

Keeping a diary

For people with Parkinson's, keeping a diary about how they are coping with their Parkinson's, their medications, and any problems they experience can be very useful. It can also be of benefit for carers to record their experiences of caring. This can be helpful preparation for when you visit a doctor or another health or social-care professional. It can also help you to demonstrate how variable Parkinson's can be for the person you care for and, consequently, how your role as a carer can vary from day to day and, indeed, during each day. Some carers also find keeping a diary provides them with an emotional outlet for their feelings.

What kind of diary should I use?

Whatever suits. There are templates and diaries specifically designed for carers available, or you may prefer simply to write an account of each day in a notebook or on your computer.

What should I put in the diary?

Be as honest as possible and include anything you find difficult that you would like help with. This will be valuable to the doctor or other professional that you give the diary to.

Below is a guide to help you complete your diary. Ignore any questions that aren't relevant to your situation. Include basic information about you and the person you care for – e.g. date of birth and contact details for doctor etc.

ABOUT YOU

- How many hours a week do you care?
Include everything you do; the questions below will help you identify them all.
- Do you have any health problems yourself? Do these affect your ability to do caring tasks? In what way? Does caring affect your health? (Back problems? Stress? Anxiety or depression? Lack of sleep?)
- What other roles do you have apart from being a carer? (Parent? Employee? Child?)
- How does caring affect these relationships and your relationship with the person you care for?

INFORMATION ABOUT THE PERSON YOU CARE FOR

- Who are you caring for? What is your relationship to them?
- How long have they had Parkinson's? What particular problems do they have with their Parkinson's?
- Do they have other health problems that you need to accommodate?
- Think about how they were before they had Parkinson's and how they are now. What has changed?
- What other tasks do you perform? What personal care do you have to provide the person with? Describe what you do to help.

- Can the person you care for be left on their own or do you have to be there to keep an eye on them?
- Does the person you care for have any communication problems? Does this affect your social life? Do you have to be an advocate for them?
- Do you have to be responsible for the person's medication? If yes, what does this involve? (For example, reminding them to take it? Giving it to them and making sure they swallow it?)

HOUSEWORK

Think about the housework you have to do and make sure you include this. Do you have any help with this?

LIVING SITUATION

- Do you live with the person you care for? What is access to and in the home like?
- If you do not live with the person you care for, are there any difficulties as a result? (For example do you live a long way from them? Do you have other responsibilities that limit the time you can give them?)
- Do you have a car? If not, what alternative forms of transport are available to you?
- Do you have enough money to live on, or are finances tight?

YOUR NEEDS AS A CARER

- How is caring for you? Do you find it difficult and feel it will be difficult to continue? Would extra help help you cope?
- What extra help do you think you need? List in order of priority.
- What parts of the caring role do you want to do (if any)? What parts can you manage without help? What do you find particularly difficult? What do you definitely not want to do?

EMPLOYMENT/EDUCATION

- If you work, what kind of work do you do? Part-time or full-time?
- What arrangements are made to care for the person you care for while you are at work? Is this something you need extra help with?
- How easy is it to take time off work in an emergency? Is there anyone who can help the person you care for in an emergency if you are unavailable?
- If you are a young carer, is your education affected by caring? If so, in what ways?

LEISURE

- Do you get any time for yourself? How often?
- Is there something you would like to do that you cannot do because of your caring responsibilities?
- Do you need breaks to help you deal with wider responsibilities, such as attending a school sports day?

Source: Parkinson's UK - Keeping a Diary: For Carers information sheet.