



"Dedicated to improving the health, well-being and quality of life of patients and their families."

QUARTERLY

How democracies can maximize voting rights and minimize fraud when people with cognitive impairment want to vote

Jason Karlawish, MD

Case 1: *A nursing home returns 50 ballots and all are for the same candidate and that candidate is also the social worker at that facility.*

Case 2: *An activities director explains that persons who get to vote at her facility are those who know who are the candidates and can discuss the issues.*

Case 3: *An activities director at a nursing home explains that he would have liked to encourage the residents to vote but the deadline for applying for ballots passed before he could send in the ballot applications.*

Each of these cases highlights the range of the ethical, social and legal issues raised by voting by persons with dementia. Voting by persons with cognitive impairments is among the next frontiers in the disability and voting rights movements. How can democracies negotiate the balance between encouraging voting by persons with cognitive impairments who retain the capacity to vote, while at the same time keeping persons who no longer have this capacity from voting?

State laws need to clearly define what is the capacity to vote.

What does it mean to have the capacity to vote? Is it simply stating, "I want to vote?" Or should the person know something about what voting is and even, like the activities director described above, know about the candidates and the issues?

In our society, we have generally endorsed the notion that a person needs to have capacity, or in legal terms competency, to vote. But states have crudely codified this with prohibitions on voting by persons who are insane, "mentally incompetent," or "under guardianship because of mental illness." All of these criteria attempt to capture the issue that persons who are not competent to vote should not vote, but all of them fall

flat on basic principles of law and ethics. We do not say someone is not competent because of this status (for example, mentally ill), but because of what they cannot do as a result of functionally significant cognitive impairments.

In the case of the capacity to vote, we need a standard that captures the essence of what it means to vote. And this standard should be as objective as possible. That is, it should not rely on a person making the "right choice" or on knowing what are the electoral

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What is Assisted Living?

Interview with Terry Klaassen, founder of Sunrise Senior Living

Kara Krissel, MPH

When considering senior care alternatives, the terms pile up: personal care homes, community residential facilities, basic care facilities, and adult residential care homes are only a few of the terms used to describe what most closely fits the idea of “assisted living” (1).

What is assisted living? The definitions of an assisted living facility are diverse, but generally emphasize homelike environments, independence, privacy, personal care, and dignity. The Assisted Living Federation of America (ALFA), one of the industry’s main trade groups, defines an Assisted Living Facility or residence as a special combination of housing, personalized supportive services and health care designed to meet the needs – both scheduled and unscheduled – of those who need help with activities of daily living. These activities include feeding, bathing, grooming, toileting and transferring.

“...assisted living is ideal for people with memory impairments or some form of dementia, because these individuals are best served in an environment where they feel comfortable, secure and as close to home as possible.”

Terry Klaassen, founder Sunrise Senior Living

Unlike nursing homes that are subject to detailed federal regulations, assisted living is only state regulated. It is no surprise then that the kinds of care for people living with Alzheimer’s disease and with cognitive impairments in these facilities varies between states and within states. Some facilities offer special care units for people living with Alzheimer’s disease and related cognitive impairments, while other facilities offer secure Alzheimer’s units that require a specific license, and still other facilities have no requirements for Alzheimer’s units.

To help us make sense of the multiple terms and definitions used to describe assisted living, we spoke with one expert in the field, one of the founders of *Sunrise Senior Living*, Terry Klaassen. *Sunrise Senior Living* is one of the leading providers of assisted living, with over 370 communities in 34 states, the District of Columbia, Canada and the United Kingdom and with over 20 years of service.

Q: What is assisted living?

A: Assisted living is a combination of environment and services that are designed to respond to the unique individual. So it is both creating an environment that is really a reflection of home, warmth and comfort, and providing services in a way that meets the specific unique needs of the individual.

Q: Why should someone leave their home and move into an assisted living facility?

A: It can be different reasons for different individuals, but I would say in general, when a person needs to receive services that are either too complicated or expensive to receive in their own home, then that motivates them to consider an alternative where they

can receive their services in an efficient and affordable manner.

Q: How is assisted living different from a nursing home?

A: There are critical differences. The first is environment, particularly when we are

considering someone who has some kind of memory impairment or dementia. Environment has such an impact on how we feel about ourselves and how we relate to individuals. Someone with a memory impairment may not be aware of exactly where they are, but they may know the difference between things that signal a nursing home - florescent lighting and tile floors - and things which represent home - plush carpeting, incandescent lights, and soft seating. The environment is a huge difference between assisted living and skilled nursing facilities. The other key difference is in how services are delivered. Assisted living really works under a premise of encouraging independence and individuality, which means that a person doesn’t fit into a bathing schedule or a meal schedule, but that they can get their services when they want them. They can sleep as late as they would like to sleep, they can get breakfast at 10:00AM instead of 6:30AM, and they can receive their bath in the

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Advance Life Planning and Dementia: What have we learned?

Karen B. Hirschman, PhD MSW

What is *advance life planning*? Advance Life Planning (ALP) is a new term that tries to capture planning for various aspects of our future, including: health care preferences, living situation options (i.e., staying in your own home, moving to a smaller home, retirement community, assisted living), and a formal will or advance directive for health care.

Over the past 18 months, 15 family members from our Memory Disorders Clinic (MDC) and 15 family members from an outside location were interviewed about advanced life planning as part of a research study. Many family members stated that they did not think to have the conversation with their spouse or parent or did not know how to bring up the topic with their relatives. Several family members said they wished they had talked with their relative, noting that making decisions was and is sometimes more difficult because they do not know what their relative would have wanted.

What can we learn from those patients and families that did have advance life planning conversations?

The timing of advance life planning discussions often coincides with a medical issue or move, that involved the patient, other family members, or friends. Many of these conversations involve health care professionals or lawyers in addition to family members. Most advance life planning discussions are informal, meaning these discussions occurred over dinner, visiting a sick friend, after the death of a friend or family member, and while planning for retirement or "*getting affairs in order*". And not surprisingly, family members said these discussions were a natural part of their relationship with their family member.

Some people who were interviewed expressed that as a result of this experience with their relative they had put together a living will or had talked with their children about what they would and would not like regarding their health care preferences. Several people said they wished they had known what they know now. While hindsight may be 20/20, these family members have provided us with insight into the importance of advance life planning and talking with our relatives, not just for persons with dementia, but for all of us.

Tips family members have shared that we can all learn from:

1. Informal conversations are a good "*springboard*" to discuss your preferences. Use your every day life experiences or something you read about in the news to open a dialogue with each other.
2. Talk with your health care providers about your health care preferences.
3. Use formal documents such as a living will or a Durable Health Care Power of Attorney to help guide you in talking with your relative.

Living will - a legal document in which a person can state the kind of health care they do or do not want under certain circumstances.

Power of Attorney- a legal document in which a person can name someone close to them to make health care decisions for them in the event that they cannot make decisions for themselves.

Some of the results from this study will be presented at the 57th Annual Scientific Meeting of The Gerontological Society of America in Washington, DC in November (2004). In addition, the following recent publications of Dr. Hirschman's have been made possible by patients and their families that attend the MDC at the Alzheimer's Disease Center:

Hirschman KB, Shea JA, Xie SX, & Karlawish JHT. The development of a rapid screen for caregiver burden. *Journal of the American Geriatrics Society*. 2004; 52(10): 1724-1729.

Hirschman KB, Xie SX, Feudtner C, & Karlawish JHT. How does an Alzheimer's Disease patient's role in medical decision-making change over time? *Journal of Geriatric Psychiatry and Neurology*. 2004; 17(2): 55-60.

Dr. Hirschman is on the Research Faculty at the School of Nursing and a Fellow at the Institute on Aging, at the University of Pennsylvania. She recently completed a postdoctoral training fellowship in neurodegenerative diseases in the School of Medicine at PENN. For more information on this research or copies of articles please contact: Dr. Karen Hirschman at 215-573-3755 or via email at: hirschk@nursing.upenn.edu.



News from Penn's ADC

Events

How dementia affects artistic talent

The IOA Visiting Scholars series presents valuable educational lectures by experts in the areas of aging research, policy, and clinical care. Sessions are open to the public and free of charge. The next Visiting Scholar will be Robert Storr, MFA Rosalie Solow Professor of Modern Art, New York University presenting "The Mind in the Hand" (December 2, 2004 - University of Pennsylvania John Morgan Building Class of '62 Hall). For more information on this and a schedule of upcoming sessions, please visit www.uphs.upenn.edu/aging or call the IOA at (215) 898-3163.

Staff News

Former staff news...

Congratulations to Henrique Fernandez, MD! Dr. Fernandez has accepted the position of Chief Medical Resident at the University of Connecticut Internal Medicine Program, beginning in July 2006. Dr. Fernandez worked as a clinician in our satellite Latino Memory Disorders clinic from 2001-2003.

Current staff news...

Valerie Cotter, MSN, CRNP, FAANP, Director of Education, Alzheimer's Disease Center and Director of the Adult Health & Gerontology Nurse Practitioner Programs, School of Nursing presented "Restraint Free Care in Older Adults with Dementia" while a Visiting Scholar at Aomori University of Health and Welfare in Aomori, Japan on July 21-28, 2004. Ms. Cotter also gave this lecture at Keio University Hospital, Tokyo where she was hosted by Keio University and the Keio Medical Society.

Welcome new staff...

We welcome Jonathan Rubright and James Beaver. Both Jonathan and James have joined our team as research assistants working with Dr. Jason Karlawish.

Farewell...

I take this opportunity to say farewell. Although my time working for the Alzheimer's Disease Center has been short, it has been nothing short of wonderful and memorable experiences. As of October 29, 2004, I will be leaving the Alzheimer's Disease Center to pursue a career change. It has been a pleasure meeting many of the patients, families and community members. Thank you for welcoming me, and I wish you all the best.

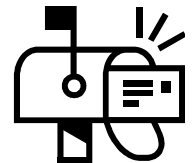
Kara B. Krissel,

Associate Director, Education and Information Transfer Core, Alzheimer's Disease Center and Editor of the ADC Quarterly

What is this envelope for?

Do you like what you are reading? Are you provoked? Entertained? Do you think the *Quarterly* is worth more than the paper it's printed on? If so, please help us keep on publishing. Your gifts are gratefully accepted and will help keep the *Quarterly* in print.

To send a tax deductible gift, please make the check payable to the "Trustees of the University of Pennsylvania" and indicate "Memory Disorders Clinic" in the memo line. We have included a self addressed, prepaid envelope for your convenience.



Thank you!

TARP: An alternative to crossword puzzles

Do you want to learn a language? Study great literature? Investigate the cosmos? Or just hang out with friends with similar interests? As a member of TARP, you have the opportunity to do all these things, and then some.

Recent studies have shown that participating in meaningful cognitive activities may help prevent memory problems and other cognitive impairments. So, what exactly is a meaningful cognitive activity? Watching television, reading a book, completing a crossword puzzle? An article published in the *New England Journal of Medicine* (June 2003) found that reading, playing board games, and playing musical instruments were among those activities generally associated with a lowered risk of dementia. TARP provides an opportunity to participate in all of these activities and more.

The Temple Association for Retired Persons (TARP) was founded more than 30 years ago, specifically for those people who have retired from their regular lines of work and want to keep on learning. Sponsored by

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Voting...Continued from Page 1

issues. A recent U.S. court case achieves these conditions: the capacity to vote means that a person understands the nature and effect of voting and can make a choice.

How could the activities director, who at present asks her residents questions about the election, apply this more objective and fair standard? To assess a person's ability to understand the nature of voting, she could ask "Suppose today is election day for governor in Pennsylvania. What will the people of Pennsylvania do today to pick the next governor?" A person who understands the nature of voting would answer that people will go to the polls and vote. To assess whether the person understands the effect of voting, she could ask, "When the election for governor is over, how will it be decided who is the winner?" The answer should capture the idea that who ever has the most votes wins. Finally, she could present the resident a simple description of the two candidates and ask which one the person would be more likely to vote for.

There are two next steps in cleaning up discriminatory and ambiguous laws about the capacity to vote. First, we need to study how persons with varying degrees of cognitive and educational levels perform on an instrument that measures the capacity to vote. Specific questions include is it necessary to assess the ability to choose? That ability may simply add no additional information than the ability to understand the nature and effect of voting because persons who can understand those two things may be likely to be able to make a choice. Second, how does the ability to want to vote compare to the ability to understand what is

voting? The answer to this question may reveal frankly disturbing data: some people who say they want to vote may not know what is voting. Democratic societies will need to deliberate on how to address this.

Third, are there strong correlations between widely accepted measures of overall cognition, such as the Mini-Mental State Exam, and performance on the measure of the capacity to vote? If such correlations do exist, society can better focus on those persons who need a more detailed assessment.

When should we assess whether a person has the capacity vote?

We should assess voting capacity when it is in question. We must not do this in a manner that is discriminatory and in violation of voting laws and civil rights. For example, we should not screen all persons over 65 who come to a polling booth. This would discriminate on the basis of age, violating the 26th amendment to the US constitution.

In long-term care settings, where questions may arise as to whether a voter is competent, an assessment of capacity using the standard described above can help to clarify tough cases. Such cases are likely to arise when staff or election officials in a nursing home approach a resident and ask him or her if he or she wants to vote. In such a situation, a simple "yes" may not mean a person adequately understands what is voting.

In addition, assessment is warranted to limit disenfranchisement based on unwarranted assumptions that a person is not competent because they are not

What are the pressing issues? An agenda for public policy and education.

- State laws need to be changed to recognize that a person who understands the nature and effect of voting and can make a choice is competent to vote.
- Public education is needed...
 - To change the mistaken view that persons who are mentally ill or cognitively impaired should not be voting.
 - To convey that voting for another person who is not competent to vote is unacceptable.
- Voting machines and ballots should be made accessible to people with cognitive disabilities.
- Uniform guidelines are needed for voting in long-term care with adequate funding to assure they are implemented and assessed for their efficacy in maximizing residents' voting rights.

To learn more about the project "Examining the ethical, legal and social issues raised by voting by persons with dementia" visit the web site www.uphs.upenn.edu/adc.



Assisted Living...

Continued from page 2

morning if they are a morning person, and in the evening if they are an evening person.

Q: What are the kinds of people who should not consider living in assisted living?

A: I honestly can't answer that question, because I do believe that again assisted living is a response to what people want. So a person who wants to feel more secure and who wants more social interaction than they would receive in their own private home, assisted living is perfect for them. Someone who again requires more services but doesn't want to try to arrange those services on their own, because of the expense of having someone come into the home instead of going somewhere where the services can be managed more efficiently, assisted living is a perfect place for them. I certainly believe, and I feel very strongly about this, that assisted living is ideal for people with memory impairments or some form of dementia, because these individuals are best served in an environment where they feel comfortable, secure and as close to home as possible.

Q: The Sunrise mission is "to champion quality of life for all seniors." Your mission seems to embrace the popular phrase "aging in place." What does this phrase mean?

A: Aging in place means that it is not about a chronological individual's age or their disability that should define whether or not assisted living is the appropriate place for them. What should define it is can that individual's needs be appropriately met and is that setting the place that gives that individual the greatest quality of life, irrespective of criteria.

Q: Please describe the services a Sunrise assisted living facility offers to residents who have Alzheimer's disease or related cognitive impairments.

A: It is a full range of support services from the hospitality services, the meal service and housekeeping to certainly personal care services, assistance with bathing and dressing and all the things that used to be referred to as custodial care. At Sunrise, this is your home. So no matter what an individual needs, we will work to meet those needs. If we don't have it within our own internal system, we will at least offer an individual to bring it in from the outside, just like they

For more information on Assisted Living and other long term care facilities contact:

American Association of Homes and Services for the Aging (AAHSA)

AAHSA offers a series of free "Consumer Tips" on finding home and community services, assisted living facilities, nursing homes, and continuing care retirement communities.

<http://www2.aahsa.org/>

Assisted Living Federation of America (ALFA)

ALFA is an association exclusively dedicated to the assisted living industry and the population it serves.

www.alfa.org

National Center for Assisted Living (NCAL)

NCAL is the assisted living voice of the American Health Care Association (AHCA), the nation's largest organization representing long term care providers

www.ncal.org

The Centers for Medicare & Medicaid Services (CMS)

Provides detailed information about the past performance of every Medicare and Medicaid certified nursing home in the country.

www.cms.hhs.gov

would in their own home. So the unique therapies or services that may not be integrated into our own service plan, through home care agencies or even hospice, we can bring those services in. Sunrise is an individual's home, and we work with the individual and the family to provide whatever services they may want or need.

Q: You manage assisted living facilities in a number of different states. This gives you first hand experience with the variations in state regulations. Are there any model states?

A: Yes, there have been some excellent model states. We find these models to be the states that build their regulations around empowering consumer choice. We all recognize that this field needs regulation. It needs regulation that gives fundamental, health and fire safety to all of the consumers, but then allows consumers to choose what options within the state are right for them. It would only be good social policy

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Voting...

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oriented to date, day or year; don't know who is president; or can't manage their finances.

The need to pay attention to voting in long-term care.

Democratic nations need to maximize access to the polls. One place where particular efforts are needed is long-term care facilities. Many of the allegations of voter fraud arise from claims that voting in a long-term care facility was inappropriate. In our group's study of voting in long-term care facilities in Philadelphia, we found that activities and social work staff have the bulk of the task of voter registration and access. They may miss deadlines for registration and ballot application, and struggle to decide whether a person can vote. Clearly, they have a lot of power over whether someone votes. One activities director told us "The right to vote is such a basic right. Guidelines would help to make sure there are fair, objective applications, not 'I'm sure she's not going to vote for the person I like, so I'm not asking her to the polling place.' You do have quite a bit of power and authority over folks."

Long-term care staff, who are already busy with the care of the residents, should not have to shoulder the burden of voter registration, absentee balloting and dealing with the tough cases that may arise only to then take the heat for claims by the loser of a close election that inappropriate voting occurred at the facility.

Long-term care facilities need uniform guidelines that include clear roles for election officials. Some states have meritorious examples. Iowa has provisions to bring ballots to people who are not available on voting day as a result of unexpected illness, and Maryland routinely sends polling officials to all facilities. Leaders in long-term care, voting rights and election officials need to develop guidelines based on consensus of what are best practices.

Thank You !

The University of Pennsylvania's Memory Disorders Clinic thanks the *James Previti Family Fund of the Homebuilding Community Foundation* their generous contribution.

TARP...

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Temple University, the organization boasts a lively, no-pressure academic atmosphere in which students take a variety of courses in fields like art and architecture, computers, current events, finance, health, history, humanities, languages, law, literature, music, philosophy, psychology, bridge and chess, science, and theatre and films.

Classes are held from Monday to Thursday during the day. On Friday mornings, TARP presents the Friday Forum, a weekly series featuring guest speakers with diverse and interesting backgrounds. This program is open to the public.

TARP is conveniently located in center city Philadelphia at 1515 Market Street. The spring 2005 semester begins on January 24. For more information and a course catalog, call 215.204.1505 or e-mail tucctarp@temple.edu.

Assisted Living...

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to have regulations that safe guard the health and welfare of individuals served in assisted living. We applaud states that recognize that the industry is focused on individual empowerment and that the regulations need to support that philosophy.

Q: Would a uniform set of regulations make sense?

A: The model of a regulatory approach makes sense. The importance of it being administered on a state level is that within the current model, states differ in how they zone and how they administer these regulations. Some are administered through the Department of Health and Human Services, others are through the Department of Social Services. So, I believe that there can be a consistent model, but I think the administration and the actual implementation has to be done at a state level, because of those other overarching unique state structures.

References:

(1) Assisted Living State Regulatory Review 2004; National Center for Assisted Living. March 2004



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Research Opportunities at Penn's Alzheimer's Disease Center:

Interested in volunteering to advance the standard of care? To learn more about these research opportunities contact Gerri Anselmo, clinical research coordinator at 215-662-4377 or email her at ganselmo@mail.med.upenn.edu.

- A study to examine if a medication used for other conditions can slow down the progression of Alzheimer's disease and delay the emergence of problematic behaviors
- A clinical trial of a new investigational drug for Alzheimer's disease
- A study to determine if taking a cholesterol lowering drug can slow the progression of Alzheimer's disease
- A study to determine if taking high doses of three specific vitamins can slow the progression of Alzheimer's disease
- A study to determine if a measure of brain waves generated in response to sound can detect the presence of Alzheimer's disease
- A longitudinal study to search for the presence of specific proteins in the spinal fluid that mark the presence of Alzheimer's pathology at a time when the symptoms are too mild for the disease to be detected by clinical examination

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