MS Society policy position statement
Statutory employment support (UK-wide)

June 2017

Issue

MS is a neurological condition that affects around 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 symptoms in their 20s and 30s when they are in their prime working years, and studies have shown that many people lose years from their working lives as a result[1]. While most people with MS want to stay in employment, many eventually go part-time or become self-employed but, in some cases, they withdraw from employment entirely as a result of the barriers they face to work.

We are concerned that people with MS should be able to keep working for as long as this is right for them and should not be inhibited from working by barriers other than unavoidable MS symptoms. They should have access to the right support to reduce the impact of MS symptoms where possible and to address other barriers they face such as lack of awareness of, and access to, employment support services and information.

To remain in work for longer, people with MS need support from services such as Access to Work, Fit for Work and Work Choice, yet the level of awareness of these services remains low among people with MS and employers.

Currently, government efforts are focused on supporting disabled people to re-enter employment, yet what people with MS tell us is that once they leave work they do not look to re-enter employment, due to the severity of their symptoms.

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[1] [1] Kobelt et al (2017) New insights into the burden and costs of multiple sclerosis in Europe, Multiple Sclerosis Journal – the study showed that 36% of working age adults with MS are in work, and that most people with MS start seeing symptoms in their 20s and 30s, while diagnosis usually happens in people's 30s and 40s

Rather, people with MS require timely and joined up interventions that support them in staying in employment while their symptoms permit

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

Evidence/Findings

- **People with MS are likely to leave work or change working patterns**
  The current average employment rate of people with mild MS is 37% and for people with severe MS it is 4%[2]. Prior to leaving work entirely, many people with MS change their working pattern – 35% of people with MS work part-time, compared to the national average of 27%[3]. There is a significant gap in employment rates between people with MS (36%)[4] and the overall population (75%)[5] in the UK, which means that people with MS may lose a significant number of working years.

- **MS Symptoms are a barrier to staying in work**
  A majority of people with MS who responded to an MS Society survey and are out of work said that they stopped working because of the severity of their MS symptoms which made working impossible[6]

- **Access to statutory support services is limited outside the welfare system**
  Currently, statutory employment support services such as Work Choice are available to people with MS largely via the benefits system limiting their ability to reach those who need help to stay in work. Some people with MS may avoid claiming benefits for as long as they can, meaning that these services are not available to people with MS who could benefit from voluntary, personalised support[7]. A Freedom of Information request by the MS Society revealed that in the year from April 2015 to March 2016, only 10 people with MS have been referred to Work Choice, and this number has

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[2] Bajorek, et al.(2016), The impact of long term conditions on employment and the wider UK economy

[3] MS Society – My MS My Needs 2 survey, 2016

[4] [4] Kobelt et al (2017) New insights into the burden and costs of multiple sclerosis in Europe, Multiple Sclerosis Journal

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

[6] MS Society survey of xxx people conducted in 2016 – 80.3% of respondents who are not working said they left work because of their MS symptoms

[7] Eligibility and referral to Work Choice is done only at Jobcentre Plus by Work Coaches or Disability Employment Advisers

fallen significantly from previous years, where referral numbers ranged from 30 to 50[8].

- **Low level of awareness of available sources of support**
  People with MS and employers have a low level of awareness of the Access to Work scheme[9], which has previously been described as 'the best kept secret in government'[10]. A lack of awareness of the scheme and the adjustments that it can help fund means that employees are less likely to request adjustments that may help them to stay in their role[11].

  Fit for Work is a voluntary service that allows GPs and employers to refer an individual once they have been off sick for four weeks or longer, and provides an advice hub and access to occupational health services. However, evidence from both people with MS and employers show that far too few people have heard of the service. At the same time, the service only allows for referrals to be made once an individual has been off work for over four weeks, and referrals cannot be made more than once in a 12 month period. People with MS, a long-term and fluctuating condition, would benefit from reforms to the service that allow multiple referrals as needed, and a more proactive approach that provides access to occupational health before an individual is signed off from work.

  Work Choice is a statutory, voluntary employment support programme for disabled people contracted by the DWP. Yet, for people with MS who are working and require support to stay in work there is little help available. The vast majority of referrals to the Work Choice programme are for unemployed disabled people, with as little as 2% of referrals for disabled people who are in employment[12].

- **Employment and health support are not joined up**
  There is a lack of focus among health care professionals on employment outcomes. However, since it is health professionals that make an MS diagnosis, and continue to see most people with MS on a semi-regular basis, they are well placed to signpost people to employment support as early as possible[13]. The MS Society is currently undertaking research into how and when health professionals can support people with MS regarding employment.

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[8] Department for Work and Pensions, Central Freedom of Information Team (2017) *Freedom of Information request response 10 February 2017*, FOI 165, p.3

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

[10] House of Commons Library Briefing Paper – Key Statistics on People with Disabilities in Employment (Briefing Paper number 7540, 14 December 2016)

[11] Overall 54% of respondents to the APPG for MS inquiry have had adjustments put in place, but this number went up to 78% when the respondents themselves asked for adjustments

[12] Department for Work and Pensions – Work Choice: official statistics (August 2015)

[13] MS Society – response to the government's consultation paper Work, health and disability: Improving lives

Recommendations for governments

- Governments must work to improve knowledge of employment rights, including the right to reasonable adjustments.
- The governments should focus on improving the employment retention support available to people with MS who are in employment, ensuring that this provision is available when it is needed, and is widely advertised so that employers and individuals who could benefit from it know about it
- The UK Government should commit to maintaining the combined level of funding provided to the Work programme and Work Choice as a minimum for employment support programmes going forward.
- The DWP should use the Work and Health Innovation Fund to pilot additional interventions to help people with MS at risk of leaving work to retain their job.
- Access to employment support for people with MS should be voluntary and not subject to inappropriate conditionality
- The governments should recognise that some people with MS cannot work due to their condition; there must be adequate financial support for those who cannot work.
- The UK government should undertake an information campaign to raise awareness of the Access to Work scheme, and carry out ongoing monitoring of the impact of promotion activity on levels of awareness
- The UK Government should reform the Fit for Work service and Fit for Work Scotland to make them more suitable for people with long term conditions such as MS. This should include revision of the eligibility criteria, so that a person can be referred before they’re off sick, and can be referred again within 12 months. The UK Government should also raise awareness of the service among employers.
- The DWP should undertake to investigate what support should be offered to better support those who are in work but struggling to retain their job, and what role the Jobcentre Plus should play in this, to prevent unnecessary work exits.
- Work should be adopted as a clinical outcome within relevant health service frameworks. Health care professionals should be able to sign-post people with MS to relevant, voluntary employment services. However, this must not negatively impact access to services for those who are unable to work.