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| **Title** | |
| Haahr A, Kirkevold M, Hall EO, Ostergaard K. Living with advanced Parkinson's disease: a constant struggle with unpredictability. J Adv Nurs. 2011;67(2):408-17. | |
| Agreement | 220/526 |
| Final Agreement | 418/526 |
| **Agreed** | |
| Certain routines around medication is important to have to make sure medication is taken ‘on time’  Living with PD is being deeply dependent on medication  *‘The night before... I have poured a glass of water, found a banana and my medication and put it by the door, ready to take. Usually I wake up at 7 and straight away I take my medication and in within a certain time it will work’ QPwP*  The need for frequent medication and increased dosage became evident, and it became more and more important to get medication on time: *‘As I have to take medication seven times a day, you need to keep certain times, and then you come to accept that you have to stick to those times within a margin of 10 minutes. You can almost set your clock by it’. QPwP*  *When we go shopping downtown, locally… I say to my husband, I don’t want to go at noon, because it is medication-time, and it takes some time before it works … I will stand there like a statue unable to move anywhere. People are looking strangely, they really are, and I don’t like it. Even if people in town know that I am slow …you really don’t feel good… I simply don’t want to advertise for the disease. QPwP*  Medication time – living a fixed schedule. Each day began by taking medication on a fixed schedule, and the whole day depended on medication-time*: ‘Today I live on pills. All our life depends on it. What time of day is it, and what pills do I need…all day, I need to think of when to take my medication’.* *QPwP* Forgetting medication-time meant instant pay-back in terms of immobility.  Some enjoyed the forgetfulness of being preoccupied doing the gardening or being sociable, having a feeling of being able, but the consequences could be serious:  *I like to go to the seaside every day. I am never there for more than half an hour from when I leave the house. And I could live with that, if I only knew that I could trust time. Then it is no trouble. But I get talking to people and forget everything about those rotten pills. And suddenly… I am stuck. QPwP*  ‘*It is awkward. And you cannot plan that in 1½ hour you will be doing this and this, because if the medication doesn’t work, whether it is too little or too much, then you are not well. Everything falls apart. You get an invitation – yes, I might come…right?’ QPwP* | |