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| **Title** | |
| Hasson F, Kernohan WG, McLaughlin M, Waldron M, McLaughlin D, Chambers H, et al. An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease. Palliat Med. 2010;24(7):731-6. | |
| Agreement | 469/725 |
| Final Agreement | 598/725 |
| **Agreed** | |
| However, this goal was prevented by a lack of access to domiciliary palliative care services such as hospice care. Few carers were fully aware of these services, with many viewing them as being predominantly for patients with cancer at the end of life. It is highly likely that this contributed to a failure to access such help at home.  *‘It’s only for cancer [The Hospice], isn’t it?’ (FC11) Qcarer*  Findings revealed that access to palliative care and clinical services was uncoordinated and patchy, with carers explaining that they had accessed them on an ad hoc basis. Carers had to actively seek out information and access services on the patients’ behalf. All were frustrated that professional care was not in place for patients and carers at the start of the disease trajectory.  In addition, some carers were confused over the role boundaries and duties of the health and social care professionals involved. One carer recommended a specific multidisciplinary team be established to deal with neurological illness.  *‘Either you could get a complete multidisciplinary team, either employed in an area to cover all neurological illnesses, or a team to cover one specific illness for maybe a larger area. Because there seems to be a vague boundary between the responsibilities that one person has and the responsibility another has. They just don’t seem to work as a team or have any team effort as such. You are nearly taking pot luck with each one in turn.’ (FC15). Qcarer*  The lack of signposting to services resulted in some patients not obtaining help from allied health professionals such as physiotherapists, occupational therapists or speech and language therapists, even though carers felt this would have been beneficial.  While specialists were seen as invaluable, accessing them was problematic with patients and carers facing lengthy waiting times. When they did meet, the quality of the interaction between the specialist, patient and carer was variable with meetings brief, focusing on medication, with little or no psychological support or signposting to other types of services. All carers voiced the need for regular surveillance of the patients’ needs by specialists.  *‘The neurologist saw him every six months and agreed the tablets; they didn’t have a lot of time.’ (FC10) Qcarer*  *‘She [PDNS] would have helped to explain things afterwards to you, if you didn’t fully pick it up at the consultation itself.’ (FC15). Qcarer*  Many carers relied upon their GP for help. GPs were highly rated, especially when they made home visits or when they accessed information on the carer’s behalf.  Some carers gave examples of a lack of awareness and detailed knowledge of the disease among health and social care professionals including GPs. They thought this may have impacted negatively on the patient’s health.  Some carers gave examples of a lack of awareness and detailed knowledge of the disease among health and social care professionals including GPs. They thought this may have impacted negatively on the patient’s health.  Moreover some felt there was a clear lack of communication between the primary and specialist health care providers with the carer having to act as a go-between. One said:  *‘. . . it was frustrating, very frustrating because you were the liaison with the health people, with the GP and you were at them to constantly to go back and say this is not working.’ (FC2) Qcarer*  Former carers agreed that they should have been provided with a more integrated care package, regular access to specialist practitioners with clear signposting to other services and information. Carers also stated that they wanted information to help them fulfil their caring role, with specific advice and training available | |