

Improving Dementia Care Through Informed Consent

The Improving Dementia Care in Older Adults Act (S. 3604) was introduced in the last session of Congress to address an important issue in nursing home resident care. The bill would implement a standardized protocol for obtaining informed consent from nursing home residents prior to the administration of an antipsychotic drug. While longstanding federal standards mandate that a resident has the right to be fully informed about his or her care (including medications and other treatment), participate in care planning and reject care (at his or her discretion), too often these protections are not interpreted or enforced in a way that ensures that the individual (or, for those residents who lack capacity, his or her representative) has truly consented to treatment.

Many states have their own informed consent laws, however, they vary in respect to both their protectiveness and applicability to the nursing home drugging issue. Given the known dangers of using antipsychotic drugs on eld-

erly people with dementia (including a high risk of heart attack, stroke and Parkinsonism), this is a critical issue for consumers. S. 3604 would provide added protection to nursing home residents in states with weak or nonexistent informed consent laws. Our research indicated that of the 50 states and the District of Columbia, 24 of the 51 (47%) have either no informed consent laws concerning nursing home residents or have standards that are considerably weaker than the proposed federal protocol.

In Recognition

As of October 2012, Cynthia Rudder, founder and former Executive Director of the Long Term Care Community Coalition, is no longer with the organization. She leaves a record of achievement that the LTCCC community and those who work to improve the quality of life and care of long-term care residents can be justly proud. There is not enough space to mention all of LTCCC's accomplishments under Cynthia's leadership. It begins with the effort to achieve a single standard nursing home code and its work to successfully fight back former President Ronald Reagan's proposals to deregulate the nursing home industry. It continued with its critically important staffing and nurse aide training initiatives.

She conducted probing policy analysis and research, vigilant advocacy, and coalition building in order to strengthen long-term care regulations, surveillance

and enforcement, and established these activities as hallmarks of the organization.

For many years she was the lone consumer voice on important committees such as the State Hospital Review and Planning Council. In addition, she helped educate the consumer advocacy community on financing and

NYS enforcements now available online. Go to ltccc.org/enforcements/archives.shtml for complete, searchable information or see page 5 inside for selected actions.

> munity on financing and reimbursement issues, and the impact and importance these issues have on achieving quality care.

We thank her for all that she has done on behalf of nursing home and assisted living residents over these many years. And we wish her the best of luck in all her future endeavors. \Box

In This Issue...

My Mother's Nursing Home Nightmare 3
Enforcement Actions
Action Alert Mailing List

continued on page 2

Improving Dementia Care continued from page 1

LTCCC's Research

In order to gain insights into the various states' protections, and how they compare to the proposed federal bill, LTCCC researched state informed consent laws pertaining to a nursing home resident's rights. We found that, in general, there are two ways in which a state's informed consent law could be more protective than those proposed in the federal bill:

(1) By requiring a physician to personally inform a resident of his or her rights. S. 3604 requires that a facility inform the resident of certain side effects and risks of antipsychotic medications, attempted treatment modalities, and other relevant information; the prescriber of the medications, however, must only be "involved" in the information process. The phrase "involvement of the prescriber" is vaguely worded and also leaves the physician's role in the information process open to a facility's interpretation; in fact, the resident's physician in some circumstances. A number of the state laws explicitly require the resident's physician to convey information to a resident directly, which eliminates the interpretive aspect behind the wording of "involvement" of the physician (or other prescriber).

(2) By requiring information and/or consent to be in writing. The second possible way a state law may be stronger than the proposed federal requirements comes from Section 5(b)(i)(I) of the federal bill as well. That section begins, "the facility...must inform the older adult..." By only requiring a facility to inform a resident of his or her rights, it would likely be up to the facility to decide whether to convey the information to the resident orally or in writing, and to receive the resident's consent either orally or in writing. This is less protective than the requirement in some states that a facility must provide a resident with a written statement of the resident's rights and also require a resident to indicate consent in writing. In addition, some states require a resident to be informed both orally and in writing of his or her rights, and consent in writing.

In our study of the 50 states and the District of Columbia, we found that 21 of 51 state laws (41%), are more protective than the Improving Dementia Care in Older Adults Act by requiring that physicians directly inform a resident of his or her rights and/or that a facility must inform the resident in writing, or both orally and in writing. Fortunately, Section 5(e) of the Improving Dementia Care in Older Adults Act, titled "No Preemption," addresses the possibility of a state having stronger informed consent protections by not allowing anything in it to preempt a provision of existing state or federal law that provides more protective rights to a resident.

LTCCC's purpose in undertaking this study was to gain insights into states' requirements and how they compare to the protections proposed in the federal bill. *continued on page 3*



The Monitor is published quarterly. SPRING 2013 • Volume 64

Staff

Richard J. Mollot, *Executive Director* Sara Rosenberg, *Office Manager* Daniel Butler, Public Policy Intern Ilan Norwood, Public Policy Intern LONG TERM CARE COMMUNITY COALITION Working to improve long term care through research, education & advocacy

> 242 West 30th Street • Suite 306 • New York, NY 10001 Phone (212) 385-0355 • Fax (212) 239-2801 website: www.ltccc.org

Board of Directors

Geoff Lieberman, *President* Deborah Truhowsky, Esq., *Vice President* Joan Burke Martin Petroff, Esq.

This newsletter is made possible through funding by the following foundations: FJC-Foundation of Philanthropic Funds • Robert Sterling Clark Foundation Layout and design by www.pattiedesign.com

My Mother's Nursing Home Nightmare

The following article is written by Laurie Kash, a private citizen who reported this issue to LTCCC and agreed to tell her mother's story, in her own words,

She did well for the first three weeks of her rehabilitation and was close to the point of being discharged. One night, the nurse caring for my mother failed to

once her case was resolved. The views and opinions expressed in this article are those of the author and do not necessarily reflect those of LTCCC.

My mother's story is one of a beloved and active 87 year old woman who walked into the Jewish Home of Rochester on February 13, 2006 and within a short time, became paralyzed from the chest down, while those entrusted



with her care failed to take basic medical and nursing actions.

My mother, once an active and highly functioning woman, suffered a blow to her head in late 2005. Shortly after that fall, she suffered a loss of balance. On the recommendation of her physician she was admitted to the Jewish Home for rehabilitation so that she could regain the balance she had lost after her fall and return to living at home. had been ordered.

For the next six days her complaints of pain increased, in spite of taking pain medications, and obvious signs of spinal cord involvement. She was evaluated by Dr. Larsson, the doctor in charge of her medical care at the Jewish Home, but no diagnosis was made. Pain medications were all that was provided to her.

She continued to decline. A week later, she was *continued on page 4*

Improving Dementia Care continued from page 2

As of this writing, we are finalizing our report, which will include an overview of every state's informed consent laws and their relevancy if the Improving Dementia Care in Older Adults Act is passed.

This report, which will be available on www. nursinghome411.org, should be helpful to nursing home residents, their representatives and other stakeholders across the United States.



LTCCC is supporting the campaign by the National Consumer Voice for Quality Long-Term Care to pass S. 3604. To support S. 3604 as an individual, please go to http://wfc2.wiredforchange.com/

o/8641/p/dia/action/public/?action_KEY=8917. To support S. 3604 as a group, sign on to the Consumer Voice support letter [http://wfc2.wired forchange.com/o/ 8641/p/dia/action/public/?action_KEY=8918].

perform an ordered catheterization. My mother had to get out of bed in the middle of the night to empty her overfull bladder. She was unable to make it and was found on the floor by the nursing staff after slipping in her own urine. She complained immediately of back pain. No bed alarm was in place at the time, even though one

Nursing Home Nightmare continued from page 3

again found on the floor in her room by the nursing staff. Again, there was no bed alarm in place. She was again evaluated by Dr. Larsson. He sent her for a CT scan, which showed a fracture of one of her vertebrae. She returned to the Jewish Home after the CT scan but no treatment of her fracture and declining

neurological condition was offered other than increased pain medication for her steadily increasing pain.

She was never evaluated again by Dr. Larsson or any other physician or nurse practitioner after the CT scan showed that she had the fractured vertebrae. In the next few days my mother's decline continued to the point that she could no longer bear weight on her legs at all. Since repeated pleas from her children to have her sent to a hospital and for more medical intervention went unheeded, the family asked an out of town relative who is also a doctor to come to see her.



This individual determined that my mother was paralyzed from the chest down. It had now been two weeks since the first fall. She was rushed to the hospital where it was determined that the damage to her spinal cord caused by the fracture, swelling and bleeding was now irreversible. She lived for an additional three years confined to a wheelchair paralyzed from the chest down.

DOH Investigations

We complained to the New York State Department of Health (DOH) but after six investigations conducted by three offices into the handling of my mother's injury, most concerns were dismissed. The neglect was blatant, but DOH identified only one deficiency and rated that as causing no actual harm. It was apparent to outside expert physicians that there were repeated violations from the standard of care that is outlined in New York State. Nursing home staff repeatedly violated their own care plans. How could the three arms of the DOH fail so blatantly in their findings when violation after violation is staring them in the face?

Pursuing Legal Action Under Article 2801-d

In 2008, after the sixth and final investigation came

to its unacceptable conclusion, I filed a Freedom of Information Act (FOIA) request to seek information from DOH on the basis for their conclusions. I was told that this information could not be released. At this point the family brought a legal action against the Jewish Home and Dr. Larsson in New York State Supreme Court in Monroe County which alleged negligence, medical malpractice and violation of §2801-d of the New York Public Health Law, a section added by the legislature in the 1980s to protect nursing home patients from abuse. The statutory claim was initially dismissed by the trial court but the Appellate Division, Fourth Department, determined on appeal that Mrs.

Kash was indeed entitled to make such a claim in addition to her other common law negligence and malpractice claims. The action was resolved after a jury was selected in New York State Supreme Court in October 2010. The details of the resolution of the case were to be kept confidential.

The family continued the suit after my mother's death for two reasons: first, to seek justice for my mother's physical and emotional pain and suffering; second, to see that this type of tragedy never happens again. We are dedicated to meaningful change in the laws on institutional oversight and meaningful implementation of the existing laws. Clearly, the DOH does not enforce existing minimal standards.

In light of the failures of the DOH it is my belief that families of loved ones should pursue legal action under 2801-d for nursing home neglect. It may, in many instances, be the only recourse to force nursing *continued on page 7*

Quarterly Enforcement Actions Against Nursing Homes

Selected Enforcement Actions of NYS Attorney General					
Medicaid Fraud Control Unit ¹ Took Action Against 4 Nursing Home Personnel 9/16/12 - 12/15/12					
Nursing Home	Location	Defendant	Narrative	Sentence	
The Hurlbut	Rochester	Thomas, Gloria, Business Office Manager	Defendant diverted over \$20,000.00 from the patient fund account for her own use, used the business account to steal \$585 worth of Wegmans gift cards, and \$462 worth of money orders from the Hurlbut.	9/24/2012: Five years Probation and Restitution Ordered \$22,293.35 (\$10,000 to the Hurlbut and \$12,293.35 to the insurance company that previously paid out to the Hurlbut for the loss.) Two restitution orders were signed and filed.	
Loretto Health and Rehabilitation Center	Syracuse	Stevens, Celeste, Certified Nurse Aide	The defendant was assigned to give intense supervision to a resident, whose Care Plan required 2-person transfers. Stevens attempted a one person transfer and he fell to the ground. Without telling anyone what happened, she had another CNA help her transfer him into bed and falsely recorded a 2 person assist. After the resident complained of pain it was discovered that he had suffered a fractured right hip.	12/4/2012: One year Conditional Discharge. ²	
Medford Multicare Center	Medford	Grayovski, John, Certified Nurse Aide	The defendant transferred an elderly resident without assistance during which the resident fell and suffered a skin tear. The defendant failed to report the incident and covered up the tear with a bootie, later denying the one person transfer. After the tear was discovered, the resident received 13 stitches to treat the wound.	12/12/2012: Three years Probation Supervision with the condition that he not work caring for disabled or incompetent people for three years, and surrender of his CNA certificate.	
Pathways Nursing & Rehabilitation Center	Niskayuna	Howard, Elesia, Certified Nurse Aide	While bathing and clothing a 72-year old female resident, the defendant yelled and pinched her breast.	9/26/2012: One year Conditional Discharge. Condition being surrender of her CNA certification.	

¹The unit prosecutes cases of patient abuse in nursing homes.

²Conditional discharge means if similar act is committed during the time period defendant can be brought back to court.

Federal Civil Money Penalties ¹ Against 5 Nursing Home: 9/1/12 – 11/30/12 ²				
Name Of Home	Location	Survey Date	Amount	
Adirondack Medical Center-Mercy	Tupper Lake	4/26/2012	\$4,050.00	
Barnwell Nursing and Rehab Center	Valatie	3/13/2012	\$3,250.00 ³	
Chittenango Center for Rehabilitation and Healthcare	Chittenango	7/23/2012	\$3,250.00 ³	
Elant at Fishkill	Beacon	1/10/2011	\$39,050.00 ⁴	
Our Lady of Hope Residence	Latham	3/20/2012	\$2,925.00 ³	

¹Civil Money Penalties (CMPs) – a federal sanction against nursing homes that fail to comply with quality care requirements. ²As reported by CMS. For more detailed information contact the FOIA Officer at CMS 212-616-2220. This list will be posted on LTCCC's website every three months.

³Amount reflects a 35% reduction as the facility waived its right to a hearing as permitted under law.

⁴ Fine imposed in accordance with settlement agreement between CMS and the facility.

Quarterly Enforcement Actions Against Nursing Homes

Selected Administrative Actions By The NYS Office of Medicaid Inspector General

Action Taken Against 7 Nursing Home Personnel 9/16/12 - 12/15/12¹

OMIG works to protect New York State citizens residing in long term care facilities by making sure that those responsible for their care do not engage in abusive and fraudulent activities. This is done through OMIG's ensuring that those who are enrolled as providers into the Medicaid program are properly vetted, investigating allegations of fraud and abuse within long term care facilities, and finally, excluding providers who have abused their positions as care givers. In addition to conducting their own investigations, the OMIG makes determinations to exclude based on other agency actions, including the State Education Department (SED), the Medicaid Fraud Control Unit (MFCU), and Human Health Services (HHS). A single provider can receive multiple exclusions, based on different indictments and convictions. This involved process works to protect residents of long term care facilities, because it ensures that even if one conviction is overturned, the abusive provider is still banned from receiving Medicaid funds based on other convictions.

Nursing Home	Defendant	Location	Narrative	OMIG Exclusions ² Based Upon
Beechwood Home	Shelly Trombetto, LPN	Getzville	Ms. Trombetto stole prescription narcotic pills from the nursing home's narcotic storage cabinet for her own use.	MFCU Conviction: 6/28/2012
Crown Center for Nursing and Rehabilitation	Jennie Damon, LPN	Cortland	Ms. Damon forcibly gave insulin to a resident who refused it and then made a false statement that she had never given insulin against the resident's will.	MFCU Conviction 6/13/2012
Dr. William O. Benenson Rehabilitation Pavillion	Jessie Joiner, LPN	Flushing	Ms. Joiner did not assist an 85-year-old resident who had been knocked out of her wheelchair. Not only did she not seek medical attention for the resident, but she also failed to report the incident. The resident	MFCU Conviction 6/13/2012 SED Licensure
			suffered a broken hip which later required surgery. Ms. Joiner also admitted to stealing more than 20 Percocet pills from another resident for her own	Action 6/6/2011
			personal use.	MFCU Indictment 7/11/2010
Glen Island Center for Nursing and	Eufemia Fe Salomon Flores, RN	New Rochelle	Between April 20, 2001 and March 8, 2012, Ms. Salomon Flores inflated the PRI scores submitted on behalf of nursing home residents. Since PRI scores are	MFCU Conviction 4/16/2012
Rehabilitation			used to determine the level of care residents need, this led to the nursing home's being reimbursed at a higher rate than what they were entitled to, and Ms. Salomon Flores executed a confession of judgment for \$2.2 million. Ms. Salomon Flores also failed to report on her 2008 tax return \$307,000 worth of income she had received from Glen Island through bogus companies for which she had a tax liability of \$31,000. She had not paid those taxes.	MFCU Indictment 4/17/2011
Grace Plaza Rehabilitation and Nursing Center	Jackie Lynn Everett, LPN	Great Neck	Ms. Everett diverted narcotics that were meant for nursing home residents, taking them for her own use.	MFCU Conviction 6/13/2012
				MFCU Indictment 3/14/2011
Northwoods Rehabilitation and Extended Care	Gail Klein, LPN	Troy	On multiple occasions Ms. Klein falsely documented applying medication to a disabled resident's bed sores, when in fact she had not, as captured on MFCU video	MFCU Conviction: 4/6/2012
Facility			surveillance of the resident's room. She also failed on multiple occasions to dispense medications or provide treatment to the same woman.	MFCU Indictment: 6/2/2010
Penn Yan Manor	Gail Jensen, LPN	Penn Yan	Ms. Jensen worked as a nurse while her ability to practice was impaired by the ingestion of Xanax and Percocet. While on duty, she was observed falling asleep, stumbling, slurring her speech and not making eye contact.	SED Licensure Action 5/21/2012

¹In addition to these actions, all of the providers which were reported as having actions taken against them by the Medicaid Fraud Control Unit in previous newsletters have been excluded by OMIG. Please see our newsletter archives at www.ltccc.org/newsletter for their names. ²Exclusion means that no payments will be made to or on behalf of any person for the medical care, services or supplies furnished by or under the supervision of the defendant during a period of exclusion or in violation of any condition of participation in the program. Additionally, any person who is excluded from the program cannot be involved in any activity relating to furnishing medical care, services or supplies to recipients of Medicaid for which claims are submitted to the program, or relating to claiming or receiving payment for medical care, services or supplies during the period. OMIG may take a variety of exclusion actions against a provider based upon: indictments; convictions; consent orders or HHS

exclusion.



Special Focus Facilities (SFF)

The federal Centers for Medicare and Medicaid Services (CMS) initiated the Special Focus Facility (SFF) program to address the widespread problem of nursing homes that have persistent, serious problems. Often these facilities exhibit "yo-yo" compliance: they correct problems found during a survey (inspection) but then are unable or unwilling to maintain standards and fall out of compliance again, repeatedly. From a consumer perspective, the SFF program can be a valuable tool to crack down on nursing homes that are persistently failing their residents and, by identifying and fixing (or removing) a state's worst nursing homes on an on-going basis, eventually improve nursing home care overall.

Once a facility is selected for inclusion in the SFF program it receives special attention from the state, including a federally mandated requirement that the state conduct at least twice as many surveys as normal (approximately two per year). The goal is that within 18-24 months of being in the program a facility will either: (1) develop long term solutions to its persistent problems or (2) be terminated from participation in the Medicare and Medicaid programs. Termination usually means that a facility is sold to a new operator or closed. Due to resource limitations, only 136 nursing homes across the country are selected for participation in the SFF program at any given time. On average, states have about two SFFs; since New York is one of the largest states in the country it is supposed to have at least five.

Since CMS started to make the names of SFFs public, this program is an important tool that consumers can use to learn about facilities in their communities with persistent problems. The federal nursing home information website, Nursing Home Compare (www.medicare.gov/nhcompare) now includes information on whether or not a facility is an SFF. CMS updates a list of all SFFs in the country quarterly. See http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandComplianc/downloads/sfflist.pdf.

Following is the latest information on SFFs in New York State.

The numbe	SPECIAL FOCUS FACILITIES IN NEW YORK STATE – As of December 31, 2012 The numbers in parenthesis indicate the number of months the home has been on the list and identified as an SFF.					
Facilities Newly Identified as a SFF	Facilities That Have Shown		Facilities That Have Recently Graduated from the SFF Program ³	Facilities No Longer Participating in the Medicare & Medicaid Program ⁴		
None	Marcus Garvey Nursing Home (11)* Pleasant Valley (9) Van Duyn Home And Hospital (14)	Blossom South Nursing And Rehabilitation Center (19) * Rosewood Heights Health Center (9)*		Countryside Care Center (22)		

¹Nursing homes that have shown significant improvement, as indicated by the most recent survey. If the improvement continues for about 12 months (through two standard surveys), these nursing homes will graduate from the SFF list.

²Nursing homes that have failed to show significant improvement.

³These nursing homes have had sustained significant improvement for about 12 months (through two standard surveys). "Graduation" does not mean that there may not be problems in quality of care, but does generally indicate an upward trend in quality improvement compared to the nursing home's prior history of care.

⁴These are nursing homes that were either terminated by CMS from participation in Medicare and Medicaid within the past few months or voluntarily chose to leave the program.

*On the SFF list for the second time.

Nursing Home Nightmare continued from page 6

homes to operate at a meaningful standard of care. I will always be grateful to our attorney, Stephen Schwarz of Faraci Lange for his diligent pursuit of justice, shining a light on the whole tragedy of what happened to our mother.

I promised my mother that we would continue to pursue her case even if she was not alive to see the case to its end. I hope that nothing like this can ever happen to a resident of a nursing home again.

My mother was a wonderful and courageous woman who deserved much better than living the

way she did for the final three years of her life. By winning the appeal on the Public Health Law claim she has also left a positive legacy to help others injured by nursing home neglect in the future to seek justice. I know she would have been very proud of that.

To see the YouTube interview about this case with WHEC TV News please go to this link: http://www.youtube.com/watch?v=ifl4ZqOHQXI.

For more information about my mother and her case search the Internet for "Gertrude Kash." \Box

LTCCC

242 West 30th Street, Suite 306 New York, NY 10001 NON-PROFIT ORG. U.S. POSTAGE PAID NEW YORK, NY Permit No. 893

Visit our homepage, www.ltccc.org, for the latest news, action alerts or to make a donation!

NO THIS CAR CONSULTY COATTON

NEW YORK STATE OFFICIALS:

Governor Cuomo State Capitol, Albany, NY 12224 Phone: 518-474-8390 E-Mail: Go to: http://governor.ny.gov/contact/ GovernorContactForm.php

Nirav Shah, MD, Commissioner NYS Department of Health (DOH) Corning Tower Empire State Plaza Albany, NY 12237

Keith W. Servis, Director Center for Health Care Quality & Surveillance NYS DOH 875 Central Avenue Albany, NY 12206

Jason Helgerson, Medicaid Director Deputy Commissioner, Office of Health Insurance Programs NYS DOH Empire State Plaza Corning Tower #1466 Albany, NY 12237

Action Alert Mailing List

Greg Olsen, Acting Director NYS Office for the Aging 2 Empire State Plaza Albany, NY 12223

Atty. General Eric T. Schneiderman The Capitol Albany, NY 12224-0341

New York State Assembly:

To write to your representative in the Assembly, address your letters to him or her at NYS Assembly, Albany, NY 12248. The general switchboard for the Assembly is 518-455-4000. In addition to your personal representative, it is important that the following leaders hear from you:

Assemblymember Sheldon Silver, Speaker speaker@assembly.state.ny.us Assemblymember Richard N. Gottfried, Chair Committee on Health gottfriedr@assembly.state.ny.us

Assemblymember Joan Millman Chair, Committee on Aging millmaj@assembly.state.ny.us

New York State Senate:

To write to your Senator, address your letters to him or her at NYS Senate, Albany, NY 12247. The general switchboard for the Senate is 518-455-2800. In addition to your personal senator, it is important that the following leaders hear from you:

Senator Dean Skelos Temporary President and Majority Leader skelos@nysenate.gov Senator David Valesky Chair, Committee on Aging valesky@senate.state.ny.us

Senator Kemp Hannon Chair, Committee on Health hannon@nysenate.gov

To obtain the names of your personal state government representatives, go to The Citizen Action Center on our website: www.ltccc.org.

FEDERAL OFFICIALS:

To contact your federal representatives visit our action alert center at www.ltccc.org or call the congressional switchboard 202-225-3121.

