

The Parkinson's  
Disease Academy

Issue 2 - May 2006



# MasterStrokes

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## Editorial

**The treatment of Parkinson's disease has come a long way since I did my medical training. I recall at that time, an elderly lady I used to see making her way along a long Edwardian terrace in typical festinant gait – my first encounter with Parkinson's.**

I have subsequently quoted frequently from Lord Brain's "Diseases of the Nervous System" (1969) 'The sufferer should be encouraged to lead an active life as long as possible but should avoid fatigue. A 'zip' fastener on the trousers is a convenience.' As an afterthought, I presume, an editor had added to the text 'L-dopa in doses up to 5 grams looks promising'!

It never ceases to amaze me just how far we have come since this text book was published. As recently as 10 years ago we were being told that the PD drug market had reached a standstill and the treatments we had [at that time] would be the best we could offer! There have been remarkable steps forward since then with recent additions to our therapeutic armamentarium and still more to come.

Many of these new therapeutic options offer improved quality of life for people with PD with less risk of distressing side effects in either the short- or longer-term. The possibility

**"We have, in the past, mainly confined everyday treatments to the oral route for PD, but why not a patch?"**



of new routes for administration also opens up greater possibilities, particularly for patients who have swallowing difficulties or need smoother control of symptoms.

We have used apomorphine by subcutaneous route for many years, but this is not an attractive option for many and it has its own

problems. We have used the buccal absorption option for selegiline (Zelapar™) and will have just seen the launch of a transdermal patch for PD and the administration of dopa via PEG intra-duodenal infusion (i.e. Duodopa™).

Is there room for these new treatments? Will people with PD accept these different administration routes and will our Health Service funders (PCTs or their successors) agree to fund these options? There are many unanswered questions. We have in the past mainly confined everyday treatments to the oral route for PD, but why not a patch? Continuous slow release of medication which avoids the need

## The newsletter for graduates and mentors of The Parkinson's Disease Academy

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to remember taking medication may well improve concordance, and possibly reduce side effects such as nausea.

Whatever the drug and its route of administration, we need to ensure individuals get the right treatment for their condition, and continued follow up. Publication of the NICE Guidelines this summer should help this process.

With so much activity in this disease area, we all need to maintain and update our knowledge of PD management continually as these new treatment modalities develop, and there is no better way than through membership of the BGS SIG for PD and attendance at one of the 'Masterclass activities'.

It would seem that the more we

enhance PD services throughout the country, the greater the demand for PD specialist training (see Jane Liddle's article below). So many SpRs have expressed an interest, we will be running a specialist registrar masterclass in July. Watch the PDSection and BGS websites for further details.

**Doug MacMahon**

## PD Services in Sheffield

**At the end of last year Sheffield officially launched its Integrated PD service which includes Specialist PD geriatricians, neurologists, a GP with Special interest in PD and Parkinson's disease nurse specialists.**

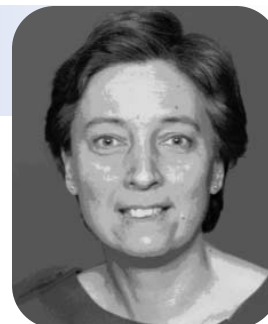
Consultant geriatrician Jane Liddell tells us how things improved after she attended the first PD Masterclass and how Parkinson's disease services in Sheffield have gone from strength to strength.

"I went into the Masterclass in order to improve my knowledge of Parkinson's disease and also learn how better to develop local services for my Parkinson's disease patients. The course fulfilled my requirements as my knowledge improved enormously and gave me ideas on how to improve the service as well as look for funding for specific areas.

I had already made my Day Hospital clinic more specialised to look after Parkinson's patients but I needed the extra knowledge to help develop a Parkinson's service for older people. I had arranged GP meetings with the help of the local neurologists, to explain the benefits of referring to a geriatrician working in a Day

Hospital setting and the multidisciplinary treatment that is available there for older patients and those with co-morbidities. Also, I increased awareness of my developing service to the hospital through presentations at the weekly Grand Round. Another geriatrician with an interest in Parkinson's disease was appointed on the other side of the city.

Following the PD Masterclass, I gained more confidence and following discussions with the PCT for older people in Sheffield (one of four PCTs), a Parkinson's Disease Stakeholder Group was set up. The group was multidisciplinary including both hospital and community staff - nurses, therapists, neurologists, geriatricians and a GP. It has brought together all disciplines with an interest in PD in Sheffield. We have discussed local issues involving city wide management of PD patients in Sheffield, referral pathways to neurology and geriatric medicine and further management pathways. Also within our remit was an application to the PD Society for start up funding for a PD nurse specialist for older people, medication issues, continence, and community matrons etc. We have



also undertaken teaching sessions for the local GP's from which we had very positive feedback. By meeting every two months we have built up a team and work together well. The Stakeholder Group provides a very good forum for discussion and support for future developments. By trying to develop consistent systems we hope to improve the overall care for all Parkinson's patients in Sheffield, and it has helped to develop vital parts of the service which now includes a PD nurse specialist for older people.

The GP who attends the stakeholder group subsequently joined the Masterclass and is able to provide useful insight to the primary care problems and how to overcome them from a GP point of view. We have also noticed considerable interest in Parkinson's disease amongst our specialist registrars training to be geriatricians."

**Jane Liddle**  
**Consultant Geriatrician**

# Using Essence of Care to benchmark continence management of individuals with PD



**As the first nurse consultant to attend a Parkinson's Disease Masterclass my course audit focussed around an already identified service need, that is the development of a benchmarking tool to help improve continence care for people with Parkinson's disease (PD).**

The process followed during the course of this work describes step by step, the development of a tool kit that may be of benefit to all those involved in PD management, regardless of profession and location. Although PD is predominately referred to as a "movement disorder", other non-motor symptoms are common (Chaudhuri et al ), the most troublesome cited being urinary incontinence and constipation.

Managing the non-motor symptoms in PD is challenging as many problems are multifactorial and require specialist assessment and management. When managing these problems, professional boundaries are crossed.

Individuals with PD, like anyone else, can experience problems associated with incontinence and it is estimated that up to 75% of people with PD will develop urinary difficulties (Stocchi et al 1997). Incontinence, coupled with the existing motor and non-motor symptoms in PD, can be very distressing for sufferers, and add to the burden of the disease.

The most commonly reported urinary symptoms in PD and parkinsonism are:

- urinary frequency,
  - urgency of micturition
  - urge incontinence
  - difficulty in voiding
- (Rigby and Whelan 2001)

### Rationale behind development of the course audit

When a patient with PD presented to our service with a continence problem we could not be sure if their problem was related to their PD or part of another pathology.

Similarly, the continence nurse specialists we referred our patients to did not always appreciate the functional problems that people with PD experience, for example, the physical difficulties of getting to the toilet or undoing their clothing. This meant the care and management of the problem did not always reflect individual patients' needs. There was also the underlying issue that early incontinence problems in PD could be a 'red flag' to a differential diagnosis like Multiple System Atrophy (Macphee 2001), which we needed to be aware of.

Taking all these points into consideration as a PD team, we wanted to know what continence services for people with PD should look like and audit how our own services measured up against others.

A literature search yielded limited information on continence and PD services and again a paucity of literature on audit and management of continence problems in PD.

As the need to audit our continence service had already been demonstrated, continence and PD seemed the ideal audit to undertake. Following advice and support from my mentor, we felt the **Essence of Care** (Department of Health DH 2001) document could support this process.

### Essence of care

Essence of Care (EoC) was first published in 2001 and arose from a commitment in **Making a Difference** (DH1999) to explore the benefits of bench-marking to help improve the quality of the fundamental and essential aspects of care. These aspects of care

**Box 1: Factor 1 - Information for patients**

Patients have no evidence based information about bowel and bladder care	Patients have restricted access to have to request evidence based information about bowel and bladder care	Patients have free access to general evidence based information about bowel and bladder care	Patients have free access to evidence based information about bowel and bladder care that has been adapted to meet individual patient needs
E	D	C	B
			A

are:

- Personal and oral hygiene
- Privacy and Dignity
- Pressure Ulcers
- Continence Bladder and Bowel Care
- Food and Nutrition
- Record Keeping
- Principles of Self Care
- Communication
- Safety of People with Mental Illness

The benchmarking process outlined in EoC takes a structured approach to sharing and comparing practice, enabling identification of best practice or developing action plans to improve practice. Within the Essence of Care process the Department of Health (DH) has identified what would be classified as 'best practice' and given this an 'A' score. At the other end of the scale worst practice is identified and given an 'E' score. Within the Continence benchmark there are 11 factors that practitioners can score themselves (see example at Box 1).

What the DH has not done is identify the evidence that practitioners need to collect to achieve an 'A' score.

In my opinion additional work was needed to establish best practice in continence care and PD before we could audit our service. I felt this could be achieved through an "expert" comparison group. Establishing such a group would enable us to take the first step towards developing a specific benchmark for PD and

continence. We established a small comparison group of national experts to progress the work (see Box 2).

### Steps to development of the benchmark

#### Agreeing Best Practice

The comparison group reviewed the current DH continence documentation within EoC, establishing key points that directed best practice and linking these to the A score for each of the factors laid down by DH. Although these key indicators can be used for all client groups, they were adapted to meet the needs of patients with PD.

#### Collecting evidence

Following identification of the areas of 'best practice', a decision was reached about what supporting evidence of achievement was needed. Initially this entailed a semi structured questionnaire for patients and staff, which members of the comparison group piloted in their own work areas. The questionnaire was adapted following the pilot. As I was lead in my own area on EoC I was able to provide examples of documentation to the comparison group and a consensus was reached on the format for our EoC tool kit.

#### Scoring

Results of the pilot within our own areas demonstrated that there were difficulties in determining how to score. I used my experience of working with EoC

on other aspects of care within my Trust to help the comparison group agree the format for the tool kit.

#### Developing the tool kit

The tool kit was designed as a resource pack to assist practitioners through the EoC process, making it both relevant and meaningful. There are six sections with explanatory notes for use in a step by step process.

#### Individual Pack Sections

##### Section 1: Patient semi-structured interview

Patient involvement is very important within EoC. This section of the tool kit enables practitioners to ask patients relevant questions pertaining to the factors in EoC about the care they receive.

##### Section 2: Documentary evidence

This section highlights the relevant factors for practitioners to examine and collect documentary evidence to support EoC.

##### Section 3: Clinical Environmental evidence

This section is subdivided into different factors to enable practitioners to examine environmental issues

##### Section 4: Scoring

Each aspect of care is subdivided into individual elements. Within each of the elements are the standards determined by DH, and examples of the evidence required to ensure an 'A' score. Using the information gathered from Sections 1,2 and 3, practitioners should be able to give their service an initial score.

##### Section 5: Comparison Group Scores

This section examines the individual factors for each aspect of care and asks the comparison group to document their own scores and supporting evidence. As a result of discussions within

#### Box 2 - Comparison Group

- Annette Bowron - Consultant Nurse Northumbria
- Phyll Taylor – Independent Continence Advisor Exeter
- Sharon Eustice – Nurse Consultant for Continence Cornwall
- Angela Billington – Director of Continence Service Bournemouth
- Deborah Rigby – Continence Service Manager Bristol
- Maggie Saunders - Clinical Lead for Continence (physiotherapist) Sheffield
- Facilitator and Mentor - Sue Thomas, Nursing Policy Adviser RCN London

the comparison group, practitioners may need to readjust their score.

**Section 6: Action Plan**

This sheet simply allows practitioners to document any action required to improve any areas of their practice as a result of the benchmarking process.

**Consultation process**

Once completed, the tool kit was distributed to a variety of organisations for endorsement.

**The way forward**

The launch of the Parkinson's disease Essence of Care toolkit to improve continence management for individuals with PD takes place in early 2006. The pack has been

endorsed by The Royal College of Nursing, Parkinson's disease Society UK, The Parkinson's Disease Nurse specialist Association, The British Geriatrics Society PD Special interest Group, The James Parkinson Centre, Cornwall and Promocon. Regional workshops to assist practitioners to use the tool kit are to be held throughout the year.

The first will be held at Wansbeck General Hospital, Newcastle in April. If you would like a copy of the tool kit this can be obtained from Parkinson's disease Society,

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*Annette Bowron  
Consultant Nurse*

## Measurements of impairment and/or disability in Parkinson's Disease - the available evidence

**In the full version of this paper, we set out to find information on locally used rating scales for the assessment and measurement of disability in patients with PD, and to obtain available evidence and recommendations regarding reliable, validated and widely used rating scales in PD.**

Parkinson's disease (PD) is a progressive disabling disorder, the assessment of which should include a multidisciplinary approach using various measures and scales of impairment and disability to capture therapy interventions, research and for epidemiological purposes. Guidance and recommendations on choosing appropriate scales are not widely available. Symptoms of PD fall into the

categories of **motor** (bradykinesia, tremor, rigidity) or **non-motor** (sensory, autonomic, neuro-psychiatric), including drug related symptoms (dyskinesia, wearing off).

Management of PD requires a multi-disciplinary team (MDT) effort from an early stage of the disease involving physiotherapists (PT), occupational therapists (OT), speech therapists, PD Nurse specialists, General Practitioners (GP), Specialists with interest in PD (Neurologists, Geriatricians or Physicians with interest in PD) and social workers etc. The management of the disease can be planned in four stages i.e. **Diagnosis, Maintenance, Complex and Palliative** as described in 'Parkinson's Aware in Primary Care', a guide developed

by The Primary Care Task Force for the PD society ([www.parkinsons.org.uk](http://www.parkinsons.org.uk)).

**Impairment, disability and handicap**

The best framework for considering important outcomes is the *International Classification for impairment* (any loss or abnormality of psychological, physiological or anatomical structure), *Disability* (any restriction or lack of ability to perform an activity in a manner, or within the range, which is considered normal) and *Handicap* (a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal for that individual). Patients may be assessed for

reasons such as diagnostic/prognostic, measurement/quantification, patient management process, planning and/or running services, research and epidemiological. *Outcome measurement tools* (instruments, questionnaires, rating forms etc) are used to document change in one or more patient characteristics over time. Generally there is a limited use of outcome measures and one of the major barriers to use outcome measures is a lack of knowledge of available instruments and their properties. All assessment tools may not be applicable to patients with PD due to disease progression and variable response to therapy during the course of the illness. There are published measurement tools that can be used by various members of the MDT, designed for PD. In patients with PD, physiotherapists, for example, assess functional performance in relation to walking, turning and changing direction, standing up, sitting down, turning in bed, stairs, car transfers, reaching, grasping and manipulating objects and writing.

#### What we found

Locally, five different scales are in use in five different hospitals and two of them are well known (Webster and Tinetti balance scale). Of the other three, one is a disability scale and the other two are mixed (impairment and disability) scales.

Our literature search identified eighty impairment and/or disability scales and measures in more general use and these we grouped into mood scales, cognitive assessment scales and quality of life scales respectively. We "sub-grouped" the eighty scales into impairment, disability and mixed (impairment + disability), having 35, 34 and 11 scales in each group respectively. These were separated in turn, into 'motor' and 'non-motor' groups.

#### Physiotherapy and PD

One systematic evaluation performed in 2002, of rating scales of impairment and disability in PD, identified 30 studies describing clinimetric properties of 11 scales for impairment and disability. Rating scales are commonly used in physiotherapy assessment. One meta-analysis looking at the effects of physiotherapy, was performed in 2001, supporting benefits of physiotherapy to PD patients. There were two RCT's on people with PD using rating scales to monitor patients. A Cochrane database systematic review - 2004, on physiotherapy versus placebo or no intervention, has shown that there was insufficient evidence to support or refute the efficacy of physiotherapy in PD, as small number of patients were examined (11 trials were identified involving 280 patients) and the possibility of publication bias.

#### The UPDRS

In this study, the most commonly described/included scale was Unified Parkinson's Disease Rating Scale (UPDRS) in 21 out of 102 (5%). In another systematic review of North American RCTs, on drug trials using PD medications, UPDRS was the most commonly used scale (32.8%, from 137 studies).

The clinimetric characteristics of some for this scale (version 3, 1987) are that it is a 42 item scale with time taken to administer being 10-20 minutes (+/- 7.98). A total 199 points is possible. It was developed from parts of other scales and is in 5 sections. Most components of this index have been tested for reliability.

Even across off and on state examinations, the motor section of the scale has a stable factor structure and internal consistency of the ADL. The motor section indicates a redundancy of items. This was underscored by a previous study that successfully

reduced the ADL and motor section of the UPDRS to 8 items each, without losing reliability and validity. The scale has been used in many trials, and extensively evaluated. However, the ADL section is conceptually unclear as it includes several impairment items (salivation, falling, freezing, tremor and sensory complaints).

#### Hoehn Yahr Staging (H&Y)

This scale is widely used, having five items. It is over 30 years old, having been developed before the Levodopa era. Progressively higher stages correlate with neuro-imaging studies of dopaminergic loss and a high correlation exists between the H&Y scale and some standardised scales of motor impairment and disability (UPDRS, CURS, NUDS and EDS) and also quality of life scales (PDQ 39).

Weaknesses include the scale's mixing of impairment and disability and its non-linearity. It supplies no information on non-motor problems. Direct clinimetric tests have been limited but it fulfils at least some criteria for reliability and validity. (No evidence for construct validity, as noted by Ramaker et.al, in the systematic review).

The best inter-observer agreement was achieved for the H&Y scale.

#### Webster (WRS)

This is a 10 item scale. Little evidence has been published on validity and reliability. One disability (self care) and nine impairment items make it conceptually unclear.

From a factor analysis, assessed in one study, three factors were derived, including (a) arm swing, gait, self care and posture; (b) speech and facies; (c) seborrhoea. Four studies showed that the scale displays poor to moderate inter-rater reliability. Postural instability is a major feature of PD, occurring

in the later stages of the disease, but it is not evaluated in the Webster scale. There is consistent inter-observer assessment of the bradykinesia item, in this scale.

#### **Columbia University Rating scale (CURS)**

The scale has 25 items and was used widely before the introduction of UPDRS in 1981. There have been only a few published studies on validity and reliability. Available studies show that the CURS has a moderate to good validity and reliability. The factor was evaluated in only one study which included 95 patients with PD plus syndromes not applicable to PD.

In both CURS and WRS the items assessing rigidity (fundamental in defining the disease) were among the least reproducible.

#### **Schwab and England ADL scale (S&E)**

Where 0% equals vegetative and 100% equates to completely independent, this scale has been the standard assessment tool in PD in hundreds of studies. The clinimetric properties however, have never been examined, but available data suggest moderate to substantial validity and reliability.

#### **Discussion**

Parkinson's disease is a common cause of disability. Drug treatment is remarkably effective in the early stages. As the disease progresses, patients become increasingly disabled despite optimal drug therapy. A short spell of multidisciplinary rehabilitation may improve mobility. PD rating scales are generally reliable but are not widely used. UPDRS is the core assessment of PD; its clinimetric properties are well known, but cognitive and psychic disorders need complementary approaches.

Scales to assess depression and cognitive function are being used widely. ADL rated by UPDRS allow

a global assessment of the patient handicap that may be completed by patients.

For clinical research purposes, time tests and dyskinesia scales following CAPISIT procedure are required. Hypokinesia of gait in moderately disabled PD patients is best assessed by combined analysis of stride parameters and locomotion related sub-scores from conventional rating scales. Ambulatory monitoring as an outcome measure has potential for improving the evaluation of ambulation and providing insight into participation in monitoring motor function and recovery in neurological disease.

There is a newly developed easily applicable, reliable and validated, 10 item Lindop Parkinson's Mobility scale (due to be published). This is being considered for further tests by a multi-centre study, in the West of Scotland.

The non-motor symptoms in PD range from cognitive and psychiatric problems to sleep disturbance, sexual dysfunction, bowel problems and dribbling of saliva. In a recent survey these symptoms were rated as the most disabling symptoms by the patients with PD but these symptoms have been comparatively neglected. A recently published Non-Motor Symptom Assessment Scale helping to raise awareness of these issues, is still to be validated. Severity and duration of PD has been quantified using SPECT striatal uptake of 123I-FP-CIT and this can be a useful tool in overcoming variable clinical features of PD and the masking effects of drug therapy.

There is a wide variety of scales and measures of PD available and these have been filled in by different members of the MDT, the patient and the carer.

Characteristics of a useful

measure or scale should be: appropriateness to the task, valid, reliable, reproducible, efficient and easy to use with little special training and it should be sensitive to change in the underlying condition yet relatively insensitive to symptom fluctuation.

#### **Conclusions**

It was noted throughout this study that a wide variety of validated measures have been used locally and generally, for the assessment of patients with PD. There are mostly motor and few non-motor assessment scales available.

Finding up-to-date information on valid and reliable rating scales can be time-consuming. Most validity and reliability studies have been performed on UPDRS, but the H&Y scale is also widely utilised and accepted.

Controlled clinical trials and outcomes research are at the heart of information based medicine and neurological scales are essential tools in clinical trials designed to provide information. Multiple scales have been used by various members of the MDT to obtain valuable information. This may be an exhausting experience for the already disabled patient and to their carer and this should be taken in to consideration when choosing scales and questionnaires. Up-to-date information and recommendations on the use and types of rating scales on PD should be more easily accessible.

The full and referenced version of this study appears on the PD Section website

[www.pdsection.org.uk](http://www.pdsection.org.uk).

*Dr P M Karunaratne  
Associate Specialist  
Borders General Hospital  
undertook this review during  
her attendance at the PD  
Masterclass*

# Progressive Supranuclear Palsy



**Progressive Supranuclear Palsy (PSP, also known as Steele Richardson Olszewski Syndrome) is a progressive neurodegenerative disease originally described in 1964 and classically characterised by early falls and a vertical eye movement disorder. Due to clinical variability it is often misdiagnosed.**

This article seeks to combine a lay and medical professional approach to the history, clinical features and best management of PSP.

## Overview

As referenced in the paragraph

below on epidemiology, recent research confirms PSP to be at least as common - and most neurologists would agree, at least as nasty - as its 'cousin' Motor Neurone Disease. Yet, whilst the latter is as well known as Parkinson's Disease (PD) and Alzheimer's, the former remains little known, tucked away in the shadow of PD. Yet, in its classical form, clinically, pathologically and biologically, PSP remains quite distinct and different.

There are four main reasons for this:

- ◆ History
- ◆ difficulties in differential diagnosis
- ◆ lack of diagnostic markers
- ◆ the label 'parkinsonism'

Historically, PSP was not recognised as a distinct and separate condition until the early sixties, before which it was considered to be a form of rapidly progressive PD or one of many other similar known disorders. Even today, it is still grouped with Multiple System Atrophy (MSA) under the label 'Parkinson's Plus', or more accurately, as a form of parkinsonism (although there is rarely tremor in PSP, which is axial

in distribution, rather than 'one sided' as usual in PD).

Classical PSP, with its characteristic features of gaze palsy and staring eyes, is not difficult to differentiate from PD. However, PSP is now known also to present in a form that closely resembles PD. These two different forms have been labelled PSP-Richardson (or PSP-R), and PSP-Parkinson's or (PSP-P). PSP-P, particularly in the early stages, is clinically extremely difficult to differentiate from PD and MSA.

Today, there is still no diagnostic marker for PSP (such as a blood or cerebrospinal fluid test), although serial MRI scanning, for example of the superior cerebellar peduncle, can provide supporting evidence in differential diagnosis. Nevertheless, it is only by pathological examination of brain tissue that a clinical diagnosis can finally be confirmed and so this is commonly referred to as the 'gold standard'. Even today, some 30% of those who approach the PSP Association, join after having received an initial diagnosis of PD, other neurodegenerative disease or stroke.

## Epidemiology

Patients typically present in their 60's and there is no gender difference. Using robust community-based studies the crude population prevalence of PSP is between 4.9 and 6.5 cases per 100,000, making PSP as common as motor neurone disease. The average time from symptom onset to death ranges from 5-8.6 years, however mean delay of diagnosis is 4.7 years. The cause of death is usually bronchopneumonia.

## Aetiology and Pathology

The cause of PSP is unknown, but

## PSP vs PD - recognising it and treating it

- ◆ PSP is a comparatively rare but devastating condition still closely associated with PD.
- ◆ Diagnosis of the classic form requires early falls (within 1 year) and a vertical eye movement disorder, although the clinical spectrum of PSP is undoubtedly broader than previously thought.
- ◆ 'Parkinsonism' is still used as a label for PSP but this differs from PD with the presence of symmetrical bradykinesia and rigidity, with no rest tremor.
- ◆ The diagnosis is clinical and should be made by a specialist. It can be supported by serial scanning.
- ◆ Management is largely palliative and multidisciplinary.

it is likely that the majority of cases develop from the triggering of disease, perhaps by exogenous toxins, in a genetically susceptible individual. The most distinctive pathological features are neuronal degeneration and neurofibrillary tangles (composed of abnormal tau protein accumulation) found predominantly within the basal ganglia, some brain stem nuclei and to a lesser extent the thalamus and cortex.

**Clinical Features**

Premorbid diagnosis of PSP requires the presence of falls within the first year of onset and a supranuclear eye movement disorder.

Mobility difficulties and falls (usually backwards) are the most common symptoms at presentation. Most patients exhibit parkinsonism, in the form of rigidity and bradykinesia, often leading to an early diagnosis of Parkinson's Disease (PD). However, in PSP the parkinsonism is usually symmetrical (PD is almost always asymmetrical at onset), with the rigidity often worse in the axial (neck and truncal) muscles than the limbs. Rest tremor is unusual in PSP but the patients may have a mild postural tremor. Facial expression is often markedly reduced, with very low blink frequency, and sometimes frontalis over activity.

With advancing age up gaze is often mildly reduced, but in PSP patients down, up and sometimes horizontal gaze, is limited, often dramatically. However, in the early stages patients may only have slowing of the vertical saccades (speed with which the eyes move between targets). Patients often complain of gritty, dry eyes, photophobia and double or blurred vision and occasionally an inability to open their eyes to command (eyelid apraxia).

Cognitive deficits and neuropsychiatric features may be found early in the course of the disease but are often fairly subtle.

Changes in personality, forgetfulness, irritability, anhedonia and disinhibition are common. Approximately 18% of PSP patients suffer from depression or anxiety which, in PD patients, is much more common. Apathy, however, is very common in PSP although is often under-recognised. The prototypic 'dysexecutive dementia' is evidenced by difficulties with verbal fluency, working memory, concept formation, planning and execution. PSP patients also exhibit severe slowness in response time, not evident in PD. Short-term memory however, appears to be relatively spared in PSP.

Bulbar dysfunction develops early, with patients developing a severe growling dysarthrophonia, leading to difficulties with communication. Swallowing is also affected and can deteriorate rapidly sometimes requiring percutaneous endoscopic gastrostomy (PEG) feeding. Drooling of saliva and constipation are also common.

Despite these classical clinical features some PSP patients follow a more benign clinical course, similar to PD, highlighting the difficulties with diagnosis (these patients are currently termed PSP-P, as described above).

**Management**

PSP is a clinical diagnosis and referral to a neurologist or geriatrician with an interest in movement disorders is recommended. Cranial MRI (magnetic resonance imaging) can help exclude other causes and may show changes such as midbrain atrophy or changes in the cerebellar peduncles which would support the diagnosis of PSP.

Drug treatment in PSP is very disappointing. A trial of levodopa is usually recommended, although most patients show only a minimal or non-sustained improvement (unlike PD patients). Of the other parkinsonian drugs, amantadine is occasionally of some benefit, but should be used with caution as it

can cause confusion. Cholinesterase inhibitors and drugs targeting other neurotransmitter systems are not of any benefit. Amitriptyline (doses 10 – 50mg) can be useful to aid sleep and dry secretions. Antidepressants may improve mood although there are no randomised control trial data. Botulinum toxin injections may help disabling dystonia or apraxia of eyelid opening. Mirror-prism spectacles can make it possible for patients with severe limitation of extra-ocular movements to read and feed themselves.

Care of PSP patients is mainly palliative and requires a multi-disciplinary approach. Physiotherapists can help mobility and provide appropriate walking aids. Speech and language therapy advice is needed to improve speech and provide relevant communications aids (remembering the difficulties with vision and dexterity). Almost all patients need regular assessment and advice on swallowing techniques, and discussion of PEG (percutaneous gastrostomy) insertion may be required. Occupational therapy and social services can help make adaptations to the patient's home and give advice on nursing home placement if necessary. Advice with regard to future care planning, legal options of Power of Attorney, trusteeship, advance directives and consideration for brain donation may also be needed.

**The PSP Association**

The PSP (Europe) Association provides information and support for patients and carers, and has two dedicated PSP nurses available for advice. Further details can be found at [www.pspeur.org](http://www.pspeur.org) or telephone 01327 860299/342.

**Dr David Burn**  
*Member of the PSP Association's Medical Advisory Panel and Reader in Neurology*  
**Dr Naomi Warren**  
*Newcastle University*  
**Brigadier Michael Koe, Chief Executive of the PSP Association**

## Advanced PD Masterclass Programme

12 - 14 May 2006 - KNOWLEDGE SPA, PENINSULA MEDICAL SCHOOL, TRELISKE CAMPUS

### Objectives:

- ◆ To share the latest knowledge, views, and opinions on growing points in the treatment of PD
- ◆ To update former Academy graduates on changes that have occurred since their attendance on the course
- ◆ To satisfy Clinical Governance agenda to show that practice is evidence-based and up-to-date
- ◆ To be aware of Policy and Practice changes, and discuss implementation plans

Friday - 12 May 2006		
14:00 Session 1	Welcome and introduction: The PD Academy – 5 years on What have we achieved, and what next?	Chaired by Dr Doug MacMahon, Cornwall
14:30	Diagnostic Testing – The role(s) of scanning	Prof David Brooks, London
15:00	Neuroprotective Strategies: attainable?	Prof Tony Schapira, London
<b>15:45</b>	<b>Tea</b>	
16:15 Session 2	What's coming up doc?	Prof Peter Jenner, Lonon
17:00	New Kids on the Block	Dr Carl Clarke, Birmingham
17:45	Closing remarks	Dr Doug MacMahon, Cornwall
<b>18:00</b>	<b>Drinks and canapés, Knowledge Spa</b>	
<b>19:00</b>	<b>Dinner and networking, Knowledge Spa</b>	
<b>21:30</b>	<b>Close</b>	
Saturday - 13 May 2006		
09:00 Session 3	Welcome and introduction: perspectives from Auld Enemies:	Chaired by Dr Graeme Macphee, Glasgow
09:15	Adjuvant Treatments : Agonists & Amantidine	Dr Carl Clarke
10:00	Adjuvant Treatments : Comtl & MAOI	Dr David Stewart, Glasgow
<b>10:45</b>	<b>Coffee</b>	
11:15	Initial drug treatment lessons from recent trials: Discussion	Dr K Ray Chaudhuri, London
12:00	Speaker tbc	
<b>12:45</b>	<b>Lunch &amp; exhibition</b>	
13:30 Session 4	Dementia in all its glory	Dr David Burn, Newcastle
14:15	Depression	Dr John Hindle, N. Wales
<b>15:00</b>	<b>Tea</b>	
15:30 Session 5	Non motor symptoms in PD	Dr K Ray-Chaudhuri, London
16:15	Closing remarks	Dr Jagdish Sharma, Newark

Sunday - 14 May 2006		
Session 6	From Theory into Action	Chaired by Dr Peter Fletcher
10:00	Implementation of National Policy – opportunities and threats	Mr Steve Ford Chief Exec PDS(UK) Dr Jane Liddle (Sheffield)
<b>11:00</b>	<b>Tea</b>	
11:15	What about NICE?	Dr David Stewart, Dr Doug MacMahon, Dr John Hindle
11:45	The research agenda where will it all fit?	Dr Keeran Breen, Research Director PDS
12:10	Closing remarks and presentation of audit award	Dr Peter Fletcher
<b>12:30</b>	<b>Lunch and depart</b>	

### Are you a Masterclass graduate?

Would you like to mentor a course member yourself? The Faculty will be holding a further mentor training session on the evening of Thursday, 11 May and the morning of Friday 12 May, prior to the Advanced Masterclass. The objectives are:

#### Objectives:

- ◆ To provide an opportunity to share mentorship experiences
- ◆ To update mentors on the new Mentorship guidelines
- ◆ To present plans for academic endorsement of the Masterclass programme
- ◆ To be aware of policy and practice changes, and to discuss implementation plans for the ongoing course

If you would like to participate in the advanced masterclass or mentor meeting, please contact RED at [redpublishing@btopenworld.com](mailto:redpublishing@btopenworld.com)

## Dates for your diary

### 11th National Conference Multidisciplinary Care in Parkinson's disease and Parkinsonism

11 July

Royal College of  
Physicians, St Andrews  
Place, Regents Park,  
London

Email [info@mepltd.co.uk](mailto:info@mepltd.co.uk)

### Movement Disorders - 10th International Congress

28th October - 2nd  
November 2006

Kyoto, Japan

More details at:  
[www.movementdisorders.org](http://www.movementdisorders.org)

### Parkinson's Awareness Week

Parkinson's Awareness Week 2006 starts on 24th April. This year, the Parkinson's Disease Society (PDS) will be using the Awareness Week as a springboard to launch a national campaign - Get It On Time! - which stresses the need for all patients with Parkinson's to get their Parkinson's medication on time when in hospital or in a care home. The PDS (UK) is planning to concentrate on hospitals during the Awareness week, and the campaign will be expanded to include access to medication in care homes later in the year. JPC will be joining in this campaign and targetting local hospitals to Get it on Time! PDS will be asking hospitals to take this matter seriously and to ensure that every patient gets their Parkinson's medication on time every time during a hospital stay.

## Expert nursing jobs to be cut as part of plan to relieve NHS cash crisis

The national press has made much in the past couple of months, of the financial black hole, that is the NHS.

Reported on the BBC website <http://news.bbc.co.uk/1/hi/health/4862318.stm> is the warning of health charities and nursing unions that specialist nurses i.e. nurses with expertise in long term problems (including PD), are being seen as a "soft target" for staff cuts.

The posts of community-based nurses in particular, are under threat. According to Vicky Gutteridge, a multiple sclerosis

specialist nurse whose job was recently rescued by supplementary funding from the MS Society, specialist nurses in neurological disorders are working in a "Cinderella service" and are therefore very vulnerable.

Speaking on behalf of the Multiple Sclerosis Trust, Nicola Russell said: "We are worried that MS may be seen as a soft target for cost-cutting because it has a lower profile than some other diseases. The PD Society, Macmillan Cancer Relief and the British Society for Rheumatology have also expressed concern.

### Reassurance


The BBC goes on to report that a spokesman for the Department of Health in England has sought to allay fears by acknowledging the key role held by specialist nurses in providing care closer to patients' homes, "especially for people with long term conditions.

He is reported to have said: "We would expect trusts to have such nurses at the heart of their plans."

Let's hope our PD nurse specialists are at the heart of any future plans!

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**Legal Category:** POM. Prescribers should consult the Summary of Product Characteristics for the full information on side-effects, warnings and precautions. Further information is available from SCHWARZ PHARMA Limited, Schwarz House, East Street, Chesham, Bucks HP5 1DG, United Kingdom. **Date of Literature Preparation:** April 2006.

Information about adverse event reporting can be found at [www.yellowcard.gov.uk](http://www.yellowcard.gov.uk)  
Adverse events should be reported to the Drug Safety department at  
SCHWARZ PHARMA Limited (UK) on 01494 797 500 or [drugsafety@schwarzpharma.co.uk](mailto:drugsafety@schwarzpharma.co.uk)

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