



You Can, Too!

by Todd Bern



(Todd's article in the last Fall newsletter, took him from shock to serenity. This brings him to his NOW. From depression and sadness to dedication, satisfaction and a positive view of the future, not the shocking past. He's happy to share this. And we hope that you are, too.

-ed.<<)

Blackness. I didn't remember the attack with my friend. I didn't remember the paramedics, which I was awake for, or their taking me to the hospital. Merely blackness. I could hear some voices but I couldn't hear what they were saying.

Finally my eyes opened up but only for 30 seconds. Then I went to sleep. I didn't know how much time there was, I guess about a minute when I was awake every day. I was so groggy. I do know this: my mother was at the hospital and she said that I had a stroke. Leave it to my mother to be plain spoken about it.

At five days into it, I was awake 15 minutes to every six hours. I didn't realize what had happened to me even though I had had a stroke. It just didn't occur to me.

A week and it did. I was fully awake and was aware. And scared. In fact, horrified. I couldn't talk. My right side was paralyzed, and "they" said it would be a long time, even permanent. They said with the right type of therapy, I would come along great. I was more horrified. I couldn't even say "yes" or "no" and I couldn't read. My intellectual capacity was fine, but it was frustrating not to speak. That frustration lasted about 2 years.

I was confused also. For example, I woke

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Open Letter:

to all disabled persons in general and to stroke survivors in particular

by Frank Lim

(Nancy and Ted first met Frank at the "Young Adult Stroke Group" that currently meets monthly at Northwest Hospital. His stroke caused significant physical, communication, and adjustment challenges but he continues to fight back strongly and he is delighted with his progress. That is why we think you would enjoy his vision—and his suggestion to you!

-ed.<<)

Dear Fellow Disabled:

This malady known as a stroke, or brain attack, is equal opportunity! It has no regard for a person's age, gender, color, creed or political affiliation. Diet and exercise play a starring role, though not in all cases. The chances of surviving a stroke are not predictable and nor is recovery. The best factor in our recovery is our inner strength or our motivation. This implies the inner desire to fight and win back from the illness whatever was lost. Most of us were active in our chosen fields, whether they be in business, homelife, or sports. It would take

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up and had to go to the bathroom so I got up and on I went. Leave it to me I didn't know my right side was paralyzed, fell hard and got a bloody lower lip. You can still see a scar on my lip. Subsequently, I was tied to the bed at night.

The third week I could get "yes" or "no" and a few words. My family was admitted to the hospital, and so were many friends with repeat visits. My parents were there every day. I didn't know until later how much that meant to me and how much my mother said "keep it coming, and keep it positive." My mother was particularly strong.

But I kept on crying even though I was better in the hospital. My fourth through six weeks in the hospital were good, but not as good as I would like. I thought, if I work hard in the hospital or at home I will make it.

You don't know how much I left behind. Before the stroke I was a relatively happy person, although intermittently stressed out. I had a full life and it was only half done. The careers: fulfillment director, information technologies manager, convention manager, Web designer, Web director, Web manager and doughnut clerk. The arts: theatrical acting (in 50 plays), painting, papermaking, candle making, gardening. And the activities: hiking, biking, weight lifting, aerobics, dancing, swimming, meditation, and Buddhism.

That was all left behind. In the first part of my stroke, I realized this more and more, and I got depressed more and more.

When I got home I was wheelchair-bound and was only talking with one word. Three months later I was four-pronged-cane bound and was talking with three words.

Six months later I was doing five words, two syllables, and was talking for some time. I was also lifting my arm up and walking with an average cane, slowly and on level ground, but constantly walking.

At nine months I moved out of my parent's house and in with some friends in Arcata. I was still blocked, still terribly depressed. The whole time I lived there I

grew physically and mentally. It's that year where I began to workout and, oh, it was difficult, but I began to do aerobics and weight lift every other day.

A year and a half I began to read out loud. It was not a light book. *Awakening the Buddha Within*, which I had read before, was 400 pages, with small type and difficult. I should have started with a small book with big type, but oh well, when Todd wants to do something he will. I was reading it out loud for six months.

Then something happened. Something slowly. I didn't know what it was at first. Maybe it was a result of the Buddha book or maybe it was a result of my telling myself I was happy (which I wasn't) - subliminal psychology. What happened is that it made me genuinely happy, content with my life. It made me more compassionate to others. Life is so special now, so simple. And way NOT stressed out.

At two years I thought I would be "out of" the stroke, that I would be symptom free at four years (hmmm—imagine that). It kept climbing to five years, then seven, then ten, until I stopped counting. I didn't realize how large a part of my brain the hemorrhage took out. Once I realized this, or the fact that I am happy, I didn't care what year I will be symptom free. I like the way I am, not the way I should be.

People all over have serious and difficult things happen to them, some much more than me. I'm not saying this was a traumatic thing that has happened to me. It is. Rather, people all over have life changing things. You may have thought of me as self-centered, but I didn't know that until the past few years.

I've been working on a web site, paid work, for all about a year and a half. I hike and walk, lift weights, do yoga, meditate—some of the things I did before and some different. I'm doing more unusual things than I did before, for example, painting differently with my left hand. Now I will be going to rural southern Oregon to be a caretaker at a sanctuary, something I had planned before my stroke.

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Open Letter*(Continued from page 1)*

months or years to regain what had been lost. The road to recovery is quite difficult and replete with chances to quit. Oh, how easy it would be to have somebody else do things for us. But only a "jellyfish" or a "softy" would buy into that kind of fertilizer. After we have survived the cardiovascular accident, the next item on the agenda is to fix the "short circuit" that happened. To achieve that goal, lots of manipulation is called for, either by a therapist or some other qualified person. Each of us is spastic in various degrees. Such spasticity cannot and should not be used as an excuse not to move that body part. The body WILL recover, but no one knows when. For instance, when we re-learn to use our hand through exercise, it may take about five years but with proper therapy, it may take only two years. These times are obviously taken out of the blue. This is not a scientific paper but the rambling of a stroke survivor. The point is GET MOVING AND DO SOMETHING! Everyone is allowed to grieve any loss. All would agree that we had lost a lot when we had the CVA. But for anyone to wallow in self-pity for an indefinite time is generally frowned upon. "Time" is undefined but "indefinite" is defined by society, ranging from a few months to a few years. The terms are ambiguous but the idea is that we must not indulge in self-pity for any extended period. There simply should be no room for this negative emotion in any of us. Our confidence is already quite low. To engage in self-pity would bring that self-esteem even lower. Therefore, let us improve ourselves, physically and mentally by exercising and retraining the brains we have left.

Emotional and psychological support are important items for our recovery. Our immediate family (significant other included) and friends are our main source of that support. We will have difficult times ahead and they are who we must depend upon. We must fall back on them and our inner selves for added strength. But no matter how our families love us, we ultimately and literally

hold our lives in our own hands. There are no two ways to deal with this. Our recovery depends on each of us. It would be quite difficult at the moment to see the benefits or merits of this particular matter. The only thing we can go on is the fact that our loved one(s) is/are doing such for our benefit. This smacks of "faith" but, after all, that is all we have. For example, we may have to use a child's coloring book which is really demeaning but under the surface, this exercise allows us to re-learn eye-and-hand coordination. Henceforth, we should not be caught unaware or surprised when someone asks for positive benefits learned from such a negative experience. It seems like a dichotomy of terms but it really is not. Strange as it seems, there is a positive side to this negative trauma. As mentioned above, it is hard to imagine that any good could come back from such a malady.

We are in the middle of the commotion, so we cannot really see what is happening. We can and should "always stress the positive and minimize the negative", as the saying goes. There is absolutely nothing to be gained from feeling useless except perhaps disgust and derision from everyone around. A person who lies around, bemoaning and cursing the fate that has befallen him/her, gets nothing but hate and abomination from others, both able-bodied and disabled alike. But for one who does not show signs of being put upon but rather quietly fights back to regain his/her loss, should be applauded for the effort. That is the only thing we could expect of ourselves—to try our best. There are many who do just that.

Sadly but realistically, some of us would run out of time before improvement. No one knows who has or who has not any more time. All we can do is try, for if we do not try, we might as well roll over and die. It would be much easier for everyone concerned. Under all this verbiage, there is an underlying theme that should be brought out.

There is nothing in the world more important than to have the feeling and

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Book Review: *by Ted*
"The Aphasia Handbook"

(from the National Aphasia Association)

An exceptional book. As a handbook it offers a concise but encompassing survey of the subject. From introductory comments to suggested further reading at features practical and useful information. Throughout, the text presents material with casual everyday language.

The book serves as a guide to a complex subject. At the same time it is easy to read. Toward explaining its material it features excellent organization and style of presentation.

By opening the book - you are immediately fronted with relevant information. There was no preliminary digression. Many books start with a long winded introduction. Not in this case. Here the focus was aphasia from page one to the end.

To begin there is a brief overview of the entire book. Then the text is divided into six chapters. Each chapter starts with an outline that identifies major topics. Individual topics focus on a core theme surrounding by a cluster of related ideas. Because of its organization it is easy to find any particular topic.

The sequence of chapters progress from short introductory comments, through more fuller treatment and continuing advice. At the start, caretakers and family are concerned about survival. Basic information is sufficient. Within a short period there is a demand for more and different types of information. The book captures the variety of information appropriate for a changing situation.

The style of the book makes a significant contribution. At times the handbook reads like an elementary text but it contains a serious message. The pages are bright, have relatively large print, bold type for emphasis, and two colors (blue and black) for most of the text. Overall, it is easy to read.

As an example of its style the book



provides a definition of aphasia (pg. 2). A reader is immediately alerted that there is a problem with communication. Following, at a different part of the same page, is a list of specific problems associated with aphasia. Difficulties with talking, understand others,

reading, writing, and handling numbers are identified. Each aspect is given an individual line.

The layout of the presentation promotes a piece by piece approach. Almost like a cookbook. A reader is drawn to one thought, processing the information before continuing. Therefore, a more complete definition is broken into small bits of information. Simple illustration reinforce the text.

The headings of the chapters serve as an outline of the book. For each chapter, a representation sample of the ideas contained are included. There are many suggestion that were only superficially scanned. To find a fuller exposition read the book.

Chapter one is short. It introduces the handbook, sets basic definitions, shows its style, offer communication tips, and suggestions for the use of an advocate.

Chapter two is the longest covering a variety of topics. It begins with a discussion about stroke and its consequences. Next, there is more information about aphasia. Being in and leaving the hospital. Finally, there is a section about speech therapy.

Chapter three addresses the critical issue of support, at home and from outside agencies. Financial matters are mentioned.

Chapter four places emphasis on communication with others particularly with relations with caretakers and family.

Chapter five covers the rights as a patient and as a disabled person.

Chapter six is a catch all. There is a glossary that explains relevant words. A list of useful organizations and places to find

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They Didn't Listen to My Daughter

by Lesley Low



I first became aware of how communication affects relationships when I first met my husband. Neil has an acquired, severe, hearing loss in his left ear and despite the use of a hearing aid, he depends a great deal on visual cues to understand others. He

often has difficulty following conversations and misses key auditory information. He has learned to compensate for his loss and uses strategies and techniques to improve his ability to interact with those around him. I, too, have had to learn and utilize strategies to improve communication and reduce misunderstandings.

Understanding and improving communication became a passion for me, when it became apparent that my youngest daughter Meghan, had communication deficits. By the time she had reached the age of three, it became evident that few people outside the immediate family could comprehend or value her messages. At a day care center she attended, the staff expressed frustration with her and described her as stubborn and unwilling to cooperate. At home she complained that the day care didn't listen to her or give her a chance to talk.

We privately sought the help of a speech-language pathologist and the results of therapy were clearly remarkable, opening up new lines of communication for Meghan. She was diagnosed with both receptive and expressive language problems, processing difficulties, and dyslexia. While observing her therapy sessions, I was amazed by the progress she made while engaging in what appeared to be simple games and exercises with her clinician. I came to the realization that I could make a difference in the lives of others who have trouble with communication.

Communication, the exchange of information and ideas, is an active process that engages our abilities to clearly formulate, convey, and interpret messages and their meanings. Communication can be represented in many modalities: verbal, written, symbolic, or signed. Considering the complexity of communication, is not surprising that messages can often be misinterpreted or imprecise and are dependent on the ability of both communication partners. <<

Open Letter:

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satisfaction of knowing that we gave it our best effort. In the final analysis, we may not have PHYSICALLY recovered but we personally know the amount and the quality of the effort we had put into the task of recovery. That is the essence of our being here in the first place.

In summary, we must be motivated to get back which was lost, or as much of it as possible and we must improve our lot in life. We get our strength from within and from our support systems. We must not indulge in useless self-pity. It is counter-productive and gets us nowhere. In our temporary stay here on earth, we want to be remembered for our accomplishments. As human beings, it is our very nature to want to have done something worthwhile. Why not recovery? ...Good luck! Keep trying!

Sincerely, Frank

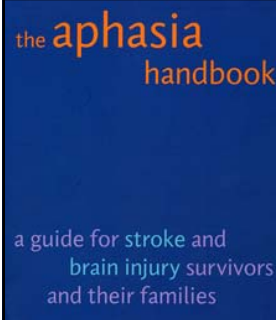
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I still participate in speech therapy and learn and improve four and a half years into it. In my speech therapy group there are people who have gone for 15 years, and they are still improving! 15 years! I feel humbled and inspired.

Now I can talk and write and even do big words like **vocabulary**. (Vocabulary: that's a big word, isn't it?) I write blogs or e-mail or this very thing you are witnessing, the UW Aphasia newsletter. I write and it's highly satisfying. **If I can do it, maybe, just maybe, you can, too!** <<



This book
and other Aphasia
resources are available at
www.aphasia.org

Book Review

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more information are identified. Finally, there is an index to find topics in the handbook.

A final observation. The book is clearly targeted at caretakers and families. Professional medical personnel are already familiar with the topic. By the nature of aphasia, survivors are rarely able to use the book. Therefore, the handbook will be most useful for caretakers and family members.

Caretakers and families play two different but important roles. To begin, define a caretaker who is supporting a survivor on a day to day basis. An example would be a married couple. A stroke has a dramatic impact. Both partners are in shock. No doubt, they are overwhelmed by events. Under the circumstance it is unlikely to read a book. In this case, the handbook would be most useful for the introductory comments and chapter one. Over time, the book would be a valuable reference.

Family is defined as relatives, close friends, or one whom will be an advocate. In the previous example, the adult children would be ideal. They would be thoroughly familiar with the survivor but they have a different perspective. They have the ability to read and understand the information in the handbook. In this case, the entire book would have an immediate impact. <<

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Publisher's Corner

As we celebrate the onset of Spring, many of us may be challenged by thoughts of spring cleaning, how quickly the year is going by, and whether or not we will fit into those summer clothes! However, spring time can also bring thoughts of growth and renewal, recommitment to personal goals, and a sense of new adventures ahead. As Frank Lim and Todd Bern share with us in the issue—it really is all about how we look at things in life.

I am very much a "cup half full" type of person. I know that I got that from those who have mentored me in my life—my parents, my husband, and a number of teachers and colleagues. I have to believe when we are faced with challenges in life, that we can either "fold and go home," or "pick ourselves up by the boot-straps" and go forward. Some folks would say that decisions in life aren't always that easy—not simply binary. However, I firmly believe that how we *begin* to address a challenge in life is all about attitude!

Wishing you the most productive, positive and rewarding Spring, Nancy Alarcon

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