

## AUTOPSY UPDATE

The Alzheimer's Association frequently receives inquiries about autopsies such as how they can be arranged, how much they cost and whether or not an autopsy should be performed.

Diagnosis and research are the two main reasons for doing an autopsy on an Alzheimer's patient. While the diagnosis of AD can now be up to 90% accurate, it can only be positively confirmed through autopsy. This provides important medical history and genetic information for families.

Autopsy data also provides information about the prevalence of AD which affects the amount of funding available from the government for medical research.

Brain tissue for research purposes is also important to further ongoing investigation in finding a treatment and cure.

Contrary to some reports, brain tissue is still needed for this effort.

Planning ahead helps families in making the decision for autopsy. This is a family decision and discussions in advance allow all family members to participate at a time when they are not in the midst of sorrow.

According to Betty DeMasters, MD, University of Colorado Health Sciences Center Pathologist, who has performed many autopsies for AD patients, the key to obtaining a smooth autopsy procedure at the time of death is to work with the attending physician or nursing home physician and plan for the autopsy in advance. Since the tissue must be removed soon after death, it is important for the family to have made prior arrangements.

Dr. DeMasters suggests the primary physician needs to be an advocate for the patient and family in arranging the autopsy at the hospital at which they practice or the facility where the AD patient has been hospitalized.

A recent survey of Denver Metro Area hospitals showed many were willing

to perform autopsies for past patients as well as those who died in the hospital. In all cases the primary physician was the key to arranging the procedures.

Costs for autopsy vary for each facility. The fees range from no charge for hospital in-patients to \$500 - \$1000 for outpatients for brain autopsy only. The following steps should be taken to prearrange a brain autopsy:

- Involve principal family members in the decision making process.
- Contact the attending physician and discuss the intention of the family to have a brain autopsy at time of death.
- State your request for an autopsy in writing and provide copies to your physician, care center and/or nursing home. Ask that it be placed in the patient's medical record.
- Work with the primary physician to determine the procedure at time of death – where the autopsy will be performed and the

procedure.

- All states require a signed autopsy permit. Permit forms are available from your hospital or the pathologist selected for the procedure. Sign, but do not date the consent form, and have it placed in the patient's medical record. You may also wish to keep a copy.
- It is advisable to also plan with the funeral director that the body is not to be embalmed before brain removal.
- If the brain tissue is to be donated for research, this procedure also needs to be discussed in advance with the primary physician and pathologist selected to perform the autopsy. The

family needs to sign an additional consent form stating the brain tissue is to be sent to the National Brain Bank. (As of this writing the National AD Autopsy and Brain Bank at the University of California, San Diego (619) 534-6858 is in need of more tissue. Dr. George G. Glenner, who heads this research project is trying to find a definitive diagnosis for AD and each brain is tested for this purpose.) There is a \$55-\$65 fee for shipping the tissue Federal Express as they must receive it within 24 hours.

- Families can expect a written report after the autopsy is performed. Local reports generally require 60-90 days for completion. The report from the

pathologist who will do the National Brain Bank may take four-six months.

For Denver area families unable to prearrange an autopsy through their primary physician, Dr. Jill Gould of the Arapahoe County Coroner's office will perform the procedure.

Arrangements need to be set up in advance with the coroner's office so necessary consent forms and medical history can be obtained. For further information on this service and current fees, please contact Dr. Jill Gould at 795-4956.

## FREQUENTLY ASKED QUESTIONS ABOUT AUTOPSY

### CLINICAL TRIAL OPENS FOR LINOPIRINE

Linopirine (DuP 996) is an investigational drug which may have potential benefit in alleviating symptoms of Alzheimer's disease, while linopirine is not expected to cure the disease or stop its progression, it is hoped that in clinical trials the drug will improve such symptoms as memory and attention and that it will improve the patient's daily functioning. The trial is a placebo-controlled design, meaning that some patients will receive the drug and some will receive the drug and some will receive a placebo. Each patient must meet eligibility criteria. This particular drug test is being conducted by the Colorado Medicine Research Center. Please call 744-7000 for details. If you are interested in additional facts, please call the Chapter office at 733-1669.

*Q. Who may request an autopsy?*

A. Legally, the next-of-kin or guardian is the person to make that decision. If the spouse is deceased, the oldest child is considered next-of-kin.

*Q. Is a complete autopsy performed?*

A. No. In instances where Alzheimer's Disease is suspected, only the brain tissue need be examined for diagnosis; however, a complete autopsy is recommended.

*Q. Where is the autopsy performed?*

A. If death occurs in a hospital, the autopsy may be performed in that facility. If death takes place in a nursing home, other arrangements will have to be made with a pathologist.

*Q. Can I have an open casket?*

A. Yes. Brain tissue removal leaves no disfigurement.

*Q. Hasn't the patient suffered enough? Why put him/her through anything more?*

A. It may appear callous to discuss a need for autopsy when dealing with those emotionally burdened, but a refusal based on "they have suffered enough" is the result of an emotional state of mind. Only through autopsy can the diagnosis be confirmed.

*Q. Is it important for children of Alzheimer's Disease patient to have confirmed diagnosis through autopsy?*

A. Yes. As our knowledge increases, it becomes more important for families to have complete medical records. If other family members develop dementia, an autopsy-confirmed diagnosis of previous cases will be essential for any early treatment the future may bring.