### IF YOU ENCOUNTER RESISTANCE

If you wish to discuss the possibility of an autopsy, but your doctor or funeral director is resistant, please contact the CJD Foundation at 1.800.659.1991 or or the National Prion Disease Pathology Surveillance Center (NPDPSC) immediately at 216.368.0587. There is a national pathology network working with the NPDPSC and autopsies are usually performed within a matter of hours. Memorial arrangements should not be affected.

#### **AUTOPSY IS FREE TO FAMILIES**

through the NPDPSC and the support of the Centers for Disease Control and Prevention. This free service is offered to any suspected or confirmed CJD case in the United States.



### RESULTS OF AN AUTOPSY

If you are like most families, you will want the results immediately. Realistically, these tests take weeks to complete. The initial report of the autopsy results will be sent to your physician approximately 5 - 6 weeks after the autopsy is performed. DNA results take longer, usually 10 - 12 weeks.

We recommend that you review the report with your physician. If you have further questions, please call the CJD Foundation and we will help you.



**Creutzfeldt-Jakob** Disease Foundation, Inc.

The CJD Foundation, Inc. PO Box 5312 Akron, Ohio 44334 1.800.659.1991

HelpLine 1.800.659.1991 www.cjdfoundation.org help@cjdfoundation.org



**Creutzfeldt-Jakob** Disease Foundation, Inc.

# AUTOPSY INFORMATION



HelpLine 1.800.659.1991

www.cjdfoundation.org help@cjdfoundation.org

# YOUR REALITY TODAY

You are dealing with a loved one stricken with Creutzfeldt-Jakob Disease. We know this is a painful, difficult time. You are coping with an ugly disease that steals your loved one away day by day.

CJD usually has a rapid course. It brings many questions and few, if any, answers. We wish the reality was different.

Prion disease researchers are working hard to change that reality. You deserve answers and support as you cope with the illness of your loved one.

The CJD Foundation offers support and information. Please contact us at **1.800.659.1991** or **help@cjdfoundation.org**.

## PURPOSE OF AN AUTOPSY

- It is the only way to confirm CJD
- Autopsy provides answers.
   There are different types of CJD, which can only be discovered through an autopsy.
- Autopsy results can determine whether or not your loved one's form of CJD was genetic.
- CJD brain tissue is rare and greatly needed to advance research.
- Answers will help in the grief process. It is a family's one chance for answers.
- Autopsy results help the Centers for Disease Control and Prevention track the types and demographics of patients with CJD in the United States.

#### **TYPE OF AUTOPSY**

The only autopsy needed is of the brain itself. All tissue is treated with great respect and kept permanently to be used for CJD research.

www.cjdfoundation.org

#### **MYTHS ABOUT AUTOPSY**

MYTH: There can be no viewing at the funeral home.

**TRUTH**: Viewing of the body is possible if that is your desire. In a correctly performed autopsy there should be no sign that an autopsy has taken place.

### MYTH: Embalming is not possible after an autopsy.

**TRUTH**: Embalming is possible. In some states it is even required unless there are religious reasons not to embalm. We have an embalmer's guide available on our website and an educational DVD for funeral directors and embalmers.

### MYTH: The funeral will be delayed by days.

**TRUTH**: The funeral will not be delayed at all in most situations. If there is a need for extra time, it is usually only a delay of one day. This is VERY rare.

#### www.cjdsurveillance.com

To set-up an autopsy free of charge, contact the National Prion Disease Pathology Surveillance Center (NPDPSC) at 216.368.0587