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Volume 13, Fall 1998



*Someone to Stand by You*



Memory Walk ..... 19

## Chapter Expanding to Larger Quarters

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### **Passages, Closed Doors, and Windows of Opportunity**

**P**ASSAGES: The New York City Chapter of the Alzheimer’s Association was born of compassion, nurtured with generosity and inspired by the challenges confronting New York’s Alzheimer’s community in 1977. Its first year revenues were \$85,000. Over the past two decades the Chapter has grown into an organization with gross annual revenues of more than \$3 million. We currently operate with a staff of 20 employees, who are supported by 400 volunteers. Forty percent of our volunteers are health professionals, and *all* have been trained by Chapter staff to provide a broad range of services to the Alzheimer’s community.

Our mission is, as it was at the Chapter’s genesis, to support research until a cure is found, and to create and promote comprehensive, humane care while supporting persons with the disease, their families and caregivers. As the population ages, however, and with no cure for Alzheimer’s yet in sight, demands for the Chapter’s services and programs continue to grow.

These circumstances have created a number of urgent needs for the New York City Chapter. Primary among them is the lack of adequate office space to accommodate the many education programs designed to provide a broader base of professionally trained caregivers. Trained caregivers are essential to meet the special needs of those affected by Alzheimer’s disease and other dementias. Inadequate facilities also have made scheduling patient, family and caregiver meetings more complex. The shortage of meeting rooms has grown critical enough that staff regularly must seek space at other organizations for essential educational and planned giving seminars and conferences.

**CLOSED DOORS:** To add to our lack-of-space woes, a few months ago we were faced with two unexpected complications. The first was when we learned that Leona Helmsley, then-owner of the Graybar Building (our office site), had decided to sell the property and thus discontinue subsidizing our rent and utilities. Mrs. Helmsley, as a very generous benefactor of this Chapter during our tenancy, had assured that our rent was kept stable and considerably under market cost.

*Continued on page 5.*

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## Director's Corner



## From Outrage to Culture Change

*Dementia Care is one of the richest areas of human work. It requires very high levels of ability, creativity and insight. In our involvement with those who have dementia, we are pushing our humanity to its outer limits.*

*– Tom Kitwood, Bradford, England*

In the Chapter's new space, we expect to showcase an environment in which persons with Alzheimer's disease with all their strengths and capacities will have a chance to flourish.

Join us; plug into their vitality and energy – become – and stay – inspired!

*– Jean Marks*

# Board Welcomes New Directors

## Dianne Zimmerman

Dianne Zimmerman (RN; BSN) is the senior marketing manager of the Alzheimer's Management Team at Pfizer Inc in New York City. (Pfizer markets Aricept, the anti-Alzheimer's drug developed in Japan by Eisai Co. Ltd.) The Chapter benefited from Ms. Zimmerman's efforts during the 1997 and 1998 Memory Walks, and in last year's fundraising gala.

Ms. Zimmerman has 18 years experience in the pharmaceutical industry. She also has extensive expertise in medical education and communications across the spectrum of health care settings. She has worked with physicians in the areas of immunology, oncology, asthma and allergy.

Prior to joining Pfizer, Ms. Zimmerman managed a clinical research organization that focused on Phase IV clinical trials to relating to estrogen replacement therapy, insomnia and diabetes. Previously, Ms. Zimmerman worked in pediatric oncology at Children's Hospital, Dana Farber Research Unit and as an operating room nurse at the Harvard University School of Medicine, Children's Hospital in Boston. She received her BS degree in nursing from Northeastern University and is currently enrolled in a pharmaceutical MBA program at St. Joseph's University in Philadelphia.



## William Kaye

William Kaye is chief executive officer of Crest Uniform Company, a leading supplier of uniforms to the health care, food service, and hospitality industries. Crest was founded in the 1930s as a small sewing shop in Appomattox, Va, by Bill's father Emanuel Kaye. The family business flourished and became a leading supplier of nurse's uniforms to the U.S. Army and Navy during World War II. Mr. Kaye entered the family business in 1963, after serving as a lieutenant in the U.S. Navy. From 1950 to 1975, Crest supplied health care apparel to such chains as J.C Penney and Sears. In 1975, Crest began servicing national food-service companies with uniforms. On numerous occasions, Crest's design team has won the National Association of Uniform Manufacturers and Dealers "Uniform of the Year" award.

After graduating from Miami University in Oxford, Ohio with a degree in Political Science and Economics, Mr. Kaye attended New York University Law School. In 1970, he took over from his father as CEO. Bill and his wife Linda are the parents of a son and a daughter. The Kayes reside in New York City and Westchester County.

To reserve a seat at our next **Planned Giving Seminar**, call Lynne V.P. Raymond at (212) 983-0700. Everyone considering making a planned gift or involved in the planned giving resolution process is invited to attend. This includes attorneys, CPAs, insurance brokers, bank estate planners, and, of course, potential planned gift donors. Attendance capacity is limited, so make your reservation early!

*To learn more about making gifts of:*

Life Insurance  
IRAs, Pension Funds, E-Bonds  
Gift Annuities and Annuity Trusts

All of these gifts can provide generously for you and your family  
*as well as the Charity.*

**Please join us from 5:30 p.m. – 7:00 p.m.**

**Tuesday, September 22, 1998**

at The Princeton Club  
14 West 44<sup>th</sup> Street – Room 402

Your moderator will be Mr. Milton Miller, CPA, Member, Chapter Board of Directors  
Maureen E. Foley, CLLU, ChFC  
Other speakers also will join us.

## Editor's Note

At our Chapter, the staff and our many volunteers are at the vanguard of a shift in attitudes about the best ways to help persons with Alzheimer's. But the transition to what we envision as a new mindset, a "culture of caring," is being slowed by both the exigencies of government (reduced funds for AD research, home care and other aid to families) and by neglect and other abuses that nursing homes, hospitals—and the health care "professionals" who should know better—are visiting on those who are most vulnerable. Jean Marks' "Outrage" page provides a running account of some of the worst treatment received by some of our readers' loved ones.



As we struggle to make the point that persons with Alzheimer's are not "victims," all too often we see them and their families being victimized. In large and small ways, we fight for the dignity they deserve. Our dementia specialist training program prepares home care aides to assist with Alzheimer's patients (see page 9).

Under Ruth Rothbart Mayer, our consumer-directed home care program has helped families through the process of applying for Medicaid Home Care, and empowered them to hire their own home care staff.

Caring for someone with AD at home is always a challenge. Men may find these duties even more daunting, since our society hasn't prepared them to be caregivers. Jack Pollock (who's been there) offers some survival strategies for men who suddenly find themselves in the position of trying to care for their wives (see page 6).

—Chris MacLeod

# OUTRAGE

*This daughter, a health care professional, wrote of two emergency room experiences and one hospitalization, two incidents for her mother; one for her aunt. Unfortunately, space limitations prevent the use of the entire account.*

*– Jean Marks*

## THEY CANNOT SPEAK FOR THEMSELVES

Caring for my mother who has dementia has made me feel like a very inexperienced juggler trying to keep too many balls in the air. By far, the greatest challenges occurred when my mother was admitted to the hospital, the emergency room or intensive care. Unfortunately, I have had experience in all three areas.

In my mother's case, she was taken to the emergency room with second degree heart blockage and pneumonia. They put her on an external pacemaker and sent her to intensive care unit. They explained the pacemaker to her and told her not to touch anything including the IV. Within five minutes of being left alone, she had pulled everything off and they had to redo the procedure. In the meantime, my father, who is a semi-invalid, had been informed by the nursing home that she was in an intensive care unit, spent all of his limited energy to arrange for someone to accompany him to the hospital to be with her. As he gets to her room, she is being taken to another floor to have the pacemaker put on again. Additionally, the doctor has scheduled a permanent pacemaker to be put in within the next two days before talking to me who holds the health care proxy.

On another occasion, in a different hospital, my mother was admitted to the emergency room and then transferred to a regular room while I worked out the details to place her in a nursing home. She could not feed herself without help and that help was not always available. The day I arrived in the hospital from California, I found my mother with food in her hair, as well as under her nails, mixed with feces. This is one of my nightmare memories and it still takes my breath away.

She had been in restraints (another issue) and sat in a chair for most of the day. In talking to the nurses on the phone before I arrived, I suggested that she be placed in the hallway next to the nurses' station so she would have the stimulation of watching people walk by. From sitting in this inactive position for weeks, I was

afraid she would forget how to walk. Whenever another family member was present, we would take my mother for short walks, lessening her fear (which at first was quite substantial) and increasing her confidence and endurance.

I soon learned that the assumption that my mother's basic needs were being met was incorrect. That would only happen with intervention from the family. Her medical needs were always met but eating meals, getting to the bathroom, being changed, getting water if she was thirsty, etc. would not be taken care of because she could not tell the staff that she had needs. For example, a pitcher of water and a cup would be placed on her table but she would not understand what to do with the cup even if it was filled with water and she became thirsty. Meals were served and sometimes food was cut into small bitesized pieces but she could not feed herself well enough to eat very much of the meal, if at all. When she sat for hours in restraints—and would eventually go to the bathroom as she was sitting in a chair—she could not tell the nurses that she needed to be changed. She could not figure out how to push the button to summon help. So she sat there without being cleaned and that caused another series of problems.

I often hear people say, well, she is demented, and it probably does not matter to her anyway. But what is true is that it matters a great deal to me. My goal is to get my mother the best care possible. And I have the major expense of long distance telephone bills and American Airlines tickets to prove it.

I have decided that I need to voice my concerns about dementia patients who have to go to acute care facilities. I urge other families to voice their opinions and describe their experiences. The whole area of dealing with dementia patients needs more community and governmental awareness and that has to start with us, the caregivers.

The second complication was, that upon acquiring the Graybar Building, new management presented us with a significantly increased and incrementally escalating multi-year rent schedule. In ensuing discussions with the new landlords, it became clear that there would be no adjustments or concessions to the Chapter's rent.

**WINDOWS OF OPPORTUNITY:** Therefore, we are pleased to report that later this year the Chapter will be moving to new offices at 360 Lexington Avenue, (at 40th Street), with over 10,000 square feet of space. Since the existing space has been gutted, the office suite is being designed to our specifications. By tailoring the new office site to meet our current and projected needs, and updating our equipment and furnishings, we will be able to expand our successful existing programs, and launch new initiatives identified during our long-range planning process.

The quality of programs and services offered by the Chapter depends in large part on the strength of its infrastructure. In designing the unfinished space at 360 Lexington Avenue, one of the opportunities we will have is to install an updated telephone system to accommodate staff, volunteers and the HELPLINE service. There will be additional opportunities to acquire other more sophisticated and appropriate equipment, including computers, essential to current staff and volunteer work as well.

The move and renovation also makes it possible for us to house a Training Institute for professional care providers...a goal thought unattainable until circumstances closed the doors to our present location for us. The Institute will be designed to build the capacity of individuals and institutions who care for persons with dementia so that the best and most advanced techniques and therapies are understood and implemented. Physicians, nurses, social workers, researchers, policy makers and care facility administrators will be able to observe and participate in developing effective methods for Alzheimer's patient and caregiver care. The Institute will be a teaching model for professional care providers that the Chapter hopes to see replicated nationally, thus ensuring competent and humane care into the twenty-first century.

The Chapter's move to enhanced and expanded quarters, together with its developing programs, will keep us on the cutting edge of Alzheimer's care. However these advances will require substantial and timely new capital investments.

In order to set long-term Chapter goals with financial assurance, we must broaden our income base significantly with increased investment from endowments, individuals, corporations and foundations. Therefore, during this fiscal year 1999, the goal of the New York City Chapter will be to augment our current base of annual philanthropic support for facilities, operations and programs. This must be successfully accomplished in order to lay the foundation for continued leadership in Alzheimer's and other dementia

research, and patient, family, and professional provider care for the new century.

Construction and renovation of the 360 Lexington Avenue space offers a variety of naming opportunities for gifts supporting our critical capital enhancements. As you can see from the schedule of philanthropic naming opportunities listed below, a gift of from \$10,000 to \$500,000 can underwrite and name many of the Chapter facilities, including the entire suite at the new address.

The New York City Chapter, on the occasion of its imminent move to new, expanded, architect-designed office, conference and Training Institute areas, would be pleased to recognize gifts with perpetual naming opportunities honoring the generosity of the donor, his or her family or organization, or a donor-designated honoree. A permanent plaque in memory, honor, or tribute to a designated person(s) or organization will be placed adjacent to the area named. Major naming donors also will be recognized in Chapter publications and at prominent commemorations, unless preference for anonymity is indicated.

*Continued on page 16.*

## SCHEDULE OF PHILANTHROPIC NAMING OPPORTUNITIES FOR NEW CHAPTER OFFICES

<b>Name Entire Suite of The Alzheimer's Association, New York City Chapter</b>	<b>\$500,000</b>
<b>Options: Your name(s), In memory of... As a tribute to...</b>	
<b>Name The Training Institute</b>	<b>\$250,000</b>
<b>Name The Conference Room</b>	<b>\$50,000</b>
<b>Name The Training Room</b>	<b>\$50,000</b>
<b>Name The Viewing Room</b>	<b>\$50,000</b>
<b>Name The Reception Area</b>	<b>\$50,000</b>
<b>Name The Helpline Offices (3)</b>	<b>\$40,000</b>
<b>Name Executive Offices (3)</b>	<b>\$35,000</b>
<b>Name Program Staff Offices (15)</b>	<b>\$25,000</b>
<b>Name Staff Lounge</b>	<b>\$20,000</b>
<b>Name Work Stations (7)</b>	<b>\$10,000</b>

Your gift can be structured in several ways. Outright gifts of cash or other assets and multiyear pledges provide immediate support to the Chapter. A variety of trusts and other planned gift arrangements can bring maximum benefits to you and your family, as well as allow the Chapter to set long-term goals with financial assurance.

# SOMETHING'S WRONG WITH MOM

## Advice for the Male Caregiver

By Jack M. Pollock

**M**onroe was worried. His wife of thirty-three years seemed somewhat different. Formerly outgoing and sociable, Marie was becoming withdrawn. Among friends, she would be quiet. Monroe would have to carry the conversation. Sometimes she would begin a sentence, and get lost somewhere in the middle. Lately she was habitually losing or misplacing her keys or glasses. She had always paid the bills and balanced the checkbook. Now she made so many mistakes that Monroe had to take over. Marie had gradually stopped cooking, and they began eating out more often. In restaurants, the waiters would ask Marie for her order, but she would say nothing. Embarrassed, Monroe would place the order for her. His children would sometimes tell him, "Dad, something's wrong with Mom." Monroe would shake his head "I think she's just tired. Maybe it's menopause."

Familiar scenario? The rest of the story is equally familiar: a series of visits to doctors followed by a diagnosis of early Alzheimer's. Monroe now knows he has a problem. He will learn, as time goes by, how big a problem it is.

Caring for his wife is a role Monroe never envisioned, and for which he is totally unprepared. How can he possibly learn to do the many things she used to do? Can he cook, shop, keep house, launder, iron, deal with repairs, take care of finances, handle the mail, and take out the garbage? And even if he learns to do all these things, what about his job? Will he be able to function in the office? And when he's working, who will take care of Marie? Should he retire and devote himself to the care of his wife? Is he emotionally ready for that? What would it be like, caring for an Alzheimer's victim who happens to be the one dearest to him in the world?

Fortunately for Monroe, he is not entering uncharted territory. Male caregivers before him have struggled with the same problems. They have suggestions.

Here Monroe, are some suggestions for you.

### **SUGGESTION #1: DON'T ASK, "WHY ME?"**

This question is unanswerable. Alzheimer's is an equal opportunity disease; it strikes the rich and the poor, the educated and the illiterate, the strong and the frail. If you are the caregiver, you have been chosen. Your fortitude is being put to the test. You can do it. You have resources within you of which you are not even aware.

### **SUGGESTIONS #2: DON'T FEEL GUILTY.**

Coping with Alzheimer's will tax your patience. You may get angry. You may feel like a monster. Remember you are only human. We all have our limits. If your patient asks the same question again and again, don't blame her, blame the disease. You and your wife, Monroe, are fighting a battle against Alzheimer's.

### **SUGGESTION #3: DON'T TRY TO DO IT ALONE.**

As the disease progresses you will need help, if only to get away for a while. An Alzheimer's patient may need 24-hour supervision. She may pace during the night or day, will eventually need help in dressing, bathing, eating and going to the toilet. There are times when you will feel totally worn out. If you can afford it, get someone to take care of her at least part of the day. If money is a problem, try to get a family member, friend, or neighbor to help.

### **SUGGESTION #4: DON'T RETIRE FROM LIFE.**

Cutting yourself off from family and friends won't do you or your patient any good. You need to remain part of the real world, the world of normal people, to escape the nightmarish prison of Alzheimer's. If you are still working and enjoy your job, don't retire prematurely. Your work may provide a solace and a balance. Friends may feel squeamish about visiting. Encourage their visits, and get out yourself. You need to have a social life to retain your sanity. Whether your interests are cultural, sports, avocational, or travel, pursue them as much as possible under these difficult circumstances. It will preserve not only your sanity, Monroe, but your health. A sick caregiver is no help to the patient.

### **SUGGESTION #5: TAKE CARE OF YOURSELF PHYSICALLY**

Eat properly and exercise. Get enough sleep at night (even though this is easier said than done). Take a vacation from time to time to recharge your batteries. Eventually you may become lonely and yearn for female companionship. When your wife has reached an advanced stage, you may wish to consider dating. This is not an easy decision. Platonic or not, your relationship with someone of the opposite sex should not make you feel guilty or disloyal. You are only human, and have human needs. Your love for your wife can remain intact.

### **SUGGESTION #6: JOIN A SUPPORT GROUP.**

You may think you don't need it. But you will be surprised to find how helpful it is to speak to people who are meeting the same difficulties you are. For some reason, men are reluctant to join support groups. Some think it is an admission of weakness. Your first reaction, Monroe, like that of many men may be, "Support groups are not for me. I am not a joiner. I can deal with my own problems." Perhaps you can. But Alzheimer's will sneak up on you and confront you with issues you have never before faced. In a support group you will learn not only how to deal with day-to-day crises, but where to get information about legal and financial matters and where to get help when you need it. And most important, you will be

speaking to people who have been there or are there now, and to people who know what you are going through.

#### **SUGGESTION #7: DON'T DESPAIR.**

Circumstances may arise for which you think there is no solution. Train yourself to feel that wherever the problem, you will find a way to deal with it. Most often, this works. You may be surprised to find out how creative you can be. However, you are not Pollyanna. Somewhere in the back of your mind you will know that at a certain point, you have done all you could. On the other hand, there will be times when you will want to wring your hands and weep. This is nothing to be ashamed of.

#### **SUGGESTION #8: FINALLY, MONROE, BE PROACTIVE.**

This disease is your enemy. Fight it any way you can.

Join the Alzheimer's Association. Volunteer for the Alzheimer's Helpline, or serve in the Alzheimer's office. Donate money for research or for services to families. Tell your legislators that you want them to set aside funds for Alzheimer's research and programs to care for persons with AD in the home. Support efforts to make nursing homes more aware of the special needs of Alzheimer's patients.

Of course it is easier to give advice than to follow it. It will not be an easy road ahead of you, Monroe. But it is vital that you not travel that road alone. You will need the support of family and friends. And you will need all your own courage and strength. You are joining a fraternity of caregivers all over the world, a sad fraternity to be sure, but one in which incredible heroism has been displayed. It has become a truism that Alzheimer's can have two victims: the patient and the caregiver. Don't let it defeat you.

## **State of the Art Adult Day Center to Open in Brooklyn**

This fall, the Family Resource and Adult Day Service Center of Brooklyn will open in a newly-constructed facility at 1 Prospect Park West. The Park Slope Geriatric Day Center (PSGDC) will develop and supervise the programs at the new Center.

The purpose is to support area families who are struggling to stay intact after the onset of Alzheimer's. To maximize benefits to clients and their families, the Center will be open 12 hours a day, six days a week.

This safe, home-like environment will include a library, dining room and participant kitchen, a hair and manicure salon, and even a handicapped-accessible whirlpool spa. Regardless of the extent of their disabilities, clients will be offered activities which will be designed to enhance and maintain their current physical and cognitive functioning.

A case-management team will be on hand to assist families and caregivers in obtaining the services they need over the short and long-term process of caring for persons with dementia. This Center will also host workshops sponsored by the Alzheimer's Association, as well as serving as a training site for "dementia capable" personal care assistants.

Marianne Nicolosi, PSGDC's executive director, will oversee the new Center – which is still offering naming opportunities and memorials to contributors. Licia Berlinck, a longtime Alzheimer's Association volunteer, has donated her professional skills to design the site's environment, making it barrier-free and dementia-friendly.

For further information, call the PSGDC at (718) 499-7701.



*(From left): Iris Mulle from Borough President Howard Golden's office; DYCD Commissioner Marty Oesterreich; DFTA Commissioner Herb Stupp; PSGDC Board President Emilie Roy Corey; Jean Marks from the Alzheimer's Association; Marianne Nicolosi PSGDC executive director at the groundbreaking.*

# Accessing Medicaid Home Care Services in New York

*A daughter telephones from her mother's bedside in the hospital. Her mother has suffered a stroke and in a matter of days she will be discharged from the hospital to face the costs of round-the-clock home care services. She will certainly need these services for the months to come, if not for the rest of her life. The daughter is desperate. Her mother's lifetime savings total \$100,000 but the care she requires will cost at least \$3,000 per month. The math is simple and frightening. The daughter sees her mother's savings depleted and wonders how her mother can stretch her money. Is there some program available that could help her to maintain herself in her home?*

Introduction: Medicaid is a joint federal and state program providing medical assistance to people meeting certain income and resource criteria. It is a health-care program with coverage for hospital care, nursing-home care, dental care, prescription drugs and a variety of home-care services, including nursing, home-health-aide services, physical, occupational and speech therapy and limited personal-care services in the home.

Unlike Medicare, which is the federal health-insurance program that provides acute-care medical coverage for persons over 65 and certain disabled persons, Medicaid provides personal-care services for custodial-care patients. In contrast, Medicare provides very limited personal-care services and only if the patient has a skilled nursing or rehabilitation need. An individual who is eligible for both Medicare and Medicaid is characterized as a dual-eligible beneficiary.

**Personal Care Services Defined:** Generally, personal-care (custodial-care) services are those that assist the Medicaid recipient in the activities of daily living, such as dressing, bathing, transferring, toileting and feeding. Medicaid may also provide housekeeping services. Depending upon the patient's needs, "sleep-in" home-attendant care may be available or "split-shift" care (two 12-hour shifts per day).

**Income Limit and the Spend down Program:** The income limit for Medicaid home-care services is \$604 per month. In setting the \$604 limit, Medicaid does not take into account the cost of food, clothing or shelter. **However, an individual whose income exceeds \$604 per month may still be eligible if he incurs or pays medical charges equal to his excess countable income.** For example, if Mr. Smith has income of \$1000 per month he will be eligible for Medicaid home-care services providing he spends down \$396 per month ( $\$1000 - \$604 = \$396$ ). He may accomplish the spend down by presenting his Medicaid service provider with the receipts for out-of-pocket medical expenses, and also health-insurance premiums. He may also pay to the Medicaid provider the spend down amount.

**Asset Limits:** Broadly speaking, to be eligible for Medicaid home care, an individual may not have more than \$3,500 in assets, \$1,500 in a burial fund and an irrevocable pre-needs funeral agreement arranged through a funeral home. **A primary residence, including a house, condo-**

**minium or cooperative apartment is exempt and is not counted as an asset.** There is no dollar limit on the value of the home as far as Medicaid is concerned. However, if the home is sold, the proceeds are countable as an asset for Medicaid eligibility purposes, unless the proceeds are used to purchase another home or other exempt resource. Essential personal property such as clothing, furniture, personal effects and a car are also exempt.

**Transfer of Assets:** Before applying for Medicaid home care, an individual who has assets in excess of the legal limit may transfer his or her assets to any person or trust. Such a transfer will not incur a penalty period for accessing the program. For example, an individual may transfer assets of any amount in one month so as to reduce his net worth to the permitted level and then, in the month immediately following, be eligible for Medicaid home care. A penalty period may be incurred but only if the application is for Medicaid nursing-home and the Lombardi home-health-care programs. **Remember, there is no penalty period for transfer of assets when applying for Medicaid home care!**

**Trusts in Medicaid Planning:** Various types of irrevocable trusts are available to shelter assets and certain income streams of elderly or disabled persons who apply for Medicaid home-care services. The basic Medicaid Trust allows an individual to protect savings, stocks, bonds and the home from Medicaid recovery and still receive income from these assets. In addition, a Supplemental Needs Trust may be used to pay a person's bills, including those for both necessities and luxuries, without jeopardizing that individual's eligibility for Medicaid.

**Transferring the Home:** Remember, the individual's home—a house or apartment—is an exempt asset for purposes of initial Medicaid eligibility, however, upon the death of the Medicaid recipient, the home may be subject to a Medicaid demand for reimbursement. It may be appropriate, therefore, to transfer the home in order to protect it. For accessing Medicaid home-care, the transfer of the home will not trigger a penalty period of ineligibility. However, it is not good planning to simply transfer ownership of the home to a person other than a spouse. Such a transfer may incur a substantial tax liability and a penalty period if Medicaid nursing-home coverage is required. The

*Continued on page 16.*

# Celebrating the Caregiving Professional

“**R**emain committed but it is important to know when to take time for yourself. Take care of your needs so you can maintain a healthy balance between work and responsibility to yourselves and your families. Few will know your name, but many know of the work you are doing.” These are the words of Georgianna Whyte, Director of Patient Services at CABS Home Attendant Services. She was one of the speakers at our June 5<sup>th</sup> graduation ceremony for recent students of our dementia training programs.

The exuberant mood of the graduates, their families, their employers and staff from the Alzheimer’s Association filled the Public Hearing Chambers at City Hall.

Fourteen members of the graduating class included home care aides from Royal Health Care Services, Allied Health Care Service, CABS Home Attendant Service, and Services for the Underserved. Graduates completed a one month internship in a nursing home dementia unit or day care site, complemented by weekly discussion groups at the Alzheimer’s Association. Students were then assigned to a person with dementia and received in-home visits by the Alzheimer’s Association. Aides also attended monthly support groups sponsored by the Association. These groups provided an opportunity to discuss problems and reinforce concepts learned earlier. Upon completion of this five month internship program, graduates receive “Dementia Specialist” certification.

Anne Thomas, Gladys Harburger and Adeena Horowitz awarded the certificates and honored each graduate by providing examples of how each person had enriched our world and the lives of dementia patients.

Willy Senders, Nursing Home Coordinator, then introduced twenty-three graduates from Crown Nursing Home, Tarrytown Nursing Home and Woodmere Nursing Home. While each facility has a different approach to accomplishing their goals, all have demonstrated a commitment to enhancing the quality of life for dementia residents. Graduates completed a six week training course which set the stage for developing dementia care programming at their homes.

The celebration continued in the rotunda where graduates and guests feasted while mingling with restless participants of the City Council budget process. The budget was approved as we exited City Hall.

We are encouraged by this enthusiastic collaboration with the NYC Chapter of the Alzheimer’s Association in our attempt to create a more holistic person-centered approach to dementia care.

We are also very excited about our first venture with an Assisted Living Facility—Prospect Park Residence in Brooklyn—which recently opened a dementia floor called the “Living Room.” We just completed a six week training with them and will continue to work together with a goal of creating an ideal residential alternative for people with dementia.

– Anne Thomas



*Left to right: Denise James's husband, Andrine Frage's family, Andrine Frage and Polly Alicia.*



*Left to right, front: Martha Tyler, Yvette Rodriquez, Polly Alicia. Left to right, back: June Chapman, Anne Thomas, Marlo Opont, Maria Rodriquez, Audrey Forth.*

## GRADUATION

June 5, 1998

### Members of Class

Polly Alicia, Marie G. Alteon, Elaine Artman, Jill Burke, June R. Chapman, Megan S. Cox, Patricia Cross, Marie DeLeon, Audrey Forth, Andrine Frage, Lucille Gore, Tiffany Grant, Antoinette Hampton, Paula Harris, Ruth Hydol, Magdalene Jackson, Denise L. James, Edith King, Frank Langrin, Pauline Lawrence, Deena Mark, Anthony Matese, Joann Molito, Camille Niles, Marlo Opont, Lovangelene Pearson, Agatha Phillips, Advira Providence, Mary Quinlan, Maria Rodriquez, Yvette Rodriquez, Frieda Rosengarten, Margaret Segers, Leba Sonneberg, Diana Tardonna, Leslie Telles, Martha Tyler, Maureen White, Emilia Yopez.

## MONDAY, September 14

Legal/Financial Seminar  
 Time: 12:00 - 1:30 p.m.  
 Place: Chapter Office  
 Speaker: David Dorfman, Attorney

## MONDAY, September 14

New York City Chapter Annual Meeting  
 Time: 6:15 - 7:45 p.m.  
 Place: The Rockefeller University  
 Caspary Auditorium  
 1230 York Avenue at 66th Street  
 Keynote Speaker: Jack Ford

## WEDNESDAY, September 16

Orientation Meeting for Family Members  
 Time: 5:30 - 7:00 p.m.  
 Place: Chapter Office

## THURSDAY, September 17

Topic: Finding the Common Ground, A Dialogue between Families and Home Care Workers  
 Time: 9:30 a.m. - 11:00 a.m.  
 Place: Empire Blue Cross/Blue Shield  
 622 Third Ave. (40th & 41st Street)  
 Speakers: Anne Thomas, CSW; Ruth Rothbart Mayer, CSW; home care worker and family member to be announced.  
*Sponsored by the RWJ Consumer Directed Home Care Project*

## TUESDAY, September 22

Orientation Meeting for Family Members  
 Time: 12 Noon - 1:30 p.m.  
 Place: Chapter Office

## MONDAY, September 28

Medicaid Home Care Seminar: A Practical Guide to the System  
 Time: 12 Noon - 1:30 p.m.  
 Place: Chapter Office  
 Speaker: Adeena Horowitz, CSW, NYC Chapter staff; Joanne Spellane, Attorney  
*Prior attendance at a Legal and Financial Planning Seminar required.*

## MONDAY, September 28

Legal/Financial Seminar  
 Time: 5:30 - 7:00 p.m.  
 Place: Chapter Office  
 Speaker: Anne Miles, Attorney

## THURSDAY, October 1

Orientation Meeting for Family Members  
 Time: 8:30 - 10:00 a.m.  
 Place: Chapter Office

## THURSDAY, October 1

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

## MONDAY, October 5

Legal/Financial Seminar  
 Time: 12:00 - 1:30 p.m.  
 Place: Chapter Office  
 Speaker: Richard Anderson, Attorney

## WEDNESDAY, October 7

Topic: Easing The Transition From Home to Nursing Home  
 Time: 6:00 - 8:00 p.m.  
 Place: Chapter Office

## WEDNESDAY, October 7

Orientation Meeting for Family Members  
 Time: 5:30 - 7:00 p.m.  
 Place: Chapter Office

## THURSDAY, October 8

Brooklyn Education Meeting  
 Time: 1:30 - 3:30 p.m.  
 Place: Crown Nursing Home  
 3457 Nostrand Ave.  
 Brooklyn, NY 11229  
 Topic: Legal and Financial Planning Seminar  
 Speaker: Michael Long, Attorney

## FRIDAY, October 9

Orientation Meeting for Family Members  
 Time: 12 Noon - 1:30 p.m.  
 Place: Chapter Office

## WEDNESDAY, October 14

Orientation Meeting for Family Members  
 Time: 5:30 - 7:00 p.m.  
 Place: Chapter Office

## THURSDAY, October 15

Bronx Education Meeting  
 Time: 1:30 - 3:30 p.m.  
 Place: Bronx Veterans Administration Medical Center  
 130 West Kingsbridge Road  
 Bronx, NY 10468  
 Room 4A-24  
 Topic: Legal and Financial Planning Seminar  
 Speaker: Anne Miles, Attorney

## MONDAY, October 19

Medicaid Home Care Seminar: A Practical Guide to the System  
 Time: 12 Noon - 1:30 p.m.  
 Place: Chapter Office  
 Speaker: Adeena Horowitz, CSW, NYC Chapter staff; Joanne Spellane, Attorney  
*Prior attendance at a Legal and Financial Planning Seminar required.*

## MONDAY, October 19

Education Meeting  
 Time: 6:00 - 7:30 p.m.  
 Place: Empire Blue Cross/Blue Shield  
 622 Third Avenue  
 Topic: Research and Treatment: Update and Report from the 1998 Alzheimer's Disease International Conference  
 Speakers: Peter Davies, Ph.D., Albert Einstein College of Medicine

## THURSDAY, October 22

Queens Education Meeting  
 Time: 1:30 - 3:30 p.m.  
 Place: Visiting Nurse Service  
 41-61 Kissena Boulevard  
 Flushing, NY 11355  
 Topic: Legal and Financial Planning Seminar  
 Speaker: Ronald Fatoullah, Attorney

## MONDAY, October 26

Legal/Financial Seminar  
 Time: 5:30 - 7:00 p.m.  
 Place: Chapter Office  
 Speaker: Peter Strauss, Attorney

## TUESDAY, October 27

Orientation Meeting for Family Members  
 Time: 12 Noon - 1:30 p.m.  
 Place: Chapter Office

## THURSDAY, October 29

Topic: Finding the Common Ground, A Dialogue between Families and Home Care Workers  
 Time: 4:30 - 6:00 p.m.  
 Place: Chapter Office  
 Speakers: Anne Thomas, CSW; Ruth Rothbart Mayer, CSW; home care worker and family member to be announced.  
*Sponsored by the RWJ Consumer Directed Home Care Project*

## MONDAY, November 2

Legal/Financial Seminar  
 Time: 12:00 - 1:30 p.m.  
 Place: Chapter Office  
 Speaker: Michael Long, Attorney

## TUESDAY, November 3

Key Elements of Dementia Care: A Series for Family Caregivers, Day 1  
 Time: 9:15 a.m. - 1:00 p.m.  
 Place: Chapter Office (Registration required)

## WEDNESDAY, November 4

Topic: Easing The Transition From Home to Nursing Home  
 Time: 6:00 - 8:00 p.m.  
 Place: Chapter Office

## THURSDAY, November 5

The Zachary & Elizabeth M. Fisher Annual Mayoral Conference on Alzheimer's Disease  
 Time: 8:00 a.m. - 4:00 p.m.  
 Place: The New York Hilton Hotel & Towers  
 1335 Ave. of the Americas (53rd to 54th)  
 New York, NY  
 PLEASE CALL 212-983-0700 FOR A REGISTRATION FORM & INFORMATION

## MONDAY, November 9

Education Meeting  
 Time: 6:00 - 7:30 p.m.  
 Place: Empire Blue Cross Blue Shield  
 622 Third Avenue  
 Topic: Recognizing and Coping with the Stresses of Caregiving  
 Speakers: Sharon Shaw, Ph.D.; Rea Kahn, RN, MPS

## TUESDAY, November 10

Key Elements of Dementia Care: A Series for Family Caregivers, Day 2  
 Time: 9:15 a.m. - 1:00 p.m.  
 Place: Chapter Office (Registration required)

## WEDNESDAY, November 11

Orientation Meeting for Family Members  
 Time: 5:30 - 7:00 p.m.  
 Place: Chapter Office

## FRIDAY, November 13

Orientation Meeting for Family Members  
 Time: 12 Noon - 1:30 p.m.  
 Place: Chapter Office

## MONDAY, November 16

Medicaid Home Care Seminar: A Practical Guide to the System  
 Time: 12 Noon - 1:30 p.m.  
 Place: Chapter Office  
 Speaker: Adeena Horowitz, CSW, NYC Chapter staff; Joanne Spellane, Attorney  
*Prior attendance at a Legal and Financial Planning Seminar required.*

## MONDAY, November 16

Legal/Financial Seminar  
 Time: 5:30 - 7:00 p.m.  
 Place: Chapter Office  
 Speaker: Jeffrey Abrandt, Attorney

## TUESDAY, November 17

Key Elements of Dementia Care: A Series for Family Caregivers, Day 3  
 Time: 9:15 a.m. - 1:00 p.m.  
 Place: Chapter Office (Registration required)

## WEDNESDAY, November 18

Orientation Meeting for Family Members  
 Time: 5:30 - 7:00 p.m.  
 Place: Chapter Office

## MONDAY, November 23

Topic: Medicaid Home Care, Focus on Surplus Income  
 Time: 4:30 - 6:00 p.m.  
 Place: Chapter Office  
 Speakers: Ruth Rothbart Mayer, CSW, and others to be announced.  
*Sponsored by the RWJ Consumer Directed Home Care Project*

*Continued on page 14.*

### 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 indicated 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.

### ALL MEETINGS ARE FREE OF CHARGE

The NYC Chapter Office is located in the GRAYBAR Building, 420 Lexington Avenue, (between 43<sup>rd</sup> and 44<sup>th</sup> streets), Suite 610, New York, N.Y. 10170

For our monthly Manhattan Education meetings we wish to thank Empire Blue Cross Blue Shield for generously donating space.

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

# Getting the Help You Need

## PART II

The first of this three-part series outlined the interview process which emphasized the importance of *knowing what your needs are*, *knowing how to convey them* to a potential employee and *listening carefully to their answers*. In Part II the selection process will continue with

### The Personal Interview

Try to limit the meeting to one hour. This will help you stay focused and establish a professional tone to the interview. Your goal is to verify information received from the screening, get a better idea of how well this person will work with you and your family member, and provide more detail about the job requirements.

- Begin the interview by setting a comfortable and accepting tone.
- If possible, meet privately or with another family member present for a better evaluation of the interviewee.
- Have the person tell you about himself or herself but keep personal information to a minimum in order to emphasize their work background and experience, what their needs and expectations are.
- Ask why and how they became involved in the home care field.
- Inquire about their most recent jobs, what they liked/disliked, why they left.
- Determine if they have received any training, specifically concerning Alzheimer's disease and if they have ever dealt with people with Alzheimer's disease or other forms of dementia.
- Describe your family member's current condition as well as your involvement with the care.
- Discuss how you will evaluate performance and encourage their feedback to establish a working relationship.
- Discuss the rate of pay, days and hours of employment. If you are in Consumer-Directed Home care, describe Concepts record-keeping.

After determining that the interviewee meets your basic requirements, discuss their responsibilities as listed below (modify to suit your family member's needs as necessary). **Remember that a personal assistant's main concern is the daily care of your family member. Household tasks can only be accomplished during the time they are in the home and can only be done if the family member's basic care needs have been met.** (You might want to have these brief points listed below typed to hand to the interviewee):

#### A) Personal Care

1. Bathing
2. Dressing
3. Oral hygiene

#### B) Activities

1. Escort and/or transport to programs, doctors, family/friend visits, cultural events, etc.
2. Keep family member active through physical activities (walks, light exercise, massage)
3. Involve family member in own care; i.e., choosing clothing, dressing, household chores, cooking
4. Encourage social stimulation through board games, cards, puzzles, crafts, reading, movies, music

#### C) Household Chores

1. Light housekeeping
2. Laundry
3. Grocery shopping

Remember to ask for three personal references (check them *prior* to hiring). When you are sure that you are going to offer this person the position, introduce him or her to the family member. If your family member is resistant to change or fearful of new people, avoid statements like, "this is the person who will be taking care of you," instead try, "this is someone I'm talking to about helping me around the house."

Before the interviewee leaves, summarize your discussion, ask if they have any questions. Make sure you verify address and phone numbers and tell them when they can expect to hear from you about a final decision.

This article is the second of a three-part series outlining the essential elements of how to recruit, interview and hire home care workers. Part III will cover the Hiring Process, a Written Agreement and Developing Back-Up Resources. We hope this advice is helpful in organizing your efforts. A more detailed booklet will be available soon. If you would like a copy, call Anne Thomas (ext. 211) or Adeena Horowitz (ext. 210). For more information about the RWJ Consumer-Directed Home Care Project call Ruth Rothbart Mayer (ext. 204).



## Point of View

### About Maximillian

Maximillian was born in Germany in 1914. His father died when Maximillian was not yet two years of age.

When Hitler came to power, it became clear that Maximillian could not study at a German university as a non-Aryan. He worked instead for his mother's import-export business until he finally left for America in 1938. He settled in New York City where he later married and had a daughter, whom he describes as "such a delight." Maximillian is greatly interested in philosophy and psychology, and is an ardent reader of Kant and Freud.

He is now retired and tends to his small art collection. He and his wife live in Manhattan along with their cat, Princeley.

## MAXIMILLIAN

"I think one of the important things that happens to a person when they have Alzheimer's is that they make sense of it. In a way, it's almost as if you genuinely find out that you have to die.

"I've had a number of years when I considered dying. As I get older, I realize that I have no religion or nothing else, and that I want to live. And the quality of my death became very important to me. I've often felt that what I was doing here would get me a good death. I wanted to leave with a good conscience and having felt that I did the best I could in my life. I wanted to be able to get several of my girlfriends with my wife together at my funeral, like the mistress of Mitterand who stood next to his wife the day he was buried, you know. I wanted to do things like that. I wanted to get my daughter to understand me ... understand that I wasn't a son of a bitch. That's what I wanted to do. Then I realized that death doesn't come like that. That it comes ever much slower.

"Since a year ago, when my Alzheimer's was diagnosed, I have had many, many parts of the house falling down inside of me. This I am certain of. You know, some days now I don't know where I am in the street for a split second. The other day I was all confused in the street and I had to ask somebody where I was, and I realized the magnitude of the disease. I realized that this is a whole structure in which a window falls out, and then suddenly before you know it, the whole facade breaks down. How terrible as I see how this goes on! When I observe that, it is enormously hard to take.

"Do you know what Alzheimer's is? I'll say this loud...**Alzheimer's is soul murder!** That's my name for it. This is the worse thing that can happen to a thinking person. You can feel yourself, your whole house inside and outside, break down.

"So I went to the Alzheimer's Association. I thought I would see one or two other people in my support group who felt like me, but there isn't anybody who feels like I do. I surmise that they don't want to hear it. At the beginning, they attacked me terribly. I changed the whole tenor of this group, I think, by saying the things that I do. One woman said something like, 'I don't want him here. He always likes to talk about death...that's his specialty. I don't want to hear this, if it comes true or not.' So they sit there, hoping fervently that a cure will come...

"I told the Association that I believe a cure will come, the way it comes for AIDS or for other things, when a strenuous effort is made by influential people who are affected by Alzheimer's to force a greater amount of research. There's not enough research being done! Research

depends on how much money is available for it and how much effort is made to do it. It's only when the public cries out and lots of money is involved in finding a cure that something gets done.

"I want to speak out **now**, while I am still alive! And I want to tell people so that they can prepare for it, and do something about it money-wise. The enormity of Alzheimer's disease is unspeakable. This soul murder is greater than cancer. It's inhuman and it's undignified. It's the absolute theft of what you treasure, unless you're a person who only eats and has sex.

"I remember seeing a fellow at the Met, Rudolf Bing. He had Alzheimer's. As an Alzheimer's man, he finally had a young woman with whom he wanted live and have his last pleasure. And those doctors took that away from him. What a crime that was, not letting this man to live the way he wanted to! This should be said. And he lived for so damn long afterwards...

"You know, I wanted to join the Hemlock Society, but I haven't had the guts. I want to find ways and means to find a doctor who will give me and my doctor the pills. To wait for this is terribly difficult for me.

"I can't find a soul mate about this disease. Nobody is willing to really talk about it."

*Maximillian's story is excerpted from "Early Stages: Changing Our Views of Alzheimer's," by Paulette Michaud.*

*This work, compiled by Ms. Michaud under the auspices of the Charlotte and Jeremiah Kaplan Fellowship program for work in the field of aging at the Columbia University School of Social Work, represents the fruits of the field work Ms. Michaud conducted at the New York City Chapter of the Alzheimer's*

*Association. Her book of interviews with early stage persons with Alzheimer's records their reactions to AD, as well as their own invaluable insights.*



# Fall 1998 Calendar *Continued*

## **TUESDAY, November 24**

Key Elements of Dementia Care: A Series for Family Caregivers, Day 4  
Time: 9:15 a.m. - 1:00 p.m.  
Place: Chapter Office (registration required)

## **TUESDAY, November 24**

Orientation Meeting for Family Members  
Time: 12:00 Noon - 1:30 p.m.  
Place: Chapter Office

## **TUESDAY, December 1**

Key Elements of Dementia Care: A Series for Family Caregivers, Day 5  
Time: 9:15 a.m. - 1:00 p.m.  
Place: Chapter Office (Registration required)

## **WEDNESDAY, December 2**

Topic: Easing The Transition From Home to Nursing Home  
Time: 6:00 - 8:00 p.m.  
Place: Chapter Office

## **THURSDAY, DECEMBER 3**

Orientation Meeting for Family Members  
Time: 8:30 - 10:00 a.m.  
Place: Chapter Office

## **THURSDAY, DECEMBER 3**

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

## **MONDAY, December 7**

Legal/Financial Seminar  
Time: 12:00 Noon - 1:30 p.m.  
Place: Chapter Office  
Speaker: Jay Sangerman, Attorney

## **TUESDAY, December 8**

Key Elements of Dementia Care: A Series for Family Caregivers, Day 6  
Time: 9:15 a.m. - 1:00 p.m.  
Place: Chapter Office (Registration required)

## **WEDNESDAY, December 9**

Orientation Meeting for Family Members  
Time: 5:30 - 7:00 p.m.  
Place: Chapter Office

## **FRIDAY, December 11**

Orientation Meeting for Family Members  
Time: 12:00 Noon - 1:30 p.m.  
Place: Chapter Office

## **MONDAY, December 14**

Education Meeting  
Time: 6:00 - 7:30 p.m.  
Place: NEW LOCATION Empire Blue Cross/Blue Shield Medicare Offices 800 Second Avenue (42nd Street)  
Topic: Open Discussion: Caring for a Relative with AD, Coping, Managing and How to Survive.  
Speakers: To be announced

## **WEDNESDAY, December 16**

Orientation Meeting for Family Members  
Time: 5:30 - 7:00 p.m.  
Place: Chapter Office

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## **Request for Media Respondents**

Our chapter frequently receives requests from the news media to profile individuals and families who are dealing with a diagnosis of Alzheimer's disease or a related disorder.

We are looking for individuals or families who would be available and willing to be interviewed by the media for newspaper or magazine articles, for radio or television programs on specific topics related to Alzheimer's Disease. When we receive requests, they are often with minimal advanced notice.

If you are interested in participating in media events, please let us know by completing the attached form and returning it to the chapter office. A chapter staff member will be in touch with you to review your interest in participating.

*Please provide us with the following information:*

Name \_\_\_\_\_

Address \_\_\_\_\_

Telephone Numbers: Work \_\_\_\_\_

Home \_\_\_\_\_

Name of diagnosed person \_\_\_\_\_

Relationship to yourself:

spouse \_\_\_\_\_ parent \_\_\_\_\_ sibling \_\_\_\_\_

other \_\_\_\_\_ (specify)

*Please provide a brief description of your situation:*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

# To Care, or Not to Care

## Book Reviews

### An Ocean of Time...

#### Alzheimer's: Tales of Hope and Forgetting

by Patrick Mathiasen, M.D. (Scribner; 1997)

For many busy doctors, diagnosing Alzheimer's conveniently absolves them from further efforts on the patient's behalf. It is precisely at this point of grief and confusion that psychiatrist Patrick Mathiasen--medical director of the Northwest Hospital Geriatric Psychiatric Center in Seattle--steps in.

He tries to enable both his patients and their families to find meaning in "the long goodbye" that is Alzheimer's. The disease steals memory and alters personality, but it needn't erase dignity.

Mathiasen's most intriguing case studies show how the fragments of memory that remain can be pieced together, jigsaw puzzle style, to provide snapshots of significant moments in these people's lives--before they become irretrievably lost.

There's the mother who effects a reconciliation between her two sons by vividly conjuring up the time when they were "my babies." Another mother gives her daughter peace of mind by dispelling the haze around the circumstances of her birth.

These moments of clarity are dredged up from a past that--to someone with Alzheimer's--is indistinguishable from the present. As Dr. Mathiasen observes, "I think there is wisdom in not challenging these people's sense of reality."

To some, their delusions are a refuge. Bridget, irrepressible at age 89, sings and dances to the tunes of her youth in Ireland. For Mario, giving voice to a favorite aria returns him to his carefree days in Amalfi. Lawrence believes he is still playing first base for the Havana Blue Devils. Samuel, an art collector, is unreachable until a nursing home's awful artwork provokes his disdain.

Dr. Mathiasen has noticed a tendency to attribute too many mental problems in the elderly to Alzheimer's. One World War II veteran's paranoia and violent behavior turned out to be the result of post-traumatic stress disorder. In another difficult case, the doctor felt that a female patient's complete withdrawal from the world around her was due to depression--and with aggressive treatment, she recovered.

Like a current running beneath the surface of "An Ocean of Time" is Mathiasen's conviction that "there is a life force struggling up through the depths of Alzheimer's...it has shown me glimpses of the truth hidden down amid the swirling distortions." As his own Alzheimer's-stricken aunt used to say when Mathiasen's father took the boy to visit her at The Caring Arms home, "Little do you know. Little do you know." His book is a prescription for linking caregiving with compassion and respect.

### The Bad Daughter

by Julie Hilden. (Algonquin Books, 1998)

We've seen "bad" daughters before. Shakespeare's King Lear had two of them. They rationalized betraying their father by saying the old man was losing his mind (Alzheimer's?).

Patti Reagan hurt her parents by writing a candid, if spiteful account of growing up neglected. But when the family had to face the crisis of Ronald Reagan's Alzheimer's disease, the prodigal daughter found her way back to grace.

Julie Hilden's antecedent exists in the supremely self-centered character of Veda--daughter of Mildred Pierce. In the film version of James M. Cain's novel, Joan Crawford won an Oscar as Mildred, the mother who slaved and sacrificed so that her daughter wouldn't have to. When Mildred finally sees Veda for the conniving little bitch that she is, she is devastated.

At least Mrs. Hilden's Alzheimer's spares her the horror of seeing how Julie has portrayed her as an angry, frustrated divorcee whose drinking and emotional outbursts embarrassed her upwardly-mobile daughter long before anyone suspected Alzheimer's.

As Mrs. Hilden goes from malevolent force to helpless invalid she remains a cipher. She exists only as "my mother." We hear her name, Patty, only once near the end of the book. It is "my aunt," referred to as a "crude...plain and heavy" woman who steps in to take charge of Mrs. Hilden's care until her death in 1992 at age 53.

One can sympathize with Julie's situation. Now 29, she chose to go off to Harvard, and then to Yale Law School, instead of giving up those opportunities to maintain an open-ended death watch. But she can't stop blaming her mother for casting a shadow over her life.

Of course, it's her mother's fault that she cheats on her boyfriends, lies to colleagues at her law firm--and damn it, that woman might even have passed the dreaded Alzheimer's gene on to her!

Julie ponders whether or not to go for genetic testing. Never mind that scientifically, no test result would be definitive. Her memoir is scripted to allow for a climax to her own personal drama.

Could she risk having a child? Full of self-importance, Julie muses, "This genetic curse stops with me. My death is the last it will take. There is an end to suffering in the world."

If Ms. Hilden decides to spare herself--and us--the likelihood of a daughter as blithely venal and self-justifying as she is, she has our hearty support.

What a pity that Ms. Hilden's impressive gifts as a writer are harnessed to such a stunted and narcissistic consciousness. But what's truly alarming is that the mostly positive critical reaction to "The Bad Daughter" indicates that we've reared a generation that will feel no pangs of conscience when they cast off their ailing parents.

– Chris MacLeod

# Accessing Medicaid Home Care

Continued from page 8.

desirable alternative is to transfer the home (and other assets) into a Medicaid Trust for the following purposes:

1. To eliminate or postpone gift and capital-gains taxes;
2. To reduce the penalty period (for nursing-home eligibility);
3. To secure the individual's right to continue to live in the house for the duration of his or her lifetime and ;
4. To avoid probate of the individual's estate.

Note that the home continues to be exempt even after the Medicaid recipient moves permanently to a nursing home if the applicant's spouse, a child under the age of twenty-one, a blind or disabled child of any age, or sibling with an equity interest in the house lives there.

**The M-llq and Home Care:** When the applicant applies for Medicaid home-care assistance, his application must be accompanied by his financial history for a period of no more than the three preceding months. In addition, the application must include a physician's order designated as form M-llq in New York City. Some physicians do not fully understand that if the M-llq does not adequately express the patient's medical needs, Medicaid may either deny service or agree to provide service that is not sufficient. The participation of the elder-law attorney who will review the form with the physician may be crucial to achieving adequate hours of service.

**Home-Care Program for Dementia Patients:** For those Medicaid-eligible individuals who are suffering from Alzheimer's disease or related dementia, the Consumer-Directed Personal Assistance Program for the Cognitively Impaired permits caregivers to exercise control over the hiring, training, supervising (and firing) of personal-care

workers. All the paperwork—payroll, Social Security, taxes -- is handled for the employer-employee by a special home-care agency.

**How to Apply for Medicaid Home Care:** The submission of the M-llq to Medicaid's local Community Alternative Systems Agency (CASA) will begin the application process. The CASA office will call to arrange visits by a registered nurse, case worker, and, in some instances, a physician to assess the patient's needs and social environment.

Rules for applying for Medicaid nursing-home coverage will be the subject of a forthcoming article.

**For Additional Information:** Telephone (212) 983-0700, the Alzheimer's Association, to access home health care and other related benefits and attend a Medicaid Homecare Seminar.

**Carole C. Lamson** is a partner with Lamson & Petroff, a law firm concentrating in the rights of older adults and the disabled. She is a member of the National Academy of Elder Law Attorneys and the Elder Law Section of the New York State Bar Association. Her recent article on the use of Supplemental Needs Trusts in planning for the elderly and disabled appeared in the August 1998 issue of *The CPA Journal*.



## Chapter Expanding *Continued from page 5.*

Since its establishment in 1977, the New York City Chapter has represented innovation, insight, integrity, inspiration, support and competence in the world of Alzheimer's disease care. It has been and continues to be a place of discovery. What makes this so? In part, its uniquely collegial culture—an environment that stimulates citywide, even national, collaboration. In part it is focus: New York is a community with a strong, shared singleness of purpose — we care for one another.

We at the New York City Chapter invite you to share in our vision for the future care of persons with Alzheimer's disease and other dementias as we plan to meet their needs in the 21st Century. Won't you please join us on this passage into the future and help make it a safer, more understanding and compassionate one for those with Alzheimer's?

For more information about the renovation of the New York City Chapter's new location, and how you can help open our "Windows of Opportunity" by naming a facility within our new offices, please call us at 212-983-0070.

— Lynne V. P. Raymond, Director of Development

*Castle Senior Living, L.L.C.  
Cordially Invites the Professional Community  
To join them in the celebration of . . .*

**THE LIVING ROOM  
AT PROSPECT PARK RESIDENCE**

*A floor dedicated to providing care, respect  
and independence to residents with Alzheimer's  
and related memory impairments.*

*Wednesday, September 16, 1998  
8:00 a.m. - 11:00 a.m.  
Breakfast Buffet*

**PROSPECT PARK RESIDENCE**

One Prospect Park West  
Brooklyn, New York 11215  
**718-622-8400**

*RSVP by Monday, September 14*

# BULLETIN BOARD

## Conference on Adult Day Services

On September 14, The New York State Adult Day Services Association (Region 8) is sponsoring the third annual conference for health professionals at the Brookdale Center on Aging of Hunter College (425 East 25th Street in Manhattan). The seminars and workshops will address the topic, "Adult Day Services: Are We Ready?" The event runs from 8:30 A.M.-5 P.M. Our NYC Chapter (of the Alzheimer's Assn.) is among the co-sponsors. For information and registration, call Allison Nidetz at (718) 630-7588.

## Don't Miss the Chapter's Annual Meeting!

If you haven't gotten the invitation, our 11th Annual Chapter Gathering will be held Monday, September 14 in the Caspary Auditorium at The Rockefeller University (1230 York Ave. at 66th St.). Jack Ford, anchor of "Today" weekend and NBC News Chief Legal Correspondent, will be the guest speaker. The meeting, which is scheduled to run from 6:15-7:45 P.M., will be preceded by a reception that begins at 5:30 P.M. Please RSVP the Chapter office at 212-983-0700.

## Key to Dementia Care: A Training Series for Family Caregivers

Due to the overwhelming success of the first training series for family members, the chapter is pleased to offer the same program beginning November 3. The six sessions offered Tuesday mornings from 9:15 A.M. - 1:00 P.M. at the chapter office provide a practical and comprehensive overview of issues that concern family members including treatment and research, communication, activities, personal care, and managing problem behaviors. Anne Thomas and Jed Levine are the co-trainers for the program. Prior to attendance at an Orientation Meeting and a Legal and Financial Planning Seminar is recommended. Seating is limited, and a brief telephone interview is held to determine the prospective candidates eligibility. There is no fee for the program, although contributions are certainly welcome. For more information, please contact Anne Thomas, CSW at (212) 983-0700.

This program is for family caregivers only. Mount Sinai Medical Center offers a four-week education and support program for individuals with memory loss and their caregivers. For more information call Feroza Marker, OTR at (212) 241-9250 or Elizabeth Fine, CSW at (212) 241-5673.

## 15th Annual Mayor's Conference

The NYC Chapter, in conjunction with the City's Department for the Aging, is sponsoring an annual event of significance to both family caregivers and health care providers. On Thursday, November 5, the New York Hilton Hotel (1335 Sixth Ave. in Manhattan) will host the Mayor's Conference. Panels of professionals will discuss issues ranging from research to long term care options. Caregivers will be sharing their experiences, and there will be time for questions as well as informal networking. The conference--which includes lunch--runs from 8 A.M. - 4 P.M. Advance registration is recommended. To sign up, or to receive a more detailed brochure call (212) 442-3087.

## Volunteers Wanted for New Dementia Day Care on Upper East Side

The CARE Program, a social model day program at The Lenox Hill Neighborhood House, 331 East 70th Street, is looking for volunteers. If you are interested, or for more information, call Elizabeth Geary or Aimee Beyda at 744-3022, ext. 301.

## Introduction to Alzheimer's

The Mid-Manhattan Public Library at Fifth Avenue and 42nd Street is offering two sessions on Alzheimer's disease for the general public.

**October 7** - Understanding Alzheimer's and Related Dementias. *Presenter:* Gladys Harburger, Alzheimer's Assoc., New York City Chapter.

**October 21** - Resources for Long Term Care. *Presenter:* Jed Levine, Alzheimer's Assoc., New York City Chapter.

Both sessions will be held from 6 to 7 P.M. in the 6th floor conference room.

## VOLUNTEER POSITIONS AVAILABLE

**The 24 hour Helpline  
(212) 983-0700**

“Stands by New York’s Alzheimers community” round-the-clock, 365 days a year, at no charge to callers. Manned by specially trained volunteers who respond from the office and by call forward from home on weekends and evenings, this valuable resource offers information, referrals and support to family and paid caregivers, relatives of patients, and anyone in need of help regarding a dementia patient or services. It responds to more than 2,000 calls per month.

**POSITION AVAILABLE:  
Helpline Counselor**

**Days, evenings and  
weekends.**

To provide caregivers with immediate access to a team of dedicated volunteers and concerned professionals who are familiar with Alzheimer’s disease.

**Duties:** Answering telephone, provide informational materials to help caller. refer caller to community resources as appropriate, refer caller to professional staff as required.

**Call Cynthia Roy  
(212) 983-0700**

# A WEEK TO REMEMBER ALZHEIMER’S October 1998 Schedule of Events

We cordially invite everybody to join us and participate in any or all of these *Week to Remember Alzheimer’s* activities:

**During Week of October 4:**

- The Chapter places a full page ad in *The New York Times*. Through this ad we recognize all who support our efforts. It also helps focus public awareness on those who suffer with or have died from Alzheimer’s disease, *and* on the devotion and dedication of their caregivers. A schedule of this special “Week’s” events also is featured with an invitation for everyone to join us.

**Saturday, October 10:**

- 5:30 p.m. An Ecumenical Ceremony of Remembrance will be held during this mass at the Church of St. Agnes (East 43rd Street, between Lexington & Third Avenue)

**Wednesday, October 14**

- SAFE RETURN “Good Samaritans Award Ceremony.” NYC Police Commissioner Howard Safir presents awards to Good Samaritans who have helped find lost Alzheimer’s patients (The Press Room, One Police Plaza, 11:00 a.m.)

**During Week of  
October 11-18:**

- Illumination in purple, (Alzheimer’s signature color) of: The Empire State Building, Con Ed Building, and MetLife Building

- Barnes & Noble Stores feature Alzheimer’s-related literature, and display Memory Walk posters and registration brochures

**Sunday, October 18:**

- *MEMORY WALK*, the end point celebration of *Week to Remember Alzheimer’s ...* Thousands of New Yorkers walk to honor those with the disease and their families and caregivers, or to remember those who have been lost to Alzheimer’s. For more information about *walking the WALK*, please call 1-800-METLIFE. Proceeds support research, the services and programs of the New York City Chapter of the Alzheimer’s Association.

# Memory Walk '98 - New Route, Old Memories

This year's October 18 Memory Walk should be an exciting day of festivities. We'll start out at Battery Park at the tip of downtown Manhattan, and after a 2-mile walk board a ferry to Ellis Island. Once on the Island, we'll have time to share in the memories recorded by those who stopped here on their way to new lives in America. Then we'll have a picnic. The fun will include live entertainment and goodie bags for all.

On Ellis Island, family, friends and caregivers who are in the front lines in the struggle against Alzheimer's will create a tribute to those claimed by the disease. We'll build our own "Memory Wall." On it, everyone will be able to write words of remembrance honoring those already lost – and those we are in the painful process

of losing – to this disease. Please bring photographs and mementos to attach to the wall display which will bring your person recognition and attention from all who pass by.

In previous walks, many of us have worn stick-on badges saying "Walking for Phyllis" (substitute the name of your own loved one). These will again be available, and we encourage you to add these badges of honor to the wall as well. Children will be able to draw on this wall, leaving pictures, perhaps of happier times with grandma or granddad. Each individual memory will send a message, yet the wall as a whole will be even more powerful than the sum of its parts. Our continued commitment sends the message that life is meaningful.

We are excited that our Memory Walk 1998 Honorary Co-Chairs are Mayor Rudolph Giuliani and Keith Hernandez (the former star of the New York Mets). There is no registration fee for children under the age of 10, but they must sign in before boarding the ferry. There will be prize drawings for which everyone who has registered will be eligible.

We are offering added incentives for you to ring up sponsorship contributions from friends, family and co-workers. If you collect \$50 in donations, you will receive a Memory Walk T-shirt; if you raise \$200, the prize is a Memory Walk golf shirt; for those who rack up \$500 or more, a terrific Memory Walk windbreaker will be yours. You might organize a team of walkers where you work -- you can promise them a day of fun.

These goals are not as tough to achieve as you might think. You are representing more than just a worthy cause, you are mobilizing to battle an illness that the public is finally beginning to perceive as the major health threat of the next century. Last year's top fundraiser, Florence Cohen, raised \$4,452! Let that be your inspiration.

In '96 and '97, New York's Memory Walks raised more than \$200,000 for our Chapter. That money has meant more funds available to us for research and the programs that have made such a difference to the families we serve in this area.

Corporate sponsors are also playing a part. Sprint is the National Sponsor of Memory Walk 1998. Eisai Inc. (which developed the drug Aricept) is the New York Corporate Chair. Other major supporters are Pfizer Inc., the Dr. Gerald J. and Dorothy R. Friedman Medical Foundation, Price Waterhouse, MetLife, the New York Design Center, United HealthCare, Senior Quarters Corp., The Actors Fund of America, ARAMARK, DemoWORKS, Inc., and Lyons Lavy Nickel Swift. WABC-TV and WCBS 88 Newsradio are our media sponsor, so we're expecting a higher profile in coverage of this year's Memory Walk.



# Timetable



It is not too early to send in the attached form and register for Memory Walk. You will then be sent a brochure with all the details and a form for recording the donations of those who sponsor your walk. (If you can't join us on October 18, consider a contribution. All checks should be made payable to the Alzheimer's Association - NYC Chapter.) If you are forming a team and you need multiple registration forms, call 1-800-MetLife. If you would like to volunteer to help us with Memory Walk, please call 1-800-308-2341.

On that special Sunday, you'll see our purple banners in Battery Park (rain or shine). Registration and check-in are from 9:00 - 9:45 A.M. Then comes some welcoming words followed by a brief warm-up. We begin our walk at 10:00 A.M. At 10:30, we begin boarding the ferries for Ellis Island. It should be shortly after 11:00 o'clock

when we all arrive at Ellis Island and festivities get underway. Hope to see you there!



-- Chris MacLeod

Thank you for your support and welcome to the *Memory Walk* team!!

## Memory Walk Registration Form

To register, please complete this form, **make your check payable to the Alzheimer's Association - NYC** and mail today:

Alzheimer's Association Memory Walk - NYC  
c/o OAI  
2801 M Street, NW, Washington, DC 20007

(Please Print)

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_

I will be walking: \_\_\_\_\_ as an individual

\_\_\_\_\_ with a team Team name \_\_\_\_\_

\_\_\_\_ Enclosed is my \$15 registration fee.

I am not able to participate in Memory Walk, but want to make a donation. Enclosed is my check for:

\_\_\_\_ \$1,000    \_\_\_\_ \$ 500    \_\_\_\_ \$250    \_\_\_\_ \$100  
\_\_\_\_ \$50        \_\_\_\_ \$25    Other \$ \_\_\_\_\_

\_\_\_\_ I would like to **volunteer** for Memory Walk and/or other Chapter activities.

My company has a matching gift program.  
Name/address of company \_\_\_\_\_

Signature \_\_\_\_\_

Send in the Registration Form, watch your mail for a Memory Walk Registration Brochure or call 1/800/308-2341 to request one!



*Someone to Stand by You*

New York City Chapter  
420 Lexington Ave., Suite 610  
New York, NY 10170

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