



MS Society policy position statement

The role of employers (UK-wide)

August 2017

Issue

MS is a neurological condition that affects over 100,000 people in the UK. Due to the fluctuating and progressive nature of the condition, people are affected differently by symptoms that include fatigue, pain, loss of mobility, visual impairment and cognitive problems.

People typically start to experience MS in their 20s and 30s when they are in their prime working years. While most people with MS want to stay in employment, in the UK only 36% of people with MS who are of working age are in work¹, compared to the overall employment rate of 75%². This means that people with MS may lose years from their working lives³.

We're concerned that people with MS should be able to keep working for as long as this is right for them and should not prematurely leave work due to inadequate policies and procedures and lack of support from employers. However, our research found that overall, people with MS do not think that employers are doing as much as they can to support them to stay in work⁴.

The disability employment gap – the difference between the employment rate of disabled and non-disabled people – has barely changed over the last 20 years,

¹ Kobelt et al (2017) New insights into the burden and costs of multiple sclerosis in Europe, Multiple Sclerosis Journal

² Office for National Statistics, UK labour market July 2017
<https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/bulletins/uklabourmarket/july2017>

³ According to a large scale MS Society survey conducted in 2016 only 44% of people with MS aged under 60 are in full or part-time employment, compared to the employment rate in England of 70-75% - My MS My Needs 2 survey, MS Society, 2016

⁴ MS Society survey conducted with people with MS as part of the response to the government's Green Paper on Work, Health and Disability: Improving Lives, 2016 – 49% of respondents said disagreed or strongly disagreed when asked whether 'most employers do as much as they can to support people with MS to stay in work'.

hovering around 30%⁵. To halve the gap, as the government aims to do, will require action not just from the state but from employers too.

This policy position paper on employment focuses on the role of employers in supporting people with MS and is part of a series of three papers covering statutory employment support and transitions out of employment. This is a series of live documents which will continue to develop over time through our ongoing research.

Evidence/Findings

We have identified a number of barriers that can make it difficult, or even impossible, for people with MS to hold down a job. Barriers that need to be addressed by employers include:

1. Issues around disclosure

People with MS can choose whether to disclose their condition to their employer, as they are not under legal obligation to do so. While a majority of people with MS who are in employment do disclose their condition to their employer, some do not. This may be because people with MS face barriers to disclosure such as a fear of discrimination and bullying, or lack awareness of available support such as Access to Work. Also, working cultures in the UK that require long working hours, working while sick and keeping up with a fast-paced working environment can impact on an employee's willingness to disclose their condition⁶.

2. Difficulties in getting reasonable adjustments

Lack of understanding about reasonable adjustments among employers can create difficulties for people in MS in having adjustments put in place. 87% of people with MS disclosed their MS to their employer, but only 57% have discussed support in the workplace, such as adjustments, with their employer. Those working for smaller organisations are less likely to have reasonable adjustments made for them than those working for medium or larger sized organisations⁷.

3. Experiences of discrimination

Thirty percent of people with MS who are in work have reported experiencing discrimination by colleagues or managers over the last 5 years⁸. This includes being denied promotions or having duties being removed without consultation. In many cases discrimination was manifested as being

⁵ Work and Pensions Committee – [Disability employment gap seventh report of session 2016-2017](#) (2017), p. 5

⁶ [All Party Parliamentary Group for MS – Employment that Works: Supporting People with MS in the Workplace \(2016\)](#) – p.20

⁷ [All Party Parliamentary Group for MS – Employment that Works: Supporting People with MS in the Workplace \(2016\)](#)

⁸ [All Party Parliamentary Group for MS - Employment that works: Supporting people with MS in the workplace \(2016\)](#) - p.22.

pressured to leave work or take redundancy due to unsupportive attitudes and difficulties in getting reasonable adjustments, which can be a result of lack of awareness of support on the part of the employer.

4. Inadequate policies and procedures

While many employers accommodate people with MS to the best of their ability, and are proactive in putting in place supportive policies and procedures, some employers fail to follow best practice or even to fulfil their legal obligations. For example, some employers have absence policies that allow time off for MS-related medical appointment and treatment, but this is not universal, although this is something that many employees with MS have raised as an adjustment they would like to see happen⁹.

5. Lack of awareness by employers of support that is available for helping employees stay in work

The large majority of employers have a reasonable understanding of their legal obligations, but a much lower level of confidence on where to find advice and information relating to workplace adjustments and to MS as a condition¹⁰. There is a general lack of awareness among employers of support that is available through the Access to Work scheme to fund adjustments. This is largely due to a lack of publicity of the scheme by the government¹¹.

Also, recommendations made by Access to Work assessors are non-binding, and evidence shows that some employers refuse to implement the needed adjustments that are recommended¹². The majority of employers are unaware of other sources of support available through Disability Confident, which is a government scheme that aims to change employers' attitudes towards hiring and retaining disabled employees¹³. There is therefore a low level of awareness among employers of where to find information on the various sources of support.

6. Insufficient number of flexible and part-time jobs

Research by the TimeWise Foundation found that disabled people need to earn at least £10.63 per hour to meet minimum income standards, or the equivalent of a full time salary of £19,500 per year, which it argued is the threshold for a 'quality' job. Yet the research also found that only 6.2% of quality job vacancies are advertised with options to work flexibly or on a part-

⁹ [All Party Parliamentary Group for MS – Employment that Works: Supporting People with MS in the Workplace \(2016\)](#), p. 23-24

¹⁰ [All Party Parliamentary Group for MS – Employment that Works: Supporting People with MS in the Workplace \(2016\)](#)

¹¹ [Work and Pensions Committee \(second report\) – Improving Access to Work for Disabled People \(2014\)](#)

¹² [All Party Parliamentary Group for MS – Employment that Works: Supporting People with MS in the Workplace \(2016\)](#)

¹³ MS Society response to Improving Lives: Work, Health and Disability Green Paper (2017), p. 43

time basis¹⁴. Thirty-five percent of people with MS work part-time, compared to the national average of 27%¹⁵, showing a clear need for more quality jobs that provide for flexible or part time working, to allow people with MS to remain in employment for longer.

7. Experiences of leaving work

Once people with MS decide to leave work due to their symptoms, too many describe leaving work as a poor experience. This can have psychological impacts through knocks to their identity and self-esteem.

People who do have to leave work due to their MS should be enabled to achieve the positive things that work provides, such as having a purpose, developing skills, and socialising in other ways. They must also receive adequate financial support. We are undertaking further research into the experiences of leaving employment of people with MS.

Recommendations for government

- The UK government needs to do more to ensure full compliance by employers with their legal obligations under the Equality Act around discrimination and in providing reasonable adjustments. Redress should be sought by the government in cases where this is shown not to be happening
- The UK government should provide specific information/guidance to help employers understand what is 'reasonable' in regard to reasonable adjustments
- External accreditation of the government's Disability Confident scheme should be strengthened in order to render the scheme more meaningful
- The UK government should include information about reasonable adjustment to triggers for absence management processes and related sanctions in its information provision for employers, such as its Disability Confident guidance. This should also include guidance on recording disability related absence separately to ill health related absence.
- The DWP should consider restricting the ability to advertise jobs on their Universal Jobmatch service only to employers who sign up to Disability Confident, as a way to encourage take up of the scheme and to ensure that people with MS are hired by employers who are committed to best practice in employing people with disabilities
- Governments across the UK should include information on how to adopt positive workplace cultures and practices that are visibly positive about disability in their information provision for employers, for example through Disability Confident, and include case studies to help employers understand ways in which this can be achieved

¹⁴ [TimeWise Foundation/Joseph Rowntree Foundation – How flexible hiring could improve business performance and living standards](#) (2016)

¹⁵ MS Society – My MS My Needs 2 survey (2016)

- Improved information about service availability and legal obligations, for example via a 'one stop shop', should include easy access to case studies and examples of good practice by both large and small employers from different sectors of the economy. The 'one stop shop' should offer advice to employers via telephone and drop-in centres, and could be run by an expert disability organisation.
- Governments across the UK need to do more to ensure that employers are aware of the business case for employing disabled people, to help incentivise employers to improve their policy and practice.
- Governments across the UK should lead by example by routinely advertising their own vacancies as 'being open to flexibility' at national and local levels, and should investigate how to support employers to advertise more roles on a part-time or flexible basis.
- The Government should work with employers and charities to establish best practice around transitions out of employment for disabled people. This should include examples about how this process can best be managed and be made as positive an experience as possible. The MS Society is currently conducting further work to establish how this could work best for people with MS.

Recommendations for employers

- Employers should consider how their perceived working culture impacts on disabled people's willingness to apply for jobs at their organisation or to disclose their condition.
- There is a wider need for 'normalisation' of reasonable adjustments such as remote working, flexible working hours and part-time working.
- Employers must ensure that their legal obligations to stamp out disability-related discrimination are met fully, and are encouraged to train staff and management on disability equality to minimise incidents of unsupportive attitudes and bullying
- Employers should work together and with charities and other civil society organisations to share best practice in hiring and supporting people with MS to remain in work
- Employers should seek to create working cultures that are positive about disability, and ensure positive messaging about disability in job adverts that actively ask candidates whether they require any reasonable adjustments to the interview process.
- Employers should consider advertising more quality jobs with the option to work flexibly or part-time, in order to attract and recruit more people with MS, who are not able to work full-time due to their MS symptom
- Employers should work to ensure that their HR policies and procedures support people with MS to stay in work, for example create absence policies that allow people with MS to take time off for treatment that is recorded separately from other sickness absence.
- Employers must comply with their legal obligations with regards to reasonable adjustments and seek information from sources such as Disability

Confident and Access to Work should they feel that their understanding of workplace adjustments and MS is insufficient to fairly deal with an employee with MS.

- Employers should support their employees' transition out of work once they decide working is no longer right for them. We are currently conducting further work to establish how employers can best support people with MS as they transition out of work.