



A loving mother  
with her son

## *In loving memory of Ilene Veltman by her son Jeff...*



A loving son with  
his mother

How do you say goodbye to your mom?

On May 16, 2007 I said goodbye to my mom, Ilene Veltman. She died from PSP - progressive supranuclear palsy. She was only 71 years old. I am her youngest child and I was the last person to say goodbye to her on her final day.

When we look back at photos we see early signs of the disease around 1999 with a noticeable difference in her eyes which we later found out is called 'sun setting'. It is possible that she may have had it even earlier, which means she lived with this disease for about 10-15% of her life. The majority of her life she was a healthy, happy, independent, optimistic, and vibrant woman. To witness the degenerative effects of PSP on someone of her nature was undoubtedly the most challenging thing I have ever had to experience so far. In her final days she was unable to feed herself, go to the bathroom alone, talk, and move for the most part. In the very end she couldn't even get out of bed.

I admit it is challenging to see the "glass half full" with PSP -- however I should note that we were fortunate in some regards. One thing about PSP is you certainly are afforded many chances to say your goodbyes. Another thing about witnessing this disease, as it was when my wife had cancer it does put things into perspective. Life has a way of taking your eye off the ball, in other words the things that are most important to you. For me it is those I love; my family and friends.

It's all too easy to get wrapped up in life's 'little' daily 'problems' - making sure you can pay your bills, keeping a business a float, from time to time an irrational three year old child and many other challenges. It's these daily complications that make us forget how important it is to take that giant step back and look at things clearer instead of stressing out. I know this is easier said than done, however when we are confronted with an illness like PSP it does give you that wake up call you need to put things into perspective. We get way too comfortable in our lives and tend to forget how good we have it.

I should also mention that we were very fortunate to have had superb, in-house nursing care. In the end, my mom had nurses 24-7 with two nurses per shift on certain days. In addition we had a very caring and helpful staff from the hospice center. Lastly, my mom had regular visits from a massage therapist who practiced a progressive style of Asian message therapy. I know this is not something everyone can afford; we do consider ourselves very fortunate to have had this type of care.

It took a long time to reach the true prognosis. At the beginning, the doctors thought it was frontal lobe disorder which is really a general way of saying they didn't know what was up. Then, the doctors said it was a Parkinsonian-like disease. When they finally diagnosed my mom with PSP it was, to some extent, a relief to have a name for my mom's illness even though there wasn't a cure. At one point my mom underwent surgery to relieve pressure on her spinal chord. After the surgery, for a single day, there was a noticeable difference. She was talking like she used to and she said her head felt "clearer". It was a wonderful feeling as if we were awakening from a nightmare; unfortunately it only lasted one day.

There were many symptoms we noticed in the early days of this illness that, at first, we didn't know why they were happening. At the time my mom was overly agitated when it came to making plans. She called us on the phone a lot. We thought it was because her dad was dying of cancer. Her father also noticed something was different about her but we all just thought it was stress. She also began to have problems with her balance and started to fall backwards. It was around this time that my folks decided to move out of the house I grew up in since it had two floors. They moved into a ranch style apartment which made it much easier for her to get around.

Over time it became increasingly challenging for her to communicate. For a while she was 'parroting' everything we said. Towards the end my mom merely made guttural, almost moaning-like sounds, which after a while, we all became accustomed to. From time to time she would use single words so the nurses would know what she needed. One of the more difficult aspects of PSP was that my mom clearly understood what was going on around her; she just couldn't express herself. Every now and again she would laugh at a joke that was said in the room. Granted her humor became debased and she found toilet humor to be the funniest, but we didn't care; it was always nice to have a good laugh.

My mom's inability to communicate was something that deeply troubled me. I would lay awake at night thinking about how hard it must be for her to lose her speech. It took me a while but I finally came up with something that was really quite simple and effective. It was a binary method of communication, similar to how computers 'talk'. We would simply ask her a 'yes' or 'no' question. If the answer was 'yes' then she would squeeze our finger once. If the answer was 'no' then she wouldn't squeeze. This actually worked quite well for a little while.

Now that my mom is gone there are two things that plague me, both of which have solutions. One is that I find myself asking if there was more I should have done. I visited her every Friday afternoon with our three year old son and then again, every Sunday with the family. Recently a very good friend of ours lost his step-father to Parkinson's disease. We both agreed that we can't tear ourselves up by asking these questions. The bottom line is we did as much as we could and to leave it at that.

Another thing I find disturbing is that the general public is unaware of PSP; even some physicians are unaware of this disease and many cases are diagnosed as Parkinson's disease. More funding is needed for research to help find the cause, treatment, and cure of PSP. In addition, we need to educate the general public about this disease so that they can become pro-active about finding the correct diagnosis for their loved ones; particularly when the traditional treatments for a misdiagnosed disease are not effective.


With only 20,000 people in the United States with PSP, you can imagine our surprise to find out that one of my oldest friend's mother was also diagnosed with PSP. She has only had it for shortly over two years. I should mention my friend and I grew up only six blocks from one another. I have often wondered if there is something locally in the environment that may have contributed to their shared illness.

The last thing I'd like to say before I end this letter is how my family shares a common feeling about my mom's passing. Many of us have conflicted emotions now that she is gone. On one hand we are relieved that she is no longer suffering from this debilitating illness, however, we also feel guilty having these feelings since we sorely miss her as anyone would when you lose a dear member of your family.

Please join me in supporting the programs and services of CurePSP. With your help, we can continue to educate communities about progressive supranuclear palsy, support those affected by this disease and find the cause, treatment, and cure for PSP.

Thank you for letting me share my story with you in memory of my mother – Ilene Veltman. I appreciate your taking the time to read this.

Peace,



Jeffrey Veltman

P.S. To see a tribute page, as well as information about our upcoming fundraiser, please visit [www.jbinteraction.com/ilene](http://www.jbinteraction.com/ilene) and [www.jbinteraction.com/psp](http://www.jbinteraction.com/psp). To read more information about PSP visit [www.curepsp.org](http://www.curepsp.org).