All-Party Parliamentary Group for MS

Employment that works

Supporting people with MS in the workplace

Report of the All-Party Parliamentary Group for MS Employment Review

"Just tell, just ask"

Foreword

A diagnosis of MS is a life changing experience which brings with it numerous uncertainties and questions.

During what can often be a distressing and upsetting time, initial concerns may focus on the immediate questions regarding the condition and how fundamentally life might change: one's treatments, expected prognosis, and concerns about lifestyle and familial challenges.

Work is an important part of this. Work is central to many people's identity, and the relationship between MS and work can be difficult to navigate. Should you disclose to your manager? If so, when? Is it better to wait and see how your MS will affect you? Should you tell your colleagues? How will they react? Or should you keep it all to yourself in case nobody understands?

Staggeringly, up to 80% of people with MS retire within 15 years of diagnosis.[1] Clearly better support needs to be available in order to bring this figure down. It's what people with MS want.

The All-Party Parliamentary Group for MS wanted to play its part in helping to navigate this difficult relationship. We sought to better understand the experiences of people with MS and the professionals who are there to guide them through these questions.

From detailed evidence taken from people with MS, we learned there are a number of barriers and hurdles that can often seem insurmountable for people with MS – not only getting work but, crucially, remaining in employment following diagnosis. Foremost are the person's health, the workplace culture, a person's access to appropriate service provision, and an effective accurate welfare support which meets the needs of the individual.

> **"Staggeringly, up to 80% of people with MS retire within 15 years of diagnosis.[1] Clearly better support needs to be available in order to bring this figure down. It's what people with MS want."**

As this report sets out, a number of often quite small changes could help overcome these challenges. Modest actions by individuals, employers and Government can make all the difference.

This is a timely report with Government's promise to halve the disability employment gap and the recently released Improving Lives Work Health and Disability Green Paper. We hope employers, people with MS, the Government and services take heed of these recommendations as part of these wider policy developments.

I would like to thank my fellow group officers and Parliamentarians who contributed to the report and for all those who took the time to give evidence to the Review.

Simon Hoare MP
Chair of the All-Party Parliamentary Group for MS

Contents

It is clear that people with MS face many, sometimes substantial, obstacles to staying in and entering work. There are many ways in which the UK Government, employers, and health and employment support providers can address these obstacles, supporting people with MS to stay in quality work for as long as is appropriate.

Executive Summary

The employment journey of many people with MS is a story of two halves. From responses to our call for evidence, the APPG found that most people with MS are either in work or out of work and not looking to return. This report suggests that as MS progresses from diagnosis, many people reduce or change their working pattern before withdrawing from employment altogether. Once people with MS leave employment, they rarely re-enter the workplace.

The Review identified four main types of obstacles that determine the employment journeys of people with MS. These are health and work, workplace and employer cultures, issues with employment support services and the welfare system.

> **“Shockingly, almost a third (30%) of respondents who are currently in work said they had experienced MS-related stigma or discrimination by colleagues or managers over the past five years.”**

1 I Health and Work

MS and its symptoms were identified as the primary barrier that people with MS face in entering and remaining in employment. People told the APPG that MS limited the range of jobs and hours they could do and, within employment, symptoms such as fatigue made working increasingly difficult. In some cases, work exacerbated their symptoms further.

It was clear that in some cases, the obstacles presented by MS will be insurmountable and people with MS may reach a point where work is no longer possible. However, in many cases, a lack of services and unhelpful employer attitudes and behaviours are compounding these difficulties.

2 I Workplace cultures

Of respondents currently working, just 54% of their employers have made reasonable adjustments to their role. Just 44% of respondents with MS not currently working but who had worked within the last five years received support from their employer to help them stay in employment. Evidence highlighted a persistent lack of understanding of MS among employers and colleagues and difficulties getting adjustments made to working conditions. Shockingly, almost a third (30%) of respondents who are currently in work said they had experienced MS-related stigma or discrimination by colleagues or managers over the past five years.

3 I Service provision

The Review found that existing service provision across UK Government bodies is failing to tackle these issues and adequately support people with MS to enter work and stay in work for as long as possible. Significant issues were highlighted with access to health, employment support and welfare services.

Access to the right help with employment from health professionals emerged as an issue. Additionally, only 27% of survey respondents said a health professional had had a conversation with them within the last year about their employment situation.

UK Government sources of targeted employment support do not appear to be filling this gap or reaching people with MS who need it. For example, awareness of employment support schemes including the Work Programme, Work Choice and Access to Work was felt to be very low. This is concerning as our evidence made clear that, when accessed, this support can have positive effects.

Too often services are not joined up and lack of coordination means people with MS are falling through the gaps.

Referrals from health services to employment support were highlighted as often being too slow. Respondents to our survey felt that many employers wait too long to arrange support for

> **“Access to the right help with employment from health professionals emerged as an issue. Additionally, only 27% of survey respondents said a health professional had had a conversation with them within the last year about their employment situation.”**

employees with MS. Of respondents whose employers know about their MS and have spoken about it with them, 22% said their employer waited until they prompted them to have this conversation.

4 I Welfare system

The current welfare system is unhelpful in supporting people with MS who want to work. Concerns were voiced about the ability of the Work Capability Assessment (WCA) to accurately identify barriers to employment as well as the adverse impact of recent disability benefit reforms which have reduced support.

Lack of information sharing between different parts of the welfare system is exacerbating problems with service provision.

5 I Much needed improvements

To help people with MS enter and stay in employment there are a number of improvements that are required. In particular, a focus is required on helping people with MS stay in work for as long as possible and adapting their working lives as their condition changes.

Key Recommendations

Recommendations for the UK Government:

Improve the provision of employment retention support, for example through the Work and Health Programme and Disability Confident.

Work with employers and progressive condition charities – such as the MS Society – to establish best practice for transitions out of employment for disabled people. This should include the provision of adequate career guidance to enable the consideration of alternative roles.

Consistently recognise that some people cannot work due to their health, and follow through on this understanding in policy and practice. This must include the provision of adequate support for people who cannot work, in order that they can lead as full lives as possible, and avoid the problems that can be associated with economic inactivity.

> “Many [people with MS] appear to have been forced to leave work as the disease has progressed and their symptoms have worsened...”

Recommendations for Service Providers:

Employment support service providers should ensure their employment programmes engage with employers wherever possible, to facilitate their active involvement in the support of people with MS.

Work should be adopted as a clinical outcome within relevant health service measurement frameworks, such as the Clinical Commissioning Group Improvement and Assessment Framework in England.

Recommendations for employers:

Adopt policies and practices which promote inclusion and opportunity for disabled employees, and deal quickly and effectively with instances of bullying, harassment or discrimination in the workplace. Wherever possible, employers should adopt a disability absence policy.

For a full list of our recommendations, please see page 44.

Introduction

MS is a progressive, incurable, neurological condition, which affects more than 100,000 people in the UK.[a] Most people begin experiencing MS symptoms between the ages of 20-40, so many people are working when they are diagnosed. Symptoms can cause a variety of difficulties which, in combination with associated problems at work, can increasingly impact on people's ability to work. Previous research has reported that around 15 years after the onset of MS, between 60% and 80% of patients would have lost their jobs.[2]

There have been significant changes to the world of work in recent decades. There is now a shared understanding that disabled people can work in mainstream jobs, and that external barriers should be dismantled. For example, disabled workers are entitled in law to 'reasonable adjustments'[b] at work, to ensure they are not seriously disadvantaged when doing their jobs. There is now increasing recognition that diverse workplaces are better workplaces.[3] The use of digital technologies is also changing the way we work.

Yet, low employment rates amongst people with MS remain, and are part of a pattern of enduringly low employment rates amongst disabled people more widely; it seems there have been at best marginal improvements in disability employment outcomes relative to non-disabled people since the late-1990s.[4] This has been accompanied by persistently high incapacity benefit caseloads amongst disabled people.[5] Concerns over these trends culminated in a 2015 General Election manifesto commitment by the Conservative Party to halve the disability employment gap by 2020.[6] The principle of this commitment was supported by the other main political parties.

In November 2015, the UK Government announced plans for a new Work and Health Programme to replace existing employment programme provision from 2017. In addition a Green Paper outlining reforms to improve employment support is was released at the end of October 2016.

In this context, the All-Party Parliamentary Group for MS launched a review into employment support for people with MS. This report examines the obstacles preventing people with MS working for as long as they are able, and makes recommendations for the UK Government, businesses, and other stakeholders about solutions to tackle these. While many of the obstacles identified relate particularly to the progressive, fluctuating, and neurological nature of MS, some are also relevant to improving the employment situation of people with a range of other disabilities.

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[a] MS Society estimate based on 2010 incidence and prevalence rates (Mackenzie et al. 2013) adjusted for accuracy based on the assumption that 82% of cases from this study can be validated (estimate based on Alonso et al. 2007). These adjusted rates have been applied to 2014 population estimates (Office of National Statistics).

[b] The Equality Act 2010 states employers are required to make reasonable adjustments to any elements of a job which place people with MS at a substantial disadvantage compared to non-disabled people. In Northern Ireland, where the Equality Act does not apply, this duty exists under the Disability Discrimination Act.

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About the Review

About the All-Party Parliamentary Group for MS

The APPG for MS is a cross-party group of MPs and Peers with an interest in MS. At its AGM in 2015 the group agreed to hold a review into the available employment support for people living with MS to provide a substantive evidence base on this issue.

The MS Society is the secretariat of the group and provides both administrative and financial support for the group's work.

In conducting this Review, the APPG has focused on paid employment. As such, the term 'work' in this report, refers exclusively to paid work. The APPG notes the significant value of volunteering and unpaid caring work, both for individuals who undertake it as well as on wider society.[7] The report is UK wide, though some observations and recommendations may vary in applicability due to different national contexts.

Methodology

In gathering evidence for the Review the APPG wanted to ensure that it examined a complete employment journey of people with MS, including the experiences of those out of work, looking for work as well as those already in employment. The APPG considered both written and oral submissions.

Written submissions to the Review

A consultation period was given for written submission for both people with MS and relevant professionals and their organisations.

A survey of people with MS was promoted online. It was open for responses from Monday 11 April to Monday 16 May 2016. We received 1,511 complete responses to this survey.[c]

A separate survey was sent out to professionals with particular expertise and insight. This was open for responses for eight weeks from Monday 29 February to Friday 29 April. We received responses from 21 professionals or organisations. These are listed in Appendix One.

Oral submissions to the Review

Three oral evidence sessions were held in the Houses of Parliament, in January, March, and June 2016. At each session there were speakers with lived experience of employment and MS, as well as speakers from professional organisations with relevant expertise. Individuals and organisations who provided oral evidence are listed in Appendix One.

The Review also considered substantial data from My MS My Needs 2[d] – the largest quantitative survey of people with MS which collected over 11,000 responses.

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[a] Those who responded to the survey did so through self-selection, thus the survey responses may not form a representative sample. In addition, respondents' geographical location was not recorded.

[d] MS Society, 2016

Employment profile of people with MS

MS can be expensive – a neurological condition like MS can cost, on average, an additional £200 a week.[8] Maintaining quality employment, coupled with other forms of statutory financial support, is an important aspect of managing these extra costs.

The employment rate for the UK population as a whole (aged 16 – 65) is 75%.[9] Yet, of the 1,511 people with MS who responded to the survey, only 55% were working. Similar studies have found an even lower percentage of people with MS are working.[e] For example, according to the MS Society's My MS My Needs 2 survey,[f] 35% of respondents were working either full-time or part-time. The Review survey also suggest that a higher proportion of people with MS who are working are working part-time (45%) compared to the national average (27%),[10] a finding which is consistent with the My MS My Needs 2 survey results.

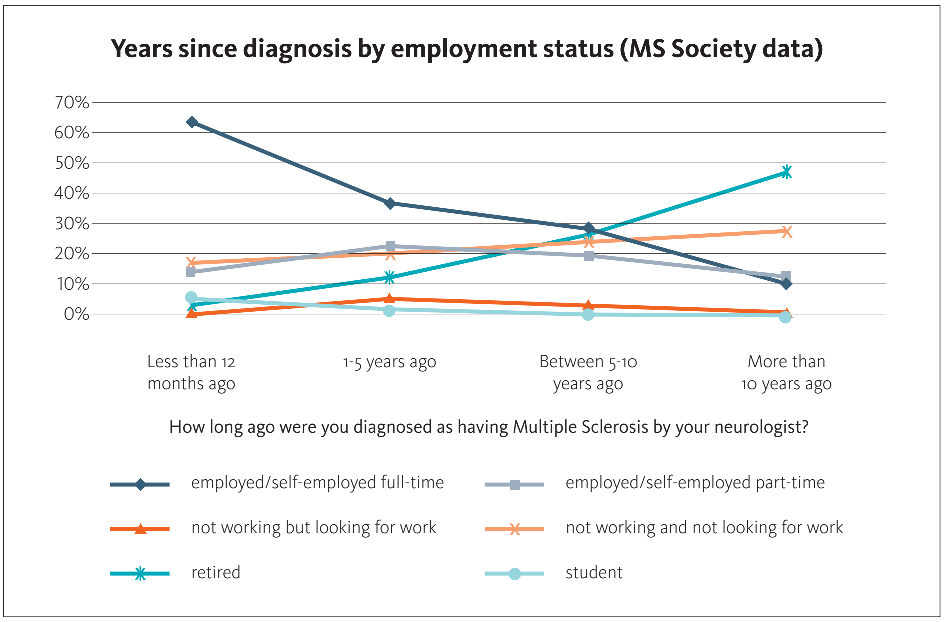
39% of survey respondents were not working and not looking for work. While inactivity rates vary across studies, they consistently show many people with MS are not working and not looking for work – an important fact to consider when designing employment policies to support people with MS. 6% of survey respondents were not working but looking for work.

MS leads people to make changes to their work, then to withdraw from the workplace

The MS Society's My MS My Needs 2 survey[g] shows that many people with MS make changes to their working arrangements. For example, people make physical changes or adaptations and change their working hours, often within the first 12 months since Diagnosis.

Data on the type of employment also suggests a similar trend, with people with MS changing their working patterns in the initial years after diagnosis before withdrawing from the workplace altogether. The Review survey shows that many people with MS withdraw from the workplace early, before retirement age.

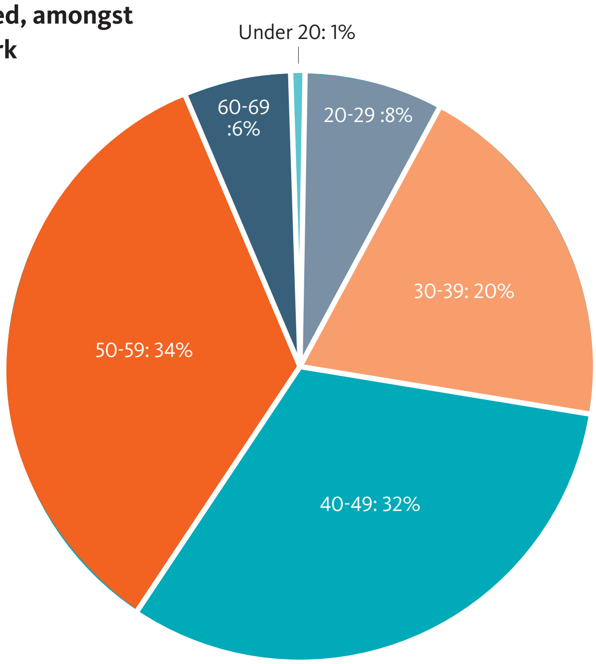
[e] This may be due to a self-selection bias, given that the survey was advertised as being about employment (even though it was emphasised that it was not only for people in employment).
[f] Evidence from the My MS My Needs 2 survey was presented by the MS Society during the third evidence session, and submitted to the APPG review in writing.
[g] The MS Society's My MS My Needs to survey was undertaken in 2016, and answered by over 11,000 people with MS. The study is published as a technical report.



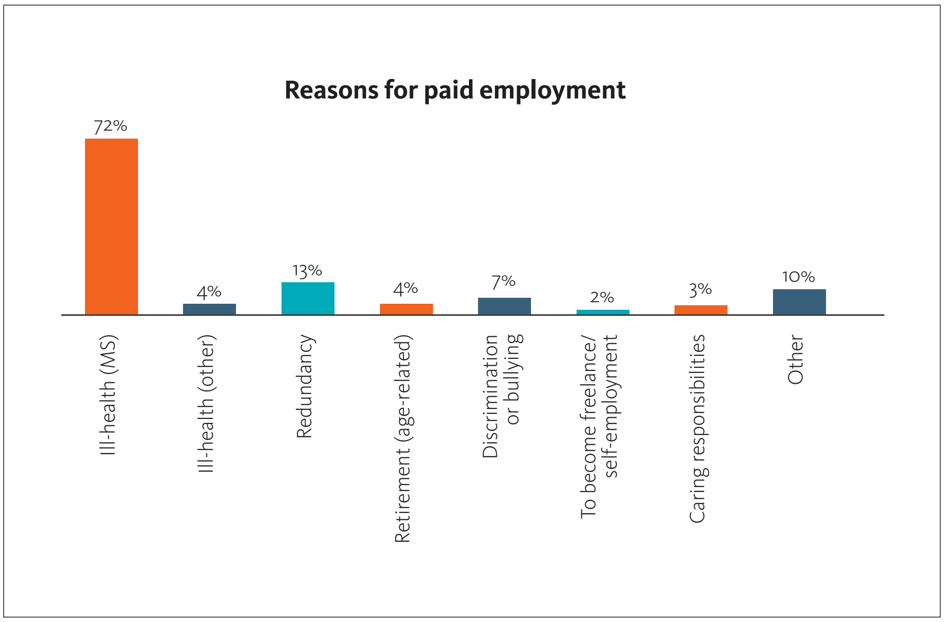
The percentage of people in full-time employment decreases with time since diagnosis, especially within the first ten years. Conversely, there is an initial increase in part-time working following diagnosis, followed by a reduction some years after diagnosis which could be explained by people leaving the workplace altogether due to mounting symptoms.

Using Review survey data, we estimate that on average, those who were not in work and not looking for work due to their MS lost 19.4 working years (assuming an average retirement age of 65).

Age at which respondents last worked, amongst those not working or looking for work

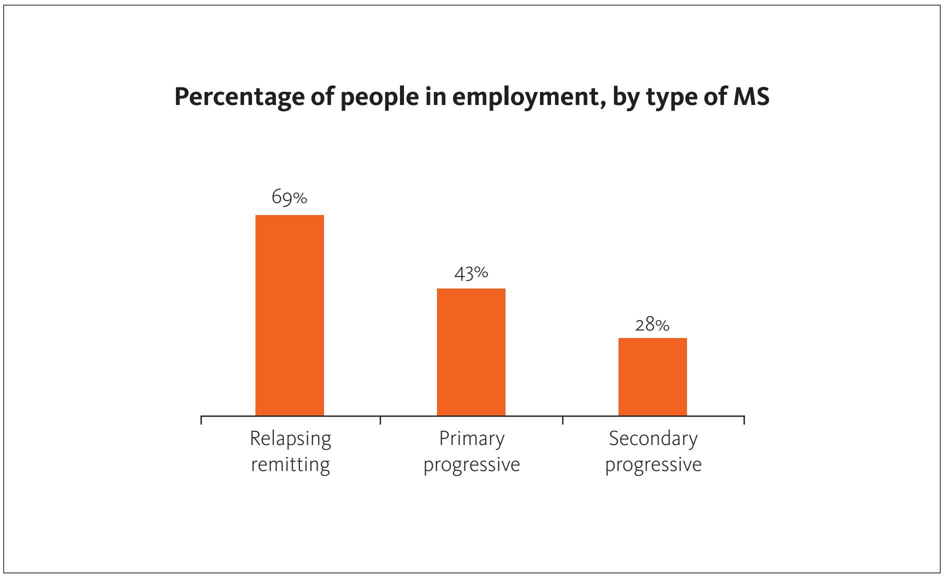


The Review survey data also indicates that people feel MS is the reason they leave work: 72% of people not in work and not looking said that they stopped working due to their MS. Similarly, of the 591 respondents not working and not looking for work, 54% responded that they're not able to work due to having MS, 32% said they retired due to ill-health (which is likely to be due to MS), and 14% said they retired due to age.



This data is indicative of a life course journey experienced by many people with MS: diagnosed while working full-time, gradually reducing working hours due to MS symptoms, then eventually leaving the workplace and becoming economically inactive over the longer term.

Employment outcomes of people with different types of MS



According to Review survey data it seems that people with relapsing remitting MS are more likely to be in employment than people with either primary or secondary progressive MS. Other studies also indicate this pattern, though some suggest lower employment rates.[11]

1 Health and work

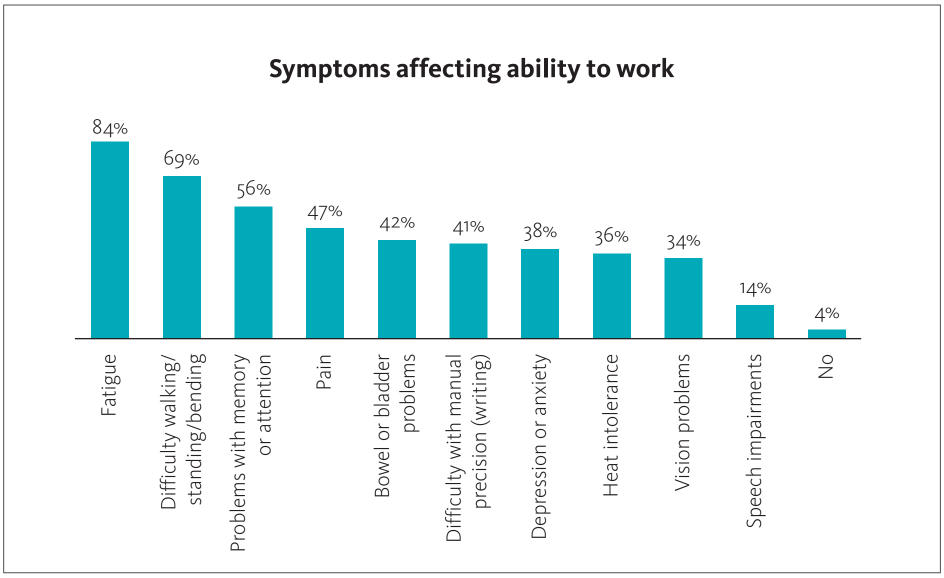
Obstacles

MS symptoms impact people's working lives

> **"Many [people with MS] appear to have been forced to leave work as the disease has progressed and their symptoms have worsened… Particular symptoms such as high levels of fatigue, reduced mobility, visual or bladder problems, cognitive changes may have impacted on their abilities/roles at work. Some people highlight that they have become increasingly overwhelmed prior to either reducing hours and or finally deciding to leave paid employment."**
> Anonymous, health professional

Evidence gathered by the Review demonstrated that MS symptoms pose a significant, and sometimes insurmountable, barrier to employment. Respondents said a wide range of MS symptoms had impacted on their ability to work.

> **"Being fatigued limits the speed at which I can work… If I get too hot in the office this can also cause increased fatigue, sickness and difficulties moving around the office safely. Many days I struggle to concentrate or think straight and this means I forget to complete important tasks, or lose my train of thought mid-sentence when instructing colleagues. Due to nerve pain and visual difficulties caused by optic neuritis, I have been provided with specialist equipment in the office… If I become too fatigued and run down, this can also impact my mental health, which means I can become quite down and struggle to get up of a morning and perform efficiently at work."** Amy, person with MS



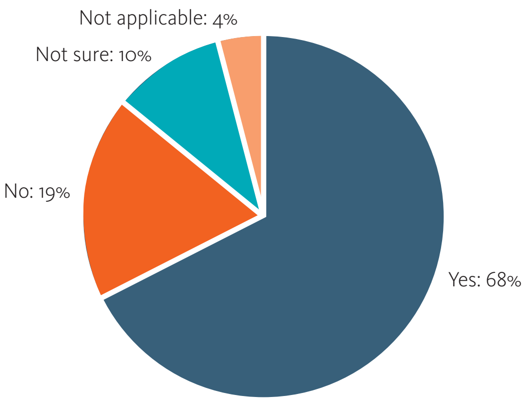
Among the 831 survey respondents currently working, fatigue was the symptom that had impacted the most, affecting 84%. This was followed by mobility issues (difficulty walking/standing/bending/ moving around), which affected 69% of respondents currently working, and problems with cognition (memory, attention or problem solving), which affected 56% of respondents currently working.

The effects that the combination of physical, mental and emotional MS symptoms can have on people in a work context are significant. Survey respondents who currently work reported a large number of impacts, including concentration difficulties, inability to do physical tasks or to move around due to muscle weakness and mobility issues, and concerns around how they are perceived by others.

Two thirds (68%) of the 831 survey respondents who are currently working feel that having MS has affected their career progression. Written responses highlighted a number of impacts:

- performance impacted both by symptoms, and by work absences preventing skill-learning
- being unable to progress due to inability to complete training or put in the hours necessary
- having to take on an alternative position, junior role, or change career due to altered ability
- difficulty obtaining a new job due to fear of moving (lest manager is not as understanding)
- higher sickness absence records; repeatedly applying for jobs but not getting them

Do you think that having MS has affected your career progression?



The fluctuation of MS symptoms can compound health-related barriers to employment. Moreover, having to continually adjust to changing symptoms poses additional difficulties in fulfilling a work role.

For many, MS symptoms cause such significant barriers to employment that they withdraw from work as the condition progresses. People withdraw due to coming to terms with MS, finding symptoms insurmountable in their current employment, or working exacerbating their symptoms.

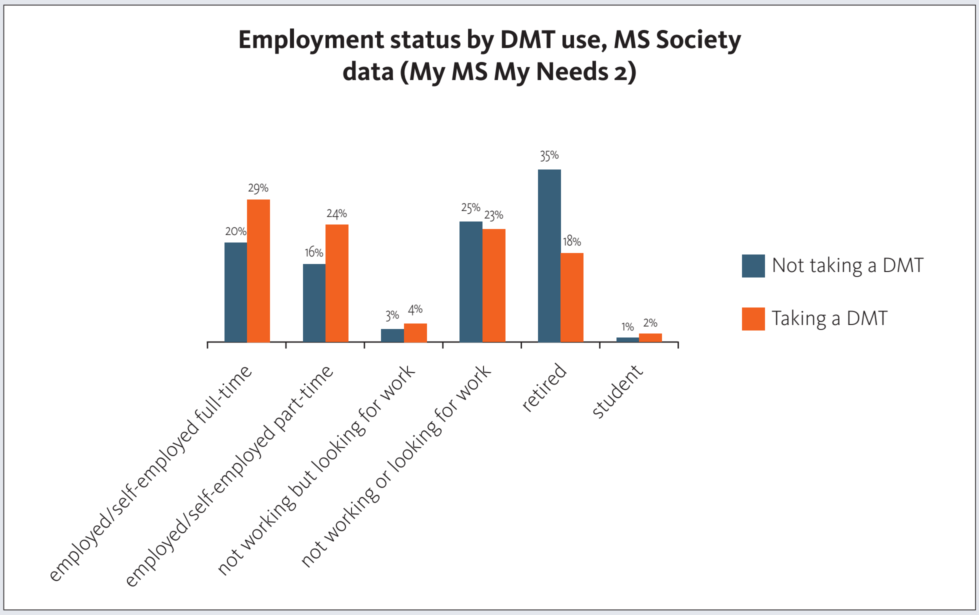
> **"The reality is that smaller organisations require employees to cover a range of job demands and often a range of job roles and do not have the flexibility to provide alternative job roles or adaptations to the current job... this places excess challenges in keeping people with MS in work."** Dr Tanya Campbell, Occupational Therapist, OH Assist Ltd

Having an employee who is struggling to perform their job role reliably, or is off work as a result of their MS symptoms, can negatively impact a business. Smaller organisations may experience greater impacts, and their ability to provide suitable adjustments to job roles may be less. Depending how this is handled, it could augment difficulties faced by employees with MS. However, respondents to the Review highlighted that in some cases, where businesses are able to work past this initial impact, they can reap rewards by maintaining employees with valuable skills.

> **"We look at it as Sue adds a lot of value to our company. She's a specialist in pharmacy bookkeeping accounts, so for us it was not [just] about how do we help Sue because she needs it, it's also keeping her in work, keeping up her skills, everything she can offer us as an organisation keeping that within the business, and over the years there have been a lot of ideas in growth of the business that have come from Sue."** Sarah Duggan, HR professional, Quill Pinpoint Ltd (MS Society Employer of the Year award winner 2016)

The relationship between Disease Modifying Treatments (DMTs) and employment status

The Review received mixed evidence on the impact of DMTs on employment status for people with relapsing forms of MS; while survey data collected for the Review did not suggest that DMTs have an impact on work status, data from the larger My MS My Needs 2 survey suggests that DMT use does have an impact on work outcomes.[h] The latter survey shows that of those people not taking a DMT, 20% (n=482) were working full-time and 16% (n=379) were working part time. By comparison, of people who were taking a DMT, 29% (n=952) were working full-time and 24% (n=782) were working part-time. So those taking a DMT were more likely to be working both full-time and part-time than those who were not. Similarly, respondents not taking a DMT were more likely to be retired, or not working and not looking for work, than their counterparts who were taking DMTs.



Psychological impacts of employment problems

"...confidence takes a knock every time there is an episode, or the individual feels, and generally it's the individual who feels more strongly that they've let the employer down, their confidence takes a battering... if our confidence gets damaged the chance of us being productive is also damaged." Roy O'Shaughnessy, Chief Executive, Shaw Trust

"I was struggling, walking was getting harder, I was having the occasional fall in the classroom. The fall wasn't physically hurting me, but for your own reputation, for your own esteem, that's where the hurt was." Matt, who has MS

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[h] All data from My MS My Needs 2 about DMTs refers to people with relapsing forms of MS who could potentially benefit from taking them.

The Review found that psychological difficulties associated with having MS can pose a barrier to employment. Receiving an MS diagnosis, experiencing fluctuating MS symptoms, and concomitant changing ability at work can have profound psychological impacts.

The impact on a person's self-identity can be significant, as they adjust to the limitations MS imposes. People's confidence in their ability to fulfil their job role can also be shaken, as they experience fluctuating symptoms and functional abilities. Frustration and self-esteem issues can arise from having to ask for help at work, and admitting to needing support. Some report feeling that they're letting down their employer. These issues can in turn lead to anxiety and depression, which are known to be associated with MS. These psychological impacts can conspire to effect an early exit from the workforce.

> **"One of the common scenarios is someone who's had a relapse of MS, so things have suddenly got worse, they return to work, and often they have a graded return that is relatively fast or they go back to work very quickly after the MS, and at that point they will be anxious because they've recently had a relapse, fatigued, again because of the relapse, and concerned about cognition. By the end of the afternoon the fatigue is much more, that can lead to a cognitive slip that can lead to increased anxiety. If you're anxious, of course, you get more fatigued, if you're anxious you have difficulty remembering things and concentrating, and then you get into this terrible downward spiral..."** Dr Diane Playford, Vocational Rehabilitation Team at Queen Square, National Hospital for Neurology and Neurosurgery

The psychological impacts of MS symptoms may then be compounded by negative experiences at work arising from poor management practices, inappropriate behaviour, or even discrimination (discussed further below). Such experiences can further impact on self-esteem and self-confidence. This can contribute to early exit from the workforce, and additionally can make people fearful of ever returning to work.

Finally, whatever their reason for leaving work, those out of work often experience low confidence and self-belief in relation to their ability to work, which impacts on their ability to get back into the workplace again.

> **"Trying to find employment with a progressive condition with uncertain trajectory is challenging as the person has often lost confidence and doesn't see themselves as attractive a candidate as an able bodied person."** Anonymous, health professional

For those who are unable to return to work due to the impact of their MS, issues around loss of identity and self-esteem can be significant, particularly where their career was an important part of their self-concept.

> **"As soon as my employer (a high street bank) learnt of my condition I was offered a full pension on ill-health grounds. I was a Bank Manager for small business and had a very responsible and busy career... I had been off sick for six months straight... I was very sad about losing my career. I felt that part of me had died and my standing and identity was lost. I was a nobody... I was in mourning for myself for many years... I have to realise that as an individual my role as a husband and father is what I am all about, but I still feel that loss."** Andrew, who has MS

Availability and quality of timely health services

> **"Employment support... is intrinsically linked to the healthcare support that people with MS need and receive. The effective management of symptoms is a key factor to help people with MS function across all aspects of their life, including work. The support that is available to people with MS from health professionals with expertise in MS is therefore crucial."** Amanda Croft, Policy Officer, MS Trust

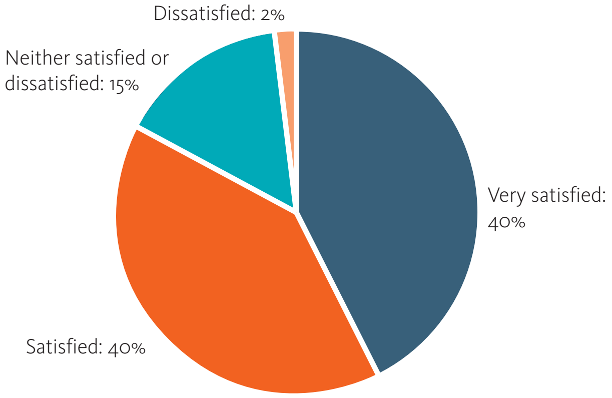
Evidence submitted to the Review showed significant gaps in access to health and care services for people with MS.

Given that the symptoms of MS have a profound impact on an individual's ability to function, timely diagnosis and access to the right treatment, care and support is essential to maximise effective management of the condition. Moreover, there is now clinical recognition of the importance of treating MS early to improve long term health outcomes.[12] National Institute for Health and Clinical Excellence (NICE) guidance states that care for people with MS should employ a coordinated multidisciplinary approach, involving consultant neurologists, MS nurses, physiotherapists, occupational therapists, speech and language therapists, psychologists, dietitians, social care, continence specialists, and GPs.[13] Consideration should also be given to referring those with persisting memory or cognitive problems to an occupational therapist and a neuropsychologist to assess and manage these symptoms.[14]

Notwithstanding the above, many people with MS experience difficulties in accessing MS specialists and allied health professionals when they need to do so.[15] Lack of access to MS Nurses was highlighted to the Review as a particular problem. Similarly, it was highlighted that people with MS rarely have access to an appropriately qualified neuropsychologist; the availability of such expertise is highly limited within NHS Trusts. This must be addressed.

Where people with MS are able to access the right professional support, overall they are satisfied. Moreover, a number of examples were given by survey respondents about ways in which health professionals helped them with work issues.

How satisfied/dissatisfied were you with the support you received from your healthcare professional?



However, it would appear that health professionals do not routinely discuss employment with their patients with MS. Only 27% (n=412) of respondents said a health professional had a conversation with them within the last year about their employment situation. Just 19% (n=171) of those currently working or looking for work had had a conversation about their employment situation with a health professional within the last year in which signposting and support was offered. Seventeen percent (n=159) had had a conversation about their employment situation in which no signposting and support was offered. Since work is such an important aspect of people's lives, on which both MS symptoms and treatments can impact, it is concerning that conversations about work are generally not taking place.

Occupational health services

> **"It took months after diagnosis to get referred to my NHS OT – my GP managed it eventually – she is brilliant, very supportive... She gave me confidence that I was doing everything I could and that it was ok to ask my employer to make adjustments. She came and met my first employer and... wrote a summary for my second employer so they could agree the reasonable adjustments before I accepted the position."** Tamsin, who has MS

Survey respondents in work were asked whether they had received support to manage issues they have at work from a variety of services. Among those who had accessed support, occupational health services were the biggest provider of support, with 40% (n=298) accessing this type of support.

Occupational health services tend to be attached to particular employers, whether as an in-house or contracted service. They provide advice on health and work to employees and their managers. They advise about the functional impact of MS at work, and make recommendations about reasonable adjustments that could be made. They can also provide advice around medical retirement on health grounds.

Where respondents had access to occupational health services, they were broadly satisfied with the service received, and many reported helpful conversations and support.

Worryingly, access to occupational health physicians is largely limited to larger employers in the UK, as there is a very limited availability of occupational health physicians within the healthcare system.

The UK Government has tried to expand access to occupational health support through the Fit for Work Service which is available in England, Scotland and Wales. The service offers advice to employees who are on long-term sickness absence (of four weeks or more), and to their employers. While the Fit for Work service has the potential to be helpful, at present very few people with MS have been referred to the service. Just 1% of the 831 respondents currently in work had accessed this service.

However, there are concerns about the suitability of the Fit for Work service for people with conditions such as MS. The lack of opportunity for a referral until an employee is off sick and expected to be off for four weeks or more, and the lack of opportunity for a repeat referral within a 12-month period of an initial referral, currently makes this service often unsuitable for people with fluctuating and progressive conditions like MS.

Vocational rehabilitation services

> **"We believe the following barriers to effective service delivery and development...No mechanism for the service to grow, even though we are over - subscribed, and 'profitable'. This is because despite the commitment to work in the Quality Outcomes Framework, vocational rehabilitation is not seen as a priority. This could be overcome if work status was routinely recorded as a health outcome. Because we cannot grow we cannot see patients at risk of job loss in a timely manner..."** Diane Playford, Vocational Rehabilitation Team at Queen Square, National Hospital for Neurology and Neurosurgery

Evidence provided to the Review suggested that the provision of specialist vocational rehabilitation services with expertise around neurology, is very patchy. Many vocational rehabilitation services do not provide access to a range of different allied health professionals, and some staff do not have any professional training in vocational rehabilitation. An estimate was given that at most, such services can only treat 10% of the population who would benefit. Similarly, the Review heard evidence that there are currently too few community neurological rehabilitation services that can support people with their vocational needs.

Is work good for health, for people with MS?

There is a lack of consensus amongst people with MS about whether work is good for their health. A small majority of respondents (52%) agreed or strongly agreed that work is good for health. However, only 34% of those who are not working and not looking for work agreed or strongly agreed and an equal number disagreed. The interaction between work and health is complex for many people with MS; there can simultaneously be some aspects of working that are good for a person with MS, while other aspects are not.

"Although work made me feel like a valued member of society, I constantly found I was making mistakes (brain fog) and was at a permanent low ebb health wise! Relapses were strong and constantly having to fight intense fatigue left me too weak to function properly." Debbie, who has MS

Positive impacts of work highlighted by responses included increased financial security, positive effects on mental health and a sense of purpose and pride. Others drew attention to the opportunity for regular social interaction afforded by work. However, work can exacerbate MS symptoms especially when it is stressful or involves many physical tasks. This can cause extreme fatigue and difficulty balancing work with other important aspects of life that contribute to good health.

"At the stage I am at now my health was suffering when I was working. I left teaching last year as I was unable to manage my job and it was having a negative effect on my MS symptoms." Victoria, who has MS

Whether work is good for health is contingent on various factors such as a person's symptoms, and the extent to which their MS has advanced.

Solutions

Improved access to MS healthcare and employment-oriented healthcare

> **"...from a health perspective the most significant factors leading to successful work retention are the person wanting to remain in work, a supportive employer, honest conversations about the difficulties as well as the skills, an early responsive intervention, good fatigue management, and, at a minimum, access to both a psychologist and an occupational therapist."** Dr Diane Playford, Vocational Rehabilitation Team at Queen Square, National Hospital for Neurology and Neurosurgery

The Review identified that effective condition management is key to improving employment outcomes, and preventing early exit from the workforce. A need for support – including strategies – around fatigue management was identified as important, since this MS symptom has a profound impact on people's ability to work. Similarly, support both with identifying the impact of, and adjustments to manage, cognitive symptoms was highlighted as being important. The importance of this support being provided by appropriately qualified health professionals was underlined by a number of Review respondents.

> **"Having support from health professionals who can give personalised advice on condition management in the workplace is therefore crucial to support people with MS to look after their health needs at work and to ensure they are able to stay in employment."** Shaw Trust

Evidence presented suggested a need for swift referral into appropriate services in cases of relapse, to avoid negative consequences for people's employment situation. In addition, evidence also suggested that there is a need for people with MS to be able to access health services as and when they need them, with timely access to a full multi-disciplinary team. A need for greater access to psychological support was identified, to help people come to terms with their diagnosis, developing symptoms, and how this affects their abilities.

> **"Certainly more emphasis needs to be given to employment as an important outcome for individuals with MS...That changed focus includes initiating discussions with people about work and careers soon after diagnosis and coordinating care through multidisciplinary teams."** Rachel Suff, Public Policy Adviser (Employment Relations), Chartered Institute of Personnel and Development

Evidence to the Review suggested that improving access to health professionals with specialist skills around vocational outcomes can play an important role in assessing patients' functional abilities, accurately identifying health barriers and how these might be overcome.

> **"There is an urgent need for better and consistent vocational rehabilitation services staffed and led by appropriate specialist staff."** Dr Perry Moore, Clinical Neuropsychologist and Research Lead, The Walton Centre NHS Foundation Trust

It was clear from the Review's evidence that there is a need for more employment provision within healthcare services. In particular, a number of respondents said that access to vocational rehabilitation services needs to be improved.

Evidence from health professionals about what an ideal employment support programme for people with disabilities such as MS, would comprise included:

- access to an occupational therapist, psychologist, neurological psychologist, physiotherapist, rehabilitation consultant
- specialist assessment/work analysis to identify people's functional limitations and the match between job demand and individual's cognitive, physical and emotional capability
- recommendations and advice for both employees and employers following assessment
- setting up work trials and job brokering, possibly in partnership with other providers
- psychological support e.g. counselling, cognitive behavioural therapy, relaxation/mindfulness techniques
- education on self-management of symptoms
- ongoing support and monitoring

Evidence suggested that health professionals need support to consistently discuss employment with their patients, so that the impact of symptoms on work, and similarly the impact that any treatments may have, is routinely discussed.

Work as a clinical outcome

> **"Certainly more emphasis needs to be given to employment as an important outcome for individuals with MS, and ...other long-term conditions. That changed focus includes initiating discussions with people about work and careers soon after diagnosis and coordinating care through multidisciplinary teams."** Dr John Chisholm CBE, Health and work lead, member of Council and Trustee, RCGP

> **"Work is one of the most important social determinants of health and essential to a feeling of self efficacy and confidence. A sustained return to work should be seen as a key indicator of clinical success and supported not just by health but by social services and government agencies working together to achieve meaningful outcomes for patients"** Dr Emer Mc Gilloway, Neurorehabilitation Consultant, King's College Hospital NHS Foundation Trust

Evidence to the Review suggested the adoption of work as a health outcome within healthcare could help to improve the provision of vocational rehabilitation services as commissioners recognise the importance of employment, and ensure that adequate consideration is given to the impact on employment of any healthcare and treatments. It might also help to improve access to information for people with MS, through better signposting.

Access to occupational health services

> **"I do believe everyone should have access to an occupational health specialist to... see if they could work, and if so, what role and if any adjustments would be required. I am aware there is a 'Fit for Work' service that GPs can access but my understanding is that it is very limited in what it can offer."** Susan Martin, Occupational Health Specialist Practitioner, Oxford Health NHS Foundation Trust

The need for improved access to occupational health services was identified in the course of the Review; while many people had access to an occupational health service, and found it helpful, others did not have access to this service, but wanted access. The Review heard evidence that those working for small and medium enterprises (SMEs) were particularly likely to need greater access to occupational health services. Evidence on the role of occupational health services was submitted to the Review, including the provision of advice and guidance about the condition, and on improving employers' understanding of their duties under the relevant legislation.

> **"The Fit for Work service... gives advice as well as supporting people... It's voluntary so the employer has to agree to take part in it, but I think there's more scope for using that service to support particular employee groups so people with long-term health conditions, disability and so on, and playing a supportive and preventive role. Also, you can only access that service once a year, I think that goes against supporting people with fluctuating and chronic conditions and so on, so there could be scope there."** Rachel Suff, Public Policy Adviser (Employment Relations), Chartered Institute of Personnel and Development

The Fit for Work service is intended to meet the need for increased provision of occupational health advice. Yet, evidence to the Review suggested that improvements to the Fit for Work Service are needed to make it more appropriate for people with complex neurological conditions. In particular, the point at which people can be referred in to the service needs to be revisited.

Self-referral into services

> **"People with MS in work may require prompt intervention [or] support when experiencing difficulties at work. This can occur weeks [or] months or years after last contact so self-referral is vital."** Anonymous, health professional

Improving access to occupational health services, community neurological services and vocational rehabilitation by making sure that people can access these services via self-referral was remarked upon by several Review respondents. This is important given that people may require prompt interventions when facing difficulties at work, so that these difficulties do not escalate.

2 Workplace cultures

Obstacles

Employer outlook

> **"...the importance of a positive organisational culture, where disability is visible...this is core to creating an environment where employees feel able to bring their whole self to work, and [is] particularly important for a non-visible health condition like MS."**
> Helen MacFarlane, Principal Consultant, Business Disability Forum

Data gathered for the Review suggests that employers' outlooks seem to be generally improving. Of those no longer working and not looking for work, 31% of those who had last worked longer than five years ago said they had received support to help them stay in employment and manage their MS at work compared to 44% of those who had last worked within the last five years.

Yet, evidence presented to the Review indicated that disability and chronic health conditions are sometimes not visible and are not systematically recognised as being part of normal working life. This can manifest itself in various ways, including a lack of information provision around working with disability policies and procedures which assume periods of ill-health are temporary, and widespread lack of understanding that people who look healthy might not be. This lack of normalisation and visibility can lead to an employee with a disability being perceived as an undesirable employee from the perspective of both employer and employee.

The Review heard that some employers can approach ill-health from a risk-limitation perspective. This is unhelpful as it can lead to employers believing that their staff should only be at work when fully fit, which is not appropriate to employees with MS given the condition's fluctuation and the degree of functional impairment experienced even when in relative remission.

> **"...a lot of the focus in the organisations I've worked in... has been a risk based focus, and that is about employment litigation, that is about safeguarding the business and about minimising workload... we're tick boxing around the legislation trying to avoid unlimited awards rather than perhaps having open minds."** Sally, HR professional with MS

Moreover, fear of running foul of legislation and negative attitudes towards disability can impact organisations' willingness to employ people with disabilities.

> **"A major barrier for our customers is that employers often seek ready-made employees who are proficient in their role with minimum training, training support or cost to the employer. Extra support or training is viewed as inconvenient, time consuming and costly... we would like to see greater focus on SMEs, who may not understand and be fearful of the role disabled people can play in their workforce."**
> Scott Parkin, Specialist Health Adviser, Papworth Trust

Common business cultures that normalise long hours, working while sick, and requiring fast paced work can also be alienating for people with conditions such as MS. These cultures can have consequences for employees' willingness to disclose.

> **"The drift towards longer working hours in general puts people with MS at a disadvantage as fatigue would prevent them working these hours and may be considered less motivated or committed by employers, with a consequent effect on their career and perception of performance. Employees often report that they are unable to challenge demands of employers as they worry about putting their job at risk."** Anonymous, health professional

> **"For me, my personal decision not to disclose is because it didn't feel normal, and I think that is a huge cultural shift..."** Sally, an HR professional with MS

People with MS self-manage their condition on a daily basis. Yet, it was highlighted that employers often neglect to discuss directly with the employee themselves any support they might need.

> **"often the patient knows better than anyone what is needed... [but] you are very rarely asked yourself what is it you need in terms of self-management, and when you are living with a chronic health condition in work you are effectively self-managing that in work – there is nothing your employer is doing for you to manage your health, it is only you that is doing that."**
> Sally, an HR professional with MS

Evidence collected for the Review suggested that the relationship between an employee and their line manager is fundamental in either equipping and enabling the employee to continue working and performing well, or in undermining and discouraging them (be it intentionally or unintentionally). However, line managers do not seem to be equipped to have conversations with their employee about their health and related issues.

> **"...the role and the significance of the line manager – and this is underpinned by really good research – is so very significant when it comes to health at work, in fact, is the key enabler in terms of the self-management of health in the workplace."** Sally, an HR professional with MS

> **"I can't really emphasise the role of line managers enough because often now in organisations responsibility for people management is devolved down to line managers so it's the relationship that they have with somebody."** Rachel Suff, Public Policy Adviser (Employment Relations), Chartered Institute of Personnel and Development

Employer attitudes towards disability can also cause issues for those looking to enter or re-enter work. A majority (74% n=65) of respondents looking for work feel that employers' attitudes to MS make it hard for them to find a job. This is consistent with evidence from the survey and evidence sessions. While many of those who are making hiring decisions may not be intentionally discriminating against people with MS, subconscious bias and assumptions may play a role.

> **"I think on the part of employers, the line managers who do a lot of the hiring now in organisations, a lot of the time it's lack of confidence, a lack of familiarity, stereotyping definitely and unconscious bias."** Rachel Suff, Public Policy Adviser (Employment Relations), Chartered Institute of Personnel and Development

This subconscious bias and unhelpful outlook can manifest itself in a lack of suitable jobs being advertised. While Review evidence suggests that traditional 35+ hour a week, full-time jobs are likely to be unsuitable for the majority of jobseekers with MS, only 6.2% of vacancies in the UK offering a salary deemed high enough to live on (the full-time equivalent of £20,000 or more) mention flexible working options, including part-time options.[16] This presents a significant barrier for people with MS to get into work – or to move from one role to another – and employers are likely to be missing out on employing skilled employees with MS.

Lack of understanding of MS

> **"...Employers, we thought they would want more advice around the terms of the Equality Act and reasonable adjustments, what they actually wanted was information about the disease... I think there's enormous fear amongst employers, particularly of making things worse, of the stress of work making things worse, and so they feel quite trapped and quite powerless."** Dr Diane Playford, Vocational Rehabilitation Team at Queen Square, National Hospital for Neurology and Neurosurgery

The Review heard evidence that many employers' lack of understanding of MS causes a number of issues. Firstly, it can exacerbate fears as the employer does not know what to expect, and how to respond. Secondly, it can result in very unhelpful assumptions, particularly around expectations that an employee who had disclosed they have MS will be like another person with MS known to the line manager, colleague or HR manager.

Lack of understanding about MS and its varied, and often hidden, symptoms and individual presentation can also lead to issues around people being disbelieved about having MS, or about the impact that it has on them.

> **"I think that the vast majority of employers, large and small, have relatively little understanding or even practical experience of [MS]. For many of them... it will be the only time that they ever get an employee coming to them to say they've got MS. The problem is they really don't understand what it means and they don't particularly understand what fatigue means and it's really difficult even if you've got MS to explain."** David, an HR professional with MS

> **"...even though people were saying 'yes, you've got MS and we'll do these things', because I looked well people paid lip service to that, and then when push came to shove, which it often did, there was still the expectation that you could do the work, that you would carry on, that you would keep pushing and keep working."** Rebecca, who has MS

For a full understanding of MS, and the impact it can have on an individual in the workplace, specialist assessment may be needed of the match between job demands and the individual's cognitive, physical and emotional capability, to ensure the right adjustments and support are put in place.

Such neuropsychological assessment and work analysis requires specialist input from neuropsychologists and occupational health physicians. However, evidence suggests that the availability of such support is diminishing.

> **"...in the past I had many successful visits [to the employer], often a joint visit by a neuropsychologist and an occupational therapist to help explain MS, how it might affect aspects of work and where it would not, and any helpful adaptations that might assist. Unfortunately there is rarely sufficient funding for NHS services to do this now and the opportunity is lost."** Dr Perry Moore, Clinical Neuropsychologist and Research Lead, The Walton Centre NHS Foundation Trust

Where a lack of understanding of MS is combined with a workplace culture that does not encourage engagement with employees about their health and its impact on their work, the result can be detrimental to, and undermine, the employee with MS.

Experiences of stigma and discrimination

> **"My employers moved me to a quieter shop claiming it was for the benefit of my health – even though I had no problems at the shop I was in. They used my MS as a way to move me as I had complained that my line manager had not acknowledged my illness"** Nic, who has MS

Evidence gathered highlights that disability discrimination in the workplace is an issue and cause of barriers to employment for people with MS. Discrimination leads many to exit the workforce earlier than they might otherwise have done, and recruitment discrimination prevents many people from getting back into it.

Thirty percent (n=252) of respondents currently in work said that they had experienced MS-related stigma or discrimination by colleagues or managers over the past five years. These included instances of being denied training, promotion, or a job offer, or having the issue of their career progression ignored, and being side lined. Some described experiences of having duties they felt capable of being removed without consultation, or of being demoted. Occasionally discrimination is clear, and overt, where a person with MS is told that it is their MS that is the reason they are not being given an opportunity. However, more often discrimination seems to be insidious.

> **"I've been told that there is no point in me being given any training as I don't have the capability for career development. This meant that I felt even more negative than I already did about my abilities."** Kate, who has MS

> **"My main issue is that I am obviously disabled and many interviews I attend end with me sitting in reception because there is no access. If you ask in advance of the interview if there is disabled access the interview will get cancelled with the standard excuses."** Nicole, who has MS

Respondents' answers also contain many distressing examples of bullying and degrading treatment on the part of managers and colleagues. A wide range of behaviours are discussed, including offensive comments, gossiping, active exclusion, imitation (e.g. of speech impediments), and being the butt of jokes.

Where reasonable adjustments had been put in place some respondents experienced resentment from their colleagues, accompanied by offensive and degrading treatment in some instances. Situations were also described in which, once made, reasonable adjustments were overlooked, ignored, and undermined.

Many respondents described feeling forced out of work. Some described situations in which they felt pressurised to leave their job, whether through resignation, taking redundancy, or taking ill-health retirement, due to colleagues' unpleasant or unsupportive attitudes. Examples of the latter include a lack of adjustments being made to their role, or opportunities for redeployment being denied, without adequate reason given. Others had their employers try to dismiss them due to competency issues or having taken too much sick leave.

Evidently such treatment is unacceptable and inimical to ensuring that people with MS are able to continue working for as long as possible. Moreover, experiences of stigma or discrimination can lead to people with MS changing their behaviour in what may ultimately be counterproductive ways, for example, declining to disclose their MS to a future employer, or acting in ways that have repercussions for their health.

Difficulties around reasonable adjustments

> **"Usually organisations are quite confident and experienced in providing the kit but less so in the soft adjustments, and that's where it can fall to inexperienced, unconfident line managers, and it's the soft adjustments which are so important to many people with MS, even though these are low cost or no cost provisions."** Helen MacFarlane, Principal Consultant, Business Disability Forum

Difficulties around reasonable adjustments were continuously highlighted as an issue by the Review. Eighty-seven percent (n=726) of respondents had disclosed their MS to their employer, but only 57% (n=472) reported having had their employer discuss support in the workplace, such as reasonable adjustments, with them. So, there is a 30% gap between the number of people with MS who have disclosed, and the number of employers who have offered support. Even where reasonable adjustments are made, they're often not reviewed regularly: half (50% n=225) of respondents who have had reasonable adjustments made had not had these reviewed.

The survey results suggest that those working for smaller organisations and private organisations are less likely to have reasonable adjustments made for them than those working for medium/large sized and public organisations. Forty-seven percent (n=62) of those working for a small organisation have had reasonable adjustments made for them, compared to 59% (n=299) of those working for a large organisation.[i] This may be linked to the finding that those working for larger sized and public sector organisations are more likely to ask for reasonable adjustments.

Lack of understanding, or misunderstanding, about reasonable adjustments seem to be common among employers. For example, adjustments can be viewed as difficult, costly, only needed temporarily, or as unfair favourable treatment of a disabled employee. A substantial number of respondents also described situations in which they had to push to get reasonable adjustments recommended by health professionals or Access to Work assessors made, by reluctant or unwilling employers.

> **"… I had a very knowledgeable therapist. She came to my office, and gave them some very good advice – which they then chose to ignore. As they say, you can lead a horse to water, but you can't make it drink."** Jennifer, who has MS

Misunderstanding may be due in part to the lack of legal clarity about 'reasonable adjustments'. While the duty to make adjustments applies to all companies, what is deemed reasonable may vary according to a variety of factors, including company size.

> **"We do battle a bit against some misunderstandings about reasonable adjustments, a lot of people, a lot of employers seem to think they're only temporary or that they can't treat a disabled person more favourably in making adjustments, such as giving increased breaks. Legally that's not the case, they can and they should. Other problems with reasonable adjustments legally, it's quite hard to advise someone, 'Yes, the thing you are seeking is definitely a reasonable adjustment'. Ultimately only an employment tribunal can decide that… "** Angela Brosnan, Solicitor and MS Legal Officer, Disability Law Service

Helen Macfarlane, Business Disability Forum, differentiated between "hard" adjustments such as "physical kit, chairs, software" and soft adjustments such as "flexible working hours and working at home." It was felt that lack of experience in making such adjustments, and a lack of openly available case study examples to learn from, can leave managers and HR professionals floundering around the provision of appropriate adjustments.

> **"…when I came into HR I'd never done it before, so I was trying to look at what have other organisations done to support people… there was nothing really available, examples of, we made this adjustment, we made that…"** Sarah Duggan, HR professional, Quill Pinpoint Ltd (MS Society Employer of the Year award winner 2016)

Absence management was one issue around which respondents reported adjustments not being made. Hitting absence trigger points can lead to stress and anxiety for people with MS, or even being dismissed or choosing to leave a job.

> **"My employers use the Bradford Index[j] to score sickness time off… The OH doctor recommended my sickness for my MS be collated as one episode to avoid a trigger on this index. Following a recent episode off work again with my MS I am now facing a stage two as Human Resources have decided to ignore OHS recommendations… I work for the NHS."** Karen, who has MS

> **“Following my last relapse… I was unable to work… I returned to work after 2 weeks sick leave and my manager told me that if I had one more day off sick then he would terminate my contract. I felt unsupported and depressed. Rather than live under the threat of dismissal, I left my post.”** Amanda, who has MS

Some employers have policies allowing time off for MS-related medical appointments, and plan work schedules around the employee’s treatment schedule. But this is not universal.

> **“I have 18 days a year… of needing to go into hospital…to get treatment… Disability days should be so, so key for getting someone with a chronic illness who’s undergoing treatment and should be able to get back to work, but what sort of employer would be happy if you take 18 days off sick a year?”** Matt, who has MS

Finally, people with MS can also lack knowledge about their right to reasonable adjustments, despite the status of MS under the Equality Act.[k,l] Where people with MS are not in work, lack of knowledge about this entitlement could prevent them from seeking employment. Similarly, lack of knowledge about adjustments may deter those in employment from disclosing, which in turn means they cannot be supported by their employer, or gain support from Access to Work. Survey data shows that employees who ask for reasonable adjustments to their role are far more likely to have adjustments put in place: overall 54% (n=447) of respondents’ employers have made reasonable adjustments to their role, but where respondents have asked for adjustments, this figure rises to 78%.

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[j] The ‘Bradford Index’ or Bradford Factor is a tool used by some human resource professionals to measure worker absence. It was developed as a way of highlighting the disproportionate level of disruption caused by short-term absence compared to single instances of prolonged absence.

[k] MS is one of very few conditions which is automatically considered a disability under the Equality Act.

[l] The Equality Act 2010 does not apply in Northern Ireland, where there has been no such equivalent legislation; the state of the law relating to disability discrimination is different to that applicable in England, Scotland and Wales.

People with MS self-manage their condition on a daily basis. Yet, it was highlighted that employers often neglect to discuss directly with the employee themselves any support they might need.

Solutions

Adequate information provision for employers

> **“Within the work environment, reasonable adjustments, flexible working hours, scheduled work breaks with a place to rest, improved awareness of MS amongst colleagues, and increased support from employers and colleagues may all assist individuals with MS to remain in work, and schemes like Access to Work are important.”** Dr John Chisholm CBE, Health and Work lead, member of Council and Trustee, Royal College of General Practitioners

Those who gave evidence to the Review identified a need for more condition specific information for employers, to help them understand the full impact of MS. Review respondents felt this would help managers understand their employee’s needs, and to introduce appropriate reasonable adjustments to accommodate them.

Responses to the question ‘Is there any other support that could help you with work issues caused by your MS?’:

“Better understanding of the illness and the Disability Act by managers. Biggest issue is always having to explain that my illness doesn’t disappear or get better. The symptoms are always there it’s just how we cope and manage them.” Paul, who has MS

“It would be nice if there was something to provide my work with to understand what it’s like with MS. So there is more information for my work to look at before judging.” Gemma, who has MS

Evidence gathered in the Review suggested a need for greater provision of information for employers about reasonable adjustments, and examples of their application. This would help them to make appropriate adjustments for their staff. According to research by the Business Disability Forum, while most employers report mid to high confidence in knowing their legal obligations (75%), they report a lot less confidence in where to seek advice and guidance outside their organisation as it relates to workplace adjustments (41%).[17]

> **“While …the Equalities Act demands appropriate accommodations, [it does] not seem to require the employer to understand the condition and therefore properly understand the needs a person might have. Changing this requirement would shift an emphasis … to a shared understanding. In my work it is often through developing a good understanding of the problem that provides the key to appropriately managing and supporting the individual.”** Dr Perry Moore, Clinical Neuropsychologist and Research Lead, The Walton Centre NHS Foundation Trust

> **“The most important factor is probably how well the person with MS and employer understands MS, including how variable and unpredictable it can be. MS is different for everyone; it is not possible to predict what will happen. Everyone will experience different symptoms at different times and the impact of the symptoms on work will very much depend on the type of work and personal experience of MS. Education programmes delivered by someone with expertise in MS and how it relates to employment may be a helpful intervention in some cases.”** Amanda Croft, Policy Officer, MS Trust

A solution to this lack of understanding remarked by a number of respondents was the provision of education about MS for employers. Suggestions about the form this might take include the provision of an education programme, as well as education delivered to employers during the course of any intervention by occupational health services, employment programme providers, or health professionals.

> **“We need to develop services and support which reflect the specific needs and the context of SMEs (small and medium employers). These services – which might include training resources, specific advice on employee health problems, or broader Occupational Health advice – need to understand SMEs’ business needs and capabilities… Third, we need to improve SME access to advice and support, simplifying and optimising the channels we use for communicating on workforce health issues, alongside other issues relating to business support and growth.”** Antonella Cardone, Executive Director, Fit for Work Global Alliance

A particular need among SMEs for information and support was remarked by respondents, as they may not have access to the resources enjoyed by larger organisations. This reflects evidence reported in the barriers section, that people working for SMEs were less likely to ask for, and receive, reasonable adjustments to their roles.

Positive workplace cultures

> **"A friend of mine was setting up his own small motor factory and asked me if I'd like to join the team… They knew my situation, I was MS, I said, 'I could be ill one day, I could be fine the next.' They said 'it's not a problem, we'll work around you'… I was a driver for the first four years, then I found it difficult when my eyesight started to play up and the fatigue, I thought better leave this now… Spoke to my colleague, 'not a problem, we'll put you on the phones in the shop'… I go into work, if I look rough, they'll either send me home or put me on a desk… When I went down to three days… [they said] 'We'd rather you stay because it's harder to train somebody else to do your job than it is for you to leave…'"** Mark, who has MS

The Review heard evidence from some people with MS who had had very positive experiences of being supported by their employers. What seemed to be consistent across these examples was the employers' positive attitude towards disability, as well as the value they placed on retaining an employee with valuable skills who adds to their business.

> **"What is best practice around creating a positive culture? That it embraces disability such that employers, employees and job applicants feel confident around health related issues like disclosure and adjustments and what role HR policies play in that."** Rachel Suff, Public Policy Adviser (Employment Relations), Chartered Institute of Personnel and Development

> **"It is vital that there is a shift in attitudes among employers and society at large to recognise the important contribution people with long-term health conditions such as MS make. Greater awareness of the benefits of having a diverse workforce, the support on offer to both employers and employees with MS, and the ways in which people's support needs can be met in the workplace would help to improve their chances of finding and staying in work."** Shaw Trust

Given the evidence submitted to the Review which suggests that ensuring the company is positive about disability will help to foster a culture in which disability is embraced, there is a need for more widespread awareness amongst employers of the benefits of having a diverse workforce. Evidence to the Review highlighted the importance of practices that signal to employees the companies' desire to be supportive, whether that is needed now or down the line. The importance of putting messaging in place that encourages people to disclose their disability, and responding to disclosure in positive ways, was remarked. The provision of disability passports outlining agreed adjustments can ensure better experiences for disabled employees. Review respondents also touched on the provision of buddying or mentoring schemes, and disability networks, in discussing practices which can help create cultures which are positive about disability.

> **"As an organisation we're working hard to upskill our people leaders, to avoid people with disability having to explain their condition and renegotiate their adjustments every time they move role or change manager. I know that one or two other organisations have a passport to do this, and that is something that we're looking into as well… We have, as I touched on earlier, a strong disability network… its role is about building awareness and understanding, but it also creates a support network and it acts as a place where we in HR can sense check our approach and gain valuable counsel…"** David Conder, Associate Partner, KPMG

Finally, the importance of ensuring the whole organisation is geared up and embracing disability was remarked, rather than letting it be seen as something just for HR to address.

> **"We have a disability standard that we use, it's a management tool that organisations can use, and that I think is really important, that's about embedding disability across all ten areas of an organisation, not just keeping it in HR but looking at procurement, ICT, facilities management, all aspects"** Helen MacFarlane, Principal Consultant, Business Disability Forum

Enhanced training provision for managers

> **"[Managers need] to have the confidence as well as the competence, not just being able to implement policies and so on, but not to be scared and nervous of having conversations with people."** Rachel Suff, Public Policy Adviser (Employment Relations), Chartered Institute of Personnel and Development

In evidence gathered for the Review, people with MS called for better managers able to communicate with them about their health and support needs.

> **"Constant communication about how my illness is currently - monitoring and addressing if my hours are still suitable."** Lucy, who has MS

Making sure that line managers are equipped to support employees with disabilities, and helping them to feel confident about having conversations about health and disability, is critical. According to our evidence, training given to line managers is essential to achieving this. Managers must also understand the role that employees play in self-managing their condition at work, and how they can support this. The importance of training as a means of reducing subconscious bias was also underlined.

> **"We are proactively taking steps to ensure everyone understands and can mitigate bias in all its forms, whether that's unconscious bias, whether it's a protective or confirmation type bias, and we think that that means that our people are better... and able to support others better as a result..."** David Conder, Associate Partner, KPMG

HR policies

> **"If we start with the policies and procedures around managing disability and health and so on, I think they are the bedrock in an organisation for encouraging a positive, open and supportive culture where the needs of the individual are at the centre of that approach..."** Rachel Suff, Public Policy Adviser (Employment Relations), Chartered Institute of Personnel and Development

The importance of having the right policies and procedures in place around managing disability and health in the workplace was remarked upon frequently during the evidence gathering for the Review. This was felt to be fundamental in creating workplace cultures which ensure that disabled people are treated equitably and fairly.

> **"My employer has been fantastic really. I work for a very large company department and I've kept them informed of various things throughout my time from the diagnosis... my trigger points have been increased because I've got a long-term health condition where I have had long periods of sickness so the trigger points are more than they are if I didn't have a health condition."** Daniel, who has MS

> **"Disabled staff may require time off work to help them manage their disability, such as to attend appointments or consultations or have treatment related to the ongoing management of their disability. Disability and ill-health are not the same thing. The RCN recommends that disability related absence is captured separately to that related to ill-health."** Royal College of Nursing

In particular, Review evidence suggested there is a need for improvement in the provision of disability leave policies. Some people with MS responding to the Review wanted a disability policy which differentiated between disability related leave, such as medical appointments, and sick leave.

> **"HR has an important role to play in encouraging line managers, having the policies in the first place but understanding that you need to distinguish between sickness absence and somebody that needs to take leave in an organisation because of a reason related to their disability."** Rachel Suff, Public Policy Adviser (Employment Relations), Chartered Institute of Personnel and Development

> **"A disability leave policy can include the provision of separate periods of time off for the purpose of (for example) treatment, therapy, rehabilitation, training or waiting for adjustments to be executed."** Huma Munchi, Policy Officer, Trades Union Congress

Other respondents with MS called for adjustments to be made to the point at which their level of absence triggers absence management mechanisms, to take account of their MS. Case law has established that triggers for disciplinary sanctions under absence management policies are subject to the duty to make reasonable adjustments.[18]

According to the Business Disability Forum, more than 70% of employers already have policies that distinguish between disability related absence and sickness absence, but one in four employers are operating with higher levels of legal risk by treating disability related absence and sickness absence the same.[19] Given the number of Review respondents who raised the issue of difficulties experienced due to MS-related absences, there is clearly a need for good practice to become even more widespread.

Another domain in which HR policies can make a positive difference is in how absence is managed. In particular, the importance of having a return to work policy in place was remarked.

> **"When it is time for a member of staff to return to work there should be a clear policy in place – that is not linked with any disciplinary procedure – and the advice of the employee's GP or medical specialist should be followed. A range of options should be open to the returning staff member and where appropriate there should be alterations of work stations, retraining offered, changes to working times and patterns, and a review of transport arrangements to and from work."** Huma Munchi, Policy Officer, Trades Union Congress

One of the areas in which many people with MS experienced barriers to employment was in relation to career progression. Many respondents felt that their way to progression within their company was barred, whether or not they were actively seeking promotion. In designing HR policies to try and halve the disability gap, Government and employers should give attention to how opportunities for development, promotion and progression can be increased for disabled people, including those who are working part-time.

Linking to calls for better information provision for employers, respondents highlighted that companies may need access to HR expertise in order to get the right policies and practices in place. This may particularly be needed for smaller organisations, which do not have the resources and expertise of larger organisations.

> **"Other forms of support that may be helpful include... access to expert HR advice on issues such as managing flexible work patterns, and recording sick leave, time off for hospital appointments, and absence due to disability separately. Many small and medium employers do not have the kind of HR services that larger employers have, and even larger employers may need assistance to understand the best HR practices for managing someone with a condition like MS."**
> Amanda Croft, Policy Officer, MS Trust

> **"... an ability to access a specialist disability HR service I think would also be very useful. Disability discrimination law is the most complex area of law under the Equality Act, there are two extra strands, people are very nervous about it, so I think specialist HR services would be useful."** Angela Brosnan, Solicitor and MS Legal Officer, Disability Law Service

Ensuring positive change

> **"There needs to be a way for employers to be made to agree reasonable adjustments and when they have to keep to them without the employee having to ask because it is a very difficult position for the employee to have to keep asking and being ignored plus it just undermines your ability to do your job to the best of your ability..."** Tamsin, who has MS

One of the barriers identified by a number of respondents with MS was employers' refusal to make adjustments, even where these had been suggested by a health professional, Access to Work, or an employment support provider. Consistently, the need for binding enforcement mechanisms was raised in evidence provided, to ensure that employers take any recommendations from external parties under full consideration.

> **"There should be some incentive/mandate for employers (including SMEs) to consider adjustments suggested by OH/OT specialists."**
> Dr Ali Hashtroudi, accredited specialist in occupational medicine

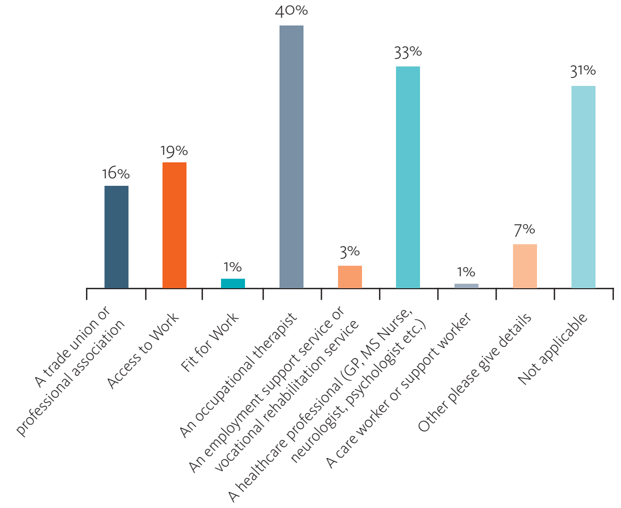
Another way to encourage better working practices by, in some cases, reluctant employers is financial incentives and/or compensation. This was discussed by several Review respondents as a way to incentivise better practice, or to alleviate uncertainty for employers caused by the symptoms of conditions such as MS. Financial incentives, or rebates, for companies implementing policies to support employees with disabilities were suggested. The issue of compensating employers, via insurance schemes or UK Government programmes, for periods in which an employee is off or unable to work full-time or at full productivity, was also suggested.

3 Availability and quality of employment support services

Obstacles

Lack of employment services

> **"You can feel very alone with an illness, let alone trying to get back to work as well, so support for me would be somebody who has knowledge about disabilities and employment and can guide me"**
> Paula, Who has MS



Have you received support to manage issues you have at work because of your MS from any of the following? Please tick all that apply

Results from the Review's survey highlighted that very few respondents in work have accessed employment support services to help them manage issues they have at work because of their MS; only 3% (n=24) have accessed either an employment support or vocational rehabilitation service.

The largest employment support programme is the Department of Work and Pensions' Work Programme, available to claimants in England, Wales and Scotland. Unemployed people claiming Jobseeker's Allowance (JSA) or Employment and Support Allowance (ESA) are referred on to the programme from their local Jobcentre Plus (JCP) – in most cases as a condition of receipt of benefits.

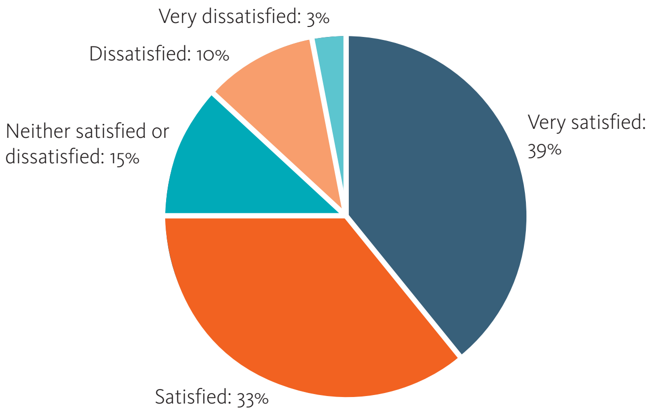
Work Choice is a voluntary employment programme which helps disabled people with more complex barriers to work, living in England, Wales and Scotland.[20] Work Choice can take on referrals for people who are already working but need support to maintain their employment, though this is not the mainstay of its work. In 2014 – 2015, there were 20,740 referrals to Work Choice for 18,800 individuals, of which just 520 were for either transitional or retention customers.[21,m] Similarly, between April 2015 to March 2016 there were 15,330 referrals for 13,970 individuals of which a total of 460 were for transitional/retention customers.[22]

Yet among people with MS there is a greater need for retention support than for support to get into work.

> **"… we had one client with MS who had been working for the prison service as a prison officer, who came to us for in-work support. They were concerned that as their condition was progressing and they experienced relapses, they would have to leave their job. By working with them and their employer, we were able to support them to be moved to different roles in the prison, first as a training officer, and then as their needs changed, to personal assistant to the governor of the prison. We arranged for the prison to appoint a 'buddy' to help with lifting and carrying duties and purchased adaptive equipment, such as an electronic hole puncher and stapler and drag and dictate voice activated computer package to support the individual in their new role. By providing support to both the individual and the employer, we were able to ensure that the client was able to stay working for an employer they enjoyed working for, and that the employer did not lose a valued employee."** Shaw Trust

Access to Work provides an example of how important support to retain employment can be for people with MS. Many respondents felt that the support from the service was what enabled them to do their job.

How satisfied/dissatisfied were you with the support you received from Access to Work?



However even this often helpful programme came under criticism with respondents raising a number of concerns. These included:

- an onerous application process
- poor customer service
- lack of funding available where an applicant's employer was not considered eligible
- the introduction of restrictions in funding available, as well as restricted eligibility criteria
- decision delays following application and assessment
- lack of continuity of advisor
- difficulties with having to pay out of pocket and wait to be reimbursed.

Particular issues were raised by longer-term Access to Work customers, around what was felt to be a reduction in the quality of services received, including a reduction in the financial support available and the quality of customer service.

> **"I was very satisfied with my initial application but the next time I made contact... I had to continually chase them and they added to the stress I was experiencing due to worsening symptoms. Also due to reduced support it made it harder to get the equipment they originally supported..."** Emma, who has MS

It was also noted that Access to Work is not able to enforce any recommendations for improvements, meaning that unsupportive employers may choose to ignore their recommendations. For example, Access to Work might state that the employer must fund any equipment needed,[n] but the employer does not implement this.

Employment services are also not providing adequate support for those few people with MS looking for work. In response to the question 'Do you think you could benefit from any (further) support to help you prepare for starting or returning to work?': 84% (n=75) said yes. Evidence given by two major employment support providers also suggests that very few people with MS are accessing this type of support to get back into work.

The Review also identified a lack of support to change career path. Many survey respondents outlined their inability to continue in the profession or role for which they were trained and/or in which they had experience, due to their MS symptoms. A lack of advice or support when looking at new career options became apparent from survey respondents' answers as did a lack of financial help available for them to re-train.

Poor awareness of support available

> **"The most important barrier we would highlight is the general lack of awareness, among employers and individuals, of the support available for people with long-term health conditions. In particular, the lack of awareness of schemes such as Access to Work or the ongoing employment support provided by Work Choice."** Working Links

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[m] DWP do not give separate statistics for the number of Work Choice referrals for transitional customers – those transferred over to Work Choice from WORKSTEP – and retention customers who are in employment and have become disabled or had an existing disability worsen in a way that puts their prospects of continued employment at serious risk.

[n] Access to Work threshold levels at which employers must pay 100% of costs vary according to the size of the employer. See https://www.gov.uk/government/publications/access-to-work-guide-for-employers/access-to-work-factsheet-for-employers#how-much-will-this-cost-me

In addition to problems around service provision which result in barriers to employment for people with MS, there are also issues around people's awareness of the support that is available.

As noted, the Fit for Work Service is currently receiving a lower than expected number of referrals, which is likely to stem at least in part from low levels of awareness about this service. This was also remarked in the Fit for Work Pilot evaluation.[23]

Only a third (33% n=29) of survey respondents looking for work were aware of Access to Work, and just 19% (n=141) of respondents in work had accessed it. This is thought to indicate low levels of awareness of the service – a view reinforced by people with MS saying there needed to be help available for things with which Access to Work can help. Moreover, many respondents raised concerns about not being able to get to work due to having their Motability vehicle removed following a Disability Living Allowance (DLA) to Personal Independence Payment (PIP) assessment, without mentioning Access to Work provisions. Lack of widespread knowledge about this service is very concerning; it may stop those looking for work applying for certain jobs, reducing their chances of getting into employment, and may mean that people who could be helped to maintain their employment are leaving the workplace.

Similarly, there seems to be a lack of knowledge amongst people with MS of the range of out of work support available to them, and how to access this.

> **"It's been fantastic hearing about what you've [organisations providing Work Choice and Work Programme] been saying today, but to be honest, it's the first time I've heard of you. If I haven't heard of you then where do we go from there?"** Matt, who has MS

Asked where they would look for information about the support available to get into employment, the majority of respondents said they would look on the internet. Many would also contact the Jobcentre, and the MS Society. A few said they would ask their MS Nurse. Many also gave responses such as "what support?" or "no idea".

Improving awareness and understanding of this support is absolutely imperative in supporting people with MS back into work where appropriate.

Access to legal advice, and advice about legal rights, constitutes another area in which respondents lack awareness of service provisions. There were a significant number of respondents who referenced issues relating both to discrimination at work, and situations in which employers refused to make reasonable adjustments, who wanted access to legal advice or advocacy. Lack of awareness of the right to reasonable adjustments, previously remarked on in this report, also suggests an unmet need for legal advice and information. Yet, there are services available which can provide this type of support, in the form of ACAS and the Equality Advisory and Support Service.

> **"I have particular concerns about who to refer people with MS to for further support if they are finding that their employers are not agreeable to change or if they are going through grievance processes."**
> Anonymous, health professional

Slow referrals, lack of integration between services

> **"Early intervention from therapists to support people to remain in work is particularly effective. This can include supporting early positive disclosure to employers and/or management/strategies and education to support the person, as well as liaising with employers, line managers, occupational health or human resources – either writing letters or meeting with them"** Paul Cooper, Professional Advisor, College of Occupational Therapists

A recurring theme throughout the evidence is the importance of early intervention, to prevent problems mounting. Yet, there was also a repeated concern expressed around slow referral to services and waiting lists.

While early referral can lead to effective prevention or intervention, this is far more difficult when a person's employment is already in a state of crisis, or when they've been out of work for some time. Opportunities to provide practical support may also be missed. Poor awareness of support may exacerbate late referrals, as people cannot self-advocate for referral into services.

> **“So often people only come to the attention of services when things are going wrong at work, there’s about to be a disciplinary hearing, and that’s a really big predictor of work loss, so the moment somebody is referred you need to be able to respond, and an 18 week waiting list is not good enough, it needs to be seen as a clinical emergency.”** Dr Diane Playford, Vocational Rehabilitation Team at Queen Square, National Hospital for Neurology and Neurosurgery

Of particular concern is the lack of systematic signposting towards or referral for employment support, from the point of diagnosis. According to NICE Quality Standards on MS, employment rights should form part of the initial information provided to patients at diagnosis.[24] While some may not have any immediate concerns about their employment situation, many find the decision about whether to disclose their diagnosis difficult. Additionally, being equipped with knowledge about rights at work, and about support available, at the earliest stage possible makes it more likely people will seek to exercise their rights.

Evidence supplied by a major employment support provider showed that their clients with MS had been out of work for longer than average, with over a third out of work for more than six years compared to an average of 22% of other clients across the whole caseload. Similarly, getting referrals through from the Jobcentre Plus (JCP) in a timely fashion was highlighted as a problem, with concerns raised that by the time the referral process is complete, some have lost motivation to engage in services.

Evidence from the survey suggests that employers are leaving it later than ideal to offer support. Out of the survey respondents’ employers who are aware of their employee having MS and who have spoken with them about how they can offer them support in the workplace, 50% (n=235) first had this conversation with them when the respondent first told them they had MS. But 33% (n=154) only had this conversation when the respondents’ symptoms got worse, and a further 22% (n=103) waited until the respondent prompted them. Again, there is clearly room for improvement here.

Lack of coordination between services can be a barrier to ensuring employment support. For example, lack of transfer of information between JCP and organisations providing employment support programmes to JCP customers around change in status, or contract details. Fears around data sharing, from fear of falling foul of the Data Protection Act, can exacerbate these issues.

> **“Whilst some Jobcentre Plus offices have worked hard in building good relationships with providers, our advisors can still experience conflicting advice, a hostile response to queries and an unwillingness to provide information on key issues. We believe some form of shared database would prove hugely beneficial, this is particularly in reference to a customer’s change in circumstances... Our experience has been that Jobcentre Plus is poor in informing us of this change.”** Scott Parkin, Specialist Health Adviser, Papworth Trust

The lack of integrated support is another area of concern - while some larger employment providers are able to provide access to their own in-house team of health professionals who can give personalised advice on condition management in the workplace, little evidence was seen to suggest that holistic support including individuals’ own MS specialists is systematically on offer.

> **“I think that we should be working closer with the healthcare providers, so we should be working with consultants and any nurse practitioners that have got a holistic approach, so basically we’re supporting each individual as a team rather than as separate organisations.”** Clare Richardson, Vocational Rehabilitation Consultant, Remploy

Solutions

Retention

> **"To have fewer people with MS leaving their job just years after their diagnosis, we need greater awareness of the importance of employment and continuing on the chosen career path. We also need self-management and career coaching services together with guidance on how to initiate a discussion on required work adaptations for people with MS."** Elisabeth Kasilingam, Managing Director, European MS Platform

Most people with MS are diagnosed when they are working, but existing and previous employment programmes do not focus enough on retention support.

Retention provision should include support to resolve issues with existing employment, or where this is not possible (for example, due to working for a smaller employer unable to make the type of adjustments needed) support to find alternative employment. Moreover, evidence submitted suggested a need for retention support to be ongoing; regular personalised support and review of a person's needs is important due to the changing nature of MS.

One employment support programme provider said that the messaging of the UK Government's Disability Confident scheme focuses on "encouraging employers to hire more people with disabilities or health conditions". They highlighted that more needs to be done to highlight the value of existing members of staff with health conditions or disabilities.

Improved retention of people with MS could also be achieved through the provision of additional help with adapting to changing capacity and the consideration of different roles. The Review identified an unmet need for support for people with MS who feel they can no longer continue in their role due to their MS, but who do feel they have the capacity to work in a different role. A need for improved careers advice for people with MS was highlighted, including information about how to access financial support to re-train.

Access to individual, tailored employment support services

> **"There needs to be a clear understanding of the match between job demand and the individual's cognitive/physical and emotional capability...The programme needs to take account that there is NOT a one size fits all, but the need to look at individual needs, that this often requires more specialist assessment and work analysis."** Dr Tanya Campbell, Occupational Therapist, OH Assist Ltd

With regard to employment support programmes, the Review heard evidence which identified good practice in the provision of Work Choice and the Work Programme from providers of those services, particularly around taking small steps towards sustainable employment, while focusing people's skills and interests. A need for focusing on building confidence was remarked, especially for those who had been out of the workplace for some time.

> **"He [Henry]... started both in a Pilates course with us as well as attending a group in confidence building, he then also went on to have one-to-one sessions with a health advisor to look at things like sleep management. As with many of our clients he found the process of applying and interviewing for work highly stressful, as do we all, which had a negative effect on his health, and it was during this time that the combined support with his employment advisor and his health advisor was really critical."** Luke Jeavons, Head of Service Design & Innovation, Ingeus UK

Adopting an individualised, holistic and flexible approach was also seen to be important, as each person's needs and barriers to work can be very different, and the impact of their health condition can vary. Moreover, the provision of holistic support to deal with any other barriers that might affect someone's ability to work is important.

> **"...we have to ...ensure that if they're moving to work then that's a good thing, not only for their lifestyle but also financially, and sometimes we get people right to the door of an employer and they back off because of the financial concerns... What really works, despite all the innovations, is spending time with people, listening to them, understanding what their real challenges are to finding work."** Brian Bell, Director for Employability and International, Working Links

Evidence from review respondents suggests a need for the provision of additional support around disability related advice, such as disclosing MS, reasonable adjustments, and rights at work, for those in and out of work, and the provision of specific support to overcome health related barriers. The importance of advice relating to rights, such as what needs to be declared at application and interview, was underlined in other evidence submitted to the Review, as was the provision of support around symptom management in a work context.

> **"Current DWP support is rightly aimed at the majority of people with ill-health problems. Unfortunately neurological conditions as a whole do not fit comfortably within the framework. Variability and fatigue continue to be poorly understood, as is cognitive change. The range of physical, emotional and cognitive symptoms are often too complex for generic services to know where someone with MS 'fits'."** Anonymous, health professional

The importance of gaining a clear understanding of the match between job demand and the individual's capability lead some health professionals who provided evidence to express concern that for people with MS, generic employment service provisions may be inadequate. Requiring generic employment services to seek advice and support from specialist health resources as part of their contract was suggested as a solution.

The use of specialist approaches to helping people out of work to find employment, including work trials, and job brokering, was remarked by some Review respondents. Working closely with, and providing support to, employers as well as employees, from the point of diagnosis, was felt to be an important aspect of effective employment support programme provision.

Improving awareness of service provisions and rights

> **"Making sure people are aware of the support they can access whilst in work to help them to stay in work is important to ensure they do not leave employment before necessary, and before they would want to. It is important also... that employers are made aware of the support available to them to help them to understand the needs of an employee with MS and how they can make adjustments to support them."** Shaw Trust

Evidence gathered showed that many people with MS are not accessing support either to stay in work, or to get into work due to lack of awareness about support available including their legal rights.

Improving awareness is therefore critical. In particular, improving awareness of the Access to Work service was suggested, to make sure employers know about the support this service can offer them.

> **"I was moved to HR so I was Googling around and it [Access to Work]'s quite difficult to come at, it's not something that jumps out at you as an employer that this is there, and I think maybe that should be more publicised."** Sarah Duggan, HR professional, Quill Pinpoint Ltd (MS Society Employer of the Year award winner 2016)

> **"More needs to be done to ensure employers know about the Access to Work fund and reasonable adjustments. There should be training and information on both."** Huma Munchi, Policy Officer, Trades Union Congress

The Review noted that previous investment in marketing for the Access to Work Service was effective: the DWP spent around £50,000 on a 12-month "targeted marketing campaign" from June 2012, which saw a 78% increase in views on the GOV.UK 'how to claim' page.[25] We also note that most witnesses to the Work and Pensions 2014 inquiry into Access to Work felt it "still suffered from inadequate marketing and that awareness remained low, particularly amongst smaller employers and disabled people with particular types of impairments" [26] ; that the Committee noted that "Improved marketing should lead to increased uptake"[27] ; and recommended "Proactive promotion of Access to Work, by JCP Work Coaches and contracted providers, to people leaving incapacity benefits and trying to find work would be one step in this direction."[28] o

Joined up support

> **"We recognise that it is difficult to be an expert in every field therefore we work with organisations who are experts in their own fields. We think there is an opportunity for more joined up funding and increased multi-agency work, particularly with health services and this will enable more holistic support for customers..."** Working Links

In addition to identifying the need for a range of expanded support, it was felt that improving joint working could improve people's experiences of and access to services. The importance of ensuring that people with MS have access to employment supports from the point of diagnosis was a recurring theme throughout evidence submissions, to ensure people know their rights and the services on offer to them.

> **"[Occupational Therapists] would like to see a more joined up approach across employment services, health and social care. This could include: public health prevention, early intervention, occupational health, vocational rehabilitation, employment services, disability employment services, benefits etc."** Paul Cooper, Professional Advisor, College of Occupational Therapists

Different ideas were suggested about what form joined up supports should take, including amalgamation of service provisions, improved coordination, and better signposting and referral mechanisms. The Review heard that providers have a significant role to play in referring clients into the right services, and working in conjunction with other service providers, where they recognise that such support is needed.

The importance of working closely and reciprocally with health services in particular was underlined. The Review heard that health professionals also need to be supported to consistently signpost people with MS to employment services for support around their work issues.

> **"[There should be] funding of combined clinics/vocational rehabilitation programmes where rehab professionals, occupational health, DWP representatives, and relevant voluntary agencies, and primary care can come together to optimise support for return to work..."** Dr Emer Mc Gilloway, Neurorehabilitation Consultant, King's College Hospital NHS Foundation Trust

Some Review respondents touched upon the issue of joint working needing to be improved at the highest levels, between UK Government Departments and the NHS.

Involvement of employers

> **"We have found that good employer engagement is vital. Convincing employers of the benefits of a diverse workforce and encouraging them to think of candidates' accessibility and health needs in their recruitment processes is a key way of supporting people with long-term health conditions into work. Work trials, job-carving [°] and the creation of more flexible jobs are all important ways that employers can be more accessible for people with long-term health conditions."** Shaw Trust

A number of submissions to the Review also highlighted the involvement of employers as essential in interventions to help employees and prospective employees with MS.

> **"The most important feature of the support we provide is our model of working with the employer and the individual as a three way relationship. This helps the employer understand the support which may be required and gives all parties the opportunity to ask questions, and have a long-term point of contact for assistance or advice."**
> Working Links

Similarly, submissions suggested a role for health professionals to engage directly with employers.

> **"Often a workplace has not been provided with information about the condition and how this might affect the individual. Support to the employer is vital in giving the employer the confidence to support the patient. A commitment to ongoing support to employer and patient is also necessary to foster confidence and give advice. One off advice and lack of a person to turn to when things go wrong often means that the work trial will fail"** Dr Emer Mc Gilloway, Neurorehabilitation Consultant, King's College Hospital NHS Foundation Trust

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All data from My MS My Needs 2 about DMTs refers to people with relapsing forms of MS who could potentially benefit from taking them

[°] Job carving refers to the creation, or modification, of a role to suit an individual's skills and abilities. It is used to ensure that a job can be successfully performed by a disabled person, while simultaneously meeting the needs of an employer.

Many people with MS, whether in employment, unable to work, or hoping to work in the future, rely on disability benefits to cover extra costs and maintain their independence.

4 Welfare system

Obstacles

Unhelpful processes and criteria

> **"This is a very difficult tightrope to walk. Risking taking a job is now a double jeopardy with the punitive nature of ESA tests...mean[s] even the most heavily disabled or sick receive no support. If you are receiving enough to live currently and would not after reclaiming after failing at a new job."** Stephen, who has MS

Many people with MS, whether in employment, unable to work, or hoping to work in the future, rely on disability benefits to cover extra costs and maintain their independence.[29] Yet, evidence gathered suggested several ways in which the existing welfare system is not providing the support needed and in many cases is counter-productive to helping people with MS enter and remain in employment.

The often stressful nature of the process of claiming benefits was highlighted as an issue. Going through it can use up considerable time, energy, and emotional and cognitive resources, which cannot then be applied to getting into employment. Moreover, some people have found the experience so stressful that their health has worsened.

> **"I lost higher rate PIP mobility in February this year. I asked for a Mandatory Reconsideration and this was successful in getting the decision reversed. The process took up a lot of my time and affected my mood very badly. I was unable to concentrate on my work and my business has suffered as a result."** Christine, who has MS

In addition, current assessment descriptors and eligibility criteria for the main disability benefits, PIP and ESA[q] are not adequately reflecting the needs or realities of people with MS.

A number of those who submitted evidence to the Review outlined concerns about the Work Capability Assessment (WCA) for ESA. The WCA splits eligible claimants into two groups – the Work Related Activity Group (WRAG) and the Support Group – depending on the severity of the barriers they face to employment. Consistent concerns have been expressed about the accuracy of the WCA in identifying the barriers people face to employment. In particular, capturing the fluctuating and hidden symptoms of a complex condition, like MS.

> **"ESA assessment is a very blunt tool when used on people with neurological conditions."** Anonymous, health professional

> **"It is important that a high quality, upfront assessment is in place to ensure people receive the right support for them. These assessments must be high quality, accurate and felt to be a straight-forward and positive experience by those assessed."** Shaw Trust

Furthermore, the WCA does not consider wider barriers to work, such as housing, debt, skills and qualifications or structural and societal barriers to employment, such as the discrepancy between the number of people with MS looking for skilled but flexible and part-time employment, and the availability of such roles.

Like the WCA, issues with how PIP assessments are currently working can negatively impact people's ability to work. Many people responding to the Review highlighted concerns around the loss of Motability vehicles following reassessment, due to tighter eligibility criteria for the higher mobility rate of PIP compared to (DLA). This has reduced from 50 metres to 20 metres under PIP, meaning those who can walk over 20m, even with aids such as walking sticks, no longer qualify for this support. The Government estimated that the number of people receiving the highest rate of mobility support would be 428,000 lower by May 2018 under PIP than DLA.[30] Many people are concerned about their ability to work if they lose their Motability vehicle.

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[q] Personal Independence Payment (PIP) helps with some of the extra costs caused by long-term ill-health or disability, for people aged 16 to 64. It replaces Disability Living Allowance. It is currently being rolled out across England, Wales, Scotland and Northern Ireland for new claimants. It is also being rolled out to claimants currently receiving Disability Living Allowance across England, Wales and Scotland, who are reassessed for PIP. This process will commence in December 2016 for DLA claimants living in Northern Ireland.

Limited access to appropriate support through the benefits system

> **"We spend a significant amount of time trying to help customers with financial concerns which are often linked to benefit issues. In our experience, customers can even be put off work as they are wary their condition may worsen and are worried they will have to go back through the process of reapplying for benefits."** Working Links

Issues with the accuracy and the appropriateness of assessments can mean people with MS are struggling to access the financial support they need to cover extra costs and meet their needs. Some respondents highlighted that financial worries can act as a barrier to returning to work.

These concerns are exacerbated by changes included in the Welfare Reform and Work Act 2016 which will reduce support for those in the Work Related Activity Group (WRAG) when they come into force.

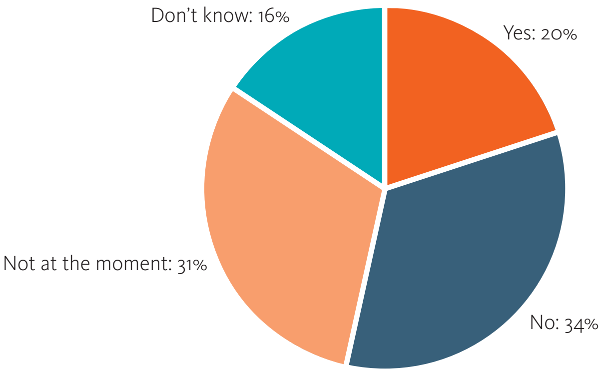
In addition, access to appropriate employment support through the benefits system was particularly felt to be inadequate and often very difficult. A number of submissions highlighted people with MS being unable to access specialist support that met their needs.

Currently, in England, Scotland and Wales, support for some claimants on JSA and ESA WRAG is provided on a mandatory basis through the Work Programme. A previous survey of people with MS by the MS Society found that of those in the WRAG (n=126), two thirds (66%) reported they had received no support to help them get back to work and 61% disagreed that the support they had received would help them to find a job.[31]

In contrast, access to Work Choice – a specialist employment programme for those with substantial barriers to work – is voluntary. Some evidence submissions reported claimants had come off ESA and claimed JSA in order to be able to access this support.

> **"It can be difficult for people to access the right support in relation to their benefits, for example they have been told they need to come off ESA and go onto JSA before accessing work choice. This can add to an already stressful situation making the process of finding work even more difficult."** Dr Diane Playford, Vocational Rehabilitation Team at Queen Square, National Hospital for Neurology and Neurosurgery

If you were offered support* to help you think about or prepare for employment in the future, would you take it up? *support that would not affect your benefits in any way.



There is a clear but, unfortunately, unmet appetite for voluntary specialist support. Among ESA support group claimants, 20% (n=33) said they would take up support which would not affect their benefits in any way to think about or prepare for employment in the future, 16% (n=26) said they did not know, while 31% (n=56) said not at the moment.

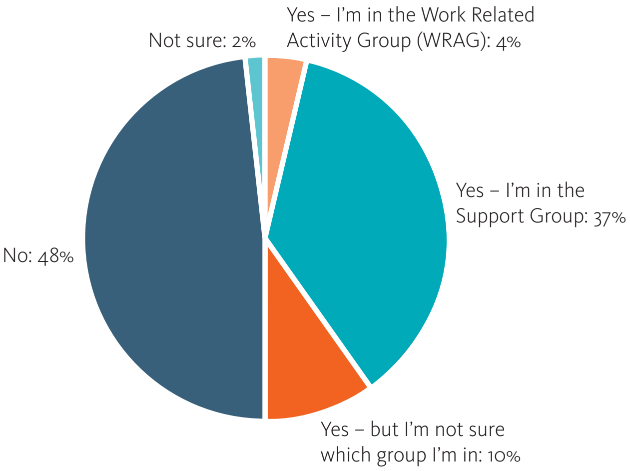
A particular concern by Review respondents, including both employment support providers and health professionals, was the replacement of Disability Employment Advisors (DEAs), with Work Coaches, who have less specialist knowledge. They felt this was a loss of both information and expertise for disabled people. Health professionals were also concerned that this represented a loss of advice and support for them, as DEAs act as a bridge between the welfare and health sectors.

> **"When I met with her [a disabled employment adviser from the local job centre] recently she highlighted that the DEA roles within the job centre may be stopped soon due to lack of funding. Roles within the job centre she stated will be more generic. This is a concern as the DEAs are able to provide specific employment guidance for people with long-term conditions and in particular are people whom therapists can contact who have up to date knowledge and information on the ever changing work programmes, work choice options."** Anonymous, health professional

Given that access to employment services is primarily via the benefits system this also limits the number of people with MS who can easily access them. For example, some people who have recently left employment (and who are therefore more likely to be able to return to work more easily), may initially avoid engaging with the benefits system, meaning they are only able to access employment support months or years down the line, when they are significantly further from the workplace.

Of survey respondents who are currently out of work, only half are receiving ESA. A number of those not claiming ESA expressed interest in employment support, demonstrating that employment services need to be available more widely than through the out-of-work benefits system.

Do you currently receive Employment and Support Allowance (ESA)?



Another problematic aspect of access to employment support being via benefits is the present requirement that they are able to work at least 16 hours a week, following pre-employment support.

Given the fluctuating nature of MS, people with the condition are unlikely to know exactly how many hours a week they will be able to work in future. Moreover, the number of hours they feel able to work may depend on the terms of the job they take on. Therefore this requirement may be barring people from accessing the support available through Work Choice.

Current cliff edges in the payment of ESA once people re-enter employment are also acting as a barrier to work. The Review heard from some employment support providers that people are afraid to take on employment and lose their ESA in case it does not work out.

> **"Some people receiving Employment Support Allowance (ESA) who have a fluctuating condition such as MS, have concerns that if they move into work, the fluctuating nature of their condition might lead them to periodically fall out of work again. This would mean them having to go through the process of losing ESA and having to apply for it again, including having to undergo another Work Capability Assessment. This can therefore create a fear of losing ESA, and create a barrier to people moving into work."** Shaw Trust

This and other evidence also suggests people with MS do not know about permitted work rules, whereby people can work for up to 16 hours a week – or whether they are allowed to volunteer while receiving ESA. This is problematic as volunteering and permitted work constitute an important stepping stone into work, particularly for those with fluctuating conditions. The transfer to the tapering structure of Universal Credit may eventually alleviate this issue, though it remains a concern in the meantime.

Solutions

Information sharing across the welfare system

> **"It is important to ensure Jobcentre Plus staff have the training and assessment tools they need to ensure they can… make the appropriate referral to tailored employment support as quickly and efficiently as possible. Linked to this, there is room for improved data sharing between Jobcentre Plus and providers"** Working Links

For those accessing support through the welfare system evidence consistently suggested that better information sharing was needed between the welfare system and employment providers. The WCA is by no means a sufficient assessment of all the barriers a person faces to employment, as it does not address barriers such as low confidence and self-esteem, low expectations, or discrimination. Therefore, it makes sense that relevant information, which could help employment providers, and prevent people with MS from having to repeat information, is passed on.

Signposting across the welfare system could also be improved more generally to ensure people with MS are aware of other support from which they could benefit. For example, some of those losing mobility support following reassessment to PIP might instead be able to get support to and from work through Access to Work.

Access to Work cannot however be seen as a panacea. For example, some people may be unable to secure necessary employer contributions to Access to Work support and other adjustments. Moreover the MS Society has previously reported that, without a Motability car, people with limited mobility may struggle to achieve other important daily activities such as shopping, attending medical appointments and socialising with family and friends. This could also leave them with much less energy to be able to manage at work.

Evidence gathered for the Review suggested that there are some concerns with the service provided by the JCP in coordinating referrals on to employment providers. Employment providers reported issues getting referrals through in a timely fashion, as well as poor relationships with certain offices. Therefore JCP must ensure that it is working well with all employment support providers.

Support for those unable to work

> **"I work 16 hours a week, four hours over four days, but it is exhausting. It means that I do not have the energy, physically or mentally, to do anything else apart from exist! When I do have leave from work and can find some time to do some gentle exercise and relax, my health improves a great deal. The only reason I work is to pay the bills and not have to go through the pain and stress of dealing with the DWP and more medicals. My work is not helping my health, it is making it worse!! I am terrified about what will happen when I have to stop working and whether I'll be able to pay my rent and bills."** Deborah, who has MS

Many people with MS are likely to reach a stage in their condition where working is no longer possible. For these people, it is essential that the welfare system provides adequate and appropriate support without subjecting claimants to unnecessary burden or stress. Worryingly, some respondents wrote of remaining in employment despite detrimental impacts on their health, due to the need to earn money. Some discussed fear of stopping work due to not wanting to feel like a burden on society, and fear of having to go through benefits assessment processes.

There is therefore a need for more support for people transitioning out of work due to their MS. Evidence to the Review also suggested a need for advice around finances/benefits for those looking to leave work due to their health. For those who had to stop working it was felt that more help to adjust psychologically and to find other meaningful activities is important.

Increase the number of Disability Employment Advisors

> **"I'm a little bit concerned about some of the things at Jobcentre Plus where the disability employment advisor role seems to be diminishing and getting replaced by a more generalist role. Where things work very well it's about having a good relationship with the DEAs, and if that role gets watered down I think that's probably a worry."** Brian Bell, Director for Employability and International, Working Links

Increasing the numbers of DEAs once again was highlighted in evidence to the Review as a way of providing important supports to people with MS and a source of information and advice for employers and health professionals. *Improving Lives: The Work, Health and Disability Green Paper*, states that the Government is recruiting an additional 300 DEAs, taking the total to 500.[32]

Conclusion

It is clear that people with MS face many, sometimes substantial, obstacles to staying in and entering in work. On average, those who are not in work and not looking for work due to their MS lose 19.4 working years (assuming an average retirement age of 65); but this does not have to be the case.

This Review has made it clear that there are many ways in which the UK Government, employers and health and employment support providers can address these obstacles, supporting people with MS to stay in quality work for as long as is appropriate.

A greater focus on job retention and support, transitions to new roles and support once work is no longer possible are critical issues for policy focus and improvement in service provision. Much better publication of existing services including Access to Work and the Fit for Work service is needed, along with greater provision of employment related legal advice from the point of diagnosis.

Better access to health and vocational services within NHS provision is urgently needed. Access could be improved significantly through the adoption of work as a clinical outcome. Similarly, timely integration between health and employment service provisions should be a priority for the forthcoming Health and Work programme. The UK Government should promote collaboration between health and employment services, and investigate the viability of integrating them into a unified occupational health infrastructure in the future.

Improving the working practices and cultures of employers, as well as their capacity to support disabled people, is crucial. Employers must embrace and value a diverse workforce by adopting improved disability leave policies and a less risk-averse approach, which ultimately will ensure companies continue to benefit from talented and expert people with MS.

But, it is not just employers – the UK Government can and must take action to improve employer practices and cultures and ensure compliance with duties under the Equality Act. While the Review identified some examples of excellent practice, it also identified a general need for more information and advice for employers about employing disabled people, particularly around the application of reasonable adjustments, which should help employers to overcome unhelpful attitudes and practices. Disability Confident and Fit for Work could play a vital role in providing this information, signposting to other materials and encouraging employers to adopt disability friendly practices.

For people unable to work due to their health, the benefits system must provide adequate financial support, without unnecessary burden or fear of having support taken away. The negative effects that are often associated with economic inactivity must be minimised, and people with MS who transition out of employment should be supported to contribute to society in other ways.

This Review a helpful step step in removing obstacles to work for people with MS – the Health and Work Programme in particular presents a significant opportunity to make real progress in improving employment support for people with MS. We hope that employers, the UK Government and employment and health providers take heed and act on these recommendations, working together to unlock the potential of people with MS.

Most people with MS are diagnosed when they are working, but existing and previous employment programmes do not focus enough on retention support.

Recommendations

Recommendations for the UK Government:

i. **Improve the provision of employment retention support, for example through the Work and Health Programme and Disability Confident.**

ii. **Work with employers and progressive condition charities – such as the MS Society – to establish best practice for transitions out of employment for disabled people. This should include the provision of adequate career guidance to enable the consideration of alternative roles.**

iii. **Consistently recognise that some people cannot work due to their health, and follow through on this understanding in policy and practice. This must include the provision of adequate support for people who cannot work, in order that they can lead as full lives as possible, and avoid the problems that can be associated with economic inactivity.**

iv. Work to improve information sharing across the welfare system, including claimant information being passed on to employment support providers.

v. Improve the provision of careers guidance for those who are no longer able to continue working in the field in which they have qualifications or experience due to health problems or disability.

vi. Make access to the Work and Health Programme available on a voluntary basis; access should not be dependent on either being on a particular benefit, or being able work a particular number of hours.

vii. Improve and expand the support available under the Access to Work service, paying particular attention to ensuring timely delivery and customer satisfaction. This must include close monitoring of the changes to this programme that were introduced in March 2015.

viii. Bring in external validation of level two of the Disability Confident scheme to check for systematic engagement with the steps laid out in the guidance.

ix. Investigate how separate schemes and sources of employment support, such as the Fit for Work and Access to Work, could be better joined up and promote further collaboration.

x. Work with employers to ensure that they have easy access to condition-specific information relating to employing disabled people that meets their needs, and enables them to apply best practice.

xi. Review levels of public awareness of statutory sources of support including the Health and Work Programme, Fit for Work, Access to Work and employment legal advice helplines and take any necessary action to ensure that people and organisations that need to use these services know about them, and how to access them.

xii. Work with the Fit for Work Service to improve its provision and resources, in order to ensure it is suitable for fluctuating and progressive conditions like MS. In particular eligibility criteria should be revised, and information about a wider range of health conditions should be made available.

xiii. The DWP should commit to continued and increasing investment in specialist DEAs, ensuring all disabled people who need support can benefit from their specialist expertise and experience.

xiv. The DWP should evaluate the impact of recent changes to disability benefit criteria on the employment of disabled people including those with MS, with particular regard to the enhanced mobility component of PIP, and the reduction to the ESA WRAG component.

xv. The DWP should ensure that those accessing disability benefits are systematically signposted to available employment support which could benefit them, such as the Access to Work service.

Recommendations for Service Providers:

xvi. **Employment support service providers should ensure their employment programmes engage with employers wherever possible, to facilitate their active involvement in the support of people with MS.**

xvii. **Work should be adopted as a clinical outcome within relevant health service measurement frameworks, such as the Clinical Commissioning Group Improvement and Assessment Framework in England.**

xviii. Work and Health Programme service providers should offer specific service provisions around disability related advice, such as disclosure and reasonable adjustments, and tailored support to overcome health-related barriers, either provided in-house or through signposting to more specialist services.

xix. Health professionals should routinely discuss employment and work-related issues with people with MS. In parallel, third sector organisations should provide appropriate information resources to support these discussions.

Recommendations for employers:

xx. **Adopt policies and practices which promote inclusion and opportunity for disabled employees, and deal quickly and effectively with instances of bullying, harassment or discrimination in the workplace. Wherever possible, employers should adopt a disability absence policy.**

xxi. Ensure that their recruitment processes are set up in such a way as to encourage disabled people to apply for jobs, and to enable them to participate fully in the recruitment process.

xxii. Include adequate disability awareness training, which covers with fluctuating conditions and invisible symptoms such as MS, as a part of a normal induction programme for their employees. Managing staff with disabilities should also be included as part of line manager training.

Appendix: list of contributors

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