



LONG TERM CARE (LTC) E- NEWSLETTER – October 2012: Volume 10, Number 8

Welcome to the [LTC E-NEWSLETTER](#), a monthly electronic newsletter of the [Long Term Care Community Coalition](#). Note to Readers: To go directly to an article, click on its page number in the Table of Contents. Once you are at the article, click on any underlined text for a link to more information or to send a message in “Spotlight on Advocacy.”

Please support LTCCC’s work to protect the frail elderly and disabled who rely on long term care.
[Click here to donate \\$5 \(or whatever you care to give\).](#)

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[New Report: Home Alone: Family Caregivers Providing Complex Chronic Care](#)

The United Hospital Fund and the AARP Public Policy Institute have released a new report on the level of care that family members are providing across the country. Family members have traditionally been thought of as helping with assistive, nonmedical tasks like food shopping, cleaning and dressing. According to the national survey conducted by the authors, “There are more than 42 million unpaid family caregivers in the United States, and of the 46 percent of family caregivers performing medical and nursing tasks, three out of four provided medication management – including administering IVs and injections – for a family member with multiple chronic physical and cognitive conditions.”

[<http://www.uhfnyc.org/publications/880853>]

Paper Reviews Affordability of Long Term Care Services & Supports

The long term care “marketplace” is currently undergoing major changes. As a result of the preference of many consumers to access care and services in the least restrictive setting possible, more and more people are delaying or avoiding nursing home placement and seeking access to home and community based services (HCBS). In response, states and the federal government are working to improve access to HCBS; the 2010 Affordable Care Act (so-called Obamacare) included numerous provisions to improve the availability of HCBS for seniors and disabled people. At the same time, the federal government and the states are facing significant budgetary constraints, resulting in a squeeze on financing of public healthcare programs.

This paper from the AARP Public Policy Institute, [A New Way of Looking at Private Pay Affordability of Long-Term Services and Supports](#), written by Ari Houser, presents data on the affordability of private pay long term care services and supports for every state. Among the major findings detailed in the report are:

- There is wide variation in affordability between states and markets.
- Private pay nursing home care is not affordable for middle-income families anywhere.
- While less costly than nursing homes, home health care is still unaffordable for middle-income older people at typical levels of use.
- There is a no relationship between income and nursing home affordability.
- There is a clear relationship between income and home health affordability.

[<http://www.aarp.org/home-family/caregiving/info-10-2012/private-pay-affordability-ltss-insight-AARP-ppi-ltc.html>]

LTCCC Report: Federal Requirements & Regulatory Provisions Relevant to Dementia Care & The Use Of Antipsychotic Drugs

The inappropriate use of antipsychotic drugs on people with dementia, particularly in nursing homes, is a significant problem. As readers of this e-newsletter and LTCCC’s [Monitor](#) newsletter know, it is an issue which we have been advocating on vigorously, especially after May 2011, when the U.S. Inspector General issued a report indicating

that nursing homes across the country were failing to “comply with federal regulations designed to prevent overmedication, giving nursing home patients antipsychotic drugs in ways that violate federal standards for unnecessary drug use.”

Last month, we announced the launch of our new web page, [nursinghome411.org/?articleid=10042](http://www.nursinghome411.org/?articleid=10042), with information and resources on the antipsychotic drugging issue. This page now has LTCCC’s newest report, *Federal Requirements & Regulatory Provisions Relevant to Dementia Care & The Use Of Antipsychotic Drugs*, which presents an overview of federal law and oversight related to antipsychotic drugging. The report includes detailed information – in an easy to use format – on all of the federal regulatory requirements that we identified as being relevant to antipsychotic drug use in nursing homes. This information is presented using the system that nursing home surveyors use to cite for deficiencies, with each of the federal requirements identified by the F-Tag utilized by surveyors. Each F-Tag description includes a citation to the federal code, the relevant federal guidance and a short narrative on how and why it is relevant in the context of antipsychotic drug use. We believe it will help surveyors, advocates, families and providers by providing a concise resource on the relevant requirements.

[\[http://www.nursinghome411.org/?articleid=10042\]](http://www.nursinghome411.org/?articleid=10042)

[Spotlight on Advocacy: Support Senate Bill 3604: Informed Consent for Antipsychotics in Nursing Homes](#)

LTCCC has been working with consumer representatives from around the country to advocate against the inappropriate use of antipsychotics on individuals with dementia. This is a pervasive problem, particularly in nursing homes, where close to 25% of residents are given powerful and dangerous antipsychotics. [For more information and resources on this issue please visit LTCCC’s dedicated website page:

[http://www.nursinghome411.org/?articleid=10042.](http://www.nursinghome411.org/?articleid=10042)]

As part of this advocacy, we have been working with U.S. Senate leaders to introduce legislation to improve the requirements around informed consent for the use of antipsychotics on individuals with dementia. Though federal law has long mandated that individuals (or their representatives, if they lack capacity), must be given the opportunity to provide informed consent, including the right to be fully informed in advance about their care and treatment and the right to refuse treatment, too often these rights are ignored in practice. Thus, LTCCC and other advocates have been working with U.S. Senate staff to strengthen requirements around informed consent. One of our advocacy partners in this effort, the [National Consumer Voice for Quality Long Term Care](#), has set-up the following action alert that people can use nationwide to let their U.S. Senators

know that they support this bill. Please take a moment to send a message now.

Can you imagine if you had surgery and your doctor did something you hadn't discussed with him or her?

Can you imagine if a potentially dangerous drug was given to you without your knowing or understanding?

Actually you do not have to imagine it.

26% of all nursing home residents are given antipsychotic medications; 88% of these residents are elderly people with dementia who are being given antipsychotic medications that the FDA warns put them at serious risk of medical complications and death. Yet far too often, no one discusses these dangers with residents and their families or whether or not these medications should be given.

S. 3604, the Improving Dementia Care Treatment for Older Adults Act - introduced by Senators Kohl (D-WI), Grassley (R-IA), and Blumenthal (D-CT) - would require nursing homes to obtain informed consent before an antipsychotic medication is prescribed for a resident with dementia. A process would be developed for providing clear information about possible side effects and risks associated with antipsychotics, as well as any alternative treatments, including non-drug interventions.

"Informed consent" means patients have a choice and know the risks and benefits of a medication or procedure – this is a critical part of ethical health care delivery in the United States.

Nursing home residents with dementia, or an individual with legal authority to act on their behalf, should have the same clear rights to informed consent when it comes to antipsychotic medications that can be life-threatening.

Please [click here](#) to send a message now or go to http://wfc2.wiredforchange.com/o/8641/p/dia/action/public/?action_KEY=8899.

We're on the Web!

NEW!: [Materials on the Affordable Care Act and Mandatory Managed Long Term Care in New York](#)

www.ltccc.org: Our main website, with access to all of our issues, policy briefs and research.

www.assisted-living411.org: For information on assisted living, including consumer issues and policies.

www.nursinghome411.org: For information on developments in nursing home care, regulation and policy issues.

LTCCC Links of Interest

[View](#) the latest enforcement actions against nursing homes in New York State.

[Read](#) the latest edition of LTCCC's quarterly newsletter, The Monitor.

LTCCC study: Government Monitoring & Oversight of Nursing Home Care in [Word](#) or [PDF](#).

Long term care information booklet in [Chinese](#) and [English](#) for Chinese consumers: What You Need to Know about Long Term Care.

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