



Grant agreement no.: 2022-1-CY01-KA220-ADU-000089474

Project acronym: ShapeMS

Project title: Shaping the future of people with Multiple Sclerosis

Step-by-step guide for employers

Short version

D2.4 Step-by-step guide for employers



**Co-funded by
the European Union**

The European Commission support for the production of this publication does not constitute an endorsement of the contents which reflects the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

Table of content

Table of content	2
Overview	3
Introduction	4
Background	5
Guide for employers	6
1 Emotional support	6
2 MS and the law (including confidentiality and safety)	7
3 Supporting your employee	7
4 Reasonable adjustments.....	9
5 Working from home.....	10
Why to become an inclusive ambassador	11
1 Win-win approach	11
2 Visit the ShapeMS platform.....	12
3 Platform’s material for employers	12
Conclusions	15
References	16



Overview

This guide aims to raise awareness and provide practical suggestions and guidance to employers. The purpose is to promote a deeper understanding of the challenges these employees face and to indicate how best to relate to them.

At the beginning we describe the characteristics of MS, with the intent of increasing knowledge of the condition. In the main body of the guide, guidance is given to employers regarding the emotional support to be offered to people with MS, the regulatory framework regarding the inclusion of these people and how to properly support their employees with MS.

All employees have a right to be respected at work and to be given the tools they need to be successful. For people with MS, reasonable accommodations allow them to continue to show up to work, be productive and contribute in meaningful ways.

An inclusive, people-first workplace culture can also boost happiness and lessen stress, both of which have shown to reduce symptoms of MS.

Therefore, it is essential to create inclusive environments that meet the specific needs of these employees. An inclusive work environment is also beneficial for employers.



Introduction

Nowadays, one of the challenges for employers is to create inclusive work environments. This step-by-step guide is for employers and aims to raise awareness about inclusion in the workplace. It provides practical guidance to improve the workplace, suggestions to support and sustain the work experience of people with MS, and highlights the benefits and opportunities of creating a more inclusive work environment for all.

The main goal is to raise awareness about multiple sclerosis (MS) and its impact on the workplace, offering employers concrete strategies and guidance for building a mentally healthy and inclusive work environment that recognizes the emotional and practical issues people with MS may experience.

The guide aims to provide employers with communication skills and strategies, as well as emotional and psychological support, to cultivate an inclusive work environment that welcomes and supports employees with MS, with the goal of turning employers into inclusive ambassadors.



Background

MS is a lifelong, unpredictable, autoimmune disease that causes lesions in the brain and spinal cord. MS occurs when the immune system attacks nerve fibres and myelin, the protective fatty covering of our nerves, causing inflammation. MS can occur in both adults and children.

The resulting scar tissue blocks electrical signals to the brain disrupting normal body movement and function. MS can cause various symptoms including: vision loss, pain, fatigue, trouble with coordination and movement.

These symptoms will not only differ from person-to-person, but they can also range in severity and duration.

There are **different types of MS** that could be diagnosed:

- *Relapsing-Remitting MS (RRMS)*: it is estimated that of those diagnosed with MS, over 80% have the Relapsing-Remitting type. In this form, MS “attacks,” which are a flare-up of disease symptoms, may occur every so often amid periods of relief. It can be weeks or even years between episodes.
- *Secondary Progressive MS*: overtime, the RRMS type can turn into a secondary progressive form of MS, where the disease advances at a slow, steady, unrelenting pace. This can occur more often for those who are not benefiting from treatment.
- *Primary Progressive MS*: about 10% of individuals are diagnosed with a primary progressive form of MS where the disease worsens over time without periods of relief.

As an employer, **it is important to learn about MS**. Helping an individual living with MS can be confusing. Because MS is such an individual condition, it’s difficult to know exactly how it will affect your employee.

It’s important to try to establish an **open dialogue with your employee**, so you can find out what support they need, and ask them any questions you may have.



Guide for employers

1 Emotional support

Mental health problems occur more often in people with MS than the general population. Furthermore, they occur more often in people with MS than any other neurological or chronic condition.

It is not known whether this is a symptom of MS, or whether it happens as a result of the symptoms common to people with MS that can impact so profoundly on daily life, such as fatigue, pain and mobility difficulties alongside the unpredictable nature of the condition.

It is for this reason that supporting people with MS in relation to their mental health is of utmost importance to lessen the impact of their MS and improve their functioning physically, psychologically and socially.

Findings from several systematic reviews have highlighted that work can be beneficial for an individual's overall well-being, particularly if good quality supervision is present and there are favourable workplace conditions. In addition, researchers have found that individuals frequently identify work as providing several important outcomes including:

- a sense of purpose;
- acceptance within society;
- opportunities for development.

Because of this relationship between mental health and the work environment, it is important that there is emotional and psychological support from employers.

As employers, to support your employees with MS there are **some actions** to take:

- *Listen*: by listening, you will gain an understanding of what they are experiencing. Listening to someone does not mean that you have to do anything in particular to change their circumstances.
- *Ask what you can do*: if you feel able to help, ask what you can do rather than decide what the person needs.
- *Recognise that the individual is unique*: if you know more than one person with MS, think of them as unique individuals with their own experiences rather than trying to layer one person's experience over the other's.
- *Think about how their lives might have changed*: MS is different for each person and leads to physical changes, emotional changes, changes in how they relate to others and to themselves. People with MS face new challenges in their surroundings, including in the work environment.
- *Try not to 'fix' it*: MS cannot be fixed. By learning to accept this, you can help the person with MS to accept their disease as well.
- *Provide a mentally healthy workplace*.



2 MS and the law (including confidentiality and safety)

As the employer of someone with MS, you have certain duties:

- To put in place any reasonable adjustments your employee needs in order to do their job.
- Not to treat them unfairly. This means you can't harass them or discriminate against them, or allow them to be harassed or discriminated against by someone else at work.

You should take care to ensure that any information your employee shares with you about their MS remains confidential. For example:

- Do not discuss their MS with anyone else, unless they have said you can.
- Do not discuss their MS with them in situations where other people may be able to find out – for example, in an email that could be passed on to someone else, or in an open-plan office.
- If your employee has an occupational health assessment, clarify with them exactly who can see the report.
- If you have any meeting notes discussing your employee's MS, or any other documents that give any details of their condition, make sure they are kept secure.

As an employer, it is important to help the employee contact the HR department to learn about eligible benefits, such as long-term disability and family leave, both paid and unpaid. Depending on the type of MS and the predicted disability, now may be the right time to investigate how to secure disability benefits.

As an employer, or HR manager, it might be useful to engage with these professional figures to better understand the specific needs of employees in their day-to-day actions.

You can pay for extra equipment or support for your employee with MS, such as:

- adaptations to the equipment they use,
- special equipment,
- taxi fares to work if they can't use public transport or drive,
- a support worker or job coach to help them in the workplace,
- disability awareness training for their colleagues,
- a communicator at a job interview,
- case manager for employee with MS,
- account manager for employers.

3 Supporting your employee

For many people with MS, having a supportive employer is what enables them to manage their condition at work and keep their jobs.



It is therefore up to the HR manager to facilitate individualized planning, tailoring working conditions to the specific needs of the person with MS.

The best way is to establish an **ongoing conversation**, between employer and employee, to express concerns, understand what he needs and how he can be helped. If the employer knows someone else with MS, they should avoid making comparisons between the employee and the other person.

Everyone's MS is different. Although the instinct might be to show sympathy and condescension, an emotional response is not helpful. It is better to focus on the support you can offer the employee.

Don't pressure your employee into making decisions, or changes to any aspect of their job, particularly if they are newly diagnosed or recovering from a relapse. Give them time to process their situation and think through their options.

Talking to your employee needs to be more than a one-off conversation. Try to foster a relationship with your employee in which they feel they can trust you, and you can both talk about any of your concerns. For example, you could arrange a quarterly meeting – separate from their performance review – to talk about how their MS is affecting them and whether any reasonable adjustments you've agreed on are working for them.

Your employee's MS can also have an impact on other members of staff

Your employee's MS can also have an impact on other members of staff. They may be worried about what's happening to the person with MS, particularly if the person hasn't told anyone else at work about their MS.

As the employer, it's your responsibility to make sure these issues are addressed sensitively, while also respecting your employee's confidentiality.

You may want to discuss with your employee whether they want to tell their colleagues about their MS. If the other members of staff know why they are being asked to do extra work, for example, they may be happier to do so.

Any decision about telling other members of staff has to come from the person with MS.

Managing relapses

If your employee is having a relapse, they may not be able to work. Supporting them through this time is a vital part of their ongoing management.

Keep in touch with your employee, without pressuring them into returning to work. Although you may want to know when they'll be back, the unpredictable nature of MS makes it impossible to know how long it will take them to recover.

Encourage your employee not to make any major decisions about work – like changing jobs, reducing their hours or stopping work completely – during a relapse. They may be



feeling particularly vulnerable, and any decision they make at this time may not be the best one for them.

4 Reasonable adjustments

It is an employer's legal duty to ensure reasonable adjustments are made to negate any disadvantages a person with a disability may encounter when undertaking work duties, in comparison to those who are not affected by a disability.

What is considered 'reasonable' will depend on the company and the job your employee does. Many reasonable adjustments cost little or nothing to put in place.

Examples of reasonable adjustments that people with MS have asked for include:

- a chair or stool to sit on,
- flexible or reduced working hours,
- working from home,
- moving their work station away from a source of heat, or closer to a toilet,
- time off for medical appointments.

An occupational health assessment can identify any reasonable adjustments that would help your employee.

Types of adjustment

Adjustments will vary from person to person in line with specific individual needs. It is therefore difficult to provide a full list of reasonable adjustments.

However, the following are a few examples of how they can be applied:

- A person who is affected by visual impairment is provided with suitable assistive technology such as screen readers, digital screen magnification programmes and other adaptive hardware to help them use equipment such as PCs and laptops.
- Flexibility in working hours, including bespoke start/finish times, extended breaks, and temporary reductions in working hours when an employee is most affected by their condition.
- Review of everyday tasks as per the employee's job description. Could involve creating a bespoke role for the employee so that they can focus on tasks that are more accessible, either temporarily or on a permanent basis.
- Providing access to parking spaces that are close to the entrances and exits of workplace buildings.

How occupational health can help



Occupational health (OH) is a specialist medical advisory service which is designed to provide support to both employers and employees in the proactive management of workplace health and wellbeing.

An OH assessment can help both parties to identify the most appropriate reasonable adjustments that need to be made to ensure the disabled employee is not disadvantaged.

5 Working from home

Working from home is a common accommodation request. For individuals with MS, working from home could mean the difference between continuing to work or not working altogether.

Technological advancements have increased telework options and expanded opportunities for people with disabilities. Allowing work from home can accommodate MS symptoms and can boost morale and productivity, making the practice a win-win for the employee and the employer.

As an employer, there are some useful tips you could give your employees for working remotely in a healthy way:

- *Get a comfortable, yet supportive business chair.* Wireless technology allows us to work from our couch, recliner, or even bed, but working long hours from these positions can lead to bad work habits and posture.
- *Avoid home distractions.* When you are on the clock, do not watch TV, take personal calls, surf social media or play Sudoku or Words with friends. Your employer will likely have some kind of productivity metric to evaluate you and distractions can take you away from your productive time. Your productivity is the key to ongoing employment.
- *Stay disciplined.* Many people can be productive working from home in short spurts, but it requires discipline to work-from-home consistently. Once you get an at-home work routine, stick to it. If you start to fall out of that discipline, then your work will slip.



Why to become an inclusive ambassador?

1 Win-win approach

Employers need to transform their businesses to manage the staff members who are affected by MS because it is a win-win approach. Having inclusive workplace policies benefit employees and the business as well.

Benefits for employers:

- 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.

To be an inclusive employer, they need to develop a good workplace environment and a healthy workforce. This is a long-term process incorporating different work functions and a variety of people. Business leadership, management teams, human resources and general staff should all be involved.

Illness is inevitable in a workforce but good attendance management policies are preventative measures that are effective, cost saving and influence a healthy workplace.

The aims of the inclusive workplace policies should be:

- To create a positive culture, where diversity, inclusion and respect are at the core of all our activities.
- To create an inclusive environment in which individual differences and the contributions of employees are recognised and valued.
- To ensure that employees are engaged with the development and implementation of this policy.
- To encourage positive action to overcome disadvantage and discrimination wherever we witness it.
- To ensure equality, diversity and inclusion is promoted through our work, both internally and externally.
- To create a working environment that promotes dignity and respect for all.
- To implement inclusive recruitment practices.
- To regularly review the provision of support and information to ensure that it is accessible, fair and appropriate for all key stakeholder groups.



2 Visit the ShapeMS platform

The ShapeMS learning platform (<https://learning.shape-ms.eu/moodle/>) includes a variety of information, materials and training videos related to work opportunities and how to ensure an inclusive work environment for people with MS.

The goal is to provide the resources, information and tools in order for young adults with MS to remain in the workforce for as long as possible, and raise awareness, educate their employers and teach them how to provide the respective accommodations.

This program is designed to: bridge gaps, reduce myths, and create an environment where both employers and people with MS can work together to succeed.

The target groups are:

- Young adults with MS.
- Employers.
- Volunteer mentors with MS.
- Caregivers of people with MS.

This curriculum is carefully designed to meet the specific needs of these target groups, promoting a complete approach to inclusivity.

For employers, the focus is on providing decision-makers with insights and tools to create workplaces that are supportive and inclusive for individuals with MS.

The curriculum also reaches out to mentors, who are people with MS who want to guide younger people, providing them with effective mentoring skills.

The platform is free and easy to use: to access the material simply create credentials and log in. From the home page you will be able to view the complete list of all modules, which can be accessed freely and at no cost.

3 Platform's material for employers

In the ShapeMS platform there are 10 useful modules to create an inclusive work environment:

- Module: Understanding Multiple Sclerosis (MS)
- Module: Inclusive Workplace Policies and Procedure
- Module: Accessibility and Workplace Design
- Module: MS Mental Health Awareness and Practical Recommendations for employers
- Module: Supporting Career Development for Employees with MS



- Module: Effective Communication Techniques for Creating an Inclusive Workplace
- Module: Feedback and Continuous Improvement in the workplace
- Module: Work-Life Balance and Flexibility
- Module: Inclusive Recruitment and Onboarding
- Module: Building a Supportive Workplace Community

The module “Understanding Multiple Sclerosis (MS)” is designed to educate all employees about the basics of MS, including its symptoms, challenges and impact on those diagnosed.

The module “Inclusive Workplace Policies and Procedure” aims to provide the basis for inclusive policies and procedures in the workplace. It focuses on creating a supportive and accessible environment for all employees, including those with MS.

The module “Accessibility and Workplace Design” is focused on the practical issues of making a workplace accessible to employees, especially individuals with MS.

The module “MS Mental Health Awareness and Practical Recommendations for employers” covers employees' emotional and mental health requirements, particularly those with MS.

The module “Supporting Career Development for Employees with MS” helps employers to provide tools and knowledge to support employees with MS in their career growth and promotion.

The module “Effective Communication Techniques for Creating an Inclusive Workplace” is focused on employers who want to improve their communication skills and create a workplace that is inclusive for employees with MS.

The module “Feedback and Continuous Improvement in the workplace” is for employers who want to promote an inclusive workplace culture and continuously improve their practices to support employees with MS.

The module “Work-Life Balance and Flexibility” highlights the significance of achieving a work-life equilibrium and practicing flexibility in the workplace, with a specific emphasis on employees with MS.

The module “Inclusive Recruitment and Onboarding” aims to assist employers in establishing an all-inclusive recruitment and onboarding process that guarantees individuals with MS an equal opportunity to join the workforce.

The module “Building a Supportive Workplace Community” aims to promote a workplace culture in which all employees, including those with MS, actively support and understand their colleagues.



All of these modules have a final quiz, consisting of true/false answer questions, to test effective understanding and internalization of what is learned during the lectures and workshops.



Conclusions

We have produced this step-by-step guide for employers, which includes the following topics and main purposes:

- inclusive workplace policies,
- strategies for emotional and psychological support to be offered to these employees,
- tips for creating supportive work environments, development of an inclusive workplace culture and how to become an Inclusive Ambassador.

We also highlighted how the **ShapeMS platform can be a valuable resource to provide information and train employers on these issues**, thanks to its modules consisting of theoretical lectures, experiential workshops, and quizzes to test skills acquired.



References

Empowering people affected by MS to live their best lives. (s. f.-a). National Multiple Sclerosis Society. <https://www.nationalmssociety.org/es/;https://www.nationalmssociety.org/Living-Well-With-MS/Work-and-Home/Employment/Accommodations>

How to support an employee with Multiple Sclerosis. System Concepts Ltd. (2023, 11 April). <https://www.system-concepts.com/insights/how-to-support-an-employee-with-multiple-sclerosis/>

Information for employers. (s. f.). MS Society. <https://www.mssociety.org.uk/care-and-support/everyday-living/working-and-ms/information-for-employers>

ShapeMS Platform. (s. f.-b). <https://learning.shape-ms.eu/moodle/>

ShapeMS Project – Shaping the future of people with Multiple Sclerosis. (s. f.). <https://www.shape-ms.eu/>

Working out MS in the workplace: a practical toolkit for employers. (2016). European Multiple Sclerosis Platform (EMSP). <https://www.emsp.org/wp-content/uploads/2016/01/PPP-Working-Out-MS-in-the-Workplace-Toolkit-Jan2016.pdf>

Working with Multiple Sclerosis | Shift.ms. (s. f.). <https://shift.ms/learn-about-ms/living-with-ms/working-with-ms>

