

#### Why is brain donation important?

Brain donation is helpful to both family members and researchers. A brain donation and the resulting brain autopsy can either confirm or disprove a diagnosis of Alzheimer's disease (AD) or other dementia. Many families find that getting such diagnostic confirmation provides closure or resolution to the caregiving experience. An autopsy report also may help to minimize concern and confusion during future discussions of the family's medical history.

Brain donation also contributes greatly to scientific research. The information that it provides is vital to researchers who are working to better understand the effects of neurodegenerative disease on the brain. Without this research, the development of better treatments would be limited. She [my mom] thought of it as an especially important thing to do, having seen her mother, father, and mother-in-law go through dementia. She passed on a weekend, but it all fell into place. They [the ADRC and the funeral home] worked together to take care of everything. When you care for someone who has Alzheimer's disease and you have been exposed to the disease, I mean ... why wouldn't you do it if it can make other people's lives easier?"

> Terry Hays, son of ADRC brain donor Marie Hays



UPMC Montefiore Suite 421 West 3459 Fifth Avenue Pittsburgh, PA 15213-2582

412-692-2700 adrc.pitt.edu



University of Pittsburgh



## How does an individual enroll in the Brain Donation Program?

An individual can indicate his or her interest in the Brain Donation Program at any time prior to death. We recommend that you contact the Alzheimer's Disease Research Center (ADRC) 24-hour phone line at 412-692-2700 as soon as you make the decision to participate in the Brain Donation Program.

There are no special procedures at the time of death, but it is very important to have the brain autopsy performed before funeral preparations and ideally within 12 hours of death to be of maximum research value. There is, however, still immense value in having a brain autopsy performed between 12 and 24 hours after death.

#### Who can authorize the brain donation?

The legal next of kin of the deceased must authorize the brain donation before the brain autopsy can actually be performed. This is done via a group phone conversation with ADRC personnel shortly after death.

#### Who receives the results?

A report is sent to the deceased's next of kin within several months of the completion of the brain autopsy.

#### What effect will brain donation have on funeral arrangements?

Brain donation should not have any effect on a person's funeral arrangements. The procedure is performed very carefully, in a manner that does not interfere with plans for open-casket viewing. Arrangements to expedite the procedure for religious reasons can be made.

### Should families talk to their funeral director in advance?

Yes. We recommend that families work with funeral directors to make as many prearrangements as possible. Planning ahead can help to avoid increased stress at a very difficult time. If you do not have a funeral director, we encourage you to consider selecting one in advance.

### How does the deceased get to and from the brain donation site?

Transportation is generally provided by the funeral home. If this is not possible, the ADRC can arrange for transportation through a service. Costs will be covered by the ADRC for center participants.

### Can individuals without an AD/dementia diagnosis enroll in the program?

Yes. It is very important to study the brains of individuals without a diagnosis of AD or other dementia. Researchers are interested in learning more about changes that are found in the healthy brains of older adults. This will help to identify exactly which brain changes are related to disease and which are related to aging.

## What is the cost of participating in the Brain Donation Program?

For ADRC participants, there is no charge for the brain autopsy procedure.

For additional information about the Brain Donation Program, please call the University of Pittsburgh **Alzheimer's Disease Research Center** at **412-692-2700**.

# ADRC

**Alzheimer's Disease Research Center** Brain Donation Program

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