

## **PARKINSON'S UK, EDINBURGH BRANCH**

### **NOTE OF MEETING OF RESEARCH INTEREST GROUP, EDINBURGH, SATURDAY FEBRUARY 8, 2014**

The Edinburgh Research Interest Group welcomed Dr Carl Counsell, Clinical Reader and Hon Consultant in Neurology, University of Aberdeen, to talk about a recently completed part of his on-going research on living with Parkinson's. Since 2003, Carl and his team, including research nurses, have been aiming to follow all newly diagnosed people with Parkinson's in the Aberdeen area, tracking how their condition progresses, the types of symptoms people experience and their quality of life. To put into perspective any changes in participants' health that are simply due to getting older, the team is comparing people with Parkinson's to a control group of similar age without the condition, and they are also following a group of carers for people with Parkinson's to track how their lives change over time.

Because the slides of Carl's presentation are now available on the Edinburgh Branch website, this report aims simply to highlight some important features of his research. Carl stressed the effort that has gone into tracking down all newly diagnosed patients. They did not want to contact only those who ended up in neurology clinics, because they might have missed many of the older patients or those who do not go to their GPs. They sought referrals from GPs, consultants, hand-searched referral letters, used electronic searching of GP and hospital discharge data and screened older patients looking for symptoms of Parkinson's. This thorough approach identified a cohort of patients with a much higher average age (71.9 years) on diagnosis than much other research which has relied on finding patients in neurology clinics. All but sixteen of the 377 patients identified consented to take part in the research, which involves an annual assessment, with interim assessments as required. The cohort has proved very stable, with few moving away from the area or opting to withdraw from the research. Carers and the control group are also followed up annually.

In presenting his results, Carl was concerned that his audience should not find them depressing. People with Parkinson's did have lower survival rates after five years than the control group, but 50% of the deaths were clearly not related to Parkinson's. The statistics for death or dependency after three and five years were markedly worse for people with Parkinson's plus, vascular Parkinson's or dementia with Lewy bodies than for the much larger group of Parkinson's patients. Measuring motor

function and cognitive function showed a decline over three years that was only slightly worse amongst the surviving people with Parkinson's than for the control group. When testing for depression, the team found greater deterioration in the Parkinson's group, although Carl felt that the measures used often described frustration rather than deep depression. Patients' perceptions of their quality of life were relatively stable, showing a slight decline, and about a quarter of those reviewed had developed mild dyskinesias, some so mild that they had not yet noticed them themselves, although the consultant might observe perhaps a slight wiggle of the leg during the assessment session. By identifying the baseline characteristics and symptoms of the newly diagnosed patients, the team is building evidence to identify predictors of poor outcomes for patients.

The parallel study of carers aims to describe the impact of caring for someone with Parkinson's over time and to identify factors, for both patient and carer, which predict the carer prognosis. They used the Crossroads ABC scale, which includes factors such as inconvenience, disturbed sleep, physical strain and upsetting behaviour, to ask carers to assess the stress or disruption to their lives at the time of initial diagnosis and after three years. At this point, for almost all the categories, the majority of carers are reporting that they are 'not at all' stressed. The one exception is the question about whether the person with Parkinson's has changed: only 34% said that was not a concern at the outset, and three years later, only 26% were responding 'not at all'.

This ongoing research, which has received considerable funding through Parkinson's UK and is currently funded to 2016, is collecting valuable information about how motor and non-motor symptoms develop, about the development over time of the side effects of medications and how Parkinson's affects quality of life and independence for both patient and carer. The team's detailed findings aim to help healthcare professionals make better decisions about treatment and provide better information for all those whose lives are affected by Parkinson's. Carl also outlined plans for the future, including further follow-up of the cohort over time; further analysis, including systematic reviews of prognosis, prognostic modelling and analysis of carer outcomes; and a collaborative project to pool data with colleagues in Sweden, Norway, Cambridge and Newcastle engaged on parallel research.