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| **Title** | |
| Den Oudsten BL, Lucas-Carrasco R, Green AM. Perceptions of persons with Parkinson's disease, family and professionals on quality of life: an international focus group study. Disabil Rehabil. 2011;33(25-26):2490-508. | |
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| *‘I have notice this also I do not sleep. Sleep is disrupted, I wake up, I go back to sleep . . . at 7 I have to take the first pill to protect the stomach, and then at 8 I take the meds for the Parkinson. The side effect of the medication affects sleep. Sometimes this affects the QoL’. QPwP*  *You have to take medication several times a day, and, therefore, this influences your daily activities. Fortunately, we have combination preparations nowadays. We do not have to take 25 different drugs anymore’. QPwP*  *‘Taking medicines at short intervals limits the time for my personal activities’. QPwP*  Some persons stressed the importance of their treatment, for example, ‘*if there was a fire in my house I would go for my pills’* (UK) *QPwP*. However, not everyone was completely satisfied with the side effects of medicines. The effect of treatment is not always that steady during the day; persons are not fully functioning then (on/off period), which in turn affects the well-being of persons: *‘tend to have long periods where the pills are not working’* (UK) *QPwP*.  *‘It would be better if medical assessments and appointments looked more at the person as a whole and looked at their home environment to get an idea of care needs. By looking at what the person can no longer do (a more holistic approach)’. (UK) QPwP*  *I have to go to the rehabilitation centre every week. This takes me four hours (and it is only a few kilometres)!’ QPwP*  Another side effect, which was discussed in the Dutch caregiver group, was that some persons became severely disinhibited. Such disinhibition was, for instance, expressed by disturbing urges to gamble or to have sex. Caregivers emphasised that their partners were not used to behave like this; the urges started, when the medication was initiated. Many persons and caregivers reported that they had a good relationship with their neurologist, enabling them to discuss these sensitive subjects. Some participants indicated that as a result, other medication was prescribed and that they thereafter were free of these urges. It was concluded that medication can relieve cardinal features, on one hand, but, on the other hand, can cause new problems.  Persons added a third aspect of how medication has an impact on their QOL by referring to the fact that medication should be used at different time points during the day, a situation that interferes with planning and performing their daily activities. For instance, *‘Taking medicines at short intervals limits the time for my personal activities*’ (Italy).  Although persons can now use combination preparations, persons and caregivers still pointed out that they always have to reckon with the daily use of medication. To illustrate this point, during the (Dutch) focus group session, some persons had to ask for a break in order to take their medication on time.  All patients and relatives agreed that it is not easy to find out what kind of help you can get. One of the patients learned on the focus group that he was in title to get physiotherapy for free, he had Parkinson for 3 years and nobody told him! So what they really wished was an office or something similar where they could get the information they needed!’ (Norway)  *‘Information is scarce, the first visit with the neurologist you might ask questions, but at this moment questions are few. It is true that they told as that they are available for any doubt. We looked and found information on internet.’ QCarer*  However, it seems that it is not always clear for persons and their caregivers to find out what help  you can get (Norway, The Netherlands Spain). One of the persons heard in the focus group that he was in title to get physiotherapy for free (Norway). The knowledge that persons and partners could apply for care within reasonable time when needed is directly influencing QOL. | |