A Patient’s Guide to Rapidly Progressive Dementia (RPD)

This material is provided by UCSF Weill Institute for Neurosciences as an educational resource for patients.

UCSF Weill Institute for Neurosciences
Memory and Aging Center

Models for illustrative purposes only.
What is dementia?

When medical professionals use the term “dementia,” it refers to a brain problem that makes it difficult for a person to complete daily tasks without help. Symptoms of dementia vary from person to person and may include memory problems, mood changes, or difficulty walking, speaking, or finding your way.

What is Rapidly Progressive Dementia?

Rapidly progressive dementias (RPDs) are dementias that progress over a relatively short period of time, typically over weeks to months, and sometimes up to 2-3 years. RPDs are rare and often difficult to diagnose. Early and accurate diagnosis is very important because many causes of RPDs can be treated.

What causes RPD?

Many conditions can cause RPD. Some possible causes include:

- Autoimmune diseases (conditions that over-activate the immune system)
- Unusual presentations of common neurodegenerative diseases (such as Alzheimer's disease)
- Prion diseases (rare forms of neurodegenerative disease)
- Infections
- Impaired blood flow to or in the brain
- Exposure to toxic substances
- Vitamin deficiencies
- Cancer
- Toxicity from prescribed medications
- Recurrent seizures

What happens in RPD?

The progression of RPD varies from patient to patient and in part depends on the underlying cause. Patients typically develop problems with their thinking, mood/personality/behavior, ability to speak or understand, or ability to control their movements. Many are often treatable and reversible if diagnosed quickly. For some other RPDs, there are no cures and progression of symptoms is inevitable. There may be some treatment to help relieve specific symptoms.

How is an RPD diagnosed?

RPD can be difficult to diagnose, so it is often necessary to see a doctor who specializes in these conditions. The doctor might ask about the patient’s progression of symptoms, any similar illnesses in biological relatives or any recent possible exposures (i.e., toxins, travel history). The doctor may request some laboratory testing, such as blood, urine and cerebrospinal fluid (the clear liquid that surrounds the brain and spinal cord); brain imaging (such as an Magnetic Resonance Imaging) and/or an electroencephalogram (a non-invasive test that measures brain electrical activity from the scalp). The information gathered by the physician and tests might help to determine the cause of disease.

How are RPDs treated?

Treatment depends on the type of RPD that was diagnosed. For example, if the RPD is the result of a cancer or a hormone imbalance, treatments that target these specific conditions may help treat the RPD. Unfortunately, for many causes of RPD, there is no cure available. For these cases, however, we can sometimes treat the symptoms, make patients more comfortable, and improve their quality of life.

Resources

UCSF Memory and Aging Center – Rapidly Progressive Dementia Workup: memory.ucsf.edu/rapidly-progressive-dementia-workup

The Penn RPD Center – Rapidly Progressive Dementia: ftd.med.upenn.edu/about-ftd-related-disorders/what-are-these-conditions/other-disorders/rapidly-progressive-dementia

CJD Foundation: cjdfoundation.org

The National Prion Disease Pathology Surveillance Center provides information and free brain autopsy service in the United States: cjdsurveillance.com

Media

University of California Television YouTube Channel: “Rapidly Progressive Dementia: From Prions to Antibodies” youtube.com/watch?v=SK_mvNwFBvw

University of California San Francisco Memory and Aging Center: “CJD, a personal story” youtube.com/watch?v=VTAmIZGpjNs