



The National Aphasia Association
 a•pha•sia (uh-fay'-zhuh) n. An impairment of the ability to use or comprehend words, usually acquired as a result of a stroke or other brain injury.



Celebrating Our 20th Anniversary ~ 1987-2007

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October 2007

NEWSLETTER

MESSAGE FROM THE PRESIDENT OF THE NAA

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As the weather turns cooler (for some), things at the NAA are “heating up.” We are involved in many activities to raise awareness of aphasia. We are excited about exhibiting at the American Speech Language-Hearing Association Annual Convention in Boston next month. This is a wonderful opportunity for us to be visible and network with more than 12,000 people. Our participation in the Combined Federal Campaign (CFC) is in full gear and we have been attending many informational fairs throughout NYC to let people know about the NAA and aphasia. We continue to increase our collaborative efforts with various related associations as there is “strength in numbers”!

Our Annual Appeal letters are on their way and we hope that we can count on your generosity this year as well. Our efforts would not be possible without your continued support. As always, feel free to share this newsletter with others who might be interested and direct them to our website www.aphasia.org and our resource line (800) 922-4622.

We are always anxious to hear from you and we are proud to be able to serve you!

Best Regards,
Barbara C. Martin



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APHASIA AND EMOTIONS!

**Dr. Alizah Brozgold is a Rehabilitation Psychologist at
St. Vincent's Hospital Manhattan and
a member of the NAA Multicultural Task Force.**

Depression and sadness are common emotional changes after a stroke. Other common reactions are: intense anger and frustration, refusing to accept the changes caused by the brain injury, and also a kind of reflex crying that may not match the mood or situation. For example, someone may begin crying while talking about even a happy occasion. When you ask if they're feeling sad, they will tell you that the crying just 'came on' but that they were not feeling sad at that moment.

Now you may be thinking at this point: "Well, of course people are depressed after a stroke. Who wouldn't be?" These emotional changes are normal reactions to a terrible experience. This is true. At the same time, emotional changes are also caused by the damage in the brain left by the stroke. Just as the brain controls our arms and legs, it also controls our emotions and behavior. These emotional changes can also recover over time along with the physical recovery. Many people with depression after stroke are also helped by taking medication to improve their mood and outlook.

When people with aphasia have a strong emotional reaction, they are often unable to use words to express it. This can be especially frustrating and leave the person feeling very upset, helpless, and out of control. With time and recovery, the ability to put strong feelings into words can return, although this can remain an area of frustration for people with aphasia.

How do you deal with the emotional changes after stroke?

Here is a list of recommendations for you:

1. Give yourself time. There is a wonderful Ethiopian proverb: "Slowly, slowly even an egg begins to walk." The process of rehabilitation and recovery takes enormous patience and determination.
2. Find out as much as you can about aphasia, stroke, and the emotional changes that go with them.
3. Accept help from your friends, relatives, therapists, and doctors. Remember that we all take turns needing help and support. Give the people who love you the chance to 'give back' some of the support you gave them at an earlier time.
4. Meet and talk with other stroke-survivors and co-survivors in a support group near you.
5. Find a therapist to talk to about your emotional changes. There are psychologists who specialize in working with stroke survivors and people with aphasia.
6. Express yourself in other ways if you are unable to speak: dance, sing, write, play a musical instrument, etc.
7. Find ways of lowering your stress and anxiety – exercise, prayer, yoga, meditation, acupuncture, etc.
8. Remember: "A stroke is something that happens to people. The stroke is *not* the person."

WE NEED YOUR INPUT!!

The National Aphasia Association (NAA, www.aphasia.org) has recently created a Multicultural Task Force. The purpose of this group is to enhance the understanding of aphasia and its clinical services when working with individuals from linguistically and culturally diverse backgrounds.

One of the goals of the task force is to create a database with resources for clinicians and clients and their families. We would be interested in hearing from you regarding your needs as a bilingual speaker and/or minority individual with aphasia or as a professional working with bilingual speakers and/or minority individuals with aphasia.

Please let us know what you think may help your work with persons with aphasia from culturally and linguistically diverse groups. Also, let us know what kind of information you may need from an organization like the NAA as a bilingual and/or minority person with aphasia

Please send your thoughts to Ellayne Ganzfried, Executive Director, NAA,
at ganzfried@aphasia.org .

THE NAA GOES TO BOSTON!

For the 1st time in 16 years-the NAA will have a formal presence at the American Speech-Language-Hearing Association (ASHA) Convention to be held in Boston, MA on November 15-17. We will have a Booth in the main Exhibit Hall and will be distributing information packets and other goodies! If you are attending the convention, please be sure to stop by and say hello-we will be in Booth 1400.

We also need volunteers to help “man” the booth during the Convention.

Please email Ellayne Ganzfried at Ganzfried@aphasia.org

if you can spare an hour or so and help raise aphasia awareness!

Several “friends” of the NAA are presenting at the Convention on a variety of relevant topics. There are too many to mention (don’t want to forget anyone) so check your Convention Program for details.

We want to feature information about ALL Aphasia Groups ,Centers and events

so please email us at naa@aphasia.org with your announcement or

an article of interest about your program.

You can also visit our website www.aphasia.org for all current listings.

Speaking Out! 2010 NAA is Seeking Co-Sponsors

We are still working on Speaking Out 2008 but we need to plan for the future!

Please consider being a co-sponsor for Speaking Out 2010.

The National Aphasia Association is seeking a Co-Sponsor for the Speaking Out! Conference to be held in 2010. The Co-Sponsor can be a clinic, hospital, non-profit organization, university or other academic institution, or consortium of local organizations and/or agencies. The Co-Sponsor jointly plans the Speaking Out! Program with the National Aphasia Association, has sole and complete financial responsibility for implementation of the program, and is featured in all marketing efforts.

The National Aphasia Association is soliciting proposals for potential co-sponsors.

Preference will be given to Co-Sponsors from the Western United States.

We are seeking co-sponsors who can:

- ⇒ develop and implement a program oriented to both consumers and professionals, which is consistent with the goals of NAA;
- ⇒ demonstrate the ability to handle local arrangements and logistics required for a conference of 200-400 individuals;
- ⇒ work cooperatively with NAA to maintain the established identity of the Speaking Out! Conference, while adding innovation and creativity to the conference

The benefits of co-sponsorship include:

- ⇒ national and local media attention
- ⇒ the opportunity to establish a national network which features the NAA
- ⇒ a major contribution to public, consumer, and professional education about aphasia
- ⇒ an educational opportunity for all members of the organization

Final proposals will be due by March 1, 2008 and the co-sponsor will be selected during the spring of 2008.

The co-sponsor for 2010 will be announced during the Speaking Out! 2008 conference in

New York City, NY June 19-21, 2008

For more information about co-sponsorship, please contact:

**Ellayne Ganzfried, Executive Director
NATIONAL APHASIA ASSOCIATION
(212) 267-2814
ganzfried@aphasia.org**

Click on the link below to read a wonderful article called

“Caring for Those Without Words”

written by John Liechty, an NAA Advisory Council member.

The article appeared in the October 2007 issue of the Journal of Neuroscience Nursing.

http://www.aphasia.org/aphasia_community/aphasia_community.html

Brain On Strike-Part 1—By Ethel Lee-Miller

“I am moved to send you my essay because of the incredible pride feel and I hope I see in the lives of my sister Eileen Erickson and her husband, Paul Benson. Paul has been recovering with aphasia for two and a half years and his recovery offers such hope for others who may still be suffering alone. It is my hope that you will find room for this 1400 word essay in your NAA newsletter. Both Paul and Eileen have edited and approved this article. Thank you for the opportunity to join in as an advocate for aphasia education.” Read Part 1 in this newsletter-Look for Part 2 in next month’s newsletter!

Brain On Strike-Part 1—By Ethel Lee-Miller

In January 2005 some of my brother-in-law’s brain cells went on strike. He went in for a routine surgery. And those pesky brain cells, they kicked back, folded their little brainy arms, put their feet on their gray matter desks and said, “We’re done.” Some of them not only kicked back. They kicked—completely. Paul had a series of strokes, which turned his world upside down.

When I met my sister at the hospital that day, we went to the Intensive Care Unit and saw my usually smiling, healthy brother-in-law hooked up to more machines and wires than Dr. Frankenstein could have rigged. Paul’s eyes followed my twin sister as she rushed to the side of the bed.

“Paul! Paul, are you all right?”

“Yes, thanks,” came his strangely flat reply.

Whew! Eileen and I looked at each other. He’s here. He’s alive! Relief.

But his right arm didn’t move. He couldn’t wiggle his toes.

And when we spoke...

“Paul, what did the doctor tell you?”

“Yes, thanks.”

“Paul, Where is the doctor?”

“Yes, thanks.”

Whoa. This is odd.

Over the next few weeks, months, one year, then two years, with daily therapy, Paul regained the abilities to stand, walk, move his hand, and speak more, gaining strength and mobility. To all who *see* him he *is* the old Paul. But there’s that odd speech quirk. ***Aphasia- a communication disorder arising from brain trauma that damages the language areas of the brain. Does not affect a person’s intelligence.***

Paul has what is known as fluent aphasia. Every few sentences he hits a blank wall in speech. The word he wants is locked in the cerebral files and those brains cells are still perversely on strike. Months of speech therapy attempted to train other cells to operate to handle the workload, but you know as well as I that replacements are never the same as the originals, and not as reliable either.

“I can see the word in my head,” Paul said, looking up.

‘We have to get to the airport early for the baggage’ came out as ‘We have to get there early for the ballgame.’ This was followed by a surprised or disgusted look on his face, depending on his coping skills that day. Odd quirk indeed. A huge quirk.

This is a man with amazing coping and compensation skills. A former pilot, flight instructor, motorcycle safety instructor, artist, and cartoonist, Paul uses cues from his life to aid conversation. In the first year of recovery, he started sketching quick, little US maps on a pad of paper he kept with him to pinpoint the exact location of what he was talking about.

“Oh, you mean Frank, in Arizona.”

“No, no,” he says impatiently, jabbing at his map, “Farther west.”

“Oh, you mean your friend in Oregon.”

“Yes, yes,” he says delightedly, with a big smile.

He pulls bits of information from my life to expand what he is trying to explain to me. “She’s in the same state as your stepdaughter.”

“Oh, Connecticut.”

“Yeah.”

He has a new quantitative vocabulary. **“Rich’s daughter is 10, 11, 12, 13, 14, 15, 16, 17...17 years old.”**

He resolved daily, and still does, to do physical therapy, occupational therapy, speech communication classes, vision therapy, to take yet another blood test, brain test, eye test, or speech test. He writes his name over and over on primary-lined paper. He sits with his reading instructor, who is an aphasia success story, reading slowly aloud. He relearned the sequential steps of making a cup of tea for himself. He is determined not to let this monster brain disorder conquer him.

The Brain on Strike Part 2— to follow in next month’s newsletter

NEWS AND NOTES

⇒ **GoodSearch.com** is a new search engine that donates ad revenue, about a penny per search, to the charity its users designate. Use it just like any search engine, and it's powered by Yahoo!, so you get the same great results.

⇒ **SPEAKING OUT 2008** to be held June 19-21, 2008 at New York University. Stay tuned for program information and registration details. Call the NAA office at (800) 922-4622 for more information.

⇒ **The NAA IS LOOKING FOR VOLUNTEERS TO ASSIST WITH OFFICE ACTIVITIES. Call us at (212) 267-2814 if you are interested**

⇒ **Lookin' For Me (1997)** –Now Available on DVD

Interview with three persons with aphasia produced for local cable channel in Portland, OR, in cooperation with NAA State Representative Sandra Neuburger, M.S., CCC-SLP, for National Aphasia Awareness Week in 1997.

⇒ **Stroke of Genius screening and concert** in Los Angeles, November 14th, at UCLA. It will feature Marc Black playing songs off the Stroke of Genius CD, a presentation of the documentary with a question and answer session and an appearance by Dan Mountain, subject of the documentary. The show will be presented with assistance from UCLA, the [National Aphasia Association](#), and the [National Stroke Association](#). Contact marcblackmarc@aol.com for more information