

Thinking it Through

Brain donation, vital to research on Alzheimer's disease and lifelong brain health, requires commitment from surviving family members. A daughter moves past her own sadness and indecision and honors her mother's wish to be a brain donor.

by Carol Edwards

Mary Spriggs was the oldest of six; a West Philadelphia High grad, and, in time, a mother to six of her own. An Amtrak housekeeper and active union supporter, she sometimes took her children along to rallies if no one could watch them at home. Mary's daughter, Kathy Spriggs, now 53, recalls, "If we complained about going, she'd look right at us and say, 'Those people need benefits, or better wages' or whatever it was," Kathy recalled, 'and we *will* go help them get what they need.' And we were out the door."

Her mother "could take care of business," said Kathy. "Her siblings brought their problems to her and she'd find a way to help." When Mary faced breast cancer, "She said she would beat it, and she did. But to ease things for us, just in case, she pre-arranged and prepaid her own cremation, funeral, and urn."

The family's rock starts to crumble

Then Mary — the reliable sister, mother, grandmother — started to falter. She put salt instead of sugar in her pies. She caused a microwave fire. She grew paranoid, installing multiple door locks but forgetting how to use them, locking herself out. When repeated phone calls went unanswered, Kathy drove to her mother's apartment and found her sitting in the dark. Mary had forgotten to pay her bills. The electricity had been cut off; her cordless phone was useless.

Kathy knew the 2006 evaluation at the Penn Memory Center "would not be good news." Mary's mother, Margaret White, "lost her memory the same way, and died totally gone." And sadly, Kathy was right. The diagnosis was Alzheimer's.

"I was sad," Kathy said, "but when they discussed brain donation with us, my mother lit up and said right out, 'I want to give my brain. We gotta' find a cure for this. I don't want any of y'all to die like Mama.'" As next of kin, Kathy was respon-

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photo | Carol Edwards

"For Our Families, For Our Future"

Kathy Spriggs, daughter of Penn Memory Center brain donor Mary Spriggs (right) holds a photo of her mother and fellow union activists taken at a rally in the 1970s. They hold placards urging workers to vote union, 'for our families, for our future.' "That's the way my mother felt about donating her brain to Alzheimer's research," Kathy said. "She saw the way the disease took her own mother, my grandmother, and when she got the diagnosis herself, she wanted to do the most she could to help science overcome it, so our family, and all other families might be able to avoid Alzheimer's in the future. For my mother, that meant being a brain donor."





I thought about the brain donation paperwork from time to time, but I resisted dealing with it . . . After my sister died, I just couldn't face the idea of my mother dying, too.

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sible to authorize the procedure. "I didn't know how I felt about it then, so I just took the papers and left it at that."

● ● ● Over time the disease ran its inevitable course. Mary became ever-more debilitated. "My daughter would be feeding her baby with one hand and feeding my mother with the other," Kathy said. "Her memory was gone, but once or twice, out of the blue, she said, 'You gotta' give my brain to research. You gotta do it.' It was unreal to me how that thought held in her mind."

Kathy's mind, however, was elsewhere. Mary now had to be placed in a nursing home. Then Kathy's sister died, young and unexpectedly. Kathy still tears up talking about it. "I thought about the brain donation, but I resisted dealing with it. After my sister died, I just couldn't face the idea of my mother dying, too."

By now, Mary no longer spoke. "I'd talk to her, hoping for a response, but nothing," Kathy said. "Yet when I saw her in my mind's eye, she still talked. And sometimes I could hear her say to me, 'You'll be sure my brain goes to science, right?'"

● ● ● As the new year 2011 dawned, Kathy Spriggs at last felt ready to open the door to that possibility. Here's how she tells it.

"I called (Penn Memory Center brain donation coordinator) Marianne Watson. She faxed the authorization. I signed it, and faxed it back, and that day, Friday, I went to see my mother. She didn't open her eyes much by then, but I held the paper up and I said, quietly, 'Look, Mom, I signed the papers, so when you pass, your brain will go to science. You can go whenever you're ready now. I did what you wanted.' And after not saying a word for eight months, she opened her eyes and said, 'You did?'"

That Monday, on a clear, cold January morning, Mary Spriggs died, at age 81. As Kathy parked her car at the elementary school where she works as a classroom assistant, her cell phone rang. "When I saw it was the nursing home calling I knew she had passed. I sat there in kind of a daze, and then the kids were around my car waving and saying 'Good Morning,' and I said to myself, 'before I can cry, I need to call Penn about the brain donation.'"

● ● ● On a hot, sun-soaked morning this past June, Kathy Spriggs sat on her living room couch, holding the just-received report of the examination of her mother's brain. Though written in highly scientific language, Kathy had figured it out.

In essence, the report said Mary Spriggs' brain showed all the pathology of someone who died with advanced Alzheimer's disease. No tumors, no strokes, no head trauma to blame. Mary's memory, her personality, her functioning, all were destroyed by Alzheimer's — the fastest-growing cause of death in the US, and unlike heart disease, cancer, stroke, or even HIV/AIDS, the only major killer that still cannot be prevented, cured, or even slowed.

● ● ● What the report didn't say is where all the hope rests.

Mary Spriggs' brain tissue will be studied now and for decades, helping researchers at Penn and across the globe better understand this disease. As an African American, her donation may also help investigators identify factors unique to the disease in this population, so underrepresented in scientific research in general. And when what's learned from Mary's brain tissue is added to data drawn from the tissue of thousands of other donors, some with Alzheimer's and others with normal cognition, the big leaps of knowledge — the breakthroughs — might become possible.

When people offered their sympathy on her mother's passing, Kathy Spriggs would sometimes share a bit about Mary, her disease, and her determination to become a brain donor, if she thought they would be interested. "When I said my mother was a brain donor for Alzheimer's research, some people reacted like I was crazy. But two people at my school asked me how they could get their parents evaluated. Even after she's gone, my mother's still helping people get what they need."



For more on brain donation . . .

To read articles on other brain donors or to download the Penn Memory Center Brain Donation brochure, go to our website, www.pennadc.org, click on "Research We Do" then click on "Brain Donation"

Husbands or wives who care for a mate with dementia face a significant risk for developing their own cognitive problems. One study following 1,200 such older couples for 12 years found caregiver spouses had a 600% greater risk of developing dementia themselves than similar non-caregiver spouses.

found older women caring for a debilitated spouse were 31% more likely to have low cognitive function test scores than similar non-caregiver wives.

Factors contributing to cognitive dysfunction continue to affect caregivers even if they place their spouse in a nursing home,



Decline in cognition and function of spousal caregivers threatens their health and quality of life.

It also threatens the fabric of long term care as now woven.

Currently, spouses and other unpaid family caregivers provide more than 80% of the long-term care services rendered in the US to persons with dementia.

Researchers from the Stress and Coping Project at the University of Washington and colleagues reviewed eight such caregiver studies, in which spouses averaged 30 years of marriage, and provided 35 hours of direct care per week.

Review echos worrisome findings

Studies have long shown that caregiver spouses have higher levels of problems including social isolation, depression, decreased physical activity, troubled sleep, weight gain, and metabolic syndrome. These factors, many linked to chronic stress in caregivers, contribute to greater risk for developing cognitive problems. "Chronic stress causes unremitting secretion of cortisol," a hormone which can cause degeneration of the hippocampus, a brain region crucial to memory and learning, the review states.

One study found caregivers of AD patients had lower scores for attention, visual processing speeds, and memory than same-age non-caregivers. A 2004 Harvard study

studies find. Many spouses report persistent depression and anxiety at levels as high as when they cared for their mate at home. Death of the care recipient is generally handled well over time, yet a sizeable caregiver minority (23%) continue to experience psychiatric difficulty even after bereavement, the review reports.

Caregiving burdens threaten a spouse's health and quality of life, and could stagger society's finances. If states must pay to give the "sick" spouse the care and services a "well" spouse once provided for free, it could be a big bill. In the US, unpaid family caregivers provide 8.5 billion hours of care per year to persons with dementia.

"The future demands studies and interventions that focus on caregiver cognitive and functional health and prevention of decline, as many risk factors identified in this review are amenable to change," the authors state, to hopefully prevent "the 'ironic tragedy' — dementia in both members of the caregiving dyad." ■

Aiding caregiver burden, a PMC class offers insights, strategies, and more, worked on together

Studies described in the article at left reveal some of the many tolls of caregiving. At the Penn Memory Center, a periodic 6-week psychoeducational class offers knowledge, insight, and techniques to help caregivers take better care of their loved one, and themselves, as they adjust to life with Alzheimer's disease.

Unlike a support group, the course has a weekly curriculum. Topics include better managing your loved one's — and your own — behavior and emotions, especially negative and distressing ones, and finding the "fuel" you'll need for the long term.

"Hard as it seemed at first to ask for it, I learned some real strategies to get help, and to keep myself together so I can give the rest of my family what they need, too," one participant said.

Group members and PMC facilitators at a recent 6-week caregiver class. Sessions run throughout the year.



For more on the caregiver course . . .

Go to our website, www.pennadc.org, click on "News and Events" then click on "Caregiver Class" to download a brief overview of some class topics



Racing to slow the onset of Alzheimer's

Researchers **John Trojanowski, MD, PhD, and Virginia Lee, PhD, MBA**, co-directors of the Center for Neurodegenerative Disease Research (CNDR), are racing to slow down the onset of Alzheimer's. Every 70

seconds a baby boomer receives this diagnosis. The Alzheimer's Association predicts AD will claim upwards of 15 million people and cost more than \$1 trillion by 2050. Fox 29 interviewed the duo and learned more about the disease, its effects on people's lives, and the enormous economic burden we will all have to carry. They also discuss CNDR's novel drug development program. <http://tinyurl.com/fox29-racing>



Keeping a job after AD diagnosis? On Coach Pat Summitt

Jason Karlawish, MD, in a Philadelphia Inquirer story, noted that he was impressed when he heard that 59-year-old Pat Summitt had gone public with her diagnosis of Alzheimer's disease and that the University of Tennessee had let her stay on as its women's basketball coach. As the retirement age creeps upward and doctors get better at diagnosing dementia earlier in its course, increasing numbers of people will grapple with how to stay productive as their minds falter. Meanwhile, employers, families, and friends will need to figure out how to deal with workers who may still have a lot to offer but need support. "We have to learn how to set up systems that will allow talented people to still contribute," he said. <http://tinyurl.com/karlawish-summitt>



Statins and memory loss

The Philadelphia Inquirer investigated cognitive impairment associated with cholesterol-lowering drugs, noting the FDA has told makers of six statin brands to revise prescribing information to add "memory impairment" or "memory loss" to the list of adverse reactions reported by some users. Many researchers — and drug firms — once hoped that statins might ward off dementia, but "it just didn't work," said **Steven E. Arnold, MD**, PMC director. <http://tinyurl.com/arnold-statins>



At Ann's Choice

The PMC enjoys a rich research and educational relationship with Ann's Choice, an Erickson Living Community of 2200 in Warminster, PA. Fifty-five residents are in PMC's 'Resilience' study; hundreds more will have one-hour cognitive assessments to join new studies there. **Steven E. Arnold, MD** (above) spoke to a large audience on early findings of 'Resilience,' noted at the Alzheimer's Association International

Conference in Paris in July. PMC neuropsychologist and olfaction and gustation (smell and taste) researcher **Paul Moberg, PhD, ABPP** (below, right) presented and took questions on "How Smell and Taste Change over our Lifetime."



On aging and memory, and AAN prize

When thoughts or information seem to vanish into thin air, some wonder if the next step is Alzheimer's, Woman's Day reports. PMC Assistant Director **David Wolk, MD** is featured in the article. Also, in July

Dr. Wolk was awarded the Norman Geschwind Prize in Behavioral Neurology from the American Academy of Neurology, recognizing "outstanding research in the field of behavioral neurology." <http://tinyurl.com/wolk-womansday-prize>



AD: Test if you can't treat?

New methods to detect AD — easier brain scans, an eye test, a blood test — are coming. The Associated Press reported on debate at the Alzheimer's Association International Conference on whether to test patients when meaningful treatments aren't yet available. "You often hear that the 'Big A' (Alzheimer's) has replaced the 'Big C' (cancer)" as a major source of fear, said **Jason Karlawish, MD**. A researcher has no obligation to disclose results to a patient until there is a meaningful treatment, Karlawish argued. Over 180 media outlets (NPR, USA Today, Philadelphia Inquirer) ran the story. <http://tinyurl.com/karlawish-treatment>



To see more Penn Memory Center media activity . . .

Including stories on new diagnostic guidelines for Alzheimer's, new PET scanning methods to detect AD, and more, go to www.pennadc.org, click on "News and Events" then click "Media Activity"

Chronic back pain may affect more than your golf game or your dreams of auditioning for *Dancing with the Stars*. Studies show that persistent pain can cause shrinkage of some brain regions and impair cognitive performance. Now a study finds that treating an aching back may help restore affected brain areas and improve cognitive function.

In findings published in the *Journal of Neuroscience*, researchers at McGill University used MRI to measure thickness and function of certain brain structures, and then compared cognitive test results of back pain sufferers before and after study participants had surgery or received long-lasting analgesic injections that relieved their pain.

Compared to pain-free subjects, back pain sufferers showed losses in gray matter in six specific brain regions, including the prefrontal cortex, which is important to working memory. They also exhibited poorer performance on attention-demanding tasks. Researchers suggest these cognitive impairments result from the load chronic

Treat your back pain, restore your shrinking brain?



A backache tonight, brain loss down the road?

pain puts on cognitive brain networks. Six months after successful treatment, brain abnormalities seen earlier had slowed down or been partially reversed, the study reported. Brain activity, measured by fMRI, and cognitive performance also improved. "If you can make the pain go away with effective treatment, you can reverse these abnormal brain changes," one study author said.

<http://www.jneurosci.org/content/31/20/7540.full>

If as a child, you grumbled about practicing the piccolo while your pals went to the playground, you'll be happy to learn that results of a new study on music and late-life cognition suggest you made the right choice. Even if it's been years since you last played.

The University of Kansas Medical Center study tested cognitively normal adults age 60-83 with similar education and health, categorized by their musical background: those who had 10+ years music training, 1 to 9 years music training, or no such training. All the musicians were amateurs who began playing at about age 10. More than half had played piano.

The 10+ year trained musicians did the best on cognitive tests, followed by the less-trained, then the non-musicians. They also had statistically significant higher scores than the non-musicians in tests of visuospatial memory, of naming objects, and of the brain's ability to adapt to new information.

Schools cutting music budgets in a tight economy, take note . . .



Playing music early boosted cognition scores scores later

Half the 10+ year trained group still played an instrument on a regular basis, but they didn't outscore others in their group who quit playing long ago. This would suggest it is the duration of musical study and the age of acquisition that are most critical, study authors said.

<http://www.apa.org/news/press/releases/2011/04/music-lessons.aspx>



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is breathed upon by
hope's
perpetual breath
• William Wordsworth

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Planned giving, matching gift programs, and a range of tax-advantageous structured giving approaches are also available. To learn more about how your support can strengthen and advance the work of the Penn Memory Center, please contact Michael Balaban at 215-573-4028 or balabanm@upenn.edu.

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