|  |  |
| --- | --- |
| **Title** | |
| Fox S, Cashell A, Kernohan WG, Lynch M, McGlade C, O'Brien T, et al. Palliative care for Parkinson's disease: Patient and carer's perspectives explored through qualitative interview. Palliat Med. 2017;31(7):634-41. | |
| Agreement | 376/625 |
| Final Agreement | 376/625 |
| **Agreed** | |
| There was an overall lack of information at diagnosis. Some participants were missing basic information about PD, even to know that it is incurable. Some participants would have liked all of the information up front to prepare for advanced illness:  *I wanted to know, what I wanted to ask … is there a progression, is there a time scale … some people mightn’t want to know about that at all, but I would prefer to know, so you can deal with it then, and you can be prepared for it. (PwPD 10)*  PwPD and carers were sometimes unsure of what services or supports were available and/or didn’t know how to access these. Most who were experiencing advanced disease highlighted the importance of having sufficient and timely information to adapt homes, contact relevant services and prepare emotionally  Carers found it difficult making tough decisions about the care of their loved one and would value support:  *I found it difficult making the right call, whether to call the doctor or to take him in [to hospital], judging whether he was going to be ok, things like that. When you have no experience, when you are going through it for the first time and you are trying to find your feet, I found that very stressful. (Carer 8)*  Limited and sporadic contact with healthcare teams left some PwPD and carers feeling ‘alone’ facing their illness; *PD is ‘a one-man show, and anything I got I got it myself’ (PwPD 7).*  Participants felt unsupported when meeting different HCWs at every clinic or hospital visit and felt that support ‘dropped off’ when they returned home following a hospital or respite stay. Many participants perceived that their doctor was only interested in their medication needs, overlooking social and psychological needs which were often more distressing.  Poor cohesion between services, and uncertainty about the available support services caused frustration for participants, impinging on carers’ ability to care for the PwPD:  *The doctor, he promised us everything, he promised us loads of home help, it isn’t available, it just isn’t available, we were actually very very lucky to even get the one hour five days a week, that’s what we were told and there was never a question of coming in again during the day, that was never going to happen. (Carer 8)* | |