My 25th Anniversary

-by Dennis

(The other day, Dennis celebrated his 25th anniversary. The 25th anniversary of his stroke.

Ted and Bob thought this would be a good time to explore the long (LONG) term impact of strokes.

So, we went to talk with Dennis. - ed.)

This is your 25th anniversary. How do you think this time has worked for you?

Well, I know for the first five years, I was, I wanted to cry and wanted to kill myself. Ah, maybe the first 2 or 3 years. I mean everything was learning just how to be in a wheel chair. Just - I mean just. Not learning how to walk. And my speech was zero.

I had a baby, 8 months old, and my wife wanted to go - soon. I had a house that I bought about 6 months before I got hurt. I mean everything was going down.

At first, I was a miserable guy. I don’t know why I didn’t kill myself. But they say that it’s because of 2 reasons. You are courageous or you are dumb, stupid. And, I was the stupid guy. I don’t want to kill myself.

About every year, I call my ex-wife. And, my daughter, Jennifer. She came here and visited me a while ago. Now, she’s an English teacher, and she’s studying for her Master’s.

What do you think has improved over the 25 years?

Well, the number one thing for me is my speech. I know it’s finally progressing, a little bit each year.

The walking, I don’t know. Not very good, it’s not no better. It’s not always worse, but not very good. But that’s the way it is. My speech is getting there. I can’t write and read, but finally I can talk a little bit, as best

(Continued on page 2)

On Caregivers

-by Nancy

The physical and emotional care and support that are willingly given to the dear person suffering from a brain accident rewards the giver.

But, immense and unexpected effects of the accident can also land upon the caregiver.

We continue to work and to do research on the needs and the support of caregivers here, in the Clinic and in the Department. This is in addition to the primary effort we devote to those living with speech, language and hearing challenges.

We constantly work to improve our abilities to respond to the needs of individuals with communication challenges and the caregiver.

These following notes show some of our continuing and expanding professional efforts.

Aphasia Survivor and Caregiver Retreat

Saturday, June 5th

Mark your calendar! Save the date!

UW Speech and Hearing Clinic 4131 15th Ave NE – Seattle, WA

- A day-long retreat for individuals with aphasia and for their caregivers.

- To request your registration information, provide your mailing address or email address and: Call 206-685-2212 or email shclinic@uw.edu

Limited seating, so make your request now!

(Continued on page 4)
How did your speech improve?

For five months, another place, I had this speech pathologist, and we had one every day for the first five months of just one word, until I got it.

So she’d tell me just one word, and then she says, "boy," and I try it too, "boy," and she "boy, boy, boy, boy" and she gets I got it and then when I had it in my mind, next time she says, "What is the word? Boy." and I said, "OK." Next word, girl, and then bang, what’s girl, girl, girl, boy, and then that whole 6 months was one word.

Somebody (Some words) I understand: table, chair, but nothing like "they", "us", that’s way out. But if I can tell you something I can tell you: who it is, where it is, apple, the dog, that's much easier than adjectives or something. I got no idea.

She said, "they". What is they? For me it's, it's...

Too indefinite? How long did that take? Could you get a word a day, or longer than a day?

Yeah, like one day, and come back the same, next day, and the next day, until I got it in my mind, cemented, really, until I know that’s a dog, make sure it’s a dog, and a cat’s a cat, and that’s how I learned.

I couldn’t speak a word, not one I really needed, I couldn’t one word I couldn’t say. I was learning how not walk out, learn how to a wheelchair. That’s how bad I was. I was a case.

For a while, she had a book where she gave me, where if she showed me, if I want a girl, she points. She didn’t know I could talk at all. I was really bad. I was worse, but she had a big book that I used to have, that is in my house somewhere.

On this group here, I think it’s important that we have understanding how the group is most important. My speech even a couple years ago, wasn’t very good. And sometimes I had a couple words I understand, but at least I am a little more, not precise, at least I can talk a little easier, but still I think I am the worst one.

I know everybody in our “family”, I think it’s every, all of us are getting better and better.

I know when I go to other places, I know like in St. Vincent’s (Dennis has volunteered weekly for over 15 years at St. Vincent’s living care community for older adults.) There was a school and the stroke association. We, people stroke, going back to school. Write and read, and walking and talking, and all that, you know. They told us, its no longer, we’re finished. It was so expensive. So, I volunteer at St. Vincent’s. Some people can walk fine, but some people they don’t even try to get better. I go there once a week, every Friday.

Every year we have a big get-together, where we have a luncheon. It was this last Saturday. I had my suit, my tie and jacket on. We had over 200 volunteers there. And they were kids 6 to 7 years old, and on the other side, is like 81 years old. It’s a wide range of people.

They give presents to volunteers, and every 5 years, you get an award, 10, 15, 20, 25, every five years. It’s such a great place to visit. Imagine living there. So many people are just very passionate. Just so nice too, pleasant.

And after 25 years ago, I’m still trying, still learning, how to least talking. As I said to Nancy, almost 20 years I still go, but there’s 85 people, 85% of people close the door, T.V. off, and that’s goodbye, and I think that I know it’s wrong, but that’s up to them.

They need more. Don’t close the door, especially people who stroke 6 to 7 years, 18 years old, lots of young kids, that’s even worse.

The only problem is so expensive, you go anywhere, you gotta pay for it. And that’s a disappointment, as far as I feel.
Should be part of your organization from your insurance. They only go couple of years, months, one on one, and they kick you out, and that’s one of the worst things, because one on one is so important, especially two, three years right after your stroke.

Pay for your therapist for years, not like six months and they’re out. They do that, sometimes not even six months, it usually kick you out of the hospital 6, 7 days. That’s one of the biggest problems, that people more vocalize one on one, and it’s so much money, now it’s up to something 100 dollars a month - I mean hour. It’s ridiculous.

Don’t go home and take a nap for a while. Immediately, as close as to immediately, till you get situated, you know, frustrated, make sure you get help and stuff, so important that speech is one on one. It's most, most important, and even if doesn't ever, doesn't matter it doesn’t have to talk at all, soon or later some kind of mind, even if it’s write it down, or now you get a computer, all kinds of way.

When I was, 25 years ago, you learn how to talk, or I mean write before you can talk, or just one word. They thought I was never talking. And that’s when I started to write and write and write, but I can’t write what I’m trying to say.

What I would talk to them is I feel that 2 years is not enough, from the hospital speech and hearing therapists. 2 years, sometimes people just start to wake up.

I think somewhere when you can talk with a group, like a group of doctors. So I think doctors, they’re most important because they’re in charge of it, especially when you’re in the hospital. And even better for them, even the nurses are better.

The doctors are important and some of them, they don’t even talk about it. Most of them, some of them they’ll be away (look away from you) when you’re talking. I’m not sure why.

Don’t stop, especially with stroke or head injury of any diseases. Somebody, especially the writing and reading, and speech – most important.

The wheelchair – personally, I feel the wheelchair’s OK. Obviously, you try to get better, but speech is most important. The doctors, that’s number one; that’s part of your life! I mean, that’s where it is.

The 2nd thing is, people from the group, the stroke survivors, and they say as far as I feel that is: this is my life, it’s what happened, 25 years ago, now what have I done in the last 25 years? It’s up to them. You want, you want to kick out, you want to just go home, that’s fine. You want to stay here and learn to walk and talk and read and write, that’s up to them.

It’s a long, long road.

One of my grandfathers said, “Look kid, when you’re 90, you can take a rest, but before that, don’t bitch.”

That’s a good one, Ted, good way to put it.

You gave a presentation about cars to our group. How did it feel?

The first couple of times – nervous; but that was really nice. About my favorite car. Had everybody to talk of their favorites.

I did research in the pretty big library in Ballard. It’s a beautiful library. Boy and the roof is all… you can’t believe that. The roof is green stuff growing.

You can read the paper. At least you can do some, probably get the sports.

Sports, number one! I take a Sunday paper. The whole, one paper, takes the whole week. You know, you get frustrated sometimes.

Before the stroke, when I was a normal person per se, I thought I was. Other people were, any kinds of diseases, strokes, head injuries – all together, they were different. But after I got the stroke, I think it’s a whole different ballgame. Just, it’s hard to describe it. But, you’re on the other side of the coin. You’re there.

And, you have moved to Ballard. That’s a very big change.

I really searched it. Well, Renton is another
great little place to live. But couple things, anytime, anything here, any stores and stuff, I have to drive. You can’t walk.

And the second thing is the house is just too much to handle. So now, I’m in Ballard.

And, you know, it’s about time. One place where I cannot drive with a car, I can put my wheelchair and go.

Well, walk, but mostly, for me it’s probably a wheelchair. I don’t feel like a wheelchair is not good. I think it’s part of my life. I’m fine, I have no qualms about my wheelchair. I bring my wheelchair and I go all around.

It’s all it is, one street. That’s one of the best things, you know and like I said in the winter I don’t mind. I can’t, I don’t like anywhere in the winter. But in the spring and summer and fall, I go almost every day, just almost everyday. But I get in my wheelchair and I go. I don’t mind, which is fine, really.

Number one, I do it almost every day. And no wonder, downstairs in the lobby, they have this place where I can watch the world going by. I can just have a really nice chair, and sit in there and look at, they have the fire going.

We can see outside, and I bring my wheelchair, and even in the winter with my robe, and I watch there, for hours, and I just. Yeah, I love that, and once in a while I go at night, you know, 7, 8 o’clock at night, in the winter with the fire’s going, and I can just sit outside.

God, I love that place.

(Continued from page 3)

Restarting Stroke Support in Tacoma
The “Tacoma Area Stroke Support Group” invites area stroke survivors and caregivers to meet on April 1st from 6:30-8:15pm with Nancy Alarcon, Speech-Language Pathologist from the University of WA.

The evening will focus on the types of services available to stroke survivors and their loved ones in the community. Come and share your ideas and experiences. Join us on April 1st at the:
TACID Building
6315 South 19th
Tacoma, WA

www.tcid.org for directions and a map.

Stroke and Head Injury Caregivers Online Support Group
It is associated with the UW SPHSC Clinic, and is a place to share resources, stories, and support, as well as to access student volunteers for help with babysitting, communication partners and other services.

Stroke and Head Injury Caregivers online support group: http://groups.google.com/group/uwcaregivers

Instructions:
After clicking link above, find "Join this group" in the right hand column. It will prompt you to log in (if you have gmail) or create a Google account.

This does not mean you have to change your email. It will take you to a quick form where you enter the email you want to use and a password.

You can then choose a nickname that will show up in the discussions, and select how often you want updates delivered to your email (weekly, daily, as they are posted, etc).

It's that easy! Members can post, create discussions, upload files, and just connect in general.

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