PARKINSON’S DISEASE SUPPORT WORKERS ADVISE ON SYMPTOM CONTROL

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Introduction  The symptoms of PD vary but with no cure, people with advanced disease experience distressing symptoms, such as motor complications, dementia, depression, pain and gastrointestinal symptoms which can be difficult to manage. There are many unmet needs such as lack of information, ad hoc delivery of services and a lack of preparation.

Aims & Methods  To investigate the palliative care needs of people with Parkinson’s Disease as perceived by support workers. Semi structured interviews were undertaken with seven PDUK support workers. With permission interviews were audio recorded, transcribed and analysed using content analysis. Demographic variables were recorded.

Results  Participants included two information and support workers, an information manager, a branch and voluntary support officer, a manager, a service development officer and an education and training officer who provide advice to people with PD. Seminars with nursing home staff and in-service GP training sessions are held to increase understanding of PD and its symptoms such as ‘freezing’. The participants stressed the importance of clients’ PD medication timetable when in a hospital or nursing home settings. They also advocate for more nurse specialists and for early referral to therapists for clients to learn how to deal with symptoms and improve their quality of life.

Conclusion  People with PD can experience distressing symptoms both physically and psychologically. Increasing the knowledge and understanding of their health professionals regarding PD symptom control and medication effects within a palliative care approach would help alleviate their distress and increase their quality of life.