



# **PARKINSON'S DISEASE**

## **Patient Checklist**

Developed in cooperation with

**Nederlandse Vereniging voor Neurologie**

(Dutch Neurology Association)

**Nederlandse Vereniging voor Neuro Verpleegkundigen**

(Dutch Association of Neurology Nurses)

**Stichting Netwerk Gezinszorg**

(Familycare Network Foundation)

**Nederlandse Vereniging voor Logopedie & Foniatrie**

(Dutch Logopaedics & Phoniatics Association)

**Nederlandse Vereniging voor Ergotherapie**

(Dutch Ergotherapy Association)

**Koninklijk Nederlands Genootschap voor Fysiotherapie**

(Royal Dutch Society for Physiotherapy)

**Nederlandse Vereniging voor Verpleeghuisartsen**

(Dutch Association for Doctors Practicing in Nursing Homes)

**Parkinson Patienten Vereniging**

(Parkinson Patients' Association)

## Introduction

Patients can be overwhelmed by the amount of information they may receive at a consultation with a healthcare professional (HCP). This checklist has been developed to help you, the patient prepare as best as possible for these consultations.

We advise you to read the checklist carefully prior to the consultation with your doctor and mark the items of importance to you

It covers subjects that will be discussed during the consultation and it focuses on four stages: examination, diagnosis, care and treatment plan, and the actual treatment itself. It tells you who you will consult at each stage

During the first stage you will consult mostly your GP and the neurologist, but sometimes you may also consult a nurse as several hospitals do provide nurse practitioners at the outpatients' clinic.

The GP or neurologist may also refer you to a physiotherapist, an ergo therapist, a speech therapist, or a remedial Mensendieck or Cesar physiotherapist. The specialist who refers you to a therapist will discuss with you the reason for the referral and help you decide which therapist is most suited to treat you. These therapists will inform you in the same way and since you will not be referred to all the therapists at the same time, these consultations have been grouped under the heading of 'therapists' in the checklist.

Each consultation will address:

- 1 Issues which your healthcare professional (HCP) will inform you about
- 2 Issues / Questions that you want to discuss; you can write these down in the checklist
- 3 - Information that you can provide the healthcare professional with.

You are not the only one who should receive information. The HCP expects you to inform them in return.

This information is important in order to adjust treatment and counselling adequately to each patient's specific situation.

In the column on the left hand side of each page, topics have been noted which are important to discuss.

If you have some topics of your own which you would like to be discussed, you can note them in the column on the right hand side of the page.

This communication guideline has been developed in cooperation with the Nederlandse Vereniging voor Neurologie (the Dutch Neurology Association), the Nederlandse Vereniging voor Neuro Verpleegkundigen (the Dutch Association of Neurology Nurses), Stichting Netwerk Gezinszorg (the Familycare Network Foundation), Nederlandse Vereniging voor Logopedie & Foniatrie (the Dutch Logopaedics & Phoniatics Association), Nederlandse Vereniging voor Ergotherapie (the Dutch Ergotherapy Association), Koninklijk Nederlands Genootschap voor Fysiotherapie (Royal Dutch Society for Physiotherapy), Nederlandse Vereniging voor Verpleeghuisartsen (Dutch Association for Doctors Practicing in Nursing Homes), Parkinson Patienten Vereniging (the Parkinson Patients' Association).

An accompanying communication guideline to the checklist has been developed for HCPs and specialists.

## **The initial consult with the GP**

### **Your GP will discuss with you**

#### **1 Examination:**

- necessity of a physical examination
- additional examination if desired

#### **2 Medical policies:**

- the preliminary diagnosis after taking a medical questionnaire
- GP's advice on the continuation
- possible referral to a neurologist
- your GP will remain your contact for any questions you and your partner might have
- with each new symptom you should contact your GP and not immediately attribute it to Parkinson's Disease or the medication.

#### **3 Information:**

- what the Parkinson Patients' Association can do for you

#### **Other subjects you find important to discuss:**

- information about the disease through leaflets and brochures

#### **Questions you want to ask your GP:**

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#### **Information you can give your GP:**

- your symptoms and problems
- your personal perception of the diagnosis
- your general health
- the medication you are using, including the medication which you can buy without prescription

## **Examination**

### **Your personal notes**

**Follow-up consultation with your GP**

**Your GP will discuss with you:**

**1 Any symptoms or problems you might be experiencing:**

- are these symptoms new or in relation to Parkinson's Disease
- is the medication working adequately, does the actual taking of the medication cause any problems
- is the (advanced) referral necessary

**2 Partner / Volunteer care:**

- does your partner assist you in your daily care
- is it necessary to decrease your partner's efforts and what possibilities are available to do so
- is referral to another HCP / carer necessary
- what is the GP's role when moving (house) or if admission into a care facility is necessary

**Other subjects you find important to discuss:**

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**Questions you want to ask your GP:**

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**Information you can provide your GP with:**

- the symptoms and problems you and your partner experience and any new symptoms
- the effects of the medication

**Care and treatment**

**Your personal notes**

**The initial consult with the neurologist**

**Examination**

**The specialist will discuss with you:**

**Your personal notes**

**1 Your partner is welcome to join the consultation**

**2 The findings of any previous examinations or tests taken elsewhere**

**3 The preliminary diagnosis after taking a medical questionnaire**

**4 The probable (follow-up) examinations:**

- nature and purpose of the examination
- preparation and examination
- perception (pain to be expected)
- results
- risks and complications

**5 If you agree with the proposed examinations**

**Other subjects you find important to discuss:**

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**Questions you want to ask your specialist:**

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**Information you can provide your specialist with:**

- any other symptoms or illnesses you are suffering from
- the effect of the symptoms on you daily routine or working life

## **Follow-up consultation with the neurologist**

**The specialist will discuss with you:**

### **1 The results of the examinations**

### **2 The explanation of Parkinson's disease:**

- it is a chronic disease
- life expectancy is no less
- probable causes
- complaints and problems with medication and other influential factors
- the average progress of the disease

### **3 The Parkinson's Patients' Association and what they can do for you**

### **4 Your contact during treatment**

- availability and replacement

### **5 Follow-up consultations**

- when, with whom, how often
- possible consult with a nurse practitioner (if present)

**Other subjects you find important to discuss:**

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**Questions you want to ask your specialist:**

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**Information you can provide your specialist with:**

- the consequences and changes in your own personal situation (physically, mentally, and socially)
- problems that can be expected to occur in your daily life or at work

## **Diagnosis**

**Your personal notes**

## **Follow-up consultation with the neurologist**

## **Care and Treatment Plan**

### **The specialist will discuss with you:**

### **Your personal notes**

#### **1 The treatment and possibilities of treatment**

##### **medication:**

- purpose and effect
- effect on the quality of life
- when to take the medication
- time for reflection
  - - treatment without medication
- possibility of an operation in the future
  - - if you agree with the treatment

#### **2 Multi disciplinary treatment:**

- the other (medical) attendants involved in the treatment and mutual rapport
- contact with your GP

#### **Other subjects you find important to discuss:**

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#### **Questions you want to ask your specialist:**

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#### **Information you can provide your specialist with:**

- you and your partner's expectations concerning the treatment
- your consideration to choose for or against treatment with medication (in case of pregnancy or a wish thereto)

## **Follow-up consultation with the neurologist**

## **Care and Treatment**

### **The specialist will discuss with you:**

### **Your personal notes**

#### **1 The effects of the disease on you:**

- physically
- mentally
- and socially

#### **2 Progress of treatment:**

- does the medication work satisfactorily
- which factors do influence the effect of the medication
- the taking of the medication
- if extra medication or other medications are necessary
- alternative treatments

#### **3 Progress of treatment by other (medical) attendants:**

- is the treatment / exercise effective
- is (new) referral necessary

#### **Other subjects you find important to discuss:**

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#### **Questions you want to ask your specialist:**

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#### **Information you can provide your specialist with:**

- any changes in your personal situation (symptoms and problems)
- your attitude towards the disease and the treatment
- how do people around you cope with the disease and treatment



**The initial consult with a nurse practitioner at the outpatients' clinic**

**Care and Treatment Plan**

**The nurse (practitioner) will discuss with you:**

**Your personal notes**

**1 The problems you experience with:**

**accepting the disease**

**performance of activities**

- posture (standing / walking)
- sleeping (turning in bed)
- use of hands (trembling, rigidity)
- tiredness
- average daily activities
  - diet and metabolism
- eating / drinking
- swallowing
  - -going to the toilet
- delayed, difficult bowel movement
- difficulty passing water
  - skin
  - pain
  - sexuality
  - living situation
- transport / driving a car
- housekeeping
- work / hobby
- family situation
  - communication and keeping in contact with
- talking
- writing
- learning ability
- memory / concentration
  - medication:
- side effects
- when to take the medication

**2 Nursing policies**

- planned consultations
- mutual rapport with the neurologist and possible HCP at home
- contact with the patients' association

**3 Follow-up consults:**

- availability / replacement

**Other subjects you find important to discuss:**

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**Questions you want to ask the nurse practitioner:**

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**Information you can provide the nurse practitioner with:**

- problems to be expected at home
- lifestyle and changes due to the disease

**Follow-up consultation with a nurse practitioner at the outpatients' clinic**

**Care and Treatment**

**The nurse (practitioner) will discuss with you**

**Your personal notes**

**1 Progress of the nursing policies:**

- any new symptoms or problems in taking care of yourself
- are you satisfied with the nursing activities and what is the result
- is the partner or another family member involved in the daily care
- have arrangements been made to relieve the partner or family member

**2 Mutual rapport with the other HCPs in the hospital and / or at home**

**Other subjects you find important to discuss:**

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**Questions you want to ask the nurse practitioner:**

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**Information you can provide the nurse practitioner with:**

- any changes in your personal situation
- effect of the reactions from people around you
- how do you cope with the effects of the disease
- your attitude towards the nursing care

## **The initial consult with a district nurse / a carer**

## **Care and Treatment Plan**

### **The district nurse will discuss with you:**

### **Your personal notes**

#### **1 The course of intake and indication**

#### **2 The problems you experience with:**

- accepting the disease
- performance of activities
  - posture (standing / walking)
  - sleeping (turning in bed)
  - use of hands (trembling, rigidity)
  - tiredness
  - average daily activities
    - diet and metabolism
  - eating / drinking
  - swallowing
    - - going to the toilet
  - delayed, difficult bowel movement
  - difficulty passing water
    - - skin
    - - pain
    - - sexuality
    - - living situation
  - transport / driving a car
  - housekeeping
  - work / hobby
  - family situation
    - - communication and keeping in contact with
  - talking
  - writing
  - learning ability
  - memory / concentration
    - - medication:
  - side effects
  - when to take the medication

**3 Nursing policies**

- planned consultations
- mutual rapport with the neurologist and possible attendants at home

**4 Follow-up consults:**

- availability / replacement

**Other subjects you find important to discuss:**

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**Questions you want to ask the district nurse:**

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**Information you can provide the district nurse with:**

- did you have contact with home care before
- do you have contact with a nurse practitioner at the hospital (name and telephone number)

**Follow-up consultation with a district nurse / a carer**

**Care and Treatment**

**The district nurse will discuss with you**

**Your personal notes**

**1 Progress of the nursing policies:**

- any new symptoms or problems in taking care of yourself
- are you satisfied with the nursing activities and what is the result
- the possibility to extend the amount of care when the need for care increases (intensive home care, day-care, care during weekends, at night)

**2 Partner / Volunteer care:**

- is the partner or another family member involved in the daily care
- have arrangements been made to relieve the partner or family member

**3 Mutual rapport with the other (medical) attendants in the hospital and / or at home**

**Questions you want to ask the district nurse:**

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**Other subjects you find important to discuss:**

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**Information you can provide the district nurse with:**

- any changes in your personal situation, symptoms and problems

**The initial consultation with a therapist**

Physiotherapist - Ergo therapist - Speech therapist - Remedial Mensendieck or Cesar physiotherapist

**The therapist will discuss with you**

**1 Reason for referral**

**2 Necessity for any additional questions / examinations**

**3 Results of any additional questions / examinations**

**4 Treatment plan:**

- rough contents
- duration and frequency
- method
- facility
- explanation to you and your partner of the treatment / exercises to do at home

**5 Mutual rapport with the other (medical) attendants in the hospital and / or at home**

**6 Availability / replacement**

**Other subjects you find important to discuss:**

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**Questions you want to ask the therapist:**

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**Information you can provide the therapist with:**

- the symptoms and problems that initiated the referral

**Care and Treatment Plan**

**Your personal notes**

**Follow-up consultation with a therapist**

**Care and Treatment**

**The therapist will discuss with you:**

**Your personal notes**

**1 Progress and effect of the therapy / exercises:**

- do therapy / exercises need adjustment
- are alternative therapy / exercises advisable

**2 Do you need assistance with obtaining / applying for (therapeutic) appliances**

**3 Are you willing to join a discussion group, sport group, dance group etc, this might be favourable for you**

**Other subjects you find important to discuss:**

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**Questions you want to ask the therapist:**

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**Information you can provide the therapist with:**

- any changes in your personal situation
- what is your attitude towards the therapy or exercises
- are you capable of doing the exercises at home
- do you understand the instructions or information