Dear Colleagues and Friends:

These are exciting times for the Office of the Ombudsman for the Institutionalized Elderly, over which I have presided as Ombudsman since December 2010.

I am pleased to say that our Volunteer Advocate Program (VAP) — which has grown from 145 active advocates in Spring 2011 to more than 200 active advocates today — has received national recognition for its outreach efforts. In March, the VAP program was selected by the National Ombudsman Resource Center to participate in a national webinar devoted to states’ successful outreach and marketing efforts. Feedback about the program was excellent. Kudos to Deirdre Mraw, the OOIE Statewide Volunteer Coordinator, and her staff for a job well done.

The OOIE has also launched a new program called I Choose Home - NJ. I Choose Home - NJ is the name given to New Jersey’s federal/state Money Follows the Person program. Under this program, people who are eligible for Medicaid and who live in nursing homes or state developmental centers, may be able to move back to a home or community-based setting with appropriate services and supports. The OOIE is working in partnership with the NJ Department of Human Services’ divisions of Aging Services, Developmental Disabilities and Disability Services to help create greater public awareness of home- and community-based options for institutionalized people.

Finally, the OOIE continues to spread the word about the importance of advance care planning. In April, OOIE staff attended and/or presented at several events on, and in advance of, National Health Care Decisions Day. At these events, we distributed information about advance care planning, including copies of “Five Wishes” (an excellent advance care planning document), and information about the state’s new Practitioner Order for Life Sustaining Treatment (POLST). Extensive advance care planning information is available on a new OOIE web page titled Your Care, Your Choice, http://www.nj.gov/ooie/helpful/yourcareyourchoice.html.

In the meantime, the Office continues to strengthen the Regional Ethics Committees located throughout the state. These Ethics Committees (RECs) are an excellent resource to long-term care facilities and to families. RECs provide much-needed education, conflict resolution, and ethical guidance to facilities and families when difficult decisions — often related to end-of-life or whether to provide or withhold life-sustaining treatment — must be made.

Our OOIE investigators and volunteers provide excellent advocacy to vulnerable seniors living in long-term care communities. Every day, cases come across my desk that show the huge and positive difference we are making in the lives of some of the state’s most vulnerable citizens. I am incredibly proud of the high degree of dedication and expertise demonstrated by the OOIE team.
“Do not regret growing older. It is a privilege denied to many.” ~ Author Unknown

Volunteer Partners with Twilight Wish Foundation

The unsellish act of one of our advocates, Jocelyn Havison, epitomizes the way in which both Twilight Wish and the OOIE Volunteer Advocate program enrich the lives of New Jersey's senior population.

A resident of The Homestead in Sussex County and an Air Force Veteran, Thomas Conklin, 72, has been fighting multiple sclerosis for more than 38 years. After noticing that Conklin was unable to get around with his existing wheelchair, Havison decided that she needed to help Conklin acquire a power chair that would give him the freedom to do the things he had come to enjoy, including venturing outdoors.

Working with Conklin's wife, Linda, and facility staff, Havison made contact with Twilight Wish Foundation. Twilight Wish Foundation identified a donor to underwrite the cost of the power chair, which was delivered to The Homestead on May 1.

A special thanks to our advocate, Jocelyn, for her compassion, leadership, and perseverance making the impossible possible!

More information about Twilight Wish Foundation can be found at http://www.twilightwish.org/

Champions of Change

According to the White House “Champions of Change” website: “All across the country, ordinary Americans are doing extraordinary things in their communities to out-innovate, out-educate, and out-build the rest of the world.”

Gina Liberali Cavallo, OOIE's Volunteer Advocate in Passaic County, has gone beyond the doors of her assigned facility, Wayneview Care Center, to lend a hand in her community in the aftermath of Superstorm Sandy. Gina stepped in and organized teams of volunteers in the shore towns of Lavallette and Ortley Beach, and matched those who want to help with those affected – restoring the shore while restoring our faith in humanity!

As a result, Gina has been nominated, and is now a semi-finalist, to be honored as a White House Champion of Change and was selected by NJ First Lady Mary Pat Christie as a “New Jersey Hero.”

Our advocates really do make a difference in their community! Congratulations, Gina!
For those unfamiliar with I Choose Home - NJ (MFP), it is a federal program with two main goals: to move people out of institutions back into the community, and to reinvest Medicaid dollars saved back into home- and community-based services so that more people can age in place. Residents who are eligible for Medicaid, and have been living in an institutional setting for more than 90 days, may be able to participate in the program and transition out into an independent setting with Medicaid supports and services in their home. The State of New Jersey receives an enhanced federal Medicaid match for the first year that the individual resides in the community. Those cost savings are then invested to create more possibilities for others to remain in their homes and receive the services they need, rather than going into a nursing home.

OOIE now has a team of six staff members working full time on this project, in addition to help from our Chief of Staff and our graphic design specialist. Our Director of Outreach and Advocacy, Amy Brown, heads this initiative. Our Outreach and Advocacy Coordinators - Lea Hernandez, Jennifer Sills, Nikiah Nixon, and Dina Donnelly - who cover four NJ regions - are in the field every day educating nursing facility staff, residents, and their families about the basic eligibility requirements, and potential services offered through I Choose Home - NJ. Staff is also attending numerous professional and community events - conferences, seminars, trainings, senior expos, health fairs, and the like - to spread the I Choose Home message that "A Nursing Home May Not Be the Only Option.

It is an exciting time for I Choose Home - NJ in the Ombudsman's Office. Help us spread the word that A NURSING HOME MAY NOT BE THE ONLY OPTION. If you or someone you know is Medicaid-eligible, has a residency in a nursing home for more than 90 days and wants to move out, please call us: 1-800-HOME-005.

Money Follows the Person initiative becomes

OOIE Polls Volunteer Advocates in First-Ever Satisfaction Study

Late last year, the OOIE initiated a comprehensive satisfaction study among its approximately 200 volunteer advocates. This survey was critical to OOIE's continuous improvement process and provided a formal way for volunteers to provide their feedback and suggestions to the Volunteer Advocate Program. The survey was developed by the OOIE State Coordinator with input from the Regional Volunteer Coordinators. Communications were put forth in advance of the survey distribution to notify the volunteers and to encourage their participation. The survey was anonymous and all results were analyzed by an independent research firm.

Here is what the Office of the Ombudsman learned from our Volunteer Advocates:

The volunteers were asked about their employment status and length of time with the program. Almost 55% of our volunteers have been with the program for more than forty years, more than 67% are retired and about 24% work full or part time.

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How long have you been a Volunteer Advocate for OOIE?

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<thead>
<tr>
<th>Length of Time</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Less than 1 year</td>
<td>16.8%</td>
</tr>
<tr>
<td>1-3 years</td>
<td>24.8%</td>
</tr>
<tr>
<td>4-6 years</td>
<td>18.8%</td>
</tr>
<tr>
<td>7-9 years</td>
<td>12.9%</td>
</tr>
<tr>
<td>10 or more years</td>
<td>10.9%</td>
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Which of the following best describes your employment status?

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Retired</td>
<td>67.3%</td>
</tr>
<tr>
<td>Currently employed FT</td>
<td>12.9%</td>
</tr>
<tr>
<td>Currently employed PT</td>
<td>8.9%</td>
</tr>
<tr>
<td>Other</td>
<td>10.0%</td>
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Training and Professional Development

The initial section of the survey gathered feedback on the support given to the Volunteer Advocates in the form of orientation for new volunteers, ongoing training opportunities and references for future training and development programs. The comment section provided great insight into the training needs of the volunteers and, with the exception of the interest in webinar-based trainings, the volunteers largely agree with the quality of trainings.

Communication and Support

Nine questions were included to evaluate the communication and support between the volunteers and OOIE staff. On a scale of 1 through 5 (1 = strongly disagree; 5 = strongly agree), the average ratings range from a low of 3.91 (facility staff understanding the role of the volunteer advocate) to a high of 4.49 for support received from the program's regional coordinators. The OOIE was encouraged to see a 4.46 rating in response to the question: I am clear on my roles and responsibilities as a volunteer advocate.

Overall Satisfaction

The final ratings on the survey gathered feedback on "big picture" items such as the volunteer's overall satisfaction, passion toward the work and likelihood of recommending others to serve as an OOIE Volunteer Advocate.

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<thead>
<tr>
<th>Survey Item</th>
<th>Average Rating</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am passionate about my work as a volunteer advocate.</td>
<td>4.47</td>
<td>92</td>
</tr>
<tr>
<td>I feel I make an impact in the facility</td>
<td>4.33</td>
<td>91</td>
</tr>
<tr>
<td>I feel supported in my efforts within the facility.</td>
<td>4.09</td>
<td>91</td>
</tr>
<tr>
<td>I envision continuing as a volunteer advocate for some time.</td>
<td>4.25</td>
<td>92</td>
</tr>
<tr>
<td>Overall, I am satisfied with the volunteer advocate experience.</td>
<td>4.35</td>
<td>93</td>
</tr>
<tr>
<td>I would recommend others to the OOIE Volunteer Advocate Program.</td>
<td>4.55</td>
<td>94</td>
</tr>
</tbody>
</table>

The OOIE has never surveyed our volunteers in this way before. Based on this survey, it appears that the Volunteer Advocates are highly satisfied with their experience. They are very passionate about their work and are likely to recommend the volunteer work to others. We will use these results to improve support for our volunteers and will inform of future trainings as we enhance the quality of life of New Jersey’s nursing home residents.

(For the complete Volunteer Advocate Satisfaction Survey, please visit our website at www.nj.gov/ooie)
Talk to Your Loved Ones and Doctors about Advance Care Planning

By James W. McCracken

Isaac Asimov said, “Life is pleasant. Death is peaceful. It’s the transition that’s troublesome.”

But what if that troublesome transition could be avoided or lessened just by communicating effectively with your loved ones?

Whatever your age or physical condition, now is the best time to have “the conversation” with your loved ones and your doctors about advance care planning.

Advance care planning is a process where you communicate with your loved ones and care providers to make sure the treatment and care you receive is aligned with what a good life looks like to you, especially if you are unable to speak for yourself. It isn’t always easy, but it is important to make sure that you are cared for and treated in a manner consistent with your wishes should you become seriously incapacitated or nearing the end of your life – or both.

“The conversation,” is the most critical part of advance care planning (ACP) and can remove some of the challenges when you are seriously ill, and even when you are dying, and make that time of transition more about what it should be – living.

Advanced care planning is a process that involves reflecting on your goals, values, and treatment preferences in the context of your current health and possible future situations and communicating those goals to loved ones and doctors; identifying someone to make decisions on your behalf in case you can’t; documenting your decisions; and revisiting those goals, values, and preferences as circumstances and feelings change.

You’ve likely heard of some of the most common advance care planning documents - living wills, health care proxy, advance directives – and the recently available POLST (Practitioner Order for Life-Sustaining Treatment). Keep in mind these documents are valuable only to the extent that you’ve clearly talked to loved ones and health care providers about what is in them.

The types of decisions you might wish to make as part of the advance care planning process include:

- Who will make decisions on your behalf?
- Identifying what a good life looks like to you. For example, what you want to be able to do (gardening, listening to music, communicating with loved ones) or religious beliefs that should be followed when making health care decisions
- Establishing goals of care. For instance, do you wish to receive aggressive treatment so you can hit a particular milestone (graduation, birth of grandchild) or do you wish to receive treatment for only so long as you are living your definition of quality of life?
- Whether you want specific treatments, (for instance, a feeding tube)
- Defining what type of physical space you want. Do you want music or total silence? Do you want lots of family in attendance or very few?

There are some very good reasons for you to begin this discussion now. Here are a few of them:

- You will be prepared. When a crisis hits or a critical decision has to be made, you will have an advantage. You will have a blueprint, conceived of and created by you, to help you and your loved ones make difficult medical and ethical decisions about your care.
- You will be a pioneer. While it has been reported that 33 percent of Americans currently have an advance directive, only 16 percent of New Jersey residents are similarly prepared.
- You will strengthen the connection with those closest to you. During the “conversation,” you and your loved ones will be talking about your values, your goals, and the things that make your life worth living - some potentially deep emotional terrain.
- You will protect those you love. If you have not clearly explained the care you want or don’t want, the people you love will be forced to guess. One study showed that 63 percent of surrogates didn’t know what their loved one wanted. Studies also show that surrogates who had to make decisions without any guidance from their loved ones had higher levels of stress and more frequent, prolonged bouts with depression.
- You take control. “The conversation” will lay out your priorities, values, and goals so your proxy can make decisions consistent with them.

The consequences of not having an advance care plan are significant. For instance, despite the fact that 70 percent of Americans surveyed say they want to die at home, the reality is that only 30 percent actually do.

Go ahead, have that talk – today.

This article appeared in several daily newspapers in New Jersey in advance of National Health Care Decisions Day on April 16.

Additional information about Advance Care Planning resources is available at www.nj.gov/ooic/helpful/yourcareyourchoice.html.

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Find us on Facebook @ www.facebook.com/NJElderOmbudsman

Morning America. So it’s likely that the people closest to you will have heard about it.

And you don’t have to start from scratch: many “how-to” resources exist to assist you in this process. Materials and information are available through The Conversation Project, The American Bar Association, Engage with Grace, and Five Wishes, among others. Many of these tools are available for free.

So, be a pioneer, be prepared, connect with and protect your loved ones, and take steps to live your life on your terms until the very end.

The importance of advance care planning has become a frequent topic in the media including recent segments on ABC News, Oprah, NBC’s Rock Center, and Good Morning America.