

*Paving the Path to Participation:  
Employment and People with  
MS/Neurological Conditions*



EUROPEAN  
MULTIPLE SCLEROSIS  
PLATFORM

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## **\*European Employment Pact for People with Multiple Sclerosis\***

*The Paving the Path to Participation project is an initiative from the European Multiple Sclerosis Platform (EMSP), an organisation that represents 37 member societies from 34 European countries- more than 700,000 people with MS in Europe. It is a project supported by the European Commission under the DG Justice PROGRESS programme and is aimed at tackling the difficult employment issues faced by people with multiple sclerosis and other neurological and chronic conditions.*

The **Employment Pact** was created from EMSP discussions with members and people with Multiple Sclerosis, with support from other stakeholders and policy makers. Together, we can ensure that people with MS and other chronic conditions can enjoy their full rights and fully benefit from participating in society and the European economy. Although all European countries have protective social legislation, in practice people with multiple sclerosis, chronic 'invisible' conditions and disabilities do **not** enjoy a right to work in the current marketplace, experiencing inequality and lack of opportunities. Their right to work as described by the **Universal Declaration Of Human Rights**, in Article 23 and Article 24, are often ignored, thus diminishing their life opportunities.

### Article 23:

- (1) Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.
- (2) Everyone, without any discrimination, has the right to equal pay for equal work.
- (3) Everyone who works has the right to just and favourable remuneration ensuring for themselves and their family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.
- (4) Everyone has the right to form and to join trade unions for the protection of their interests.

### Article 24:

Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

## **Why an Employment Pact for People with MS?**

In a recent EMSP survey of 1,200 young people (18-35 year olds) with MS across Europe it is the symptoms of their condition, attitudes of employers to people with MS and discrimination **were the most common barriers** to accessing work. Multiple Sclerosis (MS) is a neurological condition usually **diagnosed during the prime working years** of life. **The EU Youth Employment Initiative and Youth Guarantee** are focused on this issue, demonstrating EU solidarity and budgetary support for people **Not in Education, Employment or Training (NEETs)**. Due to the unpredictability and fluctuating nature of MS, a person's quality of life,

as well as their abilities to work, can be negatively impacted<sup>1</sup>. People who are highly educated and skilled are edged out of the workplace because of lack of understanding and prejudice. These are some of the same people who are needed to make up the working number of people (6:1) to support the pension of every single retiree in the European Union. However, by combining efforts and supporting people with MS, the majority of people who want to work can successfully remain in work or return to employment. Paid work opens up opportunities, provides income, a sense of purpose, dignity and social connectivity. In business, holding onto and nurturing talent and capability rather than losing valuable staff makes good business sense. Loyalty and commitment can go a long way in what can be a difficult business environment.

Under the ***United Nations Convention on the Rights of People with Disabilities***, Article 27 specifically deals with Work and Employment of people with Disabilities: ***State Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities<sup>2</sup>.***

## Action Now

Now is the time to make this happen. To ensure a better future, it is vital the work skills and abilities of the European population living with MS are harnessed so individuals can continue working and contributing to their own financial security. Employing people with MS is good for the person, good for business, great for the socio-economic situation of their country and the EU. Disclosing a chronic illness such as multiple sclerosis has been shown to '*positively affect(s) employment status and tenure*'; yet many people with a chronic illness continue to hide their condition out of past experiences and lack of understanding.<sup>3</sup>

Whether you represent a small business, are a medium sized employer or are part of a larger multi-national organization, the **Pact** is a step towards recognising the importance of workplace health and diversity and their value to the workplace. Successful business depends on motivated, able and healthy staff as the European Network for Workplace Health has shown<sup>4</sup>.

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<sup>1</sup> 'Ready to Work? Meeting the Employment and Career Aspirations of People with MS, June 2011. Bevan et al <http://www.theworkfoundation.com/Reports/289/Ready-to-Work-Meeting-the-employment-and-career-aspirations-of-people-with-Multiple-Sclerosis>

\*Pact = an agreement between two or more parties.

<sup>2</sup> United Nations Convention on the Rights of Persons with Disabilities <http://www.un.org/disabilities/convention/conventionfull.shtml>

<sup>3</sup> 'Disclosure of diagnosis of multiple sclerosis in the workplace positively affects employment status and job tenure, Nov. 2013 AK Kirk-Brown et al Multiple Sclerosis Journal <http://msj.sagepub.com/content/20/7/871>

<sup>4</sup> 'Promoting Healthy Work for People with Chronic Illness: A Guide to Good Practices [http://www.enwhp.org/uploads/media/ENWHP\\_Guide\\_PH\\_Work\\_final.pdf](http://www.enwhp.org/uploads/media/ENWHP_Guide_PH_Work_final.pdf)

By supporting this Pact business leaders are demonstrating their commitment to creating a healthy workplace for all staff. By recognising the particular needs of staff members with MS and other chronic conditions, others in the business benefit- a general policy towards good health is good for every one. Good workplace policies focused on health improve an individual's quality of life while adding value by promoting better health and increasing people's motivation. By proactively engaging in a process to create a healthy workplace, businesses will increase productivity and person engagement. The benefits of a healthy workplace extend far beyond avoiding absenteeism and poor performance; they (the 'benefits') can also mean business and personal success for all involved<sup>5</sup>. EMSP has compiled a useful Checklist for Businesses to use as a guide for their workplaces.

### Checklist: The main points

#### ✓ Employment Policy

This business ensures the employment policies of the organisation are in accordance with national law, European Disability Regulation and in the spirit of the Universal Declaration Of Human Rights Articles 23 and 24.

#### ✓ Equal Opportunity and Proactive Employer

Staff members will be appointed into the workforce based on their abilities to fulfil their duties, their contribution to business and their commitment to the mission of the organisation. People with suitable experience and qualifications will be considered.

Disclosure of a condition/disability such as multiple sclerosis or other chronic condition *does not* prejudice applicants.

#### ✓ Recruitment

Recruitment procedures will be regularly reviewed to ensure applicants from all backgrounds are aware of the positive employment policies of the organisation.

Although disclosure can be strongly encouraged it is not expected as we respect and recognise an individual's right to privacy.

#### ✓ Training and Awareness in the Workforce

All staff members will receive regular information and diversity training on the particular challenges faced by people with disabilities in the workplace.

#### ✓ The Working Environment

Specific processes and practices are in place to ensure the work environment meets the needs of staff, in the spirit of the United Nations Convention on the Rights of People with Disabilities, Article

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<sup>5</sup> *Working for a Healthier Tomorrow: Review for the Secretary of State for Health and the Secretary of State for Work and Pensions*  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/209782/hwwb-working-for-a-healthier-tomorrow.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/209782/hwwb-working-for-a-healthier-tomorrow.pdf)

27. We will make use of the Toolkit as provided by EMSP that provides a framework for workplace adaptations provide a work environment that is open, inclusive and accessible. Where there is an issue, staff members shall be encouraged to voice their needs using a model of needs assessment leading to mutually agreed adaptations.

These may include:

- Flexible work hours and arrangements
- Accessible building and toilet facilities.
- Policy and supports for planned 'return to work'
- Designated rest area for staff

**✓ Due Process**

We are confident that should any issue arise due to the fluctuating nature of the condition/disease, we have the right processes and information to support our employee as they deal with their condition.

**✓ Flexible working conditions**

This organisation adheres to Health and Safety guidelines<sup>6</sup>. Where the fluctuating nature of MS and other neurological conditions is considered, the changing needs of the employees will be discussed and appropriate adaptations will be made.

**✓ Monitoring**

There will be designated times for monitoring using feedback forms, regular staff meetings and quarterly evaluations from in-house Diversity champions, followed by an annual review. The conclusions of the review will be published with recommendations for future improvements.

***This Pact has been compiled based on:***

- ***Recommendations from the Panel discussion held in the European Parliament, on the 9<sup>th</sup> July 2013, co-organised by MEP Angelika Werthmann, Alzheimer Europe, the European Parkinson's Disease Association and EMSP***
- ***Discussions with people with MS, business leaders and representatives from MS societies across Europe and government representatives.***
- ***Information and research from The Work Foundation, The European Network for Workplace Health Promotion (ENWHP) and other organisations. Through this Pact we seek to inform, inspire and create positive change for all people with MS and other neurological conditions in Europe. It is by motivating people with knowledge of the issues, inspiring them to innovate and equipping people with the tools to that together we will make a positive difference.***

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<sup>6</sup> European Agency for Safety and Health at Work: <https://osha.europa.eu/en/legislation/guidelines>

**The European Multiple Sclerosis Platform ([www.emsp.org](http://www.emsp.org))**

EMSP represents their interests at European level, working with 39 national associations to achieve its goal of high quality equitable treatment and support for people with MS.

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