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MADISON NEUROLOGY LLC

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Neurology Care 7 days a Week. Because Your Brain Matters.

Creutzfeldt-Jakob Disease (CJD)

Patient education guide · Neurodegenerative & Memory · Madison Neurology LLC

What is it?

Creutzfeldt-Jakob disease is a rare, rapidly progressive brain disorder caused by prions — abnormally folded proteins that trigger other proteins to misfold. It leads to rapidly worsening dementia, movement problems, and neurological decline over weeks to months. It affects about 1-2 people per million per year and is not contagious through casual contact.

How does it happen?

About 85% of cases are sporadic (a random protein misfolding event with no known trigger). Roughly 10-15% are inherited (PRNP gene mutations). Acquired forms — from contaminated surgical instruments or, historically, human growth hormone, and variant CJD linked to BSE ('mad cow') — are now extremely rare.

Common symptoms

- Rapidly progressive memory loss and confusion over weeks to months
- Jerky muscle movements (myoclonus), often triggered by sound or touch
- Balance and coordination problems
- Visual disturbances
- Behavior and personality changes, agitation, or depression

How is it diagnosed?

MRI shows characteristic patterns, and spinal fluid tests (RT-QuIC, 14-3-3, tau) strongly support the diagnosis; RT-QuIC is highly specific. EEG may show typical periodic patterns. Genetic testing identifies inherited forms.

How is it treated?

There is currently no treatment that stops or slows CJD, and care focuses on comfort: controlling myoclonus, agitation, and pain; supporting nutrition; and helping families. Early involvement of palliative care and hospice provides meaningful comfort and dignity. Family support organizations offer specialized guidance.

What does the future hold?

CJD progresses rapidly — most patients pass away within a year of symptom onset. Because it is so rare and fast-moving, care at experienced centers and connection with the CJD Foundation help families navigate decisions, genetic questions, and grief.

Questions patients commonly ask

Q: Is CJD contagious?

A: No. It does not spread through casual contact, hugging, or sharing a home; special precautions apply only to certain medical procedures and tissue handling.

Q: Should family members be tested?

A: Genetic counseling is recommended when the inherited form is suspected; testing relatives is voluntary and guided by a genetics professional.

Q: Why did this happen?

A: In most cases it is a random biological accident of protein folding — nothing the person did or was exposed to.

National support groups & resources

- **CJD Foundation** — cjdfoundation.org — 1-800-659-1991
- **National Organization for Rare Disorders** — rarediseases.org — 1-800-999-6673
- **National Institute on Aging** — nia.nih.gov — 1-800-438-4380

(Organization contact details were current at the time of compilation; please verify online.)

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