

Ratgeber Parkinson – Englisch

Parkinson's disease

Plain and simple

The Guide



A Sandoz Brand

In simple terms

Parkinson's disease

1

Causes

- Dopamine deficiency

In most cases, unknown ("primary syndrome").

Possible causes:

- Free radicals
- Environmental toxins
- Heredity
- Accelerated aging
- In the secondary syndrome:
Another disorder



Symptoms

The main symptoms are:

- Slow/loss of movements
- Trembling
- Increased muscle tension ranging as far as stiffness
- Difficulty walking or balancing

Non-



Deep brain stimulation



Physical/
occupational
therapy, sport

drug therapy



Speech therapy



Psychological care

3

Drug therapy

Objective: to eliminate dopamine deficiency and improve symptoms. In general, doctors draw on six groups of active substances, often in combination with each other.



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Tips for Daily Life

5



Balanced diet



Domestic care



Healthy sleep



Happy partnership

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Important note for readers

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Dear Reader,

Approximately 250,000 to 280,000 Germans have Parkinson's disease, according to the German Parkinson's Disease Society (DPG). This neurological disorder takes the form mainly of tremors, slow or impaired movements, increased muscle tension ranging as far as stiffness, and difficulty walking or balancing.

In the early stages of the disease, movement problems can usually be successfully treated with medications. Patients themselves can also enhance their well-being through their own activities and adaptations in everyday life. This includes sports, a healthy diet, adequate sleep and emotional balance. This guide provides you and your family with valuable tips.

Please talk to your doctor or pharmacist if you have any other questions.

We wish you good health.
Your 1 A Pharma Team

What is Parkinson's disease?

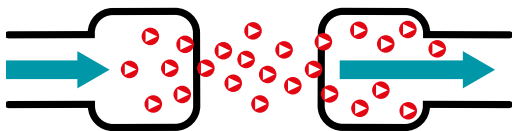
Parkinson's disease is one of the most common progressive disorders of the central nervous system. It is also known as primary parkinsonism or idiopathic (= no known cause) Parkinson's disease (IPD).


According to the German Parkinson's Disease Society, approximately 250,000 to 280,000 people have the disease in Germany, primarily people between the ages of 50 and 79. More men than women are affected. The German Parkinson's Disease Society estimates, based on current studies, that the number of patients will increase significantly by 2030. It is primarily the longer life expectancy of people that is responsible for this.

What happens in Parkinson's disease?


In Parkinson's disease patients, the chemical processes in the brain go haywire. Certain messenger substances, such as dopamine, allow the brain cells to communicate with each other. Parkinson's disease, on the other hand, causes certain nerve cells that produce dopamine to gradually die off. This results in movement difficulties and loss of movements, in the worst cases even movement rigidity and muscle

stiffness, postural instability and tremors. Medical professionals speak of a “syndrome” when several signs of illness (symptoms) – as in Parkinson’s disease – make up a disease. The British doctor James Parkinson first reported on the disease in 1817. The condition was therefore named after him.



The messenger substance dopamine  allows brain cells to communicate with each other in healthy individuals.



Dopamine deficiency  causes movement difficulties and loss of movements in Parkinson’s disease patients

Parkinson’s disease is a chronic disorder, which means that it develops slowly over a long period of time. It is also progressive. This means that the symptoms worsen over time. The disease is not contagious, however.

What are the causes of Parkinson's disease?

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In most cases, the reason why dopamine-producing nerve cells are dying off is unknown (idiopathic Parkinson's disease). Some scientists place the blame on free radicals. Free radicals are a product of certain metabolic processes. Environmental toxins, for example heavy metals, may also be a possible cause. In rare cases, the predisposition for this disease is inherited. Parkinson's disease may be favoured when the normal – age-related – die-off of nerve cells in the brain is speeded up (accelerated aging). Why this happens is still unknown, however.

Many scientists blame a combination of these four factors – free radicals, toxins, genetic factors, accelerated aging – for someone developing Parkinson's disease.

In addition to primary Parkinson's disease, there are secondary and atypical forms. "Secondary" means that the Parkinson's disease is caused by another disorder or another condition. These include long-term effects of certain drugs, tumours, "calcification" of the vessels in the brain (arteriosclerosis), strokes, head injury, brain inflammation and other types of brain damage.

In atypical Parkinson's disease, patients complain of a rapid worsening of their condition and symptoms. This includes frequent falls backward or dementia at the beginning of the disease. Often, atypical Parkinson's disease occurs in the context of other disorders called "neurodegenerative diseases". These are gradually progressive, only intermittently occurring or inherited disorders of the nervous system.

What are the symptoms of Parkinson's disease?

Doctors speak of Parkinson's disease when, in addition to the slowness or loss of movements, known as "akinesia" and "bradykinesia", one of the following three ("cardinal"/key) symptoms is present:

- Trembling (tremor)
- Increased muscle tension, which leads to stiffness (rigor)
- Gait or balance disorders (postural instability)



Loss of movements



Tremors



Increased muscle tension



Balance disorders

An additional criterion is that the symptoms arise over a prolonged period of time.

Akinesia makes dressing and undressing, for example, more difficult. Spontaneous and involuntary movements are sometimes completely absent. This often impacts patients the most, because even activities that are taken for granted are then hardly or no longer possible. A patient who was able to move normally shortly beforehand may now need outside help from one moment to the next.

The first sign may be that an arm swings less than normal when walking. Voluntary movements such as walking, standing up or turning can only be done very slowly and with great difficulty. Spontaneous and involuntary movements are sometimes completely absent. External signs may be a stooped posture and a shuffling walk. To turn around, a patient needs many small intermediate steps. Akinesia also affects gestures and facial expressions – such as with rigidity. Swallowing and speech disorders may also occur. In many Parkinson's disease patients, the voice becomes quieter or more monotone (microphony). Others have problems due to increased saliva production when eating. In others, the handwriting changes (micrography).

Resting tremor occurs especially when patients are completely relaxed or when they let their arms hang while standing or walking. Trembling usually begins on one side and gradually becomes a slow, rhythmic tremor. First it affects the hands, then later the feet or jaw as well. Typical is a movement reminiscent of counting coins or rolling a pill between the thumb and forefinger. During exertion, cold weather or under severe stress, the tremor often increases temporarily. In contrast, the tremor disappears during sleep. When making voluntary movements, for example when reaching out to shake hands or hold a steering wheel, the tremor decreases.

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This should be distinguished from what is called an "essential tremor", when the patient's hands tremble while holding something or performing a movement. Medical professionals call this an action tremor – in contrast to the resting tremor of Parkinson's disease. The cause of essential tremor is largely unknown.

During rigor, the muscles of the arms, legs or trunk, for example in the neck and shoulders, stiffen. These symptoms may exceed age-related movement restrictions or arthritis symptoms.

“Postural instability” causes unsteadiness when walking and standing. The patient is bent forwards or backwards when walking and standing, which increases the risk of falling.

Not every patient has all four major symptoms. In addition to these movement-related (“motor”) complaints, there are numerous other symptoms.



Sleep disorders
or sleep attacks



Depression



Concentration
disorders



Sweats



Constipation
and problems
passing urine



Sexual function
disorders

These may include:

- Increased sebaceous secretion with dandruff and greasy, shiny facial skin (seborrhoeic dermatitis).
- Impaired sense of smell
- Delusional disorders
- Memory disorders
- Behavioural disorders
- Abnormal sensations and pain, for example in the arms and legs or on the skin

The course of the disease and the symptoms can differ greatly from one patient to another.

How is Parkinson's disease diagnosed?

If a person's handwriting gets smaller, it may or may not be the first indication of Parkinson's disease. The same is true for other signs such as frequent falls, an impaired sense of smell, problems with everyday hand gripping, such as when brushing the teeth, or severe muscle tension. Observations of family members often help. The German Society for Neurology (DGN) has published a guideline along with other specialist societies, professional associations and organisations. This makes it easier for physicians to make an early diagnosis of "Parkinson's disease". In addition to akinesia, at least one of the three named cardinal symptoms must also be present.

There are also numerous other methods for ascertaining the correct diagnosis. These include comprehensive examinations and functional tests of the nervous system, for example of the reflexes and eye movements. The response to medications that have proven themselves in Parkinson's disease also supports the diagnosis. For this, physicians may use a test with dopamine agonists, L-dopa or apomorphine. All of these are active substances that have proven successful in numerous cases of Parkinson's disease.

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Imaging procedures have also been used when Parkinson's disease is suspected. These include computed tomography (CT), magnetic resonance imaging (MRI) and positron-emission tomography (PET).

How can Parkinson's disease be treated?

The good news for patients is that their condition can be treated. The therapy consists of several building blocks. The most important one is the use of medications. Crucial here is regular communication between the treating doctors, such as neurologists, psychiatrists, internal medicine specialists and the family doctor.

Drug therapy

Dopamine deficiency in the brain causes most of the symptoms in Parkinson's disease. The objective of drug therapy is therefore, usually, to counteract this deficiency. In addition, the medications are supposed to stop trembling and muscle stiffness. Even in the early stages of the disease, the movement difficulties are usually well handled with medication. It is important for the medication to be taken punctually at the time specified by the doctor.

Therapists very frequently combine different medications. The most successful active substances for the treatment of Parkinson's disease include:

- L-dopa/ dopa-decarboxylase inhibitors (including pump-delivered therapy)
- Dopamine agonists
- MAO-B inhibitors (monoamine oxidase B inhibitors)
- Anticholinergics
- COMT inhibitors (catechol-O-methyltransferase inhibitors)
- Glutamate antagonists/NMDA-receptor antagonists (including amantadine)

In some patients, unwanted symptoms can occur at the beginning. These are side effects. Doctors see fluctuations in patients who take L-dopa over a long period of time. In these patients, the effect varies and exaggerated movements occur – the consequences of progressive disease. Therefore, doctors usually prescribe L-dopa as late as possible, but as early as medically necessary. Previously, the Parkinson's guidelines recommended that treatment with other drugs, usually dopamine agonists, be preferred.

The side effects do not occur with every active substance or in every patient equally. Most subside after a few days. Sometimes medicines that are taken simultaneously can have an effect on one another. Interactions then occur. It is essential to inform your doctors before starting to take a medicine if you are already taking other medicines – even ones you have obtained without a prescription.

 **Important**

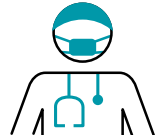
Have regular checkups with your doctor. Parkinson's is a progressive disease. The effect of certain medications may be reduced over time. This makes it necessary to adjust the medication after a while, under certain circumstances.

Non-drug therapy

In some patients, the symptoms can no longer be controlled by medication. Even patients who are largely stabilised by medication are often helped by additional, non-drug treatment. Changes in lifestyle can also have a beneficial effect on the disease course.

Surgical procedures (deep brain stimulation)

In many Parkinson's patients, the effect of L-dopa is reduced over time. The possible result is exaggerated movements. In cases where there is no alternative drug, brain surgery may help. Even with a tremor that cannot be treated with medication, surgery may be an option. With the procedure called "deep brain stimulation", the doctor places electrodes at a certain place in the brain. They have a positive effect on akinesia, tremor and rigor.



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Speech therapy

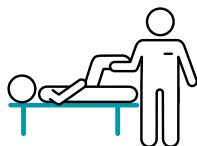
Parkinson's disease can cause speech and swallowing disorders. Often, the voice becomes very quiet and unclear. Regular breathing before speaking and between sentences may help.



Use short sentences. Make a conscious effort to speak loudly. A trained speech therapist helps with body perception, breathing, movement, posture and voice. These exercises can be continued by the patient independently.

Physical/occupational therapy and sports

Physical therapy is an important addition to drug therapy. It usually consists of stretching exercises and endurance and strength training.



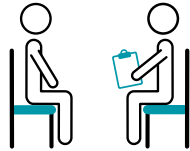
This improves and maintains

mobility in the joints and muscles. Occupational therapy helps the patient deal with everyday tasks independently and participate in hobbies for as long as possible. It trains the patient in the use of aids as needed. It also demonstrates how the home environment can be adapted to the needs of Parkinson's disease patients. This applies, for example, to dressing, eating and body care. If appropriate, the occupational therapist might involve family and friends to assist the patient in his or her everyday tasks. Regular sports activities can also enhance the treatment and general well-being of the patient. This allows many patients to control their physical symptoms better. Not

every type of sport is suitable for every patient. Which sport and to what extent should be decided by the patient in consultation with his/her doctor. Choose a time for your activities when your medications are working well and you feel rested.

Psychological care

Maintaining a positive attitude towards life despite the diagnosis of Parkinson's disease is certainly not always easy. However, it is of great importance for a positive effect on health as the condition continues. Parkinson's disease does not necessary lead to a life of constant physical decline and disability. Over time, many patients develop a positive attitude towards life. They preserve their energy, activities and important interpersonal relationships.



Nevertheless, Parkinson's disease may be associated with numerous stresses, for family members as well, including due to depression. Depression is a condition to be taken seriously. Please contact a psychologist or neurologist if you suspect you have depression.

Tips for daily life

In addition, every patient can independently contribute to alleviating symptoms – in addition to medication.



Balanced diet



Domestic care



Healthy sleep



Happy partnership

Balanced diet

Even if there is no special “Parkinson’s disease diet”, balanced nutrition and sufficient fluids help. For example, they prevent constipation, which is a common problem in Parkinson’s disease. The body requires sufficient amounts of energy, protein, vitamins, minerals and fibre. Eat a lot of cereal products, fruit and vegetables. Avoid fat, saturated fatty acids,

high-cholesterol foods and sugar. You should drink alcohol in moderate amounts only. Small portions distributed throughout the day help combat loss of appetite, nausea and the resulting weight loss.

When taking L-dopa, a protein reduction may be appropriate in the advanced stages. Discuss this with your doctor.

Domestic care

If independent care is no longer possible, especially as the disease progresses, nursing care may be an option. This is done at home or in a nursing home. Talk to your health insurance provider regarding whether it will pay for such expenses in your case.

Healthy sleep

Parkinson's disease and its drug treatment may impact sleep behaviour. Many patients awaken easily and are usually very tired during the day. They often talk or cry out in their sleep, or have very vivid dreams. They have leg movements, twitches and spasms. Sometimes, they find it hard to turn over in bed. They occasionally wake up because of an urgent need to pass urine.

What helps?

- Maintain a regular day and night routine as much as possible.
- Try to get up and go to bed at the same times daily.
- Drink as little as possible for four hours before going to bed. Go to the toilet immediately beforehand.
- Maintain a somewhat cooler temperature in the bedroom than in other rooms. Make sure that the bedroom is sufficiently dark. Ensure restfulness and quiet.
- Go to bed only if you really feel tired. If you have not yet fallen asleep after about 15 minutes, get up again and do something relaxing. Listen to music, for example, until you become sleepy.
- Avoid alcohol, coffee and nicotine, heavy high-calorie meals, and excessive physical activities for four to six hours before sleep.

Happy partnership

Parkinson's disease can also impact your partnership. Openness and acceptance are important. A couple's therapist may help in case of problems. He or she can help you work on the relationship and on finding new solutions in conflict situations. It is important that both partners have a detailed awareness of the disease. Don't hesitate to take your partner with you to visits to the doctor. In the context of the disease and treatment with medications such as L-dopa, there may be sexual function disorders. In men, erection disorders may occur. A urologist (a doctor who specialises in the urinary system) helps in such cases.

Many older couples find that it is more pleasant for them to have sexual intercourse in the morning. This is the time of day when testosterone levels are at their highest in men. This increases the man's ability to maintain an erection. Patients should plan their sexual activities for when their medications are working the best and the symptoms are weakest.

Where can I get help?

Deutsche Parkinson Gesellschaft (DPG) e. V.

Reinhardtstr. 27 C • 10117 Berlin
www.parkinson-gesellschaft.de

The German Parkinson's Society is an association of doctors. They desire to improve the care of patients and enable the early diagnosis, prevention or cure of Parkinson's disease. The DPG supports research and wants to further develop diagnostic methods and research new forms of treatment.

Kompetenznetz Parkinson e. V.

Administrative Office
Struthweg 1 • 35112 Fronhausen-Bellnhausen
Phone: 06426 8195946
kontakt@kompetenznetz-parkinson.de
www.kompetenznetz-parkinson.de

The association of doctors and researchers aim to connect Parkinson's disease experts from various levels nationwide. Patients also receive abundant information and contact points.

Deutsche Parkinson-Vereinigung (dPV) e. V.

Moselstraße 31 • 41464 Neuss

Phone: 02131-74027-0

bundesverband@parkinson-mail.de

www.parkinson-vereinigung.de

The dPV is a self-help organisation. It is made up of Parkinson's patients, their family members and supporters. The working areas of the federation include public education and political lobbying. The dPV is also there to counsel and support patients, family members and medical professionals.

Parkinson Web

Gertrudis-Klinik Parkinson-Zentrum GmbH

Karl-Ferdinand-Broll-Straße 2-4 • 35638 Leun-Biskirchen

Phone: 06473-305-0

Parkinson-Center@t-online.de

www.parkinson-web.de

Parkinson Web is a cooperation of the Deutschen Parkinson-Vereinigung e. V. and the Gertrudis-Klinik Biskirchen. The platform offers comprehensive information for family members and patients.

Visitors can share their experiences with patients and experts in the forum.

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Einfach verstehen.