Why I support brain banking

Parent Dame Stephanie Shirley, who is also an entrepreneur, philanthropist and founder of The Shirley Foundation, explains why she thinks donating the brains of autistic people for medical research is so important.

BY DAME STEPHANIE SHIRLEY

"WE KNOW THAT autism is brain-related and researchers know the importance of brain banks allowing access to post mortem brains. But why should anyone sign up to brain banking, which most people find distasteful?

“The Shirley Foundation founded the medical research charity, Autistica which funded the Oxford Brain Bank. I’m proud that my son’s brain is in it and he can help medicine by providing detail that you just can’t get from MRI.

“I’m also proud that (Oxford being a partner) his precious brain tissue can contribute to BrainNet and similar international collaborations. It means a lot to me that his brain can help others now that it is no longer of use to him.

“Control tissue from people not affected by autism is needed for comparison so my brain is scheduled to also go there on my death. Of course, it’s not easy to face one’s mortality. My tissue donation is the very last gift I shall make.

“I like to be practical. When travelling, I carry a plasticised card summarising the actions to be taken immediately on death (or beforehand). Time wasted in not contacting the organisations concerned may mean that my body cannot be used as I intend.

“An autism brain bank is being planned in Canada, but only the UK, Netherlands and USA have brain tissue from autistic people. Worldwide there are only about a hundred autism brains and it’s a real challenge to get more. The UK gets only one or two brains each year.

Resistence to organ donation

“Personally, I hope that the law is changed so that all body parts can be harvested post mortem, subject to individual opt-out. Until that happens, recruitment can only be significantly improved by working with parent-led organisations.

“Psychological, cultural and practical factors affect both donation and tissue collection. From potential donors and their families, yes, but professional resistance has also proved to be a major issue. No-one had anticipated how strong and widespread this negative response would be.

“Brenda Nally, who was Autistica’s outreach worker, tells me that experience to-date has been that professionals who work with autistic people and their families have resisted passing information to them about research and the need for brains to be donated. Perhaps they feel that to raise the subject would be insensitive.

“Some societies believe that the body must be whole and complete in order to move to whatever is considered its next phase. Most civilisations have a strong respect for the human body, whether alive or dead and practices refer similarly to organ donation as to post mortem material. British culture accepts burial and cremation but is squeamish about cutting into human bodies, perhaps especially the head.

“Brains have to be removed and collected within two days of death. I saw my beloved son in his coffin after his brain had been removed. He was wearing some sort of bonnet and looked perfectly okay. A gruelling two-hour interview to capture his social and medical history included being..."
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asked for instructions on the fate of any tissue deemed to be no longer of use. As I guess most people would, we gave consent to lawful disposal via hospital incineration. It was all very tactfully handled.

“Such discussions taking place immediately after death, when families are still in shock, can be distressing. It can be helpful to speak of the deceased contributing to research and so, in a sense, living on. People making the pitch for brain banking have to have warmth and compassion as well as science.

My reasons for donating
“Focus groups for affected individuals and their relatives can help to determine what motivates brain donations, and what puts people off.

“I understand why people have reservations: the brain being the very basis of personality, the seat of consciousness… the emotions crackling through its neurons and synapses prompt theories of mind and of the soul.

“But I feel that my son’s brain being used for research gives dignity and meaning to his troubled life. It’s not just an empty loss.

“Some people suspect that research is a eugenics-driven attempt to eliminate autism. This is deeply misleading. Research is needed to understand and clarify the different ways in which autism affects the brain and so ultimately improve each person’s quality of life.

“Most families with experience of autism are very positive about supporting brain research, once they are able to gain information and appreciate how future generations will benefit.

“The families of existing brain donors are equally positive about their experience of contributing to the research; nor do they come to regret their decision.

“Crucially, those people with autism who have been able, prior to their death, to make an informed decision to donate their brain, have also been keenly motivated to do so.”

A word on governance
“Some families will want to know about governance. They seek reassurance that post mortem tissue is treated properly – as carefully and respectfully as a living subject.

“The Medical Research Council initiated the UK Network of Brain Banks and provides assurance. Its Steering Committee has expertise in ethics and the law, as well as brain banking. As scientists everywhere are learning to do, there’s also non-professional representation.

“Donation is not always possible – there may be medical, technical or even ethical reasons why it is inappropriate in an individual case; the decision to donate a brain is essentially personal and must never be taken under pressure. But there is a strong need for us all to give it consideration.”

Find out more
• You can read The National Autistic Society’s position statement on brain tissue donation at www.autism.org.uk/brain-tissue-donation. If you have a viewpoint on this difficult issue, we’d love to hear it. Email yourautismmag@nas.org.uk or post on Facebook.
• The Brain Bank for Autism’s Helpline number is: 0800 089 0707