Twenty-one months ago I was diagnosed with AD. Since that time, I have learned a number of approaches that may help others. My major purpose in sharing this information is to communicate effective ways to face the realities of AD.

**Approach #1: Do your best to make use of valuable time.**

Avoid feeling sorry for yourself. Instead focus on remaining positive and learning about participating in research studies, especially brain and dementia research studies. A song from the Second World War seems especially germane to a positive approach: “Accentuate the positive, eliminate the negative, latch on to the affirmative, but don’t mess with Mr. In-between.” To illustrate my last remark, Jonah in the whale, Noah in the ark. What did they do when everything seemed so dark? They accentuated the positive, eliminated the negative, latched on to the affirmative, but did not mess with Mr. In-between.

**Approach #2: Take care of important financial affairs.**

Make use of services of an elder care attorney who is experienced in dementia-related issues. Establish a health care proxy, living will, and power of attorney so your wishes will be acted upon. The earlier
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you complete these items, the easier it will
be for those you have delegated to carry
out your wishes.

**Approach #3: Keep your mind as alert and active as possible.**

There are numerous ways to keep your mind active with regular activities, such as crossword puzzles and memorizing items. The AARP website (http://www.aarp.org) is among the better sources for these activities, such as “brain aerobics.”

**Approach #4: Stay healthy by exercise and proper diet.**

Studies have shown that regular exercise when combined with a healthy diet is helpful in keeping your mind alert and able. Your doctor should be consulted if you plan to expand your physical activity level. Many health tips stress that what is good for your heart is good for your brain, including your ability to think and remember. Good sleeping habits help the body respond better to mental activities.

**Approach #5: Volunteer to participate in Alzheimer’s research.**

Boston University and other medical schools are looking for volunteers to participate in studies. Even though participation may not improve your condition, it may help others now and in the future. Positive approaches certainly should take precedence to feeble or absence of effort to confront the realities of your situation.

**Approach #6: Remain as active and social as possible.**

Maintain contacts with old and new acquaintances. Outreach to others will greatly expand your horizons and outlook. Reaching out to others who have Alzheimer’s may serve you well in viewing your own situation from a different perspective. It will assist others in becoming more positive under trying conditions.

**Approach #7: Become as knowledgeable as possible about the status of Alzheimer’s research.**

Seek out this information and ask your healthcare professionals to interpret it for you. The amount of research in this area is staggering. One source of information is the Alzheimer’s Association. Meetings are regularly scheduled by local chapters, which are useful to keep abreast of developments. Periodic appointments with your neurologist are crucial in understanding your condition. The tests that accompany these visits provide ongoing assessment of where you are with the disease.

**Approach #8: Recognize and accept that changes in your emotional and cognitive state are a reality of living with AD.**

One major reality is recognizing that your care partner often has a clearer under-
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standing of your emotional and cognitive status than you do. As a result, you are more aware of changes and their insights help you adjust in a positive manner.

Approach #9: Get help from support groups, family, and friends.

One of the most positive results of writing this essay has been a deeper understanding of myself and the positive responses I have had to the condition. I more deeply appreciate the help provided by my care partner and wife, Patricia, and the value of speaking at programs and to caregivers. As a result, my confidence in living with the condition in a positive manner has been expanded. My appreciation of the support group leaders and the contribution of the support group members are even more significant.

Approach #10: Accentuate the positive.

The most significant aspect of this experience is the way I changed over this period. I find myself crying at heart-rending television programs and movies. Newspaper articles or senseless violence produce a new, but similar type of effect. My desire to help others is expanding, as is my determination to stay positive despite the realities of Alzheimer’s. However, the lyrics of a bygone song remain deeply embedded in my mind. “You’ve got to accentuate the positive, eliminate the negative, latch on to the affirmative, but don’t mess with Mr. In-between.” Remain positive, it does make a difference!

Question and Answer

Q Are there any supplements or “medical foods” that can help to treat Alzheimer’s symptoms?

A There are countless supplements and nutritional drinks that claim to help prevent Alzheimer’s or boost brainpower. To date, there is limited scientific evidence that any marketed brain booster can significantly alter the course or symptoms of Alzheimer’s. Many brain boosters are a mixture of vitamins, herbs, and other substances that have been studied individually without promising results. It is unclear whether a combination of these compounds taken together can produce a more encouraging outcome, but supplements can be expensive and consumer caution is warranted.

A product may be marketed as a “medical food” meaning that it requires a doctor’s prescription. Axona is an example of a medical food marketed for Alzheimer’s. Medical foods are regulated by the Food and Drug Administration (FDA) to some extent for safety, but do not undergo the rigorous trials for efficacy that drugs do. Medical foods aimed at the treatment of Alzheimer’s will likely become more available in the near future and you will need to consult with your doctor about any possible benefits of these products.

Individual response to supplements or medical foods can vary. You may be curious about certain products or perhaps you have experienced a positive outcome from their use. The use of supplements is a personal decision, but it is important to inform your doctor of any nutritional supplements you are taking.
RESEARCH UPDATES

Gammaglobulin Alzheimer’s Partnership (GAP)

The GAP Study will examine the safety, effectiveness and tolerability of Gammaglobulin, a form of Immune Globulin Intravenous (IGIV) in patients with mild to moderate Alzheimer’s.

Antibodies that bind to beta amyloid are present in IGIV, which is made from the blood of several thousand healthy adults. It is hoped that the antibodies in IVIG can help to clear beta amyloid protein from the body and prevent its destructive deposition in the brain. This clinical trial aims to slow the progression of Alzheimer’s rather than just treating symptoms.

GAP is recruiting 360 participants ages 50 to 89 at 36 sites nationwide. This Phase III clinical trial expands on earlier testing, and is part of the final phase in studying IGIV as a potential treatment for AD before seeking approval from the Food and Drug Administration. IVIG has a good safety record and is already approved for use in other medical conditions.

The trial is being conducted by the Alzheimer’s Disease Cooperative Study, a nationwide consortium of research centers and clinics coordinated by Paul Aisen, MD at the University of California, San Diego. For information about this study see: http://clinicaltrials.gov/ct2/show/study/NCT00818662?term=Alzheimer%27s%2C+IVIG&rank=3&show_locs=Y#locn.

Nerve Growth Factor Study (CERE-110) Underway

Alzheimer’s disease results in the destruction of brain cells and the connections between these cells (synapses). Nerve growth factor is a naturally occurring protein that is thought to be able to restore the health of certain brain cells. CERE-110 is an experimental drug designed to help produce nerve growth factor in the brain to enhance brain cell function and to prevent further damage to cells. Ceregene, the company, that makes CERE-110, and the Alzheimer’s Disease Cooperative Study have embarked on a clinical trial of nerve growth factor that aims to arrest disease progression for a period of time rather than simply treating symptoms.

This study is more complex than most clinical trials in that it requires a brain surgery procedure to deliver the CERE-110 compound into the regions of the brain thought to be most affected by Alzheimer’s. This procedure has undergone initial safety studies in animals and humans and is now in a Phase 2 study to further evaluate safety and efficacy.

Fifty participants with mild-to-moderate Alzheimer’s are being enrolled around the country. Although all of the participants will have a surgical procedure, only half will receive actual treatment. If this study proves to be as beneficial as preliminary trials have shown, all study participants will eventually be given the actual treatment.

For more information on this clinical trial, contact Sarah Walter at 858-622-5863 or Lisa Ann Melia at 858-458-8848, or see http://clinicaltrials.gov/ct2/show?term=CERE-110&rank=2.
How to Save Money on Prescription Drugs

Everyone is looking for ways to economize, and the medicine cabinet is a great place to begin. Consider the following ways to evaluate your prescription drug costs and take action to save money:

1) Ask for generics – Some physicians prescribe medications without offering a generic option. Not all prescriptions have an available generic, but there is usually a significant cost savings if they do. Ask your doctor or pharmacist to review your medication list with you to determine any generic options.

2) Check for over-the-counter options – Some medications that used to be "prescription only" may be available over-the-counter (OTC). Check with your pharmacist to determine if the kind of medication you need is available in a less expensive non-prescription form. Confirm with your physician before making any changes from prescription to OTC medications.

3) Look into retailer discounts - Major retailers including Wal-Mart and Target offer a host of generic prescriptions for as little as $4 per month, and $10 for a 3-month supply. These are the costs without insurance. Go to each retailer’s website where they publish current lists of the drugs available for lower prices.

4) Buy in bulk - Many insurance plans offer mail-order pharmacy options where you can purchase a 90-day supply of medications at a lower cost than if you were to pay a monthly co-payment at your local pharmacy. Call your insurance company to find out if they offer this.

5) Evaluate your Medicare D plan - Not all prescription drug plans under Part D are created equal. The Medicare website offers a "formula finder" where you can enter your medication list and it will produce a list of the plans that cover your prescriptions. http://www.medicare.gov/. You then need to call each plan to discuss the premiums and co-pays. If you have not enrolled in a Medicare prescription drug plan, you can enroll during the Annual Election Period that runs from November 15th - December 31st. If you have a Part D plan and are trying to manage your out-of-pocket costs, AARP has a "doughnut hole" calculator to help you determine your prescription drug costs at http://doughnut.hole.aarp.org/

6) Look into Patient Assistance Programs – If you are uninsured or have very limited income some pharmaceutical companies may provide medication free of charge. NeedyMeds is an informative nonprofit organization that helps low-income or uninsured patients connect with various programs that may provide financial assistance with medications. http://www.needymeds.org.

7) Reduce consumption – Ask your doctor if there are lifestyle or dietary changes, including exercise and stress reduction, that might help you to reduce your need for certain medications. The more medication you take, the more potential for side effects and drug interactions. Reducing the drugs you take may help your health as well as your wallet!

Editor’s note: This article is revised from a posting by Susan Soest Valoff, LCSW from the Elder Care Guides care management blog on August 11th, 2009. We are grateful to Elder Care Guides for permission to reprint this content.
Living Words
Writing to Improve Lives
By Joyce Finkle

The Alzheimer’s Association South Carolina Chapter and its early-stage dementia and caregiver’s support group has had the privilege of working with our local Wofford college as well as the Hub City Writer’s Project from Spartanburg, South Carolina on a project we call Living Words. Caregivers from our early-stage support group had expressed the need for more activities for their partners with Alzheimer’s and for creative things to do together. We looked at this request as a challenge and found that when needs are addressed creatively, excitement and energy accompanies the efforts.

We developed Living Words as a way to involve local writers who had sensitivity and awareness about dementia and who could lead persons with dementia and their caregivers in a variety of writing exercises. Living Words is comprised of two parts. The main part is a 10-week, one-hour a week workshop model, with volunteer guest writers who guide participants in a variety of writing exercises about particular emotions, insights, or memories. The styles and topics selected for the series include childhood memories and life experiences, haiku, creative fiction, nature writing, and poetry. Shared reminiscences, laughter, and fellowship precede the writing activity. The workshops are designed to be fun and failure-free.

Lane Filler, a guest writer at a workshop writes: What was most compelling to me about doing a writing exercise with folks suffering from Alzheimer’s is that I tend to think of sufferers of that disease as people who have lost their memory. They haven’t of course. They have simply lost their moorings...They remember their deep past as clearly, actually more clearly, than I remember yesterday and it was a privilege to be transported back with them.

Peggy Jones is living with dementia and participated in a writing workshop. She wrote a story relating to something she was good at. In the first part of the writing session, she shared that she was a good mother and nurturer, even in difficult situations. She wrote the following story that illustrates this skill:

My oldest son’s name is Russell. We call him Russ. He was always a very mischievous child. All my life I knew that the greatest thing that could happen to me would be to have a son.

He was always into something. I went into the kitchen one day and he was pouring syrup in circles on the eyes of the stove. I yelled out, “Russ, what are you doing?” He looked up at me with a sweet little smile and a twinkle in his eye and said, “Momma, I’m makin’ pancakes for you.”

He would always say the sweetest things so I couldn’t punish him – and he still loves his momma.

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The second component of Living Words is a blog of writing samples from people who attended workshops, instructors, and others. You can read our blog at http://blogs.wofford.edu/living_words/. One caregiver, Marlu, writes:

*Buddy had a difficult time accepting the diagnosis. It took about one year before he finally accepted it. It was difficult for me because I couldn't talk about it with anyone. Buddy had to accept it first. He would not want anyone feeling sorry for him so I knew he would have to accept it; then he could talk about it and face it head on. He had to be able to tell my daughter and his son so they could see that he was going to be okay as long as he had anything to do with it.*

*We talked about it often. When he found things that became difficult for him, I always made light of it. I've never taken myself too seriously, but it was going to be a change for him.*

*I tried to think. “If the table was turned, what would I need?” I knew it was extremely important that he keep his dignity. If I could help him do that, he could accept his diagnosis.*

If you would like to learn more about Living Words or about why we think this program is so valuable, contact us at http://www.livingwordsprogram.com. Information and instructions from ten different workshop sessions can be used by those who want to start their own workshops. Our program organizers will provide technical assistance and evaluation tools.

Questions? Comments? Contact us at our website and let's all get writing!

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Speaking Our Minds
What it's Like to Have Alzheimer's
Revised Edition

By Lisa Snyder, MSW, LCSW

Gain insight into the experience of living with Alzheimer's by reading this collection of first-hand accounts. Speaking Our Minds was first published in 1999 and is now available in an updated edition through Health Professions Press. The book provides a view into the day-to-day experience of Alzheimer's through the reflections of seven diverse individuals who share their thoughts, experiences, and feelings about living with memory loss and other symptoms.

By interweaving each person’s responses from in-depth interviews with her own comments, the author explores the many dimensions of the Alzheimer's experience. Readers can learn more about:

- The uniqueness of each person’s experience and symptoms
- Coping strategies people use to face challenges and losses
- The changes that are experienced as the disease progresses
- How to identify with and listen to persons with Alzheimer's

Discussion questions provide material for use in support groups or trainings and classes about Alzheimer’s. Speaking our Minds - What it’s Like to Have Alzheimer's is available through bookstores, online, or through the author. A portion of proceeds from books purchased through the author goes to the UC San Diego Shiley-Marcos Alzheimer’s Disease Research Center. Contact Lisa Snyder at lsnnyder@ucsd.edu for more information or to order a copy.
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