



The Parkinson's  
Disease Academy

Issue 5 - May 2007

# MasterStrokes

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## Editorial

In a medical context the best-known quotation

by the poet Arthur Hugh Clough (1819-61) is probably 'Thou shalt not kill; but need'st not strive, Officiously to keep alive'\*. For this

editorial, however, I have chosen as my theme the title of another of his poems: 'Say not the Struggle Naught availeth'. I thought it would be useful to pause and look back on how much progress has been made in the management of Parkinson's disease over the past 15 years or so.

Three true stories from the mid-nineties.

Another busy clinic behind me, I am discussing the need for more PD clinics to deal with the demand. A senior colleague comments that we cannot justify investing more resources in my 'little hobby'.

At a scientific meeting on PD somewhere in Europe, the chair of the session calls for a vote on some aspect of management. Clearly dismayed when the choice of the delegates does not mirror his own preferred option, an explanation occurs to him. 'How many of the audience are neurologists?' A smattering of hands are raised. 'And how



many are geriatricians?' A veritable forest. 'Ah! That explains it – an atypical audience!'

A 'focus group' of doctors is discussing how PD services are best organised. A contentious issue is 'what is a reasonable

wait for first appointment'. I report that we are aiming for, and largely achieving, first review within six weeks of referral. 'Impossible' says a colleague. 'My waiting time is six months and that of many of my colleagues, over a year.

Six weeks is not only unachievable but unreasonable. Anyway – what is the rush?'

At this time I regularly struggled to persuade GPs (and other physician colleagues) to refer their patients to me as 'everybody knew' that PD was an easy diagnosis and the treatment is levodopa. Likewise PD was widely regarded as purely a motor disorder and multidisciplinary services with specialist nurse support were very uncommon. It is gratifying to

**'Say not the  
Struggle Naught  
availeth'**

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

Editor: Doug MacMahon Subeditor: Suzie Thomas

Other faculty members: Dr David Burn, Consultant neurologist Newcastle; Dr Carl Clarke, Consultant neurologist Birmingham; Dr Peter Fletcher, Consultant Physician Cheltenham; Dr John Hindle, Consultant Geriatrician Llandudno; Dr Graeme MacPhee, Consultant Geriatrician Glasgow; Dr Jagdish Sharma, Consultant Geriatrician Grantham; Dr David Stewart, Consultant Geriatrician Glasgow; Dr Richard Walker, Consultant Geriatrician Northumbria

consider the progress that has been made since then. We now have many more options for managing the motor disorder and modern management has resulted in us seeing much less in the way of severe complications than we used to. The importance of non-motor symptoms is increasingly recognised as is the role of the multidisciplinary team. In particular the psychiatric complications are recognised and we have newer pharmacological options to help ameliorate these. We may be on the verge of a whole new approach to pharmacological management targeting non-dopaminergic neurotransmitter systems and are beginning to sense that we might be able to influence disease progression. The number of specialist clinics has grown enormously, helped in no small way by the PD Masterclass and the inspiration this has given to its graduates. Relationships between geriatricians and neurologists have improved substantially and there are now many good examples of joint working. We are looking at how a 'specialist' might be more formally recognised with appropriate training and accreditation (described by Peter Fletcher in the last MasterStrokes). This would be a major step forward in ensuring the quality of services.

Of course all is not rosy and we must not become complacent. At the very time that medical specialism in PD is being recognised, specialist nursing is increasingly under threat. In an even more precarious position are specialist AHP services for PD. It is important that we continue to fight for the right of patients to be managed by experts in PD of whatever discipline.

Nonetheless I think it is clear that we should be proud of what has been achieved and not get downhearted when, at times, it seems all too difficult. 'Say not the Struggle...'

\* This, incidentally, comes from his satire on hypocrisy 'The Last Decalogue' and is intended to be ironic.

**Dr. David A. Stewart**  
Associate Medical Director,  
Emergency Care and Medical Services  
Mansionhouse Unit  
Victoria Infirmary  
Glasgow

Founder Faculty Member PD Masterclass



## NICE Guideline: Parkinson's Disease - '360°' Audit

**The Parkinson's Disease Society joins forces with the Royal College of Physicians.**

### Introduction:

The Royal College of Physicians, London [RCP] and the Parkinson's Disease Society are collaborating in an audit of Parkinson's Disease services to assess the current services available, one year after the publication of the guidelines, and to provide a base line against which future Parkinson's Disease services development may be measured.

### Background:

In June 2006, NICE published its Guideline [N1053] Parkinson's Disease: National clinical guideline for diagnosis and management in

primary and secondary care. The guideline identified 7 key priorities for implementation:

- ◆ Referral to expert for accurate diagnosis
- ◆ Diagnosis and expert review
- ◆ Regular access to specialist nursing care
- ◆ Access to physiotherapy
- ◆ Access to occupational therapy
- ◆ Access to speech and language therapy
- ◆ Palliative care

The Parkinson's Disease audit will adopt the

methodology used for a similar audit carried out in conjunction with the MS Trust following the publication of the MS Guideline in 2003.

[<http://www.rcplondon.ac.uk/college/ceeu/ms>].

The audit is styled as a "360<sup>o</sup> audit" because it audits the guideline from four different perspectives: the patient, the provider [Hospital Trusts], the commissioners [PCT management] and the NHS management [strategic health authorities]. This method allows "triangulation" [in this project - quadrangulation], to determine the quality of service delivery from various standpoints.

At a time of significant financial constraint within the NHS, services in specialised areas of care are under some threat. The audit will provide a basis for assessing the impact of any service changes on the delivery of care to people with Parkinson's disease.

### Objectives:

The objectives of the audit will be:

1. To audit the implementation of the standards recommended within the NICE Guideline
2. To improve patient care for people affected by Parkinson's Disease
3. To determine whether the views of health care commissioners, health care providers and people with Parkinson's Disease about the quality, availability and accessibility of services are at variance.
4. To provide a benchmark against which future development of Parkinson's Disease services may be assessed.

### Method:

A multi-disciplinary steering group made up of key stakeholders will be established to oversee the project, assist in identifying the key questions and reviewing the analyses from the collected information. They will also be active at the end of the audit in shaping the report and assisting in effective dissemination.

In order to match the experience of patients to a specific service, questionnaires will be sent to:

- 3 specific strategic health authorities [SHA]

all the PCTS associated with the SHAs

all the acute hospital Trusts associated with the SHAs

The responses from these three sources will be matched to the responses from patient questionnaires from patients with postcodes [first three digits] that map to the 3 SHAs.

The key question to be addressed will be:

Does the lived experience of people with Parkinson's disease match the services described by

- ◆ The service commissioners
- ◆ The services providers

Beyond this, services will be assessed using the NICE 7 key recommendations as a framework.

- i. Questionnaires to SHAs, PCTs and Acute Trusts will seek to determine whether the services required of the NICE Guideline are in place and whether their function is being monitored.
- ii. Questionnaires to PCTs and Acute Trusts will seek more detailed information with regard to the organisation and provision of services, in order to allow an analysis which "drills down" into service provision and will allow benchmarking between services within the 3 SHAs e.g.
  - ◆ Waiting time for new patients in Parkinson' Disease [movement disorder] clinics
  - ◆ Number of specialist neurologists/ specialist geriatricians
  - ◆ Number of PD specialist nurses.
- iii. Questionnaires to PD patients will include specific questions with regard to the service received and free text options.

This format will allow a quantitative and a qualitative analysis of the data and has provided invaluable insight into the services received and perceptions of the services received from the perspective of patients.



#### Funding:

Funding arrangements are being finalised and will include the Parkinson's Disease Society and the Royal College of Physicians. It is hoped that professional and specialist

societies with an interest in this topic might be able to make contributions to the costs.

#### Conclusion:

The project provides an exciting opportunity to obtain objective evidence regarding services for people with Parkinson's Disease and to see whether the recommendations of the NICE Guideline are being adhered to. Previous similar projects have provided the basis for informed discussions at local and national level for service improvement resulting in highly quality health care.

**Jonathan Potter, Clinical Director,  
Clinical Effectiveness and Evaluation  
Unit, Royal College of Physicians,  
London**



## Parkinson's Disease Academy: Report on 3rd Mentors' Meeting, April 2007

**A small group of established and new mentors assembled in Troon, Scotland, in April for the 3<sup>rd</sup> Meeting of Mentors associated with the Parkinson's Disease Academy.**



Mentorship has been an integral part of the experience of master classes held by the PD Academy from

the beginning and continues to underpin the adult learning experience.

The meeting began with a session from Dr Graeme Macphee who discussed the general nature and benefits of mentoring in medicine based on his experience on the course run by Dr Nancy Redfern at the Northern Deanery. We then undertook a short demonstration of skills practice based on the three-stage EGAN model with a 'conscripted' mentee which nicely illuminated some of the issues round mentee resistance! Fortuitously we found a leverage point and an action strategy was formulated!

This was followed by small group work where participants were given the opportunity to be a mentor or mentee bringing real life issues to the meeting. A lively discussion and feedback ensued thereafter in informal session and also over dinner. Although the skills practice was intended primarily to familiarise people with the model, several participants commented on the significant value of the brief mentoring they had received! Perhaps this was the benefit of having a group of self-selected, empathic, interested people.

On the next morning we had two excellent sessions from external speakers; the first from Vicky McLeod who has a wide experience in academic and business circles of appraisal skills and performance management. Vicky provided us with a very thought-provoking and practically helpful session where we again rehearsed practical listening skills in duos. The session provided much food for thought, not only in terms of pertinence to the Academy but also in relation to our own professional responsibilities whether performing appraisal or being an appraisee.

Thereafter, Theresa Stoker provided us with a very well-received practical session in advanced PowerPoint. She built from simple to

intricate presentations as well as providing us with written and CD material.

During the last session of the day Dr Doug MacMahon, Chair of Faculty, discussed the possibility of piloting audit projects based on the recent NICE Guidelines through graduates of the Academy. It is proposed that this will complement the proposed Parkinson's Disease Society Royal College of Physicians audit work around the NICE Guidelines. At the time of writing an audit template is currently being developed in conjunction with Dr Dorothy Robertson and this will be available when finalised on the Section website.

Further mentors' meetings are planned; the next will be again held in Troon, Scotland 27-28<sup>th</sup> September 2007. Bookings for this can be made via RED Publishing [redoffice@btinternet.com](mailto:redoffice@btinternet.com)

We thank Red Publishing for organising the event and Boehringer-Ingelheim Ltd who kindly

sponsored the meeting through an unrestricted educational grant.



**Dr Graeme Macphee**  
Chairman BGS PD Section

**Do you want to be a Masterclass Mentor? Due to demand a second Masterclass Mentor meeting will be held in Troon Scotland 27-28th September 2007**

**Assembly will be from 5pm on the 27th and the course will complete by 1pm on 28th**

**Places are limited so early booking is advisable. Contact [redoffice@btinternet.com](mailto:redoffice@btinternet.com) or phone for an application to 01872 225552**

**This meeting is supported by an unrestricted educational grant from**

**Boehringer Ingelheim Ltd**



## **Hospital Doctor of the Year Award 2007**

**This is your chance to enter the Hospital Doctor of the Year Award 2007**

**Boehringer Ingelheim Ltd and Parkinson's Disease Society UK have teamed up to support a Parkinson's Disease Hospital Doctor of the Year Awards again in 2007.**

**Last year's winner was Dr Jane Liddell and her PD team from Sheffield. Jane is a graduate of our first PD masterclass.**

If your team is really making a difference to Parkinson's care, you should be entering the Hospital Doctor Awards 2007. Simply complete an entry form, follow the judging criteria and



you could put your team in the spotlight, share your best practice with others, and win your team a well deserved night out at the Awards ceremony in London.

**Closing date for entries is 6th July 2007**

**WHO CAN ENTER?**

Any NHS team of staff led by a consultant or associate specialist can enter. There is no charge for doing so.

**HOW TO ENTER**

Write a proposal of no more than 1,500 words in Microsoft Word format to cover:

**The Hospital:** type of unit, population served, demography, level of resources, staffing levels and research.

**The Team:** set out your philosophy and

approach, and outline your main priorities. List your team members and describe their roles. Give details of the main doctor's role. Give evidence of achievements.

**Innovation:** Explain any new developments, how they came about and what difference they have made. What makes you different? What achievements are the team most proud of?

**Why you should win:** A 200-word summary of the innovations and achievements that make your team special.

Complete the online entry form and attach your proposal; access this at

<http://www.hdawards2007.co.uk/>

**For help with your application, contact Kathy Lambart on**

**0800 5877601/Email:**

[kathy.lambart@rbi.co.uk](mailto:kathy.lambart@rbi.co.uk)



## New Parkinson's Disease Management Guidelines

**Parkinson's Disease**  
(Revised 2007 BGS Compendium Document 6.1)

**Background - Epidemiology**

Parkinson's Disease is one of the commonest

neurological conditions to affect older persons. The prevalence & incidence are both age related, with an overall prevalence in the general population of around 160 per 100,000 and an annual incidence of 13 per 100,000. Many population studies have shown the rising

prevalence with age (up to around 2% of the population aged 80 and over). Those surveys that fail to show the increase in the oldest groups are thought to be incomplete and show ascertainment bias (since the prevalence in residential and nursing homes is up to 10%). It is a frequent cause of falls, fractures, and hospital admission. As such, it is a costly disease, especially in the later stages.

### Diagnosis

The costs of treatment (health and social care) have been estimated at between £560,000 and £1.6 million per 100,000 population (i.e. per 160 patients, or an annual cost of between £3,500 and £10,000 per person.) Significant cost drivers include the onset of motor fluctuations, psychiatric symptoms, and institutional care [1,2,3]

Diagnosis of PD remains predominantly clinical. Diagnosis can be difficult and relies on the recognition of the cardinal features of bradykinesia, rigidity and tremor. This can be complicated in the elderly by the presence of co-morbidity such as dementia or cerebrovascular disease.

Diagnostic error is common with an error rate of up to 50% in a community-based study [4]. Accurate diagnosis is the cornerstone for predicting prognosis and planning of management. It is strongly recommended, therefore, that all patients with a suspected diagnosis of PD be referred for specialist assessment by an experienced clinician, ideally before treatment is started. The use of standard diagnostic criteria, such as the UK PDS Brain Bank has been shown to increase diagnostic accuracy (see appendix) [5].

The manner in which the diagnosis is communicated to patients and carers is very important and has been shown to have a significant effect on quality of life many years later [6]. This should be carried out by an experienced clinician allowing adequate time and backed up with written information. It is good practice to arrange a second consultation to ensure that the information imparted has been understood and to allow further questions. The PD Nurse Specialist has a valuable role to play in this process.

### Investigation

Response to treatment is an important aspect when establishing the diagnosis. However, acute challenge tests using either oral levodopa or subcutaneous apomorphine are

insufficiently sensitive or specific & are not recommended for routine use [7].

C.T. brain scans show no abnormality in PD and are likewise not recommended routinely. In selected patients with an atypical presentation (e.g. prominent gait disorder, dementia) a C.T. scan may be of value in establishing an alternative diagnosis such as multiple cerebral infarcts or hydrocephalus. Laboratory testing will sometimes be appropriate - e.g. the exclusion of Wilson's disease or other more common confounding issues such as thyroid function and syphilis serology.

In cases of diagnostic uncertainty, access to functional imaging using FP-CIT SPECT scanning can be helpful in distinguishing parkinsonian from non-parkinsonian syndromes.

### Assessment

Although the earliest and more apparent effects of PD are on the motor system, non-motor problems are also very important in contributing to the overall impact of the condition. It is important, therefore, that assessment covers the physical, mental and social domains [8]. Comprehensive assessment will necessarily be multidisciplinary. Physical assessment should include not only motor but sensory and autonomic function as well as the impact on activities of daily living, speech and swallowing. The mental domain should include assessment of cognitive function and mood as both dementia and depression are common. The social environmental domain includes assessment of quality of life.

A number of standardised assessment tools are available and their use is encouraged. Routine use of such tools allows 'hidden' problems to be identified and allows monitoring of progression. Standardised assessment also facilitates clinical audit. Appropriate tools include the Unified Parkinson's Disease Rating Scale (UPDRS) for motor assessment, Mini Mental State Examination (cognitive), Geriatric Depression Scale (GDS15) and PDQ39 (quality of life). More specialised assessments are carried out by the relevant therapists as the need arises. The NMS Quest is a recently validated screening tool for the detection of non motor symptoms in PD  
[http://www.parkinsons.org.uk/pdf/nms\\_questionnaire.pdf](http://www.parkinsons.org.uk/pdf/nms_questionnaire.pdf)

<http://www.parkinsons.org.uk/Templates/Internal.asp?NodeID=101727> (accessed March 07)

Management of PD in elderly patients is made more challenging by the common occurrence of co-morbidity, both physical and psychiatric. This not only makes diagnosis more difficult but also presents management problems. Associated polypharmacy increases the potential for drug interactions and adverse effects. A full medical assessment is therefore essential. Specialists in Geriatric Medicine who are trained and experienced in managing complex problems in the elderly are well placed to carry out this function.

PD is a progressive condition and patients deteriorate gradually over time. This can be insidious with increasing impairment and handicap going unrecognised. Regular, planned follow-up by the specialist team is therefore advised.

Stage of disease can be classified according to the Hoehn & Yahr scale, which ranges from 1.0 (unilateral involvement only) to 5.0 (wheelchair bound or bedridden). This, however, concentrates on impairments rather than disability or handicap and is of limited use in the management of individual patients. A more useful paradigm has been developed which describes four stages in the evolution of the disease through diagnosis, maintenance, complex and palliative stages [9]. The appropriate management at each of these stages is outwith the remit of this short paper, but described in the 'guideline papers' and the NICE clinical guideline referenced below [7,10,11]

As the disease progresses, dependency and psychiatric co-morbidity increase. In order to address the spectrum of need, a comprehensive service providing outpatient clinics, Day Hospital, inpatient assessment / rehabilitation and long term care is required.

#### **Good Practice Statements**

A number of 'guidelines' have been published, and are referenced below [7,10,11].

U.K. Specialist Guidelines [7] written primarily for the specialist practitioner

Primary Care Guidelines [10] written primarily for the primary care team in the four stage structure [9]

American Algorithms [11] contain management issues and algorithms for common situations arising in PD - primarily for the specialist

practitioner.

NICE have recently published a clinical guideline which is referenced under further reading.

#### **Models of Service**

In the U.K, the identified medical specialist may be a geriatrician or a neurologist. It is helpful if the two departments can work collaboratively, and will benefit from close working relationships with a PD Nurse Specialist and a dedicated Multi-disciplinary team [12]. This will normally have elements of physiotherapy, occupational therapy, speech and language therapy, dietetics, and psychology. Exact relationships and location vary depending on the types of service configuration, management structures, rurality/population density, and transport availability. Some departments offer programmed multi-disciplinary sessions - often at diagnosis and at intervals thereafter. Others have open access or referral protocols, depending on local policies [13].

#### **Relationships**

In addition to the components mentioned above, close working relationships are desirable with Neurosurgery, Psychiatry (including old age psychiatry), Psychology, and other disciplines.

#### **Training / Education**

Hitherto, knowledge of PD and movement disorders has been acquired in a rather indeterminate manner during general professional and higher specialist training in geriatric medicine. With the increasing specialisation and subspecialisation of Modernising Medical Careers to the standards and competencies defined by PMETB this approach will become increasingly untenable. Experience in other specialties and subspecialties suggest that some form of accreditation will become necessary if not a formal CCT in Movement Disorders. Reflecting this possible direction of travel, the PD Academy was founded in 2002 and has run 9 formal Masterclasses for geriatricians who are keen to learn more about running a Service – 3 more have been recruited to and/or are planned. Similar courses are available for specialist nurses and other disciplines. Attendance at specialist meetings (Parkinson's Disease and Movement Disorders) is desirable as part of the portfolio of continuing professional development (CPD/CME).

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## Further reading

Further information on many of these topics can be found on the BGS PD section website, accessed through the main web site at [www.bgs.org.uk](http://www.bgs.org.uk)

*Parkinson's Disease in the Older Patient*. Eds JR Playfer, JV Hindle. Arnold, London 2001 ISBN 0 340 75914 3

Prodigy Guidance Parkinson's Disease [http://www.prodigy.nhs.uk/parkinsons\\_disease](http://www.prodigy.nhs.uk/parkinsons_disease)

National Institute for Health and Clinical Excellence (NICE), *Parkinson's Disease Guidelines* <http://www.nice.org.uk/guidance/CG35>

## APPENDIX: PD - UK PDS BRAIN BANK DIAGNOSTIC CRITERIA

### Step 1 - Diagnosis of Parkinsonian syndrome

Bradykinesia plus at least one of the following...

- Muscular rigidity
- Rest tremor
- Postural instability

### Step 2 - Exclusion criteria including

- History of repeated strokes
- History of repeated head injury
- History of definite encephalitis

### Step 3 - Supportive prospective criteria (at least three required)

- Unilateral onset
- Rest tremor present
- Evidence of progression
- Persistent asymmetry
- Excellent response to L-dopa
- Severe L-dopa-induced chorea
- L-dopa response for 5+ years
- Clinical course of 10+ years



## Dates for your diary

<b>11th International Congress of Parkinson's Disease and Movement Disorders</b>	June 3-7, 2007 Istanbul, Turkey. Contact: The Movement Disorder Society, 555 E. Wells Street, Suite 1100, Milwaukee, WI 53202-3823 USA; TEL: +1 414-276-2145; FAX: +1 414-276-3349; E-mail: <a href="mailto:congress@movementdisorders.org">congress@movementdisorders.org</a> ; Web site: <a href="http://www.movementdisorders.org">www.movementdisorders.org</a>
<b>Multidisciplinary care in PD and Parkinsonism. From Science to Practice</b>	4 July 2007 at Royal College of Physicians, London. Bookings <a href="http://www.mepltd.co.uk">www.mepltd.co.uk</a>
Meetings organised by Schwarz	21 June 2007, Royal College of Surgeons, London 27 June 2007, Royal College of Physicians, Edinburgh Details from Geriatric Medicine or Nick Spicer [nick.spicer@schwarzpharma.com]
<b>Masterclass Mentor Meeting</b>	27-28 September 2007, Troon, Ayrshire, Scotland. Contact <a href="mailto:redoffice@btinternet.com">redoffice@btinternet.com</a> or phone for application to 01872 225552.
The Andrew Sims Centre on Psychiatric problems of older people with PD	4 October 2007, The Hilton Hotel, Neville Street, Leeds. Contact Laura Ward, Customer Support Officer, The Andrew Sims Centre, The Mount, 44 Hyde Terrace, Leeds, LS2 9LN or fax to 0113 305 5632
<b>BGS Scientific Autumn Conference. Parkinson's Disease Section will be featured in one of the parallel sessions of the Conference.</b>	November 21-23, 2007, Harrogate. Watch <a href="http://www.bgs.org.uk">www.bgs.org.uk</a> [Notices/BGS Autumn Conference]. Preliminary programmes will be sent to all members of the BGS towards the end of August. Non-members wishing to attend can send email to conference organisers whose contact details appear on that page of the website.



## 18 Week Patient Pathway developed for Parkinson's Disease

Delivering an 18 week patient pathway from GP referral to the start of treatment by the end of 2008 is a key objective for the NHS. 18 week Pathways have now been developed in PD and are available to see on <http://www18weeks.nhs.uk>

The pathways have been developed through GPs (nominated by the Royal College of GPs), and Consultants (nominated by their appropriate Royal College and professional bodies) in conjunction with National Diagnostic Clinical Leaders.

For each of the 18 week commissioning pathways:-

1.The Pathway PDF document contains the visual pathway mapped into the template. Only the key information is available on here, for further detail look at the Supplemental Information document. This document is best printed in colour; however, can be printed in black and white.

2.The Supplemental Information document contains further detail on the pathway including references to guidelines, explanations of clock stops and starts.

**Further information about the 18 week pathway can be found on the English Department of Health website [www.dh.gov.uk](http://www.dh.gov.uk) search for 18 week pathway on the search engine.**



## The Nuts & Bolts of a Parkinson's Disease (PD) Service

**But what is a service? An organised system of labour used to address needs is the Collins English Dictionary definition. All a bit vague which is possibly why that the evidence base for how to best address service delivery is so thin.**

There are six things to consider when building a service.

First; why do it? Have you inherited patients with Pd? Has service development been imposed following retirement or because the PCT has decided it needs one? Have your own observations prompted development or maybe you already have a special interest in movement disorders. What motivates the clinician may have a bearing on how s/he goes about this.

Second; who is the service for? Known incidence and prevalence rates and population structure will indicate how many people with Pd there are locally. In Gloucestershire there are around 1400 people with Pd and around 150 new cases annually. This is higher than expected for a population of 550,000 but Gloucestershire is 1.5% above the national average for over 65's.

Third; will the service be for all these patients or just some of them - every single patient with a movement disorder or just those with Pd? Will it be only for patients in the complex stage or will it also embrace diagnostic and maintenance phase patients? What about

palliative care? Will there be an age limit? Will there be a geographical limit or will patients cross traditional catchments?

Fourth; where will these patients be seen? Secondary care has traditionally offered the Day Hospital and outpatients but will patients be seen following referrals from colleagues in other specialties on the wards? We try hard not to admit people with Pd but are there beds for patients that need "sorting out" – if so where? Plans have to be set against the changing NHS. Community hospitals may be fewer but PCT's are keen to promote those that are left and patients often prefer to be seen in their locality Community Hospital rather than in the DGH. Also in the community;

GP's surgeries are increasingly coming together in larger buildings and in nursing homes a number of patients in a particular home could be seen on a single visit. Domiciliary visits are possible but are an expensive use of time.

Fifth; managing people with Pd is difficult for a lone clinician. The Pd Nurse Specialist (PDNS) is an invaluable resource in sharing that workload but for the doctor and the nurse to work efficiently some sort of *modus operandi* has to be established. The PDNS is central in supporting assessments and diagnosis, helping with drug management, offering nursing advice and intervention, promoting education for patients, carers and other interested parties, facilitating liaison, managing

**"There are six things to consider when building a service"**

palliative care and by acting as a key worker. Our anecdotal experience of introducing a PDNS to the Cheltenham & Tewkesbury part of Gloucestershire is that there are fewer visits to the General Practitioner, longer gaps between visits to hospital and generally patients prefer to see the nurse rather than a doctor. Truly a win, win, win situation.

As regards “others” there are probably three levels. Closest to the patient are friends, family, carers plus charitable organisations like the PDS and Age Concern. Next closest are the allied health professions including SALT, OT, Physiotherapy, Dietetics, Psychology, Social Work and others. Finally there is the outer ring which comprises the GP, Geriatrician and/or Neurologist and ideally the Old Age Psychiatrist too.

Sixth; how will the service operate? How does the referral arrive and who reads it first? Many of us long for the flexibility of having a single medical secretary in a single location, fielding all the letters regardless of where and how quickly that patient might be seen. Who will see the patient first may depend on the content of the letter. This might routinely be a nurse, a doctor or, based on the letter, a response from another member of the team. Clearly whoever sees the patient should write



the letter but if this is true inter-professional working, namely that everyone talks to everyone, then the letter, ideally written to the patient, should be copied to all those involved in the care. Other models include writing to the GP and copying to the patient or writing two separate letters, but in all cases copying to whichever health care professionals are appropriate.

Thinking and reflection alone will not build a service and at some point the clinician has to get on with it. It is though easier to show leadership and to address the issues that may hinder progress by considering these six stages. They will also get you through the graph that so many of you remember from the Masterclass: an initial huge wave of enthusiasm that takes the clinician up the curve only for expectation and reality to collide leading to a deep dive into despair. However, building a decent service does not happen overnight and the realisation that the time course is potentially quite long and therefore the project is do-able pulls the clinician out of that nadir and s/he starts to climb the curve as time goes forward.

In summary the six stages comprise why are you doing it, who are you doing it for, all or just some, where are you going to do it, with whom are you going to do it and how are you going to run it? Considering the six stages may help recognise that there may be a false dawn, that it is best not to get into the steep decent and that by keeping ones eyes firmly on the horizon, maybe very slowly, the building of the service will move forward.

Good Luck.

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