Parkinson's and Lewy Body Dementia

Parkinson's and Dementia

Parkinson's is a progressive, degenerative neurological condition. It primarily involves a disturbance in the co-ordination of movement and has three main motor symptoms: tremor, rigidity and bradykinesia (slowness of movement).

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning. It is a broad term used to describe a loss of memory, intellect, social skills, rationality and what would be considered normal emotional reactions.

A number of people with a diagnosis of Parkinson's disease will develop cognitive impairment perhaps resulting in a diagnosis of dementia. The cause may be:

- Parkinson's or
- Alzheimer's disease, cardiovascular disease or some other disease process.

If the physical symptoms (falling, stumbling, slowness of movement) precede the cognitive symptoms (memory, language, speaking) by one year a diagnosis of Parkinson's will be made.

Conversely, when cognitive symptoms are identified before physical problems arise the diagnosis will usually be Lewy Body Dementia (DLB).

What are Lewy Bodies?

Lewy Bodies are accumulations of microscopic protein deposits in the brain, primarily of a protein called alpha-synuclein. They are named after Dr. Frederich Heinrich Lewy, who first described them in 1912 in conjunction with Parkinson's. Scientists believe their formation is related to malfunctions in the way the brain disposes of used or damaged proteins. However, how exactly and why Lewy Bodies form is still under investigation.

The brains of people with Parkinson's show a large number of Lewy Bodies in an area called the substantia nigra which is responsible for movement. In DLB, they appear not only in the substantia nigra but also in the cortex, where many 'higher thought' processes take place. Researchers are still uncertain as to whether Lewy Bodies are the cause of DLB and Parkinson's or merely a symptom of underlying problems in the brain.

What are the symptoms?

Similar to Alzheimer's disease, one of the most common initial symptoms of DLB is impaired memory of recent events. Many people also have episodes of confusion, problems with language, and difficulty making decisions. These symptoms may fluctuate considerably, with the person perhaps able to function normally one day and be almost unable to speak the next. These fluctuations may occur daily or even hourly in some cases.

People with DLB may also experience very detailed visual hallucinations. Adding to these symptoms may be physical impairments similar to those found in Parkinson's. These include a hunched posture, shuffling walk and limb stiffness, tremors and bradykinesia (slowness of movement).

Symptoms of DLB will vary. Some people can become obsessive and lose emotional control with sudden outbursts of anger and distress. Some may suffer falls because their ability to judge distances or make movements accurately is disrupted. DLB is a progressive condition which means the symptoms become worse over time.

As with Alzheimer's disease, a definitive diagnosis of DLB can only be made by examining the brain after death. However, in 1996 a group of researchers and clinicians issued guidelines for clinically diagnosing the condition. A diagnosis requires the finding of persistent cognitive deficits and either fluctuating cognition, visual hallucinations, or Parkinson's-like symptoms, called parkinsonism.

One or more of the three distinctive Lewy Body symptoms should develop soon after the initial onset of cognitive difficulty. Because DLB shares many symptoms with other forms of dementia, including Alzheimer's, Parkinson's, and vascular dementia (caused by blood flow problems in the brain), it can be very difficult to diagnose, so diagnosis must be made by a Specialist.

What treatment is available?

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As with most other forms of dementia, there is no cure for DLB. The current strategy for treatment is to treat the three main symptoms: cognitive decline, motor disturbance and psychosis (hallucinations)

Psychologists and counsellors in movement disorders and cognitive problems can suggest strategies and techniques which can help cope with the symptoms of DLB and Parkinson's while maintaining their regular Parkinson's medication.

Some psychotic symptoms can be difficult to treat medically as many people with DLB are extremely sensitive to anti-psychotic medications, which can cause or greatly worsen parkinsonian motor disturbances.

If tranquillising drugs are given, for example to control hallucinations, the newer 'atypical' neuroleptics may be used under the advice and care of a specialist doctor such as a Psychiatrist or a Neurologist. These generally have fewer side effects than the older drugs but may increase the risk of stroke and must be used with great caution.

Cholinesterase inhibitors, which were developed to treat Alzheimer's disease, are also used in the treatment of DLB (although they, too, can worsen parkinsonian symptoms). Cholinesterase inhibitors act to raise the level of acetylcholine, an important chemical messenger in the brain.

Levels of acetylcholine are lower in patients with Alzheimer's and DLB and raising the level of acetylcholine circulating in the brain can provide modest cognitive benefits. Anecdotal experience and recently completed clinical trials have shown that cholinesterase inhibitors not only improve cognition in DLB patients, but that they may also reduce psychotic symptoms as well.

Medications are one of the most controversial subjects in dealing with DLB. A medication that doesn't work for one person may work for another person. Prescribing should only be done by a doctor who is thoroughly knowledgeable about DLB. As with any new medications the person should be closely monitored and at the first sign of an adverse reaction, consult with a doctor.

Diagnosis

A thorough dementia diagnostic evaluation includes physical and neurological examinations, patient and family interviews (including a detailed lifestyle and medical history) and neuro-psychological and mental status tests.

The patient's functional ability, attention, language, visuo-spatial skills, memory and executive functioning are assessed. In addition, brain scans (CT and MRI scans) blood tests and other laboratory studies may be performed to rule out other causes for dementia symptoms.

People with DLB stand to benefit from advances made in fighting both conditions. Current research into the formation of Lewy Bodies in Parkinson's disease could yield results for DLB.

With the incidence of dementia on the rise as our population ages, an improved understanding of the mechanisms that underlie dementia with Lewy Bodies and other neurodegenerative conditions could benefit millions of older persons and their families.

Risk Factors

Advanced age is considered to be the greatest risk factor DLB, with onset typically, but not always, between the ages of 50 and 85. Some cases have been reported much earlier. DLB appears to affect slightly more men than women. Having a family member with DLB may increase a person's risk. Observational studies suggest that adopting a healthy lifestyle (exercise, mental stimulation, nutrition) might assist in reducing the risk of many forms of dementia.

Prognosis and Stages

No cure or definitive treatment for DLB has yet been discovered. The condition has an average duration of 5 to 7 years. It is possible, though, for the time span to be anywhere from 2 to 20 years, depending on several factors, including the person's overall health, age and severity of symptoms.

Defining the stages of progression for DLB is difficult. The symptoms, medicine management and duration of DLB vary greatly from person to person. To further complicate the stages assessment, DLB has a progressive but fluctuating clinical course.

It is typical to observe a significant progression, followed by change back to a higher functioning level. Downward fluctuations are often caused by medications, infections or other compromises to the immune system, but may also be due to the natural course of the condition.

What sort of research is being done on dementia with Lewy Bodies?

One of the biggest research needs for DLB is good information about how well various medications work for controlling symptoms. However there are significant obstacles to performing large, rigorously controlled studies on the effect of medications on DLB. Clinical trials are complicated by low numbers of people with a clear diagnosis of dementia with Lewy Bodies.

Caring for people with DLB

There is an increased risk when a person with dementia lives alone. However whether this continues to be an acceptable risk will need to be reviewed regularly by family, carers and professionals. The person's own wishes and concerns must also be considered.

A person living alone may:

* Forget to eat or take prescription medication
* Forget to bathe or change their clothes regularly
* Lack awareness of potentially hazardous situations such as fire and electrical appliances in the home, or traffic outside.
* Show poor judgement about who they let into the house
* Forget to feed or care for pets
* Have unrealistic ideas or suspicions which can lead to trouble with neighbours, the police or in the community.

In general:

- When speaking to someone with DLB make sure they are paying attention to you. Try to make eye contact before speaking.
- Try to say exactly what you mean, speak slowly and do not ask complicated questions.
- Give the person time to think about what you have said and to respond.
- Talking with them about memories can help them re-visit happier times and encourage them to talk with you.
- Help them to be understood by taking the time to find out exactly what they are trying to say.
- Ensure that they are always in a safe environment.
- Movement disorders, like falling can be helped at Movement Disorder Clinics.

Finally, **try to avoid** baby talk to some-one with DLB, and **avoid** talking about the person in front of them. Remember to treat them as you would like to be treated. Ensure that they carry a contact phone number in a pocket or purse but do not include their full address as this can make them vulnerable. It may also be appropriate for them to wear a Medic Alert bracelet.

Caring for Carers

With the onset of DLB the carers' role may become more complex. Relationships will change and it is important for carers to maintain their own physical and mental health.

The feelings of loss and grief which accompany the realisation that the life planned will now change is real and normal. It is essential that carers find friends, counsellors and supporters to whom they can turn for their own well being while attending to the person with Parkinson's and DLB.

Isolation can occur as a result of the slow withdrawal from social functions because symptoms such as poor balance, poor communication skills and lack of understanding by the community make it difficult.

Understanding this, carers need to organize regular respite for themselves – either a couple of hours a week for rest and recreation or in the form of time spent away on holiday from the 24 hour care that has now presented itself.

Joining a Support Group will give access to others who are living with similar problems and who can offer advice and friendship.

Carers are often reluctant to accept respite or support due to the complexities of Parkinson's management issues. These issues can also be discussed with a counsellor from one of the organisations found on the back cover.

Carers Australia, Alzheimer's Australia and Parkinson's Australia can all offer advice on these issues as well as access to services available to help the carer take the respite they will need.

Bibliography:

'Dementia'/ 'What is Parkinson's Dementia with Lewy Bodies'
– Parkinson's Disease Society. UK
www.parkinsons.org.uk – Ph: 0011 44 20 7233 9908
'What is Dementia?' – Alzheimer's Australia. www.alzheimers.org.au
'Carers and Parkinson's Disease' – Community Disorder Support, Kingston Centre. Victoria. Australia.
'Lewy Body Dementia Association' – (USA) www.lewybodydementia.org
'Lewy Body Society' – (UK) www.lewybody.org
'Parkinson's Disease Dementia' – Vol.10, No 3. Feb 2006 Alzheimer's Society.
'Treatment of DLB at Mayo Clinic' – www.mayoclinic.org/lewy-body-dementia

Where can I go for help?

Alzheimers Australia:

Alzheimer's Australia is the national peak body for people living with dementia, their families and carers and provides leadership in policy and services. State based services provide information, education and support.

National Dementia Helpline: 1800 100 500
Or visit: www.alzheimers.org.au

Parkinson's Australia:

The national body, which offers links to all State organizations. The State offices offer telephone support, information sheets and advice to people living with Parkinson's.

National helpline: 1800 644 189
Or visit: www.parkinsons.org.au

Carers Australia & Commonwealth Carer Resource Centres:

Provide support services to unpaid carers of people with conditions like Parkinson's and dementia.

Freecall: 1800 242 636
Or visit: www.carersaustralia.com.au

Commonwealth Carelink Centres & Aged Care Assesment Teams (ACAT):

Offer case management services and can put people in touch with practical support services (ie. Respite). They can also refer people to memory services to test cognitive functioning.

Freecall: 1800 052 222
Or visit: www.health.gov.au

Movement Disorder Clinics; Are specialised clinics that offer a multi-disciplinary approach to supporting people who are living with Parkinson's. They are also well equipped to diagnose and treat conditions like DLB. Look for them in your State directory.

The Australian Psychological Society – can provide a list of Neuro-psychologists with expertise in dementia. **www.psychology.org.au**

Neuropsychologists – have standardised tests to assess cognitive functioning. They can also put strategies in place to help cope with the challenges of DLB or dementia. Your GP, Neurologist or local ACAT team can refer you.