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A guide for Health Care Professionals to have Conversations on Work with People with Multiple Sclerosis

Why and how should
HCPs talk to people
with MS about work?

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Introduction

What is the purpose of this guide?

There is a strong relationship between work and health. In many cases, work has been found to have a positive effect on the health and wellbeing of people with a range of chronic health conditions, including Multiple Sclerosis (MS). Furthermore, many people with MS would like to work and see it as a valuable part of their recovery. But they face a number of health and social barriers to achieving this ambition.

This is a guide for neurologists and other health care professionals (HCPs) to help them hold effective conversations regarding work with patients with MS. The document contains information and practical guidance on why, how and when to conduct such conversations.

Ready for Work Expert Panel | HCPs

- Prof. Jürg Kesselring, Valens Rehabilitation Centre, Switzerland
- Prof. Eva Havrdova, MS Centre, Prague
- Prof. Sven Schippling, Neurologist, University Hospital Zürich, Switzerland
- Daphne Kos, Faculty of Kinesiology and Rehabilitation Sciences, KU Leuven, Belgium and RIMS (Rehabilitation in MS)
- Vicky Matthews, MS Nurse Specialist, United Kingdom

Ready for Work Expert Panel | Other experts

- Frédéric Destrebecq, European Brain Council, Belgium
- Graham Halsey, Well Working Matters, United Kingdom
- John Golding, Past President of EMSP, Norway
- Denisa Pâslaru, Blogger and Patient Representative

How was the guide developed?

This document is based on the strong academic evidence and utilises the knowledge gathered by scores of specialists in the field. It was created with the valuable feedback provided by hundreds of people with MS whom we are in direct contact with on a regular basis.

We recommend this resource for use by all HCPs working with patients with MS. It will assist them to effectively conduct conversations with patients about employment.

Endorsement

This guide has been formally endorsed by the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) and Rehabilitation in MS (RiMS).

What are the aspects of MS that are relevant for the work discussion?

Loss of working years

At least 700,000 people in Europe have MS. With 70% diagnosed during their prime working years (between the ages of 20 and 40)¹, many report their fluctuating health condition has an impact on their employment and career opportunities². People living with MS often find themselves having to change or quit jobs. An estimated 50–80% are unemployed within 10 or more years of disease onset.³

Across Europe, employment rates for people with MS are low, ranging between 26% and 42%⁴, while up to a third of those affected retire early due to their MS⁵. The evidence is clear: people with MS are at an increased

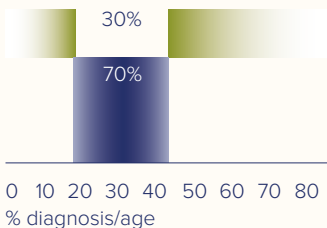
risk of becoming unemployed and economically inactive during their prime working years, with a potentially dramatic influence on their life course and opportunities.⁶

Many symptoms associated with MS create challenges during a person's working life. Fatigue is often reported as the most challenging symptom when it comes to finding and retaining work. There are also mobility and dexterity-related symptoms, pain and heat intolerance, and cognitive issues, including difficulty concentrating.⁷ Severity of the condition is a key factor in predicting employment^{8,9}, with one study finding considerable variations in employment rates for people with mild MS and severe MS¹⁰.

MS and work

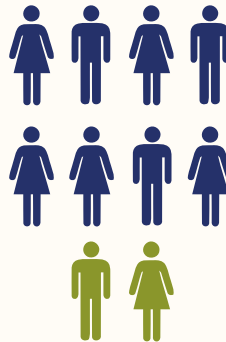
700,000 people in Europe have MS

70% are diagnosed during prime working years



Unemployment

8 out of 10 stop working



60 to 80% of people with MS lose their jobs within 15 years of onset.

Up to a third retire early.

Only between 26 and 42% of people with MS in Europe work.

An estimated 17% are fired by their employers.

Poor symptom management in the workplace as well as a knowledge deficit on the side of employers also have a significant, negative impact on employment rates for people with MS¹¹. Many leave employment due to difficulties managing their condition at work or factors which make work increasingly difficult. This includes employers being unable or unwilling to make job modifications which might allow them to remain and excel in work¹².

The challenge of co-morbidity

People with MS face an increased risk of developing other health problems which may form a further barrier to work¹³. Such comorbidities include

hyperlipidaemia, hypertension, arthritis, irritable bowel syndrome and chronic lung disease¹⁴.

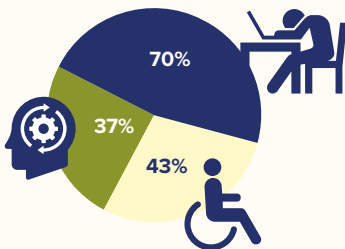
A very relevant fact is that the rate of incidence of depression and anxiety among people with MS is two to three times higher than that of the general population¹⁵. Such high rates of mental health comorbidity are a particular challenge as mental health problems are independently associated with higher levels of unemployment and economic inactivity¹⁶.

Evidence also suggests that the cumulative burden of two or more health conditions is higher than the sum effect of individual conditions.^{17,18,19}

Symptoms

MS symptoms most contributing to loss of employment:

- fatigue (70%)
- restricted mobility (43%)
- cognitive issues (37%)



Co-morbidity

Risk of co-morbidity* in MS: 2 to 3 times higher than that of the general population

* Developing additional mental health problems, such as depression



Supporting people with MS to gain and/or retain employment with the right employer and right infrastructure may reduce the risk of developing comorbid mental health problems and can enable independent living.

Employment and health outcomes

A large body of evidence indicates that unemployed people have lower physical and psychological wellbeing than their employed counterparts.^{20,21,22} Those who are unemployed are more likely to have a chronic illness and poorer mental health, and to require more frequent medical consultations.

For people with MS, unemployment is correlated with negative psychological and physical health effects²³ to such an extent that it is a contributing factor to higher mortality rates²⁴.

On the other hand, employment has a proven positive effect on health and wellbeing, especially in relation to mental health outcomes²⁵. This is particularly true of good quality work^{26,27}: work that is fulfilling, sufficiently well paid and stimulating.

Switzerland

The Swiss MS Society estimates that a **three-month period of sick leave** costs society **€15,000**

The **annual cost to society of early retirement** is approximately **€60,000**



United Kingdom

1 in 5 people who reach six weeks of sick pay eventually leave the workplace*



* Estimation from the Department for Work and Pensions



Economic and social cost

The costs associated with MS are not restricted to the health system. Of the €15bn per year spent on the total costs of MS across Europe²⁸, over half is associated with 'indirect costs', including informal care and lost productivity²⁹.

The inability of many people with chronic illnesses to participate in work means increased social and economic costs for the individual and their families, as well as for society as a whole.

Unemployment, low economic activity and early retirement are associated with higher public spending, lower tax yields and lower overall productivity. Productivity related costs include those associated with presenteeism and sickness absence. For instance, the Swiss MS Society estimates that lost production due to a three month sickness absence costs society €15,000³⁰.

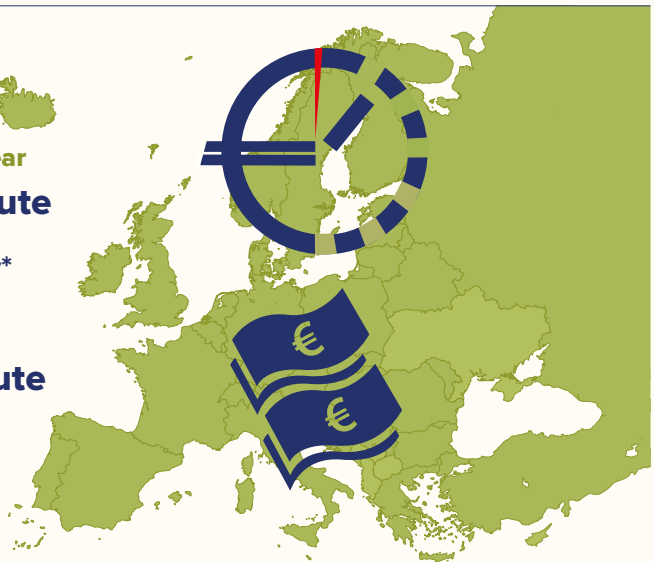
Europe

**total costs of MS
across Europe are in
excess of €15bn per year**
€ 3,000 per minute

**loss of productivity*
alone accounting for
36% of these costs**

€ 1,000 per minute

* Loss of productivity for MS patients can mean short-term sickness leave and early retirement



Why is it important for health care professionals to talk about work?

Many people with MS can work, and would like to work³¹. However, along with their symptoms, a culture of low expectation, stigma, self-stigma and discrimination all present barriers to realising such ambitions. Help can come through positive initiatives such as talking with patients about their work ambitions and opportunities, and empowering them to engage workplace conversations which focus on their individual strengths. They need to be supported to look at what they can do at work rather than what they cannot, to focus on capacity rather than on incapacity.

Adherence through conversation

Effective communication has positive effects on adherence, the degree to which patients follow the recommendations of their health professionals³². It also contributes to patient's likelihood of returning to work.³³ This guide has been designed to facilitate such high quality conversations about work.

Return to work

Returning to work and the benefits attained from this need a partnership approach between the clinicians, the persons with MS and the employers.

Employers need to understand what is being asked of them, by way of

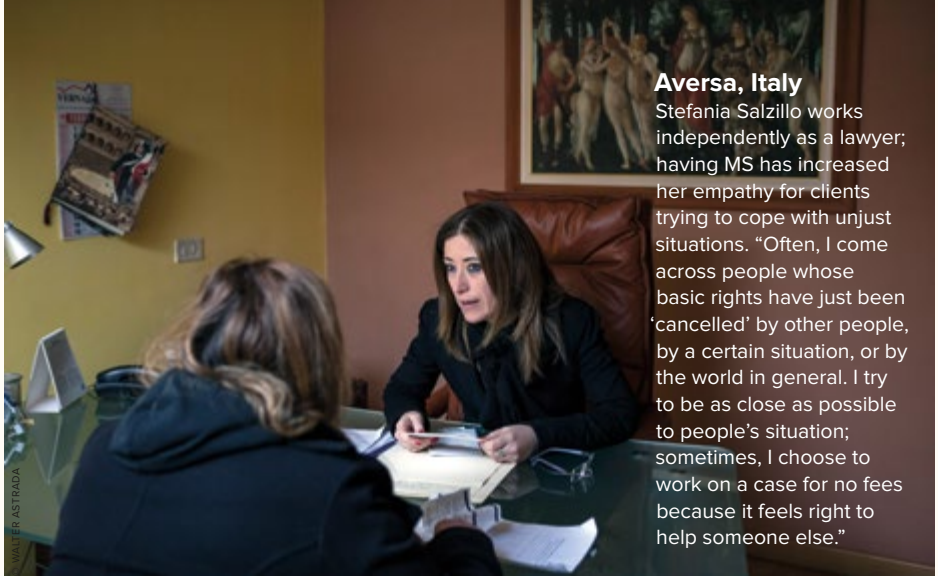
making reasonable accommodations, allowing time for treatment within a working week and maintaining a healthy regular conversation with their employee regarding their changing needs.

A Health Passport could be a useful tool to enable the employee with MS to build the evidence they have gained into one document and have it to hand as they move around a company. This prevents the need to continue to “tell their story” to new managers each time there is a change.

Relation between work and wellbeing

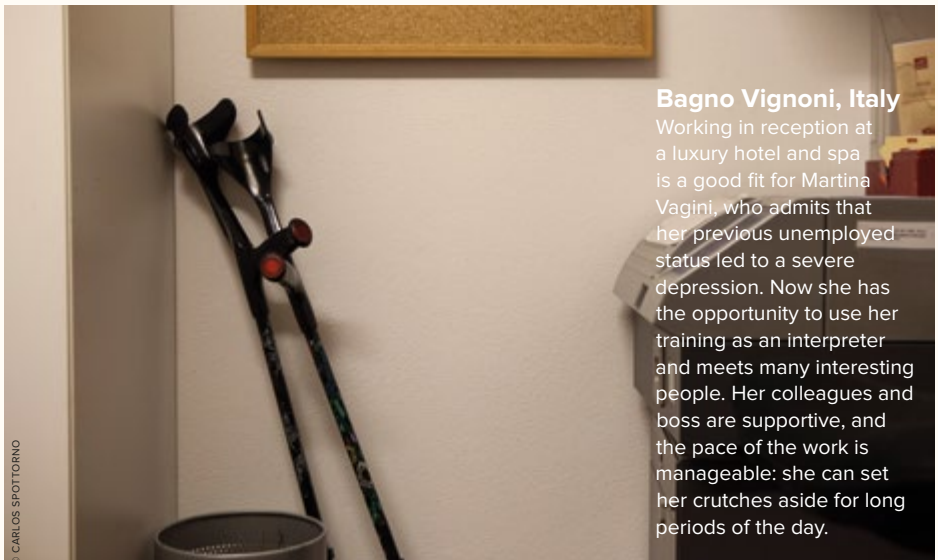
An extensive body of research suggests returning to or staying in work should be considered a clinical health outcome due to the role work can have in improving health and wellbeing, promoting recovery and rehabilitation, and ultimately improving quality of life³⁴.

Good quality work – characterised by opportunities for learning, variety, control and autonomy, positive social relations, security, fairness and a balance between efforts and reward – has been found to be protective of health³⁵. This is why HCPs should view work as a “clinical outcome” and recognise it as a topic within their sphere of influence³⁶.



Aversa, Italy

Stefania Salzillo works independently as a lawyer; having MS has increased her empathy for clients trying to cope with unjust situations. “Often, I come across people whose basic rights have just been ‘cancelled’ by other people, by a certain situation, or by the world in general. I try to be as close as possible to people’s situation; sometimes, I choose to work on a case for no fees because it feels right to help someone else.”



Bagnone, Italy

Working in reception at a luxury hotel and spa is a good fit for Martina Vagini, who admits that her previous unemployed status led to a severe depression. Now she has the opportunity to use her training as an interpreter and meets many interesting people. Her colleagues and boss are supportive, and the pace of the work is manageable: she can set her crutches aside for long periods of the day.

Symptom management at work

Poor symptom management in the workplace has been highlighted as having a significant role in causing people with MS to drop out of employment³⁷. An improvement in this area could lead to a rise in employment rates. Health care professionals have a vital role in helping people with MS understand and manage their condition. This places them at unique vantage point from which they are able to support their MS patients to become or remain a fully active part of society.

Recovery goals

Work is often an important part of our lives. As well as an income, it provides social networks, status and a sense of purpose. Many people with chronic illnesses, including MS, can work and want to work. They see working as an important goal of their clinical care and even a marker of their recovery.

It is important that HCPs work with patients to identify what patients believe would improve their health and wellbeing. This may be broader than symptom management. HCPs should also strive to determine the goals of treatment for each individual patient and what the barriers to achieving them are.

Opportunity for independence

By initiating a conversation about broader recovery goals, including work, and being positive about the possibility of work, a health care professional can transform a person's confidence and self-efficacy.

Early and effective intervention

By integrating conversations about work as a routine part of clinical consultations with HCPs, we can identify potential work difficulties and take action to address them early.

Much as early diagnosis and early intervention are important in a clinical setting to reduce or even hinder some elements of disability, preventing people falling out of work in the first place is also crucial in reducing longer term harms. It is better to support people to stay in a job than it is for them to experience job loss and have to seek new employment.

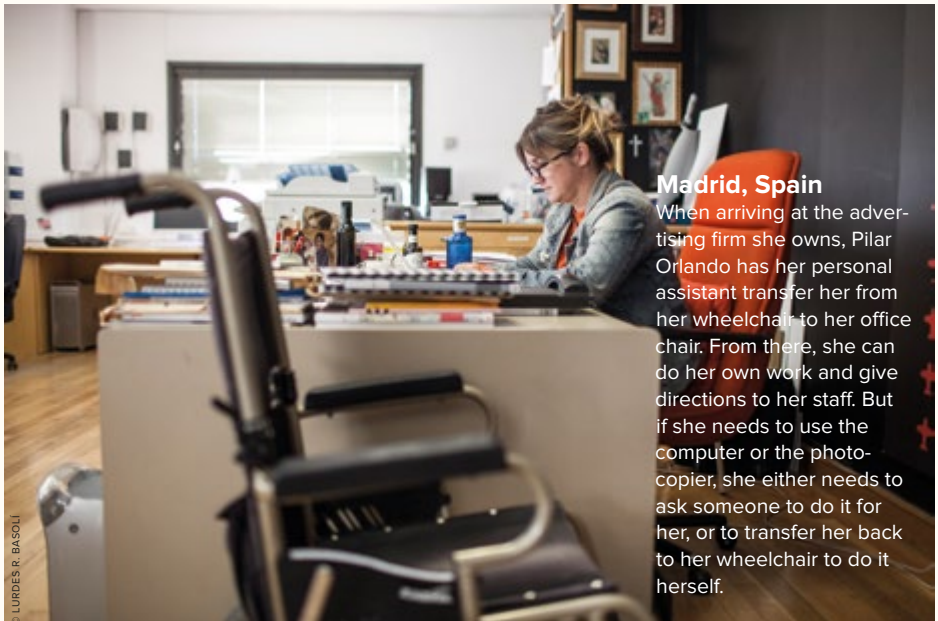
Evidence indicates that the longer employees are away from work, be that in terms of periods of sickness absence or unemployment, the harder it is for them to return³⁸. The Department of Work and Pensions in the UK estimates that 1 in 5 people who reach six weeks

of sick pay eventually leave the workplace. Long-term absence and unemployment can lead to isolation, inactivity and a loss of self-confidence. They also have negative financial implications. These are all factors that inhibit health and wellbeing. Early intervention is therefore crucial.

Problematic treatment

A further consideration is that some medications used in the treatment of MS may cause symptoms which are problematic for certain jobs.

For example, affecting the ability to control mechanical vehicles. It is important that people with MS working in occupations where they may be automatically barred due to taking symptomatic drugs – such as train drivers or pilots – are encouraged and facilitated to seek expert employment advice. Further, this may be a consideration when making decisions about appropriate treatment for an individual patient.



Madrid, Spain

When arriving at the advertising firm she owns, Pilar Orlando has her personal assistant transfer her from her wheelchair to her office chair. From there, she can do her own work and give directions to her staff. But if she needs to use the computer or the photocopier, she either needs to ask someone to do it for her, or to transfer her back to her wheelchair to do it herself.

How to manage workplace disclosure?

Individual decision

Patients may ask you about whether they should disclose their health conditions to their employer. This is a complex and highly individual decision. There are both benefits and challenges to disclosure, and it is important that the patient considers these before making a decision.

Evidence indicates that disclosure often has a positive effect on job retention.³⁹ Disclosure at work is generally the gateway to receiving more support, be that in terms of getting access to occupational health, greater flexibility in working hours or other minor workplace accommodations. For instance, a quiet room where they can rest or their desk placed in the vicinity of the toilet.

To disclose, or not, is very personal. But to access support, it may be a discussion people need to consider having at work, with their manager or with HR.

Risk of discrimination

However, disclosure may also bring the risk of discriminatory treatment. This is outlawed in many European countries. For example, MS is a named condition in the UK Equality Act which outlaws workplace discrimination⁴⁰. Also, protection from discrimination for people with disabilities forms part of the 2000 EU Framework Directive for Equal Treatment in Employment and Occupation.

Nevertheless, we know from the real life experiences of people with MS that such discrimination still occurs. People with MS should seek advice if they have any concerns about how their disclosure might negatively affect their work status.



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- 40 E.g. against the law to discriminate (directly or indirectly), harass or victimise anyone with the condition, including in the workplace – Equality Act, 2010. See: www.legislation.gov.uk/ukpga/2010/15/contents

About us

EMSP

The European Multiple Sclerosis Platform (EMSP) is firmly committed to its ultimate vision of a world without multiple sclerosis (MS). EMSP works according to a three pillar approach to ensure that people with MS have a real voice in determining their own objectives and priorities: campaigning through advocacy and awareness-raising, collecting and sharing knowledge and expertise, encouraging research and data collection.

For further details, please visit

www.emsp.org

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Work Foundation

Through its rigorous research programmes targeting organisations, cities, regions and economies, now and for future trends, The Work Foundation is a leading provider of analysis, evaluation, policy advice and know-how in the UK and beyond. The Work Foundation addresses the fundamental question of what Good Work means: this is a complex and evolving concept. Good Work for all by necessity encapsulates the importance of productivity and skills needs, the consequences of technological innovation, and of good working practices. The impact of local economic development, of potential disrupters to work from wider economic governmental and societal pressures, as well as the business-needs of different types of organisations can all influence our understanding of what makes work good.

Central to the concept of Good Work is how these and other factors impact on the well-being of the individual, whether in employment or seeking to enter the workforce.

For further details, please visit

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