Updated March 2004

Parkinson's Disease Society

Parkinsonism 14

PDS Information Sheet

The main symptoms of Parkinson's (tremor (shaking), stiffness and slowness of movement) are also the main symptoms of a number of conditions which are grouped together under the term 'parkinsonism'. Parkinson's disease is the most common form and is sometimes referred to as *idiopathic Parkinson's disease (IPD)*, which means its cause is unknown. This form accounts for only about 85% of all people with parkinsonism. A number of different and distinct conditions are responsible for the remaining 15%.

Diagnosing IPD or the other parkinsonism conditions is not always easy as there are no special tests that can prove absolutely whether or not someone has a particular condition. Diagnosis is usually based on medical history and clinical examination. In many cases, parkinsonism develops gradually and it can take some time before symptoms become obvious enough for the person to consult a doctor. Everyone with parkinsonism is different, which also makes diagnosis more difficult.

Specialists who see a lot of people with parkinsonism come to recognise certain symptoms that mean a diagnosis of IPD is likely. Occasionally the person being diagnosed may also have features that are more unusual, that enable the doctor to diagnose a different form of parkinsonism. However, often this is not possible because the initial symptoms of these other conditions can be so similar to IPD that without a definite diagnostic test, it may be very difficult, particularly in the early stages, for even a specialist to decide whether the person has Parkinson's or another form of parkinsonism.

In making a diagnosis of IPD, specialists will also expect a certain response to anti-Parkinson drugs, such as levodopa (trade names *Sinemet* and *Madopar*). How well and how much someone responds can usually only be judged once the person has started on a course of drugs. Some doctors also use what is known as a 'challenge test' at diagnosis. This means giving someone a single dose of levodopa or an injection of Apomorphine, another dopaminergic medication, and measuring the person's response.

For practical purposes all people with IPD should show an initial good response to levodopa (provided a large enough dose is given for long enough), and failure to do so starts to cast doubt on the diagnosis. People with other causes of parkinsonism *usually* do not respond, or respond less well, but, to confuse matters, some may also show a good response.

Unusual symptoms alone, or poor response to drugs alone, will not automatically mean the person doesn't have IPD. However, if specialists see someone with unusual symptoms who is not responding to drugs, they may take these as pointers that the person might not have IPD and investigate further.

When this is the case, the terms "atypical parkinsonism" or "Parkinson's plus" are often used. These terms are not diagnoses, but simply indicate that the person probably doesn't have ordinary IPD. These 'labels' can be unsettling for people who have gone from thinking that they have IPD to the 'limbo' of not having a definite diagnosis. Symptoms that allow the doctor to make a more specific diagnosis may only appear as the condition develops.

If the unusual symptoms are evident enough, the person whose diagnosis is in question might be diagnosed with multiple system atrophy (MSA) (sometimes called striatonigral degeneration, Shy Drager syndrome, or olivopontocerebellar

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atrophy) or progressive supranuclear palsy (PSP or Steele-Richardson-Olszewski disease). If tremor is the only feature and it seems different from the tremor found in IPD, then a person may be diagnosed with Benign Essential Tremor (BET). Sometimes people who have had a stroke may also experience a form of parkinsonism known as vascular or arteriosclerotic parkinsonism. Some drugs can cause a reversible drug-induced form of parkinsonism. *See the PDS information sheet Drug Induced Parkinsonism (FS38)*. There are also several other rarer possible causes.

Additional Diagnostic Techniques

It is hoped that there will be advances in some diagnostic techniques in the near future that will assist doctors in telling the difference between IPD and other forms of parkinsonism and reduce the numbers of people who are misdiagnosed.

These include *MRI brain scanning* (normal in IPD, BET and drug-induced parkinsonism, abnormal in vascular parkinsonism, and often abnormal in MSA and PSP); *an electrical recording (EMG) of the urethral or anal sphincter* (often abnormal in MSA and PSP); *special recordings of pulse and blood pressure known as autonomic function tests or AFTs* (more often abnormal in MSA), and *a dopamine transporter chemical scan*, known as a Dat Spect Scan or DaTSCAN (normal in BET and drug-induced parkinsonism, abnormal in IPD, MSA and PSP, but not able to differentiate between IPD, MSA and PSP). Further information on DaTSCAN can be found in the PDS information sheet, *DaTSCAN (code FS48)*. None of these tests alone can make a definitive diagnosis. However, sometimes they exclude a particular condition, and sometimes (either used alone or combined as a "battery" of tests), they can strengthen the case for a particular diagnosis, but only when considered together with the person's medical history and clinical findings.

Further Help

Whatever form of parkinsonism a person has, it is important to emphasise that the PDS is there for all people with parkinsonism, not just those with IPD, so that people with an alternative diagnosis can belong to the PDS and use our services.

For people who have a diagnosis of MSA, PSP or BET, the following organisations may be able to offer more specific support.

Benign Essential Tremor and other conditions featuring tremor

The National Tremor Foundation,
Harold Wood Hospital (DSC), Gubbins Lane,
Romford, Essex, RM3 OBE
Tel: 01708 386399
Freephone: 0800 3288046
Email: tremorfoundation@aol.com
Website: www.tremor.org.uk

Multiple System Atrophy

Sarah Matheson Trust
Pickering Unit
St. Mary's Hospital, Praed Street, London,
W2 1NY
Telephone: 020 7886 1520
Website: www.msaweb.co.uk

Progressive Supranuclear Palsy

PSP (Europe)Association

The Old Rectory, Wappenham, Towcester,
NN12 8SQ
Tel: 01327 860299
Email: psp@pspeur.org
Website: www.pspeur.org/

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Produced by Bridget McCall, PDS Information Department.

All PDS information sheets are reviewed on a yearly basis in January and updated as soon as relevant new information becomes available.

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