



Engaging Aging

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Walking One Another Home

by Sister Paula Cooney, IHM

"I vow to God, as a member of this Religious Community..."

In some variation of these words, we, as women and men religious, made a commitment to be with one another in this journey we call religious life. As I look back at that moment in my own life, I certainly was conscious that I would be praying, ministering, and living with members of my IHM congregation in the years ahead. Even though I was aware of there being older sisters, it was not in my frame of reference that I would be an elder myself. I did not consider that I would be called on to be for others in ways of friendship and support that would demand so much. Now, having a friend diagnosed with Alzheimer's, I have awakened, as have many others, to a call for the deepest meaning of friendship.

Alzheimer's Disease takes from us the person as we have known her for many years even though she is still physically present. This can leave us feeling very much alone and even abandoned as we experience our friend leaving us a little more each day. Not even the bond of our friendship can stem the tide of this relentless disease. How do we move forward and live with our friend in this journey? ***I would like to share some of the ways that I have found to be successful.***

- Acknowledge the changes and ask for help. Denial can be the greatest barrier to supporting your friend. Encourage him or her to get a full assessment at the earliest signs of change. This can give her ways of maintaining her strengths and continuing to live with the disease.
- Find support for yourself. As in the instructions when you fly, "Put the oxygen mask on yourself first." The Alzheimer's Association has much to offer. Find others in your own religious community with whom you can share your feelings and learnings. This is a special gift we can give one another.
- Learn the ways of "being with" that fit your friendship. Learn to listen to what is being said. She is always trying to communicate! (Continued on Page 2)

The people who walked in darkness have seen a great light;

Upon those who dwelt in the land of gloom a great light has shown.

You have brought them abundant joy and great rejoicing.



Isaiah 9:1-2

Sister Paula Cooney, a member of the IHM Sisters of Monroe, Michigan, currently serves as Administrator of Regina Residence, the retirement facility for the Sisters of St. Joseph of Orange, CA



Walking One Another Home (Continued from Page 1)

- Share her story with the care-support team. Her quality of life will be greatly enhanced when she is known. What ministries has she been involved in? What does he enjoy doing in his free time? What gives her joy? What would she choose not to do? Gather pictures – labeled so others can share them as well.
- Focus on the strengths that remain. Include her in the activities she is able to participate in and enjoy. As an example, perhaps she never missed a community gathering. Stop for a moment and ask: Do I want her there for me or for her? Sometimes that is a painful question to ask, but as friend, you are her advocate in making some decisions others may not understand.
- Rejoice in the “windows” that allow you to see her as she has always been. Laugh! It may be a knowing look, a smile, a few words put together that make sense.
- Be ready to celebrate his life in its fullness when the time comes. In many ways you hold the story that needs to be told. Include the whole of the journey – this last leg of it as well. It is all grace!

One of the most effective approaches to Alzheimer’s care for professional caregivers that I have found is based on the work of Virginia Bell and David Troxil, ***A Friend’s Approach to Alzheimer’s Care***. The authors emphasize that the caregiver must be trained to be in **RELATIONSHIP** with the person with Alzheimer’s Disease in the manner of a friend walking with a friend. This is the gift that we have been given and is ours to share with others.

I would like to share with you a journal reflection, “Passion,” (see below) written by one of my Monroe IHM sisters who has journeyed with many of our members with Alzheimer’s. It spoke to me. I trust it will to you as well.

Passion

Deep within I experience

the loss

the fear

the unknowns of another’s soul.

My eyes see

the glaze

the brokenness

the tears

My hands feel

the squeeze

the holding ons

the comfort they bring

My feet walk

the steps

the unfamiliar halls

the endless journeys

My heart aches

questions

cries

And

My soul

transforms it all

into gifts of love

trusting friendships

priceless treasures



By Marge Fogarty, IHM

Palm Sunday, April 9, 2006





The Delicacy of Speech and Action

**by Sister Anne Frances Klein, OP, Registered Nurse
Nashville, Tennessee**

She thrust the covers aside and a stiff arm forced its way from under the quilt. "I need to find my room...no, you don't understand... I need to find my room." "Sister," the nurse responded, "you are in your room, and it's not time to get up." As the quilt came back over her body, Sister screamed, "You are killing me."

Such alarming words may shock caregivers who help religious brothers or sisters suffering from dementia or Alzheimer's disease. This uncharacteristic behavior from someone you have known and loved throughout your religious life requires a response with delicacy of speech and action, one that can bring about true healing.

First, generalized distress may point to a specific discomfort. Often the sister or brother cannot verbalize the specific problem; rather, he or she demonstrates a more universal disquiet. For example, while sitting on a chair, a sister became so agitated that the caregiver feared she would fall. The sister moaned and thrashed about. The nurse asked the sister what was wrong but she only continued to yell, "No! No, please...I can't!" After observing her hands grasp the seat, the caregiver realized there was a small piece of velcro against the sister's skin. Sister had no way of verbalizing the specific discomfort; instead, that discomfort had become a universal malaise. If the velcro had not been removed, it might have led to a dangerous situation for the patient or the nurse. With this type of keen observation one may prevent generalized distress in a sister or brother.

Identifying specific problems also helps caregivers to enter a person's world of suffering. For example, changing an incontinent person with Alzheimer's disease during the night may induce a state of delirium. One sister in this situation thought robbers were entering her room, and the sight of the caregiver approaching her bed increased her distress. Because the sister had lost the ability to reason, pulling her into a rational world would only cause more harm. Instead the caregiver entered the world of her suffering and pressed the call button. When a second nurse came in, they both played the "robber game," saying, "You get out of here and leave her alone!" The first caregiver then left the room, while the other reassured the sister, "They are gone. Now, may I help you put on something dry?" Though this may seem overly imaginary and even dramatic, this world of robbers is nonetheless real and threatening to the suffering individual. Living in that world with the other, and enabling her to take some measure of control may bring about greater peace of heart.

Finally, caregivers need to develop a sensitivity to the emotions which may surface in seemingly disjointed conversations. Often nurses and loved ones become distraught when people suffering from Alzheimer's disease converse. Their thoughts seem fractured and nonsensical. In these cases, one must separate the specific confusing details from the generalized emotion that surrounds the conversation. Emotions such as anger, envy, resentment and control may indicate an immediate difficulty. Frequently people with Alzheimer's disease avoid taking a bath for fear of being sucked down the drain. Small interventions such as reassuring the person and covering the drain with a plastic piece often help. On the other hand, forcing the person and not addressing his or her fear could cause anger towards the caregiver who is trying to keep the person clean and comfortable.

Although it may seem a daunting task to care for religious brothers or sisters with dementia or Alzheimer's disease, the rewards are immeasurable when one enters their world of suffering by identifying specific problems and emotions. Finally, reception of the sacraments, priestly blessings, and the use of sacramentals such as holy water, heal on a level unknown to us, especially when a religious brother or sister has a difficult time expressing the problem.

A Personal Journey

by Sister Barbara Schlatter, CPPS, St. Louis, MO

Both my parents died of Alzheimer's disease...

Small signs... As I look through their things, I see signs of Mother's dementia when she was seventy. A good cook, she liked to list in a notebook what she served company so that she wouldn't repeat the same meal when they came again. In that notebook I see the progression of the disease: her handwriting getting shaky; her sentences unfinished; and her script no longer staying on the lines.

Taking its toll... Caring for Mother took its toll on Dad. Because the piles on his desk always looked neat, I thought he was keeping up with financial matters. But when I looked through the piles, I saw there was little order in the stacks; he wasn't getting some bills paid and once had the electricity turned off. So I started taking care of his bills. He was losing weight. Finally his doctor told him he would die before my mother if he didn't put her in a nursing home.

Placement... We found what seemed like a good facility a short distance from their home. In 1990, as Dad and I left Mother at the nursing home, it felt like we were abandoning her. Dad visited her every day and did her daily laundry. I saw her weekly and once a week ate dinner with Dad. Although it was a relief to have Mother receiving 24 hour care, I felt guilty that I wasn't doing more for her or for Dad. I continued my full time high school teaching.

Surprises... As Mother lost her ability to speak and to recognize some people, she still surprised us with what she could do. During one of her last visits home, I sat down with her on the organ bench and placed her hands on the top rank. I started playing one of her favorite songs, "I Left my Heart in San Francisco," on the second rank. For several lines of the song, her fingers remembered how to play along.

Holy moment... Mother was always a gentle woman. She continued to be so at the nursing home. On a visit, I saw her standing with three women, all probably suffering from Alzheimer's disease. From a distance, none seemed impaired as they were involved in a lively conversation. As I got closer, I realized all of them were speaking gibberish, but each waited for the other to finish speaking before she replied. All of them nodded and made facial expressions to acknowledge the other's contribution to the "conversation." It was a holy moment.

Letting go... As Mother's condition worsened, she ate less, forgetting even how to swallow, but still hung on. Dad and I told her we would miss her, but that it was all right if she wanted to die and be with God. She still held on. My brother in Colorado had last visited her about a month previously. I wondered if she were waiting for him. I called him on the phone and held the receiver to her ear. I could hear him say, "It's OK if you go, Mother. I'll miss you, but you can be with God." I could tell that she was hearing something, but she made little other reaction. Within twenty-four hours, however, she died. That was 1993. (Continued on Page 5)



(EDITOR'S NOTE: Responding to our invitation, Sr. Barbara submitted a brief article describing her experiences of having both parents diagnosed with Alzheimer's Disease. Sister also included some journaling regarding her experiences. With her permission, we have opted to share with you her more personal journal entries. We found these words to be both powerful and grace-filled. We are grateful to Sister Barbara for her courageous humility as she welcomes us into her personal journey.)



A Personal Journey (Continued from Page 4)

More changes... Dad continued to live alone at home, but gradually needed more help. In 1995 an auto accident placed him in need of nursing care, so he went to the same care facility where my mother had been. After a year, Dad agreed with my brother and me that we should sell his home. I had always thought this would be a difficult process, but Dad made it so freeing. With many items we showed to Dad, he said, "Sell it." Had he not given this "permission," I would have felt duty bound to save the chair he had sat in, the bookcase he and my mother had purchased, etc.

Denial... The doctor was convinced my Dad had Alzheimer's disease. I disagreed. In conversations as I pushed his wheelchair, he asked about my teaching and showed interest in my activities.

Losses... While Mother had remained gentle until her death, my usually gentle father did not. I suspect the losses overwhelmed this man who had rarely expressed strong emotion. He had lost his wife, his home, his privacy, his mobility. Confined to a wheel chair, he depended on others to bathe, change, and clothe him.

Sacred space... We attended Sunday Mass together. Since he had lost his hearing aid, I would point out the words of the prayers in the missalette. Sometimes he would fall asleep, but he always woke up for Communion. I felt privileged to worship with this man who had been so faithful in his own parish.

Farewells... I would come to see Dad every Wednesday at suppertime, and it became evident that he needed more help with eating. Gradually, he, like my Mother, found it difficult to swallow. Like her, he lapsed into a coma. My sister-friends gathered around his bed, singing his favorite hymns, as he died in 2001.

Research... Both my mother and dad had been part of the Memory and Aging Project (MAP), an Alzheimer's disease research project connected with Washington University School of Medicine in St. Louis. Mother and Dad donated their brains to MAP at their deaths, and autopsies indicated that both of them had Alzheimer's disease.

Decision... At Dad's death, I, too, became a participant of MAP, with my friend, Sister Toni, as my partner. I am involved in an Adult Children's Study designed to detect the earliest signs of AD in those at possible higher risk for the disease. I participate in regular assessments of my mental abilities, PET scans, MRIs, and lumbar punctures.

Challenges and gifts... I have had temporary adverse reactions to the lumbar punctures. I have been embarrassed when I could not answer some of the questions that test my memory. But if I have the disease, I want to contribute whatever I can to research. MAP has made great strides in identifying markers of the disease.

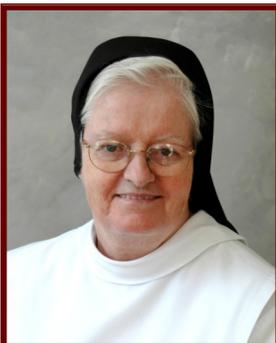
Questions... Since both my parents had AD, I presume I am more at risk. When I turned 60, I recalled that my mother's disease was evident at age 70, so I asked myself, "What will I do with what might be my last alert years?" Whenever I forget something, I become anxious, thinking, "Is this the start?" I worry about becoming involved in some ministry that might extend into a time when I will start losing my abilities.

Hopes... I try to remember that God made me who I am, and I want to return everything to God, but I am always reminding God that returning it little by little does not hold great appeal. I have not yet been able to say with total conviction the words of St. Ignatius, "Take Lord, receive, all my liberty," especially the words, "my memory and understanding." Throughout my life, however, I have found truth in the words of Theodore Roethke...

"I learn by going where I have to go."



Criteria for Accessing Dementia Services



The Dominican Sisters of Mission San Jose make every effort to keep sisters with dementia at our Motherhouse, in St. Martin's Residence, so they can maintain their friendships with sisters and staff, and be constantly monitored.

**Sister Mary Jarlath, OP,
Director of Health Services**

In collaboration with the Sisters of the Holy Family in Fremont, California, we

entered On Lok Lifeways, a Pace program, in 2002. Two generous grants from the National Religious Retirement Office allowed the two communities to bring about renovations needed to facilitate this new program that has proven to be a great help to both communities over these six years.

Initially, the nursing staff notes the most common signs of dementia: inability to recall daily activities; keeping extensive lists; forgetfulness; loss of memory; inability to recall names of people they live with; confusion in dressing; inability to follow two or three step directions; and repetition of questions in a short time frame. The next step is diagnosis by On Lok Lifeways and community professionals.

In order to determine the condition of each sister, observation by the medical staff as well as the diagnosis by the sister's doctor would indicate that she suffers from dementia. A sister may be tested by a psychologist, undergo a brain scan, and be closely observed by trained geriatric professionals.

Throughout the days when sisters are beginning to show signs of dementia, much care is taken that the sister is guided appropriately to the local resources that can be helpful. An alert and caring staff strives to see that every sister receives the help she needs. Since we are not a large community, this is not as difficult as it might be. The community also belongs to the Alzheimer's Safe Return Program which helps to ensure that sisters who wander off the property are returned safely.

The Marianists in the Dayton service area who retire to assisted living and nursing care live at Mercy Siena, a public facility operated by the Sisters of Mercy. When a brother needs special dementia care the decision is made in consultation with the nursing staff and our own support team.

Criteria factors for placement include safety, socialization, and personal dignity. Often, interventions can be accomplished without having to permanently transfer a brother to the dementia unit. For example, he may be "day cared" to participate in social programming, or be assisted with his meals in a special dining room. Otherwise, he is able to remain with his community.

Furthermore, as the brother progresses through the stages of dementia and his behaviors are modified, he may return to his room in assisted living or be placed in the nursing home as close to his Marianist brothers as possible.

In the event that a brother is moved to the dementia unit, he is still brought to daily Liturgy, attends monthly community parties, and is taken out to eat with the community periodically for as long as possible.

Placement decisions are difficult ones. There is a sense of loss when a brother leaves his community setting, as well as a strong concern about preserving his Marianist identity in a lay setting. But there is also a sense of relief if we are able to provide safety, better socialization, and proper stimulation to meet his particular needs.

Grief is a big factor in dealing with these decisions. It is very emotional to witness the loss of cognition in such highly educated men who have been leaders in their communities, schools, parishes, and missions around the world. Support staff is available to help brothers address their feelings regarding such changes among their peers.

Overall, the community enjoys the assurance that the best possible care will be provided for its brothers.

**Judy Moehl,
Medical Coordinator**



From the Offices of NRRO...**Sister Janice Bader, CPPS, Executive Director****Brother Robert Metzger, SM, Associate Director of Planning & Education**

As I write this article, we are approaching the Thanksgiving holidays. In reflecting on the months since last Thanksgiving, I realize there is so much for which to be grateful! One of the blessings for which I am particularly grateful is the arrival of Brother Robert (Bob) Metzger, S.M. as a member of our staff. Brother Bob is a member of the Society of Mary (Marianists) and has been one of NRRO's volunteer consultants for nearly twenty years. He is a wonderful addition to our very dedicated staff of five persons.

Brother Bob has taken on the job that I held prior to being named Executive Director. As the Associate Director of Planning and Education, he will be over-seeing the publication of *Engaging Aging*.

I am happy to place this responsibility in his very competent hands. I know that both he and Sister Sherryl, our editor, will continue to welcome your suggestions of topics that you would like to see addressed in future issues of this publication.

Welcome, Brother Bob. May this be just the beginning of a growing friendship between you and the readers of *Engaging Aging*.

As I write my first article for *Engaging Aging*, many thoughts have crossed my mind. The first is that it is only a few days before Thanksgiving and I am thinking of all the people for whom I am thankful this year. I think everyone will join me in giving thanks to all those who have given so generously to the Retirement Fund for Religious over the last 20 years. Because of their kindness, NRRO has been able to distribute more than a half billion dollars to religious institutes throughout the United States for their elderly members. Another group of people to whom I am very grateful are the many people, both religious and lay, who have volunteered as financial, eldercare and leadership consultants to religious institutes all over this country. The consulting service actually began several years before the first collection took place in our parishes and has probably helped religious institutes as much as the money raised during the last 20 years.

Another of those thoughts that has crossed my mind is that we are nearing the 21st collection of the Retirement Fund for Religious. Our country is in the midst of the biggest economic problems that most of us have seen in our lifetime. Yet we will have the annual collection and, with the grace of God, anything we collect will be considered a special blessing. Let us continue to pray for the success of this national collection.

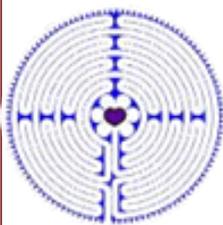
One of the ways we try to assist communities is to offer educational programming. An upcoming program is *Person-Centered Care Essentials Training Conference*. This program trains two people from each institute to educate their own staff in the principles of person-centered care. The program is being offered in Baltimore on February 18-19, 2009 and in Chicago on April 15-16, 2009. A large grant from the Retirement Research Foundation allows us to offer this program at no charge. Each institute needs only to pay their own travel and accommodations. If your congregation is more than 50% unfunded for their past service liability, NRRO will also assist you in paying for these expenses as well. The brochure and registration form can be found on our website: www.usccb.org/nrro. Click on the link "Upcoming Workshop."

A final thought is that this edition of *Engaging Aging* will be sent out early in the Advent Season. Be assured of the prayers of the Retirement Office staff for you and your communities during this blessed Season. May the birth of Jesus bring you much peace and joy.



From the Editor's Desk

Sister Sherryl White, CSJ, Ph.D., Psychologist, Pittsburgh, PA



As we grow older, loss of recent memory is not unusual. We find ourselves unable to recall the names of people we just met, where we put our keys, or what we had for breakfast. Remote memory, however, excepting any disease process, generally remains unaffected by aging. We are able to revisit the distant past, reflecting on the twists and turns of our life journey, reveling in its wealth of meaning and mystery. It is as if we are released from the trivial details of the present and invited into a depth of wonder and awe.

While preparing this issue of *Engaging Aging*, I found myself drawn into just such a memory. It was a winter day, much like this one; overcast and cold. I was facilitating an Advent retreat, watching participants prayerfully, carefully walking the path of a labyrinth traced upon the floor. The light was low, the music soft, the moment perfect.

Suddenly, the doors of the room burst open and a Sister entered, exclaiming, "How wonderful!" With a widening smile and uplifted arms, she stepped onto the maze and began twirling about, ignoring the rubrics of ritual imposed upon the prayer. No one moved to stop her or to correct her dance of wonder. They simply drew in upon themselves more tightly, shutting out the "chaos" she created.

Eventually, the music ended and the dancer of delight went on her way. "What was that about?" asked a retreatant, clearly irritated. Barely able to speak, I replied,

"Alzheimer's Disease. She was diagnosed yesterday." For all of us, the time of seeming "chaos" became a moment of mystery, an invitation into the profound depths of life beyond our understanding.



For the next two years, I journeyed with that sister as her spiritual director. In the midst of losing her memory, language skills, ability to walk, eat, and even swallow, she was the one who became the giver of gifts. There was, in her, the presence of Presence, of Divine Mystery. She came to embody for me the Mystery who challenges and calls us all to the absurd – to surrender, emptying, humility, dying, and love beyond all cost. This Presence mandates that we cross those defining lines of societal success, control, power, and propriety to risk the dance of wonder and awe.

As you read these pages of *Engaging Aging*, I hope you will take the extra time to look between and beyond the lines of the articles. Listen to the wisdom, expertise, and compassion of our authors. Look beneath the nervous laughter of those self-proclaimed "senior moments" we all experience. Listen to the thoughts and feelings that rise within your own minds and hearts as you contemplate the lives of those who carry this diagnosis.

Especially in this season of miracles, when humanity is gifted with salvation in the form of an infant, may we hold ourselves open to the invitations of grace beyond our understanding. May all be well. May the blessings of these holy days of Advent and Christmas be yours.



Merry Christmas & Blessed New Year

From the Staff of the National Religious Retirement Office

*Seated: Mrs. Monica Glover; Brother Robert Metzger, SM;
Standing: Mrs. Jean Smith; Sister Janice Bader, CPPS;
Brother Henry Sammon, FMS, JCL*

Mark your calendars. . .

2008

December: Special Assistance and Supplemental Grant Distribution

December 13-14: Retirement Fund for Religious National Collection



2009

January 5: Direct Care Assistance Application Forms for 2009 Mailed to Treasurers of Religious Institutes (and also available online at www.usccb.org/nrro)

January 16-18: Planning and Implementation Workshop, San Antonio, TX

February 18-19: Person-Centered Care Essentials Seminar, Baltimore, MD

March 15: Direct Care Assistance Application Forms Due at NRRO

April 1-3: Planning and Implementation Assistance Workshop; Chicago, IL

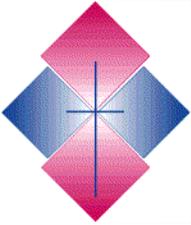
April 15-16: Person-Centered Care Essentials Training Conference; Chicago, IL

June:
Distribution of Direct Care Assistance
Distribution of Planning Assistance
Distribution of Implementation Assistance



Direct Care Assistance Goes “Electronic” at NRRO By Brother Henry Sammon, FMS, JCL, Associate Director

For the past year and a half, the staff at NRRO has toyed with the idea of revising the Basic Grant Application and at the same time making it internet accessible. Needless to say this was not as easy as we thought. To maintain the integrity of our database, any changes had to be carefully thought out to their logical conclusion. We are happy to report that we finally succeeded with the help of very talented programmers. Beginning in 2009 the application will be e-mailed to all institutes that have e-mail addresses in our database. It will also be placed on the NRRO website. The application has been renamed the Direct Care Assistance Application and we have attempted to make the application less daunting to complete. Many of the mathematical calculations will be automatic and error messages will appear if you input some data incorrectly. We have also imbedded in the application “prompts” to aid you in answering the various parts. Paper application will still be mailed to those institutes that either do not have computers and/or access to the internet. If an institute does not have internet access but does have a computer with Microsoft EXCEL, please let us know and we can send you the application form on a CD. Any feedback once the applications are distributed would be greatly appreciated by the NRRO staff.



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The National Religious Retirement Office coordinates the national collection for the Retirement Fund for Religious and distributes these monies in grants to eligible religious institutes for their retirement needs.

The National Religious Retirement Office supports, educates and assists religious institutes in the U.S. to embrace their current retirement reality and to plan for the future.

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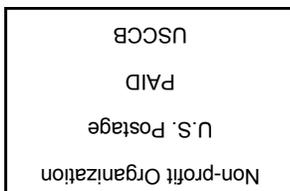
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