

Parkinson's UK Edinburgh Branch **Newsletter June 2013**

*Our aim is to inform members about forthcoming events, foster a sense of community, encourage participation in regular activities, and feature your efforts. We welcome suggestions – please get in touch with Helen Harris, Helen@edinburghparkinsons.org. We also remind you of the **wealth of information on the Parkinson's UK and Branch websites**.*

From the entries that follow you will see there have been a number of events since the last issue that are relevant to the matter of **pain and Parkinson's**. What has emerged is that for advances to be made in helping people deal with pain, the medical profession needs to take note of its prevalence and its nature and those with Parkinson's need to ensure they inform them of their experiences. In the meantime there are strategies that can help.

Pain and Parkinson's Workshop



This event was conceived and managed by Branch Members Sheila Edward, Pat Cox, Marian McIntyre and Margaret Seager as well as supported by Werner Remmele from Fife. It was participant-led and provided an opportunity for people to discuss their experience of pain while clinicians gave presentations on pain and its management – Dr Richard Davenport, Consultant Neurologist, Fiona MacPherson, Clinical Nurse Specialist Chronic Pain and Alison Stewart, Lead Parkinson's Nurse Specialist. The Branch website has a full report of the day including *pdf* files of the formal presentations – go to *Recent Meetings* on the menu for the *Research Interest Group*.

In summary, recognised types of pain were identified as: musculoskeletal, radicular (sharp, shock-like shooting pain travelling down the leg or arm, tingling, numbness, or a burning sensation in the toes and fingers), central (mouth, chest, rectum and genitalia), shoulders and limbs, as well as headaches, dystonia (spasms/cramps, abnormal posturing), and restless leg syndrome. Management of pain matters because it is common and affects quality of life, yet little research has been done in this area. Current pain management is often generic rather than specific to PD and sadly it can also be ignored by some Health Care Practitioners who don't see it as proper PD symptoms. Further advancement of our understanding is also frustrated by some patients not declaring their pain. The methods by which people cope are many and varied. The less conventional include: pilates, yoga, Tai Chi, cycling, vigorous exercise, Alexander Technique, podiatry and orthotics, a massage chair, Indian Head Massage, a hot bath with a sherry, bed socks, and a Gin and Tonic!

Annual Lecture “Non-motor Symptoms of Parkinson's”



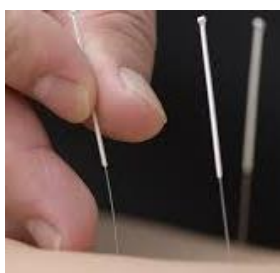
The lecture was given on 25th April by **Professor Ray Chaudhuri**, King's College Hospital. Presentation slides, audio recordings and a summary by Branch member Fiona Taylor can be downloaded from the Branch website on the *Research Interest Group* menu. Professor Chaudhuri's investigations include symptoms of fatigue, day time sleepiness, violent dreams, insomnia, urinary frequency, constipation, sexual problems, loss of smell, apathy, anxiety, poor concentration, memory loss, depression, and dementia. In addition, **pain** is one of the areas he wants included as a *major* non-motor symptom. He's currently conducting research on “*Measuring Pain*”

in Parkinson's." The project, funded by Parkinson's UK, will build on pioneering work that led to the development of the Parkinson's sleep scale and the questionnaire for non-motor symptoms, both of which are routinely used world-wide. The questionnaire is available to Lothian patients to complete.

Measuring pain in PD is the first step towards understanding what causes it and will also allow assessment of the effectiveness of new treatments and on-going evaluation of treatment interventions. Increased awareness by the medical profession about the types of pain experienced by people could also prevent it from being 'missed' as a symptom; so more people would have access to treatments. A significant and encouraging revelation of the presentation was the suggestion that **once pain and other non-motor symptoms can be correctly diagnosed some types can very easily be treated.**

Some of the suggestions for pain management matched the conventional approaches mentioned by participants in the March "Pain and Parkinson's Workshop" – drug therapy, TENS machine, physiotherapy, hypnotherapy, cognitive behavioural therapy, massage, aromatherapy, pain management programmes and acupuncture, which is a topic recently covered by the Branch at their monthly meeting in April

Acupuncture and Parkinson's



The main thrust of Professor Chaudhuri's lecture was that PD patients should be treated holistically by clinicians i.e. the whole person, not just the symptoms. Acupuncture is a complementary therapy using a holistic approach. At the Branch Meeting in April **Caroline McGuire**, Physiotherapist in Neurological Rehabilitation at the Astley Ainslie Hospital spoke on "Acupuncture and Parkinson's." Caroline has been practising acupuncture for over fifteen years and has a particular interest in its application to neurological conditions.

Acupuncture has been used in China for millennia, being mentioned in ancient Chinese texts for symptoms that would now be diagnosed as Parkinson's.

While taking a holistic view, the type of PD symptoms that an acupuncturist might seek to improve are movement issues, mood, sleep, cold limbs, pain, speech, and side-effects of drugs. Unfortunately, the NHS main focus of use of acupuncture is for musculo-skeletal issues such as back pain and osteoarthritic symptoms. If seeking out an acupuncturist for a holistic approach, check that they are registered with the British Acupuncture Council. Other registration bodies are The British Medical Acupuncture Society (for healthcare professionals who practise acupuncture) and the Acupuncture Association of Chartered Physiotherapists (for physios who include acupuncture in their treatments). A fuller report of Caroline's presentation can be found on the Branch website under *Branch Meetings* then *Previous Events* and click on the link for *Acupuncture Talk* under *April 10, 2013*.

Physio-led Exercise



With her physiotherapist hat on, **Caroline McGuire** has established a five session, once-a-week Exercise Class for Branch Members at her Optimum Physiotherapy practice in the Bilston Glen Business Centre and first run as a pilot in 2012. The courses are on-going and each has no more than six people. Sessions begin with a warm-up to music then participants work through a circuit of six specially-chosen exercises that can be adapted to suit *and* made more challenging as people progress. Feedback from those who have attended include *improvement in all-over mobility and flexibility, a lifting of the spirits as well as enjoyment of*

the camaraderie of the group, and all for £15 per course. For maximum benefit, those attending should work at home with a hand-out of stretching exercises designed to fit in with daily activities. Participants can return for a repeat course of sessions. To book or for further information, please contact Kate or Patrick Mark, Patrick@edinburghparkinsons.org or on 0131 663 3108.

Regular Gentle Exercise Classes

The Gentle Exercise class was one of the first major activities established by the Branch. The class is run by **Lynne Scott** and is based on her long-standing experience as a yoga teacher and yoga therapist. As Lynne has been facilitating the class for over ten years she is very aware of the effects of Parkinson's on the mind and body. The aim is to support flexibility, strength, balance and co-ordination. Voice work is also included. Exercises involve working with breath and movement together, which not only helps with breathing, it encourages mental focus, allowing participants to separate from the rest of their day and create some 'therapeutic space' for themselves.

Men and women attend, including carers. Exercises are adapted for the individual as necessary and some people work seated. The success of the classes is demonstrated by the regularity with which participants attend; we encourage you to come and try it out. Classes run throughout the year on Wednesdays, 11:30am –12:30pm at Portobello Indoor Bowls & Leisure Centre (this venue will shortly change) and on Thursdays, 1:30pm – 2:45pm at Drylaw Parish Church. For further information or to book, please contact Liz McBain, 0131 315 2493, Liz@edinburghparkinsons.org.

QMU Study on Attitudes to Exercise



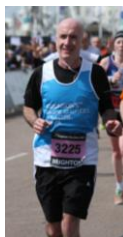
Some Branch members were involved in a research project by Queen Margaret University physiotherapy students looking at how people with Parkinson's regard exercise and what barriers there might be to exercising on a regular basis. The project was supervised by Senior Lecturer, *Gillian Baer* and Lecturer *Jane Hislop*. The team of researchers presented their findings at the Drop In on 3rd May.

Identified barriers include: physical issues (the interference of PD symptoms, the timing of medication, fatigue), environmental (crowded locations, not knowing the staff, transport to the venue, availability of support) and psychological (embarrassment, anxiety, depression, apathy, self-doubt). Aspects that facilitate people with PD taking regular exercise include: the benefits of social interaction, having a competitive streak, support from loved ones, encouragement and camaraderie of the group, being someone with a sense of humour and determination, having knowledgeable instructors available, ease of transport as well as friendly facilities.

The students feel they have learned some highly useful information from the study and believe their observations will be carried forward to benefit their new careers. Their QMU supervisors will be looking at how they can develop the study and make the results more widely available among the physiotherapy community.

The Parkinson's UK Helpline offers a 'listening ear' to anyone with Parkinson's or their families who need to talk to someone, safe in the knowledge that their call is confidential and the person listening understands Parkinson's. It is available Monday to Friday 9.00am – 8.00pm and Saturday 10.00am – 2.00pm, FREEPHONE 0808 800 0303 (calls are free from UK landlines and most mobile networks), hello@parkinsons.org.uk.

Fund-raising Activities



James Mark, son of Patrick and Kate, ran the **Brighton Marathon** in April and raised over £800 for Parkinson's UK. Although James has participated in various major runs in past years, this was his first marathon. He completed it in a highly respectable time of 3 hours, 41 minutes. The early morning mist and cloud gave way to bright sunshine as the run progressed. We say "Well done!" and a huge thank-you for the money raised.

The **annual coffee morning** in April buzzed with friendly chatter among the tea tables while the stalls were kept busy raising funds. The final total for the event came to over £1800. The Singing4Fun group sang some renditions from their ever-expanding repertoire and the Dance for Parkinson's group demonstrated a piece learned during the recent visit by Rambert Dance Company. Our sincere thanks to Annette McLeod, Liz McBain, the Ladies of Craiglockhart Parish Church and all others who worked hard to make this the success it was.

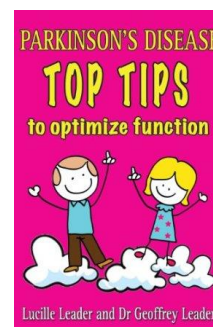


This was held in early May at Stuart's Melville Pavilion which proved an extremely comfortable venue. The event raised over £350. Chas & Dave of the *Flaming Heather* ceilidh band kept the dance-floor filled. There were interludes of Mo Morgan leading some line-dancing and Branch Member, Linda Remally singing three beautiful solo a-chapello numbers. A huge thank-you to Liz, Bill and Kirsty McBain for their organisational skills and to Mo and Linda.

The **Branch Annual Lecture**, covered elsewhere in this issue, raised £650 for research activities. Thank-you to all who gave donations.

Book Suggestions

Lucille Leader & Dr Geoffrey Leader are internationally recognised pioneers in the field of nutritional management of Parkinson's. For some years they've been advocating an integrated (holistic) approach to the management of PD, including the aspects of nutrition and relief of pain. "**Parkinson's Disease, Top Tips to Optimize Function**" (Denor Press, 2011) provides a highly accessible guide for people with Parkinson's and their carers. The approach looks at different aspects of daily life: *How to Maintain Energy, Taking Drugs More Effectively, Swallowing Problems, Sleep Issues, Incontinence, Stress Management* and many more. The bullet point approach allows quick and easy assimilation of the information and the illustrations keep the tone light-hearted.



Leader & Leader's previous book "**Parkinson's Disease: Reducing Symptoms with Nutrition and Drugs**" revised in 2009 (Denor Press) is a bigger read, explaining more of the science behind their suggestions (but still in an accessible way). It also includes personalised assessment schemes to determine how long your dosage of L-dopa works for you and what the minimum dose is that will effectively serve you.

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. It is a charity registered in England and Wales (258197) and in Scotland (SC037554), tel. 0808 800 0303, www.parkinsons.org.uk.

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