

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

Intro to the Dementia Care Advocacy Toolkit

Dementia care is a growing concern, as our population ages and more people live longer with Alzheimer's and other forms of dementia, particularly in nursing homes. The inappropriate use of antipsychotic drugs on people with dementia compounds these concerns for many individuals and families. Close to 20% of nursing home residents are given powerful and dangerous antipsychotics. This is especially alarming because these drugs are not clinically indicated for treatment of symptoms related to dementia and are associated with increased risk of death in the elderly. A 2011 study on antipsychotic drug use by the Office of the Inspector General of the U.S. Department of Health and Human Services found that too many nursing homes "fail to comply with federal regulations designed to prevent overmedication." The US Inspector General stated that "Government, taxpayers, nursing home residents, as well as their families and caregivers should be outraged - and seek solutions."

In response to these findings and the Inspector General's call to action, LTCCC and other advocates have been working to reduce the inappropriate use of antipsychotics and improve dementia care, particularly in our nursing homes. The **Dementia Care Advocacy Toolkit** has been developed to provide residents, families and those who work with them easy-to-use and accessible information to support improved care, quality of life and dignity for people with dementia.

The Toolkit is the product of a two-year project in which we worked with Family Councils and LTC Ombudsmen to provide education and engagement on some of the issues most relevant to good dementia care and the reduction of inappropriate and dangerous antipsychotic drugging. LTCCC's executive director attended meetings of two nursing home Family Councils and the Alliance of NY Family Councils. During each meeting he discussed a relevant dementia care standard and how that standard supported their advocacy for better care and the avoidance of inappropriate drugging.

The Toolkit is available for free in the Learning Center of LTCCC's website, www.nursinghome411.org.

Acknowledgements

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