

CREUTZFELDT-JAKOB DISEASE:

A Friendly Guide to Understanding,
Symptoms, and Care





This resource is not intended for professional medical advice, it is for general informational purposes only. Please consult your physician or medical specialist for diagnosis, advice and treatment.

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CREUTZFELDT-JAKOB DISEASE:

KEY FACTS

01

Rarity: CJD is extremely rare, with approximately 1-2 cases per million people worldwide each year.

02

Progression: Symptoms can develop rapidly and lead to severe neurological decline within months

03

Diagnosis: Diagnosis is based on clinical evaluation, imaging, EEG, and CSF analysis.

04

No Cure: There is currently no cure or effective treatment, but supportive care can help manage symptoms.

CREUTZFELDT-JAKOB DISEASE:

What is it?

Creutzfeldt-Jakob Disease (CJD) is a rare, degenerative brain disorder caused by prions—abnormal, misfolded proteins that can induce normal proteins in the brain to also misfold.

This process leads to rapid brain damage and a variety of neurological symptoms. CJD is classified as a type of transmissible spongiform encephalopathy (TSE), which includes other conditions like mad cow disease (BSE) in cattle.



Causes and Risk Factors

CJD is caused by prions—misfolded proteins that can induce normal proteins in the brain to also misfold, leading to neurodegeneration. Here's a closer look at the different forms of CJD and their causes:

- **Sporadic CJD:**
 - The most common form, occurring in about 85% of cases.
 - It typically arises without any known cause and is thought to occur randomly, usually in older adults.
- **Familial CJD:**
 - This form is inherited and accounts for about 10-15% of cases.
 - It is linked to mutations in the PRNP gene, which provides instructions for making the prion protein. If someone inherits a mutation, they may develop CJD, usually at an earlier age.

CREUTZFELDT-JAKOB DISEASE:

What are the symptoms?

Symptoms of CJD can develop rapidly and progress quickly, often within weeks to months. They may vary depending on the form of the disease, but common symptoms include:

Common Symptoms:

Neurological Symptoms

- Cognitive Decline: Memory loss, confusion, and difficulty concentrating or reasoning.
- Personality Changes: Mood swings, depression, anxiety, or behavioral changes.
- Visual Disturbances: Blurred vision or hallucinations.
- Coordination Problems: Difficulty walking, loss of balance, and coordination issues.

Motor Symptoms

- Muscle Weakness: Generalized weakness and decreased strength.
- Involuntary Movements: Jerky movements, tremors, or spasms.
- Difficulty Speaking: Slurred speech or trouble articulating words.

Sleep Disturbances

- Changes in sleep patterns, including insomnia or excessive daytime sleepiness.

Rapid Progression:

- Symptoms can worsen quickly, often leading to severe disability within months, and affected individuals may enter a comatose state as the disease progresses.



CREUTZFELDT-JAKOB DISEASE:

Diagnosis of the condition

Diagnosing CJD can be challenging due to the rarity of the disease and its overlapping symptoms with other neurological disorders. The diagnostic process typically involves:



Typical testing methods include:

- **Medical History and Symptoms:** A thorough evaluation of the patient's medical history, including any risk factors or potential exposure to prions, along with a review of symptoms.
- **Neurological Examination:** A detailed neurological exam assesses cognitive function, motor skills, coordination, and reflexes.
- **Electroencephalogram (EEG):** This test measures electrical activity in the brain. In CJD, certain patterns of brain wave activity may be observed.
- **Magnetic Resonance Imaging (MRI):** MRI scans can help identify characteristic changes in the brain, such as hyperintensities in specific regions.
- **Cerebrospinal Fluid (CSF) Analysis:** A lumbar puncture may be performed to analyze CSF for the presence of specific proteins associated with CJD, such as 14-3-3 protein or tau protein.

CREUTZFELDT-JAKOB DISEASE:

Progression of the condition

Creutzfeldt-Jakob Disease (CJD) is a rare, rapidly progressive, and fatal neurodegenerative disorder caused by the accumulation of abnormal prion proteins in the brain.

The progression typically begins with subtle symptoms such as memory lapses, mood changes, and difficulties with coordination or vision.

These initial signs quickly escalate over weeks to months, leading to pronounced cognitive decline, confusion, and behavioral changes.

As the disease advances, individuals often develop severe neurological impairments, including muscle stiffness, involuntary movements, and difficulty speaking or swallowing.

In the later stages, patients may enter a comatose state, with complete loss of mental and physical function.

The rapid progression of CJD, which typically results in death within a year of symptom onset, underscores the urgency of early diagnosis and supportive care, though no cure currently exists.



CREUTZFELDT-JAKOB DISEASE:

Is there a cure?

Currently, there is no cure for Creutzfeldt-Jakob Disease, and treatment focuses on managing symptoms and providing supportive care.

Here are some common approaches:

Palliative Care:

- Focuses on improving the quality of life for both patients and their families through symptom management and emotional support.

Medications

- Medications may be prescribed to manage specific symptoms, such as pain, anxiety, or agitation. However, no treatments can stop the progression of the disease.

Supportive Care

- Physical therapy can help with mobility and coordination, while speech therapy may assist with communication difficulties.

Psychosocial Support

- Counseling and support groups can provide emotional support for both patients and their families as they navigate the challenges of the disease.

Advanced Care Planning:

- Discussing care preferences and end-of-life planning is essential, as CJD often leads to significant disability.



CREUTZFELDT-JAKOB DISEASE:

Helpful Resources



**If you have a loved one diagnosed with CJD,
here are some ways to provide support:**

- **Be Informed:** Learn about CJD to better understand what they are going through and how best to help.
- **Listen and Validate:** Provide a listening ear and validate their feelings. Being present can be comforting during this challenging time.
- **Assist with Daily Activities:** Offer help with daily tasks and routines as their abilities decline. This support can be invaluable.
- **Encourage Professional Help:** Help them access appropriate medical care and therapy to manage symptoms effectively.

CREUTZFELDT-JAKOB DISEASE:

Final Thoughts

Creutzfeldt-Jakob Disease is a complex and challenging condition that deeply impacts individuals and their families.

By raising awareness, understanding the symptoms, and providing compassionate support, we can help those affected navigate this difficult journey.

If you or someone you know is facing CJD, remember that resources, medical support, and community assistance are available to help you along the way.



OUR SERVICES: DEMENTIA SUPPORT SPECIALIST CONSULT

At Remember the Carer we enhance the lives of caregivers and loved ones living with cognitive change.

We provide effective life strategies and simple wellbeing solutions, personally designed for you.

Our Dementia Support Specialist is dedicated to serving you with practical strategies, and simple solutions designed to improve your experience of caregiving, and enhance your wellbeing.

HOW WE CAN HELP:



Unpacking and
Understanding the
Diagnosis.



Practical Behavioral
Strategies



Living Well Strategies



Caring for the Caregiver



Future Planning



Allied Health Referrals
& Community Support

OUR SERVICES: WELLBEING & LIFE STRATEGY COACHING

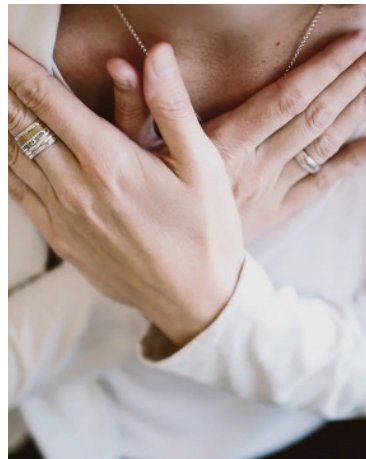
**Whether you simply need someone to listen,
or you're seeking coaching for wellbeing, life strategy
or neuroscience techniques, we're here for you.**

**These private sessions allow us to meet your unique needs,
helping you find clarity and direction
with practical steps forward.**

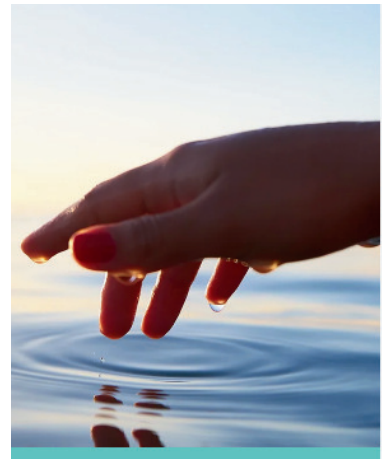
Our wellbeing and life strategy sessions are designed to provide you with a safe and nurturing space to explore your thoughts and feelings, creating a supportive environment where you can express yourself freely, knowing that you're in a judgment-free zone.

During your first appointment with our wellbeing & life Strategy coach, you'll engage in a warm and supportive conversation where your story can be expressed and heard and whatever matters most to you. This includes unpacking the biggest barriers and challenges that you're facing, to explore your goals and dreams no matter how big or small, because vision is key.

Once a clear understanding of your situation, has been established we will explore creative strategies for you to pivot and map out practical steps toward living your best life. You will also receive a comprehensive blueprint and support plan tailored to your unique journey.



Heart & Soul Care:
Reconnecting with your
Unique Being



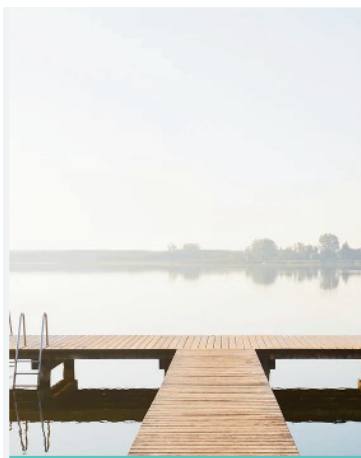
Breakthrough & Recovery:
Strategies for Anxiety, Stress
& Burnout



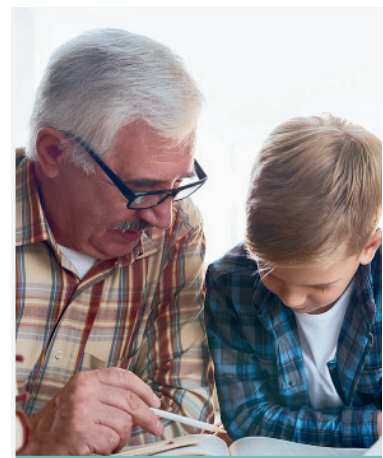
Healthy Boundaries:
Guilt-free living & quality
relationships



Healthy Mindset:
Building Strength,
Confidence & Resilience



Finding Equilibrium:
Reclaiming Rest
and Life Balance



**Memory, Attention
& Learning Strategies**

OUR SERVICES: NEUROSCIENCE COACHING & RESOURCES

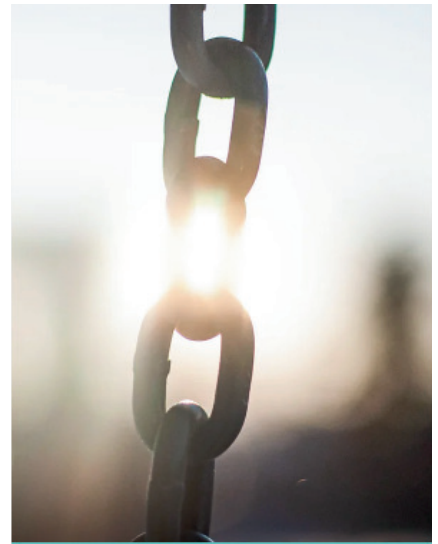
Neuroscience Coaching incorporates evidence-based techniques harnessing the power of neuroplasticity and brain anatomy principles to enhance daily functioning, in many areas of life including the following:



Motivation, Inspiration
& Productivity Strategies



Language & Communication
Strategies



The Neuroscience of
Addiction

OUR SERVICES

SCHEDULE AN APPOINTMENT

MEET THE TEAM



Allied Health Referrals
& Community Support



Empowerment
Programs



Information
Resources



REMEMBER THE CARER

At Remember the Carer we enhance the lives of caregivers
and loved ones living with cognitive change.

We provide effective life strategies and simple wellbeing solutions,
personally designed for you.

Our dedicated Dementia Support Specialist, and our
compassionate team of Certified Dementia Practitioners,
Wellbeing and Neuroscience Coaches are here to serve.



With twenty years of vast experience in dementia care and cognitive change
...you're in great hands.

