



*The Tree Unites the
Branches; The Branches
Bear the Fruit*

The ORANJ TREE

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Best wishes to our ORANJ family and *ORANJ Tree* readers for Good Health and Happiness in 2014

ORANJ has had a very successful year, ending in our plenary meeting on October 16, 2013. Medford Leas was an excellent host and attendance was close to capacity. The meeting occurred just after the Bill of Rights, S2502, had been passed in both houses of the legislature and was waiting only for the governor's signature. The article on the next page describes the process which led to this successful conclusion.

Dr. Elaine Fultz, former professional staff member of the US House of Representatives, provided an excellent overview of Social Security, its successes, problems, and prospects. Her most important conclusions were as follows:

- Benefits are modest. Yet they are most beneficiaries' main source of income.
- Benefits will replace a smaller share of earnings in the future than they do today.
- Revenue increases or benefit cuts will be needed to balance Social Security.
- Lawmakers have many options to raise revenues and improve adequacy.
- Research shows that Americans value Social Security and are willing to pay for it.

The other speaker, Beth Sparling, Executive Director of Crane's Mill Retirement Community, spoke on essential inputs for collaborative discussions. She particularly emphasized the need for trust, respect, commitment, willingness to share information and follow-up. In essence, she pointed out that collaborative discussions require transparency and, in turn, strengthen transparency in management-resident relationships.

Beginning on January 1, 2014, Helen Vukasin will begin her term as Acting President of ORANJ.

David Hibberson

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The Fountains at Cedar Parke, *Atco*
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Friends Village, *Woodstown*
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Hackettstown
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The Pines at Whiting, *Whiting*
Seabrook, *Tinton Falls*
Stonebridge at Montgomery,
Skillman
Wiley Christian Retirement
Community, *Marlton*
Winchester Gardens, *Maplewood*

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A HISTORY OF THE BILL OF RIGHTS

On October 17, 2013, Governor Christie signed into law the “Bill of Rights for Continuing Care Retirement Community Residents in Independent Living.”

This is a signature achievement for ORANJ because it assembles in one document the rights that are significant for all residents of a CCRC including those that apply particularly for residents in Independent Living (IL).



David Hibberson (left) and Senator Robert Singer

Background

Discussion of a possible Bill of Rights has been the main agenda item of the ORANJ Legislative Committee since 2011. In the course of drafting a bill, the committee referred to a report by US Senator Robert Kohl, Chair of the Special Committee on Aging, in June 2010. The committee was particularly concerned with the financial risks to residents entering a CCRC. It followed an earlier report by Congressman Thomas Bliley in 1997, examining the health and cost effects of CCRC practices.

The committee also considered recently passed legislation in NJ which focused on the rights of residents living in assisted living facilities in NJ. In addition, it drew from a leaflet published by the NJ Department of Community Affairs in 2003, titled “Consumer Rights in a Continuing Care Resident Community.”

The NJ Bill of Rights

Some resident rights have existed for a long time but now included are those that were enacted in more recent years. This bill embraces many of the problems that may be encountered by CCRC residents in independent living as well as by prospective residents. The bill codifies, and makes available to all, the rights that protect these residents in communities that do not live up to these standards. The bill is divided into the following sections:

- Entry rights
- Rights when in residence
- Rights when contemplating or being transferred to an assisted living facility or nursing unit for temporary or permanent residence
- Communicating residents’ rights
- Financial considerations rights
- Termination of residents’ rights
- Penalties for violating residents’ rights

Initially the draft included two additional items related to protection for the refund associated with the down payment in some residents’ contracts. These were:

- Placing a portion of the new resident’s entrance fee in an escrow account, which meant that this money would not be available to the administration.
- Requiring that the refundable portion of the entrance fee be paid within a period of one or two years after a resident left a community. (This was in contrast to the repayment after the vacant unit was again occupied.)

Discussions with Relevant Parties

A draft of the bill was circulated to CCRC providers, including financial officers, ORANJ Regional Vice Presidents and Residents Association members. ORANJ also contacted officers of the NJ Department of Community Affairs and executives of LeadingAge of NJ. In addition, we received helpful comments from Professor Kathleen Peason of Penn State University, who specializes in issues associated with CCRCs.

Comments from CCRC residents were mostly positive but administrators and financial officers generally objected to the two additional items as too costly and burdensome. Therefore, the ORANJ Legislative Committee reluctantly decided to remove these and a few other minor items from the final draft, which was approved by the full committee.

Process through the Legislature

Identical bills were assigned to the Senate Health, Human Services and Senior Citizens Committee (HHSS) and to the Assembly Health and Senior Services Committee (HSS). David Hibberson, Chair of the ORANJ Legislative Committee, communicated with both Senate and Assembly committee chairs requesting their support. He also solicited support from all CCRC presidents of resident associations and had formal meetings with legislative leaders, including Chairman Dr. Herbert Conaway (HSS) and Chairman Joseph Vitale (HHSS), to explain the importance of the bill for the welfare of CCRC residents. The bill was first passed by the Senate and later by the Assembly. David Hibberson also negotiated with Princeton Public Affairs Group, a professional lobbying organization presumably associated with LeadingAge NJ, representing providers of CCRCs, hospitals and nursing homes in NJ. Additional changes were proposed by the Department of Community Affairs and were adopted in large part.

Final passage of Bill S2052 occurred in August 2013, when the bill passed unanimously on floor amendments and a floor vote in the fourth reading. It was signed into law by Gov. Christie on October 17 and S2052 became P.L. 2013, c.167

http://www.njleg.state.nj.us/2012/Bills/PL13/167_.PDF
<http://legiscan.com/NJ/text/S2052/2012>

DEATH WITH DIGNITY:

Ethical Issues in the End-of-Life Health Care Debate

Highlights of a paper by Ted Handler

Disclaimer – This article is offered to stimulate debate on the issue. It does NOT represent the views of ORANJ or any of its members, pro or con, on the issue.

Introduction

In the political fray surrounding the construction of the Affordable Care Act (ACA), the provision which would have included end-of-life planning discussions as a covered component of a patient's annual physical examination was eliminated for political reasons. Nevertheless, there is tremendous potential for good, in terms of patient satisfaction and even modest cost savings, in addressing "death with dignity" (a political term; the medical term is "physician-assisted dying"). As patients have benefited from the life-extending effects of medical

advancements, sudden deaths, such as heart attacks and strokes, have gradually been replaced by more prolonged deaths, due to dementia and related conditions, causing endless suffering and significantly raising costs of care.

Although national lawmakers have failed to craft policies to inform and guide practitioners' approaches to death, some states, notably Oregon and Washington, have taken the lead in passing such legislation. Their efforts represent a large step in the direction of preserving patient autonomy, justice in the delivery of medical care, and improvement in patient satisfaction.

Death with Dignity Acts in Oregon and Washington

The Oregon and Washington acts were enacted in 1997 and 2002, respectively. The laws permit terminally ill adult patients with a prognosis of less than six months to die by lethal drug overdose by barbiturates such as phenobarbital or secobarbital. Death happens quickly and families describe it as peaceful.¹ The process is hedged with multiple safeguards including the need for two physicians who agree on a prognosis of six months, plus a determination by a third physician that the patient is free of any mental condition that could affect his/her ability to make an informed decision. The physician is allowed to sign the patient's death certificate listing the underlying terminal disease as the cause of death if the patient requests that he/she do so.

Do the Acts Meet Patients' Needs?

Research in both states shows that patients tend to choose physician-assisted dying over palliative or comfort care because they fear "losing autonomy" (over 90% in each state), "being less able to engage in activities which made life enjoyable" and "loss of dignity." There have been virtually no medical complications from ingestion of the life-ending drugs. Additionally, according to a study in Oregon, families of patients who have taken part in the program felt more prepared and accepting of the death than comparison family members.

Apart from religious concerns, the main objection to the program has been that physicians may disagree on the prognosis for length of life. Therefore some physicians are uncomfortable about placing undue emphasis on this criterion. Some physicians also fear a change in doctor-patient relationships as patient choice undermines medical authority.

¹Ganzini, Linda, et al. "Mental health outcomes of family members of Oregonians who request physician aid in dying." *Journal of Pain and Symptom Management* 38.6 (2009): 807-815.

End-of-Life Policies in The Netherlands

The Netherlands have taken a far more liberal approach and differ from American policies in four major ways. In the Netherlands, a patient who seeks assistance with dying need not be a resident of the country. Second, the patient need not be terminally ill; he/she needs only prove that his/her suffering is unbearable and that he/she has no prospect of improvement. Third, a patient's minimum age is twelve, instead of eighteen. Finally, a patient can request physician-assisted suicide, where a patient administers a lethal dose, as in the US, or euthanasia, where the physician may administer the lethal dose if the patient or patient's family is unable to do so. Euthanasia was legalized in the Netherlands in 2002. There is a current debate in the Netherlands whether physician-assisted suicide should be extended to patients suffering from dementia who have advance directives specifying that they be put to death when they have lost a certain level of mental function that they cannot regain.

Conclusion

As principles of patient care have lagged behind life-saving medical advances, we have seen the growth of a subset of the American population who lose their dignity and ability to enjoy life when terminal illness sets in, and who prefer physician-assisted dying to hospice or palliative care. These patients have benefited from "Death with Dignity" policies if they happened to reside in Oregon or Washington. These policies protect patients from financial coercion and appear to improve families' abilities to cope with the loss of their loved ones. They meet patients' best interests and are justifiable by principles of major medical ethics. The policies could be improved by allowing physician-assisted dying where patients claim that their suffering is unbearable and that there is no prospect of improvement, as is currently permitted in the Netherlands. There is clearly a need to extend "Death with Dignity" policies in the US.

A copy of the complete paper can be obtained from TedHandler@gmail.com

PREPARING FOR AND COPING WITH SUPERSTORM SANDY

**Information provided by Charlotte McAfee,
President of Arbor Glen Residents Association**

After our experience with "Irene," which preceded "Sandy" by one year, we contacted the State of New

Jersey's Office of Emergency Management for training to develop our own campus CERT (Community Emergency Response Team) consisting of five residents and three staff members.

One project of the CERT team was to create a display to illustrate the contents of a "go-bag" that each resident needed to assemble for an emergency evacuation. Included were flashlights, food and water, medications, personal documents and cash.

Our community formed a resident Watch Group consisting of 35 residents who watched to make sure that all was well for the residents in his/her section. At the beginning of each watch the volunteer visited each resident, then made a round each hour.

Management established a central command post that communicated within the CCRC using runners, including staff and able-bodied residents. They responded to problems noted by resident watch volunteers. They also communicated with residents' families if the resident did not have a cell phone.

The community was without electricity for three days and would have evacuated if the power outage had continued longer.

With the help of their food supplier, the community was able to continue to serve hot food throughout the day. The emergency stopped elevator service and limited light to hallways and stairwells.

The personal touch offered by our resident watch group, as well as by our staff and management, was most important during our emergency. Residents responded by turning mealtimes into party times with wine and other goodies. The closeness that resulted from the many demonstrations of caring during the storm led to many parties among the "survivors" commemorating the unforgettable events generated by Superstorm Sandy.

Arbor Glen gave assistance to doctors in a neighboring medical center who were stranded by the gasoline shortage, and cared for staff and family whose homes had been made uninhabitable by the storm.

Long after the storm was over, each resident was visited by a member of the CERT team, giving the resident an opportunity to reflect on the Sandy experience, on what worked and what didn't. The results will help the community to improve their preparedness plans for the future.

Our community's efforts during the storm demonstrate that we are guided by our Quaker principles; we have a reputation for a culture of caring: residents caring for each other. We also believe that it's not what happens to you that matters, but how you deal with it.