



The Parkinson's
Disease Academy

Issue 8 - Summer 2008

MasterStrokes

CONTENTS

- 3rd UK NMS meeting report ... 2
- Masterclass Photo ... 3
- DBS Overview ... 4
- DBS Quick Reference ... 7
- Palliative Care ... 8
- A Patient's View ... 10
- Parkinson's in Hutt ... 12
- Putting the Pieces Together ... 13

PUBLICATIONS INFORMATION

MasterStrokes is published quarterly by:
RED Publishing Ltd, Bridge House, New
Bridge Street, Truro TR1 2AA
Email: redpublishing@btopenworld.com
Tel: 01872 225552

DISCLAIMER

The opinions expressed in articles and letters in MasterStrokes are the views of the authors and contributors, and unless explicitly stated to the contrary, are not those of RED Publishing Ltd, or The Parkinson's Disease Academy, faculty members or the organisations to which the authors are affiliated.

The mention of trade, corporate or institutional names and the inclusion of advertisements in the Newsletter does not imply endorsement of the product, post or event advertised.

© The Parkinson's Disease Academy
Production: Frances Higgs



Movement Disorders Section

Editorial



Parkinson's disease in the UK NHS at 60

"So," said my 78 year old with newly-diagnosed Parkinson's disease, "*what you're saying is that I've lived long enough to get Parkinson's disease?*" There is indeed no such thing as a stupid question!

The first description of 'the shaking palsy', now universally known as 'Parkinson's disease' [Pd] comes only 12 years after The Battle of Trafalgar and 2 decades before Queen Victoria's accession – this is modern history and Pd has the distinction of not having been described by Hippocrates. Even with its Mediterranean diet, it seems improbable that many in the population of Kos lived long enough to develop illnesses that we now think of as age-related. In his first aphorism Hippocrates observes: "*Life is short*" (but equally wisely "*Science is long.*") He would not have had the demographics to observe the condition that Charcot was to label Pd 2,200 years later.

To paraphrase John Cleese in *The Life of Brian*: "*what did the NHS ever do for Pd?*" Prior to the NHS there was fee-for-service General Practice (terrifying for the poor), a poorly-developed secondary care, which was an *ad hoc* sector combining voluntary, charitable and other various hospitals, plus the private sector - mainly in large cities with teaching hospitals. What the NHS brought about was a *universal service* of care, with primary care the jewel in the crown but with the district general

hospital and its growing number of consultant specialists not far behind. Despite the NHS, the killers remained: the infectious diseases including tuberculosis [TB] and chronic 'incurable' diseases like stroke usually at younger ages than now.

In answer to my patient, the reduction in coronary artery and cancer mortality (although less so incidence and clearly not prevalence) have allowed him to live long enough to get Pd which has as its main risk factor getting older – so he is correct. However, in an international comparison with countries where as few as 1% make it to age 65, the most remarkable observation is that he survived childhood. He did so pre-NHS, perhaps reflecting a World War II diet but mainly because of the public health achievements of the Victorians post James Parkinson. Yes; tuberculosis was a killer in 1948 but, by 1936, when streptomycin was introduced, the incidence had already fallen to a hundredth of what it was in 1836 with average life expectancy at the inception of the NHS more than 50% higher at 67 years than when Pd was described in 1817.

So what is the future for Pd in the UK's NHS? Childhood and young adult survival will hopefully continue to improve but not by much. Well done the Victorians.

For the previous big killers – vascular disease and cancer – the challenge is not just to hold down mortality - average survival rose to 78 years by 2006 largely during

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

Editors: Doug MacMahon & Sue 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

the latter 3 decades of the NHS - but to drive down the incidences. In that context The Quality and Outcomes Framework in Primary Care is to be welcomed. Well done the NHS.

But this leaves the NHS with an ageing population and degenerative diseases that have aetiologies that cannot easily be defined and prevented - a challenge for all of Geriatric Medicine and not just specialists in Pd. Care in its widest sense must be planned now not least as those of working age make up a diminishing percentage of the population. Yet Pd services in 2008 are as fragmented as secondary

care was pre-1948. Will the NHS at 60 be brave enough to commission *universal services* for people with diseases like Pd? Choice is fine but patients collecting consultants' opinions is not a rational model of proper care. Moreover services for Pd are best delivered as near to the patient as possible and by a team that crosses the primary/secondary care interface as well as the interfaces between professions. Of course patients *do* want the very best but they want it on their doorstep. In an NHS that is 60 is that too much to ask? The Pd Academy thinks not.

Peter Fletcher



3rd meeting of UK PD Non-Motor Group, London, March 2008

Report on the Third Meeting of the UK PD Non-Motor Group held on Saturday 8 March 2008 at the Royal Society of Medicine London

An International Faculty presented 'state of the art' reviews on a wide raft of non-motor symptoms (NMS) in Parkinson's disease to a large audience at the Royal Society of Medicine in March this year. This report reviews some of the topics covered.

Professor Tolosa (Barcelona) began by reviewing the evidence for a 'premotor' stage in PD when NMS such as constipation, impaired olfaction and sleep disturbance may be emerging. Professor Shapiro from London then discussed when it was appropriate to initiate treatment in Parkinson's Disease. Traditionally the view has been to delay treatment until so called 'functional disability' emerges but there may now be consensus moving towards earlier treatment based on clinical study data such as the TEMPO study and also theoretical considerations in preserving and supporting compensatory mechanisms in early disease. Professor Brooks presented a comprehensive and fascinating overview of the imaging of dementia and depression in Parkinson's disease. One practical feature was that modern imaging techniques are challenging the former view that abnormalities of serotonin are a principal cause of depression in PD. Professor Brooks highlighted that conventional treatments with SSRI drugs may therefore not be the most effective drug therapy under such circumstances.

Professor Carl Clarke (Birmingham) gave an appraisal of drug therapy for motor and non-motor symptoms highlighting the dearth of evidence in therapeutic terms for many non-motor symptoms. Professor Clarke highlighted that similar to the controversy of when to start treatment there is no clear indication of what drug or drug class is best in early PD. He also reviewed the shortcomings of previous trials in terms of short duration and end points that did not incorporate quality of life measures. Hopefully the PD Med trial will provide some additional key evidence when this reports next year. Professor Clarke also highlighted some new developments in the treatment of Parkinson's disease but suggested progress was being made on an incremental basis and that immediate treatments are unlikely to make a vast difference to the quality of life for PD patients. Safinamide is a new MAOB inhibitor and an inhibitor of glutamate release which may provide some additional benefits in cognitive function for patients and this is being explored in clinical trials.

Professor Richard Brown (London) reviewed the management of apathy and depression highlighting the importance to both patients and carers in terms of quality of life. Apathy may occur as a feature of depression but may also occur in isolation and can be difficult to manage although behavioural therapy can be useful. Dr Graeme Macphee (Glasgow) reviewed the increasing importance of impulse control disorder in Parkinson's disease linked to dopamine agonist therapy. Patients and carers need to be well educated about potential behaviours such as

pathological gambling, hypersexuality and binge eating and regular surveillance must take part in the clinic involving carers as much as possible as these problems may be hidden from family members. Therapeutic approaches are lacking in evidence base but empirical approaches have been to stop, reduce or switch dopamine agonists as well as the use of other adjunctive drug therapy. Professor Odin (Bremerhaven) reviewed the management of sexual dysfunction in Parkinson's disease noting that both hypo and hypersexuality (again linked to dopaminergic therapies) may be a source of distress both for patients and carers.



Gillian Johnson, Clinical Specialist – Speech and Language Therapist at King's College, London, discussed the approach to implementing the NICE guidance on communication and swallowing. In contrast to traditional views she noted that some speech and swallowing symptoms may be responsive to modification of dopaminergic therapy. However,

speech and language therapy has generally been shown to be the most efficacious therapeutic method for improving voice and speech function in combination with optimisation of dopaminergic treatment. The Lee Silverman voice treatment programme aims to restore oral communication in people with PD but there are still issues regarding the availability of this therapy for patient on a national basis. Professor Martine Visser from the Netherlands concluded the meeting with her work on modelling health related quality of life (Hr QOL) in PD. She concluded that multiple factors including disabilities, non motor symptoms and axial motor symptoms affect Hr QOL and require a multidisciplinary approach.

Overall the meeting highlighted the explosion of activity in this former wasteland of phenomenology in PD. Nevertheless, further research is urgently required to underpin evidence based management of NMS and the gauntlet has been thrown down to all working in the field. Congratulations to the Chair of PDNMG, Prof RayChaudhuri and his team for producing another excellent educational and networking day.

Graeme MacPhee



This year's Masterclass programmes (Classic and Specialist Registrar), have trained a further 45 doctors in Parkinson's disease management. Doctors on the Specialist registrar course at the Knowledge Spa in Truro take time out to pose for a photo shot.

For 2009 training dates for the masterclasses are:

**Classic Masterclass 20-22 May 2009 / 25-27th November 2009
Specialist Registrar masterclass 6-10th July 2009**



Deep Brain Stimulation for Movement Disorders

Commissioning Deep Brain Stimulation for Movement Disorders Including Parkinson's Disease A Brief Overview of DBS & Current National Practice

Surgery for Parkinson's Disease (PD)

Surgical lesional procedures for Parkinson's Disease first proved successful in the 1950's, but rapidly declined after the introduction of Levodopa and other dopaminergic agents in the late 1960's. However, in the mid 1980's the realisation that medication had its limitations, including severe "On-Off" phenomenon (predictable or not) and disabling dyskinesia, caused a rethink. Concurrently, the development of sophisticated techniques to increase the precision of surgical interventions, including imaging & electrophysiology, together with a greater understanding of basal ganglia anatomy & pathophysiology led to a resurgence of interest in neurosurgery to relieve parkinsonian symptoms.

Since the seminal publications of Professors Benabid & Pollak which highlighted the benefits of chronic stimulation of the thalamus & subthalamic nucleus, in addition to those subsequently chronicling the stimulation of the globus pallidus, deep brain stimulation (DBS) has become the neurosurgical procedure of choice for the management of movement disorders in those patients, including PD, who are losing their quality of life and can no longer be managed by pharmacotherapy.

Currently, DBS for Parkinson's Disease targets three basal ganglia sites; the thalamus, globus pallidus interna (GPi) and subthalamic nucleus (STN). The procedure, dependent on the DBS centre, can be performed under a general anaesthetic (GA) or a combination of GA and local anaesthetic. The procedure involves the fixation of a frame to the patient's skull, brain imaging using either computerised tomography (CT) scan or magnetic resonance imaging (MRI) but usually both. In addition, microelectrode recording may be utilised to define target location. All of these methods allow the precise localisation of target structures in the brain compensating for distortion and brain shift; the accuracy is generally within 1mm. A small burr-hole allows the accurate placement of the DBS lead to position the electrodes within the chosen target dependent on the targeted symptoms to be ameliorated. The DBS leads are then connected to the implantable pulse generator, usually

located beneath the skin below the clavicle by a subcutaneous extension. The pulse generator can independently stimulate both sides of the brain; a rechargeable pulse generator is also now available subject to stringent patient & clinical criteria.

There is also heightened interest in stimulation of the pedunculo-pontine nucleus (PPN) a target located bilaterally within the upper brainstem. It is thought that this nucleus provides more robust clinical efficacy for PD patients with primary axial symptoms such as postural instability, gait ignition difficulties & "on-gait" freezing. DBS has been demonstrated to improve the quality of life in multiple studies and has been determined to have Class 1b evidence. PD patients are able to benefit with improved quality of life from DBS irrespective of whether tremor is the predominant symptom or the "classic" symptoms of akinesia, bradykinesia, rigidity or dyskinesia.

To date, there are approximately 50,000 patients worldwide who have received DBS therapy including 10,000 patients recruited to clinical studies contributing to over 830 clinical publications since January 1996.

The Funding Situation

Currently many of the Neuroscience activities do not have a specific HRG coding and supporting tariffs; however this should not be a barrier to prescribing procedures and therefore local commissioning. Many such specialised procedures find themselves in similar situations and as such have been designated 'specialised services'.

Commissioning for **Specialised Neurosciences Services** within the NHS in England is covered by the Specialised Services National Definition set no. 8. (SSND). 'These definitions identify activity that should be regarded as specialised and therefore subject to collaborative commissioning arrangements'. Local specialised commissioning groups and their associated primary care trusts are therefore responsible for commissioning those services that are identified as specialist and specifically those named within the definition set.

DBS for PD is specifically named as specialist service 8a within the Specialised Neurosciences Services (Adult) Group 8. Regional commissioners need to plan, procure and "risk

share” the costs of this specialist service amongst its primary care trusts within its jurisdiction.

Procedures such as Deep Brain Stimulation have special consideration under the Payment by Results (PBR), a national tariff programme. Centres fulfilling appropriate criteria attract an agreed NHS uplift on base tariff for specialist procedures, whilst the deep brain stimulator system itself is excluded from the tariff payment. Centres performing the procedure negotiate a rate for the DBS stimulator system with their commissioners, typically on a cost-per-patient basis.

Considering the above, in the relevant context for the commissioning of Deep Brain stimulation for Parkinson’s disease (DBS), will help ensure that appropriate patient referrals are appropriately funded. An Interventional Procedure Guidance (19) Nov 2003, was issued for DBS in Parkinson’s disease where it stated that ‘Current evidence on the safety and efficacy of DBS for PD appears adequate to support the use of the procedure, provided that normal procedures are in place for consent, audit and clinical guidance.’ Subsequently, in June 2006, NICE Clinical Guideline 35 for Parkinson’s Disease was issued and stated that DBS is a considered intervention option for later disease state management.

In Wales, specialist services are commissioned by Health Commission Wales (Specialist Services) (‘HCW(SS)’), an executive agency of the Welsh Assembly Government responsible for providing a strengthened Specialist Health Services Commissioning body that commissions tertiary and other highly specialised services throughout Wales. In June this year the Welsh Health Minister announced that a new programme for DBS was to be commissioned by HCW and that £400,000 new funding for 2008/2009 to provide treatment for patients with DBS was to be made available.

Similarly, for specialised services, Scotland acts as a single region and all services are funded on behalf of the geographic NHS Boards by National Services Division (NSD). Funding is set annually with final funded value being based on projected actual expenditure, with overspends funded through additional bottom-slicing and any underspends returned by NSD. Where a specialised service is not available in Scotland, it is possible for the patient to be treated in England as long as appropriate consent is given.

DBS Therapy Delivery & Evidence

As a specialist service, patients can be referred for consideration for DBS at a number of neurosurgical centres across the UK. Patient assessment is critical to the outcome of DBS therapy and involves the input of a

multidisciplinary team who consider the patient’s function, psychology, neuropsychiatry, current medication regimens and concomitant illnesses. In addition, brain imaging insures no abnormalities that would affect clinical outcome. It is also critical to establish appropriate, realistic patient goals of DBS therapy which often determine the choice of the stimulated target site.

Thalamic Stimulation: Professor Benabid et al discovered that high frequency stimulation during destructive lesioning could abolish tremor reporting 88% tremor reduction success in 26 patients^{1,2}. Since then deep brain stimulation of the ventral intermediate (Vim) thalamic nucleus, has proved very successful in the long-term management of patients with PD and Essential tremor^{3,4,5}. The functional nature & programmability of the stimulation, which make the effects reversible and adaptable over time, are two advantages over the permanent surgical lesion of thalamotomy. However, functional outcome has been reported to be superior with stimulation over tremor⁶. In addition, stimulation seems to induce less adverse effects than traditional destructive thalamotomy, particularly when bilateral. However, as with the ablative surgery in this region, thalamic stimulation does not improve akinesia nor does it help dyskinesias. Thalamic stimulation is especially indicated in the “tremor-dominant” PD patient, the results being robust long-term⁴.

Pallidal stimulation: High frequency stimulation of the globus pallidus appears to have an efficacy similar to that of pallidal lesions^{7,8}. Pallidal stimulation offers significant but often variable improvements of the “off” state but achieves a significant reduction in dyskinesias, reported at 84%, during the “on” state^{9,10,11}. Depending on the location of the stimulating electrode, pallidal stimulation has a variable effect on parkinsonian features versus LD-induced dyskinesias¹². A randomised study in Argentina compared lesion versus stimulation of the posteroventral pallidum but was too small to provide reliable evidence on their comparative efficacy¹³.

Subthalamic stimulation: Greater experience has been gained with the implantation of the subthalamic nucleus (STN). Since the small subthalamic nucleus is overactive in PD and is the major excitatory driving output of the basal ganglia, stimulation has the largest potential to normalise the excessive and abnormal discharge patterns of other basal ganglia structures, thereby improving all the motor features of PD. Such bilateral stimulation has been shown to have significant effects on underlying parkinsonism in the “off” state including tremor, rigidity, akinesia, dystonia, balance, speech and freezing of gait^{14,15,16,17}. In the “on” state the

anti-parkinsonism effect is so striking that, in contrast to pallidal stimulation, levodopa dosage can be dramatically reduced, normally within the range of 50-60%, with amelioration of dyskinesias^{16,18}. The impact of these motor function changes has a significant impact on a patient's quality of life affecting all dimensions of health-related well-being post-surgery^{19,20,21}

**Clive Woodard, BSc (Hons),
Development Manager,
Movement Disorders, Medtronic UK,
with additional contributions from
Reimbursement Team, Medtronic**

References

1. Benabid A, Pollak P, Louveau A, *et al*. Combined (thalamotomy and stimulation) stereotactic surgery of the VIM thalamic nucleus for bilateral Parkinson's Disease. *Applied Neurophysiology* 1987; 50: 344-346.
2. Benabid A, *et al*. Long-term suppression of tremor by chronic stimulation of the ventral intermediate thalamic nucleus. *Lancet* 1991; 337: 403-406.
3. Benabid A, Pollak P, Gao D. Chronic electrical stimulation of the ventralis nucleus of the thalamus as a treatment of movement disorders. *J. Neurosurgery* 1996; 84: 203-214.
4. Rehnrota S, *et al*. Long-term efficacy of thalamic deep brain stimulation for tremor: Double blind assessments. *Movement Disorders* 2003; 18: 163-170.
5. Sydow O, *et al*. Multicentre European study of thalamic stimulation in essential tremor: a six year follow up. *J. Neurol. Neurosurg. Psychiatry* 2003; 74: 1387-1391.
6. Schuurman PR, *et al*. A comparison of continuous thalamic stimulation and thalamotomy for suppression of severe tremor. *N. Engl J Med*. 2000; 342: 461-468
7. Siegfried J, Lippitz. Bilateral chronic electrostimulation of ventroposterolateral pallidum: a new approach for alleviating parkinsonian symptoms. *Neurosurgery* 1994; 35: 1126-1130.
8. Pahwa R, Wilkinson S, Smith D *et al*. High frequency stimulation of the globus pallidus for the treatment of Parkinson's Disease *Neurology* 1997; 49: 249-253.
9. Thobois S, *et al*. The deep brain stimulation for parkinson's disease study group. Deep brain stimulation of the subthalamic nucleus or the pars interna of the globus pallidus in Parkinson's Disease. *N Engl J Med*. 2001; 345: 956-963
10. Volkmann J *et al*. Safety and efficacy of pallidal or subthalamic nucleus stimulation in advanced PD. *Neurology*. 2001; 56: 548-551.
11. Krack P. *et al*. Subthalamic nucleus or internal pallidum stimulation in young onset Parkinson's Disease. *Brain* 1998c; 121: 451-457
12. Bejjani B *et al*. Pallidal stimulation for Parkinson's Disease: two targets? *Neurology*. 1997; 49: 1564-1569.
13. Merello M, Nouzeilles MI, Kuzis G *et al*. Unilateral radiofrequency lesion versus electrostimulation of posteroventral pallidum: a prospective randomised comparison. *Movement Disorders* 1999; 14: 50-6.
14. Limousin P, Pollak B, Benazzou A *et al*. Bilateral subthalamic nucleus stimulation for severe Parkinson's Disease. *Movement Disorders* 1995; 10: 672-674.
15. Krack P, Pollak P, Limousin P, *et al*. Stimulation of subthalamic nucleus alleviates tremor in Parkinson's Disease. *Lancet* 1997; 350: 1675.
16. Moro E, Scerrati M, Romito LMA *et al*. Chronic subthalamic nucleus stimulation reduces medication requirements in Parkinson's Disease. *Neurology* 1999; 53; 85-90.
17. Deuschl G. *et al*. A randomised trial of deep brain stimulation for Parkinson's disease. *N Engl J Med*. 2006; 355: 896-908.
18. Krack P, Limousin P, Benabid AL *et al*. Chronic stimulation of subthalamic nucleus improves levodopa-induced dyskinesias in Parkinson's Disease. *Lancet* 1997; 350: 1676.
19. Just H, Ostergaard K. Health-related quality of life in patients with advanced parkinson's disease treated with deep brain stimulation of the subthalamic nuclei. *Mov Disord*. 2002; 17: 539-545.
20. Lagrange E. *et al*. Bilateral subthalamic nucleus stimulation improves health-related quality of life in PD. *Neurology*. 2002; 59: 1976-1978.
21. Martinez-Martin P. *et al*. Bilateral subthalamic nucleus stimulation and quality of life in advanced Parkinson's Disease. *Mov Disord*. 2002; 17: 372-377.



Deep Brain Stimulation Quick Reference Guide

Hospital	Neurosurgeon	Neurologist
Ninewells - Dundee	Mr. S. M. Eljamel	Dr. Robert Swingler
Western General Hospital - Edinburgh	Professor Ian Whittle	Dr. Richard Davenport
Newcastle General	Mr. Alistair Jenkins	Dr. David Burn
Walton Centre - Liverpool	Mr. Paul Eldridge & Mr. Jibril Farah	Dr. Malcolm Steiger & Dr. Nicholas Fletcher
Queen Elizabeth Hospital - Birmingham	Mrs. Rosalind Mitchell	Dr. Hardev Pall & Prof. Adrian Williams
John Radcliffe Hospital - Oxford	Professor Tipu Aziz	Dr. Ralph Gregory
Frenchay Hospital - Bristol	Professor Steven Gill	Dr. Peter Heywood & Dr. Alan Whone
Queens Medical Centre - Nottingham	Mr Surajit Basu	Dr Guy Sawle
Queens Hospital - Romford	Mr. Ian Low	Dr. Anjum Musbahuddin
Charing Cross Hospital - London	Mr Dipanker Nandi	Dr. Peter Bain & Dr. Sean O'Riordan
Kings College Hospital - London	Mr. Richard Selway & Mr Keyoumars Ashkan	Dr. Michael Samuel
National Hospital - London	Professor Marwan Hariz & Mr Ludvic Zrinzo	Dr. Patricia Dowsey-Limousin & Dr. Tom Foltynie
Royal Hallamshire Hospital - Sheffield	Mr. Jeremy Rowe	Dr. Richard Grunewald
Southern General Hospital - Glasgow	Mr. Laurence Dunn	Dr. Donald Grossett
Addenbrookes Hospital - Cambridge	Mr. Colin Watts	Dr. Roger Barker



Palliative Care in Parkinson's Disease



Idiopathic Parkinson's disease (iPD) is a chronic neurodegenerative disorder with no cure or proven disease-modifying therapy at the current time: as such, it could be argued that therapy is palliative from the outset.

In 1998, it was proposed that iPD could be divided into four stages: diagnosis/adjustment, maintenance (a "honeymoon" period for some), complex and palliative [ref 1]. Palliative, as defined by the WHO in 2006, involves the prevention and control of symptoms, and support of the best quality of life for patients and families regardless of the stage of disease or need for other therapies. As regards iPD, MacMahon and Thomas gave the definition of the palliative stage of disease as that where adequate dopaminergic therapy ceases to be tolerated (side effects begin to outweigh benefits or what has been described as "*diminishing returns*" [ref 2]), surgery (deep brain stimulation) is not appropriate, and/or advanced comorbidity exists.

The length of time an individual spends in each phase differs and is not entirely predictable. As the average age at diagnosis of PD is the mid-60s, and as disease course averages 15 years [ref 3], it is also entirely possible that someone with iPD does not die *of* PD but *with* PD (in other words that the primary cause of death is not PD but another disease process such as cancer, ischaemic heart disease or respiratory disease). The recently published Sydney multicentre study 20 year data suggest that iPD was a significant contributor to death in only 54% [ref 4].

The NICE Parkinson's disease guidance published in 2006 [ref 5] suggest that care for PD should be undertaken by a specialist in the disease and that palliative care requirements be considered throughout all phases of the disease. Patients and their next of kin should have the opportunity to discuss end of life issues with appropriate professionals at any time they wish.

Of course, not every patient will easily and predictably pass through the 4 stages outlined by MacMahon and Thomas. Also patients and their next of kin will differ in the extent to which they wish to discuss end of life issues and the timing of these discussions – one can well imagine a spouse having different questions and needs at one timepoint from his or her affected partner, for example. An individualised approach based on listening to the needs of patients and their next of kin is required.

Ethical areas which need to be considered in later stage disease could include:

- ◆ Advance directives / care plans / "ceilings of treatment"
- ◆ Resuscitation decisions
- ◆ A patient-held careplan
- ◆ Feeding issues
- ◆ Wills and probate
- ◆ Lasting power of attorney

These ethical issues are very broad with important legal and social implications that cannot be done justice here so the reader is best referred to a standard textbook such as the Oxford Textbook of Palliative Medicine (see further reading).

Patients and their next of kin may naturally wish to know at every stage of disease the likely *trajectory* they might expect. This, like much of non-cancer palliative care, is poorly researched. From the Sydney PD cohort, 20 year data show that 83% of individuals are demented at this stage if they haven't already died and almost all have moved from home into a care environment [ref 4]. Thus, having an idea of the individual's wishes while he or she is able to express them can be seen to be of importance.

Non-motor problems such as swallowing difficulties, dysarthria, dementia and autonomic failure predominate in the later stages of the illness [ref 4]. One systematic review [ref 6] of all advanced and progressive neurological disorders revealed 9 shared problems across all disorders:

- ◆ Mobility problems
- ◆ Communication difficulties
- ◆ Weakness
- ◆ Muscular spasm
- ◆ Swallowing difficulties
- ◆ Constipation
- ◆ Bladder dysfunction
- ◆ Psychiatric problems

In iPD, motor symptoms such as freezing affect the daily lives of those affected [ref 4], sleep disorders and tiredness are also problems that are encountered.

Further research can be expected in the later

stages of disease in the near future as non-cancer palliative care develops a real “head of steam”. Prospective research is particularly lacking as many reports in the palliation of iPD take the form of surveys or audits, particularly relying on interviews with the caregivers and spouses of predeceased people with iPD. This is partly due to historical accident, as one expert puts it, “*many textbooks [and, by extension, historical experts] do not recognize PD as a life-threatening illness.*” [ref 7]

When to start the conversation with patients and their next of kin? This is partly answered by the NICE guidance that one should always be willing to sensitively respond to patients’ enquiries. However, certain scenarios may indicate to carers and clinicians alike that disease is progressing. These may include the move from maintenance to complex disease (not always an obvious transition) or developing dementia and losing independence. Also, as in some older persons, some - but not all - falls can demonstrate incipient frailty and herald later decline.

One question that colleagues in Palliative Care use to inform discussions with patients and next of kin is the “question of surprise”, that is to say, “Would you be surprised if this person died within the next 6 months?” If the specialist feels that the answer to this question is no, then end of life planning might be considered reasonable. Other prompts outlined in the Gold Standards Framework of 2005 [ref 8] include patient choice or need and specific indicators of advanced or terminal disease such as end-stage dementia. Again, it is important to reiterate that there can be no “one size fits all” approach.

In conclusion, to begin with the words of Val Buxton, Director of Policy, Campaigns and Information for the Parkinson’s Disease Society, responding to the launch of the NHS End of Life Care Strategy in July of this year:

“Our research and experience has shown that people with advanced stage Parkinson’s are not

getting the support they require. All people with Parkinson’s, their carers and relatives should have the opportunity to access a range of high quality specialist palliative care services appropriate to their physical, psychological, social and spiritual needs...” [ref 9]

This sentiment is echoed in the Hely work [ref 4] which demonstrates that only 47% of individuals see their specialist at 20 years, frailty and cognitive decline being amongst the principal factors preventing the remainder attending clinics. “*Their extreme disability is therefore a hidden problem...*”, to quote the paper, “*... An outreach service from health professionals with a knowledge of PD would be of value.*” One such service exists in my own University teaching hospital where frail elderly individuals with iPD attend a day hospital with its own dedicated transport where a PD Nurse Specialist and Geriatrics Nurse Consultant provide a monthly joint clinic. An outreach service is also provided for those too sick or frail to attend this unit.

One of the main arguments, in my opinion, in favour of Geriatrics-trained physicians maintaining PD services is the overlap in practice that can be taken from end of life issues in Geriatrics in general to dealing with PD. Of course, there are very many Neurologists providing PD services who have embraced good practice in this area as well.

As more is known about the course of end-stage PD, and as more specialist palliative care teams become interested in and experienced with non-cancer care, it can be hoped that services will develop and improve. In the meantime, PD specialists can maintain links and working relationships with their local Palliative Care teams, counselling services, social services, CRUSE bereavement support and similar groups, to provide, it is hoped, excellent multi-disciplinary care.

**Ian Thompson,
King’s College Hospital, London**

References

1. MacMahon D, Thomas S *Practical approach to quality of life in Parkinson’s disease* J Neurology 1998 245; Supp 1: S19-22
2. Robertson *Rehabilitation in Parkinson’s disease* CME Geriatrics 2008; 10(1): 51-7
3. MacMahon D et al. *Validation of pathways paradigm for the management of PD* Parkinsonism Rel Disord 1999; 5: S53
4. Hely M et al. *The Sydney multicenter study of Parkinson’s disease: the inevitability of dementia at 20 years* Mov Disord 2008; 23(6): 837-44
5. NICE Clinical Guidance CG035 (June 2006) available online at <http://www.nice.org.uk/CG035>
6. Saleem T, Leigh P, Higginson I *Symptom prevalence among people affected by advanced and progressive neurological conditions – a systematic review* J Pall Care 2007; 23(4): 291-9
7. Goy E et al. *Neurologic disease at the end of life: caregiver descriptions of Parkinson disease and amyotrophic lateral sclerosis* J Pall Med 2008; 11(4): 548-54

8. Thomas, K *The gold standards framework* London DOH 2005 available online at <http://www.goldstandardsframework.nhs.uk>
9. http://www.parkinsons.org.uk/about_us/press_room/news_archive/

Further reading

1. Thomas S, MacMahon D *Parkinson's disease, palliative care and older people (2 parts)* Nurs Older People 2004; 16(1): 22-6 & 16(2): 22-6
2. Borasio G et al. *Palliative medicine in non-malignant neurological disorders* in Doyle D et al. (eds) *The Oxford Textbook of Palliative Medicine* (3rd Ed. OUP 2005)
3. Kristjansson L et al. *Palliative care and support for people with neurodegenerative conditions and their carers* Int J Pall Nurs 2006; 12(8): 368-77
4. Goy E et al. *Parkinson disease at the end of life: caregiver perspectives* Neurology 2007; 69: 611-12
5. Elman L et al. *Palliative care in amyotrophic lateral sclerosis, Parkinson's disease and multiple sclerosis* J Pall Med 2007; 10(2): 433-457

**Dr Thompson wrote the above article
as part of course work for the SpR Masterclass (3) 2008**



A Patient's View



Roger Weatherly was diagnosed as having Parkinson's disease in March 1999, one day before his 50th birthday. Here, from an entirely personal perspective, he offers some observations about what kinds of management and treatment have proved most helpful for him as he lives with PD, and what part he feels consultants can play in supporting someone with a long term degenerative disease.

Doug MacMahon

A quick self-portrait, before I offer you my thoughts... At 50 years of age I had enjoyed nearly thirty years within the teaching profession, in rewarding posts in the maintained and independent sectors. I took on a headship of a preparatory school at the age of 37; for the next eleven years my wife and I worked together, enjoying the arrival of five children of our own and running the school. In the mid 1990's, having qualified as a school inspector, I moved into full-time inspection and consultancy work, and all seven of us moved to Cornwall. As the diagnosis was confirmed our children were aged 11, 8, 7, 7 & 22 months. We also had two dogs, much of our spare time was spent walking, and we took active holidays. I was driving up to 40,000 miles a year.

First Steps - The GP

It is now more than ten years since, wondering what might be wrong with me, I went to see my GP presenting symptoms of stiffness and fatigue. In those days I actually knew my GP, and, more crucially, he knew enough about me to come to a judgement that further investigation was needed. Today I guess the situation is more patchy, and there is need for all GP's to be sufficiently aware of likely PD symptoms (could consultants help here?) so that everyone who needs assessment is promptly referred. I was fortunate; I saw a consultant within a few weeks, but not everyone does.

The Initial Consultation

I remember this vividly. The most important thing was the precious gift of time, almost an hour, coupled with a listening ear. I learned that diagnosis was by elimination – hence the need for a brain scan, for example. Here, also, was a service of expertise, someone who offered a collaborative approach to investigating what might be wrong with me, an approachable, reassuring professional.

The Team

Once the diagnosis had been made, as my relationship developed with the consultant who had seen me initially, he introduced me to the rest of the consultants and to other health professionals – in particular I found the Parkinson's disease Nurse Specialist held most of the information, and much of the advice, that I needed. She introduced me to Occupational therapists, Physiotherapists, Speech and language Therapists, Dieticians and an excellent Masseuse, an impressive and supportive team. What I have appreciated most over the years is the occasional phone call from many of these specialists, "just to see how you are...."

The Parkinson's Disease Society

Early introduction to the wealth of support available nationally and within my local branch was a great support, especially in the early days. Advice about how one might cope financially and a helping hand with the daunting task of form filling, excellent information booklets and, locally, the pleasure of getting to know others with PD, have been especially appreciated.

Ongoing Support

PD is a degenerative and presently incurable disease. The greatest help my consultant and his team have given me is "being there with me" as the years have unfolded. Specifically, two areas of support have been of huge value; firstly helping me keep my independence, and secondly inviting me to have appropriate control over the management and treatment of my condition.

There have been many adjustments to make over the years since my diagnosis; for example, accepting I cannot walk the hills and mountains of Scotland with my younger children, as I did with the elder two, or (possibly more pressing on a practical front) coping with the need to stop working, in December 2003, with my consultants' helpful and sensitive support. My wife, as my main carer, has taken over many of the domestic and household tasks I can no longer undertake. I have had to learn to deal with the emotional changes my disability has caused, adjusting my expectations of myself and others, and I have learned to respond to fatigue rather than fight it. I have yet to master a problem of weight gain now that strenuous physical activity is often impossible. Throughout this complex and often stressful transition, my consultants have been the hub connecting and integrating all the support, treatment and advice I have so freely received. In summary, for me the following ten areas are pivotal (and I believe, since each individual patient

is given the same attention, that all of us, to meet our needs, will have personal variations of these headings understood and prioritised): in no particular order of importance these ten combine to keep this particular Parkie perky...

1. Offering me control over decisions, when appropriate
2. First empathising and listening - then offering advice
3. Knowing and training a team of specialist practitioners
4. Working closely with medical colleagues in other disciplines
5. Respecting and accommodating my priorities, where possible
6. Collaborating with me in managing my illness
7. Always determined to achieve early intervention when needed
8. Showing a track record of commitment to finding a cure
9. Being supportive of the work of the Parkinson's Disease Society
10. "Being there with me", always.

Roger Weatherley





Parkinson's in Hutt - is it any different?

Dr Althea Lord, Graduate of Masterclass 1 (now living and working in New Zealand) writes here of her experiences of developing PD services in New Zealand. Althea keeps in contact with the alumni through Masterstrokes and the Academy faculty and sent along two of her colleagues to participate in the 2008 Masterclass programme. These were our second and third international attendees on the Masterclass. Althea is also doing her bit to encourage new interest in PD with medical students - James Fasham a Medical student from Bristol is currently undertaking his elective with Althea down under. Well done Althea on flying the Masterclass flag!

The patient and carer issues - the consultation is no different whether it is in Portsmouth, England or Hutt, New Zealand. I now work as a Geriatrician in a small district health board just outside Wellington. A large portion of our current referrals are mostly for those in the complex stage with very few referrals for new or early PD. Hutt has two visiting neurologists who do a weekly general neurology clinic. Older patients are seen in Geriatric outpatient clinics or on home visits but there is no dedicated sessional time. The Palliative Care service from Te Omanga Hospice continues to evolve and now includes patients with long-term conditions. Their involvement for symptom control but also end-of life care has been invaluable.

A Field Officer, employed by Parkinson's Wellington is kept busy with increasing referrals. There are similar posts across the country with few Nurse Specialist posts mostly in research. Parkinson's New Zealand is an umbrella organization supporting patients, carers and health professionals and takes an active part in research, education and service development. There is still to be developed a co-coordinated pathway for the management of Parkinson's as long-term condition. Did you notice that the word 'Disease' has been omitted from the titles of the organizations?

A Movement Disorders meeting was set up last year and the Neurologists, Geriatricians and Psychiatrists in Hutt and Wellington hope to meet at least three times a year. The two sessions that have been held so far have been of good value

and also well attended.

Education of carers on the basics of PD was identified as a priority and a teaching session was held in July. 130 people made their way on a very wet and windy afternoon for "Understanding2Care – Parkinson's" a half-day seminar hosted jointly by Parkinson's Wellington and Hutt Valley District Health Board. A few patients attended and the rest were carers from Aged Care Facilities, some informal carers and some hospital staff. The session opened with a carer telling us the story and showing us a DVD of her husband who had Parkinson's and also suffered a stroke. This was followed by presentations by the Field Officer, Physiotherapists, Speech & Language Therapist and Geriatrician. This will hopefully be the start of more seminars not only on Parkinson's but also on other topics pertinent and relevant to carers looking after older people.

The PD Academy is truly international. The Senior Medical Officer from Hutt was accepted for the modules this year. As a participant in the 1st PD MasterClass the support I have received has been invaluable and this is still ongoing. There is still much to do and it is our dream that in Hutt, the services for people with Parkinson's will improve. We'd love to keep you posted.

**Althea Lord
Geriatrician
HVDHB
August 2008**





PARKINSON'S ACADEMY

putting the pieces
together

Parkinson's Disease 2nd Advanced Masterclass

12th September 2008 Holiday Inn Filton - Bristol



Gold Sponsors



Boehringer
Ingelheim

Silver Sponsors



Lundbeck



THE PARKINSON'S ACADEMY

In association with the

MOVEMENT DISORDERS SECTION, BRITISH GERIATRICS SOCIETY

FAX/POST APPLICATION FORM FOR PARKINSON'S DISEASE ADVANCED MASTER CLASSES

WHO ARE THESE COURSES FOR?

All previous graduates from the Parkinson's Disease Classic or SpR Masterclasses, Mentors & Speakers.

WHAT WILL THE COURSE INVOLVE?

This conference will provide attendees with an update and review of new therapeutic modalities and current guidelines for Parkinson's disease management

WHAT WILL IT COST?

There will be a charge of £125 + VAT for the course, which includes all course materials and refreshments. You are encouraged to apply to your employing Trust for Study Leave, and approval. Graduates will be responsible for their travel costs and any accommodation required.

WHEN AND WHERE WILL THE COURSE BE HELD?

Advanced Masterclass 2

Holiday Inn Filton, Bristol – 12th September 2008

PROGRAMME

Friday 12th September. 2nd Advanced Masterclass. Holiday Inn Filton, Bristol

09.30	Coffee and Exhibition	13.45	'DaTSCAN - capabilities and limitations' <i>Dr Paul Kemp</i>
10.00	Welcome & Introduction: After NICE – what's New? (a review of new therapeutic modalities and where they fit with NICE recommendations) <i>Dr Doug MacMahon, Cornwall</i>	14.30	Dementia in Parkinson's Disease – a review <i>Ira Leroi, Manchester</i>
10.45	Co-morbidities and their importance in older people <i>Dr Graeme Macphee, Glasgow</i>	15.15	Refreshments & Exhibition
11.30	Using Duodopa - experience to date <i>Dr Paul Worth</i>	15.35	Essential Tremor <i>David Stewart</i>
12.15	Discussion	16.15	Surgical update <i>Alan Whone, Bristol</i>
12.30	Lunch & Exhibition	17.00	Closing remarks <i>Dr Doug MacMahon, Cornwall</i>
		17.15	Depart

PERSONAL DETAILS (PLEASE USE BLOCK CAPITALS)

Dr
Surname
Forenames
Current Post
Work address

Postcode

Send no money yet, cheque required on acceptance

Home Address

Postcode
Home inc STD
Work
Fax
E-mail
Mobile

* Please note submission of this form does not guarantee acceptance.

RETURN APPLICATIONS TO:

RED Publishing Ltd, 1st Floor, Bridge House, New Bridge Street, Truro, Cornwall, TR1 2AA
Email: redpublishing@btpenworld.com for a form to complete on line Fax: 01872 225554