

European Physiotherapy Guideline for Parkinson's Disease

Developed with twenty European professional associations

Information for people with Parkinson's



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The development of this guideline was initiated and mainly financed by ParkinsonNet and the Royal Dutch Society for Physical Therapy (KNGF), the Netherlands



This Guideline is endorsed by the Association for Physiotherapists in Parkinson's Disease Europe (APPDE), the European Parkinson's Disease Association (EPDA) and the European Region of the World Confederation for Physical Therapy (ER-WCPT).



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

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

1st edition, December 2014

Design by Puntkomma

Reference to this publication

Keus SHJ, Munneke M, Graziano M, et al. European Physiotherapy Guideline for Parkinson's disease. 2014; KNGF/ParkinsonNet, the Netherlands

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European Physiotherapy Guideline for Parkinson's Disease

The European Physiotherapy Guideline for Parkinson's disease supports physiotherapists in taking decisions towards patient-centred, evidence-informed practice. It also offers people with Parkinson's disease (pwp) information and tools to manage their movement-related health to focus on goals that are important to them. Here we provide information for people with Parkinson's and, if applicable, their carers, to support optimal self-management and physiotherapy care.

A joint collaboration of 19 European countries

ParkinsonNet, a non profit foundation at the Radboudumc university medical centre aiming to improve Parkinson's care, and the Royal Dutch Society for Physical Therapy (KNGF) initiated the development of this first European Physiotherapy Guideline for Parkinson's disease. The Guideline Development Group (GDG) represents professional physiotherapy associations from 19 European countries. Pwp were involved in the Guideline development from the outset and have contributed throughout the process. The Guideline is endorsed by the Association for Physiotherapists in Parkinson's Disease Europe (APPDE), the European Parkinson's Disease Association (EPDA) and the European Region of the World Confederation for Physical Therapy (ER-WCPT).

Appendix 1

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

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

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

1. Exercising regularly

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

Some general advice for keeping active:

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

2. When should you visit a physiotherapist?

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

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

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

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

What to expect when you visit a physiotherapist?

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

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

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

Before your visit:

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

At your visit:

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

Appendix 2

Pre-assessment Information Form (PIF)

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

Date: _____

Your name: _____

Your physiotherapy goal

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

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

3. How effective were these methods?

4. What are your expectations of physiotherapy?

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

6. Any other questions you want to ask?

Falls

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

- No
- Yes

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

- No
- Yes

9. How afraid are you of falling over?

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

Freezing of gait

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

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

- No
- Yes

Physical activity

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

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

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

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

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

14. Why did you stop?

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

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

16. Please tick whether you experience these sensations:

Domain	Activity	Difficult	Not difficult
Physical functions	easily out of breath		
	muscle weakness		
	stiffness		
Pain	pain		

Appendix 3

Information for carers & home care professionals

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

How to assist pwp with moving around and performing activities?

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

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

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