

COVER STORY

Foggy future

As nation ages, dementia is becoming a significant economic burden

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SHUTTERSTOCK/PHOTO ILLUSTRATION BY JAMES C. WATTS

Peter McDougal always thought of his father, Steven McDougal, as being one of the sharpest, most brilliant men around.

Steven, a former chief of Atlanta-based U.S. Centers for Disease Control and Prevention's Immunology branch in the division of HIV/AIDS, sexually transmitted diseases and tuberculosis laboratory research, identified the primary receptor for HIV in the 1980s, and he also helped slow the epidemic in people with hemophilia.

He had not yet retired from the CDC when he was diagnosed with Lewy Body Disease, progressive dementia that can cause visual hallucinations, features of Parkinson's disease and sleep disorders.

"He was going strong for a while, then the Parkinson's kind of arresting tremor set in," said Peter, a psychologist for Fulton County Schools and swim instructor for the Avondale Tidal Waves. "He always told us it was late-onset

Parkinson's, that it was nothing, and most people with it live until old age. That was just my dad not letting us worry, and maybe some denial himself."

Slowly, the dementia took over Steven's life, Peter said. At first it was small things, like having a word on the tip of his tongue he couldn't identify, but it progressed to forgetting his loved ones' names. Steven passed away in 2014 at age 68 after battling the disease for over a decade.

"He never really seemed to forget who you were until the very end," Peter said. "There was a hard incident at the hospital when he thought I was some other scientist who had won an award... All his God-given talents and the things we took for granted were taken away from him."

Unfortunately, stories like McDougal's are increasingly common, because dementia is on the rise.

Estimates vary on how many suffer from dementia, which is an umbrella term that includes Lewy Body, Alzheimer's

disease (AD), Parkinson's disease, Huntington's disease and many others. But AD makes up estimated 60 to 80 percent of cases of dementia, and over 5.4 million Americans are currently living with it, including 130,000 in Georgia.

Because dementia is a disease of aging and more people are living past the age of 65, the number of new cases in the U.S. could be many as 16 million by 2050.

"We know pretty well what the demographics of the country are going to be in 20 or 30 years, and it would take something highly unusual like a drastic change in mortality to change those projections very much," said **Michael Hurd**, director of the **RAND Center for the Study of Aging**. "Unless there's a medical breakthrough, we'll have many more people with dementia and many more people affected in the working population who will be helping those people. It will be a very significant economic burden."

Deke Cateau, chief of strategic

implementation at **A.G. Rhodes Health & Rehab** and a dementia-certified staff member, said at least 50 percent of Atlanta-based nursing home residents now have some form of dementia, but he estimates the actual number is closer to 75 or 80 percent.

"As we're seeing the population age in our nursing homes, so too are we seeing a rise in signs and symptoms," Cateau said.

Dementia research has never been more critical, but research dollars being allocated to fight the disease are not proportionate to its economic burden.

According to a RAND Center on Aging report, the economic burden of dementia was \$109 billion, or up to \$215 billion when the monetary value of informal care is factored in. By comparison, the 2013 economic burden of cancer was \$77 billion and heart diseases cost \$102 billion in 2013, the most recent year the data set was available.

Despite creating a larger burden on the



PHOTO/SPECIAL

Peter McDougal's father, Steven, suffered from Lewy Body Disease.

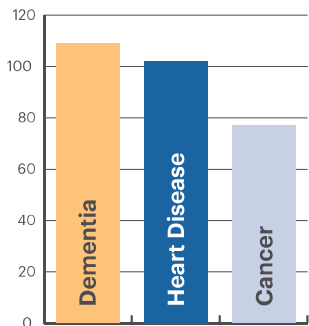


JOANN VITELLI

The EXERT study tests whether physical exercise can slow the progression of early Alzheimer's.

ECONOMIC BURDEN

In 2013 in the U.S. in billions of dollars



- **\$109 billion** — Economic burden of dementia; \$215 billion with indirect care costs.
- **\$102 billion** — Economic burden of heart disease
- **\$77 billion** — Economic burden of cancer

SOURCE: RAND CENTER ON AGING

nation than either heart disease or cancer, dementia receives far less funding from the federal government than either disease. In 2015, agencies like the National Institutes of Health committed \$5.4 billion for cancer research and \$1.2 billion for heart disease, but only \$566 million for AD research, according to the AARP.

Although funding is scarce, Georgia scientists are conducting groundbreaking research to better understand the disease and improve the lives of those suffering from it. Not long ago, dementia research was based mainly on finding a cure. But today's studies are more focused on earlier diagnoses, slowing the disease's effects and advancing treatments.

Stephen Miller, professor at **The University of Georgia** and director of its Bio-Imaging Research Center Clinical Program, is conducting a study examining whether the carotenoids Lutein and Zeaxanthin, compounds in fruit and vegetables that give them their vibrant colors, can boost brain function in older adults. Participants in the study are given supplements for a year, and Miller's team studies the difference in their brain health before and after using non-invasive MRI.

"Dementia is a huge problem in terms of adults losing functional independence, so much of our lab spends time looking for early markers of dementia, early ways of diagnosing and trying to look at things we can do to increase cognitive abilities through rehabilitation, advancement and nutritional supplements," Miller said.

Whitney Wharton and **Joe Nocera**, assistant professors of neurology at **Emory University School of Medicine**, are taking part in the multi-center EXERT Study that is testing whether physical exercise can slow the progression of early AD. They use brain imaging and spinal fluid to look for AD symptoms before and after participants complete an 18-month exercise program at a local YMCA. One group's regimen is mostly cardiovascular, and the other group is performing mainly low-impact balancing tasks.

"The precursor to this is there is a lot

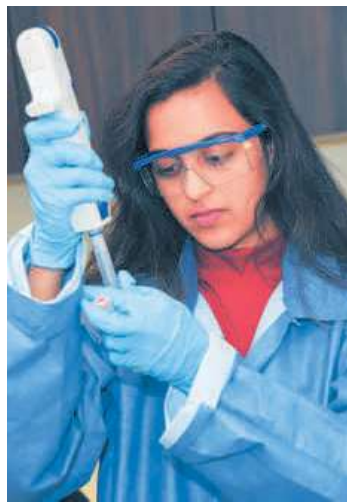


of data in the aging population showing that exercise is really good for the brain," Nocera said. "But we don't know what it does for somebody with a very high risk for AD. That's what this study hopes to answer."

A study at **Georgia Tech** led by **Scott Moffat**, associate professor of psychology, uses virtual environment technology or virtual reality to assess spatial memory in the elderly. The tests are conducted at a computer, which analyzes how successfully participants can find their way through a maze of virtual rooms and hallways.

"A really classic feature of dementia is wandering, and some of the brain systems that are the first to degenerate in AD are also the systems that support the navigation memory system," Moffat said. "The motivation is this might be an early way to detect signs of AD either through behavioral problems with 3D navigation or through studying brain mechanisms that support navigation."

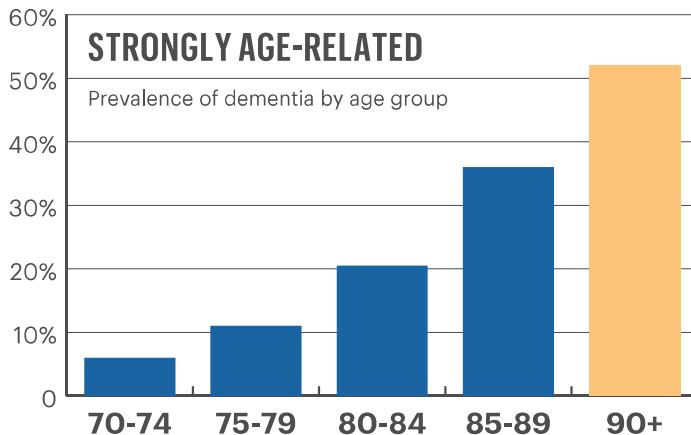
African-Americans are twice as likely as Caucasians to be diagnosed with dementia. **Fayron Epps**, assistant professor of nursing at **Georgia State University**, devotes her research to promoting quality of life for these individuals and their family caregivers. She was recently awarded a grant by GSU to conduct a culturally informed community health assessment of Fulton and DeKalb counties' African-American populations to develop nursing science programs related to their health and aging. Epps thinks the disparity might be linked to African-Americans' higher risk of heart disease and diabetes.



Emory is testing participants' spinal fluid as a part of the EXERT study.

"I can tell you I think a main reason [for the disparity] is lifestyle, because brain health and heart health go hand in hand," Epps said. "If you don't take care of your heart, your brain fails in some way."

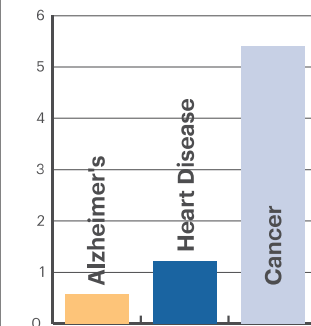
A recent study cited by The New York Times in November 2016 found that dementia prevalence in the U.S. actually declined from 11.6 percent of adults over 65 in 2000 to 8.8 percent in 2012. However, Hurd said the study's results are not firmly established and, even if the test group correctly reflects the overall population, the costs of the disease are still rising rapidly.



SOURCE: ADAMS AND HRS

FEDERAL RESEARCH DOLLARS

In 2015 in the U.S. in billions of dollars



- **\$566 million** — Alzheimer's
- **\$1.2 billion** — Heart disease
- **\$5.4 billion** — Cancer

SOURCE: AARP

A big reason dementia is so costly is it often requires non-medical, around-the-clock care for years, which means family members of dementia sufferers must either pay to bring in a professional or give up their careers to become caregivers themselves.

"These individuals often live for a number of years where they're physically okay but mentally incapacitated, and that has a very high economic cost," Miller said.

Due to research advancements, dementia treatments are shifting away from pharmaceuticals and becoming more individualized, Cateau said.

For example, one of A.G. Rhodes' residents with dementia refused to sleep at night, instead choosing to linger around the nurse's station after hours. Instead of giving her some type of sleeping medication, her caregivers looked into her history and found out she had been a night nurse herself, so they made arrangements to shift her sleep schedule to allow her to stay up late.

"We look at the symptoms and behaviors and we use a less medically inclined approach," Cateau said. "It has been proven that the medication currently available for dementia really isn't having the kind of effects that were intended. There's no magic pill you can take... In some cases these medications do more harm than good, and in some cases it can be deadly."

Even without a cure for dementia, great strides are being made in improving the quality of life for people who have it. And thanks to studies like Hurd's, which are helping to raise awareness about the prevalence and burden of the disease, there is hope for more funding in the future.

"Since our article, there has been some movement to increase funding in NIH and other places for dementia research and Alzheimer's, as I think people have begun to realize the cost," Hurd said. "It's a bit too early to know what will happen, but I read a recent budget proposal that seems to have support from both Democrats and Republicans to increase funding, and that's very gratifying." ❧