



Perspectives

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

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Lost, Stolen, or Strayed

An essay by Brian McNaughton

Brian and his wife, Jean, live in Invercargill, New Zealand. Brian has vascular dementia, which is usually caused by a series of small strokes in the brain.

Contrary to popular expectations, I am still a reasonable, functioning 68 year-old. I eat and sleep unaided, make arguably intelligent conversation, have most of my orifices unhampered by pads, bags, and bibs and am still very efficient at seeing the ridiculous in the words and actions of others (never of myself).

I like to believe I am free to pursue most activities though it disturbs me that even while I am composing this masterpiece, Jean has the builders erecting a high gate to completely secure this property we call home. Her protests that its sole purpose is to keep the southerly gales from our front door are about as believable as my ability to memorize the latest joke sent to me by email.

You need to understand that in July, 2000, while inspecting the images of an MRI scan with Jean and my neurologist, we were to hear this proclamation: "You have the brain of a 76 year-old and it is aging rapidly!" Thus began my plunge into the fascinating world of those of us that have to continue their lives with the

stigma of a dreaded and much maligned condition. I had vascular dementia and this diagnosis would forever change my life and the lives of all who I loved and cared for. The only upside I could see was that I had progressed from youngest to eldest of the family in thirty seconds.

I would be deceiving you to say that our world collapsed at the announcement of this condition. Yes, my professional life as a pharmacist ceased at once (and me only 62 years old), but the rather foolish expectations of a life of continuing leisure buoyed us both for some weeks. With the searching for knowledge about a condition completely unknown to us both came the fear of the future and an even greater fear of the unknown. Lost and stolen? Certainly. Status, position, confidence, and understanding, all placed out of reach and out of sight. Gone. And no one even suggested that it may be worth hunting in the rubble to find the odd link that

might open up a new life in which hope and satisfaction might walk again. Dementia was the complete antithesis of life and hope, so we were lead to believe.

The human spirit is a wonderful concept. The epic journeys of men like Scot and Shackleton, the unbelievable courage of Londoners during the blitz and the sparkle of life and hope in the eyes of a terminal cancer patient. All of these and so many more instances must declare that

(continued on page 2)

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(continued from page 1)

hope and life are never lost. And so it proved to be for Jean and me.

There is a wonderful poem by A.A. Milne in which Christopher Robin asks passers-by what they were going to do “this fine day”, only to receive the expected roles serious people always play. Then he asks a stray puppy:

*“Where are you going to this fine day?”
I said to the puppy as he went by.
“Up to the hills to romp and play.”
“I’ll come with you puppy,” said I.*

If a puppy had the sense to stray up into the hills and leave the somber expected roles behind, then so could Jean and I. And we have. Of course not every day is a day for romp and play. Never the less the anticipation of Jean opening that gate is even more inviting than yearnings for times past.

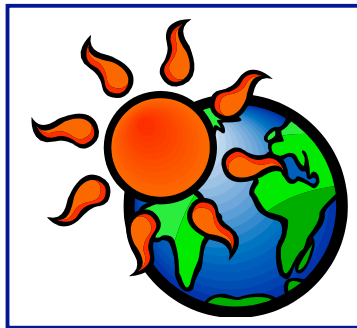
The sun only shines as it pleases and it pleases me greatly to be where I can cast off much of the baggage dementia asks me to bring along, even for just a few hours. Baggage such as loneliness, loss of esteem, fear of rapid downward progress, acceptance that this moment is the best there will ever be and it gets worse from now on. And I have found a strange and exciting fact. The more often I stray from the expected, the lighter my load becomes. Jean postulates that we can forge new pathways in our brains if only we try hard enough and expect to succeed. One way to do this is perhaps to consciously stray from the known way into unknown areas.

My education was centered around the sciences, and language took a very back

seat. Wanting to express my thoughts and demystify this condition has forged new skills and given me a sense of achievement. It isn’t getting easier but I can begin to write with a confidence I have never had before, even if it makes little rhyme or reason to others.

What am I trying to communicate? If we passively shut up shop in the early stages of our disease and just concentrate on what a horrible card fate has dealt us, then we deserve to be miserable and should be ashamed of making the lives of those who love us so stressful. Instead, look for those opportunities to stray from the beaten path. Leave your dark rooms and open your hearts if you have trouble opening your minds. Hard at first I must admit, but easier the harder you try.

I took a phone call yesterday afternoon. A young lady in a car sales firm asked me if Jean and I would care to go to a function at 6:00 pm that night. Yes! We got into our finery and turned up as invited. No function, no guests, nothing. The problem? I had the message wrong as usual. Fifteen minutes later, we were dining together in a pleasant restaurant and thoroughly enjoying ourselves. Off the old pathways, away from the expected roles and we were having a ball.



I would not be so conceited as to put myself up as an example to many. But I can tell you that when the sun does shine, I endeavor to make each spark so real that I can hang on forever. And forever is as long as I can hold on for. What is lost or stolen is lost and stolen. What you are left with is just that. Grasp it with all your heart and have another day in the life of YOU!

MAILBOX



Dear Readers,

This issue of *Perspectives* ushers in two new and exciting changes. For the past ten years, *Perspectives* has been sustained by your subscription fee that covers production and mailing costs. Beginning with this current issue, the Shiley-Marcos Alzheimer's Disease Research Center at the University of California, San Diego, has agreed to provide *Perspectives* as a free email newsletter. Subscribers now have the option of paying to receive the printed newsletter by surface mail, or receiving the newsletter by email for free. This email option makes *Perspectives* available to more people and is a less costly option for many of our readers.

I will finish out all existing surface mail subscriptions and when your subscription has expired, I will renew it based on your choice of free email or paid surface mail. Please feel free to contact me with any questions or concerns about this change.

The second change is evident in the newsletter's colorful new format. This is also made possible through the generosity of the Shiley-Marcos Alzheimer's Disease Research Center. I welcome any feedback you have about this new look or about the content of the newsletter.

Please spread the word that *Perspectives* is now available free of charge by email! Tell your friends, family, or colleagues, to email me at lsnyder@ucsd.edu to subscribe. Thank you for your continued interest in *Perspectives* and as always, I look forward to your correspondence or written contributions for the newsletter.

Best regards,
Lisa Snyder

New Resource



The National Institute on Aging Alzheimer's Disease Education and Referral (ADEAR) has recently published their *2004-2005 Progress Report on Alzheimer's Disease*. This extensive and beautifully illustrated booklet provides summaries of some of the most important federally funded Alzheimer's research advances from the last two years. It also provides an update on research trends in preventing, treating, and ultimately, in curing Alzheimer's and related disorders.

A copy of the *2004-2005 Progress Report on Alzheimer's Disease* can be obtained free of charge by calling ADEAR at 1-800-438-4380. You can also find the full text of the report on ADEAR's new web site at: <http://www.alzheimers.nia.nih.gov>.

ADEAR provides a wealth of resources and information for both families and professionals concerned about Alzheimer's and related disorders and is well worth investigating by phone or through the internet.

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All articles, unless otherwise cited, are written by Lisa Snyder. For citation purposes, refer to the article author, title, and the newsletter's complete name.

Program Spotlight



In a few regions around the world special “cafes” are being developed where people with Alzheimer’s and their families can socialize with one another in a fun and supportive

environment. Inspired by a program that started years ago in the Netherlands, the Colorado Chapter of the Alzheimer’s Association and HealthONE Alliance in Denver, Colorado, have developed their own variation on this concept and call it “Memory Café.”

Memory Café began in October, 2003, and is offered quarterly. The Café provides socialization and an evening of music, dancing, and conversation for people with early-stage Alzheimer’s, their families, care partners, and friends. The program runs for up to two hours, includes a very brief educational presentation and light snacks, and often has a seasonal or holiday theme. It is free of charge and draws, on average, about 70 people. Participants interact in a convenient, comfortable setting where they can enjoy discussion, singing, or dancing with others who share an understanding of Alzheimer’s. There are many repeat participants and as one care partner reported, “The evening brings out the best in my spouse.”

Memory Café rotates to different sites throughout the greater Denver region to provide easier access to as many families as possible. If you would like more information about how to get a Café started in your area contact Pat Holley at the Alzheimer’s Association Colorado Chapter at 303-813-1669.

QUESTION AND ANSWER

Q

I get frustrated when I try to read novels or watch movies because I can’t always keep track of the plot or the characters. Is there any way that I can stay involved with these activities despite my memory loss?

A

Many people find that reading short stories or magazine articles can be more rewarding. If you can finish the article or story in one sitting, you may be more likely to be able to keep track of the content. If you have access to the internet, you might want to explore Amazon’s new Short Stories section. This internet book-seller has started selling short stories from popular authors that you can download from your computer. Each story averages about seven pages and costs only 49 cents. You can review their selections and place your order at <http://www.Amazon.com>.

Some people take a few notes while they are reading so they can remember the main characters of the story or key parts of the plot. You can also try discussing what you are reading with someone else. The communication and mental stimulation may increase your ability to process and retain the material.

Concerning movies, you may want to consider travelogues or documentaries that are not based on a plot as much as on scenery or other action. Sometimes musicals or comedies can be enjoyable because their focus may be more on lighter entertainment rather than complex stories. Also, repetition can enhance learning. If you have a home VCR or DVD player, consider buying some movies for home use. You can watch them as often as you like and the plot and characters will become more familiar to you over time.

National Alzheimer's Association Advisory Group of People with Dementia

On January 30th, 2006, the National Alzheimer's Association convened the first meeting of its new Advisory Group of People with Dementia at its offices in Chicago. This Advisory Group and meeting was spearheaded by the Call to Action petitions circulated last fall by people with dementia, family members, and professionals who wanted to see people with dementia have greater involvement in the mission and services of the National Alzheimer's Association. Kathy O'Brien, former senior vice president of the Association's Programs and Community Services, organized the Advisory Group as a means of opening discussion between people with dementia and the Alzheimer's Association.



The purpose of the nine-member Advisory Group is for the National Alzheimer's Association to gain insight from people with early-stage dementia into their needs and challenges. The Advisory Group will provide feedback on current and potential activities of the Association and help develop recommendations to increase the participation of people with dementia in the leadership and services offered by the Association and its chapters.

After receiving many applications from people across the country interested in serving on the Advisory Group, careful consideration was given to selecting members who will serve for one year and who represent people from diverse geographic and ethnic backgrounds.

In the day-long meeting in Chicago, members of the Advisory Group provided

valuable insights into their experiences of living with dementia and identified the following key suggestions that warrant attention by the Alzheimer's Association:

- ❖ Provide more early-stage services and increase access to those services, especially to people in underserved areas.
- ❖ Change the face of Alzheimer's through media and education to alleviate stigma about the disease and to reflect the earlier stages of the disease rather than just focusing on the late stages.
- ❖ Increase physician education and sensitivity about Alzheimer's and related disorders so that people with dementia don't feel excluded from their evaluations and care.
- ❖ Involve people with dementia directly in the Alzheimer's Association's advocacy and planning work.
- ❖ Team up with other community-based organizations to promote services for people with early-stage dementia.
- ❖ Address the special concerns of early-onset individuals – those diagnosed with dementia before the age of 65.
- ❖ Develop new assistive technologies such as easy-to-use cell phones or computers that could maximize functioning for people with early-stage dementia.

In the afternoon, an NBC Network camera crew filmed the discussion and also interviewed some of the advisory board members independently for future broadcast on the national nightly news. Clearly by their contributions and activism, these advisory board members are already "changing the face of Alzheimer's" and the National Alzheimer's Association has a great deal to gain from their invaluable perspectives and expertise.

Understanding and Participating in Clinical Trials



A clinical trial is a test or study of a new drug, device, or procedure. Some clinical trials test the safety of a medication while other trials test how effectively a medication works in relieving symptoms or providing treatment. A clinical trial may also test new tools or techniques to help with the diagnosis or evaluation of a medical problem.

Clinical trials occur in three phases before any new medication or treatment can be approved by the Food and Drug Administration (FDA). In a Phase I trial, researchers test a new drug or treatment in a small group of people for the first time to evaluate its overall safety and dosage and to identify any side effects. In Phase 2 trials the drug or treatment is given to a larger group of people to see if it is effective and to further evaluate its safety. Phase 3 trials usually involve higher numbers of participants and last longer than the previous trials. They also confirm effectiveness, monitor any side effects, and may compare the new drug with any standard therapy currently being used to evaluate or treat the disease in question. At the end of Phase 3 trials, the FDA has usually collected enough data to determine whether the drug warrants approval.

Clinical trials for new medications have various designs, but usually the most scientifically respected design is a “placebo-controlled double-blind study.” Placebo-controlled means that up to half of the

study participants will be receiving a placebo – a look-alike pill that actually has no active ingredients. This allows the researchers to compare those who receive treatment with those who do not. “Double blind” means that neither you nor the researchers know whether you are receiving the treatment or the placebo. This method assures that there is no bias on the part of the researchers when they are evaluating the effectiveness of the drug.

Some people do not want to participate in a clinical trial if there is a chance they will just be receiving a placebo. It is well documented, however, that people who are unknowingly taking the placebo sometimes experience improvement of their symptoms or condition simply because they believe they are taking something that could be of benefit to them. Also, some receive increased positive attention from repeated visits with the clinical trial medical team and this support can increase feelings of well-being.

All of the currently approved treatments for Alzheimer’s would not be available now without the volunteers who participated in the clinical trials.

All clinical trials have inclusion and exclusion criteria. These criteria are based on your age, health status and history, and other medications that you may already be taking that could interfere with the medication under investigation. If you do not qualify for one trial, you may qualify for a different one, and with rapid advances in science, there are more and more exciting new trials being conducted. Participation in research can be very rewarding for you, your family, and for the benefit of future generations. For information on clinical trials in your area, contact Alzheimer’s Disease Education and Referral (ADEAR) at 800-438-4380 or call your local chapter of the Alzheimer’s Association.

RESEARCH UPDATES

Alzheimer's Disease Neuroimaging Initiative (ADNI)

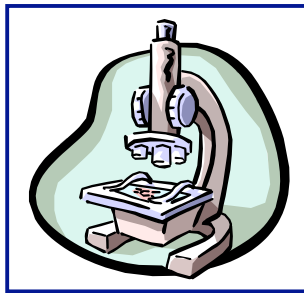
Many scientists believe that early detection of abnormal memory changes is key to better diagnosis, treatment, and possible prevention of Alzheimer's and related memory disorders. One year ago, *Perspectives* featured information on a large new study called the Alzheimer's Disease Neuroimaging Initiative (ADNI) that aims to find the most effective methods for tracking changes in the brain and body fluids of people at risk for, or in the early stages of, Alzheimer's. This ambitious study, taking place in sites across the United States and Canada, is now underway and is recruiting participants. The study needs 200 people with Alzheimer's, 400 people with Mild Cognitive Impairment (abnormal changes in memory or thinking that increase risk for Alzheimer's), and 200 people with no known memory problems.

Neuroimaging involves methods of taking pictures of the brain and includes procedures such as magnetic resonance imaging (MRI), and positron emission tomography (PET). ADNI is using MRI and PET scans, protein biomarkers (substances found in the blood, urine, and spinal fluid), and clinical and neuropsychological evaluations to track participants over two-to-three years. The information obtained by studying changes over time could help doctors and researchers make a more accurate diagnosis of MCI or Alzheimer's, select who may be most appropriate for specific treatments, and monitor treatment effectiveness or re-

sponse. This is a groundbreaking study that will provide crucial information for the detection, evaluation, and treatment, and possible prevention of Alzheimer's and related disorders. If you would like more information about ADNI or would like to be screened for participation in the study, contact Alzheimer's Disease Education and Referral (ADEAR) at 800-438-4380 for the research site nearest to you. You can also find the sites on the internet at <http://www.clinicaltrials.gov>.

Antioxidants and Alzheimer's

There is some research suggesting the benefits of antioxidants in maintaining brain cell health. Antioxidants eliminate "free radicals" from the body. Free radicals are products that are released from normal cells but can cause damage to the cell, or accumulate in the plaques that form in the brain of a person with Alzheimer's. Antioxidants sweep up free radicals and help the body to eliminate them. As such, there is some hope that antioxidants might help to prevent or reduce brain cell damage in people with Alzheimer's.



Antioxidants can be found in many fruits and vegetables or in vitamin or nutritional supplements. This study will investigate whether certain antioxidants (Vitamin E, Vitamin C, alpha-lipoic acid, and Coenzyme Q10) have an effect on cell health that can be measured in the spinal fluid and blood of study participants. The ability to measure these effects will help scientists understand whether antioxidants have a helpful role in the treatment of Alzheimer's. For more information on study sites, contact ADEAR or visit the clinical trials web site (see above for phone and web site information).

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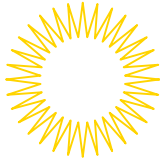
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