

FREQUENTLY ASKED QUESTIONS ABOUT BRAIN DONATION

Why should I donate my brain? Why is it important?

Donating your brain tissue in the hours immediately after your death will add to our current understanding of what causes many movement disorders. This gift of brain tissue advances our understanding of these neurological disorders and is one step in the path to a cure. Direct analysis of the shape of the nerve cells, its contents [what abnormal cell bodies are inside the nerve cell], what abnormalities are seen outside the nerve cell, how the nerve cells communicate with each other and where exactly in the whole brain are there consequences of these initial nerve cell changes. These changes are then compared with your medical record, including, if possible, a videotape of your motor examination. Technological advances [tools for analysis] make brain donation now even more important than 50 years ago when this technology did not exist. Recent tools for analysis include biochemical assays, staining techniques that uncover deficits not otherwise seen, electron microscopes that allow us to look at the internal organs of the nerve cell and what crosses the cell membrane behavior and genetic probes to understand the code that directs nerve cell growth and behavior.

When do I need to make a decision?

When you are thinking about it [like right now]. When you can weigh your options and make an informed choice. When you are writing down your advance directives about how you want to be treated when and if there comes a time that you cannot make those decisions for yourself. When you read the information about a brain donor program and discuss your options with your family [especially your life partner or adult children]. When you share your thoughts with your religious leader. When you discuss brain donation with your doctor or other health care professional. When you realize it is a precious gift to neuroscience and to your family. When you understand that it costs next to nothing...a few stamps and a few phone calls to set up a plan.

How do I make a decision?

Make your decision freely. First, learn as much as you need to know. Discuss the options with the people you trust will follow your wishes. Make your own personal decision and explain that decision to the people you trust. Listen to your family. Listen to your doctor. You can decide to not donate your brain. Those whom you trust must respect your wishes. Making no decision at all leaves all the hard choices to those whom you love at a time when they are mourning your passing. So, be sure to take care of those closest to you. Is it “yes,” “no,” or “maybe?”

Are there any religious considerations I need to think about?

The majority of world religions supports autopsy [the legal name that covers organ donation] if there is a hope this knowledge that will improve the lives of others in the future. The majority of world religions recognize the mandate to heal and the call to compassion. This gift of hope may provide relief for those who have symptoms now and may also provide a healthier future for generations to come. Please consult your religious leader to learn how your religion interprets brain donation.

What is the procedure for brain donation through the New York Brain Bank?

- Call the research nurse at Columbia University's Center for Parkinson's Disease and other Movement Disorders at 212-305-5779. Speak slowly and clearly. Leave your complete name, address including zip code and your telephone number. Tell her you want to receive information about the brain donor program for movement disorders. It will be mailed promptly.
- Complete a single page personal plan listing the names, addresses and telephone numbers of your next of kin, your family doctor, the neurologist who diagnosed you first, the neurologist who has cared for you more recently, the funeral home you plan to use and any comments that will help us understand your preferences. If you have participated in a clinical research study, it would be important to add that information at the bottom. If you are concerned that those closest to you are uncomfortable about your plan, you can also sign and date a Letter of Intent that explains the reasons why you have made this choice.
- Mail the single page plan [and Letter of Intent, if you wish] in the pre-addressed envelope provided. We will review your information, send you a thank you note and answer any remaining questions. You are welcome to call any time to update information or change your mind.
- At time of death, call the 24 hour EMERGENCY PAGER: 917-899-2045. Page the doctor immediately. You can expect a return call within minutes. Do not hesitate to page again. We understand that this is an anxious time. Hearing twice from your family is better than having never gotten the call at all. We are on-call 24 hours a day, 7 days a week, for emergencies and brain donation. Over the telephone we work together with your next of kin, family or friends to carry out your wishes. Your personal plan offers us a framework to accomplish your goal within hours of your death. Your family doctor or the doctor who knows the circumstances of your death and is close at hand will complete and sign the death certificate before the funeral home transports your body to the pathology suite.

What will happen to my brain? How will it be used?

- The brain tissue is analyzed to establish an accurate diagnosis. Diagnosis of most movement disorders can only be made with greatest accuracy after brain tissue is examined directly. We then use the tissue for scientific research purposes to understand the process that causes the loss of cells or chemicals in the brain. This basic research provides new avenues of exploration into developing new therapies.
- Brain donation [also called post-mortem examination or autopsy] will not disfigure your body. A specially trained physician, a pathologist, who is as skilled as a surgeon in performing the procedure, performs the examination. The skin incision is at the back of the skull. An open casket is possible.
- The entire body does not have to be examined. In almost all cases, the examination is limited to the brain. This is sufficient to enable us to make a diagnosis and carry out biochemical assays, histological analyses and other techniques to understand the brain.
- Brain donation will not delay the funeral. Since brain donation is done within hours of the time of death, we are able to work with your family and funeral home to transfer your body for immediate brain donation so that funeral services are not delayed and religious mandates are met.
- The cost of brain donation is free of charge. Only the cost of telephone calls made by your family to our on-call doctor, your local doctor, your funeral home and the bonded telegram service is incurred. Transportation and autopsy services are pre-arranged by the brain donor program coordinator [212-305-5779] and funded by generous foundations.

What is the background of the New York Brain Bank donor program?

The brain donors of the 1940s and 1950s provided neuroscientists with tissue that allowed us to discover that a lack of available dopamine caused the signs and symptoms of Parkinson's disease. The Nobel Prize for Medicine was shared by Arvid Carlsson who made this discovery in the early 1960s. Many academic neurologists used to facilitate brain donation for their patients. The neurologist would call the pathologist who would agree and do the brain removal at no cost. At this time, the economics of most hospitals prevent such casual generous arrangements. Therefore, the New York Brain Bank provides this service for families of people with movement disorders across the USA.

Please discuss brain donation with your movement disorder specialist and encourage this doctor's participation in your plan. Pre-planning is essential, less stressful and less costly.