TO INFORMED CONSENT](http://www.templehealth.org/ICTOOLKIT/html/ic toolkitpage1.html)**. Temple Health has a very useful resource from which the above checklist and definition of informed consent are taken. It is available at <http://www.templehealth.org/ICTOOLKIT/html/ic toolkitpage1.html>.