



MEMORY DISORDERS CLINIC



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

NEWSLETTER

How Do We Stage Dementia?

by Jennifer Klocinski, MA and Val Cotter, MSN, CRNP

Two common questions asked during a visit to the MDC are 1) what is the stage of my relative's illness and 2) what should I expect in the future? These are important questions that we try to address at each visit. But you don't have to wait for a visit to the MDC to find the answer to these questions. This article is designed to help a person learn where someone with dementia falls in the disease course and gain a sense of what to expect in the near future.

Why is staging dementia important?

Staging is useful because if a patient exhibits symptoms atypical for a specific stage this can alert the caregiver and health care team that there may be a problem other than the underlying dementing illness. For example, an increase in confusion over a period of hours or days may be a sign of infection or the result of a new medication and should be assessed. Staging also allows caregivers to prepare for the next phase in the illness. This has benefits for both the caregiver and the patient. Knowing what's to come can help one cope and lessen the stress of caregiving and help prepare caregivers on what assistance or education they may need to provide better care for

themselves and the patient. Sometimes knowledge actually is power.

What are the stages of dementia?

There are multiple ways to stage dementia and several tools that we use to help us describe where along the disease continuum someone is. We stage dementia in five categories: mild, moderate, severe, profound and terminal.

How do we stage dementia?

Clinicians assess an individual's disease stage by assessing cognition, behavior, and function.

- **Cognition:** This includes multiple domains of which memory is only one. For example, it includes the ability to speak as well as comprehend others, the ability to recognize friends and family, and to exercise good judgment.
- **Function:** This is the ability to perform day-to-day activities including personal care and social roles. These activities are usually organized into two groups, Basic and Instrumental Activities of Daily Living (BADLs and IADLs). A list of these activities can be found on page 3.
- **Behavior:** This is an assessment of personality changes and how a person acts in social situations and at home.

The table on page 2 describes each stage of dementia according to these three areas.

Common tools that we use to make these assessments are the Mini-Mental State Exam (MMSE), Severe Impairment Battery (SIB), Clinical Dementia Rating (CDR) Scale, Dementia Severity Rating Scale (DSRS), and the BADLs and IADLs mentioned before.

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Each of these tools has strengths and weaknesses so a combination of two or more can give a better picture of how someone is doing.

We recommend becoming familiar with the Basic and Instrumental Activities of Daily Living. These are the easiest to assess and most valid measure of severity. The key issue is whether there is a change in the person's ability compared to how they performed the activity before they had cognitive problems. Each activity is assessed as either performed independently, with assistance or dependently. Dementia results in the loss of these abilities. IADLs are more complex than BADLs and therefore we lose the ability to perform IADLs before BADLs. Persons with Alzheimer's disease typically lose BADLs in the reverse order that they gain them in childhood: dressing, grooming, toileting, transferring and feeding.

The following are examples of patients in various stages of dementia:

Mrs. Smith is a 75 year old widow. During a visit to the clinic her Mini Mental State Exam score was 18. She

was unable to give details of her son's recent birthday party. Last week she gave the paperboy \$100. She had trouble expressing herself and jumped from topic to topic. Her IADLs are as follows: she is having difficulty using the phone, can prepare simple meals (e.g. warm soup on the stove and fix a sandwich), and

MMSE (Mini Mental State Exam):

Measures memory, language and praxis
 Scores range from 0 to 30
 As the score declines impairment increases.
 Useful cut-off scores are :
 Mild = >19; Moderate = 12-19; Severe = < 12

her daughter balances her checkbook and pays her bills. Her BADLs are as follows: she dress herself but may need help picking out an appropriate outfit, bathes herself and has no problems with incontinence. Mrs. Smith has been accusing family members of stealing from her when she misplaces an object. Mrs. Smith has moderate dementia.

continued on next page

5 Stages of Alzheimer's Disease

	MILD	MODERATE	SEVERE	PROFOUND	TERMINAL
Function	<ul style="list-style-type: none"> IADL-independent or decreased ability with complex tasks. BADL - independent 	<ul style="list-style-type: none"> IADL - dependent or with assistance BADL - independent or reminders, assistance needed 	<ul style="list-style-type: none"> IADL - dependent BADL -dependent (incontinent, able to feed self, able to walk) 	<ul style="list-style-type: none"> IADL - dependent BADL - dependent (unable to walk, feeds with assistance) 	<ul style="list-style-type: none"> Unable to walk or sit up without assistance. Unable to smile or hold head up.
Cognition	<ul style="list-style-type: none"> Difficulty learning new information, memory loss interferes with everyday activities Difficulty with time relationships Mild word finding difficulty Mild judgment impairment 	<ul style="list-style-type: none"> Substantial memory loss, disorientation in time, often to place. Conversation disorganized, rambling. Judgment impaired. Decreased attention span. 	<ul style="list-style-type: none"> Only fragments of memory remain. Severe language impairment. Inconsistent recognition of familiar people. Short attention span. 	<ul style="list-style-type: none"> Speaks < 6 words Consistent difficulty in recognizing familiar people 	<ul style="list-style-type: none"> Few words spoken.
Behavior	<ul style="list-style-type: none"> Mild personality changes. Less engaged in relationships. Appears normal. 	<ul style="list-style-type: none"> May have psychotic symptoms, wander, exhibit verbal or physical agitation. Sleep disturbance. Appears well enough to attend functions outside of home. 	<ul style="list-style-type: none"> Emotional lability Restlessness. Inability to focus on tasks. Appears too ill to attend functions outside of the home. 	<ul style="list-style-type: none"> Repetitive vocalizations, calling out More passive. 	<ul style="list-style-type: none"> Passive

IADL = instrumental activities of daily living; BADL = basic activities of daily living. See page 3 for definitions.

Note: Individuals progress through the stages of dementia gradually therefore, an individual may fall between stages (i.e. mild-moderate stage)



Staging Dementia...*continued from previous page*

Mr. Jones is a 70 year old married gentleman. During a visit to the clinic his Mini Mental State Exam score was 23. His wife reports that he is having difficulty keeping track of his appointments and has recently double scheduled himself several times. She also notes that although he is still balancing their check-book and paying the bills it is taking him much longer and he has asked her to review it. She also reports that he had difficulty finding his doctors office after it changed locations. Mr. Jones is usually the life of the party but during a recently cocktail party he was quiet and reserved. Mr. Jones's wife reports that her husband is always neatly groomed and dressed. During the clinic visit Mr. Jones became frustrated several times when he could not find the word he wanted to use. Mr. Jones has mild dementia.

The influence of caregiver distress on staging:

Various factors can make staging a person's illness more challenging. A clinician must obtain information from a person who knows the patient well in order to properly assess the stage of illness. This person is often referred to as "the knowledgeable informant" and is usually the spouse or an adult child who provides care. A knowledgeable informant's mood and distress

influences their ability to accurately assess the patient's function and behavior. Therefore, treating a caregiver's distress not only benefits the caregiver but also may have an important impact on the care of the patient.

A final note, the table on page 2 shows how behavior symptoms do not uniformly worsen as the disease progresses. Behavior problems worsen in the moderate to severe stages but then wane.

<p>Basic & Instrumental - Activities of Daily Living: The key to accurate dementia staging.</p> <p>BADLs: Basic ADLs feeding, toileting, transferring, dressing, grooming, and bathing</p> <p>IADLs: Instrumental ADLs using the telephone, meal preparation, cleaning/ household maintenance, managing money, managing medication, using transportation, and shopping</p>

Early Stage AD Support Group

by Valerie T. Cotter, MSN, CRNP

Recently the Memory Disorders Clinic partnered with the Southeastern Pennsylvania Chapter of the Alzheimer's Association to develop a support group for persons with early stage Alzheimer's disease (AD) and their caregivers. We did this because there is a paucity of strategies to actively enhance each person's capabilities and adjustment. We recognized the need in the community, built on our mutual strengths, and successfully implemented our first eight-week group for 10 individuals.

The group, involving weekly meetings for persons with early-stage AD with a concurrent session for family caregivers, quickly became cohesive and developed a shared understanding and perspective about AD. Each week included a topic for discussion; research and medical update, coping strategies, transitions, focus on family, planning for the future, managing stress and spirituality. The participants indicated that

it was very helpful meeting others in similar situations and sharing feelings, both positive and negative.

This group will continue meeting monthly at Ralston House. We are planning for a new group to start in April. Please contact Valerie Cotter at (215-898-1795, cottvert@nursing.upenn.edu) if you are interested in joining our supportive and caring group.

I would like to acknowledge and sincerely thank Marie Boltz, Serita Kimble, Pam Barton and Christine McBennett for their loving guidance, warm acceptance and professionalism, which created a special place for individuals with memory loss and their loved ones to openly speak their minds and experience a sense of empowerment on their journey together.

See page 7 for a poem written by Harry LeFever, a participant in the group.



Why I Went into Dementia Care? Interview with Marianne Watson, RN

by Tanya Nagahawatte

The staff member featured in this issue of the MDC Newsletter is Marianne Watson, RN, a clinical nurse specialist. Many of our families are familiar with Marianne who works closely with Drs. Christopher Clark, Jason Karlawish, Christian Kohler and Marjorie Marenberg during patient visits and provides much needed support and information for families between visits by phone.

TN: Marianne, what is your role at the MDC?

MW: My role is to interview and evaluate patients and caregivers in the clinic. I oversee the resource center; manage recruitment for the brain autopsy program; and coordinator the normal control study, a very important part of Alzheimer's disease research. Finally, I help to recruit patients and caregivers to participate in our research studies and help run some of the clinical trials.

TN: How long have you been working at the Memory Disorders Clinic?

MW: I have been working here for 8 years. I started with Dr. Clark at the Graduate Hospital. In 1995 we moved to the University of Pennsylvania and two years later we moved from the Hospital to the Ralston House.

TN: What were you doing before you came to work at the Memory Disorders Clinic?

MW: After a few years at home with my kids, I was a substitute school nurse. It was a great way to ease back into my nursing career. After that I worked with the renowned Dr. Gerald Marks, a colorectal surgeon who ran the Comprehensive Colorectal Cancer Center at Jefferson Hospital.

TN: What are some aspects about dementia care that you enjoy?

MW: I love working with the geriatric population. Even though many patients have significant memory loss we can connect on some level and I derive great satisfaction from that. When our families come in, it's like greeting old friends; we get to know each other so well. I look forward to coming to work each day, knowing I might be able to help someone.

TN: What are some of the changes that you have seen since you have been here at the MDC?

MW: The focus of some of our diagnostic studies has shifted. We used to do cerebral blood flow tests and rely on SPECT scans. For a time we did PET scans.

Now volumetric MRI's and spinal fluid evaluations are done routinely to add another dimension to the diagnosis.

In the early 1990's, the only prescription medication for Alzheimer's disease was Cognex. Now three other medications have replaced it: Aricept, Exelon and Reminyl. We now know that Vitamin E is helpful in slowing down the progression of Alzheimer's disease. I was involved in the original study in which Vitamin E was tested; it was quite surprising to uncover that Vitamin E was effective.

TN: So what are your hopes for the future in the clinic and dementia care?

MW: Certainly the ultimate goal would be to find a way to prevent Alzheimer's disease. It would be incredible if we could arrest the progression of the disease and find a cure. I think we are headed in the right direction; there is a lot of research going on. We are constantly involved with studies testing new treatment methods. I'm proud to be on the research team and look forward to the future.

Reminiscent Video Project:

We are continuing to study the beneficial effects of a personal reminiscent videotape for patients and their families. In return for a personalized video, which contains family photos set to music, we are asking participants to complete a questionnaire so that we may determine if this form of therapy facilitates socialization among family and friends in addition to giving you, the caregiver, a break from the daily routine.

To learn more about this project please call Marianne Watson at 215.662.4373, or email watsonma@mail.med.upenn.edu.



“Alzheimer vaccine” AN-1792 Clinical Trial Terminated

by Jennifer Klocinski, MA and Jason H. T. Karlawish, MD

On March 1st Elan Corporation and Wyeth-Ayerst Laboratories announced that the Phase II A clinical trial of AN-1792 was terminated after 15 study participants became ill. AN-1792 was the experimental immunotherapy commonly referred to as the “Alzheimer’s vaccine.” Over the last two years there has been much excitement about what seemed to be such a promising new therapy. So, what happened?

However disheartening this development is it is not completely unexpected. Traditional vaccine’s work by provoking an immune response to a foreign invader (e.g. a virus). AN-1792 was not a vaccine in the traditional sense. It was designed to provoke an immune reaction to one of the body’s own proteins, beta-amyloid 42 (A β 42). This is the protein that makes up most of the amyloid plaques, a hallmark of Alzheimer’s disease.

are safe and truly effective the experimental treatment must go through three phases of study. The goal of Phase I is to assess the safety of the experimental treatment and usually involves only a handful of people. The Phase I study of AN-1792 involved only 80 people from the United Kingdom and 24 people from the U.S. The results of the Phase I trial of AN-1792, announced in 2000, suggested that the vaccine was safe.

During Phase II the experimental treatment’s efficacy and best dosage is assessed as well as continued monitoring of the treatment’s safety. A Phase II A trial is a smaller version of a Phase II trial and has the same purpose. The Phase II A clinical trial of AN-1792 began in October and enrolled 375 people with mild to moderate AD in Europe and the US.

Time to face up to the ethical challenges of AD research

This is not the end of trying interventions that manipulate the immune system in an effort to treat AD. There are other potentially promising interventions. But in light of the experience with AN-1792, how will we design and conduct these trials? Specifically, are the potential benefits still worth pursuing, or do we think that pursuing immune system interventions is too risky? The fundamental issue here is deciding what kinds of risks are acceptable in the pursuit of new treatments. And if we do decide to continue this line of research, how will we enroll patients in it? In particular, the community of researchers and patients and their caregivers needs to decide whether we will enroll patients who are not competent but can simply assent to enrollment. Regardless of the choice we make, we will need to come up with an acceptable way to determine that a patient is or is not competent to enroll. We all want to discover a definitive treatment, but we should do this in a way that does not violate our fundamental values.

The preclinical animal studies indicated that injections of AN-1792 prevented amyloid from forming plaques and eliminate some existing plaques in mice genetically engineered to produce human amyloid. A key question during clinic trials of AN-1792 in humans was its effect on the immune system. One concern was that AN-1792 could lead to an autoimmune reaction in which the body launches a systemic attack on its own tissue. Inflammation would be one sign of an autoimmune reaction.

To ensure that treatments available for use in humans

During the Phase II A clinical trial of AN-1792 four of 97 individuals in France experienced symptoms of inflammation in the central nervous system (brain and spinal cord) after receiving multiple doses of AN-1792. As a result, in January 2002, The Elan Corporation and Wyeth-Ayerst Laboratories suspended the Phase II A clinical trial of AN-1792.

It is standard practice to temporarily suspend a clinical trial after the report of a significant side effect so that an investigation can be conducted into the cause of the side effect. The temporary suspension of the AN-



Memory Disorders Clinic Joins Alzheimer's Association for Safe Return Registration Drive

by Jennifer Klocinski, MA

As many as 60% of people with dementia wander and may be come lost at some point during their illness. Often families don't realize a relative is at risk for becoming lost until an incident of wandering occurs. And becoming lost can lead to serious injuries. To address this problem the Alzheimer's Association developed a program to assist families when a loved one becomes lost and to help return individuals who have been found.

The program is called Safe Return. This is a nationwide program that has helped more than 5,700 individuals find their families since it's creation in 1993. Their rate of success in finding lost individuals is nearly 100% nationwide. The program in Southeastern Pennsylvania has 1,393 enrollees and since 2000, has assisted 43 individuals who have become lost to return home.

Although this is a successful and much needed program, many people are unaware of its existence. The West Philadelphia community is one area of the city that has been underserved by Safe Return. Census data and prevalence rates suggests that as many as 2,500 individuals with a dementing illness live in West Philadelphia. Prior to the start of our West Philly Safe Return initiative only 93 individuals were registered for the program, well below the number of people in need of this valuable program.

The Memory Disorders Clinic with the help of the University of Pennsylvania School of Medicine Aging Interest Group and the local chapter of the American Medical Student Association joined the Southeastern Pennsylvania Chapter of the Alzheimer's Association to conduct a registration drive for the Safe Return program to address this problem. A two-day registration drive was held on October 22nd and 23rd. We were extremely fortunate to get the support of four sites to host the registration drive in West Philadelphia. The Early Grey Roberts Adult Day Care Center; Elderwatch Plus; LIFE, an all-inclusive care program for frail elders; and United Community Clinics, a University of Pennsylvania student run multidisciplinary clinic located at the First African Presbyterian Church joined in the registration drive.

Our hard work and effort has paid off. During the two-day drive 39 people were registered for Safe Return, an increase of over 40%. The impact of the registration drive has extended beyond the two-day event as applications continue to arrive from these locations. This successful initiative will continue with future drives at area churches.

If you would like more information about Safe Return or know of a site interested in hosting a registration drive please contact Jennifer Klocinski by email at jennifer@mail.med.upenn.edu or by phone at (215) 573-4634.

New Alzheimer's Association HELPLINE

The Southeastern Pennsylvania Chapter of the Alzheimer's Association has announced a new Caregiver Helpline. The Helpline is now available 24 hours a day, 7 days a week, 365 days a year. The new number is 1-800-272-3900. The Helpline provides information, referrals and support.

How to Donate to the MDC:

Your gifts are gratefully accepted and help to fund new and innovative research, education and care. Your support can be given through donations to the University of Pennsylvania and specifically directed to the Memory Disorders clinic.

To send a gift, make the check payable to the "Trustees of the University of Pennsylvania" and indicate Memory Disorders Clinic" in the memo line.

Send the check to:
Memory Disorders Clinic
Attention: Program Administrator
University of Pennsylvania
3615 Chestnut Street, Room 212
Philadelphia, PA 19104

Contributions are tax deductible. To find out more about our program needs please visit our website at www.ups.upenn.edu/ADC or contact our main office at (215) 662-7810.



Current Research Opportunities for all Ages, with and without Memory Loss:

Primary Prevention Instrument Study:

This study assesses the usefulness of new or improved paper and pencil tests to measure a person's memory and thinking skills and will compare different methods to collect information from individuals participating in a clinical trial.

Participants must be 75 years or older and cannot have a diagnosis of Alzheimer's disease. Participants must also have a study partner (e.g. someone who knows you well). Participants will receive an annual memory evaluation. The study will last 4 years and is sponsored by the Alzheimer's Disease Cooperative Study (ADCS).

Clinical trial of investigational drug CP-427,920 in patients with Alzheimer's disease:

The main goal of this trial is to see if the investigational drug (called CP-427,920), can treat the symptoms of Alzheimer's

Disease. Another goal is to learn more about possible side effects of this potential new medication. The sponsor of this clinical trial is Pfizer Incorporated, a pharmaceutical company.

A study of the relationship between CSF Cortisol and APOE genotype:

The purpose of this study is to discover if the increased risk of developing AD that is associated with APOE-e4 genotype is due to its affect on the stress hormone cortisol and does the affect of APOE-e4 change as we age. Participants are needed with and without Alzheimer's disease and between the age of 18 and 90 years. This study involves two visits. The sponsor of this study is the National Alzheimer's Coordinating Center

For more information on any of these studies contact Kris Gravanda by email krisg@mail.med.upenn.edu or phone at 215.349.5903.

Creative Contributions:

The following poem was written by Mr. Harry L. LeFever, a participant in our first Early Stage Patient Support Group. After serving as an officer in the US Marine Corps during the Korean War, Mr. LeFever was a teacher of English in the American Studies program at Springfield High School in Delaware County and later a Professor of English and Humanities at Delaware County Community College. Mr. LeFever has three daughters and five grandchildren and currently lives in Springfield with his wife Mary.

There's a bore in my head
from a blind worm
feeding day and night.

It bears me no malice;
It does what it is designed
to do--ineluctably.

It chews silently,
but I can measure
what has been taken.

Almost benevolently
it first nibbles at
the cluttered present--

an acquaintance's name,
the title of a book,
an appointment.

I'm told this sleepless worm
will devour all that I cherish--
all that is sweet and true.

I tried to deceive this--
My dumb, blind worm.
I offered wasted thoughts.

the worst teacher I ever had,
the first girl I dated,
my DI in boot camp.

Ah yes, the silent worm
wouldn't bite. It has had
the taste of rich memories.

What will I think when my
avaricious worm has
devoured all that I cherish?

Smiling, I said to my family
"At the nadir of my night
place me on an iceberg."

Wife and daughter smiled..."Dad,
there won't be any icebergs...
Global warming...you know?"

We laughed, embracing each other.
Although I could not dismiss
my worm, he can't devour love.

H.L. LeFever, 1999



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Vaccine Trial...continued from Page 5

1792 clinical trial is one mechanism to insure the safety of research participants. If it was determined that the inflammation was not related to AN-1792 the clinical trial would most likely resume.

However, after the initial suspension of the trial an additional 11 people developed these alarming symptoms. The independent Safety Monitoring Committee concluded that the trial be terminated and that no one should receive additional injections. The exact cause of the inflammation is still unknown and researchers will continue to investigate.

While the clinical trial of AN-1792 failed to show the treatment was safe and effective it does advance our knowledge regarding immunotherapy for Alzheimer's

disease. Researchers will continue to study the data collected thus far and monitor those who did participate. This trial also provides reassurance that our system for developing and testing emerging therapies does provide appropriate safeguards. In other words, the system worked. Potentially harmful side effects were noted and appropriate action took place to ensure the safety of all participants.

This clinical trial illustrates the underlying goal of all clinical research, to gain generalizable knowledge. There is no guarantee that research subjects will gain therapeutic benefit from participation in a clinical trial but we will advance our knowledge. Without trial participants we would not have the medications available today nor would there be hope for future treatments and a cure.

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