

Working out MS in the Workplace:

A Practical Toolkit for Employers



e m s p

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Multiple Sclerosis is a neurological condition where the protective covering of the nerves, the myelin sheath, is damaged by the immune system. This causes scars along the nerve fibres, hence multiple sclerosis, multiple scars. There are four main types: Relapsing/Remitting; Secondary Progressive; Primary Progressive and Benign.

MS is usually diagnosed during the prime working years of a person's life, between the ages of 20-40 years of age. Many people stay at work and continue on their career path. Some experience impairments but with small adaptations, they continue in their jobs.

People with MS are not a homogenous group; the effects of the condition vary greatly from person to person. However, there are many similarities in experiences including fatigue and the fluctuating nature of the condition. Across the world people with MS are continuing to work, advance in their chosen careers and are staying professionally active.

www.emsp.org/about-ms

What is the European MS Platform (EMSP)?

The EMSP is the umbrella organisation for

40 MS societies from 35 European countries representing more than

700,000 people with MS and the

1,5 million people directly affected by the condition.

EMSP represents their interests at the European level and works to achieve the goals of high quality equitable treatment and support for persons with multiple sclerosis throughout Europe.

Paving the Path to Participation

This toolkit is part of the European Employment Pact, a pledge to support people with multiple sclerosis in the workplace. It is an active effort to build flexibility into businesses and provides practical information for employers.

The likelihood of being in the workforce with a health condition in Europe is high - 23.5% of the working population report having an illness, with 19% stating they had long-term health conditions¹. All businesses will sooner or later face the challenge of adapting to this reality. We are encouraging you to equip your business now, to be prepared and build flexibility into workplace strategies.

“If you’re a good employer of somebody with MS, you’re a good employer in general because you will have the right kind of work policies, conditions and awareness within your organisation.”

Maggie Alexander
EMSP Chief Executive (2012–2016)

¹ European Network for Workplace Health Promotion (2013). PH work: promoting healthy work for people with chronic illness. 9th Initiative (2011–2013) www.enwhp.org/enwhp-initiatives/9th-initiative-ph-work.html

FOR THE
LOVE OF
WORK

Work is good for physical and mental health as well as general wellbeing. It gives people a sense of purpose, provides financial independence and opens doors to further opportunities. Thus, it is an excellent way to make social connections and be actively involved in society.

According to a report from The Work Foundation on the career aspirations of people with MS **75% of people with MS** declared that the condition had impacted their employment and career opportunities¹. Moreover, the same study showed how people with MS lose an average of **18 working years** due to their condition.

EMSP wants to transform how businesses manage the staff members who are affected by MS or other chronic diseases. By providing practical support and guidance to businesses, people with MS can continue in work while the business benefits by holding onto experienced staff.

Developing a good workplace environment and a healthy workforce is a long-term process incorporating different work functions and a variety of people. Business leadership, management teams, human resources and general staff are all involved.

Illness is inevitable in a workforce but good attendance management policies are preventative measures that are effective, cost saving and influence a healthy workplace². Early intervention can mitigate against long-term absence as people return to work while healing and/or undergoing treatment. It is possible to effectively manage absence by being prepared and having strategies in place including step-by-step guidelines for staff.

² National Institute of Disability Management and Research (NIDMAR)
http://www.nidmar.ca/education/education_online/online_module_descriptions.asp?progID=1

From Theory to Practice in the Workplace

WHAT
TO DO?

Don't panic. Don't stress. Treat people as you would other members of your workforce - with respect and in a professional manner.

Create a safe environment to disclose long-term conditions or health issues.

People may need some extra support to make adjustments. Talk with individuals and avoid making assumptions about a person's condition.

Apply early intervention with Attendance Management Policies and assessments to make accommodations/adaptations for a return-to-work plan. It may be necessary to have outside assistance to develop these plans.

Introduce related guidelines and designate a special team to implement them (such as a focused Employee Health Team).

Share the responsibilities with designated tasks and follow-up.

Implement relevant procedures, evaluation and follow-up.

Acknowledge the limitations of in-house capacity and seek the professional support of a disability management professional and/or state agency.

WHY A
TOOLKIT FOR
EMPLOYERS?

A tool for people with MS or other neurological/long-term conditions to open the dialogue about making adaptations in the workplace:

Disclosure of a health condition in the workplace can be a difficult decision. However, by informing the employer, people can be supported with reasonable accommodation and have their rights recognised.

A practical guide for businesses to enhance or build their policies in terms of recruitment, attendance management and return-to-work procedures.

These actions have a knock-on affect influencing workplace health initiatives as well as diversity and inclusion efforts. Concepts such as *Attendance Management Policies*, *Return-to-Work* and *Reasonable Accommodation* describe the strategies to retain valuable staff, reduce work-place absence as well as meet the changing needs of the modern workforce.

Setting up the right framework

All businesses have policies and procedures that inform staff, management, customers and service providers on how that business is run. It is essential to have policies that can be adapted to the changing health of the workforce.

The Employer will:

- Commit to uphold equal employment legislation, anti-discrimination policies, diversity and inclusion programmes and training.
- Review recruitment procedures to ensure employment policies are up-to-date and inclusive. Selection criteria, promotion and decisions are based on an individual's skill-set, education and experience.
- Provide staff with specific information on legislation, company procedures, health advice and relevant contact details in the employee handbook, on notice boards in staff areas, signs and intranet. By doing so, the employer will set a standard of discretion that creates a safe environment.
- Support any employee facing challenges in the workplace (diagnosed with MS/other chronic illness). The individual can disclose with confidence and know that appropriate actions will be taken to address any issue in a collaborative way.
- Ensure that a good attendance management and return-to-work policies are part of the Company's procedures.
- If applicable to the company, provide support to Human Resource (HR) and line managers by recognising and dealing with health conditions in line with their policies and procedures.

Once the key concepts of *attendance management* and supporting people to *return to work* are part of the business functions, they can be introduced implemented along the lines of:

- Adhering to legislation as part of good business practice
- Supporting reintegration into the workplace
- Accommodating potential changes in employee circumstances
- Reducing recruitment, training and insurance costs

WHAT ARE YOUR VALUES?

Assessing the current workforce

HOW TO DO
IT?

- **Monitoring the workforce:** employers need to know who needs to be supported.

The Human Resources department/staff will maintain records of the current workforce health. This ensures people with MS (or other conditions) who need specific support to perform, can get the adjustments they require. The data collection also ensures an attendance management system is implemented:

know **who** is absent, for **what length** of time and **how** to support them back to the workplace.

Disclosing health conditions to the employer is not always mandatory. However, employers can promote and encourage a safe environment in which people are comfortable disclosing their health conditions without it having a negative impact on their career/job. In many situations, employees fear revealing their conditions to their employers - it can be perceived as a weakness and may lead to discrimination and job loss. It is up to the employer to provide the right place and information to the workforce so people are at ease to discuss their conditions knowing they are protected and that any adaptations required will be implanted.

- **Identifying the challenges** faced within the organisations by the people with MS or other conditions in order to address those in the most suitable way.

It is crucial to determine what are the difficulties encountered by the individuals and work together to find solutions to adapt the working environment. It is recommended to have a multi-disciplinary team approach including: the employer (Employee relations staff, Human Resources officer), the employee, the occupational therapist or healthcare professional if needed. This will provide the setting for an objective assessment and rational discussion towards concrete solution proposals.

- **Assessing the policies in place:** the employer will ensure the internal policies are relevant and flexible so they can be adapted accordingly. Reasonable accommodation may include flexible working hours, closer proximity to the toilet facilities, a quiet place to rest during lunchtime, job sharing and other options.

YOU CAN'T CHANGE WHAT YOU DON'T MEASURE!

Preventative Actions Recommended to the Employer

1. Initiate changes in the work environment: flexible-working conditions available for any employee that needs them (based on business and employee needs). Employees need to be made aware of the options.



One of the reasons some employees do not disclose illness in the workplace is prejudice and not wanting to stand out. People want to be recognised by the employers and co-workers as a capable colleague, like any other. The idea of receiving special treatment that could eventually lead to misunderstandings within the team or place them in an isolated situation prevents people from talking with their employers. Any individual can be sick or affected by long-term conditions in the future. Therefore, being sick or having special needs does not mean you are “not normal”. In order to change that mind-set, the employer will ensure information and policies are shared as part of the daily business. This will have two advantages: it will encourage dialogue between the employer and the employee but also positively change the work environment, and thus actions, of co-workers and colleagues.

2. Assessing and identifying the issues before the employee goes on sick leave can be enormously beneficial. The employee knows they are supported by their employer, which has a direct impact on their wellbeing. Limit the length of time and the impact on the employee by responding to symptoms earlier; e.g. discuss changing the work schedule, offering a flexitime option, clearly define tasks. Working things out before a crisis results in a better outcome for all. It is extremely important to continue to involve the individual in work events. Maintaining contact when an individual is on sick-leave is an extremely powerful message; it shows that the employer has not forgotten them.



MAKING IT WORK

Appoint a team of people to develop the return to work programme in your organisation. Include the appropriate people from Human Resources (HR), management, leadership, union representative and general staff.

Who?

It is useful to have an **Employee Relations** individual who is slightly removed from the direct manager. They will be viewed as more independent and therefore act as a third party with the employee, line manager and HR. It will ensure consistency in terms of follow-through on return-to-work plans and referrals to Occupational Health professional. Working with HR, they are in the position to **identify** those individuals who have been out of work or had extended absence due to ill health. These individuals can devote the necessary time to the issues unlike a manager who may be under their daily business pressure.

A good **attendance management policy** clearly states what steps an employee needs to take when they get sick, who to contact, when to make contact and the actions needed to help them return to work.

Maintain contact

As part of the **attendance management**, employers need to know which staff members are absent (who), why they are absent (chronic illness, disability or other reason) and the length of time off work (days, weeks). If an individual has been off work due to the symptoms of MS, maintaining contact with them is important.

Understanding the issues for the person who is off work is a vital part of the on-going relationship between employee and management. Knowing this information will allow the employer and employees to develop together a return-to-work plan.

Meeting with the staff member

Pre-return work assessments as well as analysis of current work are necessary. This will help determine if a staff member is ready to return to work.

The process requires a range of appropriate staff or external expertise for:

- Medical assessment
- Health and safety assessment
- Reintegration (identifying the adaptations required or barriers)
- Return-to-work: plan together with the staff member who has been out of work

Developing the Return-to-Work schedule

Work with the employee and support team on a definitive but adaptable time frame for returning to work: are employees ready to return to work? What changes need to be made?

Follow-up with discussions on return-to-work strategy: identify the barriers that prevent the individual returning to work and develop plan to overcome these together with a Disability Management professional, Occupational Therapist or other experts.

Set specific dates for implementation and review. If something is not working out, all parties must be prepared for changes.

Keep the plan under review

As people's health improves or changes, it is important to have the option to make further adaptations. The plan is more likely to succeed when people are communicating regularly and the individual knows there is always the option to review as circumstances change.

Remember

- Employees are not always obliged to inform their employer about health conditions but it is important that individuals can self-identify if they need support.
- When people feel safe to disclose their health status they will talk through the issues with the Employee relations person, Human Resources or another designated member of staff.
- A coordinated, consensus approach will allow for discussion on what reasonable adjustments can be made to support people to stay in work.
- Collaboration is a key to success.



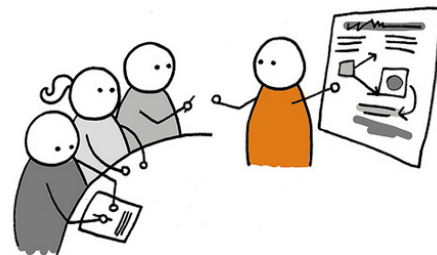
Practical Example

If an employee is diagnosed with MS or another condition and is on sick leave:

- Designated **Employee Relations** person to follow-up with the employee.
- Regular contact by telephone to ensure employees are aware of the company support systems as well as the return to work procedures. Ensure the designated member of staff is appropriately skilled to have the conversation. An unqualified person can do serious damage to a company's reputation at such a sensitive time for the employee on sick leave.
- Let people know about Employee Assistance Programmes and any support provided through the business. Make it easy to access the information on return to work programme or employee support on the company intranet and notice boards.
- Transparency will pay dividends in loyalty, workplace health and staff morale.

Training- Diversity, Inclusion and Disability Awareness

All staff benefit from being in a work environment where they can be themselves. **Diversity** is the range of human differences including age, ethnicity, gender, religious belief, physical ability, sexuality, social class and all the ways people differ. **Inclusion** is about empowerment and organisational strategies where the inherent worth, dignity and strengths of all people are acknowledged and welcomed. **Disability** definitions vary from person to person so it is important to discuss how people define themselves; try not to make assumptions³.



- Disability awareness training for companies is part-funded by many European states. Find out from your local business network whether your company is eligible for funding and have a training specialist visit your business.
- Proactively engage with staff: provide training opportunities on diversity and inclusion, information sessions for new and long-term staff so they are aware of company policies and procedures. Invite local organisations to speak at company events.
- Evaluate the training by surveying staff and providing regular, dated updates (quarterly) on internal procedures to ensure training and awareness had an impact on behaviour and attitudes. Suggested survey questions are in Appendix 2.

Diversity is a fact of the modern workplace; inclusion is a good business decision.

³ International Labour Organisation *Managing Disability at Work* http://ilo.org/wcmsp5/groups/public/---ed_emp/documents/publication/wcms_103324.pdf

Evaluating the impact of your policies

Set up internal measurements of attendance rates with qualitative and quantitative costs to the business

- Evaluate the health of your workforce and attendance rates before implementing changes.
- Use surveys, staff meetings and group sessions to get a real idea.
- Reflect on the policies by evaluating how the policies have or have not worked and implement a strategy to change.
- Discuss and implement measures in coordination with employees.



“ We each have our own disabilities. But don’t think that it is impossible for a person with a neurological disease to hold down a job, because it is not. Most people like me go months or years without even having symptoms. It is a matter of a few adaptations ”

MS advocate Lori Schneider,
First person with MS to scale Mount Everest

MAKING IT WORK

Having policies in place ensures employees:

- Maintain career and professional life
- Rehabilitate by returning to work
- Continue to be financially independent
- Continue to use their education and experience on the job and improve their skills
- Have confidence that illness will not always be a barrier



And for businesses:

- Hold on to valuable employees
- Decrease cost for temporary staff and prevent loss of productivity
- Reduce recruitment and training costs
- Meet legal requirements
- Lower exposure to risk and insurance costs as a result of lower claims
- Enhance workplace diversity

Appendix 1. Employer's checklist⁴

Items	Indicators	Recommendations
Employment policy	- Compliance with National law - Compliance with European Disability regulations	Available for all employees
Recruitment	Regularly reviewed	Date and document the last review
Equal opportunities and proactive employment	Appointment of people based on their qualifications	Recruitment guidelines
Disclosure of conditions/disability	- Safe environment to do so - Procedures in place to engage with the employee	Integrated in the internal policies
Training and awareness in the workforce	- Information available for the staff - Training on diversity and inclusion	Regular information dissemination Once or twice a year
The working environment	Processes and practices set to meet the needs of staff	Integrated in the Employee's handbook
Due process	- 'Return-to-work' process in place - External assistance available if required	Human resources should review and update the current procedures
Flexible working conditions	- Compliance with National Health and Safety legislation - Possibility to discuss with employer to investigate adaptations to the workplace	Integrated in the internal policies and in the Employee's handbook
Monitoring	- Regular monitoring processes in place - Publications of the results	Every 6 months Yearly publication

⁴ EMSP European Employer's Pact for People with MS,
http://www.emsp.org/attachments/article/299/EMSP_PACT.pdf

Appendix 2. Example of self-assessment survey

As part of understanding the current situation for your workforce, surveys are useful, anonymous ways for staff to tell you what's going on for them. It will provide data to understand how well current policies in place are working, identify training gaps and be a catalyst to adjustments. To start with, here are a number of questions to build your survey. As always, it is vital to have an open and sensitive approach given the delicacy of the issues.

<p>1. Do you have a diagnosed medical condition? Yes/No/Prefer not to say</p> <p>2. How does MS/your condition impact your attendance at work?</p> <p>3. Does your workplace provide a contact person/Human resources person to discuss any issues?</p> <p>4. If 'yes', have you used this support?</p> <p>5. Does your condition effect your work? Yes/No If yes:</p> <ul style="list-style-type: none"> • Medical reason due to symptoms • Physical obstacles/accessibility in the workplace • Stress • Other <p>6. What has supported you as you remain in employment?</p> <ul style="list-style-type: none"> • Support from family • Assistance from Human Resources/work • Support from health professional • Financial support • Personal commitment • Self-management course • Personal • Other <p>7. Does your current position match with your qualifications/educational background? Yes/No</p> <p>8. Did you have to change your career plan? Yes/No If yes, why?</p> <ul style="list-style-type: none"> • Personal motivation • Diagnosed with MS/illness • Symptom • Other <p>9. If you work part-time, what are your reasons for working part-time:</p> <ul style="list-style-type: none"> • Limited opportunities for additional work • Symptoms of MS/illness • Personal choice • Issues with employer • Other: <p>10. If you work part-time, was it your decision?</p> <p>11. If you were offered full-time work, would you take it?</p> <p>12. What would affect your decision?</p>	<p>Environment: relations to your boss/colleagues, facilities</p> <p>13. What kind of issues do you have at your workplace?</p> <ul style="list-style-type: none"> • Physical obstacles, e.g. facilities are inaccessible or inadequate • Psychological challenges, e.g. stress due to the demands of work • Flexibility • Managing fatigue during the workday, e.g. access to a place to rest <p>14. Have you disclosed your condition in your workplace?</p> <p>15. If yes, what made you decide to disclose?</p> <ul style="list-style-type: none"> • Symptoms could not be hidden • Needed time off for medical reasons • Good employment practices in the organisation • Other <p>16. If yes, how did your colleagues/boss react?</p> <ul style="list-style-type: none"> • More accommodating, flexible • Negatively, discrimination • Other <p>17. Have there been a change in how people relate to you? Yes/No</p> <ul style="list-style-type: none"> • Positive, please describe your experience • Negative, please describe your experience <p>18. If you have not disclosed, what are the reasons?</p> <ul style="list-style-type: none"> • Unnecessary • Fear of losing the job • Fear of people's reactions to you • Other <p>18. Did you change your role in the workplace after disclosure? Yes/No</p> <p>19. If yes, what were your reasons for changing your role?</p> <p>20. What will assist you to continue in your place of work in the future? <i>Please tick what are important and add your comments.</i></p> <ul style="list-style-type: none"> • You enjoy your current job • Accommodating workplace • Flexible working hours • Support from your colleagues, your employer • Support from your local/national MS society/support organisation • Other <p>19. If it was your decision to work reduced hours, what aspects of your job influenced your decision?</p> <p>20. What do you think are the most common barriers in the workplace for young people with MS or other long-term illness?</p> <ul style="list-style-type: none"> • Economic situation • Lack of opportunities • Symptoms of MS • Psychological affect of health condition • Fear of discrimination • Other <p>21. How do you think work affects your participation in society?</p> <p>22. Does your workplace meet your needs in terms of health care assistance? Yes/No</p> <p>23. What would be of assistance to you?</p>
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Other general questions on diversity and inclusion:

1. What does diversity and inclusion mean to you?
 2. What is your understanding of unconscious bias?
 3. How has your experience and background prepared you to be effective in this environment with the company diversity value/initiative?
 4. What do you see as the most challenging aspect of a diverse working environment?
 5. What steps have you taken to meet this challenge?
 6. What kinds of experiences have you had working with others with different backgrounds than your own?
 7. Tell me about a time you had to alter your work style to meet a diversity need or challenge?
 8. Have you ever disclosed personal details in your workplace?
 9. Have you been discriminated against?
 10. How have you handled a situation when a colleague was not accepting of others' diversity?
 11. What does it mean to have a commitment to diversity? And how would you develop and apply your commitment at this company?
 12. Do you know what is the diversity value at your current employer? What impact did you make on this value?
 13. What efforts have you made, or been involved with, to foster diversity competence and understanding?
 14. What have you done to further your knowledge about diversity? Have you included diversity in your professional development?
- How**
have you demonstrated what you have learned?
15. What kind of leadership efforts would you make to ensure a commitment to the diversity initiative or value?
 16. What strategies have you used to address diversity challenges? What were the positives and negatives?
 17. What do you believe to be the three most effective ways of creating an encouraging work environment?

Appendix 3. Useful Websites

There are many elements to promoting workplace health and improving opportunities for people with MS to gain work and to stay in their careers. Some of these providers have worked with EMSP on employment projects.

<p>Multiple Sclerosis Information</p> <p>EMSP Members in Europe www.emsp.org/emsp-members</p> <p>MS International Federation www.MSIF.com</p> <p>Shift.MS www.shift.ms</p> <p>European Brain Council www.europeanbraincouncil.org</p> <p>European Federation of Neurological Associations www.efna.net</p> <p>Health Promotion</p> <p>European Network for Workplace Health Promotion www.enwhp.org</p> <p>The Work Foundation www.theworkfoundation.com</p> <p>International Labour Organisation www.ilo.org</p> <p>Return to Work</p> <p>Fit for Work http://fitforwork.org/</p> <p>National Institute for Disability Management and Rehabilitation https://www.nidmar.ca</p> <p>Wellworking Matters www.wellworkingmatters.co.uk</p>	<p>Diversity and Inclusion</p> <p>Managing Disability in the Workplace http://ilo.org/wcmsp5/groups/public/---ed_emp/documents/publication/wcms_103324.pdf</p> <p>Business as Unusual www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_316815.pdf</p> <p>Kanchi www.kanchi.org</p> <p>Multimedia</p> <p>Circle of Truth: Disclosure of MS at Work https://youtu.be/Sd1_nrHZIJ4</p> <p>The Ability Factor: ILO https://youtu.be/ooltoKFhUek</p> <p>Mental Health</p> <p>Mind www.mind.org.uk</p> <p>GROW www.grow.ie</p> <p>World Health Organisation www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health</p>
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1. European Network for Workplace Health Promotion (2013). PH work: promoting healthy work for people with chronic illness. 9th Initiative (2011–2013) www.enwhp.org/enwhp-initiatives/9th-initiative-ph-work.html
2. The Work Foundation, *Ready to Work?: Meeting the Employment and Career Aspirations of People with MS* www.theworkfoundation.com/Reports/289/Ready-to-Work-Meeting-the-employment-and-career-aspirations-of-people-with-Multiple-Sclerosis
3. National Institute of Disability Management and Research [Online]. www.nidmar.ca/education/education_online/online_module_descriptions.asp?progID=1
4. International Labour Organisation Managing Disability in the Workplace http://ilo.org/wcmsp5/groups/public/--ed_emp/documents/publication/wcms_103324.pdf
5. EMSP European Employer's Pact for People with MS, www.emsp.org/attachments/article/299/EMSP_PACT.pdf

Every year, the EMSP constituency gathers at the organisation's Spring Conference. Since 2009, this annual event also focused on getting young people with MS together to ensure their needs are turned into priorities. At the 2013 event, EMSP asked what the most important issues for young people with MS were. Two points were prominent:

- 1) **Work opportunities:** the unemployment figures for young people are at an all-time high in Europe, particularly for people with disabilities.
- 2) **Support in employment:** people are being discriminated against and, despite their skills, are losing their jobs. Many employers don't have the full information about the fluctuating nature of MS. Knowing their rights and providing solutions for employers would mean people could deal better and stay in the work place longer.

For more information, please visit EMSP website: www.emsp.org

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