

NOBLE

A New Study for People with Mild to Moderate Alzheimer's Disease

A special newsletter for participants in the Noble Research Study

Spring 2016

Letter from the Director



Dear NOBLE Study Participants,

Last fall when I wrote this column we had enrolled 75% of the 450 people needed for the NOBLE study. I am pleased to let you know that

we not only completed enrollment in December, but we surpassed our goal for 450 and enrolled 484 people at 49 research sites around the country. About half are women and half are men, close to an even split. I speak for all of us on the NOBLE team in thanking you for participating in this most important study. We could not conduct our research without you.

In this issue we feature a variety of articles. Did you know poor sleep has been linked to Alzheimer's disease? There have been several studies over the years looking at this connection. Mostly recently researchers at UC Berkeley made a finding last year.

We know that living with Alzheimer's is quite challenging; we understand because we witness it in our participants every day. We also know that there are ways of coping, especially in the mild to moderate phases. In this issue we

present a list of tips for living your best life with an Alzheimer's diagnosis. We hope you will find it useful.

Dr. Daniel Potts of the University of Alabama - Birmingham started an interesting program that combines art therapy, life story preservation and education to people living in community dwellings and students at the university. The Art to Life Program at the University of Alabama - Birmingham pairs students with Alzheimer's patients where they work together to arouse memories, talents and stories. It's a heartwarming story that is sure to make you smile.

Also in this issue, as we have done before, we include a resource list of programs and services available to Alzheimer's patients and their families. You never know when you may need one of the programs and we want to make it easy for you to find this invaluable information.

Until next time,

Lon

Lon Schneider, M.D., M.S.,
Keck School of Medicine of USC

Class Teaches Mental Benefits of Art Therapy

By Hannah Widener
Contributing Writer, *The Crimson White*/University of Alabama



Daniel Potts said he first noticed something was off with his father in 1998. When Potts' parents moved to Tuscaloosa in 2000, his father took a job parking cars and started to forget where he had parked the cars and often locked the keys in them. Sometimes he would get lost on the parking deck and not know where he was. It was then Potts thought his father might have Alzheimer's disease.

"I think I was in denial, or perhaps I just didn't want to see it," Potts said. "So that's been a source of guilt for me as his child and as a neurologist to not be aggressive enough to intervene early on."

Once Potts' father had progressed into the disease and could not stay at home all day, the family said they decided it would be best to

take him to the Caring Days adult day care center in Tuscaloosa. It was there that Potts' father was introduced to art therapy.

Potts said he was amazed by the watercolor paintings his father had made. Through painting, his father's memory, mood and cognition appeared to improve.

Potts began to write poetry and eventually started putting together a book titled "The Broken Jar," a collection of his father's art and his poetry. When the book was finished, Potts gave the book to the Caring Days facility. After his father passed away, Potts said he knew he had to do something, so he and his family started the Cognitive Dynamics Foundation.

"We started Cognitive Dynamics, which is a foundation that's about improving quality of life through the arts," Potts said. "Shortly after

Potts was amazed by the watercolor paintings his father had made. Through painting, his father's memory, mood and cognition appeared to improve.

we did that I came to admit with Dr. Jacqueline Morgan, wanting to see how we might involve the Honors College in an educational experience with this. We knew we wanted to combine art therapy, life story and education, and knowing Dr. Morgan, she said, 'Let's find a way to do this.'"

The Art to Life program gives students a chance to interact with participants who have Alzheimer's. Jacquelynn Myrick, a junior majoring in psychology, is the current student facilitator of the program.

The class has two parts: a lecture that introduces the students to the story behind Art to Life and how the disease itself works and a lab where the students are divided into groups to work with participants.

Myrick said one of her favorite memories in the program is working with a woman who shared her Hispanic heritage and love of dancing.

"Our art therapist, Karen Gibbons, brought in some music and started playing the Cha Cha," Myrick said. "The next thing I know, Dr. Potts looks over at Ms. Jackie and asked her if she wants to dance. She stood up in art therapy with the biggest joy and the most laughter and starts dancing with Dr. Potts and teaching the rest of us how to dance."

Myrick said when the patients paint, it invokes more of an emotional memory than a specific one. The program has almost finished writing a manual for other educational institutions that want to adopt the program and get students involved with art therapy.

Potts said the program has not only transformed his life and the lives of his students, but the participants' lives as well.

"We had one woman who used to be a former artist and had macular degeneration," Potts said. "She couldn't see her art. So the art therapist said, 'We're going to show all of our students your art and let them tell you what they think of it.' We went around the room and all of the students described the art, so then the art therapist said, 'So what do you think about this now?' She, in tears, said, 'There's something there – a new beginning. You've given me my life back. I never thought I would feel colors again.'"



Poor Sleep Linked to Toxic Buildup of Alzheimer's Protein, Memory Loss

By Yasmin Anwar
University of California Berkeley

Poor sleep, more common in old age, is linked to the protein implicated in Alzheimer's disease. Sleep may be a missing piece in the Alzheimer's disease puzzle. UC Berkeley scientists have found compelling evidence that poor sleep — particularly a deficit of the deep, restorative slumber needed to hit the save button on memories — is a channel through which the beta-amyloid protein believed to trigger Alzheimer's disease attacks the brain's long-term memory.

"Our findings reveal a new pathway through which Alzheimer's disease may cause memory decline later in life," said UC Berkeley neuroscience professor Matthew Walker, senior author of the study published in the journal *Nature Neuroscience*.

Excessive deposits of beta-amyloid are key suspects in the pathology of Alzheimer's disease, a virulent form of dementia caused by the gradual death of brain cells. An unprecedented wave of aging baby boomers is expected to make Alzheimer's disease, which has been diagnosed in more than 40 million people, one of the world's fastest-growing and most debilitating public health concerns.

The good news about the findings, Walker said, is that poor sleep is potentially treatable and can be enhanced through exercise, behavioral therapy and even electrical stimulation that amplifies brain waves during sleep, a technology that has been used successfully in young adults to increase their overnight memory.



"This discovery offers hope," Walker said. "Sleep could be a novel therapeutic target for fighting back against memory impairment in older adults and even those with dementia."

A power cleanse for the brain

The study was co-led by UC Berkeley neuroscientists Bryce Mander and William Jagust, a leading expert on Alzheimer's disease. The team has received a major National Institutes of Health grant to conduct a longitudinal study to test their hypothesis that sleep is an early warn-

ing sign or biomarker of Alzheimer's disease. Heavy deposits of the toxic protein, beta-amyloid are linked to poor sleep and may be paving the way for Alzheimer's disease. While most research in this area has depended on animal subjects, this latest study has the advantage of human subjects recruited by Jagust, a professor with joint appointments at UC Berkeley's Helen Wills Neuroscience Institute, the School of Public Health and Lawrence Berkeley National Laboratory.

"Over the past few years, the links between sleep, beta-amyloid, memory, and Alzheimer's disease have been growing stronger," Jagust said. "Our study shows that this beta-amyloid deposition may lead to a vicious cycle in which sleep is further disturbed and memory impaired."

Using a powerful combination of brain imaging and other diagnostic tools on 26 older adults who have not been diagnosed with dementia, researchers looked for the link between bad sleep, poor memory and the toxic accumulation of beta-amyloid proteins.

"The data we've collected are very suggestive that there's a causal link," said Mander, lead author of the study and a postdoctoral researcher in the Sleep and Neuroimaging Laboratory directed by Walker. "If we intervene to improve sleep, perhaps we can break that causal chain." A buildup of beta-amyloid has been found in Alzheimer's patients and, independently, in people reporting sleep disorders. Moreover, a 2013 University of Rochester study found that the brain cells of mice would shrink during non-rapid-eye-movement (non-REM) sleep to make space for cerebrospinal fluids to wash out toxic metabolites such as beta-amyloid.

"Sleep is helping wash away toxic proteins at night, preventing them from building up and from potentially destroying brain cells," Walker said. "It's providing a power cleanse for the brain."

Specifically, the researchers looked at how the quantity of beta-amyloid in the brain's medial frontal lobe impairs deep non-REM sleep, which we need to retain and consolidate fact-based memories.

In a previous study, Mander, Jagust and Walker found that the powerful brain waves generated during non-REM sleep play a key role in transferring memories from the hippocampus — which supports short-term storage for information — to longer-term storage in the frontal cortex. In elderly people, deterioration of this frontal region of the brain has been linked to poor-quality sleep.

For this latest study, researchers used positron emission tomography (PET) scans to measure the accumulation of beta-amyloid in the brain; functional Magnetic Resonance Imaging (fMRI) to measure activity in the brain during memory tasks; an electroencephalographic (EEG) machine to measure brain waves during sleep; and statistical models to analyze all the data.

'A vicious cycle'

The research was performed on 26 older adults, between the ages of 65 and 81, who showed no existing evidence of dementia or other neurodegenerative, sleep or psychiatric disorders. First, they each received PET scans to measure levels of beta-amyloid in the brain, after which they were tasked with memorizing 120 word pairs, and then tested on how well they remembered a portion of them.

The study participants then slept for eight hours, during which EEG measured their brain waves. The following morning, their brains were scanned using fMRI as they recalled the remaining word pairs. At this point, researchers tracked activity in the hippocampus, where memories are temporarily stored before they move to the prefrontal cortex.

"The more you remember following a good night of sleep, the less you depend on the hip-

(continued on page 7)

Resources for AD Patients and Their Caregivers

Sometimes caring for a loved one can feel overwhelming and justly so. With proper support and resources you can manage the byways and deal with the challenges that the disease brings.



Check out local resources in your community by calling the local chapter of the Alzheimer's Association. They often offer a plethora of information and support. To find your local chapter visit the national website at www.alz.org. The Alzheimer's Foundation also offers community resources. www.alzfdn.org

The Alzheimer's Disease Education and Referral Center, part of the NIA, can provide you will more assistance than you could possibly need from brochures and books to caregiving tip sheets and resource lists to legal and financial issues to safety. Well worth spending time here. <http://www.nia.nih.gov/alzheimers/about-adear-center>

Ask your research site or your local chapter of the Alzheimer's Association if they have a caregiver support group. Such support groups are immensely helpful with ideas and useful resources as your loved one's disease progresses. Start going to meetings as soon as possible.

Study you and your loved one's day to determine the times of the day when your loved one is least confused and plan your routine around those times. Bear in mind that this could change so be flexible and adapt as necessary.

Stay connected with friends and family; don't allow yourself to become isolated. Rekindle old friendships and find new ones.

Friends and family may offer help from staying with your loved one while you go on errands to bringing over dinner. People often sincerely want to help but often don't know what to do or what you need. Let them help; don't be afraid to ask.

Allow yourself to take a break. If you have a hobby, pursue it. Go to the movies, engage in a book club, keep up with your gardening. Ask family and friends to stay with your loved one if your interest involves leaving the house. Or if your hobby is collecting sea shells at the beach, take your loved one with you. Finding shells can be an easy and enjoyable activity for both of you.

Take care of your own health. Don't allow yourself to become stressed or run down. If you get sick you won't be able to care for your loved one and that won't do either of you any good. Eat healthy, take your vitamins, go on a daily walk, and get plenty of sleep.

Finally, begin to plan for the future. Waiting will not stop the inevitable. If you haven't already, pull together your financial and legal documents, investigate long term care options and determine what services are covered by health insurance and Medicare.



If your hobby is collecting sea shells at the beach, take your loved one with you. Finding shells can be an easy and enjoyable activity for both of you.

Poor Sleep

(Continued from page 5)

pocampus and the more you use the cortex," Walker said. "It's the equivalent of retrieving files from the safe storage site of your computer's hard drive, rather than the temporary storage of a USB stick."

Overall, the results showed that the study participants with the highest levels of beta-amyloid in the medial frontal cortex had the poorest quality of sleep and, consequently, performed worst on the memory test the following morning, with some forgetting more than half of the information they had memorized the previous day.

"The more beta-amyloid you have in certain parts of your brain, the less deep sleep you get and, consequently, the worse your memory," Walker said. "Additionally, the less deep sleep you have, the less effective you are at clearing out this bad protein. It's a vicious cycle.

"But we don't yet know which of these two factors — the bad sleep or the bad protein — initially begins this cycle. Which one is the finger that flicks the first domino, triggering the cascade?" Walker added.

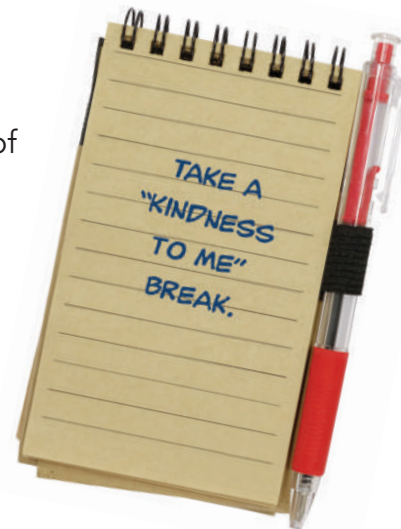
And that's what the researchers will determine as they track a new set of older adults over the next five years.

"This is a new pathway linking Alzheimer's disease to memory loss, and it's an important one because we can do something about it," Mander said.

Other co-authors and researchers on the study are Shawn Marks, Jacob Vogel, Jared Saletin and Vikram Rao at UC Berkeley, Brandon Lu at the California Pacific Medical Center and Sonia Ancoli-Israel at the University of California, San Diego. The study was funded by a grant from the National Institute of Aging.

Tips for Living Your Best Life with Alzheimer's

1. Keep a routine. It can be both comforting and helpful.
2. To make it easier to get things done take advantage of the times of day when you feel your best.
3. Carry a notebook to keep track of important info such as names, relationships, phone numbers, appointments, your address, and directions to your home.
4. Keep a list of important names and phone numbers next to the phone.
5. Put sticky notes around the house with reminders to yourself.
6. Maintain important relationships with family and friends. They can be your rock.
7. Keep photos of friends and family in a handy place. Place sticky notes on them with their names and relationship to you.
8. Labels cupboards and drawers with pictures and words that describe contents
9. Ask a friend or family member to remind you of important things you need to do such as taking medicine and going to appointments.
10. Do what you love. Focus on favorite, meaningful activities that you enjoy and can do safely on your own such as crafting, baking, visiting family, daily walks with friends, listening to music, etc.
11. Get in some form of exercise every day, something you can do safely.
12. Spend time with your pet or someone else's. They are often the best listeners and the greatest comforters. Multiple studies have shown the positive effects of pets on people.
13. Finally, be easy on yourself and acknowledge that your brain is changing. Give yourself a kindness break; you deserve it.



A Publication of the Alzheimer's Disease Cooperative Study
University of California San Diego
9500 Gilman Drive
La Jolla, CA 92093-0949

www.adcs.org
www.noblestudy.org