LEWY BODY DISEASE

This Help Sheet explains Lewy Body disease (also known as Lewy Body dementia). It is a form of dementia with particular characteristics making it different from other dementias.

What is Lewy body disease?
Lewy body disease (LBD) is a type of dementia, that is, it is a condition that causes gradual deterioration in thinking, communication and behaviour. Some specific features that occur regularly in LBD and not in other types of dementia are: Parkinson’s disease-like symptoms (tremor, shuffling, stiffness, slow walking, quiet speech and loss of facial expression) visual hallucinations (seeing things that aren’t there) and fluctuations in levels of awareness and alertness.

What is the cause?
Lewy body disease is caused by the degeneration and death of nerve cells in the brain. When the cells are examined by microscope, they contain spherical structures called Lewy bodies that are thought to contribute to the death of the cell. The reason for these bodies developing in the cells is unknown. There are no known risk factors and no evidence that LBD is inherited.

How is Lewy body disease diagnosed?
The diagnosis is made by taking a careful history about the pattern of symptoms from the person and other people who know him / her. Cognitive and other neuropsychological tests, physical examination and blood tests will be part of the assessment. Other causes of dementia such as vascular dementia may be ruled out by CT or MRI scan, but LBD does not have a particular appearance on scans that can definitively diagnose it. The Lewy bodies can only be found by examining brain tissue after death.

There are three cardinal symptoms for diagnosis, two of which should be present for diagnosis. These are:
- Visual hallucinations
- Parkinsonism
- Fluctuation in mental state – a person may be lucid and clear at one point and confused a few hours or minutes later. This needs to be distinguished from delirium in which a person has an underlying physical illness.

Other features suggestive of LBD are:
- Rapid eye movement sleep disorder—that is, they thrash out, move around or yell during dreams
- Severe sensitivity to antipsychotic drugs

Memory problems do not always occur early on. Some of the first things noticed might be difficulty with concentration and paying attention or spatial problems e.g. having trouble judging distance which might cause falls. Other symptoms are low blood pressure, collapses and faints or loss of bladder control. Delusions (false beliefs) and depression are also common.

Who gets LBD?
The condition is slightly more common in men. It is thought to be the cause of 20-35% of all dementias.

How does LBD progress?
Usually LBD progresses more rapidly than Alzheimer’s disease. Eventually, it is difficult to tell them apart because all the symptoms become similar and the person becomes increasingly dependent. The average lifespan after diagnosis is seven years.

Is there treatment available?
Cholinesterase inhibitor drugs (donepezil, rivastigmine and galantamine) that are used in Alzheimer’s disease may be helpful in slowing down the progression but are not curative. Because people with LBD may be very sensitive to antipsychotic drugs and may get life-threatening side-effects, it is difficult to treat the hallucinations. And, because the anti-Parkinson’s medications may make psychotic symptoms worse, it is hard to treat the Parkinsonian movement symptoms (like tremor and stiffness). Drug treatment has to be very carefully balanced.
How is LBD related to Parkinson’s disease?
In LBD, the Lewy bodies are found mainly in the upper part of the brain, the cortex where our thinking goes on. In Parkinson’s disease the Lewy bodies are found in the sub-cortex where movement is controlled. However, as both conditions deteriorate, the Lewy bodies become more widely spread. People with Parkinson’s disease then develop dementia and those with LBD get more movement problems. If the Parkinson’s disease was diagnosed more than a year before the dementia, then the diagnosis is “dementia due to Parkinson’s disease”. If the dementia came first, then it is Lewy body dementia. The conditions are at each end of a spectrum; sometimes they overlap and it is not always easy to distinguish between them.