

# Working out MS in the Workplace:

## A Practical Toolkit for Employers



## Introduction

Multiple Sclerosis (MS) is a complex inflammatory disease of the central nervous system. It is the most common neurological disorder among younger adults, with diagnosis typically occurring between the ages of 20 and 40. The effects of MS vary greatly from person to person, but common symptoms that can impact on employment include fatigue, mobility issues and difficulties with memory and every-day thinking. A recent report by MS Ireland found that:

- 7 out of 10 employees say MS has limited their career potential
- Productivity losses due to MS cost Irish society €135.5 million per year<sup>1</sup>



However, many people with MS continue to work for years after diagnosis and advance in their chosen careers. Many people with MS will require little or no adjustments to their working situation in order to remain in employment and where adjustments are required, there may be practical and financial assistance available from the government to support employers in implementing these.

This guide aims to:

- Provide employers with an understanding of some of the most common ways in which MS can impact on employment
- Provide some practical guidance for managing MS in the workplace
- Give an overview of the supports that are available from the government to help employers retain employees with MS

Businesses that adopt policies and practices such as those outlined in this document can benefit by:

- Holding on to valuable employees
- Decreasing costs of temporary staff and preventing loss of productivity
- Reducing recruitment and training costs
- Meeting legal requirements
- Enhancing workplace diversity.



***“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)*

## Managing MS in the workplace - key points

### 1. Create a safe environment where people feel comfortable disclosing long-term conditions or health issues

Many people choose not to disclose illness or disability in the workplace because they are afraid of prejudice and do not want to appear less capable than their colleagues. However, there are many different reasons why someone may need support from their employer for an illness or long-term condition at some stage in their working life. 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.

Employers can help by creating an environment where being sick or having additional needs does not mark someone out as 'abnormal'. For example, this might be done by regularly sharing information on the company policies relating to illness and disability, or by promoting awareness of different options in relation to flexible working practices (subject to business and employee needs). This might also be done by providing disability awareness training for staff – see the section on **'Supports available for employers'** for more information on this.

### 2. Collaborate with the employee to discuss potential adjustments and accommodations

Symptoms of MS vary widely – it is important not to make assumptions about what an employee will or won't be able to carry on doing. Many people might not need any adjustments or adaptations at all and will benefit simply from knowing that their employer is willing to provide support for them should they need it.

Research has found that, for many people with MS, fatigue is the most common symptom associated with the decision to reduce working hours or leave employment<sup>2</sup>. Some examples of possible reasonable accommodations to help deal with fatigue include:

- Changes to work schedules to allow more regular breaks
- Allowing an employee to perform some or all of their work from home from time to time
- Allowing an employee to sit rather than stand in jobs that usually require standing for long periods, such as a cashier
- Offering a quiet place/location with a couch or chair to take rest during the day
- Varying of work demands and activities
- Job sharing

Other symptoms that may impact on an employee's ability to carry out their duties include mobility difficulties, eyesight problems, continence problems, memory difficulties and loss of dexterity in the limbs. Some examples of reasonable accommodations for these problems include:

- Installation of hand rails in the toilet
- The use of voice recognition software for someone who finds typing difficult
- The use of reminders/alerts to help with remembering tasks and appointments
- Moving a desk so it is nearer to the toilet
- Allowing an employee to park closer to the building
- Provision of a supportive chair

There may be financial support available from the government where there is a cost implication for implementing an adjustment or adaptation – see the section on **'Supports available for employers'** for more information on this.

### 3. Apply early intervention

Intervening early is key to maximising the chances of an employee continuing in their role with minimum disruption. Work with the employee to assess and identify issues and limit the impact of their MS by responding to symptoms early – for example, discussing changes to the work schedule or offering flexitime or home-working options. Working things out before a crisis results in a better outcome for all and the employee will know they are supported, which has a direct impact on their wellbeing.

See the section on **'Developing and implementing policies'** for more information on this.



## Developing and implementing policies

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. An employer who is committed to this will:

- Commit to uphold employment legislation, anti-discrimination policies, diversity and inclusion programmes and training. In Ireland, the relevant pieces of legislation that pertain to this are the Employment Equality Acts 1998-2015
- Review recruitment procedures to ensure employment policies are up-to-date and inclusive. Selection criteria, promotion and decisions should be based on an individual's skill set, education and experience
- Provide staff with access to specific information on applicable legislation, company procedures, health advice and relevant contact details e.g. employee handbooks and/or company intranets. By doing so, the employer will be helping to create a safe environment where employees will feel supported if they need to disclose health issues
- Support any employee who is facing challenges in the workplace, including a diagnosis of a chronic illness such as MS. The individual can disclose their diagnosis with confidence and know that appropriate actions will be taken to address any issue in a collaborative way
- Ensure that good attendance management and return-to-work policies are part of the company's procedures
- Provide support to HR and line managers in 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 and 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

## 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 so that employers can 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 information to the workforce so people are at ease to discuss their conditions knowing they are protected and that any adaptations required will be implemented.

- 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 and the occupational therapist or other healthcare professionals 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



## Attendance management and return-to-work

A good attendance management policy clearly states what steps an employee needs to take when they get sick, who to contact, when to make the contact and the actions needed to help them return to work. If resources within the organisation allow, it can be useful to have an employee relations individual who is slightly removed from the direct manager. They will be viewed as more independent and can 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 appropriate professionals, such as occupational health.

If an individual has been absent from work due to the symptoms of MS, maintaining contact with them is important. Understanding the issues for the person who is off work, and how MS is affecting them, is a vital part of the ongoing relationship between employee and management. Knowing this information will allow the employer and employee to work together to develop a return-to-work plan. For example, if fatigue is a particular issue for the employee then considerations around work schedules may need to form part of the discussion from early on.

Before an employee returns to work, an analysis of the individual's current role and responsibilities, and what, if any, adjustments may be needed, is necessary. This process may require 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 employee who has been out of work

The employer, employee and support team should work together on a definitive but adaptable timeframe for returning to work. Specific dates should be set for implementation and review, and if something is not working out all parties must be prepared for changes.



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## Diversity, inclusion and disability awareness

Diversity is a fact of the modern workplace and creating an environment where the inherent worth, dignity and strengths of all people are acknowledged and welcomed is a good business decision. Disability definitions vary from person to person so it is important to discuss how people define themselves and not to make assumptions<sup>3</sup>. This is particularly true in the case of an illness like MS which is extremely varied in its effects. Many people with MS will choose not to disclose their illness to other colleagues even if they have informed their immediate manager and HR. However, creating an environment where difference and diversity are acknowledged and accepted may give people the confidence to seek support and understanding from others should they need it. Providing disability awareness training as part of a general programme on inclusion and diversity can help with this – see **'Supports available for employers'** for more information on how to access disability awareness training.

## Evaluating the impact of policies

Employers should set up internal measurements of attendance rates with qualitative and quantitative costs to the business. This can be done by:

- Evaluating the health of your workforce and attendance rates before implementing changes
- Use of surveys, staff meetings and group sessions
- Reflecting on the policies by evaluating how the policies have or have not worked and implement a strategy to change
- Discussing and implementing 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*

## Supports available for employers

### Financial supports

A lot of the reasonable accommodations described above can cost very little to put in place. Where there is a cost involved, employers may get some financial support towards this.

**Workplace Equipment Adaptation Grants** can be accessed by employers in the private sector to meet the needs of employees with disabilities. A grant is available up to a maximum of €6,350<sup>4</sup> and may be used towards the costs of adapting equipment or premises.

The **Wage Subsidy Scheme** offers financial incentives for employers in the private sector to employ people with disabilities who work more than 20 hours per week. Where it is perceived that there is a productivity shortfall of 20% or more for a disabled employee in comparison to a non-disabled peer, the employer can apply for a subsidy of €5.30 per hour<sup>5</sup>.

Employers can contact their local Employment Services Office or Citizens Information Centre to inquire about these two schemes. Further information can also be found at [www.welfare.ie](http://www.welfare.ie).

The **Disability Awareness Training Support Scheme** is a grant that employers can access to source disability awareness training for their staff. The purpose of the training is to deliver clear and accurate information about disability and to address questions or concerns that employers and employees may have about working with people with disabilities.

The training is aimed at providing participants with an understanding and awareness of the issues surrounding disability, including:

- An overview of relevant anti-discrimination and equal opportunities legislation
- General and specific information on disabilities, perceptual awareness exercises and disability etiquette



Grants of 90% of eligible training costs, up to a maximum of **€20,000**, are available to private companies in the first year and 80% in the second and subsequent years. Eligible costs include actual fees paid in respect of external programmes trainer's fees for in-house staff training, open learning/computer/web based training programme fees and learning materials e.g. manuals, books, clearly associated with the relevant training programme to a maximum of **€650**<sup>6</sup>.

Contacts for the Disability Awareness Training Support Scheme can be found at [www.welfare.ie](http://www.welfare.ie).

The **Employee Retention Grant Scheme** is designed to help employers in the private sector to retain an employee who has acquired an illness or disability that impacts on their ability to do their job. The grant facilitates employers to implement a retention strategy so that the employee can either remain in his/her current role or be re-trained so that they can take up employment in another department. Further information on this grant and contact details for the scheme can be found on [www.welfare.ie](http://www.welfare.ie)<sup>7</sup>.

### Information and advice

The **Employer Disability Information Service** is a centrally based national resource for advice and information for employers on the employment of people with disabilities. The website contains information on a range of issues including reasonable accommodation, conducting back to work interviews and health and safety. The website is [www.employerdisabilityinfo.ie](http://www.employerdisabilityinfo.ie) and there is also a helpline which can be contacted on **01 676 2014**.

The **National Disability Authority** has produced some guidelines on retaining employees who acquire a disability. This guide provides employers with information about how to help employees who have acquired a disability to stay in work or return to work after a period of recovery. The guide can be accessed on their website, [www.nda.ie](http://www.nda.ie).



Further information can be found at [www.welfare.ie](http://www.welfare.ie)

## Appendix 1. Employer's checklist<sup>8</sup>

Items	Indicators	Recommendations
<b>Employment Policy</b>	<ul style="list-style-type: none"> <li>• Compliance with national law</li> <li>• Compliance with European Disability Regulations</li> </ul>	<ul style="list-style-type: none"> <li>• Available for all employees</li> </ul>
<b>Recruitment</b>	<ul style="list-style-type: none"> <li>• Regularly reviewed</li> </ul>	<ul style="list-style-type: none"> <li>• Date and document the last review</li> </ul>
<b>Equal opportunities and proactive employment</b>	<ul style="list-style-type: none"> <li>• Appointment of people based on their qualifications</li> </ul>	<ul style="list-style-type: none"> <li>• Recruitment guidelines</li> </ul>
<b>Disclosure of conditions/disability</b>	<ul style="list-style-type: none"> <li>• Safe environment to do so</li> <li>• Procedures in place to engage with the employee</li> </ul>	<ul style="list-style-type: none"> <li>• Integrated in the internal policies</li> </ul>
<b>Training and awareness in the workforce</b>	<ul style="list-style-type: none"> <li>• Information available for the staff</li> <li>• Training on diversity and inclusion</li> </ul>	<ul style="list-style-type: none"> <li>• Regular information dissemination</li> <li>• Once or twice a year</li> </ul>
<b>The working environment</b>	<ul style="list-style-type: none"> <li>• Processes and practices set to meet the needs of staff</li> </ul>	<ul style="list-style-type: none"> <li>• Integrated in the Employee Handbook</li> </ul>
<b>Due process</b>	<ul style="list-style-type: none"> <li>• 'Return-to-work' process in place</li> <li>• External assistance available if required</li> </ul>	<ul style="list-style-type: none"> <li>• Human resources should review and update the current procedures</li> </ul>
<b>Flexible working conditions</b>	<ul style="list-style-type: none"> <li>• Compliance with national health and safety legislation</li> <li>• Possibility to discuss with employer to investigate adaptations to the workplace</li> </ul>	<ul style="list-style-type: none"> <li>• Integrated in the internal policies and in the Employee Handbook</li> </ul>
<b>Monitoring</b>	<ul style="list-style-type: none"> <li>• Regular monitoring processes in place</li> <li>• Publications of the results</li> </ul>	<ul style="list-style-type: none"> <li>• Every 6 months</li> <li>• Yearly publication</li> </ul>

## 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.

- 1. Do you have a diagnosed medical condition?**  
Yes/No/Prefer not to say
  - Other
- 2. How does MS/your condition impact your attendance at work?**  
Yes/No
- 3. Does your workplace provide a contact person/Human resources person to discuss any issues?**
- 4. If 'yes', have you used this support?**
- 5. Does your condition effect your work?**  
Yes/No
 

**If yes:**

  - Medical reason due to symptoms
  - Physical obstacles/accessibility in the workplace
  - Stress
  - Other
- 6. What has supported you as you remain in employment?**
  - Support from family
  - Assistance from Human Resources/work
  - Support from health professional
  - Financial support
  - Personal commitment
  - Self-management course
  - Personal
- 7. Does your current position match with your qualifications/educational background?**
- 8. Did you have to change your career plan?**  
Yes/No
 

**If yes, why?**

  - Personal motivation
  - Diagnosed with MS/illness
  - Symptom
  - Other
- 9. If you work part-time, what are your reasons for working part-time:**
  - Limited opportunities for additional work
  - Symptoms of MS/ illness
  - Personal choice
  - Issues with employer
  - Other:
- 10. If you work part-time, was it your decision?**
- 11. If you were offered full-time work, would you take it?**
- 12. What would affect your decision?**  
**Environment: relations to your boss/colleagues, facilities**

**13. What kind of issues do you have at your workplace?**

- 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

**14. Have you disclosed your condition in your workplace?**

**15. If yes, what made you decide to disclose?**

- Symptoms could not be hidden
- Needed time off for medical reasons
- Good employment practices in the organisation
- Other

**16. If yes, how did your colleagues/boss react?**

- More accommodating, flexible
- Negatively, discrimination
- Other

**17. Have there been a change in how people relate to you? Yes/No**

- Positive, please describe your experience
- Negative, please describe your experience

**18. If you have not disclosed, what are the reasons?**

- Unnecessary
- Fear of losing the job
- Fear of people's reactions to you
- Other

**19. Did you change your role in the workplace after disclosure? Yes/No**

**20. If yes, what were your reasons for changing your role?**

**21. What will assist you to continue in your place of work in the future? Please tick what are important and add your comments.**

- 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

**22. If it was your decision to work reduced hours, what aspects of your job influenced your decision?**

**23. What do you think are the most common barriers in the workplace for young people with MS or other long-term illness?**

- Economic situation
- Lack of opportunities
- Symptoms of MS
- Psychological affect of health condition
- Fear of discrimination
- Other

**24. How do you think work affects your participation in society?**

**25. Does your workplace meet your needs in terms of health care assistance?**

Yes/No

**26. What would be of assistance to you?**

**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?

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## 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.

### Multiple Sclerosis Information

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EMSP Members in Europe  
[www.emsp.org/emsp-members](http://www.emsp.org/emsp-members)

MS International Federation  
[www.MSIF.com](http://www.MSIF.com)

Shift.MS  
[www.shift.ms](http://www.shift.ms)

European Brain Council  
[www.europeanbraincouncil.org](http://www.europeanbraincouncil.org)

European Federation of Neurological Associations  
[www.efna.net](http://www.efna.net)

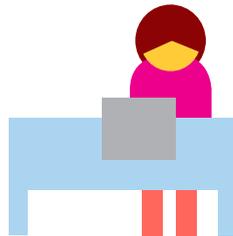
### Health Promotion

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European Network for Workplace Health Promotion  
[www.enwhp.org](http://www.enwhp.org)

The Work Foundation  
[www.theworkfoundation.com](http://www.theworkfoundation.com)

International Labour Organisation  
[www.ilo.org](http://www.ilo.org)



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## Return to Work

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Fit for Work

<http://fitforwork.org/>

National Institute for Disability Management and Rehabilitation  
<https://www.nidmar.ca>

Wellworking Matters  
[www.wellworkingmatters.co.uk](http://www.wellworkingmatters.co.uk)

### Diversity and Inclusion

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Managing Disability in the Workplace  
[http://ilo.org/wcmsp5/groups/public/---ed\\_emp/documents/publication/wcms\\_103324.pdf](http://ilo.org/wcmsp5/groups/public/---ed_emp/documents/publication/wcms_103324.pdf)

Business as Unusual  
[www.ilo.org/wcmsp5/groups/public/---ed\\_emp/---ifp\\_skills/documents/publication/wcms\\_316815.pdf](http://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_316815.pdf)

Kanchi  
[www.kanchi.org](http://www.kanchi.org)

### Multimedia

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Circle of Truth: Disclosure of MS at Work  
[https://youtu.be/Sd1\\_nrHZIJ4](https://youtu.be/Sd1_nrHZIJ4)

The Ability Factor: ILO  
<https://youtu.be/o0lt0KFhUek>

### Mental Health

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Mind  
[www.mind.org.uk](http://www.mind.org.uk)

GROW  
[www.grow.ie](http://www.grow.ie)

World Health Organisation  
[www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health](http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health)

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The Toolkit was developed as part of the European Employment Pact, a pledge to support people with Multiple Sclerosis in the workplace. This is part of the Paving the Path to Participation (PPP) project which aims to stimulate policy change that will support maximum participation of people with MS in the European labour market. Further information is available at [www.emsp.org/projects/paving-the-path-to-participation/](http://www.emsp.org/projects/paving-the-path-to-participation/)

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## About EMSP



The EMSP is the umbrella organisation for 41 MS societies from 36 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.

[www.emsp.org](http://www.emsp.org)

## About MS Ireland



Multiple Sclerosis Ireland is the only national organisation providing information, support and advocacy services to the MS community. We work with people with MS, their families and carers and a range of key stakeholders including health professionals, students and other interested in or concerned about MS to ensure that we meet our goals.

MS Ireland is chiefly a services driven organisation, focused on providing timely, person-centered services that create independence and choice for person with MS and their family.

[www.ms-society.ie](http://www.ms-society.ie)

## References

1. MS Ireland, 2015. 'Societal Costs of Multiple Sclerosis in Ireland 2015'. Dublin: UCD and Novartis (http://ijmsc.org/doi/abs/10.7224/1537-2073.2014-051).
2. International Labour Organisation Managing Disability at Work [http://ilo.org/wcmsp5/groups/public/---ed\\_emp/documents/publication/wcms\\_103324.pdf](http://ilo.org/wcmsp5/groups/public/---ed_emp/documents/publication/wcms_103324.pdf)
3. <http://www.welfare.ie/en/Pages/Workplace-Equipment-Adaptation-Grant.aspx>
4. [http://www.welfare.ie/en/Pages/Wage-Subsidy-Scheme\\_holder\\_3176.aspx](http://www.welfare.ie/en/Pages/Wage-Subsidy-Scheme_holder_3176.aspx)
5. [http://www.welfare.ie/en/Pages/Disability-Awareness-Training\\_holder.aspx](http://www.welfare.ie/en/Pages/Disability-Awareness-Training_holder.aspx)
6. <http://www.welfare.ie/en/Pages/Employee-Retention-Scheme.aspx>
7. EMSP European Employer's Pact for People with MS, [http://www.emsp.org/attachments/article/299/EMSP\\_PACT.pdf](http://www.emsp.org/attachments/article/299/EMSP_PACT.pdf)

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