

**Michigan Brain Bank  
Brain Donation & Autopsy Program**



**MICHIGAN MEDICINE**  
UNIVERSITY OF MICHIGAN

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**Michigan Brain Bank – North Campus Research Complex., 2800 Plymouth Rd., Building 60 Office**  
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**Email: UMHSBRAINBANK@med.umich.edu**

## Brain Donation & Autopsy: Why is it Important?

Autopsy, examining the body after death, has many benefits. For families, learning the precise cause of the patient's illness may be a tremendous relief and help to ease uncertainty and doubt. It gives relatives accurate information about the cause of symptoms and confirms or modifies the diagnosis made during life. Autopsy provides relatives with accurate information about their family's medical history needed for their care and for future generations.

Results of an autopsy, also known as a postmortem examination, is becoming increasingly important as we learn more about Alzheimer's disease, Parkinson disease, Amyotrophic Lateral Sclerosis (ALS), and other neurodegenerative disorders. It is likely in the future to affect treatment recommendations for family members. Additionally, when an autopsy is done, brain tissue is stored and may be available for additional studies even many years later. For example, this tissue could be used for genetic studies that are important for research and provide useful information to relatives.

Autopsies are also an extremely important source of information about how the disease affects the anatomy of the brain. This information is used to direct future research into the causes of memory loss, their progression over time, and clues about effective treatment approaches. For example, researchers recently have found that a previously unrecognized abnormality in brains of patients with dementia called Lewy bodies may be present in 40% of persons with Alzheimer's disease and may account for some symptoms. We would never have learned this unless we conducted autopsies in addition to our clinical care. What we know about neurodegenerative disorders has only been possible because of the commitment of patients and families like you. Even if individual family members do not benefit directly from a brain autopsy, it can lead to a better understanding of neurodegenerative disorders for future generations and an important measure to assess public health and quality of care.

We hope this booklet will help answer your questions about brain donation and autopsy. It includes the forms you'll need to make arrangements for an autopsy and a checklist to help complete the process. If the patient is a nursing home resident, it is important that you share this booklet with nursing home staff.

For most people, the time immediately following the death of a family member is very difficult, and therefore not a good time for making important decisions such as this. It is best to make the decision about whether or not to request a brain autopsy well in advance, with less stress and with consideration for the wishes of the patient and family. It is also necessary to make arrangements for an autopsy in advance. We hope this booklet will help you to accomplish these goals.

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## Frequently Asked Questions

### Can there still be an open casket?

Yes. The removal of brain, spinal cord, teeth (only molars), or hair will not cause any noticeable disfigurement.

### Will the funeral arrangements be delayed?

With preplanning and careful coordination, there should be no delays for typical funeral arrangements. The procedure will be performed within the first 24 hours after death. The Michigan Brain Bank staff will work with funeral directors to expedite the transition from the place of death to the Medical Center, and from the Medical Center to the funeral home. Completion of Forms A-1 or A-2, and B, located in the back of this booklet before the time of death and forms C and D at the time of death will assist in preventing delays.

### Do I have to tell my relatives, or will they know the brain has been removed?

You do not have to tell anyone if you do not wish to. Only on close inspection would anyone know that an autopsy has been performed.

### Does donating brain tissue for research purposes interfere with religious beliefs?

Brain donation does not conflict with most religious beliefs. If you have any questions concerning this issue, please contact your religious leader, priest, minister, imam, or rabbi.

### Who can legally grant permission for an autopsy to be performed?

Prior to death, an individual or family member can indicate their intent by signing a **provisional** consent. This permits arrangements to be planned. However, after death, the person's legal next-of-kin must authorize the autopsy before it can be performed. The following persons, in order of priority, may provide such consent:

- 1) Spouse
- 2) An adult son or daughter
- 3) Either parent
- 4) An adult brother or sister
- 5) A guardian of the decedent at the time of death.
- 6) Any other person authorized or under obligation to dispose of the body.

If there are several individuals in a category they must all agree. For example, in priority level 2 above, all adult children have equal authority and must be in agreement. Signing a provisional consent can help others by documenting a patient's wishes.

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### Which organs are examined at autopsy?

Under normal circumstances, the brain is the only organ examined. However, under special circumstances other organs can be requested, such as spinal cord, or a complete autopsy can be requested, in which all major organs are examined. Specific authorization would be needed from next-of-kin for a complete autopsy or requests for any organs other than brain.

### Will an autopsy report be sent to the family?

Yes. By completing **Form B** in this booklet, you assure that a written report of the autopsy results will be sent to you. Typically, the report is sent to the family **3 to 4 months** after completion of the autopsy procedure. Once you've received the autopsy report, contact your local physician identified on Form B and he/she will be able to discuss the autopsy results and its implications with you.

### What should we do with the report?

We recommend that you keep the report in a safe place for future reference. The numbers on the report are important because they help family members obtain further information in the future if it is needed.

### Who else will see the autopsy report?

The autopsy report is a medical document to be seen only by persons who have specific permission (usually the next-of-kin and local physician identified on Form B). At the University of Michigan, clinical research studies keep their records separate from patient medical charts. These research records are kept confidential to the full extent of the law. The Brain Bank is a national resource and shares data with investigators using the Brain Bank for research studies. Information is sent to investigators without identifying personal information to maintain confidentiality.

### What will happen with my information and/or biospecimens used in this study?

With appropriate permissions, your biospecimens and collected information may also be shared. As a research institution, our goal to advance medical science and the health of the communities we serve is facilitated through partnerships with external entities, including other medical centers, universities, governmental agencies, foundations, and industry. These studies may lead to improved understanding and advances in the diagnosis and treatment of neurodegenerative disorders. All tissue requests are reviewed by the Michigan Brain Bank Oversight Committee and its director. Samples are provided for biochemical and genetic studies labeled with numbers rather than names to keep information anonymous. The results of these studies may also lead to commercial products or patents. Families will not be responsible for any development costs nor share in the profits of any commercial application. If you want to learn about the results of any research studies that have included the patient's brain tissue you may contact the Michigan Brain Bank Coordinator at (734) 647-7648 for further information.

If you are participating in the Alzheimer's Clinical Trials Consortium (ACTC) studies and agree to donating your brain to the ACTC-Brain Donation Program, your brain is to be  
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removed, retained, and processed according to Alzheimer's Clinical Trials Consortium Neuropathology protocols. A set of tissue samples will be provided to the Massachusetts General Hospital (MGH) Neuropathology department for storage and future research.

### **Will genetic analysis be performed routinely?**

No, genetic testing is not appropriate or possible for the majority of brain tissue we receive. We store frozen brain tissue in every case possible since it is most appropriate for genetic analysis. Genetic studies may be performed in some instances, and this will depend on the neurological disease under investigation or if a familial history can be identified. These studies may be done at the University of Michigan or at other collaborating laboratories.

### **If genetic analysis is performed, will family be informed?**

Family members are not automatically informed when genetic testing of tissue is done. To inquire about the availability of genetic test results, contact the Brain Bank Coordinator at (734) 647-7648. All genetically related individuals may request the results of genetic testing. Results will be released only to a physician, who will assist with counseling and interpretation of results. There is a possibility that genetic test results will be unavailable or impossible to interpret with certainty.

Relatives have the right not to know the results of any genetic test(s). Relatives may not want to know about test results or may want to keep this information out of their medical records because it has the potential to affect insurability, employability, and social esteem.

### **Who else will see the results of genetic tests if they are performed?**

Results of genetic tests, like other research results, are kept separate from patient medical charts in the Michigan Brain Bank database and are kept confidential to the full extent of the law. These genetic test results are linked to personal information in the database. Genetic test results are shared with other investigators when appropriate for their research. In these cases, results are shared without identifying personal information to maintain confidentiality.

### **Are there any costs or fees involved?**

There is no charge for the arrangement and performance of the autopsy. If a patient moves to another area, the Michigan Brain Bank Coordinator will work closely with you to locate a local hospital and pathologist to perform the autopsy. In these cases, there may be charges for brain removal that would be responsibility of the family. There are no charges for research testing.

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### Who could profit or financially benefit from the study results?

Research can lead to new discoveries, such as new tests, drugs, or devices. Researchers, their organizations, and other entities, including companies, may potentially benefit from the use of the data or discoveries. You will not have rights to these discoveries or any proceeds from them.

### Where is the autopsy done?

Pathologists at the University of Michigan will perform the autopsy for patients living in Ann Arbor and the surrounding area. The Michigan Brain Bank Coordinator will help families of patients outside this area make pre-arrangements for a local pathologist to perform the autopsy.

### What are the “Necessary Pre-Arrangements” for post-mortem examination?

The Michigan Brain Bank Coordinator and authorized personnel would have access to the electronic information in patients’ medical records to create an entry in the Michigan Brain Bank database and will be stored as research data. Information from medical records stored as research data is only accessible to authorized Michigan Brain Bank personnel and password protected in the Michigan Brain Bank database. The Michigan Brain Bank will not share personal information with persons not directly involved in the pre-arrangement process.

### When should pre-arrangements for an autopsy be made?

Planning should begin as soon as your decision is reached. **Autopsy preparations must be made before the time of death.** To indicate your “intent” for a brain autopsy, you should complete and sign either **Forms A-1 or A-2** in this booklet and return it to the Brain Bank staff.

**Form A-1 or A-2** simply indicates your advance “intent” to make the autopsy arrangements. The form itself is not legally binding. The actual autopsy consent will have to be given at the time of death by the legal next-of-kin. Upon completion of either **Forms A-1 or A-2**, it will be placed in the patient’s UM Hospital medical record.

Your decision about brain autopsy pre-arrangements should be shared with immediate family members, medical caregivers, and your funeral director, to avoid last minute confusion.

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## What Needs To Be Done At The Time Of Death?

The responsible family member or legal guardian should oversee the final arrangements of the deceased. The following checklist shows the steps to follow:

1. Notify the patient's attending physician. If death occurs at home, the physician, nurse or funeral director can give you the phone numbers for the local agencies that need to be notified. After this process is completed, the funeral director can begin transportation service.
2. Call the University Hospital paging service at (734) 936-6267 and ask the operator for the Michigan Brain Bank Coordinator, pager #9198.
  - a. Leave your phone number, along with area code, where you can be reached.
  - b. Have the following information ready for the staff:
    - i. Name of the deceased and the location of death.
    - ii. Deceased's 9-digit UM Hospital registration number or the date of birth.
    - iii. Most recent medical history and time of death.
    - iv. Name and phone number of the funeral director, so they can be called with the directions to take the body to UM Hospital or local pathologist.
3. Contact the funeral director. You may wish to place his/her phone number on the inside front cover of the booklet. The funeral director must be told that the body **should not be embalmed** and must be kept cool until after the autopsy by the pathologist. The funeral director will transport the body to the UM Hospital or to the local pathologist. The funeral director should bring **Forms A-1 or A-2, B, C and D** to the pathologist.
4. If the autopsy is to be performed at the UM Hospital, you will receive a phone call from a UM ADC staff member asking for verbal consent to perform the autopsy procedure. This call will be placed and witnessed by a UM hospital operator. If you are present at the hospital, you will sign a written consent form. Similar procedures will be followed at other hospitals. The autopsy should be completed within 24 hours.
5. Continue with your funeral arrangements.

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## The Forms You Need

**Form A-1:** This form states that it is the wish of the patient to donate his/her brain for autopsy and research after death. It is not legally binding. A signed copy of this form should be placed in the Hospital, Physician or Nursing Home Medical Record.

**Form A-2:** This form allows a legal next-of-kin to give provisional consent for autopsy if the patient is unable to make the decision. Again, it states the wish of the next-of-kin only and is not legally binding. A signed copy of this form should be placed in the Hospital, Physician, or Nursing Home Medical Record.

**The Brain Bank must receive a signed copy of Form A-1 or A-2 for enrollment in the Brain Autopsy Program and to begin pre-arrangements.** When you send us a signed copy we will return it with your enrollment letter, and you should keep the forms with this booklet. The legal next-of-kin will still need to give permission for the autopsy at the time of death. Depending on the circumstances, permission will be given verbally, as described on the previous page (step 4), or by completing a written form at UM Hospital.

**Form B:** This form indicates who should get a copy of the brain autopsy report. Form B, after it has been **completed and signed**, should be given to the funeral director to take with the body to the pathologist.

**Form C:** This form describes the procedures for the nursing staff to follow after the patient has died. A copy of this form should be placed in the patient's chart **along with**

**Form D**, every time they are admitted to a hospital or nursing care facility. It should be given to the funeral director to take with the body to the pathologist.

**Form D:** This form is placed in the patient's chart **along with Form C** and documents the date and time of the patient's death. This form should be completed by the physician or nursing staff. The form also records the patient's medical history and should be filled out as completely as possible by the patient's nurse and family. The Brain Bank staff can help you complete the form if needed. The form should be given to the funeral director to take with the body to either the UM Hospital or to the local pathologist.

**KEEP THIS BOOKLET FOR FUTURE REFERENCE IN A SAFE PLACE KNOWN BY SEVERAL FAMILY MEMBERS.**

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## FORM A-1 Provisional Consent for Brain Autopsy Pre-Arrangements by a Legally Competent Adult

### Directions:

This form is to be completed by a legally competent adult wishing to indicate his/her own desire to set up prearrangements for an autopsy with brain, spinal cord, teeth (molars only) and hair donation to the University of Michigan Brain Bank.

***In the hope that this authorization will further the understanding of neurological disease,***

I \_\_\_\_\_,  
(Print Name)

***authorize the pre-arrangements necessary for a postmortem examination of my brain, spinal cord, teeth, and hair for Research, clinical and educational purposes in the interest of advancing medical knowledge. I have read and understand the information provided in this document.***

***Patient agreed to a brain autopsy after death*** (Check Yes or No and Initial only if patient is unable to sign due to physical limitations).

☐ Yes ☐ No

Patient Initials

\_\_\_\_\_

\_\_\_\_\_  
Signature of Patient

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date

Most likely, the patient's spouse or an adult son or daughter will sign the autopsy consent. The pathologist will determine who the appropriate legal next-of-kin is at that time and whether their consent for autopsy is valid.

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## FORM A-2 Provisional Request for Brain Autopsy Pre-Arrangements for a Patient Who Is Unable to Give Consent

### Directions:

This form is to be completed by a legally competent adult (as listed below) on behalf of a patient who is unable to give consent. This completed form indicates his/her wish to have the patient enrolled for autopsy pre-arrangements with brain, spinal cord, teeth (only molars), and hair donation to the University of Michigan Brain Bank.

***I, being a legally authorized (spouse, son, daughter, brother, sister, or guardian)***

***representative of \_\_\_\_\_,***  
**(Print Name of Patient)**

***authorize the pre-arrangements necessary for a postmortem examination of brain, spinal cord, teeth, and hair for research, clinical and educational purposes in the interest of advancing medical knowledge. I have read and understand the information provided in this document and I understand that the legal autopsy consent must be given after the patient has expired.***

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Relationship

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Relationship

\_\_\_\_\_  
Date

The autopsy consent form can only be signed by the legal next-of-kin after a person has passed away. However, a non-binding pre-arrangement for autopsy can be made by any one of the following individuals:

- a. The spouse
- b. An adult son or daughter
- c. Either parent
- d. An adult brother or sister
- e. A guardian of the deceased at the time of death
- f. Any other person authorized or under obligation to dispose of the body

Most likely, the patient's spouse or an adult son or daughter will sign the autopsy consent. The pathologist will determine who is the appropriate legal next-of kin at that time and whether their consent for autopsy is valid.

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**FORM B Authorization for Release of Autopsy Report Information**\_\_\_\_\_  
Print Name of Patient\_\_\_\_\_  
U of M Registration #**Directions:**

Please print the name of the next-of-kin and the physician (optional) who may receive copies of the autopsy report.

**Next-of-Kin:**

Name\_\_\_\_\_

Relationship\_\_\_\_\_

Address\_\_\_\_\_

City State Zip\_\_\_\_\_

Telephone Number (\_\_\_\_\_) \_\_\_\_\_

\_\_\_\_\_  
Signature**Local Physician: (Optional)**

Name \_\_\_\_\_

Address \_\_\_\_\_

City State Zip\_\_\_\_\_

Telephone Number (\_\_\_\_\_) \_\_\_\_\_

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## FORM C    Nursing Information on Postmortem Procedure

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 Print Name of Patient

---

 U of M Registration #

---

 Name of Local Hospital / Nursing Home

---

 Local Patient Registration #

This patient is participating in a brain autopsy program for neurology research. Please keep a copy of this sheet with Form D on the inside front cover of the patient's hospital or nursing home medical record/chart.

### The nursing staff are asked to follow this protocol when the patient dies:

- 1) **Call the physician in charge of the patient.** Have the physician "pronounce" the patient as soon as possible. Ask if the cause of death warrants calling the Medical Examiner's Office.
- 2) **Call the family.**
- 3) **Page the UM Brain Bank coordinator at:** (734) 936-6267. Ask for pager# 9198. Also, call the local pathologist, if shown below.
- 4) **Complete Form D.** Describe the patient's medical history for the past 2 weeks. Copies of a recent H & P and assessments would be helpful.
- 5) **Contact the funeral home.** When the family is ready, please move the body to a hospital morgue/mortuary COLD ROOM (4 C) within 2 hours, if possible.
- 6) **There must be no embalming until after the brain tissue is removed**
- 7) A completed **Form D** (attached) must accompany the body to the pathologist.

### Physician in Charge of Case

### Pre-arranged Local Pathologist(optional)

---

 Name (Please Print)

---

 Name (Please Print)

---

 Address

---

 Address

---

 City                      State                      Zip

---

 City                      State                      Zip

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 (\_\_\_\_\_) \_\_\_\_\_  
 Area Code Telephone

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 (\_\_\_\_\_) \_\_\_\_\_  
 Area Code Telephone

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**FORM D Patient Medical History at Death**

**To be completed by the physician or nursing staff and sent with the body for the autopsy. Please fax to (734) 615-1117 or email [UMHSBrainBank@med.umich.edu](mailto:UMHSBrainBank@med.umich.edu).**

Patient Name: \_\_\_\_\_ UofM Registration #: \_\_\_\_\_

Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_ Date of Death: \_\_\_\_/\_\_\_\_/\_\_\_\_ Time: \_\_\_\_\_

Sex: Male/Female                      Handedness: Right/Left

Clinical diagnosis at time of death:

\_\_\_\_\_  
\_\_\_\_\_

Immediate cause of death and the events leading to death over the past 2 weeks:  
Describe any memory, emotional, and/or physical changes during this time:

\_\_\_\_\_  
\_\_\_\_\_

Medications received over the past week – Dosage & Schedule:

\_\_\_\_\_  
\_\_\_\_\_

History of neurological illness: Include date of onset and nature of symptoms, the rate and progression of symptoms, any symptoms of motor dysfunction, sensory problems, or pain. Any recent signs of stroke or infectious illness?

\_\_\_\_\_  
\_\_\_\_\_

Past Medical history, other diagnosed medical illnesses, past surgery or traumatic injury. Any other medications taken during the past month?

\_\_\_\_\_  
\_\_\_\_\_

Family history, number of siblings: age and cause of death of parents, if known; any illness of family members resembling patient's?

\_\_\_\_\_  
\_\_\_\_\_

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## Telephone Numbers You May Need

For routine questions and pre-arrangements, you may call **(734) 647-7648** weekdays from 8:30 am to 5:00 pm and ask for the Brain Bank Coordinator or use the paging system below.

When it is time to have the brain autopsy performed, the Brain Bank staff can be reached at any time, day or night, by calling the University Hospital Paging system at **(734) 936-6267** and ask for **Pager #9198**.

Leave your name and phone number (with the area code and extension) where you can be reached. You can expect to receive a return call in approximately 30 minutes.

## Funeral Home Information

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Contact Person: \_\_\_\_\_

*For patients and families who live outside the state of Michigan all or part of the year, please provide a local pathologist that will complete the autopsy.*

## Information on the Local Pathologist

Pathologist's Name: \_\_\_\_\_

Weekday Phone: \_\_\_\_\_

Evening Phone: \_\_\_\_\_

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