Happy New Year!

Hope this year has started out well and we wish you and your family all the best in 2009!

The NAA is gearing up for a productive year. Our Emergency Responder project is in full swing and we had two successful trainings with the New York City Police Department. We have recently scheduled trainings in New Jersey. Plans have begun for our 2009 Benefit which will coordinate with National Aphasia Awareness Month in June. The NAA has been invited to present and exhibit at several state speech and hearing association conferences during this year. We are cosponsoring the Midwest Regional Aphasia Conference in Toledo, Ohio in October and hope to plan at least one more regional event in 2009. The Multicultural Task Force (MTF) continues to develop resources that are culturally sensitive and available in various languages. We also plan to do several surveys this year to determine how we can best meet your needs.

We are excited about our goals and we welcome you to join us. There is much more that can be done when we work together to raise awareness of aphasia and advocate on behalf of persons with aphasia and their families!

Share this newsletter with others who might be interested and direct them to our website www.aphasia.org and resource line (800) 922-4622. We always welcome feedback and love to hear from you.

Best Regards,
Barbara C. Martin

Email us at naa@aphasia.org or call.
We Got Mail!

We received this note in response to Eileen Erickson’s article about Caregivers and the Caregiver’s Bill of Rights:

Eileen Erikson writes,

*I have learned how to care for myself first.*

*But, in my own way, in my own time.*

For me, this has been the most important aspect of learning to care for myself...doing it in my own way and in my own time. I am still learning how to care for myself, and I am learning that this caring needs to give me pleasure, comfort and breathing room. It does not matter if others, no matter how well-meaning, think that the caring should take another form. The Caregivers Bill of Rights is new to me. I have printed it and will put it beside the sign on my bathroom mirror which reads,

**I Matter.**

With thanks to Eileen Erikson for her article,

Barbara- Brooklyn, NY
Caregiver's Bill of Rights: Express Difficult Feelings

The Angel Clips Her Wings, or, a Halo Is Just Another Thing to Keep Clean

“You are an angel.”
“You are a saint.”
“I could never do what you do.”

I am uncomfortable when folks say these things to me as they observe my role as a caregiver. What do I do? I am a 24/7 caregiver in the post-stroke, aphasia world of my husband. To some degree or another I am involved in my husband’s life. I organize his medical and social world. We both strive to live life in spite of aphasia. It’s hard but we manage.

Still, I often feel like the angel in a card my sister gave me. It’s one of those 3D photos. If you look at it one way, the little cherub-faced girl has a halo, twinkly eyes and a dimpled smile. If you turn the photo ever so slightly she sprouts horns, demonic eyes and sharp little teeth take over the cute smile. Yeah, I do that too.

I lose my patience with my husband’s difficulties. I mutter under my breath. I stomp around the house. I yell at him for no reason. The first time I yelled at him because he could not find the words to say, “I can’t find the clothing detergent”, I was torn up with guilt. He has aphasia. He knows what he wants to say but some words just don’t come out. And I yelled, “I have no idea what you are talking about!” Then I dissolved into tears.

Recounting this story to a friend, she said, "Be an angel when you die. Now you’re a human. “ Huh! Could I be just human? I have since discovered I have no choice. I have to be human. No one can be perfect. I voluntarily clipped my wings. (continued on page 4)
I still carefully plan for his needs, my needs and our needs. But if I lose it, sometimes I can say, “I am sorry, sometimes this life gets hard for me too. “

Accepting my own humanity has made me more aware of my own needs. Knowing my husband might need my attention at unpredictable times I try to tell him in advance when my attention is needed somewhere else. This can mean just reviewing our day’s calendar together. Then if I hear him calling, “Eileen, Eileen,” I can say, “Right now I have to finish writing out these checks. I will help you in about one hour.”

Clipping my angel wings has also helped me to ask for extra attention. Before my husband’s stroke, he could not read my mind. That is still true. Now he also cannot read some of the nonverbal signals he could read before. I have learned to say, “I am really, really tired today and need some extra attention from you.” Yes, I ask for the attention I need.

After my husband's stroke, it was painful to realize he could not figure how to use his arms to hug me. I showed him where to put his arms. The left arm was easy; the right arm needed help. But we practiced. Now I get really good hugs, both when I ask for them and when I don’t.

Clipping my angel wings has not been so bad.

By Eileen Erickson
I have the right to take care of myself. This is not an act of selfishness. It will give me the ability to take better care of my loved one.

I have the right to seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.

I have the right to maintain facets of my own life that do not include the person I care for just as I would if he or she were healthy. I know that I do everything that I reasonably can do for this person and I have the right to do some things just for myself.

I have the right to get angry, be depressed, and express difficult feelings occasionally.

I have the right to reject any attempt by my loved one (either conscious or unconscious) to manipulate me through guilt or anger.

I have the right to receive consideration, affection, forgiveness, and acceptance for what I do for my loved one as I offer these attributes in return.

I have the right to take pride in what I am accomplishing and to applaud the courage it has taken to meet the needs of my loved one.

I have the right to protect my individuality and my right to make a life for myself that will sustain me in times when my loved one no longer needs my full-time help.

I have the right to expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made toward aiding and supporting caregivers.

A version of the Caregiver’s Bill of Rights hangs on the wall in my den. I apologize for not being able to attribute it to any particular author. It has been on the wall since 2005 when my husband had a stroke and I took on the many, many, many facets of my role as caregiver.

This list has comforted me, confounded me and guided me over the years as I sought to redefine my life. It allows me to reflect on what works and what doesn’t as I strive to be my own person.
As with many endeavors, the Asheville Area Aphasia Support Group (AAASG) grew out of an acute need. For me, it was the need for my husband, George, who experienced a stroke in August 2002, to receive ongoing help after his formal therapies ended. Like most people, my husband and I did not know much about aphasia until it suddenly became part of our lives. The National Aphasia Association provided us with helpful information about this disorder and how to set up a community support group. I then contacted the director at Care Partners, the center here in Asheville where my husband had received speech therapy, to see if I could start a support group at their facility. Care Partners immediately agreed to give us meeting space and by November 2002, we held our first meeting with four people with aphasia. (We now have 26 members with more to come!)

(continued on page 7)
Soon I began asking experts on aphasia to speak to our group, which was meeting for one hour twice monthly. When Dr. Ruby Drew, a professor at Western Carolina University, spoke to our group, she suggested that we add a “speech therapy” component. She arranged to have this no-cost therapy provided by WCU graduate clinicians under the supervision of a certified speech and language pathologist. For all of us this relationship has been a “win-win” situation as the graduate clinicians are able to earn clinical hours while our group members receive ongoing aphasia therapy. We now meet for three hours once weekly for a one-hour group support session and two one-hour individual therapy sessions under the leadership of Dr. Leigh Odom, a new faculty member at WCU. This September we launched a one-hour support group for family and friends of people with aphasia under the leadership of Dr. Nancy Helm-Estabrooks. Many of the materials we use for assessment, therapy and family education have been bought with contributions from the Chaddick Foundation here in Asheville.

Another person who has been supportive of the AAAG is Carolyn Crook, MS, MAHEC/Heart Disease and Stroke Prevention Coordinator. She provides a direct link to what is going on at the state level with stroke legislation and initiatives. Carolyn spearheaded a statewide conference on aphasia for Speech-Language Pathologists, aphasia patients and caregivers. This took place in October, 2007 and was held at the Arboretum in Asheville. The SLP’s in attendance were able to earn .5 CEUs. The objectives of the conference were:

- Identify various psychosocial aspects of speech/language disorders
- Assess the patient for various speech/language disorders
- Explore new SLP therapies for various patient populations
- Recommend post event resources to the patient

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This summer (2008) we held a photography workshop with eight of our group members. Again, Care-Partners provided space for the two-hour, twice weekly sessions over a six-week period. The idea for this workshop came from Dr. Nancy Helm-Estabrooks, a professor at the University of North Carolina-Chapel Hill.

Dr. Estabrooks, along with Dawn Roe, a professional photographer and professor at Rollins College, wrote a grant proposal for this workshop. The idea was to help people with aphasia to express themselves through photography. I was able to obtain funding for this project with the help of Robin Jones, RN, Stroke Program Coordinator at Mission Hospitals and Mitzi Holmes, Director of In-Patient at Care-Partners. Dawn Roe volunteered her time as did Dr. Ruby Drew, Dr. Estabrooks and two WCU graduate clinicians who assisted participants. These funds were used for digital cameras and other materials, including mounting of the best pictures for a show this fall. We think that the show will be an excellent opportunity to further educate the public about aphasia.

Some members of the AAASG had volunteered as participants in a research study “Assessing Life Interest and Values in People with Aphasia.” The principal investigator for this study is Katarina Haley, a professor at UNC-Chapel Hill. In a spirit of reciprocity some of our group members have received no-cost cognitive-linguistic exams at the UNC-Chapel Hill, Aphasia Research Clinic. The comprehensive reports generated from these exams include treatment recommendation.

All-in-all, the Asheville Area Aphasia Support Group exemplifies what can be accomplished with community support. We have received many kinds of assistance from various people, organizations and facilities. Because we are the only such group in Western North Carolina, we have participants who drive over sixty miles to join us for therapy. Their willingness to do so seems to underscore both the need for such a group and our success in filling that need.

_Edna Tipton, Founder_
_Ashville Area Aphasia Support Group_
Our Aphasia Group at the MGH Institute of Health Professions Aphasia Center in Boston is a fun-loving group. We currently have over 35 members. We come from all walks of life and share the common bond of living with aphasia or related disorders. Members meet on a weekly basis to enjoy conversations. We have lively discussions on many topics. Meetings give us the opportunity to connect with other people with aphasia and learn about community services. We also share laughs and find new friends. Meetings are held Friday afternoons and are facilitated by Institute professionals and graduate student clinicians. Many of us meet for lunch in the lobby of the Institute before group meetings. During meetings our spouses and caregivers have organized their own separate group. At their meetings they offer each other support and share helpful ideas about living with someone with aphasia.

In addition to weekly meetings, members and clinicians plan group outings each semester. We have lots of fun together so outings are well attended. Several outings have consisted of specially adapted tours of some of the Boston area’s best museums. We have visited the Museum of Fine Arts, the Omni Theatre at the Science Museum and the Peabody Essex Museum. We also attend Boston’s most important cultural event—Red Sox games! This summer we watched the Sox beat the Texas Rangers 19-17. Just recently we had a great time touring the Sam Adams Brewery. And don’t forget our winter holiday parties and summer barbecues! Obviously, we love the opportunity to get together as a group and always welcome new members.
“I like to do what I am doing with my therapist. I’ll be able to write words and talk. I know what I am talking about but I have trouble writing the words. I like the Institute. It helps me to say what is in my mind with a different way.” - MS

“After my stroke, I could not communicate with other people. I was in a wheelchair and walking with a cane...My insurance ran out and I met Marjorie Nicholas at the VA during rounds and hit it off with her. Marjorie then began working at MGHHP and I went with her. I was their first client. I like MGHHP because I started speaking again while going there. Look at me now.” - RA

“I like the group very much they are friendly toward you.” – JL
“Seven years ago I come down here, I couldn’t talk. Seven years later I can talk. I got my license. They’re wonderful (here). There were six of us and 37 now… Christmas we go out to eat. We go to ball games together.” -JC

“I like group because it gives opportunity to meet different people. It doesn’t matter that I have aphasia. The supervisors and student clinicians are very nice. I have many friends that I have met here.” - MS

“It helps me to talk and in the group I have friends. I like the outings and at this center we have outings.” - JW

Fall 2008 • Sam Adams Brewery Tour
The “Aphasia Center” at the MGH Institute of Health Professions is located in the Charlestown Navy Yard, in Boston, Massachusetts. The center was established in 2002. It is part of the nationally recognized graduate program in Communication Sciences and Disorders. As part of the master’s degree program, students must complete a “clinical practicum.” The Aphasia Center provides second-year graduate students the opportunity to work with adults with communication disorders, such as aphasia. Students provide supervised diagnostic evaluations and individualized treatment at no cost to clients. Many clients are referred but the Center also welcomes self-referrals. Find us on the web: www.mghihp.edu/aphasiacenter
The NAA would like to take this opportunity to thank you all for your continued support particularly during these difficult economic times.

We can report to our donors that the NAA, like all not-for-profits, have felt the pinch of the recent financial crisis, however the NAA Finance Committee which oversees all investments has been exceedingly careful and thus we can report that although donations have fallen off a bit, we have suffered NO loss as a result of the stock market crises.

Visit our Website

www.aphasia.org

For the latest information and events!!
Here is an interesting article about the challenge of numbers and shopping for people with aphasia:

Supermarkets, numbers, perseveration are perplexing:
Let’s sort out the basics, how do persons with aphasia shop?

By Hariklia Proios, PhD CCC-SLP

Picture this in your mind. In the local newly renovated supermarket, in spite of the crowd, you spot a check out counter with no one standing on line. Deliberately avoiding the overcrowded counters you decide to walk slowly toward the empty counter. Due to the hemi paresis, your gait is slightly impaired on the right side of your body, but you manage to push your cart and get there. That was easy-too easy. But getting there doesn’t mean you’re home free; you must still run the gauntlet of buying the items in your cart, with perhaps only 50 dollars in your pocket. Following the walkway to the line, you realize you are standing in front of an automatic counter-no surprise, in this famously high tech supermarket. Trundling your trolley and counting the cost of the items on the conveyer belt, you try to shift lines and leave. But there is no turning back. The people behind you silently watch your performance with raised eyebrows as you proceed to do math in your head.

The point I want to make is that keeping track of numbers in memory is difficult especially under pressure. New technology has changed the way we look at supermarkets and shopping. The story demonstrates how your whole life and everything that has to do with number processing has changed and we must act upon these changes to get our products. Deliberately avoiding the automatic check-out is too easy. But scanning each item, while simultaneously keeping track of cost, does take a great deal of mental work.

(continued on page 15)
The challenge of numbers and shopping for people with aphasia continued!

To do math you need to have both short term memory intact and language skills such as computational operations which requires higher level attention (Eagle, 2002, Just and Carpenter 1992). Studies in aphasia and calculation have shown dissociations between number reading and math. For example, a patient would be able to add but not correctly read numbers, or to use calculating algorithms without self-awareness of a conceptual basis (Cohen et al., 1994). Another patient was able to transcode (translate form) numbers but only verbal or Arabic numbers (Cohen and Dehaene, 2003).

Perseveration is the ubiquitous symptom of patients with aphasia and some have it more often than others. In the American Heritage Dictionary of English Language (2000) it is defined as an “uncontrollable repetition of a particular response despite the absence or cessation of a stimulus; the tendency to continue or repeat an act or activity after the cessation of the original stimulus.” In the literature, the former definition is called recurrent perseveration. The latter definition is commonly referred to as stuck-in-set perseveration, the continuous and inappropriate maintenance of a current set. Perseveration describes this event: you do a calculation whose result is, i.e., “five thousand” and then you are asked do a new calculation and you repeat “five thousand.”

Try this task for fun!

Ask any family member, friend or acquaintance to sequentially add in their heads the series of Arabic numbers 1000 + 40 + 1000 + 30 + 1000 + 20 + 1000 + 10 = (say the numbers out loud or write each one down for them sequentially in the order above on a sheet of paper. Do not show the previous number. For example, say “please add the following numbers in your head 1000…40…1000… 30 1000 …20…1000…10, okay now tell me or write the sum.” (continued on page 16)
If they say 5000 they have just perseverated even without having aphasia!!!!!! If you ask enough people to do this you should see that >70 % should give you that incorrect answer 5000 (correct is 4100). (Brugger and Gardner, 1994). When it comes to, why this may happen? See answer below.

Obviously, even individuals without aphasia could easily show aphasic symptoms. The disruption of faculties underlying calculations can be defeated using mnemonic strategies (associations between numbers and nouns or numbers and images). Starting off you can train yourself at home by translating Arabic numbers (e.g. 1) into word numbers (e.g. one) or transcoding Arabic numbers into nouns or images (e.g. 1 is “cookie” etc) in order to improve domain-specific memory. Practice categorizing both the Arabic and word numbers. Mastering these techniques while practicing the actual calculations needed can be useful for organizing memory stores. A careful shopper with aphasia can access lists of food items on supermarket websites online and estimate costs before even leaving home or a use a calculator while shopping. This gives an advantage of using the time needed to do the calculations before facing the actual task of shopping. Lastly, acknowledging that is human nature to ask a supermarket manager for help (explaining that you have aphasia and need time) is a practice of instructing others about aphasia. Most generally, helping the NAA spread the word about the rights of the individual person with aphasia is always a good idea!!!

**ANSWER:**
Perseverative response may occur because the partial sum has non-explicit repetitive digit changes at the first (thousands) or third position (decades). For example, in 1000+40=1040 it is the third position that changes, whereas in 1040+1000=2040 it is the first position that changes. At the end, however, the final result changes at the second digit position (i.e., the 1 in the hundreds position in 4100), which is the critical lure.
Look for our special newsletter next month on Primary Progressive Aphasia (PPA). Our February 2009 newsletter will be devoted specifically to PPA.

Welcome to our new intern Debby Huszagh! We are thrilled to have her in the office and she will be helping with several projects.

Sign up to be the NAA Group of the Month! Spotlight your group and activities- let everyone know what makes your group unique and special. Pick any month between July-December 2009.

Contact Ellayne Ganzfried at Ganzfried@aphasia.org or call (800) 922-4622 to reserve your place!

“Night Sky” by Susan Yankowitz

Stay tuned for details on our 2009 Benefit featuring a full production of the play “Night Sky” by Susan Yankowitz which is the moving story of Anna, a brilliant astronomer, who is struck by a car and rendered aphasic.

You won’t want to miss it!
We want to feature information about ALL Aphasia Groups, Centers, events and personal experiences 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.