



The Challenges of Neurodegenerative Diseases in the Workplace: what can be done at EU level?

Panel discussion in the European Parliament report, 9th July 2013, Brussels

This event was hosted by Angelika Werthmann, Member of the European Parliament and co-organised by Alzheimer Europe, the European Multiple Sclerosis Platform and the European Parkinson's Disease Association.



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Summary

The panel discussion hosted by Angelika Werthmann, Member of the European Parliament on 9th July 2013 on “The Challenges of Neurodegenerative Diseases in the Workplace” can be regarded as an important landmark in the advocacy efforts aimed at improving the quality of life for people with neurodegenerative diseases, such as Alzheimer’s disease, multiple sclerosis or Parkinson’s disease, in the workplace.

The most positive outcome of this event was the pledge made by Angelika Werthmann to present a Written Declaration in support of “Neurodegenerative diseases in the workplace”. This Written Declaration will identify some action areas on which the Council of the European Union and the European Commission will be asked to act. Furthermore it will kick off the awareness-raising about the challenges faced by people with neurodegenerative diseases in the workplace and the implementation of long-awaited measures that will meet these people’s needs and expectations.

The other significant deliverables / outcomes of the panel discussion were:

- The presence and/or expression of support received from a number of Members of the European Parliament;
- The successful collaboration between organisations representing three different but intersecting disease areas: Alzheimer Europe, the European Multiple Sclerosis Platform and the European Parkinson’s Disease Association;
- The attendance and special interest shown by representatives of the European Commission, of the industry and of the research community;
- Last but not least, the event provided a chance for policy-makers to hear directly from people personally affected by these conditions.

“Staying in the workplace means that people with neurodegenerative diseases can maintain self-esteem, a regular life and independence...”

I think the neurodegenerative diseases community needs all the support of national and European policy-makers”.

**ANGELIKA WERTHMANN, Member of European Parliament,
Chair of panel discussion**

Welcome and introduction

Angelika Werthmann, Chair, Member of European Parliament, Austria, ALDE

Ms Werthmann explained what motivated her to lead a parliamentary initiative in support of people affected by neurodegenerative diseases.

“Early diagnosis is very important to help people with neurodegenerative diseases stay active for as long as possible - in terms of self-esteem, independence and regular life. Their stay in the workplace is also important for society - we already have too many unemployed people.”

Ms Werthmann said employers have to be as flexible as possible when it comes to accommodating a person with a neurodegenerative disease.

“Sometimes, this could mean the possibility of working from home, which is a normal thing today. We can fight social intolerance and discrimination through such measures”

She addressed the issue of the growing number of people affected by neurodegenerative disease – which will double in the future with the ageing population in Europe. It is vital to take action and support the people with neurodegenerative diseases as of today by addressing their needs in the political agenda.



“The neurodegenerative diseases community needs all the support from national and European policy-makers”.

The total cost of brain diseases in Europe is estimated at 800 billion euros per year;

There are at least 9 million people living with neurodegenerative diseases in Europe;

Horizon 2020 is the EU's new programme for research and innovation - with a budget of 80 billion euros.

Working with Parkinson’s disease

*Heather Clarke, European Political Affairs Officer,
European Parkinson’s Disease Association (EPDA)*



**EPDA is the European umbrella organisation for Parkinson’s disease, with 45 member societies. It represents over 1 million people.*

Introducing her speech, Ms Clarke highlighted the need for all relevant players in society to support people with neurodegenerative diseases to find and keep jobs. *“Assisting people with a chronic condition to remain in the workplace benefits not only the individual and their family but also the public purse as there are less disability pay-outs and informal carers can also work”.*

She added that *“as the pension age increases, a larger proportion of the workforce will experience chronic disease and disability. Actions by employers and governments to help people stay in work will become even more of a priority”.*

Ms Clarke underlined a number of specific actions and strategies that employers can undertake to support people with Parkinson’s in the workplace:

- simple physical alterations to the workplace, such as providing a quieter environment, a rest area and a parking space;
- allowing time off for people with Parkinson’s to attend their medical appointments;
- the possibility of remote working, a practical and efficient solution for many.

Parkinson’s disease is a chronic degenerative brain disease - with no cure - which affects all aspects of daily living. Its spread and impact are alarming:

More than 1 in 10 people diagnosed with Parkinson’s disease are younger than 50;

The number of people affected will double by 2030;

The current cost of 13.9 billion euros is likely to rise to over 27 billion by 2030.

“Each person with Parkinson’s is unique and the condition affects every individual differently. But, for many, the need to remain economically active and engaged is vital”.

Ms Clarke reinforced the need to raise awareness of EU equalities legislation. *“Some people with Parkinson’s disease fall under the legal definition of having a disability and they are protected from disability discrimination and unfair treatment by the EU Directive. This means employers must ensure that someone is not directly or indirectly discriminated against and are obliged to make reasonable adjustments to help someone to stay in work. Many people are not covered by legislation and job insecurity adds to their anxiety.”*

Parkinson’s disease is a long term condition and with the right treatment for the right person, many people will have full, productive and independent working lives for many years. Ms Clarke concluded *“life does not end with the diagnosis”.*

EPDA messages for managing neurodegenerative diseases in the workplace

- Referral to a specialist and early diagnosis and treatment are important aspects of keeping people with Parkinson's active. These have been shown to not only reduce the economic impact to both the individual and to society but also enable people living with the disease to remain in the workplace for longer.
- Treatment of Parkinson's does not just rely on medical treatments, such as medications and surgery. Many other health and social care disciplines play a vital role in management – including physiotherapy, speech and language therapy, occupational therapy, podiatry and dietetics.
- Flexible working hours and conditions are important in keeping people with Parkinson's economically active.
- Support from employers can make a huge difference. For example, one employer permitted his staff member with Parkinson's to use a folding bed in the stockroom for napping during his lunch hour so as to reduce fatigue and enable him to continue working. An employer may be prepared to allow alteration of work patterns, job share or working from home, for example.
 - Minor workplace adjustments can help: www.epda.eu.com/en/parkinsons/in-depth/managing-your-parkinsons/daily-living/work/adaptations-or-adjustments/
- Feeling in charge of the disease and managing medication are important for keeping people with Parkinson's active.
- Helping to raise awareness, reducing stigma and removing discrimination are important for keeping people with Parkinson's in the workplace.
- Helping people with a chronic condition to remain in the workplace benefits not only the individual and their family but also the economy as there are less disability pay-outs and informal carers – the wives, husbands, children, can also work.
- The Parkinson's community cannot implement the changes on its own. The community needs the support of national and European policy-makers to ensure that the socio-economic burden of the disease does not accelerate further as the population continues to age.

The challenges faced by people with dementia

Annette Dumas, EU Public Affairs Advisor, Alzheimer Europe



[Alzheimer Europe](#) is an umbrella organisation with 34 member societies in 31 countries across Europe, all representing the interests of over 7 million people with dementia and more than 21 million carers.

Figures from the United Kingdom:

Only 18% of those diagnosed under the age of 65 continue to work;

Only 27% of carers keep their jobs after the diagnosis.

**Dementia is a neurodegenerative disease which progressively destroys brain cells, leading to cognitive and behavioural changes. Alzheimer's disease is the most common form of dementia. It is a very complex condition, with no known cure or prevention.*

Dementia is a costly disease: 21,000 euros per year/ person (56% for informal care).

Ms Dumas briefly presented the challenges of living with dementia: fall in performance and inadequate work arrangements after diagnosis, lack of self-esteem, discrimination and stigma at work and in society; carers risk losing income and pension rights. She also touched upon the differences that exist between Member States.

Alzheimer Europe's representative also pointed at the common misconception of considering Alzheimer's disease as a purely age related illness. People under 65 can develop dementia and often "*are not diagnosed in time because of this misconception*".

Ms Dumas presented a series of recommendations in supporting people with dementia:

- promote early diagnosis and treatment of dementia;
- raise awareness about dementia and provide information about dementia at individual, community, work and political level;
- respect the rights of people with dementia in the workplace;
- involve people with dementia in organisations and activities such as the planning of services and policies;
- identify data on the met and unmet needs of people with dementia in the workplace.

Alzheimer Europe's representative also mentioned a few EU programmes and initiatives which could help the cause of people with dementia: [the European Innovation Partnership on Active & Healthy Ageing](#); the [EU 2020 Strategy 'New Jobs, New Skills' flagship](#), the [Social Investment Package](#); the [European Disability Strategy 2010-2020](#) and [Horizon 2020](#).

Alzheimer Europe's recommendations

- Promote early diagnosis
- Raise awareness about the disease: this should lead to a cascade of developments that will help empower people with dementia take their life in their own hands, tackle stigma and discrimination, make employers aware of the remaining work capacities of the people with dementia and adapt the work environment, engage municipalities as partners in supporting people with dementia in the workplace, raise understanding of policy makers about this new challenge and engage them to put in place innovative policies in the field of work, access to care, pensions, support to informal carers.
- Respect the rights of people with dementia in the workplace.
- Recognise the remaining work capacities of people with dementia.
- Importance of involving people with dementia in organisations and activities including for planning of services and policies (example of existing Working groups including European Working Group of People with Dementia set up by Alzheimer Europe).

EU-supported actions on neurodegenerative diseases

*Philippe Cupers, Head of Neurosciences Sector,
Directorate-General for Research and Innovation, Health
Directorate, European Commission*



Philippe Cupers acknowledged the societal and economic importance of supporting people with neurodegenerative diseases.

"One European out of three is likely to be affected by a brain disorder. Every minute I'm speaking, 1,5 million euros are being spent on healthcare for brain disease - this will be even worse as the population ages".

"Behind the brain research science there is the suffering of millions of people in Europe being affected by brain disorders".

Mr Cupers also underlined the essential role that brain research can play for the future of people affected by neurodegenerative diseases, reminding that the European Commission contributed 2 billion euros to brain research between 2007 and 2013, through its Seventh Framework Programme (FP7).

The European Commission's representative referred to a number of past efforts directed at helping people with neurodegenerative diseases:

- 400 million euros worth of support for research on neurodegenerative diseases, including 200 million on Alzheimer's disease since 2007;
- Wide range of means for actions: from individual frontier research grants to joining forces with industry and supporting coordination among Member States;
- Organisation of a series of events under the umbrella of the European Month of the Brain 2013.

Mr Cupers mentioned that EU institutions have clear plans to further increase their support for people with neurodegenerative diseases through the [Horizon 2020](#) programme. These initiatives will cover essential areas such as societal changes, excellence in science and industrial leadership.

The costs of brain diseases in Europe are estimated at 800 billion euros per year.

[Horizon 2020](#) is the financial instrument implementing the [EU 2020 strategy](#) aiming at securing Europe's global competitiveness. Running from 2014 to 2020 with an 80 billion euros budget, the EU's new programme for research and innovation is part of the drive to create new growth and jobs in Europe.

The experience of a young person with multiple sclerosis

Shana Pezaro, European Multiple Sclerosis Platform (EMSP)

*[EMSP](#) is a pan-European umbrella organisation of 38 members in 34 European countries and represents 600,000 people who are affected by multiple sclerosis.



Ms Pezaro's speech provided a powerful blend of personal experience and general observations on the challenges facing people with multiple sclerosis (MS).

"I was finally diagnosed with multiple sclerosis 6 years ago, aged 28. By that point I was extremely ill. I was first sent to hospital at 7 years old, with neurological symptoms. By the age of 14, I was missing on average of one day a week of school. At 17 years old, I nearly died in hospital. I didn't really ever go back to school and so I taught myself my A-level exams at home over the next two years. I then studied Theatre and Film at the University of Bristol. I was constantly ill, in and out of hospital, but I graduated aged 22".

Despite all these difficulties, Ms Pezaro was determined to work. *"I worked for the television company for 2 years. In that time I was in and out of hospital with severe kidney infections and extreme face pain, falling down stairs, tripping over... Finally, I decided that I couldn't cope with doing that job, in that industry, with my health problems. So I set up a children's stage school and theatrical agency. After 5 years I had 300 students, 13 members of staff and I was very, very ill".*

Although she eventually had to give up working, Shana Pezaro said she is content to have stayed employed or self-employed for as long as she did. However, she mentioned she would not have been able to accommodate an employee living with MS.

Now a campaigner for the rights and needs of people with MS, Shana Pezaro said she is convinced that *"people with multiple sclerosis desperately want to work, but employers simply do not want to risk employing someone with a fluctuating health condition."*

Shana Pezaro outlined a few priorities which should be included in the MS-related agenda at both national and European level:

- make special funding and education available for employers recruiting people with MS;
- promote and enforce best practice on flexible working;
- and promote the concept of person-centred participation.

Facts on multiple sclerosis (MS):

- 600,000 people live with MS in Europe;
- 70% are diagnosed in their 20s and 30s;
- Two in five people with MS aged under 35 are unable to work.

EMSP recommendations on the challenges for people with MS on the job market

Supporting people with MS: It is not about charity, it is about tapping into talent

The ultimate aim is for people with MS to be recognised for the contribution they can make to companies and to the wider culture of the EU. We believe this can be achieved by providing:

- **Expertise and education** on MS for small to medium-sized businesses;
- **Financial support for employers** to tackle disability-related requirements;
- **Best practice** to encourage work adaptations enforced from the top;
- **Support for person-centred participation** - people with MS being actively involved in planning and in making decisions about factors which influence their lives.

General examples of what might be needed to support people with MS in finding and keeping jobs:

- **An adapted workplace** – and adaptations can be simple: accessibility, areas to rest, for many: workspace located near toilets and restrooms
- **Flexible hours:** days when people with MS are very active can be followed by days when they need to pace themselves or work from home
- **Better awareness of employers and colleagues** - people do not know what MS is and how to respond to those living with MS;
- **Better support for job seekers and better integration** for the “lucky ones” who have a work contract;
- **Support for changes of career** - in some cases, people diagnosed with MS need to find less stressful and less physically demanding jobs;

Taking the opportunities

Paid work opens up opportunities, provides income, a sense of purpose, dignity and social connectivity.

Also, for people with neurodegenerative disorders - like MS, it is crucial to stay active. This is why the recent pledge of German Chancellor Angela Merkel to provide €6 billion for 2014 and 2015 in funding for programmes dedicated to unemployed young people in Europe is a very good opportunity (there are more than 14 million unemployed young people in Europe).

However, policy-makers should be reminded that €6 billion is only a tiny fraction of the total costs of brain disorders in European countries – estimated at €800 billion in a study published by the European Brain Council. Therefore, the message becomes clear: **investment in employment programmes, with special emphasis on people with neurodegenerative diseases, is a necessity for a well-functioning society.**

The focus on MS and other neurodegenerative diseases can act as a platform for the EU Parliament to continuously help to improve the understanding of the different health challenges within the member states.

For more information on the challenges of living with MS visit www.emsp.org and www.underpressureproject.eu.

Policy action and conclusions

Angelika Werthmann, Chair, Member of European Parliament

At the end of the panel discussion, Ms Werthmann offered to bring a fresh perspective towards improving the quality of life of over 9 million people living with neurodegenerative diseases in Europe.

She proposed to launch a “Written Declaration” in the European Parliament which would give people with neurodegenerative diseases better opportunities within Europe.

“We are the politicians, we are the stakeholders and we will be asked urgently to take the appropriate steps. I do not think I’m being too optimistic if I aim to have the Written Declaration ready by September-October. I was aware of the need of cooperation in this field - that was one of my goals and we have already achieved it.”

This panel discussion - a successful step forward towards a strong collaboration between patients’ organisations and policy decision makers - was a striking eye opener supported by the facts and figures produced during the presentations.

The challenges of people affected by neurodegenerative diseases in the workplace are an increasing socio-economic burden to society and can represent an ordeal for the persons with this condition and their carers. This compels us - patients and patient representatives, national and European policy makers - to work together towards concrete actions—which will address these challenges. Now is the time to act for a better future.

In an ensuing [Press Release](#), the three co-organisers of the event – Alzheimer Europe, the European Multiple Sclerosis Platform, and the European Parkinson’s Disease Association - highlighted common areas on which the Written Declaration should focus:

- Raise awareness
- Adapt social legislation
- Adapt the workplace
- Promote early intervention.

Three important media outlets picked up the message:

- an [op-ed piece](#) in EurActiv signed by Shana Pezaro;
- a [report](#) in The Parliament Magazine on the outcome and highlights of the event;
- an [article](#) in Medical News Today constructed around the press release.



Background notes

Alzheimer Europe (<http://www.alzheimer-europe.org/>)

Alzheimer Europe (AE) is a non-profit organisation which aims to improve the care and treatment of Alzheimer patients through intensified collaboration between its member associations.

In the longer term, AE is striving to become the coordination and information centre for all organisations working in this specific field, such as day care centres, sitting services, training centres for professionals and related organisations.

With the current and steady increase in life-expectancy of Europe's population, the number of people affected by age-related disease such as Alzheimer's disease and related disorders is forecast to increase dramatically in the next few years.

More importantly, the majority of Alzheimer people with dementia live at home and are cared for by their relatives and friends. Although many organisations are active in supporting them, carers often work alone, and lack in know-how and inspiration which could be given by others.

What is the Alzheimer 's disease?

Between 50 and 70% of all people with [dementia](#) have Alzheimer's disease - a degenerative disease, which slowly and progressively destroys [brain](#) cells. The disease affects memory and mental functioning (e.g. thinking and speaking, etc.), but can also lead to other problems such as confusion, changes of mood and [disorientation](#) in time and space. At first the symptoms such as difficulty with [memory](#) and loss of intellectual abilities may be so slight that they go unnoticed, both by the person concerned and his or her family and friends. However, as the disease progresses, the symptoms become more and more noticeable and start to interfere with routine work and social activities. Practical difficulties with daily tasks such as dressing, washing and going to the toilet gradually become so severe that in time the person becomes totally dependent on others. Alzheimer's disease is neither infectious nor contagious. It is a terminal illness, which causes a general deterioration in health.

Who is affected by Alzheimer's disease?

On the basis of comparisons of large groups of people with Alzheimer's disease with others who have not been affected, researchers suggest that there are a number of risk factors. This means that some people are more likely to suffer from the disease than others. However, it is unlikely that the disease could be traced to a single cause. It is more likely that a combination of factors lead to its development, with the importance of particular factors differing from one person to another.



The European Multiple Sclerosis Platform (www.emsp.org)

EMSP represents their interests at the European level, working with more than 30 national associations to achieve its goals of high quality equitable treatment and support for Europeans with MS.

EMSP's missions are the following:

- Exchanging and disseminating information relating to MS considering all issues relevant for people affected by MS.
- Encouraging research of all kinds that is appropriate to MS through recognised medical and other organisations.
- Promoting the development of joint action programmes with the participation of national MS societies in Europe, aiming at improving the quality of their activities and services.
- Acting as a focal point for liaison with the institutions of the European Union (EU), the Council of Europe and other European organisations, in order to propose new measures to advance the rights of persons with disabilities and to ensure their full and effective participation in society.

What is multiple sclerosis?

Multiple sclerosis (MS) is a complex, long-term, disabling disease. It affects twice as many women as men, and is usually first diagnosed between the ages of 20 and 40, at a critical stage in adult life with often considerable family and work responsibilities. To date, no cure exists. There are currently over 600,000 people diagnosed with MS in Europe.

The European Parkinson's Disease Association (www.epda.eu.com)

The EPDA is the only European Parkinson's disease umbrella organisation. It represents 45 member organisations from 36 European countries and advocates for the rights and needs of more than 1.2 million people with Parkinson's and their families. Numbers of people with Parkinson's are forecast to double by 2030 primarily as a result of the ageing population. The EPDA's vision is to enable all people with Parkinson's in Europe to live a full life while supporting the search for a cure. In order to achieve its vision, the organisation hopes to raise the profile of the disease and enable people living with the condition to be treated effectively and equally.

What is Parkinson's?

Parkinson's is a progressive, chronic and complex neurodegenerative disease that has no cure. It affects all aspects of daily living and is the most common neurodegenerative disease after Alzheimer's disease. The average age of onset is 60 years, although more than one in 10 people are diagnosed before the age of 50. Parkinson's is more prevalent in men than women, and may affect people of all ethnicities. The effects of Parkinson's invariably involve the physical, cognitive and psychological domains, and impact across nearly every cultural, social and economic boundary.

It is estimated that Parkinson's disease costs €13.9 billion annually and this is estimated to double by 2030.

Who gets Parkinson's?

There are more than 1.2 million people living with Parkinson's in Europe and this number is forecast to double by 2030 primarily as a result of the ageing population. The average age of onset is 60 years, although more than one in 10 people are diagnosed before the age of 50. Parkinson's is more prevalent in men than women, and may affect people of all ethnicities. It is important to remember that Parkinson's can affect anyone.

Symptoms

The severity of Parkinson's will differ from person to person as every case is different. Yet it is predominantly characterised by problems with body movements – known as motor symptoms. These symptoms include tremor, rigidity and slowness of movement. However, Parkinson's is also associated with symptoms that are not directly related to movement – known as non-motor symptoms – which include fatigue, bladder disturbances, pain and depression.

The symptoms can be controlled using a combination of drugs, therapies and surgery; however, there is currently no cure for the disease and it is not known why people get the condition.

Special thanks go to:

- Ms. Werthmann for initiating and co-hosting this event in the European Parliament and for her political support to the cause of millions of people affected by neurodegenerative diseases across Europe;
- Ioana Grigore, Ms Wertmann's assistant for the coordination of the event;
- Alzheimer Europe, the European Multiple Sclerosis Platform and the European Parkinson's Disease Association for their contribution to the content of the event and logistics preparation;
- The European Multiple Sclerosis Platform for the preparation of the event report.