

## ***'Just Invisible'***

### **Report Synopsis on living with the Advanced Stage of Parkinson's Disease**

#### **Background/ objectives**

The more advanced stages of Parkinson's disease have received little attention outside the clinical field with the result that there is a wide information gap about people's needs at this stage of the condition and the needs of their carers. This arises in part because of the problems in calculating the number of people affected by this stage of the disease. Suggestions range from 20 to 50% attending outpatient clinics but these are simply estimates. They do not take into account those who are not currently attending hospital clinics and those in long term care; these estimates also do not allow for the under-diagnosis of advanced stage Pd, particularly amongst the elderly.

Having identified people at this stage of the condition as a priority for additional support and information, the Parkinson's Disease Society, supported by the Wolfson Trust, commissioned a research study looking at the needs of people living with and caring for Parkinson's in the advanced stages of the disease, and exploring the impact of strategies for meeting their needs.

The primary purpose was to produce detailed evidence from those living with advanced stage Parkinson's that would lead to improvements in the quality of life for people living with and caring for Parkinson's disease at this stage through:

- § Enabling a better understanding of the impact of this stage of the disease
- § Developing an understanding of the challenges faced by people living with advanced stage Parkinson's and their support needs
- § Analysing the responses of those taking part in the study to challenge and improve where necessary current practices
- § Shaping future management of this stage of the condition

#### **Methodology**

The project was conducted by an external researcher <sup>1</sup> in collaboration with PDS staff and adopted a questionnaire approach, a small number of which were followed up with interviews. A total of 443 postal questionnaires were completed and 27 interviews conducted over a period of 18 months. The project design encouraged carers to complete separate surveys from their person with Parkinson's.

This represented:

- § 217 people with advanced Parkinson's
- § 210 carers
- § 16 former carers

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<sup>1</sup> Sue Thompson

The sample included members and non-members of the Society. Of the 54% members, 26% were from PDS Branches, 17% volunteered through The Parkinson magazine and 10% came through PDS Community Support Workers. 13% came from Press coverage.

The profile of the sample population is:

- § 29% were under 65 years
- § 39% were aged between 65 and 75 years
- § 32% were over 75
- § 89% lived in their own or a relative's house
- § 11% were in residential or nursing care

Despite vigorous recruiting attempts, only 8 respondents came from a Black and Ethnic minority background. Great effort was also taken to achieve geographical coverage of the UK, using census population data.

### **Areas focussed on**

The questionnaire focussed on seven key areas affecting quality of life:

1. Health and issues of daily living
2. Formal and informal support
3. Knowledge of services and service access
4. Quality of support and service
5. Information
6. Aspects of caring
7. The future

### **What is Advanced stage Parkinson's disease**

There is currently no clinical consensus regarding what constitutes 'advanced stage' Parkinson's disease and so defining advanced Parkinson's can be complex and difficult. Current practice is based on a spectrum of models from a 'care pathway' model<sup>2</sup> to a list-based approach including non-clinical features.<sup>3</sup> The physical and psychological challenges present are variable and individual. The experiences of Parkinson's are unique and individual; symptoms vary, responses to medication vary, disease progression is unpredictable and the fluctuations experienced are individually unique. Based on established clinical models the project adopted a working definition of advanced stage Pd as experiencing two or more of the following features:

- § Drug treatment is no longer as effective
- § an increasingly complex regime of pharmaceutical treatments is needed
- § 'off' periods

<sup>2</sup> MacMahon DG, Thomas S 1998

<sup>3</sup> Jahanshahi, 1998

- § dyskinesias
- § mobility problems and falls
- § swallowing problems
- § psychiatric signs (depression, anxiety, hallucinations, psychosis) are present
- § reduced independence, need for help with daily living
- § a recognition that the condition has become less controlled and less predictable

### Key findings:

#### 1. Health and issues of daily living for people with Parkinson's disease

- § Over three-quarters reported major walking difficulties
- § 93% reported problems with fatigue and with balance problems
- § 81% reported problems with falls
- § Some physical problems such as incontinence were particularly devastating for both the person with Parkinson's and the carer since they are often responsible for much additional anxiety, isolation and necessitate considerable need for support and help. Indeed 66% described bladder problems of which a number of respondents made a clear link between continence difficulties and depression, and this is clearly an important area that is currently under investigated.
- § 81% reported communication problems
- § 93% experiencing problems with writing
- § 73% experienced dyskinesia
- § 71% had difficulty with tremor
- § 70% reported pain
- § 69% with drooling difficulties
- § 69% with memory difficulties
- § Both people with Parkinson's and their carers reported high levels of physical, social and emotional isolation and stress – nearly 90% of people reported depression, frustration and anger; these figures are also supported by carers' evidence.

#### 2. Formal and informal support

- § Service provision was rated as poor in 41% of the responses. Where there was access to a Nurse Specialist (PDNS) better co-ordination and regular reviews were more likely to occur. Those without this specialist support reported feeling alienated and isolated. Some respondents considered that their access to services diminished as the disease advanced.
- § For the majority of the group, care from a family carer was the normal pattern but some were also (or in a few cases solely) in receipt of outside help and support, provided by statutory services, voluntary services or under a privately paid

arrangement. Nearly a half of carers had looked after their person with Parkinson's for over 10 years and 10% reported being a carer for over 20 years.

- § For those who are in touch with statutory services, only a minority expressed a high level of satisfaction with the services they received.
- § For many people, remaining in their own home was of paramount importance, yet the scope for alteration to maximise its capability was an anxiety. Access to aids and equipment to facilitate independent living and the availability of adaptations to the home environment were fragmented and subject to a lengthy period of assessment followed by delays in completion. Advice on suitability was often lacking and a quarter of respondents had never seen an Occupational Therapist and 39% reported having no co-ordinator to guide them in accessing services.
- § Some respondents self-funded the equipment but experienced difficulty in obtaining devices to support their individual needs (which frustrates the policy of maintaining more people in their own homes). There were additional concerns over financial constraints, viability and safety.

### 3. Information

- § Information-provision is a broader question than simply ensuring that knowledge is available, accessibility and the mode of delivery are crucial aspects, and the boundaries between information and advice are often blurred for people with Parkinson's and carers. Appropriate timing of information giving is essential, and the diagnosis period, which is the usual point at which information is made available, is not suitable for most people.
- § People with Parkinson's would particularly have valued more information on Parkinson's itself, medication and side effects, the later stages of Pd and service access and content.
- § Carers shared the above needs but also highlighted information/advice on practical caring and on mental health issues and many felt their needs for information and advice on emotional aspects of caring had been ignored. Professional carers also emphasised the need for more information and better understanding of Pd and on caring for people with the condition.
- § A third of respondents reported that financial costs were a worry to them. Access to financial advice and information especially about the benefits system is reported as extremely important and some respondents were unclear about where to find this.
- § Evidence suggests that the information needs about the later stages of Pd are complex and require handling with great sensitivity in terms of the timing, content and detail. Many respondents wanted practical help and advice as well as information.
- § Many indicated the need for personal or "face to face" information support
- § The selection and access to residential or nursing care also raised fears: many reported feeling unsupported in making choices. Indeed, their experiences of such care often arose from crisis referrals and were not viewed favourably. For many the financial implications of such choices and for caring at home placed additional anxiety and burden on them.

#### 4. Carers' needs

- § The burden of caring on family carers was significant and is often more demanding than at the early stages of Parkinson's disease. The task usually involved intimate personal care and at times they had to deal with emotionally and psychologically difficult issues. 45% of family carers had been looking after the person for over 10 years and 10% for over 20 years. For some carers the sense of isolation was intensified by changes in the nature of the relationship with the person with Parkinson's and their apparent withdrawal from previous responsibilities.
- § Over half (59%) of carers spent most or all of the day caring for the person with Parkinson's and 78% of carers reported that they were up to help at least once a night – for 16% of all carers this was more than 3 times per night.
- § Almost three quarters of those questioned considered their own health had been affected and 71% reported that it had affected their own mental and emotional health. Many carers felt under considerable stress due to the demands on them and having to manage a fragile situation.
- § Many felt that outside support and services were unable or unwilling to meet the needs of the person for whom they were caring and were ignorant of their own needs as carers: some described services as “chaotic” and there were suggestions that services in some areas were almost wholly crisis-led. Good quality support was crucial to the well-being of both the person with Pd and the carer, when provided it reassured the carer that some at least of the responsibility for care was shared and it also reduced anxiety and stress.
- § Carers' organisations and the Parkinson's Disease Society were cited as important sources of help for a number of carers but poor access to alternative care for the person with Pd was a major barrier for a significant proportion. What many carers said they wanted was more informed understanding and support and they stressed that they needed personal contact with a professional – this is at least in part an indication of the degree of isolation felt but it would also have been more appropriate for the emotional as well as the physical support they required.
- § Only a quarter of family carers in the project had received an assessment of their needs.
- § Accepting the need for outside support in the home or alternative accommodation was often a difficult decision to reach, and some carers would have liked help and advice with this decision.

#### 5. Respite Care

- § Knowledge of the services offering respite care was in some cases low. Only 19% of the respondents had been offered a period of respite care in the past 12 months.
- § Demand for respite care is an area of unmet need in many parts of the country. An indication of the high level of potential need for respite care is evidenced by the 30% of people with Parkinson's and 54% of carers who stated that respite care would be useful to them.
- § Access to respite care is low due to poor service information and a lack of local available appropriate facilities.

- § As Parkinson's progresses respite care provided in the past will become unsuitable.
- § Some respondents found home based respite care more appropriate both for themselves and for the person with Parkinson's to maintain a routine and to facilitate independent living.
- § Both respite and residential or nursing care had often proved inappropriate in meeting respondents needs and this meant they were unwilling to consider this option in the future despite acknowledging a clear need.

### The future

- § Both people at an advanced stage of Parkinson's and their carers reported serious concerns about the future, whether this involved further deterioration of their Parkinson's or anxieties about future support. Such concerns were exacerbated where current experiences of outside support were poor. Levels of stress and anxiety had been raised for some contributors by the apparent failure of statutory services to meet their needs, or even to appear to give such needs serious consideration.
- § Nearly one half of all respondents reported that they had had no opportunity to talk about the future; people with Parkinson's expressed great anxiety about future progress of their condition and future care provision.
- § Carers' concerns were closely related to the fragility of the current situation and the consequences of even slight changes to their situation in the immediate future.

**It has emerged clearly from the study that services should be designed in the future to address the whole spectrum of care and support required by people in the advanced stages of Parkinson's and their carers. The services described mirror the NSF for Long term conditions Quality Requirement 9, where it is stated that "people in the later stages of long term neurological conditions are to receive a range of palliative care services when they need them to control their symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care".**

### Meeting the needs of those living with Advanced stage Pd - Conclusions:

Advanced Parkinson's disease is a complex stage of the disease that exacts a heavy physical and psychological toll on those living with it. Many of those responding were living in extremely fragile situations with little access to support or information.

For their quality of life to be the best possible in their terms, people with advanced stage Parkinson's (and carers, where appropriate) require regular medical assessment and review from specialist services that are co-ordinated and informed. Improved access to a PDNS, allied health professionals and to primary care staff is needed. A crosscutting theme from the project is the need to focus on the stage of the condition rather than assuming that the difficulties are age-based. Services have to be flexible, reliable and view the person and their carers' needs comprehensively.

More information was wanted about the disease, the medications, the financial support and the support networks that are available. This was needed continuously in a variety



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of formats other than just in writing. Many respondents wanted the support of face-to-face information giving and valued this highly.

Better understanding of the disease at this stage by all involved would ease the frustrations and feelings of isolation and the specific concerns highlighted in the study. There are real fears about the future but future planning and support are rarely offered or met.

**References:**

Jahanshahi M, (1998) Parkinson's Disease: A Self-Help Guide for Patients and their Carers. London: Souvenir

MacMahon DG, Thomas, S (1998) Practical approach to quality of life in Parkinson's Disease Journal of Neurology 245 (Suppl) S19-22

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