|  |  |
| --- | --- |
| **Title** | |
| McLaughlin D, Hasson F, Kernohan WG, Waldron M, McLaughlin M, Cochrane B, et al. Living and coping with Parkinson's disease: perceptions of informal carers. Palliat Med. 2011;25(2):177-82. | |
| Agreement | 413/1020 |
| Final Agreement | 607/1020 |
| **Agreed** | |
| Owing to the difficulties in making a clinical diagnosis of PD, carers recalled the diagnosis period as something that was often difficult, with confirmation frequently delayed. They recalled frequent tests and many visits to the General Practitioner (GP) without a satisfactory outcome. When cases were referred to a neurologist, there was often a lengthy wait and many carers found the experience unsatisfactory.  Whilst the role of the GP was highly valued by all, some believed that their GPs lacked an in-depth knowledge of the condition and its treatment. Therefore, carers placed greater emphasis on accessing the neurologist for continued medical care, yet delayed or irregular medial reviews with specialists, combined with the lack of a continued and co-ordinated approach between and across service providers (both statutory and voluntary), appeared to have a negative impact on the person with PD and on the carers. For example, carers perceived that their relative’s condition and medication were not adequately monitored and this resulted in inadequate symptom management (i.e. constipation, fatigue and stiffness). In addition, communication with and access to health and social care professionals, such as social workers or occupational therapists, were not evident or linked to diagnosis and were often delivered on an ad hoc basis. This resulted in some relatives and carers not being aware of accessible services, until the development of a crisis.  *I think sometimes one hand doesn’t know what the other hand is doing . . . because I mean I have phoned up about things and its pass-the-buck sort of thing (IC7) Qcarer*  Carers commented that, as the illness progressed, they gradually provided more physical, social and emotional support to their relative. Tasks undertaken ranged from providing personal care (i.e. feeding, bathing and dressing) to managing and administrating medicines, to assistance with mobility and transport.  All the carers commented on the lack of information provided following diagnosis. Specific information needs were identified, such as the progression and effects of PD, medication and its side effects and advances in treatment to help them prepare for the future. Information from health and social care professionals was felt to be patchy and not forthcoming, which led carers to seek information on the internet, from other people with the condition or elsewhere.  *Yes yes we would use the internet a good bit and also there are a lot of leaflets that they [PDUK] publish (IC1) Qcarer*  *Go round finding out of the people (PDS Group) what drug they are on and if I see any improvement. But then I am able to talk to them (IC5) Qcarer*  Whilst some carers wanted to know everything about PD at the start, others did not want to know  too much information in case they or their relative could not cope and become depressed  There were difficulties accessing information about entitlements, benefits and equipment. Most were not aware what help was available, to what they were entitled, or whom to contact and were unsure how to complete the necessary forms, viewing the process as very time consuming. This resulted in some not even claiming for support with others only finding out by chance what was available. Those who did apply for assistance found requests for help rejected, which caused them further upset and frustration.  *Benefits! (we) knew nothing about that at all. We lost 4 years of benefits and I just happened to find out about the way about them (IC18) Qcarer*  Many condemned the lengthy timeframe to obtain and access supportive equipment for people with PD. Consequently, this resulted in many carers paying privately for trained carers to assist with activities of daily living, equipment and respite relief, adding to the financial burden of caring. | |