

### **Is autopsy the same as body donation?**

No. An autopsy is an examination of the body to determine the cause of death. Persons participating in body donation can also have an autopsy.

### **When should plans be made for autopsy?**

The moment of death of a loved one is a time of great emotional stress. Discussion of the need for an autopsy may be intrusive at this time. It is usually less difficult to deal with this decision before death. It is important to make the necessary arrangements for autopsy well in advance. The person's doctor and the funeral home director should be informed of the family's decision.

In addition, family members need time to discuss this issue and to explore any possible disagreements.

As valued members of the Seattle Longitudinal Study you are in a unique position to contribute to scientific research.

### **How will the family be informed of the autopsy findings?**

The next-of-kin will receive a letter from the University of Washington research physician explaining the major findings.

### **How do I find out more?**

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Seattle Longitudinal Study  
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Suite 206  
Seattle, WA 98109  
(206) 281-4050

## **GIVE THE GREATEST GIFT**

### **TISSUE FOR RESEARCH ON THE AGING BRAIN**

You are probably familiar with organ donations of the heart, kidneys, or eyes to sustain the health and even the life of persons in need.

Similarly, the donation of brain and other tissues to research is a precious and unique gift; it will help scientists understand the nature of the aging brain and other major organ systems in normal adults.

Future generations will benefit from this gift which could lead to successful treatment and prevention of illness.

## **Why is tissue needed for scientific research?**

Examination of the major organ systems can open the door to many of the mysteries of aging. New and innovative scientific techniques are being used to study the changes that occur in the normal aging process. Comparison of a person's mental abilities test scores and changes found in major organ symptoms may help the understanding of the normal aging process.

As surprising as it may seem, we still do not know what changes occur in the bodies of healthy persons as they age. Most studies have been done in younger people. Without tissue of normal elderly people for comparison, scientists cannot determine precisely which changes are related

to disease and which are due to the normal aging process. Especially important is tissue from normal individuals who have mental abilities test scores to use in the analysis.

## **Is there any charge for autopsy?**

No. Ordinarily the cost would be between \$1000 and \$2000. However, there is no charge to our research subjects or their families.

It is important to choose a mortuary ahead of time. One of the services some mortuaries provide is transportation of the deceased. The University of Washington provides transportation of the body from place of death to University Hospital where the autopsy is performed. The University of Washington would then provide

transportation from the U of W to the funeral home after the autopsy.

## **What effect will an autopsy have on funeral arrangements?**

An autopsy should not affect any of the funeral arrangements. It is possible to have an open casket. Removal of the major organ systems, under the supervision of a pathologist, does not leave any apparent marks. An autopsy is done as soon as possible after death.

## **What is the procedure for providing autopsy consent?**

The Autopsy Consent and Authorization should be obtained from the person involved and the legal next-of-kin. Doctors will need assurance that the family is in general agreement on allowing the autopsy.

University of Washington Neuropath Core  
Brain Aging and Neurodegeneration Brain Bank  
Autopsy and Tissue Donation to Brain Bank

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Instructions on filling out:  
Autopsy and Brain Donation Program Consent Form  
&  
Consent for Autopsy Form

The Legal Next-of-Kin must sign these consent forms. A non-relative cannot sign for a donor unless they have been specifically authorized to consent to autopsy in a Durable Power of Attorney (DPOA) document. If there is no Legal Next-of-Kin or a person authorized to consent in a DPOA, then consent may be given by a person who has been officially appointed as the Executor of the Estate.

Those areas of the forms that need your attention are highlighted in yellow.

Autopsy and Tissue Donation to Brain Bank Consent Form:

The donor, if able, should sign and print their name, and date, where indicated. The Legal Next of Kin or Legally Authorized Representative should sign and print their name, and date, where indicated.

Consent for Autopsy:

The Next of Kin or Legally Authorized Representative should sign and print their name, and date, where indicated in addition to providing their initials, phone number and address where indicated. The Consent for Autopsy also requires Witness signature and printed name where indicated.

**What is the "restrictions" line on the Autopsy Consent for?**

This line allows the person authorizing autopsy to specify any wishes such as "brain only", "open casket", "body donor", etc. Please add any additional restrictions important to your family.

**Can husband and wife consent for each other?**

Yes. However, it is a good idea for any elderly couple, even if neither has cognitive impairment (problems with thinking and memory), to obtain consent from their children in addition to their spouses. Unforeseen circumstances may arise that may make it impossible for one to confirm consent for the other.

**What if my next of kin has dementia or I do not have any next of kin?**

A donor whose next of kin has cognitive impairment must have consent signed by the next closest relative, or someone named as their legal guardian, or someone who has been given the express authority to consent to autopsy in a Durable Power of Attorney. Someone who has none of the above must consent for him- or herself. Please note that there is no next of kin in the restrictions line on the Autopsy Consent form.

**Who can witness my Autopsy Consent form?**

If the consent is signed in our clinic, one of our staff members can be the witness. If you sign the form at home, a friend, neighbor, or relative needs to witness your signature. Both the person authorizing the autopsy and the witness must put the date of their signatures.

For more information please call:

SEATTLE LONGITUDINAL STUDY

ROBIN DUNLAP 206-281-4050

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## Some Information about Brain Tissue Donation for Research

For more information or to update us, please call:

SEATTLE LONGITUDINAL STUDY

Clinical Research Study

ROBIN DUNLAP 206-781-4050

Contact Name & Phone

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### **Why do we need brain tissue donations?**

You are probably familiar with organ donations of the heart, kidneys, or eyes to sustain the health and/or life of persons in need. The donation of brain tissue for research is a similarly unique and precious gift. This donation will help doctors and scientists to understand the nature of neurodegenerative disease, a group of diseases that cause progressive loss of brain function. Neurodegenerative disease is debilitating and sometimes deadly.

### **What if I don't have a neurodegenerative condition?**

Donations from people who do not have any neurodegenerative disease are very important to us. We need much more information about what changes occur in the brains of healthy persons as they age. Most previous studies of the brain in healthy persons have been done in younger people. Without being able to compare tissue from older persons without neurodegenerative disease to tissue from patients who do have a neurodegenerative disease, we cannot determine which changes are related to the disease and which are due to normal aging. For this reason, we urge healthy older persons without dementia to consider brain donation.

### **Will having an autopsy affect my funeral arrangements?**

No. The procedure is done without leaving any apparent marks. It is still possible to have an open-casket funeral. NOTE: the autopsy and brain donation program does NOT provide cremation or burial.

### **Who is legally able to authorize an autopsy for research?**

Consent for post-mortem examination of the brain must be given by the legal next-of-kin. The only exclusion to this rule is if there is a person who has been specifically authorized to consent to autopsy in a Durable Power of Attorney document. If there is no legal next-of-kin or a person authorized to consent in a DPOA, then consent may be given by a person who has been officially appointed as the Executor of the Estate. In all cases, the doctors need assurance that the family or authorized person/s is still in agreement on allowing the autopsy to move forward at time of death. As such, it is the policy of the autopsy and brain donation program to call the legal next-of-kin or authorized person at time of death for a final approval before moving forward with the research-related autopsy.

### **Will there be any additional costs to my family if I agree to a research autopsy?**

There will be no charges from us or the University of Washington. Free autopsy is offered to all eligible research subjects. The autopsy and brain donation program provides transportation from the place of death to Harborview Medical Center. Your funeral home will provide transportation from the medical center to the mortuary. This means only one trip for the mortuary, so there ordinarily would not be any extra charges from the funeral home. If the mileage from Harborview Medical Center to the funeral home is much more than originally planned, there may be an extra charge from the funeral director. You and your family want to make sure this is clear ahead of time.

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### **How long will it be before the deceased is released from Harborview Medical Center?**

In most cases, remains are available the afternoon after the autopsy. Delays are often due to difficulty in reaching the next-of-kin. If the death occurs on a weekend, the deceased is usually released the following weekday afternoon. In the event of staffing limitations, there may be some delay.

### **Will my family get an autopsy report?**

We will provide the family with a letter which lists findings and provides a brief discussion of the neuropathology diagnosis. You may feel free to ask questions about this letter and discuss the findings with autopsy and brain donation program staff. Because there will be no physical examination of the body, we cannot provide information about the cause of death or any physical findings in the body.

### **When are autopsy results available?**

The research neuropathology examinations take quite a while to be performed for a number of technical reasons. Therefore, the neuropathology examination can take four months or more to be completed. However, it may be done sooner. Be assured that we will provide the family with results as soon as they are available.

### **Who provides the death certificate?**

Death certificates are issued by Harborview Medical Center, the UW Medical center, and/or the HMC/UW attending physician **only** when the subject is an inpatient at a UW Medical Center facility when he or she expires. Otherwise, the death certificate should be provided by the facility where the person has expired.

### **Can I still be an organ donor?**

You may still express a wish to be an organ donor. The criteria for organ donation are very strict. Organs are not accepted from anyone who has any infection, cancer, or any type of dementia at time of death. You may indicate your wish to be considered as a possible organ donor by giving advance directives to your next of kin, your personal physician, and hospital. Organ donation would precede the brain autopsy and would take place as soon as possible following discontinuation of artificial respiratory and cardiac support.

### **Can I make skin and/or eye donations?**

Having dementia makes a person ineligible for skin and eye donations. Having cancer makes a person ineligible for anything but eye donations. If you wish to donate skin, you should indicate this in your advance directive. We will also note it on your autopsy consent form.

If you wish to be considered for eye and/or cornea donation, you need to arrange this *in advance* with the Lion's Eye Bank (206-682-8500), and provide us with a copy of your Eye Bank consent form to file with your autopsy consent form. **Note:** Eye tissue must be taken within 8 hours of the time of death.

### **Why can't people with dementia make organ or tissue donations?**

There are some rare, but especially severe, forms of dementia that are caused by micro-organisms and can be transmitted to other people. The "mad cow disease" that you may have heard of is one of these. Because, prior to brain autopsy, there is no way to know definitively what the cause of dementia is, tissue from persons with dementia cannot be accepted for transplant.

### **Can I donate my entire body to research? ♦ I have already donated my entire body to research-is that enough? ♦ I left my body and brain to science in my will.**

It is possible to coordinate donation of your body to science along with brain autopsy and brain tissue donation. The Willed Body Program at the University of Washington is a program that coordinates whole body donation to the UW Medical School for research purposes. Sometimes, people are

referred to the autopsy and brain donation program by the Willed Body Program. Others will mention that they would like to donate their body as well as their brain. Important things to note are:

1. Brain autopsy takes priority over body donation. We will provide you with a wallet card that reflects this priority.
2. Donating your body to research will not guarantee that you will have a research brain autopsy. In fact, *research brain autopsies will not be done on donated bodies if you have not enrolled in the autopsy and brain donation program as well.*
3. Advance arrangements with the Willed Body Program (UW Biological Structures) are required for body donation (Contact Mavis Montgomery at 206-543-1860).
4. Some people have left their body and/or brain to the University in their **will** or **final directives**. *This is not adequate unless prior arrangements have also been made to enroll in the autopsy and brain donation program and/or the Willed Body Program.*
5. Sometimes the Willed Body Program is not able to accept a body even if the person has been enrolled in the program. For this reason people **must** make advance, alternate arrangements with a funeral home or mortuary to provide services in the event that a body is not accepted. *This does NOT affect brain donation. Even if the body is not accepted by the Willed Body Program, the autopsy and brain donation program will still want to obtain the brain tissue from research subjects.*
6. The remains of a deceased person accepted by the Willed Body Program may not be available for interment/cremation for as long as two years following the date of death.

#### **How will my family or doctors know what to do at the time of death?**

Once you have a signed consent for autopsy, program staff of your research study will do the following:

- ◆ Make copies of the consent forms for you to give to your doctor, funeral home, and relatives.
- ◆ Provide you with a wallet card which has the telephone numbers to call at the time of death.
- ◆ Provide you with "alert stickers" with the numbers to call at the time of death. Most families keep one of these stickers by their telephone. You should also have one of these stickers placed in your medical chart every time you are admitted to a hospital (even for day surgery), or if you move into a nursing home (even for rehabilitation or respite care).
- ◆ We will periodically contact you to update our records and to schedule follow-up visits.

#### **Once I have given consent, what else do I need to do?**

If you have any changes in your address or telephone number, you need to notify us so we can update our records. We also need to know whenever the address or phone number of your next-of-kin changes, or if the person who is your next of kin changes. If you are the caregiver of a person with dementia, we ask that you keep us up to date so we can be sure that any adult care centers, nursing homes, etc. know what to do if the person dies while under their care.

If a significant change in your health (physical, or mental), or the health of the person with dementia occurs between contacts with us, please call us with an update. We may wish to schedule an extra clinic visit, or contact other health care providers in order to keep our information up to date.

If you or the person for whom you are the caregiver moves out of the Puget Sound Area, please contact us about alternate arrangements.

Future generations will benefit from this gift, which could lead to successful treatment and prevention of these tragic illnesses.

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**University of Washington Neuropath Core  
Brain Aging and Neurodegeneration Brain Bank  
Autopsy and Tissue Donation to Brain Bank  
Consent Form**

**Alzheimer's Disease Research Center  
Campus Box 359645  
325 9<sup>th</sup> Avenue  
Seattle, WA 98104**

**Co-Directors: Thomas J. Montine, MD. Ph.D.  
& Joshua Sonnen, MD  
Research Manager: Aimee Schantz, M.Ed.  
Phone: 206-897-5248 / Fax: 206-897-5249**

**RESEARCHER'S STATEMENT**

The purpose of this consent form is to give you the information you will need to help you decide whether to donate your brain tissue and cerebral spinal fluid to the University of Washington Neuropath Core Brain Aging and Neurodegeneration Brain Bank. Please read this form carefully. You may ask questions about what we are requesting, the risks, the benefits, your rights as a volunteer, or anything else about the research or this form that is not clear. When all of your questions have been answered, you can decide if you want to donate your brain tissue and cerebral spinal fluid to the Brain Bank or not. This process is called "informed consent." We will give you a copy of this form for your records. The University of Washington will keep the original.

**PURPOSE OF THE STUDY**

The purpose of the brain bank is to help research related to brain aging and neurodegenerative disease - a group of diseases that cause progressive loss of brain function - by collecting brain tissues from people who have had these diseases or others who have had normal aging. This tissue is stored so that it can be distributed to researchers throughout the country who are studying these diseases.

**STUDY PROCEDURES**

If you consent to donate your brain tissue, we will take your brain tissue and cerebral spinal fluid at the time of your autopsy. We will take some of the samples of your brain tissue and submit them to the University of Washington's Neuropathology Department for analysis. Your family will receive a report of neuropathological findings, if they so desire.

We will also keep samples of your brain tissue and cerebral spinal fluid in our brain bank. These tissue samples will be sent to scientists all over the country to be used in research related to neurodegenerative disorders. The brain tissue and cerebral spinal fluid samples will be kept in the brain bank until they are used up or destroyed. When we send the tissue to a researcher, we may send the following information with the tissue: the results of clinical assessments performed during your participation in research, the final neuropathological findings, your age, and whether you are male or female. All information will be sent linked to a code and without information that can identify you.

To be in this study you must be willing to allow research data to be shared between the clinical research study that is enrolling you in this autopsy and tissue donation program and the Brain Bank. This will insure that the medical information and/or any clinical research findings collected by the clinical research study will be linked to the research findings that come from studying your brain tissues. The Brain Bank and the clinical research study will share our data with each other.

**RISKS, STRESS, OR DISCOMFORT**

There are no physical risks from the study procedures. There may be risks that your private information may become known by others. The brain bank will take precautions in an effort to keep this from happening. We will label your tissue samples and the information about your diagnosis, age, and gender with a code. Only the brain bank's data manager and assistant staff will have access to this code, which will be kept on password-protected computers in locked files separate from the tissue samples.

Another thing to think about is that the tissue may be used in genetic research (about diseases that are passed on in families). Because these tests will be done for research only, and researchers will not be able to identify you personally, we will not be able to give your families the results.

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## BENEFITS OF THE STUDY

You will not benefit directly by participating in this study. Your participation will help doctors and scientists to understand the nature of neurodegenerative disease and disorder and in the future might help people who are suffering from these diseases and disorders.

## SOURCE OF FUNDING

The study team and the University of Washington are receiving financial support from the National Institutes of Health.

## OTHER INFORMATION

You may refuse to participate and you are free to withdraw from this study at any time without penalty or loss of benefits to which you are otherwise entitled. All of the information you provide will be confidential. Information that may identify you and the code that links it to your research data will be kept indefinitely.

Government or university staff sometimes review studies such as this one to make sure they are being done safely and legally. If a review of this study takes place, your records may be examined. The reviewers will protect your privacy. The study records will not be used to put you at legal risk of harm.

Research using samples from the brain bank may lead to new drugs, tests, or treatments. Samples may also be used in research to develop new commercial products. You or your family will not receive any of the profits, if there are any, from the use of the samples.

The choice to let us keep samples of your brain tissue and cerebral spinal fluid is up to you. No matter what you decide, it will not affect your regular care. Even if you decide now that you want to donate your brain to the Brain Bank, you can change your mind at any time. Just let us know that you do not want to donate your brain tissue and cerebral spinal fluid for research.

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Clinical Research Study

Phone

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Printed name of study staff obtaining consent

Signature

Date

## SUBJECT'S STATEMENT

This study has been explained to me. I agree to allow the UW ADRC Brain Aging and Neurodegeneration Brain Bank to store my brain tissue and cerebral spinal fluid for future research about neurodegenerative disorders. I also agree to allow the researchers to provide medical information as described above about me to other researchers studying my tissue. If I have questions later about this research, I can ask one of the researchers listed in the letterhead of this document. If I have questions about my rights as a research donor, I can call the Human Subjects Division at (206) 543-0098. I will receive a copy of this consent form.

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Printed name of subject

Signature of subject

Date

When subject is not able to provide informed consent:

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Printed name of representative

Signature of representative

Date

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Relationship of representative to subject

Copies to:   Researcher  
                  Subject

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