

Keeping a diary – for carers

If you care for someone with Parkinson's, you may find it helpful to keep a diary. This information gives suggestions of what you might want to record.

Why should I use a diary?

You may want to use a diary for different reasons. Keeping details of what you do day to day in relation to your caring role can be a helpful way to find out and keep track of how much you're doing, how you're coping and whether you need any support.

Recording what you do in your caring role can be helpful when speaking to a health professional, such as a Parkinson's nurse. It may help to remind you of things or give a clearer picture of your situation to the person you're talking to.

A diary may also be useful when applying for welfare benefits, as it can demonstrate how Parkinson's affects daily life for you and the person you care for.

Some people find it helpful to keep a diary if they are preparing for a carer's assessment. For information about arranging a carer's assessment, call our helpline on **0808 800 0303**.

What kind of diary should I use?

You can use any kind of diary or notebook to write down what you do and how you feel over the course of each day.

If you have a computer, smart phone or tablet device, you may prefer to keep an electronic diary or use an app.

What should I put in my diary?

About you

There are some pieces of general information which you can include on a cover page. These will be things that never or rarely change. Examples of this might be:

- How many hours a week do you care for your loved one? (Remember to include everything that you do, including washing and cleaning)
- Does anyone else help you with caring? What do they help you with?
- Do you have any health problems yourself? Do these affect your ability to do caring tasks? In what way?
- Does caring affect your health? (Eg back problems, stress, anxiety, depression or lack of sleep)
- What other roles do you have apart from being a carer? (Parent? Employee?)
- How does caring affect your relationships, including your relationship with the person you care for?
- Who gives you emotional support? Do you need more help with this?
- Are you in touch with any professionals or carer organisations who provide you with support?
- Have you registered yourself as a carer with your GP? Have you had a carer's assessment?

About the person you are caring for

- Who are you caring for? What is your relationship to them?
- How long has the person you care for had Parkinson's?
- How does their Parkinson's affect them?
- Do they have other health problems that you need to accommodate?

Include basic information about you and the person you care for such as date of birth, doctor's name and consultant's details.

Diary content

What you write in your diary will depend very much on your own individual situation. You should be as honest as possible and include anything you feel is relevant to you, especially anything you find difficult that you would like help with.

We have listed some questions below as a guide to help you think about your circumstances. These may not be relevant to you and you may prefer to just record changeable things or when something out of the ordinary happens in your day-to-day routine, such as:

- sleeping patterns
- details of hospital visits
- unexpected problems
- 'on'/'off' episodes and effects
- mobility, including freezing episodes
- falls

Think about recording when good things happen too – this may help motivate you during bad periods.

Include anything else that you feel is important. 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.

Not everyone in a caring role will have time to record a detailed diary entry every day – do it when you can, it doesn't have to be every day.

Medication

Are you responsible for the person's medication? If yes, what does this involve? (For example, reminding them to take it?)

Personal care

What personal care do you provide the person with? Describe what you do to help. Do you help with:

- washing, showering or bathing?
- dressing?
- going to the toilet?
- lifting?
- assistance at night?
- eating and drinking?

Housework

- How much housework do you do? (Eg cooking, laundry, cleaning, shopping, managing finances)
- Do you have any help with this?

Housing

- Do you live with the person you care for?
- What is access to and around the home like?
- What condition is the house in?
- Is it a bungalow or do you have stairs? How easy is it for the person you care for to use the stairs?
- Would a different type of housing be more suitable? If so, do you want to stay in the area you live in, or do you have relatives in another part of the country that you would like to live near?
- 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?)

General wellbeing

- Do you provide assistance or help with anything else?
- Can the person you care for be left on their own?
- Do you provide emotional support?

- Do you take them to medical and social care appointments?
- Do you have a car? If not, what alternative forms of transport are available to you?
- Does the person you care for have any communication problems? How does this affect you?
- Do you have enough money to live on, or are finances tight?
- How is your mood? Do you feel you need any emotional support?
- Has your caring role had an impact on your own relationships or social life?

Your needs as a carer

- How do you feel about being a carer? Do you find it difficult?
- What extra help do you think you need? List the extra help in order of priority. For instance, would regular respite care be helpful?
- How would you want this to be arranged? (For example, for a weekend, a week, day care at a day centre, someone to come into your home to provide care?)
- Would a community alarm help?
- Would access to welfare benefits help?
- Which parts of your caring role can you manage without help?
- Do you need more information or training related to Parkinson's?

Employment/education

- If you work, what kind of work do you do? How many days a week?
- What arrangements are made 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? Does your school know your role at home? Would you like your school to know? Is there anything you would like help with? Would you like to meet with other young carers?

Leisure

- Do you get any time for yourself? How often?
- Do you need breaks to help you deal with other things? Have you considered a respite break? How easy is it for you to spend time away from your caring role doing something you enjoy?

More information and support

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at parkinsons.org.uk/nurses

Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email hello@parkinsons.org.uk. We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can also put you in touch with one of our Parkinson's local advisers, who give one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

We also have a self-management programme for people with Parkinson's, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you, visit parkinsons.org.uk/selfmanagement

Our website parkinsons.org.uk has a lot of information about Parkinson's and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at parkinsons.org.uk/localtoyou

Visit parkinsons.org.uk/forum to chat to other people with similar experiences on our online discussion forum.

Thank you

Thank you very much to everyone who contributed to or reviewed this information sheet:

Roisin Coulter, Parkinson's Local Adviser

Gillian Carey, Parkinson's Nurse

Sue Martin, Parkinson's Local Adviser

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

Our information

All of our most up-to-date information is available at **parkinsons.org.uk/information-support**
If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/ordering-resources** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**

Keeping a diary – for carers (FS70/2017)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to [Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ](#), or email publications@parkinsons.org.uk. Thank you!

1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in I care for someone with Parkinson's
 I have a friend or family member with Parkinson's I'm a professional working with people with Parkinson's
 Other (please specify)
-

2. Where did you get this information from?

- GP Specialist Parkinson's nurse Parkinson's UK local group Parkinson's UK local adviser
 Ordered directly from us Call to the helpline
 Other (please specify)
-

3. Has it answered all your questions?

- Yes, completely Yes, mostly Not sure Partly Not at all

4. How easy was it to understand?

- Very easy Easy Not sure Quite difficult Very difficult

5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- It helped a lot It helped a little No change It didn't help It made things worse

6. What is your ethnic background?*

- Asian or Asian British Black or Black British Chinese Mixed White British White other
 Other (please specify)
-

*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

Want to hear more from us?

- I would like a response to my feedback I would like to be a member of Parkinson's UK
 I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

If you've answered yes to any of these options, please complete your details below.

Name

Address

Email

Telephone

How would you prefer us to contact you? Email Post Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at [parkinsons.org.uk/termsandconditions](https://www.parkinsons.org.uk/termsandconditions)

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

Together we can bring forward the day when no one fears Parkinson's.

Parkinson's UK

Free confidential helpline **0808 800 0303**

Monday to Friday 9am–7pm, Saturday 10am–2pm. Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices).

For more information see **www.ngts.org.uk**

hello@parkinsons.org.uk

parkinsons.org.uk



Last updated July 2017. We review our information within three years.
Please check our website for the most up-to-date versions of all our information.
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