



Participant Feedback from Service Evaluation: "Exploring the experience of finding out you have parkinsonism: What helps at this time?"

This leaflet provides a summary of the findings of the above survey, which was distributed during the summer of 2013. Responses were collated in the autumn of 2013 and re-analysed in the winter of 2013 due to additional responses being received. **Thank you** to all who took the time to complete our survey. We really appreciate you sharing your experiences.

Demographics

Surveys were provided to people with a diagnosis of parkinsonism, who were attending appointments with the Parkinson's Nurse Specialist, Neurology, Medicine for the Elderly Parkinson's Specialist or Clinical Psychology services. We received 32 responses overall; of these 23 reported receiving their diagnosis of parkinsonism within NHS Lothian secondary care services. In order to evaluate patients' experience of receiving this diagnosis within NHS Lothian secondary care services, only their responses are reported below. However, all responses were considered in a lengthier report developed for a university project; thank you to all who responded.

The average age of respondents who received their diagnosis within NHS Lothian secondary care services was 71 years; 61% of these respondents were male. Their duration of diagnosed parkinsonism ranged from 0-16 years, with the mean duration being 6 years.

Experience of clinician at diagnostic appointment

Participants' reported experience of the clinician providing their diagnosis was positive. All participants indicated that the professional providing their diagnosis was at least one of the following three characteristics: *understanding*, *sensitive* or *respectful*. Over half endorsed all three of these qualities for the clinician providing their diagnosis. Most participants (87%) described the length of their diagnostic appointment as "*about right*" and almost all (91%) felt they could ask questions during their appointment.

Information provision

Just less than a quarter of respondents would have liked to have received more information about their appointment prior to attending. A finding of particular concern was that over a quarter of participants did not report being told information about their condition. Just over half of respondents received written information and/or a website address; in all but one case this was supplementary to information provided verbally. Just over a third were given a contact name in case of future queries.

The majority of all respondents who did receive information reported that they understood all or most of it (90%). Just over half of respondents described the information they received as "excellent" or "good", while around a third described the information provided as "adequate". Around two-thirds thought the amount of information received was "about right"; with the remainder reporting that they would have liked to have received more information.

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Support

Around three-quarters of participants were aware that they could bring someone to their appointment. Just over a third of those who attended alone had not been aware they could bring someone. Over half were asked about what support they had from family or friends. The majority of respondents (81%) were informed about a support group that they could access. One quarter of participants were told how their family/friends could access support.

As *all* participants were current patients in NHS Lothian secondary care services, the experiences of support experienced by *all* participants will next be reported. A high proportion (86%) of all respondents had used the Parkinson's Nurse Specialists service. Of those who had, all reported that they had found the service to be at least one of the following three characteristics: *understanding*, *sensitive* or *respectful*, with almost half reporting that they found the service to be all three of these. Half of *all* participants reported having found other services to be helpful; these included other health professionals along with exercise classes and groups specifically for people with parkinsonism.

Decision/Appointment Navigator

The role of a "Decision Navigator" was introduced. This is a member of staff who meets with you before your appointment to talk through what you would like to discuss at their appointment. They can then attend the appointment with you and take notes, then sit with you afterwards to talk through what was discussed. Over half of *all* respondents, and of those diagnosed within NHS Lothian secondary care services, reported that they would have liked a Decision Navigator when they were diagnosed. One theme arising from comments provided by respondents is that this would help them prepare for and process their diagnosis. This would also have met the needs of participants who wished for more information prior to their appointment and wanted to talk to someone afterwards. The final theme arising was that where participants did not need this, this was either due to the service having been good enough, or due to their own resources, such as support from others or describing being able to manage without this role. Some commented that if they did not have these resources, this role would be useful for them too.

Suggested implications for practice

The wide range of participants' duration of diagnosed parkinsonism means these responses do not allow a thorough evaluation of secondary care services in NHS Lothian in their *current* form (e.g. within the last two years). However, the responses have enabled us to explore whether (over the last 16 years) these services have been providing diagnoses in a way that would comply with current recommendations.

The findings of this service evaluation suggest that information provision needs to be improved to meet current guidelines (NICE, 2006; SIGN, 2010), ensuring that both verbal and reliable written information is provided to all receiving a diagnosis of parkinsonism. Support options for the family and friends of those receiving this diagnosis could also be discussed more frequently. Trialling the use of a "Decision Navigator" or similar role, tailored to the needs of those receiving a parkinsonism diagnosis (e.g. "Appointment Navigator"), appears to be an effective way of meeting current recommendations regarding delivering a diagnosis and would be welcomed by a large proportion of patients. It would also be helpful to inform and encourage patients to consider bringing a relative or friend to their appointment, if they wish.

The positive descriptions of clinicians, both those providing a diagnosis and those offering follow-up support, suggests combining these improvements with clinicians' competent interpersonal manner may help patients' future health-related quality of life to be enhanced (Global Parkinson's Disease Survey Steering Committee, 2002).

Thank you to the Parkinson's Nurse Specialists, Neurologists and Medicine for the Elderly Specialists in NHS Lothian who supported this study and to the Edinburgh Parkinson's Research & Education Fund for funding the study. For further information or to access the full article regarding this service evaluation, please contact Heather Langham (Trainee Clinical Psychologist) at: heather.langham@nhs.net