



Perspectives

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

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Understanding the Booming Business of “Brain Boosters”

A growing number of supplements and nutritional drinks are being marketed as elixirs that can stimulate thinking abilities, prevent or treat memory loss, or boost brainpower. For most consumers, it can be hard to tease out fact from fiction about these claims. Given that the current treatments for Alzheimer's are limited and clinical trials of promising drugs can be painfully slow, it is likely that more and more people are going to seek out supplements in the hope of boosting their brain function. This article provides a brief overview of the types of brain boosters currently available and what one might realistically hope to gain from their use.



Supplements and Nutraceuticals

Many brain boosters found in health food stores or through other distributors are mixtures of vitamins, herbs, and other substances that may have been studied individually in people with Alzheimer's without promising results. For example, many brain boosters include Omega 3 fatty acids (specifically DHA) or ginkgo biloba even though neither of these compounds has been shown in large, well-conducted clinical trials to be effective in treating Alzheimer's. It is unclear whether a combination of these ingredients taken

together can produce a more encouraging outcome, but supplements can be expensive and consumer caution is warranted.

The Food and Drug Administration (FDA) does not review data on the effectiveness of nutritional supplements or “nutraceuticals.” The manufacturers of nutritional supplements are not required to provide the FDA with any evidence of a product's safety or ability to provide significant treatment. Thus consumers may be enticed by the effective marketing of claims based on little or no research. The makers of a supplement cannot advertise that the product can treat a specific disease such as Alzheimer's (because this has not been rigorously proven), but they can, however, make more general claims about the supplement's benefit to “memory function” or “brain health.”

To add to the confusion, a substance may have undergone clinical trials to determine efficacy in treating Alzheimer's, but when results are found to be negative, it may then be marketed as a supplement that does not require FDA approval. For example, Alzhemed, a promising drug for treatment of Alzheimer's underwent a series of large and reputable clinical trials to determine both safety and efficacy. The drug disappointed many when the clinical trial outcomes ultimately did not reveal

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“Brain Boosters”

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significant benefit compared to placebo and therefore there was no justification in approving the drug for treatment. The makers of Alzhemed went on to reintroduce the drug to the public as a supplement called Vivimind™ that now sells in Canada and over the internet as a brain booster.

Because there is no FDA oversight, the purity or potency of supplements and nutraceuticals can vary considerably between manufacturing brands and there is currently no scientifically based recommended dose of these supplements for people with Alzheimer’s. Many people assume that if something is “natural”, it can’t be harmful, but some supplements do have side effects or inter-

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actions with other medications that could compromise your health.

Individual response to supplements can vary. Some consumers may feel they are benefiting from a particular supplement by feeling more alert or energetic. Sometimes just the thought that you may be doing something beneficial for your brain can lead to a feeling of improved mood or thinking. To date, however, there is limited scientific evidence that any marketed brain booster can sig-

nificantly alter the course or symptoms of Alzheimer’s, and certainly there is no supplement that can provide a cure.

You may be curious about the marketed benefits of 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 or other health care provider of any nutritional supplements you are taking so any positive or negative effects can be monitored.

The Emergence of “Medical Foods”

A medical food (a category defined by the FDA) can be marketed as treatment for a specific disease and aims to provide a nutritional means of treatment that cannot be derived from regular food consumption. For example, levels of glucose (an energy source) are reduced in the brains of people with Alzheimer’s. A product called Axona™, a powder mixed with water to make a beverage, aims to compensate for this reduction by providing an alternative source of energy to the brain. Axona is marketed as a medical food to

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treat Alzheimer’s. A controlled clinical trial of Axona in persons with Alzheimer’s suggested that there may be a cognitive benefit at 90 days, but this was not apparent after 180 days of treatment.

Medical foods require a prescription from a doctor. Medical foods are regulated by the FDA to some extent for safety in that they consist of ingredients “generally recognized as safe” (GRAS), but do not need to undergo the rigorous trials for safety and efficacy that drugs do. At present, the Alzheimer’s Association does not endorse the use of Axona as a treatment for Alzheimer’s, but some physicians are beginning to prescribe the medical food to patients who are seeking any possible benefit. Use of Axona can produce side effects including diarrhea, so ongoing medical observation is important.

Other medical foods aimed at the treatment of Alzheimer’s will likely become available in the near future. See page 6 for a clinical trial currently being conducted on Souvenaid™, a once-a-day milkshake formula made up of ingredients (including DHA and anti-oxidants) said to help maintain healthy neurons (brain cells) and synapses (the connections between brain cells).

It is important to consult with your doctor about any possible risks or benefits of these products. The use of nutraceuticals and medical foods may interfere with your participation in other hopeful clinical trials aimed at treating or slowing the progression of Alzheimer’s, so it is important to weigh your decisions carefully when exploring alternative therapies.



Caring Tips From Individuals with Alzheimer’s

Participants in the Alzheimer’s Association Colorado Chapter support groups for individuals with Alzheimer’s or a related disorder contributed the following tips to help others know ways of being helpful to someone with Alzheimer’s:

Don’t plan too many things in one day.

Give me time to try something; don’t take over.

Talk to me directly.

Never ask, “Don’t you remember? It makes me feel stupid and belittled.”

It is okay to use humor with us.

Please let me finish my thoughts without interrupting me. When I’m interrupted, I go blank.

It is not “Old Timer’s disease.” We can be young and get it. It is not our fault.

Have patience with me. I might have to review things three or four times.

I don’t like it when they tell me they’re “caretakers.”

Avoid giving orders or advice too much. Use please and thank you.

My hands no longer obey my brain. It comes and goes.

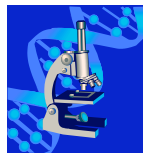
Avoid constant reminders that I am not moving fast enough.

Remember it is a pleasure to have people visit. It helps if it’s a potluck and they wash the dishes.

The support of others gives me hope.

We realize how important family and friends are and their sacrifice. It’s not pleasant to have Alzheimer’s, but we appreciate all that people do.

RESEARCH UPDATES



Dominantly Inherited Alzheimer's Disease Network (DIAN) study

The National Institute on Aging (NIA) is funding a collaborative, international study that links research sites in the United States, England, and Australia in an effort to better understand the genetics of early-onset inherited Alzheimer's disease (AD). This rare form of AD generally affects individuals under age 60 and often has an age of onset in the 30s or 40s. Multiple family members can be affected and children of these early-onset parents are at much greater risk of developing AD.

DIAN is a 6-year study that aims to enroll adult children of people with early-onset AD in order to identify the sequence of brain changes in these individuals before symptoms outwardly appear. Because these genetic forms of AD account for fewer than 5% of all cases, research into inherited early-onset AD has been hindered by difficulty getting enough people enrolled for research. This international collaboration attempts to overcome these barriers by enrolling participants from three countries in one study. Study participants will have genetic and cognitive testing and brain scans, and will also provide blood and cerebrospinal fluid samples. By being able to gain greater understanding into the earliest possible changes in the brain of someone at risk for genetic early-onset AD, scientists hope to learn more about all forms of AD so that therapies can be developed to delay or even prevent disease progression.

For more information about DIAN, visit <http://www.dian-info.org> or contact Wendy Sigurdson at 314-362-2256.



Souvenaid Clinical Trial

Results from a large randomized, double-blind, placebo-controlled, study of Souvenaid, a nutritional drink for people with Alzheimer's, were recently published in the journal *Alzheimer's and Dementia*. The objective of the trial was to restore synapses (the connections between brain cells) in persons with AD by providing a variety of nutrients which Souvenaid contains.

Researchers enrolled 225 people with mild AD who were randomly assigned to take a 125-milliliter dose of the cocktail once a day, at breakfast, or a similarly packaged drink without the active ingredients (placebo). Although some results on memory performance were encouraging, there were no significant benefits in improved thinking or functioning in persons who received the supplement.

Two additional trials with Souvenaid are now underway in the US and in Europe in the hopes of more promising results. For more information on these clinical trials see <http://www.souvenaid.com/>.

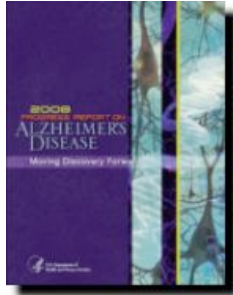


Generic Form of Aricept Approved

In December, 2009 the Food and Drug Administration (FDA) announced the approval of a generic version of Aricept that will be available through Mutual Pharmaceuticals at the end of 2010. The generic medication will dissolve on the tongue and be of particular benefit to persons with Alzheimer's who have difficulty swallowing pills. Generic drugs are usually less expensive, too, which could provide welcome relief for those with high prescription drug bills.

HELPFUL RESOURCES

2008 Progress Report on Alzheimer's Disease: *Moving Discovery Forward*



Alzheimer's disease research is moving forward in many scientific domains. Although progress can feel slow to those experiencing the impact of Alzheimer's or a related disorder, each year

there is progress made that provides new knowledge to pave the way for advances in diagnosis, treatment, and perhaps one day, prevention of the disease. The National Institute on Aging is the primary Federal agency supporting research in Alzheimer's disease and age-related cognitive change. The National Institute on Aging's annual report on Alzheimer's disease research is now available online.

The latest report, *2008 Progress Report on Alzheimer's Disease: Moving Forward in Discovery*, summarizes current scientific directions and highlights findings from research funded by National Institutes of Health (NIA) through the year 2008. Highlighted topics include progress in laboratory science; genetic and non-genetics causes and risk factors; advances in methods of diagnosis; the search for effective therapies; updates in clinical trials; and coping and caregiver support.

This year's report is available online on the NIA website. Due to budget cuts, single printed copies are not available. To download or read the *2008 Progress Report on Alzheimer's Disease*, go to <http://www.nia.nih.gov/Alzheimers/Publications/ADProgress2008>.

The Calm Before the Storm - *Family Conversations about Disaster Planning, Caregiving, Alzheimer's Disease, and Dementia*



The recent devastation in Haiti reminds everyone around the world that we are all vulnerable to the unpredictable and potentially tragic consequences of a natural disaster. Surviving

and recovering from a disaster can create particular challenges for persons with Alzheimer's or a related disorder and for their families. It is important that families consider strategies for managing potential natural disasters and to have – to the extent possible – a plan of action in the event of an emergency.

The Hartford Financial Services Group and the Massachusetts Institute of Technology (MIT) AgeLab created *The Calm Before the Storm: Family Conversations about Disaster Planning, Caregiving, Alzheimer's Disease, and Dementia*, a comprehensive 40-page booklet to help persons with dementia and their families better plan for natural disasters. The booklet includes a wealth of helpful and thoughtful information as well as a variety of worksheets, checklists, and resources.

Download or order a printed copy at: <http://www.thehartford.com/calmbeforethestorm/index.html>. Booklets can also be requested by writing to:

The Hartford
The Calm Before the Storm
200 Executive Boulevard
Southington, CT 06489

Include your complete address and requested booklet quantity.

The Memory Fitness Center

A Comprehensive Activity-Based Program

The Muller Center for Senior Health, Abington Memorial Hospital in Abington, Pennsylvania developed the **Memory Fitness Center** program in 2009. The Memory Fitness Center provides a program designed to reinforce memory skills of older adults experiencing memory loss and/or those who have been recently diagnosed with Alzheimer's, a related dementia, or mild cognitive impairment. Participants in the program do not need the services of a traditional adult day program, and would in many cases feel out of place in such a setting. They do, however, need more support and more meaningfully structured activities than general senior centers provide.

The Memory Fitness Center provides sessions that are four hours long, three days each week. Participants choose their schedule. Activities provide cognitive stimulation, physical exercise, and an opportunity for socialization with peers. Program activities include games, puzzles, current events, music, exercise, book reviews, speakers, community outings, and inter-generational groups. These, along with support and friendship from others in the group, help participants feel more confident and comfortable in social situations.

Family caregivers have noted that participants who had withdrawn from former activities are more comfortable resuming them. Participants also join our group activities with enthusiasm, taking pride in learning something new and in contributing to discussions. They state they look

forward to the meetings and are eager to discover what each day's activities entail. Comments include:

"I love coming here; I look forward to it and I always feel good when I am here."

"I didn't think I could still solve a puzzle, but I did!"

"Now I know I can still learn something new, and that makes a big difference to me. I feel good about doing something to help myself."

Family care partners have also provided positive feedback. Comments include:

"I see such a difference in my mother on the days she comes to the program; she is more alert and much more responsive."

"When Ed gets up on Tuesdays he wants to get ready quickly so he won't miss his class; he has become much more confident."

"My mother even tries to answer questions on Jeopardy now; she says she feels she knows things again."

The Memory Fitness Center offers a monthly support group for those with memory loss and their family members. A facilitator leads each group meeting, enabling care partners and individuals with memory loss to meet separately with their peers and discuss feelings openly and honestly. Speakers are scheduled on topics of interest to group participants. The group is open to all in the community.

For more information about the Memory Fitness Center, contact Kathy Rovine, CTRS (Certified Therapeutic Recreation Specialist) at 215-441-6888 or email her at krovine@amh.org.



ALZ is Not About Me, You See

By John Dana MacInnes

ALZ is not about me,
at least as far as I can see;
ALZ is about those I love
and how happy they can be.

ALZ is not about me...

I have had my day in the sun,
and am proud of what I have done;
But now those days are on the wane,
and others have their chance to shine.

ALZ is not about me you see...

Fondly I recall two wonderful marriages,
both too short,
and a loving family of children,
grandchildren, and great-grandchildren;
Long will I remember churches well-built,
camps filled with children,
and teens having a ball;
And problems in an urban center made
better one-by-one.

Now I rejoice in seeing a library emerging
into a whole fantastic new building,
and a new team of trusted Trustees
to guide its new day;
Nor does Oakland Housing Inc.
any longer depend on my prime
as they have a great new leadership cadre
and a vision that's fine.

You see, ALZ is not about me...

My shining days may be dimming,
but life for me is not done.
May God grant me peace,
whatever those sunset days may bring,
As I've always loved the sunset's glow.

ALZ is not about me, you see...

Editor's note: John is a former Pastor and was President of United Community Services of Metropolitan Detroit. He served on the Board of Oakland Housing in Michigan and was President of his local Library Board of Trustees. He is now serving on the Alzheimer's Association's Early-Stage Advisory Group and resides in Michigan.



Brainstorming

We asked people with early-stage Alzheimer's: "What advice would you give to someone who is newly diagnosed with Alzheimer's or a related disorder?"

"Don't try to make big changes in your life right away. Things will change, but not all at once."

"Find a support group so you know that you're not the only one."

"Get out of the house, stay active, and meet people."

"Know that you can't do everything on your own now and sometimes you don't always know what you can or cannot do. Don't be afraid to ask for help when you need it"

"Focus on doing things that you can do."

"Don't worry too much and don't be ashamed. Alzheimer's is something that happened that you can't control. Don't give up on having a good life!"

"Be open about the transition you are going through. I know my wife will eventually have to do more of what I used to do (like the checkbook), but it's gradual, so I'm including her more in the transitions."

"Don't think of it as a 'take over' when someone else offers assistance. It's a partnership when you get assistance. Become partners."

"Maintain a sense of humor! That's the most important piece of advice of all!"

Editor's note: We gratefully acknowledge the participants of the early-stage support group at the University of California, San Diego Shiley-Marcos Alzheimer's Disease Research Center for offering this wise advice to others.

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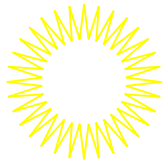
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