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| **Title** | |
| Read J, Cable S, Lofqvist C, Iwarsson S, Bartl G, Schrag A. Experiences of health services and unmet care needs of people with late-stage Parkinson's in England: A qualitative study. PLoS One. 2019;14(12):e0226916. | |
| Agreement | 634/1630 |
| **Agreed** | |
| Once no longer physically able to attend specialist hospital outpatient clinics some of them described being formally discharged to community services, whereas others just failed to attend as they felt that little more could be done for them and any benefits did not justify the difficulties attending:  *“I can’t get to the hospital*, *because of setting it all up*. *The size of the car*, *couldn’t’ get in the taxi because it had seats*, *where they take the ramps up and sit there*. *Those are very expensive”*.  *(Participant: 1010) QPwP*  Once unable to attend hospital outpatients appointments the participants described becoming reliant on their GP and PDNS for management of symptoms, including declining physical ability, fatigue, pain, constipation and urinary tract infections, as well as for the limiting age related comorbidities such as arthritis that several experienced. Regarding the latter, they experienced a lack in coordination and continuity of care for their multiple symptoms and comorbidities, which was seen as a particular challenge given the increasing difficulty of attending multiple appointments:  “*Trying to coordinate doctor*, *doctors*, *nurse*, *neurologist*. *All working on different things*. *A second thing I’d change would be trying to see the same doctor twice. All a bit disjointed. Like a jigsaw.” (Participant: 1094) QPwP*  Several of the participants at stage 4 described their focus on maintenance of current functioning and prevention of further decline by ensuring a healthy diet and attending singing and exercise classes arranged by local multidisciplinary centres offering Parkinson’s specific facilities and courses, also including information about symptoms, finances and signposting to other relevant services:  *“and there’s dietician*, *yes I’ve had a dietician there*. *And I’ve been back there again recently*, *few months ago*. *The consultant referred me*, *losing weight and I was*, *I was likely to lose weight but they’ve put me on a diet me so I’ve put on another six pounds*. *So I*, *I’ve been steady for the last six months.” (Participant: 1038) QPwP*  **Needing to fit into the system is detrimental to normality, independence and sense of self.** Many examples were provided of organisational structures shaping the contact between the participants and health professionals and care providers. This included whether GPs carried out home visits and the visit schedules of care providers and supply deliveries:  “*They don’t always turn up*. *And they don’t give you precise times*, *so you’re gonna have to stay here the whole day waiting for somebody to come and deliver something.” (Participant: 1059) QPwP*  Similarly, there were descriptions of having to ‘fit in’ to the busy, inflexible care structures when admitted to hospital. Ward routines did not always accommodate the needs of Parkinson’s, for example, where timing of drug administration was dictated by ward routines and medicines were not understood or given at the correct time:  *“One of the problems was with Levodopa*, *was how you*, *you peak at certain times and drop off the next time and the challenge is to be on an even keel*, *in* [hospital] *they couldn’t read the instructions on the bottle*, *some of them*. *Not sure they gave me the right amount*, *right time.”*  *(Participant: 1094) QPwP*  Such institutional inflexibility was also experienced in care homes where participants experienced that they had to ‘fit in’ to the routine for personal care, meals, drug rounds and even control of room lights or heating:  *“I am woken up at seven for the first lot of tablets*. *The second lot come at nine*. *A carer will come at about ten to start to get me up*, *washed on the loo and dressed*. *So that I might be given breakfast at 11*:*30–12*:*00.” (Participant: 1055) QPwP*  Although not necessarily overtly told that ‘nothing more can be done’, several participants perceived that to be the case, reportedly after completing physiotherapy courses without physical improvement, lack of symptom improvement despite medication changes, and reduced involvement with health professionals due to limited availability of PDNS and OT’s, and GPs  unable to do home visits:  *“and er I begin to think well ‘what’s the point*?*’ because I stay on the same medication*. *So long*, *and nothing’s changed*. *Well I think there’s just not anything else they can do*. *It’s just a question of how long I’m going to be here for and how am I going to cope*. *And that’s it really*. *I don’t think there is anything anyone can do.” (Participant: 1106) QPwP* | |