



# PARKINSON'S GOES TO WORK



Guide for people with Parkinson's  
disease of working age

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## Parkinson's goes to work

There are over 10,000 people in Finland who suffer from Parkinson's disease. The majority of them are retired, around 3000 have got this disease in working age. Every year some hundred Finnish people have to tell their employer this bad news: "I have received a diagnosis of Parkinson's disease". Many of them take some time before they tell about their disease; some people hide the disease from their coworkers for years before informing their employer of the diagnosis with slightly shaking hands.

This disease is sad especially from the employee's point of view, the illness is se-

vere and there is no cure for it at the moment. What does this disease mean in the workplace for the employee with Parkinson's, the coworkers and the employer? What should be done? This Parkinson's brochure is designed to give answers to those questions.

## Take it easy

Parkinson's is a slowly progressive disorder. Changes develop gradually; a year with this disease is a short time. During the initial phase of Parkinson's the worst is worry about the future and how things will work out with the illness. One of the main concerns is worry about work and income.

## WHAT IS PARKINSON'S DISEASE?

The main symptoms of this disease are:

- tremor particularly at rest and while walking
- muscle rigidity
- slowness of movement
- problems with balance
- symptoms result from the lack of a chemical messenger, called dopamine, in the brain
- symptoms get worse over time, generally slowly
- the exact cause of Parkinson's disease is not known
- there is no cure for the disease, but symptoms can be relieved with medication and rehabilitation

## Parkinson's affects everybody differently

There are many different symptoms in this disease. Every patient has his or her own Parkinson's, which progresses in its own unpredictable manner. It is common belief that there are good medications for the disease. This is true, and there are also other good disease treatments. However, their influence and effect are very individual and change (usually decrease) with time. Additionally, each patient has his or her own work with its specific requirements, so it is difficult to assess the impact of the disease on an individual's ability to work.

## No Panic

Your coworker is the same Eve or Ethan as before. At first he or she can perhaps continue working as earlier; however, changes in work ability have to be clarified and need to be considered. The patient can have mood changes, the disease adds stress. Understanding this could help in the workplace.

## Keep up to date

Gradually symptoms start to increase... tremor, rigidity, slowness, problems with balance. Typical for this disease is that it advances, slowly but surely. When the medications are regularly reviewed and adjusted, the patient feels better. However, daily changes are typical for this disease, sometimes changes even during a day; the effects of the medications vary. When the employee is not anymore able to work as before, support helps, studies have confirmed this. Do not urge the patient to "hurry up", it does not help, on the contrary.

## Controlled progression

It is good for the patient and also for the coworkers that the patient adapts to reduced work ability. If needed the employer is obliged to take "moderate action in supporting the disabled with work and career"

(Equality law 5 §). Moderate in this connection means financial cost to the employer. There are several ways to proceed. Evaluation of work ability gives a good ground:

- change job description
- lighter work
- change work practices
- flexible working
- rest breaks
- telecommuting
- share work

## The Social Insurance Institution of Finland (KELA) and pension insurance companies help

When the work ability starts essentially to reduce and the employee is faced with disability he or she can get rehabilitation from pension insurance companies and KELA.

This support can include for instance:

- work trial
- job coaching
- re-education
- aids and equipment
- entrepreneur support.

During rehabilitation the employee is entitled to financial help and support. The employer does not need to pay extra for vocational rehabilitation, on the contrary: successful vocational rehabilitation reduces sick leaves and future retirement costs. When symptoms of the disease increase there are different ways in which the work ability can be supported, e.g. the Disability law ensures a personal assistant for a severely disabled employee who can also help at work, and a partial disability pension is a good solution before the full-time pension.

## Information on Parkinson's disease

[www.parkinson.fi](http://www.parkinson.fi)

A book named Parkinson as a companion traveler written by neurologist Kari Aho is a thorough description of the stages of his disease.

Information on rehabilitation:  
[www.kela.fi](http://www.kela.fi) and the home pages of pension insurance companies (Varma, Ilmarinen, Etera, Eläke-Fennia, Eläke-Tapiola, Keva)

## Exploit work experience

The best result for all involved is when the remaining work ability and perhaps a long work experience are exploited in planned co-operation with occupational health and the employee considering at the same time the patient's condition and work requirements.

The question is about years not decades. Approx. the half of those employees who have got this disease in working age retire within two years after the diagnosis, but there have also been patients who have continued working with this disease even 15 years before retirement.

For many people work is a so important part of life that they do not want to give it up easily. These patients are usually well educated and very motivated to advance their work career, which usually ensures a good contribution.

## Do not guess, find out

There are only few workplaces where people know what Parkinson's really is. Years ago people used to be afraid of this disease or at least they were suspicious.

Even today many people are so afraid of losing their job that they try to hide their disease as long as possible. However, this

disease is not contagious, does not spoil products or the good image of a company

An employee with Parkinson's does not tolerate haste or tight timetables as before; he or she becomes tired easier than before. When the disease progresses it may affect finger dexterity, reduce facial expressions and voice loudness, it may also make the handwriting smaller and messy. In later phases it may perhaps affect the memory. But one can live with it – the patient, the employer and coworkers as well.

## Telecommuting on some weekdays

I received the diagnosis of Parkinson's in 2007 and told immediately about it to the employer and coworkers; I could not have hidden the disease and did not feel it as necessary. My symptoms are rigidity on the left side and problems with balance.

My work is challenging in managing different EU-projects. The work demands travelling to different countries in Europe and also holding meetings. I have coped with Parkinson's quite well, but I have also diabetes and in winter 2010 I became rather tired. There are "peak days" in my job, which cannot be avoided in any way - you have to write final reports or there are other deadlines. In those cases working days usually last until the evening.

## Stories

Every patient with Parkinson's of working age has his or her own story.

Here are a couple of stories on different situations in workplaces

In spring winter some hair fractures were found in my foot. I had a walking stick, but it was still difficult to walk. Many times I took a taxi to come to work in time – I felt myself clumsy and slow in the morning. I

## *Parkinson's disease caused fatigue and I could nap on my PC. Work took all my energy.*

was also on sick leave, work piled up.

Finally in spring I was so exhausted that I had to tell my employer that I could not continue the same way. He suggested a meeting with the occupational health doctor; the doctor, my supervisor, personnel manager and me participated in that meeting. Before that I had talked to the doctor myself and we had come to the conclusion that the doctor – not me – would make a proposal to my employer: I would start working 2-3 days at home, where I could rest - if needed - during the day and then continue with the work.

The employer approved this proposal. Additionally, my supervisor suggested that I would not start working on office days until at 10 a.m. so that I would have enough time in the morning. Of course I would then work longer in the afternoon when I work better and have more energy.

The employer has bought the tools (PC etc.) to my home and I have remote desktop connection to my workplace. The employer pays the half of the Internet connection costs. If needed, even a physiotherapist from the occupational health comes to check the ergonomics. I write my tasks in an hour list and keep a "diary" on my work. This helps me prioritize my duties and reduces unnecessary stress.

In my case telecommuting is possible and I'm very satisfied with the current arrangement. I believe that my employer is also satisfied.

*A woman, 55 years*

### **Partial disability pension**

I got the diagnosis in 2005. I felt as if I saw my life from outside, like an actor in a film.

First I did not tell about my disease in the workplace. Instead of casual clothing I started to use suit and tie. Under the formal

clothing I hid my symptoms, the rigidity of the left arm and upper body. The following year I applied for an adaptation training course and told about the diagnosis to my employer and a couple of coworkers. It was difficult to tell, but I preferred to stop hiding the disease.

I was busy in education planning work and as a trainer. At the same time there were several trainings going on, mainly web courses, but also classroom teaching. In meetings I was crusty and waspish. Parkinson's disease caused fatigue and I could nap on my PC. Work took all my energy.

In 2008 I got partial disability pension. At the same time I gave up a part of my duties, e.g. planning of time taking order trainings. A shorter working day has been a good decision. Now I have time and energy also for other things than work.

Work is still interesting and an important part of my life. However, during the part-time retirement work load has slowly increased. I have planned new trainings, social media has become as a part of the daily life, training takes perhaps more time than before – all in all haste is again a part of the working days.

In the workplace we have decided that another worker would start to learn my tasks so that if needed we could share the duties and I had a deputy during possible sick leaves or rehabilitation periods. A trained coworker would reduce my concerns about work when I'm at home.

*A man, 53 years*

### **Changed work practices**

My first symptoms were stuttering and difficulty in forming words. Then I had problems with balance during walking or cycling. A diagnosis was made a year ago. I

## *Knowledge and long experience in customer service do not help if speech trembles and the voice becomes more and more quieter during a conversation.*

got the Levodopa medication at the same time.

The following day I told about my disease to my employer and also to my coworkers. I'm an optician. The disease was totally strange for me.

My employer asked me what kind of disease Parkinson's is. I answered I do not know. This is almost all that I have discussed the disease with him. My coworker had an acquaintance suffering from the same disease and he told about his experiences.

Clumsy fingers and finger energy deficit had already earlier changed my work practices. Part of an optician's work are eye tests and proving of contact lenses. However, the main part of the work is customer service. All these areas require clear speech and assertive approach. Knowledge and long experience in customer service do not help if speech trembles and the voice becomes more and more quieter during a conversation.

At work I feel myself really disabled and embarrassed while the others have to take care also of my duties. We are four opticians; when one is out of the game, the percentage shortfall is drastic. I spend my working day alphabetizing customer data sheets and entering the data into files. The employer told me that I can continue working as long as I can.

I have never been on sick leave due to my disease. I just went to the occupational health doctor to talk about disability pension and the next step is to talk about the same matter to my employer.

I can only say thank you to my coworkers. They have not made my work difficult, on the contrary.

*A woman, 53 years*

### **An entrepreneur's long way to diagnosis and relief**

Perhaps Parkinson's was already a part of my life, when I "luckily" experienced a years' period with only 3-5 hours' sleep at night. At that time I felt myself as a superman. I was 30 years old.

Actually I recognized symptoms later, in 2000, when I was 43. Hassle stopped insidiously. Symptoms differ depending on work. My work quality remained as I'm strict in what I give away. I started to work longer, decision-making became more difficult.

First the demanding jobs had to be done before 2 p.m., then before noon, before 9 and finally before 7 in the morning to be able to do something. The consequence was that my morning began at 3-6 at night. I spent weekends at work.

All the time I found out new ways in which I could manage the work. An entrepreneur can work how long he or she wants. I was more and more tired.

The mood changed from optimism to pessimism, from one end to another. In better days I "bought" and in worse days "sold" everything.

The symptoms increased quickly and showed as rigidity and slowness. I failed in shaking hands, my hand stuck on the door knob, my head did not reach the pillow when I went to bed.

It took a painfully long time to get the diagnosis; I used to be diagnosed as fit. I started to suspect myself. A year after the first visit to a doctor the reason for my first sick leave was finally clarified. I got the diagnosis in 2003 when I was 46 years old.

Parkinson's came to work and fulfilled

*But death did not come. With medication and good mood I began to feel better. I continued in the same company as an assistant. So Parkinson's disease does not always hinder activities and work.*

my leisure time. Till 2005 I had given up my partnership and leadership. At the same time I got a year's sick leave and then pension.

But death didn't come. With medication and good mood I began to feel better. I continued in the same company as an assistant. In 2006 we still established a new firm, where I worked till 2008 according to my condition. After the diagnosis I had to give up the driving license. However, I obtained it back. In 2008 I also got a stimulator, which evened changes and I could decrease medication.

Parkinson's disease does not always hinder activities and work. It is individual. Some people can work longer; others' work ability reduces more quickly. Those who have energy and work ability should be able to continue at work as long as they can.

Making a diagnosis of this disease is usually difficult and a heavy period. It would be good to be able to recognize the disease in an early phase to avoid overworking. The society offers today many ways to continue working; they have only to be found. Working hours and atmosphere influence on everybody's work ability. Family members' support is vital; important is also the support from other Parkinson's patients, when you share experiences with them. Every day you have to remember your medications, physical training and stretching.

*A man, 53 years*

*We wish to thank all the people in Parkkispaiikka and in the Parkinson's groups for patients in working age in Helsinki and Facebook for contributing to making this brochure.*

The Finnish Parkinson's Disease Association is working for those who suffer from the Parkinson's disease or other more rare neurological diseases: information, advice, adaption training and rehabilitation courses, holiday and emotional support activities.

In queries for the disease, social security and physical activities please call the telephone service of the Parkinson's Disease Association +358 203 77667.



SUOMEN PARKINSON-LIITTO RY  
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