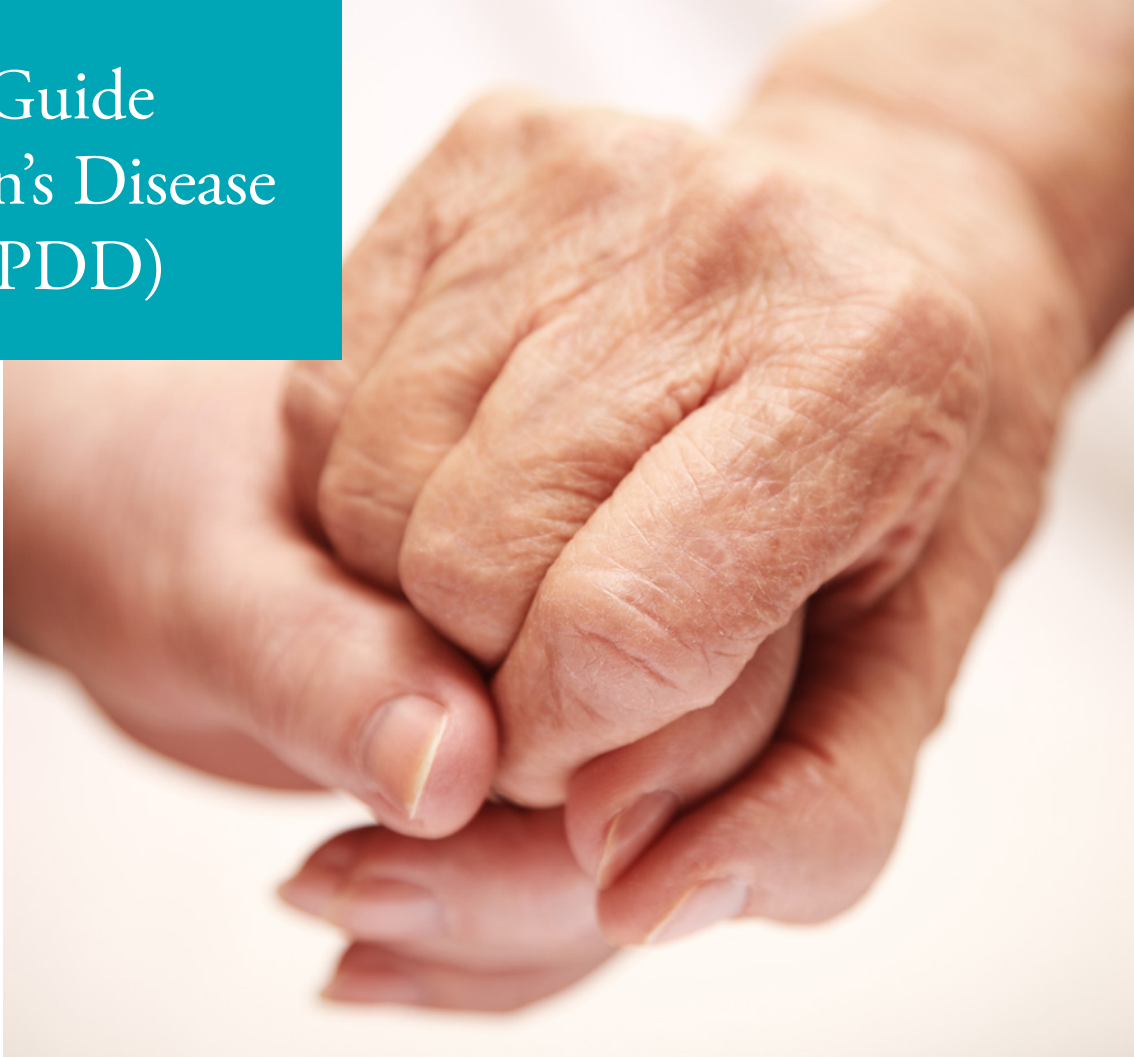


A Patient's Guide to Parkinson's Disease Dementia (PDD)

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



What is dementia?

Dementia is a general term for any disease that causes a change in memory and/or thinking skills that is severe enough to impair a person's daily functioning. Symptoms of dementia vary from person to person and may affect one's ability to remember things, concentrate, plan and organize, communicate or find one's way around, among other possible symptoms. There are many causes of dementia and Parkinson's disease can be one of them. Not at all people with Parkinson's disease develop dementia.

What is Parkinson's disease dementia?

Parkinson's disease dementia (PDD) is changes in thinking and behavior in someone with a diagnosis of Parkinson's disease (PD). PD is an illness characterized by gradually progressive problems with movement, most commonly involving slowing of movements, a tremor present at rest, and walking instability which can cause falls. PDD has similarities to a related condition called dementia with Lewy bodies (DLB) that also causes changes in thinking, behavior and movement but in DLB the movement problems start after the thinking and behavior symptoms.

What causes PDD?

The cause of PDD is unknown. Scientists know that in Parkinson's disease, there is a large build-up of a protein called alpha synuclein that clumps together to form "Lewy bodies". Alpha synuclein occurs normally in the brain, but we do not yet understand what causes it to build up in large amounts. As more and more proteins clump in the nerve cells, the cells lose their ability to function and eventually die. Early in PD, the disease process affects parts of the brain important for movement, but as the disease progresses,

eventually parts of the brain that are important for mental functions such as memory and thinking become injured.

How is age related to PDD?

Both PD and PDD are more common with increasing age. Most people with PD start having movement symptoms between ages 50 and 85, although some people have shown signs earlier. Up to 80% of people with PD eventually develop dementia. The average time from onset of movement problems to development of dementia is about 10 years.

What happens in PDD?

People with PDD may have trouble focusing, remembering things, or making sound judgments. They may develop depression, anxiety or irritability. They may also hallucinate and see people, objects, or animals that are not there. Sleep disturbances are common in PDD and can include difficulties with sleep/wake cycle (asleep during the day and awake at night) or REM behavior disorder, which involves acting out dreams.

PDD is a disease that changes with time. A person with PDD can live many years with the disease. Research suggests that a person with PDD may live an average of 5–7 years with the disease, although this can vary from person to person.

Are there medicines to treat PDD?

Though there is no cure for PDD yet, there are medications that help manage the symptoms. These medications are called cholinesterase inhibitors, and they can help if a person with PDD is having memory problems. Some examples of these medicines are donepezil, rivastigmine, and galantamine. Sleep problems may be managed by sleep medications such as melatonin.

Because people with PDD are usually very sensitive to medications, any new medication, even one that is not being used for the brain, needs to be reviewed with the person's provider to avoid potential contraindication.

How can we manage hallucinations?

It may not be necessary to treat all hallucinations of a person with PDD. Hallucinations are often harmless, and it is okay to allow them to happen, as long as they are not disruptive or upsetting to the person or his/her surroundings. Sometimes, recognizing the hallucination and then switching the topic might be an efficient way of handling frustrations that occur because of a hallucination. If hallucinations need medical treatment, your provider may be able to discuss and suggest some options. However, many of the medications used to treat hallucinations may make movement symptoms worse.

How can we support the sleep/wake cycle of PDD?

For people with PDD who are confused about the day-night cycle, some daily strategies can be helpful. At night, starting a "lights out" routine that happens at the same hour everyday, where all curtains are closed and lights are turned off, can help the person understand that it is sleep time. During the day, opening the curtains, allowing patients to spend as much time in the daylight as possible, avoiding naps, and organizing stimulating activities, can be helpful. Having lots of calendars and clocks in every room might also help a person with PDD be less confused about the time of day.

What other things help?

There are various ways to help a person with PDD. Speech therapy may help improve communication between people with PDD and others. Physical therapy may help strengthen and stretch stiff muscles, and help to prevent falls.

Research has shown that physical exercise helps to enhance brain health and improves mood and general fitness. A balanced diet, enough sleep, and limited alcohol intake are other important ways to promote good brain health. Other illnesses that affect the brain, such as diabetes, high blood pressure, and high cholesterol, should also be treated if present.

Resources

Family Caregiver Alliance: caregiver.org

National Institutes of Health: nih.gov

Research: clinicaltrials.gov

National Parkinson Foundation: parkinson.org

Michael J. Fox Foundation for Parkinson's Research: michaeljfox.org

Coping with Dementia: Advice for Caregivers (Parkinson's Disease Foundation): pdf.org/en/spring03_dementia

Alzheimer's Association: alz.org/dementia/parkinsons-disease-symptoms.asp