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Join Me – Donate your Brain to Research to Find a Cure for Alzheimer’s

By David Bull - www.caregiver4caregivers.com

Reality is ... that the only way to know 100% if someone has Alzheimer’s is by completing an autopsy. And yes ... I can tell you it was confirmed that my mother did in fact have Alzheimer’s.

Even though Mom was formally diagnosed with Alzheimer’s disease years ago and has now been gone for several years, I recall the initial reaction I had when I was told the story of how both her and my father had made the decision to donate their brains to research.

My mother had volunteered to be part of a drug testing program at the time, known today as ‘Excelon’. During the initial setup and testing for the program she was asked to consider the concept of donating her brain for research. Apparently, and typical of my mothers community minded spirit she readily agreed, but then came the twist. She looked over at me father who had accompanied her to the testing of course and just gave him that look that wives seem to always have. That unspoken way of saying “WELL!!!!” ... the end result was that both brains were now going to be donated for research into finding a cure. My father’s only comment was to say “well I’m using it at the moment but when im finished with it ...”

All these years later this brain donation story has become a source of humour in the family. Apart from the obvious legal aspect of setting up the inevitable time where the brain actually changes hands and any updates or renewals to the paperwork involved.

Every so often my father, comments about having to go to the brain bank. This is followed by a barrage of terrible puns and other comments relating to:

- Does he still have the brain and do they still want it?
- Is he caring for it or is it somehow getting damaged?
- After the testing ... will he get it back ... because he is still using it?

Despite all this joking there is a serious reality that families really should discuss openly and with the goal of preparing for the future ... The human brain is complex and difficult to study in living people. It is also too complicated to replicate in the laboratory. Therefore, much of the research into Alzheimer’s disease and other dementias relies on examination of brain tissue that has been donated after the person has died. This research allows scientists to investigate the basic underlying causes of dementia and, if possible, to discover how they relate to the symptoms experienced by the person during life. This work is also essential for observing the effects of currently available treatments for dementia. Better understanding is the first step towards better treatments.

Many people with dementia and their relatives are interested in the possibility of brain donation for research after their death. Scientists are very

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Join Me – Donate your Brain to Research to Find a Cure for Alzheimer’s (continued)

grateful for the generosity of the families concerned, especially as this process has to be carried out very soon after the person’s death. To ensure this research is thorough, it is also extremely important to have access to brain tissue from people who do not have dementia. This is known as control tissue, and is in even shorter supply than tissue from people with dementia. It is crucial that scientists have control tissue so that they can compare it directly with tissue from a person with dementia. These valuable donations are essential for developing new and better treatments for people with dementia and in the search for a cure.

Brain tissue donation must occur as soon as possible after death, ideally within 48 hours. Since this is a distressing time for the family, it is important to

discuss brain tissue donation in advance and make sure an arrangement is in place. With research by family members arrangements can be made to assist with the process and in many cases the funeral director can also take on the responsibility if organized in advance. It is a short procedure and does not interfere with funeral arrangements. The body is then returned to the funeral director chosen by the family.

In my case I’d like to believe that I will still be using my brain for some time ... but then you never know ... in the meantime its a worthwhile discussion to have with your loved one .. let’s face it .. as a caregiver I would prefer to see a cure than have to go through a caregiver role or even worse be the one requiring it.



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