

## Breaking the Barriers – A European Employment Pact for Multiple Sclerosis

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### Abstract

In March this year, the European Multiple Sclerosis Platform (EMSP) launched its European Employment Pact for people with multiple sclerosis (MS) and other neurodegenerative conditions. A call to action for the Pact will follow in May. EMSP is inviting all relevant stakeholders, from businesses to decision-makers, to pledge support. People who are highly educated and skilled are edged out of the workplace by inadequate 'return to work' policies, lack of understanding and prejudice. EMSP considers this unacceptable.

### Keywords

Employment, work, multiple sclerosis, pact, EMSP

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### European Employment Pact for People with Multiple Sclerosis



The European Employment Pact for people with multiple sclerosis (MS) offers a way forward in tackling the barriers and challenges faced by people with MS and other neurodegenerative conditions in the workplace.

The Pact is mainly addressed to businesses, whether small and medium enterprises (SMEs) or multinational companies, which are prepared to recognise the value of policies that enhance workplace health and promote diversity. It is also meant as a call to action to all relevant stakeholders who share the view that inclusive employment is not only a basic human right, but also good for business and good for society.

### Why Support the Pact?

By supporting this Pact, business leaders will demonstrate their commitment to creating a healthy workplace for all. Health-focused workplace policies improve an individual's quality of life while promoting increased productivity.

By upholding such policies, decision-makers will also show their resolve in tackling important challenges, such as youth unemployment, workplace discrimination and health inequalities.

By partnering with the European Multiple Sclerosis Platform (EMSP) in promoting and implementing the Pact, patient organisations and other non-governmental organisations (NGOs) will enable the creation of a cross-border movement dedicated to improving employment for people with disabilities:



## MS Facts

- 700,000 people in Europe have MS
- 70% diagnosed during prime working years
- 9 million people with neuro-degenerative diseases
- € 800 billion = cost of brain conditions in Europe

**€ 1,5 million per minute\***  
are being spent on brain conditions in Europe

\* European Brain Council, Cost of Brain Diseases in Europe, 2010

**65% of the 1300 respondents to our young people with MS survey said they are currently employed or doing voluntary work ...**

**... but 80% usually stop working within 15 years of the onset of the disease**

**Activity in the workplace for young people with MS**

**8 out of 10 stop working\***

**e m s p**  
EUROPEAN MULTIPLE SCLEROSIS PLATFORM

\* Work Foundation, Ready to Work?, 2011

*Access to decent work through changes in policy, workplace and social education transforms lives. People can escape the vicious circle of social exclusion, marginalisation and poverty” (International Labour Organisation [ILO]).<sup>2</sup>*

### Pact Launch

The launch of the Pact took place in the European Parliament in Brussels on 24 March and was hosted by MEP Rosa Estaras-Ferragut under the title “Breaking down the barriers: Access to employment and the economics of brain health”. Co-chairing the event was MEP Jeroen Lenaers.

Mr Lenaers admitted that the lack of awareness of the challenges faced by people with MS in the workplace is a significant problem:

*I was surprised to learn that MS is a disease that hits mostly during the prime working years. I was also surprised by how simple it would be to implement the workplace adaptations required by people with MS.*

*With all the unemployment in Europe at the moment, I feel that in the long term we need all the employable people we have in order to make sure our economy stays viable.*

MEP Rosa Estaras-Ferragut said that “discrimination is a very important issue because people with MS are at a disadvantage in accessing employment. There is a lack of information and a lack of active policies which can ensure that these people remain at work”.

Ms Estaras-Ferragut indicated that MEPs are currently working on two initiatives that could improve this situation: drafting a report on the implementation of United Nations’ Convention on the Rights of Persons with Disabilities and persuading the European Commission to deliver on a four-year-old plan to propose a European Accessibility Act.

MS advocate Shana Pezaro represented the voice of MS patients at the event. She has been living with this condition for seven years. When she received her diagnosis, after having suffered from different

symptoms for many years, she decided to sell her business and limit herself to voluntary work. She also acknowledges the crucial importance of employment:

*Gaining and maintaining employment is one of the biggest issues facing people with MS across Europe. Many work places are not physically accessible, but the biggest barrier to employment can be employers' negative attitude to chronic illness. Some employers are absolutely fantastic, but for many others there is a huge amount of misunderstanding about MS.*

EMSP and its partners are set to return to the European Parliament on 26 May to start raising signatures in support of the Employment Pact.

## Believe and Achieve

EMSP's recent efforts to tackle unemployment among people with MS started with the Believe and Achieve programme, an initiative offering meaningful work opportunities with important businesses to young people who have MS. This approach was suggested by EMSP member societies during our 2013 annual conference and finally took shape in spring 2014.

It was then that an EMSP cross-border survey clearly showed that young people with MS want to work. Indeed, 65 % of the 1,300 respondents (aged 18–35 years) said that they were either employed or doing voluntary work.

These findings paved the way to an agreement between EMSP and two corporate partners for a pilot programme of Believe and Achieve: 15 paid internships made available in eight European countries at the start of 2015. For every one of these positions, EMSP is offering coaching for both intern and employer and is constantly monitoring progress.

The main challenge for people who have MS who are already working is that without the type of support that EMSP provides through Believe and Achieve, they risk ending their professional careers far too soon. A study<sup>1</sup> shows that 80 % of them usually stop working within 15 years of the onset of MS.

Businesses that do not have effective 'return to work' policies to support employees lose experienced and skilled staff.

## Checklist for Businesses

Successful businesses depend on the skills, motivation and well-being of their staff. Proactively creating workplace adaptation policies ensures added value and personal success for all involved. EMSP has compiled a useful checklist for businesses who adhere to the pact:

*Employment policy:* Businesses will ensure that their employment policies comply with national law and European disability regulations while upholding the Universal Declaration of Human Rights, Articles 23 and 24.

*Recruitment:* The related procedures will be regularly reviewed to ensure that applicants from all backgrounds are aware of the employment policies. Although disclosure is strongly encouraged, it is not a requirement, for individuals' rights to privacy must be respected.

*Due process:* Should any matter arise because of the fluctuating nature of the condition, a return to work process should be in place. This would involve a staff committee and the dissemination of information.

*Equal opportunities and proactive employment:* Staff members will be appointed based on their ability to fulfil the duties of the role and their commitment to the mission of the organisation. People having suitable experience and qualifications will be considered irrespective of their medical condition.

Other items on the checklist include flexible working conditions, training and awareness, monitoring and absence management. More details are available in the Pact document (accessible at [www.emsp.org](http://www.emsp.org)).

## What is Multiple Sclerosis?

Multiple sclerosis is a neurological condition usually diagnosed during the prime working years of a person's life. Seventy per cent of all diagnoses occur between 20 and 40 years of age. Currently, two in five<sup>2</sup> people with MS who are younger than 35 are unable to work or study because of the condition. Currently, 700,000 people live with MS in Europe.

## What is the European Multiple Sclerosis Platform?

Through its network of 39 MS societies in 34 countries, the EMSP runs advocacy and awareness-raising programmes to ensure high-quality access to treatment, care and employment for people who have MS, while also supporting research in this area. ■

1. Work Foundation, *Ready to Work?* 2011. Available at: [http://www.theworkfoundation.com/DownloadPublication/Report/289\\_289\\_MS3.pdf](http://www.theworkfoundation.com/DownloadPublication/Report/289_289_MS3.pdf) (accessed 30 April 2015).  
2. International Labour Organisation, 2014. Available at: <http://www.ilo.org/global/lang-en/index.htm> (accessed 30 April 2015).