



**LONG TERM CARE (LTC) E- NEWSLETTER – November 2012: Volume 10, Number 9**

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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**[Settlement Reached To End Medicare’s “Improvement Standard” - Skilled Maintenance Services Can Be Covered by Medicare](#)**

The [Center for Medicare Advocacy](#) reports on a significant settlement achieved in an important class action lawsuit on the so-called “improvement standard” for [Medicare](#) coverage of nursing and therapy services:

For decades, Medicare beneficiaries – particularly those with long-term or debilitating conditions and those who need rehabilitation services – have been denied necessary care based on the

"Improvement Standard". This illegal practice has resulted in Medicare coverage for vital care being denied to thousands of individuals on the grounds that their condition was stable, chronic, not improving, or that the necessary services were for "maintenance only." The use of this illegal standard has had a particularly devastating effect on patients with chronic conditions such as Multiple Sclerosis, Alzheimer's disease, ALS, Parkinson's disease and paralysis. The lawsuit, *Jimmo v. Sebelius*, was brought on behalf of a nationwide class of Medicare beneficiaries by six individual beneficiaries and seven national organizations representing people with chronic conditions, to challenge the use of the illegal Improvement Standard.

The Center for Medicare Advocacy's website has more information and resources on the case and its ramifications for elderly and disabled consumers, including self-help packets, FAQs and a summary of the case. Click on the title above or go to the link below for their website page on the case.

[\[http://www.medicareadvocacy.org/medicare-info/improvement-standard-2/-summary\]](http://www.medicareadvocacy.org/medicare-info/improvement-standard-2/-summary)

## **Concerns Continue Over Danger of Bed Rails**

The November 15 issue of [Biomedical Safety & Standards](#) (BS&S) reports on how consumer groups, including the [National Consumer Voice for Quality Long Term Care](#), "have opened another front in the long battle to prevent injury of patients from use of devices commonly thought to promote safety—bed rails—by involving the Federal Trade Commission." BS&S reports that

The FDA has reports of more than 525 deaths associated with the use of bed rails. The Consumer Product Safety Commission (CPSC) has reports of more than 155 deaths as well. Most often, these deaths are a result of entrapment... which, particularly where a portable bed rail is concerned, can occur when the device slides outward as the child or adult leans into the handle or rail. Altogether, 7 entrapment zones have been identified with use of bed rails.

Manufacturers such as Bed Handles Inc have been allowed to make advertising claims that include "makes any bed a safer bed," and "stable in all directions and can be firmly pulled, pushed, lifted, and leaned on," unfettered by requirements to prove such claims.

[Note: Reference links removed from above text.]

The consumer groups are urging the FTC to stop the manufacturer Bed Handles from making false claims about its products and, among other things, recall certain models of their products. The BS&S report also notes that

It's important to know that although elderly patients fall at a much higher rate than the general population, and a fall at an advanced age can be catastrophic, research demonstrates the following:

- \* The presence of bed rails does not deter adults or children from trying to get out of bed;
- \* There is no evidence that side rails prevent falls;
- \* There are already evidence-based methods to reduce the incidence of bed-related falls, including lowering bed height and placing anti-slip matting at the bedside;
- \* Bed rails themselves can be more dangerous to patients than falls;
- \* A fall with a bed rail in place is more dangerous than a fall without a rail, because of the change in trajectory of the fall; and
- \* Patients can be injured or killed through use of these devices.

[\[http://journals.lww.com/biomedicalsafetystandards/Fulltext/2012/11150/Safe, Portable Bed Rails There s No Such Thing.1.aspx\]](http://journals.lww.com/biomedicalsafetystandards/Fulltext/2012/11150/Safe_Portable_Bed_Rails_There_s_No_Such_Thing.1.aspx)

## **Past Antipsychotic Drug Exposure Found to Increase Risk of Parkinson's Disease**

A 15 year study of 2991 individuals in France has found that past exposure to antipsychotic medications increases the risk of development of Parkinson's Disease. According to a report on the research findings in [Medwire News](#), the researchers "believe that about one in five cases of PD could be avoided by restricting use of antipsychotics. Most patients in their study received the drugs for nonpsychiatric indications, including insomnia, anxiety, vertigo, and gastrointestinal problems, despite such use being discouraged."

The authors are careful to note that the study was conducted with individuals who had received so-called first generation antipsychotics and that the risk for second generation antipsychotics (also known as atypical antipsychotics) is unknown. The second generation antipsychotics were supposed to have less negative side effects. However, research to date indicates that many of the significant problems associated with the first generation

drugs have continued in the second generation (though the kind and magnitude of side effects appears to vary, sometimes significantly, within the second generation).

The researchers noted that

neuroleptic [antipsychotic] use may expose, rather than cause, parkinsonism, but they also point out that only 30% of the patients in their study who developed PD [Parkinson's Disease] after drug exposure had symptoms of parkinsonism at the time of the exposure.

The researchers also observe that insomnia and anxiety can be early manifestations of PD, which could have triggered prescription of neuroleptics in patients already destined to develop PD. But when they looked at past use of benzodiazepines, which are often prescribed for these conditions, they found no association with PD.

The research was reported on in the journal [\*Neurology\*](#) [*Neurology* 2012; **79**: 1615–1621], wherein the authors noted that "[a]lthough the mechanisms underlying this relation need further exploration, our findings plead for a limitation of the use of these drugs in elderly people...."

[[http://www.medwire-news.md/47/101959/Psychiatry/Antipsychotic\\_drug\\_exposure\\_may\\_have\\_neurologic\\_consequences.html](http://www.medwire-news.md/47/101959/Psychiatry/Antipsychotic_drug_exposure_may_have_neurologic_consequences.html)]

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

*NOTE: WE ARE CONTINUING THIS ACTION ALERT FROM OUR LAST ISSUE. IF YOU HAVE NOT ALREADY, PLEASE SEND A QUICK MESSAGE IN SUPPORT OF THIS IMPORTANT U.S. SENATE BILL!*

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>.]

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](http://wfc2.wiredforchange.com/o/8641/p/dia/action/public/?action_KEY=8899).

## We're on the Web!

[www.ltccc.org](http://www.ltccc.org): Our main website, with access to all of our issues, policy briefs and research.

[www.assisted-living411.org](http://www.assisted-living411.org): For information on assisted living, including consumer issues and policies.

[www.nursinghome411.org](http://www.nursinghome411.org): For information on developments in nursing home care, regulation and policy issues.

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## 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's dedicated webpage on antipsychotic drugs and dementia care:  
[nursinghome411.org/?articleid=10042](http://nursinghome411.org/?articleid=10042).

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

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

[SIGN-UP FOR THE LTC E-NEWSLETTER \(OR UNSUBSCRIBE\)](#)!