

Keeping a Diary: People with Parkinson's

Keeping a weekly or monthly diary of how you cope with your Parkinson's disease, the drugs you take, the side effects and problems you experience, including any changes in behaviour or emotions, can be very helpful, particularly when visiting your doctor or other professionals. It can also be useful when applying for financial benefits.

When you visit your doctor or other professionals, you often do not have a lot of time to go into detail about how you are. You may see the doctor when you are having a good day but the reality is that most of the time you are finding things difficult and need more help. The diary enables the doctor to see how you have been coping over a period of time and helps to pinpoint areas where you are having difficulties. It may also show them how your abilities can vary from day to day and indicate patterns, in symptoms or effects of medication that need sorting out. You can also use it to record any embarrassing issues that you want help with but find difficult to ask about.

What kind of diary should I use?

We have attached a sample diary and a blank diary sheet that you can photocopy if you find it useful. However, you may prefer to use another kind of diary or simply write an account of each day in a notebook. If you have a computer, you may prefer to keep an electronic diary. Use whatever suits you best. It is helpful if you write details about drugs in red, and problems with movement and other symptoms in blue.

Then you and your doctor can see at a glance if there is any connection between problems with movement or other symptoms and the drugs you are taking.

What should I include?

We have listed some questions below to help you think about your circumstances. However, these are a guide only and if they are not relevant to you, ignore them. Include anything else that you feel is important that the questions do not ask. Again, you may find it helpful to colour-code your entries so that information on drugs is in one colour, symptoms in another, and so on.

About you

- How long have you had Parkinson's?
- What particular symptoms cause you problems?
- What is important to you?
- What would you like to do that you are unable to do without help?
- What are your personal circumstances?
- Do you work? If so, what do you do? Is there anything about your working life you need help with?
- Do you live alone? Or with someone else?

If you live alone:

- Do you have someone who helps you with your Parkinson's who doesn't live with you (for example a daughter or son or friend who does your shopping for you or takes you to hospital appointments) or do you cope entirely on your own?
- What aspects (if any) of living on your own make it hard for you to cope?

The PDS information sheet *Living Alone* has more information that you may find helpful.



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If you are not living alone:

- Does anyone you live with provide you with help and support to manage your Parkinson's (sometimes called a 'carer')? If so, what is their relationship to you? What is their health like?
- Do they get any support? Is there any support they would like?

It can sometimes be helpful for the person with Parkinson's and their carer to complete a diary each, particularly if their needs are being assessed together. There is an accompanying information sheet called *Keeping a Diary: for Carers*. Some people may find it helpful to use the blank diary included with this information sheet to record the person with Parkinson's week on one side and the carer's week on the other.

Communication

- Do you have any problems with communication? If so, what? (Handwriting, speech, facial expression?)
- Sometimes communication difficulties such as poor speech and lack of facial expression can make it harder for people to understand you or get to know you. Tell them what you want to say or what is important for you in your diary.

Drug management

- What drugs do you take, how often and when do you take them?
- Do you need help to remember to take your tablets?
- Can you manage the safety caps on the bottle?
- Do you experience side effects such as 'off' periods during the day or when out and about, or involuntary movements (dyskinesias)? If so, how does this affect your life and your ability to do certain things?

General movement

- Do you have problems with balance or feeling unsteady on your feet?
- Do you experience pain?

Getting up

- Do you have a problem getting out of bed? If so, do you need help? Who helps you? What do they help you with? How do you get out of bed? Do you have problems with initiation of movement? Is your balance poor? Do you have trouble getting the bedclothes or duvet off and on?

Washing/dressing

- What do you find particularly difficult?
- Do you have problems with washing (including bathing or showering) or dressing?
- Can you get in and out of the bath or shower without help?
- Can you dry yourself afterwards or do you need help?
- Can you cut your toenails yourself or do you need help?
- Do you need help with shaving or washing your hair?
- What do you need help with when dressing or undressing? Socks, tights, underwear, buttons, zips, make-up, jewellery, shoes, coat?
- How long does it take you to get dressed or undressed?

In the home

- How well can you move around in your home? Do you ever fall or stumble or get stuck? Are there particular times of the day or particular activities when this is more likely to happen?



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- Do you use any equipment to help you with movement?
- How long does it take to perform movements? What movements do you find particularly difficult?
- When you move do you need to use furniture/door frames for support? Do you need the help of someone else?
- Have you had an assessment by an occupational therapist? If so, did they recommend any equipment or adaptations to help you? If so, what? (Stairlift, stick, rollator, wheelchair?) Do you use them?
- Do you need help with eating or drinking? If so, what help do you need?

Outside the home

- How confident are you about managing on your own when you go out?
- Do you need someone to go with you for reassurance and support?
- Do you get tired easily?
- Do you have problems getting about because of mobility problems?

At night

- Do you need help to turn over in bed at night?
- Do you have to get out of bed during the night to go to the toilet? How many times?
- When you are out of bed at night, does someone have to be awake to help you? If so, what sort of help do you need? Is your balance affected at night and are you unsteady on your feet? Do you get confused or frightened when you cannot get moving? When you get to the toilet, are you able to

stand alone or do you have to hold on to someone or something for support?

Wellbeing

- Do you feel stressed, anxious or depressed? Are there particular things that make you feel like this?
- Do you need emotional support?
- Are there leisure activities you enjoy that you need help with? (Sport or gardening?)
- For many people with Parkinson's, leisure may include visits to shopping centres that are out of town. Do you need help to get there and does someone have to be with you? Do you have access to appropriate transport to do this?
- What about holidays? Do you have a holiday? If not, would you like one? Do you know that specific holidays for people with disabilities are available?

(See the *RADAR Guide for Disabled People: Holidays in Britain and Ireland*, available at the price of £10 from the PDS distribution house Sharward Services.)



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Tel: 020 7931 8080 **Fax:** 020 7233 9908

Helpline: 0808 800 0303. (The Helpline is a confidential service.

Calls are free from UK landlines and some mobile networks)

Email: enquiries@parkinsons.org.uk **Website:** www.parkinsons.org.uk

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Charity registered in England and Wales No. 258197 and in Scotland No. SC037554.

A company limited by guarantee. Registered No. 948776 (London)

Registered office: 215 Vauxhall Bridge Road, London SW1V 1EJ

Revised March 2008

To obtain any PDS resource, please go online to www.parkinsons.org.uk or contact Sharward Services Ltd, the appointed PDS Distribution House, at Westerfield Business Centre, Main Road, Westerfield, Ipswich, Suffolk IP6 9AB, tel: 01473 212115, fax: 01473 212114, email: pds@sharward.co.uk



Example of a diary page	
Day: Wednesday 25 June	
Time	
6am	Out of bed with help.
7am	Levodopa (Sinemet Plus), selegiline (Eldepryl), ropinirole (Requip) Breakfast 7.30am
8am	Washed and dressed with help – can't do buttons up on my own. Tremor in hands makes putting on underwear difficult.
9am	Rested for an hour and read the paper.
10am	Went to Tesco. Had to walk the full length of the car park as no spaces. Felt tired by the time we got to shop so rested in café for 20 minutes.
11am	Began to go off at about 11.30am while still shopping.
12noon	Lunch – needed help to cut food up as tremor very bad because I was off. Levodopa (Sinemet Plus), ropinirole (Requip)
1pm	Started to go on about 1pm.
2pm	Slept one hour.
3pm	Walked in the garden unaided for half an hour.
4pm	Freezing episode.
6pm	Levodopa (Sinemet Plus), ropinirole (Requip) Supper
7pm	Fell in bedroom – fortunately Anne was able to help me up off the floor – cuts on arm.
8pm	Mobility poor.
10pm	Levodopa (Sinemet CR) Go to bed at 10.30. Same problems with clothes as I had this morning.
Night	Woke three times during night, restless legs.



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Diary sheet	
Day: _____	
Time	
6am	
7am	
8am	
9am	
10am	
11am	
12noon	
1pm	
2pm	
3pm	
4pm	
6pm	
7pm	
8pm	
10pm	
Night	