



Parkinson's  
Disease Society

## Talking to your doctor

This information sheet has been prepared in response to requests from people with Parkinson's disease wishing to get the most out of their visits to their doctor.

### Be prepared

It often helps to make a list of the concerns you want to discuss with your doctor. Try to keep them as brief and specific as possible and put the most important questions at the top of the list.

Think about what you hope to gain from the visit:

- Are there symptoms that you want to discuss?
- Do you think that you need a review of your drugs?
- Make a note of the time and dose of each medication, the length of time it takes for them to become effective, and the results if you have had any change to your medication regimen.
- Would you like a referral to a therapist?
- Has anything happened since your last visit that you feel the doctor should know about? For instance, major life changes such as a house move, bereavement, or other illnesses which might have made your symptom control worse.

If you have particular problems, think about how to describe them before you see the doctor. Try to be as factual as possible, neither exaggerating nor underplaying the symptoms. Don't feel you have to talk in medical jargon either; just use the words that you feel comfortable with.

It may be helpful to complete a weekly or monthly diary of how you have managed, or of your symptoms. This may help you to describe

your experiences or how you feel to the doctor. See the Parkinson's Disease Society (PDS) information sheets *Keeping a Diary: For Carers and Keeping a Diary: People with Parkinson's*.

The more information your doctor has about your condition, the better able they will be to help you and address any worries you have.

If you find it difficult to ask the questions on the list, or find it hard to communicate because of the Parkinson's, give the list to the doctor.

Make sure you have with you any information that the doctor might need. Take with you any glasses or hearing aids that you use, to ensure that you can see and hear as well as possible. If you have communication problems, make sure the doctor is aware of these and any methods or equipment you use to make it easier for you to communicate.

Take with you your tablets in the bottle or packaging, particularly as people with Parkinson's are often on complicated drug regimens involving several different types of tablets. It can be hard to remember the names of each one. GPs whom we consulted said that they found it much easier to discuss the tablets if their patients showed them the bottles or packets of tablets rather than referring to 'small white ones' or 'the ones I take at night'.

### Appointments

It is helpful to check before you make an appointment that any correspondence from the consultant has arrived with your GP. It is especially important to do so if the consultant has changed your drug regime.

Remember that most doctor appointments can be quite short. If you have several problems to discuss, or your list of questions seems



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quite long, it may be best to make separate appointments or to ask for a double appointment.

If your GP or hospital doctor works with a Parkinson's Disease Nurse Specialist, ask if you can talk to them. They may be able to answer some of the concerns you have.

### **Take someone with you**

You may find it helpful to take someone with you when you visit the doctor. They may be able to give you moral support, act as an advocate for you if you find it hard to communicate, or help you remember what was said and take notes for you, particularly if you find it difficult to write.

Let them know in advance what you want from your visit to the doctor so they can remind you if you forget something or ask on your behalf if you get stuck.

However, GPs told us that it is often helpful for them to see their patients alone as well. Sometimes, people are unwilling to admit the reality of situations for fear of upsetting relatives, or find it difficult to ask about sensitive issues when someone else is with them.

A carer or relative may also have concerns about the person they care for that they feel they can't discuss openly in front of the patient. They may find it helpful to write a letter to the Doctor before the patient's appointment. This may also help the doctor to ask appropriate questions.

This is obviously an individual choice, but you could consider alternating between going to see the doctor with someone else and going on your own.

### **In the doctor's surgery**

Be honest. Many people feel that they have to put their best face on for the doctor and

show them how well they are coping, when the reality is quite different. This is natural but it isn't going to help you, as the doctor can only give you the best treatment if they know what is really happening. So don't worry if it is a bad time of day for you. It is good for your doctor to see you when your Parkinson's is at its worst.

Don't be afraid to ask questions. If you don't understand something the doctor has said, ask them to repeat it and make sure you understand before you leave the surgery. You have a right to understand your condition and to ask questions about your treatment. If you are going to get the best from your treatment, you need to make sure you understand what you need to do. Take notes if you think it will help you. Don't be afraid to tell the doctor your concerns – if they don't know what is really bothering you, they can't help you.

Don't be afraid to ask about subjects that you feel embarrassed about. Many people find it difficult to ask about sex or incontinence, for instance. Even if you feel embarrassed, make sure that you do talk to the doctor about anything that is important to you, however embarrassing you find it. You won't be the first person to have asked!

You may find it helpful to write down the answers to the questions and any instructions the doctor gives you, to help you remember when you have left the surgery. If you have trouble writing, ask the doctor to write it out for you.

If you need written information, ask them if they can either supply it or point you in the direction of someone who can help, such as a Parkinson's Disease Nurse Specialist.



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## Medication

If you are prescribed medication, make sure you understand what it is treating and how you are supposed to take it. If you are confused by some of the instructions, ask the doctor for clarification. Your local pharmacist should also be able to provide you with information about the medication you are taking. They often have more time to explain about any drugs you have been prescribed and how the side effects may change or affect you. Make sure the doctor knows about any other medications you are taking, and any vitamins or supplements. Ask them what you should do if you have any side effects from the medication.

Take the medication as prescribed and don't stop the treatment without consulting your doctor. If you feel the medication isn't working, or you are finding the regime difficult to follow, discuss this with your doctor. Complications don't necessarily mean that the drugs aren't effective. You may just need an alteration to your regimen.

Some people with Parkinson's and their carers have suggested that it might be a good idea to see your doctor when the tablets are working well and at the end of the dose, so that the doctor can see both extremes.

Sometimes, doctors use technical language or medical jargon to describe symptoms or treatment. If you don't understand a term, ask them to explain it to you. No one will think you are stupid. It's much better to admit you don't understand than pretend you do and then find you don't know what you are supposed to do when you get home.

The PDS booklet *The Drug Treatment of Parkinson's Disease* provides information on all the drugs that are currently prescribed in

the UK to treat Parkinson's. It also includes a glossary of terms and some helpful 'dos and don'ts' with regard to medication.

## Keep informed

If you understand your Parkinson's, you will find it easier to cope and to make decisions about your care. Keeping informed of developments in Parkinson's will help you communicate with your doctor. The PDS has many information resources to help you, as well as a freephone helpline staffed by nurses 0808 800 0303 **Text Relay:** 18001 0808 800 0303 (for textphone users only) available Monday–Friday, 9am to 8pm (except bank holidays), Saturdays 10am to 2pm.

Ask your doctor how many people they have seen with Parkinson's. Are there any tips they can give you that have helped their other Parkinson's patients?

If you and your doctor can work together to learn about your Parkinson's, then it can often remove your anxieties. They may be interested to know that you have contacted the PDS and what information is available to help them and their patients with the management of Parkinson's.

It is always useful for Parkinson's information to be available at GP surgeries, both for doctors and their patients. You could enquire whether the surgery would display leaflets or a poster about Parkinson's and the PDS.

## Useful resources

The Patients Association  
PO Box 935  
Harrow

Middlesex HA1 3YJ

Helpline: 0845 608 4455

Email: [helpline@patients-association.com](mailto:helpline@patients-association.com)

Website: [www.patients-association.com](http://www.patients-association.com)



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The Patient Association is a National UK organisation that campaigns for patients' rights and provides information to help negotiate health services. It publishes booklets, including *You and Your Doctor*, which provides information on how to get the best from your doctor.

Bloomsbury Publishing Plc 1993. ISBN: 0 7475 12922 or 9780 747 512929

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**Embarrassingproblems.com**

A website that which provides information and advice on embarrassing health problems that you may find hard to discuss with anyone. Includes a section on talking to your doctor about them.

**How to Get the Most from Your Doctor by Dr Jonathan Douglas**

Good communication between patient and doctor is of tremendous importance. Unfortunately, the relationship can be hindered by factors such as fear, embarrassment, anger, frustration, cultural differences and unrealistic expectations. This book explores many of these issues and offers insight and hints on how to improve communication.



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215 Vauxhall Bridge Road, London SW1V 1EJ, UK

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

**Helpline:** 0808 800 0303 **Text Relay:** 18001 0808 800 0303 (for textphone users only)

(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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To obtain any PDS resource, please go online to [www.parkinsons.org.uk](http://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:** parkinsons@sharward.co.uk