Laura Simon has not slept well for the past six months. Every night she lies awake, worrying about her mother, Sylvia, who lives alone in a small apartment 400 miles away.

Did Sylvia take her medications today? Did she remember her appointment with Dr. Crane? Did she get out today to buy groceries? Laura called her mother twice today, but lately, Sylvia seems confused on the phone. And Laura knows that Sylvia’s failing eyesight and hearing loss further serve to insulate her from others.

Laura has talked to her mother about getting more help at home, and once broached the subject of having Sylvia come to live with her. But Sylvia insists that she does not need more help, wants to remain at home, and never wants to be a burden to her daughter.

Enough.

Laura awakens one morning after a fitful sleep and phones her mother. No answer. After trying again with the same result, she starts to worry. After several repeated attempts to phone, she tracks down the building manager. He opens Sylvia’s door and finds her lying unconscious on the bathroom floor, after what looks like a fall out of the bathtub.

The building manager calls an ambulance, and Sylvia is transported to the hospital. Laura rushes to the airport and flies out on the next plane, leaving behind a concerned husband, her own worried children, and mounting job responsibilities.

Stepping Back

As Laura’s story poignantly illustrates, the challenges of long-distance caregiving can be frustrating, unpredictable, and overwhelming. Could Laura have prevented what happened to her mother? Could she have done more to get her mother to accept help? Could she have coerced her mother to come live with her?

continued on page 4
From the Executive Director: Rallying our Troops
Advocates Sound Clarion for State, Federal Legislators

W
e are so close to a catastrophe, we are so close to a
cure.” These were the words of actor and activist
David Hyde Pierce, testifying before the United
States Congress April 30 at the National Public Policy Forum.
Mr. Pierce, who plays the role of Niles Crane on the television
show Frasier, was referencing the 14 million baby
boomers who will develop Alzheimer’s disease over the next
45 years.

Dr. Marilyn Albert of Harvard Medical School and Chair of the national Alzheimer’s Association’s Medical and Scientific
Advisory Council (also see page 11) echoed Mr. Pierce’s point in
her testimony before Congress. She stated, “If we don’t ade-
quately support research, no health care system in the world
will be able to cope with the ramifications.”

Tidal wave. The potential catastrophe that
David Hyde Pierce identified was reinforced
when the MA Chapter recently released data on
the increase in prevalence of Alzheimer’s disease
(see story, page 7). In the period between the
1990 Census and the 2000 Census, the number of people in Massachusetts with Alzheimer’s dis-
ease increased to 140,000, a 17% increase.

Even more frightening, the population group
aged 45 to 54, the vanguard of the baby
boomers, grew by 46% during this same period.
This means that starting in 2020, this baby
boom population bulge will begin to reach the
age of 75, the period of greatest risk for
Alzheimer’s disease.

Ticking clock. On April 25 and April 30, Alzheimer’s
advocates rallied at the State House in Boston and the Capitol
Building in Washington, DC respectively. The message was sim-
ilar in each setting: despite the hard times, our government
must step forward to support families, caregivers and
researchers—we have run out of time.

At the Alzheimer’s Association’s April 25th LEAD event
rally at the State House, 235 people with Alzheimer’s
disease joined family and professional caregivers to urge law-
makers to protect programs and initiatives benefitting people
with Alzheimer’s disease and their families. The State House
program featured a panel of individuals representing The
journey through Alzheimer’s Disease, this year’s theme for the
annual event (see story, page 7).

Brandes professor Dr. Bernard Reisman, who was
recently diagnosed with Alzheimer’s disease, spoke movingly
about its impact: “A professor needs to use his head. This situa-
tion is something like that of a pitcher whose pitching arm
goes out,” he said.

Dr. Reisman continued by praising the hundreds of adva-
crates who traveled to our Massachusetts State House to press
our cause. “Coming into this spacious and awesome room is
only overwhelmed by the people here who are working to
advance this issue,” he noted. “I say thanks to
you on behalf of all the people across the state.”

Professor
Reisman, we offer our
own appreciation. To
you, to the 235 adv-
crates jammed into
the State House, to
the 500 Alzheimer’s
Association pioneers who gathered in Washington to press for
more funding for research... to all of you, we say THANKS!

“if we don’t adequately support research, no health
care system in the world will be able to cope with the ramifications.”

—Dr. Marilyn Albert

Sandra Gavin
(PHoto by Joseph Gavin)

Debra Katt-Lloyd
(Photo by Brenda Vitale)
When the time comes for long-term care, most elders prefer to remain in their present location, even if staying put means living at a distance from their caregivers. Although the distance factor can create many legal and financial pitfalls, you and your elder can take certain steps to avoid them.

When care is being provided on a long-distance basis, the elder should establish a current estate plan that is recognized in the elder’s state of residence. Generally speaking, the estate plan includes a Will as well as documents that protect the elder in the event that he or she becomes incapacitated.

Variations. Remember that the law varies from state to state; planning that may be appropriate in your state may not be appropriate in the elder’s state. To this end, it may be best to hire an elder law attorney practicing in the elder’s state. In this way, you can be sure that the advice you and the elder receive will pertain to the law of that state, and that any necessary state-specific provisions will be incorporated into the estate plan documents.

The most common legal issue confronting caregivers is lack of authority to handle financial and medical decisions when the elder becomes incapacitated. With the proper documents in place, this authority can be granted to the person the elder chooses. Thus, family members should discuss with the elder the need to nominate someone to handle financial and medical matters while the elder can still express his or her wishes.

In Massachusetts, the elder would execute (1) a durable power of attorney relative to financial decisions; and (2) a health care proxy relative to health care decisions. In each document, the elder names someone to handle his or her financial and health care decisions when the elder no longer can.

Protection. Together, a durable power of attorney and health care proxy protect the elder from guardianship, which is the time-intensive, emotional, expensive, and very public process of having a decision maker appointed for the elder by the court. With this in mind, if there is a possibility that the elder may ultimately move to the caregiver’s state, it would be wise to consult with an attorney in each state when the documents are being drafted to ensure that they would be valid in either state. Otherwise, it is possible that the elder could lose the protection of the documents, especially if the elder moves after losing his or her capacity to execute new documents.

Financing long-term care also causes many caregivers and elders to falter. Many times, the elder and family hope that public benefits (i.e., Medicaid) will pay for his or her long term care. In fact, each state is different with regard to obtaining approval, and vast differences between states are likely to exist with regard to various issues, including asset limits and the effect of gifts.

Proper planning can ensure that the elder receives benefits sooner rather than later. Furthermore, there are differences in each state’s estate recovery efforts, which are the state’s efforts to recover benefits paid for care from the estate of a recipient who has passed away. Here, proper planning can minimize the exposure of the elder’s estate to recovery efforts.

Even though long-distance caregiving is a legal minefield, it is possible to minimize problems by addressing issues before they arise. In this regard, long-distance caregivers should actively seek information and seriously consider working with an elder law professional in their elder’s geographical area to aid them in avoiding the pitfalls outlined.

Proper planning can ensure that the elder receives benefits sooner rather than later.
Long-Distance Caregiving continued from page 1

We live in an increasingly mobile society, in which family members live further and further apart from each other. A 1997 survey conducted by the National Council on Aging on long-distance caregiving found that nearly 7 million Americans provide or manage care for a relative or friend aged 55 or older who lives at least one hour away. Caring for an elder is rooted in our oldest traditions. It is a difficult but worthwhile task, made harder by our social mobility.

Feelings. It is common to feel overwhelmed, guilty, and even angry when you live far from an elderly relative who requires support. You may be commuting back and forth, or spending hours on the phone with doctors, nurses, or other service providers.

In addition, you may feel trapped between the needs of your own family and your elderly relative. You may feel pressured at work as you spend time on the job trying to resolve crises from afar. And you may feel especially frustrated that, despite your best efforts, your relative ignores or resists all your good advice and suggestions.

Understanding the Solution

It may be reassuring to learn about several strategies to make long-distance caregiving more manageable. First, plan ahead. Assess the needs of your relative and take action now, not later when a crisis is underway. Second, be frank. Talking openly with your elderly relative will alleviate anxiety that you are “taking over.”

Third, enlist support from others. Asking for help from other family members, even when you think they are not involved, may yield surprising results. Finally, accept your own limitations. Caring for an elder involves balancing many sets of competing needs—those of the elder, your family, and your own.

It is very difficult indeed to assess an individual’s real needs over the telephone. Plan a visit soon to assess the situation. In planning your visit, you should include your relative as much as possible. Let him or her know you’re concerned, and that you want to visit and discuss the situation.

Preparation. Schedule appointments with doctors, lawyers, or other service providers in advance. If your relative is willing to share sensitive information with you, ask him or her to gather medical, financial, and legal information such as current medications, bank accounts, insurance policies, wills, and advance directives.

Making Assessments

Be sure to look for specific signals in assessing your relative’s needs. Have there been obvious changes in mental or physical functioning?

For example, is he or she sleeping and eating well? Does your relative appear withdrawn, anxious, or depressed? Is he or she struggling to manage daily activities like bathing, dressing, shopping, or meal preparation? Are there any obvious health or safety problems? Is the house messy or unclean? Are there unpaid bills or papers lying about?

While you should certainly listen to what your relative tells you about these matters, you should also gather your information by personal observation—directly but unobtrusively. An elder experiencing memory loss or dementia is likely to have limited insight into his or her behavior and needs. Many are also quite adept at “covering” for their losses, and you should be alert to signals that all is not well beneath the surface.

Professional help. If you cannot travel to your relative, you should consider hiring a professional, such as a Geriatric Care Manager (GCM), to assess the elder’s needs. After visiting with your relative, the GCM can make recommendations about care plan options and provide ongoing monitoring.

Find out what services and programs are available in your relative’s town or city. The Internet is a great place to start, but beware of information overload. In dealing with social service bureaucracies, be persistent, take notes on services offered, and get the name of a contact person for future reference.

Also, gather information on informal supports, such as friends and neighbors that your relative can call in a crisis. Keep a list of phone numbers in a visible place near the elder’s telephone, and keep a copy yourself. If your relative is isolated and lives alone, consider installing a personal emergency response system in the apartment or home.

Launching Your Plan

Once you locate appropriate services and decide to implement an action plan, you must remain sensitive to your relative’s view of the situation. He or she may be afraid of accepting strangers into the home or nervous about the cost of services. Reassure your relative that your goal is to preserve dignity and autonomy, not to control or take away independence. If necessary, ask for help from a person outside the family (friend, doctor, or clergy member) who your relative knows and respects.

Relocation. If you remain unsuccessful in stabilizing your relative’s living situation despite a well-developed action plan, you will need to decide whether you can continue to shoulder the burden of long-distance caregiving as your relative’s needs increase. This may be the best moment to consider relocating your relative to a facility near you, or even into your own home.
Elders suffering from memory loss are usually resistant to moving voluntarily. The desire to remain in familiar surroundings is understandable; it frequently takes a crisis, such as a hospitalization, to initiate the move.

In deciding whether to bring your relative into your home, there are practical, financial, and emotional issues to consider. What is the quality of your relationship with the elder? Has it been loving and respectful, or stressful and conflicted?

**Bigger picture.** It’s also important to consider the impact this move will have on your own family. Is there enough space? How much care does your relative need? How will your children or spouse react to sharing you with another family member? What financial arrangements can you make with your relative to pay for the costs of care?

For the elder, the move will likely represent a drastic lifestyle change. He or she is leaving behind a lifetime of stabilizing memories, social supports, and routines.

**Partnerships**

Whenever possible, include your relative in the decision making process, and allow as much control and choice as possible during this transition. Emphasize the positive benefits of the change, such as spending more time with children and grandchildren.

The logistical details of the actual move can feel overwhelming for everyone. You can aid in the transition process by doing as much advance planning as possible and by remaining calm. Make a list of moving details.

**Organizer.** Consider hiring a professional organizer to assist in cleaning, packing, and organizing. If you are accompanying your relative by plane to his or her new home, consider reserving first class seats—they are roomier and you will receive better in-flight attention.

Your loving compassion is essential to providing the care our elders need, particularly when they live at a distance. But, as Laura discovered, compassion alone can be insufficient when the elder’s needs or even worse, when a crisis occurs.

Compasion must be mixed with careful thought, planning, and when necessary, professional assistance in order to ensure the care you provide or arrange for is effective and rewarding for all. In Laura’s case, her mother’s crisis enabled her to persuade Sylvia to accept more help at home with daily activities—and sparked a frank dialogue between them about the future.

**Caring for an elder is rooted in our oldest traditions. It is a difficult but worthwhile task, made harder by our social mobility.**

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**Book Review: Paving the Way, Gently**

**Moving a Relative with Memory Loss: A Family Caregiver’s Guide**

*By Laurie White, M.S.W. and Beth Spencer, M.A., M.S.W.*


**Reviewed by Catherine J. Votaw, M.S., R.N.**

Home-based or residential care for a frail family member? Many of us have needed guidance in addressing this excruciatingly delicate and difficult issue.

The rich, pure reflections offered by White and Spencer, educators and dementia care consultants, will help readers weave together their own individualized family plans for moving memory-impaired relatives into residential care. The authors offer a variety of resources and explore the essential components of planning and orchestrating the move in a clear, empathic style.

**Prism examined.** No emotional nuance or logistical contingency has been omitted or simply waved away. For example, the research and decision-making process itself is analyzed in detail; as well as when and when to involve the memory-impaired relative in visits to prospective residences, and what to say.

The authors also help readers prepare themselves for these exploratory visits, and offer a comprehensive checklist of points to investigate, from care planning to costs to staff training. Make sure to visit at mealtime!

**Rethinking promises.** White and Spencer note that the decision to move or not to move the relative with memory impairment generally falls to the family. They encourage family members to write down the pros and cons of the proposed move, as a way to clarify each person’s thinking.

A list of reasons why moving is hard—not the least of which is the symbolic value of moving itself—helps identify possible reasons for inner conflict people may feel about moving a relative out of her home and into residential care. The authors rightly observe that clarifying feelings and achieving as much harmony among family members as possible surrounding the decision are important prerequisites to a successful move.

**Creative ideas.** Short boxed case studies throughout the book drawn from the authors’ clinical practice offer valuable caregiving tips. A particularly effective example of activity modification is sketched out in which a mother in residential care and her daughter work out flexible ways to prepare holiday cards together over a period of several years.

Additional sections on personalizing the loved one’s room, visiting after the move has taken place, forging relationships with staff members, and caring for oneself add depth and valuable information. White and Spencer directly confront feelings to expect on the part of everyone involved throughout the moving process, and offer supportive coping mechanisms.

Snapping the locks shut on my mother’s suitcase the night before her nursing home admission more than five years ago will remain one of the saddest hours of my life. Reading White and Spencer’s hopeful, sensitive treatment of the moving process helped to release some of the loneliness and pain surrounding that time, and to affirm the difficult decision my family had made.

I recommend this book unequivocally to readers facing similar challenges.

Catherine J. Votaw, M.S., R.N. is the Massachusetts Chapter’s Editor, a family member, and a medical education and communications specialist.
Advocacy

National Public Policy Forum
By Kate Doyle

Eleven Massachusetts advocates attended the National Alzheimer’s Association Public Policy Forum April 26-30 in Washington, DC. The four-day event featured a wide range of workshops on various public policy topics, leaving plenty of time for networking among advocates from chapters and agencies in other states.

In addition to meeting with Rep. Markey and his aide Anelique Skoulas, advocates held meetings with Congressmen John Oliver and James McGovern. They also met with other staff members, including Amy Rosenbaum, Policy Director for U.S. Rep. Martin Meehan; Christine Locke, Legislative Aide to U.S. Rep. Michael Capuano; Mike Capsa, Aide to U.S. Rep. John Tierney; Caroline Powers, Aide to U.S. Rep. Stephen Lynch; Ann Jablon, Chief of Staff to U.S. Rep. Richard Neal; Joe Racalto, Health Care Aide to Congressman Barney Frank; Dr. David O’Neil Washington, Health Policy Fellow for Senator Edward M. Kennedy; and Michael Leighs, Senior Staff Aide to Senator John Kerry. Our Massachusetts advocates met with the state’s congressional delegation to lobby for increased research funding, modernization of Medicare to include prescription drug coverage, and continued funding for the Safe Return program.

Medicare Changes

Has Medicare coverage changed for people with Alzheimer’s disease? Since the recent New York Times article (March 31, 2002) dealt with this topic, the question seems to be on everyone's mind—and the answer is yes.

On September 1, 2001 Medicare contractors were informed that they can no longer automatically deny claims based solely on the Alzheimer diagnosis. This change does not guarantee that all claims for Alzheimer’s patients will be paid. Instead, Medicare contractors are being instructed to review these claims based on the beneficiary’s overall medical condition.

Rationale. In other words, Medicare may pay for speech, occupational, and rehabilitation therapies for people with Alzheimer’s, including mental health services. The coverage for Alzheimer’s disease has been clarified to make it more evident how Medicare processes claims for patients with Alzheimer’s disease. Medicare had been denying claims for needed medical care because of the incorrect belief that an individual with Alzheimer’s cannot benefit from various interventions.

The set of instructions given to Medicare contractors about Alzheimer’s disease reflects the commitment of the Centers for Medicare and Medicaid Services (CMS) to ensure that people with Medicare coverage receive the benefits to which they are entitled under the program. If you have any questions, please feel free to contact the MA Chapter at (617) 868-6718.

Kate Doyle is the Massachusetts Chapter’s Director of Public Policy.
LEAD Event Advances Mission
Advocates Lobby to Increase Alzheimer’s Awareness

More than 230 advocates and 50 legislators and aides gathered at the State House in Boston April 25 for the Alzheimer’s Association’s annual Legislative Education and Awareness Day (LEAD), co-sponsored by the Legislative Caucus on Older Citizens’ Concerns.

This year’s theme, The Journey through Alzheimer’s Disease, was sensitively and effectively explored through a panel presentation. The panel featured an early-stage patient, Dr. Bernard Reisman, Professor of Contemporary Jewish Studies at Brandeis University; a family caregiver, Pat Wellington; and professional caregivers John Ford, Esq. of Greater Lynn Legal Services; Dan O’Leary, Executive Director of Mystic Valley Elder Services; Anne Marchetta, Executive Director of Community Family, Inc.; and Kate Marshall, Director of Special Care Program at Concord Park.

Following opening remarks, Chapter Board Chair Sanford Auerbach, MD presented a plaque of appreciation to State Legislative Caucus on Older Citizens’ Concerns.

LEAD panelists inspired the audience at the State House in Boston. They included (L to R): Kate Marshall, Director of Special Care Program at Concord Park; Anne Marchetta, Executive Director of Community Family, Inc.; Dan O’Leary, Executive Director of Mystic Valley Elder Services; Pat Wellington, a family caregiver; early-stage patient Dr. Bernard Reisman, Professor of Contemporary Jewish Studies at Brandeis University; and Atty. John Ford of Greater Lynn Legal Services.

Clear voices. In response to these issues, the panel members emphasized the need for advocates to make their voices heard, and to push for increased state funding to ensure that agencies involved can continue to meet the needs of the people they serve. The morning’s events concluded with lobbying visits by audience members to their individual legislators, urging them to support our legislative priorities in this year’s state budget.

The Journey through Alzheimer’s Disease touched upon many facets of our long term care system, a system that will soon be overwhelmed unless we take steps to meet the pressing needs of families impacted by Alzheimer’s disease. I would like to thank all the panelists and advocates who made the day a great success! 

—Kate Doyle

A Family Caregiver’s View

My husband, Mark, 83, has had Alzheimer’s disease for eight years. My friend, Dr. Reisman, thinks the term “caregiver” is too clinical. I agree with him, but by any name, we are the ones who are there in the disoriented hours of the day and in the confused, wandering hours of the night. It is confining, it is heartbreaking, and it is exhausting . . .

Life with an Alzheimer sufferer is a juggling act with a lot of balls in the air at once. It is like a scavenger hunt without clues, as when a much-hunted-for eggbeater suddenly turns up in the freezer . . .

The writer, Iris Murdoch, had Alzheimer’s disease. It is ironic that in the last line of her final published work, she writes of a character, “He’s come to a place where there is no road.” That passage struck me as descriptive of my husband’s condition; as a caregiver, I would add, “where there is no road map.”

New Report Says 140,000 in Massachusetts Have Alzheimer’s

The Massachusetts Chapter and the Executive Office of Elder Affairs has released a town-by-town prevalence report showing that the number of older people in the Commonwealth who are coping with Alzheimer’s disease has risen to almost 140,000, a growth of 17% from 1990 to 2000.

“Alzheimer’s disease and population trends are on a collision course,” Secretary of Elder Affairs Lillian Glickman said in a statement accompanying the report, which was released at the Chapter’s annual Legislative Education and Awareness Day rally April 25 at the State House in Boston.

The 2000 U.S. Census, which forms the basis of the report, shows that the single greatest 10-year population jump in Massachusetts—46%—occurred among baby boomers between the ages of 45 and 54. Epidemiologists have warned that without a cure for the disease, these baby boomers, who represent the largest generation in American history, will not only enjoy a longer life span than any previous generation, but will also experience Alzheimer’s in numbers “which are certain to overwhelm—and potentially bankrupt—an unprepared health care system,” Massachusetts Chapter President Jim Wessler said.

“Especially at a time when programs that serve people with Alzheimer’s are being victimized by budget cuts, we must focus attention on these alarming numbers and work together to address them.”

For a copy of the report, contact Jeanette Rosa-Brady at (617) 868-6718 or visit our web site at www.alzmass.org.
Train the Trainer Program for Dementia Care Professionals
A professional education program designed to teach participants to become trainers within their community agencies or facilities. One or two representatives attend to learn about Alzheimer's disease and dementia, Habilitation therapy, behavior issues, activities, and more. After the program, the representatives return to their facilities to teach other staff members. Pre-registration is required for this full day of training. The charge is $500 for two representatives from an agency. Alzheimer's Association, Cambridge Office, 36 Cameron Ave., Cambridge. Call Donna Smart-Gorham at (617) 868-6718.

September 11, October 9
Take Control of Alzheimer’s Disease: for Early Stage Patients and their Care Partners
A three-week course for people with early stage Alzheimer’s disease and their care partners. Participants will learn how to take control of certain aspects of Alzheimer’s disease and to slow its progression. Contact Donna Smart-Gorham in the Cambridge Office at (617) 868-6718.

October 4, 11, and 18 (1-3:00 p.m.)
Activity-Based Alzheimer’s Care
A new training program for activity and program professionals. Topics covered include activity-based care for persons with AD, assessment and care planning, program design, quality activities, program evaluation, and teamwork. Alzheimer’s Association, Cambridge Office, 36 Cameron Ave., Cambridge. For more information, contact Erin Whalen at (617) 868-6718, ext. 213.

October 23
Home-Based Care Techniques for Families
This free six-part seminar will teach families a new therapeutic approach to caregiving. Family caregivers will learn how to work with the person with Alzheimer’s disease in order to take more control over the often-difficult disease symptoms. Presented by Dr. Paul Raia. Families must plan to attend all six sessions. There is no charge for the course, but pre-registration is required. Call Donna Smart-Gorham in the Cambridge Office at (617) 868-6718.

October 30; November 6, 13, 20, & 27; and December 3 (1-3:00 p.m.)

Family Orientation
An education meeting for family members. Topics include diagnosis, treatment, medications, planning, home management, and more. Each Family Orientation session is repeated on a monthly basis. The program is free of charge. Locations, times, and dates are listed below:

Cambridge: Held at Cambridge Office of Alzheimer’s Association, 36 Cameron Ave., Cambridge. Presented by Dr. Paul Raia. Pre-registration is not necessary and the program is free of charge.
August 15, September 19, October 17 (10:00 a.m.-12:00 p.m.)

Lowell: Held at Alzheimer’s Association, Lowell Area Office, HealthSouth at St. Joseph’s, 220 Pawtucket St., Lowell. Presented by Debra Katt-Lloyd. Pre-registration is not necessary and the program is free of charge. Call (978) 937-5576 for more information.
August 14, September 11, October 9 (10:00 a.m.-12:00 p.m.)

Newton: Sponsored by the West Suburban Alzheimer’s Partnership. Held at Newton Senior Center, 345 Walnut St., Newton. Presented by Pamela Kunkemeiuller. Pre-registration is not necessary and the program is free of charge.
August 14, September 11, October 9 (6:45-8:45 p.m.)

Northampton: Held at VNA and Hospice Alliance, 168 Industrial Ave., Northampton. Pre-registration is recommended; call (413) 787-1113. Free of charge.
August 14, September 11, October 9 (3:30-5:00 p.m.)

August 22, September 26, October 24 (1:30-3:30 p.m.)

Springfield: Held at Good Life Center, 1600 E. Columbus Ave., Springfield. Pre-registration is not necessary and the program is free of charge.
August 27, September 19, October 17 (10:00 a.m.-12:00 p.m.)

Wellesley: Sponsored by the West Suburban Alzheimer’s Partnership. Held at Wellesley Council on Aging, 219 Washington St., Wellesley. Presented by Peggy Mullen. Pre-registration is not necessary and the program is free of charge.
August 27, September 24, October 21 (10:00 a.m.-12:00 p.m.)

Westwood: Sponsored by the West Suburban Alzheimer’s Partnership. Held at Westwood Council on Aging, 210 Nahatan St., Westwood. Presented by Peter Byron. Pre-registration is not necessary and the program is free of charge.
August 15, September 19, October 17 (1:30-3:30 p.m.)

All meetings are free of charge unless marked by ☑. Times may be subject to change. Please call the number listed for each program. ☑ indicates pre-registration is required. If in doubt, call our Helpline at 617/868-6718. Visit www.alzmass.org for up-to-date listing.
Save the Dates
Watch for These Upcoming Events!!!

**Take Steps to End Alzheimer’s**
10th Annual Memory Walk
**September 21-22, 28-29**

Details of 9 walks statewide are listed at right! ➔

Alzheimer’s at Tanglewood: An Encore
**Sunday, August 11**

Join us for an afternoon performance of the Boston Symphony Orchestra! Renowned violinist Gil Shaham will be the featured soloist and Neeme Järvi will conduct the orchestra in the music of Tchaikovsky and Prokofiev.

Guests are invited to picnic on the Tanglewood lawn at noon and then enjoy a scrumptious dessert buffet in the Hawthorne Tent before proceeding to the Tanglewood Shed for the 2:30 p.m. performance. Tickets are priced at $125 and $75 for the reception and concert, and $50 for the reception only.

Contact Kathryn Hedgepeth at (413) 787-1113, e-mail kathryn.hedgepeth@alz.org or visit the Chapter web site (www.alzmass.org) for ticket information.

**Annual Meeting**
**Tuesday, September 10**

The Annual Meeting of the Massachusetts Chapter of the Alzheimer’s Association will be held during the afternoon at the College of the Holy Cross in Worcester. It is free of charge and everyone is welcome—invitations will be available early in August. For more information contact our Cambridge Office at (617) 868-6718, or visit our web site after August 1 at www.alzmass.org.

12th Annual Professionals Conference,
Western Regional Office
**Wednesday, November 13**

**Empowering the Patient**

8:00 a.m. - 4:00 p.m. Springfield Sheraton, One Monarch Place, Springfield, MA

Contact Jeannie Banas at (413) 787-1113 or e-mail jeannie.banas@alz.org for further information.

**Coming this Fall: Basic Training for New Support Group Leaders**

Free training workshops offered to new and prospective leaders of Alzheimer family and patient support groups in our Chapter area.

Contact Debra Katt-Lloyd for further information and dates at (978) 937-5576.

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**Saturday, September 21**
Northern Quabbin Valley Walk, Athol/Royalston Middle School, Athol. Contact Wanda Landry at (978) 248-6334 or wlandry821@hotmail.com.

**Sunday, September 22**
Greater Boston Walk (main walk), Canal Park at the CambridgeSide Galleria, Cambridge. Contact Sheila Watnick at (617) 868-6718 x208 or memorywalk@alzmass.org.

**Central Massachusetts Walk,** Worcester Senior Center, Worcester. Contact Tamara Cullen at (508) 791-5543 or tamara@110.net.

**Northern Essex Walk,** Bradley Palmer State Park, Topsfield. Contact Patricia Lavoie at (978) 777-2700 or palzcare@aol.com.

**Northern Middlesex Walk,** Boarding House Park, Lowell. Contact Donna Koski at (978) 682-3582 or proeldercare@aol.com.

**Southeastern Massachusetts Walk,** Heritage State Park Visitors Center, Fall River. Contact Judy Elste at (508) 675-2101 x404 or judith404@bristolelder.org.

**Saturday, September 28**

**Neponset Valley Walk,** Bird Middle School, Walpole. Contact (781) 278-6029 or smcquaid@cchcs.org.

**Sunday, September 29**
Pioneer Valley Walk, Stanley Park, Westfield. Contact Ginny Sinkoski at (413) 787-1113 or kathryn.hedgepeth@alz.org.

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African-American Forum Strikes Harmonious Chord

By Michael P. Kincade, Sr.

Against the backdrop of a bright, sunny morning, the first annual African-American Community Forum on Memory Loss convened April 5 at the George Washington Carver Den in Dorchester. Multicultural Outreach Manager and conference host Michael P. Kincade, Sr. welcomed an overflow audience of 200 caregivers and concerned family members.

The first speaker, Rev. Ray Hammond of Bethel AME Church, set the tone for the day by describing how his mother’s experience with AD has affected his family. In his remarks, Rev. Hammond thanked the Alzheimer’s Association for providing support and education, and closed with an emotional passage from The Velveteen Rabbit.

In this passage from the classic children’s storybook, the Skin Horse character explains to the Velvet Rabbit what it takes to become Real. He confides that the process of becoming Real takes a long time, during which you become old, and may lose your hair and some of your parts, but once you have become Real it is all worth it.

Reverend Hammond utilized this passage to illustrate how our loved ones living with Alzheimer’s disease grow old and frail, but we love and care for them, for they will always be Real.

The next speaker, Dr. Pamela Sheridan, a researcher at Beth Israel Hospital, discussed the differences between normal memory loss and AD, bringing a sense of humor to the subject. As she shared stories and insights about past patients and family members to help humanize the disease, many audience members laughed and voiced agreement.

At the end, Dr. Sheridan spent most of her allotted time answering questions from the audience. The morning panel discussion addressed the lack of African-Americans involved in research, as well as legal issues many AD patients and their caregivers encounter.

After a delightful lunch, the afternoon focus turned to caregivers and their burdens. Dr. Jane Cloutterbuck, a researcher at the University of Massachusetts, presented her recently completed study of local African-American caregivers and the burdens they face.

Some highlights of the study illustrated how African-American caregivers are able to get help from their extended families, as well as the extraordinary efforts many make to find professional services. The study also showed that many Black caregivers rearranged their lives to stay home and provide care before sending a family member to a residential facility.

Panel. Wrapping up the day was a panel discussion of professionals whose families had been touched by AD. Shirley Coffey, a long-time caregiver, talked about the difficulties she faced finding proper care for her mother, who had died from AD. State Representative Gloria L. Fox, who had participated in an awards ceremony for four local caregivers earlier in the program, challenged the audience to become more politically active.

Daphne Jones, Director of Admissions for Goddard House, a local residential facility, addressed the myths many African-Americans have about nursing homes. She talked about how some caregivers believe nursing homes are just places where people go to die, where the level of care is poor and unprofessional.

Myth debunked. Ironically, during her presentation an audience member stated she was told never to send anyone to Goddard House due to the inferior care they provided. Before Daphne could respond, another participant refuted the claim by sharing how her mother was a resident at Goddard House, receiving first-rate care. This interchange formed a perfect example of how a rumor is formed and spread throughout the community, but in this case was debunked on the spot.

Michael P. Kincade, Sr. is the Chapter’s Outreach Manager.


“He was a Real Rabbit at last, at home with the other rabbits.”

—The Velveteen Rabbit
Chapter Hosts Discussion of Newly Funded Research
Part II: Escaping Alzheimer’s and Other Mysteries

By Gerald Flaherty

Part 1 of this three-part series appeared in our Spring 2002 Newsletter and described the work of Drs. Barbara Shukitt-Hale and David Harper, who were among eight Massachusetts researchers to receive a highly competitive grant award from the Alzheimer’s Association in 2001.

Dr. Shukitt-Hale, Harper, and the four grantees whose similarly outstanding work is detailed below, were honored at a December reception and panel discussion at the Alzheimer’s Association in 2001.

This series helps us keep our readers up-to-date about the types of scientific investigations our Association supports,” said Roberta Rosenberg, Chair of the Chapter’s Medical & Scientific Advisory Committee, “and strengthens our relationships with leaders in the scientific community.”

Robert D. Moir, Ph.D., of Massachusetts General Hospital in Boston, spoke about LRP-Mediated Catabolism of Secreted and Amyloidogenic APP. A-beta protein is the principal component of amyloid, the insoluble and toxic material that accumulates in the brains of people with Alzheimer’s disease. Unraveling the mystery of how and why amyloid accumulates in the brain has been the focus of most Alzheimer research for the past decade.

Amyloid formation appears to be very sensitive to A-beta concentration; only modest increases in the amounts of this molecule are needed to initiate and maintain the disease process. Most research to date has investigated how A-beta is made and the factors that can cause or promote the molecule’s over-production. However, recent findings suggest that understanding the mechanisms involved in A-beta clearance may be just as important, or indeed more so, for developing effective treatment strategies.

Clearance process. Dr. Moir is studying how A-beta clearance may be inhibited by slight elevations in the levels of common brain proteins. An important pathway for A-beta clearance involves a protein called the low-density lipoprotein receptor related protein (LRP).

Dr. Moir’s research has already shown that at least one LRP-binding protein not involved in A-beta clearance is elevated in the Alzheimer brain. He is investigating how these LRP-binding proteins may inhibit A-beta clearance through interaction with each other and competition for the available LRP binding sites.

Thomas T. Perls, M.D., M.P.H., of Beth Israel Deaconess Medical Center in Boston, has drawn much attention for his work on Discovering the Genetic Basis for Why Centenarians Markedly Delay or Escape Alzheimer’s Disease. According to Dr. Perls, scientists have discovered comparatively little about genetic factors involved in the more common, late-onset form of Alzheimer’s that occurs randomly. One intriguing finding shows that Alzheimer’s rarely strikes centenarians (people who live to 100). His project attempts to identify genetic variations that enable these individuals to escape or delay dementia.

Dr. Perls’ research will expand on previous work with 137 pairs of brothers or sisters who had achieved the age of 100, in which his team found evidence that a region on chromosome 4 might be involved in avoiding or delaying Alzheimer’s. The expanded project will search for additional Alzheimer-protective regions in 280 pairs of centenarian siblings.

Gold standard. In the future, Dr. Perls’ team hopes to further expand the project by cataloging up to 10,000 single subunit genetic variations on all known genes in centenarians and noncentenarian controls. This extensive analysis may provide a gold standard of genetic characteristics of disease resistance, and may eventually lead to discovery of new drug targets for Alzheimer’s or other disorders.

Carlos A. Saura, Ph.D., of Brigham and Women’s Hospital in Boston, received his grant for work on the Evaluation of Presenilins as Antiamyloidogenic Targets in Alzheimer’s Disease through the Characterization of PS1/PS2 Conditional Knockout Mice.

A steadily increasing body of research suggests that abnormal processing of amyloid precursor protein (APP) is a key event in Alzheimer’s disease. During processing, sequential clipping of APP by two different enzymes produces beta-amyloid (Ab or A-beta), the protein fragment that aggregates into the amyloid plaques regarded as one hallmark of Alzheimer abnormality. Steps involved in APP processing and Ab aggregation may offer prime targets for Alzheimer therapies.

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Neuropsychologist Marilyn S. Albert, Ph.D., Chair of our national Medical and Scientific Advisory Council, moderated the December panel discussion at our Cambridge Office honoring Massachusetts scientists who received research grants in 2001 from the Alzheimer’s Association. Dr. Albert is Professor of Psychiatry and Neurology at the Harvard Medical School and directs the Harvard-Mahoney Neuroscience Institute as well as the Geriatric Neuropsychological Unit at Massachusetts General Hospital. She is a founding member and past Board Chair of the Massachusetts Chapter.

(Continued from page 10) How does the research on amyloid plaques in the brains of people with Alzheimer’s disease contribute to the discovery of potential treatment strategies? The research on amyloid plaques in the brains of people with Alzheimer’s disease contributes significantly to the discovery of potential treatment strategies. The amyloid plaques, regarded as one hallmark of Alzheimer abnormality, consist of beta-amyloid (Ab or A-beta), the protein fragment that aggregates during Alzheimer’s disease. Understanding the factors that cause or inhibit the accumulation of these plaques can lead to the identification of novel drug targets. The research conducted by Dr. Perls and others aims to unravel the genetic characteristics of disease resistance and may eventually result in the discovery of new drug targets for Alzheimer’s and other disorders. By studying the mechanisms involved in amyloid plaque formation and aggregation, scientists are making significant strides towards developing effective treatments for Alzheimer’s disease.
Iris Screening Touches Hearts

More than 70 Association supporters gathered on Valentine’s Day in Boston for dinner and the preview screening of the Miramax film Iris starring Judi Dench and Kate Winslet. Iris is based on the book Elegy for Iris by John Bayley about his experiences caring for his wife, the acclaimed British writer Iris Murdoch. She had Alzheimer’s disease and died in 1999.

Actor Jim Broadbent received an Academy Award earlier this year for his portrayal of the elder Bayley in the film. Special thanks to Alzheimer’s care consultant Howard Block for his insightful remarks prior to the film screening.

Running out of gift ideas? Honor someone you love! Do you know people who have everything? Donate a gift to the Alzheimer’s Association, Massachusetts Chapter to honor that special someone. Your gift will be put to good use helping people with Alzheimer’s disease and their families in Massachusetts.

We are fortunate to have a cadre of loyal and dedicated volunteers, including Arlington high school students Liz Diamandis (C), an 8th grader at Ottson Middle School in Arlington and third-generation Association volunteer; and Nelia Tabares (R), a Somerville High School student. In addition to serving as volunteers for Memory Walk, Liz and Nelia have volunteered their valuable time during school vacations for the past two years to help with administrative responsibilities at the Chapter’s Cambridge Office. Thanks, also, to Cheryl Meads (L) of North Truro, who served the Association as a Development Intern this past spring. Cheryl graduated with honors in May from Emmanuel College. The Chapter is appreciative of Cheryl’s outstanding work as well as her contagious enthusiasm and commitment. For information on volunteer opportunities at the Alzheimer’s Association, please call (617) 868-6718 (Cambridge Office) or (413) 787-1113 (Springfield Office).

Alzheimer’s Association President Jim Wessler (R) and Director of Development Heidi Ganss (L) recently accepted a generous gift from the Massachusetts State Elks. Shown here with Wessler and Ganss are Louis Connolly, State President of the Massachusetts Elks (2nd from R) and his wife, Judie (2nd from L), of Tewksbury. Thanks to Lou, Judie, and the many other members of the Benevolent Society of Elks.

In addition to volunteering her time and talents to sing to Alzheimer’s patients in long term care facilities, 12-year-old Janelle Guernette of Acushnet put her voice to work to raise money for the Alzheimer’s Association. Janelle’s voice teacher, Sharon Jensen, offered her students the opportunity to raise money for critical programs and services—the child who raised the most would receive free voice lessons for a year! Congratulations to Janelle and thanks to Sharon for inspiring philanthropy in our youth.

Betty Thomson of Danvers, wife of Bob Thomson, who hosted The Victory Garden on PBS for 12 years, recently authored the Alzheimer’s Association’s Spring Appeal as a way of reaching out to other families struggling with the challenges associated with Alzheimer’s, and to help raise funds for critical programs and services. Bob Thomson, who has Alzheimer’s disease, is a resident of a long-term care facility in Massachusetts where Betty visits him every day.

The Alzheimer’s Association is grateful for the many gifts we’ve received in honor of Bob Thomson, and we thank the entire Thomson family for sharing their story with others. For more information on making a gift to the Alzheimer’s Association, please contact our Development Office at (617) 868-6718.
**Medicine & Science:** continued from page 11

Dr. Saura’s project focuses on the therapeutic vulnerability of proteins called presenilin-1 (PS-1) and presenilin-2 (PS-2), which appear to play a key role in processing APP. Research has shown that specific variations in the genes that code the presenilins cause about 40 percent of familial Alzheimer’s, a rare form of the disorder that tends to strike people in their 40s and 50s.

**Role of presenilins.** Dr. Saura’s team has created a special strain of genetically engineered mice that produce human APP and in which PS-1 and PS-2 are inactivated in adult animals. These mice will provide a living laboratory for exploring whether inactivation of PS-1 and PS-2 affects Notch signaling (Notch is a protein that influences prenatal cell development) in the adult brain, as well as whether this inactivation prevents production of Ab and plaque formation. The insights Dr. Saura gains may provide important clues about the usefulness of presenilins as therapeutic targets.

Michael S. Wolfe, M.S., Ph.D., also of Brigham and Women’s Hospital, spoke about his work In Search of Presenilinase. Production and deposition of the amyloid-beta peptide is implicated in the etiology of Alzheimer’s disease. The last step in the production of the amyloid-beta peptide is a protein-cutting reaction catalyzed by an enzyme (specifically, a protease) called gamma-secretase.

Gamma-secretase is a complex enzyme composed of multiple components, one of which is presenilin, and this protease is considered an important therapeutic target for Alzheimer’s disease. In order to activate gamma-secretase, presenilin itself must be cut into two pieces, a process carried out by an unknown protease, dubbed presenilinase. Because presenilinase regulates gamma-secretase activity, this presenilin-cutting protease is likewise central to understanding the biochemical mechanisms underlying Alzheimer’s disease, and also may be an important therapeutic target.

**Molecular scissors.** Dr. Wolfe aims to identify presenilinase using molecules designed to interact with and inhibit this enzyme. Using a similar strategy, he previously identified presenilin as the molecular scissors of the gamma-secretase complex. He has designed small molecules that should mimic the site in presenilin cut by presenilinase—molecules that should be recognized by presenilinase but that should not themselves be cut. Presenilinase activity would be blocked by these molecules.

With such blocking agents in hand, Dr. Wolfe can then modify their structures to create molecular probes for presenilin that remain permanently bound to the protease, tagging it for identification. He is also developing related molecules that should be cleaved by presenilinase, allowing simpler means of measuring its activity. [7]

Gerald Flaherty is the Chapter’s Director of Special Projects.

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**Education: Breakthrough in Helpline Services! Technological Advances Streamline Support, Expand Reach**

By Erin Whalen, Chapter Helpline Coordinator

Coping with Alzheimer’s disease has been characterized as the 36-hour day, which rings true for many of us. Although we’re glad the day does not contain that many hours, it does present twenty-four, which is the number of hours the Helpline will now be open.

Thanks to a collaborative effort with the national office of the Alzheimer’s Association, the Helpline will now remain open after regular office hours and will offer telephone language translation services. By providing round-the-clock services seven days per week, the Helpline will enable individuals with Alzheimer’s disease, their caregivers and family members to access information, support, and intervention for emergency situations at any time of day.

**Flexibility.** The importance of this expansion of services will be realized by anyone who has cared for someone with Alzheimer’s disease. The Helpline will now be able to assist caregivers with questions about sleep disturbances when they are actually occurring at 2 a.m. No matter what time of the day it is, services will be available.

This major Helpline enhancement will further enable the Alzheimer’s Association to meet the needs of a growing population of people with Alzheimer’s disease. It will allow adult children who are caregivers to call after their own children have gone to bed; it will allow caregivers to call in a quiet, private moment in the evening; and it will allow working caregivers time to call from home.

Information and support is now available around the clock. Please call 1-(800)-548-2111 to utilize these services. Help is available!

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Greg McGauley of Harwich and Scott Kerry of Eastham ran the Boston Marathon in honor of the 140,000 people with Alzheimer’s disease in MA. (Photo by Prudence Kerry)
Western MA News

Bravo Broadway Raises $3,000!

Bravo Broadway, an April fundraiser with the Springfield Symphony Orchestra, raised $3,000 for the Chapter’s support and education programs. One hundred twenty guests enjoyed a pre-concert reception and music by such composers as Andrew Lloyd Webber, Leonard Bernstein, and Richard Rodgers. Mercy Medical Center was the Presenting Sponsor and Bacon & Wilson Attorneys at Law served as Patron Sponsor.

The event also acknowledged more than 20 years of service and advocacy by Malfalda “Muffie” Albano. Mrs. Albano, a member of the Silver-Haired Legislators, also volunteers with Greater Springfield Senior Services, Mass. Senior Action Council, Springfield School Volunteers, AARP, and the Older Women’s League.

Special thanks to the planning committee, especially Co-Chairs Cheryl Dunn and Sheri Iodice, for their enthusiasm and many hours of hard work.

First Western Regional Family Conference Draws Raves

More than 50 family caregivers gathered April 18 for the first Family Conference organized by the Western Regional Office, Through the Eyes of a Caregiver: a Family Perspective. The conference was held at the Genesis Spiritual Life Center in Westfield, MA. The morning began with a presentation on healthy caregiving by Gary Davis from Beverly Healthcare, who encouraged caregivers to put their own emotional safety first.

Workshops. Attendees then split into two groups. Half heard about local resources and services from Tom McMullen, Western Regional Coordinator of the MA Family Caregiver Support Program, and our very own Virginia Sinkoski, Helpline and Outreach Coordinator in the Springfield Office. The remaining families participated in a workshop titled “Family Dilemma—Placing a Loved One,” led by William Johnson, a social worker from Geriatric Consulting in Belchertown.

The event ended with a special presentation by Dr. Kathy Horvath from the Geriatric Research Education and Clinical Center (GRECC) at the E.N. Rogers Memorial Veterans Hospital in Bedford, who provided concrete suggestions about improving home safety. The day was truly appreciated by all, and new contacts and sources of support were established. We are already looking forward to next year.

—Jeannie Banas, Education Coordinator

Alzheimer’s at Tanglewood Encore Set for August 11

The second annual Alzheimer’s at Tanglewood fundraiser will be held Sunday, August 11, 2002. Guests are invited to picnic on the grounds and then enjoy a sumptuous array of desserts in the Hawthorne Tent. The afternoon performance of the Boston Symphony Orchestra will be led by Neeme Järvi, guest conductor. Renowned violinist Gil Shaham will be featured in Tchaikovsky’s Violin Concerto.

In a departure from the first event, all tickets for Alzheimer’s at Tanglewood: an Encore are located in The Shed. “This guarantees everyone a seat out of the elements,” said Co-Chair Fredrica Sloan. “Guests may choose to move out to the lawn if the weather is good, but they can still enjoy the concert if it’s raining or unusually warm.” Tickets also include a pass for reserved parking near the reception area.

Thanks to EPOCH at Melbourne, an assisted living facility not far from Tanglewood, guests also have an option of parking off-site and taking a shuttle bus to the concert. “Some people don’t want to fight the Lenox traffic. Thanks to Diane Weinstein, EPOCH’s administrator, we are pleased to provide complimentary bus service to and from the concert,” said Karen Gold, the event’s other Co-Chair. Anyone interested in bus transportation may call the Western Regional Office at (413) 787-1113.

Tickets may be ordered via e-mail at Kathryn.Hedgepeth@alz.org or by calling (413) 787-1113. The deadline for ordering tickets is July 7, 2002.
Support Group listing continued from back cover

Lynn: Lisa Mercurio or Mark Hend 781-596-2922
Malden: Mary Darling 781-324-4999 X216
Mansfield: Christine Filocco or Deborah Sp 508-261-1333
Marlboro: Bonnie Plankey or Jessica Sogi Joyce Henderson 508-485-4040
Medford: Douglas Lloyd or Sheila Walk 781-395-5542
Mendon: Marlene Fregeau or MaryPat McDav 508-473-0862
Merrimac: Patricia Lavoie 978-803-3296
Methuen: Donna Koski 978-682-3582
Middleboro: Robella Coates or Carol Ann L 508-947-4774
Milford: Marlene Fregeau 508-473-0862
Millbury: Michelle Stevens 508-793-0088
Nahant: Rev. David Dodge 781-581-1202
Natick: Judy Sabol 508-650-9003
Los Pecora 508-655-5000 X988
New Bedford: Jenny Nelia 508-998-7807
Newburyport: Patricia Lavoie 978-777-2700
Newton: Mara Klein 617-928-0007
Emily Safer 617-558-6443
or Carol Westheimer 781-455-8588
North Adams: Beth Hinkley 413-664-4536
Norwood: Mary Beth Whitlefield 781-769-4495
Peabody: Linda Smith 978-531-2254 x137
Pittsfield: Louise Posnick 413-445-2300
Robert Hamilton 413-499-0524
Beth Hinkley 413-499-1992
Plymouth: Deborah Feurado 508-746-7016
Quincy: Kathy Prince 617-471-5712
Beverly Moore 617-233-1145
Reading: Anne Marie Bourque or Marie Amne 781-944-1132
North Adams: Beth Hinkley 413-664-4536
Scituate: Marla Kaplan 781-681-1065
Somerset: John Rogers 508-679-2240
South Hadley: Gerri Bennett 413-532-8098
Southbridge: Roger Lamontagne or Susan Klezko 508-248-7344
Springfield: Ellen Nepomuceno 413-781-5070
Denton: Karen Sprague or Marsha Phillips Young 781-344-7661
Tewksbury: Eileen St. Cyr 978-657-0800
Sharon Hooper or Paula Dretich 978-851-3121
Turners Falls: Molly Chambers 413-733-5555
Wakefield: Lynn Zaloga 781-224-2800
Ware: Stasia Wozniak 413-967-2245
Wareham: Carolyn Cardoza 508-758-2173 or 508-991-5015
Watertown: Ruth Gordon 617-491-1823
Webster: Carolyn Racioc 508-949-3598
Wellesley: Amy Beck 781-237-6400
Peggy Mullen 508-533-7020
West Springfield: Lois Goralski 413-781-1282
Westboro: Julie Palmieri 508-836-4354 x3706
Westfield: Ellen Nepomuceno 413-781-5070
Weston: Shirley Earle 781-893-0154
Westport: Susan Oliveira 508-636-1026
Westwood: Peter Byron 781-326-5652
Weymouth: Barbara Orlandi 781-337-3121
Denise Moore or Julie Barcelo 781-340-9100
Wilbraham: Beth Vettori 413-596-0006
Williamstown: Fredrica Sloan 413-458-8127
Winchester: Valerie Gramolini 978-897-7455
Woburn: Jennifer Jaroch 781-932-0350
Worcester: Faith Bandana 508-791-5543
Laurie Googins or Ann Fitman 508-753-4791
Allison Leger 508-752-2546
Debbie DeRossier 508-754-3800 x126
Therese Delongchamp or Martha Danilowicz 508-755-7277
Wortthington/Cummington: Sandra Epperly or Lucille Temple 413-238-5584
Specialized Groups

Adult Child Caregivers
West Roxbury: Susan O’Connell or Margaret Wright 617-325-1230
Caregivers of Mentally Retarded Adults with AD
Kevin Leahy 781-324-4303
Families of VA Patients with AD
Bedford: Jennifer Hill 781-687-2701
Interfaith Support Group
Framingham: Malka Young 508-875-3100
Springfield: Marcia McKenzie 413-787-1113
People under 65 with Early Stage Alzheimer’s and Their Caregivers
Cambridge: Elaine Silverio 508-429-1577
People with AD and their Caregivers
Wellesley: Peggy Mullen 508-533-7020
People with Younger Adult Caregivers
Wellesley: Peggy Mullen 508-533-7020
People with Elderly Caregivers
Brockton: Geralann DiDomenico 508-427-6099

Support Groups

Our web site support group leader list at www.alzmass.org is also updated more frequently. For information about support groups on Cape Cod or the Islands, call that Chapter at (508) 775-5656.

Please call the listed group leaders for details.

We make every effort to keep this list up-to-date, but some listings may be incorrect because production of the Newsletter takes nearly three months, and because we are not always notified of a change. If you have any contact problems, please call our Helpline at (617) 868-6718.

These support groups are free and open to the public. In addition, many day programs and long-term care facilities offer groups for families of their patients. Support groups are independently run and this listing should not be construed as a recommendation.

We need your support!

We rely on private contributions to provide critical programs and services for Alzheimer’s patients and their families. Please help. We urge you to use the enclosed envelope to make your tax-deductible gift and be as generous as you can.
Support Groups

Support groups provide a forum for family members and friends of people with Alzheimer's disease or another dementing illness. Groups also exist for people who have early-stage Alzheimer’s disease—refer to Specialized Groups at the end of the alphabetized list of communities.

At these groups, people learn about the disease, share concerns and information, and support each other in coping with the effects of Alzheimer’s disease or one of the related disorders. Groups may vary in size, frequency of meeting, and leadership style but are often termed life-saving by their members. continued on page 15

Abington: Marie Bates 781-871-0200
Acton: Joanne Chaulk or Jean Flemming 978-264-9643
Agawam: Judy Pothul 413-821-9911
Amherst: Melissa Rohde 413-546-6800
Andover: Rachel Zalvan 978-623-8321
Arlington: Laurie August 781-316-3400
Athol: Wandra Landry 978-249-3717
Attleboro: Mary McCormick 508-222-6655 or Ginny McDermott 508-222-0118 x2122
Sharon Leary 978-226-6150
Nicole McGurin 508-222-4950
Ayer: Jeannette Coutu or Gary Davis 978-772-1704
Belmont: Nava Niv-Vogel or Lauren Storck 617-484-0949
Beverly: Lorraine Bettencourt 978-927-4227 x23
Boston: Barbara Hawley or Maureen Tardelli 617-724-0055
or 617-391-7878
Bourne: Judy Anthony 508-759-0654
Braintree: Denise Hughes or Chris Togneri 781-848-2714
Bridgewater: Kathy Hayes or Sue Daniels 508-697-0929
Brookline: Marie Albert, RN 508-587-6556
Brookline: Pattie Chase or Howard Block 617-232-8848
Burlington: Stacey Kohler or Sue Mike 617-277-4289
Burlington: Stacey Kohler or Sue Mike 781-744-8114
or Nancy Kinton 781-721-0788
Cambridge: Alice McCarter or Mary Costello 617-491-1815
Trudy Bauer or Ruth Gordon 617-828-7450 x307
Chelmsford: Pat Keene 978-251-8491
Susan Anitkowak 978-534-9522
Chicopee: Judy Pothul 413-821-9911
Concord: Arlene Parillo or Kate Marshall 978-897-2569
or 978-369-4728
Danvers: Gwen Kopka 978-750-4540
D’arcy Adams 978-774-4400 x3064
Jeanne Parent 978-777-5717
Gayel Cote 978-762-7825 x14
Dartmouth: Sharon Jensen 508-991-8600
Dorchester: Donna Allen 617-825-5000
Duxbury: Sandi Wright 781-585-2397
East Longmeadow: Ellen Nepomuceno 413-781-5070
Mary Anne Stout 413-525-8150
Easthampton: Wendy Perras 413-527-7737
Fall River: Maureen Hebert 508-679-0011
or Paulette Masse 508-379-9700
or Judy Elste 508-675-2101
Fitchburg: Alice Murphy or Joanne Harris 978-343-5368
or Judy Wilson 978-632-1230
Foxboro: Diane Caldwell 508-337-8419
Framingham: Susan Scheib 508-879-8000
or Catherine Ziesmer
Gardner: Judy Wilson 978-632-1230
Ray Cornnier 978-632-5477
Gloucester: Maureen Powers 978-281-1750
Great Barrington: Kelly Thorne 413-528-2650
Hadley: Linda Wallace or Jennifer Read 413-584-5057
Haverhill: John Freeman 978-346-4743
or Nancy Savarese 978-683-2771
Hingham: Jo Ann Mitchell 781-749-5417
Eleanor Blair 781-749-4774
Holden: Naomi Sohiman 508-829-0270
Hyde Park: Wendy Marks 781-449-5368
Jamaica Plain: Tara Fleming or Susan Kelley-Grasso 617-983-2300
781-668-6718
Kingston: Hollie Spooner 781-585-4100
Lee: Dolores Thimot 413-243-4747
Leicester: Eva Dawson 508-987-8056
Littleton: Gail Mallardo 978-486-3512
Longmeadow: Sheila King 413-567-6212
Lowell: Scott Souci or Margaret Swanson 978-459-0546
Ludlow: Barbara Messler 413-589-7581

Support Group listing continues on inside cover