

## LTCCC's Mission: To Protect Nursing Home Residents

LTCCC's work to protect nursing home residents is needed now more than ever. We are the only organization in New York, and one of very few in the United States, wholly dedicated to improving quality of care and dignity for residents. Unfortunately, serious problems persist in nursing homes, including neglect, use of chemical restraints, and even verbal and physical



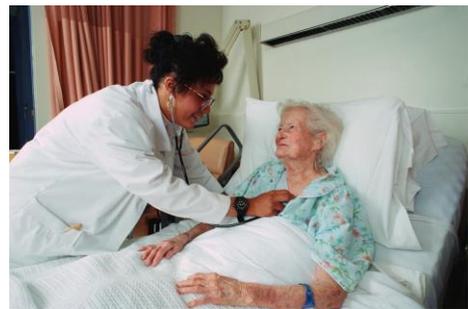
abuse. A recent federal study found that one in three people who go to a nursing home for short-term rehab suffer harm, the majority as a result of poor or inadequate care. As shocking as this is, the



rate of harm for long-term residents, most of whom have Alzheimer's Disease or other dementia, is undoubtedly far greater, since these people are often not able to make their voices heard when they are abused or neglected.



Nursing home care has always been central to LTCCC's mission. The goal of our work is to ensure that elderly and disabled residents receive the care they need and are treated with dignity. We are dedicated to safeguarding residents from abuse and neglect. We strive to provide a voice for residents, who often cannot speak for themselves, and educate the public, caregivers and our government leaders about the issues that nursing home residents face every day and which, too often, are ignored.



With the increasing numbers of people living to old age and needing 24-hour a day care, including those with Alzheimer's Disease and other dementia, this work has become more and more crucial.

***Following are highlights of our work, including several personal stories that show the problems we are dedicated to addressing and some of our recent activities to ensure safety, comfort and dignity for the frail elderly and disabled who depend on long term care.***

## Personal Stories

*LTCCC is dedicated to improving care, quality of life and dignity for nursing home & assisted living residents. We speak out for those who have suffered neglect or abuse, and advocate for better care and accountability when people are harmed. Following are a few representative personal stories. Please note that we have changed their names to protect their privacy.*

- ◆ **Jennifer** suspected that her 89 year old grandmother was being abused after she noticed some bruises. Having been told that the bruises were a result of her banging on the handrails, Jennifer decided to verify this by placing a hidden camera in her grandmother's room. The resulting video showed evidence of ongoing physical abuse. For instance, an aide was recorded twisting her grandmother's arm and slamming her against her bed.
- ◆ **Helen** came back from visiting her family and went to the home's smoking lounge around 9pm. She was found lying on the lounge floor around 9am the next morning. According to the state citation, it's not known how long Helen, who had two above-the-knee amputations, had been lying there undiscovered. What happened to the monitoring the facility was supposed to provide? How could nobody have noticed that Helen was not in her room that evening, overnight or in the morning?

- ◆ When **George** was admitted to his nursing home, he was capable of carrying out his activities of daily living and was only beginning to show the symptoms of forgetfulness attributed to Alzheimer's Disease. However, less than a year after moving to the facility, George died from a bloodstream infection brought on by severe bedsores. His son felt certain that the two antipsychotic medications (Seroquel and Haldol) that were given to his father were responsible for his death. At trial, the nursing home's own medical expert testified that he believed that the medications (for which George had no medical need) predisposed him to skin breakage that resulted in the bedsores.



- ◆ **Anna** lived her life with dignity and was loved by her family. She was admitted to a nursing home for rehab following a fall. Three weeks into her stay, a nurse failed to perform the daily catheterization of her bladder, which was part of her care plan. As a result, Anna had to get up in the middle of the night to go to the bathroom. She was unable to make it and was found on the floor after slipping in her own urine. She complained immediately of back pain.

The gravity of this injury was not diagnosed by staff and was treated only with pain medicine. A week later she was found again on the floor. At that point she was sent for a CT scan which revealed a fractured vertebrae. She returned to the facility but no treatment of her condition was offered other than more pain medication.

Anna continued to decline in health. Pleas from her family for more medical intervention went unheeded. Finally a relative from out of town, who is also a doctor, came to see her and determined that she was paralyzed from the chest down. She was rushed to the hospital where it was determined that the damage to her spinal cord was now irreversible. She lived for an additional three years, paralyzed and confined to a wheelchair.

## Improving Dementia Care

**LTCCC is dedicated to improving care and quality of life for people with Alzheimer's Disease and other dementia.** The majority of nursing home residents suffer from dementia. Rather than being provided appropriate dementia care, many residents are chemically restrained with powerful and dangerous antipsychotic drugs, despite the FDA "black-box warning" against their use on elderly people with dementia, due to significant risk of heart attack, stroke, Parkinsonism and other serious problems.

**While a number of groups are working for a cure for Alzheimer's Disease, very little attention is being paid to improving care and quality of life for people who have dementia now, or who will be diagnosed before there is a cure.** While someone may have dementia, they are still



very much able to experience life in their own way: have joy or feel pain, be engaged or bored, etc.... LTCCC is committed to improving dementia care and quality of life, and helping families and caregivers understand that the individual with dementia is still very much alive. Giving someone with Alzheimer's antipsychotic drugs to restrain them may stop the *outward* signs of agitation, but they don't address the *cause* of that agitation, which is often a response to something that can be easily addressed without drugs, such as hunger, boredom or fear.

**Through our caregiver & family outreach, targeted policy research and advocacy, we are succeeding in making sure that improving dementia care is a priority for nursing homes and the government agencies responsible for overseeing nursing home care.**

## Advocating for Better Care, Quality of Life & Dignity

We work vigilantly, every day, to protect nursing home residents from abuse and neglect, improve care and ensure that the elderly and their families have the best information possible to make good choices. We could not do this without support from our donors!

For example, when a federal study determined that ***an astounding one in three people who go to a nursing home for short term rehab are harmed, the majority as a result of inadequate care and monitoring. Six percent of these people die as a result*** LTCCC took immediate action. We conducted a quick-response analysis of nursing home citations and found that they had actually *dropped* 33%. We issued a nation-wide press release to alert the public, spoke to numerous members of the press and used our findings to highlight the need to improve nursing home resident protections with policymakers and stakeholders. ***Our supporters enabled us to undertake this critical activity and ensure that the experiences of these individuals and families received the attention that they deserved.***

***While our focus is on systemic improvement, we never forget that we are protecting individual people, most of whom are frail, but none of whom are undeserving of decent care and basic dignity.***

## **Protecting Elderly New Yorkers Facing Nursing Home Care**

New York State is planning major changes in how people access nursing home care, which will have significant repercussions for choice and quality across the state. As soon as it receives final federal approval, New York is going to require that everyone on Medicaid (the majority of nursing home residents) join a private Medicaid Managed Care insurance plan in order to go to a nursing home. Right now, an elderly person in Flushing, for instance, can go to any of the 59 nursing home in Queens or any of the 600+ facilities in the state. Under Medicaid Managed Care, her plan will only have to contract with eight nursing homes in Queens. If she wants to go to a different facility, for any reason, she will have to figure out how to change plans. In addition to severely limiting choice, this system will put significant pressure on nursing homes to cut spending on resident care (so that their rates will be attractive to the managed care plans).

***We have been working arduously to advocate for nursing home resident protections with state leaders and educate the public about what is going on.*** LTCCC is one of two consumer representatives (and the only one dedicated to protecting nursing home residents) on the State's Nursing Home Transition Workgroup.

Two examples of specific activities/accomplishments:

1. Representing nursing home resident on the NY State Nursing Home Transition Workgroup, we successfully advocated for inclusion of stronger quality incentives for nursing homes and an increase in the numbers of homes with which plans will be required to contract (which is very important for ensuring that families have access to care in their communities).
2. Our report, *Mandatory Managed Care in New York State Nursing Homes*, received tremendous feedback from state leaders, stakeholders and the news media. One of the leaders of the NY State nursing home transition planning team said that this report provides "...lots of good information that we can use as we transition into managed LTC." Following are a few additional responses we received:
  - "Amazing work, thanks.... Just sent this to all my staff members, many of them service coordinators who will benefit." – New York Non-Profit Leader
  - "This is a really sobering report.... Thank you for the good work." – New York City Community Organizer & Advocate
  - "...what a great report! The LTCCC does it again!" – National Non-Profit Leader
  - "Congratulations on such an outstanding report! Thank you very much for shining a light on this incredibly important subject." – New York LTC Ombudsman Leader
  - "Thank you... that is both a breathtaking and of course sad report. ...You should be very proud of the report- it looks like a herculean effort and I hope it has an effect on people in power and others." – Family Member & Grassroots Advocate

The Long Term Care Community Coalition is a federally recognized, non-profit organization dedicated to providing a strong voice for individuals and families faced with dementia, nursing home and other long term care needs. We depend on our supporters to sustain our work. If you can, please consider making a donation today . Donations can be made on-line at [www.ltccc.org/about/support.shtml](http://www.ltccc.org/about/support.shtml) or by sending a check to "Long Term Care Community Coalition," One Penn Plaza, Suite 6252, NY, NY 10119. We dedicate 100% of your tax-deductible donation to our mission to protect nursing home and assisted living residents. ***Any amount is truly appreciated!***