

CREUTZFELDT-JAKOB DISEASE (CJD)

CAREGIVING CHALLENGES

The sudden onset and rapid progression of CJD can be particularly stressful and overwhelming for friends, family and caregivers. Many families feel frustrated at the difficulty clinicians have in diagnosing CJD and feel isolated due to the rarity of the disease. Family counseling may help in coping with the rapid and dramatic changes required to take care of your loved one. In addition, caregiver associations such as the Family Caregiver Alliance and the Alzheimer's Association may have suggestions or support groups that are geared towards families taking care of patients with a degenerative neurological condition.

One of the biggest challenges for caregivers is finding the time and energy to take care of themselves. However, it is important to attend support groups, talk with friends, get exercise and plenty of sleep, and participate in other activities to help maintain a balance, as and this will allow the caregiver to provide better care for their loved one. Also, it is beneficial to accept help from others and to ask for help when needed, especially with tasks such as grocery shopping, running errands, and picking up prescriptions.

STRATEGIES FOR COPING

As there is currently no cure for CJD, treatment usually focuses on alleviating symptoms and making the patient comfortable. This means that medications may be given to control muscle spasms, reduce insomnia, manage aggressive behaviors, or calm anxiety. Myoclonus (sudden jerking movements of the body or limbs) occurs often in CJD. In most circumstances, these movements do not appear to disturb the patient. But they can be very upsetting for loved ones to watch. If myoclonus interferes with patient care or quality of life, or is bothersome to a patient, a physician can prescribe medications that may help alleviate these symptoms. At the end-stage of the illness, medications may be given for comfort care and to relieve any potential pain. Close collaboration with a physician or other health care provider is essential to optimize the management of these symptoms. Hospice organizations can be very helpful in the management of symptoms and arrangement of in-home care. Visiting nurses, home health aids, volunteer services and other community resources may likewise be helpful in providing the monitoring and assistance that goes beyond what a family can manage on their own.

ENVIRONMENT AND SAFETY

Providing a safe environment to prevent injury and addressing aggressive or agitated behavior is an imperative for the family taking care of someone with CJD.

A person with CJD eventually becomes dependent for all basic needs (eating, toileting, and bathing). Most likely you will need adaptive equipment to help you take care of your loved one. Your local physician can help you by ordering a home safety evaluation by an occupational therapist (OT). An evaluation by a physical therapist (PT) can sometimes be helpful as well, particularly in the early stages of the disease when patients have more mobility of limbs. The OT and PT will determine what adaptive equipment may be helpful. For example, a transfer bench and grab bars may facilitate safe bathing and a gait and transfer belt may help prevent falls in someone with an unsteady gait. A commode and/or adjustable hospital bed for the bedroom might be helpful for someone with

limited mobility. Sometimes people with CJD develop very stiff muscles. A PT can show you exercises that may help with this stiffness.

In some cases, behavior modification may be helpful for controlling unacceptable or dangerous behaviors. Behavior modification consists of rewarding appropriate or positive behaviors and ignoring inappropriate behaviors (within the bounds of safety). Reality orientation, with repeated reinforcement of environmental and other cues, may help reduce disorientation.

PLANNING FOR THE FUTURE

At the end stage of the disease, patients with CJD will be bed-bound, often not speaking or moving. Most patients will eventually die from aspiration pneumonia (a lung infection that is caused by not being able to swallow one's secretions; the secretions go into the lungs instead of the stomach).

Legal advice may be prudent early in the disease process to help form an advanced directive. A social worker can help you with this. An advanced directive is a legal document that outlines what type of care the affected individual would like at the end of life. As early as possible in the course of the illness, it is a good idea to think about who will be making decisions for the person with CJD when they are no longer able to do so for themselves. One should consider having a Durable Power of Attorney for Health Care and/or Finances appointed while a the person is still able to make such decisions; a Durable Power of Attorney can legally make medical or financial decisions for the patient when the patient is not capable of doing so for themselves. This is the time when difficult questions must be asked. It is important to determine what type of medical and or surgical intervention they would like in case of emergency.

Some questions to consider include:

1. If I have difficulty breathing, do I want to be placed on a respirator (an artificial breathing machine)?
2. If I develop an infection or pneumonia, do I wish to be treated or just receive comfort care?
3. If I can no longer swallow safely, do I wish to have a feeding tube placed into my stomach, or an IV placed in my arm?
4. If my heart stops beating, do I wish to receive CPR?

In our experience, families are always grateful that they dealt with these difficult questions early on, rather than at the last minute.

For the family taking care of a person with CJD, there are many challenges and many questions. Below is a list of organizations that may be able to help and websites that provide additional information on CJD.

RESOURCES

[Creutzfeldt-Jakob Disease Foundation, Inc.](#)

P.O. Box 5312

Akron OH 44334

(800) 659-1991

Toll-free Helpline. Answered 9-5 EST Monday through Friday

Centers for Disease Control and Prevention (CDC)

1600 Clifton Road, Atlanta, Georgia
(800) 311-3456 or (404) 639-3396

National Organization for Rare Diseases (NORD)

P.O. Box 8923
New Fairfield, CT 06812-8923
(203) 746-6518 or (800) NORD-6673

National Institute of Neurological Disorders and Stroke (NINDS)

National Institutes of Health
31 Center Drive MSC 2540
Bethesda, MD 20892-2540
(301) 496-5751 or (800) 352-9424