KNGF Guidelines

for physical therapy in patients with Parkinson's disease

Parkinson's disease

KNGF

Royal Dutch Society for Physical Therapy

As a result of international collaboration in guideline development, the Royal Dutch Society for Physical Therapy (Koninklijk Nederlands Genootschap voor Fysiotherapie, KNGF) has decided to translate her Clinical Practice Guidelines into English to make the guidelines accessible at an international level.

International accessibility of clinical practice guidelines in Physical Therapy makes it possible for physical therapists to use guidelines as a reference for treating their patients. Besides, by this, international collaboration in further development and the updating process of guidelines is made possible.
At a national level, countries could endorse guidelines, and adjust guidelines to their local situation if necessary.

The KNGF represents 20,000 members. The most important activities of the Society are: representing the members' interests, developing the quality of the area of physiotherapy and fortifying the position of physiotherapists in the Netherlands.
In order to develop the quality of physical therapy, the KNGF has invested in Quality Assurance. One of these programs has led to the development of Clinical Practice Guidelines.

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Clinical practice guidelines for physical therapy in patients with Parkinson's disease

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Introduction

These evidence-based clinical practice guidelines by the Royal Dutch Society for Physical Therapy (KNGF) embody the diagnostic and therapeutic processes for patients with Parkinson's disease (PD). In the second part of this document, entitled 'Review of the evidence', the choices made in these guidelines are underpinned by the evidence available and described in detail. Appendix 1 contains an overview of the abbreviations and concepts used in the guidelines. These guidelines are developed in cooperation with the Dutch Institute of Allied Health Care (NPi) and with financial support of the Dutch PD Association.

Definition of Parkinson's disease

These guidelines are aimed at the treatment of patients with PD, with sufficient mental function to comply with treatment, who have no other prominent health problems (co-morbidity). These KNGF-guidelines do not automatically apply to other parkinsonisms, such as multiple system atrophy (MSA) and progressive supra-nuclear palsy (PSP). For the treatment of osteoporosis-related problems, the guideline development group (see A.4.) refers to the KNGF-guidelines Osteoporosis. When no severe mental impairments are present (e.g. impairments in cogni-tion, attention, personality and fear), patients with PD can be trained in the same way as their contemporaries. General principles of physical training are not discussed in these guidelines, therefore. The following areas are not covered by these guidelines due to their specialist nature: for problems with writing we recommend that the patient is referred to an occupational therapist; for speech problems the patient should be referred to a speech therapist; for urology problems to a physical therapist trained to treat pelvic floor disorders.

Professional target group

These guidelines are applicable by every physical therapist, irrespective of the work situation. In order to be able to deliver optimal care to patients with PD, we recommend that the physical therapist has specific expertise. Knowledge and skills can be developed through the use of these guidelines and by attending courses which address specific aspects of PD, for example, pathology, diagnostics and management of PD (see appendix 2). The guidelines can also be used by referring physicians, to indicate the potential application of physical therapy in the overall management of PD.

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Pathogenesis

PD is a progressive neurological disorder. Degeneration of dopamine-producing cells in the substantia nigra (part of the basal ganglia) leads to a decreased dopamine-production. The cause of the damage is unknown. Therefore, in the literature, it is also referred to as the idiopathic form of PD.

A clinical diagnosis of 'PD' is made if a patient shows bradykinesia accompanied by at least one of the following symptoms:

1. Rigidity of the muscles;
2. Resting tremor (4-6 Hz);
3. Balance impairments that are not caused by primary visual, vestibular, cerebellar or proprioceptive dysfunction.

Limitations in activities (disabilities) and participation restrictions arise as a consequence of impairments in body functions and body structures. For an extensive description see table 5 and 6, respectively.

Epidemiology

In the Netherlands PD prevalence is approximately 1.4% among people older than 55 years, and increases with age (55-64 years: prevalence 0.3%; > 95 years: prevalence 4.3%). There is no significant difference in prevalence between men and women. Based on demographics, the absolute number of patients with PD in the Netherlands is expected to rise to almost 70,000 by 2015. The incidence of PD in the Netherlands is estimated at 7,900 patients each year.

Natural course

Although PD is progressive, the natural course of health problems varies substantially from patient to patient. Usually, it has progressed to a bilateral disorder three years after the first (unilateral) symptoms were observed. Balance problems develop about two to three years later. On average, recurrent falling starts ten years after the first symptoms. Eventually, almost all patients will have impaired balance and will suffer from repeated falls. Because of increasing problems with balance, patients may become permanently confined to a wheelchair. In later stages, non-motor symptoms may arise, such as dementia. Furthermore, health problems of these patients increase when age-related co-morbidity is present. Patients, whether living on their own or in nursing homes, often die of

pneumonia or heart failure. Aspiration pneumonia can be directly caused by primary health problems, such as difficulties with swallowing. The severity of the disease is often classified according to the Hoehn and Yahr classification (see table 7).

Prognosis

Patients with PD can be classified as tremor-dominated or akinetic-rigid. An akinetic-rigid type of PD presents with the initial symptoms of rigidity and hypokinesia. These patients are characterized by problems with maintaining balance and with gait (including freezing), and show a more rapid course of the disease. In the tremor-dominant group, the disease tends to develop more slowly, with dementia and cognitive impairments occurring less frequently. Prognostic factors that indicate a rapid progression, which cannot be influenced, are: 1) diagnosis at an older age; 2) presence of severe depression; 3) dementia and 4) comorbid arteriosclerosis. Prognostic factors that can be influenced are: 1) physical inactivity and 2) falling.

Physical inactivity increases the risk of developing complaints including osteoporosis, constipation, and cardiovascular and respiratory problems. In combination with the increased risk of osteoporosis, falling can lead to fractures or other physical injury and to (increased) fear to move, resulting in a reduced level of activity and a further increased liability to new falls.

The role of the physical therapist

For patients with PD, the objective of the physical therapist is to improve the quality of life by maintaining or increasing the patient's independence, safety and well-being. This is achieved through prevention of inactivity and falls, improving functional activity and decreasing limitations in activities. Treatment goals and successive interventions can be determined based on the phases patients go through (quick reference card 3). The physical therapeutic intervention goals apply to the phase addressed, but are also important in subsequent phases.

Early phase

Patients in the early phase have no or little limitations. According to the Hoehn and Yahr classification, they are classified in the stages 1 to 2.5. The goal

of therapeutic intervention in this phase, but as well in the subsequent phases is:

1. prevention of inactivity;
2. prevention of fear to move or to fall;
3. preserving or improving physical capacity (aerobic capacity, muscle strength, and joint mobility).

The physical therapist can achieve these goals by giving information and advice, exercise therapy (possibly in a group), with specific attention to balance and physical capacity.

Mid phase

In the mid phase, patients develop more severe symptoms; performance of activities become restricted and problems with balance and an increased risk of falls arise. Patients are classified in stages 2 to 4, according to Hoehn and Yahr. The goal of therapeutic intervention in the mid and late phases is to preserve or stimulate activities. Exercise therapy is focused on the following problem areas:

- transfers;
- body posture;
- reaching and grasping;
- balance;
- gait.

Cognitive movement strategies and cueing strategies can be used and if necessary the caregiver* can be involved in the treatment applied.

Late phase

In the late phase of the disease, patients are confined to a wheelchair or bed. They are classified in stage 5, according to the Hoehn and Yahr classification. The treatment goal in this phase is to preserve vital functions and to prevent complications, such as pressure sores and contractures.

Indications for physical therapy

Physical therapy is indicated if there is/are:

- limitations in activities and impairments in function especially with respect to transfers, body posture, reaching and grasping, balance and gait;
- inactivity or a decreased physical capacity;
- increased risk of falls or fear to fall;
- increased liability to pressure sores;
- impairments and limitations as a result of neck

and shoulder complaints;
- need for information about the consequence of PD, especially regarding the limitations in activities concerning posture or movement.

The strain on the caregiver can also be a reason for referral when the patient's activities are greatly limited (e.g. lifting instruction if the patient is confined to a wheelchair or bed). Early referral is recommended (immediately after diagnosis) to prevent or decrease complications as a result of falling and inactivity.

I Diagnostic process

The diagnostic process consists of taking the medical history, an analysis of the medical history, performing a physical examination and drawing up a treatment plan. The objective of the diagnostic process is to assess the severity and nature of the patient's health problems and to evaluate the extent to which physical therapy can influence these problems. Starting point is the patient's request.

I.I Referral

If a patient is referred by a primary care physician (PCP) or a medical specialist, the physical therapist assesses whether the referral contains sufficient information concerning possible co-morbidity (e.g., osteoporosis and other disorders that decrease mobility, such as arthritis, rheumatoid arthritis, heart failure and COPD). Furthermore, it is important for the physical therapist to know if other forms of parkinsonism were excluded. Information should be received on the course of the health problem, on possible mental disorders related to PD, on the treatment policy, and on the result of the medical treatment.

I.II History-taking

When taking the patient's history, the physical therapist assesses and records the health problems (see quick reference card 1). In addition, the patient's expectations regarding interventions and treatment outcome are recorded. The physical therapist tries to assess whether the patient's expectations are realistic. When mental impairments or physical impairments or limitations impede the patient in answering questions, and when the patient is largely dependent on others for care, it is necessary to involve the caregiver

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* The term caregiver refers to both the partner and any other person who takes care of the patient.

to get an accurate picture of the patient's health problems.

Formulating the objectives for physical examination

The information obtained whilst taking the patient's history should be used to formulate a number of objectives for physical examination. These objectives are focused on the examination of: physical capacity; transfers; body posture; reaching and grasping; balance and gait.

I.III   Physical examination

Due to fluctuations in good (*on*) or bad (*off*) response to the use of levodopa, mobility problems of patients with PD can vary greatly during the day. Therefore, during physical examination, the physical therapist has to find out if the patient is in an *on* or *off* period. The physical therapist can make use of quick reference card 2 as a means to perform a structured physical examination. Whilst taking the medical history the physical therapist determines if the patient has other disorders that need to be included in the physical examination (e.g. neck-shoulder complaints or back complaints that seem to be associated with PD).

I.IV   Outcome measures

Outcome measures serve as an aid in charting and objectively assessing problems associated with PD. Furthermore, a number of outcome measures can be used again later to evaluate the effects of treatment. As a result of medication, motor function and activity limitation can vary greatly during the day. Therefore it is important that measurements are performed at the same time of the day as the initial measurement, assuming that patients always take their medication at the same time. See appendix 3 for an overview of possible medication.

The Patient Specific Complaints questionnaire, a patient preference outcome scale, is used to evaluate the extent to which the patient feels limited in activities, and the most important limitations in activities (see appendix 4.1). In addition, this questionnaire can be used to develop a list of the patient's most important problems. Incidence of falling and possible risk of falling is determined with the History of Falling Questionnaire (see appendix 4.2). Patients who have fallen more than once in the past year

receive a falls diary (see appendix 4.3).

In addition, several measures for identification can be used: fear to fall is identified with the (modified) Falls Efficacy Scale (see appendix 4.4); balance problems are assessed using the Retropulsion test (impaired postural responses to external perturbations) (see appendix 4.5); freezing of gait is evaluated with the Freezing of Gait Questionnaire (see appendix 4.6); in case of doubts with respect to the patient's level of activities in comparison with the Dutch Standard of Healthy Moving, the LASA Physical Activity Questionnaire can be used (see appendix 4.7); the Six-minute walk test should be performed in patients who are not troubled by freezing; the Ten-meter walk test should be used to evaluate comfortable walking speed (see appendix 4.8 and 4.9, respectively); with the Modified Parkinson's Activity Scale, the quality of movement during certain ADL can be documented (see appendix 4.10); the Timed Up and Go test is used to determine how quickly certain activities can be performed (see appendix 4.11).

I.V   Analysis

To conclude the diagnostic process, the physical therapist should answer the following questions:

- Is physical therapy indicated for the patient?
- Can the guidelines be applied to this individual patient?

Physical therapy is indicated when:

1. the patient is limited in one or more activities (transfers, body posture, reaching and grasping, balance and gait);
2. the patient's physical capacity is getting worse or if there is a risk this will happen;
3. the patient has as increased risk of falling or has a fear to fall, or
4. there is a need for information or advice on the disorder, natural course and prognosis, especially on posture and movement and functioning in daily life.

The patient is only eligible for physical therapy if there are no medical problems for which therapy would be contraindicated, no personal or social factors that would prevent compliance with therapy, and if the physical therapist determines that the patient's impairments in functions, limitations in

activity and the behavioral aspects can be influenced by physical therapy.

If physical therapy is indicated and the guidelines are applicable, the physical therapist formulates, in consultation with the patient, a treatment plan in which individual treatment goals are included. If the physical therapist does not feel that therapy is appropriate, he should inform the referring physician and may advise referral to another allied health discipline or to a medical specialist.

I.VI   Treatment plan

The treatment plan will primarily focus on the main problem that is in line with the patient's request.

In formulating the main goals (intended treatment outcome), the patient's motivation, capability and understanding are taken into account. Physical therapeutic goals for patients with PD are:

1. to stimulate the patient's safety and independence in the performance of activities, with the emphasis on:
    a. transfers;
    b. body posture;
    c. reaching and grasping;
    d. balance;
    e. gait;
2. to preserve or improve physical capacity;
3. to prevent falling;
4. to prevent pressure sores;
5. to stimulate insight into impairments in function and limitations in activities, especially of posture and movement.

Besides treatment goals, the treatment plan includes the interventions that will be carried out to achieve these goals, the expected number of sessions, treatment frequency, and treatment location (at home, in the clinic, in the hospital or care home). The choice of the location is determined by the treatment goal and will also depend on the patient's and therapist's personal capabilities and on external factors. If treatment is primarily aimed at enhancing functional activity, it will preferably take place at the patient's home. Enhancing physical capacity can take place in the therapist's clinic.

II   Therapeutic process

II.I   General focal points for treatment

Involvement of the caregiver

It is very important to involve the caregiver in treatment. The caregiver can assist in using cues and cognitive movement strategies when the patient has problems applying these learned strategies in daily life (e.g. in case of a poor mental function). The patient will benefit from one instruction at a time, especially if there are mental impairments, such as impairments in memory and attention. It is important to reduce the strain on the caregiver. This is possible, for example, by teaching the caregiver lifting techniques when the patient with PD is confined to a wheelchair or bed, and by indicating how to act in case of freezing and *on/off*-periods.

Avoidance of dual tasking

Most patients with PD are unable to pay full attention to all tasks when performing several tasks simultaneously (dual or multitasking). In particular, patients with PD need to pay specific attention in order to safely perform 'automatic movements' such as walking. Dual tasks can have a negative effect on gait and balance, which can give rise to unsafe situations in daily life as well as during treatment. Avoiding performance of dual tasks, during treatment as well as in daily life, increases safety of patients with PD and can decrease falls. Accordingly, the physical therapist should not give further instructions during the performance of an activity or movement as this will lead to a dual task.

Multidisciplinary agreements

Often, different disciplines are often involved in treatment of patients with PD (especially those who are in the late stages or have a complex presentation). The moment at which another discipline becomes involved, and by which procedure, depends on the referring physician and on the way health care is organized in the region where the physical therapist operates. It is recommended that agreements are made with the patient, caregiver, and other persons concerned in relation to the organization of care. This will help to fine tune the package of multidisciplinary care received by the patient.

(Relative) contra-indications

- When a patient has a deep brain stimulator implanted (e.g. STN-stimulation) the use of diathermia (short wave, microwave) is contra-indicated at any time and for any part of the body.
- Mental impairments, such as impairments in cognition (e.g. poor memory, dementia and severe hallucinations), personality and attention, are relative contra-indications for treatment of problems that are associated with PD, because these impairments influence the patient's ability to learn.
- Freezing problems form a relative contra-indication for hydrotherapy. Hydrotherapy can only take place for patients who are affected by freezing if they are individually supervised.
- General fatigue can influence both treatment plan and schedule (e.g. spreading out exercises during the day).

Frequency and duration of treatment

Duration and frequency of a course of physical therapy depend strongly on the needs and potential of the patient, and on the course of the disease. For each patient treatment will focus on the main problem related to his* need. If the patient has achieved the goals specified, or if the physical therapist does not expect any changes as a result of therapy (improvement, maintenance or prevention of worsening) treatment should be discontinued. Treatment should also be discontinued if the physical therapist assesses the patient is able to achieve the treatment goals on his own (without therapeutic supervision). To improve functional ADL a treatment period of four weeks is recommended. During the first sessions it will become clear if the use of cues will be helpful. To improve physical capacity, a treatment of at least eight weeks is recommended. Provided patients are given adequate instructions, they can perform the exercises on their own at home; therefore, a low treatment frequency (e.g. once a week to adjust the exercise program) is sufficient. Goals should be evaluated every four weeks and adjusted, if necessary, throughout the treatment program; information and advice should be given regularly throughout this process.

Group treatment

The choice of group or individual treatment depends on the treatment goals, the intended result, the patient's abilities and external factors (such as the availability of exercise groups). If personal goals are most prominent, e.g. improvement of transfers, individual treatment is most suited. The physical therapist can provide specific instruction and attention, with the additional advantage that patients will be less distracted by their environment than during group treatment.

Group treatment is more suited to general goals. This may be the case when providing a maintenance program, and when the goals are related more to physical performance e.g. improving physical capacity or increasing well-being by and during activity. Furthermore, group therapy provides an opportunity for patients and their caregivers to learn from one another, there is contact with fellow-sufferers, the social aspect may increase subjective feelings of well-being, and compliance with therapy might be increased. Depending on patient-specific problems, the therapist will direct the patient to either a specific exercise group for patients with PD, or to a more general exercise group for the elderly (see appendix 2). Group size depends on the treatment goal and the level of functioning of participating patients (to a maximum of eight patients). Furthermore, in the case of group treatment it is important that goals are set and aimed for individually.

Focal points in the treatment of patients with Parkinson's disease

- When making appointments the physical therapist should take into account the patient's good and bad periods during the day (on/off periods).
- The cognitive function and the patient's age determine the pace and degree of difficulty of the therapy.
- The physical therapist can train the patient while to recognizing response fluctuations (wearing off-phenomenon, on/off-problems, dyskinesias, freezing), which occur with long-term medication use and as the disease progresses. If necessary the patient can discuss with his medical specialist if any adjustments in medication are needed.

II.II   Treatment strategies

Cognitive movement strategies

To improve transfers, cognitive movement strategies are used in which complex (automatic) activities are divided into separate elements consisting of relatively simple movement components, which are performed in a sequence. By doing this, the person has to think consciously about his movements and is thus helped to avoid dual tasking during complex (automatic) ADL. Furthermore, the movement or (part of the) activity will be practiced and rehearsed in the mind. It is important that movements are not performed automatically; performance has to be consciously controlled.

Cueing strategies

The performance of automatic and repetitive movements is disturbed as a result of fundamental problems of internal control. So-called cues are used to complete or replace this reduced or even absent internal control. Cues are stimuli either from the environment or generated by the patient; they increase the patient's attention and facilitate (automatic) movement. It is suggested that cues allow a movement to be directly controlled by the cortex, with little or no involvement of basal ganglia. Not all patients benefit from using cues. Cues can be generated internally (bow, stretch, wave) or externally. External stimuli can be divided into moving stimuli (light of a laser pen, a moving foot, a falling bunch of keys) and non-moving stimuli (sound of a metronome, stripes on the floor, and the grip of a walking-stick).

With regard to therapeutic use of cues, a distinction is made between rhythmical recurring cues and one-*off* cues (see table 1). Rhythmical recurring cues are given as a continuous rhythmical stimulus, which can serve as a control mechanism for walking. The distance between (frequency of) rhythmical cues during walking will be based on the number of steps needed to perform the Ten-meter walk test at comfortable pace. One-*off* cues are used to keep balance, for example when performing transfers and for initiating ADL, or when getting started again after a period of freezing.

Table 1. Cues.

Rhythmic recurring cues	
Auditory	• the patient moves on music of a walkman • the patient moves on rhythmical ticking of a metronome • the patient or someone else sings or counts
Visual	• the patient follows another person • the patient walks over stripes on the floor or over stripes he projects to himself with a laser pen • the patient walks with an inverted walking-stick and has to step over the grip
Tactile	• the patient taps his hip or leg
One-*off* cues	
Auditory	• initiation of movement, for example, stepping out at the third count
Visual	• initiation of movement, for example, by stepping over some else's foot, an object on the floor or an inverted walking-stick • maintenance of posture, for example, by using a mirror or by focusing on an object (clock, painting) in the environment
Cognitive	• initiation of movement (and continuation of walking), for example, by focusing on the spot the wants to go to, and not on the doorway he has to go through

Table 2. Core areas for aids in Parkinson's disease.

Problem area	Aids or adjustments
Balance	• walking aid (i.e. rollator)
Transfers or changing body position	• raised toilet • stand-up chair • aids that facilitate getting in or out of bed (such as high-low bed, elevator to lift a patient, sliding board, handles on the sides of the bed)
Mobility	• walking aid (i.e. rollator) • other aids that improve mobility (such as wheelchair, scoot mobile)
Falling and increased falls risk	• walking aid (i.e. rollator) • hip protectors • shoes with sufficient support and soles with sufficient grip

Treatment strategies per treatment goal
Quick reference card 4 shows an overview of the treatment strategies that can be chosen for different treatment goals.

Aids
The use of aids can be advisable for some patients with PD. The physical therapist (together with the occupational therapist if necessary) provides the appropriate aid and relevant training in the use of (walking) aids (see table 2). He also provides information on who is responsible for the maintenance and repair of the aids.
Besides, the physical therapist can refer the patient to an occupational therapist for advice regarding possible adjustments in the home environment. For patients with recurrent falls, a nurse can give advice on the purchase of hip protectors.

II.III   Evaluation
The physical therapist evaluates treatment outcome by testing it with respect to the treatment plan goals. On this basis, the treatment plan can be adjusted. The same outcome measures that were used during initial assessment should be used for comparison. If the patient has difficulties communicating, the caregiver can help with evaluation of the treatment program.

The evaluation process consists of:
• evaluation of changes in movement strategies and posture: at the beginning of every treatment session;
• evaluation of changes in physical capacity: after at least eight weeks;
• evaluation of final treatment outcome by means of its 'global perceived effect': at the end of the treatment (see appendix 4.12).

II.IV   Aftercare
Preservation of activities in daily life
Learned strategies to stimulate the activities in daily life are sometimes retained for only a short period of time. Introducing permanent cues (to initiate as well as to continue the movement) in the home environment can aid effective long-term use of the strategies. It is important to review patients periodically to check that they are able to continue with the strategies effectively. Because of the progressive nature of PD it is important for patients to stay active. Effects of physical activity aimed at improving bone mass are visible only after a year (see the KNGF-guidelines 'Osteoporosis'). Therefore, the physical therapist should encourage the patient to keep on exercising and moving after treatment has ended. The patient can keep a diary in which frequency and extent of

exercise are recorded; the Borg scale can be used to measure the feeling of exertion during exercise (see appendix 4.13).

An appointment for a review can be made to assess whether the effects of therapy have been maintained or whether the patient has developed new problems. If necessary, therapy can be restarted immediately after the review.

II.V   Final evaluation, conclusion and reporting
The patient can be discharged from therapy when the treatment goals have been achieved or when the physical therapist takes the view that physical therapy has no additional value. The patient may also be discharged if the therapist expects him to be able to achieve the treatment goals on his own (i.e. without therapeutic supervision). At discharge, but preferably also during the treatment period, the physical therapist informs the referring physician about, among other things, (individually determined) treatment goals, treatment plan and treatment outcomes.

The physical therapist should write his final report for the PCP or referring physician in accordance with the KNGF-guidelines entitled 'Communicating with and reporting back to primary care physicians'. For the report contents, the guideline development group refers to the KNGF-guidelines entitled 'Physical therapy documentation and reporting'. The guideline development group recommends reporting if the patient was treated according to the guidelines, on which points, why treatment deviated from the guidelines (if applicable), and if a follow-up appointment was made.

Review of the evidence

A Introduction

The evidence-based clinical practice guidelines by the Royal Dutch Society for Physical Therapy (KNGF) on Parkinson's disease are a guide for physical therapeutic intervention in patients with PD. The diagnostic and therapeutic processes are described conform to the methodical physical therapeutic interventions. In this review of the evidence, choices made in these KNGF-guidelines 'Parkinson's Disease' are underpinned by the evidence and described in detail. Additional information is also given.

The KNGF-guidelines should be considered as 'the state of the art' for physical therapeutic intervention. These guidelines aim at optimizing the physical therapist's intervention according to the latest scientific literature, and according to current views within the profession.

> **Definition**
> KNGF guidelines are defined as 'a systematic, centrally formulated and developed guide, which has been developed by professionals and focuses on the context in which methodical physical therapy of certain health problems is applied, taking into account the organization of the profession'.[1-3]

A.1 Definition of the health problem

These guidelines describe the diagnostic and therapeutic process in patients with PD. The guidelines are aimed at the treatment of patients with PD, who have sufficient mental function to comply with treatment and show no other prominent health problems (co-morbidity). These KNGF-guidelines are not automatically applicable to other parkinsonisms, such as multiple system atrophy (MSA) and progressive supranuclear palsy (PSP). These parkinsonisms are characterized by a fast progression and a variable range of additional neurological problems that are not addressed in these guidelines (e.g. cerebellar ataxia and spasticity). Furthermore, several parkinsonisms (e.g. PSP or vascular parkinsonism) are accompanied by the appearance of, sometimes severe, cognitive

impairments that may impede the exercise and use of, for example, cognitive movement strategies. In the case of some disorders (e.g. PSP) reckless behavior may occur, due to which usually a limitation of activities will have to take place. On the other hand, some patients with another parkinsonism show particular impairments or limitations that are similar to those of patients with PD. If these patients also have sufficient mental function to comply with treatment, certain elements of these guidelines may be applied to them. For the treatment of osteoporosis-related problems, the guideline development group (see A.4.) refers to the KNGF-guidelines 'Osteoporosis'.[4]

Patients with PD reach their VO_{2max} sooner than their healthy contemporaries[5], but can, in the absence of severe cognitive problems, be trained in the same way as their contemporaries[6]. Therefore, general principles of physical training are not discussed in these guidelines.

Problems with writing and speech fall outside the scope of the physical therapist. In the case of problems with writing the patient should be referred to an occupational therapist. In the case of problems with speech, the patient should be referred to a speech therapist. Micturation disorders should be referred to a pelvic floor physical therapist. Because of its specialist character, this intervention is not described in these guidelines.

A.2 Objectives

The objective of these guidelines are to describe 'optimal' physical therapeutic care for patients with PD with respect to effectiveness, efficiency and tailored care, based on current scientific, professional, and social views. This care has to lead to a complete (or desired) level of activities and participation and has to prevent chronic complaints and recurrences. Furthermore, these guidelines are explicitly meant to improve care based on current scientific evidence and expert opinion; to stimulate uniformity and quality of care; to define tasks and responsibilities of the professions, to provide insight into these tasks and responsibilities, and to stimulate co-operation between professions; to support the physical thera-

pist in deciding whether or not to treat and, if so, to apply the best possible diagnostic and therapeutic interventions.

Recommendations are formulated in terms of professional requirements, which are necessary in order to apply these guidelines.

A.3 Clinical questions

The guideline development group that prepared these guidelines looked for answers to the following clinical questions:

1. What specific health problems related to PD are important for the physical therapist?
2. What physical therapeutic diagnostic information is necessary to be able to formulate the treatment objectives and a treatment plan?
3. What forms of treatment and prevention have a scientific basis and are useful?
4. What forms of treatment need and prevention are useful based on consensus of the guideline development group?

A.4 Formation of the guideline development group

A guideline development group of experts was formed in December 2001 to answer the clinical questions outlined above. A balanced division of members was taken into consideration in forming the guideline development group, according to expertise, experience and/or academic background. These KNGF-guidelines were developed in cooperation with the Dutch Society of Exercise Therapists according to the methods of Mensendieck and Cesar (VVOCM). For both professional organizations comparable guidelines for PD were developed in 2004. The guideline development group developed the first draft of the guidelines in a period of twelve months. During this period an introductory meeting, two Delphi-rounds, a newsgroup discussion, and several consensus meetings took place. All members of the guideline development group declared they had no conflicting interests regarding the development of the guidelines. Development of the guidelines took place from December 2001 to December 2003.

A.5 Procedure of the guideline development group

The guidelines have been developed in accordance

with the 'method to develop and implement guidelines'.[1,2,7,8] In this method, among other things, practical instructions have been formulated for the strategy to gather literature. In the 'Review of the evidence' of these guidelines the specific keywords, the sources consulted, the period in which the literature was collected, and the criteria to exclude or include literature are reported. The members of the guideline development group individually selected and graded documentation, which was considered as scientific evidence. Although the scientific evidence was prepared individually or in small subgroups of members of the guideline development group, the result was discussed in the entire guideline development group. The scientific evidence has been summarized in a conclusion, including the extent of the evidence. Apart from scientific evidence, other aspects are of importance for the recommendations, including: reaching common consensus, efficiency (costs), availability of means, required expertise and education, organizational aspects and the desire to link with other uni- or multidisciplinary guidelines. If no scientific evidence was available, recommendations were been formulated on the basis of consensus within the guideline development group. A review panel of expert professionals (see G. Acknowledgements) commented upon the recommendations. Once the draft mono-disciplinary guidelines were completed, they were sent to a secondary guideline development group comprising external professionals or members of relevant professional organizations, or both, in order that a general consensus could be achieved with other professional groups or organizations, and with other existing uni-disciplinary or multidisciplinary guidelines. In addition, the wishes and preferences of patients were taken into account by means of a panel of patients (composed by the Parkinson's Patient Society).

A.6 Validation by intended users

The guidelines were systematically reviewed by intended users for the purpose of validation, prior to publication and distribution. The draft guidelines on PD were assessed by a group of fifty physical therapists, working in different settings. Physical therapists' comments and criticisms were recorded and discussed by the guideline development group and, if possible or desirable taken into account in the final

version of the guidelines. The recommendations on practice are derived from the available evidence, on the other above-mentioned factors and on the evaluation of the guidelines by intended users.

A.7 Formation of the steering group

The development of the guidelines was guided as a process by the steering group, consisting of representatives of the KNGF (A. Verhoeven MSc and M. Heldoorn PhD, policy employees KNGF), and the Dutch Society for Physical Therapists in Geriatrics (NVFG) (E. de Jong, secretary until September 2002; M. van Gennep, secretary from September 2002), the Dutch Society of Exercise Therapists according to the methods of Mensendieck and Cesar VVOCM (Mrs. J. van Sonsbeek and Mrs. H. Verburg, national quality officials), the Dutch Institute of Allied Health Care (NPi) (H.J.M. Hendriks PhD, senior scientist and program manager 'Guidelines Development & Implementation') and the Dutch Parkinson's Disease Association (P. Hoogendoorn MSc, chairman).

A.8 Structure, products and implementation of the guidelines

The guidelines consist of three parts: the Practice guidelines, the Review of the evidence, and a quick reference card in plastic of the key points of the guidelines (the Summary). These parts of the guidelines can be read separately and independently. The guidelines were distributed in June 2004 through a special issue of the Dutch Journal of Physical Therapy on PD. The guidelines are implemented according to a documented implementation strategy.[1-3,7,8]

A.9 Professional target group
A.9.1 Physical therapists

The KNGF-guidelines can be used by all physical therapists, irrespective of the work situation. In order to be able to give optimal care to patients with PD, some advice is given regarding the furnishings of the practice and available equipment (see appendix 4.15), furthermore it is recommended that the physical therapist has specific expertise. This specific expertise shows itself in:

- knowledge of, and insight in: recent developments which have to do with neurology and developments in medical treatment; neuropsychological aspects; emerging impairments in function

and limitations in activities; additional care and treatment, including the need for occupational and speech therapy input; advantages and disadvantages of aids.

- knowledge of skills with respect to: movement examination and analysis, impairments in functions and limitations in activities; adequate treatment techniques and possibilities; measurement of clinical signs, such as determinants of diseases and evaluation of the effectiveness of interventions with the help of reliable and valid outcome measures.

Physical therapists can obtain knowledge and skills by studying and using the guidelines, and by following courses in which specific aspects with regard to pathology, diagnostics and treatment of PD are discussed (see appendix 2).

A.9.2 Referring physicians

These guidelines can also be used by referring physicians, to indicate the potential application of physical therapy in the overall management of PD (see paragraph A.14). See paragraph B3 for an extensive overview of the health problems for which patients can be referred to a physical therapist.

A.10 Reading indication

Physical therapists with no or little knowledge of PD are advised to start at paragraph A.12.
Physical therapists with sufficient knowledge of PD, but with little experience in treating patients with PD, are advised to read the sections on diagnostic and therapeutic processes.
Physical therapists with extensive knowledge of PD and large experience in the treatment of patients with PD, are advised to use these guidelines to evaluate their daily practice.

A.11 Evidence for the conclusions and recommendations

Literature was collected using the electronic databases MEDLINE, CINAHL, PEDRO, EMBASE and the Cochrane library over the period of 1980 to 2003. Keywords used in the search were 'Parkinson's disease'. Regarding interventions, this search strategy was combined with: 'physiotherapy', 'physical therapy', 'physical therapy techniques', 'exercise movement

Table 3. Grading of the level of evidence for intervention studies.

A1	meta-analyses (systematic reviews), which include at least some randomized clinical trials at quality level A2 that show consistent results across studies;
A2	randomized clinical trials of good methodological quality (randomized double-blind controlled studies) with sufficient power and consistency;
B	randomized clinical trials of moderate methodological quality or with insufficient power, or other non-randomized, cohort or patient-control group study designs that involve inter-group comparisons;
C	patient series;
D	expert opinion.

techniques', 'training', 'exercises', and 'exercise therapy'. Regarding outcome measures this combination was completed with: 'sensitivity and specificity', 'exercise test', 'physical examination', and 'treatment outcome'. Additional literature was collected from experts and secondary references in publications. The guidelines are, as much as possible, based on the conclusions found in randomized clinical trials (RCT's), systematic reviews, and meta-analyses. The systematic reviews of Deane et al.[9,10], the meta-analysis of De Goede et al.[11] and the already published guidelines in Great Britain[12] were valuable in this process.

Some of the recommendations in the guidelines are based on consensus reached within the guideline development group. This is because from the literature available in April 2003 it was not possible to establish a generally accepted exercise program, which was, with respect to form, content, intensity and duration, fully based on qualitatively well-performed studies.

For the interpretation of results found in the literature, differences in the study designs were taken into account. The level of evidence for the studies that were included were graded using criteria developed by the Evidence-Based Guidelines Meeting (EBRO platform), under the auspices of the Dutch Institute for Health Care Improvement (CBO) (see table 3). These judgment lists and criteria are compiled on the basis of consensus for the development of guidelines in the Netherlands.[13,14]

Conclusions were drawn regarding the effectiveness of separate interventions, which were based on the review of the literature and discussion of the guideline development group, and they were followed by a recommendation (see table 4). When scientific evidence was derived from systematic reviews, meta-analyses, (randomized) clinical trials and study designs that involve inter-group comparisons, the recommendations have been assigned a level 1, 2 or 3 qualification, depending on the evidence level.

Table 4. Grading of the recommendations according to the level of evidence.

Level of scientific evidence of the intervention study	Description of conclusion or recommendation in the guidelines
1. Supported by one systematic review at quality level A1 or at least two independent trials at quality level A2	'It has been demonstrated that …'
2. Supported by at least two independent trials at quality level B	'It is plausible that …'
3. Supported by one trial at quality level A2 or B, or research at quality level C	'There are indications that …'
4. Based on the expert opinion (e.g. of working group members)	'The working group takes the view that …'

When scientific evidence is unavailable or unknown, but the subject is so important that inclusion in the guidelines was preferred, the recommendations were made on the basis of consensus (level 4). Level 4 recommendations were based on the opinion of (international) experts or on consensus within the guideline development group. Apart from health gain, side effects and risks were also considered when formulating the recommendations.

If no clinically relevant effect was demonstrated in the available studies at level A, B or C, the recommendation was formulated as 'there is insufficient evidence that…'.

A.12 Parkinson's disease

A.12.1 Pathogenesis and diagnosis

PD is a progressive neurological disorder.[15] Degeneration of dopamine producing cells in the substantia nigra (part of the basal ganglia) leads to a decreased dopamine production. The first symptoms of the disease become manifest when 60% to 80% of these cells are damaged.[16] Because the cause of the damage is unknown, in the literature it is also referred to as the idiopathic form of PD. Environmental factors[17], such as exposure to pesticides and, in patients who present with PD under 50 years of age, genetic factors[18] seem to play a role in the cause of the disease.

Clinical diagnosis

PD can only be diagnosed with certainty post mortem, if, with pathological anatomical tests, so-called Lewy bodies can be demonstrated in the substantia nigra and other pigmented nuclei of the brain.[19,20] Ten to twenty percent of patients have another diagnosis on post mortem examination, for example MSA and PSP, parkinsonism caused by medication and vascular parkinsonism. Using the criteria of the Brain Bank of the UK PD Society, 19 only a probable diagnosis can be made.

The clinical diagnosis of 'PD' is made if there is bradykinesia accompanied by at least one of the following disorders: 1) rigidity of the muscles; 2) rest tremor (4-6 Hz); 3) balance impairments that are not caused by primary visual, vestibular, cerebellar or proprioceptive dysfunction.[20]

Additional examination

The value of additional examination is very limited in the case of PD. In patients with a characteristic presentation of the disease, a one-*off* scan, preferably using MRO (does not show abnormalities in the case of PD) may be useful.

In the case of an atypical presentation of the disease, additional examination is useful to make an alternative diagnosis more or less probable. The MRI-scan shows, among other things, cerebro-vascular lesions. With SPECT- and PET-scans (Single Photon Emission Computed Tomography and Positron Emission Tomography, respectively) the functional integrity of the dopaminergic system in the striatum can be judged; this can differentiate between the idiopathic form of PD and other forms of parkinsonism (especially within the scope of scientific research). For an extensive overview of the cause, diagnosis and treatment of PD, see the treatment guidelines according to Olanow et al.[21]

A.12.2 Epidemiology

Based on the most recent population study, the Erasmus Rotterdam Health and Elderly (ERGO) study, the number of patients with PD in 1996 in the Netherlands was estimated to be 48,000 in the population of 55 years and older.[22] In the Netherlands the prevalence (approximately 1.4 % among persons older than 55 years) increases with age (55-64 years: 0.3%; > 95 years: 4.3%).[22] There is no significant difference in the prevalence between men and women. Based on demographic developments, it is expected that the absolute number of patients with Parkinson's disease in the Netherlands will rise to almost 70,000 in the year 2015.[23] The incidence of Parkinson's disease in the Netherlands, standardized to the Dutch population in 2000, is estimated at 7,900 patients each year.[24]

A.12.3 Consequences of Parkinson's disease

To describe the health problems which are a consequence of PD, the guideline development group made use of the 'International Classification of Functioning, Disability and Health'.[25] Figure 1 presents a global overview of the health problems connected with PD and the factors influencing these problems.[26]

Figure 1. Global overview of impairments, limitations and participation restrictions associated with Parkinson's disease (adapted from the diagram published by Kamsma, 2002).

Parkinson's disease: dysfunction of the basal ganglia, caused by degeneration of dopamine-producing cells in the substantia nigra (ICD-10: G20)[1]

Functions

Primary impairments:

- musculoskeletal system;
- pain;
- sensory functions;
- mental functions;
- digestive tract;
- uro-genital functions;
- sleeping functions.

Secondary impairments:

- musculoskeletal system;
- cardio-vascular system;
- respiratory system;
- pain;
- mental functions;
- digestive tract;
- uro-genital functions;
- sleeping functions.

Activities

Limitations in:[2]

- mobility, such as transfers and changing body position, (maintaining body position), reaching and grasping and gait;
- other activities, such as household activities.

Participation

Participation problems in:

- interpersonal interactions and relationships;
- education, work and employment;
- self-care and domestic life
- community, social and civic life.

External factors (positive and negative), such as

- attitudes, support and relationships (among others, partner, primary care physician, employer);
- accommodation (e.g. furnishing, housing type);
- education, work and employment (kind, circumstances, conditions and relations).

Personal factors (with positive and negative influences on functioning as a whole, and with that on the quality of life) such as:

- age;
- socio-cultural background;
- habits in exercising;
- attitude (e.g. in relation to work);
- coping.

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[1] *Code of the International Classification of Diseases.*
[2] *Limitations in activities to different gradations, until full independence.*

Impairments in functions and limitations in activities

As a (direct) consequence of PD, or as a consequence of the medication used or inactivity, impairments may arise in the function of the musculoskeletal system, the cardiovascular system, the respiratory system, pain, sensation and mental function (see table 5).

Consequences of health problems relevant to physical therapy are within the domains of (in arbitrary order): transfers, body posture, reaching and grasping, balance and gait (see table 6).

Table 5. Overview of the impairments that link with PD. Problems in the cells printed in green fall within the scope of the physical therapist.

Musculoskeletal system, cardiovascular system, respiratory system	Pain and sensory functions	Mental functions	Others

• Body posture:
  - generalized change in posture towards flexion, often in combination with latero-flexion
  - decreased reactions of posture and balance
  - falling
	• pain in the musculo-skeletal system:
	  - due to postural problems
		• fear of falling or moving	• sleeping problems caused by problems with rolling over bed

• gait pattern: reduced stride length, height, and speed, trunk rotation and arm swing, falling
  - tremor*
  - dystonic posturing: moving delayed and quality affected by rigidity, bradykinesia, akinesia (freezing)
  - facial hypokinesia
  - fatigue
	• pain in the gastrointestinal tract[(med.)]:
	  - due to constipation, caused by decreased activity
		• fear[(med.)]	• sleeping problems by a different cause:
			  - lively dreams
			  - nightmares*
			  - shortened REM sleep
			  - nycturation
			  - pain
			  - restless legs
			  - excessive daytime sleepiness

• insufficient muscle function (strength, stamina) and length	• neck- and en occipital headache by orthostatic hypotension*	• depression, especially in geriatric patients[(med.)]	• digestive and urogenital tract:
			  - swallowing problems
			  - salivating
			  - nausea, vomiting[(med.)]
			  - perseverance of weight (loss)
			  - urge-incontinence[(med.)]
			  - constipation and soiling (leaking of fluid from the intestines)[(med.)]
			  - impotent
			  - hypersexualiteit[(med.)]

Musculoskeletal system, cardiovascular system, respiratory system	Pain and sensory functions	Mental functions	Others

• insufficient mobility of the joints	• central pain (from the CNS): a vague, general feeling from tension to pain, especially occurring in young patients with Parkinson's disease; in that half of the body that is most impaired with regard to motor activity	• hallucinations[(med.)]	• voice and speech
			  - extent to which the speech is fluent and rhythmical
			  - articulation
			  - palilalia (repetition of words or sentences)

• insufficient stamina	• restless legs: unpleasant or even painful feeling in the legs during inactivity (for example when falling asleep), sometimes decreased by moving (walking) and stimulating (rubbing, hot shower)	• higher cognitive functions (e.g. decreased flexibility)	Functions of the skin • Sweating (too much or to little) • Increased activity of the sebaceous gland causing a greasy skin
• orthostatic hypotension[(med.)], liability to fall*: - response fluctuations*, such as: *wearing off*; *on/off*-problems; dyskinesia; freezing or dystonic posturing.	• dystonia, especially in the feet, particularly during the *off*-period (therefore also early in the morning) because the effect of medication has worn *off*	• mood alterations	
	• pins and needles • deafness	• loss of initiative	
	• deviating sensibility for temperature	• deterioration of attention and memory	
	• decreased smell	• limited internal imagination of visuo-spatial stimuli	
		• personality changes	
		• dementia	

*   *In these problems the physical therapist has an advisory task, although treatment of the problem falls outside the scope of the physical therapist; (med.): problems which are (partly) caused by medication.*

Transfers
The performance of transfers, such as rising from a chair and sitting down, getting in or out of bed, and turning over in bed are limited.[27-29] Patients are especially limited in the performance of transfers in the advanced stages of the disease.[30]

Body posture
Body posture in patients with PD is characterized by a generalized change in posture towards flexion, often in combination with latero-flexion. These postural problems can lead to pain in the musculoskeletal system. The cause of the postural problems is unknown. The generalized change in posture towards flexion may be one of the causes of (recurrent) falling. Secondary muscle weakness of, particularly, the back and neck extensors may arise, but also of the muscles of the shoulders (adductors), hip (extensors), buttocks and legs (extensors). A temporary change in posture towards flexion, on the other hand, might be functional if it is meant as a 'cue' to be able to start moving. In addition to the generalized change in posture towards flexion, reduced trunk flexibility can arise as a consequence of rigidity and bradykinesia.[31,32] Reduced trunk flexibility can cause problems in preserving balance and performing activities, such as reaching.[32]

Reaching and grasping
Reaching, grasping, manipulating and replacing objects is often disturbed, causing problems while performing compound, complex activities, such as getting dressed and eating. In relation to stationary objects, speed and joint mobility are reduced. Furthermore, the grasping forces used are high, especially in the execution of precision tasks of low weight objects.[33] Moving objects (e.g. a coin rolling away) on the contrary, seem to work as an external cue to normalize grasping.[34]

Balance
Preserving balance is a major problem for many patients with PD.[35,36] Disturbed postural reflexes cause balance problems. The amplitude of these reflexes is abnormal.[37,38] Furthermore the reflexes are not adjusted to the actual circumstances of the patient.[39-41] Probably akinesia, bradykinesia and rigidity are responsible for this. Patients with PD have problems processing sensory information, which might aggravate balance problems.[42]

Gait
The gait pattern of patients with PD is often characterized by a reduced stride length and height, walking speed, rotation of the trunk, and arm swing.[43-47] At equal walking speeds, step frequency in patients is increased compared to that of healthy contemporaries.[48] The abnormal gait pattern is increased during dual tasking[49], and festination and freezing can occur[50]. Festination and freezing occur especially during attempts to start walking (hesitation), while passing narrow spaces, such as a doorway, during rotating movements, and during performance of dual tasks while walking. Especially in patients who frequently freeze during walking, variability of stride length is enhanced.[51,52]

Inactivity
Patients with PD tend to be inactive.[53] This may partly be due to fear to move or fear to fall. Through inactivity, secondary disorders may arise, which include decreased aerobic capacity, decreased muscle function (muscle strength, length and stamina), decreased mobility of joints, and decreased bone quality (osteoporosis). Furthermore, inactivity might lead to gastro-intestinal dysfunctions (e.g. constipation).

Falling
PD is a predisposing factor for falls.[54-57] Patients with PD have, compared to their contemporaries, a two[58] to six[59] times greater chance of falling 'once' and a nine times greater chance of recurrent falls[59]. The cause of these falls is most often intrinsic in nature, such as problems with posture and balance (especially during turning, rising from a chair and bending forward), freezing, orthostatic hypotension, and neurological or cardiovascular co-morbidity.[59,60] Extrinsic factors, such as doorsteps and bad lighting, play a much smaller role. In combination with the increased chance of osteoporosis, falling can lead to fractures or to other physical injuries.[58,61] Patients with PD often fall forward.[62] In comparison with 'healthy' elderly less fractures of the wrist occur in patients with PD, since these patients break their falls to a lesser extent with the outstretched hand. The problems of falling can lead to loss of independence or admission into a

Table 6. Limitations in activities.

Transfers: starting and performing complex movements with risk of falling, for example:
- sitting down and rising;
- getting in or out of a car;
- getting in or out of bed;
- turning in bed;
- getting *on* or *off* a bicycle or home-trainer.

Posture: increasing generalized change in posture towards flexion.

Reaching and grabbing:
- personal care, such as toileting and getting dressed, especially buttoning up;
- household activities, such as:
  - cutting;
  - screwing in;
  - brushing teeth;
- problems with writing (micrographia);

Balance: tendency to propulsion with risk of falling, especially during:
- performing transfers;
- changing body position;
- walking (climbing stairs);
- turning.

Walking:
- starting, stopping and turning around;
- freezing at the start of walking or during walking, with risk of falling;
- problems with dual tasking* with risk of falling;
- obstacles, for example:
  - doorway;
  - doorstep;
- long distances.

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* Dual tasking means the simultaneous execution of two motor tasks or a cognitive and a motor task.

nursing home.[63] Moreover, it can decrease the quality of life considerably.[64] Predictors of falls are: falls in the past year, a decreased arm swing during walking, dementia, and a long sickness period.[58] In the case of two or more falls in the previous year, patients with PD have a very high liability to fall again within the next three months.[65] A history of two or more falls had a sensitivity of 86.4% (95% CI 67.3-96.2%) and a specificity of 85.7% (95% CI 71.2-94.2%) in predicting a fall in the next 3 months. Anti-Parkinsonian medication usually has little or no influence on the postural problems and impaired balance.[36,37] Medication

may even increase the likelihood of a fall occurring – both because of increased mobility and because the medication can cause dyskinesias, freezing or orthostatic hypotension.[59] As a consequence of (near) falling, patients can develop fear to move (fear to walk, fear of making transfers). Inability to stand up and knowing that falling can cause a (hip) fracture play a role in the onset and preservation of this fear.

Mental impairments
In the treatment of patients with PD, mental impairments reduce the potential for a successful outcome

of treatment and the ability to use strategies. Patients have problems with spontaneously changing strategy (set shifting), with memory, and with choosing the right strategy in case of varying stimuli and circumstances (cognitive inflexibility). Furthermore, they may suffer from complex behavioral disorders, sleeping problems, psychotic behavior and dementia.[66] Besides, the use of medication can cause cognitive impairments, such as depression, confusion, memory defects, and visual hallucinations (see appendix 3).

Participation problems
Problems with participation can occur in the area of social relations, work, hobby, and sports in patients with PD.

A.12.4   Natural course of the complaints
Relatively little is known about the natural course of PD. Although always progressive, the natural course is very variable.[67] The first symptoms are usually unilateral.[21] Around three years after the first symptoms present, it typically develops into a bilateral disorder, usually still with intact balance.[68] Problems with balance develop about two to three years later, although some patients reach this stage only seventeen years after the start of the disease.[68] Recurrent falling starts on average ten years after the first symptoms.[69] Eventually, nearly all patients will have impaired balance and will fall repeatedly. This forms a threat to quality of life.[70] Initially, patients with balance problems can stand and walk on their own, but on average after eight years, falling becomes, in combination with the other symptoms, a more severe problem. Eventually the balance impairment can become so severe that the patient is permanently confined to a wheelchair or bed, if he has no help of others. Less than five percent of patients with PD are confined to a wheelchair or bed eventually.[71] In later stages non-motor symptoms may arise, such as dementia.
In geriatric patients PD is often accompanied by depression. Furthermore the health problems of these patients can be complex due to age-related co-morbidities. Patients living independently in the community as well as in nursing homes, often die of (aspiration) pneumonia, heart failure[72,73], sepsis due to infection in the urogenital tract, or complications after pressure sores and falling[74,75]. Aspiration pneumonia is often the direct cause of primary health

problems (swallowing problems). Patients with PD have a life expectation similar to their contemporaries.
The severity of the disease is often classified according to the (modified) classification of Hoehn and Yahr (see table 7).[76] However, this classification is only a rough one, with large variability, especially in stage 1. Furthermore, a patient can be classified in two stages, depending on whether the patient is on the *on-* or *off* period (e.g. during the o*n*-period in stage 2 of the Hoehn and Yahr classification and during the *off*-period in stage 4 of the Hoehn and Yahr classification).

A.12.5   Prognostic factors
Jankovic et al. distinguish tremor-dominant and akinetic-rigid types of PD.[77]
In the akinetic-rigid patients, rigidity and hypokinesia are the initial symptoms. This group is characterized by problems with balance and gait (including freezing).[78] Besides that, these patients show a more rapid course of the disease (among others in the motor and cognitive areas).[77] In case of comorbid arteriosclerosis the prognosis seems even worse.[79]
In the tremor-dominant group the process often develops more slowly[79-81] and dementia[80] and cognitive impairments[81] occur less frequently.
In patients who are diagnosed at a young age, the cognitive functions and postural reflexes often remain unimpaired for a long time.[77,82] For patients with recurrent falls, and for patients with insufficient physical activity, the prognosis is unfavorable.[83] The guideline development group takes the view that physical inactivity and falling are prognostic factors which can be positively influenced by physical therapy.

A.12.6   Policy
The general treatment goal is to optimize the daily functioning and to prevent secondary complications. Different medical and paramedical treatments can be used to achieve this.[15]

Medical policy
Treatment with medication
The limitations the patient with PD presents will determine when and what type of medication will be started.[15] See appendix 3 for an overview of possible medication. As a rule, medication is only started if

patients are unable to perform their work or hobbies well because of the complaints, or if the mobility of the patients is affected. Sometimes, in addition to the medication, surgical intervention as indicated takes place.[21]

Medication options are:[21,84,85]

- amantadine;
- dopamine agonists;
- dopamine MAO-B inhibitor;
- anticholinergics;
- levodopa.

If the symptoms are mild, sometimes treatment is started with amantadine (Symmetrel®), which reduces hypokinesia and rigidity. Besides, amantadine can be prescribed to reduce dyskinesias. The working mechanism of this is unclear. In geriatric patients, amantadine causes a lot of side-effects and is therefore prescribed less often.

Because amantadine is limited in its effectiveness in treating symptoms of PD, dopaminergic medication is often commenced. Dopamine agonists (Parlodel®, Permax®, Requip®, Sifrol®) are the first choice, especially for younger adults. This medication stimulates (for the greater part), the postsynaptic dopamine receptors in the striatum), just as dopamine does; by doing so it imitates the natural substance dopamine. In some cases, they are already prescribed in the first phase of the disease, or later, in combination with levodopa. A MAO-B inhibitor (Eldepryl®) is also often used in an early stage of the disease, or in combination with other medicines.

Anticholinergics (Artane®, Akineton®) have a positive effect on resting tremor, by restoring the impaired balance between the substance acetylcholine and dopamine in the brain. Just as amantadine, the anticholinergics cause a lot of side-effects in geriatric patients. Therefore, this medication is prescribed less among these patients.

Most effective is levopoda (Sinemet®, Madopar®), a substance that is transformed in the brain into dopamine; this way the shortage of dopamine is supplied. In view of the unfavorable effects in case of long term usage, prescription of levopoda is postponed for as long as possible. Not all the major symptoms of PD react equally well to the dopaminergic treatment. The effect on bradykinesia and rigidity is often good, the effect on the resting tremor is variable, and the effect on the impaired postural reflexes is limited. In combination with levopoda, the substance entacapone (Comtan®) is often prescribed. This substance inhibits the breaking down of levopoda and by doing so it makes the treatment more effective.

In case of long term usage of levopoda (longer than 2 to 5 years) the wearing-*off* phenomenon starts taking place; when this happens the frequency and the dose of the separate substances need to be increased to retain a constant effect. Furthermore, patients have

Table 7. Classification according to Hoehn and Yahr.

1	Not disabling, mild, unilateral symptoms (e.g. tremor, posture, locomotion, and facial expression).
2	Bilateral involvement, without impairment of balance. Possibly already a light kyphotic posture, slowness and speech problems. Postural reflexes are still intact.
3	Significant slowing of body movements, moderate to severe symptoms, postural instability (no recovery on the Retropulsion test*), walking is impaired, but still possible without help, physically independent in ADL.
4	Severe symptoms, rigidity and bradykinesia, partly disabled, walking is impaired, but still possible without help.
5	Fully disabled, walking and standing impossible without help, continuous nursing care is necessary.

* *The working group defines recovery as: 'the patient recovers by himself and needs a maximum of two steps.*

to deal with the *on-* and *off*-problems. In case of long term usage of levopoda freezing can occur during both *on-* and *off*-periods. Furthermore, the (long term) usage of levopoda might lead to neuropsychiatric complications, dyskinesias, and sudden and unpredictable variation in the *on-* and *off*-periods. If an *off*-period occurs suddenly in a patient, an apo-morphine pump (dopamine agonist) is sometimes preferred.

Surgical treatment
Through stereo-tactic interventions parts of the basal ganglia can be ruled out by a lesion (-tomy) or stimulation via high frequency electro-stimulation.[21] Possible target areas for the intervention are the globus pallidus, the subthalamic nucleus (STN) and the thalamus. Depending on the target area such an intervention causes in particular a decrease of dyskinesias (pallidotomy) or tremor (stimulation of the thalamus or subthalamic nuclei). The interventions applied most often are unilateral pallidotomy and bilateral STN-stimulation.
Stimulation of the basal ganglia can take place unilaterally or bilaterally, but it is mostly done unilateral because of the risk of complications. Stimulation takes place by connecting an electrode in the brain to a pacemaker. Complications might occur as a consequence of:
- the intervention itself (by damaging the surrounding tissue);
- the applied equipment (e.g. infections);
- the lesions or stimulation (among others falling problems, paraesthesia, and headache).

Allied health policy
In addition[1] to medication treatment and (possible) surgical treatment, treatment by allied health professionals is possible.[21,35] Most important interventions are physical therapy, exercise therapy Cesar, exercise therapy Mensendieck, occupational therapy, and speech therapy.

Physical therapy
The objective of physical therapy for PD is to improve the quality of life by improving or preserving independence, safety and well-being through exercise. In a number of intervention studies the effectiveness of physical therapy in PD was studied. This did not lead, however, to unequivocal conclusions. In recently per-

formed Cochrane reviews the authors concluded that, until now, there is insufficient evidence for the effectiveness of exercise therapy, and the preference of one form of exercise therapy over another.[9] In a third systematic review (meta-analysis), which included RCT's and matched controlled trials, the authors concluded that physical therapy or exercise therapy has a positive effect on gait (speed and stride length) and on performance of activities in daily life.[11]

Occupational therapy
Occupational therapy aims to solve practical problems arising in daily activities, for example in the area of living, work, hobby and recreation, self-care, transport, housekeeping and communication. Examination and treatment focus on: an optimal planning of activities during the day; carrying out activities, if needed in a different manner; coping with freezing; learning (the use of) ergonomic principles. Furthermore the occupational therapist has an advisory role in the purchase and use of aids and facilities, and in adjusting the home environment and the interior of the house in such a way that ADL can be performed more easily. The occupational therapist gives instructions to the caregiver*. In a recent Cochrane review it was concluded that there is still insufficient evidence for the effectiveness of occupational therapy in patients with PD.[86]

Speech therapy
Speech therapy aims at teaching the patient to cope with, or to decrease, the limitations and participation problems, which are connected with communication, eating and drinking. Examination and treatment focus is on: motor skills of the mouth, swallowing, breathing, posture, mimics, articulation and intonation, tempo and rhythm of speech, and on the use of alternative communication aids (e.g. computer, communicator). In two recent Cochrane reviews it was concluded that for patients with PD with dysarthria, despite the described improvement of the speech disorders, there is insufficient evidence for the effectiveness of speech therapy and the preference of one form of speech therapy over another.[87]

Multidisciplinary approach
When a patient's needs are complex, a multidisciplinary treatment is indicated. A multidisciplinary

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* The term caregiver refers to both the partner and any other person who takes care of the patient.

team may include, in arbitrary order, a neurologist, a rehabilitation physician, a primary care physician, a nursing physician, a physical therapist, an exercise therapist, an occupational therapist, a speech therapist, a (neuro)psychologist, a recreational activities supervisor or an occupational therapist (especially in case of relatively young patients), a social worker, and a PD specialist nurse.

It is necessary that all different disciplines treating a patient communicate with each other. Most often the neurologist, the (PD) nurse, or the rehabilitation physician will act as team coordinator, but this depends on the regional organization of health care. In the Netherlands there is, at the moment, the possibility of a so-called Short Stay, or multidisciplinary rehabilitation in day care, in a number of locations (see appendix 2).

Admission to a nursing home
The main reasons for referral to a nursing home are physical decline and falling problems, especially if these are accompanied with confusion and increasing dementia.[63] Sometimes (temporary or permanent) admission to a nursing home or related forms of care are indicated although there are no (or only minimal) physical or psychological complaints.[88] This occurs mostly where there are problems related to the home circumstances (e.g. the temporary lack of a caregiver).

A.13 The role of the physical therapist

The objective of the physical therapist for PD is to improve the quality of life by improving or maintaining the patient's independence, safety and well-being through exercise. This is achieved by prevention of inactivity, prevention of falls, improving functions and decreasing limitations in activities. Based on the phases the patient goes through, treatment goals with accompanying interventions can be determined. Quick reference card 3 describes the different phases the patient goes through with a number of specific treatment goals for each phase. These treatment goals apply to the phase addressed, but also remain important in later phases. Quick reference card 3 is based on studies of Turnbull[89] and Kamsma[26].

A.13.1 Physical therapy in the early phase

Patients in the early phase of PD have little or no limitations. They are, according to the Hoehn and Yahr classification, classified in stages 1 to 2.5. The goal of physical therapy in this and the following phases is:
1. prevention of inactivity;
2. prevention of the fear to move or to fall;
3. preserving or improving physical capacity (aerobic capacity, muscle strength, and joint mobility).

The means by which the physical therapist can achieve these goals are by giving information and advice, and by (group) exercise therapy, with specific attention to balance and physical capacity.

A.13.2 Physical therapy in the mid phase

In the mid phase, patients develop more severe symptoms and limitations in activities. In addition, problems with balance arise, with an increased risk of falling as a consequence. In this phase patients are classified in the stages 2 to 4 according to the Hoehn and Yahr classification. The goal of the physical therapist in this and in later phases is to preserve or improve activities. This is achieved by exercising function and activities (by exercise therapy). In treatment, which is preferably given at the patient's home, five core areas can be identified:
1. transfers;
2. body posture;
3. reaching and grasping;
4. balance;
5. gait.

Cognitive movement strategies and cueing strategies are applied. If necessary the caregiver will be involved in the treatment.

A.13.3 Physical therapy in the *late phase*

In this phase of the disease the patient is classified in stage 5 according to the Hoehn and Yahr classification. The patient is confined to a wheelchair or bed. The treatment goal in this phase is to preserve vital functions and to prevent complications, such as pressure sores and contractures. This is achieved by actively supported exercising, correcting the body posture in bed or in the wheelchair, and by giving information and advice with regard to the prevention of pressure sores and contractures. In this therapy, the caregiver will be involved.

A.14 Referral

A.14.1 Setting Indication

The guideline development group takes the view that physical therapy treatment is indicated in case of the following impairments or limitations:[12,90,91]

- restrictions in activities and impairments in functions especially with respect to transfers, body posture, reaching and grasping, balance and gait;
- inactivity or a decreased physical capacity;
- increased risk to fall or fear to fall;
- increased liability to pressure sores;
- impairments and limitations as a result of neck and shoulder complaints;
- need for information about the consequence of PD, especially regarding those limitations in activities which have to do with posture or movement.

When related to the patient's limitations in activities, the caregiver's needs can also be a reason for referral (e.g. lifting instruction in case the patient is confined to a wheelchair or bed).

A.14.2 Early referral

Early referral (immediately after diagnosis) to a physical therapist is recommended to prevent or decrease complications as a result of falling and inactivity.[90-92] This is in line with the recommendation in the 'Guidelines diagnostics and treatment of patients with PD' of the Commission Quality Promotion of the Dutch Society for Neurology.[15]

A.14.3 Providing information

The physical therapist needs the following information from the referring Physician:[93]

- name, date of birth and address of the patient;
- date of referral;
- diagnosis;
- co-morbidity (including osteoporosis and mobility-limiting disorders such as arthritis, rheumatoid arthritis, heart failure and COPD);
- course of the health problem; treatment policy until now and its result (preferably a copy of the medical correspondence);
- reason for referral (patient's request or the objective that the referring physician wants to achieve with the referral);
- name, address, and signature of the physician.

Furthermore the referring physician should inform the physical therapist if other forms of parkinsonism are excluded. It is desirable that the physical therapist receives information, preferably by a copy of the medical correspondence, on the course of the health problems, on possible mental disorders of the patient related to PD, on the treatment policy, and on the result of past and ongoing other treatments.

B Diagnostic process

During the diagnostic process the physical therapist determines if physical therapy is indicated and if these guidelines can be applied to the patient concerned. The diagnostic process consists of taking the medical history, analysis of the medical history, performing a physical examination and drawing up a treatment plan. The starting point for the diagnostic process is the patient's request (including the most important complaints).

The physical therapist assesses purposively, conscientiously, systematically and methodically (module Methodical Conduct of Physical Therapy Diagnosis and Intervention KNGF[94]) which impairments (in functions), limitations in activities (disabilities) and participation problems are of most immediate concern to the patient. He assesses the prognosis, and the patient's needs for information.

B.1 Referral

If a patient is referred by a primary care physician (PCP) or medical specialist, the physical therapist assesses whether the referral contains sufficient information (see paragraph A.14.3).

The objective of the diagnostic process is to assess the severity and nature of the patient's problems, and to evaluate the extent to which physical therapy can influence these problems. The starting point is the patient's own goal. It is necessary that the physical therapist receives information on possible co-morbidity (among others osteoporosis or other disorders that decrease the mobility, such as arthritis, rheumatoid arthritis, heart failure and COPD). Furthermore it is important for the physical therapist to know if other forms of parkinsonism are excluded. Information should be received on the disease course, on possible mental impairments related to PD, on treatment policy, and on the results of medical treatment thus far.

B.2 History-taking

While taking the medical history the physical therapist asks questions which are necessary to determine the patient's problems (see quick reference card 1). Also the patient's expectations regarding the interventions and treatment outcome are recorded. The physical therapist tries to assess whether the patient's expectations are realistic. When mental factors or physical disorders result in communication difficulties, and when the patient is mainly dependent on others for care, it is necessary to involve the caregiver to get an accurate picture of the patient's problems. Based on the history-taking, the physical therapist formulates treatment goals, together with the patient.

B.3 Analysis to formulate the objectives to be tested

Based on the information obtained while taking the medical history, the physical therapist formulates a number of problems to be tested in a physical examination. Possible objectives are: 1) physical capacity; 2) transfers; 3) body posture; 4) reaching and grasping, and 5) balance and gait.

B.4 Physical Examination

The health problems of patients with PD can vary widely during the day. Therefore, during physical examination, the physical therapist should determine if the patient is in an *on-* or *off*-period. The physical therapist can make use of quick reference card 2 as a guide to perform a structured physical examination of 'physical capacity', 'transfers', 'body posture', 'reaching and grasping', 'balance', and 'gait'. Based on the medical history the physical therapist determines if the patient has other disorders that need to be included when physical examination is performed (e.g. neck-shoulder complaints or back complaints that seem to be connected with PD).

B.5 Outcome measures

Outcome measures serve as an aid in charting and objectively assessing health problems. Furthermore, a number of outcome measures can be used to evaluate (preliminary) treatment effectiveness. A broad range of outcome measures is available to identify and evaluate health problems related to PD. The majority of these instruments, however, is developed for the benefit of scientific research and is focused on iden-

tifying health problems and evaluating the effects of treatment in groups of patients with PD. The value of these instruments for use with individual patients is still unclear. The guideline development group selected outcome measures which seemed to be most suitable for use in daily practice. In this selection process, clinimetric properties were of a decisive nature. The guideline development group takes the view that for this purpose outcome measures linked to the level of limitations (in activities) domain of the International Classification of Functioning, Disability and Health (ICF) are most suitable.[25]

The guideline development group makes a distinction between outcome measures that should always be used, and outcome measures that can be used in addition, dependent on the treatment goal.

As a result of medication, motor problems can vary greatly during the day. Therefore it is important that measurements are performed at the same time of the day, assuming medication intake takes place at the same time each day.

B.5.1 Questionnaire Patient Specific Complaints

In order to objectively identify and evaluate the extent of limitations in most important activities, the guideline development group recommends the use of the Patient Specific Complaints questionnaire, a patient preference outcome scale (see appendix 4.1). The Patient Specific Complaints questionnaire is a measuring instrument to determine the functional status of individual patients.[95] It lists the limitations (and participation problems) frequently encountered in daily life and perceived by the patient as being important. For this reason the questionnaire is suitable to specify and evaluate individual treatment goals. in the case of patients with low back pain, it can distinguish between patients with and without progress and demonstrates responsiveness. In this patient population the Patient Specific Complaints questionnaire is responsive.[95]

Patients select the five most important complaints regarding their physical activities they would like to improve. The activities have to be relevant for the patient personally, have to be carried out periodically (weekly), and have to be inevitable. At follow up the patient must have performed the activity again, so that a follow-up measurement can take place. For each activity the patient indicates how troublesome

it was to carry out that activity in the foregoing week on a Visual Analogue Scale (VAS) of 100 mm. The score is the distance in millimeters from zero (left side of the line) to the mark the patient set. The three most difficult activities can be evaluated. For external communication a total score can be determined by adding up the scores of the three most difficult activities. At the beginning and at the end of the treatment period the patient indicates how hard it was to perform these three activities in the foregoing week. With the follow-up measurement preceding score is shown to the patient.

The VAS is easily understood by most patients from diverse cultural groups and can be used frequently and repeatedly. The use of the VAS requires no specific training.

B.5.2 Questionnaire History of Falling

Patients with PD who have fallen more than once in a year, have a very high liability to fall again within the next three months.[65] Incidence of falling and the possible risk of falling are mapped by means of a short structured questionnaire – the History of Falling questionnaire (see appendix 4.2).[96,97] Patients who fell more than once in a year receive a falls diary (see appendix 4.3). The falls diary gives insight into the frequency and circumstances of falling. The falls diary is very extensive, but it concerns a severe and troublesome problem. It is recommended to ask the caregiver to fill in the falls diary together with the patient.

B.5.3 (Modified) Falls Efficacy Scale

Confidence in maintaining balance (preserving body posture) seems to be a mediator in the elderly between the fear to fall and functional ability.[98] If patients have fallen in the past year, or if there have been moments that they almost fell, it is necessary to identify the fear to fall objectively. The (modified) Falls Efficacy Scale is an extensive test in which patients are asked about the fear to fall ('none' to 'a lot'), they experience during the performance of ten different activities (FES; see appendix 4.4).[99] In this test some items in the original FES, namely 'getting in and out of bed', 'personal grooming', and 'getting on and *off* the toilet without falling' are replaced by 'cleaning the house, such as sweeping and dusting', 'doing simple shopping', and 'climbing up and down the stairs'. Furthermore the scoring system is simpli-

fied (range 0 to 3).

The range of the total score is 0 to 30. In a population of elderly still living at home (55-85 years of age) a score of 3 or more in the modified FES (patient has fear to fall), especially in combination with more than one fall in the past year, is a good predictor for recurrent falling.[99] Currently it is unknown to what extent these data can be applied to patients with PD. The original FES has been found to be reliable and valid in a population of elderly living at home.[100,101] Furthermore, it appeared responsive for 'improvement after rehabilitation' in a population of stroke patients in the first period after stroke.[102]

B.5.4 Freezing of Gait questionnaire

During physical examination it is difficult to score freezing, because it occurs rarely during the clinical assessment.[30] Physical therapists are especially dependent on the patient's self-report. If patients have recently experienced that their feet were glued or stuck to the ground, the physical therapist asks the patients to fill in the six questions of the Freezing of Gait questionnaire (FOG questionnaire; see appendix 4.6).[103] This instrument is suitable to identify freezing in a population of patients with PD.[103]

B.5.5 LASA physical activity questionnaire

If there are doubts with respect to the patient's level of activities (Dutch Standard of Healthy Moving)[104], the guideline development group advises the use of the LASA physical activity questionnaire (LAPAQ; see appendix 4.7).[105] The LAPAQ is a valid and reliable method to measure physical activity of the elderly and is easier to use than instruments like a seven days activity diary or a pedometer. The time needed to complete the LAPAQ is about six minutes.

Based on the above the guideline development group formulated the following recommendations:

Inventory (and objective evaluation) of the most important problems during history-taking (level 4)
The guideline development group takes the view that the Patient Specific Complaints Questionnaire (for patient specific complaints in the performance of activities and assessment of the treatment goal) and the History of Falling Questionnaire (retrospective)

should be used when taking the medical history of a patient with PD.

Inventory of freezing during history-taking (level 4)

The guideline development group takes the view that the FOG questionnaire should be used in patients with PD who have recently experienced that their feet seemed glued or stuck to the ground.

Inventory and evaluation of falling or near falling (level 4)

The guideline development group takes the view that, if patients with PD have fallen in the past year, or if they have experienced near falls, the FES and (prospective) falls diary should be used to identify and evaluate these problems.

B.5.6 Retropulsion test

Numerous tests are available to assess balance problems, but none of them measure the whole spectrum of balance reactions. The most used, quick and easy to perform test is the Retropulsion test, by which an unexpected, quick and firm jerk on the shoulder is given in a backward direction (see appendix 4.5).[106] Currently this test seems the most reliable and valid test by which to assess balance in patients with PD.

B.5.7 Parkinson's Activity Scale

The Parkinson's Activity Scale (PAS) can be used to assess problems with functional mobility.[107] In the modified version of the PAS, the item gait-akinesia is extended with two dual tasks (see appendix 4.10). The PAS is a comprehensive practical test for gait and transfers (including rolling over in bed). It takes around ten to fifteen minutes to administer. The test is a valid and reliable instrument for patients with PD and gives relevant information for the diagnostic and therapeutic processes.

B.5.8 Timed Up and Go test

The Timed Up and Go test is a short, practical test by which gait and balance are tested (TUG; see appendix 4.11).[108] The TUG is a valid and reliable instrument for patients with PD.[109] It is important that the patient wears the same footwear during every measurement.[110]

B.5.9 Six-minute walk test

Patients with PD have a tendency to be inactive. To identify and evaluate the physical capacity of patients who are not troubled by freezing, it is recommended that the Six-minute walk test is performed (see appendix 4.8).[111] This test is functional, easy to apply, and reliable for this group of patients.[112] Furthermore the Six-minute walk test can detect changes within this population (which are the result of training).[113] If the test is performed in a marked out, square track, the physical therapist should not walk together with the patient.[114] If the test is performed on a treadmill the inclination grade has to be zero and, if indicated by the patient, the speed can be increased (this should not be done by the patient himself).[115] It is important that the patient wears the same footwear for each assessment[110] and that the physical therapist encourages the patient to the same extent[114].

B.5.10 Ten-meter walk test

The Ten-meter walk test is a reliable instrument to identify the comfortable walking speed of patients with PD who are able to walk independently (see appendix 4.9).[112] Furthermore, the number of steps needed to walk ten meters at a comfortable pace is used to determine the stride length (in connection with the possible use of visual cues). During the performance of the test a walking aid may be used if necessary.

Based on the above the guideline development group formulated the following recommendation:

Objective inventory and evaluation of complaints (level 4)

The guideline development group takes the view that during physical examination of patients with PD the following outcome measures can be used for an objective inventory:
1. the Retropulsion test (problems with balance, general impression);
2. the Parkinson's Activity Scale (PAS) (functional mobility);
3. the Timed Up and Go test (TUG) (functional mobility and balance);
4. the Six-minute walk test (physical capacity in the absence of freezing);
5. the Ten-meter walk test.

B.6 Analysis

To round up the diagnostic process, the physical therapist answers the following questions:

- Is physical therapy indicated?
- Can the guidelines be applied to this individual patient?

Physical therapy is indicated if the patient:

1. is limited in one or more activities (transfers, posture, reaching and grasping, balance and gait);
2. has (or has the risk of) a decreased physical capacity caused by inactivity;
3. has an increased risk of falling or has fear to fall;
4. has an increased chance of pressure sores; or
5. has the need for information or advice on the disorder, natural course and prognosis.

The patient is only eligible for physical therapy treatment if there are no medical problems for which therapy would be a contraindication, no personal or social factors that would influence compliance, and if the physical therapist assesses that the impairments in functions and activities, as well as behavioral aspects, can be influenced by physical therapy.

If physical therapy is indicated and the guidelines are applicable, the physical therapist, in consultation with the patient, formulates, a treatment plan in which the individual treatment goals are included. If the physical therapist cannot confirm the indication for physical therapy he should contact the referring physician. It is possible that the physical therapist will advise a referral to another allied health discipline or to a medical specialist.

B.7 Treatment plan

After taking the medical history and performing physical examination, the physical therapist formulates, in consultation with the patient, a treatment plan. The treatment plan includes the physical therapeutic treatment goals and prioritizes them. The main treatment goal, the point of focus in the treatment plan, is in line with the patient's needs. In the formulation of the treatment goals and the main goal, the motivation, ability and the understanding of the patient are taken into account.

Possible treatment goals for patients with PD are:

1. to increase safety and independence in the performance of activities, with the emphasis on:

- transfers;
- posture;
- reaching and grasping;
- balance;
- gait;

2. to preserve or improve physical capacity;
3. to prevent falling;
4. to prevent pressure sores;
5. to stimulate insight into impairments in functions and limitations in activities, especially in the area of posture and movement.

If the patient is treated by another allied health discipline, treatment will be attuned to this discipline. After formulation of the treatment goals, the physical therapist selects the appropriate interventions to achieve the formulated goals. These can be exercising functions or activities, but also giving information. Besides treatment goals and interventions, the treatment plan includes the expected number of treatment sessions needed, frequency of treatment sessions, and treatment location (at home, in the clinic, in a care facility). The starting point for the information plan is the need for information, advice and coaching which is identified during the diagnostic process.

C Therapeutic process

C.1 General treatment principles

C.1.1 Location of the treatment

Physical therapy takes place in the primary health care practice, the patient's home, a rehabilitation center, a nursing home or a hospital. The choice of location is determined by the objectives of treatment, but also depends on the abilities of the patient and the physical therapist, as well as on external factors.[12] Absorbing new information is often slower in patients with PD, and the use of the acquired knowledge and skills in other circumstances is limited.[91,116] Limitations in activities are often related to the home environment. Treatment focused on increasing activities preferably takes place at the patient's home. Improvement of the physical capacity preferably takes place in the physical therapist's practice (if there is room and equipment suitable for this purpose), at a gym, or during the performance of recreational activities.

Based on the above the guideline development group formulated the following recommendations:

Improvement of activities (level 4)
The guideline development group takes the view that treatment of patients with PD focusing on improvement of functional activities preferably takes place at the patient's home.

Improvement of physical capacity (level 4)
The guideline development group takes the view that improvement of the physical capacity of the patient with PD preferably takes place in the physical therapist's practice (if there is room and equipment suitable for this purpose), at a gym, or during the performance of recreational activities.

C.1.2 Involvement of the caregiver
It is very important to involve the caregiver in the treatment. Caregivers can assist in using cues and cognitive movement strategies when the patient has problems applying these strategies in daily life (e.g. in case of a reduced cognitive function). The number of instructions should be limited, and the patient will benefit from only one instruction at a time, especially if he has cognitive impairments, for example in attention and memory. Caregivers do not have to fulfill the role of a therapist. However, they often are a key figure in the care of patients with PD, and patients with complex problems can only function in the home environment when a caregiver is present. It is important to facilitate the patient's care by, for example, teaching lifting techniques to the caregiver when the patient with PD is confined to a wheelchair or bed, and by teaching how to assist the patient during freezing and *on*/*off*-periods.

C.1.3 Dual tasks
When performing two or more tasks at the same time (dual tasking or multitasking), patients with PD find it difficult to pay full attention to all tasks. Mostly, they need to pay specific attention when performing 'automatic movements' safely, such as walking. The negative effect on gait and maintaining balance can lead to unsafe situations, in daily life as well as during the treatment.[46,117-120]
Avoiding performance of dual tasks, during treatment as well as in daily life, increases the safety of patients

with PD and decreases falls. Physical therapists teach patients to perform activities one after the other and consciously, using visual guidance if necessary.[121,122] The physical therapist gives the patient a simple instruction before the performance of an activity or movement. During performance of an activity or movement no further instruction is given, as this will lead to dual tasking. In therapy, optimization of one activity has to be fully completed before commencing optimization of the next activity.

C.1.4 Time of treatment
It is important to take *on*- and *off*-periods into account when planning treatment. Cognitive moving strategies and cueing strategies are best used during the *on*-period, because at this time neurological problems have less influence on the level of performance. Also, physical capacity should be trained during these periods. Patients who are regularly *off* need cognitive movement strategies especially during the *off*-periods.

Based on the above the guideline development group formulated the following recommendations:

Exercising activities (level 4)
The guideline development group takes the view that exercising activities in patients with PD have to take place in the *on*- as well as in the *off*- period.

Training of physical capacity (level 4)
The guideline development group takes the view that it is advisable to train physical capacity (including strength) in patients with PD during the *on*-period.

C.1.5 Tempo of exercising
If impairments of cognitive functions are present, the physical therapist can only make limited use of cognitive movement strategies. Also, the amount of advice given by the physical therapist will be limited. The physical therapist has to adjust tempo and difficulty of the therapy. Fatigue has a negative effect on the performance of activities. Therefore, in the case of fatigue, tempo and schedule of treatment (e.g. spreading of the exercises during the day) need to be adjusted.

C.1.6 Recognizing a response fluctuation

A well-controlled medication regime is the responsibility of the primary care physician and the medical specialist (mostly the neurologist, sometimes a geriatric physician or rehabilitation physician). However, because of regular patient contact physical therapists are able to recognize response fluctuations at an early stage. These fluctuations often arise when the disease progresses or when medication is used over a long time and can be partly corrected by an adjustment of medication. If the patient is experiencing response fluctuations they should contact their medical specialist.

Based on the above the guideline development group formulated the following recommendation:

Recognizing response fluctuations(level 4)
The guideline development group takes the view that the physical therapist has a signaling function in patients with PD.
The physical therapist has to draw the patient's attention to response fluctuations.

C.1.7 Contra-indications

Deep brain stimulator

A deep brain stimulator forms an absolute contra-indication for diathermia (short waves or micro-waves). The high frequency electric current that is caused by diathermia can reach the implanted system and in this way cause severe tissue damage (with severe consequences for the patient), or damage or disorganize parts of the implant (regardless if the stimulator is *on* or *off*).[123] Depending on the applied electrodes (coil or capacitor plates), its localization, the dose (continuous or pulsating), and the intensity used, electromagnetic pulses may disorganize the stimulator, even if it is switched *off*. Furthermore, the implanted metals, including the electrodes, can concentrate the electromagnetic field, leading to the body tissue in that area being heated, which can result in functional disorders and even necrosis. The Dutch Governmental Control on Public Health has published a serious warning about this (letter 2001-14-IGZ). The Governmental Control states that implants must not be situated in the area treated. The safe distance of electrodes from the electromagnetic fields has not been determined and it is advisable to err on the side of safety and choose an alternative form of therapy.

The Governmental Control warning concerns ultra short wave therapy (not ultra sound therapy therefore). However, it is advisable not to place an ultra-sound over the stimulator, as the mechanical vibration may disturb the performance of the apparatus, and reflection of the vibrations on the stimulator or electrodes may cause heating of brain tissue by interference.

Mental impairments

Mental impairments, such as impairments in cognition (e.g. poor memory, dementia and severe hallucinations), personality and attention are relative contra-indications for the treatment of health problems related to PD. These impairments influence the patient's learning ability, making it difficult to pass on information and give advice. In such cases the caregiver plays an even greater role in applying cognitive movement and cueing strategies. If (unstable reaction to) medication underlies these impairments, physical therapy, physical therapeutic treatment or exercise can be postponed (in consultation with the referring physician) until the patient has adjusted well to the medication.

Freezing

Freezing is a relative contra-indication for hydrotherapy. In this case hydrotherapy is only possible with individual supervision.

C.1.8 Frequency and duration of the treatment

The duration and frequency of treatment sessions and the course of treatment depends strongly on the requirements and potential of the patient, and on the response to treatment. For each patient treatment will focus on the main problem which is related to the patient's requirements. If the patient has achieved the specified goals, or if the physical therapist does not expect changes (improvement, preservation or prevention of worsening) by physical therapy, treatment will be discontinued. Treatment will also be discontinued if the physical therapist expects that the patient is able to achieve treatment goals on his own (without therapeutic supervision). This is discussed with the referring physician. An exercise period of at least four weeks is required to decrease limita-

tions in activities, and to improve the ADL.[116,124-127] During the first sessions it will become clear if using cues is advisable. A period of 8 weeks of exercise is required to improve the patient's physical capacity. The patient can perform the exercises on his own at home, provided that he is well instructed. Also, the patient's safety has to be guaranteed. A low treatment frequency (e.g. once a week to adjust the exercise program) could be sufficient.

Based on the above the guideline development group formulated the following recommendation:

Frequency and duration of the treatment (level 3)
There are indications that a period of at least four weeks is needed to decrease limitations in functional activities. To improve physical capacity, exercising for at least eight weeks is necessary, in which period a low frequency of treatment (e.g. once a week to adjust the exercise program) is sufficient.
Quality of the article found: C (Kamsma et al.[116], Comella et al.[124], Dam et al.[125], Patty[126], Thaut et al.[127]).

C.2 Treatment strategies

If the patient's understanding, insight and memory are sufficient, the physical therapist makes use of cognitive movement strategies and cueing strategies. Often the patient's learning ability becomes clear after a number of treatments. In this, feedback of the caregiver is important.

C.2.1 Cognitive movement strategies

The physical therapist can apply cognitive movement strategies to improvement transfers.[91,116,121,128,129] In cognitive movement strategies, complex (automatic) activities are transformed to a number of separate elements which are executed in a defined sequence, and which consist of relatively simple movement elements. By doing this, complex movements are organized in such a way that the activity is performed consciously. Dual tasking during complex (automatic) activities in daily life is thereby avoided. Furthermore, the movement or (part of the) activity will be practiced and rehearsed in the mind. It is explicitly not intended that the activity or the movement will become automatic. Performance has to be consciously controlled and can be guided by using cues for initiation.[129]

C.2.2 Cueing strategies

The performance of automatic and repetitive movements is disturbed as a result of fundamental problems of internal control. So-called cues are used to complete or replace this reduced or even absent internal control. Cues are stimuli from the environment or stimuli generated by the patient, which increase attention and facilitate (automatic) movements. It is suggested that cues allow a movement to be directly controlled by the cortex, with little or no involvement of basal ganglia. Not all patients benefit from using cues. Cues can be generated internally (bow, stretch, wave) or outside the body. Stimuli outside the body can be divided into moving stimuli (light of a laser pen, a moving foot, a falling bunch of keys) and non-moving stimuli (sound of a metronome, stripes on the floor, the grip of a walking-stick).

With regard to therapeutic use of cues, a distinction is made between rhythmical recurring cues and one-*off* cues (see table 1). Rhythmical recurring cues are given as a continuous rhythmical stimulus, which can serve as a control mechanism for walking. The distance between (frequency of) rhythmical cues during walking will be based on the number of steps needed to perform the Ten-meter walk test at comfortable pace. One-*off* cues are used to keep balance, for example when performing transfers and for initiating ADL, or when getting started again after a period of freezing.

Types of cues
- auditory, for example stepping out on the third count to initiate a movement, or by use of a walkman, metronome, singing or counting (by patient or caregiver) to continue walking;[127-132]
- visual, for example: stepping over one's foot, over an object on the floor to initiate walking; following somebody, stripes on the floor or projection of a laser pen handled by the patient, or walking with an inverted walking-stick by which the patient has to step over the grip constantly to continue walking;[128,129,133,134-138]
- using of a mirror;[134]
- focusing on an object (clock, painting) in the environment to improve posture;
- tactile, for example tapping on the hip or the leg;[129]
- cognitive, for example focusing on the place the patient wants to go, and not on the doorpost, to

initiate walking;
- or a mental picture of the appropriate stride length to continue walking.

C.3 Treatment goals

Depending on the findings in the diagnostic process (based on referral, history-taking and physical examination), the treatment of patients with PD is focused on one or more of the following treatment goals:
- stimulate safety and independence in the performance of activities, with emphasis on: transfers; posture, reaching and grasping, balance or gait;
- preserve or improve physical capacity;
- prevention of falls;
- prevention of pressure sores;
- stimulate insight into impairments in functions and limitations in activities, especially of posture and movement.

During the therapeutic process goals are constantly evaluated and, if necessary, adjusted. In this, providing information and advice is a recurrent part. Because of the progressive nature of the disease, preservation and prevention of further decline can be a treatment goal.

C.3.1 Improvement of the performance of transfers

Goal: to perform transfers (more) independently.
Strategy: to train transfers by applying cognitive movement strategies and cues to initiate and continue movement.

Two controlled studies (level B) demonstrate that cognitive movement strategies can improve the performance of transfers.[26,128] For a detailed description of the applied cognitive movement strategies we refer to the study of Kamsma et al., see appendix 5.[116] Cues improve the initiation of the transfer. The treatment in the study by Nieuwboer et al. consisted of 3 treatment sessions of 30 minutes a week over 6 weeks. The exercise program, that took place at the patient's home, was, among others, focused on using cues to improve gait and cognitive movement to improve the performance of transfers. The activities were trained under different circumstances.
The study of Müller et al. (level B) demonstrated that patients with PD can improve the performance of

their daily activities, including transfers, by following an exercise program that is focused on cues, as well as on cognitive movement strategies.[129]

Based on the above, the guideline development group formulated the following recommendations:

The application of cognitive movement strategies improves the performance of transfers (level 2)
It is plausible that in patients with PD the application of cognitive movement strategies improves the performance of transfers.
Quality of the articles found: B (Kamsma et al.[116], Nieuwboer et al.[128]).

The use of cues in combination with the application of cognitive movement strategies improves the performance of transfers (level 3)
There are indications that the use of cues in combination with the application of cognitive movement strategies improves the performance of transfers in patients with PD.
Quality of the article found: B (Müller et al.[129]).

C.3.2 Normalizing body posture

Goal: conscious normalization of body posture.
Strategy: to exercise relaxed and coordinated movement, to provide feedback and advice.

There are indications (level 3) that axial rotation while sitting and reaching (with preservation of balance), and body posture, may be improved by an individual exercise program consisting of thirty sessions for ten weeks. This is based on a randomized level B study.[112] In this study, patients were taught to move in a more relaxed manner. Mobility as well as coordination improved by this approach.
Eight principles underlay the exercise program, covering seven phases – from easy (lying prone) to difficult (standing position):
1. (Conscious) use of proper muscles stimulates coordination.
2. A wider joint mobility does not occur by stretching, but by relaxation. Relaxation is achieved by moving slowly whilst maintaining quiet respiration using diaphragmatic breathing.
3. The emphasis lies on the axial structures (neck and back). Exercises to increase relaxation and

mobility of the extremities follow after exercising the axial structures.

4. Isolated efficient movements of the axial structures are easier to learn in a supported position, where the patient can focus on the least number of segments possible.

5. When the patient becomes more competent in performing the exercises, they can be made more complex, either by decreasing support (from lying to standing) or by increasing the number of segments that have to be coordinated.

6. Each phase builds on the previous phase with each session starting with rehearsing exercises from previous phases.

7. In each phase the exercises are functional, to make the transfer to daily activities easier.

8. Patients learn to perform the exercises independently and consciously (cognitively), so they can continue these at home (after treatment has ended).

In a randomized study, Stallibrass demonstrated (level B) the effectiveness of a twelve-week exercise program, focused on the coordination of muscle activity whilst maintaining posture and movement.[139] This exercise program was based on the Alexander technique.[140]

The Alexander technique assumes that the impaired balance between head, neck and back cannot be restored by simply taking another, 'better' posture, since in that way new tension patterns arise. The physical therapist assesses changes in muscle activity, balance (preserving body posture), and coordination by means of observation and palpation; next, he provides feedback on the changes which the patient tries to achieve by a learning and consciousness-raising process.

Patients learn to move in a more relaxed fashion and to preserve their posture. The basic principles are taught on the basis of simple daily activities, such as sitting, gait and lying.

Based on the above the guideline development group formulated the following recommendation:

Exercise programs to improve coordination of muscle activity make the performance of activities easier (level 3)

There are indications that in patients with PD, exercise programs to improve coordination of muscle activity make the performance of activities easier.
Quality of the article found: B (Stallibrass et al.[139]).

The guideline development group takes the view that in patients with PD the change in posture towards complete flexion can often be corrected by conscious activity, by applying visual feedback (mirror) or verbal feedback (also from the caregiver).[141] To preserve the effect the patient has to be working consciously on the correction of posture all the time.

Based on the above the guideline development group formulated the following recommendation:

Change in posture towards flexion can often be corrected by applying feedback (level 4)
The guideline development group takes the view that in patients with PD the change in posture towards flexion can often be corrected by applying feedback, either verbal or with the help of a mirror.

C.3.3   Stimulate reaching and grasping

Goal: to improve reaching and grasping, and manipulation and movement of objects.
Strategy: to apply cueing strategies and cognitive movement strategies, and to avoid dual tasking.

The exercise of reaching, grasping, and moving objects often takes place in cooperation with an occupational therapist. Cueing strategies (to initiate and continue the activity) and cognitive movement strategies, and also avoidance of dual tasking are important in improving the ability to reach, grasp and move objects.[91]

Based on the above the guideline development group formulated the following recommendation:

Application of cueing strategies, cognitive movement strategies and avoiding dual tasking (level 4)
The guideline development group takes the view that in patients with PD reaching, grasping and moving objects is improved by applying cueing strategies, cognitive movement strategies and avoiding dual tasking.

Tremor usually becomes worse in the case of fear or emotion and cannot be decreased by physical therapy. Relaxation (e.g. according to, Jacobson[142], Schultz and Luthe[143]) or Halliwick (hydrotherapy)[144] can decrease tremor. In patients suffering from freezing, hydrotherapy can take place only with individual supervision.

Based on the above the guideline development group formulated the following recommendations:

Relaxation methods (level 4)
The guideline development group takes the view that in patients with PD tremor is decreased by relaxation methods.

Hydrotherapy (level 4)
The guideline development group takes the view that in patients with PD hydrotherapy can take place only with individual supervision.

C.3.4   Stimulate balance
Goal: to optimize balance during the performance of activities.
Strategy: exercises for balance and training strength.

Hirsch et al.[145] and Toole et al.[146] demonstrated in their studies (level B) that an exercise program of ten weeks (60 minutes, 3 times a week) exercising balance and training strength is an effective treatment for problems with balance in patients with PD. The balance exercises consisted of pro- and retropulsion tests, in which the patient learned to make use of visual and vestibular feedback, and of training the strength of the knee-flexors and knee-extensors and the muscles of the ankle at 60 percent of the maximum strength.

In the treatment of problems with balance in healthy elderly persons, three strategies proved to be effective:[147]
1. walking outside three times a week, completed with a home exercise program (30 minutes, 3 times a week) with: a) walking variations (forward, sideward, walking on toes, stepping over an object, walking while turning, and walking from sitting position); b) exercises to increase the mobility of, among others, neck, knees and hips

and c) exercises to strengthen the muscles of the leg;
2. tai chi (two group sessions a week for fifteen weeks);
3. referral to occupational therapy to identify and alter any dangers present in the home environment.

It is plausible that these interventions are also effective in patients with PD, especially in the early phase of the disease. If the strategies are applied in patients with PD, the specific Parkinson's-related problems have to be taken into account.

Based on the above, the guideline development group formulated the following recommendations:

Exercises to improve balance (level 2)
It is plausible that an exercise program consisting of exercising balance and training strength is effective in stimulating the balance in patients with PD.
Quality of the articles found: B (Hirsch et al.[145], Toole et al.[146]).

Exercises to prevent falls (level 1)
It has been demonstrated that, in healthy elderly persons, an exercise program focused on walking, mobility of the joints and muscle strength, and tai chi decrease the number of falls.
Quality of the article found: A1 (Gillespie et al.[147])

C.3.5   Improvement of gait
Goal: to walk safely (and independently) and to increase (comfortable) walking speed.
Strategy: to exercise walking with the use of cues and cognitive movement strategies, to give instruction and to train muscle strength and mobility of the trunk.

The studies of Lewis et al.[138] and of Morris et al.[45] (both level C), demonstrated that the use of rhythmic recurrent visual cues improves stride length and step frequency in patients with PD.
The studies of Thaut et al.[127] and Behrman et al.[148] (both level B) and the studies of McIntosh et al.[130], Howe et al.[137] and Freeland et al.[136] (all level C) demonstrated that the use of rhythmic recurrent auditory cues improves walking speed, stride length and step

frequency in patients with PD.

The study of Nieuwboer et al.[128] (level B), demonstrated that using visual and auditory cues, combined with instruction to improve foot take-*off*, stride length and body posture, improves gait initiation and stride length in patients with PD.

The study of Müller et al.[129] (level B), demonstrated that an extensive (home) exercise program, focused, among others, on using cues, improves gait initiation and stride length in patients with PD.

It is currently unclear which patients benefit from using cueing strategies and which patients do not.

Based on the above the guideline development group formulated the following recommendation:

Applying visual and auditory cues improves gait (level 2)

It is plausible that in patients with PD gait is improved by applying visual and auditory cues, which have been taught during active gait training.

Quality of the articles found: B (Thaut et al.[127], Behrman et al.[148], Nieuwboer et al.[128]).

Application of cues in combination with the application of cognitive movement strategies improves gait initiation and stride length (level 3)

There are indications that the application of cues in combination of cognitive movement strategies improves gait initiation and stride length.

Quality of the article found: B (Muller et al.[129])

The physical therapist can give instructions which are focused on improvement of gait during training of all possible forms of walking, with variability in, for example, walking direction, stopping, turning, presence of obstacles, and terrain. In order to help the patient remember the instructions, a lot of rehearsing is needed; besides, the attention of the patient has to be focused on one item only all the time. Each instruction causes in principle a dual task. Therefore, it is important to assess for each patient whether the negative effect is not greater than the positive effect. The guideline development group advises relating the instruction to other movements, for example (in the case of increasing the arm swing) to swinging the arms in rhythm with the steps.

Instructions to normalize gait can be effective. Three B-level studies who reported improvement of gait had incorporated instructions to improve gait in the training involved.[116,141,148]

Based on the above the guideline development group formulated the following recommendations:

Arm swing, wide base, heel contact (level 2)

There are indications that in patients with PD the instruction to exaggerate arm swing (training of the trunk rotation), walk with a wide base, and good heel contact are effective in the improvement of gait (walking speed or stride length)

Quality of the articles found for arm swing: B (Behrman et al.[148]); for wide base: B (Formisano et al.[141]); for heel contact: B (Kamsma et al.[116]).

Taking large steps (level 2)

It is plausible that training the patients with PD to take large steps is effective in the improvement of walking speed.

Quality of the articles found: B (Behrman et al.[148]; Formisano et al.[141]).

Standing upright, turning suddenly (level 4)

The guideline development group takes the view that in patients with PD the following instructions are effective in the improvement of gait: standing upright (possibly with the use of a mirror for visual feedback); preventing sudden turns (and losing balance), for which the instruction is: 'Make a larger turning circle'.

Comfortable walking speed, stride length and trunk rotation can improve through the use of a treadmill to exercise gait.[149] A mirror placed in front of the treadmill provides visual feedback about the body posture. If patients supports themselves with their arms on the bars alongside the treadmill (as on a gangplank), by which the bodyweight is partly supported (preferably 20%), patients can walk faster and make larger steps.[149] The same effects on gait were found by de Goede et al., who used treadmill training as part of their group treatment to improve gait and ADL.[150]

Based on the above the guideline development group formulated the following recommendation:
Treadmill (level 2)
It is plausible that in patients with PD (up to H&Y III), gait exercises on a treadmill increase comfortable walking speed and stride length. Quality of the article found: B (de Goede et al.[150], Miyai et al.[149]).

Cognitive movement strategies can be used after a motor block or a period of freezing. Before stepping out, the patient can first sway from one leg to the other, supported by counting or by the order: 'One, two and walk…,' to facilitate initiation of walking.

Based on the above the guideline development group formulated the following recommendation:

Application of cognitive movement strategies to stimulate the onset of walking (level 4)
The guideline development group takes the view that in patients with PD the following cognitive movement strategies stimulate the onset of walking: stand upright; bring the weight on the heels; transfer the weight to one leg; step out with the other leg, make a large step, and keep on walking.

Freezing can be prevented in part by making use of rhythmic recurring cues and by keeping instructions to a minimum.
To make the start of movements easier (after freezing), use can be made of:
- flexing and extending the knees;
- transferring the weight from the left to the right foot and back, possibly with swaying back and forth a few times;
- suddenly swinging the arms in front ('pointing the direction');
- first make a step backwards, and then forwards;
- first stand upright, than stretch, have a short moment of conscious relaxation and correction of posture before initiating the movement again;
- raising the non-weight-bearing leg and stepping out making a substantial first step;
- applying one-*off* cues.

Based on the above the guideline development group formulated the following recommendation:

Use of prompts (level 4)
The guideline development group takes the view that in patients with PD the use of prompts makes the start of movements easier after freezing.

A randomized study (level B) demonstrated that a strength training program of 16 sessions for 8 weeks, consisting of resistance training (60% maximum strength, 12 repetitions) with the emphasis on lower extremities and muscles of the abdomen, is an effective tool to improve stride length and walking speed.[151]

Based on the above the guideline development group formulated the following recommendations:

Training of muscle strength (level 3)
There are indications that gait in patients with PD improves by training the strength of the lower extremities.
Quality of the article found: B (Scandalis et al.[151]).

Training of trunk mobility (level 4)
The guideline development group takes the view that gait in patients with PD improves by increasing or preserving trunk mobility.

C.3.6 Prevention of inactivity and maintenance or improvement of physical capacity
Goal: maintenance or improvement of physical capacity.
Strategy: providing information on the importance of exercising or playing sports, training of aerobic capacity, muscle strength (with the emphasis on the muscles of the trunk and legs), joint mobility (among others, axial) and muscle length (among others, muscles of the calf and hamstrings).

Providing information
'PD, moving and health' (in Dutch) provides information for patients with PD.[152] Patients are encouraged to continue, or return to playing sports.[53] Patients are encouraged to strive for the 'Dutch Standard of Healthy Moving'.[104] Depending on the problems present, exercise is increased and more pleasurable

when taking place in a group. These groups can be specific exercise groups for patients with PD (e.g. swimming and gymnastics), or exercise groups for the elderly in general (see appendix 2).

Based on the above the guideline development group formulated the following recommendation:

Providing information (level 4)
The guideline development group takes the view that providing information on (increasing) exercise or playing sports to patients with PD immediately after the diagnosis, has a preventive effect on deterioration of the physical capacity of these patients.

Training joint mobility
Level B studies showed that exercise programs focused on improving joint mobility, combined with training of gait and balance, improve motor skills (Comella et al.[124], Patti et al.[126,] Pachetti et al.[153], Marchese et al.[134]), ADL (Comella et al.[124], Patti et al.[126], Formisano[141], Palmer et al.[154], Pachetti et al.[153] and mental functioning (Comella et al.[124], Patti et al.[126]). One level B study (Hurwitz[155]) showed that an exercise program focused on improving joint mobility, in combination with improving mobility and self-care, improved memory, among others. Furthermore, one level B study (Schenkman et al.[112]) showed that an exercise program focused at improving joint mobility and coordinated moving incorporated in ADL improves functional axial rotation and reach (balance).

Training of strength
Three level B studies (Bridgewater et al.[156], Hirsch et al.[145] and Toole et al.[146]) and two level C studies (Reuter et al.[157], Scandalis et al.[151]), showed that exercise programs which are, among others, focused on improving muscle strength (of the lower extremities and trunk), may also improve muscle strength in patients with PD (in the early to middle phase). In the study of Scandalis et al.[151] Sixteen sessions were delivered during a period of eight weeks. In the study of Toole et al.[146], strength was trained at 60% of maximum strength resistance, with up to 12 repetitions of the exercises based on the muscle strain.

Training aerobic capacity
Two level C studies (Reuter et al.[157], Baatile et al.[158]) showed that exercise programs focused on improving aerobic capacity also improve motor skills.
One level B study (Bergen et al.[159]), demonstrated that an exercise program, which is focused on improvement of aerobic capacity, can also improve the aerobic capacity of patients with PD in the early phase.

Based on the above the guideline development group formulated the following recommendation:

Improvement of joint mobility (level 2)
It is plausible that an exercise program focused on the improvement of joint mobility combined with activity related (e.g. gait or balance) exercises improves ADL functioning.
Quality of the articles found: B (Comella et al.[124], Marchese et al.[134], Patti[126], Formisano et al.[141,] Palmer et al.[154], Pachetti et al.[153])

Improvement of muscle strength (level 2)
It is plausible that in PD a program focused on the improvement of muscle strength increases muscle strength.
Quality of the articles found: B (Bridgewater et al.[156], Hirsch et al.[145], and Toole et al.[146]) and C (Reuter et al.[157], Scandalis et al.[151]).

Improvement of aerobic capacity (level 3)
There are indications that an exercise program focused on the improvement of aerobic capacity improves motor skills.
Quality of the articles found: C (Reuter et al.[157], Baatile et al.[158]).

Training physical capacity (level 4)
The guideline development group takes the view that the exercise program needs to be formulated for each patient, in line with the patient's physical problems and needs.

For patients with osteoporosis the KNGF-guidelines 'Osteoporosis' have to be followed.
Preserving the physical capacity preferably takes place during those times of the day when the patient is functioning well (e.g. during *on*-periods), as only

then the patient is able to exercise optimally. Patients are offered an exercise program with fitness equipment (including a home trainer, if necessary with low resistance) and a treadmill. Furthermore, information is provided on (increasing) exercises and playing sports, at home as well as in exercise groups (Parkinson's specific or elderly in general). The physical therapist can facilitate the exercise program at home. A diary serves as an evaluation instrument (see appendix 4.14). Aids, such as a walking stick, poles (Nordic Walking), a rollator or a bicycle with an electric aid engine can support this. Providing information on the aids themselves and supporting the application for the aids falls inside the scope of the occupational therapist.

C.3.7 Prevention of pressure sores
Goal: prevention of pressure sores.
Strategy: giving advice and (in)active exercising to stimulate good posture in bed or in a wheelchair (possibly in consultation with an occupational therapist) and cardiovascular functioning, and to prevent contractures.

Although most interventions to prevent pressure sores are performed by nurses, the physical therapist is actively involved in taking measures to prevent pressure sores.[160,161] The occupational therapist provides advice on support while sitting and lying, and on aids, especially for static activities (e.g. a hand splint and a tray on a wheelchair). Furthermore the expertise of the occupational therapist is used in the selection of pressure relieving products such as pillows, and the adjustment of wheelchairs and beds. For possible advice on nutrition, the patient is referred to a dietitian.

Physical technical applications
There is insufficient evidence that the use of physical technical applications (e.g. ultrasound, UKG, infrared or ultraviolet light and laser) are effective in the treatment of pressure sores. Extensive information on treatment and prevention of pressure sores can be found in the 'NHG Standard (M70) decubitus' (http://nhg.artsennet.nl) and the 'CBO Guidelines Decubitus 2002' (http://www.cbo.nl).

C.3.8 Falls prevention
Goal: reduce and/or or prevent falls.
Strategy: list possible causes of falls with a falls diary; providing information and advice, improvement of body posture, strength training, improvement of coordination and balance, concentrating on the cause of the problems such as maintaining balance and increased falls risk; reduce the fear to fall (possibly with the use of hip protectors).
To gain insight into the frequency of falling, the circumstances in which falls take place and the possible causes of falls, the guideline development group advises patients together with their caregivers, to fill in a falls diary (see appendix 4.3).[59,91,120,162]
To prevent falls, the physical therapist should provide balance training and inform the patient about aids, the role of the occupational therapist and about the side-effects of medication which can be related to falling, such as orthostatic hypotension. Fear to fall plays an indirect role in falling. Therefore, part of the physical therapeutic treatment of patients with PD is to decrease this fear.
See paragraph C.3.2 for the treatment of poor body posture and insufficient trunk mobility as causes for falling. If freezing is the cause of falling: see paragraph C.3.5.

Falls
The guideline development group takes the view that it is advisable to refer the patient to courses for falls prevention, which aim at improving strength, balance (preserving the body posture) and coordination (see appendix 2). In the case of patients with an increased falls risk KNGF-guidelines 'Osteoporosis' should be consulted. See paragraph C.3.4 for the physical therapeutic training of balance.

Based on the above the guideline development group formulated the following recommendation:

Fall incidents (level 4)
The guideline development group takes the view that it is advisable to refer patients with PD to a course for falls prevention in the early stage of the disease.

There is insufficient evidence that falls training (training of falling or techniques of falling) is an effective means to reduce the fear of fall or the falls risk. Based

on the fundamentally disturbed posture and balance reactions, the guideline development group expects no effect of such training. The guideline development group even takes the view that such training might have negative effects.

Patients are often bothered by wearing shoes with smooth soles, rubber soles ('stick' to the floor) or high heels.84 In this case the physical therapist can provide information about this to the patient.

Based on the above the guideline development group formulated the following recommendation:

Footwear (level 4)
The guideline development group takes the view that in patients with PD information and advice on footwear may decrease the number of falls.

Occupational therapy might prevent falling in the elderly.[147] Although extrinsic factors (e.g. doorsteps and insufficient lightning) play a much smaller role than intrinsic factors in falling, an inventory of the dangers in the daily life situation, in combination with adjustments to the home, can be advisable to prevent falling.

The physical therapist takes responsibility (if necessary together with the occupational therapist) for the application of, and the training in the use of the different (walking) aids (see table 2). They also provide information on who is responsible for the maintenance and repair of the aids. See paragraph C.3.9 for a more detailed discussion of the possible aids.

Orthostatic hypotension can be a side-effect of medication (levopoda, selegeline and dopamine agonists). This causes a partial or complete syncope, not only occurring during standing up or after exertion, but also when the patient is standing for a long time. Patients with PD can be given the same advice as the elderly persons with orthostatic hypotension in general:

- while standing, activate the muscles of the leg[163,164], look out for instability of the posture;
- hold one leg higher (on a 'platform') in case of a feeling of dizziness;[165]
- provide information on avoiding to get up quickly, to stand still for a long time, and to lie flat (in the daytime) for a long time.[163]

Based on the above the guideline development group formulated the following recommendation:

Orthostatic hypotension (level 4)
The guideline development group takes the view that in patients with PD, information and advice on orthostatic hypotension can help to prevent fall incidents, which are a consequence of hypotension.

Fear to fall
Fear to fall might lead to inactivity and is further associated with an increased falls risk. At the moment it is unclear how the physical therapist can decrease the fear to fall. A reduction in fear to fall may occur if the patient is taught how to stand up from a sitting position on the floor.

Based on the above the guideline development group formulated the following recommendation:

Standing up after a fall (level 4)
The guideline development group takes the view that by teaching patients with PD how to stand up from a sitting position on the floor, the fear to fall decreases in these patients.

C.3.9   **Aids**
In case of patients with PD the use of aids can be advisable. The physical therapist can provide the patient with proper information and refer to an occupational therapist in time to identify possible adaptations in the home environment (see table 8).

Walking aids, such as a walking-stick and rollator, can increase the independence and safety of patients with PD. However, at the same time they can make walking more complex and more difficult, as by using these aids the performance of a dual task is required. Furthermore, inadequate use of, for example, a rollator, can worsen the posture. Patients suffering from freezing benefit more from a rollator with so-called compression brakes which are activated when a patient leans on the rollator. Cubo advised against a walking frame for patients who suffer from freezing.[166] In case of severe difficulty in maintaining balance, a wheelchair should be advised, because of co-morbidity related to a high risk of falls.

Based on the above the guideline development group formulated the following recommendations:

Walking aids (level 4)
The guideline development group takes the view that providing information and advice on (walking) aids to patients with PD, and training patients in the (temporary) use of these aids, decreases the incidence of falls in these patients.

Walking frame (level 3)
There are indications that in patients with PD the use of a walking frame has to be advised against in case of freezing.
Quality of the article found: B (Cubo et al.[166]).

In comparison to 'healthy' elderly, patients with PD sustain more fractures of the hip (see paragraph A.12.3). It has been demonstrated in the healthy elderly (level 1) that hip protectors (a kind of fortified underpants) are effective in reducing hip fractures due to falls.[167] A problem when prescribing hip protectors is, however, that they are often not worn (at the right moments, for example at night) which makes them less effective.[168] In patients who have recurrent falls a nurse can give advice when purchasing them. In the healthy elderly, it has been demonstrated (level 1) that hip protectors prevent hip fractures through fall incidents, when the hip protectors are worn at the right moment.

Based on the above the guideline development group formulated the following recommendation:

Hip protectors (level 1)
It has been demonstrated that, in an elderly, high-risk population living in institutional care, hip protectors prevent hip fractures due to falls, when the hip protectors are worn at the right moment.
Quality of the articles found: A1 (Parker and Gillespie[167]); A2 (Schoor et al.[168]).

C.4   Information plan
During the diagnostic process, the need for information and advice is identified. Based on this, the physical therapist formulates an individual information plan. Information is possible from the moment that the diagnosis is made. Bodenheimer et al. distinguish two forms of information and advice in chronic patients: the traditional information and the information to stimulate self-management.[169] Providing disease specific information is part of the traditional information, for example: 1) information on the syndrome; 2) the importance of the hour medication should be taken; 3) the importance of compliance with therapy; 4) the objective of the therapy; 5) the use of aids; 6) the importance to keep on exercising and, if possible, to play sports; 7) information on

Table 8. Core areas for aids in Parkinson's disease

Core area	Aids or adjustments
Balance	• walking aid (e.g. rollator)
Transfers or changing body position	• raised toilet • stand-up chair • aids that facilitate getting in or out of bed (such as high-low bed, patient lift, sliding board, handles on the sides of the bed)
Mobility	• walking aid (i.e. rollator) • other aids that increase the mobility (such as wheelchair, scoot mobile)
Falling and increased falls risk	• walking aid (i.e. rollator) • hip protectors • shoes with sufficient support and soles with sufficient grip

the Dutch PD Association; 8) information on the role of the caregiver. Skills enabling the patient to react adequately to (new) problems are part of the information stimulating self-management. Patients learn to deal with the progressing problems and by doing so gain confidence in their own capabilities. Central to this are the action plans made by the patient, in whom the patient sets goals that can be achieved in the short term. For example: the next two weeks I'm going to walk outside for half an hour every Monday, Wednesday and Friday afternoon. To assess the feasibility of a goal, patients can be asked to indicate on a scale from zero to ten how certain that goal will be achieved. Experience shows that a score of seven or higher is sufficient for a feasible goal.[169]

When mental impairments are present (e.g. impairments in attention and memory) it is important to discuss only one subject at a time and to keep the information or advice short. In providing information and advice, existing information material, such as brochures and video's can be used. These can be obtained from the Parkinson's Patient Society and the NOC/NSF.

The physical therapist makes a plan and evaluates to what extent the goal is achieved (according to the module Methodical Conduct of Physical Therapy Diagnosis and Intervention). With respect to information and advice, the physical therapist asks himself: Does the patient know what he ought to know and is he doing what he should be doing?

C.5 Change in behavior

In treatment of patients with PD, behavioral change has an important place in decreasing inactivity, preventing fall incidents, and increasing the potential to treat these patients. Supplying information is central to behavioral changes. The model of Van der Burgt and Verhulst serves as a starting point in supplying information to patients in allied health.[170]

Van der Burgt and Verhulst integrated the ASE-model for determinants of behavior (Attitude, Social Influence and Personal Efficacy)[171] and the step-by-step educational model proposed by Hoenen et al.[172] According to the ASE-model, the most important determinant of behavior is the patient's intention to show that behavior. The intention to change behavior is influenced by:

1. the attitude of a person with respect to a certain behavior;
2. social norms (e.g.: How do others perceive the change in behavior?) and
3. self-efficacy, the extent to which one considers himself capable of showing a behavior or not.

The step-by-step model in relation to information consists of six steps: 1) being open; 2) understanding; 3) wanting; 4) being able; 5) doing; and 6) keep on doing. The final step can only be taken if the preceding steps have been taken.

When treatment takes place within a team, it is very important that all the members of that team work according to the same method and are informed about each other's steps.

C.6 Compliance with therapy

At least one out of three patients has problems with exercising at home or with holding on to advice provided.[173] The three most important factors that hamper compliance with therapy are:

1. the problems that patients experience in following the instructions of the physical therapist;
2. the lack of positive feedback;
3. a feeling of helplessness (e.g.: It won't help me).

A number of measures can be taken to increase compliance with therapy.[173] A good relation between physical therapist and patient is essential. The patient must have the feeling that he is listened to and understood. The guideline development group distinguishes between compliance with therapy during the treatment period (short term) and the compliance after treatment period (long term).

C.6.1 Compliance with therapy in the short term

Behavioral change plays an important role in encouraging compliance with therapy in the short term, applying methods such as reminders and positive feedback. These methods link the desired behavior (e.g. the performance of exercises) to daily routines, as a result of which the new behavior might become a routine. The physical therapist teaches the patient to use reminders, for example by instructing the patient to perform a certain exercise always after the eight o'clock news. If mental impairments hamper the use of reminders, the caregiver assists in performing the

desired behavior (see paragraph C.1.2). The positive consequences of (compliance to) therapy are emphasized by giving positive feedback.

C.6.2 Compliance with therapy in the long term

To increase compliance with therapy, the feeling of self-efficacy, perception of the complaint and behavioral abilities of the patient are of importance. For compliance with therapy in the long term, confidence in one's own capabilities (the feeling of self-efficacy) is essential. Goals have to be achievable for the physical therapist and the patient (see paragraph C.4). Also, giving positive feedback on the goals achieved (or parts of it) plays a role.

Particularly in patients with PD it is very important to strive for a new goal only when the previous goal has been achieved. Therefore, working step-by-step is essential and has to be taken into account when trying to achieve a change in behavior. If the caregiver is involved in the treatment, care should be taken to ensure that they do not overload the patient with information. This goes for the instructions during exercising as well as for giving information and advice.

During and after therapy, emphasis is put on what has been achieved. That which has not (yet) been achieved is used to provide information about what is difficult for the patient or what the problems are. Also non-compliance with therapy needs to be a subject of discussion - try to discover the cause and look for alternatives. The patient's perception of a complaint determines the future actions of the patient and must therefore be clarified.

On the one hand this is done by asking patients what they think about their complaints and if they think they will return. If necessary, the physical therapist adjusts this perception by giving information. Alternatively this is done by asking patients what they have already tried to do themselves to reduce the problems. Also, the patient's behavioral abilities determine how problems arising in the future will be dealt with. To increase patients' behavioral abilities, they patients need to learn how they can apply their knowledge to future situations, for example by supplying information on the working mechanism and best application of cueing strategies and cognitive movement strategies. Although the therapist should

strive for this practical application, it has to be clear that this can be a bottleneck too (see paragraph C.1). The patient benefits from good cooperation between the physical therapist and the (referring) physician and the report and support of each other's advice. The same goes for the cooperation of members of a multidisciplinary team.

C.7 Specific physical therapy techniques

No studies are available which demonstrate that cryotherapy, thermal therapy, massage, and manipulative techniques are effective for decreasing problems related to PD.

With respect to the treatment of co-morbidity (for example typical problems in the elderly such as arthritis) the guideline development group refers to the guidelines concerned.

Based on the above the guideline development group formulated the following recommendation:

Specific physical therapy techniques (level 4)
The workgroup takes the view that cryotherapy, thermal therapy, massage, and manipulative techniques should not be used in patients with PD.

C.8 Evaluation

The physical therapist evaluates the treatment outcome regularly and systematically by comparing it to the treatment objectives. On the basis of this, adjustment of the treatment plan can take place. In the case of complications during treatment, the patient can be referred back to the physician. The frequency of evaluation depends on the objective of treatment. The application of techniques to improve postural or movement behavior is evaluated frequently (at the start of each following session). The evaluation of the physical capacity, on the other hand, can only take place after a longer period. To evaluate the outcome of treatment the same outcome measures that were used during history-taking and physical examination are used.

Central to the evaluation is measuring the effect of treatment on the patient's daily functioning. The functional status of the patient is determined based on changes on the Patient Specific Complaints questionnaire. The guideline development group takes the view that in addition to the Patient Specific

Complaints questionnaire, measurement of the 'Global Perceived Effect' should also be used (see appendix 4.12).

Based on the above the guideline development group formulated the following recommendation:

Evaluation (level 4)
The guideline development group takes the view that the treatment of patients with PD should be evaluated with the Patient Specific Complaints questionnaire (PSK) and measurement of 'Global Perceived Effect'.

C.9   Aftercare
Preservation of improved activities in daily life
Strategies to stimulate ADL are sometimes effective for a short period of time only. Introducing permanent cues (to initiate as well as to continue the movement) in the home environment can be an aid to retaining the effects of treatment outcome for a longer period of time. It is important to evaluate the patient after a certain period of time.
Because of the progressive nature of PD, it is important for patients to stay active. Effects of physical activity aimed at improving bone mass become visible only after a year (see the KNGF-guidelines 'Osteoporosis'). Therefore, the physical therapist encourages the patient to keep on exercising after the treatment period has ended. The patient may keep a diary in which the frequency and extent of exertion is noted (see appendix 4.14), in order to increase the possibility that the patient will continue the active lifestyle. The Borg scale is used to quantify the feeling of exertion (see appendix 4.13). The Borg scale is a valid measurement instrument to determine the exertion intensity, showing good correlations with physiological criteria.[174]

Check-up
An appointment for a check-up can be made to assess how well the effects of treatment have been retained and if any new problems have developed. If necessary, therapy can be continued immediately after check-up. It is possible for patients to receive a prolonged period of treatment. It is the task of the physical therapist to assess whether treatment is appropriate and to remain alert to the possibility that the patient could become dependent on the physical therapist.

C.10   Final evaluation, conclusion and reporting
When treatment goals have been achieved, or when the physical therapist takes the view that physical therapy has no longer an additional value, the treatment will be discontinued.
The treatment will also be discontinued if the physical therapist expects the patients to be able to achieve the treatment goals on their own (without therapeutic supervision). At discharge, but preferably also during the treatment period, the physical therapist should inform the referring physician about, among other things, the (individually determined) treatment goals, the treatment process and the treatment outcome. The Dutch Institute of Allied Health Care (NPi) has developed a manual for reporting by order of, and in close cooperation with, the Royal Dutch Society for Physical Therapy (KNGF), the Dutch College of General Practitioners (NHG), and the Dutch Society of Exercise Therapists according to the methods of Mensendieck and Cesar (VVOCM).[93] With this manual, agreements can easily be made on the time frame in which the physical therapist reports to the referring physician, the content of this report and situations in which reporting should take place. This manual is also used for reporting between physical therapists in primary and secondary health care. The manual can be accessed online on the HOF-site of the NPi: http://www.paramedisch.org/hof/. Reporting occurs according to the KNGF-guidelines 'Physical therapy documentation and reporting' (revised version).[175] Besides the minimally required data it is advisable to mention in the final report:
- if the patient has been treated according to the guidelines
- on which points and why the treatment deviated from the guidelines; and
- if appointments are made for a check-up.

D   Legal status of the guidelines
These guidelines are not statutory regulations. They provide knowledge and make recommendations based on the results of scientific research, which healthcare workers must take fully into account if high-quality care is to be provided.[175] Since the recommendations mainly refer to the average patient, healthcare workers must use their professional judgment to decide when to deviate from the guidelines if that is required in a particular patient's situation.

Whenever there is a deviation from recommendations in the guidelines, this must be justified and documented.[1,2,8]

E   Revisions of the guidelines

The method for developing and implementing guidelines states that all guidelines should be revised within a maximum of three to five years after the original publication.[1,2,8] This means that the KNGFtogether with the guideline development group, will decide whether these guidelines are still accurate in 2007, but at the latest in 2009. If necessary, a new guideline development group will be set up to revise the guidelines. The current guidelines will no longer be valid if there are new developments that necessitate a revision.

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Appendix 1

Overview of abbreviations and concepts used in the guidelines

Akinesia: Difficulty with starting a movement, especially during the *off*-periods.

Balance: The overall term for a number of functions, among which postural and balance reactions, vestibular functions, coordinative functions (control over and coordination of conscious movements), and proprioceptive functions, which together determine if a person is able to keep his balance (sufficiently).
N.B. In the ICF the term 'balance' is only used with regard to vestibular functions.

Bradykinesia: **Delayed performance of voluntary movements.**

Cognitive movement strategies: Conscious performance of actions in which complex (automatic) activities are transformed to a number of separate elements that have to be executed in a set order, and which consist of relatively simple movement components.

Physical capacity: The overall term for the ICF-terms:
- exercise tolerance functions such as aerobic capacity;
- mobility of joints;
- muscle strength.

Cueing strategies: Usage of stimuli, whether or not consciously (but with attention), in the environment or aroused by the patient to facilitate moving.

Dual tasking: Performing several motor or cognitive tasks simultaneously.

Dyskinesia: Abnormal, involuntary movements during the on period, often becoming more intense during activities.
Side effect of long-term usage of medication, especially levodopa.

Fatigue: An overwhelming feeling of tiredness, exhaustion or lack of energy, which may occur as a consequence of depression, sleeping problems, or akinesia.

Festination: Walking accelerated with quick, short, shuffling steps. Increases with the duration of the disease. Festination is strongly associated with freezing and falling.[4]

Freezing: Temporary, involuntary inability to move, especially during the *off* periods. Mostly, the episodes of freezing are short (< 10 seconds), and of a temporary nature. Sometimes, a complete akinesia occurs, but mostly freezing manifests itself in trembling legs.[1] Freezing can be preceded by festination and might lead to falls incidents.
Freezing occurs especially in case of starting, turning, and when approaching a destination, a small doorway or obstacle(s).[1,2] Stress, deprivation of sleep, fear, and emotional excitement can enhance freezing. Freezing occurs especially after a long term treatment with levodopa and in an advanced stage of the disease.[3] After a disease period of five years freezing can be found in more than 50 percent of the patients.[2]

Hypokinesia:	Lack of activities, which expresses itself, among others, in: 1) loss of automatic movements, 2) decreased movement of the arm(s), 3) masked face.
Idiopathic:	With unknown cause.
Incidence:	The number of new cases of a certain disease in a community during a defined period (e.g. a year).
Micrography:	Smallness of handwriting.
Mobility:	Moving by changing body position or location, going from one place to another, carrying, moving and manipulating objects, walking, running or climbing, and moving by using different forms of transportation.[5] N.B. Contrary to the ICF, this term is not used with regard to the mobility of joints or bones.
Dutch Standard of Healthy Moving:	A moderately intensive physical activity for half an hour at least five days, but preferably every day of the week.[6] Thirty minutes continuously is not needed; it can also be three blocks of ten minutes. The minimal duration is five minutes continuously. Examples for moderately intensive physical activity for adults are: walking at a speed of 5 to 6 km/hour and cycling at a speed of 15 km/hour. For people over 55 years of age, for example, a walking speed of 3 to 4 km/hour and cycling speed of 10 km/hour is acceptable. However, for non-active people, with or without limitations, all extra physical activity is welcome.
Nycturation:	Urinating frequently at night.
***On/off*-periods:**	Fluctuations in mobility as a consequence of the effectiveness of the medication. During the *off* period the medication is taken, but not effective. When the medication is effective, it is called the on period.
***On/off*-problems:**	Predictable and unpredictable fluctuations in the mobility as a consequence of the good (*on*) or poor (*off*) response to the use of levopoda. Arises by a long-term use of levodopa. During the on period the patient might suffer from dyskinesias.
Orthostatic hypotension:	A decrease in blood pressure in case of quick changes of the body posture (e.g. transfer from sitting to standing position). The symptoms are dizziness, everything going black, fainting, tachycardia and headache.
Prevalence:	Number of cases of a disease that is present in a community at a certain time.
Prognostic factors:	Factors that are related to continuation of the complaints. These factors can either have a favourable effect on the course of the complaints or an unfavourable effect, which might lead to an increase or continuation of the complaints.
Propulsion:	Tendency to fall forward.

Response fluctuations: Fluctuations in the effectiveness of medication which occur frequently when the disease progresses and by long term usage of medication (e.g. *wearing off, on/off*-problems, dyskinesias, freezing).

Retropulsion: Tendency to fall backwards.

Rigidity: Stiffness of the muscles, characterized by the cog-wheel phenomenon, in which the muscles lengthen jerkily during passive extension.

Rest tremor: Rhythmic (alternating) trembling, often of the hands. Especially present in rest and giving the impression of counting money or pill rolling. Disappears or decreases by intended movements, is absent during sleep and is aggravated by emotion or attention. Intensity may change (spontaneously).

Muscle strength: Functions which are related to the strength developed by the contraction of the muscle or muscle groups.[5]

Syncope: A sudden unconsciousness that can last a few seconds to several hours, sometimes preceded by dizziness, perspiration and nausea. This unconsciousness can be caused by hypoxia of the brain, a sudden change in blood composition or brain dysfunction.

Transfer: Move oneself from one surface to another (e.g. turning in bed).[5]

Urge incontinence: Being insufficiently able to hold one's water in case of micturation urge and therefore passing urine (often on the way to the toilet).

Wearing-off phenomenon: The tendency that by long-term usage of levopoda the usual dosage becomes less effective. Associated with an abrupt loss of mobility.

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Appendix 2

Current information

Courses and training

- 'Bewegingsbehandeling bij ziekte van Parkinson' (Movement treatment in case of Parkinson's disease), organized by the University Center (UC) ProMotion, Institute for Human Movement Sciences, Groningen University (RUG), The Netherlands;
- 'Centraal neurologische aandoeningen' (Central neurological disorders)' of the Dutch Institute of Allied Health Care (NPi), Amersfoort, The Netherlands;
- 'Fysiotherapie in de Geriatrie' (Physical therapy in Geriatric Patients), a post-collegetraining organized by the 'Hogeschool van Utrecht' in close cooperation with, and under auspices of, the Dutch Society for Physical Therapy in Geriatric Patients (NVFG).

General movement groups for elderly

- 'Meer Bewegen voor Ouderen' (Moving More for Elderly; MBVO) / 'Sport Stimulering Senioren (Sport Stimulation Seniors; SSS).
- 'GALM-SCALA-projects': national sports stimulating projects for seniors at the age of 55 to 65 with a disorder (SCALA 'Sports stimulation strategy for people with a Chronic Disorder: Active All Your Life') and without a disorder (GALM 'Groningen Active Life Model'). For informationon the GALM-region consultants see the NOC/NSF website http://www.sport.nl and UC ProMotion in Groningen (in cooperation with the Netherlands Institute for Sports and Physical Activity (NISB)).
- Wherever a sufficient number of members of the Parkinson's Patient Society want to 'be active' together, this society looks for opportunities to organize this (http://www.parkinson-vereniging.nl).
- The NOC/NSF publication 'Parkinson's disease, moving and health' can be pointed out to patients who want to exercise on their own.
- The website http://www.sportiefbewegen.nl informs patients with a chronic disorder about the positive effects of sports and moving. By showing a number of sporting and moving opportunities, the site tries to stimulate everybody to play a sport (more) or move (more). Also for patients with Parkinson's disease this site gives information on sporty moving.

Falls Prevention

'Halt U Valt' (Stop You Fall)

Programs are running under the name 'Halt U Valt' in different locations in the Netherlands. These courses seem especially suitable for people who just became familiar with the diagnosis Parkinson's. These courses are easily accessible and given at innumerable locations. 'Halt U Valt' is an initiative of 'Consument en Veiligheid (Consumer and Safety), TNO 'Preventie en Gezondheid' (Prevention and Health), GGD (Area Health Authority) 'Fryslân' and the GGD 'Hart voor Brabant'. Information: Consument en Veiligheid, Amsterdam, e-mail: infodesk@consafe.nl.

'In Balans' (In Balance)

The NISB (http://www.nisb.nl) organizes the information and movement program 'In Balance', which pays attention, among others, to safety at home, usage of medication, and to special movement exercises based on tai chi.

'Kennisnetwerk Valpreventie' (Knowledge web of Fall Prevention)

The initiators of this program are the VU Medical Centre, 'ZonMw' and 'Consument en Veiligheid (Consumer and safety)'. Also involved are representatives of local GGD's (Area Health Authorities), GGD Nederland and TNO 'Preventie en Gezondheid' (Prevention and Health).
The website of 'Kennisnetwerk' contains, among others, a description of relevant projects, literature and information on newly published material. From 2004 on the website is only accessible for students of the program. http://www.kennisnetwerkvalpreventie.nl

Multidisciplinary treatment

- Nursing home Maartenshof, Groningen, The Netherlands : Short Stay (after referral by a neurologist admission takes place for a limited period for physical assessment and treatment);
- Rehabilitation Center 'Het Roessingh', Enschede, The Netherlands: day care rehabilitation;
- Rehabilitation Center Breda, The Netherlands: day care rehabilitation;
- Nursing home Maartenshof, Groningen The Netherlands: day care rehabilitation.

Appendix 3

Medication in Parkinson's disease

Medication	Name of substance	Most important characteristics	Side-effects, relevant for the physical therapist
Artane®	trihexyphenidyl	• anticholinergics, especially decreasing tremor	• cognitive impairments (especially confusion, memory malfunction) • orthostatic hypotension
Akineton®	biperidene	• anticholinergics, especially decreasing tremor	• see Artane®
Britaject®	apomorphine	• injection of dopamine-receptor agonist (a pump is also possible) • as a remedy in severe and frequent therapy-resistant *off*-periods (>25% of the day)	• orthostatic hypotension • more severe dyskinesias during the *on*-periods • cognitive impairments • personality changes
Comtan®	Entacapone	• provides a more stable plasma level of levopoda, and thus decreasing the end-of-dose phenomena	• dyskinesias • cognitive impairments
Dopergin®	Lisuride	• dopamine-receptor agonist, imitates the effect of dopamine	• cognitive impairments (especially visual hallucinations) • orthostatic hypotension • increase of freezing • peripheral edema (especially in the feet) • sleepiness • nausea
Eldepryl®	selegiline	• inhibits the breaking down of dopamine in the brain • intensifies and prolongs the effect of levodopa • possibly decreases freezing	• orthostatic hypotension • sleeping impairments (if taken too late in the day, since the substance is transformed into amphetamine)
Kemadrin®	procyclidine	• anticholinergics, especially decreasing tremor	• see Artane®

Medication	Name of substance	Most important characteristics	Side-effects, relevant for the physical therapist
Madopar®	levodopa/benserazide	• in the body levodopa is transformed to dopamine • strongest means to fight the symptoms (especially bradykinesia, rigidity) • effect on rest tremor is often varying • often poor effect on the disturbed postural reflexes	• cognitive impairments (especially visual hallucinations) • orthostatic hypotension • response fluctuations (especially if used for more than 2-5 years)
Parlodel®	bromocriptine	• dopamine-receptor agonist	• see Dopergin®
Permax®	pergolide	• dopamine-receptor agonist	• see Dopergin®
Requip®	ropinirole	• dopamine-receptor agonist	• see Dopergin®
Sifrol®	pramipexol	• dopamine-receptor agonist	• see Dopergin®
Sinemet®	levodopa/carbidopa	• in the body levodopa is transformed to dopamine • strongest means to fight the symptoms (especially bradykinesia, rigidity) • effect on rest tremor is often varying • often poor effect on the disturbed postural reflexes	• cognitive impairments (especially visual hallucinations) • orthostatic hypotension • response fluctuations (especially if used for more than 2-5 years)
Symmetrel®	amantadine	• improves hypokinesia and rigidity, but is only weakly effective	• decreases dyskinesias • cognitive impairments (among others confusion) • orthostatic hypotension • peripheral edema • sleeping impairments

Appendix 4

Measuring instruments

Appendix 4.1   Patient Specific Complaints Questionnaire

> **The Patient Specific Complaints questionnaire is filled in by the patient.**

Activities and movements in which the consequences of Parkinson's disease might trouble you.
Your complaints influence your daily activities and movements which are difficult to avoid. The consequences of Parkinson's disease are different for everyone. Each person wants to improve certain activities through treatment.
Below, there are a number of certain activities and movements that are difficult for you to perform because of your Parkinson's disease-related problems. Try to recognize the problems, caused by Parkinson's disease, that you were troubled by during the past week.
Colour or mark the dot for this activity.
We ask you to mark those problems which YOU FIND VERY IMPORTANT and which YOU WOULD LIKE TO CHANGE MOST in the NEXT MONTHS.

- lie in bed
- turn in bed
- getting out of bed
- getting out of a chair
- sit down on a chair
- sit for a long time
- get in or out a car
- ride in a car or bus
- cycle
- stand
- stand for a long time
- light work in and around the house
- heavy work in and around the house
- walk inside the house
- walk outside
- run
- carry an object
- pick up something from the ground
- lift
- pay a visit to family, friends or acquaintances
- go out
- sexual activities
- perform a job
- perform hobbies
- perform housekeeping activities
- play sports
- travel
- other activities: ....

The five most important activities are:

1. ....

2. ....

3. ....

4. ....

5. ....

Example of how to fill in: problem walking

If you place the line on the *left*, it means that, for you, walking is *not much of an effort*.

no problem |———————————————————————————   impossible
at all

If you place the line on the *right,* it means that for you walking is a *great effort*.

no problem   ———————————————————————| ——   impossible
at all

Date of filling in: ....

Problem 1 ....
How difficult was it to perform this activity during the past week?

No problem   ———————————————————————————   impossible
at all

Problem 2 ....
How difficult was it to perform this activity during the past week?

No problem   ———————————————————————————   impossible
at all

Problem 3 ....
How difficult was it to perform this activity during the past week?

No problem   ———————————————————————————   impossible
at all

Problem 4 ....
How difficult was it to perform this activity during the past week?

No problem   ———————————————————————————   impossible
at all

Problem 5 ....
How difficult was it to perform this activity during the past week?

No problem   ———————————————————————————   impossible
at all

N.B. If desired, a total score can be determined by adding up the scores of the three most difficult activities.

Appendix 4.2 History of Falling Questionnaire

> The History of Falling Questionnaire will be administered by the physical therapist to determine if the patient has ever fallen (or experienced near misses), and if so, how often and under which circumstances.

Falling

Falling in general:

1. Have you fallen or stumbled in the past 12 months for any reason, even if it had nothing to do with your Parkinson's disease?
2. How many times have you fallen in the past 12 months (daily/weekly/monthly, etc.)
3. Are you afraid of falling?

If fallen, ask to clarify for each fall (or the pattern):

4. Where were you when you fell?
5. What were you doing or trying to do at the time?
6. What do you think caused the fall?
7. Did you loose consciousness prior to the fall?
8. Can a pattern be identified in the falling?

Near falls

Near falls in general:

9. Have you had any near falls in the past year?
10. How often did you have near falls in the past year?

In case of near falls, ask to clarify the pattern:

11. What sort of things are you usually doing when you nearly fall?
12. Why do you think you nearly fall?
13. How do you save yourself from near falls?

➤ **If the patient has fear of falling (FES) or if he has fallen more than once in the past year: increased risk of falling!**

Appendix 4.3   Falls diary

> **The falls diary has to be filled in after each fall incident by the patient and his partner or caregiver.**

You have fallen. We would like to know more about the circumstances prior to, during, and after you fell. Would you be so kind to answer all the questions below. Every time, choose the answer that is most appropriate for your situation.

Prior to the fall

1.   Where were you when you fell?
     ☐ inside
     ☐ outside

2.   Were you in a familiar or unfamiliar environment?
     ☐ familiar environment
     ☐ unfamiliar environment

3.   What was the surface (e.g. carpet, polished tiled floor, grass)?

     ....

4.   Were there any obstacles? (e.g. chairs, cars, doorway)
     ☐ yes
     ☐ no

5.   What kind of footwear were you wearing? (e.g. slippers, boots, nothing)

     ....

6.   Did you have the feeling of freezing just before you fell?
     ☐ yes
     ☐ no

7.   Were you dizzy just before you fell?
     ☐ yes
     ☐ no

8.   Did you loose consciousness before you fell?
     ☐ yes
     ☐ no

9.   Were you troubled by palpitations?
     ☐ yes
     ☐ no

10.   Were you troubled by dyskinesias?
        ☐ yes
        ☐ no

11.   Were you *on* or *off* (was the medication effective or not)?
        ☐ *on*, the medication was effective
        ☐ *off*, the medication was not effective
        ☐ no idea

12.   Did you feel sleepy?
        ☐ yes
        ☐ no

13.   Did those who were with you prior to the fall, think you were confused, or did you feel confused?

        ☐ yes, namely: ....
        ☐ no

14.   Were there any recent changes in your medication?
        ☐ yes
        ☐ no

15.   How long before the fall did you take your medication for the last time? ....

During the fall
16.   At what time did you fall? ....

17.   Did you have something in your hands when you fell?
        ☐ yes
        ☐ no

18.   What were you doing when you fell? (e.g. getting out of a chair, turning during walking)

        ....

19.   Were you distracted by something or someone when you fell? (e.g. did you talk to someone)
        ☐ yes
        ☐ no

20.   Were you just changing your body posture when you fell?
        ☐ yes, namely: ....
        ☐ no

After the fall

21.   Did you need help to get up again after you fell?
      ☐ yes
      ☐ no

22.   Were you troubled by amnesia after the fall?
      ☐ yes
      ☐ no

23.   Did the fall cause physical injury?

      ☐ yes, namely: ....
      ☐ no

24.   Did you have to be taken to the hospital after the fall?

      ☐ yes, because: ....
      ☐ no

25.   Do you have fear of falling or moving?
      ☐ yes
      ☐ no

Remarks:

....

....

....

....

....

....

....

....

....

....

Appendix 4.4   (Modified) Falls Efficacy Scale (FES)

The (Modified) Falls Efficacy Scale (FES) is filled in by the patient.

Not ► ► ► ► ► ► ► ► Very

How worried are you that you might fall when:	*0*	*1*	*2*	*3*
cleaning the house, such as sweeping and dusting?	☐	☐	☐	☐
getting dressed and undressed?	☐	☐	☐	☐
preparing a simple meal?	☐	☐	☐	☐
taking a bath or shower?	☐	☐	☐	☐
simple shopping?	☐	☐	☐	☐
getting in and out of a chair?	☐	☐	☐	☐
getting up or down the stairs?	☐	☐	☐	☐
walking nearby the house?	☐	☐	☐	☐
reaching for something in a deep, low closet?	☐	☐	☐	☐
getting to the telephone before it stops to ring?	☐	☐	☐	☐

0 = not worried
1 = a little worried
2 = fairly worried
3 = very worried

Appendix 4.5   Retropulsion test

The retropulsion test is performed by the physical therapist.

During the test the physical therapist is standing behind the patient.

The retropulsion test is performed as follows:
- The physical therapist gives a sudden, firm and quick backwards pull to the shoulder of the patient.
- The test is performed several times, the first time without notification of what is going to happen.
- The test is performed again several times with notification of what is going to happen. In doing so, the ability of the patient to adjust to an unexpected disturbance is tested.
- A normal reaction is the one in which the patient takes two big and quick steps back, and the physical therapist does not have to catch the patient because the patient nearly falls.

Appendix 4.6   Freezing of Gait (FOG) questionnaire

> **The Freezing of Gait (FOG) questionnaire is filled in by the physical therapist.**

Range of scores from 0 (normal / none / never) to 4 (impossible / always / maximum time)

1. During your <u>worst</u> state – do you walk:
    - ☐ normally
    - ☐ almost normally … somewhat slow
    - ☐ slow but fully independent
    - ☐ need assistance or walking aid
    - ☐ unable to walk

2. Are your gait difficulties affecting your daily activities and independence?
    - ☐ not at all
    - ☐ mildly
    - ☐ moderately
    - ☐ severely
    - ☐ unable to walk

3. Do you feel that your feet get glued to the floor while walking, making a turn or when trying to initiate walking (freezing)?
    - ☐ never
    - ☐ very rarely: about once a month
    - ☐ rarely: about once a week
    - ☐ often: about once a day
    - ☐ always: whenever walking

4. How long is your <u>longest</u> freezing episode?
    - ☐ never happened
    - ☐ 1 to 2 seconds
    - ☐ 3 to 10 seconds
    - ☐ 11 to 30 seconds
    - ☐ unable to walk for more than 30 seconds

5. How long is your <u>typical start hesitation</u> episode (freezing when initiating the first step)?
    - ☐ none
    - ☐ takes longer than 1 second to start walking
    - ☐ takes longer than 3 seconds to start walking
    - ☐ takes longer than 10 seconds to start walking
    - ☐ takes longer than 30 seconds to start walking

6. How long is your <u>typical turning hesitation</u>: (freezing when turning)
    - ☐ none
    - ☐ resume turning in 1 to 2 seconds
    - ☐ resume turning in 3 to 10 seconds
    - ☐ resume turning in 11 to 30 seconds
    - ☐ unable to resume turning for more than 30 seconds

Appendix 4.7 LASA Physical Activity Questionnaire (LAPAQ)

The LASA **Physical Activity Questionnaire (LAPAQ) is filled in together with the patient**

Observation

1. The respondent is confined to bed (*end of questionnaire*)
2. The respondent is confined to an electric wheelchair (*end of questionnaire*)
3. The respondent is confined to a mechanical (normal) wheelchair (*go to question 2*)
4. None of the above (1 to 3) is applicable (*go to question 6*)

Now, I am going to ask you questions about your physical mobility pattern.

1 Do you move outside in a wheelchair?
☐ no (*end of questionnaire*)
☐ yes

2 Did you move outside in your wheelchair the past 2 weeks?
☐ no
☐ yes

3 How many times did you move outside in your wheelchair the past 2 weeks?

.... times (0 to 50)

4 How long did you, each time, usually move outside in your wheelchair?

.... hours (0 to 10); 11 = do not know; 12 = refused

.... minutes (0 to 59); 60 = do not know; 61 = refused

5 Do you walk outside? With walking outside we mean walking to go shopping or doing other daily activities, like visiting someone. We do not mean: a walking tour.
☐ no (*go to question 10*)
☐ yes

6 Did you walk outside during the past two weeks? With walking we mean walking to go shopping or doing other daily activities, like visiting someone. We do not mean: a walking tour.
☐ no (*go to question 10*)
☐ yes

7 How many times did you walk during the past two weeks?

.... times (0 to 50)

8   How long did you usually walk each time?

.... hours (0 to 10); 11 = do not know; 12 = refused

.... minutes (0 to 59); 60 = do not know; 61 = refused

9   Do you cycle? With cycling we mean cycling to go shopping or doing other daily activities, like visiting someone. With cycling we do not mean: a cycling tour.
☐ no (*go to question 14*)
☐ yes

10   Did you cycle during the past two weeks?
☐ no (*go to question 14*)
☐ yes

11   How many times did you cycle during the past two weeks?

.... times (0 to 50)

12   How long did you usually cycle each time?

.... hours (0 to 10); 11 = do not know; 12 = refused

.... minutes (0 to 59); 60 = do not know; 61 = refused

13   Do you have a garden (including allotment)?
☐ no (*go to question 20*)
☐ yes

14   During how many months per year do you work regularly in your garden? For example raking, planting, trimming, etc. By regularly we mean at least once a week.

.... months (0 to 12)

15   Did you work in the garden during the past two weeks?
☐ no (*go to question 20*)
☐ yes

16   How many times did you work in the garden during the past two weeks?

.... times (0 to 50)

17   How long did you usually work in the garden each time?

.... hours (0 to 10); 11 = do not know; 12 = refused

.... minutes (0 to 59); 60 = do not know; 61 = refused

18   Did you dig in the earth during the past two weeks?
- ☐ no
- ☐ yes

19   Do you do sports (no mind games)?
- ☐ no (*go to question 31*)
- ☐ yes

21   Which sport did you do most time during the past two weeks?
You can choose one of the sports on the list.
- ☐ distance walking
- ☐ distance cycling
- ☐ gymnastics (for elderly)
- ☐ cycling on a home-trainer
- ☐ swimming
- ☐ (country) dancing
- ☐ bowling
- ☐ tennis / badminton
- ☐ jogging / running / fast walking
- ☐ rowing
- ☐ sailing
- ☐ playing billiards
- ☐ fishing
- ☐ soccer / korfball / basketball / field hockey
- ☐ volleyball / baseball
- ☐ skiing
- ☐ else ……………………………………

22   Can you describe this other sport?

....

....

23   How many times did you do this sport during the past two weeks?

.... times (0 to 50; if 0 *go to question 25*)

24   How long did you usually do this sport each time?

.... hours (0 to 10); 11 = do not know; 12 = refused

.... minutes (0 to 59); 60 = do not know; 61 = refused

25   Do you do another sport (no mind games)?
- ☐ no (*go to question 30*)
- ☐ yes

26   Offer a list. Mark the sport on which the second most time is spent.
      Which other sports did you do during the past two weeks?
      ☐ distance walking
      ☐ distance cycling
      ☐ gymnastics (for elderly)
      ☐ cycling on a home-trainer
      ☐ swimming
      ☐ (country) dancing
      ☐ bowling
      ☐ tennis / badminton
      ☐ jogging / running / fast walking
      ☐ rowing
      ☐ sailing
      ☐ playing billiards
      ☐ fishing
      ☐ soccer / korfball / basketball / hockey
      ☐ volleyball / baseball
      ☐ skiing
      ☐ else: ……………………………………

27   Can you describe this other sport?

      ....

      ....

28   How many times did you do this sport during the past two weeks?

      .... times (0 to 50; if 0 *go to question 30*)

29   How long did you usually do this sport each time?

      .... hours (0 to 10); 11 = do not know; 12 = refused

      .... minutes (0 to 59); 60 = do not know; 61 = refused

30   How many times did you perspire while sporting during the past two weeks?

      .... times (0 to 50); 51= do not know

31   Do you do light household tasks? With light household tasks we mean: washing the dishes, dusting,
      making the bed, doing the laundry, hanging out the laundry, ironing, tidying up, cooking meals.
      ☐ no (*go to question 34*)
      ☐ yes

32   How many days did you usually do light household tasks during the past two weeks?

      .... days (0 to 14); 15 = do not know; 16 = refused

33 For how much time a day did you usually do light household tasks?
We try to get an average estimate of the time that is spent on the total of these tasks. It is possible that someone irons one day and does the laundry the other day, while other activities, such as tidying up, occur daily.
In the estimation of the time spent on light household tasks it is not really important which activity the respondent performs, since all activities require just an equal amount of energy.
Remind the respondent of the fact that the time that is spent on resting in between has to be excluded.

.... hours (0 to 10); 11 = do not know; 12 = refused

.... minutes (0 to 59); 60 = do not know; 61 = refused

34 Do you do heavy household tasks? With heavy household tasks we mean: window cleaning, changing the bed, beating the mat, beating covers, vacuuming, washing or scrubbing the floor, and chores with sawing, carpeting, repairing or painting.
☐ no (*go to question 37*)
☐ yes

35 How many days did you do heavy household tasks during the past two weeks?

.... days (0 to 14); 15 = do not know; 16 = refused

36 for how much time a day did you usually do heavy household tasks?

.... hours (0 to 10); 11 = do not know; 12 = refused

.... minutes (0 to 59); 60 = do not know; 61 = refused

37 You just told me about your physical activities in general and about your physical activities of the past two weeks. Were the past two weeks normal as compared to the rest of the past year?
☐ no
☐ yes (*end of questionnaire*)

38 In what way where the past two weeks different?
☐ disease (physical)
☐ depression
☐ bad weather
☐ family occasion
☐ holiday
☐ else, namely: .... (describe the other reasons)

Appendix 4.8   Six-minute walk test

Performing the test

With the Six-minute walk test the distance that a patient can cover in six minutes is measured:

- If the test is performed in a marked out, square track (e.g. by using cones), do not walk beside the patient.
- If the test is performed on a treadmill, the inclination grade has to be zero, and on the indication of the patient the speed can be increased (this is not done by the patient himself).

It is important that the patient wears the same footwear during every measurement, and that the patient is encouraged to the same extent.

Instruction

The instruction goes as follows: 'The goal of this test is to determine how far you can walk in six minutes. When I say "start", walk the agreed track as fast as possible (if necessary point out the cones), until I say you can stop. If you want to slow down or stop, it is no problem. It is also no problem if you want to go faster. Try to walk at such a pace that after six minutes you have the feeling that you could not have gone any further (that the maximum is reached).'

Appendix 4.9   Ten-meter walk test

The Ten-meter walk test is a reliable instrument to calculate the comfortable walking pace of patients with Parkinson's disease who are able to walk independently. Furthermore the number of steps necessary to walk ten meters at comfortable pace is used to determine the stride length (for the use of cues). In performing the test a walking aid might be used, if necessary.

In this test the patient covers a distance between two lines, which are 10 meters apart. The patient is instructed to walk at a comfortable pace. He begins this test 5 meters before the first line and stops 5 meters after the second line. Thus, the pace is not influenced by starting and stopping (too early). Time is recorded from the moment that the patient crosses the first line with one foot to the moment that the patient crosses the second line with one foot.

The test is repeated three times, after which the average pace (distance / number of seconds) and the average number of steps of the three walking tests will be determined.

It is important that the patient wears the same footwear during every measurement.

Appendix 4.10   Modified Parkinson's Activity Scale (PAS)

> **The Modified Parkinson's Activity Scale (PAS) is filled in by the physical therapist.**

I Chair transfers

Starting position: The patient is seated in a chair (height 40 cm), with his hands in his lap.

Information: *I will ask you later to rise from the chair. You may lean with your hands on the arm of the chair or your knees. When standing, you will have to wait a second.*

1-A Rise and sit down without using hands

Will you rise without using your arms on the knees or chair?

- normal, without apparent difficulties ☐ 4
- mild difficulties (toes dorsiflex to maintain balance, arms swing forward to keep balance or use of 'consciously performed rocks' (compensations) with the trunk) ☐ 3
- difficult, several attempts needed or hesitations, very slow and almost no flexion of the trunk ☐ 2
- impossible, dependent on physical assistance (*perform I-B*) ☐ 0

Will you sit down again without using your arms?

- normal, without apparent difficulties ☐ 4
- mild difficulties (uncontrolled landing) ☐ 3
- clear abrupt landing or ending up in an uncomfortable position ☐ 2
- impossible, dependent on physical assistance (*perform I-B*) ☐ 0

1-B Rise and sit down with using hands (only if rising without using hands is impossible)

Will you try to rise again? When standing, you will have to wait a second again.
You may use your hands now.

- normal, without apparent difficulties ☐ 2
- difficult, several attempts needed or hesitations, very slow and almost no flexion of the trunk ☐ 1
- impossible, dependent on physical assistance ☐ 0

Will you sit down again? You may use your hands again.

- normal, without apparent difficulties ☐ 2
- abrupt landing or ending up in an uncomfortable position ☐ 1
- dependent on physical assistance ☐ 0

II Gait akinesia

Starting position: The patient sits in a chair (height 40 cm), with his hands in his lap. The middle of the U-shape (taped on the floor) is situated three meters in front of the chair. The lengths of the sides of the U are 1 meter. First, the preferred side with regard to turning is determined by asking the patient to walk and turn. Then the test is performed; during this test the turn will be to the side that is not preferred. The patient has to be able to walk without the help of others.

Information: *Do you see the tape in U-shape? I will ask you later to rise. You may, if you want, use your hands. Then you walk to the U and turn to the left/right inside the U. It is up to you how you do this. Then you go back to your chair and sit down. It is not about doing it as fast as you can. It is about doing it safely. Is that clear?*

II-A Without an extra task

Will you rise, walk to the U and come back?

Start akinesia (possibly assist with rising, which is not scored)
- normal, without apparent difficulties ☐ 4
- hesitation or short festination ☐ 3
- unwanted arrest of movement with or without festination lasting 5 seconds or less ☐ 2
- unwanted arrest of movement with or without festination lasting more than 5 seconds ☐ 1
- dependent on physical assistance to start walking ☐ 0

Turning 180°
- normal, without apparent difficulties ☐ 4
- hesitation or short festination ☐ 3
- unwanted arrest of movement with or without festination lasting 5 seconds or less ☐ 2
- unwanted arrest of movement with or without festination lasting more than 5 seconds ☐ 1
- dependent on physical assistance to start walking ☐ 0

II-B Now a bit more difficult: while carrying a plastic cup which is half full of water.

Start akinesia (possibly assist with rising, which is not scored)
- normal, without apparent difficulties ☐ 4
- hesitation or short festination ☐ 3
- unwanted arrest of movement with or without festination lasting 5 seconds or less ☐ 2
- unwanted arrest of movement with or without festination lasting more than 5 seconds ☐ 1
- dependent on physical assistance to start walking ☐ 0

Turning 180°
- normal, without apparent difficulties ☐ 4
- hesitation or short festination ☐ 3
- unwanted arrest of movement with or without festination lasting 5 seconds or less ☐ 2
- unwanted arrest of movement with or without festination lasting more than 5 seconds ☐ 1
- dependent on physical assistance to start walking ☐ 0

II-C Now even more difficult: while counting backwards (in threes, starting with a number between 20 and 100)

Start akinesia (possibly assist with rising, which is not scored)

- normal, without apparent difficulties ☐ 4
- hesitation or short festination ☐ 3
- unwanted arrest of movement with or without festination lasting 5 seconds or less ☐ 2
- unwanted arrest of movement with or without festination lasting more than 5 seconds ☐ 1
- dependent on physical assistance to start walking ☐ 0

Turning 180°

- normal, without apparent difficulties ☐ 4
- hesitation or short festination ☐ 3
- unwanted arrest of movement with or without festination lasting 5 seconds or less ☐ 2
- unwanted arrest of movement with or without festination lasting more than 5 seconds ☐ 1
- dependent on physical assistance to start walking ☐ 0

III Bed mobility

Starting position: The patient is standing in front of the bed on the preferred side.

Information: If you are standing in front of your bed at home, at which side is your pillow?

III-A Without cover

Will you lie down on your back on the cover, just like you would do at home? Be sure that you are comfortable when you lie down.

• normal, without apparent difficulties	normal	☐ 4
- difficulty with lifting legs	1 × difficulty	☐ 3
- difficulty with moving trunk	2 × difficulty	☐ 2
- difficulty with reaching adequate end position (functionally limiting or uncomfortable: with head uncomfortably against the head of the bed or with legs which are not relaxed (with too much flexion)	3 × difficulty	☐ 1
• dependent on physical assistance (patient asks clearly for help or does not reach an acceptable end position)	dependent	☐ 0

If the patient lies uncomfortably: ask him to lie straight, before rolling over to the side in bed!

*Will you roll over onto your side? To the **left**. Be sure that you lie down comfortably on your side.*

• normal, without apparent difficulties	normal	☐ 4
- difficulty with turning trunk/pelvis	1 × difficulty	☐ 3
- difficulty with moving trunk/pelvis	2 × difficulty	☐ 2
- difficulty with reaching adequate end position (functionally limiting or uncomfortable: underlying shoulder and arm insufficiently in protraction and free, the head uncomfortably against the head of the bed, or less than 10 cm between trunk and the edge of the bed)	3 × difficulty	☐ 1
• dependent on physical assistance (patient asks clearly for help or does not reach an acceptable end position)	dependent	☐ 0

*Will you roll over onto your side? To the **right**. Be sure that you lie down comfortably on your side.*

• normal, without apparent difficulties	normal	☐	4
- difficulty with turning trunk/pelvis	1 × difficulty	☐	3
- difficulty with moving trunk/pelvis	2 × difficulty	☐	2
- difficulty with reaching adequate end position (functionally limiting or uncomfortable: underlying shoulder and arm insufficiently in protraction and free, the head uncomfortably against the head of the bed, or less than 10 cm between trunk and the edge of the bed)	3 × difficulty	☐	1
• dependent on physical assistance (patient asks clearly for help or does not reach an acceptable end position)	dependent	☐	0

Will you rise and sit on the edge of the bed with both feet on the ground?

• normal, without apparent difficulties	normal	☐	4
- difficulty with turning trunk/pelvis	1 × difficulty	☐	3
- difficulty with moving legs	2 × difficulty	☐	2
- difficulty with reaching adequate end position (no symmetric and comfortable sitting posture on the bed)	3 × difficulty	☐	1
• dependent on physical assistance (patient asks clearly for help or does not reach an acceptable end position)	dependent	☐	0

III-B With cover

Will you lie down on your back under the covers? Be sure that you lie down comfortably under the covers

• normal, without apparent difficulties	normal	☐	4
- difficulty with moving trunk or leg	1 × difficulty	☐	3
- difficulty with adjusting cover (three or more adjustments or reaching no adequate covering, for example part of the back uncovered)	2 × difficulty	☐	2
- difficulty with reaching adequate end position (functionally limiting or uncomfortable: with head uncomfortably against the head of the bed or with legs which are not relaxed, with too much flexion)	3 × difficulty	☐	1
• dependent on physical assistance (patient asks clearly for help or does not reach an acceptable end position)	dependent	☐	0

If the patient lies uncomfortably: ask him to lie straight!

*Will you roll over onto your side? To the **left**. Be sure that you lie down comfortably under the covers.*

- normal, without apparent difficulties   normal   ☐ 4
  - difficulty with turning trunk/pelvis   1 × difficulty   ☐ 3
  - difficulty with adjusting cover (three or more adjustments or reaching no adequate covering, for example part of the back uncovered)   2 × difficulty   ☐ 2
  - difficulty with reaching adequate end position (functionally limiting or uncomfortable: underlying shoulder and arm insufficiently in protraction and free, the head uncomfortably against the head of the bed, or less than 10 cm between trunk and the edge of the bed)   3 × difficulty   ☐ 1
- dependent on physical assistance (patient asks clearly for help or does not reach an acceptable end position)   dependent   ☐ 0

*Will you roll over onto your side? To the **right**. Be sure that you lie down comfortably under the covers.*

- normal, without apparent difficulties   normal   ☐ 4
  - difficulty with turning trunk/pelvis   1 × difficulty   ☐ 3
  - difficulty with adjusting cover (three or more adjustments or reaching no adequate covering, for example part of the back uncovered)   2 × difficulty   ☐ 2
  - difficulty with reaching adequate end position (functionally limiting or uncomfortable: underlying shoulder and arm insufficiently in protraction and free, the head uncomfortably against the head of the bed, or less than 10 cm between trunk and the edge of the bed)   3 × difficulty   ☐ 1
- dependent on physical assistance (patient asks clearly for help or does not reach an acceptable end position)   dependent   ☐ 0

Will you rise and sit on the edge of the bed with both feet on the ground?

- normal, without apparent difficulties   normal   ☐ 4
  - difficulty with moving trunk or leg   1 × difficulty   ☐ 3
  - difficulty with adjusting cover (three or more adjustments)   2 × difficulty   ☐ 2
  - difficulty with reaching adequate end position (no symmetric and comfortable sitting posture on the bed)   3 × difficulty   ☐ 1
- dependent on physical assistance (patient asks clearly for help or does not reach an acceptable end position)   dependent   ☐ 0

Appendix 4.11   Timed Up and Go test (TUG)

The Timed Up and Go test is used to determine how quickly the following activities can be performed at a comfortable speed:
- rise from a chair;
- walk three meters;
- turn round;
- walk back to the chair and
- sit down.

In the starting position the patient is sitting in a chair (seat height approximately 45 centimeters) with his feet resting on the floor. The arms of the patient rest on the arms of the chair. If necessary the patient may use a walking aid. The patient has to be able to walk without the help of others.

The physical therapist measures the time that the patient needs to perform the test.

Appendix 4.12   Global Perceived Effect

The activity I wanted to improve was: ....

This activity is now:

- ☐ 1 worse than ever
- ☐ 2 much worse
- ☐ 3 slightly worse
- ☐ 4 not changed
- ☐ 5 slightly improved
- ☐ 6 much improved
- ☐ 7 greatly improved

… compared to the situation at the beginning of the treatment.

Appendix 4.13   Borg-scale

Patient score	Feeling of exertion (not shown to the patient)
6	extremely light (rest)
7	
8	
9	very light, e.g. walking calmly
10	
11	fairly light
12	
13	fairly heavy, constant tempo
14	
15	heavy
16	
17	very heavy
18	
19	extremely heavy
20	exhaustion

Appendix 4.14   Diary

> **The diary is filled in by the patient.**

Explanation of diary

The diary is meant to evaluate the performance of the exercise program. The exercise diary is an important aid in the support of your movement activities. Based on your diary the physical therapist is able to determine your progression and to prevent overload. Furthermore, the diary will make clear if the exercise load has to be adjusted. Finally, the diary provides clear information on the way you are coping with your complaints and if you have developed an active lifestyle.

A number of items in the diary you have to fill in are explained as follows:

1.	Night's rest	Point out how your night's rest was (good/sufficient/ moderate/bad).
2.	Exercises	Describe the exercises you performed on that day.
3.	Number of exercise periods	Report the total number of periods that you exercised today. Only the exercise periods performed as part of the exercise program you received from your physical therapist should be reported, not exercise as part of activities of daily life.
4.	(Mean) duration of the exercise periods	Report the mean duration of the exercise periods that day.
5.	Number of resting periods	How often did you have to rest during the exercises?
6.	Cause of resting periods	What was the cause that made you needed to rest?
7.	(Mean) duration of the resting periods	What was the mean duration of the resting periods?
8.	Total exercise duration	How long did you exercise today in total?

N.B. The items above are about what you really have done, not what you planned to do.

9.	Borg-score	The Borg-score is an aid to estimate the subjective load, the level of exertion, on a scale of 6 to 20. Indicate how heavy the load is during exercising. This can only be done if you are familiar with using the Borg-scale.
10.	Special circumstances	If there were special circumstances, you can describe them here, such as: Injuries, complaints, or abnormal weather conditions.
11.	Feeling afterwards	How did you feel when the exercise period was over; did you have complaints for a long time after the exercise, and how severe were these complaints?
12.	Other remarks	Here you can describe everything you find important, and that is not yet written down.

MONTH: _____ **DIARY OF:** _____

	Monday	Tuesday	Wednesd.	Thursday	Friday	Saturday	Sunday
Date							
1. Night's rest							
2. Exercises							
3. Number of exercise periods							
4. Duration per exercise period							
5. Number of resting periods							
6. Cause of need to rest							
7. Duration of resting periods							
8. Total exercise duration							
9. Borg-score (6-20)							
10. Special circumstances							
11. Feeling afterwards							
12. Remarks							

Appendix 4.15   Advice concerning practice room layout

To carry out the diagnostic and therapeutic process as described in the KNGF-guidelines it is advisable to have in the practice room:

- an environment resembling the patient's home environment to enable the performance of a range of possible activities;
- an exercise room or treadmill to perform the Six-minute walk test and to train physical condition and walking;
- a mirror for visual feedback when correcting body posture;
- a metronome or a similar instrument to give auditory cues;
- an exercise room if therapy in a group is desired.

Appendix 5

Cognitive movement strategies

Sitting down
- approach the chair with firm steps, at good pace;
- make a wide turn in front of the chair and stop straight in front of the chair: you must have the feeling that you walk around something (first, practice this, for example, with a cone in front of the chair, later without the cone); if necessary, turn at the rhythm of the cue you already used when you were approaching the chair;
- place your calf or back of the knee against the seat;
- bend slightly forward and bend through the knees, keep your weight well above your feet;
- move with your hands towards the arms of the chair or the seat, seek for support with your arms;
- lower yourself in a controlled manner; sit down well, at the back of the chair.

Rise from a chair
- place your hands on the arms or the side of the seat;
- move your feet towards the chair (just in front of the chair legs, two fists apart);
- shift your hips to the edge of the chair;
- bend your trunk (not too far, nose above the knees);
- rise gently, from your legs, let your hands lean on the arms of the chair, the seat or your thighs, and then extend your trunk completely (if necessary, make use of a visual cue). In case of starting problems rock back and forth a few times and rise at the third count.

Stand up after a fall
Rest after the fall
- turn from lying, through side-sit (pushing up the trunk with hetero-lateral arm and homo-lateral elbow support), to the position on hands and knees;
- crawl to an object to pull yourself up (for example chair, bed);
- bend the strongest leg and place the opposite arm on the object (rifleman's position);
- push yourself up with legs and arms.

Getting in bed
It is advisable to slide the covers to the foot of the bed first (like an accordion); the top of the cover points in the direction of the head of the bed, so it can be pulled easily over the patient.
For aids and other provisions (for instance, a bed adjustable in height) the working group refers to an occupational therapist.

Strategy 1
- approach the bed with firm steps, possibly with the use of a rhythmical cue , and make a wide turn in front of the bed (not over one leg), and walk at a good pace until you feel the bedside with your calf or back of your knee;
- sit down on the edge of the bed (be sure there is enough distance to the pillow);
- lower the upper part of the body in the direction of the pillow, and place the weight on the elbow;
- lift the legs one by one into the bed so that you are lying on your side;
- grab the covers with your free arm;
- lower the upper part of the body onto the mattress and try to lie comfortably by moving your backside;
- pull the covers over the body.

Strategy 2
- approach the bed forwards with firm steps, if necessary make use of a rhythmical cue;
- bend forward, lean with your hands on the mattress and crawl onto it in such a way that you are positioned on your knees, lengthwise, at the middle of the mattress;
- lie down on your side (be sure there is enough distance to your pillow);
- grab the covers with your free arm and pull them over your body.

Strategy 3
- approach the bed forwards with firm steps, if necessary make use of a rhythmical cue, make a wide turn in front of the bed (not over one leg), and walk at good pace until you feel the bedside with your calf or back of your knee;
- sit down on the bed, with sufficient distance and in diagonal direction to the pillow, with the arms as backward support;
- place your legs, one by one, on the mattress, turn until you are lengthwise on the mattress;
- grab the covers at the end of the bed, slide your feet under the covers;
- lower yourself quietly until you are lying on your back, hold on to the covers and pull them over your body.

Turning in bed, from a position on the back
Smooth sheets (satin) or satin pyjamas make sliding or turning easier.
Socks can give more grip on the sheets and, with that, make turning easier.

Strategy 1 (through head/shoulders)
- move the cover to the side opposite to the one you want to turn to;
- lift the cover with your arms and pull up your knees while you are lying on your back, put your feet flat on the bed;
- move your body to the side, alternating with your feet, your pelvis, and your head and shoulders, in the opposite direction of the turn;
- place your arm which is on the side you want to turn to next to your head, then turn your head and shoulders, use your free arm for the direction;
- then lower your knees in the direction of the turn, if possible make some room under the covers with your free arm;
- lie down comfortably.

Strategy 2 (through legs/pelvis)
- move the cover to the side opposite to the one you want to turn to;
- lift the cover with your arms and pull up your knees while you are lying on your back, put your feet flat on the bed;
- move yourself to the edge of the bed (alternating with your feet, pelvis, head and shoulders), in the opposite direction of the turn;
- place your arm which is on the side you want to turn to next to your head;
- pull up your knees as far as you can (in the direction of your chest, your feet on the mattress) and 'drop' in the direction of the turn (if necessary lift the cover with your free arm), roll over with your pelvis;
- head and shoulders follow the free arm;
- lie down comfortably.

Strategy 3 (through arm swing)
- lift the cover and pull up your knees, while you are lying on your back, and put your feet flat on the bed;

- move yourself to the edge of the bed (alternating with your feet, pelvis, head and shoulders), in the opposite direction of the turn;
- outstretch one or two arms vertically;
- bend your knees or keep your legs straight, whatever you prefer;
- make a rolling movement with your total body, using an arm swing;
- lie down comfortably.

N.B. For all three strategies it is important that the patient does not roll *off* the bed and lies in the middle of the mattress.

Getting out of bed: from lying on the back to sitting on the edge of the bed
The following tips might make it easier to get out of bed:
- at night a nightlight is on to make visual feedback possible.
- on the bed are no light covers or smooth sheets.
- the patient wears smooth (satin) pyjamas and socks for more grip.
- the bed is not too low.
- handy aids are: elevator to lift a patient, sliding board, handles on the sides of the bed (occupational therapist).

Strategy 1
- move your body a bit from the middle to the edge of the bed.
- roll over on your side (see turning in bed);
- pull your knees further to your chest;
- open the cover;
- place your top arm next to your bottom shoulder;
- bring your feet over the edge of the bed and, at the same time push yourself up with both arms (if helpful, support sitting up with your bottom arm straight and the hand of your other arm placed nearby your elbow).

Strategy 2
- bend your knees, put your feet flat on the bed;
- move yourself to the edge of the bed (alternating with your pelvis, shoulders and feet), in the opposite direction of the turn;
- lift the covers;
- shift your feet over the edge of the bed and, at the same time roll over to your side;
- place the hand your top arm on the bed near the elbow of your other arm;
- bring your feet over the edge of the bed and, at the same time push yourself up with both arms (if helpful, support coming to sit with your bottom arm straight and the hand of your other arm placed nearby your elbow).

From sitting on the edge of the bed to standing
Strategy
- sit upright on your buttocks;
- lean on your arms, place your fists a bit behind your body;
- shift your buttocks to the edge of the bed;
- lean with your arms on the edge of the bed;
- place your feet right in front of the bed, approximately 20 cm apart;
- bend forward (with your nose above your knees);
- stand up from your legs, if necessary rock first.

KNGF Guidelines

for physical therapy in patients with Parkinson's disease

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