

Communication card

When you attend a medical appointment for Parkinson's disease (PD), it is important to make the most of your short time with the doctor. Prepare for your appointment by writing down the questions you want to ask, and noting any important points about your symptoms and treatment that you would like to discuss.

To start you on your way, this communication card provides an overview of some 'Key questions' and 'Essential points'. This is only meant to serve as a guide, as there will be other personal questions you will want to ask but, if it helps, then take the card along to your appointment to act as a prompt.

Key questions

Here are some examples of the questions that you might wish to ask your doctor.

- Why am I taking this medication?
- Why has this medication been changed/added to my regimen?
- How long will I stay on this medication?
- What side effects can occur with this medication?
- Does my medication produce long-term complications?
- I am unhappy about part of my treatment. Can something be done about it?
- I find a certain symptom very troubling. Can this be treated?
- What should I do if I experience side effects with my treatment?
- Now, or in the future, I will need help at home. Whom should I contact?
- What can I do in order to improve my living surroundings, as a person with PD?
- I feel overwhelmed and could do with some emotional support. Can you recommend a local organisation and/or counsellor to help?
- *If you have been recently diagnosed as having PD:* Although I don't currently have serious mobility problems, can I be referred to a physiotherapist for advice on exercises/activities to improve the way that I move now and to prevent problems in the future?
- *If you experience stiffness in muscles and joints, and/or have difficulty with movements such as getting up from a chair, turning in bed or keeping your balance:* Can I be referred to a physiotherapist to seek advice regarding my mobility problems?



Essential points

When you meet with your doctor, there are certain things that are especially important to talk about.

- Describe any symptoms that you have experienced, including whether they have worsened or improved since the last visit, e.g., poor control of movement, stiffness, shaking/tremor, difficulty walking, sickness, dizziness, etc.
- Explain when your symptoms occur, for example, shortly before your next dose, early in the morning, after a certain event/trigger, or in relation to food.
- Discuss all concerns or worries about PD or the medication you are taking – i.e., your opinion regarding PD and its treatments.
- Let the doctor know if you would like a change in your medication.
- Tell the doctor about any other medications you are taking, including any bought over-the-counter.
- Keep the doctor up-to-date on any significant changes in your life – for example, stressful events, or changes affecting your medical routine. These events could influence your symptoms.
- Discuss how people around you are coping with the disease and its treatment.
- Make sure you understand exactly how and when your medication should be taken, before you leave the surgery/clinic. If necessary, write these instructions down, or ask to have them written down for you.

General discussion points

Here are some other topics related to everyday life that you may wish to discuss.

- Posture (standing, walking).
- Sleeping, turning in bed.
- Use of hands (trembling, rigidity).
- Depression and anxiety.
- Tiredness and typical daily activities.
- Diet – eating, drinking, swallowing – and exercise.
- Going to the toilet – delayed or difficult bowel movements, difficulty passing water.
- Skin condition/problems.
- Pain.
- Sexual issues.
- Living situation – transport, housing.
- Talking, writing, learning ability, memory and concentration.

Here are some useful points to help when communicating with your carer/partner.

- Stay calm.
- Be open and honest about PD.
- Be clear about when you need help.
- Discuss your feelings.
- Be patient and understanding, and ask for patience from your carer when movement is slow or frozen.
- Try to focus on areas other than PD.
- Enjoy life together, while maintaining some outside contacts/interests.
- Show your appreciation.