

# Monitoring your Parkinson's

**M**any people with Parkinson's find that keeping a diary is a helpful way of monitoring their condition.

## Why is a diary useful?

When you visit your doctor or other health professional, you often don't have a lot of time to talk in detail about how you are. You may also see them when you're having a good day but the reality is that most of the time you are finding things difficult and need more help.

A diary can be an effective way of letting your doctor know what problems you're experiencing, the changes in your condition from day to day or over a period of time, and how well your medication is controlling your symptoms. It can also help remind you of things you want to discuss during your appointment that you may otherwise forget.

You can also use it to record any embarrassing issues that you want help with but find difficult to ask about.

If you are applying for welfare benefits, a diary can also be useful for keeping track of the different stages of the application process. Keeping a record of how your condition affects you will be helpful if you are asked to explain this on a benefits claim form.

## 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. If you have problems writing or typing, you could also record your diary using a mobile phone or recording device (using video or audio). Use whatever suits you best.

It may be helpful if you write details about drugs in red, and problems with movement and other symptoms in green. Then you and your doctor can see at a glance if there is any connection between the two.

If you have a carer, it may be helpful for them to complete a diary too, particularly if your needs are being assessed together.

**Find out more:** see our information sheet *Keeping a diary for carers*.

## What should I include?

We've listed some questions below to help you think about what to write in your diary. However, these are just a guide and if they are not relevant to you, ignore them.

Include anything else that you feel is important that the questions don't cover.

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. You may also want to add the names of professionals involved such as your GP, Parkinson's nurse or specialist.

If you're repeating the same entries every day, then it might be more useful to only record when things change, such as if your symptoms are getting worse or you find it difficult to do certain things for the first time. A diary works best when you try to record the most relevant parts of the day. But naturally there may be some days when you don't feel like keeping a log of what has happened.

## About you

- How long have you had Parkinson's?
- What particular symptoms cause you problems?
- What would you like to be able to do without help?
- 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 (for example a daughter or son or friend who does your shopping for you or takes you to hospital appointments) or do you manage entirely on your own?
- What aspects (if any) of living on your own make it hard for you to cope?

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?

## Communication

- Do you have any problems with communication? If so, what? (Handwriting, speech, facial expression?)

## **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?
- Do you have any difficulties opening the safety caps on the bottles?
- Do you experience side effects such as 'off' periods during the day or when out and about, or involuntary movements (dyskinesia)? If so, how does this affect your life and your ability to do certain things?

## **General movement**

- Do you have problems with balance?
- Do you experience pain?

## **Getting up**

- Do you have a problem getting out of bed? If so, do you need help? Who helps you? How do they help?
- How do you get out of bed?
- Do you have trouble changing your bedding?

## **Washing/dressing**

- Do you have problems with washing (including bathing or showering) or dressing? What do you find particularly difficult?
- 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, stumble or get stuck? Are there particular times of the day or particular activities when this is more likely to happen?
- Do you use any equipment to help you move around?
- How long does it take to perform movements?

- What movements do you find particularly difficult?
- When you move do you need to use furniture or 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 your mobility problems prevent you from getting out and doing things?

## **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, depressed or experience low mood? Are there particular things that make you feel like this?
- Do you need emotional support?
- Do you feel understood and supported by your doctor or other health professionals you see?
- Are there leisure activities you enjoy that you need help with? (Eg sport or gardening)
- Do you enjoy going shopping and need access to appropriate transport to do this?
- What about holidays? Do you have a holiday planned? If not, would you like one? Do you know that holidays specifically for people with disabilities are available?

## 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](https://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](mailto: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](https://parkinsons.org.uk/selfmanagement)

Our website [parkinsons.org.uk](https://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](https://parkinsons.org.uk/localtoyou)

Visit [parkinsons.org.uk/forum](https://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](https://parkinsons.org.uk/donate)**. Thank you.

## **Our information**

All of our most up-to-date information is available at **[parkinsons.org.uk/information-support](https://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](https://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](mailto:publications@parkinsons.org.uk)**

## Monitoring your Parkinson's (FS69/2017)

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](mailto: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

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Address

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Email

Telephone

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**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](http://www.ngts.org.uk)**

**[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**

**[parkinsons.org.uk](http://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.  
PKFS69

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