



## Neurodegenerative diseases in the workplace

**SUMMARY** *Hundreds of thousands of working-age Europeans suffer from neurodegenerative diseases (NDD) such as Alzheimer's disease (AD) and other dementias, Parkinson's disease (PD) and multiple sclerosis (MS).*

*With an increase in retirement age and in life expectancy, the number of both NDD patients and carers of working age is expected to increase in the coming decades.*

*Patients, carers and their employers face numerous challenges in the workplace. The Equal Treatment Directive requires employers to accommodate disabled employees.*

*The EU supports research on NDD diagnosis and treatment and helps coordinate Member States' research through 'Joint Programming Initiatives'. The European initiative on Alzheimer's and other dementias aims for early diagnosis, sharing of best practice and improved knowledge.*

*The European Parliament has repeatedly emphasised the importance of addressing the challenges of NDDs in research, social and health policies. MEPs have called for promotion of flexible employment policies for people with chronic neurological disorders.*

*NGOs call for awareness-raising, improved diagnosis and better access to support services for patients and carers.*

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### Neurodegenerative diseases

Neurodegenerative diseases (NDD) are characterised by the progressive loss of the structure or function of nerve cells – neurons – including their death. Three NDDs – [Alzheimer's disease](#) (AD), [Parkinson's disease](#) (PD), and [multiple sclerosis](#) (MS) – account for the majority of cases.

In addition, there are a number of rare NDDs, which affect less than one in 2 000 people. These include spinal muscular atrophy (SMA), amyotrophic lateral sclerosis (ALS) and other motor neuron diseases, Huntington's disease, and prion diseases (for example Creutzfeldt-Jakob disease).

Stroke, brain cancer and spinal cord injuries, which exhibit similar symptoms and issues, are sometimes mentioned in connection with NDDs.

### Alzheimer's disease and other dementias

[Dementia](#) is serious loss of cognitive ability. AD is the most common cause of dementia in the EU, accounting for 50 to 70% of all dementia. It is characterised by a shrinking of the brain and reduced levels of some neurotransmitters (chemical substances that transmit nerve impulses).

Dementia usually starts with memory problems and progresses slowly until patients are no longer able to care for themselves. Symptoms of dementia include difficulty in solving problems and completing familiar tasks, problems with



Image courtesy of NASA

*Stephen Hawking, theoretical physicist suffering from amyotrophic lateral sclerosis (ALS), speaks at NASA.*

words, impaired judgment, and changes in mood and personality.

Dementia mostly affects people over 65, and is a leading cause of disability in the elderly. Only one third of dementia patients under 65 suffer from AD, other dementias are more common among [younger people](#).

As AD eventually leads to other illnesses such as pneumonia, it is a life-shortening condition.

The causes of AD are not known, and the disease is not preventable. The most important risk factor is age.

The diagnosis of AD is complex, and there is no single test to diagnose the disease. As a result, the diagnosis is often made some time after the onset of the first symptoms.

Presently there is no cure, but medication can slow the progression of the disease and reduce symptoms, so that patients can remain active for a longer period.

### **Parkinson's disease (PD)**

PD is the second most common neurodegenerative disease after AD. It is characterised by problems with body movements such as tremor at rest, slowing of voluntary movements, impaired speech, and muscle weakness. Other possible symptoms include pain, sleep disturbance, depression, loss of sense of smell, constipation and dementia.

PD is a chronic and progressive neurological condition connected to a lack of dopamine and other neurotransmitters. The disease progresses slowly. Although it is not life-threatening, it can shorten life expectancy.

The disease is not preventable, and its cause is not known. The main risk factor is age.

Diagnosis is difficult, and there is often a delay between the first onset of symptoms and diagnosis.

Currently, there is no cure, but early pharmacological treatment can improve quality of life. The disease is best treated in a multidisciplinary approach, which includes

physiotherapy, speech and language therapy and occupational therapies.

### **Multiple sclerosis (MS)**

MS is most often diagnosed when people are in their 20s and 30s, although it can also develop in older people and sometimes in children. MS is a chronic inflammatory disease which impairs the functioning of the nervous system. It is considered as an autoimmune condition in which the body's immune system attacks cells in the central nervous system.

MS is long-term, fluctuating and evolves unpredictably. It has only a small effect on life expectancy, so that people can expect to live with MS for a long time.

Symptoms include spasticity, bladder and bowel problems, double vision, tremor, dizziness, depression, fatigue and pain. Most patients experience only some of these symptoms.

MS is a fluctuating disease, in which periods without disease activity are followed by 'MS attacks' which can cause lasting damage.

As with other NDDs, diagnosis is difficult and there is no single test, so that there will be a delay between the first symptoms and the diagnosis.

There is currently no cure for MS, but medication can reduce the frequency and severity of MS attacks.

## Neurodegenerative disease in Europe

AD, PD and MS account for the vast majority of NDD cases in Europe, with other NDDs much rarer. As there are no central registers for these diseases, the number of cases is estimated through epidemiological studies.

The costs of the diseases include direct healthcare costs (e.g. medical consultations, hospitalisation, medication and other treatments), direct non-medical costs (social services, special accommodation, informal care), and indirect costs (lost productivity and lost income).

**Prevalence and cost of NDDs in Europe (2010)**

Disease	Number of subjects (million)	Cost per subject (€PPP)	Total cost (million €PPP)
Dementia	6.3	16 584	105 163
Parkinson's	1.2	11 153	13 933
MS	0.54	26 974	14 559

Numbers refer to the 27 EU Member States, Iceland, Norway and Switzerland. Costs are adjusted for the different price level (purchasing power parity, PPP) in each country.

source: [Cost of disorders of the brain in Europe 2010](#)

**Alzheimer's disease and other dementias**

An estimated 6.3 million Europeans were affected by dementia in 2010. This number is expected to double as life expectancy increases.

AD is relatively rare among people of working age. About two thirds of dementia patients under 65 suffer from other forms of dementia. According to [Alzheimer Europe](#), dementia affects less than one in 1 000 persons under the age of 65, but one in 100 in the 65-69 age group. AD becomes more common with increasing age and affects more than one in three persons over the age of 90. More women than men are affected because women tend to live longer.

The cost of dementia in Europe in 2010 has been estimated at €PPP 105 billion.

**Parkinson's disease**

PD affects around 1.2 million Europeans. The number of new cases is expected to double by 2050.

The average age of onset is around 60 years of age, but some 4% are diagnosed under the age of 50. PD is slightly more common in men than woman.

The cost of PD in Europe is estimated at €PPP 13.9 billion.

**Multiple sclerosis**

MS affects around half a million Europeans. Most MS patients are of working age, and the disease is most common in the age group of 35-49 years. It is more common in women than in men. The estimated total cost is €PPP 14.6 billion.

**NDD in the workplace**

MS, which is normally diagnosed in a patient's 20s or 30s, affects a large number of people of working age. Dementia and PD normally affect elderly people, but in some cases the disease starts at an earlier age (early onset). Although exact figures are not available, these diseases affect hundreds of thousand of Europeans under 65.

The majority (59%) of respondents to the global [survey on employment and MS](#), carried out by [MS international federation](#) in 2010, are employed, and more than two thirds of them work full time. A [study on the economic impact of MS](#) shows that more than a third of MS patients retired early.

The 2011 [MS barometer survey](#) evaluated how well employment and job retention for MS patients are supported in European countries. It found large differences in awareness campaigns, incentives to employ MS patients, and their employment rates.

A minority (18%) of people under 65 diagnosed with dementia continue to work.

A [Finnish study](#) of working-age PD patients showed that PD often leads to early retirement (median: 1.7 years after diagnosis). Those who did continue to work were younger and more recently diagnosed, had milder symptoms and were supported through adjustments in the workplace.

With [rising retirement ages](#) in Member States, more people aged 60 to 68 will be in active employment. As a consequence, more early-onset cases of AD and PD are expected among people of working age.

Continuing to work not only provides income and reduces costs, but may also have a positive influence on the patient's health. On the other hand, a stressful work situation may have negative health impacts.

**Issues for employees**

Different issues arise in the workplace as the disease progresses. In the early stage, when first symptoms, such as memory problems,

occur, employee and employer are normally unaware of the cause of the problems. Employees may try to hide problems or compensate by working longer hours. Employers may note an unexplained drop in performance. Employees may be dismissed or decide to leave their job if the disease interferes with their job performance.

After the disease (and possibly disability) has been diagnosed, employees face a number of decisions. They must decide if and when to inform their employer and colleagues, whether and how to continue to work, taking into account their financial obligations. Patient's organisations advise employees to get a certificate of disability and/or incapacity to work, which provides protection against discrimination and facilitates access to financial and material support.

After informing the employer, a patient may require [accommodations](#) (working hours, breaks, assistive technology, '[empowerment](#)') and possibly a change in responsibilities. Patients are advised to inform colleagues about their condition.

Depending on the severity of the disease and the personal financial situation, part-time work or early retirement are alternatives to consider.

As the diseases are progressive, it may be necessary in some cases to plan ahead for a gradual exit from working life, taking into account the practical and financial implications.

At all stages, it is important to have awareness of and information about the

disease and available support services, in order to take the best possible decisions.

Stigmatisation of the disease may result in negative attitudes from colleagues or supervisors.

### Stephen Hawking and ALS

[Stephen Hawking](#), the famous theoretical physicist, was diagnosed with [amyotrophic lateral sclerosis \(ALS\)](#) at age 21, almost 50 years ago.

ALS is a motor-neuron disease which occurs more frequently in men than women. ALS normally leads to death within 2 to 3 years after diagnosis, but Hawking has a rare, slow-progressing form of the disease. While ALS causes dementia in some patients, Hawking's mental abilities were untouched, and he has had a successful career as one of the world's leading physicists. He receives round-the-clock care and speaks with a computer device which he operates with his cheek.

Like many NDDs, ALS exhibits tremendous variability and affects patients in different ways.

### Issues for employers

Employers who help a patient with NDD stay in the workplace stand to benefit from the knowledge and experience of that person, although they may have to find them a role which maximises benefits while minimising business risks. The [challenges for employers](#) include recognising early symptoms of the diseases<sup>1</sup>, supporting the employee and making accommodations, knowing the legal situation and ensuring that workers with NDD do not cause safety risks to themselves or others.

### Informal care

With [increasing life expectancy](#) (in 2050, 28% of the EU population is projected to be over 65), the number of AD and PD patients is expected to grow.

As a consequence, more and more persons will find themselves in the situation of providing informal care for a

family member suffering from an NDD while continuing to work. In the UK, 60% of people under the age of 65 who provide care for a dementia patient continue to work.

This group of people can benefit from more flexible working arrangements such as teleworking, part-time work or flexible working hours.

### Initiatives

In 2011, Employers' Forum on Disability, the European Federation of Neurological Associations, Microsoft and Merck Serono

launched the [ms&work](#) campaign, which aims to address the needs of people with MS in the workplace.

The European Network for Workplace Health Promotion has published a [good practice guide on chronic illness at work](#), and launched national information campaigns aimed at employers.

## EU policy

### Legislation

The Equal Treatment Directive ([2000/78/EC](#)) prohibits discrimination of disabled persons and requires employers to provide 'reasonable accommodation' for disabled employees.

### Health policy

Although health policy is primarily the responsibility of Member States<sup>2</sup>, the EU may carry out actions to support, coordinate or supplement Member States' actions (Article 168 [TFEU](#)).

#### *Dementia and other NDDs*

The [Council Conclusions of 16 December 2008](#) consider neurodegenerative diseases a priority, and call on Member States to establish national strategies and to improve the distribution of information to patients, families and carers.

In 2009, 465 MEPs signed a [Declaration on priorities in the fight against AD](#) which calls for promotion of pan-European research on the causes, prevention and treatment, for improvement of early diagnosis, and for support to Alzheimer's associations.

In July 2009, the Commission announced a [European initiative on Alzheimer's disease and other dementias](#), which aims to promote early diagnosis, respect for patients' rights, and sharing of best practice, to improve epidemiological knowledge, and to coordinate research. In its [resolution of 19 January 2011](#), the EP calls for the taking into account of the specific needs of women, who account for twice the number of

patients and a disproportionate number of carers.

#### *Mental health*

The EP [resolution of 6 September 2006](#) on EU mental health strategy calls for employers to introduce "mental health at work" policies in order to improve incorporation of persons with mental disorders into the labour market and ensure non-discriminatory treatment. It calls for the combating of stigma through awareness and information campaigns.

Parliament's [resolution of 19 February 2009](#) on mental health calls on Member States to give people with mental-health problems full access to employment, and stresses the need for research on NDDs.

#### *Health for Growth programme*

The [Health for Growth](#) programme (2014-2020) proposed by the Commission would have a budget of €446 million to support innovation in health systems, better healthcare, disease prevention, and protection from cross-border health threats. In June 2012, the EP's ENVI Committee adopted a [report on Health for Growth](#) (rapporteur: Françoise Grossetête, EPP, France) which emphasises action on age-related and neurodegenerative diseases.

### EU-supported research

The Seventh Framework Programme (2007-2013) provided €400 million for research on neurodegenerative diseases, including AD. The [research projects](#) aim at a better understanding of the diseases, improved diagnostic tests and new treatments.

For the upcoming research programme [Horizon 2020](#) (2014-2020), the ITRE Committee's [report](#), voted in November 2012 (rapporteur: Teresa Riera Madurell, S&D, Spain), amends the Commission proposal to include research on NDD.

Additional funding for research on AD is provided through the [Innovative Medicines Initiative](#), jointly funded by the EU and the European pharmaceutical industry.

NDDs were selected as the subject for the first Joint Programming Initiative (JPI). JPIs coordinate the research agendas of Member States around major challenges that are too big for individual countries. The [Joint Programming Initiative on NDD](#) was launched in 2011 and brings together 25 countries.

### Employment policy

In 2012, 408 MEPs signed a [written declaration](#) on tackling multiple sclerosis in Europe, which calls for the promotion of flexible employment policies for people with chronic neurological disorders.

### Expert and stakeholder positions

The [European Brain Council](#) asks the EU and Member States to make disorders of the brain a priority topic, support research in this area and encourages initiatives to provide improved knowledge on the prevalence and cost of brain disorders.

[Alzheimer Europe](#) favours national dementia plans and better data collection, and advocates early diagnosis, awareness campaigns and policies that respond to the needs of patients and carers.

Regarding employment issues, the [Alzheimer's Society](#) calls for changes to enable patients and carers to continue working. These include raising awareness of dementia and its symptoms, improved diagnosis and access to support services.

The [EMSP Code of Good Practice in MS](#) calls for open communication with employers to identify and overcome barriers in the workplace, for high quality vocational rehabilitation, and for information and awareness-raising programmes about the Equal Treatment Directive.

The [consensus statement](#) published by the European Parkinson's Disease Association

(EPDA) points out that early and appropriate pharmacological treatment enables PD patients to remain in the workplace for longer. It deplores a lack of support in the workplace and advocates raising awareness in order to reduce stigma and improve acceptance of PD patients in the workplace. EPDA's [Pledge for Parkinson's](#) calls for NDDs to be made an EU healthcare priority, funding for PD research and establishing best practice in the management of PD.

### Main references

[Employment and MS](#), MS in Focus, 2010, Issue 16

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[Cost of disorders of the brain in Europe 2010](#), European Neuropsychopharmacology 2011 Nr. 21, p. 718–779

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<http://www.library.ep.ec>

<http://libraryeuroparl.wordpress.com>

### Endnotes

<sup>1</sup> If the symptoms affect work performance, the employer may suggest that the employee seek specialist medical advice.

<sup>2</sup> Alzheimer Europe provides a [summary of national policies, and support services](#).