

Alzheimer's Research: Symposium Held at New York Academy of Science

On February 28, 2001, a three-hour symposium to review current and future therapies for Alzheimer's disease was held at the New York Academy of Science. The symposium was sponsored by four organizations: The Institute for the Study of Aging, the New York Academy of Sciences Neuroscience Section, the New York City Chapter of the Alzheimer's Association, and the New York City Metro Area Chapter of the Society for Neuro-

science. The first meeting of its kind in New York City, it brought together clinicians, scientists and the Alzheimer's Association to discuss the newest clinical information on AD. Although there are NIH-funded Centers and Programs in Alzheimer's Disease at every major academic center in the metropolitan area, until this symposium there was no local forum for regular

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New Heights for Alzheimer's Association

At 7:30 A.M. on the morning of Saturday, February 11, 2001, New Yorker Kenneth G. unfurled the Alzheimer's Association banner at Uhuru Peak (19,340 feet above sea level) at the summit of Mount Kilimanjaro, Africa's highest point and the world's highest free-standing mountain.

By reaching the peak of Mt. Kilimanjaro, Ken fulfilled a lifelong, mountain-climber's dream, and he dedicated his achievement to a loved one with Alzheimer's disease.



When asked several weeks before his challenging expedition, why he would be making this strenuous climb, Ken responded somewhat generally and in mountain climbing terms. It was only upon his return to New York City that he says his true purpose came into focus. In a letter addressed to the Alzheimer's Association he described this purpose, by saying,

"It was not until last night that I realized the true purpose of my climb," he wrote. "I now know that an unyielding focus and commitment will allow me to face challenges I once thought to be beyond my abilities – including my loved one's Alzheimer's. As a result, I've gained a sense of freedom and confidence about life's concerns. Appropriately, *Uhuru* means freedom in Swahili."

We congratulate Ken on his accomplishment.

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Director's Corner



Looking Backward and Forward

Fifteen years ago this month I joined the Alzheimer's Association as Executive Director of your New York City Chapter. Back then the NYC Chapter was a necessary idea waiting to happen. Alzheimer's disease (AD) itself was still, to all but those unfortunate enough to have it reach into their families, a barely recognized and totally misunderstood affliction.

Today, in large measure due to your support and the hard work of extraordinary staff members, volunteers and a committed Board, both Alzheimer's disease, and certainly the New York City Chapter, are far better known.

Fifteen years ago we had no cure for Alzheimer's. That is (alas) still the case today. But fortunately, today, and this represents a significant change from the mid '80s, the diagnosis of AD is more certain and can be accomplished much earlier. This allows those diagnosed and their families to make plans and organize their lives more effectively than was the case back then. Moreover, there are now four medications available to slow the progression of the disease. Just this month, *Reminyl* joined *Cognex Aricept* and *Exelon* as the latest FDA approved drug (another acetylcholinesterase inhibitor) for the treatment of the disease. In addition, innovative interventions like nerve growth factor and vaccines are being researched and discussed in the popular press. Progress. Hope.

Fifteen years ago there was no meaningful long term care system in America, and little in the way of training or support for those who delivered hands-on care. Amazingly, we still have no rational, integrated or affordable long term care system, and policy makers still struggle with this need in terms of design and cost. Moreover, paid caregivers remain as under-appreciated and certainly as underpaid for the difficult job they do as ever. And as for caregiving families, the burden has barely been lifted by the growing awareness of AD and scientific advances.

But all is not bleak and hopeless. More and more we read of progress being made in laboratories around America and the world. Just a few months ago, Congress approved a significant increase in funding for research through the National Institutes on Health (NIH) and Aging (NIA). There is reason for optimism. Likewise, as the large baby-boomer generation tackles the care needs of its parents' generation, and as it begins to approach the age where it itself directly confronts AD in its midst, more attention will undoubtedly be paid to the need of providing systemically for long term care than ever before.

That having been said, we cannot relax. We need *your* participation in advocacy as we continue to work with legislators to effect AD-sensitive laws and regulations. We need *you* to help us spread the word about the many remaining needs of the Alzheimer's community.

As you do these things with us, we promise you our ongoing, indeed our increased, efforts, to truly make a difference in the lives and well being of every single person in the Alzheimer's community who needs our help. And, as always, we thank you for being there.

— John A. Jager
Executive Director

Dementia Training Program

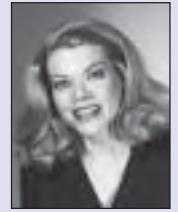
On April 11th, congratulations were in order for the third group of home attendants who successfully completed a 43-hour Dementia Training Program which focused on caring for people with Alzheimer's disease and other dementias. The fifteen participants chosen for this training represented three Medicaid home care agencies: Family Home Care Services of Brooklyn and Queens, RAIN Home Attendant Services, Inc., and The First Chinese Presbyterian Community Affairs Home Attendant Corporation. The graduation ceremony and reception were held in our Chapter's Training Center. To mark the occasion, speeches were given by several members of the Association's staff and two of the graduates. Certificates of Achievement were awarded as proud agency staff, family members, and friends looked on. Once again, I would like to offer my heartfelt best wishes to this group of outstanding graduates!



— Paulette Michaud

Editor's Note

For those who live it, or live with it, there's no vacation from Alzheimer's. Of course, that also applies to the staff and volunteers at the NYC chapter. Activity here will be stepped up to an even more demanding level as the year's most rewarding events cycle through the calendar.



"Rewarding" refers to more than the emotional satisfaction our work provides; it also means that the chapter is depending on the financial boost that will come from our gala benefit (the "Forget-Me-Not-Ball") June 7, as well as Memory Walk on October 7.

Looks like "7" may be our lucky number, but our goals can't be left to chance. It is too early to assess how generous New York taxpayers were when presented with the effortless and painless option of checking a box on their income tax return to donate to the Alzheimer's Association.

Our very presence on that form attests to Alzheimer's higher profile. A major goal of the annual "Week to Remember" campaign has been to increase Alzheimer's awareness by way of a full-page New York Times ad—funded by individual and corporate donors—and the illumination of such landmark structures as the Empire State Building in purple, the Association's signature color.

Every page of this newsletter (distributed free to readers, though hardly free to produce) is devoted to "hoping and coping." If you live with Alzheimer's, you know you can't do it alone. Neither can we...

—Chris MacLeod



On-line Info on Prescription Drug Assistance Programs

The Pharmaceutical Association has a very informative website which provides a directory of patient assistance programs for most, if not all, of the major manufacturers. Patient assistance programs will help pay for the cost of prescription medications when patients can not otherwise afford them. These programs do not apply when someone has Medicaid or other prescription drug coverage. Generally the prescribing doctor or nurse practitioner must contact the drug company for more information about how to apply for these assistance programs. These programs will pay for some of the anticholinesterase medications that are prescribed for Alzheimer's disease, as well as other medications that many older people take. The website is:

www.Pharma.org/searchcures and click on the 2001-2002 Directory of Prescription Drug Assistance Programs



For information about government-supported drug assistance programs in all 50 states, including EPIC, here in New York State, see:

www.RxHope.com

PUBLIC POLICY UPDATE: Federal and State Alzheimer's Advocacy

FEDERAL ADVOCACY ACTIONS

Family caregivers, early stage patients, chapter directors and public policy staff from all over the country gathered in Washington, DC for the 13th Annual Public Policy Forum from March 31 - April 3rd. Attendees had the opportunity to hear about public policy issues of immediate and continuing concern to the Alzheimer's community and what may or may not materialize in the new Congress.

Most importantly, advocates were able to bring their concerns directly to the attention of Congress through visits to Capitol Hill to their Senators and Representatives. There are now 130 members of the bipartisan Congressional Alzheimer's Disease Task Force whose members are committed to deepening the knowledge and understanding of Alzheimer's in the House and the Senate.

One had only to hear the family, personal, and financial crises expressed during the Congressional visits and to the media by early stage patients and the families of younger persons with Alzheimer's to understand that the devastating impact of the disease cannot be ignored. The needs for research, family caregiver supports, and long term care coverage were reinforced over and over. The issues were further empha-

sized by the release of a 50 state study showing a jump of 54 percent by 2010 in Medicare costs for Alzheimer's – with dire consequences for the health care system. Once the babyboomers enter the age of risk between 2010 and 2050, the threats to Medicare and Medicaid are overwhelming unless there is a cure

As such, the goal of \$1 billion in Alzheimer research funding at the National Institutes of Health, with a \$200 million increase this year, was the first priority of this spring's public policy forum.

As I have noted in earlier issues of this newsletter, and at the risk of being redundant, it remains unclear whether Congress will maintain Medicare or move toward a private insurance model; include prescription drug coverage as part of the Medicare benefit package; undertake to contain the costs of Medicaid by allowing states to have greater flexibility in deciding how, for whom, and for what Medicaid monies are to be spent. These issues will be at the center of intense, heated, and continuing debate between advocates for maintaining the federal government's role and those who want to reduce it through privatization or turning programs over to the states. There will be no easy resolution of these issues.

STATE ADVOCACY

The National Public Policy Forum workshops addressed a variety of issues which mirror our Coalition of NYS Alzheimer's Chapters Legislative Agenda's priority issues and efforts of the NYC chapter staff. Issues workshops addressed included: long term care worker shortage problems and the need for better wages, benefits, and dementia-trained aides; state prescription drug coverage efforts and the high costs of medications; improving and expanding home and community based care; respite care; assisted living; and quality care at the end of life.

The state budget is moving particularly slowly this year and may not be passed until as late as the fall. The work force issues in home care and residential care have emerged as paramount issues in NYS with provider organizations, consumer groups, and advocates seeking solutions to staffing needs. The Coalition member chapters and the NYC chapter are continuing to focus on the worker shortage and the need for additional nursing home staff, particularly aides. A critical point here is assuring that any Medicaid monies the state provides to nursing homes for safe staffing\additional staff be tied to direct care staff. Furthermore, workers must receive increased wages and benefits and be trained in dementia care.

As of this writing, there is no word on when the NYC Department for the Aging (DFTA) will make determinations

on use of the Family Caregiver Support Program funds. A meeting with interested organizations including the NYC Alzheimer's chapter was held at DFTA to discuss how the funds might best be used, but no decisions have been made. NYC will receive approximately \$2.5 to \$3 million of the \$7 million NYS will receive from this federally funded new program.

The NYC chapter lobby day, originally scheduled for March 6th, was cancelled due to heavy snow that resulted in the closing of the NYS Legislature. Lobby day has been rescheduled for June 5th.

Ann Berson
Public Policy Coordinator



Chapter Welcomes New Staff Members

Hola! Mucho Gusto. Mi nombre es Karina Aguilar. En marzo tuve el placer de unirme a la familia de la Asociación de Alzheimer, capitulo de Nueva York. Más aún es un privilegio poder servir a la comunidad en especial a las personas que hablan español. Recientemente regrese a la ciudad de Nueva York después de haber vivido diez años en Buffalo, NY. Allí obtuve mi título en Servicios Humanos y de Salud en 1995, mi especialidad fue Geriatria Social y desde entonces trabajo con personas mayores de 60 años. Mi carrera me ha llevado a trabajar con personas que aunque son independientes, necesitan un poco de ayuda. A la vez, he trabajado con personas que necesitan de alguien la mayor parte del tiempo por causa de la demencia, especialmente Alzheimer.

En 1999, empecé a trabajar con la Asociación de Alzheimer en el area oeste de Nueva York, y terminé mis estudios de maestria en Administración de Servicios de Salud. Mi experiencia en el area oeste de NY fue tan positiva, que en realidad es una alegría poder hallar en Nueva York un lugar donde poder seguir ejerciendo mi profesion. Mi tarea en la asociación es incrementar nuestros programas y charlas educativas en los cinco condados de, y a la vez proveer estos programas en español. Espero llegar a conocer la ciudad y sus comunidades y unir fuerzas con todos aquellos que sirven a la población afectada por la demencia. Usted me puede llamar si necesita ayuda, información o quiere que yo vaya a su comunidad y charlemos de la enfermedad de Alzheimer.

Hello! It's a pleasure to introduce myself. My name is Karina Aguilar. In March I was pleased to become a staff member of the Alzheimer's Association, New York City chapter. It is my privilege to serve the community, especially those who speak Spanish. Recently, I returned to New York City from Buffalo, NY. I earned a Health and Human Services Degree with a concentration in Social Gerontology from the State University of New York in 1995. Ever since then I have worked with older people. It has been my joy to work with seniors who are independent, and those who, due to dementia, needed more assistance.

In 1999 I began to work at the Alzheimer's Association – Western New York chapter as Family Services Coordinator. While in Buffalo I finished my Masters in Health Services Administration. My experience at the Western NY chapter was so inspiring that I feel truly fortunate to have found a role at the New York City chapter. In the future I hope to increase our educational programs and caregiver programs in the five boroughs, as well as providing the same topics in Spanish. I look forward to going around the city, getting to know the communities and joining forces with those who serve the population affected by dementia. Please feel free to contact me at (212) 983-0700, ext. 241, if you have any questions, need information or if you know of a Spanish speaking individual or community organization that you think would benefit from talking to us.

Karina Aguilar, MS – *Diversity and Outreach Coordinator*

The NYC Chapter also welcomes:

Albert E. Cummings, Executive Assistant

Albert comes to the chapter after serving as assistant to the Director of the New York City Department for the Aging's Alzheimer's and Long Term Care Unit.

Linda Otero, Program Assistant

We are pleased to welcome Linda to the chapter staff. She has worked as a Program Assistant for Lifespines, a non-profit organization providing services for the developmentally disabled and mentally retarded population.

Alyson Raifman, Special Events/Public Relations Coordinator

The New York City Chapter is pleased to announce that Alyson has joined the staff as the Special Events/Public Relations Coordinator. Alyson received her Masters in Health Service Administration, with a concentration in Long Term Care from The George Washington University and will sit for the Nursing Home Administrator's License in June. Previously, Alyson worked for the Alzheimer's Association, Greater Washington Chapter and Public Policy office.

Are You A Healthy Caregiver?

Are you so committed to caregiving that you may have neglected your own physical, mental, and emotional well being?

There are seven simple steps you can take to ensure that you are healthy caregiver:

1. See your physician regularly.
2. Get screened for stress and depression.
3. Get plenty of rest.
4. Eat well-balanced meals.
5. Exercise regularly.
6. Accept help from others.
7. Call the Alzheimer's Association.

The Alzheimer's Association – an important resource for caregivers. The Association offers: support groups and help lines, referrals to local resources, educational resources, and ways to become involved in advocacy efforts.

meetings and exchange of ideas and information.

Why is this kind of forum more important than ever? Because drugs now being tested are aimed at what many believe to be the CAUSE of AD. When scientists learn how the drugs are faring in the clinics, they can return to their laboratories and design better ones. Clinicians need to hear about new drugs in development so that they can propose human trials. And of course patients and their families are eager for this information and can participate as subjects in these trials.

The symposium was chaired by Dr. Samuel Gandy, of New York University and the Nathan Kline Institute, and by Dr. Richard Mayeux of Columbia University. Drs. Gandy and Mayeux explained that these meetings would be held twice a year in the hope of bringing together senior and junior researchers in the field. They in turn introduced Dr. Howard Fillit of the Institute for the Study of Aging and Mr. Jed Levine, of the NYC Chapter of the Alzheimer's Association. Dr. Fillit spoke briefly of the world-wide search for drug therapies, and Jed Levine followed by calling attention to the 18.4 million dollars for research raised by the National Alzheimer's Association and to the urgency felt by the millions of Alzheimer's patients and their families.

The keynote speaker was Dr. Kenneth Davis of the Mt. Sinai School of Medicine. With a detailed sequence of slides, Dr. Davis presented a comprehensive analysis of what happens in the Alzheimer brain and of present and potential therapies. The telltale signs of the disease – the *plaques* and *tangles* in the brain – were graphically demonstrated in the slides. The plaques, Dr. Davis explained, were clumps of a protein called *beta amyloid*. This protein is produced by an enzyme in the brain called *beta secretase*, which cuts off a piece of a larger protein called the *amyloid precursor protein (APP)*. These pieces form aggregations, called plaques. The other characteristic of Alzheimer's is the tangle of nerve fibers, containing a protein called *tau*. Dr. Davis believes that the amyloid plaques occur before the tangles. (Current theory indeed holds the amyloid plaques chiefly responsible for Alzheimer's disease.) The good news is that, according to Dr. Davis, there exist many compounds that can block the aggregation of amyloid. Finding these and making them work in the human brain is a consummation devoutly to be wished.

Among current therapies, there are of course Cognex, Aricept, and Exelon. These are temporary at best, and don't work for everyone. The newest medication, Reminyl, was recently approved by the Food and Drug Administration. Non-steroidal anti-inflammatory drugs (NSAIDS), Dr. Davis suggested, may delay the onset of Alzheimer's disease. On

the other hand, Cox2 inhibitors (e.g. Celebrex), he believes, are probably ineffective. Antioxidants such as vitamin E do appear to be weapons against AD, as is the class of drugs called *statins*, such as Lipitor and other anticholesterol drugs. The statins appear to reduce the risk of AD by preventing the formation of beta amyloid. As to the development of a vaccine to prevent or reduce AD, Dr. Davis sees the vaccine as hopeful, but a long way off. The vaccine worked in transgenic mice, and is now in early trials in humans. In response to a question, Dr. Davis conceded that use of the vaccine in humans might produce an auto-immune response. Eventually, Dr. Davis believes, there may be a cocktail of drugs to treat AD, just as there is today in the treatment of AIDS.

Dr. Davis was followed by two young researchers, Dr. Scott A. Small, of Columbia University College of Physicians and Surgeons, and Dr. Larry M. Refolo of the Nathan S. Kline Institute for Psychiatric Research. Dr. Small discussed imaging techniques in the brain. Alzheimer's disease begins in the region of the brain called the hippocampus. It is well known that definitive diagnosis is presently done only at autopsy. It would be important to diagnose the disease early, and this might be done by a sophisticated imaging technique of the hippocampus called "functional imaging." Until now, functional imaging has not been sufficiently sensitive, relying on brain shrinkage, or atrophy. Dr. Small, however, has developed a method to visualize failing brain function before the brain structure shrinks. Early diagnosis would make early treatment possible. What kind of treatment? One answer was suggested in the presentation of the next speaker, Dr. Refolo.

Dr. Refolo presented a study of the link between cholesterol metabolism and AD. Dr. Davis had earlier noted that anticholesterol drugs seem to work against AD. Dr. Refolo's research shows that cholesterol lowering drugs reduce production of beta amyloid. This may occur because the expression of the APOE gene, a risk factor for AD, is regulated by cholesterol. Cholesterol controls expression of the APOE gene which, in turn, leads to formation of new apoE protein. The level of the apoE protein, in turn, controls the production of beta amyloid. A fascinating question now presents itself: Can lowering dietary cholesterol reduce the risk of Alzheimer's disease?

Dr. Davis ended his presentation by noting that there are still many unanswered questions in the field of Alzheimer's research. We continue to hope that more symposia such as these will speed the answers to these questions and eventually bring about the end of Alzheimer's.

– Jack M. Pollock

Caregiver Lyric

Drinking Time like glorious reprobates
drugged on years of friendship,
oneness, twoness, a love called marriage . . .

Suddenly the intruder comes, a jokester
in a pie-bald costume of disease.
Suddenly, a no-gender steroidal,
a presence, a tottering prehensile
drunk on pumped-up muscle,
shoves its weight against our sanctuary,
our private temple hideaway.
And the walls are tumbling down.

Come the tears . . .
fragile, tiny, always new-born recognitions.
Viscous truths, the tears slip out, slide down
from some naked place with its legs spread wide,
and Time the midwife, Life the lover standing by.

Come the tears,
bubbling up from the fathomless well
of that imp, that seer,
that fortune-telling God, Unconscious.
Come the tears, sparkling with mystery
like iridescent clarities.

Bursting little grapes, come the tears
filled with the sad, the sweet,
the tart, the unfulfilled,
the longed for, the possessed and the lost,
never-to-be-found-again.

You walk arm-in-arm. "Oh, look!"
Not sure if it was seen or heard.
(And later on, knowing it was neither.)
You watch the brain of the other half of you
slowly split away, like a geologic-driven chaos.
Yet, in the aftermath of ripping, wrenching sounds
- the movement of the unmoveable,
the inconceivable . . .
a cape, a bay, an undiscovered land,
a sea that never was, is. Is there!
Fate decrees: an Hawaii rises,
an Atlantis disappears.
Come the tears, strangely meaning hope,
for the dead ones cannot cry.

So, come the tears like squalling infants
brimming with the always possible –
the perfect beauty of the sentient soul.

Come those microscopic drops of ocean
down the cheek . . . as reminders:
I'm the sculptor, dancer, painter,
I'm the architect, the singer, the poet,
I'm the artist of my Self!

Come the tiny salty torrents . . .
I'm becoming, I'm becoming,
I'm becoming one with lone-ness.
And yet, with a sleight of hand, of heart,
I must, with love, for the one I've loved,
I must perform the magic of the two-ness
no longer there.

Until otherwise informed.

◆ Doris Schwerin

Poet's Corner

The Caregivers Sonnet

Sometimes I feel great,
can't wait
to tackle a world
unfurled.

I roll out of bed,
my head
planning things to do
that are new.

I get quickly dressed
with zest;
my normal breakfast
a royal repast.

I hug and kiss my wife
and face the realities of life.

◆ Eli Stern

DEMENTED

(in honor of someone who was close to me)

It happens;
You forget
This or that.

You may feel
Some loss of control.
You're letting some things go.
Not on purpose, no.

Fried brains,
Don't fail me now.

The doctors speak hope
To pain.
Please, not now.

Let me cry
Before I die.

Remember me
As I was . . . before.

◆ Richard



CAREGIVER CORNER

SAFE RETURN

OVER 60% OF ALZHEIMER'S PERSONS WILL WANDER – ARE YOU PREPARED?

Wandering is a common and potentially life-threatening behavior that may accompany Alzheimer's disease. Individuals with this disease may become disoriented and lost, in their own neighborhood or far from home. More than 60% of Americans diagnosed with Alzheimer's disease may wander off and get lost sometime during the course of the disease.

The **Safe Return Program** is the only nationwide program that assists in the identification and safe, timely return of individuals with Alzheimer's disease or other dementias who wander and become lost. In April 2001, The National Safe Return celebrated its 8th anniversary.

If a registrant in the **Safe Return Program** wanders and is found, the person who finds him/her can call the 24-hour Safe Return toll-free number located on the wanderer's identification bracelet, wallet card or clothing tags. The **Safe Return** operator immediately alerts the family members or caregiver listed in the database so they can be reunited with their family member.

If a person is reported missing by a family member or caregiver, **Safe Return** notifies the New York City Chapter. We are able to fax to all hospital ER's, shelters, transit and Port Authority. If necessary we are able to access the media, and help publicize the case. We are very fortunate in New York to have a Detective from the Missing Persons Squad assigned to the **Safe Return Program**. The New York City

chapter is very proactive in its response to a missing person. We are in frequent touch with the family during and after the crisis. In New York City we have a near 100% recovery rate for those persons who are registered and wearing the identification bracelet.

There is a one-time fee of \$40.00 for the program and all the materials. If the fee imposes a financial hardship, call the office and we can make arrangements to provide assistance.

A Safe Return

Shopping mall security guards found 85 year old Anna walking in the Kings Plaza Mall. She was wearing a thin nightgown and bedroom slippers on a very cold day in November. Confused, disoriented, cold and hungry she had no idea how to get home. After reading her Safe Return identification bracelet, the security guards called the 800 number. Anna's daughter was immediately notified and arranged to meet the police and take her mother home, which was more than 2 miles away. She had been missing for at least 3 hours. After her safe return we counseled the family and were able to find a day center for her, which helps keep her engaged, happy and safe during the day.

For further information and registration forms, call Gail Hoffmann, Coordinator, Safe Return Program 212-983-0700. You can also register by printing a form from the Safe Return page on our Website: www.alzheimernyc.org.

Understanding Wandering

- ❖ No longer recognizes familiar people, places, and objects
- ❖ Feels lost in a new or changed environment
- ❖ Tries to fulfill former obligations, such as going to work or taking care of a child
- ❖ Takes medications that have side effects such as restlessness and confusion
- ❖ Tries to relieve stress caused by noise, crowds, or isolation
- ❖ Experiences confusion at certain times of the day or night
- ❖ Is restless due to lack of physical activity
- ❖ Is fearful of unfamiliar sights, sounds, or hallucinations
- ❖ Searches for something specific such as food, drink, the bathroom, or companionship
- ❖ Looks for a way out of the home

Tips to Prevent Wandering

- ❖ Check to see if the person is hungry, needs to go to the bathroom, or feels uncomfortable.
- ❖ Encourage movement and exercise to reduce anxiety and restlessness.
- ❖ Involve the person in daily activities such as folding laundry or preparing a meal.
- ❖ Remind the person that you know to find him and that he's in the right place.
- ❖ Reduce noise levels and confusion.
- ❖ Reassure the person who may feel lost, abandoned, or disoriented.
- ❖ Alert police ahead of time that you care for a person with dementia.
- ❖ Make a plan of what to do if the person becomes lost.

– Action Series, Steps to Ensuring Safety: Preventing Wandering and Getting Lost, 1999.

From the moment three years ago that I suspected that my husband, Don, had Alzheimer's disease, I began a personal research project, sending for information from all over the world, combing the Internet and talking to the Alzheimer's Association. I got organized. I opened a post office box so Don would not see any of the materials being sent to me. When it was time to tell him about my concerns, I had a plan and a back up plan ready.

This is my approach to each development as the disease progresses. I do not mean to accuse myself of being detached. A certain amount of sadness, tears and frustrations are in the mix.

On the day of the evaluation feedback, my husband and all five of his children were present. Everyone, including Don, cried and held and consoled each other. Don was probably the most consoling of all. He took it better than the rest of us because he was glad he wasn't being rushed off to surgery for a brain tumor. He saw this diagnosis as something that he could accept gradually.

He has a remarkable attitude about the disease even now. His greatest problems are speaking and performing tasks of any nature. More recently he has lost his abilities to decipher the difference in numbers and amounts of money. However, he has not lost the essence of his personality or his memory of people, places and things. He will tell you, as best as he can articulate, that he prefers to dwell on what he can do, not what he cannot do. I have actually found new ways to respect and fall in love with this man. We get through our lives trying to take it a day at a time, while retaining a sense of humor. I will even admit to patting myself on the back for having it so together in dealing with this crazy disease.

But recently, the smallest things grabbed me and threw me into a bout of mourning that I did not see coming. Our Saturday errands have always been fun dates for us. We would complete half of our tasks and generally find a great little café for lunch. More often than not, it would be an opportunity for a few glasses of wine, lots of great conversation and laughter – with several undone errands by day's end. We still run errands. We still stop for lunch. The dynamic has, of course, changed. I do the selecting, the ordering and the paying. Usually this is under the eyes of a young waiter giving me that “this pushy broad won't even let her husband talk” look. I got beyond any concern over such observations a long time ago. We still have conversations, but now it is our usual guessing game: he tries to tell me something and I try to provide him the words. We still laugh, but I know that I understand the humor a little more.

Recently, we dropped the car off for an oil change and walked around the area. It led to a lunch stop at a wonderful little bistro. On this day, I found myself wanting the old way back — I wanted the old Don back. I didn't want anything to do with my “Alzheimer's project.” All the feelings came rushing through the overwhelming feeling was he's never coming back. I could barely get through the lunch without breaking down and I didn't want him to know what was happening. This was followed by several days of inconsolable tears and angst.

I tried to keep these feelings from Don, but he knew there was something wrong. I realized that I had felt this kind of grief before. It was when I was told my mother had six months to live and, again, after she had died I realized that I would never see her again. This felt the same, and I realized that I

had been thrown into a very real state of mourning over the loss of the man that he once was. This time I wasn't feeling bad for him. I was feeling bad for me. I still am. The grief doesn't go away once you have realized your loss. However, acknowledging it allows one to deal with it more effectively.

Discussions with a therapist and our early-stage support group provided me the opportunity to express my feelings with abandon. We talked about the cruelty of this disease to those who love the patient. I even ended up telling Don about it despite my sense not to share it with him. Always having been distrustful of “loony” therapists, he was very concerned why I felt the need to go there and he was persistent for an answer. I told him that I love him as much, maybe more, today than ever, and that I think the way he handles' Alzheimer's is remarkable. However, I added, there are times that I really miss the parts of him that have gone away and I just need to talk and think about that once in awhile. Every bit himself, he was very empathetic. He smiled, albeit with tears in his eyes, and told me, “I understand how that must feel.” I needn't have worried about the impact it would have on him. Minutes later, the whole subject had left his mind. He was happily engrossed in a Chicago Bulls game, of which he had no clue about opponent, score or time. If there is anything that is kind to the patient about this disease, it's the built-in protection from dwelling on losses. At least that applies in my husband's case — so far. I don't know if we have a choice about the manner in which we grieve, but I believe that some caregivers and other family members mourn the loss every day throughout the progression of Alzheimer's disease. Others mourn in stages. If I can choose, I choose the latter. I believe it will be in my nature to do that. After all, this time, I was grieving the loss of the man he once was. Can it be that it will be easier when there is less to lose? Once it's all over, does the ongoing mourning — whether constant or in phases — diminish the final grief. Do we become grateful that the end has come?

The search for these answers substantially conflicts with my day-at-a-time approach to the disease. But, I believe it's healthy to examine our feelings, mourn our losses, and face the reality when we get hit broadside as I did. Perhaps it would have been better to consciously open myself to do it before it came rushing in without warning.

Lately, Don has done several things that remind me that his strength of personality still shines through. I cannot assume anything about what is still there and what is not. For example, he has been thinking about taking advantage of the local YMCA's weekly senior free day of exercise. While considering it, he remembered that when he signed up last year, he ran into great difficulty with writing his name and remembering his address and phone number. It had embarrassed him, and he hadn't been able to articulate his problem to them. This time he asked me if I could make him a little card on the computer that says what he has and that it causes problems with talking and writing. I was taken aback and impressed. Not only had he remembered the event from last year, but he had found a way to handle it and was willing to give it a try once again.

This is the kind of thing that makes me fall in love with him all over again. I am going to choose to not mourn daily. When the feelings come, I want to acknowledge them and let them come for as long as they exist. **I will cry, but I also will laugh.**

– Judy Bow. Courtesy Rush Alzheimer's, Disease Center NEWS.

MONDAY July 2

Legal/Financial Seminar
Time: 12 Noon – 1:30 p.m.
Place: Chapter office

THURSDAY July 5

Orientation Meeting for Caregivers
Time: 8:30 - 10:00 a.m.
Place: Chapter office

Queens Orientation Meeting for Caregivers
Time: 12:30 – 2:00 p.m.
Place: Samuel Field YM-YWHA Cape Conference Room 59-28, Little Neck Parkway, Little Neck, NY

Medicaid Home Care Seminar: A Practical Guide to the System
Time: 5:30 – 7:00 p.m.
Place: Chapter office
Prior attendance at a Legal/Financial Seminar required.

MONDAY July 9 **NEW MEETING**

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter office
Topic: Understanding and Coping With the Stresses of Caregiving. Two Workshops for 1) Adult Children, and 2) Spouses and Siblings

TUESDAY July 10

Orientation Meeting for Professionals
Time: 9:30 – 11:00 a.m.
Place: Chapter office

WEDNESDAY July 11

Orientation Meeting for Caregivers
Time: 5:30 – 7:00 p.m.
Place: Chapter office

FRIDAY July 13

Orientation Meeting for Caregivers
Time: 12 Noon – 1:30 p.m.
Place: Chapter Office

MONDAY July 16

Medicaid Home Care Seminar:
A Practical Guide to the System
Time: 12 Noon – 1:30 p.m.
Place: Chapter office
Prior attendance at a Legal/Financial Seminar required.

Legal/Financial Seminar
Time: 5:30 – 7:00 p.m.
Place: Chapter office

WEDNESDAY July 18

Orientation Meeting for Caregivers
Time: 5:30 – 7:00 p.m.
Place: Chapter office

TUESDAY July 24

Orientation Meeting for Caregivers
Time: 12 Noon – 1:30 p.m.
Place: Chapter office

ALL MEETINGS ARE FREE OF CHARGE

The NYC Chapter Office is located at 360 Lexington Avenue (between 40th and 41st Streets), 5th floor, New York, N.Y. 10017.

We wish to thank CAPE at the Samuel Field YM-YWHA for the generous donation of space for the Queens Orientation meetings.

THURSDAY July 26

Legal/Financial Seminar
Time: 5:30 p.m. – 7:00 p.m.
Place: Chapter office

WEDNESDAY August 1

Easing the Transition from a Home to a Residential Care Facility
Time: 6:00 – 8:00 p.m.
Place: Chapter office

THURSDAY August 2

Orientation Meeting for Caregivers
Time: 8:30 – 10:00 a.m.
Place: Chapter office

Queens Orientation Meeting for Caregivers
Time: 12:30 – 2:00 p.m.
Place: Samuel Field YM-YWHA Cape Conference Room 59-28, Little Neck Parkway, Little Neck, NY

Medicaid Home Care Seminar: A Practical Guide to the System
Time: 5:30 – 7:00 p.m.
Place: Chapter office
Prior attendance at a Legal/Financial Seminar required.

MONDAY August 6

Legal/Financial Seminar
Time: 12 Noon – 1:30 p.m.
Place: Chapter office

WEDNESDAY August 8

Orientation Meeting for Caregivers
Time: 5:30 – 7:00 p.m.
Place: Chapter office

FRIDAY August 10

Orientation Meeting for Caregivers
Time: Noon – 1:30 p.m.
Place: Chapter office

MONDAY August 13

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter Office
Topic: Coping With AD: Early, Middle, and Late Stages
New! Special Session for Spanish-speaking caregivers.

WEDNESDAY August 15

Orientation Meeting for Caregivers
Time: 5:30 – 7:00 p.m.
Place: Chapter office

MONDAY August 20

Medicaid Home Care Seminar:
A Practical Guide to the System
Time: 12 Noon – 1:30 p.m.
Place: Chapter office
Prior attendance at a Legal/Financial Seminar required.

Legal/Financial Seminar
Time: 5:30 – 7:00 p.m.
Place: Chapter office

THURSDAY August 23

Legal/Financial Seminar
Time: 5:30 – 7:00 p.m.
Place: Chapter office

TUESDAY August 28

Orientation Meeting for Caregivers
Time: Noon – 1:30 p.m.
Place: Chapter office

WEDNESDAY September 5

Easing the Transition from a Home to a Residential Care Facility
Time: 6:00 – 8:00 p.m.
Place: Chapter office

THURSDAY September 6

Orientation Meeting for Caregivers
Time: 8:30 – 10:00 a.m.
Place: Chapter office

Queens Orientation Meeting for Caregivers
Time: 12:30 – 2:00 p.m.
Place: Samuel Field YM-YWHA Cape Conference Room 59-28, Little Neck Parkway, Little Neck, NY

Medicaid Home Care Seminar:
A Practical Guide to the System
Time: 5:30 – 7:00 p.m.
Place: Chapter office
Prior attendance at a Legal/Financial Seminar required.

MONDAY September 10

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter office
Topic: Meeting the Special Needs of Persons with Dementia in Health Care Settings

WEDNESDAY September 12

Orientation Meeting for Caregivers
Time: 5:30 – 7:00 p.m.
Place: Chapter office

THURSDAY September 14

Orientation Meeting for Caregivers
Time: 12 Noon – 1:30 p.m.
Place: Chapter office

MONDAY September 17

Medicaid Home Care Seminar: A Practical Guide to the System
Time: 12 Noon – 1:30 p.m.
Place: Chapter office
Prior attendance at a Legal/Financial Seminar required.

WEDNESDAY September 19

Orientation Meeting for Caregivers
Time: 5:30 – 7:00 pm.
Place: Chapter office

THURSDAY September 20

Legal/Financial Seminar
Time: 5:30 – 7:00 p.m.
Place: Chapter office

MONDAY September 24

Legal/Financial Seminar
Time: 5:30 – 7:00 p.m.
Place: Chapter office

TUESDAY September 25

Orientation Meeting for Caregivers
Time: Noon – 1:30 p.m.
Place: Chapter office

Early Stage Group at the Chapter Office – Openings for the Early Stage Group are currently available. This group is aimed at helping individuals who have been told they have a diagnosis of early stage Alzheimer's Disease. Members need to be able to acknowledge their memory loss and communicate their feelings and experiences. Information & support are offered by professional leaders. A personal interview is required. Call the group leader for an appointment before attending the group.

**Early Stage Group
at the Alzheimer's Association
360 Lexington Avenue
(40th & 41st Streets)
TIME: 11:30 A.M. – 1:00 P.M. Fridays
CONTACT: Sheila Crandles
212-983-0700**

PLEASE NOTE: Orientation Meetings for families new to Alzheimer's disease are held five times a month in the Chapter office and once a month in Queens. The dates are listed above.

All meetings subject to change. Please call (212) 983-0700 for more information, and to reserve a seat. Reservations are mandatory for all meetings.

*This article is a collaborative effort of the New York City Alzheimer's Disease Centers:
Mount Sinai School of Medicine, NYU Silberstein Aging & Dementia Research Center
and Taub Institute at Columbia University*

What is Mild Cognitive Impairment?

Many individuals are concerned about memory problems as they get older, and ask themselves whether memory loss is normal or an early indication of a more serious problem. Signs of impaired memory, discovered by poor performance on cognitive tests, may be an early sign of what is called Mild Cognitive Impairment (MCI). Clinicians have been trying to understand the problems associated with MCI, an important condition receiving increased medical attention. As the possibility of preventing or delaying the onset of Alzheimer's disease with pharmacological agents has moved closer to becoming a reality, MCI has become the focal point of many research activities.

What is MCI?

People with MCI have memory decline and often other cognitive problems that are somewhat worse than are experienced by most older adults. While they are forgetful, they are able to function fairly normally in their everyday activities. However, many people with MCI will gradually become worse and receive a diagnosis of dementia within several years.

How is MCI evaluated?

Individuals with MCI have a very different experience from people with Alzheimer's disease when they receive the results of an evaluation of their memory problems. They are generally told that they have a mild but significant problem that may or may not get worse. The possibility of further deterioration to a diagnosis of Alzheimer's disease may concern people, but many will not deteriorate significantly. MCI is evaluated through a combination of assessment by a trained clinician and objective cognitive tests. There must be a significant decline in cognitive functioning, but no other causes for cognitive problems such as neurologic disorders, psychiatric illness, substance abuse, or serious medical illness. A CT or MRI scan can help rule out some possible causes for these excessive memory problems. Studies have estimated that between about 5% and 17% of older adults may have MCI.

Are there treatments for MCI?

For some people, MCI is a stage of decline between normal aging and dementia. For others, it is a condition that will remain stable or even improve. Currently, there are no pharmacological treatments that have been proven to benefit people with MCI. All three Alzheimer's Disease Centers (ADCs) in New York City are currently conducting MCI clinical trials of potentially helpful drugs. One of the largest of these (*The Memory Impairment Study*) is being conducted by the Alzheimer's Disease Cooperative Study, a federally funded, nationwide consortium of ADCs. In this study, people with MCI are treated with Vitamin E (an antioxidant), Aricept (an FDA approved treatment for Alzheimer's disease) or placebo. Subjects with MCI are being followed over a three-year treatment period to determine whether long term treatment with Vitamin E and Aricept can delay further decline and a diagnosis of Alzheimer's disease.

The NYU-ADC, in collaboration with the Alzheimer's Association, is currently conducting a study to understand the psychological and emotional impact on older adults of being told they have MCI. The goal is to develop supportive, non-drug interventions that would be helpful to them.

Readers comments or suggestions for future topics are invited.

Please write to: Jed Levine, Director of Programs and Services

Alzheimer's Association, NYC Chapter

360 Lexington Avenue, 5th Floor · New York, NY 10017 or e-mail to: Jed.Levine@alz.org.

We will respond in future newsletters.

CURRENT CLINICAL TRIALS AT THE NYC ALZHEIMER'S DISEASE CENTERS

Silberstein Aging and Dementia Center – New York University

Clinical trial of Galantamine for mild cognitive impairment (MCI): Galantamine (Reminyl) is a new cholinesterase inhibitor that has recently been marketed for the treatment of AD. This study will test its effectiveness in delaying AD in individuals with mild cognitive impairment. Participants will receive either galantamine or a placebo for up to two years, with visits to the Center every three months.

Clinical trial of CP-457, 920 for AD: This study will test the effectiveness of an interesting, novel drug treatment in patients with mild to moderate Alzheimer's disease. Subjects will receive either this new compound, or the marketed drug Aricept, or a placebo for a period of three months. Patients will be required to make visits to the Center every two weeks.

Clinical trial of Neotrofin for AD: This interesting compound has neuroprotective effects and may slow the progression of AD. The current study will test higher doses than previously examined. Patients with mild to moderate AD will receive either this compound or a placebo, but all participants will eventually receive Neotrofin. The total period of the study is 6 months.

Clinical trial of Memantine in AD: In a recent study, this novel compound, which may have neuroprotective and memory enhancing effects, improved symptoms in patients with relatively severe AD. The new study seeks to confirm these results by treating AD patients with either Memantine or placebo for 6 months.

To learn more about these and other clinical trials at NYU, call the Clinical Trials Coordinator at 212-263-5708.

Taub Institute — Columbia University

Alzheimer's Disease Vitamin Study: A study for people with Alzheimer's disease to determine whether vitamins B12, B6 and folate can reduce levels of homocysteine. Reducing levels of homocysteine may be beneficial in slowing disease progression. To learn more, call Gina Garcia-Camilo at 212-305-5805.

Dementia Prevention Study: Researchers at Columbia University are seeking healthy women 65 years of age and older who have a family history of AD or memory problems for a four-year, placebo controlled study to determine whether estrogen can prevent memory loss. Participants will be paid. To learn more, call Evelyn Dominguez-Rivera at 212-305-5805.

Memory Study: Researchers at Columbia Presbyterian Medical Center are seeking men and women aged 55 and older, with and without memory problems, to participate in a study examining memory and other thinking processes. Participants will be paid for a one-time visit to our medical center. To learn more, call Effie Mitsis at 212-305-1927.

Healthy Adults 60+: People over the age of 60, in good health, without memory problems who wish to participate in a research study on understanding normal aging and memory, may earn \$10/hr at Columbia-Presbyterian Medical Center (Res. Found. For Mental Hygiene). No medication is prescribed. Call Yesenia Camacho at 212-543-5956 for more information. Spanish-speaking participants welcome.

Mount Sinai School of Medicine

Guanfacine/Aricept Study: We are currently conducting a study which combines Guanfacine, or a matching placebo, with Aricept, to test improvements in cognition and behavior associated with Alzheimer's Disease. All patients are eligible for 1 additional year of treatment upon completion of the study - at no cost. For more information please contact Stacey Kleinbaum at 212-241-1514.

HomeFree Study: The purpose of this study is to determine if the HomeFree device reduces the time spent caring for someone with Alzheimer's disease (AD). The HomeFree device is designed like a digital watch. It contains a computer chip that sends out an alarm if the AD individual enters an unsafe area of the home, or attempts to leave the home unsupervised. The study is open to mild to moderate AD persons living at home, and residing with a caregiver. For further information about the study please contact Elizabeth Fine, CSW at 212-241-5673.

Capacity to Discuss Advance Directives: This is an interview study for those who have been diagnosed with Alzheimer's disease (AD) and their caregivers. The interview will give the AD individual a chance to learn about advance directives (documents that allow you to give directions for your future medical care). This discussion will offer the opportunity to ask questions, and talk about these issues with a doctor and family members. To find out more about the study, please call Dr. Margaret Sewell at 212-241-0438.

Dear Friend:

During the week of **Monday, October 1 – Sunday, October 7, 2001**, we will be in the midst of our **“Week to Remember Alzheimer’s”** activities once more. A full week’s schedule of events has been designed to remember those who have Alzheimer’s disease, and honor those who care for them.

October 1-7, 2001 will be our sixth annual **“Week to Remember Alzheimer’s”** – a consciousness-raising time during which we reach out to the community to make the services and educational programs of the Alzheimer’s Association, New York City better known – especially to those who may need our help.

“A Week to Remember Alzheimer’s” 2001 activities will include:

- **Mayor’s Proclamation**
Presented during a special Memory Walk 2002 “kick off” breakfast hosted by the Mayor at Gracie Mansion on May 17
- **The following buildings will be aglow in purple, our signature color:**
 - October 1-8 The Zeckendorf Towers
 - October 1-5 Con Edison
 - October 2-4, 9-11 The Empire State Building
- October 3 - **SAFE RETURN “Good Samaritan” Awards Presentations**, for outstanding recoveries of lost Alzheimer’s patients (Ceremony will begin at 10:00 A.M. at One Police Plaza)
- October 1 – 7 Book signings and Alzheimer’s-related displays at local Barnes & Noble book stores
- October 7 – **MEMORY WALK 2001, A Celebration of New York**
Registration and Walk begin at 9:00 A.M. at South Street Seaport, Pier 16

We are soliciting friends of the Alzheimer’s Association, New York City to make a contribution so that we will have the resources necessary to continue to help the growing number of families touched by this dreaded disease. All contributors of \$50 or more will be listed in a full-page tribute in *The New York Times* just before or during **“Week to Remember Alzheimer’s”**. This ad will be completely underwritten.

The many, many families our Chapter has been able to assist have expressed their thanks in many ways. Here are two excerpts from letters sent to Chapter staff:

“Words can’t express my thanks to you for the assistance, warmth and care you pulled together to aid my mother in getting her help. Her situation can’t be changed, but through your efforts she now is less stressed and can sleep easier at night.”

~ From a Daughter

“It’s nice to know that there’s not only someone else who understands the exact situation that I am now facing, but that there is someone who I can talk to objectively and intelligently...(the Chapter’s) meeting were a great comfort for me ...mainly because of your strong, sensitive, compassionate leadership of the group. I was appointed my wife’s Guardian several years ago so her life is now in my and God’s hands. Thank you for planting the seeds of love and responsibility that have been given to me. Bless You.”

~ From a Husband

The people who wrote these touching words are expressing their deepest thanks to you. You, the friends who through your generous past donations have made it possible for the Chapter to help.

Please support our ***“Week to Remember Alzheimer’s”*** as generously as you can. Your donation means a great deal to the tens of thousands we serve who suffer with the disease, and to those who provide care through its duration.

Sincerely,

Jack Pollock

Chairman

“A Week to Remember Alzheimer’s”

PS Your contribution must be received no later than July 20, 2001 for you to be included in our New York Times ad. (A \$50 minimum is required to be listed due to space constrictions.)
All contributions are fully tax-deductible.



Holocaust Reparations

Question: My mother has been receiving Holocaust reparations for many years. I understand that for purposes of Medicaid eligibility Holocaust reparations are exempt as income and resources, but must be segregated from other savings. My mother's reparations have been combined over the years with her retirement savings. May the reparations payments still be considered exempt?

Answer: Yes! It is generally assumed that to be an exempt resource the accumulated payments received by Holocaust survivors must be segregated from other savings such as retirement funds. This assumption, unfortunately, has led to many cases in which Medicaid was incorrectly denied. The applicable New York State regulation only requires that those exempt funds be "identifiable." Thus, reparation payments that have been commingled will be considered exempt providing the Holocaust payments are documented as having been received.

Paying for Another's Medical Care

Question: I am helping my friend pay for her medical costs. Last year I spent more than \$10,000 on her behalf. Is this a gift for which a tax may have to be paid?

Answer: Each year a person may transfer up to \$10,000 to another person free of gift tax. Significantly, there is no dollar limit on the amount a person can give each year for the benefit of another person's medical care. However, the gift must be made directly to the medical provider (such as the doctor or the home health care

agency). This gift can be made in addition to the annual gift tax amount.

Question: My friend is living at home and I am paying for her medical care. I also pay a portion of her rent and other personal expenses. Last year I spent more than \$15,000 on her behalf. May I deduct her medical expenses from my income?

Answer: You are entitled to deduct her medical expenses from your income providing that she is your dependent. For her to qualify as your dependent, you must furnish more than one-half of her total support during the calendar year. If indeed she qualifies as your dependent, you are then entitled to an itemized deduction for her medical expenses to the extent that they exceed 7.5% of your adjusted gross income. You may also claim her as an exemption.

Medigap Insurance for the Medicaid Recipient

Question: My mother recently entered a nursing home as a Medicaid-covered patient, Should she cancel her Medigap insurance?

Answer: Medigap insurance is specifically designed to supplement Medicare's benefits. Depending upon the particular plan, a Medigap insurance policy will pay various deductibles and copayments which Medicare will not pay. Medicaid may also pay those deductibles and copayments, including the 20% of the approved amount for doctor services (not paid by Medicare). Nevertheless, there are many physicians that your mother may want to visit outside of the nursing home who

will not accept Medicaid. To cover the 20% coinsurance in those instances, your mother is well advised to maintain her Medigap policy. Note that her monthly payment for the Medigap insurance is a deduction from her surplus income that she otherwise would be required to pay to the nursing home.

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Contributions Gratefully Acknowledged in Memory Of:

March 1 ~ May 31, 2001

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We have made every effort to acknowledge contributions and spell names correctly. If we have inadvertently omitted or misspelled your name, please let us know. We depend upon our friends to keep us going financially through donations, tributes, and bequests.

Medicaid 2001 Planning Checklist

The following represent the essential elements of Medicaid planning and the options available under law to protect the Medicaid applicant's home and resources for the benefit of the spouse, family members and friends. The following is not intended to explain the issues in depth but to serve as a reminder that there are sound planning strategies available to conserve assets.

- ✓ **Protecting the Home:** Generally, for long-term care planning it is inappropriate to transfer ownership of a house or apartment to another person. Such a direct transfer may incur a substantial period of ineligibility for Medicaid nursing-home coverage along with a costly tax result. A more desirable alternative which eliminates tax liability and significantly reduces the Medicaid penalty period is to transfer the home to a trust that provides that the occupants have the right to continue to live in the house for the remainder of their lives.
- ✓ **The Rule of Halves – Never Too Late to Shelter Assets:** An individual who has assets in excess of the Medicaid limits may protect approximately 50% of his assets and qualify for Medicaid even if he is facing immediate placement in a nursing home or already is in a nursing home!
- ✓ **Getting the Medicaid Application Right:** The preparation of the Medicaid application for either home care or nursing-home coverage requires the services of a legal professional who is familiar with the constantly shifting rules of maximizing the amount of assets to be protected, including the house or apartment; securing the appropriate Medicare supplemental health insurance; managing the disbursement of personal injury awards and settlements; properly identifying Holocaust reparations and other exemptions; and resolving the disposition of taxes, life insurance, pensions and annuities.
- ✓ **The Durable Power of Attorney:** A properly drafted Durable Power of Attorney with broad gifting powers is an essential planning instrument for purposes of Medicaid planning. Without it, a guardianship may be required to access an individual's funds.
- ✓ **No Penalty Period for Medicaid Home Care:** There is no period of ineligibility for transfer of assets when an individual applies for Medicaid home care regardless of the amount of assets transferred or when they were transferred.
- ✓ **Nursing Home Eligibility:** With proper legal planning, the maximum period during which a Medicaid applicant may be counted ineligible for Medicaid nursing-home coverage is 36 months for transfers to individuals and 60 months for transfers to trusts. Note that the 36-month or 60-month window is a look-back period not a penalty period. The penalty period may be much shorter or, in some cases, avoided entirely with proper legal planning.
- ✓ **Financial Protection for the Well Spouse:** A married couple does not have to spend down its savings to the statutory level of approximately \$87,000 before the unwell spouse applies for Medicaid nursing-home coverage.
- ✓ **Conserving Assets of Disabled Persons:** A disabled individual may enjoy the benefits of an inheritance, personal injury award or his own funds in excess of the approved amounts – and not jeopardize his eligibility for Medicaid and other entitlements – with the establishment of a Supplemental Needs Trust.

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Are You a Widow/Widower of an Alzheimer's Patient? Or Do You Know Someone Who Is?

You can help others learn more about your unique experiences with loss. A graduate student doing a thesis wants to contact widowed caregivers of spouses with Alzheimer's disease, in order to learn from their experiences in order to help others. If you are at least 60 years of age and widowed at least a year, or if you know someone who is, please contact Karen Gleeson and you will receive a short questionnaire. All results will be kept completely confidential, and your name will not be used. Karen Gleeson, 560 Dean Street, Apt. 3L, Brooklyn, NY 11217 or you may call (718) 783-4196 or email <karenglee@earthlink.com>

Caregivers Program

The Caregivers Program is designed for Alzheimer's individuals and their caregivers (family or paid). The program provides education and support to caregivers, and maximizes functional ability of individuals with memory problems. The program is offered once a week for 7 weeks, and is offered in Spanish and English. To find out more about the program contact Feroza Marker, OTR at 212-241-9250.

Family Adjustment to Nursing Home Placement Study

If you are a family member of a new nursing home resident, admitted within the past month and are the primary person responsible for the resident, you could be a part of a research program to learn more about the experiences and needs of family caregivers after nursing home placement. Placing a loved one into a nursing home is one of the hardest things an individual will ever have to do. The information you provide will be used to develop better services for families like yours, offering crucial help in this stressful time. The purpose of the study, sponsored by a grant from the National Institutes of Health, is to learn what it is like to place a family member in a nursing home. Participants will receive \$25 for each interview that they complete, for a total of \$50. Participants will also receive a report of the study results. The interviews will last about one hour and will be conducted at a time that is convenient for you. The interview can be conducted at either your home or the nursing home. You will be interviewed again four months later. You are free to change your mind at any time. The nursing home will not learn about any of your answers. For more information contact: Dr. Deborah Majerovitz • York College, City University of New York • 94-20 Guy R. Brewer Blvd. • Room 4D-06 • Jamaica, New York 11451 • (718) 262 2498 • majerovitz@york.cuny.edu.

Support Groups for Latinos

The New York City Chapter, Cobble Hill Health Education & Wellness Center, and the NYC Latino Alzheimer's Taskforce will hold a training for professionals: "Early Stage Support Groups for Latinos" in the summer. For more information, call Elizabeth Figueroa at (718) 858-9508.

Our On-Line Store

If you would like to purchase books, obtain free literature, or help support the Alzheimer's New York City Chapter, please visit our website: www.alzheimernyc.org, where you will find a link to our online store and donations page. If you would like to obtain a copy of our bibliography, please call Yvette Bynoe at 212-983-0700 Ext. 217 or e-mail at Yvette.Bynoe@alz.org.

Coming This Fall! Dementia Care Mapping: A Person-Centered Approach to Care

Dementia Care Mapping is a new method of evaluating and improving the quality of care that is given to persons with dementia in day centers, residential homes, geropsychiatric units or any other formal care settings. A three-day Basic Course presented by Health Hill Institute will be offered at two New York Chapters of the Alzheimer's Association this fall. The Long Island Chapter will co-sponsor the course with Chestnut Grove on September 12-14, 2001 and the **New York City Chapter** will host the course on October 24-26, 2001.

Developed in England at the University of Bradford and pioneered by the late Tom Kitwood, author of *Dementia Reconsidered*, Dementia Care Mapping (DCM) is based on the principle of person-centered care. DCM can be used to deliver clear and reliable information as an aid to quality assurance programs, as a tool to identify staff training and development needs, and as a means of evaluating the effective use of care planning.

Heather Hill Institute is part of the University Hospitals Health System Heather Hill Hospital & Health Partnership, a 250 bed healthcare continuum in Chardon, OH, specializing in innovative programs for persons with dementia. This course is designed for those who have a special interest in improving the quality of formal care, staff training and developmental issues in dementia settings.

For further details, please contact Eileen Lipstreuer, Director of Marketing – Dementia Services at Heather Hill (440) 279-2477 or by email at elipstreuer@heatherhill.org

Memory Diagnostic Evaluations Also Available for Spanish-Speaking Persons

The Multicultural Memory Evaluation Program (MMEP) offers comprehensive diagnostic memory evaluations for persons over the age of 50 who are experiencing memory loss and other cognitive impairments. Evaluations can be performed in Spanish for monolingual Spanish patients. The MMEP is part of the NYU Silberstein Aging and Dementia Research Center. Call Dr. Angelica Perez or Enitza Carril for an appointment or to find out more about our services: (212) 263-2245.



*Mark Your Calender for
Monday, August 6, 2001!*

On that date the NYC Chapter of Alzheimer's Association will sponsor an evening of dinner and chamber music.. The event will be held at the Barge, a unique concert hall in a converted tobacco barge, moored at the foot of the Brooklyn Bridge.

Because seating at the Barge is limited, you will be "right in the middle of it." Tickets will be priced reasonably. Parking is free.

We expect a huge demand for this event, so "first come, first served."

Look for your invitation in the mail.

Memory Walk 2001

Memory Walk is a Sunday morning walk sprinkled with entertainment, and highlighting notable New York sites and personalities. Mayor Giuliani, our Memory Walk 2001 Chairman, along with Mets great Keith Hernandez, is expected to lead over 3,000 participants. This year, we will begin and end the walk at Pier 16 at South Street Seaport where we can picnic and enjoy the water views from both piers, as well as fantastic entertainment.

Memory Walk 2001 provides a terrific opportunity for family members, caregivers and friends to demonstrate their love for those diagnosed with Alzheimer's disease and their families, as well as support for those who are working to manage and conquer it. The Chapter will provide badges that can be personalized to honor a loved one for all walkers. Again this year, we are positioning our Memory Wall at the Seaport at the end of the walk. During your picnic lunch and while you enjoy the entertainment; your badges, posters, photographs and other mementos can be displayed on it. (The Alzheimer's Memory Wall will remain on exhibit at Pier 16 for 3 days.)

Each registered walker is eligible for prizes and all walkers receive refreshments, identifying wristbands and other goodies. \$100 will get each Memory Walker a Memory Walk 2001 tee-shirt, however walkers are encouraged to collect additional contributions and obtain as many pledges as possible in support of their participation. Aim high – help us reach our goal of a minimum of \$200 per walker!

- Raise \$100 and receive the official Memory Walk 2001 tee-shirt
- Raise \$200 and receive the official Memory Walk 2001 tee-shirt and cap
- Raise \$500 and receive the official Memory Walk 2001 tee-shirt and hooded sweatshirt
- Raise \$800 and receive the official Memory Walk 2001 tee-shirt and windbreaker
- Raise \$1000 and receive the official Memory Walk 2001 tee-shirt and leather varsity jacket



Check out our new route!

BECOMING A TEAM BUILDER FOR OUR 2001 "WALK" . . .

We are encouraging as many companies, organizations and individuals as possible to build teams of ten or more walkers to participate and win prizes. We also are asking that your company send us the names of community outreach or human resources representatives so that we can contact them to increase walker turnout in 2001. You can also be part of our Memory Walk 2001 Committee. Your ideas and enthusiasm can make Memory Walk 2001 a great success for all! Be creative and put the fun back in fundraising. Boost your team's fundraising efforts with some fun competition and great incentives. Discover your group's fund-raising potential! Prizes will be awarded for the largest team, best t-shirt, top fundraising team, youth team, corporate team, most spirited team, and more! If you are interested in being a team leader or joining our Memory Walk 2001 Committee please call Alyson Raifman, Special Events Coordinator at 212-983-0700, ext 220.

Last year the top three fundraisers turned in a total of more than \$35,000 to fight Alzheimer's disease. Congratulations and thank you!! The top corporate team to 'walk the Walk' fielded a team of over 300 members...*more* congratulations and thank you, *too*!!

AIM HIGH - Raise \$200 in a week . . . *7 ways 7 days* . . . to get people to contribute to Memory Walk. All you have to do is ask! It is a great cause and here is a simple plan.

Day 1	Put in your own contribution	\$25
Day 2	Ask your spouse/partner	\$25
Day 3	Ask 2 relatives for \$20	\$40
Day 4	Ask 3 friends for \$15	\$45
Day 5	Ask 4 co-workers for \$10	\$40
Day 6	Ask 5 neighbors for \$5	\$25
Day 7		\$200!

Set a goal for yourself. **And join us on October 7, 2001 at South Street Seaport!**

MARK YOUR CALENDARS FOR OCTOBER 7! AND SET YOUR PERSONAL AND TEAM GOALS AT \$500, \$1000, \$5000 OR MORE!

Memory Walk 2001

Sunday, October 7, 2001 ~ South Street Seaport

REGISTRATION FORM

My Fund-Raising Goal is: _____

Name _____

Title _____

Company/School _____

Address _____ State _____ Zip _____

Phone (w/area code) _____ Fax (w/area code) _____

e-mail address _____

I will be walking as (circle one) *a team captain* *a team member* *an individual*

If you are on a team complete the following: Team Name _____

Representing (name of organization/school/company) _____

I am walking in honor/memory (circle one) of _____ Please send me additional materials:

- Information on forming a Memory Walk team
- Brochures (indicate quantity) _____
- Information on the Alzheimer's Association - New York City Chapter
- Information on volunteer opportunities

I am unable to walk but:

- Enclosed is my contribution of (circle one)
\$1000 \$500 \$250
\$100 \$50 \$25 other _____

Please make all checks payable to: The Alzheimer's Association - New York City Chapter

I wish to contribute by credit card:

American Express # _____

Visa # _____

MasterCard# _____

Exp. Date _____

Signature: _____

Please fax or mail this response form to:

Memory Walk 2001 Event Office · 7 Park Avenue · Suite 26 · New York, New York 10016
Telephone: 212-725-7141 • Fax: 212-725-7149

SUPPORT GROUP OPENINGS

The New York City Chapter currently sponsors over 85 Family Support Groups for spouses, adult children, siblings, etc. Some support groups are composed of only spouses (S) or adult children (C), while others are mixed (M), that is, made up of all different caregivers. Before attending a group you first need to call the group leader to schedule a personal interview. The Chapter is hoping to start a new group aimed at serving family members caring for individuals with early onset Alzheimer's disease, which means they were diagnosed at a young age, (from 30 to 60 years). If you are interested in this new group or if you have any questions about our support groups, please contact our Support Group Coordinator, Sheila Crandles, at 212-989-0700, Ext. 214. Openings are now available in the following support groups:

BROOKLYN

Mixed Groups

Sephardic Community Center

(Ocean Parkway & Avenue S)

DAY AND TIME 10:30 A.M. – 12 Noon Mondays

CONTACT: Miriam Shamah 718-627-4300, ext. 227

Jewish Community House (Bay Parkway & 78th Street)

DAY AND TIME: 10:30 A.M. – 12:00 P.M. 1st & 3rd

Thursdays

CONTACT: Janie Eisenberg 212-243-5135,

Carol Landau 516-764-2277

Neptune Avenue (Ocean Parkway)

DAY AND TIME: 3:00 – 4:30 P.M. 1st & 3rd Thursday

CONTACT: Jack Pollock 212-721-3537,

Pearl Goldfarb 718-377-0737

Young Israel of Avenue I (Midwood)

DAY AND TIME: 6:00 – 7:30 Wednesday

CONTACT: Fred Moskovitz 718- 252-2580

NEW GROUP CURRENTLY BEING FORMED

MANHATTAN

Council Senior Center (West 72nd St.)

DAY AND TIME: 12:00 Noon – 1:30 P.M. Fridays

CONTACT: Ruth Rothbart Mayer 212-799-7205

(There is a concurrent activities program for persons with mild/moderate dementia.)

3 New Groups Currently Being Formed

Mixed Group

West 56th Street & Broadway

DAY AND TIME: 2:00 -3:15 1st & 3rd Tuesday

CONTACT: Barbara Bloom 212-262-8179

Spouses' Group

St. Vincent's Manhattan

DAY AND TIME: 2:00-3:30, 2nd & 4th Tuesday

CONTACT: Rosemarie Greene 212-604-7332

Adult Children's Group

West 56th Street & Broadway

DAY AND TIME: 12:15-1:30 P.M. Thursdays

CONTACT: Deborah Rubin 212-757-4202

There are openings in the following 3 daytime groups held at the Chapter Office: - 360 Lexington Avenue, between 40th & 41st Streets.

Adult Children

DAY AND TIME: 12:45 – 2:00 P.M.

Every other Wednesday

CONTACT: Lorraine Ruggieri

212-362-6500

Mixed Groups

DAY AND TIME: 2:00 – 3:30 P.M. Thursdays

CONTACT: Susan Hason 646-486-3840, Eleanore

Rothenberg 212-831-5586

360 Lexington Avenue (40th & 41st Streets)

TIME: 12:30 – 1:30 P.M. Every Other Friday

CONTACT: Marge Blaine 718-469-5308

QUEENS

Hillside Hospital (Glen Oaks)

DAY AND TIME: 11:00 – 12:00 1st & 3rd Wednesday

CONTACT: Lisa Weissman 718-470-8140, Jennifer

Chillemi 718-470-8447

Save The Date! ✓

Second Annual Early Stage Conference

Friday, December 7, 2001

Grand Hyatt Hotel in New York City

8:00am



Someone to Stand by You

New York City Chapter

360 Lexington Avenue

5th Floor

New York, NY 10017

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