



Mission: A newsletter for Individuals with Aphasia and for the community

Created by Individuals with Aphasia —

— Supported by the University of Washington Speech & Hearing Clinic

A Student's Perspective

— by **Julie Sagona**, Student clinician

My first awareness of speech and language therapy began at the age of nine when I helped my younger sister, afflicted with a stutter, pronounce her "s" correctly in "snowman." Taken to our school district's speech therapist, Laura's stutter soon improved. Laura's self-confidence also developed as quickly as her speech improved. I am sure that she would not be the vibrant young woman she is now without the help from her speech therapist. I came to study in the field of communication disorders because I saw what a huge difference a speech-language pathologist can make in someone's life.

When I began college here at the University of Washington, I

knew that I wanted to be involved in a field that incorporated science and working with people. I chose to study biochemistry, which I soon found did not satisfy my desire to work directly with people. After studying for one



particularly memorable biology mid-term about the kidney system of flatworms, I told my mother that I was through with biochemistry. Because of our experience of working with Laura's speech therapist, we knew what the career of speech therapy entailed and decided that it was the right match for me. I eventually graduated with a BS in Speech and Hearing Sciences, and was later accepted at the same school for my

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Master's degree. The classes that I take now are much more interesting to me than the hard sciences because they speak directly of real life as we see it, instead of the mundane details of organisms and chemical reactions.

Because of my shared experience with my younger sister, my goal is to treat children in the public schools. I have always enjoyed being around children and they seem to like me too. At 5'2", perhaps they think that I am one of them!

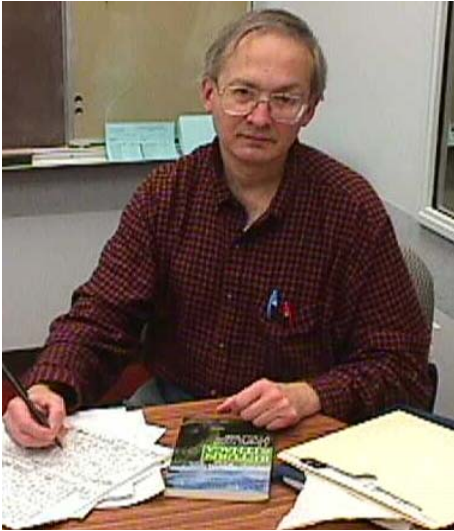
For six months before I began the master's program here at UW, I lived with my grandparents. Since the age of 6, I was allowed to spend the night at their house on "special" weekends where I would learn how to sew, knit, and play poker. The opportunity to spend so much time with them last year was something we all enjoyed. During that summer, I learned how to live with two people who live with an entirely different point of view than me. I began to learn how to truly respect another person's opinion. The three of us are still very close; I think of them as my best friends as well as my grandparents.

To me, being a clinician for clients older than myself, whether they are 30 or 70, is a challenge. This is because it can be difficult to balance the younger/older and clinician/client

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Recovery: Twenty years and counting

— by **Ted Paluchowski**, Aphasia survivor



An intriguing book: *Return to Ithaca* by Barbara Newborn. I found the book easy to read with its straight forward prose. At the same time I discovered a surprising depth of thought throughout the narrative. To appreciate the complex flow of ideas in the book, you must acknowledge two intertwined stories.

One of those stories concern a stroke survivor with an emphasis on the first six or seven months of recovery. At the time, the author had recently graduated from college and was anticipating a new life with her fiancée and beginning a teaching career. The stroke disrupted all of her plans. Suddenly, she found herself disabled particularly with aphasia. After released from the hospital she was sent to her parents home for further treatment and rehabilitation.

After months of intensive therapy, she expressed a frustration with the pace of rehabilitation. With encouragement with the family physician she stopped therapy and decided to return to Ithaca. Although her family was hesitant she reasoned that she was familiar with the area and still had a large cohorts for from undergraduate years for support.

Overall, her return proved to be a positive experience. To be sure, there were rough times. For example, when her attempt to return to teaching ended with a shattering disaster. Confronted with the situation she enrolled as a student in a local university. Once again in a familiar academic environment, with assistance from faculty and other students, she began to recover her use of language.

The second story outlines events following the next twenty years before writing the book. In the interim years the author sought opportunities to challenge her disabilities. During that time she earned two graduate degrees and worked in responsible professional positions. As an undergraduate she majored in English and Communication and was a certified teacher. Within a few years after her stroke she earned a graduate degree in communication. Some years later she earned another graduate degree and is a qualified rehabilitation counselor. Similarly, she chose challenging positions. She worked in the family business in a public contact position despite aphasia. For years she worked with children suffering head injury. Currently, she is Chief of Staff at a hospital specializing with stroke survivors and their family.

Given that background the author offers a unique perspective on stroke and recovery. When she writes about the trauma and devastation of a stroke it is based on personal experience. But she also offers an optimistic view of recovery. The author has had years to think about her experience supplemented with graduate level education. The result is a thoughtful many layered text. A second reading is well worth the effort. As an example, her discussion of aphasia had many dimensions. Aphasia severs the ability to communicate. A survivor is left with a terrible isolation. Aphasia separates a survivor from society and perhaps more disturbingly from

one's self. The psychological chaos can be overwhelming.

As a concluding note, I highly recommend this book for survivors and their caretakers.

Ed. note: Return to Ithaca, originally published in 1997, is available through Element Books, Inc.



Anchors Aweigh!

— by **CDR JR Scott, USN**

This is an update on a story that I started in June titled, "It's Not Just a Job. It's an Adventure!" The original story discussed my stroke of August 2002, my medical care, and efforts to minimize the effects caused by aphasia. One key piece of information, which was unknown at that time, was whether I would be able to remain in the Navy. I am very happy to tell you that I will be continuing my career as a Naval Officer.

In my last story, I indicated that I would be undergoing cognitive testing to determine what deficits I still had from my stroke. I spent a day and a half working through the battery of tests and then the neuropsychologist collated, analyzed, and prepared my test results. The final report concluded that while I still had some residual effects caused by my stroke, the results were still within the acceptable range. With that, the Navy neurologist, in charge of my care, was ready to call me "Fit for Full Duty."

Since that time, I have received new orders to Naval Air Systems Command (NAVAIR) at Patuxent River, Maryland and I am busy at work in my new program management assignment. My mild aphasia will always be a part of me, but I have learned a number of ways to minimize the effects. I now have new challenges to overcome!

I would like to personally thank three graduate clinicians who helped me work toward recovery: Emily Stewart, Brenda Coulson, and Karen Nordstrum. I wish each of them the best in their new assignments. They will be using their expertise, learned here at University of Washington (U.W.), to help new patients who have special rehabilitation needs.

I would also like to thank the members of the aphasia group at U.W. Being able to actively converse with others who have similar problems was very beneficial to me. I know we all enjoyed our time together and I believe we all grew from this weekly interaction. Good luck to everyone there!

Finally, Nancy Alarcon, the Director of the U.W. Speech and Hearing - Thank you! You were "just what the doctor ordered" when it came to my speech difficulties. I am thankful for your help and your thoughtful insights.

It was a strange twist of fate that sent me on a short tour of duty at the U.W. Speech and Hearing Clinic. I am grateful for the sense of pride and purpose that everyone so freely shared with me. ~~My thoughts and prayers will stay with you all.~~

Final Note: Thanks to my daughter, Kelly, who drew the ship and anchor picture. It shows that we, as a family, are underway again!



Answers From The Web

--- by **Bob Anderson**, Aphasia survivor

Since my stroke(s), I continue to be puzzled by what happened to me and how that continues to affect me – and in ways that sometimes seems strange.

All of us with aphasia have had some similar difficulties – and we're all different and recovering differently. I have appreciated others sharing their thoughts with me and perhaps some of my comments in this article will be useful to YOU.

References to provide needed health information include health care professionals, family or friends, books, journals, or magazines, seminars, even TV specials. A great way to help find out answers is the Web. I need to be careful searching the Web, though, because the things that I look for can also be confusing, outdated, or inappropriate. Here's a small list of addresses, grouped by function (I saved the best one for last):



Health Organizations

(These are good for much more than just aphasia)

Catalog of Internet Resources: Health Studies

<http://publ.ac.uk/link/med.html>

This is perhaps the most complete listing of health websites. Good, but takes time to go down the path you might want to take to find something.

National Institutes of Health

<http://www.nih.gov>

There are 27 Institutes, but two are useful for info about our strokes:

-- National Institute of Neurological Disorders and Stroke, which lists under Disorders all of the various kinds of aphasia. Very Good
 -- National Institute on Deafness and Other Communication Disorders, which provides a lot

of pages on Voice, Speech, and Language, all of which are tied to strokes and aphasia. Very Good

Mayo Clinic

<http://www.mayoclinic.com>

Everybody knows and trusts Mayo. This gives you a lot of info about virtually any health problem you could have. Very good.

American Academy of Family Physicians

<http://familydoctor.org>

Your relationship with the old family doc was comfortable and this is, too. If Mayo missed something or wasn't clear, or need to find a doc, try this. Good.

Umbrella "Patient Toolkit": <http://healthlinks.washington.edu/patient>

If you have lost my list, use this one. Very good. Includes many of list and adds the remark that "your personal health care provider is the best source of information". But, it omits the BEST site and that one is also on the UW campus – figure that one out (scroll down to the last one).

Stroke

(The first 2 sites are devoted exclusively to stroke)

American Stroke Association

<http://www.strokeassociation.org>

This is a division of the American Heart Association. Lots of info about stroke. Note: lots for the caregiver! Lots of good publications and: **Stroke Connection** – free bi-monthly magazine – Very good – you can subscribe online.

National Stroke Association

<http://www.stroke.org>

A lot of info similar to that from American Stroke, but also a lot that's different. Worthwhile checking out both. Stroke Smart - \$12/yr – bi-monthly magazine.

American Heart Association – <http://www.americanheart.org>
Some info about the heart. Most stuff aimed at the specialists. The magazine "Stroke" is targeted at medical professionals - \$260/yr.

Aphasia

(Zeroing in on aphasia, in particular)

Aphasia Hope Foundation – <http://www.aphasiahope.org>
Excellent – articles, resource list, audio/video/written clips from survivors, caregivers, and more

National Aphasia Association – <http://www.aphasia.org>
Facts and readings about aphasia, connecting with others, "aphasia" Newsletter – semiannually – for \$25 donation or free (can be read online). Very Good.

American Speech-Language-Hearing Association – <http://www.asha.org/public>
The organization of professionals that help those of us with aphasia. Most of the site is for professionals, but has very good public info about aphasia and associated disorders.

Aphasia treatment clinics

(Organizations to help us AFTER the hospital)

BC Aphasia Centre-<http://bcaphasia.org>
Excellent. Info about what the Centre does for people with aphasia, about people and how they have been affected, samples of writing and speech, documentaries, the Centre's plans.

York-Durham Aphasia Centre
<http://ydac.on.ca>
Excellent. Similar to BC site, but enough different to also check it out.

Aphasia Center of California
<http://www.employees.org/%7Eaccadmin/index.html>
Good info about their programs, about aphasia, and their newsletters can be read online. But, the most complicated address of this list.

UW Speech and Hearing Clinic – <http://depts.washington.edu/sphsc/clinic.htm>
My (our) favorite, of course! Info about their services and programs, connections to the school, and the online newsletters produced here.

Best one-stop website for Aphasia/Stroke/Brain and much more!

Neuroscience for Kids - <http://faculty.washington.edu/chudler/neurok.html>
The name could mislead someone with the "Neuroscience" and "Kids", but it's the most fun, most interesting, most cleverly written way to lead someone into: What happened with stroke and aphasia; How your brain works; What CRTs and MRIs are and how your brain looks; Resources, books and articles that are readable; Experiments and activities to learn about our functioning brain. I've had fun (and learned) from this for a year and am still uncovering things.

You may think that this is an exhaustive listing of websites. Not. I have 54 sites bookmarked on my computer-there are more, and I keep finding really worthwhile ones.

Pick one or two to try. If you're not completely satisfied, try another.

--- Bob



A Student’s Perspective—

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dynamic. Living with my grandparents has helped me understand how to find this balance. In addition, my successful experiences of treating adult clients have given me a comfort level that parallels my comfort with working with children.

As part of the Master’s degree program, student clinicians treat different types of clients each quarter. These clients need treatment for their voice, stuttering, speech articulation, or language. It is very interesting and enjoyable to work with clients with different forms of communication disorders. Working with a variety of clients has helped me realize that there is a huge amount of information about each type of communication disorder that I have only just begun to learn about. I look forward to expanding my knowledge base here at school and later while on the job.

I got into this field because I love to work with people, which I hope comes across in my work. My reward for this is the satisfaction of knowing that I have helped someone take a step, no matter how small, towards more functional communication.

Publisher’s Note

I remember my grandmother asking me, “How do you do this? Doesn’t it make you sad?” She was referring to my summer job back East working with children with disabilities. She wasn’t sure how I could see beyond the impairments. Looking back, that’s when I began to recognize the inspiration and the reward received from working with individuals with challenging communication needs. On a fundamental level maybe it comes down to how we look at the cup: “half full” or “half empty?” Do we see possibilities?

Ted Paluchowski’s thoughtful review of “Return to Ithaca” by Barbara Newborn reveals her remarkable journey of recovery over 20 years. Ted and I met the author nearly 4 years ago at the “Speaking Out” Conference for stroke survivors, family and friends, and professionals in Michigan. In her book, Ms. Newman writes of her personal recovery that inspires us to aim for the future, to reach for new heights, and to keep the door open on “recovery” even 20 years post stroke. Ted’s article in and of it’s self is remarkable. Written “in his own words,” Ted insisted on editing his article by himself. He wanted it to reflect how his own language continues to evolve over time, how he continues to recover six years post stroke.

When we first met during the Christmas break last year, I was struck by JR Scott’s tenacity – his determination to recover as much as possible and hopefully get back to work. Now one year later, his ship has set sail. Members of his stroke group here at the Speech and Hearing Clinic were saddened to see JR and his family head East this Fall. Yet, we were proud to see his progress and his determination to continue in his chosen profession come to fruition.

A remarkable issue highlighting the endurance of spirit and the evidence of continued recovery many years post stroke! These personal stories are the perfect gift to each of us this holiday season. We hope you’ll consider submitting an article to a 2004 issue of “In Search of...,” to share your own experiences living with aphasia.

Happy holidays and best wishes for the new year!
Nancy Alarcon, M.S., CCC-SLP

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