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| **Title** | |
| Hounsgaard L, Pedersen B, Wagner L. The daily living for informal caregivers with a partner with Parkinson’s disease – an interview study of women’s experiences of care decisions and self-management. Journal of Nursing and Healthcare of Chronic Illness. 2011;3(4):504-12. | |
| Agreement | 327/1341 |
| Final Agreement | 379/1341 |
| **Agreed** | |
| *Now suddenly it’s me that has to be the protective one. For a long time my husband would not admit that he was sick and therefore refused to take his medicine. I couldn’t understand it, because his job was under threat due to the symptoms and the medicine would help. (informant 8)*  The task of administering medication played a central role in the women’s everyday lives. Most PD medications need to be taken at precise intervals to prevent muscle stiffness, which means that capacity for self-care is reduced. As the disease gradually developed, self-administration of medicine decreased. This woman took the following responsibility:  *My husband can’t remember any longer if he has taken his medicine and I know how important it is, so I’ve quite simply developed a system with different colored egg boxes and an alarm clock. It works really well, but I still have to keep an eye on him. Now and again, on bad days, he can forget why the alarm is going off. (informant 3)*  The women all took on a role in relation to the administration of medicine. Close observation of the partners’ condition was necessary to make the administration possible. The women therefore gave high priority to observation and medicine regulation. They were surprised that their observations were not actively discussed during check-ups at the neurological outpatient department. Their experiences of everyday life were not used:  *My husband sat in the outpatients with the doctor and told how it was going really well and that he didn’t have any side-effects from the medicine. I thought that the doctor must surely know that PD patients often have a memory like a sieve. The doctor didn’t ask how I thought it was going. (informant 9)*  The women expressed that they needed to discuss observations in relation to medicine regulation and find out how they could expect the illness to develop. Therefore, at a later point, they considered calling the outpatient department to seek the advice of health professionals.  This woman was not able to direct others’ attention to her need for support until she buckled under and became both physically and psychically worn out. She was not in receipt of support owing to lack of information about the available support from the health service system. | |