A Conversation with Manville Jennings

By Manville Jennings and Melissa von Stein

Manville Jennings is 58 years old and has been diagnosed with Posterior Cortical Atrophy, a dementia thought to be a variant of Alzheimer’s disease. Melissa von Stein is a Care Coordinator at the Rochester, New York Chapter of the Alzheimer’s Association. We hope this conversation conducted in Rochester in January, 2011 will help others who are going through similar situations.

MvS: When did you start to notice changes in yourself that made you question that something was wrong?

MJ: It was about 3 years before my current diagnosis. I actually told my primary doctor when I was still in Portland, Oregon that I thought I was having cognitive issues but he attributed it to other things. I was having problems with basic math, spelling, reading, and writing.

MvS: When did you decide to go to the doctor?

MJ: It took me nine months to sell our home in Portland, Oregon. When I got to Rochester, my wife could see that something was going on. She had me go to our primary care doctor. I told him about my symptoms. He pretty much knew what the problem was because the first thing he did was to set me up with a specialist which led to my first diagnosis.

MvS: What were your first thoughts upon being diagnosed?

MJ: Shocked, disappointed, worried about my wife and family, and what does this all mean?

MvS: What is your understanding of Posterior Cortical Atrophy?

MJ: It has changed since my first diagnosis was Frontal Lobe Dementia. It’s complicated because it’s somewhat rare. Right now I understand that instead of settling in the memory part of your brain, the Alzheimer’s settles in the vision part of your brain.

MvS: How has the diagnosis affected you?

MJ: First, it was good to know that I was not going crazy. That alone helped us to move forward and find out what we had to do next. It allowed us to be proactive. I have had to be tested, get educated about my condition, and learn about living with Alzheimer’s.

MvS: What are the greatest challenges you encounter?

MJ: I would say number one would be the type of Alzheimer’s that I have. Communicating is always a challenge, as well as short-term memory and I have vision issues due to the type of Alzheimer’s that I have. When you add it all up it means that

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how I live my life today is very different than it was a year ago and that it continues to change. So keeping up with it is a challenge every day, and I was only 57 when I was diagnosed.

I try to take my time and not get frustrated and I either find a way to get my point across or ask for help. Where I get frustrated is when I try to do things that were very easy for me and now they are not, such as writing like this. I also have problems with sequencing, like counting money and cooking.

**MvS:** Have you employed any strategies for helping with these symptoms?

**MJ:** Only that I try to recognize what I can do or cannot do at this time.

**MvS:** What changes have you made in your life since your diagnosis?

**MJ:** The one that had the most impact is not being able to do the work that I did for over 30 years. My background was in television broadcasting as a creative writer, producer, and director. Other than that, I try to continue doing things that I like to do such as staying active and finding ways to be productive.

**MvS:** What advice do you have for professionals?

**MJ:** That’s easy. Find a cure.

**MvS:** What sources of support have been most beneficial to you?

**MJ:** My wife, Laurene, is the most important person in my life right now. I cannot imagine being here without her help. The downside is the burden that she has to carry. We do have family on both sides that have been supportive but she is here day in and day out managing our lives.

My wife and I go to support groups and I have participated in "Visions & Voices" and "Early-Stage Advisory" through our local chapter of the Alzheimer’s Association and we have also participated in "Meet Me at the Mag," "Bed and Breakfast," and other events. We get a lot of helpful information. We also meet new people who are in the same boat. (Editor’s note: See the Rochester, New York chapter of the Alzheimer’s Association’s, website at [http://www.alz.org/rochesterny/](http://www.alz.org/rochesterny/) to learn more about these programs.)

**MvS:** What do you feel is the greatest misconception about Alzheimer’s and related dementias like Posterior Cortical Atrophy?

**MJ:** That this disease only affects older people.

**MvS:** Any other thoughts or concerns?

**MJ:** I am glad that the National Alzheimer’s Association has been active and up front. I would like to see a more aggressive local grassroots effort to put Alzheimer’s on the front burner and to educate the public.
More Reasons to Walk

Researchers from the University of Pittsburgh analyzed the relationship between walking and brain structure in 426 people including: 299 cognitively healthy adults; 83 people with Mild Cognitive Impairment (MCI); and 44 people with Alzheimer’s. The researchers kept track of how far each study participant walked every week. After 10 years, all participants underwent a specific kind of MRI (brain imaging) exam that measures brain volume.

When they entered the study in 1989-1990, participants were asked how many city blocks they walked in an average week, whether for exercise, chores, or any other reason. Follow-up questionnaires every three years showed that the number of blocks walked remained steady over time. In addition, participants were given the Mini-Mental State Exam (MMSE), a brief test of cognitive (thinking) skills, at various times throughout the study. The MMSE is used to help doctors make a diagnosis of MCI or Alzheimer’s.

As shown by MRI, brain volume was preserved in healthy adults who walked at least 72 city blocks, or 6 miles, per week. MMSE scores showed walking six miles a week was associated with a 50% decline in Alzheimer’s risk over 13 years. Walking more than 72 blocks a week offered no additional benefit. People with MCI or Alzheimer’s needed to walk at least 58 city blocks, or approximately 5 miles, per week to maintain brain volume and slow cognitive decline. Over 10 years, scores on the 30-point MMSE dropped by an average of five points in those diagnosed participants who were sedentary, compared with one point in those who walked 5 miles per week. The findings showed that greater amounts of physical activity were associated with greater brain volume and may help to prevent onset of MCI or Alzheimer’s or slow rate of decline in persons who already have these memory disorders.

New Prevention Initiative

The Alzheimer’s Prevention Initiative is led by Eric Reiman, M.D., and Pierre Tariot, M.D., from Banner Alzheimer’s Institute in Arizona, in collaboration with the Arizona Alzheimer’s Consortium and other academic and scientific partners around the world. Through this initiative, researchers plan to conduct prevention trials in cognitively normal people who, based on their age and genetic background, are at the highest risk of developing memory and thinking difficulties. They are in the process of developing an Alzheimer’s Prevention Registry, consisting of healthy people who may be interested in participating in upcoming prevention trials. If your friends or family members would like more information and updates about this global Alzheimer’s Prevention Initiative or if they are interested in participating in Alzheimer’s prevention trials, they can visit http://www.ADprevention.org or call (888) STOP-ALZ (toll free).
We asked participants of the weekly early-stage Alzheimer’s support group at the University of California, San Diego’s Shiley-Marcos Alzheimer’s Disease Research Center:

**What are some of the ingredients that make up a good day for you?**

Here are the answers:

“I get out of the house and listen to music while we’re in the car. I go out with someone who takes me to the kinds of places I like to go and I select the music while he’s driving. I like serious music – classical music. I’m interested in it and it stimulates my thinking.”

“I still play tennis – I’m 91 and luckily I can still find people to play with. I also like swimming. I feel better after a swim. It keeps me from sitting around and moping.”

“My wife and I have a close relationship with our family, so that makes a good day when we talk on the phone or visit with them. Some of them live on the other side of the country so it gives us a good excuse to travel.”

“Just getting out of bed in the morning and going out makes every day a good day.”

“Getting chores done and completing what is planned and written down on the calendar. Then it feels like I’ve had a successful day.”

“Working in the garden, sewing, and talking with my sister and my husband. I’ve forgotten how to put a pattern together, but I still sew. My sons get a lot of handkerchiefs! And I like to mend things. I also paint every Saturday in a painting group.”

“Keeping our house in order in case someone comes by – I enjoy keeping things clean.”

“A martini goes into making a good day! At my age, I just can’t have too much alcohol, but it’s a way of sitting down with my wife or friends and relaxing.”

“Sailing – There is nothing like it when you’re completely independent and relying on the wind.”

“I walk and I go to the gym and that makes me feel better and makes for a good day.”

“I don’t focus on losses as much as what is good and positive. I stay busy and go to work at my son’s business, and that’s good for me. My family treats me like a king and it’s a thrill to see them all of the time. Also, making someone smile is an important part of a good day for me.”

“Eating! Going out to lunch.”

“I like to cook and garden. Ideally a recipe for a good day is half a day of activity, a quarter day of reading, and a quarter day of social time.”

“Doing anything that you enjoy is an important ingredient to a good day. Have some fun!”
HELPFUL RESOURCES

New Progress Report on Alzheimer’s Disease

The National Institute on Aging’s latest annual report on Alzheimer’s research is now available. *2009 Progress Report on Alzheimer’s Disease: Translating New Knowledge*, summarizes current scientific directions and highlights key findings from the National Institutes of Health-funded Alzheimer’s research. Findings include:

- discovery of new genes and biological mechanisms that cause Alzheimer’s;
- earlier disease detection using neuroimaging and biomarkers;
- links between Alzheimer’s and other age-related diseases;
- lifestyle factors that may protect against Alzheimer’s;
- successful cognitive aging;
- clinical trials underway now to prevent or treat Alzheimer’s and cognitive decline;
- research-tested strategies to support caregivers.

Also included are a brief overview on Alzheimer’s and tables that list ongoing federally-funded clinical trials.

The report is available free of charge online or on CD and is produced by the National Institute on Aging, the primary federal agency supporting research in Alzheimer’s and age-related cognitive change. Read online, download, or order the free 2009 Progress Report on CD by going to [http://www.nia.nih.gov/Alzheimers/](http://www.nia.nih.gov/Alzheimers/) or by calling 800-438-4380.

Taking Action Workbook

The *Taking Action Workbook*, is a guide for people living with Mild Cognitive Impairment (MCI) or early Alzheimer’s that is available from the Alzheimer’s Association. This workbook is based on the belief that we cannot let limitations interfere with what we can still do. Persons with early-stage dementia can take charge of their own health and well-being. This workbook can be used alone, with family members, or with friends and is divided into 12 chapters that address common concerns and includes educational information and perspectives of people living with memory loss.

One reader says, “If my Mom and Dad would have had access to the simple, straightforward information contained in this workbook back in the late 1980’s, when Mom was first experiencing symptoms of early-onset Alzheimer’s, it could’ve made the next several years easier for both of them (and for their kids, of course). While preparing for living with this disease is so fraught with fear, working through the steps outlined could go a long way toward assuaging the accompanying anxiety about feeling out of control.....I am going to keep the knowledge that this resource exists close and will distribute it, as the need arises.”

Torbay Dementia Leadership Group
A New Advocacy Group in Southwestern England

Editor’s note: The following information was submitted by Norm McNamara, chair of the Torbay Dementia Leadership Group. Also see his poem featured on this page.

The Torbay Dementia Leadership Group was set up in June, 2010 and is run by a membership of seven or eight people who all have a diagnosis of some form of dementia. We keep the number of members limited because with this illness, there would be far too many distractions with a large group. We work alongside the National Health Service of Torbay and also the Alzheimer Society and various dementia-related charities.

Our aim is to enrich and improve the lives of people living with dementia. One way we do this is by consulting on new booklets being published for people with dementia. We discuss and edit the proposed content of the booklets and make them easier to understand from our point of view. We also invite dignitaries from the health service and local general practice doctors to our meetings which are held twice a month at the Alzheimer Society office in Torquay.

Our goals for the future are to try and educate health workers that the need for long and lengthy paperwork is very unnecessary for Alzheimer’s patients when a few bullet points could say exactly the same thing. We also want to see doctors take a different approach towards people with dementia, especially those with younger-onset dementia.

For more information on this advocacy group, contact Norm McNamara at normmc1957@yahoo.co.uk.

POETRY CORNER
All Seeing Eyes

By Norm McNamara

As the party started, I sit and watch with glee,
The children running round, it’s clear for all to see,
That in their little world, a world so full of fun,
Excitement in their eyes, of a future still to come,
The way they look at life, through excited eyes,
Never worrying about tomorrow, today is where it lies,
We can learn so much from them, learn from day to day,
That it’s now that really matters, whatever comes our way,
My dementia is invisible; they don’t see what grownups see,
They just see their grandad, as happy as can be,
If only all us grownups, could do the very same,
Just see the person standing there, without dementia’s name.

Editor’s note: Norman McNamara resides in Devon, Great Britain. He is author of the books More Than Words: Poems Written and Spoken by an Alzheimer’s Sufferer and Me and My Alzheimer’s. Both books are available online through I-Proclaim Bookstore at http://i-proclaimbookstore.com.
Let’s Talk
Altering Attitudes about Alzheimer’s

By Deb Bryer, RN

“It makes me feel like I’m part of society again.”

“It helps me know that I’m not alone in the struggle to keep my brain.”

These quotes are from participants in Let’s Talk, an innovative program of the Alzheimer’s Association St. Louis, Missouri Chapter. Through this program, memory-impaired individuals receive friendly, supportive telephone calls from other individuals who have memory loss.

Most programs for people with dementia are developed by social service or medical professionals and may include input from people with dementia. Let’s Talk, however, was conceived of by a person with dementia. Following a needs assessment through which people with memory loss and their family members identified service gaps, a task force was formed to develop new programs. One of the task force members was Ted Grazman. At the age of 61, he had been diagnosed with Alzheimer’s. Once diagnosed, Mr. Grazman wasn’t satisfied with sitting at home and waiting silently for his dementia to progress. He was committed to keeping his mind active and to helping others. He attended task force meetings, speaking passionately about a telephone-based peer support program he envisioned that would allow people with early-stage dementia to reach out to one another. Aided by one of his sons, Mr. Grazman developed his idea into a formal program proposal that he brought to the task force. The entire task force was won over. His proposal was used as the basis for a successful grant application, and Let’s Talk became a reality.

Since 2004, just as in Mr. Grazman’s vision, volunteers with early-stage memory loss have been coming to the Alzheimer’s Association office in St. Louis where they make telephone calls to others with memory loss. Call volunteers and call recipients share coping strategies, provide emotional support, offer friendship, and empower one another through sharing their personal experiences.

For the call recipients, it may be the one time they can talk to someone who really understands what they’re going through. One call recipient mentioned feeling shame about her diagnosis. The Let’s Talk volunteer told her, “It’s nothing to be ashamed of. It’s just like if somebody broke their arm and it had to be in a cast. Nobody would say anything about that, would they?” Another volunteer, talking to a depressed call recipient said, “I don’t have anything to give you that’s golden, but don’t ever give up. Keep trying to find something that will keep you happy. Find anything to do and keep doing it.”

Let’s Talk reaches individuals in rural areas, those who live alone, and those who can’t get out to attend other support programs. Currently, it serves people with early-stage memory loss in Missouri and in ten neighboring Illinois counties. For more information, contact the Alzheimer’s Association St. Louis Chapter at 314-432-3422 or 1-800-272-3900 and ask for Deb Bryer or email to debra.bryer@alzstl.org.
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