

Ready for Work

Promoting Positive Work Outcomes for Europeans with MS

A Collaboration between The Work Foundation, the European Multiple Sclerosis Platform and Novartis International AG

The scope of MS in Europe

At least 700,000 people in Europe have multiple sclerosis (MS). More than one million additional people are affected through their role as carers and family members.

MS is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body. MS can occur at any time in life, but affects people most frequently between the ages of 20 and 40, often affecting both their education and employment status.

On average, 37 per cent of people with mild MS are employed, although many have to change or quit their jobs due to fluctuating functional capability. More than 75 per cent of people with MS report that the condition has impacted their employment and career opportunities. Only about 50% of people with MS will be employed 10 years after diagnosis. Up to 35 per cent of people with MS in Europe retire early due to their condition. This has a number of consequences. First, premature work loss reduces the productive capacity of the workforce and, if people move onto disability-related welfare benefits, increases societal costs and also reduces tax revenues. Second, if people with MS do not get early access to treatment the costs of healthcare can increase as the severity of their condition develops¹. Third, as a result of the reduced availability of social services, a considerable burden of the costs associated with MS falls on those with the condition and their carers. Indeed, the professional careers of 57 per cent of relatives of people with MS are adversely affected.

¹ UK data shows that people living with MS who have a Expanded Disability Status Score (EDSS) of between 0 and 3 have an average cost to the NHS (including both direct & indirect costs) of £11, 841 compared with an annual cost of £59,018 among those with an EDSS of between 7 and 9 (Kobelt et al, 2006).

Our Vision

“Workability” (supporting people into employment) should become a priority outcome of the clinical care. This will lead to maximising work productivity, inclusiveness and therapeutic benefits for the patient.

In pursuing this aim we will raise awareness of the importance of improving ‘brain health’ (e.g. better cognitive performance and reduced mental fatigue in the context of work).

Supporting our Vision

Importance of employment for the economic health of communities is clear. Not only that, work can have therapeutic benefits for many people with chronic or fluctuating health conditions, including MS². In fact work can improve brain activity and postpone deterioration in brain activity³. The concept of ‘Workability’, although becoming more prominent is far from being a ‘mainstream’ concept in clinical settings. Work outcomes for people living with MS vary considerably, yet many are willing and able to work and derive social, psychological and financial benefits from remaining active, independent and fulfilled through work.

We have identified four pillars where the workability could be improved:

- a. The work-focused nature of conversations between clinicians and people living with MS;
- b. The challenges and barriers faced by people living with MS who wish to make the transition

² See, for example: Waddell, G. and Burton, A.K. Is work good for your health and wellbeing? London: Department for Work and Pensions, 2006; Haro, J. M., Novick, D., Bertsch, J., Karagianis, J., Dossenbach, M., & Jones, P. B. (2011). Cross-national clinical and functional remission rates: Worldwide Schizophrenia Outpatient Health Outcomes (W-SOHO) study. The British Journal of Psychiatry, 199(3), 194-201.

³ For example, research shows that the onset of dementia is delayed by 6 weeks for every additional year spent at work - <http://news.bbc.co.uk/1/hi/health/8048523.stm>

from education to employment, find work, or to stay in or return to work;

c. The quality of the jobs available to people living with MS and the practical steps which employers can take to co-create fulfilling work;

d. Realising the benefits of improved workability. This includes the economic, clinical and social benefits for wider society, healthcare systems, employers (including SMEs), individuals with MS and their carers.

Our ultimate goal is to align health, labour and social policies and practice that keep people with MS as healthy and productive as possible, for resulting significant public health and economic benefits for society.

We will primarily work on

Building the case for Workability. While there is growing evidence of the importance of work to many people living with MS, the clinical and 'business' cases for prioritising Workability are not universally accepted and are not embedded in the way clinicians and employers think and behave. We will distil the key data and messages from the existing research and identify gaps in the evidence. This will include data from clinical research on functional capacity and work, building work-focussed treatment plans around the aspirations of patients; practical interventions (e.g. vocational rehabilitation; job retention; self-management; case management), the economics of early intervention and work productivity and the evidence of successful workplace accommodations and adjustments – including in smaller organisations.

Overcoming barriers to Workability. Some of these barriers are practical (functional capacity; fluctuations; fatigue; co-morbidity), others are attitudinal (stigma, lack of confidence, low expectations among physicians or negativity or anxiety among employers) and others are about systems or institutional barriers (healthcare system incentives, support in welfare systems, etc.). Multistakeholder engagement and collaboration is key to our success. There remains a need to identify how people living with MS can be best supported to access the labour market and how sustainable changes can be made to the primary barriers they face. We will focus on tools to help match the skills and aspirations of individuals living with MS to the demands of their work, ensuring access to good quality work and minimising the underutilisation of their skills.

Who are we?

- **The Work Foundation** (www.theworkfoundation.com) at Lancaster University specialises in applied research and policy-oriented research that examines the impact of chronic and fluctuating health conditions on the work and workability of people across the EU. Our 'Fit for Work' (www.fitforworkeurope.eu) project has produced data and policy recommendations across 30 European countries and, in 2011 we published the results of a study looking at the impact of MS on employment in the UK. We have expertise in research, communication, advocacy and the coordination of cross-national coalitions and collaborations in the field of workforce health & productivity. Our work has influenced national policy, clinical practice and raised awareness and capability in employing organisations (including SMEs) and among individuals living with chronic conditions.

- **The European Multiple Sclerosis Partnership - EMSP** is the umbrella organisation for 39 MS societies from 34 European countries. It represents their interests at the European level and works to achieve its goals of high quality equitable treatment and support for persons with multiple sclerosis throughout Europe.

EMSP has focused strongly on employment issues for people living with MS. **Believe and Achieve** (<http://www.emsp.org/projects/believe-and-achieve/>) is a paid internship programme giving young people with MS an opportunity to gain professional experience in a partner business in Europe and **Paving the Path to Participation** (<http://www.emsp.org/projects/paving-the-path-to-participation/>) is a project to dismantle barriers that prevent people accessing employment and to enhance and develop best practice in the employment of people with MS and other neurodegenerative diseases.

- **Novartis International AG** provides innovative healthcare solutions that address the evolving needs of patients and societies. Headquartered in Basel, Switzerland, Novartis International AG offers a diversified portfolio to best meet these needs: innovative medicines, eye care and cost-saving generic pharmaceuticals. Novartis International AG is the only global company with leading positions in these areas. In 2014, the Group achieved net sales of USD 58.0 billion, while R&D throughout the Group amounted to approximately USD 9.9 billion (USD 9.6 billion excluding impairment and amortization charges). Novartis Group companies employ approximately 120,000 full-time-equivalent associates. Novartis International AG products are available in more than 180 countries around the world. For more information, please visit <http://www.novartis.com>.