

Society for Neuro-Oncology Speech
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By Susan Sontag

I'd like to thank Dr. Guha and the Staff at SNO for giving me the chance to speak. Over the last 12 years I've had the opportunity to talk to a lot of doctors. But they weren't all in the same room at the same time like tonight. So it's a little overwhelming.

You've probably heard many stories like mine before. But I'd like to tell you my story anyway, so that you're reminded of why you've chosen the career path you have.

I've known Rick now for over 50 years. For 40 of those 50 years everything was great. We went to junior and senior high school together. (I was the class salutatorian. Rick wasn't). Then we both graduated from colleges in Claremont, California. I attended Pomona. Rick was at Harvey Mudd. We were married shortly after graduation and raised three children together.

By the early 1990's our children were off to college. Things were settling down. But I was still busy with volunteer work, church and the usual things that women do to keep engaged with life. And Rick was seeing the real results of almost 15 years of building a company from next to nothing to an international corporation. Life was good. Probably not too different from the lives many of you have right now.

Then in June of 1994 Rick and I had our world changed forever. Overnight I lost my short-term memory. I was confused and nauseated. I lost my balance. I didn't know what was happening to me.

At first the doctors at Mayo Clinic thought I'd had a stroke. But then after almost 4 months of testing and waiting I got even worse news. I had a Category 3 astrocytoma. The odds then were that I wouldn't be on this earth longer than about 18 months.

But after an experimental treatment protocol of radiation and chemo a miracle happened. I lived. And I'm standing here today in front of you 12 years after that dreadful diagnosis. I'm not sure what the odds are of this happening. Rick calls me the lone data point on the far end of the bell curve. I'm not sure what that means. But I suspect it means there aren't many others who have made it as long as I have.

My survival comes with a penalty, however. I'm sure most of you are well acquainted with my kind of slow speech, slow movement and confusion that comes from the cancer and its treatment. So it should be no surprise to you to know that the most devastating thing about this disease is that it has changed who I am.

I am no longer positive and confident. I can't perform many of the simple tasks I used to take for granted—like cooking meals. I am at a loss in a social situation. In short I am no longer the Susan Sontag I used to see in the mirror for all the years before this happened.

It has been very difficult adjusting to my new persona. I remember when I was competent. I remember when I was strong. And I remember how I could manage my life and the lives of three children with ease. It makes me sad that I am no longer that person.

So when you leave here and go back to your clinics and labs and have that bad day and need some motivation to get over that next hurdle, think of me. Or think of you or your spouse facing the situation I now face. It should reassure you that you made the right career choice. And maybe, just maybe, it will provide that spark you need to find the cause and a potential cure for this devastating disease.

Thank you.