

# Dementia Care Without Drugs

Report on the Results of a Symposium for Caregivers, LTC  
Ombudsmen and Other Stakeholders on Improving Quality of  
Life & Care for Residents with Dementia

**The Long Term Care Community Coalition**



## **Recognition**

This program was made possible by a generous grant from the Fan Fox and Leslie R. Samuels Foundation. We would also like to thank: Tena Alonzo and Ann Wyatt for their excellent, thoughtful presentations and the wonderful work they do everyday to improve quality of life for nursing home residents; MFY Legal Services and Maro A. Constantinou, Senior Staff Attorney, for providing CLE accreditation and participating in the panel discussion; and Paula Goolcharan and Shanequa Mack, of the NYC LTC Ombudsman Program, for their support of the program and participation in the panel discussion.

Most importantly, we would like to express our deep appreciation to the individuals who attended the program for their interest in and dedication to improving the lives of people with dementia.

**For more information and resources on improving dementia care and reducing the use of antipsychotic drugs, visit our website: [www.nursinghome411.org](http://www.nursinghome411.org).**

**If you are interested in bringing this program to your community, please call 212-385-0355 or email [info@ltccc.org](mailto:info@ltccc.org) for more information.**

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[www.ltccc.org](http://www.ltccc.org) [www.nursinghome411.org](http://www.nursinghome411.org) [www.assisted-living411.org](http://www.assisted-living411.org)

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## Introduction

Care and quality of life for people with Alzheimer's Disease and other forms of dementia are issues of growing concern for the elderly, their loved ones and the people that work with them. Almost 60% of all residents in nursing homes have dementia, according to the Alzheimer's Association. Of these, nearly 40% have been given powerful and dangerous antipsychotic drugs, even though they have no diagnosis of a psychotic condition and despite the FDA's "black box warning" against giving antipsychotics to elderly people with dementia. Not only can these drugs have an overpowering sedative effect, they also greatly increase the likelihood of a stroke, heart attack or Parkinsonism. As a result, the federal Centers for Medicare and Medicaid Services (CMS) has launched a national campaign to reduce the use of antipsychotic drugs in nursing homes through goal-setting, provider education, increased enforcement and public education.



The goal of this symposium was to create change in dementia care and antipsychotic drug use in nursing homes in New York City by educating care staff, family members and other resident representatives about this widespread (yet under-recognized) problem and equipping them with knowledge and skills they can use to help their patients and loved ones receive appropriate dementia care that is comforting and avoids unnecessary drugging.

The symposium was held in November 2013 at Jewish Home Lifecare nursing home in Manhattan. Approximately 250 people attended the program, representing a broad range of stakeholders including nursing home staff, family members, LTC Ombudsmen, elder law attorneys and government agency staff (both nursing home surveyors and attorney general's office staff).

Following are the results from two surveys of attendees. The first survey was conducted at the end of the program. The second was conducted three months after the program, to see what (if any) lasting impact it had on the attendees. Both surveys were anonymous. Given our goal, to equip people with the knowledge and skills they can use to integrate practical change in dementia care, this report focuses on the results of the second survey.

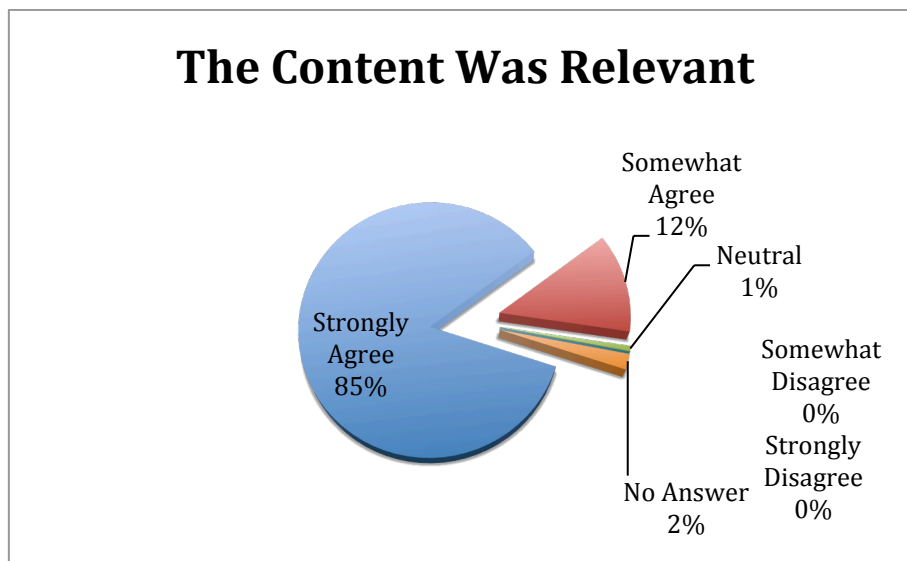
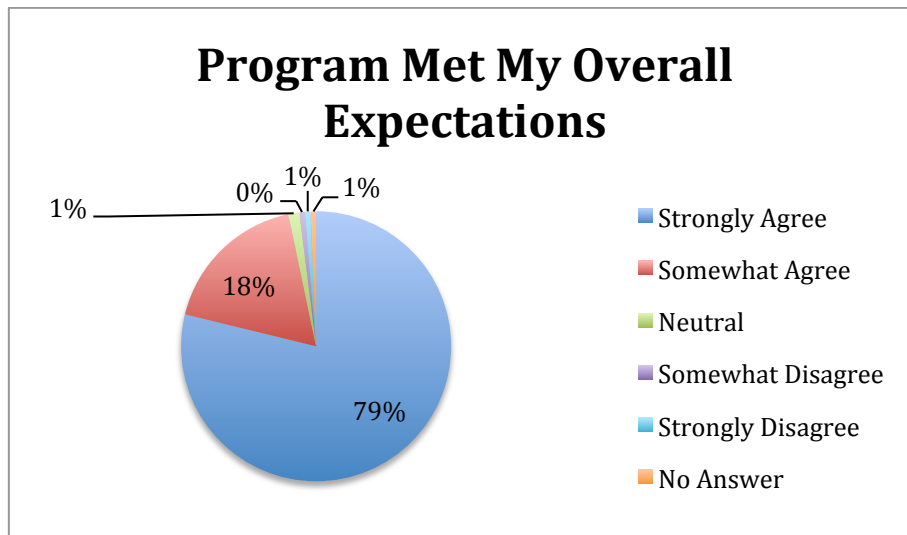


**For more details on the program, please see page 11 for the symposium flyer, which includes the agenda and speaker bios.**

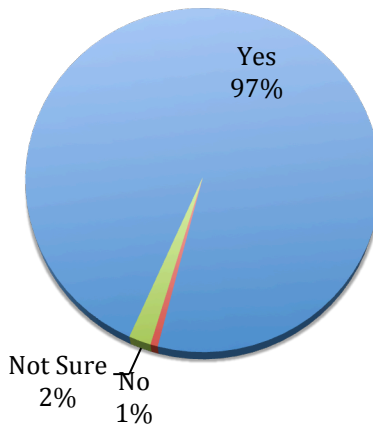
## SURVEY ONE: DAY OF THE PROGRAM

The symposium was held over two days in November, with each day providing a single, stand-alone program comprised of three presentations and a panel discussion. As noted above, approximately 250 people attended (residents, staff and family from our host nursing home were invited to attend for all or part of the program without registering). Survey One was included in the packets distributed to all attendees. A total of 151 surveys were turned in at the end of the day, representing a 60% response rate.

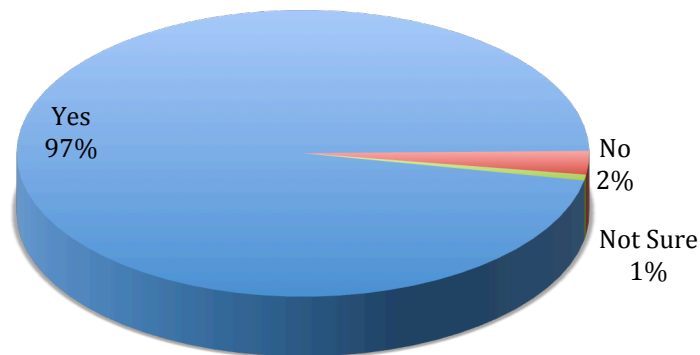
The following four graphs show responses to this survey.



### Was the Program Meaningful for You (Personally or in Your Work)?



### Do You Think the Program Will Be Useful to You in the Future?



As these graphs indicate, the large majority of attendees found the program relevant, meaningful and useful. Following are a sample of the comments that we received:

*"Deeply meaningful- I am a caregiver & there is no end to growing & learning."*

*"It showed that if we try something different it will make a difference for my resident."*

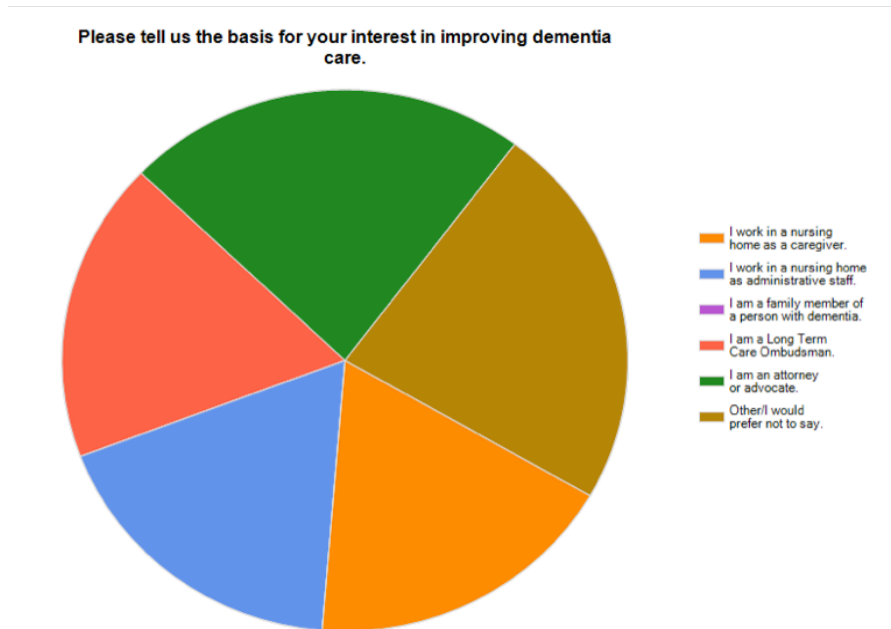
*"I work with Dementia residents and this gives me ammunition to better help me understand and care for them."*

*"Very practical...with a strong theoretical and policy framework."*

*"Now I can understand my mother more clearly and how she reacts in life."*

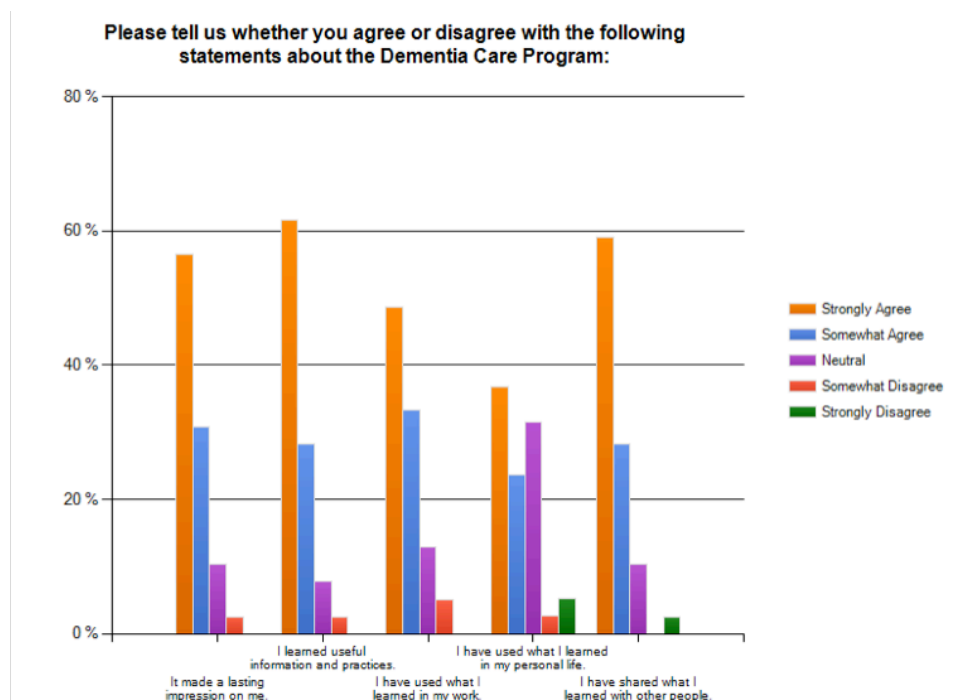
## SURVEY TWO: THREE MONTHS AFTER THE PROGRAM

Thirty-nine individuals completed the follow-up survey, a rate of approximately 15%. They represented a broad range of attendees.



Those who indicated “other” included survey agency staff, law enforcement and a caregiver in a day health program. No one selected family member, though one individual wrote that he/she had a number of bases of interest, including as a family member of someone with dementia.

The following chart relates to the central purpose of the program: did it have a meaningful impact on the attendees and their work and personal lives?



We were gratified to see a strong positive response overall, indicating that the ‘lessons learned’ in the symposium continued to be meaningful to attendees. “Strongly Agree” was the most selected choice for each of these questions and, when combined with the other positive response (“Somewhat Agree”) accounted for a large majority of responses to each question. Eighty-seven percent (87%) indicated that that the program made a lasting impression on them (strongly agreed=56.4% + somewhat agreed=30.8%); 82% indicated that they had used what they learned in their work; 87% indicated that they had shared what they learned with others and 60% indicated that they had used what they learned in their personal lives. The fact that use in an attendee’s personal life garnered the smallest majority of positive responses is likely a result of the fact that the majority of attendees come to the issue of dementia care in a professional capacity.



82% of attendees report using what they learned in their work.

87% report sharing what they learned with others.

60% said they have used the knowledge and skills in their personal lives.

#### Sample comments:

*“I use the knowledge in my practice everyday ... it has now become second nature. Also, I try to share with colleagues.”*

*“There is a greater awareness in examining the drugs members take and I can now offer suggestions for other intervention.”*

*“The information was stimulating, and put pieces of a puzzle I was working on in place for me.”*

*“Utilized some of the techniques on a family friend who is in the moderate stage.”*

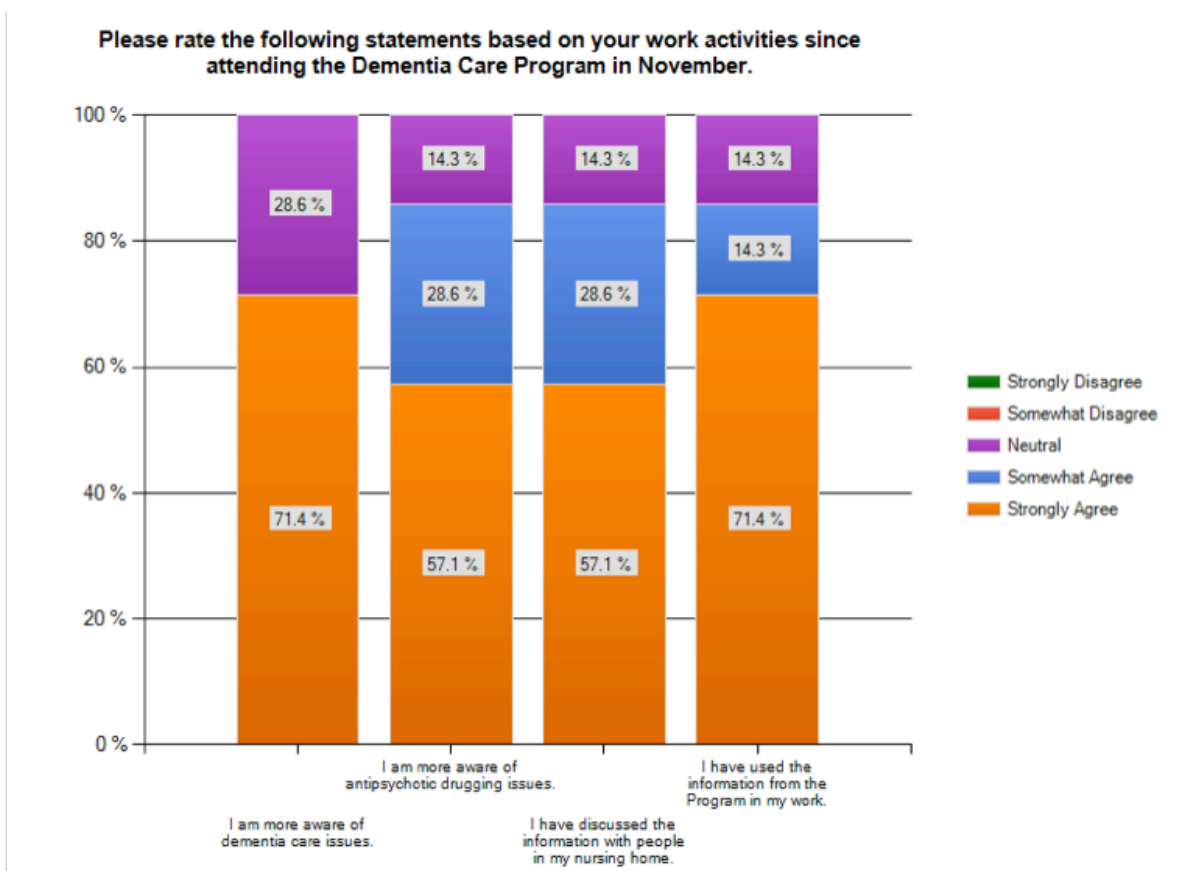
*“I shared all the information I received from the program with our MDS teams to solve the difficult problems in our dementia unit.”*

*“I feel like an apostle for what all of you have given us! I copy handouts and give them to others working in dementia care.”*



The following three sections relate specifically to attendees who identified themselves as nursing home caregivers, Long Term Care Ombudsmen and advocates/attorneys.

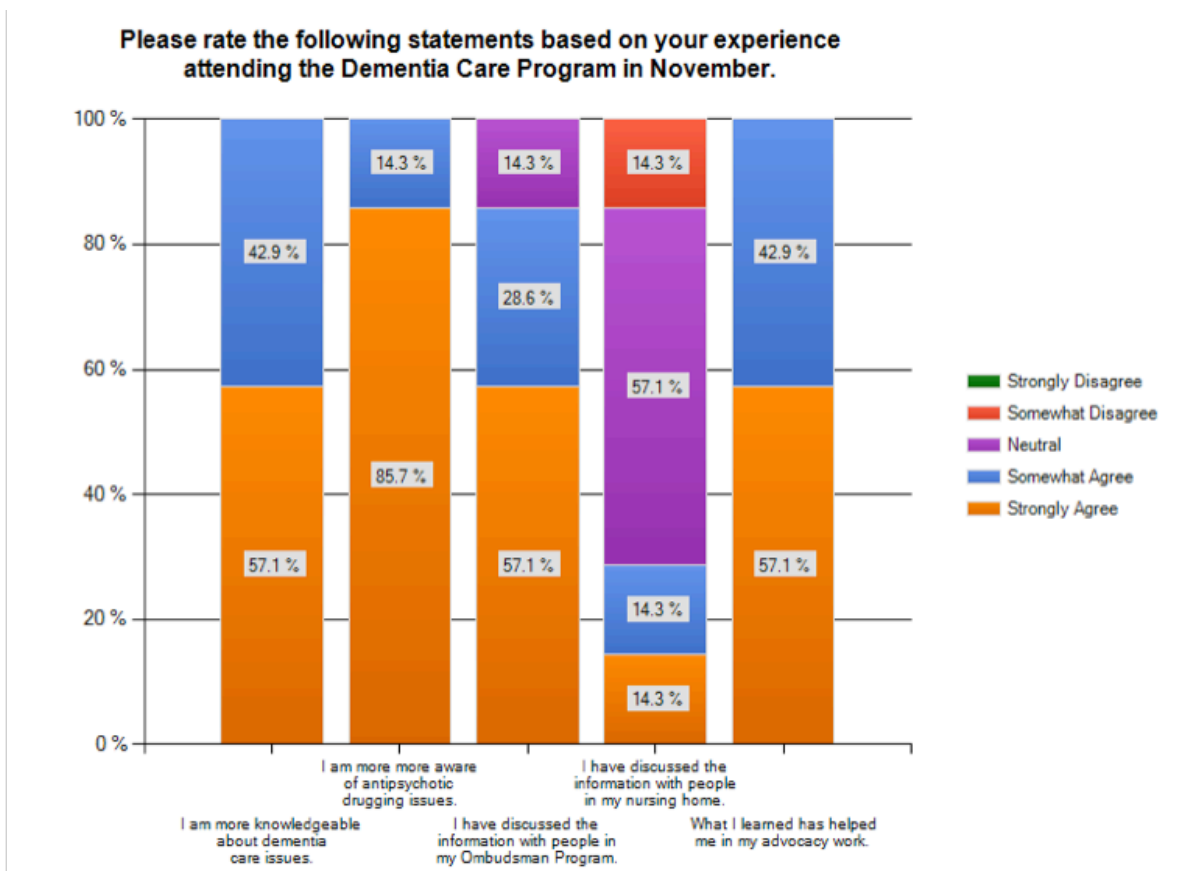
## 1. Nursing Home Caregivers



The questions presented in this chart focused specifically on the attendees who work in nursing homes and their activities since attending the program: seven of the 39 individuals who completed this survey. A large majority of them indicated that, in relation to their work activities, they are more aware of dementia care issues, more aware of antipsychotic drugging issues, have discussed information from the program with people in their nursing homes and have used the information from the program in their work. As the chart shows, there are some distinctions relating to the strength of agreement (“strongly” vs. “somewhat”), which we believe is likely to be indicative of the extent to which the statement is reflective of the respondents’ experiences. We were pleased to see that there were no negative responses to any of these questions.

In a follow-up question, four out of seven (57%) indicated that they have seen a reduction in the use of antipsychotics in their nursing home since attending the program. None had seen an increase but three (43%) were not sure whether rates had gone up, down or were stable.

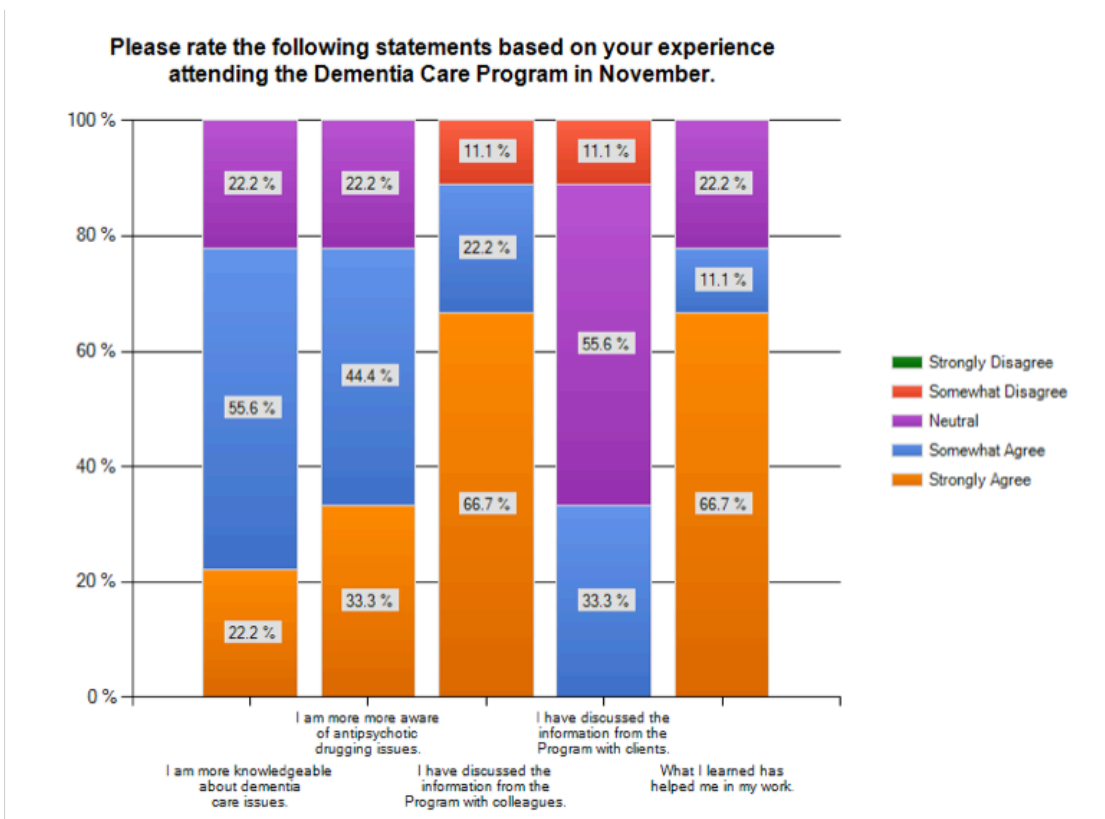
## 2. Long Term Care Ombudsmen



As with the direct care workers, seven LTC Ombudsmen completed this survey. While their range of responses was more diverse it was also overwhelmingly positive. Based on their experience at the dementia care program, 100% indicated that they are now more knowledgeable about both dementia care and antipsychotic drugging issues and 100% indicated that what they learned has helped them in their advocacy work. (columns 1, 2 and 5, above, comprised entirely of “Strongly Agree” and “Somewhat Agree” responses). A large majority shared what they learned in the dementia care program with others in their LTC Ombudsman Program. However, only 29% indicated that they have shared what they learned with people in the nursing homes in which they work.

The ombudsmen were also asked whether they are seeing any change in the use of antipsychotic drugs in the nursing homes they visit. Five of them (71%) indicated they were not sure or did not know and two of them (29%) said no. None of the ombudsmen reported seeing either an increase or a decrease in antipsychotic drugging rates.

### 3. Advocates & Attorneys



Nine respondents identified themselves as being advocates and/or attorneys. Their use of the knowledge and skills presented at the dementia care program is very high, though not at the levels reported by direct care workers or LTC Ombudsmen. Over 75% indicated that they are more knowledgeable now about both dementia care and antipsychotic drugging issues. Most importantly, in terms of the long-term value of the program, over 90% reported having shared information from the program with both colleagues and clients. Over 75% have found that what they learned was helpful to them in their work.

### Conclusion

The results of the two surveys indicate that this program provided a robust formula for both sustaining the interest of varied stakeholders and fortifying them with the knowledge and skills they can use to make a difference in the lives of people with dementia. The breadth of the program – which covered basic legal and regulatory standards as well as practical information on how to achieve better dementia care – combined with the diversity of the audience – which brought together nursing home staff, family members, LTC Ombudsmen and other stakeholders – appeared to foster learning and communication. Importantly, the anonymous follow-up survey (conducted three months after the program) indicated a high degree of retention and utilization across the range of attendees.

## Dementia Care Without Drugs

*A Symposium for Nursing Home Staff, Family Members, LTC Ombudsmen & Advocates interested in improving Quality of Life & Comfort for Residents With Dementia.*

*Presented by*

**The Long Term Care Community Coalition**

*To Be Held At*

**Jewish Home Lifecare, 120 W 106th St, NYC**

**Wednesday, November 13 or Thursday, November 14  
9 A.M. – 3 P.M. [NOTE: This is a one day program.  
Attendees may sign-up for either day.]**

*Come learn about...*

- *How people with dementia can be comforted & soothed without powerful medications;*
- *Care practices that benefit both staff & residents;*
- *Federal dementia care requirements & the national campaign to improve care and reduce unnecessary drugs;*
- *How nursing homes can use this campaign to achieve quality standards, provide more comfortable care for their residents & a better work environment for staff.*

### **Seats Are Limited!**

**R.S.V.P. by November 5. Registration is \$25 (includes lunch & materials). Limited scholarships are available for CNAs, LTC Ombudsmen & Family Members. This program is accredited for both legal (CLE) and dementia care (CEU) education.**

**To reserve a seat: Go to [www.ltccc.org](http://www.ltccc.org) and click on the yellow button on the right: "Symposium: Dementia Care Without Drugs." For multiple reservations or questions call 212-385-0355 or email [sara@ltccc.org](mailto:sara@ltccc.org).**



**You  
Can Help  
Someone With  
Dementia Live a  
Better Life!**



This program is made possible by a generous grant from the Fan Fox & Leslie R. Samuels Foundation. Two Continuing Legal Education (CLE) credits are available for attorneys (please pay \$15 in addition to \$25 registration). CLE will be administered by MFY Legal Services. The National Council of Certified Dementia Practitioners has approved the program for six CEUs for Certified Dementia Practitioners, Certified Dementia Care Managers and Certified Alzheimer's and Dementia Trainers.

# DEMENTIA CARE WITHOUT DRUGS:

## IMPROVING QUALITY OF LIFE & COMFORT FOR RESIDENTS WITH DEMENTIA

### AGENDA

9-9:30am - Welcome and opening remarks.

9:30-10:30 – The National Campaign to Reduce Antipsychotic Drug Use: What You Need to Know About the Campaign, the Law and Relevant Regulatory Standards. Speaker: Richard Mollot.

10:30-10:45 – Break.

10:45-12pm – Palliative Care for Dementia Patients: Adopting a Culture of Comfort. Speaker: Tena Alonzo.

12:00-12:45 – Lunch.

12:45-1:45 – Leading the Way: Implementing Good Practices and Overcoming Challenges in the Nursing Home. Speaker: Ann Wyatt.

1:45-2:00 – Break.

2:00-3:00 – Panel Discussion. Our speakers will be joined by an Attorney from MFY Legal Services, Inc.'s Nursing Home Residents Project and Paula Goolcharan, Director of the NYC LTC Ombudsman Program, for a lively Q & A on overcoming the challenges that we all face to improving care and dignity for people with dementia.

*What if the resident who is crying out or hitting is not just “lost” to dementia, but expressing a need such as hunger, fear, or physical discomfort?*

*What if we could comfort them with a piece of chocolate, a simple adjustment to their pillow or a quick hug, rather than giving a potentially dangerous medication?*

*We CAN do it! You CAN make a difference!*

### SPEAKERS

**Tena Alonzo** is the Director of Research and Dementia Programs at Beatitudes nursing home in Phoenix, AZ. The care practices at Beatitudes were featured in a 2010 *New York Times* article, “Giving Alzheimer’s Patients Their Way, Even Chocolate,” and most recently in *The New Yorker Magazine*. Ms. Alonzo and her department have created an innovative training model that focuses on the comfort of the person with dementia and empowers staff members to anticipate his or her needs. The training also focuses on the person-directed approach to care.

**Ann Wyatt** is the Project Coordinator for the palliative care project of the Alzheimer’s Association, NYC Chapter, working extensively with Cobble Hill, Isabella and Jewish Home to establish innovative, comprehensive palliative care programs for people with advanced dementia. She has also worked in recent years with the Cobble Hill-Isabella Collaboration Project, concerned with creating more person-centered care environments.

**Richard Mollot** has been Executive Director of LTCCC since 2005. He is one of six consumer advocates from across the U.S. who met with CMS Administrator Berwick in 2011, urging him to address the widespread overuse of antipsychotic drugs in dementia care. This led to the national Partnership to Improve Dementia Care in Nursing Homes, which set national goals for the reduction of antipsychotic drug use in nursing homes, established trainings for caregivers and surveyors, revised regulatory guidelines and established Coalitions to Improve Dementia Care in every state.