

European Physiotherapy Guideline for Parkinson's Disease

Developed with twenty European professional associations



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Available for downloading at www.parkinsonnet.info/euguideline are

- Guideline (this document)
- Guideline information for people with Parkinson's
- Guideline information for clinicians
- Development and scientific justification

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Preface

We are pleased to present you with the first European Guideline for Physiotherapy in Parkinson's disease, and hope this document will support the judgements and decisions you make during your clinical practice with people affected by Parkinson's disease. Professional associations from 19 European countries have joined their forces to develop this Guideline. It is an example of the standing of physiotherapy profession in this clinical area of neurological practice.

In this Guideline, you will find currently available evidence-informed material to answer questions that you might have. This includes evidence from good clinical research, expert opinion from physiotherapists across Europe, and preferences of people with Parkinson's disease to treatment and management options. To optimise the use of this Guideline, we have attempted to keep it short, simple and written in a manner that assists clinical decision-making towards patient-centred care and that helps establish good communication between those involved in the management of the condition.

Even though this Guideline primarily targets physiotherapists, it includes specific information for policy makers, other health professionals and for people with Parkinson's disease. All these groups of people are essential for the implementation of best physiotherapy practice with Parkinson's disease. Examples of information physiotherapists may wish to share with other groups include the information supporting people with Parkinson's disease in taking an active role in their health management and the criteria for referral to physiotherapy. For this reason, documents specifically developed for people with Parkinson's and for clinicians are available at www.parkinsonnet.info/euguideline.

Where to start? Chapter 1 provides a reading indication for all groups of intended users. However, even if you are a physiotherapist with extended Parkinson-expertise, we still advise that you familiarise yourself with the entire document and use it as a reference guide to update specific aspects of your knowledge and practice as need arises.

Finally, do keep in mind that any guideline is a decision-supporting tool, and not a protocol or a cookbook with recipes for practice. This Guideline requires that physiotherapists complement it by using their professional expertise to ensure a high standard of physiotherapy management for people with Parkinson's disease throughout Europe.

We hope you will find it of use in your practice.

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In alphabetical order

*contributed financially to the Guideline development

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Finland

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Belgium

Axxon*



France

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Cyprus

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Chapter 1

About this Guideline

1.1 A reading indication for all target groups

This Guideline aims to support decision making for physiotherapy practice in Parkinson's disease. It thereby supports people with Parkinson's disease (pwp) from the point of diagnosis onwards to manage their movement related impairments and activity limitations and focus on goals that are important to them. It is expected that the audience (or readership) of this Guideline are not just physiotherapists, but also pwp and other health professionals. Each person may use this Guideline in a different way, based on his or her profession and personal expertise.

Physiotherapists

The Guideline Development Group (GDG) primarily developed this Guideline for physiotherapists, irrespective of their work setting. By studying and using this Guideline, therapists can obtain knowledge that helps them improve practice with pwp. Given the complexity of Parkinson's disease, in aiming to provide optimal care, the GDG advises that physiotherapists receive education specific to the correct use of this Guideline, collaborate with other Parkinson's expert health professionals, and assess and treat sufficient pwp annually to upkeep their skills and knowledge. Chapters 4 to 7 describe physiotherapy for pwp. Helpful pintables are available in the Appendices 1 to 6.

As a reading indication:

- Chapter 2, About Parkinson's disease, is the advised starting point for physiotherapists with limited Parkinson's specific knowledge
- Chapter 4, Physiotherapy for people with Parkinson's disease is the advised starting point for physiotherapists with sufficient Parkinson's specific knowledge, but with little experience in treating pwp
- Chapter 7, GRADE-based recommendations for each physiotherapy core area and the Quick Reference Cards (at the back of this Guideline) are the advised starting points for physiotherapists with extensive Parkinson's specific knowledge and skills aiming to use this Guideline to evaluate their current practice

For people with Parkinson's disease and their carers:

- Appendix 1 provides Information on movement related self-management and what to expect from physiotherapy
- Appendix 2 provides a Pre-assessment Information Form useful when referred to a physiotherapist
- Appendix 3 provides information for carers and home care professionals

Also available in a larger font size in a separate pdf file, available for downloading at www.parkinsonnet.info/euguideline

For neurologists and other health professionals:

- Information for clinicians: referral criteria
- Information for pwp: self-management support, carer information and the physiotherapy Pre-assessment Information Form

Available as separate pdf files, available for downloading at www.parkinsonnet.info/euguideline

- Appendix 11, A model for collaborative Parkinson's care

For decision support, this Guideline provides recommendations and advice. Recommendations are based on a systematic search, selection and appraisal of evidence. Advice is based on scientific evidence combined with clinical expertise of Parkinson-expert physiotherapists.

To optimise usability of this Guideline, Information for people with Parkinson's, Information for clinicians and Development and scientific justification plus a weighing of the benefits and burdens are available as separate pdf files, available for downloading at www.parkinsonnet.info/euguideline. Here you will also find an overview of and links to official translations of this Guideline, as well as supportive materials.

1.2 Limitations of this Guideline

The methods used to develop this Guideline ensure that the GDG systematically collected, selected and appraised the best research evidence available and agreed as appropriate with clinical experts and pwp. Therefore, physiotherapists should apply the recommendations in order to deliver optimal care. The recommendations will be applicable to the majority of pwp. However, as is the case with all evidence-informed guidelines, there will always be individuals and situations for which the recommendations are not applicable¹. This can be partly explained by the fact that in research many pwp are excluded because of age or cognitive impairments². Physiotherapists may choose to disregard the recommendations provided in this Guideline based on their professional judgement and autonomy. This Guideline does not override the individual responsibility of health professionals to make appropriate decisions based on the circumstances of the individual, in consultation with the pwp and their carers. However, in case of deviation, this should be justified and documented.

1.2.1 Atypical parkinsonisms

The recommendations of this Guideline are based on research and clinical practice in (idiopathic) Parkinson's disease. They do not automatically apply to the less prevalent atypical parkinsonisms, such as vascular parkinsonism, progressive supra-nuclear palsy (PSP), multiple system atrophy (MSA) and parkinsonism caused by medication. Most controlled clinical trials exclude people with forms of parkinsonism other than Parkinson's disease from participation in. Evidence for the efficacy of physiotherapy in this group is therefore insufficient. A large, non-controlled trial did show benefits of a one to six weeks, high intensity (3 hours per day on five to seven days a week), interdisciplinary rehabilitation program which included cueing and strategies for complex motor sequences as described in this Guideline³. Clinical experts however suggest that the response to physiotherapy intervention in this group is less marked than with pwp.

People with atypical parkinsonisms can exhibit clinical features similar to Parkinson's disease, but can also show significant differences, such as on average a faster progression, absence of or limited response to anti Parkinson medication and a shorter survival period. The symptoms are often characterised by a range of additional neurological problems such as cerebellar ataxia and spasticity. These are not addressed in this Guideline. In addition, many people with atypical parkinsonisms, specifically PSP and vascular parkinsonism, often have prominent cognitive decline at an early disease stage. This has implications for the treatment options, such as the applicability of cognitive movement strategies, and the advice required. People with PSP often show 'motor recklessness' and concomitant injurious falls⁴. In these persons, usually a limitation of activities will have to take place. On the other hand, some persons with atypical parkinsonisms show particular impairments or limitations that are similar to those of Parkinson's disease. If these persons also have sufficient mental function to comply with treatment, recommendations of this Guideline may be applicable. Experts however expect that the benefit of the interventions have a shorter duration. Appendix 8 provides a detailed overview of red flags in the medical diagnoses of Parkinson's disease⁴.

1.2.2 Multi-morbidity and co-morbidities

Parkinson's disease is a multi-morbid condition with pwp facing a variety of Parkinson-related impairments in functions and activity limitations (Appendix 9). In addition, many pwp will have co-morbidities. More than their contemporaries, pwp are prone to sustain broken bones and hips, specifically in the presence of dementia⁵. Other co-morbidities common to pwp and of importance to decisions in physiotherapy care are arthritis, heart circulation problems (predicting a delayed memory recall) and diabetes⁵⁻⁸. Therapists should therefore always recognise that most pwp have several medical problems rather than one disease⁹. Often it is not clear which impairments and limitations are caused by the disease itself, which by the treatment, and which by other conditions. Given this complexity, it is important that therapists have sufficient knowledge and skills to ensure chronic disease management: knowing how different diseases interact (particularly physical and mental health disorders), to help pwp to make decisions about their health care in the face of competing priorities and to support pwp self-management⁹.

For several co-morbidities, mono-disciplinary guidelines are available, such as on osteoporosis, pelvic floor problems, neuropathic pain and training of physical capacity. Chapter 5.13 provides suggestions for intervention adjustments when specific co-morbidities are present.

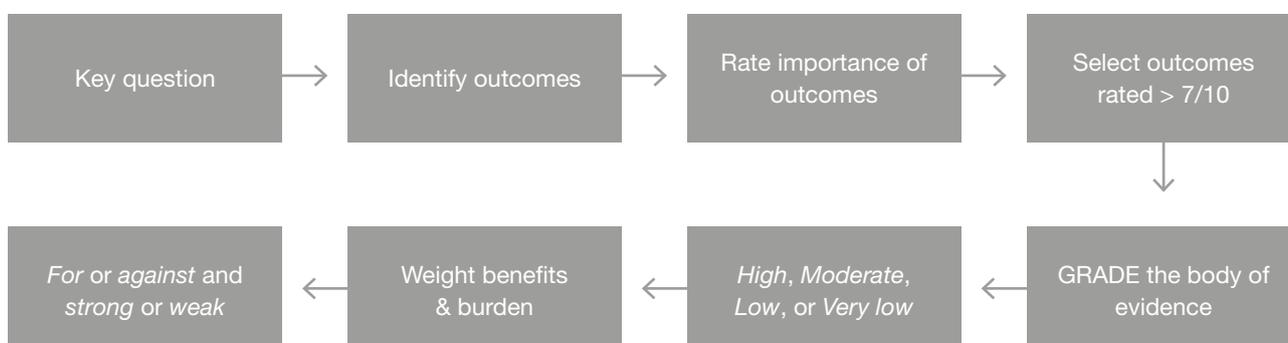
1.2.3 Exclusions

- The GDG advises pwp with urologic impairments and limitations to consult a physiotherapist with specific pelvic floor-expertise as these problems are of a specialist nature. Currently, controlled clinical trials regarding physiotherapy interventions for pelvic floor impairments and limitations specifically in pwp are unavailable.
- Even though writing limitations are part of manual activities (one of the core areas in this Guideline), and can be a target for physiotherapy, they are not included in this Guideline as they are extensively covered in the Occupational Guideline for Parkinson's disease¹⁰.

1.3 Development of this Guideline

The GDG developed this Guideline according to international standards for guideline development, addressing all items of the Appraisal of Guidelines for Research and Evaluation Instrument (AGREE, www.agreetrust.org) and using 'Grading of Recommendations Assessment, Development and Evaluation' (GRADE) to develop the recommendations.

Fig. 1.3 From key questions to recommendations



1.3.1 The Guideline Development Group

As a first step, the GDG gained insight into barriers physiotherapists currently experience when wishing to provide care to pwp. These were identified by means of a web-based survey in which 3,405 physiotherapists throughout Europe participated and by means of focus groups with 50 expert users of the 2004 KNGF Guideline. In addition, barriers in current care reported by pwp and therapists were identified in the international literature

The barriers were transformed into key questions to be addressed in the Guideline. For this, controlled clinical trials (CCTs) were systematically searched for, selected and appraised. Of the 122 CCTs identified, the GDG excluded 52 for various reasons²⁴⁻⁷⁵. The GDG categorised the 70 remaining CCTs according to the evaluated physiotherapy interventions (Table 1.3.1)⁷⁶⁻¹⁴⁵.

Table 1.3.1 Categories of physiotherapy interventions for pwp

- Conventional physiotherapy
- Treadmill training
- Cueing
- Strategies for complex motor sequences
- Massage
- Martial arts
- Dance

The GDG classified the outcomes used in the selected CCTs into capacity or performance measures on the different International Classification of Functioning (ICF) domains and scored the importance of the classes of outcomes. Only outcomes with a mean score of 6.5 or above on a scale of one to 10, that is critical outcomes, were used for the evidence grading. Next, the GDG extracted all trial details necessary for the grading process and graded the quality of the evidence for each question and outcome: high, moderate, low or very low. To intervention effect was estimated by means of a meta-analysis. Finally, the GDG graded the recommendations as 'strong' or 'weak'. This strength reflects the generalisability of the effects amongst all pwp; the extent to which the benefits of the intervention outweigh undesirable effects (such as falls, burden of treatment and costs); the availability; and the values and preferences of patients and therapists, if known¹⁴⁸.

More details to the Guideline development and scientific justification are presented in a separate pdf file, available for downloading at www.parkinsonnet.info/euguideline.

1.3.2 Selecting physiotherapy measurement tools

Use of measurement tools supports structured, objective and transparent assessment, evaluation and communication. However, this only is the case when appropriate tools are selected and the results well interpreted. The GDG has selected outcome measures for use in routine practice in individual pwp.

To determine the final set of tools, first the GDG checked the overview of tools recommended in the current Guideline¹⁴⁹, identified through the European survey¹¹ or focus groups with Parkinson expert physiotherapists for completeness. Of all 37 identified tools, the GDG gathered information regarding psychometric properties: validity, reliability, responsiveness and interpretability, as well as and feasibility to use (Table 1.7)¹⁵⁰. Based on these properties, the GDG selected the final set of recommended tools.

Given the focus of physiotherapy treatment and communication, tools on the activities and participation component of the ICF are considered preferable. The majority of tools available were developed for the benefit of scientific research and are focused on use in groups of pwp. The value of these instruments for indication and evaluative purposes in individual pwp is still unclear and may lead to false security. As a rule of thumb, when used in single pwp, these tools are less responsive because the measurement error in a single person is larger than it is in groups. Consequently, a single pwp a change in activity limitations needs to be larger in order to be picked up by the than it needs to be in groups of pwp.

Table 1.3.2. Selection criteria for measurement tools

Criteria	Meaning
Validity	Does it measure what it is supposed to measure? Does it have the same meaning for pwp? Is it within the scope of physiotherapy for pwp? Is it linked to the level of limitations in activities domain of the ICF?
Reliability	Are results consistent when used in consistent conditions?
Responsiveness & interpretability	Can it detect change over time? Can we assign a qualitative meaning to the (change in) quantitative scores?
Feasibility	Do benefits outweigh the burden in terms of costs, time, space and effort? Is it currently used by (many) physiotherapists? Is it available in many languages?

1.3.3 Update of this Guideline

Planned at the latest by 2019. The copyright holder of this Guideline will decide whether the Guideline needs an update. This depends on the amount and strength of new scientific evidence, changes in barriers in current care or changes in the organisation of care. New evidence will be appraised conforming methods used for this Guideline by a writing group assigned by the copyright holders. All participating associations will be offered the possibility to participate in this process. At www.parkinsonnet.info/euguideline, the users of the Guideline will be invited to share their experience and knowledge.

1.4 Implementation of this Guideline

1.4.1 Striving for equality of care throughout Europe

Currently, the delivery of allied health care services to pwp is inadequate and many people who require such care are not being referred to the relevant specialist.^{151;152} Even when clinical practice guidelines are available, management practices often do not match their recommendations^{11;153;154} The European Parkinson's Disease Standards of Care Consensus Statement provides practical help to ensure equal access for pwp to good quality and specialised care across Europe.¹⁵⁵ Essential to this is the implementation of evidence-informed guidelines.¹⁵⁵

This Guideline provides decision support for physicians who need to know when to refer; for physiotherapists who need to know what to assess, advise, coach and train, when and how; and for pwp who need to know what they can do themselves, when and how, but also when to ask for physiotherapy and what to expect. The GDG advises pursuit in addressing the identified barriers and suggestions for improvement when implementing this Guideline.

1.4.2 Translation, adaptation, education

In this joint collaboration, the representatives of the 19 participating countries have aimed to develop a Guideline feasible for use throughout Europe. The GDG strongly recommends translation and adaptation of this Guideline to optimise implementation. To assure quality and transparency of translation, the copyright holders of this Guideline and, if available, a member of the GDG whose mother language equals the language for the translation (that is a native speaker), must be involved in these processes. The GDG group member will check for clear language, correct use of terminology and jargon, as well as the overall message of the Guideline. Translation needs to be done by a highly educated, native speaker experienced in translating texts from English; preferable by an official translator. After a check for spelling, grammar, style and consistency, the translated text should be reviewed by a panel of native speaking physiotherapists to evaluate understanding and ease of use. If required, the translation should be adjusted.

Tools need to be understood in the same way in different languages and cultures. Therefore, aiming to support equal implementation of tools throughout Europe, the GDG has searched for measurement and assessment tools available in several European languages and of which psychometric properties have been confirmed in different populations. For these tools, the GDG assumes that a forward-backward translation into again another language is likely to leave psychometric properties unchanged, at least the validity. Otherwise, a standardised validation process is required, with pwp being native speakers of the language being tested¹⁵⁶. This pwp sample should include samples from different ages, genders, severities of PD and educational levels (conform MDS standards: http://www.movementdisorders.org/about/updrs/non-english_translation.php). This is a time consuming process. The GDG expects that this is more important for questionnaires than performance based tests. Moreover, non-official versions could be available. However, the GDG advises to be cautious about making conclusions when using non-official versions and not to use them for evaluation purposes.

To endorse implementation, the copyright holders encourages adapting the format and cover of translated and adapted versions of this Guideline to local, regional or national standards and preferences. Moreover, when the feasibility of the recommendations is limited by contextual or cultural issues, development of amendments to tailor the Guideline to the national situation is advised. ParkinsonNet and the APPDE may be contacted to provide collaborative support towards education related to the implementation of this Guideline.

The GDG strongly recommends translation and adaptation of this Guideline to optimise implementation. To assure quality and transparency of translation, the copyright holders of this Guideline must be involved in these processes

1.4.3 ParkinsonNet

Since the publication of the 2004 KNGF Guideline in the Netherlands the ParkinsonNet implementation strategy has been developed. ParkinsonNet provides Parkinson's-specific training to selected health professionals, re-organises allied healthcare to increase the treatment volumes of therapists and makes expert health professionals visible to other professionals as well as to pwp.¹⁵⁷ It also supports communication amongst health professionals as well as between professionals and pwp.¹⁵⁸ To achieve this, within the catchment region of a hospital, dedicated physiotherapists are selected (through an open invitation to all therapists present in the region) to receive (continuous) training to work according the Guideline. Communication amongst the therapists, as well as with other health professionals and pwp is supported, such as through (educational) meetings and a secured web-based community. The expert therapists are visualised by web-based sources and printed folders, and preferred referral is supported. Evaluation has shown that ParkinsonNet doubles treatment volumes even within a short period of six months (the study period) and increases the quality of physiotherapy care, whilst reducing costs.¹⁵⁹ Moreover, evaluation of the connectedness of health professionals within the ParkinsonNet showed that especially therapists

treating more than nine pwp a year were associated with stronger connectedness with other health professionals than those treating less than 10 pwp a year. As connectedness between professionals is known to influence clinical decision making and the coordination of patient care, this knowledge is of high importance to the size of future networks.¹⁶⁰ Supported by the positive results, ParkinsonNet was endorsed by professional healthcare organizations and the Dutch national Parkinson Association. In 2010, national coverage within the Netherlands was achieved by 65 unique, multidisciplinary Parkinson's specific networks. Currently, ParkinsonNet is supporting re-organisation of Parkinson care and the implementation of evidence-based Parkinson guidelines in Germany and the U.S.A.

The GDG recommends that national professional and Parkinson associations collaborate to initiate implementation of this Guideline by taking advantage of the lessons learned from ParkinsonNet (Table 1.4.3). Specific attention is needed for care in institutionalised, long term care facilities, where care for pwp is generally suboptimal¹⁶¹.

GDG advice: Recommended steps to consider for guideline implementation

<i>What</i>	<i>How</i>
<i>Service concentration</i>	<i>Increasing treatment volumes allows physiotherapists to specialise in Parkinson's; ensure a good geographical dispersion so pwp can be visited at home</i>
<i>Education</i>	<i>Continuously train (selected) therapists in use of the guideline, using in-person courses, e-learning, illustrative materials on exercising and functional movement</i>
<i>Collaboration & communication</i>	<i>Support preferred referral to the expert therapists to increase treatment volumes; involve pwp in the implementation process, such as through publications, meetings and materials Support communication and collaboration amongst the expert therapists, as well as with other health professionals and with pwp, such as by organising network meetings and web-based facilities</i>
<i>Visibility</i>	<i>Make the expert therapists known to other health professionals and to pwp, for example by using printed information or an online search engine</i>

Chapter 2

About Parkinson's disease

Parkinson's disease is a progressive, neurodegenerative disease. Due to its complexity, it puts a high burden on people with Parkinson's disease, their families and society.

2.1 Epidemiology and costs

Parkinson's disease is the second most common neurodegenerative disease following Alzheimer's disease. Approximately 1.2 million people live with Parkinson's disease throughout Europe¹⁶². In Western Europe's five most populous nations, the number of pwp over age of 50 years was estimated in the United Kingdom (UK) at 90,000; Germany 110,000; France 120,000; Italy 240,000; and Spain 260,000¹⁶³. These numbers will double by 2030 as our population is ageing¹⁶³. The incidence is approximately 1.5 times higher in males than it is in females.¹⁶⁴ Most people with Parkinson's disease (pwp) have received their diagnosis Parkinson's disease when they were older than 60 years; in around 5%, pwp were younger than 40 years. Consequently, the prevalence increase with age, from about 1.4% over the age of 60 to about 4.3% over the age of 85^{165;166}.

With an estimated annual cost of €13.9 billion across Europe the economic impact of Parkinson's disease is enormous^{162;167}. Overall cost estimates vary from country to country, but the largest component of direct cost is typically inpatient care and nursing home costs¹⁶⁸. In addition, high indirect costs arise from lost productivity and carer burden¹⁶⁸. The costs increase with disease progression, from €5,000 per pwp per year in the early stage of the disease, to over €17,000 in the end stage^{14;168;169}.

2.2 Pathophysiology: environmental and genetic factors

Because of an unknown cause, dopamine-producing cells in the substantia nigra progressively degenerate. Epidemiologic studies have consistently found a positive association between Parkinson's disease and pesticides¹⁷⁰, but also a negative association with cigarette smoking¹⁷¹. The explanation for the inverse association with smoking is not clear yet. Motor impairments and limitations may make it difficult to smoke¹⁷²; not starting to smoke in early adult life may be an early sign for Parkinson's disease¹⁷²; or nicotine may have a protective effect against the development Parkinson's disease¹⁷³. In 5% to 10% of all pwp, genetic mutations are responsible. The likelihood of a genetic variant is larger in cases of onset before 40 years and a positive family history.¹⁷⁴ Genetic and environmental factors are now thought to interact and increase the risk of an individual to develop Parkinson's disease.¹⁷⁴ The degeneration of cells leads to decreased levels of dopamine in projections from the substantia nigra to the striatum, frontal lobes and limbic circuitries.¹⁷⁵ Over time, lesions in non-dopaminergic brain areas (such as the locus coeruleus and the pedunculopontine nucleus) play an increasing role.¹⁷⁶ For such varied reasons, Parkinson's disease has a complex phenotype.

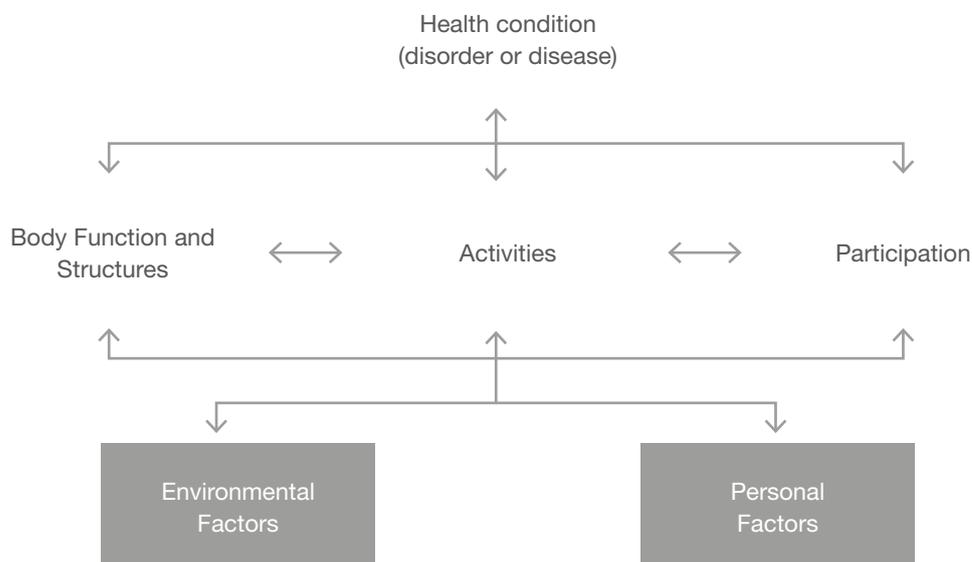
2.3 Diagnosis

The diagnosis is primarily based on clinical criteria: presence of bradykinesia and the progressive reduction of speed and amplitude of repetitive movements^{177,178}. In addition, rigidity, rest tremor or postural instability needs to be present and the so-called red flags need to be absent. The red flags include a symmetrical start of symptoms, falls within the first year and no response to levodopa (Appendix 8).⁴ Even though MRI is supportive, no test or assessment can fully differentiate between Parkinson's disease and atypical parkinsonism. Parkinson's disease can only be diagnosed with 100% certainty via post-mortem examination of the brain^{179,180}. In the early stages particularly, the symptoms of Parkinson's disease and atypical parkinsonism can closely resemble each other (10-20% overlap)⁴. Not surprisingly, in the community, up to 35% of pwp are misdiagnosed by general practitioners¹⁸¹. Therefore, diagnosis are preferably set by a neurologist specialised in movement disorders who can achieve a diagnostic accuracy of more than 90%^{182,183}. The most common reasons for misdiagnosis are presence of essential tremor and atypical parkinsonisms.

2.4. The ICF for Parkinson's disease

The complexities of Parkinson's disease create a wide variety of problems. These problems can be a direct consequence of the disease, but also of the Parkinson's medication or inactivity of the pwp. For the majority of affected persons, it is a very incapacitating disease, however, the variability in the rate of the progression, as well as in daily functioning is large¹⁸⁴⁻¹⁸⁷. To describe this functioning, the classification system of the International Classification of Functioning, Disability and Health (ICF classification) can be used¹⁸⁸. It provides a common language and basis for the understanding and describing of health and health-related problems. The aim of using this common language is to improve communication about functioning of pwp between health care workers, researchers, and social policy makers. The ICF classification is used alongside the ICD-10 classification, developed for worldwide recording and comparison of morbidity and mortality¹⁸⁹. In the ICF, disability and functioning are the outcomes of the interaction between a health condition and contextual factors. It provides us with names, codes, and descriptions of all factors. Three levels of human functioning are classified: 1) physiological and psychological functions (Body Functions) and anatomical parts (Body Structures); 2) execution of a task or action (Activities); and 3) involvement in a life situation (Participation). Contextual factors can be either Personal or

Fig. 2.4 ICF: functioning as outcome of interactions between health conditions and contextual factors



Environmental. These can be a facilitator or a barrier, such as the physical, social and attitudinal environment (Environmental Factors) and age, gender, experiences and interests (Personal Factors). Personal factors are not coded, because they are associated with a large social and cultural variance. All five factors are interconnected (Fig. 2.4).

Impairments are problems in body functions and structure. Impairments in body functions generally correspond to the so-called signs and symptoms of disorders in the Statistical Classification of Diseases and Related Health Problems (ICD-10; www.WHO.int). They may induce problems in activities or participation: activity limitations or participation restrictions. However, their relationship is not linear, but largely depends on personal and environmental factors. These factors can influence functioning positively or negatively. For example, pwp may have sufficient confidence, physical capacity, and motor planning skills to walk without limitations in a clinical situation. Still, they may be limited in walking around their house to exercise. Narrow passages, created by their outdoor furniture and plants may provoke them to freeze. This is a so-called environmental factor. Also negative thinking like 'I do not like to exercise, I would rather stay seated in my chair' may prevent them from exercising. This is a so-called personal factor. Moreover, two pwp with the same severity of Parkinson's disease may have the same capacity to perform tasks when in a standardised environment, but their performance might differ significantly in their natural environment due to their personal factors and their environment's characteristics. The ICF distinguishes two constructs of functioning: capacity and performance. Capacity is the person's ability to execute tasks in a standard environment, such as the pwp's home, the community or the therapy setting. Performance is the actual performance of a person executing tasks in his or her current environment. It is important to relate to these constructs during history taking and physical examination, as well as when communicating with the pwp and other health professionals. Pwp are faced with a large variety of impairments and limitations, primarily or secondarily associated with Parkinson's disease, or drug-related. These, as well as participation restrictions and external factors influencing a pwp's daily functioning are provided in Appendix 9. The appendix also includes ICF domains and codes. In general, in physiotherapy practice the codes are not used. However, they may be important for collaboration and communication in specific settings, such as in multidisciplinary rehabilitation care. The GDG however advises a physiotherapist to use ICF wording in all communicating and patient records. Appendix 4 provides an ICF-based assessment and report sheet.

2.4.1 Impairments in motor functions

Bradykinesia, slowness and reduction of movement, is the most characteristic impairment, present in 77% to 98% of pwp¹⁷⁷. Tremor at rest occurs in around 70% at the time of diagnosis¹⁹⁰, but may be experienced by up to 100% of persons at any stage of the disease¹⁹¹. Rigidity is found in 89% to 99%¹⁷⁷. It is characterised by increased resistance present throughout the range of passive movement of a limb¹⁷⁸. It may be associated with pain, such as shoulder pain, which can be a presenting impairments¹⁹². In addition, rigidity of the neck and trunk (axial rigidity) may occur, resulting in abnormal axial postures such as antecollis and scoliosis¹⁷⁸. Postural deformities resulting in flexed neck and trunk posture and flexed elbows and knees are often associated with rigidity, but generally occur late in the disease¹⁷⁸. Although considered a cardinal sign, impaired balance reactions due to loss of postural reflexes, are generally a manifestation of the late stages. However, dynamic postural control during turning may be altered even in the early stages, within three years after diagnosis¹⁹³.

2.4.2 Impairments in non-motor functions

Parkinson's disease is not only characterised by impairments in neuromusculoskeletal and movement-related functions. It is becoming increasingly apparent that pwp also suffer from a wide variety of non-motor impairments (Appendix 9)^{194,195}. In fact, they are responsible for a considerable reduction in quality of life¹⁹⁶. Often, they remain unnoticed by health professionals, because pwp are either embarrassed to discuss these impairments, or are unaware that they are linked to

Parkinson's disease¹⁹⁷. Although the impairments correlate with advancing age and disease severity, they may even precede the expression of motor impairments by more than a decade^{194;198;199}. Up to 70% of pwp experience non-motor symptoms, and they may even be present in the early stage of the disease²⁰⁰. Examples of early non-motor impairments are olfactory dysfunction, REM sleep behaviour disorder, constipation, and depression^{194;198;199}. In addition, mental impairments, specifically impaired executive function and memory, as well as prolonged reaction time can be present at diagnosis¹⁸⁶.

Executive dysfunction is characterised by impairments in²⁰¹:

- Internal control of attention (versus attention guided by external cues), essential for non-routine tasks
- Set shifting: changing attention from one to another stimulus
- Planning: identify and organise the steps to achieve a goal
- Conflict resolution: inhibition of predominant responses
- Concentration
- Retaining and using information
- Dual task performance
- Decision-making: considering advantages and disadvantages of different options
- Social interactions: understanding others' intentions, desires and humour

It is essential for goal-directed behaviour and thus for functioning in daily life. It includes activities related to mental control and self-regulation, such as paying attention, planning, organising, remembering details and managing time and space. It is associated with both motor and non-motor symptoms, including gait and falls, particularly under dual task conditions, apathy, depression, visual hallucinations and changes in personality such as a decrease in spontaneity and a lack of concern for self-care²⁰¹. Presence of these factors may decrease adherence to physiotherapy treatment, similar to their reduction in adherence to medication intake²⁰².

Examples of late non-motor impairments are dementia, urinary incontinence, and sexual dysfunction. Approximately one out of five pwp will experience a major depression²⁰³. Other common impairments that influence choices are anxiety (reported in up to 40% of pwp), apathy (up to 50%) and pain (up to 70%)²⁰³⁻²⁰⁶.

2.4.3 Activity limitations and restriction in participation

The arising motor impairments may induce both limitations in the activities of daily life or other activities and restrictions in participation (Appendix 9). Impairments in functions that are most bothersome to pwp include moving and speaking slowly, tremor, rigidity, pain, psychic instability, swallowing, drooling, speech and the fluctuating response to medication²⁰⁷⁻²⁰⁹. Activity limitations that mostly affect the daily life of pwp include the performance of transfers, dexterity, communication, eating, gait, and gait-related activities²⁰⁷⁻²⁰⁹. Additionally, pwp are likely to become inactive. This threatens their physical capacity, thereby further limiting their activities, and increasing their risk of co-morbidities. Chapter 4 provides a more detailed insight into limitations in relation to physiotherapy.

2.4.4 Quality of life

Parkinson's disease severely threatens quality of life, more than stroke or arthritis¹⁹⁶. The loss in quality of life increases with disease progression¹⁴. In particular, late motor and non-motor impairments have a dramatic impact on the person's quality of life. Non-motor impairments such as depression, as well as psychosocial well-being are the major determinants of quality of life^{196;210}. Other important determinants of life quality include difficulty turning and recurrent falls^{196;210;211}. The impact on quality of life also extends to partners and other family members²¹².

2.5 Disease progression, prognostic factors and mortality

The variability in impairments of functions, activity limitations and participation restriction between pwp is high and unpredictable. Still, many pwp, specifically those of the Postural Imbalance and Gait Disorder (PIGD)-type, will present with limitations in the early stages and even upon their first neurologist visit²¹³⁻²¹⁵.

Postural and axial symptoms (such as impairments in gait) evolve more rapidly than other motor features and appear to be the best index of disease progression²¹⁶. Therefore, in clinical practice, many physicians use the Hoehn and Yahr staging scale (HY) to classify pwp based on disease progression (Table 2.5.1). It should however be noted that this tool is specifically recommended for demographic presentation of groups of pwp, is not linear and does not include non-motor functioning²¹⁷. Based on the HY stages, pwp are regarded as being in the early or uncomplicated phase (HY 1 to 2); in the complicated phase (HY 3 to 4); or in the late phase (HY 5)¹⁵. HY 3 is characterised by the onset of axial impairments and is associated with a marked deterioration in quality of life (Table 2.5.1)²¹⁶. It is estimated that only 4% of pwp reach the late phase²¹⁸.

Individual variation in progression of the disease is large. In general, women reach HY 3 earlier than men²¹⁸ and earlier experience motor complications such as motor fluctuations, dyskinesias and freezing of gait²¹⁹. Consequent to longer duration of disease and treatment, pwp with a younger age-of-onset have a higher rate of treatment related motor complications than other subtypes²²⁰. Most commonly, four clinical subtypes of Parkinson's disease are distinguished (Table 2.5.2)^{185;221-223}.

To monitor progression, physicians often use the Unified Parkinson's Disease Rating Scale (UPDRS) or the newer MDS-UPDRS revised by expert members of the Movement Disorder Society (MDS)²²⁹. This tool provides a composite score for disease severity, including mental and motor functions, activities of daily living and complications. In treated pwp, the average annual progression in motor symptoms is approximately 2.2 points on the UPDRS motor examination (part III)²¹⁶. Percentages of pwp admitted to nursing homes at 10 years after diagnoses, range from 7% to 27%. The main reasons for placement in a nursing home are falls, hallucinations, dementia and carer strain²³⁰⁻²³³. Expert community care and intensive, short-term expert clinical intervention is likely to delay nursing home placement by reducing the number of hip fractures and optimisation of medication²³⁴⁻²³⁶. Pwp have a 1.8 to 2.3 increased mortality risk²³⁷. The increased risk can in part be ascribed by dementia, being the largest predictor for mortality in pwp^{237;238}. Pneumonia is the most common cause of death in pwp, generally occurring in HY5²³⁹⁻²⁴².

Table 2.5.1 Description of the Hoehn and Yahr staging scale and disease phases

HY	Description	Phase
1	Unilateral involvement only; minimal or no functional disability	Early
2	Bilateral or midline involvement; no impairment of balance	Early
3	Bilateral; mild to moderate activity limitations; impaired postural reflexes; physically independent	Complicated
4	Severe activity limitations; still able to walk or stand unassisted	Complicated
5	Confinement to bed or wheelchair unless aided	Late

Table 2.5.2 Subtypes of Parkinson's disease

Subtype	Associations clinical features
Earlier disease onset (<55 years)	Late onset of falls (approximately 15 years) ²²³ Late onset of cognitive decline ²²³ Early onset of freezing (50% after 10 years versus 15 years) ²²⁴ Higher risk for anxiety ²²⁵ Shorter time to dyskinesias and wearing-off ²¹⁸ Longer time to Hoehn and Yahr 3 ²¹⁸
Tremor dominant	Poorer response to levodopa, but slower disease progression ^{223;226} Lower risk for depression and mood impairments ²²⁵ Longer time to and lower risk of dementia compared to PIGD-type ²²⁷ Longer time to Hoehn and Yahr 3 compared to PIGD-type ²²⁷
Postural imbalance and gait disorder (PIGD)*	Predominant gait and posture impairments Higher prevalence and severity of depressive symptoms ^{225;228} Higher prevalence of dementia ²²⁶
Rapid disease progression without dementia	Older age at onset ²²³ Early depression ²²³ Early midline motor symptoms ²²³ In 70% a tremulous onset ²²³ At post-mortem

* at autopsy, some of these pwp turn out to have MSA or PSP²²³

Chapter 3

Overall healthcare management for Parkinson's disease

The overall goal of Parkinson's disease management is to optimise activities, participation and quality of life of people with Parkinson's disease by considering functioning, personal and environmental factors. Currently, the focus is on symptom control and compensation. Symptomatic treatments include a variety of drugs and rehabilitation. Most allied health interventions use compensatory strategies, often because people are referred later in the course of the condition. No treatment slows down disease progression.

The information in this chapter is primarily based on three recently published multidisciplinary guidelines:

- the 2006 UK Clinical Guideline Parkinson's disease by the National Institute for Health and Care Excellence (NICE)¹⁵
- the 2010 Dutch Multidisciplinary Guideline for Parkinson's disease¹⁴, an update version of the NICE guidelines with an additional recommendation for collaboration
- the 2011 Guidelines on Parkinson's disease by the European Federation of Neurological Societies (EFNS) and the Movement Disorder Society's European Section (MDS-ES)²⁴³.

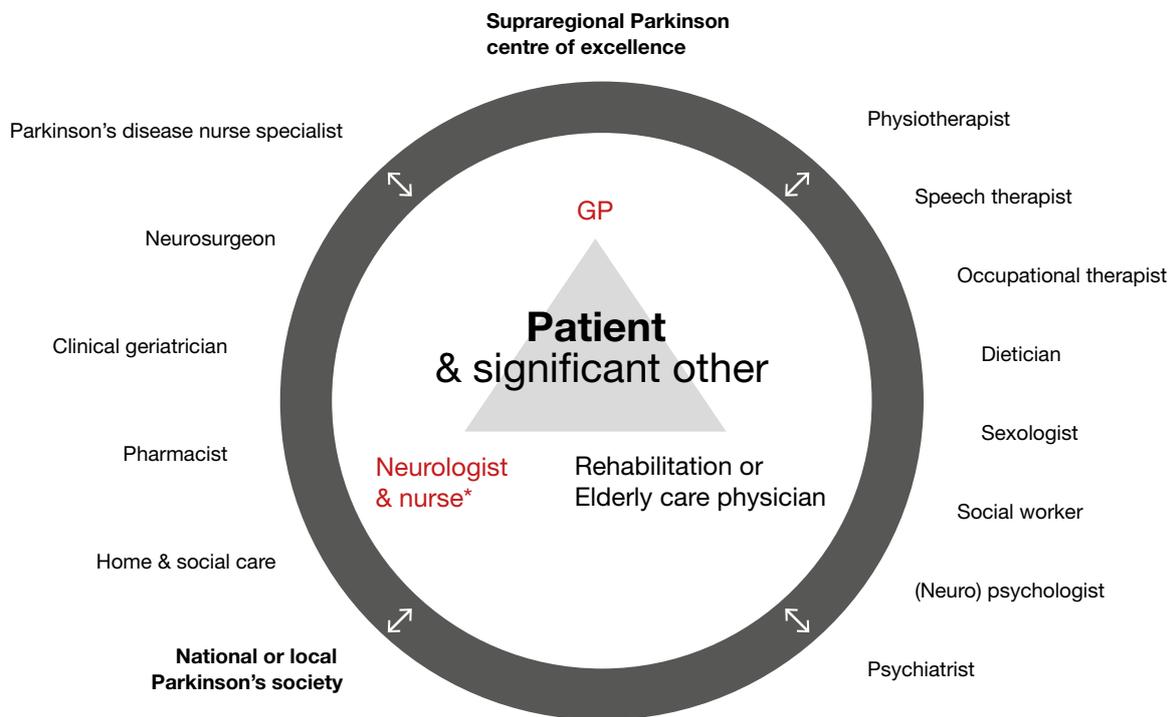
3.1 Multiple health professionals

Because of the complex nature of Parkinson's disease, as many as 19 health professions and institutions can be involved in care for people with Parkinson's disease (pwp) (Fig. 3.1)^{15;158}. Ideally, the general practitioner, a neurologist with Parkinson-expertise and a nurse or other care coordinator are always involved. All other professionals should be involved in the care when needed (Appendix 11). Role specificity of each profession may vary from country to country.

3.1.1 Patient centred care, collaboration and communication

Patient centred care is associated with greater well-being and physical functioning. It entails providing "care that is respectful of and responsive to individual pwp preferences, needs, and values, and ensuring that pwp values guide all clinical decisions"²¹. Although health professionals have the right intentions, patient-centredness remains far from being routinely implemented in current clinical practice²¹. To support patient-centred care, this Guideline provides information such as the GRADE-based recommendations, of use when discussing treatment options with pwp and tools such as the Self-management Information (Appendix 1) and the Pre-assessment Information Form (Appendix 2). The GDG advises involvement of the carer if agreed upon by the pwp. This allows essential information on the pwp's functioning the home environment to be gained, involving the carer to optimise treatment adherence, as well as educating the carer and agreeing upon realistic expectations regarding physiotherapy treatment.

Figure 3.1 A care model for pwp



*in most situations the care coordinator

Pwp want collaboration between professionals involved in their care Guideline development and scientific justification. When many health professionals are involved in the care for a single pwp, great effort is required to keep the care patient centred. The extent to which particular health professionals are involved will vary over time, again, according to the pwp's priorities. All should aim to communicate and collaborate with the pwp and one other, based on the pwp's specific goals. A care coordinator may support the pwp to select their main problems at a given time and to identify health professionals required to target these. Health professionals need to listen carefully to the pwp's needs and preferences; they need to be aware of each other's expertise and refer on to, or involve other health professionals in a timely manner. Some interventions are intensive in treatment or exercise frequency. When these are required, the pwp may require support to prioritise problems and choose which intervention to postpone. The GDG advises to avoid contradictory advice at all times.

To facilitate good collaboration and communication, this Guideline provides a Parkinson's specific ICF overview and report sheet (Appendices 4 and 9) and an overview of health professionals who may possibly be involved, including a short role description (Appendix 11)^{14;15}. The GDG advises to make local agreements on which health professional is responsible for the coordination of care and on when and how to communicate. This will help to know who is doing what and when and to adjust treatments to complement one other. Paragraph 6.8.1 provides advice regarding the contents of timing of communication

GDG advice: General requirements for coordination of care

- *Communication with pwp and carer to gain insight into needs and experiences*
- *Frequent communication with neurologist, general practitioner and other care providers involved in a specific pwp*
- *Care support at home, if required through home visits*
- *Develop a care plan, together with the pwp*
- *Carry out and evaluate effectiveness of a care plan and make timely changes as required*

3.1.2 Expertise

Parkinson's disease is complex, as is the selection of an optimal treatment strategy. This should dictate that all health professionals who treat pwp have Parkinson-expertise. The GDG is aware that this is not always possible, but emphasises that health professionals have a responsibility to realise their own limitations of expertise and call in or contact an expert for advice if necessary.

3.2 Pharmacological management: symptomatic relief and motor-complications

Medication is the first choice in care for pwp. It aims to correct the neurotransmitter imbalance within the basal ganglia circuitry. Parkinson treatment frequently necessitates multiple doses of several medications. This is one of the reasons why adherence to medication intake in pwp is generally low.²⁴⁴⁻²⁴⁶ Other reasons include cognitive problems, fear of adverse events, limitations in swallowing and reduction in fine hand motor function.²⁴⁴ Physiotherapists may recognise low adherence, either by the pwp telling them or by seeing impairments that would be expected to reduce with the prescribed medication.

They should support the pwp in medication related communication with the care coordinator or prescribing physician. It is important for a physiotherapist to know what impairments of Parkinson's disease medications can improve, as well as possible adverse events of medication (Appendix 12).

GDG advice: Physiotherapists need to know benefits and adverse events of medication to:

- *increase the benefits of physiotherapy treatment*
- *set realistic expectations*
- *recognise low adherence*
- *support the pwp in medication related communication and reduce unnecessary prescribing*

Symptomatic relief through medication

Current pharmacological management is largely based on the dopamine precursor levodopa and dopamine agonists. Levodopa is still the 'gold standard' in treatment; it offers the best symptomatic relief of rigidity, bradykinesia and tremor.²⁴⁷ As protein intake reduces the benefits of levodopa, a protein-redistribution diet is often advised.^{248;249} In addition to levodopa, dopamine agonists are prescribed to alleviate other disabling complications such as restless legs syndrome, sleep fragmentation and early morning akinesia or dystonia. Over the past decade, a commonly tested strategy has been to start with an agonist and to add levodopa later if the agonist alone cannot control the worsening of symptoms. However, previously, it was common practice to combine an agonist with levodopa within the first months of treatment ('early combination strategy'). There are no studies assessing whether one strategy is better than another is. Dopamine agonists, whilst considered to have a smaller effect than dopamine replacement medication, are often prescribed in the early stages of the disease in young onset patients who are more prone to develop motor complications. Mono-Amine Oxidase (MAO)-B inhibitors are

often used in an early stage of the disease, or as adjuvant to levodopa, to reduce motor complications. With disease progression, pwp develop features that do not respond well to levodopa, such as autonomic dysfunction, postural instability, falling, and dementia. Freezing is usually worse in the off state and can be reduced by lengthening the on state through manipulation of levodopa²⁵⁰.

Medication induced motor-complications: response fluctuations & dyskinesias

Medication controls symptoms, but also induces complications (Appendix 12)¹⁴. Side effects or adverse events may trouble pwp from the start. In addition, after approximately five years of treatment, the smooth response to medication reduces and non-motor complications such as neuropsychiatric complications and motor complications (Table 3.2.1) develop.

Table 3.2.1 Most common medication induced motor complications

Response fluctuations on and off states	Fluctuations between on and off states: in on states, the medication is working well, whereas in off states the medication dose is insufficient or ineffective. Initially, these states are predictable and linked to the time of medication intake. Before the next dose, pwp may experience predictable wearing-off. Over time, this will become unpredictable.
Early morning dystonia	Uncontrollable and sometimes painful muscle spasm, described by pwp as 'severe cramping'. Related to response fluctuations.
Dyskinesias	Involuntary, large amplitude and fidgety movements. Often occurring at peak dose: peak-dose-hyperkinesia. Primarily caused by dopamine. Less severe dyskinesias may arise when using high dose dopamine agonists.

Treatment of medication induced motor-complications

To a certain extent, adjustments in medication intake can reduce these motor complications. It is therefore important that all health professionals recognise the complications and support pwp in medication related communication with the care coordinator or prescribing physician. Several treatment strategies are used to reduce the frequency and severity of these motor-complications (Table 3.2.2) However, it is noteworthy that few general practitioners, geriatric specialists or neurologists prescribe uniformly.²⁴⁷

Table 3.2.2 Medical interventions used to reduce motor complications

To retain a constant effect	Increasing dose and frequency of levodopa
To reduce predictable fluctuations	adding a COMT- or MAO-B to slow down the breakdown of dopamine in the periphery and in the brain respectively
To reduce duration and frequency of unpredictable off states	subcutaneous apomorphine injections or an apomorphine pump
To reduce severe dyskinesias	reduction of levodopa or adding amantadine; apomorphine pump*
To reduce unpredictable motor-complications	intraduodenal levodopa**

*Apomorphine pump: in pwp who need more than five injections a day, apomorphine can be administered with a pump using a small, subcutaneous needle; **Intraduodenal levodopa: continuous intraduodenal levodopa infusion is known as Duodopa pump or continuous levodopa/carbidopa intestinal gel infusion (LCIG). It is a monotherapy, meaning pwp will not need other Parkinson medication. Levodopa/carbidopa is administered through a pump into the small intestine for which an extension tube is inserted through a percutaneous endoscopic gastrostomy²⁵¹. Costs involved are three to four times higher than in an apomorphine pump and six to eight times higher than in deep brain stimulation (3.3 Neurosurgery). The size and weight of the infusion pump can be cumbersome and limiting the pwp in exercising. The high costs, adverse events related to the infusion system or surgical procedure and the need for an experienced team limits its use^{252,253}.

3.3 Neurosurgery

In addition to medication, neurosurgery is an option for some pwp²⁵⁴. Lesioning procedures, such as a thalamotomy, were applied for many years but have been largely replaced by deep brain stimulation (DBS) in most countries. DBS provides high frequency electro-stimulation through permanent implanted electrodes in the brain, using a pacemaker. Thus, DBS mimics the effect of a lesion without the need for destroying brain tissue. DBS has rapidly replaced ablative stereotactic surgery as it does not require making a destructive lesion in the brain; it can be performed bilaterally; the stimulation can be adjusted postoperatively; and it is in principle reversible²⁵⁴. The most frequently applied DBS targets for the treatment of Parkinson's disease are the subthalamic nucleus (STN). Other target are the thalamus and the globus pallidus pars interna (GPi). DBS on each target improves a different range of symptoms. Bilateral STN-DBS is effective in reducing impairments in motor functions (tremor, rigidity and dystonia) during the off state, off time, dyskinesias, the required levodopa doses for optimal functioning and quality of life.²⁵⁵ Levodopa-responsive gait and balance impairments have the potential to improve following DBS, but can also decline due to surgical effects.²⁵⁵ Other complications may include consequences of the intervention itself, such as bleeding or infections (in approximately 2% of cases), or consequences of the stimulation such as limitations in verbal fluency, axial motor symptoms, anxiety, delirium, impulsivity, depression and suicide. Patient selection aims to identify those most likely to benefit from surgery and unlikely to encounter severe adverse effects (Table 3.3).¹⁴

Table 3.3 Main neurosurgery indications in pwp

- Late stage Parkinson's disease
- A clear reduction of off related symptoms with levodopa
- Severe, unpredictable response fluctuations or severe dyskinesias despite optimal medication;
- Treatment resistant tremor;
- Absence of: dementia; severe depression or (non-iatrogenic) psychosis; low general health; balance or speech limitations as main problem; severe cerebral atrophy; vascular brain lesions

3.4 Rehabilitation

Current medical management is only partially effective in controlling the progressing impairments, limitations and participation restrictions pwp are faced with. This particularly considers motor and non-motor impairments that occur late in the course of the condition, including freezing, impaired balance and cognitive impairments. Medication may even worsen them. Consequently, even patients with optimal medical management face mounting and varied problems in daily functioning. Therefore, a wide variety of healthcare professionals may be required in addition to the GP, the neurologist and the nurse. Most commonly involved are physiotherapists, speech and language therapists, occupational therapists, dieticians and (neuro) psychologists. Most often lacking, but required for problems of high importance to pwp are sexologists. Regardless of the work setting, communication across and between the professions and with the pwp is of utmost importance.²⁵⁶ Advocated for people with long-term, changeable conditions are integrative approaches, such as multi- and interdisciplinary collaboration (Table 3.4)^{257;258}. The overall aim is to optimise quality of life through Parkinson's specific care, with multiple, complementary health professionals and incorporating pwp preferences and goals into treatment.

Table 3.4 Modalities and descriptions of integrated care

Uni- or mono-disciplinary care	Professionals work from a consultative standpoint; patients may be referred on to other clinicians, but one practitioner retains central responsibility; limited communication between professionals.
Multi-disciplinary care	The patient will see various health professionals within a team who working independently, parallel, and not collaboratively; each professional is responsible for a different patient care need.
Inter-disciplinary care	More person-centred; goals developed and managed by a team of health professionals together with the patient; open and continuing communication between the patient and all involved practitioners.
Trans-disciplinary care	Used more in an educational setting where different professionals share insight and knowledge about a specific problem; requires time for professionals to understand the 'language' and 'perspectives' of other disciplines and to integrate these to assist in dealing with a shared problem.

3.5 Disease modification

Interventions that affect the underlying pathophysiology of the disease and reduce the rate of disease progression provide disease modification. This can be through neuroprotection or neurorestoration. To date, there is no evidence for a modifying effect in Parkinson's disease for any intervention, be it vitamin-E, co-enzyme Q10, dopamine agonists or MAO-B inhibitors^{14;15}. Animal studies do however show that physical activity may directly interact with the neurodegenerative process, likely mediated by brain neurotrophic factors and neuroplasticity.²⁵⁹⁻²⁶² Also, vigorous exercise, sufficient to increase heart rate and the need for oxygen, is associated with a reduced risk for Parkinson's disease and improved cognitive functioning.²⁵⁹ Moreover, it increases gray matter volume of the brain in elderly (decreased by ageing), and improves functional connectivity or cortical activation related to cognition²⁵⁹. Finally, there is emerging evidence that exercise improves corticomotor excitability in pwp, suggesting potential neuroplasticity.⁹⁸ Given that exercise is biologically protective against degenerative processes, it is plausible that exercise may slow down disease progression in pwp. This is promising, but not clear yet. To date there has been limited evidence to support this in human models however it is an area of growing research.

Chapter 4

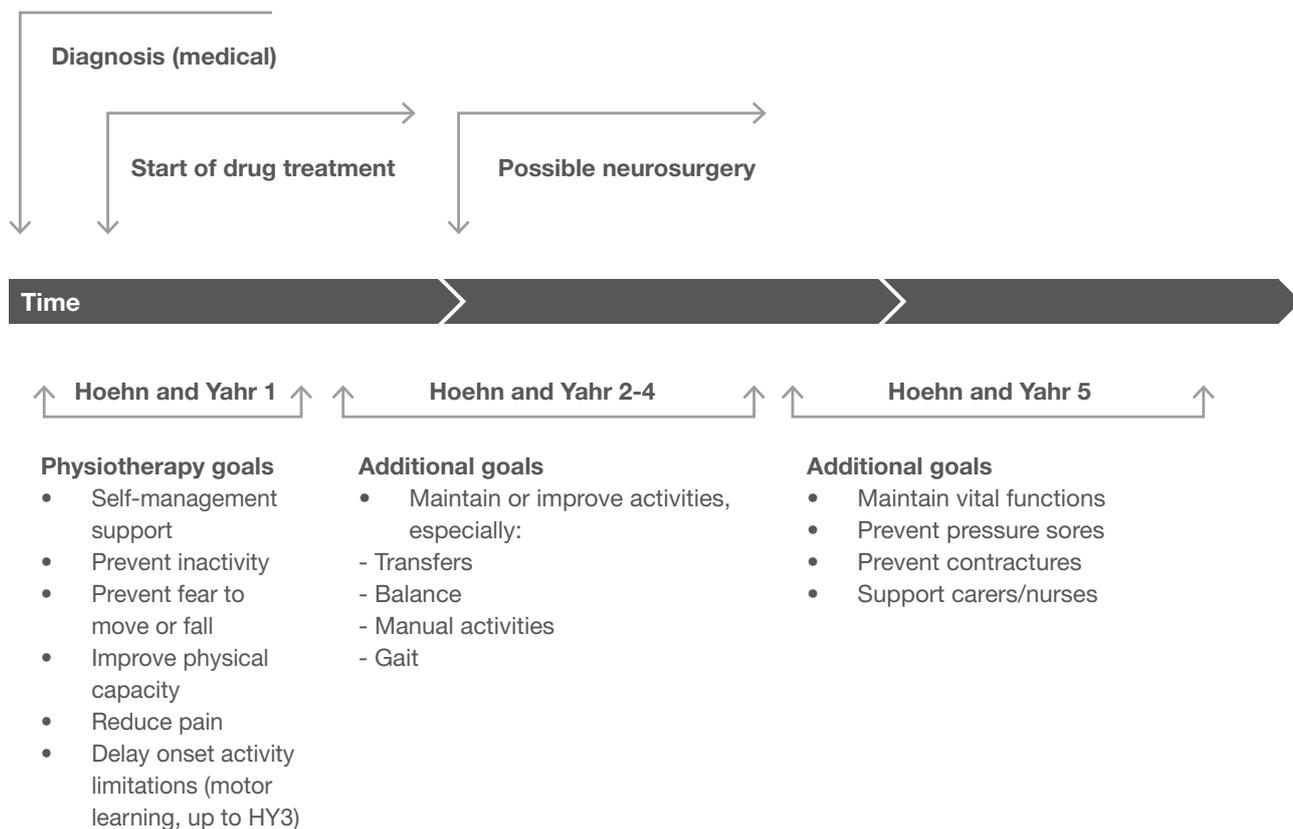
Physiotherapy for people with Parkinson's disease

Physiotherapy aims to 'maximise quality of movement, functional independence and general fitness, and minimise secondary complications whilst supporting self-management and participation, and optimising the safety' of people with Parkinson's disease.²⁶³

4.1 Core areas

The five core areas physiotherapy addresses in people with Parkinson's disease (pwp) are physical capacity, transfers, manual activities, balance and gait^{264;265} Posture, the sixth core area described in the 2004 KNGF Guideline, is considered to be part of the core areas transfers, manual activities, balance and gait, and therefore included in those core areas. In addition to the core areas, respiratory function and pain management will be touched upon, as these also have been identified as being important to physiotherapy care for pwp²⁶³. The main focus of physiotherapy, as well as the treatment goals, is person-specific, but also linked to the current stage of disease progression of that person (Fig 4.1)^{149;265;266}. Hoehn and Yahr stages are described in 2.5.1.

Fig 4.1. Core areas of physiotherapy related to disease progression



4.1.1 Physical capacity

Physical capacity entails the capacity of the neuromuscular and cardiorespiratory system, expressed by exercise tolerance, joint mobility plus muscle tone, power and endurance. Sufficient physical capacity, comprised of muscle strength, endurance, coordination and range of motion, is a precondition for performing activities of daily life and participation in society²⁶⁵. Pwp have a tendency towards a more inactive lifestyle. It is however noteworthy that pwp taking dopamine-agonists are at risk for compulsive exercising^{267;268}.

Compared to their healthy contemporaries, pwp are about one-third less active^{269;270}. This is in part (24%) predicted by disease severity, gait impairments and limitations in activities of daily living²⁷⁰. Mental impairments (such as depression, apathy and dementia), fatigue and personal factors such as self-efficacy also influence this behaviour²⁷¹. Moreover, inactivity may be part of a compensatory strategy to prevent falls; fear of falling is common in pwp and may result in a reduction of outdoor physical activities²⁷².

Inactivity reduces muscle strength and length, especially in the weight bearing muscles of older people²⁷³; in pwp, leg muscle strength is reduced and associated with increased fall risk and reduced walking speed^{274;275}. In contrast to their contemporaries, for pwp hip strength is specifically related to sit to stand performance, not knee extensors strength²⁷⁵. Muscle power can be calculated by multiplying muscle strength and speed. It is related to the performance of balance and mobility activities^{274;276-278}. In pwp, muscle strength is a larger determinant of reduced muscle power than bradykinesia is. Reduced muscle power is also related to reduced performance of balance and functional mobility^{274;276-278}.

Many pwp additionally present with a generalised change in posture towards flexion, often in combination with latero-flexion, of an unknown cause. Long-term postural changes may lead to secondary muscle weakness of, particularly of the back and neck extensors, but also of the muscles of the shoulders (adductors), hip (extensors), buttocks and legs (extensors). An inverse linear relationship exists between volume of physical activity and multi morbidity, including pain, osteoporosis, depression and cardiovascular diseases^{270;271}. Physical inactivity increases the risk of many adverse health conditions, including major non-communicable diseases such as coronary heart disease, type 2 diabetes, and breast and colon cancers, plus shortens life expectancy²⁷⁹. Physical exercise over and above the recommend minimum, plus the breaking of sedentary behaviour is expected to lead to reduced premature mortality and further health improvements, particularly cardiovascular functioning.

4.1.2 Transfers

As the disease progresses, complex motor sequences, such transfers and manual activities, may no longer be performed automatically^{280;281}. Transfers which are particularly problematic include rising from, and sitting down onto a chair, getting in or out of bed, and turning over in bed^{108;282}. A common problem during sit-to-stand transfers is that pwp fail to lean forward far enough when standing up, thus falling back into the chair²⁶⁵. Likely factors that play a role are weak limb support against gravity and poor timing of velocity in forward movement of the trunk²⁸³. Specifically reduced muscle power of the hip extensors may be one of the contributing factors²⁷⁵. External factors contributing to difficulty turning in bed are bedcovers, reduced levels of levodopa at night and low visual guidance²⁶⁵.

4.1.3 Manual activities

Alike transfers, manual activities may become difficult to perform because of the complex motor sequences required. The fluidity, coordination, efficiency and speed of reach and dexterity of movements are often diminished. Impaired timing and integration of movement components may play a role, as well as impaired regulation of the necessary force and impaired precision grip²⁸⁴⁻²⁸⁶. Next to these problems, a tremor may affect manual activities although resting tremor generally disappears

or diminishes when a movement is initiated. However, the tremor can return in isometric action of the muscles for example when holding an object for longer periods. In some pwp, an action tremor may be observed affecting voluntary movement²⁸⁷.

4.1.4 Balance and falls

Falls are very common in pwp. In prospective assessments, fall rates range from 38% to 54% for a three-month period²⁸⁸ to 68% for a 12-month period²⁸⁹ and up to 87% for a 20-month period²⁴¹. Usually five years after onset of the first impairments, limitations in changing and maintaining body position (that is balance) develop due to progressively impaired postural reflexes. Impairments in proprioception, reduced trunk flexibility, as well as Levodopa medication may further decrease balance^{290;291}. Falls were assumed, on average, to emerge five years thereafter²⁹², however, recently it has become clear that even in the early stages, pwp have an increased fall risk^{214;293}. The reduced fall risk seen in later stages may be explained by increasingly sedentary lifestyle or simply immobility²⁸⁸. Falls are particularly present in those whose initial symptom was a gait disorder²⁹⁴.

Consequences of falls

Falls increase physical, social and financial burden of the disease. As many as 65% falls may result in injuries, of which one out of three in a hip or pelvis fracture²⁹⁵. As such, pwp have a two to fourfold higher probability of hip fractures than their peers^{296;297}. Fractures occur more often due to a coexistent osteoporosis, caused by immobilisation and perhaps endocrine disorders²⁹⁸. Compared with their peers, pwp with a hip fracture are likely to be hospitalised for a longer period, have a longer and less successful postoperative rehabilitation and more likely to be discharged to a skilled nursing facility^{299;300}. This may explain why falls are among the leading causes of carer stress²¹².

Factors associated with falls

Factors associated with falls are partly disease-specific, such as freezing, reduced step height, bradykinesia, freezing of gait, and impaired postural reflexes^{289;301-304}. In addition, generic factors can also be identified, such as the side effects of sedative drugs, daily intake of alcohol and urinary incontinence^{301;302;304;305}. The role of the stooped posture in falls is unclear. On the one hand it may impair voluntary stepping to preserve balance, whilst on the other hand it may in part be a natural protective response to prevent backward falls³⁰⁶. As a consequence, pwp who actively adopt an upright posture may become more unstable³⁰⁷.

Pwp who have fallen have a very high likelihood of falling again within the next three months³⁰⁸ which may in part be explained by their fear of falling. However, even pwp who have not yet fallen may develop a fear of falling²⁷². Moreover, this fear may lead to ADL restrictions, another risk factor for future falls³⁰⁹⁻³¹¹. Mobility limitations associated with greater fear of falling are rising from a chair, difficulty turning, start hesitation, festination, loss of balance and shuffling³¹². Also reduced self-perceived balance confidence level is associated with increased fall risk³¹³. Most falls in pwp occur indoors, when turning, standing up, bending forward, or the concurrent performance of two tasks (dual tasking)³⁰².

Dual tasking

Dual and multitasking activities can also contribute to falls because of decreased psychomotor speed and attentional flexibility³¹⁴. This is especially the case when the additional task is a cognitive or a complex task³¹⁵. When walking tasks become more complex, healthy elderly sacrifice the performance of a mental task (such as answering a question) in order to optimise their gait and balance; this is called the 'posture first' strategy. However, pwp show increasing mistakes in both their mental and motor tasks³¹⁶. This may be explained by the reduced movement automaticity (such as for walking),

impairments in attention³¹⁷, decreased attentional flexibility³¹⁸ and impairments in prioritising tasks³¹⁶. As a consequence, multiple tasking can lead to freezing of gait or loss of balance when pwp are walking^{319;320}. Even the attention required to listen to the physiotherapist while exercising is an example of dual tasking, and can lead to freezing of gait or loss of balance when pwp with executive dysfunction are walking^{319;320}.

4.1.5 Gait

Limitations in gait arise even in early stages of the disease. Two types are distinguished: the 'continuous' and the 'episodic' gait disorder³²¹.

Continuous: general impairments

Continuous gait disorder includes an asymmetrically reduced or absent arm swing, a stooped posture, reduced and variable step length, and difficulties turning around in the standing or recumbent positions observed in a person with bradykinetic-rigid type of Parkinson's disease. As the disease progresses, gait becomes slower and the typical parkinsonian gait develops with shuffling and short steps, a bilaterally reduced arm swing and slow, en bloc turns. Step length even further reduces when a cognitive task is added (dual tasking)³²² or when walking in complete darkness³²³.

Average walking speed in pwp is estimated at 0.88 m/s, with pwp in HY 3 to 4 being 24% slower than those in HY 1 to 2³²⁴ and a further reduction when walking in complete darkness³²³. This is much slower than the international standards for walking speed required to use a pedestrian crossing, which is 0.94 m/s to 1.2m m/s³²⁵. Moreover, pwp with a self-selected walking velocity lower than 0.98m/s³²⁶ to 1.1 m/s³²⁷ are likely to be at higher risk to fall. Not surprisingly, reduced walking speed is correlated with ADL limitations³²⁸. Moreover, it is an independent risk factor for mortality (odds ratio 16.3)³²⁹.

Episodic: freezing of gait

In addition to the continuous gait disorder, pwp can demonstrate an episodic gait disorder, such as festination and freezing. Pwp are suddenly unable to generate effective stepping movements³³⁰. When pwp experience festination of gait, their feet are involuntary behind their centre of gravity. As a result, they will rapidly and involuntarily take increasingly small steps which increases the risk for (near) falls. When pwp take a corrective step forward, this leads to propulsion; when pwp lose balance and take corrective steps backward, it leads to retropulsion. During freezing episodes, pwp feel as if their feet have become 'glued to the floor'³³¹. Most often freezing does not present as complete akinesia, but rather as shuffling with small steps or trembling of the legs³³².

Many pwp experience freezing. In a cohort of pwp recruited to receive exercise, most likely comparable to the population for which this Guideline is developed, half of the pwp experienced freezing³³³. It is associated with reduction in ADL³²⁸.

Although, the prevalence of freezing increases with longer disease duration and greater severity, it can be present in early stages of the disease, even in drug-naïve pwp³³⁴. Freezing most commonly appears when pwp start walking (start hesitation), are making turns, going through narrow passages like a door, performing dual tasks (such as talking while walking), reaching an open space, when reaching upon a target, or when walking in complete darkness^{323;335-337}. Most freezing episodes are brief, lasting less than 10 seconds³³⁶. In more advanced stages of the disease freezing may persist for minutes. Freezing mainly occurs in the off states (off freezing) and improves with dopaminergic medication; however, occasionally freezing occurs during on periods (on freezing) as a possible side effect of dopaminergic medication. Executive function as measured by the SCOPA-COG is a significant predictor of FoG³³⁸

4.1.6 Additional areas

Pain

Pain is an important and distressing symptom in pwp. The neurophysiology of pain perception is not well understood. Dopamine appears to modulate the experience of pain perception by increasing the pain threshold³³⁹. Dopamine is involved in the assessment of pain and related to its emotional experience, be it with large individual variations³⁴⁰. Reduced dopamine levels may result in decreased processing of pain signals and reactions to perceived danger. Pain perception can either be increased or reduced, regardless of cognitive impairments³⁴¹. Pain in pwp is associated with age (less pain at higher ages), gender (women experience more pain), disease duration and severity, severity of depression, systemic co-morbidity like diabetes, osteoporosis and rheumatoid arthritis³⁴². Percentages of pwp experiencing a form of pain range from 35% to 85%^{204;343;344}. For clinical purposes, pain in pwp can be categorised as primary or secondary, based on its clinical description (Table 4.1)³⁴⁵. Musculoskeletal pain is the most prevalent in pwp³⁴⁵.

Table 4.1. Categorisation, clinical description and prevalence of pain in pwp

	Clinical description	Estimated prevalence ³⁴²
Primary pain	<ul style="list-style-type: none"> Central or primary neuropathic pain: burning, nagging, tingling, itching or shooting pain sensation which cannot be attributed to the nervous system; may be an early sign of Parkinson's disease, often presented asymmetric (such as in one shoulder); changing locations including unexpected locations such as genitals or even outside the body Akathisia-related: the inner feeling of restlessness leading to inability to keep still 	10-12%
		unknown
Secondary pain	<ul style="list-style-type: none"> Musculoskeletal pain: often secondary to hypokinesia, akinesia, rigidity and long-term postural changes, most often in shoulder, hip, knees and ankles 	45-74%
	<ul style="list-style-type: none"> Dystonia: including numbness, pins and needles, cold; often present in the feet, in the morning (early morning dystonia) when medication is not working anymore (off state), or face or neck when medication is at its peak (peak dose dystonia): 	8-47%
	<ul style="list-style-type: none"> Radicular-neuropathic pain: pain in the root or peripheral distribution of a nerve, such as radicular-peripheral pain and neuropathy 	5-20%
	<ul style="list-style-type: none"> Constipation related pain* 	unknown

*Not included in the Ford 2010 classification

Some pain symptoms may be explained using the traditional biomedical pain model that focuses upon structural and biomechanical abnormalities. However, a biopsychosocial model may provide a better explanation of chronic pain and its associated disability. A widely used biopsychosocial model in musculoskeletal pain is the fear-avoidance model. It describes how individuals develop chronic musculoskeletal pain as a result of avoidance of activities based on fear.^{346;347} Psychosocial social factors relevant to pain experience in people with lumbar pain are passive coping strategies (that is becoming passive and protective), emotional stress (such as anger, depression or reduced mood), fear (such as to move) and the impact and number of stressful life events.³⁴⁸ These may also be relevant in pwp. However, the exact mechanism of pain processing and modulation in pwp remains unclear.²⁰⁴

Pain in pwp is frequently under-recognised and is often inadequately treated. Medical options to treat pain are both Parkinson's specific and general drugs. Adjustments in dopaminergic treatment may reduce pain related to rigidity, akinesia, akathisia and dystonia²⁰⁴. Dystonia may also be reduced with Botulinum toxin injections.²⁰⁴

Respiratory problems

Due to the disease pathology and the side effects of medication, pwp are faced with respiratory limitations³⁴⁹⁻³⁵¹. Often, they are a complication of hospital admission³⁵². They may lead to emergency hospitalisation and even death^{240,352}. Pneumonia is the most common cause of death in pwp, generally occurring in Hoehn and Yahr stage 5²³⁹⁻²⁴².

Potential causes to respiratory limitations include:

- Deterioration in swallowing function (dysphagia)³⁵³
- Upper airway obstruction and chest wall restriction³⁴⁹
- Respiratory muscle weakness and impaired cough function³⁵⁴
- Restrictive physiology³⁴⁹
- Sleep disordered breathing³⁵⁵
- Decreased physical activity levels, resulting in a loss of endurance, maximal fitness levels and overall pulmonary function³⁵⁶

An intact cough mechanism is important for clearing airway debris^{357,358}. The inspiratory, expiratory and bulbar muscle weakness may result in impaired cough and reduced peak cough flow³⁵⁹. The consequent reduction in peak cough flow leads to ineffective airway clearance, which can accelerate the development of respiratory failure and death.

Although therapists treat and research the impact of intervention on the motor symptoms that mainly affect mobility, there is an awareness of the likelihood that pulmonary complications will contribute towards disability, especially in the later stages. Timely therapeutic interventions therefore are required to improve the quality of life and survival of these pwp.

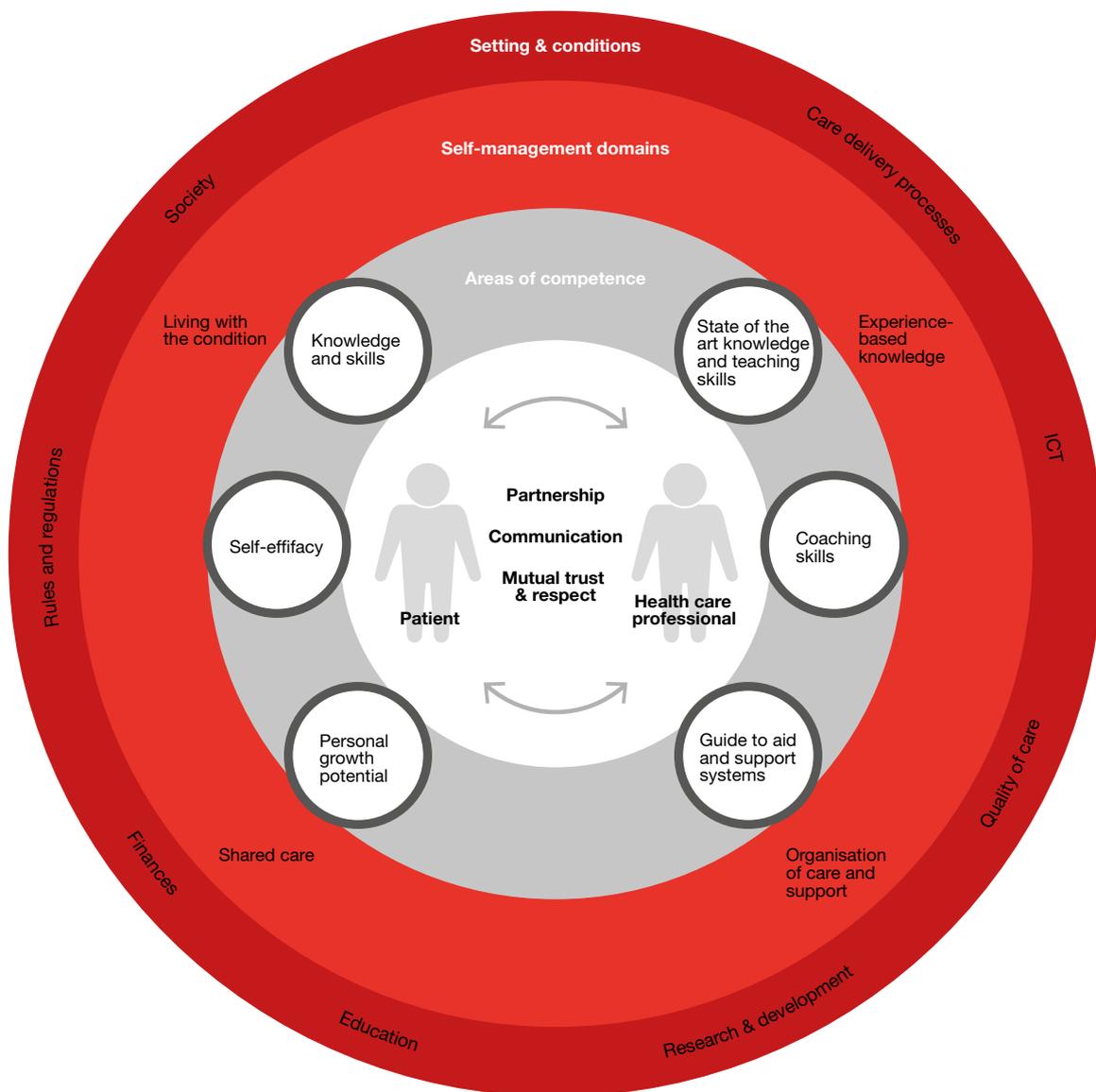
4.2 Patient-centredness and self-management support

Patient centeredness and self-management support are part of the well-known Chronic Care Model³⁶⁰⁻³⁶². This model focuses on collaboration between well informed, active patients and prepared, proactive health professionals. By providing decision-support towards structured, evidence-based, continuum of care, this Guideline aims to further support using this model.

Patient-centredness is increasingly recognised as a crucial element of quality of care^{363,364}. It is also central to this Guideline. It has been defined as “providing care that is respectful towards and responsive to individual patient preferences”³⁶⁴. A patient-centred approach is warranted, as crucial to behavioural interventions like physiotherapy is that the interventions fit with the needs, motivation and abilities of the pwp and their carers^{17,207}. Increased self-control increases motivation³⁰. Moreover, given the complexity of the disease and the wide scope of possible deficits and limitations to be addressed, it is important that the pwp is empowered to make an informed choice of priorities and interventions²⁰⁷. By promoting the pwp (and carer) to self reflect, prioritise and apply problem solving skills related to issues of activity performance and participation, self management can also be promoted⁶⁹.

Respect for the pwp's autonomy and a focus on self-management is essential when aiming to provide optimal physiotherapy. Self-management is most commonly defined as "An individuals' ability to cope with symptoms, treatment, physical, psychosocial and social consequences and lifestyle changes to a chronic condition".³⁶⁵ It entails collaboratively helping patients and families to acquire the knowledge, skills and confidence to manage their chronic illness, suggesting strategies that might help with management, and routinely reassessing problems and noting accomplishments.³⁶⁶ Evidence suggests that collaborative care programmes not only improve the quality of care and lead to better outcomes for people with chronic conditions, but also lower societal costs³⁶⁷. Next to knowledge, skills and self-efficacy, self-management requires social support, such as from the family, and professional support, such as from the physiotherapist. Therefore, fundamental to successful self-management strategies are good communication, partnership, trust and respect between the pwp, the carer and the health professional. This is visualised in the Generic model of self-management developed by the Dutch Federation of Patient Organisations and the Dutch Institute for Healthcare Improvement (Fig. 4.2)³⁶⁸.

Fig.4.2 Generic model of self-management



As suggested by the name 'self'-management, it is essential that the pwp takes an active role, but may need support to do this successfully. Both the pwp and the healthcare professional require competences to optimise self-management. For the pwp, the necessary competencies include self-efficacy and Parkinson's specific knowledge and skills. To support self-management, the health professional needs to have sufficient Parkinson's specific knowledge, skills to share this knowledge and coach the pwp, as well as guiding the pwp towards useful resources. In addition, learning from the experiences of peers supports self-management. In addition, personal and environmental factors, such as socioeconomic background and access to information technology, can increase or limit self-management.

Given the scope of this Guideline, self-management will concentrate on physical activity levels and movement related limitations in activities. This however is only one part of self-management of pwp. Other areas to consider, for example, might include adherence to medication, nutrition, speech, sleep, and choices made to maintain their general wellness. Ideally, a care co-ordinator oversees the full spectrum of self-management. Often, this is a Parkinson's disease nurse specialist working in collaboration with a neurologist. It is important that physiotherapists are aware of the potential treatment benefits that may be realised through the skills of other allied health, nursing and medical professionals. Moreover, health professionals involved with a specific pwp should communicate with each other and with the care coordinator, optimising the benefits for the pwp.

For change to occur, it is the physiotherapist's role to coach the pwp in self-management, in such a way that the he or she becomes motivated to change. It is essential to recognise that motivation to change is not a stable personality trait. In addition, the physiotherapist strives for adherence by supporting the pwp in becoming the owner of their management. This might be achieved by encouraging the pwp's autonomy through negotiating, providing and accepting the choices the pwp makes, even though they may not be the best evidenced, or may differ from the therapist's view.

The number of sessions and frequency required to support self-management is pwp specific. In general, a pwp with more complex problems, limitations in cognition or communication, a low educational level, a lack of a social network or a cultural background in which health professionals are expected to make all decisions (passive pwp), can be expected to require more intensive and prolonged support.

4.2.1 Behavioural change: long and short-term motivation

Self-management involves a patient-centred approach, focussing on behavioural change. This is applicable to all pwp, at any stage of their condition. A variety of behavioural interventions are described in the literature, although it unclear which specific strategy is best utilised in Parkinson's disease³⁶⁹. General strategies effectively applied in a wide range of chronic conditions have been shown to promote behavioural change, including motivational interviewing (a goal-oriented, patient-centred interviewing style aiming to change behaviour by facilitating intrinsic motivation) and the self-determination theory (focussing on competence, interaction and autonomy or ownership)³⁷⁰⁻³⁷⁶. Without a detailed description of these strategies, we would like to highlight the requirements for behavioural change that physiotherapists can support:

- Knowledge: the pwp has sufficient knowledge about his or her problem and benefits of interventions
- Concern: the pwp has a reasonable level of concern over his or her present and future limitations
- Competence: the pwp feels sufficiently competent to perform the required, new behaviour (self-efficacy)
- Self-esteem: the pwp considers him or herself worth the effort

The 5As model (Assess, Advise, Agree, Assist and Arrange), a patient-centred model frequently used for enhancing behavioural change, provides a framework to address these needs in clinical practice³⁷⁴. A detailed overview of what to target and examples of how to achieve this, using the 5As model, is provided in Table 4.2^{375;377-383}. It is supportive aiming to motivate to change and long-term adherence.

Table 4.2. Enhancing self-management and adherence using the 5As model

	What	Examples how to
Assess	<p>Current activities & strategies Main problem (using GAS) Beliefs & motivation: - Importance of change - Readiness to change and to accept advice - Self-efficacy - Willingness to be a partner in care Carer & social support</p>	<ul style="list-style-type: none"> Let the person talk <ul style="list-style-type: none"> - use single, open-end questions - endorse question-asking - reflect and summarise what the pwp says Show empathy, using verbal and non-verbal behaviour
Advise	<p>A change The importance of being a partner in care</p>	<ul style="list-style-type: none"> Ask-Tell-Ask <ul style="list-style-type: none"> - ask what the person wants to know - tell the required information - ask whether this was the information looked for - ask whether other questions remain Supply individualised information
Agree	<p>Upon goals Upon interventions Upon carer involvement</p>	<ul style="list-style-type: none"> Collaboratively set SMART* goals; suggest options: one short term (such as two weeks) and one long-term (such as three months) Collaboratively select interventions; suggest options regarding contents, frequency, duration and length of treatment period; ask for intervention preferences; let the pwp identify pros and cons of suggested options; negotiate how a programme can be tailored to personal needs Agree to what extent the carer needs to be involved Discuss at the start when to stop treatment (if any) and how to continue from there Beware of persons agreeing out of politeness or fear Offer decisional delay
Assist	<p>In anticipating barriers In using opportunities In correctly applying the intervention</p>	<ul style="list-style-type: none"> Examine the gap between current behaviour and set goals Identify at least one barrier (such as regarding safety, time or motivation) and brainstorm collaboratively how to overcome this Provide clear instructions (verbal and written) and demonstrate Let the person paraphrase and perform the activities agreed upon Provide positive feedback Explain benefits, such as <i>If you use an external rhythm, you will be able to cross the street much more safely</i> Use autonomy-supporting phrases, such as <i>What type of external rhythm would you prefer, perhaps a metronome or your own music?</i> Link interventions to daily routines
Arrange	<p>Support and follow-up for guidance, motivation and evaluation</p>	<ul style="list-style-type: none"> Supply materials & tools, such as an exercise diary or activity monitor Agree with pwp and carer upon when and how the carer may support, such as not to overload pwp with information Collaboratively agree upon ongoing contact and time to (intermittent) follow-up, such as by telephone or a consult Communicate with the other health professionals involved with that pwp, if the pwp agrees As long as necessary – that is as long as intrinsic motivation is not strong enough to maintain the behavioural change-, provide positive feedback focussed on achievements (for extrinsic motivation) Discuss possible non-adherence (go to <i>Assist</i>) Adjust ineffective interventions (go to <i>Assess</i>) Remember that self-management support in chronic conditions such as Parkinson's disease is an ongoing process

*SMART: Specific, Measurable, Attainable, Relevant and Time-based.

Motivation to change

There are two classical types of motivation generally described: intrinsic and extrinsic motivation. With intrinsic motivation, a specific behaviour is sufficiently rewarding in itself and therefore motivates and promotes its own continuation. For example, when exercising itself makes people feel good. Unfortunately, often this is not the case when people start to exercise, and at this stage, extrinsic motivation is required. Physiotherapists can encourage this by selecting goals (outcomes) of suggested therapeutic interventions that the pwp values highly; educate about the evidence of benefits, identify personal or environmental barriers and how to overcome these; ensure social support (such as from caregivers or peers); and focus on appropriate supervision^{271,383,384}. For example, in an exercise group, the sense of fun and belonging may act as motivation to attend again and to participate regularly. During exercising, the physiotherapist may increase extrinsic motivation by providing positive feedback on the performance of exercises and telling the pwp that their effort used to manage their condition is noted and valued.

Long-term adherence

For adherence into the long-term however, intrinsic motivation is most important: experiencing the actual value of exercise, enjoying it and hence being motivated to continue³⁷¹. The physiotherapist can support the pwp in selecting the optimal type, intensity and frequency of exercise. This will help to increase pwp feeling of treatment ownership. Also self-efficacy remains important: pwp with high self-efficacy are more than twice as likely to engage in regular exercise than those with low self-efficacy, independent of their disease severity²⁷¹. When treatment takes place within a team, all team members should aim to communicate and collaborate with the pwp and each other based on the pwp specific goals. This will ensure optimal, patient-centred care. wAfter termination of a supervised treatment period, pwp will often continue with a home exercise program, health gaming using systems like the Nintendo Wii (6.7.4 Use of e-health) or a community exercise group. Regular physiotherapy review will then support long-term adherence.

4.2.2 Training of pwp, carers and therapists to optimise self-management

The concept of self-management support and the strategies used in coaching patients is new to many physiotherapists. Specific education and training in order to gain the relevant expertise (such as in motivational interviewing) will be necessary. Information on this is often available through the national professional physiotherapy association.

Training to support self-management can be profitable also for pwp. Information on self-management courses, patient groups and online health communities is often available through the national Parkinson associations. The European Patient Education Programme Parkinson's (PEPP) is a general self-management training, which focuses on education of pwp and on psychosocial support, including elements of health promotion. A multidisciplinary team of experts from Estonia, Germany, Italy, The Netherlands, Spain and The United Kingdom developed this programme. Non-controlled studies have shown that the PEPP reduces psychosocial problems and the need for support in both pwp and their carers. The programme manual is available in English, Dutch and German.³⁸⁵⁻³⁸⁷ In some countries, educational courses are provided.

4.3 Carer Involvement

The involvement of the carers, such as relatives or friends, in the overall care process and therefore in the physiotherapy treatment, is desirable. Carers may be able to provide additional information to the impairments and limitations perceived by pwp in daily life, such as recall of fall events. Therefore, the GDG advises asking that pwp bring their carer to at least the first visit, if they agree. Moreover, carers can learn strategies to facilitate movement and support practice using trained strategies. Physiotherapists can educate carers to limit the number of instructions given at a time, break down movements and/or not to distract the pwp while walking. However, the Guideline Development Group would like to stress that it is up to the pwp to decide whether and, if so, how the carer will be involved. Moreover, carers should not be expected to fulfil the role of a therapist.

Chapter 5

Physiotherapy history taking & physical examination

5.1 How to decide upon the treatment goal?

Through history taking and physical examination, the physiotherapist and person with Parkinson's disease (pwp) determine whether there is an indication for physiotherapy³⁸⁸. The five core areas are targeted from both the pwp and the physiotherapist perspective. If the pwp agrees, it is helpful to include and consider the carer's perspective. If a pwp does not present red flags for physiotherapy intervention (5.13), an indication for treatment within the core areas of physiotherapy where this pwp needs supervision might include:

- self-management support, such as for behavioural change
- exercising to improve fitness and physical function or to prevent secondary complications
- practice to delay the onset of activity limitations
- training of compensatory strategies to decrease activity limitations.

Should the therapist consider that physiotherapy is not the appropriate intervention at a particular time, this needs discussion with the pwp. In addition, the referring physician needs to be informed. When a pwp reports impairments or limitations, which are outside the scope of physiotherapy, it is important to consider advising the pwp to consult another health or social care professional (Appendix 11). If there is an indication for physiotherapy intervention, the physiotherapist and the pwp need to negotiate to agree upon the treatment goals, the applicability of this Guideline and the interventions to select. These goals can relate to prevention of secondary complications, maintenance and improvement. They are essential to aid decisions upon which intervention to choose. Therefore, the GDG advises the physiotherapist to take sufficient time to carefully select treatment goals and appropriate measurement tools, ensuring a structured process that is also made apparent in records.

5.2 How to incorporate measurement tools?

5.2.1 What are the benefits of using measurement tools?

The GDG would like to stress that a measurement tool only bring benefits if the information it provides is interpretable. Therefore, the GDG advises that physiotherapists who are unfamiliar with the recommended tools participate in education in the use of these tools or search for peers to train them. Carefully selected and properly used measurement tools support physiotherapists and pwp to make structured, objective and transparent:

- Identification of (risk for) impairments, activity limitations and participation restriction, as well as environmental barriers
- Goal setting to meet the pwp's needs
- Development of an appropriate treatment plan targeting the identified problems
- Communication with each other, as well as with other health professionals

Moreover, use of measurement tools during and at completion of a treatment period:

- Support the pwp to adjust appropriate short and long term goals
- Motivate the pwp in adherence to the treatment to meet these goals

- Motivate the pwp in self-management
- Enable monitoring of change due to the intervention
- Provide a record of changes that identify future risks for falling and loss of physical capacity
- Support the physiotherapist and pwp in deciding upon (dis)continuation or change of treatment
- Permit communication with the referring physician and other health professionals

5.2.2 Which tools are recommended?

The GDG selected 18 measurement tools which are valid and reliable when used for pwp, can be used in context of healthcare and physiotherapy practice across the European countries and are feasible in terms of time and costs (Table 5.2). In addition, six of these can also be used to monitor change (5.15). Appendix 14 provides an overview of the measurement tools according to the ICF framework.

Table 5.2 Recommended measurement tools and estimated time required for their use				
PWP at home				
Pre-assessment Information Form (PIF) (Appendix 2) <i>Supportive: 'Freezing of gait' video</i>				
HISTORY TAKING				
What information is collected is based on which information is already provided with the PIF <i>Supportive: Quick Reference Card 1</i>				
Only in pwp who report a (near) fall on the PIF: remaining questions History of Falling Only in pwp who report freezing on the PIF: additional questions New Freezing of Gait Questionnaire Only in pwp who report a previous (near) fall or fear of falling: ABC* or FES-I (for less ambulant pwp)				
PHYSICAL EXAMINATION				
Which core areas need further assessment is based on the outcome of History Taking – often two core areas				
Balance	Gait	Transfers	Dexterity	Physical Capacity
• Push & Release (2")	• 10MW* (5") • 6MWD* (8")	Bed related: • M-PAS Bed (10")		• 6MWD* with Borg 6-20 (8")
Stationary: • BBS* (20")	• Rapid Turns (2")			
Transfers related: • M-PAS Chair (5") • FTSTS (2")		Chair related: • M-PAS Chair (5") • FTSTS (2")		• FTSTS (2")
Gait related: • M-PAS Gait & TUG* (5") • Rapid Turns (2") • DGI*, FGA or Mini-BESTest (15")	• M-PAS Gait & TUG* (5")	• TUG* (5")		

"minutes; ABC, Activities Balance Confidence Scale; FES-I, Falls Efficacy Scale International; M-PAS, Modified Parkinson Activity Scale; TUG, Timed Up & Go; FTSTS, Five Times Sit To Stand; DGI, Dynamic Gait Index; FGA, Functional Gait Assessment; BBS, Berg Balance Scale; 10MW, 10 Meter Walk; FOG, freezing of gait; 6MWD, Six Minute Walk Distance; # no tools with good validity, reliability and feasibility are available for this core area; *can be used for evaluation (5.15).

5.2.3 When and how to use these tools?

For each recommended tool, this Guideline provides a description of how to use it as well as a scoring form (Appendix 5). For physiotherapists who do not use electronic or paper patient records specific to their work setting, this Guideline provides an ICF-based form to structure clinical assessment and reporting (Appendix 4). As a result of medication intake, a pwp's impairments and activity limitations can vary greatly during the day. The GDG advises to use questionnaires and tools assessing physical capacity when the pwp is functioning optimally. However, the GDG also recommends assessment of activities at the times of the day when they are most limited. Most commonly, this is during the off states. Other activity limitations, such as balance, may occur in both on and off states. If such differences in ability are reported by the pwp, the GDG recommends assessment in both periods, and for the physiotherapist to schedule the time of appointments accordingly. For example, use the first visit to assess the pwp in the on period and a second visit to assess the pwp in the off state. Circumstances of measurement can influence the outcome, therefore, the GDG advises to record the time of assessment (in relation to medication state and time of day) and to repeat measurements as near to the same time as possible during the follow-up review.

GDG advice: Record circumstances of measurement and copy circumstances during follow-up measurements as closely as possible

- *Time of the day and tiredness of the pwp*
- *Time after medication intake and dose*
- *If applicable to the specific pwp: on or off state*
- *Specific location, such as in the clinic, at the pwp's home or outdoors*
- *Materials used, such as a bed with a hard mattress or a 43 cm chair with soft seat*
- *Clothes and shoes worn by the pwp*
- *Assistive devices or personal assistance used*

5.2.4 What about time constraints?

The GDG advises careful selection of appropriate tools for each individual as no single pwp requires the use of all 18 tools. The GDG however does recommend using the Pre-assessment Information Form, the 10 Meter Walk and the Goal Attainment Scaling for each pwp (Table 5.2.4).

GDG advice: Measurement tools to use in all pwp

- *Pre-assessment Information Form (PIF; 5.3.1) to know what to target in history taking and physical examination, including:*
 - *First items of the History of Falling Questionnaire*
 - *First items of the Parkinson's specific Index for Parkinson's Disease (PSI-PD)*
 - *First items of the New Freezing of Gait Questionnaire*
 - *Physical activity levels*
- *10 Meter Walk (10MW; 5.7.4) to use the 3-Step Falls Prediction Model for decision support regarding falls prevention*
- *Goal Attainment Scaling (GAS; 5.12) to support setting and evaluating SMART goals*

Outcome of the history taking supports the physiotherapist to decide upon which core areas to assess physical. For each core area, except for dexterity, the GDG recommends specific tools (Table 5.2). Most of these tools are recommended to gain structured insight into the pwp's most important problems. Only a few tools can evaluate change. Using the recommended tools will take time. However, the information gathered is essential for gaining optimal insight into the impairments and activity limitations, setting goals and monitoring change. Given the complexity of Parkinson's disease and its related slowness, the GDG recommends using at least two sessions to carefully assess, set goals and select an intervention. Starting treatment on the first visit, without thorough assessment may result in providing low quality, non-patient centred care without reaching goals. The GDG recommends sharing this with the pwp at the first visit, endorsing feasible expectations.

GDG advice: assessment time

Inform the pwp that at least two physiotherapy sessions are needed to carefully assess the pwp's functioning, set goals and select the optimal intervention

5.3 How to support people with Parkinson's disease in preparing for their first visit?

A pwp is often slower when moving around as well as in their thinking and planning processes. When possible, ask pwp to fill in a Pre-assessment Information Form (PIF) at home, before their first visit (Appendix 2). Thus, the time available during the physiotherapy visits is optimally used.

5.3.1 Pre-assessment Information Form

Table 5.3.1a WHO recommendations for physical activity levels

In adults (18 to 64 years):

- Aerobic physical activity for:
 - ≥ 150 minutes / week at moderate intensity
 - or ≥ 75 minutes / week at vigorous intensity
 - or an equivalent combination thereof
- The aerobic activity should be performed in bouts of at least 10 minutes duration
- Muscle-strengthening activities involving major muscle groups on ≥ 2 days / week
- For additional health benefits:
 - 300 minutes of moderate intensity aerobic physical activity / week
 - or 150 minutes of vigorous intensity aerobic physical activity / week
 - or an equivalent combination thereof

In old age (≥ 65 years), equal to adults, but in addition:

- In case of poor mobility: physical activity to enhance balance and prevent falls on ≥ 3 days / week

GDG advice: Pre-assessment Information Form (PIF)

- *Send or hand-out the PIF days before the first physiotherapy visit, allowing the pwp time to consider the most important limitations; if this is not feasible, hand it out to be completed in the waiting room*
- *Inform the pwp about the importance, where applicable, of asking the carer for support when filling in the PIF*

With the PIF, information related to the core areas of physiotherapy is gathered regarding: a) the pwp's important problems; b) freezing of gait; c) falls; and d) physical activity levels

a) To the pwp important problems

Many pwp are not aware what problems physiotherapy addresses. Therefore, they may not fully inform their physiotherapist on present activity limitations. The Patient Specific Index for Parkinson's Disease (PSI-PD) provides a list of mainly activity limitations that pwp frequently encounter, perceive as being important and can be targeted by physiotherapy³⁸⁹. Thus, the PSI-PD supports structured and comprehensive identification of these problems. As a part of the PIF, pwp mark all items on the PSI-PD they encounter. During the first visit, the physiotherapist supports the pwp to prioritise these items (5.4.2).

b) Freezing of gait

The PIF includes a question from the New Freezing of Gait Questionnaire (NFOG-Q)³⁹⁰. This question is supportive for identifying pwp at fall risk (table 5.11). It is often difficult to provoke freezing during clinical assessment, therefore physiotherapists are dependent on the pwp's (and carer) self-report. However, many pwp who experience freezing do not recognise it as such. Part of this may be explained because many pwp think of freezing as coming to a stop, whereas often the stop is not complete with some residual trembling in place or forward shuffling³⁹¹. The GDG recommends that pwp watch the online video on freezing by Nieuwboer and Giladi, preferably before their first visit, otherwise during their first visit to increase the probability of recognising a freezing episode.. The video can be viewed at www.parkinsonnet.info/euguideline.

Table 5.3.1b Examples moderate and vigorous intensity activities

Domain	Examples moderate physical activity	Examples vigorous physical activity
Recreation, sports and leisure-time activities	Walking on flat surface (4.5 to 6.5 km/hr)* Bicycling at 8 to 15 km/hr* Recreational swimming Playing doubles in tennis Ballroom dancing Playing golf Table tennis Horseback riding walking Bowling Yoga General exercises (at home)	Walking uphill or upstairs, or running (≥ 8 km/hr)* Bicycling ≥ 16 km/hr, or uphill* Swimming steady paced laps Playing singles in tennis Aerobic dancing Field hockey Soccer Horseback riding jumping Jumping rope Martial arts (such as judo, karate) Most competitive sports
Job-related activities, housework, house maintenance and activities related to caring for family	Farming Carrying light loads Mowing, sweeping and gardening Painting outside Washing windows Cleaning gutters Elder care (such as dressing, moving)	Fire fighting and forestry Heavy lifting Digging, shovelling and chopping Heavy construction Scrubbing floors Carrying groceries up stairs Wheeling a wheelchair (self)

* Moderate equals approx. 7,000 (in old age) to 8,000 steps/hr (for adults); vigorous approx. 8,000 to 9,000 steps/hr in healthy people; in pwp, with gait impairments present , these levels will be achieved at lower frequencies

c) Falls

For falls management, it is important to appreciate the complex and multifactorial pathophysiology, including impairments and activity limitations in balance and gait³⁹². Therefore, the GDG recommends routine falls assessment. As a first step in assessing fall risk, the GDG recommends using the History of Falling Questionnaire to gain insight the history of falling and in the confidence in keeping balance. The two main questions of this questionnaire are included in the PIF: has this pwp had any (near) falls in the past year? If any of these two questions is answered positively, the additional questions of the History of Falling Questionnaire are recommended to address during History Taking. The question on previous falls supports identifying pwp at fall risk (table 5.11).

d) Physical activity levels

The GDG advises physiotherapists to follow the recommendations for physical activity levels described by the World Health Organization (WHO; Table 5.3.1a)³⁹³. To gain insight into the pwp's physical activity levels, questions based on the NHS General Practice Physical Activity Questionnaire³⁹⁴ are included in the PIF: activities on odd rows require 'moderate intensity', whereas activities on even rows require 'vigorous intensity'.

GDG advice: physical activity levels

Compare the pwp's physical activity levels reported in the PIF to the WHO recommendations

National health programmes in most countries endorse these recommendations, perhaps slightly adapted. For example, in many countries it is recommended to engage in at least 30 minutes of moderate-intensity physical activity on most, preferably all, days of the week³⁹⁵. Older adults who cannot do the recommended amounts of physical activity due to health conditions are advised to be as physically active as their abilities and condition allow. Intensity of exercise is a subjective classification. Most activities can be carried at either moderate or vigorous intensity (Table 5.3.1b)³⁹⁵⁻³⁹⁷. Moderate intensity activities refer to activities that take moderate physical effort and make people breathe somewhat harder than normal with an increase in heart rate, but they can still carry out conversation, whereas vigorous intensity activities take hard physical effort and makes people breathe much harder than normal so conversation is difficult or impossible. The intensity relates to the energy expenditure, the ratio of work metabolic rate to a standard resting metabolic rate (MET). One MET is defined as the energy expenditure for sitting quietly, which, for the average adult, approximates 3.5 ml of oxygen uptake per kilogram of body weight per minute (1.2 kcal/min for a 70-kg individual). For example, a 2-MET activity requires two times the metabolic energy expenditure of sitting quietly. A moderate intensity equals 3.5 to 6 METs whereas vigorous intensity equals greater than 6 METs (Table 5.3.1b). A more detailed overview of activities and corresponding METs from the 2011 Compendium of Physical Activities³⁹⁸. It is however important to keep in mind that what is moderate intensity to a 40-year-old man might be vigorous for a man in his 70s or a 60-year-old pwp. As witnessed in the general population, pwp will differ in fitness levels. This is even made more variable by the clinical stage they are in with this progressive condition. Moreover, due to the Parkinson's specific impairments and activity limitations, pwp are likely to achieve higher levels of intensity than their healthy contemporaries carrying out the same activities.

5.4 History taking: What to address?

Tools recommended to select from in History taking: ICF level (ICF code)

- *Patient Specific Index for Parkinson's disease: Performance measure of activities and participation (d1-d9)*
- *History of Falling Questionnaire: Performance measure of maintaining a body position (d415)*
- *Activities Balance Confidence Scale: Performance measure of changing and maintaining body position (d410-d429)*
- *Falls Efficacy Scale International: Performance measure of changing and maintaining body position (d410-d429)*

The objective of history taking is to gain insight into the severity and nature of what bothers the pwp and to decide upon which impairments and activity limitations to target during the physical examination. In addition, the pwp's own tricks to overcome specific problems and expectations regarding the interventions and treatment outcome are recorded. During History Taking, information reported on the PIF can be further clarified.

The physiotherapist also aims to assess whether the pwp's expectations are realistic. When mental factors or physical disorders result in communication difficulties, and when the pwp is mainly dependent on others for care, it is necessary to involve the carer to get an accurate picture of the pwp's problems.

5.4.1 Quick Reference Card 1 (QRC1)

QRC1 provides an overview of impairments, activity limitations and participation restrictions of interest. The GDG developed QRC1 using the QRC1 from the 2004 KNGF Guideline¹⁴⁹, the 72-item MDS-Unified Parkinson's Disease Rating Scale (MDS-UPDRS)²²⁹ and the 39-item Parkinson's Disease Questionnaire for Quality of Life (PDQ-39)³⁹⁹. These two tools are often used and of high importance in research to evaluate the efficacy of physiotherapy in groups of pwp. However, in clinical practice in individual pwp, detection of benefits is not expected by using these tools in isolation. Moreover, most of the information gathered with these tools is not relevant for goal setting or for deciding upon the physiotherapy intervention. There is some clinical applicability however, as several items from the MDS-UPDRS allow identification of orange (caution) and red (contra-indication) flags for physiotherapy treatment (5.13). Issues in the QRC1 related to the MDS-UPDRS are marked with an asterisk. Physiotherapists working in a multidisciplinary team may need to use certain items of the MDS-UPDRS. For this, training is required and costs are involved for non-MDS members⁴⁰⁰.

Mental functioning

As mental functioning of the individual pwp influences physiotherapy options, it is preferable that the referring physician informs the therapist of any identified issues on the referral form. Specifically gained information regarding mental functions is of importance as most physiotherapists are not trained to assess these. For example, the neurologist may be able to provide results of the Mini Mental State Examination (MMSE)⁴⁰¹, with important information regarding attention, executive functions and memory. Another tool for mental functioning increasingly used, and with a greater ability to detect differences between pwp than the MMSE, is the Scales for the Outcome of PARKinson's disease COGNition (SCOPA-COG)^{402;403}. This tool includes five memory tasks, four attention tasks and seven tasks for executive function. It is available in several languages⁴⁰⁴. Other examples of tests used for mental functioning include:

- Attention: Serial Sevens test or by saying the months of the year backwards - impaired on the Sevens test >1 wrong answer is given; on the months test in case of >1 month left out, incorrect order of months or test taking >90 sec
- Executive functions: Verbal fluency test - as many words starting with an 's' within 1 minute (impaired when <10 words), or with the clock drawing test (impaired when numbers on wrong spot or arms not placed at 10 minutes past two)

- Memory: The person is asked to remember three words given and asked to recall them some minutes later (impaired when <3 words remembered)

Detailed information and scoring forms of these tests are not provided as they fall outside the scope of this Guideline. The GDG advises physiotherapists to gain information on mental functioning from the referring physician, or advise a pwp to undertake medical or neuropsychological consultation.

5.4.2 Patient Specific Index for Parkinson's Disease (PSI-PD)

Of all presently perceived activity limitations marked on the PIF, the pwp selects the three to five most important ones: What bothers you most of all? What would you like to improve most of all? This prioritising is often difficult for the pwp, therefore, the GDG advises this is done at the first visit with support of the physiotherapist. The prioritisation of limited activities supports decision making towards the specific core areas for physical examination (QRC2). Together with other information collected through history taking and physical examination, the prioritised activity limitations can be used for goal setting using the Goal Attainment Scaling (5.12.1).

5.4.3 History of Falling Questionnaire

If any of the two items of the History of Falling Questionnaire in the PIF (that is question 7 or 8) are answered positively, the GDG recommends completing the remaining questions during history taking. These additional questions will provide insight into the circumstances of the falls. The questionnaire uses a specific language pwp are familiar with, thus increasing the chance falls are recalled⁴⁰⁵. Details of locations and landings of falls are generally reliably recalled. The activities during which the falls occur, their frequency and avoidance-strategies, however, may necessitate probing by the physiotherapist⁴⁰⁵.

5.4.4 New Freezing of Gait Questionnaire (NFOG-Q)

If the item of the NFOG-Q in the PIF (that is question 10) has been answered positively, the GDG recommends completing the remaining questions of the NFOG-Q during history taking⁴⁰⁶. These additional questions will provide insight frequency and duration of freezing episodes related to turning and when initiating the first step.

5.4.5 Activities Balance Confidence Scale (ABC)

The ABC is a 16-item questionnaire in which pwp rate their balance confidence in performing various ambulatory activities without falling.⁴⁰⁷ It can be also administered by face-to-face or telephone interview. Items are rated on an 11-point ordinal scale; a score of 0% represents no confidence, while a score of 100 % represents complete confidence. The individual items are of importance for making decisions about which aspects of balance to target and the overall score is of importance for assessment of fall risk and for evaluation,. The overall score is calculated by adding the 16 item scores and then dividing this by 16. The ABC scale can be used for higher-functioning pwp to support decision making towards physical examination and treatment. It is supportive in identifying pwp who are at fall risk (Table 5.11)⁴⁰⁸. In addition, it can be used to evaluate change. Moreover, it is an determinant of functional walking capacity as measured with the 6MWD³¹³.

5.4.6 Falls Efficacy Scale International (FES-I)

In less ambulant pwp, the FES-I can be considered as an alternative to the ABC⁴⁰⁹. The FES-I is developed by the Prevention of Falls Network Europe (www.profane.eu.org). It assesses how concerned people are about the possibility of falling during the performance of indoor, outdoor and social activities⁴⁰⁹. The 16 activities items are scored on a four point ordinal scale

from 1 (not at all concerned) to 4 (very concerned). An interview-based administration method is recommended in frail people, especially those with cognitive impairment.⁴¹⁰ Several versions of FES exist with a different number of items, such as the FES, the FES-I, the Short FES-I, and the FES(S). The FES-I is preferred as it has been validated in many languages⁴¹⁰⁻⁴¹⁹. When clinical time is limited, the Short FES-I can be used. This short form includes items 2, 4, 6, 7, 9, 15 and 16 of the original FES-I. However, it should be noted that the FES-I, rather than the short FES-I, allows for better insight into indoors and outdoors activity-related fear of falling, thus providing essential information for goal setting and selection of the intervention. Finally, because of inadequate knowledge of psychometric properties of the FES-I for pwp, it should be used and interpreted with caution.

5.5 Physical examination: What to examine?

GDG advice: physical examination

The results of history taking will lead to exploration of one or more core areas through a physical examination

If feasible, examine activity limitations at the location where and time when they are bothersome to the pwp

5.5.1 Quick Reference Card 2 (QRC2)

QRC2 provides a tick list of most frequent impairments and activity limitations for each core area. In addition, specific tools are recommended to gain in depth insight into the impairments and activity limitations in a structured and objective way. Impairments reflect the problem of the physiological and psychological body functions, whereas activity limitations are difficulties an individual may have in executing activities. Even though physiotherapy aims to prevent activity limitations and to improve or maintain activities and participation, the GDG also advises assessment of impairments. The aim of assessing capacity within a certain activity (such as walking) is to indicate the highest probable level of functioning that a person may reach in a given domain at a given moment. Therefore, as earlier mentioned, it is important to document the circumstances of the assessment (Section 5.2.3). Several tools, such as the Timed Up and Go and the Modified Parkinson Activity Scale can be used for more than one core area, whilst other tools are core area specific. Some tools are recommended for identification of impairments and limitation only, whereas others can also be used to monitor change.

5.6 Measurement tools for Balance

Tools recommended to select from when assessing Balance: ICF level (ICF code)

- *Modified Parkinson Activity Scale: Chair and Gait: Capacity measure of mobility (d4)*
- *Timed Up and Go: Capacity measure of mobility (d4)*
- *Dynamic Gait Index: Capacity measure of changing and maintaining body position (d410 – d429)*
- *Functional Gait Assessment: Capacity measure of changing and maintaining body position (d410-d429)*
- *Mini-BESTest: Capacity measure of changing and maintaining body position (d410 – d429)*
- *Berg Balance Scale: Capacity measure of changing and maintaining body position (d410 – d429)*
- *Five Times Sit and Stand Test: Measure of muscle power and endurance (b730 and 740) and capacity measure of changing and maintaining body position (d410-d429)*
- *Push and Release test: Measure of involuntary movement reaction functions (b755)*

Changing and maintaining body position requires the interaction of many systems. Moreover, it encompasses static balance, maintaining equilibrium when stationary, and dynamic balance, maintaining equilibrium when moving. Therefore, a comprehensive assessment is needed, using several, but not all of the recommended multiple tools.

The Modified Parkinson Activity Scale and the Timed Up and Go are recommended in all pwp for assessment of the capacity of changing and maintaining body position during functional mobility. The choice for other tools to assess the capacity depends on whether the pwp's reported main complaint is related to static or dynamic balance, and on what the acquired information will be used for (such as what to address in the intervention; to estimate fall risk; for evaluation purposes).

In a pwp reporting difficulties maintaining balance when walking, tools that demand moving base of support are appropriate: the Dynamic Gait Index (DGI), the Functional Gait Assessment (FGA) or the mini-BESTest. In pwp in whom most problems occur during stationary base of support, such as standing and weight shifting, the GDG recommends using the Berg Balance Scale (BBS).

For each of these tools, the overall score is supportive in identification of pwp at risk for falling (Table 5.11) and, except for the FGA, for evaluation of change (Table 5.15). Scores on the individual test items are supportive for identification of underlying impairments, such as poor dynamic control of centre of gravity or abnormal weight distribution. This is relevant information towards goal setting and selection of intervention. In addition, measures for impairments underlying balance are needed to assess involuntary movement reaction functions and lower extremities muscle strength and power. For these purposes, the GDG recommends using the Push and Release test and the Five Times Sit and Stand Test respectively. Finally, other factors contributing to fall risk need to be taken into account (5.11).

5.6.1 Modified Parkinson Activity Scale (M-PAS)

The M-PAS is a capacity measure, supporting detailed insight into the most important activity limitations in pwp that can be targeted by physiotherapy⁴²⁰. It assesses limitations of functional mobility, including aspects of balance, gait and transfers. The test consists of 18 activities covering three aspects of functional mobility: Chair Transfers (2 items), Gait Akinesia (6 items) and Bed Mobility (8 items). The M-PAS Gait Akinesia includes the TUG test that can be carried out with a motor dual task (walking whilst carrying a tray with cups of water) or a cognitive dual task (walking whilst counting backwards). With the M-PAS Gait Akinesia, the activity is scored qualitatively. Simultaneously, the time needed to perform the activity can be measured, thus providing the TUG scores. It is important that the pwp wears the same footwear during every measurement⁴²¹. Bed transfers are tested with and without the use of a duvet or blanket, and the quality of movement is scored. All items are scored on an ordinal scale, ranging from 4 (best) to 0 (impossible or dependent on help). Thus, the M-PAS gives relevant information towards goal setting and selection of the intervention. Depending on the core area(s) selected for physical examination, different parts of the M-PAS can be used. To assess balance, the M-PAS parts Chair Transfer and Gait Akinesia are recommended.

5.6.2 Timed Up & Go (TUG)

The TUG is a quick capacity measure for functional mobility⁴²². It measures the time needed to rise from an armchair, walk three meters, turn, walk back and sit down again. The TUG is included in the M-PAS (part Gait Akinesia) and the Mini-BESTest. Longer times to complete the TUG are associated with increased fall risk (Table 5.11). To increase accurateness to identify pwp at risk for falling, the GDG recommends testing during the off stage.⁴²³ In addition to the timed score, the GDG recommends documenting turn safety.

5.6.3 Mini-BESTest, Dynamic Gait Index (DGI) and Functional Gait Assessment (FGA)

The Mini-BESTest, Dynamic Gait Index (DGI) and Functional Gait Assessment (FGA) allow for evaluation of static and dynamic balance. As all three tools have good psychometric properties, are feasible for use and are supportive for identifying pwp at fall risk (table 5.11). All three have benefits and drawbacks:

- The Mini-BESTest covers most activities and has best psychometric properties, but its responsiveness is unknown: it cannot however be used for evaluation
- The DGI and Mini-BESTest have an established cut-off point for being at risk for falling
- The FGA is considered the improved version of the DGI and includes an item on backward walking, but involves a time-consuming preparation period: taping the floor on approximately 15cm, 25cm and 38cm outside a 30cm wide walkway is required
- Many items of the FGA and DGI are comparable, by which they might be combined

The GDG recommends selecting any of the three tools, based on the current clinical expertise of the physiotherapist in using these tools and need for a balance specific tool for evaluative purposes.

With the mini-BESTest, balance when performing 14 activities is scored⁴²⁴. These include the TUG (5.6.2), the Push & Release Test (5.6.6) and quality of gait while changing walking speed, avoiding obstacles and pivot turning. Each of the 14 MiniBESTest items is scored from 0 to 2, with 0 indicating the lowest level of functioning.

With the DGI, balance when performing eight gait related activities is scored⁴²⁵. These include quality of walking speed change, going around and over obstacles and stair walking, as well as the number of steps required for a pivot turn. The performance is scored from 0 to 3, with 0 indicating the lowest level of functioning. The DGI maximum score is 24. It is supportive in identifying pwp who are at risk of falling (Table 5.11) and can be used for evaluation of change over time (Table 5.15). A drawback to the DGI is the lack of an item related to backward walking. Therefore, the GDG recommends using the FGA with the DGI. To do so, only three more activities need assessment: walking with a narrow base of support, walking backwards and walking with eyes closed. With these activities and all items of the DGI except for 'ambulation around obstacles', also a separate FGA score can be calculated⁴²⁶. The maximum score of the FGA is 30, with higher scores indicating better function. The FGA score allows for further identification of those pwp at risk of falling. Specifically the item on backward walking provides important information related to balance during chair transfers. Again, to increase accurateness to identify pwp at risk for falling, the GDG recommends testing during the off stage⁴²³.

5.6.4 Berg Balance Scale (BBS)

The 14-item Berg Balance Scale (BBS) assesses activity limitations in the performance of everyday life activities requiring balance⁴²⁷. Items involve functional tasks such as steps required for a pivot turn, sit to stand, several tests for static balance with different base of supports, functional reach, picking an object up from the floor and stepping on a stool. The items are scored from 0 to 4, with 0 indicating the lowest level of function. The maximum score is 56. The BBS is supportive for identifying pwp at fall risk (table 5.11). A drawback of the BBS is that many pwp score at maximum. This ceiling effect could be because Parkinson specific activity limitations with dual tasks and freezing are not assessed even though in some pwp item 11 may result in freezing. Moreover, the BBS does not include walking. Therefore, the GDG recommends using the BBS only in less mobile pwp in later stages and for pwp who mainly have problems with stationary balance.

5.6.5 Five Times Sit to Stand (FTSTS)

The FTSTS is a quick measure of balance which is supportive in identifying pwp who are at risk of falling (Table 5.11)⁴²⁸. The time needed to rise from a 43-centimetre chair is measured. The GDG recommends using the FTSTS in pwp whose balance when performing transfers is questioned, in combination with the Push & Release Test. The FTSTS is supportive for identifying pwp at fall risk (table 5.11). In contrast with the DGI/FGA (5.6.3) and the BBS (5.6.4), this test does however not provide detailed information on balance limitation during gait related activities and stationary balance.

5.6.6 Push & Release Test

The Push & Release Test assesses balance control in quiet stance⁴²⁹. The Push & Release Test provides information on involuntary movement reaction functions which are of importance to maintaining balance when walking backwards (such as when opening a door or sitting down on a chair; see FGA) and for walking on a slippery surface. To carry out the Push and Release Test, the physiotherapist stands behind the pwp, hands against the scapulae, and asks the pwp to lean back. Then the hands are suddenly removed. Balance performance is scored on a five point ordinal scale, ranging from 0 (recovers independently with one step of normal length and width) to 4 (falls without attempting a step or unable to stand without assistance).

Most neurologists and many therapists are more familiar with the pull test (such as MDS-UPDRS item 3.12), used to diagnose balance problems in Parkinson's through assessing the ability to withstand sudden perturbation when suddenly pulled backwards off balance. However, the GDG advises use of the Push & Release Test, as it is more sensitive when used in the off states, is more feasible to administer it in frail pwp and has better face validity for physiotherapy. Nevertheless, when used for communication with a referring neurologist only, physiotherapist may choose to use the pull test as described in the MDS-UPDRS (5.4.1).

5.7 Measurement tools for Gait

Tools recommended to select from when assessing Gait: ICF level (ICF code)

- *Modified Parkinson Activity Scale, parts Chair and Gait: Capacity measure of mobility (d4)*
- *Timed Up and Go : Capacity measure of mobility (d4)*
- *Six-Minute Walk: capacity measure of walking (d450)*
- *10 Meter Walk: capacity measure of walking (d450) AND Measure of gait pattern functions (b770)*
- *Rapid Turns test: Measure of gait pattern functions (b770)*

5.7.1 Modified Parkinson Activity Scale (M-PAS)

The GDG recommends using the M-PAS part Gait Akinesia to assess the quality of gait (5.6.1).

5.7.2 Timed Up & Go (TUG)

The GDG recommends using the TUG to assess walking speed during functional mobility (5.6.2).

5.7.3 Six-minute Walk (6MWD)

The six-minute walk (6MWD) allows for objective assessment and evaluation of walking distance⁴³⁰. Moreover, it allows for assessment and evaluation of exercise capacity (5.10.1) and prolonged observation of gait. The distance walked on a flat, hard surface in a period of 6 minutes is measured⁴³¹. The 6MWD is performed indoors, along a long, flat, straight, enclosed corridor with a hard surface. It is important that the pwp wears the same footwear at each assessment and that the physiotherapist encourages the pwp to the same extent^{421;432}. The GDG recommends using the Borg Scale 6-20 when performing the 6MWD (5.10.2) to provide information of the individual's rate of perceived exertion whilst undertaking the test.

5.7.4 10 Meter Walk (10MW)

Walking speed is of importance to pwp's safety, such as when crossing the street. With the 10 Meter Walk (10MW), both comfortable and fast walking speed can be assessed and evaluated¹³¹. In addition, it allows for determination of stride length, important if considering the use of visual cues, and cadence (step frequency), important if considering the use of auditory cues (6.6.1). If necessary, walking aids may be used during the test. When space available is insufficient, the 10MW can be shortened to a 6MW. These tests have not been validated to be used in monitoring change. The 10MW has not been validated to evaluate dual task gait. It is supportive for identifying pwp at fall risk (table 5.11).

5.7.5 Rapid Turns test

For pwp who report freezing on the questions of the PIF, the GDG recommends using the NFOG-Q to gain insight into the prevalence and severity of their freezing. In addition, the GDG recommends using the Rapid Turns test to try to provoke freezing and know what to target with the intervention³³¹. With the Rapid Turns test, the pwp is asked to perform repeated full, narrow turns, in both directions, and at high speed³³¹. If this still does not provoke a freezing episode, dual tasks can be added to the task. It is often difficult to distinguish festinating steps that occur before freezing from pure festination without subsequent freezing of gait³⁹¹. To differentiate voluntary stops from freezing of gait, use the following characteristics of freezing of gait³⁹¹:

- A flexed posture with fixed flexion in the hip, knee and ankle joints
- Often an incomplete stop, with some residual trembling in place or forward shuffling
- Often preceded by a progressive decrease in step length and increase in cadence
- The pwp experiences the feeling of being glued to the floor

5.8 Measurement tools for Transfers

Tools recommended to select from when assessing Transfers: ICF level (ICF code)

- *Modified Parkinson Activity Scale, parts Chair and Bed: Capacity measure of mobility (d4)*
- *Timed Up and Go: Capacity measure of mobility (d4)*
- *Five Times Sit and Stand Test: Measure of muscle power and endurance (b730 and 740) and capacity measure of changing and maintaining body position (d410-d429)*

5.8.1 Modified Parkinson Activity Scale (M-PAS)

To assess the quality of either bed or chair transfers, Chair Transfer and Bed Mobility of the M-PAS (5.6.1) are recommended.

5.8.2 Timed Up & Go (TUG)

The GDG recommends using the TUG to assess the speed of a chair transfer combined with gait and turning (5.7.2).

5.8.3 Five Times Sit to Stand (FTSTS)

The FTSTS is a quick measure of balance during a chair transfer (5.6.5).

5.9 Measurement tools for Dexterity

Tools recommended to select from when assessing Dexterity: ICF level (ICF code)

No tools specific to assess carrying, moving and handling objects can be recommended, as not validated for the population of pwp

The only tool for dexterity with assessed validity, reliability and responsiveness in pwp is the Nine-hole Peg Test⁴³³. It assesses fine hand and finger movement and may be supportive in evaluating training of fine hand motor function. However, it gives no insight into quality of performance or in what to target in treatment. Moreover, costs are involved in its use. Therefore, the GDG only advises using it if it is readily available at the work location (often in hospitals when a department for occupational therapy is present)

5.10 Measurement tools for Physical Capacity

Tools recommended to select from when assessing Physical Capacity: ICF level (ICF code)

- *Six-minute walk with Borg Scale 6-20: Measure of exercise tolerance functions (b455)**
- *Five Times Sit and Stand Test: Measure of muscle power and endurance (b730 and 740) and capacity measure of changing and maintaining body position (d410-d429)*

5.10.1 Six-minute Walk (6MWD)

The six-minute walk (6MWD) allows for objective assessment and evaluation of sub-maximal level of functional exercise capacity and walking distance, as well as for prolonged observation of gait (5.7.3). In accordance with the recommendations of the American Thoracic Society Statement, the use of a treadmill for 6-minute walk testing is not recommended as people are unable to pace themselves on a treadmill⁴³¹. The GDG recommends using the 6MWD when the physical capacity of the pwp is questioned, i.e. when low levels of activity are reported on the PIF. When the distance walked during the 6MWD is reduced, a thorough search for the cause of the impairment is warranted, which should also include assessment of muscle power. In addition, referral onwards for the following tests may then be helpful: pulmonary function, cardiac function, ankle–arm index, nutritional status, orthopaedic function, and cognitive function⁴³¹. When the 6MWD is used to evaluate change in endurance, the absolute change should be reported. For example, ‘the pwp walked 50 m farther’. The GDG recommends using the Borg Scale 6-20 when performing the 6MWD to assess exercise tolerance functions.

5.10.2 Borg Scale 6-20

For many pwp, physiotherapy treatment includes exercising, be it supervised or not. The Borg Scale 6-20 measures perceived exertion⁴³⁴. It is a valid measurement tool to determine the exertion intensity, showing good correlations with physiological criteria such as heart rate, in healthy middle-aged and elderly populations^{435;436}. Although the validity, reliability and feasibility of the Borg Scale 6-20 have not been evaluated in pwp specifically, the GDG sees no reasons why it should not be used in pwp as recommends its use. Pwp are asked to give a score to their overall muscle fatigue and breathing, ranging from 6 (no exertion at all) to 20.

5.10.3 Five Times Sit to Stand (FTSTS)

The Five Times Sit to Stand (FTSTS) is a quick measure of functional mobility, supportive in identifying pwp with insufficient leg muscle power and endurance (5.6.5).

5.11 How to estimate fall risk?

Measurement tools used for the core areas Balance and Gait can support clinical decision-making regarding to fall risk. For several tools, cut-off scores to discriminate fallers from non-fallers have been published (Table 5.11). In addition, PIF scores on falls and freezing combined with the comfortable walking speeds assessed with the 10MW provides a strong predictor for pwp in need for falls-related intervention. This 3-step model categorises those at low, medium, and high risk for falling in the next 6 months (the absolute risks being 17%, 51%, and 85% respectively).³²⁷ This is supportive in selecting those who require an interdisciplinary assessment, an individualised physiotherapy or participation in a general exercise class.

GDG advice: 3-Step Falls Prediction Model

Combining two answers from the PIF with walking speed measured with the 10MW provides decision support regarding falls prevention

In general, cut-off scores will provide information on fall risk in the coming three to six months⁴³⁷. The sensitivity of a score relates to the proportion of pwp at fall risk who indeed test positive. Therefore, the higher the sensitivity of a tool for a cut off point, the higher the chance that pwp are correctly classified as being at risk. For example, a pwp with an ABC score of 65% is more likely correctly classified being at fall risk than a pwp who has fallen once the past year: a sensitivity of 93% versus 77%. Often a combination of different tools will be used in an individual pwp. When scores of several of these tools reach the cut-off point, the sensitivity is likely to be even higher than the individuals scores presented in the table. Thus, the cut-off scores may be helpful in clinical practice. However, the GDG stresses that the full clinical picture of the specific pwp is required for decision-making. In addition to the cut-off scores alone, the physiotherapist should note:

- Presence of freezing of gait^{327;334;438}
- Presence of dementia^{289;439}
- Presence of (even mild) cognitive impairments, such as in working memory and response generation^{440;441}
- Presence of urinary incontinence⁴⁴²
- Loss of arm swing²⁸⁹
- UPDRS item rapid alternating tasks²⁹³
- Reduced attention and executive function^{443;444}
- Number of years since diagnosis²⁸⁹
- Environmental factors, such as overload of furniture in the pwp' home, slippery floors, loose rugs, poor lighting and inadequate footwear
- Adverse events of medication (Appendix 12), such as causing hallucinations
- Presence of co-morbid conditions, such as diabetic neuropathy
- Frequency and safety of activities carried out during the day (such as multitasking)

Table 5.11 Cut-off scores supportive for identifying pwp at fall risk

Tool	N of pwp	Hoehn and Yahr range / mean	Cut-off score	Sensitivity (%) AUC or OR
History of falls (12 months)	349	1-5 / 2.4	≥ 1fall	77% ²⁸⁸
	113	1-3 / ?	≥ 1fall	77%, OR 5.36 ⁴³⁸
	109	1-4 / ?		OR 4.0 ²⁸⁹
ABC	20	2.9 / ?	<69%	93% ³¹¹
	49	2-3 / ?	< 76%	84%, AUC 0.76 ⁴⁰⁸
	122	? / 2.8	< 80%	OR 0.06 for non-fallers ³¹³
DGI	45	2-3 / 2.6	≤ 22	89% ⁴⁴⁵
	49	? / 2-3	< 19	68%, AUC 0.76 ⁴⁰⁸
	70	1-4 / 2.3	≤ 19	64% ⁴⁴⁶
FGA	80	1-4 / 2.5	≤15/30	72%, AUC 0.80 ⁴⁴⁷
	80	1-4 / 2.4	≤15/30	predictive: 64%*, AUC 0.80 ^{*437}
BBS	49	2-3 / ?	< 44	68%, AUC 0.85, OR 48.9 ⁴⁰⁸
	70	1-4 / 2.3	≤ 45	64% ⁴⁴⁶
	80	1-4 / 2.5	≤ 47	72%, AUC 0.79 ⁴⁴⁷
	80	1-4 / 2.4	≤ 47	predictive: 79% AUC 0.87 ^{*437}
	45	2-3 / 2.6	≤ 54	79% ⁴⁴⁵
Mini-BESTest	80 ^{***}	1-4	<20	88% ⁴⁴⁸
	97	1-4	<22	89% ⁴⁴⁹
	8	2.4	<21	predictive AUC 0.87*, 86%*; AUC 0.77**, 62% ^{***437}
	110		<19	79% AUC 0.75 ⁴⁵⁰
FTSTS	82	1-4 / 2.4	>16sec	75%, AUC 0.77 ⁴⁵¹
TUG	45	2-3 / 2.6	≥ 7.95s	93% ⁴⁴⁵
	70	1-4 / 2.3	≥ 8.5s	68% ⁴⁴⁶
	122	? / 2.8	≥ 16s	OR 3.86 ³¹³
10MW ^{****}	78	1-4 / 2.6	< 0.98 m/s	80%; AUC 0.80 ³²⁶
3-Step Falls Prediction Model	205	1-4 / 2.6	10MW* <1.1 m/s & ≥1fall/12mnths & freezing of gait 1 month	AUC 0.80 (95% CI 0.73–0.86) ^{327*}

AUC, area under the curve: >0.70 is adequate; OR, odds ratio: how many times more likely is it that pwp scoring above the cut off are correctly classified as fallers; *predictive for next 6 months; **predictive for next 6 months;*** n=29 lost to follow-up; ****comfortable, self-selected walking speed

5.11.1 Falls Diary

In pwp, a Falls Diary is a feasible tool to gain insight into falls and is therefore advised in clinical practice⁴⁵². Therefore, the GDG recommends providing the Falls Diary to pwp who have are likely to be at risk of falling, such as those who have previously fallen (reported in the PIF)^{302;308}. The falls diary gives insight into the frequency and circumstances of falling. The pwp daily marks on the diary whether a fall has occurred. If falls have occurred, the pwp provides information on the circumstances. It is expected that these circumstances will support decision making towards the selection of interventions or adjustment thereof. The GDG recommends asking the pwp, where appropriate, to fill in the circumstances with support of their caregiver.

5.12 How to describe treatment goals?

History taking and physical examination should provide all the information necessary to determine whether there is an indication for physiotherapy (5.1). If physiotherapy is indicated, the physiotherapist supports the pwp in goal setting. The pwp may have many goals, which cannot all be addressed at the same time. Therefore, the physiotherapist supports the pwp in selecting their most bothersome problem and negotiates to decide upon the main goal, the period of intervention and the level of outcome. Describing additional, easier to reach sub goals may increase the pwp motivation. These cover a shorter period (such as two weeks instead of 12 weeks, as for the main goal) and are a requirement for achieving the main goal (such as to evaluate the ability to increase physical activity levels, or to carry out certain exercises). The GDG advises the physiotherapists to describe SMART goals⁴⁵³.

GDG advice: set SMART goals

- *Specific: avoid wide goals*
- *Measurable: using one of the recommended measurement tools*
- *Attainable: where both the pwp and physiotherapist expect its feasibility*
- *Relevant: to this individual pwp and within the scope of physiotherapy*
- *Time-based: by when it is expected this goal should be achieved*

By the nature of the disease, pwp are losing function⁴⁵⁴. The GDG would like to stress to keep that in mind when regarding the feasibility of goals. When doubts arise about the feasibility of a particular goal and adherence to an intervention, the pwp can be asked to indicate its achievability on a scale from zero to ten; a score of seven or higher can be considered feasible⁴⁵⁵. Action plans can be phrased in such a way that the pwp has a confidence level of at least seven on a 10-point scale that the targets set are achievable.

5.12.1 Goal Attainment Scaling (GAS)

The Goal Attainment Scaling (GAS) provides a method to score the extent to which the pwp's individual goal is achieved in the course of intervention^{456;457}. It provides a client/family centred approach to evaluation⁴⁵⁸. Although no psychometric data are available for its use in pwp, given its usefulness in neurorehabilitation in general as well as in people with psychogeriatric impairments, the GDG advises its use for pwp^{459;460}. It allows for formulating a goal on five levels of outcome: the optimum result (expected level), two levels above and two levels below with an equal distribution of the levels should around the expected level of performance (Fig. 5.12). Preferable only one component of the behaviour is measured for a goal at a time, for example changes in the duration or changes in a frequency per week. As setting these goals and levels can be a time consuming process, the GDG advises to use the GAS for one short-term goal (for example 2 weeks) and one long-term goal (for example 12 weeks) only. For communication, the GAS level reached can be used. Also, a GAS t-score can be calculated using the GAS calculation spreadsheet^{456;461}.

GDG advice:

Use GAS scores together with change scores collected with other measurement tools appropriate for evaluation when communicating about results of treatment

Fig. 5.12 Example of using the GAS for describing goals

Attainment level	Goal of the pwp	Level reached*
Much less than the expected level (-2)	In 12 weeks, I will be able to exercise at moderate intensity for less than 110 minutes on a week	
Somewhat less than the expected level (-1)	In 12 weeks, I will be able to exercise at moderate intensity for 130 minutes a week	
At the Expected level (0)	In 12 weeks, I will be able to exercise at moderate intensity for 150 minutes a week (such as 30 minutes on five days a week)	
Somewhat better than the expected level (+1)	In 12 weeks, I will be able to exercise at moderate intensity for 170 minutes a week	
Much better than the expected level (+2)	In 12 weeks, I will be able to exercise at moderate intensity for more than 190 minutes a week	

*in this example to tick after 12 weeks

5.13 Red and orange flags for physiotherapy (including co-morbidities)

Red flags

Impairments that necessitate advice that a pwp undertakes medical consultation:

- Serious mental impairments: illusions (misinterpretations of real stimuli), hallucinations (spontaneous false sensations) and impulse control disorders such as taking extra non prescribed medication, repetitive activities, obsession for food, gambling or excessive sexual drive
- Complex motor complications, such as unpredictable on-off states, severe dyskinesias and off-state dystonia (painful cramps or spasms)
- Pwp with DBS: not to use anything with an electrical component, as it can affect the DBS battery if close enough to the chest where the battery is implanted: short wave and microwave treatment, ultrasound treatment and electrical stimulation such as TENS or interferential⁴⁶². No manual pressure near the wires.
- Pain in the chest, cardiac arrhythmias or irregular changes in blood pressure during exercise
- Poorly controlled type 2 diabetes mellitus
- Acute systemic diseases
- COPD: recent pulmonary embolism (< 3 months ago) causing severe hemodynamic strain, pneumonia and exceptional loss of bodyweight: >10% in the past half year or >5% in the past month⁴⁶³
- Severe cardiovascular impairments, such as recent myocardial infarction (heart attack), severe cardiac ischemia during exercise, thrombophlebitis, severe anaemia, acute pericarditis or myocarditis, hemodynamically serious aortic stenosis or mitral valve stenosis, cardiac valve failure constituting an indication for surgical intervention, atrial fibrillation with rapid ventricular response at rest (> 100 bpm), within 10 days after a period of fever or present fever for pwp with cardiac impairments; or poor compliance with prescribed cardiovascular medication such as beta blockers^{464;465}
- Other medical problems for which physiotherapy in general would be contraindicated
- See also risk factors during physical activity (6.7.5)

Orange flags

Impairments that may influence physiotherapy assessment or (decisions in selecting) interventions, or may urge advice for a pwp to undertake medical consultation before starting physiotherapy treatment:

- Atypical parkinsonisms (1.2.1)
- Mental impairments which may influence the pwp's ability to understand, learn and adhere to the intervention: cognitive impairments (such as memory and attention), psychosis, persistent depressed mood, dementia and severe hallucinations,
- Previous inactivity⁴⁶⁵: start at low intensity levels, increase gradually
- Severe general fatigue, which may influence both treatment plan and schedule. This can be avoided, such as by spreading out exercises over the day, increasing number of rest periods during treatment, adjustment of treatment dose and/or type of exercise.
- Fear of exertion, to fall or to move
- In pwp with freezing and severe axial rigidity problems, it is advised that hydrotherapy is always individually supervised
- Visual impairments
- Pain and fatigue: exercise tolerance, fear⁴⁶⁶
- Chronic cystitis: (fear to) uncontrolledly pass urine⁴⁶⁶
- Psychiatric disorders or a major depression: fatigue, (inadequate) pain (cognitions), reduced initiative or motivation⁴⁶⁶
- Diabetes Mellitus, in case of wounds, sensory defects, retinopathy of grade ≥ 3 and blood glucose values ≤ 5 and ≥ 15 mmol/L⁴⁶⁴ Note that hypoglycaemia may occur up to 72 hours after intense aerobic exercises and strength training in people using exogenous insulin⁴⁶⁶
- Pulmonary problems, avoiding desaturation (usually O₂ saturation to remain $\geq 90\%$ during exercising and not to fall by $\geq 4\%$; consult the pwp's pulmonologist or cardiologist for individual saturation values⁴⁶⁴
- Hypotension: a resting systolic blood pressure ≥ 200 mmHg or diastolic blood pressure ≥ 115 mmHg⁴⁶⁷
- Beta-blocker therapy: reduces the maximal oxygen consumption (VO₂max) attainable, this serves to increase the exercise intensity at all work rates. Beta-Blocking drugs cause a decrease in heart rate and cardiac output at rest and during exercise, a decrease in myocardial contractility and a decrease in coronary and muscle blood flow
- Osteoarthritis: pain, reduced strength

5.14 How to describe a treatment and information plan?

The starting point for the information plan is the need for information, advice and coaching, identified during the diagnostic process. After formulation of the treatment goals and consideration of red and orange flags, the physiotherapist selects the appropriate interventions to achieve the agreed SMART goals (5.12). When more than one intervention is possible to reach the goal, the physiotherapist provides information on each intervention, including possible pros and cons, to the pwp. Besides treatment goals and interventions, the treatment plan includes agreement on (expected) number and frequency of treatment sessions and non-supervised exercising, the treatment location (at home, in the clinic, in a care facility) and how to continue at completion of a treatment period.

5.15 Which tools can be used to monitor change?

Has the treatment changed the activity limitations addressed? Are the set goals met? The GDG advises to use the GAS, supported by selected tools (Tables 5.2 & 5.15) to:

- Support making decisions on the continuation, change or discontinuation of treatment
- Motivate the pwp in adherence to the treatment
- Communicate with the referring physician and other health professionals

GDG advice:

Use measurement tools to evaluate the effects during the intervention period, as well as at the end. If required, adjust the treatment plan or complete the treatment period. The activities performed with the selected tools can be part of your training plan.

GDG advice:

Always relate tools used for evaluation to the goals set for the individual. As Parkinson's disease is progressive, goals can be towards improvement, maintenance of a status quo or reduced speed of deterioration

5.15.1 When is change real change?

Each measurement is associated with some error. Therefore, in order to identify real change, the difference between scores of two measurement points should be larger than the measurement error. Values expressed by the minimal detectable change (MDC) and the smallest detectable difference (SDD) exceed this measurement error. Only when change scores are equal to or larger than these values a real change has occurred. For several of the tools recommended these values are available (Table 5.15). However, different studies have provided different MDC or SDD values for each tool. So, which data to use? The more pwp included in the study to establish the MDC or SDD, the more accurate the estimation will be. Moreover, baseline scores, specifically when floor or ceiling effects occur, will influence the MDC and SDD values. Therefore, take caution when reporting on change. Moreover, an MDC or SDD may reflect real change statistically, but may be of no importance to the pwp. For this, the minimal important change (MIC) is used. It is the smallest difference in score in the impairment or limitation measured which patients perceive as beneficial and would mandate, in the absence of troublesome side effects and excessive cost, as a change⁴⁶⁸. However, there is no consensus on the best method to determine MIC¹⁵⁰. As, the MIC is unavailable for any of the included recommended tools, the GDG recommends basing the evaluation of change on an MDC or SDD and accompanying it with the patient perception of the change using the GAS.

Table 5.15 Minimal detectable change scores for measurement tools in pwp

Tool	Core area(s)	N in study	HY	Baseline mean	Minimal Detectable Change
ABC	Balance	37	1-4 (median 2)	70%	13% ⁴⁶⁹
		24	1-3	91%	12% ⁴⁷⁰
DGI	Balance	72	1-3	21.6/24 points	3 points (13.3%) ⁴⁷¹
BBS	Balance	37	1-4 (median 2)	50/56 points	5 points ⁴⁶⁹
		26	1-3	54/56 points	3 points* (5%) ⁴⁷²
10MW	Gait: comfortable speed	37	1-4 (median 2)	1.16m/s	0.18 m/s ⁴⁶⁹
		26	1-3	-	0.19m/s* ⁴⁷²
10MW	Gait: fast speed	37	1-4 (median 2)	1.47m/s	0.25 m/s ⁴⁶⁹
TUG#	Balance, Gait,	6	1-4	9,89 s	0.67 s ⁴⁷³
		24	1-3	10.6sa	4,85 s ⁴⁷⁰
	72	1-3	11.8s	3.5s (29.8%) ⁴⁷¹	
	37	1-4 (median 2)	15s	11s ⁴⁶⁹	
	26	1-3	-	1.63* ⁴⁷²	
6MWD	Gait	37	1-4 (median 2)	316m	82m ⁴⁶⁹

HY, Hoehn and Yahr; *Smallest Detectable Difference, SDD; # when goal is speed

Chapter 6

Physiotherapy interventions: rationale and recommendations

6.1 Modalities of physiotherapy interventions

With regards to physiotherapy interventions, targeting impairments and activity limitations experienced by people with Parkinson's disease (pwp), three modalities of care can be identified: exercise, practice and movement strategy training, each of which supported by providing information and education (Fig. 6.1)²⁶⁶. This chapter provides a detailed description of each modality, as well as GRADE-based recommendations regarding specific contents and outcome. Evidence-based information on the optimal number of sessions a week, session time and length of a treatment period are unavailable. These decisions will depend on the treatment goal, the selected intervention, the potential of the pwp and the response to the treatment. GDG recommendations for minimum treatment period, frequency and session duration for each intervention category provided in this chapter are based on the averages of controlled clinical trials (CCTs) supportive to the 'for' recommendations (Appendix 17). However, is important to keep in mind that behavioural changes will need longer periods. Moreover, as the GDG advises increasing the number of unsupervised sessions and decreasing the number of supervised sessions over time, it is important to discuss this with the pwp at the start of intervention. Good instruction and feedback on performance and goals is essential, as well as agreement on how to continue after the treatment period. The 5A's model may be helpful to enhance self-management and adherence (Table 4.3).

Figure 6.1 Physiotherapy intervention type, goal and focus for pwp by disease stage

Intervention	Goal	Focus	Hoehn and Yahr				
			1	2	3	4	5
Education*	<ul style="list-style-type: none"> Self-management support Prevention inactivity / increase physical activity levels Prevention fear to move or fall Falls prevention Increase awareness and motivation Educate hospital-based professionals when admitted, for any cause 	<ul style="list-style-type: none"> Pwp preferences Disease specific expectations Pwp' role in preventing, recognising and reacting adequately towards (new) problems Benefits and fun of (varied) exercising Rationale and benefits of other interventions Importance of treatment adherence Role pwp, carer and physiotherapist Parkinson's associations: information, activities and peer contact 					
Exercise <ul style="list-style-type: none"> Not physiotherapist-supervised Conventional physiotherapy Treadmill training Tai Chi Dance 	<ul style="list-style-type: none"> Improve physical capacity Prevent secondary complications Reduce pain Prevention of fear to move or fall 	<ul style="list-style-type: none"> Physical capacity: exercise tolerance, joint mobility and muscle tone, power and endurance; progressively increase intensity; use of an exercise diary Functional mobility: balance, transfers, manual dexterity, gait; focus on large and high speed movements On state exercising for maximal effects 					
Practice <ul style="list-style-type: none"> Exercise 'upgraded' 	Additional to exercise: <ul style="list-style-type: none"> Delay onset of activity limitations Motor learning: original or novel motor skills 	Additional to exercise: <ul style="list-style-type: none"> Cognitive engagement: cues, dual-task, attention Context specificity Many repetitions and positive feedback Progression in complexity From on to off state practice 					
Strategy training <ul style="list-style-type: none"> Complex motor sequences** Cueing 	<ul style="list-style-type: none"> Reduce fear to fall or move Motor learning: adapted motor skills Compensation 	<ul style="list-style-type: none"> Individual training Functional (dual) tasks Breaking down complex motor sequences into simple components Attention External cues: visual, auditory, tactile Progression in difficulty From on to off state practice Support nursing personnel (HY5) 					

Pwp, person with Parkinson's; * if agreed upon by pwp, also targeting carer; ** formerly called cognitive movement strategies; table Rochester, Nieuwboer & Lord 2011, adapted with permission

GDG advice: general considerations when providing exercise, practice or movement strategy training

As described in detail in 6.7:

- choice of treatment site
- adjustment for mental impairments, pain and fatigue
- adjustment for fluctuations in daily functioning
- use of e-health
- knowing when to stop physical activity for safety reasons

6.2 How to interpret the recommendations?

Next to the rationale, this chapter provides recommendations for or against the use of specific interventions. The recommendations aim to support decision making when selecting the appropriate and pwp-preferred intervention. Even though the number of published CCTs evaluating physiotherapy for pwp has grown exponentially the past decades, the field is still evolving compared to the medical field. Therefore it is important to keep in mind that the absence of evidence may simply be a lack of data and is not necessarily evidence of absence of a benefit⁴⁷⁴.

For each intervention and outcome combination, recommendations can be *for* or *against* and *strong* or *weak* (Table 6.2; Appendix 17). The classification reflects the quality of the evidence (*high*, *moderate*, *low* or *very low*, depending on the influence of study limitations on the outcome) and the outcome of the meta-analyses, weighted against the burden of the specific intervention.

In case of a recommendation against an intervention for a specific outcome, benefits probably do not outweigh risks and burdens. Most commonly, effects show a positive trend, but the (wide) confidence interval of the effect includes 0. It does not mean that the specific intervention has negative effects on that outcome. Risk and burdens are often very low.

The follow-up after completion of a treatment period in the included CCTs was generally short. Only seven CCTs had a follow-up of 10 weeks or more^{79;97;100;110;112;120;134}. Consequently, this Guideline is only able to provide recommendations regarding benefits on the short-term.

6.3 Pwp education

Providing information and advice is essential to optimise health literacy and to empower pwp (and the carer) to take an active role in condition management. Parkinson and physiotherapy associations often provide helpful brochures. In addition, the GDG advises to tailor education to the needs, preferences, impairments, activity limitations, restrictions in participation and external factors specific to that pwp. For this, history taking and physical examination is essential.

Table 6.2 Levels of recommendations 'for' or 'against' a specific intervention

Level	Meaning	Pwp point of view
Strong for	<p>The GDG is confident that benefits do outweigh risks and burdens</p> <ul style="list-style-type: none"> • Positive effect (MD) with a CI excluding 0 • GRADE quality of the evidence Moderate or High • Very limited risks or burden 	Most informed pwp would choose this intervention
Weak for	<p>Benefits probably do outweigh risks and burdens:</p> <ul style="list-style-type: none"> • Positive MD with a CI excluding 0 • GRADE quality of the evidence Low or GRADE quality of the evidence Moderate or High, but very small effect or great imprecision (large CI) • Very limited risks and burden <p>Future High quality CCTs may increase the quality of the evidence or the effect size by which the recommendation becomes 'strong for' or may turn a small MD into a negative MD or decrease the precision (that is the CI to include 0), by which the recommendations becomes 'weak against'</p>	Pwp's choices regarding this intervention will vary according to their values and preferences
Weak against	<p>Benefits probably do not outweigh risks and burdens</p> <ul style="list-style-type: none"> • Positive MD, but with a CI including 0 • GRADE quality of the evidence Low, Moderate or High • Very limited risks and burden <p>Future, high quality CCTs: May decrease CI width, by which the recommendations becomes 'weak for' or may turn a small MD into a negative MD, by which the recommendations becomes 'strong against'</p>	Pwp's choices regarding this intervention will vary according to their values and preferences
Strong against	<p>The GDG is confident that benefits do not outweigh risks and burdens</p> <ul style="list-style-type: none"> • Negative MD with a CI excluding 0, or MD=0 • GRADE quality of the evidence Moderate or High • Very limited risks or burden <p>or:</p> <ul style="list-style-type: none"> • High risks or burden 	Most informed pwp would reject this intervention

MD, mean difference; CI, confidence interval; CCTs, controlled clinical trials

GDG advice: general contents of education, tailored to the needs of a specific pwp

- *What to expect: information on Parkinson's disease (Appendix 9) and medication (Appendix 12) related to mobility limitations*
- *The pwp's role in self-management: striving for an active lifestyle and recognising and reacting adequately towards red flags for exercising and (new) limitations (Appendix 1)*
- *Rationale and evidence of exercising, practice and compensatory strategies (when applied)*
- *Importance of treatment adherence*
- *Role of the Parkinson association (local, national or European, www.epda.eu.com): information, activities and peer contact*

6.4 Exercise

Exercise entails 'a physical activity that is planned, structured and repetitive aiming to increase or maintain physical fitness'.⁴⁷⁵ It also aims to prevent secondary complications³⁸³ and may even induce neuroprotection (3.5). Exercise addresses physical capacity and functional mobility, focussing on balance, transfers and gait related activities. Functional exercise aiming to induce motor learning is called 'Practice' (6.5). Exercise can be performed individual or in a group, and can be supervised or unsupervised.

Physiotherapists can advise or coach pwp towards exercising and a more active lifestyle. When the pwp's preferences and barriers require so, they can provide physiotherapist-supervised exercising, in this Guideline categorised as 'Conventional physiotherapy' (6.4.2). Others pwp may prefer dance (6.4.4) or Tai Chi (6.4.5) both of which can be provided in the clinic or community-based. The GDG advises the physiotherapist to aim for a combination of types of exercises on different days of the week, focussing on physical capacity and functional mobility.

6.4.1 Promotion of exercising and an active lifestyle

Pwp are encouraged to strive for the WHO recommendations for physical activity (Table 5.3.1). Behavioural and social approaches are effective in increasing physical activity levels in the general population⁴⁷⁶, as well as in pwp^{477;478}. The 5A's model (Table 4.2) supports gaining insight into the pwp's barriers and preferences regarding exercising: exercise history, enjoyable activities, impairments and activity limitations, social support and options in the community. This is helpful to design a person-specific, enjoyable and feasible exercise regimen.

GDG advice: increasing levels of physical activity

- *Improve knowledge and skills regarding behavioural change*
- *Gain insight into the pwp's barriers and preferences regarding exercising; pay specific attention to pwp with co-morbidities, cognitive dysfunction and a lack of motivation*
- *Set and agree upon pwp specific, SMART goals in collaboration with the pwp, for example to:*
 - *Decrease daily sitting time*
 - *Walk rather than drive short distances, such as to a store*
 - *Take the stairs instead of the elevator*
 - *Continue or return to exercises and sports pwp enjoy doing*
 - *Participate in a (Parkinson) exercise, dance or Tai chi group*
 - *Implement a home exercise programme*

- A period of physiotherapist-supervised exercising; conventional physiotherapy (6.4.2)
- Use an exercise diary
- Advice (walking) aids to support exercising
- Support pwp in assessing effective community services and resources
- Provide intermittent follow-up, with the timing based on the pwp specific needs⁴⁷⁷

6.4.2 Conventional physiotherapy

Under Conventional physiotherapy, the GDG has categorised all physiotherapist-supervised active exercise interventions, targeting gait, balance, transfers or physical capacity, or a combination thereof.

GRADE-based recommendations for conventional physiotherapy

Strong recommendation for using conventional physiotherapy to improve:

- walking speed
- muscle strength (torque and weight; knee extensors)
- movement functions (UPDRS III)

Weak recommendation for using conventional physiotherapy to improve:

- functional mobility (TUG)
- balance capacity (BBS, FR)

Weak recommendation against using conventional physiotherapy to improve:

- stride/step length
- cadence
- walking distance
- freezing of gait (FOG-Q)
- timed turn
- balance performance (FES, ABC)
- falls
- activity levels
- quality of life (PDQ-39, EQ-5D)

GDG advice: conventional physiotherapy

- Set and agree upon individual, SMART goals in collaboration with the pwp (also in case of group treatment)
- Train for a minimum of eight weeks, three times a week for 45 minutes
- Provide physiotherapist supervised training, supported by self-supervised exercising on other weekdays: facilitate a home exercise program, using an Exercise Diary (Appendix 5.6): consider group treatment (Appendix 7)
- Base decision for group or individual treatment on the pwp's treatment goal, abilities, motivation and preferences, as well as external factors such as the availability of exercise groups
 - Groups: focus on prevention and general improvement of physical capacity and functional mobility; consider Practice (6.5); to increase exercise confidence and support pwp to move on to a community exercise group or non-supervised exercising at home; to learn from peers; for social aspect (also for carers) and fun; adjust group size to treatment goals and levels of functioning of the pwp in the group, on average eight; monitor safety issues
 - Individual: in case of need for individual instruction and attention, as well as limited distraction by the environment; consider Practice (6.5) and Movement strategy training (6.6) for circumstance-specific activity limitations

- *General contents:*
 - *Combine exercises for physical capacity and functional mobility, such as training knee and hip extensor power while rising from a chair, ankle plantar flexion power while climbing stairs, endurance while walking in changing directions*
 - *Preferably focus on functional-task exercises, using large and fast movements whilst lying down, sitting, standing or walking*
 - *When offering isolated resistance exercises, address large before small muscle group exercises and multiple-joint before single-joints*
 - *Focus on attention and provide augmented feedback, for example, by using cues*
- *Select specific exercises based on individual goals, preferences and feasibility, considering:*
 - *Standing up from, and sitting down onto the floor*
 - *Standing and walking on foam, with and without perturbation (pushes & pulls) to the trunk*
 - *Sitting down onto and rise from a chair (while dual tasking)*
 - *Getting into and out of bed*
 - *Rolling over in bed*
 - *Walking taking large steps, with large amplitude arm swings (consider Nordic walking / pole striding)*
 - *Walking around and over obstacles*
 - *Walking with sudden stops and changes in walking direction, including walking backwards*
 - *Walking and keeping balance while dual tasking, such as talking, carrying an object or turning head left to right to wall mounted dots or photos and telling what is seen*
 - *Turning round in open and narrowed, small spaces: when pwp are at fall risk, aim for turning in a wide arc rather than a sharp change of direction (pivot turn)*
 - *Climbing step or stairs*
- *Information from the Falls Diary provides decision support regarding interventions targets including muscle power; location and circumstances; dual tasking; fear of falling or not being able to get up from the floor (do not train pwp how to fall); postural changes; orthostatic hypotension; (walking) aids; side-effects of medication*
- *Gradually increase intensity and beware of under dosed prescription of exercising:*
 - *Based on perceived exertion: on Borg Scale 6-20 from 13 (moderate intensity) to 14 (in case of beta-blockers use) or 17 (hard intensity)*
 - *Based on heart rate: increase exercise duration or percentage of the maximum heart rate, trained between 40 to 60% for moderate intensity exercising, and 60 to 80% for vigorous intensity exercising*
 - *Based on repetitions: increase in load, speed and number of repetitions from 1 to 3 sets of 8 to 15 repetitions at 60% to 80% of the one repetition maximum (or, if not feasible, the four repetitions maximum)*
- *If applicable, training use of (walking) aids to support exercising*
- *If feasible and safe, support pwp towards non-physiotherapist supervised exercising with intermittent follow-up; discuss this early in a treatment period to set realistic expectations*

Details to the GDG advice

The recommendations are based on 27 controlled clinical trials (CCTs) in which 1139 pwp participated, most with a Hoehn and Yahr stage of 1 to 3 (Appendix 17, Development and scientific justification)^{76;79;81;82;85-87;89;92;93;96-98;100;105;106;110;116;127;129;131-133;138;140;143;145}. Often, exercises were part of functional mobility training. Some focused mainly on muscle power or strength^{92;93;105;133}, on high-amplitude movements (LSVT-BIG)⁹⁶ or on gait, using Nordic walking (pole striding)¹²⁷. Most CCTs were carried out in clinics, but some in the pwp's home^{76;79;82;100} or at a gym^{116;143}. In general, interventions in the community were less supervised and had a longer treatment period. The mean difference found for increase in walking speed (0.15m/s) could make the difference between unsafe and safe street crossing. Effects on falls were consistently positive, but non-significant at trial end, and at 10 to 20 week follow-up^{79;100}.

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The reduced movement speed and amplitude in pwp is targeted by aiming for large amplitude and high speed movements^{265;479-484}. Moreover, proprioception and related tactile and haptic sensory functions are often impaired in pwp²⁹⁰. Therefore it is of importance to focus on attention and provide augmented feedback, providing concurrent feedback on performance⁴⁸⁵.

General falls training, including learning how to fall, is offered widely. However, no CCT evaluating the efficacy of this intervention for pwp has been published yet. Based on the fundamentally altered posture and balance reactions in pwp, the GDG expects no effect of such training and even takes the view that such training might have negative effects.

When pwp report side-effects of medication which are associated with falling tough, such as visual hallucinations and orthostatic hypotension^{486;487}, they should be advised to talk to prescribing physician to assess whether adjustments in medication can reduce the side effects. Orthostatic hypotension causes a partial or complete syncope. This may occur during standing up or after exertion, but also when the pwp is standing for a long time. Active strategies proposed to prevent this are actively tiptoeing, leg crossing, bending-forward and squatting⁴⁸⁸.

Aids, such as a walking stick, a wheeled walking frame, poles (Nordic Walking) or a bicycle with an electric aid engine can support exercising and increase a pwp's independence and safety. However, at the same time they can make walking more complex, as using an aid while walking may be considered a dual task. Moreover, inadequate use of aids can worsen posture. For safety reasons, pwp with freezing episodes are advised against using a standard walking frame⁴⁸⁹. They benefit more from a wheeled walking frame with compression-type brakes activated when the pwp leans on the frame. Pwp who benefit from visual cueing (6.6.1) may benefit from a wheeled walker projecting a laser line on the floor to step over. In case of severe difficulty in maintaining balance, a wheelchair should be advised because of co-morbidity related to a high risk of falling. Whether it falls inside the scope of the occupational therapist or rehabilitation physician to provide information on aids and support pwp in the application for the aids, it is often the physiotherapist who trains pwp in correct use of the aids.

In addition to the 27 CCTs the recommendations were based on, several CCTs compared different conventional physiotherapy interventions. Be aware that all these results come from single CCTs:

- Positive MDs with the confidence interval excluding 0 were found for conventional physiotherapy primarily targeting balance (external perturbations and destabilising challenging activities) versus range of motion on the BBS, but not on the ABC¹³⁶; for conventional physiotherapy targeting freezing of gait with, versus without additional action observation on the FOGQ, but not on the TUG and BBS¹²³; for forced versus voluntary exercise (forced being 30% more rounds per minute on a stationary bicycle, at comparable heart rates) on the UPDRS III¹²⁸.

- No differences were found between conventional physiotherapy versus Wii Fit™ games balance training providing feedback or cognitive stimulation on the BBS¹²⁵; for conventional physiotherapy targeting gait and strength, with, versus without increased attention to sensory feedback during exercise (that is lights off, eyes shut, instructions focusing attention on sensory feedback) on walking speed, step length, the TUG and the UPDRS III¹³⁰; for conventional physiotherapy with additional mental practice versus relaxation on walking speed and the TUG⁸⁰; for Nordic Walking versus general gait training (both including a focus on large movements and uphill walking) on the UPDRS III and walking speed¹²⁷; for water- versus land-based physiotherapy on the BBS, FR, TUG, turn time or gait patterns¹⁴².

Also of interest is the finding that in the elderly population, functional-task exercises compared to resistance exercises have comparable effects on strength, but are more effective at improving functional task performance^{490,491}. Generally accepted recommendations for exercising are for large before small muscle group exercises; multiple-joint exercises before single-joint exercises; and higher-intensity before lower-intensity exercises⁴⁹².

Intensity

The optimal duration and intensity of exercise interventions for pwp at different stages of the disease are not clear^{493,494}. Most likely, it will never be clear as the activity limitations, possibilities and preferences of pwp vary widely. The GDG advice is based on the intensity of the CCTs included, taking into account possibilities and requirements for motor learning (6.5.1). CCTs evaluating prolonged training⁷⁶, or short but highly intensive training⁹³ showing the largest effects on quality of life, with a mean difference larger on the PDQ-39 larger than 5.6. Effect sizes on walking distance were the largest when the intervention included high intensity, progressive strength training^{92,133}. Most likely effects are dose dependent, with training at higher MET or percentages of maximum heart rate resulting in larger benefits⁹⁸. It is a known fact that in general, exercise is under-dosed, even in CCTs. Therefore, the GDG recommends estimating the MET of chosen exercises, such as by using the Compendium of physical activity³⁹⁸, and using the Borg Scale 6-20 for perceived exertion when exercising. During exercise targeting physical capacity, a moderate to hard intensity of physical exercise is aimed for, taking in account safety such as in use of beta-blockers^{76,93,492,494,496}. When targeting muscle strength and power specifically, be it concentric or eccentric, progression can involve an increase in load, speed and number of repetitions^{76,93,492,494,496}. In aerobic exercising, progressing the individual can involve an increase in the duration of exercising or the percentage of the maximum heart rate (HRR) at which it is trained⁴⁹⁶. Pwp reach their VO₂ max sooner than their healthy contemporaries. Nevertheless, when no severe mental impairments are present, such as impairments in cognition, attention, personality and fear, the pwp can be trained to increase their physical capacities equal to their contemporaries.

Supervision and adherence

Effects of supervised training are larger than those of non-supervised home exercises.^{96,132} In the included CCTs, effects on walking distance were smaller after gym-based interventions^{116,143} than after clinic-based interventions^{92,131,133}, with a mean difference of 5.4 versus 34.0 meter. However, adherence to such brief, highly supervised interventions may be high but is likely to decrease on the long-term⁴⁷⁷. This may explain why in older adults, adherence to home-based exercise programs is larger than to centre-based programs⁴⁹⁷. Also in pwp, a trend was found toward more sustained improvements in the home-based programs than in the centre-based programs⁴⁷⁷. Strategies to increase adherence may include collaborative goal setting (pwp with physiotherapist), use of an exercise diary, adjustment of exercise

programs to individual needs and preferences and intermittent followup⁴⁷⁷. Therefore, as well as for the costs aspect, the GDG advises to decrease supervised exercising over time and increase non-supervised exercising, providing self-management support.

Safety

Pwp reach their VO₂ max sooner than their healthy contemporaries^{496,499}. This should however not withhold them from physical exercise. In addition, up to 50% of pwp may have an inadequate heart rate increase during sub-maximal exercise, likely caused by cardiac sympathetic denervation leading to autonomic dysfunction. Pwp should therefore be screened to identify their limitations in exercise performance, especially those using beta-blockers as these may further limit physical activities. The intensity of exercise needs individual prescription. Finally, limitations with keeping balance should be taken into account when designing a home exercise program. None of the CCTs reported increased falling after physiotherapy intervention even though this could be expected due to increased mobility⁵⁰⁰. Only one CCT reported exercise-induced hypotension after intense uphill-walking uphill in hot weather, but pwp recovered within 10 minutes after fluid intake¹²⁷. Therefore, GDG concludes that conventional physiotherapy is a safe intervention, especially when the contents of the intervention is specifically adjusted to the pwp's impairments and activity limitations.

6.4.3 Treadmill training

GRADE-based recommendations for treadmill training

Strong recommendation for using treadmill training to improve:

- *walking speed*
- *stride length*

Weak recommendation for using treadmill training to improve:

- *walking distance*
- *balance capacity (BBS)*

Weak recommendation against using treadmill training to improve:

- *cadence*
- *gait related functional mobility (climbing stairs or a 8.8cm step)*
- *knee extensors muscle strength (torque)*
- *movement functions (UPDRS III)*

GDG advice: treadmill training

- *Set and agree upon individual, SMART goals in collaboration with the pwp (also in case of group treatment)*
- *For safety reasons:*
 - *Ensure that pwp have the cognitive and physical ability to utilise the treadmill, understand and use the necessary safety precautions*
 - *Consider supervised or non-physiotherapist supervised treadmill training taking into account cognitive and physical ability*
 - *Use an overhead harness or dead man's switch, such as a magnet attached to a cord that clips to the pwp which cuts power to the treadmill when pulled at*
 - *In pwp with freezing of gait, take care when accelerating and decelerating*

- *Train at minimum four weeks, three times a week for 30 minutes*
- *Contents of training:*
 - *Ask pwp to focus on large steps*
 - *Focus on attention and provide augmented feedback such as by using cues*
 - *Consider adding a cognitive dual task while asking pwp to maintain stride length*
 - *Consider placing a mirror in front of the treadmill to provide visual feedback about body posture*
- *Gradually increase intensity and beware of under dosed prescription of exercising:*
 - *Based on perceived exertion: on Borg Scale 6-20 from 13 (moderate intensity) to 14 (in case of beta-blockers use) or 17 (hard intensity)*
 - *Based on heart rate: increase exercise duration or percentage of the maximum heart rate, trained between 40 to 60% for moderate intensity exercising, and 60 to 80% for vigorous intensity exercising*
 - *Based on walking speed: from 60% to 80% of the 6MWD walking speed*
- *If treadmill training is physiotherapist-supervised, support pwp towards non-physiotherapist supervised treadmill training with intermittent follow-up, if feasible and safe; discuss this early in a treatment period to set realistic expectations*

Details to the GDG advice

The recommendations are based on 11 CCTs in which 259 pwp participated, most with a Hoehn and Yahr stage of 1 to 3 (Appendix 17, Development and scientific justification)^{83;84;98;99;111;117;118;124;126;144}. Treadmill training can be part of conventional physiotherapy, but is also offered in the community as stand-alone intervention. In most of the CCTs, treadmill training was provided in a clinical setting, fully supervised, using an overhead harness for safety. In these CCTs, treadmill training was a safe and acceptable intervention for pwp with the cognitive and physical ability to utilise the treadmill, understand and use the necessary safety precautions and have adequate supervision^{501;502}. One CCT also showed safety of a home-based treadmill training without supervision or a safety harness in pwp who reported maximum one fall in the foregoing 12 months but no postural instability or freezing⁸⁴. For general exercise safety, see Conventional Physiotherapy.

In the home-based CCT, dual tasks were added safely⁸⁴. No judgement can be made regarding loading or unloading, as this was only evaluated in one small trial¹⁴¹. Not all physiotherapists and pwp may have access to a treadmill, and moreover, not all pwp may feel confident walking on a treadmill. The reduced movement speed and amplitude in pwp is targeted by aiming for large steps and high speed^{265;479-484}. Moreover, proprioception and related tactile and haptic sensory functions are often impaired in pwp²⁹⁰. Therefore it is of importance to focus on attention and provide augmented feedback, providing concurrent feedback on performance⁴⁸⁵.

6.4.4 Dance

GRADE-based recommendations for treadmill training

Weak recommendation for using dance to improve:

- *functional mobility (TUG - tango only)*
- *balance capacity (BBS, Mini-BESTest)*

Weak recommendation against using dance to improve:

- *walking speed*
- *stride length*

- *walking distance*
- *freezing of gait (FOG-Q)*
- *quality of life (PDQ-39)*
- *movement functions (UPDRS III)*

GDG advice: dance

- *Set and agree upon individual, SMART goals in collaboration with the pwp*
- *Train a minimum of 10 weeks, twice a week for 60 minutes*
- *Contents of dance:*
 - *Large amplitudes of movement*
 - *Starts, stops and turns*
 - *Single leg standing*
 - *Weight shifting*
 - *Controlled displacement of the centre of mass over the base of support*
 - *Backward walking*
 - *Walking in confined spaces*
 - *Stepping in multiple directions*
 - *Complex movement sequences*
- *Backward stepping, as common in tango may induce falling: take caution when selecting pwp for tango classes and adjust the specific contents of the tango dancing to the pwp's impairments and activity limitations.*
- *If dance is physiotherapist-supervised, support pwp towards non-physiotherapist supervised dance with intermittent follow-up, if feasible and safe; discuss this early in a treatment period to set realistic expectations*

Details to the GDG advice

The recommendations are based on three CCTs in which ¹¹⁹ pwp participated, most with a Hoehn and Yahr stage of 1 to 4 (Appendix 17, Development and scientific justification)^{94;101;103}. The largest CCT was carried out in a community-based setting⁴⁷⁴. All CCTs provided twice weekly a 60-minute tango class, with the total period ranging from 10 to 52 weeks. At 52 weeks, many pwp dropped out of the tango group: from 20% at 3 months up to 50% at 12 months⁹⁴. For this reason as well as for comparability, in the meta-analyses of all studies the outcome at 12 weeks was used. None of the CCTs followed-up after completion of the dancing classes. Long-term adherence to a dance group may be infeasible⁹⁴.

Dance is becoming more and more popular as complementary form of exercise for pwp and recommended by many Parkinson associations. The most widely used type of dance by pwp is tango, but also ballroom dancing, Irish set dance and salsa classes are used. Dance often incorporates direct practice of walking in the situations that commonly provoke freezing⁹⁴. The music provides an external rhythm, which can be considered as auditory cueing (6.6.1). As dance requires high-level multitasking and progressive motor skill learning, dance is both physically and cognitively challenging⁹⁴. It aims to improve gait, balance and mood⁵⁰³. An additional CCT comparing partnered versus non-partnered tango, in which the pwp danced with people without Parkinson's, reported equal effects (all CIs including 0) on the BBS, TUG and gait patterns cadence and stride length; partnered pwp expressed more enjoyment and interest in continuation¹⁰⁴. Tango dancing may induce falling as it involves backward stepping. Therefore, the GDG group advises caution when selecting pwp for tango classes and if required adjust the specific contents of the tango dancing to the pwp's impairments and activity limitations. Irish set-dancing seems a safe and acceptable intervention⁵⁰⁴.

6.4.5 Martial arts: tai chi

Strong recommendation for using Tai Chi to improve:

- *movement functions (UPDRS III)*

Weak recommendation for using Tai Chi to improve:

- *number of falls*
- *balance capacity (BBS)*
- *walking speed*
- *stride length*
- *walking distance*
- *functional mobility (TUG)*
- *muscle strength (torque)*
- *standing related balance capacity (Functional Reach)*

GDG advice: Tai Chi

- *Set and agree upon individual, SMART goals in collaboration with the pwp*
- *Train for a minimum of 24 weeks, twice a week for 60 minutes*
- *Contents of Tai Chi:*
 - *Combine deep breathing and relaxation with slow and rhythmic movements*
 - *Include single leg standing, weight shifting, controlled displacement of the centre of mass over the base of support, stepping in multiple directions and complex movement sequences*
 - *Aim for large amplitudes of movement*
- *If Tai Chi is physiotherapist-supervised, support pwp towards non-physiotherapist supervised Tai Chi with intermittent follow-up, if feasible; discuss this early in a treatment period to set realistic expectations*

Details to the GDG advice

The recommendations are based on three CCTs in which 200 pwp participated, most with a Hoehn and Yahr stage of 1 to 4 (Appendix 17, Development and scientific justification)^{83;84;98;99;111;117;118;124;126;144}. Except for one CCT, which evaluated Qigong¹³⁴, the form of martial arts evaluated was Tai Chi^{102;112}. In these CCTs, Tai Chi was specifically designed to improve balance and gait in pwp. The recommendations are mainly based on the largest CCT, in which Tai Chi is provided during 24 weeks, twice weekly for 60 minutes¹¹². This CCT showed that Tai Chi is a safe and acceptable intervention, with effects maintained at 3-month follow-up¹¹². The reduced movement amplitude in pwp is targeted by aiming for large amplitude movements^{265;479-484}. Tai chi is the most frequent applied type of martial art. Many Parkinson associations recommend it. However, not all pwp may have access to a (physiotherapist-supervised) Tai Chi training group and costs to participate in a Tai Chi class may be problematic.

6.4.6 Whole body vibration

GRADE-based recommendations for whole body vibration

Strong recommendation against using WBV because of safety considerations

The recommendation is based on two CCTs in which 42 pwp participated with an unknown Hoehn and Yahr stage (Appendix 17, Development and scientific justification)^{78;95}. With Whole body vibration (WBV), vibration is transmitted from a vibrating platform into the body, most often through the feet. It is offered in clinical settings as well as in the community. It aims to

improve muscle strength, bone mineral density and balance⁵⁰⁵. In pwp, WBV showed no effects with a confidence interval excluding 0^{78;95}. Moreover, WBV devices are likely to exceed what is considered safe vibration for even brief (a few seconds a day) exposure resulting in both acute and chronic injury to the musculoskeletal, circulatory and nervous systems⁵⁰⁶. The ISO-Threshold of Limit Values focuses on the intensity of the vibration (g), which is depending on the displacement (d) and/or the frequency (hz) at which a platform might operate: $g=[D(2\pi*Hz)^2]/9.81$. The GDG considers that these safety risks outweigh the (possible) benefits until more is known about the safety of the devices.

6.4.7 Massage of trigger points

GRADE-based recommendations for massage of trigger points

Weak recommendation for using massage of trigger points to improve:

- *patient-based treatment effect*

GDG advice: Massage of trigger points

- *Set and agree upon individual, SMART goals in collaboration with the pwp*
- *Provide massage of trigger points or Neuromuscular therapy (NMT) for at minimum eight weeks, two times a week for 45 minutes*
- *Contents of NMT: compress trigger points by gliding, lengthening strokes applied with moderate compression parallel to muscle bundles in the neck, back, and extremities*
- *Always to combine NMT with other categories of intervention, as there is no evidence that NMT improves physical capacity or functional mobility*

Details to the GDG advice

The recommendations are based on one CCT in which 32 pwp participated with a mean Hoehn and Yahr stage of 1.6 (Appendix 17, Development and scientific justification)⁸⁸. Massage of trigger points or Neuromuscular therapy (NMT) can be part of conventional physiotherapy. Here however, we present it as a separate type of intervention, as it is not a type of exercise and is provided as a stand-alone intervention by massage therapists. In the single CCT evaluating its effects in pwp, a massage educator provided NMT with the aim of reducing pain and spasm⁸⁸. The only critical outcome of NMT showing a positive effect (with a confidence interval excluding 0) was the patient-reported treatment effect⁸⁸.

6.4.8 Reducing pain experiences

Physiotherapy to reduce pain in pwp has not yet been evaluated in a CCT. Therefore, no GRADE-based recommendations are available. However, if pain in Parkinson's disease is not medication related, physiotherapeutic intervention may be indicated. The intervention, based on the mechanisms of pain, will include pain education, addressing the influence of fear on pain and the importance of staying physical active. Explain Pain by Butler & Moseley⁵⁰⁷ may be helpful. A Visual Analogue Scale for pain may be used to evaluation. Treatment may include:

- Exercising including range of motion exercises and postural adjustments for musculoskeletal and neuropathic pain; gradually increase exposure to routine activities, agreed upon on forehand, using a time-dependent approach instead of a pain-dependent approach
- Pain relief through TENS and manual therapy
- Peripheral desensitisation techniques
- Motor imagery and mirror therapy
- Cognitive strategies

None of these have been evaluated in pwp. Therefore, the GDG advises applying recommendations from general clinical practice guidelines on pain. As pain is complex to treat, the GDG advises to support the pwp in consulting a physiotherapist with specific expertise in treating pain and using evidence-based guidelines for pain treatment.

6.4.9 Reducing respiratory impairments

Two CCTs are published evaluating the efficacy of physiotherapy to reduce respiratory impairments in pwp^{50;70}. However, none of the identified critical outcomes were included (1.3.5 and Appendix 14). Therefore, no GRADE-based recommendations are available.

Inspiratory muscle training aims to improve pulmonary function and perceived dyspnoea⁵⁰, and expiratory muscle strength training programmes aim to generate adequate respiratory pressure for coughing to clear foreign materials thus protecting the airways^{354;508}. Both techniques sustain characteristics of voice production to enable good communication, as well as preserving respiratory and swallowing functions^{50;349;354;356;508}. Moreover, physiotherapy guidelines recommend routinely monitoring any person with neuromuscular weakness for clinical features of ventilatory problems, and management with assisted cough strategies and ventilatory assistance accordingly⁵⁰⁹. These assisted cough strategies, including air stacking, glossopharyngeal breathing, manually assisted coughing and mechanical insufflation–exsufflation, have all been demonstrated to be effective in people with neuromuscular weakness⁵¹⁰⁻⁵¹⁵.

6.5 Practice

Exercise can be 'upgraded' into practice. Practice entails repetitive motor execution to improve the fluency of motor skills, either of original motor skills or, through motor learning, of novel motor skills.

6.5.1 Optimising motor learning

Motor learning is defined as 'a set of processes associated with practice or experience leading to relatively permanent changes in the capability for movement'.⁵¹⁶ These processes involve interactions of the fronto-parietal cortices, the basal ganglia and the cerebellum^{517;518;518}. Three phases of motor learning are distinguished:

1. Acquisition: considerable improvement across several sessions of practice
2. Automatisation: skilled behaviour requiring minimal cognitive resources, stable over time and resistant to interference, such as in dual tasking
3. Retention: motor skills readily executed after long delays without further practice on the task

The ability to carry out complex tasks and negotiate complex environments relies upon automaticity. Automaticity depends on intact basal ganglia function and therefore is increasingly disturbed in pwp. Even though limited, pwp are capable of motor learning^{483;485;519;520}. In general, pwp benefit from practice, but require a higher training dose to achieve results comparable with their contemporaries and show more variable clinical benefits⁵²¹⁻⁵²⁴. Because the basal ganglia are critical for the automatisation, acquisition of skills may be relatively preserved, but automatisation and retention are less efficient compared to age matched controls⁴⁸⁵. The ability to learn a novel skill may be preserved by compensation of the basal ganglia dysfunction with activation of other brain structures such as the cerebellum^{520;525;526}. As the potential for learning is believed to diminish over the disease course, the greatest benefits may be gained at the earlier, mild stage (Hoehn and Yahr 2 to 3)^{483;485;519;527-529}. Taking into account general principles for motor learning and using external cues will enhance acquisition, automaticity and retention^{108;483;485;519;520;530-532}.

GDG advice: from Exercise to Practice - optimising motor learning in pwp

- *Aim for optimal motivation of pwp*
 - *highlight the need to change and the personal benefits*
 - *agree upon challenging, but feasible goals (step by step progression), preferred by the specific pwp*
 - *provide positive feedback on performance and objective results related to the goal*
- *Aim for functional tasks and context specificity, such as by practising in the home*
- *Aim for many repetitions, adjusted to personal goals and capacity*
- *Supply visual or auditory cues*
- *Gradually increase task and context complexity and cognitive engagement, such as in dual task training*
- *Focus on explicit learning strategies, goal directed and conscious*
- *Balance between practice and rest, advising pwp to go for a rest after a practice period as required*
- *Consider using action observation and mental imagery*

A structured, graded approach allowing explicit learning and sufficient repetition is generally recommended to facilitate a change in activity performance (Table 6.5.1).^{533;534} However, altered motor learning can be evident even in the early stages of the condition due to impairments in frontal, executive functions that reducing working memory, attention, planning, problem solving, multitasking and initiation of actions.⁵¹⁹ Moreover, anxiety, depression or fatigue will influence capacity for motor learning. This has implications for clinical practice (Table 6.7.2).

Interventions that aim to improve motor skills and motor learning in pwp include cued functional training (6.6.1) and dual-task training (6.5.2)⁴⁸⁵. These are supported by the use of action observation and mental imagery (6.5.3) and provision of cues and feedback on results and performance.

6.5.2 Dual task training

Dual-task training has not yet been evaluated in a CCT although two CCTs are underway^{535;536}. Hence no GRADE-based recommendation is available. However, laboratory experiments have shown that with instruction, pwp without cognitive impairments are able to prioritise walking and reduce attention to a concurrent cognitive task^{122;537-540}. This is of importance, as dual tasking is difficult to avoid in daily life. Moreover, laboratory experiments have shown improved dual task gait after dual-task gait training using visual cues^{541;542}, after treadmill training with virtual obstacles⁵⁴³, and using an attentional strategy (focusing on taking big steps) with or without concurrent auditory cue⁵⁴⁴.

During dual-task gait training, pwp aim to improve walking speed and step length, using visual or auditory cues, while simultaneously undertaking a variety of motor or cognitive challenging tasks^{535;536}. The complexity of both the gait and additional task can be increased progressively. Cognitive tasks known to cause gait interference in older people include⁵³⁶:

- Verbal fluency: for example ask the pwp to name to name cities starting with a specific letter
- Discrimination and decision making tasks: for example ask the the pwp to change gait direction to the right when you say yellow and stop walking when you say red
- Working memory tasks: for example ask the pwp to distract number by three starting at 90
- Mental tracking tasks: for example, tell the pwp a story and ask the pwp how many times you use a specific word
- Reaction time tasks:

Examples of dual tasks while walking when aiming for functional training include asking the pwp to describe a certain route or how the past weekend was spent, carrying a tray with water filled glasses, closing buttons or picking objects up from the floor⁵³⁶.

Table 6.5.1 An example of how to apply general principles to optimise motor learning

Starting point: a challenging, but feasible goal: “To rise from my comfortable chair at home, while carrying a tray with a full cup of water, without falling or spilling water, within 3 weeks”

Task Complexity	Goal	Type of training	Example of training
Simple	Improve performance of the specific task	Stable task and context	<ul style="list-style-type: none"> Daily practice: rising from the specific chair To optimise the pwp’s motivation, practice may be started with the sofa seat adjusted to a height the pwp can get up with some effort, but safely. If the height cannot be adjusted, a chair with the preferred height and with comparable softness of the seat may be used. Start practising without a cup, then add a half filled cup. External cues support the sit-to-stand transfer, such as verbal commands for each step of the transfer or a visual focus point to move towards
Medium	Improve generalisability to comparable tasks	Task variability Stable context From a set to a random order of tasks	<ul style="list-style-type: none"> Daily practice, of which three times a week physiotherapist-supervised, rising from the specific sofa, but also from other chairs, couches or beds of lower heights, seat softness and with or without arm rests. Gradually fill the cup with water, supported by cues. Start with daily the same order of tasks, then continue to a different (random) order each day
High	Improve generalisability to comparable tasks and under different circumstances	Task and context variability From a set to a random order of tasks	<ul style="list-style-type: none"> Daily practice, of which three times a week physiotherapist-supervised, rising from the specific sofa, but also from other chairs, couches or beds of lower heights, seat softness and with or without arm rests while talking to someone (a dual task). Using a full cup of water, supported by cues. Start with daily the same order of tasks, then continue to a different (random) order each day Start with training in the on period, then continue with training in the off state

6.5.3 Action observation and mental imagery

In healthy people, cortical motor areas are recruited not only during actual execution of movement, but also during mental rehearsal of a movement (motor imagery) or simply during observation of someone performing a movement (action observation)⁵⁴⁵⁻⁵⁴⁷. Consequently, repetitive imagining of oneself undertaking a skilled movement or observing a skilled movement, without actually doing the movement may lead to improved skills. Indeed, both strategies have been found effective in people following stroke and is often applied in combination with real physical practice⁵⁴⁸⁻⁵⁵⁰. Both strategies are largely based on response-produced sensory information and are believed to share the same neural mechanisms in the mirror neurons⁵⁵¹. Mirror neurons fire when an action is performed, but also when the same action is perceived, thus contributing to premotor action perception⁵⁵². However, in pwp, brain activity during motor imagery is different from that of their healthy contemporaries⁵⁵³ therefore, findings may not be generalisable.

6.6 Movement strategy training

The rationale of movement strategy training is to compensate for the deficits with the internal (automatic) generation of behaviour. It includes cueing, attention and strategies for complex motor sequences (formerly called cognitive movement strategies; see Glossary). When the strategies are applied to activities, they induce motor learning, possibly by gaining efficiency in compensatory pathways⁴⁸³. To improve transfers or manual activities, often a combination of cueing, attention and sequencing strategies is used. To improve gait, often a combination of cueing and strategies for complex motor sequences are used.

6.6.1 Cueing and attentional strategies

GRADE-based recommendations for cueing and attentional strategies

Strong recommendation for using cueing for gait to improve:

- walking speed

Weak recommendation for using cueing for gait to improve:

- step length
- gait related balance capacity (DGI)
- movement functions (UPDRS III; UPDRS posture & gait score)
- freezing of gait (FOG-Q)

Weak recommendation for using cueing during transfers to improve:

- functional mobility (timed sit-to-stand)

Weak recommendation against using cueing for gait to improve:

- stride length
- cadence
- functional mobility (TUG)
- standing related balance capacity (Functional Reach)
- balance performance (FES, ABC)
- quality of life (PDQ-39)

GDG advice: cueing and attentional strategies

- *Set and agree upon individual, SMART goals in collaboration with the pwp (also in case of group treatment)*
- *Provide physiotherapist supervised training, supported by self-supervised exercising on other weekdays: facilitate a home exercise program, using an Exercise Diary (Appendix 5.6)*
- *Train cueing for a minimum of three weeks, three times a week for 30 minutes - longer for attentional strategies and when people are in advanced stages*
- *Start with exploring the pwp's own tricks and tips*
- *Examples of cueing strategies:*
 - *Visual: stepping over strip(s) of tape on a floor, someone's foot or a laser line projected on the floor*
 - *Auditory: walking on the beat of a metronome or pwp preferred music such as by using a smartphone*
 - *Tactile: walking on the vibration rhythm of a vibrating wrist band*
- *Frequency of cueing:*
 - *Use the 6MWD or 10MW to determine baseline step frequency*
 - *To improve walking distances (specifically outside the pwp's home) in non-freezers: explore cueing frequencies up to 10% above baseline frequency*
 - *To improve gait stability during functional and complex activities, mostly inside the pwp's home: explore cueing frequencies up to 15% below baseline frequency*
 - *To improve gait in freezers: explore cueing frequencies up to 10% below baseline frequency*
- *Examples of attentional strategies*
 - *Thinking about taking big steps*
 - *Choosing a point of reference to walk towards*
 - *Making wide turns (arc versus pivot)*
 - *Lifting knees high up*
- *Examples of attentional strategies to initiate movement:*
 - *Rocking from left to right before starting to walk*
 - *Combine rocking with the instruction (or thinking) of taking a big step*
 - *Taking a step backwards before starting to walk*
 - *Suddenly swinging the arms in front ('pointing the direction')*
 - *For bed transfers: Rocking bend knees from left to right before rolling over*
 - *For chair transfers: Rocking trunk forwards and backwards before rising from a chair*
- *If feasible and safe, support pwp towards non-physiotherapist supervised cueing with intermittent follow-up; discuss this early in a treatment period to set realistic expectations*

Details to the GDG advice

The recommendations are based on nine CCTs in which 378 pwp participated, most with a Hoehn and Yahr stage of 2 to 4 (Appendix 17, Development and scientific justification)^{77;90;107;114;115;119;122;135;139}. Most CCTs were carried out in clinics and one, the largest (N=153), at the pwp's home and surroundings¹²². In all, auditory cues were applied and in most also visual cues. One CCT evaluated the efficacy of cues for sit-to-stand transfer¹¹⁴. Effects of cueing seemed specific, such as when cueing was used to improve gait. Manual activities did not improve¹²². However, effects did transfer to non-cued walking⁴⁸⁵.

The effects of cueing on freezing of gait as measured with the FOG-Q was positive, but with a confidence interval including 0. However, sub-analyses on freezers only (63 of 153 CCT participants), a significant reduction on the FOG-Q of 5.5% was found^{122;554}.

The mean difference found for walking speed (0.07m/s) could make the difference between unsafe and safe street crossing. Most CCTs only evaluated effects at the end of treatment. The one large trial that evaluated at six week follow-up showed an attenuation of the effects obtained immediately after training, underscoring the need for permanent cueing devices and frequent top-up practice sessions¹²². Cueing training at the pwp's home seems a safe and acceptable intervention¹²². However, not all physiotherapists are able to train pwp at their homes.

Rationale

The basal ganglia disorder reduces the internal control required to time and scale automatic and repetitive movements. External cues and attentional strategies replace this reduced internal control. External cues are defined as temporal or spatial external stimuli associated with the initiation and ongoing facilitation of motor activity (gait).¹²² They can be visual, aiming to generate amplitude, or auditory or (even though hardly used) tactile, aiming to generate rhythm⁵⁵⁵. By using the cues, movements are controlled more via the premotor and parietal cortex and the cerebellum⁵⁵⁶. Also in the later stages, when attention and executive functions are limited and can no longer compensate for the loss of gait automaticity²⁰¹, cues can guide attention, decreasing the reliance on internal control of attention^{557;558}. Cues may act to focus attention, particularly during the performance of more complex tasks and thus aid in gait prioritisation.⁵⁵⁵ As a result, auditory cues may improve gait even during a dual task^{559;560}. However, not all pwp benefit from using cues. Currently, there is a lack of evidence regarding which pwp benefit and which do not. However, if a pwp benefits from cues, this will be observable after one single training session. Cueing may even be beneficial for pwp with mild cognitive impairments, both for single and dual-task walking speed and stride length⁵⁶¹.

Attentional strategies are distinct from cueing, as they need to be self-generated and provide an internal focus on the movement. As they are generated through executive processes, using prefrontal and frontal pathways, they may be more attentionally demanding than externally generated strategies.⁵⁶² Often attentional strategies and cues are used in combination. Both can be one-off, merely to initiate movement, or continuous, to prevent freezing during movement. Cues can also assist during exercise training to generate more optimal movement.

Type of cue

The effectiveness of cues is person- and context-specific. Also pwp preferences vary, even though most pwp prefer auditory cues over visual cues using a small flashing light emitted from a pair of glasses¹²². Foremost, cues must be meaningful to the specific pwp. It is the role of therapists to explore the effectiveness of several cues with their pwp, starting with the individual's experiences and preferences in using cues. The quality and application of these self-invented cues can possibly be optimised. Even within a specific cueing modality such as visual cues, changes can be made. For example, using 2-dimensional visual cues (such as by means of lines of coloured sticky tape on the floor) or 3-dimensional visual cues (such as by means of thin wooden sticks) may influence effectiveness. To prevent freezing, a combination of a frequency stabilising cues with appropriate attentional strategies and instructions for large steps (which may be supported by visual cues) is suggested⁵⁵⁵. To improve turning at home, such as in the bathroom, auditory cueing can be combined with lines marked on the floor (visual cues)⁵⁶². No CCTs have evaluated the effects of cues for the initiation of gait. Transverse line visual cues⁵⁶³ and sensory (cutaneous) cues⁵⁶⁴ may enable pwp to begin walking at higher speed. Moreover, visual (target) cues facilitate (hand) movement initiation⁵⁶⁵, as does the instruction (or thinking) of taking a big step⁵⁶². Metronomes are a good means of practising auditory cues. However, to motivate pwp in continuing use of the cues, pwp may prefer music. Auditory cues with easily adjustable frequencies, using music or metronome beats, are freely downloadable to smart phones.

Cueing frequency

The optimal cueing frequency needs to be explored during treatment. This will depend on the activity and context in which the cues are used. For example, the frequency of a rhythmic auditory cue will generally be lower for walking indoors (such as from the bathroom to the kitchen) than for walking outdoors (such as when walking to a shop). To determine the appropriate frequency, first a baseline frequency when walking at a comfortable (or fast) speed needs assessment using the 10- or 6-meter walk test (5.7.4). Walking speed is best improved using cueing frequency up to 10% above baseline frequency for longer distances, specifically outside the pwp home, and up to 15% below baseline frequency for gait stability during functional and complex activities, mostly inside the pwp' home⁵⁶². In freezers however, cueing frequencies above baseline may trigger freezing of gait⁵⁶⁶. Moreover, cues may be less effective in freezers, due to the highly disordered rhythmic component of movement⁵⁵⁵.

6.6.2 Strategies for complex motor sequences

GRADE-based recommendations for strategies for complex motor sequences

Strong recommendation for using strategies for complex motor sequences to improve:

- *functional mobility (PAS and PAS chair transfers)*

Weak recommendation for using strategies for complex motor sequences to improve:

- *stride length*
- *patient-based treatment effect*

Weak recommendation against using strategies for complex motor sequences to improve:

- *walking speed*
- *step length*
- *cadence*
- *movement functions (UPDRS III)*

GDG advice: strategies for complex motor sequences

- *Set and agree upon individual, SMART goals in collaboration with the pwp (also in case of group treatment)*
- *Provide physiotherapist supervised training, supported by self-supervised exercising on other weekdays: facilitate a home exercise program, using an Exercise Diary (Appendix 5.6)*
- *Train for a minimum of three weeks, three times a week for 30 minutes*
- *Train task-specific*
- *Start with exploring the pwp's own tricks and tips*
- *Train at the location where the pwp's activity limitations are present (often at the pwp home), or when this is impossible, mimic this environment*
- *Support strategies for complex motor sequences by using cues*
- *Steps to consider:*
 - *Observe the pwp in performing the activity; analyse limited components*
 - *Agree with the pwp about the most optimal (mostly four to six) movement components*
 - *Summarises the sequence of components: use key phrases, support with visuals*
 - *Physically guide the pwp in the performance of the selected components*
 - *Ask the pwp to rehearse the consecutive components aloud*
 - *Ask the pwp to use a motor imagery of the consecutive movement components*
 - *Ask the pwp to carry out the components consecutively, consciously controlled*

- *If feasible and safe, support pwp towards non-physiotherapist supervised cueing with intermittent follow-up; discuss this early in a treatment period to set realistic expectations*

Details to the GDG advice

The recommendations are based on six CCTs in which 210 pwp participated, most with a Hoehn and Yahr stage of 1 to 4 (Appendix 17, Development and scientific justification)^{108;109;119-121;137}. Two of the six were carried out at the pwp's home^{21;137}. Treatment duration and frequency ranged from a boost of 16 45-minute sessions within a two week period¹²⁰, to a 1-year period with 60-minute sessions at gradually decreasing frequency, starting at one session a week for a month, followed by one session every two weeks for two months and 10 to 20 sessions in total in the final 40 weeks¹⁰⁸. As strategies for complex motor sequences are often combined with cueing strategies, their recommendations for duration and frequency are used. Applying strategies for complex motor sequences did not lead to pwp undertaking risky behaviours or falling, making it a safe intervention⁵⁰⁰. Effects were specific to the setting (home versus clinic, 22% versus 9%)⁵⁶⁷ and activity¹⁰⁸. However, not all physiotherapists will be able to train pwp at their homes.

Three months after completion of a home treatment, one CCT showed reduced effects (approximately 50%), but still significantly improved compared to the baseline scores⁵⁶⁷; another CCT reported that while controls deteriorated at follow-up, the intervention group tended to continue to improve, with the sit-to-stand time decreasing 14% by week 4 and 32% by week 12¹³⁷.

Rationale

Strategies for complex motor sequences involve breaking the task down into simple components. The components are performed in a defined sequence with conscious control, and if required guided using external cues. In using strategies for complex motor sequences the need for and possibility of dual tasking during complex (automatic) activities is minimised^{58;108;265;281}. A possible neuroanatomical explanation for the success of strategies for complex motor sequences is that the visual cortex can access motor pathways via indirect projections involving the cerebellum, rather than via the basal ganglia.

The selection and training of the strategies follows a structured stepwise approach and uses mental or motor imagery. Based on the preferences of the pwp, the carer may be involved and the number and contents of the components, as well as the order of the steps may vary. The number of components that can be trained at the same time depends on the abilities of the specific pwp. To obtain the optimal result, the training of these activities should be task-specific, within the context of functional tasks of everyday living²⁶⁵. On the website of the Association of Physiotherapists in Parkinson's Disease Europe (www.appde.eu), pwp and physiotherapists can share their examples of strategies for complex motor strategies. Often, strategies for complex motor sequences are supported by external cues, such as a visual anchor point when standing up, and exercises to improve physical capacity, such as muscle power exercises for the legs aiming to improve rising from a chair). It is explicitly not intended that the activity or the movement will become automatic.

6.7 General treatment considerations

6.7.1 Choice of treatment site

Physiotherapy can take place in a community gym, a primary health care practice, the pwp's home, a rehabilitation centre, a nursing home or a hospital. The objectives of treatment, the preferences and abilities of the pwp and the abilities of the physiotherapist determine the choice of location. Activity limitations are often related to the home environment. Moreover, the learning of new skills is often task and context specific, which may be explained by the incorporation of external feedback into the motor program^{108;485;530-532}. Therefore, the GDG recommends that treatment focused on improving activities is provided within the context of functional tasks of everyday living, preferably at the pwp's homes. Treatment at home has the added benefits of enabling direct evaluation of the applicability of the strategies in normal daily functioning and of meeting and involving the carer in a more natural context.

On the other hand, general exercises to improve physical capacity and functional mobility can be performed at any location, unless specific room or equipment is preferred. Therefore, improvement of the physical capacity can take place at a gym, during the performance of recreational activities, in the physiotherapist's practice, and also in the pwp's home.

GDG advice: treatment location and timing

- *Improve physical capacity at the time of the day when pwp are at their best*
- *Improve limited activities at the time of the day when, and at the location where they are most bothersome to the pwp*

6.7.2 Adjusting for fluctuations in daily functioning

Pwp in the off state may not be as responsive as when on. This is not the result of cognitive impairment, but of lower medication levels. Response fluctuations should be taken into account when planning treatment sessions. Typically, activity limitations are most troublesome in off states. Specific strategies to overcome the problems may first be taught in the on period, but if needed or used in the off states it will eventually need to be mastered in the off states. Physical capacity can be optimally trained when pwp are at their best, i.e. during the on periods. Because of regular contact with the pwp, physiotherapists are able to recognise response fluctuations at an early stage. The fluctuations can be partly corrected by an adjustment of medication. Therefore, if response fluctuations or low adherence to medication intake is noticed, the pwp can be advised to discuss this with the care coordinator or physician who holds main medical responsibility. This most often is the neurologist.

6.7.3 Adjusting for mental impairments, pain and fatigue

Evidence on the benefits of physiotherapy to reduce mental impairments is sparse but growing. For now, the GDG advises to take them, as well as pain and fatigue, into account when providing physiotherapy and adjust treatment accordingly.

GDG advice: mental impairments

- *Take sufficient time for the history taking and physical examination*
- *Support pwp in prioritising problems*
- *Enhance motivation using challenging but feasible goals and providing positive feedback*
- *Enhance awareness about the need to change and about what is in it for this pwp*
- *Start with motor learning training in an early stage*
- *In early stages, practice dual tasks; in later stages limit dual tasks by executing task sequentially*

- *Use implicit learning strategies when still feasible, as explicit strategies may load cognition too much**
- *Keep information or advice short*
- *Limit the amount of instruction given during practice to prevent dual tasking*
- *Load task difficulty to promote positive rewarding*
- *Provide feedback on performance and outcome*
- *Support pwp in decision-making towards feasible and fun non-supervised exercises*
- *Support pwp in planning non-supervised exercising*
- *Provide written and visual information for non-supervised exercises: what, when, how*
- *Support pwp towards exercising, aiming to improve executive function***

**goal directed, conscious learning (explicit) versus unconscious learning (implicit); **the number and quality of CCTs evaluating the efficacy of exercise, alone or combined with training of cognitive functions is limited, but growing^{68,89,125,568}*

GDG advice: pain

- *Educate pwp about pain (6.4.8)*
- *Adjust the type, load, frequency and duration of exercise to avoid pain*
- *Aim for time-contingent planning of progression of exercising*
- *Advise pwp to talk to prescribing physician about pain to assess whether adjustments in medication can reduce pain*

GDG advice: fatigue

- *Educate pwp about what tiredness is and is not normal when exercising (6.7.5)*
- *Adjust the type, load, frequency and duration of exercise to avoid fatigue*

6.7.4 Use of e-health

E-health includes informative websites, online health communities, apps, telemedicine, online consultation, and much more. The Internet and other electronic support can be a source of information and support for monitoring, providing feedback and increasing motivation, aiming to support self-management and adherence. However, it is essential to inform pwp that not all information on the Internet and e-health applications is of equal quality. Moreover, not all information related to Parkinson's will be applicable to each pwp's needs. A physiotherapist can help pwp in identifying the more reliable Internet sources, such as the EPDA website and the resources from the national Parkinson's organisations.

E-health applications can increase treatment fun and adherence. Some pwp may prefer simple sms reminders to perform exercises, whereas others may prefer using a Parkinson exercise app (www.appde.eu). Also available are exercise diaries or data from activity monitors that can be shared online. These give pwp insight into their daily physical activity levels (did I achieve my personal goals?) and the physiotherapist into adherence and the need for support. In addition, online health communities can be used to share experiences, exchange knowledge, and increase disease-specific expertise, but also to bridge geographical distances and enable interdisciplinary collaboration across institutions and traditional echelons.⁵⁶⁹ Finally, personal health communities offer the individual pwp the unique opportunity to store all medical information in one central place, while allowing transparent communication across all members of the pwp's health care team⁵⁶⁹.

Access to computers is increasing throughout Europe. Despite this, in 2011, 42% of the people aged 55 to 64 years and 65% of those aged 65 to 74 years had never used the internet⁵⁷⁰. In general, these percentages are higher for eastern and

southern Europe, and lower in northern and western Europe. Therefore, it is important that physiotherapists explore the potential for use of e-health with each pwp individually. Otherwise, DVDs with Parkinson's-specific exercises, such as the one developed for the 2004 KNGF-Guideline (www.appde.eu), or the activity games, such as using Nintendo Wii or the X-Box Kinect, may be of interest.

6.7.5 Knowing when to stop physical activity

Inform pwp that feeling tired and sweaty during exercise is normal, but to stop exercising and seek medical advice if they experience^{464;465}:

- nausea
- tightness or pain in the chest for more than a few minutes
- unusual breathlessness, such as more than 40 breaths per minute
- severe fatigue or dyspnoea
- dizziness or light-headedness
- a sensation of their heart skipping or adding beats
- pain
- breaking into a cold sweat
- if monitored: reduction of systolic blood pressure during exercise by more than 10 mmHg

6.8 Evaluation and the continuum of care

The GDG recommends evaluating:

- the pwp's understanding, performance, satisfaction and adherence of the physiotherapy intervention every session (Table 4.2)
- the attainment of the treatment goal at the end of the agreed upon treatment period, as described with the GAS
- the progression of attainment of the treatment goal halfway during the agreed treatment period, or in case of prolonged treatment, every four weeks

The GDG recommends using measurement tools applied for inventory reasons, which can also be used for evaluation (Table 5.15), to support the GAS outcome. It is important to keep the circumstances of measurement stable, especially the location and time of measurement (5.2.3). Doing so, it is important to keep in mind that pwp are, by the nature of the disease, losing function⁴⁵⁴. For feasibility purpose, make the activities performed with the selected tools part of your treatment plan.

GDG advice: Completing a treatment period

- *When treatment goals are achieved*
- *When the physiotherapist takes the view that physiotherapy has no longer an additional value*
- *When the physiotherapist expects pwp are able to achieve the treatment goals on their own, without therapeutic supervision*

Patient-centeredness is a crucial element of quality of care and central to this Guideline.^{363;364} A valid instrument to measure patient-centeredness in care for pwp is the Patient-Centered Questionnaire for Parkinson's Disease (PCQ-PD).⁵⁷¹ However, the PCQ-PD is extensive and targeted at health institutes, not single care providers. To gain insight into the pwp's experiences with the physiotherapy care provided, the GDG has therefore made a adapted version (Appendix 6). To evaluate pwp satisfaction with physiotherapy care provided, the MedRisk Instrument is available (copyrighted and owned by MedRisk). Validated versions of this instrument are available in English, Spanish and Italian, and more are underway.⁵⁷²⁻⁵⁷⁵

6.8.1 Communication

At the completion of a treatment period, but also during the treatment period in case of prolonged treatment, the physiotherapist should communicate with the referring physician. When standards for communication are available through the national physiotherapy association, these should be followed. When other health professionals are involved in care for a pwp simultaneously, the GDG recommends to ask the pwp's permission to contact this health professional aiming to, if needed, adjust the interventions to one other, taking into account the preferences of and strain on the pwp.

GDG advice: Recommendations for contents of communication with health professionals

- *Relevant impairments, activity limitations and restrictions in participation*
- *The overall physiotherapy treatment goal and sub-goals*
- *Selected treatment modalities, period and frequency, including self-management support*
- *If the pwp has not been treated according to this Guideline: on which points and why the treatment deviated from this Guideline*
- *The treatment effect, preferably supported by data from appropriate measurement tools and their interpretation*
- *Whether follow-up agreements or appointments are made*

When psychosocial problems, response fluctuations or low adherence to medication intake are noticed, the pwp can be advised to discuss this with the care coordinator or physician who holds main medical responsibility. This most often is the neurologist. Finally, if required, the physiotherapist can assist in referral towards palliative care.

6.8.2 A continuum of care

Self-management support in chronic conditions such as Parkinson's disease is an ongoing process. Moreover, Parkinson's disease is progressive, thus in addition to existing impairments and activity limitations, new ones can be expected. Physiotherapists can be considered the physical medicine experts in the management of Parkinson's disease. However, supervised physiotherapy intervention cannot be ongoing, and does not need to. Therefore, the GDG recommends that physiotherapists discuss and agree with pwp, as early as during history taking, how to continue after completion of a treatment period.

Pwp can be supported in their self-management by the supply of tools such as the Exercise Diary (Appendix 5.6), an activity monitor, visuals of exercises using prints, visuals and apps. Moreover, they can be guided towards community support groups and exercise classes. The GDG also advises to discuss and agree upon time to and means of (intermittent) follow-up and monitoring. If for example a telephone or email is provided, agree upon who will originate the contact and when. Time to a next appointment for follow-up or monitoring will depend on the pwp specific circumstances and needs. Carers and, if applicable, home care professionals can be assisted in understanding movement related problems in pwp (Appendix 3).

GDG advice: continuum of care

Agree upon and arrange ongoing monitoring at varying time periods, such as from one to 12 months, to suit individual circumstances and needs.

6.8.3 Late stage treatment

In this phase of the disease, pwp may be confined to a wheelchair or a bed (Hoehn and Yahr 5). The treatment goal in this phase is to preserve vital functions and to prevent complications, such as pressure sores and contractures. Exercise and movement strategy training may still be efficacious, but scientific evaluation for this group of pwp is lacking. Generally, the 5% to 10% of pwp staying in institutionalised, long term care facilities, receive suboptimal care by health professionals without Parkinson's-specific expertise¹⁶¹.

Based on consensus, the GDG advises to achieve goals in this stage by:

- Involving the caregiver or nursing personnel in the intervention, if the pwp agrees
- Actively support exercising to minimise (a further) reduction of physical capacity
- Providing information and advice with regard to the prevention of pressure sores and contractures
- Correct body posture in bed or wheelchair
- Support frequent changes of position
- Advice and train caregivers and nursing personnel in supporting pwp performing transfers, if possible by using compensatory strategies and to the pwp meaningful cues
- Report skin changes (such as redness, blisters or open sores) promptly

An occupational therapist may provide advice on support while sitting and lying, and on aids, especially for static activities (such as a hand splint and a tray on a wheelchair). Furthermore, the expertise of the occupational therapist is used in the selection of pressure relieving products such as pillows, and the adjustment of wheelchairs and beds. For possible advice on nutrition, the pwp is referred to a dietician.

Chapter 7

GRADE-based recommendations for each core area

GRADE-based recommendations per core area and outcome aim to support physiotherapists and pwp in their shared decision-making when selecting a type of interventions for a specific impairment or limitation.

Recommendations and GDG advice presented in Chapter 6 are based on 70 CCTs⁷⁶⁻¹⁴⁵. Data from 55 CCTs were used for the meta-analyses and recommendations developed by using the GRADE method (Appendices 15 and 17, Guideline development and scientific justification), whereas the results of the other 15 CCTs were used for the general considerations. In this chapter, results are provided per core area, outcome and type of intervention (Table 7).

Three of the presented outcomes, classified as critical by the GDG, are not specific to one of the core areas of physiotherapy treatment for pwp: motor functions, quality of life and the patient reported treatment effect. Motor functions are evaluated with the Unified Parkinson's Disease Rating Scale (UPDRS) III. This motor part of the UPDRS provides an overall score for movement related functions and activities. It is frequently used by neurologist to gain insight into disease progression. For groups of pwp engaged in physiotherapy research, it is an important outcome. However, it is not recommended for use by physiotherapists in individual pwp (5.4.1). Quality of life is one of the overall goals of Parkinson management is to optimise quality of life (2.4.4). Quality of life is influenced by a variety of impairments, activity limitations, restrictions and personal and environmental factors. Physiotherapy addresses only part of these. Not all items of the PDQ-39 are of importance to, or can be improved by physiotherapy. Moreover, questions have risen on the quality, interpretation and responsiveness of the PDQ-39 (Appendix 16, Guideline development and scientific justification).

Unfortunately, no CCTs have evaluated the effects of physiotherapy for manual activities using critical outcomes. Therefore, no GRADE-based recommendations are available. Results from non-CCTs show improved speed of execution as well as bi-manual coordination after bimanual figure drawing (500 to 600 drawings)⁵²³; improved reaching speed after a four week (4/wk, 60 minutes) physiotherapy training consisting of multiple repetitions of whole body movements, focussing on maximal bigness and attend to the perceptual feedback⁴⁸⁰; and reduced bradykinesia after six minute action observation (repetitive 3Hz finger movements)⁵⁷⁶.

Table 7 GRADE-based recommendations for physiotherapy interventions with a positive effect for pwp

Level	Meaning
Strong for	Positive effect and 0 outside confidence interval of effect; Evidence quality moderate/high
Weak for	Positive effect and 0 outside effect confidence interval; Quality of evidence low or moderate/high but only small effect or very large confidence interval
Weak against	Positive effect, but 0 inside confidence interval of effect

Core area	ICF level	Outcome	Types of interventions							
			Conventional physiotherapy	Treadmill	Massage	Cueing	Strategies for CMS	Dance: tango	Tai Chi	
Balance	Balance capacity	No of falls	Weak against						Strong for	
		BBS	Strong for	Weak for					Strong for	
		FR	Strong for			Weak against			Strong for	
		DGI				Weak for				
		Mini-BESTest							Strong for	
Balance & Gait	Balance performance	FES / ABC	Weak against			Weak against				
		Capacity of functional mobility	Timed turn	Weak against						
			Timed stairs		Weak against					
Gait	Walking capacity	Speed	Strong for	Strong for		Strong for	Weak against	Weak against	Strong for	
		Stride length	Weak against	Strong for		Weak against	Weak for	Weak against	Strong for	
		Step length	Weak against			Weak for	Weak against			
		Cadence	Weak against	Weak against		Weak against	Weak against			
		Distance	Weak against	Weak for				Weak against	Strong for	
		Walking performance	FOG-Q				Weak for		Weak against	
			Capacity of functional mobility	TUG	Weak for			Weak against		Weak for
Transfers	Capacity of functional mobility	PAS					Strong for			
		Sit-to-stand				Weak for				
Physical Capacity	Muscle functions	PAS – Chair				Strong for				
		Strength	Strong for	Weak against					Strong for	
	Walking capacity	Walk distance	Weak against	Weak for				Weak against	Strong for	
Movement functions		UPDRS III	Strong for	Weak against		Weak for	Weak against	Weak against	Strong for	
	P&G Score*				Weak for					
	PDQ-39	Weak against			Weak against		Weak against			
	Other	Quality of life	EQ-5D	Weak against			Weak against		Weak against	
PDQL			Weak against							
Patient-based treatment effect			CGI			Weak for				
			PSI-PD					Weak for		

*UPDRS III items 15 & 29–30 only; ** for combined PDQ-39, EQ-5D and PDQL-scores: weak against

Outcomes: ABC, Activities Balance Confidence Scale; BBS, Berg Balance Scale; CGI, Clinical Global Impression; DGI, Dynamic Gait Index; EQ-5D, EuroQol 5-D; FOG-Q, Freezing of Gait Questionnaire; FES, Falls Efficacy Scale; FR, Functional Reach; PAS, Parkinson Activity Scale; PDQ-39, Parkinson's Disease Quality of Life Questionnaire 39; PDQL, Parkinson Disease Quality of Life Questionnaire; PSI-PD, Patient Specific Index for Parkinson's disease; TUG, Timed Up and Go; UPDRS, Unified Parkinson's disease Rating Scale

Conventional physiotherapy: all physiotherapist-supervised active exercise interventions targeting gait, balance, transfers or physical capacity, or a combination thereof

Strategies for CMS (complex movement sequences): formerly called cognitive movement strategies

Appendix 1

Self-management: information for people with Parkinson's disease

Self-management means that you take responsibility, to the best of your ability, for dealing with the issues Parkinson's creates. Given the scope of this Guideline, this information concentrates on physical activity and movement activities. However, this should be only one part of the focus of your self-management. Other things to consider include your medication intake, nutrition, speech, mood and sleep. Your neurologist or Parkinson's disease nurse specialist will be able to tell you more about these, and refer you on to the appropriate healthcare professional when needed. Try to decide on your own priorities and organise a balanced programme with the support of professionals with Parkinson's-specific expertise. You may need to see different experts as time goes on. There are things you will need to ask health professionals like physiotherapists, as it is their role to keep you moving safely and independently, and to help you to keep your body in as good a working condition as possible. However, what you can do for yourself is:

1. Exercise regularly
2. Recognise the time when you may need to visit a physiotherapist
3. Get the best out of your visits to a physiotherapist

1. Exercising regularly

On average, people with Parkinson's disease are one-third less active than other people of the same age. Not doing enough exercise can actually be more harmful to you than taking up activity. Physical inactivity increases the risk of developing adverse health conditions, including heart disease, type 2 diabetes and osteoporosis. Therefore, try to exercise regularly.

Some general advice for keeping active:

- Try to reduce your daily sitting time; walk rather than drive short distances, such as to a store; take the stairs instead of the escalator or elevator
- Try to exercise at least 150 minutes a week, making an effort to get warm, a little sweaty and out of breath, to the extent that it is difficult to hold a conversation. For example, exercise for 30 minutes on five days a week. If 30 minutes in one go is too much, try shorter periods, such as three times 10 minutes.
- To keep fit and healthy, you need more than just one style of exercise. For example, try some exercise that helps you build muscle power one day, then something that improves your endurance the next day. Add exercise of a type that keeps your joints flexible: make large movements. Preferably choose functional-task exercises, using large movements whilst lying down, sitting, standing or walking. This will improve your day-to-day function, such as walking and keeping your balance.
- Choose types of exercise you like and that suit your physical capabilities. This makes it easier to stick with it. For example, some people like playing a sport whilst others need to exercise while sitting or lying down.
- If you can exercise with others, this offers social support that helps you to keep motivated. If there is a Parkinson's specific or general exercise, dance or Tai Chi group near where you live, consider joining.
- Exercise at the times of the day when you feel best and your medication is working well.
- Try to link the exercises to your daily routine.
- Feeling tired and starting to sweat during exercise is normal. Please stop exercising and seek medical advice if you break into a cold sweat or if you feel pain, nausea, tightness or pain in your chest for more than a few minutes, unusual breathlessness, dizziness or light-headedness or a sensation of your heart skipping or adding beats.
- Please consult your physician before starting any type of exercise if your doctor has told you that you have one or more of the risk factors for heart disease, if you have recently experienced a heart attack or other heart problem or if you have previously been inactive.

2. When should you visit a physiotherapist?

In all stages of the disease, a physiotherapist can provide you with advice and education. If required, a physiotherapist will also provide treatment. Physiotherapy treatment aims to prevent, stabilise or reduce movement related problems. You are advised to consult a physiotherapist:

- As soon as possible after your diagnosis for self-management support.
- When you find it difficult to exercise regularly.
- When you have questions on exercise types, frequency, intensity or safety.
- When you experience:
 - walking problems like slowness, hesitation or feeling glued to the floor (freezing)
 - any balance problems, like recent falls or near falls or if you are afraid you might fall
 - problems rising from a chair, rolling over in bed or getting in and out of a car
 - pain, for example in your neck, back or shoulders.

It is important that your neurologist knows when you are visiting a physiotherapist. In some countries, referral by a physician or general doctor may be necessary to obtain reimbursement of your physiotherapy care costs.

Care for Parkinson's is complex. Therefore, it is important that you visit a physiotherapist with Parkinson's specific expertise. If no such physiotherapist is around, you might inform the physiotherapist you are visiting about the European Physiotherapy Guideline for Parkinson's Disease or hand over a copy of the Guideline's Quick Reference Cards (www.parkinsonnet.info/euguideline).

What to expect when you visit a physiotherapist?

A physiotherapist assesses your mobility problems and analyses why they occur. This may take two appointments. If you experience your main problems at your home, the physiotherapist may assess you at your home. If physiotherapy is indicated, you and the physiotherapist together set your individual goals and develop a treatment plan. Physiotherapy treatment may include a combination of advice, education, (home) exercise and training of so-called compensatory strategies. The duration of a treatment period, as well as the frequency of the visits will depend on your individual goals and treatment plan.

The physiotherapist will support you in your self-management and therefore discuss and agree with you upon time and means of ongoing contact. How often you return to visit the physiotherapist will depend on your individual circumstances and needs.

3. How to get the best out of the visits to your physiotherapist

Before your visit:

- Write down your problems and questions you want to ask; you can use Pre-assessment Information Form (PIF, Appendix 2) to help you organise your thoughts

At your visit:

- Above all, be honest explaining how you feel, and ask for further explanation if you are not sure whether you understand what your physiotherapist is saying.
- Consider bringing your carer.
- Be ready to explain your main problems, how they affect your daily life (such as at home, in the community or at work), and what you would like to achieve.
- Describe methods or treatments you have already tried to reduce these problems and what effect they had. The physiotherapist may suggest different treatment options.
- If your physiotherapist cannot help with a specific issue, he or she can advise you about treatment options provided by other health professionals for this issue. Your physiotherapist may also provide you with the necessary contact details.
- Remember that you and your physiotherapist are partners in care, so try working together on some of the following ideas:
 1. Decide together what your goals of treatment should be: what to achieve, and by when?
 2. Agree upon a realistic plan.
 3. Plan follow-up visits together. This allows you to ask for feedback, for example to make sure you exercise correctly. Remember to get in contact if you have questions about the plan or are not sure you are on the right track.
 4. When you cannot adhere to the exercise plan, discuss the problems with the physiotherapist. Try to agree upon adjustments that will help you continue with some activity.
 5. Remember that you need to keep active for as long as possible, so agree upon how to continue at home upon completion of a treatment period.
 6. Agree upon what your physiotherapists should communicate to your referring physician.

Appendix 2

Pre-assessment Information Form (PIF)

Please fill in this 4-page form before you visit your physiotherapist the first time. It gives you (and your carer) the chance to think about the problems you would like the physiotherapist to address. This information will help your physiotherapist in building a picture of what you consider your main problems, as well as your physical capability.

Date: _____

Your name: _____

Your physiotherapy goal

1. What problems would you like to work on first?

2. In what way have you tried to tackle these problems?

3. How effective were these methods?

4. What are your expectations of physiotherapy?

5. Any other information you want your physiotherapist to know about, such as health problems other than Parkinson's?

6. Any other questions you want to ask?

Falls

7. In the last 12 months, have you fallen at all for any reason, any trips or slips, even if they probably had nothing to do with Parkinson's disease?

- No
- Yes

8. Have you had any near misses in the last 12 months when you nearly did, but were able to stop a full fall?

- No
- Yes

9. How afraid are you of falling over?

- Not at all
- A little
- Quite a bit
- Very much

Freezing of gait

Freezing is the feeling of your feet being glued to the floor. Sometimes it is accompanied by trembling of the legs and small shuffling steps. It may happen when you start walking, when you make a turn, when you are walking through narrow spaces or when you are walking in crowded places. If you are not sure if you freeze, please watch the freezing of gait video at www.parkinsonnet.info/euguideline

10. Have you experienced freezing episodes over the past month?

- No
- Yes

Physical activity

11. For every activity you have carried out during the past week, please fill in for how long this was for. Please give a total for all 7 days together.

Activities	Total time spent over the past 7 days
Walking on ground level (indoors, outdoors or on a treadmill)	minutes:
Walking uphill, upstairs or running	minutes:
Bicycling on ground level (outdoors or on a treadmill)	minutes:
Bicycling uphill or at a fast pace (outdoors or on a treadmill)	minutes:
Dancing, recreational swimming, gymnastics, exercise group training, yoga, playing doubles in tennis or playing golf	minutes:
Swimming steadily paced laps, playing singles in tennis or rowing	minutes:
Sweeping, washing windows or raking in the garden or yard	minutes:
Digging in the garden or yard, heavy construction, heavy lifting, chopping wood or shovelling snow	minutes:
Other activities, please describe:	minutes:

12. Compared to other weeks, have you been as physically active this week?

- More active this week
- Same
- Less active this week

13. What regular activities have you stopped during the past 12 months?

14. Why did you stop?

15. Please tick whether you find these activities difficult to perform or if you experience other problems such as freezing, losing balance or pain when performing them:

Domain	Activity	Difficult	Not difficult
Walking	walking indoors		
	walking outdoors		
	turning		
	start walking		
	climbing and descending stairs		
	walking while performing dual tasks		
	walking through narrow passages		
	stop walking		
Transfers	turning in bed		
	getting into or out of bed		
	getting into or out of a car		
	getting into or out of a chair		
	getting onto or off a toilet seat		
	getting into or out of a bath		
	picking up an object from the floor		
	getting up from the floor		
	getting on or off a bicycle		
Manual activities	in domestic life, such as when preparing meals, doing housework		
	in self-care, such as when eating, washing and dressing		

16. Please tick whether you experience these sensations:

Domain	Activity	Yes	No
Physical functions	easily out of breath		
	muscle weakness		
	stiffness		
Pain	pain		

Consider bringing your carer or a friend with you when you visit your physiotherapist. Two heads are better than one!

Appendix 3

Information for carers & home care professionals

Many people with Parkinson's disease (pwp) are cared for by informal carers such as their husband, wife, children or friends, or by formal home care professionals. National Parkinson associations provide general information, means of communication and support for carers. In addition, the information on this page aims to provide more understanding about movement related problems of pwp.

How to assist pwp with moving around and performing activities?

- Different pwp experience different problems. In general, pwp become slower and need more time:
 - To move around, like walking from one room to the other or opening doors:
allow for more time
 - To communicate, for example, when talking, writing, using a computer or a phone:
allow time
- The most common problems which can be addressed by physiotherapy, are:
 - Starting and continuing to walk, especially in crowded areas, when needing to avoid obstacles such as furniture or when going through narrow spaces such as doorways: **Do not leave objects on the floor that may be tripped over, and allow sufficient walking space throughout the house**
 - Keeping balance, especially indoors, when lighting is insufficient, when doing two things at the same time and when turning: **To prevent falls, ensure good lighting, do not leave objects on the floor that may be tripped over and support pwp to avoid doing two activities at the same time, such as walking and talking or carrying objects, if these activities make them more unsteady**
 - Performing transfers such as rising from sofa and sitting down again, rolling over in bed and adjusting sheets, getting into and out of a car and getting up from the floor: **Pwp may have their own or physiotherapy-trained strategies to do this; ask for these**

- People's problems can vary from day to day and even from hour to hour. The latter is usually a result of the fluctuating effects of the Parkinson's medication: **Try to find the best times of the day to perform activities such as dressing, washing and going for a walk**
- Doing two things at the same time becomes difficult for most pwp: **If this is a problem, avoid talking to pwp when they are moving around or exercising**
- Keeping active is very important to pwp: **Try to support pwp in staying active, even if it is just by walking in and around the house and taking the stairs instead of the elevator; allow them to do things for themselves, even if it takes longer**
- Pwp know best how and to what extent they want help: **Always respect the person's autonomy and ask what help they want from you.**

For informal carers: It is important to agree with the pwp upon when and how you may support them. Two heads are better than one. Therefore, if agreed, you are encouraged to go with the pwp when visiting a physiotherapist (or other health professional). In addition, the physiotherapist may be able to provide you with information or strategies on what will best support them, whilst at the same time, reducing your personal physical and emotional stress.

Appendix 4

ICF-based patient assessment & report sheet

Name / ID number: Date of birth: Diagnosis: ICD-20: Parkinson's disease		Long term goal: (See GAS-form) Short term goal:
Pwp Perspective		Past (near) falls: ABC / FES-I NFOG-Q/freezing: Activity level: Identified core areas:
Health Professional Perspective	Body-Structures/Functions *	Activities & Participation *
	6MWD & Borg 6-20: Push and Release: Rapid Turns / freezing: Stride length / cadence:	M-PAS: TUG: BBS / Mini-BESTest / DGI / FGA: FTSTS : 10MW: 6MWD :
	Environmental factors	Personal factors

*A selection of appropriate measurement tools will be made based on the outcome of History Taking

Appendix 5

Forms of recommended measurement tools

Forms for the following tools are included, in alphabetical order:

1. 3-Step Falls Predication Model
2. 10 Meter Walk (10MW)
3. Activities Balance Confidence (ABC) Scale
4. Berg Balance Scale (BBS)
5. Borg Scale 6-20
6. Exercise diary
7. Dynamic Gait Index (DGI) & Functional Gait Assessment (FGA)
8. Falls Diary
9. Falls Efficacy Scale International (FES-I)
10. Five Times Sit To Stand (FTSTS)
11. Rapid Turns test
12. Goal Attainment Scaling (GAS)
13. History of falling
14. Mini-BESTest
15. Modified Parkinson Activity Scale (M-PAS)
16. Patient Specific Index for Parkinson's Disease (PSI-PD): included in the PIF and GAS
17. New Freezing of Gait questionnaire (NFOG-Q)
18. Push and Release Test (P&R Test)
19. Six Minute Walk Distance (6MWD)
20. Timed Get-up and Go (TUG)

App. 5.1 3-Step Falls Prediction Model

This tool combines scores from other tools

Date: _____

Name pwp: _____ Physiotherapist name: _____

Interpretation of added sub-scores

Total score: 0 2 to 6 8 to 11
 Probability of falling in the next six months: Low (17%) Moderate (51%) High (85%)

Tool to copy score from	Question	Sub-scores
PIF History of falling	Has the pwp fallen in the past 12 months?	Yes=6 No=0
PIF NFOG-Q	Has the pwp experienced freezing in the past month?	Yes=3 No=0
10MW Walking speed	How fast is the pwp's self-selected comfortable walking pace?	<1.1m/s=2 ≥1.1m/s=0

Total scores are supportive for selecting pwp requiring:

- Low: participation in a general exercise class
- Moderate: Individualised physiotherapy exercise
- High: Interdisciplinary assessment

Source: Paul SS, Canning CG, Sherrington C, Lord SR, Close JC, Fung VS. Three simple clinical tests to accurately predict falls in people with Parkinson's disease. *Mov Disord* 2013; 28(5):655-662

App. 5.2 10 Meter Walk (10MW)

General information:

- assistive devices are allowed, physical assistance not
- the test can be performed at preferred walking and at fastest speed possible
- measure and mark a 10-meter walkway, such as with tape or chalk; allow 2 additional meters at the ends for acceleration and deceleration
- if a 14 meter space is unavailable, a 6MW can be performed, requiring 10m space
- carry out three trials to calculate a mean time and speed
- start timing when the toes of the leading foot crosses the first line
- stop timing when the toes of the leading foot crosses the second line
- calculate the average time over the three trials
- when used to estimate cueing frequency: count number of steps needed for the 10MW

Patient Instructions:

- For comfortable speed: *I will say ready, set, go. When I say go, walk at your most comfortable speed until I say stop.*
- For maximum speed: *I will say ready, set, go. When I say go, walk as fast as you safely can until I say stop.*

Date: _____

Name pwp: _____ Name physiotherapist: _____

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- If applicable, on or off state: _____
- Location: _____
- Shoes worn by the pwp: _____
- Assistive devices used by the pwp: _____

Speed	Time trial 1 (seconds)	Time trial 2 (seconds)	Time trial 3 (seconds)	Mean time 10MW (seconds)	Speed (m/s)
Comfortable speed					
Fast speed					

At risk for falling: see 3-step falls prediction model (Appendix 5.1)

Minimal detectable change: comfortable speed 0.18m/s (16% of baseline score) and fast speed 0.25m/s (17% of baseline score)⁴⁶⁹

Step frequency	Steps trial 1	Steps trial 2	Steps trial 3	Mean no of steps 10MW	Steps/minute
Comfortable speed					
Fast speed					

App. 5.3 Activities Balance Confidence (ABC) Scale

Many, but not all, persons with Parkinson’s disease fall. Physiotherapy may help to improve balance. By answering these questions, you will provide your physiotherapist with essential information regarding your confidence not to fall. You may consider asking your carer, partner or family to help you answering the questions.

General instructions:

- For each of the following, please indicate your level of confidence in doing the activity without losing your balance or becoming unsteady: please tick one of the percentage points on the scale
- If you do not currently do the activity in question, try to imagine how confident you would be if you had to do the activity. If you normally use a walking aid to do the activity or hold onto someone, rate your confidence as it you were using these supports.

Date: _____ Your name: _____

How confident are you that you will not lose your balance or become unsteady, when you:

	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
1. walk around the house?										
2. walk up or down stairs?										
3. bend over and pick up a slipper from the front of a closet floor										
4. reach for a small can off a shelf at eye level?										
5. stand on your tiptoes and reach for something above your head?										
6. stand on a chair and reach for something?										
7. sweep the floor?										
8. walk outside the house to a car parked in the driveway?										
9. get into or out of a car?										
10. walk across a parking lot to the mall?										
11. walk up or down a ramp?										
12. walk in a crowded mall where people rapidly walk past you?										
13. are bumped into by people as you walk through the mall?										
14. step onto or off an escalator while you are holding onto a railing?										
15. step onto or off an escalator while holding onto parcels such that you cannot hold onto the railing?										
16. walk outside on icy sidewalks?										

Source: Powell, LE & Myers AM. The Activities-specific Balance Confidence (ABC) Scale. J Gerontol Med Sci 1995; 50(1): M28-34

App. 5.4 Berg Balance Scale (BBS)

Date: _____

Name pwp: _____ Name physiotherapist: _____

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- If applicable, on or off state: _____
- Location: _____
- Shoes worn by the pwp: _____
- Height chair: _____

Item & total scores

1. Sitting unsupported _____
2. Change of position: sitting to standing _____
3. Change of position" standing to sitting _____
4. Transfers _____
5. Standing unsupported _____
6. Standing with eyes closed _____
7. Standing with feet together _____
8. Tandem standing _____
9. Standing on one leg _____
10. Turning trunk (feet fixed) _____
11. Retrieving objects from floor _____
12. Turning 360 degrees _____
13. Stool stepping _____
14. Reaching forward while standing _____

Total (range 0–56): _____

At risk for falling: $<47^{437;447}$; Minimal detectable change: 3 points (5% of baseline score)⁴⁷²

Equipment required:

- Stopwatch
- Ruler or other indicator of 5, 12,5 and 25 cm
- Two chairs of reasonable height : one with and one without arm rests
- Step or stool of average step height

Source: Berg KO, Wood-Dauphinee SL, Williams JI et al. Measuring balance in the elderly: validation of an instrument. Can J Publ Health 1992; 83 S2: 7-11

General:

- Give instructions as written and record the lowest response category that applies for each item
- In most items, the pwp is asked to maintain a given position for a specific time. Progressively more points are deducted if:
 - the time or distance requirements are not met
 - the pwp's performance warrants supervision
 - the pwp touches an external support or receives assistance from the physiotherapist
- Pwp should understand that they must maintain their balance while attempting the tasks
- The choices of which leg to stand on or how far to reach are left to the pwp

Assessments*1. Sitting to standing*

Please stand up. Try not to use your hand for support.

- 4 able to stand without using hands and stabilise independently
- 3 able to stand independently using hands
- 2 able to stand using hands after several tries
- 1 needs minimal aid to stand or stabilise
- 0 needs moderate or maximal assist to stand

2. Standing unsupported

Please stand for two minutes without holding on.

- 4 able to stand safely for 2 minutes
- 3 able to stand 2 minutes with supervision
- 2 able to stand 30 seconds unsupported
- 1 needs several tries to stand 30 seconds unsupported
- 0 unable to stand 30 seconds unsupported

If pwp is able to stand 2 minutes unsupported, score full points for sitting unsupported. Proceed to item #4.

3. Sitting with back unsupported but feet supported on floor or on a stool

Please sit with arms folded for 2 minutes.

- 4 able to sit safely and securely for 2 minutes
- 3 able to sit 2 minutes under supervision
- 2 able to sit 30 seconds
- 1 able to sit 10 seconds
- 0 unable to sit without support 10 seconds

4. Standing to sitting

Please sit down.

- 4 sits safely with minimal use of hands
- 3 controls descent by using hands
- 2 uses back of legs against chair to control descent
- 1 sits independently but has uncontrolled descent
- 0 needs assist to sit

5. *Transfers - arrange two chairs (one with and one without armrests) or a bed and a chair*

Please transfer to the seat with armrests. When you sit down, please return to the seat without armrests.

- 4 able to transfer safely with minor use of hands
- 3 able to transfer safely definite need of hands
- 2 able to transfer with verbal cuing and/or supervision
- 1 needs one person to assist
- 0 needs two people to assist or supervise to be safe

6. *Standing unsupported with eyes closed*

Please close your eyes and stand still for 10 seconds.

- 4 able to stand 10 seconds safely
- 3 able to stand 10 seconds with supervision
- 2 able to stand 3 seconds
- 1 unable to keep eyes closed 3 seconds but stays safely
- 0 needs help to keep from falling

7. *Standing unsupported with feet together*

Place your feet together and stand without holding on.

- 4 able to place feet together independently and stand 1 minute safely
- 3 able to place feet together independently and stand 1 minute with supervision
- 2 able to place feet together independently but unable to hold for 30 seconds
- 1 needs help to attain position but able to stand 15 seconds feet together
- 0 needs help to attain position and unable to hold for 15 seconds

8. *Reaching forward with outstretched arm while standing*

Now, lift your arm to 90 degrees. Stretch out your fingers and reach forward as far as you can.

- 4 can reach forward confidently 25 cm (10 inches)
- 3 can reach forward 12 cm (5 inches)
- 2 can reach forward 5 cm (2 inches)
- 1 reaches forward but needs supervision
- 0 loses balance while trying/requires external support

Place a ruler at the end of fingertips when arm is at 90 degrees. Fingers should not touch the ruler while reaching forward. When possible, ask pwp to use both arms when reaching to avoid rotation of the trunk.

9. *Pick up object from the floor from a standing position*

Pick up the shoe/slipper, which is in front of your feet.

- 4 able to pick up slipper safely and easily
- 3 able to pick up slipper but needs supervision
- 2 unable to pick up but reaches 2-5 cm from slipper and keeps balance independently
- 1 unable to pick up and needs supervision while trying
- 0 unable to try/needs assist to keep from losing balance or falling

10. Turning to look behind over left and right shoulders while standing

Turn to look directly behind you over the left shoulder to [pick an object to look at directly behind the pwp]... and to the right.

- 4 looks behind from both sides and weight shifts well
- 3 looks behind one side only other side shows less weight shift
- 2 turns sideways only but maintains balance
- 1 needs supervision when turning
- 0 needs assist to keep from losing balance or falling

11. Turn 360 degrees

Please turn completely around in a full circle. Pause. Then turn a full circle in the other direction.

- 4 able to turn 360 degrees safely in 4 seconds or less
- 3 able to turn 360 degrees safely one side only 4 seconds or less
- 2 able to turn 360 degrees safely but slowly
- 1 needs close supervision or verbal cuing
- 0 needs assistance while turning

12. Place alternate foot on step or stool while standing unsupported

Place each foot alternately on the step/stool. Continue until each foot has touched the step/stool four times.

- 4 able to stand independently and safely and complete 8 steps in 20 seconds
- 3 able to stand independently and complete 8 steps in > 20 seconds
- 2 able to complete 4 steps without aid with supervision
- 1 able to complete > 2 steps needs minimal assist
- 0 needs assistance to keep from falling/unable to try

13. Standing unsupported one foot in front – demonstrate first

Place one foot directly in front of the other. If you feel that you cannot place your foot directly in front, try to step far enough ahead that the heel of your forward foot is ahead of the toes of the other foot.

- 4 able to place foot tandem independently and hold 30 seconds
- 3 able to place foot ahead independently and hold 30 seconds
- 2 able to take small step independently and hold 30 seconds
- 1 needs help to step but can hold 15 seconds
- 0 loses balance while stepping or standing

Score 3 points: length of step exceeds length of other foot and width of stance approximates the pwp's normal stride width.

14. Standing on one leg

Stand on one leg as long as you can without holding on.

- 4 able to lift leg independently and hold > 10 seconds
- 3 able to lift leg independently and hold 5-10 seconds
- 2 able to lift leg independently and hold L 3 seconds
- 1 tries to lift leg unable to hold 3 seconds but remains standing independently.
- 0 unable to try of needs assist to prevent fall

App. 5.5 Borg Scale 6-20

Date: _____

Name pwp: _____

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- If applicable, on or off state: _____
- Location: _____
- Type of exercise: _____

Instructions to the pwp:

During the exercise, I want you to pay close attention to how hard you feel the exercise work rate is. This feeling should reflect your total amount of exertion and fatigue, combining all sensations and feelings of physical stress, effort, and fatigue. Do not concern yourself with any one factor such as leg pain, shortness of breath or exercise intensity, but try to concentrate on your total, inner feeling of exertion. Try not to underestimate or overestimate your feelings of exertion; be as accurate as you can

6	No exertion at all (at rest)
7	Very, very light
8	
9	Very light
10	
11	Fairly light
12	
13	Somewhat hard
14	
15	Hard
16	
17	Very hard
18	
19	Very, very hard
20	Maximal exertion

Source: Borg G. Borg's Perceived Exertion and Pain Scales. Champaign, IL: Human Kinetics; 1998

App. 5.6 Exercise diary

Date: _____

Your name: _____ Any remarks: _____

Please fill in how many minutes you spent each day of the week on each of the described exercises and how hard you feel the exercise work rate was using a Borg Scale 6-20 score (Appendix 1.4)

Description of exercise type, duration and frequency (times per week)	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
1.	minutes: Borg:						
2.	minutes: Borg:						
3.	minutes: Borg:						
4.	minutes: Borg:						

App. 5.7 Dynamic Gait Index (DGI) & Functional Gait Assessment (FGA)

Date: _____

Name pwp: _____ Name physiotherapist: _____

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- If applicable, on or off state: _____
- Location: _____
- Shoes worn by the pwp: _____
- Height chair: _____

Item & total scores DGI

- 1. Gait level surface _____
- 2. Change in gait speed _____
- 3. Gait with horizontal head turns _____
- 4. Gait with vertical head turns _____
- 5. Gait and pivot turn _____
- 6. Step over obstacle _____
- 7. Step around obstacles _____
- 8. Steps _____

Total score (range 0-24) _____

At risk for falling: DGI <19⁴⁴⁶

Minimal detectable change: 3 points (13% of baseline score)⁴⁷¹

Item & total scores FGA

- Total DGI score minus scores item 3, 4, 7 _____
- 3. Gait with horizontal head turns _____
- 4. Gait with vertical head turns _____
- 9. Walking with a narrow base of support _____
- 10. Walking with eyes closed _____
- 11. Walking backwards _____

Total score (range 0-30) _____

At risk for falling: <15

Note: DGI and FGA both assess gait with vertical and horizontal head turns, but the instructions are different. Therefore, when both DGI and FGA are used, these items need to be scores twice

Source DGI: Wrisley et al. 2003; original: Shumway-Cook A, Woollacott MH. Motor control: theory and practical applications. Baltimore: Williams & Wilkins; 1995. p 323-4, tbl 14.2.6) <http://www.lww.com>; Source FGA: Wrisley et al., Phys Ther 2004; 84 (10): 917-918

Equipment required:

- Two (shoe)box of 11.5cm height each
- Two cones
- Stopwatch
- Stairs with railing
- Tape or chalk (to mark the walkway)
- A marked 6 meter long, 30cm wide walkway

Assessment and scoring:

- Use instructions as written (*italic*)
- On all items, mark the highest category that applies

Note: When only interested in using the DGI, do not consider the information on time (s) and size of deviation from the walkway (cm)

DGI/FGA 1. Gait Level Surface.

Walk at your normal speed from here to the next mark (6m)

- | | |
|-------------------------|---|
| (3) Normal | Walks 6m in <5.5s, no assistive devices, good speed, no evidence for imbalance, normal gait pattern, deviates ≤15cm outside of the walkway |
| (2) Mild impairment | Walks 6m in 5.5 to 7s; uses assistive device, slower speed, mild gait deviations, or deviates 15 to 25cm outside the walkway. |
| (1) Moderate impairment | Walks 6m in >7s; slow speed, abnormal gait pattern, evidence for imbalance, or deviates 25-38cm outside the walkway. |
| (0) Severe Impairment | Cannot walk 6m without assistance, severe gait deviations or imbalance; deviates greater than 38cm outside the walkway or reaches and touches the wall. |

DGI/FGA 2. Change in Gait Speed.

Begin walking at your normal pace (for 1.5m), when I tell you "go," walk as fast as you can (for 1.5m). When I tell you "slow," walk as slowly as you can (for 1.5m).

- | | |
|-------------------------|---|
| (3) Normal | Able to smoothly change walking speed without loss of balance or gait deviation. Shows a significant difference in walking speeds between normal, fast, and slow speeds. Deviates ≤ 15cm outside the walkway |
| (2) Mild Impairment | Able to change speed but demonstrates mild gait deviations, deviates 15 to 25cm outside the walkway, or no gait deviations, but unable to achieve a significant change in velocity, or uses an assistive device. |
| (1) Moderate Impairment | Makes only minor adjustments to walking speed, or accomplishes a speed change with significant gait deviations, deviates 15 to 25cm outside the walkway, or changes speed but loses balance but is able to recover and continue walking |
| (0) Severe Impairment | Cannot change speeds, deviates > 38cm outside walkway, or loses balance and has to reach for wall or be caught. |

3. Gait with Horizontal Head Turns

FGA: Walk from here to the next mark 6m away. Begin walking at your normal pace. Keep walking straight; after 3 steps, turn your head to the right and keep walking straight while looking to the right. After 3 more steps, turn your head to the left and keep walking straight while looking left. Continue alternating looking right and left every 3 steps until you have completed 2 repetitions in each direction.

DGI: Begin walking at your normal pace. When I tell you to “look right,” keep walking straight but turn your head to the right. Keep looking right until I tell you “look left,” then keep walking straight but turn your head to the left. Keep your head to the left until I tell you, “look straight,” then keep walking straight, but return your head to the centre.

- | | |
|-------------------------|--|
| (3) Normal | Performs head turns smoothly with no change in gait. Deviates ≤ 15 cm outside walkway |
| (2) Mild Impairment | Performs head turns smoothly with slight change in gait velocity (e.g. minor disruption to smooth gait path), deviates 15-25cm outside walkway, or uses an assistive device. |
| (1) Moderate Impairment | Performs head turns with moderate change in gait velocity, slows down, deviates 25-38cm outside walkway but recovers, can continue to walk. |
| (0) Severe Impairment | Performs task with severe disruption of gait: staggers 38cm outside walkway, loses balance, stops or reaches for wall. |

4. Gait with Vertical Head Turns

FGA: Walk from here to the next mark (6 m). Begin walking at your normal pace. Keep walking straight; after 3 steps, tip your head up and keep walking straight while looking up. After 3 more steps, tip your head down, keep walking straight while looking down. Continue alternating looking up and down every 3 steps until you have completed 2 repetitions in each direction.

DGI: Begin walking at your normal pace. When I tell you to “look up,” keep walking straight, but tip your head and look up. Keep looking up until I tell you, “look down.” Then keep walking straight and turn your head down. Keep looking down until I tell you, “look straight,” then keep walking straight, but return your head to the centre.

- | | |
|-------------------------|--|
| (3) Normal | Performs head turns with no change in gait, deviates ≤ 15 cm outside walkway. |
| (2) Mild Impairment | Performs task with slight change in gait velocity (e.g. minor disruption to smooth gait path), deviates 15-25cm outside walkway or uses assistive devices. |
| (1) Moderate Impairment | Performs task with moderate change in gait velocity (slows down, deviates 25-38cm outside walkway), but recovers, continue to walk |
| (0) Severe Impairment | Performs task with severe disruption of gait: staggers 38cm outside walkway, loses balance, stops or reaches for wall. |

DGI/FGA 5. Gait and Pivot Turn

Begin with walking at your normal pace. When I tell you, "turn and stop," turn as quickly as you can to face the opposite direction and stop.

- (3) Normal Pivot turns safely ≤ 3 s and stops quickly with no loss of balance
- (2) Mild Impairment Pivot turns safely in >3 s and stops with no loss of balance, or pivot turns safely ≤ 3 s and stops with mild imbalance, requires small steps to catch balance.
- (1) Moderate Impairment Turns slowly, requires verbal cueing or requires several small steps to catch balance following turn and stop.
- (0) Severe Impairment Cannot turn safely, requires assistance to turn and stop.

DGI/FGA 6. Step over Obstacle

Begin walking at your normal speed. When you come to the shoebox, step over it, not around it, and keep walking.

- (3) Normal Is able to step over 2 stacked shoeboxes taped together without changing gait speed; no evidence of imbalance.
- (2) Mild Impairment Is able to step over one shoebox without changing gait speed; no evidence of imbalance
- (1) Moderate Impairment Is able to step over one shoebox but must slow down and adjust steps to clear box safely. May require verbal cueing.
- (0) Severe Impairment Cannot perform without assistance.

DGI 7. Step Around Obstacles

Begin walking at your normal speed. When you come to the first cone (about 6' away), walk around the right side of it. When you come to the second cone (6' passed first cone), walk around it to the left.

- (3) Normal Is able to walk around cones safely without changing gait speed; no evidence of imbalance.
- (2) Mild Impairment Is able to step around both cones, but must slow down and adjust steps to clear cones.
- (1) Moderate Impairment Is able to clear cones but must significantly slow speed to accomplish task or requires verbal cueing.
- (0) Severe Impairment Unable to clear cones, walks into one or both cones, or requires physical assistance.

DGI 8/FGA10. Steps

Walk up these stairs as you would at home (ie, using the rail if necessary). At the top turn around and walk down.

- (3) Normal Alternating feet, no rail.
- (2) Mild Impairment Alternating feet, must use rail.
- (1) Moderate Impairment Two feet to a stair; must use rail.
- (0) Severe Impairment Cannot do safely.

FGA 7. Gait with narrow base of support

Walk on the floor with arms folded across the chest, feet aligned heel to toe in tandem for a distance of 3.6 m. The number of steps taken in a straight line are counted for maximum of 10 steps.

- (3) Normal Is able to ambulate for 10 steps heel to toe with no staggering.
- (2) Mild impairment Ambulates 7–9 steps.
- (1) Moderate impairment Ambulates 4–7 steps.
- (0) Severe impairment Ambulates <4 steps or cannot perform without assistance

FGA 8. Gait with eyes closed

Walk at your normal speed from here to the next mark (6 m) with your eyes closed.

- (3) Normal Walks 6m in <7s, no assistive devices, no imbalance, normal gait pattern, deviates no greater no 15cm outside walkway.
- (2) Mild impairment Walks 6m in 7-9s, uses assistive device, deviates 15-25cm outside walkway
- (1) Moderate impairment Walks 6m in <9s, abnormal gait pattern, imbalance, deviates 25-38cm outside the walkway
- (0) Severe impairment Cannot walk 6 m (20 ft) without assistance, severe gait deviations or imbalance, deviates greater than 38cm outside the walkway or will not attempt task.

FGA 9. Ambulating backwards

Walk backwards until I tell you to stop.

- (3) Normal Walks 6m, no assistive devices, good speed, no evidence for imbalance, normal gait pattern, deviates no greater no 15cm outside the walkway.
- (2) Mild impairment Walks 6m, uses assistive device, slower speed, mild gait deviations, deviates 15–25cm outside the walkway
- (1) Moderate impairment Walks 6m, slow speed, abnormal gait pattern, evidence for imbalance, deviates 25–38cm outside the walkway.
- (0) Severe impairment Cannot walk 6m without assistance, severe gait deviations or imbalance, deviates greater than 38cm outside the walkway or will not attempt task

App. 5.8 Falls Diary

Physiotherapy may help to improve balance. By filling in this diary, you will provide your physiotherapist with essential information on what to address in treatment. You may consider asking your carer, partner or family to help you filling in the diary.

Explanation of (near) falls

- Fall: a sudden, unexpected event that results in coming to rest unintentionally on the ground or at some other lower level
- Near fall: an involuntary or uncontrolled descent not ending on the ground or at some other lower level

How to fill in the diary:

- At the end of each day, please write 'No' if you did not had a (near) fall that day, otherwise please fill in the time(s) of your fall(s)
- In case of falls: for the first two falls, please answer the questions in the tables left

Week: _____ Your name: _____

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Fall							
Near fall							

Falls	1st fall this week	2nd fall this week
Where were you when you fell?		
What were you doing or trying to do at the time?		
What do you think caused you to fall?		
How did you land?		
What injuries did you sustain?		
How did you get up again?		
What health care did you receive?		

Near falls	1st near fall this week	2nd near fall this week
What were you doing when you nearly fell?		
Why do you think you nearly fell?		
How did you save yourself from falling?		

App. 5.9 Falls Efficacy Scale International (FES-I)

Date: _____ Your name: _____

General instructions

Physiotherapy may help to improve balance. By filling in this form, you will provide your physiotherapist with essential information on what to address in treatment. You may consider asking your carer, partner or family to help you filling in the form.

Please reply thinking about how you usually do the activity. If you currently do not do the activity (such as if someone does your shopping for you), please answer to show whether you think you would be concerned about falling *if you did the activity*.

For each of the following activities, please tick the box that is closest to your own opinion to show how concerned you are that you might fall if you did this activity.

How concerned are you when....	(1) Not at all concerned	(2) Somewhat concerned	(3) Fairly concerned	(4) Very concerned
Cleaning the house (such as sweep, vacuum or dust)				
Getting dressed or undressed				
Preparing simple meals				
Taking a bath or shower				
Going to the shop				
Getting in or out of a chair				
Going up or down stairs				
Walking around in the neighbourhood				
Reaching for something above your head or on the ground				
Going to answer the telephone before it stops ringing				
Walking on a slippery surface (such as wet or icy)				
Visiting a friend or relative				
Walking in a place with crowds				
Walking on an uneven surface (such as rocky ground, poorly maintained pavement)				
Walking up or down a slope				
Going out to a social event such as religious service, family gathering or club meeting				

Source: www.profane.eu.org

App. 5.10 Five Times Sit to Stand (FTSTS)**Equipment required**

- Chair with arm rests, of reasonable height (43-45 cm)
- Stopwatch

General Instruction

- Pwp sits with arms folded across chest and with their back against the chair
- Ensure that the chair is not secured (that is against the wall or mat)
- Demonstrate what you mean to ensure they understand the instructions
- It is OK if the pwp does touch the back of the chair, but it is not recommended.
- Timing begins at "Go" and stops when the pwp's buttocks touch the chair on the fifth repetition.
- Inability to complete five repetitions without assistance or use of upper extremity support indicates failure of test
- Try not to talk to the pwp during the test as it may decrease the pwp's speed

Instructions for the pwp:

"I want you to stand up and sit down 5 times as quickly as you can when I say 'Go'. Make sure you fully stand between repetitions of the test and not to touch the back of the chair during each repetition and straighten your legs as much as you can when standing up"

Date: _____

Name pwp: _____ Name physiotherapist: _____

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- If applicable, on or off state: _____
- Location: _____
- Height chair: _____

Score: _____ seconds

At risk for falling: >16s

Source: Whitney SL, Wrisley DM, Marchetti GF, Gee MA, Redfern MS, Furman JM. Clinical measurement of sit-to-stand performance in people with balance disorders: validity of data for the Five-Times-Sit-to-Stand Test. Phys Ther 2005; 85(10):1034-1045

App. 5.11 Rapid Turns test

Equipment required, for dual tasking:

- See M-PAS (item 8) or Mini-BESTest (item 14) for dual tasking activity

General instructions

Ask the pwp to perform:

- starting from standstill
- repeated 360° narrow turns
- on the spot
- in both directions
- at high speed
- demonstrate first

If no freezing is provoked, a gait trajectory back and forth and dual tasks can be added to the test. For feasibility purposes the GDG recommends to use the Modified-PAS Gait Akinesia for this.

Date: _____

Name pwp: _____ Name physiotherapist: _____

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- If applicable, on or off state: _____
- Location: _____
- Shoes worn by the pwp: _____

Score (mark):

- Freezing
- No freezing

Specifications regarding freezing

- side of turning while freezing: _____
- if applicable, type of dual task needed to evoke freezing: _____
- other: _____

Source: Snijders AH, Haaxma CA, Hagen YJ, Munneke M, Bloem BR. Freezer or non-freezer: Clinical assessment of freezing of gait. Parkinsonism Relat Disord 2012; 18(2):149-154.

App. 5.12 Goal Attainment Scaling (GAS)

General instructions

At the end of history taking and physical examination, goals are defined and agreed upon by the pwp together with the physiotherapist.

Describing goals

The goals are written in a language the pwp understands and SMART:

- **Specific:** such as rising from a specific chair, walking in a specific location
- **Measurable:** such as using one of the recommended measurement tools
- **Attainable:** the pwp and physiotherapist agree that the goal is feasible
- **Relevant:** to this specific pwp, within the core areas of physiotherapy
- **Time-based:** when should this goal be achieved?

The GDG recommends to set one short-term goal (for example 2 weeks) and one long term and to described each goal at five levels of attainment. The levels are equally distributed around the pwp' expected level of performance. When describing the five levels is not feasible because of time constraints, set the zero score and rate all other levels retrospectively.

Evaluation

Each goal is evaluated by the pwp and the physiotherapist at the negotiated treatment period, and preferably also halfway to gain better insight into the feasibility of the goal and to motive the pwp. Each goal is rated on the 5-point scale: -2, -1, 0, +1 or +2.

Date: _____

Name pwp: _____

Attainment Level	Level	Goal of the pwp	Level Reached
<i>Much less</i> than the expected level	-2		
<i>Somewhat less</i> than the expected level	-1		
<i>At the</i> Expected level	0		
<i>Somewhat better</i> than the expected level	+1		
<i>Much better</i> than the expected level	+2		

Source: Kiresuk T.J., Smith A., Cardillo J.E. Goal attainment scaling: applications, theory and measurement. Hillsdale, NJ: Lawrence Erlbaum Associates; 1994; Lannin N. Goal attainment scaling allows program evaluation of a home-based occupational therapy program. Occup Ther Health Care 2003; 17(1):43-5

App. 5.13 History of Falling

Date: _____

Name pwp: _____

General instructions

- These questions are addressed only when 'yes' is answered to any of the two questions of the History of Falling in the PIF (that is question 7 or 8)
- Information on the occurrence of falls and avoidance-strategies may need probing
- The GDG recommends providing a Falls Dairy to pwp with past (near) falls.
- Support the pwp in providing as much information as possible by prompting the questions

Assessment

1a. *How many times have you fallen in the last 12 months?*

Prompt to clarify, for the past 3 falls, or in case of a high falling frequency, in general:			
1b. Where were you when you fell?			
1c. What were you doing or trying to do at the time?			
1d. What do you think caused you to fall?			
1e. Do you remember how you landed?			

2a. *How often would you say you have near misses?*

Prompt to clarify, for the past 3 near falls, or in case of a high near-falling frequency, in general:			
2b. What sort of things were you doing when you nearly fell?			
2c. Why do you think you nearly fell?			
2d. How did you save yourself from falling?			

Source: Stack E, Ashburn A. Fall events described by people with Parkinson's disease: implications for clinical interviewing and the research agenda. Physiother Res Int 1999; 4(3):190-200

App. 5.14 Mini-BESTest: Balance Evaluation Systems Test**Materials:**

- A firm chair (preferably comparable to the chair which is causing the greatest problems to the pwp and is used frequently), without arm rests or wheels
- Temper® / T-foam™: 4 inches thick, medium density T41 firmness rating
- Incline ramp
- Stopwatch
- Box of 23cm height (such as shoeboxes taped together)
- Tape to measure and mark on the floor: 3 meter distance from chair

General instructions

- Use instructions as provided (*italic*)
- If a pwp must use an assistive device for an item, score that item one category lower
- If a pwp requires physical assistance to perform an item, score 0 for that item

Date: _____

Name pwp: _____ Name physiotherapist: _____

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- Shoes (should be flat-heeled shoes or shoes and socks off): _____
- If applicable, on or off state: _____
- Location: _____
- Height chair: _____

Sub-scores and total score

Anticipatory	item 1-3	sub-score:	/ 6	=
Reactive postural control	item 4-6	sub-score:	/ 6	=
Sensory orientation	item 7-9	sub-score:	/ 6	=
Dynamic	item 10-14	sub-score:	/ 10	=
Total	item 1-14	total score:	/ 28	=

At risk for falling: <19

Source: www.bestest.us; Final revised version of the MiniBEST, 3/8/13 © 2005-2013 Oregon Health & Science University

4. Compensatory stepping correction- forward

Stand with your feet shoulder width apart, arms at your sides. Lean forward against my hands beyond your forward limits.

When I let go, do whatever is necessary, including taking a step, to avoid a fall

- (2) Normal: Recovers independently with a single, large step (second realignment step is allowed)
- (1) Moderate: More than one step used to recover equilibrium
- (0) Severe: No step or would fall if not caught or falls spontaneously

Stand in front of the pwp with one hand on each shoulder and ask the pwp to lean forward. Make sure there is room for them to step forward. Require the subject to lean until the subject's shoulders and hips are in front of toes. After you feel the pwp body weight in your hands, very suddenly release your support. The test must elicit a step. Be prepared to catch the pwp.

5. Compensatory stepping correction- backward

Stand with your feet shoulder width apart, arms at your sides. Lean backward against my hands beyond your backward limits. When I let go, do whatever is necessary, including taking a step, to avoid a fall

- (2) Normal: Recovers independently with a single, large step
- (1) Moderate: More than one step used to recover equilibrium
- (0) Severe: No step or would fall if not caught or falls spontaneously

Stand behind the pwp with one hand on each scapula and ask the pwp to lean backward. Make sure there is room for the subject to step backward.) Require the pwp to lean until their shoulders and hips are in back of their heels. After you feel the pwp's body weight in your hands, very suddenly release your support. Test must elicit a step. Be prepared to catch subject.

6. Compensatory stepping correction- lateral

Stand with your feet together, arms down at your sides. Lean into my hand beyond your sideways limit. When I let go, do whatever is necessary, including taking a step, to avoid a fall

Left

- (2) Normal: Recovers independently with 1 step (crossover or lateral OK)
- (1) Moderate: Several steps to recover equilibrium
- (0) Severe: Falls or cannot step

Right

- (2) Normal: Recovers independently with 1 step (crossover or lateral OK)
- (1) Moderate: Several steps to recover equilibrium
- (0) Severe: Falls or cannot step

Stand to the side of the pwp, place one hand on the side of the subject's pelvis and have the pwp lean their whole body into your hands. Require the pwp to lean until the midline of the pelvis is over the right (or left) foot and then suddenly release your hold. Be prepared to catch the pwp.

Score: use the side with the lowest score to calculate sub-score and total score.

7. Stance (feet together); eyes open, firm surface

Place your hands on your hips. Place your feet together until almost touching. Look straight ahead. Be as stable and still as possible, until I say stop

Time in seconds: _____

- (2) Normal: 30 s
- (1) Moderate: < 30 s
- (0) Severe: Unable

Record the time the pwp is able to stand with feet together. Make sure the pwp looks at a non-moving target 1.2-3.6m away.

8. Stance (feet together); eyes closed, foam surface

Step onto the foam. Place your hands on your hips. Place your feet together until almost touching. Be as stable and still as possible, until I say stop. I will start timing when you close your eyes

Time in seconds: _____

- (2) Normal: 30 s.
- (1) Moderate: < 30 s.
- (0) Severe: Unable.

Assist the pwp in stepping onto foam. Have the pwp step off of the foam between trials. Flip the foam over between each trial to ensure the foam has retained its shape.

9. Incline- eyes closed

Step onto the incline ramp. Please stand on the incline ramp with your toes toward the top. Place your feet shoulder width apart and have your arms down at your sides. I will start timing when you close your eyes

Time in seconds: _____

- (2) Normal: Stands independently 30 s and aligns with gravity.
- (1) Moderate: Stands independently <30 s OR aligns with surface.
- (0) Severe: Unable.

Once the subject closes eyes, begin timing and record time. Note if there is excessive sway.

10. Change in gait speed

Begin walking at your normal speed, when I tell you 'fast', walk as fast as you can. When I say 'slow', walk very slowly

- (2) Normal: Significantly changes walking speed without imbalance.
- (1) Moderate: Unable to change walking speed or signs of imbalance.
- (0) Severe: Unable to achieve significant change in walking speed AND signs of imbalance.

Allow the pwp to take 3-5 steps at normal speed, and then say "fast". After 3-5 fast steps, say "slow". Allow 3-5 slow steps before the subject stops walking.

11. Walk with head turns – horizontal

Begin walking at your normal speed, when I say “right”, turn your head and look to the right. When I say “left” turn your head and look to the left. Try to keep yourself walking in a straight line.

- (2) Normal: performs head turns with no change in gait speed and good balance.
- (1) Moderate: performs head turns with reduction in gait speed.
- (0) Severe: performs head turns with imbalance.

Allow the pwp to reach normal speed, and give the commands “right, left” every 3-5 steps. Score if you see a problem in either direction. If the pwp has severe cervical restrictions allow combined head and trunk movements.

12. Walk with pivot turns

Begin walking at your normal speed. When I tell you to ‘turn and stop’, turn as quickly as you can, face the opposite direction, and stop. After the turn, your feet should be close together

- (2) Normal: Turns with feet close FAST (< 3 steps) with good balance.
- (1) Moderate: Turns with feet close SLOW (>4 steps) with good balance.
- (0) Severe: Cannot turn with feet close at any speed without imbalance.

Demonstrate a pivot turn. Once the pwp is walking at normal speed, say “turn and stop.” Count the number of steps from “turn” until the subject is stable. Imbalance may be indicated by wide stance, extra stepping or trunk motion.

13. Step over obstacles

Instruction: “Begin walking at your normal speed. When you get to the box, step over it, not around it and keep walking.”

- (2) Normal: Able to step over box with minimal change of gait speed and with good balance.
- (1) Moderate: Steps over box but touches box OR displays cautious behavior by slowing gait.
- (0) Severe: Unable to step over box OR steps around box.

Place the box 3m away from where the pwp will begin walking. Two shoeboxes taped together works well to create this apparatus.

14. Timed up & go with dual task [3 meter walk]

TUG: *When I say ‘Go’, stand up from chair, walk at your normal speed across the tape on the floor, turn around, and come back to sit in the chair.*

Time in seconds: _____

TUG with Dual Task: *Count backwards by threes starting at _____. When I say ‘Go’, stand up from chair, walk at your normal speed across the tape on the floor, turn around, and come back to sit in the chair. Continue counting backwards the entire time*

Time in seconds: _____

- (2) Normal: No noticeable change in sitting, standing or walking while backward counting when compared TUG without Dual Task
- (1) Moderate: Dual Task affects counting or walking speed >10% compared to the TUG without Dual Task
- (0) Severe: Stops counting while walking or stops walking while counting.

Have the pwp sitting with back against the chair. Time from the moment you say “Go”. Stop timing when the pwp buttocks hit the chair bottom and the pwp’s back is against the chair. With Dual Task: While sitting determine how fast and accurately the subject can count backwards by threes starting from a number between 100-90. Then, ask the subject to count from a different number and after a few numbers say “Go”.. Score dual task as affecting counting or walking if speed slows (>10%) from TUG and or new signs of imbalance.

App. 5.15 Modified Parkinson Activity Scale (M-PAS)

Modified Parkinson Activity Scale – Chair Transfers

Date:

Name pwp:

Name physiotherapist:

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- If applicable, on or off state: _____
- Location: _____
- Height chair: _____

Please take a seat and place your hands in your lap. In a moment, I will ask you later to rise from the chair. You may lean with your hands on the arm of the chair or your knees. When standing, you will have to wait a second.

1.a. Rise without using hands

Please rise without using your arms on the knees or chair

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

2.b. Sit down without using hands

Please, sit down again without using your arms

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

1.b. Rise with using hands (only scored if rising without using hands is impossible)

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

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

2.b. Sit down with using hands (only scored if rising without using hands is impossible)

Please, sit down again. You may use your hands.

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

Modified Parkinson Activity Scale – Gait Akinesia

Date: _____

Name pwp: _____ Name physiotherapist: _____

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- If applicable, on or off state: _____
- Location: _____
- Height chair: _____

Please take a seat and place your hands in your lap. Do you see the tape in U-shape? In a moment, I will ask you to rise. If you want to, you may use your hands. Then you walk to the U and turn inside the U. It is up to you how you do this. Then you return to the chair and sit down. It is not about doing it as fast as you can. It is about doing it safely. Is that clear? Now, please rise, walk to the U, turn within the U, and return to sit down in the chair.

Non-preferred turning side (at item 3 to 8, the pwp is asked to turn to this side):

- left
 right

Now, please do that once more, but this time turning to the [non-preferred side]

3. Start akinesia without an extra task (possibly assist with rising, which is not scored)

- [4] normal, without apparent difficulties
 [3] hesitation or short festination lasting up to 2 seconds
 [2] unwanted arrest of movement with or without festination lasting 2 to 5 seconds
 [1] unwanted arrest of movement with or without festination lasting more than 5 seconds
 [0] dependent on physical assistance to start walking (after freezing)

4. Turning 180° without an extra task

- [4] normal, without apparent difficulties
 [3] hesitation or short festination lasting up to 2 seconds
 [2] unwanted arrest of movement with or without festination lasting 2 to 5 seconds
 [1] unwanted arrest of movement with or without festination lasting more than 5 seconds
 [0] dependent on physical assistance to start walking (after freezing)

Now a bit more difficult: while carrying a plastic cup with water. Please rise, walk to the U, turn within the U and return to sit down in the chair

5. Start akinesia with a motor dual task (possibly assist with rising, which is not scored)

- [4] normal, without apparent difficulties
- [3] hesitation or short festination lasting up to 2 seconds
- [2] unwanted arrest of movement with or without festination lasting 2 to 5 seconds
- [1] unwanted arrest of movement with or without festination lasting more than 5 seconds
- [0] dependent on physical assistance to start walking (after freezing)

6. Turning 180° with a motor dual task

- [4] normal, without apparent difficulties
- [3] hesitation or short festination lasting up to 2 seconds
- [2] unwanted arrest of movement with or without festination lasting 2 to 5 seconds
- [1] unwanted arrest of movement with or without festination lasting more than 5 seconds
- [0] dependent on physical assistance to start walking (after freezing)

Now even more difficult: while counting backwards in threes, starting with 100. Please rise, walk to the U, turn within the U and return to sit down in the chair*

7. Start akinesia with a cognitive dual task (possibly assist with rising, which is not scored)

- [4] normal, without apparent difficulties
- [3] hesitation or short festination lasting up to 2 seconds
- [2] unwanted arrest of movement with or without festination lasting 2 to 5 seconds
- [1] unwanted arrest of movement with or without festination lasting more than 5 seconds
- [0] dependent on physical assistance to start walking (after freezing)

*Provide an example of counting backwards, starting at 110

8. Turning 180° with a cognitive dual task

- [4] normal, without apparent difficulties
- [3] hesitation or short festination lasting up to 2 seconds
- [2] unwanted arrest of movement with or without festination lasting 2 to 5 seconds
- [1] unwanted arrest of movement with or without festination lasting more than 5 seconds
- [0] dependent on physical assistance to start walking (after freezing)

Modified Parkinson Activity Scale – Bed Mobility

Date: _____

Name pwp: _____ Name physiotherapist: _____

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- If applicable, on or off state: _____
- Location: _____
- Height chair / bed: _____
- Bed cover used: _____
- Pillow side (when standing in front of the bed): _____

Starting position:

- The pwp is standing in front of the bed
- Before rolling (items 10 and 13), the pwp is, if required, assisted to lie comfortably on his back
- If not tested at home, put the pillow on the correct bed end: *If you are standing in front of your bed at home, at which side is your pillow?*

9. Lying down without a cover

Please, lie down on your back on the cover, just as you would do at home. Be sure that you end up in a comfortable position

- [4] normal, without apparent difficulties
- [3] with 1 difficulty*
- [2] with 2 difficulties*
- [1] with 3 difficulties*
- [0] dependent on physical assistance: pwp asks clearly for help or does not reach an acceptable end position

- difficulty lifting legs
- difficulty moving trunk
- difficulty reaching an adequate end position: functionally limiting or uncomfortable: head uncomfortably against the head of the bed or legs which not relaxed due to too much flexion

10a. Rolling over without a cover to the left

Please, roll over onto your side. To the left. Be sure that you end up in a comfortable position

- [4] normal, without apparent difficulties
- [3] with 1 difficulty**
- [2] with 2 difficulties**
- [1] with 3 difficulties**
- [0] dependent on physical assistance: pwp asks clearly for help or does not reach an acceptable end position

- difficulty with turning trunk/pelvis
- difficulty with moving trunk/pelvis
- difficulty reaching an adequate end position, functionally limiting or uncomfortable: underlying shoulder and arm insufficiently in protraction and free, head uncomfortably against the head of the bed or less than 10cm between trunk and the edge of the bed

10a. Rolling over without a cover to the right

Please, roll over onto your back. Now, roll over onto your other side. To the right. Be sure that you end up in a comfortable position

- [4] normal, without apparent difficulties
- [3] with 1 difficulty**
- [2] with 2 difficulties**
- [1] with 3 difficulties**
- [0] dependent on physical assistance: pwp asks clearly for help or does not reach an acceptable end position

- difficulty with turning trunk/pelvis
- difficulty with moving trunk/pelvis
- difficulty reaching an adequate end position, functionally limiting or uncomfortable: underlying shoulder and arm insufficiently in protraction and free, head uncomfortably against the head of the bed, or less than 10 cm between trunk and the edge of the bed

11. Getting out of bed without a cover

Please, rise and sit on the edge of the bed with both feet on the ground

- [4] normal, without apparent difficulties
- [3] with 1 difficulty***
- [2] with 2 difficulties***
- [1] with 3 difficulties***
- [0] dependent on physical assistance: pwp asks clearly for help or does not reach an acceptable end position

- difficulty with turning trunk/pelvis
- difficulty with moving legs
- difficulty with reaching adequate end position: asymmetric, uncomfortable

12. Lying down with a cover

Please, lie down on your back under the cover. Be sure that you end up in a comfortable position under the covers

- [4] normal, without apparent difficulties
 - [3] with 1 difficulty*
 - [2] with 2 difficulties*
 - [1] with 3 difficulties*
 - [0] dependent on physical assistance: pwp asks clearly for help or does not reach an acceptable end position
- difficulty moving trunk or legs
 - difficulty with adjusting the cover (> three times) or reaching no adequate covering, such as with part of the back uncovered
 - difficulty reaching an adequate end position. functionally limiting or uncomfortable: head uncomfortably against the head of the bed or legs not relaxed due to too much flexion

13a. Rolling over with a cover to the left

A. Please, roll over onto your side. To the left. Be sure that you end up in a comfortable position under the covers.

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

13b. Rolling over with a cover to the right

Please, roll over onto your back. Now, roll over onto your other side. To the right. Be sure that you end up in a comfortable position under the covers.

- [4] normal, without apparent difficulties
- [3] with 1 difficulty**
- [2] with 2 difficulties**
- [1] with 3 difficulties**
- [0] dependent on physical assistance: pwp asks clearly for help or does not reach an acceptable end position

- difficulty with turning trunk/pelvis
- difficulty with adjusting cover (>3 times) or reaching no adequate covering, such as with part of the back uncovered
- difficulty reaching an adequate end position: functionally limiting or uncomfortable: underlying shoulder and arm insufficiently in protraction and free, head uncomfortably against the head of the bed, or less than 10cm between trunk and the edge of the bed

14. Getting out of bed with a cover

Please, rise and sit on the edge of the bed with both feet on the ground

- [4] normal, without apparent difficulties
- [3] with 1 difficulty***
- [2] with 2 difficulties***
- [1] with 3 difficulties***
- [0] dependent on physical assistance: pwp asks clearly for help or does not reach an acceptable end position

- difficulty with moving trunk or legs
- difficulty with adjusting the cover (>3 times)
- difficulty with reaching adequate end position: asymmetric, uncomfortable

App. 5.16 New Freezing of Gait Questionnaire (NFOG-Q)

General instructions

These questions are addressed only when 'yes' is answered to the first question of the NFOG-Q in the PIF (that is question 10)

Assessment

2. How frequently do you experience freezing episodes?

- Less than once a week
- Not often, about once a week
- Often, about once a week
- Very often, more than once a day

3. How frequently do you experience freezing episodes during turning?

- Never > continue with question 5
- Rarely, about once a month
- Not often, about once a week
- Often, about once a week
- Very often, more than once a day

4. How long is your longest freezing episode during turning?

- Very short: 1 sec
- Short: 2-5 sec
- Long: between 5 and 30 sec
- Very long: unable to walk for more than 30 sec

5. How frequently do you experience episodes of freezing when initiating the first step?

- Never > continue with question 7
- Rarely, about once a month
- Not often, about once a week
- Often, about once a week
- Very often, more than once a day

6. How long is your longest freezing episode when initiating the first step?

- Very short: 1 sec
- Short: 2-5 sec
- Long: between 5 and 30 sec
- Very long: unable to walk for more than 30 sec

Source: Nieuwboer A, Rochester L, Herman T, Vandenberghe W, Emil GE, Thomaes T et al. Reliability of the new freezing of gait questionnaire: agreement between patients with Parkinson's disease and their carers. *Gait Posture* 2009; 30(4):459-463.

App. 5.17 Patient Specific Index for Parkinson's Disease (PSI-PD) – prioritisation

General instructions

At the beginning of the history taking, the input of the Pre-assessment Information Form (PIF) is gone over. Now, the pwp is supported in prioritising activities identified for being difficult to perform in the PIF (that is question 15).

Patient instruction

I ask you to mark those five problems which you find *very important* and which you would *like to change* most in the *next months*.

Order priority	Activity	Core area
1		
2		
3		
4		
5		

NOTE: The identified limited activities are supportive for deciding which core areas to address in physical examination. In case of limitations outside the core areas of physiotherapy, the pwp may be assisted in referral towards another health professional such as an occupational therapist or a speech and language therapist.

Source: Nijkraake MJ, Keus SHJ, Quist-Anholts GWL, Bloem BR, De Roode MH, Lindeboom R et al. Evaluation of a Patient Specific Index for Parkinson's Disease (PSI-PD). *European J Phys Rehabil Medicine* 2009; 45(4):507-512

App. 5.18 Push and Release Test (P&R Test)**General instructions**

- Pwp stands in a comfortable stance with eyes open.
- Physiotherapist stands behind the pwp.
- Physiotherapist instructs pwp to do whatever necessary to regain balance, including taking a step.
- Physiotherapist's hands placed on pwp's scapulae
- Pwp pushes backward against the palms of the physiotherapist's hands, without pwp' heels lifting of the ground
- Physiotherapist flexes elbows to allow backward movement of trunk and supports pwp's weight with hands.
- When pwp's shoulders and hips move to a stable position just behind heels, physiotherapist suddenly removes hands, requiring pwp to take a backward step to regain balance.
- Pwp has to take a step for test to be properly executed. A step is counted only if it is required for pwp to maintain balance not to reorient feet.
- Time at which physiotherapist releases hands from pwp vary to ensure pwp cannot anticipate release.

Date: _____

Name pwp: _____ Name physiotherapist: _____

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- If applicable, on or off state: _____
- Location: _____

Score

- 0 = Recovers independently with 1 step of normal length and width
 1 = Two to three small steps backward, but recovers independently
 2 = Four or more steps backward, but recovers independently
 3 = Steps but needs to be assisted to prevent a fall
 4 = Falls without attempting a step or unable to stand without assistance

Only a 0 score is considered a normal response.

Source: Horak FB, Jacobs JV, Tran VK, Nutt JG. The push and release test: An improved clinical postural stability test for patients with Parkinson's disease. *Movement Disorders* 2004; 19:S170

App. 5.19 Six Minute Walk Distance (6MWD)

According to the guidelines of the American Thoracic Society

General instructions

- 30 meter hallway
- Cones, lap counter or paper & pen
- Tape (brightly coloured for the starting line)
- Stopwatch

General instructions

- Before the test starts, pwp should sit at rest in a chair, located near the starting position, at least 10 min
- During the test, pwp should use their usual walking aids, appropriate shoes and comfortable clothes
- Mark the corridor every three meters; mark turnaround points with cones
- A “warm-up” period before the test should not be performed
- Use an even tone of voice when using the standard phrases of encouragement
- Do not talk to anyone else during the walk and do not walk with the pwp
- Let the pwp see you click the lap counter once each time the pwp crosses the starting line
- Using the Borg Scale 6-20 after the test provides insight into perceived exertion
- Starting position: standing at the starting line, together; start the timer as soon as the pwp starts to walk

Date: _____

Name pwp: _____ Name physiotherapist: _____

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- If applicable, on or off state: _____
- Location: _____
- Shoes worn by the pwp: _____

Distance walked: _____ laps = _____ meters

Minimal detectable change: 82m (26% of baseline score)⁴⁶⁹

What, if anything, kept you from walking farther?

Instructions for the pwp before the test

The object of this test is to walk as far as possible for 6 minutes. You will walk back and forth in this hallway. Six minutes is a long time to walk, so you will be exerting yourself. You will probably get out of breath or become exhausted. You are permitted to slow down, to stop, and to rest as necessary. You may lean against the wall while resting, but resume walking as soon as you are able. You will be walking back and forth around the cones. You should pivot briskly around the cones and continue back the other way without hesitation. Now I am going to show you. Please watch the way I turn without hesitation. [Demonstrate by walking one lap yourself. Walk and pivot around a cone briskly] Are you ready to do that? I am going to use this counter to keep track of the number of laps you complete. I will click it each time you turn around at this starting line. Remember that the object is to walk as far as possible for 6 minutes, but do not run or jog. Start now, or whenever you are ready

Instructions for the pwp during the test

- After the 1st minute: You are doing well. You have 5 minutes to go
- When the timer shows:
 - 4 minutes remaining: Keep up the good work. You have 4 minutes to go
 - 3 minutes remaining: You are doing well. You are halfway done
 - 2 minutes remaining: Keep up the good work. You have only 2 minutes left
 - 1 minute remaining: You are doing well. You only have 1 minute to go
 - 15 seconds to go: In a moment I am going to tell you to stop. When I do, just stop right where you are and I will come to you
- At 6 minutes: Stop
- If the pwp stops at any time prior, you can say: "You can lean against the wall if you would like; then continue walking whenever you feel able"

App. 5.20 Timed Get-up and Go (TUG)

See also M-PAS (item 8) or Mini-BESTest (item 14) for dual tasking activity

Materials required

- A standard height armchair (seat height 46 cm, arm height 67 cm) or the chair used for the M-PAS or Mini-BESTest
- A cone or a line taped line at 3m from the front of the chair
- A stopwatch

General Information

- Start the time at 'Go'; the test ends when the pwp's buttocks touch the seat.
- During the test, pwp should use their usual walking aids and shoes and comfortable clothes
- Assistive devices should be provided after the pwp has risen from the chair, to prevent the pwp leaning on it when rising
- The pwp should be given a practice trial which is not timed

Date: _____

Name pwp: _____ Name physiotherapist: _____

Circumstances of measurement:

- Time of the day: _____
- Time after medication intake: _____
- Medication dose: _____
- If applicable, on or off state: _____
- Location: _____
- Shoes worn by the pwp: _____
- Assistive devices used: _____
- Height chair: _____

Pwp instructions

- Please sit on the chair. Place your back against the chair and rest your arms on the chair's arms.
- Do you see the taped line / cone? When I say 'Go', stand up from the chair, walk at your normal speed across the tape on the floor / to the cone, turn around, and come back to sit in the chair

Time needed to complete: _____sec

At risk for falling: >8.5s⁴⁴⁶; Minimal detectable change: 3.5s (30% of baseline score)⁴⁷¹ to 11s (73% of baseline score)⁴⁶⁹

Did the pwp stop counting while walking or stop walking while counting?

Physiotherapist remarks regarding quality and safety of the turn:

Source: Podsiadlo, D., Richardson, S. The timed 'Up and Go' Test: a Test of Basic Functional Mobility for Frail Elderly Persons. Journal of American Geriatric Society. 1991; 39:142-14

Appendix 6

Patient-Centred Questionnaire for PD

This 4-page questionnaire focuses on your experiences with physiotherapy care regarding Parkinson's disease during the most recent physiotherapy treatment period. Your answers will help to improve physiotherapy care.

Communication and collaboration among your health professionals

1. Did you visit one of the following health professionals related to Parkinson's disease during the physiotherapy treatment period?

You may mark more than one circle!

- Neurologist
- Primary Care Physician
- Occupational therapist
- Speech therapist
- Psychologist
- Social worker
- Other, namely:

2. Were all your health professionals aware of each other's involvement in your treatment?

- No, not at all
- Yes, to some extent
- Yes, seemed fully aware
- I don't know

3. Did you get conflicting information from your health professionals?

- No, not at all
- Yes, to some extent
- Yes, throughout the care period
- I don't know

Accessibility of your physiotherapist

4. In general, was the length of time you had to wait before you could visit your physiotherapist a problem for you?

- Not a problem
- Not much of a problem
- A moderate problem
- A serious problem

5. In general, was the time spent in the waiting room a problem for you?

- Not a problem
- Not much of a problem
- A moderate problem
- A serious problem

6. Have you made satisfactorily agreements with your physiotherapist about when and how to get in contact in future?

- No, not at all
- Yes, to some extent
- Yes, to a moderate extent
- Yes, to a great extent

Empathy and expertise of your physiotherapist

7. Did your physiotherapist listen carefully to you?

- No, not at all
- Yes, to some extent
- Yes, to a moderate extent
- Yes, listened carefully

8. Did your physiotherapist explain things clearly?

- No, not at all
- Yes, to some extent
- Yes, to a moderate extent
- Yes, explained clearly

9. Did your physiotherapist seem competent to you regarding the treatment of Parkinson's disease?

- No, not at all
- Yes, to some extent
- Yes, to a moderate extent
- Yes, to a great extent

Patient involvement: how did your physiotherapist support you to make your own decisions

10. Did you have the opportunity to schedule appointments with your physiotherapist at a time you preferred?

- No, not at all
- Yes, to some extent
- Yes, to a moderate extent
- Yes, to a great extent
- I do not know

11. Did your physiotherapist adapt the treatment to your personal situation and preferences?

- No, not at all
- Yes, to some extent
- Yes, to a moderate extent
- Yes, to a great extent

12. Were you encouraged to participate in decisions about your treatment with your physiotherapist?

- No, not at all
- Yes, to some extent
- Yes, to a moderate extent
- Yes, to a great extent

Emotional support by your physiotherapist

13. Did your physiotherapist pay attention to your caregiver?

- No, not at all
- Yes, to some extent
- Yes, to a moderate extent
- Yes, to a great extent
- Not applicable

14. Did your physiotherapist actively involve your caregiver in decisions about your treatment?

- No, not at all
- Yes, to some extent
- Yes, to a moderate extent
- Yes, to a great extent
- Not applicable

15. Were you supported by your physiotherapist in coping with the consequences of Parkinson's disease? such as acceptance of disease progression

- No, not at all
- Yes, to some extent
- Yes, to a moderate extent
- Yes, to a great extent
- Not applicable

Information

16. Have you been informed about the importance of staying physical active?

- No, not at all
- Yes, to some extent
- Yes, to a moderate extent
- Yes, to a great extent

Satisfaction

17. Overall, how do you rate the quality of physiotherapy that you have received this period?

- Excellent
- Very good
- Good
- Fair
- Poor

Room for additional remarks

Source: questions adopted from the Patient-Centered Questionnaire for Parkinson's Disease (PCQ-PD): Van der Eijk M., Faber MJ, Ummels I, Aarts JW, Munneke M, Bloem BR. Patient-centeredness in PD care: development and validation of a patient experience questionnaire. Parkinsonism Relat Disord 2012; 18(9):1011-1016

Appendix 7

General outline of group treatment

With this information, the GDG aims to support physiotherapists in providing 'conventional physiotherapy' group treatment to people with Parkinson's disease (pwp). Before starting group treatment, the GDG advises individual history taking and physical examination (Chapter 5) and SMART goals set for each pwp participating.

Target population:

- Pwp without major safety issues related to balance limitations for whom general exercise training at home, a community-based exercise group, or at a gym is (not yet) feasible, and who are motivated to participate
- Their carers: Consider the benefits of carer support by organising a room for the carers to meet and talk to one another whilst the pwp is exercising; this may be supervised by a physiotherapist to answer non-patient related questions

Treatment goal

- General goals (Chapter 6)
 - Exercise adherence into the long-term to influence fitness, general health and wellbeing
 - Prevention of secondary complications (HY 1-4)
 - Motor learning (HY 2-3)
 - Become confident exercising, aiming to move on to non-supervised exercising, such as at home, at the gym, or in a regular exercise group
 - Learn from one another and meet other people who may share similar experiences and difficulties
 - Feelings of well-being and belonging
- Personal goal: needs to be set and evaluated individually

Group size and constellation:

The GDG advises pwp are selected for a group treatment based on their:

- Individual goals and preferences regarding exercises: these will direct the selection of specific group exercises
- Limitations, especially cognitive, cardiovascular and musculoskeletal: pwp should be at comparable levels of functioning

To allow for good individual and group dynamics and ensure maximal safety, a suggested group size of 6 to 8 people is recommended per therapist. For safety, additional helpers may be present. These could be the carers, if the pwp agrees upon this.

Organisation

- Time of the day: preferably when pwp are functioning optimally, such as in their on-period
- Frequency and duration (6.4.2): conventional physiotherapy is best provided for a minimum of 8 weeks, three times a week for 45 minutes; group treatment can be part of this, as can a home exercise program
- Location: any location where a group of pwp can exercise, including a (physiotherapy) clinic, a (rehab) pool, a gym, a community facility or outdoors
- The participants may:
 - exercise as a group
 - start and finish as a group, but exercise individually in the time between: when setting out a circuit, each individual can select exercises relevant to individual goals and keep a personal record of what has been done

General contents:

- Combine exercises for physical capacity and functional mobility
- Preferably focus on functional-task exercises, using fast, large amplitude movements whilst lying down, sitting, standing or walking
- When offering isolated resistance exercises: address large before small muscle group exercises and multiple-joint before single-joints
- Focus on attention and provide augmented feedback such as by using cues, virtual reality or exergaming
- Aim for progressive training:
 - When addressing physical capacity, such as in number of repetitions, load or speed (6.4.2)
 - When addressing motor learning, such as from a stable to a variable task and context, from single to dual task training and from practising in a set to a random order of tasks (6.5)
- Consider advice and training in (walking) aids to support exercising
- Include a warming-up and cooling-down (relaxation)

Select specific exercises based on individual goals, preferences and feasibility, considering:

- Standing up from, and sitting down onto the floor
- Rolling over on the floor
- Standing and walking on foam, with and without pushes & pulls to the trunk
- Sit down onto, and rising from a chair (while dual tasking)
- Walking:
 - around and over obstacles
 - with sudden stops and changes in walking direction, including walking backwards
 - turning round in big and small spaces
 - while dual tasking, such as talking, carrying an object or turning head left to right (and telling what is seen)
- Use cueing (6.6)
 - visual, such as by walking over tiles or taped or chalked lines on the floor
 - auditory, such as by using a metronome, music or pwp' counting
- Climbing step or stairs
- Trampoline jumping with adequate support
- Treadmill training
- Consider water-based exercising (hydrotherapy)
- Consider complementary forms of exercise like dance, Tai Chi, Nordic walking and boxing

Materials to be considered

- General: stopwatch, measuring tape, foam, mats, exercise balls, elastic bands, cones, cuff weights, wall mounted coloured stickers or numbers to focus on, treadmills, cross trainer bicycles
- Specific to functional task exercises: steps and chairs of different heights, slanted and rocker boards, cups or glasses (to fill with water), serving trays
- For cueing: metronome, music, mp3-players, tape, 3-dimensional wooden or plastic lines

Sources of support

- Links to additional sources to support exercising available at the website of the European Parkinson's Disease Association (EPDA): www.epda.eu.com
- Examples of physiotherapy exercises and tips and tricks used for and by pwp available at the website of the Association of Physiotherapists in Parkinson's Disease Europe (APPDE): www.appde.eu

Appendix 8

Red flags for Parkinson's and their most likely diagnosis

Signs and Symptoms	Most likely diagnosis
Pattern of distribution <ul style="list-style-type: none"> • Symmetrical • Asymmetrical* • Lower-body phenotype 	PSP, MSA CBD (very asymmetrical) VP
Course of the disease <ul style="list-style-type: none"> • Rapid progression (HY 3< 5 years) • Stepwise progression • Remission 	PSP, MSA VP VP, drug-induced parkinsonism
Medication <ul style="list-style-type: none"> • No/insufficient response to levodopa (>1g per day of levodopa over 1 month) • Early/profound levodopa intolerance • Levodopa-induced dyskinesia* • Non-dopa responsive pain 	No response: PSP, CBD; partial response: MSA DLB, VP MSA, DLB, VP All forms of AP
Tremor <ul style="list-style-type: none"> • Asymmetrical pill-rolling tremor* • Irregular, jerky tremor 	seldom: MSA MSA, CBD
Myoclonus	MSA (outstretched fingers), CBD, PSP, DLB, SCA 2, PARK9
Dysphagia and dysarthria <ul style="list-style-type: none"> • Early, severe dysarthria • Early, severe dysphagia • Dysphonia (spasmodic) 	AP PSP, MSA MSA
Dystonia <ul style="list-style-type: none"> • Orofacial • Cervical • Axial <ul style="list-style-type: none"> - Pisa sign* - Camptocormia* • Limbs* • Generalised 	MSA, PSP (blepharospasm), drug-induced MSA (antecollis), PSP (retrocollis) MSA; Drug induced (both typical and atypical anti-psychootics, anti-depressants, anti-emetics, choline-esterase inhibitors, dopaminergic medication; Spine deformities; scoliosis MSA, Alzheimer's disease, Myopathy, myasthenia, CIDP), drug-induced, spine deformities, arthritis, paraneoplastic
<ul style="list-style-type: none"> • Fixed 	MSA, drug-induced MSA, CBD, Hereditary parkinsonism (PARK 1,2,6,7,9,14, Hereditary dystonia syndromes (DYT 3,5,12,16, SCA3, Intoxications: neuroleptics, carbon-monoxide, manganese, Accumulation diseases: Wilson's disease NBIA1, Miscellaneous: hemi-parkinsonism-hemi-dystonia, neuroacanthocytosis, Huntington's disease CBD (early), MSA (late in the course of the disease)

Signs and Symptoms	Most likely diagnosis
Pyramidal involvement	VP, MSA, PARK2,9
Ataxia (cerebellar)	MSA, SCA 2,3,17, Neuronal intranuclear inclusion disease
Gait and balance disorders <ul style="list-style-type: none"> • Early postural instability • Use of walking aids/ wheelchair dependency* 	PSP; to a lesser extent: MSA, CBD and VP < 3 yrs: MSA, PSP; 3-10 yrs: other forms of AP
Sensory disturbances <ul style="list-style-type: none"> • Cortical • Polyneuropathy 	CBD Drug induced: amantadine, intoxication (carbon-disulfide, manganese, solvents, carbon-monoxide), infectious (Syphilis, HIV), Paraneoplastic (parkinsonism and polyneuropathy - fast progression!), endocrine (hypoparathyroidism), metabolic (gangliosidosis), mitochondrial (MERFF, POLG mutation), neurodegenerative (neuronal intranuclear inclusion disease, MSA)
Eye movement disturbances <ul style="list-style-type: none"> • Supranuclear palsy • Round-the-house-phenomenon • Saccadic eye movements <ul style="list-style-type: none"> - Delayed initiation - Delayed execution • Gaze impersistence • Square wave jerks • Dysmetria/overshoot • Nystagmus • Ocular apraxia • Oculogyric crisis 	PSP PSP CBD PSP MSA, SCA, PSP MSA, SCA, PSP MSA, SCA MSA, SCA CBD Drug-induced parkinsonism (anti-psychotics, anti-emetics), juvenile parkinsonism, bilateral thalamic lesions
Autonomic dysfunction <ul style="list-style-type: none"> • present early and severely • cold, discolored extremities ('cold hands sign') 	MSA, DLB (to a lesser extent) MSA
Cognitive dysfunction <ul style="list-style-type: none"> • Early and profound • Relatively late* • Relatively mild cognitive dysfunction • Apraxia • Aphasia 	PSP, DLB, FTD, Huntington's Disease, NPH CBD, VP MSA CBD, PSP (to a lesser extent) CBD, PSP (to a lesser extent)
Psychiatric symptoms <ul style="list-style-type: none"> • Apathy (early)* • Disinhibition <ul style="list-style-type: none"> - Emotionally - Pseudo-bulbar disinhibition • Hallucinations, delusions 	PSP Early: PSP, to lesser extent: MSA PSP, CBD DLB (early)
Sleep disturbances <ul style="list-style-type: none"> • REM sleep behaviour disorder • Sleep apnoea syndrome • Nocturnal inspiratory stridor 	PD, MSA, DLB MSA MSA

CBD, corticobasal degeneration; DLB, dementia with Lewy bodies; MSA, multiple system atrophy MSA; PSP, progressive supranuclear palsy; VP, vascular parkinsonism

More information can be found in the 2012 publication by MB Aerts et al⁴

Appendix 9

ICF for Parkinson's disease

Basal dysfunction, caused by degeneration of dopamine- producing cells in the substantia nigra (ICD-10: G20)



Core impairments in functions

- b1: Mental functions: delirium (b110); dementia (b117); changes in temperament and personality, such as mood and confidence (b126); impaired energy and drive functions, such as reduced motivation and impulse control* (b130); sleep impairments (b134); reduced attention (b140); reduced memory (b144); psychomotor impairments, such as moving and speaking slowly (b147); impairments in emotion, such as anxiety* (b152); impairments in perceptual functions, such as reduced visuospatial perception and hallucinations* (b156); impairments in higher level cognitive functions, such as in planning, decision-making and mental flexibility (b164); impairments in mental functions of language, such as verbal perseveration (b167)
- b2: Sensory functions and pain: seeing impairments including visual acuity* (b210); dizziness* (b240); impairments in smell (b255); impaired proprioceptive function (b260); tingling (b265); (central) pain (b280)
- b3: Voice and speech functions: reduced pitch and loudness of voice (b310); impaired articulation (including dysarthria) (b320); reduced fluency of speech (b330)
- b4: Functions of the cardiovascular and respiratory systems: impairments in blood pressure, such as orthostatic hypotension* (b420); impaired respiration functions including muscle functions and limited coughing (b440-450); reduced exercise tolerance* (b455); sensation of dyspnoea (b460)
- b5: Functions of the digestive system: impaired ingestion, including drooling, vomiting* and impaired swallowing (b510); constipation* (b525); reduced weight maintenance (b530)
- b6: Genitourinary and reproductive functions: impaired urination, including (urge)incontinence* (b620); impaired sexual functions, including impotence and increased sexual interest* (b640)
- b7: Neuromusculoskeletal and movement-related functions : reduced joint mobility* (b710); reduced muscle power* (b730); impaired muscle tone functions, including rigidity and dystonia (b735); reduced muscle endurance* (b740); impaired motor reflex functions, including simultaneous contraction of antagonists (b750); impaired movement reaction functions, including balance reactions (b755); reduced control of voluntary movements, including dysdiadochokinesia; reduced 'motor set' causing starting problems and reduced or absent internal cues causing problems in automated, sequential movements (b760); impaired involuntary movement functions, including bradykinesia, tremor and dyskinesia* (b765); gait pattern impairments, including asymmetry, freezing, reduced step length, trunk rotation and arm swing (b770); on/off states* (b798)
- b8: Functions of the skin and related structures: impairments in sweating and sebum production (b830); skin related impaired sensations (pins and needles) (b840)

*can be medication induced

Activity limitations and participation restrictions

in:

- d1: Learning and applying knowledge: acquiring skills (d155); writing (d170); solving problems (d175); making decisions (d177)
- d2: General tasks and demands: undertaking multiple tasks (d220); carrying out daily routine (230); handling stress; other psychological demands (d240)
- d3: Communication: speaking (d330); producing non-verbal messages (d335); writing messages (d345)
- d4: Mobility: changing and maintaining body position (d410-415); transferring oneself (d420); carrying, moving and handling objects (d430-d449); walking and moving, including walking speed (d450-d469); moving around using transportation (d470-d489)
- d5: Self-care: washing oneself (d510); toileting (d530); dressing (d540); eating (d550) and drinking (d560); looking after one's health (d570)
- d6: Domestic life: shopping (d620); preparing meals (d630) and doing housework (d640)
- d7: Interpersonal interactions and relationships: basic interpersonal interactions (d710); particular interpersonal relationships with strangers, formal persons, family and husband or wife (d730-d779)
- d8: Major life areas: education (d810-839); work and employment (d840-d859); economic life (d860-d879)
- d9: Community, social and civic life: community (d910); recreation & leisure (d920); religion (d930); political (d950)



Environmental factors:

- e1: Products and technology, including drugs, assistive devices, financial assets;
- e2: Natural environment and human-made changes to the environment, including population density, light intensity;
- e3: Support and relationships, including family, friends, colleagues, health professionals;
- e4: Attitudes, including of people;
- e5: Services, systems and policies, including housing, transportation, social support, communication, health services, education

Personal factors#, including

- age and gender
 - education
 - experiences, preferences, motivation
 - co-morbidity and coping skills
- not ICF classified, because of large social and cultural variances

Appendix 10

Measurement tools according to ICF domains

Name / ID number: Date of birth: Diagnosis: ICD-20: Parkinson's disease		Long term goal: Goal Attainment Scaling (GAS) Short term goal:
Patients Perspective	<ul style="list-style-type: none"> Pre-assessment Information Form (PIF) * <p><i>History-taking</i></p> <ul style="list-style-type: none"> Patient Specific Index for Parkinson's Disease (PSI-PD) * 	<ul style="list-style-type: none"> Pre-assessment Information Form (PIF) * <p><i>History-taking</i></p> <ul style="list-style-type: none"> Patient Specific Index for Parkinson's Disease (PSI-PD) * History of Falling Questionnaire <p><i>Walking (performance)</i> New Freezing of Gait Questionnaire (NFOG-Q)</p> <p><i>Changing and maintaining body position (performance)</i></p> <ul style="list-style-type: none"> Activities Balance Confidence (ABC) Scale *# or Falls Efficiency Scale international (FES-I)*#
Health Professional Perspective	<p>Body-Structures/Functions *</p> <p><i>Exercise tolerance functions</i></p> <ul style="list-style-type: none"> 6-minute walk with Borg Scale (6-20) <p><i>Movement functions: Involuntary movement reaction functions</i></p> <ul style="list-style-type: none"> Push and Release Test <p><i>Gait pattern functions</i></p> <ul style="list-style-type: none"> Rapid Turns test Stride length and cadence during 10MW 	<p>Activities & Participation *</p> <p><i>Mobility (capacity); that is balance, gait and transfers</i></p> <ul style="list-style-type: none"> Modified Parkinson Activity Scale (PAS) Timed Get-up and Go (TUG)# <p><i>Changing and maintaining body position (capacity), i.e balance</i></p> <ul style="list-style-type: none"> Berg Balance Scale (BBS)#, Mini-BESTest, Dynamic Gait Index (DGI) or Functional Gait Assessment (FGA) Five Times Sit to Stand (FTSTS) <p><i>Walking (capacity), that is gait</i></p> <ul style="list-style-type: none"> 10-meter walk test (10MW)# 6-minute walk distance (6MWD)# <p><i>Carrying, moving and handling objects, that is manual activities</i></p> <ul style="list-style-type: none"> no validated tools for pwp
	<p>Environmental factors</p> <ul style="list-style-type: none"> Pre-assessment Information Form (PIF)* <p><i>History-taking</i></p> <ul style="list-style-type: none"> Patient Specific Index for Parkinson's Disease (PSI-PD) * 	<p>Personal factors</p> <ul style="list-style-type: none"> Pre-assessment Information Form (PIF) * <p><i>History-taking</i></p> <ul style="list-style-type: none"> Patient Specific Index for Parkinson's Disease (PSI-PD) *

* for all pwp, to gain a first insight into the pwp complaints and to decide upon which impairments and activity limitations to target in physical examination;
also for evaluative purpose

Appendix 11

Model for collaborative Parkinson's care: health professionals and referral criteria

Adapted model for optimal care¹⁴. Health professionals in red are **only involved when indications for referral are met**, whereas those in green are **always involved**. Task descriptions will vary nationally. When certain health professionals are not present, it is important to collaborate locally, aiming to ensure all responsibilities are covered.

Rehabilitation medicine¹ or elderly care physician² always involved in case of complex motor and non-motor impairments deals with:

- interdisciplinary analyses of limitations and restrictions
- day hospital referral or continuous interdisciplinary care
- support in employment¹
- assessment of (e.g. walking) aids & home adjustments¹
- palliative care²

Pharmacist deals with:

- provision of medication, including verification and interaction / side effects
- treatment adherence

Psychiatrist deals with:

- energy and drive impairments, e.g. reduced motivation and impulse control
- emotional impairments, e.g. anxiety
- temperament & personality impairments, e.g. mood
- depression
- impairments in perceptual functions, e.g. hallucinations
- sleep impairments
- dementia

Speech therapist deals with:

- reduced voice pitch & loudness
- impaired articulation (e.g. dysarthria)
- impaired swallowing (including drooling)
- reduced speech fluency

Clinical geriatrician deals with:

- frail elderly with complex problems, not well managed with medicines & psychiatry
- comorbidity, falls and polypharmacy

National Parkinson's Society

- advice & support from fellow members and health professionals
- representation of interests

Sexologist deals with:

- impaired sexual functions, e.g. altered performance or interest
- changed sexual perception
- information, e.g. sexual aids
- restrictions in intimate and sexual relationships

Supraregional Parkinson centre of excellence

- to provide multidisciplinary diagnostics and resultant treatment plan
- provide specialised treatment (e.g. DBS)

Neurosurgeon deals with:

- severe, unpredictable response fluctuations or dyskinesias
- resistant tremor

Social worker deals with:

- psychosocial problems, e.g. coping
- carer burden (mental and financial)
- limitations & restrictions in interpersonal relationships, e.g. with carer
- loss of meaningful daytime activities
- information & support (financial) benefits

Occupational therapist deals with:

- home life, work, leisure time related limitations & restrictions (incl. cognitive problems, need for assistive devices & home adjustments)
- carer experienced limitations in providing support or care

Physical therapist deals with:

- (risk of) reduced physical capacity & performance
- gait limitations (e.g. freezing)
- limitations in transfers
- limitations in manual activities
- reduced balance; falls
- pain experience & perception

Neuropsychologist deals with:

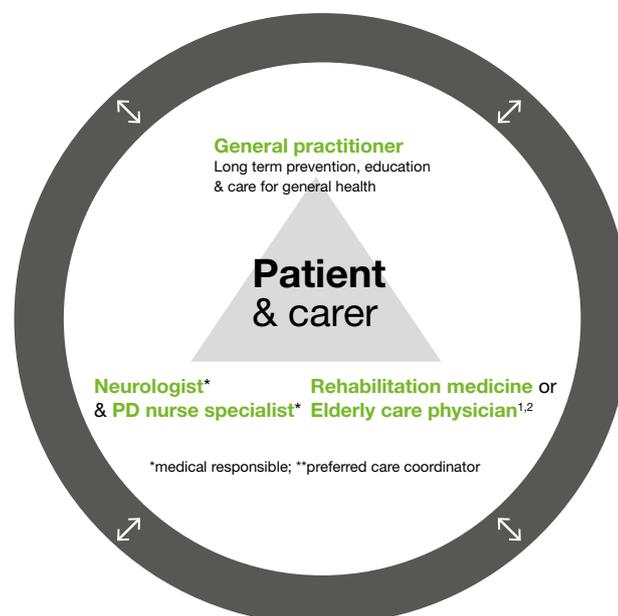
- patient/carer stress
- complex psychosocial limitations & restrictions
- limitations in acceptance & coping
- limitations in interpersonal relationships, e.g. with carer
- impairments in temperament, in personality and in fear, with or without medication
- cognitive impairments

Dietician deals with:

- weight loss; risk: >5% in 1 month or >10% in 6 months
- reduced quality or quantity of nutritional intake
- medication related nutritional advice (e.g. peri operative)
- constipation

Home care services deals with:

- restrictions in self-care, e.g. dressing
- restrictions in domestic life, e.g. housework



Appendix 12

Medication: effects and adverse events

As new medications are produced, and the pharmacology of those in existence becomes better understood, some of what is written below will change, so the GDG advises to consult local drug compendiums if in-depth knowledge is necessary

Group: substances	Mechanism	Effects	Adverse events
Levodopa: L-dopa	Transformed into dopamine in the brain (Most effective symptomatic Parkinson medication)	Reduces bradykinesia and rigidity. No effect on resting tremor, axial symptoms (including speech, gait and balance impairments). No effect on motor complications.	Hypertonia; orthostatic hypotension, cardiovascular dysfunction, nausea (commonest side effect), headache, gastrointestinal dysfunction. Long term: response fluctuations, dyskinesias, dystonia, confusion, hallucinations, sleep disorders, visual hallucinations.
Dopamine agonists: Pramipexol Ropinirole Rotigotine Apomorphine	Stimulates the postsynaptic dopamine receptors in the striatum	Reduces hypokinesia and rigidity	Orthostatic hypotension*, freezing, insomnia, somnolence (drowsiness)*, dizziness*, constipation, peripheral oedema (especially in the feet), nausea & vomiting, confusion, psychosis, visual hallucinations, impulse control disorders including compulsive exercising (primarily in young patients). Long term: alike levodopa, but much less
Amantadine	Antagonistic effect on the glutamate receptors	Reduces dyskinesias and tremor. No effect on non- motor problems and disease complications.	Hallucinations, confusion, agitation, orthostatic hypotension, dizziness, anxiety, impaired coordination, sleeping impairments, insomnia, nightmares, ataxia, peripheral oedema, nausea & vomiting, headache, constipation, diarrhoea, anorexia
MAO-B inhibitor: Selegiline Rasagiline	Reduces breaking down of dopamine.	Reduces motor symptoms (early stage) and levodopa-induced motor complications. No effect on motor fluctuations or depression.	Orthostatic hypotension, hallucinations, painful joints (Rasagiline mono treatment)
COMT inhibitors: Entacapone Tolcapone	Reduces the metabolism of levodopa, extending its plasma half-life and prolonging the action of each levodopa dose.	Limited effect on motor symptoms (UPDRS part II, ADL). For adjunctive use with carbidopa/levodopa in case of end-of-dose motor fluctuations.	Dyskinesias, cognitive impairments, cardiovascular complications, neuropsychiatric complications, nausea, diarrhoea, urine discolouration, liver injury (Tolcapone).
Anticholinergics: Akineton	Restores impaired acetylcholine neurotransmission and striatal dopamine balance	Reduces resting tremor and (minimal) bradykinesia	Memory, confusion, reduced sweating, blurred vision, urinary retention, nausea, constipation, dry mouth, delayed gastric emptying affecting levodopa absorption
Beta-blockers: Propranolol	Unknown	Unknown effect on tremor	Bradycardia*

Glossary

Augmented feedback	Concurrent feedback on performance, such as by using cues, virtual reality and exergaming
Balance	In this Guideline used for the ICF term <i>Changing and maintaining body position</i>
Bradykinesia	Slowness and reduction of movement
Cadence	Steps taken per unit of time
Contemporaries	People of approximately the same age
Cognitive movement strategies	see Strategies for complex movement sequences
Conventional physiotherapy	In this Guideline a category of intervention including all physiotherapist-supervised active exercise interventions targeting gait, balance, transfers or physical capacity, or a combination thereof
Dual tasking	Concurrent performance of two tasks
Dystonia	Painful cramps or spasms
Festination	Suddenly inability to generate effective stepping movements: rapidly and involuntary taking increasingly small steps increasing the risk for (near) falls
Freezing of gait	Suddenly inability to generate effective stepping movements: often not presented as complete akinesia, but rather as shuffling with small steps or trembling of the legs
Functional mobility	Activities needed for daily functioning. In this Guideline focussing on balance, transfers, gait and manual activities
HY	Hoehn and Yahr staging scale (2.5.1)
MET	Metabolic Equivalent of Task: the ratio of work metabolic rate to a standard resting metabolic rate for a specific activity, used as a measure for exercise intensity based on energy expenditure
Motor and non-motor complications	Side effects of medication influencing motor functioning, such as response fluctuations in on and off state including unpredictable on-off states; (severe) dyskinesias; off state dystonia; and neuropsychiatric limitations
Motor fluctuations	Fluctuations between on and off states. Initially on and off states are predictable and linked to the time of medication intake. Before the next dose, pwp may experience predictable wearing-off. Over time, this will become unpredictable
Muscle power	The result of muscle strength times speed
Off state	State in which the medication dose is insufficient or ineffective
On state	State in which the medication is working well
Parkinsonism	causes of parkinsonism other than Parkinson's disease, including multiple system atrophy (MSA); progressive supranuclear palsy (PSP); dementia with Lewy bodies (DLB); drug-induced parkinsonism; corticobasal degeneration (CBD); and vascular parkinsonism (VP); often with a faster disease progression
Peers	People equal of another in abilities, qualifications, age, background, such as other physiotherapists or other people with Parkinson disease
PIGD	Postural Imbalance (or instability) and Gait Disorder (or Difficulty)
Physical capacity	Capacity of the neuromuscular and cardiorespiratory system, expressed by exercise tolerance, joint mobility and muscle tone, power and endurance, required to perform of activities
Range of motion exercises	Exercises targeting joint mobility and muscle tone and power
Response fluctuations	see Motor fluctuations
Rigidity	Increased resistance present throughout the range of passive movement of a limb
Strategies for complex movement sequences	Compensatory strategies requiring pwp to understand how to break down a complex task in simple components and carry the components out with attention. Formerly called <i>Cognitive movement strategies</i> , which is widely used in the literature, but confusing to practitioners
Wearing off	see Motor fluctuations

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Quick Reference Card 1. History taking

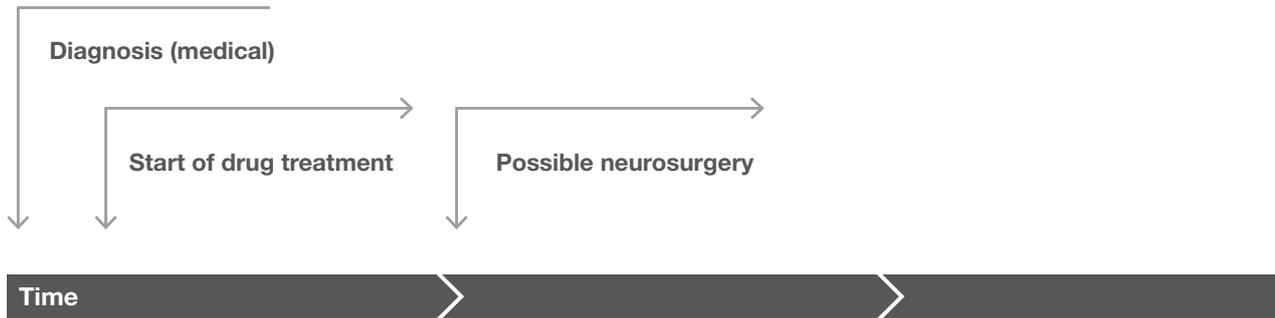
Interest	Supportive	Paying attention to
Perceived problems	PIF 5As model	<ul style="list-style-type: none"> The pwp most important problems: support the pwp to prioritise problems Carer involvement
Medical information	Preferably upon referral from physician	<ul style="list-style-type: none"> Parkinson: diagnosis; year of diagnosis; disease stage# Motor complications: motor fluctuations, unpredictable on and off states*, dyskinesias* and off state dystonia* (if severe, advise pwp to anticipate medical consultation) Mental complications: executive dysfunction such as in concentration, holding and using information, decision-making, planning, shifting attention from one to another stimulus and dual task performance; anxiety; apathy; depression*; illusions*; hallucinations*; impulse control disorders (e.g. repetitive activities)* Pain: time of day, location (e.g. specific or general), quality (e.g. cramping, tingling, shooting), severity* Comorbidity: heart failure; osteoporosis; COPD; arthritis; diabetes; pressure sores Current (non)medical treatment: type, intensity and adverse events possibly influencing physiotherapy options Earlier treatment for problem referred for: type and outcome
Participation		Problems with relationships; profession and work; social life, including leisure activities
Functions & activities	PIF	Getting in and out of bed; rolling over; rising from a chair or toilet seat and sitting down; getting into and out of a car; getting up from the floor (after a fall)
	PIF History of falling ABC or FES-I Falls Diary	While standing, bending forward, reaching, making transfers, walking (backward), turning or dual tasking In pwp reporting on the PIF: <ul style="list-style-type: none"> a (near) fall, use the History of Falling for insight in frequency and circumstances (e.g. orthostatic hypotension and difficulty dual tasking) a (near) fall or fear of falling, use the ABC or (for less ambulant pwp) the FES-I for insight in activities related balance confidence Provide a Falls Diary to all pwp who have fallen for insight in fall frequency and circumstances
	PIF Manual dexterity	Reaching, grasping and moving objects in household activities, such as small repairs, cleaning, cooking, slicing food and holding a glass or cup without spilling; or in personal care, such as bathing and getting (un)dressed
	PIF FOG video New FOGQ	<ul style="list-style-type: none"> Upon step initiation, while walking (backward), turning or dual tasking; freezing of gait; gait speed and safety; location and circumstances when limitations arise Use of aids; walking short and long distances; relation to falls In pwp reporting freezing of gait on the PIF: use the New FOGQ for insight in frequency and duration of freezing related to step initiation and turning
	PIF	<ul style="list-style-type: none"> Exercise tolerance, including feeling easily out of breath, rapid onset of fatigue* and general tiredness; joint mobility; muscle tone, power and endurance Physical activity levels compared to WHO recommendation: 75 min/wk vigorous exercise or 150 min/wk moderate intensity
Tips & tricks		Tips & tricks the pwp uses to reduce or compensate for the problems: are these adequate?
External factors		Personal Age and gender; insight into the disease; coping; experiences; preferences; motivation; coping skills; feeling isolated and lonely; being tearful; anger; concern for the future; awareness (to change); motivation (to adhere to a specific intervention)
Expectations pwp		Environmental Drugs (see Medical information); assistive devices; financial assets; attitudes of and support from carer, family or friends, the primary care physician and the employer; accommodation (interior, kind of home); work (content, circumstances and conditions); transportation
		With regard to: <ul style="list-style-type: none"> general prognosis physiotherapy treatment: contents, frequency and outcome self-management: need for information, advice and coaching

#such as using the Hoehn and Yahr classification; *items included in the (MDS-)UPDRS

Quick Reference Card 2. Physical examination

	Physical capacity and pain	Transfers	Manual dexterity	Balance	Gait
<p>Tick list</p> <p>Observe the pwp well when rising from the waiting room chair, walking into your clinic, closing the door and taking of a coat</p> <p>Include any reported or detected sensory alterations plus description</p>	<p>Muscle power</p> <ul style="list-style-type: none"> <input type="checkbox"/> hip extensors <input type="checkbox"/> knee extensors <input type="checkbox"/> ankle flexors <input type="checkbox"/> other, namely: <p>Muscle tone</p> <ul style="list-style-type: none"> <input type="checkbox"/> hamstrings <input type="checkbox"/> calf muscles <input type="checkbox"/> other, namely: <p>Joint mobility</p> <ul style="list-style-type: none"> <input type="checkbox"/> cervical spine <input type="checkbox"/> thoracic spine <input type="checkbox"/> other, namely: <p>Exercise tolerance</p> <ul style="list-style-type: none"> <input type="checkbox"/> exertion <input type="checkbox"/> respiration control <p>Pain</p> <ul style="list-style-type: none"> <input type="checkbox"/> musculoskeletal <input type="checkbox"/> neuropathic <input type="checkbox"/> other, namely: 	<ul style="list-style-type: none"> <input type="checkbox"/> sitting down on chair/sofa <input type="checkbox"/> rising from chair/sofa <input type="checkbox"/> getting up from the floor <input type="checkbox"/> getting in bed <input type="checkbox"/> getting out of bed <input type="checkbox"/> rolling over in bed <input type="checkbox"/> sitting down on toilet seat <input type="checkbox"/> rising from toilet seat <input type="checkbox"/> getting in car <input type="checkbox"/> getting out of car <input type="checkbox"/> other, namely: <p>Safety</p> <ul style="list-style-type: none"> <input type="checkbox"/> a fall <input type="checkbox"/> a near fall <input type="checkbox"/> other, namely: 	<ul style="list-style-type: none"> <input type="checkbox"/> reaching <input type="checkbox"/> grasping <input type="checkbox"/> moving objects <p>Limited activities:</p>	<ul style="list-style-type: none"> <input type="checkbox"/> while standing <input type="checkbox"/> while rising from a chair <input type="checkbox"/> during forward walking <input type="checkbox"/> during backward walking <input type="checkbox"/> when turning <input type="checkbox"/> when freezing <input type="checkbox"/> when bending forward <input type="checkbox"/> when reaching and grasping <input type="checkbox"/> when dual tasking, to know: <p>Safety</p> <ul style="list-style-type: none"> <input type="checkbox"/> a fall <input type="checkbox"/> a near fall <input type="checkbox"/> other, namely: 	<p>Gait pattern impairments</p> <ul style="list-style-type: none"> <input type="checkbox"/> decreased walking speed <input type="checkbox"/> decreased trunk rotation <input type="checkbox"/> decreased arm swing <input type="checkbox"/> shortened stride length <input type="checkbox"/> variable stride length <p>Festination or freezing:</p> <ul style="list-style-type: none"> <input type="checkbox"/> upon step initiation <input type="checkbox"/> upon turning <input type="checkbox"/> when avoiding obstacles <input type="checkbox"/> when passing doorways <input type="checkbox"/> during forward walking <input type="checkbox"/> during backward walking <input type="checkbox"/> when dual tasking, to know: <p>Safety</p> <ul style="list-style-type: none"> <input type="checkbox"/> a fall <input type="checkbox"/> a near fall <input type="checkbox"/> other, namely:
<p>Supportive tools</p> <p>* can also be used for evaluative purposes</p>	<ul style="list-style-type: none"> <input type="checkbox"/> 6MW & Borg 6-20 <input type="checkbox"/> 5TSTS 	<p>Bed:</p> <ul style="list-style-type: none"> <input type="checkbox"/> M-PAS Bed <p>Chair:</p> <ul style="list-style-type: none"> <input type="checkbox"/> M-PAS Chair <input type="checkbox"/> TUG* <input type="checkbox"/> 5TSTS 	-	<p>General:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Push and Release test <p>Transfers:</p> <ul style="list-style-type: none"> <input type="checkbox"/> M-PAS Chair <input type="checkbox"/> 5TSTS <p>Gait</p> <ul style="list-style-type: none"> <input type="checkbox"/> M-PAS Gait <input type="checkbox"/> TUG* <input type="checkbox"/> DGI* / <input type="checkbox"/> FGA / <input type="checkbox"/> Mini-BES Test <input type="checkbox"/> Rapid Turns Stationary: <input type="checkbox"/> BBS* 	<ul style="list-style-type: none"> <input type="checkbox"/> M-PAS Gait <input type="checkbox"/> TUG* <input type="checkbox"/> 10MWT* <input type="checkbox"/> 6MW* <input type="checkbox"/> Rapid Turns
<p>In all pwp</p>	<p>3-step Falls Prediction Model: to identify pwp requiring interdisciplinary falls assessment, individualised physiotherapy or general exercising</p> <p>Goal Attainment Scaling (GAS): to describe and evaluate a SMART treatment goal</p>				

Quick Reference Card 3. Treatment goals



↑ **Hoehn and Yahr 1** ↑ **Hoehn and Yahr 2 to 4** ↑ **Hoehn and Yahr 5** ↑

Physiotherapy goals

- Self-management support
- Prevent inactivity
- Prevent fear to move or fall
- Improve physical capacity
- Reduce pain
- Delay onset activity limitations (motor learning, up to H&Y3)

Additional goals

- Maintain or reduce limitations in transfers, balance, manual activities and gait

Additional goals

- Maintain vital functions
- Prevent pressure sores
- Prevent contractures
- Support carers/nurses

Education:

Parkinson's disease limitations and risks; benefits physical activity; core areas, rationale and benefits of physiotherapy interventions; pwp and physiotherapist roles

Exercise:

Physical capacity and functional mobility; functional-task exercise; large amplitudes; on state; progressive; consider conventional physiotherapy, treadmill training, Tai Chi, dance

Additional in H&Y5:

Support nursing personnel
Additional in H&Y5:
Bedbound related complications

Practice:

Original or novel motor skills; context specificity; many repetitions; progression complexity; dual task, cues and positive feedback; on to off state practice

Focus in H&Y5:

Coach carers and nursing personnel

Strategy training

External, meaningful cues; attention; strategies for complex motor sequences; compensation and adapted motor skills; optimising pwp's own tricks; on to off state; sufficient mental function required

Quick Reference Card 4. GRADE-based recommendations

Data from 55 controlled clinical trials (CCTs) were used for the meta-analyses and GRADE-based recommendations. Results of these and another 15 CCTs were used for the Guideline Development Group advice for each type of intervention (Chapter 6).

Level	Meaning
Strong for	Positive effect and 0 outside confidence interval of effect; Evidence quality moderate/high
Weak for	Positive effect and 0 outside effect confidence interval; Quality of evidence low or moderate/high but only small effect or very large confidence interval
Weak against	Positive effect, but 0 inside confidence interval of effect

Core area	ICF level	Outcome	Types of interventions						
			Conventional physiotherapy	Treadmill	Massage	Cueing	Strategies for CMS	Dance: tango	Tai Chi
Balance	Balance capacity	No of falls	Weak against						Strong for
		BBS	Strong for	Weak for					Strong for
		FR	Strong for			Weak against			Strong for
		DGI				Weak for			
		Mini-BESTest						Weak for	
Balance & Gait	Capacity of functional mobility	FES / ABC	Weak against			Weak against			
		Timed turn	Weak against						
Gait	Walking capacity	Speed	Strong for	Strong for		Strong for	Weak against	Weak against	Strong for
		Stride length	Weak against	Strong for		Weak against	Weak for	Weak against	Strong for
		Step length	Weak against			Weak for	Weak against		
		Cadence	Weak against	Weak against		Weak against	Weak against		
		Distance	Weak against	Weak for				Weak against	Strong for
		FOG-Q	Weak against			Weak for		Weak against	Strong for
Gait, Balance & Transfers	Capacity of functional mobility	TUG	Weak for			Weak against		Weak for	Strong for
		PAS					Strong for		
Transfers	Capacity of functional mobility	Sit-to-stand				Weak for			
		PAS – Chair					Strong for		
Physical Capacity	Muscle functions	Strength	Strong for	Weak against					Strong for
	Walking capacity	Walk distance	Weak against	Weak for				Weak against	Strong for
Other	Movement functions	UPDRS III	Strong for	Weak against		Weak for	Weak against	Weak against	Strong for
		P&G Score*				Weak for			
		PDQ-39	Weak against			Weak against		Weak against	
	Quality of life	EQ-5D	Weak against						
		PDQL	Weak against	Weak against					
		Patient-based treatment effect	CGI			Weak for			
		PSI-PD					Weak for		

*UPDRS III items 15 & 29–30 only; ** for combined PDQ-39, EQ-5D and PDQL-scores: weak against

Outcomes: ABC, Activities Balance Confidence Scale; BBS, Berg Balance Scale; CGI, Clinical Global Impression; DGI, Dynamic Gait Index; EQ-5D, EuroQol 5-D; FOG-Q, Freezing of Gait Questionnaire; FES, Falls Efficacy Scale; FR, Functional Reach; PAS, Parkinson Activity Scale; PDQ-39, Parkinson's Disease Quality of Life Questionnaire 39; PDQL, Parkinson Disease Quality of Life Questionnaire; PSI-PD, Patient Specific Index for Parkinson's disease; TUG, Timed Up and Go; UPDRS, Unified Parkinson's disease Rating Scale

Conventional physiotherapy: all physiotherapist-supervised active exercise interventions targeting gait, balance, transfers or physical capacity, or a combination thereof

Strategies for CMS (complex movement sequences): formerly called cognitive movement strategies