

360 Lexington Ave., 5th Floor  
New York, NY 10017  
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Volume 18, Winter 2001



*Someone to Stand by You*

## An Important Letter from the Executive Director

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**New York City Chapter  
Newsletter**

**Y**ou've probably noticed our newsletter's altered look. Instead of the glossy paper we've used for years, this edition is (and future ones will be) printed on less expensive, lighter, and non-glossy stock as an economy measure. With difficulty, we have just been obliged to carve more than \$250,000 out of a \$3.3 million annual operating budget previously approved by the Board of Directors. Income is simply not keeping up with expenses. Office and program supplies, conference participation, printing costs, staff travel (local and long distance), even a staff position already approved but not yet filled, these and other projected expenses have been reduced or fallen victim to the necessary austerity. Further cuts, should they become necessary, will have us confronting decisions about the very programs on which our community depends and for which we are in business.

What has brought us to such dire straits? Undoubtedly the impact of an adverse stock market has left and continues to leave its mark. Reduced portfolios mean less money to go around. Competition, always fierce, is fiercer still as numerous worthy charities clamor for attention and support. And the unspeakable tragedy of September 11<sup>th</sup> will undoubtedly cloud the future of fundraising for months, perhaps years, to come. We grieve and are saddened, but the need continues.

And so we turn again to you, our valued friends, supporters and clients. We know you're out there – generous individuals, organizations, foundations and corporations – since when it comes to the needs of our community, you've always come through for us before.

Within the past several weeks you should have received our Year End Campaign letter soliciting your support. It's more crucial than ever that you help us now. Please. Be as generous as you can so that the New York City Chapter, your chapter, will remain that singular source of information and support that can make all the difference for hard-pressed New Yorkers, those afflicted and their caregivers, facing the tragedy of Alzheimer's disease. Another envelope is enclosed for your convenience.

Thank you very much. Here's wishing you all the very best for the holidays and peace in the coming year.

**John A. Jager**  
Executive Director



*Bill Ritter, co-anchor of WABC-TV and Master of Ceremony at Memory Walk 2001, officially welcoming teams and walkers.*

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Visit our website at: [www.alzheimernyc.org](http://www.alzheimernyc.org)



*June Schofield, NYC Chapter  
volunteer, preparing breakfast yogurt  
and donuts for participants of  
Memory Walk 2001.*



*Below: Angela Rickher and Laura Wilson  
of Program Services at our National  
Office presenting John Jager, Executive  
Director of the NYC Chapter donations  
collected from staff members at the  
National office.*



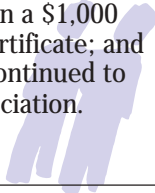
*Miss New York State, Andrea Plummer  
and Miss New York City, Alice  
Budman announcing the Memory Walk  
2001 raffle winners.*

Memory  
Walk 2001



Our annual fundraiser, scheduled for October 7 of this year was a Memory Walk, for which we anticipated three thousand walkers over a route that was to include the World Trade Center and World Financial Center. We held instead, a gathering at the South Street Seaport, for which, under the circumstances, we felt fortunate to have a thousand people in attendance. It was a wonderful and inspiring event.

Many, many thanks to all the participants and volunteers! You made this year a special one! Three outstanding fundraisers this year were Florence Cohen, captain of the "Stark Striders Team", who won two Continental Airline tickets to anywhere in the USA; Milton Miller, a member of an Alzheimer's Association support group team and Board Member, who won a \$1,000 Brooks Brothers gift certificate; and Marjorie Shapiro who continued to raise funds for the Association.



We acknowledge with gratitude the financial support of more than 90 chapters of the Alzheimer's Association, their staff members and boards, as well as colleagues from our National office in Chicago, all of whom contributed generously to the NYC Chapter's Memory Walk, helping to offset major financial losses resulting from the September 11 tragedies.



Alice Stockton Rossini, anchor at 1010 WINS radio addressing the participants.



Members of the Elsai team manning their table.



Sandra Martinez, the NYC Chapter's Development Associate registering individuals at Pier 17.

## Thank You Sponsors!

### National Sponsors:

GE- Long Term Care Insurance

### Local Sponsors:

1010 WINS \*Atwood Designs Systems \*AXA Financial \*Barnes & Noble \*Bowne Printing \*Bristol-Myers Squibb \*Brooks Brothers \*Castle Senior Living \*Continental Airlines \*Dannon \*Digital Angel \*Eisai/Pfizer \*Hearthstone Alzheimer Care \*Hill & Knowlton \*Isabella Geriatric Center \*Krispy Kreme \*Lawrence Stevens Fashion \*Marsh & McLennan \*MetLife \*New York Design Center \*Novartis \*Sequoia Restaurant \*South Street Seaport \*Savoy Retirement Communities \*South Street Seaport Museum \*Sunrise Assisted Living \*Vitamin Shoppe \*WABC-TV



Team members of the Savoy Retirement Communities.

## Editor's Note

This year's Memory Walk was overshadowed—as everything else has been—by the events of September 11.



Because the route we had planned to follow veered into the restricted zone near Ground Zero, the decision was made to move the event indoors. We had the top floor atrium space in the Pier 17 building at the South Street Seaport all to ourselves. In some ways this was an improvement, because it meant that everyone was on hand to provide an audience for the speakers (WABC-TV news anchor Bill Ritter emceed) and the entertainers rather than proceeding along the Memory Walk course. And the "Walls of Remembrance" were as evocative of Alzheimer's human toll as ever.

However, even before Sept. 11, we began to experience the flow of contributions dry up. The Chapter has too much to do to rely on just a trickle of funds—we must have a surge! The economic slowdown may explain some of the shortfall, but my own feeling is that many whom we have helped, advised and supported turn away from us when their loved one finally becomes part of the A.D. death toll.

I felt this desire for a break myself, but it was only a temporary reaction. Then I realized that A.D. would never be "over" for me or my family, and we still had to make the effort for the next generation. That's why I am proposing that all you battle-hardened A.D. veterans—or should I say survivors—become part of an informal Alzheimer's Alumni Association. Discover the satisfaction of helping us out, of offering us support—and know that we can also be of service in your bereavement, if need be.

—Chris MacLeod

# PUBLIC POLICY UPDATE:

All New York has been directly or indirectly deeply affected by the devastating and tragic events of September 11th. In the aftermath, thousands upon thousands of persons of all ages in New York City are in need of services to help them cope with unimaginably difficult times. Among those in need of support services are both persons with Alzheimer's and their caregivers. The Alzheimer's community's need for services, always an issue, has only intensified. Persons with Alzheimer's lost those who cared for them. Caregivers themselves lost family and friends.

These terrible events of September 11th took place at a time when the state legislature and the governor had been unable to resolve the budget issues of funding for human and social services. As you know, the state legislature passed a "bare bones" budget in August which did not provide for these needs throughout the state. At the time of this writing, the legislature is scheduled to reconvene, and a "supplemental budget" to include human and social service needs is being sought by advocates throughout the state. As of now, the outcome is unknown. But we do know that the tens of billions of federal and state dollars needed to provide disaster relief to New York City will be of first importance.

Nevertheless, our Coalition of New York State Alzheimer's Association chapters through its 2002 Legislative Agenda must continue to advocate for quality home and community-based and residential care for persons with Alzheimer's. Our priority issues will include the following:

- Seek funding and support to advance the work of the chapters and the Alzheimer's Disease Assistance Centers (ADACs) in providing education, training, counseling, support services and diagnostic services;
- Seek mandated dementia care training for staff to promote quality of care in home and community-based and residential care;
- Seek funding for in-home, overnight and social adult day care respite services to provide for and assure caregiver relief.

Your participation in advocacy efforts in New York in 2002 will be welcome and needed. Please contact the New York City Chapter if you want to join with us.

Ann Berson  
Public Policy Coordinator  
October 2001



## Caregiver Corner ~ El Rincón del Cuidador

### TWELVE STEPS FOR CAREGIVERS

1. Although I cannot control the disease process, I need to remember I can control many aspects of how it affects me and my relative.
2. I need to take care of myself so that I can continue doing the things that are most important.
3. I need to simplify my lifestyle so that my time and energy are available for things that are really important at this time.
4. I need to cultivate the gift of allowing others to help me, because caring for my relative is too big a job to be done by one person.
5. I need to take one day at a time rather than worry about what may or may not happen in the future.
6. I need to structure my day because a consistent schedule makes life easier for me and my relative.
7. I need to have a sense of humor because laughter helps to put things in a more positive perspective.
8. I need to remember that my relative is not being "difficult" on purpose; rather that his/her behavior and emotions are distorted by their illness.
9. I need to focus on and enjoy what my relative can still do rather than constantly lament over what is gone.
10. I need to increasingly depend upon other relationships for love and support.
11. I need to frequently remind myself that I am doing the best that I can at this very moment.
12. I need to draw upon the Higher Power which I believe is available to me.

### DOCE PASOS PARA EL CUIDADOR

1. Aunque no puedo controlar el proceso de la enfermedad, necesito recordar que puedo controlar muchos aspectos de como me afecta a mi y a mi familia.
2. Necesito cuidarme para poder continuar haciendo las cosas que son importantes.
3. Necesito simplificar mi vida para que mi tiempo y energía estén disponibles para las cosas que son realmente importante en este momento.
4. Necesito cultivar el don de permitir a otros que me ayuden, porque cuidar a mi ser querido es un trabajo muy grande para una persona.
5. Necesito tomar un día a la vez, en vez de preocuparme de lo que pueda o no pueda pasar en el futuro.
6. Necesito estructurar mi día porque un horario regular hace la vida más fácil para mi ser querido y yo.
7. Necesito tener un buen sentido del humor porque la risa ayuda a poner las cosas en una perspectiva positiva.
8. Necesito recordar que mi ser querido no esta siendo "difícil" a proposito; más bien su comportamiento y emociones son distorcionadas por la enfermedad.
9. Necesito enfocarme y disfrutar con mi ser querido lo que el/ella todavia puede hacer en vez de lamentar las cosas que ya no están.
10. Necesito depender cada vez más de otras relaciones para recibir amor y apoyo.
11. Necesito recordar que estoy haciendo lo mejor que puedo en este momento.
12. Necesito recurrir a un Poder Superior el cual se que esta disponible para mi.

# BREAKING NEWS ABOUT MEDICARE

## From the Medicare Advocacy Project

### Medicare Advocacy Project Scores Significant Victory

In a significant development, The Centers for Medicare and Medicaid Services (formerly HCFA) recently issued a Program Memorandum, which prohibits the automatic denial of claims for medical services based solely on the diagnosis of dementia. A Program Memorandum provides specific rules and guidelines for the Medicare program. For years, Medicare has refused to pay for some medical services for beneficiaries with Alzheimer's disease solely because of their diagnosis. Beginning immediately, Medicare will not use the dementia diagnostic codes alone as a basis for determining whether Medicare covered services are reasonable and necessary. The Program Memorandum, *Medical Review of Services for Patients with Dementia*, can be obtained on line at <http://www.hcfa.gov/pubforms/transmit/AB01135.pdf> or from Leslie Fried at the Medicare Advocacy Project.

### How This New Policy Will Affect Individuals with Alzheimer's Disease

The new Program Memorandum explains that due to advances in diagnostic techniques, physicians and psychologists can diagnose individuals with certain dementias at the earliest stages of the disease. It makes clear that individuals with Alzheimer's disease may benefit from pharmacological, physical, occupational, speech and other therapies. Therefore, Medicare will cover evaluation and management visits and therapies if these therapies are reasonable and necessary for the Alzheimer's beneficiary. For example, if an individual with Alzheimer's disease has an unsteady gait and physical therapy is necessary, Medicare will pay for the individual's physical therapy. Medicare payment of medical services and procedures will be determined based on the individual assessment and needs of the Alzheimer's beneficiary, rather than denied solely because of the dementia diagnosis. For more information:

Leslie B. Fried, ABA/Alzheimer's Association  
Medicare Advocacy Project  
[friedl@staff.abanet.org](mailto:friedl@staff.abanet.org)  
(202) 662-8684

Centers for Medicare and Medicaid Services (formerly Health Care Financing Administration): [www.hcfa.gov](http://www.hcfa.gov);  
[www.medicare.gov](http://www.medicare.gov)

*Prepared by Leslie B. Fried, ABA/Alzheimer's Association  
Medicare Advocacy Project*

*This project is supported in part by a grant from the Archstone Foundation.*

*October 2001*

## VACCINE / nfo

The Phase IIA trials of AN-1792, the Alzheimer's vaccine began in September 2001, and will be completed in September 2003. 375 patients with mild to moderate AD are being studied at eleven sites in the US and several in Europe. The trial is a randomized, double-blind, placebo-controlled study, which means that some participants, chosen at random, will be given the vaccine by injection; others will be given an inactive substance. Neither the participants nor the researchers will know who received the actual vaccine until the trials are completed. The goal of the study is to evaluate the clinical impact of creating an immune response (formation of antibodies) to the A-beta peptide in persons with AD.

This is the second part of a three part process to test a drug for safety and effectiveness before it is allowed on the market. Phase I trials established the safety of the vaccine in a small sample of persons with AD. There is no evidence yet that the vaccine will be effective in human subjects, and there are many other theories about effective treatment of AD that are being tested in other trials.

None of the investigational sites are in the Northeast. They are in Arizona (2), California (3), Florida (3), Minnesota (1), Oklahoma (1), and Texas (1). It is our understanding that as of this writing, the AN-1792 trials are either no longer recruiting subjects and will not accept participants from out of their area. We encourage you to consider participation in other local AD trials at centers in New York City. For information on trials in the three federally funded NIA - Alzheimer's Disease Centers (ADC's) please see the insert in this newsletter. For information on other trials, please see the Bulletin Board section, or go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov), the website of the National Institutes of Health. Information on the vaccine trial can be found by clicking on *Randomized Safety, Tolerability and Pilot Efficacy of AN-1792 in Alzheimer's Disease*.

Jed A. Levine



## THE HANDHOLDER'S HANDBOOK

By Rosette Teitel

A book serves many purposes both for the reader and for the author. For the reader, a book may inform, provide pleasure, stimulate thought, and help to distract the mind from the cares of the day. For the author a book may not only serve these functions, but, as in the case of *The*

*Handholder's Handbook*, may also serve to contend with the pain of a prolonged and calamitous episode.

In twelve carefully planned chapters, Rosette Teitel comes to terms with the realization that her husband of many years has Alzheimer's disease, and after the initial shock, embarks on a plan to cope with its awful reality. Less a handbook than a compilation of anecdotal incidents intermingled with very detailed practical advice, she explores such topics as the diagnosis and progression of the disease, how to survive, how to help and get help, and much more.

In a provocative and thoughtful chapter titled, "Sources of Strength and Courage," Ms. Teitel discusses many aspects of support for the caregiver as well as the ways in which a caregiver copes with the problems of dealing with an Alzheimer patient. Acknowledging that while family members may generally be supportive, she believes that many are not only uncertain about what to do, but are also ill-equipped to contend with the stresses and strains that so frequently erupt when dealing with dementia. While the caregiver rightfully expects the support of a child or sibling, such support may be withheld, and in a telling passage she asserts that a grown child, although an adult, is still a parent's baby, and as such may be powerless to provide the needed support.

Lack of support from friends can be particularly disturbing to the caregiver who may desperately need to shore up his or her personal resources. Making the point that friends are chosen rather than "born to," such lack of support can be devastating. Suggesting that forgiveness is therapeutic, the author recommends that you do not eliminate from your life those who could not be available to you in a time of great stress.

In a discussion of the three ways in which caregivers generally deal with patient problems: criticism, encouragement, and active management, Ms. Teitel cites studies that have shown that managing a patient with criticism is associated with poor adjustment of a caregiver to a new role, while the opposite is true of encouragement. Interestingly, while active management takes account of a variety of ways to safeguard, help, stimulate and monitor the patient in an effort to vary the daily agenda, active management and criticism are both associated with a greater sense of burden as well as a greater desire to institutionalize the patient. While no single managerial strategy works for all caregivers, the important thing for the caregiver to understand, and to accept, is that dementia is progressive and not subject to control, and that a patient's bizarre behavior is not intentional. With that understanding comes a degree of acceptance as each caregiver develops his own strategy for coping with this, the most difficult of all illnesses.

- Bernard Saper

### "I Need Now to Rest for a While"

*In the time I cared for you,  
I watched you,  
felt you,  
knew you,  
better than I watched, felt or knew myself.  
In the time I cared for you,  
we were together  
greater  
than your suffering alone.  
I need now to rest for a while.  
I am exhausted  
from watching,  
feeling,  
knowing,  
caring  
beyond myself.  
I need now to rest for a while.  
I need to get watched,  
feel,  
know myself better.  
I need to find some concerns,  
my own concerns,  
because  
I am now alone.*

- John Warner

This poem was given to Jane Zierer by another member of the Grief Recovery Workshop run by Ronnye Haplern.



Sharon B. Shaw, CSW, top left, with graduates of Fall 2000 Support Group Leader Training Workshop. The workshop, held 3 times a year, prepares new leaders for family caregiver and early stage support groups.

## ASK ELLICE



**QUESTION:** *Last month, while residing in a nursing home, my mother fell out of her wheelchair and broke her hip. This is the third time she fell; and I am seriously considering filing a lawsuit against the home. But Mother is on Medicaid, and as I understand the rules, she may have no more than \$3,750 in resources. My question is — what is the point in filing an action against the facility if under the rules all the proceeds of the action must go to the government?*

**ANSWER:** There is every reason to file the action against the nursing home, assuming you believe there was serious negligence on the facility's part. Under both Medicaid and Health Department laws and regulations, you would be entitled to keep *all* the proceeds of the case and still get full nursing home Medicaid benefits. First, the Medicaid rules discount any income received as the result of a legal action against a nursing home because of improper and/or inadequate treatment. Second, the New York State Public Health Law gives nursing home patients the right to sue a facility for the violation of the patient's bill of rights, including the right to receive non-negligent care, and specifically exempts the proceeds from such a suit as income and/or resources in consideration of the resident's eligibility for Medicaid. Of course, many residents and their families would find it most problematical to file a lawsuit against a facility while still remaining there; and even though there are strong laws on the books against retaliatory action by a facility, these lawsuits are extremely rare. Then there is the issue of the amount of damages the resident could recover. Under our tort system, the "worth" of an individual is ordinarily determined by computing potential lost future earnings. Thus, if a young person is permanently injured or dies, there is a lifetime of earnings to be compensated for. But if the injured party is old, the law says there is no

"value" or actual damages, for which the tortfeasor need compensate the resident. Thus, the value of an elderly person's injury is ordinarily determined by punitive damages, or pain and suffering. For example, in the case of a truly negligent fall from a wheelchair, a family recently recovered \$45,000 as pain and suffering — and while Medicaid tried to recoup these funds, the family was allowed to keep the personal injury award and full Medicaid benefits as well. Other examples of common nursing home injuries, all of which would give rise to a violation of the patient's bill of rights, include: failure to receive the correct medicines; the right to be free from pressure or "decubitus" ulcers; the right to be free from malnutrition and dehydration; the right to eat and not have a feeding tube placed in the resident unless absolutely essential to the resident's medical care — and then to have the tubes properly administered; and the right to be free from negligent scalds and burns.

**QUESTION:** *Mother recently entered a hospital from her nursing home, is a Medicaid patient, and wants to return to the facility. Unfortunately, the facility is refusing to take her back. Is there anything I can do?*

**ANSWER:** Yes. There are two rules which protect the resident here. First, under the Medicaid rules, Mother is

entitled to a "bed hold" of 15 days after leaving the nursing home. This means that Medicaid will pay the nursing home for that 15 day period to hold the bed for Mother until she returns to the facility while she is being treated in a hospital. In addition, the resident is entitled to receive an additional 5 days on bed hold for good cause shown. What is rarely recognized however is *even after the 20 day traditional bed hold period has expired*, the former resident of a nursing home still in a hospital is entitled to the next available bed at his or her home nursing home. So even if the 20 day period has lapsed, be sure to ask if Mother's former facility has any suitable available beds. Assuming the patient could be adequately treated there, the facility can not refuse to take the patient back.

*We invite your inquiries. Please send them to the Alzheimer's Association, New York City Chapter's office.*

\* \* \* \* \*

**\*Ellice Fatoullah** served on the Board of the Alzheimer's Association, New York City chapter, and as Chair of its Public Policy Committee for seven years. She is the principal of Fatoullah Associates, a law firm specializing in Elder Law planning and litigation issues, with offices in New York City, and New Canaan, Connecticut.



## Graduates

On September 5<sup>th</sup>, the Association's Training Center was the setting for a special graduation ceremony for 15 home care attendants who successfully completed an intensive Training in Dementia Care. The participants are employees of the Central Harlem Home Attendant Program and All Metro home care agencies. Certificates of Achievement were awarded to the graduates as agency staff, family members and friends proudly looked on. Following the ceremony, a reception was held to celebrate the graduates' accomplishments. All in all, it was a very festive and memorable occasion. Congratulations again to the graduates!

~ Paulette Michaud

## WEDNESDAY January 2

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

## THURSDAY January 3

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 January 7

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

## TUESDAY January 8 **\*\*New Meeting\*\***

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

## WEDNESDAY January 9

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

## FRIDAY January 11

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

## MONDAY January 14

Educational Meeting  
Time: 6:00 – 7:30 p.m.  
Place: Chapter office  
Topic: Getting Through: Effective Communication With The Person Who Has AD  
Speaker: Kassie Witte, MS, FAAA

## WEDNESDAY January 16

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

## TUESDAY January 22

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

## THURSDAY January 24

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

## MONDAY January 28

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

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

## MONDAY February 4

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

## WEDNESDAY February 6

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

## THURSDAY February 7

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

### 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 the following for their generous donations of space for the Orientation Meetings: CAPE at the Samuel Field YM-YWHA, CNR, Fort Washington Houses, and The Park Slope Geriatric Day Center, Inc.

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.

## FRIDAY February 8

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

## MONDAY February 11

Educational Meeting  
Time: 6:00 – 7:30 p.m.  
Place: Chapter office  
Topic: A Frank Discussion About End of Life Issues and Treatment Options  
Speaker: Judith Ahronheim, M.D., Chief of Geriatrics, St. Vincent's Medical Center

## WEDNESDAY February 13

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

## WEDNESDAY February 20

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

## THURSDAY February 21

**\*\*Nueva Reunión\*\***  
**Introducción a la enfermedad de Alzheimer**  
Hora: 5:30 – 7:00 p.m.  
Lugar: Park Slope Geriatric Day Center, 1 Prospect Park West, Brooklyn

## MONDAY February 25

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 and Financial Planning Seminar required.

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

## TUESDAY February 26

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

## THURSDAY February 28 **\*\*New Meeting\*\***

Orientation Meeting for Caregivers  
Time: 4:00 – 5:30 p.m.  
Place: CNR, 596 Prospect Place, Brooklyn

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

## MONDAY March 4

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

## WEDNESDAY March 6

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

## THURSDAY March 7

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.

## FRIDAY March 8

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

## MONDAY March 11

Educational Meeting  
Time: 6:00 – 7:30 p.m.  
Place: Chapter office  
Topic: Understanding Anger From The Perspectives of The Caregiver and The Person With AD  
Speakers: TBA

## WEDNESDAY March 13

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

## THURSDAY March 14

Brooklyn Educational Meeting  
Time: 10:00 a.m. – 12:00 p.m.  
Place: TBA  
Topic: Legal and Financial Planning; Medicaid Update

## MONDAY March 18

Medicaid Home Care Seminar:  
A Practical Guide to the System  
Time: 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 March 20

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

## THURSDAY March 21

Bronx Educational Meeting  
Time: 10:00 a.m. – 12:00 p.m.  
Place: TBA  
Topic: Legal and Financial Planning; Medicaid Update

## TUESDAY March 26

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

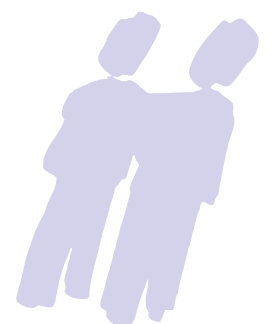
### **\*\*Nueva Reunión\*\***

**Introducción a la enfermedad de Alzheimer**  
Hora: 5:30 – 7:00 p.m.  
Lugar: Fort Washington Houses  
99 Fort Washington Avenue

## THURSDAY March 28

Queens Educational Meeting  
Time: 10:00 a.m. – 12:00 p.m.  
Place: TBA  
Topic: Legal and Financial Planning; Medicaid Update

Legal and Financial Seminar  
Time: 5:30 - 7:00 p.m.  
Place: Chapter office



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

# Speaking with your doctor about treatments for Alzheimer's Disease: What to Ask and What to Expect to Hear

An important step in obtaining appropriate health services is communicating with health-care professionals - knowing what questions to ask your doctor. All too often patients and caregivers are unaware of what to ask and how to proceed in finding adequate treatment. By making some preparation in advance, individuals can help play an active role in the quality of their medical care and establish a good patient-doctor relationship.

An appropriate comprehensive evaluation for Alzheimer's disease (AD) is critical for diagnosis, and includes a medical and psychiatric history, neurological evaluation, and cognitive testing. Laboratory tests that are used to determine the cause of memory disorders include complete blood count, blood chemistry, B12 and folate, thyroid function tests, syphilis test, and neuroimaging (MRI or CT Scan). Your physician (a doctor specializing in neurodegenerative diseases such as AD) may be instrumental in coordinating your medical care and ordering the appropriate tests.

If a probable diagnosis of AD has been determined, (a definitive diagnosis can only be done upon an autopsy), the following questions may be asked of the physician:

## **1. What treatment options are available for the cognitive changes in a person with AD?**

While there is no cure for AD, a number of medications can improve cognition or slow decline of the illness. In general, these medications are recommended for patients who are in the mild to moderate stages of the illness. The Food and Drug Administration has approved four medications (tacrine, donepezil, rivastigmine and galantamine) for the treatment of AD, all of which belong to the class of cholinesterase inhibitors. These agents improve cognition and overall function in some individuals with AD. Other medicines are currently being investigated for their potential to delay onset or slow the progression of Alzheimer's disease. These include antioxidants, estrogen, anti-inflammatory agents, and anti-amyloid agents. Alpha-tocopherol (vitamin E) has been shown to delay decline in moderate stage patients. While estrogen may delay the onset of dementia in women, it has not been shown to slow the course of the illness once it has been diagnosed. Anti-inflammatory agents may delay the onset of AD, but have not been shown to slow the course of the illness. Patients may choose to use these drugs for their other benefits, but they should not be started to improve the symptoms of AD, except by participants in a clinical trial. Ginkgo biloba has not yet been demonstrated to have a significant effect for patients with AD. Medicines that interfere with the production of amyloid show promise, and are now being tested on a very limited basis in research settings.

## **2. What about other so-called "memory improvement" products?**

There are many products on the market that claim to have beneficial effects on memory. Many are classified as nutritional agents or supplements and therefore can be purchased without a doctor's prescription. Typically, there is little clinical research to truly see if they have any efficacy. Some of these agents may interfere with other medications or be harmful if taken in large amounts. Contact your doctor for further advice.

## **3. Are there research studies for which a person with AD could be eligible? How should they be evaluated in terms of potential risks and benefits?**

Fortunately, there is much interest in the development of new treatments for AD. People often fear that they are "guinea pigs" if they enter research. Prior to administering any new medication to people, several steps have been performed to determine their safety. Also, all research studies are very closely monitored to ensure patient safety. If you participate, you may not gain direct benefit from these programs yourself, yet you will contribute to the important mission that strives to treat or cure AD. Feel free to ask your doctor if he or she knows of research studies. Another way to find out about clinical trials for AD is to call your local chapter of the Alzheimer's Association or the Alzheimer's Disease Education and Referral Center (800-438-4380). If there is a study of interest to you, you may wish to share this information with your doctor, who can advise you about whether a study is appropriate for you or your relative with AD. Keep your doctor informed if you decide to participate to help the doctor monitor medical care.

#### **4. Is there help for the AD person who is having changes in mood or behavior?**

People with AD are at increased risk of developing behavioral disturbances, including agitation, sleep disruption, appetite changes, anxiety, depression, apathy, paranoia, delusions (believing things that are not true) or hallucinations (seeing or hearing things that are not actually present). If any of these behaviors cause distress for the person with AD or the caregiver, they should be discussed with the patient's physician. A variety of medicines can treat these behaviors. The doctor will choose a specific medication based upon the target behavior, side effect profile, pre-existing medical conditions, and other medications already being prescribed for the patient.

#### **5. What other assistance is available that could be helpful to the AD person and the family?**

Providing care for an individual with AD can be a very stressful experience. Family caregivers are at increased risk of experiencing depression, anxiety, financial strain, social isolation, or substance abuse. Education and counseling have been shown to help caregivers cope and delay the placement of patients in nursing homes. Family caregivers and patients can also benefit from support groups, where they can share their feelings and learn ways to manage their responsibilities and functional impairments. Persons with AD may also benefit from attending adult day care programs. Hiring a home health aide can help to reduce the burden of caring for the AD person. Information about these services is available through your local chapter of the Alzheimer's Association.

### ***Current Clinical Trials at the NYC Alzheimer's Disease Centers***

#### **Mount Sinai Medical Center – Alzheimer's Disease Research Center**

**CATIE Study:** Many people with Alzheimer's disease suffer from hallucinations, delusion, agitation, or aggression over the course of the illness. These symptoms place a huge burden upon caregivers and can often necessitate nursing home placement. The National Institute of Health is sponsoring a nationwide study to determine the most effective treatments for these symptoms. Participants will receive detailed evaluations, free medications and monitoring for nine months. For information, please contact Hillel Grossman, MD at 212-659-8736. This is a Mount Sinai School of Medicine IRB approved study. GCO#99-0052(2), IRB approved through 9/30/02.

**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. GCO #84-119. MSSM IRB approved from 8/1/00 to 3/31/01

**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 which 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 AD persons living at home who live with a caregiver. For further information about the study please contact Elizabeth Fine, CSW at 212-241-5673. GCO #00-1010PS, IRB approved through 12/31/01.

**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 and 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. GCO #00-0266. MSSM IRB approved from 9/11/00 to 5/14/01.

#### **Taub Institute at Columbia University**

**Memantine Study:** we are seeking men and women, 50 or older, with an NINCDS-ADRDA diagnosis of Alzheimer's Disease to participate in a study to evaluate the safety and efficacy of Memantine versus placebo in the treatment of moderate to severe AD. To learn more, call Leslie Reyes at 212-305-2077.

**Dementia Prevention Study:** We 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.

**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 at 212-305-5805.

**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.

**Genetic Linkage Study:** We are seeking Caribbean Hispanic families from the Dominican Republic for a study to identify genes that may increase the risk for AD. If you have at least two living family members diagnosed with AD, please call Vincent Santana at 1-877-636-5677 or Jennifer Williamson at 212-305-4655.

**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.

**Study for Healthy Seniors:** Studies are planned to develop measurement instruments to be used for the prevention of AD. Healthy seniors aged 75 and older, who would like more information about this study, may call Ruth Tejada at 212-305-5805.

## **William and Sylvia Silberstein Aging and Dementia Research Center New York University School Of Medicine**

### **UPCOMING STUDIES FOR ALZHEIMER'S DISEASE AND MILD COGNITIVE IMPAIRMENT**

#### **Study for Normal Volunteers**

**ADCS Instrument Project for Primary Prevention:** Normal elderly volunteers who are at least 75 years of age will be evaluated once a year for four years as part of a study to improve the design of future primary prevention trials for Alzheimer's disease. Participants will receive cognitive evaluations annually and will also be eligible for free books about aging and memory.

#### **Trial for Mild Cognitive Impairment (MCI)**

**LY451395 for MCI:** Individuals with mild memory problems may participate in the evaluation of a novel compound that has potential to reduce memory loss. Treatment is for 18 weeks and participants will receive one of two doses of this compound or a placebo. Patients will be required to make 6 visits to the Center over the 18 week period.

#### **Trial for Alzheimer's Disease (AD)**

**LY451395 for AD:** Patients with mild to moderate Alzheimer's disease may also participate in the evaluation of this new compound. Subjects will be treated for 18 weeks and will receive one of two doses or a placebo. This novel medication has shown potential to enhance memory. Patients will be required to make 6 visits to the Center over the 18 week period.

For more information about these pharmaceutical studies, call the Clinical Trials Coordinator, at **(212) 263-5708**.

# 14th Annual Chapter Gathering

This year's gathering, held at The Rockefeller University, incorporated the twin pillars of our association's



support system, science and hope. After a brief welcome, board of directors co-president Irvine Flinn introduced special guest David Shenk. His book, "The Forgetting," is both comprehensive and compassionate as it surveys the Alzheimer's toll at both the personal and the societal level.

Mr. Shenk thanked the chapter's Jed Levine for allowing him access to an early stage support group (with their approval) that he was able to follow for two years—taking note of their issues and their eventual decline.

Shenk, noting a large and growing group of people who

have received an early diagnosis of Alzheimer's, says that many of these early-stagers will have their cognition intact for quite a while—a condition that new medications will sustain over an indefinite time period.

For the author, it was "humbling to see how caregivers rose to the challenge...and they're getting something back, too," he said. Despite "the pain, which can last the better part of a decade, [caregivers] are living in this rich inner core of humanity.

"This insidious disease slowly peels us away from ourselves," Shenk continued, "and when we do beat this disease, I don't think we'll want to forget about it; it tells each one of us who we are and what we're made of."

Then, co-president William Kaye presented the Chapter Recognition Awards to a richly deserving twosome, Tony and Margaret Finocchiaro. Over the past 12 years, Tony served as a Chapter director, treasurer and on the finance committee. Margaret was involved with Safe Return, the Help Line and in other volunteer capacities. The Finocchiaros are moving to Northern Virginia, where we hope they'll help out the local chapter.



*Special guest, David Shenk, author of "The Forgetting".*

Dr. Jeffrey N. Nichols, chief of Geriatrics at Cabrini Medical Center, described by Jed Levine as "a visionary hospital administrator who has set the standard of humane care for persons with Alzheimer's" and whose "holistic approach to institutional care" resulted in Cabrini's "Windows to the Heart." This, the first acute-care dementia resource in any hospital in New York City, has made a tremendous difference in how patient, caregiver and family members experience what can be the terrifying experience of hospitalization and helplessness. The Chapter "shares Dr. Nichols' vision of compassionate, person-centered care."

Many who attend our annual gathering look forward to the research update. This year, we had a presentation by the vice president of medical and scientific affairs of the National Alzheimer's Association, Bill Thies, Ph.D. He reminded us that the first patient diagnosed by Dr. Alois Alzheimer, in 1906, was only 51 years old. All along, this disease has been comparatively rare in

younger people. It was also difficult to persuade the medical establishment to think of Alzheimer's as separate from the normal aging process.

Dr. Thies remarked on how scientists have been able to recreate the pathology of A.D. (plaques and tangles) in mice, but that the intellect of those creatures is hardly comparable to that of humans, making research progress harder to measure.

The average person lives approximately seven years after being diagnosed with A.D. Yet the disease may be developing for 20 years prior to the observable symptoms. This, said Dr. Thies, offers a window of opportunity to prevent or postpone the onset. Many of the current studies seek to find if Vitamin E, ginkgo biloba, or statins (cholesterol lowering drugs) or anti-inflammatories have this effect. It has also been observed that people with low blood pressure, higher educational achievement and a lifestyle that includes regular exercise are less likely to develop A.D. Four drugs have been FDA approved—the latest, Reminyl, in 2001—and others (such as neurotrophins and cholinesterase inhibitors) are in the pipeline. The FDA website lists more than two dozen current and upcoming clinical drug trials related to A.D.

Dr. Thies enumerated the approaches current medical research is taking as (1) developing a vaccine against amyloid deposits (Elan Pharmaceuticals); (2) a secretase inhibitor to prevent the accumulation of amyloid plaques (at Bristol Myers-Squibb Gamma); (3) compounds that dissolve amyloids; and (4) compounds that attack TAU and tangles. Noting that no matter what the results, the current vaccine study will assist scientists, Dr. Thies was also heartened by the 450 research plans submitted in competition for the four research awards the Chapter presented next.

These grants, ranging from \$99,880 to \$240,000 over the next three years, were presented by Howard Bender and Natalie Post, members of the early stage support group and were awarded to Annat F. Ikin, Ph.D. (Mt. Sinai); Nikolaos Robakis, Ph.D. (Mt. Sinai); Einar M. Sigurdsson, Ph.D. (N.Y.U.) and Jonathan D. Smith, Ph.D. (Rockefeller University).

Executive director John A. Jager thanked everyone for attending, and drew our attention to David Shenk, who was signing copies of his book, with a portion of the proceeds going to the Alzheimer's Association.



*Vice-President of Medical and Scientific Affairs of the National Alzheimer's Association, Bill Thies, Ph.D.*



*Board Co-President, Irv Flinn congratulating Tony and Margaret Finocchiaro after receiving the Chapter Recognition Award.*



*(From left to right) Lynne Raymond, Director of Development NYC Chapter; Lou Davis, former Board Member; and Marilyn Cohen, Board Member.*

# AFTER THE DISASTER

As a city we have all been affected by the events of Sept. 11<sup>th</sup>. We would like to express our deepest sorrow to those whose lives have been altered by these tragic events.

Through the 24-hour Helpline, the support groups, the education programs, and Safe Return we have encountered families who are coping with the dual burden of the loss of a relative or friend who was in the World Trade Center, and caring for a family member with AD. We have helped families who have been displaced, forced to move from downtown, and in some cases, forced to move their relative with dementia. We have heard from those concerned about their relative who was experiencing additional anxiety and confusion, due to the stimuli of watching too much disaster coverage on TV. People called who needed someone to stay with their family member so they could attend a memorial service.

In the support groups we are witnessing increased feelings of grief, sadness, fear and anger, which has made caregiving more stressful.

We encourage families to call on the chapter to get help. We can provide counseling, information, referral, and assistance with care planning. The chapter has organized a wide network of respite providers who have generously agreed to assist families who have been affected by the disaster by offering their services on a "compassionate" basis.

## Some tips on caring for yourself in these stressful times:

- Try to take care of yourself, recognize that you have experienced great stress and try to be gentle and patient with yourself.
- If you are a caregiver, make time for yourself. Seek out community resources: home care, adult day care, and respite care. **Get a break from caregiving.** Ask a friend, neighbor or family member to help out.
- Be specific when you ask for help, such as staying with your relative to give you a break, or doing the laundry or shopping.
- Prioritize; make "to do" lists of things that must be done; put other tasks on a "wait" list.
- Set limits for yourself; you may want to learn/use relaxation or stress reduction techniques.
- Eat well-balanced meals, even if you don't feel like it.
- Increase fluid intake.
- Decrease use of caffeine and do not abuse alcohol or drugs
- Try to be aware of your feelings; don't be afraid to experience them and talk about them.
- Try to get plenty of rest, recognize that there may be temporary changes in your sleep patterns.
- Use your support systems – family, friends, colleagues, clergy, and support groups
- Be willing to ask for and accept the concern and help of others.

If your relative with dementia is repeatedly asking about the disaster, or is concerned about their safety use a calm reassuring approach. Give only the amount of information that they can process, which will be different for each individual, according to their stage of the illness. Use reassuring statements such as, "We are safe now" or "Our government has everything under control." Limit or avoid exposure to disaster related television or radio coverage. If the person is severely or persistently agitated seek appropriate medical/psychiatric evaluation and treatment.

Call the New York City Chapter's 24 hour Helpline at **212-983-0700** if you need to speak to someone about your caregiving situation, or if you need referral to a mental health professional. For emergencies, go to the nearest Emergency Room.

Jed A. Levine

(Tips partially adapted from the American Red Cross in Greater New York)

## My Mother Says She was Left Back

My mother ceases to eat.  
I say that eating was the last sign  
of her tenaciousness,  
the last expression of her passion  
except for rare outbursts of "I love you"  
or grabbing your hand or anyone's  
and kissing it.

Eating passionately did not, finally  
suffice. I say that first she died  
then she quit eating. Then she bid us goodbye.  
I say that what she was chewing in her last  
years  
didn't provide the nourishment she craved.  
It's amazing that she went on for so long.  
Perhaps  
what would have killed her, had she lived  
longer  
also kept from her a perspective through which  
she would have despaired.  
Or maybe a relentless, incommunicable despair  
that pervaded her being, was refracted  
through the prism of her dauntless soul  
into ecstasy or peace.

*I witnessed, fifty-four years earlier,  
her leaning over the side of a hospital bed  
in the Catskill Mountains, her face over a pan  
that my father held .*

*I'd slowly approached her as she was wheeled  
out of her room, an angelic look upon her face,  
a wan smile. She said to me  
"Don't worry, Mickey  
I'll be all right."*

Our mother's food-tray card read  
DOUBLE PORTIONS

and until she stopped eating, she'd scarf every morsel no matter what, and when the last spoonful was gone, lick the spoon, the cups, the bowls. If you put your hand on her arm then and said "How's it going, Mom?" she'd brush it aside. "You're going to eat me out of house and home. I sometimes said to her, as she once said to my brother and me. She also used to say, "All I have to do is *look* at food and gain weight!" and here she was eating everything in sight – even off someone else's tray when a new orderly sat her too close to one – and her body found an equilibrium at ninety-eight pounds. I wonder whether the plague and snarls in her ninety-five-year-old brain prevented her from appreciating that irony. I wouldn't bet on it; I don't give up on anyone, especially she who hadn't given up on me even when I'd given up on myself. People will surprise you like when I'd said to her a year before when she was dressed in calf-high white socks and a girlish dress, "Mom, you look like a schoolgirl today" and she glanced at me, turned her gaze to the table top in front of her. Then shouted "Yeah! - I was left back!"

~ Morty Sklar

# Honor/Memorial Contributors List

8/1/01 - 10/31/01

**Jules Aaronson**  
Susan Lawrence Kirschenbaum  
**Stella Abruzzese**  
Fred Abruzzese  
Mr. & Mrs. Thomas Adamo  
Ms. Fran Angeloro  
Helen Angeloro  
John & Marie Murphy  
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Community Advisory Program for the Elderly  
**Kathleen Amber**  
Building Owners' & Managers' Association of Greater New Y  
**Sally Anastasi**  
Alfonso & Hilda De La Barrera  
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**Conseuola Barcelo**  
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# Caregiver Corner

## Kitchen Safety

Providing a safe, secure home environment is a challenge for many Alzheimer's caregivers. The need to provide a protective and comforting home is important, both for the person with the disease and the caregiver. The bathroom and the kitchen are the two major "danger zones" and require special attention as most accidents happen in those rooms. The kitchen is the physical and emotional heart of many homes and an especially attractive place to people with dementia. Because of its popularity and potential dangers, you will need to pay special attention to making your kitchen safe for your family member. Families have devised many modifications for the kitchen to increase safety for the AD person, and reduce worry for the caregiver.

For example, in the early stage of the disease, your family member may still want to prepare meals or make a cup of tea and clean up afterwards. However, she may no longer have the ability to perform these tasks safely and properly. This may be a hard role for her to give up. At this time, you may want to make kitchen chores easier and safer to do while restricting only the potentially dangerous activities. For example, you may want to buy an electric tea kettle or install a circuit breaker on the stove so your relative can still cook- but only when you keep an eye on her.

As the person becomes more confused, you may have to limit her role to helping prepare food and cleaning up. This limitation can be very upsetting to people who are accustomed to cooking. During this period, you may have to put latches on cabinets and drawers to keep confused persons away from dangerous items. If you are concerned about breakage, consider buying plastic plates and cups. If your family member deteriorates further and still insists on helping out, you may have to install a gate or door and make the kitchen off limits. It is important to evaluate safety. Try to make the kitchen safe before you resort to making it off limits. This will cut down on the amount of "policing" that you may have to do.

Your changes should respond to the problems at hand. Your relative may continue doing kitchen tasks safely and independently at first, with supervision later on and, finally not at all. She may also just lose interest in the kitchen at some point.

**Here are some tips from caregivers that reduced the hazards for people with dementia in the kitchen.**

### THE STOVE

- \* Remove the knobs from the stove.
- \* Remove the burner knobs and tape the stem with masking tape.
- \* Install stove knob covers.
- \* Place an aluminum cover over the top of the stove completely hiding both the burners and the burner knobs.
- \* Replace a gas stove with an electric one.
- \* Turn off the stove's circuit breaker or remove the fuse.
- \* Replace the pilot on a gas stove with an electric starter.
- \* Lock the oven door
- \* Use a microwave

### THE REFRIGERATOR

- \* Put a lock on the refrigerator
- \* Prop up the front of the refrigerator so that the door closes automatically.
- \* Remove the door handle to the freezer, use a string pull to open the door and place the string on the top of the refrigerator, out of sight.

### THE SINK AND WATER

- \* If you have your own hot water heater, reduce the temperature in the heater to below the scalding point (approximately 120 degrees).
- \* Install automatic temperature mixers to regulate temperature safely.
- \* Install automatic shut-off mechanisms that turn off the hot water when it reaches a predetermined temperature and prevents burns.
- \* If flooding is a danger when the patient is unsupervised, some caregivers turned off the water using the valves under the sink.
- \* Remove the stopper from the sink, so it cannot easily flood.

### MISCELLANEOUS SAFETY TIPS

- \* Remove knobs from, or unplug appliances, such as the coffee maker, toaster or can opener.
- \* Cover a sharp counter edge with plastic padding.
- \* Install childproof latches for cabinets and drawers.
- \* Remove poisons, such as cleaning fluids, insecticides, etc., from accessible cabinets.
- \* Disconnect or camouflage the garbage disposal.
- \* Clear out the refrigerator of old food and things that might be harmful if consumed in large quantities, for example: old pickles, salad dressings, peppercorns, and exotic foods such as jalapeno peppers or sesame paste.

This article is, in part, an abridged excerpt from "Homes that Help: Advice from Caregivers for Creating a Supportive Home" by Richard V. Olsen, Ph.d. et al., published by The New Jersey Institute of Technology Press, 1993. (Published with permission from the author.)

You can purchase "Homes that Help" from the New York City Chapter, for \$15.00 plus \$4.00 shipping and handling. Please send your request and a check to the Alzheimer's Association, NYC Chapter, 420 Lexington Avenue, Suite 610, New York NY 10170, Attention: Yvette Bynoe.

# BULLETIN BOARD

## Marathon Swim (MIMS)

Support Group Member, Mark Dempsey raised nearly \$3,500 for the Alzheimer's Association of New York City. He completed the Marathon Swim, a 28.5 mile event through the East, Harlem and Hudson Rivers. It is the longest swim marathon held on an annual basis. The race starts and finishes at Battery Park and the Hudson River, just south of the Fire Boat House. Swimmers begin at the Battery then head north up the East River, counter-clockwise around Manhattan Island. They swim north into the Harlem River, through Spuyten Duyvil, and then south down the Hudson River to the Battery.

Thank you, Mark, and congratulations on your accomplishment.

## Surgical Treatment for Alzheimer's Disease

New York Methodist Hospital (Brooklyn NY) is enrolling participants for a study investigating the implantation of a surgical device to determine if it will stop or slow the progression of Alzheimer's disease. Candidates should be age 62-85, in the early or middle stages of Alzheimer's disease and in otherwise good health. Caregivers will be reimbursed for reasonable travel expenses. For more information please call 1-888-4MY-MIND or 1-888-469-6463

## The Sunday Program at CSC

Council Senior Center, a community program of the National Council of Jewish Women New York Section is pleased to announce a Sunday program on the Upper West Side of Manhattan for people with mild memory impairment. While providing respite for family caregivers, the program is designed to engage participants in energetic fun and stimulating recreation. This program is funded through the Van Ameringen Foundation. For information call Ruth Rothbart Mayer, 212-799-7205 ext. 18.

## Helpline Update

The New City Chapter is pleased to announce that we have extended our evening and weekend Helpline coverage to include Long Island. In partnership with the Long Island Chapter of the Association, several new volunteers from LI have been trained, and serve on the line. If you need to talk to someone for information, referral or support you can reach one of our trained Helpline specialists at **(212) 983-0700** 24 hours a day.

## TimeSLIPS Moving Announcement

The "TimeSlips" art exhibition, mentioned in the fall newsletter, was canceled due to new security precautions initiated at the Empire State Building, however, we're happy to announce that the exhibition has found a new home at the YWCA of the City of New York.

Artist Beth Thielen's fanciful sculptures, based on characters from stories created by people with Alzheimer's, may be viewed now through December 30th, 2001 at the Elsa Mott Ives Gallery/YWCA-NYC, located at 610 Lexington Ave @ 53rd Street. Gallery hours are Monday through Friday, 9:00AM-7:00PM and Saturday, 10:00AM-3:00PM. For gallery information, please call 212-735-9732, or visit [www.ywcanyc.org](http://www.ywcanyc.org).

Ms. Thielen's whimsical menagerie found its new home due to the support of a unique partnership including TimeSlips Project New York, the Alzheimer's Association - New York City Chapter, Brookdale Center on Aging/Hunter College, Grand Central Partnership and the YWCA of the City of New York.

# SUPPORT GROUP OPENINGS

The New York City Chapter currently sponsors over 100 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. If you have any questions about our support groups, please contact our Support Group Coordinator, Sheila Crandles, at 212-983-0700, Ext. 214.

## **BROOKLYN**

### **Mixed Group**

**Alzheimer's and Aging Resource Center** (Sheepshead Bay)

**DAY & TIME:** 1:30 – 3:00 PM Every Other Thursday

**CONTACT: Henni Fisher 718-646-7001**

(Although there is no out-of-pocket expense, if you have insurance your company will be billed.)

**Palm Gardens Adult Day Health Care Center**

**DAY & TIME:** 5:30 – 7:00 PM 1<sup>st</sup> & 3<sup>rd</sup> Monday

**CONTACT: David Yanofsky 718-438-5300**

**Methodist Hospital** (Park Slope)

**DAY & TIME:** 5:30 P.M. – 7:00 P.M. Every Other Wednesday

**CONTACT: Lianna Dressner 718-780-5533**

**Kings Bay Y** (Sheepshead Bay)

**DAY & TIME:** 7:30 – 9:00 PM 1<sup>st</sup> and 3<sup>rd</sup> Thursday

**CONTACT: Henni Fisher 718-646-7001**

(Although there is no out-of-pocket expense, if you have insurance your company will be billed.)

## **MANHATTAN**

### **Mixed Groups**

**Two Groups now at the Council Senior Center**

(West 72<sup>nd</sup> St.)

**DAY & TIME:** 11:00 – 12:30 P.M. Tuesdays

**CONTACT: Reeva Mager (of Dorot) 212-769-2850**

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

**CONTACT: Ruth Rothbart Mayer 212-799-7205**

*We thank the Council Senior Center for hosting Dorot's support group while Dorot is undergoing major renovations.*

**360 Lexington Avenue** (40<sup>th</sup> & 41<sup>st</sup> Streets)

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

**CONTACT: Susan Hason 646-486-3840**

### **New Mixed Group in Spanish**

**Mt. Sinai Medical Center \*** (5<sup>TH</sup> Ave & 98<sup>th</sup> St.)

**DAY & TIME:** 2:00 – 3:00 P.M. Mondays

**CONTACT: Debra Phillips 212-659-8989**

### **Daughter's Groups**

**360 Lexington Avenue** (40<sup>th</sup> & 41<sup>st</sup> Streets)

**DAY & TIME:** 12:30 – 1:30 P.M. Tuesdays

**CONTACT: Dawn Marrero 212-983-0700**

**West 56<sup>th</sup> Street & Broadway**

**DAY & TIME:** 12:15 – 1:30 P.M. Thursdays

**CONTACT: Deborah Rubin 212-757-4202**

**360 Lexington Avenue** (40<sup>th</sup> & 41<sup>st</sup> Streets)

**DAY & TIME:** 6:45 – 8:15 P.M. 1<sup>st</sup> & 3<sup>rd</sup> Wednesday

**CONTACT: Jeanne Lieb 212-496-1198**

### **Spouses' Groups**

**St. Vincent's Manhattan**

**DAY & TIME:** 2:00–3:30, 2<sup>nd</sup> & 4<sup>th</sup> Tuesday

**CONTACT: Rosemarie Greene 212-604-7332**

**360 Lexington Ave** (40<sup>th</sup> & 41<sup>st</sup> Streets)

**DAY & TIME:** 5:00 – 6:15 P.M. 1<sup>st</sup> & 3<sup>rd</sup> Tuesday

**CONTACT: Sheila Crandles 212-983-0700; Sharon Shaw 212-222-8924**

### **Adult Children's Groups**

**360 Lexington Avenue** (40<sup>th</sup> & 41<sup>st</sup> Streets)

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

**CONTACT: Marge Blaine 718-469-5308**

**C.V. Starr** (1<sup>st</sup> Ave & 85<sup>th</sup> Street)

**DAY & TIME:** 6:00 – 7:30 P.M. 1<sup>st</sup> & 3<sup>rd</sup> Tuesday

**CONTACT: Christopher Chin 212-879-7400, ext 108;**

**Susan Kunkel 212-746-7075**

## **QUEENS**

### **Mixed Group**

**Flushing Hospital** (Parsons Blvd.)

**DAY & TIME:** 2:00 – 3:30 P.M. 2<sup>nd</sup> & 4<sup>th</sup> Wednesday

**CONTACT: Trudy Chaiken 718-428-4278**

### **Adult Children's Group**

**Kew Gardens** (Queens Blvd. & Union Turnpike)

**DAY & TIME:** 6:00 – 7:30 P.M. 2<sup>nd</sup> & 4<sup>th</sup> Wednesday

**CONTACT: Joanne Loughlin 212-263-8395**

### **New Early Stage Group in Brooklyn**

**Alzheimer's and Aging Resource Center**

(Sheepshead Bay)

**DAY & TIME:** 1:30 – 3:00 P.M. Every Other Thursday

**CONTACT: Henni Fisher 718-646-7001**

(Although there is no out-of-pocket expenses, if you have insurance your company will be billed.)



Someone to Stand by You

New York City Chapter

360 Lexington Avenue

5th Floor

New York, NY 10017

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