BC EMERGENCY MEDICINE NETWORK

This material has been reviewed and approved by the patient partners with the Patient Voices Network.

# Creutzfeldt-Jakob Disease (CJD)

Creutzfeldt-Jakob Disease (CJD) is a rare, degenerative, fatal disease of the brain. While rare, approximately 30 to 40 people living in Canada die from it each year. CJD can be found in every country around the world

Early **symptoms** may include confusion, depression, forgetfulness, difficulty sleeping, behavior changes, impaired vision, abnormal physical sensations, and difficulty with voluntary coordination.

Once a person begins showing signs or symptoms of CJD the disease advances quickly over 2 to 12 months.

More advanced symptoms include balance problems, difficulty with speech and movement, increased risk of pneumonia, dementia, coma and eventual death.

### What causes CJD?

CJD is caused by an abnormal prion – a protein found on the surface of cells. Prions attack the brain, killing cells and creating gaps in tissue or sponge-like patches. The symptoms can take up to 30 years to begin.

### How does a person get CJD?

About about 85 to 90 per cent occur without a known cause. Ten to 15 per cent of cases run in families. Less than 1 per cent of the time, CJD is passed to a person by instruments or transplanted tissue used in eye, brain or spine surgery. CJD does not spread through person to person contact.

## WHAT IS THE TREATMENT?

A tentative diagnosis of CJD is made based on:

+ symptoms.
+ tests on the fluid surrounding the spinal cord.
+ brain images using CT and MRI scans, and recordings of the brain's electrical activity using EEG.

The diagnosis can only be confirmed through an autopsy.

There is currently no cure for CJD. Treatment involves physical and occupational therapies. A person with CJD eventually becomes confined to bed and must be fed by a tube. Families upon hearing the diagnosis should contact a hospice, through their family doctor or community support services, as it may not be available immediately. In the meantime, they should have a care plan and assess if the patient can be left alone at home and to accommodate the shifting needs of the patient. Creating a soothing environment at home that limits stimuli (i.e. such as no loud sounds, sudden touches, flickering television and covering reflective surfaces like mirrors, windows, etc)  may help.

## IS CJD RELATED TO VARIANT CJD (vCJD)?

CJD and vCJD are not the same disease. They are part of a group of diseases caused by abnormal prions. The symptoms are similar, although vCJD usually occurs before the age of 30. vCJD is sometimes called human mad cow disease, or human bovine spongiform encephalopathy (BSE). It is thought to be passed to humans from eating cow parts infected with BSE prions.

## RELEVANT RESOURCES

+ For more information on CJD, visit the Canadian Alzheimer Society web page on Creutzfeldt-Jakob disease at https://alzheimer.ca/en/Home/About-dementia/Dementias/Creutzfeld-Jakob-Disease.

+ For more information on vCJD, visit HealthLinkBC File #55b Variant Creutzfeldt-Jakob Disease(vCJD).

## TO LEARN MORE ASK

+ Your family doctor.
+ HealthLinkBC - call 8-1-1 (7-1-1 for deaf or hard of hearing) or go online to www.HealthLinkBC.ca

## RECOMMENDED FOLLOW UP

☐ Follow up with your primary care provider in ____ days.



Find this information sheet on the BC Emergency Medicine Network website: www.bcemn.ca/clinical_resource/creutzfeldt-jakob-disease/