

### SOARRING A Publication of Mennonite Home Communities

# UNDERSTANDING DEMENTIA Dr. Leon Kraybill discusses the facts.

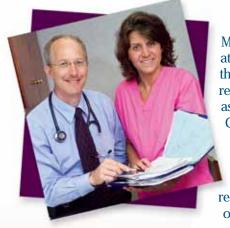
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**Dr. Leon Kraybill, CMD,** pictured with LPN & Team Leader Physician Nurse Dalynn Miller, is a native of Lancaster County, growing up on a farm in Elizabethtown. He attended Lancaster Mennonite School, Goshen College, Temple Medical School, and the Lancaster General Family Practice Residency. After 15 years of family practice, he returned to training in a geriatric fellowship with Lancaster General. He currently works as a geriatrician with Geriatric Associates. He is Medical Director for Mennonite Home Communities, and provides care for about 180 of the Mennonite Home Residents.

Dr. Kraybill has received a 2004 Quality Initiative Award from the American Medical Directors Association for research in geriatrics. He has focused his research on residents with dementia and ways to respond to behavioral problems without medication. He recently completed the data collecting portion of the study for some of the residents of Rosevue 3 at the Mennonite Home.

## Remembering, Reminiscing, Supporting, Walking and Honoring are all words that describe two important events of Mennonite Home Communities (MHC). Many of our residents struggle with the heart-wrenching condition of Alzheimer's disease and other related dementias.

At the Alzheimer's Support Group, held at 7:00 pm the fourth Monday of each month in the chapel, families of those suffering with Alzheimer's disease and dementia can receive and give support. Educational opportunities are available as speakers come to share their experiences and knowledge.

At the annual Alzheimer's Memory Walk, held at 9:00 am, Saturday, October 22, 2005, MHC, has the privilege of being a platinum sponsor. In addition, we need families and friends to walk and raise funds with our Mennonite Home Communities staff team to fight the terrible disease of Alzheimer's though research and education. All monies raised benefit the Alzheimer's Association.

Contact Treva Bollinger, Director of Social Work, at 393-1301 for more information about either of these wonderful opportunities.

## THE FINANCIAL IMPACT OF ALZHEIMER'S

by Greg Pierce, Director of Development

Most people are aware of the potential impact of Alzheimer's disease on a family. The financial impact on the organizations providing care is also enormous. It will only get worse; the Alzheimer's Association reports that 4.5 million Americans now have the disease and this number will double by 2025,\* Furthermore, nearly half of those over 85 years of age are affected!\*

As a volunteer dining assistant on Rosevue 3 (a specialized care floor for Alzheimer's and other dementias), I have seen the intensity of the care required by these residents. Alzheimer's residents have an expected average length of stay of over four years,\* about double that of other residents.\*

The cost of the required care may approach \$350,000, based on national averages. The duration of care forces many Alzheimer's residents onto Medicaid, where reimbursements cover only part of our costs, leaving MHC with a shortfall of over \$70 per day. Ideally, benevolent donations would be available to cover this shortfall.

Alzheimer's families value the commitment of Mennonite Home Communities to provide lifetime care, regardless of their financial resources. One resident stated: here because of the assurance of continuing care in a Christian environment. When Alzheimer's disease struck, we were devastated emotionally and physically. My spouse now requires health care, but I don't worry about the financial aspect because of the benevolent care fund. Nobody knows when they may be relying on that assurance of continuing care.

Collectively, the friends of MHC can help us address this problem. Memorial gifts and contributions to the annual campaign directly support our benevolent care fund. The development department helps donors to determine the most tax-efficient forms of gifts and bequests. Donors frequently achieve increased income during their lifetime, while gaining the satisfaction of helping others. Please call Greg Pierce, Director of Development, at 390-4903, for a confidential discussion of how you can help.

## MY JOURNEY WITH FRONTOTEMPORAL DEMENTIA

Paul had been the solid ground upon which our marriage of thirty-six years was built. His compassion and caring were combined with a driving ambition to succeed in his work. He became a leader in business and his star was rising, so I was more than surprised when Paul suddenly became detached, indifferent and apparently bored with his work and his recreation. This man, who played tennis like a man possessed, started walking off the court in the middle of games.

His confusion and disorientation made it difficult for him to negotiate social exchanges or activities. When our family doctor was made aware of the changes in Paul, his assessment was that Paul was experiencing depression and anxiety, compounded by an increasing severity of his asthma symptoms. He was consequently treated with antidepressants, anti-anxiety medications and modifications to his asthma regimen.

Nonetheless, the episodes of confusion, followed by exhaustion, continued and accelerated. We were then referred to a psychologist who treated Paul unsuccessfully for six months. As the situation was becoming more distressing to me, Paul was becoming more withdrawn and apathetic. After termination from his third job in twelve months, I persuaded him that something was terribly wrong and that we should request an MRI to eliminate the possibility of a brain tumor. That decision eventually led us to Dr. Clark at a memory disorder clinic in Philadelphia.

After sixteen months of incorrect and misleading medical assessments, we

Grandson Michael, Paul & Ann Palmer, granddaughter Anneliese and family pet Henry learned that Paul had Frontotemporal Dementia (FTD), that he would likely die within two to ten years and that the disease was untreatable. Paul was fifty-six years old.

Through the advice of many caring people, I was encouraged to quickly apply for social security disability, find an attorney specializing in elder law (to create an estate plan, a living will and a power of attorney), hire a financial planner and work with our pastor to plan Paul's memorial service while he could still contribute his own thoughts on the matter.

I had resolved to care for Paul at home, but as his care needs increased, I found that in order for me to return to work for supplemental income and insurance, I needed to enroll Paul in an adult daycare program. Not long after this, Paul began to lose his ability to discriminate between food and pictures of food — he would sometimes attempt to cut and eat pictures of food in magazines, eventually eating anything resembling food such as gladiola bulbs and clay pots. His language skills began to deteriorate and he was soon incapable of responding

to questions. Paul's sleep patterns became erratic and he would frequently pace the house in the dark of night.

After many missteps, I brought Paul to the Mennonite Home and finally have the peace of mind that Paul is in a safe place with creative and loving people. An early diagnosis is almost impossible to come by, but it is so critical with this disease. It is essential to the preservation of financial resources, obtaining care information, networking with FTD care groups and, most importantly, enjoying what time you have with your loved one.

To learn more about FTD read Lisa Radin's "What if it's Not Alzheimer's" and visit www.aftd.com.

There is a free caregiver conference sponsored by UPenn and the Alzheimer's Association on November 11. Seating is limited so reservations should be made early through the Alzheimer's Association of Delaware County. Ann will be attending and has offered to provide transportation to anyone wishing to attend with her. She can be contacted at Eloisepa@aol.com



#### WHAT IS DEMENTIA?

Dementia is the term used by the medical field to describe a significant decline in two or more areas of brain functioning. Memory loss is the area most commonly identified, but changes can occur in language, judgment, abstract thinking, mood, personality or initiative.

The term dementia replaces outdated terms such as senility or organic brain syndrome. The diagnosis of dementia does not imply that there is psychological illness or that the person is "crazy."

Dementia and aging are not synonymous. As people age, they usually experience such memory changes as slowing in information processing, but these kinds of changes are benign. By contrast, dementia is progressive and disabling, and not an inherent aspect of aging.

Advancements in diagnosis and treatment benefit many people with dementia. Early diagnosis allows the individual and family to appreciate the present and anticipate the future. Depending on the type of dementia, medication may be recommended to help slow the decline. Currently, there are no medications that significantly reverse or correct the progressive decline of dementia.

The diagnosis of dementia can be overwhelming to an individual and their family. The first step is to take a big breath and not panic. You should seek out and work with a physician who is knowledgeable about dementia and its treatment. You should be aware of the many local resources and support networks.

Dementia is a very common medical condition. All of us do or will interact with someone who has dementia. Despite its disabling and progressive endpoint, most people with dementia can live very full and satisfying lives. By educating ourselves and learning about this condition, we will be able to

respond compassionately and appropriately to those around us.

#### Are there different kinds of dementia?

Dementia is the general term describing all types of cognitive impairment. There are numerous different types of dementia. Each type will reveal itself in different ways. In addition, each individual with dementia will experience the condition uniquely. Thus, there is great variety in dementia and each person must be recognized and treated as an individual. Two types of dementia may be present in the same person (mixed dementia).

1. Alzheimer's type dementia is the most common cause of mental decline in older years, accounting for 60-70% of dementia. It typically begins after age 60. It almost always has a gradual onset and a continuous progression. Alzheimer's disease advances at widely different rates. The duration of the illness may often vary from 3 to 20 years. The areas of the brain that control memory and cognitive skills are affected first, but as the disease progresses, cells die in other regions of the brain.

Initially, Alzheimer's disease frequently shows itself with memory loss, disturbances in language and speech, failure to recognize known objects, and difficulties in planning and organizing. Many people with the condition seem to have little awareness that they have changes in these areas. Because of the impaired perception of their surroundings, many people show behavioral changes or agitation later in the illness.

2. Dementia with Lewy Body (DLB) is now thought to be the second most common type of degenerative dementia in older people, accounting for 10-15% of cases. It often is accompanied with Parkinson-like symptoms of tremors, stiffness or impaired balance. There is typically a day to day fluctuation in symptoms. Visual hallucinations are common and sleep is impaired. Severe memory impairment does not necessarily occur in the early stages but is evident in later stages.

Lewy Body dementia frequently responds very poorly to antipsychotic medication, but may respond the best of all dementias to the memory supporting medicines.

- 3. Vascular dementia occurs because of damage to the brain due to lack of blood flow, in the same way that a stroke occurs. Vascular changes may cause 10-20% of dementia. The memory loss typically occurs in an abrupt or stepwise pattern, rather than the steady progression of Alzheimer's. Common symptoms include speech impairment, onesided weakness or paralysis, and emotional fluctuation. Often the individual's personality remains unchanged. Vascular dementia is the one type of dementia that will sometimes stabilize and not progress.
- 4. Frontotemporal dementia (4-20%) is a more unusual type of dementia that often appears at a younger age of 45-60. Early on, it shows personality changes, unusual social behavior, loss of inhibitions, and obsessive actions. Repetitious actions and phrases are common, as well as poor judgment. Bizarre dress, food obsessions, and progressive loss of speech are common.

There are other less common types of dementia. It is not always possible to determine the exact type of dementia in a particular individual. Treatment can be considered without an exact diagnosis. The medical knowledge about these conditions should continue to improve and new treatment options should be released in the future.

- Common and ordinary memory changes
- Changes that may be abnormal

#### Memory

- forgetting a name or telephone number and remembering it later when reminded
- forgetting a close relative's name or not remembering a conversation even when reminded of it
- occasional temporary or minor forgetfulness, i.e. forgetting where you parked the car
- forgetfulness that interferes with daily function, such as how to cook a favorite meal
- using more lists when you go to the store
- unable to shop without a list, even for a few items

#### **Normal Tasks**

- having to redial a phone number because you pushed the wrong button or forgot to include the area code
- requiring numerous attempts to dial a number, or not able to dial at all
- problems with common objects like keys or toaster

#### Language

- stumbling over a word
- unable to name a familiar objects or substituting incorrect words
- need directions written out, rather than verbal
- difficulty following written or spoken directions

#### **Time & Place**

- forgetting the exact date
- not knowing the correct month or year
- temporary disorientation, but able to re-orient quickly
- totally lost in a familiar place

#### **Judgment**

- trouble with minor decisions (what to wear, where to eat)
- dressing inappropriately for the weather, or wearing the same clothes, or placing underwear over the clothes
- misjudgment of a social context
- inappropriate public comments out of character for the individual

#### **Finances**

- harder to organize and pay bills and balance checkbook, but can do with time and effort
- unable to do math correctly or balance checkbook despite much effort or supervision

#### **Misplacing Things**

- misplace wallet, keys or glasses
- putting items in inappropriate places (wallet in freezer), unable to retrace steps

#### **Personality**

- occasional anger or irritability, but subsequent remorse
- consistent change in character or personality
- frustration with self, or criticism of self and society
- suspicious or fearful or paranoid, accusing others of stealing what they have misplaced

#### **Dr. Leon Kraybill, CMD**Geriatric Associates

#### Web Resources:

Alzheimer's Association www.alz.org

Lewy Body Dementia - www.lewybodydementia.org

Frontotemporal Dementia - www.ftd-picks.org





I would like to thank everyone who helped make our June Fest such an incredible success. Members of the Auxiliary put endless hours into the delicious chicken meals. All of our volunteers and staff members really pulled together to create one fantastic and memorable day for everyone in attendance. We sold more than 2,700 chicken halves and made more than \$11,000 from the auctions and other activities. We do not have a total count finalized at this time. We could not have been successful without the generous help of so many businesses, friends, churches, our auxiliary and staff. Thank you, so very much, and God bless each of you!

> - Kathy Maule Volunteer Coordinator



#### 2nd Annual **Sub Sale**

#### **SEPTEMBER 23. 2005**

for the Alzheimer's Memory Walk featuring Turkey and Italian Subs

\$5.00 per Sub

To place an order, please call Erin Leaman at 390-4908

#### **Woodcrest Villa** Annual Craft Fair **OCTOBER 22, 2005**

9:00 am - 1:30 pm **Bluebird Commons** Look for Signs

## THE VOLUNTEER CONNECTION

Charles Eliot, a well known American educator and president of Harvard University, once said, "Books are the quietest and most constant of friends; they are the most accessible and wisest of counselors, and the most patient of teachers." Our featured Woodcrest Villa (WCV) residents could not agree more because their love of books has always played a big part in the lives of Margaret Derstine, Gloria Miller and Ruth Cassel. Our WCV residents, all volunteers for our community library, devote almost 20 hours each week to assure the library is in order and filled to the brim with exciting new bestsellers and the older classics we all love.

Margaret Derstine, a WCV resident for 11 years, started her devotion to literature back in college where she worked in the school library. After graduation, Margaret spent 23 years as a teacher at Locust Grove Mennonite School, followed by 15 years as the school librarian. When Margaret moved to WCV, she "was libraried out" and needed some time to reenergize. After 3 years, her passion for books was renewed and she began volunteering at

WCV's library in addition

to giving tours of the

Biblical Tabernacle

Information Center.

at the Mennonite

When Margaret became involved, our library contained approximately 1,500 books. Today, our two libraries contain a combined 3,100 donated books by WCV residents. Our library also offers 50 weekly and monthly magazines of which some are donated subscriptions. Margaret took on the task of cataloging the library to enhance our check-out system. The outcome has been a streamlined and userfriendly system.

Gloria Miller is a Lancaster native of 72 years with many hours of volunteer time before making WCV her home in 2000. She volunteered in the library at Providence Elementary School for 7 years and spent 14 years on a volunteer basis at the Blind Association in their radio talking library department. In addition, Gloria cataloged her church libraries.

Ruth Cassel has also donated a lot of time in various capacities prior to helping the Bluebird library in 2004. Ruth has served at Hospice, Red Cross, Grandview United Methodist Church, and the Manheim Township Library. A three-year resident of WCV, Ruth also gives her time to the Wellspring Video Library located at the Lancaster General Health Campus.

The time and dedication Margaret, Gloria and Ruth commit to our libraries is easily recognized in the catchy displays which draw you in and clearly show that a lot of care and experience is behind it all. Residents, family members and employees are appreciative of their endless effort.



## Shining Stars

Recognizing employees for the dedication and hard work that is done each and every day to make Mennonite Home and Woodcrest Villa a wonderful place for residents to live.

April



**Mim Leaman** Woodcrest Villa Receptionist



**Sharon Landis** Rosevue Receptionist



**Betty Lou Bitzer** Medical Records Secretary

May



**Jean Arnold** RN Supervisor 11-7



**Dalynn Miller** LPN & Team Leader Physician Nurse



**Sharon Shirk** Restorative Nurse



**Deborah Church** CRA Leader Meadowvue



**Crystal High** RA



**Lisa Howry** CRA Leader Rosevue Ground

#### **Mennonite Home Communities**

1520 Harrisburg Pike Lancaster, PA, 17601

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Mennonite Home Communities Marketing Department, 2001 Harrisburg Pike, Lancaster, PA 17601.

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