

Brain Donation

In May of 2002 after two years of scans and tests to eliminate everything else, we were told that Jack, my husband, had Alzheimer's Disease. The room, where we were standing, so many details of that sad moment are still fresh in my memory. Our doctor at the Gerontology Clinic was excellent, caring and competent, but as time went on, I often asked about the diagnosis, since what I observed in my husband didn't quite fit the typical symptoms of AD. He was involved in several Stanford/SRI studies, all non-invasive, naturally, and apparently none of the MRIs indicated that he had anything other than AD

Long ago my parents had both willed their bodies to the Yale Medical School (My mother was pretty tickled that she would be matriculating at Yale). My father had been diagnosed with AD in 1967. When he died, my Mother asked for the autopsy results, and it was found that he hadn't had AD, although the outcome was likely the same. Given that there may be hereditary factor in AD, it was a relief for my brother and me that we didn't have that in our family medical history.

When my husband's abilities were declining markedly, I wondered if his brain might be useful in research, and for our three son's sakes I hoped to find that Jack hadn't had AD. And, of course, we wanted to know what had caused all that grief. I didn't now where to start to make arrangements, or if it would be both possible and affordable. Fortunately, Solna Braude, a fellow support group member, knew the steps from her own experience with her late brother.

She gave me contact information for the Parkinson's Institute in Sunnyvale and described the brain research going on at the Mayo Clinic in Florida, which focuses on Parkinson's and Alzheimer's. They sent me information and paperwork. There was no pressure, the decision to send them Jack's brain was entirely up to our family. Since there is necessarily a short timeline between death, harvesting and sending the brain to Florida, I needed to be sure in my mind that I was doing the right thing for Jack, and I needed to tell the doctor, the funeral director, the Parkinson's Institute immediately when Jack passed on that part of him would be going to the Mayo Clinic.

I appreciate that this is difficult to consider. It was for me, and I was already totally convinced that it was the right thing to do, that it would be Jack's legacy to his family and to research which might help others in the future.

The Parkinson's Institute met the funeral director at the crematorium the day he died, harvested Jack's brain, packed it protectively and sent it to Jacksonville. (There was no charge to us.)

About a year later the PI forwarded a copy of the Mayo Clinics exhaustive report which they had just received. I had no idea that so much would be considered. Turns out he had not AD, but Lewy Body Disease, with only mild Alzheimer's indicators. Would it have made a difference in his treatment if we had know this in 2002? Would it have made a difference in the outcome? We can not know. Dr.Langston at the Parkinson's Institute kindly invited us over and spent considerable time with one of our sons and me going over the report and explaining the significant findings to us. He thanked us for the role Jack's brain would play in current research and in the future, since it would be preserved to be studied again as there are new discoveries.

If you would like more information, feel free to contact me through the Parkinson's Institute.

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