



Advocacy Around Antipsychotic Medications

Claire Curry
The Consumer Voice webinar
September 6, 2012



Know Pertinent Resident Rights

Resident Right to be Informed



The resident has 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;

42 CFR § 483.10(b)(3)



- Informed consent is possible only if residents are given accurate information about the risks, benefits and alternatives to any proposed treatment.
- Informed consent is critically important for dangerous drugs like antipsychotics. These drugs carry the Food and Drug Administration's highest level of safety warning, the BLACK BOX warning of increased risk of death and other serious side effects.
- Be wary of nursing homes and doctors who take short-cuts and give antipsychotics without informed consent

Resident Right to be Involved in Care and Treatment



The resident has the right to:

- Be fully informed in advance about care and treatment and of any changes in that care or treatment that may affect the resident's well-being
- Participate in planning care and treatment or changes in care and treatment, unless adjudged incompetent or otherwise found to be incapacitated under the laws of the State.

42 CFR 483.10(d)

Resident Right to Refuse Treatment



The resident has the right to refuse treatment, to refuse to participate in experimental research, and to formulate an advance directive

42 CFR § 483.10(b)(4)

Residents Right to be Free from Restraints



The resident has the right to be free from any physical or chemical restraints imposed for purposes of discipline or convenience, and not required to treat the resident's medical symptoms.

42 CFR 483.10(a)

Who Can Exercise Residents Rights?



- The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United States.
- For residents adjudged incompetent under the laws of a State by a court of competent jurisdiction, the rights of the resident are exercised by the person appointed under State law to act on the resident's behalf.
- For residents who have not been adjudged incompetent by the State court, any legal-surrogate designated in accordance with State law may exercise the resident's rights to the extent provided by State law.



Know Other Pertinent Regulations

Antipsychotic Medications



- (2) *Antipsychotic Drugs*. Based on a comprehensive assessment of a resident, the facility must ensure that—
- (i) Residents who have not used antipsychotic drugs are not given these drugs unless antipsychotic drug therapy is necessary to treat a specific condition as diagnosed and documented in the clinical record; and
 - (ii) Residents who use antipsychotic drugs receive gradual dose reductions, and behavioral interventions, unless clinically contraindicated, in an effort to discontinue these drugs.

Unnecessary Drugs



- Each resident's drug regimen must be free from unnecessary drugs. An unnecessary drug is any drug when used:
 - (i) In excessive dose (including duplicate drug therapy); or
 - (ii) For excessive duration; or
 - (iii) Without adequate monitoring; or
 - (iv) Without adequate indications for its use; or
 - (v) In the presence of adverse consequences which indicate the dose should be reduced or discontinued; or
 - (vi) Any combinations of the reasons above.

Find Out What Has Already Been Tried



- What steps have been taken to discover underlying causes for a resident's conduct?
- Have staff asked if the resident is cold, hot, hungry, thirsty, irritated by loud, institutional noise levels, or lights, or the need to go to the bathroom, or to be changed...?
- Have patterns been looked at closely to eliminate triggers and anticipate resident needs?

Ask questions if antipsychotics are suggested



- Ask your doctor if he/she has personally examined the resident to make sure s/he is not simply calling in a prescription because staff requested that “something has to be done”.
- Ask your doctor to discuss with you the black box warning, and review all of the risks, benefits, and alternatives before you give consent for antipsychotics.
- Ask what specific medical symptoms the drug is indicated for.
- Ask what else could be tried.
- Ask for a second opinion from another doctor.

General advocacy tips



- Regularly review a list of the drugs the resident is taking
- Attend the resident's care plan conference (with resident consent if possible)
- Ask for the same caregivers to be assigned on an ongoing basis
- Share ideas and suggestions about alternatives based on your knowledge of the resident
- Don't be afraid to "just say no" if all other options haven't been tried

Seek Help If Necessary



- Know the grievance procedure at your facility and how to get answers and accountability.
- Get to know your local ombudsman and how to contact the state ombudsman when needed.
- File a complaint with your state survey agency.

Seek Help If Necessary



- Get involved in the Family Council at your facility to share issues and answers.
- If there is no Family Council, start one.
- Identify local resources and advocacy groups for quality long term care.
- Join the National Consumer Voice for Quality Long Term Care and make use of those resources to stay up to date and informed.