

Guidelines for Occupational Therapy in Parkinson's Disease Rehabilitation

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Preface to the English translation

The English version of this guideline is a direct translation of the complete Dutch text published in 2008 (see copyright & credits), except for a few minor corrections and adaptations to increase comprehension. The guideline has been developed in accordance with international standards for guideline development. In addition to internationally published evidence and expert opinion, the expert opinion of the Dutch Guideline Working Group has been used for development of the recommendations. Accordingly, the specific vision and context of occupational therapy in the Netherlands may emerge in the choice of key questions, in the reference to handbooks and under “other considerations” (e.g. concerning the organization of healthcare or the availability of resources and training to therapists). The user of this guideline should bear in mind that this context may differ from the context in other countries. Nevertheless, we believe that this guideline is the first to describe best practice in occupational therapy in Parkinson’s disease rehabilitation according to international standards of guideline development and covering both assessments and interventions.

Preface

With justifiable pride, we recommend this guideline to you.

This is not just any guideline. It is an evidence-based guideline for occupational therapy. What's more, it has a "twin" in speech and language therapy. As far as we know, it is one of two unique monodisciplinary evidence-based guidelines in allied health professions to come out at the same time: *Occupational Therapy in Parkinson's Disease* and *Speech and Language Therapy in Parkinson's Disease*, Guidelines from the Dutch Association of Occupational Therapy (Ergotherapie Nederland) and the Dutch Association of Speech Therapy and Phoniatrics (NVLF). These guidelines were developed simultaneously and in close collaboration.

The primary aim of developing a guideline is to guarantee the level of care and, where possible, to improve it by making it more efficient and effective. By "effective" we mean safer, more acceptable to both the person providing treatment and the client and more applicable and practicable. In other words, guidelines are necessary and useful because they create advantages for the content, provision and organization of care.

A new guideline is an important innovation because it bundles the best available scientific evidence. It is also innovative in the sense that the evidence is viewed from a practical perspective. A guideline provides professionals with valuable recommendations about good and proper care. A practical guideline describes the care content from the available scientific evidence and incorporates the experiences of therapists and clients. The provision of care is, after all, based on a partnership between the client and therapist. Moreover, it is aimed at participation and is thus context-oriented. But this Guideline offers even more. The group of researchers and professionals from Nijmegen collaborated intensively on these guidelines. Not only does the correlation between the guidelines and the Parkinson's Disease Guideline of the Royal Dutch Society for Physical Therapy (KNGF) from 2004 provide a solid foundation for monodisciplinary treatment, it also facilitates the collaboration between the various allied health disciplines. It is precisely this collaboration that is a critical factor of success for the provision of good care in which the needs of the client are served. Integrated care plays an increasingly important role in how the quality of care is experienced.

As Cervantes's character, Don Quixote, said in 1605, "the proof of the pudding is in the eating" and this guideline's value will have to be proven in practice. Before that happens – before occupational therapists actually begin to apply the guideline in practice – an implementation process will have to be completed. This is an important task for the professional associations.

To our great satisfaction, steps have already been taken to also evaluate the use of the guidelines through scientific study. This will make it possible to determine the extent of the

application of the guidelines in detail and, for example, to study the relationships between the application of the guidelines and the outcome of the care.

We would like to pay our compliments to this classic example of strengthening care - its content, provision and organization - through collaboration!

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Summary

Overview of recommendations

This overview contains a listing of the recommendations as formulated in the guideline.

For background information and a justification, please refer to the texts in Part II.

PwP stands for person with Parkinson's disease.

Indication for occupational therapy (Section 3.3)

Recommendation 1

Occupational therapy is indicated for persons with Parkinson's disease or their caregivers when:

1. The PwP experiences limitations in activities or participation problems in the following areas:
 - a. Living/caring: personal care, functional indoor and outdoor mobility, housekeeping, caring for family members and pets
 - b. Work: paid and unpaid work
 - c. Leisure: hobbies, going out, social contacts
2. The caregiver experiences problems in supervising or supporting the PwP in daily activities.
3. The referrer has questions regarding the PwP's safety and self-reliance with respect to carrying out daily activities.

Concluding occupational therapy (Section 3.4)

Recommendation 2

Concluding the occupational therapy is advised as soon as the set objectives (or revised objectives) have been achieved, when there are no further occupational therapy intervention options or when the PwP and caregiver are satisfied with the current level of functioning in activities and participation.

Reporting between the occupational therapist and referrer (Section 3.5)

Recommendation 3a

The information in the referral to the occupational therapist should contain, at least, the following data:

- personal details of the PwP
- insurance details
- date of referral/registration
- details of the referrer (name, address, telephone number, field)
- details of the general practitioner
- referring diagnosis, medical case history and co morbidity
- current medications and, preferably, previously used medications (including the reasons for discontinuation)

- Indication and nature of the referral, an advisory consultation or an initiation of treatment)
- if known: which other professionals/fields are involved

Recommendation 3b

The occupational therapist reports to the referrer and the Parkinson's disease nurse specialist upon conclusion of an intervention. If the occupational therapy intervention is long-term in nature, the care provider will also make interim reports (at least once per year). In the report, the occupational therapist will state at least the implemented intervention(s), the intervention period and frequency, the effect and the expected prognosis. If possible, the intervention results should be supported by measured outcomes. The significance of these results should be succinctly – but clearly – described. The choice of measuring tools should comply with the *Guideline for Occupational Therapy in Parkinson's Disease Rehabilitation*. When psychosocial problems and/or fluctuations in response to medication are observed, this is reported to the Parkinson's disease nurse specialist or care coordinator.

Identifying the nature and background of the patient's occupational issues (Section 4.3.1)

Recommendation 4a

To identify and prioritize the PwP's occupational performance issues, using the Canadian Occupational Performance Measure (COPM) is recommended instead of using the currently available standardized ADL questionnaires.

Recommendation 4b

In addition to the COPM, administering the Occupational Performance History Interview (OPHI-II) or parts thereof is recommended when more information and background is needed regarding occupational identity, coping and motivation with respect to meaningful occupational performance.

Identifying the nature and background of the caregiver's occupational issues (Section 4.3.2)

Recommendation 5a

To identify the caregiver's occupational issues, administering the COPM is preferable to administering standardized caregiver questionnaires.

Recommendation 5b

In addition to the COPM, the interview topics from Appendix 4 ,Caregiver Burden Interview, can be used to gain more insight into the burden experienced by the caregiver. The use of an ethnographic/ narrative style of interviewing is recommended.

Clarifying the context of problems related to specific activities (Section 4.3.3)

Recommendation 6

To analyze the context of *specific* activities in which the PwP or the PwP's caregiver experiences problems, the occupational therapist preferably evaluates the following aspects: meaning of the activity, habits/routines, social aspects, space and objects, the complexity of the activity and coping and adapting strategies. The occupational therapist can do this by means of an interview, observation or a combination of the two.

Assessment of timing of activities and energy distribution (Section 4.3.4)

Recommendation 7

If a PwP suffers from fatigue or fluctuating performance, it is recommended to discuss the daily activities in relation to the physical or mental burden and capacity by means of an activity log (Appendix 4).

The PwP completes this log for three successive days (including a weekend day) and includes 1) the time, nature and duration of the activities, 2) the degree of fatigue and 3) the times at which medicine was taken.

In the follow-up discussion of this log, the PwP indicates to what extent different activities are found to be physically or mentally strenuous, fatiguing or – as the case may be – relaxing. Additionally, if a PwP experiences response fluctuations, questions on the influence of these fluctuations on their choice and planning of activities are relevant.

Observation of skills and activities (Section 4.3.5)

Recommendation 8a

It is recommended to administer the Assessment of Motor and Process Skills (AMPS) to a PwP in order to substantiate the degree of independence, effort, efficiency and safety of occupational performance and to gain insight into the PwP's skills which either hinder or facilitate occupational performance.

Recommendation 8b

Instead of the AMPS, the occupational therapist can administer the Perceive Recall Plan and Perform System (PRPP) in order to observe and analyze the occupational performance of the PwP. This applies if the focus of the observation is specifically on information processing or if there are no suitable AMPS tasks for the individual.

Recommendation 8c

In order to examine the writing problems experienced by a PwP, it is recommended to evaluate the following aspects: writing problems experienced, writing posture, penmanship, writing speed, fine motor skills and, specifically, the effect of cues, conscious attention and dual tasks on writing.

For this examination, the occupational therapist can use the evaluation points which appear in Appendix 5: Handwriting Evaluation.

Assessment of impairments in body functions and structures (Section 4.3.6)

Recommendation 9

To assess the nature and extent of impairments in body functions and structures, which are relevant to interpreting limitations at the level of skills, activities and participation it is recommended to collect as much data as possible from assessments conducted by professionals in other related fields that are authoritative in the areas concerned.

If such data are not available, the occupational therapist confers with the referrer as to whether further examination is indicated.

Assessment of the environment (Section 4.3.7)

Recommendation 10

It is recommended to assess the environment guided by knowledge of 1) the physical environmental factors which specifically facilitate or hinder the occupational performance of someone with Parkinson's disease and 2) the factors important in fall prevention. The main themes in evaluating the physical environment in which the occupational performance of the PwP and caregiver(s) takes place pertain to the accessibility of and mobility throughout the various spaces, orientation and the utility of the facilities, furniture and implements.

For this, the occupational therapist can use the questions and points of attention which appear in Appendix 7 of this guideline. as a guide.

Planning for time and location for assessment (Section 4.4)

Recommendation 11

It is recommended that the assessment takes place once a stable medication regime has been established.

If a PwP experiences response fluctuations, it is recommended that the time of assessment is planned such that:

- insight can be gained into the performance during both the *on* and the *off* phase.
- interviews designed to clarify the occupational issues occur during an *on* phase.

Recommendation 12

It is advisable to observe the PwP in performing activities in his usual performance context (instead of in a clinical setting) in order to gain insight into problems relating to safety, efficiency and independence.

To evaluate how a PwP can deal with new environmental contexts, occupational performance can purposefully be observed in an unfamiliar environment.

Supervising the general learning process (Section 5.3)

Recommendation 13

When supervising or instructing the PwP in activity performance or during skills training, it deserves recommendation to consider the following points:

- connect the instruction method to the person's individual learning style;
- give instructions step-by-step (having the PwP learn one thing at a time);
- let the PwP learn with conscious attention; use a conscious learning process (explicit learning);
- provide a clear structure;
- create the right context for learning (in the home, leisure or working environment);
- provide enough opportunity for practice and repetition;
- give instructions before or after the occupational performance, not during;
- provide reminders (i.e. an instruction sheet).

Specific interventions (Section 5.4)

Recommendation 14

It is advised to encourage the use of self-management strategies in order to improve the recognition and management of occupational performance issues..

A prerequisite is that the cognitive capacities of the person are sufficient for learning and to applying problem-solving skills, either with or without the help of an external structure.

Recommendation 15

Advising a PwP on daily structure and activities is recommended to increase satisfaction with occupying time and to optimize opportunities for engagement in meaningful occupational performance.

This intervention is indicated if the particular PwP:

- 1) suffers greatly from slowness, fatigue or fluctuating performance;
- 2) takes little initiative in initiating activities;
- 3) can no longer carry out certain activities and has questions about suitable alternatives.

Recommendation 16

To help a PwP to reduce stress, tension and time pressure in daily activities, an occupational therapist can employ the following interventions:

- advising the PwP and caregiver about reducing the time pressure in the planning and organization of activities;
- improving the feeling of personal effectiveness in carrying out activities by encouraging self-management and optimizing occupational performance;
- teaching the PwP to carry out activities in a relaxed manner.

Recommendation 17

Practicing arm/hand motor skills is advised as part of meaningful activities and contexts for the PwP and only if he is sufficiently capable (i.e. motor and cognitive functioning) of practicing these skills

Recommendation 18

It is recommended to evaluate the effect of the the strategy of “consciously focusing attention on problematic sub-aspects of the occupational performance” on a PwP and, if the effect is positive, to advise and train its use in activities.

A prerequisite for applying this strategy is that the person is able and willing to put in the effort of focusing attention in the situations concerned.

Recommendation 19

If a PwP has problems in carrying out complex movement sequences (i.e. in reaching/grasping or transfers), it is recommended to evaluate the effect of cognitive movement strategies (step-by-step occupational performance) and, if the effect is positive, to advise and train its use in activities.

Recommendation 20

If a PwP has problems with carrying out dual tasks, it is recommended to evaluate the effect of reorganizing and simplifying multi-task activities into activities which consist of a sequence of single tasks (or sub-tasks). If the effect is positive, it is recommended to advise its use in daily occupational performance.

Recommendation 21

If a PwP has movement problems related slowness, reduced amplitude or freezing, it is recommended to evaluate the effect of cues on the PwP’s occupational performance and, if the effect is positive, to advise and train the use of these cues in activities.

Recommendation 22

It is recommended to advise a PwP and his caregiver(s) about modifications to the physical environment if these modifications promote the safety, effectiveness and efficiency of performing activities.

It deserves recommendation to accompany the advice about aids and environmental adaptations with instructions and training in their use.

Recommendation 23

Depending on the occupational issues, it is recommended to use one or more of the following interventions to optimally advise and supervise a PwP's caregiver:

1. encouraging self-management strategies.
2. providing information to increase understanding of the effect of Parkinson's disease on meaningful occupational performance.
3. advising and training the caregiver in skills required to supervise, and support the PwP in occupational performance.
4. advising the caregiver about relevant aids, adaptations and other modifications to the environment that can ease physical care giving burden.
5. stimulate and advice the caregiver in looking for opportunities to maintain or reacquire own activities

Aspects related to planning the intervention (Section 5.5)

Recommendation 24

It deserved recommendation to conduct the occupational therapy sessions in the relevant context (home, leisure or working environment) if the interventions are directed at improving activity performance or skills.

Recommendation 25

If a PwP experiences response fluctuations, it deserves recommendation to plan the time of intervention, such that:

- the learning of new strategies occurs during the *on* phase;
- the application of strategies and alternatives is practiced at moments these strategies and alternatives are needed by the PwP.

Recommendation 26

Individual interventions are preferable above interventions in a group setting when interventions are directed at training occupational performance skills in activities.

Group intervention can be considered for programs that are aimed at providing information and exchanging experiences about general disease related problems or topics.

Guideline for Occupational Therapy in Parkinson's Disease: Assessment Flow Chart

Aim assessment

Evaluating and analyzing meaningful occupational performance:

1. Identifying problems experienced in activities and participation, and the priorities in these.
2. Evaluating and analyzing aspects of the person, activity and environment which hinder or facilitate meaningful occupational performance.
3. Analyzing the potential for changing aspects of the person, activity and environment in order to positively influence the occupational performance.

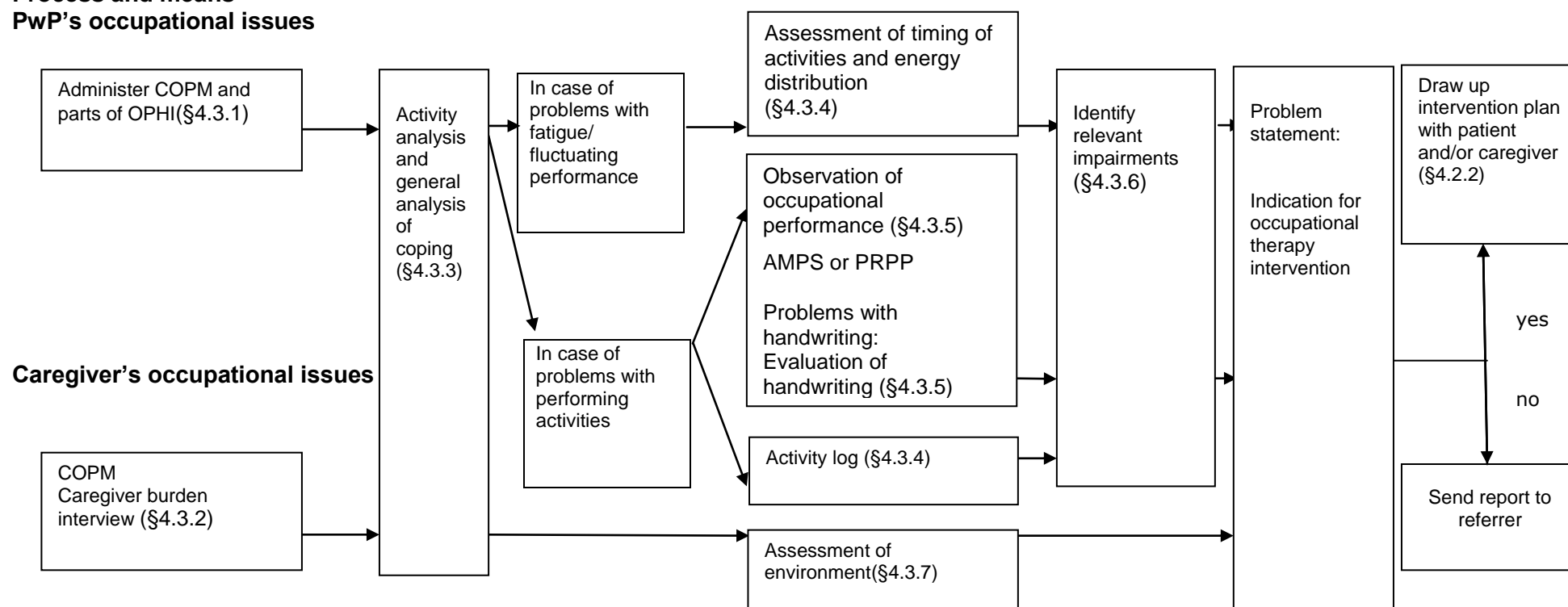
Specific points of attention

In case of response fluctuations:

- Ensure that a good picture is obtained of the performance during *on* and *off* periods;
- also inquire about problems during the night;
- Interviews designed to clarify that occupational issues should preferably take place during the *on* phase.
- Observation: preferably in the relevant context of the occupational performance

Process and means

PwP's occupational issues



Guideline for Occupational Therapy in Parkinson's disease: Intervention guide

General aim

Maintaining or optimizing meaningful occupational performance (in living/caring, work and leisure) of the patient and/or caregiver in his living and working environment.

Potential basis for change

1. the patient (PwP)
2. the activity
3. the physical environment
4. the caregiver/social environment

A combination of focal points, interventions and strategies is usually required in achieving an intervention goal.

The emphasis within a combination can differ, depending on:

- the preference of the PwP or caregiver
- the potential for changing the PwP, caregiver, activity and environment. For the PwP and caregiver, this pertains primarily to capacity to learn new information or skills, motivation to change, severity of limitations and capacity.

Points of attention in instructing the patient

- adapting to the personal learning style of the PwP;
- giving instructions step-by-step (having the PwP learn one thing at a time);
- having the PwP learn explicitly (with conscious attention and conscious learning process);
- providing clear structure;
- creating the right context for learning (in the living and working environment);
- providing enough opportunity for repetition and practice;
- giving instructions before or after the performance, not during;
- giving a visual instruction sheet as a reminder.

In case of response fluctuations:

- teaching new strategies, preferably during the *on* state;
- applying and practicing at the moment the strategy is needed.

Guideline for Occupational Therapy in Parkinson's Disease: Intervention Guide (continued)

Potential interventions (general) Informing – Advising – Coaching – Instructing – Practicing – Giving feedback

Interventions aimed at	Potential basis for change:			
	Patient (PwP)	Activity	Physical environment (§5.7.9)	Caregiver (§5.7.10)
Encouraging self-management §5.4.1	<p>Insight into the effect of the disease on meaningful occupational performance</p> <p>Using a problem-solving approach towards problems in activities and participation</p> <p>Recognizing and applying one's own learning style</p>			<p>Insight into the effect of the disease on meaningful occupational performance</p> <p>Using a problem-solving approach</p> <p>Supporting the PwP in using a problem-solving approach</p>
Optimizing daily structure and activities (§5.4.2)	Modifying daily structure and activities to abilities/possibilities and response fluctuations	Changing the nature, time & duration of an activity; Making the activity less burdensome in method & sequence	Putting up schedules and, if necessary, reminders	Supervising the patient in maintaining a daily structure (schedule)
Dealing with stress and time pressure in activity performance (§5.7.3)	<p>Having insight into the effect of stress and time pressure</p> <p>Modifying the planning and organization of activities to altered pace and response fluctuations</p> <p>Being able to apply relaxation</p>	Simplifying the activity: breaking down complex actions into simple sub-tasks	Focusing on arrangement and location of things to reduce situations involving time pressure (e.g. location of the telephone)	Reducing time pressure for the PwP
Practicing arm/hand motor skills (§5.4.4)	Awareness of the importance of continuing to use motor skills in activities and how this can be achieved	Modifying the activity to abilities/possibilities (creating the right challenge)	If necessary, modifying the environment to create the right challenge	Creating the right challenge for the PwP when supervising an activity
Applying focused attention strategy (§5.4.5)	Performing activities with attention focused on problematic aspects	Simplifying the activity	Reducing distracting factors	Ensuring there is less distraction Supervising the PwP in focusing attention

Interventions aimed at	Potential basis for change: Patient (PwP)	Activity	Physical environment (§5.7.9)	Caregiver (§5.7.10)
Applying cognitive movement strategies (§5.7.6)	Performing activities step-by-step Applying the step-by-step performance of transfers in activities	Simplifying the activity: breaking down complex actions into simple steps		Instructing the PwP step-by-step
Minimizing dual tasking in activities (§5.7.7)	When possible, performing one task at a time	Simplifying the activity: breaking down complex actions into simple sub-tasks	Reducing distracting factors in the environment Creating possibilities in the environment for reducing simultaneous tasks (e.g. trolley, places to sit)	Creating a situation with fewer simultaneous tasks for the PwP: activity and environment
Applying cueing strategies (§5.5.8)	Trying out suitable cues Using cues in activities		Setting up visual cues in the environment	Providing the PwP with cues (e.g. type of instruction)
Optimizing the physical environment (§5.7.9)	Insight into possibilities and procedures Using aids and adaptations safely and effectively	Simplifying the activity by using aids/adaptations	Structuring environment and recommending aids and adaptations to compensate for reduced skills and increased risk of falling	Insight into options and procedures Effectively supervising the PwP in the use of aids and adaptations
Advising and supervising caregivers (for themselves) (§5.7.10)		Making the care tasks less burdensome (reducing, simplifying)	Using aids and adaptations to reduce the caregiver burden	Using a problem-solving approach Creating room for one's own activities Identifying any need for support from third parties Increasing competence in supervision and care Using aids and adaptations safely and effectively for care

1. General introduction and justification of methodology

1.1 Background and motivation

Thanks to advances made in medical treatment, the symptoms of Parkinson's disease can be kept under control for a longer period of time. Nevertheless, Parkinson's disease remains a progressive disease which is accompanied by increasingly greater limitations in carrying out everyday activities. For many persons with Parkinson's Disease (PwPs), this leads to major problems in social and societal participation. Occupational therapy focuses on increasing or, for as long as possible, maintaining the level of meaningful activities and societal participation of people with Parkinson's disease.

In 2003, Deane et al. conducted a study among 169 occupational therapists in England to survey their current practice for PwPs(1). A follow-up study explored what these therapists thought the best practice should look like (2). From this, there was a reasonable consensus among the 150 respondents regarding the role of occupational therapy in PwPs, but a discrepancy was also revealed between the current practice and the best practice. Furthermore, the occupational therapists reported a lack of expertise with respect to treating PwPs effectively (1;2). This lack of expertise is confirmed by research in the Netherlands (3). The content of the occupational therapy sessions is primarily based on the expertise of individual occupational therapists, which results in a wide range of working methods (4). Due to a lack of methodologically sound intervention studies, there is thus far no clear scientific evidence for the effectiveness of occupational therapy for PwPs (5-7).

The aforementioned issues led to the plan to develop and implement a national occupational therapy guideline for Parkinson's disease under the auspices of the Dutch association of occupational therapy, Ergotherapie Nederland. The underlying principle is that, despite the lack of specific scientific evidence, a guideline can make a positive contribution to the systematic improvement of the quality of care. It promotes the transparency and uniformity of professional practice (8). Moreover, a guideline provides an important basis for new scientific research in which the effectiveness of occupational therapy in Parkinson's disease rehabilitation can be tested.

The guideline is a systematically developed set of recommendations for optimal occupational therapy practice for PwPs and their caregivers and is based on current scientific literature and insights within the profession as of 2008. This guideline was developed by using the method of guideline development according to the Dutch Institute for Healthcare Improvement CBO and the quality requirements described in the AGREE-instrument (9).

1.2 Aims of the guideline

The specific aims of the guideline are:

1. To improve the uniformity and quality of occupational therapy in PwPs and their caregivers.

2. To improve the efficiency of occupational therapy in PwPs and their caregivers. This is achieved, on the one hand, by clarifying the indication for referral to occupational therapy and, on the other, by providing therapists with directions for the content and duration of the treatment.
3. To promote multidisciplinary collaboration by clarifying the role of the occupational therapy in the multidisciplinary team.
4. To provide direction to research. The guideline clarifies what pieces of evidence are still missing and in which areas research is required.

1.3 Key questions

The guideline answers the following general questions:

1. What disease specific aspects of Parkinson's disease are important for occupational therapists to know and consider? (Chapter 2, background information)
2. What is the role of occupational therapy in Parkinson's disease rehabilitation? (Chapter 3)
3. What should the occupational therapy assessment of PwPs and their caregivers consist of? (Chapter 4)
4. What occupational therapy interventions should be considered in the treatment of PwPs and their caregivers ? (Chapter 5)

The specific key questions are stated at the beginning of Chapters 3, 4 and 5.

1.4 Target group

The guideline primarily provides recommendations for the occupational therapy assessment and treatment of patients with idiopathic Parkinson's disease. The guideline also devotes attention to occupational therapy interventions for caregivers of PwPs.

The guideline is not directly applicable to patients with other forms of parkinsonisms, such as multiple system atrophy (MSA), progressive supranuclear palsy (PSP) or vascular parkinsonism. These parkinsonisms are characterized by a more progressive course and other accompanying symptoms. However, some general principles within the recommendations can provide direction for the occupational therapy assessments and interventions that can be used for these patient groups.

Within occupational therapy, it is preferable to use the term "client" for the individual who comes to the occupational therapist for assessment and treatment. This can either be the individual with the disease or someone close to him or her. However, for the sake of clarity regarding which client is meant, we use the terms "Person with Parkinson's Disease (PwP)" and "caregiver" in the guideline.

1.5 Intended users

The *Guideline for Occupational Therapy in Parkinson's Disease Rehabilitation* was written initially for occupational therapists who assess and treat PwPs and their caregivers. The guideline is also informative for all physicians, such as neurologists, general practitioners and geriatricians, who refer PwPs to occupational therapy and for other care providers who collaborate with the occupational therapist.

1.6 Basic principles

The following basic principles were used to develop the guideline:

- For as much as possible, the *Guideline for Occupational Therapy in Parkinson's Disease Rehabilitation* is based on knowledge from published scientific research. In cases in which no scientific evidence is available, the working group of content experts has formulated recommendations based on a consensus regarding “best practice.”
- *The International Classification of Functioning, Disability and Health* (ICF, World Health Organization 2001) is used as a basis for describing the consequences of Parkinson's disease for the domains “activities” and “participation”, and a classification which is familiar to occupational therapists is used for the subdivision.
- The occupational therapist is provided with practical recommendations for the assessment and treatment of PwPs.
- The processes described are recognizable as steps within a methodological top-down occupational therapy process.
- A client-centered approach is used in which the PwP, the caregiver and their occupational issues are the main focus.

1.7 Primary contributors to the guideline

The proposal and initiative for developing and implementing a national guideline for occupational therapy came from the Parkinson Centrum Nijmegen (ParC). The project leaders are Prof. Dr. B.R. Bloem, medical director of ParC, and Dr. M. Munneke, scientific director of ParC.

The guideline was developed under the auspices of Ergotherapie Nederland. This means that Ergotherapie Nederland is the commissioning party as well as the owner of the guideline. I. Sturkenboom, occupational therapist and researcher at UMC St Radboud, was responsible for developing the guideline. The guideline was written in cooperation with a primary working group of seven content experts and the project leaders (see Appendix 1). In putting together the primary working group, an attempt was made to appoint representatives of various contexts and regions across the Netherlands.

All primary working group members and the project leaders have declared to have no conflicts of interest in developing the guideline.

1.8 Patient's perspective

The PwPs' and caregivers' perspective is included in the guideline by also including relevant scientific literature which addresses the perspective of PwPs and caregivers. A panel of patients and caregivers from the Dutch Parkinson's Disease Association, the Parkinson Vereniging (PV), has also evaluated the draft of the guideline from their perspective.

1.9 Methodology

The guideline's aims and general key questions were formulated during the first meeting of the primary working group. The specific key questions were formulated at a later point by the authors and came about following a first review of the literature relating to the general key questions stated in Section 1.3.

Based on the specific key questions, the first author systematically searched the literature and evaluated its quality and content. Draft texts, which incorporated the evaluated literature, were then written by the first author (IS) with the assistance of the second author (MT).

The primary working group discussed these draft texts at face-to-face meetings and via e-mail and came to a consensus about the recommendations. Draft version B was the result. This version was submitted to a secondary working group of 18 content expert occupational therapists (see Appendix 1) along with targeted questions. Based on their feedback, the guideline was amended and became draft version C.

Next, 55 occupational therapists employed the draft guideline during the test phase and evaluated it for usefulness, clarity and completeness. These were occupational therapists who were being trained as part of *ParkinsonNet*. They came from different regions and contexts and had varying experience with the treatment of PwPs (www.parkinsonnet.nl).

At the same time, draft version C was evaluated by representatives of the multidisciplinary team (see Appendix 1) and an expert on guideline development from the CBO. A panel of PwPs and caregivers also evaluated draft version C of the guideline for relevance, completeness and applicability from their own perspective. The project leaders also provided feedback based on their expertise.

The comments were incorporated into draft version D, which was then submitted for evaluation to 49 occupational therapists during the training of professionals for *ParkinsonNet* for southern regions in the Netherlands. The focus of this evaluation was on the feasibility of implementing the guideline in daily practice.

The last changes have led to the provisional guideline which has been passed on to the professional association for collating and further publication.

1.10 Scientific basis

1.10.1 Literature

General

For as much as possible, the recommendations from the guideline have been based on evidence from published scientific research. Relevant articles in Dutch and English published between 1985 and 2008 were sought using systematic search strategies. The electronic databases Pubmed, Cinahl, Psychinfo, Embase and the Cochrane library were used for this purpose. In light of the fact that it quickly became apparent that there are no good randomized trials involving occupational therapy in Parkinson's disease rehabilitation, a broad search was made for other types of research as well as descriptive and evaluative literature.

The main search terms used were, in the first place, "Parkinson* disease" AND "occupational therapy," "Parkinson* disease" AND "activities of daily living" and "Parkinson* disease AND rehabilitation."

Parkinson's disease

The general chapter on Parkinson's disease drew its content mainly from overview articles and medical books on the pathology of the disease. Articles on studies which examined the perspective of PwPs and caregivers were also used, as was a textbook on the multidisciplinary treatment of PwPs(10), and the current monodisciplinary KNGF guideline for Parkinson's disease (11).

Occupational therapy assessment

In light of the limited literature on the occupational therapy assessment process in Parkinson's disease, the guideline was based on general processes, methods and tools within occupational therapy which are potentially well-suited for use with PwPs. A specific search was then made in the literature for the scientific value of the various tools and methods.

Occupational therapy intervention

For the interventions, the search strategy was refined by searching for evidence on specific interventions which, according to the literature on multidisciplinary treatment and the expert judgment of the working group members, are used in the paramedical treatment of PwPs and their caregivers. The literature was evaluated for its scientific value and usefulness for the intervention as part of occupational therapy. Specific attention was paid here to the relevance of the intervention to improving meaningful occupational performance.

A search was also made for publications on effective occupational therapy interventions for other chronic impairments which could also be relevant as part of occupational therapy interventions for PwPs and their caregivers. Examples include such topics as dealing with fatigue, caregiver interventions, fall prevention, aids and modifications.

1.10.2 **Strength of evidence**

The selected articles were evaluated for quality and classified according to the level of evidence. For the evaluation of intervention studies, use was made of the evaluation forms and criteria of the CBO. The CBO classification was not used for evaluating assessment tools, as this is only suitable for medical diagnostic tests or if there is a reference test or gold standard against which the measuring tools can be tested. This was not the case for the occupational therapy assessment tools.

However, the assessment tools were reviewed for evidence of quality of reliability and validity. The conclusion of the literature review is based on this.

In Tables 1.1 and 1.2, the grading of levels of evidence for single intervention studies and for conclusions of the literature review are explained.

Table 1.1 Classification of the methodological quality of intervention studies

Class	Description
A1	Systematic review of at least two independently conducted A2 level studies
A2	Randomized, blinded comparative clinical trial of good quality and sufficient size
B	Comparative study, but not with all the features listed under A2 (including the patient control study and cohort study)
C	Non-comparative study
D	Expert opinion

Table 1.2 Classification of the level of evidence of the conclusions

Level	Evidence	Phrasing
Level 1	Study at Level A1 or at least two independently conducted study at Level A2	Researchers have demonstrated
Level 2	One study at Level A2 or at least two independently conducted studies at Level B	It is likely that...
Level 3	One study at Level B or C	There are indications that...
Level 4	Expert opinion	Experts believe that...

1.10.3 **Recommendations**

In addition to scientific evidence, other aspects are important to consider before coming to a recommendation. These include organizational aspects, the need for special expertise and suitability for daily practice. These aspects appear under the heading “Other considerations.”

The final recommendations for practice derive from integrating the conclusions from the literature with the other considerations. It is thus possible that the strength of a recommendation is weaker or, as it may be, stronger than the level of evidence in the conclusion. Table 1.3 gives an overview of the grading of the strength of the recommendations.

Table 1.3 Classification of the strength of the recommendations

Strength of the recommendation	Preferred phrasing in the formulation
Strong	<p>Positive recommendation: Strongly recommended/should/must/is the first choice/has been indicated/is required/is the standard</p> <p>Negative recommendation: Strongly advised against/should not/must not/is not an option/is contraindicated</p>
Moderately strong	<p>Positive recommendation: Recommended/advisable/preferable/aspires to/deserves recommendation</p> <p>Negative recommendation: Not recommended/is discouraged/does not deserve recommendation</p>
Weak	<p>Positive recommendation: To be considered/is an option/ there is possible room/ can</p> <p>Negative recommendation: There is perhaps no room/ it does not seem worthwhile</p>
None	No advice or recommendation can be given/not possible to make a choice/no preference can be stated

1.11 Structure and summary of Part II

This introductory chapter provides the justification for developing *the Guidelines for Occupational Therapy in Parkinson's disease Rehabilitation*. Chapter 2 provides background information about the disease and the multidisciplinary treatment. In Chapter 3, the role of the occupational therapist in Parkinson's disease is described and recommendations are made with respect to indications for making referrals to occupational therapy. This chapter is relevant to referrers and other professionals involved. Chapter 4 contains a detailed explanation of the occupational therapy assessment. The assessment process and the assessment tools are described and recommendations are made based on the literature and the considerations of the working group. The background for each key question is provided, then the scientific basis with conclusions, followed by the considerations of the working group and, finally, the recommendation. In the same way, Chapter 5 describes the occupational therapy interventions for enabling occupational performance..

1.12 Availability

The Dutch version of the *Guidelines for Occupational Therapy in Parkinson's Disease Rehabilitation* is available in digital form on the website of Ergotherapie Nederland and ParkinsonNet. A hardback version is also available for sale.

The Guideline has been included in the course materials for the training of ParkinsonNET occupational therapists.

1.13 Legal significance

Guidelines are not statutory regulations, but rather insights and evidence based recommendations, that health professionals need to follow in order to provide high-quality care. Since the recommendations are primarily based on the symptoms seen in the average PwP, health professionals can deviate from the guideline when they deem necessary in accordance with their professional autonomy. However, any deviation from strong and moderately strong recommendations should be justified and documented.

1.14 Procedure for revising the guideline

According to guideline development standard, a guideline should be revised within five years following publication. This means that Ergotherapie Nederland will determine in 2013 by the latest whether the guideline is still up-to-date. If necessary, a new working group will be assembled to evaluate the guideline and update it according to the best evidence available at the time. The validity of the current guideline will lapse if new developments lead to the initiation of a revision process.

1.15 External financial support

The development of the guideline was made possible through financial support from the Nuts/Ohra Foundation and the Dutch Parkinson's disease Association (*Parkinson Vereniging*). The potential interests of these organizations did not influence the contents of the guideline.

1.16 Word of thanks

We would like to extend a special thanks the Dutch Parkinson's disease Association (*Parkinson Vereniging*) and the Nuts/Ohra Foundation for their financial support in developing this guideline and to all members of the secondary working groups and the panel of patients and caregivers. We also thank Mrs. M. Schmidt, coordinator at Parkinson Centrum Nijmegen, who took the first initiative in developing a guideline for occupational therapy in Parkinson's disease. In addition, we would like to thank C. Haaxma, assistant physician in neurology at UMC St. Radboud, for her contribution to the medical background texts in Chapter 2.

2. Parkinson's disease

2.1 Pathogenesis

Parkinson's disease is a chronic progressive condition with the primary feature being the loss of dopamine-producing cells in the substantia nigra (situated high in the brainstem; part of the basal ganglia) [12]. This results in a lack of dopamine, which reduces the stimulating function of the basal ganglia on the motor cortex. Inevitably, cells and functions of various other non-dopaminergic neural circuits are affected and this leads to the so-called non-dopaminergic impairments (e.g. autonomous disorders, sleeping disorders). The cells which remain contain distinctive pink-colored inclusion bodies, the so-called Lewy bodies (12). The cause of Parkinson's disease is unknown. Recent findings point to the influence of a combination of environmental and genetic factors (12). The familiar visible symptoms of Parkinson's disease appear when the dopaminergic neurons have been reduced to approximately 20% of their original number (12).

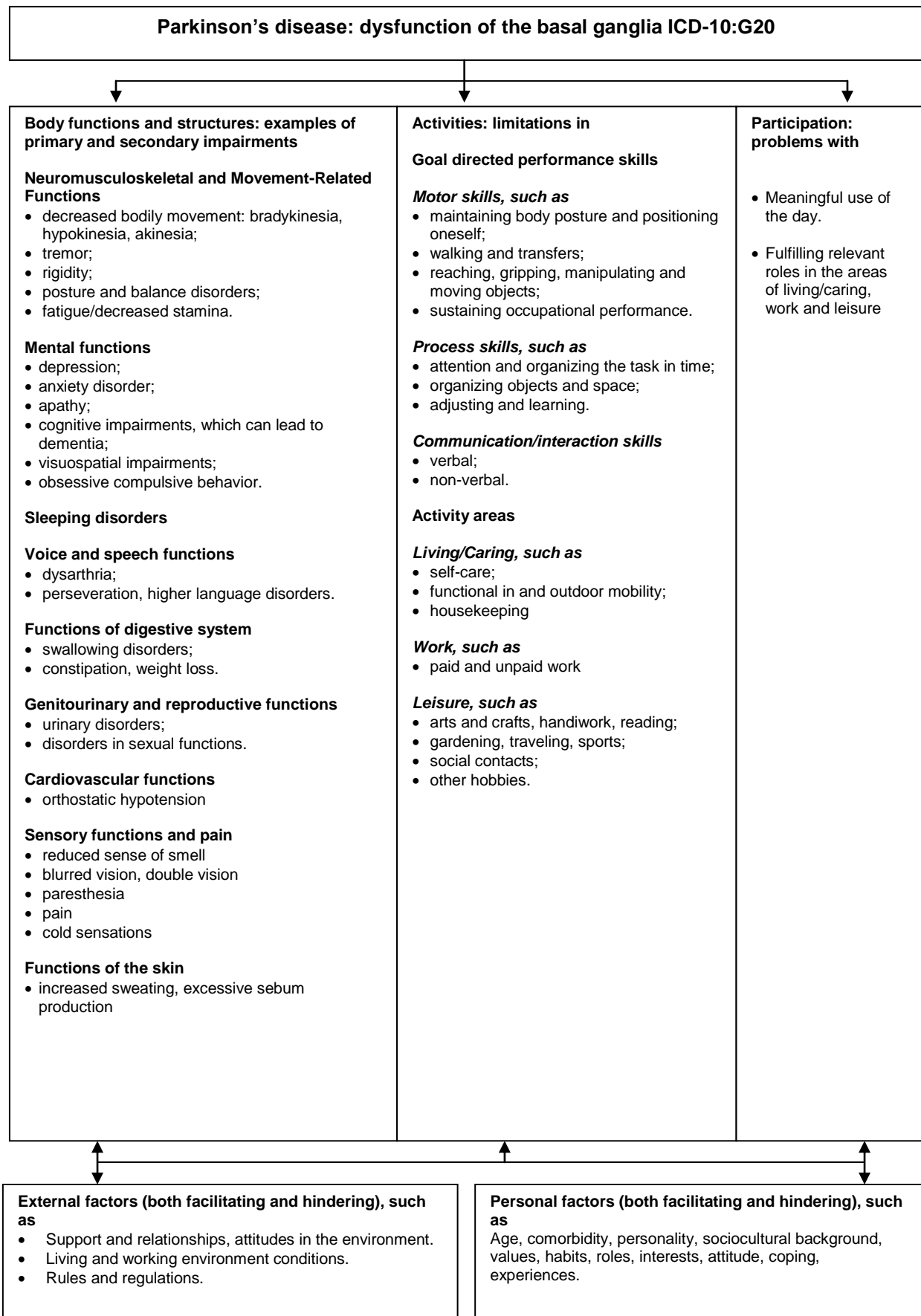
2.2 Epidemiology

After Alzheimer's disease, Parkinson's disease is the most common neurodegenerative disorder. It has a prevalence of approximately 0.3% in the overall population and approximately 1% in the population over the age of 60 (13). In the Netherlands, the total number of individuals with Parkinson's disease is thus estimated to be 50,000. The incidence increases with age. The average age at which the disease emerges is 60-65, though in 5-10% of the PwPs the first symptoms appear prior to the age of 50 (12). As the population of the Netherlands continues to age, it is expected that the number of PwPs will rise significantly and double over the next twenty years.

2.3 Consequences of Parkinson's disease

Based on the framework of the World Health Organization's 'International Classification of Functioning' (ICF-model), Figure 2.1 provides an overview of the health problems which are related to Parkinson's disease and the factors which can influence these problems. The terminology of the ICF is only used in the main headings. Categories and terminology commonly used in occupational therapy determine the phrasing of limitations in activities. Disorders in functions can occur as a result of Parkinson's disease itself, but also as a result of medication or inactivity. Whether an individual experiences problems in activities and participation depends not only on the presence and severity of the disorders in functions, but also on personal and external factors (see ICF model).

Figure 2.1



2.3.1 *Impairments in functions*

Below an explanation of some of impairments commonly seen in Parkinson's disease are explained, such as impairments in movement-related functions, mental functions, voice and speech functions and sleeping disorders.

Movement-related impairments

Characteristic motor symptoms of Parkinson's disease are bradykinesia, hypokinesia, rigidity, tremor and disturbed posture reflexes (14).

The term *bradykinesia* is used when movements occur more slowly and with a smaller range of movement. With repetitive movements, the range of movement becomes increasingly small: "extinction." Bradykinesia is particularly noticeable in quick, repetitive movements, such as shaking, knocking and brushing. There might also be a disturbance in the timing of various movement components in a composite movement, such as a reach-to-grasp movement (15;16).

Hypokinesia means that the person makes fewer *automatic* movements. Characteristic examples of this are a decreased arm swing while walking and decreased facial expression or hypomimia (which results in a "mask-like face").

The phenomenon akinesia indicates that movements can suddenly no longer be initiated or continued – so-called "freezing." This symptom occurs mainly in conjunction with a series of successive automatic movements, such as in walking, talking and writing.

Rigidity means there is an increase in muscle tone caused by a disorder of the extrapyramidal system. This is in contrast to spasticity, in which there is increased muscular tension resulting from a pyramidal tract disorder). Rigidity can be observed in the passive movement of an arm, leg or the head. The increased muscle tone may then feel like the so-called "leadpipe" phenomenon, in which the entire range of motion is rigid. *Dystonia* is a sustained muscle contraction in which a body part assumes an abnormal position. In Parkinson's disease, dystonia occurs primarily in the hands and feet (13).

The *tremor* associated with Parkinson's disease is generally a distal resting tremor (4-6 Hz) involving the thumb (and is thus called the "pill-rolling" or "money-counting" tremor) which disappears or diminishes when a movement is initiated. The tremor can return when the individual assumes a fixed position (e.g. keeping an arm extended) or holds objects for a longer period of time. Sometimes, a tremor is observed – particularly among younger PwPs – which occurs over the entire track of a voluntary movement. This is known of as an action tremor.

PwPs eventually encounter problems with *posture* and *balance*. Posture and balance disorders which can appear at a relatively early stage include a stooped posture, a decreased arm swing and decreased rotation in the torso. Postural instability and falling are later phenomena (13).

The disease is often accompanied by *reduced stamina* as well as mental and physical *fatigue* (17-20). The cause of fatigue in Parkinson's disease is not yet well understood, but multiple factors - such as physical components, depression, dyspnea and sleeping disorders - are likely to play a role. However, research has shown that the fatigue experienced is relatively unrelated to the degree of motor problems and that fatigue can also be present in patients who do not suffer from depression (18). Fatigue can vary during the day and often increases as the day progresses. It is partly dependent on the effect of the medication (see response fluctuations in Section 2.5.3).

Impairments in mental functions

Cognitive deterioration can occur in Parkinson's disease, particularly during the later stages of the disease. In the early stages of the disease, a neuropsychological test can already detect impairments in memory, attention and executive functions (21).

A common cognitive problem in Parkinson's disease is decreased flexibility in changing the focus of attention (problems with alternating and divided attention) (22). It is also more difficult for patients to filter non-relevant auditory and visual stimuli (problems with selective attention) and their ability to concentrate can fluctuate (problems with maintaining attention) (23). The processing of information might slow down (bradyphrenia) and memory functions can change. There is not so much a disturbance in the holding of information, but rather a disturbance in the spontaneous retrieval of that information from memory (24;25). Problems in executive functioning can lead to problems in organization, planning and problem-solving (24). PwPs have a greatly increased risk of developing dementia (26).

In addition to emotional problems that can occur as part of the process of accepting the disease (i.e. adjustment problems), many PwPs develop depression (27;28). Fear and apathy are also common.

Disturbances in visuospatial functions can also occur. For example, Parkinson's disease can lead to impairments in estimating spatial relationships and the ability to see contrasts(29;30).

Sleeping disorders

Sleeping disorders, such as REM sleep-related disorder, problems with falling and staying asleep, nightmares and Excessive Daytime Sleepiness (EDS), can appear with Parkinson's disease and have a big impact on the quality of sleep and thus on mood and degree of fatigue during the day. Serious sleeping problems are often a reason for sleeping apart from one's partner.

Impairments in voice and speech functions

Many PwPs develop voice and speech disorders in the form of dysarthria with decreased volume, decreased articulation, faster or slower speech rate and a monotone, high pitch voice (31;32).

2.3.2 *Severity and progressions of symptoms*

Parkinson's disease is progressive, but the exact progression of symptoms varies per individual (33;34). The classic motor symptoms are often preceded by a number of non-motor symptoms, such as smell disorders, constipation, depression and sleeping disorders. The first motor disorders usually begin unilaterally (12). Though the contralateral side also becomes affected at a later stage, the first side generally remains the most affected.

The Hoehn and Yahr scale provides a rough, but still useful classification of the severity of the disease (35).

Table 2.2 Classification according to the modified Hoehn and Yahr scale (11;13)

Stage	Description
1	Initial stage with minor symptoms on one side of the body.
1,5	Unilateral symptoms with initial axial problems.
2	Bilateral symptoms. No impairment of balance. Possibly already kyphotic posture, slowness and speech problems. Postural reflexes are still intact.
2,5	Mild symptoms with slight impairment on retropulsion test (unaided recovery).
3	Mild to severe symptoms, some posture and balance problems. Walking is impaired, but still possible without assistance. Physically independent.
4	Severe symptoms, some assistance is required. Walking and standing are impaired, but still possible without assistance.
5	Final stage. Completely disabled. Walking or standing is not possible without assistance. Continuous care is required.

Not everyone progresses through the stages as described in this scale. Less than 5% of PwPs ultimately end up in a wheelchair or bedridden [36]. With today's medical treatment, overall life expectancy is almost average.

The process is more favorable (e.g. slower progression, less frequent and later occurring postural instability and cognitive deterioration) for PwPs whose predominant motor symptom is a tremor than for PwPs who suffer mostly from bradykinesia and rigidity (33;34;37). A higher age of onset and cognitive deterioration are associated with a faster progression of the disease (33;37;38).

2.3.3 *Limitations in performance skills*

Motor skills

Maintaining body posture and positioning oneself for the task

PwPs with impaired balance need external support to perform activities while standing. Severely stooped posture has a negative effect on the ability to use arm movements efficiently and this can accordingly limit the ability to reach high. Many PwPs fail to adjust

their body position appropriately for the task requirements. For example, when reaching for an object located farther away, the individual will not step closer, but try to reach further. This can increase the risk of falling. Or, failing to step backward leads to standing too close to the workspace and this reduces efficient or effective activity performance.

Walking, transporting and transfers

The abnormal gait (characterized by a reduction in stride length, stride height and speed) is usually exacerbated during dual tasks, such as when objects have to be moved or when the individual is thinking about something or talking to someone while walking (39). If the PwP suffers from freezing, this mainly occurs when starting to walk, passing through close spaces, making turns and performing dual tasks (40). Problems can therefore specifically arise when transporting objects. In propulsion walking speed increases, steps become smaller and the person has difficulty stopping.

Transfers (e.g. chair, toilet, bed, bath, car) are usually difficult. PwPs have difficulty performing the *transfer* with sufficient speed, and usually do not bring their torsos forward enough (41;42). Sitting at a table can be difficult due to problems with moving the chair while “half” standing at the same time. Many PwPs have difficulty with bed mobility, such as turning over in bed (not rotating the torso enough) and getting in and out of bed (41;42).

Reaching, gripping and manipulating objects

The fluency, coordination, efficiency and speed of composite and fine motor movements are usually diminished. This affects the ability to grasp and manipulate objects. The impaired timing and integration of movement components play an important role in this, as do the smaller range of motion and impaired regulation of the necessary force (43;44). Moreover, the generalized stooped posture and decreased flexibility and use of the torso can limit the functional reach in activities. (45). If a PwP needs his hands to stabilize himself during a standing activity, this also limits the functional use of the arms/hands in activities. If a resting tremor recurs when the patient holds objects for a longer period of time (i.e. when writing), this impacts negatively on activity performance.

Sustaining occupational performance: endurance

The rate of performance is usually slower due to the impairments in motor and cognitive functions, and performing activities require more effort and energy. In addition, mental and physical fatigue and reduced stamina make it difficult to sustain activities.

Process skills

Attention and organizing the task in time

PwPs have difficulty performing tasks which normally do not require conscious attention and which should happen more or less automatically. They have to think more about the progress of the different sub-actions (41). Due to reduced mental flexibility, activity performance is more difficult when there are distracting factors in the environment or if several tasks have to be performed simultaneously. This manifests in the occurrence of hesitations or interruptions

in occupational performance. The activity usually proceeds more chaotically and more time is required to complete it. The PwP may also have difficulty finishing the actions in a timely manner.

Organizing objects and space

Clinical practice shows that it is sometimes difficult for PwPs to look for and locate required objects in a systematic manner. This can be due to cognitive problems, such as impaired memory or impaired planning. PwPs often organize objects inefficiently in relation to one another (e.g. too close together or too spread out). This impacts on the safety and efficiency of task performance.

Adjusting to problems

Due to the many limitations that can be present, a great deal is required of the patient to adjust the environment or way of working in order to enable safe and independent occupational performance. However, many PwPs are unable to adjust their occupational performance adequately or are slow in noticing and responding to problematic situations during the task. This might be due to the inability to spontaneously generate solution strategies and impaired information processing, attention and memory functions (23;24;46-48).

While most PwPs are able to learn new information, this requires additional time and a quiet environment. Too much information at once can be confusing.

In providing instructions account must be taken of the fact that PwPs have difficulty with implicit learning. Therefore, They information can best be given in an explicit manner (25). Generalizing a learned skill to a new situation is difficult for PwP.

Communication/interaction skills

Voice and speech disorders usually result in decreased intelligibility. At the same time, communication is less supported by non-verbal expression and gestures. Patients can also have difficulty following and understanding conversations optimally.

The writing skills of a PwP often change quite early in the disease. The letters become smaller (micrography) as the sentence progresses and therefore the words become less legible. The writing speed can also change (49-53). Penmanship worsens in situations of dual tasks, such as when taking minutes during a meeting or when making notes during a telephone conversation.

2.3.4 Limitations in activities

Living/Caring

Self-care

Problems related to self-care are very common with Parkinson's disease (54;55). These problems can pertain to eating, drinking, washing, dressing, brushing one's teeth, personal grooming, going to the bathroom and taking medicine.

Motor disorders have a particular effect on:

- actions requiring fine motor skills, such as handling fasteners;
- actions requiring larger alternating or rotating movements, such as buttering and cutting bread, washing hair and brushing teeth;
- actions requiring balance, such as clothing the lower part of the body and bending over or reaching to get things out of a closet or cabinet.

At the same time, bradykinesia, rigidity and a stooped posture make it more difficult to reach certain body parts (e.g. back, buttocks, head) or objects. This can make it more difficult, for example, to tuck in the back of a shirt or to put food in the mouth. When a tremor occurs while holding a utensil or cup, this usually impairs eating and drinking.

As many self-care tasks take place in confined spaces, this can exacerbate problems with turning and walking, making it difficult to maneuver safely and effectively. Cognitive problems can increase limitations in self-care, for example with respect to collecting and organizing necessary objects and taking medicine at the right time. The activities require more effort and time (55).

Functional mobility

For a discussion of walking and *transfers*, see Section 2.3.3. PwPs are more prone to falling incidents (56-58). Studies examining the risk factors for falling associated with Parkinson's disease indicate that problems with stability, *transfers*, walking (e.g. freezing, propulsion) and orthostatic hypotension play a primary role (56). Reduced attention and executive function impairment also play a role [59]. As a result of falling, or near falling, patients can develop excessive kinesiophobia (fear of movement). This can lead to inactivity and social isolation. The strongest predictor for falling is an earlier fall in the previous year (58).

Though no literature is available on cycling in connection with Parkinson's disease, clinical practice demonstrates that it is not so much cycling itself but rather getting on and off the bike that is problematic. For driving a car, impairments in cognitive functions and visual perception have a serious impact on driving skills, like adjusting speed and steering (60-62). Limitations in motor skills might impact on the ability to use the accelerator, brake and steering wheel (63). Driving a car with automatic transmission is usually easier. PwPs with a driver's license should notify the Central Office for Motor Vehicle Driver Testing that they have Parkinson's disease. The person's driving ability is then determined by means of a medical evaluation and, if deemed necessary, a supplemental driving test. Predictors for driving skills are disease duration, the person's ability to see contrasts and the extent of cognitive and motor impairment (64).

Housekeeping

Housekeeping activities, such as cleaning, shopping for groceries, cooking, ironing, organizing finances and making small repairs, are complex composite activities. They require a high degree of cognitive and motor skills. Given the impairments associated with Parkinson's disease, problems in performing housekeeping activities are to be expected. In this regard, cognitive performance is particularly predictive (65). There is evidence to suggest that housekeeping tasks are given up or taken over by caregivers at an earlier point than self-care tasks are (55;66).

Work

For younger PwPs, work is an important, meaningful activity (54;66). However, Parkinson's disease can have a strong impact on the capacity for performing work-related activities (67). A study conducted in the United Kingdom shows that four out of five PwPs have difficulty working as a result of the disease (67). Van Brenk and Analbers (2004) surveyed in the Netherlands a small group of PwPs who were still working in order to gain insight into which specific problems they encounter at work. The most frequently stated problems pertain to limitations in writing and computer use, fatigue, impossibility in pacing tasks and existing obstacles in the physical work environment (68).

Many PwPs have to give up paid employment. Nearly half (46%) of the PwPs have stopped working after having had the disease for five years, and 82% after ten years (69). Not only the severity of the symptoms but also the lack of support in the work environment and the lack of options for early retirement can play a role (67). In a survey taken among 85 PwPs in the Netherlands, a lack of energy and other physical complaints were cited as important reasons for stopping work (70).

Leisure

The possibilities for performing activities such as handicrafts, gardening, cycling, walking and sports decrease as the disease progresses (55). Feelings of shame, insecurity and anxiety can have an extra inhibiting effect on going out and maintaining social contacts (71). Higher cognitive impairments, depression or apathy make it more difficult to seek out new situations or try out new activities. Fear of falling can lead to inactivity, while fatigue is also associated with reduced participation in leisure activities (17;72).

2.3.5 *Participation problems*

Participating in the different life domains and continuing to spend one's days in a meaningful way may become more difficult and can no longer be taken for granted. The aforementioned impairments and limitations play a role in this, as do personal factors as well as physical and social environmental factors (see ICF model). With respect to personal factors, for example, the individual's personal experiences, expectations and motivation can support or hinder participation.

2.3.6 *Quality of life and the PwP's perspective*

Parkinson's disease has a major negative impact on the quality of life of PwPs. Studies have found a close correlation between the presence of depression and a lower quality of life (36;73;74). The quality of life also decreases with increasing limitations, symptom fluctuations and fatigue (19;72-76).

When asked to state the worst aspects of Parkinson's disease, PwPs more often mention their limitations in activities than the impairments (77). In qualitative studies on perceptions of

and experiences with Parkinson's disease, PwPs state that accepting the disease is difficult (54;66;78). They mention feelings of frustration with the limitations and shame about the symptoms and the way in which they perform activities (54;66;78;79). Many PwPs experience a loss of control of their body, their thoughts, their situations and the future. They can no longer take their occupational performance for granted. This contributes to a feeling of insecurity and a lack of confidence in their body and themselves (80;81). Insecurity is primarily mentioned in the context of participation in the "outside world" (71;80). Participation and daily activities change as a result of the disease. Certain activities are given up because they are too difficult and take up too much time, because there is a feeling of shame about performing them or because those close to the patient find that the activities have become too dangerous (66). Dependency increases and the PwP's world is at risk of shrinking. When stopping with work, PwP's miss most social contacts, prestige and an aspect of identity are missed the most (70). Many PwPs try to go back to work or find work-related activities (66;70).

Through trial and error, patients try to adapt to the altered range of capabilities. Strategies reported by PwPs themselves include balancing medication intake and lifestyle, taking more time for activities, constantly planning for potential problems, modifying an activity or asking for help from others (54;66). Comparing themselves to others in the same situation is also a strategy mentioned.

2.3.7 *Quality of life and the caregivers' perspective*

Caregivers of a PwP – especially those who are partners – experience a heavy physical and psychosocial burden and this has a negative impact on their own health and well-being (82-84). The caregiver burden becomes greater as the PwP's functional limitations increase (83-86). There are also other specific factors which serve as predictors for the caregiver's experienced caregiver burden. The most important are depression, hallucinations, confusion, falling and personal factors, such as social support and coping style of both the PwP and the caregiver (83;85;87-92). There is a high correlation between the PwP's quality of life and that of the caregiver (82;83;86). For the well-being and performance of both the PwP and the caregiver, it is important to always consider the perspective and the possible issues of concern of the caregiver. A number of small studies have shown that caregivers need emotional support as well as information and advice on how to deal with specific disease-related problems (90;93;94).

2.4 Medical diagnosis

The diagnosis of Parkinson's disease can only be confirmed post-mortem by demonstrating the presence of Lewy bodies, which can develop in both the substantia nigra and the cortex.

Clinically, a presumptive diagnosis can only be made based on (95;96):

1. The presence of an asymmetrical hypokinetic rigid syndrome. At least two of the following disorders must be present, including either bradykinesia or resting tremor:

- bradykinesia
 - resting tremor
 - rigidity
 - postural instability
2. A good, sustained reaction to levodopa.
 3. The absence of specific exclusion criteria (the so-called “red flags”) (12;97). Examples of these are: pyramidal tract disorder, cerebellar abnormalities, prematurely manifest cognitive impairments, prominent postural instability or falling in the first three years, quick or step-by-step progression, symmetrical onset.

The presence of “red flags” can indicate other forms of parkinsonisms, such as: progressive supranuclear palsy (PSP), multiple system atrophy (MSA), corticobasal degeneration (CBDG), essential tremor (ET), vascular parkinsonism, drug-induced parkinsonism and dementia with Lewy bodies (98). The differential diagnosis is important because the therapeutic options and prognosis for these forms of parkinsonisms are different than those for idiopathic Parkinson’s disease(13).

Table 2.3 Most important differential diagnoses (abridged version from *Parkinson Handbook 2007*) (13)

Clinical syndrome	Clinical features	Progression
Drug-induced parkinsonism	<ul style="list-style-type: none"> • frequently occurring; • symptoms often symmetrical; • rapid tremor; • action tremor more often than resting tremor; • sometimes accompanied by tardive dyskinesias; • dopamine receptor-blocking medication (e.g. neuroleptics). 	<ul style="list-style-type: none"> • dependent on recognition of syndrome and proper therapy; • usually resolved within three months following discontinuation of iatrogenic medication; can take up to twelve months before complaints fully disappear.
Multiple system atrophy (MSA)	<ul style="list-style-type: none"> • parkinsonism, often symmetrical; • ataxia; • autonomous disorders; • cognition largely unimpaired. 	<ul style="list-style-type: none"> • quick progression; • median survival: 9 years.
Progressive supranuclear palsy (PSP)	<ul style="list-style-type: none"> • parkinsonism, often symmetrical and axial; • vertical gaze paresis; • significantly impaired balance; marked by frequent backward falls • cognitive deterioration (particularly in the frontal lobes). 	<ul style="list-style-type: none"> • quick progression; • median survival: 6-10 years.

Corticobasal degeneration (CBDG)	<ul style="list-style-type: none"> • asymmetrical parkinsonism; • cognitive impairments (e.g. apraxia, alien limb syndrome). 	<ul style="list-style-type: none"> • quick progression; • median survival: 8 years.
Vascular parkinsonism	<ul style="list-style-type: none"> • parkinsonism affecting the lower limbs more than the upper limbs (“lower body parkinsonism”); • gradual progression is suggestive, but not necessary; • balance impairment; • cardiovascular risk factors; • background of TIA/CVA (transient ischemic attack/cerebrovascular accident). 	<ul style="list-style-type: none"> • varies, usually quick progression; • cognitive deterioration in later stages.
Dementia with Lewy bodies	<ul style="list-style-type: none"> • cognitive deterioration with fluctuations in attention and alertness; • hallucinations; • autonomous disorders; • excessive sensitivity to neuroleptics with an increase in symptoms. 	<ul style="list-style-type: none"> • quick progression in which cognitive deterioration is most evident.
Essential tremor (ET)	<ul style="list-style-type: none"> • symmetrical action tremor; • often a positive family history of ET; • no symptoms of hypokinetic rigid syndrome; • improvement of tremor with alcohol (in 50% of cases). 	<ul style="list-style-type: none"> • slow progression of action tremors without parkinsonism.

2.5 Intervention

The general aim for interventions in for PwPs is to optimize daily performance and social and societal participation. In order to achieve this, various medical and paramedical interventions are possible.

2.5.1 *Multidisciplinary approach*

When there are complex issues of concern, it is desirable to have the involvement of a multidisciplinary team. Professionals who can participate in this multidisciplinary treatment team include – in no particular order – neurologists, geriatricians, general practitioners, specialists in rehabilitation medicine, specialist physicians in nursing homes, psychiatrists, neuropsychologists, Parkinson’s disease nurse specialists, physical therapists, speech and

language therapists, occupational therapists, sexologists, dietitians and social workers. Good coordination between the various practitioners is required.

In the Dutch *Multidisciplinary Guidelines for Parkinson's*, recommendations are made for coordinating and organizing optimal network care for PwPs(99).The multidisciplinary guideline also provides recommendations for the indications for the role of the various professionals that may be involved in Parkinson's disease.

2.5.2 *System approach*

Given the chronic and degenerative nature of Parkinson's disease, PwPs become increasingly dependent on assistance. Caregivers, such as partners, children and neighbors, play an important role in supporting the PwP from both a psychosocial and practical perspective. This support is usually the crucial factor in sustaining living at home. As previously stated in this chapter, Parkinson's disease has a major impact on the health and well-being of caregivers. For this reason, quality care in Parkinson's disease should devote attention to the social system surrounding PwPs and, where necessary, interventions carried out by the multidisciplinary team should also focus on the caregivers and family.

2.5.3 *Medical intervention*

Medication

A medication regime aimed at easing Parkinson's symptoms can start when the symptoms have an impact on daily functioning. It is not started merely for cosmetic reasons.

The basic functions of medication are (14;100;101):

- correcting the shortage of dopamine (levodopa, dopamine-agonists, inhibiting dopamine breakdown);
- blocking the relative excess of acetylcholine;
- supporting medication (e.g. treatment for constipation, incontinence, sleeping problems, depression).

Appendix 2 contains the most frequently used medications for Parkinson's disease, including their effects and a few of the most important side effects. As is true for nearly all medication, abrupt discontinuation can result in dangerous negative effects (withdrawal or rebound symptoms).

Side effects of medication

After using dopaminergic medication for an average of two to seven years, fluctuations in the effect of the medication can occur (response fluctuations) (13). This manifests in predictable and/or unpredictable fluctuations in the severity of the symptoms in the course of a day. Motor fluctuations lead to an increase of Parkinson's symptoms during an "off phase," when dopamine levels are too low, and in pathologically excessive movement (dyskinesias) during an "on phase" when dopamine levels are too high. Patients in fact fluctuate during the day between the different states:

- *off* phase
- *on* phase, but with “acceptable” (i.e. non-impairing) dyskinesias
- *on* phase, with impairing/debilitating dyskinesias

When response fluctuations appear, a good *on* phase entirely without dyskinesias no longer exists..

Dopaminergic medication – particularly dopamine agonists – can lead to obsessive behavior problems. This can involve punding (stereotyped, purposeless, wholly disruptive behavior) or addictions to medication, sex, gambling, shopping, the internet, eating or stealing (102). Especially younger PwPs who already had minor addictive or compulsive tendencies prior to starting the medication run a greater risk of such reactions.

Neurosurgical intervention

When PwPs have been treated with dopaminergic medication for a long period and the disease is at an advanced stage, a point may be reached at which the medication options maintaining a reasonable quality of life are exhausted. The PwP then suffers from severe response fluctuations. In such a situation, neurosurgical intervention may be considered. In most cases, the subthalamic nucleus (STN) is electrically stimulated by means of electrodes implanted in the brain. On the one hand, the advantage of this operation lies, in the possibility of reducing the medication so that fewer side effects occur and, on the other hand, in directly counteracting tremors or dyskinesias (14;103). Unfortunately, not every PwP can undergo this operation; due to the risks involved, strict inclusion and exclusion criteria apply (104).

2.5.4 Paramedical intervention

Physical therapy

In 2004, the Royal Dutch Society for Physical Therapy (KNGF) published the first evidence-based guideline for physical therapy with Parkinson’s disease (11). This guideline was developed in cooperation with the Professional Association for Remedial Therapy (VVOCM), as there is no difference in the treatment options of both professional groups with respect to Parkinson’s disease.

The aim of physical therapy and remedial therapy (Cesar and Mensendieck) in Parkinson’s disease rehabilitation is to improve or maintain the independence, safety and well-being of the PwP through and during movement. This is achieved by preventing inactivity, preventing falls, maintaining and improving mobility and reducing limitations in activities and restrictions in participation related to mobility. Six domains are distinguished:

1. transfers (e.g. standing up from a chair and rolling out of bed)
2. body posture
3. reaching and gripping
4. balance
5. walking
6. physical capacity (i.e. muscular strength, joint mobility, general condition)

The disease progression is divided into three phases: early (Hoehn & Yahr 1-2.5), middle (Hoehn & Yahr 2-4) and late (Hoehn & Yahr 5). In the early phase, the aim is to prevent inactivity, fear of moving and fear of falling and to maintain and/or improve stamina. The aim in the middle phase is to maintain or encourage activities in the aforementioned domains. It is particularly in this phase that cooperation with an occupational therapist can be indicated. The aim of treatment in the late phase is to maintain vital functions and prevent complications, such as pressure sores and contractures. Close cooperation with the nursing staff or other professional and non professional caregivers is essential in this stage.

The interventions consist of providing information, instructions and exercises. Depending on the goal, the patient's preference and the patient's general performance (including cognitive function), can determine whether exercise are performed individually or in a group, in a clinic, at home or at a gym and with a low or high level of supervision.

Recommendations for interventions which are based on evidence of two or more controlled studies are: 1) the use of cueing strategies to improve walking; 2) cognitive movement strategies to improve the performance of transfers; 3) specific exercises to improve balance; 4) training joint mobility and strength (to improve physical capacity).

Speech and language therapy

The first speech and language therapy guideline for Parkinson's disease was developed at the same time as the occupational therapy guideline for Parkinson's disease (105).

In Parkinson's disease, the speech and language pathologist focuses on three domains: 1) speech problems (dysarthria and communicative blocks), 2) oropharyngeal swallowing disorders and 3) loss of saliva, and the limitations and participation problems which can result from this.

The aim of the speech and language therapy treatment of the dysarthria is to improve intelligibility and the communication between PwPs and their environment. The most successful treatment of dysarthria focuses on increasing the loudness of the voice, which simultaneously activates breathing, voice quality and articulation, making the patient easier to understand. Various studies make it reasonable to assume that this technique, known as the Lee Silverman Voice Treatment (LSVT), in which the PwP receives intensive treatment (three to four times a week) over a short period (four weeks), is effective (106;107). In the Dutch adaptation of this specific approach for PwPs, the PwP is also taught to speak in a lower pitch in order to prevent the voice going higher when talking louder (Pitch Limiting Voice Treatment, or PLVT). There is evidence to suggest that this technique results in a more relaxed, improved voicing (108).

For the speech and language therapy treatment of swallowing disorders and loss of saliva experienced by PwPs, there are as of yet no proven Parkinson's-specific interventions. The treatment largely consists of applying common techniques and modifications (31).

Occupational therapy

The aim of occupational therapy is to reduce restrictions in participation in meaningful activities and roles. Both the PwP and the caregiver receive attention in this regard. The specific role of the occupational therapist is laid out in Chapter 3 and discussed in greater detail in the rest of this guideline.

PwPs and specialists in Parkinson's disease rehabilitation acknowledge the added value of the role of the occupational therapist, but the effectiveness of occupational therapy in Parkinson's disease has not yet been demonstrated (5;109). This is mainly due to a lack of high quality studies.

3. Occupational therapy in Parkinson's disease

3.1 Introduction

This chapter discusses the role of the occupational therapist for patients with Parkinson's disease and their caregivers and contains practical information regarding referral and financing. In this way, the chapter gives referrers to occupational therapy and other connected professionals a short overview of what occupational therapy can offer to PwPs and their caregivers.

Specific recommendations are made for the following key questions:

1. When is occupational therapy indicated for Parkinson's disease?
2. When does the occupational therapy intervention conclude?
3. When and how do the occupational therapist and the referrer report to each other?

3.2 Role of occupational therapy in Parkinson's disease

3.2.1 *Meaningful occupational performance*

The general aim of occupational therapy in Parkinson's disease is to enable the *meaningful* occupational performance of PwPs within their own context (1;2;5;109;110). Meaningful occupational performance entails the selecting, organizing and performing of activities and roles in a particular environment and with a particular meaning for the individual. These are activities, roles and tasks which can be grouped in the following areas (111):

1. Living/caring: activities such as personal care, functional indoor and outdoor mobility, housekeeping, caring for family members and pets
2. Work: paid and unpaid work
3. Leisure: hobbies, going out, social contacts

By performing meaningful activities, the individual shapes his identity and roles and imparts meaning to his life (111;112;112). Accordingly, occupational performance that contributes to social and societal participation is a determining factor for well-being, health and quality of life (112).

Occupational performance comes about through a *dynamic interaction and synthesis* of the person, the occupation and the environment (Fig. 3.1). There is optimal occupational performance when there is a good fit between the individual's desires and skills and the demands of the occupation and the environment.

Parkinson's disease disrupts this balance and adaptation is necessary at the level of the person, the occupation or environment in order to achieve a new balance. Occupational therapists supervise the PwP in this process of change to optimize the occupational performance.

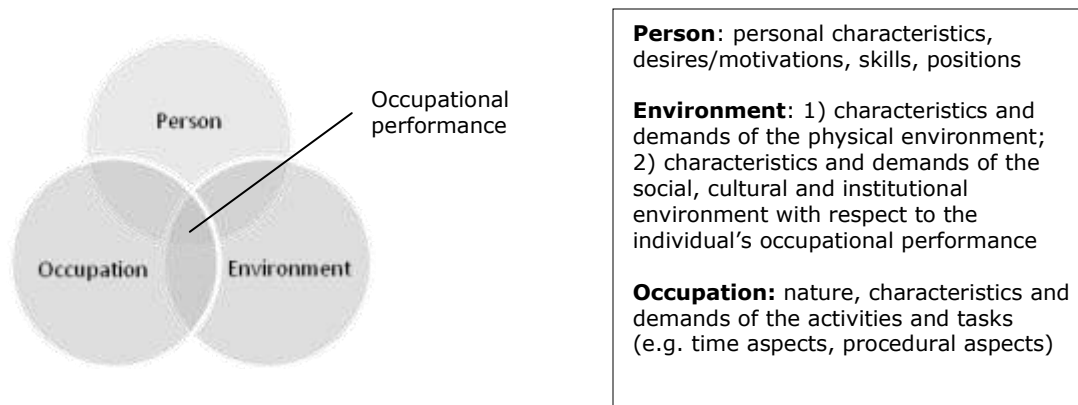


Fig 3.1 Elements of occupational performance (based on the PEO model, Law 1997)

3.2.2 *The occupational therapy intervention*

The occupational therapy process follows a phased methodical approach. In the diagnostic phase, the occupational therapist first identifies the patient's issues with regard to occupational performance. The therapist invites the PwP to tell about his roles and activities, the problems he experiences in occupational performance and what this means to him. In a similar way, attention is also devoted to any occupational issues faced by the caregiver. Together with the PwP or caregiver, the occupational therapist then analyses which aspects of the person, occupations and environments inhibit or support occupational performance. The focus is not on the separate aspects, but rather on the synthesis and fit of these three components. Identifying the facilitating factors for occupational performance is highly important because they will be used extensively in the interventions. Based on an analysis of the assessment data, the therapist, can determine together with the PwP and caregiver whether there is an indication for occupational therapy intervention. If this is the case, an intervention plan with goals and an action plan is drawn up in consultation with the patient and caregiver. There may also be an indication for referral to professionals in other fields.

The occupational therapy interventions are aimed at changing aspects of the person, activity and environment. The opportunities for change differ per person and situation. Interventions are usually also designed to accommodate the issues of concern of the caregiver, since his or her insight, well-being and skills are often prerequisite for the occupational performance of the PwP. The emphasis of the general aims and interventions can shift as the disease progresses:

- When the PwP still has few limitations and is able to perform desired activities independently, the occupational therapist can provide information and advice about ways to maintain or improve daily occupational performance.
- If assistance is required in performing (parts of) activities, the primary focus of the intervention is on training compensatory strategies which the PwP can employ either personally or with the supervision of the caregiver. If necessary, this occurs in combination with simplifying task performance or modifying the environment. It may

also be necessary to modify the pattern of the activities in the day to enable the PwP to continue to spend his days in a meaningful way, within his capacities.

- As Parkinson's disease progresses, a greater need for aids, adaptations, and third-party care arises. The occupational therapy interventions then focus more on providing advice about suitable environmental adaptations and advising caregivers on supervising and caring for the patient during daily activities.

During the entire intervention period, the occupational therapist will collaborate with other relevant professionals involved in the care of the patient. Regular and systematic evaluation provides information for adjusting and concluding the occupational therapy interventions.

3.3 Indication for occupational therapy

A need for occupational therapy can be pointed out by the PwP, caregivers and those close to the PwP. In order to do this, they need to be aware of what the occupational therapist can offer. In the Netherlands, a doctor should always be the one who makes the actual referral. For PwPs, this is ordinarily a neurologist, geriatrician, specialist in rehabilitation medicine, specialist physician in a nursing home, general practitioner or company doctor.

Key question 1

When is occupational therapy indicated in Parkinson's disease?

Scientific basis

There are currently no qualitatively sound studies on the effectiveness of occupational therapy in patients with Parkinson's disease (5). The indications for occupational therapy are therefore based on how occupational therapists view their role with respect to Parkinson's disease (see Section 3.2.1).

A survey among occupational therapists in the United Kingdom indicates that PwPs are usually referred only in a later stage of the disease when they are already experiencing a lot of limitations (1). In the best practice study, occupational therapists reported a preference for seeing patients shortly after the diagnosis is made (2).

Conclusion

Level 4	Given occupational therapy's focus on optimizing meaningful occupational performance in the domains of living/caring, work and leisure experts believe that there is an indication for occupational therapy if the PwP experiences problems in these areas. D Deane, 2003, Deane, 2002, Kirkwood, 1997
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Other considerations

The working group is of the opinion that occupational therapy is indicated as soon as the PwP begins to encounter problems with occupational performance. This is often quite early in the disease progression, i.e. shortly after the diagnosis is made. The working group expects that

in this early phase, the occupational therapist can prevent the patient from unnecessarily or prematurely dropping out of meaningful activities by providing targeted information and advice.

For the caregiver, an indication for occupational therapy arises when the caregiver has occupational issues with respect to supervising or caring for the PwP during daily activities. These occupational issues can fall within the area of knowledge and skills in supervising the PwP in meaningful occupational performance or they can concern maintaining or reacquiring activities for oneself.

Based on the experience of the working group members, referrers may have questions regarding the safety and self-reliance of a PwP for diagnostic reasons. Such questions can pertain to advice about the suitability of the patient's living environment, the assistance and support required in activities or options related to work.

Recommendation 1

Occupational therapy is indicated for persons with Parkinson's disease or their caregivers when:

1. The PwP experiences limitations in activities or participation problems in the following areas:
 - a. Living/caring: personal care, functional indoor and outdoor mobility, housekeeping, caring for family members and pets
 - b. Work: paid and unpaid work
 - c. Leisure: hobbies, going out, social contacts
2. The caregiver experiences problems insupervising or supporting the PwP in daily activities.
3. The referrer has questions regarding the PwP's safety and self-reliance with respect to carrying out daily activities.

3.4 Concluding occupational therapy

Parkinson's disease is a chronic and progressive disease. Accordingly, it is very likely that the patient and caregiver will continue to encounter new problems in meaningful occupational performance.

Key question 2

When does the occupational therapy intervention conclude?

Scientific basis

Occupational therapy interventions conclude when the set goals have been achieved or when the patient and caregiver are satisfied with the current level of functioning in activities and participation (113). It is important that realistic and time-based intervention goals are set, geared to the expected possibilities of maximizing the fit between the person, occupation and environment. The intervention effect and goals should be evaluated in a timely manner, as it could become apparent during the intervention period that the target is no longer feasible. At the same time, the insight of the patient and the caregiver usually changes as a result of the interventions, allowing for other priorities to be set (114). The goals are then revised or the occupational therapy intervention is concluded.

There are no studies from which conclusions can be drawn regarding the optimal duration of occupational therapy intervention for PwPs.

Conclusion

Level 4	Experts believe that an occupational therapy intervention concludes when the set goals have been achieved and/or when the patient and caregiver are satisfied with the current level of functioning in activities and participation. D Steultjens, 2005
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Other considerations

In the Netherlands, ten hours of domiciliary occupational therapy is funded for the patient – and possibly for the caregiver as well – by basic health insurance per calendar year. The working group is of the opinion that non-stop continuous occupational therapy intervention is not desirable. However, it may well be that, after finishing the intervention, occupational therapy will *once again* be indicated at a later point in the disease's progression. A new referral would then be appropriate.

Recommendation 2

Concluding the occupational therapy is advised as soon as the set objectives (or revised objectives) have been achieved, when there are no further occupational therapy intervention options or when the PwP and caregiver are satisfied with the current level of functioning in activities and participation.

3.5 Reporting between the occupational therapist and the referrer

Key question 3

When and how do the occupational therapist and the referrer report to each other?

Scientific basis

Not available.

Other considerations

Agreements on reporting have been made in the form of recommendations in the Dutch multidisciplinary guideline for Parkinson's disease (99). Minimum reporting requirements for occupational therapy also apply. The below recommendations conform to these sources.

Recommendation 3a

The information in the referral to the occupational therapist should contain at least the following data:

- personal details of the PwP
- insurance details
- date of referral/registration
- details of the referrer (name, address, telephone number, field)
- details of the general practitioner
- referring diagnosis, medical case history and comorbidity
- the current medication and, preferably, the previously used medication (including the reasons for discontinuation)
- Indication and nature of the referral (one-off advisory consultation or an initiation of treatment)
- if known: which other professionals/fields are involved

Recommendation 3b

The occupational therapist reports to the referrer and the Parkinson's disease nurse specialist upon conclusion of an intervention. If the occupational therapy intervention is long-term in nature, the care provider will also make interim reports (at least once per year). In the report, the occupational therapist will state at least the implemented intervention(s), the intervention period and frequency, the effect and the expected prognosis. If possible, the intervention results should be supported by measured outcomes. The significance of these values should be succinctly – but clearly – described. The choice of measuring tools should comply with the Guideline of Occupational Therapy in Parkinson's Disease Rehabilitation. When psychosocial problems and/or fluctuations in response to medication are observed, this is reported to the Parkinson's disease nurse specialist or care coordinator.

3.6 Financing of occupational therapy

In the Netherlands, compensation for costs of occupational therapy depends on the health care setting in which is offered. For treatment in hospitals and rehabilitation centers, compensation is part of the total care package. For treatment in nursing homes, the occupational therapy is financed by the Exceptional Medical Expenses Act (AWBZ). Basic health insurance covers a maximum of ten hours per year of domiciliary occupational therapy intervention (EEE). Supplementary insurance sometimes provides for more hours of EEE. It may be that the insurance company has contracts with certain clinics or institutions. In the case of a clear occupational therapy indication for the caregiver, some insurance companies allow a separate referral to occupational therapy for the caregiver. Note: This information applied at the time of writing this guideline (2008) and for the Dutch situation.

4. Occupational therapy assessment

4.1 Introduction

This chapter elaborates on the occupational therapy assessment process for PwPs and their caregivers. In addition to providing information about the assessment and drawing up the intervention plan (Section 4.2), it answers the following key questions:

Assessment resources and methods (Section 4.3)

Identifying the patient's occupational issues

4. What is the value of the following methods for identifying the occupational performance issues faced by PwPs: standardized ADL questionnaires, Canadian Occupational Performance Measure (COPM) and Occupational Performance History Interview (OPHI-II)?

Identifying the caregiver's occupational issues

5. What is the value of the following methods for identifying the occupational issues faced by the caregivers of PwPs: standardized caregiver questionnaires, administering COPM and the method of ethnographic interviewing?

Analyzing the context of problems in specific activities

6. What must be discussed in order to analyze the context of specific activities in which the PwP or caregiver experiences problems?

Assessment of timing of activities and energy distribution

7. What is the best way to examine the timing of activities and energy distribution of PwPs?

Observation of occupational performance

8. a) What is the value of the following methods for assessing occupational performance: the Assessment of Motor and Process skills (AMPS), the Perceive Recall Plan and Perform System (PRPP)?
8. b) What aspects need to be assessed to best evaluate handwriting in PwPs?

Assessment of impairments in body functions and structures

9. How does the occupational therapist collect data on impairments in body functions and structures in PwPs?

Assessment of the physical environment

10. Which aspects should be evaluated in assessing the physical environment where PwPs and their caregivers engage in occupations?

Planning time and environment for assessment (Section 4.4)

Time

11. What is an appropriate time of day for occupational therapy consultations during the assessment phase for PwPs with response fluctuations?

Environment

12. Which environmental setting is best for observing the occupational performance of PwPs?

4.2 The occupational therapy assessment process

4.2.1 Collecting data

During the assessment phase, the occupational therapist collects, analyzes and interprets the occupational performance data together with the PwP or caregiver. On the basis of this data, it can be determined whether there is an indication for occupational therapy interventions, what the intervention goals are and what type of interventions are appropriate for to address these goals.

In the assessment, the occupational therapist uses a needs-based *top-down* approach. This means that the occupational issues at the level of activities and participation are used as a basis, followed by an analysis of which underlying factors connected to the person, occupations and environment influence the occupational performance (111;115;116). In the assessment, the occupational therapist identifies not only the occupational issues and the aspects which hinder occupational performance, but also the strong points of the person and his occupational performance, as well as the supporting factors in the environment. This is essential for determining the intervention possibilities.

General questions for the assessment process:

1. Identifying the occupational issues in the area of participation and activities: What are the questions, concerns and desires with respect to occupational performance? Which limitations do the PwP or caregiver experience in occupational performance? What do these limitations mean to them?
2. Assessment of activities and influencing factors: What is the degree of safety, independence and efficiency of meaningful occupational performance? Which personal factors facilitate or hinder occupational performance? Which skills facilitate and hinder occupational performance? What impairments contribute to the problems? To what extent does the daily routine (i.e. type of activities and distribution of activities over time) influence occupational performance? Which physical environment factors facilitate or hinder occupational performance? Which sociocultural factors facilitate or hinder occupational performance?
3. What are the possibilities for changing aspects of the person, activities and/or social and physical environment for positively influencing occupational performance?

Given the complexity of factors which potentially influence occupational performance, the occupational therapy assessment is usually extensive. However, a thorough assessment ensures a more targeted intervention and benefits the efficiency, effectiveness and quality of the intervention (117).

Depending on the occupational issues of the PwP or caregiver, the occupational therapist uses various methods and means to collect data. These can be subdivided into interviews, questionnaires, work and home visits and observations of occupational performance. Where possible, the occupational therapist also uses data which has already been collected by other care professionals.

There are currently no occupational therapy standardized questionnaires, observations and tests which are specifically designed for PwPs (118). Therefore, in selecting tools for this guideline, the literature was reviewed for:

- the relevance and quality of Parkinson's-specific measuring tools in the area of participation and activities for the occupational therapy assessment;
- the relevance and quality of generic occupational therapy tools for use on PwPs and their caregivers.

The Assessment Flow Chart (see Part I) contains a summary of the steps and tools recommended in the guideline.

4.2.2 *Defining an assessment conclusion and drawing up an intervention plan*

In order to draw a conclusion from the assessment, the collected data is analyzed from the perspective of the PwP, caregiver and occupational therapist in order to give insight in:

- the priorities as well as problems experienced with respect to occupational performance;
- the expectations with respect to occupational performance;
- the quality of occupational performance;
- the factors which support and inhibit desired occupational performance;
- the potential for changing aspects of the individual, task and environment .

It is important to verify whether the perspectives of the PwP and the caregiver correspond and, if not, to identify the differences and their significance for determining the goals and the interventions. It is also important to verify whether the visions of the PwP and the caregiver correspond with that of the occupational therapist (119).

In collaboration with the PwP and caregiver, a judgment is made as to whether there is an indication for occupational therapy intervention (or the continuation thereof) and, if so, which goals will be worked towards and in what way (the type of interventions, coordination with other professionals involved).

The occupational therapy goals must be directed to 1) the occupational issues of the PwP and caregiver and 2) the domains which the occupational therapist can focus on based on his

role. The final and/or long-term goals are formulated at the participation level. Short-term goals can be formulated at skill or activity level.

In order to evaluate the effectiveness of the intervention, goals should be measurable and time based.

4.3 Assessment methods and means

4.3.1 Identifying the PwP's occupational issues

In order to evaluate the PwP's issues related to occupational performance, the occupational therapist first assesses how the PwP experiences his participation and activities, the problems and limitations he encounters in this regard and what these mean to him. To ascertain this, the patient's subjective judgment and personal account are important. The PwP's personal account provides a lot of information on his occupational performance patterns (i.e. daily routine, roles, habits) and his values, desires and requirements with respect to occupational performance.

Key question 4

What is the value of the following methods for identifying the occupational performance issues faced by PwPs: standardized ADL questionnaires, Canadian Occupational Performance Measure (COPM) and Occupational Performance History Interview (OPHI-II)?

I. Standardized ADL questionnaires

Scientific basis

A number of standardized questionnaires for PwPs measure limitations in activities (120;121). Internationally, well known and mostly used scales are the Schwab and England Scale (SES) and the Unified Parkinson's Disease Rating Scale (UPDRS). A section of the UPDRS is designed to measure limitations in activities of daily living (UPDRS-ADL).

In their systematic review of questionnaires designed to measure impairments and limitations of PwPs, Ramaker et al. (2002) conclude that not all parts of the ADL section are aimed at measuring limitations in activities. Certain parts are more focused on impairments in body functions, such as the questions on tremor and sensory complaints. They also report that no clinimetric data on validity and reliability is available as it pertains to the Schwab and England Scale.

Conclusion

Level 4	Experts believe that the value of existing standardized and Parkinson's-specific questionnaires for measuring limitations in activities has not yet been sufficiently demonstrated. D Ramaker, 2002
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Other considerations

To a certain extent, a standardized ADL questionnaire can provide insight in the degree of limitations. This is valuable as part of multidisciplinary *screening*, when following the disease progression or when evaluation takes place at group level. However, the scores give no indication of what these limitations mean for the individual PwP. In addition, ADL questionnaires contain only selections of ADL activities. The questionnaires are thus not broad and specific enough to evaluate and prioritize all problems experienced in meaningful occupational performance. The working group is of the opinion that such a questionnaire must always be followed up by an interview in order to get a complete picture. For this reason, administering ADL questionnaires has no clear added value above starting with an interview focusing on problems experienced. Therefore the working group finds such questionnaires less suitable for the occupational therapy assessment at the individual level. Individualized measuring tools and methods which fully evaluate the patient's problems and priorities are more appropriate.

Recommendation

See end of Section 4.3.1

II. The Canadian Occupational Performance Measure

Description of the tool

The Canadian Occupational Performance Measure (COPM) is an individualized measure for identifying the most important issues in occupational performance from the person's perspective(122). It gives direction to the intervention goals. By re-administering the COPM during or after the intervention period, it is possible to evaluate changes in perceived occupational performance.

In a semi-structured interview, the patient tells which problems he is experiencing in his occupational performance in the areas of self-care, productivity and leisure. The patient then selects the five most important activities in which he would like to see change. He rates each of these activities on a scale of 1 to 10 for competency in performance as well as on a scale of 1 to 10 for his satisfaction with the performance.

It takes an average of 30-45 minutes to administer the COPM. A follow-up test takes much less time (10-15 minutes).

Scientific basis

The COPM is based on the Canadian Model of Occupational Performance (CMOP) (122). This is a widely used occupational therapy practice model. There are no studies which have tested the specific application of the COPM for PwPs, though the tool has been studied in a variety of chronic conditions. Some studies focused on a specific diagnosis group, such as stroke patients, while other studies tested the tool as it pertained to a diverse group of 'individuals with limitations in occupational performance'.

Carswell (2004) provides an overview of studies on the COPM upto 2003, including studies on the clinimetric features (123). However, many of these studies only pertain to a small group of patients or were carried out in a vastly different context compared to the situation in the Netherlands. Since 2003, however, a number of Dutch studies have been conducted on the clinimetric features and usefulness of the COPM. The findings of these studies will now be discussed.

Studies on validity indicate a clear added value of the COPM compared to standardized self-evaluation questionnaires because The COPM identifies unique or more specific problems which are not covered by the other measuring tools (114;124).

A study on test-retest reliability shows 80% of congruence in problems reported, but with respect to the prioritization of the five most important problems, the level of correspondence between the two tests is only 64-66% (114;125). This shows that priorities are subject to change. Within individual interventions, this is less of a problem because goals can be adjusted during the occupational therapy process (114).

In a study conducted by Cup et al. (2003), the test-retest reliability of *average* scores for performance and satisfaction was found to be good, with a correlation of 0.89 and 0.88 respectively (114). Eyssen et al. (2005) found a lower test-retest reliability for the average scores (ICC=.67 and ICC=.69), but the test and retest were each performed by a different therapist. The researchers of this study state that the reliability of both the selection of problems and the scores would probably be higher if the interview techniques of the different therapists were more uniform and the problems were more specified at the level of sub-activities (125).

For a clinically relevant difference in performance or satisfaction, the difference in the average score must amount to two points (122;126).

Patients find the COPM valuable for identifying and prioritizing their problems and, while they find the rating difficult, they see it as worthwhile (124).

Conclusion

n/a	<p>The COPM has a clear added value for identifying the problems patients experience in meaningful occupational performance compared to self-evaluation lists.</p> <p>The COPM has not been specifically studied with respect to PwPs.</p> <p>Eyssen, 2005, Dedding, 2004, Cup, 2003</p>
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Other considerations

While there are no studies which have tested the specific use of the COPM for PwPs, it is reasonable to assume that the COPM is also valid for PwPs. This is because the COPM is an individualized tool and inquires about problems in domains which apply to everyone, regardless of the disease.

Based on its expertise, the working group sees a number of specific points of attention with respect to administering the COPM to PwPs:

- It is advisable to inquire also about problems experienced during the night (i.e. going to the bathroom)
- It is advisable not only to inquire about problems experienced in activities, but also to explicitly inquire further about satisfaction with how the day is spent.
- For PwPs with serious communication problems, extra time and effort is required to find out the perspective of the patient. Therapists should not rely on facial expression as this is often reduced in PwPs. However, this holds true for all forms of interviewing. See also the recommendation in Section 4.4.1.
- For PwPs who have a somber mood or a depression, it can be challenging to elicit perspectives on problems in activities. In such case, the occupational therapist needs good conversational skills to obtain information about the meaning of the activities for the patient (114). It is also necessary to ask further questions when a PwP states, for example, that “everything is a problem” and “nothing goes well anymore.”
- For PwPs with response fluctuations, it is important to find out to what extent the PwP’s opinion differs for the different situations (118), as the problems could be specifically connected to the *on* or *off* phase. The therapist inquires about when the problems arise and how the PwP rates his performance and satisfaction for both phases.

The COPM is a well-known tool for most occupational therapists in The Netherlands.

Recommendation

See end of Section 4.3.1

III. The Occupational Performance History Interview (OPHI-II)

Description of the method

The OPHI-II is a semi-structured interview in which the person is invited to tell about his occupational life story. In the process, two types of information are collected (127;128):

1. Information on facts, circumstances and occurrences in the person’s life and how the individual spends his time in the present and how he spent his time in the past.
2. Narrative data which provides insight into the meaning the person imparts to his life and insight into the life that he wants to lead.

The OPHI-II consists of three parts:

1. The semi-structured interview regarding the person’s occupational performance in the past. This interview focuses on qualitative data related to five themes: roles, daily routine, occupational performance situations, activity options and crucial events in one’s life.
2. Converting the information from the interview into three rating scales:
 - Occupational identity: expectation of success, estimation of possibilities and limitations, interests described, experienced effectiveness in the past
 - Occupational competence: being goal-oriented, taking satisfaction from occupational performance, meeting expectations

- Occupational behavior settings: refers to the environment in which the individual operates
- 3. A story about one's life history in which the information from the interview is visually displayed.

The OPHI-II assesses the person's motivation, experience and satisfaction in the past, present and future. In this way, the occupational therapy interventions can be properly tailored to the perceptions and values of the individual client. In addition, it gives the occupational therapist insight into the picture the individual has of his own occupational competence and occupational identity (119).

In principle, the OPHI-II is suitable for every person who is capable of sharing information about their life history. Some conversational topics in the OPHI-II require a good level of trust between the therapist and the patient. The therapist must make a personal judgment regarding when it is appropriate to discuss these topics.

The OPHI-II manual emphasizes that the occupational therapist can be flexible with respect to administering the OPHI-II (129). It indicates the following options: 1) administering the OPHI-II in full, with a personal choice of the order of the topics to be discussed; 2) administering only those sections of the OPHI which are relevant to the individual's situation; 3) switching from interview to, for example, observation or a tour of the house, if this is better suited to the person's needs and preferences and fits within the assessment.

Administering the entire OPHI-II takes at least 45 minutes, though in most cases more than an hour. When administering the OPHI-II in its entirety, it is best to break it into two or more shorter interviews.

Scientific basis

The OPHI-II is based on the Model of Human Occupation (MOHO) by Kielhofner (127) and thus has a strong theoretical basis. With respect to the clinimetric properties of the OPHI-II, there is only one published study that evaluates the validity of the three sub-scales of Occupational Identity, Occupational Competency and Occupational Behavior Settings (130). This study indicates that the internal validity of the three sub-scales of the OPHI-II appear to be sufficient, as does the reliability of rating by various therapists. There is no study that compares the OPHI to other tools.

Conclusion

Level 4	Experts believe that the OPHI-II is conceptually suitable for measuring a person's occupational identity, occupational competency and occupational behavior settings. D Kielhofner, 1997
n/a	The OPHI-II has not been sufficiently evaluated on all aspects of validity and reliability in order for a conclusion to be drawn regarding its value as a measuring tool.

Other considerations

An interview based on the topics of the OPHI-II helps obtain important qualitative data on the person's occupational identity, experienced occupational competency, coping style, interests and motivations. Occupational performance is placed in the context of the person's life. The working group believes that this data is valuable in the assessment of PwPs, particularly with respect to giving direction to targets and interventions aimed at changing meaningful daily occupational performance.

Due to the time it takes for all topics of the OPHI-II to be discussed, it is not advisable to apply the OPHI-II in its entirety for short interventions or for a clear, simple occupational issue. However, given the flexibility in administering the interview described in the most recent manual, the occupational therapist can also choose to discuss a selection of topics in greater detail. For a complex occupational issue, the opinion of experts is that the time invested to effect a more comprehensive administration of the OPHI-II ultimately contributes to a faster and better targeted intervention.

Occupational therapists in the Netherlands still have minimal experience with the OPHI-II. This is expected to change quickly, since the OPHI-II has been included as an important assessment tool in the standard *Occupational Therapy in Older Persons with Cognitive Impairments* (119). Increasing numbers of occupational therapists in the Netherlands are familiar with the OPHI-II.

Recommendation 4a

To identify and prioritize the PwP's occupational performance issues, using the Canadian Occupational Performance Measure (COPM) is recommended instead of using the currently available standardized ADL questionnaires.

Recommendation 4b

In addition to the COPM, administering the Occupational Performance History Interview (OPHI-II) or parts thereof is recommended when more information and background is needed regarding occupational identity, coping and motivation with respect to meaningful occupational performance.

4.3.2 Identifying the caregiver's occupational issues

The caregivers of PwPs usually experience a heavy burden in both a physical and emotional sense. Accordingly, there is a chance that caregivers will also develop physical or psychological complaints, become less capable of performing care tasks or even have to stop providing care. This naturally has negative consequences for the well-being and performance of the PwP. It is therefore essential, in caring for PwPs, to center attention to the PwP as well as to the social system surrounding the PwP. For this reason, the occupational therapist devotes attention to the caregiver's occupational issues in the assessment.

The focus of the occupational therapist is on issues related to occupational performance. The occupational therapist devotes specific attention to assessing the caregiver's burden and competencies in relation to supporting the PwP's occupational performance and the effect

this has on the caregiver's own occupational performance. With respect to caregivers, occupational issues can pertain to 1) the care they provide to the patient (because it is meaningful to them) and/or 2) the activities outside this care that are important to their own well-being but that are at the same time under pressure due to the care they provide to the patient.

An initial review indicated that there are no tools or methods for identifying caregiver's occupational issues which are specific to occupational therapy, and specific to the problems faced by caregivers of PwPs. For addressing the key question, the choice has been made to review at the suitability of the tools and methods which are either related to occupational therapy in a general sense or geared to identifying the problems faced by caregivers.

Key question 5

What is the value of the following methods for identifying the occupational issues faced by the caregivers of PwPs: standardized caregiver questionnaires, administering the COPM and the method of ethnographic interviewing?

1) Standardized caregiver questionnaires

Description of the tool

While there are various generic questionnaires for identifying the care burden of caregivers, the working group has limited itself to a discussion of the *Belastungsfragebogen Parkinson Angehörigen-kurzversion* (BELA-A-k) because it has specifically been developed for the caregivers of PwPs(131). The questionnaire consists of 15 questions in four domains:

1. Achievement capability/physical symptoms
2. Fear/emotional symptoms
3. Social functioning
4. Partner-bonding/family

Each question is scored according to the degree to which the problem and its consequences are a burden to the caregiver ('bothered by') and according to the degree to which supervision is desired for the problem ('need for help').

Scientific basis

With respect to the Dutch version of the BELA-A-k, there is one published study which was conducted among fifty partners (131). To assess the reliability, the study looked at the internal consistency of the questions in the different domains and in the total score. Aside from the domain of social performance ($\alpha = 0.62$), the reliability was above 0.70 ($\alpha = 0.74-0.90$) for the scores on the degree to which the problem and its consequences are a burden to the caregiver. For the scores on the degree to which attention is desired during any supervision, the internal consistencies for two domains (skills/physical performance, emotional performance) and the total score was above 0.70 ($\alpha = 0.77-0.92$). The scores were 0.62 and 0.65 for the other two domains. There were high correlations between the score of the caregiver burden and the degree to which supervision is desired. To assess the validity, the

caregiver burden score was compared with parts of other measuring tools which measure comparable dimensions. This comparison revealed a significant, but low correlation ($r=0.39-0.61$). The experiences of the partners regarding the usefulness and relevance of the questionnaire were positive. The reproducibility and responsiveness were not tested.

No literature is available on the usefulness of this tool for the occupational therapy assessment. It maps out the psychosocial burden, but it is not exclusively oriented towards problems in meaningful occupational performance.

Conclusion

Level n/a	Based on the literature, no clear conclusion can be drawn regarding the usefulness of the BELA-A-k for the occupational therapy assessment.
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Other considerations

The BELA-A-k can be used by all care providers and does not require training.

The items are relevant in evaluating the psychosocial burden experienced by the caregiver.

The working group is of the opinion that responses on some areas of the BELA-A-k can suggest an indication for occupational therapy. An example would be when problems are reported in perceived competency in caring skills as reflected in the domain “Achievement capability/physical symptoms.”

However, the BELA-A-k is not *specifically* designed for assessment of problems experienced in meaningful occupational performance and an additional assessment would still be necessary to identify the caregiver’s occupational issues.

Recommendation

See end of Section 4.3.2

II) The Canadian Occupational Performance Measure (COPM)

Description of the tool

To identify the caregiver’s occupational issues, the occupational therapist can use a semi-structured interview which focuses on problems and concerns experienced in meaningful occupational performance. The format of the COPM can be used for this purpose. For a description of the COPM, see Section 4.3.1. The caregiver tells about his own occupational profile and indicates which problems he experiences in occupational performance related directly to his role as caregiver.

Scientific basis

For a description of the clinimetric features of the COPM, see the summary of the literature in Section 4.4. There is no available evidence with respect to the use of the COPM for caregivers of adult patients. However, the set-up of the COPM is such that it can potentially be administered to anyone who experiences a limitation in participation or activities (132).

Conclusion

Level 4	<p>The COPM has not been specifically studied in the population of caregivers of adult patients.</p> <p>Experts believe that the COPM can be used for <i>each person</i> to identify self-perceived occupational performance issues.</p> <p>D Law, 1990</p>
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Other considerations

Most occupational therapists are familiar with the methodology of the COPM and might find it useful to administer it to caregivers, according to the key points mentioned above in “Description of the Tool.”

Recommendation

See end of Section 4.3.2

III) Method of ethnographic interviewing

Description of the method

The method of ethnographic interviewing is used to uncover the underlying beliefs and values of the interviewee and find out underlying meanings and experiences (133;134). It refers to a narrative style of interviewing.

A few features for interviewing caregivers according to ethnographic principles are (119;133;134):

- The therapist acknowledges the expertise of the caregiver; the subjective account of the caregiver is the main focus.
- The therapist attempts to find out the caregiver’s underlying perceptions, beliefs and values by inquiring about the meaning of situations and behaviors. In doing this, attention is paid to symbols and the imagery and metaphors used by the caregiver. These provide a great deal of information on the meaning and perception.
- The therapist accepts the caregiver’s account as it is. Therapists do not interpret it from their own personal or professional standards and values, but reflect on how these visions differ and what this means for determining goals and interventions.

The method prescribes only the style and aim of the interview, not the subject matter or questions. The method of ethnographic interviewing is not specifically designed for caregivers. A similar interviewing style is used for interviewing the patient according to the OPHI-II.

Scientific basis

Research underscores the importance of assessing the caregivers’ perception. As a matter of fact, it has been shown that caregivers initiate care based on their own perception of the

situation (135). There may be large differences between the occupational therapist's findings and the caregiver's findings with respect to the care situation (133). Therapists have the tendency to look at the care situation too objectively and want to immediately resolve the practical problems. For caregivers, the care situation has a highly subjective meaning (136). Their motivation for providing care, their personal way of dealing with the problems and their acceptance of the situation play an important role in how they experience the care. The expectation is that insight into the perspective of the caregiver will enable a better collaboration and an improved determination of goals (135).

An ethnographic style of interviewing makes it possible to determine the caregiver's perspective. This provides an important basis for the interventions (119;134;136). Since ethnographic interviewing is a style of interviewing and not a measuring tool, data on clinimetric features is not applicable.

The method of ethnographic interviewing is not specifically designed for caregivers, nor does it prescribe any concrete themes. However, based on literature on the caregiver burden associated with Parkinson's disease (137) and occupational therapist literature related to the advising of caregivers (119;119;136;138), the working group has proposed themes which are important for assessing occupational issues and which can be well documented with this method. These themes are: physical burden, practical problems, psychological burden and social relationships within the context of care. Appendix 3, Caregiver Burden Interview, contains sample questions for each theme which can be used during the interview with the caregiver. From the answers provided by the caregiver, the link should be made to activities and occupational performance.

Conclusion

Level 4	Experts believe that an ethnographic style of interviewing is suitable for gaining insight, as an occupational therapist, into the views and perception of the caregiver. D van Uden, 1999, van Melick, 1998, Gitlin, 1995, Hasselkus, 1990
Level 4	The working group believes that the physical burden, practical problems, psychological burden and social relationships within the context of care as experienced by the caregiver can be evaluated appropriately by using the method of ethnographic interviewing. D working group

Other considerations

Dutch occupational therapists still have minimal experience with interviewing caregivers according to ethnographic principles. However, this will quickly change due to the fact that this methodology has also been included in the standard *Occupational Therapy in Older Persons with Cognitive Impairments* (119). Increasing numbers of occupational therapists in the Netherlands have been trained in using an ethnographic style of interviewing.

Recommendation 5a

To identify the caregiver's occupational issues, administering the COPM is preferable to administering standardized caregiver questionnaires.

Recommendation 5b

In addition to the COPM, the interview topics from Appendix 4, Caregiver Burden Interview can be used to gain more insight into the burden experienced by the caregiver. The use of an ethnographic/narrative style of interviewing is recommended

4.3.3 Analyzing the context of problems related to specific activities

To get an idea of the factors which play a role in specific occupational performance issues, it is important to analyze the context of the activities concerned.

This involves analyzing the activity itself and assessing how the person has dealt with the problem so far. This gives direction to further assessment and interventions.

Key question 6

What must be discussed in order to analyze the context of specific activities in which the patient or caregiver experience problems?

Scientific basis

In the literature on occupational therapy, there are various visions and models for analyzing activities (139-141). The models indicate which characteristics and demands of the meaningful activity can be analyzed.

The various models for analyzing activities have been designed by expert occupational therapists and are based on theoretic frameworks from occupational therapy (139-141).

No activity analysis model has been developed specifically for Parkinson's disease. Knowledge about Parkinson's disease can put the focus of the analysis on certain aspects. For example, time aspects are important with respect to fluctuations in performance as well as fatigue. The complexity of the activity is important with respect to problems with performing automatic activities, dual tasking and executive functioning skills. Based on knowledge about activity analysis and Parkinson's disease, the working group is of the opinion that at least the following aspects should be addressed:

1. Aspects of the activity analysis:

- Meaning of the particular activity for the person: e.g. personal associations, role fulfillment, cultural value, the effect of the activity on identity.
- Habits and routines: how is the person used to performing the activity and what are important personal and cultural values in this regard?
- Time aspects: when does the activity take place, how often, how much time does it take and is there a relationship between the time of the day and the problem?
- Social aspects: who is present and what does any assistance encompass?

- Space and objects: where does the activity take place and what are characteristics of the materials used and the environment in which the activity is performed?
 - Complexity of the activity: which and how many different sub-actions does the activity contain, what is the degree of predictability in the course of the activity and are there many or few automatic actions? Which cognitive and motor skills are required?
2. *Coping* and adapting strategies: how has the person dealt with the problem, has he tried to perform the activity in a different way and what was the effect of the attempted solution strategies?

Conclusion

Level 4	Experts believe that models for activity analysis are useful for assessing the characteristics, requirements and meaning of activities. D Creek, 2006, Kinébanean, 2006, Blesedell Crepeau, 2003
Level 4	The working group believes that the meaning of the activity, habits/routines, time aspects, social aspects, space and objects, the complexity of the activity and <i>coping</i> and adapting strategies are important evaluation aspects for analyzing the background and context of the activities in which the PwP reports a problem. D working group

Other considerations

The principles and models of activity analysis are part of general occupational therapy knowledge and skills and the application of these would therefore have to lie within the capabilities of an occupational therapist. It is expected that occupational therapists who are familiar with Parkinson's disease will be able to address the relevant aspects and ask targeted questions.

The aspects of information, which have already been acquired during interviews using the COPM or OPHI-II or interviews with the caregiver, do not need to be inquired about again. The complexity of the activity for the person can also be observed (see Section 4.3.5).

Recommendation 6

To analyze the context of *specific* activities in which the PwP or the PwP's caregiver experiences problems, the occupational therapist preferably evaluates the following aspects: meaning of the activity, habits/routines, time aspects, social aspects, space and objects, the complexity of the activity and coping and adapting strategies. The occupational therapist can do this by means of an interview, observation or a combination of the two.

4.3.4 Assessment of timing of activities and energy distribution

If a PwP suffers from fatigue or fluctuating performance, it is important to carefully analyze how these relate to activity patterns and/or the time of taking medication. This provides a

basis for interventions aimed at better matching activity patterns (i.e. energy demands) to the person's own capabilities (i.e. capacity).

Key question 7

What is the best way to evaluate the timing of activities and energy distribution of PwPs?

Scientific basis

Activity logs are used in occupational therapy for assessing activity patterns. Standardized activity logs are the Occupational Questionnaire and the Activity Record (142). On these logs, the person fills in what he has done every half hour for each part of the day. He then answers questions about these activities. The Activity Record features eight evaluation topics per activity namely: pain, competency, difficulty, meaning, pleasure, the need for rest and two about fatigue.

The Occupational Questionnaire and the Activity Record are theoretically embedded in the Model of Human Occupation by Kielhofner (142). There is limited scientific basis for these lists. There is no literature in which the use of the Occupational Questionnaire and the Activity Record is described or tested with respect to PwPs.

Based on its knowledge on fatigue and response fluctuations in Parkinson's disease (see Chapter 2) and practical experiences with assessing the balance between energy demands of activities and capacity of PwPs, the working group is of the opinion that the following aspects are important:

- nature, time and duration of activities (activity pattern)
- the degree of physical and/or mental effort (energy demand) required by the activity
- the degree of fatigue experienced
- times for taking medicine and its effect (response fluctuations)

To gain insight into the variation in activity patterns and burden experienced, it is most advisable to keep a log for three successive days, including a weekend day. The number of three days follows from a study on PwPs who use a log to evaluate response fluctuations. Recording for more than three days can be a burden to the PwP and three days provides enough information to be able to draw the same conclusions on fluctuations in performance as when more days are recorded (143).

Since the log tracks successive days, it can indicate whether the activities of one day influence the degree of fatigue on the following day.

The working group has drawn up a sample of a log which is suitable for PwPs and has included it in Appendix 4. While the working group based this on the principles of the Occupational Questionnaire, it has limited registration from the perspective of simplicity and relevance to PwP. Aspects registered are activities engaged in, the degree of fatigue experienced and the times for taking medicine. The influence of any response fluctuations on the selection and planning of activities can be discussed with the PwP during the follow-up discussion. The PwP also indicates which activities are found to be very physically or mentally strenuous or fatiguing, which are found to be somewhat strenuous or fatiguing and which are found to be relaxing or energizing.

To make this comprehensible, during the follow-up discussion the degree of effort can be indicated on the daily schedules by using color codes. For example: strenuous/fatiguing = red, somewhat strenuous/fatiguing – yellow, relaxing/energizing = green. The therapist and the PwP then look together at whether the fatigue is connected to the medication or the demands of the activities.

Conclusion

n/a	From the literature, no clear conclusion can be drawn as to whether the Occupational Questionnaire and the Activity Record are worthwhile and useful in evaluating the activity patterns of PwPs.
Level 4	The working group believes that the nature, time and duration of activities, the degree of effort, the degree of fatigue experienced and the presence of response fluctuations are important aspects in gaining insight into the relationship between activity patterns and fatigue or response fluctuations of a PwP. D working group
Level 4	The working group believes that the activity log, as drawn up based on the working group's expertise (Appendix 4), is a useful alternative which concentrates on aspects relevant to PwPs. D working group

Other considerations

With its detailed evaluation points and scoring options, the Occupational Questionnaire is a rather complex questionnaire and, as such, the working group expects that it might be too confusing and burdensome for many PwPs. The activity log as drawn up by the working group is easier to fill in and serves as a basis for further discussion between the therapist and patient.

Recommendation 7

If a PwP suffers from fatigue or fluctuating performance, it is recommended to discuss the daily activities in relation to the physical or mental burden and capacity by means of an activity log (Appendix 4).

The PwP completes this log over three successive days (including a weekend day) and states 1) the time, nature and duration of the activities, 2) the degree of fatigue and 3) the times at which medicine was taken.

In the follow-up discussion of this log, the PwP indicates to what extent different activities are found to be physically or mentally strenuous, fatiguing or – as the case may be – relaxing. Additionally, if a PwP experiences response fluctuations, questions on the influence of these fluctuations on their choice and planning of activities are relevant.

4.3.5 Observation of occupational performance

Observing the PwP in meaningful activities provides the occupational therapist objective information about the safety, efficiency and independence in performing activities and the quality of the necessary performance skills. The added value of doing an observation in addition to self-evaluation is confirmed by a study conducted by Shulman et al. (2006) which looked at the correspondence between the subjective judgment of PwPs regarding their performance and the findings from objective observations of their performance (144). The researchers find a discrepancy here. PwPs overestimate their performance in the early stage of the disease, while they tend to underestimate their performance in a later stage. There was more correspondence in self-evaluation and observation with respect to simpler tasks and less correspondence with respect to more complex tasks in which more cognitive skills were required.

For this guideline, three observation methods were selected which have been standardized and specifically developed by and for occupational therapists. These are the Assessment of Motor and Process skills (AMPS), the Perceive Recall Plan and Perform System (PRPP), and tests and observations from a Dutch observation protocol for evaluating adults with problems in writing (145). While no further observation methods for specific activities or skills are mentioned in this chapter, the working group has chosen to do so for the writing evaluation. As a matter of fact, writing problems are frequently reported and usually appear at an early point in the progression of Parkinson's disease. Dutch occupational therapists can use the Dutch protocol for evaluating the writing of adults. The question is to what extent the observations and tests in this protocol are applicable and comprehensive for evaluating writing in Parkinson's disease. The A-one is an observation method which is frequently used by occupational therapists in the Netherlands in neurology (146). However, the A-one has not been included in the key question because it was primarily developed for people with cortical brain disorders, such as a cerebrovascular accident (CVA), and is thus less suitable for analyzing the problems associated with Parkinson's disease.

Key question 8

8a What is the value of the following methods for assessing performance skills: the Assessment of Motor and Process skills (AMPS), the Perceive Recall Plan and Perform System (PRPP)?

8b What aspects need to be assessed to best evaluate handwriting in PwPs?

I The Assessment of Motor and Process Skills (AMPS)

Description of the tool

The AMPS is a standardized occupational therapy observation tool that was developed in the United States in 1991 and has been translated into Dutch. The AMPS enables the occupational therapist to (115):

- make a judgment on the degree of independence, effectiveness, efficiency and safety in the patient's occupational performance.

- gain insight into motor and process skills which hinder occupational performance or, as it may be, support it.
- acquire an indication of the options to improve occupational performance: whether it seems possible for the person to improve actual skills or whether interventions need to focus on compensations by modifying activities, the environment or the amount of support.
- measure the change in the quality of occupational performance after some time has passed by means of a retest.

The patient is observed while performing at least two personal or instrumental activities of daily living which are selected from a list of standardized tasks. In the latest version of the AMPS from 2005, this list contains 85 tasks. Preconditions for the selection of the tasks are that the patient is familiar with the tasks as described in the manual and that the tasks are relevant and not too easy for the patient. The tasks are ordered according to difficulty and there are different variations in similar tasks to account for different habits/cultures. The patient chooses which tasks he wants to perform from the preselection.

Performance is evaluated on the physical effort required to carry out the activity, whether it occurs efficiently and safely and whether the patient can do it independently. The patient receives a score for sixteen motor skills and twenty process skills. The motor skills are targeted actions which are necessary for moving oneself or objects while performing an activity. Process skills are targeted actions which are necessary when performing an activity, for choosing and using the right materials and aids, organizing the occupational performance in time and being able to change one's performance when problems arise.

The AMPS is re-administered and the new results are compared with the original results. Given the way in which the AMPS has been validated, the same activities from the first AMPS test do not need to be performed in order to compare the scores.

To administer the AMPS, it is important that the therapist is trained and individually calibrated and that the standardized procedure is followed for the interview, performance and scoring. The results will not be valid if one deviates from the standard procedure.

Scientific basis

The AMPS is standardized and validated for individuals aged three and older in various countries (including the Netherlands) and can be applied to all diagnosis groups (115). The clinimetric features of the AMPS have been tested extensively. However, there is no published study in which the AMPS has been *specifically* tested on PwP (Fisher, personal communication, 2008). The AMPS has been used in a Parkinson's disease study in which the effectiveness of chronic thalamic stimulation was evaluated (147). The study examined whether the reduction of the tremor during stimulation also improved occupational performance. Differences in performance were demonstrated and it thus appears that the AMPS is responsive for measuring changes in the performance of PwPs.

Only the most relevant studies on the clinimetric features of the AMPS are discussed below.

Validity

The internal consistency of the skills ($\alpha = 0.93-0.98$) as well as the tasks ($\alpha = 0.80-0.96$) are good (115). With the exception of the skill of lifting, there is no significant difference between male/ female in the difficulty of the tasks and skills (148). Since there is no other comparable observation method, no true gold standard can be used for comparison. Nevertheless, the correlation was examined with self-evaluation questionnaires, functional limitations level tests and impairment level tests (149;150). The correlation values of the AMPS with the FIM, MMSE and CAMCOG fall between 0.62 and 0.67. While this indicates that there is a correlation, it is still measuring another construct. In comparison to questionnaires, the AMPS process skills scale, in particular, provides unique information about the degree of functional limitations (149). Process skills also have a highly predictive value for the person's degree of independence: according to experts, 94% of people with dementia with a process skill under the cut-off value of 1.00 logit need assistance (151).

Reliability

Compensating for the evaluator's individual calibration, the reliability between different therapists is good (95%) (115). The stability of the evaluator's calibration was evaluated among Swedish occupational therapists over a period of 5-15 months after the training (152). Of the evaluators, 93-95% retained the same level of severity in scoring motor and process skills. Test-retest reliability was evaluated among 55 elderly and the correlations between the first and second test were 0.88-0.86 [153]. For six of the eight people who exhibited a significance difference between the tests, there was actually also a difference in performance.

Differences of at least 0.3 logits in total scores on the AMPS can be clinically relevant (115). This is based on RASH analysis calculations with data from the AMPS database.

Conclusion

Level n/a	<p>The AMPS has been extensively tested on various aspects of validity and reliability and, following administration, is suitable for passing judgment on 1) the patient's independence, effort, efficiency and safety in daily occupational performance and 2) which motor and process skills hinder and promote occupational performance.</p> <p>The AMPS has not been specifically studied in Parkinson's disease.</p> <p>Fisher, 1990 (in Fisher, 2005), Fisher, 1991 (in Fisher, 2005), Merrit, 2003, Bernspång, 1999, Doble, 1999, Hartman, 1999, Robinson, 1996, Bernspång, 1995</p>
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Other considerations

It is reasonable to assume that the diagnostic value of the AMPS can be generalized for PwPs. This is due to the fact that the observation method scores skills which every person needs to perform activities. In other words, the AMPS is tied to a performance skill, not a particular disease.

A limitation of the AMPS is that the person can only be observed when performing the standardized tasks. The more difficult AMPS tasks are usually irrelevant for patients who have no role, or a limited role, in housekeeping activities.

Most Dutch therapists are familiar with the AMPS. However, a therapist should be trained and personally calibrated to administer the AMPS.¹ As of 2007, 1,048 Dutch occupational therapists have been trained in the AMPS (Hensgens, personal communication, August 2007).

Recommendation

See end of Section 4.3.5

II The Perceive Recall Plan and Perform System (PRPP)

Description of the tool

The PRPP is a standardized clinical reasoning model that is used for observing and analyzing the patient's occupational performance (154). It was developed in Australia and is based on the Australian Occupational Performance Model. The PRPP examines occupational performance from the perspective of information processing.

The PRPP is a tool used in the observation of the person during any activity in his daily routine. The first step of the evaluation involves a task analysis in order to evaluate to what extent the person is proficient in the activity and which problems are encountered. The assessor looks at mistakes in skipping or repeating steps, precision and time. The second analysis focuses on identifying observable problems in four dimensions of information processing: perceiving, recalling, planning and performing. These dimensions are divided into sub-categories and determinants which are scored. analysis focuses on identifying observable problems in four dimensions of information processing: perceiving, recalling, planning and performing. These dimensions are divided into sub-categories and determinants which are scored.

The interpretation of the data provides information about the person's occupational performance skills and gives direction to the intervention.

¹To become an AMPS Calibrated Rater, an occupational therapist must complete the following steps:

1. Attend a five-day [training course](#)
2. Test 10 clients who perform 2 or 3 [AMPS tasks](#)
3. Independently interview and score *live* clients (the use of video tapes is not acceptable). Two of the ten clients may be co-scored. *Co-scoring is defined as two therapists observing a client at the same time, but scoring the client's performance independently.*
4. Enter the data into the computer using the [AMPS computer-scoring program](#)
5. Submit exported data using the online Rater Calibration Center within three months of taking the course.

Taking a course in administering the tool is a prerequisite for using it.

Scientific basis

The theoretic basis of the tool is a model on information processing in the performance of activities (Romiszowski's Skill Cycle Model) and has been further developed by means of patient observations (154). The PRPP has been found to be valid, reliable and useful in studies involving patients with acquired brain damage. These were small-scale studies conducted during the developmental phase of the tool (154). A case study shows how the PRPP can be used in planning interventions (155). Further research has been conducted, but the data has not yet been published (situation in June 2008).

There is no specific data on the use of the PRPP with PwPs (Ranka, personal communication, 2007). However, the manual states that the PRPP is suitable for every diagnosis group and every disorder severity (154).

Conclusion

n/a	<p>There is evidence to suggest that the PRPP is suitable for observing and analyzing occupational performance of adults and identifying problems in perceiving, recalling, planning and performing.</p> <p>The PRPP has not been specifically studied with respect to Parkinson's disease.</p> <p>Fry & O'Brien, 2002, Chaparro, 1996</p>
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Other considerations

The PRPP tool can be used for the observation of *all* meaningful activities of the patient and is thus widely applicable. The PRPP examines occupational performance from the perspective of information processing, and the working group is of the opinion that this is highly relevant for PwPs.

PRPP courses were first offered in the Netherlands in 2006. Consequently, only a small number of Dutch occupational therapists have been trained in the use of the PRPP prior to the publication of this guideline.

Recommendation

See end of Section 4.3.5

III. The evaluation of handwriting

A Dutch protocol for evaluating the handwriting of adults consists of (145):

- identifying the experienced writing problems (e.g. starting problems, legibility, speed or cramped handwriting).
- an observation of the writing posture and pen grip.
- an evaluation of the penmanship.

- an evaluation of the writing speed. The Handwriting Speed Test (HST), which has also been standardized for adults, can be used for the observation of writing speed (156)
- An evaluation of fine motor skills. The Nine Hole Peg Test is used in the protocol for this purpose (157)

Scientific basis

No study has been conducted on the applicability of the above observations and measuring tools to PwPs. Limitations in handwriting skills which frequently occur in Parkinson's disease and their possible underlying function impairments have been studied (see Chapter 2) (49-52). Based on the findings of these studies, it would seem relevant to evaluate the above aspects, such as handwriting problems, writing posture, penmanship, graphomotor skills, fine motor skills and writing speed.

Based on the literature on possible strategies for improving the handwriting skills of PwPs (49-52), the working group is of the opinion that evaluating the influence of particular strategies on the PwP concerned should be part of a handwriting observation. In this way, one can observe whether there is a difference in the size of the handwriting when the person writes on lined paper, graph paper or blank paper (i.e. with or without visual cues), during dual tasks (e.g. talking on the telephone and writing) and with or without focused attention on the writing size. The strategies and evidence for this have been worked out in Chapter 5.

Conclusion

Level n/a	The applicability of existing standardized handwriting observations and tests for adults have not been specifically studied with respect to Parkinson's disease.
Level 4	The working group believes that aspects of handwriting problems, writing posture, penmanship, writing speed and fine motor skills are relevant for evaluating the handwriting problems of PwPs. It is also useful to evaluate the influence of cues, focused attention and dual tasks on handwriting. D working group

Other considerations

A comprehensive handwriting evaluation only needs to take place if handwriting came up as a distinct occupational issue during the COPM. In opting for the evaluation, it is important to consider what someone wants to use writing for (e.g. for a signature or grocery list or for taking notes at meetings or writing poems) and whether someone would like to continue writing or opt for alternatives, such as using a stamp, computer or preprinted lists.

The Dutch handwriting protocol described above is not available in English. This is why the working group, in collaboration with the experts who developed the protocol, has added a Handwriting Evaluation appendix to the English version of the guideline which includes the observations from the protocol which are relevant to PwPs (see Appendix 5).

Recommendation 8a

It is recommended to administer the Assessment of Motor and Process Skills (AMPS) to a PwP in order to substantiate the degree of independence, effort, efficiency and safety of the occupational performance and to gain insight into the patient's skills which either hinder or facilitate occupational performance.

Recommendation 8b

Instead of the AMPS, the occupational therapist can administer the Perceive Recall Plan and Perform System (PRPP) in order to observe and analyze the occupational performance of the PwP. This applies if the focus of the observation is specifically on information processing or if there are no suitable AMPS tasks for the individual to perform.

Recommendation 8c

In order to examine the writing problems experienced by a PwP, it is recommended to evaluate the following aspects: writing problems experienced, writing posture, penmanship, writing speed, fine motor skills and, specifically, the effect of cues, conscious attention and dual tasks on writing.

For this examination, the occupational therapist can use the evaluation points which appear in Appendix 5: Handwriting Evaluation.

4.3.6 *Assessment of impairments in body functions and structures*

In the general literature on occupational therapy, various opinions are written about the role of the occupational therapist in assessing impairments. These seem to be based primarily on the perspective of the role of the occupational therapist in a particular team and a particular setting.

Key question 9

How does the occupational therapist collect data on impairments in body functions and structures in PwPs?

Scientific basis

There is no specific literature regarding the role of occupational therapists in assessing impairments in PwPs and the way this is done.

The strength of the occupational therapist lies in observing and analyzing problems in meaningful occupational performance (111;115). In doing so, the occupational therapist examines how impairments in body functions and structures influence occupational performance. The occupational therapist evaluates specifically the quality of goal-directed performance skills. As stated in Section 4.3.5, observation methods are used for this purpose. The AMPS looks at goal-directed motor and process skills and the PRPP looks at goal-directed skills within the domains of perceiving, recalling, planning and performing.

The International Classification of Functioning (ICF) classifies goal-directed skills under activities and not under body functions (115). According to the structure of this classification, the occupational therapist does not play a primary role when it comes to the assessment of PwPs in evaluating body functions at impairment level, such as balance reactions, joint mobility, strength, cognition and incontinence.

To enable interpretation of limitations in activities and participation, it is desirable for the occupational therapist to have insight into possible underlying impairments (115). The various impairments which can occur in Parkinson's disease are discussed in Chapter 2. In addition, accompanying symptoms must be taken into account in the case of comorbidity.

Conclusion

Level 4	Experts believe that the occupational therapist primarily examines what kind of influence impairments have on body functions and structures at the performance level. The effectiveness of targeted occupational performance skills and performance in activities are mapped out. D Fisher, 2005
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Other considerations

On the basis of observations and interviews, the occupational therapist can make hypotheses regarding the presence of impairments. Out of consideration for the efficiency of the therapist and the burden experienced by the PwP, the person should not be subjected to the same examinations by different disciplines. The occupational therapist can collect relevant data on the precise nature and extent of impairments from assessments conducted by other care professionals involved with the PwP who have specific expertise in the areas concerned. Examples of disciplines which collect data at the impairment level are neurology, physical therapy, speech and language therapy, neuropsychology and psychiatry. Appendix 6 contains a list with examples of frequently used measuring tools at the impairment level in Parkinson's disease.

If no data is available, the occupational therapist can consult with the referrer as to whether further examination is desirable. Good multidisciplinary collaboration and communication are essential.

Recommendation 9

To assess the nature and extent of impairments in body functions and structures – which are relevant to interpreting limitations at the level of skills, activities and participation – it is recommended to collect as much data as possible from assessments conducted by professionals in other related fields that are authoritative in the areas concerned. If such data are not available, the occupational therapist confers with the referrer as to whether further examination is indicated.

4.3.7 *Assessment of the physical environment*

The performance of daily activities is always within a physical, social and cultural context. The environment shapes, the meaning of the person's occupational performance and characteristics of the environment can facilitate or hinder the independence, efficiency and safety of occupational performance. The influence of the context on occupational performance applies even more in the case of PwPs(41;42;158). Assessing the environment is therefore essential in the occupational therapy assessment.

Whether the home, leisure or working environment should be assessed is based on the areas of occupation in which the PwP experiences problems. Which aspects should be evaluated in the environment greatly depends on the activities that the person performs or wants to perform and the problems that he experiences in doing so or the problems that are anticipated.

It is possible that the interviews conducted with the PwP and caregiver (i.e. COPM, OPHI-II) have already provided insight in the social and cultural context in which the occupational performance takes place.

This section will therefore specifically address the assessment of the physical environment.

Key question 10

Which aspects should be evaluated in assessing the physical environment in which PwPs and their caregivers engage in occupations?

Scientific basis

There is no validated Dutch tool for assessing the physical environment. In a standard for home visits from the Dutch Association of Occupational Therapy (*Ergotherapie Nederland*) a checklist has been included (159). This checklist was drawn up by experts after a review of the literature and is based on existing lists used, but it has not been scientifically tested (159). The checklist only focuses on evaluating the living/caring environment and not on evaluating a work or leisure environment outside the home. The setup of the checklist is quite broad and not specific to problems which frequently occur in Parkinson's disease.

Physical environmental factors can facilitate or hinder the occupational performance of the PwP, both from a cognitive and a motor perspective (41;42;158;160). In this way, the environment influences the extent of independence and safety in the occupational performance of the PwP. For example, freezing is usually triggered in small and crowded spaces and narrow passageways. Another characteristic example is that, due to their motor problems, PwPs are more dependent on good visibility of the environment. Good lighting is therefore important.

Based on knowledge about Parkinson's disease and knowledge from the Dutch *Occupational Therapy Guideline for Fall Prevention (Ergotherapierichtlijn Valpreventie)* (161) and the standard *Occupational Therapy in Older Persons with Cognitive Impairments*(119), the working group has formulated key points for assessing the physical environment of PwPs

(see Appendix 6). These key points can be used as a guide for assessing the home, leisure and working environment. The key points pertain to the accessibility of and mobility throughout the various spaces and the utility of the facilities, furniture and implements. Orientation also receives attention.

Conclusion

n/a	There is no validated standardized assessment available for evaluating the physical environment which is suitable and specific for use for PwPs.
Level 4	Experts believe that the environment should be evaluated based on knowledge regarding the physical environmental factors which can contribute to facilitating or hindering the performance of a PwP and based on knowledge regarding fall prevention. D working group

Other considerations

The Dutch Standard for Home Visits only focuses on the living/caring environment and not on the work or leisure environment. The setup is quite broad and not specific to problems which frequently occur in Parkinson's disease.

The list, containing key points and questions formulated by the working group (see Appendix 7) has been specified for Parkinson's disease and can be used as a practical tool for occupational therapists.

Recommendation 10

It is recommended to assess the environment guided by knowledge of; 1) the physical environmental factors which specifically facilitate or hinder the occupational performance of someone with Parkinson's disease and 2) the factors important in fall prevention. The main themes in evaluating the physical environment pertain to the accessibility of and mobility throughout the various spaces, orientation and the utility of the facilities, furniture and implements.

For this, the occupational therapist can use, as a guide, the questions and points of attention which appear in Appendix 7 of this guideline.

4.4 Planning for time and location for assessment

4.4.1 Time

Key question 11

What is a suitable time of day for occupational therapy consultations during the assessment phase?

Scientific basis

PwPs with response fluctuations can experience significant and sudden changes in the nature and extent of motor and non-motor impairments (162;163). As a result, performance in activities will vary in the course of the day.

When interpreting observation data of PwPs with response fluctuations, it is important to consider the person's condition at the time of the observation (i.e. *on* or *off*). The findings and conclusions thus pertain to the performance at the time of observation.

A medical protocol for the evaluation of PwPs states the importance of evaluating PwPs during both the *on* phase and the *off* phase (164). The protocol also states that PwPs should be on a stable medication regime in order for a meaningful pronouncement to be made about the performance.

Conclusion

Level 4	Experts believe that PwPs should be evaluated during both the <i>on</i> phase and the <i>off</i> phase and that the assessment times should be geared to this. PwPs should be on a stable medication regime at the time of the assessment. D Langston, 1992
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Other considerations

The aim of the assessment and its form (i.e. interview or observation) provide direction for determining the suitable time for PwPs with response fluctuations.

It will be more pleasant and effective for both the PwP and the therapist if the person can communicate easily (both in the sense of talking and cognitively following the conversation). It is therefore best for the interview to take place during the *on* phase. It is, however, important to address in this interview which problems are experienced during different phases. These phases may be:

- the *off* phase
- the *on* phase without dyskinesias or with acceptable dyskinesias
- the *on* phase, with impairing dyskinesias

The observation of activities is most worthwhile during the phase in which the problems are experienced. However, it is preferable to observe activities during the PwP's different phases in order to get a complete picture of the performance and intervention options.

Recommendation 11

It is recommended that the assessment takes place once a stable medication regime has been established.

When a PwP experiences response fluctuations, it is recommended that the time of assessment be adjusted to this, such that:

- insight can be gained into the performance during both the *on* and the *off* phase.
- interviews designed to clarify the occupational issues preferably occur during an *on* phase.

4.4.2 Location

The performance of activities can be observed in a clinic, institution or the person's own environment. The question remains what is preferable for the occupational therapy assessment of PwPs?

Key question 12

Which environmental setting is best for observing the occupational performance of PwPs?

Scientific basis

In the literature, various experts agree that the occupational performance of a PwP is influenced by the environment and the context (41;42;158;160). For example, freezing occurs more often in an environment with narrow passageways. For this reason, certain motor problems occur more often in the domestic setting than in a clinical environment.

No study exists which has specifically examined the influence of location on the occupational therapy assessment of PwPs.

In a number of studies that use the occupational therapy observation measuring tool called The Assessment of Motor and Process Skills,(AMPS) it has been shown that there are small but significant differences in the quality and effectiveness of performance skills, depending on whether the patient is observed in the domestic setting or in the clinic (165-167). The various studies were conducted on patients with dementia (N=19), elderly patients (N=20) or patients with a head injury (N=20). The process skills, in particular, were found to be better in the domestic setting.

Conclusion

Level 4	Experts believe that the physical performance of PwPs is influenced by the performance context. D Snijders, 2008, Kamsma, 2004, Montgomery, 2004, Morris, 2000
Level 2	It is likely that, for elderly or people with cognitive problems, the quality and effectiveness of skills in the performance of meaningful activities will vary depending on whether the activity is observed in a domestic setting or a clinic. B Darragh, 1998, Nygard, 1994, Park, 1994

Other considerations

Conducting observations at the therapist's workplace requires less travel and expenses for the therapist. However, as patients with cognitive problems score better in their process skills in a domestic setting, PwPs with cognitive problems probably score better at home as well. The working group shares the opinion of experts in the literature that the performance of PwPs is influenced by the context.

The aim of occupational therapy observations is to gain realistic and reliable insight into the person's quality of meaningful occupational performance (i.e. safety, effort, efficiency and independence). That is why the working group feels that it is preferable to observe PwPs in the environment where they usually engage in activities. This provides a good picture of the effect that this environmental context has on the PwP's occupational performance and facilitates optimal tailoring of the intervention.

However, if the aim of the observation is to evaluate how the PwP can deal with new situations, it might be useful to perform an observation in a different setting than the person's own familiar environment.

Recommendation 12

It is advisable to observe the PWP in performing activities *in* his usual performance context (instead of in a clinical setting) in order to gain insight into problems relating to safety, efficiency and independence.

To evaluate how a patient can deal with new environmental contexts, occupational performance can purposefully be observed in an unfamiliar environment

5. Occupational therapy interventions

5.1 Introduction

This chapter discusses the occupational therapy interventions which can be used for PwPs and their caregivers. First, general recommendations are made on the subject of guiding PwPs in learning new skills and changing behavior. After that, key questions are answered about the value of specific interventions. The recommendations indicate to what extent these interventions should be used by occupational therapists in the rehabilitation of a PwP and/or his caregiver.

The following key questions are answered:

Supervising the learning process (Section 5.3)

13. Which key points are important in enabling PwPs to learn new skills and strategies?

Specific interventions (Section 5.4)

14. What is the value of encouraging self-management in PwPs and their caregivers as part of the occupational therapy intervention?
15. What is the value of advising a PwP on the timing and choice of activities to increase satisfaction with daily activity patterns and participation?
16. How can the occupational therapist effectively enable the PwP to deal with stress and time pressure in daily activities?
17. To what extent is the training of motor skills of the arm/hand effective for maintaining or improving occupational performance?
18. What is the value of focusing attention as a strategy to improve occupational performance?
19. What is the value of applying cognitive movement strategies (step-by-step occupational performance) to improve occupational performance?
20. When is it useful to advise and supervise the patient in minimizing dual tasks?
21. What value does the use of cues have for improving occupational performance?
22. Is advice about changes in physical environmental factors effective in optimizing meaningful occupational performance of PwPs?
23. Which interventions can the occupational therapist use to optimally advise and supervise the PwP's caregiver?

Aspects related to planning the intervention (Section 5.5)

24. Which environmental setting is best for occupational therapy interventions involving PwPs?
25. What is an appropriate time of day for intervention sessions for PwPs with highly fluctuating performance?
26. Which delivery format is preferable for the occupational therapy intervention: group intervention or individual intervention?

The Intervention Guide (see Part I) provides an overview of the occupational therapy interventions and principles that are recommended in the Guideline.

5.2 Background to the occupational therapy intervention

Occupational therapy interventions in Parkinson's disease are aimed at effecting a change in the occupational performance, performance possibilities or performance competencies of the patient or caregiver. These changes can be at the level of the person himself, the activity or the social and physical environment. The strategies and interventions that are selected depend on the preference of the PwP or caregiver as well as the potential for changing aspects of the person, the activity and the environment. A combination of interventions usually applies.

At level of the person, changing occupational performance can involve interventions directed at:

- improving and maintaining skills during the performance of activities.
- applying compensatory skills or strategies during the performance of activities.
- increasing insight and knowledge in order to adequately deal with current and future limitations in daily activities (self-management).

If the person has limited potential to change or learn, due to, for example, cognitive limitations or severe motor limitations, interventions will be more geared towards external compensation. This means that the activities will be modified, aids and adaptations will be utilized or that the caregiver or other health professionals will provide support and supervision.

At the beginning of each intervention session, an evaluation takes place of the experiences of the PwP and caregiver with the advice provided or skills practiced in the previous session. At the times indicated in the intervention goals, an evaluation is made as to whether the intervention goals have been achieved or need to be revised. The opinion and experiences of the patient and caregiver as well as the observations and opinion of the occupational therapist are important in this process.

It may be useful to re-administer relevant measuring tools to evaluate the intervention goals and gain insight in the extent of change that has taken place during the intervention period.

The COPM and the AMPS are ideal evaluation tools for this purpose. For a description of these tools and their clinimetric features, please refer to Chapter 4.

5.3 Supervising the learning process

The occupational therapy intervention in PwPs is usually directed at teaching the application of strategies, altering performance methods and changing habits and routines. This implies that the PwP is expected to learn new skills and change his behavior.

Key question 13

Which key points are important in enabling PwPs to learn new skills and strategies?

Scientific basis

In the literature on guiding behavioral change, experts describe the steps and determinants of behavioral change (168). A person will only consciously opt for and use other strategies, methods and habits (new behavior) if he is open to behavioral change, understands and recognizes the need for it, is prepared to adopt new behavior and is capable of doing so (168;169). With respect to being *open* to behavioral change, it is important to take into account the patient's emotions, expectations and concerns. With respect to being *prepared* (behavioral intention), social influences – in addition to the person's attitude and confidence in his own abilities – also play a role (168). Being *capable* depends on the person's skills as well as the environmental conditions and possibilities. The ultimate goal is for the person to sustain the behavior. Receiving *feedback* is usually an important incentive in this regard. For a detailed description of the steps and determinants for behavior change, reference is made to relevant textbooks and articles on this topic (168;170).

In the general literature on teaching and instructing patients, experts state that it is important in the instructional approach to take into account the patient's personal learning style to ensure the maximum learning effect (168). Kolb (1995) has drawn up the various learning styles and their corresponding instructional approaches. For more in-depth information, please refer to this work (171).

There are numerous experimental psychological studies on the learning ability of PwPs. Siegert conducted a systematic review of the studies up to 2005 related to implicit learning using a word learning test. Using six studies, he confirmed that PwPs have difficulty with implicit learning (172). Van Spaendonck and Buytenhuijs have specifically studied whether PwPs benefit from an explicitly presented structure when learning words. It has been shown that PwPs can reproduce more words when using this structure (25;173). Experts in the application of motor learning in PwPs state that, in light of their difficulty with dividing and switching attention, PwPs must learn to perform activities with focused attention (41;42). For the intervention, this means that it is recommended to let a PwP learn one thing at a time and that instructions are not given during the occupational performance, but before and/or after it (41). Repetition and practice are necessary for the proper learning of strategies. The fact that

PwPs need more time and repetitions to adapt their motor skills to a new situation is emphasized by experimental studies conducted by Krebs on procedural motor learning (174).

The aforementioned studies involved patients in the early and middle phases of Parkinson's disease who are not suffering from dementia.

Conclusion

Level 4	Experts believe that, when intervention is aimed at changing patients' behavior, the steps and determinants of behavioral change should be taken into account. D van der Burgt, 2003, Balm, 2000
Level 4	Experts in the area of learning believe that, in the learning process, the personal learning style of the patient should be taken into account. D van der Burgt, 2003, Balm, 1995
Level 2	It is likely that PwPs have difficulty with implicit learning. SR Siegert, 2006
Level 2	It is likely that PwPs benefit from an explicitly presented structure in order to learn new information. B van Spaendonck, 1996, Buytenhuijs, 1994
Level 4	Experts believe that, when providing instructions during skills training, the following points are important with respect to PwPs: ask for focused attention, one thing at a time, do not give instructions during the occupational performance, but before and/or after it. D Kamsma, 2004, Morris, 2000
Level 3	There are indications that PwPs need more time and repetitions to adapt their motor skills to altered circumstances. B Krebs, 2001

Other considerations

The recommendations in the general literature about teaching and enabling behavior change are not specific to PwPs. However, since many PwPs have difficulty learning new information, skills and behavior, it seems even more important to take into account the PwP's personal learning style and carefully go through the steps for behavior change. This increases the chance of an effective intervention.

While the studies on implicit learning in PwPs focus primarily on the teaching of semantic information, clinical experience has shown that it could also be useful to offer external structure when teaching patients new skills or methods. The working group expects that

instructing oneself in stepwise performance can provide this structure. If the PwP cannot reproduce the steps, these can be written down or illustrated as a reminder. When it comes to PwPs with limited capacity for change, such as those with severe cognitive problems, the emphasis is more on changing the activity or the environment in order to enhance occupational performance. It may be necessary for the caregiver to provide structure by giving instructions.

Recommendation 13

When supervising or instructing the PwP in activity performance or during skills training, it deserves recommendation to consider the following points:

- connect the instruction method to the person's individual learning style;
- give instructions step-by-step (having the PwP learn one thing at a time);
- let the PwP learn with conscious attention and using a conscious learning process (explicit learning);
- provide a clear structure;
- create the right context for learning (in the home, leisure or working environment);
- provide enough opportunity for practice and repetition;
- give instructions before or after the occupational performance; not during ;
- provide reminders (i.e.a visual instruction sheet).

5.4 Specific interventions

5.4.1 Encouraging self-management

Given the fact that Parkinson's disease is a chronic disease, it is important that people have insight into their disease, learn to anticipate problems in activities and participation and learn how they can deal with problems in meaningful occupational performance. Education, coaching, empowerment and encouraging self-management are important elements in this regard.

Key question 14

What is the value of encouraging self-management in PwPs and their caregivers as part of the occupational therapy intervention?

Description of the intervention

Self-management is encouraged by guiding people in setting their own personal goals and action plan following a problem-solving approach (175). The steps of self-reflection and the identification and consideration of potential solutions are important in this regard.

Within the occupational therapy intervention, applying self-management principles serves the goal of maintaining and improving meaningful occupational performance. The person's insight into problems in meaningful occupational performance is increased by providing him with information and feedback and by encouraging self-reflection. Prioritizing goals with respect to activities and participation is encouraged, as are the identification and consideration of

potential solutions. There are a few occupational therapy group programs that aim to improve self-management of PwPs and employ an approach of empowerment and mutual learning (175-177).

When insight and problem-solving skills are limited due to impairments in executive functions, the steps for problem recognition and problem solving are taught in a structured fashion. Through targeted feedback from the practitioner, the patient learns strategies for self-examination, self-instruction and self-evaluation (178). This training strategy is recommended in the Dutch guideline for cognitive rehabilitation of patients with acquired brain injury' (*Richtlijn Cognitieve Revalidatie Niet-Aangeboren Hersenletsel*) for patients with slight or moderate impairments in executive functions (178).

Scientific basis

Within occupational therapy, only one article has been published about the process and experiences of a self-management group program for PwPs. This article reports the findings of the PwPs and their caregivers (176). Two hundred people followed the self-management program. The participants were very satisfied with the course and said they felt more capable of dealing with the effects of the disease and able to participate more in meaningful activities.

A number of studies have also been conducted in other disciplines on the effect of a group program aimed at increasing self-management among PwPs. Sunvisson (2001) shared the results of a program with a psychosocial intervention based on self management principles provided by a nurse in combination with a physical therapy movement program (179). The results showed that, while there was improvement in the area of psychosocial well-being and movement, this was not generalized to daily life. The researchers proposed that an activity-oriented approach may perhaps be more useful.

The EduPark Patient Education Programme is an education program aimed at learning skills in order to deal with psychosocial problems in daily situations (180). It was developed by a consortium of seven European countries for PwPs and their caregivers. In the Netherlands, it is known of as the PEPP Program (*PEPP-programma*) (181). Basic principles of this program include self-management and empowerment. The program was evaluated in seven countries for feasibility and effectiveness (180;182). Participants did not have severe cognitive problems and the majority were in Hoehn and Yahr stage 1-3. Even though there were no significant improvements in mood and disease-related quality of life directly following the program, the participants appreciated the program and they found that they were better able to deal with psychosocial problems (180;182).

The specific training in self-regulating skills that is recommended in the Dutch guideline for cognitive rehabilitation of patients with acquired brain injury has not been studied among PwPs.

Conclusion

Level 3	There are indications that PwPs and caregivers are better able to deal with problems in their daily life after participating in programs aimed at encouraging self-management. C Sutter, 2006 B Macht, 2007, Simons, 2006
Level n/a	Strategy training to have patients with slight to moderate executive problems implement self-regulating strategies has not been studied among PwPs.

Other considerations

Though the scientific evidence regarding the effect of encouraging self-management is still limited, the working group is of the opinion that this intervention is important in enabling occupational performance of people with a chronic disorder such as Parkinson's disease. If PwPs and caregivers learn to anticipate new problems in meaningful occupational performance and learn to manage these adequately, they will be more self-reliant and the effectiveness of the occupational therapy intervention will increase. However, a condition is that patients have the capacity to learn to apply problem-solving skills, regardless of external structure. This may not be possible for PwPs with severe cognitive problems.

Recommendation 14

It is advised to encourage the use of self-management strategies of PwPs and their caregivers in order to improve the recognition and management of occupational performance issues.

A prerequisite is that the cognitive capacities of the person are sufficient for learning to apply problem-solving skills, either with or without the help of an external structure.

5.4.2 Optimizing daily structure and activities

The way that PwPs are able and willing to spend their time can change and this can result in feeling of dissatisfaction with activity patterns. The reason for this dissatisfaction can be:

- that fewer activities can be performed due to fatigue and slowness or the risk/fear of falling;
- that the performance capacity strongly fluctuates;
- that the motivation for performing activities has changed due to a reduced feeling of personal effectiveness ("I can't do it"), depression, excessive demands from the social environment or apathy due to impaired executive functions;
- that the PwP can no longer perform certain activities, tasks and roles and is looking for alternatives.

Key question 15

What is the value of advising a PwP on the timing and choice of activities to increase satisfaction with daily activity patterns and participation?

Description of the intervention

The following interventions are described based on the experiences of the working group. Depending on the reason for dissatisfaction with how the patient occupies his time, the focus can be on:

- A. Setting priorities in activities and rescheduling activities so that the pattern of activities is better suited to the patient's abilities;
- B. Structuring the day to provide external guidance;
- C. Choices with respect to possible activities.

Ad A. Setting priorities and rescheduling activities

The following aspects are covered:

1. Giving information on the principles of balancing the demands of activities with the abilities and energy levels of the person. It is also important to provide insight into the varying demands of activities and activity patterns and how one's own abilities can fluctuate depending on the situation, and how one can influence this. Not only physical aspects, but certainly psychosocial aspects play a role in this.
2. Analyzing the day/week (see assessment) with the PwP and adjusting the activity pattern in a way that it better suits the person's abilities. In modifying the activity pattern, the PwP usually has to set priorities and reconsider previous standards and values with respect to activities. Considerations are:
 - Is change possible and desirable with respect to the frequency, time and duration of activities?
 - Is assistance (or partial assistance) necessary and desirable with respect to certain activities in an effort to make more energy and time available for other activities?

In scheduling different activities and periods of rest, attention is paid to the times when the medicine takes effect (when the PwP feels best), which activities and contexts are energizing (provide satisfaction, are relaxing) and which activities and contexts require energy (require a lot of physical effort or are stressful). Situations in which time pressure is experienced often have a negative effect on the performance of PwPs. Advice is given on reducing time pressure, for example, by carefully planning activities and allowing enough time for them (see also Section 5.4.8).

Experience shows that a scheduled afternoon nap works well for many PwPs.

When fatigue is strongly connected to poor quality of sleep, consultation with a neurologist or Parkinson's disease nurse specialist is desirable in order to establish whether there are medical interventions or advice which can improve the quality of sleep.

Ad B. Structuring the day

If the lack of initiative in planning and performing activities is a problem, a structured day or week program can be drawn up together with the PwP and caregiver. This program provides external guidance and prompts. Encouragement and positive reinforcement from someone in the environment usually is and remains necessary as well. An important factor in promoting motivation for occupational performance is that the choice of activity matches the interests of

the person and that success can be experienced. Information can be provided on the importance of continuing to perform meaningful activities for the sake of both physical and psychosocial well-being.

If a lack of initiative is thought to be related to underlying depression, it is first necessary to refer the patient to a general practitioner, psychiatrist, or neurologist in order to determine suitable intervention options.

Ad C. Choosing activities

In this intervention, the occupational therapist advises and supervises the PwP in choosing and taking up (or resuming) activities. These activities should match the interests, motivations and capabilities of the person. At the same time, the therapist looks at how the environment can support engagement in activities.

Scientific basis

There are no studies on the effect of advising a PwP on prioritizing, and rescheduling activities.

Packard (1995) set up a structured occupational therapy group program for energy conservation for patients with chronic disease who suffer from fatigue. This program incorporates pacing occupations, balancing activity and rest and using a daily/weekly schedule as a structure. The effectiveness of this energy conservation program is examined in a randomized controlled trial involving 169 patients with multiple sclerosis (183;184). Patients from the intervention group rated the impact of fatigue as less severe ($p < 0.05$) and felt more capable of using strategies to deal with the fatigue ($p < 0.0001$). However, it is not known which specific part of the program (the content, method of delivery or patients' characteristics) made it effective.

There is also no evidence available regarding the effect of using structured daily or weekly activity schedules for PwPs with apathy and decreased motivation towards activities. In the literature on senile patients with apathy, motivating them by means of a planned daily structure is mentioned as an intervention, but its effect has not been studied (185;186).

Conclusion

Level n/a	The effectiveness of interventions aimed at advising PwPs on daily activities and structure has not been studied.
Level 2	<p>It is likely that a program for teaching the application of energy-saving principles – in which the consideration of priorities as part of one's day and the allocating and scheduling of activities (daily structure) – is effective for people who suffer from fatigue due to multiple sclerosis.</p> <p>A2 Mathiowetz, 2005</p>

Level 4	Experts believe that motivating patients by means of a planned daily structure can be suitable for senile patients with apathy. D Politis, 2004, Landes, 2001
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Other considerations

While the study by Mathiowetz (2005) focuses on patients with multiple sclerosis, the expectation is that the conclusion can also apply to PwPs. From its own experience, the working group believes that principles of energy conservation in the timing and organization of daily activities are successfully applied as an occupational therapy intervention for many patients with chronic fatigue.

Furthermore, the working group has positive experiences with the use of a planned daily structure (see Intervention B) and consulting about possible activities (see Intervention C).

Recommendation 15

Advising a PwP on daily structure and activities is recommended to increase satisfaction with occupying time and to optimize opportunities for engagement in meaningful occupational performance.

This intervention is indicated if the particular PwP:

1. suffers greatly from slowness, fatigue or fluctuating performance;
2. takes little initiative in initiating activities;
3. can no longer carry out certain activities and has questions regarding suitable alternatives.

5.4.3 Dealing with stress and time pressure

Stress and time pressure negatively influence the severity of the symptoms of Parkinson's. This often hinders the performance of activities.

During the assessment phase, it is important to have identified which factors contribute to stress and in which daily situations this stress occurs. PwPs often have problems of slowed information processing and slowed motor performance. This is likely to give them the feeling of not having enough time and make them more sensitive to time pressure. They may also be tense or afraid of failing when other people are watching. The occupational therapist can supervise the PwP in learning how to deal with stress and time pressure in daily situations. For specific mood or behavioral problems, referral to professionals in disciplines such as social work or psychology is desirable.

Key question 16

How can the occupational therapist effectively supervise the PwP in learning how to deal with stress and time pressure in daily activities?

Scientific basis

The study by Deane on current and best practice in occupational therapy in PwPs in the United Kingdom mentions interventions such as stress management, the use of relaxation techniques and time management by occupational therapists (1;2). However, it does not describe what these interventions entail in the occupational therapy intervention for PwPs.

The Dutch guidelines for the cognitive rehabilitation of patients with acquired brain injury recommend that patients with delayed information processing be taught certain strategies to help reduce the time pressure associated with activities (178). Fasotti (2000) has described this strategy training as *Time Pressure Management Training* which has been found to have a positive effect on patients with traumatic brain damage (187).

Based on general principles of stress management, relaxation techniques, time management and the specific strategies from Time Pressure Management Training, the working group has formulated a number of interventions which it believes are useful for PwPs.

1. Advising on the reduction of time pressure in the planning and organization of activities by taking into account the slowness of motor performance and by using strategies from Time Pressure Management. The main principle in this intervention is that the person has enough time to perform the activity. Things to consider are: choosing a suitable time of performance, the careful planning of the activity in advance, the step-by-step performance of tasks (avoidance of simultaneous tasks) and the preparation of the environment.
2. Increasing the PwP's feeling of his own effectiveness in the performance of activities by encouraging self-management and optimizing occupational performance by using all the interventions described in this chapter which are relevant to the person. This may reduce the fear of failure, feelings of shame and stress.
3. Supervising the PwP in learning to perform daily activities in a relaxed manner in various situations.

Conclusion

Level 3	<p>There are indications that strategy training aimed at teaching patients to deal with delayed information processing resulting from brain damage is effective for dealing with time pressure in daily activities.</p> <p>B Fasotti, 2000 D Consortium on Cognitive Rehabilitation, 2007</p>
Level 4	<p>Occupational therapists believe that principles of stress management, relaxation techniques and time management can be applied in interventions to teach the PwP to deal with stress and time pressure in daily activities.</p> <p>D Deane, 2003 D Working group</p>

Other considerations

The working group expects that occupational therapists are familiar with strategies for dealing with slow performance through the careful planning and organization of activities.

In the Netherlands, stress management is primarily performed by psychosocial health professionals and the teaching of relaxation techniques, such as progressive muscle relaxation and breathing techniques, is done by physical therapists. However, the working group is of the opinion that the occupational therapist can provide support in the application of learned principles of relaxation and stress management in various activities and situations. Consultation and coordination is necessary with the physical therapists and psychosocial health professionals who are involved.

Recommendation 16

To help a PwP reduce stress, tension and time pressure in daily activities, an occupational therapist can employ the following interventions:

- advising the PwP and caregiver about reducing the time pressure in the planning and organization of activities;
- improving the feeling of personal effectiveness in carrying out activities by encouraging self-management and optimizing occupational performance;
- teaching the PwP to carry out activities in a relaxed manner.

5.4.4 *Practicing arm/hand motor skills*

As mentioned in Chapter 2, problems with reaching, gripping and manipulating frequently occur in Parkinson's disease and hinder the performance of many daily activities. Therapy can focus on maintaining or improving the motor skills of the arm and hand in order to maintain or improve the performance of activities. This is possible by using these skills consciously and regularly; defined as "practicing" in this guideline. Compensatory strategies may also be needed to facilitate motor skills. The section limits itself to the practicing of motor skills of the arm/hand. The value of compensatory strategies is discussed in other sections.

Key question 17

To what extent is the practicing of motor skills of the arm/hand effective for maintaining or improving occupational performance?

Description of the intervention

Preventive advice is given on continuing to perform activities in order to prevent skills from declining at a faster rate than is expected according to the disease progression.

The emphasis of the occupational therapists in this intervention is on creating the conditions for enabling the individual to perform meaningful activities which require the skills that the PwP wants to maintain or improve. To do so, the activities are graded according to difficulty and the environment is set up in such a way that the performance of the activity provides the right challenge for the PwP with regards to the skills to be practiced.

Scientific basis

Studies indicate that PwPs who are slightly or moderately impaired still have the capacity to improve their arm/hand motor skills (188-192). These studies were highly experimental and focused on improving the speed and quality of the use of the arm and hand. A significant improvement was realized, but only for the trained task. These studies do not, however, examine whether improvements are relevant to activities in daily life.

Based on the motor learning theories and experience, experts also indicate that the practicing of purposeful actions can be useful. For example, Morris (2000) advises the regular performance of functional tasks which require fine motor function in order to maintain and improve this skill (42).

Conclusion

Level 2	It is likely that PwPs who are slightly to moderately impaired have the capacity to improve the speed and accuracy of arm/hand movements in a trained task. B Agostino, 2004, Behrman, 2000, Swinnen, 1999, Platz, 1998, Soliveri, 1992
Level 4	Experts believe that the regular practicing of fine motor skills in functional tasks is useful for maintaining and improving these skills. D Morris, 2000

Other considerations

Though there are no specific studies on the effect of practicing arm/hand motor skills in the performance of meaningful activities, the above conclusion indicates that the effect of training is task-specific. This makes it likely that the methodology of the occupational therapist in which skills are practiced in meaningful activities can be useful in improving the performance of those specific activities.

Practicing arm/hand motor skills has only been studied in patients with slight to moderate impairment. Based on experience, the working group knows that it is usually only possible for severely impaired patients to perform activities with external compensation (i.e.. assistance, aids). In addition to the question of whether the person can still learn motor skills would the training of skills, usually be too burdensome.

Recommendation 17

Practicing arm/hand motor skills is advised as part of meaningful activities and contexts for the PwP and only if he is sufficiently capable (i.e. motor and cognitive functioning) of practicing these skills.

5.4.5 Occupational performance with focused attention

PwPs have difficulty performing routine-based actions such as transfers, handwriting, cutting, eating and dressing. Normal speaking, automatic or routine occupational performance

requires little conscious and focused attention. PwPs find that they have to think more when performing these actions.

Key question 18

What is the value of focusing attention as a strategy to improve occupational performance?

Description of the intervention

The occupational therapist can supervise the PwPs in learning to perform activities with their attention consciously focused on certain problematic aspects of the movement. For example, preparing a sandwich with focused attention on the action of spreading butter onto the bread or dressing oneself with focused attention on fastening the buttons. Attention can be focused by visualizing the action in advance, by providing self-instruction or, by looking at the body part in action. Focusing attention can be considered as a mental cue (see section 5.4.8).

Scientific basis

In a number of studies, it has been shown that movement patterns and skills improve when PwPs focus their attention on certain aspects of the movement.

Morris et al. (1996) evaluated this with respect to walking. In three experiments, they compared the effect of 1) visual cues, 2) conscious attention and 3) no specific intervention relating to the gait pattern on sixteen PwPs and sixteen healthy people. Visual cues and conscious attention were both found to have an equally favorable and significant effect on the walking speed and step length of the PwPs up to two hours after the intervention. The PwPs did, however, had to be reminded to use the strategies (193).

Oliveira (1997) applied the focused attention strategies in an experimental study on handwriting in which eleven PwPs with micrographia were compared with fourteen healthy people. In freestyle writing, the writing of the PwPs was smaller ($p < 0.05$). When receiving the repeated instruction to write “large,” the size of the writing was equal to that of the control group. The effect of writing larger was maintained for a short time after the intervention (49).

Experts believe that performing actions with focused attention can also be useful for the performance of Activities of Daily Living (ADL) (110).

Conclusion

Level 2	It is likely that performing walking and writing with conscious focused attention improves the quality and effectiveness of the performance. B Oliveira, 1997, Morris, 1996
Level 4	Experts believe that performing actions with focused attention can also be useful for the performance of ADL activities. D Kielhofner, 1997

Other considerations

In the above studies, effects are only measured in the quality of movements and not in the effects on activity performance. It is still unclear how long after training the person can apply this strategy spontaneously.

Though the performance of the action can improve with focused attention, a disadvantage of this strategy is that it requires substantial cognitive effort. The patient must, however, be able and willing to make this effort. The application of this strategy also put conditions on the environment and the task. For example, there should be as few distracting factors as possible so that the PwP can focus well.

Recommendation 18

It is recommended to evaluate the effect of the strategy of “consciously focusing attention on problematic aspects of the occupational performance” on a PwP and, if the effect is positive, to advise and train its use in activities.

A prerequisite for applying this strategy is that the person is able and willing to put in the effort of focusing attention in the situations concerned.

5.4.6 Applying cognitive movement strategies

PwPs have more difficulty performing complex tasks that require the use of both hands or several simultaneous movements than performing a simple movement. For example, cutting and eating with utensils is much more difficult than reaching for a cup. To compensate for the problem with respect to performing complex movements, PwPs can learn to perform these actions step-by-step and with focused attention (cognitive movement strategies) (194;195).

Key question 19

What is the value of applying cognitive movement strategies (step-by-step occupational performance) to improve occupational performance?

Description of the intervention

Kamsma (1995) has worked out and described this compensation strategy for both performing transfers and bed mobility (194). In essence, it entails reorganizing the automatic complex motor actions in a number of steps. For these steps, it is important that:

- each step can be performed separately, i.e. each step ends in a stable resting position;
- the steps should not be too small because this would delay the continuation of the movement too much (10);
- the steps can be performed in a logical, fixed order and together lead to the final goal of the complete action;
- the steps can be performed with conscious attention;
- the movements are simplified by reducing the need for axial rotations.

The PwP learns to perform these steps with focused attention and in the right order, following his own instructions (out loud or to himself). The PwP is encouraged to go through and

visualize the steps, even prior to beginning. Appendix 8 contains examples of cognitive movement strategies for transfers such as those included in the physical therapy guidelines of the Royal Dutch Society for Physical Therapy (KNGF).

The principles of cognitive movement strategies are also applied by occupational therapists in facilitating ADL activities for PwPs(110).

Scientific basis

Various authors agree that breaking down complex tasks into steps is useful for improving the performance (42;158;194). Kamsma (1995) compared the effect of this strategy with the effect of a general training program for walking and transfers on two groups of PwPs. For the PwPs who were trained according to cognitive movement strategies (experimental group), the transfers improved significantly. The improvement in transfers was not transferred to other motor skills and activities. For both groups, the average Hoehn and Yahr score had somewhat worsened after a year. The experimental group, however, exhibited significant improvement in turning over in bed and standing up from a chair ($p<0.01$)[194].

In the study by Nieuwboer, the cognitive movement strategies were applied in combination with other interventions. Six weeks after stopping with the intervention, the PwPs had improved on the Parkinson Activity Scale ($p<0.0007$) (196). Transfers and walking tasks are included in this observational scale.

Conclusion

Level 2	It is likely that the learning of cognitive movement strategies aimed at body transfers of PwPs is effective in facilitating the performance of these transfers. B Nieuwboer, 2001, Kamsma, 1995
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Other considerations

The question is to what extent the above conclusion can be generalized for other daily activities focused on by the occupational therapist. As indicated by Kamsma (1995), the strategy only applies to activities which can be divided into steps with stable resting positions. Numerous complex fine motor actions (e.g. fastening buttons and writing) cannot be adequately reduced to simple steps. For PwPs with evident cognitive problems, remembering and reproducing the steps can be too difficult. The step-by-step plan can be presented to them in writing or with pictures. In some cases, it may be necessary for the caregiver to call out the steps.

It has not yet been studied whether cognitive movement strategies can sufficiently be generalized to various other functional situations. If PwPs have learned to perform the sit-to-stand transfer in steps, will they also apply this to standing up to get the telephone or standing up while dressing? The working group is of the opinion that the application in various activities should receive attention in the intervention and evaluation.

Recommendation 19

If a PwP has problems in carrying out complex movement sequences (i.e. in reaching/grasping or transfers), it is recommended to evaluate the effect of cognitive movement strategies (step-by-step occupational performance) on a PwP in activities which can be divided into steps with stable resting positions and, if the effect is positive, to advise and train in its use in activities.

5.4.7 *Minimizing dual tasks*

A “dual task” is a task in which the attention may have to be divided between two things, such as transporting objects while walking (walking and carrying) or keeping notes during a meeting (listening and writing). Many Pwps have difficulty dividing their attention and quickly switching from one thing to another (alternating attention). As a result, the simultaneous performance of several sub-tasks detracts from the quality and safety of the occupational performance. This can involve a motor dual task, a cognitive dual task or a motor-cognitive dual task (39). The essence is that attention must be divided and this is difficult for a PwP. A complex functional activity almost always involves several dual tasks and requires both alternating and divided attention.

Key question 20

When is it useful to advise and supervise the PwP in minimizing dual tasks?

Description of the intervention

The occupational therapist can inform the patient about the effect that the simultaneous performance of several sub-tasks has on the quality of the occupational performance. The therapist can also advise and supervise the PwP with respect to reducing dual or multi-tasks in his daily occupational performance. The PwP learns to avoid distracting factors, where possible, and to reorganize the activity so that he can focus on performing one sub-task at a time. A few examples include: not conducting a conversation while using the computer, sitting down while dressing. This requires careful planning and a structured approach.

Scientific basis

Published studies on this intervention come from physical therapy and evaluate the influence of dual tasking on walking. These studies recommend advising the PwP to avoid simultaneous tasks (11).

Morris (2006) is of the opinion that PwPs who experience slight problems with dual tasking can still perhaps improve the skill of performing several tasks simultaneously by means of systematically graded training (197). In this case, avoiding dual tasking is specifically not needed. It has not yet been studied if avoiding dual tasking improves the performance of daily activities.

Conclusion

Level 4	Experts believe that avoiding dual tasking is useful for improving the gait pattern – unless patients have slight problems with dual tasks. D Morris, 2006, Keus, 2004
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Other considerations

Based on clinical experience, the working group is of the opinion that advising on minimizing dual tasks is not only useful for walking tasks, but also for complex functional activities which involve several simultaneous tasks. The limiting factor here is that not all functional activities can be divided into simple tasks or be performed without distracting environmental factors. Examples of such activities include eating in a family setting or driving a car.

Recommendation 20

If a PwP has problems with carrying out dual tasks, it is recommended to evaluate the effect of reorganizing and simplifying multi-task activities into activities which consist of a sequence of single tasks (or sub-tasks). If the effect is positive, it is recommended to advise its use in daily occupational performance.

5.4.8 Using cues

In Parkinson's disease, the internal control for performing automatic and repetitive movements is impaired. To facilitate movement, the lack of internal control from the basal ganglia must be compensated. External cues can help start movements and keep them going (42). Cues are stimuli from the environment or stimuli generated by the patient himself. Cues are classified according to type of stimulation and the frequency of repetition (11).

Rhythmic cues (for ongoing movement)	
Auditory	<ul style="list-style-type: none">• Moving to music or to the rhythm of a metronome.• The PwP or someone else counts or sings.
Visual	<ul style="list-style-type: none">• Walking over lines or a certain visual pattern (e.g. sidewalk tiles or floor patterns).• Following another person.• Rhythmically repeated visual stimulus (pulsing laser light).• Graph paper or lined paper for writing (49).
Tactile/ proprioceptive	<ul style="list-style-type: none">• Tapping on the leg.• Rhythmic vibration (cueing device) (198).

Single cues (to initiate movement)	
Auditory	<ul style="list-style-type: none"> • Start signal: e.g. counting and starting at 3, or someone gives the instruction to start.
Visual	<ul style="list-style-type: none"> • Focusing on a point or object in the environment (e.g. a painting, mirror, clock, bright spot) (42). • Stepping over something (e.g. someone's foot, an object or an inverted walking stick). • A moving object (199).
Tactile/ proprioceptive	<ul style="list-style-type: none"> • Shifting weight to one leg. • Moving one's own body (e.g. lifting one's legs, moving trunk back and forth, stretching).

Key question 21

What value does the use of cues have for improving occupational performance?

Description of the intervention

By observing the person performing activities, it is possible to find out whether the person already consciously or subconsciously uses cues, what these cues are and how the person responds to them. The cues that best suit the activity and the capabilities of the person are determined based on this analysis. The PwP and caregiver are informed about how the cueing strategy works. Then the PwP needs to practice using the appropriate cues in the relevant activities and situations. A number of examples are:

- For the problem of freezing while walking or turning, lines can be installed and used on the floor in narrow spaces like a bathroom or closet.
- For problems with letting go of objects, the use of a start signal can be practiced when letting go of a cup when drinking.

Scientific basis

Lim (2006) made a systematic review of studies up to the year 2005 which evaluate the effect of rhythmic cues on walking (200). Only one qualitatively sound study was found, and it was conducted in a laboratory. Auditory rhythmic cues were found to have a positive effect on step length. There was insufficient evidence for visual and tactile cues, though it should be noted that no proper studies had been conducted in this regard.

Since then, Rochester (2005) and Nieuwboer (2007) have studied the effect of cueing on walking in a domestic setting (201;202). Both studies found cueing to have a positive effect on step length and speed. The study by Nieuwboer (2007) also found that patients had more self-confidence in performing activities after the intervention ($p=0.04$), but that no functional improvement in activities or quality of life was experienced. The training effect of cueing on walking was reduced when the cues were no longer used (202).

There are only two small studies on the effect of cueing on skills or activities other than walking. In an experimental study in which eleven PwPs with micrographia were compared with fourteen healthy people, Oliviera (1997) evaluated the influence of visual cues (lines and dots) on the size of the handwriting. While the letter size in freestyle writing was significantly

smaller for PwPs compared to the control group, ($p < 0.05$), this was not the case with the visual cues. The effect of writing larger was maintained for a short time after the intervention (49).

Ma (2004) conducted an experimental study to evaluate the effect of a simple auditory cue as a start signal when reaching for an object. In the study, sixteen PwPs were compared with sixteen healthy test subjects. It was found that this cue results in a faster and more forceful but less fluid movement among PwPs (203).

Conclusion

Level 2	It is likely that the use of auditory rhythmic cues can improve aspects of the gait pattern. SR Lim, 2006 B Nieuwboer, 2007
Level 3	There are indications that the use of visual cues (lines and held up letters) has a direct positive effect on the size of handwriting. B Oliviera, 1997
Level 3	There are indications that a simple auditory cue has an effect on the reaching movement. The movement becomes faster and more forceful, but less fluid. Cues can be used, depending on the desired result. B Ma, 2004

Other considerations

For the occupational therapist, it is of primary importance whether the effect of cueing means that the PwP can perform better in meaningful activities in his own environment. Current research has not yet sufficiently demonstrated this. Based on clinical experience, however, the working group is of the opinion that the use of cues can help some patients in performing daily activities in the domestic setting, such as the use of lines in the bathroom. During the intervention session, the therapist can immediately determine if the PwP responds to certain cues. It therefore seems useful to try out the use of cues during activities with the individual patient. This may already have been addressed during the assessment phase. Training in the proper use of the cueing strategy follows if it is apparent that the PwP benefits from the cues.

As the physical therapist looks specifically at the use of cues in walking and moving, collaboration is necessary to discuss what cues seem useful for the patient and who will train what aspects.

Recommendation 21

If a PwP has movement problems related to slowness, reduced amplitude or freezing, it is recommended to evaluate the effect of cues on the PwP's occupational performance and, if the effect is positive, to advise and train the use of these cues in activities.

5.4.9 *Optimizing the physical environment*

The occupational therapist can advise the PwP and caregiver on changes in the physical environment. Aids, adaptations and other modifications to the physical environment are employed with the aim of further enhancing occupational performance or making it safer, less strenuous or easier. This compensates for cognitive and motor problems. Aids and adaptations can also be used by caregivers to make care giving tasks less strenuous. Modifications are considered if the use of strategies is not possible or not sufficient for optimizing the performance of activities.

Key question 22

Is advice about changes in physical environmental factors effective in optimizing meaningful occupational performance of PwPs?

Description of the intervention

After analyzing the problem areas and the potential for changing the physical environment, the occupational therapist informs the PwP and caregiver about the possible options for changing the space or the materials. It is important to remain critical with respect to whether the changes to the physical environment will *really* contribute to greater independence, safety and efficiency in occupational performance. Another precondition is that only those changes that the PwP and caregiver have accepted and agreed on should be implemented. It is preferable to first try out an aid or modification, but this is not always possible.

Information is then provided on the availability of materials, any application procedures and reimbursements. The occupational therapist ensures that the person can also adequately manage with the aids and adaptations, given that misuse can entail safety risks.

Though the advice is specific to the person and context, the working group's experience is that there are several common recommendations on reorganization, modifications, adaptations and aids for PwPs. These recommendations can pertain to:

- creating an unobstructed walking and turning route for people who suffer from freezing;
- removing obstacles that form a risk for falling;
- setting up visual reminders, structure and overview in the arrangement of space and objects for people with cognitive problems;
- rearranging space and objects based on ergonomic principles for people with fatigue;
- installing visual cues in places where it is important;
- creating support points or possibilities for sitting during activities for people with impaired balance;

- increasing the transfer height and paying attention to ergonomic sizes and proper support from furniture;
- recommending specific materials, adaptations and tools (aids);
- making materials heavier or lighter;
- changing the size and shape of the objects to reduce the manipulation required or to enable better grip;
- changing the structure of materials;
- installing good lighting and sufficient visual contrasts.

This is illustrated with a number of examples in Appendix 9.

Scientific basis

There are no relevant studies on the effect or use of certain modifications, aids and adaptations specifically for PwPs.

A Cochrane systematic review by Gillespie (2003) on fall prevention found that modifications recommended by experts are effective in reducing fall incidence for people who have fallen at least once (204). Six qualitatively sound, randomized studies on the changing of environmental factors were included in the review. This review also forms the basis for the recommendation on modifying the environment in the Dutch Occupational Therapy Guidelines for Fall Prevention (*Ergotherapie richtlijn Valpreventie*) (161).

A systematic review by Steultjens (2004) of studies on the effectiveness of occupational therapy interventions for elderly patients living at home concludes, on the basis of a number of qualitatively sound, randomized studies, that there is strong evidence that advising and teaching the use of aids leads to a more independent and safer performance in this group of elderly patients (205). The beneficial effect of home modifications on the performance of elderly patients living at home is also confirmed in a 2006 study by Gitlin(206).

Conclusion

Level 1	It has been demonstrated that home modifications recommended by experts are effective in reducing fall frequency for people who have fallen at least once. SR Gillespie, 2003
Level 1	It has been demonstrated that advising and teaching the use of aids and adaptations to elderly patients living at home leads to more independent and safe performance. SR Steultjens, 2004 A2 Gitlin, 2006

Other considerations

While the above studies focused on a general group of elderly or people with a history of falling, it is likely that the conclusions also apply to PwPs. This expectation is based on the working group's clinical experience and on findings that problems specific to Parkinson's, like freezing, are partly influenced by constraints in the physical environment.

Given the fact that many PwPs find it difficult to learn a new skill, the working group emphasizes the importance of providing the person with enough supervision in learning how to use the aid or adaptation.

Recommendation 22

It is recommended to advise a PwP and his caregiver(s) about modifications to the physical environment if these modifications promote the safety, effectiveness and efficiency of performing activities.

It deserves recommendation to accompany the advice about aids and environmental adaptations with instructions and training in their use.

5.4.10 *Advising and supervising caregivers*

Caregivers usually experience a heavy burden and need recognition and understanding for their situation. In caring for PwPs, the extent of functional limitations and the non-motor aspects are determining factors for the degree of caregiver burden experienced (see Chapter 2). A number of studies have shown that caregivers of PwPs need emotional support as well as information and advice on how to deal with specific problems (90;93;94).

The aim of interventions directed to the caregiver is, on the one hand, to maintain his well-being and, on the other hand, to increase his competence in dealing with and supervising the PwP. The question is which interventions the occupational therapist can use to contribute to this aim.

Key question 23

Which interventions can the occupational therapist use to optimally advise and supervise the PwP's caregiver?

Scientific basis

There are no occupational therapy studies which describe or evaluate specific interventions involving the caregivers of PwPs.

In other fields, a qualitatively sound study evaluated occupational therapy for dementia patients with dementia and their caregivers according to the standard for *Occupational Therapy in Older Persons with Cognitive Impairments*(117;207;208). This study showed that

this intervention is effective (as well as cost-effective) and, that three months after stopping there was an increased feeling of competence among caregivers and a reduced dependency of patients.

According to this standard, the consultation method is the theoretical framework for the manner of advising the caregiver (119). The basic assumption is that both the occupational therapist and the caregiver have their own expertise. The caregiver is regarded as an expert in his own situation and has an active role in solving problems, whereas the occupational therapist reinforces and enables the use of self-management.

The following interventions are used in advising and supervising caregivers according to the program for occupational therapy in dementia (119):

- The effect of the disease on meaningful occupational performance is explained in order to increase the insight into occupational performance and the behavior of the patient and caregiver.
- The caregiver is advised on possible ways of supervising and supporting the patient to optimize the meaningful occupational performance of the patient and to reduce the caregiver burden. Information is provided on the nature and extent of supervision and assistance needed by the patient to perform activities. This is followed by a discussion of what this means for the way in which the caregiver provides supervision. Specific competencies are discussed and practiced. The caregiver then has the opportunity to apply the new method of supervision. The occupational therapist evaluates the progress and experiences in a follow-up visit.
- Caregivers are encouraged and supervised to look for ways they can maintain or reacquire their own activities in order to achieve a better balance between strenuous and relaxing occupations. This may require providing information on the possibilities of daycare and assistance with caring for the patient. Referral to a social worker may be indicated.
- Advice is given on relevant aids, adaptations and other modifications to the physical environment which facilitate care or which increase the independence of the patient.

A program developed in the United States for supervising the caregivers of patients with dementia uses the same principles and types of interventions in the supervision of caregivers (209;210). This program has also had a positive effect on the caregivers' well-being and their interaction with the patient.

In the literature on caregiver burden in Parkinson's disease and dementia, the same aspects are experienced as highly burdensome and caregivers' occupational issues are largely comparable (211;212). Therefore, the expectation of the working group is that similar types of interventions can be effective for caregivers of PwPs. This expectation is confirmed for interventions aimed at self-management and looking for ways to maintain or reacquire one's own activities. Such interventions have been worked out in the Psychosocial Education Program Parkinson (PEPP), with which caregivers and PwPs have had a positive experience (see also Section 5.4.1) (180).

Conclusion

Level 1	It has been demonstrated that an occupational therapy intervention program partly aimed at advising and supervising the caregiver of patients with dementia is effective for reducing the caregiver burden. A2 Graff, 2006 and 2008, Gitlin, 2005 and 2003
Level 4	The working group believes that interventions that have proven to be effective for caregivers of dementia patients can also be effective for caregivers of PwPs. D working group

Other considerations

In recent years, there has been considerable interest in the supervision of caregivers in occupational therapy and many training programs now devote attention to it. In the Netherlands, occupational therapy can be indicated separately for the caregiver. Basic health insurance covers ten hours of occupational therapy per calendar

Recommendation 23

Depending on the occupational issues, it is recommended to use one or more of the following interventions to optimally advise and supervise a PwP's caregiver:

1. encouraging self-management strategies;
2. providing information to increase understanding of the effect of Parkinson's disease on meaningful occupational performance;
3. advising and training the caregiver in skills required to supervise, and support the patient;
4. advising the caregiver about relevant aids, adaptations and other modifications to the environment that can ease physical caregiving burden;
5. stimulate and advice the caregiver in looking for opportunities to maintain or reacquire activities.

5.5 Aspects related to planning the intervention

5.5.1 *Environmental setting*

The location of the occupational therapy intervention can depend on the personal possibilities of the patient, the intervention goals and the availability of occupational therapy in the patient's area. However, the question is what specific considerations apply to PwPs.

Key question 24

Which environmental setting is best for occupational therapy interventions involving PwPs?

Scientific basis

In addition to the finding that the occupational performance of PwPs is influenced by the environment and context, it is also reported that their ability to generalize is usually limited (41;42;158). For these reasons, experts state that it is best for training at the activity level to take place in the patient's own environment (41;42).

One study has specifically focused on evaluating the effect of a home-based physical therapy intervention on the quality of walking and transfers at home and in the hospital (196). This study found that the quality of transfers and walking at home had improved ($p < 0.0007$, total score on Parkinson Activity Scale 12.6% increase) six weeks after stopping the intervention. In the hospital, the improvement was far less significant ($p = 0.03$, total score Parkinson Activity Scale 5% increase). This study underscores the opinion of experts that the training effect is context-specific.

Conclusion

Level 3	There are indications that learned motor skills are better performed in the environment in which the PwP has practiced them. B Nieuwboer, 2001
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Other considerations

Occupational therapy intervention goals are aimed at maintaining or improving meaningful occupational performance and this is connected to the context in which the patients live and work. In light of the above conclusion, interventions in which skills and activities are practiced seem most appropriate in the context in which the occupational performance normally takes place.

Recommendation 24

It deserves recommendation to conduct the occupational therapy sessions in the relevant context (home, leisure or working environment) if the interventions are directed at improving activity performance or skills.

5.5.2 Time

Key question 25

What is an appropriate time of day for intervention sessions for PwPs with highly fluctuating performance?

Scientific basis

There are no studies which have compared the effectiveness of interventions during the *on* phase and the *off* phase. In the *Guidelines for Parkinson's Disease of the Royal Dutch*

Society for Physical Therapy (KNGF), it is recommended that the practicing of activities should take place during both the *on* phase and the *off* phase (11).

Conclusion

Level 4	Experts believe that PwPs should practice activities during both the <i>on</i> phase and the <i>off</i> phase. D Keus, 2004
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Other considerations

The working group is of the opinion that the aim of the intervention and the type of intervention determine the appropriate time of the intervention. It is preferable for strategies or alternatives to optimize occupational performance to be explained and taught during the *on* phase because this is when cognitive performance is optimal and the patient is more capable of processing new information. However, the application of alternatives and practice of new skills takes place at moments that the patient needs the strategies or alternatives most and this can be during either the *on* phase or the *off* phase.

Recommendation 25

When a PwP experiences response fluctuations, it deserves recommendation to plan the time of intervention such that:

- the learning of new strategies preferably occurs during the *on* phase
- the application of strategies and alternatives is preferably practiced at moments when strategies and alternatives are needed by the Pwp

5.5.3 *Delivery form*

An intervention can take place in groups or individually. Group intervention is usually financially attractive to the organization. The question is in which situations group intervention or individual intervention provide added value from the perspective of effectiveness.

Key question 26

What delivery format is preferable for the occupational therapy intervention: group intervention or individual intervention?

Scientific basis

There have been no studies which compare the effectiveness of group or individual intervention on PwPs. Regarding group interventions, an occupational therapy intervention program addressing self-management for PwPs and their caregivers is described in the literature (176). The subjective evaluation of the participating PwPs indicates that contact with other PwPs and learning from one another in the group was positively experienced. Whether this group intervention had a positive effect on the performance in meaningful activities in the patient's own context has not been studied.

Problems with alternating attention and generalization of learned skills to a new situation influence a PwP ability to learn (see scientific basis in Section 5.3). Considering this, the working group concludes that when the patient is required to apply performance skills in activities in his own context, individual intervention can be more effective than group intervention.

Conclusion

Level n/a	The added value of contact with other PwPs during a group intervention has not been studied regarding results in improved performance in meaningful activities in the patient's own context.
Level 4	The working group believes that, for PwPs, individual intervention is more effective than group intervention for learning to apply performance skills in activities in the patient's own context. D working group

Other considerations

The working group is of the opinion that group interventions can be useful when they involve the transfer of knowledge (e.g. what occupational therapy can offer or Parkinson's disease in relation to meaningful occupational performance) or the mutual sharing of knowledge and experiences. From practical experience, however, the working group observes that for some patients contact with other patients has a negative influence (i.e. when attention is severely affected)

Recommendation 26

Individual interventions are preferable above interventions in a group setting when interventions are directed at training occupational performance skills in activities.

Group intervention can be considered for programs that are aimed at providing information and exchanging experiences about general disease related problems or topics.

APPENDICES

Appendix 1 Contributors to the guideline

Commissioning party

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Project leaders

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- Dutch Parkinson's Disease Association (*Parkinson Patiënten Vereniging*): drs. P. Hoogendoorn, former chairman.
- Occupational therapy programs: Dr. J. Verhoef, occupational therapy instructor/researcher, Rotterdam University of Applied Sciences.
- Physical therapy: Drs S. Keus, physical therapist/researcher, Leiden University Medical Center (LUMC), 1st author of physical therapy guidelines (KNGF) and Cesar & Mensendieck exercise therapy (VvOCM) in Parkinson's disease.

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Secondary working group of occupational therapists:

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- Drs. H.M. Smeding, neuropsychologist, Academic Medical Center (AMC), Amsterdam.
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- Mrs. H.E.A. ten Wolde, social worker, Maartenshof *Nursing Home*, Groningen.

Patients and caregivers

A panel of four PwPs and two caregivers from the working group of the Dutch Parkinson's Disease Association.

Test group Version C:

- 55 occupational therapists from the ParkinsonNet regions of Alkmaar, Apeldoorn, Arnhem-Zevenaar, Ede-Wageningen, Delft, The Hague, Deventer, Doetinchem, Eindhoven, Haarlem, Gooi, Gouda, Nijmegen-Boxmeer, Oss-Uden-Veghel, Venlo, 's-Hertogenbosch, Zoetermeer, Zutphen.
- three occupational therapists from the Meander Medical Center, Amersfoort.

Test group Version D:

- 46 occupational therapist from the ParkinsonNet regions Bergen op Zoom, Breda, Heerlen-Kerkrade, Helmond-Geldrop, Hoorn, Maastricht, Roermond, Sittard-Geleen, Tilburg-Waalwijk, Weert, Zeeland-Noord, Zeeuws Vlaanderen (Terneuzen).

Miscellaneous

- Dr. J.J.A. De Beer, CBO, guideline development program.
- Mr. R. Aaldersberg, chairman, Parkinson's Advisory Council on Care.

Appendix 2 Medications for Parkinson's disease

Group	Effect	Substance name	Preparation
1. Levodopa	<ul style="list-style-type: none"> – combination of levodopa and decarboxylase inhibitor – reduces hypokinesia, muscle stiffness and, to a lesser extent, tremor – strongest medicine 	levodopa/benserazide	Madopar®
		levodopa/carbidopa	Sinemet®
		levodopa/carbidopa/entacapone	Stalevo®
2. Dopamine agonists	<ul style="list-style-type: none"> – dopamine receptor agonist: stimulates the dopamine receptors 	bromocriptine	Parlodel®
		pergolide	Permax®
		ropinirole	Requip®
		pramipexole	Sifrol®
		apomorphine (subcutaneous injection)	APO-go®
3. COMT inhibitors	<ul style="list-style-type: none"> – in combination with levodopa to reduce end-of-dose phenomenon 	entacapone	Comtan®
4. MAO-B inhibitors	<ul style="list-style-type: none"> – inhibits the breakdown of dopamine in the brain 	selegiline	Eldepryl®
	<ul style="list-style-type: none"> – extends and enhances the effect of levodopa when taken simultaneously 	rasagiline	Azilect®
5. Anti-cholinergics	<ul style="list-style-type: none"> – reduces almost exclusively tremors 	trihexyphenidyl	Artane®
	<ul style="list-style-type: none"> – occupies only a small space, particularly for young people, in the treatment of Parkinson's disease 	biperiden	Akineton®
6. Amantadine	<ul style="list-style-type: none"> – reduces muscle stiffness, hypokinesia, and, to a lesser extent, tremor – less efficacious than levodopa – fairly good effect on dyskinesias at later stage of disease 	amantadine	Symmetrel®

Side effects

The primary side effects are:

- confusion, hallucinations, delusions
- sleeping disorders
- response fluctuations (peak-dose dyskinesia and end-of dose akinesia)
- nausea, dry mouth, orthostasis

Directions

All medication should be taken with water or during a meal, except for levodopa preparations, which must be taken a half hour prior to a meal or a half hour after a meal, but not with protein-rich food (i.e. dairy products).

COMT inhibitors and MAO-B inhibitors should always be taken with the levodopa preparation.

Appendix 3 Caregiver burden interview

Interview purpose:

- to find out what the occupation and the role of the caregiver mean to the caregiver.
- to gain insight into the caregiver's values and standards (see guideline).

Sources for interview topics and sample questions:

- Mantelzorgers (Caregivers)(136).
- Standaard ergotherapie bij geriatrische patiënten met niet-ernstige cognitieve stoornissen en hun centrale verzorgers (*Occupational Therapy in Older Persons with Cognitive Impairments*)(119).
- Adviseren als ergotherapeut (Advising as an occupational therapist)(138).
- Psychosocial Problems in Parkinson's Disease (137).

The themes and questions below are not intended as a questionnaire and can be brought up in random order during the interview; this is guided by the caregiver's account. Asking for examples can often clarify the underlying idea. Imagery is often incorporated into the caregiver's account. It is important to remember this imagery and, where possible, to repeat it in the interview and inquire further about it. This provides a great deal of information about the caregiver's perception.

Theme: Physical burden

Sample questions:

"Can you describe an ordinary day?"

"Looking at your own daily schedule, for which activities of your do you provide assistance or support?"

"Do you find yourself physically capable of this?"

"In what way is it burdensome to you?"

"Would you want to change anything about this way of providing assistance/support?"

"What would you like to see changed/improved?"

Theme: Practical problems

Sample questions:

"Do you sometimes feel uncertain about your approach or how to deal with your"

"Do you sometimes feel that you lack the necessary knowledge or skills?"

"How do you solve it then?"

"How did you develop your own approach to dealing with your?" "Were you able to fall back on information or skills that someone had taught you?"

"Are there others who help you care for your?"

"Have you found there to be extra costs since your has had Parkinson's?"

“Can you give an example of that?”

“Do these extra costs affect your daily activities and/or chores?”

“Has your pleasure/satisfaction/perception also changed as a result?”

“Do you need any practical information at the moment?”

Theme: Psychological burden

Sample questions:

“Do you see caring for your as a burden?”

“What do you find to be the most difficult thing to deal with?”

“How would you describe this burden?” (Note: pay attention to imagery)

“How does this burden affect your own daily life?”

“Is there a way for you to deal with this burden?”

“Which of these ways is the most useful/effective for you?”

“Do you experience support in caring for your? (see also question about assistance in care)

“What does this support consist of?”

“Do you still have enough opportunity and space for your own activities?”

“How do you make sure of this and/or approach this?”

If the answer is no: “How do you deal with that loss?”

Theme: Relationships within the care context

Sample questions:

“Has your contact with your changed?”

“What do you see as the biggest change?”

“Has the interaction with people from your environment changed?” “Does this apply particularly to you or, or do you find that both of you are treated differently?”

“Are there people in your environment who have become more/less important?”

Appendix 4 Activity log: evaluation of activity patterns and fatigue

For each time period of the day (each half hour) and night (each hour), list your general activities and the times medication was taken. Then, under "Fatigue," rate how tired you are at that moment on a scale of 1 (not tired) to 5 (extremely tired).

Example

Time	Activity	Fatigue
07:30-08:00	Getting up, going to the bathroom	1 (2) 3 4 5
08:00-08:30	Getting and reading the newspaper	1 (2) 3 4 5
08:30-09:00	Showering and dressing	1 (2) 3 4 5
09:00-09:30	Making tea, eating breakfast	1 2 (3) 4 5

Day: Mon/ Tues/ Wed/ Thurs/ Fri/ Sat/ Sun Date: Name:

Time	Activity	Fatigue
		1 = not tired 5 = extremely tired
00:00-01:00		1 2 3 4 5
01:00-02:00		1 2 3 4 5
02:00-03:00		1 2 3 4 5
03:00-04:00		1 2 3 4 5
04:00-05:00		1 2 3 4 5
05:00-06:00		1 2 3 4 5
06:00-07:00		1 2 3 4 5
07:00-07:30		1 2 3 4 5
07:30-08:00		1 2 3 4 5
08:00-08:30		1 2 3 4 5
08:30-09:00		1 2 3 4 5
09:00-09:30		1 2 3 4 5
09:30-10:00		1 2 3 4 5
10:00-10:30		1 2 3 4 5
10:30-11:00		1 2 3 4 5
11:00-11:30		1 2 3 4 5
11:30-12:00		1 2 3 4 5

Time	Activity	Fatigue				
		1 = not tired				
		5 = extremely tired				
12:00-12:30		1	2	3	4	5
12:30-13:00		1	2	3	4	5
13:00-13:30		1	2	3	4	5
13:30-14:00		1	2	3	4	5
14:00-14:30		1	2	3	4	5
14:30-15:00		1	2	3	4	5
15:00-15:30		1	2	3	4	5
15:30-16:00		1	2	3	4	5
16:00-16:30		1	2	3	4	5
16:30-17:00		1	2	3	4	5
17:00-17:30		1	2	3	4	5
17:30-18:00		1	2	3	4	5
18:00-18:30		1	2	3	4	5
18:30-19:00		1	2	3	4	5
19:00-19:30		1	2	3	4	5
19:30-20:00		1	2	3	4	5
20:00-20:30		1	2	3	4	5
20:30-21:00		1	2	3	4	5
21:00-21:30		1	2	3	4	5
21:30-22:00		1	2	3	4	5
22:00-22:30		1	2	3	4	5
22:30-23:00		1	2	3	4	5
23:00-23:30		1	2	3	4	5
23:30-00:00		1	2	3	4	5

Times of medication intake

Medication	Time 1	Time 2	Time 3	Time 4

Appendix 5 Handwriting evaluation

Below is a selection of evaluation points from the Dutch protocol for the evaluation of handwriting, supplemented with specific points of attention for people with Parkinson's disease.

I) Identifying experienced writing problems

In the COPM interview handwriting can be identified as an occupational issue. Examples of additional questions are:

- What do you (or would you like to) use writing for?
- How important is writing to you?
You can ask the patient to score from 1 "unimportant" to 10 "very important."
Can you elaborate on this?
- How satisfied are you with your level of writing?
You can ask the patient to score from 1 "impossible" to 10 "very easy."
Can you elaborate on this?
- How satisfied are you with the handwriting result?
You can ask the patient to score from 1 "unsatisfied" to 10 "very satisfied."
Can you elaborate on this?
- How useful is handwriting to you?
Possibly ask the patient to score from 1 "useless" to 10 "highly useful."
Can you elaborate on this?
- How do you deal with problems in handwriting at the moment?
- What do you think of alternative options to handwriting? To what extent do you make use of these alternative options?
- What are your wishes and expectations with respect to handwriting?

II) Observation of writing posture

Writing hand: Left/right

Distance from nose to working surface

<input type="checkbox"/>	normal (=distance from wrist to elbow)
<input type="checkbox"/>	close
<input type="checkbox"/>	far

Sitting posture

<input type="checkbox"/>	normal (upright and a fist-length between trunk and table)
<input type="checkbox"/>	leans against the table
<input type="checkbox"/>	slumps
<input type="checkbox"/>	restless movement

Position of the trunk

<input type="checkbox"/>	normal (no movement of the trunk)
<input type="checkbox"/>	accompanying movement of the trunk
<input type="checkbox"/>	lateroflexion to the left/right

Position of the shoulder of the writing hand

<input type="checkbox"/>	normal, (horizontal shoulder line)
<input type="checkbox"/>	elevated
<input type="checkbox"/>	protracted
<input type="checkbox"/>	retracted

Progression of the arm

<input type="checkbox"/>	normal (combination of the below with the exception of the trunk)
<input type="checkbox"/>	from the thumb and fingers
<input type="checkbox"/>	from the wrist
<input type="checkbox"/>	from the elbow
<input type="checkbox"/>	from the shoulder
<input type="checkbox"/>	from the trunk

Location of forearm

<input type="checkbox"/>	normal (forearm and elbow on the table)
<input type="checkbox"/>	underarm without elbow on the table
<input type="checkbox"/>	only hand on the table

Position of wrist

<input type="checkbox"/>	normal (slight dorsiflexion)
<input type="checkbox"/>	mid position
<input type="checkbox"/>	palmar flexion/ulnar deviation
<input type="checkbox"/>	extreme dorsiflexion

Position of the hand i.r.t writing line

<input type="checkbox"/>	normal (non-inverted) = under writing line
<input type="checkbox"/>	smudge position = on the writing line
<input type="checkbox"/>	inverted = above the writing line

Contact of forearm with writing surface

<input type="checkbox"/>	normal (moves the paper)
<input type="checkbox"/>	wrist raised above the writing surface
<input type="checkbox"/>	entire forearm raised above the writing surface
<input type="checkbox"/>	

Use of non-writing hand

<input type="checkbox"/>	normal (moves and stabilizes the paper)
<input type="checkbox"/>	no function, either on/off of table
<input type="checkbox"/>	supports the head

Position of the upper arm

<input type="checkbox"/>	normal (slight abduction)
<input type="checkbox"/>	adduction
<input type="checkbox"/>	excessive abduction

Position of the forearm

<input type="checkbox"/>	normal (slight pronation)
<input type="checkbox"/>	mid position
<input type="checkbox"/>	excessive pronation
<input type="checkbox"/>	unstable forearm/wrist (pronation and supination)

Muscle tone

<input type="checkbox"/>	normal tone
<input type="checkbox"/>	reduced tone shoulder/forearm/hand
<input type="checkbox"/>	increased tone shoulder/forearm/hand

Mirror movements

<input type="checkbox"/>	not/hardly noticeable
<input type="checkbox"/>	occasionally noticeable
<input type="checkbox"/>	frequently noticeable
<input type="checkbox"/>	In: other hand/mouth/feet

III) Observation of pen grasp**Type of pen grasp**

<input type="checkbox"/>	dynamic tripod grasp
<input type="checkbox"/>	lateral tripod grasp
<input type="checkbox"/>	dynamic quadruped grasp
<input type="checkbox"/>	lateral quadruped grasp
<input type="checkbox"/>	interdigital tripod grasp
<input type="checkbox"/>	pen grasp with extended fingers
<input type="checkbox"/>	Other:
<input type="checkbox"/>	varying pen grasp

Pen pressure

<input type="checkbox"/>	normal pen pressure
<input type="checkbox"/>	inadequate pen pressure
<input type="checkbox"/>	excessive pen pressure

Position of the pen in the hand

<input type="checkbox"/>	distal to the MCP joint
<input type="checkbox"/>	at the MCP joint
<input type="checkbox"/>	in the web space

Dynamics

<input type="checkbox"/>	dynamic pen grasp (with thumb-finger movements)
<input type="checkbox"/>	static pen grasp (without thumb-finger movements)

Intensity of grasping

<input type="checkbox"/>	supple pen grasp
<input type="checkbox"/>	cramped pen grasp (hyperextension of DIP joint, white knuckles)
<input type="checkbox"/>	loose, unstable pen grasp

Shape of the web space

<input type="checkbox"/>	open, round
<input type="checkbox"/>	oval-shaped
<input type="checkbox"/>	closed

IV) Observation of paper position

In the box below, draw the position of the paper and reading text on the table

--	--

☐ regularly changes position of paper and/or reading text

Repositioning paper

☐ normal (shifts paper up with non-writing hand)
☐ does not reposition paper adequately
☐ does not reposition paper

V) Penmanship and graphomotor evaluation

Fluidness of the movement

☐ Fluid
☐ irregular, interruptions
☐ Shaky
☐ jerky
☐ spikes

Linear direction of sentence(s)

☐ normal
☐ up and down
☐ descending
☐ ascending

Pressure on the paper

By taking a photocopy of the written text, it is easy to see the pressure used while writing and the difference in pressure used for the various writing tasks.

☐ normal
☐ too hard
☐ very light

Pressure on pen

☐ normal ☐ hard ☐ much too hard

Space between letters and/or words

☐ even ☐ Variable ☐ highly variable

Size of the letters or other graphomotor output

☐ normal ☐ Irregular
from large to small ☐ inadequate

Type of script

☐ slanting to the left/right ☐ Upright
☐ separate, block letters ☐ Cursive ☐ composite

Legibility

☐ clearly legible ☐ Legible ☐ poorly legible

Writing speed

(for the formal, standardized test, see Handwriting Speed Test)

☐ normal ☐ irregular : delayed ☐ slow ☐ very slow
☐ irregular: accelerated ☐ fast/hurried ☐ very fast

Specific to Parkinson's disease:

Take into account any effects from *on* and *off* phases or medication.

Look at spontaneous penmanship/writing and look at the effect on the quality of the writing and writing result of:

- using visual cues, such as writing on lined or graph paper;
- increasing conscious and conscious attention by writing in a different script (block letters instead of cursive) or by focusing on writing large (exaggerated). (with the PwP instructing himself to write with large letters);
- writing during dual tasks (e.g. writing while talking on the telephone).

Appendix 6 Impairments scales

Below are examples of measuring tools that are frequently used to examine impairment in body functions in Parkinson's disease.

Test	Distinguishing characteristics
UPDRS (Unified Parkinson's Disease Rating Scale)	Specific to Parkinson's disease Test for measuring severity of disease <ul style="list-style-type: none"> I. Mentation, behavior and mood II. Activities of Daily Living (ADL) III. Motor examination IV. Complications of therapy V. Modified Hoehn & Yahr staging VI. Schwab & England ADL scale
SCOPA-AUT* (SCOPA= Scales for Outcome in Parkinson's Disease)	Specific to Parkinson's disease Test for autonomous impairments
SCOPA-COG* (SCOPA= Scales for Outcome in Parkinson's Disease)	Specific to Parkinson's disease Test for: <ul style="list-style-type: none"> • Memory • Attention • Executive functions • Visuospatial functions
SCOPA-Sleep* (SCOPA= Scales for Outcome in Parkinson's Disease)	Specific to Parkinson's disease Test for sleeping problems
H.A.D.S (Hospital Anxiety and Depression Scale)	Generic Self-evaluation questionnaire suitable for ruling out anxiety disorder and depression
B.D.I. (Becks Depression Index)	Generic Self-evaluation questionnaire for determining severity of depression
Berg Balance Scale	Generic Test for balance For details see the KNGF Parkinson's disease guideline

* available in English on www.scopa-propark.eu

Appendix 7 Assessment of the physical environment

Question	Points of attention
Does the PwP experience problems with the <i>accessibility</i> to and <i>mobility</i> throughout the buildings and rooms?	<p>This pertains to the independence and safety in moving towards the rooms that the person wants to or has to use. Note:</p> <ul style="list-style-type: none"> – nature and layout of the house or building – spatial arrangement of furniture and objects (amount of space for walking and turning) – width of passageways – floors or surface (degree of slipperiness, visual patterns and contrasts, loose mats) – doorsteps, steps or stairs – lighting – use of walking aids
Does the PwP have problems <i>using</i> facilities, furniture and tools?	<p>This pertains to the independence, efficiency and safety of use. Note:</p> <ul style="list-style-type: none"> – transfers (e.g. chair and/or couch, dining room chair, bed, toilet seat, shower and/or bath) – situations in which one has to bend over and/or reach far (e.g. picking up mail, getting things out of a closet, operating light switches) – situations in which time is a factor (e.g. location of telephone, bathroom)
Does the PwP have problems with respect to the <i>orientation</i> of the home, leisure or working environment?	<p>This pertains to the PwP being able to find his way around and locate things. Note:</p> <ul style="list-style-type: none"> – arrangement and layout of rooms and objects (logic, structure, visibility)
Are the <i>aids</i> and <i>adaptations</i> present adequate?	<p>This pertains to, for example, rise-and-recline armchairs, wheeled walkers, stairlifts, bed transfer aids, electric wheelchairs, hoists, mobility scooters. Note:</p> <ul style="list-style-type: none"> – Motivation and acceptance of using the aids and adaptations. – Safety and skill in use.
Can assistance be reached when necessary?	<p>This pertains to:</p> <ul style="list-style-type: none"> – Residence and accessibility of caregiver (during the day, at night) – Presence and location of telephone, alarm
Which necessary changes are possible in the environment?	<p>Depending on the problem, take note of possibilities for:</p> <ul style="list-style-type: none"> – changing the spatial layout and introducing structure – installing any visual cues – installing support points – raising furniture – installing places to sit – changing lighting – using aids

Appendix 8 Examples of cognitive movement strategies

According to: *Guidelines for Parkinson's Disease from the Royal Dutch Society for Physical Therapy* (KNGF), 2004 [11]

Sitting down

- Approach the chair with firm steps, at a good pace;
- Make a wide turn in front of the chair and stop right in front of it: you should have the feeling that you are walking around something (practice this first, for example with a cone in front of the chair and later without the cone); if necessary, turn at the rhythm (with a cue) that you already used when approaching the chair.:
- Place your calves or the backs of your knees against the seat;
- Bend slightly forward and bend your knees, keep your weight well above your feet;
- Move your hands towards the armrest or seat, seek for support with your arms;
- Lower yourself in a controlled fashion, sit down well, at the back of the chair.

Standing up from a chair

- Place your hands on the armrest or side of the seat of the chair;
- Move your feet towards the chair (just in front of the chair legs, two fist-lengths);
- Shift your hips forward to the edge of the chair;
- Bend your trunk (not too far, with your nose above your knees);
- Rise gently, from your legs, let your hands lean on the armrest, seat or your thighs and then straighten out your trunk fully (if necessary, use a visual cue as a target). If you have trouble starting to rise, first rock back and forth a number of times and rise at the count of three.

Standing up from the floor after a fall

Rest a bit after the fall

- Turn from a lying position, through a side-sit (pushing up your trunk with a hetero-lateral arm and homo-lateral elbow support) onto your hands and knees;
- Crawl towards an object which you can use to pull yourself up (e.g. chair, bed);
- Bend your strongest leg and place the opposite arm on the object (rifleman's position)
- Push yourself up with your legs and arms.

Getting in and out of bed and turning over in bed

General tips:

- Use a nightlight so that visual feedback is possible.
- Use light blankets or a comforter and smooth sheets.
- Wear smooth pajamas (e.g. satin) and socks for more grip.
- Make sure the height of the bed is not too low.
- Other aids may be recommended by the occupational therapist.

Getting into bed

It is important to first fold down the covers to the foot of the bed (like an accordion); the top edge of the cover points in the direction of the headboard so that you can pull it easily over you.

Getting into bed, Option 1

- Approach the bed with firm steps, using a rhythmical cue if necessary, and make a wide turn in front of the bed (not over one leg); continue walking until you feel the edge of the bed against your calves or the backs of your knees;
- Sit down on the edge of the bed (keeping enough distance from the pillow);
- Lower your upper body towards the pillow, placing your weight on your elbow;
- Lift your legs up onto the bed, one by one, into a side-lying position;
- Grab the covers with your free hand;
- Lower your upper body onto the mattress and assume a comfortable lying position by moving your backside;
- Pull the covers over your body.

Getting into bed, Option 2

- Approach the bed head-on with firm steps, using a rhythmical cue for if necessary;
- Bend forward, support yourself on the mattress with your hands and crawl onto it so that you are on your knees halfway down the length of the mattress;
- Lie down on your side (ensure your head will reach the pillow);
- Grab the covers with your free hand and pull them over your body.

Getting into bed, Option 3

- Approach the bed with firm steps, using a rhythmical cue if necessary, and make a wide turn in front of the bed (not over one leg); continue walking until you feel the edge of the bed against your calves or the backs of your knees;
- Sit on the bed, with sufficient distance and in diagonal direction to the pillow, , leaning back on your arms;
- Place your legs on the mattress, one by one, turn until you are lengthwise on the mattress;
- Grab the covers at the foot of the bed, slide your feet under them;
- Slowly lower yourself backwards until you are lying on your back, while holding onto the covers and pulling them over your body.

Turning over in bed

Turning over in bed from a supine position, Option 1: using head/shoulders

- Move the cover to the side opposite of where you are turning;
- Lift the cover up with your arms, pull up your knees while on your back, then put your feet flat on the bed;
- Move your body sideways, alternating your feet, pelvis, head and shoulders, in the opposite direction of the turn;
- Place your arm (on the side you are turning towards) next to your head in a flexed position, then turn your head and shoulders, using your free arm to direct yourself;
- Next, lower your knees in the direction of the turn, freeing up space, if necessary, under the covers with your free arm;
- Adopt a comfortable position.

Turning over in bed from a supine position, Option 2: using legs/pelvis

- Move the blanket to the side opposite of where you are turning;
- Lift the blanket up with your arms, pull up your knees while on your back, then put your feet flat on the bed;
- Move yourself to the edge of the bed (alternating your feet, pelvis, head and shoulders) in the opposite direction of the turn;
- Place your arm (on the side you are turning towards) next to your head in a flexed position;
- Pull up your knees as far as possible towards your chest with your feet on the mattress and allow yourself to fall in the direction of the turn (if necessary, lift the blanket with your free arm), continue rolling with your pelvis;
- Follow with your head and shoulders and free arm;
- Adopt a comfortable position.

Turning over in bed from a supine position, Option 3: using an arm swing

- From a supine position, lift the cover up with your arms and pull up your knees, then put your feet flat on the bed;
- Move yourself to the edge of the bed (alternating your feet, pelvis, head and shoulders) in the opposite direction of the turn;
- Stretch out one or both arms vertically;
- Pull your knees up if you prefer;
- Make a rolling motion with your entire body using an arm swing;
- Adopt a comfortable position.

Getting out of bed from a supine position

Getting out of bed, Option 1

- Move your body a little away from the middle towards the edge of the bed;
- Roll onto your side (see rolling over in bed);
- Pull your knees further towards your chest;
- Push back the covers;
- Place your top arm next to your bottom shoulder; slide your feet over the edge of the bed and at the same time push yourself up with both arms (using the elbow of your bottom arm as a support and placing your top arm halfway);
- Next: see going from a sitting to standing position

Getting out of bed, Option 2

- Bend your knees and put your feet flat on the bed;
- Move yourself to the edge of the bed (alternating your pelvis, shoulders and feet) in the opposite direction of the turn;
- Push back the covers;
- Slide your feet over the edge of the bed and push yourself up with your bottom arm (placing your top arm halfway across the elbow of your bottom arm);
- Next: see going from a sitting to standing position

Getting out of bed: from sitting on the edge of the bed into a standing position

- Sit up straight on both buttocks;
- Support yourself with your arms, placing your fists slightly behind your body;
- Shift your backside towards the edge of the bed;
- Take support with your arms on the edge of the bed;
- Place your feet right in front of the bed, roughly 8 inches apart;
- Bend forward (with your nose above your knees);
- Stand up from your legs, rocking back and forth if necessary.

Appendix 9 Modifying the physical environment

General advice aimed at	Specific examples
Creating an unobstructed walking and turning route.	<ul style="list-style-type: none"> • Rearranging furniture. • Reducing the number of objects in a room.
Removing potential obstacles	<ul style="list-style-type: none"> • Removing loose mats. • Removing loose cords lying across walking routes.
Introducing structure and overview	<ul style="list-style-type: none"> • Organizing closets according to a clear structure. • Storing items necessary for an activity all in a set place. • Reducing the amount of things in one spot.
Recommending the use of visual reminders	<ul style="list-style-type: none"> • Putting labels or color codes on closets. • Using a bulletin board, calendar or schedule planner.
Rearranging things based on ergonomic principles	<ul style="list-style-type: none"> • Storing all items necessary for an activity in a set place near to the workspace. • Placing things in such a way that bending over or reaching far is not needed.
Setting up visual cues	<ul style="list-style-type: none"> • Taping lines to the floor in front of a closet to indicate the turning route. • Hanging a mirror at a particular height in the bathroom to encourage standing up straight. • Laying tiles in a particular pattern in the garden.
Creating support points and places to sit or improving postural support	<ul style="list-style-type: none"> • A chair in the bedroom for sitting on while dressing. • A handle around the sink to hold on to. • A support post next to the bed for the transfer. • A chair with better upper body support.
Increasing the transfer height	<ul style="list-style-type: none"> • Raising the bed/chair/couch. • A raised toilet bowl. • A car with higher point of entry.
Recommending aids, adaptations and tools	<ul style="list-style-type: none"> • A clothes hook to make it easier to put on and take off a jacket. • A motorized bike or a mobile scooter. • A software program to reduce the effect of tremors on mouse use.
Making materials heavier or lighter	<ul style="list-style-type: none"> • A heavier utensil if this reduces the effect of a tremor. • Lighter pans in the case of reduced strength.
Changing the size and shape of objects	<ul style="list-style-type: none"> • Gardening tool with a long handle to enable working while standing upright. • A knife with an enlarged handle. • Changing fasteners in the case of permanent problems in fine motor function.
Changing the structure of materials	<ul style="list-style-type: none"> • Using satin bottom sheets to facilitate turning over in bed. • Using a jacket with satin inner lining to make it easier to put on.
Installing good lighting	<ul style="list-style-type: none"> • Nightlight next to the bed. • Good lighting on route to the bathroom.

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