



Perspectives

A Newsletter for Individuals with Alzheimer's or a Related Disorder

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Making Sense of Memory

For most people with Alzheimer's or a related disorder, memory loss is one of the first signs of a problem. While some slowing of memory formation and recall is a normal part of aging, the memory loss of Alzheimer's affects daily activities such as keeping up with appointments, maintaining a checkbook, or cooking a complex meal. But why can some things be remembered and others seem to dissolve almost immediately? There are many types of memory and multiple areas of the brain involved in the creation and storage of memory.

Sensory Memory

Throughout our daily activities, we experience thousands of sensations through our sight, smell, taste, sound, and touch. These sensations are briefly retained in our "sensory memory." Many sensory memories are fleeting, lasting only a few seconds. Only information that we pay closer attention to (listening intently to the words of a song or looking closely at a photograph) is then transferred to another level of memory where it may be better preserved. Many people with Alzheimer's can be overwhelmed in situations with too much sensory stimulation (loud parties or crowded shopping malls, for example). The brain can't process the information as effectively to get it into memory.



Short-Term Memory

If a person is not overly distracted and can pay enough attention to information that is received from the senses, the information moves into "short-term memory." This is a temporary holding area (perhaps only seconds) in the brain where information is stored briefly before moving into long-term memory.

Working Memory

Another way that the brain temporarily holds information is through "working memory." This type of memory is used to hold information for a short time while the brain processes it. Working memory is used in processes that require reasoning, such as retaining the meaning of several sentences in order to understand a paragraph, or performing and retaining all of the steps of a task in order to accomplish it.

Long-Term Memory

Long-term memories can last anywhere from a day to many decades and are called either "declarative memories" or "procedural memories." Declarative memory includes all memories that are consciously available to us when we try to remember. This type of memory includes memories of specific events ("episodic memory") such as the birth of a child. It also includes memory for the meaning of words, social

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Making Sense of Memory

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customs, and the purpose of various objects and how they work (“semantic memory”).

Procedural memory includes “how to” knowledge like the finger movements required to play the piano or the actions necessary to ride a bicycle. Procedural memories are acquired through repetition over time (remembering how to walk or how to open a door). These kinds of memories can be accessed without a conscious effort to remember.

Brain Regions Involved in Memory

Scientists believe that no one area of the brain is solely responsible for forming and storing memories. Many areas are involved, each with varied responsibilities for perceiving and processing information, and for storing it as different types of memory. New memories are initially stored in the hippocampus, which is one of the first areas affected by Alzheimer’s. Changes in this area affect the brain’s

ability to take in new information and retain it for storage.

Another region of the brain, the amygdala, sits near the hippocampus and is involved in the emotional aspects of memory formation and storage. Was an event associated with pleasure, pain, or fear? The strength of the emotions involved in an event may help to determine how strongly that event is remembered.

The cerebellum is also involved in memory, specifically procedural memories. The cerebellum regulates balance and coordination and along with brain structures called the basal ganglia, is in charge of forming and storing memories involving movement, such as how to swim or dance.

Memory Strategies

Although Alzheimer’s can affect all forms of memory, these strategies can help with retaining information:

Pay attention when you are trying to remember something. Too much stimulus (trying to read while the TV is on) can interfere with attention and memory.

Practice repetition. When you are trying to learn a new activity, do it over and over until it becomes familiar.

Use multiple brain functions to help with remembering. When you watch a TV program, talk about it with someone afterwards. This stimulates multiple areas of thinking and can help with memory.

Get adequate sleep. Sleep is required to “consolidate” memories, a process that moves short-term memories into long-term storage.

Break tasks down into small steps. It is easier to remember how to do something when it is done one small step at a time. Finish one step before starting the next.

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Informative FREE Resource



The National Institute on Aging (NIA) has a new edition of *Alzheimer's Disease: Unraveling the Mystery*, an illustrated 80-page book written for people with Alzheimer's disease (AD), their families, health care professionals, students, and others interested in Alzheimer's. This update to the 2003 edition helps readers understand AD, its impact on individuals and society, and research advances to prevent or diminish the effects of symptoms. The new edition:

- describes the basics of the healthy brain;
- focuses on changes that occur in a brain affected by AD;
- highlights findings from recent NIA-funded research into the causes of AD, new developments in diagnosis, and the search for new treatments; and
- addresses issues of concern to AD care partners and families.

The book also includes a glossary, a comprehensive list of organizations offering more information, and a list of recommended reading.

To view, download, or order free copies of *Alzheimer's Disease: Unraveling the Mystery*, call NIA's Alzheimer's Disease Education and Referral (ADEAR) Center at 1-800-438-4380 or go online to: <http://www.nia.nih.gov/Alzheimers/Publications/Unraveling>.

Brainstorming

We asked people with memory loss:

Are there any daily routines that are helpful to you?

Here are some of the replies:

“First thing in the morning I get on the treadmill and I also do medium weights. I make sure to get exercise every day.”

“I put my house keys in the same place and then if I have to go out and I want to remember to take something with me, I’ll put it with the keys so I don’t forget it.”

“Every day I remember to wake up. That’s an important routine!”

“I do the laundry on a certain day of the week. That way it stays manageable and I can actually get it done.”

“I have a routine about where I put my tools because if I don’t put them right back after I use them, I’ll never find them again!”

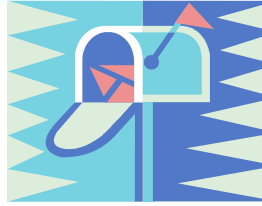
“My wife and I take a walk every morning and we usually go on the same route. That way, if I go alone sometimes, the route is familiar and I’m more likely to find my way back home.”

“I take a nap every afternoon. I kick off my shoes at about 2:00 and get some rest. I wake up refreshed and my mind feels clearer.”

“I make a point of watching the nightly news. It’s not always fun, but my husband and I talk about the issues that they discuss and I think it’s good for my brain.”

“I live alone with my little dog. Every morning I feed her at the same time as I take my medications. If I don’t do it then, I may forget to feed her or feed her twice. And she won’t tell me if I’ve already fed her. She’ll just eat again!”

Mailbox



Dear Editor:

I always get a boost from *Perspectives*.

Even the poignant personal journeys are positive (like Kris Bakowski's from the last issue) because they show people struggling to communicate and "be real" about a disease with which they or their loved one have been diagnosed, just as people with cancer might be struggling. Too often, as I work with caregivers of persons diagnosed with dementia, I observe denial and anger by the person diagnosed, combined with one or more reactions from their families that indicate communication has been a problem in the relationship over time and certainly is not going to get better when faced with this diagnosis. So, I am grateful to read about another approach – it seems so hopeful. I have suggested *Perspectives* to clients.

Sincerely,

Kathy Dolan
Family Caregiver Support Specialist
Skagit Senior Information and Assistance
Burlington, Washington



ANNOUNCING:

Austin's Camp: Building Bridges
Second Annual Kid's Camp
July 19-25, 2009
Chouteau, Oklahoma

Dear Readers,

Austin's Camp: Building Bridges is the realized dream of Tracy Mobley, a mother diagnosed with early-onset dementia who

was concerned about the limited emotional, social, and educational support available to her young son. Last year the idea of a camp for teens of parents or grandparents with AD was piloted and turned out to be a great success. Austin, who is now 14, and nine other teens, experienced the first camp at a YMCA camp in Oklahoma. There, they had six days away from home to have fun together, share support, and have information about dementia directed specifically to their needs and concerns. The teens are eagerly looking forward to a return to camp this coming summer and invite others to join them and the camp staff.

Camp Building Bridges is now under the umbrella of the Oklahoma and Arkansas Chapter of the Alzheimer's Association and will be held at Camp Takatoka in Chouteau, Oklahoma, about 45 miles southeast of Tulsa. The cost of camp is \$600 plus a \$50 registration fee. Scholarships are available. Last year, several Alzheimer's Association chapters helped young people from their areas with transportation costs and families are encouraged to contact their local chapter for assistance if they do not live within driving distance of Oklahoma.

The camp is specifically organized for 13-to-16 year olds who have a parent or grandparent with early-onset dementia (dementia diagnosed before age 65). For more information call Allen or Tracy Mobley at 417-933-5520 or email to tiger@centurytel.net. You can also find more information on the camp online at: <http://www.freewebs.com/campbuildingbridges08/index.htm>. The website also provides a wide range of resources and information for teens who have a loved one with Alzheimer's or a related disorder.



Memories at the Museum – Exploring Art and Alzheimer’s



Fall, 2006 marked the beginning of a rich collaboration between the University of California, San Diego’s Shiley-Marcos Alzheimer’s Disease Research Center (ADRC) and the San Diego Museum of Art (SDMA). Inspired by an innovative program at the Museum of Modern Art in New York called “Meet Me at MOMA”, Lisa Snyder, clinical social worker at the ADRC, trained an enthusiastic group of SDMA docents to conduct tours for men and women with Alzheimer’s. During their training, docents were given an overview of the symptoms of Alzheimer’s and specific ways of facilitating discussions with people with memory loss that might engage their visual, verbal, and mental abilities. The program, entitled *Memories at the Museum*, offers one-hour tours for people with Alzheimer’s or a related disorder four times a year. Separate simultaneous tours are provided for an accompanying family member or friend or the companion can accompany their partner with memory loss in their group if they would prefer to share the experience together. The program is entirely free of charge.

Joe LaBonte rarely misses a tour and states, “Wiley Ferguson and the other docents bring the paintings to life. The ex-

perience brightens the horizon and you feel better about things.” Joe’s wife Donna notes the benefit of separate docent-led groups as it affords each their own pace. She states, “It’s a wonderful social outing and it’s very educational.”

Memories at the Museum has also proven to be a rich experience for SDMA docents. Ruth Broudy, SDMA Manager of Docent Programs, recently followed a docent-led tour of guests with Alzheimer’s through the exhibition of the painter *Everett Gee Jackson* and recalls how fulfilling it was to hear memories come alive for one of the participants who had known the painter personally when he was a professor at San Diego State University. The participant clearly discussed fascinating details about Jackson’s life. Broudy states, “The program helps to bring out the uniqueness of each person with memory loss. Each of these individuals is someone very special and we tend to forget that when someone has Alzheimer’s.”

In another tour, a daughter began to cry as she observed her mother discussing one of the exhibits. Vas Prabhu, SDMA Director for Education and Interpretation who was observing the program, handed her a tissue and expressed concern. The daughter told Vas, “It’s amazing to hear my mother talk about Post Impressionism and her experiences in seeing these works in New York City when she was a young woman. I’m her primary caregiver and I am so caught up in the day-to-day...it feels so good to know that she can access these happy memories!”

The New York MOMA has inspired other museums around the country to begin similar programs. Perhaps you can inspire a museum in your area to join in. It can be a creative and memorable experience for all involved.

Research Update: International Study to Investigate Early Inherited Form of Alzheimer's

The adult children of people diagnosed with inherited Alzheimer's disease (AD) are the focus of a new study to better understand the biology of the disease. Researchers are seeking 300 volunteers with a biological parent with a known genetic mutation causing rare and typically early-onset forms of AD to join the Dominantly Inherited Alzheimer's Disease Network (DIAN) study. This is a six-year study funded by the National Institute on Aging (NIA), part of the National Institutes of Health (NIH). The scientists hope to identify the sequence of brain changes in early-onset Alzheimer's even before symptoms appear and by understanding this process, to also gain insight into the more common late-onset form of AD.

The vast majority of people with Alzheimer's have the late-onset form of the disease, in which symptoms of memory loss become evident at age 60 or older. Less than five percent are diagnosed with the inherited form of AD, sometimes as early as their 30's or 40's. Until now, research into inherited early-onset Alzheimer's was hindered by the rarity of the condition and geographic distances between patients and research centers. DIAN is designed to overcome those challenges.

"This collaborative, international effort will link a network of research sites in the United States, England, and Australia to family members of people with these rare forms of Alzheimer's," said NIA Director Richard J. Hodes, M.D. "By sharing data within the network, we hope to advance

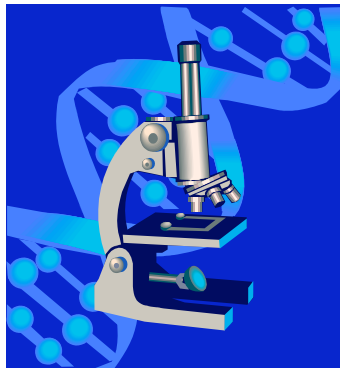
our knowledge of the brain mechanisms involved in Alzheimer's, eventually leading to targets for therapies that can delay or even prevent progression of the disease." The study is being led by John C. Morris, M.D., director of the Alzheimer's Disease Research Center at Washington University School of Medicine in St. Louis, Missouri.

Each study participant will undergo the same assessments, including genetic analysis and cognitive testing. Researchers will build a shared database of blood and cerebral spinal fluid samples and neuroimages, including MRI and PET amyloid protein images. These assessments, samples, and images should enable researchers to determine the type and sequence of changes in the brain in early-onset inherited Alzheimer's.

"While three mutated genes -- amyloid precursor protein (APP), presenilin 1 and presenilin 2 -- are known causes of inherited early-onset Alzheimer's, DIAN researchers now hope to find the biomarkers, or indicators, that herald the disease at its

earliest stages," said Marcelle Morrison-Bogorad, Ph.D., NIA Division of Neuroscience director. "By closely monitoring the biomarkers of the DIAN volunteers, both those with and those without the mutated genes, we should gain insight into the underlying pathology behind both early and late-onset forms of the disease."

People interested in participating in the DIAN study should contact DIAN Global Coordinator Angie Berry at Washington University at 314-286-2442, or go to <http://www.dian-info.org>. Study participants must be aged 18 or older.



Profile in Advocacy: Support Group Participants Write to Congress

The Early Stage Memory Loss Education and Support Group at Northwestern University in Chicago, Illinois wrote this letter to their local senators and congressmen. This advocacy was inspired by their desire to change the public perception and stigma surrounding dementia, to enhance resources available to those coping with memory loss, and to increase funding for continued research in the field. Support group members chose to use the word “dementia” throughout this letter to describe the many diseases that affect the brain including Dementia with Lewy Bodies, Vascular dementia, Alzheimer’s disease, and Frontotemporal dementia. Please feel free to use this letter as a template to write to your own local representatives. We hope that by sharing this letter with similar groups and individuals, others will be encouraged to speak out about this important health issue, and become empowered to advocate for increased awareness and support for dementia research.

Since the time this letter was authored and sent out, Senator Barack Obama has become President-Elect Barack Obama.

*Kristen Pavle,
Support Group Co-Facilitator*

November 10, 2008

Dear Senator Obama:

I am one of the 7.5 million people with a *diagnosis of dementia* and a member of the memory loss support group at Northwestern University. Dementia, including Alzheimer’s disease, is a devastating and

irreversible loss of mental functioning that affects my daily life. I am writing to share with you the importance of funding dementia research and increasing public awareness of this disease.

Every 71 seconds, a person is diagnosed with dementia in this country. People are living longer than they ever have and age is the greatest risk factor for developing dementia. Nearly half the population over 85 years has some form of dementia. By the year 2050 the number of persons with dementia is projected to jump to 16 million. These alarming statistics reveal the magnitude of this health crisis and the importance of acting NOW.

I am excited about the new dementia research that focuses not only on drug trials but also on ways to improve my quality of life. This gives me hope that one day there will be a cure for future generations. Without your help to increase funding for research we are further from reaching this goal; the longer we go without a cure the more this disease will cost our country financially. If you know someone with dementia, you know how important it is to find a cure.

I urge you to support research funding for dementia and to make public awareness of dementia a priority on your agenda. By the time you have finished this letter, another person will have been diagnosed with dementia. Dementia affects all ethnicities, cultures, socioeconomic classes, men and women; this disease could affect you one day. Please advocate on behalf of this cause; we all must work together to conquer this disease.

Sincerely,
Members of the Early Stage Memory Loss Education and Support Group at Northwestern University



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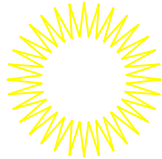
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