

BRAINS FOR DEMENTIA RESEARCH

Increasing knowledge - Finding a cure

A partnership between the Alzheimer's Research Trust and Alzheimer's Society

Testimonial

Donating one's brain for dementia research: A personal perspective

Fifteen years ago my husband began to suffer from memory problems. He decided to take early retirement from work, sought medical advice and was diagnosed with Alzheimer's disease the following year. He was 57 and we had been married for just 7 years. One of our ways of coping was to become involved in research and when the subject of brain donation was broached it seemed a relatively easy decision to make. We were both of the opinion that after death anything which could be of use to future generations could be removed prior to the funeral. Our early upbringing during post war shortages may well have influenced our "make best possible use of everything" philosophy. Now, 8 years later, Ted has reached the end stages of this devastating disease and I can only hope that if he was able to be aware, he would still want the donation to go ahead. Experiencing Ted's dementia journey has, for me, turned what was essentially a practical decision into an emotional one. This disease must be conquered. If I go away I become quite anxious that his Care Home will forget about the arrangements and I re write them at the front of his care plan. For me, I have to trust that my children will remember. It has become very important to me that we have this chance to contribute to research.

Making the arrangements for donation at a time when the end of life was still way in the future and when Ted had gone through the trauma of the diagnosis but could still fully understand the process, was ideal timing for us. However as a second marriage following divorce and not sharing children we had become accustomed to making decisions between ourselves rather than as a family. The advice is to discuss donation with your family but we didn't do this, we merely informed our children.

I began to explore thoughts about brain donation more widely when I was asked to talk about it on a training day. I discovered that although many people had signed up for organ transplant purposes, none had donated their brains. None knew that healthy brain tissue was needed although some, whose partners had dementia, had arranged donation of their partner's brain, mainly for diagnostic purposes. This finding has recently been echoed in a survey commissioned in the UK. Feelings about brain donation were generally positive. One person actually preferred the thought that her father's brain could be used for research to the thought that someone else could be walking round with his heart or other organ inside them. However a few were uncomfortable with the idea but didn't know why. On discussion we decided it was because although the heart is essentially a pump and a kidney is essentially a filtration system, your brain is who you are – the mechanism behind all your thoughts, your knowledge your skills and your personality. I think this feeling is very important. Through taking part in some research I was given a picture of part of one of the scans of my brain and I think it's amazing that inside this structure is everything that makes me *me*. It is what enables me to weave 60 bobbins into a complicated lace pattern and in my husband's case enabled him to produce amazing sculptures.

I have heard a brain Bank described as a diagnostic service for families and a research resource for scientists. As well as wanting to aid research I do eventually want to know whether the pathology found in my husband's brain matches the clinical signs he has shown during the course of his illness. Is this morbid curiosity? I know it's important for me, possibly because I've always been more attracted to Science than Arts in my education. But does this mean that I no longer care about my husband's body? I have spoken to people who are not comfortable about their loved ones undergoing a post mortem. Can we be confident in the rhetoric which states that their body will be treated with dignity and respect and that the dissection be as minimally invasive as possible?

On exploring religious responses online I discovered that the only religion against donation is Shinto. People of this faith consider the dead body to be impure and dangerous and believe injuring a dead body is a serious crime. Nevertheless I have heard anecdotally that some priests may advise against donation and also there may be practical problems when the faith says that the body must be buried on the same day as the death. I have had discussions about whether the removal of someone's brain could somehow interfere with what happens to the spirit immediately after death. Some spiritualists believe that organ removal may leave the departing soul earthbound. Others say that if the donor has agreed then this final act of generosity accumulates good karma. While online I discovered discrepancies between different sites relating to how much time may elapse following death, for the donation to be effective.

Re reading our own paperwork it says that a report on the post mortem is routinely sent to the consultant and the GP. If requested a report can also be sent to the family. In my husband's case he is no longer under the active care of a consultant and his GP is the GP who visits the Care Home and not the one who supported us both throughout his illness until he no longer lived at our home. In our case I would prefer the report to come to me and for me then to be able to choose which medical personnel I wish to support me in understanding the contents.

To summarise:

- People won't necessarily think of donation for research and a direct approach will be needed in most cases.
- Timing is important
- Relationships within families are not always straightforward
- Giving accurate information about post mortem details requires great sensitivity
- Understand that spiritual beliefs are complex and not always logical
- Clear instructions are needed about what to do following the death
- Discuss with the family how they wish to receive the diagnosis.