Dementia with Lewy Bodies
Information for patients and families

What is Dementia with Lewy bodies?
Dementia with Lewy bodies (DLB) is a brain disease that causes you to have trouble thinking and moving. It gets worse over time. DLB is also called Lewy body disease or Lewy body dementia.

What are the symptoms?
People with DLB usually have thinking problems and a mix of 3 main symptoms.

The 3 main symptoms are:

1. **Trouble moving**
   For example they:
   - move slowly
   - shuffle when they walk and have stiff arms and legs
   - don’t have much facial expression
   
   These symptoms are similar to Parkinson’s disease.

2. **Visual hallucinations**
   This means they may see objects, people, or things that are not there.

3. **Sudden changes in the way they behave**
   For example, they may act near normal and suddenly become sleepy or confused and then go back to acting near normal.
What causes DLB?

We don’t know what causes DLB. It’s different from Alzheimer’s disease, even though both diseases affect thinking. It’s also different from Parkinson’s disease, even though the nerve cells in both diseases develop abnormal round structures called “Lewy bodies.”

For now, doctors can only be sure of a DLB diagnosis after an autopsy (examining the body after death).

Are there treatments?

Right now, there is no cure for DLB, but there are treatments that can help. Some medicines used to treat Alzheimer’s disease can help people with thinking and memory problems. Some medicines used to treat Parkinson’s disease can help with problems walking or stiffness in arms and legs.

What about safety?

Since DLB affects your thinking and movement, it can eventually become unsafe for a person with DLB to:

- try to follow instructions on a medicine bottle
- make legal decisions
- use a stove
- drive
- walk by themselves (there’s a chance they can lose their balance and fall)