

Memory Matters



*A publication for the patients, families and friends of the Johns Hopkins Memory & Alzheimer's Treatment Center
Fall/Winter 2009*

Staff Spotlight

Question: How has your work with the patients and families of the Memory Center impacted you?



**Jennifer Mason, RN, BSN,
Clinic Nurse**

"It's amazing to see the commitment of the caregivers to their loved ones. And while some caregivers were originally the 'bread-winners' and providers for their families, they now find themselves in a new, more maternal, caring role. So for me, the greatest reward is really being there to help and support those people on their new journey."



**Nicole Thornton,
Clinic Office Assistant**

"When some families come into the clinic, they can be anxious and tense. By being friendly and making them feel comfortable, I know that I can help them relieve some of their stress—that gives me the greatest joy."

This is a newsletter for you. We encourage you and your family to share your comments and story ideas with us. Feel free to call Marina Tompkins, LGSW, at 410-550-9031 or e-mail mtompki2@jhmi.edu.

R_x for Both the Patient and Family

Treatment for individuals with memory loss typically makes you think of medication, however, there are other methods, such as adult day programs, which have shown to improve a patient's quality of life. Adult day programs are often untapped, valuable resources. They offer patients opportunities to interact with others and participate in activities in a safe and stimulating environment. In addition, they offer families opportunities to catch up on shopping, spend time with friends or to simply relax.

While adult day programs have many benefits, families often find it difficult to encourage their loved ones to attend. Persons with dementia may be apprehensive and scared. Here are some tips to introduce an adult day program into your loved one's life:

- If you are apprehensive, call for a tour so that you can see what might interest your loved one and discuss any obstacles you anticipate. Make sure that you are on-board with the program.
- Give a convincing reason. Some attend a program because they see their participation as their "club," "class" or "job." People with dementia enjoy being needed and attending an adult day program gives them an opportunity to help others.
- Start with a few, short days. Two visits a week is typically the minimum for someone with memory loss. It usually takes a new person a few weeks to adjust to the new schedule, so patience is key.
- Reinforce the positive. Support any positive experiences that your loved one has.
- Try again later. Sometimes the first attempt does not work. Trying again after a few months often proves successful.
- Ask a member of your Memory Center care team for more tips.

Paying for Adult Day Programs

Program costs usually range from \$60 to \$80 a day.

Some are covered by long term care insurance, but usually are not covered by private insurances or Medicare.

Financial assistance is available through the Alzheimer's Association, (1-800-272-3900) and the local Department of Aging—Maryland residents call 1-800-243-3425.



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MEDICINE

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Calendar of Events

Beginning the Journey Together Program

Eight consecutive weekly meetings that discuss a variety of memory-related topics such as research, coping with stress and legal issues. The Fall/Winter 2009 session is currently enrolling patients and families. Info: Patient and Family Services Coordinator, 410-550-6337

Oct. 28: Frederick County Caregiver Conference

8:30 a.m. to 12:30 p.m., Mt. St. Mary's Conference Center, Frederick
Info: Alzheimer's Association, 301-696-0315

Oct. 31: Journey to Hope Conference on Memory Loss

9 a.m. to 2 p.m., Johns Hopkins Bayview Medical Center, Baltimore
Info: Johns Hopkins Memory and Alzheimer's Treatment Center, 410-550-8146

Nov. 4: Conference for Practical Issues in Caregiving

First Assembly of God Church, C.T. Chalgwin Gymnasium, Elkton
Info: Alzheimer's Association, 410-561-9099

Nov. 4: Southern Maryland Dementia Care Conference

8:30 a.m. to 2:30 p.m., Greater Waldorf Jaycee Center, Waldorf
Info: Alzheimer's Association, 301-934-5856

Nov. 6: Upper Shore Dementia Caregiver Conference

8:30 a.m. to 12:30 p.m., Grasonville Senior Center, Grasonville
Info: Alzheimer's Association, 410-561-9099

Nov. 7: Baltimore County Caregivers Mini-Conference

1 to 4 p.m., Pikesville Senior Center, Pikesville
Info: Baltimore County Department of Aging, 410-887-2594

Nov. 7: 5th Annual Pythias A. and Virginia I. Jones African American Community Forum on Memory Loss

Coppin State University, Baltimore
Info: Alzheimer's Association, 410-561-9099

Nov. 11: Caregivers Conference: Shedding Light on Dementia Care

8:30 a.m. to 3:30 p.m.,
The Church of the Good Shepherd Parish Hall, Burke, VA
Info: 703-324-5425

Nov. 14: A Woman's Journey Conference, Johns Hopkins' Annual Women's Health Conference

8:15 a.m. to 4:15 p.m., Hilton Baltimore, Baltimore
Info: Johns Hopkins Medical Institutions, 410-955-8660

If you have any questions about an event, please call the phone number listed.

Proactive Safety

Having what you need before you need it

While another dusting of Maryland snow was falling, a woman was washing dishes when she heard a knock on her front door. She opened it to find the police there with her mother, an Alzheimer's disease patient at the Memory Center. It only had been a few minutes before that she had left her mother watching television in another room. Now, her mother was standing outside on the snow-covered steps without a coat. Although this patient returned home safely, not all stories like this have a happy ending.

Since those affected with Alzheimer's or other forms of dementias are unable to judge potentially dangerous places and situations, wandering can be especially harmful. Unfortunately, this growing problem is frequently overlooked by individuals with dementia and their families. The Alzheimer's Association reports that about six of every ten people with Alzheimer's will wander.

The good news, though, is that 89 percent of individuals who wander are located within one mile of their home. By enrolling in the Medic Alert + Safe Return Program, you can increase your loved one's chances of returning safely. Created by the Alzheimer's Association, the Medic Alert + Safe Return Program includes an identification bracelet that contains critical medical and contact information that can save lives. Also, authorities can notify the listed contacts if the person is found.



Medic Alert + Safe Return bracelet

The Memory Center encourages our families to be proactive and enroll in this program.

For information on the Medic Alert + Safe Return bracelet, ask one of our Memory Center team members or call the Alzheimer's Association at 1-800-272-3900.



It's Not Always Alzheimer's: An Intimate Look at FTD

Most people think that memory loss is a result of Alzheimer's disease (AD), but this is not always the case. Dementia can be caused by other diseases, such as Frontotemporal Dementia (FTD), which is the second most common cause in people under age 65. And although people can be affected by FTD as early as their 30s, the average onset is typically mid 50s.

FTD affects the frontal and temporal lobes of the brain. Unlike AD, where decline or change in memory is often the first symptom, initial symptoms of FTD are related to changes in social behavior, such as a decline in social conduct, personal habits and speech. In the later stages of the illness, memory loss, disorientation and declining motor skills begin to show. FTD is frequently a familial illness. "In addition, 40 to 50 percent of FTD cases have a family history of dementia. Scientists have found that mutations in several genes cause this disease in some, but not all, cases," says Chiadi Onyike, M.D., assistant professor of psychiatry and behavioral sciences at The Johns Hopkins University School of Medicine and co-director of the FTD and Young-Onset Dementias Clinic.

Providing Support to Patients with FTD and Their Families

The FTD and Young-Onset Dementias Clinic, a specialty clinic of the Memory Center, provides diagnosis and treatment of FTD, as well as caregiver counseling and education, long-term care planning, assistance with work transitions and retirement planning. Each individualized care plan outlines the patient's needs, helps to develop ways to foster their well-being, and offers education and support to their family and caregivers. "Education for the patient

and family is a key element to providing care. It helps people understand the illness, links them with support groups and community resources, and helps them begin to plan for the long term," says Dr. Onyike.

For the past three years the FTD Clinic has provided a support group for families coping with FTD, in collaboration with the local chapter of the Alzheimer's Association. Other support services include individualized consultations to address a family's psychosocial needs, educational programs such as the annual spring Dementia in Midlife Conference (sponsored jointly with the Alzheimer's Association of Greater Maryland), the fall Journey to Hope Conference on Memory Loss, and the 8-week early stage memory loss program for patients and families.

For more information about FTD, call 410-502-2981.



Chiadi Onyike, M.D.,
Co-director, FTD and Young-Onset Dementias Clinic

Dr. Onyike leads clinical and research programs in FTD. He has provided care to FTD patients and support to their families for more than five years. He currently directs the Baltimore site of a multicenter FTD clinical trial, and other epidemiologic and clinicopathologic studies of FTD.

Difference Between FTD and AD

| Characteristic | FTD | AD |
|------------------------|--|---|
| Average age at onset | Mid 50s | After 65 years old |
| Affected area of brain | Focal atrophy (changes or shrinkage of the brain) of the frontal and anterior temporal lobes | Global atrophy (i.e., of all brain regions) |
| First Symptoms | Changes in personality, social conduct and speech | Decline in memory but social skills remain intact |
| Medications | Vary to treat symptoms | Aricept, Namenda |
| Genetic Linkage | MAPT, PGRN, CHMP2B, VCP, FUS | APOE4, APP, PSI, and PS2 |
| Diagnostic Tools | Interview and examination, neuropsychological testing and brain scans (MRI and PET) | Interview and examination, neuropsychological testing and brain scans (MRI and PET) |
| Definitive Diagnosis | Autopsy | Autopsy |



The Johns Hopkins Memory & Alzheimer's Treatment Center

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Christopher Durso, M.D.

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Contact us!

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Clinic Information

410-550-6337

Research Clinical Trials

410-550-6493

Community Outreach

410-550-2281

In Her Words...Ellie McGuire, volunteer



"The opportunity to volunteer at the Memory Center this summer has been wonderful. I have been so lucky to experience all aspects of a day at the Memory Center. One of my favorite activities has been shadowing Dr. Lyketsos and Dr. Marano in the Memory Clinic. They have not only given me the opportunity to interact with patients, but also have helped me understand the qualities that make our center so unique—the support offered to patients and their families, the compassion of our doctors and the friendly, but professional, atmosphere that encompasses the Memory Center.

Being here also has fostered my interest in geriatric psychiatry, by giving me insight to the many different challenges facing this particular field today. I hope that as I move on to college, I will be able to continue to pursue my interest in psychiatry. I would love to be able to come back and work at the Memory Center in the future, or help to establish comparable memory centers throughout the world."

The Johns Hopkins Memory and Alzheimer's Treatment Center team would like to extend a great thank you to Ellie and Eric Weaver. Their time and service to our patients and families are greatly appreciated. They will be missed and we wish them the best of luck in their senior year of high school!

Patient and Family Support Groups

Support groups offer patients and loved ones a safe place to speak with others who have similar concerns and questions about coping with memory loss or related disorders. They provide mutual support, practical information and help members learn more about living with memory loss. They are free and open to the public.

Beginning the Journey

A program for individuals with early stage memory loss and their families

If you have been recently diagnosed with Alzheimer's disease or mild cognitive impairment and are interested in meeting with other individuals who share your same diagnosis, please contact Marina Tompkins, LGSW, at 410-550-9031 or e-mail mtompki2@jhmi.edu.

Caregiver Support Group, offered twice a month

Second Thursday of every month, 12:30 to 1:30 p.m.

Hopkins ElderPlus, Mason F. Lord Building, East Tower, 1st Floor

Second Wednesday of every month, 6 to 7:15 p.m.

Plaza Conference Room, John R. Burton Pavilion

For more information about caregiver support groups, call Susan Guido or Deny Stiasny at 410-550-7044.

Give the Gift of Knowledge

Memory Center researchers are seeking individuals who are interested in participating in a variety of memory-related studies. Some studies require no medication and compensate participants for time and travel.

For more information about research opportunities, call 410-550-6493.