

# European Physiotherapy Guideline for Parkinson's Disease

Developed with nineteen  
European professional associations



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On behalf of the Guideline Development Group

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**TO BE REVIEWED** The referral criteria **(are endorsed?)** by the European Section of the Movement Disorders Society, ES-MDS



The *Movement Disorder Society*

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## Preface

We are pleased to present you with the 1<sup>st</sup> European Guidelines for Physiotherapy in Parkinson's disease, and hope this document will support the judgements and decisions you must make during your clinical practice.

In this guideline you will find currently available evidence-informed material to answer questions that you and your patients might have; this includes evidence from controlled clinical trials, expert opinion from physiotherapists across Europe where robust clinical evidence is unavailable and patient preferences. If you are new to this area of neurological practice, please take the time to read the entire document thoroughly. If you already have Parkinson-expertise, you might wish to start with the overview of recommendations (Chapter 1) and the four Quick Reference Cards. 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.

To optimise the use of the guideline by clinicians in clinical practice, we have attempted to refrain from using complicated language, kept it short and simple, and written the document in a manner that assists clinical decision making and measurement of outcome; for example, we would not recommend 10 measurement tools where one would be sufficient to review the effectiveness of physiotherapy intervention.. The guideline also supports you when communicating with your patient, and with other professionals, amongst who are the referring physicians.

This document is agreed upon by the professional associations from 19 European countries is an example of the standing of our profession in this clinical area of neurological practice.

Even though the guideline is primarily targeted at physiotherapists, there is some specific information included for policy makers, other health professionals and for patients. These groups of people are essential for the implementation of best physiotherapy practice with Parkinson's disease. Examples of information you may wish to share with these groups include Referral i.e. the 'when' and 'why' in Chapter 4, or information supporting patients in taking an active role in their health management in Appendix 6.

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

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*See page 5 for all members*

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Cyprus: Cyprus Physio



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1. Sponsored by Parkinson Luxembourg



2. Sponsored by MultiPark



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# Chapter 1. Background

## 1.1. Motives for development of this guideline

Parkinson's disease, or Parkinson's, is a complex disorder, characterised by a wide array of motor and non-motor problems for which medical intervention alone is insufficient. Many allied healthcare professionals can be involved in the management of Parkinson's disease, of which physiotherapy is the most applied and supported by scientific evidence. In 2004, in the Netherlands the first evidence-informed guideline with practice recommendations for physiotherapy in Parkinson's was published by the Royal Dutch society for Physical Therapy (KNGF). An external audit in 2008 showed that this guideline is one of the few Parkinson's disease guidelines which are of good quality. Moreover, it still is unique in its field, but it needs an update. Following a request from the Association of Physiotherapists in Parkinson's disease Europe (APPDE), the KNGF agreed upon a proposal of ParkinsonNet to update and adapt the guideline into a European guideline for physiotherapy in Parkinson's disease. The development is endorsed by the APPDE, the European Region of the World Confederation for Physical Therapy (ER-WCPT) and the European Parkinson's Disease Association (EPDA), an umbrella organisation representing 45 national member organisations ([www.epda.eu.com](http://www.epda.eu.com)). As many as 19 member organisations of the ER-WCPT, as well as people with Parkinson's disease (pwp) and their representatives participated in the development process.

## 1.2. Methods of development

This guideline was developed according to international standards for guideline development, addressing all items of the Appraisal of Guidelines for Research and Evaluation Instrument (AGREE, [www.agreetrust.org](http://www.agreetrust.org)). Moreover, the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach was used to develop the recommendations ([www.gradeworkinggroup.org](http://www.gradeworkinggroup.org)) (see Ch. 1.8 XX).

### 1.2.1 The guideline development group

Each physiotherapy association was represented by one person in either Writing Group, Reading Group or Review Panel. Together, these people make up the Guideline Development Group (GDG). Selection to either Writing or Reading Group was initially based on preference of the association's representatives for either group. For those interested in the Writing Group, geographic dispersion throughout Europe and knowledge and skills, either scientific or clinical, were considered. In addition, in both the Writing and Reading Group two pwp were selected for full membership. The members of the Writing Group (10 persons) started their activities after the initiation of the European survey (REF XXX). They prepared the first drafts of the contents, literature review and recommendations. Most of this was done by electronic communication. During the development process, the Writing Group met three times (June 2011, February and November 2012). During the process of development by the Writing Group, members of the Reading Group provided feedback. Members of the Review Panel provided feedback on the penultimate concept of the guideline (January 2013?XX). Finally, a panel of the European Section of the Movement Disorder Society reviewed and agreed upon the final criteria for referral to a physiotherapist (February 2013?XX). The development process was evaluated by an international Steering Group, with extended expertise in physiotherapy, neurology, Parkinson's disease, the patient perspective and guideline development in general. Individuals with intellectual conflict of interest were prevented from participating in decision-making relevant to the declared interest.

### 1.2.2 Involvement of people with Parkinson's disease

This guideline is made for healthcare professionals and pwp. Therefore, pwp were involved at all stages throughout the development process: their perceived barriers in current care were identified and they were part of the Writing, Reading and Steering Group. In addition, the penultimate concept of the guideline was published online for public feedback.

### 1.2.3 Using existing guidelines

The KNGF 2004 guideline, unique in its field, was the starting point for the development of this guideline.<sup>1,2</sup> In addition, the 2010 Dutch Multidisciplinary guideline for Parkinson's disease was used.<sup>3</sup> This guideline concerns an update of the 2006 NICE guideline<sup>4</sup>, extended with recommendations for

interdisciplinary collaboration and care organisation. However, the 2004 KNGF guideline was not simply updated. Aiming to provide recommendations to optimise care, as a first step, insight was gained in barriers in current care.

**1.2.4 Identifying barriers in current care**

For this guideline, barriers in current care as perceived by general physiotherapist, users of the KNGF guideline, and pwp were used. Barriers in delivering optimal care amongst physiotherapist throughout Europe were identified by means of a web-based survey. The survey was sent to 9,646 physiotherapists of 17 European countries. Of the responding 3,405 physiotherapists, 84% had treated at least one pwp the past year. These physiotherapists identified many barriers for delivering optimal care (Table 1.2.4a). Points for improvement of the 2004 KNGF guideline were identified through focus groups with 50 expert users, Dutch ParkinsonNet physiotherapists (Table 1.2.4b). In addition, barriers in current care reported by both therapists or patients pwp were indentified in the international literature using the search terms "Patient's perspective" OR "Patient Satisfaction"[Mesh]) AND "Parkinson Disease"[Mesh]', as well as through 8 focus group discussions of 40 pwp and 20 informal carers (Table 1.2.4c).<sup>5-9 10, 11, 9</sup> All barriers and suggestions for improvement are used for the development of this guideline and are advised to consider when implementing this guideline.

<b>Low treatment volume</b>	The median annual treatment volume reported was as low as 4 unique pwp annually, ranging from 2 to 5 in different countries. The reported optimum treatment volume was 10 unique pwp annually
<b>Limited knowledge and skills</b>	The majority reported limited Parkinson's specific knowledge and skills: only 16% reported (very) high self-perceived Parkinson-expertise, but in physiotherapists with a treatment volume ≥5 ('experts') this increased to 26%
<b>Referral at too late a stage</b>	To 33%, referral at too late a stage this is a major barrier. Even though physiotherapy is important from disease onset, most of the pwp treated were in the complicated phase (H&Y 3 and 4)
<b>Time constraints</b>	One in three physiotherapists report limited time with the patient as a major barrier. Parkinson's disease is a complex condition involving slowness of movement, speech and thinking. As a result physiotherapy assessment and treatment can require more time than other patient groups.
<b>Collaboration</b>	25% would like more communication with their peers on pwp and related issues
<b>Measurement tools</b>	40% of the experts did not use measurement tools. The main reasons were lack of time (32%), insufficient knowledge and skills (29%), difficulty interpreting results (25%) and unavailability of tools (23%). Also tools not recommended in the 2004 guideline are used, e.g. Berg Balance and Tinetti Balance & Gait
<b>Intervention</b>	Cognitive movement strategies and physical capacity training, recommended in the KNGF, were applied by less than 60% of therapists. For most interventions, only 50% of physiotherapists felt above average competent applying them.

*\*unique number of pwp assessed and, if indicated, treated annually*

<ul style="list-style-type: none"> <li>• How to recognise parkinsonisms from Parkinson's disease?</li> <li>• How do impairments in cognition and comorbidities influence physiotherapy treatment?</li> <li>• What are referral criteria for other health care professionals?</li> <li>• How to optimise communication with other health professionals, including referring physicians?</li> <li>• How to use and interpreted measurement tools?</li> <li>• Why are certain measurement tools excluded?</li> <li>• How to discuss expectations towards the intervention with the pwp?</li> <li>• How to support self-management, also after termination of treatment?</li> <li>• What are the general contents of a group treatment protocol?</li> </ul>
---

**Table 1.2.4c Pwps needs towards optimal care**

- ✓ Care by specialised healthcare providers
- ✓ Active involvement in clinical decision making
- ✓ Possibility to choose own physiotherapist
- ✓ Information about the expected treatment effect
- ✓ Treatment at home
- ✓ Taking in account fluctuations in daily functioning
- ✓ Information on mobility and exercise
- ✓ Emotional support, e.g. interest, motivation, taken seriously
- ✓ Discussion of the role of the carer
- ✓ Parkinson's specific knowledge in home care professionals
- ✓ Multidisciplinary collaboration: avoid conflicting information and advise; information exchange
- ✓ Self-management support

**1.2.5 From barriers to key questions**

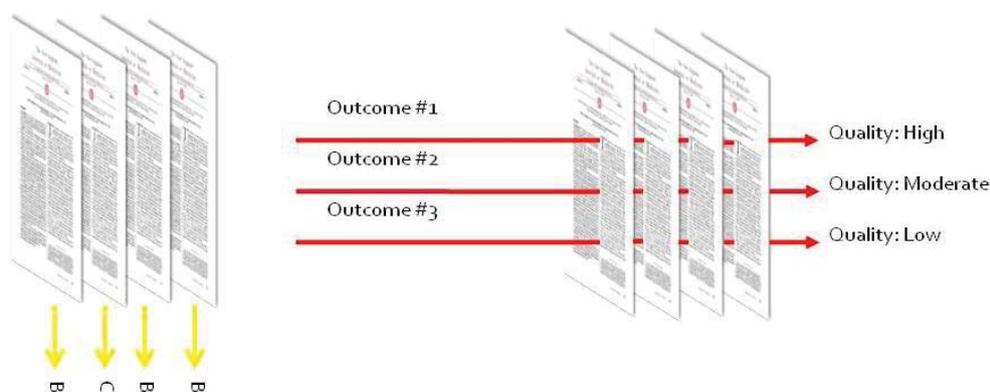
Partly, the identified barriers need to be targeted when implementing the guidelines. Other barriers could be used to improve the current KNGF guidelines into these European guidelines. For this purposes, barriers and points for improvement were transformed into key questions which could be addressed. For example, *What are the consequences of cognitive impairments to physiotherapy treatment? And Should treadmill training be used versus no treadmill to improve walking speed?* For feasibility purposes, only for key questions for which to the knowledge of the GDG evidence was available, a systematic literature search was carried out (Appendix 1). All others questions were addressed by expert opinion and non-systematic literature search.

Literature was searched using the PubMed (up to December 2012; (Appendix 1). Only controlled clinical trials were selected: trials in which two groups of pwp participated, of which at least one received a physiotherapy intervention. To identify these studies in PubMed, the Cochrane method for systematic literature search was used, with the adjustment that besides RCTs also non-randomised clinical controlled trials were selected. In addition, PEDRO was searched using the wildcards 'Parkinson' and 'Parkinson's', and Writing and Reading Group members contributed trials not yet identified. Finally, XX CCTs were used.

**1.2.6 From key questions to recommendations: GRADE**

Evidence relating to clinical effectiveness was appraised using the GRADE Summary of Findings tables. GRADE is endorsed by many major organisations, e.g. the Cochrane Collaboration, the World Health Organisation (WHO), the U.K. National Institute for Health and Clinical Excellence (NICE), and the British Medical Journal. With GRADE, the 'body of evidence' for each key question was graded, instead of separate publications as was common in 2004 (Fig 1.2.6). Where possible, data from published meta-analysis were used.

**Fig. 1.2.6 Grading the body of evidence for each critical outcome**



KNGF guideline 2004

European guideline: GRADE

Key questions were formulated based on the barriers identified. All outcomes used in the publications were classified capacity of performance measures on the different ICF domains. Writing and Reading Group members scored the importance of these classes of outcomes (Appendix 2). Only outcomes with a mean score of seven or up (i.e. critical outcomes) were used for the evidence grading. In the grading process, controlled clinical trials start off on 'high' quality. Possible reasons for downgrading were risk of bias, inconsistency, indirectness or imprecision of the results and publication bias (Table 1.2.6). Finally, the recommendation is graded 'strong' or 'weak'. The strength reflects the generalisability of the effects amongst all pwp; the extent to which the benefits of the intervention outweigh undesirable effects (e.g. falls, burden of treatment and costs); the availability; and the values and preferences of patients and therapists if known.

**Table 1.2.6 Appraising the quality of evidence using GRADE**

Quality	Reasons for downgrading evidence
High (=RCT*)	<ol style="list-style-type: none"> <li>1. Risk of bias*, e.g. no (report of) randomisation procedure, blinding or intention to treat analyses, or high numbers of drop outs</li> <li>2. Inconsistency of the results over studies</li> <li>3. Indirectness of the evidence</li> <li>4. Imprecision, e.g. small sample size*</li> <li>5. Publication bias, i.e. only positive effects published</li> </ol>
Moderate	
Low	
Very low	

\*most frequent downgrading reasons for this guideline; RCT, randomised controlled trial

### 1.2.7 The selection of measurement tools

Use of measurement tools supports structured, objective and transparent assessment, evaluation and communication. But only if the tools are well selected and interpreted. A first step in this selection process was done by the GDG. An overview was made of all tools recommended in the current guideline<sup>12</sup>, those identified through the European survey and focus groups with Parkinson expert (ParkinsonNet) physiotherapists (see Ch. 1.2.5 XX) and those suggested by members of the Guideline Development Group (Appendix 9). Of all these tools, information was gathered regarding psychometric properties (i.e. validity, reliability, responsiveness and interpretability) and feasibility (Table 1.2.7).<sup>13</sup> Based on these properties, tools were selected for recommendations in this guideline. Given the focus of physiotherapy treatment and communication, tools on the activities and participation component of the ICF are preferred. The majority of tools available are 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. As a consequence, a change in activity limitations needs to be larger in order to be picked up by the tool in a single pwp, compared to in groups of pwp. The GDG selected outcome measures which seemed to be most suitable for use in daily practice in individual pwp.

**Table 1.2.7. 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, i.e. related to the core areas and, preferably, 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 in the construct to be measured? 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 Target groups & how to use this guideline

This guideline aims to support decision making towards and within physiotherapy practice in Parkinson's disease. Thereby, supporting pwp from diagnosis onwards to manage their movement related impairments and activity limitations and focus on goals that are important to them. To achieve this goal, the target

groups and tools of this guideline are not only physiotherapists, but also pwp and other medical and allied health professionals. Each group may use the guideline in a different way.

### **1.3.1 Physiotherapists**

These guidelines are primarily developed for physiotherapists, irrespective of their work setting. By studying and using these guidelines, they can obtain knowledge and skills. However, given the complexity of Parkinson's disease and aiming to provide optimal care, it is advised that physiotherapists receive education specific to the correct use of these guideline, collaborate with other Parkinson expert health professionals and assess and treat many pwp annually (see Ch. 5.4)

As a reading indication:

- Physiotherapists with no or little Parkinson's specific knowledge are advised to start at chapter 3 (Parkinson's disease);
- Physiotherapists with sufficient Parkinson's specific knowledge, but with little experience in treating pwp with Parkinson's disease, are to start at Chapter 6 (History Taking & Physical Assessment);
- Physiotherapists with extensive Parkinson's specific knowledge and skills are advised to use these guidelines to evaluate their practice using Chapter 9 (Graded Recommendations) and the Quick Reference Cards (at the back of this Guideline).

### **1.3.2 People with Parkinson's disease s and their carers**

- Information on self-management and physiotherapy for pwp (Appendix 6)

### **1.3.3 Neurologists and other referring physicians**

- Criteria for referral to a physiotherapist (chapter 4)
- Quick reference cards 3 & 4 summarising Parkinson's specific treatment goals and strategies (at the back of this Guideline)

### **1.3.4 Other health professionals involved**

- Criteria for referral to a physiotherapist (Chapter 4), indicating possibilities for collaboration

## **1.4 Limitations of the guideline**

The methods used to develop this guideline, ensure that the best research evidence available was systematically collected, selected and appraised, and surmounted with clinical expertise and preferences of physiotherapist's 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, let alone just evidence-based guidelines, there will always be persons people or situations for which the recommendations are not applicable.<sup>14</sup> Partly this can be explained by the fact that in research many pwp are excluded, e.g. because of age or cognitive impairments.<sup>15</sup> Therefore, physiotherapists can always disregard the recommendations provided in this guideline based on their autonomy. This guideline does not override the individual responsibility of healthcare professionals to make appropriate decisions in the circumstances of the individual, in consultation with the person with Parkinson's disease and/or their carer. However, in case of deviation, this should be argued and documented.

### **1.4.1 Parkinsonisms**

The recommendations of this guideline are based on research and clinical practice in Parkinson's disease, therefore they do not automatically apply to (less prevalent) atypical parkinsonisms, such as vascular parkinsonism, progressive supra-nuclear palsy (PSP), multiple system atrophy (MSA) and parkinsonism caused by medication. Atypical parkinsonisms have clinical features equal to Parkinson's disease, but also significant differences, e.g. on average a faster progression, absence of or limited response to anti Parkinson medication and a shorter survival period. Moreover, they are often characterised by a variable range of additional neurological problems that are not addressed in this guideline (e.g. cerebellar ataxia and spasticity). In addition, many persons with atypical parkinsonisms (e.g. PSP or vascular parkinsonism)

have prominent cognitive decline, often at an early stage of the disease. This will have implications for the treatability (e.g. the applicability of cognitive movement strategies) and the advice to be provided. For most controlled clinical trials, people with forms of Parkinsonism other than idiopathic Parkinson's disease are excluded from the study. Evidence for the efficacy of physiotherapy in this group is therefore insufficient. Clinical experts however, suggest that the response to physiotherapy intervention in this group is less marked than with pwp. Finally, persons with PSP often show 'motor recklessness' and concomitant injurious falls.<sup>16</sup> In these persons, usually a limitation of activities will have to take place. On the other hand, some persons with 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, certain recommendations of these guidelines may be applied to them. It is however expected, that the benefit of the interventions is expected to have a shorter duration. A detailed overview of Red and Orange Flags in the medical diagnoses of Parkinson's disease is provided in Appendix 3.<sup>16</sup>

#### **1.4.2 Multimorbidity and comorbidities**

Parkinson's disease is often referred to as a multimorbidity. In addition, many pwp will have comorbidities. However, most of the research on which recommendations of this guideline are drawn have excluded patients with comorbidities or high age.<sup>15</sup> Therapists should therefore always recognise that most patients have several medical problems rather than one disease.<sup>17</sup> It is not always 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 patients to make decisions about their health care in the face of competing priorities and to support patient self-management.<sup>17</sup>

Next to the many Parkinson-related impairments in functions and activity limitations, pwp are faced with comorbid diseases. More than their contemporaries, they are prone to sustain broken bones and hips, specifically in the presence of dementia.<sup>18</sup> Other comorbidities common to pwp, which are of importance to decisions in physiotherapy care are arthritis, heart circulation problems (predicting a delayed memory recall) and diabetes.<sup>18-21</sup> For several comorbidities, monodisciplinary guidelines are available, e.g. on osteoporosis, pelvic floor problems, neuropathic pain and training of physical capacity (i.e. limitations in muscle strength, aerobic endurance and range of movement).

#### **1.4.3 Exclusions**

- Pwp with urologic impairments and limitations (see Appendix 4) are advised 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 often reported in physiotherapy practice, they are not included in this guideline as they are considered to be part of the core areas of occupational therapy.

### **1.5 Guideline implementation: 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.<sup>22;23</sup> Even when practice guidelines are available, management practices often do not match their recommendations.<sup>22;24</sup> (XX REF survey) 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.<sup>25</sup> Essential to this is the implementation of evidence-informed guidelines.<sup>25</sup> Regarding the current guideline, physicians need to know when to refer; physiotherapists need to know what to do and when; and patients need to know do what do themselves, when to ask for physiotherapy and what to expect.

### **1.5.1 Implementation: translation, adaptation, education**

In the joint collaboration, the representatives of the 19 participating countries have tried to develop a guideline feasible for use throughout Europe. To further optimise implementation, translation and adaptation is recommended.

For translation of the guideline, the dual panel method is recommended.<sup>26</sup> To assure quality and transparency, the copyright holders of this guideline must be involved in these processes. For translation, in addition, a member of the GDG whose mother language equals the language for the translation needs to be involved. The first translation should be reviewed by a panel of physiotherapists (with and without Parkinson-expertise) to ensure acceptability of wording and ease of use.

Aiming to support equal implementation of tools throughout Europe, the GDG has searched for 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. Some non-official versions could be available, but the physiotherapists should be very cautious about making conclusions when using this kind of translated tools. They are not recommended to use in the evaluation purpose.

Studying psychometric properties of translated versions is more important for questionnaires than performance based tests. The objective in adapting measurement tools is to ensure that items are understood in the same way in different languages. Apart from differences induced by the translations, there may also be differences in cultural issues. When measures are used cross-culturally, there is a standardised procedure by which they must be translated and validated.<sup>26</sup> This is a time consuming process.

To endorse implementation, the copyright holders encourages adapting the format and cover of translated and adapted versions of the 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 these guidelines.

### **1.5.2 ParkinsonNet**

With the publication of the 2004 guideline, in the Netherlands the ParkinsonNet implementation strategy has been developed. ParkinsonNet, provides Parkinson's specific training to selected health care professionals, re-organises allied healthcare to increase the patient volume of therapists and makes expert healthcare professionals visible to other professionals as well as too patients. It also supports communication amongst health care professionals as well as between professionals and patients.<sup>27</sup> To achieve this, within the adherence 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 guidelines. Communication amongst the therapists, as well as with other health professionals and patients is supported, e.g. through (educational) meetings and a secured web-based community. The expert therapists are visualised by web-based sources and printed folders, and preferred referral was supported. Evaluation has shown that ParkinsonNet doubles patient volume even within a short period of six months (the study period) and increases the quality of physiotherapy care, whilst reducing costs.<sup>28</sup> Moreover, evaluation of the connectedness of healthcare 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.<sup>29</sup> Supported by the positive results, ParkinsonNet was endorsed by professional healthcare organizations and the national patient society. In 2010 national coverage within the Netherlands was achieved by 65 unique, multidisciplinary Parkinson's specific networks. The GDG recommends that national associations of health professionals (preferably physiotherapy) or pwp initiate implementation of this guideline by taking advantage of the lessons learned from ParkinsonNet (Table 1.5.2)

*Table. 1.5.2 Recommended steps to consider for guideline implementation*

<b>What</b>	<b>How</b>
<b>Selection</b>	Select physiotherapists who are motivated to work with pwp, ensuring good geographical dispersion (so pwp can be visited at home)
<b>Education</b>	(Continuously) train the selected therapists in correct use of the guideline
<b>Collaboration &amp; communication</b>	Support preferred referral to these therapists (to increase patient volumes); support communication and collaboration amongst these therapists and with other (regional or local) health care professionals and patients, e.g. by organising network meetings and activities
<b>Visibility</b>	Make these therapists known to other professionals and pwp, e.g. by using printed information and an online search engine

### **1.6 Update of this guideline**

Latest 2017, the copyright holder of the guideline decides whether the guideline needs to be updated. This depends on the amount and strength of new scientific evidence, changes in barriers in current care (and therewith changes in key questions) or changes in the organisations of care. New evidence will be appraised conform methods used for this guideline the, by a writing group assigned by the copyright holders. All participating associations will be offered the possibility to participate in this process. All users of the guideline are invited to share their experience and knowledge on this through [TO FOLLOW].

## Chapter 2. Parkinson's disease

Parkinson's disease is a progressive, neurodegenerative disease. It is a complex disease which puts a high burden on people with Parkinson's disease (pwp), 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 Europe.<sup>30</sup> In Western Europe's five most populous nations, the number of pwp over age of 50 years was estimated at U.K. 90,000; Germany 110,000; France 120,000; Italy 240,000; and Spain 260,000.<sup>31</sup> Due to ageing of the population, these numbers will be doubled by 2030.<sup>31</sup> The incidence is approximately 1.5 times higher in males than it is in females. The majority of diagnosis Parkinson's disease is made in persons over the age of 60 years; in around 5%, the diagnosis is made before the age of 40 years. Consequently, the prevalence increase with age, from about 1.4% over age 60 to about 4.3% over age 85.<sup>32;33</sup> With an estimated annual cost of €13.9 billion across Europe the economic impact of Parkinson's disease is enormous.<sup>30;34</sup> Overall cost estimates vary from country to country, but the largest component of direct cost is typically inpatient care and nursing home costs.<sup>35</sup> Costs increase with disease progression.<sup>35;36</sup> Typically high indirect costs arising from lost productivity and carer burden.<sup>35</sup> The costs increase with disease progression, from €5,000 in the early stage of the disease, to over €17,000 in the end stage.<sup>3</sup>

### 2.2 Pathophysiology: environmental and genetic factors

Resulting from an unknown cause, dopamine-producing cells in the substantia nigra degenerate progressively. Epidemiologic studies have consistently found that some exposures are inversely (e.g., cigarette smoking) or positively associated with Parkinson's disease (e.g., pesticides).<sup>37</sup> In 5% to 10% of all pwp, genetic mutations are responsible. The likability for a genetic variant is larger in case of an onset before 40 years and a positive family history.<sup>38</sup> Genetic and environmental factors are now thought to interact and affect the risk of an individual to develop Parkinson's disease.<sup>38</sup> The degeneration of cells leads to decreased levels of dopamine in projections from the substantia nigra to the striatum, frontal lobes and limbic circuitries.<sup>39</sup> Over time, lesions in non-dopaminergic brain areas (e.g. the locus coeruleus and the pedunculopontine nucleus) play an increasing role.<sup>40</sup> As a consequence, Parkinson's disease has a complex phenotype.

### 2.3 Diagnosis

The diagnosis is primarily based on clinical criteria.<sup>41;42</sup> The conventional core criteria for parkinsonism (UK PDS Brain Bank) include bradykinesia (progressive decrement of both the speed and amplitude of repetitive movements) and at least one of the following: rigidity, rest tremor or postural instability, as well as the absence of the so-called Red Flags for Diagnosis, such as a symmetrical start of symptoms, falls within the first year and no response to levodopa (Appendix 3).<sup>16</sup> Even though MRI is supportive, no test or assessment can fully differentiate between Parkinson's disease and a parkinsonism. Parkinson's disease can only be diagnosed with 100% certainty via post-mortem examination of the brain.<sup>43;44</sup> Especially in the early stages, the symptoms of Parkinson's disease and atypical parkinsonism can closely resemble each other (10-20% overlap).<sup>16</sup> Not surprisingly, in the community, up to 35% of patients are misdiagnosed by general practitioners: 15% of patients with a diagnosis of Parkinson's disease do not fulfil strict clinical criteria for diagnosis and 20% of persons unjustly received the diagnosis Parkinson's disease.<sup>45</sup> Therefore, diagnosis are preferably set by a neurologist specialised in movement disorders, who can reach an accuracy of more than 90%.<sup>46;47</sup> The most common reasons for misdiagnosis are presence of essential tremor, vascular parkinsonism and atypical parkinsonian syndromes.

### 2.4. Which health problems are associated with Parkinson's disease?

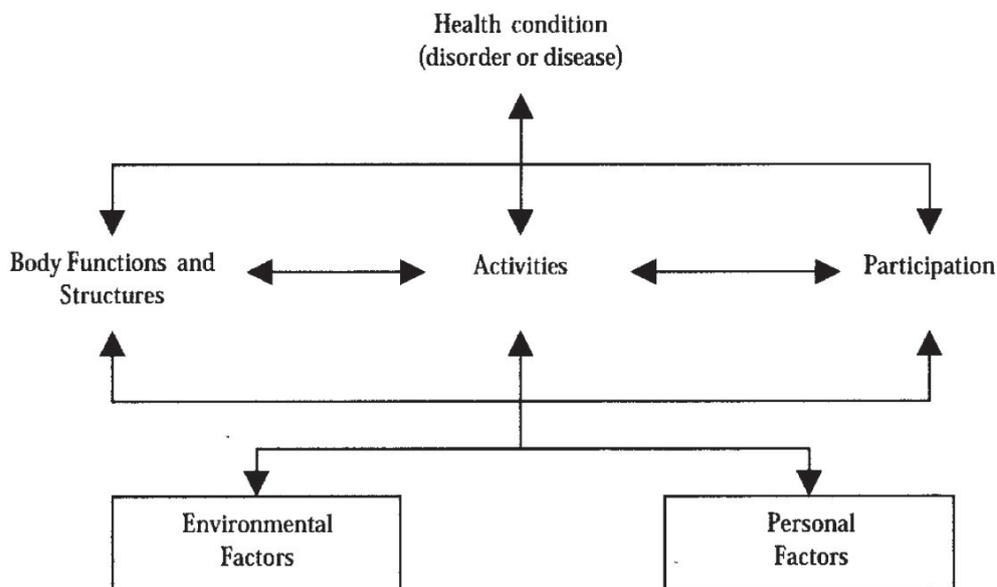
Parkinson's disease is a complex disease, with a wide variety of problems. These problems can be a (direct) consequence of the disease, but also as a consequence of the Parkinson medication or inactivity of the pwp. For majority of affected persons, it is a very incapacitating disease. However, the variability in the rate of the progression, as well as in daily functioning is large.<sup>48-51</sup>

### 2.4.1 The ICF classification

To describe this functioning, the classification system of the International Classification of Functioning, Disability and Health (ICF classification) can be used.<sup>52</sup> It provides a common language and basis for the understanding and describing 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 with the ICD-10 classification, developed for worldwide recording and comparison of morbidity and mortality.<sup>53</sup>

In ICF, disability and functioning are viewed as outcomes of interactions between health conditions and contextual 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 Environmental. These can be a facilitator or a barrier, e.g. the physical, social and attitudinal environment (Environmental Factors) and age, gender, experiences and interests (Personal Factors). As personal factors are associated with a large social and cultural variance, they are not coded. All five factors are intercorrelated (Fig. 2.4). ICF provides us with names, codes, and descriptions of all factors.

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



Impairments are problems in body functions and structure. Impairments in body functions generally correspond to what is known as signs and symptoms of disorders in the ICD-10. They may induce problems in activities or participation: activity limitations or participation restriction. However, their relationship is not linear, but largely depends on personal and environmental factors. These factors can positively or negatively influence functioning. For example, a person with Parkinson's disease may have sufficient confidence, muscle strength, joint mobility, 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; an environmental factor. But also negative thinking, like 'I do not like to exercise, I rather stay seated in my chair' may refrain them to exercise; a personal factor. Moreover, two pwp with the same severity of Parkinson's disease may have the same capacity to perform tasks when performing in a standardised environment, but their performance might differ significantly in their natural environment due to their personal factors and their environment's characteristics. Therefore, two constructs of functioning are distinguished: capacity and performance. Capacity is a person's ability to execute tasks in a standard environment such as the pwp's home, the community and the therapy setting. Whereas, 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 assessment, as well as when communicating with the pwp and other health professionals.

### 2.4.2 *Impairments, limitations and restrictions in Parkinson's disease*

Pwp can be faced with a large variety of impairments in functions and limitations in activities, primarily or secondary 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 4. The appendix also includes ICF domains and codes. In general, in physiotherapy practice the domains and codes are not used. However, they may be important for collaboration and communication in specific settings, e.g. in multidisciplinary rehabilitation care. Of higher importance than the ICF codes, is the ICF wording. The GDG advised to use these when describing the pwp's impairments in functions, activity limitations and restriction in participation. Appendix 12 provides an ICF-based assessment and report sheet.

#### *Impairments in motor functions*

Bradykinesia, slowness and extinction of movement, is the most characteristic impairment, present in 77% to 98% of person with Parkinson's disease.<sup>41</sup> Tremor at rest occurs in around 70% at times of diagnosis<sup>54</sup>, but up to 100% of persons at any stage of the disease<sup>55</sup>. Rigidity is found in 89% to 99%.<sup>41</sup> It is characterised by increased resistance present throughout the range of passive movement of a limb.<sup>42</sup> It may be associated with pain, e.g. shoulder pain, which can be a presenting impairments.<sup>56</sup> In addition, rigidity of the neck and trunk (axial rigidity) may occur, resulting in abnormal axial postures (e.g., antecollis and scoliosis).<sup>42</sup> 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 disease.<sup>42</sup> Although considered to be 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 diagnosis.<sup>57</sup>

#### *Impairments in non-motor functions*

However, Parkinson's disease is not characterised by impairments in neuromusculoskeletal and movement-related functions only. It is increasingly becoming apparent that pwp also suffer from a wide variety of non-motor impairments (Appendix 4).<sup>58;59</sup> In fact, they are responsible for a considerable reduction in quality of life.<sup>60</sup> Often, they remain unnoticed by healthcare professionals, because pwp s are either embarrassed to discuss these impairments, or are unaware that they are linked to Parkinson's disease.<sup>61</sup> Although the impairments correlate with advancing age and disease severity, they may even precede the expression of motor impairments by more than a decade.<sup>58;62;63</sup> Up to 70% of pwp experience non-motor symptoms, and they may even be present in the early stage of the disease.<sup>64</sup> Examples of early non-motor impairments are olfactory dysfunction, REM sleep behaviour disorder, constipation, and depression.<sup>58;62;63</sup> But also other mental impairments, specifically impaired executive function, memory and psychomotor velocity can be present at diagnosis<sup>50</sup> Examples of late non-motor impairments are dementia, urinary incontinence, and sexual dysfunction. Approximately one out of five pwp will experience a major depression.<sup>65</sup> Other common impairments that are important to choices made in physiotherapy management are anxiety (reported in up to 40% of pwp), apathy (up to 50%) and pain (up to 70%).<sup>65-68</sup>

#### *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 4). 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 medication.<sup>69-71</sup> Activity limitations that mostly affect the daily life of pwp include the performance of transfers, dexterity, communication, eating, gait, and gait-related activities.<sup>69-71</sup> 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 in limitations in relation to physiotherapy.

### 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 PIGD-type, will present with activity limitations in the early stages and even upon at their first visit to a neurologist.<sup>72-74</sup>

Postural and axial symptoms (e.g. impairments in gait) evolve more rapidly than other motor features and appear to be the best index of disease progression.<sup>75</sup> Therefore, in clinical practice, many physicians use the Hoehn & Yahr staging scale (H&Y) 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 functioning.<sup>76</sup> Based on the H&Y stadia, pwp are regarded being in the early or uncomplicated phase (H&Y 1-2); in the complicated phase (H&Y 3-4); or in the late phase (H&Y 5).<sup>4</sup> H&Y 3 is characterised by the onset of axial impairments and is associated with a marked deterioration in quality of life (Table 2.5.1).<sup>75</sup> It is estimated that only 4% of pwp reach the late phase.<sup>77</sup>

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

H&Y	Description	Phase
1	Unilateral involvement only; minimal or no functional disability	Early
2	Bilateral or midline involvement; no impairment of balance	Early
3	Bilateral disease: 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

Individual variation in progression of the disease is large. However, disease progression may be slightly faster for women, reaching H&Y 3 earlier than men.<sup>77</sup> Likewise, women also earlier experience motor complications, i.e. motor fluctuations, dyskinesias and freezing of gait.<sup>78</sup> 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 subtypes.<sup>79</sup> Most commonly, four clinical subtypes of Parkinson's disease are distinguished.<sup>49;80-82</sup> (Table 2.5.2 XX)

Table 2.5.2 Subtypes of Parkinson's disease

Subtype	Associations clinical features
Earlier disease onset (<55yrs)	Late onset of falls (approx. 15 yrs) <sup>82</sup> Late onset of cognitive decline <sup>82</sup> Early onset of freezing (50% after 10yrs vs. 15 yrs) <sup>83</sup> Higher risk for anxiety <sup>84</sup> Shorter time to dyskinesias and wearing-off <sup>77</sup> Longer time to H&Y 3 <sup>77</sup>
Tremor dominant	Poorer response to levodopa, but slower disease progression <sup>82;85</sup> Lower risk for depression and mood impairments <sup>84</sup> Longer time to and lower risk of dementia compared to PIGD-type <sup>86</sup> Longer time to H&Y3 compared to PIGD-type <sup>86</sup>
Postural imbalance and gait disorder (PIGD)*	Predominant gait and posture impairments Higher prevalence and severity of depressive symptoms <sup>84;87</sup> Higher prevalence of dementia <sup>85</sup>
Rapid disease progression without dementia	Older age at onset <sup>82</sup> Early depression <sup>82</sup> Early midline motor symptoms <sup>82</sup> In 70% a tremulous onset <sup>82</sup> At post-mortem

\* at autopsy, some of these patients turn out to have MSA or PSP<sup>82</sup>

To monitor progression, physicians often use the Unified Parkinson's Disease Rating Scale (UPDRS). 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).<sup>75</sup> 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 strain.<sup>88-91</sup> 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 medication.<sup>92-94</sup> Pwp have a 1.8 to 2.3 increased mortality risk.<sup>95</sup> The increased risk can in part be ascribed by dementia, being the largest predictor for mortality in pwp.<sup>95;96</sup> Pneumonia is the most common cause of death in pwp, generally occurring in H&Y5.<sup>97-100</sup>

## 2.6 Quality of life

Parkinson's disease severely threatens quality of life, more than for example stroke or arthritis.<sup>60</sup> The loss in quality of life increases in each phase, from on average 33% in the early phase to 85% in the late phase.<sup>3</sup> Mainly the late motor and non-motor impairments have a dramatic impact on the persons' quality of life. Non-motor impairments such as depression and psychosocial well-being are the major determinants of quality of life.<sup>60;101</sup> Other important determinants of quality of life are axial signs, including movement related impairments and limitations such as difficulty turning and recurrent falls.<sup>60;101;102</sup> The impact on quality of life also extends to the partner and other family members.<sup>103</sup>

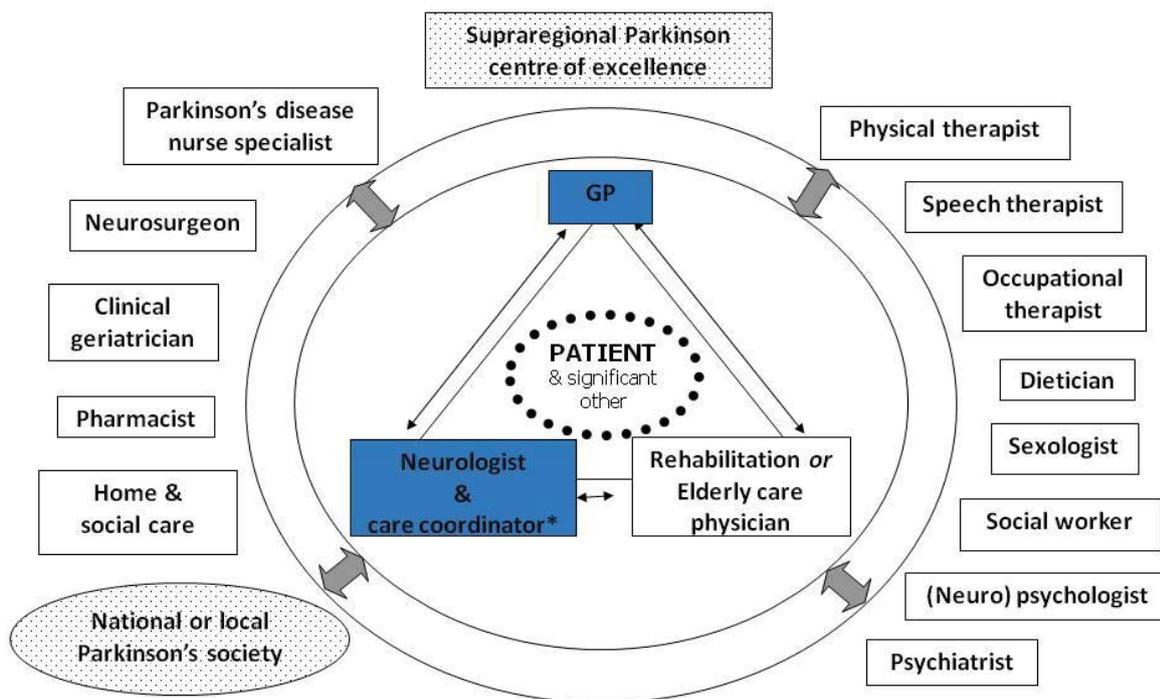
## Chapter 3. Main management

The overall goal of Parkinson management is to optimise activities, participation and quality of life of people with Parkinson's disease (pwp) by considering functioning, personal and environmental factors. Current therapeutic strategies are mainly focused on symptom control and compensatory strategies. Symptomatic treatments include a variety of drugs and rehabilitation. Compensatory strategies are used by most allied health interventions. As yet, there is no treatment that has been demonstrated conclusively to slow condition progression. The information in this chapter is primarily based on three recently published multidisciplinary guidelines: the 2006 NICE (UK) clinical guideline Parkinson's disease; the Dutch 2010 Multidisciplinary Guideline 'Parkinson's disease (an update version of the NICE guidelines surmounted with recommendation for collaboration); and the 2011 EFNS/MDS guidelines on Parkinson's disease.<sup>3;4;104</sup>

### 3.1 Multiple health professionals

Because of the complex nature of Parkinson's disease, as many as 19 healthcare professionals and institutions can be involved in care for pwp (Fig. 3.1).<sup>4;27</sup> Optimally, always involved should be the general practitioner, a neurologist with Parkinson-expertise and a care coordinator (e.g. the Parkinson's disease nurse specialist). All other professionals will be involved in the care when the criteria for referral are met (Appendix 5). Role specificity of each profession may vary from country to country.

Figure 3.1 A care model for people with Parkinson's disease



*\*in most situations preferably the same*

#### 3.1.1 Collaboration

Pwp have expressed the need for collaboration between professionals involved in their care. To facilitate this, this guideline provides a Parkinson's specific ICF (Appendix 4) and an overview of healthcare professionals who may possibly be involved, including a short role description of each (Appendix 5).<sup>3;4</sup> The health professional's involvement should be integrated and relevant with a clear rationale underpinning its effectiveness for the different problems of the pwp. This will minimise any mental and physical strain therapy might add to the person and carer. Therapists need to be aware of each other's expertise and

refer on to, or involve other health professionals in a timely manner. When more intensive interventions are offered, it will become necessary to sequence different interventions during that time depending on the patient's priorities, and contradictive advice should be avoided. A care coordinator may be supportive to the pwp. Preferably, local agreements are made on which professional is responsible for the coordination of care (Table 3.1.1)

**Table 3.1.1 General requirements for coordination of care**

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

### 3.1.2 Patient centred care and communication

Patient centred care entails “Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions”.<sup>9</sup> But even though patient centred care is associated with greater well-being and physical functioning, at no additional costs, and healthcare professionals have the right intentions, patient-centredness remains far from being implemented in current clinical practice.<sup>9</sup> Specifically when many health professionals are involved in care for a single pwp, all efforts are required to keep care patient centred. A care coordinator may support the pwp in selecting their main problems at that given time and to identify which health professionals might be involved to achieve this. Healthcare professionals involved should listen carefully to the pwp's needs and preferences. Moreover, they should know which other healthcare professionals are involved, or could be involved for problems bothering the pwp. They should communicate well with other health professionals involved, to know who is doing what and when and to adjust treatments to complement one other. Preferably, local agreements are made between healthcare professionals on how and when to communicate. Recommendations regarding communication for physiotherapists are included in the Chapter XX.

### 3.1.3 Expertise

The complexity of the condition, which includes motor and non-motor problems and large number and variety of possible treatment strategies, should dictate that all pwp are treated by health professionals with Parkinson-expertise. The GDG are aware that this is not always possible, but emphasise that healthcare professionals have a responsibility to realise their own limitations of expertise and call in or contact an expert for advice if necessary. Physiotherapy-specific requirements defining expertise can be found in Ch. 4 (Referral to Physiotherapy)

## 3.2 Pharmacological management

Medication is the first choice in care for pwp, aiming to correct the neurotransmitter imbalance within the basal ganglia circuitry. Whilst polypharmacy is best avoided in the older person, Parkinson treatment frequently necessitates multiple doses of several medications. It is therefore important for a physiotherapist to know what aspects of Parkinson's disease, the medication can or cannot influence, as well as its possible adverse events (Appendix 8). This may increase the benefits of physiotherapy treatment, reduce unnecessary prescribing and unrealistic expectations. It should however also be noticed that adherence to medication intake in pwp is generally low.

### 3.2.1 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 offering the best symptomatic relief of rigidity, bradykinesia and tremor.<sup>105</sup> As protein intake reduces the benefits of levodopa, a protein-redistribution diet is often advised.<sup>106;107</sup> 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 worsening of symptoms cannot be controlled with the agonist alone. However,

previously, it was common practice to combine an agonist like bromocriptine or lisuride with levodopa within the first months of treatment ('early combination strategy'). There are no studies assessing whether one strategy is better than the other.

Dopamine agonists are recommended in the early stages of the disease in young onset patients who are more prone to develop motor complications. Other Parkinson medication, i.e. selegiline, amantadine, anticholinergics and beta-blockers, have only modest antiparkinsonian efficacy and are therefore not considered as first choice. Finally, 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 freezing of gait, autonomic dysfunction, postural instability, falling, and dementia. The phenomenon of freezing is usually worse in the off state, and can be reduced by lengthening the on state through manipulation of levodopa.<sup>108</sup>

**3.2.2 Medication induced motor-complications: response fluctuations & dyskinesias**

Medication allows for control of symptoms, but also induces complications (Appendix 8)<sup>3</sup>. In addition to possible troubling side effects or adverse events that may trouble pwp from the start, additional complications will arise after approximately five years of treatment. Over time, there is a reduction in the smooth response to medication, made more difficult by the development of motor and non-motor complications (e.g. neuropsychiatric complications), the most common of which are:

Table 3.2.1 Most common medication induced motor complications	
Response fluctuations on and off states	Fluctuations between on and off states. During on states the medication is working well, whereas during off states the medication dose is insufficient or ineffective. Initially, these states can be predicted and linked to the medication intake time. Before the next dose there may be a predictable wearing-off. However, over time, they will become unpredictable
Early morning dystonia	A common symptom related to response fluctuations. Dystonia is an uncontrollable and sometimes painful muscle spasm. Pwp will describe it as 'severe cramping'
Dyskinesias	Involuntary, large amplitude and fidgety movements. They often occur at peak dose and are therefore referred to as peak-dose-hyperkinesia. Although primarily caused by dopamine, less severe dyskinesias may arise when using high dose dopamine agonists.
On state freezing	Commonly associated to excessive chronic use of levodopa

**3.2.3 Treatment of medication induced motor-complications**

To a certain extent, these complications of medication can be reduced with adjustments in medication intake. It is therefore important that all health professionals recognise the complications, enabling them to support the patient 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.<sup>105</sup>

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: pwp who receive apomorphine and need more than five injections a day, apomorphine can be administered with a pump. This includes a small subcutaneous needle and is reversible. Pwp will need other

medication as well; **\*\*Intraduodenal levodopa**: continuous intraduodenal levodopa infusion is known as Duodopa pump or continuous levodopa/carbidopa intestinal gel infusion (LCIG). It is a monotherapy, pwp will not need other medication on the side. Levodopa/carbidopa is administered through a pump into the small intestine. For this, a Jet-PEG, an extension tube, is inserted through a percutaneous endoscopic gastrostomy.<sup>109</sup> Costs involved are 3 to 4 times higher than in an apomorphine pump and 6 to 8 times higher than in deep brain stimulation (see Ch.3.3). Moreover, the size and weight of the infusion pump can be cumbersome and limiting the pwp in exercising (see Ch 5.X). Its use is limited by these high costs, the adverse events related to the infusion system or surgical procedure and by the need for an experienced team.<sup>110;111</sup>

### 3.3 Neurosurgery

In addition to medication, neurosurgery is an option for some pwp.<sup>112</sup> Lesioning procedures, such as a thalamotomy, were applied for many years but have been largely replaced by deep brain stimulation (DBS) in most countries. By high frequency electro-stimulation through permanent implanted electrodes in the brain in conjunction with a pacemaker, DBS mimics the effect of a lesion without the need for destroying brain tissue. DBS has rapidly replaced ablative stereotactic surgery due to several advantages: 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 reversible.<sup>112</sup> 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.<sup>113</sup> Levodopa-responsive gait and balance impairments have the potential to improve following DBS, but they can also decline due to surgical effects.<sup>113</sup> 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 speech limitations (e.g. 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).<sup>3</sup>

**Table 3.3 Main neurosurgery indications in people with Parkinson's disease**

<ul style="list-style-type: none"> <li>✓ Late stage Parkinson's disease</li> <li>✓ A clear reduction of off related symptoms with levodopa</li> <li>✓ Severe, unpredictable response fluctuations or severe dyskinesias despite optimal medication;</li> <li>✓ Treatment resistant tremor;</li> <li>✓ 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</li> </ul>
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### 3.4 Rehabilitation

Current medical management is only partially effective in controlling the progressing function impairments (particularly motor and non-motor impairments that occur late in the course of the condition), activity limitations and restrictions in participation issues such as freezing, impaired balance or cognitive impairments respond poorly to medication, and may even be worsened by medication. Consequently, even patients with optimal medical management face mounting and varied problems in daily functioning for which a wide variety of healthcare disciplines can be involved. 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 individual is of utmost importance with the individual assured of on-going, regular reviews of their general condition.<sup>114</sup> Advocated for people with long-term, changeable conditions are integrative approaches, such as multi- and interdisciplinary collaboration (Table 3.6).<sup>115;116</sup> The overall aim is to optimise quality of life through Parkinson's specific care, with multiple complementary health professionals and incorporating patient preferences and goals into treatment.

Table 3.4 Modalities and descriptions of integrated care	
<b>Uni- or mono-disciplinary care</b>	Practitioners work from a consultative standpoint. Patients may be referred on to other clinicians, but one practitioner retains central responsibility; communication between clinicians can be very limited.
<b>Multi-disciplinary care</b>	The patient will see various health professionals within a team who working independently - not collaboratively - and in parallel, each responsible for a different patient care need.
<b>Inter-disciplinary care</b>	A more person-centred approach with goals developed and managed by a team of healthcare professionals together with the patient; open and continuing communication between the patient and all involved practitioners
<b>Trans-disciplinary care</b>	Used more in an educational setting where different professionals share insight and knowledge about a specific problem; requires time for the differing professionals to understand the 'language' and 'perspectives' of the disciplines and integrate these to assist in dealing with a shared problem; e.g. a case conference, where a case is discussed in depth

### 3.5 Disease modification

Disease modification can be defined as treatments or interventions that affect the underlying pathophysiology mechanism of the disease and reduce the rate of disease progression. This can be through neuroprotection or neurorestoration. To date, there is no evidence for a modifying effect in Parkinson's disease for any medical intervention, be it vitamin-E, co-enzyme Q10, dopamine agonists or MAO-B inhibitors.<sup>3;4</sup> However, animal studies show that physical activity may directly interact with the neurodegenerative process, likely mediated by brain neurotrophic factors and neuroplasticity.<sup>117-120</sup> Vigorous exercise, sufficient to increase heart rate and the need for oxygen, is associated with reduced risk for Parkinson's disease and improved cognitive functioning.<sup>117</sup> Moreover, it has been shown that it increases gray matter volume of the brain and improves functional connectivity or cortical activation related to cognition. There is also emerging evidence that exercise improves corticomotor excitability in pwp, suggesting potential neuroplasticity.<sup>121</sup> Given that exercise is biologically protective against degenerative processes, it is plausible that exercise may slow down disease progression in pwp.

## Chapter 4. Referral to physiotherapy

This chapter aims to support clinicians in considering referral to physiotherapy.

### 4.1. About the development of this Guideline

This European Guideline has been developed collaboratively between professional physiotherapy associations from 19 European countries. It is an updated and improved version of the Guidelines developed by the Royal Dutch Society for Physical Therapy (KNGF) in 2004. These evidence-informed guidelines still are the only clinical practice guidelines specific for physiotherapy in Parkinson's disease. In addition to a review of the evidence, recommendations to reduce barriers inhibiting optimal physiotherapy care have been developed. These barriers were identified through a pan-European physiotherapy survey (response n=3,405), meetings with expert users of the KNGF guideline as well as with people with Parkinson's disease (pwp). The European Guideline has used GRADE, Grades of Recommendation Assessment, Development and Evaluation, to rate the evidence and from which to draft recommendations. The GRADE system is currently endorsed by many major organisations and journals, such as the Cochrane Collaboration, the World Health Organization, the U.K. National Institute for Health and Clinical Excellence (NICE), and the British Medical Journal. This Guideline has reviewed literature from as recently as December 2012, and as a result, the levels and description of the recommendations may differ from those published in the Guidelines published by the KNGF, the European Federation of Neurological Societies (EFNS), the Movement Disorders Society (MDS) and NICE.<sup>1;4;104;122;123</sup> Pwp were involved in the development of this Guideline from the start onwards.

### 4.2. When and why to refer for physiotherapy?

The American Academy of Neurology recommends that clinicians discuss the potential of physiotherapy with a pwp at least annually.<sup>124</sup> The Guideline Development Group endorses this and has drafted criteria for referral, based on stage of the disease, risk for or present problems and context (Table 4.2).

Table 4.2 Referral criteria for pwp to physiotherapy

Based on*	Description
<b>Stage:</b> Early	Soon after the diagnosis of Parkinson's disease, for advise, education and coaching towards self-management, including support to stay physical active; if required, to start more supervised, tailored intervention, e.g. to prevent limitations through motor-learning
<b>Specific impairments or limitations in activities</b>	At presence of: <ul style="list-style-type: none"> <li>• (Risk for) reduced physical capacity</li> <li>• Mobility limitations regarding:                             <ul style="list-style-type: none"> <li>○ transfers, e.g. rising from a chair or rolling over in bed</li> <li>○ gait, including freezing</li> <li>○ balance, including falls</li> <li>○ manual activities</li> </ul> </li> <li>• Pain, unrelated to medication</li> </ul>
<b>Context:</b> hospital admission	If admitted to a hospital for any cause, aiming to educate pwp and healthcare professionals, training them in the prevention of decubitis, falls and decrease of physical capacity

\*In addition, specifically trained physiotherapists in the United Kingdom, have a qualification in non-medical prescribing. They have the ability to prescribe, as well as supply and administer medicines to individually named patients.<sup>125</sup> The terms by which this process occurs are legislated and monitored under strict guidance.

Early referral is desired because difficulties in daily activities, without loss of independent function can be present in even in the early stages of Parkinson's disease. At Hoehn & Yahr 1-2, total scores on the Unified Parkinson's Disease Rating Scale (UPDRS) total scores can be below 20.<sup>73;126</sup> This is particularly the case in pwp with postural instability and gait disorders (PIGD).<sup>72</sup> Another reason for early referral is the importance of maintaining sufficient levels of activity in order to prevent secondary complications. Exercise has multiple physiological, psychological and physical benefits and may even result in neuroprotection<sup>127</sup>. During a one-off consultation, a physiotherapist can evaluate the needs for advise, education, coaching towards self-management, and if required start training. During the course of the

condition, the number of impairments in functions, activity limitations and restrictions in participation will increase. There is consistent data supporting physiotherapy referral and use in Parkinson's disease for transfers and mobility problems, gait disturbances, balance, falls and freezing.<sup>128</sup> The most recent evidence is provided in Chapter 9 of this Guideline. Finally, it is recommended that a physiotherapist is consulted when pwp are admitted to hospital.<sup>129</sup> The lack of Parkinson-expertise of healthcare professionals may enhance the risk for adverse events during hospital stay.<sup>130</sup> Problem areas include adverse events related to medication (e.g. wrong timing, withdraw, or use of contra-indicated drugs), swallowing and immobilisation.<sup>129</sup> As a consequence, pwp show an increased incidence of, amongst other adverse events, falls and decubitus.<sup>130</sup> Physiotherapy will focus on the prevention of falls (e.g. through education, exercise and ambulatory aids), prevention of decubitus, as well as preservation of physical capacity, focussing on pwp as well as on other health professionals involved in hospital care (e.g. nurses).

### 4.3 To which physiotherapist to refer?

Parkinson's disease is complex; impairments and limitations vary over the day and evidence on physiotherapy-specific interventions for pwp is constantly increasing. The Guideline Development Group therefore recommends that all pwp are referred to physiotherapists with Parkinson-expertise. Whilst there is no golden standard for 'Parkinson-expertise', this phenomenon is associated with the number of pwp treated annually. Physiotherapists with a annual treatment volume of seven report higher self-perceived expertise than those treating less than four pwp annually.<sup>131</sup> Results of the survey carried out in as first step of the development of this guideline (n=3,405 physiotherapists throughout Europe), revealed that on average most physiotherapists treat as few as four pwp annually. This treatment volume is unlikely to be sufficient to gain and maintain Parkinson-expertise. According to the therapists, the median optimum needed treatment number to gain and retain sufficient expertise was 10, with 50% of the answers ranging from 6 to 20. It is understood that in many working situations this number will be hard to reach. Unsurprisingly, most physiotherapists recorded a limited 'self-reported Parkinson-expertise', plus most therapists stated they were unaware of the KNGF Guideline, which has been freely available in Dutch and English since 2004. In addition to treatment volume, several other indication of Parkinson-expertise may be indentified (Table 4.3)

**Table 4.3 Preferred characteristics of physiotherapists to refer pwp too**

- ✓ Familiar with, and trained in applying the European Physiotherapy Guideline
- ✓ Received general postgraduate education on Parkinson's disease or movement disorders
- ✓ A higher than average patient volume (average is four pwp annually)
- ✓ Familiar with Parkinson's specific referral criteria to other health care providers
- ✓ Closely collaborating with other health care providers with Parkinson-expertise
- ✓ Receiving continuous, up-to-date education on Parkinson's disease from (inter)national recognised experts

### 4.4. What information is helpful to the physiotherapist upon referral?

Specific information provided upon referral will support the physiotherapist and pwp in setting a realistic treatment goal and selecting the most appropriate intervention. Moreover, it minimises requests from the pwp for information already available, thus reducing patient and carer burden (Table 4.4).

**Table 4.4 Information supportive upon referral**

#### Essential

- ✓ Diagnosis, distinguishing Parkinson's disease from parkinsonisms
- ✓ Stage of disease, e.g. a Hoehn & Yahr classification
- ✓ Reason for referral
- ✓ Disease-specific complications such as severity of motor fluctuations, dystonia and dyskinesia
- ✓ Other health complications that will influence physiotherapy options, e.g. heart failure, osteoporoses, diabetes, anxiety, cognition and apathy
- ✓ Current medication and (possible) adverse events

#### Helpful

- Relevant impairments in functions, limitations in activities and participation, e.g. by supplying (MDS-) UPDRS items scores
- Other interventions tried for the problems referred for, and results thereof
- Other current interventions, e.g. speech and language therapist or psychologist
- Expected outcome of physiotherapy intervention

#### 4.5. What to expect from physiotherapy?

This guideline supports physiotherapists in taking decisions towards patient-centred, evidence-informed practice. Depending on the complexity of problems in a specific pwp, the slowness in movement, processing information and in communication, as well as problems in prioritising problems, history taking and physical examination may take one hour (one or two sessions). Physiotherapists will, whenever possible, provide pwp with form to fill in before their first visit, and will use standardised measurement tools to gain systematic insight in current problems. Together with the pwp, the physiotherapist will decide upon the treatment goal and select appropriate interventions. Interventions will include a combination of advise, education, exercise and possibly compensatory strategies (Table 4.5). General exercise principles should be applied. Compensatory strategies should be based on the pathophysiology of Parkinson's disease, including cueing strategies to improve gait plus attentional (or cognitive) movement strategies to improve the performance of transfers.

During the intervention period, as well as at the end of a session, measurements will done to evaluate the effects, and if required adjust the treatment plan or terminate physiotherapy treatment. At the end of a treatment period, or during in case of prolonged treatment, the physiotherapist will communicate with the referring clinician about the treatment goal, plan and (expected) effect, supported with the interpretation of data collected with the used measurement tools.

Table 4.5 Overview and grading of physiotherapy interventions for pwp

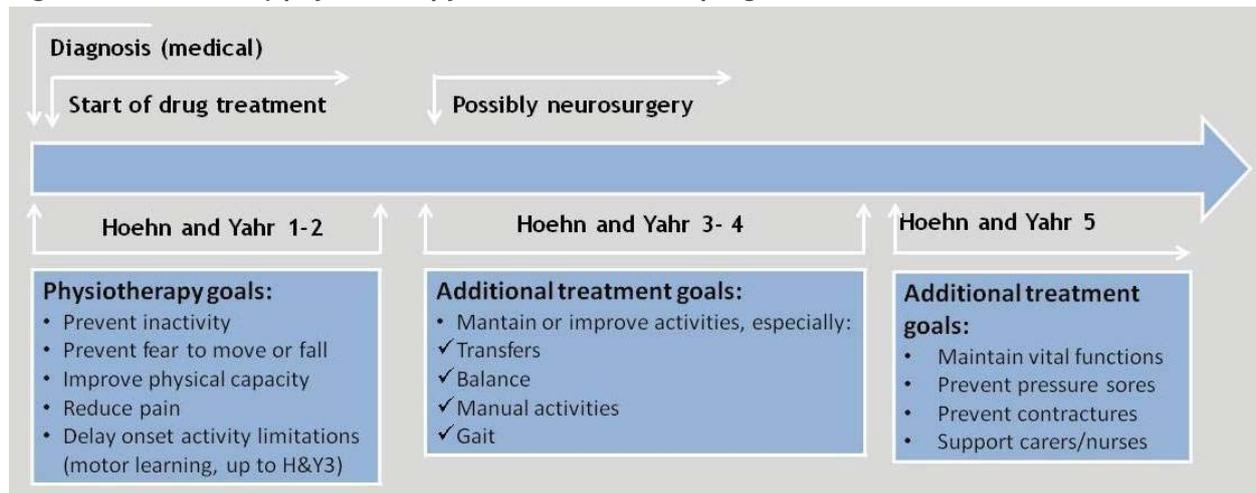
*Grades EU guideline will be added*

Problem	Possible interventions	Graded evidence level
<b>Transfers &amp; general mobility</b>	Cueing strategies	KNGF: 2; MDS: II
	Attentional (or cognitive) movement strategies	KNGF: 2
	Combination of cueing and attentional movement strategies	KNGF: 3
	Movement initiation training	NICE: II
	Training functional independence, including mobility & ADL	NICE: II
	Training coordination of muscle activity (e.g. Alexander Technique)	KNGF: 3; NICE: III
	Advice regarding safety in the home environment	NICE: II
<b>Gait</b>	Gait re-education	KNGF: 2; NICE: II
	Cueing strategies	EFNS/MDS: II
	Dual task specific cueing strategies	EFNS/MDS: III
	Treadmill training for gait velocity	KNGF: 2; EFNS/ MDS: II
	Exercise-based interventions	EFNS/ MDS: II
	Muscle strength	KNGF: 3
	Freezing: cueing strategies in the home	MDS: II; EFNS/ MDS: II
	Freezing: cueing strategies in differing environments e.g. outdoors	MDS: III; EFNS/ MDS: III
	Freezing: combining treadmill training and cueing strategies	MDS: II; EFNS/ MDS: II
<b>Balance &amp; falls</b>	Treadmill training	MDS: II; EFNS/MDS: II
	Strength and balance exercises to improve balance	KNGF: 2
	Physical capacity exercises for balance & near falls	MDS: II; EFNS/ MDS: II
	Functional balance exercises	NICE: II
	Tai Chi or Qigong	EFNS/ MDS: II
	General elderly population recommendations	EFNS/ MDS: IV
	Physical capacity exercises for falls (strength, balance)	MDS: III; EFNS/ MDS: II
<b>Physical capacity</b>	Strength	KNGF: 2
	Joint flexibility	KNGF: 2
	Aerobic exercise	NICE: II; EFNS/MDS: II
<b>Dexterity</b>	Cueing and attentional movement strategies	KNGF: 4
<b>Pain</b>	-	-

## Chapter 5. Core areas of physiotherapy

Physiotherapy aims to support people with Parkinson's (pwp) in maintaining or improving functional independence, safety and well being. The core areas physiotherapy addressed in pwp are physical capacity, transfers, manual activities, balance and gait<sup>132;133</sup>. 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 5.1)<sup>12;133;134</sup>.

Fig 5.1. Core areas of physiotherapy related to disease progression



### 5.1 Physical capacity and inactivity

Sufficient physical capacity i.e. muscle strength, endurance, coordination and range of motion, is a precondition for performing activities of daily life and to participate in society<sup>133</sup>. Pwp have a tendency towards a more inactive lifestyle; compared to their health contemporaries, they are about one-third less active<sup>135;136</sup>. 24% is calculated as predicted by the disease severity, gait, and disability recorded in daily living activities<sup>136</sup>. Mental impairments (e.g. depression, apathy and dementia), fatigue and personal factors such as self-efficacy also influence this behaviour<sup>137</sup>. 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 activities<sup>138</sup>.

Inactivity plays an important role in reducing muscle strength and length, especially in the weight bearing muscles of older people<sup>139</sup>; in pwp, leg muscle strength is reduced and associated with increased fall risk and reduced walking speed<sup>140;141</sup>. In contrast to their contemporaries, for pwp hip strength is specifically related to sit to stand performance, not knee extensors strength<sup>141</sup>. Moreover, in pwp, muscle strength is the major determinant of reduced muscle power (i.e. strength times speed), not bradykinesia. Muscle power is related to changes in/ performance of balance and mobility activities<sup>140;142-144</sup>.

Many pwp additionally present with 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, e.g. pain, osteoporosis, depression, and cardiovascular diseases<sup>136;137</sup>. 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 expectancy<sup>145</sup>.

### 5.2 Transfers

Complex movements such as transfers are often difficult for pwp<sup>146;147</sup>. 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<sup>148;149</sup>. 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 chair<sup>133</sup>. Likely factors that play a role are weak limb support

against gravity and poor timing of velocity in forward movement of the trunk<sup>150</sup>. Turning in bed is also complex due to bedcovers, reduced levels of levodopa at night and low visual guidance<sup>133</sup>.

### 5.3 Manual activities

Manual activities are complex movements because they require a combination of sequentially executed sub-movements. Moreover, they can be limited by a reduced trunk flexibility<sup>151</sup>. The fluency, 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 grip<sup>152-154</sup>. 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 of time. In some pwp, an action tremor may be observed affecting the entire track of a voluntary movement<sup>155</sup>.

### 5.4 Balance and falls

Falls are very common in pwp. In prospective assessments, fall rates range from 38% to 54% for a three-month period<sup>156</sup> to 68% for a 12-month period<sup>157</sup> and up to 87% for a 20-month period<sup>99</sup>. Usually five years after onset of the first impairments, limitations in changing and maintaining body position (i.e. balance) develop due to progressively impaired postural reflexes. Impairments in proprioception, reduced trunk flexibility, as well as Levodopa medication may further decrease balance<sup>158</sup>. Falls were assumed, on average, to emerge five years thereafter<sup>159</sup>, however, recently it has become clear that even in the early stages, pwp have an increased fall risk<sup>73;160</sup>. The reduced fall risk seen in later stages may be aggravated by increasingly sedentary lifestyle or simply immobility<sup>156</sup>. Falls are particularly present in those whose initial symptom was a gait disorder<sup>161</sup>.

#### 5.4.1 Consequences

Falls increase physical, social and financial burden. As many as 65% falls may result in injuries, of which one out of three in a hip or pelvis fracture<sup>162</sup>. As such, pwp have a two to fourfold higher probability of hip fractures than their peers<sup>163;164</sup>. Fractures occur more often due to a coexistent osteoporosis, caused by immobilisation and perhaps endocrine disorders<sup>165</sup>. 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<sup>166;167</sup>. This may explain why falls are among the leading causes of carer stress<sup>103</sup>.

#### 5.4.2 Associated factors

Factors associated with falls are partly disease-specific, e.g. freezing, reduced step height, bradykinesia, freezing of gait, and impaired postural reflexes<sup>157;168-171</sup>. In addition, generic factors can also be identified, such as the side effects of sedative drugs, daily intake of alcohol and urinary incontinence<sup>168;169;171;172</sup>. 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 falls<sup>173</sup>. As a consequence pwp who actively adopt an upright posture may become more unstable<sup>174</sup>.

Pwp who have fallen, have a very high likelihood of falling again within the next three months<sup>175</sup> which may in part be explained by their fear of falling. However, even pwp who have not yet fallen, may develop a fear of falling<sup>138</sup>. Moreover, this fear may lead to ADL restrictions, another risk factor for future falls<sup>176-178</sup>. Mobility limitations associated with greater fear of falling are rising from a chair, difficulty turning, start hesitation, festination, loss of balance and shuffling<sup>179</sup>. Also reduced self-perceived balance confidence level is associated with increased fall risk<sup>180</sup>.

Most falls in persons with Parkinson's disease occur indoors, when turning, standing up, bending forward, or dual tasking<sup>169</sup>.

#### 5.4.3 Dual tasking

Dual and multitasking activities can also contribute to falls because they represent a combination of decreased psychomotor speed and attentional flexibility<sup>181</sup>. This is worse when dual tasking combines a

motor and mental task, for example when walking and talking. When walking tasks become more complex, healthy elderly sacrifice the performance of a mental task (e.g. 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 tasks<sup>182</sup>. This may be explained by impairments in attention<sup>183</sup>, decreased attentional flexibility<sup>184</sup> and impairments in prioritising tasks<sup>182</sup>. As a consequence, multiple tasking can lead to freezing of gait or loss of balance when pwp are walking<sup>185;186</sup>.

## 5.5 Gait

Limitations in gait have been identified in early stages of the disease. The so called 'continuous gait disorder' and 'episodic gait disorder' may both be observed as gait patterns in pwp<sup>187</sup>, as described below.

### 5.5.1 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. 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)<sup>188</sup>. Specifically reduced walking speed is an independent risk factor for mortality (odds ratio 16.3)<sup>189</sup>.

### 5.5.2 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 movements<sup>190</sup>. When pwp experience festination of gait, their feet are involuntary behind their centre of gravity. This forces them to rapidly take involuntary increasingly small steps, with increasing 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'<sup>191</sup>. Most often freezing does present as complete akinesia, but rather as shuffling with small steps or trembling of the legs<sup>192</sup>. Freezing is experienced by 80% of pwp with a disease duration longer than eight years<sup>193</sup>. 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 pwp<sup>194</sup>. Freezing most commonly appears when pwp start walking ('start hesitation'), are making turns, going through narrow passages like a door, performing dual tasks (e.g. talking while walking), reaching an open space, or reaching upon a target<sup>195-197</sup>. Most freezing episodes are brief, lasting less than 10 seconds<sup>196</sup>. In more advanced stages of the disease freezing may persist for minutes. Freezing mainly occurs in the off-periods (Off freezing) and improves with dopaminergic medication, however, occasionally freezing occurs during on-periods (On freezing) as a possible side-effect of dopaminergic medication.

## 5.6 Additional areas

### 5.6.1 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 threshold<sup>198</sup>. Dopamine is involved in the assessment of pain and related to its emotional experience, be it with large individual variations<sup>199</sup>. 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 impairments<sup>200</sup>. Pain in pwp is associated with age (less pain at higher age), gender (women experience more pain), disease duration and severity, severity of depression, systemic comorbidity like diabetes, osteoporosis and rheumatoid arthritis<sup>201</sup>. Percentages of pwp experiencing a form of pain range from 35% to 85%<sup>66;202;203</sup>.

For clinical purposes, pain in pwp can be categorised as primary or secondary, based on its clinical description (table 5.6)<sup>204</sup>. Musculoskeletal pain is the most prevalent in pwp<sup>204</sup>.



## Chapter 6. History Taking & Physical Assessment

### 6.1 How to decide upon the treatment goal?

Through history taking and physical assessment, the physiotherapist and person with Parkinson's disease (pwp) determine whether there is an indication for physiotherapy<sup>213</sup>. The five core areas are targeted from both the pwp and the physiotherapist perspective. If agreed by the pwp, the relative's or carer's perspective may also be examined. If a pwp does not present red flags for physiotherapy intervention (Ch 6.14), physiotherapy is indicated when this pwp:

- requires physiotherapy specific education or support for self-management
- is at risk for secondary complications which can be prevented with physiotherapy
- is bothered by impairments in body functions, activity limitations or participation restrictions, which are within the core areas of physiotherapy

In case the physiotherapist considers that physiotherapy is not the appropriate intervention at that particular time, this needs to be discussed with the pwp. In addition, the referring physician needs to be informed. When a pwp reports impairments or activity limitations which are outside the scope of physiotherapy, it is important to consider advising the pwp to consult another health or social care professional when indicated (see Appendix 5). 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 the guideline and the interventions to select. These goals can relate to prevention of secondary complications, maintenance and improvement. As the treatment goal is essential to aid decisions upon which intervention to choose, the GDG advises to take sufficient time to carefully select this goal and to use measurement tools to structure this process and to make the process apparent in records.

### 6.2 How to incorporate measurement tools?

#### 6.2.1 What are the benefits of using measurement tools?

The GDG would like to stress that measurement tools only bring benefits if the information they provide can be interpreted. 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. When well selected and used appropriately, measurement tools will support physiotherapists and pwp in structured, objective and transparent:

- Identification of (risk for) impairments in functions, 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 healthcare professionals

Moreover, when assessments are used on a regular basis as well as at termination of treatment, the information obtained with these tools can also be used to:

- 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
- Monitor change due to the intervention
- Monitor changes to identify future risks for falling, loss of mobility and physical capacity
- Support the physiotherapist and pwp in deciding upon continuation, change or discontinuation of treatment
- Communicate with the referring physician and other health professionals

#### 6.2.2 Which tools are recommended?

31 Measurement tools were considered for recommendation (Appendix 9). Of these, 16 were selected on the basis of their validity and reliability when used for pwp; that they could be used in context of healthcare and physiotherapy practice across the European countries, and which covered four of the five core areas (Table 6.2.2). Six of these tools can also be used to monitor change (Ch.6.13). Reasons for

exclusion were being out of the scope of physiotherapy or limited psychometric properties (see Ch 1.2.7 for selection criteria). A detailed description of these tools is provided in chapters 6.3 to 6.12. An overview of the measurement tools according to the ICF framework is in Appendix 11.

**Table 6.2.2 Recommended measurement tools and time required for their use**

PWP at home (30 min)				
Pre-assessment Information Form (PIF) (Appendix 7) & Nieuwboer & Giladi video: Freezing of gait				
HISTORY TAKING (10-20 min)				
Consult QRC1 and continue with PIF: Prioritisation of limitations <i>In pwp who report a (near) fall on the PIF: remaining questions</i> History of Falling <i>In pwp who report freezing on the PIF: additional questions</i> New Freezing of Gait Questionnaire <i>In pwp who report a previous (near) fall or fear of falling: ABC* or FES-I (for less ambulant pwp)</i>				
PHYSICAL ASSESSMENT				
Which core areas are further assessed is based on the outcome of History Taking				
Balance (15-30 min)	Gait (15 min)	Transfers (10 - 15 min)	Dexterity	Physical Capacity (10 min)
General: Push and Release test (2min) Transfers: M-PAS Chair (5min); 5TSTS (2min) Gait: M-PAS Gait & TUG* (5min); DGI* & FGA (<10min); Snijders and Bloem FOG test (2min) Stationary: BBS* (20min)	M-PAS Gait & TUG* (5min) ; 10MWT* (5min); 6MW* (10 min); Snijders and Bloem FOG test (2min)	Bed: M-PAS Bed (10min) Chair: M-PAS Chair (5 min) ; TUG* (5 min)	#	6MW* with Borg Scale (10min); 5TSTS (2min)

Abbreviations: ABC, Activities Balance Confidence Scale; FES-I, Falls Efficacy Scale International; M-PAS, Modified Parkinson Activity Scale; TUG, Timed Up & Go; 5TSTS, Five Times Sit To Stand; DGI, Dynamic Gait Index; FGA, Functional Gait Assessment; BBS, Berg Balance Scale; 10MWT, 10 Meter Walk Test; FOG, freezing of gait; 6MW, Six Minute Walk. # no tools with good validity, reliability and feasibility are available for this core area. \*can be used for evaluation (see Ch.6.13).

### 6.2.3 When and how to optimally use these tools?

In the appendices, for all tools a description of how to carry them out is provided as well as scoring forms. In Ch. 6.4 to 6.10, more detail is provided for the recommended tools. For physiotherapists not using electronic or paper patient records specific to their work setting, an ICF-based form is provided to structure clinical assessment and reporting (Appendix 12). As a result of medication, a pwp's impairments and activity limitations can vary greatly during the day. Therefore, it is important to carefully decide when to use the tools. In general, questionnaires and tools assessing physical capacity are advised to use when the pwp is optimally functioning. The GDG advises to assess activity limitations at the times of the day when pwp is most bothered by them. Most commonly, this will be during the off periods. Other limitations, such as balance, may occur in both on and off periods, by which assessment in both periods is advised. This should be taken into account when making appointments. For example, the first visit could be aiming to assess the pwp in the on period, whereas the second visit could be used to assess the pwp in the off period. Moreover, when tools are also used for evaluation, it is important to use them under equal circumstances as the initial measurement as these can influence the outcome (Table 6.2.3).

**Table 6.2.3 Circumstances of measurements that may influence outcome**

<ul style="list-style-type: none"> <li>• Time of the day and tiredness of the pwp</li> <li>• Time after medication intake</li> <li>• If applicable to the specific pwp: on or off period</li> <li>• Specific location, e.g. in the clinic, at the pwp' home or outdoors</li> <li>• Materials used, e.g. a bed with a hard mattress or a 43 cm chair with soft seat</li> <li>• Clothes and shoes worn by the pwp</li> <li>• Assistive devices or personal assistance used</li> </ul> <p>The GDG advises to register these circumstances and keep them stable during follow-up measurements</p>
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#### **6.2.4 What about time constraints?**

The GDG advises to carefully select tools for use in each pwp. No single pwp requires the use of all 16 tools. Three tools however are advised to be used in each pwp: 1) the History of Falling Questionnaire to gain insight in fall risk, 2) the Parkinson's specific Index for Parkinson's Disease (PSI-PD) to gain insight in the to the pwp most important problem that can be targeted with physiotherapy, and 3) the Goal Attainment Scaling (GAS) to support goal setting for the limitations identified through the history taking and physical assessment. Based on the information obtained with the history taking, the physiotherapist decides upon which core areas are needed to assess physically. For each of the core areas, except for dexterity, specific tools are recommended (Table 6.2.2). Most of the tools are recommended to gain structured insight in the for the pwp most important problems. Only a few tools are also recommended for evaluation of change. Using the recommended tools will take time (Table 6.2.2), however, the information gathered is essential for gaining optimal insight in the impairments and limitations, setting goals and monitoring change. It may be assumed that if a therapist does not use the tools, it is because essential information is lacking or that information needs to be gathered in another, less structured and perhaps less valid way. Most likely, at least two physiotherapy sessions are needed before the goals can be set and the intervention selected. Starting treatment on the first visit, without thorough assessment may result in providing low quality, non-patient centred care without reaching goals. It is advised that physiotherapists share this with the pwp at the first visit, to endorse feasible expectations.

### **6.3 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. To optimally use the time available during the physiotherapy visits, it is advised that, when possible, the pwp is asked to fill in a Pre-assessment Information Form (PIF) at home, before the first visit (Appendix 7).

#### **6.3.1 Pre-assessment Information Form (PIF)**

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

##### *a) The patient important problems*

Many pwp are not aware what problems may be addressed with physiotherapy. 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 physiotherapy<sup>214</sup>. Thus, the PSI-PD supports structured and comprehensive identification of these problems. As a part of the PIF, pwp are asked to mark all items on the PSI-PD they encounter. During the first visit, the physiotherapist supports the pwp in prioritising these items (see 6.4.1).

##### *b) Freezing of gait*

It is often difficult to provoke freezing during clinical assessment. Therefore, physiotherapists are especially dependent on the pwp's 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 shuffling<sup>215</sup>. To increase the probability that freezing is recognised, the GDG recommends that pwp are asked to watch the online video on freezing by Nieuwboer and Giladi (*XX note: currently exploring possibility to make it available on CD and provide a link to website where the video can be found*). Preferably this is done preceding their first visit, otherwise during their first visit. In addition, the PIF includes a question from the New Freezing of Gait Questionnaire (N-FOGQ)<sup>216</sup>. The GDG advises that also the significant other or carer is asked.

##### *c) Falls*

For the management of falls, it is important to appreciate the complex and multifactorial pathophysiology, including impairments in functions and activity limitations in balance and gait (see 6.11 *Fall risk*)<sup>217</sup>. Therefore, the GDG recommends routine fall assessment. As a first step in assessing fall risk, the GDG recommends the use of the History of Falling Questionnaire to gain insight the history of falling

and in the confidence in keeping balance (see QRC1). The two main questions of the History of Falling Questionnaire are included in the PIF: whether or not this pwp has had any (near) falls in the past year. If these are answered positively, the additional questions of the History of Falling Questionnaire are recommended to address during History Taking.

*d) Levels of physical activity*

The GDG advises to follow the recommendations for physical activity described by the World Health Organization (WHO) (Table 6.3.1)<sup>218</sup>. Questions based on the NHS General Practice Physical Activity Questionnaire<sup>219</sup> is included in the PIF to gain insight in the pwp's levels of physical activity. These can be compared to the WHO recommendations.

**Table 6.3.1 WHO recommendations for physical activity**

***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

The GDG group expects that in most countries these recommendations are endorsed by national programs, or only 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 week<sup>220</sup>. When older adults cannot do the recommended amounts of physical activity due to health conditions, they 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 6.3.2)<sup>220-222</sup>. Moderate 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 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 6.3.2). A more detailed overview of activities and corresponding METS from the 2011 Compendium of Physical Activities<sup>223</sup>. 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. Due to the Parkinson's specific impairments in functions and activity limitations, pwp are likely to achieve higher levels of intensity than their healthy contemporaries carrying out the same activities.

**Table 6.3.2** *Examples moderate and vigorous activities*

Domain	Examples moderate physical activity	Examples vigorous physical activity
Recreation, sports and leisure-time activities	Walking on a 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 ( $\geq 8$ km/hr)* Bicycling $\geq 16$ km/hr, or uphill* Swimming steady paced laps Playing singles in tennis Aerobic dancing Field hockey Soccer Horseback riding jumping Jumping rope Martial arts (e.g. 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 (e.g. dressing, moving)	Fire fighting and forestry Heavy lifting Digging, shovelling and chopping Heavy construction Scrubbing floors Carrying groceries up stairs Wheeling a wheelchair (self)

\* in case of gait impairments, moderate and vigorous intensity will be achieved at lower velocities; in healthy people, moderate equals approx. 8,000 steps/hr for adults and 7,000 in old age; vigorous approx. 9,000 steps/hr for adults and 8,000 in old age

## 6.4 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 in functions and activity limitations to target during the physical assessment. Quick Reference Card 1 (QRC1) provides an overview of impairments in functions, activity limitations and participation restrictions that are advised to address. In addition, the pwp's own tricks to overcome specific problems and expectations regarding the interventions and treatment outcome are recorded. The physiotherapist tries 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.

### 6.4.1 Quick Reference Card 1 (QRC1)

QRC1 is based on a combination of the expert opinion of the GDG, on items of the 72-item MDS-Unified Parkinson's Disease Rating Scale (MDS-UPDRS) and the 39-item Parkinson's Disease Questionnaire for Quality of Life (PDQ-39) to make them clinically relevant to the practitioner. The tools are often used and of high importance in research to evaluate the efficacy of physiotherapy in groups of pwp, however, in clinical practice with the individual pwp, no benefits are expected to be detected 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 us to identify orange (caution) and red (contra-indication) flags for physiotherapy treatment (Ch 6.14). Issues in the QRC1 which are 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 (see Movement Disorders Society at [www.movementdisorders.org/updrs](http://www.movementdisorders.org/updrs)).

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 physiotherapists are not trained to assess these. For example, the neurologist may be able to provide results of the Mini Mental State Examination (MMSE)<sup>224</sup>, results of which provide the physiotherapist with important information regarding attention, executive functions and memory. Other examples include:

- Attention: The 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 past 2)
- Memory: Remembering three words (impaired when <3 words remembered)

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)<sup>225;226</sup>. This tool includes five memory tasks, four attention tasks and seven tasks for executive function ([www.scopa-propark.eu](http://www.scopa-propark.eu)).

#### **6.4.2 Patient Specific Index for Parkinson's Disease (PSI-PD)**

The pwp has marked all presently perceived limitations on the PIF. Of these, the pwp now needs to select 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 to pwp. Therefore, it is recommended to do this at the first visit so the physiotherapist can provide support. If the prioritisation of the PSI-PD is done before the physical assessment, the results of the PSI-PD can support decision making towards the specific core areas for physical assessment (QRC2). Together with the information that will be collected through history taking and physical assessment, the limitations prioritised with the PSI-PD can be used for goal setting using the Goal Attainment Scaling (Ch. 6.12.1).

#### **6.4.3 History of Falling Questionnaire**

If any of the two items of the History of Falling Questionnaire in the PIF (i.e. question 7 or 8) has been answered positively, the remaining questions are advised to address during history taking. These additional questions will provide insight in circumstances of the falls. The questionnaire uses a specific language pwp are familiar with, thus increasing the chance falls are recalled.<sup>227</sup> Details of locations and landings of falls are generally reliable recalled. The activities during which the falls occur, their frequency and avoidance-strategies, however, may necessitate probing by the physiotherapist.<sup>227</sup>

#### **6.4.4 New Freezing of Gait Questionnaire (N-FOGQ)**

If the item of the N-FOGQ in the PIF (i.e. question 10) has been answered positively, additional questions of the N-FOGQ are advised to address during history taking.<sup>228</sup> These additional questions will provide insight frequency and duration of freezing episodes.

#### **6.4.5 Activities Balance Confidence Scale (ABC)**

The ABC is a 16-item questionnaire in which patients rate their balance confidence in performing various ambulatory activities without falling.<sup>229</sup> 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. For making decisions in what aspects of balance to target, the individual items are of importance. For assessment of fall risk and for evaluation, the overall score is of importance. 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 assessment and treatment. It is supportive in identifying pwp who are at fall risk (Table 6.11a).<sup>230</sup> In addition it can be used to evaluate change. Moreover, it is an determinant of functional walking capacity as measured with the 6MW.<sup>180</sup>

#### 6.4.6 Falls Efficacy Scale International (FES-I)

In less ambulant pwp, the FES-I can be considered as an alternative to the ABC.<sup>231</sup> The FES-I is developed by the Prevention of Falls Network Europe (www.propane.eu.org). It assesses how concerned people are about the possibility of falling during the performance of ten different indoor, outdoor and social activities.<sup>231</sup> The 16 items are scored on a four point ordinal scale from 1 (not at all concerned) to 4 (very concerned). In frail people, especially when cognitive impairments are present, an interview-based administration method is recommended.<sup>232</sup> Several versions of falls efficacy scale exists, with a different number of items (e.g. the FES, FES-I, Short FES-I and FES(S)). The FES-I is preferred as is has been validated in many European countries.<sup>232-241</sup> 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 in (also outdoors) fear of falling-related activities, 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.

#### 6.5 Physical assessment: What to examine?

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

##### 6.5.1 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 in the impairments and limitations in a structured and objective way. Impairments reflect to the problem of the body functions (both physiological and psychological), 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 as well as participation, also impairments in functions should be assessed. The aim of assessing capacity within a certain activity (e.g. 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. Several tools, e.g. the Timed Up and Go and the Modified Parkinson Activity Scale can be used for more than one core area. 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.

#### 6.6 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)*
- 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' reported main complaint is related to static or dynamic balance, and on what the acquired information will be used for (e.g. 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) and the Functional Gait Assessment (FGA). In pwp in whom most problems occur during stationary base of support, such as standing and weight shifting, the Berg Balance Scale (BBS) is recommended.

For each of these tools, the overall score is supportive in identification of pwp at risk for falling (Table 6.11a) and, except for the FGA, for evaluation of change (Table 6.13). 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 to the measurement of the capacity of changing and maintaining body position, the measures for underlying impairments are needed to assess involuntary movement reaction functions and lower extremities muscle strength. For these purposes, the Push and Release test and the Five Times Sit and Stand Test respectively are recommended. Finally, other factors contributing to fall risk need to be taken in account (6.11 *Fall risk*).

### **6.6.1 Modified Parkinson Activity Scale (M-PAS)**

The M-PAS is a capacity measure, supporting detailed insight in the most important activity limitations in pwp that can be targeted by physiotherapy.<sup>242</sup> 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 double task (carrying a tray with cups of water) or a cognitive double task (counting backwards) or added. 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 measurement.<sup>243</sup> Bed transfers are tested with and without the use of a duvet or blanket. All items are scored on an ordinal scale ranging from 0 (best) to 4 (impossible or dependent on help) with detailed information on the quality of movement. Thus, the M-PAS gives relevant information towards goal setting and selection of the intervention. Depending on the core area(s) selected for physical assessment, different parts of the M-PAS can be used. To assess balance, the M-PAS parts Chair Transfer and Gait Akinesia are recommended.

### **6.6.2 Timed Up & Go (TUG)**

The TUG is a quick capacity measure for functional mobility.<sup>244</sup> Pwp are asked to rise from an arm chair, walk three meters, turn, walk back and sit down again. The time needed to perform this is measured. When used for assessment of the core areas Balance or Gait, this is done during execution of the M-PAS Gait Akinesia. A prolonged time to complete TUG is associated with increased fall risk (Table 6.11a). To increase accurateness to identify pwp at risk for falling, testing during the off stage is recommended.<sup>245</sup> In addition to the timed score, a score for safety of the turn can be added.

### **6.6.3 Dynamic Gait Index (DGI) and Functional Gait Assessment (FGA)**

With the Dynamic Gait Index (DGI), balance when performing eight gait related activities is scored<sup>246</sup>. This includes quality of gait 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 on a 4-point ordinal scale ranging from 0 (lowest level functioning) to 3. The maximum score is 24. It is supportive in identifying pwp who are at fall risk (Table 6.11a). Moreover, it can be used for evaluation of change over time (Table 6.7.7). When using the DGI, the GDG recommends assessing three more activities: 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', the score of the Functional Gait Assessment (FGA) can be calculated (Table 6.11a)<sup>247</sup>. The maximum score of the FGA is 30. The score of the FGA allows for further identification of those pwp at fall risk. 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, testing during the off stage is recommended.<sup>245</sup>

#### 6.6.4 Berg Balance Scale (BBS)

The 14-item Berg Balance Scale (BBS) assesses limitations in the performance of ADL requiring balance<sup>248</sup>. 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 on a 5-point ordinal scale, ranging from 0 (lowest level functioning) to 4 (a maximum), yielding a total of 56 points. However, many pwp score at maximum. This ceiling effect could be due to the fact that Parkinson specific limitations with double tasks and freezing are not assessed (although in some pwp item 11 may result in freezing). Moreover, the BBS does not include walking. Therefore, the BBS is recommended for use in less mobile pwp in later stages and for pwp who mainly have problems with stationary balance.

#### 6.6.5 Five Times Sit to Stand (FTSTS)

The FTSTS is a quick measure of balance which is supportive in identifying pwp who are at fall risk (Table 6.11a)<sup>249</sup>. The time needed to rise from a 43 centimetre chair is measured. The 5TSTS is recommended for use in pwp whose balance when performing transfers is questioned, in combination with the Push & Release Test. It does however not provide detailed information on balance limitation during gait related activities and stationary balance (see DGI, FGA and BBS).

#### 6.6.6 Push & Release Test

The Push & Release Test assesses balance control in quite stance.<sup>250</sup> The Push & Release Test provides information on involuntary movement reaction functions which are of importance to maintaining balance when walking backwards (e.g. 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 1 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 (e.g. 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 periods, 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 (see 6.4.1).

### 6.7 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 Test: *capacity measure of walking (d450) AND Measure of gait pattern functions (b770)*
- Snijders & Bloem Freezing of Gait Test: *Measure of gait pattern functions (b770)*

\* see 6.10.1

#### 6.7.1 Modified Parkinson Activity Scale (M-PAS)

To assess the quality of gait, the M-PAS part Gait Akinesia is recommended (see 6.6.1).

#### 6.7.2 Timed Up & Go (TUG)

The TUG is recommended to assess the velocity of gait during functional mobility (see 6.6.2).

#### 6.7.3 Six-minute Walk (6MW)

In pwp without freezing of gait, the six-minute walk (6MW) allows for objective assessment and evaluation of walking distance.<sup>251</sup> Moreover, it allows for assessment and evaluation of exercise capacity (see 6.10.1) and prolonged observation of gait. The distance that is walked on a flat, hard surface in a period of 6

minutes is measured.<sup>252</sup> The 6MW 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.<sup>243;253</sup> The GDG recommends using the Borg 6-20 when performing the 6MW (Ch. 6.10.2).

#### 6.7.4 10 Meter Walk Test (10MWT)

Walking speed is of importance to pwp safety, e.g. when crossing the street. With the 10 Meter Walk Test (10MWT), both comfortable and fast walking speed can be assessed and evaluated.<sup>254</sup> In addition, it allows for determination of stride length, important to the use of visual cues, and cadence (step frequency), important to the use of auditory cues (Ch. 7.2.1). During the performance of the test a walking aid may be used if necessary. When insufficient space is available to carry out the 10MWT, it can be shortened to six meters. However, the data can then not be used to monitor change.

#### 6.7.5 Snijders & Bloem Freezing of Gait test

For patients who report freezing on the questions of the PIF, it is recommended to try to provoke freezing to know what to target with the intervention. The GDG recommends the freezing of gait test developed by Snijders & Bloem: ask the pwp to perform repeated full, narrow turns, in both directions, at high speed.<sup>191</sup> If this does not provoke freezing, double tasks can be added to the task. It is however often difficult to distinguish festinating steps that occur before freezing from pure festination without subsequent freezing of gait.<sup>215</sup> Supportive to differentiate voluntary stops from freezing of gait are the characteristics of freezing of gait<sup>215</sup>:

- A flexed posture with fixed flexion in the hip, knee and ankle joints
- Often a not complete 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*

### 6.8 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)*

#### 6.8.1 Modified Parkinson Activity Scale (M-PAS)

To assess the quality of either bed or chair transfers, the M-PAS parts Chair Transfer and Bed Mobility are recommended (see 6.6.1).

#### 6.8.2 Timed Up & Go (TUG)

The TUG is recommended to assess the velocity of a chair transfer combined with gait and turning (see 6.6.2).

#### 6.8.3 Five Times Sit to Stand (FTSTS)

The FTSTS is a quick measure of balance during a chair transfer (see 6.6.5).

### 6.9 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 have been identified*

### 6.10 Measurement tools for Physical Capacity

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

- Six-minute walk with Borg Scale: *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)*

\*In pwp who are not troubled by freezing

### 6.10.1 Six-minute Walk (6MW)

In pwp without freezing of gait, the six-minute walk (6MW) allows for objective assessment and evaluation of submaximal level of functional exercise capacity and walking distance, as well as for prolonged observation of gait (6.7.3). The measurement of heart rate or level of overall fatigue using the Borg 6-20 scale (see 6.10.2) is optional for assessing exercise tolerance functions. 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 treadmill.<sup>252</sup> The GDG recommends using the 6MW when the physical capacity of the pwp is questioned, i.e. when low levels of activity are reported on the PIF. When the 6MWD is reduced, a thorough search for the cause of the impairment is warranted, e.g. by assessing muscle strength. In addition, referral onwards for the following tests may then be helpful: pulmonary function, cardiac function, ankle-arm index, muscle strength, nutritional status, orthopaedic function, and cognitive function.<sup>252</sup> When the 6MWD is used to evaluate change in endurance, the absolute change should be reported (e.g. the pwp walked 50 m farther). The GDG recommends using the Borg 6-20 when performing the 6MW (Ch. 6.10.2).

### 6.10.2 Borg 6-20

For many pwp, physiotherapy treatment includes exercising, be it supervised or not. The Borg 6-20 is a measure for perceived exertion.<sup>255</sup> It is a valid measurement tool to determine the exertion intensity, showing good correlations with physiological criteria such as heart rate, also in healthy middle-aged and elderly persons.<sup>256;257</sup> Although the validity, reliability and feasibility of the Borg 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. Just before the cooling down of their exercising, pwp are asked to give a score to their muscle fatigue and breathing, ranging from 6 (no exertion at all) to 20 (maximal exertion). The GDG also recommends using the Borg 6-20 when performing the 6MW.

### 6.10.3 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. The time needed to rise from a 43 centimetre chair is measured (see 6.6.5).

## 6.11 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 6.11a). Sensitivity 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 to be 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 a single 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 decisions should not be made on these cut-off scores alone. The full clinical picture of the specific pwp is required for decision making, taking in account:

- Cut-off scores for fall risk (Table 6.11a)
- Presence of other predictors of fall risk (Table 6.11b)
- Presence of freezing of gait<sup>194;258</sup>
- Presence of dementia<sup>259</sup>
- Reduced attention and executive function<sup>260;261</sup>
- Environmental factors, e.g. overload of furniture in the pwp's home, slippery floors, loose rugs, poor lighting and inadequate footwear
- Adverse events of medication (Appendix 8), e.g. causing hallucinations
- Presence of comorbid conditions, e.g. diabetic neuropathy
- Frequency and safety of activities carried out during the day (e.g. multitasking)

Table 6.11a Cut-off scores supportive for identifying pwp at fall risk

Tool	H&Y	Cut-off score	Sensitivity (%) , AUC or OR
History of falls		≥ 1fall/yr ≥ 2 falls/yr	77% <sup>156</sup> , OR 5.4 <sup>258</sup> ; AUC 0.77, OR 4.0 and 1.54 for each additional fall <sup>157</sup> 68% <sup>156</sup>
ABC	mean 2.9 mean 2-3 mean 2.8	<69% < 76% < 80%	93% <sup>178</sup> 84%, AUC 0.76 <sup>230</sup> OR 0.06 for non-fallers <sup>180</sup>
DGI	2-3 mean 2-3 1-4	≤ 22 < 19 ≤ 19	89% <sup>262</sup> 68%, AUC 0.76 <sup>230</sup> 64% <sup>263</sup>
FGA	1-4	15/30	AUC 0.80 <sup>264</sup>
BBS	3 1-4 1-4 mean 2.4 2-3	< 44 ≤ 45 ≤ 47 ≤ 47 ≤ 54	68%, AUC 0.85 (50x more likely) <sup>230</sup> 64% <sup>263</sup> 72%, AUC 0.79 <sup>264</sup> 79% AUC 0.87 (6 months) <sup>265</sup> 79% <sup>262</sup>
5TSTS	1-4	>16sec	75%, AUC 0.77 <sup>266</sup>
TUG	2-3 1-4 mean 2.8	≥ 7.95s ≥ 8.5s ≥ 16s	93% <sup>262</sup> 68% <sup>263</sup> OR 3.86 <sup>180</sup>

\*Abbreviations: H&Y, Hoehn & Yahr; 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?

Table 6.11b Predictors for future fall risk identified in multiple regression analyses

Tool	Odds ratio
Dementia	6.7 <sup>157</sup>
Urinary incontinence	5.9 <sup>267</sup>
Loss of arm swing	4.3 <sup>157</sup>
Falls in preceding 3 months	3.0 <sup>189</sup> for ≥ 2 falls future 2 yrs
UPDRS item Rapid alternating tasks	2.2 <sup>160</sup>
Each disease year	1.3 <sup>157</sup>

Cut-off scores provide information on fall risk in the near future (e.g. 6 months) rather than further on.<sup>265</sup>

### 6.11.1 Falls Diary

To pwp who have previously fallen (reported in the PIF) or who are likely to be at fall risk, the GDG recommends providing the Falls Diary.<sup>169;175</sup> The falls diary gives insight into the frequency and circumstances of falling. The pwp is asked to mark daily on the diary whether a fall has occurred. If falls have occurred, the pwp is asked to provide information on the circumstances. Specifically the circumstances will support decision making towards the selection of interventions or adjustment thereof. The GDG recommends asking the pwp to fill in the circumstances with support of their caregiver.

### 6.12 How to describe treatment goals?

History taking and physical assessment has provided all information to decide whether there is an indication for physiotherapy (see 6.1). If so, 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 the to the pwp most bothersome problem and negotiates to decide upon the main goal, the time frame and the level of outcome. To enhance pwp's motivation, the GDG advises to also establish sub goals. These cover a shorter time period (e.g. two weeks instead of 12 weeks, as for the main goal) and are a requirement for achieving the main goal (e.g. to evaluate the ability to increase levels of physical activity, or to carry out certain exercises). The GDG advises to describe SMART goals<sup>268</sup>:

- ✓ Specific: avoid wide goals
- ✓ Measurable: using one of the recommended measurement tools
- ✓ Attainable: do both the pwp and physiotherapist expect its feasibility
- ✓ Relevant: to this specific pwp, within the field of physiotherapy
- ✓ Time-based: when should this goal be achieved?

#### 6.12.1 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.<sup>269</sup> It allows for formulating the goal on five levels of

outcome: the optimum result, two above and two 2 below (Fig. 6.12). Although no psychometric data are available for its use in pwp, given its usefulness in neurorehabilitation in general as well as in psychogeriatric patients, the GDG advises its use in pwp.<sup>270;271</sup> The GAS is not applied to every sub goal, but just to the main goal. For communication purpose, the GAS scoring form can be used together with change scores collected with measurement tools (see Ch. 6.13).

Regarding the feasibility of goals, the GDG would like to stress to keep in mind that pwp are, by the nature of the disease, losing function<sup>272</sup>

**Fig. 6.12 Example of using the GAS for describing goals**

Attainment Level	Goal of the person with Parkinson's disease	Level Reached*
<i>Much less</i> than the expected level	In 12 weeks, I will be able to exercise at moderate intensity for 20 minutes on three days a week	
<i>Somewhat less</i> than the expected level	In 12 weeks, I will be able to exercise at moderate intensity for 30 minutes on three days a week	
<i>At the</i> <b>Expected level</b>	In 12 weeks, I will be able to exercise at moderate intensity for 30 minutes on five days a week	
<i>Somewhat better</i> than the expected level	In 12 weeks, I will be able to exercise at moderate intensity for 30 minutes on > than five days a week	
<i>Much better</i> than the expected level	In 12 weeks, I will be able to exercise at moderate intensity for > 30 minutes on > five days a week	

\*in this example to tick after 12 weeks

### 6.13 Which tools can be used to monitor change?

Has the treatment changed the limitations addressed? Are the set goals met? In addition to the GAS, several tools which are recommended for structured and objective history taking or physical assessment can also be used for evaluation (Table 6.13). Data on change provided with these tools:

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

It is of utmost importance that the data acquired with these tools are always related to the goals set. Parkinson's disease is progressive. Therefore, goals can be related to improvement, but also to maintain a status quo or to reduce the speed of deterioration. Only in relation to the goals, information on change collected with measurement tools makes sense.

#### 6.13.1 When is change real change?

Each measurement brings along errors. Therefore, in order to speak of 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 6.13.). However, different studies have provided different MDC or SDD values for each tool. 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, may also influence the MDC and SDD values. Therefore, caution should always be taken when reporting on change. Moreover, an MDC or SDD may be a statistic real change, 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 change.<sup>273</sup> However, there is no consensus on the best method to determine MIC.<sup>13</sup> Moreover, of none of the tools recommended an MIC is available. Therefore, the GDG recommends that the evaluation of change is based on an MDC or SDD and should always be accompanied with the patient perception of the change using the GAS.

**Table 6.13 Minimal detectable change scores for Parkinson measurement tools**

Tool	Core area(s)	N in study	H&Y	Mean at baseline	Minimal Detectable Change
ABC	Balance	37	1-4 (median 2)	70%	13% <sup>274</sup>
		24	1-3	91%	12% <sup>275</sup>
DGI	Balance	72	1-3	21.6/24 points	3 points (13.3%) <sup>276</sup>
BBS	Balance	37	1-4 (median 2)	50/56 points	5 points <sup>274</sup>
		26	1-3	54/56 points	3 points* (5%) <sup>277</sup>
10MWT	Gait: comfortable speed	37	1-4 (median 2)	1.16m/s	0.18 m/s <sup>274</sup>
		26	1-3	-	0.19m/s* <sup>277</sup>
10MWT	Gait: fast speed	37	1-4 (median 2)	1.47m/s	0.25 m/s <sup>274</sup>
TUG#	Balance, Gait, Transfers	6	1-4	9,89 s	0.67 s <sup>278</sup>
		24	1-3	10.6s	4,85 s <sup>275</sup>
	72	1-3	11.8s	3.5s (29.8%) <sup>276</sup>	
	37	1-4 (median 2)	15s	11s <sup>274</sup>	
6MW	Gait	26	1-3	-	1.63* <sup>277</sup>
		37	1-4 (median 2)	316m	82m <sup>274</sup>

H&Y, Hoehn & Yahr; \*Smallest Detectable Difference, SDD; # when goal is velocity

## 6.14 Red and orange flags for physiotherapy

### 6.14.1 Red flags

Impairments that urge the necessity to advise a pwp to anticipate medical consultation:

- Mental impairments: illusions (misinterpretations of real stimuli), hallucinations (spontaneous false sensations), impulse control disorders (e.g. taking extra non prescribed medication, repetitive activities, obsession for food, gambling, excessive sexual drive)
- Complex motor complications, such as unpredictable on-off periods, severe dyskinesias and OFF-state dystonia (painful cramps or spasms)
- Other medical problems for which physiotherapy would be contraindicated in general, e.g. severe cardiovascular impairments
- Using anything with an electrical component in pwp with DBS, as it can affect the DBS battery if close enough to the chest where the battery is implanted. Therefore, short and microwave treatment, ultrasound treatment and electrical stimulation (e.g. using TENS or interferential) are currently contraindicated no matter how innocuous until more evidence is provided.<sup>279</sup> Also, no manual pressure should be applied near the wires.

### 6.14.2 Orange flags

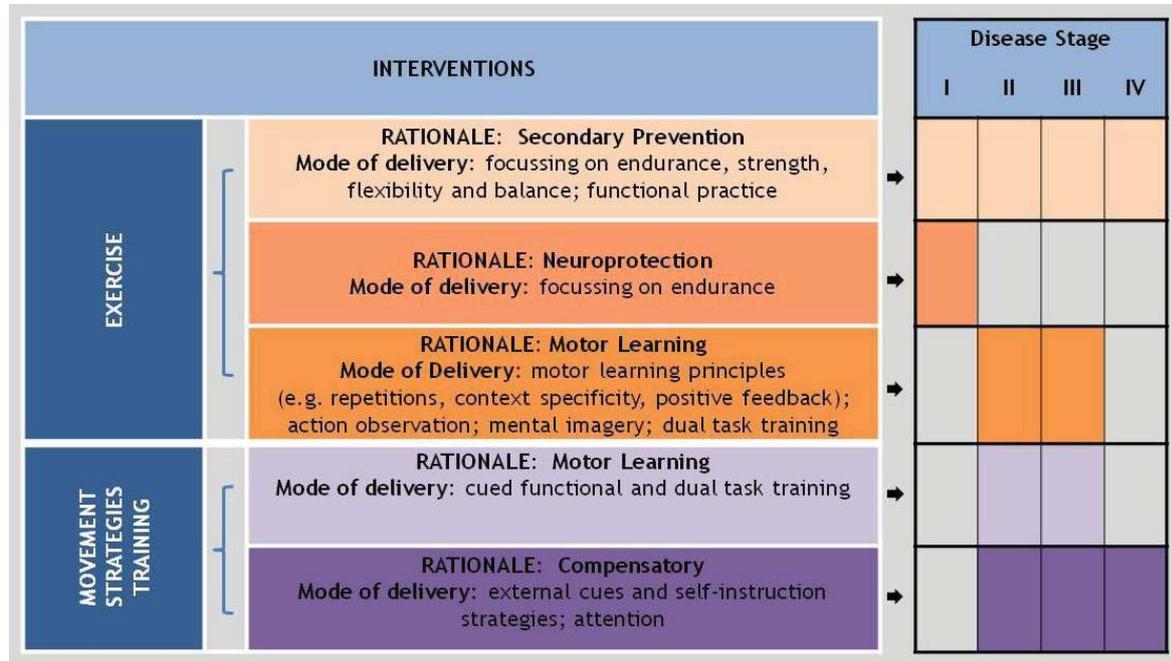
Impairments that may influence physiotherapy assessment or (decisions in selecting) interventions and may urge to advice for a pwp to anticipate medical consultation before starting physiotherapy treatment:

- Parkinsonisms (see Ch 2.4.1)
- Mental impairments which may influence the pwp's ability to understand, learn and adhere to the intervention: cognitive impairments, psychosis, persistent depressed mood, dementia and severe hallucinations,
- Severe general fatigue which may influence both treatment plan and schedule, but can be circumvented, e.g. by spreading out exercises over the day, increasing number of rest periods during treatment, adjustment of treatment dose and/or type of exercise.
- Severe pain
- General orange flags for physical exercising in relation to blood pressure and heart rate, e.g. beta-blocker therapy: reduces the maximal oxygen consumption (VO<sub>2</sub>max) 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
- Duodopa pump: pwp should be encouraged to take care with the pump when doing exercises
- In pwp with freezing and severe axial rigidity problems, it is advised that hydrotherapy is always individually supervised

## Chapter 7. Rationale to the interventions

Physiotherapy interventions, targeting impairments and limitations experienced by people with Parkinson's disease (pwp), can be divided into exercise and movement strategy training (Fig. 7.1)<sup>134</sup>

Figure 7.1 Physiotherapy interventions for pwp



This figure is adopted with permission from Rochester, Nieuwboer & Lord, 2011<sup>134</sup>

### 7.1 Exercise

Exercise entails 'a physical activity that is planned, structured and repetitive, and has the goal of increasing or maintaining physical fitness for the purpose of conditioning any part of the body'.<sup>280</sup> By addressing muscle strength, endurance, flexibility or balance, or a combination thereof, it aims to ensure sufficient physical capacity and balance, and prevent secondary complications.<sup>127</sup> Moreover, it may even induce neuroprotection (Ch. 4.5 Disease modification). When exercise is mimicking daily life activities and skills (i.e. functional exercise), it also aims to induce motor learning (Ch. 7.3). Physiotherapists can advise or coach pwp to do exercises and coach pwp toward a more active lifestyle, taking advantage of the pwp's preferences and sports history.

#### 7.1.1 Promotion of physical activity

Pwp are encouraged to strive for the WHO recommendations for physical activity (Table 6.3.1). Physical exercise over and above the recommend minimum is expected to lead to reduced premature mortality and further health improvements, particularly in regard to cardiovascular health. In the general population, behavioural and social approaches are effective to increase levels of physical activity.<sup>281</sup> Therefore, the GDG recommends using the 5A's model (Table XX 5A's model), e.g. to gain insight in barriers and preferences aiming to support pwp implementing an 'exercise regimen' they enjoy doing into their ADL. Depending on the pwp' preferences, impairments in functions and activity limitations, and options in the community, pwp can be supported to continue, or return to playing sports they enjoy doing, to implement a home exercise program, or to participate in an (Parkinson) exercise group. However, in many old people, walking at moderate speed in an urban context and taking the stairs instead of the elevator is likely to be the most feasible change in physical activity for old people.

#### 7.1.2 Type and Intensity

The optimal type and intensity of exercise interventions for pwp at different stages of the disease are not clear.<sup>282;283</sup> More likely, they will never be clear, as the limitations, possibilities and preferences of pwp vary widely. Therefore only general recommendations can be provided: large before small muscle group

exercises; multiple-joint exercises before single-joint exercises; and higher-intensity before lower-intensity exercises.<sup>284</sup>

In general, exercise is under dosed. Therefore, the GDG recommends using the Borg 6-20 scale for perceived exertion. During exercise targeting physical capacity, a moderate to hard intensity of physical exercise is aimed for. This is reached at Borg score 12 to 14. Pwp reporting a Borg score of 9 (very light) are advised to increase intensity, whereas pwp reporting a Borg score of 19 (extremely hard) are advised to slow down. For safety reasons, pwp using beta-blockers are advised to not cross a score of 14.<sup>285</sup>

Both to optimise pwp' motivation and for optimal training effect, the GDG recommends progressive exercise training. Regarding strength training, be it concentric or eccentric, the progression can be realised in increase of power, speed or number of repetitions, with the exercise intensity progressing from 60% to 80% of the 1 repetition maximum.<sup>283;284;286</sup> Regarding aerobic exercise, progressing can be in the duration of exercising and in the % of the maximum heart rate (HRR) at which is trained: from 40-60% for a moderate level to 60-80% for a vigorous level.<sup>286</sup> Pwp reach their VO<sub>2</sub>max sooner than their healthy contemporaries. Nevertheless, when no severe mental impairments are present (e.g. impairments in cognition, attention, personality and fear), they can be trained to increase their physical capacities equal to their contemporaries.

In elderly, functional-task exercises compared to resistance exercises have comparable effects on strength, but are more effective at improving functional task performance.<sup>287;288</sup> Therefore, the GDG recommends, if feasible, functional-task exercises, unless the pwp prefers resistance exercises.

### **7.1.2 Safety**

Pwp reach their VO<sub>2</sub>max sooner than their healthy contemporaries.<sup>289;290</sup> This should however not withhold them from physical exercise. In addition, up to 50% of pwp may have an inadequate heart rate increase during submaximal 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 should be tuned individually. Finally, limitations with keeping balance should be taken in account when designing a home exercise program.

### **7.1.3 Reducing pain experiences**

If pain is not medication related, physiotherapeutic intervention may be indicated. The intervention, based on the mechanisms of pain, will address pain education (e.g. using the book Explain Pain by Butler & Moseley<sup>291</sup>) including explaining the influence of fear, and the importance of staying physical active. Treatment may include:

- Exercising including range of motion exercises and postural adjustments for musculoskeletal and neuropathic pain; graded increase of activity; time-dependent exercising, instead of pain-dependent: agree upon steps on forehand
- Pain relieve through TENS and manual therapy
- Relaxation
- Peripheral desensitization techniques
- Motor imagery and mirror therapy
- Cognitive strategies
- A Visual Analogue Scale for pain may be used for evaluation

However, none of these have been evaluated in pwp. The GDG recommends 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.

### **7.1.3 Reducing respiratory limitations**

Inspiratory muscle training aims to improve pulmonary function and perceived dyspnoea<sup>292</sup>, and expiratory muscle strength training programmes aim to generate adequate respiratory pressure for coughing to clear foreign materials thus protecting the airways<sup>293;294</sup>. Both techniques sustain characteristics of voice production to enable good communication, as well as preserving respiratory and swallowing functions<sup>208;212;292-294</sup>.

## 7.2 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’.<sup>295</sup> Three phases can be distinguished: I) The *Early* or *Fast Learning phase* in which considerable improvement can be seen across several sessions of practice; II) The *Intermediate* or *Slow Learning phase* in which the skilled behaviour is thought to require minimal cognitive resources and to be resistant to interference (enabling dual tasking) and the effects of time; III) The *Late* or *Retention phase* in which the motor skill can be readily executed after long delays without further practice on the task. These processes involve several brain networks and their dynamic interactions. These networks are composed of loop circuits formed by the fronto-parietal cortices, the basal ganglia and the cerebellum.

### 7.2.1 Optimising motor learning

The ability to carry out complex tasks and negotiate complex environments (inducing dual tasking) relies upon automaticity which is dependent on intact basal ganglia function. Therefore, in rehabilitation, it is reasonable to believe that motor learning of skills rather than repetitive use of one simple movement produces a more pronounced change in the neural circuitry through cortical reorganisation. General principles to optimise motor learning can be addressed in physiotherapy (Table 7.2.1a&b).<sup>296-300</sup>

**Table 7.2.1a General principles to optimise motor learning**

- Many repetitions, adjusted to the specific pwp’s goals and capacity
- Balance between practice and rest, e.g. advise the pwp to go for a rest after a practice period, as the pwp chooses
- Positive feedback on performance and objective results related to the goal (Table 9.2. “5As model”)
- Context specificity, e.g. by practising at the pwp’s home
- Aim for optimal patient motivation, e.g. through patient preferred goals and attention and awareness during training

**Table 7.2.1b An example of how to apply general principles to optimise motor learning, starting with 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"> <li>➤ Daily practice, of which three times a week physiotherapist-supervised, rising from the specific chair</li> <li>➤ 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.</li> </ul>
Medium	Improve generalisability to comparable tasks	<b>Task variability</b> Stable context  From a set to a <b>random order</b> of tasks	<ul style="list-style-type: none"> <li>➤ Daily practice, of which three times a week physiotherapist-supervised, rising from the specific sofa, but also from other chairs, couches or beds of different heights, seat softness and with or without arm rests</li> <li>➤ Start with daily the same order of tasks, than continue to a different (random) order each day</li> </ul>
High	Improve generalisability to comparable tasks and under different circumstances	<b>Task and context variability</b>  From a set to a <b>random order</b> of tasks	<ul style="list-style-type: none"> <li>➤ Daily practice, of which three times a week physiotherapist-supervised, rising from the specific sofa, but also from other chairs, couches or beds of different heights, seat softness and with or without arm rests while talking to someone (a dual task)</li> <li>➤ Start with daily the same order of tasks, than continue to a different (random) order each day</li> <li>➤ Start with training in the on period, than continue with training in the off period</li> </ul>

**7.2.2 Parkinson's specific impairments**

Pwp can demonstrate altered motor learning even in the early stages of the condition. The basal ganglia, specifically the striatum, and cerebellum that are affected in pwp are critical for motor learning (automatisation phase). There are impairments in frontal, executive functions that influence motor learning by reducing working memory, attention, planning, problem solving, multitasking and initiation of actions.<sup>301</sup> This has implications for clinical practice (Table 7.2.2).

Pwp benefit from practice, but they show more variable clinical benefits and generally need for higher dosages of training to achieve comparable results than their contemporaries.<sup>302-305</sup> The first stage of learning where skills are acquired may be preserved, but the later stage skill automaticity and retention may be reduced.<sup>306</sup> In addition, pwp can also develop anxiety, depression and fatigue that further reduce the capacity for motor learning.

Specific interventions may improve motor skills and motor learning in pwp)<sup>306</sup>, including cued functional training, dual-task training (e.g. a combination of cognitive and motor training), action observation and mental imagery training, supported with feedback on results and performance. The potential for learning is believed to diminish over the disease course, therefore the greatest benefits may be gained at the mild stage (H&Y2-3).<sup>299;307-309</sup> A structured, graded approach allowing explicit learning and sufficient repetition is generally recommended to facilitate a change in activity performance.<sup>310;311</sup>

**Table 7.2.2 Parkinson induced impairments and their implications for physiotherapy**

<b>Impairments or changes in body functions</b>	<b>Implications for clinical practice</b>
Reduced retention and automaticity of motor skills <sup>301</sup>	Consider motor learning in early stage <sup>299</sup> ; Context specific training <sup>299</sup> Prolonged training at high frequency <sup>299</sup> Possibly improved by a rest after practice <sup>301</sup>
Reduced implicit learning (later stages) <sup>308</sup>	Focus on explicit learning* strategies Goal-directed task and information Enhance motivation and awareness
Reduced movement speed and amplitude	Use goal directed and task specific external information, focusing on large amplitude and high speeds movements <sup>299;312</sup> Use feedback to improve motor learning in the early stage
Impaired proprioception and related tactile and haptic sensory functions <sup>158</sup>	Provide intrinsic and extrinsic feedback (see Table 6.2.1) Focus on explicit learning
Cognitive impairments: decision making, planning, concentration	Start with motor learning training (easy task first) Use explicit learning strategies Feedback Goal directed action
Pain: reduces motor excitability of the motor cortex and thus reduces neuroplasticity	Adjust the type, load, frequency and duration of exercise to avoid pain; time-contingent learning. Advise pwp to talk to prescribing physician about pain to assess whether adjustments in medication can reduce pain
Fatigue	Focus on implicit learning* Adjust the type, load, frequency and duration of exercise to avoid fatigue
Reduced motivation caused by anxiety or depression	Enhance motivation (Ch. 6.1 Self-management) Enhance awareness Promote social activities Load task difficulty to promote positive rewarding

\*goal directed, conscious learning (explicit) versus unconscious learning (implicit)

**7.2.3 Motor learning through 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).<sup>313-315</sup> As a consequence, repetitive imagining 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 practice.<sup>316-318</sup>

Both strategies are largely based on response-produced sensory information and are believed to share the same neural mechanisms in the mirror neurons.<sup>319</sup> This system maps the sensory signals of action observation and motor imagery onto the same neuronal substrate involved in motor programming and execution of what had been observed or imagined. However, in pwp, brain activity during motor imagery is different from that of their healthy contemporaries<sup>320</sup> Therefore, results may differ.

### 7.3 Movement strategy training

The rationale of movement strategy training is to compensate for the deficits with the internal (auto-matic) generation of behaviour. It includes cueing, attention and self-instruction strategies\*. When the strategies are applied to activities, they aim induce motor learning, possibly by training compensatory pathways.<sup>299</sup>

\*During the development of these guidelines, it came to the attention of the GDG that the term cognitive movement strategy, whilst now widely used in the literature, is confusing to practitioners. Therefore, they will now be referred to as self instruction strategies. **or rather call these 'Strategies for complex motor sequences'?** They still comprise of compensatory strategies that require the pwp to understand how to break down a complex task in simple components and carry the components with attention.

#### 7.3.1 Cueing and attentional strategies

Due to the basal ganglia disorder, the internal control required to time and scale automatic and repetitive movements is reduced. External cues and attentional strategies are used to 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).<sup>321</sup> They can be auditory, visual or tactile (Table 7.3.1). By using these cues, movements can be controlled more directly via the premotor and parietal cortex and the cerebellum, with little or no involvement from the basal ganglia.<sup>322</sup>

Attentional strategies are distinct from cueing as they need to be self-generated and provides 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.<sup>323</sup> Often they are used in combination.

Not all pwp benefit from using cues. As yet, there is no insight into which pwp benefit and which do not. However, if a patient benefits from cues, this will be visible after one single training session.

Both cueing and attentional strategies can be one-off, merely to initiate movement, or continuous, to prevent freezing of gait.

Table. 7.3.1 Examples of cueing and attentional strategies

Strategy	Examples
Visual cueing	Strip(s) of tape on a floor: to step over Someone's foot: to step over Laser beam(s): to step over
Auditory cueing	Using a metronome: walk on the beat Pwp preferred music: walk on the beat
Tactile cueing	continuous vibration of a wrist band: walk on the vibration
Attention	Thinking about taking big steps Choosing a point of reference to walk towards Making wide turns (arc versus pivot), lifting knees high up
Proprioceptive	Rocking from left to right before starting to walk Taking a step backwards before starting to walk Rocking bend knees from left to right before rolling over Rocking trunk forwards and backwards before rising from a chair

#### How to select and apply cueing strategies?

The effectiveness of cues is patient-specific. Selection will be guided by the targeted activity, the context and the preference of the pwp. It is the role of therapists to explore the possible effectiveness of several cues with their pwp, starting off with the patient'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 (by

means of lines of coloured sticky tape on the floor) or 3-dimensional visual cues (by means of thin wooden sticks) may give a large difference in effectiveness.

Additionally, in rhythmic cues the optimal frequency needs to be explored. 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 (e.g. from the bathroom to the kitchen) than for walking outdoors (e.g. when walking to a shop). To determine the appropriate frequency, the number of steps needed to perform the 10-meter walk test or the 6-minute walk test can be used as a baseline. The frequency of beats (steps per minute) can be increased or decreased in order to evaluate the effect on gait. Caution should however be taken in freezers. Whereas increasing cueing frequencies above baseline values may have a gait-enhancing effect in non-freezers, it may provoke freezing episodes in freezers.<sup>324</sup>

### 7.3.2 Self-instruction strategies

Complex motor sequences, such as rising from a chair and rolling over in bed, can no longer be performed automatically. With self-instruction strategies they are broken down into simple components. The components are performed in a defined sequence with conscious control, and if required also guided using external cues. In using self-instruction strategies the need for dual tasking during complex (automatic) activities is minimised.<sup>133;147;149;325</sup> A possible neuroanatomical explanation for the success of self-instruction strategies is that the visual cortex can access motor pathways via indirect projections involving the cerebellum, rather than the basal ganglia. To obtain the optimal result, the training of these activities should be task-specific, within the context of functional tasks of everyday living.<sup>133</sup> Often, self-instruction strategies are combined with external cues (e.g. a visual anchor point when standing up) and exercises to increase physical capacity (e.g. muscle strength exercises of the lower extremities in order to improve rising from a chair).

#### How to apply self-instruction strategies?

The selection and training of the self-instruction strategy follows a structured stepwise approach and uses mental or motor imagery (Table 7.3). 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 patient. To obtain the optimal result, the training should be task-specific and within the natural performance context. If required, preferred and effective, external cues can be used to guide the movement.

**Table 7.3 Steps to consider when applying self-instruction strategies**

<ol style="list-style-type: none"> <li>1. Observe the pwp in performing the activity: analyse limited components</li> <li>2. Agree with the pwp about the most optimal (mostly four to six) movement components</li> <li>3. Summarises the sequence of components: use key phrases, support with visuals</li> <li>4. Physically guide the pwp in the performance of the selected components</li> <li>5. Ask the pwp to rehearse the consecutive components aloud</li> <li>6. Ask the pwp to use a motor imagery of the consecutive movement components</li> <li>7. Ask the pwp to carry out the components consecutively, consciously controlled</li> </ol>
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## Chapter 8. General treatment considerations

### 8.1 Patient-centredness

Patient-centredness is increasingly recognized as a crucial element of quality of care.<sup>326;327</sup> It is also central to this guideline. It has been defined as *providing care that is respectful towards and responsive to individual patient preferences*.<sup>327</sup>

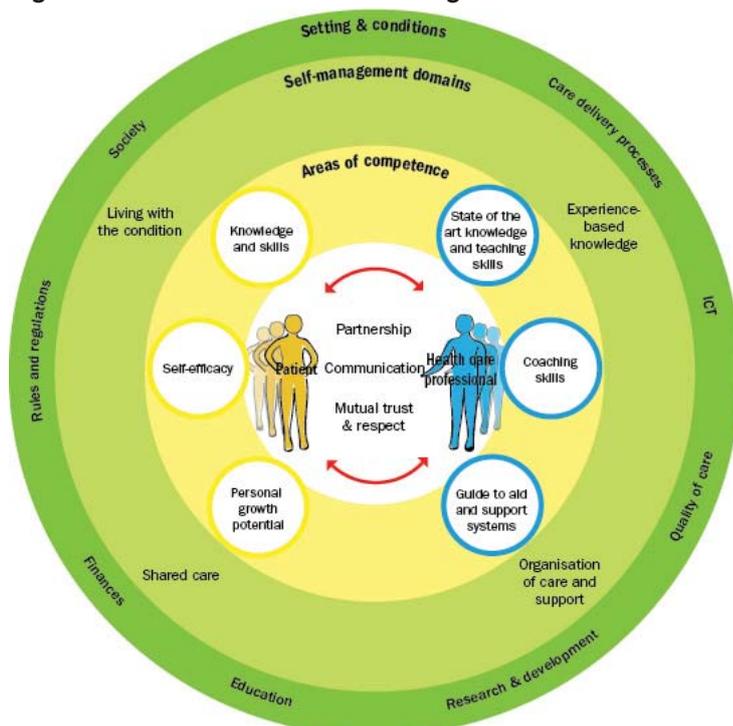
A patient-centred approach is warranted, as crucial to behavioural interventions like physiotherapy is that the interventions fit with the needs, motivation and abilities of the people with Parkinson's disease (pwp) and their carers.<sup>5;69</sup> Due to the complexity of the disease and the wide scope of possible deficits and limitations to be addressed, it is important that the pwp is empowered to make an informed choice of priorities and interventions.<sup>69</sup> By promoting the pwp (and carer) to self reflect, prioritise and apply problem solving skills related to issues of activity performance and participation, also self management can be stimulated.<sup>328</sup>

### 8.2. Support for self-management and adherence

Respect for the pwp's autonomy is essential to good physiotherapy, as is a focus on his or her self-management and adherence to physiotherapy recommendations. One of the most common used the definitions of self-management is: *An individuals' ability to cope with symptoms, treatment, physical, psychosocial and social consequences and lifestyle changes to a chronic condition*.<sup>329</sup> Self-management 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.<sup>330</sup> Evidence suggests that collaborative care programmes not only improve the quality of care and lead to better outcomes for patients with chronic conditions, but also lower societal costs.<sup>331</sup>

Self-management requires knowledge, skills and self-efficacy, as well as social support (e.g. from the family) and professional support (e.g. from the physiotherapist). Fundamental to successful self-management strategies are the elements of good communication, partnership, trust and respect between the pwp, the carer and the health professional as visualised in the Generic model of self-management developed by the Dutch Federation of Patient Organisations and the Dutch Institute for Healthcare Improvement (Fig. 6.1).<sup>332</sup>

Fig.6.1. Generic model of self-management



As suggested by the name 'self'-management, it is essential 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 Parkinson's specific knowledge and skills and self-efficacy. 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. Self-management can further be supported by learning from the experiences of their peers. Moreover, personal and environmental factors that can increase or limit self-management need to be taken into account, e.g. socioeconomic background and access to information technology.

Given the scope of this guideline, self-management will concentrate on physical activity 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 and sleep. Ideally, the full spectrum of self-management is overseen by the care co-ordinator. 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 and medical professionals. Moreover, health care 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. It can change as a result of professional acting. 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 therapists' view)

The number of sessions and frequency required to support self-management is patient 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 care professionals are expected to make all decisions (passive patients), can be expected to require more intensive and prolonged support.

### **8.2.1 Behavioural change**

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 disease.<sup>333</sup> General strategies effectively applied in a wide range of chronic conditions have been shown to promote behavioural change, including motivational interviewing and self-determination theory (SDT).<sup>334-340</sup>

Requirements for behavioural change, which can be supported by physiotherapists, are:

- Knowledge: the pwp has sufficient integrated knowledge about his or her problem;
- 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-esteem: the pwp considers him or her worth the effort.

When these are achieved, the human need for autonomy (the pwp feels ownership), competence (the pwp feels capable to change) and relationship (the pwp feels connected) will be met. The 5As model, a patient-centred model frequently used for enhancing behavioural change, provides a framework to address these needs in clinical practice.<sup>338</sup> The 5As meaning Assess, Advise, Agree, Assist and Arrange. A detailed overview of what to target and examples of how to achieve this, using the 5As model, is provided in Table 8.2.<sup>127;298;339;341-345</sup>

#### ***How might physiotherapists motivate pwp for 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 people feel good about exercise, because of the exercising itself. Unfortunately, often this is not the case when people start to exercise, and at this stage, extrinsic motivation is required. For example, a friend or an understanding physiotherapist should be

identified so they can provide positive feedback. Another source of extrinsic motivation might be found in a fun exercise group, where the sense of fun and belonging acts as motivation to attend again and to participate regularly.

Table 8.2. Enhancing self-management and adherence using the 5As model

	What	Examples how to	
ASSESS	Current activities & strategies	Let the person talk	
	A S S E S S	Main problem (using GAS)	- use single, open-end questions
	Beliefs & motivation: <i>Importance of change; Readiness to change and to accept advise; Self-efficacy; Willingness to be a partner in care</i>	- endorse question-asking - reflect and summarise what the pwp says	
	Carer & social support	Show empathy (verbal and non-verbal behaviour)	
ADVISE	A change	Ask-Tell-Ask	
	The importance of being a partner in care	- ask what the person wants to know - tell the required information - ask whether this was the information looked for and whether other questions remain Supply individualised information (see XX 8.2.2)	
AGREE	Upon goals	Collaboratively set SMART* goals; suggest options: one short term (e.g. two weeks) and one long-term (e.g. three months)	
	Upon interventions Upon carer involvement	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	In anticipating barriers	Examine the gap between current behaviour and set goals	
	In using opportunities In correctly applying the intervention	Identify at least one barrier (e.g. 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, e.g. <i>If you use an external rhythm, you will be able to cross the street much more safely</i> Use autonomy-supporting phrases, e.g. <i>What type of external rhythm would you prefer, perhaps a metronome or your own music?</i> Link interventions to daily routines	
ARRANGE	Support and follow-up for guidance, motivation and evaluation	Supply materials & tools, e.g. an exercise diary or activity monitor Agree with pwp and carer upon when and how the carer may support, e.g. not to overload pwp with information Collaboratively agree upon ongoing contact and time to (intermittent) follow up, e.g. by telephone or a consult Communicate with the other healthcare professionals involved with that pwp, if the pwp agrees As long as necessary - i.e. 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	

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

### 8.2.2 Patient education

Providing information and advice is essential to optimise health literacy and to empower the patient (and the carer) to take an active role. Although patient education of a general type can be provided (Table 6.2), it should always be tailored to the needs and limitations specific for that person. The needs and limitations are identified during the history taking and physical assessment.

**Table 6.2. Recommended general contents of patient (and carer) education**

- Information on Parkinson's disease and Parkinson medication related to movement, e.g. the possible influence on gait, balance and transfers: what to expect (see Appendix 4);
- The patient's role in self-management: recognising and reacting adequately in case of (new) problems
- If physiotherapy treatment is required, explain the rationale of a selected physiotherapy intervention and the importance of adhering to this intervention;
- Referring to the patient association (national and European, [www.epda.eu.com](http://www.epda.eu.com)) for information, activities and contacts with peers.

Be aware of possible cognitive impairments such as impairments in attention, memory, planning and decision-making; it is important to tune into this condition, for instance by discussing only one subject at a time and keeping the information or advice short. Supplementary material such as brochures and websites can be used. Brochures can often be obtained from the national patient or physiotherapy associations. Also be aware that a pwp in the *off* state may not be as responsive as when *on*; this may be misinterpreted as cognitive impairment, whereas the cause of a slower response is due to lower medication levels.

### 8.2.3 Feasibility of goal and intervention

To assess 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 feasible.<sup>346</sup> Action plans can be phrased in such a way that patients have a confidence level of at least 7 on the 10-point scale that they will achieve the targets set.

### 8.2.4 Optimising short and long term adherence

Extrinsic motivation is the most important element to adherence in the short term.. Physiotherapists can encourage this by selecting goals (outcomes) of suggested therapeutic interventions that the pwp values highly. For example, if the intervention is through selected exercises, the physiotherapist encourages the pwp by telling them how well they are performing the exercises, and that the effort being used to manage their condition has been noted and is valued.

For adherence into the long-term however, intrinsic motivation is most important, i.e. experiencing the actual value of exercise, enjoying it and hence being motivated to continue<sup>335</sup>. The physiotherapist can promote this by supporting the pwp in selecting the optimal type, intensity and frequency of exercise, thus building on the pwp' ownership of his treatment. When treatment takes place within a team, it is very important that all members of that team aim for equal interaction with the pwp and collaborate with each other (e.g. be informed about each other's goals and interventions), to ensure optimal, patient-centred care. Remember that longer-term adherence may be achieved through non-person contact, but with regular physiotherapy review e.g. use of gaming systems like the Nintendo Wii or the X-Box Kinect systems (see below).

### 8.2.5 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 that pwp are informed that not all information on the internet and e-health applications are of equal quality. Moreover, not all information related to Parkinson's will be applicable to each pwp. A physiotherapist can help patients in identifying the more reliable internet sources, such as the EPDA website and the national resources from the Parkinson's

Organisations. E-health applications can be selected to use for e-coaching, e.g. using short message services (sms / text) reminders to perform their exercises, e-mail to use as communication for a check-up, and pwp and therapist shared online physical activity diaries or data from activity monitors to give pwp insight into their daily physical activity (did I achieve my personal goals?) and the physiotherapist in obtaining insight into adherence and the need for support.

Online health communities can be used to share experiences, exchange knowledge, and increase disease-specific expertise, but also bridge geographical distances and enable interdisciplinary collaboration across institutions and traditional echelons.<sup>347</sup> 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 each patient's health care team.<sup>347</sup>

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 internet.<sup>348</sup> 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. For patients without access to the internet, support of exercise through the use of a DVD can be considered, as well as the use of activity games (e.g. using Nintendo Wii or the X-Box Kinect).

#### **8.2.6 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 (e.g. in motivational interviewing), whether or not related to pwp specifically, 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 patient health communities is often available through the national patient associations. The European Patient Education Programme Parkinson's (PEPP) is a general self-management training, which focuses on patient education and psychosocial support, including elements of health promotion. This programme is developed by a multidisciplinary team of experts from Estonia, Germany, Italy, The Netherlands, Spain and The United Kingdom. Research (without the use of controls) has 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.<sup>349-351</sup> and in some countries, educational courses are provided.

#### **8.3 Considering fluctuations in daily functioning**

Response fluctuations should be taken into account when planning treatment sessions. Typically, limitations in activities will be most troublesome in off periods. Specific strategies to overcome the problems may first be taught in the on period, but if needed or used in the off periods it will eventually need to be mastered in the off periods. Physical capacity can be optimally trained when pwp are at their best, that is during the on periods. Because of regular patient contact physiotherapists are able to recognise response fluctuations at an early stage. The fluctuations can be partly corrected by an adjustment of medication. Therefore, when 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.

#### **8.4 Treatment site**

Physiotherapy takes place in the primary health care practice, the pwp' homes, a rehabilitation centre, a nursing home or a hospital. The choice of location is determined by the objectives of treatment, the preferences and abilities of the pwp, and the abilities of the physiotherapist. Limitations in activities are often related to the home environment. The learning of new skills is often task and context specific.<sup>149;352;353</sup> 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' 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, gait or balance 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.

### **8.5 Taking in account mental impairments**

Pwp show overall (cognitive) slowing, a greater reaction time variability, problems with planning and abstract reasoning, a reduced working memory, and a set-shifting impairment leading to decreased performance when attention needs to be divided.<sup>354;355</sup>

Therefore, the GDG recommends to take sufficient time, not only for the history taking and physical assessment, but also for the intervention sessions; limit the amount of instruction given during practising; discuss only one subject at a time and keep the information or advice short; and provide written and visual information for non-supervised exercises (see also Tables 7.4.2. 'Implications clinical practice' and 8.2 'The 5 A's model').

### **8.6 Individual or group treatment**

The choice of group or individual treatment depends on the treatment goal, the pwp's abilities and motivation and external factors, such as the availability of exercise groups. If personal goals are most prominent (e.g. improvement of transfers), or when strategies need to be mastered (e.g. cueing), individual treatment is most suited. The physiotherapist can provide specific instruction and attention and limit the degree of distraction by the environment. Group treatment is more suited for prevention and general improvement of physical capacity or gait, but may also target motor learning. It can be a means to make pwp more confident and support them in moving on to exercising on their own, at the gym, or in an exercise group for the elderly. Group therapy also allows pwp and their carers to learn from one another and have contact with fellow-sufferers. Finally, the social aspect of group treatment may increase subjective feelings of well-being and joy, and increase adherence to treatment. Depending on pwp-specific problems, the therapist may direct the pwp to general exercise group (for the elderly), or to a specific exercise group for pwp. Group size depends on the treatment goal and the level of functioning of the pwp in the group. Importantly, safety issues must be particularly monitored in group therapy. In general, a maximum of eight pwp is advised. The GDG would like to stress that also when group treatment is preferred, treatment goals need to be set and evaluated individually.

### **8.7 Carer Involvement**

The involvement of the carers (e.g. a relative or a friend) the overall care process and therefore in the physiotherapy treatment, is essential. 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, it is advised to ask pwp to bring their carer to at least the first visit, if they agree.

Moreover, carers can learn strategies to facilitate movement and help pwp practice and use the strategies they learnt. Physiotherapists can educate carer's to limit the number of instructions given at a time, break down movements and/or not to distract the pwp while walking. However, the GDG would like to stress that it is to the pwp to decide whether and, if so, how the carer will be involved and. Moreover, carers do not have to fulfil the role of a therapist.

### **8.8 Frequency, duration and length of the treatment period**

Evidence-based information on optimal treatment frequency (e.g. number of sessions a week), duration (session time) and length of treatment period is unavailable. They will depend on the treatment goal, the selected intervention, the potential of the pwp and the response to the treatment.

In general, based on the effective interventions of studies described in XX Chapter 10, to improve activity limitations, a treatment period of at least four weeks, at a high frequency (minimal 3 sessions a week) with sessions lasting 30 to 60 minutes is recommended. When cueing strategies are selected as intervention, during the first session it will become clear if using cues is beneficial for the specific pwp. When the goal is related to the improvement of physical capacity, treatment duration of at least 6 weeks is suggested for improvements in physical functions. However, behavioural changes will need longer. A frequency of five times 20 to 60 minutes exercising a week is suggested, depending on goals, preferences and feasibility. When feasible and safe, from the start, a combination of physiotherapist supervised and non-supervised sessions are made. Provided pwp are given adequate instructions, they can perform the

exercises on their own at home; therefore, a low treatment frequency (e.g. once a week to adjust the exercise program) may be sufficient. The GDG suggests to increase the number of unsupervised sessions and decrease the number of supervised sessions over time, and discuss this with the pwp at the start. Towards the end of a treatment period, pwp are supported towards increased non-supervised exercising. Good instruction and feedback on performance and goals is essential, as well as agreement on how to continue after the treatment period (see XX Table 8.2 'The 5A's model').

## 8.9 Evaluation, communication and after care

### 8.9.1 Evaluation

The GDG recommends evaluating:

- ✓ the pwp's understanding, performance, satisfaction and adherence of the physiotherapy intervention every session (Table 8.2. '5As: see ASSIST)
- ✓ 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 6.13), to support the GAS outcome. It is important to keep the circumstances of measurement stable, especially the location and time of measurement (Table 6.2.3). Doing so, it is important to keep in mind that pwp are, by the nature of the disease, losing function<sup>272</sup>

When treatment goals have been achieved, or when the physiotherapist takes the view that physiotherapy has no longer an additional value, the treatment will be discontinued. The treatment will also be discontinued if the physiotherapist expects the pwp to be able to achieve the treatment goals on their own (without therapeutic supervision).

Patient-centredness is a crucial element of quality of care and central to this guideline.<sup>326;327</sup> A valid instrument to measure patient-centredness in care for pwp is the Patient-Centered Questionnaire for Parkinson's Disease (PCQ-PD).<sup>356</sup> However, PCQ-PD is extensive and targeted at health institutes, not single care providers. Therefore, for the purpose of this guideline, an adaptation has been made which can be used to gain insight in the pwp's experiences with the physiotherapy care provided (Appendix 14).

### 8.9.2 Communication

At discharge, but also during the treatment period in case of prolonged treatment, the physiotherapist should inform the referring physician about, among other things, the (individually determined) treatment goals, the treatment process and the treatment outcome (table 8.9.2). 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' permission to contact this health professional aiming to, if needed, adjust the interventions to one other, taking in account the preferences of and strain on the pwp.

**Table 8.9.2 Recommendations for contents of communication with healthcare professionals**

- ✓ Relevant impairments in functions, limitations in activities and participation restrictions
- ✓ The overall treatment goal and sub goals
- ✓ Selected treatment modalities, period and frequency, including self-management support
- ✓ If the pwp has been treated according to the guidelines, and if not, on which points and why the treatment deviated from the guidelines
- ✓ The (expected) treatment effect
- ✓ If agreements or appointments are made for a check-up

*All preferably supported by data from appropriate measurement tools and their interpretation*

When during assessment or treatment psychosocial problems, 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. Finally, if required, assist in referral towards palliative care.

#### **8.9.1 Aftercare: 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 new and impairments and limitations can be expected, next to aggravation of the existing ones. However, physiotherapy intervention cannot be ongoing, and does not need to. Therefore, the GDG recommends to discuss and to agree with the pwp, as early as during history taking, upon how to continue after treatment termination. At discharge, pwp can be supported in their self-management by supplying tools such as an exercise diary, an activity monitor, visuals of exercises (e.g. printed or video), guidance towards community support groups and exercise classes. The GDG also recommends to discuss and agree upon ongoing contact and time to (intermittent) follow up (Table 8.2 '5A's' see ARRANGE): when to have contact and how. If for example a telephone or email is chosen, also agree upon who will originate the contact. Carers and, if applicable, home care professionals can be assisted in understanding movement related problems in pwp (Appendix 15). The GDG recommends revising home exercise programs every 3 months.

## Chapter 9. Graded recommendations

This chapter provides recommendations for or against the use of specific interventions described in Chapter 7. The recommendations aim to support decision taking when selecting the appropriate and pwp preferred intervention.

### 9.1 What treatment strategies improve the performance of walking?

#### 9.1.1 Treadmill training

Outcome	Intervention	Versus	H&Y	No of studies (total N pwp)	Average -duration - frequency -session time -total time	Overall effect (CI)	Evidence summary	Strength recommendation benefits	Remarks effects
Movement functions, Gait patterns: Walking speed	Treadmill	No treadmill	1-3	7 (153)	6-8 wks 2-3/wk 30-45 min	SMD 0.50 (0.17-0.84) <sup>357</sup>	Moderate	Strong for	Consistent effects, also most recent studies <sup>358-360</sup> ; progressive training and high intensities likely better outcomes
Movement functions, Gait patterns: Stride length	Treadmill	No treadmill	1-3	5 (95)	4-8 wks 2-3/wk 30-45min	SMD 0.42 (0.00-0.84) <sup>357</sup>	Moderate	Strong for	Small but consistent effects, also in most recent studie <sup>360</sup>
Movement functions, Gait patterns: Walking distance	Treadmill	No treadmill	1-3	2 (41)	4-8 wks 2-4/wk 30-45 min	SMD 357.57 (288.82-426.31)	Low	Strong for	Inconsistent results, also in most recent study <sup>358</sup>
Movement functions, Gait patterns: Cadence	Treadmill	No treadmill	1-3	4 (78)	4-8 wks 3/wk 30-45min	SMD 1.06 (-4.32, 6.44)	Low	Weak against	Inconsistent results, also in most recent study <sup>360</sup>
Functional mobility (5 step and stairs test)	Treadmill	No treadmill	1-3	2 (45)	6-8 wks 3/wk 40-60min	SMD 0.25 (-0,19-2,00)*	Low	Weak against	Inconsistent results
Capacity measure of changing and maintaining body position (BBS)	Treadmill	No treadmill	2-3	1 (31)	8 wks 2/wk 30 min	MD 8.29 (1.07-15.51) <sup>361</sup>	Low	Weak for	One study, many drop outs, intervention included also ROM exercises
UPDRS-motor	Treadmill	No treadmill	1-2	1 (20)	8 wks 3/wk 45 min	MD -0.10 (-7.96-7.76) <sup>361</sup>	Low	Weak against	Another more recent study showed equal results <sup>358</sup>

\*CI needs recalculation, will be smaller

*General considerations regarding treadmill training:*

- It is a safe and acceptable intervention<sup>357</sup>
- Effects are not associated with body weight support or loading<sup>362</sup>
- Most likely effects are dose dependent: training at higher MET or percentages of maximum heart rate is better<sup>121</sup>
- Not all pwp may have access to a treadmill

**9.1.1 Cueing**

**9.1.2 Dance**

**ETC.**

**AN UPDATED VERSION OF THIS GUIDELINE WITH ADDITIONAL TABLES TO FOLLOW MID OCTOBER**

# Appendices to the European Physiotherapy Guidelines for Parkinson's disease

## Appendix 1 Key questions & systematic literature search

Key question	Systematic literature search?
What treatment strategies improve performance of transfers?	Yes
What treatment strategies improve performance of manual activities?	Yes
What treatment strategies improve performance of balance?	Yes
What treatment strategies improve performance of gait ?	Yes
What treatment strategies improve performance of physical capacity?	Yes
What treatment strategies reduce pain?	Yes

Step	Aim	Search	Hits
1	Parkinson's*	"Parkinson Disease"[Mesh] AND "Parkinson Disease, Secondary"[Mesh] OR Parkinson OR 'Parkinson's disease' OR Parkinsonism	70,896
2	Physiotherapy**	"Physical Therapy (Specialty) "[MESH] OR "Physical Therapy Modalities"[MESH] OR Rehabilitation[MESH] OR Exercise[MESH] OR "Exercise Therapy"[MESH] OR "Resistance Training"[MESH] OR "Muscle Stretching Exercises"[MESH] OR "Breathing Exercises"[MESH] OR Physiotherapy OR "physical therapy" OR exercise OR rehabilitation	636,517
3	Combine 1 & 2	#1 AND #2	4,306
4	RCTs/CCTs*	(randomized controlled trial [pt] OR controlled clinical trial [pt] OR randomized [tiab] OR placebo [tiab] OR clinical trials as topic [mesh: noexp] OR randomly [tiab] OR trial [ti]) NOT (animals [mh] NOT humans [mh])	786,164
5	Systematic reviews	((("meta-analysis" [pt] OR "meta-anal*" [tw] OR "metaanal*" [tw] OR ("quantitativ* review*" [tw] OR "quantitative* overview*" [tw] ) OR ("systematic* review*" [tw] OR "systematic* overview*" [tw]) OR ("methodologic* review*" [tw] OR "methodologic* overview*" [tw]) OR ("review" [pt] AND "medline" [tw])) AND ("2008/01/01"[PDAT] : "2012/31/12"[PDAT]))	47,207
6	Guidelines	((("guideline" [pt] OR "practice guideline" [pt] OR "health planning guidelines" [mh] OR "consensus development conference" [pt] OR "consensus development conference, nih" [pt] OR "consensus development conferences" [mh] OR "consensus development conferences, nih" [mh] OR "guidelines" [mh] OR "practice guidelines" [mh] OR (consensus [ti] AND statement [ti]))) AND ("2003/01/01"[PDAT] : "2012/31/12"[PDAT]))	18,670
7	Combine 3 & 4	#3 AND #4	575
8	Combine 3 & 5	#3 AND #5	45
9	Combine 3 & 6	#3 AND #6	9
		("Palliative Care"[Majr]) AND #1	32
		("Patient's perspective" OR "Patient Satisfaction"[Mesh]) AND "Parkinson Disease"[Mesh]	97

\*equal to Cochrane filters: \*Higgins JPT, Green S (editors). Cochrane Handbook for Systematic Reviews of Interventions Version 5.0.2 [updated September 2009]. The Cochrane Collaboration, 2009. Available from [www.cochrane-handbook.org](http://www.cochrane-handbook.org); \*\* equal to Cochrane filter with terms added

## **Appendix 2 Graded classes of outcomes**

All outcomes reported in the CCTs used for this guideline are grouped on ICF domains and graded by the GDG for their importance

**TO FOLLOW**

## Appendix 3 Red flags for Parkinson's and their most likely diagnosis

More information can be found in the 2012 publication by MB Aerts MB et al<sup>16</sup>

Signs and Symptoms	Most likely diagnosis
Pattern of distribution <ul style="list-style-type: none"> <li>• Symmetrical</li> <li>• Asymmetrical*</li> <li>• Lower-body phenotype</li> </ul>	PSP, MSA CBD (very asymmetrical) VP
Course of the disease <ul style="list-style-type: none"> <li>• Rapid progression (H&amp;Y 3&lt; 5 years)</li> <li>• Stepwise progression</li> <li>• Remission</li> </ul>	PSP, MSA VP VP, drug-induced parkinsonism
Medication <ul style="list-style-type: none"> <li>• No/insufficient response to levodopa (&gt;1g per day of levodopa over 1 month)</li> <li>• Early/profound levodopa intolerance</li> <li>• Levodopa-induced dyskinesia*</li> <li>• Non-dopa responsive pain</li> </ul>	No response: PSP, CBD; partial response: MSA  DLB, VP MSA, DLB, VP All forms of AP
Tremor <ul style="list-style-type: none"> <li>• Asymmetrical pill-rolling tremor*</li> <li>• Irregular, jerky tremor</li> </ul>	seldom: MSA MSA, CBD
Myoclonus	MSA (outstretched fingers), CBD, PSP, DLB, SCA 2, PARK9
Dysphagia and dysarthria <ul style="list-style-type: none"> <li>• Early, severe dysarthria</li> <li>• Early, severe dysphagia</li> <li>• Dysphonia (spasmodic)</li> </ul>	AP PSP, MSA MSA
Dystonia <ul style="list-style-type: none"> <li>• Orofacial</li> <li>• Cervical</li> <li>• Axial                             <ul style="list-style-type: none"> <li>○ Pisa sign*</li> <li>○ Camptocormia*</li> </ul> </li> <li>• Limbs*</li> <li>• Generalized</li> <li>• Fixed</li> </ul>	MSA, PSP (blepharospasm), drug-induced MSA (antecollis), PSP (retrocollis)  MSA; Drug induced (both typical and atypical anti-psychotics, 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  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)
Pyramidal involvement	VP, MSA, PARK2,9
Ataxia (cerebellar)	MSA, SCA 2,3,17, Neuronal intranuclear inclusion disease

Signs and Symptoms	Most likely diagnosis
Gait and balance disorders <ul style="list-style-type: none"> <li>• Early postural instability</li> <li>• Use of walking aids/ wheelchair dependency*</li> </ul>	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"> <li>• Cortical</li> <li>• Polyneuropathy</li> </ul>	CBD Drug induced: amantadine, ntoxication (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"> <li>• Supranuclear palsy</li> <li>• Round-the-house-phenomenon</li> <li>• Saccadic eye movements                             <ul style="list-style-type: none"> <li>○ Delayed initiation</li> <li>○ Delayed execution</li> </ul> </li> <li>• Gaze impersistence</li> <li>• Square wave jerks</li> <li>• Dysmetria/overshoot</li> <li>• Nystagmus</li> <li>• Ocular apraxia</li> <li>• Oculogyric crisis</li> </ul>	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"> <li>• present early and severely</li> <li>• cold, discolored extremities ('cold hands sign')</li> </ul>	MSA, DLB (to a lesser extent) MSA
Cognitive dysfunction <ul style="list-style-type: none"> <li>• Early and profound</li> <li>• Relatively late*</li> <li>• Relatively mild cognitive dysfunction</li> <li>• Apraxia</li> <li>• Aphasia</li> </ul>	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"> <li>• Apathy (early)*</li> <li>• Disinhibition                             <ul style="list-style-type: none"> <li>○ Emotionally</li> <li>○ Pseudo-bulbar disinhibition</li> </ul> </li> <li>• Hallucinations, delusions</li> </ul>	PSP Early: PSP, to lesser extent: MSA PSP, CBD DLB (early)
Sleep disturbances <ul style="list-style-type: none"> <li>• REM sleep behavior disorder</li> <li>• Sleep apnea syndrome</li> <li>• Nocturnal inspiratory stridor</li> </ul>	PD, MSA, DLB MSA MSA

## Appendix 4 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); impairments in temperament and personality, e.g. mood and confidence (b126); impairments in energy and drive functions, e.g. reduced motivation and impulse control\* (b130); sleep impairments (b134); reduced attention (b140); reduced memory (b144); psychomotor impairments, e.g. moving and speaking slowly (b147); impairments in emotion, e.g. anxiety\* (b152); impairments in perceptual functions, e.g. reduced visuospatial perception and hallucinations\* (b156); impairments in higher level cognitive functions, e.g. in planning, decision-making and mental flexibility (b164); impairments in mental functions of language, e.g. verbal perseveration (b167)
- **b2: Sensory functions and pain:** seeing impairments, e.g. visual acuity\* (b210); dizziness\* (b240); impairments in smell (b255); 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, e.g. orthostatic hypotension\* (b420); reduced exercise tolerance\* (b455)
- **b5: Functions of the digestive system:** impaired ingestion, e.g. drooling, vomiting\* and impaired swallowing (b510); constipation\* (b525); reduced weight maintenance (b530)
- **b6: Genitourinary and reproductive functions:** impaired urination, e.g. (urge)incontinence\* (b620); impaired sexual functions, e.g. impotence and increased sexual interest\* (b640)
- **b7: Neuromusculoskeletal and movement-related functions :** reduced joint mobility\* (b710); reduced muscle power\* (b730); impaired muscle tone functions, e.g. rigidity and dystonia (b735); reduced muscle endurance\* (b740); impaired motor reflex functions, e.g. simultaneous contraction of antagonists (b750); Involuntary movement reaction functions, e.g. balance reactions (b755); reduced control of voluntary movements, e.g. dysdiadochokinesia, reduced 'motor set' causing starting problems and reduced or absence of internal cues causing problems in automated, sequential movements (b760); impaired involuntary movement functions, e.g. bradykinesia, (resting) tremor and dyskinesia\* (b765); impairments in gait patterns, e.g. asymmetry, freezing, reduced step length, velocity, trunk rotation and arm swing (b770); on/off periods\* (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:

- **d1: Learning and applying knowledge:** acquiring skills (d155), writing (d170), solving problems (d175) and making decisions (d177)
- **d2: General tasks and demands:** undertaking multiple tasks (d220), carrying out daily routine (230), Handling stress and other psychological demands (d240)
- **d3: Communication:** speaking (d330), producing non-verbal messages (d335), writing messages (d345)
- **d4: Mobility:** changing body position (d410), maintaining body position (d415), transferring oneself (d420), carrying, moving and handling objects (d430-d449), walking and moving (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) and 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) and economic life (d860-d879)
- **d9: Community, social and civic life:** community (d910), recreation & leisure (d920), religion (d930) & political (d950)

### Environmental factors:

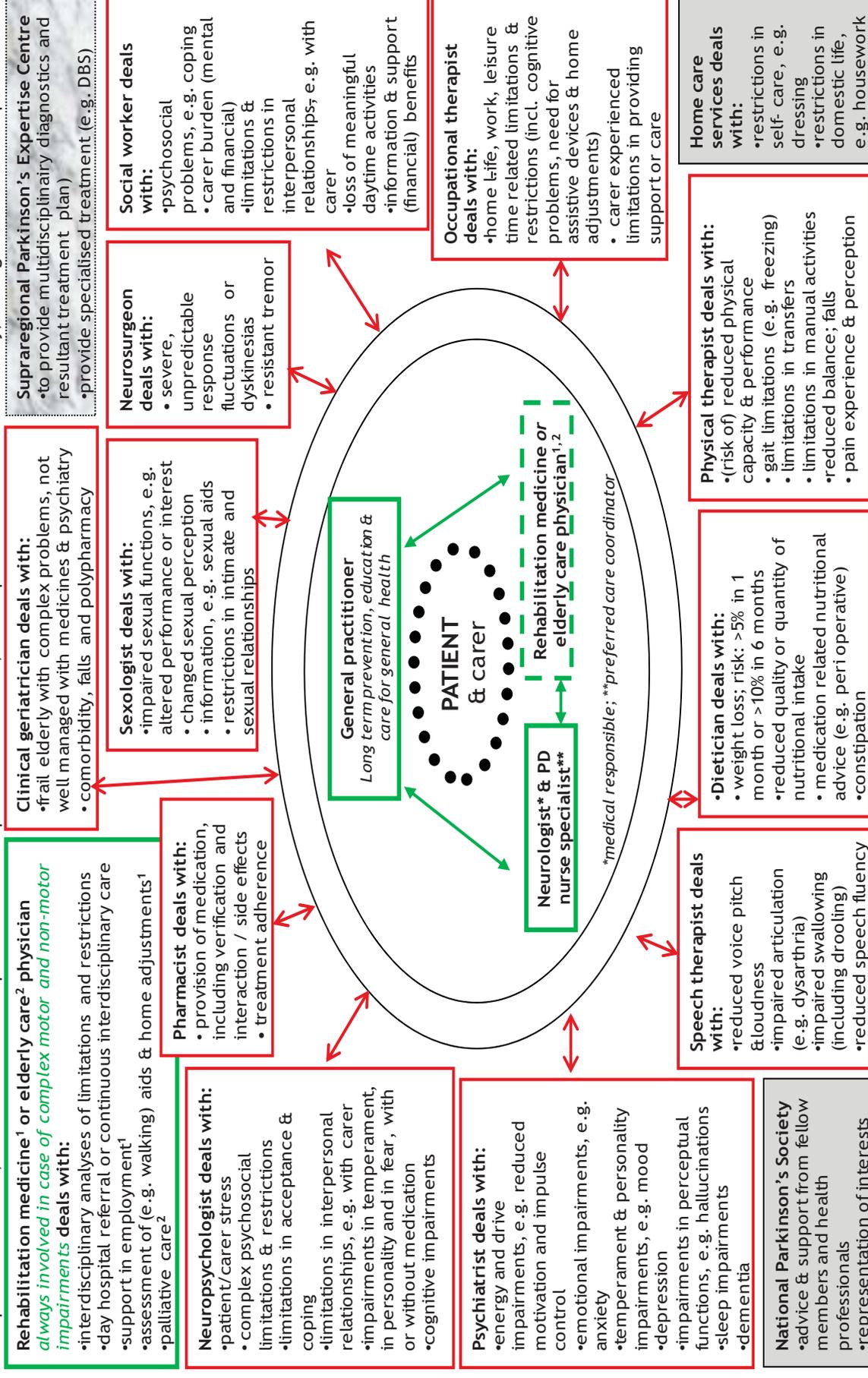
**e1: Products and technology**, e.g. drugs, assistive devices, financial assets; **e2: Natural environment and human-made changes to the environment**, e.g. population density, light intensity; **e3: Support and relationships**, e.g. family, friends, colleagues, health professionals; **e4: Attitudes**,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

### Personal factors#, e.g.:

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

## Appendix 5 Model for Parkinson care: health professionals and referral criteria

The model presents 'optimal care'. Initially developed by 19 Dutch professional associations<sup>3</sup>, adapted by the GDG. **Health professionals in red are only involved when indications for referral are met**, whereas **health professionals in green are always involved**. Most likely, there will be local or national differences in task descriptions. Moreover, often not all health professionals are present. Therefore, it is important to collaborate locally, aiming to ensure all responsibilities are covered.



## Appendix 6 Self-management: Patient information

Self-management means that you take responsibility for dealing with the problems Parkinson's creates to the best of your ability. Given the scope of this guideline, we will concentrate on physical activity and movement related activities. However, this should be only one part of the focus of your self-management. Other things to consider include adherence to medication, nutrition, speech 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 if and 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, there are also some things you can do for yourself, such as:

1. Exercising regularly
2. Recognising the time when you may need to visit a physiotherapist
3. Getting the best out of your visits to a physiotherapist

### 1. Exercising regularly

People with Parkinson's disease tend to be one-third less active than their contemporaries. 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 coronary heart disease, type 2 diabetes and osteoporosis. Therefore, try to exercise regularly.

#### *Some general advice for keeping active:*

- 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 time periods, such as 3 times 10 minutes.
- Choose types of exercise you like, as this makes it easier to stick with it. In Table 1, several types are provided.
- To keep fit and healthy, you need more than just one style of exercise. For example, try some exercise that helps you build muscle strength and endurance on one day, then something that improves the condition of your heart and lungs the next day. Add exercise of a type that keeps your joints flexible, plus something to improve day-to-day function, such as walking and keeping your balance.

## Self-management: Patient information - page 2 of 3

- Choose the style of exercise that suits your physical capabilities. For example, some people like playing a sport whilst others need to exercise while sitting or lying down.
- 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 (e.g. go for a outdoor walk to the local shops rather than driving, or walk up and down the stairs after breakfast)
- If you can exercise with others, this offers social support that helps you to keep motivated. If there is a (Parkinson's specific) exercise group near where you live, consider joining.

### 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 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 falls and near falls
  - 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, and in some cases, 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* and hand over a copy of the Quick Reference Cards (page XX-XX of this guideline).

## Self-management: Patient information - page 3 of 3

### 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 the guide on the next page to help you organise your thoughts as well as the Pre-assessment Information Form (PIF, Appendix 7).

#### *At your visit:*

- Above all, be honest, tell how you feel, ask for further explanation when 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 (e.g. 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 healthcare 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. Collaboratively negotiate and agree upon the ultimate treatment goal and a realistic plan: What do you want to achieve, and by when?
  2. Collaboratively plan when you should have a follow-up visit with the physiotherapist. 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.
  3. When you cannot adhere to the exercise plan, discuss the problems with the physiotherapist. Try and agree upon adjustments that will help you continue with some activity.
  4. Remember that you need to keep active for as long as possible, so agree upon how to continue (at home) when your course of treatment is finished.
  5. Finally, agree upon what should be communicated to your referring physician.

## Appendix 7 Pre-assessment information from (PIF)

Please fill in this 3-page form before you visit your physiotherapist the first time. It gives you (and your carer) the chance to think about what problem you would like the physiotherapist to address. This information is essential for your physiotherapist as it helps him or her build a picture of what you consider your main problem(s), as well as your physical capability.

Date:	Your name:
-------	------------

### Your physiotherapy goal

1. What problem(s) would you like to work on first?
2. In what way have you tried to tackle these problem(s)?
3. How effective were these methods?
4. What would you like your physiotherapist to do for you?
5. Any other information you want your physiotherapist to know about?
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?

- 0 No  
0 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?

- 0 No  
0 Yes

9. How afraid are you of falling over?

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

## Pre-assessment information from (PIF) - page 2 of 3

### Freezing of gait

Freezing is the feeling of your feet being glued to the floor. Sometimes it is accompanied with 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. *Before answering question 10, please, first watch the video on freezing of gait at [XXX link to website](#)*

10. Did you experience “freezing episodes” over the past month?

0 No

0 Yes

### Physical activity

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

Activities	Total time spent over the past 7 days
Walking (ground level or on a treadmill)	minutes:
Walking uphill, upstairs, running	minutes:
Bicycling (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?

0 *More active this week*

0 *Same*

0 *Less active this week*

**Pre-assessment information from (PIF) - page 3 of 3**

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
<b>Walking</b>	walking indoors		
	walking outdoors		
	turning		
	start walking		
	climbing and descending stairs		
	walking while performing dual tasks		
	walking through narrow passages		
	stop walking		
<b>Transfers</b>	turning in bed		
	getting in or out of bed		
	getting in or out of a car		
	getting in or out of a chair		
	getting on or off a toilet seat		
	picking up an object from the floor		
	getting up from the floor		
	getting on or off a bicycle		
	getting in or out of a bath		
	getting on or off a toilet seat		
<b>Manual activities</b>	household activities		
	personal care, such as dressing and washing		
	moving an object		
<b>Physical functions</b>	easily out of breath		
	muscle weakness		
	stiffness		
<b>Pain</b>	pain		

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

## Appendix 8 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
<b>Levodopa:</b> L-dopa	Transformed into dopamine in the brain <i>(Most effective symptomatic Parkinson medication)</i>	Reduces bradykinesia and rigidity. No effect on resting tremor, axial symptoms (e.g. speech, gait and balance impairments). No effect on motor complications.	Hypertonia; orthostatic hypotension, cardiovascular dysfunction, nausea (commonest side effect), headache, gastrointestinal dysfunction. <i>Long term:</i> response fluctuations, dyskinesias, dystonia, confusion, hallucinations, sleep disorders, visual hallucinations.
<b>Dopamine agonists:</b> 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 (primarily in young patients). <i>Long term:</i> alike levodopa, but much less
<b>Amantadine</b>	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
<b>MAO-B inhibitor:</b> 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)
<b>COMT inhibitors:</b> 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). <i>For adjunctive use with carbidopa/levodopa in case of end-of-dose motor fluctuations.</i>	Dyskinesias, cognitive impairments, cardiovascular complications, neuropsychiatric complications, nausea, diarrhoea, urine discolouration, liver injury (Tolcapone).
<b>Anticholinergics:</b> 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
<b>Beta-blockers:</b> Propranolol	<i>Unknown</i>	<i>Unknown effect on tremor</i>	Bradycardia*

## Appendix 9 Measurement tools considered for recommendation

On the following pages, psychometric properties and feasibility for use in pwp of all measurement tools that the GDG considered for recommendation in this guideline are provided. In alphabetical order: first the included, than the excluded tools.

Included measurement tools	Excluded measurement tools
<ul style="list-style-type: none"> <li>• 10 Meter Walk Test (10MWT)</li> <li>• Activities Balance Confidence (ABC) Scale</li> <li>• Berg Balance Scale (BBS)</li> <li>• Borg Scale 6-20</li> <li>• Dynamic Gait Index (DGI)</li> <li>• Falls Efficacy Scale International (FES-I)</li> <li>• Freezing test Snijders &amp; Bloem</li> <li>• Functional Gait Assessment (FGA)</li> <li>• Goal Attainment Scaling (GAS) - goals evaluation form</li> <li>• History of falling</li> <li>• Modified Parkinson Activity Scale (M-PAS)</li> <li>• New Freezing of Gait Questionnaire (NFOGQ)</li> <li>• Patients Specific Index PD (PSI-PD)</li> <li>• Push and Release Test (P&amp;R Test)</li> <li>• Six Minute Walk Distance (6MWD)</li> <li>• Timed Get-up and Go (TUG)</li> </ul>	<ul style="list-style-type: none"> <li>• 2-Minute step test</li> <li>• Balance Evaluation Systems Test (BESTest)</li> <li>• Freezing of Gait Questionnaire (FOGQ)</li> <li>• Functional Reach (FR)</li> <li>• Global Perceived Effect (GPE)</li> <li>• LASA Physical Activity Questionnaire (LAPAQ)</li> <li>• Lindop Scale</li> <li>• Mini Balance Evaluation Systems Test (Mini BESTest)</li> <li>• Movement Disorder Society's (MDS) revision of the UPDRS (MDS-UPDRS)</li> <li>• Nine Hole Peg Test</li> <li>• Parkinson Activity Scale (PAS)</li> <li>• Parkinson's Disease Questionnaire (PDQ-39)</li> <li>• PHONE FITT</li> <li>• Physical Activity Scale for the Elderly (PASE)</li> <li>• Pull Test</li> <li>• Purdue Pegboard Test</li> <li>• Survey of Activities and Fear of Falling in the Elderly (SAFFE)</li> <li>• Tinetti Performance Oriented Mobility Assessment (POMA) , Gait (G) and Balance (B)</li> <li>• Unified Parkinson's Disease Rating Scale (UPDRS)</li> <li>• WALK-12 Questionnaire</li> </ul>

<b>Abbreviations and explanation of terminology:</b>	
<b>AUC</b>	AUC, area under the ROC curves indicates accuracy to discriminate: 0 to 100, with cut-off scores >0.9, excellent; 0.70-0.90, adequate; <0.70, poor <sup>13</sup>
<b>Capacity (ICF)</b>	Executing tasks in a standard environment, indicating the highest probable level of functioning in a given domain at a given moment
<b>Ceiling effect</b>	The tool is not sensitive enough to assess good functioning people as many people score the highest score: the tool items may be too easy
<b>Cronbach's <math>\alpha</math></b>	Cronbach's alpha: coefficient of internal consistency of results across items within the test; cutt-off scores: $\alpha \geq 0.9$ excellent, $\geq 0.8$ good, $\geq 0.7$ acceptable, $\geq 0.6$ questionable, $\geq 0.5$ poor, and $< 0.5$ unacceptable.
<b>Concurrent validity</b>	Measure for correlation of the tool to another (validated) tool, measured at (approximately) the same time, using Spearman's or Pearson's rho (r). A form of criterion validity (see also predictive validity)
<b>Convergent validity</b>	Degree to which the scores of tools which theoretically are the same relate. A form of construct validity; see also discriminative validity
<b>Current use</b>	Based on results of the European guideline survey: low= $<10\%$ ; intermediate= $<10-35\%$ , high= $>35\%$
<b>Discriminative validity</b>	Degree to which scores of tools which theoretically are different can be discriminated. A form of construct validity; see also convergent validity
<b>Floor effect</b>	The tool is not sensitive enough to assess badly functioning people as many people score the lowest score: the tool items may be too difficult
<b>ICC</b>	Intraclass correlation coefficient, measure for intra-rater (test-retest) and inter-rater reliability; cut-off scores: $> 0.89$ , excellent; $0.80-0.89$ , good; $0.70-0.79$ moderate; $<0.69$ , poor
<b>ICF</b>	International Classification of Functioning, Disability and Health
<b>LOA</b>	Limits of agreement: represent mean difference and 95% limits of agreement between two measurements, i.e. the 95% limits include 95% of differences between two measurement.
<b>MCIC</b>	Minimal Clinical Important Change: changes that are meaningful to patients
<b>MDC</b>	Minimal Detectable Changes: smallest minimal change falling outside the measurement error
<b>MCID</b>	Minimal clinical important difference: see MCIC
<b>Performance (ICF)</b>	Executing tasks in the current environment, describing what an individual does in his or her current environment
<b>k</b>	Weighted Kappa: agreement beyond that what be expected by chance; cut-off scores: $\leq 0$ =no agreement; $0.01-0.20$ =slight; $0.21-0.40$ =fair; $0.41-0.60$ =moderate; $0.61-0.80$ =substantial; $0.81-1.0$ almost perfect <sup>363</sup>
<b>r</b>	Correlation coefficient, with cut-off scores $>0.6$ , excellent; $0.30-0.60$ , adequate; $<0.30$ , poor; see concurrent and predictive validity
<b>Predictive validity</b>	The extend to which the tool predicts the future score on another (validated) tool. A form of criterion validity (see also concurrent validity)
<b>ROC</b>	Receiver operating characteristic: a graph showing the sensitivity (y-axis) versus 1-specificity (x -axis) for all possible cut-off points
<b>SDD<sub>diff</sub></b>	Smallest detectable difference between two raters (1.96 x $\sqrt{2}$ x error): when a patient is scored by two different raters, and the scores differ $> SDD$ , the patient is likely to have improved/ deteriorated
<b>SEM</b>	Standard error of measurement: the standard deviation of the sampling distribution estimating the precision: how are repeated measures with the same tool distributed around the "real" score
<b>Sensitivity</b>	Proportion of patients with the problem (e.g. falls, balance problems) who test positive
<b>Specificity</b>	Proportion of patients without the problem who test negative

5 Times Sit-to-Stand (FTSTS)

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Capacity measure of Changing and maintaining body position (i.e. balance)	Balance measure: time needed for 5 times sit to stand	Discriminative validity fallers vs non-fallers, H&Y 1-4, >16s (AUC 0.77, sens 0.75, spec 0.68) <sup>266</sup> Moderate to good concurrent validity: BBS r=0.71, 6MWT r=-0.60, ABC r=0.54 <sup>266</sup>	Excellent Interrater reliability: ICC=0.99 Moderate test-retest reliability ICC=0.76 <sup>266</sup>	Unknown in pwp	Assessment time 2 min; Required materials : stopwatch, 43cm chair; Current use unknown  Benefits: Quick measure for balance & leg strength  Drawbacks: not widely used yet; not for evaluation

10 Meter Walk Test (10MWT)

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Capacity measure of Walking (i.e. gait)	Time in seconds required for 10 meter walk: velocity (m/s) for comfortable and fast speed; assistive devices can be used; also possible in shorter distances at home, e.g. a 6MW	Concurrent validity UPDRS ADL, r=0.41 <sup>364</sup> ; comfortable speed accounted for 23% of variance in UPDRS motor and total scores <sup>364</sup> Good convergent validity comfortable speed with Posturo-Loocomotor-Manual Test scores (r=0.76) <sup>365</sup>	Excellent test-retest reliability: comfortable speed, ICC=0.96; fast speed, ICC=0.97 <sup>274</sup> Good test-retest reliability comfortable speed: ICC=0.87 <sup>366</sup> ; walking speed, ICC=0.8, and step frequency ICC= 0.80 <sup>277</sup>	H&Y1-4: MDC <sub>95</sub> for comfortable speed 0.18 m/s (mean baseline 1.16 m/s); MDC <sub>95</sub> for fast speed 0.25 m/s (mean baseline 1.47 m/s) <sup>274</sup> H&Y 1-3: MDC <sub>95</sub> 0.19m/s <sup>277</sup>	Assessment time 5 min; Required materials: stopwatch, marked pathway of ≥ 12 m (10m plus 2m at end for deceleration); Current use >35%  Benefits: next to velocity assessment, the 10MWT allows for assessment of step and stride length, thus useful for cueing intervention  Drawbacks: large space required

NOTE: different methods of conducting the 10MWT have been described (e.g. regarding number of trials and calculation average)

Activities Balance Confidence (ABC) Scale

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Performance measure of Changing and maintaining body position (i.e. balance)	Questionnaire (interview or self-report), level of self-confidence: 16 ambulation activities, 11 point ordinal scale: 0%-100% (no to complete confidence). Total score: mean <sup>229</sup>	Good convergent validity: TUG r=-0.44; walking sub-scale of NUDS r=-0.48, p=0.02; item 1 (mobility) of the PD Quest-Short Form r=0.51 <sup>275</sup> Concurrent validity: BESTest: r=0.636 <sup>367</sup> ; BBS r=0.64; BESTest r=0.79; HY r=0.59; UPDRS motor r=0.52; UPDRS Total r=0.73 <sup>264</sup> , 6MW R <sub>2</sub> =17.1% <sup>180</sup> Adequate discriminative validity: 1) fallers vs non-fallers: mean HY3, ABC < 76% (AUC 0.76, sens 0.84, spec 0.62) <sup>230</sup> ; mean HY 2.8, ABC ≤80% (OR 0.06) <sup>180</sup> ; ABC <69% (AUC 0.82, sens 0.93, spec 0.67) <sup>178</sup> ; 2) pwp (HY 1-3) vs controls: sens 0.86, spec 0.52 <sup>368</sup> ; 3) between HY stages: HY1 (baseline 94.9 %) vs HY3 (baseline 81.0 %) <sup>275</sup> ; HY1.8 vs HY3.5 <sup>369</sup>	Moderate to excellent test-retest reliability: ICC=0.94; H&Y 1-4 <sup>274</sup> ; ICC=0.79; H&Y 1-3 <sup>275</sup> SEM= 4.01 <sup>275</sup>	H&Y 1-4, mean baseline 70%; MDC <sub>95</sub> 13% <sup>274</sup> H&Y 1-3, mean baseline 91%; MDC <sub>95</sub> 11.12 % <sup>275</sup>	Assessment time 15 min; No materials or costs materials; Current use 10-35%  Benefits: Parkinson's specific



Dynamic Gait Index (DGI)		Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Capacity	Observation balance when performing gait related activities	Adequate discriminative validity fallers vs non-fallers: HY 2-3, DGI $\leq 22$ = at risk (sens 0.89, spec 0.48) <sup>262</sup> ; HY3, DGI < 19 = at risk (AUC 0.76, sens 0.68, spec 0.71) <sup>230</sup> ; HY1-functioning) to 3. Total score max 24	Good test-retest reliability: ICC=0.84 <sup>276</sup> No systematic bias: LOA 2.9 to -3.0 points <sup>276</sup>	H&Y 1-3, mean baseline 21.6: MCD 2.9 points, (13.3% change) <sup>276</sup>	Assessment time 10 min; Required materials: shoe box, 2 cones, stairs, 6m walkway, 0.5 m wide; Current use 10-35%  Benefits: better discriminative validity for fallers vs non-fallers than TUG and BBS <sup>230;373;377</sup> ; can be combined with Functional Gait Assessment (FGA)  Drawbacks: need for specific material

Falls Efficacy Scale International (FES-I)		Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Performance	FES-I: 16-item questionnaire on self-confidence (efficacy) to avoid falling administered.	Unknown in pwp	Unknown in pwp	Unknown in pwp	Assessment time 10 min; No materials or costs; Current use 10-35%
Changing and maintaining body position (i.e. balance)	Interview or self-report. 4-point ordinal scale: 1 to 4 (highest fear to fall). Total score range 16 to 64.	Unknown in pwp	Unknown in pwp	Unknown in pwp	Benefits: validated in many European countries (www.profrane.eu.org); preferred in current scientific studies evaluating physiotherapy for pwp; provides better insight (more activities) than Short FES-I  Drawbacks: not validated in pwp
<i>NOTE: a Swedish version (FES(S)) differs in number of items and scoring options, suitable for the Swedish population; FES(S): Correlations with SAFFE <math>r=-0.74</math>; physical functioning (SF-36) <math>r=0.66</math>; fast gait speed, <math>r=0.63</math>; TUG <math>r=0.61</math>; UPDRS Parts II <math>r=-0.58</math> and III <math>r=-0.46</math>; comfortable gait speed, <math>r=0.30</math>; disease duration, <math>r=-0.28</math>; and age <math>r=-0.07</math>.<sup>138</sup>; Good test-retest reliability, ICC=0.87; SEM=12.3 points; Discriminative validity: lower scores females vs men and for pwp reporting previous falls, FOF or unsteadiness versus those not who do not<sup>138</sup></i>					

Freezing test Snijders & Bloem		Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Body functions: Gait pattern functions	Dichotomous measure to assess freezing: pwp are asked to repeatedly make rapid 360° narrow turns from standstill, on the spot, in both directions; if required add dual task	Sensitivity to provoke freezing 0.65; sensitivity entire battery of three trials (normal speed, fast speed, and with dual tasking) & turning variants (180° vs. 360° turns; both directions, wide and narrow; slow and fast) 0.74 <sup>191</sup>	Unknown in pwp	Not applicable: used for the assessment of freezing only	Assessment time 2 min; No materials or costs; Current use: unknown  Benefits: easy and best test available to provoke freezing  Drawback: does not always provoke freezing, double tasking may still need to be added (M-PAS Gait Akinesia)

**Functional Gait Assessment (FGA)**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Capacity measure of Changing and maintaining body position (i.e. balance)	Observation of balance when performing gait related activities: 10 items, 4-point ordinal scale: 0 (lowest level functioning) to 3	Good concurrent validity with BBS ( $r = 0.78$ ) <sup>264</sup> Discriminative validity fallers vs non-fallers: H&Y mean 2.5 FGA $\leq 15/30$ (AUC 0.80, sens 0.72) <sup>264</sup> ; H&Y 1.5-4, AUC 0.81 (ON) to 0.89 (OFF) <sup>245</sup>	Excellent test-retest reliability: ICC=0.91 <sup>264</sup> Excellent interrater reliability: ICC=0.93 <sup>264</sup>	Unknown in pwp	Assessment time 10 min; Required materials: shoe box, 2 cones, stairs, 6m walkway, 0.5 m wide; Current use: unknown  Benefits: in older people, higher discriminative validity for fallers, as well as more reliable than BBS <sup>264</sup> ; can be combined with DGI  Drawbacks: not widely used yet
<b>NOTE: Equates to the DGI: exclusion of walking around obstacles; addition of 3 sensory integration tasks: gait with narrow base of support, ambulating backwards, gait with eyes closed</b>					

**Goal Attainment Scaling (GAS) - goals evaluation form**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Patient-centred goals and treatment effects in all ICF components	Setting SMART goals with pwp (and carer); each goal 5 levels of outcome: optimum, 2 above, 2 below. Sum score, independent of number of goals, max 50 (all goals met)	Face validity: patient decides upon goals, what to evaluate Furthermore, unknown in pwp	Unknown in pwp	Unknown in pwp	Assessment time describing SMART goals 10 min; scoring level reached (evaluation) 1 min; No materials or costs; Current use <10%  Benefits: supports setting SMART goals  Drawbacks: may be time-consuming to describe a goal on 5 levels; especially when >1 goal is chosen
<b>NOTE: There is strong evidence for the reliability, validity and sensitivity of the GAS in physical and neurological rehabilitation in general<sup>276</sup>; in (frail) elderly, the GAS has adequate concurrent validity with ADL measures (<math>r = 0.45</math> to <math>0.59</math>)<sup>378-380</sup> Cognitive impairments may reduce its feasibility, validity, reliability and responsiveness<sup>270</sup>; GAS can detect clinically relevant change in geriatric day hospital care<sup>381</sup> and is more sensitive than standardized ADL measures<sup>379</sup></b>					

**History of falling**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Performance measure of Changing and maintaining body position (i.e. balance)	Questionnaire: interview or self-report, retrospective number of (near) falls, circumstances & causes; 2 to 13 questions	Face validity: based on optimal time span for recall (in elderly) <sup>382</sup> , specific vocabulary to optimise recall of falls in pwp <sup>277</sup> Retrospective falls report good discriminative validity to identify pwp at fall risk: $\geq 1$ fall in previous year (sens 77%, spec 60%), $\geq 2$ falls in previous year (sens 68%, spec 81%) <sup>156</sup> ; a fall in the previous year OR 4.0 <sup>157</sup> to OR 5.0 <sup>169</sup>	Unknown in pwp	Unknown in pwp	Assessment time 5-15 min; No materials or costs; Current use 10-35%  Benefits: past falls best predictor of future falls, designed for pwp  Drawbacks: retrospective, thus under reporting

**Modified Parkinson Activity Scale (M-PAS)**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Capacity of measure of functional mobility (i.e. changing body position and walking)	14-item observation performance functional activities: chair transfer (2 items); gait akinesia (6 items); bed mobility (6 items). <sup>2,42</sup> Quantitative and qualitative scoring on an ordinal scale from 0 (best) to 4 (impossible or dependent on help)	Face validity: based on core areas and limitations in activities described in evidence-based physiotherapy guidelines for pwp <sup>242;383</sup>	Excellent test-retest reliability ICC=0.93 in OFF, ICC=0.81 in ON; poor to excellent test-retest reliability subscores in ON and OFF, range ICC=0.41-0.91 <sup>2,42</sup> Good to excellent interrater reliability (Kappa 0.86 to 0.98) <sup>2,42</sup> Adequate internal consistency (PAS total score Cronbach's $\alpha$ 0.85; chair transfer 0.76; gait akinesia 0.75; bed mobility with/without covers 0.79/0.89) <sup>2,42</sup>	Unknown	Assessment time 30 min; Required materials: chair, cup, water, bed, bed cover; Current use 10-35%  Benefits: supportive for gaining insight in quality of movement specific for physiotherapy in pwp  Drawbacks: cannot be used for evaluation

**New Freezing of Gait Questionnaire (NFOGQ)**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Performance measure of Walking (i.e. gait)	Clinician-administered tool assessing clinical aspects of freezing of gait (FOG) and influence on QOL: three parts (9 items, total score range 0-28): Part I, dichotomous, to exclude patients without FOG; Part II (items 2-6, score range 0-19): FOG duration & frequency; Part III: impact of FOQ on daily life (items 7-9; score range 0-9) <sup>384</sup>	Poor concurrent validity with time spent frozen during TUG tasks (r=0.35) or number of FOG events (r=0.30). <sup>216</sup> ; for freezers only with H&Y (r=0.30) and falling (r=0.35) <sup>385</sup>	Good reliability between pwp and carers, ICC=0.78; Reliability pre-post video good for pwp (ICC=0.88) and excellent for carers (ICC=0.97) <sup>385</sup> High internal consistency: Cronbach's $\alpha$ 0.84, equal loading factors <sup>3,85</sup>	Unknown in pwp	Assessment time 10 min; Required materials: video; Current use: unknown  Benefits: a golden standard to assess FOG lacks; watching the video improves scoring FOG duration; items 2-6 provide a structured means to gain insight in the circumstances of freezing and are therefore included in the PIF  Drawbacks: usefulness for clinical practice unknown
<i>NOTE: Compared to the original, 6-item FOGQ, the N-FOGQ has extra the video explaining freezing, Part I (1 item), item 2 of Part II (to assess overall FOG, frequency only) and Part III; the 2 items for gait were removed</i>					

**Patients Specific Index PD (PSI-PD)**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Patient-centred problems in all ICF components	Questionnaire: interview & (partly) self-report to identify, prioritize and rate severity of patient relevant limitations	Good content validity: predefined list of impairments based on the KNGF guideline	High test-retest agreement for domains (core areas: 74%-82%), but with low Kappa values (0.43 to 0.60) as positive and negative outcomes were not equally distributed <sup>214</sup>	Unknown in pwp	Assessment time 10 min; No materials or costs; Current use <10%  Benefits: provides insight in quality of performance, targets for treatment  Drawbacks: assistance required for ranking
<i>NOTE: In this guideline, the items of this tool are included in the Pre-assessment Information Form (PIF)</i>					

**Push and Release Test (P&R Test)**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Body functions: Involuntary movement reaction functions	Measure reactions to external perturbation 1 trial, unexpectedly: clinician stands behind patient, hands against patient's scapulae; active or passive lean back; clinician suddenly removes hands. 5 point ordinal scale: 0 (recovers independently with 1 step of normal length and width) to 4 (falls without attempting a step or unable to stand without assistance	Good convergent validity with self-report history of falls ( $r=0.6$ ) <sup>386</sup> Discriminative validity fallers vs non-fallers: OFF phase sens P&R Test 89% vs Pull Test 69%; ON phase sens P&R Test 75% vs Pull Test 69%; OFF phase spec P&R Test 85% vs Pull Test 98%; ON phase spec P&R Test 98% vs Pull Test 83% <sup>387</sup>	Good inter-rater reliability: ICC=0.84 <sup>386</sup>	Unknown in pwp	Assessment time: 2 min; No materials or costs; Current use unknown  Benefits: Compared to Pull Test: more gentle & safer in frail pwp, more sensitive in pwp with low balance confidence (but less so for those with high balance confidence), higher inter-rater reliability (due to more consistent forces applied) and higher sensitivity than in the off phase (comparable in the on phase)  Drawbacks: not known by neurologists (communication)

**Six Minute Walk Distance (6MWD)**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Capacity measure of Walking (i.e. gait)	Distance in meters walked in 6 minutes, at fast speed, as a measure for functional fitness. <sup>252;388</sup> Assistive devices can be used if kept consistent from test to test; pwp should not exercise vigorously 2hr before the test and relax 10 min on a chair before starting the 6MWD (e.g. during history taking)	Good convergent validity: regular physical activity $r = -0.56$ , $R^2 = 0.32$ <sup>389</sup> ; H&Y $r = 0.38$ ; BBS $r = 0.64$ ; TUG $r = 0.64$ ; FOGQ $r = 0.43$ and UPDRS $r = 0.27$ <sup>390</sup> ; score accounted for 43% of variance UPDRS motor and UPDRS total <sup>364</sup> Decreases with disease duration: 173m HY3 vs HY1-1.5 <sup>73</sup> Impaired balance & fall risk influence 6MWD <sup>390</sup>	Excellent test-retest reliability: ICC=0.96 <sup>274</sup> , 0.93 <sup>391</sup> , 0.95 <sup>366</sup>	HY1-4, mean baseline 316m: MDC <sub>95</sub> 82 m <sup>274</sup>	Assessment time: 10 min; Required materials: stopwatch; $\geq 30m$ , flat, straight hard surface (indoors or outdoors), marked every 3m, with a bright coloured tape at the starting point; 2 cones to mark the turnaround points; pen, paper; Current use >35%  Benefits: can be used as treatment  Drawbacks: large space required and large variation in 'average' distances : 300-600m <sup>274;366;389;392;393</sup> . In COPD, a learning effect has been noted (improvement through practice) 6% <sup>252</sup>

**NOTE:** A 2MWD is insufficient in picking up the endurance problems in earlier stage pwp<sup>3</sup>

**Timed Get-up and Go (TUG)**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Capacity measure of functional mobility (i.e. changing body position and walking)	Time (s) to: rise from arm chair, walk (3m), turn and sit down to the chair; mobility, balance, walking ability, fall risk	Good convergent validity: BBS, $r=-0.78$ , fast gait speed, $r=-0.69$ ; comfortable gait speed, $r=0.67$ ; UPDRS total, $r=0.50$ <sup>371</sup> ; H&Y, $r=0.75$ <sup>394</sup> Adequate discriminative validity fallers vs non-fallers, at risk: HY 2-3, TUG $\geq 7.95$ s (sens 0.93, spec 0.30) <sup>262</sup> ; HY1-4, TUG $\geq 8.5$ s (sens 0.68, spec 0.53) <sup>373</sup> ; H&Y 1.5-4: AUC 0.68 (ON) to 0.80 (OFF), More accurate in OFF <sup>245</sup> ; HY mean 2.8, TUG >16s (OR 3.86) <sup>180</sup> ; early stage PD (AUC 0.65. sens 0.69; spec 0.62) <sup>160</sup> Score increases with disease severity: 2.5sec difference HY3 vs HY1-1.5 <sup>73</sup>	Poor to good test-retest reliability: ICC=0.85 <sup>274</sup> ; ICC=0.80 <sup>276</sup> ; ICC=0.69 <sup>275</sup> Excellent inter rater reliability experienced PTs and inexperienced PTs in ON phase, ICC=0.99; good in inexperienced PTs in OFF phase ICC=0.87 <sup>395</sup> SEM= 1.75 <sup>275</sup>	H&Y 1-4, mean baseline 15 s: MDC <sub>95</sub> 11 s <sup>274</sup> H&Y 1-3, mean baseline 10,6 s: MDC <sub>95</sub> 4,85 s <sup>275</sup> H&Y 1-4, mean baseline 9.88 s: MDC 0.67 s <sup>278</sup> H&Y 1-3, mean baseline 11.8s: MDC 3.5 s <sup>276</sup> H&Y 1-3, mean baseline unknown: SDD 1.63 <sup>277</sup>	Assessment time 5 min; Required materials: stopwatch, chair, track mark; Current use >35%  Benefits: well known & easy to administer; add TUG <sub>cog</sub> and TUG <sub>man</sub> for dual tasks  Drawbacks: Beware if treatment goal relates to safety and not velocity.

**2-Minute step test**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Body functions: Exercise tolerance functions	Measure for aerobic endurance (alternative to 6MWT): number of times knees are raised up to level of tape on wall in 2 min; in case of balance problems hands can be placed on the wall <sup>396</sup>	In HY1-3: due to fatigue 2min into 1 min test, mean score 23 steps <sup>397</sup>	Unknown in pwp	Unknown in pwp Current use unknown  Benefits: easy to administer  Drawbacks: not validated for pwp (only high test-retest reliability and discriminative validity in community dwelling elderly <sup>396;398</sup> )	Assessment time <5 min; Required materials: tape, stopwatch, wall; Current use unknown  Benefits: easy to administer  Drawbacks: not validated for pwp (only high test-retest reliability and discriminative validity in community dwelling elderly <sup>396;398</sup> )

NOTE: Alternative: 1 min stairs step test: safe and feasible test for lung problems, similar info to 6MW

**Balance Evaluation Systems Test (BESTest)**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Capacity measure of Changing and maintaining body position (balance) AND Body functions: Involuntary movement reaction functions	Observation of balance during 36 activities, e.g. sit to stand and stand 1 leg (from BBS), challenged gait tasks (from TUG, DGI), FR and dual-task items: 3 point ordinal scale: 0 (severe) to 2 (normal), max 108	Good concurrent validity with Mini BESTest $r=0.96$ <sup>399</sup> ; ABC ( $r=0.76$ ), BBS ( $r=0.87$ ), FGA ( $r=0.88$ ) <sup>264</sup> Good discriminative validity fallers vs non fallers, AUC 0.84; average score 19% difference; cut-off scores: 69% (sens=0.84, spec=0.76); 84% (sens=1.0, spec=0.39) <sup>399</sup> ; AUC 0.85, cut-off score 69% <sup>264</sup>	Mostly HY2-3 Good test-retest reliability ICC=0.88 <sup>264</sup> ; ICC=0.88 <sup>399</sup> ; Inter-rater reliability adequate for section II, ICC=0.79 and good for other sections ICC=0.91 <sup>399</sup> ; excellent for total ICC=0.96 <sup>264</sup>	Unknown in pwp  Benefits: discriminates fallers vs non fallers better than FGA and BBS <sup>264</sup>  Drawbacks: time consuming and complex; both activities & body function included in one balance score, difficult to interpret; not widely used yet	Assessment time 35 min; Required materials: shoe box, 2 cones, stairs, stopwatch, 0.5m wide walkway; Current use unknown  Benefits: discriminates fallers vs non fallers better than FGA and BBS <sup>264</sup>  Drawbacks: time consuming and complex; both activities & body function included in one balance score, difficult to interpret; not widely used yet

**Freezing of Gait Questionnaire (FOGQ)**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Clinician-administered questionnaire assessing clinical aspects of freezing of gait (4 items) and gait (2 items); 5-point ordinal scale: 0 (absence of symptoms) to 4	Adequate discriminative validity fallers vs non-fallers: AUC .0.73 (sens 0.75; spec 0.59) <sup>160</sup> ; accuracy 65% <sup>400</sup> Adequate concurrent validity with UPDRS ADL (r=0.42), walking capacity (r=0.41), ADL (r=0.45) <sup>364</sup> ; UPDRS ADL (r=0.43), UPDRS motor (r=0.40) <sup>384</sup> , correlations, better in off than on phase: UPDRS ADL (off r=0.66; r=0.40), UPDRS motor (off r=0.49, on r=0.28), and "freezing when walking" (off r=0.74, on r=0.43) <sup>401</sup>	Good test-retest reliability (10wks different); ICC=0.84 <sup>401</sup> ; Good inter-rater reliability: ICC=0.84 <sup>21</sup> ; Good to excellent internal consistency: $\alpha$ 0.89 to 0.96 <sup>401;402</sup> FOGQ(S) Excellent reliability, ICC=0.93 <sup>403</sup>	Unknown in pwp	Assessment time 5 min; No materials or costs; Current use 10-35%  Benefits: Item 3 ('Do you feel that your feet get glued to the floor while walking, making a turn or when trying to initiate walking (freezing)?) is associated with frequency of freezing: <sup>216;401;404</sup> and more sensitive in detecting freezers than UPDRS item 14 (85.9% vs. 44.1%) <sup>401</sup>  Drawbacks: contains general gait items only, reducing its FOG-specificity <sup>401</sup>	
<b>NOTE:</b> Swedish, self-administered version, FOGQ(S): Higher median scores for fallers than non-fallers (12.5 vs 5.0; n=37) <sup>405</sup> , also on the self-administered form (8 vs 2; n=225) <sup>403</sup> ; Adequate concurrent validity with UPDRS part II (ADL), UPDRS item 14 (freezing), and HY (r=0.65-0.66), UPDRS items 32-35 (dyskinesia) and 36-39 (motor fluctuations) (r=0.62); UPDRS motor (r=0.59), FES (r=0.59), UPDRS items 15 (walking) (r=0.56), 13 (falling not related to freezing) (r=0.55) and 29 (gait) (r=0.54), TUG (r=0.40) <sup>405</sup> Excellent correlation between clinician-administered and self-administered versions (ICC 0.91). Correlations were higher in the self-administered form for UPDRS 14 (0.76) and FES (-0.74) <sup>403</sup>					

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Functional Reach (FR)	Measuring forward reach while standing in a fixed position: performance: Three trials are done and the average of the last two is noted <sup>406</sup>	Correlation with UPDRS ADL r=-0.52 <sup>364</sup> Poor to adequate discriminative validity fallers vs non-fallers: HY2-3, FR $\leq$ 31.75cm = at risk (sens 0.86, spec 0.52) <sup>262</sup> ; HY1-4, FR $\leq$ 19 (sens 0.77, spec 0.65) <sup>373</sup> ; <25.4cm (sens 30%, spec 92%) <sup>407</sup> ; AUC 0.52 (sens 0.52; spec 0.53) <sup>160</sup> fallers mean (sd) = 23.11 (8.12)cm vs nonfallers mean (sd) = 31.70 (5.61) cm <sup>262</sup>	Poor to excellent test-retest reliability: in pwp with fall history ICC=0.93; in pwp without fall history ICC=0.42 <sup>408</sup> ; ICC=0.73 <sup>274</sup> ; ICC=0.84 <sup>366</sup> Poor inter rater reliability: ICC=0.64 <sup>277</sup> Moderate intra rater reliability: ICC=0.74 <sup>277</sup>	HY1-4, mean baseline 21 cm: MDC 9 cm <sup>274</sup> ; HY 1-3: SDD 11.5 <sup>277</sup> MDC: 4cm for pwp with history of falls; 8cm for pwp without history of falls; general 12cm <sup>277;408</sup>	Assessment time 5 min; Required materials: corner, duct tape, yardstick mounted horizontal to the wall; Current use high  Benefits: widely used, easy to administer  Drawbacks: questionable reliability

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Global Perceived Effect (GPE)	Questionnaire: Interview or self-report of perceived treatment effects in all components (worse than ever) to 7 (greatly improved)	Unknown in pwp	Unknown in pwp	Assessment time 1 min; No materials or costs; ; Current use <10%  Benefits: easy to administer  Drawbacks: no psychometric data available for pwp; scores are strongly influenced by current status: do transition ratings truly reflect change?	

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
LASA Physical Activity Questionnaire (LAPAQ)	Questionnaire: Interview or self-report of perceived treatment effects in all components (worse than ever) to 7 (greatly improved)	Unknown in pwp	Unknown in pwp	Assessment time 1 min; No materials or costs; ; Current use <10%  Benefits: easy to administer  Drawbacks: no psychometric data available for pwp; scores are strongly influenced by current status: do transition ratings truly reflect change?	

Activities and Participation: Performance of measure of physical activity	Questionnaire: interview or self-report to gain insight into level of physical activity	Discriminative validity: decreases with age (-3% for each year) and with disease severity (-3% for each point on the UPDRS) <sup>13,6</sup>	Unknown in pwp	Unknown in pwp	Assessment time 30 min; No materials or costs; Current use: <10%
					Benefits: time-consuming
					Drawbacks: no reliability and responsiveness known for pwp (in community dwelling elderly, good convergent validity with physical activity and predictive validity for time spent daily on physical activity <sup>409</sup> )

### Lindop Scale

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Capacity of functional mobility (i.e. changing body position and walking)	Observation performance functional activities (6 gait; 4 bed) : STS, TUG, turn, pass doorway, bed transfers evaluated mainly in seconds or number of steps; 4 point ordinal scale: 0-3 (worst-best)	Good face validity: covers core areas KNGF guideline <sup>12,410</sup> Moderate concurrent validity with UPDRS-motor, $r=0.67^{410}$	Inter-rater reliability: LOA total score (mean difference) = $0.041^{410}$ The percentage agreement between raters ranged from 82% to 100% agreement for all 10 items of the scale <sup>410</sup> Adequate internal consistency: Cronbach's $\alpha=0.86^{410}$	Unknown in pwp	Assessment time 20 min; Required materials: stopwatch, chair; track mark, bed; Current use <10%  Benefits: specifically designed for physiotherapy for pwp  Drawbacks: comparable to M-PAS, but less established data on psychometric properties and less detailed qualitative scoring options

### Mini Balance Evaluation Systems Test (Mini BESTest)

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: measure of Changing and maintaining body position (i.e. balance) AND Body functions: Involuntary movement reaction functions	Observation balance during 14 activities, 3 point ordinal scale: 0 (severe) to 2 (normal), max score 28	Good concurrent validity with BESTest $r=0.96^{399}$ ; BBS, $r=0.79$ , and UPDRS, $r=-0.51^{374}$ Good discriminative validity fallers vs non fallers, AUC $0.84^{399}$ ; average score 27% difference; cut-off scores: 20/32 (63%) (sens 0.88, spec 0.78), 23/32 (72%) (sens 0.96, spec 0.47) <sup>399</sup> ; HY1-2 vs HY3-4 AUC=0.91; cut-off point >21 (sens .89; spec .81) <sup>374</sup>	Mostly good test-retest reliability, ICC=0.92 <sup>399</sup> Excellent inter-rater reliability, ICC=0.91 <sup>399</sup>	Unknown in pwp	Assessment time 15 min; Required materials: shoe box, 2 cones, stairs, stopwatch, 0.5m wide walkway; Current use unknown Benefits: no ceiling effect (as with the BBS); discriminates fallers vs non fallers better than FGA and BBS Drawbacks: does not differentiate between different causes of imbalance

Note: Swedish translated version Correlations with BBS  $r=0.94$ , TUG  $r=-0.81$  and FES(S)  $r=0.26^{417}$

**Movement Disorder Society's (MDS) revision of the UPDRS (MDS-UPDRS)**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Composite score for disease severity	Observation & (Part I & II) patient report, mainly functions: Part I, non-motor experiences of daily living; Part II, motor experiences of daily living; Part III, motor examination; Part IV, motor complications	Good to excellent concurrent validity: with original UPDRS AUC 0.99 <sup>412</sup> ; Total score, r=0.96; Part I, r=0.76; Part II, r=0.92; Part III, r=0.96; Part IV (items 32-39: dyskinesias & motor fluctuations on UPDRS vs. total Part IV MDS-UPDRS), r=0.89 <sup>413</sup> ; Part I, r=0.81; validated nonmotor scales (HADS, SCOPA-COG), r=0.72-0.89 <sup>414</sup>	Adequate to good internal consistency: Cronbach's $\alpha$ Parts I & IV 0.79, Part II 0.90, Part III 0.93 <sup>413</sup> , Part I 0.85 <sup>414</sup>	Unknown in pwp	Assessment time: 30 min ( $\leq$ 10min for interview Part I, 15min for part III. Motor and 5 min part IV); Costs: training and certification required: free for MDS members (membership health professionals =\$100; non-members: \$250 USD); Required materials: paper, chair, app; Current use unknown  Benefits: see UPDRS; non-English translations ongoing  Drawbacks: see UPDRS; not widely used yet

**Nine Hole Peg Test**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and participation performance measure of carrying, moving and handling objects	Time (s) to complete task: visuomotor control, fingertip pinch, and release <sup>415</sup>	Good sensitivity to detect motor dysfunction in the early stages <sup>416</sup>	Good to excellent test-retest reliability: dominant ICC=0.88; ICC nondominant hand 0.91 <sup>417</sup>	Unknown in pwp	Assessment time: 5 min; Costs: need to buy the test; Required materials: peg test, stopwatch; Current use: unknown  Benefits: easy to administer  Drawbacks: gives no insight in quality of performance or what to target in treatment; cannot be used for evaluation

**Parkinson Activity Scale (PAS)**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Capacity measure of functional mobility (i.e. changing body position and walking)	10-item observation performance functional activities: chair transfer (2 items); gait akinesia (2 items); bed mobility (6 items). <sup>418</sup> Quantitative and qualitative scoring on an ordinal scale from 0 (best) to 4 (impossible/help depending)	Good face validity: covers core areas KNGF guideline. <sup>12;418</sup> Concurrent validity: moderate with UPDRS III (motor function; r=0.64) and good with VAS-Global Functioning (r=0.79). <sup>418</sup>	Measurement error for total score 2.6, consisting of 1.3 inter-rater error and 2.3 patient-induced error. <sup>418</sup> No significant difference experts and non-experts, with a 1hr training. SEM 0.23 <sup>418</sup>	SDD <sub>diff</sub> 7.2 points <sup>418</sup>	Assessment time 30 min; Required materials: chair, cup, water, bed, bed cover; Current use 10-35%  Benefits: supportive for gaining insight in quality of movement specific for physiotherapy in pwp  Drawbacks: cannot be used for evaluation; ceiling effect; ambiguous scoring options

**Parkinson's Disease Questionnaire (PDQ-39)**

ICF Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
<p>Quality of life (QOL)</p> <p>Questionnaire: aspects of functioning &amp; well-being of pwp.<sup>419</sup>; 39 questions on mobility (10 items); ADL (6 items); emotional well-being (6 items); stigma (4 items); social support (3 items); cognition (4 items); communication (3 items); bodily discomfort (3 items). 5 point ordinal scale: 0 (never) to 4 (always or cannot do at all). Total: 0-100.</p>	<p>Grouping of items into subscales not supported by analyses<sup>420</sup></p>	<p>Good test-retest reliability and ICC=0.84-0.89<sup>419</sup></p>	<p>MCID for 'a little worse': Mobility 0.11; ADL 0.18; overall 0.10<sup>421</sup></p>	<p>Assessment time 20 min; Costs: book with instructions must be bought; No materials required; Current use 10-35%</p> <p>Benefits: Parkinson's specific QOL measure; GDG recommends to address items of relevance in history taking</p> <p>Drawbacks: items address limitations correlated to QOL, however, score interpretation is difficult; construct multi dimensional<sup>422</sup>; grouping of items into scales complex, meaning of scale scores unclear, hampering interpretation.<sup>420</sup>; responsiveness is questionable; floor effects in many pwp; not all items are of importance to, or can be improved by physiotherapy; particularly appropriate for use in clinical trials to assess treatments and interventions (<a href="http://www.dph.ox.ac.uk/research/hstru/PDQ/Intropdq">www.dph.ox.ac.uk/research/hstru/PDQ/Intropdq</a>)</p>
<p><b>NOTE:</b> Swedish version: moderate test-retest reliability: ICC=0.76-0.93; adequate internal consistency: Cronbach's <math>\alpha = 0.72-0.95</math><sup>420</sup></p>				

**PHONE FITT**

ICF Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
<p>Activities and Participation: Performance measure of physical activity</p> <p>Interview: type, frequency &amp; intensity of physical activities<sup>423</sup></p>	<p>Unknown in pwp</p>	<p>Unknown in pwp</p>	<p>Unknown in pwp</p>	<p>Assessment time 10 min; No materials or costs; Current use unknown</p> <p>Benefits: easy to administer</p> <p>Drawbacks: no psychometric data available for pwp (in elderly (over 65's) the Phone-FITT was found valid and reliable<sup>423</sup>)</p>

**Physical Activity Scale for the Elderly (PASE)**

ICF Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
<p>Activities and Participation: Performance measure of physical activity</p> <p>12-question interview: time (hours/week) spent in each activity or participation (yes/no) : weight summed for all activities<sup>424</sup></p>	<p>Unknown in pwp</p>	<p>Unknown in pwp</p>	<p>Unknown in pwp</p>	<p>Assessment time: 5 min; No materials or costs; Current use unknown</p> <p>Benefits: easy to administer</p> <p>Drawbacks: no psychometric data available for pwp (in elderly, the PASE is a valid &amp; reliable tool to classify elderly into categories of physical activity<sup>424-428</sup>)</p>

**Pull Test**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Body functions Movement functions: Involuntary movement reaction functions	Balance performance to external perturbation in steady-stance (retropulsion) If used, unexpected, quick and firm jerk on the shoulder is preferred; 2 steps allowed <sup>429</sup> , as recommended in the 2004 KNGF Guideline <sup>12</sup> <b>MDS-UPDRS pull test (2007)</b> : scoring options: 0, Normal: No problems: Recovers <3 steps; 1, Slight: 3-5 steps, but recovers unaided; 2. Mild: > 5 steps, but recovers unaided; 3, Moderate: Stands safely, but absence of postural response; falls if not caught; 4, Severe: Very unstable, tends to lose balance spontaneously or with just a gentle pull on the shoulders; <3 steps for recovery considered normal	Concurrent validity to interview based, 'unstable' (≥2 (near) falls in the previous 6 months or using an (walking) to prevent falling) vs 'stable' group: on 1 <sup>st</sup> execution, 'unstable' significant higher than 'stable' on all tests, except the steady stance positions; 'unstable' higher than 'controls' on 1 <sup>st</sup> execution, except for Pastor rating <sup>429</sup> Predictive validity: Nutt: sens 0.63, spec of 0.88, positive 0.86, negative 0.69; overall accuracy 0.75; Bloem: sens 0.65, spec 0.85, positive 0.83, negative 0.69; overall accuracy 0.74; UPDRS: sens 0.66, spec 0.82, positive 0.83, negative 0.67; overall accuracy 0.71; SPES: sens 0.55, spec 0.92, positive 0.88, negative 0.65; overall accuracy 0.72; Pastor: sens 0.70, spec 0.69, positive 0.72, negative 0.67, overall accuracy 0.69; steady stance-positions (right/left): sens 0.45/0.50, spec 0.79/0.73, positive 0.71/0.70, negative 0.56/0.55; overall accuracy 0.61/0.61 <sup>429</sup>	Inter-rater reliability excellent for steady stance positions (k 0.98), Nutt (k 0.98) and Pastor (k 0.93); good for SPES (k 0.87) and Bloem (k 0.85); Poor for UPDRS (k 0.63) <sup>429</sup> Inter-rater reliability excellent for steady stance positions (k 0.98), Nutt (k 0.93) and Pastor (k 0.98); good for SPES (k 0.87) and Bloem (k 0.85); Poor for UPDRS (k 0.63) <sup>429</sup>	Unknown in pwp	Assessment time 1 min; No materials or costs; Current use 10-35%  Benefits: widely used, known amongst neurologists (communication)  Drawbacks: no essential information for physiotherapists

**Purdue Pegboard Test**

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and participation performance measure of carrying, moving and handling objects: visuomotor control, fingertip pinch, and release <sup>430</sup>	Count of pegs, or count of assembly items in final task	Unknown in pwp	Unknown in pwp	Unknown in pwp	Assessment time: 10 min; Costs: need to buy the material; Required materials: pegboard test; Current use unknown  Benefits: easy to administer  Drawbacks: no psychometric data for pwp; gives no insight in quality of performance or what to target in treatment

Survey of Activities and Fear of Falling in the Elderly (SAFFE)

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Performance measure of Changing and maintaining body position (i.e. balance)	6-page interview-based questionnaire : 22 items assessing feared consequences of falling: fear and avoidance towards specific activities. <sup>431</sup>	Unknown in pwp	Unknown in pwp	Unknown in pwp	Assessment time 15 min; No materials or costs; Current use unknown  Benefits: modified Swedish version has good validity & reliability  Drawbacks: no psychometric data for pwp
<p><b>NOTE:</b> Swedish translation of modified version (Yardley), mSAFFE(S): 1-page, self-administered, 17 items assessing avoidance only (scored 1, never, to 3, always).<sup>432</sup>; mSAFFE(S): Correlations with physical functioning (SF-36) <math>r=-0.76</math>; FES(S) <math>r=-0.74</math>; TUG <math>r=0.67</math>; fast gait speed, <math>r=-0.64</math>; comfortable gait speed, <math>r=-0.52</math>; UPDRS Parts II <math>r=0.52</math> and III <math>r=0.50</math>; disease duration, <math>r=0.28</math>; and age <math>r=0.08</math>.<sup>138</sup>; Discriminative validity: higher scores for females vs men and for pwp reporting previous falls, FOF or unsteadiness for than those not reporting this.<sup>138</sup>; Excellent test-retest reliability. ICC=0.92; Adequate internal consistency: <math>\alpha=0.95/0.96</math>, SEM=2.4<sup>138</sup></p>					

Tinetti Performance Oriented Mobility Assessment (POMA) , Gait (G) and Balance (B)

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Walking (POMA-G) and Changing and maintaining body position (i.e. balance; POMA-B)	POMA-B: Observation balance when performing 9 activities and external perturbation (push to sternum; function); POMA-G: Observation gait in 7 activities & body functions; on a 3-point ordinal scale: 0 (unsafe) to 2 (safe)	Moderate concurrent validity with gait speed ( $r=0.53$ , POMA-B $r=0.52$ , POMA-G $r=0.50$ ) and UPDRS motor ( $r=0.45$ ) <sup>433</sup> Adequate discriminative validity for fallers vs non-fallers AUC 0.72 (sens 0.67; spec 0.59) <sup>160</sup> POMA-B independent predictor with sens 0.71, spec 0.79, OR 0.84 <sup>83</sup> ; sens 0.76, spec 0.66 <sup>433</sup>	Moderate to good intra-rater reliability experienced raters, ICC=0.79-0.86 <sup>433</sup> POMA-G: Excellent intra-rater reliability mixed group (pwp and controls) ICC=0.95 <sup>434</sup> Good inter-rater reliability experienced raters ICC=0.84 <sup>433</sup>	Unknown in pwp	Assessment time: 15 min (POMA-B 2 min); Required materials: armless chair, walking track of at least 3 m, stopwatch; Current use >35%  Benefits: widely used in elderly  Drawbacks: floor effects, possibly due to exclusion of freezing and dual tasks; activities and body function combined in one balance score, making scores difficult to interpreted
<p><b>NOTE:</b> There are various versions of the POMA, with variations for both the name of the test and means of scoring</p>					

Unified Parkinson's Disease Rating Scale (UPDRS)

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Composite score for disease severity	Observation & patient report, 4-point ordinal scale from 0 (normal ) to 4 (severe); Part I, mentation, behavior and mood (max 16 points); Part II, ADL (max 52 points); Part III, motor (max 108 points); Part IV, complications: max 23 points	Adequate face validity: constructed by experts Satisfactory convergent validity with HY, Schwab & England scales, timed motor tests <sup>435</sup> Discriminative validity fallers vs non-fallers: UPDRS II, III and total: AUC 0.68, 0.67, 0.70, sens 0.64, 0.64, 0.74 <sup>160</sup>	Moderate to Excellent retest reliability: Total ICC=0.92; Mentation ICC=0.74; ADL ICC=0.85; motor ICC=0.90 <sup>436</sup> ; Total ICC=0.84, Motor ICC=0.74 <sup>277</sup> Poor to moderate inter-rater reliability: Total ICC=0.78, Motor ICC=0.68 <sup>277</sup> <i>NOTE: After watching the official UPDRS Teaching Tape, many differences in UPDRS scores by trained neurologists on first attempt<sup>437</sup></i>	SDD: Part III 13 points, Total score 15 points <sup>277</sup> MDC for Mentation 2 points; Part II 4 points; Part III 7 points to 13 points <sup>277</sup> ; Total 9 points <sup>436</sup> to 15 points <sup>277</sup> MDC: Part I 2/16; Part II 4/52; Part III 11/108; Total 13/176 <sup>274</sup> MCID: Part III 2.3 to 2.7 points; Total 4.1 to 4.5 points; Moderate MCID motor 4.5 to 6.7 points ; total 8.5 to 10.3 points ; Large MCID motor 10.7 to 10.8 ; total 16.4 to 17.8 <sup>438</sup>	Assessment time 30 min (10 min interview Part I; 15 min part III; 5 min part IV); Required materials: paper, chair; Costs required training: \$250; Current use 10-35%  Benefits: provides insight in asymmetry, dyskinesias, predictability off periods; the motor part is of most interest to physiotherapy  Drawbacks: mainly assesses impairments which cannot be targeted by physiotherapy, is time consuming, difficult and costly

WALK-12 Questionnaire

ICF	Scoring	Validity	Reliability	Responsiveness	Feasibility <sup>1)</sup>
Activities and Participation: Performance measure of Walking (i.e. gait)	12-item questionnaire of people report when walking at home and in their local community. Original: 5 point ordinal scale (1 to 5) ; max 60 (or transformed to a scale from 0 to 100), higher scores greater limitations	Unknown in pwp	Unknown in pwp	Unknown in pwp	Assessment time 5 min; Required materials: pen; Current use: unknown  Benefits: good validity and reliability found for modified Swedish version; originally developed for MS but also validated as a generic version  Drawbacks: no psychometric data for pwp
<b>NOTE:</b> Modified Swedish version: Item 1-3 ordinal 0-2, item 4-12 ordinal 0-4 (full range 0 best to 42 more walking difficulties). Total, summed score (range 0 to 42; higher score indicating more walking difficulties): moderate to strong concurrent validity with measures for physical functioning and gait (FOG, TUG, 10wt, FES) (>0.6) <sup>439</sup> ; Good convergent validity: explains 68% of the variance in scores of a Swedish version Falls Efficacy Scale. <sup>440</sup> ; Excellent test-retest reliability: ICC0.92; SEM 2.6 <sup>439</sup>					

## Appendix 10 Forms of recommended measurement tools

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

- 10 Meter Walk Test (10MWT)
- Activities Balance Confidence (ABC) Scale
- Berg Balance Scale (BBS)
- Borg Scale 6-20
- Dynamic Gait Index (DGI) & Functional Gait Assessment (FGA)
- Falls Diary
- Falls Efficacy Scale International (FES-I)
- Five Times Sit To Stand (FTSTS)
- Freezing test Snijders & Bloem
- Functional Gait Assessment (FGA): *see Dynamic Gait Index*
- Goal Attainment Scaling (GAS) - goals evaluation form
- History of falling
- Modified Parkinson Activity Scale (M-PAS)
- Patient Specific Index for Parkinson's Disease (PSI-PD): *included in the PIF and GAS*
- Push and Release Test (P&R Test)
- Six Minute Walk Distance (6MWD)
- Timed Get-up and Go (TUG)

## 10 Meter Walk Test (10MWT)

### 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, e.g. with tape or chalk; allow 2 additional meters at the ends for acceleration and deceleration
- if a 14 meter space is unavailable, a 6MWT can be performed, requiring 10m space
- carry out three trials to calculate a mean time and velocity
- 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 10MWT

### 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".

<b>Date:</b>	<b>Name patient:</b>	<b>Name physiotherapist:</b>
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### Circumstances of measurement:

- Time of the day:
- Time after medication intake:
- If applicable, on or off period:
- Location:
- Shoes worn by the patient:
- Assistive devices used by the patient:

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

## 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 from choosing one of the percentage points on the scale from 0% to 100%.
- If you do not currently do the activity in question, try and 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.

<b>Date:</b>	<b>Your name:</b>
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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?										

## ***Berg Balance Scale (BBS)***

<b>Date:</b>	<b>Name patient:</b>	<b>Name physiotherapist:</b>
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### **Circumstances of measurement:**

- Time of the day:
- Time after medication intake:
- If applicable, on or off period:
- Location:
- Shoes worn by the patient:
- 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):** \_\_\_\_\_

### Berg Balance Scale (BBS)

#### **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

#### **General instructions :**

- Give instructions as written
- Record the lowest response category that applies for each item
- In most items, the subject 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 patient's performance warrants supervision
  - the patient touches an external support or receives assistance from the physiotherapist
- Patients 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 patient

#### **Assessments**

##### **1. Sitting to standing**

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

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

##### **2. Standing unsupported**

INSTRUCTIONS: 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 a subject is able to stand 2 minutes unsupported, score full points for sitting unsupported. Proceed to item #4.

Berg Balance Scale (BBS)

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

INSTRUCTIONS: 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**

INSTRUCTIONS: 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**

INSTRUCTIONS: Arrange chair(s) for pivot transfer. Ask patient to transfer one way toward a seat with armrests and one way toward a seat without armrests. You may use two chairs (one with and one without armrests) or a bed and a chair.

- 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**

INSTRUCTIONS: 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**

INSTRUCTIONS: 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

Berg Balance Scale (BBS)

**8. Reaching forward with outstretched arm while standing**

INSTRUCTIONS: Lift arm to 90 degrees. Stretch out your fingers and reach forward as far as you can. (Physiotherapist places a ruler at the end of fingertips when arm is at 90 degrees. Fingers should not touch the ruler while reaching forward. The recorded measure is the distance forward that the fingers reach while the patient is in the most forward lean position. When possible, ask patient to use both arms when reaching to avoid rotation of the trunk.)

- ( ) 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

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

INSTRUCTIONS: 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**

INSTRUCTIONS: Turn to look directly behind you over the left shoulder to [pick an object to look at directly behind the patient]. Repeat 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**

INSTRUCTIONS: 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

Berg Balance Scale (BBS)

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

INSTRUCTIONS: 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**

INSTRUCTIONS: (DEMONSTRATE) 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. (To score 3 points, the length of the step should exceed the length of the other foot and the width of the stance should approximate the patient's normal stride width.)

- ( ) 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

**14. Standing on one leg**

INSTRUCTIONS: 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

## Borg Scale 6-20

<b>Date:</b>	<b>Patient name:</b>
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**Circumstances of measurement:**

- Time of the day:
- Time after medication intake:
- If applicable, on or off period:
- Location:
- Type of exercise:

**Patient instructions:**

*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. Don't 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*

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

Source: guidelines by dr. Gunnar Borg<sup>255</sup>

## Dynamic Gait Index (DGI) & Functional Gait Assessment (FGA)

Date:	Name patient:	Name physiotherapist:
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**Circumstances of measurement:**

- Time of the day:
- Time after medication intake:
- If applicable, on or off period:
- Location:
- Shoes worn by the patient:

**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)** \_\_\_\_\_

**Item & total scores FGA**

*Total DGI score minus scores items 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 backwards \_\_\_\_\_
- 11. Walking with eyes closed \_\_\_\_\_
- Total score (range 0-30)** \_\_\_\_\_

**Source:** 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>;  
 FGA: Wrisley et al., Phys Ther 2004: 84 (10): 917-918)

### Dynamic Gait Index (DGI) & Functional Gait Assessment (FGA)

#### 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

#### Differences DGI & FGA

The FGA is developed based on the DGI. As they provide additional information, the GDG suggests to use them simultaneously, be it with minor modifications. When DGI and FGA deviated, the FGA was followed:

- Originally, the DGI uses a walkway with 37.5cm width
- Originally, DGI marks the lowest category that applies
- the scoring options regarding deviations (in cm) outside the walkway, and time needed to walk 6m, are FGA specific
- Items 3 and 4 (i.e gait with horizontal and vertical head turns) are different activities in the FGA and DGI: the GDG recommends doing both, and using the correct answer for each total score when used for falls risk estimation
- In item 6 the DGI uses only one shoebox, with slightly different scoring options
- In the original FGA, item 8 (Steps) is item nr. 10

#### Assesment:

On all items, mark the highest category that applies

#### DGI/FGA 1. Gait Level Surface.

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

(3) Normal: Walks 6m; in less than 5.5 sec, no assistive devices, good speed, no evidence for imbalance, normal gait pattern, deviates up to 15cm outside of the walkway

(2) Mild Impairment: Walks 6m in 5.5 to 7 sec; uses assistive device, slower speed, mild gait deviations, or deviates 15 to 25cm outside the walkway.

(1) Moderate Impairment: Walks 6m in greater than 7 seconds; 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.

Instructions: *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 no more than 15cm outside the walkway

(2) Mild Impairment: Is able to change speed but demonstrates mild gait deviations, deviates 15-25cm 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 change in speed with significant gait deviations, deviates 15-25cm outside the walkway, or changes speed but loses balance but is able to recover and continue walking.

(0) Severe Impairment: Cannot change speeds, deviates greater than 38cm outside walkway, or loses balance and has to reach for wall or be caught.

### 3. Gait with Horizontal Head Turns

**FGA:** Instructions: *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:** Instructions: *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 center.*

(3) Normal: Performs head turns smoothly with no change in gait. Deviates no more than 15cm outside walkway

(2) Mild Impairment: Performs head turns smoothly with slight change in gait velocity (eg 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 (eg staggers 38cm outside walkway, loses balance, stops, reaches for wall).

### 4. Gait with Vertical Head Turns

**FGA** Instructions: *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** Instructions: *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 center.*

(3) Normal: Performs head turns with no change in gait, deviates no more than 15cm outside walkway.

(2) Mild Impairment: Performs task with slight change in gait velocity (eg 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, can continue to walk.

(0) Severe Impairment: Performs task with severe disruption of gait (eg staggers 38cm outside walkway, loses balance, stops, reaches for wall).

### DGI/FGA 5. Gait and Pivot Turn

Instructions: *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 within 3 seconds and stops quickly with no loss of balance.

(2) Mild Impairment: Pivot turns safely in >3 seconds and stops with no loss of balance, or pivot turns safely within 3 seconds 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

Instructions: *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

Instructions: *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

Instruction: *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

Instructions: *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 less than 4 steps heel to toe or cannot perform without assistance.

### FGA 8. Gait with eyes closed

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

(3) Normal—Walks 6 m, no assistive devices, good speed, no evidence of imbalance, normal gait pattern, deviates no greater than 15cm outside walkway. Ambulates 6 m in less than 7 seconds.

(2) Mild impairment—Walks 6 m (20 ft), uses assistive device, slower speed, mild gait deviations, deviates 15-25cm outside walkway. Ambulates 6m in 7-9 seconds.

(1) Moderate impairment—Walks 6m, slow speed, abnormal gait pattern, evidence for imbalance, deviates 25-38cm outside the walkway. Requires greater than 9 seconds to ambulate 6m

(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

Instructions: *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 than 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.

## Falls Diary

You have received this Falls Diary from your physiotherapist because you have had (near) falls in the past. 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 fall that day, otherwise please fill in the time(s) of your fall(s)
- For each (near) fall, please answer the questions in the tables below

<b>Week:</b> (e.g. 7-13 April 2014)	<b>Your name:</b>						
	<b>Monday</b>	<b>Tuesday</b>	<b>Wednesday</b>	<b>Thursday</b>	<b>Friday</b>	<b>Saturday</b>	<b>Sunday</b>
<b>Fall</b>							
<b>Near fall</b>							

<b>Falls</b>	<b>1<sup>st</sup></b>	<b>2<sup>nd</sup></b>	<b>3<sup>rd</sup></b>
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?			

<b>Near falls</b>	<b>1<sup>st</sup></b>	<b>2<sup>nd</sup></b>	<b>3<sup>rd</sup></b>
What sort of things were you doing when you nearly fell?			
Why do you think you nearly fell?			
How did you save yourself from falling?			

## Falls Efficacy Scale International (FES-I)

Date:	Your name:
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### General instructions

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 on how concerned you are about the possibility of falling. You may consider asking your carer, partner or family to help you answering the questions. Please reply thinking about how you usually do the activity. If you currently don't do the activity (e.g. 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 which 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....	Not at all concerned 1	Somewhat concerned 2	Fairly concerned 3	Very concerned 4
Cleaning the house (e.g. sweep, vacuum or dust)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Getting dressed or undressed	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Preparing simple meals	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Taking a bath or shower	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Going to the shop	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Getting in or out of a chair	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Going up or down stairs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Walking around in the neighbourhood	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Reaching for something above your head or on the ground	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Going to answer the telephone before it stops ringing	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Walking on a slippery surface (e.g. wet or icy)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Visiting a friend or relative	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Walking in a place with crowds	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Walking on an uneven surface (e.g. rocky ground, poorly maintained pavement)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Walking up or down a slope	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Going out to a social event (e.g. religious service, family gathering or club meeting)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

## ***Five Times Sit to Stand (FTSTS)***

### **Equipment required**

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

### **General Instruction**

- Patient sits with arms folded across chest and with their back against the chair
- Ensure that the chair is not secured (i.e. against the wall or mat)
- Demonstrate what you mean to ensure they understand the instructions
- It is OK if the patient does touch the back of the chair, but it is not recommended.
- Timing begins at "Go" and stops when the patient'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 patient during the test (may decrease patient's speed)

**Patient Instructions:** "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"

<b>Date:</b>	<b>Name patient:</b>	<b>Name physiotherapist:</b>
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### **Circumstances of measurement:**

- Time of the day:
- Time after medication intake:
- If applicable, on or off period:
- Location:
- Height chair:

**Score:**            seconds

## **Freezing test Snijders & Bloem**

### **Equipment required, for dual tasking:**

- See M-PAS for dual tasking activity

### **General instructions**

Ask the patient 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 double tasks can be added to the test. For feasibility purposes the GDG recommends to use the Modified-PAS Gait Akinesia for this.

<b>Date:</b>	<b>Name patient:</b>	<b>Name physiotherapist:</b>
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### **Circumstances of measurement:**

- Time of the day:
- Time after medication intake:
- If applicable, on or off period:
- Location:
- Shoes worn by the patient:

### **Score (mark):**

- [ ] Freezing
- [ ] No freezing

### **Specifications regarding freezing**

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

## Goal Attainment Scaling (GAS)

### General instructions

At the end of history taking and physical examination, goals are defined and agreed by the person with Parkinson's disease (pwp) together with the physiotherapist, and with the carer when required.

### Describing goals

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

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

The GDG recommends to set one short term goal (e.g. 2 weeks) and one long term. Each goal is described at five levels of attainment. The levels are individually set around the pwp's expected level of performance. When describing the five levels is not feasible (.e.g. too time-consuming), you might only fully set and document 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 in the feasibility of the goal and to motivate the pwp. Each goal is rated on the 5 point scale: -2, -1, 0, +1 or +2.

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

## History of Falling

Date:	Name patient:
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### 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 (i.e. question 7 or 8)
- Information on the occurrence of falls and avoidance-strategies may need probing
- The GDG recommends providing a Falls Dairy to patients with past (near) falls.

### 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?			

## ***Modified Parkinson Activity Scale (M-PAS)***

Forms are provided for each section separate, as often not all of the M-PAS will be used. Scores are provided, but a total score is not calculated as in general the M-PAS is used for qualitative identification of limitations only. However, if scores are calculated: the mean of scores on items 10a/b and 13a/b should be used; items 1a & 1b make up one score, as do items 2a & 2b. Instructions to the patient are marked in *italic*.

### **Materials CHAIR TRANSFERS:**

- A chair (comparable to the chair) which is causing the greatest problems to the patient and is used frequently

### **Materials GAIT AKINESIA:**

- A chair, as for CHAIR TRANSFERS
- A cup for 90% filled with water
- A U-shape taped on the floor: the middle of the U-shape is situated three meters in front of the middle of the chair, the lengths of the sides of the U are 1 meter.

### **Materials BED MOBILITY:**

- A bed
- A pillow, sheets and a blanket or duvet (what the patient uses at home)

## M-PAS: CHAIR TRANSFERS

Date:	Name patient:	Name physiotherapist:
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### Circumstances of measurement:

- Time of the day:
- Time after medication intake:
- If applicable, on or off period:
- 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

## M-PAS GAIT AKINESIA

Date:	Name patient:	Name physiotherapist:
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### Circumstances of measurement:

- Time of the day:
- Time after medication intake:
- If applicable, on or off period:
- Location:
- Height chair:

### Instructions:

- The patient has to be able to walk without the help of others
- After determination of the turning side, the patient is asked to carry out items 3 to 8 turning to this side
- At item 7, if required, an example of counting backwards is given, starting at 110

*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. You may, if you want to, 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?*

*Please rise, walk to the U, turn within the U, and return to sit down in the chair*

### Non-preferred turning 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)

**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)

## BED MOBILITY

Date:	Name patient:	Name physiotherapist:
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### Circumstances of measurement:

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

### Instructions:

- The patient has to be able to walk without the help of others
- After determination of the turning side, the patient is asked to carry out items 3 to 8 turning to this side
- At item 7, if required, an example of counting backwards is given, starting at 110

### Starting position:

- The patient is standing in front of the bed
- Before rolling (items 10 and 13), the patient 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 like 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: patient 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, e.g. with head uncomfortably against the head of the bed or with legs which are 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: patient 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, e.g. 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

### 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: patient 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, e.g. 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: patient 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: patient 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, e.g. with part of the back uncovered  
difficulty reaching an adequate end position: functionally limiting or uncomfortable, e.g. with head uncomfortably against the head of the bed or with legs which are 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: patient 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, e.g. with part of the back uncovered  
Difficulty reaching an adequate end position: functionally limiting or uncomfortable, e.g. 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: patient 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, e.g. with part of the back uncovered  
difficulty reaching an adequate end position: functionally limiting or uncomfortable, e.g. 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

### 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: patient 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

## ***New Freezing of Gait Questionnaire (N-FOGQ)***

### **General instructions**

These questions are addressed only when 'yes' is answered to the first question of the N-FOGQ in the PIF (i.e. 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

## ***Patient Specific Index for Parkinson's Disease (PSI-PD) - prioritisation***

### **General instructions**

At the beginning of 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 (i.e. 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*.

<b>Order</b>	<b>Priority</b>	<b>activity</b>	<b>core area</b>
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 patient may be assisted in referral towards another health professional (e.g. an occupational therapist or a speech and language therapist).

## ***Push and Release Test (P&R Test)***

### **General instructions**

- Patient stands in a comfortable stance with eyes open.
- Physiotherapist stands behind the patient.
- Physiotherapist instructs patient to do whatever necessary to regain balance, including taking a step.
- Physiotherapist's hands placed on patient's scapulae
- Patient leans passively backward into physiotherapist's hands while, with heels remaining on the ground,
- Physiotherapist flexes elbows to allow backward movement of trunk and supports patient's weight with hands.
- When patient's shoulders and hips move to a stable position just behind heels, physiotherapist suddenly removes hands, requiring patient to take a backward step to regain balance.
- Patient has to take a step for test to be properly executed. A step is counted only if it is required for patient to maintain balance not to reorient feet.
- Time at which physiotherapist releases hands from patient vary to ensure patient cannot anticipate release.

<b>Date:</b>	<b>Name patient:</b>	<b>Name physiotherapist:</b>

### **Circumstances of measurement:**

- Time of the day:
- Time after medication intake:
- If applicable, on or off period:
- 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

## Six Minute Walk Distance (6MWD)

According to the guidelines of the American Thoracic Society <sup>252</sup>

### Materials required

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

### General instructions

- Before the test starts, patients should sit at rest in a chair, located near the starting position, at least 10 min
- During the test, patients 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
- Do not walk with the patient.
- Let the patient see you click the lap counter once each time the patient crosses the starting line
- Consider using the Borg scale for perceived exertion before and after the test
- Starting position: standing at the starting line, together; start the timer as soon as the patient starts to walk

<b>Date:</b>	<b>Name patient:</b>	<b>Name physiotherapist:</b>
--------------	----------------------	------------------------------

### Circumstances of measurement:

- Time of the day:
- Time after medication intake:
- If applicable, on or off period:
- Location:
- Shoes worn by the patient:

Distance walked:                      laps =                      meters

What, if anything, kept you from walking farther?:

### Patient instructions 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'm 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 don't run or jog. Start now, or whenever you are ready*

### Patient instructions 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'm 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 participant 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"*

## Timed Get-up and Go (TUG)

### Materials required

- A standard height armchair (seat height 46 cm, arm height 67 cm); when used simultaneously with the M-PAS Chair Transfers, the GDG recommends using the chair selected for the M-PAS)
- Tape or chalk: a line to walk to at 3m from the front of the chair; when used
- A stopwatch

### General Information

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

Date:	Name patient:	Name physiotherapist:
-------	---------------	-----------------------

### Circumstances of measurement:

- Time of the day:
- Time after medication intake:
- If applicable, on or off period:
- Location:
- Shoes worn by the patient:
- Assistive devices used:
- Height chair:

### Patient 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? When I say 'Go', stand up from the chair, walk at your normal speed across the tape on the floor, turn around, and come back to sit in the chair*

Demonstrate the test to the patient. When the patient is ready, say "Go"

Time needed to complete:            sec

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; 39:142-148<sup>244</sup>

## Appendix 11 Measurement tools according to ICF domains

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

\* for all pwp in order to gain a first insight in the pwp complaints and to decide upon which impairments and limitations should be targeted in physical assessment (see chapter 5 and QRCs)

# also for evaluative purpose

## Appendix 12 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:								
Patients Perspective	Past (near) falls: ABC / FES: Freezing: Activity level: Identified core areas:									
	<table border="1"> <thead> <tr> <th style="background-color: #cccccc;">Body-Structures/Functions *</th> <th style="background-color: #cccccc;">Activities</th> <th style="background-color: #cccccc;">&amp;</th> <th style="background-color: #cccccc;">Participation *</th> </tr> </thead> <tbody> <tr> <td>                     6MW &amp; Borg 6-20:                      P&amp;R:                      Freezing:                      Stride length / cadence:                 </td> <td>                     M-PAS:                      TUG:                      BBS / DGI &amp; FGA:                      FTSTS :                      10MWT                      6MWD :                 </td> <td></td> <td></td> </tr> </tbody> </table>			Body-Structures/Functions *	Activities	&	Participation *	6MW & Borg 6-20: P&R: Freezing: Stride length / cadence:	M-PAS: TUG: BBS / DGI & FGA: FTSTS : 10MWT 6MWD :	
Body-Structures/Functions *	Activities	&	Participation *							
6MW & Borg 6-20: P&R: Freezing: Stride length / cadence:	M-PAS: TUG: BBS / DGI & FGA: FTSTS : 10MWT 6MWD :									
Health Professional Perspective										
	Environmental factors	Personal factors								

\*A selection of appropriate measurement tools is made based on the outcome of History Taking

## Appendix 13 General outline of group treatment

The information on this page aims to support physiotherapists in providing group treatment to people with Parkinson's disease (pwp). There is no gold standard with regards intervention for group treatment plus individuals will show preference for 1: 1 or group work. Service provision needs to be taken in account, as this will influence, and possibly limit what is available to pwp. The GDG advises the therapist still sets and evaluates goals individually (Ch.6) and, if applicable, communicates with the referring physician (Ch.8.9).

### 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 learn from one another whilst the pwp is exercising; this may be supervised by a physiotherapist to answer non-patient related questions

### Treatment goal

- General goals (see Ch. 7 Rationale to the interventions)
  - Exercise adherence into the long-term to influence fitness, general health and wellbeing
  - Prevention of secondary complications (H&Y 1-4)
  - Motor learning (H&Y 1-3)
  - Become confident exercising aiming to move on to non-supervised exercising, e.g. at home, at the gym, or in a general exercise group
  - Learn from one another and meet other people, who may share similar experiences and difficulties
  - Feelings of well-being and joy
- 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
- Preferences regarding exercises
- Individual limitations, especially cognitive, cardiovascular and musculoskeletal

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 (e.g. in their on-period)
- Duration: 30 to 60 minutes sessions
- Frequency: twice a week; additional exercises to do at home
- Duration: minimum 8 weeks, as this period is required to improve physical capacity
- 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:**

- For stage related contents see Figure 7.1
- Generally, classes will combine specific exercises to improve physical functions within functional activities. The specific contents of the class will be directed by the group and individual goals.
- Aim for functional-task exercises
- Aim for progressive training:
  - When addressing physical functions, e.g. in number of repetitions or speed
  - When addressing motor learning, e.g. from a stable to a variable task and context, from single to dual task training and from practicing in a set to a random order of tasks
- Include a warming-up and cooling-down (relaxation)

#### **Suggested specific exercises**

- Climbing step or stairs -for strength and balance
- Sit down and rise from a chair - for strength and transfers
- Stand up from the floor - for transfers and balance (confidence on/ off floor)
- Standing and walking on foam, with and without external perturbation - for gait and balance
- Active, amplitude based exercises in different directions, whilst standing or sitting - for improved range of movement and balance
- Walking around and over obstacles and through doorways - for functional mobility
- Taking big steps when walking, sudden changes in walking direction - for functional balance
- Turning round in big and small spaces - for turning
- Walking over lines on the floor (e.g. taped or chalked), or over tiles - for gait
- Auditory rhythm (e.g. music) led walking exercises - for endurance and gait
- Dance - for endurance and gait
- Treadmill training - for endurance and gait
- Trampoline jumping with adequate support - for endurance, strength and gait
- Nordic Walking - for endurance and range of movements
- Supervised hydrotherapy - for endurance, strength, range of movements and gait

#### **Materials to be considered**

Steps, chairs of different heights, stopwatch, metronome, music, mp3-players, foam, mats, music, balls, elastic bands, wobble board, treadmill, cross trainer bicycles

#### **Sources of support**

On the website of the Association of Physiotherapists in Parkinson's Disease Europe (APPDE) examples of physiotherapy exercises and tips and tricks used for and by pwp are shared. The websites of the APPDE and the European Parkinson's Disease Association (EPDA) also provide links to additional sources to support exercising:

- APPDE: [www.appde.eu](http://www.appde.eu)
- EPDA: [www.epda.eu.com](http://www.epda.eu.com)

## Appendix 14 Patient-Centred Questionnaire for PD

This 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

- |  |  |  |
|--|--|--|
| <p>1. Did you visit one of the following health professionals related to Parkinson's disease during the physiotherapy treatment period?<br/><i>You may mark more than one square!</i></p> <p><input type="checkbox"/> Neurologist<br/><input type="checkbox"/> Primary Care Physician<br/><input type="checkbox"/> Occupational therapist<br/><input type="checkbox"/> Speech therapist<br/><input type="checkbox"/> Psychologist<br/><input type="checkbox"/> Social worker<br/><input type="checkbox"/> Other, namely:</p> | <p>2. Were all your health professionals aware of each other's involvement in your treatment?</p> <p><input type="checkbox"/> No, not at all<br/><input type="checkbox"/> Yes, to some extent<br/><input type="checkbox"/> Yes, seemed fully aware<br/><input type="checkbox"/> I don't know</p> | <p>3. Did you get conflicting information from your health professionals?</p> <p><input type="checkbox"/> No, not at all<br/><input type="checkbox"/> Yes, to some extent<br/><input type="checkbox"/> Yes, throughout the care period<br/><input type="checkbox"/> I don't know</p> |
|--|--|--|

### Accessibility of your physiotherapist

- |   |   |  |
|---|---|--|
| <p>4. In general, was the length of time you had to wait before you could visit your physiotherapist a problem for you?</p> <p><input type="checkbox"/> Not a problem<br/><input type="checkbox"/> Not much of a problem<br/><input type="checkbox"/> A moderate problem<br/><input type="checkbox"/> A serious problem</p> | <p>5. In general, was the time spent in the waiting room a problem for you?</p> <p><input type="checkbox"/> Not a problem<br/><input type="checkbox"/> Not much of a problem<br/><input type="checkbox"/> A moderate problem<br/><input type="checkbox"/> A serious problem</p> | <p>6. Have you made satisfactorily agreements with your physiotherapist about when and how to get in contact in future?</p> <p><input type="checkbox"/> No, not at all<br/><input type="checkbox"/> Yes, to some extent<br/><input type="checkbox"/> Yes, to a moderate extent<br/><input type="checkbox"/> Yes, to a great extent</p> |
|---|---|--|

### Empathy and expertise of your physiotherapist

- |   |   |   |
|---|---|---|
| <p>7. Did your physiotherapist listen carefully to you?</p> <p><input type="checkbox"/> No, not at all<br/><input type="checkbox"/> Yes, to some extent<br/><input type="checkbox"/> Yes, to a moderate extent<br/><input type="checkbox"/> Yes, listened carefully</p> | <p>8. Did your physiotherapist explain things clearly?</p> <p><input type="checkbox"/> No, not at all<br/><input type="checkbox"/> Yes, to some extent<br/><input type="checkbox"/> Yes, to a moderate extent<br/><input type="checkbox"/> Yes, explained clearly</p> | <p>9. Did your physiotherapist seem competent to you regarding the treatment of Parkinson's disease?</p> <p><input type="checkbox"/> No, not at all<br/><input type="checkbox"/> Yes, to some extent<br/><input type="checkbox"/> Yes, to a moderate extent<br/><input type="checkbox"/> Yes, to a great extent</p> |
|---|---|---|

**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? *e.g. 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

<b>Room for additional remarks</b>
------------------------------------

Source: questions adopted from the Patient-Centered Questionnaire for Parkinson's Disease (PCQ-PD)

## Appendix 15 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 patient 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.

### Problems with moving around and performing activities in pwp and how to assist:

- 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*
  - *To communicate, for example, when talking, writing, using a computer or a phone*
- 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*
  - Rising from a chair, sofa, bed, toilet seat, and sitting down again: *Pwp may have their own or physiotherapy-trained strategies to do this; ask for these*
  - Rolling over in bed and adjusting sheet or blankets: *Again, pwp may have either their own or physiotherapy-trained strategies to do this, so ask what these are*
  - Getting in and out of a car: *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 medication: *Try to find the best times of the day to perform activities such as dressing, washing, 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). Also, 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.

# Index

Will de added

## References

### Reference List

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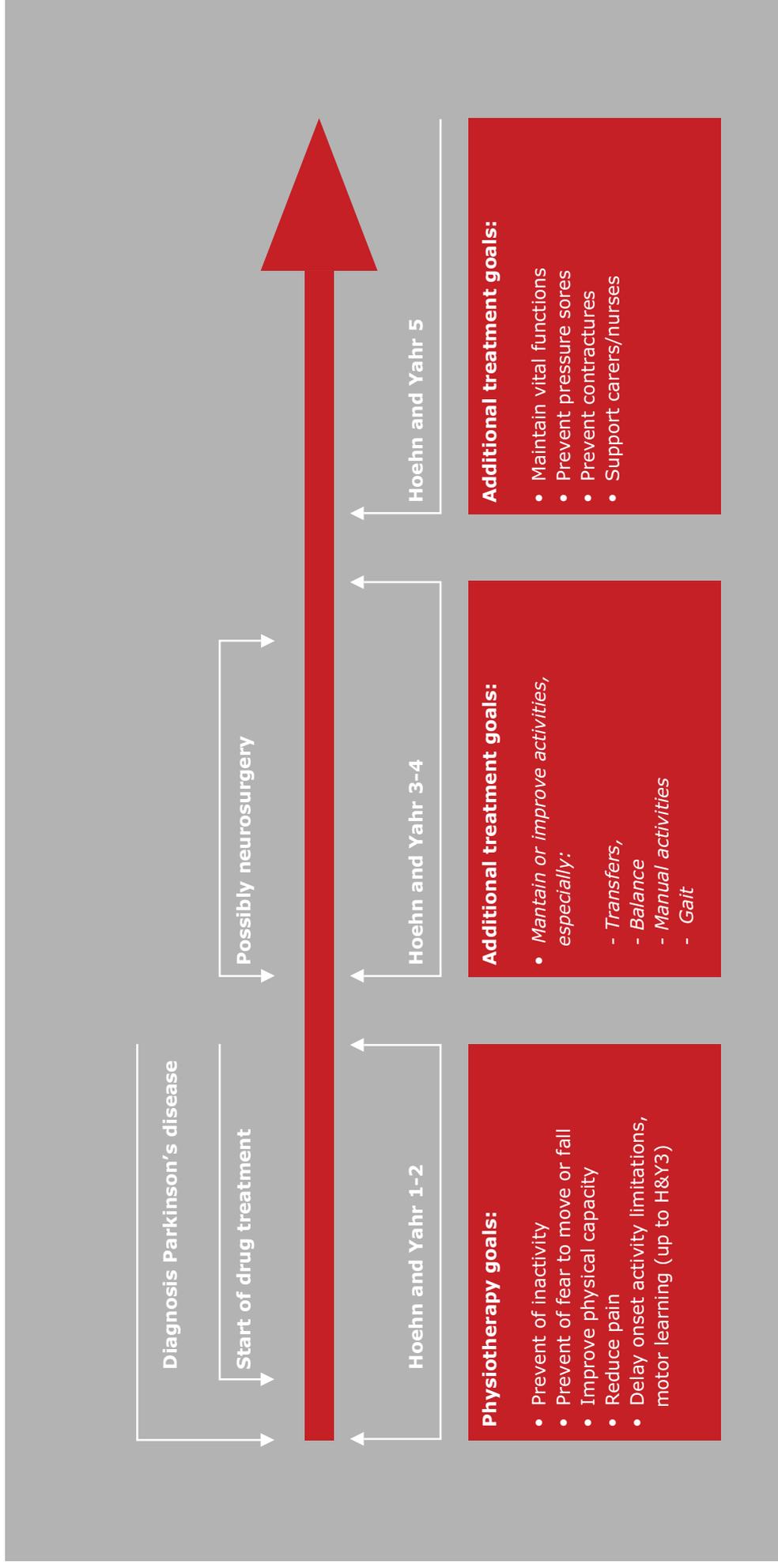
Quick reference card 1:History-taking

In addition, to gain insight in	
Patient's perceived problems	PIF Prioritise problems
Course of the disease and current status	Onset of complaints; how long since the diagnosis; result of earlier diagnostics; severity and nature of the condition
Participation problems	Problems with relationships; profession and work; social life including leisure activities
Impairments in functions and limitations in activities	Transfers Balance & falls Orthostatic hypotension; difficulty with dual tasking; <i>Use PIF &amp; History of Falling to record (near) falls and circumstances; in case of (near) falls use ABC for balance confidence or, for less ambulant pwp, the FES-I; provide Falls Diary to pwp who have fallen</i>
	Reaching & grasping What activities, e.g. household activities (small repairs, clean, cook, slice food, hold a glass or cup without spilling) and personal care (bath, get dressed/undressed)
	Gait Use of aids; short and long distances; relation to falls
	Physical capacity & Pain Physical capacity: easily out of breath; rapid onset of fatigue*, general tiredness (time of the day); muscle strength and range of movement; Pain: time of the day, location (e.g. specific or general) , quality (e.g. cramping, tingling, shooting), severity*
	Motor fluctuations unpredictable on-off periods*, dyskinesias* and OFF-state dystonia* <i>(if severe, advise pwp to anticipate medical consultation)</i>
Patient's tips & tricks	Tips & tricks the pwp uses to reduce or compensate for the problems
Physical activity	Compare to WHO recommendation of at least 75 min/wk vigorous exercise or 150 min moderate intensity
Co-morbidity	Diabetes; osteoporosis; pressure sores; and mobility-limiting disorders such as arthritis, rheumatoid arthritis, heart failure and COPD
Treatment	Current medical treatment and adverse events; earlier medical and allied health treatment (type and outcome) for current problem
Other factors	Mental factors Ability to concentrate; memory; hallucinations*; illusions*; apathy; depression*; impulse control disorders (e.g. repetitive activities)*; feeling isolated and lonely; being tearful; anger; concern for the future Personal factors Insight into the disease; socio-cultural background; attitude (e.g. with regard to work); coping (e.g. the perception of the limitations and possibilities)
	External factors Attitudes, support and relations (e.g. with partner, primary care physician, employer); accommodation (e.g. interior, kind of home); work (content, circumstances and conditions)
Expectations & motivation	Expectations of the patient with regard to prognosis; course of the treatment; treatment outcome; self-management; need for information, advice and coaching
*this information may be provided by the referring physician as they are included in the UPDRS	

Quick reference card 2: Physical examination

	Physical capacity & pain	Transfers	Reaching and grasping	Balance	Gait
<p><b>Physical examination</b></p> <p><i>Include any reported or detected sensory alterations plus description</i></p>	<p><i>Expressing itself in reduced:</i></p> <p><b>Endurance</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> exertion</li> <li><input type="checkbox"/> control of respiration</li> </ul> <p><b>Muscle strength</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> knee extensors</li> <li><input type="checkbox"/> plantar flexors of the ankle</li> <li><input type="checkbox"/> other, namely: .....</li> </ul> <p><b>Mobility of joints</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> thoracic spinal column</li> <li><input type="checkbox"/> cervical spinal column</li> <li><input type="checkbox"/> other, namely: .....</li> </ul> <p><b>Muscle length</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> calf muscles</li> <li><input type="checkbox"/> hamstrings</li> <li><input type="checkbox"/> other, namely: .....</li> </ul>	<p><i>Problems with:</i></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> sitting down (chair)</li> <li><input type="checkbox"/> rising from a chair</li> <li><input type="checkbox"/> rising from the floor</li> <li><input type="checkbox"/> getting in and out of bed</li> <li><input type="checkbox"/> rolling over in bed</li> <li><input type="checkbox"/> getting in or out of a car</li> <li><input type="checkbox"/> other, namely: .....</li> </ul>	<p><i>Problems with:</i></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> reaching</li> <li><input type="checkbox"/> grasping</li> <li><input type="checkbox"/> moving objects</li> </ul> <p>Limited activity: .....</p>	<p><i>During:</i></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> standing (eyes open / closed)</li> <li><input type="checkbox"/> rising from a chair</li> <li><input type="checkbox"/> turning while standing</li> <li><input type="checkbox"/> walking</li> <li><input type="checkbox"/> backward walking</li> <li><input type="checkbox"/> bending forward</li> <li><input type="checkbox"/> dual tasking with two motor activities e.g. walking and carrying an object</li> <li><input type="checkbox"/> dual tasking with a cognitive + motor activity e.g. walking and talking</li> <li><input type="checkbox"/> freezing</li> <li><input type="checkbox"/> reaching and grasping</li> </ul> <p><i>Problem expressing itself in:</i></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> falls</li> <li><input type="checkbox"/> near falls</li> </ul>	<p><b>Expressing itself in:</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> decreased trunk rotation</li> <li><input type="checkbox"/> decreased arm swing</li> <li><input type="checkbox"/> decreased speed</li> <li><input type="checkbox"/> shortened stride length</li> <li><input type="checkbox"/> variable stride length</li> <li><input type="checkbox"/> festination</li> <li><input type="checkbox"/> freezing: initiation</li> <li><input type="checkbox"/> freezing: turning</li> <li><input type="checkbox"/> freezing: obstacles</li> <li><input type="checkbox"/> freezing: doorway</li> <li><input type="checkbox"/> freezing: during walking</li> <li><input type="checkbox"/> freezing: dual tasking</li> </ul>
<p><b>Tools providing part of this information</b></p> <p><i>*can also be used for evaluative purposes</i></p>	<p>6MW</p> <p>Borg Scale</p> <p>5TSTS</p>	<p>Bed: M-PAS Bed</p> <p>Chair: M-PAS Chair &amp; TUG</p>		<p>Transfers: M-PAS Chair; 5TSTS</p> <p>Gait related: M-PAS Gait &amp; TUG; DGI* &amp; FGA; Snijders &amp; Bloem FOG test</p> <p>Stationary: BBS*</p> <p>General: Push and Release test</p>	<p>M-PAS Gait &amp; TUG*</p> <p>10MWT*</p> <p>6MW*</p> <p>Snijders &amp; Bloem FOG test</p>
<p>To describe a SMART treatment goal: Goal Attainment Scaling</p>					

Quick reference card 3: Specific treatment goals & interventions



Quick reference card 4: Treatment strategies

Treatment goal	Strategy
Prevent inactivity	Provide information on the importance of keeping active regarding prevention of comorbidity, cognitive function, neuroprotection and fun Promote the pwp (and caregiver) to self reflect, prioritise and apply problem solving skills related to issues of activity performance and participation
Prevent fear to move or fall	Provide information on the safety of exercising Practice transfers from the floor to sitting or standing
Delay onset activity limitations	Practice activities, using cueing strategies and applying motor learning principles: Practice from stable to variable task and contexts, from a set to a random order of tasks; many repetitions and context specificity; from single to (complex dual tasks training, provide positive feedback on performance and goal; use action observation and mental imagery
Improve physical capacity	See 'Prevention of inactivity' Address endurance, muscle strength (with emphasis on trunk and leg) and joint mobility (with emphasis on thoracic extension and rotation) and balance Progressively increase intensity, focus on large and high speed movements Aim for a combination of sustainable activities, preferred by the pwp, e.g. increased daily activities (e.g. taking the stairs, going for a walk), at a gym, in an exercise group (for the elderly or Parkinson's specific), dance, TaiChi, Nordic walking and sports (e.g. golf, tennis, cycling)
Neuroprotection	See 'Prevention of inactivity' and 'Improve physical capacity', with emphasis on endurance
Improve transfers	Practice transfers by using self-instruction strategies and cues for movement initiation in on and off phases Context specific, most likely in or around the pwp's home
Improve reaching and grasping	Practice reaching and grasping by using cues and self-instruction strategies Context specific, most likely in or around the pwp's home
Improve balance and prevent/reduce falls	Provide information and advice Target specific causes of falls, e.g. home furnishings, freezing (see 'Gait') Practice tasks appropriate to identified balance loss and train muscle strength, dance, TaiChi Context specific, most likely in or around the pwp's home If necessary, provide hip protectors
Improve gait	Practice walking using treadmill training or cueing strategies Cues for initiation and continuation, give instruction using large steps (attentional strategies) Train muscle strength and trunk mobility Context specific, most likely in or around the pwp's home
	Practice walking using treadmill training or cueing strategies Cues for initiation and continuation, give instruction using large steps (attentional strategies) Train muscle strength and trunk mobility Context specific, most likely in or around the pwp's home
Prevent pressure sores	Give advice and adjust the pwp's body posture in bed or wheelchair (possibly in consultation with an occupational therapist); (supervised) active exercises to improve cardiovascular condition and prevention of contractures