

# Voices for Quality Care

Post Office Box 2251, Leonardtown, Maryland 20650  
<http://voicesforqualitycare.org>  
 (888)600-2375

Maryland, Maine, Florida, & Washington, D.C.

*A regional non-profit all-volunteer organization of people needing long-term care services & supports, their friends & families, resident & family councils, advocates, and concerned citizens working together for quality long-term care in Florida, Maine, Maryland, and Washington D.C.*

December 2012

<b>Off-label Anti-Psychotic Drug Use in Nursing Homes</b> Page 2	<b>Another Brand of Dementia</b> Page 2	<b>Nursing Home Quality of Care Measures</b> Page 4	<b>Life Sustaining Treatment in Maryland</b> Page 4	<b>Resident &amp; Family Councils</b> Page 5	<b>Florida Nursing Homes on State's Watch List</b> Page 6	<b>Nursing Home Closure in Maine</b> Page 7	<b>Nursing Home Star Ratings in the District of Columbia</b> Page 9	<b>What has Voices done in 2012?</b> Page 10
---	--	--	--	---	--	--	--	---



## The First Step

### Moving Into a Long-Term Care Lifestyle

by Bernie Brown

An amazing lady, 57 year old Carla is living with Lupus. She is now one of the estimated 1.5 million Americans and approximately five million people worldwide affected with a form of lupus. Lupus is two to three times more prevalent among women of color than among Caucasian women.

Waking one morning over ten years ago to swollen eyes and a puffy face but not necessarily feeling ill, she eventually sought a medical opinion. Following a series of tests, blood work, and medical examinations, the doctor delivered the dreadful diagnosis -- Lupus. Lupus is believed to be a stress related illness. This chronic disease, which has no cure, attacks the organs, including the skin, as well as internal organs and tissue. Lupus brings with it extreme fatigue and weakness that causes an inability to engage in activities of daily living, much less to participate in sports of any kind.



*A common misperception is that long-term care services and supports are for the frail elderly. That often is not the case. Here is an example of a family at the beginning of the long-term care journey.*

Through her strong faith, hope, and love Carla has overcome some of the challenges brought on by her illness. Once an aspiring young athlete, racquetball, hang gliding, skiing, bowling, and white water rafting were among her choice of sports. Carla's lifestyle has changed dramatically since her diagnosis. She is now considering possible life-style alterations, including long-term and respite care.

Carla's 22-year-old son, Avery, is her primary caregiver. As her health issues have advanced so has his commitment.

However, Carla realizes the daily challenges they are faced with and worries about the future. She struggles with her decreasing options, spending a good part of her day thinking about what living arrangements would be in the best interests of her son and herself. Nursing Home fears are valid and unsettling. Her son, Avery, expresses major concerns and feels that this type of environment is not an option for his Mother. For her to stay at home would be ideal, but how to turn that into an affordable reality?

The out-of-pocket expenses of in-home care are generally out of the financial scope for the average person on a fixed income. Like many elderly and disabled people, Carla's income disqualifies her from State funded benefits but isn't enough to hire a caregiver.

Carla has collected information and has reached some milestones in this process, but still has much research ahead as do many others in similar situations. Organizations such as the Department of Aging, the Department of Social Services, and The Lupus Foundation of America offer information and possibly some relief for people who need help finding appropriate and affordable long-term care supports and services. Carla continues to search.

*For more information on lupus, contact The Lupus Foundation of America <http://www.lupus.org/newsite/index.html>*

## CAUTION: Choosing a long-term care service

*If you choose to use one of the long-term care placement organizations that assist in selecting nursing homes, assisted living facilities and other services, know where their funding, if any, comes from. We are hearing complaints about such services, some well known, that provide free referrals to clients but receive substantial fees from those facilities and services they refer to. The best nursing homes, assisted living facilities, and in-home care providers generally are operating near capacity. Many even have waiting lists. These better and best providers have no need to pay fees to placement services and therefore are generally not on the lists the services send to their clients.*

### Long-Term Care Alternatives

*Nursing homes are not the only choice for long-term care and supports. For a comprehensive list of alternatives, go to the Centers for Medicare & Medicaid Services website Nursing Home Compare and select Alternatives to Nursing Homes in the menu on the right side of the page, or paste this URL into your browser to go there directly:*

<http://www.medicare.gov/NursingHomeCompare/Resources/Nursing-Home-Alternatives.aspx>

## Off-Label Anti-Psychotic Drug Use In Nursing Homes Examined

by Susan Eddy

Anti-psychotic drugs prescribed for persons with dementia can lead to loss of independence, confusion, and falls. The Center for Medicare and Medicaid Services (CMS) has launched a partnership initiative to reduce the use of anti-psychotic drugs in the nations' nursing homes by 15 percent.

Called the Partnership To Improve Dementia Care, CMS has developed a training series on person-centered care and has set out to publicize use of anti-psychotic drugs on its Nursing Home Compare website. "Managing dementia without relying on medications can improve the quality of life for these residents," said the CMS Chief Medical Officer in announcing the initiative last May. "The Partnership To Improve Dementia Care will equip residents,

caregivers, and providers with the best tools to make the right decision."

One thrust of the initiative is to emphasize alternatives to drugs, such as increased exercise, time outdoors, managing pain, and increased individualized activities. There needs to be a more extensive assessment of the patient with input from families and caregivers, according to Dr. Steven Levinson, one of the providers in the partnership. Many things look like dementia but changes in behavior can be a result of pain, anxiety, sensory impairments, or a reaction to over-the-counter drugs.

Dr. Levinson calls for a change in thinking and in the decision-making process around the use of anti-psychotic drugs in nursing homes. In fact, CMS has begun a study in 20 to 25 nursing homes in order to understand how decisions are made whether to use or not to use anti-psychotic drugs.

## Another Brand of Dementia

by Lorrie Van Akkeren

Have you heard of Frontal Temporal Degeneration (FTD), a type of dementia not nearly as common as Alzheimer's

Disease? With far less research attention than Alzheimer's, only a handful of specialists have the expertise to properly diagnose FTD. Treatment may slow the disease progression, but it is ultimately fatal in two to 25 years with an average of ten to twelve years.

### Who gets FTD?

Anyone. However, people who have had repeated head injuries may be a bit more prone to FTD. Research has yet to establish a genetic predisposition for the disease; however, it is suspected that in some cases there can be a genetic component. Military service that occurred years ago is also suspected to play a role, and it is known that FTD can be a secondary effect of Multiple Sclerosis (MS), Parkinson's Disease, or Amyotrophic Lateral Sclerosis (ALS).

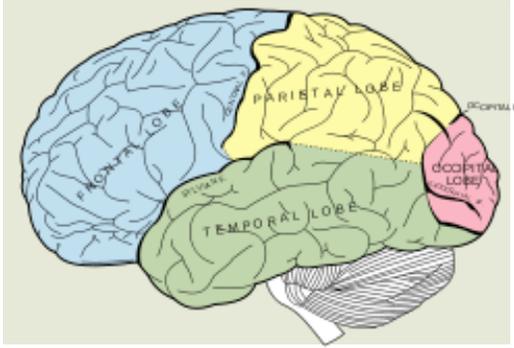
Typically, FTD begins at a younger age than Alzheimer's. Many victims develop symptoms during their productive years when they may have young children. On average, the age of onset is the 50s to early 60s, but people in their 20s have been known to develop this disease. Gender or career choice makes no difference.

### Why do these symptoms occur?

The frontal and temporal lobes of the brain are responsible for behavior, emotional responses, and language skills. In FTD, the brain shrinks much earlier than would occur in the normal aging process. Shrinkage is especially evident in the frontal and/or temporal lobes of the brain and will show up in CAT scans, MRIs, and PET scans. In addition, abnormal protein collections are found in the brain if it is autopsied after death.

### Those with Alzheimer's

Ronald Reagan	E.B. White
Perry Como	Aaron Copland
Rita Hayworth	David Niven
Barry Goldwater	Charlton Heston



Symptoms exhibited early on worsen and additional symptoms appear as more and more of the brain is affected by the shrinkage. Later in the disease process, the brain and the accompanying symptoms more closely resemble the brain and accompanying symptoms of Alzheimer’s Disease.

People close to the person with FTD first notice subtle personality changes that escalate over time. Other early signs include a decline in the speed and accuracy of job performance. Some become more docile or passive. Others become more impatient and volatile—up to and including becoming uncharacteristically violent. Judgment and decision-making may be impaired. Hygienic habits deteriorate. Compulsive behaviors may occur such as craving and eating sugary foods. Hoarding behavior appears, or if the tendency was there before, it intensifies. Short term memory may be affected. Patterns of speech and ability to express themselves may change. Often the victim is unaware that he or she has changed. If told they have changed, they do not believe it.

Eight subtypes of FTD have been identified based on specific symptom groupings. Often the most challenging subtype for families and caregivers is Behavioral Variant FTD (bvFTD). Because it is so challenging, this subtype is the focus of this article. Specific symptoms associated with this type, in addition to personality changes, are an inability to show or express empathy, difficulty controlling behavior (from verbal outbursts to violence), socially inappropriate activities (inappropriate language to inappropriate sexual behavior or statements in public) or

inappropriate responses (lack of concern for the effect of his/her behavior on others). Memory problems are a later symptom of this subtype and further complicate the behavioral problems.

**What about getting a diagnosis and treatment?**

Because FTD is a rare dementia, most doctors know little or nothing about it. It is not uncommon for the person with the symptoms of FTD to be diagnosed with other psychiatric or neurological problems such as depression, schizophrenia, bi-polar, obsessive/ compulsive disorder, or Alzheimer’s Disease. If family members suspect a diagnosis does not quite fit the symptoms or the progression of the symptoms, going to a clinic or medical center specializing in lesser known dementias may be worthwhile.

**What does all this mean?**

In a nutshell, the victim of FTD in general and bvFTD in particular becomes more and more difficult to live with and care for. If the person is in a family setting, the caregiver is challenged to provide care, support, and structure for someone who would rather be a “loose cannon” in addition to nurturing and taking care of the needs of any children in the home and holding down a job. Caregiver stress is enormous. The person who has bvFTD is oblivious to what the other family members are dealing with.

No one wants to institutionalize a loved one, but eventually, the family will no longer be able to tolerate the symptoms.

*According to The Frontal Temporal Degeneration website ([www.theaftd.org](http://www.theaftd.org)), research and medical centers specializing in FTD and its subtypes are scattered around the country. They are concentrated on the eastern and western coasts with fewer in the mid-section of the U. S. In the eastern United States specialists are available in Boston, New York City, Philadelphia, near Pittsburgh, Baltimore, Atlanta, Lexington, Louisville, Chapel Hill, and Jacksonville.*

Either care becomes overwhelming, or personal safety and the safety of children in the home become an issue. Day care or assisted living facilities may be tried, but eventually nursing home care is usually needed.

**What about nursing homes?**

A person who has FTD may be admitted to any nursing home. Unfortunately, few nursing home staffs have a good understanding of FTD and its subtypes. The resources available on the Voices for Quality Care and the Medicare websites have general information to help in a nursing home search, but this is no help in regard to quality care for the FTD patient. Support groups that focus on FTD (another rarity), however, should be able to provide some help in locating nursing homes that have a better understanding of the disease process and how to deal with it. When visiting prospective nursing homes, it is important to include questions on what training the nursing home staff members have in less common dementias such as FTD and how they tailor care when behavioral issues arise as well as questions on their previous experience with such residents. The trick is to skillfully include these questions in the list of questions in a way that will not prejudice the prospective nursing home.

Sooner or later problems are likely to arise simply because the staff members caring for this resident do not have training in this disease. A staff well-versed in caring for residents with Alzheimer’s Disease is not enough. Some administrators may have some training, but again, this is not the norm.

Of course, the first step in solving problems is working with the staff and/ or administration in the nursing home. The next step is working with the Ombudsman assigned to the nursing home. If that does not seem to be effective, the county and/ or state have offices tasked with quality of care in nursing homes. They may be able to help prevent formal complaints being filed. Voices for Quality Care has been called into problem situations in the past and

stands ready to do so in the future. In the worst case scenario, legal aid may be needed.

**Where can I learn more about FTD and the subtypes?**

Many caregivers turn to support groups for information. There is nothing like the informal exchange of practical information on all aspects of the disease and sharing the ups, downs, and the occasional humorous moments in this friendly atmosphere. A few support groups even exist for people with the disease. Luckily, there are more support groups in more states than there are doctors diagnosing and treating this problem. Some support groups try to have handouts on FTD at meetings.

**States with Support Groups in the Eastern United States:**

Massachusetts    New York  
New Hampshire    New Jersey

Maryland /Washington, DC

The complete list is on [www.theaftd.org](http://www.theaftd.org) website. This site also lists some telephone support groups for people who are too far away from the meetings.

Clinics and doctors' offices frequently have literature and reprints of articles available in the waiting rooms.

There are seminars and meetings available to professionals (with CME credit). Often lay people such as the patients and their caregivers or support people can attend and keep their knowledge up to date. Support groups occasionally have guest speakers as well. So there are opportunities for formal learning in addition to the informal learning in support groups. It is worth noting that some people have tried support groups for Alzheimer's Disease. Sometimes this works; however, attendees of support groups often feel

most comfortable in FTD support groups because they feel that 'everyone is speaking the same language'.

**Nursing Home Quality of Care Measures**

by Susan Eddy

Since 2002 Medicare has been posting evaluations of individual nursing homes on its Nursing Home Compare website. Does public reporting of measures of care prod nursing homes to improve quality of care? Not so far, according to a 2010 study funded by the government's Agency for Healthcare Research and Quality.

Scientists studied three measures of care in 8,137 nursing homes and compared the numbers 12 months before and 12 months after the onset of public reporting on the Nursing Home Compare site. Looking at short-stay patients in post-acute care, the percentage of those without moderate or severe pain did increase somewhat (from 73.8% to 77.3%). But the percentage of patients without delirium increased only slightly. And, there was no change in the percentage of patients with improved walking.

Another possible effect of reporting of nursing home quality is that consumers will choose the more highly rated facilities. Researchers did find more patients with pain risk going to high-quality nursing homes after 2002. But there was no change in the choice of facilities by patients at risk for delirium or impaired walking. The researchers did note, however, that providers may be "gaming the system" by reducing the degree of pain or delirium reported at admission.

Researchers also looked at public reporting of quality and how it may affect nursing home spending on medical services, buildings, and housekeeping. They found that the ratio of clinical expenditures to "hotel" expenditures did change after 2002, with more money going to the clinical side after public reporting of nursing home quality.

Voices notes that the Quality Measures reported on the CMS Nursing Home Compare website are self-reported by the facilities and are not checked in any way by outside, independent entities.

**Life Sustaining Treatment in Maryland**

by Clare Whitbeck

One would think that an advance directive would determine the actions of an emergency room physician or an Emergency Medical Technician (EMT) should one be sent by ambulance to the emergency room of a hospital. In Maryland, that may not be the case!

Final regulations concerning the Maryland MOLST form (Medical Orders for Life Sustaining Treatment) have now been completed. The form now must be executed for every person in Maryland who lives in a nursing home or assisted living facility, who employs a home health agency, enrolls in hospice, attends a dialysis center, or is treated at a hospital. The law says the form does not replace an advance directive. But, in reality, it will when the new regulations take effect on January 1, 2013. It will guide first responders when they consider whether to resuscitate a patient and whether some other actions must be taken.

I repeat, the MOLST form will direct the actions of first responders and emergency room doctors as well a list of medical practitioners in other medical facilities. Whenever a MOLST form is executed by a physician or physician assistant, a copy must be provided to a competent resident or the person with his/her Power of Attorney (POA) within 48 hours, or sooner if the resident is leaving the facility. If there is a MOLST form in existence, as of January 1 a nursing home or assisted living facility should be providing a copy.

There is still no place on the form for the competent person or POA to sign indicating that they agree with the provisions recorded and have received a

copy of the MOLST form. So, if a facility neglects to provide a copy, there is no other way for the person or POA to know that the form has been completed or to know what medical interventions, if any, have been ordered.

With the MOLST form about to become the final determinant of how or whether a person would be resuscitated if resuscitation is needed, now would be a good time to review

the medical records of a person in any medical facility, especially nursing homes and assisted living facilities, as well as anyone using the services of an in-home care agency to determine how the form has been completed. You will not want to be trying to figure out what the form means when a medical emergency arises and someone is in need of resuscitation.

The form should be updated every time a person goes from one facility to

another, so it is also important to see what form a receiving facility (hospital, dialysis unit, etc) will use to determine whether a person will be resuscitated if resuscitation is needed. If the form has been completed incorrectly, i.e. not in accordance with the wishes of the person, there is a procedure spelled out for voiding that form. It would be advisable to make sure that happens, if correction is needed.

## About Those Councils

*Thirty-five years ago Congress passed a law giving people who live in nursing homes and their families the right to form independent groups –known today as Resident and Family Councils. Congress, at that time, clearly understood the importance of balancing the needs of the people living in these facilities and their loved ones with the needs of the providers who run them. 35 years later, are our Resident and Family Councils positively and noticeably affecting care and life in these facilities?*



### *Voices for Quality Care is looking for independent Resident & Family Councils*

*The Goal: A Council Registry of Resident Councils run by people living in long-term care facilities and independent Family Councils run by families and friends of residents of long-term care facilities.*

*The purpose? A greater collective voice for Councils locally, statewide, and nationally.*

*Since Council membership changes frequently, we ask now that all leaders of independent Resident or Family Councils, including those that are members of Voices, contact us at [voiceshelp@voicesforqualitycare.org](mailto:voiceshelp@voicesforqualitycare.org) or by phone at (888) 600-2375 to make sure your Council is included.*

## Family Councils

Has your Family Council written a letter to an Administrator and not received timely or acceptable replies? Is your Family Council run by staff? If so, you are not alone.

Voices has recently received complaints from family members and Family Councils in Maryland nursing homes where administrators are refusing to deal with independent family councils. We suspect this is also the case in Maine, Florida, and Washington, D.C.

Family Council issues Voices is currently assisting with.

- Administrative interfere with the independence of Family Councils
- Administrative refusal to reply to written communications
- Administrative claims that family support groups run by

facility staff are, in fact, the Family Councils thereby refusing family members the right to form independent family-run Councils.

Federal law gives nursing home residents and their families certain rights including the right to privacy for meetings. In Maryland only, the Family Council Law requires that “A nursing home shall respond in writing to any written grievance or other written communication from the Family Council within 14 calendar days”. And, “A nursing home shall create and maintain a public correspondence file and a regulatory correspondence file for communications with a Family Council.”

The Maryland Family Council Law allows a facility to help establish a Family Council by running it for no more than six months. Federal regulations

prohibiting staff from attending Council meetings unless invited also prohibit staff from running a Family Council.

Our research shows that out of 8,934 complaints found meritorious by OHCQ in Maryland between 6/19/08 and 9/26/12 only seven were issued for Council related non-compliances. All seven of these citations of deficiency were for violations of the regulations for *Resident Councils*. None were for violations related to Family Council rights. In Washington DC, there were no citations of deficiencies relating to Resident or Family Councils. In Florida, between 6/12/09 and 9/28/12 there were only 7. At least 6 of these were also for Resident Councils. Maine lists only one Council deficiency between 7/16/09 and 9/14/12.

## Resident Councils

Is your Resident Council run by leaders who live in the nursing home or by the nursing home staff? Is a Resident Council meeting a place where residents can freely discuss care and quality of life issues among themselves? Does the Resident Council determine when and where it will meet? Do the leaders present requests developed in Resident Council meetings as coming from the Resident Council without identifying individual Residents making it possible to voice complaints anonymously? Does the staff respect and support the privacy, the operations, and the decisions of the Resident Council? If not, you are not alone.

In observing Resident councils in many nursing homes, Voices members have found that a substantial number of them are little more than one of many activities with minimal impact on care and life within the facility. Run by staff members rather than people living in the facility, they are often vague shadows of the groups they were initially intended to be, a voice bringing the needs, interests, and desires of residents to the attention of the staff in a safe, anonymous way.

One of the issues affecting the functioning of many Resident Councils is the concept that every person living in the nursing home, regardless of mental capacity, must be a member of the Resident Council and attend meetings. While this inclusiveness is admirable, it

does not lead to effective Resident Councils. There are ways that all people living in the home can be included in a reasonable manner that does not hinder the operations of the Resident Council.

Some suggestions :

Include only people who are able to understand the purpose of the Resident Council and indicate a desire to attend meetings.

- Be sure that everyone who does understand the purpose of the Resident Council and indicates a desire to attend meetings is able to do so, even people who are "bed-bound".
- Develop two Resident Councils, one that holds meetings for everyone and one that holds meetings only with those who understand the purpose of a Resident Council and who wish to attend.
- Or, develop an Executive Committee within a Resident Council that meets privately to discuss care and life within the facility and that presents comments, suggestions, and grievances to the Administration on behalf of all residents.
- Be clear that HIPAA applies only to the staff of the facility, not to the people living there who have the right to discuss their medical conditions, care, and any other topic with whomever they choose including other members of the Resident Council.

*A major barrier preventing Resident and Family Councils from filing complaints with survey agencies is the fear of retaliation. This is a legitimate fear. Retaliation comes in many ways and is generally subtle. Even when it is blatant, it is extremely difficult to file a complaint with a survey agency that will end in a citation of deficiency. If issues persist, it is often in the best interests of both residents and their families to first contact an ombudsman. We would encourage filing a complaint with the survey agency also, despite any possible retribution in order to alert the survey agency that these difficulties are, in fact, occurring. We also suggest that you consider letting your state legislators know of any difficulties a Council might be experiencing.*

*We have noticed that the majority of the few citations of deficiency issued involve items listed in the minutes of a Resident Council meeting that were not addressed by the nursing home in subsequent months. We suggest that Resident and Family Councils having difficulties getting their grievances or suggestions heard and acted upon first put them in either a communications log or meeting minutes. In that way, there is a record of the request that can then be addressed by an ombudsman or complaint investigator if it goes unaddressed for several months.*

*We also request that you contact Voices for Quality Care and let us know of any Family or Resident Council issues so that we can begin to address them on a more widespread basis. After 35 years, it's time the laws and regulations guaranteeing rights for Resident & Family Councils were more rigorously enforced. Together we can make that happen.*

## A Word From Florida

### One-Fifth of Florida's Nursing Homes on State's Watch List

by Brian Lee

TALLAHASSEE, FL — State records show that 20 percent of Florida's nursing

homes fail to abide by minimum care standards or fail to properly correct identified problems after an inspection.

More than two-dozen cities are home to multiple watch list facilities; those with the highest concentration include Jacksonville (10), Miami (6), Saint Petersburg (6), and Winter Haven (5).

"It's distressing to think that so many elderly and disabled residents receive mediocre care," said Brian Lee, Executive Director of Families for Better Care. "But what's just as shocking is how long some of these facilities actually remain on the list."

Over the last 30 months, some nursing homes have been on the list for months—even years. The chart below details those nursing homes on the state’s watch list for 100 days or more:

Facility name	City	Watch List Days
Coastal Health and Rehabilitation Center	Daytona Beach	1,164
Pasadena Manor	South Pasadena	563
Life Care Center	Port Saint Lucie	516
Good Samaritan Society	Daytona Beach	427
Avante	Leesburg	397
Habana Health Care Center	Tampa	379
Coral Reef Nursing and Rehabilitation Center	Miami	282
Royal Oak Nursing Center	Dade City	242
Consulate Health Care of Orange Park	Orange Park	117
Oaktree Healthcare	South Daytona	114
Edgewater at Waterman Village	Mount Dora	103
Seven Hills Health and Rehabilitation Center	Tallahassee	100

“The sheer volume of facilities on the watch list proves that operators and regulators have to do a much better job safeguarding residents and their rights,” commented Lee. “Our parents and grandparents deserve better.”

For complete watch list information, visit <http://bit.ly/FLnursinghomewatchlist>.

Families for Better Care, Inc. is a citizen advocacy organization dedicated to quality resident care in nursing homes and other long-term care settings. Executive Director Brian Lee served as Florida’s State Long-Term Care Ombudsman for most of the past decade.

Contact information:  
 Families for Better Care  
 850.224.3322  
[info@familiesforbettercare.com](mailto:info@familiesforbettercare.com)



# From Maine

## Residents Forced to Move Long Distances From Home

*A nursing home closed in rural Maine leaving no options for nursing home level care within a 30 mile radius. Nursing homes at that distance are operating at 95% of capacity. Although it has been well proven that the frequency of family visits and the monitoring of care is a major factor in good care, families of residents in this area are now forced to drive between 30 and 90 miles for such visits.*

by Jerry Kasunic

The chaos started March 30, 2011 with a letter written by Kenneth Bowden, CEO of First Atlantic Healthcare located in Portland, ME to Maine’s Department of Health and Human Services seeking a Certification of Need (CON) to build a new 60 bed nursing home facility in Ellsworth, Maine and to close the facility in Calais. Maine. According to the Atlantic Healthcare CEO, the reasons for closing the facility were:

1. Atlantic Rehabilitation and Nursing Center then served 46 residents compared to a decade prior when it served 100 residents;
2. The physical environment of the Calais nursing home was deplorable, stating that the roof repairs alone would cost approximately \$300,000.00;
3. The 39 year old structure did not meet licensure requirements when measuring rooms sizes;
4. The heating system, also in need of repair, along with the roof would be too costly based on the physical plant’s restrictions and “wasteful expenditures on such a deficient building”, and
5. The Department (DHHS) officials having reported both buildings as “needing replacement”.

In the March 2011 letter, First Atlantic Healthcare put forth the idea to DHHS that by building a new nursing home facility in Ellsworth, all of the needs of the residents living in the facility in Calais in Washington County (quality of care and life, physical plant, and environmental needs) and the licensing requirements/compliances would be met. The capital projections at that time were approximately \$8.5 million dollars (first year operational costs were projected to be roughly \$4.5 million; total

estimate with construction and operational costs: \$13 million) with estimated completion time of 16 months. Obviously, over time in closed-door meetings, DHHS agreed with First Atlantic Healthcare and granted the organization a CON to build a new nursing home.

Fast forward to late January, early February, of 2012 when news reached Washington County residents, families, and workers that the 52-bed Calais nursing home would be “mothballed”(Quoted from Bangor Daily News, Jan. 25, 2012 article.), shocking the entire community. Many residents, family members, and employees learned of the announcement only through the local news media and not from the Administration or CEO of the nursing home.

Between February and March 2012, Washington County residents, city and state political officials, nursing home workers, and union representatives scrambled to keep the nursing home open, not only to save the nursing home residents from transfer trauma, but also to keep the 92+ nursing home employees employed. A public hearing scheduled on March 6, 2012, and completed in May 2012, revealed that the Mayor of Calais wanted to pursue options of purchasing the nursing home as a public entity because the closure of the facility would be devastating to the city. During the hearings, DHHS Director Ms. Mary Mayhew stated that the town could receive grant monies from the U.S. Department of Agriculture, Rural Development program, and seek other grant and investor monies in order to purchase and operate the facility. However, the Mayor stated that the City of Calais was not in a strong enough fiscal position to leverage the funds needed for an immediate takeover of the facility on such short notice.

After the March 6th hearing, Mr. Bowden was quoted by the media as saying the Calais nursing home was losing approximately \$81,000.00 a month. As one can imagine, if any nursing home business is losing approximately \$927,000.00 annually, it would be extremely hard to keep the nursing home open. However, in an April 2011 public hearing, Mr. Bowden was quoted as saying that the Calais nursing home was actually losing approximately \$270,000 annually.

Regardless of fiscal quotations or misquotations, the nursing home that was slotted to close July 6th, 2012 actually closed June 21, 2012. The reason for the early closure was that the residents found and moved to their new homes earlier than scheduled. This writer wonders if family members and residents, being shocked by the closure announcement, panicked at the thought that the only licensed nursing home in and around Calais (30 mile radius) was closing. Facing nursing home occupancy rates in Washington County of above 95% on any given day would compound the anxiety to make any deal with nearby nursing homes, sending Mom and /or Dad to any local facility – now! - instead of chancing that the next open bed might be 2, 3, 4, or 5 hours away rather than just a 30 to 45 minute drive.

Speaking about residents and family members jumping at the chance to move, did anyone (advocates, legal aid, and regulators included) enforce the national nursing home discharge and transfer law protecting residents from involuntary discharges and placements? Were residents’ treatment plans and needs dutifully reached and known to exist upon discharging to their new facility? Or, did panic set in and the rules that bind such elder protections go unnoticed due to lack of long-term care options and non-enforcements of civil rights?



As it stands today, December 10th 2012, neither the Calais City Council nor the Mayor has addressed the nursing home issues that they so adamantly sought to protect in July. There has been no mention of a stakeholder committee formed to seek options of reopening the nursing home or seeking to protect elder residents within the city limits against the same fate – closures of assisted living and independent living facilities - the only facilities left outside of the family home to care for the elderly and disabled population.

*We hope to see this community find a way to reopen a quality nursing home in this area.*

## And From the District of Columbia

Washington, D.C. has a total of 19 nursing homes. One of these, the Jeanne Jugan Residence, has attained the highest Center for Medicare & Medicaid Services (CMS) 5-star rating with 5-stars in all listed categories, far above average. Our sincere and heartfelt praise for this wonderful achievement!

Other nursing homes with a 5-star overall rating on December 23, 2012 are Knollwood HSC, Lisner Louise Dickson Hurthome, the Methodist Home, Sibley Memorial Hospital Renaissance, and Unique Residential

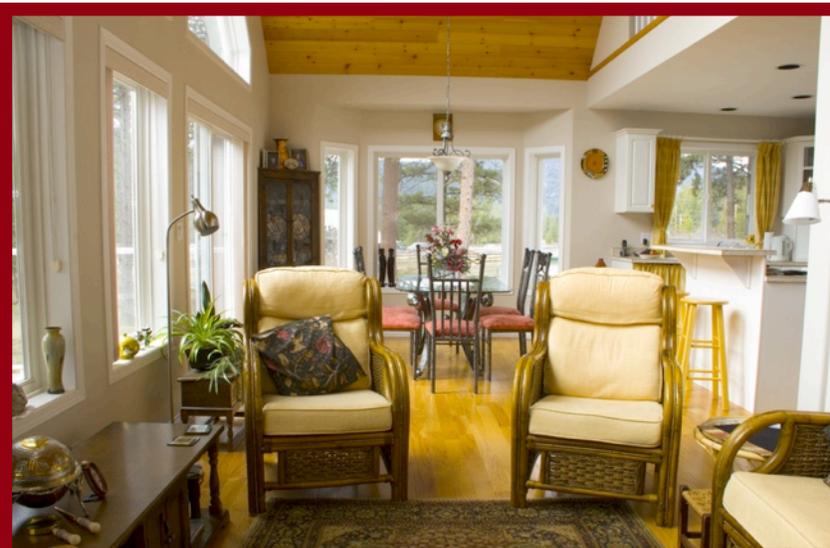
Care Center. Our congratulations to these homes also.

At the bottom of the list are two nursing homes with just 1-star ratings, far below average. Those are Deanwood Rehabilitation and Wellness Center and United Medical Nursing Home. The Deanwood facility, which has had a tarnished reputation for a number of years, lists just one owner, Efraim Rooz with Willistine Page as the Managing Employee. United Medical Nursing Home is a non-profit. Members of the Board of that facility are listed on the

CMS website as Eugene Adams, Steve Barron, Frank Delisi, David Gagan, Robin-Eve Jasper, Andrew Richardson, and Leonard Smith with Derrick Hollings as the Managing Employee.

We also want to congratulate the District of Columbia Ombudsman Program for being one of the few in the country that has managed to obtain the funding and the authority necessary to allow ombudsmen to provide services for people moving out of nursing homes into in-home and community-based care.

*Moving from this.....to this is difficult*



*"Our current level of skilled-nursing health care for the aged has not worked. Historically, government regulators have focused on health and safety. But, what about satisfaction, service, and quality of life? These are equally important in a place you plan to call home... As the next generation to require nursing home services, (baby) boomers are faced with the challenge of redefining long-term care... We need a social revolution... We need to reawaken the political clout used so well forty years ago and force the long-term-care profession into a consumer-oriented, user-friendly, service-driver industry. The choice is ours."*

*--Stella Mora Henry, R.N, Nursing Home administrator, author of The Elder Care Handbook*

## What has Voices done in 2012?



### Filed complaints with

- The Maryland licensing and survey agency the Office of Health Care Quality
- The Center for Medicaid and Medicare Services
- The Maryland Board of Examiners of Nursing Home Administrators
- The Florida State Ombudsman Program
- The District of Columbia Ombudsman Program
- The Maine Ombudsman Program
- The federal Administration on Aging

### Responded to and provided assistance for 96 helpline callers

#### Provided volunteers to represent Voices on

- The Maryland Nursing Home and Assisted Living Oversight Committee
- The Maryland Ombudsman Stakeholders Group
- The Maryland Advancing Excellence LANE
- The Center for Medicare and Medicaid National Partnership to Improve Dementia Care initiatives in Maine, Maryland, and Washington, D.C.

Monitored laws and regulations affecting people needing long-term care services in Florida, Maine, Maryland, and Washington, D.C.

### Resident & Family Councils

- Volunteers attended meetings
- Provided assistance to Family and Resident Councils
- Provided assistance to family members wishing to start a Family Council

Worked with individuals moving out of nursing homes into in-home or community-based settings

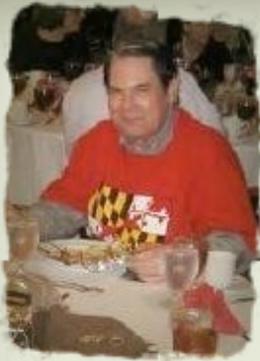
Sent volunteers to groups providing feedback to the federal Center for Medicare and Medicaid Services

Worked with advocates in many states and on the federal level in an effort to make all Ombudsman Programs independent of political interference and able to comply completely with all federal regulations and laws

#### Voices is a member of

- The Coalition for Quality Care
- The Assisted Living Consumer Alliance
- The Consumer Voice
- Maryland Association of Non-Profit Organizations

Provided volunteers to serve on the Steering Committee of the Coalition for Quality Care and the Policy Committee of the Assisted Living Consumer Alliance



*We lost Bob Bronaugh this year. His sudden death in July was a shock to all of us. Bob was a strong and steady long-term care advocate for many years, a Voices for Quality Care Board Member and volunteer since 2003, and a good friend to many of us. He was particularly active in our research projects and was well known across the country for his ability to find facts and connections on most any long-term care topic. He supported Voices as an active volunteer giving both time and funding. He devoted many hours working with callers to our helplines looking for assistance with long-term care issues. His passing leaves a large void in Voices for Quality Care operations. We miss him.*

## From the Treasurer —

It's the time of year when some of you are looking at your expenditures for the year, thinking about those things called taxes, and wondering if there's some way that you can get rid of just a little bit of taxable income so that this, that, or the other rule will fit with your income as you understand it. Voices for Quality Care is here, and we can use your tax exempt gift. It will help reach out to people who want to call us to ask questions, people who are looking for help solving a long-term care issue. If you can spare a gift for Voices at the end of the Christmas buying season, please send it to us at PO Box 2251, Leonardtown, Maryland 20659 or to my personal address which is 40502 Port Place, Leonardtown, MD 20650. If you prefer to use a credit card, you can use the donor button on the Voices for Quality Care website.

Thank you for thinking of Voices.

Clare Whitbeck

Treasurer

## From the Chair —

This has been a busy year for all Voices volunteers. Calls and emails to our helplines have increased. Our work has expanded to Maine and Florida in addition to Maryland and Washington, D.C. We spent far more time this year sorting out the issues facing people who are now taking advantage of the Medicaid Waivers and Money Follows the Person programs that allow people to move out of nursing homes and to receive long-term care services and supports in home and community-based settings. The problems here, when they occur, have been exceptionally urgent for us since in most states, these people are not entitled to assistance from Ombudsman Programs. Fortunately, more volunteers have joined us. Still, we are continually scrambling to meet all of our obligations. We seriously need your help and your support if we are to continue this most necessary work. Join us.

Happy Holidays.

Kate

## Board of Directors

**Kate Ricks — Chair**  
**Position Open — Vice Chair**  
**Clare Whitbeck — Treasurer**  
**Jackie Anderson — Family Council Committee Chair**  
**Susan Eddy — Editor-in-Chief**  
**Anna Spinella — Florida Liaison**  
**Jerry Kasunic — Maine Liaison**  
**Bernadette Brown — Prospective Director**  
**Lorrie Van Akkeren — Prospective Director**



Voices for Quality Care (LTC), Inc.

<http://voicesforqualitycare.org>

[voiceshelp@voicesforqualitycare.org](mailto:voiceshelp@voicesforqualitycare.org)

(888) 600-2375